

# Turning 18 isn't so sweet: The critical gaps in health care for young adults with disabilities



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# Background

Becoming an adult is a profound journey. But for young adults with disabilities, developmental differences and medical complexity, the journey to adulthood is a path fraught with unique challenges. As Canada's largest academic health sciences centre dedicated to care and service for children with disabilities and developmental differences, Holland Bloorview Kids Rehabilitation Hospital hears firsthand, the challenges children, youth and families experience in their medical transition from pediatric to adult care.

Each year, 70,000 young adults with disabilities in Canada transition out of pediatric care into the adult health-care system<sup>1</sup> and this number continues to grow.<sup>2</sup> While society sees 18 as a milestone of maturity—marked by voting and adult decisions—the reality for young adults with disabilities is far more complex. Often beginning their medical transition well before their 18th birthdays and continuing for the next decade, young adults face a labyrinth of barriers, from fragmented health-care systems to overwhelming financial and emotional costs, often finding themselves without the appropriate health-care support they need.

A focus on the medical transition to adulthood for youth with disabilities is essential. Many people with disabilities have lifelong health challenges that require support to meet their health-care needs. These challenges may not always be visible, meaning many young adults with invisible disabilities have the daunting task of advocating for what they need, or not being believed.

These challenges can be exacerbated by factors known to contribute to health outcomes such as where they live, how much they make, and their education.<sup>3</sup> Additionally, some young adults may face further health inequities based on their gender, race, and sexual orientation. Taken together, there are many factors that contribute to the health outcomes of young adults with disabilities, even before they must navigate their medical transition into the adult health-care system.

## A call for respectful and accessible care

Bringing awareness to medical transitions for youth with complex health-care needs began in the early 2000s, including developing best practice guidelines at the provincial level.<sup>4</sup> Since then, additional guidelines have been developed at the

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<sup>1</sup> Chafe et al., (2019). Adolescent patients with chronic health conditions transitioning into adult care: What role should family physicians play? *Can Fam Physician*. 65(5): 317-319.

<sup>2</sup> Statistics Canada (2022). [Canadian Survey on Disability \(2017-2022\)](#). Retrieved: September 4, 2024.

<sup>3</sup> Mikkonen J, & Raphael D. (2010). *Social determinants of health: The Canadian facts*. Toronto: York University School of Health Policy and Management

<sup>4</sup> Stewart et al., (2009). An Evidence-based Model and Best Practice Guidelines for The Transition to Adulthood For Youth With Disabilities, 1-90.

national level including a *Guideline for Transition From Paediatric to Adult Health Care for Youth with Special Health Care Needs* led by the Canadian Association of Pediatric Health Centres, and the development of a Child Health Hub to share information and resources for health-care providers across the nation.<sup>5</sup> Specific recommendations to improve transitions from pediatric to adult health care have also come to light including quality standards, flexible age cut-offs for transfer to adult care, as well as training and education in transitional care issues.<sup>6,7</sup>

**Despite the efforts that have been made to bring awareness to medical transitions for young adults with disabilities, their lived experiences and that of their caregivers tell a different story.**

Attitude and perception issues compound the problem. Even though health care is a fundamental right, young adults face barriers and misunderstandings that threaten their well-being. Recent reports cite systemic issues and ‘disability stigma’ as key factors in inadequate care.<sup>8</sup> The urgent need for inclusive practices and better provider education has never been clearer.

This report brings to the forefront the very real struggles that young adults face in their transition from pediatric to adult medical care. It reveals crucial findings underscoring the urgent need for systemic change. We hope this report will be a call to action to ensure young adults with disabilities transition to the adult health-care system with the care, dignity, and support they deserve.

## **Our Methodology**

Holland Bloorview Kids Rehabilitation Hospital convened an advisory group of young adults with disabilities, pediatric health-care providers, and caregivers to guide the development of a survey to capture the lived experiences of young adults and caregivers in their journey of transitioning from pediatric to adult health care. Key issues identified by this diverse group include the medical, financial, educational, employment, and social impacts.

