# Part of what makes you, you!

Information about Autism Spectrum Disorder (ASD)











For children with a new diagnosis and their families

### Land Acknowledgement

We gratefully acknowledge that this handbook was created on the location of the beautiful unceded Coast Salish traditional territory. We thank the x<sup>w</sup>məðk<sup>w</sup>əyəm (Musqueam), the skwxwú7mesh (Squamish) and the selílwitulh (Tsleil-Waututh) Nations for their hospitality.

We recognize and commit to the ongoing work of addressing Indigenous-specific racism and discrimination in British Columbia, particularly in the health care system.

#### About this Handbook

Hi parents and caregivers! The about section is for you, but feel free to go through the information with your child.

#### Who we are

Clinicians who work with families at BC Children's Hospital in the Healthy Minds Centre. The children we serve primarily come to us with neurodevelopmental differences. Many of the children experience significant emotional dysregulation and difficulties with social relationships and school functioning.

We work within a multidisciplinary team that includes psychiatrists, psychologists, occupational therapists, speech language pathologists, youth and family care workers, nurses and teachers. As a team, we provide diagnostic assessment, clarification and education to best support each family.

#### Why we made this handbook

To help children with a new or recent diagnosis of autism spectrum disorder (ASD) and their families better understand what autism means to them.

Our goal is to provide child-friendly information and resources about autism. We explore some of the feelings, thoughts, and behaviours an autistic child may experience.

#### About this Handbook

#### Who this handbook is for

Children between the developmental ages of 5 to 12 and their families.

#### How to use this handbook

Your child can read this book by themselves or with people they trust, like you or their teachers. We hope this handbook is the start of you and your child's journey in learning about autism. You will continue to learn a lot more as your child grows.

Note: Throughout the handbook, we refer to the diagnosis as 'autism,' 'autism spectrum disorder' and 'ASD'. We refer to individuals using the terms 'people with autism,' 'autistic people' and 'neurodivergent' interchangeably. Your child can choose the words that are right for them.

This handbook is dedicated to neurodivergent children and their families.

## Table of Contents

	PAGE
What is Autism?	4
Information about Autism	8
Thinking	16
Feeling	<b>17</b>
Behaving	19
Friendships	21
Autistic People	24
Matching Statements	<b>27</b>
A Story About You	28
Other Thoughts	30
Questions?	32
Resources	33

#### What is Autism?

You and your family may wonder how you get diagnosed with autism. A manual called the DSM-5\* guides clinicians when they make a diagnosis.

## The DSM-5 criteria for autism are:

This can look like:

Persistent deficits in social interaction and communication



Having trouble understanding what people think, showing how you feel, sharing your thoughts, and making and keeping friends

Restricted, repetitive patterns of behaviour, interests or activities



Getting stuck on having things done a certain way and/or getting super-focused on a topic

#### What is Autism?

- Autism is a complex developmental condition. This means that people think, talk and share experiences differently.
- You may hear people say that autistic people are "wired differently". This means that your brain works in a unique way.
- People are born with autism and it is a part of who people are.

#### Remember: EVERYONE is unique and special!



### Autism is a Spectrum

Autism is known as a spectrum because it is different for everyone. Some people *might*:

like to be around many people or prefer to be with one person at a time

have a strong interest in a fictional character or specific facts

have trouble making eye contact while listening to others

Autism spectrum disorder

talk a lot, a little or not at all

have to move their bodies in a particular way

also have anxiety, attention problems, sensory sensitivities, and/or language and thinking differences

repeat certain words and need to do things in a certain order

### Autism is a Spectrum

Autistic people are *not* all the same.





Each autistic person has their own unique abilities, challenges, and ways of being.

You may need a lot of help with some activities and less help with other activities.



#### What Causes Autism?

- No one is sure what causes autism. There are many things that make you, you. For example:
  - Biology: this includes things like cells, chromosomes and genes; autism may run in families
  - Environment: this includes the things that are around you that could influence who you are

 Researchers are working hard to figure out what causes ASD so they can better understand it.

#### Can You Share Autism?

 Autism cannot be caught or shared. It's not like catching a cold or sharing an umbrella.



