





Mental health in adolescents and young adults with cerebral palsy

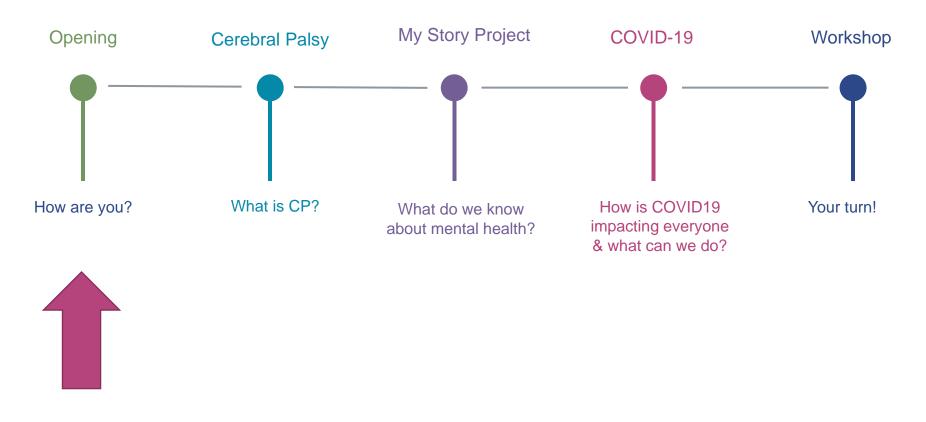
Jan Willem Gorter

Scotiabank Chair in Child Health Research, McMaster University

Executive member CP-NET



Welcome to the Workshop!



Go Green for Cerebral Palsy & Mental Health



Cerebral Palsy Awareness



How are you?

I. Take a deep breath

2. Listen to your inner self

3. How do you feel? What do you think? What did you do?

If you are in crisis

- If you are in immediate danger or need urgent medical support, call 911.
- You may also access support workers, social workers, psychologists and other professionals for confidential chat sessions or phone calls by texting WELLNESS to:
 - 686868 for youth
 - 741741 for adults

■ The Wellness Together Canada portal for mental wellness and substance use issues also offers a wide range of resources and support for Canadians.

https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/mental-health.html

Struggles

- Emotional (how you feel)
 - psychological functioning
 - general behaviour and coping skills

- Social (how you behave)
 - social skills and behaviours

Cognitive (how you think)

- difficulties with problem-solving
- decision making
- general cognitive functioning needed to complete self-care activities

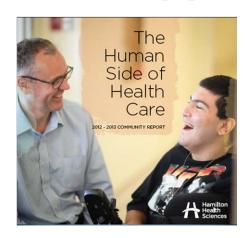
- Physical (how you body works)
 - physical symptoms, e.g. fatigue

Growing up is hard to do

NOUR

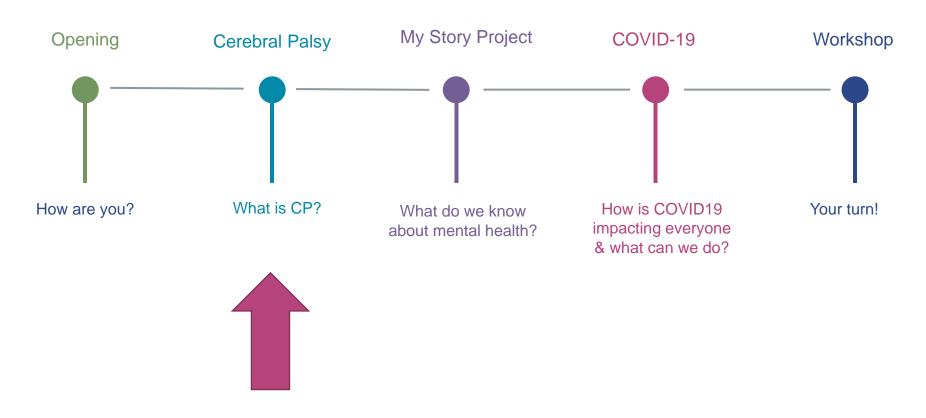
For some, it's even harder than for others.

By various reports 5-30% of children in US have special needs, chronic illness or disability. (Bloom et al, Journal of Adolescent Health. 2012;51:213–219)



VIDEO: https://youtu.be/Sv5_c0EaAhE

Welcome to the Workshop!



How do we define Cerebral Palsy?

- Cerebral palsy describes:
- a group of developmental disorders of movement and posture,
- causing activity restriction or disability,
- that are attributed to disturbances occuring in the fetal or infant brain.



Brain development during gestation and first weeks after birth

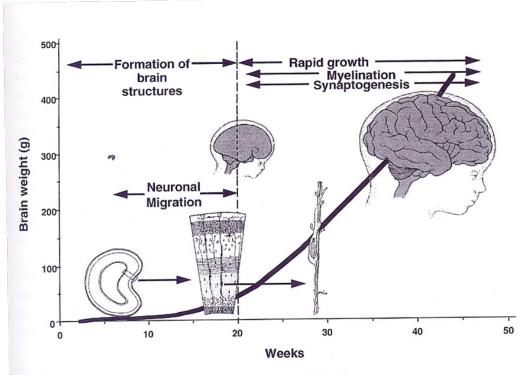
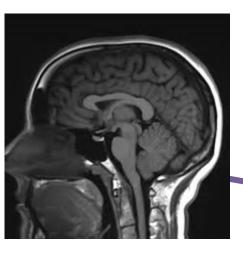
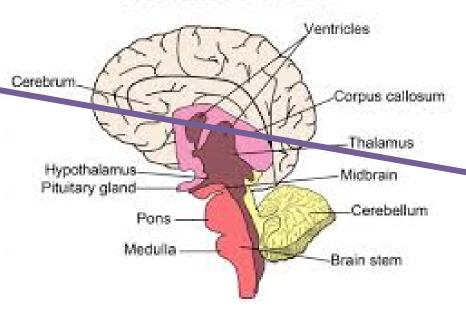


