

Supporting the Mental Health of Autistic People Living in Rural and Remote Communities

Caregivers Edition



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As a caregiver of a 21-year-old autistic son who has resided all but 6 months of his life in Northern Ontario, I understand firsthand the challenges caregivers face in rural and remote settings. It is challenging to keep a positive and healthy outlook on life with limited resources (community, health, human, financial) and limited support (family, community, professional and medical).

We often find ourselves confronted by obstacles, roadblocks, and isolation as we constantly come up with innovative measures to address the needs of our loved ones, push for more support, advocate, and spend sleepless nights thinking about their future and what that may hold.

Glimmers of hope shine when a milestone is met, an everyday activity is completed, or improvements in a long-awaited skill set are demonstrated, and you regain your momentum, purpose, and inspiration to keep moving forward.

However, sometimes, those monumental days are too few and too far between for us caregivers, and we sometimes fall into a slump. Caring for yourself is essential, as you can't care for others until your needs are met. Often, our needs are related to feeling tired, depressed, feeling misunderstood, looking for help on how to handle our emotions, and getting assistance for our mental health and well-being. This helpful guide is meant to do just that and offers skill-building exercises, self-care strategies, and, most importantly, resources for caregivers to support their own mental health and well-being in rural and remote communities, where and when they need it. I hope you find this as valuable as I have.

Wishing you the best in your caregiving journey.

- Caregiver of an autistic adult in Northern Ontario

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Welcome

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Language Disclaimer

The use of referential language as it relates to autism is a sensitive, important, and on-going conversation. We recognize that language is powerful, and our goal is to support and advocate alongside autistic people. This toolkit utilizes identity-first language ("autistic person") to reflect the growing body of research showing that autistic people prefer this terminology. It reflects the belief that being autistic is an important part of a person's identity.

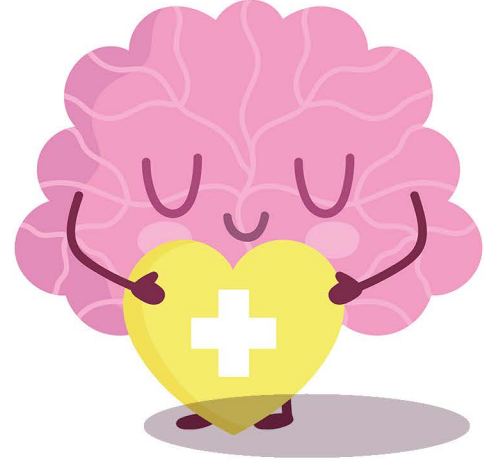
Although the research indicates that most autistic teens and adults prefer the term "autistic person", it is important to understand that each person may have a different preference for how they would like to be identified. Autonomy and self-determination are the most important aspects to consider when talking about autism. It is often best to ask an individual directly how they would prefer to be identified.

For more information on the use of referential language, see the [Autism Ontario Language Statement](#).

Welcome

What is the purpose of this toolkit?

This toolkit aims to promote positive mental health in rural and remote communities. Together with autistic people, parents and caregivers of autistic people, and mental health professionals, we created various activities with information and evidence-informed strategies you can use at any time.



Who should use this toolkit?

This toolkit is designed for **parents and caregivers of autistic children, youth, and adults** who may be struggling with their mental health or who want more information on what mental health means for rural and remote communities. Activities in this toolkit are designed for individuals across the lifespan.

What are the limitations of this toolkit?

This toolkit is not meant to replace mental health therapy or support from a health care provider. It is intended to educate and support the mental health of you and your family in addition to, or while awaiting, appropriate mental health services.

While we have compiled these resources promoting positive mental health for autistic people, this is not a resource suitable for individuals experiencing mental health crisis. Mental health crisis is any situation where a person may feel, act, or behave in a way that may result in them hurting themselves or other people.

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While these really are just band aid solutions to a much larger multifaceted issue of an inadequate amount of support in rural areas, it is important to recognize that autistic youth are not without support entirely. I know that autistic individuals have immense strength. I know and have heard countless caregivers speak on the kindness and care and understanding our neighbours' and community members show their loved ones daily. Our small rural communities are a family of people supporting our autistic members. Autistic youth in rural areas may be lacking in mental health specific support, but with the love and care of their neighbours', they are not completely without support.

- Moira Robertson, Autistic Adult and Co-Author

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Emergency Resources

If you, or someone you know is experiencing a mental health crisis, please call any of the following:

- **9-1-1 Emergency Response: 9-1-1**

Offers emergency response services including police, fire, and ambulance. Service is available 24 hours a day, 7 days a week.

If you are having an emergency, when you call 9-1-1 be prepared to answer questions about the following:

- The location of the emergency, including the street address
- The phone number you are calling from
- The nature of the emergency (e.g., feelings of suicide or self-harm)
- Details about the emergency (i.e., information on who is having the mental health crisis, where are they, who is with them, and details about a potential plan)

**** If your community does not have access to 9-1-1, please contact your local emergency services number. ****

- **9-8-8 Suicide Crisis Helpline: 9-8-8**

Offers trauma-informed and culturally appropriate support to people in Canada who are thinking about suicide. Service is available 24 hours a day, 7 days a week.

- **Talk Suicide: 1-833-456-4566 or <http://988.ca>**

Offers toll-free support to people in Canada who have concerns about suicide.

- **Kids Help Phone: 1-800-668-6868 or text CONNECT to 686868**

Youth mental health support available 24 hours a day, seven days a week.

- **Hope for Wellness Help Line: 1-855-242-3310**

Offers immediate phone and chat counselling and crisis intervention to all Indigenous peoples across Canada in English, French, Cree, Ojibway, and Inuktitut.

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“I can’t always communicate if I’m in crisis. Ward rounds in the hospital would always be awfully stressful for me, having to talk in front of a room of people. So are meetings with my psychiatrist. I feel comfortable with my care coordinator now and she’s learnt to do things like ask me direct questions rather than open ones, but not everyone is so accommodating.”

- Autistic adult ^{xii}

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Introduction to Mental Health

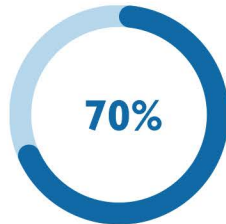
What is mental health?

“Mental health is the ability to feel, think and act in ways that help us to enjoy life and deal with difficulties”ⁱ. It is fluid and can change day by day. Sometimes people may experience positive mental health (i.e., positive emotions, satisfaction with life, feelings of acceptance, and a sense of purpose) and sometimes they may experience mental distress. Whether the person experiences positive mental health or mental distress depends on their environment, how they are interacting with their environments, and their current resourcesⁱⁱ

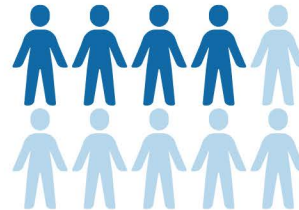


It is important to note that lifestyle practices focusing on diet, exercise, and sleep can support the mental health of the whole family! Later in this toolkit we will explore specific strategies and practices to help with this.

