

Reflection Questions and Activities from
“Caring for the Caregivers of Individuals with
Intellectual and/or Developmental
Disabilities”



Impact on Mental Health

Reflection Question: Which, if any, of these mental health issues have you struggled with? How do you know when you are struggling with your mental health? What can you do to feel better about your mental health? Who can you turn to for help with your mental health?

Impact on Physical Health

Reflection Question: Have you or any other caregivers or family members experienced the above health issues? How do you know when your role as a caregiver is impacting your health? What does it feel like when this health issue is flaring up? What can you do to alleviate this health issue? Who can help you when this health issue is flaring up?

Reflection Question: Are any of the above risk factors present for you or your family? How do you experience some of these risk factors? When do they usually arise for you?

System Navigation

Reflection Question: What barriers or issues with system navigation have you experienced? How did you recognize that you were lacking the resources to navigate the system? What steps have you taken in the past to access the needed services? Who can you contact when you get stuck?

Reflection Question: Do any of these additional factors apply to you or your family? What supports do you need to help with these factors? Who can you reach out to that you know is in a similar situation?

Positive Aspects

Reflective Question: Are any of the above protective factors present for you or your family? How do you recognize when a protective factor/positive aspect is helpful for you? Do you have any tools or resources available to you that can help develop your appreciation on these positive aspects? Who in your life is a good example of someone seeing the positive aspects in difficult situations?

Programs and Supports

Activity #1 – Creating a Team and Support Network

Despite being the primary caregiver to your child or family member, you don't need to do this alone, and will need to develop a network to support you and your family member. This activity is designed to help you assess your current network, and is adapted from the A Parent's Guide to Autism Tool Kit⁶⁸ and Challenging Behaviors Tool Kit⁶⁹ from Autism Speaks. The Planned Lifetime Advocacy Network (PLAN) also has information on building a support network that will keep your loved one safe as they age. Vela Canada can help with setting up microboards, or a decision-making team, for your loved one.

Professionals – you will need a team of professionals working together to provide individualized and specialized care to your child or family member.

- Who to consider: the individual with autism should be involved as much as possible; you as the caregiver; case manager, if applicable (from a service agency or school); medical professional that you trust; behaviour specialist who is trained and certified; educator (school or day program); mental health provider; speech language pathologist; occupational therapist; and physical therapist.
- Things to look for in your team members: a person-centred approach (they think of your child as a person first, not the disability or behaviours); collaboration (they communicate and work well with you and the rest of the team); broad thinking approach (they consider many factors and different interventions); experience with your care recipient's disability; professional judgment (they have clear goals and evaluate what is working); responsiveness to your priorities and concerns; and credentials (licensing, certification).
- Where to find your team: your child's school, doctor, or other social service agencies can often make referrals or recommendations. You can also find information online or from other parents/caregivers, through support groups in-person or online.

Informal Supports – family, friends, neighbours, or members of your faith community.

- It is important to maintain these relationships and ask for support when needed.
- It is also important to maintain your spousal relationship through open communication, spending time together, and helping each other focus on the present and what can be done today.
- You can also find support from other parents in person or online through Facebook, Twitter, and blogs.
- Faith communities can also provide support networks and avenues for connecting with additional resources

Who is in your child or care recipient's support network, including both professionals and informal supports? Is there anyone that you feel is missing from your network?

Are you and your child or care recipient getting the kind of support that you need from your network? If not, how might you ask for the support that you need?

Activity #2 – Positives, Strengths, and Values

Though information about intellectual and developmental disabilities can often focus more on challenges, it is important to focus on the strengths and positives that exist within your child, your family, and yourself.^{51,54} Be kind with yourself, and remember how much you are already doing!

What are the strengths and positives that you see in your child/care recipient, your family or network, and yourself? These can be external (e.g. a teacher who works well with your child, a supportive family member, etc.) or internal (e.g. you are persistent, you are a strong advocate for your child, etc.), or can be about your relationship with your child/care recipient (e.g. an activity you enjoy together).

What is some progress or accomplishment your child/care recipient has made? How did you help this happen?

What do you really value? What is important to you for your own quality of life and the quality of life of your loved ones? How can you make sure your values are being reflected in the way you spend your time and your interactions with your family member(s)?
