

Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs

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This work was supported by a grant from the Lucile Packard Foundation for Children's Health –Children with Special Health Care Needs



Why Shared Care-Planning?

- Care is fragmented across multiple providers and systems
- Coordination of care is lacking
- Information sharing across providers often falls to the family
- Families are asking for:
 - Help in resource and system navigation
 - Team-based care, with access to a clear contact person
 - Goals and strategies consistently used across providers
- Clinicians/teams seek a better approach including:
 - Partnership relationships with patients/families
 - Succinct, at-a-glance Medical Summaries
 - Clarity of next-steps, responsibilities and accountabilities

The Purpose of Shared Care-Planning

- 1. Improve care and reduce fragmentation for children/families and subsequently for an identified population
- 2. Guide a family-centered, multi-disciplinary team process in the joint development and use of a plan of care
- 3. Enable the child/family and their "care neighborhood" to communicate, collaborate, and operate from the "same page" or from a shared plan of care over time.
- 4. Deliver oversight using developed timelines and by ensuring responsibility and accountability for results

The Development Team

Our development team includes the following members responsible for this work to improve care and health for children with special health care needs.

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- Jill Rinehart, MD, Pediatrician, Hagan, Rinehart and Connolly, PLLC, VT
- Susan Smiga, MD, Child Psychiatrist, Geisel School of Medicine at Dartmouth

Children Youth and Families at the Center of Our Work

The Advisory Group

Organizational leaders who served as advisors and/or volunteered to support the spread of the shared plan of care:

- Beverly Baker, National Family Voices
- W. Carl Cooley, MD, Co-Chair, AAP Medical Home Advisory Group
- Denise D Dougherty, PhD, AHRQ
- Michelle Esquivel, MPH, AAP, Division for Children with Special Needs
- William Kassler, MD, PhD, Medical Director, CMS NE Regional Office
- Dennis Kuo, MD, AAP/ Council on Children with Disabilities
- Linda Lindeke, PhD, APRN, NAPNAP
- Doris Lotz, MD, NH Medicaid Medical Director
- Marie Mann, MD, Project Officer, USMCHB
- Andrew Racine, MD, AAP, Council on Children's Health and Finance
- Lee Saunders, MD, Stanford University, Information Technology
- Julie Schilz, BSN, MBA, Wellpoint
- Sarah Hudson Scholle, DrPH, Vice President, NCQA
- Geoffrey R.Simon, MD, AAP Committee Practice Amb. Med (COPAM)

Opportunities and Gaps Care Coordination & Plans of Care

Within the medical home, a practice care coordinator will ideally participate in developing a plan of care with the family and physician, and also help the family access needed services.

Lipkin, PH. Care coordination in the medical home: integrating health and related systems of care for children with special health care needs. Pediatrics. Nov 2005;116(5):1238-1244

Opportunities Care Coordination & Plans of Care

Current Context

- Health Care Reform/Affordable Care Act/Patient & Family Centered Medical Home/Health Homes – Recognition Criteria
- Meaningful Use –Under the Affordable Care Act, as a standard of meaningful use certification the mandate is " to incorporate the components of care planning into a "Continuity of Care Document (CCD) for service
- Policy and Improvement Organizations recommend including the Commonwealth Fund, AHRQ Care Coordination Atlas, Family Voices, National Quality Forum, & the Institute for Health Care Improvement

Care Coordination & Plans of Care



Coordination of care, a shared plan of care, are amazingly effective Clinician

The care coordination support is so helpful; care coordination is all I would do. Our family has benefited, I can be a parent now.

Parent

What is Pediatric Care Coordination?

- A patient and family-centered, assessment driven, continuous team-based activity designed to meet the *bio-psychosocial* needs of children and youth while enhancing person and family care giving skills and capabilities.
 - Care coordination addresses interrelated medical, social, developmental, psychological, behavioral, educational, environmental and financial needs in order to achieve optimal health and wellness outcomes.*

(*Definition adapted and expanded from: Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework, Antonelli, McAllister & Popp).

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 and access to their plan.
 - 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** highlights personal and clinical goals and joint strategies to address and /or achieve goals with timelines, responsibilities and accountabilities.



Medical Home and Care Plans – they go together, you can't have one without the other! -Family

Care plans are the solution! (But what is at the root of the need, or question?)



Achieving a Shared Plan of Care

Shared Care-Planning using a shared plan of care is a family and professional approach which blends and addresses multiple perspectives.

Achieving a Shared Plan of Care

A Shared Plan of Care "Brief" and "Implementation Guide" help the team (child/family, clinicians, coordinators and others) to achieve a shared plan of care.

The following materials and guidance are included:

- 1. A Shared Plan of Care Model
- 2. Preparation and Planning Activities
- 3. Underlying Principles
- 4. A Ten Step Approach
- 5. Tools, Tips, References and Links
- 6. Measurement Recommendations
- 7. Care Stories

1.Identify Needs & Strengths of the Patient and Family:

- Hold family-centered discussions
- Complete multi-faceted assessments

4. Implement the Plan of Care:

- Perform actions
- Oversee, track & monitor
- Evaluate progress, update and renew

2. Build Essential Partnerships:

- Set personal & clinical goals
- Share decision making
- Link to specialists and community service providers





3. Create the Plan of Care:

- Develop the medical summary
- Establish "negotiated actions"
- Add emergency & legal attachments

A Model for Shared Care-Planning: Achieved in Partnership with Families

Ten 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 with and 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.
- 5. Family-centered care teams can access the information they need to make shared, informed decisions.

