Addressing Children with Health Complexity:
Supporting Coordinated Care Organization (CCOs) in Using the Aggregate Population-level and Child-Level Health Complexity Data
eBook of Supplemental Meeting Materials
November 28, 2018

We have compiled these materials that have been provided as a resource for attendees by our speakers and partners. Hyperlinks below will let you jump to each document. In addition, at the meeting OPIP will share access to an **Online Compendium** providing access to wide array of tools identified related to: 1) Outreach and engagement, 2) Tiering and risk stratification, 3) Care Coordination and Complex Management, 4) Parent Partner and Parent Supports, 5) Evaluation Strategies and Evaluation Tools.

Section 1: Materials Provided by Organizations that Provide Parent to Parent Supports

- FACTOregon History and Reach Overview
- FACTOregon One Page Profile for Families
- FACTOregon Save the Dates – Regional Conferences
- Oregon Family to Family Health Information Center Parent-Driven Family Support Programs
- Oregon Family to Family Health Information Referral Form Eng/Span

Section 2: Materials Provided by the Panel on Care Coordination

- Overview of the Oregon Center for Children & Youth with Special Health Needs (OCCYSHN)
- Shared Care Planning Overview, OCCYSHN
- Shared Care Planning: Information for Families, OCCYSHN
- Children with Health Complexity Slideshow
- System-Level Approaches to Identify Children with Complexity & Develop Models for Complex Care Management Slideshow
- Most Vulnerable Project Summary
- Novel Interventions in Children's Healthcare (NICH) Overview
- Partnering with Insurers in Caring for the Most Vulnerable Youth with Diabetes: NICH as an Integrator NICH
- Single (AIM)-Minded Strategies for Demonstrating Value to Payers for Youth with Medical Complexity, NICH

Section 3: Materials & Resources Provided by Keynote Speaker David Bergman, MD

Dr. Bergman will be presenting on the tools, strategies and outcomes from this three-year project to transform care delivery and payment for children with medical complexity. The website below includes a summary of lessons learned, preliminary findings, and success stories. Included on the website are examples of family/provider partnerships, shared decision making, 24/7 access to care plans, payment models and costs to deliver care coordination.

- Invoking the Power of Family Partnerships to Improve Outcomes for Children with Medical Complexity
- Impacting the Health Care Spend for Children with Complex Conditions
- Access to Care: A Family-Centered Approach
- Additional resources at https://www.childrenshospitals.org/Care

Section 1: Materials Provided by Organizations
That Provide Parent to Parent Supports

FACTOregon
Empowering families experiencing disability.
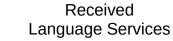
Reach and Impact 2017-2018

FACT Oregon empowers families experiencing disability to pursue whole lives by expanding awareness, growing community, and equipping families.

Counties Served

All 36

Wherever you are in Oregon, we can help!

Received Language Services

1,267

People who received support in a language other than English

Attended Activities

4,930

People who attended Trainings, Family Network events, All Ability Tri4Youth

Peer-to-Peer Supports

7,225

Communications that Family Resource Specialists had with 1,298 parents/caregivers

Received Resources and Supports

13,498

People who engaged with us in-person, by phone, and/or Newsletter

Expand Awareness
- Disability is natural
- Self-determination
- High expectations

FACT Oregon held 150+ trainings with 200+ community partners across the state

Grow Community
- Access activities
- Engage neighborhoods
- Develop relationships

Launched the All Ability Tri4Youth, a barrier-free youth triathlon and family resource fair

Equip Families
- Prepare and inform
- Support and advise
- Provide resources

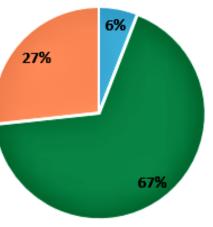Re-awarded a 5-year USDOE contract to equip Oregon families as they navigate special education

Expand Awareness — Equip Families — Grow Community

"The All Ability Tri4Youth was about doing something fun,. motivating, and joyful as a family – along with other families – in whatever way worked best our us."

"I don't know how to express what a relief it has been to trust that I could reach out to FACT Oregon and receive support through this process."

"As a parent who has been involved in the IEP process for over 15 years, I was surprised by how informative this class was. Thank you!!"

Family Reach Demographics

- 6%
- 27%
- 67%

- Birth-5 (499)
- School Aged (5,719)
- 18+ (2267)

For more information, visit www.factoregon.org or call 503-786-6082.

History and Growth

FACT Oregon empowers families experiencing disability to pursue whole lives by expanding awareness, growing community, and equipping families.

FACTOregon
Empowering families experiencing disability.

Today and Beyond: Building sustainability and capacity to serve more families in Oregon and fund new initiatives around our Whole Lives Campaign. -- Join us!

2018: Grant from **Northwest Health Foundation** to create a statewide parent leadership training program

2017: First annual **All Ability Tri4Youth**, a barrier-free triathlon for youth and young adults with and without disabilities

2017: Employment First contract with **Oregon Developmental Disabilities Services** to support families of adult children with an emphasis on planning for employment

2016: Capacity building grant from **Meyer Memorial Trust** to add parent leadership development programming and expand focus on empowering families to pursue a whole life

2013: Parent Education grant with the **Oregon Department of Education** to work with families of children birth-21 statewide. Additional emphasis on transition to adulthood

2002: $4K seed funding to form Family Action Coalition Team (FACT) from **Oregon Council on Developmental Disabilities**

2012: Grant with the **US DOE Office of Special Education Programs** to become the Parent Training and Information Center (PTI) statewide, serving families of children birth-26

2004: Contract with **Multnomah County Developmental Disabilities** to serve families of children birth-5

2006: Packet Project with **United Way** serving families of children birth-8 in the Tri-county metro area of Washington, Clackamas, and Multnomah

2009: **Oregon DHS** pilot program to serve families of children birth-18 in Tri-county metro. Expanded later as a Family Network to include Columbia, Clatsop, Lincoln, and Tillamook counties

FACTOregon.org

My Strengths

My Goals

My Interests

What Doesn't Work

What Works

Next Steps

Name

ATTENTION FAMILIES AND EDUCATORS!

FACT OREGON
ON THE ROAD

All-day regional conferences are coming your way!

Learn about:

Special Education • Planning for the Future • Advocacy • Dispute Resolution • Behavior Supports • Leadership • Financial Planning

Local Vendors & Resources • Questions & Answers

Eastern Oregon

October 19, 2018
Pendleton

October 20, 2018
La Grande

South Coast

November 3, 2018
Coos Bay

North Coast

December 1, 2018
Rockaway Beach

PDX Metro - East

January 12, 2019
Gresham

Mid Valley

February 2, 2019
Albany

PDX Metro - West

March 2, 2019
Hillsboro

Southern

May 4, 2019
Klamath Falls

FREE for parents/caregivers

Refreshments & lunch provided

Language interpretation provided

FACTOregon
Empowering families experiencing disability.

**For more information call
1 (888) 988- 3228 or (503)786-6082
or email info@factoregon.org**

OREGON FAMILY TO FAMILY HEALTH INFORMATION CENTER

The Oregon F2F HIC recommends the following parent-driven family support and information programs. The following organizations are staffed during regular business hours, serve families in every part of the state, and can respond to Spanish speaking callers immediately or within a short period of time.

Oregon Family to Family Health Information Center - 855-323-6744 (English) 503-931-8930
www.oregonfamilytofamily.org
Peer coaching and support to navigate health and mental health systems and other state, federal, and community services. Tip Sheets, toll-free phone line, website, and special-needs related publications. Free.

Swindells Resource Center - 541-732-5958 (Spanish)   503-215-2429 (English)
http://oregon.providence.org/our-services/s/swindells-resource-center/
Books, resources, free care notebooks for families, telephone support, statewide trainings on topics related to pediatric special needs, parenting classes, and much more

Autism Society of Oregon - 1-888-288-4761
www.autismsocietyoregon.org
Autism-specific resources and information, "Take a Break" funding, support and guidance. Resource directory of autism-related services and supports.

FACT (Families and Communities Together) - 1-888-988-3228
www.factoregon.org
Help with Special Education concerns, IEPs and person-centered-planning for individuals with intellectual disabilities. Translation support for numerous languages. Condition-specific parent matches for emotional support.

United Cerebral Palsy - 503-777-4166 x332
http://www.ucpaorwa.org/our-services/family-support
Serves families whose children experience disabilities that mimic Cerebral Palsy as well as those with the diagnosis of CP. Conferences, trainings, parent support, "Respitality" program, and more.

All Born (In)/ Northwest Down Syndrome Association
503-238-0522 (English) 503-239-1509 or 971-570-0942 or 503-442-5817 (Spanish)
http://allbornin.org / http://nwdsa.org
Family connections, building advocacy skills, help with special education, and works to build full lives for individuals who experience disability. New parent kits, parent support, materials, family groups, educational support and more.

Epilepsy Foundation Northwest - 503-205-1404
https://epilepsyoregon.org/support-groups/
Offers parent support group every other month in Vancouver. For those who cannot travel to Vancouver, call and ask for parent support coordinator.

Oregon Family Support Network – 503-363-8068
www.ofsn.org
Supports families who are raising children with significant mental illness. In-person services in many Oregon counties, but phone consultation is available for all Oregon residents.

This is a partial list; See reverse for more family-driven programs.
Call the Oregon Family to Family Health Information Center at 855-323-6744 for more information.

OREGON FAMILY TO FAMILY HEALTH INFORMATION CENTER

The Oregon F2F HIC recommends the following Oregon Parent Networks. The following organizations are staffed during regular business hours and can respond to Spanish speaking callers immediately or within a short period of time. Funded by the Oregon Council on Developmental Disabilities.

Multnomah, Clackamas, Washington, Clatsop, Tillamook, Lincoln, Columbia Counties
FACT Oregon   888-988-3228
Website: www.factoregon.org
Facebook Page: https://www.facebook.com/FACToregon

Yamhill, Polk, Marion Counties - **Creating Opportunities**   503-559-0424
Website: www.creatingops.org
Facebook page: https://www.facebook.com/2CreateOpportunities

Lane County - **Families Connected**   541-343-5256
Website: http://www.arcfamiliesconnected.com/

Deschutes, Crook, and Jefferson Counties - **Central Oregon Disability Support Network**   541-548-8559
Website: http://www.codsn.org/
Facebook page: https://www.facebook.com/CODSN/

Douglas County - **FEATT Family Network** 541-670-2750
Website: http://www.featt.org/
Facebook page: https://www.facebook.com/FEATT-719811931401633/?fref=pb

Klamath County – **Family Advocacy & Support Network (FASN)** 541-591-5507 or 541-880-4863
Website: www.FASNfamilynetwork.org
Facebook page: https://www.facebook.com/FamilyAdvocacyandSupportNetwork/

Harney County - **Kintsugi Disability Support Network**   541-238-2263 or 541-241-8989
Website: www.KDSupportNetwork.org
Facebook page: https://www.facebook.com/KintsugiDisabilitySupportNetwork/

Jackson and Josephine Counties - **Bridging Communities** 541-690-8542
Website: https://livingopps.org/bridging-communities
Facebook Page: https://www.facebook.com/bcoregon

This is a partial list; see reverse for more family programs.   Call 855-323-6744 for more information.

Me gustaría hablar con un/a Compañero/a de Padres de Familia

NECESITO INFORMACION SOBRE:

___ La condición o discapacidad e mi hijo/a

___ Que servicios están disponibles para él /ella ahora o en el futuro

___ Cómo conseguir servicios específicos para él/ella como terapias, cuidado dental, cuidado de salud menta

___ Como manejar la transición cuando mi hijo/a sea adolescente o cuando cumpla 18 años

___ Información sobre algo más: _____

APOYO:

___ Para comunicarme mejor con los terapeutas y proveedores de cuidados de salud

___ Para hablar con un padre/madre de un niño/a similar al mío/a, por teléfono

___ Para encontrar un grupo de apoyo en _____ (Código Postal)

___ Para explicar la discapacidad de mi hijo/a a los doctores, familiares, profesores o otras personas

___ Para saber cómo contestar cuando me hacen preguntas acerca de su condición

___ Apoyo para otra cosa: _____

SERVICIOS DE LA COMUNIDAD

___ Encontrar a un doctor, especialista o dentista que entienda nuestras necesidades

___ Encontrar recreación en la comunidad para mi hijo/a

___ Encontrar cuidado de niños seguro, una oportunidad de descanso para mí con su cuidado

___ O a encontrar algo más: _____

AYUDA ECONOMICA:

___ Pagar gastos tales como comida, alquiler, ropa, transporte o gastos médicos

___ Seguro médico, OHP (Plan de salud de Oregón), u otros asuntos financieros de salud

___ Gastos de equipo especial para las necesidades de mi hijo/a

___ Pagar por terapia, cuidado infantil u otros servicios que mi niño/a necesite

___ Pagar por alguna otra cosa: _____

––-

Por favor contáctenme vía: (Marque todas las opciones válidas)

Llámenme al número: _____

La mejor hora para encontrarme es: Mañana   Tarde   Noche   Sábado   Domingo

Mándenme un texto al número: _____

Mándenme un e-mail al correo electrónico: _____

Devuelva este formulario a: OR F2F HIC, 707 SW Gaines, Portland, OR 97239

OHSU

Oregon Family to Family Health Information Center
Oregon Center for Children and Youth with Special Health Needs

OHSU

I WOULD LIKE TO TALK WITH A PARENT PARTNER

I NEED INFORMATION ABOUT:

my child's condition or disability
what services are available for my child now or in the future
how to get my child specific health services, such as therapies, dental care, mental health care
managing transition when my child becomes a teenager or turns 18
something else: _____

SUPPORT:

to better communicate with my child's health care providers and therapists
to speak one to one with another parent who has a child that is similar to mine
    On the phone
    At a support group in _____ zip code
    Online
to explain my child's disability to health care providers, family members, teachers or the community
to know how to respond when others ask questions about my child's condition
support for something else: _____

COMMUNITY SERVICES:

locating a doctor, specialist, or dentist who understands my child's needs and our family
finding community recreation for my child
finding safe child care or respite for my child
finding something else: _____

FINANCIAL HELP:

paying for expenses such as food, housing, medical care, clothing, or transportation
insurance, Oregon Health Plan, or other health care financing issue
getting special equipment for my child's needs
paying for therapy, day care, or other services my child needs
paying for something else: _____

Please contact me/us via: (check all that apply)

Call/text me at: _____

Best time to reach me is: Morning   Afternoon   Evening   Saturday   Sunday

Email me at: _____

Name: _____

FAX to: 503 494-2755 **OR** Scan and email to: _____ or contact@oregonfamilytofamily.org
OR mail to: *Oregon Family to Family Health Information Center c/o OCCYSHN –707 SW Gaines –Portland, OR 97239*

Please feel free to call us with any questions: 1-855-323-6744

Section 2: Materials Provided by the Panel on Care Coordination

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) is Oregon's public health agency for children and youth special health needs (CYSHCN). OCCYSHN partners with families, health and service providers, and policy-makers across the state to improve health systems to meet the needs of this large and vulnerable population.

CYSHCN need more care and services than other children. Their chronic conditions might be physical, developmental, behavioral, or emotional. CYSHCN make up 16.2% of the U.S. child population, and account for 45% of the total health care costs for children.[1] Serving these children better can lead to more efficient and effective health systems for everyone.

OCCYSHN is housed at Oregon's only academic medical center, Oregon Health & Science University. This setting lends the benefits of research, education, and clinical expertise to OCCYSHN's public health work.

One in five Oregon children has a special health need.

Transforming Systems of Care for Children with Special Health Needs

Assessment and Evaluation

OCCYSHN monitors the needs and status of Oregon CYSHCN with population-based assessment and surveillance. Data is used to identify needs, and analysis is shared widely to guide informed policy and program decisions.

Family Involvement

Serving CYSHCN effectively depends on including their family members at every level of systems improvement. OCCYSHN partners with families to identify problems and to implement practical solutions.

Systems and Workforce Development

OCCYSHN provides resources and technical assistance to partners across Oregon, helping them leverage local resources and build better systems of care for CYSHCN in their communities.

[1] Newacheck, P.W., & Kim, S.E. (2005). A national profile of health care utilization and expenditures for children with special health care needs. Archives of Pediatric and Adolescent Medicine, 159, 10-17.

OHSU

Challenges for Oregon CYSHCN

Data sources available in the full report of OCCYSHN's 2015 Needs Assessment: www.occyshn.org/publications.

Medical Home

- A quarter of Oregon's CYSHCN live in rural or frontier areas, often far from specialty care and services.

- More than half of Oregon CYSHCN did not receive coordinated, ongoing comprehensive care within a medical home.

- Two thirds of parents said their CYSHCN had no care plan in place. Of those that did, half said the care plan was not shared with all the child's providers.

Transition to Adult Health Care

- Two thirds of Oregon's youth with special health needs did not get necessary services to transition to adult health care.

- Only 12% of youth surveyed by OCCYSHN reported that their doctor talked to them about finding an adult-focused health care provider when they turned 18.

Culturally and Linguistically Appropriate Services

- 6% of Oregon's population speaks English "less than very well."

- In more than 15% of Oregon households, English is not the primary language spoken in the home.

- One in five parents reported their child's health care providers were not always sensitive to their family values and customs.

Solutions for Oregon CYSHCN
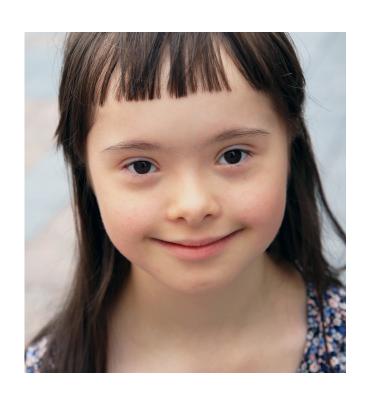
CACOON (CAre COordinatiON) Nurses
OCCYSHN supports home-visiting public health nurses in most Oregon counties. These nurses are care coordination experts who inform and empower families to manage complex care and services for their CYSHCN.

Family Involvement Program
Family members of CYSCHN work with OCCYSHN as staff and advisors. A statewide network of parents is trained and coordinated to provide support, information, and resources to other parents of CYSHCN, and to advocate for CYSHCN in their communities.

Regional Approach to Child Health
OCCYSHN convenes local and regional groups of decision-makers in various systems serving CYSHCN. Together they explore ways to identify shared goals and address issues in their regional systems of care.

Shared Care Planning
OCCYSHN contracts with public health departments across Oregon, and supports them to develop shared care plans for CYSHCN. The plans are formed by convening local teams that include families and providers of health care, education, mental health, insurance, and community services. Cross-system connections are strengthened while individual families are served.

more information

occyshn@ohsu.edu
503 494-8303
www.occyshn.org

Benjamin Hoffman, M.D., F.A.A.P., Director
hoffmanb@ohsu.edu

SHARED CARE PLANNING

Shared care planning is an approach to coordinating care for children and youth with special health care needs (CYSHCN). It is called "shared" planning because families and professionals share the work of creating a care plan and putting it into action. The process is especially useful for people getting care and services from multiple sources. OCCYSHN supports partners across Oregon to lead shared care planning efforts in their communities.

Shared care planning is a common-sense approach to bringing families and professionals together to focus on unmet needs. It's a team effort, centered around helping families address their goals for their children. Participants include representatives from health care, insurance, education, mental health, public health, and other community services.

A written care plan is developed or updated in every shared care planning meeting. The plan focuses on goals, and includes actions steps with timelines and responsible parties.

Shared care planning is also used to address the particular needs of youth and young adults with special health needs. The process helps youth and their families prepare for the transition from pediatric to adult health care.

Bringing families and professionals together in real time fosters efficient communication. In the process of serving individual CYSHCN and their families, shared care planning also strengthens local systems of care. Participating professionals connect and learn from one another, which can help them maximize local resources.

To see a shared care planning template:
ohsu.edu/xd/outreach/occyshn/programs-projects/SPoC.cfm

For an in-depth report on shared care planning for CYSHCN:
www.lpfch.org/sites/default/files/field/publications/achiev-ing_a_shared_plan_of_care_full.pdf

Shared Care Planning

...is collaborative and engages diverse knowledge and skill sets.

...is culturally and linguistically appropriate.

...responds to a family's stated goals.

...documents factors affecting a child's health and development.

...fosters mutual accountability among team members.

...establishes timelines.

...addresses gaps and redundancies in care.

...offers families a written plan and support to implement it.

The Oregon Center for Children and Youth with Special Health Needs is Oregon's Maternal and Child Health Bureau Title V public health agency for CYSHCN, located at OHSU's Institute on Development and Disability.

www.occyshn.org
occyshn@ohsu.edu
503 494-8303

OHSU

SHARED CARE PLANNING
Information for Families

Shared care planning is a process used to coordinate care and services for children with special health needs. It is called "shared" planning because you and your child's health, education, and service providers share the work of creating a care plan and putting it into action. A shared care planning meeting brings you and different people who work with your child together in a room to talk about goals and challenges. You end up with a written plan that helps your child move forward.

How Shared Care Planning Helps

You share what you know about your child with his or her teachers, therapists, health care providers, and others.
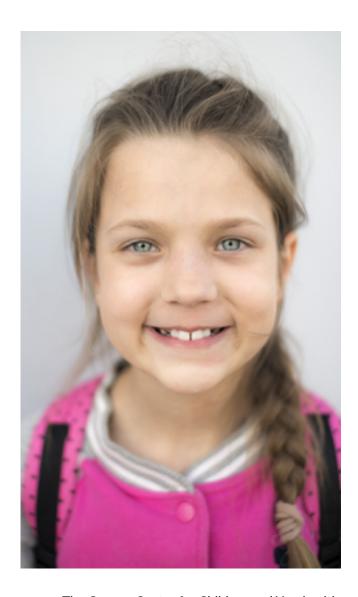
Your goals for your child are the first priority.

People with different kinds of skills and experience come together with a common goal of helping your child.

You get a clear written care plan that addresses your child's needs. The plan spells out who will do what, and when.

People at the meeting learn more about your unique child and family.

Your child's care and services are better coordinated.

(continued over)

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) is Oregon's Maternal and Child Health Bureau Title V public health agency for children and youth with special health care needs. OCCYSHN is located at OHSU's Institute on Development and Disability.

www.occyshn.org
occyshn@ohsu.edu
503 494-8303

OHSU

Frequently Asked Questions

Is a care planning meeting the same as an Individual Education Plan (IEP) meeting?

No. IEPs are focused on school goals. Shared care planning focuses on your child's overall health and well-being, including how things are going at school.

Who comes to a shared care planning meeting?

That's up to you. A typical meeting might include

- you – the parent(s) or guardian(s)
- a public health nurse or other home visitor
- doctor(s)
- therapists
- social worker
- Developmental Disabilities caseworker
- health insurance representative
- school nurse, counselor, or teachers
- child care providers
- other people you think might be helpful.

You can also invite your child (over age 12), if you think that would be best.

What happens at a shared care planning meeting?

- People introduce themselves to each other.
- You talk about your goals for your child, and describe problems you've had getting your child's needs met.
- You and the rest of the group brainstorms together about how to solve problems and meet your goals.
- A coordinated care plan is developed. It is written down, and you get a copy. The plan spells out who agrees to do what, and when.

How do I prepare for a shared care planning meeting?

- Be sure the time works for you. If not, it can be rescheduled. You are the most important person at the shared care planning meeting.
- Sign a "Release of Information." That release allows team members to share information with each other about your child. (The person who invites you to the meeting will give you this form.)
- Write down any of your child's needs that have been hard to meet (like supplies or therapies that aren't covered by insurance, child care, etc.).

- Bring any written information you want to share. Examples might include

  √ a care notebook,
  √ an Individual Education Plan,
  √ report cards,
  √ an Individual Service Plan,
  √ letters denying services or insurance.

Can I talk with another parent who has a child with special needs about shared care planning?

Yes. To be conncected with another parent contact:

Oregon Family to Family Health Information Center

855-323-6744
www.oregonfamilytofamily.org

Children with Health Complexity

Overview of New System-Level Data to be Provided About Children with Health Complexity & Starting Point Discussion About How to Leverage Data in Tri-County Region

Care Oregon – Pediatric Clinical Work Group
September 20, 2018

Agenda for Presentation

Context Setting: Background and Context on the Project: From OPIP Point of View and From KPNW Point of View

Review Specific System-level Data Being Used to Operationalize Factors Related to Health Complexity Based on Indicators of Medical & Social Complexity: Highlight Preliminary, State-Level Available Findings

  Part 1: **Pediatric Medical Complexity Algorithm**

  Part 2: Indicators of **Social Complexity**

  Part 3: **Medical** + **Social** Complexity = **Health Complexity**

Review of Potential Ways the Data Could be Used in Communities

Review of Potential Ways Data Could Be Used with Applied Examples from KPNW

Group-Discussion and Input

The data shown in this presentation are not final and subject to change.

Oregon Health Authority

OPIP

Efforts that Led Up to OPIP's Proposal

- OPIP efforts with practices and health systems focused on:
  - Identifying children and youth with special health care needs
  - Care Coordination, methods for tiering patients
  - Complex Care Management Pilot within Kaiser Permanente Northwest (KPNW)
- OPIP efforts with Early Learning Hubs and key partners on addressing developmental delays
- OPIP efforts related to population data and quality metrics
  - What is measured is what is focused on
  - What is measured can be resourced
  - What is paid for is more likely to happen

OPIP's Lens - Problem…….or Opportunity!

- Despite wonderful gains in patient centered primary care homes, coordinated care organizations, and other efforts related to complex care management, there is a **need to better support children with health complexity**.

  - In order to impact children's future health & preventable chronic conditions, we need to address **predictive social determinants of health and build resilience**

  - In order to address children with health complexity a population and **community-based approach and cross-sector engagement** is required.

- One component of this effort needs to include a system-level focus.

  - At a system-level, in order to focus on children with health complexity, there is a need to be able to identify them.

