

# The Care Conference A Tool for Family Centered Care

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I have nothing to disclose. I do not intend to discuss any unapproved/investigative use of a commercial product/device in my presentation.

# Objectives

- Highlight the role of the Patient/Family Centered Medical Home
- Discuss the need for Care Coordination that is Relational
- Discuss the Care Conference as a tool for Care Coordination



# The Problem: for those with Children with Complex Health Needs

- In multiple surveys, families report feeling abandoned by the health system
- More than half of families report at least one parent having to quit work for pay in order to care for child, almost 2/3 report financial problems
- Reported unmet needs include
  - Limited access to subspecialists, especially dental and mental health
  - Lack of help navigating the system
  - Assistance with significant financial burdens
- 4 in 10 families “very dissatisfied” by medical services
  - Poor communication among providers
  - Duplicative services, multiple poorly coordinated appointments requiring unnecessary travel
  - Limited access to community services

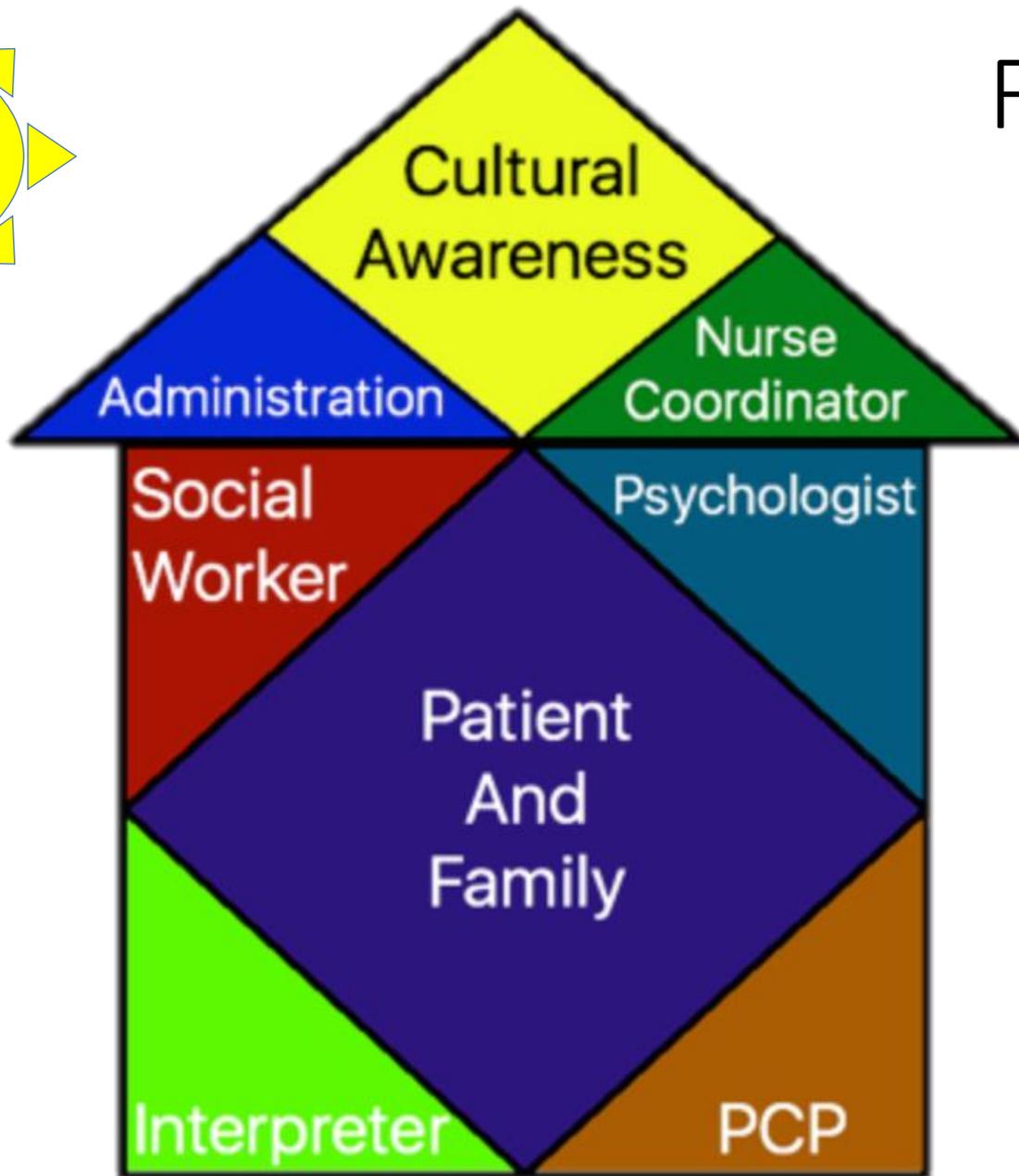
# Children with Medical Complexity and their Families

