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

www.cp-net.org
Welcome to the Workshop!

Opening

How are you?

Cerebral Palsy

What is CP?

My Story Project

What do we know about mental health?

COVID-19

How is COVID19 impacting everyone & what can we do?

Workshop

Your turn!
Go Green for Cerebral Palsy & Mental Health
How are you?

1. 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.

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

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!

- Opening: How are you?
- Cerebral Palsy: What is CP?
- My Story Project: What do we know about mental health?
- COVID-19: How is COVID-19 impacting everyone & what can we do?
- Workshop: Your turn!
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 occurring in the fetal or infant brain.

Rosenbaum et al, DMCN 2007
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.)
Injury of the brain before, during or after birth

Bilateral

Conception 6wks 20wks 30wks 40wks birth

Unilateral

Brain maldevelopments ‘1st–2nd trimester’ or genetic 9%
Periventricular lesions early ‘3rd trimester’ 56%
Grey matter lesions late ‘3rd trimester’ 18%

Krageloh-Mann DMCN 2007
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

Health Condition (e.g., CP, ASD)

Body Structure and Function

Activity

Participation

Environmental Factors

Personal Factors

World Health Organization, 2011
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

Smits et al. Lancet Child Adolesc Health 2019
Results – Self-care

Figure 2: Observed and modelled PEDIS-FSS self-care scores for each GMFCS level

Smits et al. Lancet Child Adolesc Health 2019
### Key findings in adults with CP (65 articles, n=28429)

<table>
<thead>
<tr>
<th>Outcomes Body Function</th>
<th>All adults with CP (95% CI)</th>
<th>Adults with CP Without Intellectual Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>65.1% (55.1;74.5)</td>
<td></td>
</tr>
<tr>
<td>Fatigue (Fatigue Severity Score)</td>
<td>4.1 (3.8;4.4)</td>
<td></td>
</tr>
</tbody>
</table>

#### Outcomes (Activity)

<table>
<thead>
<tr>
<th>Activity</th>
<th>All adults with CP (95% CI)</th>
<th>Adults with CP Without Intellectual Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ambulatory</td>
<td>57.9% (51.1;64.6)</td>
<td></td>
</tr>
<tr>
<td>Manual ability (little/no limitation)</td>
<td>65.5% (61.2;69.7)</td>
<td></td>
</tr>
</tbody>
</table>

#### Outcomes (Participation)

<table>
<thead>
<tr>
<th>Participation</th>
<th>All adults with CP (95% CI)</th>
<th>Adults with CP Without Intellectual Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>39.2% (31.5;47.1)</td>
<td>72.6% (58.8;84.5)</td>
</tr>
<tr>
<td>Living independently</td>
<td>29.3% (9.0;55.3)</td>
<td>90.0% (83.8;94.9)</td>
</tr>
</tbody>
</table>

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Your turn!
Adult Health Outcomes

- Living on your own
- Employment
- Relationships

Body

- Physical activity
- Pain
- Fatigue

Social

- Anxiety
- Depression

Mind
What do we know about adolescent and young adult mental health & wellbeing of people with CP?
Recent publications (2019)

Original Research

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

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>
<thead>
<tr>
<th>Category</th>
<th>Women CP Alone, % (95% CI)</th>
<th>Women CP and ND Disorder, % (95% CI)</th>
<th>Women Without CP, %</th>
<th>Men CP Alone, % (95% CI)</th>
<th>Men CP and ND Disorder, % (95% CI)</th>
<th>Men Without CP, %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schizophrenia, schizotypal disorder, delusional, and other nonaffective psychotic disorders</td>
<td>3.2 (2.5 to 3.9)</td>
<td>7.3 (5.8 to 8.8)</td>
<td>0.6</td>
<td>2.8 (2.2 to 3.4)</td>
<td>6.5 (5.1 to 7.9)</td>
<td>0.7</td>
</tr>
<tr>
<td>Mood affective disorders</td>
<td>28.6 (26.8 to 30.4)</td>
<td>28.8 (26.1 to 31.5)</td>
<td>14.3</td>
<td>19.5 (18.0 to 21.0)</td>
<td>23.3 (20.9 to 25.7)</td>
<td>8.1</td>
</tr>
<tr>
<td>Anxiety, dissociative, stress-related, somatoform, and other nonaffective psychotic disorders</td>
<td>28.6 (26.8 to 30.4)</td>
<td>29.6 (26.9 to 32.3)</td>
<td>18.0</td>
<td>19.5 (18.0 to 21.0)</td>
<td>21.7 (19.4 to 24.0)</td>
<td>11.1</td>
</tr>
<tr>
<td>Severe disability associated with physiological, psychological, behavioral, and other nonaffective psychiatric and physical factors</td>
<td>1.2 (0.8 to 1.6)</td>
<td>1.2 (0.8 to 1.6)</td>
<td>0.4</td>
<td>1.2 (0.8 to 1.6)</td>
<td>4.1 (3.0 to 5.2)</td>
<td>0.3</td>
</tr>
<tr>
<td>Disorders of adult personality and behavior</td>
<td>2.8 (2.2 to 3.4)</td>
<td>2.2 (1.3 to 3.1)</td>
<td>1.8</td>
<td>4.7 (3.9 to 5.5)</td>
<td>2.4 (1.5 to 3.3)</td>
<td>3.0</td>
</tr>
</tbody>
</table>

