



# THE BARRIERS AND FACILITATORS OF TRANSITION FROM PEDIATRIC TO ADULT HEALTH CARE IN NOVA SCOTIA

*Summary Report*

April 20, 2022



# PROJECT INFO

## PROJECT TITLE

Exploring the transition from pediatric to adult health care in Nova Scotia

## LEADS

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- Elizabeth Jeffers, Maritime SPOR SUPPORT Unit
- Julia C Kontak, Maritime SPOR SUPPORT Unit
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### LEARN MORE:

<https://mssu.ca/research/research-projects/transitions-in-care/>

## ACKNOWLEDGEMENTS

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## HOW TO CITE THIS REPORT

Cassidy, C., Pidduck, J., Higgins, A., Anderson, S., Best, S., Curran, J., Grant, A., Jeffers, E., Kontak, J.C., MacDonald, S., MacKinnon, L., Mireault, A., Rowe, L., Walls, R. The barriers and facilitators of transition from pediatric to adult health care in Nova Scotia: Summary report. Halifax, Nova Scotia: Maritime SPOR SUPPORT Unit (MSSU); 2022.

# SUMMARY REPORT

## INTRODUCTION

The transition from pediatric to adult health care is the process of a youth learning how to manage their healthcare on their own, preparing to transfer and becoming comfortable as a patient in adult health care. This transition can be challenging due to differences between the two health care systems in terms of approaches to care, level of involvement of caregivers, and expectations about youth's responsibility. During the transition process, youth and caregivers are tasked with adapting to new relationships, environments, and systems. Transition and transfer can be very difficult for some youth and can lead to poor health outcomes, being lost to follow up from the adult health system and having challenges in other areas of their life.

The goal of this research project was to explore the current practices and experiences of the transition from pediatric to adult care for youth, caregivers, and health care providers in Nova Scotia. The study focused on three health issues: inflammatory bowel disease (IBD), diabetes, and juvenile idiopathic arthritis (JIA).

## HOW DID WE DO THE RESEARCH?

Our research team conducted interviews and focus groups with nine youth, eight caregivers, and 26 health care providers on the transition from pediatric to adult care. We analyzed the information shared in the interviews and focus groups to generate themes related to the barriers and facilitators to the transition from pediatric to adult health care.

We used the COM-B (Capability, Opportunity, Motivation – Behaviour) model to guide this work. This model suggests that for any behaviour to change there must be a change in one or more of the following factors: capability (i.e., knowledge, skills), opportunity (i.e., relationships, environment) or motivation (i.e., goals, worries, identity).<sup>(1)</sup>

**The Transition of Care Committee, which brings together youth, caregivers, health care providers and community partners to improve the transition from pediatric to adult healthcare, was an important partner in this work.** They supported and informed many stages of the research project including project planning, development of the interview and focus group questions, recruitment strategies, data analysis, ideas for sharing research results and helping to develop knowledge translation products.

## WHAT DID WE LEARN?

Themes related to the youth, caregivers and health care providers experiences of the health care transition process are listed in the following tables and coded according to the COM-B Model of Behaviour components (see Legend).

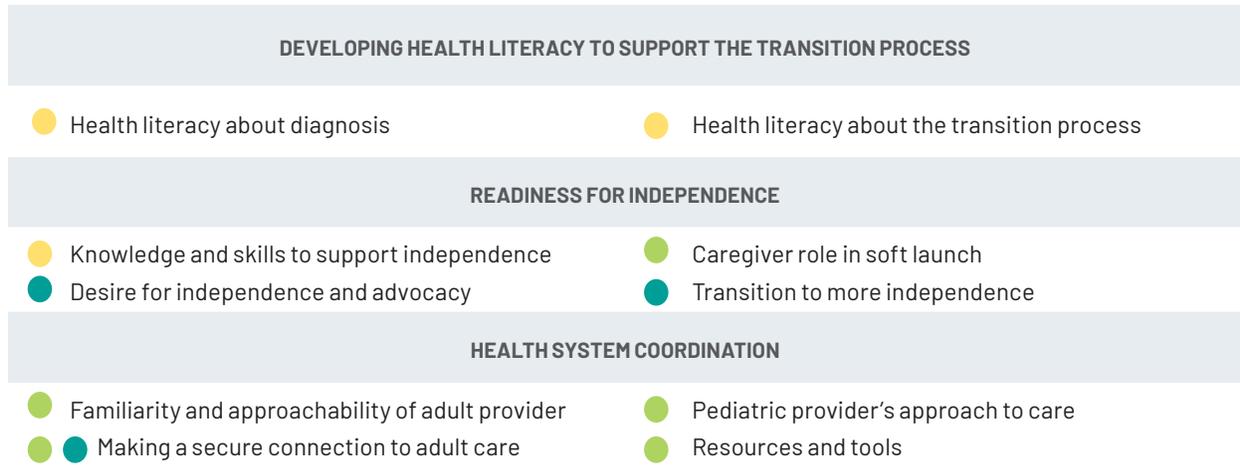
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1. Michie S, van Stralen MM, West R. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science*. 2011;6(1). <https://doi.org/10.1186/1748-5908-6-42>.

