Identifying Children and Youth with Special Health Care Needs (CYSHCN) & Understanding Their Health and Care Coordination Needs:

Real-World Methods, Models, & Strategies
We Want To Hear From You!

Type questions into the **Questions Pane** at any time during this presentation
Patient-Centered Primary Care Institute
History and Development

• Launched in 2012
• Public-private partnership
• Broad array of technical assistance for practices at all stages of transformation
  – Learning Collaboratives
  – Website (www.pcpcli.org)
  – Webinars & Online Learning
• Ongoing mechanism to support practice transformation and quality improvement in Oregon
Oregon’s PCPCH Model is defined by six core attributes, each with specific standards and measures:

- **Access to Care**
  - “Be there when we need you”

- **Accountability**
  - “Take responsibility for us to receive the best possible health care”

- **Comprehensive Whole Person Care**
  - “Provide/help us get the health care and information we need”

- **Continuity**
  - “Be our partner over time in caring for us”

- **Coordination and Integration**
  - “Help us navigate the system to get the care we need safely and timely manner”

- **Person and Family Centered Care**
  - “Recognize we are the most important part of the care team, and we our responsible for our overall health and wellness”

Read more: [http://primarycarehome.oregon.gov](http://primarycarehome.oregon.gov)
Colleen Reuland, MS
Director, Oregon Pediatric Improvement Partnership (OPIP)
Instructor, Department of Pediatrics
at Oregon Health & Science University.
My goal is that by the end of the webinar, participants will:

• Learn how and **why identifying children and youth with special health needs (CYSHCN) is different than identifying adults** with special health care needs.

• Learn about **specific methods** to identifying CYSHCN at the
  – **Practice-level**
  – **System-level**

• Within each example, learn about how this information helps to inform better **child- and family- centered care coordination processes**.
Focus for Today is on Children....... And Children are NOT Little Adults
Why are Approaches to Identify CYSHCN Different Than Those for Adults?

- The Maternal and Child Health Bureau defines CYSHCN as “those who have or are at increased risk for 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.”

- Three key points in this definition:
  - There must be the presence of a condition (not necessarily a diagnosis)
  - They utilize more services than would be expected normally
  - Includes “At risk”

- Strategies often used for adults focused on chronic conditions
  - Due to comorbidity of chronic conditions, if you pick the top four conditions you will identify most adults

- Children, for most the part, don’t have “chronic conditions”

- Approach based on diagnoses requires hundreds of diagnoses
  - Picking top four won’t get you the majority of CYSHCN

- Many children experience health consequences long before they get a diagnosis
Using this Definition, How Many CYSHCN are in Oregon?

- **Estimated Number of CYSHCN in Oregon:** 119,187*
- **13.7%** of children in Oregon are CYSHCN


<table>
<thead>
<tr>
<th>National Indicators</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child Health</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CSHCN whose conditions affect their activities usually, always, or a great deal</td>
<td>29.3</td>
<td>27.1</td>
</tr>
<tr>
<td>CSHCN with 11 or more days of school absences due to illness</td>
<td>17.8</td>
<td>15.5</td>
</tr>
<tr>
<td><strong>Access to Care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CSHCN with any unmet need for specific health care services</td>
<td>29.5</td>
<td>23.6</td>
</tr>
<tr>
<td>CSHCN with any unmet need for family support services</td>
<td>10.1</td>
<td>7.2</td>
</tr>
<tr>
<td>CSHCN needing a referral who have difficulty getting it</td>
<td>23.9</td>
<td>23.4</td>
</tr>
<tr>
<td><strong>Impact on Family</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child</td>
<td>24.7</td>
<td>22.1</td>
</tr>
<tr>
<td>CSHCN whose conditions cause financial problems for the family</td>
<td>22.7</td>
<td>21.6</td>
</tr>
<tr>
<td>CSHCN whose families spend 11 or more hours per week providing or coordinating child’s health care</td>
<td>10.0</td>
<td>13.1</td>
</tr>
<tr>
<td>CSHCN whose conditions cause family members to cut back or stop working</td>
<td>26.5</td>
<td>25.0</td>
</tr>
</tbody>
</table>
Setting the Stage: Why is Identifying CYSHCN Important for Practices (Patient Centered Primary Care Homes) & Health Systems?
At Practice-Level: Why Identify CYSHCN?

Why Patient Centered Primary Care Homes (PCPCH) should identify CYSHCN:

• Original model of medical home developed for CYSHCN given the need for comprehensive and coordinated care for this population
  – Introduced in 1967 by the American Academy of Pediatrics (AAP) as a model specifically designed for children and youth with special healthcare needs (CYSHCN)
  – Some argue it is the population for which the medical home model and set of services is MOST needed
  – A “node” within primary care is integral for this population receiving services within the health care system, community-based services, and in schools

• A key attribute of a PCPCH is population management
  – Ability to identify a population
  – Ability to look at specific services for that population
  – Ability to assess for quality and disparities in quality for this population

Measures: (Check all that apply)

• **5.A.1** - PCPCH demonstrates the ability to identify, aggregate, and display and utilize up-to-date data regarding its patient population, including the identification of sub-populations. (5 points)*

• **5.A.2** - PCPCH demonstrates the ability to stratify their population according to health risk such as **special health care needs** or health behavior. (10 points)

*5.A.1a and 5.A1b from 2014 were combined into 5.A.1*
2017 Standards: 5.C – Complex Care Management

Measures: (Check all that apply)

- **5.C.1** - PCPCH demonstrates that members of the health care team have defined roles in care coordination for patients, and tells each patient or family the name of the team member(s) responsible for coordinating his or her care.

