



IWK Health

Pediatric Rehabilitation
Services

The Village News

December's Special Dates

3 – First Sunday of Advent

8 – Feast of the Immaculate Conception

8 – First Day of Hanukkah

15 – Last Day of Hanukkah

21 – First day of Winter

24 – Christmas Eve

25 – Christmas Day

26 – First Day of Kwanzaa

31 – New Year's Eve



December 2023

- Transition from pediatrics to adult health care sessions
- Parents of Complex Children Support Group
- Recruitment Flyer--Transition Framework Co-Design
- Manual Wheelchair Study
- Transition Tips
- Interplay Research Study
- Parasport
- McMaster University Research Study
- Parent Well Being Study
- Rehab Kids Patient Recruitment Study
- Cerebral Palsy (CPPain) Survey
- Recruiting Caregivers of IWK Rehab patients
- Patients with Complex care research

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Join us to help improve the transition from pediatric to adult health care!



The [Transition of Care Committee](#) (made up of patients, caregivers, and healthcare providers) created a [Transition Framework](#), a set of guidelines to support the transition from pediatric to adult health care for pediatric, primary and adult health care. Scroll down for more information on the Transition Framework.

The trick with guidelines is that sometimes they are not followed. The project we are doing helps us to understand how to support care teams to use the Transition Framework guidelines.

We are setting up **'Co-design' sessions to develop an 'implementation strategy'** for care teams.

- Co-design means designing with patients and caregivers along with health care providers and health leaders.
- An implementation strategy will help us to figure out how to help care teams to follow these guidelines

We are inviting patients (14-24 years old), caregivers, and health care providers to these co-design sessions from 4 care areas:

- Hematology (Sickle Cell Anemia, Thalassemia)
- Gastroenterology "GI" (Inflammatory Bowel Disease "IBD")
- Ear, Nose and Throat "ENT" aka Otolaryngology (Complex Ear Conditions, Tracheostomy)
- Complex Care

As well as community partners who support youth and families from a health equity lens

We two dates in December:

- Thursday, December 7th – 5:00-7:00 pm (patients only)
- Monday, December 11th – 5:00-7:00 pm (patients, caregivers and healthcare providers)

Co-Design Session Registration

- You can register for a co-design session through this link to [MS Forms](#) or by emailing [Megan Churchill, Research Coordinator](#)
- **There is a \$50 gift card honourarium for joining**
- Please share this information with anyone who may be eligible to participate

You can also share, like or comment on the IWK FB and IG posts!!

Once we have the information from these co-design focus groups, the research team will bring the information back to the Transition of Care Committee to provide feedback on the 'implementation strategy'. We will then go back to the care teams and have

them try it out. We have different ways of measuring if the implementation went well, including surveys for youth, caregivers and healthcare providers.

Overview of Transition Framework Guidelines

To improve health outcomes for youth during the transition from pediatric to adult care, we...

| | |
|--------------------------------|---|
| Engagement | <ul style="list-style-type: none">☑ Incorporate feedback from youth and caregivers into our practice☑ Outline to youth and caregivers how their feedback has influenced our transition practice |
| Equity | <ul style="list-style-type: none">☑ Consider how health equity plays a role in transition outcomes☑ Consider how complexity of care plays a role in transition outcomes |
| Individualized Planning | <ul style="list-style-type: none">☑ Assess youth's health care skills☑ Have a system to track transition progress |
| Coordinated Transfer | <ul style="list-style-type: none">☑ Discuss transfer of care with youth and family one year prior to transfer☑ Ensure youth and caregivers know how to access care during transfer |
| Secure Attachment | <ul style="list-style-type: none">☑ Support trust building with adult and primary care services☑ Provide additional supports are provided to youth who face barriers to secure attachment |
| Evaluation | <ul style="list-style-type: none">☑ Set & track goals for transition processes and/or outcomes☑ Collect data to demonstrate improvement in transition practice & health outcomes during the transition |