Mental Health Concerns in Autistic People



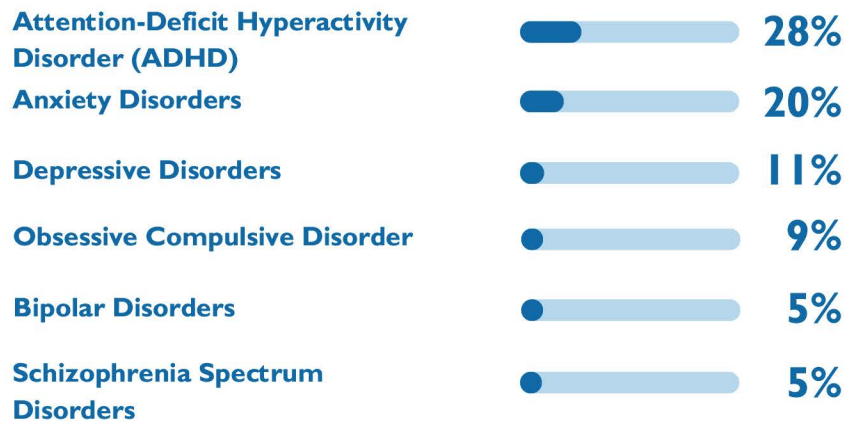
Up to approximately 70% of autistic children, youth, and adults have a co-occurring mental health condition



Approximately 40% of autistic children, youth, and adults have at least two co-occurring mental health conditions

1,2,3,5

Prevalence of Co-occurring Condition in Autistic People



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“Not everyone is wired the same. And what works for you might not work for me. I just found my way to the other side and you can find yours.”
- Noah (autistic youth)

I have learned that I am not alone, and that this is something to not be ashamed off, but to realize it is real and deserves help.”
- Austin (autistic youth)

To hear more lived experience stories about mental health, visit [POND Youth Digital Stories](#).

1. Rosen, T. E., Mazefsky, C. A., Vasa, R. A., & Lerner, M. D. (2018). Co-occurring psychiatric conditions in autism spectrum disorder. *International Review of Psychiatry*, 30(1), 40-61. <https://pubmed.ncbi.nlm.nih.gov/2968335/>
2. Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry*, 47(8), 921-929. <https://pubmed.ncbi.nlm.nih.gov/18645422/>
3. Mowat, V., Barretto, J., Dunkel-Schetter, S., & Goodman, L. (2019). Putting children and youth first: Integrating autism and mental health services for children and youth. *Kinark Child and Family Services*. <https://www.kinark.ca/wp-content/uploads/AFHM-2019.pdf>
4. Lai, M., Kassee, C., Bepey, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: A systematic review and meta-analysis. *Lancet Psychiatry*, 6(10), 819-829. <https://www.cambridge.org/core/doi/10.1017/S20541758194476447798691>
5. Kerns, C. M., Rast, J. E., & Shattuck, P. T. (2020). Prevalence and correlates of caregiver-reported mental health conditions in youth with autism spectrum disorder in the United States. *The Journal of Clinical Psychiatry*, 82(1) DOI: 10.4088/JCP.20m13242

What are co-occurring mental health conditions?

Research shows that many autistic people experience mental health conditions. These are called ‘co-occurring’ because they happen at the same time. Researchers are speculating why this high prevalence of co-occurring mental health conditions exists amongst autistic people. Some reasons include that autistic people may ^x:

- Experience increased stressors related to sensory sensitivities.
- Experience the stress of “masking” their autistic traits and the associated autistic burnout.
- Struggle with self-regulation skills.
- Experience feelings of anxiety or stress more intensely than neurotypical peers.
- Be less likely to be appropriately diagnosed with a mental health condition because their diagnosis of autism is overshadowing other symptomologies.

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“Autistic people are continually forced to mask and hide who we are to accommodate a world that generally does not accept our traits, I want people to understand that autistic people are struggling because our needs are just not being met throughout society.”

- Megan Pilatzke, Autistic Adult ^{xi}

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For more information on mental health, you can access:

- [Autism Mental Health Literacy Project](#)
- [Mental Health Matters- Introduction to Mental Health in Autistic Children and Youth](#)

What does mental health look like in rural and remote communities?

Rural and remote communities face significant barriers in addressing mental health concerns^{xiii}.

- There are struggles with recruitment and retention of qualified mental health providers.
- Government funding does not account for the large geographical areas that the health care centers are expected to support.
- The population in these communities is diverse and may present with unique considerations.
- The social determinants of health in rural communities play a substantial role in impacting well-being and overall health.



Social determinants of health: The conditions in the environments where people live that impact health, functioning, and quality of life outcomes and risks ^{xiv}. These factors include access to health care and education, financial stability, access to food and physical activity, racism, discrimination, and violence.

For an in-depth research summary on mental health in rural communities, access the [AIDE Canada Impossible Conference Research collection](#).

How does the neurodiversity movement support autistic well-being?

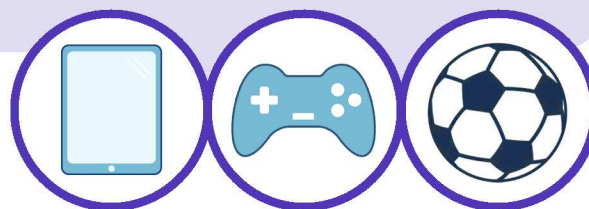
The way the world talks about autism can impact how someone feels about being autistic. Historically, the medical model of autism was the most prominent and this model viewed autism as an impairment^{xv}. Today, the medical model is mostly used by medical professionals to help with diagnosis. This diagnosis is helpful in accessing funding and appropriate services and supports.

The neurodiversity movement is a recent evolution from the medical model of autism. The neurodiversity movement views autism as a “difference” to be accepted and supported and allows for discussion and individuality in supports and accommodations ^{xvi xvii}. As a caregiver, you will hear people use different models when talking about autism and it is up to you and your autistic family member to decide how you want to talk about it. There are many ways to get involved and show your support as an ally to the neurodivergent and autistic community. Some examples include learning more about autism and autistic people and using appropriate language to support autistic people’s identity. To get started, you can access the [How to be an Ally to the Autistic Community toolkit](#).