- **5.C.2** - PCPCH describes and demonstrates its process for identifying and coordinating the care of patients with complex care needs. (10 points)

- **5.C.3** - PCPCH develops an individualized written care plan for patients and families with complex medical or social concerns. This care plan should include at least the following: self-management goals; goals of preventive and chronic illness care; and action plan for exacerbations of chronic illness. (15 points)
2017 Standard (unchanged from 2014): 5.E – Referral and Specialty Care Coordination

Measures: (Check all that apply)

• **5.E.1** - PCPCH tracks referrals to consulting specialty providers ordered by its clinicians, including referral status and whether consultation results have been communicated to patients and/or caregivers and clinicians. (5 points)

• **5.E.2** - PCPCH demonstrates active involvement and coordination of care when its patients receive care in specialized settings (hospital, SNF, long term care facility). (10 points)

• **5.E.3** - PCPCH tracks referrals and cooperates with community service providers outside the PCPCH, such as dental, educational, social service, foster care, public health, non-traditional health workers and pharmacy services. (15 points)
At System-Level: Why Identify CYSHCN?

Why health systems (including CCOs) should identify CYSHCN:

• CYSHCN need **comprehensive and coordinated care**
  – Receive services within the health care system
  – System-level approaches to coordination, and supports for families are integral roles health systems can play

• Health systems are meant to do **population management**
  – In order to manage a population, you need to be able to identify them
  – Systems should assess for quality and disparities in quality for this population
At System-Level: Why Identify CYSHCN?

• While the numbers of the CYSHCN population are relatively small (*as compared to adults*), represent a significant percentage of health care costs for children. For example:
  
  – CYSHCN represent roughly 15-20% of the childhood population and account for **80% of the healthcare expenditures** for all children
  
  – Children with *chronic* physical, mental, behavioral, and emotional conditions make up 14-16% of the pediatric population and account for **30% of the total health care costs**
  
  – 5% of patients make up **40% of hospital costs**

• Unquantifiable cost to families of CYSHCN.
  
  – In the absence of a high functioning medical home, **families are required to become care coordinators** in addition to their role as the care taker of the child
  
  – Families of CYSHCN articulate frustration at being unable to “parent” their children due to the overwhelming demands of navigating the complex systems of care and often at least one family member is not able to work
Is there a gold standard, ONE best way to identify CYSHCN?
The best methodology to identify CYSHCN depends on:

1) **WHY** you are identifying CYSHCN, and

2) **WHAT** data sources you have available
Various Reasons for Identifying CYSHCN that Impact Methodology Used

• To track and assess a broad population of CYSHCN and assess for disparities in quality
• To identify a specific population that would benefit from care coordination
• To identify a specific population that would benefit from complex care management
• To identify a specific population to allocate care coordination resources
• To identify a specific population to inform payment methodologies
  – Rate setting
  – Alternative Payment Methodology (APM) tied to care coordination
  – APM tied to reduction of costs (not all CYSHCN’s costs can be reduced)
Various Data Sources Available to Practices and Systems
(Target for this Webinar) Impact Methodology Used

1. Claims – total and cost, type of claims, type of services received

2. Diagnosis

3. Chart/EMR Data – Problem lists, clinical gestalt

4. Provider Gestalt

5. Parent report on standardized tools
   - Within population surveys
   - At time of enrollment
   - Administered within clinic
Therefore, the best methodology will be anchored to:

• Feasible and meaningful methodology that addresses the reason you are identifying CYSHCN **AND** data source(s) available
  – Within the data source, bound to reliability, validity, and sensitivity of that data source

• The best methodology for one goal may not be aligned with that of a different goal
  – Example: Best methodology for identifying CYSHCN aligned with the **MCHB definition** is **not the same** as the best methodology to identify children who **cost the most** which is **not the same** as the best methodology to identify children who **may benefit from complex care management**

• The best methodology **may require data for each person that is not available**...for example: Patient report data not available at the system-level to inform system-level allocation of resources of APMs
Given Various Reasons, Methodologies, Data Sources & Audience for This Webinar:

We will share some applied models OPIP has worked with partners to implement that:

1. Identify CYSHCN for:
   - Population management
   - Benefit from enhanced care coordination

2. Child & family-centered processes that can be used to:
   - Identify care coordination needs
   - Identify the best team to meet the child’s needs
Given Various Audience for This Webinar:

Focus spotlights on:
A) **System**-Level Strategies

B) **Primary Care Practice**-Level Strategies
**Strategy Spotlight #1: Reason/Data Source**

**Various Reasons for Identifying:**

- To track and assess a **broad population** of CYSHCN and assess for disparities in quality
- To identify a **specific population** that would benefit from **care coordination**
- To identify a **specific population** that would benefit from **complex care management**
- To identify a **specific population** to allocate **care coordination resources**
- To identify a **specific population** to inform **payment methodologies**

**Various Data Sources:**

1. Claims, Total number, type of claims, type of services received
2. Diagnosis
3. EMR Data – Problem lists, clinical gestalt
4. Provider Gestalt
5. Parent report on standardized tools
   - Within population surveys
   - At time of enrollment
   - Administered within clinic
Example Strategy #1: Identifying CYSHCN for Population-Level Assessment Using Patient Report