Through collaborative discussions, the group developed and refined survey questions to capture the experiences of young adults and caregivers. The survey was disseminated to young adults (aged 18 to 30) and caregivers of a young adult with a disability in Ontario in August 2024 by market research firm, Leger. A total of **500 young adults (aged 18 to 30) with disabilities and 302 caregivers in Ontario** completed the survey.

<sup>5</sup> Children’s Health Canada (2022). [The Transition Hub](#). Retrieved September 4, 2024.

<sup>6</sup> Toulany A, Gorter JW, Harrison M. (2022). A call for action: Recommendations to improve transition to adult care for youth with complex health care needs. *Paediatr Child Health*. 27(5):297-309.

<sup>7</sup> Ontario Health. [Transitions From Youth to Adult Health Care Services Care for Young People Aged 15 to 24 Years](#). Retrieved September 4, 2024.

<sup>8</sup> The Chief Public Officer of Canada (2019). [Addressing Stigma: Towards a More Inclusive Health System](#). Retrieved September 4, 2024.

# Unmet needs: The transition to adult care is falling short for most

Our survey reveals critical gaps in the adult health-care system, with a staggering majority of respondents reporting unmet needs. The most alarming finding: young adults with disabilities are being left behind.

Approximately **two-thirds of young adults (60%) and caregivers (63%) reported that the adult health-care system is failing to meet their needs.**

This alarming statistic highlights a health-care system that is not equipped to provide the necessary support at a crucial stage in their lives, when access to proper health care is vital for long-term health and well-being.

## Challenges in the adult health-care system

**2/3** of young adults with disabilities report their health-care needs are not being met



## A critical shortfall in adult services

Astonishingly, **half of the caregivers (50%) surveyed continue to rely on pediatric health-care providers due to the lack of health-care providers in the adult system.** The most common pediatric providers include physiotherapists, occupational therapists, speech-language pathologists, and social workers.



Driving this point home, **almost a third of young adults (32%) and caregivers (30%)** reported they do not have access to the right adult specialists and clinics, highlighting the widespread inadequacy of available services. This reliance on pediatric health-care providers points to a critical shortfall in adult services, leaving many young adults with disabilities relying on clinicians with whom they have trusted for years to meet and support their changing needs.

“

The adult health-care system is like a shopping mall, except the shopping mall has one store that's open at weird times and is five hours away from your house. Now, I have to go to 5 different places for everything that I need. The fact that my care is not in a centralized place makes it difficult to arrange scheduling and keep track of everything.”

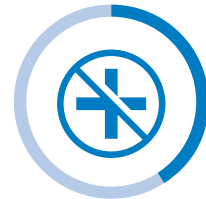
Rachel, 21

## The confidence crisis

One factor that may contribute to the challenge of finding appropriate health-care providers and specialists in the adult system is the differences in understanding disability. **More than a quarter of young adults (28%)** expressed a lack of confidence in their health-care providers' understanding of their disability. This gap in knowledge and awareness among providers contributes to feelings of being unheard and unsupported—leaving many young especially among those with invisible disabilities—leaving many young adults without the comprehensive, informed care they require.



This shortfall in provider bandwidth and understanding also has many caregivers concerned: **41% of caregivers** are not confident that the adult health-care system will adequately support their young adult if they become unable to provide care themselves.



### Demographic factors add to the complexities of experience

**40% of caregivers who identify as living in a rural location**, report that health-care providers in the adult medical system do not understand their young adult's disability in comparison to 25% of caregivers who live in suburban neighborhoods and 26% in urban locations.

**42% of young adults who identified as non-binary** felt that their health-care providers did not understand their disability compared to 27% of young adults who identified as cis-gender and 26% who identified as transgender.

Not surprisingly, **43% of caregivers living in rural locations** report they do not have access to the right adult specialists and clinics for their young adult's health-care needs, compared to 28% in urban locations and 30% suburban locations.

