

NORTH GEORGIA  AUTISM CONFERENCE

Hosted by:



Anna Shaw
Children's Institute

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Let's Talk About: Sharing Your Child's Diagnosis!

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Talking with your child

Why?

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Your emotions:

- Think back:
 - How did it feel when you were wondering why?
 - Why was your child doing some things so well and struggling with others?
 - How did that uncertainty feel?
- What emotions did you experience when you heard the diagnosis?
 - **Relief:** no longer dealing with the unknown
 - **Grief:** changes to the dreams you had for your child
 - **Worry:** about what the future will hold
 - **Determination:** a clearer understanding of how to help



Individuals Diagnosed As Adults: *What can they tell us?*

- A study in 2019 allowed adults to describe their feelings about not knowing their diagnosis as children.
 - Share their feelings in their own words:

Living with autism without knowing: receiving a diagnosis in later life
Steven D. Staggh and Hannah Belcher
HEALTH PSYCHOLOGY AND BEHAVIORAL MEDICINE 2019

Individuals Diagnosed As Adults: *Feeling different*

- *I had difficulty with changes to routines, or unexpected situations. Even if the changes were minor, I found it difficult to deal with them. (Brenda)*
- *The social thing was a problem, I couldn't do birthday parties, and I couldn't really behave with other kids for more than about 10 min. (Paul)*
- *I was completely isolated and always in trouble, pretty strongly disliked by a lot of people ... I tried to be friends with people and just got rejected. I don't know why. (David)*
- *My mum said when I was at infant school, I couldn't cope with working in the classroom with other kids, and I used to have to work in the library quite a lot. (Linda)*
- *I always knew I was different, I always knew I didn't fit in, but I didn't realise what it was, the label that went with it. (Mary)*



Individuals Diagnosed as Adults: *How they explained feeling different*

- *I just thought I was just **bad** really and didn't really fit in and people didn't like me, and I couldn't really understand why. I suppose I thought I was different but **wrong** but didn't understand what was wrong. (David)*
- *I thought maybe I'm a **bad** person, I've got a horrible personality, there's something about me people don't like, and I didn't understand why. (Brenda)*
- *I was starting to get comfortable with the idea that I don't fit in, but I didn't think of Asperger's I just thought I was **naughty** by nature. (Robert)*



Individuals Diagnosed as Adults: *Benefits of knowing the diagnosis*

- *It really was like a sort of eureka moment ... it was kind of a **relief** ... and it wasn't my fault, and that was one of the biggest things, that I realized it wasn't my fault. (Brenda)*
- *It's the **relief** of knowing what's wrong, or what has been wrong. (Linda)*
- *A **relief**, because for years and years everything has been put down to anxiety and depression. **Everything** from the last 30 years made sense, it just all fitted in and it **made sense**. (Debra)*
- *Now I know that allegedly if you're just, you don't like bright light, allergic to it. I don't know, it's like I **have explanations** for things now, I never used to have. (David)*
- *Being aware of it [ASD] has **enabled** me to **plan and prepare** for situations, knowing how I may react, and how to avoid difficult situations ... so I can keep to places and activities I am comfortable with. (Paul)*



Individuals Diagnosed as Adults: *Working through the emotions*

- *I went through several stages of feeling ... First of all, I was thinking ... It was strange, because although I knew it, I kind of felt some sort of **disbelief** as well. And there were times also, not long after as well, I felt **angry** and thinking **why me?** And other times it was the **relief**, and other times I was **pleased**. So it was a lot of different emotions, really. I think there's always going to be an element of the why me, so it sort of robs you of that right to be like everyone else. (Brenda)*
- Goal: to help address some of these feelings from the beginning
 - Those feelings help with planning these discussions.



Child's emotions

- What emotions you have seen in your child?
 - **Frustration:** why do I have to leave school for therapy so often?
 - **Sadness:** why do other children pick on me?
 - **Curiosity:** why am I doing all these tests with doctors?
 - **Embarrassment:** why are some things so hard for me?
 - **Alarm:** is what other kids say about me true?
 - **Confusion:** did I do something wrong to deserve this?
 - **Loneliness:** why I am the only one struggling?
- Biggest reason to have the talk: Addressing these thoughts



Emotions transformed

- Help them answer the questions behind those emotions:
 - **Understanding**
 - **Relief:** no longer fear the unknown
 - Increased **willingness** to participate in therapy
 - **Contribute** ideas of what they wish to work on
 - Feeling of **belonging** to a group
 - Finding role models to **look up** to
 - Studies have shown that individuals can begin to feel **proud** of belonging to a unique group or culture.



