

Dear Ms Foonsness,

My name is Miranda Wakefield. I am the parent of a child with autism, ADHD and epilepsy who qualifies for Section 28 services. I would like to take the time to share some of my experiences with child behavioral health services here in Maine.

My child has a multitude of special needs. Autism, ADHD, borderline intellectual disability, delays in gross and fine motor skills, epilepsy and very low executive functioning skills. At school she has an extensive IEP and positive behavioral support plan. She has one on one support in the mainstream classroom, individualized education for reading, writing and math, OT, PT, speech, adaptive transportation, seating and technology. Her team has weekly consult meetings with monthly BCBA consulting as well. She has a daily behavior sheet that comes home with her day broken into 15 minute intervals for tracking purposes.

In the community she has a case manager through Maine Behavioral Health. She has participated in community based counseling, OT, PT and pragmatic language groups. She has 6 medical specialists throughout the Maine Med system and has consulted with several others at the request of her primary team.

She qualifies for specialized section 28 services. I had high hopes that services would help her gain skills. We were mostly focused on basics...

- Being consistently independent with toileting.
- Increasing safety awareness in the community (parking lots for example).
- Increasing pragmatic language skills with both adults and peers.
- Implementing strategies to reduce blow ups and need for safety holds.

I'd love to say that services had a positive impact on my daughter and our family. That is not our story.

After a 7 month wait from referral to intake I was feeling pretty desperate for SOMETHING that might help. She was having regular meltdowns and even more than normal for us we were feeling increasingly like we lived life on lock down.

Within the first 18 months with our first agency (after staffing actually started) we had 2 different BCBA's, 3 different program managers and 5 different staff in the home. Once we had a 90+ day gap in services due to no staff and another time a 3 month gap. 10 staff total. The agency also changed names and policies mid way through as well due to a merger of some sort. Some staff left because they were promoted or continued to follow their schooling. 2 left for other jobs with better pay and or hours, 2 left to become stay at home parents since the position in no way paid enough to afford childcare and one "parted ways with the agency" after a physical altercation she had with my daughter in view of dozens at pick up at the school.

Due to the seemingly constant turnover at one level or another I can't say that section 28 services are ineffective - but I can say that personally I have never seen them implemented as they are intended. Over the 2.5 years we worked with over 13 staff in all between the 2 agencies. Most of the women who worked in the home with us had little or no training - and what they did have largely came from their previous employment. Supervisors turned over regularly as well so the treatment plans were rarely explained well to staff (who were also changing) and we're never fully implemented.

We switched agencies and after a 3-4 month gap had staff again. This time we had the same worker for a full year - she was a wonderful young lady but had no real official training beyond having a special needs little brother. She didn't even have her BHP certification yet. Apparently agencies have a year to get folks certified. Much of the "programming" she did with my daughter she was taking the initiative to find on pinterest. Pinterest.

By this point I was very vocal about my concerns and doubts with programming. My daughter made no meaningful progress in 2 and a half years of services. It did provide some level of respite - not having to manage the grocery store with a raging 7 year old is not without value, but the lack of training, retention and meaningful resources made specialized section 28 feel like babysitters who often escalated her behavior rather than helping. Even when they were well meaning it was rarely effective.

After assuring me that they did not intend to change her staff at a quarterly meeting 2 weeks later I was informed via email that our staff would be switching clients the next week and the replacement would shadow 2 shifts leading up to it. Unfortunately staff was not scheduled on the 2 days the new staff was available to shadow (my daughter had an OT eval one and her 4 year old brother had preschool graduation the other). It was also the last week of school - a very stressful time for my daughter. I said I would rather wait till school was out to switch, even if that meant no or minimal staffing until school was out.

I vented to the in home support worker about me having to train someone new just as Summer was starting after having planned nearly everything around our current BHP's schedule for summer (preschool for my son, membership to a museum she was comfortable going to, activities and services such as PT and OT so as not to conflict with staffing etc) and how frustrated I was with the lack of solid programming anyway. Nothing I hadn't said in meetings previously.

The next day I received an email saying they were terminating services since I wasn't happy. Nothing further. Effective immediately. After a year my daughter didn't even get to say goodbye to her staff. I learned that if you challenge an agency to meet their obligations they can drop you.

At this point as a family we are so disheartened with the services that while we are officially on a list I am not actively hounding our case manager about it. Honestly I don't have the strength to deal with it and am frustrated by the lack of progress she had even when we did have services.

Another note worth mentioning. I am SO thankful that my daughter has MaiencCare. I teach here in Maine and my health insurance is reasonably good but would not cover any of this. Accessing Katie Beckett is of course an option but the process is also daunting and labor intensive. My daughter receives MaineCare because she was my foster child first and was adopted through the foster care system - Thankfully that fact ensures that she gets MaineCare.

Early intervention of any kind has the power to do such good... section 28 services is a type of early intervention for these at risk kiddos... who will go on to be at risk adults. If not from the humanitarian side, at least from the financial side making these services as effective as possible just makes sense. Helping these children and their families develop skills that can help them be successful in the end will benefit us all - if only as taxpayers due to reduced need for adult lifelong services for some of this population. For those of us who love these children, in home services have the power to do such good... if only there was enough funding to do them right.

I am truly terrified of my daughter requiring more intensive or residential services as she gets older. I'm also scared of re-introducing in home support in order to help avoid that... in the now 15 months we have not had staff things have actually been better - she is not raging as much and I was able to relocate her bedroom back upstairs with her siblings. Every day is exhausting for her, the amount of effort she has to put in is probably truly beyond my comprehension. My fear is that having staff 20 hours a week didn't allow her enough down time... but not having staff means we are not able to focus on skills that she will need to maximize her independence which is also a vital need. I do not have faith in the system's ability to meet the requirements and treatment plans that are created but realistically I know it is only a matter of time before we will have to reach out again.

Lastly I wish that there was parent and case management support more readily available. I am blessed to be educated and have a solid family support system in place as well and mental, emotional and financial resources to meet my child's needs. It can still be overwhelming. I know that not all families have those resources. In my day to day life as educator I see this lack of support for families acutely. Even just staying on top of needed medications, remembering to request a refill each month, affording the co-pay on time, getting to the pharmacy, getting to doctor appointments when transportation isn't available etc. That is an intense barrier to many families that has long reaching impacts. I have no idea HOW to fix that, but I'm afraid the cost of not addressing it will be high and felt for many years to come, not just on a financial level but for quality of life for so very many.

Thank you for your time.

I am happy to talk in more detail if that would be of service.

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