Using Shared Plans of Care for Effective Care Coordination

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American Academy of Pediatrics-VT, Chapter President
Physician’s Computer Company User’s Conference
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Objectives

• Define “Effective Care Coordination”
• Why Shared Plans of Care?
• Achieving Shared Plans of Care
• PCC Care plan function
• Future ideas?
welcome to our new medical home!

Doctors Hagan, Rinehart and Connolly are happy to announce our new location in Burlington’s South End. New patients and transfer patients are welcome. We hope to see you soon!
Our Medical Home

- Three pediatricians: Dr. Hagan, Dr. Rinehart, Dr. Connolly
- Two pediatric nurse practitioners: Maryann Lisak and Ashley Boyd
- One main Care Coordinator (RN) Kristy
- Office manager, accounts manager, receptionists
- Six additional part time nurses, two medical assistants
- ~4000 active patients
- Insurance mix: 35% Medicaid, 55% private, <5% uninsured
Care Study #1

- 13 year old boy with autism, non-verbal, self injury, polydipsia
- Parents struggling with bolting, overall safety
- Middle school unable to educate or keep safe
- Medical issues of skin infections, enuresis, sleep dysfunction, puberty, growth
- Family above and beyond capacity of most families to deal with this at home
Coordinated Care??

Mind the Gap

• Proactive
• Timely
• Accurate
• Problem Solving communication
Family centered care is about meeting families where they are, and helping them get where they want to go…
Why is A Family-Centered Medical Home Important to family?

- Opportunity for the family to build a trusting and collaborative relationship with the pediatrician and office staff.
- Care coordination provides smooth facilitation among all members of the child’s care team including family, specialists, pharmacy staff, community and school services.
- Comprehensive source of complete patient medical history

Care Coordination

- Is the set of activities that happens between
  - Visits, Providers and Hospital Stays
  - E-mails, prior authorizations, communication between providers (community and subspecialists), insurers, prescriptions, equipment needs, in home care providers, access to community resources
Care Coordination

“Pediatric care coordination is a patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the care giving capabilities of families…”

Medical Home Index:
43 Practices, 7 plans/5 states

- Higher overall MHI score or higher domain scores for care coordination, chronic condition management, office organizational capacity
  - Lower hospitalization rates

- Higher Chronic Condition Management domain scores
  - Fewer ER visits

Patient and Family Centered Care Coordination:
A Framework for Integrating Care for Children and Youth Across Multiple Settings
Medical Home for Non-CSHN


- Decreased outpatient sick visits
- Decreased emergency department sick visits
- Increased odds of “excellent/very good” child health
- Increased health promoting activities such as being read to daily, reported helmet use, and decreased screen time
Foundation of Medical Home

- AAP policy statement (reaffirmed, 2008)
- Provision of family-centered care through developing a trusting partnership with families, respecting their diversity, and recognizing that they are the constant in a child’s life
- Acknowledge family stories and information at every step along the way
- Quality improvement, practice transformation and the AAP includes family and consumer perspectives
# 5 Key Elements of Highly Effective Care Coordination

## The Concept

1. Needs assessment for care coordination and continuing care coordination engagement
2. Care planning and communication
3. Facilitating care transitions
4. Connecting with community resources and schools
5. Transitioning to adult care

## The Person

Antonelli et al (2009); Rinehart (2014)
PFCC Principles

Dignity & Respect
Providers listen to and honor patient and family perspectives, choices and incorporate their values, beliefs into care delivery.

Collaboration
Patients, families and providers collaborate in policy, program development, implementation and care delivery.

Information Sharing
Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making.

Participation
Patients & Families are encouraged and supported to participate in care and decision making.
<table>
<thead>
<tr>
<th>Organization</th>
<th>Care Plan Specifics/Called for Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Committee for Quality Assurance (NCQA)</td>
<td>Develop individual care plan includes treatment goals reviewed and updated at each visit</td>
</tr>
<tr>
<td>Centers for Medicare and Medicaid (CMS)</td>
<td>“Visit summary of care” Mandates (ACA) care planning components “Continuity of Care Record”</td>
</tr>
<tr>
<td>National Quality Forum (NQF)</td>
<td>Plan of Care: Actively tracks up-to-date progress towards patient goals</td>
</tr>
<tr>
<td>AAP Care Coordination Policy Paper, 2002</td>
<td>Plan of care developed by family, youth, physician shared with other providers, agencies, and organizations involved with that patient’s care</td>
</tr>
<tr>
<td>IHI Care Coordination Model</td>
<td>A “planned visit” contains assessment, review of therapy, review of medical care, self-management goals, problem solving and a follow-up plan</td>
</tr>
</tbody>
</table>