“

People with disabilities often belong to multiple communities—different cultures, religions, and identities—that shape their access to health care. It’s not just about their disability; it’s about the intersection of various needs of youths like me. Too often, our unique requirements are overlooked, as many spaces fail to be truly accessible, whether it’s finding a queer-friendly doctor or a professional of colour.”

Jay, 24

Consistent with survey findings, our advisory group of young adults with disabilities, caregivers, and pediatric health-care providers echoed these challenges: the system’s shortcomings are leaving young people to fend for themselves, often relying on inadequate homecare in lieu of clinical support. Families are forced to educate and advocate on their own, facing dangerous gaps in care that can lead to life-threatening medical complications.

Without access to proper specialists, like urologists, many young adults go years without critical treatment, resulting in emergency visits and severe long-term health issues. Furthermore, pediatric health-care providers are stretching their limits to support young adults with disabilities, understanding there is no one to refer on to in the adult health-care system. These insights paint a stark picture of a health-care system failing to provide the coordinated, disability-specific support needed for a successful medical transition from pediatric to adult care.

# Barriers to care: The gap in access and inclusion in adult health care

One of the insights our report revealed was the significant and varied barriers young adults with disabilities face in accessing adult medical care. **More than 75% of young adults with disabilities reported they encountered one or more barriers when navigating the adult health-care system.**

## Barriers to access

**77%** of young adults with disabilities

face one or more barriers when accessing medical care



- **49% experienced attitudinal barriers** such as feeling judged, ignored, or treated as inferior by health-care providers. This highlights how ableism may be preventing young adults from getting the care they need.
- **32% experienced informational barriers**, meaning they have received medical information in formats that did not suit their learning, vision, and/or hearing needs. This sheds light on the fact that many young adults with disabilities may be struggling to receive medical information in formats that work for them, making it hard to ask questions or understand their health-care needs and treatment plans.
- **23% experienced physical barriers** when going to medical appointments such as narrow doors and hallways, inaccessible washrooms that cannot accommodate large wheelchairs, and lack of transfer lifts to lay on exam tables or in exam chairs.
- **14% experienced barriers related to transportation** such as finding accessible vehicles—like cars, vans, or buses with ramps—for medical appointments.



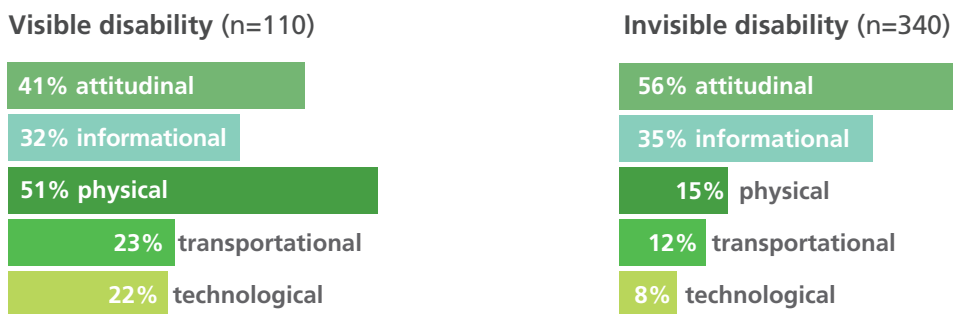


- **11% faced technological barriers** such as a lack of access to screen reading software or closed captioning. These barriers may impact an individual’s ability to engage in health-care discussions and access crucial health information, leading to frustration and disconnection from the health-care system.



Interestingly, the types of barriers experienced differed by young adults with visible versus invisible disabilities. See Figure 1 for a breakdown of experiences.

Figure 1



“

Julian’s only way to access health care is through me, because he doesn’t have the right supports in place for his appointments. He says it affects his independence as an adult who can advocate for himself, when you always have your mother in the room with you.”

