



Naar Canadees voorbeeld: samenwerken voor een goede zorg en een betere toekomst voor kinderen met ontwikkelingsbeperkingen en hun gezinnen!

Jan Willem Gorter

Scotiabank Chair in Child Health Research

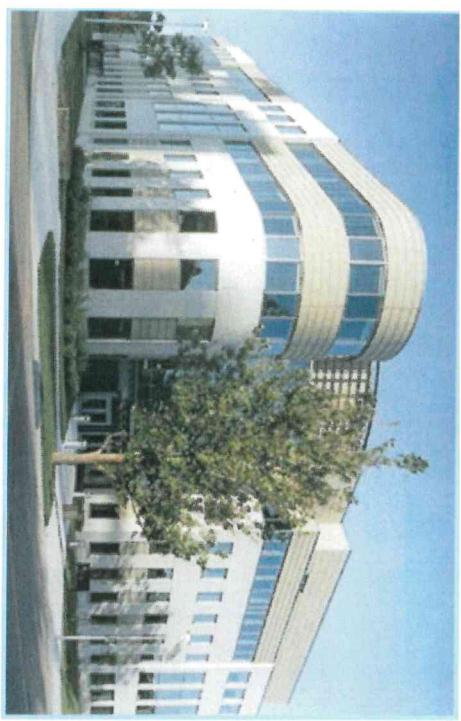
Gasthoogleraar Kinderrevalidatie

JKF
Kinderafondsen

JKF / KFA Congres Rotterdam 9 Maart 2018