Any questions? Please reach out to Megan at megan.churchill@iwk.nshealth.ca

Looking for more information on the transition to adult health care? Talk to your health care team or check out the [IWK website](#)



Support Group for Parents of Children with Complex Care Needs

Next Virtual Meeting
Wednesday, December 13, 2023
7:00-8:30pm

**This is a journey that does not have to be taken alone.
We can do this together!**

If you are interested in attending, please contact Jackie Pidduck
jacklynn.pidduck@iwk.nshealth.ca

PATIENTS AND CAREGIVERS INVITED TO DESIGN A TRANSITION STRATEGY FOR THE IWK AND NOVA SCOTIA HEALTH

The transition from **pediatric to adult care** is an important time for youth and their parents and/or caregivers.

To **improve health outcomes** along this transition, a project is underway to create **an implementation strategy** that will help the IWK and Nova Scotia Health to improve the transition to adult care.

Co-design sessions start this November!

Participants will join a **2-hour virtual session** to create practical strategies for the IWK and NSH to use based on their own experiences with the transition process.



Who can join? Patients (14-24 years old) and caregivers of a patient with **one of these health conditions:**

- Sickle Cell Anemia
- Thalassemia
- Complex Care
- Inflammatory Bowel Disease
- Complex Ear Disease
- Tracheostomy



scan to register



To register for a co-design session, please scan the QR code or contact Megan Churchill: Megan.Churchill@iwk.nshealth.ca

PEDIATRIC MANUAL WHEELCHAIR USERS NEEDED

Wheelchair Skills Training Program

Partake in a study evaluate the effectiveness of a program to teach children how to safely and efficiently perform 32 manual wheelchair skills that are essential for everyday activities

Target population


Children who use a manual wheelchair for their everyday mobility




Eligibility criteria

- ✓ Be between the ages of 3 – 21 years old
- ✓ Use a manual wheelchair regularly and be able to self-propel for 10 meters
- ✓ Have your own manual wheelchair
- ✓ Understand 2-step instructions in English
- ✓ Live in (or willing to travel to) the area of Halifax
- ✗ Children using a double hand-rim (one-sided propulsion) for maneuvering their manual wheelchair are not eligible

Description of the study

 12 manual wheelchair skills training sessions held weekly with a trained occupational therapist or research assistant at/near the IWK Health Centre

 3 evaluation sessions each spaced 3 months apart to assess wheelchair mobility

 You will receive a stipend of \$50 after each of the 3 evaluation sessions

Email Pediatric-WSTP@iwk.nshealth.ca for any questions or to partake!

Primary Supervisors: Krista Best, PhD and Jordan Sheriko, MD
(Jordan.Sheriko@iwk.nshealth.ca)



Getting Ready for Adult Care?

Check out our
transition tips!



TALK ABOUT IT

Talking about the transition to adult health care will not likely make it happen any faster, but it may help you to feel more confident and prepared when you do make the move



IWK Health

IWK HEALTH TRANSITION TIPS



START EARLY, REPEAT OFTEN

Start thinking about the skills you need early. There are lots of skills to learn, like figuring out how to get medications, knowing your health history, and being an advocate for what helps you.



IWK Health

IWK HEALTH TRANSITION TIPS



KNOW YOUR CHAMPIONS

Find people to help--at home, at school or from your health care team.

Look for people who can support you as you take on more responsibility for your health care.



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IWK HEALTH TRANSITION TIPS



ASK FOR HELP

As you take on more responsibility for your health, remember, it is ok to ask for help. Your health care team is here to support you.

If you are not sure, ask us!



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IWK HEALTH TRANSITION TIPS



TRY IT ON YOUR OWN

Try your new health care skills
while you have a support
system around you.
It is ok to make mistakes,
it is how we learn.



IWK Health

IWK HEALTH TRANSITION TIPS



You're in Charge **is a great way to start** **the conversation**

Register now for our next
online session starting
this Fall





INTERPLAY.