**Donna, mother of Julian, 23**

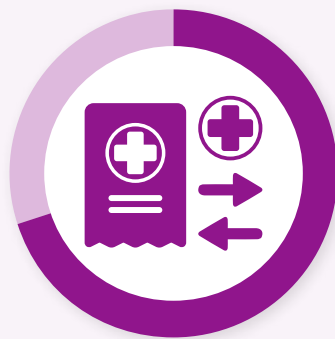
Overall, our survey findings highlight the significant challenges young adults with disabilities face in accessing health care. To improve the transition to adult health care, we must begin by prioritizing inclusive practices, accessible spaces and combating ableism. Without action, young adults with disabilities may hesitate to seek medical attention, jeopardizing their health and autonomy, especially if they need a parent or attendant present at appointments. These barriers are limited young adult’s ability to manage their own care, and can be particularly detrimental in critical areas like sexual and mental health. This restriction can be particularly detrimental in critical areas like sexual and mental health.

# The high cost of care: The financial burden

Transitioning from pediatric to adult health care comes with a steep financial burden for young adults with disabilities and their families.

**A staggering 70% of young adults and 77% of caregivers**, reported that their medical costs have increased since making the transition to adult care. Several factors may contribute to increased expenses. Services such as physiotherapy and speech-language pathology, which some children with disabilities receive through OHIP, are no longer covered in adulthood. Access to government-funded prescriptions also ends in at the age of 24, leaving many to pay out-of-pocket if they do not have private insurance. In addition to these expenses, medical devices and supplies, and accessible transportation to and from appointments can contribute to these increased costs.

## Financial implications



**70%** of young adults with disabilities face increased medical costs after transitioning to adult care

The impact is substantial. **Around 34% of young adults and 47% of caregivers shared that these costs have increased by more than \$6,000 each year**— that's at least \$500 a month.

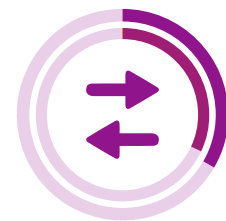


## Twice as likely to live in poverty

People with disabilities in Canada face significant financial hardships. A recent study revealed that 16.5% of people with disabilities live in poverty—more than double the 8.6% poverty rate for those without disabilities.<sup>9</sup> This represents over 1.5 million individuals, many of whom already grapple with increased costs and stretched budgets. These financial pressures add to the challenges young adults with disabilities face as they navigate the complexities (and costs) of the adult health-care system.

## Balancing health care and livelihood

Along with rising costs, the significant amount of time required to manage health care is taking a serious toll on the livelihood of young adults and their families. Many respondents have had to cut back their work hours or even quit their jobs entirely to accommodate medical appointments, creating a troubling link between health and financial stability. Specifically, **one-third of respondents (34% of young adults and 32% of caregivers)** reported having to change their education or job status to attend medical appointments, creating a balancing act between finances and health.



Finding care isn't easy or affordable. Over **half of young adults (51%) and caregivers (57%) have had to step outside the public health-care system to get the services they need,** adding even more pressure to the financial strain already incurred within the adult health-care system.



These findings reveal a deeper issue: the high cost of health care has a ripple-effect on people's lives, including their employment, education, and overall well-being. This cycle of poverty and poor health is particularly harmful to people with disabilities, who are already [disproportionately affected](#).

It also raises a critical question: what happens to those who simply can't afford the care they need? Access to health care is a fundamental right, yet for many, **financial barriers and systemic gaps make it increasingly difficult to receive adequate support.** Addressing these challenges is essential to ensure equitable care for all.

<sup>9</sup> Statistics Canada (2021). Canadian Income Survey. Poverty and low-income statics by disability status. Taken from: [Disability Poverty in Canada: A 2023 Report Card](#).

# Life on hold: The impact of health care on participation

The intersection of health care and daily life extends beyond medical appointments—it profoundly impacts the ability of young adults with disabilities and their caregivers to fully engage in everyday activities. From work to social interactions, managing health-care needs often means sacrificing their quality of life. Our survey results bear this out, highlighting just how deeply these impacts are felt.