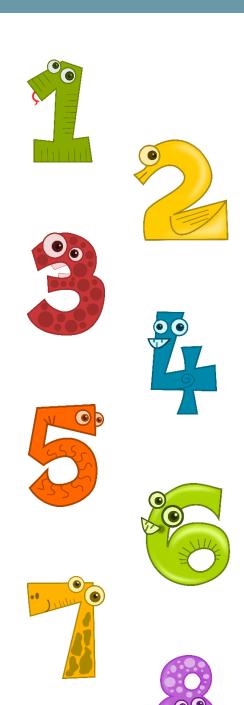


 ASD is just one way of being – like being tall, being shy, or having freckles.



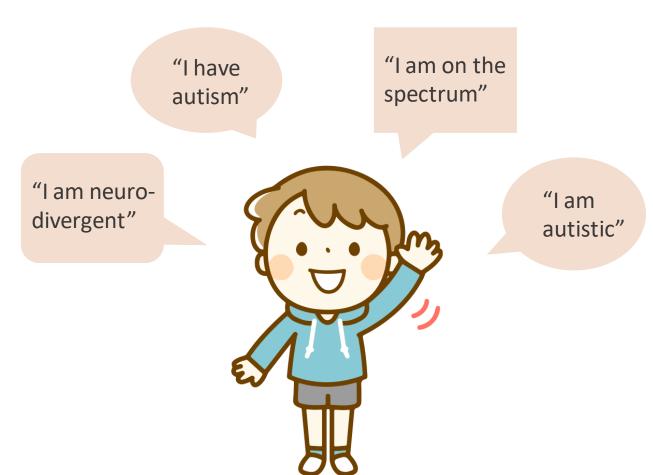
#### Who has Autism?

- No one is sure how many people in the world have autism.
- More countries are starting to count the number of people with autism more accurately.
- People of all backgrounds, genders, ethnicities and cultures are autistic.



#### What is Autism Called?

- People talk about having autism in different ways. You may hear autistic, autism spectrum disorder (ASD), being on the spectrum or neurodivergent. When you talk about yourself, you can choose the words that are right for you.
- This is Pat. Pat might say:



### Did You Know?

#### People with autism...

Can do anything!

Sing, dance, write, act, play sports, make music and art.



Work and volunteer with your hands, people, animals, computers, numbers, and so much more.



Fall in love, have relationships, get married and have children.



Attend school, college and university.

## Cool Things About Autism

#### Autistic people can:

Be really interested in art, music or math.

Have a great sense of humour.



Have a really good memory.

Be really good at taking things apart or putting things back together quickly.

Be very loyal and honest.



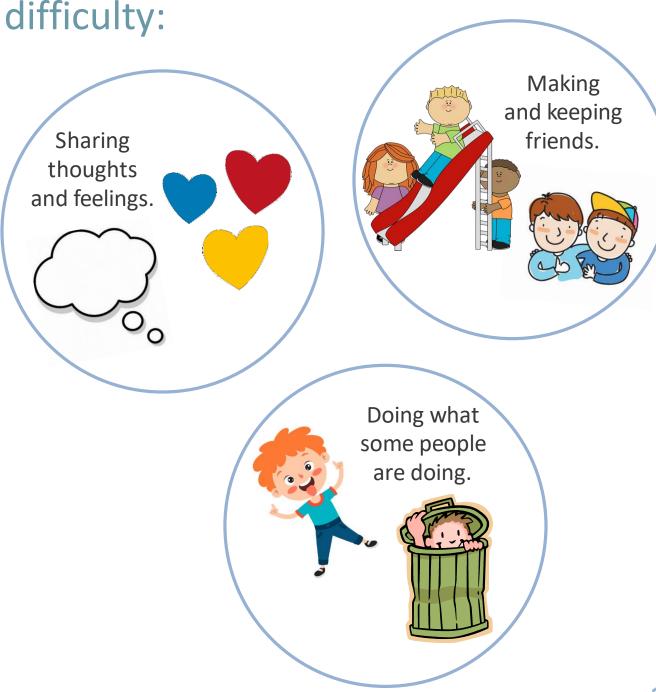
Know a lot about favourite subjects.



