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“Everyone sees me as super successful, but I’ve been struggling for years”

What we heard at the Town Hall on access to treatment and services for ADHD into adulthood

October 2022

The Ontario Drug Policy Research Network

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Background

The Ontario Drug Policy Research Network (ODPRN) recently launched an initiative to create a platform for meaningful conversation between citizens of Ontario to discuss drug policy topics of interest. This initiative is being led by the ODPRN Citizens' Panel, a group of volunteer Ontarians who have collectively come together to ensure that the ODPRN appropriately identifies issues of importance to the public, and incorporates these priorities into all aspects of our research.

The inaugural ODPRN Town Hall was held on July 27, 2022 and focused on access to treatment and services for attention deficit hyperactivity disorder (ADHD) into adulthood. This was the first of what we hope is a series of Town Halls on various topics related to drug policy in Ontario. We chose this topic as a result of a province-wide survey we conducted in late 2021 on what medication topics matter most to Ontarians.

Overall, 60 individuals attended and actively participated in the Town Hall discussion, including 7 individuals who shared their personal story of living with ADHD as an adult and 5 additional individuals who shared recordings of their story following the town hall. Individuals with ADHD and their caregivers shared stories and raised questions on access to ADHD treatment and services as an adult in Ontario. Drs. Melanie Penner and Kyle Lee, two physicians with practices focused on providing care to people with ADHD, were available to answer questions and provide a clinical perspective. Other attendees contributed to the discussion and asked questions through the virtual chat room throughout the town hall as participants shared their stories.

ADHD is a neurodevelopmental condition including behaviours that fall within three sub-types: Inattentive (e.g., difficulty sustaining attention, easily distracted, etc.), hyperactive or impulsive (e.g. high physical energy, does not think through actions, etc.), or both. Dr. Penner provided an analogy that neurotypical people run on Windows and neurodiverse people run on Mac operating systems to emphasize how ADHD is a different way of experiencing and interacting with the world. Most people think of ADHD as a childhood condition even though symptoms can persist into adulthood, which can make it difficult to receive a diagnosis and subsequently access treatment as an adult. This notion of ADHD as solely a childhood condition has caused adults with ADHD to feel stigmatized by others who discount or degrade their symptoms.

Hear the stories

Listen to the stories from 7 of the individuals who shared live during the Town Hall as well as 4 individuals who shared their story following the Town Hall:
https://odprn.ca/town-halls/adhd-town-hall/

Themes

The following themes and suggestions were raised by participants during the Town Hall:

The "minefield" of navigating an adult diagnosis

An overwhelming number of participants felt a lack of support in obtaining an ADHD diagnosis, and managing their ADHD symptoms as an adult. The process to be diagnosed and receive medication was long and cumbersome, often taking years, and many participants felt helpless when attempting to navigate the healthcare system. It was expressed that individuals with ADHD might have difficulty completing questionnaires and the paperwork required to receive a diagnosis due to symptoms of ADHD (e.g., challenges with concentration). Some participants' general practitioners (GP) were supportive but did not have a comprehensive understanding of the diagnosis, while others did not have access to a GP and did not know where to start investigating a possible diagnosis.

Conversely, this process seems to be much more straightforward for participants when receiving a diagnosis as a child because of better systems in place to facilitate the identification and diagnosis of ADHD. Participants provided examples of how the highly structured school system often flags a child who might need further assessment, and how concerns are often raised by a pediatrician that seemingly has more knowledge on ADHD compared to their family physician. Questions were raised on where to access resources on how to manage ADHD as an adult as participants found resources are often tailored towards parents supporting their child with ADHD, rather than an adult managing their own ADHD diagnosis. A list of resources shared by participants is provided at the end of this document.

"Once I got diagnosed and I got my medication, it was instant that I was able to start turning my life around, but it took 9 years of consistent work with a psychiatrist to unravel all of the chaos and rebuild my life because I wasn't diagnosed as a kid."

A childhood without a diagnosis

Participants shared stories about why they did not receive an ADHD diagnosis until adulthood. Some participants felt that they did not receive a diagnosis as a child due to a lack of support from family members that was attributed to generational shifts in the understanding of ADHD, often associated with parental cultures and beliefs that do not recognize ADHD as a legitimate diagnosis. Others felt that life as a child is much more structured and naturally, children are offered more support and accommodations for their unique needs and behaviours, making life without a diagnosis easier to manage compared to adulthood. The strategies learned in childhood were frequently lost during major life transitions into adulthood such as a first job, leaving home, or having a child. Participants attending on behalf of their children expressed several concerns about these transition periods, including whether the strategies learned in school could be applied in the workforce, and whether people in the workforce would be understanding of their child's condition. It was expressed by many individuals with ADHD that they can appear to function well in society so their day to day struggles can be easily overlooked. Finally, some participants did not realize they might have ADHD until their own child was going through the process of receiving a diagnosis.

"Although my mom never knew about ADHD, she was able to manage my disorganized state. She used to give my siblings and I rules with detailed instructions. But my major struggles started to appear when I got married and became worse after becoming a mom."

Another reason that people did not receive a diagnosis until later in life was due to the shared symptoms of other conditions that they may have already been diagnosed with, such as anxiety and depression. Many participants discussed how their co-occurring conditions can not only make the ADHD diagnosis more challenging to obtain, but can also make management of ADHD more complicated.