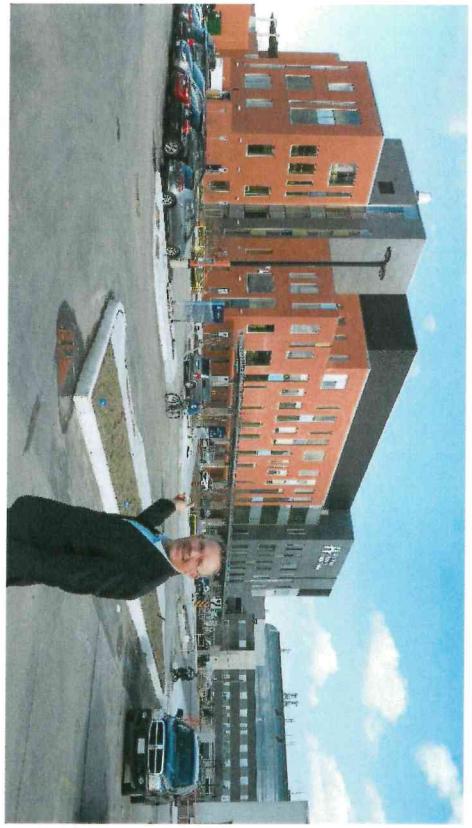
KFA

Kinderrevalidatie Fonds Adriaanstichting

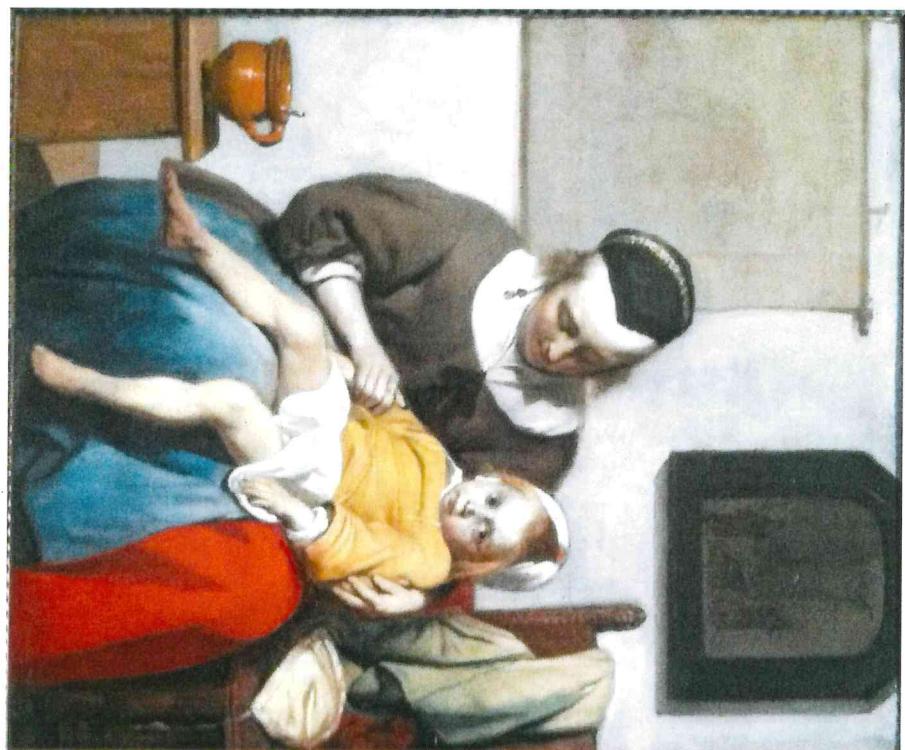


E:gorter@mcmaster.ca

T:TransitionDoctor @Dr_Gorter



Wat brengt u vandaag hier?



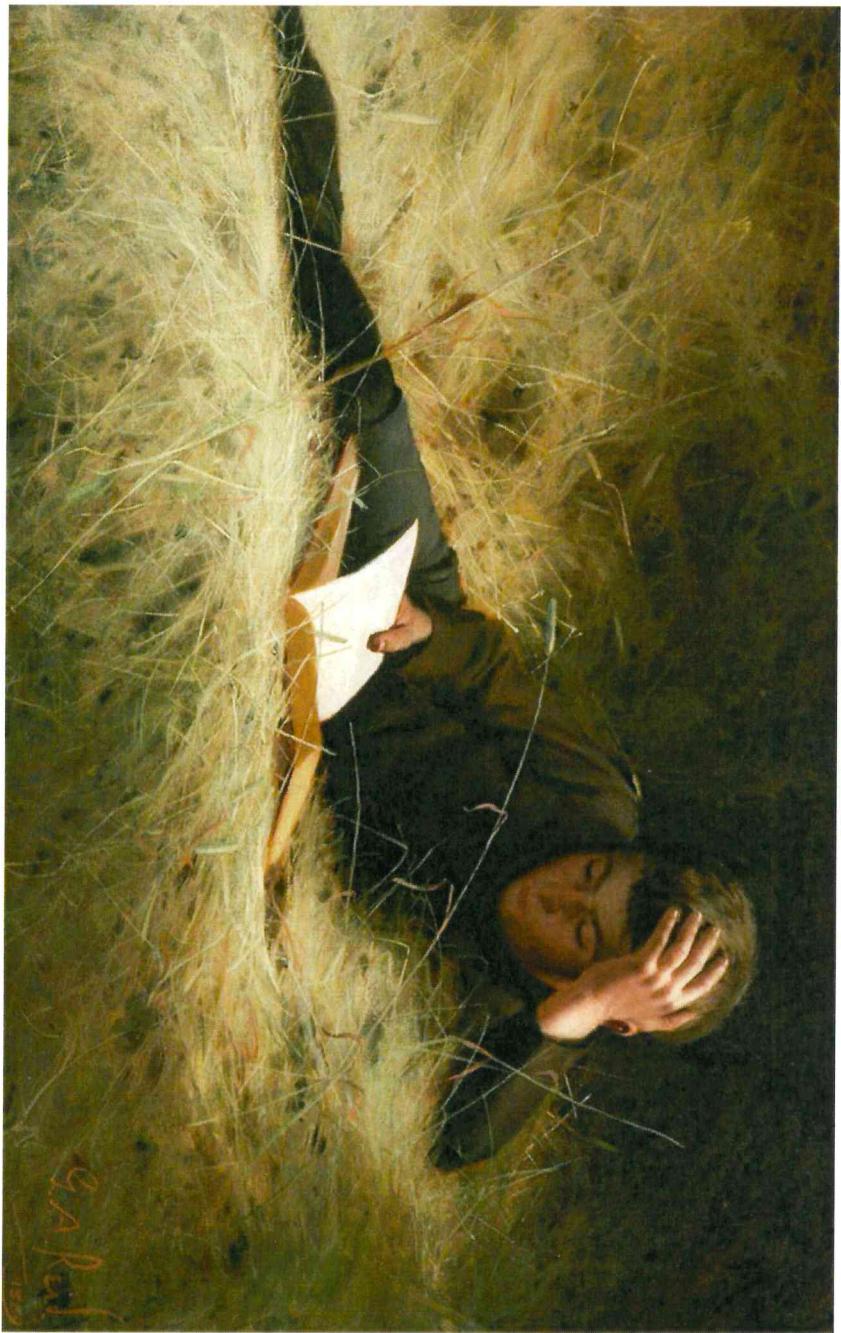
Het zieke kind
Gabriël Metsu, 1660

Wat brengt u vandaag hier?



