



Report

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

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Acknowledgments

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Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs is a product of the teamwork among the devoted individuals listed below. Many ideas, strategies and suggestions in this companion Implementation Guide originated with this team. Their commitment to improving care, and doing so in partnership with their health care improvement counterparts is a positive example of collaboration for innovation.

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Introduction and Principles

This Implementation Guide accompanies the Lucile Packard Foundation for Children's Health report *Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs*.¹ The report describes the content of a shared plan of care and a family-centered process for its development and implementation. The Guide is organized into 10 recommended stepwise activities supplemented with various tools and templates that can assist practices wishing to engage in care-planning with their patients.

Shared care-planning is a central component of coordination of care, an ideal quality within a pediatric medical home environment. Both for care within the medical home and in the context of health care reform, the effective use of care plans for patients living with chronic health conditions is an expectation.²⁻¹⁰ The purpose of this guide is to enable clinicians and health care teams or network members to partner with families and to jointly adopt and use plans of care to improve the experience and outcomes of care. The “shared plan of care” is a concise yet comprehensive, integrated, and user-friendly compilation of child and family specific information. It guides care and facilitates its coordination among the family and their lead clinical team in concert with the appropriate “constellation” of subspecialists and community resource providers.

While any child may benefit from a basic care plan, children and youth with special health care needs should have a continuously evolving plan of care, which is updated and redesigned according to their developmental trajectory and each of life's transitions.

Patient and family involvement is essential to creating a plan of care. Care plans are to be created and carried out *with* children and families, rather than *for* them. Shared care-planning is consistent with the fundamentals of family-centered care, which have been linked to better outcomes.¹¹ The development and use of shared plans of care is a team-based care coordination function. A coordinator can facilitate communication and help to coalesce team efforts; a coordinator can also ensure ongoing use, monitoring and oversight of the plan of care with the family. Financial models will be a necessary component in order to undergird and sustain practice teams to deliver continuous shared care-planning efforts.

Health care policies are raising the bar of expectation that children and families will have accessible plans of care. For example, when a Medicare patient is being transitioned from hospital to home, or between different providers regardless of settings, a plan of care is necessary. The Center for Medicaid and Medicare calls for a “visit summary of care record.” New, under the Affordable Care Act, and as a standard of meaningful use certification, is the mandate to incorporate the components of care-planning into a “Continuity of Care Document”; this standard applies to both ambulatory and inpatient care. As described in this Guide, a high quality “care record” should take the form of a shared plan of care, developed in partnership with patients and families and with joint implementation and accountability.

Objectives

As a result of learning and applying the *Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs* steps, any practice team together with their family partners will be able to:

- Engage in discussion, assessment, priority setting and declaration of shared goals
- Build trusting relationships with effective communication and collaboration
- Develop and use a shared plan of care
- Enhance the child and family experience of a culturally effective care partnership
- Improve child health and family outcomes
- Enhance the clinical team's experience of providing care

Underlying Principles

The context in which a plan of care is created and used will greatly affect whether those using the plan will succeed in their efforts. Shared care-planning builds upon a set of ten principles (Table 1).

Table 1: Ten Underlying Principles for a Shared Plan of Care

A successful shared plan of care occurs 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.
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 ongoing 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 involved providers across organizations.
10. Care is subsequently well coordinated across all involved organizations/systems.

Those using this Guide should be in agreement about:

- Why having a plan of care is important to the patient, family and clinical team
- How creating and using the plan is to be accomplished
- What comprises the minimal, necessary dimensions and components of the plan of care

Shared Care-Planning Model: Four Key Elements

Shared care-planning, as described in this guide, is based on a four-component process model (Fig. 1). It is important to ensure that all staff members are on board, and that all understand the model selected, including their role in promoting and using a shared plan of care approach with families. Table 2 provides a description of the process' model and its four key elements.

Figure 1: Shared Care-Planning Model Created in Partnership with Families

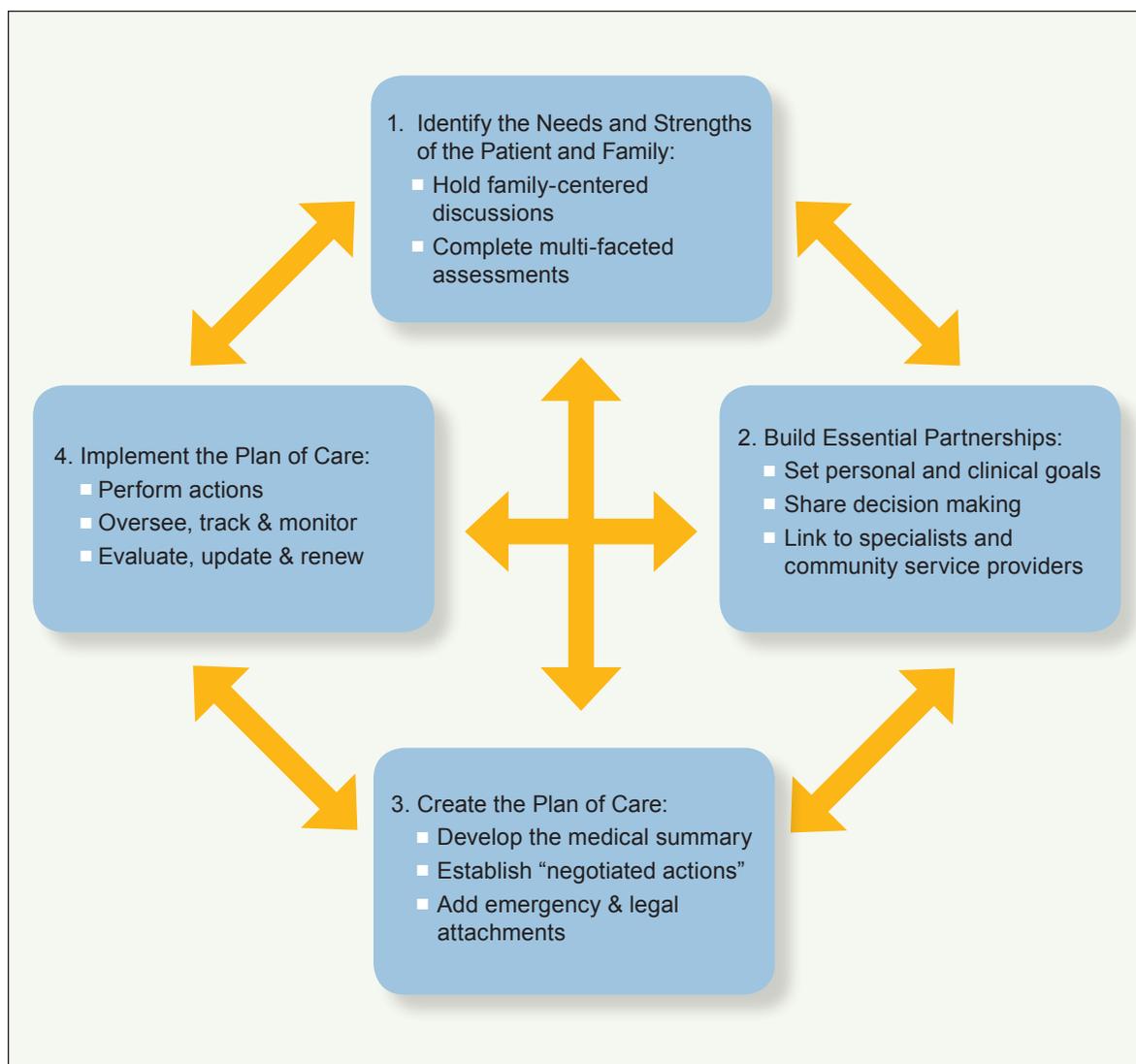


Table 2: Shared Care-Planning Model Descriptions

- **Identify the Needs and Strengths of the Patient and Family** The success of any care intervention ultimately depends upon actions taken by the patient and family, and so a plan of care must consider the family's circumstances and capacities. Health care providers, in particular, have a uniquely privileged opportunity to know and understand the family by virtue of forming a respectful and mutually trusting relationship. As a consequence, the health care team, in partnership with the family, is able to perform a comprehensive assessment of strengths, needs and gaps, and address interrelated medical, social, developmental, psychological, behavioral, educational, environmental and financial concerns.
- **Build Essential Partnerships** Effective partnerships rest on mutual interdependence in the pursuit of articulated, shared goals and outcomes. Agreeing on those goals and their underlying values allows the patient, family and providers to jointly guide care, and creates the opportunity to measure progress. Treatment and other intervention decisions thus can be made in partnership, drawing from patient and family preferences and best available evidence. Since care plans for children frequently require the services of additional community service providers, these partners need to be identified, brought into the care-planning process, and encouraged to access and use the plan of care.
- **Create the Plan of Care** Assuring high quality coordination of a child's future care requires that a care plan be in place — it cannot be otherwise. Access to a concise summary of health care events, current needed treatments, ongoing issues, and stated goals are essential. Having a plan of care is particularly beneficial for those newly involved and therefore unfamiliar with the child, family and their circumstances. Determining, agreeing on, and accepting individual responsibility for strategies necessary to meet goals are challenging but necessary tasks. For children who have conditions that are likely to worsen abruptly and require urgent care, a set of specific emergency actions should be attached to their plan of care. Other attachments may include rare condition fact sheets and legal documents outlining guardianship and decision-making privileges.
- **Implement the Plan of Care** A plan of care is only valuable as a living, changing document owned and implemented by all involved in the daily life of the child. For the medical home, the planning process needs to be incorporated as a routine part of the care of children with chronic or complex problems. At each visit progress toward clinical and personal goals (child/family) should be assessed. In the aggregate and over time, the success of a practice in documenting and achieving goals outlined in each plan of care can be used to gauge the quality of care being provided to the population of children with special health care needs.

Preparation and Planning

Before developing a plan of care with individual children and families, certain practice level “pre-work” activities are recommended, including contemplation, preparation and pre-planning. Many practices or clinics already have processes in place to work on aspects of redesigning how they serve particular populations of children and families. Implementing shared care-planning will be the work of such improvement efforts. Your practice organization and/or team should review the opportunities for improvement related to shared care-planning, agree upon the underlying principles, and determine the roles and next steps of your approach. To begin, your practice will want to:

- Review together the report titled, *Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs*. This will help by providing a common, starting point (http://www.lpfch.org/sites/default/files/field/publications/achieving_a_shared_plan_of_care_white_paper_only.pdf).
- Ask family partners why having a clearly written and shared plan of care is important to parents.
- Inquire of each clinician and staff what they hope such a tool and process will achieve for the practice.
- Complete and review the **Ten Underlying Principles for a Shared Plan of Care — Practice Assessment** and the **Ten Steps to the Shared Plan of Care: Index** (described below and found in appendices A and B); discuss how each practice task, function or care process works now, and how it could be better.
- Finally, review the Plan of Care **Practice Workflow Example** (Appendix C). This tool illustrates family, provider, and care coordinator roles prior to, during, and in between visits.