Note on Motivation

As you work through this toolkit, it’s important to consider “why” individuals may or may not want to make change or engage in any of these activities. We call these reasons our “motivations” and everyone has them, but not everyone’s is the same. As parents and caregivers, it’s important to remember that you may be motivated by different things than your family member. There are two kinds of motivation: **extrinsic** and **intrinsic**.

Extrinsic motivation uses items or activities that the person likes to increase their motivation to engage in a desired behaviour or activity. Sometimes this involves using a “first-then” statement. For example, “first you will take three deep breaths, then you can play on your iPad”.



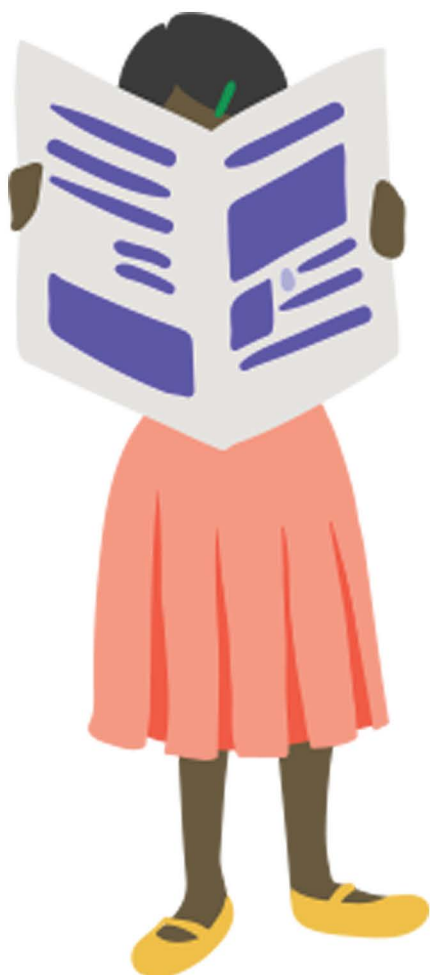
Intrinsic motivation focuses more on the individual’s desire to make change. There are several factors that can influence intrinsic motivation including challenge, control, cooperation and competition, curiosity, and recognition^{xviii}.



What's next?

The rest of this toolkit is dedicated to activities that we believe will support you in promoting positive mental health in your home. The activities include various goals for supporting the mental health of your whole family. There are some that you can use yourself, and some that you will use with your family member(s).

As you read through, it's important to remember that every person is unique, and the strategies that will help you and your family are also unique! Give something a try, and if it's not helpful, try something else! It is likely that not all the activities in this toolkit will be helpful for you specifically.



This toolkit is not a substitute for mental health counseling but is intended to help fill the gap while you, or your family member, awaits services, or until you feel ready to pursue that option.

Mental Health Promotion for the Whole Family

Audience:
Families and
Caregivers of
Autistic People
Across the
Lifespan



Activity: Mental Wellness Bucket List

Background: Taking on the role of caregiver can be challenging for many people, but caregivers of autistic people may experience unique stressors. Caregivers face challenges in balancing the needs of their autistic family member (which may include providing on-going care and playing multiple different roles) with their own needs, and the needs of the rest of their family. Caregivers may also find that many social and physical environments are not accessible to their loved one or family, and this can add to the stress of many situations.

It is important that stressors are identified and acknowledged, because they can impact caregivers' physical and mental health. Seeking strategies and support can help to reduce this stress.



As caregivers, you often focus on supporting those around you. However, it's important to remember that your mental health and well-being are critical. You cannot take care of others if you do not take care of yourself!

Goal: To identify and participate in various self-care and wellness strategies.

Activity Information: Engaging in self-care activities can support your mental health as a caregiver. Here are nine different strategies that we encourage you to try. You can print out this bingo-style card and mark down when you have tried each one. See what works for you, and what doesn't!

Activity: Mental Wellness Bucket List

Practice Mindfulness: Use an app, podcast, or guided visual to help focus on breathing and being present in the moment.

Spend Time in Nature: Try taking a walk, or just spending time outside.

Listen to Music: Create a playlist that reflects different moods—try a “happy” playlist of uplifting songs, or a “sad” playlist for when you are feeling down.

Join a Club: Look for shared interests and join a group either online or in-person to meet others who share similar interests.

Go for a Walk: Find a route in your neighbourhood that is a comfortable distance for walking.

Write in a Gratitude Journal: Use a paper notebook, or digital format to practice noticing and recording things that you are thankful for.

Engage Your Senses: Try a new food, enjoy some aromatherapy, or create a sensory exploration bin to engage your senses through different sensations.

Take a Break from Electronics: Schedule time away from screens or devices. Try a board game, read a book, listen to music, or just enjoy some quiet time.

Spend Time with Friends or Family: Find time for an activity that you love to do together.

Hints to Ensure Success: Remember that every individual is unique and the self-care strategies that will work best for you are also unique. It can be helpful to try out a few different strategies to see what works best for you and your family.

Possible Variations: Self-care strategies are important for your whole family. You might want to try these strategies together or have each member of the family focus on a different strategy at a time. It can be helpful to talk about self-care often and openly to encourage others to participate in their own wellness activities.

Self-Reflection or Discussion Questions:

1. What self-care or wellness strategy did you try first? Why?
2. What strategy are you not interested in trying? Why?
3. Which strategy did you find the most helpful? How did you know it was helpful?
4. How are you going to incorporate this strategy into your everyday life?

For more information on how to care for yourself as a caregiver, you can access the [Caring for the Caregiver guide](#).

Activity: ‘Let it Go’ List: Stories from Parents and Caregivers

Background: Sometimes as a parent or caregiver, it’s easy to get caught up in societal expectations and “trying to do it all”. Sometimes what families need is a “break” and for their caregivers to “let it go”. Here are some quotes from parents of autistic children and youth that outline times when they have found it helpful to let the “little things” go and be present in the current moments and experiences with their family.

Goal: To explore ways of reducing stress in your home, by "letting go".

Activity Information: Read these quotes from fellow caregivers and begin to think about ways you might be able “let it go” in your own life. We asked parents and caregivers to “tell us about a time when you ‘let it go’ as a parent”—here’s what they said:"

Activity: 'Let it Go' List: Stories from Parents and Caregivers

"Let it go and just be ok with not having to "be on" all the time as both child and caregiver need to have a break and feel ok with taking a break- no guilt."

"The time(s) that it's ok to let my (now teen) child just relax and be a child. This means, watch TV, or play video games."

"Tablet time calms him and lets me get things done."

"That as his/her parent I should always know what my child wants or needs... it's okay you're not a bad parent because you don't know."

"Letting go of- what 'other people' other parents, teachers, my extended family, friends- think about what I'm doing how I am parenting what I thought things would be like."

