

Hi, thank you for letting me share today. I am a mom to two amazing children, one with special needs. Some of you may remember my testimony I gave on Sept 23 during the Bob Bethell Legislation, I won't repeat that today, but I have included it in case you were not able to hear what I shared before. I spoke about the life in-between before and my struggle to navigate unmanageable debt or live within the SSI guidelines.

During the Bob Bethell Legislation it was shared that there would be a 1 million dollar review to understand why parents are choosing to have their child on the waitlist for the DD/IDD Waiver. I will not go into how shocking and concerning it is to hear that that amount of money is so easily wasted in a very unnecessary review instead of using it to get children off the waitlist and onto the waiver.

But I am going to answer the question for you today.

I choose to stay on the waitlist because we need the waiver for Medicaid. There are multiple resources that are helpful with the waiver, but the bottom line is the Medicaid. My child needs those services, but I cannot afford them without Medicaid.

For reference, I live in the greater KC area, we live with my parents because it is the only rent, I can afford. I cannot work full time because of Jude's extra needs. The first 32 days of school this year between Jude and his sister they had over 20 appointments and 3 sick days. We have not even hit flu season yet.

Jude Currently qualifies for SSI and that gives him Medicaid. On SSI for a single parent of two children the maximum you can earn is about \$3,000 a month (before taxes), if you are receiving unearned income i.e., child support it's about \$2,000. If you have earned income and unearned income, it's somewhere in-between. I fall in the middle so we will say about \$2,500 a month is what I can earn before taxes. That is an income of \$30,000 a year! That is all I can make in a year in order to keep Jude on SSI and thus receive Medicaid.

If I choose to not keep Jude on SSI and lose Medicaid that would mean I no longer have a limit in how much I can make but I would have to cover all the extra medical cost. Here are some rough costs for the year after private insurance pays:

Copays for specialist Jude has 15 specialist he sees.	\$2,400 OOP
Speech therapy, private insurance covers 20 a year. Jude gets speech once a week	\$4,000 OOP
Jude's protein drinks	\$1,100 OOP
Jude's Nourish for GTube	\$1,450 OOP
Jude's Gtube supplies	\$3,000 OOP
Jude's ER/Urgent care/Xray	\$3,500 OOP
Jude's Ear tubes/Producers	\$3,000 OOP
Jude's Dental	\$3,000 OOP

TOTAL a year \$21,450 OOP

*This does not include medications, cough assist, suction machine, large surgery and so many other things that can easily double that number.