- Leverage collection and requirements around the Consumer Assessment of Healthcare Providers® (CAHPS®) Tool

- System Level:
  
  - **Within CCOs:** CAHPS® Health Plan (CAHPS® HP) Survey for Children Includes the Children with Chronic Conditions (CCC), Collected Annually
    
    - Includes a sampling strategy to identifying potential CYSHCN based on claims and diagnoses (Children with Chronic Conditions)
    
    - A parent-report set of items, the CYSHCN Screener, developed by the Child and Adolescent Health Measurement Initiative (CAHMI) in survey
      
      - Parent report to these items determines which children are CYSHCN
      
      - Items within the survey can then be stratified by CYSHCN

  - **Within Practices:** PCPCH standards include a focus on collection of the CAHPS® CG or CAHPS® CG PCMH
    
    - Practices can add the CAHMI CYSHCN screener to their survey
    
    - Practice can create a specific sample of CYSHCN they have identified
Meant to operationalize **broad MCHB definition** for population assessment

**Asks about 5 different health consequences:**

1) Limited or prevented in ability to function
2) Prescription medication need/use
3) Specialized therapies (OT, PT, Speech)
4) Above routine use of medical care, mental health or other health services
5) Counseling or treatment for on-going emotional, behavioral or developmental problem

\[\text{a) Due to medical, behavioral or other health condition AND b) Condition has lasted or is expected to last for at least 12 months}\]
CAHMI CYSHCN Screener

Q1: Prescription (RX) Meds
Q2: Above Routine Service Use
Q3: Functional Limitations
Q4: Specialized Therapies
Q5: Mental Health

CYSHCN
Children meeting 1 or more of the above qualifying screening criteria
Example of **Heath System Use** of Strategy #1: Identifying CYSHCN for Population-Level Assessment Using Patient Report

- OPIP received a transformation contract from Willamette Valley Community Health (WVCH) to help them better use their CAHPS® data and inform QI efforts
  - OPIP is a Transformation Center TA Bank Provider

- OPIP created strategic reports of the data findings for:
  - WVCH Board
  - WVCH Clinical Advisory Panel (CAP)
  - WVCH Community Advisory Council (CAC)
  - Facilitated a meeting of system-level leaders and practices on CAHPS® findings

- Presented them the CAHPS® CCC Findings showing:
  - Proportion of WVCH respondents that are CYSHCN
  - Variations and disparities in care for CYSHCN

*Presentation on the Project:* [https://www.oregon.gov/oha/Transformation-Center/Documents/1C-PatientExperience-Reuland.pdf](https://www.oregon.gov/oha/Transformation-Center/Documents/1C-PatientExperience-Reuland.pdf)
### WVCH: One in Five Children Have a Special Health Care Need (CYSHCN)

<table>
<thead>
<tr>
<th>Children &amp; Youth w/ Special Health Care Needs (CYSHCN)</th>
<th>Non-CYSHCN</th>
<th>CYSHCN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid % (N)</td>
<td>80% (N=262)</td>
<td>20% (N= 68)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of CYSHCN Consequences</th>
<th>1 Consequence</th>
<th>2 Consequences</th>
<th>3 Consequences</th>
<th>4-5 Consequences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid % (N)</td>
<td>7% (N= 24)</td>
<td>4% (N= 12)</td>
<td>4% (N= 15)</td>
<td>5% (N= 17)</td>
</tr>
</tbody>
</table>

**The 5 different CYSHCN consequences:**

1. Limited or prevented ability to function
2. Prescription medication need/use
3. Specialized therapies (OT, PT, Speech)
4. Above routine use of medical care, mental health or other health services
5. Counseling or treatment for on-going emotional, behavioral or developmental problem

**EACH consequence must be:**

- A) Due to medical, behavioral, or other health condition; **AND**
- B) Condition has lasted or is expected to last for at least 12 months
WVCH Children scored among the **TOP 3 OF ALL CCOs** on the **Getting Needed Care, Access to Specialized Services, and Personal Doctor Who Knows Child** Domains

2015 CAHPS® HP **CHILD** Survey Data:

**WVCH Quality Domain Scores compared to other CCOs**

- **Getting Needed Care**: +6.2
- **Getting Care Quickly**: -2.3
- **How Well Doctors Communicate**: -1.8
- **Customer Service**: +0.7
- **Shared Decision Making**: +1.2
- **Access to Specialized Services**: +14.2
- **Personal Doctor Who Knows Child**: +5.5
- **Care Coordination for Children & Youth w/ Special Health Care Needs (CYSHCN)**: -1.7

**Percentage above bars:**

**Difference** between WVCH Children and CCO Means for Children

**NEGATIVE** number = **WVCH Children scored WORSE**

**Green Bars:** Range of scores among all CCOs (n=16)
VARIATIONS in WVCH Child Scores on Rating of Specialist by MENTAL HEALTH and CYSHCN Mental Health Consequence

2015 CAHPS® HP CHILD Survey Data: Rating of Specialist, by Mental Health

Rating of SPECIALIST in the past 6 months (N=39)

- 19% of children rated their Specialist as Excellent/Very Good.
- 21% rated their Specialist as Good/Fair/Poor.