Talking with your child

How?

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Setting the mood

- **Positive, matter of fact**

- Children will sense if you are upset
 - May feel that the diagnosis is “bad” or scary
 - You may not be ready to talk about it.

- **Belonging**

- Stories or videos of other people with a similar diagnosis
- Support groups, online groups

- **Similarity in differences**

- It would be boring if we were all the same
- We all have things we are good at
- We all have things that are hard for us
- Here are some of mine... what are some of yours?



Adjusting To Your Child's Level

- Autism diagnoses come at different ages & different speech skill levels
 - Can be simplified to:
 - “we all have differences”
 - Height, hair color, some wear glasses, some have allergies, like different toys, etc.
 - “we all have things we are good at and things that are hard for us”
 - Some children really want to know details
 - Signs of autism
 - How many children have autism?
 - Causes

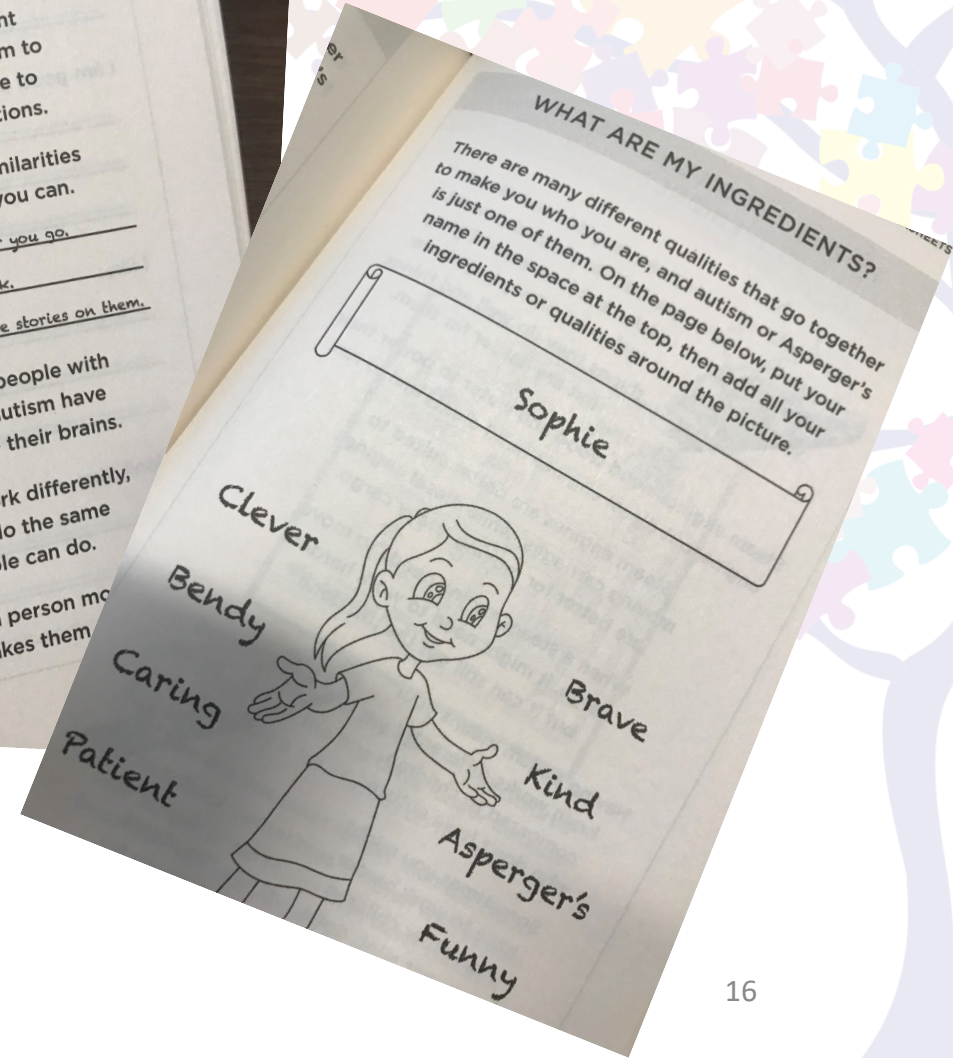
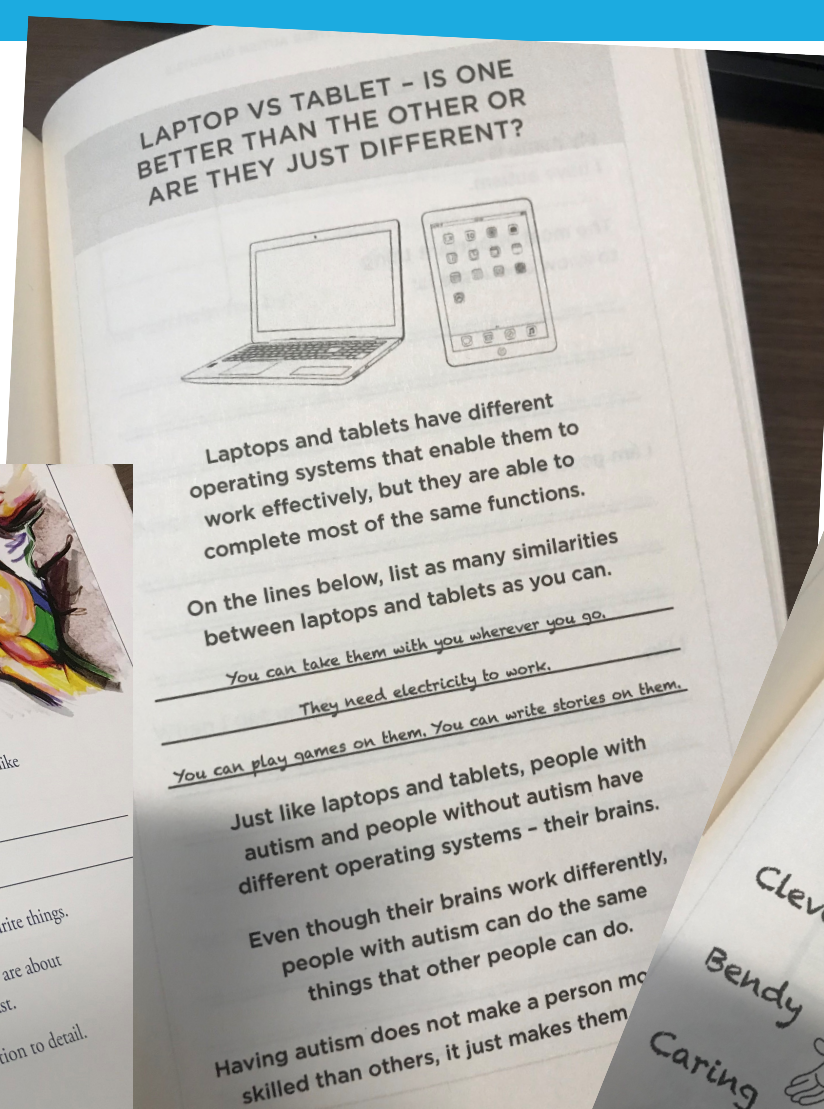
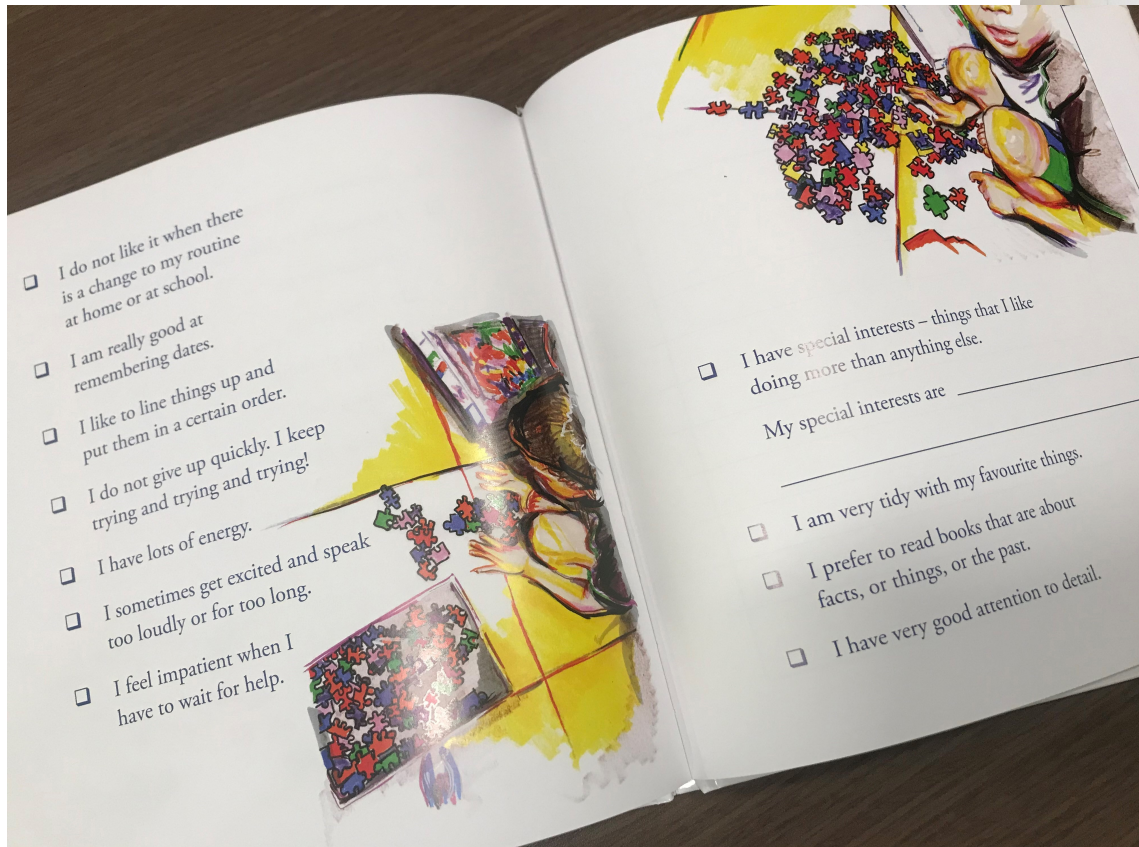


