

Editor's key points

- ▶ The coronavirus disease 2019 pandemic is exacerbating the stresses on patients with autism and intellectual disability, as well as on their families and caregivers. Acknowledging and validating caregiver burnout is a critical part of care for this population that needs to be prioritized in routine care.
- ▶ Respite care should be considered an essential service for this population, particularly during pandemics and other types of emergencies, owing to the complexity of care needs. Greater capacity needs to be built into the care system to address the needs of people with autism and intellectual disability as they age into the adult system.
- ▶ Caregiver capacity and well-being must be kept at the forefront of developmental care, with a continued focus on family rather than only individuals.

Points de repère du rédacteur

- ▶ La pandémie de maladie à coronavirus 2019 exacerbe le stress que vivent les patients atteints d'autisme et de déficience intellectuelle, de même que leurs familles et leurs aidants. Le fait de reconnaître et de valider l'épuisement des aidants est une partie essentielle des soins pour cette population, qui doit se voir accorder la priorité dans les soins courants.
- ▶ Il y a lieu d'envisager les soins de répit comme étant un service essentiel pour cette population, surtout en temps de pandémie ou d'autres types d'urgence, en raison de la complexité des besoins en matière de soins. Il faut renforcer les capacités au sein du système de soins pour répondre aux besoins des personnes souffrant d'autisme et de déficience intellectuelle à mesure qu'elles passent au système pour adultes.
- ▶ Les capacités et le bien-être des aidants doivent être maintenus au premier plan des soins développementaux, en portant continuellement une attention soutenue à la famille plutôt qu'aux individus seulement.

Caregiver burnout, gaps in care, and COVID-19

Effects on families of youth with autism and intellectual disability

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Case description

A.T. had been a part of our practice for many years, coming in for regular health checks related to his autism and moderate intellectual disability. A.T. lived at home with both parents, attended school in a small, supported classroom, and participated in therapy and community-based day programs for respite. A.T. often used physical behaviour (eg, tapping, pulling) to communicate his need for social attention from his parents.^{1,2} However, when A.T. hit puberty, his behaviour became more volatile and emotional. This coupled with his greater physical size increased the threat of harm. Medication stabilized his mood, with modest effect. Referrals made for publicly funded in-home support had limited value owing to lack of parent follow-through. Consultation with school staff was effective, particularly when A.T. had one-on-one support and access to frequent social attention and consistent structuring of the day. However, his attendance at school was variable. In contrast, at home, his parents reported that things were "manageable," but they were often quiet, with a flat affect, during visits. A.T.'s mother opened up to the pediatric health care team, sharing guilt about talking about challenges (eg, "a mother should not talk this way about her son"). She also expressed shame and frustration: "I know what they [home support] want me to do and I can't do it."

The coronavirus disease 2019 (COVID-19) pandemic furthered the challenges experienced at home, reduced access to school and community supports, and increased unpredictability for both A.T. and his parents. A.T.'s behaviour became more physically aggressive and volatile, even outside the household. His parents did not inform the clinical team about his worsening behaviour or seek support until A.T. started hitting strangers at the bus stop and police were called. Eventually A.T.'s family hit a crisis point of nearly daily episodes of aggression, including his mother suffering a concussion as a result of A.T.'s behaviour. This culminated in A.T. being dropped off in the emergency department and hospitalized indefinitely awaiting an out-of-home placement.

While serious concerns have emerged during this pandemic about the interrupted developmental trajectory for children with autism spectrum disorder,^{3,4} it is imperative that we acknowledge the gap in the system for families of older children and youth with autism and intellectual disability whose mental health and behaviour have deteriorated. During this pandemic, youth with autism and intellectual disability have experienced drastically altered routines that have increased their anxiety and rigidity. Caregivers have reduced capacity as they work from home and do not have the same external supports. A.T.'s case reveals early warning signs for family physicians and pediatricians to identify families at risk of crisis at this time.

In reviewing A.T.'s medical record, there were many entries about childhood aggression toward his caregivers, and recommendations to access community-based parenting programs to address these challenges. Unfortunately, there was minimal information documented regarding the

engagement with or the effectiveness of such programs from the perspective of A.T.'s caregivers. Most programs require caregivers to adapt, change, and respond differently to their children.^{1,5} What happens when caregivers' capacity is reduced because of financial or family stressors, language or cultural barriers, or poor mental or physical health? A cultural lens is important when considering the experience of stigma and shame.⁶ For this family, they were newcomers to Canada and visible minorities. Caregivers can also become immobilized by shame and guilt when not able to create the desired changes suggested by professionals. Over time, these stressors contribute to caregiver burnout.

As A.T. grew bigger and stronger, caregivers were unable to follow through with the strategies provided to them when he was younger. Their fear that he would hurt the therapists coming to the home and the shame about his behaviour prompted them to decline further support. It was only when the behaviour escalated during the COVID-19 lockdown and spilled over to a public domain, that the family disclosed A.T.'s persistent aggression and the effects on their mental health and safety.