The shared plan of care process is intended to meet the goals and expectations of families and their clinical teams; key specialists and essential community partners should also be identified and included in the plan of care strategies and communications.

A Ten Step Approach to a Shared Plan of Care

The shared development, use, monitoring and revision of an effective plan of care are outlined using the ten steps below. Each step is accompanied by a description of the activity, how to achieve it, what tools support it, and the literature to back it up.

“**Ten Steps to the Shared Plan of Care: Index**” queries current practice capabilities; this is best used as an overall pre-assessment. Individual actions from this Index are also included with their respective Shared Care-Planning “steps” described in the subsequent pages of this Guide. Following implementation of shared care-planning, or about every six to twelve months, the team can repeat their Index assessment to review progress.

Additional tools help strengthen and reinforce aspects of shared care-planning and are referenced and included in the appendices throughout the Implementation Guide. Process and outcome measurements are also included. Improvement tracking metrics are aligned with recommendations in the literature for performance measurement.

Ten Steps to the Shared Plan of Care: Index

1. Identify which patients and families 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 multi-faceted assessments with a child, youth and family.
4. Set shared personal (child and family) and clinical goals.
5. Identify other needed partners (e.g. subspecialists, and community providers) and link them into the shared care-planning process.
6. Develop the plan of care “Medical Summary” and merge with “Negotiated Actions” in step 7.
7. Establish the plan of care “Negotiated Actions” and merge with the “Medical Summary” in step 6.
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 plan of care model process as a life course and a population health approach.

Step 1. Identify who will benefit from a plan of care

Description

The team needs to determine together the population for whom they will be using a shared plan of care process. While any child, youth or young adult may benefit from having a plan, literature about improving care for Children and Youth with Special Health Care Needs (CYSHCN) strongly emphasizes the special importance of achieving a shared, accessible plan of care.^{2, 7}

Approaches

One way to begin is to target children and families who:

- Pose a particular worry or concern to the provider
- Indicate that they need more help or support
- Have considerable unmet basic needs or environmental risks
- Have trouble making, keeping, or getting to appointments
- Struggle to follow through with agreed upon actions or plans
- Score highly on any measure of complexity of care needs, such as that outlined within the Exeter Pediatric Associates Complexity Index (Appendix D).

Another approach is to use a tool such as the CYSHCN screener, developed by the Child and Adolescent Health Measurement Initiative.¹² It is validated and can aid in the verification of children identified with special health care needs.

Whatever approach you use, apply your selected criteria and identify specific children and families with whom to share care-planning. Some teams may argue for beginning with children of highest intensity and concern, still others may suggest that this approach is too difficult before learning routinized methods; this is an individual practice decision.

Tools

1. The Exeter Pediatrics Associates Complexity Index [HOMES Index] (Appendix D)*

Literature

1. CSHCN Screener, Bethell, C., et al. Child Resource Institute for Child and Adolescent Health CAHMI — Child and Adolescent Health Measurement Initiative, 2007; www.childhealthdata.org; <http://cahmi.org>.

Ten Steps to the Shared Plan of Care: Index — Question 1

Identify who will benefit from a plan of care.

Our team needs to (*circle one*):

1. Learn more about this 2. Try this 3. Master this 4. No improvement is needed

* The provided Appendices offer tools specific to each step of this implementation guide.

** Following the descriptions of each of the ten steps is an assessment question that should be answered by those participating in developing a shared care-planning process.

In the appendices is the “Ten Steps to Shared Care-Planning: Index” which includes the assessment questions from all ten steps. Reviewing this Index can give your group a good picture about their processes, gaps and future learning needs.

Step 2. Discuss with families and colleagues the value of developing and using a comprehensive and integrated plan of care

Description

Successful plans of care are built upon shared values, goals and clear actions with accountabilities. The purpose of Step 2 is to ensure that families are engaged as equal partners in this shared care-planning process, and as such are encouraged to speak out about all goals, strategies and plans.

Approaches

- Share with each family your vision and approach for using a plan of care, including how it is meant to support critical communication and collaboration to improve their child's health care. This also may be done with a group of families.
- Discuss how a plan of care not only summarizes current and historical medical information but also documents goals, strategies and progress over time, including who is responsible for each task or agreed to intervention.
- Describe how the plan of care clarifies roles and names responsibilities for each team member: families, youth, clinicians, coordinators of care; review how each will be accountable and /or supported in their roles.
- Express to families how important their participation is, while allowing for their varying levels of ability to be engaged. Seek to know whether they understand and agree with this approach.
 - With family permission loop them into the planning process using agreed upon communication strategies (access to the shared plan of care, regular communication via email, phone, messaging, etc.).
- Families may appreciate hearing how other parents have found a shared plan of care beneficial.
- Identify others who are important to child and family success (e.g. subspecialists, community resource partners, and school personnel).

Tools

1. There is a slide set available to help you with these teaching and learning activities. Access at http://www.lpfch.org/sites/default/files/field/publications/achieving_a_shared_plan_of_care_slides.pdf

Literature

1. McAllister, J.W., et al., *Medical home transformation in pediatric primary care — what drives change?* Annals of Family Medicine, 2013. 11 Suppl 1: p. S90-8.
2. Institute for Family-Centered Care, *Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System: Recommendations and Promising Practices*, (2008). Available at: <http://www.familycenteredcare.org/tools/downloads.html>.

Ten Steps to the Shared Plan of Care: Index — Question 2

Discuss with families and colleagues the value of developing and using a comprehensive and integrated plan of care.

Our team needs to (*circle one*):

1. Learn more about this 2. Try this 3. Master this 4. No improvement is needed

Step 3. Select, use and review multi-faceted assessments with the child, youth and family

Description

Effective Shared Care-Planning requires extensive knowledge about the patient and family, knowledge that encompasses interrelated medical, social, developmental, behavioral, educational, environmental, and financial needs in order to achieve optimal health and wellness outcomes. Gaps between desired conditions and current circumstances are considered, and strengths regarding positive resources and individual abilities are recognized. Family-centered, team-based assessment activities seek to gain an understanding of what is important to the child/youth and family. The quality of the assessment of patient and family needs will in large part drive the content and quality of the shared care plan.

Approaches

The team should decide what elements their comprehensive assessments should include. Ideally, assessment data will be obtained from various sources and integrated into a comprehensive database or child/family summary.

Basic history and physical needs are reviewed at periodic preventive care or chronic care visits. Opportunities are also found for additional bio-psychosocial and environmental assessments (e.g. during visit follow-up contacts or care coordination visits).

There are many approaches to assessment:

- A preventive care visit involves eliciting child and family concerns, timely surveillance and screening, assessment of strengths, and a discussion of family priorities for health and function over time. As a starting point the “Bright Futures” manual offers sample questions and anticipatory guidance for all age visits. These questions are typically asked to address specific-age related concerns. Other disciplines, such as pediatric psychology for example, may augment these with family functioning, coping or depression screening.^{13, 14}
- Pre-visit assessments have been shown to increase the effectiveness and efficiency of visits. The pre-visit assessments (Appendix E Pediatric Care Coordination Assessment) is typically initiated by a care coordinator or staff member using phone, email, or website formats. A pre-visit assessment asks about recent medical events (subspecialist appointments, emergency room visits, hospitalizations, tests performed); inquires about family needs, worries or questions; and identifies topics for discussion at the upcoming visit. Results are documented and can be shared with the team in a pre-visit huddle. Gaps in records or test results are resolved ahead of time.
 - Benefits resulting from these assessments include a visit with adequate time allocated, records and information updated, and concerns prioritized. Teams using this approach report better, more informed visits, less confusion, fewer missed appointments and reduced system waste or failures of care coordination.
 - The purpose of the pre-visit assessment is to better understand family concerns and priorities and encourage proactive participation in the visit and in care overall.

Tools

1. Pediatric Care Coordination “Assessment” (Appendix E)
2. Pre-visit Assessment adapted from an original form developed by Dr. Jennifer Lail.
(<http://www.medicalhomeinfo.org/downloads/pdfs/CMESeries2-PrevisitContactForm.pdf>)

Literature

1. Hagan, J., Shaw, J., and Duncan, P., *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents*, Elk Grove Village. Third Edition ed. 2008, Elk Grove Village, Illinois: American Academy of Pediatrics
2. McAllister, J.W., Presler, E., and Cooley, W.C., *Practice Based Care Coordination: A Medical Home Essential*. *Pediatrics*, 2007. 120(3): p. e723-733.

Ten Steps to the Shared Plan of Care: Index — Question 3

Select, use and review multi-faceted assessments, with the child, youth and family.

Our team needs to (*circle one*):

1. Learn more about this
2. Try this
3. Master this
4. No improvement is needed

Step 4. Set shared personal (child and family) and clinical goals

Description

Having a goal implies that there is an aim, a result, a target, or a finish line in mind. Shared goal-setting frames a plan of care that encompasses multiple perspectives. Part of planning will be to set goals that address gaps and use strengths. Children/families may have personal goals that will impact clinical goals. Giving precedence to families’ goals is consistent with a family-centered framework in which it is acknowledged that families know their children best and, thus, should be involved in all aspects of their care. Family-centered approaches lead to improved child health and family outcomes.

Goals describe activities that:

- Represent what matters to children and youth
- Advance parents’ feelings of personal confidence
- Contribute to greater understanding of issues
- Hold potential for interdisciplinary work
- Offer increased opportunities for communication and collaboration among families and team members
- Build family partnerships with their clinical team

Approaches

Goals should be articulated in the words of the person's voice who is expressing them. Patient and family goals should be stated in their own words and language. Computer generated goals, or "drop down" statements, meant to represent family priorities, miss the mark when seeking to fully engage families. If families have difficulty expressing goals you can frame questions to help them, for example:

- What matters most to you/your family?
- What are your current priorities related to your child's health and wellness?
- What do you want us to know and understand about your child and family?
- What would you like your child to be able to do or experience?
- What is your greatest concern?

