

I Have Autism and I Need Your Help

Teresa Hedley (Mom), Erik Hedley
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Preface

You never know what's good and what's bad. This was one of my father-in-law's favourite sayings, and I find myself drawing heavily upon it as I navigate the world of autism. A moody moment? An abrupt reply? A slammed door? I've discovered that difficult moments can be very revealing. They can be 'good' and instructive if we take the time to peel back the layers and figure out 'why'?

So, with this in mind, I took the liberty of applying the 'bad is good' theory to my son's grade eight school year. It was a year that produced some very thoughtful assignments and some excellent visual work, yes, but mostly, it was the year of repeated requests for consistent communication, organization, visual support and timely feedback. It was a tough year for a child with autism.

My son and I were tempted to turn our backs on the year and move on, but we thought better of it. Why not take the bottled up frustrations and turn them into something good? Why not take the year, look at it from the perspective of a teen with autism and articulate how it felt? Self awareness, after all, is the first step toward self-advocacy. If we could express what was difficult, we could also express how to create an atmosphere that would be a better fit for a student with autism. You never know what's good and what's bad.

So together we talked, we jotted and we wrote. We discussed the school year and recalled the very creative, visual projects Erik worked on and really enjoyed. We also discussed what made the year such a challenging one. He was very quick to reply, and he really hit the nail on the head: there was a lot of talking and it was hard to know what to do and how to do it. The process was very difficult to follow.

Autism is often accompanied by anxiety. Anxiety arises from not knowing what to expect and projecting what 'might happen'. The more that is known - in advance - the lower the anxiety levels. Managing autism relies on providing structure, predictability and consistency. This is precisely where things 'caved in' this past year. Anxiety levels were very high and this spilled over at home. It was a difficult year for Erik and indeed for his 'home scaffolding'.

Given that autism appears to be on the rise - one in fifty-five boys now and this

is based on 2008 data - we as special educators really have to get the methodology right for our exceptional kids. Fortunately, what is good for the exceptional population is good for all learners.

In Erik's response to me, he also hit the nail on the head regarding all three cognitive differences inherent in autism: central coherence (not being able to see the big picture and instead being side-tracked by the fascinating small stuff), theory of mind (assuming we all have similar thoughts and not being able to see things from another's perspective, also known as 'mind blindness') and executive function (finding it tricky to organize, synthesize, prioritize, manage time and so forth). All three of these cognitive differences were challenged this year given the mis-match between learning and teaching styles.

What we came up with is a list of what works and what is needed to reach kids with autism. The thoughts and perspectives are Erik's. I guided him with the structure and the writing process. He is very straight-forward, and one can sense this honesty throughout. I helped him shape his thoughts into something that is coherent and instructive. So, it is a mother and son effort and a bit of a catharsis at that!

For each point, we have jotted down the situation in italics, how it feels from Erik's perspective, and what is effective – indeed, 'best practices'.

Erik and I sent this letter, attached, to our local school board so that the ASD perspective could be shared with district teachers. Our aim is to help exceptional learners be the best they can be. This requires an understanding of the unique perspective of students with ASD. If our difficult school year and its follow up make a difference, that would be a very good thing.

You never truly know what is good and what is bad.

Teresa Hedley is a mother of three, one of whom is on the autism spectrum. She is also a teacher with a special education background. She currently works as a Parent Autism Resource Consultant for Emerging Minds, an Ottawa multidisciplinary practice serving children and youth, many of whom are diagnosed with autism. Teresa will be joining the OCDSB Special Education Advisory Committee in the fall as a representative for Autism Ontario/Ottawa.

Erik Hedley is a hard-working teen who enjoys travel and exploration, working outdoors, cottage life, swimming, skating, skiing, all sorts of computer games and old-fashioned board games, too! He will be starting high school in the fall.

Erik's Letter

Dear Mr. _____ and Mr. _____,

One of my goals this year is self-advocacy. I am going to use it now. I think you know that I have autism. I need your help.

I am leaving the school soon, but more children with an autism spectrum disorder (ASD) will be coming to the school. I am writing this so that you know how they might feel. They need you to see things from their perspective. They will be smart kids. You just need to know the best way to teach them. I need you to pass along my message.

Remember the Temple Grandin movie my class saw this year? We learned that Temple Grandin thinks in pictures. I do, too. I liked seeing that film because I really liked seeing all of the things that Temple can do inside her head. I can also do some interesting things inside my head.

I can see little details that a lot of people don't see. I can see when things change and I can see exactly what is different. To me this is really amazing!

I can memorize pictures. Sometimes I can see every page of a photo book inside my head. I know what is on each page, how the pictures are arranged, the background colour and style and the order of the pages. I thought everyone could do this but my family says, "No, this is an Erik thing."