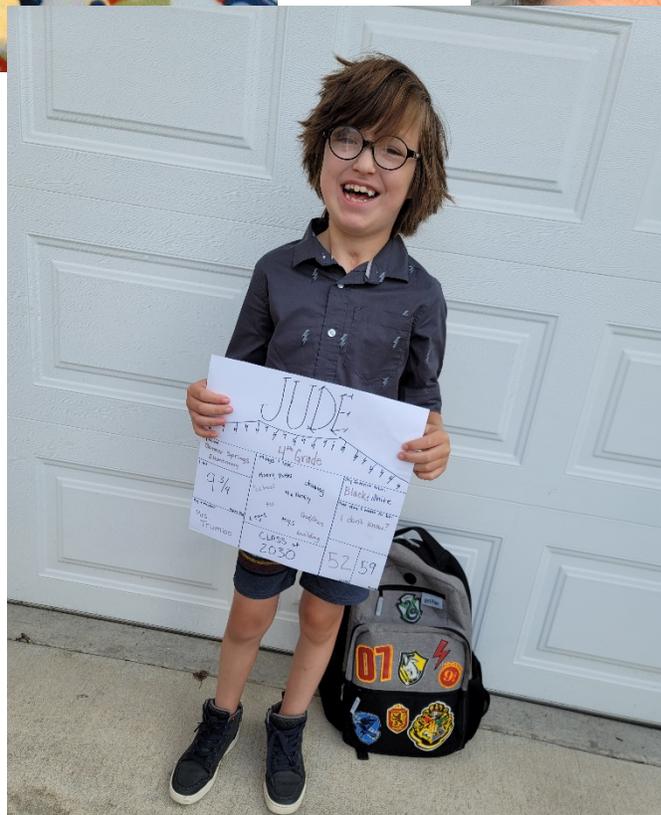
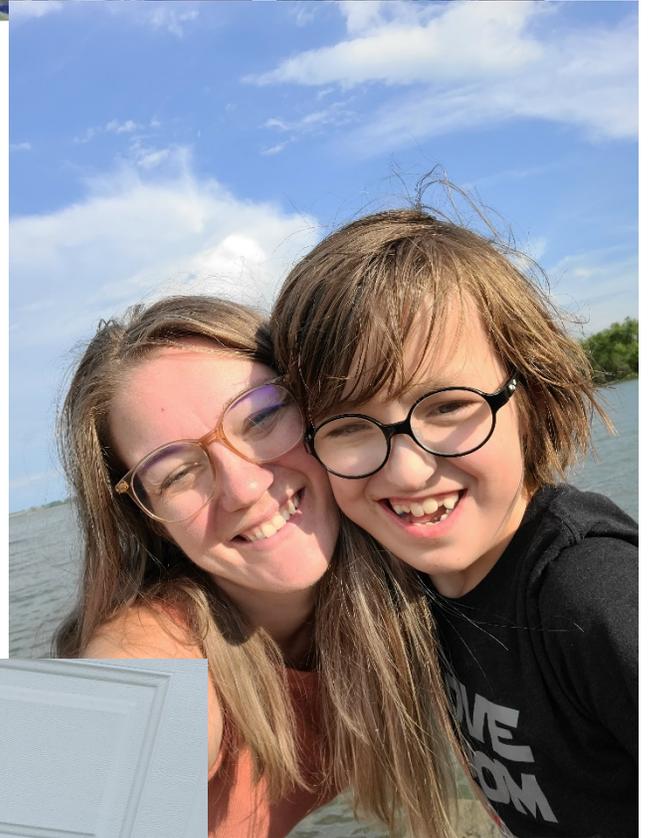
So, if I choose to come off SSI so I can make more money we now have copays of well over \$21,450. That means that I would need to find a job where I could make an additional \$30,000 a year (because taxes) above what I am already making just to break even with what was lost not being on Medicaid/SSI. I cannot keep Jude on SSI the rest of his childhood and I cannot afford the additional medical cost to take him off and stay afloat.

This is why we need the waitlist to decrease, Jude needs the services on the DD/IDD waiver, but he needs them without the incredible financial burden it places on our family. I will always choose my children's needs no matter the cost, but we should not have to be forced to have to make these decisions. My family is not alone in this, these families need the waiver not a waitlist with hopes of help one day in the future.

Thank you for listening and that you for being willing to fight to make a change!

Tracy Schinzel

tracyschinzel@gmail.com



Hi, thank you for letting me come and speak a small part of my story. My name is Tracy Schinzel. I am a single mom to two crazy wonderful life loving children. Today I want to talk about the life in between.

Jude, almost 9 ¾ years old and the biggest Harry Potter fan, was born at exactly 31wks after my water broke. While living in Boise, ID at my 20-week ultrasound a large mass was found coming from Jude's mouth. There was only a handful of doctors in the world who could deliver Jude, one of those doctors was at Children's Mercy. So just weeks before Jude arrived, we moved to Kansas City. Jude was delivered via Emergency EXIT procedure (to my knowledge still the only Emergency EXIT procedure ever done.) Jude was trached at birth and put on a vent. We were repeatedly told before and after his birth to be prepared for a low quality of life, if he even made it all. 111 days in the NICU, trach, vent, gtube and fundus, two grade 4 IVH, VP shunt, blood clots, vision, CLD, abnormal oral anatomy, we were in for a long-complicated road.

My degree in Social Work and experience working with children who have special needs I knew early intervention was the best chance for Jude. Therapies started in the NICU and as soon as we left therapies began at home and in clinics. For the first few years of his life, we averaged about 5-10 appointments a week. When Jude was born, he was placed on Medicaid, with all of his cares I could not work. My husband at the time worked while finishing school. Because of the extra help we needed with Jude and the financial strain we moved in with my parents, temporarily.