  - In order to identify children with health complexity that may benefit from complex health management, systems need:

    - Methods that are valid, reliable and meaningful **for children**

    - **Standardized and feasible** using **data available at the system-level**

    - Include data that takes into account

      Medical Complexity AND

  + **Social** Complexity
  _____

    Health Complexity

4

OPIP

THE PROBLEM – FROM MY PERSPECTIVE IN KAISER PERMANENTE NORTHWEST (KPNW)

Despite having wonderful pediatric care teams and great population management tools we still struggle with certain patients:

- Medically Complex
  - Physical Health
  - Mental Health
- Socially Complex
- Unknown

Why has it taken so long for a pediatric–focused complex health management program?

General belief organizationally that:

- Most kids are healthy
- Kids are resilient
- Childhood medical conditions are not preventable
- Adult clinicians have a bigger burden to carry and their patients are far sicker than pediatricians'
- Little understanding of the impact of ACES, mental health issues, social determinants

ADVERSE CHILDHOOD EVENTS (ACES)

KAISER PERMANENTE®

ACES are fairly common BUT

- > Almost 20% of our children will have 4 or more ACES
  - Have 20 year shorter life expectancy
  - 8 times more likely to be an alcoholic
  - 20 times more likely to use IV drugs
  - 4 times more likely to suffer from depression
- High quality programs dealing with ACES have shown a $10 return on investment for every dollar spent
  - Prevent future abuse
  - Build resiliency and coping skills

The Impact of a Stuck Fight or Flight Response

Physical Reaction		Long-Term Impact
Blood pressure rises	⟶	Heart disease
Stress hormones rise	⟶	Anxiety, insomnia, addictions, weight gain
Digestive system slows	⟶	Gastro intestinal problems
Growth and sex hormones fall	⟶	Premature aging
Immune system weakens	⟶	Infections, cancer
Sticky blood platelets increase	⟶	Heart attacks

Source: Dr. Robert Gonzalez, The Chopra Center
Copyright 2013.

eblin group

LIMBIC SYSTEM

- **HIPPOCAMPUS** – plays an important role in emotion, learning and memory.
- **AMYGDALA** – plays role in aggression, eating, drinking and sexual behaviors.
- **HYPOTHALAMUS** – monitors blood levels of glucose, salt, blood pressure and hormones.

Frontal lobe
Thalamus
Hippocampus
Amygdala
Hypothalamus
Olfactory bulb

PEDIATRIC STRATIFICATION

How do you find the most impactable?

- High Cost?

- High Utilizers?

- High Social Determinant Risks?

- High ACES scores?

- OR a Combination = Health Complexity!!

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OPIP Funded Proposal from Lucile Packard Foundation for Children's Health

- **Title: System-Level Approaches to Identify Children with Health Complexity and Develop Models for Complex Care Management**

- Goal: Inform health systems on novel and generalizable approaches **to identify children with health complexity,** use of this inform to design better support systems for children and their families

- **Time Period: August 2017-March 2019**

- **Key Partners:**
  - Oregon Health Authority (OHA Health Analytics)
  - Kaiser Permanente Northwest – Publicly & Privately insured
  - Coordinated Care Organizations

Pediatric Medical Complexity Algorithm

- Developed by a team at Seattle Children's, Validated by Center of Excellence on Quality of Care Measures for Children with Complex Needs (COE4CCN)
  - For children 0 to 18 insured
  - Developed as a way to identify a population, stratify quality metrics, and to target patients who may benefit from complex care management
- Based on claims and diagnosis
- Categorizes complexity into three categories:
  1) **Complex Chronic Disease,**
  2) **Non-Complex Chronic Disease, and**
  3) **Healthy**
- 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*)

OPIP

Preliminary Data Shown Today

- OHA and OHA Partners Ran Preliminary Data for Today's Presentation

- This data still needs to be double checked and assessed and is being shown to inform and illuminate our conversation, but should not be used outside the context of this meeting

- Final data is expected to be shared in October

The data shown in this presentation are not final and subject to change.
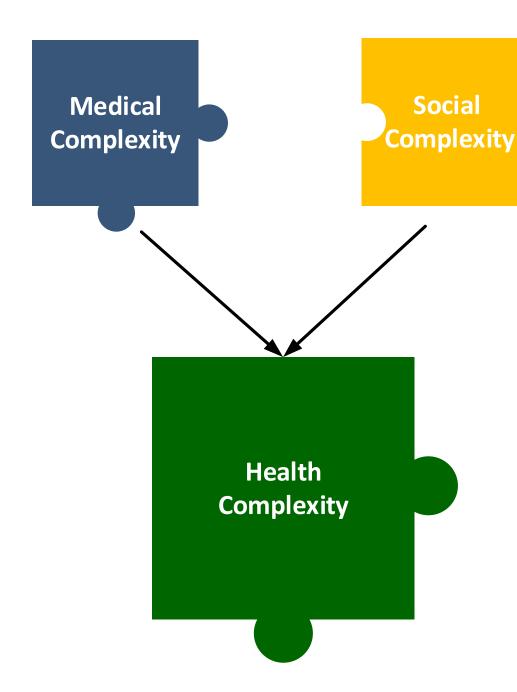
Preliminary: Pediatric Medical Complexity Algorithm Findings

Statewide Publicly Insured: N=390582

1. Complex Chronic Disease: 6.1%

2. Non-Complex Chronic Disease: 18.3%

3. Healthy: 75.6%

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Medical Complexity

Social Complexity

Health Complexity

Defined by The Center of Excellence on Quality of Care Measures for Children with Complex Needs (COE4CCN) as *"A set of co-occurring individual, family or community characteristics that can have a direct impact on health outcomes or an indirect impact by affecting a child's access to care and/or a family's ability to engage in recommended medical and mental health treatments"*.

18 Social Complexity Factors Identified by the Center of Excellence on Quality of Care Measures for Children with Complex Needs (COE4CCN) as Associated in Literature with Worse Health Outcomes and Costs

- 12 SC risk factors from literature review related to **worse outcomes**

  1. Parent domestic violence
  2. Parent mental illness
  3. Parent physical disability
  4. Child abuse/neglect
  5. Poverty
  6. Low English proficiency
  7. Foreign born parent
  8. Low parent educational attainment
  9. Adolescent exposure to intimate partner violence
  10. Parent substance abuse
  11. Discontinuous insurance coverage
  12. Foster care

- COE4CCN studies showed worse outcomes or consensus on impact:

  13. Parent death
  14. Parent criminal justice involvement
  15. Homelessness
  16. Child mental illness
  17. Child substance abuse treatment need
  18. Child criminal justice involvement

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Identifying Feasible Social Complexity Variables in Oregon

Children with Social Complexity

Children Identified & Classifications Used: A Social Complexity Count and Categorical Variable (indicating the number of social complexity risk factors identified) will be created based on available aligned with the definition of social complexity and the 18 social complexity factors associated with higher health care costs*. Social complexity is defined as "a set of co-occurring individual, family, or community characteristics that have a direct impact on health outcomes or an indirect impact by affecting a child's access to care and/or a family's ability to engage in recommended medical and mental health treatments".* Twelve feasible indicators, present during the prenatal period-lifetime of the child, include in the social complexity count are the: Child and/or Family use of TANF, Foster Care Services, Parent death, Parent incarceration, Child received mental health services, Child received substance abuse services, Parent received mental health services, Parent received substance abuse Services. Child abuse and neglect ICD-9, ICD-10 Codes, Primary Preferred Language is Not-English, Parent Disability as indicated by Medicaid Eligibility.

Standardized Scoring & Reporting Method: OPIP and OHA are developing methodologies to create two new variables which provide summary information, that is blinded, about the number of social complexity risk factors: 1) A count variable of the 12 social complexity variables, 2) A categorical variable, based on the social complexity count, that will be used for any child-level data sharing that meets data sharing requirements.

Data Sources: Three: 1) OHA Program Eligibility, 2) Administrative data used for Chronic Illness and Disability Payment System (CDPS), & 3) Integrated Client Services (ICS) Data Warehouse for the child and their parents.

- Collaboration between OHA & DHS; staffing support
- Data sources from OHA- Health Analytics and Integrated Client Data Warehouse (ICS)
  - ICS includes data across the Oregon Department of Human Services (DHS) and OHA client-based services. Includes data from the following DHS Programs: Aging and People with Disabilities, Child Welfare, Developmentally Disabled, Self-Sufficiency, Vocational Rehabilitation. Includes data from the following OHA Programs: Alcohol and Drug (AD), Contraceptive Care (C-Care), Family Health Insurance Assistance Program (FHIAP), Healthy Kids Connect (HKC), Medical Assistance Programs (MAP), Mental Health (MH), Women Infants Children (WIC). Includes data from the following external agencies: Department of Corrections (DOC), Oregon Housing and Community Services.
- Data sharing agreements
- Linkage of the child and parent to allow for child-level and population-level analysis
- Input obtained from public and private stakeholders in November 2017 and April 2018 about data methodologies

DHS Oregon Department of Human Services | Oregon Health Authority | OPIP

Available and Feasible Social Complexity Indicators to be Included in a Social Complexity County Variable and Social Complexity Categorical Variable

INDICATOR	CHILD FACTOR	FAMILY FACTOR	TOTAL
Poverty –TANF (For Child and By Parent)	X	X	X
Foster care – Child receiving foster care services DHS ORKids (since 2012)	X		X
Parent death – Death of parent/primary caregiver in OR		X	X
Parental incarceration – Parent incarcerated or supervised by the Dept. of Corrections in Oregon.		X	X
Mental Health: Child – Received mental health services through DHS/OHA	X		X
Mental Health: Parent – Received mental health services through DHS/OHA		X	X
Substance Abuse: Child – Substance abuse treatment through DHS/OHA	X		X
Substance Abuse: Parent – Substance abuse treatment through DHS/OHA		X	X
Child abuse/neglect: ICD-9, ICD-10 dx codes related to service	X		X
Limited English Proficiency: OHA data file indicating caregiver requested materials to be in Non-English Language		X	X
Parent Disability: OHA eligibility due to parent disability		X	X
Total Number of Individual Flags Included	5	7	12

Look Back Period:

Presence of the risk factor in prenatal period (Year before birth)-Lifetime of the Child.

17

Preliminary Social Complexity Findings

Import Notes About Data Being Shown:

- Linkage of publicly insured children to a parent in ICS:
  - Unable to link to a parent: 20.44%
  - 1 parent: 11.62%
  - 2 Parents: 67.94%
- This preliminary data does not include three of the twelve factors.

State-Level: Preliminary Findings on Prevalence of Each Social Complexity Variable

INDICATOR	CHILD FACTOR	FAMILY FACTOR
Poverty – TANF (for Child and by Parent)	40.62% (158,650)	31.20% (121,952)
Foster Care – Child receiving foster care services DHS ORKids (since 2012)	12.97% (50,672)	
Parent Death – Death of parent/primary caregiver in OR		1.30% (5,172)
Parental Incarceration – Parent incarcerated or supervised by the Dept. of Corrections in Oregon		19.10% (74,707)
Mental Health: Child – Received mental health services through DHS/OHA	33.08% (129,212)	
Mental Health: Parent – Received mental health services through DHS/OHA		40.00% (156,221)
Substance Abuse: Child – Substance abuse treatment through DHS/OHA	4.55% (17,763)	
Substance Abuse: Parent – Substance abuse treatment through DHS/OHA		29.01% (113,124)
Child Abuse/Neglect: ICD-9, ICD-10 dx codes related to service	Data not yet available	
Limited English Proficiency: OHA data file indicating caregiver requested materials to be in Non-English Language		Data not yet available
Parent Disability: OHA Eligibility Due to Parent Disability		Data not yet available

Look Back Period:

Presence of the risk factor in prenatal period (Year before birth)-Lifetime of the Child.

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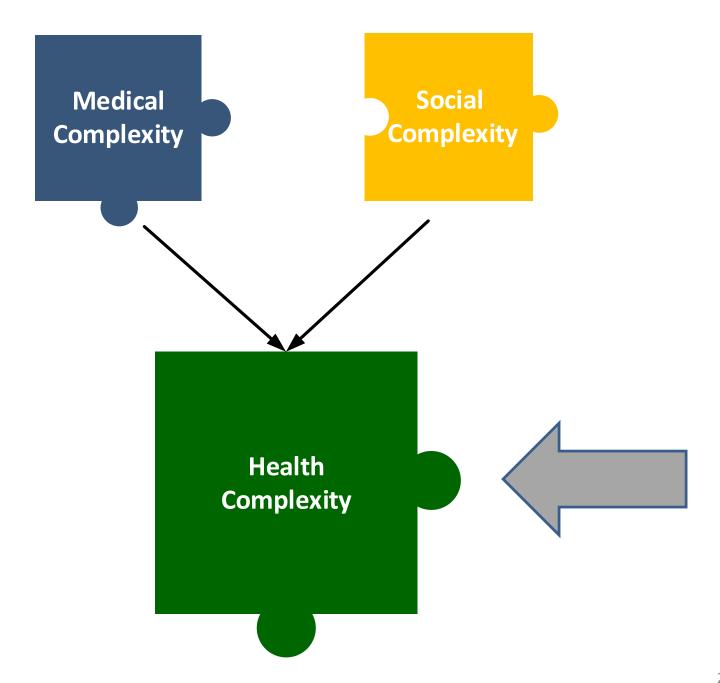
State Level Social Complexity Based on Three "Count" Variables: Preliminary Findings for Publicly Insured Children: Preliminary Data

NUMBER OF INDICATORS (SOCIAL RISK FACTORS)	CHILD FACTOR	FAMILY FACTOR	TOTAL	
0	42.98% (167,857)	46.53% (181,732) ⬅	27.89% (108,937)	Includes 20.4% of children for whom it was not possible to link to a parent
1	33.51% (130,895)	17.75% (69,342)	22.38% (87,393)	
2	14.88% (58,119)	14.17% (55,347)	14.63% (57,160)	
3	6.57% (25,680)	11.96% (46,714)	10.55% (41,214)	
4	2.06% (8,031)	9.28% (36,237)	8.60% (33,577)	
5		0.31% (1,210)	6.98% (27,272)	
6			4.76% (18,592)	
7			3.03% (11,852)	
8			1.11% (4,331)	
9			0.07% (254)	
10			Data not yet available for 3 factors	
11			Data not yet available for 3 factors	
12			Data not yet available for 3 factors	

The data shown in this presentation are not final and subject to change.

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Oregon Health Authority

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Health Complexity Categorical Variable: Purpose and Goal

- Given that **medical** complexity and social complexity will be independently examined and shared, create a categorical variable that combines the unique and different information from each analysis.
  - Categories anchored to level of medical complexity AND level of social complexity
    - ❖ Understand the population with both levels of complexity
- Build off the learnings from the COE4CCN
  - 1 or more social complexity indicators associated with costs
  - Gradient effect – The more factors the higher costs
- Create a manageable level of categories for this population level assessment
  - Systems will have the PMCA and Social Complexity categorical variables independently and create their own version for their own uses
- Ensure categories have sufficient denominators to allow for state and county-level reporting, **maintain data sharing agreements** when shared at a child-level

The data shown in this presentation are not final and subject to change.

DRAFT & Preliminary:
State-Level Health Complexity Categorical: Source Variables Related to Medical and Social Complexity

Medical COMPLEXITY (3 Categories)	SOCIAL COMPLEXITY (Total Factors Possible in Preliminary Data Shown Here N=9, Final Data N=12)		
	3 or More Indicators	**1-2 Indicators**	**None in System-Level Data**
HIGH Medical Complexity (Chronic, Complex PMCA=1)	2.7% (10530)	2.38% (9288)	.99% (3863)
MODERATE Medical Complexity (Non-Complex, Chronic PMCA=2)	8.62% (33665)	7.13% (27859)	2.58% (10067)
NO MEDICAL COMPLEXITY (PMCA=3)	23.78% (92897)	27.5% (107406)	Neither Medically or Socially Complex 24.32%(95007)

Note: OPIP and OHA is examining additional options for the Health Complexity Variable based on feedback obtained from the April 24th meeting.

The data shown in this presentation are not final and subject to change.

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Data Reports and Data Sharing Planned

Data shared in different ways:

– Population-level reports

   • Data shown for the population at a county-level and for specific age groups

   • At a state and population-level, can show prevalence of specific indicators

– CCO Population-Level Reports

   • Data shown for the population at a CCO-Level and Across CCOs

   • At a population-level, able to show prevalence of specific indicators at county-level

– Child-Level Data file to CCOs for Their Attributed Populations

   • Child-level indicator of:

   ❖ **Medical** Complexity Categorical Variable (3 categories),

   ❖**Social** Complexity Categorical Variable- **BLINDED** to WHICH Factors Contribute to the Categories(Categories TBD)

   ❖**Health** Complexity Categorical Variable (TBD, 4-6 Categories)

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From Data to Meaningful Information: Potential Uses in Communities

Some applications OPIP/OHA have identified, although we are eager to hear and learn from communities about potential uses:

1. Use the **Population-Level Findings** to Engage Community-Level Partners to:

- Understand Child and Family Needs,

- Identify Community-Level Assets, and

- Address Capacity of Services to Serve Children with Health Complexity

2. Use the Population-Level and Child-Level Findings to Identify **Opportunities to Enhance Care Coordination and Care Management**:

- Includes community-based and centralized supports for children with health complexity

3. Leveraging the Data to Support a Health Complexity Informed Approach with **Front-Line Health Care Providers**

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An example how Kaiser Permanente Northwest has used a Health Complexity Informed Approach to Develop Centralized Complex Health Management
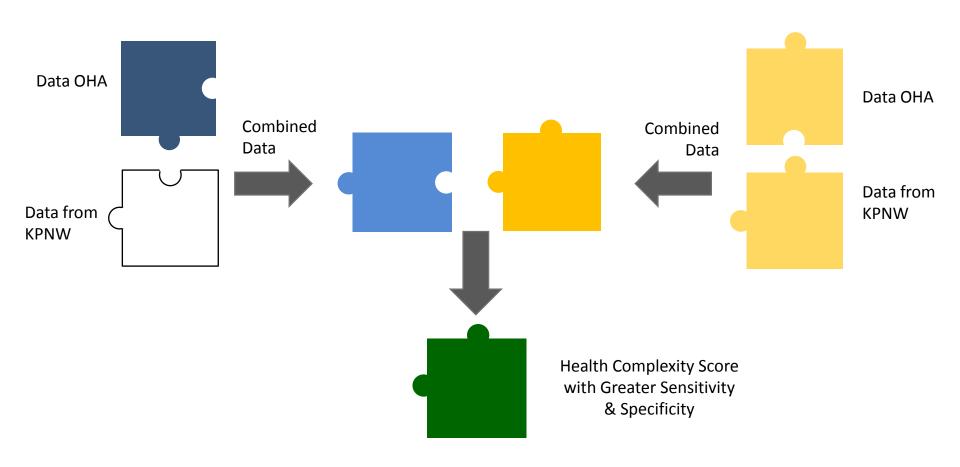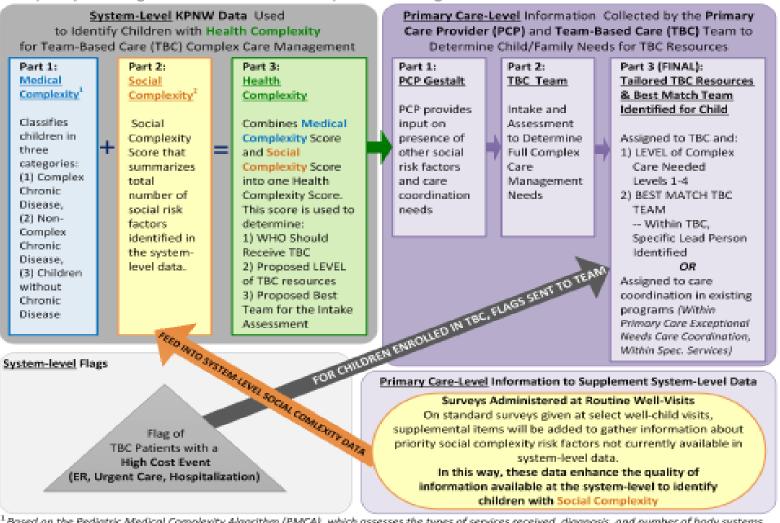

Data OHA

Data from KPNW

Combined Data

Combined Data

Data OHA

Data from KPNW

Health Complexity Score with Greater Sensitivity & Specificity

Figure 1: Overview of **System-Level** and **Primary Care-Level** Methods Within KPNW to Identify Children with Health Complexity and Assign Pediatric Team-Based Complex Care Management Resources

System-Level KPNW Data Used to Identify Children with Health Complexity for Team-Based Care (TBC) Complex Care Management

Part 1: Medical Complexity[1]

Classifies children in three categories: (1) Complex Chronic Disease, (2) Non-Complex Chronic Disease, (3) Children without Chronic Disease

+

Part 2: Social Complexity[2]

Social Complexity Score that summarizes total number of social risk factors identified in the system-level data.

=

Part 3: Health Complexity

Combines Medical Complexity Score and Social Complexity Score into one Health Complexity Score. This score is used to determine:
1) WHO Should Receive TBC
2) Proposed LEVEL of TBC resources
3) Proposed Best Team for the Intake Assessment

Primary Care-Level Information Collected by the Primary Care Provider (PCP) and Team-Based Care (TBC) Team to Determine Child/Family Needs for TBC Resources

Part 1: PCP Gestalt

PCP provides input on presence of other social risk factors and care coordination needs

Part 2: TBC Team

Intake and Assessment to Determine Full Complex Care Management Needs

Part 3 (FINAL): Tailored TBC Resources & Best Match Team Identified for Child

Assigned to TBC and:
1) LEVEL of Complex Care Needed Levels 1-4
2) BEST MATCH TBC TEAM
-- Within TBC, Specific Lead Person Identified

OR

Assigned to care coordination in existing programs (Within Primary Care Exceptional Needs Care Coordination, Within Spec. Services)

System-level Flags

Flag of TBC Patients with a **High Cost Event** (ER, Urgent Care, Hospitalization)

FEED INTO SYSTEM-LEVEL SOCIAL COMPLEXITY DATA

FOR CHILDREN ENROLLED IN TBC, FLAGS SENT TO TEAM

Primary Care-Level Information to Supplement System-Level Data

Surveys Administered at Routine Well-Visits
On standard surveys given at select well-child visits, supplemental items will be added to gather information about priority social complexity risk factors not currently available in system-level data.
In this way, these data enhance the quality of information available at the system-level to identify children with Social Complexity

[1] *Based on the Pediatric Medical Complexity Algorithm (PMCA), which assesses the types of services received, diagnosis, and number of body systems impacted. Claims and utilization available within the KPNW system used. Service provided outside of KPNW or in the past for children when they were not covered by KPNW is not included.*
[2] *Based on system-level data KPNW is able to assess about the child and family that relate to social risk factors. Data sources include program eligibility (Medicaid, Subsidized Exchange) and fields within the electronic medical record highlighting patient need (e.g. Translation) or results of parental/youth screening (Depression screening, Substance abuse screening).*

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Kaiser Permanente Northwest: Pediatric Care Together Model

Six Elements - One Team

| © 2011 Kaiser Foundation Health Plan, Inc.

Bundle Elements

1. **Patient Identification:** Pediatric risk stratification (to be developed based on disease burden, past utilization and social determinants). Once identified, PCPs will help assess and prioritize.
2. **Assessment:** Pediatric specific screening tools are used to identify gaps in care and ensure social determinants are identified.
3. **Plan of Care:** Once the team has developed a relationship and assessed the patient, they meet to collaboratively create a patient centered care plan which is then documented in the chart
4. **Team Coordination:** Team engages with the member and family. Identifies issues and works toward their goals and needs. Intensity of care highly variable and tailored to individuals
5. **Transitions:** Patients who have an inpatient stay or receive services outside our system receive care coordination to ensure a smooth, well-managed transition. Team monitors reports to identify patients in ED/inpatient.
6. **Advanced Care Planning** – when appropriate

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From Data to Meaningful Information: Potential Uses of the Information in Local Communities

1. Use the **Population-Level Findings** to Engage Community-Level Partners to:

*   Understand Child and Family Needs, Identify Community-Level Assets, and

*   Address Capacity of Services to Serve Children with Health Complexity

2. Use the Population-Level and Child-Level Findings to Identify **Opportunities to Enhance Care Coordination and Care Management**:

*   Includes community-based and centralized supports for children with health complexity

3. Leveraging the Data to Support a Health Complexity Informed Approach with **Front-Line Health Care Providers**

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Leveraging Data to Support Health Complexity Approach with Front-line Health Care Provider

- Most novel, new work ahead = Proceeding with caution and care

- Only blinded, categorical variable would be available

- Need to ensure thoughtful, appropriate uses of the

- Value of examining aggregate population-level data by practice to assess resources and health complexity management needs in the practice and/or in the community

- If shared, ensure use is aligned with goal
  - ❖ Trauma informed
  - ❖ Have resources to address areas
  - ❖ Trauma informed outreach methods
  - ❖ Support front-line assessments

- Build of parent advisor input that primary care provider likely the entity they may trust most in engaging them
  - ❖ That said, many of these families may not access their primary care routinely

Questions? Want to Touchbase? Door is Open

OPIP Project Lead

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System-Level Approaches to Identify Children with Health Complexity & Develop Models for Complex Care Management
Learning Session #1 with Coordinated Care Organizations
November 8th, 2017

A project to the Oregon Pediatric Improvement Partnership
Supported by the Lucile Packard Foundation for Children's Health

<u>OBJECTIVES FOR MEETING:</u>

1. To provide an overview of the four in-person learning sessions for Coordinated Care Organizations (CCOs) included in the OPIP project.
2. From data, to information, to implementation of complex HEALTH management- An example from Kaiser Permanente Northwest.
   a. Provide a brief overview of the KPNW Pediatrics Care Together program and key learnings relevant and useful to CCOs (a more detailed review will be provided at the Spring Meeting).
   b. Describe the specific methods KPNW has been using to identify children with medical and social complexity in order to define their health complexity.
   c. Describe how KPNW plans to use the information provided by OHA to complement and enhance their internal data.
3. To obtain input on how future learning sessions can best meet CCO needs.
4. To identify important next steps for CCOs.

