

## **Courage: The Foundation of Strength**

**By: Dr. Gertrude A. Barber**

It is no coincidence that May, the month traditionally dedicated to mothers, was chosen as Mental Retardation Month in Erie and Erie County of Pennsylvania. Repeatedly through my career as a teacher, administrator and eventually as founder of the social service agency dedicated to working with persons with disabilities, I saw the courage of mothers.

The wait for a baby is a time of joy for the whole extended family and, in a very special way, for the mother. Everyone looks forward to the day of joy – the day of the birth. With the birth of a child with a disability many unexpected changes occur. There is the dichotomy of the awareness of the magnificence of birth and realization of the extra responsibilities to be faced throughout this child's life. It is the courage I see in the mothers of these children who realize that they are gifts from God who will enrich the whole family that gives strength to the rest of the family. The mother is the reason: the mother is the courage – the one who says, "We can and will accept this child and we will expect God to help and give us strength." We cannot, however, confuse courage with not understanding the magnitude of the changes a family will undergo. The problems that ensue are sometimes enough to tear a family apart. Our studies show, however, that in this geographical area we see more intact families than the national average.

I have believed through my career that it the responsibility of the Barber Center to assist these families in working through the birth of a child with a disability. First these families have to know that there is hope. It is not as bleak a world as they thought it would be. There are many services available which will make a great difference. They must be made to understand that they need not be discouraged or ashamed – that this is not their fault. This child will need, as any child will need, medical, vocational and educational attention, but to a different degree. They can accept and love this child as they do their other children.

Early intervention is as important for the family as it is for the infant with a disability. These services play a major role in making it possible for the family to keep the child at home by teaching them to understand the difficulties the child will face and what can be done. A team approach opens a whole

gamut of professional services to enrich the life of the child. This was not always so. In any society, including the earliest tribes, there were the more capable and those less capable than average. The impact of the disability has varied with the needs of the society, its expectations and its social consciousness.

In pre-historic society the most seriously disabled did not survive past birth. Infants with severe handicaps were destroyed because they could not become hunters. Even in the intellectually enlightened society of ancient Greece there was little tolerance. Aristotle in his book *Politics* wrote "Let there be a law that no deformed child shall live." During the Middle Ages a rural economy developed and with it a place for the person with disabilities who could function in an agricultural society. The more severely affected were placed in various church or state sponsored foundling homes. Practices varied, however, and some were viewed as witches since retardation was thought to be caused by a devil. By the 17<sup>th</sup> and 18<sup>th</sup> centuries, many children remained home with their parents, though others received mystic or residential treatment. In the 1800s considerable progress was made toward understanding mental retardation, illustrated by Montessori's statement in 1899 that "Defective children were not extra-social beings but were entitled to the benefits of education."

The first hospital for the mentally retarded in the United States opened in Virginia in 1766. In a rural society, persons with disabilities posed no real problem. But as we moved toward an urban society, they were seen as a burden and went to institutions where the residents lived in an agricultural society, raising their own food. When a more sophisticated society developed, these workers became eligible for wages spelling the demise of the large institutions. The problem society confronted was how to care for all those people who were thrust into communities which still viewed mental retardation as a stigma and which still wanted these people segregated from society. Today we have come full circle – from living at home, to living in institutions, to returning to the community. For residents, group homes provide a supervised steppingstone for their return to society. In these homes, the residents are treated as individuals rather than as a group. They are accepted by the community – not just the staff. They experience having a job, earning money, taking responsibility - while living in pleasant neighborhoods. They experience the same rights and responsibilities as all citizens.

One story comes to mind which illustrates the courage of a mother whose child was institutionalized. Mary was five years old when her family was told to place her at Polk State Center for the Mentally

Retarded. (In those days there were no programs as we know them today. A family often had to come to the realization that they did not have the personal resources to keep a child such as Mary at home.) Mary's mother talked to me on many different occasions about the day that she and her husband drove to Polk State Center to leave their daughter. She recalls the gripping feeling as if her heart were being torn from her body – as the attendants took their daughter from them. She recalls feeling her legs go weak and her eyes fill with tears. It was as if it were a bad dream. She silently screamed for her daughter as she and her husband drove back to Erie, Pennsylvania.

Years later, when we were able to open a residential program here in Erie, Mary's mother came to me with hope in her heart and asked if Mary would be brought "home" to Erie to live in this new residential program. It was truly an act of courage for this mother who never forgot her daughter, to come and request care for her. Happily, this young woman did return to Erie and although she lives in a group home, she is as vital part of her family. There are only about 60 Erie County persons still in institutions today.\*

Initially, the answers to the plight of those who returned to their communities lay in the development of group homes. Recently, however, a "family-driven model" in which the family, rather than an agency, receives supervised funding to help with the care of their child has been instituted. Very poignant examples of mothers' courage have come through my experiences in dealing with grandmothers as they, in turn, deal with their feelings about what their own children are experiencing as they learn that a new baby has a developmental disability. Many grandmothers approach the situation serving as the foundation for the family, while silently working through the process themselves. Frequently, it is the grandmother who places the first call for assistance.

One grandmother I know waited as impatiently as the mother for the birth of a grandson. When Billy was born, the doctors in Erie knew that the child had what appeared to be a very rare syndrome. It was the grandmother who researched with our medical staff what this syndrome entailed and where the baby should be taken for the most thorough exam. Outwardly, this grandmother appeared confident, organized and composed, but when she came to talk privately, she wept for her own child and the dreams that might have been. She herself had faced a similar situation as a young mother. And she cried out for the pain her own child would have to endure in facing the future. The staff at our Infant Toddler program has helped this family realize the potential of the newborn and taught the entire family

techniques that will enhance the baby's future. Happily, the grandmother with her untold courage has learned the lessons right along with the Center and on a state level.

Though there has been a great change in society's attitude toward people with developmental disabilities, we still need more awareness of the talents and skills they offer society. Living in their home communities has assisted in educating both their families and the public. Parents have come to accept that their child is different and are actively engaged in the community, their church and other activities. Therefore society, in turn, is more accepting of individuals with disabilities. With training, persons with disabilities can become contributing members of their community. Attitudes are changing from "this poor dear handicapped" to "look at the things these people with disabilities do accomplish."

Of course it takes money to fund educational and vocational programs to help people with disabilities to reach their fullest potential. Lawmakers must realize that persons with disabilities can be gainfully employed in many jobs doing piece-work, in shops, performing outdoor maintenance, restaurant work and serving as aides in nursing homes. The possibilities are unlimited. Society profits from the education and the training of persons with disabilities as they pay taxes and contribute to the community, rather than being supported by the millions of dollars it took to keep the state institutions open. We become richer, more compassionate, more understanding and probably a little more humble as we interact with persons with disabilities. We need more awareness of all persons with disabilities – they are an asset to the community.

God, in His divine wisdom, has made all of us different but we all have strength to others. Even the baby with most profound handicap gives strength to his or her caregiver. Early intervention is as important for the family as it is for the infant with a disability. In the 1950's I remember the Superintendent of Schools asking me "Why bother with this group? Why invest your energies and time on this group of individuals?"

It is my sincere hope that no one will ever again be asked that question.

\*All residents of Erie County have been transitioned back to their communities; Polk State Center is scheduled for closing in 2022.