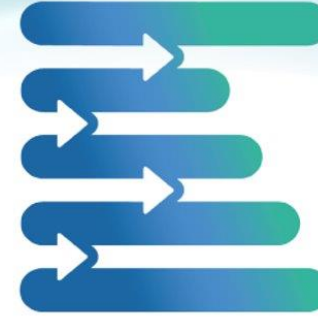




The **Ehlers-Danlos** Society

# 2025 INTERNATIONAL SCIENTIFIC SYMPOSIUM

PATHWAYS TO PROGRESS A Decade of Insights and Innovations in EDS & HSD



## PRESENTATION

# Allied Health Professionals Workshop: Moving Through the Lifespan

## SPEAKER

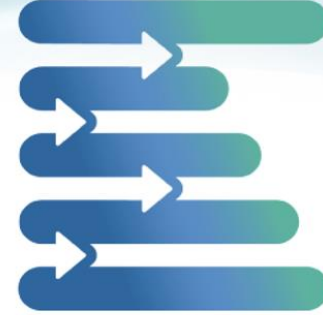
- **11:15-12:45 – Pediatric: Cylie Williams**
  - Assisted by M. Scheper, N. Streekstra, L. Russek, E. Rich, J Di Bon
- **2:00-3:30 – Adolescent/Young Adult: Mark Scheper & Nienke Streekstra**
  - Assisted by C. Williams, L. Russek, E. Rich, J Di Bon
- **4:15-5:45 – Adults over 25: Leslie Russek, Emily Rich & Jeannie Di Bon**
  - Assisted by C. Williams, M. Scheper, N. Streekstra



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# 2025 INTERNATIONAL SCIENTIFIC SYMPOSIUM

PATHWAYS TO PROGRESS A Decade of Insights and Innovations in EDS & HSD



PRESENTATION

## Allied Health Professionals Workshop: Moving Through the Lifespan – (Under 12s)

SPEAKER

**Main speaker: Cylie Williams**

- M Scheper, N Steekstra, L Russek, E Rich, J Di Bon

# Conflict of Interest

All speakers for this workshop have declared that they have no conflicts of interest or financial ownership interests relevant to the content being presented.



# You Might Want to Download...

If you want to actively engage in our technology activity, you might want to download the following onto your smartphone:

- Goose Chase scavenger hunt
- Home court app
- Pokemon

# Objectives:

At the end of this workshop, participants will be able to:

- Promote physical activity in child with EDS/HSD, or child with additional needs to support movement
- Address challenges to movement and function in children
- Highlight innovative tools and strategies to support families engaging in meaningful movement
- Integrate physical, psychosocial, and environmental considerations in physical activity recommendations

**After the workshop, participants will have access to ideas generated by the group on Miro Board**

# Outline of Activities

- Issues affecting children with HSD/EDS (or at risk of)
  - Introduction to Miro Board (participant involvement on Miro Board)
- Maintaining an active lifestyle in children (presentation)
- Obstacles to activity, and strategies for overcoming (Miro)
- Discussion of the group's ideas (presentation viewing Miro)
- Using technology to encourage movement (you can engage in any of the activities or trial some of the simple tech for kids)
  - Tips on using role modeling and tech enhancements
  - Tips and demonstrations on using apps
  - Tips and demonstrations on websites

# Introduction to Miro Board

Scan the QR code with your phone or tablet camera.

Alternatively, open the link in your browser



Use either the Miro app or website to log in and access the board

**SCAN ME**





# Using Miro Board

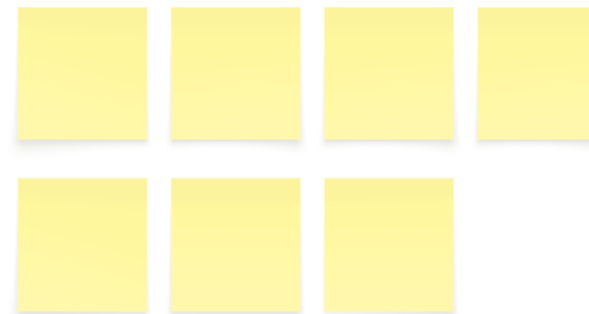
1. Right click and drag to move around the board.
2. Use your mouse wheel or trackpad to zoom in and out.
3. Select a sticky note to edit.  
Click to type directly to add text.
4. Click and hold to drag stickies to reposition them on the board.