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Agenda for This Afternoon

- **Context Setting & Gathering Feedback**
  - Overview of the in-person learning sessions for CCOs included in this project
  - Hear from you on questions and needs for more information based on the 1st section of the day
- **Spotlight from KPNW**: Identifying Children with Health Complexity and Building Pediatric Care Together to Provide Complex Health Management

  Joyce Liu, MD – Kaiser Permanente Northwest
- **Next Steps**
  - Follow-Up Survey
  - Spring Learning Session

OPIP

System-Level Approaches to Identify Children with Health Complexity and Develop Models for Complex Care Management Project: Specific Components with CCOs

Activity #3: Learning sessions with CCOs on how to use the data provided by OHA for identifying children with health complexity & KPNW pediatric complex care management models.

- **3A: Facilitate Learning Sessions of CCOs and KPNW**.
    - At these meetings, models for health system-level complex care management will be shared, including the KPNW Pediatric Care Together (PCT)
    - Learning sessions will be held after stakeholder meetings.

- **3B: Individual Interviews with CCOs implementing one or more of the models presented.**
    - OPIP will conduct interviews with CCOs that implement at least one or more of the methods shared at the Learning Sessions.
    - The purpose of the interview is to learn which data, tools, and methods the CCOs are using, modifications they have made, and successes and barriers experienced.
    - Information will inform an Issue Brief and Webinar for CCOs

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In-Person Meetings (4 Total)

Part 1: Public Private Stakeholder Meetings to Provide OHA and OPIP input on Data Scoring and Sharing Methodologies

Part 2: Learning Sessions for CCOs to provide examples and models for how to USE this kind of information in your own system:

- KPNW is a critical partner
  - Sharing today on the overall model within their system and value of health complexity data
  - At future meetings they will share tips related to onboarding assessments, care team composition, resource allocation strategies, and evaluation metrics
- Our goal is to cover:
  - Using child-level data provided by OHA related to medical complexity, social complexity, and health complexity
  - KPNW model of using system-level data to identify children with health complexity
  - Models for sharing this information with medical homes to which children are assigned within the CCO
  - Complex care management models
  - Evaluation metrics used to gauge impact of pediatric complex care management programs

Questions from the 1ˢᵗ Section of the Day from You

- We will be sending you a survey to get your feedback and to understand specific questions you have about:
  - Data Scoring
  - Data Sharing
  - Data Itself – what Makes Sense, What Doesn't Make Sense

- We will also be asking if it would be helpful to have a webinar supported update call and deep dive into methodological issues in early 2018.

- **That said, what things jumped out at you that need to be addressed?**

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Questions We Have for You to Consider

- Timing of sharing the Pediatric Medical Complexity Algorithm
    - In the proposal we noted OHA Data Sharing in Fall 2017
    - However, would it be more helpful to wait until early 2018 and use a calendar year time period?
        - Examine children enrolled with you and their care from 2014-2017
- Sharing of Social Complexity OR Waiting to share Health Complexity Composite
    - Value in the combined and global information given data limitations.
    - Potential confusion in sharing individual parts and then sharing the composite score.

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PEDIATRIC HEALTH COMPLEXITY
JOYCE LIU, MD
MEDICAID MEDICAL DIRECTOR AT
KAISER PERMANENTE, NW

November 8, 2017

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GOALS FOR TODAY

- Why Pediatric Complex Health Management?

- Importance of Health Complexity that takes into account Medical and Social Indicators

- Benefit of System Level Data

- Overview of NW pilot

- Review the basic elements of the Pediatric Care Together (formerly Team Based Care) model

- Tips for CCOs as you consider how to USE the information provided by OHA

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THE PROBLEM

Despite having wonderful pediatric care teams and great population management tools we still struggle with certain patients:

- Medically Complex
  - Physical Health
  - Mental Health
- Socially Complex
- Unknown

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LANDSCAPE OF CHILDREN IN KPNW

- Approximately 115,000 child/adolescent members
  - Majority are paneled to a pediatrician
  - Approximately 18,500 pediatric Medicaid patients
- Strong Primary Care System
  - Primary care practices function as robust medical homes, focus on care coordination
  - Integrated health system and shared electronic medical record
  - Use of questionnaires at point of care, data entry into searchable fields in electronic medical record (EMR)
- Complex health care management supports
  - Exceptional Needs Care Coordinators
  - Within specialty clinics, complex care navigators. Building complex care coordinators for children who primarily receive care through specialists.
- Population health data infrastructure
  - System-level supports to use data to inform population-level decisions and supports

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THE PROBLEM

Why has it taken so long for a pediatric–focused complex health management program?

General belief organizationally that:

- Most kids are healthy
- Kids are resilient
- Childhood medical conditions are not preventable
- Adult clinicians have a bigger burden to carry and their patients are far sicker than pediatricians'
- Little understanding of the impact of ACES, mental health issues, social determinants

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PEDIATRIC DATA

AND WE KNOW …..

- 13.5% of the Pediatric population in the US have a special health care need (asthma, seizures, …) = 10 million kids nationally
    - Accounts for 25-50% of all hospital days and 70% of overall health expenditures

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PEDIATRIC DATA

Children with medical complexity is a subset

- Medically even more complex (CF, congenital heart disease)

- Approx. 3 million kids in the US (30% of those with special health care needs)

- Of which 2million (2/3) are insured by Medicaid

  - Makes up 6% of all Medicaid patients

  - Accounts for 40% of all pediatric medical expenditures.

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PEDIATRIC MEDICAID

- These patients are at high risk of having unmet social determinants

- US spends far more on the physical health than many other countries but far less on social determinants
  - Contributes to poorer health outcomes

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SOBERING THOUGHTS

Unmet social and economic needs account for up to 80% of health outcomes

- Poor housing → increased rates of lead poisoning, asthma

- Food insecurity → increased rates of obesity, hyperlipidemia, HTN. Hospital rates for hypoglycemia are 27% higher the fourth week of the month

- Education: 25yo with college degree lives 8-9 years longer. Babies born to moms without high school degree are twice as likely to die by 1st birthday (compared to mom with a college degree)

Moral Imperative – Public Health Imperative – National Economic/Competitive Implications

Adverse Childhood Experiences are the single greatest unaddressed public health threat facing our nation today.

Robert Block, MD

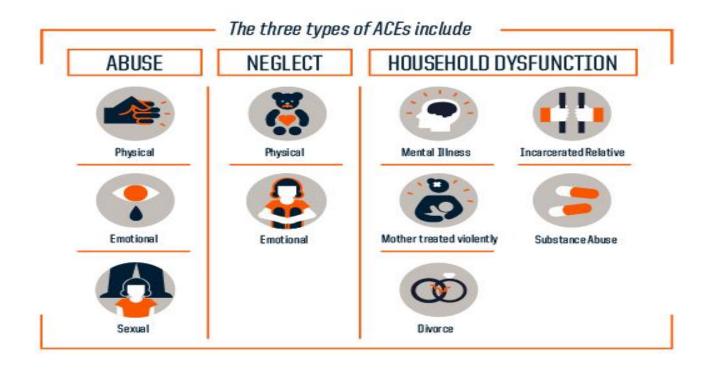former president of the American Academy of Pediatrics

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ADVERSE CHILDHOOD EVENTS (ACES)
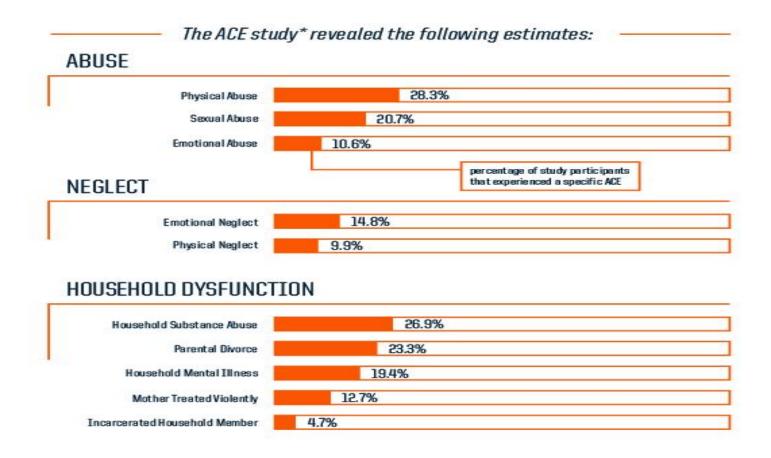
ACES are fairly common BUT

- > Almost 20% of our children will have 4 or more ACES
  - Have 20 year shorter life expectancy
  - 8 times more likely to be an alcoholic
  - 20 times more likely to use IV drugs
  - 4 times more likely to suffer from depression
- High quality programs dealing with ACES have shown a $10 return on investment for every dollar spent
  - Prevent future abuse
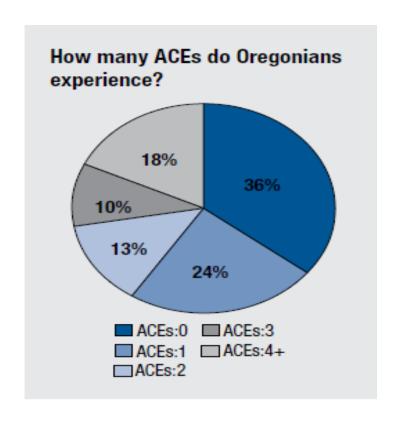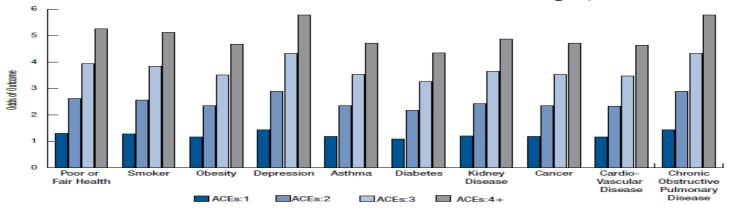 - Build resiliency and coping skills

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WHAT IS ACES SCREENING FOR?

The three types of ACEs include

ABUSE | **NEGLECT** | **HOUSEHOLD DYSFUNCTION**

Physical | Physical | Mental Illness | Incarcerated Relative

Emotional | Emotional | Mother treated violently | Substance Abuse

Sexual | | Divorce

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ARE OREGONIANS EFFECTED BY ACES?

How many ACEs do Oregonians experience?

- 36%
- 24%
- 13%
- 10%
- 18%

ACEs:0 ACEs:3
ACEs:1 ACEs:4+
ACEs:2

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OHA – PUBLIC HEALTH DIVISION - IMPACT OF ACES

The association between ACEs and health outcomes in Oregon, 2011 & 2013

This table highlights the relationship between the number of ACEs experienced and associated health outcomes. This analysis controlled for sociodemographics including age, sex, education, poverty, race and ethnicity, and for smoking for chronic obstructive pulmonary disease and cardiovascular disease.

ACEs patterns in the 2011 & 2013 BRFSS data:

- People who lived in poverty experienced at least one ACE more often than the rest of the population. Half of those who lived in poverty reported experiencing 3 or more ACEs, a rate that was twice as high as the rest of the population. (Poverty was characterized as an annual household income of less than $11,490 for an individual or $23,550 for a family of four).

- People with less education experienced a larger number of ACEs than those with more education. People with an 11th grade education or less reported the highest rate of experiencing 4 or more ACEs.

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EFFECTS OF TOXIC STRESS

The Impact of a Stuck Fight or Flight Response

Physical Reaction		Long-Term Impact
Blood pressure rises	→	Heart disease
Stress hormones rise	→	Anxiety, insomnia, addictions, weight gain
Digestive system slows	→	Gastro intestinal problems
Growth and sex hormones fall	→	Premature aging
Immune system weakens	→	Infections, cancer
Sticky blood platelets increase	→	Heart attacks

Source: Dr. Robert Gonzalez, The Chopra Center
Copyright 2013.

eblin group

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LIMBIC SYSTEM

- **HIPPOCAMPUS** – plays an important role in emotion, learning and memory.
- **AMYGDALA** – plays role in aggression, eating, drinking and sexual behaviors.
- **HYPOTHALAMUS** – monitors blood levels of glucose, salt, blood pressure and hormones.

Frontal lobe

Thalamus

Hippocampus

Amygdala

Hypothalamus

Olfactory bulb
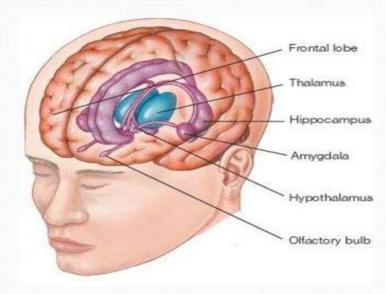
ARE THINGS THAT BLEAK?

Dig deeper and we find reasons for optimism. Find examples of smaller programs that work

- Pick the right population: high risk and impactable
- Focus care on patients' goals to build trust
- High face to face contact with patients and Pediatric Care Together (PCT) team
- Practice trauma informed care and offer trauma specific services
- Care manage the medical and mental health issues
- Attend to family issues
- Care manage the social determinants

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Call for Action

The science is clear:

Early adversity dramatically affects health across a lifetime. Today we are beginning to understand how to interrupt the progression from early adversity to early death.

Nadine Burke Harris, MD
Center for Youth Wellness

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PEDIATRIC STRATIFICATION

How do you find the most impactable?

- High Cost?
- High Utilizers?
- High Social Determinant Risks?
- High ACES scores?

- OR a Combination = Health Complexity!!

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HIGH COST AND HIGH UTILIZERS

PROS:
- Easy to do
- Likely includes the most ill
- Will include some patients with social risk factors

CONS:
- Doesn't find the most impactable (some kids have very expensive diseases)
- Won't pick up children with chronic diseases that don't come in and have poor quality outcomes

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ACES SCORE

PROS
- Lots of data to support

CONS
- Time Consuming to Ask
- Inaccuracy in reporting (under-reporting)
- Documenting in the EMR needs to be done to trend
- What do clinicians do if the answer is yes?
- PTSD response

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STATE LEVEL DATA

PROS:
- Will include both medical and social risk scores
- More efficient for the clinician
- Easier to obtain as state is providing
- Parents or teens don't need to be asked questions (less risk of PTSD response)
- Accuracy and consistency (particularly as MH and ADDM services are carved out)
- Can track progress over time
- Consistent data bases used across different organizations

CONS:
- Need to have data on both child and adult (if just moved to OR….)
- Reporting limited to OHP patients
- Need to get information to the front line medical team who care for the family

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STATE LEVEL DATA

THE DATA

- **Medical Complexity score** will be reported (complex chronic, non-complex chronic, no chronic disease)

- **Social Risk Score** will be reported but will be limited to a number for each child (won't tell us what particular risk factors are pertinent to child). Ex. Johnny Smith has a social risk score of 4

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Figure 2.0: Overview of System-Level Data used to Identify Children with Medical and Social Complexity, with the goal of Classifying Children with Health Complexity Who Would Benefit from Complex Care Management and Novel Data Sharing to CCOs/Health Systems

Children with Medical Complexity

Children Identified & Classifications Used:
A Medical Complexity Score will be used, which incorporates utilization, diagnosis, and number of body systems impacted. The three categories of complexity are:
1) Children with Complex Chronic Disease
2) Children with Non-Complex Chronic Disease
3) Children without Chronic Disease

Standardized Scoring & Reporting Method:
Pediatric Medical Complexity Algorithm (PMCA)

Data Source: Based on Oregon Health Authority (OHA) medical claims related to utilization and diagnosis. Examines all claims for publicly insured children, across all providers, in the last three years, regardless of lapse in insurance or changes to the CCO to which the child is assigned.

Child-Level Data from OHA to CCO

Data Sharing Through Project:

For children assigned to the CCO/KPNW, child-level PMCA classifications (*see three categories above*).

Periodicity
Data are currently being run, and sharing to CCOs is expected within 2017. It is currently expected that there will be annual sharing of this information.

Children with Social Complexity

Children Identified & Classifications Used: A Social Complexity Score (indicating the number of social complexity risk factors identified) will be created based on "a set of co-occurring individual, family, or community characteristics that have a direct impact on health outcomes or an indirect impact by affecting a child's access to care and/or a family's ability to engage in recommended medical and mental health treatments.*

Standardized Scoring & Reporting Method:
None currently exists. *This project supports development of a scoring algorithm. Some elements of this data may be ready at different times. Therefore, there may be sharing of data based on program eligibility and administrative data shared separately from Integrated Client Services (ICS) data.*
Data Sources: Three: 1) OHA Program Eligibility, 2) Administrative data used for Chronic Illness and Disability Payment System (CDPS) , & 3) Integrated Client Services (ICS) Data Warehouse for the child and their parents. ICS includes data across the Oregon Department of Human Services (DHS) and OHA client-based services. Includes data from the following DHS Programs: Aging and People with Disabilities, Child Welfare, Developmentally Disabled, Self-Sufficiency, Vocational Rehabilitation. Includes data from the following OHA Programs: Alcohol and Drug (AD), Contraceptive Care (C-Care), Family Health Insurance Assistance Program (FHIAP), Healthy Kids Connect (HKC), Medical Assistance Programs (MAP), Mental Health (MH), Women Infants Children (WIC). Includes data from the following external agencies: Department of Corrections (DOC), Oregon Housing and Community Services.

Child-Level Data to OHA/CCO/KPNW

Data Sharing Through Project:
OHA Medicaid/CCO/KPNW will receive child-level social complexity score[s] for children assigned to them. This data will provide information about total complexity, but won't provide specific information on specific risk factors. Data based on the program and CDPS data sources may be shared separately and at different times than data from ICS.
Periodicity: *To be determined through the project's facilitated discussions.* Data have been obtained by OHA, and they are currently being assessed for validity and additional factors. Goal is to implement data sharing by Spring 2018.

Children with Health Complexity

Children Identified & Classification Used:
A Health Complexity Score will be created that combines the Medical Complexity Score and Social Complexity Score. This project supports the facilitation of conversations across public and private stakeholders about the scoring algorithms that will be used and the final classification to be made for each child.

Standardized Scoring & Reporting Method:
None currently exists. *This project supports these data being combined for the first time.*

Data Source:
Medical Complexity & Social Complexity information at a child level for children insured by Medicaid.
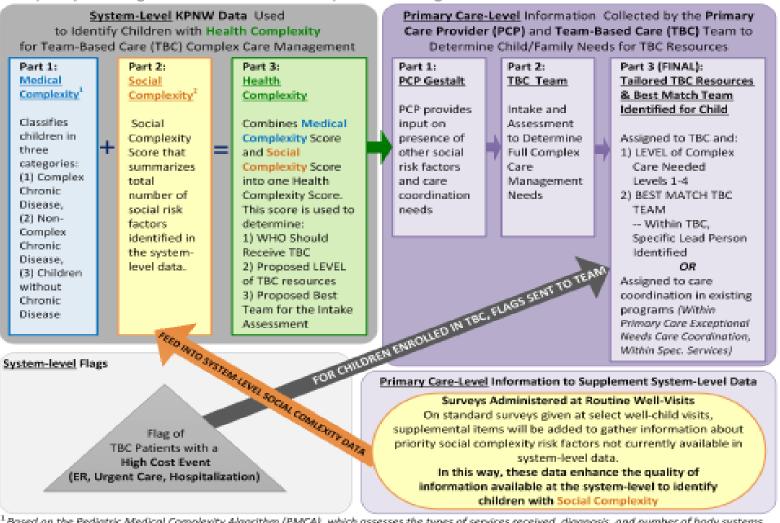
Child-level Data from OHA to CCOs/KPNW

Data Sharing Through Project:

For children assigned to their CCO/KPNW, Health Complexity Score.

Periodicity
To be determined through the project's facilitated discussions. Goal is to implement data sharing by Fall 2018.

+

=

* Social Complexity as defined by The Center of Excellence on Quality of Care Measures for Children with Complex Needs (COE4CCN)

Version 1.2 June 14th, 2017

So you get the scores - then what?..........

Figure 1: Overview of **System-Level** and **Primary Care-Level** Methods Within KPNW to Identify Children with Health Complexity and Assign Pediatric Team-Based Complex Care Management Resources

System-Level KPNW Data Used to Identify Children with Health Complexity for Team-Based Care (TBC) Complex Care Management

Part 1: Medical Complexity[1]

Classifies children in three categories: (1) Complex Chronic Disease, (2) Non-Complex Chronic Disease, (3) Children without Chronic Disease

+

Part 2: Social Complexity[2]

Social Complexity Score that summarizes total number of social risk factors identified in the system-level data.

=

Part 3: Health Complexity

Combines Medical Complexity Score and Social Complexity Score into one Health Complexity Score. This score is used to determine: 1) WHO Should Receive TBC 2) Proposed LEVEL of TBC resources 3) Proposed Best Team for the Intake Assessment

Primary Care-Level Information Collected by the Primary Care Provider (PCP) and Team-Based Care (TBC) Team to Determine Child/Family Needs for TBC Resources

Part 1: PCP Gestalt

PCP provides input on presence of other social risk factors and care coordination needs

Part 2: TBC Team

Intake and Assessment to Determine Full Complex Care Management Needs

Part 3 (FINAL): Tailored TBC Resources & Best Match Team Identified for Child

Assigned to TBC and:
1) LEVEL of Complex Care Needed Levels 1-4
2) BEST MATCH TBC TEAM -- Within TBC, Specific Lead Person Identified

OR

Assigned to care coordination in existing programs (Within Primary Care Exceptional Needs Care Coordination, Within Spec. Services)

System-level Flags

Flag of TBC Patients with a **High Cost Event** (ER, Urgent Care, Hospitalization)

FEED INTO SYSTEM-LEVEL SOCIAL COMPLEXITY DATA

FOR CHILDREN ENROLLED IN TBC, FLAGS SENT TO TEAM

Primary Care-Level Information to Supplement System-Level Data

Surveys Administered at Routine Well-Visits
On standard surveys given at select well-child visits, supplemental items will be added to gather information about priority social complexity risk factors not currently available in system-level data.
In this way, these data enhance the quality of information available at the system-level to identify children with Social Complexity

[1] *Based on the Pediatric Medical Complexity Algorithm (PMCA), which assesses the types of services received, diagnosis, and number of body systems impacted. Claims and utilization available within the KPNW system used. Service provided outside of KPNW or in the past for children when they were not covered by KPNW is not included.*
[2] *Based on system-level data KPNW is able to assess about the child and family that relate to social risk factors. Data sources include program eligibility (Medicaid, Subsidized Exchange) and fields within the electronic medical record highlighting patient need (e.g. Translation) or results of parental/youth screening (Depression screening, Substance abuse screening).*

OPIP

PEDIATRIC CARE TOGETHER – IN ACTION
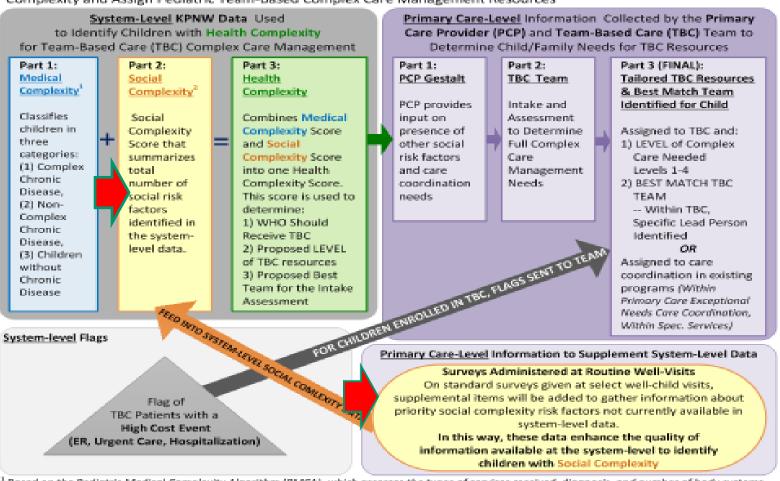
"Jill" was diagnosed with type I diabetes on 8/13/13 at the age of 15yo. PMH of ADHD and depression.

Between 8/13/13 – 11/2015
- 32 ED visits,
- 2 medical inpatient hospitalizations (1 in the PICU)
- and 2 suicide attempts. (1 requiring inpatient mental health stay)

She refused to discuss her diabetes with anyone (including family, medical staff), became tearful and was resistant to suggestions for care. The diabetes team had numerous visits with her but had a tough time getting her to comply with medical recommendations.

Mom is Spanish speaking only and was getting increasingly frustrated. She didn't know what to do with her daughter's resistance and wasn't aware of resources available to her. Additionally she was working long hours (acting as a single parent) to support Jill and her brother

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PEDIATRIC CARE TOGETHER – IN ACTION

FH: father with type 2 diabetes, dementia, Alzheimer's, in a nursing home (recently placed on hospice)

- Maternal uncle had type I DM and committed suicide, in the suicide note stated he couldn't cope with diabetes anymore.

Her PCP was very worried that she was giving up and no longer wanted to live thus asked her to be onboarded to PCT (MTS Pilot) in November, 2015
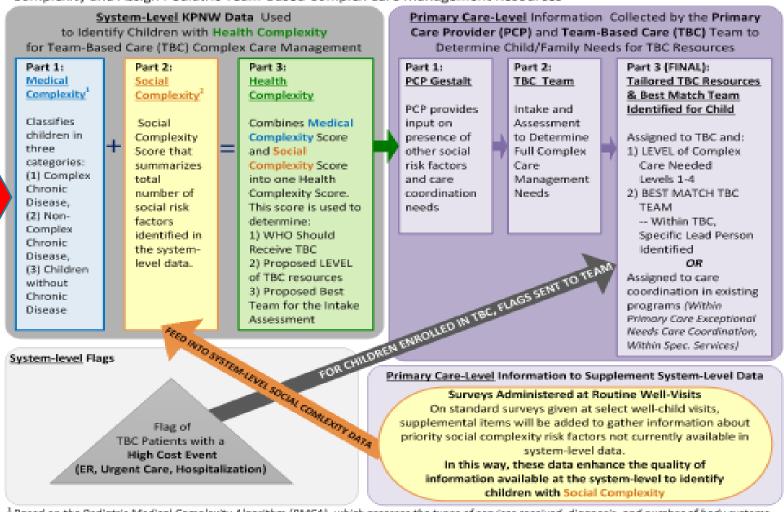
The social worker reached out to the family – realized she was refusing outpatient MH services despite suffering from significant depression (despite being recommended for intensive outpatient MH treatment)

Was failing school (wasn't attending most days)

SH: numerous stressors. Was living in a moldy apartment with holes in the floor, food insecurity, mom worked long hours to provide for her and her brother.

