



Champions for Inclusive Communities

Star Community

Orange County, VA

As a rural area with beautiful scenery and a rich, patriotic history, residents of Orange County, Virginia have numerous reasons to be proud. Among these sources of pride is their devotion to providing coordinated services to children, youth, and their families. Although the community is somewhat small (the population hovers at about 28,000) and spread out, service providers and agencies have come together to address the needs of families.

Janice LaPrade, Orange County Office on Youth and Interagency Council program planner, says of the area, "For a small community, we have a lot of things to offer." One of those organizations the community offers as a resource to families is the Office on Youth, a 25-year old agency that connects organizations in the community to work on the specific need of a child or youth.

Interagency Council: Pulling Everyone Together

The Office on Youth makes many of these connections through their Interagency Council. Representatives from a large number of agencies in the community are present on the council. Their quarterly meetings are used to pull everyone together to discuss ideas about making services more accessible to children and youth. Everyone from schools to the health sector to parks and recreation can be represented at any time, showing that this is truly a community-based effort. Dr. Diane Pappas, pediatrician at University of Virginia (UVA) Pediatrics at Orange says, "The Interagency Council is really amazing – when you go around the table, you can find out all the things others are doing and how we can connect. Being in the same room really facilitates those connections."

One of the visions the Office on Youth has is to create a "cheat sheet" of every agency in the community that could benefit families, along with contact information. Janice envisions a small, accessible flier-type handout that would be distributed anywhere, including at community venues such as health fairs and to Interagency Council partners, allowing them to disseminate to their own clients.

Tools to Increase Cultural Competence

University of Virginia Pediatrics at Orange is a strong believer in cultural competence. The staff there has found that one of the biggest cultural issues in their community is the difficulty of providing effective communication between the schools, health care providers, and families that overcomes cultural, linguistic, and other barriers. These barriers can limit families from understanding and participating fully in the educational process. UVA Pediatrics at Orange has partnered with the UVA Children's Hospital education program to have an educational consultant on-site for this very purpose – to act as a "middleman" between schools, families, and health care providers.

Another extremely helpful tool in ensuring good communication with families of other cultures is the use of a translation phone service called CyraPhone. This handy blue phone is located in Dr. Pappas's office and with one phone call she can request instant translation services into any language the family on her end needs. Using a speakerphone, both parties can hear the other clearly, and healthcare information is communicated with little to no hassle.

Keeping CYSHCN in Mind

Orange County's Office on Youth is not designed specifically for children and youth with special health care needs. However, it is not an unaddressed issue. In fact, Dr. Pappas has found that most of the children and youth who visit her practice have some kind of special need. Much of this is due to the demographics of the area: Orange County, as mentioned above, is very rural and underserved. The community, however, makes a great deal of effort to reach out to those with special needs.

One parent of a son with special health care needs, Dori Boggs, is thrilled about the pediatrician her son sees at UVA Pediatrics at Orange. Dori and her family moved to Orange County

What makes a Star Community?

ChampionsInC has created the Star Communities program to recognize exceptional communities.

Star Communities will show excellence in 6 Performance Measures:

- Families are partners
- A "Medical Home" provides coordinated care
- Children receive early and continuous screening
- Families have adequate funding/insurance to pay for services
- Services are organized so families can use them easily and are satisfied
- Youth receive necessary services to make the transition to adult life

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three years ago. It took a whole year after moving, but Dori eventually found out about the local Head Start program and immediately enrolled her son. The most beneficial result of taking that step was the Resource Handbook given to her by Head Start. In it, she pinpointed Dr. Marilyn Brown, her son's current pediatrician at UVA Pediatrics at Orange, and found she was lucky to have done so. Dr. Brown, and the practice as a whole, was progressive thinking and willing to work well with other facilities such as the transplant center where her son was also receiving services.

Medical Home Embedded in the Practice

Because the community is relatively small, UVA Pediatrics at Orange treats about half of the children in the county. Partnering with Blue Ridge Care Connection for Children, which is part of a statewide network of services for CYSHCN, UVA Pediatrics at Orange has an on-site case manager to coordinate with other subspecialty clinics. These clinics are oftentimes located in nearby Charlottesville, and the coordination of appointments makes it possible for families to make the minimal amount of trips for outside care. In addition, some pediatric subspecialty services such as pediatric cardiology and nephrology now provide services to families at the Pediatrics at Orange facility. Putting two and two together, this means that the practice is providing a coordinated medical home for nearly half of the children and their families in the community. This is an impressive feat for one practice, and one that is appreciated by families who only have to make the one-hour drive to Charlottesville a minimum number of times.

Sharing the Screening Load

Orange County has a number of methods for ensuring developmental screening is completed for children in the area. Pediatricians at UVA Pediatrics at Orange provide routine developmental screening to all patients and make referrals for any of the children they see who show a "red flag." Blue Ridge Care Connection for Children also performs screening for children and youth and refers them on to the appropriate specialty services in the community. Many of the specialty services even continue screening the child as they receive services from their practice over time.

Transition

Dr. Pappas admits that transition to adult life is by far the most difficult thing for Orange County. It is particularly complex for a small community such as this one because there are never enough resources, and many adult health care providers are uncomfortable or simply inexperienced when it comes to treating

adults with disabilities. Because of this, many youth fall into a "black hole" between pediatric and adult health care. UVA Pediatrics at Orange is hoping changes in transition will come soon, though. One promising detail is that a recently hired nurse practitioner at an adult health care practice in the area has expressed an interest in working with patients transitioning to adult life. UVA Pediatrics at Orange has an educational consultant who works with the schools and their assigned Department of Rehabilitation Services staff to identify educational and job training opportunities for youth with special health care needs. Case managers there also work with these youth to find a way to keep their social security and Medicaid benefits while still being able to work at a job and live independently.

Transition within the health care system for younger children with disabilities is fairly well addressed. Dawn Martin from Blue Ridge Care Connection for Children points out that one of the goals of their program is to help children smoothly transition to early intervention, Head Start, and so on. Once the child is ready to transition to the school system, Dawn also helps coordinate the medical aspect of the child's IEP.

One grandparent (and primary caregiver) of a child with special needs, Mark T., has been greatly satisfied with the help he's received in transitioning his 5-year old granddaughter from program to program. In his experience, every agency was efficient in making sure the correct files were transferred and preparing him in advance for the switch. In his words, "[Blue Ridge] Care Connection for Children, Orange Pediatrics [Pediatrics at Orange], and the UVA system all worked together, and it was easy for me. I always felt prepared."

Making Connections

In a nutshell, Dr. Pappas says, "You learn that you can't do this alone. You have to connect to meet all of the needs – they would just overwhelm you if you didn't." Orange County has continued to successfully provide services to children, youth, and their families by ensuring agencies such as UVA Pediatrics at Orange, the Office on Youth, and Blue Ridge Care Connection for Children are all working together. Dawn from Blue Ridge Care Connection for Children also points out the impact Dr. Pappas has had on the community: "She is right on the mark when it comes to coordination for kids with special health care needs. It's good to have a doctor on board who knows what it takes." This good leadership, combined with community-oriented agencies and effective partnering with existing resources, has made for a highly successful system of services and supports for CYSHCN and their families in this community.

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