Clinicians may follow evidence and algorithms in the framing of their clinical goals; electronic health record software may support the efficient statement of those goals. Additional goals may be stated in the clinical team's own words.

Tools

1. A Goal Setting Script to assist families to frame goals is included (Appendix F, Tips for Establishing Goals with Patients and Families). Goals are then to be documented and reviewed as part of the shared plan of care described under steps 6 & 7.

Tip: One primary care team learned from their family partners that many families did not understand how to set goals related to their children's health. They needed guidance with this step. After this team gained some experience helping families to set goals they developed a list of sample family goals to help other parents understand what these might look like.

Literature

1. Brewer, K., Pollock, N., and Wright, F.V., *Addressing the Challenges of Collaborative Goal Setting with Children and Their Families*. Physical and Occupational Therapy in Pediatrics 2013.
2. Fiks, A.G., et al., *Parental preferences and goals regarding ADHD treatment*. Pediatrics, 2013. 132(4): p. 692-702.

Ten Steps to the Shared Plan of Care: Index — Question 4

Set shared personal (child and family) and clinical goals.

Our team needs to (*circle one*):

1. Learn more about this
2. Try this
3. Master this
4. No improvement is needed

Step 5. Identify other needed partners and link them into the plan of care process — subspecialists, community resource providers and others

Description

Children and Youth with Special Health Care Needs frequently rely on an astounding number of services, providers and resources to ensure care and support. It is not uncommon for a busy pediatric practice to be unaware of many of these family resource partners. However, asking the family who lives in their home, and who is in their circle of resource supports is an essential skill. In the process, the team learns how the community resources in their neighborhood can help them to resolve puzzling problems, secure needed resources, or simply be another set of eyes and ears promoting the success of families. Similarly, families need to understand the system of services and people who may be contacting them.

Approaches

Medical Home Neighborhood Mapping is one approach that can help to facilitate accurate identification of caring partners with whom children and families are or should be involved.

This is accomplished by asking families to help you map out all of their care and community resource relationships. This can be done individually, but one practice has set an example by doing this as a part of “group” visits:

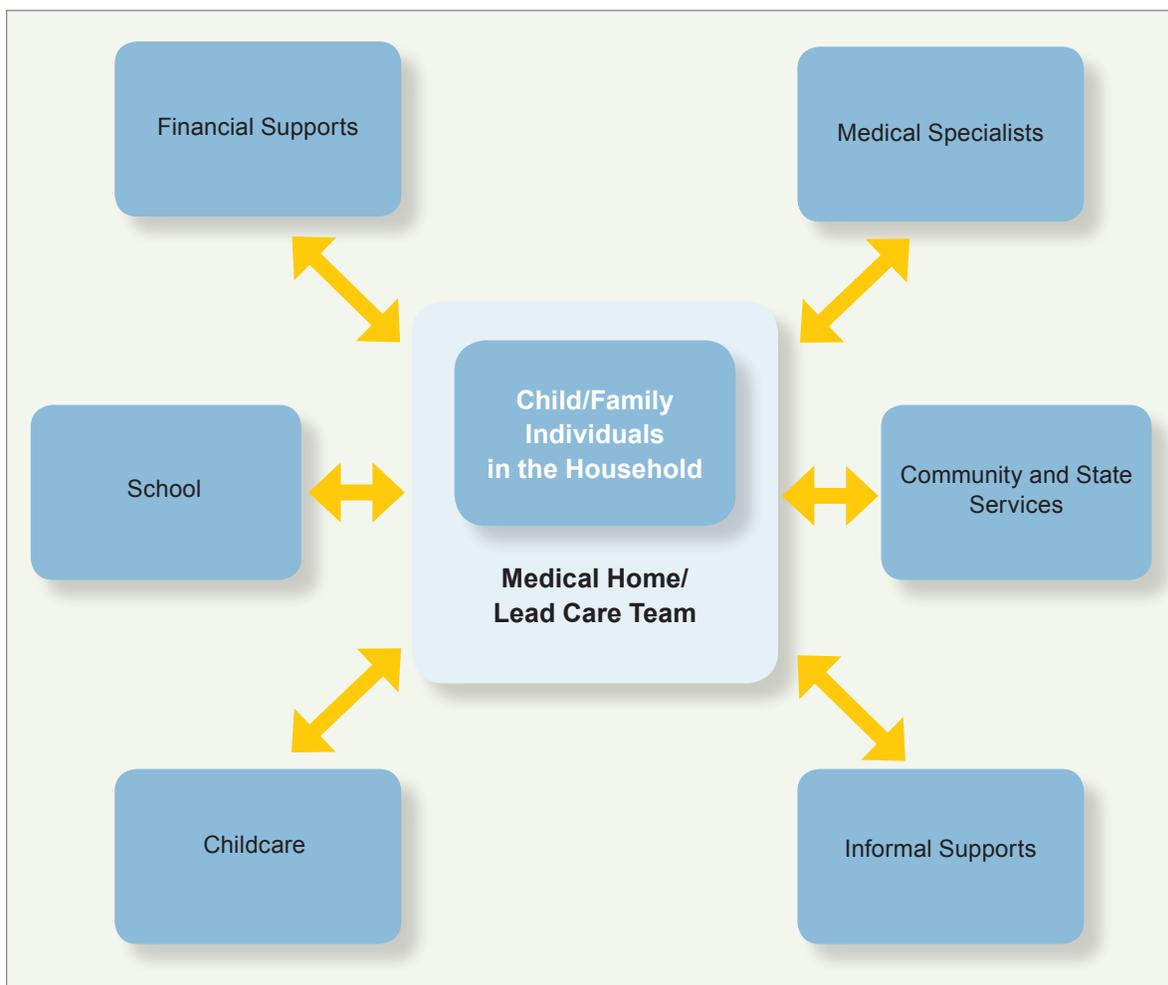
- During a group visit multiple staff, community partners and families work on and then view completed “eco maps.” This helps them to know and trust one another, and to understand the resources in their community.
- The group visit thereby becomes an event where everybody teaches and everybody learns. An added benefit is the extra face-time children and families experience with the pediatric clinician.

The diagram on page 14 is an example of a completed Medical Home Neighborhood Map. These maps describe child and family relationships with various providers, services, therapists and resources. These relationships comprise a comprehensive medical home “neighborhood.”

It is not uncommon for many of those who appear on such a map to be unaware of one another. So it is an important benefit that community providers learn about one another’s respective roles; this understanding may make them more likely to collaborate. Eco-mapping expands the reach of the practice to include community partners and contributes to more effective and efficient care. Children and families benefit with care coordination facilitated by improved communication; the burden and cost to the family, and to the health care system, may be lightened as a result of this process.

Maps or lists of care networks should become part of the patient’s record and reviewed at regular intervals.

Figure 2: Medical Home Neighborhood Map



Tools

1. A Medical Home Neighborhood Mapping Template (Appendix G) can be copied, used and completed with children, families and their team.

Literature

1. Meyer, C.H., (Ed.) (1983) *Clinical social work practices in an ecosystems perspective*. New York: Columbia University Press
2. MacDonald, H. and Callery, P., *Parenting children requiring complex care: a journey through time*. *Child: Care, Health and Development*, 2008. 34(2): p. 207-213.

Ten Steps to the Shared Plan of Care: Index — Question 5

Identify other needed partners and link them into the plan of care process — subspecialists, community resource providers and others.

Our team needs to (*circle one*):

- | | | | |
|--------------------------|-------------|----------------|-----------------------------|
| 1. Learn more about this | 2. Try this | 3. Master this | 4. No improvement is needed |
|--------------------------|-------------|----------------|-----------------------------|

Step 6. Develop the plan of care “Medical Summary” and merge with “Negotiated Actions” in step 7.

Description

The plan of care includes and combines two components: (1) the “Medical Summary” (Step 6 described here) and (2) goals with “Negotiated Actions” (Step 7, described in subsequent pages).

The Medical Summary is a concise, up-to-date profile of a child’s condition, status, treatments and needs. It includes child and family current/pertinent and historical medical facts, with interventions tried and not yet tried. The Medical Summary depicts family demographics and core knowledge including their personal preferences and goals. A succinct social and educational summary is included. Lead health care team members, community partners, and their contact preferences are listed.

Approaches

- Figure 1, Page 4, outlines a model approach to the shared plan of care. Relationship building and bio-psychosocial assessments inform its development and use. The family and all team members contribute to and participate in the creation and implementation of the plan of care.
- While any team member may initiate the creation and use of a plan of care at any point in time (such as the provider during a visit, or at the request of the family), a number of events may bring initiation and completion of the plan to the forefront.
- A practice may develop criteria for triggering plan of care related discussions and development efforts; for example:
 - The child/youth has a condition of high complexity/high intensity
 - A clear gap in communication exists (among the family, medical home, subspecialists and community providers)
 - There are apparent challenges such as language and cultural barriers, or stressful home circumstances
 - Family, clinician, coordinator of care, or others express concern or need
- Major Components of a Shared Care Plan offers an exemplar template (Appendix H). The Medical Summary is defined by Part I and Part II, which outline essential information related to a child’s strengths, chronic conditions, recent events, pertinent history, treatments tried and not yet tried, and particular needs and preferences. Some of these “fields” may be populated during visit interactions, while other facts may need to be retrieved from within the medical record (either paper or electronic).
- Different plan of care information and/or sections may be completed independently by the family/team. The team, with clinical leadership, should sit with the family to pull all of the pieces together, thereby forming the original plan of care. Creation and completion may occur during a regularly scheduled visit, as a function of separate care coordination contacts, during follow-up to an acute episode or key event, or during an all team care conference.
- Present day information is added to the plan of care in real time. While shared plans of care are created jointly, families do appreciate it when facts previously reported are pre-populated into the plan of care by team members. Valuable visit time can then be spent addressing present and future needs rather than repeating facts.

Tools

The Major Components of a Shared Care Plan outlines essential fields of the Medical Summary (Appendix H) many of which can be prepopulated and or completed with a review of recent visits.

Ten Steps to the Shared Plan of Care: Index — Question 6

Develop the plan of care “Medical Summary” and merge with “Negotiated Actions” in step 7.

