

CHILDREN WITH SPECIAL HEALTH CARE NEEDS: IDENTIFICATION AND CARE COORDINATION

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Care coordination and CSHCN

- Why now?
- Why me?
- Why children with special health care needs?
- How do we identify CSHCN?
- What do we mean by care coordination?

Why Now? Gaps in Care for CSHCN

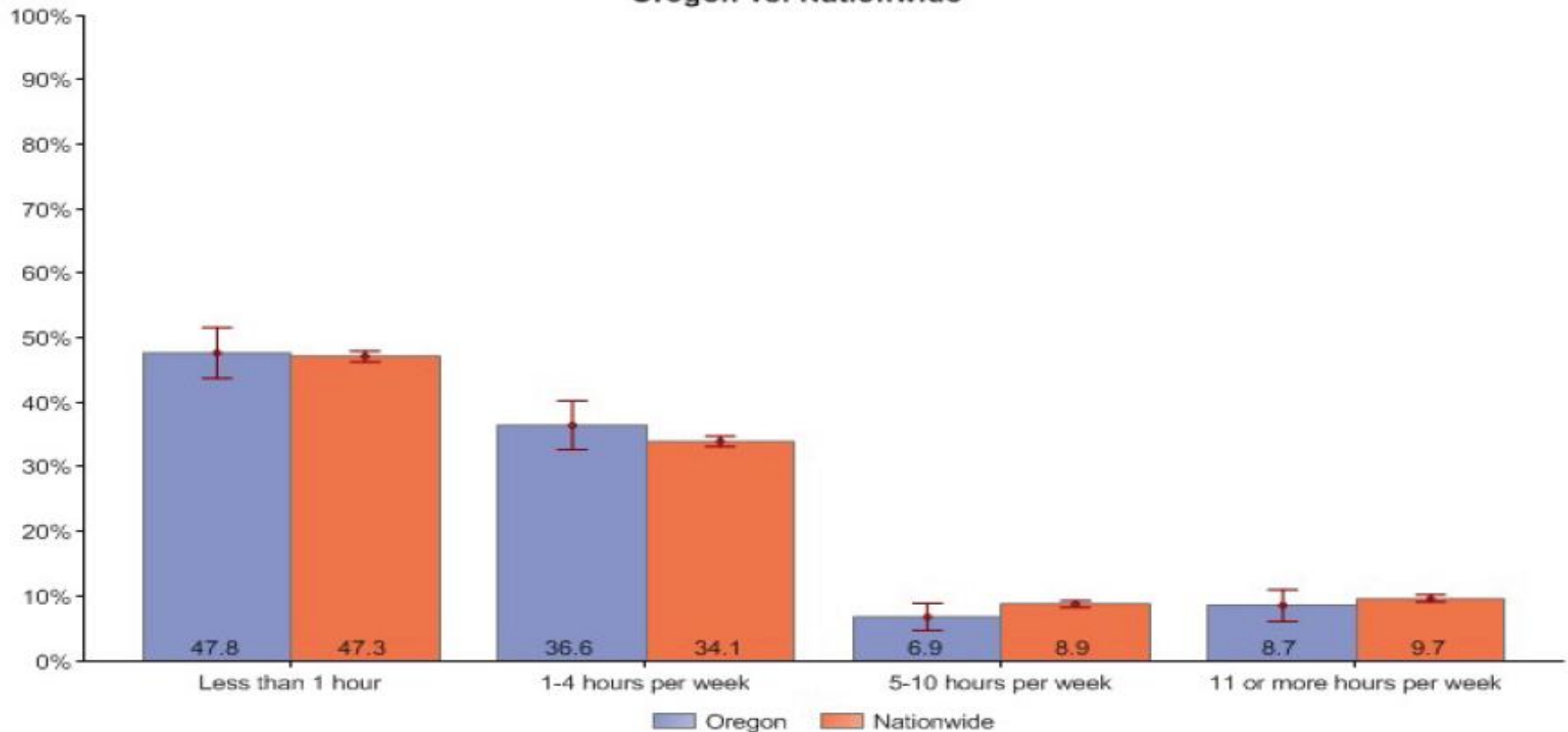
N=446

- 50% needed health care they could not get for their child
- 64% reported difficulty getting needed care
- 30% went without health care because of the cost
- 22% were unable to pay bills because of CYSHN care cost
- 28% have more than one CYSHN in the family

The Oregon Center for Children & Youth with Special Health Needs 2010

Why Now: Parents Burdened with Care Coordination

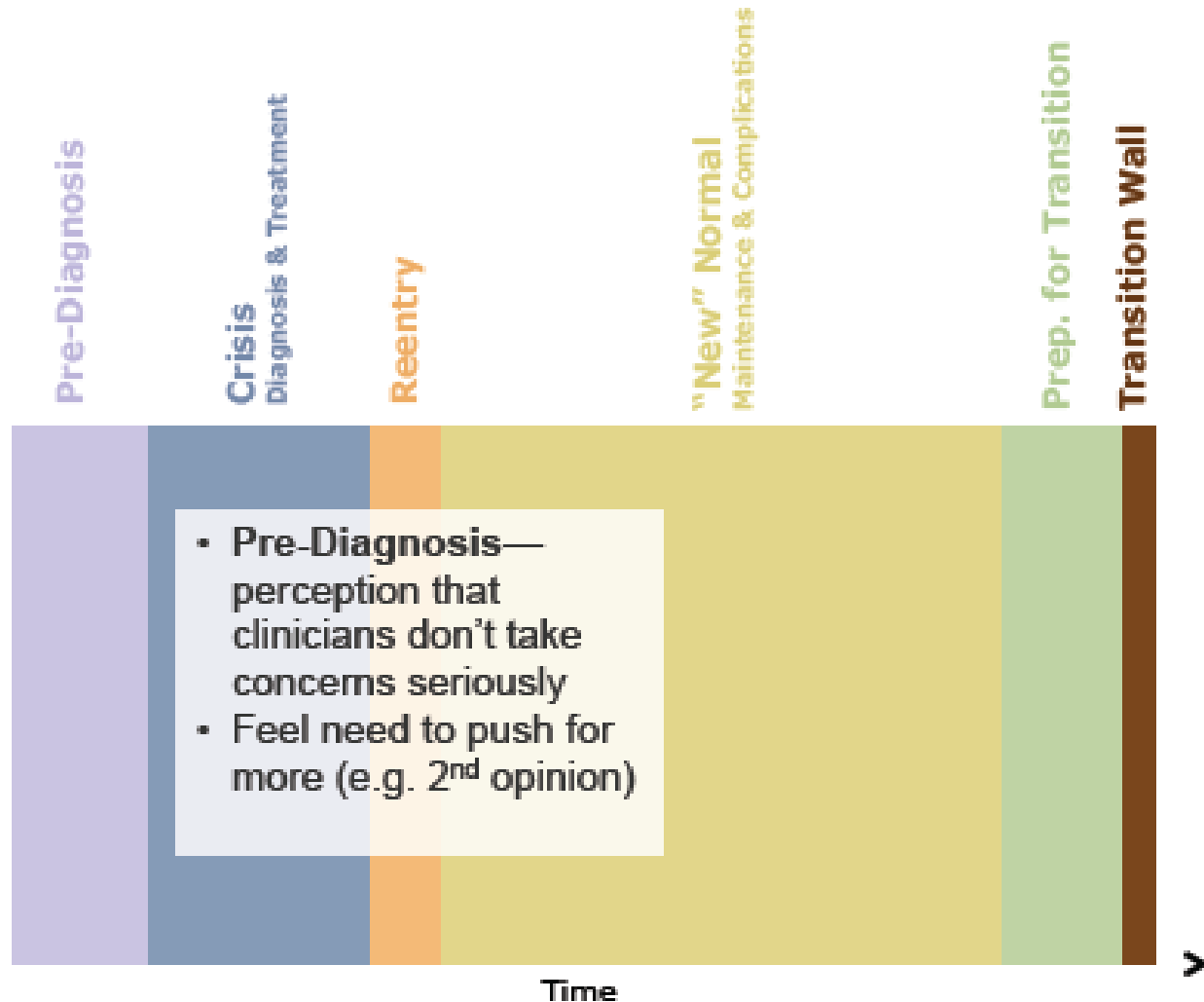
Indicator 14: CSHCN whose families spend 11 or more hours per week providing and/or coordinating child's health care
CSHCN ages 0-17 years
Oregon vs. Nationwide



