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Vermont Family Network is the Parent Training and Information (PTI) Center in Vermont. We are a parent organization that supports parents of children with disabilities in getting their children needed services so they can achieve their best possible outcomes.

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The Intersection of Poverty and Disability

By Courtney Quinlan

I have been a single parent to my son since he was 6 months old. We have moved across the country to be closer to family, I put myself through college to earn an associate degree while working part time almost 8 years ago.

One month before my son's 7th birthday he was diagnosed with Autism Spectrum Disorder. I had suspected he was on the spectrum since he was about 4 years old, but couldn't get any doctors or teachers to notice the symptoms that I did. This was my first experience learning about or even meeting anyone with autism. We were just about to move to Northampton, Ma, where I had received a full Ada Comstock scholarship to go to Smith College, the type of school I never could have imagined I would even get accepted to.

My son attended second grade that year. I never had experience creating an IEP, I suddenly had to study up on any laws pertaining to disability rights, I thought I was a prepared parent. I chose a school with a high rating, with an autism specific program and found an apartment within walking distance of his school. The year started off as any other, I was beyond busy with my own homework and trying to help my son adjust to a new school environment as well. I thought once we had the diagnosis that things would be easier for us.

Second grade, his school, the staff and my heavy workload broke us that year. My son was not offered services he qualified for, we had very little money and I had very little time as a single parent going to a school that would assign fifty to sixty hours a week of homework. It turned out that I could not properly advocate for my son and his needs while going to Smith College full time.

When my son was in kindergarten, I was diagnosed with chronic migraines and cervical dystonia, both of which cause me chronic pain. The stress of my son not having the help he needed in school began causing

my migraines to increase. I realized I had to make a choice between my education and being able to advocate for my son and his education. I chose my son. I dropped out of Smith College, began advocating for my son about twenty hours per week and calling all kinds of advocacy groups, disability rights groups and anyone I knew who had a disabled child for advice.

My son was being physically hurt, bullied, ignored and punished for his disabilities. It became an absolute nightmare and I pulled my son from school the last 2 weeks of his second grade year after he had been physically hurt for the fourth or fifth time with zero accountability on the school's part. They threatened to take me to court for truancy, but MA law stated that a child had to be absent from school for fourteen or more consecutive days. There were only ten days left in his second grade year, so I informed them he would no longer be attending.

That summer we moved back to Vermont in hopes of finding better mental health support and being in a district (Burlington School District) that had a good reputation for helping children with special needs. I gave up my free tuition to one of the top twenty schools in the country to move back to Vermont in hopes that things would be easier on both of us.

I registered my son for school and explained the troubles we had the year before and what help I believed he needed, such as, a paraeducator, modified homework, access to technology, etc. The district decided the school they thought would be the best fit for him was Champlain Elementary. My son began third grade at Champlain Elementary and after being so traumatized the year before he had an extremely difficult time separating from me, or even arriving to school on time. That year he ended up missing twenty-nine days of school. The missed days were a combination of illness, my inability to drive him in sometimes due to severe migraines or his increased anxiety and feeling of generally not being safe unless he was with me. Again I was tirelessly at the school advocating, trying to still finish my own degree and living off of student loans to help us pay rent. I couldn't work with my son missing so many days of school, I would have been fired from any job, without any recourse. I knew this and this is one of the reasons I had to stay in school, because no one could take student loans away from me if my son missed too many days of school. That year we were threatened to be taken to truancy court and I was told so by the school guidance counselor and principal in front of my son, including the fact that, worst case- scenario, DCF could get involved. I left his school shaking and went back to my car and promptly burst into hysterical tears and had to miss my own classes for the day. We made it through that year without going to truancy court.

That summer I filed for disability for both myself and my son. My conditions had also worsened and I was told to medically withdraw from classes that year by my neurologist and PCP.

The year my son was in 4th grade things had not gotten easier. We both did qualify for SSI and I had signed up for classes again, because my goal was not to remain disabled, but to figure out a way to manage my health and keep working toward my degree to support my small family. This school year presented the same types of challenges, excessive tardiness because my son had difficulty separating from me. I would later obtain a diagnosis of separation anxiety for him, but did not have a name for this at the time. I was told how I should handle my child, how I should force him into a car when he was clearly having a panic attack and attempt to drive him across town to school that way. I was using every mental health intervention we qualified for including family therapy, individual meetings with the school social worker, family based services through the Howard Center and a living skills worker. I had called an Act 264 meeting that year after being threatened to be taken to truancy court again. It was determined at that time that there were no other suggestions for services that I could be using to help my son. The year continued and his anxiety related to school greatly increased. He ended up missing thirty-eight days of

school that year and after the school year was done, I received a letter mid-July explain that in two weeks I was to show up at truancy court and have the first of 3 hearings, spanning a 6-month time period regarding my son's attendance. I had always attended every meeting the school requested, often called meetings myself, had my son on waiting lists at UHC to be reevaluated and to have other areas looked at, such as anxiety and ADD.