Jeanne McAllister, et.al, “Achieving a Shared Plan of Care for Children and Youth with Special Health Care Needs,” supported by Lucille Packard Foundation for Children 2014
PCMH cross-walk

- PCMH 2 Team-based care
  Element B - Medical Home Responsibilities
    2.B.1 - The practice is responsible for coordinating patient care across multiple settings
  Element D - The Practice Team (Must Pass Element)
    2.D.2 - Identifying the team structure and the staff who lead and sustain team-based care
    2.D.3 - Holding scheduled patient care team meetings or a structured communication process focused on individual patient care (Critical Factor)
    2.D.5 - Training and assigning members of the care team to support patients/families/caregivers in self-management, self-efficacy and behavior change
PCMH cross walk

- PCMH 5 Care Coordination and Care Transitions
  - Element C:1 - Proactively identifies patients with unplanned hospital admissions and emergency department visits
  - C:2 - Shares clinical information with admitting hospitals and emergency departments
  - C:3 - Consistently obtains patient discharge summaries from the hospital and other facilities
  - C:4 - Proactively contracts patients/families for appropriate follow-up care within an appropriate period following a hospital admission or emergency department visit
  - C:5 - Exchanges patient information with the hospital during a patient's hospitalization
  - C:6 - Obtains proper consent for release of information and has a process for secure exchange of information and for coordination of care with community partners
  - C:7 - Exchanges key clinical information with facilities and provides an electronic summary-of-care record to another care facility for more than 50 percent of patient transitions of care
PCMH crosswalk

- PCMH 6 Performance Measurement and Quality Improvement
  - Element B - Measure Resource Use and care coordination
    - 6.B.1 - At least two measures of care coordination
  - Element C - Measure Patient/Family Experience
    - 6C: 1 - The practice conducts a survey (using any instrument) to evaluate patient/family experiences on at least three of the following categories:
      * Access
      * Communication
      * Coordination
      * Whole person care/self-management support
  - Element D - Implement Continuous QI (Must Pass Element)
    - 6D:3 - Set goals and analyze at least one measure from Element 6:B
    - 6D:4 - Act to improve at least one measure from Element 6:B
    - 6D:5 - Set goals and analyze at least one patient experience measure from Element 6:C
    - 6D:6 - Act to improve at least one patient experience measure from Element 6:C
  - Element E - Demonstrate Continuous Quality Improvement
    - 6.E.3 - achieving improved performance on one utilization or care coordination measure
Hoop Jumping
Is Being a PCMH Good Enough?

“Comparison of Individual –Level Versus Practice –Level Measures of the Medical Home”

- Each practice had an NCQA level (2 at Tier 3, 3 at Tier 2)
- Of 180 parents only 52% had MH according to NSCH
- No significant association between family perception of medical home and being a practice wide medical home

Long & Garg 2015
Change Concepts for Practice Transformation

1. Laying the Foundation
   - Engaged Leadership

2. Building Relationships
   - Empanelment
   - Continuous and Team-Based Healing Relationships

3. Changing Care Delivery
   - Organized, Evidence-Based Care
   - Patient-Centered Interactions

4. Reducing Barriers to Care
   - Care Coordination
   - Enhanced Access

Straddling 2 worlds

• Old World: Fee-for-service
• New World: Get paid enough PMPM
• Old World: 99215, prolonged service
• New World: Care coordination supported by funds directed toward the practice
• Old World: Physician: patient dyad
• New World: Team based, integrated care
Pediatric Care Coordination Learning Collaborative

Following the guidelines of the Lucille Packard Foundation’s “Achieving a Shared Plan of Care Implementation Guide”

Purpose
Plan, implement and evaluate the impact of effective care coordination by working with

- Vermont’s primary and specialty health care professionals
- Patients and their families
- Community-based, child-serving agencies and organizations
Pediatric Care Coordination Participating Practices

**Northwestern Vermont**
- Hagan, Rinehart & Connolly Pediatricians, Burlington
- Timber Lane Pediatrics, Burlington
- Timber Lane Pediatrics, South Burlington
- UVMC Pediatrics, Burlington