Adjusting Your Child's Understanding

- Ask them what they know about autism
 - Help remove misunderstandings
- Encourage questions
 - Admit that you may need to look up some answers.
- Often will need to revisit many times over the years as understanding matures or new questions arise.



Helpful Worksheets: (Book list at the end)

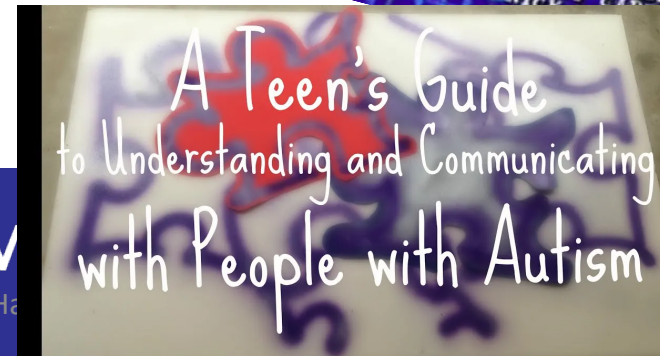


Key Ideas To Share

- The diagnosis is a **PART** of who they are.
 - We have many parts, skills, and favorite things that make us who we are.
- This is something you are born with.
 - Not something they did wrong or caught from someone else
- The difference is in the brain.
 - Not something that can easily be seen.
- We can learn to manage our challenges and use our strengths.
 - Some things may be harder or require a different path.
 - Must realize they can still follow their dreams.