According to our survey findings, **64% of young adults felt that their health-care needs limit their participation in daily activities.** This finding demonstrates the impact that a disability can have on participation in everyday activities.

## Participation and quality of life implications



**64%**

of young adults' participation in life is limited by their health-care needs

## Social isolation and support gaps

To emphasize how participation may be impacted, **87% of young adults reported they don't always have the support required to safely go out and socialize with their friends or peers.**

Further, **38% of young adults report they can rarely or never access** additional care services such as life skills development or day programs. This sheds light on the lack of services for young adults that could be helpful in improving their quality of life and social relationships with others.



“

It's going to be fun [turning 18] but I'm scared about what will happen when I need support. If I get hurt will I be able to access physiotherapy? What happens if my communications device stops working?"

**Joseph, 17**

The results of the survey suggest that the social lives of young adults with disabilities are suffering as a result of insufficient medical support. Our advisory panel expanded on this finding, reporting feelings of loneliness and isolation, due to the lack of medical supports needed to go out and spend time with friends and family.

These findings underscore the urgent need for more accessible, reliable supports to ensure young adults and their caregivers can lead fuller, more engaged lives.



## The way forward: Advocating for better health care tomorrow

Access to medical care is difficult for many, but young adults with disabilities face a distinct and often daunting set of challenges when transitioning from integrated pediatric care to a fragmented, siloed adult health-care system. From a lack of specialized care to economic hardships, the health-care system is falling in ways that demand urgent attention and action. Young adults with disabilities deserve better.

It may be a tough journey ahead, but hope is on the horizon. And change is already underway.

### **Holland Bloorview: Leading change and expanding horizons**

While our survey highlights critical gaps, Holland Bloorview is actively paving a hopeful path toward improvement. Let's examine the three top priorities—and explore what Holland Bloorview is doing today, along with our vision for a brighter future.

“

Turning 18 should be a celebration, but for youth with disabilities it signals “aging out” of the pediatric health-care system. Medical needs don't go away at 18. Holland Bloorview has been a leader and a catalyst for change in supporting systems-level solutions—including partnerships with adult health-care providers—to support youth in accessing the health care they need as they become adults.”

**Dilshad Kassam-Lallani, nurse practitioner, Holland Bloorview**

## Three key areas that require a call to action:

### 1. Coordinated care

Securing coordinated, continuous health care for those transitioning out of the pediatric care system is increasingly difficult. Young adults with disabilities are often left waiting years for primary care and specialists. A focus on supported transitions and warm hand-overs, as early as possible, is important to set young adults up for success when the transition to adult health care occurs at or around their 18th birthday.

**Holland Bloorview's current initiatives:** Teams at Holland Bloorview are partnering with adult specialists to pilot supported transition clinics. Innovative programs like our Lifespan and Spina Bifida Transition Clinics, are leveraging a solutions-focused approach, strong partnerships, and interprofessional care teams to build new models for care. These clinics are helping to ensure smoother transitions into adult health care, setting a new standard for comprehensive care.

**Our future vision:** ... an integrated system of care where no youth is transitioned out of pediatric care until comprehensive equivalent care outside the pediatric system is secured, irrespective of disability type, socio-economic status, or geographic location. By fostering better connections to specialists and ensuring comprehensive care, all young adults will receive the support they need in their health-care journey.



### 2. A health-care workforce equipped with knowledge

Many health-care providers today lack the specialized training required to deliver effective, informed and holistic disability care. Advanced knowledge and education in disability and developmental differences for adult health-care providers is a necessary step in expanding the knowledge base of disability and increasing the confidence level of adult health-care providers in how to support young adults with disabilities.

**Holland Bloorview's current initiatives:** We're at the forefront of training in Canada, operating the nation's largest developmental pediatrics program, and a variety of learning programs dedicated to transforming the care of children, youth and young adults with disabilities through education. Our innovative care models are not only making a significant impact locally but are also being shared and replicated nationally and internationally. These initiatives ensure that young adults with disabilities receive consistent, high-quality, and inclusive care, both in Canada and around the globe.

