Norman Ospina is a co-parenting, single dad. When you ask his son, Rajon Amaru, how old he is, he responds that he “has” 7 and ¾ years. In Spanish, one’s age is expressed as how many years a person has inside of them. Norman, along with his family, emigrated from Colombia to the United States 37 years ago. In 2010, Norman moved to Oakland, California, to be present for his son’s birth and to help raise him in a multilingual and multicultural community. One of their father and son rituals is celebrating half birthdays. Norman says, “It’s a good way to practice math fractions.”

Rajon Amaru has spina bifida and receives services from the California Title V program. Norman credits the Title V services “[for having] a tremendous positive impact on our son’s life, medical well-being, and physical development.” In particular, the occupational (OT) and physical therapy (PT) services that Rajon Amaru receives contribute greatly to his physical independence, emotional awareness, and overall health. There is really nothing that Rajon Amaru cannot do anywhere, compared to other typically developing second graders.

Norman is adept at helping Rajon Amaru practice the lessons he learns in school. He is also expert at helping his son execute the skills he is taught by the Title V California Children’s Services/Medical Therapy Unit (CCS/MTU) where occupational and physical therapists help him, for example, to learn to tie his shoelaces and to safely go up and down stairs. These Title V services and supports help ensure that Rajon Amaru can live a happy, healthy, and independent life filled with curiosity and dignity.

The OT that Rajon Amaru receives can later be used at his two homes to help him learn to brush his teeth correctly and wash his hands appropriately. Coupled with self-catheterization assistance that Rajon Amaru receives from Kaiser Permanente’s Spina Bifida Clinic, these are excellent ways to practice personal care and develop strong hygiene habits. This is important, as personal hygiene helps prevent many secondary health issues. In addition, healthy habits learned when children are young help promote overall health and wellness, a healthy self-esteem, and a positive attitude throughout the lifespan.

Rajon Amaru’s PT sessions involve more than stretches and exercises. The therapist also teaches him to put on and take off his braces properly, to inspect them carefully for exposed and broken rivets and cracked plastic, as well as to advocate for himself. As Rajon Amaru has limited sensation on his feet and shins, he can easily become injured by wearing braces that are damaged, broken, or not properly placed on his feet by his assigned caregivers in other settings, such as school. Inspecting his skin and braces on a daily basis is another important part of overall health and injury prevention. Individuals with spina bifida are prone to skin injuries that can affect the underlying tissue.

Whenever possible, Norman is present during Rajon Amaru’s therapies, collaborating with his son’s Title V partners, who are aware of and respect the fact that parents know their children best and are of primary importance to their children’s continued growth, well-being, and comfort. Norman appreciates that the Title V staff publicly acknowledge that parents are the ones who “breathe daily life, love, and creativity into the ongoing OT and PT work that needs to happen at home, at school, and in the community in between visits, in order for it to be the most effective.”

When Norman and Rajon Amaru are together, they work to reinforce his stretching and core muscle-strengthening regime. It helps that Norman and Rajon Amaru love nature and spending time outdoors. When they go to the beach, Norman reminds Rajon Amaru to inspect

**Holistic Title V Services Open up World of Opportunities for Father & Son**
his feet, especially between his toes, as pebbles or the hot sand that Rajon Amaru doesn’t feel can damage his skin. They also enjoy the many woods and hills in the Bay Area. While the braces help Rajon stay upright, maintain his balance, and reduce stress on his back and ankles, hiking and climbing help strengthen Rajon Amaru’s leg and abdominal muscles. Father and son also wrestle and play football and soccer. Norman admits that at first he was hesitant to play sports with his son, but has taken them up because Rajon Amaru requested and enjoys them.

Norman states that the Title V therapy services are holistic and have opened up a world of opportunities for physical activity for Rajon Amaru. While many parents fear their children with special health care needs will get hurt if they participate in activities that other typically developing children do, such as bicycling or climbing up and down steep ravines, Norman feels that the CCS/MTU services that Rajon Amaru has received since birth have helped him to develop the confidence and curiosity necessary to safely and bravely explore all that his community has to offer.

For example, when Rajon Amaru wanted to participate in a gymnastics program for young children at his afterschool program, his CCS/MTU physical therapist accepted Norman’s invitation to come to the program to look, listen, and demonstrate ways that the staff could modify their activities so that Rajon Amaru could fully participate. In addition, Rajon Amaru and his parents willingly answer teachers and students’ questions about spina bifida so they can further understand why Rajon Amaru needs braces to help him walk as well as possible. Rajon Amaru is not self-conscious about his braces and feels that wearing them to help him walk is as natural as people wearing glasses to help them see.

Like many children with special health care needs, Rajon Amaru receives services from multiple systems of care. There have been times when Norman felt that some providers did not welcome fathers as equal partners in decision-making. Even within CCS/MTU, when Norman asked whether Rajon Amaru could have two types of braces, a PT said “no”, and was not willing to discuss it further. Norman contacted a supervisor to explain his request, and the supervisor apologized for the PT’s response, emphasizing that CCS/MTU fully values parents as partners because they know their child the best and are the experts on their child.

Today, Norman’s involvement with his son’s therapy has grown to a larger systems-level partnership with the California Title V program through its California Children’s Services Family Advisory Council. The council is sponsored by his employer, Family Resource Navigators, where Norman is being trained as a family navigator. Part of his work includes providing emotional support to parents and helping other families, including other dads, navigate the systems of services to ensure their children with special health care needs are connected with the services and supports they need to lead happy, healthy lives.

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