

Learning and growth are a process, not an event. With patience, perseverance and kindness to your child, family and yourself, you can make it. Tips are offered to navigate the path forward.

Being a Supportive Partner on Your Child's Journey of Learning and Growth

By: David B. Nicholas

Aims of this Toolkit:

1. To provide ideas about nurturing learning for and with your child
2. To offer hope and perseverance in the journey of daily caregiving
3. To provide some strategies for engaging in learning and development.

What You Need to Know?

To help your child learn and move forward, it seems important that he or she sees you as supportive. That means helping your child view you as a trusted other: a protector, nurturer and coach.

How can We be that Supportive Partner?

Parents and others can become that trusted, supportive other. To do so,

- Try not to judge the individual with autism and/or other challenges. They may be engaging in a world which may be intensely difficult to understand and navigate.
- Accept the child/youth/adult on their terms. That means realizing the points of challenge and circumstances that are triggering for the child or adult.
- Start where the child is at; are there things, contexts or activities that seem to work better in the aim of engaging with her/him?
- As much as possible, set up the individual for success. Can we create opportunities where a child can succeed, yet be challenged to grow and learn?
- Engage with; that means setting up opportunities to do things and learn together.
- Explain and show – teach by explaining, but also demonstrating or problem solving. For some children, this may mean writing it out, having graphics/pictures, or developing a story narrative. Create clarity in ways that work for the individual. This may require trial and error, but follow their lead.
- Don't lose your cool. If needed, take a break and ensure you're ready to come back to the work together. Remember your child likely isn't doing what they are doing to frustrate or upset you; their world too is likely difficult and confusing.
- Persistence is key – use marathon, not sprint, thinking to manage or avoid the pitfalls of frustration and disappointment.

Supporting a lifetime of learning is not for the faint of heart. The point here is not to quit as learning is an ongoing journey. But also don't be too hard on yourself as learning can

be a complex and difficult dance that requires us to understand the steps of the learner as one of the dance partners. Be kind and patient with the other and yourself!

How Do I Get Started and Where Do I Go?

Parenting a child with autism and intellectual disability is a journey that doesn't offer a particular roadmap. What are the guideposts that your child is showing you? Are there hints that indicate what works and doesn't work for their learning? Who are the people who can give you help along the way? There is so much advice out there—in person and online. Consider the evidence as well as its 'fit' and relevance for your child and your family. A mother of 2 older children with autism tells the story about being told that she should dispose of anything in her home that was "beneath the child's chronological age level". Another said, "use anything and everything that captivates the attention of your child for learning – no matter what the age focus."

It's important to listen to credible sources, but also listen to your child and yourself. How does the advice you're hearing resonate with what your child is indicating? Bill Nason (2014) writes, "Only you understand, accept, and are totally committed to your child. You know the vulnerabilities, challenges, goals, and dreams for you and your child, but others can help provide the frameworks for making it happen" (p. 24).

What are some things that are helpful to your child in learning?

Give Yourself a Break, and Be Kind to Others and You

Allow time for rest and refreshment as tiredness, discouragement, grief, anger and depression can set in. Find ways for constructive distraction from the challenge of teaching, parenting, learning and struggle. Hope is needed, but it is sometimes hard to figure out how to integrate hope in our lives. What gives you degrees of separation from the difficulties? What helps you? Some love to talk, some don't like to talk, some blog, some read other literature, some say they have no time to read. Whatever helps you, find that for yourself, and as needed, help your child find what helps her/him in managing day-to-day. Be careful to find things that are constructive to you and your family. Below are some questions about what may be helpful for your child.

1. What makes your child feel overwhelmed or upset?

2. What soothes your child or helps her/him to become more self-regulated when overwhelmed or upset?

3. What could you do differently to help your child avoid or overcome challenges?

4. What would be two skills to try to teach your child to help manage challenges?

One Parent's Story:

Jill reflected about her and her partner's experience: "As parents on this journey, we've come through many battles, but at this point 15 years later, I have a sense of gratitude and hope despite many battle wounds. We've come to a new place of what really matters and what doesn't. And I think we appreciate our two children with autism and intellectual disability for the amazing human beings they are."

At a recent autism conference in the Q & A portion of a session, a parent asked the presenting panel, "How can I hope when my child lacks the capacity to become independent?" A panel member with autism gently reminded this weary and worried mom that, "everyone has an important contribution to make – to love and be loved. Don't underestimate what your child can accomplish." May we together realize that the battles and challenges of today will eventually be dealt with somehow. New challenges may come, but so too may answers and learning.

Find the 'sweet spot' of *not* setting the bar too low for your child, but also of accepting the specialness of their unique self. Don't we all need that balance in moving forward? How does this fit with who you are as a parent and family?

Enjoy the Specialness and Uniqueness of your Child

We can get so absorbed in the work and worry of attending to our child’s needs and seeking to learn, that we can forget or perhaps miss the uniqueness of what makes that child so special and who they are. At some point, it may be useful to take an inventory of their skills and gifts.