2015 CAHPS® HP CHILD Survey Data: Rating of Specialist, by Mental Health CYSHCN Consequence

Rating of SPECIALIST in the past 6 months (N=37)

- 19% of children rated their Specialist as Excellent/Very Good.
- 21% rated their Specialist as Good/Fair/Poor.
Example of **Practice-Level Use** of Strategy #1: Identifying CYSHCN for Population-Level Assessment Using Patient Report

• Through two different medical home learning collaboratives and partnership with Oregon Health Authority, practice-level use of the CAHPS® CG PCMH
  – Standardized sampling
  – Standardized administration with vendor
  – CYSHCN items added
  – In some sites, survey administered twice to assess for impact of medical home quality improvement efforts

• OPIP worked with sites to:
  – SHARE their data across the practice
  – USE their data to inform QI efforts
  – SHARE their data with their patients

*Presentation on part of the Project:*
[https://www.oregon.gov/oha/Transformation-Center/Documents/1C-PatientExperience-Reuland.pdf](https://www.oregon.gov/oha/Transformation-Center/Documents/1C-PatientExperience-Reuland.pdf)
Proportion of Children and Youth With Special Health Care Needs in Learning Collaborative Sites

Percentage of Children Identified as CYSHCN on the CAHMI Screener

<table>
<thead>
<tr>
<th>Site</th>
<th>CYSHCN</th>
<th>Non-CYSHCN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site 1</td>
<td>31%</td>
<td>69%</td>
</tr>
<tr>
<td>Site 2</td>
<td>27%</td>
<td>73%</td>
</tr>
<tr>
<td>Site 3</td>
<td>23%</td>
<td>77%</td>
</tr>
<tr>
<td>Site 4</td>
<td>23%</td>
<td>77%</td>
</tr>
<tr>
<td>Site 5</td>
<td>22%</td>
<td>78%</td>
</tr>
<tr>
<td>Site 6</td>
<td>9%</td>
<td>91%</td>
</tr>
<tr>
<td>Site 7</td>
<td>49%</td>
<td>51%</td>
</tr>
</tbody>
</table>

CYSHCN: Children and Youth with Special Health Care Needs
Non-CYSHCN: Non-CYSHCN
Variation in CAHPS® CG PCMH Quality Domain Achievement Scores by CYSHCN Status

Variation is statistically significant

- Access
- Communication
- Child Development
- Child Prevention
- Self-Management
- Office Staff

* Non-CYSHCN
* CYSHCN
Using CAHPS® CG PCMH Data to Evaluate Improvement Efforts from Patient Perspective

**Example from a practice:**

<table>
<thead>
<tr>
<th>Question</th>
<th>2014 Score</th>
<th>2012 Score</th>
<th>% Change</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Q48.</strong> Someone at provider's office talked to you about whether there are any problems in your household that might affect your child</td>
<td>56.5%</td>
<td>39.2%</td>
<td>+17.3</td>
</tr>
<tr>
<td><strong>Q36/Q50.</strong> Someone at provider's office asked if there are things that make it hard for you to take care of your (child's) health</td>
<td>29.3%</td>
<td>24.0%</td>
<td>+5.3%</td>
</tr>
</tbody>
</table>
Strategy Spotlight #2: Reason/Data Source

Various Reasons for Identifying:

• To track and assess a broad population of CYSHCN and assess for disparities in quality
• To identify a specific population that would benefit from care coordination
• To identify a specific population that would benefit from complex care management
• To identify a specific population to allocate care coordination resources
• To identify a specific population to inform resource allocation

Various Data Sources:

1. Claims, Total number, type of claims, type of services received
2. Diagnosis
3. Chart/EMR Data – Problem lists, clinical gestalt
4. Provider Gestalt
5. Parent report on standardized tools
   – Within population surveys
   – At time of enrollment
   – Administered within clinic
Example Strategy #2: **System-Level** - Identifying CYSHCN for Enhanced Care Coordination Using Claims/EMR

- Region-level activities to impact all children enrolled in KPNW
  - N=93,637 paneled to pediatrician. N= 115,500 in systems (includes FM)
  - 17,254 pediatric Medicaid patients
- Team Based Care (TBC) had existed for adults, but not children
- Initial pilot level activities focused on children in Mt. Scott (MTS) and new pediatric Team Based Care for Complex Care Management, with potential to spread clinics across region

**Three Parts to the OPIP Learning Curriculum & Support**

<table>
<thead>
<tr>
<th>#1</th>
<th>#2</th>
<th>#3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support for Pilot of Complex Care MTS: Developing tools, strategies and care coordination methods</td>
<td>Based on MTS learning, support to develop standardized team-based care tools for CYSHCN that will be spread around KPNW</td>
<td>Develop System-Level Methods to Identify CYSHCN that Would Benefit from Complex Care Management</td>
</tr>
</tbody>
</table>
Example Strategy #2: **System-Level - KPNW**
Identifying CYSHCN for Enhanced Care Coordination Using Claims/EMR and...in the Future... Patient Report

- **Data sources available** (currently) for all children in the system
  - Types of visits and types of services (e.g. claims)
  - Diagnoses
  - Searchable fields in the EMR (Most health systems don’t have access to this)