I had 2 weeks to get all kinds of paperwork in order during a time when the schools were closed and I had no access to his case manager, teachers, support staff or school records. It was terrifying. I had to call the district office over and over until they finally got someone to open my son's school and give me a complete copy of his school records, I gathered every evaluation he ever had, every Dr. visit within that school year and any supporting paperwork I could obtain from his therapists. I called the Disability Law Project and luckily was able to obtain Jay Diaz as a lawyer to help us, after quickly realizing that the court appointed lawyers had no experience defending or working with families who have children with disabilities and I wouldn't even get a chance to speak to them until right before the first court hearing.

The first court hearing ended with the judge saying it seemed like I was doing a lot for my son and that he needed to improve his attendance, which I didn't argue, I agreed, however there is no magic wand to make someone with autism and numerous anxiety disorders just follow directions. My son's mind works differently than mine, or than most public schools or conventional rules. I realized that this truancy system was not at all set up to help or problem solve for families of children with disabilities. Again, if we had not both qualified for SSI and I had not been able to supplement that with student loans just to keep my car running, which I used daily to take him to and from school, to all of his various appointments and to do things like laundry and buy groceries, both of which I am unable to carry much of due to my conditions.

The second court hearing was scheduled for September and the courts would be checking in to see how often my son was attending school, what services he was being provided, etc. At the second court date, we were told there would be a third court date set for December, again to check attendance, services, etc. I felt as though my parenting were under question, I was having constant anxiety attacks worried that at any moment someone could decide I wasn't providing the best home for my son and he would be taken from me. It was nothing short of a single parent's worst nightmare.

As of that September (2014) Jay Diaz and I had asked the school to completely reevaluate my son. We were told that he didn't need reevaluations yet, because it hadn't been three years. I made them aware that after one year, you may ask that your child be reevaluated at any point in time. The school argued this until I had our lawyer draft up a letter stating that this was, in fact, the law. The evaluations were supposed to be done by our third court date and I had hoped they would work in our favor, in terms of getting my son the exact services he needed to succeed in school. Unfortunately this never happened.

Our third court date came and my appointed lawyer and Mr. Diaz asked that the truancy charges be dismissed because it was clear that I had been doing everything I could to help my son. During this entire period of time, I could not enroll in school, because I couldn't handle the stress of classes, dealing with my own disabilities and being able to properly advocate and prepare for court every three months. Once again, my education was put on hold.

Without any student loan money to help supplement our combined income and unreliable child support our budget was extremely tight. Our rent alone was 60% of our income. There were numerous times when our bills were shut off, or about to be and I had to go to places such as St Joseph's house and ask for a voucher for \$50.00 to help us pay our electric bill. We had 3 Squares Vermont and I still had to make trips to the food shelf, which was difficult because my son has extreme sensory issues regarding food and

will only eat very specific types of food, making it difficult to really work with a food budget per month and make it last. I would make sure he had his foods instead of mine. The greater the financial, educational and legal stresses got, the worse my own health became.

Finally, in December of 2014, the judge dismissed the truancy case. The school had still not completed any of the standard evaluations I had asked for in September. According to law these were supposed to be completed within six weeks of the asking date. Meanwhile, my son's attendance wasn't improving, I was being pressured by the school and some mental health staff to put him on medication, which in my mind, was an absolute last resort.

During this time, my son had also received a diagnosis of separation anxiety and ADHD through the UHC child psychiatry clinic. We finally started receiving some evaluations back in March of 2015 and didn't have them all completed until the end of May of his fifth grade year. I didn't receive my son's new IEP until two weeks after his fifth grade year was complete and had to find his case manager's home phone number and call him to see where my son's IEP was.

This led to a rocky start to his sixth grade year, due to some language that was changed and had taken away a paraeducator for my son as he was transitioning to middle school. I had, again attempted to take classes and had to withdraw because my son was having a horrible time adjusting to middle school with no 1:1 support. His previous school tried to claim that he had never had a 1:1 paraeducator which simply was not true and I had statements to prove it, yet his new middle school would hear none of it and refused to give him a 1:1. My son's anxiety increased enormously entering middle school and the social pressures were too much for him, navigating his day alone became too much. He would often have panic attacks and anxiety to the point where it would make him sick and cause him to have diarrhea. I would call him out absent on those days due to his diarrhea and was told by the principal that I should just bring him in anyway and that they were sure he would be fine. I couldn't, in good conscience bring my son to school, when he was ill from anxiety about being at said school and would cry in the mornings begging me to homeschool him because no one understood him there. The year progressively got worse, I called meeting after meeting, his absences piled up and again I was being threatened to go to truancy court. This time I became proactive and called the director of the Court Diversion Truancy project myself. I explained that ours was not just a run of the mill truancy case, that my son was not out wandering the streets, that he was home with me every single day that he missed and that we had been through this before and that if we were taken to court again I was considering suing the district for discrimination. I had plenty of evaluations stating why my son had difficulty at school, I had plenty of proof that I was providing him with a myriad of services in and outside of school. That year I had verbal altercations with staff at his school who tried to shame me and my parenting and made it seem as though I wasn't concerned about my son's education. I was beyond exhausted and had been fighting the "disability battle" with the school system for four years at this point and wondered if it would ever end.