**Northeastern Vermont**
- St. Johnsbury Pediatrics, St. Johnsbury

**Central Vermont**
- Little Rivers Health Care, Bradford & Wells River
- South Royalton Health Center, South Royalton
- Associates in Pediatrics* - Berlin, Berlin
- Associates in Pediatrics* - Barre, Barre
- Middlebury Pediatric & Adolescent Medicine
- Mt. Ascutney Hospital & Health Center, Windsor
- Rainbow Pediatrics, Middlebury

**Southern Vermont**
- Green Mountain Pediatrics, Bennington
- Brattleboro Primary Care, Brattleboro
- Maplewood Family Practice, Brattleboro
- Community Health Centers of Rutland Regional, Rutland
- Just So Pediatrics, Brattleboro
- Family Medicine Associates, Springfield
<table>
<thead>
<tr>
<th>NO CARE COORDINATION</th>
<th>WITH CARE COORDINATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>“There was no continuity. We would call the primary care office with a concern and they would say “Oh, you need to talk to your specialist about that.” We would call the specialist and they would say “Oh, you need to talk to your primary care doctor about that.” It was just back and forth all the time and the concerns never got addressed.”</td>
<td>“Now there is a sense that I’m being listened to – that his medical needs are being addressed. We have a plan with where we are headed, especially with the school, we know where we are going.”</td>
</tr>
</tbody>
</table>

Maier, Parent interview, March 6, 2014
Faculty All-Stars
Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs

• Jeanne McAllister, BSN, MS, MHA

• Supported by Lucille Packard Foundation for Children’s Health-Children with Special Health Care Needs
Medical Home and Care Plans – they go together, you can't have one without the other! -Family
Shared Care Planning Model

1. Identify Needs & Strengths (Patient/Family)
   - Hold family-centered discussions
   - Complete multi-faceted assessments

2. Build Essential Partnerships
   - Set personal and medical goals
   - Shared decision making
   - Link to specialists and community service providers

3. Create the Plan of Care
   - Develop the medical summary
   - Establish "negotiated actions"
   - Add emergency and legal Attachments

4. Implement the Plan of Care
   - Perform actions
   - Oversee, track & monitor
   - Evaluate, update, renew

McAllister et al, 2014
What is a Shared Plan of Care?

- A guide for moving care forward using a clear summary of information and a collaborative approach.

- Requires a family-centered, team-based, relational course of continuous action. The family has a clear contact point and access to their plan.

McAllister et al 2014
What is in a Shared Plan of Care?

• Includes: (as a comprehensive and integrated, concise and user-friendly set of information and set decisions)

• **A Medical Summary**– which details child/ family demographic information; current medical care facts; lead team members and contacts; and core child and family knowledge including their personal preferences and goals.

• **Negotiated Actions/Next Steps/Accountability**: highlights personal and clinical goals and joint strategies to address and /or achieve goals with timelines, responsibilities and accountabilities

McAllister et al 2014
Why Shared Care Planning?

- Care is fragmented
- Lacking coordination
- Information sharing across providers falls on the parents
- Families asking for:
  - Resource and system navigation
  - Team based care
  - Problem solving discussions
Principles for Successful Use of a Shared Plan of Care

Best results occur when:

1. Children, youth and families are actively engaged in their care.

2. Communication among their medical home team is clear, frequent and timely.

3. Providers/team members base their patient and family assessments on a full understanding of child, youth and family needs, strengths, history, and preferences.

4. Youth, families, health care providers, and their community partners have strong relationships characterized by mutual trust and respect.

Jeanne McAllister et.al, “Achieving a Shared Plan of Care for Children and Youth with Special Health Care Needs,” supported by the Lucill Packard Foundation for Children, 2014
5. Family-centered “teams” can access the information they need to make shared, informed decisions.

6. Family centered care teams use a selected plan of care characterized by shared goals and negotiated actions; all partners understand the care planning process, their individual responsibilities and related accountabilities.

7. The team monitors progress against goals, provides feedback and adjusts the plan of care on an on-going basis to ensure that it is well implemented.

McAllister, 2014
8. Team members anticipate, prepare and plan for all transitions (e.g. early intervention to school; hospital to home; pediatric to adult care)

9. The plan of care is systematized; as a common, shared document; it is used consistently, by every provider within an organization, and by all providers across organizations.