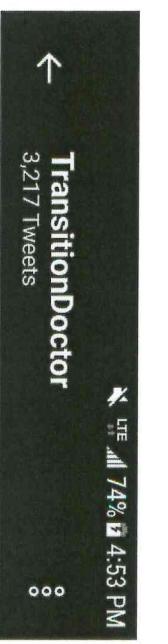
Eerste stapjes
Vincent van Gogh, 1890

Wat brengt u vandaag hier?



Forbidden Fruit,
George Reid, 1889

Ik ben hier om



- 1) Te vertellen wat ik geleerd heb in Canada over samenwerking in onderzoek met als doel goede zorg en een betere toekomst voor kinderen met ontwikkelingsbeperkingen en hun gezinnen
- 2) Te dromen waar we over 5 jaar kunnen staan met samenwerking in de kinderrevalidatie in Nederland
- 3) Te horen wat samenwerken in de kinderrevalidatie voor een ieder betekent



TransitionDoctor @Dr_Gorter · 4d
Excellent editorial with a call for compassion for people living with childhood onset condition over the

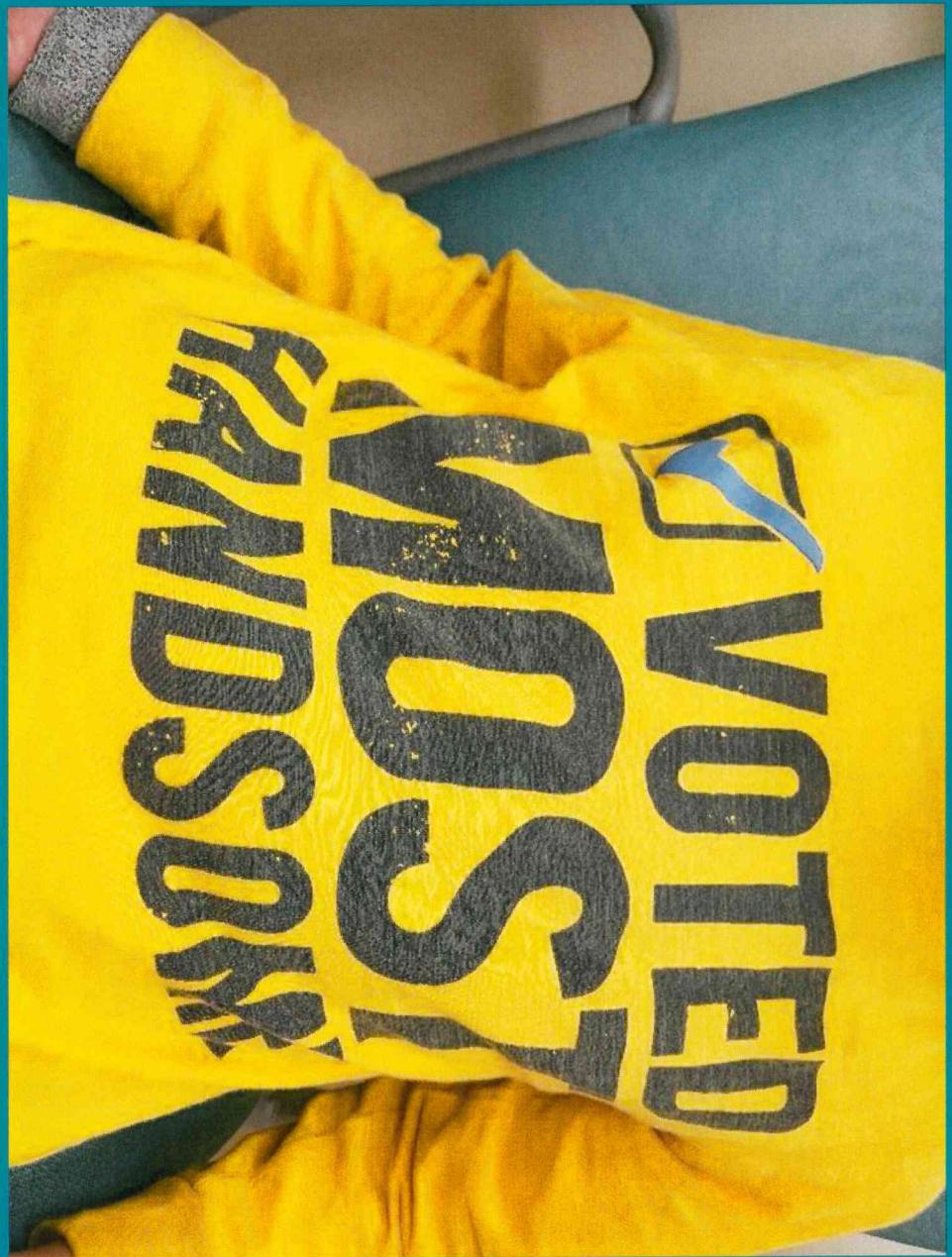
JKF Kinderfonds @JKF_Kinderfonds · 2d
Op 9 maart vindt het JKF/KFA Congres plaats. ...

