To the Oregon Senate Human Services Committee,

As we walked out of the hospital room pushing my 1.5 year old daughter in a stroller down a quiet hallway, I realized that a sound scarier than her struggling to breath was no sound at all. Frantically, I stopped to check her and she looked up at me with a drooly face, clear of tape, bandages, and tubes. She had just gotten her G-tube surgery along with a second procedure that opened her airway and stopped her previously noisy, raspy breathing. She was fine. But for months, that noisy raspy breathing, called "stridor", caused by Larygomalasia, was the only way I could tell that she was still breathing and still alive.

Hello, our names are Miranda and Jason and we are the parents of a beautiful strong five year old girl named Providence and a spunky goofy three year old boy Joshua.

We are writing in support of Senate Bill 646 and want to state what our concerns are for Senate Bill 91.

As we heard many times from medical professionals, "The parent's are the experts on their child." And as stated in the opening of this letter, we know what the sound of each breath means as well as the sound of each cry, and can tell what mood our daughter is in just by the way she moves her eyes and arms. Although much about her can be taught, some things can only be known by her parents.

Below is a bit more about our family's history with Providence:

Jason and I each went to college and met at Eastern Oregon State University. Jason has worked for the State of Oregon for nearly ten years. Miranda worked for a Tribal Government in Oregon for almost five years before she resigned due to the medical needs of Providence.

When Providence turned one years old she began having uncontrollable seizures that within three months caused her to lose her ability to eat orally, to control her head and body, to maintain eye control. These seizures weakened her lungs and respiratory muscles, and most importantly, she lost her smile and independence. We now know it as Early Infantile Epileptic Encepelopathy-37 (EIEE-37). A very rare diagnosis which was almost unknown of at the time.

In 2018 Providence was hospitalized five times, mostly for respiratory distress.

In 2019 she was hospitalized four times with at least five ER visits.

2020 was a good year with around two hospitalizations and three ER visits.

In 2021, while Miranda started working temporarily for her former employer, Providence ended up hospitalized for over 30 days during multiple admissions causing Miranda to turn down offers for her to return to work full time. In addition, Providence did not qualify for the Paid Parent Care Giver exemption, because CDDP had evaluated her for 136 hours and she was on a waiting list to get into Children's Intensive In-home Services (CIIS). Caregivers were few and far between, and we had been lucky to have two very part time helpers.

In 2022, Providence had a fall while in the care of a Direct Support Worker (DSP) and ended up with a minor brain bleed. She was hospitalized once again. Thankfully she is now ok. Around this time she transitioned into CIIS and Miranda began working as a Paid Parent Care Giver a few months later, while also finding and hiring additional DSP's.

The above events do not take into account the travel from rural Eastern Oregon to Portland for every specialist appointment such as Pulmonology, Neurology, Gastroenterology, Ear, Nose, and Throat, Medical Equipment Evaluations, Vision Evaluations, and Urology, to name a few. We also go to various local appointments such as occupational therapy, speech, chiropractic care, urgent care, and appointments with the Primary Care Provider.

To put it boldly, our daughter Providence Rector requires 24 hour observation and hands on care, 7 days a week for 365 days a year, or she will die. That is not an exaggeration. It is the hard truth that our family has had to accept and perform for at least the last 4 years.

Although we thought 2018-2019 was difficult, given the many admissions and getting a life-long diagnosis, winter of 2021 into Spring of 2022 was also not very forgiving. Providence was constantly sick for what seemed like eternity. She had several illnesses to include COVID-19 twice, Influenza, RSV, Coronavirus NL63, Coronavirus HKU1, and Human Rhinovirus. These usually resulted in a pneumonia, aspiration, bronchitis, or bronchiolitis. Yes, she did not get admitted, but that was because mom was home doing the work to keep her alive. As stated by her Pulminologist,

"Your family has essentially turned Providence's room (and home) into a miniature ICU. As long as you are able to follow protocols, give respiratory treatments every four hours, give oxygen, and monitor seizures, you keep her from admission. Yes, it's hard, but we don't admit children for respite care for the parent."

You see, prior to that conversation Miranda found herself on the floor of her bedroom closet crying on the phone to the Case Worker from CIIS saying "I'm so tired. I'm not sleeping. The one care taker is sick and the other ones haven't been trained yet. I need some type of help."