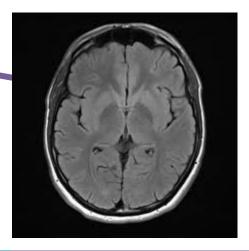
Fig. 6.1. Brain development during gestation and early postnatal life. (Illustration by courtesy of M. Squiers.)

The Brain – MRI scan

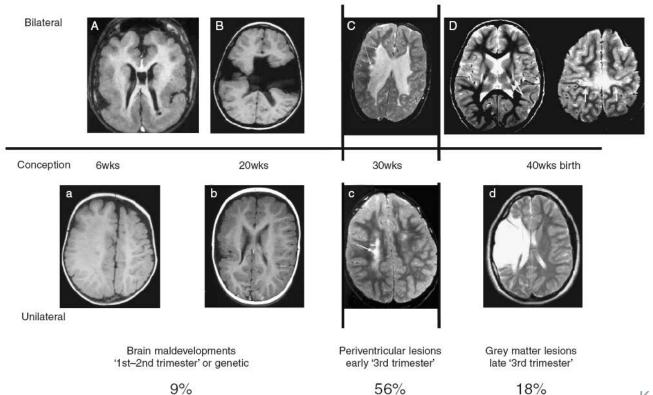


HUMAN BRAIN

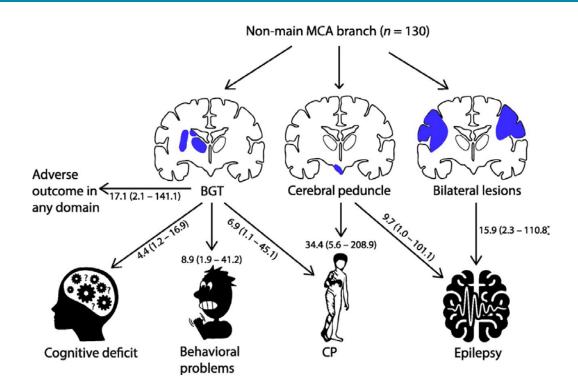




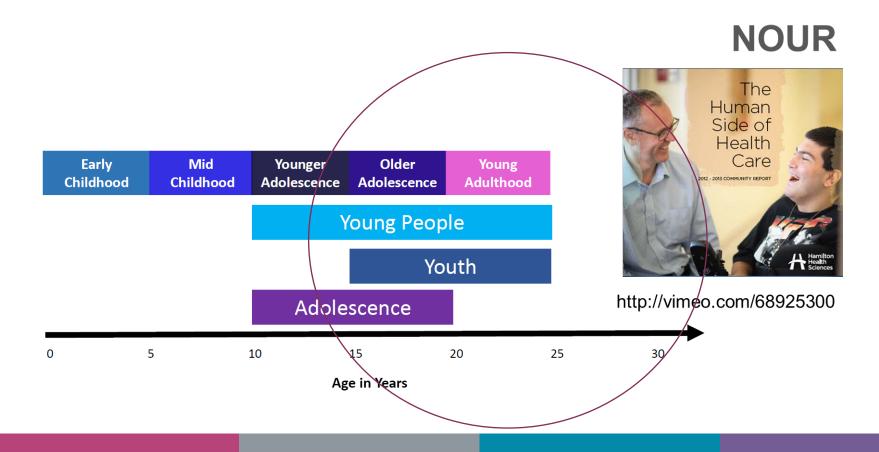
Injury of the brain before, during or after birth



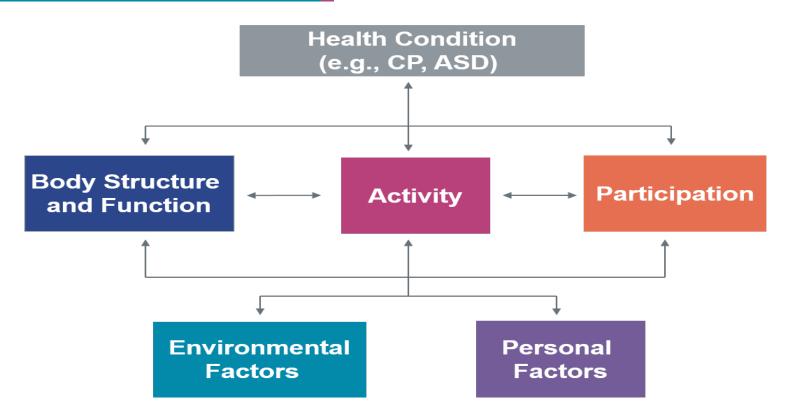
Type of CP and symptoms depend on site, extent and location of the lesion (Here in full term infants with perinatal stroke)



Growing up with CP



Clinical presentation



Background

 Many children with Cerebral Palsy (CP) are challenged in preparing their best possible futures

 Parents of children with CP desire information about their child's functional prognosis of mobility and self-care capabilities

Bailes AF, Gannotti M, Bellows DM, Shusterman M, Lyman J, Horn SD. Caregiver knowledge and preferences for gross motor function information in cerebral palsy. Dev Med Child Neurol 2018; 60: 1264–70

Results – mobility

100-PED FFSS mobility Level III Level IV PEDI-FSS mobility Age (years) Level V 100 PED FFSS mobility Age (years)

Level II

Figure 1: Observed and modelled PEDI-FSS mobility scores for each GMFCS level GMGCS=Gross Motor Function Classification System. PEDI-FSS=Pediatric Evaluation of Disability Inventory-Functional Skills Scale.