"Pick your battles, not everything is worth a fight."

"I let it go quite often as a parent. Ice cream is just cold milk, and the cone can't be worse than cereal. I feel that we have to not hold on so tight to our own expectations, spend that time bonding."

"I need to accept the things that I can't change (other people's bad behaviour). Sadly, I had to let them go from my life."

"Dinner time: I used to stress about having dinner ready "on time" until I realized that getting dinner made and everyone eating was good enough! It was not easy but good in the long term."

"Of ideals... sometimes trying and doing your best is more than enough."

"Not wearing a Halloween costume and using themed PJs instead!"

"The idea of "catching up" for my child.. their path is theirs."

"Sometimes, when it's been a rough week, we have cheese and crackers for dinner. Everyone goes to bed full and happy!"

"Clothing choices: Releasing my own desire to have my child present based on my clothing preferences or weather options was very freeing. It allowed me to appreciate their own style and comfort-level."

Activity: ‘Let it Go’ List: Stories from Parents and Caregivers

Hints to Ensure Success:

Your expectations as a parent may be different from what is important to your child, or to other family members. Take some time to reflect as a family about what is most important to you. For example, your family might really value eating a meal together as a family.

You might also want to think about whether there is any “wobble room” in these expectations. For example, while it might be important that you eat a meal together as a family, maybe not everyone needs to eat the same thing. Or maybe you eat together in front of the TV, or while playing a family game. Or maybe you eat together on weekends. The expectation might be to eat together as a family, but there might be some flexibility in what that looks like.

Possible Variations:

You can use a family calendar, whiteboard, list, or other visuals to reinforce your family’s expectations. These visual reminders can support your child in understanding what is expected, while also reminding you what the priority is. For example: “Friday night is family meal night. Bring your favourite snack and meet on the couch.”

Discussion Questions for the Whole Family:

1. What are some family expectations you can “let go”?
2. What are some family expectations that you want to hold on to?
3. What expectations might your child suggest for you to “let go”?
4. What expectations might you suggest for your child to “let go”?

To hear more shared experiences from parents and caregivers of autistic people, see the [AIDE Canada Parent Advice video series](#).

Activity: Creating a Family Media Plan

Background: Screen time and digital media can have an impact on our mental health, and when family members have different priorities related to screen time, this can also be a source of stress. It can be helpful to create a “family media plan” together with your family members.

Goal: To work together to create a family media plan.

Activity Information: To create a personalized, ‘Family Media Plan’, visit the [American Academy of Pediatrics](#).



Hints to Ensure Success: Consider doing this activity as a family, so that all family members have input into the plan and are invested in being successful together.

Possible Variations: For older children and young adults, you may want to consider reviewing this activity individually and then sharing your goals with a trusted family member or support person who can help you to be successful.

Discussion Questions for the Whole Family:

1. Was this a helpful exercise? How did it feel to work together on this plan?
2. Who do you want to share this plan with?
3. How will you encourage the use of this plan?

For more information about screen time use guidelines and strategies, you can access the [University of British Columbia’s Screen Time Use Guidelines and Strategies](#).

Exploring Strengths and Needs

Audience:
Families and
Caregivers of
Autistic People
Across the
Lifespan



Activity: Celebrating Strengths

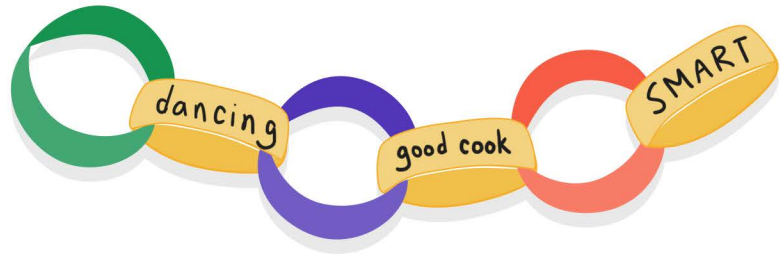
Background: Strength-based activities have been shown to support not only the mental health of autistic people, but they can also help with social engagement, learning, and self-advocacy ^{xix}.

Goal: To identify and celebrate the strengths of the members of your family.

Activity Information:

1. Cut strips of coloured construction paper (approximately 8" x 2").
2. Have each family member write a strength they have or something they are proud of on one side of the paper.
3. Once you have a collection of paper strips, your family can create “links” or “loops” with the paper and link them together.
4. Find a place in your home to hang the links to remind each other of all your strengths.

This activity was modified with permission from Understood.org. For a list of possible strengths and an instructional video, you can access [Understood.org](https://www.understood.org).



Hints to Ensure Success:

You may prefer to have each member of the family create a chain of their own!

Caregivers can model this activity to promote interest, engagement, and understanding. Siblings can also make the activity more fun by providing encouragement, empathy, and support.

Possible Variations:

Depending on your child's preferred communication style, they may prefer to draw on strips of paper, or they may use a communication device to explore the topic and then have the information transferred to paper. Alternatively, you can support your child by verbally listing their strengths.

Discussion Questions for the Whole Family:

1. Was this a helpful exercise? How did it feel to work together to create the chain?
2. How will you use this chain to remind yourselves of your strengths throughout your day-to-day lives?

Activity: All About Me

Background: “All about me” documents are a helpful tool for sharing information about a person’s strengths and interests, as well as any areas they may need help in. They are a simple document that you can use to help ensure your child’s needs are met.

Goal: To create a one-page profile that you can share with your child’s teacher, childcare provider, health care professional, or any other person who may benefit from understanding your child better.

Activity Information:

1. Decide which questions you would like your one-page profile to answer.

Here are some options:

- a. What do you think your strengths or best qualities are?
- b. What would your family, friends, and/or community say your strengths or best qualities are?
- c. Who are the people that mean the most to you?
- d. What tools do you like to keep with you? Do these things keep you calm or help you feel regulated?
- e. What do you like to spend time doing? What are your hobbies or interests?
- f. What do you need help with?
- g. How do you ask for help? How do you like others to help you?
- h. What accommodations or supports can help you to be successful?
- i. What can an employer/teacher/community member do to best support you?
- j. Is there anything else you want people to know about you?

2. Use a computer, device (i.e. smartphone or tablet) or a pen and paper to write out the answers to these questions.

3. Input your questions and answers into this template: (see next page)

For templates and examples more appropriate for adults, you can access the Autistics Edition of this toolkit series.

Identifying Information:



Name:



Preferred Name/Nickname:

What are your child/youth's preferred pronouns (eg. He/him, she/her, they/them, etc.): _____

How does your child/youth like to be greeted? (Check all that apply)

☐

Verbal

☐

Hand shake

☐

'High 5'

☐

Sit beside them

☐

Other: _____

If your child/youth needs help, is there anyone you'd like us to call for support?