# LEGEND: ● Capability ● Opportunity ● Motivation

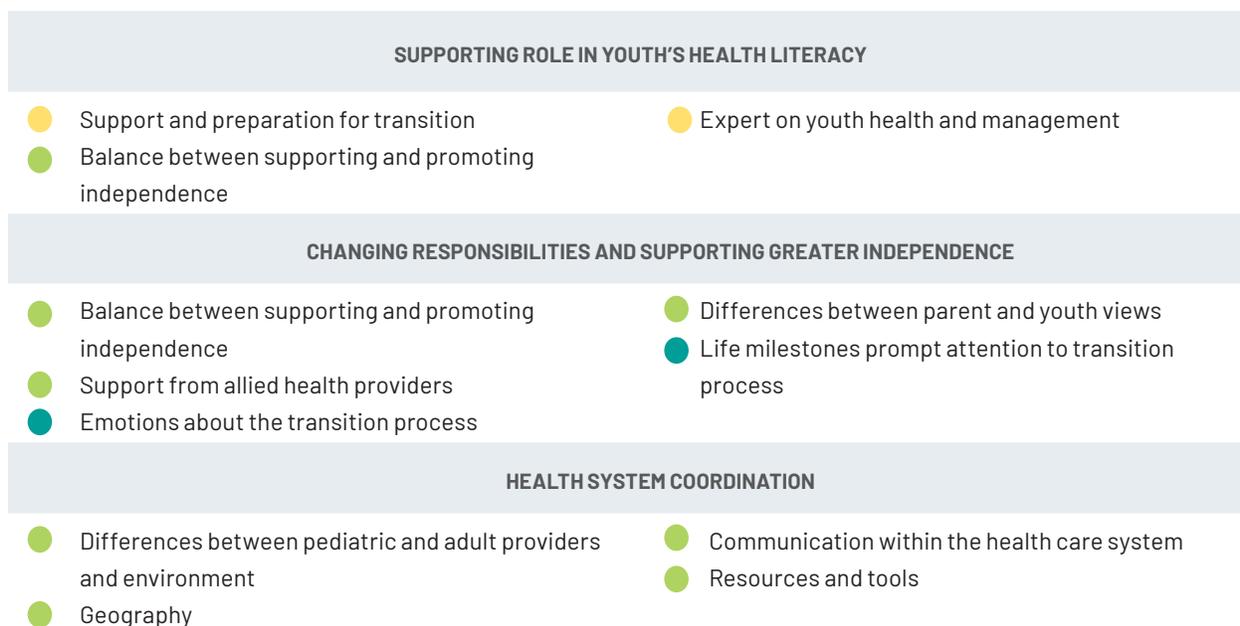
## The experiences of youth

Youth reported several barriers and facilitators to their transition experience. Youth found the transition to be easier when they developed health literacy on both their health condition and the transition process. Support from parents/caregivers and health care providers helped youth to build their readiness to be independent in their own health care management over time. For youth, the ideal health system coordination of the transition experience is a fluid process involving positive relationships with both pediatric and adult health care providers.



## The experiences of caregivers

Caregivers helped facilitate the development of youth health literacy by preparing their children for transition through support and teaching. They described a shift of responsibilities to respond to changes in youth needs for both independence and support. As they navigated the health care system, caregivers were impacted by the organization of adult health care, communication, resource access and geography.



## The experiences of health care providers

Health care providers used a wide range of knowledge and skills to support transition of care. Their primary role was to be a navigator for youth and caregivers through the transition process. Health care providers navigated barriers and facilitators in the health system, such as collaboration with other providers, communication and geography.

### KNOWLEDGE AND SKILLS TO SUPPORT TRANSITION OF CARE

- Lack of formal training about transitions in care
- Inconsistent use of a readiness checklist
- Specific knowledge and skills needed

### NAVIGATOR ROLE FOR YOUTH AND CAREGIVERS

- Importance of liaison and coordination roles
- Using youth-centred communication
- Supporting a secure connection to adult care
- Being a point of access for youth
- Shifting care responsibilities from caregiver to youth
- Using a case-by-case approach to youth care
- Wanting to avoid youth falling through the cracks

### HEALTH SYSTEM COORDINATION

- Culture of collaboration
- Connection to primary care
- Lack of consistent follow-up to adult care
- Geographic location
- Resources and tools
- Importance of the multidisciplinary team
- Time related to transition care
- Physical structure of healthcare system
- Use of virtual communication
- Payment for care

## SIMILARITIES AND DIFFERENCES BETWEEN YOUTH, CAREGIVER AND PROVIDER EXPERIENCES

There were many similarities and some differences in the experiences of youth, caregivers and providers. All groups needed to gain knowledge and skills about the transition process and wanted relevant resources. Health care providers described needing more formal knowledge and skills. Each group was also focused on shifting responsibilities and finding a balance between independence and support for youth over time. Caregivers and health care providers worried more about youth having the right level of independence and skills to support their transition. Youth and caregivers noted how the approach of health care providers influenced the transition experience. Both youth and health care providers were motivated to develop a strong connection to the adult health care system. All groups identified the need to improve communication and coordination in the health system.

## LIMITATIONS

There are several limitations to this research project. Despite extensive recruitment, there were a limited number of primary care providers interviewed and more pediatric providers than adult providers participated. There were also fewer youth and caregiver participants than planned. The project had few participants from historically underrepresented groups and questions that addressed equity were not part of interview or focus group questions. These perspectives would improve understanding of the transition process in future research.

## CONCLUSIONS

We identified a range of barriers and facilitators to support the transition from pediatric to adult care from the perspective of youth, caregivers, and health care providers in Nova Scotia. These findings will be used to inform the planning of programs, resources and/or policies to improve the transition to adult health care in Nova Scotia.