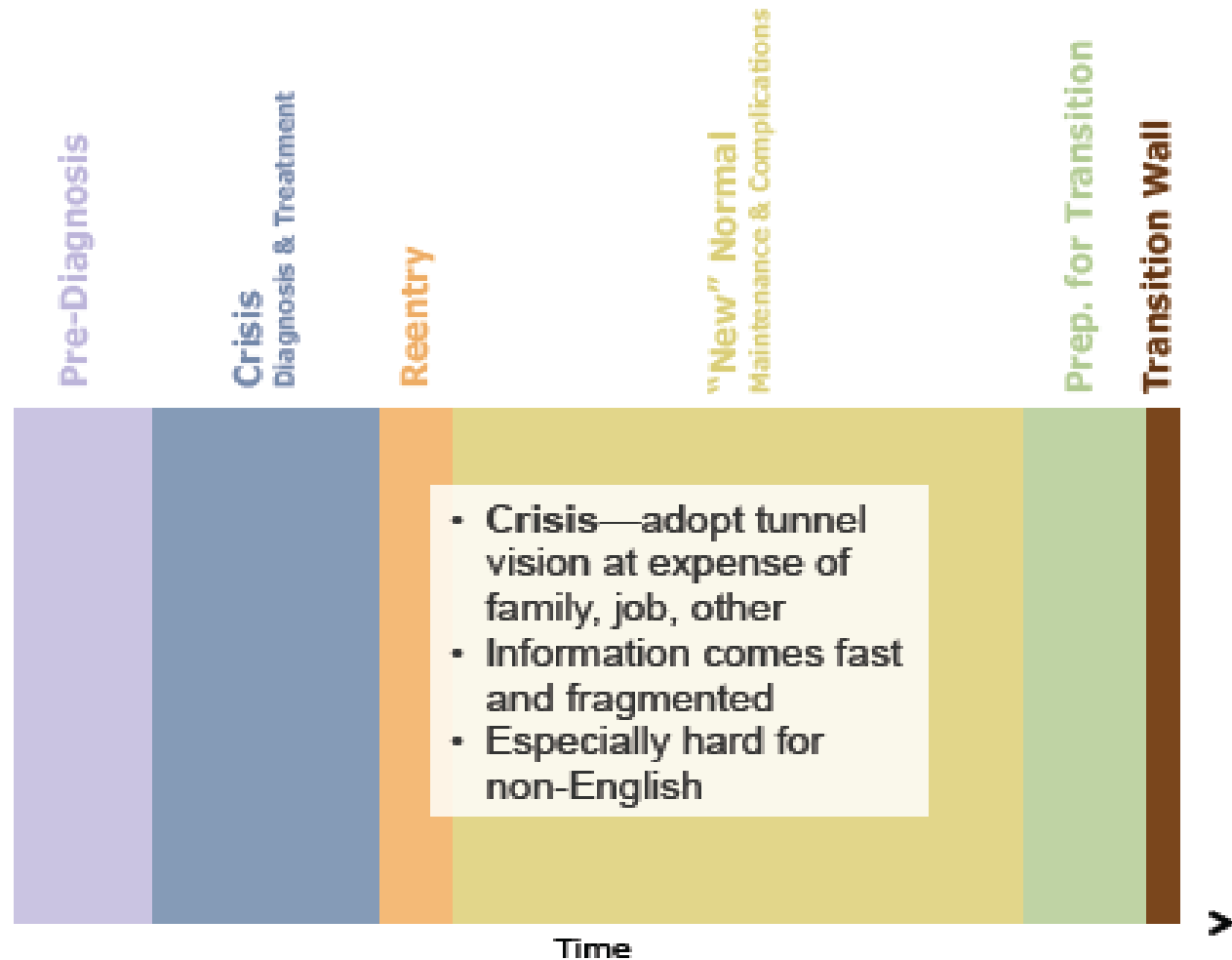
A Journey Through Chronic Illness: A Family's Perspective



