

March 23, 2015

The Honorable Nikki R. Haley
Office of the Governor
1205 Pendleton Street
Columbia, SC 29201

Dear Governor Haley:

My name is Ann Love Proctor and I am the mother a little girl (4 years old) with Cerebral Palsy. I am writing to ask for your support in making a change in the Social Security Disability eligibility requirements for all children with disabilities.

May 13, 2010, our daughter, Olivia Claire Proctor, was born at 31 weeks in Springs Memorial Hospital, Lancaster, SC and weighed 4 lbs 2 oz. Three hours after her birth, she was airlifted to Carolinas Medical Center's Neonatal Intensive Care Unit in Charlotte, NC where she spent the next five weeks (38 days) on various monitors. Olivia was released and allowed to go home on Sunday, June 20th. On Monday, June 21st, my husband and I took Olivia to our family Pediatrician for her first checkup and the Doctor immediately noted some concerns. Six months later the diagnosis of Cerebral Palsy was reached and was determined to have been caused as a result of a brain injury. It is still unclear as to when or how the actual brain injury occurred.

Following her diagnosis, we applied for Social Security Disability for Olivia. I mailed the package of information to the Department of Social Security Disabilities in Spartanburg, SC on a Tuesday afternoon and the next morning (Wednesday) my husband received a phone call saying Olivia did not qualify for the disability benefits. The Department of Social Security Disability then mailed the entire package back to us without reviewing the contents. We have talked with several attorneys and Social Security Disability representatives and each time we are told Olivia does not qualify because we make over the \$4,000 gross monthly income requirement and because of my retirement from the State. In the meantime, my husband has accepted a new job position with a daily 100-mile round trip commute.

Olivia is unable to walk, stand or sit without support and she cannot dress herself, feed herself, or go to the bathroom without assistance; neither can she securely hold a cup with her hands to drink. She cries out to us during the night to turn her over because she is unable to roll over without assistance. She requires daily home health care and will require a personal assistant during her school hours.

Since Spring, 2011, Olivia has weekly in-home Occupational, Physical and Speech Therapy. We lost the Occupational Therapist in 2013 because the company discontinued their "in-home" therapy sessions. In 2012, Olivia was evaluated and recommended for a stander, walker and specialized stroller at the requests of her therapists. The pieces of equipment were necessary for Olivia's development and were ordered from a company in Greenville, SC. Nearly 2 years later, in Spring 2014, the stander and specialized stroller were delivered. However, the walker was never ordered because the company said they would not be able to recover the expenses of the walker. In July 2014, we turned to another company located in Charlotte to order an Activity Chair with a stroller base and a walker for Olivia, again at the request of her therapists, and were told the Activity Chair could not be ordered due to the fact Olivia's insurance would not cover it because she had received the stroller and stander. The stroller and stander, in question, were originally ordered in 2012 and arrived 2 years later and during which time

Olivia's abilities and needs had changed due to her growth and development. We continue to work with the equipment companies, BCBS and Medicaid trying to obtain the equipment Olivia requires. We also are applying for grants to assist with the costs. In addition, Olivia receives six Botox injections every three months from her Rehabilitation Physician; these injections, one in each of her arms, thighs and legs, are very painful. However, the Botox injections are helping to improve her flexibility and increase her ability to walk with a specialized walker and to sit up with support.

In 2014, Olivia was evaluated by a Nutritionist who said she was under weight for her age and stated that "Olivia will require a feeding tube unless she can gain the weight on her own". Thanks to contacts with other parents of special needs children in similar situations and recommendations from her Pediatrician, we were able to adjust Olivia's diet and increase her fondness for healthy and organic food, more high protein foods, more fresh fruits and vegetables and increased calcium. Within a year, while I maintained a daily log of her food and drink consumptions, Olivia gained slightly over ten pounds and therefore avoided the feeding tube.

There are several medical waivers that our daughter should qualify for because of her brain injury, but she is continuously deemed as "too intelligent" and turned down. It seems that every waiver, grant or assistant program we apply for we are always just outside the boundaries of the qualifications. Olivia is currently on the ID/RD waiver waiting list. It will take seven to ten years for the application to be reviewed in order to see if she qualifies due to volume of applicants.

It does not seem reasonable why a child with life altering disabilities can not qualify for Social Security Disability when a child with learning disabilities or ADHD can easily qualify. A family we know has a severely autistic child and they were turned down by Social Security Disability because the parents own their business. Our family is not wealthy, but we work hard and do all we can to provide for our children. During the years when both my husband and I worked full time, our total annual income was less than \$75,000 a year. Today, because I am no longer employed, our total annual income is \$65,000. I was terminated from DHEC due to an on the job injury and not able to perform my job duties. As a result, I retired from the State. My husband and I are struggling to keep our bills paid and to provide for our family of five. It is not feasible for me to return to full-time employment because of Olivia's multiple medical appointments in five different cities, weekly in-home therapy sessions and her occasional sick days. Our other two children, 6-year old and two-year old sons, also have regular doctor and dental appointments and sick days plus we are expecting our fourth child in June. Daycare for our children is out of the question. My husband and I have checked with several daycare centers in our area and the estimated cost for 3 children is approximately \$400+/- per week plus the additional charges for a child with special needs.

In addition, we need to make additional changes and improvements both inside and outside our home in order to make it handicap accessible for Olivia, but at this time there is no extra money in our already stretched to max budget to have this work done. Recently we had to purchase a larger vehicle in order to accommodate Olivia's increasingly larger pieces of equipment (stroller and walker) for her to travel to school and appointments, etc. These pieces of equipment are necessary when we travel in order for Olivia to be able to enter and exit buildings safely.

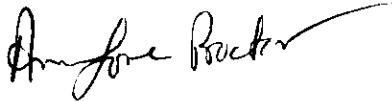
This is just a brief summary and explanations of our normal routine with a special needs child. While most parents hope their children will grow up and be successful, our hopes and prayers are for Olivia to grow up and be all she can achieve. Our goal for Olivia is to see her walk across the stage at her high school graduation, go to college and have an independent and successful life that she deserves.

My husband and I spend much time researching and talking with doctors and have found that therapeutic riding or Hippa therapy and music therapy will greatly benefit Olivia's abilities and quality of life; but here again our insurance will not cover this nor can we afford to pay out of pocket for these therapies. It is extremely difficult and heartbreaking for us to be forced to deny this precious little child an opportunity to improve her quality of life.

Therefore, we are asking for your help in introducing a bill into legislation that will eliminate the \$4000 gross monthly income limit for Social Security Disability for special needs children and base the qualifications on the child's level of disability not the parent's income. A child with a severe disability is emotionally and financially stressful for a family and more so for the thousands of families like ours who either fall through the cracks or fall just outside the boundaries for assistance. The extra income from Social Security Disability will help families with special needs children be able to make their homes more handicap accessible, purchase all necessary equipment not funded by insurance and provide additional therapy these children need to improve their quality of life. All children with special needs deserve only the very best the great State of South Carolina can provide in order for them to achieve their highest potential of independence.

Please help our family and all the families throughout South Carolina with special needs children. I have also sent a copy of this letter to US Congressman Mick Mulvaney, US Congressman Trey Gowdy, US Senator Tim Scott and to US Senator Lindsey Graham asking for their help in this matter. I would appreciate the opportunity to discuss this matter with you in person.

Sincerely



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