Name:



Telephone number:

Strengths and Interests:

What are your child/youth's strengths? What do they like to spend time doing? What are their hobbies or special interests?

Important People:

Who are the important people in your child/youth's life? Who do they go to for support or comfort?

Challenges and Accommodations:

How does your child/youth like to communicate? (Check all that apply)

- | | | |
|---|---------------------------------------|--|
| ☐ Verbal | ☐ Written | ☐ Sign language |
| ☐ Augmentative and Alternative Communication | ☐ Other: _____ | |

Is there any other information you'd like to share about your child/youth's communication?

How do they like to learn? (Check all that apply)

- | | | | |
|--|---------------------------------------|--|--|
| ☐ Verbal | ☐ Written | ☐ Visuals/Pictures | ☐ Digital media |
| ☐ One step at a time | ☐ Slower speed | ☐ Extra processing time | |
| ☐ Small chunks of information | | | |

What accommodations or supports do they need to be successful? (Check all that apply)

- | | | | |
|--|--|--|--------------------------------------|
| ☐ Visual schedules | ☐ Break cards | ☐ Timers | ☐ Quiet space |
| ☐ One step at a time | ☐ Visual instructions | ☐ Movement breaks | |
| ☐ Sensory tools, such as: _____ | | | |

Are there things people should be aware of that might upset your child/youth? (e.g., being told no, loud and unexpected noises, particular scents, etc.)

Is there anything that is often misunderstood about your child/youth?

How to be Helpful:

What does your child/youth use for comfort? Is there something they always need to have with them?

Do you have strategies that work well to calm or soothe your child/youth?

Does your child/youth know how to ask for help? If not, what does it look like when they need help?

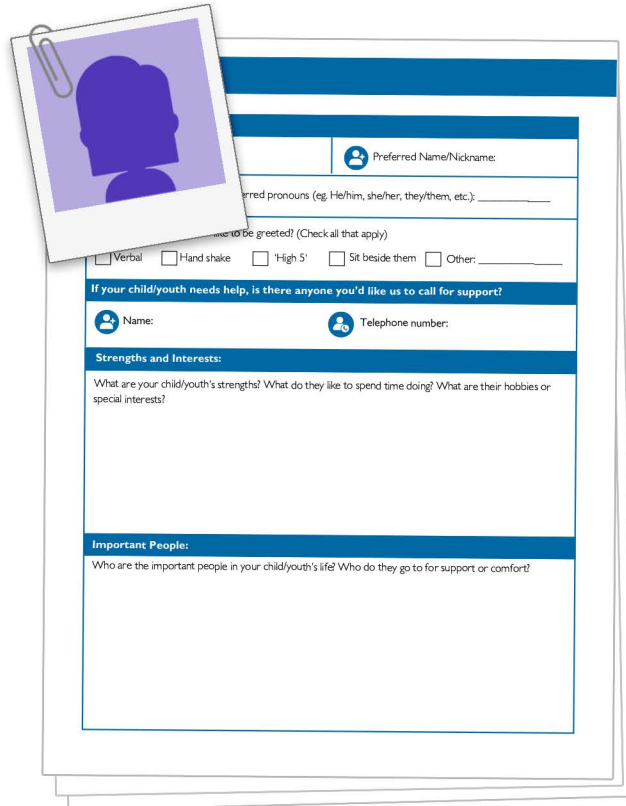
How does your child/youth like others to help them? When is the best time to offer support? In what situations should help be offered?

Is there anything else you want people to know about your child/youth?

Activity: All About Me

Hints to Ensure Success:

Attach a picture: It can be helpful to attach a photo of your child or youth to remind the reader who they are reading about.



The form is titled "All About Me" and is designed to collect information about a child or youth. It includes sections for:

- Preferred Name/Nickname:** A text field for the preferred name or nickname.
- Preferred pronouns (eg. He/him, she/her, they/them, etc.):** A text field for preferred pronouns.
- How to be greeted! (Check all that apply):** A section with checkboxes for "Verbal", "Hand shake", "High 5", "Sit beside them", and "Other: _____".
- If your child/youth needs help, is there anyone you'd like us to call for support?** A section with fields for "Name:" and "Telephone number:".
- Strengths and Interests:** A text area for describing strengths, interests, hobbies, and special interests.
- Important People:** A text area for describing important people in the child/youth's life and who they go to for support or comfort.

Possible Variations:

You may need help to answer these questions and that's okay! You can ask a family member, friend, neighbour, or community support to help you explore what information you want to include.

Self-Reflection Questions:

1. Was this a helpful exercise?
2. Who do you want to share this profile with? Who do you not want to share this with?

Activity: Supporting Positive Interactions

Background:

Engaging in meaningful goal setting can seem like a daunting task, but if you take the time to prepare for such moments, you are more likely to feel successful. Taking this time to talk and explore challenges and solutions builds empathy between yourself and your family member and helps improve your relationship. Active Listening and asking Solution-Focused questions are two ways you can support positive interactions, help build empathy, and help to remind you that “not everything is terrible”.

Strategies for Talking to Your Family Member

- **Active listening:** Really listen to your family member’s thoughts and feelings. To let them know you’re listening you can summarize what they’re saying and reflect it back to them to make sure you got it right. Active listening uses empathy, genuineness, and positive feedback to create effective communication ^{xx}.
- **Solution-focused questions:** This type of question helps the person reframe the problem they are facing and brainstorm solutions. It helps the person remember that they are the expert on their own life, and they have the ability, resourcefulness, and resilience to move from focusing on problems to shaping solutions ^{xxi xxii}.

Goal: To improve interactions between yourself and your autistic family member.

Activity Information:

1. Watch these videos to get a better understanding of empathy and empathetic listening:
 - a. What is empathy? <https://www.youtube.com/watch?v=jz1g1SpD9Zo>
 - b. Empathetic listening: <https://www.youtube.com/watch?v=t685WM5R6aM>
2. Identify a problem or challenge that you and/or your child are facing.
3. Use the questions and worksheet below to help explore different solutions or strategies to address the problem or challenge with your family member.

Activity: Supporting Positive Interactions

Solution Focused Questions

Exception Questions:

Exception questions help a person look for times in their life when they have overcome the problem they're facing.

- Can you remember a time when something like this happened before? What was different then?
- What was helpful at that time? What was unhelpful at that time?

Scaling Questions:

Scaling questions help a person measure how big they think their problems are, and help highlight ways to make positive change:

- On a scale of 1 to 10, with 1 being not worried and 10 being the most worried, how worried are you about this problem right now?
- What helps you be there? What would help you reduce this worry and move down the scale?