10. Care is subsequently well coordinated across all involved organizations/systems

McAllister, 2014
The Tools
Identify Population

- Youth with one complex chronic condition: Asthma, ADHD, Anxiety/Depression
- Children with complex medical needs
- Registry
# HOMES score

<table>
<thead>
<tr>
<th>Category</th>
<th>Criteria</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitalizations, ER visits, Subspecialty Visits (past yr)</td>
<td>1= 1 hospitalization, ED, specialist</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2= 2 or &gt;Hosp, ED, specialist</td>
<td></td>
</tr>
<tr>
<td>Office Visits, Phone calls, prolonged time for visits</td>
<td>1= 1-2 OV or MD/RN calls</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2= 3 or more OV or MD calls</td>
<td></td>
</tr>
<tr>
<td>Medical Condition(s) (One or more diagnoses)</td>
<td>1= 1-2 conditions (no complications)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2= 1 or 2 conditions with complications or 3 or more conditions</td>
<td></td>
</tr>
<tr>
<td>Extra Care and Services at MH, home, school, community setting</td>
<td>1= One service from list below</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2= Meds, technology, therapeutic assessments/treatments/procedures, care</td>
<td></td>
</tr>
<tr>
<td></td>
<td>coordination</td>
<td></td>
</tr>
<tr>
<td>Social Concerns</td>
<td>1= “At risk” family/school/community concerns</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2= Current/urgent complex social need</td>
<td></td>
</tr>
</tbody>
</table>
Reminders

**Medical Summary**

**Pebbles Flintstone 10 yrs, 1 mo 5/21/06**

**Recent and Upcoming Appointments**
- **Last Visit:** 07/17/16 (2d ago) Crusher
- **Diagnosis:** none
- **Last Physical:** 05/29/15 (1y 1m ago)
- **Next Physical Due:** 06/03/16 (6w 4d overdue)
- **Scheduled Appointments:** none

**Siblings**
- **Open Chart** Dino Flintstone 4 yrs, 3 mos 03/29/12 M

**Reminders** Modified 06/10/16
- Headed to regional soccer championships 10/11.
- Lost best friend to a neighborhood house fire in 12/10.

**Problem List** Modified 06/10/16

<table>
<thead>
<tr>
<th>Status</th>
<th>Problem</th>
<th>Problem Note</th>
<th>Onset</th>
<th>Resolved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resolved</td>
<td>Urinary Tract Infection (599.0)</td>
<td></td>
<td>03/12/10</td>
<td></td>
</tr>
<tr>
<td>Active</td>
<td>Obesity Exogenous (278.00)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active</td>
<td>Asthma Mild Persist (493.00)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Allergies** Modified 06/10/16

<table>
<thead>
<tr>
<th>Status</th>
<th>Allergy</th>
<th>Reaction</th>
<th>Onset</th>
<th>Resolved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active</td>
<td>Allergy Cat Hair (477.8)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**PCC eRx Allergies** Updated 07/19/16 10:11 AM

<table>
<thead>
<tr>
<th>Drug</th>
<th>Reaction</th>
<th>Onset</th>
</tr>
</thead>
</table>
Where to Start? Engaging Families:

During a Visit

- Doc, you may not want to come in on Tuesday…
- My son is being discharged tomorrow from Children’s after neurosurgery…

Previewing the Week Schedule

- Wow! This problem list is a mess!
- My child’s teacher says his behavior is out of control…

Phone Calls (discharges, family, community)

- I’m taking control of Asthma!
- I’m taking control of Behavioral Health!

Condition Specific

- This family hasn’t responded to calls from visiting nurses for the past month

Can Begin with:
Family, Patient, Community Partner, or Health Care Professional
Implementing the Shared Plan of Care: Pre-Visit Planning

• Before you enter the room…

• Already have recent, relevant information

• Screening tests (ACT, PHQ9)

• An agenda from the family for today’s visit

• Labs, radiology, specialist visit reports

• Follow up from community members (Vanderbilt’s, therapists, subspecialists)
# Work Flow for Care Planning

<table>
<thead>
<tr>
<th>Team Person/Roles</th>
<th>Pre-Visit Preparation</th>
<th>Visit → Caring Partnership interactions</th>
<th>After Visits → Accountable follow through</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care Coordinator</td>
<td>Gathers recent information (recent labs, subspecialist notes, community provider updates) Identifies goals</td>
<td>Updates Care Plan Family/Personal Goals Medical Goals</td>
<td>Negotiate Next Steps</td>
</tr>
<tr>
<td>Youth/Family</td>
<td>Bring Questions? Share ideas Referrals?</td>
<td>Participates in Goal Setting</td>
<td>Negotiate Next Steps</td>
</tr>
<tr>
<td>Pediatric Clinician</td>
<td>Reviews communications Asks about goals Follows up w/ referrals</td>
<td>Assesses Needs Updates Care Plan</td>
<td>Negotiates Next Steps</td>
</tr>
</tbody>
</table>

