



Strategies to Maximize Collaboration with your Health Care Team

Team Building and
Communication

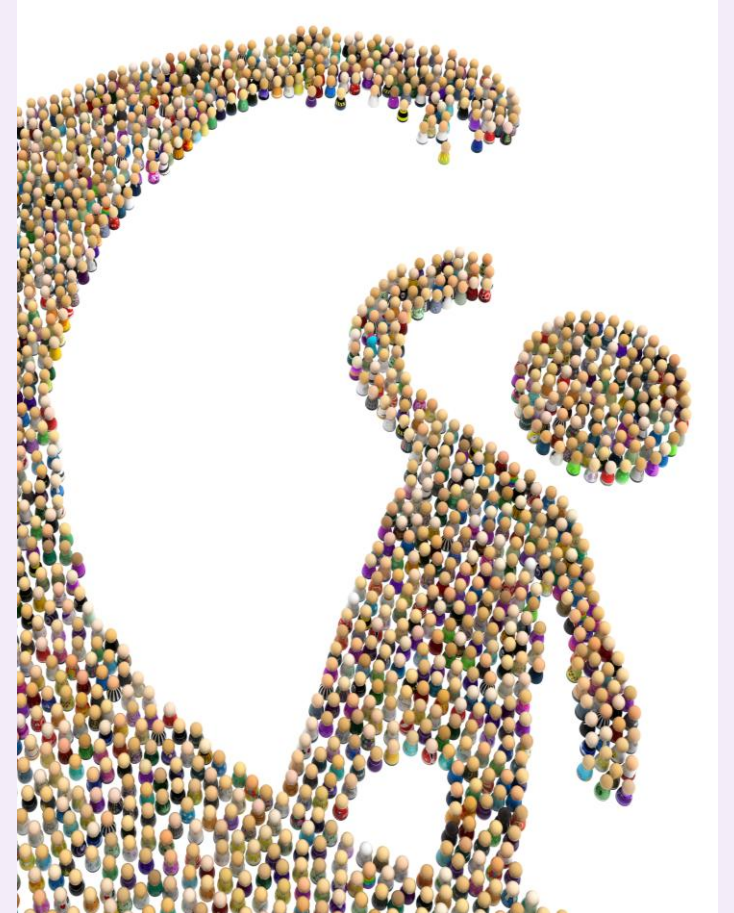
Acceptance takes time

- From a recent study of families of children and youth with complex medical needs, we heard that struggles with acceptance often occur when caring for a child with a medically complex disability
- The chaotic nature of multiple systems of care, and related stress and fatigue, can reduce a family's ability to advocate effectively for their loved one

Radu, M., Moldovan, R., Baban, A., 2022; Families with Complex Needs: An Inside Perspective from Young People, Their Carers, and Healthcare Professionals. *Journal of Community Genetics*, 13:293–302 <https://doi.org/10.1007/s12687-022-00586->

Some possible barriers to effective advocacy:

- Complicated medical jargon and conditions.
- Hard to access and organize multiple systems that provide different kinds of care
- Exhaustion and lack of available respite care
- Ongoing health problems, depression and/or anxiety, isolation
- We and our loved ones may face stigma from the outside world



Strategy #1: Think about what you need

- Acknowledge when sadness or frustration is crowding in
- Give yourself permission to see stigma where it exists and move past it as actively as you can to advocate for your child
- Find other people who are in the same boat when you can
- Get mental health treatment for yourself when you know you need it
- Seek help to find reliable respite services in your community
- Be sure to schedule your own preventative health care visits!

Strategy #2: Prioritize planning

- Families of CYSHCN (and youth and young adults), need and want close guidance from their medical team
- They want to know exactly what they need to engage in a full life at home, in school, and in the community, to the best of their abilities
- They need to know how to access all the tools and services that will support this - some of these might be:

Families need:

Clear information about how to access care across specialties, such as vision, mobility, specific rehabilitation therapies, dialysis, more

Detailed information about how to acquire the coverage they need to pay for these services

Support to organize applications, appointments, and payments to multiple systems of care, including the use of phone apps (e.g., EPIC)

Above all, they need a concrete **Individualized Care Plan** in place to coordinate and oversee the services needed to ensure health, safety, and engagement with community

Planning: First steps

Establish a working relationship with a medical practice, whether a Medical Home or the local medical clinic or practice



Schedule a first appointment to talk through your intentions to create an inclusive and **Individualized Care Plan**

What is an Individualized Care Plan?