- **Algorithms available**
  - Proprietary: 3M Clinical Risk Groups (CRGs)
  - Publicly Available:
    - CAHMI developed CCC module for CAHPS® (used for CAHPS® HP)
    - Feudner Complex Chronic Conditions
    - Perrin/Kultha’su Chronic Condition List (CCL)
    - Chronic Illness and Disability Payment System (CDPS)
    - **Pediatric Medical Complexity Algorithm**
Pediatric Medical Complexity Algorithm (PMCA)

• Developed by a team at Seattle Children’s, Validated by COE4CCN efforts
  – For children 0 to 18 insured
  – Developed as a way to **target and allocate care coordination resources**

• Categorizes complexity into three categories:
  1) **Complex Chronic Disease,**
  2) **Non-Complex Chronic Disease,** and
  3) **Without Chronic Disease**
  – Takes into account three main factors:
    • Diagnoses
    • Number of body systems impacted
    • Patient utilization
  – The three categories are co-linear with COST (*i.e. as complexity increases, so does cost*)

• Current version included in the materials

*Slide adapted from overview materials provided here:*
Pediatric Medical Complexity Algorithm (PMCA)

1) Complex Chronic Disease
   – Sig. chronic condition in two or more body systems
   – Progressive condition associated with deteriorating health and decreased life expectancy in adulthood OR
   – Technology dependent for 6 months OR
   – Malignancy, excluding those in remission for more than five years

2) Non-Complex Chronic Disease, and
   – Chronic conditions that are lifelong but not complex
     • One body system
     • Conditions not progressive
   – Episodic chronic conditions with variable duration and severity

3) Without Chronic Disease
   – No chronic conditions
   – Occasional self-limited acute (e.g. ear infection)

Slide adapted from overview materials provided here:
Development of Innovative Methods to Stratify Children with Complex Needs for Tiered Care: Assessing both Medical and Social Complexity

Center of Excellence on Quality of Care Measures for Children with Complex Needs
University of Washington and Seattle Children’s Research Institute
Social Factors Identified in Lit Review by COE4CCN and Mangione-Smith/Arthur Associated with Higher Costs

- Social Risk Factors Associated with High Costs:
  1. Severe Poverty
  2. Limited English Proficiency
  3. Parent Mental Illness
  4. Parent Criminal Justice Involvement
  5. Child welfare system involvement
  6. Homelessness
  7. Child mental illness
  8. Child substance abuse treatment need
  9. Child juvenile or criminal just involvement

Slide adapted from overview materials provided by COE4CCN and included in Lucile Packard and Child Health Foundation Meeting on CYSHCN: (http://www.lpfch.org/cshcn/about-our-work/2015-symposium/webcast)
System-Level Data Used to Identify Potential Children for Complex Care Management

Part 1: Medically Complex
(1) Complex chronic, (2) Non-Complex Chronic, (3) Healthy
Using Pediatric Medical Complexity Algorithm (PMCA)

Medically & Socially Complex
Part 2: Socially Complex
Categories TBD based on #s
Based on Available System-Level Data Related to Social Complexity Factors Predicative of High Costs

Using Part 1 & Part 2 IDENTIFY & SPECIFY:
1) Who Should Receive Team Based Care (TBC),
2) Proposed Level of Complex Care Management,
3) Proposed Best Team for Assessment

Primary Care Provider (PCP) & Team-Based Care (TBC)
Tiering of Patients & Assignment of Team

Part 1: PCP Gestalt related to Social Risk Factors & Care Coordination Needs

Part 2: TBC Team Intake and Assessment

FINAL Tailored TBC Model and Team Identified for Child:
1) LEVEL of Complex Care Needed – Levels 1-4
2) BEST MATCH CARE TEAM
   -- Within TBC, Specific Lead Person Identified AND/OR
   -- Complex care management provided within other programs (Model line, ENCC, Spec. Services)

Monthly Flag of Patients with a High Cost Event (ER, UC, Hospitalization)

Enhanced Data To Be Used for the Part 2 Identification

ALL PATIENTS:
Using Medical and Social Complexity Data to Assign System-Level Care Coordination Resources AND Best Fit Team

- OPIP and KPNW currently working to develop an algorithm that will identify **which** children should be assigned to team based care for assessment (limited resources)
  - Of those children: Identify the best person to do the care needs assessment in way that best meets the child and family needs
    - E.g.
      - High Medical Complexity, Low Social Complexity = Nurse
      - Low Medical Complexity, High Social Complexity = Social Work
  - Of those children assessed ➔ Care coordination score about the LEVEL and TYPE of care coordination resources that should be invested based on the medical and social complexity scores
    - Level: How many “touches”, level of pre-visit planning
    - Best Match Team for the Child and Family
      - PCP and MA
      - KPNW Peds Complex Care Team
        - Full Team: RN, Social Worker, Navigator, Lead MD
        - Part of the Team: RN only, Social Worker only, etc
Examination of Social Risk Factors Available the System-Level that Can be Used to Generate a Global Social Risk Score (Non-Identifying)

Of the factors in literature and noted by COE4CCN, KPNW examining the following system-level data:

1. **Poverty** – Medicaid, Children in Poverty, but Above Medicaid Limit
2. **Limited English proficiency**
3. **Parent mental health service need** – general count to be provided that is non-identifying
4. **Child welfare system involvement**
5. **Child mental health service need**
6. **Child substance abuse treatment need**
7. **Homelessness**
8. **Child juvenile or criminal justice involvement**
9. **Child truancy** (added)

