## Point-of-view article by Sally McCormick; ghostwritten for Dave Richard Published in The News and Observer IABC Gold Quill winner

By all accounts, the Special Olympics North Carolina Summer Games were a great success. But can North Carolina claim the same success "off the field?"

North Carolina's own track record for meeting the needs of North Carolinians with developmental disabilities puts us in almost last place. According to The Arc of the United States, North Carolina has the sixth largest waiting list per capita in the U.S. for services for individuals with developmental disabilities and their families. Currently, there are 7,178 people on the waiting list in North Carolina. Over 2,000 of these people have been waiting for services for more than two years.

And the number of people on the waiting list is expected to continue to grow. In just the past year, the number of people on the waiting list increased 23 percent.

The waiting list issue in North Carolina is a crisis.

Additional funding is needed to meet the needs of individuals with developmental disabilities and their families. With services, many of these people can become active, productive, contributing members of our communities.

The cost of providing services for people with developmental disabilities is not prohibitive, and, over the long term, is a cost-saving measure for North Carolina taxpayers. Many services allow individuals with developmental disabilities to live and work in their own communities at a third of the cost of a residential facility. These services also allow children with developmental disabilities to achieve more significant levels of independence and productivity as adults.

Take, for example, Kayleigh of Apex. She is seven years old and has autism. She and her family have been waiting for over three years for services such as self-help skills, personal care, necessary therapies and respite care. However, if the family can't get these services soon, the only other alternative her parents may have is to place their daughter in a residential facility where she will be given these services at a cost that is five times as much as the inhome services for which they are currently waiting.

There are also many examples of lost potential because of lack of funding for services. Kelvin of Orange County, who has cerebral palsy, has received job training and wants to work, but instead spends his days sitting in front of a TV set. He is waiting for supported employment services that will allow him to become a productive member of the workforce.

By providing services from an early age, significant savings can be realized later. Abbey, of Wilmington, is a five-year-old girl who has Rett Syndrome. Because of her developmental disability, she will have long-term and severe challenges related to daily living, communication and mobility. Research indicates that ongoing and aggressive therapies are necessary and can even prevent some of the chronic physical and medical complications related to this syndrome. Yet she has been stagnating on the waiting list for almost two years.

Often, insurance does not cover the services and therapies that individuals with developmental disabilities and their families need. The recently passed CHIPs legislation which provides health insurance to children in low-income families also does not provide for these services. Kathryn of Burgaw has had to sell her home to pay for the services her child with autism requires. And Derek's insurance company does not recognize autism as a disease, so his family has no insurance to cover the speech and occupational therapy Derek needs.

But the waiting list is not strictly a financial issue. It is a matter of conscience.

It is an outrage that people with developmental disabilities often have to wait years for services such as physical therapy, diapers, respite care, job training and group homes. Rather than helping to provide ongoing care for individuals with developmental disabilities and their families, North Carolina is forcing families to exhaust their own resources, exhaust themselves and their support networks and often to make choices they don't want to, and shouldn't have to, in order to get the help their children need.

Through the Special Olympics, we are able to realize the potential that children with developmental disabilities have in athletics. We are amazed at their accomplishments. But their ability to achieve isn't limited to the playing field.

Individuals with developmental disabilities can learn and hold jobs, can participate in community activities, can live at varying degrees of independence. With services and community supports, individuals with developmental disabilities can achieve their potential and live with dignity.

Governor Jim Hunt has been quoted as saying, "The challenge before the legislature this year is a simple one: to put our children's future first." Let's not forget the children with developmental disabilities, or the adults, and their families. There is legislation pending that will provide the additional funding required to cut the waiting list in half in the next year. With the support of North Carolina's legislators and citizens, we can eventually eliminate the waiting list.

As North Carolina turns its attention to the 1999 Special Olympics World Summer Games being held here, let's take this opportunity not only to showcase the talents and dedication of thousands of people with developmental disabilities but North Carolina's own efforts and commitment to serving our citizens with developmental disabilities and their families.

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