



How Shared Care Plans Help Children with Special Needs and their Families

BY LAUREN AGORATUS, M.A.

Shared plans of care are records of health information communicated with the medical team and patient. This allows primary care providers, specialists and others to communicate with each other, as well as allowing access to essential medical information to families of children with special needs.

Why Does Your Child Need a Shared Care Plan?

Sometimes children with special needs have multiple conditions which could be affected by each other. For example, my daughter had a kidney transplant, and when radiology wanted to do a scan with contrast for gastrointestinal bleeding, the GI doctors consulted with the renal specialists and re-calibrated the amount of dye used as it could affect kidney function. A shared care plan allows all physicians and the family to be on the same page.

Shared plans of care also minimize medical errors, reduce adverse outcomes, and avoid duplicative tests and procedures. These plans allow for supported decision-making and shared responsibility for children's care. The U.S. Department of Health and Human Services' Maternal and Child Health Bureau is fostering increased use of shared plans of care through funding grants to states on Integrated Community Systems for Children and Youth with Special Health Care Needs. The shared plan of care goal for these grants is: "1. Care Coordination: By October 2017, states will increase by 20% over baseline, the % of targeted CYSHCN who have a Shared Plan of Care."¹

Shared plans of care are a strategy to help achieve a "medical home" in which care is:

- family-centered
- coordinated
- continuous
- compassionate
- comprehensive
- culturally competent

What's In a Shared Care Plan?

A shared care plan should have all the basic information important to efficient

medical care of the child. This would include a short list of diagnoses, providers, hospitalizations/surgeries, medications, etc. Other considerations would include team roles, access to community resources, patient education resources, allergies, and emergencies.

It is important that care plans are implemented in a way that is sensitive to the family's culture and goals for their child. There must also be consideration regarding health literacy and increasing involvement of children and youth in their own healthcare decision-making. See Resources section for examples of shared care plans.

How Can Families Partner with Professions on Shared Care Plans?

Besides the primary care physician, parents are the ones most likely to have all the medical information about their child. This is particularly important during hospitalization. Families can let the team know of any precautions that need to be taken. For example, rather than just giving medications at the usual intervals, parents may have information from the pharmacy on which medications interact with others. Or perhaps specialists want to perform multiple procedures under anesthesia, some of which could be combined to reduce risk. Families can participate in shared decision-

making and better help coordinate the care of their child through use of a shared care plan. It is essential to remember that children will also need to learn to self-advocate for their healthcare. There is a great resource in English/ Spanish that children with special needs can use for regular doctor visits or post in their hospital room called "My Health Passport" (see Resources below).

Parents of children with special needs can partner with their child's medical providers through the use of a shared plan of care. The primary care physician and specialists can also communicate effectively through the use of this tool. Shared care plans can reduce medical costs and, more important, result in better health outcomes for children with special needs and their families.



ABOUT THE AUTHOR:

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References

1. https://mchdata.hrsa.gov/dgisreports/Abstract/AbstractDetails.aspx?cbAbstractSummary=D70MC28872_2015_NonResearch_2&tbKeyword=&rbKeyword=All

SHARING IS CARING : RESOURCES FOR SHARED CARE PLANS

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AMERICAN ACADEMY OF PEDIATRICS Care Plan for Child with Special Needs

www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Documents/Integrated_Care_Plan.pdf



FLORIDA CENTER FOR INCLUSIVE COMMUNITIES My Health Passport (for children)

http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf (English)
http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_Spanish.pdf (Spanish)



PATIENT CENTERED PRIMARY CARE INSTITUTE Examples of Shared Care Plans

www.pccpi.org/sites/default/files/resources/Shared%20Care%20Plans_0.pdf



LUCILLE PACKARD FOUNDATION

Achieving a Shared Plan of Care with Children and Youth
with Special Health Care Needs
(includes information for providers on implementation)

www.lpfch.org/sites/default/files/field/publications/achieving_a_shared_plan_of_care_full.pdf