A detailed, personalized plan that supports individuals with a range of complex health and social needs, including physical, behavioral, and emotional challenges

These plans aim to improve outcomes by coordinating care across various settings and services, which helps both the individual and the family's well-being and independence

Casau, A, (2025). Families as Partners: Transforming Child Health Care Together. Center for Health Care Strategies Blog, January 19, 2025.

Important Elements of a Care Plan

- A full evaluation of your child/youth's medical, social, functional, and emotional needs
- Setting individualized goals that align with your child/youth's preferences and values, involving them and your family in the process
- Advocate for an Interdisciplinary Team of healthcare professionals, social workers, and support staff working together to provide coordinated care, including Care Coordination

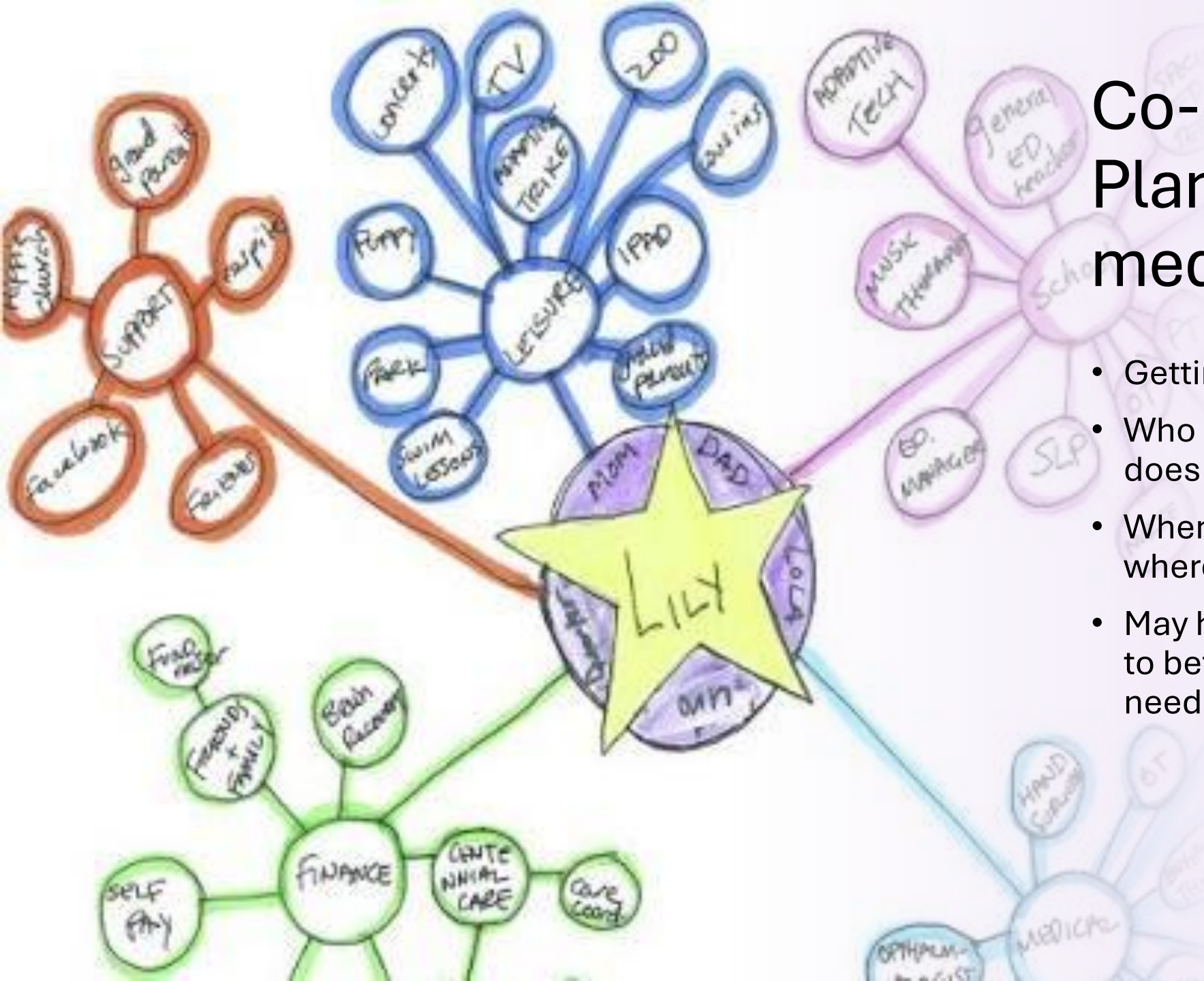
Important Elements, continued

- **Document** how communication and collaboration between you and the team members will happen
- **Detail** how they plan to set, review and adjust goals as needed
- **Talk about and make plans for barriers** that might affect your child's health and well-being, such as housing, financial stability, and access to transportation
- **Plan** to always advocate for a person-centered approach
- **List** individual's unique needs and preferences, making sure that their values and wishes guide the care process

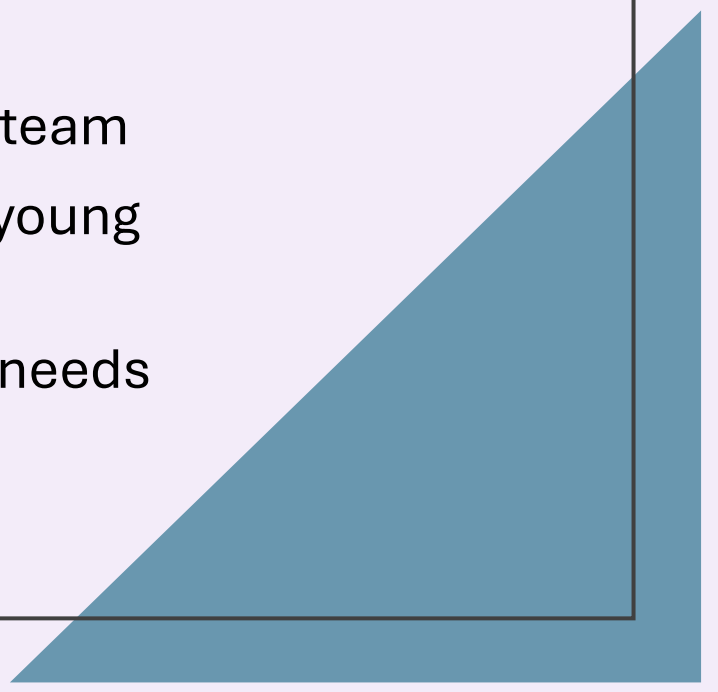
American Academy of Pediatrics - National Center for a System of Services for Children and Youth with Special Health Care Needs. Retrieved from: <https://www.aap.org>

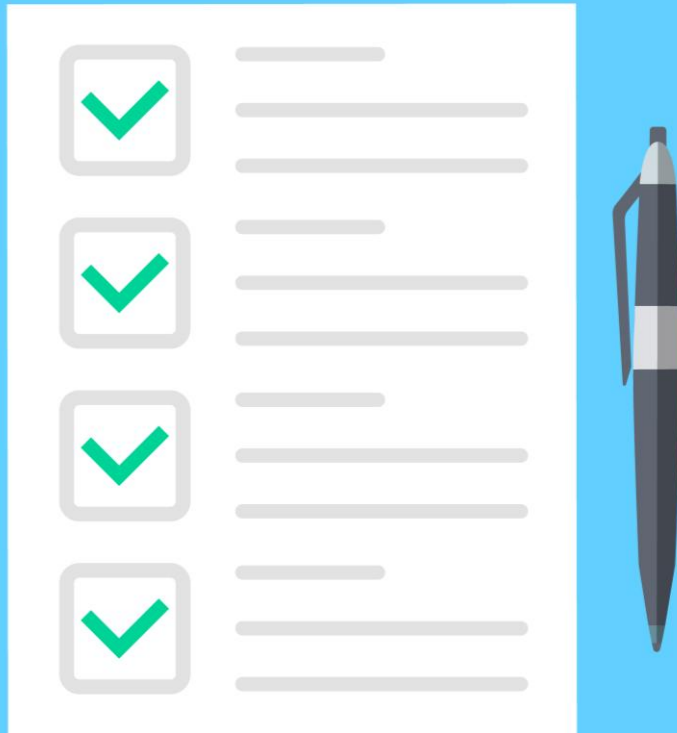
Co-create a Care Plan with your medical team