IMPLEMENTATION OF
INTENSIVE THERAPY FOR
EARLY REACH THROUGH PLAY

Share your **experiences** with **HAND THERAPY**

Complete an online survey about things that may influence early intensive hand therapy for young children with cerebral palsy.

Across Canada, we'd like to hear from:

- **Caregivers** of a child with cerebral palsy under 6 years old.
- **Occupational Therapists** who provide therapy for children with cerebral palsy.
- **Leaders** who manage occupational therapy programs.



Take a picture to participate in the survey

Participants will receive \$25

Questions? Ask us at interplay.study@ucalgary.ca

This study has been approved by the University of Calgary Conjoint Health Research Ethics Board (REB22-1692)

Parasport's in Nova Scotia

Para or Adaptive sports are competitive and/or recreational sports that are accessible to everyone, and can be played by anyone whether living with or without a disability!



Did you know there are tons of Parasport opportunities available in communities all across Nova Scotia? Visit parasportns.com to learn more about all the individual programs that are available across the province!

Examples of Parasport's Available Across Nova Scotia include;

- | | |
|---|--|
|  Para Hockey |  Wheelchair Curling |
|  Boccia |  Wheelchair Basketball |
|  Para-Canoe |  Ski & Snowboard |
|  Goalball |  Powerchair Soccer |

Map of Programs in Nova Scotia



Parasport FAQ's

Do you need to have a specific disability to participate in Parasport programs?

NO! Parasport's are designed to create a more inclusive and accessible sport environment. This means that at a recreational level they are open to participants of all abilities! Depending on your ability, certain sports may provide a better experience than others. You can check out each parasport offered in Nova Scotia at www.parasportns.com to see which sport might be the best fit for you, or you can reach out to parasport@sportnovascotia.ca if you need additional assistance or guidance!

** At competitive National levels and above all Parasport's have classification systems to group similar abilities together for competition*

How do I register for a program?

Parasport programs are not provided directly by Sport Nova Scotia, but by a variety of different organizations across the province! Each organization has their own registration process, but a centralized list of programs, links to register, and contact info can be found at www.parasportns.com! If you are having trouble finding the info for a specific sport or program, you can reach out to parasport@sportnovascotia.ca to get started!

What is the cost?

Cost varies program to program depending on the organization providing the program. Most parasport programs in Nova Scotia are low to no cost to register! If cost is a barrier, there are funding options such as KidSport available - <https://kidsportcanada.ca/nova-scotia/provincial-fund/>. There are also a number of municipalities across the province that offer subsidies for sport registration fees for youth.



I don't know what sport would be a good fit for me/ my child?

You can check out each parasport offered in Nova Scotia at www.parasportns.com to see which sport might be the best fit for you, or you can reach out to parasport@sportnovascotia.ca if you need additional assistance or guidance!

Is there a parasport program in my community?

There are parasport programs offered in communities all across Nova Scotia! You can find a map and list of available programs at www.parasportns.com!

Are there any options if there is no programs in my community?

Yes! Sport Nova Scotia offers the Parasport Program Loan which loans out the equipment, training and resources for a selection of parasports to eligible organizations to trial them in new communities! To find more info on this program visit <https://www.parasportns.com/parasport-program-loan/> or email parasport@sportnovascotia.ca

Do I need to have my own equipment?

It varies program by program depending on the organization providing the program, but for the vast majority of programs, NO! Most programs provide any specialized equipment such as sport chairs, specialized balls, etc as part of the program.





Calling parents of children with disabilities across Canada for a research study



MPOC 2.0: Field-testing the new MPOC

WHAT IS THE PROJECT ABOUT?

- Researchers at McMaster University have developed a new questionnaire to measure parents' experiences with healthcare services for their children with disabilities. Now we would like to have parents test it out!

WHO CAN PARTICIPATE?