## Barriers and enablers for physical activity

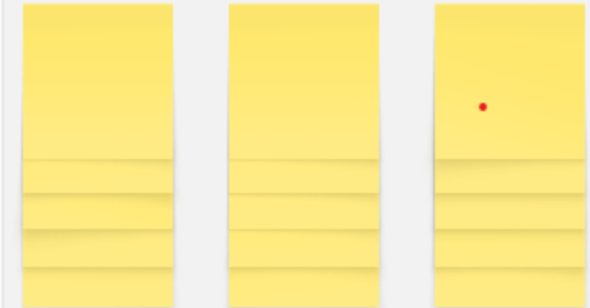
### Barriers



### Enablers



### Spare stickies to add more





# What impacts children's development and ability to achieve (F-Words in Childhood Disability)

## FUNCTIONING

**Functioning:** refers to what people do - how things are done is not what is important

## FAMILY

**Family:** represents the essential 'environment' of all children and youth

## FITNESS

**Fitness:** refers to physical and mental wellbeing

## FUN

**Fun:** includes activities that people enjoy

## FRIENDS

**Friends:** refers to the friendships established with others

## FUTURE





**Future:** is what life is all about



**Take 10 minutes to enter ideas on Miro Board**

<https://canchild.ca/research-in-practice/f-words-in-childhood-disability/>

# Why physical activity important for children

-  **Physical health**
  - Bone and muscle strength, healthy weight, heart and lung fitness, coordination and balance, foundation movement skills = activity of daily living skills
-  **Brain power**
  - Concentration, focus, memory, brain development, behaviour
-  **Mental health**
  - Reduces stress and anxiety, confidence and body image, teamwork, friendships and resilience
-  **Habit forming**
  - Prevents chronic disease, lifelong habits, promotes sleep

## Physical activity, sleep and screen time for young children

Up to 5 years	US <sup>1</sup> (<5 years)	Canada <sup>2</sup> (3-4 years)	UK <sup>3</sup> (<5 years years)	WHO <sup>4</sup> (3-4 years)
<b>Total activity daily</b>	No recommendation – active through the day	180 min in a variety of play of which 60 min is energetic	180 min in a variety of play of which 60 min is energetic	180 min in a variety of play of which 60 min is moderate to vigorous
<b>Sleep</b>	No recommendations	10 to 13 hours of good-quality sleep, which may include a nap, with consistent bedtimes and wake-up times.	No recommendations	10-13 hours of good quality sleep
<b>Sitting/ screen time</b>	No recommendations	Not restrained for >1 hour < 1 hour screen time	< 1 hour screen time	Not restrained for >1 hour < 1 hour screen time



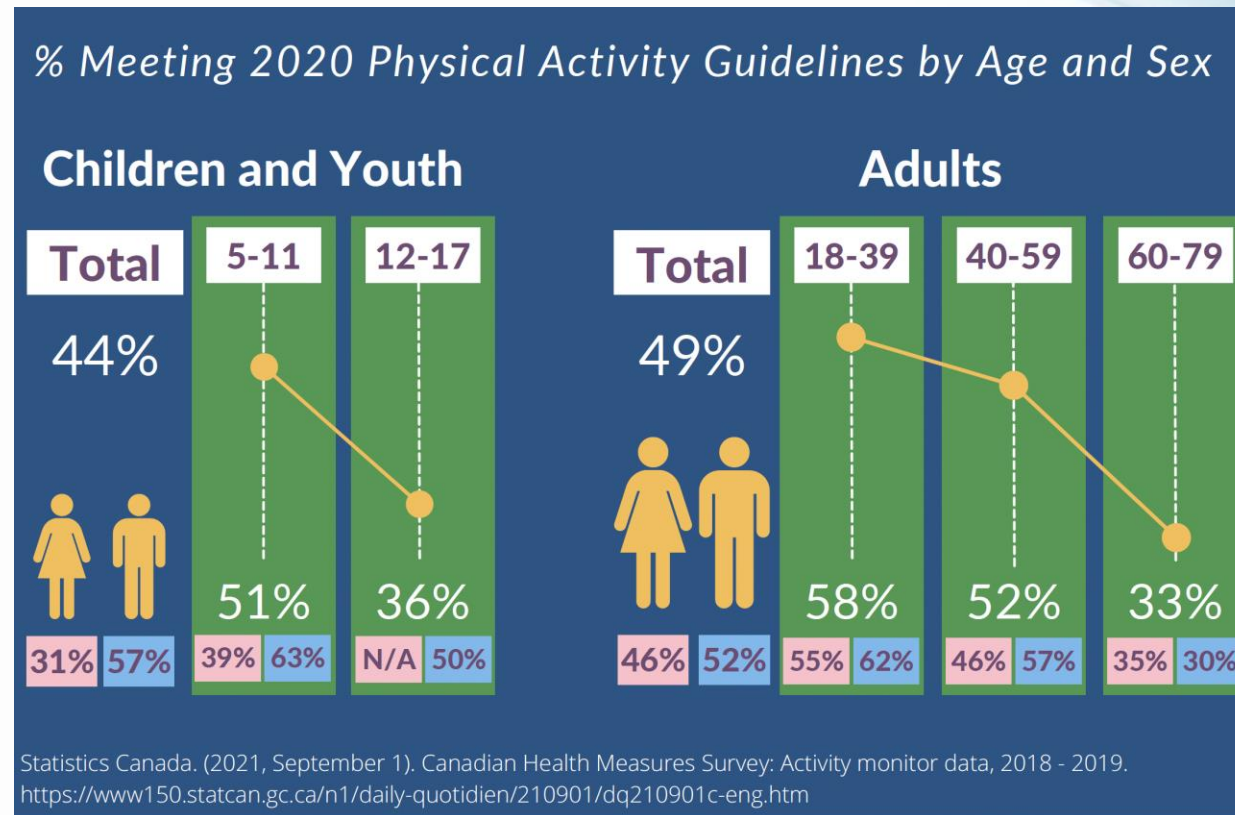
## Physical activity, sleep and screen time for older children