- High family stress, both emotional and financial
- Isolated and powerless in a fragmented healthcare system that is difficult to navigate
- Higher rates of depression, anxiety, sibling distress, mourning, child maltreatment and marital conflict
- Job loss, absenteeism and bankruptcy
- Mental health and respite care are among the most common unmet needs.



Psychosocial Factors in Children and Youth With Special Health Care Needs and Their Families Gerri Mattson, Dennis Z. Kuo, COMMITTEE ON PSYCHOSOCIAL ASPECTS OF CHILD AND FAMILY HEALTH and COUNCIL ON CHILDREN WITH DISABILITIES Pediatrics January 2019, <https://pediatrics.aappublications.org/content/143/1/e20183171>

Kuo DZ, Cohen E, Agrawal R, Berry JG, Casey PH. A national profile of caregiver challenges among more medically complex children with special health care needs. Archives of pediatrics & adolescent medicine. 2011 Nov 1;165(11):1020-6. <https://jamanetwork.com/journals/jamapediatrics/fullarticle/1107633>



# Family Centered Medical Home

Comprehensive primary care that is a **partnership** between empowered and informed families and prepared primary care physicians



**Community  
Collaboration**

*Family centered care is about meeting families where they are, and helping them get where they want to go...*



# Why is a FCMH important to families?

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

# What is Care Coordination?

- Helping to connect kids and families to the right services and resources in all areas of the child's life not just their medical care
- Helping to coordinate and communicate among these services to improve the health of kids



# Which Children and Families benefit from Care Coordination?

- All children but especially children with high need, high utilization, and medical technology
- Children and youth with special health care needs
- Complex medical needs
- Complex psychological needs
- Complex social needs
- Lots of different services and care providers

Examples: children/youth with:

Cerebral palsy

Ventilator dependency

Seizure disorder

Autism

Eating disorders

Major Depression

Attention Deficit Disorder

Substance Use Disorder



# Need for Communication can be a lot!

insurer email home  
specialist dentists prescription  
ssta transportation early intervention  
physical therapy prior authorization  
speech language pathology  
community partners nursing  
phone call occupational therapy  
equipment social services interpreter  
doctor therapist  
pharmacy  
school

# What are the goals of Care Coordination?

The goals are to provide integrated care for a child or youth through care that is:

1. Patient and family centered
2. Proactive, planned and comprehensive
3. Promotes self-care skills and independence
4. Emphasizes cross organizational relationships

So that optimal health and wellbeing can occur.



# Care Coordination should

- Connect children to services
- Facilitate provider communication
- Support families as primary caregivers
- Address the interrelated medical, social, developmental, behavioral, educational, and financial needs of families.
- Benefits across all levels of the health care system, from improving delivery of services and decreasing family burden to reducing health care costs and utilization.



# Care Coordination is not Case Management

- Case management primarily focuses on a child's main issue
- Case managers work with and guide services intrinsic to their specific agency, often within the constraints of eligibility criteria.
- Care coordinators work with and guide the team process, which includes and is driven by the needs of patients and families for services across the community
- These functions include care planning and building collaboration/partnerships with all medical and nonmedical providers working with a patient/family

# Care Coordination is Relational Coordination

*“A mutually reinforcing process of interaction between communication and relationships carried out for the purpose of task integration.”*

- Relational coordination values the quality of communication and the quality of relationships between families, patients, providers, and partners and is essential for care coordination.
- When you know each other it is easier to talk with each other and you have more ownership to make sure tasks get done



***“Successful care coordination takes into consideration the continuum of health, education, early child care, early intervention, nutrition, mental/ behavioral/emotional health, community partnerships, and social services (as well as payments for these services) needed to improve the quality of care for all children and youth including those with special health care needs, while acknowledging the importance of language and culture in achieving desired outcomes.”***

# A Care Conference is a Tool to make sure Care Coordination is happening



- Helps the family have all the care providers in one space and one larger conversation together
- Helps address family and child concerns
- Helps identify care roles
- Helps avoid duplication of services
- Helps uncover missing services
- Helps with communication challenges
- Facilitates relational coordination