Level I

Smits et al. Lancet Child Adolesc Health 2019

Results – Self-care

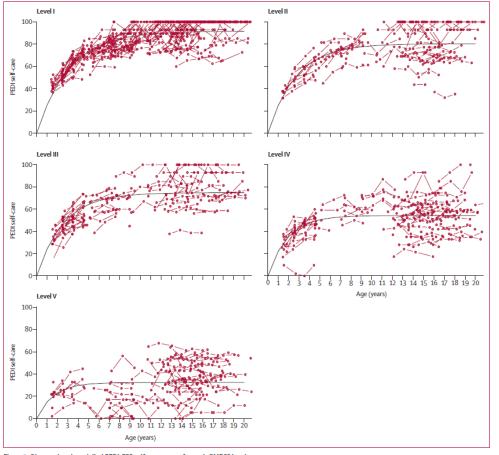


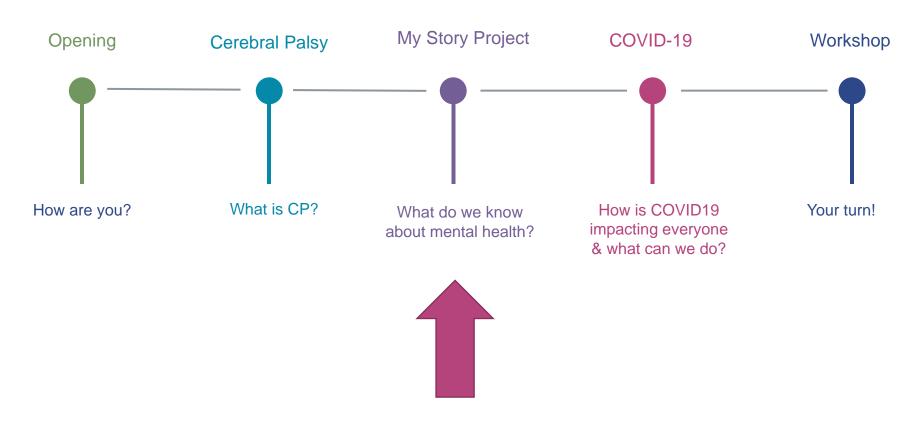
Figure 2: Observed and modelled PEDI-FSS self-care scores for each GMFCS level
GMGCS=Gross Motor Function Classification System. PEDI-FSS=Pediatric Evaluation of Disability Inventory-Functional Skills Scale.

Key findings in adults with CP (65 articles, n=28429)

Outcomes Body Function	All adults with CP (95% CI)	Adults with CP Without Intellectual Disability
Pain	65.1% (55.1;74.5)	
Fatigue (Fatigue Severity Score)	4.1 (3.8;4.4)	
Outcomes (Activity)		
Ambulatory	57.9% (51.1;64.6)	
Manual ability (little/no limitation)	65.5% (61.2;69.7	
Outcomes (Participation)		
Employed	39.2% (31.5;47.1)	72.6% (58.8;84.5)
Living independently	29.3% (9.0;55.3)	90.0% (83.8;94.9)

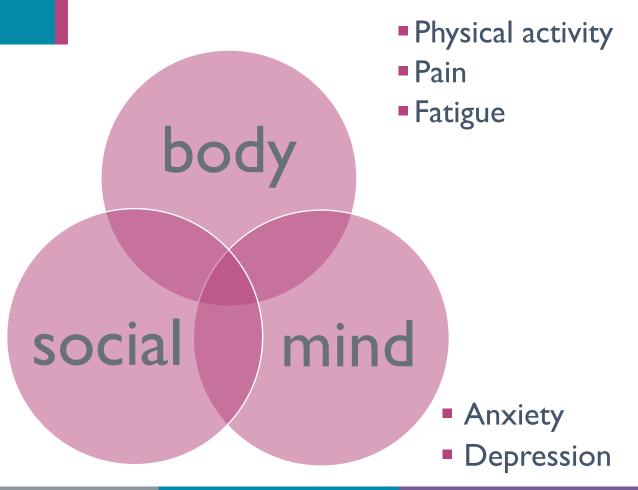
van Gorp M, Hilberink SR, Noten S, Benner JL, Stam HJ, van der Slot WM, Roebroeck ME. The epidemiology of cerebral palsy in adulthood: A systematic review and meta-analysis of the most frequently studied outcomes. Arch Phys Med Rehabil. 2020

Welcome to the Workshop!



Adult Health Outcomes

- Living on your own
- Employment
- Relationships



What do we know about adolescent and young adult mental health & wellbeing of people with CP?