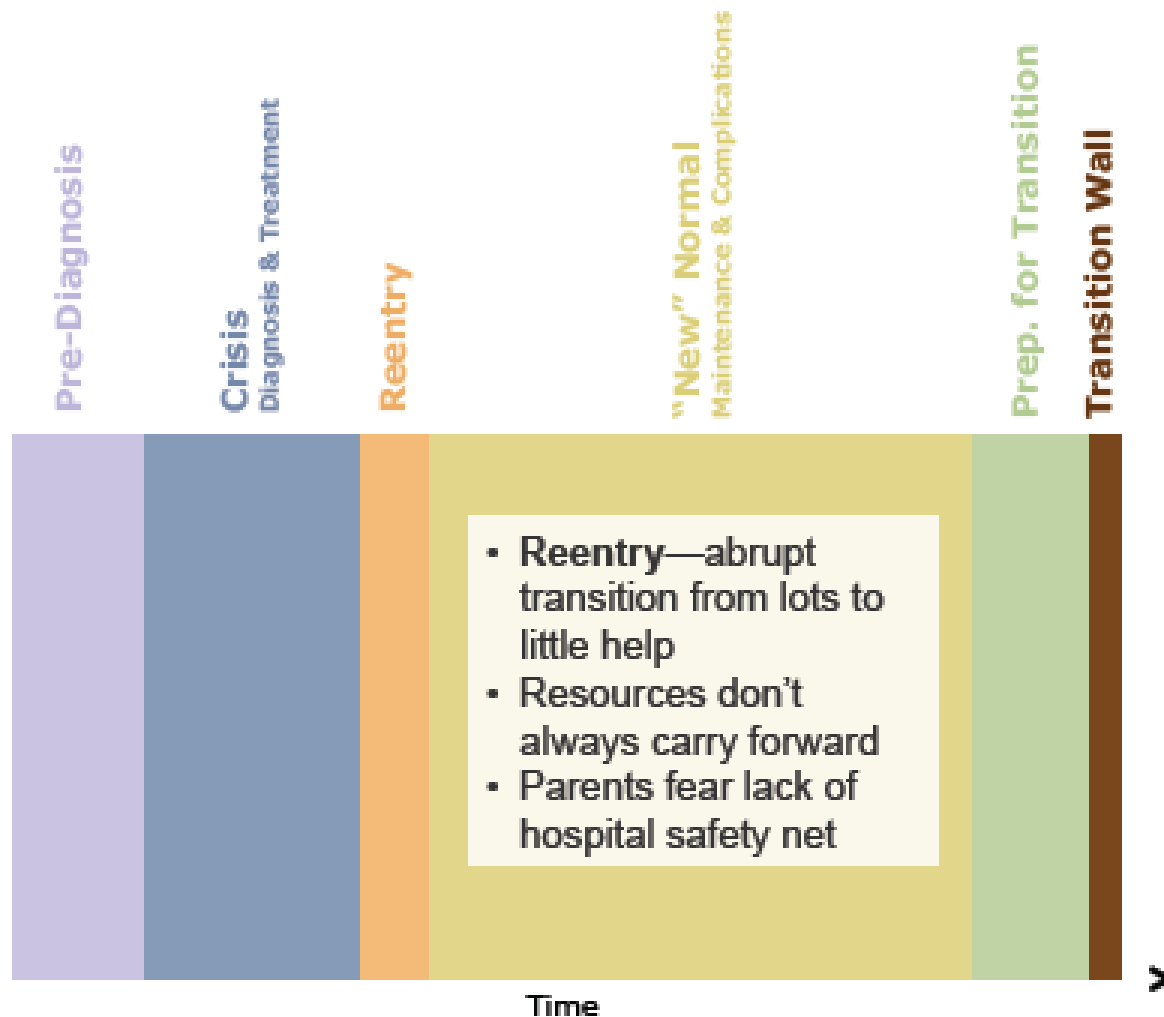
Model 1—Stages of the Experience



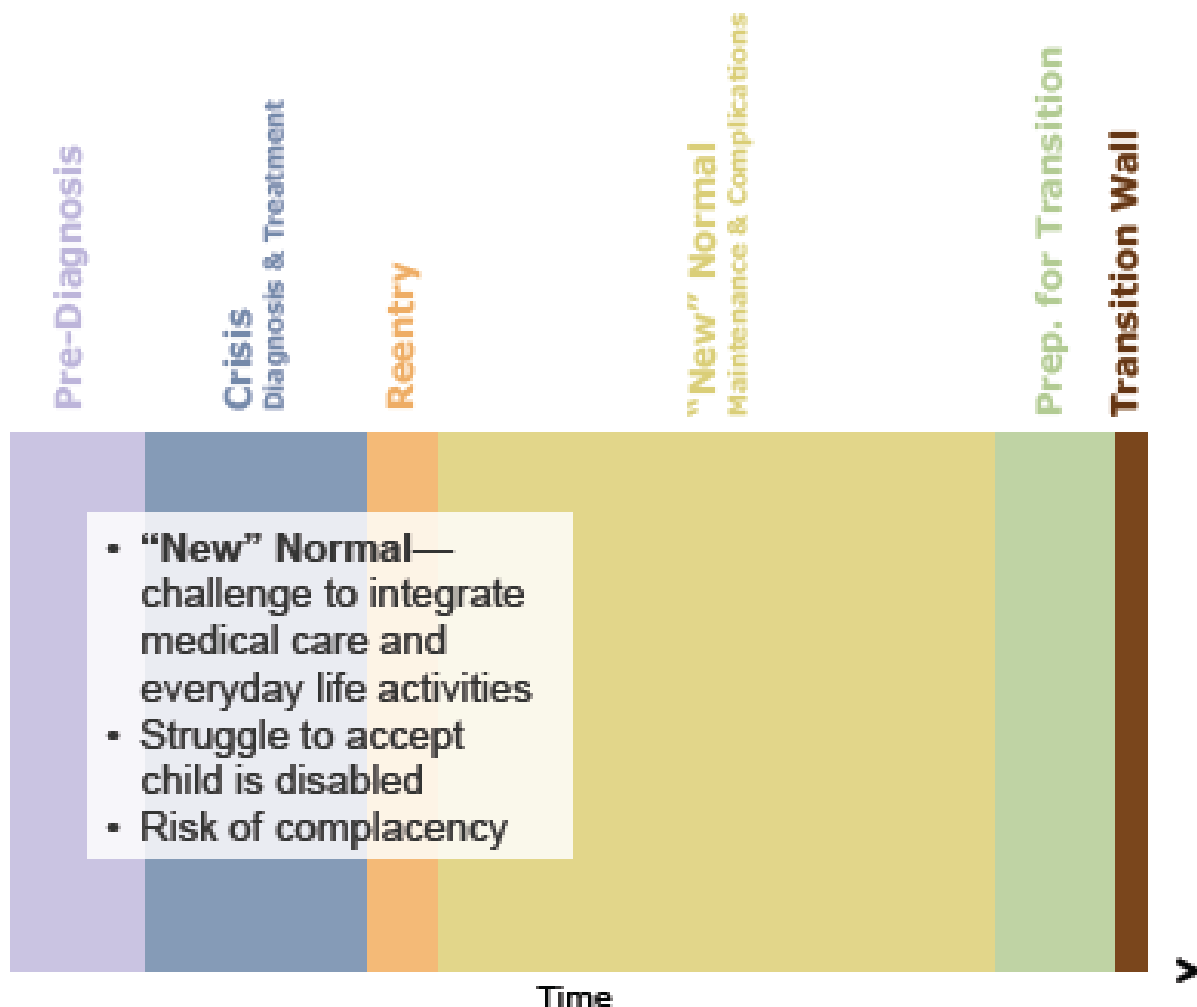
Model 1—Stages of the Experience



Model 1—Stages of the Experience

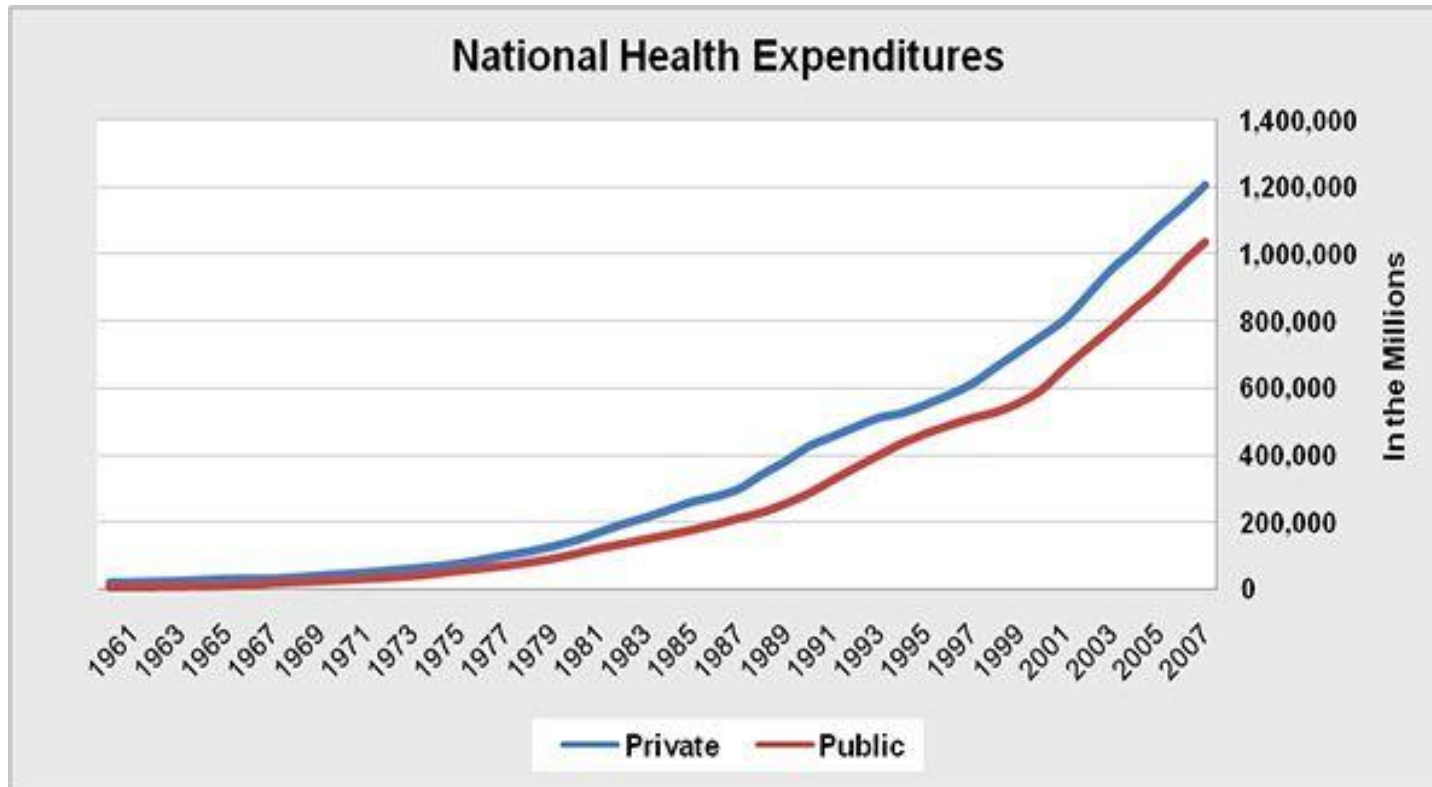


Model 1—Stages of the Experience



Why Now? Health Care Reform

- Need to bend the cost curve



Why Now: Accountable Care Act

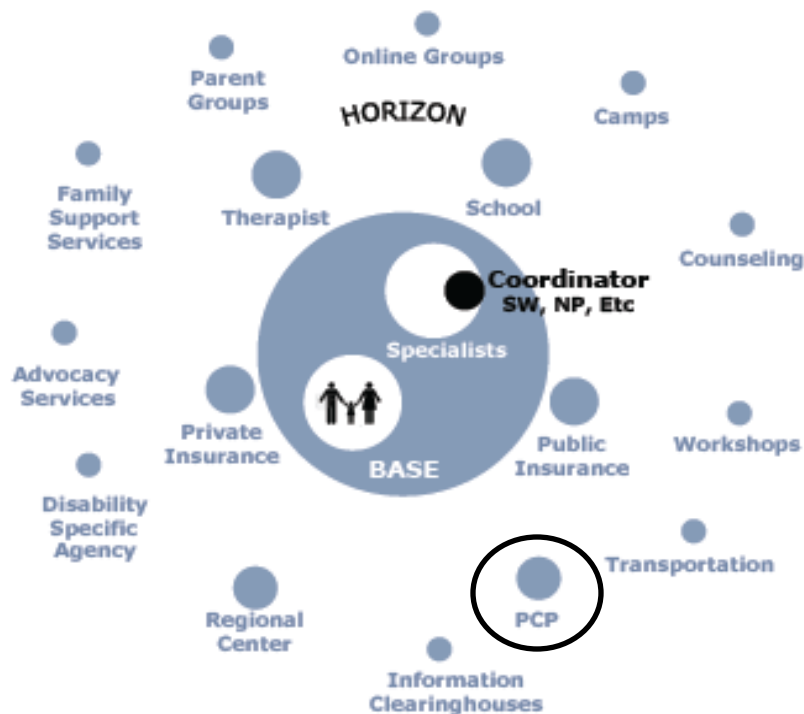
- Increased coverage for children
- Support for medical homes and care coordination
- Opportunity to develop new models of care: ACO's
- Payment reform that supports medical homes:
Centers for Medicare and Medicaid Innovation

Why Now? Changes in Oregon

- Oregon Patient Centered Medical Home Program(PCMH)
 - ▣ To address the triple aim
 - ▣ To define the attributes of a PCMH
 - ▣ To develop practice standards for a PCMH
 - ▣ To develop measures for the PCMH
 - ▣ New payment systems that align incentives for the implementation of the PCMH
- Modification of the standards for children
- ECHO learning collaborative for QI

Why Me?

Model 1—Resource Access



- From a system level resources look overwhelming
- Families have a radial model of resources
- At the center, their base (hospital or clinic) includes their team of specialists
- Insurance, schools and therapists are in their next level of resources. Some families need assistance accessing this level
- Useful resources exits beyond their horizon, but most are unknown to families

Why Me? Leader of the Team

- The patient centered medical home is at the center of reform to better meet the needs of CHSCN
- The primary care physician is best prepared to lead the team in the context of a medical home
- Success is far from assured: The track record for the development of the PCMH for Medicare patient hasn't been great
