

WHY, WHEN, AND HOW TO SHARE AN ASD DIAGNOSIS

CONTENTS:

FEATURE ARTICLE:
**WHY, WHEN, AND HOW
TO DISCLOSE AN ASD
DIAGNOSIS**
01-02

**TRY THIS
BEHAVIOUR TIP**
02

**TEACHER TIP
COMMUNICATION
CORNER**
READ ALL ABOUT IT
03

**ANNOUNCEMENT
REFERENCES**
04

When a child is assessed for Autism Spectrum Disorder (ASD), the diagnostic process often concludes with information about the diagnosis being shared with the parents of the child exclusively. What parents choose to do with this information is pivotal to the child’s own understanding and acceptance of the diagnosis, which, in turn, can have a large impact on their lives, self-image, and capacity to self-advocate. The looming question that parents often have after receiving a formal ASD diagnosis for their child is how and when should they disclose the diagnosis to the child themselves. Upon first receiving their child’s diagnosis, parents often experience a myriad of emotions including feelings of guilt, sadness, and fear of their child being stigmatized or not being able to live a normal life (Smith, Edelstein, Cox, & White, 2018). The process of the parents understanding and coming to terms with the diagnosis can be overwhelming. Additionally, when thinking of how to disclose the diagnosis to their child, parents may worry about their child’s ability to understand the diagnosis and its implications, including possible repercussions on their self-image and general outlook on life (Wheeler, 2003).

Smith et al. (2018) conducted a literature review to examine several variables around the disclosure process including the emotional impact of the disclosure, the delay between receiving the diagnosis and the parent-child disclosure, whether the child put pre-existing symptoms or difficulties in a new light following the diagnosis, as well as the parent and child’s perspective on the diagnosis. Results indicated that common concerns reported by parents included whether their child had the capacity to understand their diagnosis, the social stigma associated with the diagnosis, and the child learning to use the ASD diagnosis as an excuse as an attempt to escape/avoid situations or demands. These concerns frequently resulted in a delay in disclosure of the diagnosis that often lead to a delay in sharing the diagnosis with a broader social network. Contrary to the worries of many parents, a theme that emerged in several of the studies was the benefits of sharing the diagnosis. Youth with ASD reported that receiving the diagnosis helped to provide a concrete explanation for their difficulties and atypical reactions, which formerly had caused them confusion and frustration. Additionally, youth reported that with the knowledge of their diagnosis, they were able to be more active participants in behavioral interventions, as well as to better navigate challenging social situations.

Ultimately, in spite of the possibility of negative emotions/reactions tied to the initial sharing of diagnosis, it is important to consider that becoming aware of the diagnosis opens the door to a wealth of knowledge about the condition that often leads to a better understanding of self. Another important factor around sharing the diagnosis is consideration of the age and/or the developmental stage of the child at the time of the disclosure.

There is no “right age” to share a diagnosis with a child. When to do so will depend largely on when the child is ready and prepared to receive it. For example, one indication could be when a child starts to notice and/or remark about differences between him/her and other children. This could signify that sharing a diagnosis may assist in understanding those differences and encourage the child to participate in skill-building interventions. When the time is right to share a diagnosis, keeping it as simple and as positive as possible is advisable. Too much at once may overwhelm or confuse children, so it is best to keep the information in manageable chunks. More detail can gradually be provided

over time, as previously shared information is better understood. Given the complexities involved, accessing the support of a qualified professional to help deliver the diagnosis to your child may be a good option. Dividing the roles in this way leaves the parents free to be there for their child in a comforting capacity, instead of being the bearer of unsettling news (Wheeler, 2003).

Furthermore, before disclosing a diagnosis to your child, having a good understanding of the diagnosis and its potential implications yourself may ease the process. A study by Banach, Iudice, Conway & Couse (2010) demonstrated that a post-autism diagnosis support group for parents was effective in helping them deal with this difficult adjustment process. The support group consisted of both professionals and parents of youth who had previously been diagnosed with autism and who had gone through a similar process. This group involved discussion about coping strategies, how and where to obtain support services for their children, and specific challenges around education, and integrating within broader community. Results of this study indicated that initial and ongoing support was critical so that parents and their children could better understand and adjust to the changes triggered by a new diagnosis.

In summary, introducing a child to their ASD diagnosis is a complex process, ideally guided by some specific parameters and strategies, rather than by a precise plan; these parameters take into consideration several different variables, with each child's unique case to be carefully considered.

TRY THIS

At the beginning of the school year, it is always beneficial to establish the classroom routine with your students with ASD. This will help create a predictable environment for them as well as set the tone for the year. A common visual support used is a cue card depicting the classroom rules that students need to follow such as the one below. Try posting this cue card near your student's desk or create a larger one that can be used for the entire class. Provide daily reminders by referring to the cue card.

Class Rules	
	Line up quietly
	Raise your hand
	Walk in hallways
	Stay in your seat
	Listen to the teacher
	Work quietly
	Hands to yourself



BEHAVIOUR TIP

Behaviour Specific Praise (BSP) is an evidence-based classroom management strategy for increasing social and academic performance of students. It is a non-intrusive strategy that can be differentiated according to a student's age or developmental stage. BSP should be student-specific, action-specific and delivered in a positive manner. Here are some examples and non-examples:

Examples of BSP	Non-Examples of BSP
James, I like that you are sharing your favourite toy with your friends.	Great job!
Way to go sharing your ideas about the main character in the group discussion today, Matthew!	You did well.
Sarah, thank you for keeping your hands to yourself during circle time.	Don't touch your friends.

TEACHER TIP

Should I Let This One Go?