McAllister et al, 2014
Family Centered Assessment Tool

“No one has ever asked me these questions before…”

Parent

National Center for Medical Home Implementation:  http://www.pediatricmedhome.org/pdfs/3_Assessment_of_Care_Needs.pdf
Understanding Needs & Strengths

**Strengths**
- Concrete Support in Time of need
- Knowledge of Parenting and Child Development
- Parental Resilience
- Social and Emotional Competence
- Social Connections

**Needs**
- Worries or Developmental concerns? (Sleep, moving, language)
- Social changes? (Job, Divorce, Death, Move)
- Medical
- Educational
- Financial
- Legal

**Family**
- What would you like us to know about your child? (What does s/he do well? Like? Dislike?)
- What would you like us to know about you/your family? (Culture, values)
**Strengths Based**

![Medical Summary](image)

### Medical Summary

- **Name:** [Redacted]
- **Age:** 12 yrs, 4 mos
- **Mother:** [Redacted]
- **Father:** [Redacted]

#### Parent's Occupation
- **Modified:** 01/21/13
- **Description:** Parent resource coordinator for early intervention (EI) and works for WCAX.

#### Snap Shot (Strengths)
- **Modified:** 01/22/13
- **Description:** Hannah loves music, is supported by an engaged school team and loving family.

### Problem List

<table>
<thead>
<tr>
<th>Status</th>
<th>Problem</th>
<th>Problem Note</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active</td>
<td>Rett's syndrome (330.8)</td>
<td>Saw Rett Clinic at Boston 2/2013, study also</td>
</tr>
<tr>
<td>Active</td>
<td>Epilepsy (345.90)</td>
<td>As part of #1, Lennox Gastaut syndrome</td>
</tr>
<tr>
<td>Active</td>
<td>Developmental Delay (315.8)</td>
<td>As part of #1</td>
</tr>
<tr>
<td>Active</td>
<td>Autistic disorder</td>
<td></td>
</tr>
<tr>
<td>Active</td>
<td>Underweight</td>
<td></td>
</tr>
<tr>
<td>Active</td>
<td>BMI &lt;5th %ile (V85.51)</td>
<td></td>
</tr>
<tr>
<td>Active</td>
<td>Nutrition Failure-gtube (263.8)</td>
<td>Peptomen Jr. 1.5 via g-tube main nutrition source</td>
</tr>
<tr>
<td>Active</td>
<td>Dysphagia (787.20)</td>
<td>Swallow study no aspiration 12/2011</td>
</tr>
<tr>
<td>Active</td>
<td>Sleep Movement Disorder, unspecified (780.58)</td>
<td>Trazadone works well</td>
</tr>
<tr>
<td>Active</td>
<td>Ataxia (781.3)</td>
<td>As part of #1</td>
</tr>
</tbody>
</table>

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**Edit**

- [Add Phone Note]
- [Close]
- [Save]
- [Save + Exit]

**Logged In:** jim
<table>
<thead>
<tr>
<th>NO CARE COORDINATION</th>
<th>WITH CARE COORDINATION</th>
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<tbody>
<tr>
<td>• “Before, we were always treating symptoms...I always felt that I was leading the conversation, like: “Don’t you think we should consider doing___?” I guess I was kind of a problem parent for them.”</td>
<td>• “I don’t have to be advocating and pushing all the time. Every visit, even sick visits, at the end, we look at where we want to be and how we will take baby steps to get there, even when there are setbacks, and there are always setbacks, but I don’t get as discouraged, because we have a plan, we know where we are headed.”</td>
</tr>
</tbody>
</table>

Maier, Parent interview, March 6, 2014
# Contacts

## Demographics

**Home Address**  
Wilma Flintstone  
15 Quarry Lane  
Winooski, VT 05404

**Phone**  
Home Phone: 802-555-0194  
Work Phone: 802-555-0197  
Cell Phone: 802-555-0161  
Emg Phone: 802-555-0168

**E-mail:** stones@HannaBarbera.com  
**Account Flags:** CONFIDENTIAL

## Pebbles Flintstone

**Billing Address**  
Fred Flintstone  
1400 Rock Road  
Winooski, VT 05404

**Phone**  
Home Phone: 802-555-0105  
Work Phone: 802-555-0146  
Cell Phone: 802-555-0112  
Emg Phone:  
**E-mail:** stones@HannaBarbera.com  
**Account Flags:** Billing Problem  
**Relation to Bill Payor:** Child

## Personal Contacts

**Barney Flintstone (Uncle)**  
Phone: 802-564-2039

Note: Watches Pebbles after school.