Our team needs to (*circle one*):

1. Learn more about this
2. Try this
3. Master this
4. No improvement is needed

Step 7. Establish the plan of care “Negotiated Actions” and merge with the “Medical Summary” in step 6

Description

“Negotiated Actions” are plans and strategies selected to achieve each identified personal and/or clinical goal. Negotiated actions assign responsibility for jointly determined activities; a timeline for implementation and completion of actions is set. “Negotiated Actions” imply and require discussions among children/youth and families and their health care team. All information, including comprehensive assessments, goals, and priorities, is assembled and used to determine best agreed upon actionable strategies. Accountabilities for actions and timelines are made explicit within the negotiated action portion of the plan of care and outline who will do what, by when. Shared plan of care oversight is a mutual responsibility among the family, clinician and team; it is specifically supported with necessary coordination of care functions.

The family in partnership with their medical home team implements “Negotiated Actions.” The coordinator of care helps to operationalize these activities with the supervision and support of the lead clinician. When no coordinator is available, the lead clinician assumes this role. Together, the “Negotiated Actions” and “Medical Summary” make up a complete, shared, plan of care.

Approaches

- When jointly creating a plan of care, families are helped to indicate what roles and responsibilities they can manage and when; all acknowledge that this may vary at different points in time, and under varying circumstances.
- The support network of the family is outlined, or mapped (using the medical home neighborhood mapping tool introduced in Step 6).
- The “Negotiated Actions” become a “script” for next steps, for the family, clinicians, care coordinators (if available) and other specialists or community partners.
- Communication involves outreach to the family, planned visits, input from team members, as well as asynchronous electronic messaging to monitor progress and re-plan accordingly.
- The functions of care coordination, or a care coordinator, are activated to coalesce all identified and needed resources and actions, as well as to provide oversight for the plan of care.

Tools

1. Major Components of a Shared Care Plan (Appendix H)

- The Major Components of a Shared Care Plan serves as an exemplar form. Part III articulates the essential elements of the “Negotiated Actions.” The template can also be used to guide the development of key fields within the electronic health record. These fields can be used as a checklist against which to gauge strengths, gaps and needed enhancements of any existing care-planning approaches.

Literature

1. Adams, S., et al., *Exploring the Usefulness of Comprehensive Care Plans for Children with Medical Complexity: A Qualitative Study*. BMC Pediatrics 2013. 13(10).

Ten Steps to the Shared Plan of Care: Index — Question 7

Establish the plan of care “Negotiated Actions” and merge with the “Medical Summary” in step 6.

Our team needs to (*circle one*):

1. Learn more about this
2. Try this
3. Master this
4. No improvement is needed

Step 8: Ensure that the plan of care is accessible, retrievable and available

Description

Care plans are only valuable to the extent that they are used. Once jointly created the plan of care must be readily available, accessible and retrievable by those who are engaged with the child and family. This can present a challenge for practices.

Approaches

Current approaches to make plans of care available, accessible and retrievable are less than optimal; they are “workarounds” rather than long-term solutions. However, some current strategies may lead to better solutions.

- **EHRs** — The adoption of an electronic health record should expediently advance the development and incorporation of plans of care. Few leading electronic medical record systems support an effective plan of care with shared access and availability. Even systems that claim that they have care-planning capacity fall short when it comes to co-management and effectively sharing and providing access to, and with, families. This barrier continues in spite of related policy efforts.
- **Scanning into an EHR** — For example, one initiative uses a PDF to scan captured medical summary data and plans into the electronic medical record; they then provide the family their plan of care through their portal. It becomes a significant coordination role to reconcile the most up-to-date plan and to ensure the electronic record reflects the updates of the family in real time.
- **Paper** — Some practices still use paper plans of care, they regularly update these plans and share copies with families. Updating and revising plans of care again takes thought and time.

- **Online Templates** — Others use editable templates such as shared online files drawing upon different “cloud” based products or plans of care shared using external memory devices (such as jump-drives). There are logistical, privacy, and security implications for each of these workarounds.

Practices should continue to explore and press for potential future improved capacity of their electronic medical record systems. Goals here include the ability to document, contain, update in real time, and share the plan of care. Major Components of a Shared Care Plan (Appendix H) is a tool also designed to help frame conversations with information technology departments and/or vendors.

Tools

Major Components of a Shared Care Plan (Appendix H, outlined in Steps 6 & 7)

Literature

1. Kellerman, A., and Jones, S., *What It Will Take To Achieve the As Yet Unfulfilled Promises of Health Information Technology*. Health Affairs, 2013. 32(1): p. 63-68.
2. Meaningful use regulations: http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/downloads/Stage2_HospitalCore_12_SummaryCare.pdf

Ten Steps to the Shared Plan of Care: Index — Question 8

Ensure that the plan of care is accessible, retrievable and available.

Our team needs to (*circle one*):

1. Learn more about this
2. Try this
3. Master this
4. No improvement is needed

Step 9. Provide tracking, monitoring and oversight for the plan of care

Description

Plans of care help to assure that services for the child and family are based upon complete information including goals, interventions, and assigned responsibilities. Plans of care are an essential operational tool for effective coordination of care.

A Framework for Pediatric Care Coordination describes the characteristics of coordinated care as 1) patient and family-centered 2) proactive, planned, and comprehensive 3) designed to promote self-care skills and independence, and 4) facilitative of cross-organizational relationships.¹⁵

The care coordination Framework outlines 10 coordinating functions:

1. Provide access through personal contacts outside of regular visits
2. Continuously manage communications
3. Complete, analyze and use assessments
4. Develop plans of care with families and team
5. Manage/track tests, referrals, progress and outcomes
6. Coach patients and families

7. Integrate critical care information (or centralize input from multiple sources into one place)
8. Support and facilitate all care transitions
9. Facilitate team meetings and contribute to care conferences
10. Use health information technology (as effectively as possible)

Approaches

Many of these 10 care coordinating functions involve using a plan of care. Each team member, including family members, has some responsibility for these care coordination functions; they will help to foster more effective use of the plan of care. Team meetings, care conferences, coordination of care rounds, group visits established to create “medical home neighborhood mapping” are all strategies that foster team-based care coordination and serve to support individuals in this important role.

In addition, it is helpful if oversight responsibility is explicitly designated and supported. Coordination should be team based; individuals who take on such a pivotal role should have the support and backing of their entire team, including the family.

The provision of care coordination in practice is gaining attention. It is recommended that where practices serve as the medical home for children and youth with special health care needs, that they approach care coordination services purposefully. This involves selecting a practice-based care-coordination model that reflects their care-giving mission; is inclusive of a care coordination structure and process framework; and offers a specific care coordinator position description with specific competencies. For many practice teams the evolution of the coordination role is achieved as a joint quality improvement effort.

Tools

1. The Care Coordination Workbook — <http://www.healthit.gov/providers-professionals/implementation-resources/medical-home-practice-based-care-coordination>

Literature

1. Antonelli, R., McAllister, J.W., and Popp, J., *Making Care Coordination a Critical Component of the Pediatric Health Care System: A Multidisciplinary Framework*. 2009, The Commonwealth Fund: New York, NY.
2. McAllister J.W., Presler, E., and Cooley, W.C., *Practice Based Care Coordination: A Medical Home Essential*. *Pediatrics*, 2007. 120(3): p. e723-733.

Ten Steps to the Shared Plan of Care: Index — Question 9

Provide tracking, monitoring and oversight for the plan of care.

Our team needs to (*circle one*):

1. Learn more about this
2. Try this
3. Master this
4. No improvement is needed

Step 10. Systematically use the plan of care model process as a life course and a population health approach

Description

The plan of care is only valuable when it is used. Best use occurs when caring individuals come together, communicate and collaborate to use a shared plan of care with a child, youth and their family. Although the up front costs of shared care-planning can be substantial in terms of staff effort, there is evidence that shows positive impacts of care plans on costs to patients, families, providers and health care systems. Creating and using care plans can have value beyond their impact on individual children and their families. Once a practice has sufficient experience with care-planning, patterns of needs and opportunities become visible, especially regarding health promotion and disease prevention or the prevention of secondary or tertiary health problems. Also, when approached formally, a process of “scrubbing” patient records can identify opportunities to provide outreach and preventive population health services. Knowing your population, those with whom you are using plans of care, and thinking of these individuals collectively should enhance the practice approach and improve the health of a population of CYSHCN.

Approaches

Shared care-planning may represent a substantial change in how children and youth with special health care needs are cared for in a practice. Beginning with a plan and with modest initial expectations for change can make the implementation process more manageable. Using an improvement approach involves trying each element of shared care-planning; the experience is then reviewed and perhaps modified and tried again prior to adoption (or use of an alternative approach). A mindful testing approach coupled with reflection can lead to better care processes and outcomes. The Ten Steps to the Shared Plan of Care: Index (Appendix B) offers a tool to assess your progress toward implementing shared plans of care in practice.

Keys to successfully adopting Shared Care Plans include:

- Teamwork to apply improvement science toward a systemized process of care-planning.
- Feedback from families/youth regarding the difference having a plan of care makes in their lives.
- Learning from clinicians and other team/community partners about their experiences working with families to share a plan of care.
- Gathering opinions from other providers, (i.e., consultants and partners, who “discover” a plan of care is available for a patient).
- Producing data that describe the care and outcomes for the population of children and youth with special health care needs and their families, those whose care has been guided by a shared plan of care.

Tools

- Plan of Care Stories
 - Include individual children/youth and family stories outlining strengths and needs, goals and strategies worked on as a team, with subsequent outcomes (Appendix I).
- Plan of Care Process and Outcome Measurement Suggestions (Appendix J).
- Family Measures for Achieving a Shared Plan of Care for CYSHCN (Appendix K).
- Practice Measures for Achieving a Shared Plan of Care for CYSHCN (Appendix L).

* Specificity for plans of care with matching robust measures has been lacking. The tools and recommendations offered here are meant to align with the goals of Shared Care-Planning while addressing this gap. Because the measures have not been fully tested we would appreciate any experience feedback and suggestions for improvement (<mailto:jwmcalli@iupui.edu>).

Literature

1. Wagner, E, et al., *Guiding Transformation: How Medical Practices Can Become Patient Centered Medical Homes*. 2012; The Commonwealth Fund.
2. McAllister, J.W., Cooley, W.C., Van Cleave, J., Boudreau, A., Kulthau, K., *Medical home transformation in pediatric primary care — what drives change?* *Annals of Family Medicine*, 2013. 11 Suppl 1: p. S90-8.

Ten Steps to the Shared Plan of Care — Question 10

Systematically use the plan of care model process as a life course and a population health approach.