Recent publications (2019)

Original Research

Annals of Internal Medicine

Prevalence of Mental Health Disorders Among Adults With Cerebral Palsy

A Cross-sectional Analysis

Daniel G. Whitney, PhD; Seth A. Warschausky, PhD; Sophia Ng, MPH, PhD; Edward A. Hurvitz, MD; Neil S. Kamdar, MA; and Mark D. Peterson, PhD, MS

Research

JAMA Neurology | Original Investigation

Risk of Depression and Anxiety in Adults With Cerebral Palsy

Kimberley J. Smith, PhD; Mark D. Peterson, PhD; Neil E. O'Connell, PhD; Christina Victor, PhD; Silvia Liverani, PhD; Nana Anokye, PhD; Jennifer M. Ryan, PhD

Adults (8.7 M) incl. 7348 Individuals with CP (mean age 52 years; 49.6% female) in the US (insurance claim database)

Table 2. Age-Standardized Prevalence of Mental Health Disorder Categories for Study Participants

Category	Women			Men			
	CP Alone, % (95% CI)	CP and ND Disorder, % (95% CI)	Without CP, %	CP Alone, % (95% CI)	CP and ND Disorder, % (95% CI)	Without CP, %	
Schizophrenia, schizotypal disorder, delusional,	3.2 (2.5 to 3.9)	7.3 (5.8 to 8.8)	0.6	2.8 (2.2 to 3.4)	6.5 (5.1 to 7.9)	0.7	
and other nonlinood psychotic disorders							
Mood affective disorders	28.6 (26.8 to 30.4)	28.8 (26.1 to 31.5)	14.3	19.5 (18.0 to 21.0)	23.3 (20.9 to 25.7)	8.1	
Anxiety, dissociative, stress-related, somatoform, and other nonpsychotic mental disorders	28.6 (26.8 to 30.4)	29.6 (26.9 to 32.3)	18.0	19.5 (18.0 to 21.0)	21.7 (19.4 to 24.0)	11.1	
disturbances and physical factors	2.0 (1.0 to 2.0)	(0.7 to 2.0)		2.1 (1.0 to 2.11)	2.1 (1.0 to 2.7)		
Disorders of adult personality and behavior	1.2 (0.8 to 1.6)	4.4 (3.2 to 5.6)	0.4	1.2 (0.8 to 1.6)	4.1 (3.0 to 5.2)	0.3	
Alcohol- and/or opioid-related disorders	2.8 (2.2 to 3.4)	2.2 (1.3 to 3.1)	1.8	4.7 (3.9 to 5.5)	2.4 (1.5 to 3.3)	3.0	

CP = cerebral palsy; ND = neurodevelopmental.

Individuals with CP (mean age 33 years; 46.8% female) and matched controles in the UK (primary care data)

Table 2. Incidence of Depression and Anxiety in 1705 Individuals With CP Compared With 5115 Age-, Sex-, and Practice-Matched Controls

		Person-Years	Incidence Per	Unadjusted		Adjusted	
Variable	Events No. (%)	in 1000s	Person-Year (95% CI)	Hazards Ratio (95% CI)	P Value	HR (95% CI) ^a	P Value
Depression							
No CP	867 (17.0)	49.93	0.017 (0.016-0.019)	1 [Reference]	NA	1 [Reference]	NA
СР	312 (18.3)	12.64	0.025 (0.022-0.028)	1.43 (1.24-1.64)	<.001	1.28 (1.09-1.51)	.003
Anxiety							
No CP	697 (13.6)	51.67	0.013 (0.013-0.015)	1 [Reference]	NA	1 [Reference]	NA
СР	261 (15.3)	12.93	0.020 (0.018-0.023)	1.40 (1.21-1.63)	<.001	1.38 (1.15-1.64)	<.001

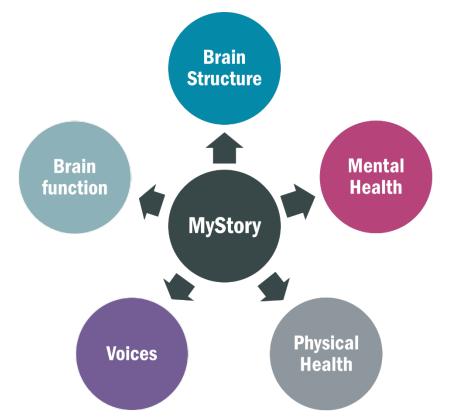
Abbreviations: CP, cerebral palsy; NA, not applicable.

diabetes, heart disease, lung disease, osteoarthritis, epilepsy, pain conditions, and general practitioner visits per year.

^a Adjusted for baseline (ie, predepression or preanxiety diagnosis) diagnosis of









http://cp-net.org







- Adolescents and Young adults with CP
- Age 13-30 years
- Longitudinal design (start in 2013, ongoing)
 - Annual Survey + hair sample (cortisol levels)
- Brain studies:
 - brain activity on MRI -fMRI
 - brain signals EEG/ERP
- Interviews (Qualitative study)



Most brain research for people with Cerebral Palsy (CP) focuses on early brain development. More research is needed to understand how the brain changes through the teenage years and into adulthood.

The MyStory Project will study physical health (fatigue and pain), mental health (anxiety and depression), chronic stress and overall well-being in adolescents and young adults with CP between the ages of 13-30.

Research Study:

If I decide to participate, what will I be asked to do?

