

THE ROLE OF ADVOCACY IN PARENTING A CHILD WITH DISABILITIES

By Jane Anthony



Editor's Note:

This article first appeared in the 2004 Southwestern edition of *Celebrating Special Children*.

As you read this resource guide and wind your way through the maze that is the service system, I would like to stress how important it is to become your child's advocate. Parents don't plan to have a child with disabilities, and most of us have no training in special education, developmental medicine, behavior management or all the allied fields like physical therapy and specialized diets. After learning about your child's needs and where services are available, you will find over time that obtaining those services now—and in the future—involves an ongoing process of advocacy.

WHEN YOUR CHILD IS YOUNG

The early years with a child who has special needs are focused on reframing your life and getting your feet on the ground. Resource guides like *Celebrating Special Children* are essential for getting started in the right direction, working to get the services needed for your child and building a network of helpful professionals along the way. These early years, with the support of the school system and the IEP process, are the time to learn the ropes and become an active participant in identifying and getting the services your child needs. It is important to find and work closely with the professionals who can mentor you along the way. Contacts and connections with other families and groups become your support network for helping to find or create needed services.

VALUE OF A DIAGNOSIS

A diagnosis, to the degree possi-

ble, is the foundation for both knowing what to expect and for getting services. The more specific the diagnosis, the more effectively you can advocate for what you really need. Thanks to advances in genetic science and other research, many disabling conditions can be diagnosed at an early age.

Early diagnosis enables parents to align themselves with one of the many affinity groups that are specific to certain conditions. An affinity group, especially in the age of Internet technology, allows access to support groups, scientific research, experts, best practices and an electronic "lifeline" to learn the coping mechanisms that work for particular syndromes. Groups help give parents an understanding of the ramifications of their child's disability and what services and treatments will be of assistance. Armed with this knowledge, the role of parenting a child with disabilities expands to include the role of advocate.

BECOME THE EXPERT ON YOUR CHILD

While it is important to learn from the professionals, you cannot leave all the decisions to them. Professionals may offer a number of different opinions. However, they can also be overworked and may give a more generalized treatment when your child needs something more specific, or you may simply disagree. You need to have reasonable expectations in order to know what progress looks like. For some who need the specialized care provided in residential facilities, quality services with good oversight are the essentials. For

others, whose children may be higher functioning, services come with labels. These higher functioning children are well aware of and may resent the labels that come with services. It is a balancing act...and knowing your child is paramount. Throughout the process of advocating for your child, you will need persistence and the courage of your own convictions. There is no one-way to go—this is uncharted territory and you will learn as you go.

LOOKING TO THE FUTURE

Although you will always need to focus on the present, it is also important to have an eye to the future. Children do not stay young for long, and the more you can plan for the future, the better the outcomes will be. While your child is in the educational system is the time to hone your advocacy skills in order to anticipate and get the essential services your child will need after graduation. Families need to have two types of strong organizational affiliations—one that is diagnosis-specific and another that has built into its mission statement the need to address the general welfare of our "children" with disabilities. Without parent advocacy you can't be sure whether necessary services for your child and the children of others will be available when needed.

MAKING SURE SERVICES ARE AVAILABLE

Parents need to advocate for services in their county and state as well as nationwide. These are rough economic times, and services for adults with special needs are sorely lacking.

Although educational services are mandated by law and continue until a child with disabilities is 22 years old, states have discretion on funding and living options after that. Virginia is very low in national rankings for funding human service needs in spite of the fact that our state has one of the highest per capita income rates. Families often feel abandoned by the state at critical times when many of the parents/caregivers are themselves growing older and facing the bleak prospects of long waits for service. Other families are fearful of losing the current services that their family member with a disability now receives. Getting and keeping these services is not an easy task.

To maximize the potential of our special needs children, parents need to be informed and support issues of mutual concern like Medicaid funding, the rights of parents and their children who are eligible for special education, transition planning and the need for a continuum of care options. Through organizations like VOR (Voice of the Retarded) and ARC (Association of Retarded Citizens), parents/caregivers have various opportunities to be heard on issues of state and national significance. (See p. 90 for additional advocacy resources.) It is important to take advantage of these opportunities: get familiar with the positions of the different groups, attend conferences and workshops, go to hearings, write letters, help families one-on-one, etc. Those who own a computer and are connected to e-mail can join list-servs to stay involved and

informed. For families that have limited resources, including single-parent families, the support of local, state, and national parent networks are all the more necessary. You will be surprised what a huge difference your involvement and that of others like you can make in the future of your child and others' with disabilities.

ADVOCACY IS KEY

Analysis of national data comparing the states reveals that it's the willingness of citizens to advocate, rather than wealth, education or other factors that explains the difference among state levels of funding for necessary disability services.

Effective advocacy depends upon having the necessary credible information to place before decision makers. For example, it is primarily the role of government to measure, provide and report on the quality and availability of services. Quality measures arise from systematic in-depth evaluations and effective oversight, while availability measures include information on what is available, recording how many are in need of services, how many are receiving services, how long families have to wait for services, and what choices families are given.

Disability issues are nonpartisan and they affect all of us regardless of wealth and ethnicity. We are one big disparate family whose children need services in the setting that is most conducive to their welfare. Each disability segment of the population is a minority and a fragment of the whole. We therefore need to work

together to increase funding for the full continuum of services. To succeed in today's economic times, disability groups must form coalitions. Although legislators tend not to pick sides if there are disputes or competition for resources among disability groups, they do tend to support proposals in which everyone wins. Get to know your legislator and offer to work on children's issues. Don't be shy—let your legislator know your child has special needs. Ask where he/she stands on issues of importance to you. We need to affect change locally, statewide and nationally. The parents who came before us were responsible for so many of the programs that now benefit our children. We in turn must insure the future by continuing to push hard to get the necessary programs and funding.

EVERY EFFORT COUNTS

Many parents eventually move from individual advocacy—worrying about the day-to-day issues affecting their child's care—to collective advocacy, which considers the bigger question of "how can I be sure these services will be available for all families?" There is a need for both types of advocacy. Recognizing that every person with special needs has unique strengths, abilities and needs, we must work to establish a full array of supports. In every case, the final determination of what is appropriate depends on the needs of the individual and choices best for them. Advocacy is what parents can do to help make the world better for their child and other children like them. ■

THINGS I WISH I'D KNOWN

These are just a few of the things I wish I had known when my son was an infant. Keep them in mind; it may make everything else a little easier to handle.

- *There is no "cookie cutter recipe." This is a major readjustment to your life and time and effort and the support of family and friends will help you along your way.*
- *Don't shoot the messenger: People who tell bad news often get the brunt of it: Remember, information is power.*
- *Don't expect easy instant answers - learning about your child and becoming his/her advocate takes time- it is a process and there is no right or wrong answer.*
- *Maintain a sense of humor.*

— J.A.