Figure 1: Overview of **System-Level** and **Primary Care-Level** Methods Within KPNW to Identify Children with Health Complexity and Assign Pediatric Team-Based Complex Care Management Resources

System-Level KPNW Data Used to Identify Children with Health Complexity for Team-Based Care (TBC) Complex Care Management

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Social Complexity Score that summarizes total number of social risk factors identified in the system-level data.

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Combines Medical Complexity Score and Social Complexity Score into one Health Complexity Score. This score is used to determine:
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3) Proposed Best Team for the Intake Assessment

Primary Care-Level Information Collected by the Primary Care Provider (PCP) and Team-Based Care (TBC) Team to Determine Child/Family Needs for TBC Resources

Part 1: PCP Gestalt

PCP provides input on presence of other social risk factors and care coordination needs

Part 2: TBC Team

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OR
Assigned to care coordination in existing programs (Within Primary Care Exceptional Needs Care Coordination, Within Spec. Services)

System-level Flags

Flag of TBC Patients with a **High Cost Event** (ER, Urgent Care, Hospitalization)

FEED INTO SYSTEM-LEVEL SOCIAL COMPLEXITY DATA

FOR CHILDREN ENROLLED IN TBC, FLAGS SENT TO TEAM

Primary Care-Level Information to Supplement System-Level Data

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OPIP

PART 1: MEDICAL COMPLEXITY

- Utilized the Pediatric Medical Complexity Model (PMCA) to categorize children into three groups:
  - Complex chronic
  - Non-complex chronic
  - Non-chronic
- Utilized a three- year look back
  - Updated based on ICD-10 codes

Remember: DOES NOT INCLUDE SOCIAL DETERMINANTS

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Figure 1: Overview of **System-Level** and **Primary Care-Level** Methods Within KPNW to Identify Children with Health Complexity and Assign Pediatric Team-Based Complex Care Management Resources

Part 2: Operationalizing KPNW System-Level Data on Social Complexity

System-Level Data Currently Available in Searchable Fields:
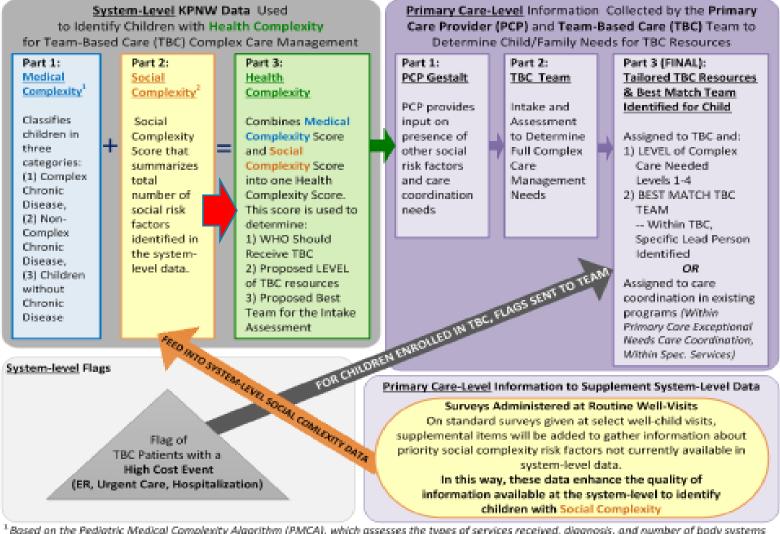
1. **Poverty**
   - Medicaid
   - Subsidized exchange
   - Children's Health Program
   - MFA
2. **Limited English proficiency**
   - Translator need
3. **Parent mental health service need**
   - State claims for Medicaid patients
   - Parent mental health Dx in KP System
   - Parent ADDM Dx in KP system
4. **Child welfare system involvement**
   - Foster care kids are tracked
   - ENCC
5. **Child mental health service need**
   - Services or Dx in KP system
   - Teen with PHQ-9 or GAD7
6. **Child substance abuse treatment need**
   - Services or Dx in KP system
   - CRAFFT results

New Social Complexity Data that will be Asked in Patient Surveys at Well-Visits (Future Data to Enhance Social Complexity Information)

1. **Poverty**
   - Insecure housing
   - Food Insecurity
2. **Limited English proficiency**
3. **Death of a loved one**
4. **Domestic violence and family stress**
5. **School absenteeism (truancy)**
6. **Child involvement with law enforcement- juvenile or criminal justice**
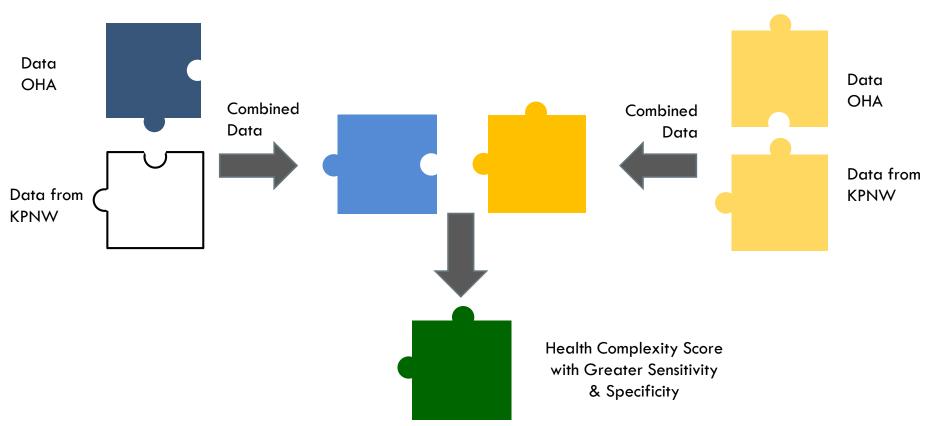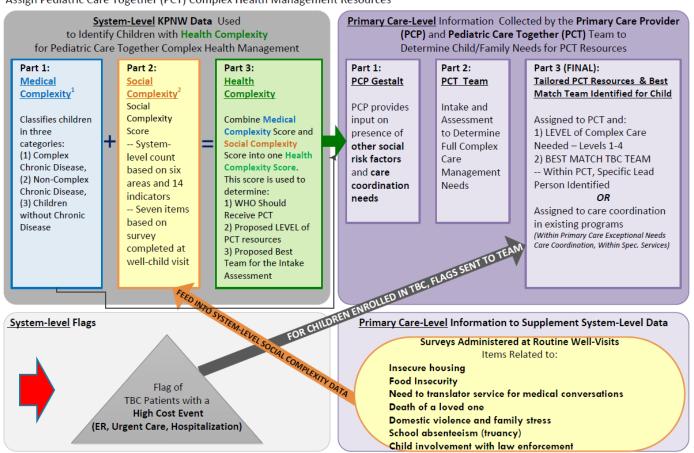
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System-Level KPNW Data Used to Identify Children with **Health Complexity** for Team-Based Care (TBC) Complex Care Management

Part 1:
Medical Complexity[1]

Classifies children in three categories:
(1) Complex Chronic Disease,
(2) Non-Complex Chronic Disease,
(3) Children without Chronic Disease

+

Part 2:
Social Complexity[2]

Social Complexity Score that summarizes total number of social risk factors identified in the system-level data.

=

Part 3:
Health Complexity

Combines Medical Complexity Score and Social Complexity Score into one Health Complexity Score. This score is used to determine:
1) WHO Should Receive TBC
2) Proposed LEVEL of TBC resources
3) Proposed Best Team for the Intake Assessment

Primary Care-Level Information Collected by the **Primary Care Provider (PCP)** and **Team-Based Care (TBC)** Team to Determine Child/Family Needs for TBC Resources

Part 1:
PCP Gestalt

PCP provides input on presence of other social risk factors and care coordination needs

Part 2:
TBC Team

Intake and Assessment to Determine Full Complex Care Management Needs

Part 3 (FINAL):
Tailored TBC Resources & Best Match Team Identified for Child

Assigned to TBC and:
1) LEVEL of Complex Care Needed Levels 1-4
2) BEST MATCH TBC TEAM
-- Within TBC, Specific Lead Person Identified
OR
Assigned to care coordination in existing programs (Within Primary Care Exceptional Needs Care Coordination, Within Spec. Services)

FOR CHILDREN ENROLLED IN TBC, FLAGS SENT TO TEAM

FEED INTO SYSTEM-LEVEL SOCIAL COMPLEXITY DATA

System-level Flags

Flag of TBC Patients with a **High Cost Event** (ER, Urgent Care, Hospitalization)

Primary Care-Level Information to Supplement System-Level Data

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In this way, these data enhance the quality of information available at the system-level to identify children with Social Complexity

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[2] *Based on system-level data KPNW is able to assess about the child and family that relate to social risk factors. Data sources include program eligibility (Medicaid, Subsidized Exchange) and fields within the electronic medical record highlighting patient need (e.g. Translation) or results of parental/youth screening (Depression screening, Substance abuse screening).*

OPIP

BASED ON KPNW DATA: WILL THEN CREATE HEALTH COMPLEXITY SCORE
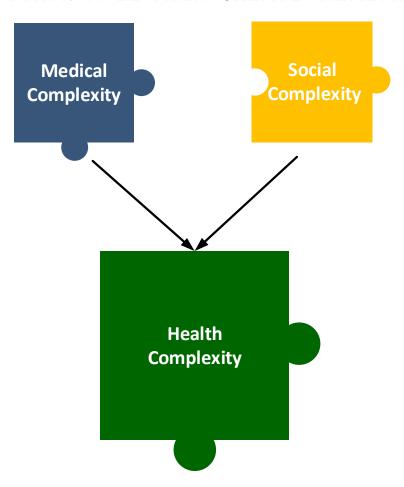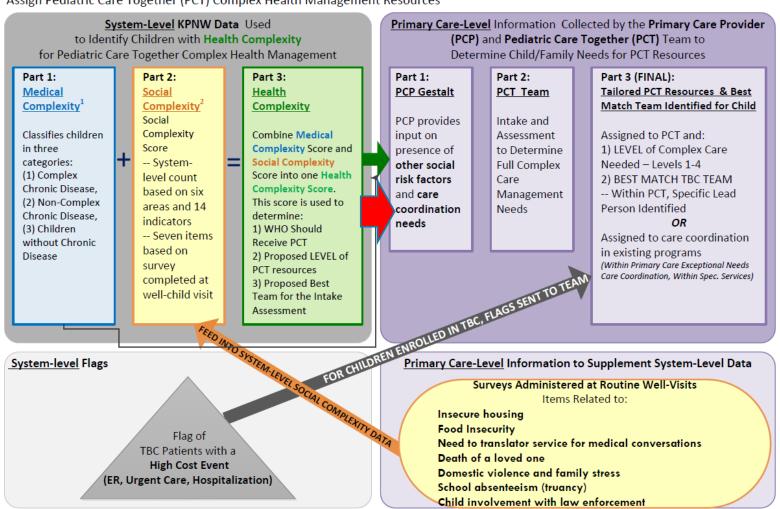
Figure 1: Overview of **System-Level** and **Primary Care-Level** Methods Within KPNW to Identify Children with Health Complexity and Assign Pediatric Care Together (PCT) Complex Health Management Resources

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[1] *Based on the Pediatric Medical Complexity Algorithm (PMCA), which assesses the types of services received, diagnosis, and number of body systems impacted. Claims and utilization available within the KPNW system used. Service provided outside of KPNW or in the past for children when they were not covered by KPNW is not included.*

[2] *Based on system-level data KPNW is able to assess about the child and family that relate to social risk factors. Data sources include program eligibility (Medicaid, Subsidized Exchange) and fields within the electronic medical record highlighting patient need (e.g. Translation) or results of parental/youth screening (Depression screening, Substance abuse screening).*

HEALTH COMPLEXITY SCORES CAN THEN BE USED TO ASSIGN AND ALLOCATE RESOURCES

- Prioritize which children/families to receive complex health management needs
  - ✓ Gather front-line data to enhance the sensitivity and specificity of the health complexity score

- Propose the best match team member for that child/family
  - ✓ Not all patients needs all the resources in pediatric care together
  - ✓ Some patients need social worker "to be on first", some patients and nurse to "be on first"

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HEALTH COMPLEXITY SCORES CAN THEN BE USED TO ASSIGN AND ALLOCATE RESOURCES

- Determine and track resource investments needed for each child/family
  - ✓ Outreach approaches used and whether off site engagement used
    - For example, we have found phone-based outreach to engage in the program doesn't work for members with high social complexity
      - frequently social workers need to go to them in their environments to build trust and get them engaged in our Pediatric Care Together program. Building trust takes time!!
    - Care teams often are providing care for multiple family members.
    - Requires proactive planning and resource allocation
  - ✓ Track level of care and health management, resources invested and number of "touches"

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DATA FROM STATE ADD MORE "COLOR" TO THE PIECES OF OUR PUZZLE TO BETTER UNDERSTAND POPULATION NEEDS AND PRIORITIZE RESOURCES

Data OHA

Data from KPNW

Combined Data

Combined Data

Data OHA

Data from KPNW

Health Complexity Score with Greater Sensitivity & Specificity

Figure 1: Overview of **System-Level** and **Primary Care-Level** Methods Within KPNW to Identify Children with Health Complexity and Assign Pediatric Care Together (PCT) Complex Health Management Resources

System-Level KPNW Data Used to Identify Children with Health Complexity for Pediatric Care Together Complex Health Management

Part 1:
Medical Complexity [1]

Classifies children in three categories:
(1) Complex Chronic Disease,
(2) Non-Complex Chronic Disease,
(3) Children without Chronic Disease

+

Part 2:
Social Complexity [2]
Social Complexity Score
-- System-level count based on six areas and 14 indicators
-- Seven items based on survey completed at well-child visit

=

Part 3:
Health Complexity

Combine **Medical Complexity** Score and **Social Complexity** Score into one **Health Complexity Score**. This score is used to determine:
1) WHO Should Receive PCT
2) Proposed LEVEL of PCT resources
3) Proposed Best Team for the Intake Assessment

Primary Care-Level Information Collected by the Primary Care Provider (PCP) and Pediatric Care Together (PCT) Team to Determine Child/Family Needs for PCT Resources

Part 1:
PCP Gestalt

PCP provides input on presence of **other social risk factors** and **care coordination needs**

Part 2:
PCT Team

Intake and Assessment to Determine Full Complex Care Management Needs

Part 3 (FINAL):
Tailored PCT Resources & Best Match Team Identified for Child

Assigned to PCT and:
1) LEVEL of Complex Care Needed – Levels 1-4
2) BEST MATCH TBC TEAM
-- Within PCT, Specific Lead Person Identified

OR

Assigned to care coordination in existing programs
(Within Primary Care Exceptional Needs Care Coordination, Within Spec. Services)

System-level Flags

FEED INTO SYSTEM-LEVEL SOCIAL COMPLEXITY DATA

FOR CHILDREN ENROLLED IN TBC, FLAGS SENT TO TEAM

Flag of
TBC Patients with a
High Cost Event
(ER, Urgent Care, Hospitalization)

Primary Care-Level Information to Supplement System-Level Data

Surveys Administered at Routine Well-Visits
Items Related to:

Insecure housing
Food Insecurity
Need to translator service for medical conversations
Death of a loved one
Domestic violence and family stress
School absenteeism (truancy)
Child involvement with law enforcement

[1] *Based on the Pediatric Medical Complexity Algorithm (PMCA), which assesses the types of services received, diagnosis, and number of body systems impacted. Claims and utilization available within the KPNW system used. Service provided outside of KPNW or in the past for children when they were not covered by KPNW is not included.*

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THE SOLUTION: PEDIATRIC CARE TOGETHER MODEL

Six Elements - One Team

Bundle Elements

1. **Patient Identification:** Pediatric risk stratification (to be developed based on disease burden, past utilization and social determinants). Once identified, PCPs will help assess and prioritize.
2. **Assessment:** Pediatric specific screening tools are used to identify gaps in care and ensure social determinants are identified.
3. **Plan of Care:** Once the team has developed a relationship and assessed the patient, they meet to collaboratively create a patient centered care plan which is then documented in the chart
4. **Team Coordination:** Team engages with the member and family. Identifies issues and works toward their goals and needs. Intensity of care highly variable and tailored to individuals
5. **Transitions:** Patients who have an inpatient stay or receive services outside our system receive care coordination to ensure a smooth, well-managed transition. Team monitors reports to identify patients in ED/inpatient.
6. **Advanced Care Planning** – when appropriate

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KEY PROGRAM ELEMENTS

MULTIDISCIPLINARY TEAM CONSISTS OF:

- RN care manager
- Pediatric Social Worker
- Navigator (non-licensed provider that lives in the community and is a liaison between the community and the medical community

ONGOING ASSESSMENTS

- Focuses on all dimensions of the patient's health including what is important to the patient, to their family
- As trust builds, medical teams goals can be incorporated

LONG TERM PLAN OF CARE

- Documented in the chart so everyone can see (including ER/inpatient team)

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TRAUMA INFORMED CARE

"Trauma-informed care is a strengths based framework that is grounded in an understanding of and responsiveness to the impact of trauma, that emphasizes physical, psychological, and emotional safety for both providers and survivors, and that creates opportunities for survivors to rebuild a sense of control and empowerment."

(Hopper, Bassuk, & Olivet, 2010)

TRAUMA SPECIFIC SERVICES

Trauma Specific Services (TSS)

- are programs, interventions, and therapeutic services aimed at treating the symptoms or conditions resulting from a traumatizing event(s).

WHAT ELSE WILL PEDIATRIC CARE TOGETHER (PCT) DO?

- Main point of contact with direct access via single phone number

- Periodic reviews of all patients and status updated with each outreach/point of contact

- Transition management. Includes coordination with specialty care (particularly when located at OHSU), post hospital care, ER follow up, mental health, or home health, …

- Use Longitudinal Plan of Care (new KPHC tool) to document patient's story, goals, wishes, and ED-prevention plans

- Attention to goals of care planning

- Collaboration and better use of community resources

- And more……

KAISER PERMANENTE®

PILOT OVERVIEW, AS OF SEP 2017

Two sites active: Mt Scott since 2016 and Rockwood since 2017.

Over 200 patients on-boarded, majority of whom are in Medicaid.

Medical complexity stratification **is complete.**
- Original runs did not include publicly insured mental health services, which is a key predicator to PMCA accuracy.

Social Complexity Stratification is **in progress.**
- Time intensive, but perspective changing process about determinants of health
  - Concept is difficult to operationalize, but valuable in the long-run

Different levels of info available for different members:
- Medicaid Members: Data from state of Oregon expected in 2018 (ADDM/MH data, parental criminal justice activity) + KPNW Data
- Non-Medicaid Members: Using combination of existing data and screening to gather data on 11 items

KAISER PERMANENTE.®

HAVING BEEN ON THIS JOURNEY……
STARTING TIPS FOR YOU

- What is measured is what is focused on
  - ✓ Value in having data to describe the importance of the child/adolescent population and their needs
  - ✓ Debunk myths about "most children are healthy"

- Identify capacity, resources and assets that exist in the community to support children with health complexity needs
  - ✓ Medical
  - ✓ Social
  - ✓ Other Issues

- Consider your own data and/or community-level information that can enhance the understanding of the population needs

- Pick a population of children with health complexity and set of partners/resources to pilot complex health management to meet their needs
  - ✓ You will identify more children with health complexity needs than are likely able to be served by specific programs and resources

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PEDIATRIC CARE TOGETHER — IN ACTION

Social worker reached out to a well respected Latino community group (well respected in the Hispanic community) and got them a Spanish speaking culturally appropriate advocate. She was instrumental in getting the family:

- financial support/resources for food

- better housing

Through this process Jill and her mom began to trust us more. By initially focusing on things important to them (including boys, school, and other goals), Jill was able to see that we saw her as not just a person with Diabetes, but an amazing resilient, and adaptable young woman who wanted to graduate high school and go to college.

PEDIATRIC CARE TOGETHER – IN ACTION

From November 2015 – April 2016 there were > 40 documented encounters with this social worker alone. By spring Jill agreed to participate in counseling, started on Wellbutrin, and started attending school regularly.

Since April 2016 there have been no inpatient stays, no UCC visits. She has been to the ER twice (once had severe gastro and needed IVF, another time with severe vaginal bleeding). Both ER visits were recommended by advice.

She has been compliant with her insulin and Wellbutrin. Her hgb A1C has improved dramatically – most recently 7.4

"Jill" graduated high school and is now working part time, and going to college part-time.

"Jill has overcome so many challenges and has had so many successes. She has truly transformed her life, and made life changes that will help her to stay healthy and happy. "

Next Steps

Follow-Up Evaluation Survey

o Feedback on Today

o Feedback on Data Scoring and Data Sharing

o Additional Information You Need and Questions You Have

o Feedback on Topics for Next Learning Session

Spring Stakeholder Meeting For You All

• Grant Time Period: April 18

• Any special considerations in terms of time?

• Proposal is to have the meeting in Salem

OPIP

System-Level Approaches to Identify Children with Health Complexity and Develop Models for Complex Care Management Project: What was NOT able to be funded by LPCHF

- One-on-one assistance and facilitation to CCOs

- Support to CCOs on implementation beyond group-level meetings

- Application and use of data that would identify CYSHCN for other reasons:

  - Children with health complexity predictive of long-term health and functioning

  - Project specifically anchored to looking at health complexity associated with worse outcomes within health care and costs

- ❖ Interested in examining and exploring how OPIP may get funding to support this work with CCOs, given our experience that implementation support on these novel methods would be valuable

- ❖ Let us know if this is of interest to you

OPIP

Questions? Want to Touchbase?
My Door is Open

OPIP Project Lead

Colleen Reuland:

reulandc@ohsu.edu

(503) 494-0456

OHA Project Lead:

Valerie Stewart:

VALERIE.T.STEWART@dhsoha.state.or.us

OPIP

Most Vulnerable Project (MVP)

The Team: In late 2016, a team self-assembled to address a neglected area: how to create socially informed care plans. Our team consists of a pediatric ID subspecialist (Louise Vaz), pediatric hospitalists (Jared Austin and Sarah Green), a general pediatrician (Katie Zuckerman), and psychologists from the NICH program (Dave Wagner and Michael Harris). We also have a qualitative researcher (Becky Jungbauer) and a multitude of student volunteers.

The Setting: Doernbecher Children's Hospital, general medicine service.

The Goal: MVP was developed to better understand the role of social vulnerabilities on how patients do after they are discharged. This was driven by real life examples we each had where knowing the lived experience of the patient would have informed a better medical care plan.

We sought to describe our patient population social risks, with a long term goal to be able to pre-emptively identify pediatric inpatients at greatest risk of an unintended hospital event (such as going to the emergency room or being readmitted). We felt that a pediatric hospitalization was a sentinel event and a vital opportunity to provide a more informed medical plan sensitive to the social needs of the patient and family, such that the child had the best chance to succeed in the outpatient setting.

In 2017, we followed 249 pediatric patients on the general medicine inpatient service, screened for social vulnerabilities, learned about challenges faced in the transition period to home through surveys, and followed them post-discharge for 90 days, tabulating their ER visits and readmissions. Of the 249 patient – caregiver dyads, 58 youth (23.3%) experienced ≥ 1 readmission and/or ED return by 30 days post-discharge.

In addition, we did a retrospective review of hospital readmissions during 2016-2017, identifying "hyperacute" readmissions, those that were readmitted within 7 days of a readmission. Over 30% of these were deemed likely preventable. We also identified a subset of patients that were "hyperutilizers" – more than 5 readmissions in the study period. Nearly all of these were medically complex, and over 50% had a social work consultation.

Lessons Learned:

- As a tertiary care center, the Doernbecher patients are often sicker and more medically complex.
- Our catchment area extends all over the state of Oregon. Thus, there is no "one size fits all" care plan for any specific social vulnerability.
- Care coordination needs are high, and the transition period to home represents a time of vulnerability irrespective of medical complexity.
- Food and financial insecurities are highly prevalent – over 25% of families indicated this concern.
- Over 60% of our caregivers had a high school education or less, demonstrating the importance of tailoring care plans to health literacy levels.
- Children who have experienced trauma in the past and/or have caregivers with mental health issues may be more likely to experience hospitalizations and discharge processes as particularly negative and stressful.
- These findings have implications for the potential benefits of screening for such risk at onset of hospitalization as well as interventions that build resilience for families during and following

hospitalization.

Caregiver quotes:

- "I had to leave my job in order to be home to care for our child."
- "When we first arrived I believe we fell through the cracks of a busy hospital. After I voiced my concern it got better"
- "There were a lot of follow up appointments to make and no real direction with who/how/ when to do so. If not for my personal knowledge of how to navigate the system being a former nurse, we would not have known how to help our son with his care."
- "Cafeteria was expensive, often skipped meals for myself during the stay."
- "Cleaning the house, grocery shopping, just returning to normal life and playing catch up. Catching up on work coworkers had tried to do but messed up. PTSD of the event."
- "Fear of specialists being 4 hrs. away and his primary Dr not being in the loop with his hospitalization.   Insurance not wanting to cover any more of our aona therapy even though it it vital and he will decline without it."
- "Getting home and myself not feeling well. Also my son's symptoms have not improved."

Next steps

- Modeling is currently underway to better understand what, if any, were the predictors of a readmission or ED visit based on the social vulnerabilities we documented.   We expect this analysis to be complete in the next 3 months.
- Qualitative interviews will be starting in December to explore caregiver perceptions of inpatient social needs screening and interventions
- Establishing an integrated care model approach at Doernbecher to including social needs within the medical plan.
- Partner with existing resources and organizations for hospital to community liaisons and to better plug families into services they need

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NICH
Novel Interventions in Children's Healthcare
www.ohsu.edu/nich

OHSU

DOERNBECHER CHILDREN'S Hospital

OHSU

NICH – A population health program

Originally developed with the goal of achieving the Triple Aim… improving care, improving health, and reducing costs in youth with medical complexity and social vulnerabilities.