Our team needs to (*circle one*):

1. Learn more about this 2. Try this 3. Master this 4. No improvement is needed

Summary

The patient and family-centered medical home description issued by the American Academy of Pediatrics (AAP) has endured the test of time.¹⁶ The AAP calls for care in a medical home that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective for all children and youth, particularly children and youth with special health care needs. The National Center for Medical Home Implementation (housed within the AAP) adds that the medical home is an approach to meeting the needs of children and families through a family-centered and team-based partnership.¹⁷

Families want a medical home with reliable partners. They frequently ask “Where and who do I go to for such care?” Clinicians want to provide high quality care, but ask, “How do I possibly do all of this?” Both questions speak to the need for clarity regarding how medical home characteristics and functions are achieved in practice, particularly amidst the fast pace that is primary care today. Individuals cannot achieve all that the medical home is meant to be on their own; teamwork within the practice, with families and community partners is fundamental to medical home implementation and to achieving the best outcomes for patients. Yet leading or working as a part of a team requires skill that needs further development.

Share Care-Planning is grounded in the fundamental principles of the patient and family-centered medical home. The Report and this Guide are themselves products of inter-disciplinary teamwork and family-professional partnership. The varied perspectives and insights inherent to teamwork are infused within the detailed steps and strategies of the shared care-planning model. Synergy among those who jointly create plans of care with children and families is an expectation infused throughout the shared care-planning model. The sum of this collaborative process should be even better than the parts.

This *Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs: Implementation Guide* emphasizes collaboration by offering suggestions on how to partner with and learn from families; what roles to take as highly functioning teams; ways to integrate information to help make sense of it, while being useful for all team members; the value of stating accountabilities and matching them with clear oversight; and continuously learning from one another about how to make the planning process part of a better experience of care and an improved process of delivering care.

In the words of Kenneth Blanchard, “None of us is as smart as all of us.”¹⁸ Shared Care-Planning opens the door for the combined input and efforts of all partners to be captured in a mutually beneficial approach. Care plans developed in this way and used consistently will better the quality of life for children with special health care needs and their families.

Literature

1. McAllister, J.W., et al., *Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs*. 2014 (in press), Lucile Packard Foundation for Children's Healthcare: Lucile Packard Foundation for Children's Healthcare.
2. Adams, S., et al., *Exploring the Usefulness of Comprehensive Care Plans for Children with Medical Complexity: A Qualitative Study*. BMC Pediatrics 2013. 13(10).
3. American Academy of Pediatrics; Committee on Children With Disabilities, *Care Coordination in the Medical Home: Integrating Health and Related Systems of Care for Children With Special Health Care Needs*. Pediatrics, 2005. 116: p. 1238-1244.
4. Wagner, E., et al., *Guiding Transformation: How Medical Practices Can Become Patient-Centered Medical Homes*. 2012, The Commonwealth Fund.
5. Homer, C.J., et al., *A review of the evidence for the medical home for children with special health care needs*. Pediatrics, 2008. 122(4): p. e922-37.
6. McAllister, J.W., Presler, E., and Cooley, W.C., *Practice Based Care Coordination: A Medical Home Essential*. Pediatrics, 2007. 120(3): p. e723-733.
7. McAllister, J.W., et al., *Medical home transformation in pediatric primary care — what drives change?* Annals of Family Medicine, 2013. 11 Suppl 1: p. S90-8.
8. McAllister, J.W., et al., *Achieving effective care coordination in the medical home*. [Erratum appears in *Pediatr Ann*. 2009 Dec;38(12):636 Note: Turchi, Renee [corrected to Turchi, Renee M]]. 2009(0090-4481).
9. McAllister, J.W., et al., *Improvement in the family-centered medical home enhances outcomes for children and youth with special healthcare needs*. Journal of Ambulatory Care Management 2009. 32(33)(0148-9917): p. 188-96.
10. Cooley, W.C. and McAllister, J.W., *Building medical homes: improvement strategies in primary care for children with special health care needs*. Pediatrics, 2004. 113(5 Suppl): p. 1499-506.
11. Kuhlthau, K.A., et al., *Evidence for family-centered care for children with special health care needs: a systematic review*. Academic pediatrics, 2011. 11(2): p. 136-43.
12. Bramlett, M.D., et al., *Differentiating subgroups of children with special health care needs by health status and complexity of health care needs*. Maternal & Child Health Journal, 2009. 13(2): p. 151-63.
13. Kazak, A.E., et al., *Screening for psychosocial risk at pediatric cancer diagnosis: the psychosocial assessment tool*. Journal of Pediatric Hematology/Oncology, 2011. 33(4): p. 289-94.
14. Kazak, A.E., et al., *Screening for psychosocial risk in pediatric cancer*. Pediatric Blood & Cancer, 2012. 59(5): p. 822-7.
15. Antonelli, R., McAllister, J.W., and Popp, J., *Making Care Coordination a Critical Component of the Pediatric Health Care System: A Multidisciplinary Framework*. 2009, The Commonwealth Fund: New York, NY.
16. American Academy of Pediatrics Medical Home Initiatives for Children With Special Needs Project Advisory Committee, *The Medical Home*. Pediatrics, 2002; reaffirmed 2008. 110(1): p. 184-186.
17. National Center for Medical Home Implementation, A.A.P. *Medical Home*. 2014 February 20, 2014].
18. Blanchard, K., *The One Minute Manager*. One Minute Manager Series, 2011: Harper Collins Publishers

Appendix A

Ten Underlying Principles for a Shared Plan of Care — Practice Assessment

These 10 principles describe effective practice partnerships with children and families. Completing this practice assessment is a good starting point to see if your practice is in agreement and ready to begin shared care-planning.

In Our Practice:	Strongly Disagree	Disagree	Agree	Strongly Agree
1. Children, youth and families are actively engaged in their care.	1	2	3	4
2. Communication with and among the medical home team is clear, frequent and timely.	1	2	3	4
3. Providers/team members base their patient and family assessments on a full understanding of child, youth and family needs, strengths, history, and preferences.	1	2	3	4
4. Children, youth, families, health care providers, and their community partners have strong relationships characterized by mutual trust and respect.	1	2	3	4
5. Family-centered “teams” can access the information they need to make shared, informed decisions.	1	2	3	4
6. Family-centered “teams” use a plan of care, which includes a medical summary and shared goals with negotiated actions; all understand the care-planning process, their individual responsibilities and related accountabilities.	1	2	3	4
7. Family-centered “teams” monitor progress against goals, provide feedback and adjust the plan of care on an on-going basis (the plan is well implemented).	1	2	3	4
8. Family-centered “teams” anticipate, prepare and plan for all transitions (early intervention to school; hospital to home; pediatric to adult care).	1	2	3	4
9. The plan of care is adopted as a common document; it is used in the same way, by every provider within an organization, and by all providers across organizations.	1	2	3	4
10. Care is (subsequently) well coordinated across all involved organizations/systems.	1	2	3	4

Appendix B

Ten Steps to the Shared Plan of Care: Index

Following the descriptions of each of the ten steps in the Guide is a question related to each of the 10 Steps below. A good approach is to review these questions as a team and arrive at a consensus about the progress, gaps and future learning needs of your group.

	Our Team Needs To:			
	Learn More About this Activity	Try This Activity	Master This Activity	No Change/ Improvement is Needed
1. Identify who will benefit from a plan of care.	1	2	3	No Action
2. Discuss with families and colleagues the value of developing and using a comprehensive and integrated plan of care.	1	2	3	No Action
3. Select, use and review multi-faceted assessments with the child, youth and family.	1	2	3	No Action
4. Set shared personal (child and family) and clinical goals.	1	2	3	No Action
5. Identify other needed partners and link them into the plan of care process — subspecialists, community resource providers and others.	1	2	3	No Action
6. Develop the plan of care “Medical Summary” and merge with “Negotiated Actions” in step 7.	1	2	3	No Action
7. Establish the plan of care “Negotiated Actions” and merge with the “Medical Summary” in step 6.	1	2	3	No Action
8. Ensure that the plan of care is accessible, retrievable and available.	1	2	3	No Action
9. Provide tracking, monitoring and oversight for the plan of care.	1	2	3	No Action
10. Systematically use the plan of care model process as a life course and a population health approach.	1	2	3	No Action

Notes: While the steps are successive, practice capacity may be strong in many related areas with gaps in others. Reflect on your strengths and weaknesses to determine your next steps strategy.

Appendix C Practice Workflow Example

A family-centered, team-based and shared plan of care engages patients and families in healthcare.

Roles of Care Partnership	Pre-Visit Activities: Anticipation and Preparation	Visit Activities: Building Partnership Relationships	Post-Visit Activities: Following Through with Accountability
Care Coordinator, or provider of care coordination	<ul style="list-style-type: none"> ■ Reach out to patient/family ■ Complete a pre-visit assessment ■ Review priorities ■ Review +/or initiate a plan of care; summarize progress/gaps ■ Huddle with team ■ Communicate/share ideas, concerns 	<ul style="list-style-type: none"> ■ Assess and discuss needs, strengths, goals, and priorities ■ Educate & share information ■ Inform the plan of care in real time ■ Facilitate communications ■ Set time for next visit or contact 	<ul style="list-style-type: none"> ■ Update/share the plan of care and implement accountable tasks ■ Ensure quality access and communication loops with resource contacts ■ Create opportunities for the ongoing engagement of patients/families ■ <i>Repeat these steps accordingly</i>
Youth and Family	<ul style="list-style-type: none"> ■ Prepare for visit or contact, review recent events, insights, expectations, goals, and hopes ■ Review existing plan of care for progress, gaps, successes, failures, and frame questions ■ Prioritize topics to address at visit 	<ul style="list-style-type: none"> ■ Share your priorities with team ■ Discuss care options together ■ Contribute to current plan of care development and/or revision ■ Ask for/acquire needed care giving/self care skills ■ Offer feedback and ideas ■ Set time for next visit/contact 	<ul style="list-style-type: none"> ■ Review care information and instructions ■ Access and communicate with team as desired or needed ■ Use, share, and implement the plan of care with health partners ■ Complete tasks responsible for ■ <i>Repeat these steps accordingly</i>
Pediatric Clinician	<ul style="list-style-type: none"> ■ Huddle with your team ■ Review pre-visit assessment data ■ Review plan of care and other data ■ Identify the need for a plan of care if none exists ■ Attend to team readiness/gaps for holding a prepared/planned visit 	<ul style="list-style-type: none"> ■ Meet with family, engage them as part of the medical home core team ■ Complete screenings and/or assessments ■ Evaluate, listen, learn, and plan ■ Frame family and clinical goals: bio-psychosocial, functional, environmental ■ Co-create, update plan of care ■ Link with referrals/resources ■ Set time for next visit or contact 	<ul style="list-style-type: none"> ■ Update/implement the plan of care completing accountable tasks ■ Monitor communications ■ Huddle with team frequently ■ Help guide team conferences ■ Supervise continuous care coordination and ensure plan of care oversight ■ <i>Repeat these steps accordingly</i>

Appendix D

Exeter Pediatric Associates Complexity Index (HOMES)

The purpose of this index is to identify the level of complexity/intensity involved in supporting children with special health care needs.