0 8 8 8 8

JKF Kinderfonds · 2d
Graag ga ik na mijn keynote presentatie in gesprek met de deelnemers van het JKF/KFA congres over de vraag wat samenwerken in de kinderrevalidatie voor een ieder betekent.

JKF Kinderfonds @JKF_Kinderfonds · 2d
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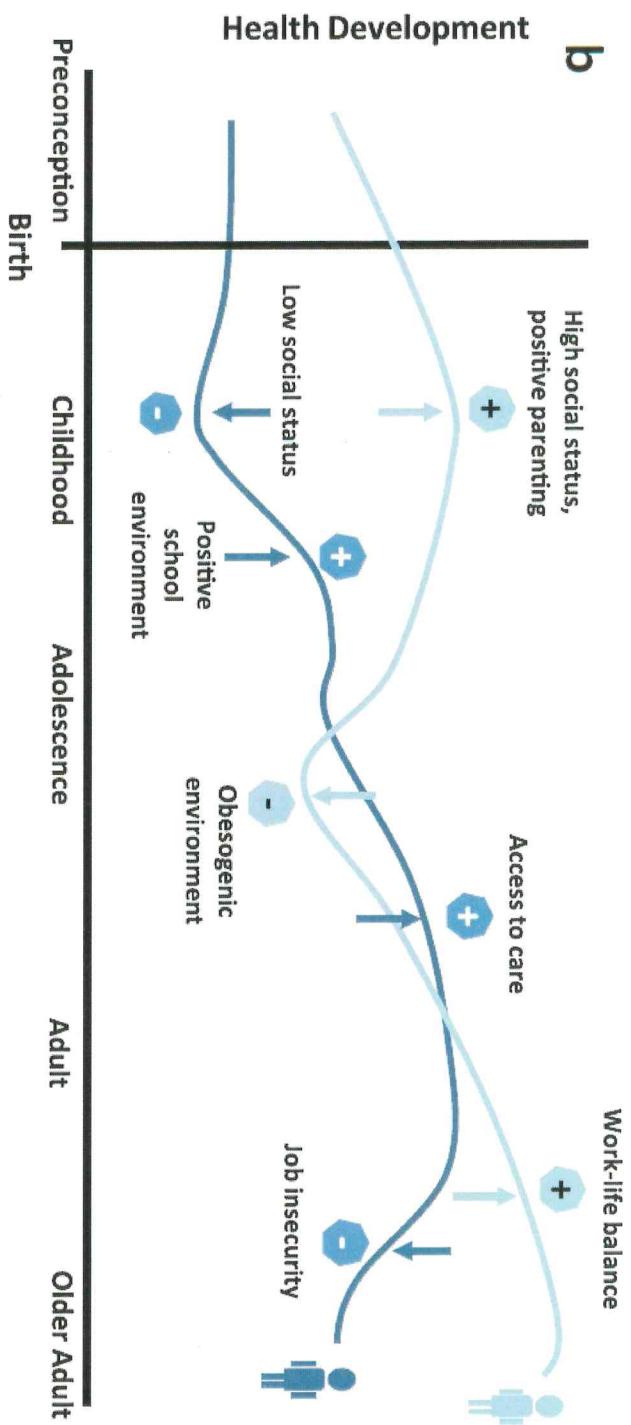
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Kinderrevalidatie - kinderen

- Als kinderen worden geboren met een aandoening of op jonge leeftijd een ziekte of ongeval doormaken dan kan dat leiden tot beperkingen in hun ontwikkeling.
- Vergelijken met leeftijdsgenootjes hebben zij, gemiddeld genomen, minder goede vooruitzichten.
- Uit onderzoek blijkt dat zij als jongvolwassenen kampen met hun gezondheid en belemmerd zijn in hun maatschappelijke participatie, zoals het vinden en behouden van een baan, zelfstandig wonen en het hebben van een partner.