Intersectionality of stigma

It became apparent throughout the discussion that stigma, gender and socioeconomic differences are prominent in the path to receiving an ADHD diagnosis and treatment in adulthood. Many participants noted stigmatizing attitudes towards ADHD through their experiences with family practitioners not supporting a diagnosis or not providing a referral to an appropriate specialist.

Specifically, gender can change how ADHD presents and is treated, with males typically showing externalized symptoms such as impulsivity, while females typically show internalized symptoms such as inattentiveness. It was expressed that girls are typically under-diagnosed and that some GPs seem to be uncomfortable when it comes to diagnosing and treating ADHD in adult females. One individual with ADHD shared how her medication does not work effectively leading up to and during her menstrual cycle, something that resonated with other town hall attendees who wondered if there are solutions for females during this time period.

Other participants felt that ADHD has become a diagnosis for those of higher socioeconomic status since it often requires a psychological evaluation which is not covered by OHIP and can cost thousands of dollars. Access to receiving both a diagnosis and appropriate treatment becomes exacerbated when considering the additional barriers that many face, such as racial discrimination, housing insecurity and segregation from family. One suggested solution was to implement government-funded specialized adult ADHD clinics.

"I think a lot of what I was dealing with was attributed to being from an immigrant background and just having difficulties at home with like housing stability or things like financial issues."

One participant noted that GPs are hesitant to diagnose people from marginalized communities with ADHD to avoid any prejudice or bias that can be seen to "pathologize" these individuals. However, they expressed that this hesitance can make it even more difficult for people from these communities who would benefit from an ADHD diagnosis.

Benefits of the diagnosis and access to treatment

While some participants worry about the stigma attached to the "label" of an ADHD diagnosis, others felt it was extremely valuable for reasons that extend beyond improved access to medication. Participants described the power that they felt when understanding how their brain functions and how motivations for someone with ADHD can be very different than typical reward incentives for those without ADHD. It was stated that knowing this can open doors to different non-pharmaceutical treatment strategies for managing ADHD, including psychotherapy and support groups. Participants emphasized the importance of developing relationships with people who understand and appreciate ADHD in order to prevent them from hiding their condition.

"He has all of these tools in place, his life is based on having people who accept him for who he is knowing that he has his quirks, you know, his things that come up that can be trying at times"

Some participants described the benefits of taking medication to treat ADHD symptoms, such as helping to initiate tasks or to inhibit distractions, increased energy, allowing the brain and body to start connecting, and being able to execute higher executive functioning. One individual stated that they cannot keep up with a society designed for neurotypical people without the help of medication, though they would prefer not to take medication if they had more resources and experienced less stigma related to their diagnosis.

Recommendations

The following recommendations were provided by both participants and healthcare providers to ensure individuals with ADHD can successfully manage their condition into adulthood:

Start early

It was advised to initiate the discussion with your child on how to manage their ADHD independently at an early age. For individuals who were diagnosed as a child, the same strategies for managing ADHD that were taught in a school setting could be applied in a similar way to the workplace. As they transition into adulthood, your child should be able to understand what medications they are taking and what the doses are. For children who have a pediatrician managing their ADHD treatment, it is suggested to begin involving their family doctor many years prior to when they turn 18 in order to optimize coordination of care and to reduce disruptions in medication access.

Improve awareness on how to recognize ADHD

A widespread awareness effort is recommended to ensure that recognition of ADHD can occur more often by educators, healthcare providers, and even family members. Educators should be aware of what ADHD looks like in the classroom and healthcare providers should have a more in-depth understanding and recognition of ADHD beyond basic medical school training. This specialized training should include tools to ensure adults with ADHD are connected to appropriate specialists that can provide a variety of treatment options and to recognize gender bias as well as social and cultural barriers that might prevent individuals from receiving optimal treatment.

Enhance support systems

Support is necessary from both loved ones and from healthcare professionals, particularly when navigating an initial diagnosis, as treatment options and medication side effects can be overwhelming. Education that is provided to patients on managing ADHD as an adult should also include where to receive additional support, such as a psychoeducational assessment and how to navigate potential treatment, including non-pharmaceutical treatment options.

Resources provided by participants

Throughout the town hall, many participants shared resources that they found helpful as they navigated their ADHD diagnosis. These have been summarized below:

- Black Girl, Lost Keys: Blog on living as a black woman with ADHD
- Centre for ADHD Awareness Canada (CADDAC)
  - ADHD in Women and Girls
  - Adult support groups
- D.I.C.E. - Disability Impact on Career/Employment: A self-assessment tool to identify how the disability influences your career, work performance, and workplace accommodations
- Frida: Online diagnosis, treatment and ongoing care for adults with ADHD
- The Hallowell ADHD Centers: Diagnosis, treatment and resources for individuals with ADHD
- How to ADHD: Resources and short videos for individuals with ADHD
- The Province of Ontario Neurodevelopmental Disorders (POND) Network: Research on neurodevelopmental disorders including ADHD
- Psychotherapy Matters: A collaborative care system that connects therapists and their clients with psychiatrists and family doctors
- WAM - Women with ADHD Meetup: A support group for women with ADHD

About the ODPRN

The Ontario Drug Policy Research Network (ODPRN) was established in 2008 in an effort to ensure that drug policy decision-makers had high-quality evidence in a timely manner to advance evidence-informed drug policy and decision-making in Ontario. This innovative drug policy research program bridges a network of scientific thought leaders with drug policy decision-makers to meet a goal of improving the health status of Ontarians.

For more information, visit odprn.ca.