- PCP's must be prepared to take the lead or it will outsourced to others such as pediatric specialists, 3rd parties such as home care agencies and the dollars will follow



Why Children with Special Health Care Needs



Willie Sutton, reputedly replied to a reporter's inquiry as to why he robbed banks by saying ***"because that's where the money is."***

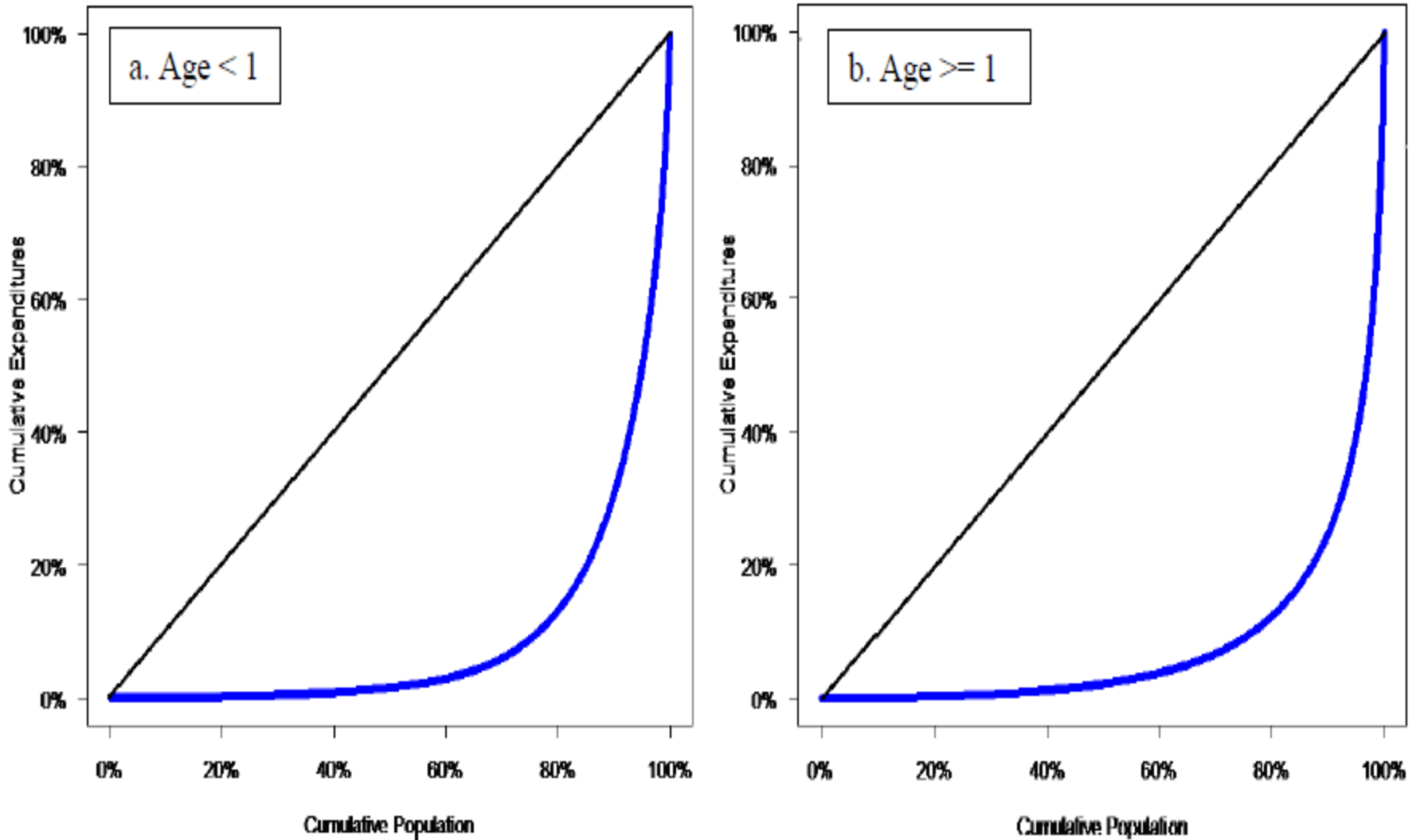
“Where is the Money” in Child Health?



Children with Special Health Care Needs
Great Opportunity and High Cost

California Childrens Services

Figure 8. Distribution of total expenditures per child, FY 2009



CSHCN: The Cost of Care

- Children with chronic conditions that expected to be lifelong, progressive and will require extensive care. Neff *JM Health Serv Res* 2004
 - ▣ 0.4% of children
 - ▣ 11% of pediatric health care costs
 - ▣ 24% of pediatric hospital charges

- Children with a chronic illness ICD 9 code which lasts > 12 months, involves several different organ systems and requires tertiary pediatric specialty care Simon *TD Pediatrics* 2010
 - ▣ 26% of pediatric hospital days
 - ▣ 40% of hospital charges



Cost of Care: The Opportunity

- 48% decrease in the number of hospital days and a \$10.7 million decrease in payments to the tertiary care center Gordon JB

Pediatr Adol Med 2007

- 45% reduction in ED visits Klitzner TS J

pediatr 2010

- 40% reduction in inpatient costs, 27% decrease in hospital stays

Casey PH Arch Pediatr Adolesc Med 2011



Why Care Coordination

- Medical Home perspective
 - OHPR attributes of a medical home
 - Access
 - Accountability
 - Treat the whole child - comprehensive
 - **Coordination and integration**
 - Family centered
- Family Perspective
 - 9% of families with CSHCN spend > 11 hours per week on care coordination
 - Quote: “Someone should write a book call *Chronic Illness Care for Dummies*. There is so much I don’t know” – Parent of a child with CSHCN