For instance, Andrea, a 13-year-old with autism and intellectual disability, was described by her mother. Andrea’s mother said, “Andrea experiences and presents us with many challenges every day and even at night. But you know, I recently took a step back and thought about how she has a quirky and funny sense of what interests her and brings her joy. And what a great singer she is! Sometimes I get so frustrated that I stop noticing the good things about Andrea. If I absorb myself negatively in how she is “different” or how annoyed I might be ‘in the moment’, I may pull away in my frustration. On the other hand, if I stop long enough to realize these important parts of who she is, I can better see how unique and special truly she is.”

What do you see as the gifts, traits and specialness that makes up your family member with autism and/or intellectual disability? Take a few minutes to list what makes them uniquely them. What are their strengths? What may be areas or ways to connect with them in new ways?

Am I a Good Parent?

As parents, we periodically question what we’re doing and whether we’re giving our best as parents. ‘How could we parent better?’ we may ask. These quandaries often seem heavier and pressing for parents of a child with disability. The landscape may seem unprecedented—at least within our prior understanding and expectations of what it is to parent. Bill Nason (2014) identifies his perspective about what constitutes a ‘good’ parent. His criteria are as follows:

- “Are you acting out of love?
- Are you trying your best?
- Do you question what you are doing?
- Do you seek out advice and try to learn as you go?
- Are you worried about being a good parent?” (p. 30).

Note that he doesn't indicate *not* feeling confused or frustrated or even making mistakes in connection with parenting success. These elements can come with the territory of parenthood, often with unique and perhaps additional questions for parents of children with intellectual- and neuro-diversity. Here are a few questions that may help us retrain our focus as parents – as nurturers and carers – for our child...

1. How have you thought about yourself and your child? Are there ponderings of hope, strength and a positive future?
2. To work toward a better future, what adjustments need to be made in moving forward? What are you doing as you engage with your child?
3. What can you do to nurture growth in your child, in their siblings, in yourself, and in others in your family?
4. What do you need? Do any of the following ideas offer tools that could help in moving forward?
 - Get the supports that *you* need.
 - Realize you know your child best, and try to get the supports that are needed (we recognize sometimes these can be hard to find, but many would argue it's worth the effort).
 - Recognize the challenges of your child's sibling(s), and think about how to continually let them know they are loved and appreciated. Fortunately, more sibling resources are emerging. Consider what siblings need, and strategize how to address those needs.
 - Pace yourself, try to squeeze in what gives 'rest and repose'.
 - If you're in a partner relationship, communicate and try to mutually engage in working well together along the journey. Realize that partnership looks differently in different families and circumstances. Parents may each cope in unique ways, yet finding a place of mutuality and fairness seems important for sustained healthy relationship building. Support for parents (as an individual, a couple or co-parents) may be beneficial, and there are counselling resources in most communities.
 - Approach your regional AIDE Hub (locations across Canada), www.aidecanada.ca and/or your local autism or intellectual disabilities advocacy office for resources. AIDE Canada's regional resource 'map' may offer helpful resources in your region.

In a recent seminar (Nicholas, 2018), the **Top 10 List of Parents' Tips for Parents from Parents** was offered. Items were:

1. Recognize the gifts and uniqueness of the individual. Temper expectation with celebration.

2. Realize the community is for all of us – not just for a select majority. So don't be bashful or ashamed – it's your community, it's your child's community, it's our community.
3. Stand your ground, understand your rights.
4. Consider carefully what battles are worth taking on.
5. Ask questions, find champions.
6. Find sources of support (people, reading, etc.).
7. Guard your energy (seek rest and what rejuvenates you).
8. Keep a sense of humor – don't forget to smile/laugh.
9. Remember the looming 'challenge of today' can change, or you'll learn somehow to deal with it.
10. HOLD ONTO HOPE: Hope takes many shapes & forms.

Do any of these tips resonate with you? Consider integrating what helps you and your family.

And realize that there is help. In AIDE's research summaries, for example, we reviewed the **Acceptance and Commitment Therapy (ACT) program**. The authors of this research (Blackledge and Hayes, 2006) noted ACT, as one example of a parent mental health support resource, supports children with ASD and their parents. For further support, consider resources such as your local autism or intellectual disability advocacy organization or AIDE Hub.

If needed, engage a mental health counsellor or other resource in your community. Some important Canada-wide resources include:

- 211 Canada: Run by the United Way, 211 provides information on health and social services in regions across the country. Dial 2-1-1 or visit 211.ca for more information.
- Kids Help Phone: A 24/7 national service that provides resources in both French and English, including counselling, referrals, and information. You can call 1-800-668-6868 to connect with a counsellor, or visit <https://kidshelpphone.ca/> for more information.
- Canadian Mental Health Association: Provides a variety of mental health services, with locations across the country. Potential services include crisis and navigation services. Contact details and locations can be found through <https://cmha.ca/find-your-cmha>

Finding supports for you as a parent and family is a gift to you, your child and your family. On your path forward, consider it not a sprint but a marathon – a marathon of challenge, yet also opportunity to learn and grow.

Keywords

autism, intellectual disability, learning, support, family wellbeing, parental stress, learning

This Toolkit was developed by Dr. David Nicholas (nicholas@ucalgary.ca).

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