Score each category 0, 1, or 2 (0 means no service, activity or concern)

Category	Criteria	Score
H ospitalizations, ER Usage & Specialty Visits (in last year)	1 = 1 hospitalization, ER or specialist visit for complex condition 2 = 2 or > hospitalizations, ER or specialist visits for complex condition	
O ffice Visits and/or Phone Calls (in last year, over and above well child visits, +/-extra charges).	1 = 1-2 office visits or MD/RN/care coordinator phone calls related to complex condition 2 = 3 or more office visits or MD phone calls for complex condition	
M edical Condition(s): One or more diagnoses	1 = 1-2 conditions, no complications related to diagnosis 2 = 1 or 2 conditions with complications or 3 or more conditions	
E xtra Care & Services at PCP office, home, school, or community setting (see Services)	1 = 1 service from the list below 2 = 2 or more services from the list below <i>Services:</i> Medications, medical technologies, therapeutic assessments/treatments/procedures, & care coordination activities.	
S ocial Concerns	1 = "At risk" family/school/social circumstances are present 2 = Current/urgent complex family/school/social	

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

Name _____ Date _____ Total Score = _____

Appendix E Pediatric Care Coordination Assessment

Child/Youth Name _____ Date _____

Family Name _____

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

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

3. Do you have any concerns or worries for your child? (Some examples below)

- Their growth/development
- Learning
- Sleeping
- Self-care
- Making and keeping friends
- Other _____
- Doing things for themselves
- Falling behind in school
- Behavior
- The future
- Playing with friends

4. Have there been any important changes since we saw you last, such as a:

- Brother or sister leaving home?
- Move to a new town?
- Sickness or death of a loved one?
- New job or job change?
- Separation or divorce?
- Other (fill in below)?

5. Can we help you with any of the following needs?

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

Notes:

Appendix F

Tips for Establishing Goals with Your Patients and Families

Setting the environment:

- Check to see if the young person and family you are about to speak with has a long history accessing health care.
- Is there a care plan on file or other noted comments to help you catch up and relate to them?
- Acknowledge to them if you have looked at their records and what information you already know.
- Let them know that you hope to learn from them how best to improve care, and that understanding what matters most to them will help you with this.
- Bring them into the process as a partner, for example:

“We have some important [clinical] care goals to discuss; first we want to be sure that we understand what is most important to you, to your child, and to your family.”

 1. What matters most to your family?
 2. What are your current priorities related to your child’s health and wellness?
 3. What do you want us to know and understand about your child and family?
 4. What would you like your child to be able to do or experience?
 5. What is your greatest concern?

Scripted ideas for helping young adults express their goals comes next:

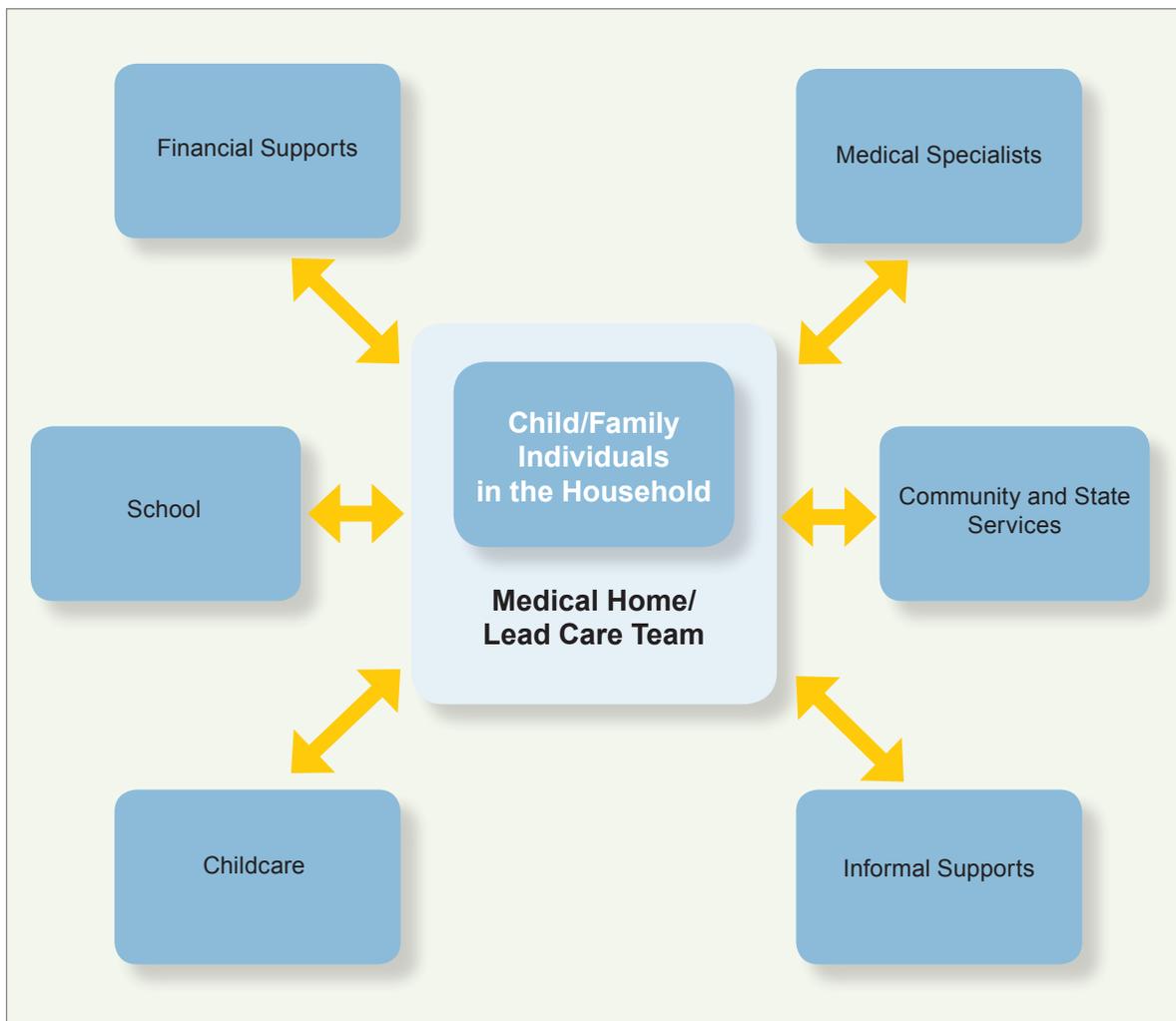
As your doctor/nurse/or other role) I/we are concerned about _____ for you.

But I/we are also very interested in what is most important to your child/you/your family right now.

- What matters to you most?
- What interests you?
- What do you like to do best?
- Who do you like to spend your time with?
- What is your favorite subject in school? (Or what do you do for work?)
- Are you involved in any clubs or other activities?
- How do you spend your free time?
- Do you have pets?
- What does a typical day look like?

Appendix G

Medical Home Neighborhood Mapping Template



Appendix H

Major Components of a Shared Care Plan

Part I Medical Summary

Describe the Child/Youth/Family

Name/Likes to be called:

- Sex
- DOB
- Race
- First language
- Emergency plan on record? (___ Yes/Link) (___ Not Needed)

Medical Home Neighborhood Mapping Contacts: (e.g. family support, health, school and community partners)	Role/Responsibilities	Best way to contact
1.		
2.		
3.		

Family structure — succinct social /educational summary; includes strengths

- Siblings (Ages, health/wellness concerns, functional ability, etc.)
- Cultural considerations/preferences
- The primary concern of the family (in their words)
- The family response to “What I/we want you to know about me/us”

Part II Medical Summary — Describe/list:

- The diagnoses
- Problem list
- Short narrative summary
- Mental status/level of consciousness
- Current interventions, treatments and therapies
- Other approaches tried and not tried
- Developmental concerns
- Environmental concerns
- Other _____

Appendix H (Cont.)

Part III “Negotiated Actions” (e.g. Strategies and plans to address each goal)

What are the family/child/youth’s identified goals (i.e., what matters to them)?

- Patient Goal(s) (dated)
- Family Goal(s) (dated)

Clinical treatment goals (best available evidence)

- Primary care clinician goal (dated)
- Sub-specialist(s) goal (dated)
- Community providers(s) goal (dated)

For each prioritized goal — identify actions/strategies, accountable persons (includes subspecialists and community partners), and a timeline for completing the actions:

Goal	Actions /Strategies	Accountable Person	Timeframe
Patient goal(s)			
Family goal(s)			
Clinical goal(s)			

Use and regularly update the plan of care

Evaluate the shared care process

- Are there methods in place for effective communication?
 - Type of communication (email, messaging, phone, face-to-face, cloud, etc.)
 - Persons communicating (family, cross-team, and community partner)
- Is the plan practical and feasible?
- Are resources obtainable?
- Are there any additional barriers?
- Are the activities adequate to facilitate use of the plan?
- Is there adequate documentation of actions?
- Is progress assessed for each goal?

Signatures and dates (lead clinician, family, coordinator, other):

Appendix I

Plan of Care Stories

The following three care stories describe patients with care complexity and are examples of how shared care-planning helps to achieve desired goals and outcomes.

MARY

Mary is a 6-year-old first grader who today is indistinguishable from her classmates — this has not always been true. Mary lives with tuberous sclerosis and her problems include: seizures, significant sleep issues, aggression, self-harm behaviors (biting self, pulling out hair, pulling eyelashes, head banging), unsafe behaviors (bolting out of the house), and incessant screaming and tantrums. Multiple medical and community resources proved ineffective until a community-based Title V Children with Special Health Needs medical social worker partnered with Mary’s family and medical home team. Consequently, existing state and local resource efforts, communications and relationships between the family and both health and mental health support services in the community improved.

The table below describes some of the shared care-planning processes and outcomes 10 months later.