Complete surveys and send in a sample of your hair for analysis (from home) A package will be mailed to you with instructions describing how to compete online or paper surveys about your experiences related to anxiety, depression, fatigue, quality of life, pain, family functioning, etc. You will also be provided instructions on how to submit a sample of hair (~50 strands) to McMaster. We are interested to see how these qualities are changing over time. We will ask you to complete the package 4 times (twice in the first year, and then once per year for two years).

You will receive a \$20 gift card for each set of surveys that you complete.





If you are 13-30 years old, have CP, and are interested in participating or if you have questions, please contact the research assistant:

Phone: 905-525-9140 ext. 27854 Email: hopmansn@mcmaster.ca







REB: 13-840, CP-NET Poster, MyStory Phase 3 (Version date: April 11, 2019)

http://cp-net.org





Brain-Behaviour correlates of Health and Well-being in Adolescents and Young Adults with Cerebral Palsy



Dr. Jan Willem Gorter (McMaster)

Dr. Darcy Fehlings (Toronto)

Dr. Mark Ferro (University of Waterloo)

Dr. Geoffrey Hall (McMaster

Dr. Sidney Segalowitz (St. Catharines)

Dr. Anna McCormick(Ottawa)

Dr. Robert Palisano (McMaster/Drexel)

Dr. Peter Rosenbaum (McMaster)

St. Joseph's Healthcare & Harmilton





Post-Docs:

Diana Parvinchi

Christine Lackner

Amanda Green

Staff: Brittany Speller, Dayle McCauley, Sarah Hopmans, Oksana Hlyva, Julia Hanes (medical student)

Anxiety

- We used the State-Trait Anxiety Inventory
- State anxiety items (20) include: "I am tense; I am worried" and "I feel calm; I feel secure."
- Trait anxiety items (20) include: "I worry too much over something that really doesn't matter" and "I am content; I am a steady person."
- Score between 0-160;
- 39-40 and higher is considered as clinical anxiety

In the MyStory project we found:

- average score 35.8 +/- 10.1
- 35% had a score > 39

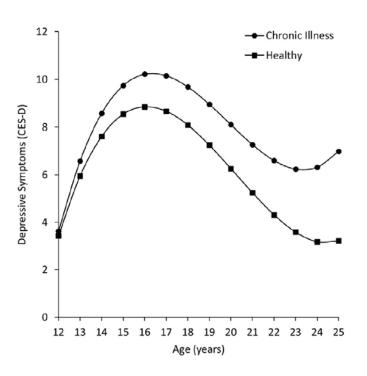
Depression

- We used the CESD-questionnaire (20 questions)
- Symptoms associated with depression, such as restless sleep, poor appetite, and feeling lonely
- Score between 0-60
- 16 and higher is a depression

In the MyStory project we found:

- average score 14.2 +/- 8.4
- 38% had a score > 16

Mental well being



Emerging adulthood is a time when youth are predisposed to the development of elevated symptoms of depression and this relationship is augmented by having a chronic illness.

Ferro et al., Journal of Affective Disorders 174 (2015) 594-601

Received: 3 May 2019

Accepted: 23 June 2019

DOI: 10.1111/cch.12705

RESEARCH ARTICLE

WILEY

Beyond stereotypes of cerebral palsy: Exploring the lived experiences of young Canadians

Hanes et al, Child Care Health Dev 2019 (Open access)

Methods



Semi-structured interview protocol ->participants could discuss issues that were important and meaningful to them

2 facilitators with CP

In community settings

Participants



- Purposive sampling
 16 participants (7 female and 9 male) + 1 father proxy
- Age range: 17-29 years; Mean=26, SD=3.0

GMFCS levels: I- V

Residence: 69% live in bigger metropolitan areas

Education: 56% completed or work on their university degrees

Who am I, when managing mental health



When it comes to mental health, there is a huge stigma... especially for men...gender roles... play a bit into that. (age 24)

Anxiety is a big thing for me.... I am caring for my [ill] mum... and I've been trying to take care of myself... There have been times when I was very stressed out and I didn't really know where I was going to turn... Whatever services I went out to get I was either under- or over-qualified because... I didn't have a mental health diagnosis but I was barely physically disabled. So for about 5 months I was homeless... couch surfing... (age 26; GMFCS I)

Hanes et al, Child Care Health Dev 2019 https://onlinelibrary.wiley.com/doi/full/10.1111/cch.12705

Psychological factors (1)

Identity formation

"I don't let CP be my main identifier and I want to be identified as a person, not as someone with a disability."

(age 27; GMFCS III)



Psychological factors (2)

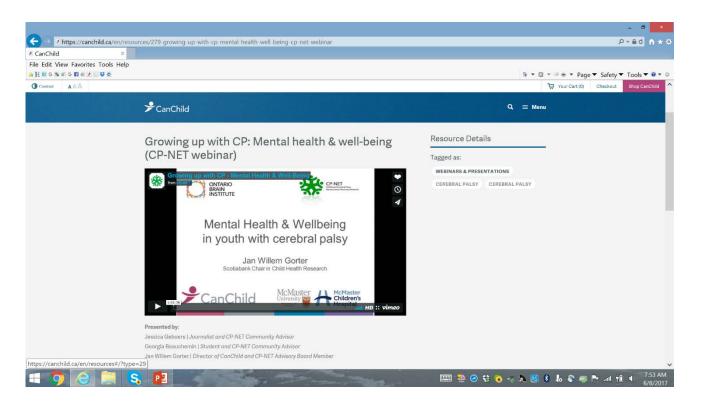
Identity formation

"When you have to explain to someone who doesn't have a disability or depression or mental health challenges, like I have both, and put it in language that that "everybody understands" it becomes less authentically about your own experience. And this drives me nuts"