Be very caring and sensitive.

## What Can it Mean to be Autistic?

Being autistic means you may have



## What Can it Mean to be Autistic?

Sometimes autism can make things hard because you may:

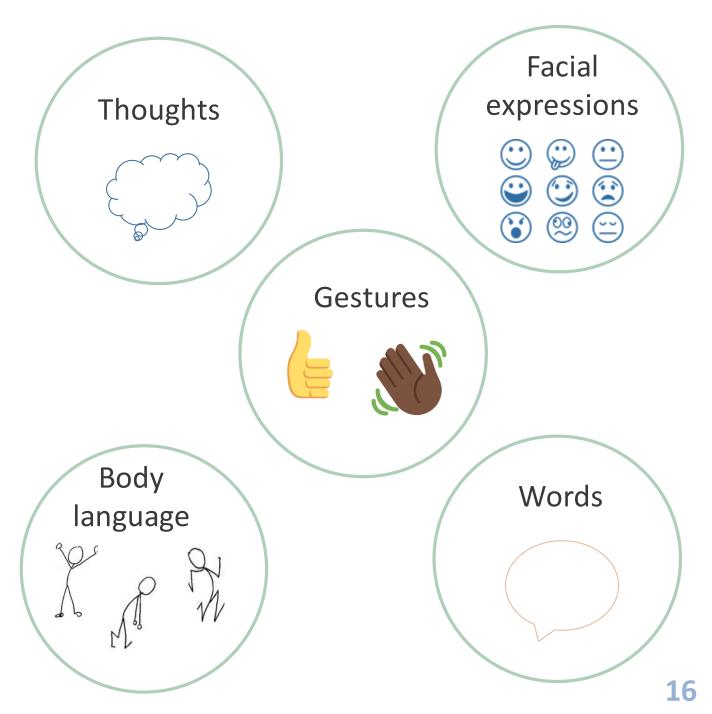
- THINK differently than some people.
- FEEL differently than some people your age.
- BEHAVE differently than some people.

#### This means:

- Some people may not understand how you think about things.
- Some people may not understand how you feel about things.
- Some people may not understand what you say and do.

## Thinking

Autistic people may have difficulty expressing and understanding:



## Feeling

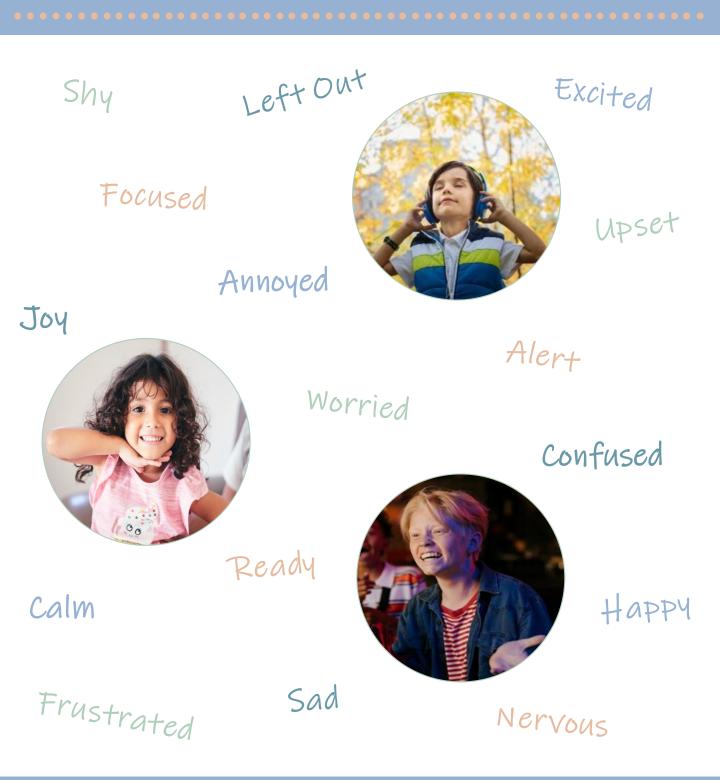
- People with ASD have the same feelings as everyone else.
- These feelings can feel really big and be hard to manage.
- It may be hard to know how other people feel.