Coping Questions:

Coping questions help a person notice when things are going well and what might make them feel better:

- How do you think you have been able to handle this difficult problem?
- What helps you to keep going even though you are so worried?

Outcome Questions:

Outcome questions help a person problem-solve and highlight what they hope will happen:

- How can I help?
- What are you hoping can be different?

Activity: Supporting Positive Interactions

Here is an example of the questions you might use if you were talking to your adolescent about conflict they are having with a peer at school:

Exception Questions:

- Can you remember when you and your friend were getting along? What was different then?
- What was going well for you and your friend? What was helpful in maintaining your relationship (e.g., what did you and your friend like to do together)?
- Are there any times now where you are still getting along?

Scaling Questions:

- On a scale of 1 to 10, with 1 being not worried and 10 being the most worried, how worried are you right now about your conflict with your friend?
- If your adolescent says they are at a 5, you can ask them what helps you be at a 5 and not a 6? What could you do to move that 5 to a 4?
- What would you notice if things were at a 4?

Coping Questions:

- How do you think you have been able to handle this conflict so far?
- What helps you to keep going to school even though you are so worried about your friend?
- How have you been able to stop the conflict from getting worse?

Outcome Questions:

- How can I help?
- What can we work on today that would help you move forward with your friend?
- What are you hoping can be different about your relationship?

Activity: Supporting Positive Interactions

Hints to Ensure Success:

Next time you are trying to engage in a meaningful interaction with your child or youth, keep these few things in mind:

- It is not your job to always have or give the answer.
- Be present in the moment and practice listening to your family member.
- Ask open-ended questions.
- Don't have expectations about where the conversation should go.
- Acknowledge your youth's experience and perspective.

Self-Reflection Questions

1. Was this a helpful exercise?
2. Is there anyone else who could benefit from having these types of conversations?

Solution Based Questions Template

**Exception
Questions:**

**Coping
Questions:**

**Scaling
Questions:**

**Outcome
Questions:**

Building Coping and Self-Regulation Skills in Children and Youth

Audience:
Families and
Caregivers of
Autistic People
Across the
Lifespan



Activity: Mindfulness for Kids

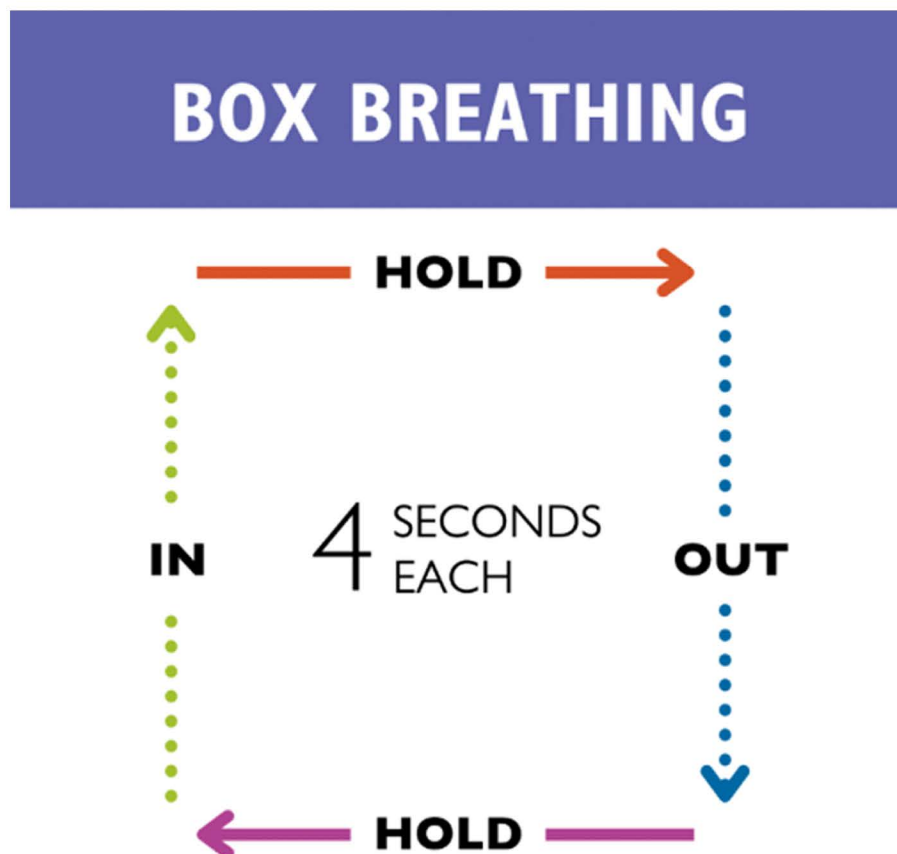
Background: There are many benefits to mindfulness, and it has been shown to increase mental wellness ^{xxiii}. Many strategies are included in this modality, and one of the simplest ones is breathing. Taking slow deep breaths is an easy way to calm our brains and give ourselves something to focus on. Rainbow breathing and box breathing are visuals to help children and youth focus on slow purposeful breathing.

Progressive muscle relaxation is another research-based tool that has been proven to increase an individuals' well-being and reduce depression and anxiety ^{xxiv}. This tool is designed to systematically engage and release muscles to promote relaxation.

Goal: To learn new coping skills.

Activity 1: Breathing Exercises

Have your child use their finger to trace one of the shapes below. As they trace the shape, they can practice taking slow deep breaths in, and then releasing the breath as they trace the next part.



Activity 1: Breathing Exercises

RAINBOW BREATHING



- 1 Slide your finger across a colour of the rainbow and take a deep breath in until you get to the end of the colour.
- 2 Slide your finger back to the beginning of the colour as you exhale.
- 3 Repeat for each colour of the rainbow.

Activity 2: Progressive Muscle Relaxation

When your child needs help with relaxation (i.e. at bedtime), help them to practice tensing and relaxing their muscles. Start from your feet and work your way up to your head:

- Have your child squeeze their toes as tight as they can for 5 seconds and then release it.
- Next move on to their feet, calves, legs and so on until you have reached the face.
- Try having your child pair the actions with breath work, so tensing your muscles as you breathe in and relaxing your muscles as you breathe out.

This exercise can help to reduce muscle tension that has built up, often because of stress or anxiety.

Hints to Ensure Success:

Keep in mind that different strategies work well for different people. If your child does not seem to enjoy one mindfulness strategy, try another one! Sometimes guided videos, podcasts or apps can add visual and/or auditory interest.

Mindfulness can also take time and practice if your child is new to guided imagery and breathwork. If your child is not interested right away, you can always come back to these strategies another time.