But there wasn't anyone to help. We had to help ourselves. Hiring and retaining caretakers is constantly ebbing and flowing in our area and we never know when we will have 4 caretakers available or if it's just me doing it alone. So, when it becomes too hard for Miranda, the next person in line is Jason, who is the bread winner of the family. He has to call into work using vacation leave or sick leave, which is very hard to save up when you have a child who is always sick and hospitalized. Thankfully due the Family Medical Care Act his job is secure and he can take intermittent leave. But what about his reputation at work? Can his co-workers rely on him when he has to call in or leave work early due to his child going to the ER? What about job promotions? We are forever grateful to his state job for being so understanding, but not everyone is blessed to have their job secured in the way he does. What of the times when he is stressed to the point of needing to take disability and lose a portion of his income? Paid Parent Care Giver exception has saved us from extreme financial difficulties in those times.

Providence's needs are unique. She requires around the clock suction and breathing treatments three times daily up to every four hours. Breathing treatments include inhalers, nebulizer treatment, shake vest, and cough assist. She has a CPAP machine for when she sleeps. Oxygen tanks and monitors. She uses a standing frame, wheelchair, arm and leg braces, a communication device, and a special bath chair. She also is on a variety of seizure medication and GI medications, as well as vitamins and supplements. She eats through a G/J Tube and needs her foods prepared for her. Simply stated, she needs her parents around as well as trained DSP's.

Providence should receive nursing care. She has qualified for nursing through Health Insurance since she was one years old – but there are no pediatric nurses in Eastern Oregon. Personal Support Workers (PSW's) or DSP's are required nursing delegation to suction and feed her but there were no delegating nurses in Umatilla County until June 2021 when a single nurse took on the local caseload. Now that nurse has 49 patients she follows at least once a month if not more. Since entering into CIIS, Providence qualifies for nursing, but there are no nursing agencies in Umatilla County.

Providence does go to school. She loves school. Currently she is in kindergarten and attends Life Skills with a one-on-one nurse. This has been a blessing for her and us. However, there are times Providence needs to come home early because of seizure activity or fever and illness. There are times she cannot go to school at all because she has pneumonia, RSV, strep throat or is vomiting and seizing. Times like this, we don't have DSP's scheduled so Miranda attends to Providence. Miranda transports her home, does her breathing treatments, gives her medications, calls the doctors and does what's necessary. These are times when Miranda will claim hours.

Miranda will also claim hours when other DSP's cannot make their shift due to illness, vacation, or any number of family issues. Miranda also claims hours over night when Providence is sick or is needing extra attending to.

This leads us to our main points for supporting Senate Bill 646:

- It removes the parent restriction and allows parents like us to do what is best for our child. It allows us flexibility to hire care takers, while also being able to be a paid care taker when necessary – which is frequent. Parents like us are not trying to take jobs away from current DSP's or PSW's, we are wanting to work in alongside them. Parents like us cannot report to a full time job because our child's needs are far too great. We have to be "on-call" all the time and need the flexibility to do so without putting our child and our family in a worse situation - such as not being able to make a living wage to financially support our child's needs.
- When Miranda started getting paid to be an in home care giver to Providence in 2022, Providence did not get admitted into a hospital that year for respiratory issues, although extremely sick, because Miranda was able to focus on the child and give the level of care that she needed. Miranda no longer needed to pick up other jobs outside the home and was able to train and support new DSP's to the fullest extent.
- Miranda was also able to stay within compliance to OARs by having a parent being home to supervise DSP's.

Concerns for Senate Bill 91:

- Ages 3 and under would not be granted hours.
    - Children like my daughter when she was diagnosed and needed extra attention and suctioning would get no hours. These children still need supports.
- It focuses on budget.
    - which is understandable. However, CIIS would be paying $46.95/hour to Nurses if there were Nurses in our area. As of now with the Paid Parent Care Giver exemption, Miranda is doing a Nurses' job for $24/hr. In addition, in 2018 a review of total attendant hours showed that 41% of hours went unused. Therefore, the state already has been saving money by not having to pay 41% of hours they are granting to disabled peoples.
- Agency Hours Cap.

    - Agencies that cover our area are already few. Making policies that control how many parents an agency can hire, etc. causes more barriers for the rural client child.

If the committee chooses to not pass any bill allowing parents to be paid caregivers, this would be damaging to many families and the client child. For our specific family, this means mom will have to work outside of the home and Providence will be left more often in the hands of her DSP's. Providence may not have a parent consistently at home to be able to make fast medical decisions that can result in hospitalizations, more frequent ER visits and life flights. If mom is unable to work, family income will be drastically decreased and this can result in Providence not being able to always make medical appointments or receive therapeutic or specialized equipment she may need. When hospitalized, parent's may not be able to afford to stay and advocate for her.

For these reasons, we ask the Oregon Senate Human Services Committee to please consider passing SB646. If the committee chooses to move forward with SB91, please consider the concerns mentioned and possibly work with families to make some amendments to the bill to include more children to qualify.

Sincerely, Miranda, Jason, Providence and Joshua