



## New MIRC Comment

1 message

Mon, Mar 17, 2014 at 3:20 PM

Reply-To: [REDACTED]  
To: vamirc@mirc.virginia.gov

**First Name** - Kathryn

**Last Name** - Rohr

**Organization Name** - Family of a Child with Special Needs

**Comment** - My husband Tom and I reside in Aldie, VA. We have a three year old son named Ian. Ian was born two and a half months early, weighing only two pounds. He spent many weeks in the NICU and has struggled with medical issues since the day he was born. He is currently covered under the EDCD consumer directed waiver of Virginia Medicaid. We are concerned that adopting the Medicaid expansion package will eliminate funding for his necessary out of state care. Ian has severe digestive disabilities. He has had several surgeries and uses a surgically placed feeding tube to receive nutrition. His body is unable to process food correctly and he will struggle to eat his entire life. Ian was an Intrauterine Growth Restriction baby and was born under the Small For Gestational Age diagnosis. As a Failure To Thrive child, his body will always have trouble performing at a level to maintain his health. We have visited numerous doctors and hospitals. Four of the hospitals have been in Virginia. It wasn't until we visited hospital number eight, at the Children's Hospital of Philadelphia, that we found a home base for Ian's care. He has been receiving care there for almost three years. After seeing about a dozen pediatric gastroenterologists in Virginia and Maryland, we finally found a doctor who is knowledgeable about Ian's diagnoses and is able to provide him the care he needs. Pediatric gastroenterology is a highly underdeveloped field. Very few providers are knowledgeable enough, and have the facilities and equipment to manage care for these children. Ian's care in Philadelphia includes gastroenterology, endocrinology, metabolic genetics, clinical genetics, diagnostics, nutrition, and surgical care. These services are imperative to his management. Pediatric specialists in Virginia were unable to meet Ian's needs. They even referred us to Philadelphia for his care. Cutting DSH funding would eliminate coverage for Ian's necessary care. I feel strongly that cutting DSH care for children on Medicaid medical waivers would be a huge detriment to their health. My son Ian would not be where he is today without the knowledge and facilities of out of state hospitals such as The Children's Hospital of Philadelphia. Because of Ian's special needs, we were forced to completely rearrange our lives. Unfortunately, I had to resign as a dental hygienist and walk away from my career in order to take care of my son. We had to sell our home in order to make ends meet financially. Even with the help of Medicaid, we had to make huge sacrifices in order to provide for him. We can only afford his care through the help of Medicaid. If DSH funding is cut, we would be forced to seek care at facilities who are less knowledgeable about his needs. It would cost Virginian parents thousands of dollars a year to receive care at necessary out of state facilities if this funding disappeared. We have always been very grateful for the Medicaid support Ian receives. We are very fortunate to have such a strong Medicaid support system. Please consider voting against the elimination of DSH care. Thank you for your time and for your support. Sincerely, Kathryn Rohr