Kathy (age 24; GMFCS IV)



CP-Net Webinar



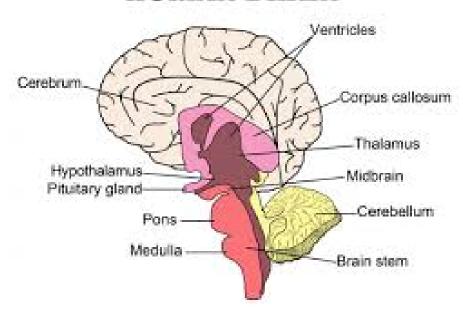
https://canchild.ca/en/resources/279-growing-up-with-cp-mental-health-well-being-cp-net-webinar

How can we help?



The Brain

HUMAN BRAIN



Struggles in CP

- Emotional (how you feel)
 - psychological functioning
 - general behaviour and coping skills

- Social (how you behave)
 - social skills and behaviours

Cognitive (how you think)

- difficulties with problem-solving
- decision making
- general cognitive functioning needed to complete self-care activities

- Physical (how you body works)
 - physical symptoms, e.g. fatigue

Proof-of-Concept EEG study in adults with CP

- ERP research is largely non-existent in CP (muscle spasticity; EEG sensitivity)
- The goals of our research were to:
 - see whether the participants can perform the tasks of the protocol
 - validate the use of our ERP methodologies in adolescents and young adults with CP.

Lackner, Segalowitz & Gorter et al, Cognitive Electrophysiology in Young Adults with Cerebral Palsy: A Proof of Concept Study, Under Review, 2020

Protocol

- Participants (10) performed several kinds of computer tasks:
 - some that are known to activate <u>primary visual</u> <u>processing regions</u>
 - some that are known to recruit <u>prefrontal regions</u> (e.g., selective attention, and context switching tasks)

Lackner, Segalowitz & Gorter et al, Cognitive Electrophysiology in Young Adults with Cerebral Palsy: A Proof of Concept Study, Under Review, 2020

Promising results

We were able to get a good signal

We were able to replicate several traditional ERP effects

 These developments mark a large step forward in ERP research in people with cerebral palsy

fMRI – Feasibility study

We aimed to answer the following questions:

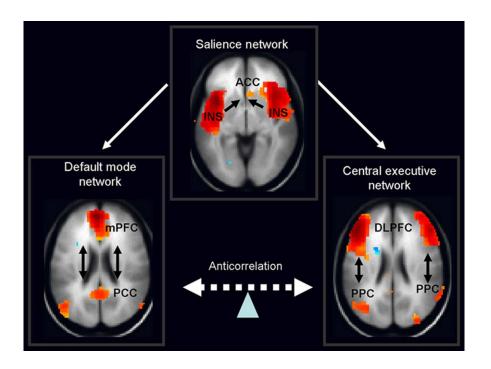
- I) Will it be feasible to scan and obtain good quality resting state functional connectivity data in young adults with CP without sedation
 - Note that the fMRI scanning protocol requires to ly down straight and remaining still in a scanner for some time
- 2) Examine the connectivity pattern(s) that may be associated with depressive mood ratings, indices of pain and fatigue, and general wellbeing in this population.





Parvinchi, Hall, Gorter et al. Under review 2020

Three large-scale brain networks:



During typical development (6-31 years) the three networks show greater density and functional segregation from other networks (Fair et al., 2007).

Findings (I)

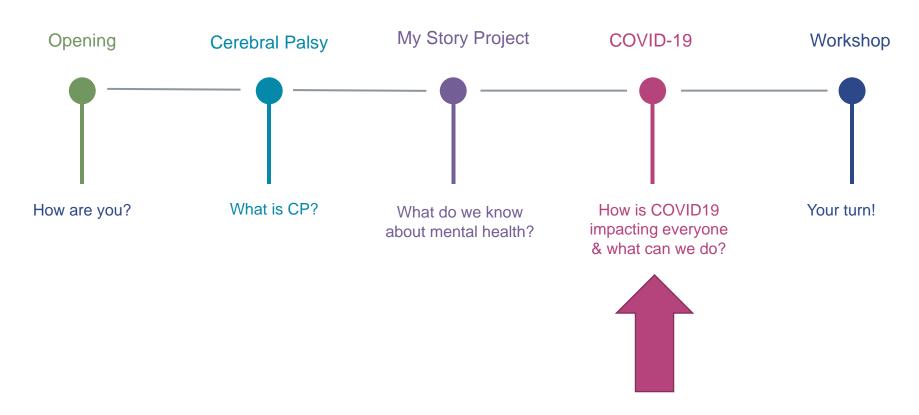
The functional connectivity networks of interest were successfully identified in the data using standard seed regions defined previously in the literature

We found a relationship between the networks and well-being.

Recap of my presentation

- Emerging evidence about mental health issues in adults with cerebral palsy
 - Large population based datasets
 - Clinical cohort studies
 - Lived experience of young people with cerebral palsy
- Brain function and neural networks can be assessed in adolescents and adults with cerebral palsy
- Future studies are needed to
 - explore the relationship between mental health and brain functioning (executive functioning)
 - identify people at risk for mental health issues
 - and develop interventions to prevent and manage mental health issues.