So, I know you are probably thinking ok what's the problem? How can we help you? Jude is amazing; I could go on forever about how incredible he is, amazing artist, intelligent, loving, biggest people person. He is who we were told he could never be! He fought for that, I fought that, years of therapies and doctors appointments working so hard, Jude is a miracle. But with all of that comes big medical bills and very little time for me to work.

As I mentioned before Jude was placed on Medicaid, we qualified for SSI and Jude also had the TA Waiver. When Jude was 2 ½ he got his trach removed! Huge big day! His doctors were uncertain how he would do through the flu season, so they made the decision to still allow his hole to remain open. His hole that his trach went into, a hole that was an opening to his lungs. Removing Jude's trach took away his automatic qualifier for the TA Waiver. After receiving an email from the TA Waiver accessor congratulating us on, "June being decapitated." (yes, you heard that right) He let me know we needed to have an assessment done. Jude was still fully dependent on his Gtube but having a Gtube is not an automatic qualifier you need to also have a certain number of points, 20 to be exact. Jude received 17 points, had this assessment been done just a couple months later Jude would have received more than 20. See when a child is 3 or older it made a difference in his mobility, Jude was a couple months under 3 and even though it was very clear his mobility would not be where it should when he turned 3 it didn't matter. Jude was to lose the TA Waiver, nursing and Medicaid through the Waiver. Even though Jude's doctors wrote multiple letters stating his need for nursing and still continual care at least through the flu season it didn't matter. The accessor said, it was a nice letter but pointless. He told me I could appeal but I would not win and so there was no use. We lost Jude's TA waiver. Jude still qualified for SSI which meant he qualifies for Medicaid that way, we still lost the nursing we needed. I was told about the DD/IDD Waiver from his case manager. I was told when he was five, I could apply and even though there was a wait list by the time he was five that wait list should not really be there because it was not supposed to exist. When Jude turned five, I applied for the DD/IDD Waiver. I was told had Jude still been on the TA waiver he could have just transferred over to the DD/IDD Waiver but because he was taken

off the waiver we no longer could transfer, and he would be put on the 7-year waiting list! SEVEN years! Jude is now 9 and still on this waiting list, however every time I call (I call every couple years) to check the years of waiting have not gone down they have gone up! As of now it is about a 10-11 year wait list to be put on the waiver! This is a waiver to help children, a waiver you cannot even apply for till the child is 5. A waiver that you can no longer be on the waitlist when the child turns 18. Jude is scheduled to go off the waitlist when he is 16! SIXTEEN!!

So now we wait, we wait in this world of in between. Jude is still on SSI because honestly, I cannot afford for him to come off SSI. If he comes off SSI, he loses Medicaid, if he loses Medicaid, I cannot afford to pay bills. Jude does not average 5-10 appointments anymore, thank you God! But he still has weekly appointments and all the in-betweens. When his allergies get bad, he gets phenomena. He misses a lot of school because of appointments and being sick. I cannot work full time because of Jude's needs. If I was able to make more money it would be just a little bit more but enough to lose SSI not enough to survive. If I make more money and lose SSI, I will have loans, medical bills and debt that I will never be able to pay. I want to be a contributing member of society; I want to raise my children to take care of themselves and give back to others. This situation does not just affect my now it effects my future what retirement will look like.

I find myself stuck in the in between, qualifying for SSI or an insurmountable debt. Constantly asking which side of poverty is it better for me to be on? Which side gives my children the best chance? Which side makes me and my children less of a burden on society?

My request is this; the waitlist needs to have a greater movement. More funding needs to be placed. Children, families, our state cannot wait for ten plus years. There needs a better exception for moving between Waivers. I know budgets are tight, certain monies are allotted to certain programs and it is not just one big bank account with money in it (that would be nice right? Haha). But when families like mine do not have access to things they need, like the waivers then we have to pull from other resources the state and government provide, we are limited in what and how we can give back. I honestly believe if someone looked, they would see that it actually cost the state more money when these families sit on waitlist then when they are placed on the waivers.

Thank you so much for letting me share!