

Meeting the Special Needs Challenge in Rural Areas:

Coordination, Cooperation, and Communication

By Cheryl Ann Hughes

In the best of circumstances, getting services for a child with special needs can be time consuming and frustrating. When that child lives in a rural area, issues that aren't a concern for families in urban and suburban settings are sometimes more complicated and can have a huge impact on the ability of a child to receive the services he or she needs.

Rural residents — and the social services organizations that serve them — are faced with numerous obstacles as they work to ensure that children with special needs get the appropriate services.

Complicating the situation in Virginia is the fact that by nature, many issues vary from locality to locality. What may be a problem for one rural area is not for another. And the system has to be flexible enough to handle these regional variations while still providing consistent care. It's a delicate balancing act to say the least.

Coordination

The sheer size of the area that needs to be covered can be the biggest obstacle to consistent service in a rural location. Often, community services are provided regionally in rural areas, meaning that one particular Community Service Board (CSB), for example, may be responsible for providing services to a number of counties. The Crossroads Services Board, for instance, services a region that includes seven counties and over 2800 square miles.

Darlene Warsing, program coordinator for the Parent Infant Education Program of Northwestern Community Services says,

"Transportation is the number one system needed." Her program offers services to four counties and one city in the Northern Shenandoah Valley area. "People have a difficult time accessing services that are far away," Warsing adds, "If a resource is 15 miles away, it may mean a door closed to many families because of the lack of available transportation. This includes regular and specialized health care, dental care, or other services. Although we try to provide the majority of our services in the natural environment, lack of staff and travel distances hamper 100 percent achievement of that goal. We do provide options for families in their county of residence."

One bright spot in the transportation scene is a pilot program currently operating in Darlene Warsing's district. Known as the Northern Shenandoah Valley Public Mobility Program, a group of human service and non-profit agencies across the region have been working together to coordinate the transportation needs of their clients.

The goal of the program is for agencies to reach more people in need by working together in a cooperative manner to make better use of existing transportation resources.

By using a common centralized and Internet-based system for transportation operations, an agency receiving a trip request for one of their clients can check the availability of its vehicles and those of the other agencies. If an agency can't provide a ride for one of its own clients, it can submit a "ride request" over the system indicating origin and destination location, day of week and time, number of passengers, client type and agency, and so on. Then

dispatchers at participating agencies can review the request, decide whether to accept it and incorporate the new stops into their vehicle schedule.

"Once deployed and tested, this could be a model for rural transportation coordination," says Mike Hite, director of the division of continuing care for Northwestern Community Services and project manager for the Northern Shenandoah Valley Public Mobility Program. This type of coordination and cooperation among agencies could be critical in helping families access appropriate services.

One twin-edged sword for rural families is the federal early intervention mandate that if a child is eligible for services, those services must be provided in the child's "natural" environment. This can be the home or child care facility, a park or playground, or anywhere the child would normally be if he/she did not have special needs.

This means that therapists need to travel, sometimes hours from their own business areas, to provide services to children with special needs in rural areas. And this can be a huge burden on the local early intervention program that must contract with the service providers.

"It's extremely hard to get services to clients in rural areas," says Beth Reed-Treadway, Council Coordinator at the Infant & Toddler Connection of Blue Ridge. Many providers are not willing to travel long distances, limiting the number of providers an agency has to work with. Often, the agency must pay providers an additional amount over the amount covered by insurance.

These financial issues are often

problematic. Because rural agencies often don't have in-house service providers, it can be necessary for a community-based agency to contract services out to private providers. Insurance payments are then paid directly to the provider for services within the community. These days, reduction in insurance payments can make it impossible for community service agencies to pay the fees of private providers.

Communication is Critical

Another area that can impede a family's ability to get the required services for their child or children with special needs is communication. Linda Chik, a coordinator for Parent Education Advocacy Training Center (PEATC) says, "Because the geographical area that community services have to serve is so large, it's possible that families don't know about the services that are available."

Families may not realize the wide range of services that are available or the wide range of special needs that are eligible for services. This type of information is available, but families often don't know where to look for it...or possibly don't know that they need it.

This is where community awareness and cooperation come in. Sometimes, because of the rural nature of communities, communication is much less formal than it needs to be in a metropolitan area. Agencies that might be in separate office buildings on opposite sides of town in a metropolitan or suburban area may share office space — or be right down the hall — from one another in a rural community. In Rockingham County, preschool screenings are advertised in the local newspapers as well as in school newsletters. Meetings of the Special Education Advisory Council are open to the public, although only the members may vote. And regional coalitions exist to share ideas and programming among members from a group of counties and cities.

"Because we're smaller," says Rebecca Hill-Shifflett, Supervisor for Special Education in Rockingham County, "we're able to communicate on a more close-knit level."

Hill-Shifflett states that neighboring counties work closely together on many issues regarding special needs. Currently, the county is participating in a grant program to improve transition along with Shenandoah, Page, and Augusta counties, as well as the cities of Staunton and Harrisonburg. "It's very exciting," Hill-Shifflett says of the progress of the transition pilot program in place. "It's a great resource for parents, students and everybody involved in the IEP process."

Referrals, too, are integral to the system in rural areas, coming from professionals, family members, and even family friends. "People become creative about ways to get to know a family largely because the size of area serviced is so big," says Darlene Warsing, coordinator of the Shenandoah Regional PIE program.

In Warsing's district, there's a well-developed system of referrals which begins at the regional hospital's neonatal intensive care unit (NICU). Parent Infant Education (PIE) staff attend weekly discharge planning meetings at the NICU, and referrals are made on discharge. All referrals are made to the Central Point of Entry at PIE. A temporary service coordinator is then assigned to guide the family through the IDEA Part C enrollment process. After the developmental evaluation is completed and the Individualized Family Service Plan (IFSP) developed, appropriate early intervention services begin.

For children who do not meet Part C eligibility, but are "at risk," families are offered enrollment in the Ages and Stages Tracking system. A bi-monthly letter is sent with age-appropriate developmental milestones, and families are encouraged to fill them out and return to PIE. "If at any time the child shows a delay or at the family's request, we provide a full evaluation," says Warsing. "We don't want them to be out there without any support." Warsing adds that parents have been very receptive to this option. "Last year, 45 families participated; three children showed signs of delay, were evaluated and entered the PIE program."

Knowledge is Power

More than anything else, parents in rural areas need to know their rights and the rights of their children. Armed with information, a parent can often be his or her child's greatest advocate. That information is available, and it's important that parents know where to look for it.

PEATC coordinator Linda Chik believes that families should contact their local CSB, which receives funding for mental health and mental retardation, as soon as they think their child may have a special need. "Once the CSB has a child in the case management system," says Linda Chik, "it is better able to respond should an emergency situation arise."

The school system, too, is an important link to CSB. Chik states that the relationship between the family and the school is critical if a family is to be able to obtain the services they need. If the school district has a Parent Resource Center available, it is another wonderful resource in negotiating the sometimes winding curves of the special education system.

Parents with concerns about their preschool-aged child can call their locality's Infant and Toddler Connection's Central Point of Entry phone number (see p.54) to talk to someone about their child's behavior or condition. Virginia's parent training agency, PEATC (see information on p.40), also offers help through various workshops and training sessions. "People have the right to get access to services for their children," says PEATC coordinator Linda Chik. And those rights extend to all parents. Whether they live in a thriving metropolitan area or a small rural community, every parent wants the best for their child with special needs. And every child deserves nothing less. ■

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