# Organizing the Care Conference

- Medical home takes the lead for care conferences
- Education team organizes IEP, 504 and EST meetings
- Department of Children and Families, school and others organize Act 264 meetings
- Care Conferences are set up by Nurse Care Coordinators or Social Workers in the Medical Home



# When do Care Conferences need to Happen?

- When there is need to clarify the care plan
- Newly identified needs or changes in needs
- Transition of medical care providers
- Transitions of community supports, educational teams
- Concern about duplication or missing services
- Annually or biannually to check in, review, revisit and reaffirm the care plan
- When the family, medical team, education team or community support teams request one

# Case Example



- A 3 year old with Autism is transitioning from CIS to EEE
- Her last care conference happened after her diagnosis with Autism Spectrum Disorder
- Numerous changes are going to happen in her care team
- There are concerns that more services are needed to support the family

# Where Do Care Conferences Happen?



- The Medical Home
- The hospital setting
- The family home
- At a community agency or school
- BUT the coordination is usually provided by the Medical Home

# Setting up the Conference

1. Coordinate with the family
2. Determine the Need for a Care Conference
3. Determine who needs to be invited to the Care Conference
4. Set the Date for the Care Conference
5. Set the location for the Care Conference
6. Send a reminder about the Care Conference

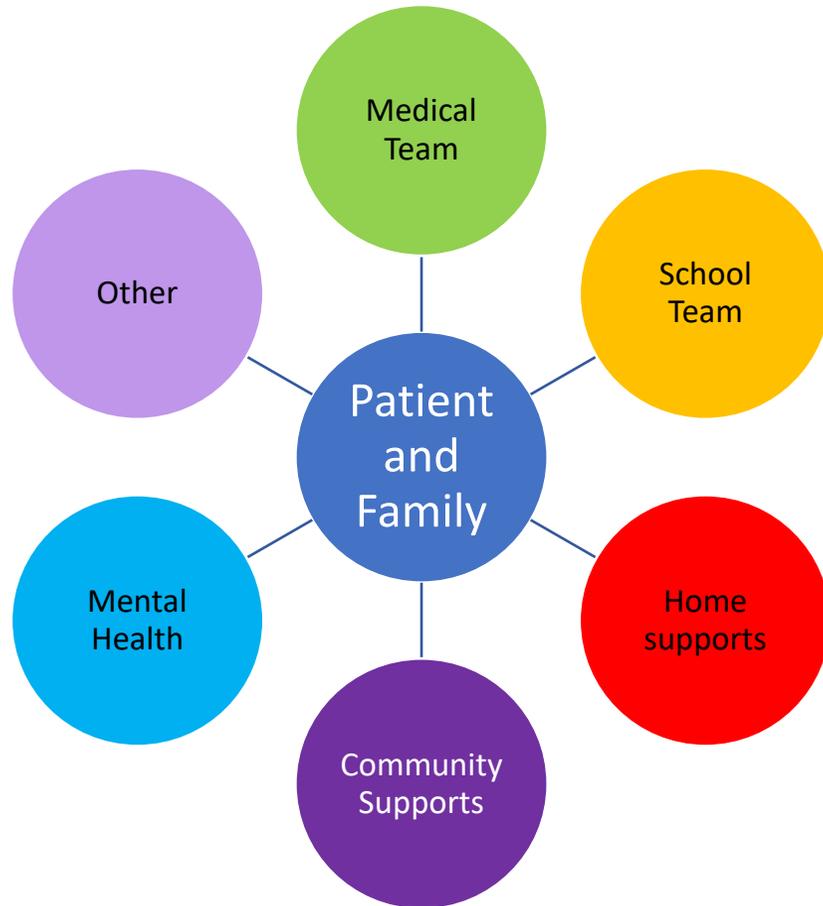


# Who Is invited to a Care Conference?

- The child or youth's caregivers:  
parent/s or guardian/s
- The child or youth (can chose not to attend)
- Primary Care Provider
- Nurse Care Coordinator or Social worker
- Other care providers involved?