- Parents of a child/youth who has been receiving developmental, medical, or behavioural services for at least 6 months in the past 5 years.
- Parents who have not previously participated in another phase of the MPOC 2.0 study.

WHAT WILL YOU BE ASKED TO DO?

- Complete a set of questions to tell us about your experiences with healthcare services.

Interested in participating?
Want more information?

Contact us at
mpoc2@mcmaster.ca



This study has been reviewed by the Hamilton Integrated Research Ethics Board under project #15702 Version #2 Jan 17 2023



Weekly Health Letters for Parents of Children with Developmental Disabilities

Facts about 90Second Wellbeing:

- 2 short health letters weekly
- Actionable tips to improve wellbeing
- Evidence-based health information
- Free
- ✓ For all parents of children with developmental disabilities (regardless of age)
- ✓ Flexible time commitment
- ✓ Confidential
- ✓ Complete the study and obtain a \$25 gift card

To learn more about this study, visit:

www.parentwellbeing.ca

Contact us at: Parent.Wellbeing@iwk.nshealth.ca

Phone: 1-877-341-8309 [Ext 6]

RECRUITING PATIENTS & FAMILIES IN IWK KIDS REHAB

Are you currently accessing care at the **IWK Kids Rehab Clinic**?

Would you like to **share feedback** about **your experience**?

We will ask you to complete a **1-1.5 hour interview** and you will be **compensated \$50** for your participation

Our research study is looking to interview patients and families about their experience with **goal setting**, the **intake interview**, and **overall functioning of the clinic**

To participate in this study you must be a patient or parent/guardian where...

- The patient has been **accessing care** at the Rehab Clinic for **at least the last 5 years**
- The patient **has not transitioned out of Rehab Clinic**
- The patient and/or parent is **comfortable having a conversation in English**

If you are interested in participating, please contact:

Sarah Jennings
Lead Researcher
sarah.jennings@dal.ca

Dr. Jordan Sheriko
Supervising Investigator
jordan.sheriko@iwk.nshealth.ca

SEEKING PEDIATRIC POWER WHEELCHAIR USERS FOR RESEARCH STUDY



Do you have a child that is a current power wheelchair user? Or are you younger than 18 and a current power wheelchair user?

Current pediatric power wheelchair users (aged 4-17) and their caregiver are invited to take part in a research study to help develop a **virtual reality game** for power wheelchair skills training

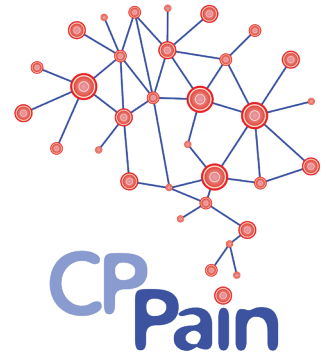
Participants will each receive a \$25 gift card for their time

INTERESTED IN PARTICIPATING OR HAVE QUESTIONS?

Please contact the Research Coordinator, Sara, at
Sara.Drisdelle@iwk.nshealth.ca

This study has been reviewed and approved by the IWK
Research Ethics Board (#1026934)





Do you have a child (<18 years old) living with cerebral palsy? Or are you younger than 18 and living with cerebral palsy?



Complete an online survey to tell us about pain experiences in cerebral palsy and its impact (those with and without pain encouraged to participate!)

