



National Center for Cultural Competence
Georgetown University Center for Child and Human Development
Centers for Excellence in Developmental Disabilities

Is Your Youth With Special Health Care Needs Prepared to Partner With the Medical Home?

Felecia Jordan Da-Silva is the parent of three young adults. One of her children has a chronic health condition and the other has a special health care need. Ms. Jordan Da-Silva is an advocate and activist for education and health issues for children and youth with special health care needs. She has worked at the state and local level, served as a member of the Federal Interagency Coordinating Council (FICC) and is an active advisory committee member of the Children and Youth with Special Health Care Needs Project of the National Center for Cultural Competence. Ms. Jordan Da-Silva and her family reside in Detroit, Michigan.

Change causes us to make many transitions in life. Youth with special health care needs and their families experience more transitions than typically developing youth and their families. Building and having a trusting relationship with my medical home and/or medical providers have been critical to these transitions of managing the health care of my two children, now young adults, with special health care needs. I had to know and feel that I was part of the decision-making process for their effective care and treatment. Knowing the process, and helping to make decisions, was important to me. This was the case, if for no other reason than to be able to manage our household, which included their sister, and to be able to maintain a job outside of the home. I strongly believe that information sharing needs to take place at all levels of the care and treatment planning process. Their medical team had the medical knowledge and skills to provide proper care and treatment, and my youth and I had the day-to-day, most current information, including medical records, to determine the effectiveness of the care and treatment plans. That is, we knew which plans were working and which ones were not working. Thus, a partnership of mutual respect, true information sharing, and cooperative decision making is vital to ensure that youth with special health care needs stay as healthy as possible.

Some transitions that take place in the life of a youth with special health care needs include changing the medical home, doctors, providers, health insurance, and surgery. Then new relationships must be built and new partnerships must be formed. Having a relationship without having a partnership is possible, but both are critical, along with complete information sharing, to maintain continuity of care for youth with special health

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care needs and their families. These critical factors play an active role in the lives of my daughter and son. Therefore, my young adults have no time to lose because of the transitions taking place in their medical team. I realize that it is a luxury to have current and new medical providers talk to each other before any of these transitions take place, but it is not always possible. For this reason, it has been a privilege and a blessing for our family to have had the same medical home for 16½ years.

We are currently in transition, rebuilding a specialty medical team for my daughter and changing medical homes for my son. I have included some of the steps I am taking to make these transitions smooth for my young adults, their current and new medical providers, and me.

My young adults with special health care needs and I have:

- ✓ worked with their doctors, and involved them as much as possible;
- ✓ made sure that their medical records were transferred in a timely manner;
- ✓ felt that it was critical to incorporate both my parental input and their input as the patients;
- ✓ made sure that they are able to describe clearly what is happening with their bodies;
- ✓ followed the decisions that were made about their care, showing our trust in the medical providers;
- ✓ felt confident in what we knew about them as individuals and as part of our family;
- ✓ considered the whole family as decisions were being made, knowing that such decisions might affect them and our family beliefs;
- ✓ accepted the transference of responsibility/control for their care and Individualized Education Plans (IEPs) when they were about eight years old, involving them as equal partners in decision making; and
- ✓ decided that it is essential to have a clear understanding of your child's/youth's abilities and special health care needs.

Teaching your children or youth with special health care needs about their abilities and disabilities helps keep things real. As transitions occur, you should have a conversation with them about what is going on, using words, descriptions, and/or pictures that they understand. You must try not to sugarcoat their disabilities. At some point, these children or youth will have to face reality. You, the caregiver/family member, must own where they are, and they must learn how to own who they are.

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Here are some ways to make the most of visits to your health care provider:

- ❑ Keep a diary (use a log or calendar) to track reactions and/or improvements to the care and treatment for assistance with further treatment planning.
- ❑ Develop a medical résumé that includes a medical history (from birth to the present), medications, care and treatment and their outcomes, surgeries, and other vital information that needs to be available in case of an emergency or a medical record is not available. Ask your Social Worker/Service Coordinator to help you gather information.
- ❑ Have questions ready before each visit.
- ❑ Take all medications with you to every visit, even if the doctor you are visiting did not prescribe them.
- ❑ Ask for more time when scheduling the next visit, if needed; most visits last 15 minutes.
- ❑ Ask whether you can use a tape recorder to make sure all the information is correct; you also can share this recording with other family members or providers and/or review the information to be clear on instructions for care.

Transition, an ongoing process, is inevitable in life. We continue to learn more about ourselves from our medical providers, other adults with special health care needs, and other families like ours. As we continue our journey, we encourage you to follow some, if not all, the same steps, because they have proven to be very beneficial in my caring for and preparing my young adults to manage their own health care needs some day. I urge you to become genuinely concerned and involved and to build strong partnerships with your child's medical home/health care providers. Good health care is a very important part of your child's staying healthy and taking full advantage of LIFE!

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