Sharing Tools

- May involve family, teacher, or counselor
 - Help to present the information
 - Another person they trust to answer questions/talk
- Simple
 - Pictures, stories, relatable (positive) TV characters
- Mature
 - Books, videos of children talking about their experience, websites



Autism Role Models

- Satoshi Tajiri (inventor of Pokemon) was very focused on insects and on videogames as well. Later, he combined these two interests to create pocket monsters – or **Pokemon**.
 - <https://the-art-of-autism.com/how-satoshi-tajiris-autism-helped-create-pokemon/>.
- Dan Aykroyd was highly focused on ghosts and police and he used these interests to develop **Ghostbusters**.
- Hannah Gadsby is a famous **comedian** who credits her autism with giving her a unique perspective on social interaction and life in general.
- Greta Thunberg credits her autism to helping her resist peer pressure and that has helped her develop into a famous **environmental activist**.
- Daniel Tammet is a famous **author** whose sensory differences help him remember numbers incredibly well (e.g., he memorized pi to 22514 digits).
- Many famous inventors, artists, and musicians are believed to meet criteria for autism (e.g., see *Different Like Me: My Book of Autism Heros* by Jennifer Elder).



Troubleshooting: *What to do if your child...*

- Uses the diagnosis as an excuse:
 - Reinforce: they can still do many things, even if they need help.
 - Remind: other people have had the same challenges and worked around them
 - Look together for books or websites with ideas to help.
- Works hard to fit in and is upset to be told he/she has a “difference”:
 - Respect their wishes to not share the diagnosis when possible.
 - As adults, everyone needs different skills to do different jobs.
- Worries about being different:
 - Remind that we all have strengths and challenges.
 - Make a list of stressful situations and (*together*) plan ways to handle them.
 - Find special interest groups/clubs: part of a group because of what they enjoy.



Sharing Practice

Pick one of the ideas we have been talking about.
Think about how you could present it to your child.
Practice on someone sitting beside you.



Talking with others



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Challenges

- Hard to talk about
 - A lot of emotions can be close to the surface
 - Child may feel embarrassed
 - Worry about a child being “labeled”
 - Worry about a child not being expected to meet their potential
 - Feeling judged or blamed
 - Sudden deluge of advice



Benefits

- Improve understanding
 - Increased awareness = increased willingness to help
 - Avoid unrealistic expectations
 - People may misinterpret behavior as “bad”
 - Provide accommodations at school or daycare
 - Have strategies to avoid outbursts and help with calming
 - Increased access to support services
 - Educate others
 - More aware when interacting with other children