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**Green** - Data exist within the system

**Orange** - Will be collecting via well visit surveys and a social complexity smartset that providers will complete
Intake RN Assessment
Kaiser Permanente North West (KPNW)

- Completed over the phone or in person
- Have a separate age appropriate Social Worker Assessments for socially complex families
- Questions in the following categories:
  - Child status
  - Medical conditions/functional status
  - Current Tx
  - Medications
  - Mental health status
  - Communication barriers
  - Living situation
  - Food/clothing/housing
  - School
Strategy Spotlight #3: Reason/Data Source

Various Reasons for Identifying:

• To track and assess a broad population of CYSHCN and assess for disparities in quality

• To identify a specific population that would benefit from care coordination

• To identify a specific population that would benefit from complex care management

• To identify a specific population to inform payment methodologies or resource allocation

Various Data Sources:

1. Claims, Total number, type of claims, type of services received
2. Diagnosis
3. Chart/EMR Data – Problem lists, clinical gestalt
4. Provider Gestalt
5. Parent report on standardized tools
Example Strategy #3: Practice-Level Identification of CYSHCN for Care Coordination

- Within practices often a two-step process:
  1. Identifying WHICH children may benefit from enhanced care coordination
  2. Assessment of the child and family care coordination needs

- Data most commonly available to practices:
  - Claims
    » Often too labor intensive, hundreds of codes
  - Provider gestalt
  - Parent report

* OPIP developed a brief on strategies using each one: Identification of Children & Youth with Special Health Care Needs (CYSHCN)*
Example Strategy #3: Practice-Level
Identification of CYSHCN for Care Coordination
Part 1: WHICH Children

• **Part A: PROVIDER GESTALT**
  o Developed standardized methods for providers to indicate need
  o Examples Used:
    i) List out the five consequences in the CAHMI definition to identify kids – pick kids with 3 or more OR mental health need.
    ii) More stringent criterion given care coordination staff resources:
        ✓ If the child had one or more specialists, or
        ✓ Child used more than one community resource, or
        ✓ Child had an obvious limitation, or
        ✓ Limited family functioning/capacity

• **Part B: PARENT REPORT**
  o Used the CAHMI CYSHCN Screener
    • New patient visits, annually OR for young children at a visit at which there are not other screens
Example Strategy #3: **Practice-Level**
Identification of CYSHCN for Care Coordination

Part 2: **WHAT** Care Coordination Needs

- Once children identified, then need to identify specific care coordination needs and best family and child-centered care team

- Tools used need to be anchored to the care coordination **resources** in the practice, **care coordination team** in the practice, and the **time and resources available to assess** for care coordination needs

- Examples provided on the next slides:
  1. Care Coordination Assessment: Jeannie McAllister
  2. Intake Assessment- Pediatric Partners in Care (Seattle Children’s)
  3. MA Pediatric Care Coordination Needs Assessment Tools
  4. Pre-Visit Contact Form Chapel Hill Pediatrics and Adolescents
  5. Exeter Pediatric Associates ‘HOMES’ Complexity Scale
  6. Care Coordination Needs Assessment: (Bob’s System)
  7. Complexity Index (Phoenix Pediatrics) David Hirsch MD
Lucile Packard Foundation for Children’s Health
Pediatric Care Coordination Assessment

Appendix E
Pediatric Care Coordination Assessment

Child/Youth Name ___________________________ Date __________
Family Name ________________________________

1. What would you like us to know about your child? What does he/she do well? Like? Dislike?
________________________________________________________________________
________________________________________________________________________

2. What would you like us to know about you/your family?
________________________________________________________________________
________________________________________________________________________

3. Do you have any concerns or worries for your child? (Some examples below)
   - Their growth/development
   - Learning
   - Sleeping
   - Self-care
   - Making and keeping friends
   - Other

   - Doing things for themselves
   - Falling behind in school
   - Behavior
   - The future
   - Playing with friends

4. Have there been any important changes since we saw you last, such as a:
   - Brother or sister leaving home?
   - New job or job change?
   - Moving to a new town?
   - Separation or divorce?
   - Sickness or death of a loved one?
   - Other (fill in below):

5. Can we help you with any of the following needs?
   - Medical (For example, help finding or understanding medical information; help finding health care for yourself or your family)?
   - Social (For example, helping someone to talk to when you need to; getting support at home; finding supports for the rest of your family)?
   - Educational (For example, explaining your child’s needs to teachers; help reading or understanding medical information)?
   - Financial (For example, understanding insurance or finding help paying for needs that insurance does not cover — such as medications, formulas, or equipment)?
   - Environmental (For example help finding clean air, air filters or safety items for your home)?
   - Legal (For example, discussing laws and legal rights about your child’s health care or their school needs)?
   - General. Please let us know what else you need help with (if we don’t know, we will work with you to help find the answer):

Notes:

Found Here:

**Intake Assessment - Pediatric Partners in Care (Seattle Children’s)**

- Completed over the phone
- Questions in the following categories:
  - Communication barriers
  - Cultural beliefs
  - Housing concerns/living arrangement
  - Caregiver status
    - Health and wellness
    - Learning disabilities
    - Safety
    - Food support
  - Child status
    - PCP info
    - Well care/prevention
    - Medications
    - Developmental status
    - Mental health
    - School