Patient, Family and Team Goals	Negotiated Actions	Process and Outcome Measures
<ul style="list-style-type: none"> Reduce the need for “crisis” support 	<ul style="list-style-type: none"> Achieve access to psychiatry Coordinate psychiatry appointments for optimal co-management between medical home and psychiatry 	<ul style="list-style-type: none"> Less use of/burden on crisis resources (mental health mobile crisis team, police, etc.)
<ul style="list-style-type: none"> Improve sleep for Mary and her family 	<ul style="list-style-type: none"> Coordinate with psychiatry to better manage medications Add a home/community behavioral interventionist Integrate goals of a sleep program across settings effectively, secure family respite 	<ul style="list-style-type: none"> Fewer errors in communication related to medications
<ul style="list-style-type: none"> Achieve ability to keep Mary safely at home (for self and others) 	<ul style="list-style-type: none"> Improve psychopharmacology, improve behavioral planning — with cohesion across settings Seek waiver to obtain: wrap-around service planning, access to a skilled in-home behavior specialist, and respite care 	<ul style="list-style-type: none"> Out of region network contract with behavioral support vendor achieved (innovation) Crisis intervention less necessary/reduced
<ul style="list-style-type: none"> Attend school each day regardless of sleep issues Increase peer contact/participation with peers 	<ul style="list-style-type: none"> Work with school team around shared goals to include: care conferencing, role of behavioral specialist, common strategies 	<ul style="list-style-type: none"> Cannot pick Mary out from her peers in kindergarten (behavioral success) Improved school attendance, making academic gains

Appendix I (Cont.)

Patient, Family and Team Goals	Negotiated Actions	Process and Outcome Measures
<ul style="list-style-type: none"> ■ Gain a profile of seizure activity — the triggers, types, and how they impact her behavior ■ Achieve optimal chronic condition management 	<ul style="list-style-type: none"> ■ Observe and record seizure activity at school and home ■ Arrange inpatient analysis at Tuberous Sclerosis specialty center for full video EEG. ■ Gather data from Mary about antecedents/language of pre-seizure aura 	<ul style="list-style-type: none"> ■ Parents in regular and timely contact and communication with: <ul style="list-style-type: none"> ● Medical Home ● Developmental waiver coordinator ● Psychiatry
<ul style="list-style-type: none"> ■ Communicate and collaborative effectively among family, medical home team, specialists and identified community team partners 	<ul style="list-style-type: none"> ■ Hold regular care conferences and care coordination rounds ■ Develop the Plan of Care and share across partners ■ Hold co-visits with identified team members and family ■ Hold at least one home and school visit by identified team members 	<ul style="list-style-type: none"> ■ Plan of Care and attachment of a seizure action plan — understood, accessible and implemented by all team members (created by subspecialist, interpreted to entire team by medical home as the locus of coordination)
<ul style="list-style-type: none"> ■ Enhance maternal well-being/ family mental health status 	<ul style="list-style-type: none"> ■ Encourage father to attend conferences ■ Fund and schedule respite ■ Arrange for case management ■ Refer to and ensure connection to psychiatry ■ Obtain maternal grief counseling 	<ul style="list-style-type: none"> ■ Mother missing less work ■ Father attends care conferences ■ Improved turn-around time for communication (including father)
<ul style="list-style-type: none"> ■ Avoid/reduce extensive and expensive hospitalizations 	<ul style="list-style-type: none"> ■ Coordinate medical home, behavioral supports, subspecialists and psychopharmacology now and going forward. 	<ul style="list-style-type: none"> ■ Inpatient psychiatry hospitalization avoided (4 hours from home)

Appendix I (Cont.)

WHITNEY

Whitney is a 15-year-old female who on her best days dreams of getting a driver’s license. Whitney has a history of longstanding uncontrolled Type 1 Diabetes. Compounding social factors also contributed to numerous school absences and truancy charges. During the 6-month period prior to switching care to an identified medical home equipped with care coordination resources and the use of a comprehensive integrated Plan of Care, Whitney had 9 ER visits and 7 hospitalizations for diabetic ketoacidosis. The table below describes some of the shared care-planning processes and outcomes 10 months later.

Patient, Family and Team Goals	Negotiated Actions	Process and Outcome Measures
<p>Overall Aim:</p> <ul style="list-style-type: none"> ■ Effective control and management of Type 1 Diabetes ■ Improved communication, collaboration coordination among teen, family, clinicians and school team. 	<ul style="list-style-type: none"> ■ Support of teen and family to achieve goals ■ Enroll in a highly functioning medical home ■ Engage with the care coordinator ■ Hold/attend care conferences ■ Develop a Plan of Care; include endocrinologist input in the emergency plan (when and when not to admit teen to hospital according to need and/or blood glucose levels) ■ Align all coordinating partners with Plan of Care goals ■ Increase contact between medical home and school with frequent communications and collaboration ■ Overcome (persistent) communication and transportation barriers to establish regular counseling 	<ul style="list-style-type: none"> ■ Access to medical home care ■ Actively engaged with a care-coordinator ■ Care conference regular attendance ■ Accessible shared Plan of Care with medical summary, goals with negotiated actions and emergency action plan attached. ■ Increased contacts for regular communication ■ Teen receiving regular counseling ■ For 10 months following creation of the care plan and onset of care coordination, 2 ER visits and 0 diabetes related hospitalizations occurred.
<p>Shared Goals</p> <ul style="list-style-type: none"> ■ Transition to insulin pump (pending Diabetes control) ■ Obtain a driver’s license ■ Improve school attendance/performance 	<ul style="list-style-type: none"> ■ Work with diabetes educator every other week ■ Work with dietician every other week 	<ul style="list-style-type: none"> ■ A1C and overall glucose “markedly improved” ■ Pump still pending ■ Decreased school absenteeism, school nurse office visits reduced, and classroom time increased.

Appendix I (Cont.)

HILARY

Hilary presented to the multi-specialty clinic’s child psychiatrist as a home bound 8-year old with full-time nursing care. Personal knowledge about who she is apart from her health conditions was lacking. Born premature with a single small kidney Hilary required a transplant at age 7. A left sided stroke at infancy leaves her with a persistent hemiparesis and mild dysarthria. Post transplant she required a feeding g-tube. Any by mouth intake proves to be a continuous source of stress between Hilary and her mother; they continue to engage in daily battles over her required fluid intake. Hilary was thought to manifest “oppositional and violent behaviors” and a need to rule out “bipolar disorder” existed. The table below describes some of the shared care-planning processes and outcomes 10 months later.

Patient, Family and Team Goals	Negotiated Actions	Process and Outcome Measures
<ul style="list-style-type: none"> ■ Reduce family anxiety ■ Deliver continuous proactive vs. reactive care (integrated) ■ Develop and share the Plan of Care with common goals and strategies ■ Coordinate and integrate child, family, medical home, and child psychiatry around common goals — including Hilary’s goals ■ Normalize social development, achieve full time school attendance ■ Increase Hilary’s self sufficiency and independence 	<ul style="list-style-type: none"> ■ Hold regular care discussions (over time) among Hilary, family and team (medical home, child psychiatrist, school and home staff, etc.) ■ Assign primary care medical home-based care coordinator the role of cross family/team member contact for communication and collaboration, keeping all focused on independence and self-sufficiency goals. ■ Continuously frame the importance of school attendance/ other child activities to achievement of independence and self sufficiency goals ■ Return to school full time 	<ul style="list-style-type: none"> ■ Family experiences a healing relationship and source of support with their care team ■ Family perception of child safety increases ■ Full school attendance is achieved ■ Child independence and self sufficiency increase ■ Home nursing is eliminated ■ Communication among family, medical home and child psychiatry are reported as “frequent, timely and respectful” ■ Life events (e.g. death of father) reveals a family who turns to their medical home extended team for support vs. precipitating a family crisis

Appendix J

Plan of Care Process and Outcome Measurement Suggestions

	Measurement Ideas	Recommendations/Tools
Better Care	<p>Clinical</p> <ul style="list-style-type: none"> Health safety — markers of safe care and clinical effectiveness Child health measures: clinical, functional, quality of life <p>Functional</p> <ul style="list-style-type: none"> Quality of life; participation in school/work/recreation Confidence in self-care <p>Patient/Family Engagement (satisfaction)</p> <ul style="list-style-type: none"> Establishment of partnership/relationship Sense of safety and support Perception of respect for family as primary care giver Ease of access to team with frequent and timely communication, shared decision making Access to community resources Progress against stated goals (clinical, functional, satisfaction) 	<ul style="list-style-type: none"> Safety: Clinical protocols, medication reconciliation, built in redundancies, “time out” before procedures Measures of health and functional status <p>Family surveys such as:</p> <ul style="list-style-type: none"> CAHPS/other question sets access at (https://cahps.ahrq.gov/cahps-data-base/data-research/index.html) Quality of Life General assessments of whether care is: “safe, effective, timely, efficient, equitable and patient centered care,” according to Institute of Medicine (IOM) recommendations
Better Population Health	<ul style="list-style-type: none"> Population of individual practice/clinic/network cohort with enhanced clinical, functional, engagement/satisfaction outcomes (as above) Population of group at large (within state, region, community, and/or identified group of patients served with a specific condition or need) 	<ul style="list-style-type: none"> Review of collective population data at network level or at the public health level such as the national child health survey
Better Per Capita Cost	<ul style="list-style-type: none"> Cost — calculated per person, per month including: <ul style="list-style-type: none"> # Emergency department visits # Hospitalizations; length of stay, readmissions, redundant tests or procedures, specialty to primary care visit ratio Progress against goals (cost neutral or savings) 	<p>Family surveys:</p> <ul style="list-style-type: none"> CAHPS access at (https://cahps.ahrq.gov/cahps-database/data-research/index.html) Medical Home Family Index ¹ *Family Measures for Achieving a Shared Plan of Care (Appendix K)
Enhanced Family Outcomes	<ul style="list-style-type: none"> Assessment of engagement in care; experience of a care partnership; ability to better manage care Reduction of worry/sense of burden Review family time lost from work/from other daily activities; family out-of-pocket expenses Family quality of life 	<p>Family surveys:</p> <ul style="list-style-type: none"> CAHPS access at (https://cahps.ahrq.gov/cahps-database/data-research/index.html) Medical Home Family Index ¹ *Family Measures for Achieving a Shared Plan of Care (Appendix K)
Enhanced Provider Outcomes	<ul style="list-style-type: none"> Professional satisfaction/vitality Teamwork; team satisfaction Team perception of effectiveness and efficiency Ability to serve more families with quality care 	<p>Provider/team surveys, (interviews or focus groups):</p> <ul style="list-style-type: none"> Adaptive Reserve ² *Practice Measures for Achieving a Shared Plan of Care (Appendix L)

* Specificity for plans of care with matching robust measures has been lacking. The tools and recommendations offered here are meant to align with the goals of Shared Care-Planning while addressing this gap. Some measures have not been fully tested. We would appreciate any experience feedback and suggestions for improvement (<mailto:jwmcalli@iupui.edu>).