 People have different ways of showing the same feeling.





#### Sometimes you may feel...



## Behaving

# People with ASD may do things that look different. Some behaviours may include:

 A repetitive action or movement, like rocking or flapping your hands (stimming).

 Getting stuck or super focused on toys, objects, and topics.

 Lining up and sorting toys, figurines and other objects.



## Behaving

#### Having ASD means you may:

- Suddenly make sounds or move your body in unexpected ways.
- Repeat words that you hear in movies or shows (echolalia).





- Not like to make eye contact. You may not like to be touched.
- Be upset by sounds and lights (sensory).
- Really like lights or touching things with your hands.

You may do these behaviours to stay away from or look for things that will make you feel better.

### Friendships

## Having autism means it may be hard to:

- Connect with others.
- Use facial expressions to show interest.
- Join and participate in groups.
- Start and keep conversations going.



## Friendships

## Having autism means it may be hard to:

- Play and work with others.
- Understand other points of view.
- Problem solve with others.
- Share creative ideas.
- Take turns.



## Friendships

Remember





You will have many good friends throughout your lifetime!

We all need to learn new skills to make friends.



#### Autistic People Who Have Done Cool Things

#### **Greta Thunberg**

Greta Thunberg is a Swedish climate activist who is known around the world for her call to action to solve climate change. Thunberg sailed across the Atlantic Ocean by herself when she was 16 years old because it was better for the environment than flying. Thunberg calls autism her "superpower".





#### Dan Aykroyd

Dan Aykroyd is a comic actor. He was kicked out of two schools as a child for his behaviour and, in his 30s, diagnosed with autism. In an interview with the Daily Mail, Aykroyd shared that one of his symptoms of ASD was his interest in ghosts and law enforcement. This helped him create the movie *Ghostbusters*.

#### Autistic People Who Have Done Cool Things

#### Satoshi Tajiri

Satoshi Tajiri is the creator of Pokémon. Tajiri chooses not to talk about autism in public. He prefers for his many accomplishments to speak for themselves.



#### **Dr. Temple Grandin**

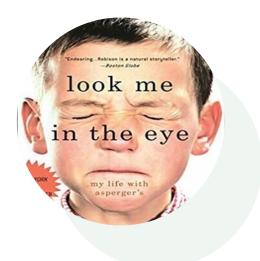
Dr. Grandin did not talk until she was three and a half years old. Her teachers taught her how to wait and take turns when playing board games. In school, she discovered her love of science. She became an author and speaker on both autism and animal behaviour. She currently is a professor of Animal Science. Many articles have been written about Dr. Grandin and a movie was made about her life.

#### Autistic People Who Have Done Cool Things

#### **Clay Marzo**

Clay Marzo is from Hawaii and was diagnosed with autism as a child. The documentary, Just Add Water, was made about Marzo because he won so many surfing competitions as a teenager. At age 15, he was the first person to receive two Perfect 10s at a national surfing competition. Marzo is now an adult and continues his career as a successful competitive surfer.





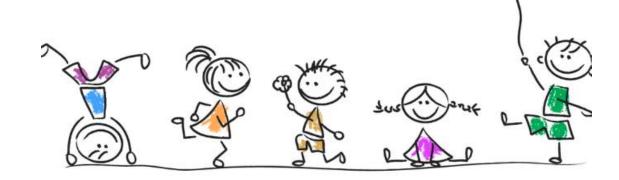
#### John Elder Robison

John Elder Robison is an autistic self-advoate best-selling author of Look Me in the Eyes and Be Different: Adventures of a Free-Range Aspergian. Robison was diagnosed with autism as an adult and has said, "It took some time, and a lot of hard work, but the knowledge of how and why I am different transformed my life".

## What People with ASD Say About Themselves

#### Which statements match you?

- I am great with details.
- I have super observational skills.
- I can spot patterns well.
- I have unique ways of thinking about things.
- I can solve problems creatively.
- I am loyal and super honest.
- When I make a commitment, I stick to it.
- I have a great imagination.
- I am resilient.