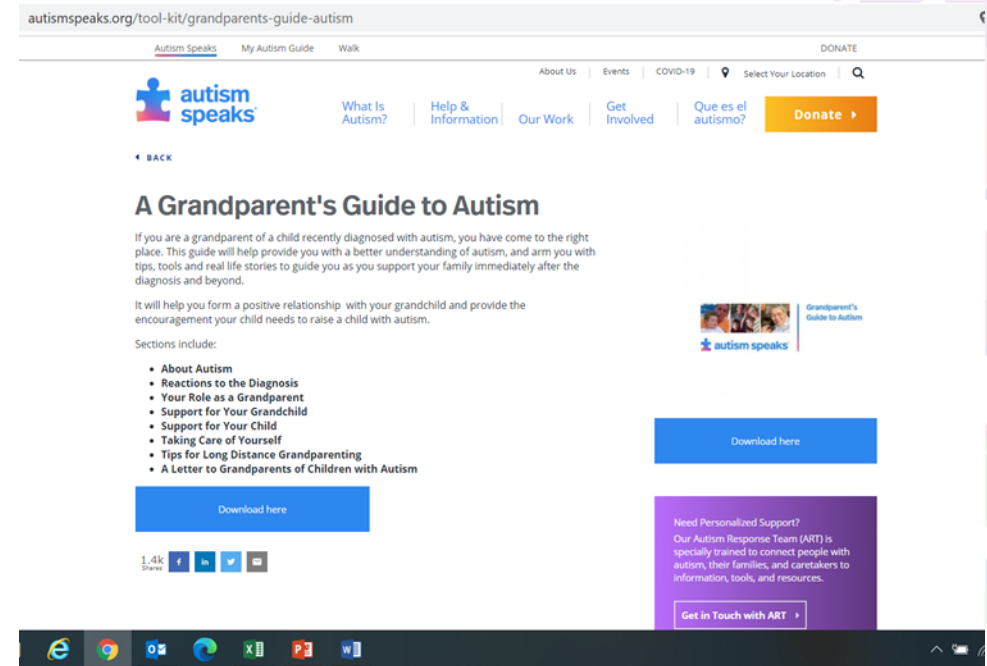
Who To Tell

- The team supporting you and your child
 - Extended family
 - Caregivers, daycare/babysitters
 - Therapists
 - Friends of the family
 - Siblings
 - Teachers
 - Classmates
 - Parents of your child's friends
- More understanding = more opportunities and supports



Extended Family

- Can be hard
 - Denial
 - Not understand the diagnosis
 - (uncommon 30 years ago)
 - “They will grow out of it.”
 - Many other statements....
- Offer information and websites
 - Autism Speaks
- Talk about benefit of early intervention
- “Diagnosis helps us know how to help.”



The screenshot shows the Autism Speaks website page titled "A Grandparent's Guide to Autism". The page includes a navigation bar with the Autism Speaks logo and various menu items like "What is Autism?", "Help & Information", "Our Work", "Get Involved", and "Que es el autismo?". The main content area features a "Download here" button and a section titled "Need Personalized Support?" with a "Get in Touch with ART" button. The page also displays social media sharing options and a "1.4k Shares" indicator.

Siblings

- Help label their **emotions**:
 - **Protect**: feeling protective with peers
 - **Embarrassed**: often complex feelings around peers
 - **Mad**: with “unfair” responses to behavior
 - **Jealous**: time-intensive needs
 - **Curious**: what are the signs, who else
 - **Worried**: thinking they might “catch” it
 - **Unsure**: wanting to help but unsure
- Strategies
 - Can mention diagnosis name
 - Emphasize strengths/challenges
 - Discuss that it is harder for them to learn some things.
 - Talk about specific ways they could help.

School staff

- Understanding how your child thinks, communicates, and learns... helps your child's teacher be more effective.
 - May be doing well and not needing any supports.
 - May help encourage peer interactions.
 - May use a 504 plan to list helpful strategies if concerns suddenly come up.
 - May qualify for an IEP to provide extra therapy and focused learning goals.
- Support based on needs, not just a diagnosis.



Classmates

- Talk with older children for permission
 - Making a presentation or writing an essay to share can be very empowering.
 - Help shape the narrative.
- Younger children
 - Share child's strengths/challenges
 - How your child is similar to them
 - How your child may be different
 - Help them think about ways they can help
 - Let them know when to get an adult to help



Important Info to Share

- Likes/dislikes, what is uncomfortable vs. soothing
- Special interests
- How your child communicates (signs, PECS, pulls hand, etc.)
- How to communicate with your child (single step commands, signs)
- Strengths and skills
- Struggles and challenges
- Sensory preferences
- Triggers
- Signs of stress (to allow intervention before a meltdown)