	US <sup>1</sup> (6-17 years)	Canada <sup>2</sup> (5-13 years)	UK <sup>3</sup>	WHO <sup>4</sup>
<b>Total activity daily</b>	60 min moderate or vigorous	60 min moderate or vigorous	Average 60 minutes per day across the week	At least 60 min of moderate to vigorous intensity
<b>Strength</b>	3x/wk	No recommendations	No recommendations	3x/wk
<b>Sleep</b>	No recommendations	Uninterrupted 9 to 11 hours of sleep per night	No recommendations	No recommendations
<b>Screen time/sitting</b>	No recommendations	No more than 2 hours per day of recreational screen time; and limited sitting for extended time	No more than 2 hours, excluding time spent on homework	Minimise sedentary time, limit recreational screen time

# Prevalence of Inactivity, Overall

- Many children do not meet the physical activity guidelines
- Girls have higher rates of inactivity than boys
- Inactivity rates are similar as children age
- Inactivity rates increase in children who have disabilities or chronic conditions, and those living in low or limited resourced countries

Audbert et al, 2021; WHO, 2022;  
 Thornton, 2023



Thornton, 2023



# Enablers and challenges to physical activity in childhood

- Use Miro Board, posting in the section for your group
- Post each idea once per group (e.g., have a designated person or coordinate postings in another way)
- Group your ideas as seems appropriate
- **QUESTIONS**
  1. What are the Obstacles to activity, movement, exercise specific to adults (over 25 years)?
  2. What are some Strategies for overcoming these obstacles?

**You have ~20 minutes for this activity**





# Review of Obstacles/Strategies

- 1. What are the Obstacles to activity, movement, exercise specific to children (12 and under)?**
- 2. What are some Strategies for overcoming these obstacles?**

# Benefits of using tech to support physical activity for children

- Novelty and fun
- Increase digital literacy
- Motivation and feedback
- Inspiration for busy families
- Increases motivation for outdoors

Force DH, Canadian Paediatric Society. Screen time and young children: Promoting health and development in a digital world. Paediatrics & Child Health. 2017 Oct 9;22(8):461.

# Strategies using tech to engage in physical activities

Role modelling strategies and enablers	Apps (Lists to trial)	Websites (list to trial)
Pictures of trying something new	Home court app	Kids Sworkit
Videoing skill to watch and refine	Pokemon Go	Go Noodle
Walking trails	Geocache app	Cosmic Yoga
Tips from Bluey and Friends	Walking trail apps	Body Coach TV
Podcast – Lets Pretend	Goose chase scavenger hunt Join code: E42M9C	
Yoto		



- **Role modelling strategies and enablers**
  - Ideal for <6's
  - Minimises tech interactivity
  - Tech becomes the enabler and component, but not the driver

# Apps

- Ideal for parents of children 6 and older
- Parent remains in control with gradual release
- Flex between tablets and smart phones

# Online/TV

- Limited for 3-6, ideal for 6 and old.
- Interactivity with Smart TVs, computer, smartphone or tablet
- May be impacted (positively?) by age limits on Youtube
- May or may not be subscriptions



# Download the PDF

- Choose from:
  - Role modelling (Cylie)
  - Apps – choose from (opt in):
    - Goose chase scavenger hunt - Join code: E42M9C
    - Homecourt (Mark)
    - Pokemon (if you join...team Red and see me about a trainer code)
  - Go Noodle (Leslie/Emily)



# Summary

- Children's physical activity requirements change over time with age, developmental stage, and skill
- Children and families require variable support to engage in physical activity
- Technology should enable with minimise screen time
- Collaborative goal setting aligning with family interests is a substantial enabler
- Handouts and summaries will be uploaded to Whoova



# Thank you for your attention