CP = cerebral palsy; ND = neurodevelopmental.
Individuals with CP (mean age 33 years; 46.8% female) and matched controls in the UK (primary care data)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Events No. (%)</th>
<th>Person-Years in 1000s</th>
<th>Incidence Per Person-Year (95% CI)</th>
<th>Unadjusted</th>
<th>Adjusted</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Hazards Ratio (95% CI)</td>
<td>P Value</td>
</tr>
<tr>
<td><strong>Depression</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No CP</td>
<td>867 (17.0)</td>
<td>49.93</td>
<td>0.017 (0.016-0.019)</td>
<td>1 [Reference]</td>
<td>NA</td>
</tr>
<tr>
<td>CP</td>
<td>312 (18.3)</td>
<td>12.64</td>
<td>0.025 (0.022-0.028)</td>
<td>1.43 (1.24-1.64)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td><strong>Anxiety</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No CP</td>
<td>697 (13.6)</td>
<td>51.67</td>
<td>0.013 (0.013-0.015)</td>
<td>1 [Reference]</td>
<td>NA</td>
</tr>
<tr>
<td>CP</td>
<td>261 (15.3)</td>
<td>12.93</td>
<td>0.020 (0.018-0.023)</td>
<td>1.40 (1.21-1.63)</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

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

a Adjusted for baseline (ie, predepression or preanxiety diagnosis) diagnosis of diabetes, heart disease, lung disease, osteoarthritis, epilepsy, pain conditions, and general practitioner visits per year.

Smith et al, JAMA Neurology 2019
• 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)
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)

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
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.

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

Julia E. Hanes¹ | Oksana Hlyva¹ | Peter Rosenbaum¹ | Matthew Freeman² | Tram Nguyen¹ | Robert J. Palisano³ | Jan Willem Gorter¹
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
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
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)

Hanes et al, Child Care Health Dev 2019
• 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)
Growing up with CP: Mental health & well-being (CP-NET webinar)

Mental Health & Wellbeing in youth with cerebral palsy

Jan Willem Gorter
Scotiabank Chair in Child Health Research

Presented by:
Jessica Geboers | Journalist and CP-NET Community Advisor
Georgia Reuchemil | Student and CP-NET Community Advisor
Jan Willem Gorter | Director of CanChild and CP-NET Advisory Board Member

How can we help?
The Brain

HUMAN BRAIN

- Cerebrum
- Corpus callosum
- Thalamus
- Midbrain
- Cerebellum
- Pons
- Medulla
- Brain stem
- Hypothalamus
- Pituitary gland
- Ventricles
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
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
Participants (10) performed several kinds of computer tasks:

- some that are known to activate primary visual processing regions
- some that are known to recruit prefrontal regions (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
We aimed to answer the following questions:

1) 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 lie 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 well-being in this population.
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).
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.
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COVID-19

How is COVID19 impacting everyone & what can we do?

Workshop

Your turn!
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


[Website Link]

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

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

Family Adjustment and Adaptation Response Model (Patterson, 1988)

Meanings
Situational, Family identity, Worldview

Demands
Stressors, Strains, Daily hassles

Capabilities
Resources, Coping behaviors

Courtesy: Dr. Jonathan Weiss:  https://asdmentalhealth.blog.yorku.ca/2020/05/supporting-mental-health-of-autistic-individuals-during-covid-times/
Belonging to a Community during COVID-19

Research Networks in Canada & COVID-19

#MyCOVIDDisabilityQ

A collaboration between

CanChild


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

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.

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 1-800-668-6868 (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 [Always There app](#) for additional support or access the [Kids Help Phone website](#).

**Hope for Wellness Help Line**
- Call 1-855-242-3310 (toll-free) or connect to the [online Hope for Wellness chat](#).
- 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 [Crisis Services Canada](#) for the distress centres and crisis organizations nearest you.

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.

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Q & A Session
COVID-19 is a time of stress – it is a process of balancing.

Family Adjustment and Adaptation Response Model (Patterson, 1988)

- **Meanings**: Situational, Family identity, Worldview
- **Demands**: Stressors, Strains, Daily hassles
- **Capabilities**: Resources, Coping behaviors

Courtesy: Dr. Jonathan Weiss: [https://asdmentalhealth.blog.yorku.ca/2020/05/supporting-mental-health-of-autistic-individuals-during-covid-times/](https://asdmentalhealth.blog.yorku.ca/2020/05/supporting-mental-health-of-autistic-individuals-during-covid-times/)
The F-Words in Childhood Disability

- FITNESS (Body structure)
- FUNCTION (Activity)
- FRIENDSHIPS (Participation)
- FAMILY FACTORS (Environment)
- FUN (Personal Factors)
- Health Condition (e.g., CP, ASD)

(Future) (Rosenbaum & Gorter, 2012)

What could you do?

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.
- ...

Courtesy: Dr. Jonathan Weiss:  [https://asdmentalhealth.blog.yorku.ca/2020/05/supporting-mental-health-of-autistic-individuals-during-covid-times/](https://asdmentalhealth.blog.yorku.ca/2020/05/supporting-mental-health-of-autistic-individuals-during-covid-times/)
What could you do?

Fitness

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

Courtesy: Dr. Jonathan Weiss: [https://asdmentalhealth.blog.yorku.ca/2020/05/supporting-mental-health-of-autistic-individuals-during-covid-times/](https://asdmentalhealth.blog.yorku.ca/2020/05/supporting-mental-health-of-autistic-individuals-during-covid-times/)
What could you do?

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.
- …

Courtesy: Dr. Jonathan Weiss: [https://asdmentalhealth.blog.yorku.ca/2020/05/supporting-mental-health-of-autistic-individuals-during-covid-times/](https://asdmentalhealth.blog.yorku.ca/2020/05/supporting-mental-health-of-autistic-individuals-during-covid-times/)
What could you do?

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
- …

Courtesy: Dr. Jonathan Weiss: https://asdmentalhealth.blog.yorku.ca/2020/05/supporting-mental-health-of-autistic-individuals-during-covid-times/
Thank you for your participation today!

And remember: We are all in this together!