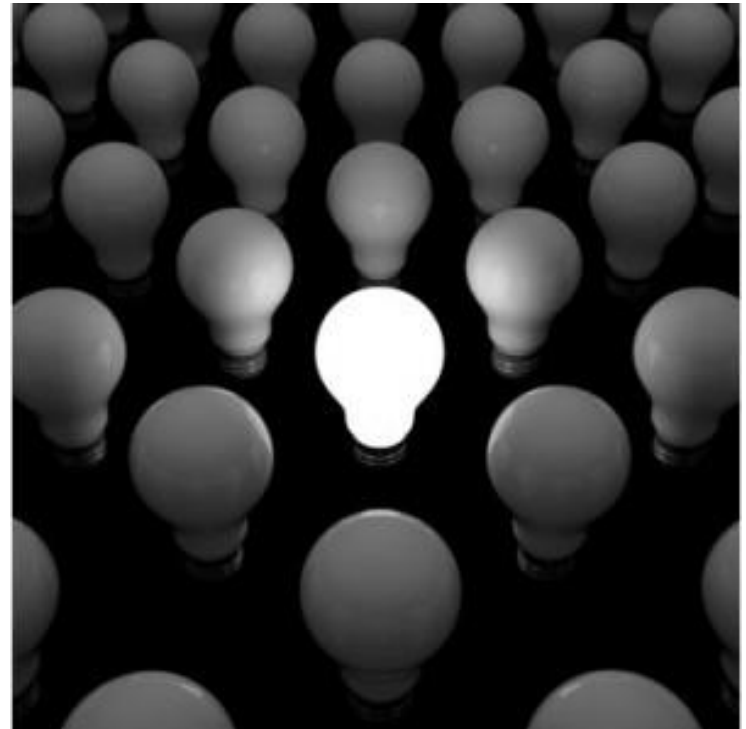
Care Coordination: Definition

Patient and family centered assessment driven, team based activity designed to meet the needs of children and youth while enhancing the care giving capabilities of families. Care coordination addresses interrelated medical, social, developmental, behavioral, educational and financial needs to achieve optimal health and wellness outcomes

Antonelli R 2009

National Quality Forum: Preferred Practices Domains

- Health care home
- Pro-active plan of care and follow-up
- Communication
- Information systems
- Transitions or handoffs
- *One additional domain:*
Family engagement

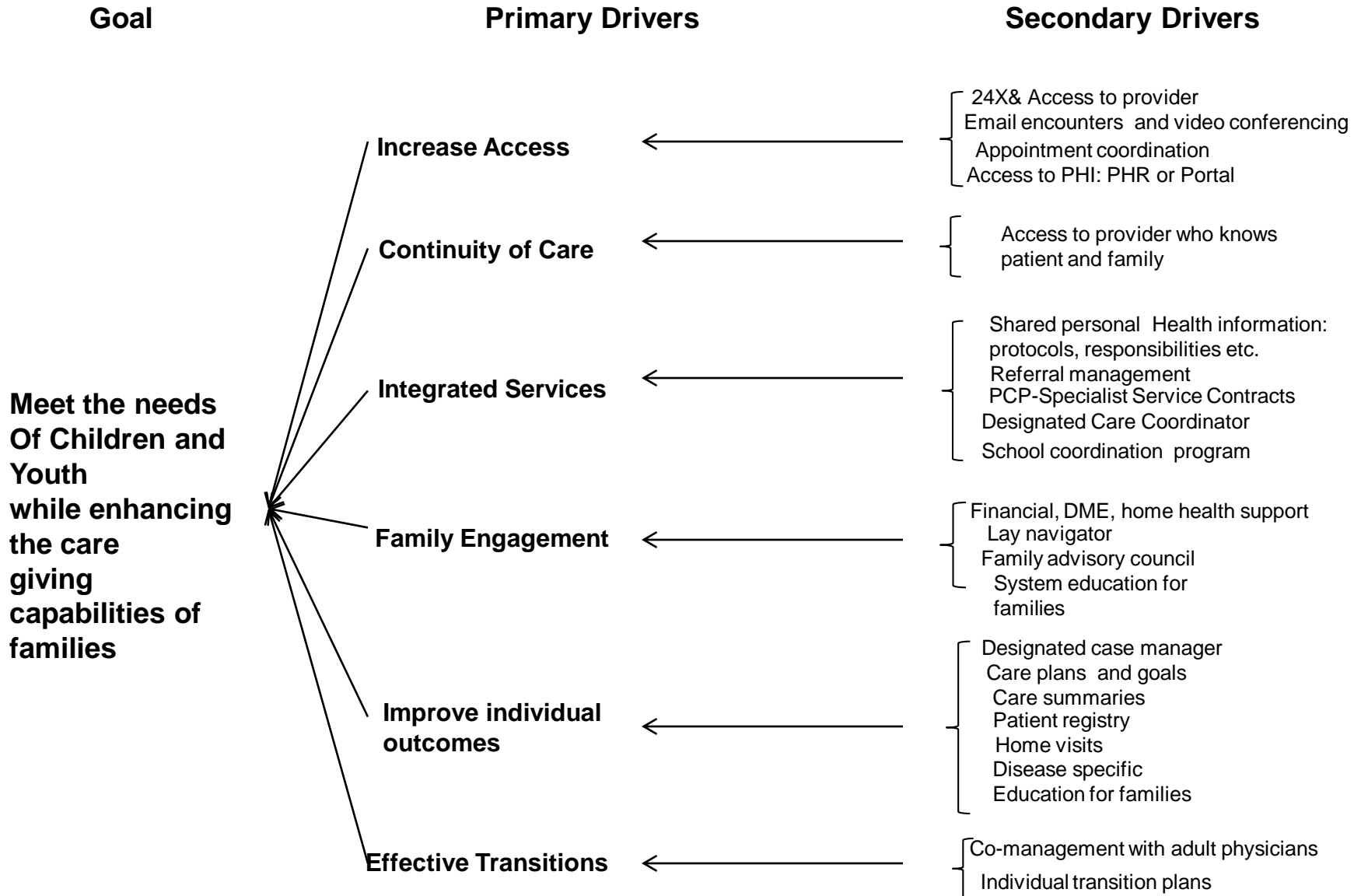


Care Coordination Attributes

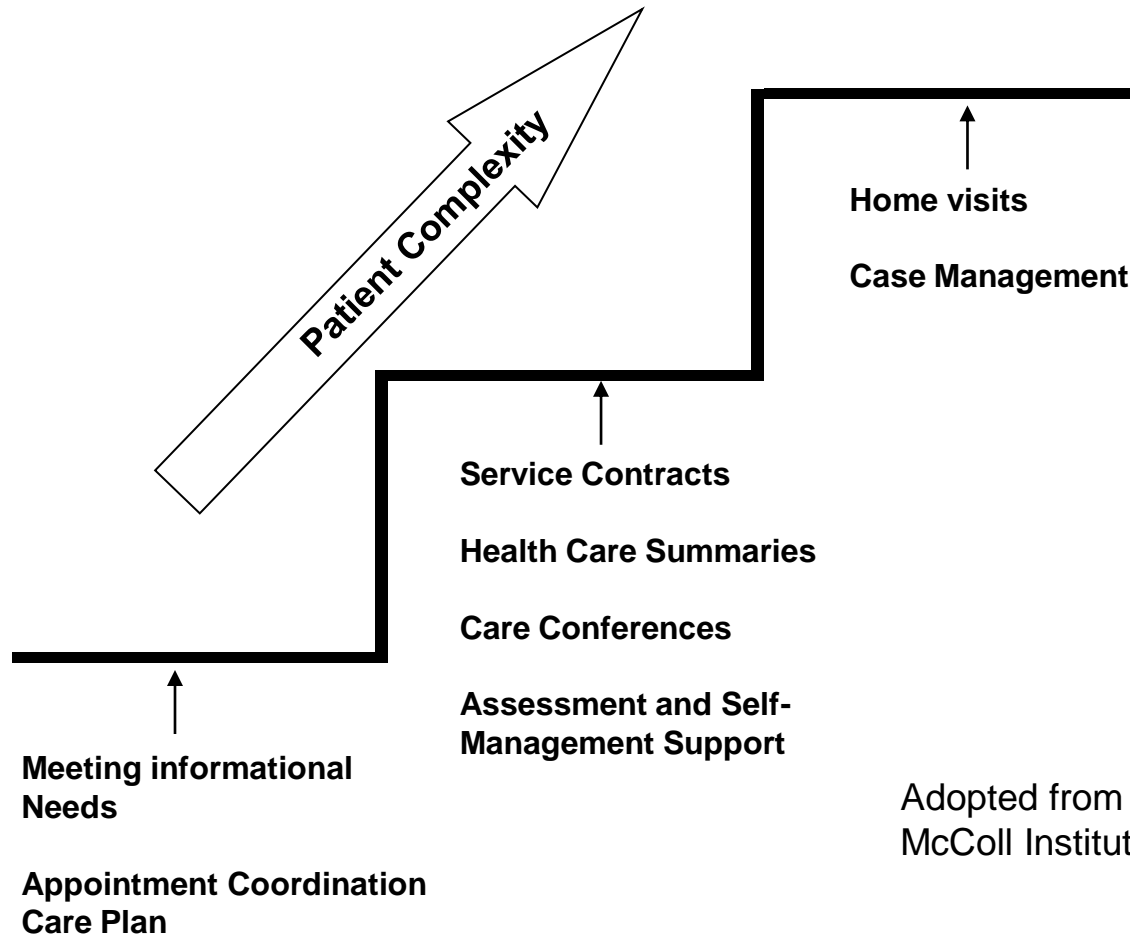
- Access
- Continuity
- Integrated Services
- Family engagement
- Improved outcomes
- Effective transitions