# Ecomapping or creating a Care Map



**Medical Team:** PCP, nurse care coordinator, social worker, specialist doctors, interpreter, dietician

**School Team:** teacher(s), SLP, OT, PT, early educator specialist, principal, school nurse

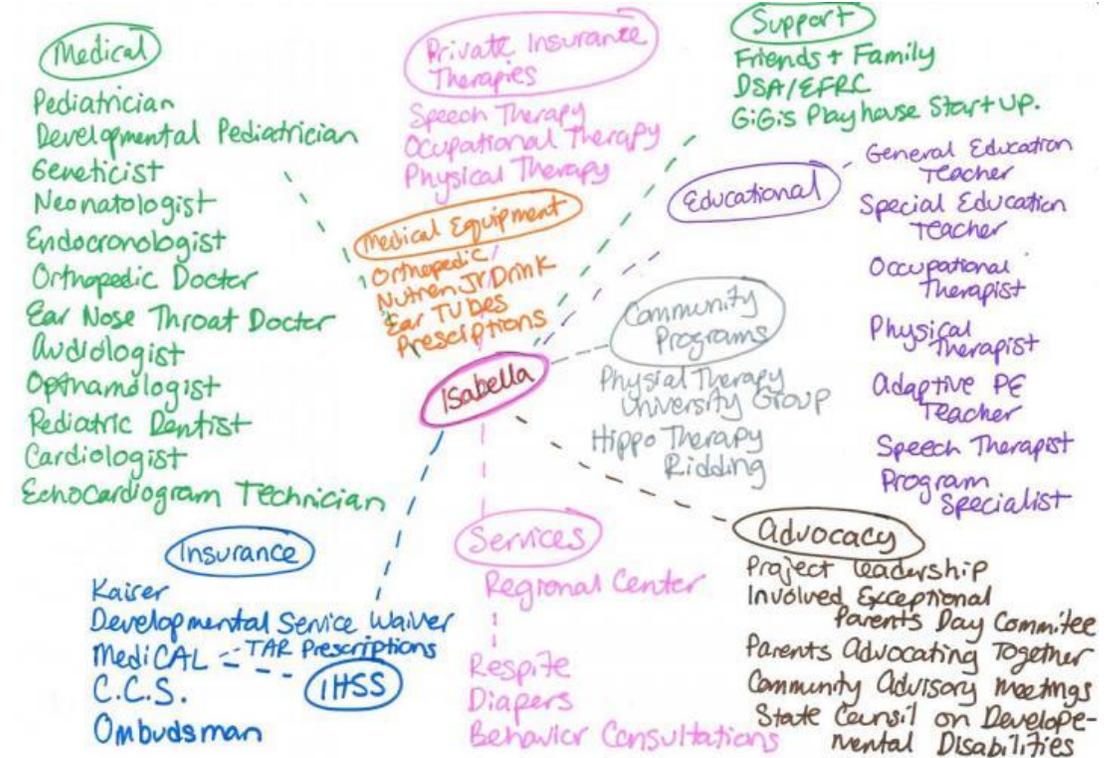
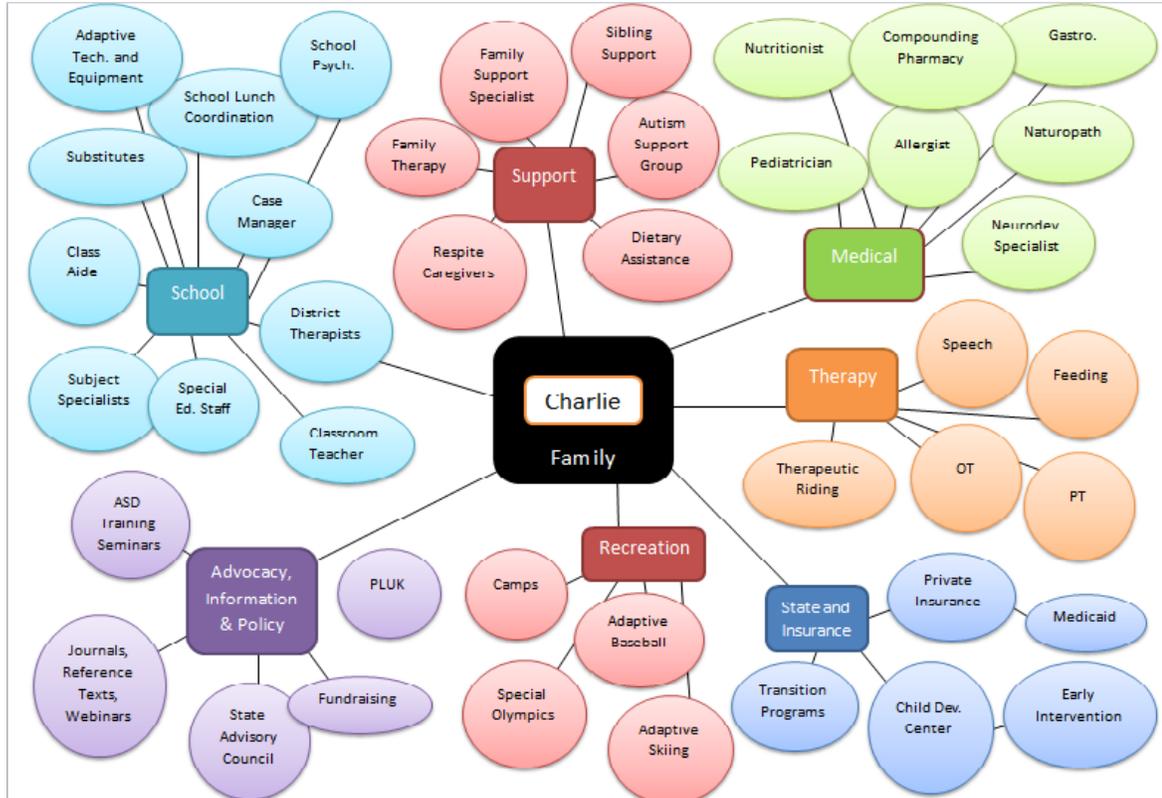
**Home supports:** VNA, CIS, SLP, OT, PT grandparent