Navigating Negative Behaviours

How do you know if the negative behaviours observed in class are worth disciplining or should they be overlooked/supported differently because of a diagnosis? Often times as teachers, we see our students acting out and we question whether they should be getting into trouble for what they have done or if it is somewhat excusable because of an underlying disability. There are a few things to consider when deciding when it is appropriate to give a consequence to a negative behaviour or if *looking the other way* is indicated.

1. Can the student control himself/herself?
2. Did the student know it was wrong?
3. Did the student know it would negatively impact others?
4. Does it make the student stand out from the rest of the class or is the entire class engaging in the same behavior?

If you answered NO to any of these questions, then you need to reevaluate how to manage the undesired behaviour. A student should not be punished if this criteria has not been met. However, if the student could control themselves, knew the behaviour was wrong, knew it would negatively impact others and is not part of a group doing the exact same thing, then yes - the behaviour cannot be excused by an ASD diagnosis.

It is crucial to consider the underlying reasons for the behaviour and know that there is no one size fits all approach when it comes to supporting our students.

Reading Comprehension & Story Grammar Marker (SGM)

Many children with ASD struggle with comprehension particularly when reading fictional texts. They may have difficulty understanding the thoughts and motives of the characters in the book. In addition, reading comprehension requires students to make inferences and draw conclusions when the information is not explicitly stated in the text. It is common for students with ASD to focus on the details of the text but fail to grasp the big picture of the author's message.



Telling a story that makes sense to the listener also presents students with ASD with challenges and writing their own story can be an overwhelming task.

Braidy, the StoryBraid® and the Story Grammar Marker (SGM)® are tools that provide a concrete framework for helping students organize their thoughts, make connections between the text to real life situations and take perspective.

The SGM was created by Maryellen Rooney Moreau, M.Ed., CCC-SLP who has expanded her materials by creating a specific collection for students with Autism. Her website contains many free resources and webinars to help Speech-Language Pathologists and Educators learn how to implement these tools. To learn more about the Story Grammar Marker and to purchase her materials visit her website at:



<https://mindwingconcepts.com/>

READ ALL ABOUT IT

Many parents have fears and questions about how to reveal an ASD diagnosis to their child. They worry about how this might affect the child's self-concept, how to answer questions their child may have, and how to help their child deal with emotions about being different. The *ASD Workbook: Understanding your Autism Spectrum Disorder* written by Penny Kershaw (2011) was created to provide support and guidance to families around disclosure of an ASD diagnosis. It presents autism, its characteristics, its day-to-day impact, and intervention strategies in a positive and easy-to-understand way. It also contains several activities for children to better understand themselves. This book and its activities are suitable for students in Grade 4 - Grade 8, but parents and educators can adapt as needed to target other age groups.

If you are interested in borrowing this or other books related to ASD, please refer to the library section of the ASD website. You can also contact Jade Lawsane at jlawsane@lbpsb.qc.ca.



THE CENTRE OF EXCELLENCE FOR AUTISM SPECTRUM DISORDER PRESENTS:



AMY LAURENT

ADDRESSING EMOTIONAL REGULATION IN CHILDREN AND ADOLESCENTS WITH AUTISM SPECTRUM DISORDER

Thank you to Andrea Bertalan (LBPSB work skills consultant) and students from the LIFE program at Lindsay Place High School for preparing this newsletter for distribution!

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WHEN:
APRIL 27, 2020
9:00-16:00

WHERE:
Holiday Inn
Pointe-Claire
Montreal, QC

PRICE:
\$95 (CAD)

INTENDED FOR:
Professionals, teachers,
educators, families &
individuals with ASD

LUNCH & SNACKS:
Included

Emotional Regulation, the maintenance of emotional states and energy is a significant challenge for many individuals on the spectrum. Difficulties staying well regulated can impact relationships, learning, daily activities and fun!

The course will begin with a brief review of the core developmental challenges faced by autistic individuals at various stages in development (i.e., pre-verbal stages, emerging language stages, and conversational stages). This introduction of regulatory challenges and social communicative difficulties will then be followed by a discussion of the interplay between these areas and their impact on an individual's social communicative competence. This relationship will be addressed from both a developmental standpoint, as well as a situational one. This talk will explore the numerous factors that impact an individual's ability to be organized and engaged with others. Practical guidelines for prioritizing the support of emotional regulation for autistic individuals across a wide developmental range will be discussed. Emphasis will be placed on supports that can be used proactively and reactively.

Amy Laurent, Ph.D., OTR/L is a developmental psychologist and a registered pediatric occupational therapist. Currently in private practice, Amy specializes in the education of children with autism spectrum disorder (ASD) and related developmental disabilities.



To register, please consult:
<http://coeasd.lbpsb.qc.ca/>

You can also watch Amy Laurent's TED Talk, by visiting:
https://www.youtube.com/watch?v=fx3cfzICG_Q



REFERENCES



- Banach, M., Iudice, J., Conway, L., & Couse, L. J. (2010). Family support and empowerment: Post autism diagnosis support group for parents. *Social work with groups*, 33(1), 69-83.
- Kershaw, P. (2011). *The ASD Workbook: Understanding your Autism Spectrum Disorder*. London: Jessica Kingsley Publishers.
- Smith, I. C., Edelstein, J. A., Cox, B. E., & White, S. W. (2018). Parental disclosure of ASD diagnosis to the child: A systematic review. *Evidence-Based Practice in Child and Adolescent Mental Health*, 3(2), 98-105.
- Wheeler, M. (2003). Getting started: Introducing your child to his or her diagnosis of Autism or Asperger Syndrome.