Medical Complexity (examples)

- End Stage Renal Disease
- Short Gut
- Cystic Fibrosis
- Leukemia and Other Cancers
- Type 1 & Type 2 Diabetes
- Pulmonary Hypertension
- Chronic Pain
- High Risk Infants
- Failure to Thrive
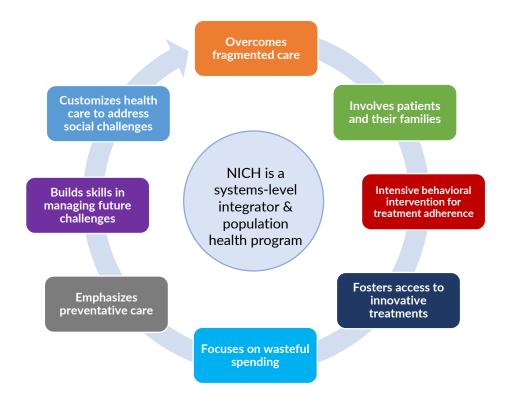
Social Vulnerabilities (examples)

- Immigrant families
- Underemployment/unemployment
- Food insecurity
- Socially isolated
- Unreliable transportation
- Mental health issues
- Non-English speaking
- Living in rural areas
- Experiencing domestic violence

NICH Serves as an "Integrator"

(Berwick et al., 2008)
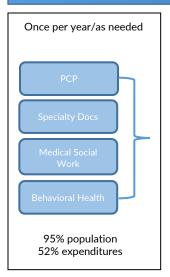
NICH addresses every system that a child and their family may interact with, recognizing that the social determinants of health are a powerful force that impacts a family's ability to care for their child.

NICH is a systems-level integrator & population health program

- Overcomes fragmented care
- Involves patients and their families
- Intensive behavioral intervention for treatment adherence
- Fosters access to innovative treatments
- Focuses on wasteful spending
- Emphasizes preventative care
- Builds skills in managing future challenges
- Customizes health care to address social challenges

NICH Summary of Services:

NICH provides proactive 24/7 skills training and coaching to patients and caregivers through weekly visits in the home, community, school and medical settings. NICH interventionists capitalize on technology to maximize contact allowing for daily prompting and reinforcement of medical regimens, appointment reminders, problem solving and to support the use of medical services at the appropriate level. NICH provides intensive case management and care coordination working collaboratively with families and community resources to address the barriers to effective health management and overall stability.

Continuum of Care / Intensity of services

Once per year/as needed

- PCP
- Specialty Docs
- Medical Social Work
- Behavioral Health

95% population
52% expenditures

Monthly/weekly/daily

- Care Coordination $
- Mental Health Services $
- DHS Oversite $

→ Wrap Around Services $$
→ Intensive Family Support Programs $$
→ Nurse Home Visiting $$

4% population
24% expenditures

24/7 Average 5x/day

NICH

1% population
25% expenditures

- G-Tube $$$$
- In Patient Programs $$$$$
- Transplant $$$$$$$

% of Population/Expenditures

Outcome Data - % Reduction After NICH

- Annual Direct Medical Costs
- Hospital Day Stays
- Hospitalizations
- Emergency Dept. Visits

0% 20% 40% 60% 80%

Reduction in Annual Direct Medical Costs

$80,000
$70,000
$60,000
$50,000
$40,000
$30,000
$20,000
$10,000
$0

$68,352 — Before NICH
$38,496 — After NICH

Making a Referral to NICH:

Anyone can make a referral to obtain NICH services for a specific child or adolescent. All referrals are reviewed for eligibility including evidence of medical complexity and/or a chronic health condition (examples on front page) along with social vulnerabilities (examples on front page) that create substantial barriers to optimal health. Not all insurance carriers will contract for NICH services, however, the NICH team will pursue single-case agreements for every referral. Please contact our Operations Coordinator, Cat Dennis, by phone (503-494-3245) or email (dennica@ohsu.edu) to discuss referrals.

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Partnering with Insurers in Caring for the Most Vulnerable Youth with Diabetes: NICH as an Integrator

Samantha A. Barry[1] · Lena Teplitsky[2] · David V. Wagner[2] · Amit Shah[3] ·
Brian T. Rogers[2] · Michael A. Harris[2,4]

Abstract

Purpose of review In this review, we outline barriers to appropriately caring for high-risk youth with diabetes and discuss efforts in partnering with insurers through Alternative Payment Models to achieve the Triple Aim (improved health, improved care, and reduced costs) for this population.

Recent findings Current approaches in caring for youth with diabetes who evidence a high degree of social complexity are woefully ineffective. These youth are vulnerable to repeat diabetic ketoacidosis episodes, poor glycemic control, and excessive utilization of healthcare resources. To effectively pursue the Triple Aim, an "integrator" (i.e., an entity that accepts responsibility for all components of the Triple Aim for a specified population) must be identified; however, this does not fit into current fee-for-service models.

Summary Integrators for youth with diabetes are limited, but early examples of integrator efforts are promising. We present one successful "integrator," Novel Interventions in Children's Healthcare (NICH), and detail this program's efforts in partnering with insurers to serve high-risk youth with diabetes.

Introduction

There has been a recent emphasis in healthcare on pursuing the "Triple Aim," which targets improvements to the individual experience of care, improvements to the health of populations, and reductions in the per capita costs of care for populations [1]. When originally outlined, several preconditions for the effective accomplishment of the Triple Aim were identified, which include "(1) recognition of a population as the unit of concern, (2) [understanding of] externally supplied policy constraints, and (3) existence of an 'integrator,' [which is defined as an entity] able to focus and coordinate services to help the population on all three dimensions at once" [2].

In the area of pediatric diabetes, there has been an influx of research aimed at identifying high-risk subgroups, which is an important first step to achieving the Triple Aim [3]. For example, some have focused on youth with diabetes who also

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experience a high degree of social vulnerability (i.e., a large number of demographic, psychological, and family risk factors), which puts them at risk for poor glycemic control, repeat diabetic ketoacidosis (DKA) episodes, and avoidable hospitalizations. Policy constraints are notable in the literature [4, 5], while solutions specific to diabetes care have been minimal. Insurers tend to be more focused on those populations with the highest utilization of healthcare resources, and while youth with diabetes have the second highest per capita spending of all age groups with diabetes [6•], they make up only a small portion of the overall healthcare spend. Furthermore, healthcare systems are not incentivized to provide innovative care to these smaller, lower cost populations. Finally, the presence of an "integrator" is a well-acknowledged necessity [7, 8], but few systems have been able to provide an integrator effectively. Health integrators typically do not bill for their services; thus, an investment is needed on the part of either the healthcare system or insurer for sustainability. In this review, we describe innovative efforts in partnering with insurers to achieve the Triple Aim in pediatric diabetes care using these three preconditions to guide the discussion. We then present an example of a successful integrator model for the most vulnerable youth with diabetes [9].

Specifying a Population of Concern

Diabetes mellitus is among the most costly economic burdens on children, families, and healthcare systems, with an estimated cost of diagnosed diabetes in the USA reaching $245 billion per year [10] and per capita medical expenditures at least four times greater for individuals with diabetes than those without [6•, 11, 12]. Of those with diabetes, children are at particularly high risk, with an estimated cost of acute care in the pediatric population reaching $25 billion per year in the USA [10] and children with diabetes having the second highest per capita spending (i.e., $17,380 in 2014) of all age groups [6•]. With the incidence of diabetes in pediatric populations increasing both in the USA and worldwide [13, 14] and complications and cost projections of poorly controlled pediatric disease showing a dramatic increase into adulthood [10, 15], this group as a whole is of considerable concern. In addition, only 1% of youth covered by Medicaid account for approximately 25% of Medicaid expenditures, and 5% of youth account for almost half of Medicaid expenditures [16] many of whom have a chronic health condition like diabetes, suggesting that there is a subgroup of the pediatric population in particular need of intensive intervention in order to successfully address the Triple Aim.

Hospital inpatient care makes up the largest component of medical expenditures for individuals with diabetes, resulting in expenses more than seven times greater than those of youth without diabetes [11] and making up almost half of total medical costs for individuals with diabetes [10]. The literature in

this area has identified many factors in youth with diabetes that co-occur with repeat hospitalizations (e.g., DKA) and excessive use of healthcare resources, including demographic factors such as lower socioeconomic and ethnic minority status [17–19], psychological factors such as mental health diagnoses [20, 21], and family factors such as single-parent household and family conflict [22–24]. Individuals with a combination of risk factors may be particularly vulnerable to acute complications, hospital visits, and the associated costs [3, 25, 26]. Thus, in order to move the needle on overall costs associated with pediatric diabetes care, this particularly complex, vulnerable subgroup of youth with diabetes must move *into* the forefront of intervention planning, clinic structure changes, and alternative payment models and *out of* exclusion criteria—all of which require a collaborative approach and a strong partnership with insurers.

Policy Constraints (and State of Policy Affairs)

In working with vulnerable populations, person-centered care that considers the family's unique combination of risk factors becomes critical. When treating vulnerable youth with diabetes, providers benefit from the flexibility to invest system resources in direct response to youths' unique needs, targeting areas with the greatest return. Diabetes treatment in the USA is beginning to address the need for person-centered care with multidisciplinary care efforts [27–29]; however, there are limits to the success of such systems when utilized within fee-for-service (FFS) models, and FFS models continue to be the norm. Volume-based FFS models assign a unit of payment to each service a provider carries out. Because providers receive more revenues for more units of service performed, these models often discourage the individualized and highly coordinated care that high-risk youth, especially those with medical conditions like diabetes, often require [30••]. Additionally, reimbursement rates are such that less than 30% of total care costs for programs are covered by insurance [4], leaving medical systems to deficit-fund multidisciplinary programs and furthermore, making it less likely that care teams will have the resources necessary to address the individual needs of vulnerable youth and their families. Currently, the FFS model is not optimal for our most vulnerable youth— those who are most costly to our healthcare system and who run the risk of the most harmful health outcomes in both the short and long term.

Thus, to achieve the goals of improved care, healthier youth, and more efficient spending, health care systems must substantively reform their payment structures to incentivize quality, health outcomes, and "value over volume" [1]. Consistent with this perspective, the U.S. Department of Health and Human Services (DHHS) has been a driving force for reforming payment structures in health care delivery and announced in 2015 targets of shifting 30% of Medicare

provider payments to alternative payment models (APMs) by 2016 and 50% to APMs by 2018 [31]. APMs are unconventional fee structures that (1) utilize one or more quality measure(s) to assess performance and assign compensation or (2) include incentives that reward providers for more effective use of resources [32]. APMs reflect a movement toward value-based, patient-centered care and, while they include centers of excellence, accountable care organizations (ACOs), and patient-centered medical homes, these are mere examples of APMs, rather than categories of APMs [30••]. Categories instead include more general payment arrangements, which can be applied to a variety of delivery models. Thus, there is meant to be flexibility in delivery methods, such that healthcare systems can respond appropriately to the needs of a given population.

The DHHS has reported meeting their APM goals for 2016, with three quarters of this progress achieved through the spread of ACOs [31]. While this is encouraging, there are concerns about concerns about Medicare and private sector misalignment, the limited progress made outside of the ACO space, variability of efforts and successes within the ACO space, and the lack of health and financial outcome data supporting such models [31]. Complicating matters further, the uncertain future of the Affordable Care Act may have implications for the scope, authority, and funding of the Center for Medicare and Medicaid Innovation (CMMI), a group formed to implement and evaluate APMs to improve quality of care while controlling costs. This may furthermore impact the CMMI's programs, including initiatives related to the patient-centered medical home, ACOs, and bundled care [33]. There are additional concerns specifically relevant to pediatric diabetes care, as (1) there are limited published APMs in pediatric care on which to model further innovations with few, if any, empirical demonstrations of success [34] and (2) the models that do exist in diabetes care have primarily focused on the patient-centered medical home [35], reflecting changes to the primary care system and not the specialty clinic systems through which children with diabetes typically receive care.

Integrator

Subsequent to specifying a high-needs population and understanding current policies and systems, Berwick and his associates [2] suggested that the third and final step toward effective accomplishment of the Triple Aim is identifying a successful "integrator," meant to accept responsibility for all three components of the Triple Aim for the specified population. Integrators are meant to play an important role in overcoming the fragmented care that encumbers the treatment of individuals with diabetes [7], involving individuals and families, redesigning care

models to foster coordinated care and access to innovative treatments, and allocating resources with an emphasis on behavior change and preventative care [2]. Possible integrators for pediatric diabetes populations are limited, with health maintenance organizations (HMOs) [36] less available to higher risk populations and historically more successful integrating finances than overall care [2] and with care coordination programs having success integrating care [37–41] with few known efforts to coordinate on a financial level. In fact, care coordination efforts often create additional financial barriers, as they are difficult to bill, and cost-analyses to continue funding are limited [3, 42]; furthermore, financial constraints often lead to extensive caseloads that are rarely conducive to the intensive care that high-risk populations necessitate [43].

While the presence of an integrator is a well-acknowledged necessity [7, 8], there are few systems that have attempted to coordinate from both financial *and* care perspectives. Although there is potential for the patient-centered medical home to act as an integrator, efforts thus far have been limited. Patient-centered medical homes are marked by care coordination, family-centered approaches, physician leadership, and enhanced access and payment [44] and have demonstrated benefits to general pediatric populations [45], pediatric populations with special health care needs [46–48], and adult diabetes populations [44]; however, few studies have demonstrated a meaningful benefit specific to pediatric patients with diabetes. This is of particular importance, as models of pediatric diabetes care often differ significantly from the care models of other pediatric chronic illnesses and those of adult diabetes, with subspecialty care visits often occurring more frequently and including a larger multidisciplinary team. One study suggested that parents of children with diabetes who identified a medical home reported less work restrictions and financial impacts associated with diabetes care [49], which is promising; however, important to the medical home concept is the idea that "medical homes" are delivery models [30••, 50] and not payment models. While in many instances medical homes enable APMs (e.g., per member per month payment, quality-based payment, global payment models) [51, 52], they are not synonymous with a specific APM [30••]. Thus, it is difficult to evaluate the medical home's potential as an integrator without specific descriptions and evaluations of underlying payment models. To our knowledge, these evaluations do not exist in the area of pediatric diabetes and are modest at best when evaluating efficacy in other populations.

One promising example of an early "integrator" effort specific to pediatric diabetes is that of the Pediatric Diabetes Intensive Case Management (PDICM) program, which published financial and health outcome data on 10 pediatric diabetes patients in 2004, but has not since published on the progress of the program [53]. The PDICM negotiated directly with third party insurers to provide three intensive diabetes management

components: specialty education, 24/7 telephone access to a certified diabetes educator and a pediatric endocrinologist, and quarterly educator assessments of self-management skills. While this program made substantial case management efforts and appears to have identified an opportunity in directly negotiating contracts with third party insurers, no additional care coordination efforts were reported. Nevertheless, improved health (e.g., decreased DKA admissions) and financial (e.g., reduced costs) outcomes were demonstrated. Further details regarding this potential APM structure were not reported. Thus, integrators within the pediatric diabetes space and rigorous evaluation of APMs have been limited, but early examples of integrator efforts have been promising.

Novel Interventions in Children's Healthcare: Integrator Example

Novel Interventions in Children's Healthcare (NICH) is an intensive, multicomponent behavioral health intervention explicitly designed to address the Triple Aim for the highest pediatric utilizers, with a specific emphasis on youth with type 1 diabetes (T1D) repeatedly hospitalized for DKA [9, 54•]. The youth served by the NICH program are typically referred by their medical providers but are sometimes identified through insurers' efforts to recognize high utilizing plan members. The majority of referred youth received inpatient care at a children's hospital at a major academic medical center in Oregon where medical staff determined that these youth had experienced or were at high risk of experiencing avoidable medical complications and associated acute care (i.e., hospital admissions, emergency department visits), presence of psychosocial vulnerability (e.g., youth mental health diagnosis, family financial insecurity, involvement of child protective services), and poor response to typical medical interventions.

NICH services include a combination of strategic and intensive family and systems interventions, health systems integration and patient needs alignment, and resource access for family and patient optimization. NICH providers (hereafter referred to as "interventionists") deliver services in the youth's natural environment (e.g., home, school, clinic, community) and are available to families 24/7 in-person, by text, or by phone. Due to the intensity of the intervention and high frequency of contact, interventionists carry a caseload of 8–10 patients. Interventionists have a range of educational and experiential backgrounds, including public health, social work, family psychology, and nursing. Program leadership provides interventionists with a week of intensive training and a high level of ongoing supervision, including 2 hours of weekly group supervision, at least 1 hours of individual supervision, and 24/7 access to supervisors via phone. Previous evaluations of health outcomes suggest that NICH is effective in reducing emergency department visits and hospital admissions for a subgroup of

youth who appear particularly vulnerable to repeat DKAs and is associated with improved glycemic control [55]. However, the NICH program is unable to serve youth until they are approved by their respective insurers. The subsequent examination of NICH as a clinical program serving in an integrator role will include a summary of successes and challenges faced in pioneering adoption of NICH as an APM in Oregon.
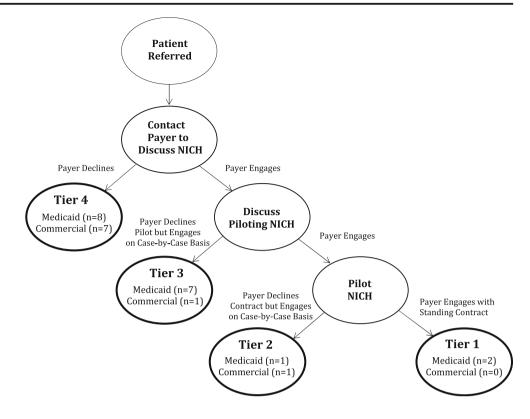
Oregon Medicaid services are delivered through 16 Coordinated Care Organizations (CCOs), which cover approximately 90% of the 1,051,000 Medicaid covered lives in Oregon, and in some instances, a state-sponsored FFS Medicaid option, which covers roughly 10% of Medicaid covered lives. The CCO model expands upon traditional Medicaid and Medicare delivery models (e.g., ACOs and MCOs) by de-centralizing provision of Medicaid and Medicare services from the State to geographically defined organizations, evaluating outcomes based on quality and access measures, and thus incentivizing better integration and coordination of care and allowing for greater flexibility in managing population health efforts that are specific to localized needs (see McConnell et al. [56] for a more thorough description). Because each CCO has its own unique infrastructure, internal resources and programs, and funding priorities, NICH has collaborated with key community and CCO stakeholders to develop an APM, wherein NICH has negotiated individual contracts with insurers (see Fig. 1). Through individual contracts, insurers make a partially capitated prospective payment for intensive NICH services. Services are initiated subsequent to the signing of the contract and discontinued at patient completion of the program or, if the patient may benefit from continued services into the following year, contract renewal is discussed. As a partially capitated payment model allows for a one-time flat-rate payment to address a portion of needs based on provider discretion, NICH providers are able to invest system resources in direct response to patients' unique needs. This is especially important given the unique combination of risk factors often present when treating a complex, high-needs subsample of the broader population; though all patients would arguably benefit from more tailored care.

Since its inception, NICH has formed relationships with CCOs throughout Oregon to fill the service gap that exists along the continuum of care for the top 5% of pediatric patients who are the most medically and socially vulnerable, and who traditionally account for nearly half of the pediatric spend. To date, collaboration efforts between NICH and insurers across Oregon have fallen into four tiers (Fig. 1). Tier 1 represents insurance companies that recognize NICH as the missing piece in their menu of options. These insurers initially piloted the program with a subgroup of their members by utilizing healthcare transformation dollars or grant funds and have since invested in the infrastructure of the program through the use of

Fig. 1 Tiers of insurer engagement in Novel Interventions in Children's Healthcare (NICH) program

standing contracts so that their members have continued access to NICH services. These insurers have also invested in case finding (i.e., identifying members on their health plan who may benefit from NICH) and encourage their care coordination specialists to collaborate closely with the NICH team to ensure the most appropriate level of care is delivered to high-risk patients before they enroll in NICH, during NICH involvement, and in the smooth transition to a lower level of care coordination once NICH services end. Tier 2 and 3 insurers fund NICH for their members on a case-by-case basis, often only approving members in their top 1% of healthcare costs. These insurers do not assist with case finding, require contract negotiations for each member approved, and do not have identified staff who coordinate care provision with the NICH team. Tier 3 insurers have always approved patients on a case-by-case basis, while tier 2 insurers showed stronger initial interest in broader access to NICH for a larger percentage of their members, engaged in small pilots of the NICH model, but scaled back their involvement due to competing factors (e.g., organizational instability, a disproportionate interest in maximizing financial benefits of participation). Lastly, tier 4 insurers have been approached by the NICH team to discuss services for their most vulnerable members and have been presented with outcome data on patients served, but have chosen not to enter into a contract with NICH or, in some

cases, have declined initial meetings intended to discuss the NICH APM.

To better understand how effective the NICH program has been in partnering with insurers, we conducted a retrospective evaluation of referrals to the NICH program from January of 2012 to September of 2016. Retrospective review of referral records included patient primary medical condition (i.e., diabetes vs. other medical conditions), insurance type (i.e., commercial vs. public), insurer tier (i.e., tiers 1–4), approval status (i.e., whether patients were approved or rejected for NICH services by their insurance provider), and level of patient engagement in NICH services. The patient engagement category delineates whether patients received treatment for 3 months or longer (i.e., "served") or received treatment for less than 3 months (i.e., "unserved") due to either a caregiver refusing NICH services or a family dropping out of NICH services within 3 months. Reasons for caregiver refusal include distrust or conflict with referring providers, perception that program participation will increase life stress, skepticism regarding need for intensive intervention, and fear that participation may result in child welfare or criminal justice involvement—often based on past negative experiences with formal services. Chi square tests were conducted to examine whether medical condition and insurance type were related to approval status and patient engagement in services.

A total of 468 Oregon patients were referred to the NICH program during the 56 months since program inception. Of

these referrals, 173 patients (37.0%) were approved for services by their respective insurance companies. An additional 30 patients covered by a payer in a neighboring state were referred, of which 1 (3.3%) was approved. Of the total approved patients, 155 (89.6%) were paid for by an APM and completed NICH services, and the remaining 18 patients did not enroll in and/or complete NICH services.

When specifically examining those patients covered by the 16 Oregon CCOs and FFS Oregon Medicaid, a total of 347 patients were referred to NICH. One hundred fifty-seven (45.2%) of these patients were approved for NICH, with approval rates ranging from 0 to 80.4% ($M = 18.8\%$, SD = 26.6%) across the 16 Oregon CCOs. Of those approved, 140 (89.2%) patients and their families completed participation in the NICH program (Table 1). Referred patients covered by Oregon CCOs were significantly more likely than any other insurers to be approved for NICH services and associated APM payment (45.2 vs. 13.2%; $X^2 = 39.5$, df = 1, $p < .001$). In addition, the vast majority of patients (86.7%) approved by commercial insurers were accounted for by a single payer in a tier 2 relationship with NICH.

Further analyses of insurer tiers revealed that, of 27 insurance companies, 2 (7.4%) are in a tier 1 relationship, 2 (7.4%) are in a tier 2 relationship, 8 (29.6%) are in a tier 3 relationship, and 15 (55.6%) are in a tier 4 relationship with NICH (Table 1). There was a significant difference in approval rates across these four tiers ($X^2 = 214.6$, df = 3, $p < .001$), with

patients covered by payers in tier 1 relationships having the highest approval rates for NICH services (m, 77.7%; SD = 3.81%; range = 75.0 to 80.4%), followed by tier 2 relationships (m, 40.0%; SD = 9.5%; range = 33.3 to 46.7%), and tier 3 relationships (m, 17.2%; SD = 10.4%; range = 5.6 to 33.3%). There were no approved cases across all tier 4 payers.

Patients with a primary diagnosis of T1D accounted for 38.2% ($n = 179$) of the total patients referred. Of these patients, 40.8% ($n = 73$) were approved for services, of which 89.0% ($n = 65$) were enrolled in and completed NICH services (Table 1). One hundred twenty-nine patients with T1D were covered by the Oregon CCOs, of which 48.8% ($n = 63$) were approved for services and 42.6% ($n = 55$) were served. Interestingly, 24.4% of patients with T1D covered by commercial insurance (10 of 41) were approved for services, with 100% of these patients being accounted for by a single commercial payer in a tier 2 relationship with NICH. Nine referred patients with T1D were covered by Medicaid from a neighboring state—none were approved.