<table>
<thead>
<tr>
<th>Category</th>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication Barrier</td>
<td>Have any communication barriers?</td>
<td>No Answer</td>
</tr>
<tr>
<td>Cultural Belief</td>
<td>Are your cultural beliefs an important consideration in decisions about your child’s health?</td>
<td>No Answer</td>
</tr>
<tr>
<td>Housing Concerns</td>
<td>Do you have any housing concerns?</td>
<td>No Answer</td>
</tr>
<tr>
<td>Child’s Living Arrangement</td>
<td>How does the child’s living arrangement impact their care?</td>
<td>No Answer</td>
</tr>
<tr>
<td>Health and Wellness</td>
<td>Do you have any concerns about your health and wellness?</td>
<td>No Answer</td>
</tr>
<tr>
<td>Learning Disability</td>
<td>Do you have any learning disabilities?</td>
<td>No Answer</td>
</tr>
<tr>
<td>Safety Concerns</td>
<td>Are there any caregiver or patient safety concerns?</td>
<td>No Answer</td>
</tr>
<tr>
<td>Food Support</td>
<td>Do you need food support?</td>
<td>No Answer</td>
</tr>
<tr>
<td>PCP Info</td>
<td>Please provide PCP information.</td>
<td></td>
</tr>
<tr>
<td>Well Care/Prevention</td>
<td>Please provide well care/prevention information.</td>
<td></td>
</tr>
<tr>
<td>Medications</td>
<td>Please provide medication information.</td>
<td></td>
</tr>
<tr>
<td>Developmental Status</td>
<td>Please provide developmental status information.</td>
<td></td>
</tr>
<tr>
<td>Mental Health</td>
<td>Please provide mental health information.</td>
<td></td>
</tr>
<tr>
<td>School</td>
<td>Please provide school information.</td>
<td></td>
</tr>
</tbody>
</table>

**PPIC Care Coordination Assessment**

Patient: Patient ID (01-01-1960)
Primary Provider: UNKNWN

<table>
<thead>
<tr>
<th>Date Performed</th>
<th>List Modified</th>
</tr>
</thead>
<tbody>
<tr>
<td>03-22-2016</td>
<td></td>
</tr>
</tbody>
</table>

[Form fields and checkboxes filled in with data relevant to the assessment categories listed above.]
Massachusetts Child Health Quality Coalition Care Coordination Task Force’s Framework -- Key Elements of High-Performing Care Coordination includes use of a structured care coordination needs assessment tool as one of its priority recommendations.

To support adoption of this recommendation, the Task Force convened a working group to identify key components for such a tool. The working group’s recommendations distill key elements from a range of different tools, and can serve as a starting point for developing your own tool. This representative sample of example tools is provided as an additional reference, offering example formats and question wording with additional context as a supplement to the recommendations.

Source: Pre-Visit Contact Form, Chapel Hill Pediatrics, provided by Jennifer Lail

### Exeter Pediatric Associates

**‘HOMES’ Complexity Scale**

<table>
<thead>
<tr>
<th>Category</th>
<th>Criteria</th>
<th>Score</th>
</tr>
</thead>
</table>
| **Hospitalizations, ER, Usage & Specialty Visits (in last year)** | 1 = 1 hospitalization, ER or specialist visit for complex condition  
2 = 2 or > hospitalizations, ER or specialist visits for complex condition |       |
| **Office Visits and/or Phone Calls (in last year, over and above well child visits, +/- extra charges).** | 1 = 1-2 office visits or MD/RN/care coordinator phone calls related to complex condition  
2 = 3 or more office visits or MD phone calls for complex condition |       |
| **Medical Condition(s): One or more diagnoses** | 1 = 1-2 conditions, no complications related to diagnosis  
2 = 1 or 2 conditions with complications or 3 or more conditions |       |
| **Extra Care & Services at PCP office, home, school, or community setting (see Services)** | 1 = One service from the list below  
2 = Two or more services from the list below  
*Services*: Medications, medical technologies, therapeutic assessments/treatments/procedures, & care coordination activities. |       |
| **Social Concerns**                           | 1 = “At risk” family/school/social circumstances are present  
2 = Current/urgent complex family/school/social circumstances are present |       |

Complexity Scores will range from 0-10  (0-3 low, 4-6 medium, 7-10 high).

Name ________________________________ Date ___________ Total Score = _____
# Care Coordination Needs Assessment:
## (Bob’s System)

<table>
<thead>
<tr>
<th>DIMENSION</th>
<th>LEVEL OF SUPPORT</th>
<th>1 (Minimal)</th>
<th>2 (Limited/Intermittent)</th>
<th>3 (Extensive)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Health</td>
<td>Health status stable, routine preventive care, may see specialist annually</td>
<td>Health status generally stable, regular office visits to review management, periodic consultation with 1 or more specialists</td>
<td>Health status unstable, frequent office visits, regular ER visits or hospitalization, frequent consultations with 1 or more specialists</td>
<td></td>
</tr>
<tr>
<td>2. Family</td>
<td>Family status stable, no major environmental stresses, traditional social supports present and utilized</td>
<td>One or more stresses may be present, family requires occasional support from office and other community resources</td>
<td>Multiple major stresses are present, family resources are overwhelmed, extensive community support needed or major concerns about care giving environment</td>
<td></td>
</tr>
<tr>
<td>3. Behavioral and Mental Health</td>
<td>Behavior health status is stable, routine anticipatory guidance</td>
<td>Regular office visits to review management or regular consultation/counseling with mental health providers</td>
<td>Behavioral health status is unstable, extensive supports from office and community professionals, may require day treatment program or in-patient treatment</td>
<td></td>
</tr>
<tr>
<td>4. Education</td>
<td>Routine monitoring of developmental/school progress, regular classroom with minimal support</td>
<td>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</td>
<td>Extensive support required, full time aide or special class for most of the day, or multiple special health procedures in educational setting</td>
<td></td>
</tr>
<tr>
<td>5. Special Issues</td>
<td>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</td>
<td>Child and family require extra time to understand healthcare rec’s, regular need for decision supports, translator required for appts, occasional missed appts.</td>
<td>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</td>
<td></td>
</tr>
</tbody>
</table>