Life Trajectories



Halfon et al. Lifecourse Health Development: Past, Present and Future. Matern Child Health J (2014) 18:344–365; Palisano et al. DMCN 2017

Kinderrevalidatie - ouders

- Voor de ouders, verzorgers en het gezin betekent het zorgen voor een kind met ontwikkelingsbeperkingen vaak een extra belasting, vanaf de babytijd tot ver in de volwassenheid.
- **Zij hebben behoefte aan ondersteuning en goede informatie om de juiste beslissingen voor hun kind, voor hun gezin en voor zichzelf te kunnen nemen.**



Alsem MW,, et al., Child Care Health Dev. 2014; 40:498-506.

Kinderrevalidatie - maatschappij

• De gezondheid en maatschappelijke vraagstukken rondom kinderen met ontwikkelingsbeperkingen en hun gezin zijn vaak complex en niet eenvoudig te beantwoorden.

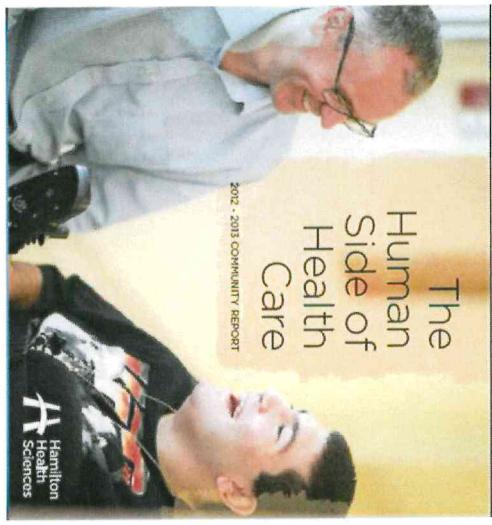
• Om te beginnen hebben we nauwelijks medische behandelingen die echt leiden tot het voorkomen of volledige genezing van de aandoening.



Rosenbaum P & Gorter JW. The 'F-words' in childhood disability: I swear this is how we should think!
Child Care Health Dev. 2012; 38: 457-63.