Conclusions

The Triple Aim targets improvements to the individual experience of care, improvements to the health of populations, and reductions in the per capita costs of care, goals that are particularly difficult to achieve for youth with

Table 1 Rates of patients served by NICH across tier, insurer, and medical condition

			Tier 1 n (%)	Tier 2 n (%)	Tier 3 n (%)	Tier 4 n (%)	Total n (%)
Patients with diabetes	Medicaid	Referred	53	13	42	30	138
		Approved	49 (92.5)	9 (69.2)	5 (11.9)	0 (0.0)	63 (45.7)
		Served	44 (83.0)	7 (53.8)	4 (9.5)	0 (0.0)	55 (39.9)
		Unserved	5 (9.4)	2 (15.4)	1 (2.4)	0 (0.0)	8 (5.8)
	Commercial insurance	Referred	0[a]	14	2	25	41
		Approved	–	10 (71.4)	0 (0.0)	0 (0.0)	10 (24.4)
		Served	–	10 (71.4)	0 (0.0)	0 (0.0)	10 (24.4)
		Unserved	–	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Patients with other medical conditions	Medicaid	Referred	119	17	46	57	239
		Approved	83 (69.7)	5 (2.9)	7 (15.2)	0 (0.0)	95 (39.7)
		Served	75 (63.0)	5 (2.9)	6 (13.0)	0 (0.0)	86 (36.0)
		Unserved	8 (6.7)	0 (0.0)	1 (2.2)	0 (0.0)	9 (3.8)
	Commercial insurance	Referred	0[a]	25	4	21	50
		Approved	–	3 (12.0)	2 (50.0)	0 (0.0)	5 (10.0)
		Served	–	3 (12.0)	1 (25.0)	0 (0.0)	4 (8.0)
		Unserved	–	0 (0.0)	1 (25.0)	0 (0.0)	1 (2.0)

Percentages reflect percent approved, served, or unserved of those referred for a respective group (i.e., medical condition, insurer, and tier)

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[a] There are no commercial insurers in a tier 1 relationship with NICH. "Medicaid" includes both CCOs and FFS Medicaid

medical and social vulnerability (e.g., high-need and high-cost or HNHC). In order to accomplish the Triple Aim, an integrator for a given population must be identified that can coordinate and manage all the resources necessary to help HNHC youth on all three dimensions. Importantly, an "integrator" as described by Berwick and his associates [2] also involves individuals and families, fosters access to innovative treatments, and allocates resources with an emphasis on behavior change and preventative care [2]. This task is difficult to accomplish with the limitations of volume-based, FFS models [57, 58] and thus, alternative models must be thoroughly examined in order to find an APM that best fits a given population and system. In the case of pediatric diabetes, HNHC youth are not just the most costly to our healthcare system, but also at highest risk of negative health outcomes associated with diabetes. Thus, HNHC youth with T1D are especially in need of an effective, tailored integrator. NICH represents one example of using an APM and is specifically developed to address the challenges of HNHC youth, their families, and the larger systems they exist within. While NICH is not without its limitations, the APM and fee structure utilized by the NICH program appear to be feasible.

Certainly, NICH has experienced many successes in partnering with insurers to provide care to the most vulnerable and challenging youth with diabetes (as well as other medical conditions); however, there are important lessons learned that could inform development and dissemination of programs like NICH. First, the current healthcare system focuses on the highest utilizing and costly patients (primarily adults), and limited incentives exist to direct resources to a population that does not account for the big spend. Because pediatric populations represent a small cohort and portion of the budget, especially when looking at the highest utilizers, insurers are less likely to enter into an APM given the relatively minimal impact on overall healthcare costs, in the short term, for a specific insurer. While this trend is notable among Medicaid and commercial insurers, it is most pronounced among commercial entities, creating variability in willingness to consider an APM for high-risk pediatric populations. There exists variability across Medicaid-funded entities as well. For example, in Oregon, Medicaid-funded CCOs with more robust membership have more resources to support innovative and intensive programs whereas smaller CCOs may lack the resources to explore such options. However, for a CCO with fewer resources and smaller membership, just one high-cost pediatric patient could contribute significantly to the overall healthcare spend. Thus, smaller insurers may be incentivized to participate in programs like NICH when the cost of the intervention program is a mere fraction of the total cost of care for a HNHC's patient.

NICH was developed as a population health effort, yet the current model of identifying HNHC pediatric patients on a case-by-case referral basis only captures a fraction of potential patients in need of intensive supports. In the true spirit of population health, programs targeting HNHC youth should include not just youth with diabetes, but youth with a variety of chronic health conditions, special health care needs, and medical complexity. With HNHC populations, taking a life course perspective and intervening early has the potential to prevent both short- and long-term health complications and costly medical care. As such, insurance providers and other stakeholders (e.g., hospitals) should consider the use of risk stratification both at initial diagnosis and across the lifespan. Given the success of early identification and intervention with high-risk youth and families in other fields (e.g., juvenile justice) [59, 60], healthcare systems should emphasize preventing acute health crises and associated high costs before longstanding patterns of maladaptive health behavior are established. Given advances in early identification of patients at increased risk of avoidable health problems [26], it seems both morally imperative and fiscally sound to desist from waiting until patients—and payers—suffer adverse consequences. In addition, given that life events (e.g., parental divorce, caregiver substance dependence, youth school failure) can influence adherence and related outcomes over time, regular screening for need of intensive intervention is warranted over the course of patient development.

Relatedly, there is value in expanding the conversation of access to high quality interventions for HNHC youth beyond Medicaid and commercial insurers to include health agencies at the county and state level, as well as community agencies serving this population. Increased collaboration among agencies serving HNHC patients should more effectively address gaps in services and barriers to equitable access, and encourage greater collective responsibility for the health and well-being of vulnerable populations. Furthermore, as CCOs begin to adopt APM models, there is opportunity to advocate for policies stipulating the allocation of APM funds toward programs effectively serving HNHC populations.

Greater awareness and advocacy for HNHC programming involves defining the population, identifying key barriers to health, and evaluating the ability of current intervention options to best meet patient needs. To this end, leveraging relationships with insurers and medical systems to develop improved methods of data collection for purposes of quantifying the population of HNHC pediatric patients who require intensive intervention (e.g., through risk stratification) can help to identify the scope of support services that would best serve these vulnerable populations. With these data, insurers and state agencies can examine their internal bandwidth for providing services that meet the unique needs of their highest risk patients, and determine whether contracting with an external agency through an APM to fill a service gap is in the best interests of the insurer and their members. Thus, having a system in place for data sharing with insurers is not only

important for patient identification and service provision, but also critical for innovative programs to be able to demonstrate outcomes (e.g., costs savings, improvements in health) and sustain the program beyond pilot funding using an APM.

Results of our evaluation of NICH uptake suggest that using an APM proved to be a success when working with insurance companies whose strategic goals align with care to HNHC youth. In addition, those insurers most engaged in the process have identified a service gap, have appreciated the need to provide a different kind of care to HNHC youth, and are invested in the integration of innovative programs like NICH (i.e., those insurance companies in tiers 1 and 2). However, there is a subset of insurers that has been more difficult to engage. Based on our experiences, engaging smaller insurers (e.g., smaller CCOs) as well as commercial insurers should be a priority in order to improve accessibility of these innovative, coordinated services to HNHC youth with diabetes as well as all medically and socially complex youth.

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Single (Aim)-Minded Strategies for Demonstrating Value to Payers for Youth With Medical Complexity

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In the current financial climate, health care institutions and providers experience substantial challenges in achieving the Triple Aim in health care reform (i.e., reducing costs, improving health, improving care). The present study describes the successes and challenges of garnering payment for a population health program, Novel Interventions in Children's Health care (NICH), for youth with both medical and social vulnerability. Using 4 real patient scenarios, this study provides examples of how to use economic data to demonstrate program value to key stakeholders (i.e., insurance providers, hospital administrators) and obtain authorization and payment for services. Health care utilization and cost data were retrieved through retrospective review of patient medical records and hospital financial records. NICH utilized distinct strategies to overcome systemic barriers, demonstrate value, and show need for intervention to key stakeholders. Strategies included highlighting patients': (a) history of utilization, (b) accumulated medical expenditures, (c) projected costs for anticipated procedures, and (d) social risk linked to poor health and high utilization. We describe each effort using real patient scenarios that feature varied medical conditions including Type 1 diabetes, chronic pain, and failure-to-thrive. Economic data can be a useful tool in garnering support for behavioral health interventions. And while these data offer programs like NICH the opportunity to make the case for investing in an alternative intervention, the strategies utilized by NICH to advocate for services can be applied by pediatric psychologists working with youth with medical complexity and social vulnerability.

Implications for Impact Statement
In order to increase service access for individuals, families, and medical teams in an ever-changing fiscal environment, psychologists and other behavioral health providers should be prepared to highlight the financial value of their efforts to health care systems and payers. This article provides (a) an example of how a behavioral health program can identify and collect economically relevant data and (b) strategies that use economic data to convince payers to authorize and evaluate the services of such programs. For each of these strategies, we provide real patient scenarios to better illustrate how behavioral health providers can make a compelling case for intervention programs through the strategic presentation of medical, social, and economic data.

The health care system at large has widely accepted the Triple Aim (i.e., reducing health care costs, improving health, and improving care; Ber-wick, Nolan, & Whittington, 2008); however, implementation and achievement of these proposed goals have been challenging. While the primary goal of the Triple Aim is to improve the health of populations, the pursuit of reducing costs (i.e., single aim) can contribute to the challenges encountered in attempting to improve health. In particular, the reliance of payers on controlling short-term costs may be in conflict with their efforts to improve patient health. Effective adaptation requires health care providers charged with improving patient health and care experience to modify typical approaches to seeking financial approval.

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A subset of the pediatric population is particularly vulnerable to avoidable short- (e.g., infection, diabetic ketoacidosis) and long-term (e.g., transplant loss, retinopathy) health complications and thus represents a population for whom a dramatic improvement in health, care, and cost can be realized. For these patients, an "integrator" (i.e., an entity who would accept responsibility for all three dimensions of the Triple Aim for a specified population; Berwick et al., 2008) may represent the greatest likelihood of Triple Aim success. Ideally, the "integrator" would help overcome fragmented care, involve individuals and families, redesign care models, coordinate care, foster access to innovative treatments, and allocate resources with an emphasis on preventative care and behavior change (Berwick et al., 2008). Although pediatric psychology as a field has demonstrated success at improving patient health (e.g., Mochari-Greenberger, Vue, Luka, Peters, & Pande, 2016), improving patient care (e.g., Talmi et al., 2016), and to a lesser extent reducing costs (e.g., Pande et al., 2015; Yarbro & Mehlenbeck, 2016), it is rare to find programs which simultaneously address all three objectives. Pediatric psychologists, in addition to other professionals who blend expertise in behavioral intervention and youth with chronic and complex medical conditions, are well-positioned to design and oversee integrator behavioral health programs to meet the needs of vulnerable youth and families in an ever-changing health care landscape. However, while integrators have been recognized as a necessity (May, Montori, & Mair, 2009; Mays, 2016), the development and adoption of payment models for "integrator" services is slow moving.

Our experiences, as well as several studies (e.g., Bruns, Kessler, & Van Dorsten, 2014), suggest that there are many challenges to obtaining reimbursement for behavioral health services for youth with chronic and complex medical conditions. First, payers may have different funding arms for medical and behavioral health programs, and categorize the services provided by pediatric psychologists under only the behavioral health arm, while the medical arm reaps the economic benefits of these services. Second, payers may not appreciate and/or have access to the social risk factors that contribute to short-term acute complications and long-term health deterioration. Third, many payers have internal programs and personnel dedicated to managing youth with medical and social complexity. These programs tend to enroll a large caseload of patients, primarily emphasize care coordination, are generally delivered by phone, and rarely staff pediatric psychologists or integrate behavioral interventions targeting disease management. In addition, payers may feel a sense of ownership over these programs and may not scrutinize them as thoroughly as external programs. Relatedly, payers often view external programs as requiring new monies rather than a reallocation of funds typically spent on avoidable medical procedures or less effective internal programs.

In such an environment, the unfortunate reality is that pediatric psychologists and/or integrators are only as successful as their ability to obtain payment for care, placing them at risk in a shifting marketplace. For instance, while integration of pediatric psychology into primary and specialty clinics has been recommended, reimbursement structures influence whether (Talmi & Fazio, 2012), how (Duke, Guion, Freeman, Wilson, & Harris, 2012), and how much care is provided to patients (Lines, Tynan, Angalet, & Shroff Pendley, 2012). The financial control over patient care can create unforeseen challenges for behavioral health providers, as they may experience pressure to bill mental health codes and diagnoses for larger returns even if they are not an appropriate fit for the treatment provided or the problems being addressed (Duke et al., 2012). Unless pediatric psychologists and behavioral health programs adapt, archaic reimbursement systems may impede their ability to deliver services.

As with many components of the health care system, reimbursement models are evolving over time in ways that create opportunities for pediatric psychologists and behavioral health programs. Historically, fee-for-service (FFS) and managed care (MC) models have dominated the marketplace. While the FFS model assigns a unit of payment to a provider for each service rendered, the MC model involves capitation, a fixed sum paid to providers, in the form of per-member-per-month metrics, for covered services. Neither model seems adequate for youth with medical complexity and social vulnerability due, in large part, to reliance on current procedural terminology (CPT) codes.

These youth often require more frequent, intense, and flexible care than is currently captured in CPT codes, resulting in difficulty with service reimbursement. In addition, The U.S. Department of Health and Human Services (DHHS) has promoted a remedy to the limitations of existing models in the form of alternative payment models (APMs) that allow for flexibility in fund allocation and health care delivery to better manage population health and emphasize value-based, patient-centered care. APMs are unconventional fee structures (e.g., bundled payment programs) that use one or more quality measures to assess performance and incentivize providers to use resources more effectively (Centers for Medicare & Medicaid Services, 2017). As of 2016, DHHS shifted 30% of their Medicare provider payments to APMs, with a goal of reaching 50% by 2018 (Daly, 2016), and APMs are projected to account for 60% of payments for physician services in 2019 (Spitalnic, 2015) and 100% by 2038.

Although the shift in funding models provides unique opportunities for integrator behavioral health programs to receive support for creatively addressing the Triple Aim in vulnerable youth, payer decisions to fund APMs are primarily based on the outcomes of a single aim—demonstration of financial return on investment (ROI). Novel Interventions in Children's Healthcare (NICH; Harris et al., 2013) represents an integrator behavioral health program that utilizes an APM and highlights ROI to payers. NICH is an intensive, multicomponent systems intervention designed by pediatric psychologists to address the Triple Aim for pediatric populations at high risk for avoidable medical complications (for a more thorough description, see Harris et al., 2013). As a health integrator, NICH delivers nontraditional care services not captured in CPT codes (e.g., helping parents identify informal and formal support for appointment transportation, bridging communication gaps between school staff and medical providers, providing 24/7 text and phone support) across multiple systems and thus requires access to unconventional payment models for sustainability (Barry et al., 2017). Like most behavioral health programs, the primary goal of NICH is to improve the lives of the youth and family served, often via improvements in health and care experience. However,

for sustainability and growth, the NICH program uses economic data to demonstrate payer ROI.

In this report, NICH is used as an example for other integrator behavioral health programs. The primary aims of this study include providing a) an example of how an integrator behavioral health program (i.e., NICH) may operate (e.g., how such a program can identify and collect relevant data) and b) strategies that use economic data to convince payers to authorize and evaluate the services of integrator programs. For each of these strategies, we provide real patient scenarios to better illustrate how behavioral health providers can make a compelling case for intervention programs through the strategic presentation of medical, social and economic data. Each scenario highlights the level of patient complexity that requires nontraditional funding, intervention strategies, and outcome data. We conclude with a discussion of successes and challenges experienced related to these attempts to secure funding.

Method

Procedure and Eligibility

Medical providers from a major academic medical center and surrounding hospitals in the Pacific Northwest referred patients to the NICH program. Eligibility criteria for NICH services included youth (a) being between birth and 18 years of age, (b) having at least one chronic or complex medical condition, (c) experiencing multiple social vulnerabilities (e.g., child welfare involvement, housing or food insecurity, caregiver mental health concerns) that put the patient at risk for significant problems with adherence (e.g., taking prescribed medications, following dietary restrictions, attending recommended appointments), and (d) evidencing experience or high risk of avoidable acute and long-term medical complications and associated utilization of hospital services.

A review of patient referral narratives and electronic communications between NICH staff and payers was conducted to capture referral reason and strategy employed in making an economic case for service authorization. A retrospective review of patient medical records and hospital financial records was conducted to capture descriptions of treatment course, health

care utilization data (prior to, during, and post NICH services), and cost data.

NICH Program Characteristics

NICH services involve intensive home- and community-based treatment for patients and their families intended to reduce barriers to disease management (Harris et al., 2013). NICH providers (known as interventionists) deliver behaviorally based skills training directed toward helping patients manage their medical condition, caregivers effectively supervise and reinforce medication adherence, and families access needed resources, connect with needed medical services, and coordinate care. Because NICH is grounded in the ecological systems theory of human development (Bronfenbrenner, 1977), NICH interventionists deliver services in the youth's natural environment (e.g., home, school, clinic, community, inpatient), are available to families 24 hr per day, 7 days per week, and utilize telecommunication to increase frequency of contact. Families receive, on average, four hours of service provision per week, with over half of this time representing face-to-face interactions between NICH staff and patients, caregivers, and other family members. Daily communication (e.g., text messages, phone calls, web-based video chat) is individualized based on youth and family characteristics and is commonly used to monitor adherence to the medical regimen, to provide frequent positive reinforcement for adherence, and to problem solve during crises (e.g., DKA events; Wagner et al., 2001).

A NICH team consists of supervisors (typically pediatric psychologists and veteran interventionists), a medical consultant, and interventionists. Interventionists' background and training vary but most have previous experience providing services to children and families experiencing poverty. Educational backgrounds commonly include public health, social work, psychology, counseling, and marriage/family therapy. The type of services delivered may vary based on interventionist/supervisor background, education, and licensure, but the overarching services and delivery method remain consistent across staff. The NICH program currently resides within the Pediatrics department of an academic medical center. Interventionists are salaried and evaluated on their ability to adhere to the model, balance a full caseload (i.e., 8–10 families), and help patients and families achieve Triple Aim outcomes.

In determining the most appropriate APM, the NICH leadership team consulted with both the chief financial officer and contracting department at the home institution. The NICH team routinely consults and collaborates with the contracting department to develop contracts with individual payers and modify contracts as the funding environment shifts. The APM represents the costs associated with running the program, including staff salaries, institutional overhead, travel reimbursement, incentive programs, and other discretionary funds used to assist families in need (e.g., fix car, license application), as well as a small margin allocated for staff turnover and salary growth over time. The institution receives the APMs, which are then used to fund staff and provide reimbursement for costs related to service provision.

NICH payer outreach. NICH program staff internally screens each referred patient and contacts payers for program funding approval. When seeking funding, NICH provides payers with a standardized summary that includes relevant patient medical information, patient and family social vulnerabilities and complexity, health care utilization trends, and treatment intervention goals. As described in Barry et al. (2017), relationships between the NICH program and potential payers fall in one of four categories: (a) no previous interaction with the NICH program, (b) refusal to fund NICH program efforts, (c) single case agreements considered on a case-by-case basis, and (d) standing contracts that reflect a population health approach to managing their most vulnerable members.

Results

When determining which strategy to use when seeking approval, NICH program leadership considers which data and information best align with the Triple Aim, are most compelling to the payer, and are most readily accessible. For example, to determine what data are most compelling, NICH staff consider:

1. Who in our institution has a relationship with payers to help us understand payer priorities, whom in payer leadership to

contact, and the best approach to take (e.g., demonstrating how our program aligns with their stated values and/or outcome metrics)?

2. What is the payer's stated mission?

3. What do payer leadership describe as their driving interest (e.g., increasing access to care, more covered lives, reduction in unnecessary utilization)?

4. What metrics does the payer need to reach?

5. Who are the payer's analysts and what trends are they observing?

Collecting this information can initially take several weeks to several months, depending on response from stakeholders, and relies on a combination of online investigation, direct stakeholder communication, and internal and external provider anecdotal reports. While some payers prioritize monetary ROI, others make clear their interest in improving health and access to care. Some payers have specific metrics they must reach (e.g., decrease in repeated admissions, increased follow-through with primary care, more preventative care accessed, decreased ED visits) that are tied to government funding and/or penalties. Payers may also be interested in testimonials from medical providers regarding the efficacy of current services, how a patient's social context may influence Triple Aim outcomes, and the short- and long-term health risks associated with a lack of improvement.

Regarding data access, some payers establish data use agreements (DUAs) to provide the NICH program with claims data as part of program evaluation. In the absence of a DUA for claims data, NICH staff approach hospital administration to gather cost of care data. However, some patients receive the majority of their care at outside institutions thereby limiting NICH access to relevant medical records and institutional costs. In these instances, NICH staff gather information from the referring provider such as number of inpatient admission days as a proxy for cost, lab values indicative of high risk of future serious and costly complications (e.g., transplant rejection), or planned costly procedures (e.g., g-tube placement) that may be avoidable. When necessary, NICH staff rely on recent published estimates for specific medical procedures or complications (e.g., Tie-

der et al., 2013). This approach allows NICH to present the payer with an approximation of the costs the payer has incurred for a patient based on past utilization, or would likely pay for specific types of care (e.g., neurosurgery for patient with severe excoriation disorder, cleanout for patient with cystic fibrosis). When possible, NICH program staff provide payers a combination of medical, social, utilization and cost data to demonstrate need for services. Below, we provide the main type of strategy used to attempt to gain authorization, a real patient scenario in which this strategy was used, and the process of service delivery and related outcomes (if accessible).

Strategy 1: History of High Utilization

Definition. NICH presents payers with a patient's utilization history (e.g., ED visits and hospitalizations) and associated costs and uses this data to predict future utilization and costs.

Case example. Scott was a 16-year-old male with Type 1 diabetes (T1D), diagnosed at five years old. In the year prior to NICH referral, Scott experienced 15 acute utilization events (ED visits and hospital admissions).

In addition to his T1D diagnosis, Scott and his family experienced a number of social vulnerabilities across systems. For example, Scott's parents cared for multiple other children, ranging in age from 6 months to 18 years of age. Scott had several mental health diagnoses (e.g., autism spectrum disorder, generalized anxiety disorder) as well as recurrent abdominal pain, and several of his siblings qualified for disability services due to medical and behavioral concerns. The family also lived far (i.e., over 50 miles) from the diabetes clinic, faced significant financial hardship related to travel, childcare, and missed work during Scott's hospitalizations, and reported low levels of social support. Scott transitioned to online school due to academic concerns that appeared driven by lack of diabetes-related accommodations and frequent absences due to medical complications. Scott's family and medical team also experienced high conflict due to conflicting explanations for Scott's recurring medical emergencies and his medical team's report to Child Protective Services (CPS) based on concern for medical neglect.

Case analysis. When seeking service authorization, NICH highlighted a number of factors in support of an intensive behavioral health program. First, NICH displayed Scott's history of diabetic ketoacidosis (DKA) episodes and related utilization trends (see Figure 1), demonstrating that he had been unresponsive to traditional interventions. Second, his medical team documented that he was increasingly susceptible to future DKAs due to metabolic vulnerability associated with having experienced multiple DKAs and that, without intensive intervention, his health management or utilization trajectory likely would not change. The payer decided to approve Scott for NICH services with the goal of interrupting the trajectory of avoidable utilization (e.g., DKA episodes), which aligned with their existing incentive measures, and stabilizing his diabetes through improved diabetes self-management.

Primary NICH interventions with Scott and his family focused on skill development related to parent-child communication around adherence to a medical regimen, the family's communication with medical providers, and Scott's independent management of diabetes and anxiety. During Scott's time in the program and in the eight months since discharge, he has only experienced one acute utilization event related to diabetes. In addition, the family's relationship with medical providers appeared more collaborative as Scott's adherence to treatment improved, and he returned to a brick-and-mortar high school. Although Scott did not demonstrate a meaningful change in HbA1c from pre to post-NICH (10.9 to 10.8), the dramatic reduction in DKA event frequency was reportedly due to improvements in parent-child communication and the family's ability to proactively manage high blood glucose levels. Actual cost of care data was not available for Scott, but the mean cost of DKA in children's hospitals is $7,142 (range of $4,125–$11,916; Tieder et al., 2013). If treating Scott's pre- and post-NICH acute utilization as DKA events (the vast majority reportedly were) and using the most conservative estimate for cost of DKA ($4,125), the total reduction in acute utilization cost following NICH enrollment was $57,750.

Strategy 2: Accumulated High Cost

Definition. NICH displays cost data to payers that reflect health care costs incurred from potentially avoidable utilization of ED and inpatient services.

Case example. Mallory was a 15-year-old female with a history of chronic pain secondary to the surgical removal of a tumor. After her surgery, Mallory had multiple lengthy hospital stays for uncontrolled abdominal pain. Both physicians and psychologists referred Mallory to NICH due to their belief that her pain crises and utilization could be avoided.
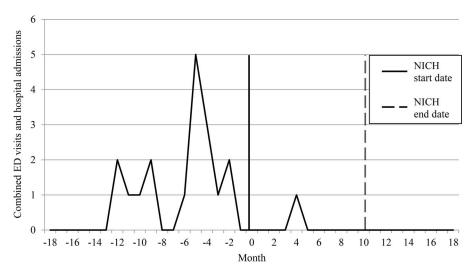
Figure 1. Scott's utilization prior, during, and after NICH.

Mallory lived with both parents but spent considerable time at her aunt's house. The medical team reported the family had limited strategies for coping with Mallory's pain and were over reliant on the ED and medication for pain management. In addition, communication between Mallory's family and medical team as well as between her medical providers was suboptimal due to several barriers. For example, Mallory's aunt did not speak English, which reportedly contributed to frequent miscommunication with medical staff and inconsistent adherence to medical recommendations across settings. Also, Mallory's procedure was performed by adult providers, but her follow-up care was provided by pediatric providers who were less familiar with the procedure and possible complications, reportedly resulting in potentially unnecessary medical tests and lengthy hospital stays. In addition, Mallory's family did not access recommended outpatient psychological care due to time and transportation barriers. Although Mallory historically did well academically and participated in extracurricular activities, pain and anxiety postsurgery resulted in withdrawal from these activities and transition to online school.

Case analysis.   At the time of NICH referral, NICH did not have an existing relationship with Mallory's insurance provider. Thus, in addition to a standard referral narrative, NICH presented the payer with an overview of NICH services, collated program outcomes, and cost data related to Mallory's recent hospital charges

(see Table 1). This initial request occurred during Mallory's second hospitalization, and a follow-up request was sent after her fourth hospitalization. After the fourth hospitalization, Mallory was discharged home on total parenteral nutrition (TPN), and the payer assigned Mallory's family to an internal case management service. After Mallory's fifth pain-related hospitalization, four months of negotiations, $300,000 worth of charges, and 67 days in the hospital, the payer approved NICH.

Primary NICH interventions included skill building related to patient coping techniques for pain, caregiver limit-setting, and caregiver-child communication. Interventions also targeted improved coordination of care and communication between family and medical team members (see Harris et al., 2015 for NICH applied to chronic pain). These interventions were associated with a range of improvements across settings. Providers reported more frequent and higher quality communication across caregivers and care settings. Interventionist observation and caregiver tracking sheets indicated more frequent adherence to mealtime enzymes and exercise regimen as well as decreased consumption of high-fat foods. Hospital records demonstrated decreased acute utilization (no ED visits or hospitalizations during NICH program participation), and Mallory was observed to return to brick-and-mortar schooling based on her report of decreased pain.