Care Coordination Driver Diagram



Tiered Care Coordination



Adopted from E.H. Wagner
McColl Institute; Seattle, WA

Identifying CSHCN: How?

Children with special health care needs (CSHCN) have a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

Maternal and Child Health Bureau

Identifying CSHCN: How?

□ Formal systems using administrative data

□ 3M Clinical Risk Groups

- Uses an episodic grouper to generate EDC or episodic diagnostic categories based on severity of ICD-9 code, time interval between encounters and other data
- EDC's are used to place children in health status categories for children with chronic conditions e.g. dominant, minor and moderate chronic

□ Complex Chronic Conditions

- Last at least 12 months
- Involve several different organ systems
- Involve one organ system and requires pediatric subspecialty care
- Hospitalization in tertiary pediatric care center

Identifying Children at Risk How?

□ Informal systems

□ Children's Hospital of Wisconsin

- Complexity: number of active specialists and organ systems (minimum of 5 and 3, respectively, for enrollment)
- Distance > 25 miles to tertiary center
 - PCP does not admit to tertiary center
 - Major psychosocial problems
 - Language barriers
 - Major technologies
 - Other miscellaneous things like multiple complex kids in the family
- Fragility:
 - Number of hospital admissions / days in year prior to referral to our program (minimum of 2 and 10, respectively, for enrollment)
 - Number of different clinic visits in year prior to referral (> 10 for enrollment)
 - Technology dependence for sustaining life

Identifying Children at Risk How? (Bob's System)

DIMENSION	LEVEL OF SUPPORT		
	1 (Minimal)	2 (Limited/Intermittent)	3 (Extensive)
1. Health	Health status stable, routine preventive care, may see specialist annually	Health status generally stable, regular office visits to review management, periodic consultation with 1 or more specialists	Health status unstable, frequent office visits, regular ER visits or hospitalization, frequent consultations with 1 or more specialists
2. Family	Family status stable, no major environmental stresses, traditional social supports present and utilized	One or more stresses may be present, family requires occasional support from office and other community resources	Multiple major stresses are present, family resources are overwhelmed, extensive community support needed or major concerns about care giving environment
3. Behavioral and Mental Health	Behavior health status is stable, routine anticipatory guidance	Regular office visits to review management or regular consultation/counseling with mental health providers	Behavioral health status is unstable, extensive supports from office and community professionals, may require day treatment program or in-patient treatment
4. Education	Routine monitoring of developmental/school progress, regular classroom with minimal support	Child has IFSP, IEP or 504 plan, most of child's needs are met in regular classroom, may require 1 special health procedure at school	Extensive support required, full time aide or special class for most of the day, or multiple special health procedures in educational setting
5. Special Issues	Child and family follow through with recommendations readily, limited need for decision supports, no or few cultural factors impact care, child/family proactively manage care	Child and family require extra time to understand healthcare rec's, regular need for decision supports, translator required for appts, occasional missed appts.	Extensive need for decision supports and care reminders, cultural issues are major barrier to care, limited capacity for self-management, or major disagreements with the care plan

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Complexity Index (Phoenix Pediatrics)

David Hirsch MD

Complexity	Description	Example
0	Well, no medical problems	Well Child
1	One moderate medical problem, involving one organ system with complications	Moderate asthma
2	One moderate or severe medical problem, involving one organ system with complications	CP, contractures
3	Two or more moderate or severe medical problems involving two or more organ systems	CP, epilepsy, MR
4	Two or more moderate or severe medical problems involving two or more organ systems with complications	Epilepsy, BPD, Tracheotomy, vent dependent

Identifying CSHCN Using Patient Centered Data

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
- No

To qualify as having chronic or special health care needs, the following criteria must be met:

5

- a) The child currently experiences a specific consequence.
- b) The consequence is due to a medical or other health condition.
- c) The duration or expected duration of the condition is 12 months or longer.

Identifying Children at Risk Why?

- Identification allows you to set appropriate rates for care
- Identification allows you to implement tiered care coordination
- Identification allows you to create a registry and intervene at a population level e.g. influenza immunization for high risk children