<https://tinyurl.com/CPAINsurvey>

1 in 100 chance to win a \$150 prepaid VISA card

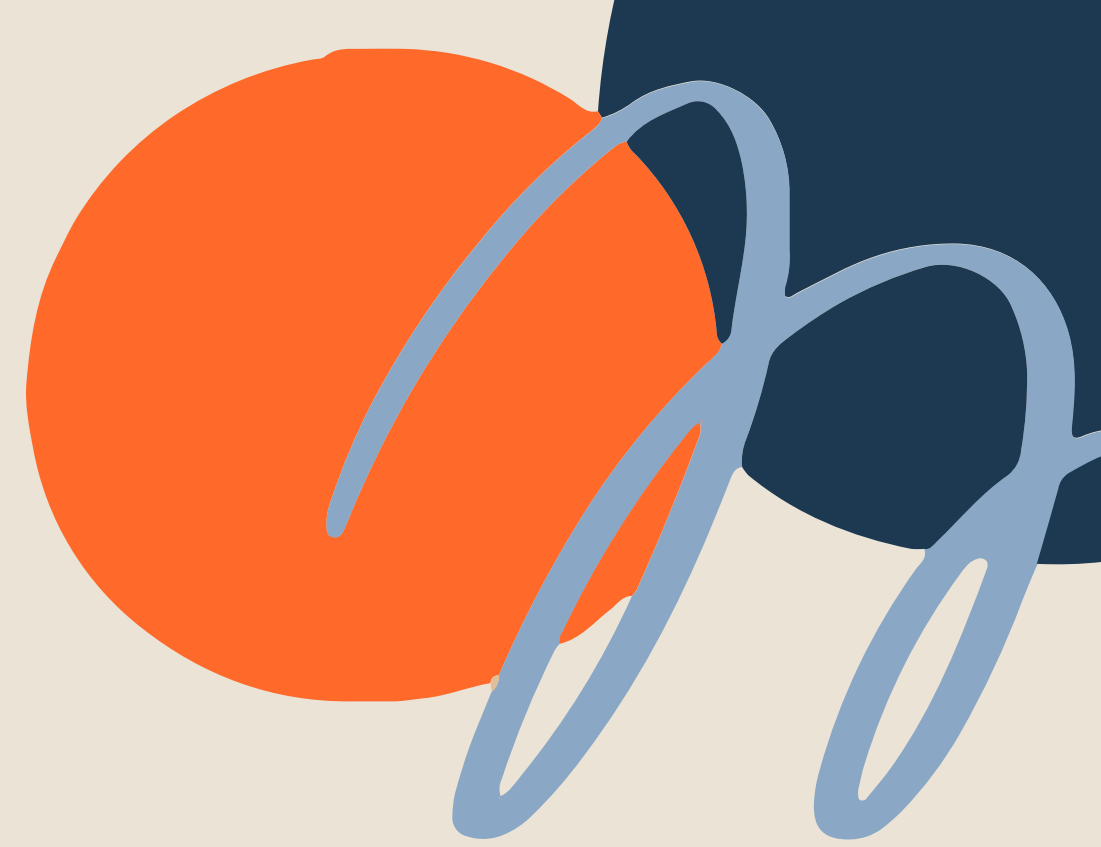
For more information contact cppain@iwk.nshealth.ca

This study received approval from the IWK Health Centre Research Ethics Board

Centre
for Pediatric
Pain Research
SCIENCE HELPING
CHILDREN




RECRUITING CAREGIVERS OF PATIENTS IN THE IWK KIDS REHAB




Our research study is looking to interview caregivers of children with physical disabilities to understand how disability impacts their risky play behaviours.

Who can participate ?



Caregivers of children aged 8-13 years, who are currently accessing the **IWK Kids Rehab Clinic** and identify with having a **physical disability**.

What you'll be asked to do:



Complete a **1-1.5 hour online interview** that will explore **family demographics** and your child's **risky play experiences**.

If you are interested in participating, please contact:

Maggie Locke
Lead Researcher
mg382955@dal.ca



RESEARCH OPPORTUNITY

If you would like to tell us your experiences, please contact:

Jennifer Lane
jennifer.lane@iwk.nshealth.ca
(902) 470-2634



Are you a youth with complex care needs?

Are you a parent or caregiver to one?

Did you live and seek care in Nova Scotia between March 2020 and March 2022?

We would like to hear your experiences with public health restrictions and service changes during the COVID-19 pandemic.

Meetings will be virtual and last about 30 minutes.



REB File #1028207