1. Agency for Health Research and Quality, *Care Coordination Measures Atlas* 2011: Rockville, MD.

2. Nutting, P.A., et al., *Initial lessons from the first national demonstration project on practice transformation to a patient-centered medical home*. *Annals of Family Medicine*, 2009. 7(3): p. 254-60.

Appendix K

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

1. Has anyone explained to you the value of care coordination (e.g. having someone at the office to help you plan, find resources, answer questions etc.)? a. Yes b. No
2. Has anyone explained to you the value of having a care plan, or "plan of care"? (Clear medical summary and goals with next steps)? a. Yes b. No
3. Is there a care coordinator at the practice who works with you to do care-planning? a. Yes b. No
4. How clear to you are the next steps in your child's care?
 - a. Very clear
 - b. Clear
 - c. A little Clear
 - d. Not at all clear
5. Do you have a current plan of care for your child yet? (Clear medical summary and goals with next steps) a. Yes b. No

(If YES, go to # 6; if NO skip to #9)

6. Does the plan of care include:
 - a. A brief medical summary? a. Yes b. No
 - b. Your child's strengths? a. Yes b. No
 - c. Your child's needs? a. Yes b. No
 - d. Your/your child's goals and preferences? a. Yes b. No
 - e. Provider/team goals? a. Yes b. No
 - f. Action steps? a. Yes b. No
 - g. Who is responsible for each step? a. Yes b. No
 - h. A timeline (date) for action and or completion? a. Yes b. No
7. What effect has the plan of care had on your ability to manage your child's care?
 - a. A very positive effect
 - b. A positive effect
 - c. A little effect
 - d. No effect

Can you describe an example? _____

Appendix K (Cont.)

8. Does care-planning help you/your child prepare for the future (changes, life events, transitions, etc.)?
- Always
 - Sometimes
 - Seldom
 - Not at all
9. Does your medical team help you to learn how to take care of your child's health care needs?
- Always
 - Sometimes
 - Seldom
 - Not at all
10. Does your medical team work together with community groups important to you and your child? (This may be school, day care, mental health supports, visiting nurses, in home service providers)
- Always
 - Sometimes
 - Seldom
 - Not at all
11. Does your medical and community team work with you to address concerns and solve problems?
- Always
 - Sometimes
 - Seldom
 - Not at all

If you can please provide an example: _____

12. Does your medical team communicate with your child's consulting physicians (subspecialists)?
- Always
 - Sometimes
 - Seldom
 - Not at all

* Specificity for plans of care with matching robust measures has been lacking. This tool is meant to align with the goals of Shared Care-Planning while addressing this gap. Because this measure has not been fully tested we would appreciate any experience feedback and suggestions for improvement (mailto:jwmcalli@iupui.edu).

Appendix L

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

PRACTICE/CLINIC _____ ROLE: _____

(These examples are intended to get you started and may be used individually or collectively)

1. Do you develop and use a plan of care with patients/families?
 - a. Yes (If yes, continue)
 - b. No (If no, you may stop here)

2. Do you use any clinical criteria or complexity scales to determine which patients you will develop a plan of care with?
 - a. Yes
 - b. No

3. Does someone on your team sit with patients and families to create some, or all, of the plan of care?
 - a. Yes
 - b. No

4. Does the plan of care that you use:

a. Include a brief medical summary?	Yes__ No__
b. Identify a child/youth's strengths?	Yes__ No__
c. Name child/family personal goals?	Yes__ No__
d. Name provider/team goals?	Yes__ No__
e. List action steps?	Yes__ No__
f. Name who is responsible for each step?	Yes__ No__
g. Show a timeline of progress/completion?	Yes__ No__

5. Is the plan of care:

a. Accessible for your patients and families (electronic/paper)?	Yes__ No__
b. Accessible to you/the clinical team (electronic/paper) ?	Yes__ No__
c. Referred to at each patient contact?	Yes__ No__
d. Renewed and/or updated frequently?	Yes__ No__

6. Does using the plan of care help you to communicate with the entire team (families/providers/staff)

a. More frequently?	Yes__ No__
b. In a more timely manner?	Yes__ No__
c. With better accuracy?	Yes__ No__

7. From your perspective, does using a plan of care help you to better communicate with, partner with, and engage families?

	Yes__ No__
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Appendix L (Cont.)

- 8) Does your plan of care process/tool help you to better coordinate care:
- a. With counterparts across health systems or health organizations? Yes__ No__
 - b. With community partners from schools, day care or other agencies? Yes__ No__
9. Does your plan of care process/tool help you co-manage care with:
- a. Pediatric specialists? Yes__ No__
 - b. Behavioral health providers? Yes__ No__
 - c. Primary care providers Yes__ No__
 - d. Other clinicians? Yes__ No__

Please specify _____

10. What effect does the use of a plan of care, as part of patient and family care, have on your own professional work satisfaction?
- a. A significant effect
 - b. A moderate effect
 - c. A little effect
 - d. No effect

(Please use one phrase or sentence to add personal detail)

Description _____

11. What effect do you believe using a plan of care has on the satisfaction of other staff members in your work setting?
- a. A significant effect
 - b. A moderate effect
 - c. A little effect
 - d. No effect

(Please use one phrase or sentence to add personal detail):

Description _____

* Specificity for plans of care with matching robust measures has been lacking. This tool is meant to align with the goals of Shared Care-Planning while addressing this gap. Because this measure has not been fully tested we would appreciate any experience feedback and suggestions for improvement. (mailto:jwmcalli@iupui.edu).

Appendix M

Glossary

Assessment — Assessment processes help the team to gain an understanding of child and family strengths, needs, goals, priorities and gaps in care. In other words, what are the goals of the family and youth and how do they synchronize, or not, with those of the clinical team? Gaining an understanding of what is important to the child/youth and family and blending this with the clinical team's recommendations is the foundation for comprehensive, integrated care-planning and can result in a shared plan of care. An assessment-driven approach also helps a practice/clinic/team to determine how best to allocate their often limited care coordination resources.

Care Coordination (CC) — Pediatric-based care coordination is a patient- and family-centered, assessment-driven, continuous team-based activity designed to meet the *bio-psychosocial* needs of children and youth while enhancing individual and family care-giving skills/capabilities. Care coordination addresses interrelated medical, social, developmental, psychological, behavioral, educational, environmental and financial needs in order to achieve optimal health and wellness outcomes.¹

Care Coordination Implementation

- Pediatric care coordination is achieved through a patient- and family-centered/medical home partnership and by using an assessment-driven, multidisciplinary team-based process.
- Personal and clinical goals are addressed with clearly articulated actions, roles and responsibilities.
- Progress is monitored and tracked.

Care Conference — A family-centered meeting that brings together an interdisciplinary team with the goal of improving communication and problem solving. A result of a care conference is the delegation of responsibilities for action items among the team and family while assisting families in an anticipatory manner as they navigate various systems of care.

Care Coordination Rounds — A multidisciplinary team meets regularly to address the health and wellness of a population of children and families for whom they share care and involvement. Family members who serve in advisory roles may be present at these meetings to speak for families but also to advocate for systems and promote specific community services. Progress updates for a population of children may be reported upon. Care coordination rounds allow for discussion about what is working well, needed system improvements, and strategies for important communication and collaborations. Care coordination rounds offer teams the opportunity to share key community contacts, found resources and successful strategies.

Children and Youth with Special Health Care Needs (CYSHCN) — According to the US Maternal and Child Health Bureau CYSHCN are those “who have, or are at increased risk of, a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

Consensus — A cooperative process in which all group members develop and agree to support a decision that is in the best interest of the whole (kids/families). In consensus, the input of every member is carefully considered and there is a good faith effort to address all legitimate concerns. Consensus has been achieved when every person involved in the decision can say, “I believe this is the best decision we can arrive at for the organization (project, people) at this time, and I will support its implementation.”²

Appendix M (Cont.)

Knowledge of the Family

A plan of care includes a child, youth and family at a glance “core knowledge” or snapshot. Core knowledge refers to and includes family:

- **Hopes and values** — What we want the team to know about our family including strengths and needs.
- **Familiarity** — What families want the team to remember about their child/youth and any preferences
- **Health literacy, beliefs and practices.**
- **Consolidated bio-psychosocial and functional information** about the child/youth and family (this is regularly updated).
- **Permission** — Documentation of family’s consent to share their core knowledge with other professionals in their community

Dimensions — an aspect or *feature* of a subject, problem or thing (e.g. to indicate the dimensions of an item or area)

Family-Centered Discussions — Conversations among providers and family members based on the understanding that the family is the child’s principle care provider and their priorities and goals are paramount in care decisions.

Huddle — A process, before, during or after a patient visit or as part of quality improvement when providers, staff and others gather to concur on goals with a family and/or to form plans for a clinic day, event, or improvement process.

Medical Home — The medical home is a community-based primary care setting that provides and coordinates high quality, planned, family-centered health promotion, acute illness care, and chronic condition management — across the lifespan.³ The American Academy of Pediatrics (AAP) believes that the medical care of infants, children, and adolescents ideally should be accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. It should be delivered or directed by well-trained physicians who provide primary care and help to manage and facilitate essentially all aspects of pediatric care. The physician should be known to the child and family and should be able to develop a partnership of mutual responsibility and trust with them.

Medical Home Neighborhood Mapping — A tool used to identify a family’s current support system and network of service providers, in other words their medical home “neighborhood.” These are often used alongside similar “maps” that identify child and family relationships and medical health history in a visual manner.

Plan of Care — By intention the plan of care is a comprehensive and integrated, concise and user-friendly set of information, which guides care. It includes at least two core components: a “**Medical Summary**” and “**Negotiated Actions**” and sometimes includes emergency and legal documents.

1. Adapted from *Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework*, Antonelli, McAllister and Popp.

2. Adapted from *Consensus through Conversation* by Larry Dressler.

3. Definition provided by the Center for Medical Home Improvement (www.medicalhomeimprovement.org)