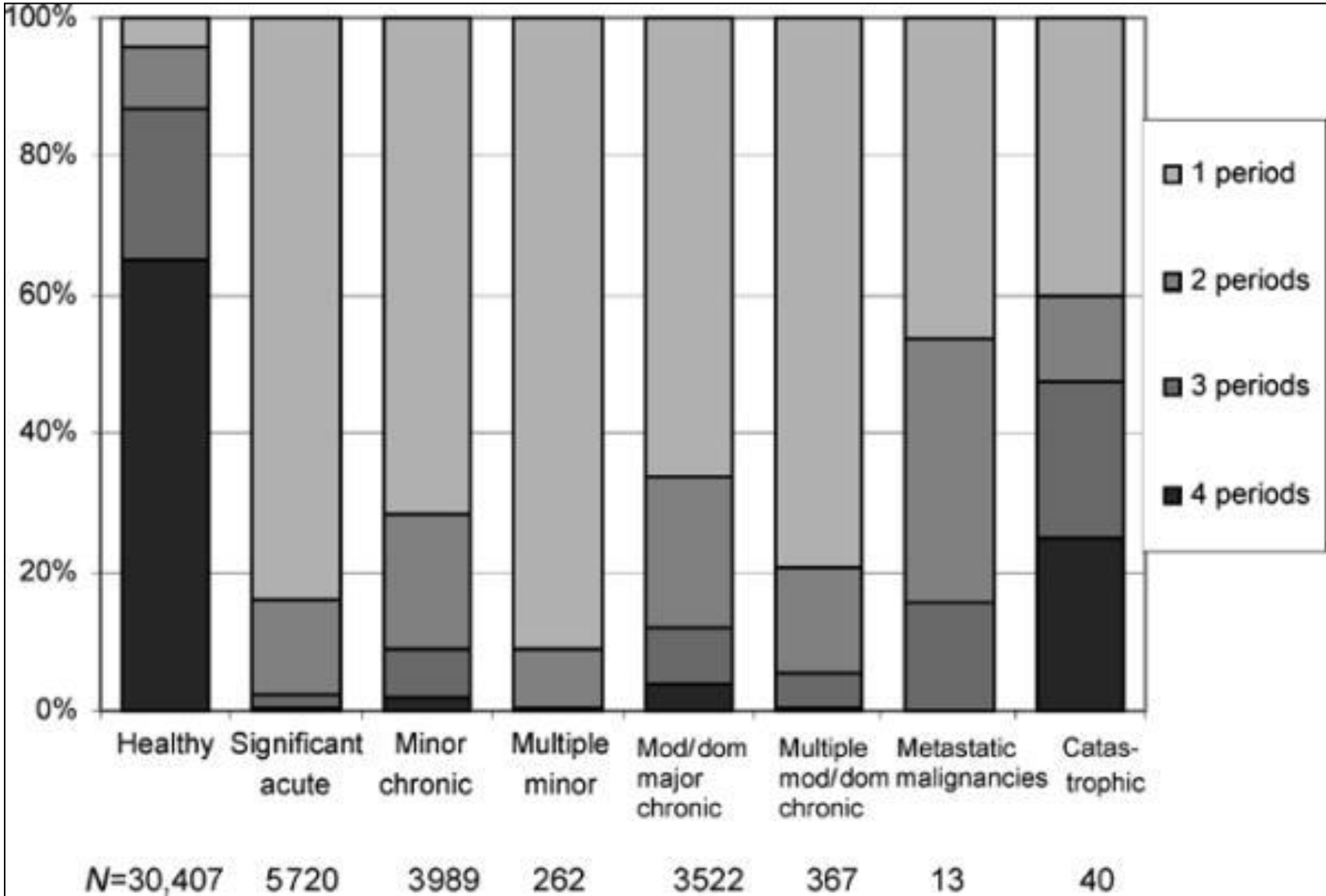
Setting rates for CSHCN

- Define your population
- Look at prior expenditures
- Project future costs
 - Depends on the duration the special health care needs
 - Different identification systems will varying power to predict duration of special needs and future expenditures

Setting Appropriate Rates: How do you Predict Future Costs

Adjusters	% Variance Explained
Age and sex	0.2
Age, sex, and subjectively rated health status	3.9
CSHCN information as adjusters	
Age sex and CSHCN status	
Age, sex and need of prescription	3.2
Age, sex and need of more health care	4.7
Age, sex and need ability limitation	3.1
Age, sex and need of special therapy	3.4
Age, sex and need of counseling	1.9
Age, sex, and all CSHCN information	7.3
Age, sex and chronic illness codes	12.1
Age, sex and prior expenditures	43.5
Age, sex, all CSHCN information, and chronic illness codes	13.5
Age, sex, all CSHCN information, and prior expenditures	48.5

Stability of Clinical Risk Groups (CRGs) classification across 4 calendar years.



Neff, John M. MD; Sharp, Virginia L. MA; Popalisky, Jean MN; Fitzgibbon, Tracy BSN
 Journal of Amb Care Management 2006

Next Steps

- Determine a system that can be used to identify and track children (registry) with special health care needs
- Engage in QI process to implement registry
- Identify a care coordination activity for your children with special health care needs
- Use QI activity to implement activity

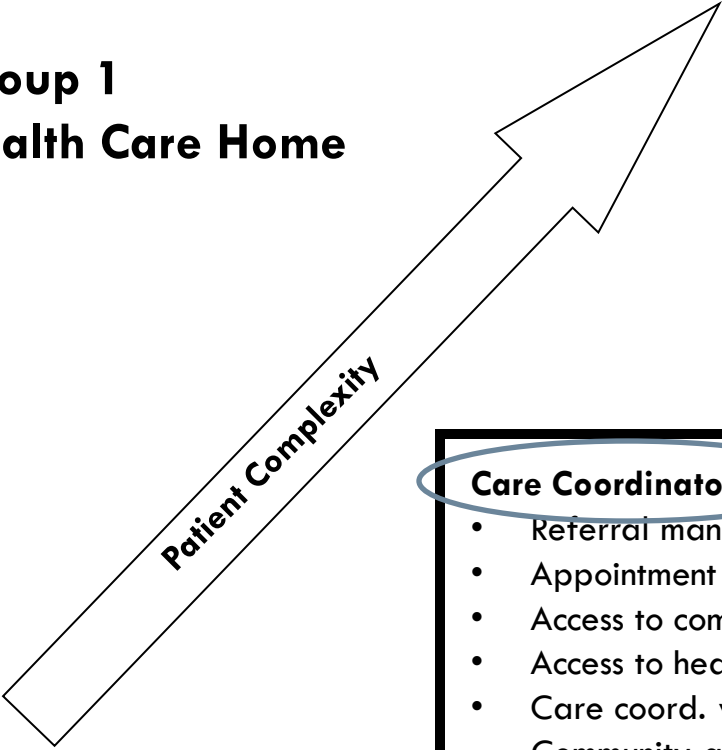
CSHCN Identification System

- What system?
 - ▣ Administrative data driven systems
 - ▣ Informal systems
 - ▣ Patient centered systems
- Creation of a registry
 - ▣ Prospective
 - ▣ Retrospective
- Maintenance of registry

Identify a Care Coordination Activity for Your Children with Special Health Care Needs

- Choose an activity that cuts across chronic illness conditions
- Build on existing quality improvement efforts in your practice e.g. asthma action plans
- Consider using a tiered approach
- Some possibilities...

Group 1 Health Care Home



Patient Complexity

Case Manager (for children With complex medical conditions)

- Disease specific
- Facilitates family education about disease and disease management

Care Coordinator

- Referral management
- Appointment coordination
- Access to community resources
- Access to health information
- Care coord. with schools and Community agencies

Team based care

- Includes pediatric specialist

24x7 Access to Health Care Home

- Access to provider who knows family
- Email and phone access to providers
- Same day appt. with PCP; appt. within 3 days for specialists

Infrastructure to support

- Patient registry
- Referral tracking
- Measuring and reporting quality indicators

Group 2 Plan of Care and Follow-up

Patient Complexity

Individualized care plan

Care plan with:

- Goals
- Treatment Plan

Family education

- Self-management skills
- System navigation

Team based implementation of care plan

- Virtual teams with primary and specialty care

Care summaries

- Integrated across specialties
- Written for family and providers

Huddles to review complex patients

Family support

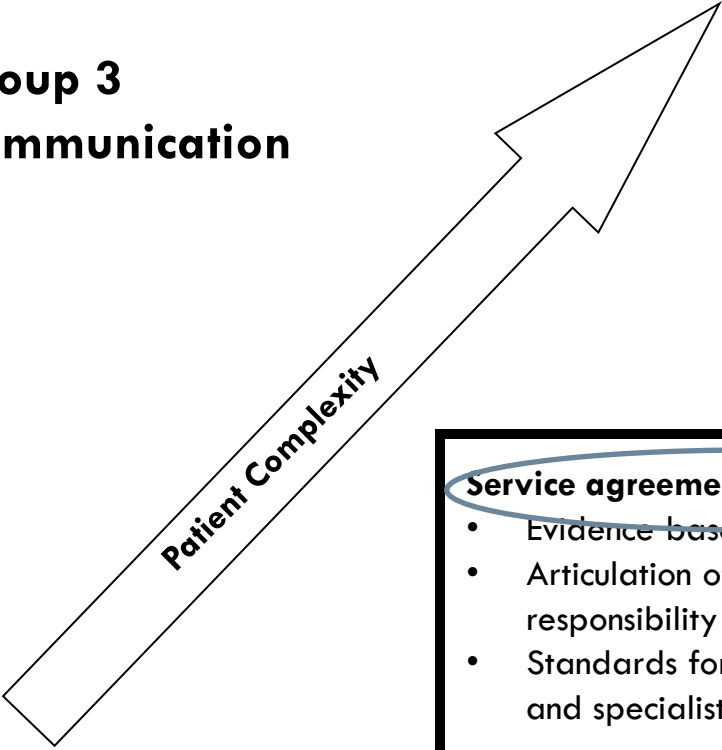
- Program enrollment
 - Financial
 - Family support
- Assistance in obtaining DME
And home health services

School coordination program

Case manager

- Distinct from care coordinator
- May be hospital or plan based

Group 3 Communication



Patient Complexity

Care coordination conferences
In person, by phone or video

Service agreements: PCP & specialist

- Evidence based protocols
- Articulation of PCP/specialist responsibility for plan of care
- Standards for access to PCP and specialists

Shared PHI (plan of care)