**Betty Rubble (Registered Nurse, Other)**  
Organization: Bed Rock School  
Address: 1245 Bed Rock Ave  
Winooski, VT 05404

Note: School Nurse
Care Conferences

• Introductions, share contact information
• Set Agenda
• Set Roles: Provider and Family facilitate meeting
• Start with Strengths
• Discussion following the Agenda
• Minutes recorded (by Care Coordinator)
• Update Plan with “Next Steps, Accountability
• Next Care Conference Date (if needed)
• Care plan is shared at end of meeting
Coordinated Care??

• Mind the Gap
Shared Care Planning

<table>
<thead>
<tr>
<th>Patient/Family/Team Goals</th>
<th>Negotiated Actions</th>
<th>Process and Outcome measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less Self- Injury</td>
<td>Psychiatry Assessment Co-management In-home behavioralist</td>
<td>Keeping family together Less need for police and Crisis support</td>
</tr>
<tr>
<td>Improve school attendance Improve education supports</td>
<td>Same behavior plan across settings Explore alternative school placement</td>
<td>Clear communication btwn home/school/providers Alternative program found</td>
</tr>
<tr>
<td>Repetitive behaviors</td>
<td>Improved psychopharm Improved wrap around services Improved behavior plans</td>
<td>Innovation: across silos of mental health, developmental disabilities, CSHN and school</td>
</tr>
</tbody>
</table>
Care Story 2

- Mary is a 4 year old with tuberous sclerosis whose self-injurious behaviors, tantrums, sleep dysfunction—heading towards inpatient psychiatry hospitalization

- Despite having a VT developmental services waiver, respite care and a team of multidisciplinary medical experts at Mass General

- Intractable seizures seemed the least of her concerns in comparison to behaviors

- Strengths: strong parent involvement and expertise, loving respite family, Mary engaging, verbal with cognitive strength (can anticipate seizures)
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<th>Process and Outcome measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less need for “crisis” intervention</td>
<td>Co-management from psychiatry, medical home and subspecialists</td>
<td>Less need for police, mental health crisis support</td>
</tr>
<tr>
<td>In-home behavioralist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improve Sleep</td>
<td>Same behavior plan across settings</td>
<td>Less communication errors about medications</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Improved work attendance</td>
</tr>
<tr>
<td>Increase Home Safety-of Mary and family</td>
<td>Improved psychopharm CSHN SW: Waiver allowed for enhanced access to in-home behavioralist</td>
<td>Innovation: region contracted with vendor outside of network</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less Crisis Need</td>
</tr>
<tr>
<td>Mary to attend school</td>
<td>Communication opened between school, behavioral plans, family, medical home</td>
<td>Making academic gains</td>
</tr>
<tr>
<td>Improve social relationships</td>
<td></td>
<td>Attendance improved</td>
</tr>
<tr>
<td></td>
<td>Cannot pick her out from peers</td>
<td></td>
</tr>
</tbody>
</table>
PARENTS’ VOICES

NO CARE COORDINATION

- I would be on hold for an hour, and then they would tell me to go to the hospital. We were going to the ER pretty much every other week.

- Don’t get me wrong, I love Dr_, but it was the structure, the organization, that was the problem.

Maier, Parent interview, March 6, 2014

WITH CARE COORDINATION

- Now, someone immediately picks up. They are always calm and responsive and find the right person to talk to me. Now, there is always a plan. I know what steps to take, and when to call back.