Possible Variations:

For more ideas for at-home mindfulness you can access these resources:

- [Mindfulness Exercises for Kids and Teens \(Positive Psychology\)](#)
- [Cosmic Kids Yoga \(YouTube\)](#)
- [Bedtime Explorers \(podcast\)](#)
- [Little Renegades- Mindful Kids cards](#)

Discussion Questions:

1. Which mindfulness strategies were your favourite?
2. Which strategies were the easiest to try?
3. Which ones were the hardest?

Activity: Understanding Body Cues

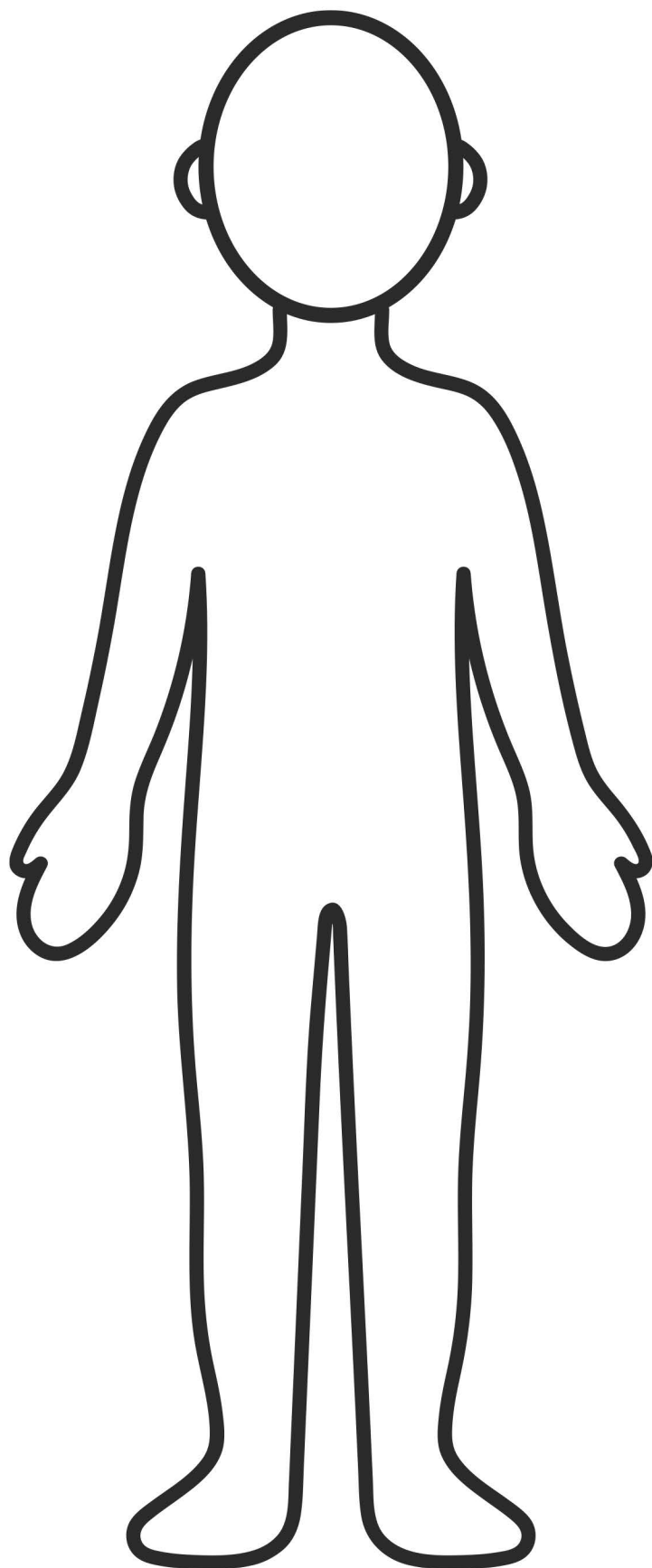
Background: The first step in helping someone understand and cope with their emotions is to learn feelings identification. We cannot expect children to be able to implement strategies if they do not know how to read their own body cues and identify what they are feeling. Without this fundamental knowledge, children will not know when they are supposed to use which self-regulation strategy.

Goal: To understand your personal body cues and begin identifying emotions

Activity Information:

1. With your child, read *A Little Spot's Emotion Coach* by Diane Alber or watch the read-aloud on [YouTube](#).
2. Draw a picture of a person or print the attached picture of a person.
3. Make a list of emotions and assign them each a colour. Refer to the book for ideas on which emotions you want to work on.
4. On the picture of the person, label or colour where in your body you feel that emotion and what it feels like. For example, your palms are sweaty when you are angry so you may put red lines or circles on the person's hands.
5. Continue with each emotion you listed.

Activity: Understanding Body Cues



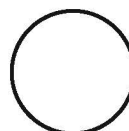
Example:

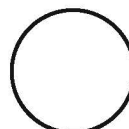


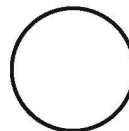
HAPPY

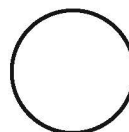
Colour

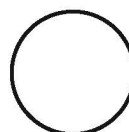
Emotion

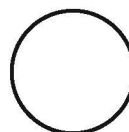


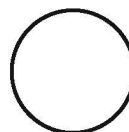












Activity: Understanding Body Cues

Possible Variations:

You may want to use an actual photograph of yourself, a drawing, or another physical representation of your body that you can label.

Discussion Questions:

1. Refer to the body outlines when you are discussing feelings with your child or when you are noticing they might be experiencing a certain emotion. For example, you could say, I think you might be feeling angry because your fists are clenched and you are stomping your feet. Or try, I am wondering if you might be worried right now because I can see you playing with your hair and your voice has gotten very quiet.
2. Always check in with your child and see what they think and if you have been a good “emotion coach.”
3. Your child might not have the answer about how they are feeling or what their body is telling them, and this is ok. The more exposure that individuals have to feelings language, the more they will start to understand these abstract topics.

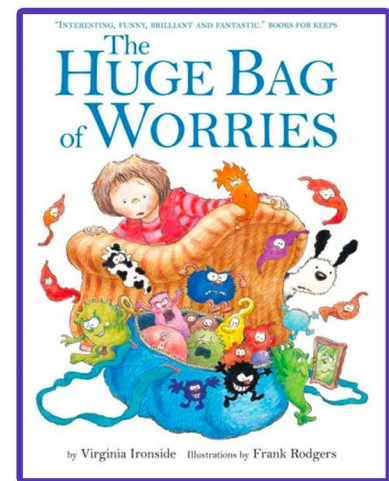
Activity: Identifying Worries

Background: Cognitive Behavioural Therapy (CBT) is based on the theory that our thoughts, feelings and actions are all connected ^{xxv}. For example, when we have anxious or depressed thoughts, we will also feel anxious or depressed, and as a result we will act in an anxious or depressed way. To start feeling better we need to find a way to break the cycle. Working on changing our thoughts is one place to start. The following activities can help with this process.

