



TRANSITION TO ADULTHOOD DURING COVID-19

The COVID-19 pandemic has impacted our usual way of living, including how we engage with the healthcare system. The purpose of this research was to better understand the positive and negative impacts of the pandemic. Young adults, parents, and researchers partnered on this research to learn about the impact of the pandemic on youth with special healthcare needs (YSHCN) aged 16-24 years, during their transition to adult healthcare services. Special healthcare needs may include developmental, physical, or mental health conditions.

►►► How did we learn about the impact of the pandemic on YSHCN?

Step 1. Interviews	Step 2. Survey	Step 3. Virtual Town Hall
<ul style="list-style-type: none"> ❖ Interviews (English & French) with 21 Canadian YSHCN and parents in 4 provinces. ❖ Youth and parents shared lessons learned from their experiences of healthcare transition during the pandemic. ❖ Rapid analysis and review of literature informed the Survey. 	<ul style="list-style-type: none"> ❖ Survey (English & French) of 516 Canadian YSHCN and parents in 10 provinces and 1 territory. ❖ Gathered information on recommendations and priorities to improve healthcare transition. ❖ Rapid analysis informed a Virtual Town Hall. 	<ul style="list-style-type: none"> ❖ A bilingual virtual town hall with over 55 attendees, including YSHCN and parents, healthcare professionals, researchers, and educators in 8 provinces. ❖ Informed strategic priority-setting and recommendations.

►►► What did we learn and what can be improved?

Below we share highlights of what we learned from YSHCN and parents, organized under **four priority domains**:

Gradual transition preparation		
Experiences of Canadian YSHCN during the COVID-19 pandemic	What did we learn?	How can we improve?
<ul style="list-style-type: none"> ❖ YSHCN experienced abrupt transfers (rather than gradual transitions) and felt unprepared. ❖ During transition preparation, parents may be included or excluded without asking the YSHCN. ❖ Social connections helped youth feel more prepared, which eased the transition process. 	<ul style="list-style-type: none"> ❖ Some YSHCN in Canada have gradual preparation, but others are not prepared. ❖ Transition care is not equitable across the country. ❖ Healthcare providers should talk with families about preferences related to the changing role of parents and caregivers as youth prepare to transition. ❖ Social supports can help empower youth in the transition process. 	<ul style="list-style-type: none"> ❖ Gradually plan and prepare YSHCN for transition. ❖ Offer YSHCN capacity-building, opportunities (autonomy, knowledge, self-management skills) to support transition. ❖ Establish Canadian transition standards with embedded health system accountability. ❖ Create diverse transition networks (support, mentorship, coping, comfort).

Coordinated and continuous care

Experiences of Canadian YSHCN during the COVID-19 pandemic	What did we learn?	How can we improve?
<ul style="list-style-type: none">❖ Long waits for care, feeling disconnected from the healthcare team.❖ Limited access to adult healthcare provider(s).❖ YSHCN unable to access equivalent services in adult healthcare to maintain and enhance their health and well-being.	<ul style="list-style-type: none">❖ There may be a lack of adult specialists to transition to.❖ Disconnection from healthcare providers during transition negatively impacts YSHCN's physical and mental health.❖ Many YSHCN and parents report stressful and unsatisfactory healthcare experiences after leaving pediatric services.❖ Complex YSHCN and families urgently need better access to consistent, specialized care across the lifespan.	<ul style="list-style-type: none">❖ Provide physical and mental health (holistic) surveillance and support across the lifespan.❖ Ensure continuous primary care for YHSCN before and after transition.❖ For complex YSHCN, assemble specialized teams of professionals that cross pediatrics & adult care.❖ Create individualized emergency plans before complex YSHCN transfer from pediatric care.

Collaborative and patient-centred care

Experiences of Canadian YSHCN during the COVID-19 pandemic	What did we learn?	How can we improve?
<ul style="list-style-type: none">❖ Reduced personal connection with healthcare providers.❖ Not feeling heard by healthcare providers.	<ul style="list-style-type: none">❖ YSHCN prefer individualized and unique care approaches rather than based on diagnosis or age.❖ Individualized strategies to support YSHCN in pediatric care should continue into adult care.❖ YSHCN want to be part of decision-making regarding parent involvement in healthcare.❖ Care strategies should include caregiver support if YSHCN autonomy is not assured.	<ul style="list-style-type: none">❖ Collaborate with YSHCN about care needs and preferences for parent/caregiver involvement in future healthcare.❖ Advocate for government policies that prioritize YSHCN care needs and protect their human rights especially in times of transitions and emergencies.

Flexibility in delivery and transfer of care

Experiences of Canadian YSHCN during the COVID-19 pandemic	What did we learn?	How can we improve?
<ul style="list-style-type: none">❖ The pandemic led to services being offered in new and different ways.❖ Virtual care: experiences can be positive and/or negative.❖ Increased flexibility can be incorporated into the transition process (e.g., YSHCN were able to stay temporarily in pediatric care longer).	<ul style="list-style-type: none">❖ We heard examples of how flexibility was possible to extend pediatric care.❖ Combined in-person and virtual care is good for YHSCN:<ul style="list-style-type: none">- allows joint pediatric/adult transition appointments.- improves access to care across settings and sectors.- fills gaps in care, stops virus spread, and lessens travel and accessibility issues.	<ul style="list-style-type: none">❖ Continue providing virtual options.❖ Expand use of virtual visits to enhance communication among pediatric and adult providers.❖ Incorporate individual & unique needs in transition plans, in close consultation with youth and parents.❖ Advocate for policy changes to healthcare funding that facilitate and support flexible care delivery (e.g., equitable pay for virtual visits).

►►► How can we leverage findings to improve transition experiences and outcomes?

Our multi-phased, patient-oriented design ensured that youth, parents, and healthcare providers were engaged throughout the project. Such engagement of a diverse and representative group of consumers of healthcare in a variety of ways is essential to the co-development of transition plans, advocacy efforts, and policies. This study offers practical guidance for Canadian patients and public (e.g. YSHCN and families, policy makers, health system leaders) to guide improvements in healthcare transition.

The priorities, recommendations, and strategies identified through this study can be used to inform professional practice, policy, guideline development, and program changes. Through this study, we identified and explored the following actions to improve transitions to adult healthcare:

- ❖ Map the people and organizations in child and adult healthcare systems to identify those who are already working together and where connections need to be made.
- ❖ Find and connect with people who are already doing some of this work or who are in a position of influence to support this work.
- ❖ Balance working on long-term changes (e.g., system-level changes) with short-term changes by finding, continuing, or building on effective approaches.
- ❖ Explore how provincial and territorial governments handle transition, identify effective or promising practices, consider how these can be applied in other areas (e.g., by finding the leaders and decision-makers who support this work and can act on changes).
- ❖ Continue to meaningfully engage diverse groups (e.g., youth, parents, pediatric and adult healthcare providers) to better understand healthcare transition experiences and opportunities for improvement.

This study aimed to learn from positive and negative healthcare transition experiences during the COVID-19 pandemic to inform the development of the best possible healthcare for YSHCN. We aim to support and reduce the burden on YSHCN and families when planning and undergoing transitions to adult healthcare systems. Findings suggest that YSHCN and their families want consistency, continuity and reassurance that their best interest is central to their care.

Knowledge translation/mobilization, advocacy, and policy initiatives are ongoing, and include plans to publish a manuscript, create a project report video, and co-host a webinar for healthcare professionals and family partners, to share our findings nationally. We will continue the conversation within the [Canadian Transition Hub](#) to determine next steps in this program of work.