- Now, (the doctor) is able to network better and is proactive. There is more of a holistic view, why are the symptoms happening, what to do to figure out the bigger picture…we have only been to the ER once in the last six months”
Medical Summary

Recent and Upcoming Appointments
- Last Visit: 06/10/14 (2d ago) Rinehart
- Diagnoses: Rett's disorder, Failure to gain weight, Sleep disorder, Epilepsy, Gastroesophageal reflux disease
- Last Physical: 02/28/14 (3m 1w ago)
- Next Physical Due: 03/06/15
- Scheduled Appointments: 09/30/14 12:00pm Care Conf Rinehart Office

Siblings
- Open Chart [redacted] 9 yrs, 7 mos [redacted] F
- Open Chart [redacted] 42 yrs, 2 mos [redacted] F
- Open Chart [redacted] 47 yrs, 7 mos [redacted] M

Reminders
- Modified 06/10/14
  **Keppra—not tolerated**
- Current Medications: 6/2014
  - Lansoprazole 15 mg BID
  - Depakote 350 mg BID
  - Rufinamide 400 mg BID
  - Trazodone 75 mg at hs (1.5 tablets)
  - Vitamin D 400 IU/day
  - Probiotic and Fiber

Rett Surveillance:
- Needs EKG each year to rule our prolonged QT
- Last done fall 2012
- Spine films annually/regularly for scoliosis last done spring 2012
- Gallstones/GI surveillance
- Osteopenia lab/s vitamin D level

Teams:
- Joanne Wexler-PCA care manager
- Amy Saunders-CSHN social worker

Logged In: Jim
Important Synopsis

Medical Summary

Medical History  Modified 06/10/14

Presented as an 18 month old with developmental regression, trichotillomania and an abnormal EEG upon neurology consult. By age 2 it was clear she had lost language, though she has preserved ambulation and genetic confirmation of MECF2 gene through Dr. Burke secured diagnosis of Rett syndrome (with milder end phenotype).

Neurology: Dr. Bingham involved in original diagnosis. Concerns for seizures at time, also has breath holding behaviors. Epilepsy first diagnosed 12/2012-negative reaction to Keppra, Lamictal started in January 2013 now at 10 mg BID. Glutamine.

2014—ongoing management issues, having 6-7 sz a day, considering Charlotte's Web (marijuana) treatment in Colorado...

Dr. Greg Holmes and Dr. Bingham and epileptologist Dr. Scott all consulting re: Hannah
5/2014 to Boston Rett center neurologist/kaufman referral to epileptologist there
Ambulation: SMO's with Deb Wilde. Sees Dr. Benjamin for spasticity/scoliosis monitoring--no interventions at this time.

Endocrine: Dr. Kacer saw in February, 2012 for puberty questions, had an episode of hypoglycemia.

Bone Health: DEXA scan 2009 (part of study), on vitamin D and Calcium supplements.

GI: Dr. D'Amico placed PEG, ongoing Nutrition concerns, constipation/diarrhea/lactose intolerance. Benefiber and Prevacid help with distress, along with Cultorel.

January 2013: Normal endoscopy and colonoscopy, but concern for "bacterial overgrowth" treated with cipro and Aminia. Developed bloody stools, so this was stopped before end of treatment. Endoscopy and colonoscopy January 2013—normal biopsies. LACTOSE INTOLERANT

Supplements: Bifido bacterium, Vitamin D, Benefiber.

Nutrition: Saw FAHC Nutrition, now CSHN RD following for G-tube handling most of her nutrition, oral feedings are for pleasure. Peptamin JR 1.5 now blended diet Casey Chumura following

Sleep disturbance: On Trazodone 75 mg at hs. Consistently works to sustain sleep in a child whom sleep was previously extremely disrupted.

Dysphagia: Swallow study shows no aspiration 12/2011. Dysphagia of thick things, saliva, etc.

Vision: Dr. Hastings sees annually. Developed astigmatism where glasses may be useful. Last visit 3/2011

Specialty Center:
Rett clinic at Boston Children's Dr. Kaufman is neurologist
Hannah Kennedy Prier Institute, was enrolled in a study of Pentosanpolysaccharide use for girls with Rett but fell out of this in 2013/2014.
Negotiated Next Steps

Goals
- Improving care team communication around seizure management
- Making the Transition to Middle School easier
- Continuity of care providers when possible
- Bolstering primary medical home in caring for needs
- Improve communication: would like to use TOBI as soon as possible—be set to use it for school next year
- Having Friends who know her already continue to develop relationships
- Maximize weight gain potential
- Manage respite/PCA money well.