**Found Here:**
<table>
<thead>
<tr>
<th>Complexity</th>
<th>Description</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Well, no medical problems</td>
<td>Well Child</td>
</tr>
<tr>
<td>1</td>
<td>One moderate medical problem, involving one organ system with complications</td>
<td>Moderate asthma</td>
</tr>
<tr>
<td>2</td>
<td>One moderate or severe medical problem, involving one organ system with complications</td>
<td>CP, contractures</td>
</tr>
<tr>
<td>3</td>
<td>Two or more moderate or severe medical problems involving two or more organ systems</td>
<td>CP, epilepsy, MR</td>
</tr>
<tr>
<td>4</td>
<td>Two or more moderate or severe medical problems involving two or more organ systems with complications</td>
<td>Epilepsy, BPD, Tracheotomy, vent dependent</td>
</tr>
</tbody>
</table>
Example Strategy #3: Practice-Level
Identifying CYSHCN for Care Coordination Tool that Combines Part 1 and Part 2 Using Provider Gestalt

• On the next slide is an example of Pediatric Needs Assessment Tool developed by the Children’s Health Alliance/Children’s Health Foundation that uses provider gestalt to identify: 1) WHICH kids should receive care coordination and 2) Assign a Level of Support Needed

• Tools takes into account medical and social complexity
Pediatric Needs-Assessment

- To guide support needed from the pediatric medical home team to optimally manage the child’s chronic conditions and overall health
- Incorporates factors beyond medical complexity including social, family, daily functioning, educational
- Often drives PCP care management approaches
- Performed by the PCP team while incorporating parent and patient input as available
- Completed at the time of visit/encounter
- Guided by risk algorithms as available
- CHA pediatricians have assessed nearly 100,000 children
## Pediatric Needs-Assessment

**Medical Complexity:** *(select one)*

<table>
<thead>
<tr>
<th>Option</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ No identifiable medical diagnoses or risk factors</td>
<td>No identifiable medical diagnoses or risk factors</td>
</tr>
<tr>
<td>□ Significant medical/MH risk factors (family history, etc.), but no current chronic disease</td>
<td>Significant medical/MH risk factors (family history, etc.), but no current chronic disease</td>
</tr>
<tr>
<td>□ One chronic medical/mental health condition</td>
<td>One chronic medical/mental health condition</td>
</tr>
<tr>
<td>□ Two or more chronic medical/mental health conditions</td>
<td>Two or more chronic medical/mental health conditions</td>
</tr>
<tr>
<td>□ Complex multisystem medical and/or MH conditions</td>
<td>Complex multisystem medical and/or MH conditions</td>
</tr>
</tbody>
</table>

☐ No  ☐ Yes  **Does child require more than usual routine care by visit or phone?**

**Desired check-in interval_____**

**Next acute follow-up_______**

☐ **NO concerns of added factors** that influence the support needed by the child/family for medical & health management

**Family Factors**

- □ Family stressors
- □ Engagement in health management
- □ Communication/Language/Cultural
- □ Family or patient trauma/limited resiliency

**Patient Factors & Services**

- □ Additional daily support needed
- □ High Risk Behavior
- □ Academic/Attendance

**Current Assessment of Overall Patient Support Needs:**

(Amount of medical and health management support needed from practice)

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>highest</td>
</tr>
<tr>
<td>2</td>
<td>lots extra</td>
</tr>
<tr>
<td>3</td>
<td>some extra</td>
</tr>
<tr>
<td>4</td>
<td>standard</td>
</tr>
</tbody>
</table>

For information contact: Julie Harris  **jharris@ch-alliance.org**  503-222-5703

*Children’s Health Alliance  Children’s Health Foundation*
Other Resources OPIP Has Created Covering Topics Related to Care Coordination We Won’t Have Time to Address Today

QI resources: [http://oregon-pip.org/resources/QI%20Tools.html](http://oregon-pip.org/resources/QI%20Tools.html)

- **Identification of Children & Youth with Special Health Care Needs (CYSHCN)**
- **Resources for Care Coordination**
- **Resources for Shared Care Plans**
- **Resources for Adolescent Care**

• Care Coordination for CYSHCN:  

**Other PCPCI Webinars:**

Shared Care Plans:


Referral and Care Coordination:

What Questions Do You Have?

Type questions into the Questions Pane at any time during this presentation.
Thanks!

• Please feel free to reach out with any further questions
  – Colleen Reuland reulandc@ohsu.edu
  – oregon-pip.org

• Please complete post-webinar survey- your feedback is important to us!