Ten Principles for Successful Use of a Shared Plan of Care

- 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 effectively implemented.
- 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 acknowledged providers across organizations. ∞ ∞ ∞ ∞ ∞
- 10. Care is subsequently well coordinated across all involved organizations/systems.



Introducing a Shared Care-Planning Process into Busy Practice Environments

Prepare, Plan, Implement (Test); Adapt, Adopt or Reinvent?

- 1) Review the "Report & "Implementation Guide"
- "Achieving a Shared Plan of Care for CSHCN" www.lpfch-cshcn.org
- 2) Complete and review the "Shared Care-Planning Principles: Agreement Worksheet"
- 3) Assess team capacity with the "Shared Care Plan Index"
- 4) Work through the "10 Steps"

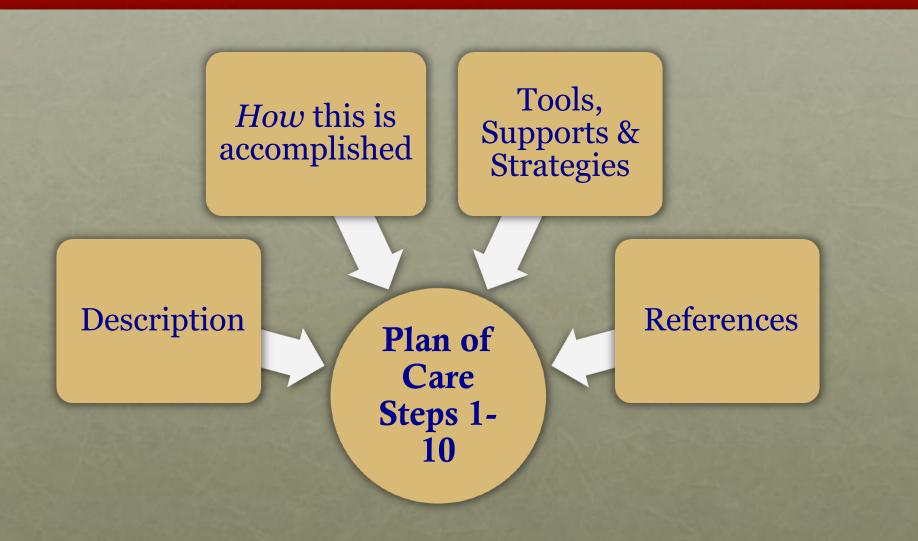
10 Step Approach to a Shared Plan of Care

- 1. Identify who will benefit from a plan of care
- 2. Discuss with families and colleagues the value of developing and using a comprehensive and integrated plan of care.
- 3. Select, use and review a multi-faceted assessments with a child, youth and family
- 4. Set shared personal and clinical goals
- 5. Identify other needed partners (e.g. subspecialists, and community providers) and link them into the shared care-planning process

10 Step Approach to a Shared Plan of Care

- 6. Develop the plan of care "Medical Summary
- 7. Establish the plan of care "Negotiated Actions"
- 8. Ensure that the plan of care is available, accessible, and retrievable (for all permissible partners)
- 9. Provide tracking, monitoring and oversight for the plan of care
- 10. Systematically use the shared care-planning model process those patients and families identified in Step 1

Shared Plan of Care – Implementation Guide



We saved that family unnecessary visits and tests by righting the ship a bit. Clinician



I love what I do...
It makes my life rich, working with these kids

Care Coordinator and PCP

Shared Plan of Care – Anticipated Outcomes* Recommended Child, Family & Team Indicators

Clinical

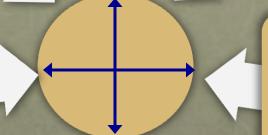
- Safety; safe regimen
- Optimal management/adherence
- Progress against goals

Functional

- School days, work days, recreation
- · Quality of life
- Progress against goals

Cost

- **V**Redundancy/waste
- Primary to specialty ratio
- ED visits
- Hospitalizations



Experience of Care

- Engaged patients/families
- Confidence in self-care
- Reduced burden
- Team/role satisfaction

^{*} Framed using the clinical values compass; Batalden, P. and Nelson, E.

Opportunities and Gaps Care Coordination & Plans of Care

To address existing system research gaps, future efforts can build from concepts defined by the National Quality Forum (NQF) to:

- 1. More specifically define and measure how care coordination should be conceptualized and implemented
- 2. Address issues with measurement of care coordination (e.g., patient perceptions of continuity, team/cross care boundary continuity);
- 3. Measure the effectiveness of care coordination for various populations.

PCORI Research Prioritization Topic Briefs: "Care Coordination for Special Needs Patients" and "Care Coordination in Primary Care" January 2014

Achieving a Shared Plan of Care with Children with Special Health Care Needs Key Resources: Report & Implementation Guide www.lpfch-cshcn



The Why, How and What of a Shared Plan of Care

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