## A Story About You

My name is	•
I am	
I live with	
(include family and pets)	•
I like to	
and	
I was diagnosed with autism spectrum disorde	` '
This is what I knew about autism before my dia	agnosis:
This is what I know about autism now:	
To me, autism means:	

True or False: I want my friends to know I have autism.

True or False: I want my classmates to know I have autism.

True or False: I want help telling my friends and family

about my autism.

## A Story About You

Some things that bother me are
Some things that make me laugh are
I am good at
I need help with
When I was younger, I liked:
·
Now that I am older, I like:
My favorite places to be are:
and
When I am upset:
I like people to come near me.
I like people to stay away from me.
I like people to be kind of far from me but in the same room.

## Other Thoughts

- Hearing the word autism may be upsetting or confusing for you and that's okay.
- You may worry about how ASD will affect your future.





- Sometimes you may worry about how your family will deal with it.
- You may wonder what your friends, neighbours or others think about you being autistic.
- At times, you will need to talk about how having ASD affects you. It is a good idea to find a trusted family member, teacher, or friend who you can be open and honest with about your questions and feelings.

#### Remember



Autism is a part of who you are and what makes you, YOU!

Every day is another opportunity to learn more about yourself.

As you learn more about having autism, you can share with others what you want them to know.

#### Questions?

Write any questions you have here after reading this handbook. You can come back to them as you continue to learn about autism.

?



#### Resources for You: Books

All My Stripes: A Story For Children With Autism
 2015 | Shaina Rudolph & Danielle Royer



I See Things Differently: A First Look at Autism
 2014 | Pat Thomas



Uniquely Wired: A Book About Autism and its Gifts
 2018 | Julia Cook



 The Girl Who Thought in Pictures: The Story of Dr. Temple Grandin.
 2019 | Julia Finley Mosca



 The Survival Guide for Kids with Autism Spectrum Disorders (and Their Parents)
 2012 | Elizabeth Verdick & Elizabeth Reeve



#### Resources for You: Books

 My Autism Book: A Child's Guide to their Autism Spectrum Diagnosis
 2013 | Tamar Levi & Gloria Dura-Vila



 I am an Aspie Girl: A book for young girls with autism spectrum conditions
 2015 | Danuta Bulhak-Paterson



#### Did you know?

You can borrow all of the books listed on pages 33-34 from the Family Support & Resource Centre (FSRC) at BC Children's Hospital. They also have many other books, videos and educational resources. The FSRC mails resources to families in BC and the Yukon free of charge for a 4 week loan period. For more information, go to <a href="http://www.bcchildrens.ca/our-services/support-services/resource-centre">http://www.bcchildrens.ca/our-services/support-services/resource-centre</a>.

#### Resources for You: Online

Amazing Things Happen (video)

https://amazingthingshappen.tv/?projects=amazing-things-happen

This uplifting animation introduces autism to non-autistic viewers, especially children. It shows how people with ASD have a unique perspective on the world, and how to be a good friend to an autistic person. Created by animator Alex Amelines.

I Am Autistic Social Story (PDF)
 https://drive.google.com/file/d/18BCcQVIfwcGkS1S x7ZWCQXs xBDb5R1o/view

Social stories are short stories that explore social situations and socially expected behaviours. Often, you can personalize the stories. This story can help prepare you to explain autism to others. Written by ASD and Hyperlexia advocate Dyan Robson.

 Pablo - Quiet Sounds | Cartoons for Kids https://www.youtube.com/watch?v=ZexYscXuv58

A cartoon series about a 5-year-old boy with ASD. All of the main characters are also on the spectrum. In this episode, Pablo helps his friend Mouse feel better in a bright, loud grocery store.

Amazing Kids - Autistic Spectrum Condition
 (Video) <a href="https://amazingthingshappen.tv/?projects=amazing-kids-autistic-spectrum-condition">https://amazingthingshappen.tv/?projects=amazing-kids-autistic-spectrum-condition</a>

In this video, children with ASD talk about how they experience the world. Animator Alex Amelines illustrated these audio excerpts, bringing these children's perspectives to life.