After further investigation, incidents were identified at school toward teachers, and calls to 911 had been occurring when A.T. was agitated. Caregivers did not know how to pursue further assessment and help for A.T.

A.T.'s case illustrates gaps between school, medical, and crisis services, especially for caregivers who themselves might be experiencing stress and burnout. In the developmental service sector, agencies do support the family unit in behaviour management and respite, but none are mandated to address or given explicit training in the evaluation of caregiver burnout.^{7,8} The Children's Aid Society (CAS) also supports families who are struggling, but they might not be called until there is a crisis and might only be able to intervene if a child is at risk.⁵ A.T. was also at the transitional age between child and adult sectors. Pediatric scope of practice is limited to patients younger than age 18, and families might not have accessed a family physician to continue care. A common period of stress for caregivers is between the ages of 16 and 25, and this is the highest risk time period for an individual with a developmental disability to develop mental health concerns.^{9,10} Pediatric specialists might conduct behaviour assessments but lack expertise in evaluating adult capacity and well-being. Adult-based services in mental health might be available to caregivers, but the 2 systems of care have no formal connection. This led to fragmentation in services for A.T.'s family and might have contributed to challenges engaging with needed services.

Discussion

There is an urgent need for family physicians, pediatricians, allied health practitioners, and therapists to actively inquire about, recognize, and validate burnout in caregivers of youth with autism and intellectual disability. By normalizing this experience, offering support, and reinforcing help-seeking, physicians and allied health professionals can strengthen their relationship with caregivers of children with autism and intellectual disability, providing a therapeutic space for caregivers that is nonjudgmental, builds trust, and promotes self-care. Interprofessional communication is critical for effective service navigation and engagement. Family physicians and pediatricians can collaborate to document the experiences of these families, their strengths and successes, challenges faced, and strategies employed. This documentation can play a critical role in crisis planning and informing how best to support youth and their families so that they can plan and prepare for accessing emergency care (**Box 1**).

For caregivers who are headed into crisis, validated screening measures such as the Brief Family Distress Scale¹¹ have been developed but they are not routinely used in clinical practice. However, screening tools must lead to intervention that is feasible, accessible, and effective. At present, we lack clear referral pathways to agencies that specifically support caregiver burnout.

In-person special education and respite programs that provide caregiver relief are a lifeline and should be considered an essential service even during a pandemic. While the risk of COVID-19 transmission needs to be factored in, the cost to the system if the family units caring for these children and youth fall apart during a pandemic needs to also be considered. In A.T.'s case, the only essential service left for him was the emergency department. Across our country, there are cases of adults with disabilities living in hospitals for years.⁹ There clearly must be a cost-benefit argument for cost savings, as well as improved quality of life for families, if more comprehensive, targeted systems of respite and

Box 1. Questions primary care physicians can ask caregivers of children and youth with autism and intellectual disability

- On a scale of 1 to 10, how able are you to manage right now?
- Who helps you right now?
- Do you have a health care provider you can reach out to for help about your and your child's well-being?
- Have you ever called 911 or thought about calling 911 regarding your child's behaviour?
- Has any agency ever offered crisis support? Do you know where you can find crisis support services?
- What do you see in your child's future? Your own future?
- Have you ever thought of ending your life or your child's life because of the difficulties of caring for your child?

support are built in for families to allow them to care for their children at home despite changes in behaviour and function over time.


For adolescents and young adults with autism and intellectual disability, a concerted effort is required between family physicians and pediatricians to bridge care. Youth with autism and intellectual disability do not achieve independence as they age; rather, by definition, these youth will experience functional impairments and require care for the rest of their lives. Having specific and trained professionals in transitional care working with pediatricians and family physicians to support the family through this unique transition is needed, with particular focus on sustainable caregiving and quality of life for caregivers and their children across the lifespan.

Case resolution

A.T. stayed in-hospital for 3 months and was discharged to a group home environment funded by CAS, with one-on-one, on-site support 24 hours a day. With this level of support, within another 3 months, he had a considerable reduction in aggressive behaviour and was in school full time. We worked with the group home to wean him off all medication this past year. A.T. has shown an increase in skill development (able to do his own laundry, learned to use a computer to call family members). He has also developed social relationships (made his first friend outside of school, reconnected with an older sibling, video calls with parents daily). Six months after his placement, CAS was able to transfer care to the adult support system for developmental disabilities. His mother recently called our office and explained how this process had “saved 2 lives.” She shared having had thoughts of dying for herself and A.T. during the period leading up to his hospitalization and believed these feelings had resolved knowing that her son was safe, well cared for, and thriving in his new placement.

Conclusion

This case showcases the damage to individuals and families, and the costs to society, when we do not work in proactive ways to plan for and identify warning signs of impending crisis, attend to developmental transitions for all members of the family, and respond quickly to support families with autism and intellectual disability in times of

crisis. A.T.’s story began long before the pandemic and illustrates considerable chronic gaps in our system of care. Family physicians, pediatricians, and allied health professionals need to work together to bridge these gaps and advocate for these families to be supported by services that are essential to them and will allow them to care for their dependents in a sustainable way. 

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Competing interests

None declared

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