I have a good sense of direction. I usually know where I am and where other things are pretty quickly. My family calls me our Erik Positioning System – E.P.S..

Now I am going to tell you about the things that are hard for me. I will try to tell you how things feel from my perspective. After that I will tell you how teachers can help me. When you see the word 'you' from now on, it means 'my teacher'.

Going into a classroom and not knowing what the plan is going to be is hard for me. When you start talking without a plan, I feel nervous because I don't know how long this will go on. I can hardly concentrate because I am wondering what will come next. I know that you use an outline for your staff meetings. You would feel lost without an agenda. That's how I feel.

- 1. I need a plan written on the board.*
- 2. I need to know what work we will be doing, about how long we have for each part, and what comes next.*

3. I need to know when things are due.

This can all be in point form. When I was younger, teachers did this for the class with pictures.

Listening to a lot of words is hard for me. Sometimes I feel like a computer that is clicked too many times. You know when you see the screen go grey and the title 'not responding'? That is how I feel. It is too much information coming in. I can't think that quickly. I feel like my brain is shutting down and maybe you see me 'not responding', too. I feel very worried.

4. I need you to slow down and speak clearly.

5. I need direct and concrete language.

6. I need outlines for the important topics.

This way I can absorb the new information at my speed.

Copying a lot of work from the board is hard for me. I feel dizzy lifting my head up and down. My hand gets tired writing a lot of words. When you talk at the same time it is way too hard. I am not responding, my hand hurts and my head is dizzy.

I am not learning.

7. If it is a detailed topic, I need notes or an outline written out.

8. I like pictures and diagrams. I think in pictures.

9. My desk needs to be facing the board and not sideways to the board.

When you ask us to write jot notes about the main ideas, this is hard for me. This is because I don't always know what the main idea is. There is an expression that says, "He couldn't see the forest for the trees." I think that is like me. I notice the interesting details but I can't figure out the whole message. So, when you ask me to write jot notes about new and hard topics and you ask me to figure out the main idea, it is nearly impossible for me.

10. I need an outline of the material written in your words. You could leave blanks and I could fill them in. Maybe you could circle or highlight key words.

11. I need you to show me how to write jot notes by giving me an outline and examples.

Because I have a hard time knowing what is important, it is hard for me to study for a test when there are so many notes and so many chapters. I feel like I don't know where to start. I don't know what we will have to do with the topics on the test.

12. I need study guides or practice worksheets.

13. I need to know what is important.

14. I need to know what I will have to do with the topics.

Sometimes I think you know what I am thinking in my head. I think you must know when I need the instructions again or when I am stuck, so I wait for you to come to me. Now I know that you probably don't know what I'm thinking. My mom always says to me, "I'm not a mind reader. How could I know what you're thinking?"

So that we are both thinking the same thing,

15. I need instructions written out.

16. I need things broken down into steps.

17. I need examples of what we are doing.

18. I need rubrics about what you expect before the assignment.

19. If you can, I need you to check with me that I am doing the right thing.

There are more things, but I think these are the most important. Now you might know what it feels like to be me. I feel nervous and stuck a lot.

I always try to do a good job at school. I know that I have to work hard. There is a paper called my individualized education plan. My mom showed it to me. It says that I learn best by having things written down ahead of time. It says I need outlines written out for me. It says I am a visual learner. It says I need practice sheets so that I know what to study. I think this plan is good for me.

20. Can you try your best to use my IEP, please?

Two of the most important things you can give me are predictability and consistency. I used to feel smart at school. This year I didn't feel as smart. I can only do a good job if I am taught the way I learn best.

I like it when my teacher says, "Be the change you wish to see in the world." Maybe by writing down how things feel for me, I can help people learn more about autism.

21. But I need you to listen

Mr. _____ and Mr. _____, thank you for listening to me. I want you to know that I am smart. I work hard. I want to do a good job. I have autism and

I need your help. Could you please pass my message along?

From Erik Hedley

P.S. Mom's Note: Please provide structure and options during unstructured times (recess and lunch). Asking students with autism to go outside and 'mingle' is like asking a visually impaired student to negotiate the playground without a guide dog. Wandering, flapping, humming and rocking are not 'autism'; they are coping mechanisms and a reaction to an unsupportive environment. I think it is best explained like this: 'Work is play and play is work.'

22. Structure and predictability are critical. Please respect the perspective.

P. P.S.: "Believe that you can make a difference for me. It requires accommodation and adaptation, but autism is an open-ended disability. There are no inherent upper limits on achievement. I can sense far more than I can communicate, and the number one thing I can sense is whether or not you think I "can do it." Expect more and you will get more. Encourage me to be everything I can be, so that I can stay the course long after I've left your classroom." (Anonymous)

23. Believe in me.

As my poppa used to say to my mom and dad: "Erik will surprise you."
I will surprise you, but I need your help.

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