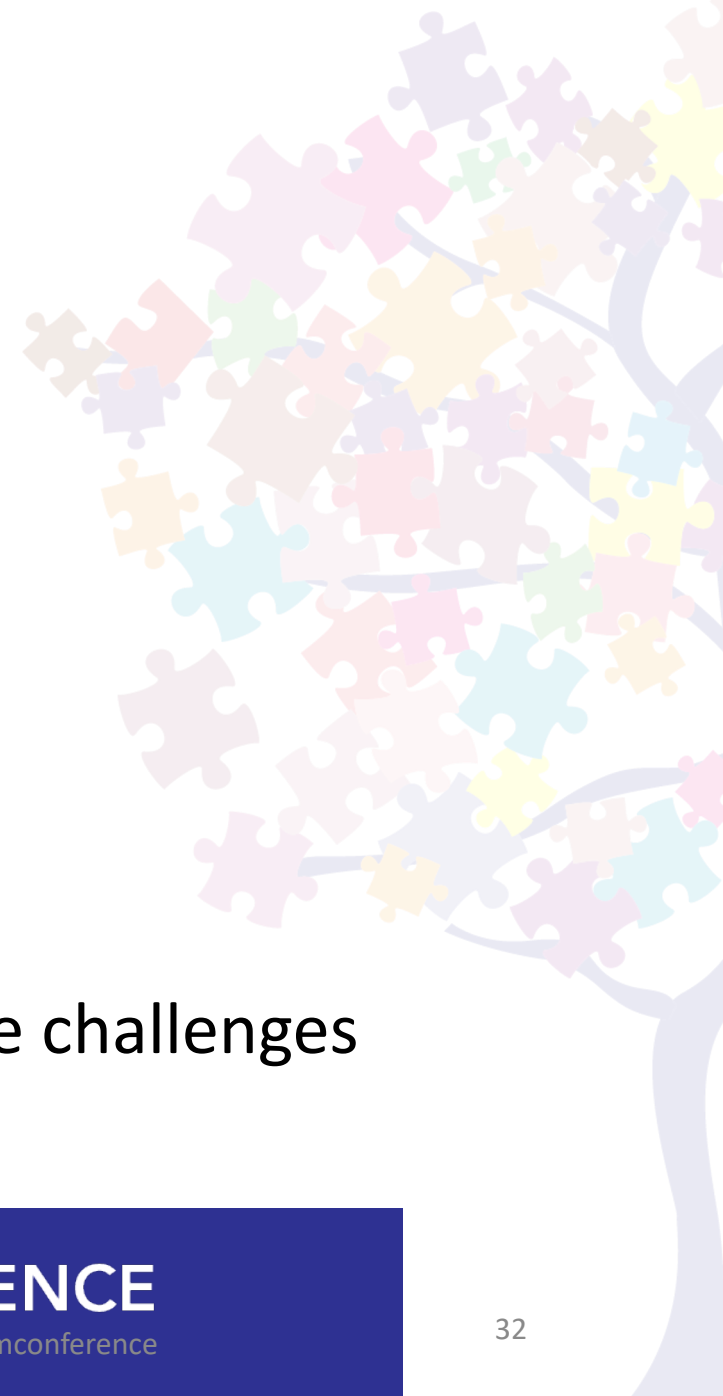
Sharing Practice

Put some ideas down on the sheet describing your child.
Think about how you could present it to your child's siblings,
grandparents, etc.
Practice on someone sitting beside you.



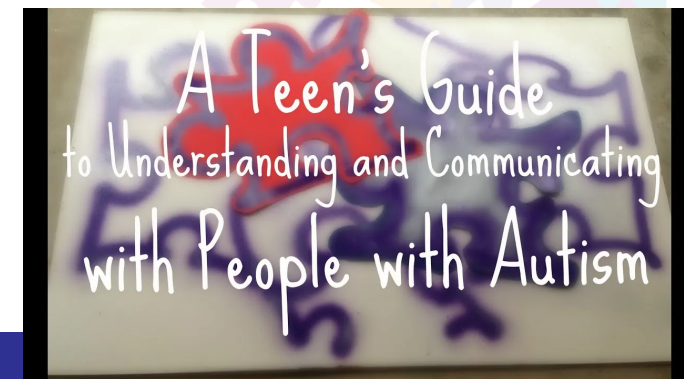
Key Points To Remember

- The unknown is scary
- It would be boring if we were all the same
- We all have things we are good at
- We all have things that are hard for us
- This is just one part of who they are
- Find role models
- Find how other people used their skills and overcame challenges
- Connect with others with similar interests