**Community support:** pastor, imam, Family Room, VFN

**Mental Health:** psychologist, Howard center, CSHN SW

**Other:** dentist, pharmacist, naturopath, traditional healer, medical equipment/technology support

# Care Maps: The Ecosystem of Care and Support



# Starting the Care Conference

## Interpreter Rules

Please observe our ground rules:

- Speak directly to the LEP patient or family member (use first-person)
- Allow the interpreter adequate time to interpret all communication
- No side conversations
- Keep your questions and statements short and simple
  - No technical terms/slang/abbreviations
  - Break up more complicated concepts if possible
  - Encourage the interpreter to set limits if needed



# Confidentiality

## Confidentiality Rules:

- HIPPA
- FERPA
- **All parties will keep information shared in the care conference private and confidential, unless we have permission to share information from parents/caregivers**
  - Providers and interpreters can face serious consequences for violating confidentiality

# Release of Information

UVM Children's Hospital Pediatric Primary Care  
Authorization to Exchange Health Information

Patient's Name: \_\_\_\_\_ Date of Birth: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

I authorize UVM Children's Hospital Pediatric Primary Care to exchange health information about my child with the providers and agencies I have listed below for the purpose of care coordination, evaluation, diagnosis, and/or treatment.

Including the following information:  Medical  Educational  Social  Mental Health  
 Screening Reports

The following methods are acceptable to me (check all that apply):

Written  Verbal  Electronic (email)

Contact or Resource	Resource Name/Address	If revision, Initial & date
Other Physicians		
School or Educational Services		
Developmental Services, CIS-EI or EEE		
Therapy Services (PT, OT, Speech Therapist)		
Mental Health Services		
Home Health, VNA, or CIS-Nursing & Family Support		
Other, e.g., WIC		
Other		

### I understand that:

- I have the right to *withdraw or modify* this authorization at any time by submitting a written notice to the Privacy Officer or Health Information Manager. This will not affect information sharing that already occurred on the basis of this authorization
- I may *refuse to sign this authorization*. Such refusal will not affect services that I may receive from the UVM Children's Hospital Pediatric Primary Care
- I may inspect or copy the protected health information described by this authorization, except in the case of confidential adolescent health information

### Expiration Date:

- This release will expire on \_\_\_\_ / \_\_\_\_ / \_\_\_\_, or  
*If no date is stated, expiration is 2 years from date signed.*

Signature \_\_\_\_\_ Date \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Printed Name \_\_\_\_\_

Relationship to Patient \_\_\_\_\_

Original to Patient Record

Copy to Patient or Guardian

# Agenda and Note Taking

- FCMH Pediatrician, Nurse Care Coordinator or Social worker run the meeting, take notes and get release to share information
- The agenda is driven first by the family
- Care team members share celebrations and concerns as well and direct the agenda secondarily

Sample Note Template:

## **Care Conference for patient X**

**Date**

### **Agenda**

Attendees/Interpreter Guidelines

1. Family Updates and Goals
2. Medical Updates
3. School Updates
4. Other service Updates

### **Goals**

### **Action Items**

**Upcoming appointments:**

**Next Care Conference:**

# Family Centered Care Conference

- **FIRST:** Family shares celebrations and concerns
- **THEN:** Care team members give information to the family and share with the other care team members
- Strengths and concerns are acknowledged
- Family is encouraged to ask for clarification, to ask questions and to advocate and negotiate

Every time you talk with a health care provider  
**ASK THESE 3 QUESTIONS**

- 1**  
**What is my main problem?**
- 2**  
**What do I need to do?**
- 3**  
**Why is it important for me to do this?**

# Case Example



- Introduction to new care team members
- Family shares that they have noticed more talking by their daughter
- Family wants services in the home still, shares concerns about transportation and isolation from community
- EEE school team shares service will happen now at school and describes what supports and how often, new team members describe what they will do to help with language and social skill development
- Primary Care provider supports clarifying diagnosis of autism
- Social work team commits to exploring needed community supports

# Shared Decision Making (SDM)

- Families (and patients) have a fundamental right to understand all reasonable options and the arguments for and against each option.
- Components of SDM process
  - Family, patients (youth), and pediatricians are involved in decisions about treatment.
  - Information is openly shared.
  - Each decision-maker openly expresses opinions or preferences about treatment options.
  - Final decision is reached by consensus and mutual agreement.
- SDM is one of six priorities for patient-centered care.
- SDM with decision support reduces health care costs

# Actionable Shared Care Plan: the things *to do list*

- Action Items are identified
- Action items are assigned
- Shared Care Plan updated
- Follow up visits are planned
- Next care conference is scheduled
- Notes of the conference are shared.



# Shared Care Plan

- Builds community collaboration and communication across services
- Builds knowledge base of services and system of care
- Determines most appropriate referrals, reducing duplication and fragmentation.
- Builds the capacity of primary care to provide long term chronic care management
- Addresses systems issues and barriers proactively (i.e. financing, insurance poverty, access to care)



# Shared Care Plan

## Examples of Templates and Tools to Create the Shared Plan of Care

- [“Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs” report, Lucile Packard Foundation for Children’s Health](#)
- [“Care Plans: Best Practices for Development and Implementation” webinar, Patient-Centered Primary Care Institute](#)
- [Developing an Effective Care Plan clinical support module for pediatric residency education #3, American Academy of Pediatrics](#)
- [Care planning resources, National Center for Medical Home Implementation](#)
- [Care Plan Template, National Institute for Child’s Health Quality](#)
- [“Care Planning Resources” Web page, National Institute for Child’s Health Quality](#)

### **Shared Plan of Care: A Tool to Support Children and Youth with Special Health Care Needs and Their Families**

Barbara Wirth, MD, MS, and Alex Kuznetsov, RD, *National Center for Medical Home Implementation and the National Academy for State Health Policy.* <https://medicalhomeinfo.aap.org/tools-resources/Documents/Shared%20Plan%20of%20Care2.pdf>

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

This report outlines the principles for the shared plan of care model and recommends core content for an integrated and comprehensive shared plan of care for children, youth, and their families. The report includes a 10-step process, outlined below, for creating an effective shared plan of care.

- Step 1:** Identify who will benefit from having a care plan.
- Step 2:** Discuss with families and colleagues the value of developing and using a comprehensive and integrated plan of care.
- Step 3:** Select, use, and review multifaceted assessments with the child or youth, and family.
- Step 4:** Set shared personal (child and family) and clinical goals.
- Step 5:** Identify other needed partners, that is, subspecialists, community resource providers, and others, and link them into the plan of care process.
- Step 6:** Develop the plan of care “Medical Summary” and merge with “Negotiated Actions” in step 7.
- Step 7:** Establish the plan of care “Negotiated Actions” and merge with the “Medical Summary” in step 6.
- Step 8:** Ensure that the plan of care is accessible, retrievable, and available.
- Step 9:** Provide tracking, monitoring, and oversight for the plan of care.
- Step 10:** Systematically use the plan-of-care-model process as a life course and a population health approach.

# In Summary: Care Conference

- A facilitated, family-centered one hour (usually) meeting among the family, primary care, community providers, schools, formal and informal family supports
- to facilitate detailed communication about strengths, challenges, current services, and gaps in services.
- And create a coordinated plan of care with shared goals, resources, and work load distribution among providers with family input and consent that informs the shared care plan.
- Care conferences address communication issues, needs of the family and helps to resolve identified and anticipated needs.

# Questions?

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