Talking Points from **Rachel Nemhauser**

1) Tell us about your experience seeking support/treatment (for yourself and or your child) in the health care setting, school setting and or community and how it affected you? My son is 14 and Autistic, but wasn’t diagnosed until he was almost 13. Trying to find a diagnosis and effective treatment for him during his early years was absolutely traumatizing to me.  We spent so much time focusing on all the things he couldn’t do, and had been convinced it was critical to seek a diagnosis. Spending several years hearing from professionals about all his deficits, but with none  knowing how to help felt terrifying and overwhelmingly sad. To this day if a doctor or therapist calls me I instinctively start to panic and get scared, afraid of what they’re about to tell me.  What saddens me is thinking that perhaps those years of fear and grief didn’t have to happen, or didn’t have to be so heavy. If the presentation and handling of Nate’s delays by the therapists and professionals around us had been strength based, optimistic, encouraging and hopeful instead of deficit based and focused only on milestones, I could have spent those years finding joy in Nate and our family.

2) What has helped you in the past and what would you want community professionals and policy makers to know? The three things that helped me the most were:

* Finding other parents experiencing similar challenges
* Learning about disability theory, and disability as a civil rights issue
* Meeting adults with I/DD who live, work and play in the community, and learning from them insights about how my son thinks, and how I can best support him.

3) What would you change if you had a magic wand? I would want the medical and therapy professionals who work with my son to understand the impact of their words, and that how they talk about disability and my child in his early years will absolutely set the tone for how I support him and treat him for the rest of his life. That’s an enormous responsibility for professionals and I wish they understood that.  I also wish I could have come across autistic adults in the medical and therapeutic settings I was interfacing with.  I think I could have found tremendous comfort in talking to autistics in order to understand the diversity of experiences and quality of life they are able to lead with the right supports around them.

|  |  |  |
| --- | --- | --- |
|  |  |   |
|  |  |