



I am Waiting!

This is our beautiful daughter, Lily Sophia. Before she was even born she suffered a catastrophic stroke that rendered her critically ill with a devastating form of epilepsy called Infantile Spasms. When she was 10 months old doctors decided that the only way to save her life was to remove the entire right half of her brain. The surgery rendered her seizure-free but left her with visual impairment, developmental delay, and paralysis on the left side of her body.

Lily was placed on the DD Waiver waitlist immediately following her diagnosis in 2007. Shortly after applying to the waitlist, our family received a letter describing that Lily would not be put onto the waitlist, but rather would “fall into a holding pool” of applicants and would remain there until she was 8 or 9 years old and could be given an IQ test to determine if she qualified for services.

We recently called the DD Waiver hotline and spoke to an administrator for clarification about the “holding pool”. We were told that the absolute earliest they would look at Lily’s level of disability and qualification for the waiver would be when she was six but it just depends on the child. When we attempted to question further how the process would work and how to initiate the evaluation she was told that it doesn’t really matter right now because the next allocation is for 2001 applicants so it is a long wait and to call back in a year to make sure they still have Lily’s name and to ask those questions again at that time.

Lily requires daily Occupational, Speech, and Physical Therapy and the use of adaptation equipment such as Ankle-Foot Orthotics. Lily can walk and is beginning to talk. She has the potential to go to college, and become a contributing member of society when she grows up. The level of function she can achieve in the future depends largely on the rehabilitation she receives as a child.

Up until 2009 our family had a private HMO insurance through Lisa’s employer. Paul (father) is a private contractor and did not have access to group insurance. Private insurance left the family with devastating copayments over \$600 each month in addition to high premiums even after employer benefits. In order to ensure that Lily had access to the services she needed Lisa (mother) walked away from a promising career to stay at home and rely on Social Security Medicaid benefits. Our family has not received any respite services and has relied on the kindness of family and friends to fundraise for various modifications to our home. We use birthday money to buy Lily’s shoes and Christmas money to travel to medical conferences. This is a choice countless NM families must make.

Please support funds for Developmental Disabilities Services and end the wait for thousands of children and adults with developmental disabilities and their families in New Mexico.

Waiting List Campaign:

**The Arc of New Mexico*Disability Rights New Mexico*PRO
NM Developmental Disabilities Planning Council**