My son's 6th grade year he missed 52 days of school. They did not end up filing truancy charges mainly because I befriended the director of the Court Diversion program and invited him to come to several IEP meetings so he could see how our case was different. After a month or more of communication with him, he told me that he would personally call the State's Attorney and recommend that our case not go to court due to circumstances regarding disability. I believe this is the only reason the district did not file, because I made them aware that the State's Attorney would be told not to file. Toward the end of his 6th grade year, in part because I was feeling pressured by the school and constantly worried we would be taken to court again, I ended up medicating my son, not because I couldn't handle his behaviors, but because I had exhausted all other options and I could not keep going as I was. My health just increasingly got worse during these four years.

It got to the point where I felt lucky that I also qualified for SSI. I never once thought I would feel lucky to be unable to work, or to live off of such little income, but I was. I was grateful, because I would have been fired from any job, there is no way I could have even paid rent if I was just receiving my son's SSI payment and child support. We would have come up short every single month. Even with my check there were months (there still are) where it is difficult to make ends meet. Every time a child support payment is skipped it takes two months for SSI or for 3 Squares Vermont benefits to adjust, so there is always a month or two where you have less income or subsidy coming in than even states on your paperwork, due to the processing of the system.

Winter is coming and I don't know how I will afford to get snow tires or fix a crack in my windshield. I'm not saying any of these things because I am looking for sympathy, or feeling sorry for myself. I know my son and I are not defined by our disabilities, yet in many aspects in life, we are. It defines what I can purchase per month, whether or not I have to skip paying a bill because we receive less food money that month, it means that when my car broke down I had to borrow a friend's car and cancel appointments that we couldn't make it to. It makes life just a bit harder for families who are already struggling. Every penny you earn is tracked, you can't have much for savings or it counts against you. I can't even remember the last time I had a savings account.

I have taken the Leadership Series from Vermont Family network and the Council on Disability Rights, I have become a volunteer advocate for families with disabilities and I have spoken to medical professionals, students and caregivers about what it is like to raise a child with disabilities, family centered care and the importance of schools trusting parents and really understanding that not one size fits all. I am very open and honest about our struggles in my blog and on social media and will speak to anyone who has an interest or is willing to listen. I feel it is a calling now, for me to advocate, for me to keep speaking up about these issues and for me to try and create change and reform where I can.

My son just began his 7th grade year, and I admit, I was physically ill the days before school started, wondering what this year would bring, whether or not I would be threatened to go to court again, if my son would be able to help himself more this year. Every single year I hope it's the year he finds himself, the year something about being in a school community clicks and he doesn't fear going every day. This is a dream of mine as well, because if school does normalize for him a bit or begins to feel like a safe place, then perhaps I can attempt to finish my own education or really work on my own health and try working part time again if possible.

So far, the first few weeks of school are going well for him, and he has a great case manager who really seems to understand both of us. I have hope, but I never allow my hope to carry me, because I have had this same hope every year of school and somehow it still ends up being a battle.

The intersection of disability, having a child with a disability, poverty and missing days of school are so closely tied, as you can see from my experiences. It often feels like a trap, as though I should either choose my education and health or my son's education and health, because so far I have not been able to manage all aspects of this and my energy will always go towards my son and his needs first. It becomes a domino effect where one piece can break the whole chain and it comes falling down.

I know many other families who have had to deal with similar circumstances and unfortunately is disproportionately affects single parents, who have no other person to rely on for income, or stay home with a child so I could work. There are very few services to help a parent in this situation, even an extremely involved parent such as myself.

I hope that this can shed some light on the struggles that families similar to mine face. There is a certain amount of guilt and shame one feels as a parent who tries so hard and still can barely make ends meet financially, educationally and often emotionally.

I thank you very much for your time and I am very honored that I was able to share my story with such an important council and hope that any of my words can help bring some clarity or insight into the circumstances many families find themselves caught in regarding the cycle of poverty, disability and truancy in Vermont.