## Resources for Your Family: Online

 Kelty Mental Health Resource Centre https://keltymentalhealth.ca/

Part of BC Children's Hospital, Kelty helps families across BC navigate the mental health system. You can also connect with peer support, and access tools and resources like articles, videos and podcasts.

Pacific Autism Family Network (PAFN)
 <a href="https://pacificautismfamily.com/">https://pacificautismfamily.com/</a>

This organization acts as an in-person and virtual knowledge hub for people with ASD and their families in BC. Connect with medical, dental and allied health service organizations, education and support services. PAFN also offers bursaries to help with program costs.

Autism Community Training (ACT)
 https://www.actcommunity.ca/

This BC-based organization offers evidence-informed resources for the ASD and special needs community. ACT holds live events and training sessions. Watch videos for parents and professionals, search for free multilingual resources in the Autism Information Database and learn about special events through their calendar.

## Resources for Your Family: Online

#### AutismBC | <a href="https://www.autismbc.ca">https://www.autismbc.ca</a>

Founded in 1975, this non-profit and registered charity encourages the inclusion and acceptance of the entire autism community. They empower, support, and connect people in the autism community across BC.

### Canucks Autism Network (CAN) https://www.canucksautism.ca/

CAN was founded in 2008 by Vancouver Canucks Coowners, Paolo and Clara Aquilini, whose son has autism. CAN is dedicated to providing programs to individuals on the autism spectrum and their families, while promoting acceptance and inclusion through community engagement and training initiatives across BC and beyond.

## Autism Information Services (AIS) <a href="http://autisminfo.gov.bc.ca/">http://autisminfo.gov.bc.ca/</a>

Connect with an Autism Support Specialist by phone, email or in person. Specialists offer general information, and can help you access funding and support. Available in English, Chinese, Punjabi, Tagalog and Vietnamese, with interpreters in over 50 languages.

## Resources for Your Family: Online

- Autism Canada | <a href="https://autismcanada.org/">https://autismcanada.org/</a>
  - Learn about what an autism diagnosis means and connect with peer and professional supports for your family. This website features videos, podcasts, and information about activities and supports to engage your child with ASD.
- Dr. Liz Angloff | <a href="https://drlizangoff.com/2021/08/09/how-to-explain-autism-to-kids/">https://drlizangoff.com/2021/08/09/how-to-explain-autism-to-kids/</a>
  - Written by Dr. Liz Angloff, an educational psychologist, this blog post provides information on explaining autism to kids.

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P12 vlasque (n.d.). *Little boy playing cook* [Digital Image]. Canva. Retrieved from https://www.canva.com/photos/MADasPHTakU-little-boy-playing-cook/

P12 FroggyFrogg (n.d.). Little boy listening to music [Digital Image]. Canva. Retrieved from <a href="https://www.canva.com/photos/MADaEpOkxAc-serious-looking-little-boy-with-eye-closed-enjoying-his-music/">https://www.canva.com/photos/MADaEpOkxAc-serious-looking-little-boy-with-eye-closed-enjoying-his-music/</a>

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### Acknowledgements

This handbook was enthusiastically created by **Leanne Mak, Ph.D.**, a Registered Psychologist working on the Child Psychiatry Unit at BC Children's Hospital, **and JiJi Pyles, M.S. CCC-R/SLP**, a Registered Speech Language Pathologist, with the support of **Brittin Oakman, MSc.** 

We sincerely thank the many people who supported the journey of creating this handbook, including:

**Rashmeen Nirmal, Ph.D., R Psych** for her time, expertise and detailed edits.

Our colleagues at BC Children's Hospital, Victoria Schmidt, RN; Sydelle Murphy, SLP; Ali Thomas, BEd; Laurie Hokanson; Michelle Horn, MPH; Pamela Harrison, MLIS and Ken Cole, Ph.D., R Psych for their feedback on various drafts and Courtney Hall, MOT for her moral support.

The organizations for their feedback and expertise, **Autism Community Training, BC Aboriginal Child Care Society** and **Canucks Autism Network**.

The **autistic individuals and their families** who read the drafts and provided invaluable feedback.

