

Testimony for the March 6, 2015 Hearing

Hello! My name is Nancy Clarke. I live in Westport with my husband, my 17 year old daughter, and my son, (William), who is 22 and has autism and is who is also intellectually disabled. He is currently a Priority 1 on what I thought was a waiting list.

I have wrestled with the question of giving testimony. While it may seem an obvious next step in the long list of ways in which we have advocated for our son since the day he was born, I have had many reservations. One of those reservations is privacy, by which I mean my son's privacy. But how would anyone understand the challenges we face if I leave out all the details, so, forgive me for sharing. The following is what I will call:

"A Night in the Life of a Priority 1 Mom"

Sunday 8:30 PM - After his night time routine, (pajamas, teeth brushing, medications, toileting), son is put to bed. Since he is incontinent during the night, I will try to wake him up to go to the bathroom before I go to bed, around 11:00PM.

Sunday 10:55 PM - about to go wake him up. Too late. Get him up. He is complying, thankfully. Have him sit on the toilet. Gather the wet laundry: sheets, blanket, pjs, underwear. Lysol the bed. Change his bed. Clean the floor. Wash him down. Get him changed into new pjs. Lysol the bathroom (toilet, floor in front of toilet, light switch, door knob, faucet handle). Yes, he has touched everything.

Sunday 11:20 PM- Check in his room. He is naked from the waist down. Tell him to put his clothes back on. Ask if everything's ok. Do you need to go to the bathroom? Etc. Can't get him to get out of bed to go. He's getting agitated. I give up.

Sunday 11:30 PM- I'm about to go to bed. Hear him moving in his room. Turn on the light, he's wet again. Get him up. He is complying, thankfully. Have him sit on the toilet. Gather the wet laundry: sheets, blanket, pjs, underwear. Lysol the bed. Change his bed. Clean the floor. Wash him down. Get him changed into new pjs. Lysol the bathroom (toilet, floor in front of toilet, light switch, door knob, faucet handle). Yes, he has touched everything.

Around midnight: I'm finally in bed. Turn off the light. Turn towards the window to admire the brightness of the moon in the night sky. I actually get back up to look more closely. Always take in a moment of beauty if you have the chance, right? But then I can see that the living room lights are on downstairs. I thought I just turned those off. Go downstairs, check the living room- no one is there. Turn off the lights. Check son's room, he's not there. The bathroom light is on. Find son in there with the electric razor. He's sitting on the toilet and has apparently been attempting to shave his pubic hair. Speechless. I remain speechless.

But then, here's a teaching moment. "The razor is for your face. Just your face. Not for your penis." Repeat three times. "Do you understand?" "Yes. I'm sorry", he says. (He doesn't really understand, and I will now have to figure out where to hide the razor until I teach him this, and until he learns). Wash him up. Get him back to bed. Clean toilet. Clean floor in front of toilet. And what on earth do I do with this electric razor? First clean it, then hide it. I'll figure this out (throw it out) tomorrow.

Monday 1:00 AM- Still awake, staring at the ceiling.

Monday- 5:45 AM. Hear movement downstairs. It's him again. Wet again. Get him up. He is complying, again, thankfully. Have him sit on the toilet. Gather the wet laundry: sheets, blanket, pjs, underwear. Lysol the bed. Change his bed. Clean the floor. Wash him down. Get him changed into new pjs. Lysol the bathroom (toilet, floor in front of toilet, light switch, door knob, faucet handle). Get him back to bed.

Meanwhile, daughter is up and getting ready for first day of 10th grade. Spend "quality time" with her and pretend none of the above happened. Play a few rounds of my word game. "You're really addicted to that game, aren't you", she says. "Yes, I am", I say. "I find it diverting."

6:45AM- Drive with her to the end of the road. Bus arrives on time 6:52AM. "Have a great day!"

Go back home. Start in on the 3 loads of wet laundry waiting.

7:15 AM: His alarm goes off. Help him wake up, shower, get dressed, make his breakfast, pack his lunch. . He is off to school at 8:00 AM.

Welcome to the day!

This may not happen every night, but when I go to sleep, I really have no idea what the night has in store for me.

Then, there are the days! My son is very "busy". He may not be left alone, ever. Ever! He finds ways of getting into trouble, only because he doesn't understand, because he really is a sweet young man. I think even the Westport Police understand this. Yes, we have had to call 911 to help us when our son has gotten out of control, physically, with a broken door and window, and bruising to me and my husband, and a knife (thankfully it was a butter knife) being but a partial list of details from some of the episodes.

In the last couple of years, we have been fortunate enough to have been given a budget from DDS for supports in the home, which we needed to advocate intensely for. I am very grateful for this. It has taken years, but we finally have found the right combination of caregivers to help us. I don't know what we would do without them. But I now have also learned that all other things being equal (which they are not) that those in-home supports may eventually preclude us from getting a residential placement for our son. For the life of me, I don't understand why in-home supports, which are presumably reserved for the most challenging cases, would preclude an individual from getting a residential placement. Let's throw some budgets at challenging cases so we can keep them at home, forever? Who masterminded that?

Another reason why I have been reluctant to submit testimony is that I really don't like to complain. And I certainly abhor the idea of complaining in public! Especially about my son. Because I love him. And currently the system is designed to take advantage of that fact, because the way the system is currently set up it presumes that we parents, no matter how hard it gets, will never stop loving and caring for our children... until we die.

DDS is in crisis! Our families can't wait!

Thank you.

Nancy Clarke