**Our future vision:** ... a system where expert care is accessible to all, regardless of disability; where seamless transitions are expected, and young adults are empowered to confidently navigate their journey with the support of knowledgeable and compassionate health-care professionals.



### 3. Support for all dimensions of the transition adulthood

Young adults with disabilities require holistic, lifelong support that extends beyond clinical care to truly flourish. This encompasses planning for education, employment, social integration, and overall well-being.

**Holland Bloorview's current initiatives:** We are proactively prompting transition planning using our electronic health-care records, and addressing crucial aspects beyond medical management like employment prospects, social engagement, community belonging and sexuality, including romantic relationships. Our approach is intersectional and personalized, recognizing the diverse identities and experiences of each young adult we serve.

**Our future vision:** ... a seamless health-care transition for every young adult with a disability that includes access to tailored support to address their unique health and social needs and allows them to thrive in all facets of life.





At Holland Bloorview, we are committed to leading the way in addressing these critical gaps in medical transitions.

**Our vision for the future is clear:** a health-care system that provides timely, coordinated care, specialized disability training for all providers, and addressing barriers that make accessing health care more challenging than it needs to be. This vision is not just a goal but a roadmap for meaningful, long-term change, lifetime wellness, and a better functioning health-care system for all.

We are not just advocating for children and young adults with disabilities; we are catalyzing transformative change across the health-care landscape. Our unique blend of expertise, lived experiences, and collaborative spirit drives us to challenge and reshape systems, enhancing quality of care and equity for all.

## How you can make a difference

You might wonder how you, as an individual, can contribute to addressing the challenges that impact more than 70,000 young adults transition to adult health care each year in our country. The answer is: you can make a big impact! By raising awareness, advocating for policy reform, and demanding better care, you become a catalyst for change.

**We all have a role to play in creating a more inclusive and effective health-care system for all.**

### Here's how you can act:



**Speak out:** Whether you're a parent, caregiver, or young adult, advocate for inclusive and accessible care.



**Promote awareness:** Share this report across your networks. Help shine a light on the need for systemic reform in the health-care system.



**Learn more and support Holland Bloorview:** Sign up for regular updates from Holland Bloorview to learn how you can take action.



## About Holland Bloorview

At Holland Bloorview we believe in creating a world where all youth and children belong. We are the only children's rehabilitation hospital in Canada focused on combining world-class care, transformational research, and academic leadership in the field of child and youth rehabilitation and disability. We help over 9,500 kids and youth with disabilities and complex medical needs access care that focuses on their physical, mental, and emotional well-being, and we power their infinite potential and possibility.

Together we dream big. Together we champion a world of possibility.

### Special thanks to report advisory group:

**Jay Baldwin**, former client

**Julian Cappelli**, former client supported by mother, Donna Cappelli

**Halla Fahmi**, social worker

**Jean Hammond**, family partnerships specialist

**Clara Ho**, manager, client and family-centred care

**Dilshad Kassam-Lallani**, nurse practitioner, child development program, Spina Bifida/Spinal Cord Injury Clinic

**Heather Keating**, clinical operations manager, transitions, community partnerships

**Zoe Komlos**, YAC member and former client

**Dr. Laura McAdam**, physician director, child development program

**Jan Magee**, family leader

**Laura Thompson**, team lead, occupational therapist, transitions team

**Korin Visca**, family support specialist

**Holland Bloorview**  
Kids Rehabilitation Hospital

**Holland Bloorview Kids Rehabilitation Hospital**  
150 Kilgour Road, Toronto, ON M4G 1R8  
T: 416-425-6220 Toll-Free: 800-363-2440  
F: 416-425-6591 E: [info@hollandbloorview.ca](mailto:info@hollandbloorview.ca)  
**HollandBloorview.ca**