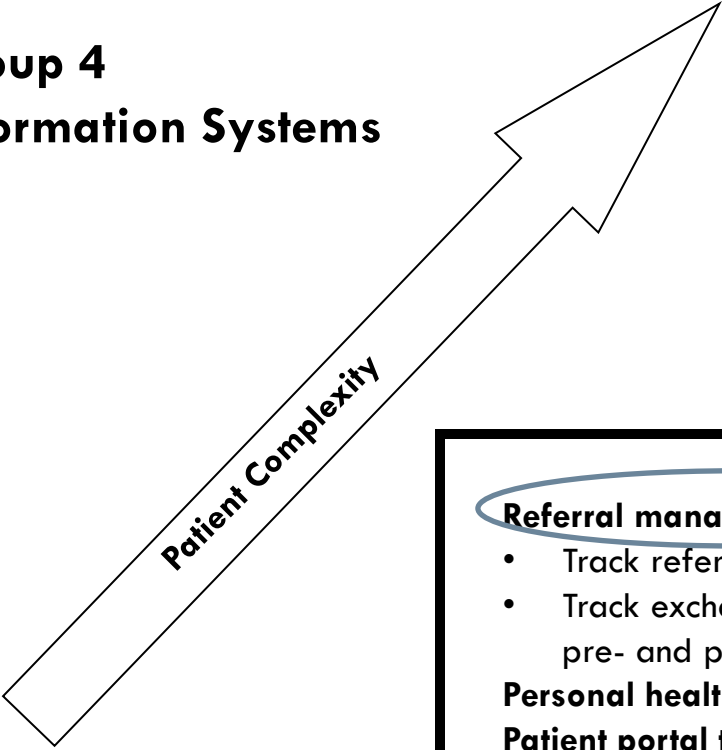
- Family control
- Shared accountability for plan of care

Access to PHI through:

- Patient portal
- PHR
- Shared paper records

**Standardized referrals and
Consultation reports**

Group 4 Information Systems



Patient Complexity

Referral management systems

- Track referral completion
- Track exchange of information pre- and post consultation

**Personal health record or
Patient portal to EHR**

Standardized, integrated Interoperable systems

- EHR
- Health information exchanges

Decision support for families

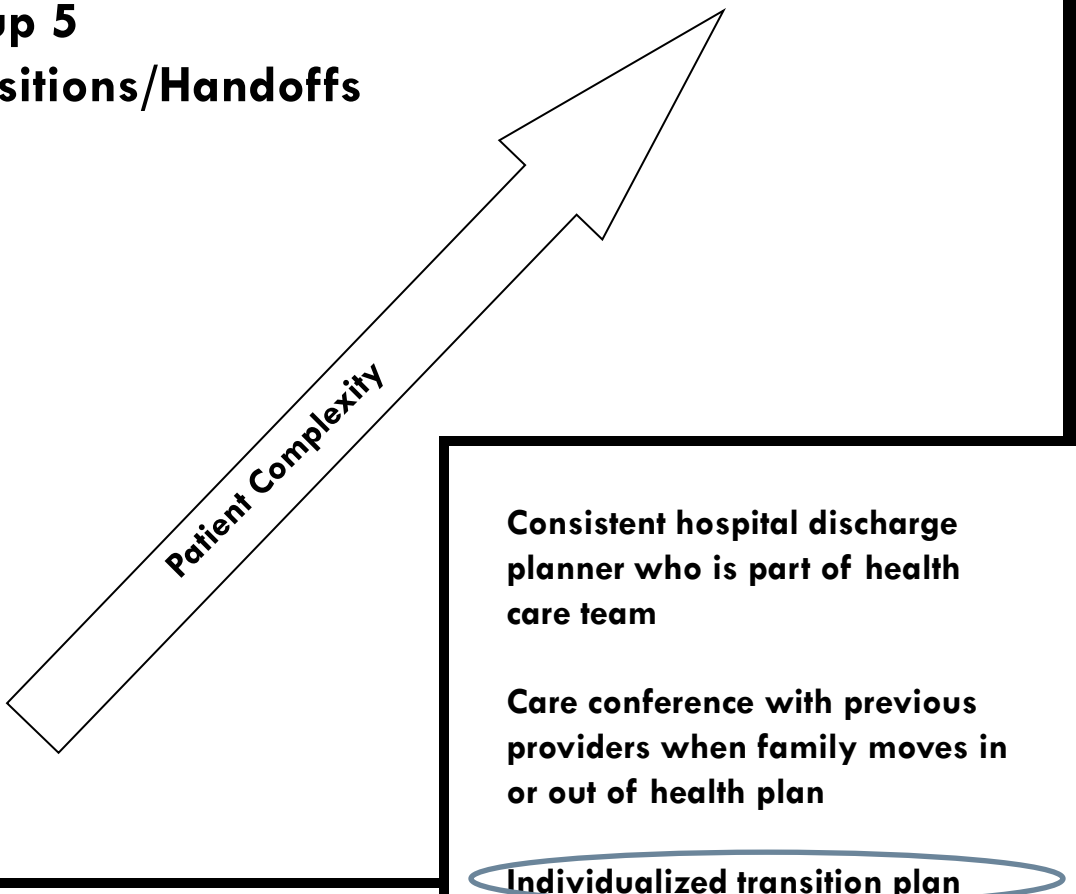
- Appointment reminders
- Care management reminders

Quality management systems

- Track quality indicators for care coordination
- Reports at health plan, practice and provider level

Group 5 Transitions/Handoffs

Patient Complexity



Co-management with
Adult providers

Consistent hospital discharge
planner who is part of health
care team

Care conference with previous
providers when family moves in
or out of health plan

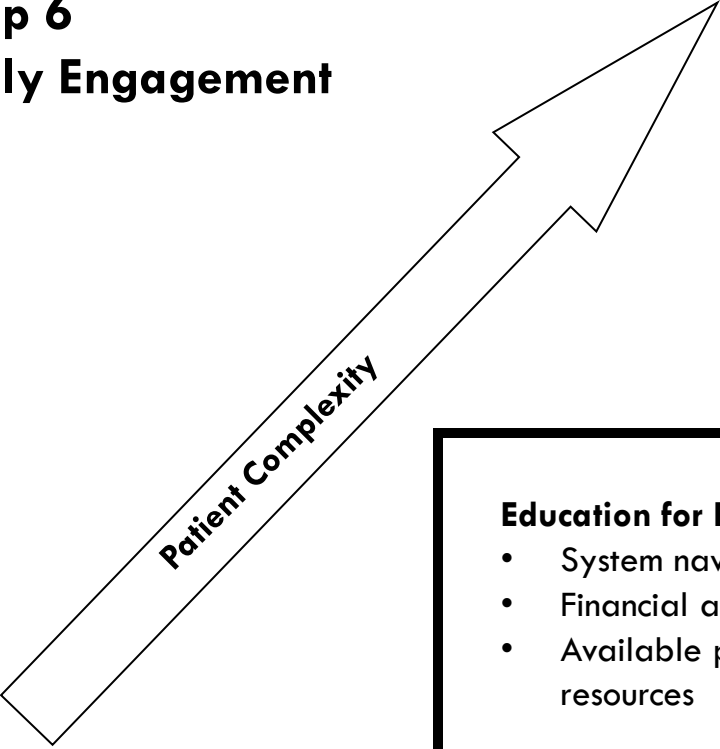
Individualized transition plan

- Transition to adult services
- Transition to and from long term care

Hospital discharge planning

- Coordinated with the PCP
- Change and update care Plan at discharge

Group 6 Family Engagement



Patient Complexity

Lay navigator for families

- Option for families
- Coordination with other educational programs

Education for Families

- System navigation
- Financial assistance
- Available programs and resources

Family Advisory Council

- Representative of Population
- Training for new members
- Participation in program
- Planning and review

Outcome for Today

“Before I came here I was confused about this subject. Having listened to your lecture, I am still confused. But on a higher level.”

Enrico Fermi

Are You Lonely ?

Tired of working on your own?

Do you *hate* making decisions?

Come to a Presentation

YOU CAN

- ⊕ SEE people
- ⊕ DRAW charts
- ⊕ FEEL important

IMPRESS your colleagues



ALL ON COMPANY TIME !!!!!

PRESENTATIONS.....

the practical alternative to work

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