

Video Transcript

25-08-2023

We have no idea what other people are managing or working through while they're living their day-to-day life. Why are we asking people to spend the energy they have explaining to other people their needs?

Well, since I was four years old, I've been diagnosed with a massive craniopharyngioma; and, if most of you can't understand what that is, it's a brain tumour.

You can't judge a book by its cover; just because someone looks "normal" they might be struggling with a lot of things. There has been a lot of times when people just haven't believed that Kathryn had a disability, before she was in chair, now permanently. We taught her from a young age that she could advocate, be respectful, but that she deserved to get the help that she needed. So, she would be a very good self advocate.

When he was born, before we were leaving the hospital, within 24 hours they do the infant hearing screening and he didn't pass that; but everyone's like "oh he was just born, it could be fluid in the ears, no big deal". Then, they started to think that we should get a more in-depth test done; so, we went to the audiologist and they did find that it [the test] was showing that he had hearing loss. There is a lot of gray areas of kids with invisible disabilities fall into. So, if a child is not responding quickly, or one thing that William does often times, someone will out of the blue speak to him and him if he's not looking at them directly, he might not understand what they're saying he just doesn't pick it up. So, he often looks at me and because he is ten, the adult is like: "OK, why is this child not responding to me?" I'll be like, "he has hearing loss you'll need to speak louder", or I'll repeat it for my son.

It seems to be the automatic response that like, "it's a rude child", "it's a disobedient child". I think the big, big, thing I would want people to know is that they should have some compassion, there are more things that could be happening, don't just label them as a bad kid.

So, our experience with an invisible disability is what I would call a cognitive impairment, as a result of illness. So, for two years, my husband, battled cancer, and one of his recurrences was two tumours in his brain. As soon as his initial recovery had passed, it [the policy] was that if he could physically get himself into the appointment, that he was not allowed to have someone else go with him. Just because he can physically get himself to an appointment, doesn't mean that he

doesn't need support in terms of like, memory and retention. So, for him, in a medical appointment especially, they would dump a lot of information on you really quickly. For him, he was able to process it [the information] in the moment and he was like: "OK, I'm with you"; and then, literally, the second he would walk out of the appointment, would have no recollection of what was just explained to him; but, because he looked like he could get himself to the appointment, he had to do that independently in terms of "the rules".

I think that the barrier, the frustration, is feeling like you need to justify what you're asking for. So, I don't think like, we never felt like we weren't willing to say we needed accommodation; but, it was the perceived judgement, or the frustration, around how that request was received. So, it was like, now I need to plead my case with you as to why I need a companion to go to an appointment because, you can't tell why I need it; but, I'm telling you I do.

Just because you have a disability doesn't mean you want pity, I don't want pity for Kathryn; and Kathryn doesn't want pity, we just want the world to be a better place, so where she can do what other people can, without so many barriers.

Just because somebody doesn't look like they have a disability, doesn't mean there isn't one there.

If everybody approached life from the perspective that everybody's just doing the very best they can, with whatever the situation is that they're faced with, we would have a lot more grace. We would let people do the best they can, and that is good enough.