A Day In The Life…

Written by Danielle Verderame, Central Region Family System Manager

April is Autism Awareness Month… April 2nd is World Autism Awareness Day. To many people, this marks a special day to celebrate those effected by ASD and to shed light on what Autism means. But for many of us**, every day** is Autism Awareness Day! A day in the life of a parent or caregiver of a child with ASD may look surprisingly similar or very strange to other parents - depending on what is going on in their lives at the moment.

In my house, we wake up, make breakfast, prepare for school and whatever else the day has in store for us. Actually, our day starts the night before, with a schedule that my son repeats over and over until he gets it just right. He likes to know exactly what his day will look like. There are lots of prompts and redirecting in the morning, afternoon and night time too. But, when you get down to it, children with autism are children just like any other. You just need to know how to interact with them.

Let's start by introducing my son…. His name is Ben and he is awesome! Ben loves swimming, dancing, listening to music and doing his artwork. He plays the drums, cooks, loves yoga, bouncing on the trampoline, riding his scooter and playing on his swing set. Ben loves the movies and learning about animals, especially humpback whales which are his favorite. Boating tops the list of things he loves to do best in the world! I don't have an autistic child. I have a child who just happens to have autism.

I'm not an autism expert, but I *am* an expert on my child. There are some things that I think most parents and caregivers of children on the spectrum may relate to:

1. The days are hectic. There is either not enough time in the day or sometimes the days can drag on.

2. We don't want unsolicited advice on how to raise our kiddos. Thank you but no thank you. If we ask then please bring it on, but if not please understand.

3. We don't want pity, we need understanding. The journey is hard but we are strong! We can get through the tough days when they come. We need support not sympathy.

4. We don't need to be stared down in the store when our children are having a "moment". Yes, guess what, we know it's happening too…. Do you think we don't? But we are working through it the best way we can. Instead of making us feel like we are the worst parents ever, maybe ask if there is anything you can do.

5. Remember that nonverbal youth still have lots to say. They may not use their voices, but look at their facial expressions, their actions, their reactions. It's all there you just need to look. Just because our kiddos may not be talking, it doesn't mean they're not paying attention and listening to every single thing you are saying.

6. Many children need processing time, and sometimes, so do we as parents.

7. Please include us….we are lonely, even the strongest of us can feel alone.

8. Not all struggles are the same. Not all milestones are the same. Not all goals are the same. We are all individuals.

9. Don't give up on us….Never give up on engaging us. It takes time. Not all parents are ready to stick their necks out there. Some parents aren't at a place of acceptance yet. Give them time, patience, and support.

Autism is *a developmental disorder characterized by difficulties with social interaction and communication, and by restricted and repetitive behavior.* According to the Centers for Disease Control, autism affects an estimated 1 in 54 children in the United States today. The more we talk about autism and learn about it, the more understanding we as a community can gain. When you meet a child, or an adult for that matter, who has autism remember it is not who they are, but only a part of them.

If you are looking for an autism support group or programming, here are a few across the state:

Autism Services and Resources Connecticut (ASRC)
Located State Wide
Autism Services and Resources Connecticut (ASRC) facilitates support groups for parents of children on the autism spectrum and families members throughout the state. For more information, visit www.autismconnecticut.org/find-local-support-group, email info@autismconnecticut.org

Torrington Area families for Autism (TAFA)
Located in Torrington CT
Torrington Area Families for Autism (TAFA) is an Autism nonprofit organization started by parents who know first hand what it means to raise a child living with autism. The goal of TAFA is to create a group focused on Autism Advocacy, Awareness and Support. They offer group activities, social outings and integrated playgroups for children. Exposure and opportunities for socialization makes a world of difference to those living with autism and their families. Support groups are currently meeting via zoom on the 4th Thursday of the month at 6:00pm.
Visit www.TAFAinc.org for more information.

Sun, Moon and Stars
Located in Watertown CT
Our mission is to promote activities, services and education to families with children on the Autism Spectrum while also providing a sense of community and support in Greater Watertown and the surrounding areas.
Visit www.sunmoonandstars.org for more information.

Bloomfield Support Group
Located in Bloomfield CT
The Bloomfield Support Group is a support group for parents of children of all ages and disabilities. Meetings are held during the school year on the fourth Monday of each month from 6 p.m. to 8 p.m. at Laurel Elementary School in Bloomfield, Connecticut. All are welcome. For more information please contact the Family Resource Center at 860-769-5518.

Asperger Parents/Grandparents Support Group
Located in Old Saybrook CT
The group is open to residents of Old Saybrook and surrounding towns.
For more information or to register, call Old Saybrook Youth and Family Services at (860) 395-3190.