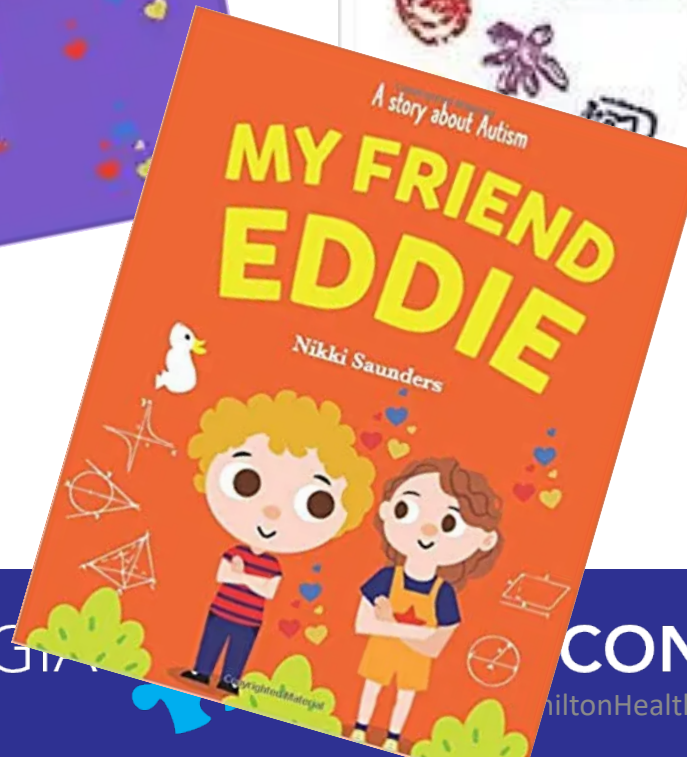
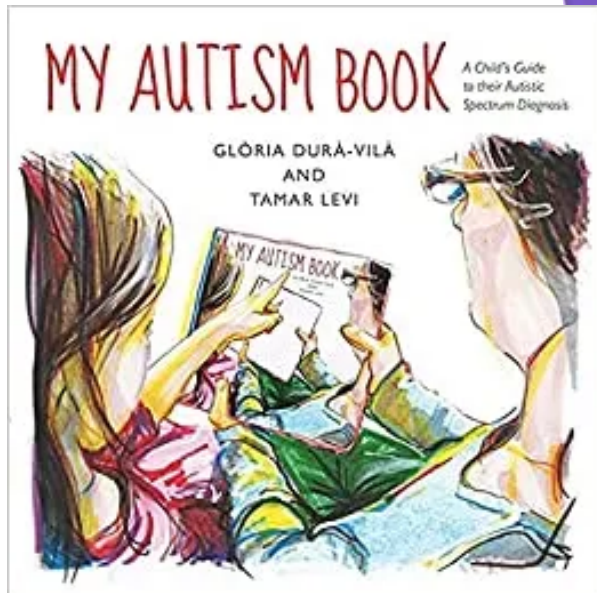
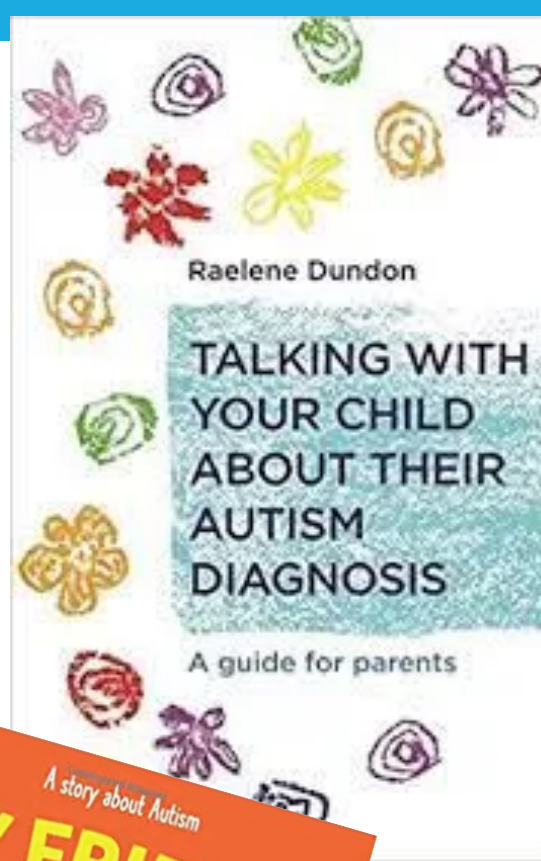
Sharing Resources

- When Carl Met George
 - PBSkids.org
- Meet Julia
 - sesamestreet.org/autism
- A Teen's Guide to Understanding and Communicating with People with Autism
- [Biographies of Autistic People – University of Washington Autism Center](http://biographiesofautisticpeople.org)
 - <https://depts.washington.edu/uwautism/resources/neurodiversity/biographies-of-autistic-people/>



Resources

Books





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