Actions

Next Steps

- Get records to Boston, including Shelly requesting video EEG
- Recommended going back to an epileptologist: Kristy to call Dr. Kaufman August-Shelly has a date for nutrition
- In the summer time will have time with the para to get used to H/I and for H/I to get used to school
- Hiring a second para (back up)
- Stephanie as para hired to be IA will support the new hire
- School has a specialist augmentative MEG Delorme to approve the TOBI and help with its use
- Consistency of nursing care at school—emergency plans—nasal midazolam—to provide
- Kasey—to increase her calories and meeting with family to increase calories/protein powder; family ready to move forward with right feeds and maximize calories in
- Neurology about meds—recent notes to be provided and Dr. R to send information

Sue smart howard-connect when needed pumps—co-visit with nutritionist
- Palliative care art therapy—art therapy with pediatric care
- Hadley/Sue Kasey to I/U on this music therapy could she use respite funds to cover this? (sholanda—>is therapist)

Care Coordination Notes (internal use)

Team Members
- Tracey Rubman (Case Management)
- Organization: Flynn Elem School: special educator
- Phone: 316-6309
- Email: trubman@bdvt.org
### Care Plan

#### Medical Summary

<table>
<thead>
<tr>
<th>Drug</th>
<th>Reaction</th>
<th>Onset</th>
</tr>
</thead>
<tbody>
<tr>
<td>amoxicillin</td>
<td>mouth swelling</td>
<td></td>
</tr>
</tbody>
</table>

#### Medication History

<table>
<thead>
<tr>
<th>Active</th>
<th>Drug</th>
<th>Formula</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adderall XR (dextroamphetamine-amphetamine)</td>
<td>capsule, extended release 24hr 20 mg</td>
<td>Take 1 capsule by mouth twice a day. Dsp. 60 capsule by Mark Williams, M.D.</td>
</tr>
<tr>
<td></td>
<td>cefadroxil (cefadroxil)</td>
<td>suspension for reconstitution 500 mg/5 ml</td>
<td>Take 0.5 teaspoon dissolved in water twice a day. Dsp. 50 ml (last 06/19/16 stop 06/29/16) by Mark Williams, M.D.</td>
</tr>
</tbody>
</table>

#### Care Plan

**07/19/16**

**Goals**
- Control Asthma
- Start soccer with asthma controlled

**Actions**

**Next Steps**

Pebbles will start taking a new medication for her asthma and will also have her inhaler for physical activity. We will follow up with the school nurse and her PE teacher and coach to assess Pebble’s progress on the new medication. We will schedule follow up appointments with Pebbles every three months to check vital signs and check-in on her medication use and overall health.

**Care Coordination Notes (internal use)**

**Team Members**

Created by Elizabeth Casey, M.D. 07/19/16 10:09am
All Practice Data

<table>
<thead>
<tr>
<th>Enrolled: 138</th>
<th>Baseline</th>
<th>6 month follow</th>
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</thead>
<tbody>
<tr>
<td>At least one care conference</td>
<td>20</td>
<td>35</td>
</tr>
<tr>
<td>Working with CSHN SW</td>
<td>56</td>
<td>65</td>
</tr>
<tr>
<td>Shared Plan of Care</td>
<td>25</td>
<td>66</td>
</tr>
</tbody>
</table>
How often did the practice help the family get needed family services?

Baseline

- Never
- Sometimes
- Usually
- Always
How often did the practice help the family get needed family services?

Sales

- Never
- Sometimes
- Usually
- Always
Complex Care Coordination
Codes

- 99487-9—Clinical Staff Reimbursement Codes, non-face-to-face
- 99488 includes one office visit plus one hour of care coordination services.
- 99487 involves one hour care coordination
- 99489 for each additional 30 minutes for care coordination
- 99215 highly complex office visit-care conferences
- Prolonged Visit
Future?

- Access to the shared care plan from community, families, medical home and subspecialists
- Adequate investment in this primary care system to support care coordination
- 16 states involved in Shared Plans of Care and outcomes measurement
- Care coordination is practice transformation for health care reform
- “App Orchard”
Thank you to our family partners

Crystal Abair
Carolyn Brennan
Tammy Carrol
Victoria Garrison
Liz Metevier LeFebvre
Peggy Mann Rinehart
Theresa Soares
Kate & Michael Stein
Shelly Waterman
Antonelli, Browning, Hackett, McAllister & Risko (2014). *Pediatric Care Coordination*, Boston children’s Hospital.


McAllister, Jeanne, *Achieving a Shared Plan of Care for Children and Youth with Special Health Care Needs*, with support from Lucille Packard Foundation for Children’s Health, 2014

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Rinehart (2014). *Pediatric Care Coordination Grand Rounds*, Burlington, VT.

Rinehart, Sheehey (2014) “*Pediatric Care Coordination Learning Collaborative” Presentation*
Questions?