

I would like to introduce myself. My name is Tamara Arellano, mother of a beautiful 8 year old girl diagnosed with cerebral palsy and a 5 year old "typical" son and 21 month old daughter recently diagnosed with hypertrophic cardiomyopathy. I write to you today because of my great concern of the insurance plans not providing habilitative benefits. This would greatly affect my 8 year old daughter. I would like to tell you a brief summary of what happened to my little girl. She was born term with no complications. She was a happy, healthy little girl. At 9 months of age she got sick for the very first time in her 9 months and during a visit to the ER they saw that her heart appeared to be enlarged during a routine x-ray. We were referred to a pediatric cardiologist where it was confirmed that her heart was enlarged and she was diagnosed with hypertrophic cardiomyopathy. This is when our real life nightmare began. A few days after she turned a year old she suddenly got very sick after receiving her 1 year vaccinations. Within a couple days of being in ICU and having 2 cardiac arrests she was rushed to Lucille Packard Children's Hospital. Once there she was placed on ECMO (Extracorporeal Membrane Oxygenation), a life support machine that was keeping her alive while she awaited a heart transplant. While on ECMO she developed a hemorrhage in her brain due to the extremely potent blood thinners she was on in order to be on this machine. ECMO saved my little girl's life but it also has its risks. To make a very long story short, she was able to come off ECMO without a heart transplant. This was truly a miracle and her heart has slowly improved on its own. ECMO is what saved her life but it is also what has left her with the challenges that she now faces. She has been diagnosed with cerebral palsy due to the bleed in her brain while on ECMO and severe global delays which is due to her 2 cardiac arrests, ECMO and the bleed in her brain. She went through more in her life during those couple months and continuing onto today that most people go through in a lifetime. She has been receiving Physical, Occupational and Speech therapy since she was a year old. I can't imagine where my little girl would be if she wasn't able to receive speech and physical therapy. At one time we were unsure if she would be able to walk,

but because of our weekly therapy appointments she is walking. She is non-verbal and will most likely never be able to speak. She can sometimes say a word or two during play routines but unless you knew her very well you wouldn't understand what she said. It is imperative that she continue to receive her weekly speech therapy. She currently is communicating using a picture book however; this has been very hard for her since she has such major motor delays. She has a hard time getting the picture on the sentence strip to hand to the person she is trying to communicate with. We have just recently started working with her with a Dynavox. This is a touch screen voice output device. It is amazing to see her face light up when all she has to do is touch the picture on the screen and hear it speak for her. She wants so badly to communicate and I believe the Dynavox will allow her to do that with practice. Speech therapy is what is going to help my child be able to communicate and become independent. I'm sorry to go on and on about how important therapy is to my daughter but I feel like you have to know a little of our story to really understand.

I write this letter to you today to express how important habilitative benefits are for my daughter. And this includes speech and physical therapy. I'm hoping you will take into great consideration the importance of habilitative benefits and not just rehabilitative benefits. Rehabilitative benefits will not cover children. Every child deserves to have insurance coverage for all therapy services, speech, PT, OT and any other therapy they may need. It also needs to be available to ALL children regardless of their diagnosis, level of disability or age. It is proven that early intervention is key to giving children with disabilities the ability to reach their full potential and go on to live a productive life in which they contribute to society by holding a job and paying taxes. Don't we all want to invest in our future? Children are our future! In the long run, providing speech, PT and OT benefits to our children will ensure a future of less people on social security and disability saving our state a huge amount of money. We owe it to our children, to our future to make certain that habilitative benefits are included in our benchmark insurance plan and not just rehabilitative benefits.

These habilitative benefits must be included and they need to not limit coverage based on discrimination of age, level of disability or type of diagnosis such as autism. The plan needs to be comprehensive for all therapies. It is not okay to just include a child that has a diagnosis of Autism to be eligible for these benefits, this is clearly discrimination. I beg you to please make certain that our children receive the proper benefits so they can receive all therapies they may need. We owe it to all the innocent children who have to work so hard at things that come so easy to most. They deserve a future of happiness and independence. Therapy will ensure this happens for them. Don't you agree that our children deserve happiness and the ability to become a contributing member of society? We owe it them and their future; frankly, I don't think we can afford not to. Again, please make sure that included in the Benchmark Insurance Plan is not only rehabilitative benefits but habilitative benefits too. Habilitative benefits need to not limit coverage based on discrimination of age, level of disability or type of disability such as autism or type of therapy. It needs to be comprehensive for all therapies. Thank you so much for your time and I truly hope you will take into great consideration the importance of including habilitative benefits to this plan. The very best scenario would be an unlimited amount of visits a year per therapy since each child is unique and requires different amounts of therapy. I do know that this can be costly so even if there has to be a limit of visits placed on therapy that is still okay as long as it is a reasonable amount and not too low. I would hope each therapy gets its own limit such as 30 speech, 30 physical and 30 OT. Please make sure that it is mandatory to offer habilitative benefits. My daughter's quality of life depends on these therapies. Thank you so much.

Sincerely,
Tamara Arellano