Table 1
Mallory's Health Care Cost Data

Type	Admit by month	Length of stay (days)	Charges	Charges/day
Inpatient	Month 1	15	$78,573.96	$5,238.26
Inpatient	Month 1	25	$94,268.02	$3,770.72
NICH first request for program authorization				
Outpatient	Month 3	N/A	$140.00	N/A
Inpatient	Month 3	11	$62,853.47	$5,713.95
Inpatient	Month 4	10	$44,472.40	$4,447.24
NICH second request for program authorization				
Inpatient	Month 5	6	$21,853.67	$3,642.17
Total		67	$302,161.52	$4509.87
NICH approved				

Note.   Cost data was only available for ED and inpatient charges incurred at NICH's home institution; two ED charges from an outside institution were not included.

Strategy 3: Projected Costly Procedure and Anticipated Spend

Definition. NICH provides payers with anticipated costs of a medical intervention that may be necessary if a patient's adherence-related behaviors do not improve (e.g., loss of transplant, G-tube placement).

Case example. Antonio was a 6-year-old male with a diagnosis of failure-to-thrive (FTT) secondary to a history of vomiting, abdominal pain, constipation, and behavioral concerns resulting in food aversion and refusal. He was referred to the NICH program after failing intensive interventions (e.g., multidisciplinary feeding clinic including psychological services, hospitalization) to address severe malnutrition following years of inadequate weight gain. Previous medical workups did not identify anatomic or functional disorders related to Antonio's ability to gain weight, and his medical team reported concern regarding his mother's understanding of his medical regimen and her ability to implement recommendations at home. At the time of referral to NICH, the medical team was discussing filing a report with CPS and placing a gastrostomy (G)-tube.

Antonio lived with his mother and two siblings. The family experienced multiple psychosocial stressors including a primary caregiver who was non-English speaking, unemployed, and had limited financial resources for food, housing and transportation. Antonio's mother also reported behavioral concerns with her children, a trauma history, and low social support. The family also lived over 50 miles away from Antonio's specialty care clinic and relied upon public transportation for attending clinic appointments. Antonio's mother reported a significant amount of parent–child conflict, child noncompliance, and other disruptive behavior. Observations suggested that she frequently displayed warmth toward her son but struggled to effectively implement behavioral recommendations at home.

Case analysis. NICH had a standing contract with Antonio's insurance provider and presented NICH services as a means to prevent G-Tube placement (est. $32,000 USD; Callahan, Buchanan, & Stump, 2001). NICH services were approved due to the high level of medical and psychosocial vulnerability faced by this patient, acute medical necessity to reverse weight loss trend, as well as the cost of a potentially avoidable medical procedure.

The NICH intervention focused on addressing psychosocial stressors that impeded mother's ability to follow through with feeding team recommendations and supported her in implementing recommended behavioral techniques in their natural environment. At discharge, Antonio was independently eating solid foods and demonstrating improved weight without feeding supplement or tube feedings. His mother had improved parenting skills including limit setting and the use of contingency systems associated with improved parent–child interaction. Based on behavioral changes demonstrated by mother, and Antonio's weight gain, G-tube placement was avoided, and his weight loss trend was reversed (see Figure 2).

Strategy 4: Describing Psychosocial Risk

Definition. NICH demonstrates increased risk of avoidable and costly medical complications due to the presence of multiple psychosocial stressors (i.e., unstable housing, caregiver mental health, and distance from medical care center).

Case example. Tracy was a 5-year-old girl who was referred to NICH upon being diagnosed with T1D. Tracy was referred to NICH due to a constellation of risk factors that led the medical team to believe that she would experience acute complications soon after discharge.

At the time of diagnosis, Tracy's father was her sole caregiver. He had a history of mental health concerns and substance dependence. They were homeless, as local shelters were not accessible for fathers with children, and his only friends were regularly using illicit drugs. Tracy was inconsistently attending school due to transportation issues secondary to unstable housing. Tracy's father had limited social support and feared having to quit his part-time employment to care for Tracy. Lack of stable housing also resulted in concern regarding how to keep insulin stored safely. Given these risk factors, medical providers expressed concern that father may have difficulty maintaining appropriate diabetes care in an outpatient setting.

Case analysis. Tracy's insurance provider had a long-standing relationship and contract with NICH. This payer also prescribed to a population health approach to medical management and understood the benefits of early intervention when
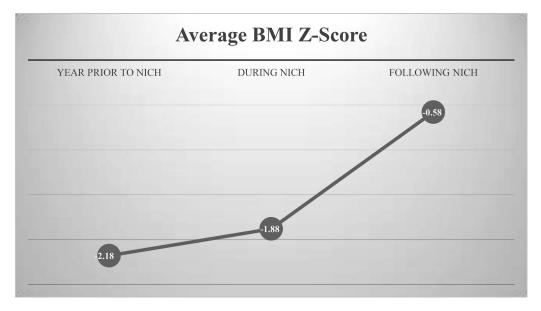
Figure 2.   Antonio's Z-BMI prior, during, and after NICH.

patients demonstrated significant social barriers to managing a chronic and/or complex medical condition. Although it is difficult to predict cost-savings for prevention cases because of the lack of sophisticated economic modeling for vulnerable pediatric populations, the population health-funding model appreciates that savings from a handful of high-cost patients allows for funding to treat prevention cases. Tracy's payer recognized that internal programs could not match the intensity and delivery method of needed services, and NICH services were approved.

The NICH intervention focused on skills building with Tracy's father related to parenting and medical care, as well as intensive care coordination and case management related to securing housing, transportation, affordable food, and access to medical and behavioral health resources. NICH eventually facilitated the family's relocation to a stable living environment with increased social support out-of-state. A year after completing the NICH program, Tracy had not experienced any DKA events, ED visits, or hospitalizations.

Discussion

As funding conditions continue to change, pediatric psychologists must adapt to ensure that vulnerable youth and their families receive the most appropriate behavioral health services. Although pediatric psychologists have developed evidence-based treatments that have demonstrated improvements in health and reductions in costs (Harris, Wagner, & Dukhovny, 2016; McGrady et al., 2015), it is unclear how the field has adapted to modified reimbursement structures, whether by developing APMs, advocating for APM approval, and/or creating infrastructure to support these attempts. This case series demonstrates a range of strategies that may be used by pediatric psychologists and their institutions to advocate for payer support of psychological services and multicomponent behavioral health programs for youth with complex and chronic health conditions.

This case series highlights the variability in patient presentation and the value of having a flexible approach when demonstrating the potential ROI of behavioral health to payers. Also, while the use of economic data to support an appeal for services can be an effective strategy, the NICH leadership team's anecdotal experiences and attempts to secure payment from different funding entities suggests that this data in-and-of-itself is not enough to establish sustainable relationships with payers. Rather, when seeking payer approval for needed behavioral health, it is most beneficial for pediatric provid-

ers to use a range of strategies singularly or in combination. For example, behavioral health programs should keep in mind that Medicaid payers are expected to meet federal benchmarks specific to the Triple Aim (e.g., reducing ED visits, hospital readmissions). As described previously, NICH tailored its "sell" to demonstrate how the program could help payers meet these benchmarks *and* realize associated cost savings (e.g., every 1% rise in HbA1c values equates to an increase in annual diabetes care costs; Wagner et al., 2001). In addition, NICH developed a partnership model with some payers that involves collaborative and ongoing evaluation of treatment outcomes (e.g., cost, care, health) as well as identification of potential patients using payer claims data. As part of the partnership, NICH has assisted payers in understanding that patient cost outcomes should be viewed within the patient's medical and psychosocial context. For example, NICH is transparent with payers at the time of referral about the anticipated financial outcomes given that interventions that increase adherence may result in cost reduction in some instances (e.g., decreased episodes of diabetic ketoacidosis), cost containment in other contexts (e.g., prevention of G-tube placement for patients with FTT, stabilization of pulmonary function for patients with cystic fibrosis), and short-term cost increase with improved long-term outcomes in other situations (e.g., patient newly listed for transplant). Pediatric psychologists' ability to ensure that payer cost-related expectations are consistent with treatment goals is integral to sustainability.

Relatedly, while patients already experiencing avoidable and costly complications may be an easy sell to payers, the real value likely lies in identifying patients at risk for these costly outcomes (e.g., Schrager et al., 2016; Simon et al., 2014) and intervening before patients have experienced negative health outcomes (and the payer has experienced significant costs). The extent of cost-savings varies across preventative interventions (Maciosek et al., 2006). However, the effectiveness of prevention efforts with youth with other concerns (e.g., antisocial behavior; Forgatch & DeGarmo, 1999) and other pediatric populations (e.g., traumatic brain injury; Ponsford et al., 2001), coupled with advances in the field's ability to identify patients at high risk of negative health outcomes (Schrager et al., 2016; Simon et al., 2014) dem-

onstrate the promise that preventative efforts can have with medically and socially vulnerable youth. In addition to the strategies previously discussed, other ways pediatric psychologists can employ their expertise include using relevant lab values (e.g., HbA1c) to demonstrate patient risk and disseminating benchmark findings to help payers comprehend the risks to patients and payer finances associated with gambling that a patient's health will improve without intervention. Pediatric psychologists and other behavioral health providers have expertise in identifying risk factors for poor health outcomes, appreciate the need for intervention across and within systems, and can create individual and systemic behavioral change, making them uniquely positioned to identify and effectively treat patients at risk for future health problems.

There are many limitations to using economic data when attempting to obtain authorization for behavioral health services for youth with medical and social complexity. Measuring the effectiveness of an integrator's efforts to meet the Triple Aim for a population is challenging when payers utilize the service for relatively few patients instead of a larger population of patients that may more accurately capture broader program success. Moreover, the possibility of members changing insurance plans midtreatment drives some payers to focus on short-term costs without the patience for and investment in long-term health and associated benefits for patients, families, payers and society. Furthermore, depending on the health care environment of a particular geographical area, the percentage of risk held related to health care costs may differ across health care institutions, payers, and states, resulting in infighting regarding which entity should financially support new programs. Perhaps most alarming to some, the possibility of modifications to the Affordable Care Act, state and federal funding, or other health care system reimbursement structures results in payer reticence to assume the risks associated with adaptation. However, we would argue that programs built to achieve Triple Aim outcomes with pragmatic financial models will always be in high demand. Although distressed by the heavy emphasis payers have placed on the single aim of cost savings, NICH program leadership has accepted the trade-off of using economic data to pursue the program's mission

while continuing to underscore the importance of program outcomes related to improved care and improved health. Perseverance appears to be the key to success, as this case series shows that variability in administrative oversight, funding priorities, and APM readiness across payers can result in a cumbersome negotiation process that is not always successful the first time around.

Limitations are present in this case series, some of which are inherent in this type of research. Due to differences in where patients received care, there was variability in access to data both across and within patient scenarios, resulting in an incomplete picture and an inability to summarize outcomes consistently across all patients. Also, we did not collect additional standardized outcome measures (e.g., quality of life, acceptance of illness, family conflict), capture indirect cost savings (e.g., provider time, parent employment, patient school attendance), or reliably gather qualitative information, limiting the conclusions that can be drawn in these areas. Because this article is a case series, these results may not reflect how NICH would be associated with change in a larger sample, and the outcomes may not be generalizable. However, we believe this article accomplished the aims of providing recommendations and examples for other behavioral health providers to apply in their own unique contexts. In future studies of the cost effectiveness of NICH, the authors aspire to include a larger sample size, standardization in measurement, inclusion of a control group, and increased collection of process and demographic data that may represent potential mediators and moderators of effectiveness.

Ultimately, the acceptance of APMs is and will continue to be influenced by many factors. Still, we believe that the sustainability and growth of programs for the most vulnerable are partly dependent on the ability of pediatric psychologists and other behavioral health professionals to highlight the value of these services. Although imperfect, the strategic adoption of pragmatic APMs behooves a field too often tied to the billable hour as opposed to the value of effective care provision. While most attempts to develop APMs and secure funding require a combination of the strategies described, we hope this case series offers valuable guidance to pediatric psychologists and other programs seeking to demonstrate their ROI to potential funders. Due of the single aim-mindedness of

potential funders, our efforts to develop and provide treatments that improve the health and care experience of vulnerable populations will likely always be somewhat tethered to our ability to demonstrate the financial value of such services to institutions and payers.

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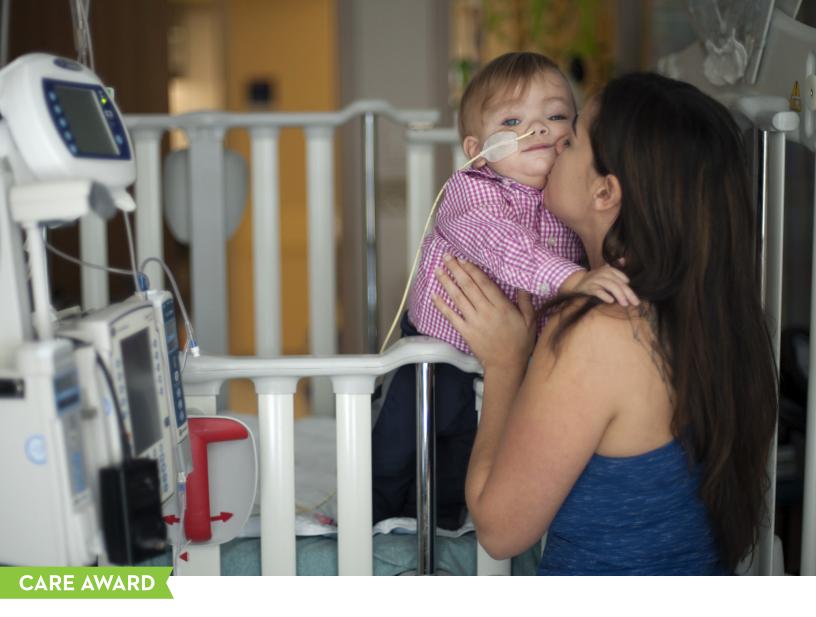
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Section 2: Materials & Resources Provided
by Keynote Speaker David Bergman, MD

CARE AWARD

Invoking the Power of Family Partnerships
to Improve Outcomes for Children with Medical Complexity

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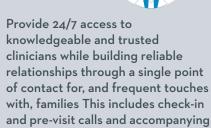
Photo: Katherine C. Cohen, Boston Children's Hospital

CHILDREN'S
HOSPITAL
ASSOCIATION

Engage

Engage families in multiple levels of involvement, such as family advisory committees, parent mentors, family navigators, self-management facilitators, and direct participants on QI teams and in related QI activities.

Access

Provide 24/7 access to knowledgeable and trusted clinicians while building reliable relationships through a single point of contact for, and frequent touches with, families This includes check-in and pre-visit calls and accompanying families to specialty visits.

Activate

Build and monitor a culture of family-centered care among all staff through ongoing activities such as family-led staff orientation and in-service education.

Partner

Create shared plans of care with active family involvement and family-derived goals that extend beyond medical treatment and short-term outcomes, and include action steps that guide family participation in goal attainment.

10

VITAL ACTIONS FOR

Effective Family Partnerships

Guide

Develop access plans with individually relevant contingency guidance developed with, and understood by, families.

Monitor

Continuously monitor families' experience of care through surveys, focus groups and individual interviews. Use this information to further improve care.

Follow-up

Use ED visit follow-up calls to ascertain how families make a decision to use the ED and how to improve alternative access options.

Question

Always question how families can become more engaged in service improvements and how care can become more family-centered.

Support

Provide tangible supports to families who are participating on QI teams such as stipends, child care and transportation.

Encourage

Provide staff support to families assuming QI and family advisory roles to foster their confidence and comfort as team members, and provide answers to questions and clarification about their roles.

CHA CHILDREN'S HOSPITAL ASSOCIATION

Families have underused expertise as health care system users. Providers and organizations can successfully use this knowledge by cultivating a culture of family-centered care. This invokes models of partnership with families in the care of children with medical complexity (CMC), as well as in the design and improvement of care delivery systems.

These concepts informed a guiding principle for the CARE Award *(see Appendix A)* and challenged participating teams. They found that aspiring to true family-centered care required

We thought we were practicing family-centered care until we were asked to partner with families differently in CARE.

—CARE QI team member

a deep and pervasive cultural change among all care delivery team members and across all systems in which they work. As one CARE QI team member related, "We thought we were practicing family-centered care until we were asked to partner with families differently in the CARE Award."

The Institute for Patient and Family-centered Care is defined as "an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients and families.

Patient- and family-centered care provides the framework and strategies for improving quality, safety and the experience of care."[1] This definition aligns with those adopted by the U.S. Maternal and Child Health Bureau and the American Academy of Pediatrics, which consider family-centered care to be a standard of practice for high-quality care.[2,3]

While family-centered care characterizes an overriding care delivery principle, the engagement of families in mutually beneficial partnerships translates that principle into active practice. Family partnerships affirm families as full members of their children's clinical care teams and engages them in the planning, testing,and implementation of care delivery improvements. Based on evidence that family-centered practices and partnerships improve outcomes for patients and families, the CARE Award called for the direct participation of families on quality improvement (QI) teams, and in the design and evaluation of clinical methods and tools grounded in shared decision-making with families and members of their health care team.[6-13]

The CARE Award Model

With funding from the Center for Medicare and Medicaid Innovation, the CARE Award convened teams from 10 children's

Levels of Family Involvement

☐ Families as colleagues in the care of their child

☐ Families on QI teams

☐ Families on Boards and other hospital committees

☐ Families assist in hiring staff

☐ Families as teachers in orienting staff

☐ Families on staff

☐ Family advisory committee

hospitals and 41 primary care practice sites to improve outcomes and reduce costs of care for children with the most complex health care needs. QI teams were expected to include clinical team members and at least one parent of a child with medical complexity. These parent partners played an active role in the development and testing of change ideas, not simply a post-hoc advisory role.

Four change concepts created the framework for a QI collaborative anchored by the development of population registries, and the design and implementation of care processes that target better planning of, and access to, the right care at the right time. The model targeted care delivered in hospital-based complex care clinics and in hospital and community-based primary care practices, aiming for improved care coordination among providers and the same quality of care in all settings. Monthly measures of concept implementation, and emergency department (ED) and hospital utilization were combined with baseline and periodic measures of medical home functionalities and the family experience

of care to assess the impact of the QI effort on CMC.

The change concepts *(Appendix B)* included: a registry to track patient status, a dynamic care team (DCT) with family and clinical care providers designated by the family, an access plan to facilitate timely access to the best care, a care plan developed with the family and shared by the DCT.

All participating sites had electronic health records that, once geared to track CMC, provided registry functions. In addition, process improvement efforts focused on the development of DCTs, access plans and care plans. The work was informed by the goal of uniform quality across sites and the importance to good outcomes for behavioral health and social determinants of health.

During the final year, the change concepts were enhanced in several ways to advance the level and quality of family engagement. First, care plans included short and long-term goals explicitly derived from the families and not solely from the clinical team members, with action steps to guide family participation in

All participants saw a significant decline in reported hospital days for enrolled patients.

Tips for Choosing Family Partners

The best family partners may be ones that are:

☐ More experienced with navigating the local health care system and managing their child's health care needs

☐ More experienced contributing as members of a QI team, or have support from other parents on the team

☐ Not in crisis, transition, or dealing with active health issues in their child

☐ Able to advocate for all families and provide constructive input, rather than focusing only on their own child

☐ Given a choice of roles including membership on a family advisory group or participation in a QI project

☐ Well-connected with family advocacy organizations and/or graduates of family leadership training programs

reaching the identified goals. Second, access plans were expanded to include contingency planning to better inform family decision-making about how, when and where to seek care, and emergency care plans that provide first responders and ED personnel with vital patient information to effectively begin treatment.

Finally, teams conducted follow-up interviews with families that had recently used the ED to better understand what determined their decision to seek emergency care.

Experience with Family Partnerships

Participating sites and their associated complex and primary care settings interpreted the expectation of family engagement in a variety of ways that evolved over the collaborative. A QI process that required direct family participation was a challenge to many of the teams, particularly some of the primary care settings. Challenges ranged from a lack of prior experience with this type of family engagement to a perception that most families had too many demands in caring for a CMC. Aligning real-time participation in meetings or calls with the availability of families created logistical challenges.

Many of the hospital-based teams felt their preexisting family-advisory committees could provide the necessary family engagement, albeit in a more reactive capacity. Among the successful efforts to more fully partner with families, Lucile Packard Children's Hospital Stanford developed parents as paid mentors for other parents, and St. Joseph Children's Hospital incorporated direct parent participation on QI teams.

During learning sessions, family voices were clearly heard and their input increasingly appreciated by participating teams, many of which revised and expanded their family partnership methods.

From the standpoint of family engagement in individual care relationships, even teams that professed adherence to the principles of family-centered care realized a higher level of family partnership was necessary. Barriers were care and access plan development, setting goals that were purely clinical in nature, and access procedures that made more sense to providers than families. In these cases, teams focused on educating families so they would follow the care and access plans created by providers, rather than work with families toward a better understanding of, and response to, their needs.

> **I appreciate hearing the voices of families—it is very important. Every member of the family panel brought enlightening thoughts to the table.**
>
> —CARE QI team member

Tips for Engaging Family Partners

Family partners may engage most productively when:

☐ Roles and expectations are clarified for all team members

☐ Pay and other incentives are provided for their time

☐ Innovative approaches and options for real-time participation and communication are offered

☐ Training in QI science and methods is provided

☐ Their suggestions and ideas are valued and acted upon when possible

☐ They are asked to review and suggest changes in care; help customize care plans for the range of family needs and situations

Learning sessions and huddle calls focused on examples of collaborative family engagement with supportive testimony from parents. Teams were asked to explain how family input was shaping the content of care and access plans. These efforts were successful when teams recruited senior leadership support to reshape their work culture, and gather and respond to family input. In some instances, this work was left to practice transformation facilitators with limited leverage to make systemic changes in culture or workflow with respect to family input.

Enhancements made to the change concepts during the CARE Award's final year generated a higher degree of partnership with families in the development of care and access plans. Care plans included more goals related to quality of life and everyday functioning, and access plan contingencies permitted families a greater ability to make access decisions based on circumstances and their child's unique characteristics. Teams interviewed over 500 families following ED visits, providing insights on the nuanced realities they face when their child's health status changes unexpectedly, and the need for prompt assistance from someone they know and trust.

Family Partnership Innovations

Most CARE Award teams found innovative and measurable ways to better partner with, and learn from, families. Examples of family engagement innovations include:

- **Four sites** developed paid roles for parents on QI teams, mentors to other parents, parent navigators or advisors. This simplified parent participation in QI team activities enhanced the parent's sense of being a valued team member, and created a shared stake in the outcomes of system changes.

- **Children's Hospital Colorado** worked with families to design an emergency plan format so they could have individualized emergency action plans. This would guide them in access of care decisions and provide information for first responders and ED

personnel on the child's health history, DCT members, and care planning goals.

- **Wolfson Children's Hospital** collected feedback from families indicating they were confused by the inconsistent terminology clinical team members used for the new tools (e.g. care plans, access plans, emergency care plans). As a result, terminology, labeling and tool formatting was standardized to make their purpose more clear.

- **Children's Hospital of Philadelphia** organized evening educational events for families. One event demonstrated the concept of care mapping to visually portray each child's array of supports, services and resources, and the relationships among them. Participating family completed a care map for their child, an activity that helped providers see the complexities that families of CMC face. Another evening was organized as a resource fair with community services and agency booths to explain their services and how to access them.

- **Lucile Packard Children's Hospital Stanford** convened a family advisory team that met monthly and actively participated in the redesign and implementation of change concepts.

CARE Award Outcomes

All participants saw a significant decline in self-reported hospital days for enrolled patients, and this decline was highly correlated with the penetration of patient-centered care plans and access plans over the course of the project. Care and access plans were vetted and tested against family feedback so that the engagement of families may have contributed to this core outcome. Family feedback and family involvement indicators on the Medical Home Index (MHI) saw 23 percent and 16 percent improvement respectively between baseline and final administrations of the MHI, and some practices reached the highest possible scores for these indicators. While high increases related to having low

scores at baseline for some clinics and practices, earlier solicitation of direct family input could have resulted in even better performance on the MHI indicators during the project.

Several family survey tools[14-17] were used at repeated intervals during the CARE Award to elicit direct input from families about their experience of care. Survey results were adjusted to account for patient age, gender, duration of case management prior to enrollment, site of care, and hospital system. After adjustment, statistically significant improvements were seen in the Family Centered Care Assessment survey overall, its decision making interaction domain, the PEDSQL-FIM survey overall, and its daily activity domain.

Conclusion

Families need to be essential partners, not only in the care of their own children, but also in the QI practices so necessary for true system change and transformation, particularly systems of care for CMC. To be successful, family partnerships should be embedded as a core value in the culture of the health care organization, with senior leadership support for provider and system change.

Family partnerships can lead to increased family confidence and ability to manage health care interventions for their child, more effective shared decision-making and care planning among the dynamic care team, increased satisfaction with the health care experience, and decreased utilization of emergency and in-hospital services. Families must be supported in this role via education, mentorship, clear definition of roles, demonstrated value and application of their suggestions, and compensation for their efforts.

Ongoing efforts to seek input from families via surveys, focus groups and interviews strengthen care improvements and support sustainability of family-focused changes to the care delivery system.

Photo: Allyn DiVito, Johns Hopkins All Children's Hospital, St. Petersburg, Florida

CARE Award Defined
The Coordinating All Resources Effectively (CARE) Award is a landmark national collaborative project aimed at improving quality outcomes and reducing the cost of care for children with complex medical conditions enrolled in Medicaid funded by the Center for Medicare and Medicaid Innovation. Children's Hospital Association partnered with 10 of the nation's leading children's hospitals, eight state Medicaid programs and Medicaid managed care organizations, more than 40 primary care practice sites, and 8,000 children and their families.

The CARE Award was designed to transform care through the provision of appropriate, coordinated care in the right setting, and develop alternative payment models that more effectively align with the new care model.