Welcome to the Workshop!



COVID-19 Fears

There is a concern that children with brain-based developmental disabilities may be more affected by COVID-19 than children without disabilities due to their unique needs and the potential for underlying health conditions that increase the risk of serious complications.

- Families in particular are concerned about:
 - The risks for their children, and
 - The type of support they may receive from the healthcare system during the COVID-19 pandemic.

https://www.child-bright.ca/new-blog/2020/5/15/covid-rapid-review

COVID-19 Facts

 A rapid review of the literature did NOT find information on the prevalence of COVID-19 in children with brain-based developmental disabilities.

RESEARCH BRIEF

Prevalence of COVID-19 amongst

However, little to no information is known regarding the potential impact

underlying conditions. Children with disabilities may have underlying

health conditions that increase their

Concerned with the potential impact

of COVID-19 on children with brain-

based developmental disabilities, the SPOR-funded CHILD-BRIGHT Network commissioned a review of

risk of serious complications from

of the virus on children with

COVID-19

the topic.

children is reportedly low worldwide and its impact on their health mild.







COVID-19 In Children With Brain-Based Developmental Disabilities: A Rapid Review

April 29th 2020

What were the objectives?

We aimed to answer whether children with brain-based developmental disabilities were more likely to be infected by COVID-19 and have complications or poorer outcomes following infection.

How was the review conducted? Current Situation We conducted a two-week rapid review in

We conducted a two-week rapid review in close collaboration with a panel of knowledge users (patients, caregivers, clinicians, decision makers) and leaders from the CHILD-BRIGHT Network.

What did the review find?

We did not find any study that specifically addressed the impact of COVID-19 in children with brain-based developmental disabilities.

Four studies, three from China and one from the United States, reported a total of seven cases of infected children (0 to 12 months) considered at risk of developing a brain-based developmental disability.

Although three of the identified children required pediatric intensive care, symptoms of COVID-19 were generally mild, most patients were discharged from the hospital and no deaths were reported.

What are the implications?

The current available information is not sufficient to inform practice or policymakers in light of the current pandemic situation and its impact on children with brain-based developmental disabilities.

There is an urgent need to further study current available data from public health agencies or health systems to assess impact on vulnerable children.

For more information, please contact: Annie LeBlanc, PhD Annie Leblanc@med.ulaval.ca Annette Mainemer, OT, PhD, FCAHS

Annette.Majnemer@mcgll.ca

Funded by the CHILD-BRIGHT Network and the SPOR Evidence Alliance. Both Networks are supported by the Canadian Institutes of Health Research under Canada's Strategy for Parient-Oriented Research (SPOR) Initiative.



Canadiar Institutes Instituts de recherche of Hostifi Research on samb du Canada.

https://www.child-bright.ca/new-blog/2020/5/15/covid-rapid-review

COVID-19 Facts

Health Canada Document on Disability, Family and COVID-19 (May 8, 2020)

COVID-19 and people with disabilities in Canada

- Overview
- Protecting people with disabilities from COVID-19
- The healthcare system and COVID-19
- COVID-19 assessment centres
- Special considerations
- Infection prevention and control measures and personal protective equipment
- Educational materials
- Mental health
- COVID-19 disability advisory group (CDAG)
- Acknowledgments

https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/guidance-documents/people-with-disabilities.html

COVID-19 is a time of stress – it is process of balancing

Family Adjustment and Adaptation Response Model (Patterson, 1988)



Belonging to a Community during COVID-19



Adult Cerebral Palsy Hub - Covid-19 Support >

PRIVATE GROUP · 87 MEMBERS

Join Group

About

A group we have set up to support our community through these difficult days of Covid-19. ... **See More**

Private

Only members can see who's in the group and what they post

Visible

Anyone can find this group



https://hbalumninetwork.ca/

Ontario Federation for Cerebral **Palsy**

https://www.ofcp.ca/

http://adultcphub.org/

Research Networks in Canada & COVID-19



CanChild	https://www.canchild.ca/en/resources/my-covid-disability-q
Child-Bright	https://www.child-bright.ca/covid-19-resources
Kids Brain Health Network	https://kidsbrainhealth.ca/

Useful Resources

COVID-19 and people with disabilities in Canada

- La COVID-19 et les personnes en situation de handicap au Canada
- Coronavirus disease (COVID-19): Guidance documents
- Maladie à coronavirus (COVID-19) : Documents d'orientation

 Children with disabilities face health risks, disruption and marginalization under coronavirus

Tips for taking care of yourself

- Stay informed but take breaks from social media and the news.
- Practise physical distancing, but stay socially connected to friends and family through:
 - email
 - phone calls
 - video chats
 - social media
- Practise mindfulness by:
 - stretching
 - meditating
 - taking deep breaths

https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/mental-health.html#_Tips_for_taking

Tips for taking care of yourself

Try to:

- eat healthy meals
- exercise regularly
- get plenty of sleep
- Think about how to use any unexpected flexibility in your daily routine.
- Focus on the positive aspects of your life and things you can control.
- Be kind and compassionate to yourself and others.
- If you can, limit your use of substances. If you do use substances, practise safer use and good hygiene.

https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/mental-health.html# Tips for taking

If you need help you can call:

- your primary health provider
- a registered psychologist
- another mental health provider in your community

You may also find the following contacts helpful.