Goal: To build skills in identifying worries and create a new tool to support coping and emotional regulation.

Activity Information:

1. With your child, read *The Huge Bag of Worries* by Virginia Ironside or watch the read-aloud on [YouTube](#).
2. Point out how the “worries” that the main character identifies look like bugs.
3. Talk about how “worries” and “bugs” are similar in that they annoy or bother us.** Ensure that you explain to your child about using their imagination, the bugs only represent their worries, they are not literal worries.
4. Choose a craft that you can do together to create your own ‘Worry Bugs’.



Option 1:



Help your child use hot glue or super glue to make a bug using 3 pom poms, googly eyes, and a small piece of pipe cleaner.

Option 2:



Give your child some play dough or other modelling clay to sculpt their own bug.

Activity: Identifying Worries

Hints to Ensure Success:

Have fun! Although this topic can feel serious and overwhelming, it is important that the time spent with your child on this activity feels safe and comfortable. The easiest way to do that is to have fun and use humor to engage your child in participating and discussing.

Discussion Questions:

1. What do you currently do when something is bugging/bothering you?
2. What happens when you try to ignore something that is bugging/bothering you? Explain how sometimes the problem goes away, but sometimes the problem gets even bigger. Just like in the story, when the main character tries to ignore her worries, sometimes ignoring our worries only makes things worse.
3. What could you try instead to help your worry bug get smaller or go away? Ideas to discuss include squishing their bug with their hand, stomping on it, flicking it off, or telling it to "go away".

Smartphone “Apps” Supporting Mental Health in Adults

App Name	App Description
Headspace	Reviews meditation and mindfulness exercises that will help reduce feelings of stress.
Self-Help Anxiety Management	A range of self-help methods that work to reduce anxiety by challenging anxiety provoking thoughts and incorporating relaxation techniques.
MoodTools- Depression Aid	Uses CBT strategies to challenge the inaccurate thoughts and provides information on behaviours that may work to reduce the intensity of distress.
Woebot	Uses CBT to deliver scripted responses to users. It is a ‘chat’ program that offers insights and skills to help the client grow into their best self.
Calm	Soothing bedtime stories, meditation, and relaxation to promote sleep.
Finch Care	Daily self-care activities used to promote the health of your digital “pet”.

Smartphone “Apps” Supporting Mental Health in Children and Youth

App Name	App Description
GoNoodle	Activities include videos on mindfulness, deep breathing, yoga, dancing, and exercise.
Breathe, Think, Do with Sesame Street	Activities to teach children breathing exercises, self-control strategies, and planning.
Moshi Kids	Soothing children’s stories, meditations, and music.
Calm Kids	Mindful meditation app that teaches yoga, breath awareness, and body scans.

Other Self-Guided Mental Health Supports

Self-Guided Workbooks Supporting Mental Health in Adults

- Mind Over Mood: Change How you Feel by Changing the Way You Think by Dennis Greenberger and Christine Padesky
- Calming the Emotional Storm: Using Dialectical Behavior Therapy Skills to Manage Your Emotions and Balance Your Life by Sheri Van Dijk
- The Mindfulness and Acceptance Workbook for Anxiety: A Guide to Breaking Free from Anxiety, Phobias, and Worry Using Acceptance and Commitment Therapy by John Forsyth
- Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness by Jon Kabat-Zinn

Self-Guided Workbooks Supporting Mental Health in Children and Youth

- What to Do When you Worry Too Much: A Kid's Guide to Overcoming Anxiety by Dawn Huebner
- Mindfulness for Teen Anxiety: A Workbook for Overcoming Anxiety at Home, at School, and Everywhere Else by Christopher Willard
- The Anxiety Workbook for Teens: Activities to Help you Deal with Anxiety and Worry by Lisa M. Schab
- The ACT Workbook for Teens with OCD: Unhook Yourself and Live Life to the Full by Patricia Zurita

Books for Caregivers of Children and Youth about Autism

- A Neurodiversity and Gentle Parenting Journey... in Color by Morénike Giwa Onaiwu * **
- The #ActuallyAutistic Guide to Advocacy by Jenna Gensic* and Jennifer Brunton***



For book ideas for children and youth, check out the [Autism Ontario's Children's Book Gift Guide](#).



*Story was written by an autistic person

**Story was written by the caregiver of an autistic person.

Books for Caregivers of Children and Youth about Mental Health

- Start Here: A Parent's Guide to Helping Children and Teens Through Mental Health Challenges by Pier Bryden and Peter Szatmari
- Raising Human Beings: Creating a Collaborative Partnership by Ross Greene
- Self-Reg: How to Help Your Child (and You) Break the Stress Cycle and Successfully Engage with Life by Stuart Shanker
- The Whole-Brain Child by Daniel J. Siegel
- Brain-Body Parenting by Mona Delahooke
- Sensational Kids: Hope and Help for Children with Sensory Processing Disorder by Lucy Jane Miller
- Advanced Parenting: Advice for Helping Kids Through Diagnoses, Differences, and Mental Health Challenges by Kelly Fradin
- Kids These Days: A Game Plan for (Re)Connecting with Those we Teach, Lead, & Love by Jody Carrington

To find out if these books are available to be borrowed, you may want to consider the [AIDE Canada Library](#), a free service for all Canadians. Their goal is to provide credible, high-quality information on autism and related disabilities.



Resources

Autism Ontario Webinars and Resources:

- [Mental Health Matters- Webinar mini-series](#)
- [Caring for the Caregiver Guide](#)

Other Online Resources:

- [Mental Health Literacy Guide for Autism](#)
- [Family Media Plan- American Association of Pediatrics](#)
- [Screen Time Use Guidelines and Strategies- The University of British Columbia](#)
- [Strengths Chain](#)
- [My Book About Me](#)

Mindfulness Resources:

- [Mindfulness Exercises for Kids and Teens \(Positive Psychology\)](#)
- [Cosmic Kids Yoga \(YouTube\)](#)
- [Bedtime Explorers \(podcast\)](#)
- [Little Renegades- Mindful Kids cards](#)

AIDE Canada Resources

- [Impossible Conference- Research Collection:](#)
- [Parent Advice Video Series](#)
- [How to Be an Ally to the Autistic Community- Toolkit](#)

Video Links

- [What is empathy?](#)
- [Empathetic listening](#)

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