Participating Sites
Children's Hospital Colorado (Aurora, CO)
Children's Mercy Kansas City (Kansas City, MO)
Children's National Medical Center (Washington, DC)
Cincinnati Children's Hospital Medical Center (Cincinnati, OH)
Cook Children's Health Care System (Fort Worth, TX)
Lucile Packard Children's Hospital Stanford (Palo Alto, CA)
UCLA Mattel Children's Hospital (Los Angeles, CA)
St. Joseph's Children's Hospital (Tampa, FL)
Children's Hospital of Philadelphia (Philadelphia, PA)
Wolfson Children's Hospital (Jacksonville, FL)

CARE Change Concepts Defined

Care transformation in the CARE Award was built on a set of closely related change concepts designed to be developed jointly with families and providers.

1. Each CARE site will have a patient registry
Registries are essential tools for population assessment and management, and quality improvement, both within individual practices and across the continuum of care.

2. Every child/family will have a dynamic care team (DCT)
Care of children with complex needs requires an effective, informed and coordinated team. The family drives the composition of the DCT and is a critical partner to other members of the team. DCT membership is representative of the care continuum that includes health care, and community and educational, providers. DCT members recognize each other by name and role, and have effective systems for timely communication among team members.

3. Every family will have an access plan containing three components:
a. An after-hours access plan that describes how and when to contact the appropriate clinical provider for health care issues. Every patient and family needs to know who to contact and how to contact them to access the right provider for the right care at all times. A provider must be available 24/7. The access plan should include a listing of all DCT members with contact information and preferred method of contact to expedite access to care.

b. A contingency plan that contains instructions for parent action when the child experiences a change in condition. It describes how and when to contact the appropriate clinical provider for health care issues. These plans are developed from scenarios suggested by families that are likely to result in their child going to the ED. The contingency plan should contain actions to prevent an acute exacerbation, actions if an exacerbation occurs, and what to do if the child does not improve, e.g. when to call 911 or take the child to the ED. It would also outline the accommodations needed for other children in the house, notification of family members, etc.

c. An emergency care plan that provides essential information for emergency responders or ED personnel who are not familiar with the child to expedite effective treatment and communication with the child's medical home/subspecialty providers. This includes a brief medical history and description of child's baseline condition, current medications, common presenting problems with suggested diagnostic studies and/or treatment, procedures to avoid, important family preferences, a list of the child's physicians/their contact information and an advanced directive form.

4. Each family will have a care plan based on patient/family goals developed via a shared process between clinicians and child/family
There is a standardized approach (including standardized documents) to care planning used with every child and family. Goals are developed from the assessment of family needs and assets for care planning. Providers and the child/family have the same understanding of roles and acknowledge the same patient goals. Care plan includes action steps to assist child/family attainment of goals. Families and providers across the care continuum have access to the care plan.

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Photo: John Maniaci, American Family Children's Hospital, Madison, Wisconsin

Impacting the Health Care Spend for Children with Complex Conditions

Children with complex medical conditions comprise 6 percent of the pediatric Medicaid population and 40 percent of the spend in Medicaid. For pediatric academic medical centers, these children may represent up to 80 percent of the total hospital days. Children's hospitals are beginning to explore new care delivery models resulting in smarter spending, healthier children and better care for this important population. To understand progress to date, we highlight important variables children's hospitals must consider related to the impact of care transformation on the healthcare spend of these children.

Ten children's hospitals implemented new care delivery concepts under the CARE Award, resulting in better care and healthier children. We tracked changes in care spend for the 8,000 enrolled children prior to and over the three-year award period.

Here is the process the hospitals undertook to impact health care spend.

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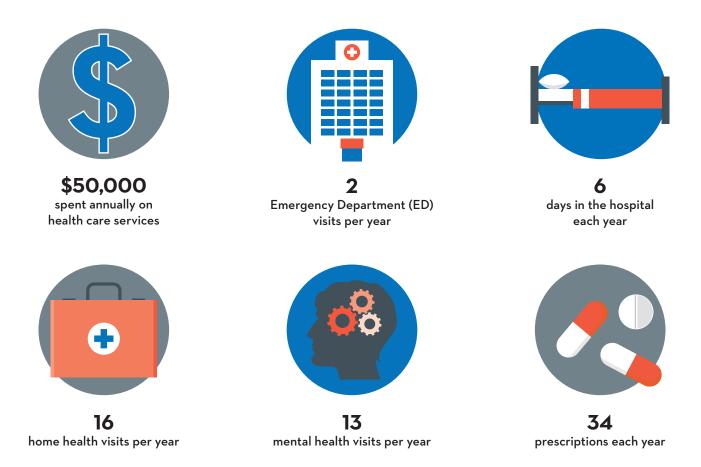
CARE Award hospitals began with the following activities to evaluate the impact of care transformation on spend for this population.

- Collection of data to analyze patterns of spend and resource use
- Implementation of care delivery model change concepts designed to impact the patients' utilization of services
- Calculations of the unreimbursed cost of the care management which guided needed changes for payment to support the program

Know Baseline Patterns of Spend and Resource Use

Children enrolled in the CARE Award use the following health care resources. At the high end, some individuals spend up to $2M on health care in a single year. Here's an example of what a child and family might experience:

$50,000
spent annually on
health care services

2
Emergency Department (ED)
visits per year

6
days in the hospital
each year

16
home health visits per year

13
mental health visits per year

34
prescriptions each year

Understand Infrastructure Costs

Many large pediatric academic medical centers began developing complex care clinics in early 2000. Nine of the 10 CARE Award sites have an established complex care clinic. The tenth site hosts a virtual care management structure. Most of the infrastructure costs for these clinics as well as the cost of infrastructure for the new care delivery model are not reimbursed in the traditional fee-for-service (FFS) insurance model. To achieve the triple aim and support smarter spending, we must first understand the cost of the new model. We can then assess the impact of the new model on decreasing overall spend in excess of these new costs. We calculated care coordination costs for these children at an average $150-$400 per child per month.

Implement a New Care Delivery Model

The care delivery model implemented across each of the CARE Award sites focuses on four elements:

- 24/7 access for the family to reach qualified providers familiar with the child's needs
- Family-driven care plans specific to each child and developed around family goals
- A team of care providers, across both primary and subspecialty care, who regularly share information on the status of the patient amongst themselves and with the child and family
- Use of access plans and contingency plans to reduce ED utilization and preventable hospitalizations

We believe these elements work together as follows to impact unnecessary utilization and spend, and decrease the burden of care for the family.

- *A focus on partnerships with families.* Partnerships are designed to recognize and enhance the family's role and expertise in the provision of care. Families with customized care plans and access plans centered on their needs will better recognize escalation of conditions and know how to respond. These resources make it easier to reach a provider familiar with the child's care, preventing potential emergency room and hospitalization visits.

- *A focus on the use of care coordinators.* Care coordinators with specific skill sets in proactive planning will enable easy access to the system of care. They can prioritize family goals across the many providers of care required for these children. Families must be in agreement with what they are doing and why they are doing it.

- *Enhanced relationships between primary care physicians, specialty physicians and community services.* Patients can receive the most appropriate care closer to home when primary care and medical home providers actively support families while ensuring access to specialists. Functioning as a team, so families know "who's on first," will prevent lapses in the system of care.

Other factors outside of care management impacting utilization and spend include: severity of the child's illness, the resources available within a community to support health outside the hospital, and state Medicaid reimbursement for appropriate access to specific services such as home health. We understand the ultimate outcome will rely on the family's discernment of the provision of care. Results from effective care coordination showed improved family satisfaction with:

- Convenient and personalized access to the child's health care team
- Care planning that enhances the families' sense of well-being
- Goal setting that results in fewer emergency room visits
- Improved family-provider partnerships

Calculate Impact on Spend

In a three-year collaborative, the spend and utilization changed as follows. Of note are significant proportions of spend related to home health and outpatient prescriptions. Together these comprised 30 percent of the total spend across the continuum of care. Both the cost and utilization of prescription drugs rises increased more than projected for this population, and thus further analysis of the opportunity for prescription management will be required.

Spend decreased from projected by
2.6%

ED discharges decreased by
26%

Hospital days decreased by
32%

Aim for a New Payment Model

Sustaining a new care delivery model will require a change to traditional reimbursement structures. Four new payment models were implemented at children's hospitals under the CARE Award. These models were designed to specifically meet the needs of this complex population.

Active Care Award Payment Models

- Care management PMPM fee with state for the provision of specific care coordination tasks
- Upside shared savings model aligning incentives across the system-owned hospital, physician network and Medicaid HMO
- State Health Home PMPM for service integration across providers
- Care management team infrastructure support with potential for shared risk
- Care management PMPM fee with local Medicaid managed care organization

Other payment model options to explore for this population include primary care capitation, ACO models, case management FTE support, and state based health homes modified for a pediatric population. The best option for understanding the opportunity to impact the spend is to work in partnership with a payer to adopt a new payment model, however simple, and monitor the population over time. New payment models enable providers to gain experience and understand the underlying utilization and spend patterns. Without the experience of piloting a new payment model, data and experience are difficult to come by for this small, high acuity, highly variable population of children.

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Photo: Michael LeGrand, Wolfson Children's Hospital, Jacksonville, Florida

Access to Care:
A Family-Centered Approach

Previous research suggests access to health insurance and a primary care provider (PCP) in a medical home can reduce emergency department (ED) utilization and hospital days for children with medical complexity (CMC)[1]. However, other studies point out that access to health insurance and a medical home does not explain all unnecessary ED utilization.[2],[3],[4] The CARE Award provided a unique opportunity to understand the reasons behind preventable ED utilization for a population that had access to health insurance and a medical home, and to test quality improvement (QI) interventions to decrease ED visits. Access to care is critical for CMC given the fragile nature of their conditions. The framework for improving access to care that ensured families have access to the right care, at the right time, with the right provider, was developed by understanding why families used the ED and how to help them manage their child when acute illness or an exacerbation occurs.

CHILDREN'S HOSPITAL ASSOCIATION

Access to Care: What We Learned from Families

Improving the care delivery system for children enrolled in the CARE Award required better knowledge of what happens when they became ill. Specifically, what did parents do when their child developed symptoms? CARE Award QI teams from the 10 participating sites interviewed more than 500 families after ED visits to uncover what led them to the ED and what could have been done to prevent the visit. Results showed that families took their child to the ED before calling their provider half the time, and over two-thirds of families felt they would have been comfortable going to their PCP instead of the ED. A sample of survey results is presented below.

SURVEY

Did you call your PCP prior to taking your child to the ED?

50%
SAID YES

Did you have an access plan in place before the ED visit?

68.2%
SAID YES

Did you feel after the ED visit that your child's medical issues could have been addressed in a visit to your PCP?

76.8%
SAID YES

CARE Award teams were then asked to interview five families each on why they used the ED instead of calling their PCP or making an appointment. Four key themes emerged from these interviews:

1. I took my child to the ED because he/she always ends up in the ED when he/she gets these symptoms

2. When I call my PCP, I get a nurse advice line and a nurse who is not familiar with my child, and does not have access to the medical record

3. It took too long for my PCP to call back

4. When I go to the ED, I get all my child's tests, X-rays and consultations in one place, and I leave with a plan. It's not efficient when I go to the PCP.

It became clear families needed a system for accessing care that:

- Told them which provider to call, when to call, and how best to reach them

- Specifically addressed the medical issues that made their child sick

- Told them how to prevent their child from becoming sick and what to do when he/she did become sick

- Provided timely phone access to a provider who knows their child and has access to his/her medical record

- Offered primary care services after-hours and on weekends

Designing Systems to Improve Access

Access to care was one of five closely related change concepts implemented (Appendix B) to transform the delivery system as part of the CARE Award.

Using these change concepts as a foundation for care transformation, each site worked with families to identify the Dynamic Care Team (DCT) that included their primary care and specialty providers, as well as other individuals important to the family, such as social workers, care coordinators, etc. Once the team members were identified, each family was given an access plan that listed their team members, and how to reach them for routine and urgent issues.

The following graphs show the time to reach our goal for high-quality adoption of two change concepts in participating complex care and primary care practices (PCP).

Measurement of high quality implementation of the change concepts included the number of enrolled children, as well as the average number of core elements of the change concept implemented.

On average, it took nine to 10 months to adopt these change concepts, with more rapid adoption taking place in the primary care practices. This lengthy implementation period was due to the considerable upfront time commitment required to identify the DCT, and review with families how to best access each team member.
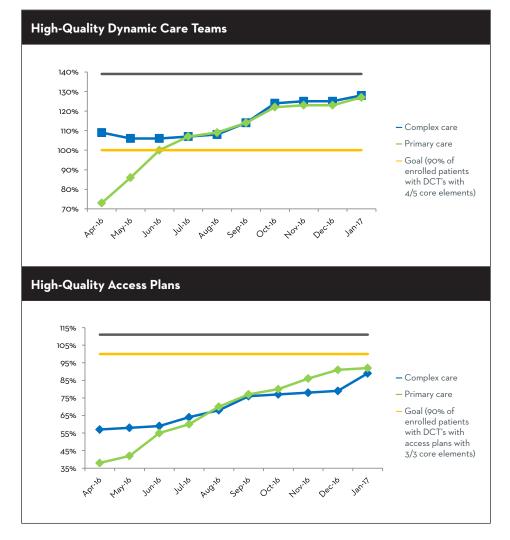
To improve access to care over the course of the CARE Award, many of the sites increased education and self-management skills to better manage acute illness, enhanced access to after-hours care/consultation, and provided phone and telemedicine access to care.

Increased Skills for Managing Acute Care Illness

Post ED visit interviews showed that for a given clinical problem, families didn't know what to do to treat the problems, who to call, or when to take their child to the ED. These insights led project leadership to enhance the access plan change concept by adding a contingency action plan and emergency care plan.

Mattel Children's Hospital UCLA had prior experience developing a program that worked with families to identify two to three clinical scenarios most likely to lead to an ED visit or hospitalization. For each scenario, team members working with the family developed a contingency plan using the Asthma Action Plan as a template. A child with chronic lung disease may have a set of interventions that enhance airway clearance. For a child with epilepsy, it could be an emergency plan for a seizure lasting more than five minutes. Separately from CARE, Mattel completed a randomized

High-Quality Dynamic Care Teams

- Complex care
- Primary care
- Goal (90% of enrolled patients with DCT's with 4/5 core elements)

High-Quality Access Plans

- Complex care
- Primary care
- Goal (90% of enrolled patients with DCT's with access plans with 3/3 core elements)

controlled trial of an intervention using action plans and a transition to home for hospitalized patients in 144 CMC. This best practice was shared with all CARE QI teams to expand the access plan functionality.

Enhanced Access to After-Hours Care

Sites were surveyed on access to care midway through the CARE Award. The survey showed all CARE practice sites provided phone access after hours. However, less than 10 percent of these sites provided triage with an M.D. or RN who was known to the family. Fifty-three percent of sites provided triage with a nurse answering service, and only 40 percent of families had access to a clinician medical record access.

Most CARE sites offered same day care, with approximately 60 percent offering extended hours and 58 percent offering extended weekend hours.

In general, primary care practices were less able to provide after-hours phone triage by an RN with access to the child's medical record. This was particularly true for independent practices.

A significant percentage of the complex care programs and PCP sites were not able to provide after-hours access from a provider who was knowledgeable about the child. This gap in care was difficult to close because of costs and necessary structural changes.

Family interviews revealed when their child experienced an acute illness, parents didn't know who to call.
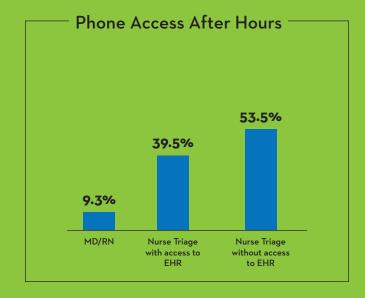
Phone and Telemedicine Care Access

Interview results showed that it was important for families to speak to someone who knows their child and can access the EMR before going to the ED. Cincinnati Children's Hospital Medical Center linked the PCP care coordinator with the triage nurse in primary care so advice would come from a trusted provider. Another strategy used by Children's Mercy Kansas City was a telemedicine link to the home for illness episodes. Providers examine, diagnose, and make recommendations for care over the telemedicine link. While these routine visits were designed as part of a more comprehensive assessment, providers identifyied issues with adherence to the treatment regimen that, when remedied, could decrease the likelihood of an ED visit. Children's National Medical Center is using telemedicine for virtual home visits and follow-up visits. Several site care coordinators initiate phone contact with high-risk families at regular intervals to identify potential problems and ensure preventive therapies are in place.
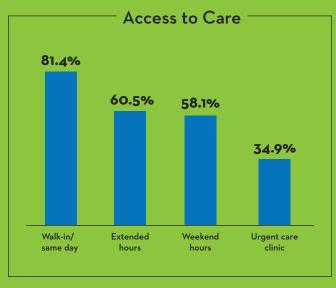
In spite of the known effectiveness of providing primary care access after-hours and on weekends, only one practice increased their access to after-hours care during the CARE Award.

SURVEY

Phone Access After Hours

MD/RN	9.3%
Nurse Triage with access to EHR	39.5%
Nurse Triage without access to EHR	53.5%

Access to Care

Walk-in/same day	81.4%
Extended hours	60.5%
Weekend hours	58.1%
Urgent care clinic	34.9%

Parent Empowerment

Outside the CARE Award, Lucile Packard Children's Hospital Stanford developed a self-management program to help families interact more effectively with the health care system. These programs address important issues relating to access to care such as, "What to do if your child is sick in the middle of the night," and "How to best communicate with your medical team." Learning is self-selected by families and intended to complement parental knowledge of how to best care for their child.

During phone contact with families after an ED visit, families were often offered follow-up education about care that can be provided at home, and tips for when to call their provider or go to the ED. Some sites used simple behavioral reminders, such as refrigerator magnets, to identify who parents should call before going to the ED.

Family Engagement in Improving Access to Care

Methods to develop action plans jointly with families and providers varied across the CARE Award sites. Several sites allocated time during the visit to identify with the family conditions that were likely to lead to an ED visit or hospitalization, and to develop an action plan that addressed preventive care and acute care. One site involved a parent advisory group in the development of a templated plan and workflow design. Other CARE Award sites found it more efficient to develop action plans and review them with families during a patient encounter. One site utilized their care coordination team to review and refine the access/action plans developed. In ED follow-up phone calls, some families said they were aware of the access/contingency action plans but did not understand how to use them. Participants believe this lack of understanding may stem from varied levels of family involvement in the plan development.
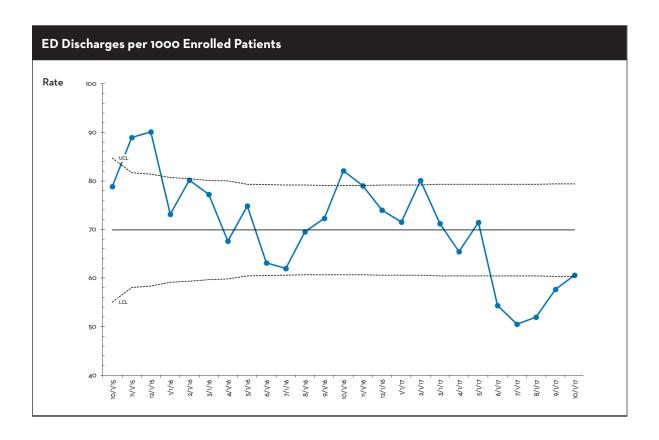
Major barriers to family engagement were time and resources. Successful sites noted it required a two to three hour time commitment to develop plans with each patient. Care coordinators, or unlicensed care coordination staff, had the responsibility to work with families to complete the plan. At some CARE Award sites, this resolved the problem of clinical providers having insufficient time to work with families to develop and maintain access/contingency action plans. PCP sites had more difficulty than hospital-based complex care services engaging families in the design of access plan templates and participation in QI activities.

> **Major barriers to family engagement were time and resources.**

5

ED Discharges per 1000 Enrolled Patients

Access and Health Care Utilization

CARE Award access and contingency plans were designed to impact ED utilization, and to a lesser extent, outpatient visits. The team hypothesized if parents knew how to treat their children when an acute situation arose, and when to call their provider before going to the ED, unnecessary ED and office visits could be avoided. As seen in the utilization chart above, change concept implementation appears related to reductions in ED visits, but further research will be needed to prove a causal relationship.

Future Opportunities to Improve Access

All CARE Award participants felt there was an opportunity for more effective family involvement in the design and implementation of care. Lucile Packard used a framework for family involvement. In this context, Human Centered Design is defined as a design and management framework that develops solutions to problems by involving the human perspective in all steps of the problem-solving process. Human Centered Design typically takes place in the context of observing the problem within context, brainstorming, conceptualizing, developing and implementing the solution.

Better use of technology is another opportunity for improvement. Most sites indicated their EHR could better integrate care coordination information and communication across the care team. Greater engagement of parents through patient portals was seen as an important way to more effectively involve families in health care team decision making. Wider use of telemedicine as an alternative encounter would facilitate access without the barriers of time and travel. Greater interoperability between EHRs would allow families to access providers after hours who had knowledge of their child's medical history.

More widespread use of contingency action plans would allow possible prevention of acute exacerbations, and provide families with the knowledge and skills to manage their child's condition at home.

Conclusion

Learning from parent surveys and interviews enabled CARE Award teams to understand gaps in the care delivery system from the patient perspective, strengthen tools that improve access to care Families and CARE Award sites reported reductions in unnecessary ED utilization.

Preliminary results from claims data shows ED and inpatient utilization reductions were achieved during full implementation of the project.

Best Practices for
Improving Access to Care

1.

Engage families in the design of the access plan and its implementation.

—Lucile Packard Children's Hospital Stanford

2.

Involve families in the negotiation of contingency action plans.

—Mattel Children's Hospital UCLA

3.

Provide continuous improvement of access plan with refinement of contingency action plans.

—All CARE Award sites

4.

Develop a rapid response from a provider who knows the patient and has access to the EHR when families call.

—Children's Mercy Kansas City, Lucile Packard Children's Hospital Stanford, St. Joseph's Children's Hospital, Children's Hospital of Philadelphia, Wolfson Children's Hospital

5.

Talk with families after ED visits, whether at their next scheduled appointment or in a follow-up phone call.

—Lucile Packard Children's Hospital Stanford, St. Joseph's Children's Hospital, Children's Mercy Kansas City

6.

Offer same day appointments, plus after-hours and weekend care.

—Cincinnati Children's Hospital Medical Center, Lucile Packard Children's Hospital Stanford, Cook Children's Health Care System, PCMH (Tampa) and Suncoast Health Clinic (Tampa)

7.

Consider telemedicine encounters for families who live far from the clinic site and have difficulty with travel.

—Children's Mercy Hospital, Children's National Health Center

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CARE Award Defined

The CARE Award, Coordinating All Resources Effectively, is a landmark national collaborative project aimed at improving quality outcomes and reducing the cost of care for children with complex medical conditions (CMC) enrolled in Medicaid funded by the Center for Medicare and Medicaid Innovation. Children's Hospital Association partnered with 10 of the nation's leading children's hospitals, eight state Medicaid programs and Medicaid managed care organizations, over 40 primary care practice sites, and 8,000 children and their families.

The CARE Award was designed to transform care through the provision of appropriate, coordinated care in the right setting, and develop alternative payment models that more effectively align with the new care model.

Participating Sites

Children's Hospital Colorado (Aurora, CO)
Children's Mercy Kansas City (Kansas City, MO)
Children's National Medical Center (Washington, DC)
Cincinnati Children's Hospital Medical Center (Cincinnati, OH)
Cook Children's Health Care System (Fort Worth, TX)
Lucile Packard Children's Hospital Stanford (Palo Alto, CA)
Mattel Children's Hospital UCLA (Los Angeles, CA)
St. Joseph's Children's Hospital (Tampa, FL)
The Children's Hospital of Philadelphia (Philadelphia, PA)
Wolfson Children's Hospital (Jacksonville, FL)

CARE Change Concepts Defined

Care transformation in the CARE Award was built on a set of closely related change concepts designed to be developed jointly with families and providers.

Each CARE site will have a patient registry

Registries are essential tools for population assessment and management and quality improvement, both within individual practices and across the continuum of care.

Every child/family will have a dynamic care team (DCT)

Care of children with complex needs requires an effective, informed and coordinated team. The family drives the composition of the DCT and is a critical partner to other members of the team. DCT membership is representative of the care continuum that includes health care, community and educational providers. DCT members recognize each other by name and role, and have effective systems for timely communication among team members.

Every family will have an access plan containing three components:

1. **An after-hours access plan** that describes how and when to contact the appropriate clinical provider for health care issues. Every patient and family needs to know who to contact and how to contact them, to access the right provider for the right care at all times. A provider must be available 24/7. The access plan should include a listing of all DCT members with contact information and preferred method of contact to expedite access to care.

2. **A contingency plan** with instructions for parent action when the child experiences a change in condition. It describes how and when to contact the appropriate clinical provider for health care issues. These plans are developed from scenarios suggested by families that are likely to result in their child going to the ED. The contingency plan should contain: actions to prevent an acute exacerbation, actions if an exacerbation occurs, and what to do if the child does not improve, e.g. when to call 911 or take the child to the ED. It would also outline the accommodations needed for other children in the house, notification of family members, etc.

3. **An emergency care plan** that provides essential information to emergency responders or ED personnel who are not familiar with the child to expedite effective treatment and communication with the child's medical home/subspecialty providers. This includes a brief medical history and description of child's baseline condition, current medications, common presenting problems with suggested diagnostic studies and/or treatment, procedures to be avoided, important family preferences, list of child's physicians/contact information, and the presence of an advanced directive form.

Each family will have a care plan based on patient/family goals developed via a shared process between clinicians and child/family

There is a standardized approach (including standardized documents) to care planning used with every child and family. Goals are developed from the assessment of family needs and assets for care planning. Providers and child/family have the same understanding of roles, acknowledge same patient goals. Care plan includes action steps to assist child/family attainment of goals. Families and providers across the care continuum have access to the care plan.

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