- Kids Help Phone: Call I-800-668-6868 (toll-free) or text CONNECT to 686868.
 - Available 24 hours a day to Canadians aged 5 to 29 who want confidential and anonymous care from professional counsellors.
 - Download the <u>Always There app</u> for additional support or access the <u>Kids Help Phone website</u>.

Hope for Wellness Help Line

- Call I-855-242-3310 (toll-free) or connect to the <u>online Hope for Wellness chat</u>.
- Available to all Indigenous peoples across Canada who need immediate crisis intervention. Experienced and culturally sensitive help line counsellors can help if you want to talk or are distressed.
- Telephone and online counselling are available in English and French. On request, telephone counselling is also available in Cree, Ojibway and Inuktitut.

Crisis Services Canada

- If you or someone you know is thinking about suicide, call the Canada Suicide Prevention Service at 1-833-456-4566.
- Available to all Canadians seeking support. Visit <u>Crisis Services Canada</u> for the distress centres and crisis organizations nearest you.

https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/mental-health.html#_Tips_for_taking

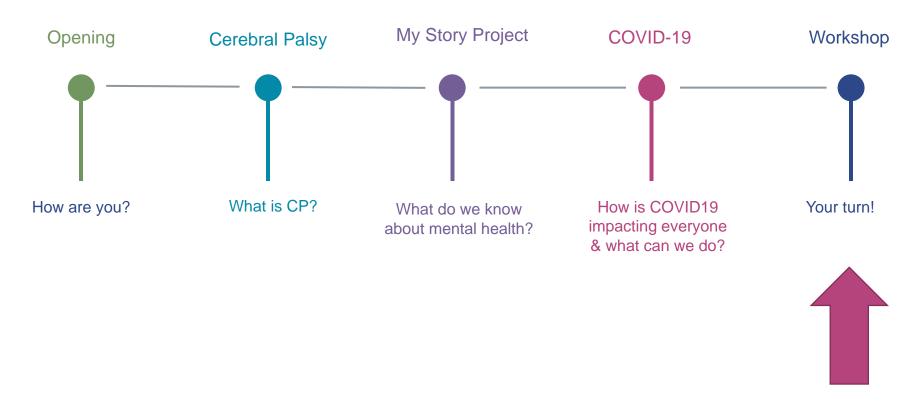
If you are in crisis

- If you are in immediate danger or need urgent medical support, call 911.
- You may also access support workers, social workers, psychologists and other professionals for confidential chat sessions or phone calls by texting WELLNESS to:
 - 686868 for youth
 - 741741 for adults

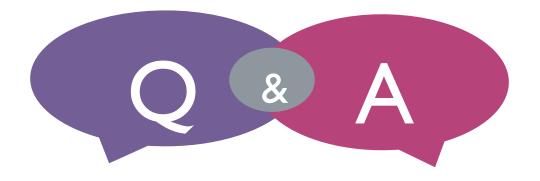
■ The Wellness Together Canada portal for mental wellness and substance use issues also offers a wide range of resources and support for Canadians.

https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/mental-health.html

Welcome to the Workshop!



Q & A Session

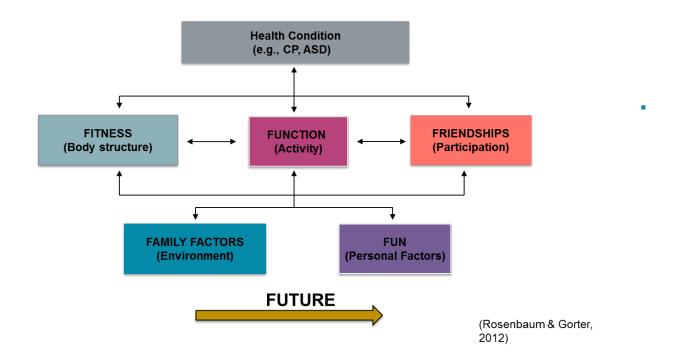


COVID-19 is a time of stress – it is process of balancing

Family Adjustment and Adaptation Response Model (Patterson, 1988)



The F-Words in Childhood Disability



https://onlinelibrary.wiley.com/doi/full/10.1111/j.1365-2214.2011.01338.x

Family and Friends

- Spend time with and take care of your family and friends.
- If it suits you, stay connected with your family and friends by calling, emailing, videoconferencing, or sending cards or letters via post mail.

• • • •

Fitness

- Eat a balanced diet and stay hydrated.
- Do physical activities and stay active.
- Try to sleep well. I Getting a good night's rest can be helpful for your mental health.

• . . .

Function

- Prioritize coping and calming. Try different calming strategies, like relaxation activities or app-based ones
- Go outside, in a safe way.
- Create structure and routine, perhaps around key activities (like sleep/wake routines, daily living ones) to ensure predictability during the day.
- Make schedules flexible to encourage being present in the planned activity.
- . . .

Fun

- Schedule in a nice thing every day, something you can do that puts a smile on your face (e.g., petting a dog, listen to music).
- Play games online with others or alone
- See when screen time is OK.
- Be creative with your time
- Do something sensory pleasing to help regulate emotions
- . . .







Thank you for your participation today!

And remember:

We are all in this together! CP-NET Childhood Cerebral Palsy Discovery Network

