Elizabeth Seton Pediatric Center: A Residence For Children With Severe Disabilities

Tatiana D. Flowers

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The Elizabeth Seton Pediatric Center cares for some of the most medically complicated children in the North East area of the United States. The facility, in Yonkers, New York, currently houses 137 residents, who all need 24-hour care and treatment. Many residents live with multiple physical and neurological (brain) disorders, which occurred either at birth or from a traumatic injury or accident. There is an admissions process at Elizabeth Seton Pediatric Center, and only the most severe applicants are accepted.

The children’s medical needs are vastly different; some are ventilator-dependent, almost all are physically disabled, and some are mentally impaired. But their daily lives are all affected in some way, shape or form because of their illnesses.

Neurological disorders manifest themselves in different ways. A child could struggle to recognize where their body parts are located, their ability to move could be impaired, language skills may disappear, mood-swings could occur, and their sleep cycles could become irregular. Some examples of more well-known neurological and physical disorders include, but are not limited to: Cerebral Palsy, Bell's Palsy, Epilepsy, Whiplash, Brain and Spinal Tumors, Traumatic Brain Injury, Tourette’s Syndrome, Autism, Muscular Dystrophy, Multiple Sclerosis, Parkinson’s Disease, and many more. Many of the children at Elizabeth Seton have already outlived their life expectancy.

The pediatric center’s core function focuses on education and administering different kinds of therapy. In the morning, every resident goes to school, where they practice different kinds of daily living tasks, depending on their age. Then they are able to participate in arts and crafts, child life activities, or different kinds of therapy such as: physical, occupational, speech, aquatic, music, art, and dance therapy. Most of these therapies are given for pain reduction and to improve overall quality of life.

Since Elizabeth Seton is a pediatric center, by law, a resident must move to another facility before they turn age 21.

For some children, Elizabeth Seton Pediatric Center is all they know. Some have lived there for their entire lives. Others rely fully on their caregivers and therapists for familial support if they have family members who won’t or can’t come visit them. Staff members say this process, known as “aging out,” is one of the hardest stages for families who are involved in their child’s life, but sometimes, it’s most devastating for the children, who sometimes die from a broken heart.

A child will be placed on multiple waiting lists at other appropriate facilities years in advance, depending on their particular needs. When a bed opens up, they sometimes have to leave the next day, without time for a proper goodbye to staff and other residents. Residents often have to move far away because there aren’t enough nearby facilities for individuals with such severe disabilities, so families are forced to move or see their children less often.

Many children end up in geriatric facilities with other resident’s who could be 50 or 60 years older than them, and since they often have neurological impairments, they may seem many years younger than they really are. Because of this, they still tend to still need childcare treatment even after they age out, but geriatric facilities are not equipped to handle this kind of pediatric care.

The pediatric center was previously located in Manhattan, and then moved to its current location in Yonkers, after raising 24 million dollars in funds from donors and grants to house a bigger population. The facility is now creating an extension with those funds to take in more ventilator-dependent children, since that is their specialization.

But parents who are going through the aging out process, Like Mindy Leiter, ask why the facility can’t raise funds to build an extension for children who age out.
Leiter is currently searching for a new facility for her 19-year-old son Jason, and she says she wishes Elizabeth Seton could raise more funds to build an extension to keep the children who age out. Her biggest concerns are finding adequate care for Jason, who has Cerebral Palsy and other health complications, and also the two-hour drive to the new facility she might choose for Jason, which is two hours away in Albany.

Staff members say they hope to be able to someday acquire enough funds to build an additional attached residence center for children once they age out. They say the Health Department is currently working on a plan to address the aging out process, a journey in which many other similar facilities face all around the country. But they would not specify when asked what exactly the Health Department is proposing as a solution.