- Getting started:
- Who is on your team? Who does what?
- When do you see them and where are they?
- May help to make [a Care Map](#) to better understand your own needs and routines



Creating a Care Plan, continued

- **Collaborate** with Care Team to create an individualized Care Plan
 - Use **Shared Decision Making** in all interactions with your team
 - Use **Supported Decision Making** to directly include your young person
 - Include **how your child or youth will communicate** their needs and thoughts (sign, AT device, gestures, eye movements)
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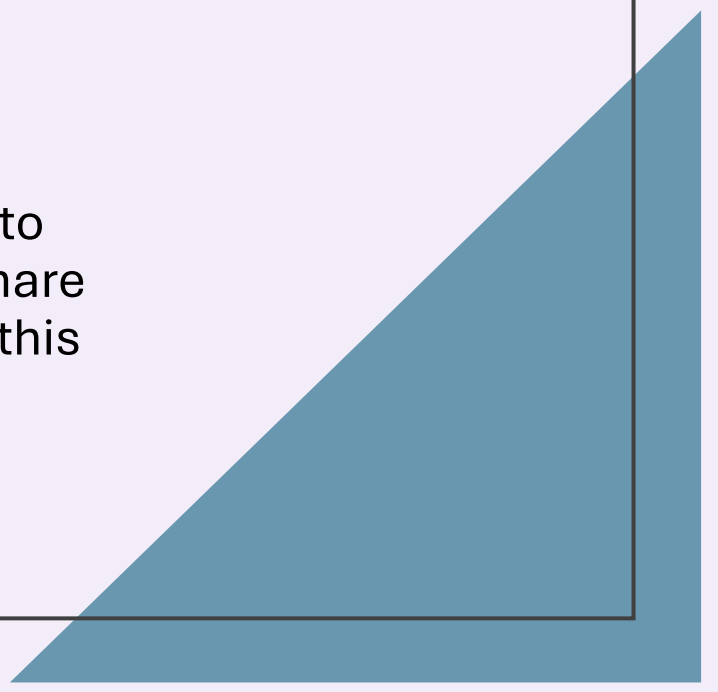
3: Optimize communication before, during and after appointments

- **Before the appointment:**
- If possible, schedule pre-appointment session
- Practice the questions you want to ask, and write them down
- Create an Emergency Information form that you will keep updated to hand to a doctor under emergency circumstances as well as at a scheduled appointment

Emergency Information Form

- Parent(s) name and contact, primary language
- Child/youths primary mode of communication
- Primary and current specialty physician (s)
- Preferred ED, pharmacy
- Diagnosis and past procedures, baseline vital signs
- Current medications
- Medication to be avoided
- Procedures to be avoided
- Common presenting problems with specific suggested managements
- Support strategies in case of difficult behaviors
- [Sample Form from Pacer](#)

During the appointment

- Be clear about your goals for the appointment
 - Listen. Ask Questions. Clarify
 - Check your body language
 - Talk about concerns from the point of view of “Interest” (I’d love to have someone work with Zack to use a speech device, please share your thoughts) rather than a demand or “Position” (I need to get this service ASAP).
 - Stay open to brainstorming a range of solutions
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After the appointment

Make	Make sure to take any notes home and put them in a dedicated file folder
Update	Update your Emergency Form accordingly
Share	Share updates with other members of Care Team as needed

Thank you! In your breakout rooms,
consider this:

When you think about your role in your work,
where does “advocacy” fit in? What is
something you could do within your practice to
make it easier for families and self-advocates to
use their voice and truly feel heard?