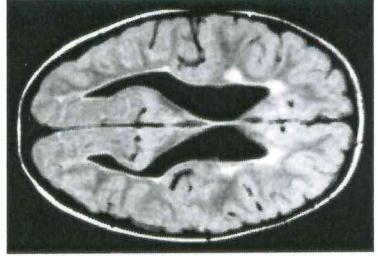
Growing up with CP

NOUR

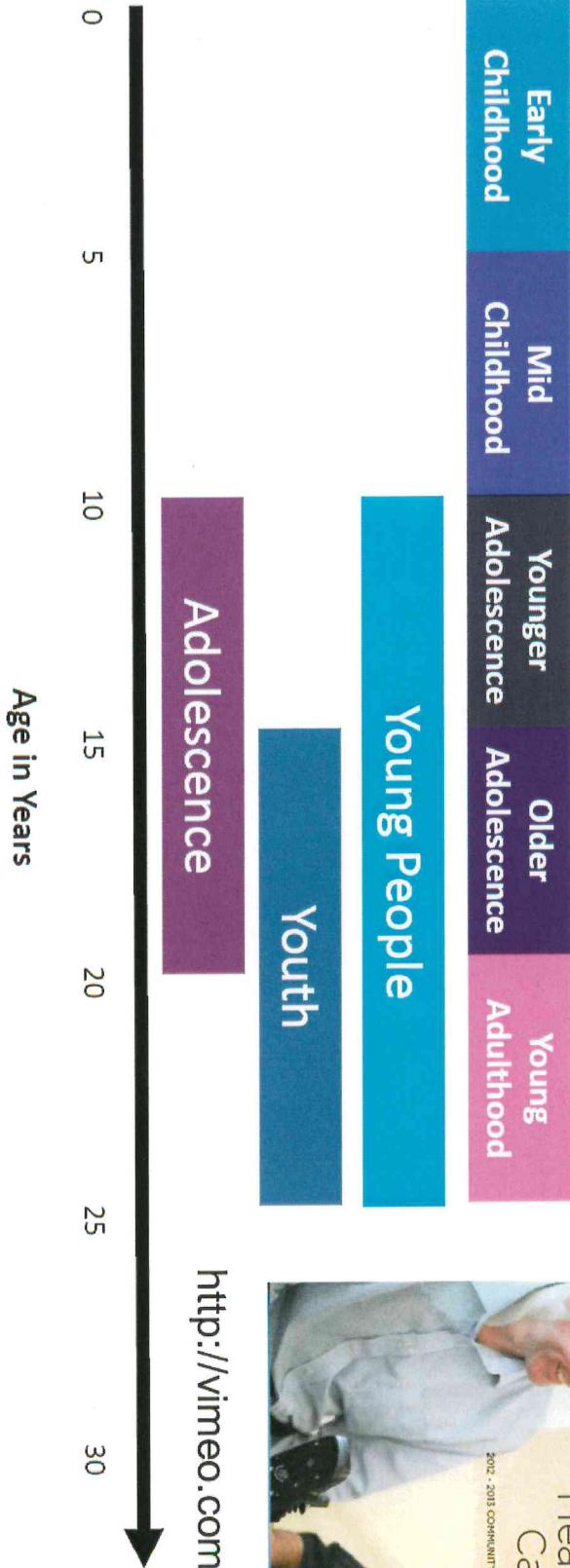


The
Human
Side of
Health
Care

2012 - 2013 COMMUNITY REPORT



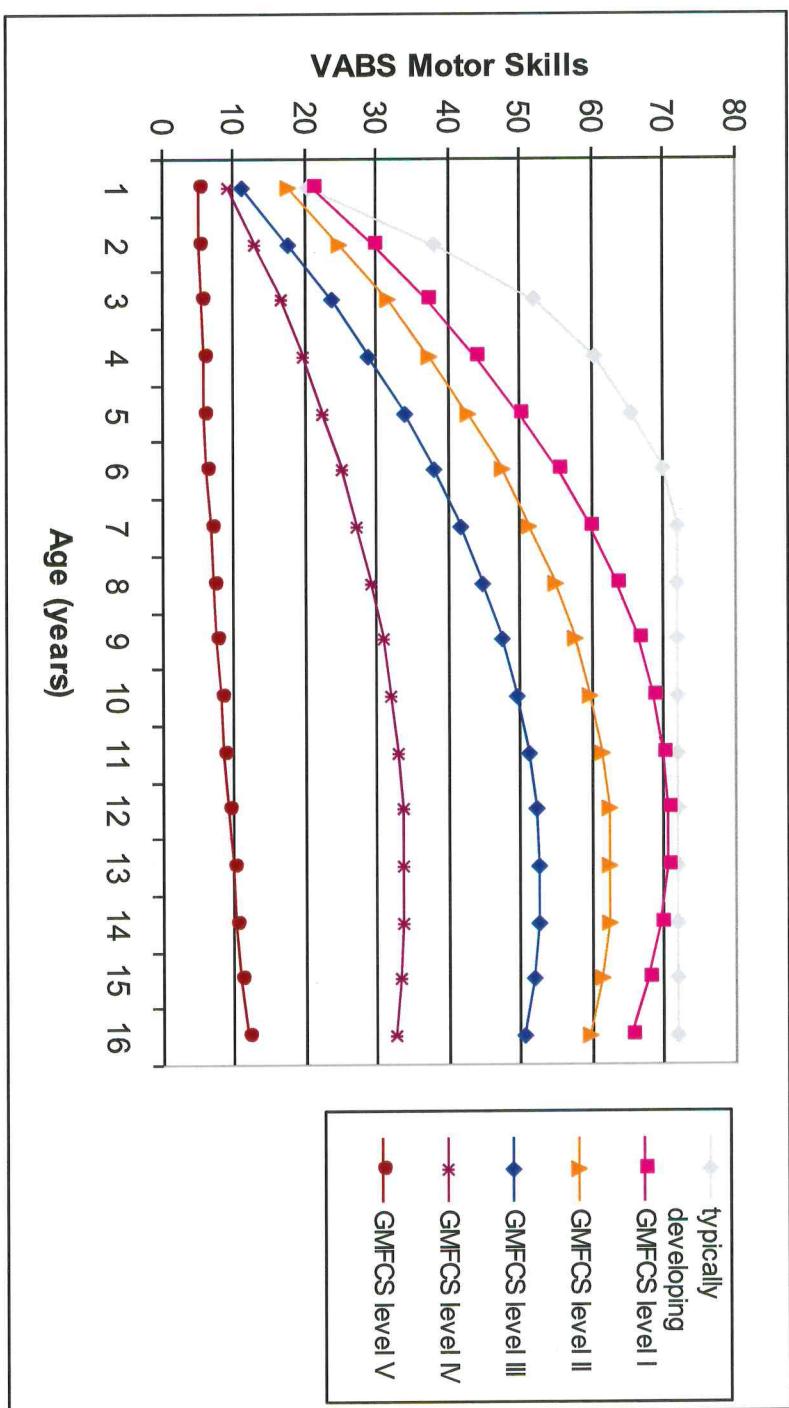
<http://vimeo.com/68925300>



CanChild

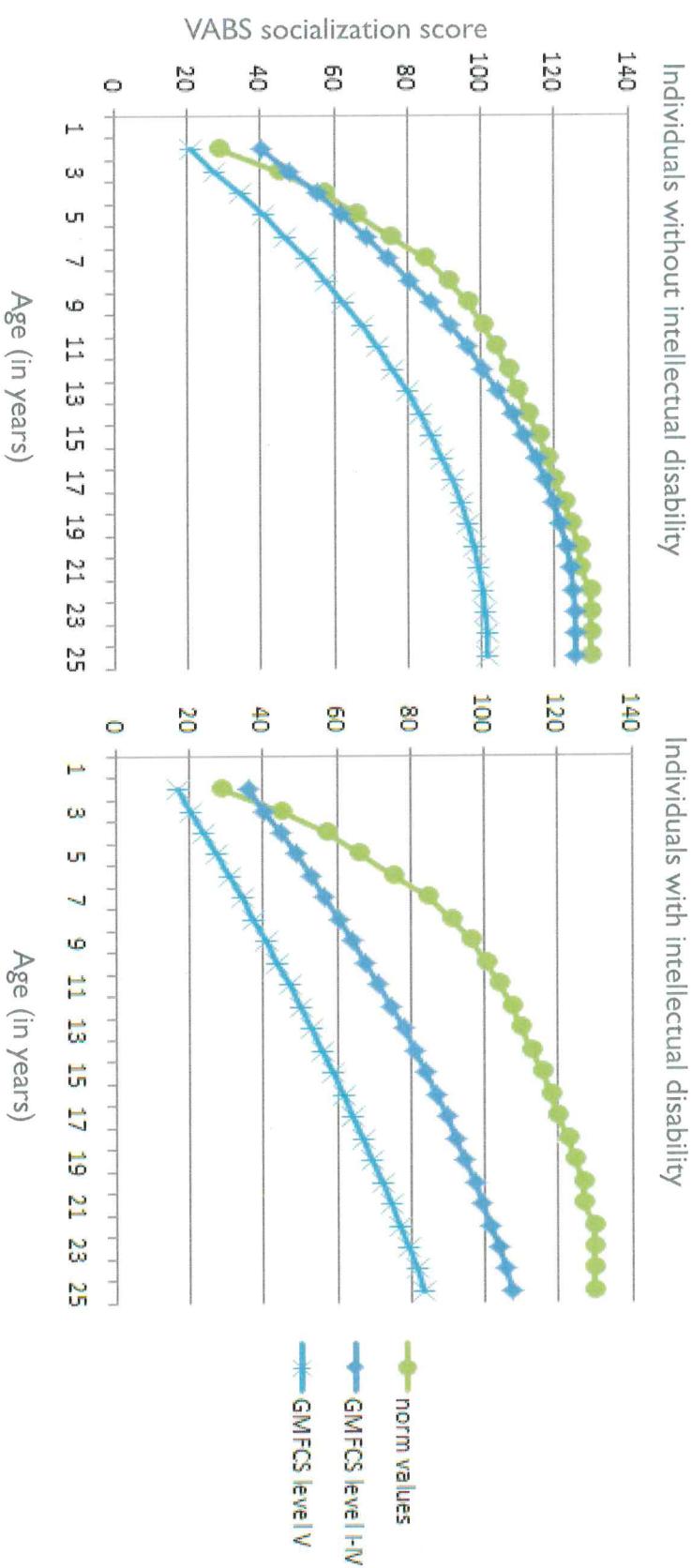


Mobility performance



Vos et al Pediatrics 2013; 132, e915

Social participation



Tan et al Dev Med Child Neurol 2014; 256, 370-377

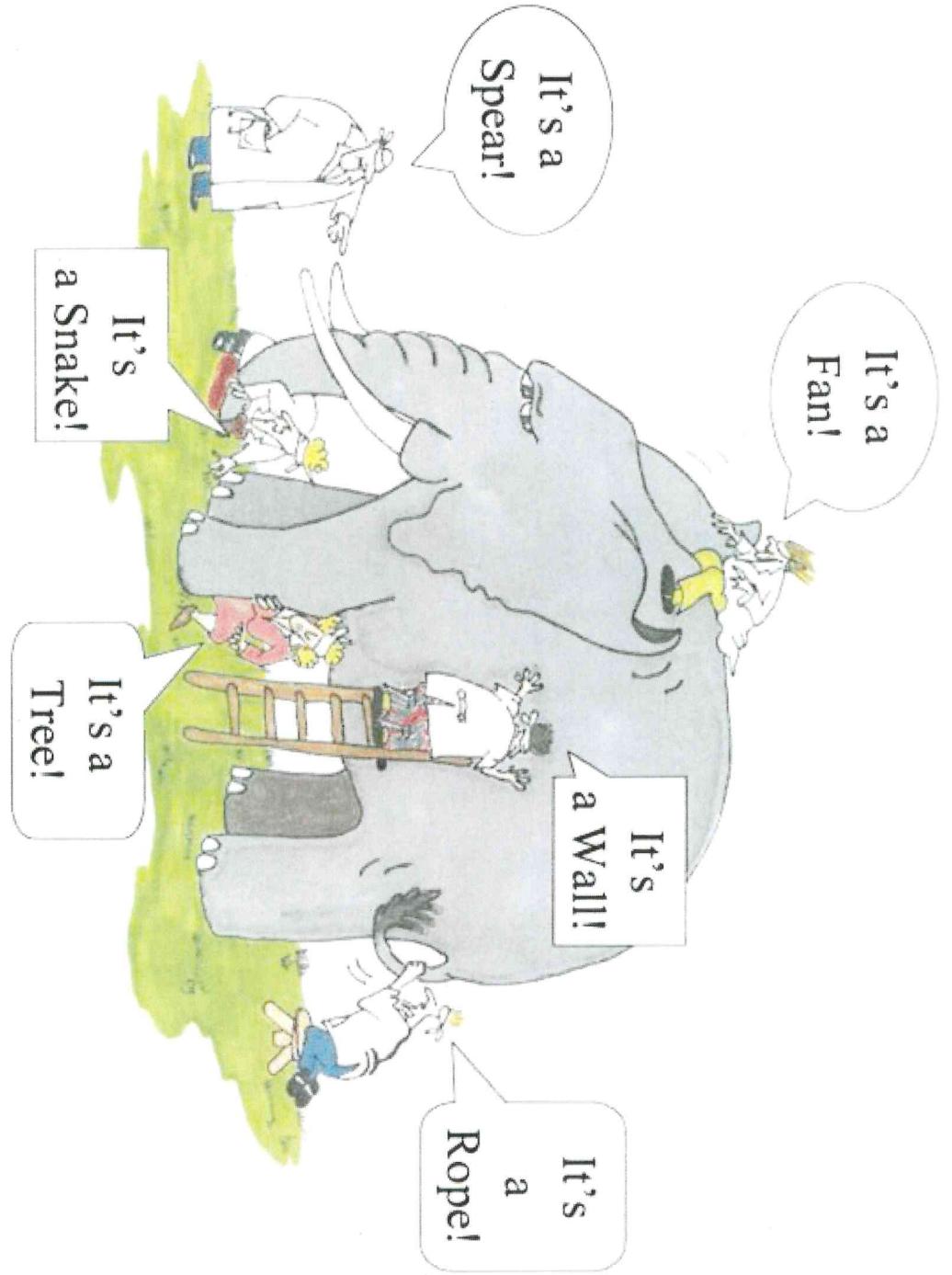
Hiaten in kennis en zorg (anno 2018)

The screenshot shows a Windows desktop environment with several icons in the taskbar (File Explorer, Internet Explorer, Task View, etc.). A web browser window is open to the URL <https://www.bosk.nl/bosk/actueel/nieuws/kinderrevalidatie-en-psychosociale-zorg/>. The page title is "Psychosociale zorg in de kind...". The menu bar includes File, Edit, View, Favorites, Tools, and Help. The main content area features the BOSK logo and navigation links: Home, Over de BOSK, Actueel, Webshop, Vraag en Aanbod, Steun de BOSK, Dossiers, and Contact. A yellow button labeled "Word lid!" is visible. The central article is titled "Martijn Klem (BOSK): "Psychosociale zorg is de grootste blinde vlek in de kinderrevalidatie!"" and discusses the lack of attention to psychosocial care in children's rehabilitation. The footer contains social media links and a copyright notice: "Vereniging van Revalidatieartsen (nieuwvenster) © 2018 BOSK".

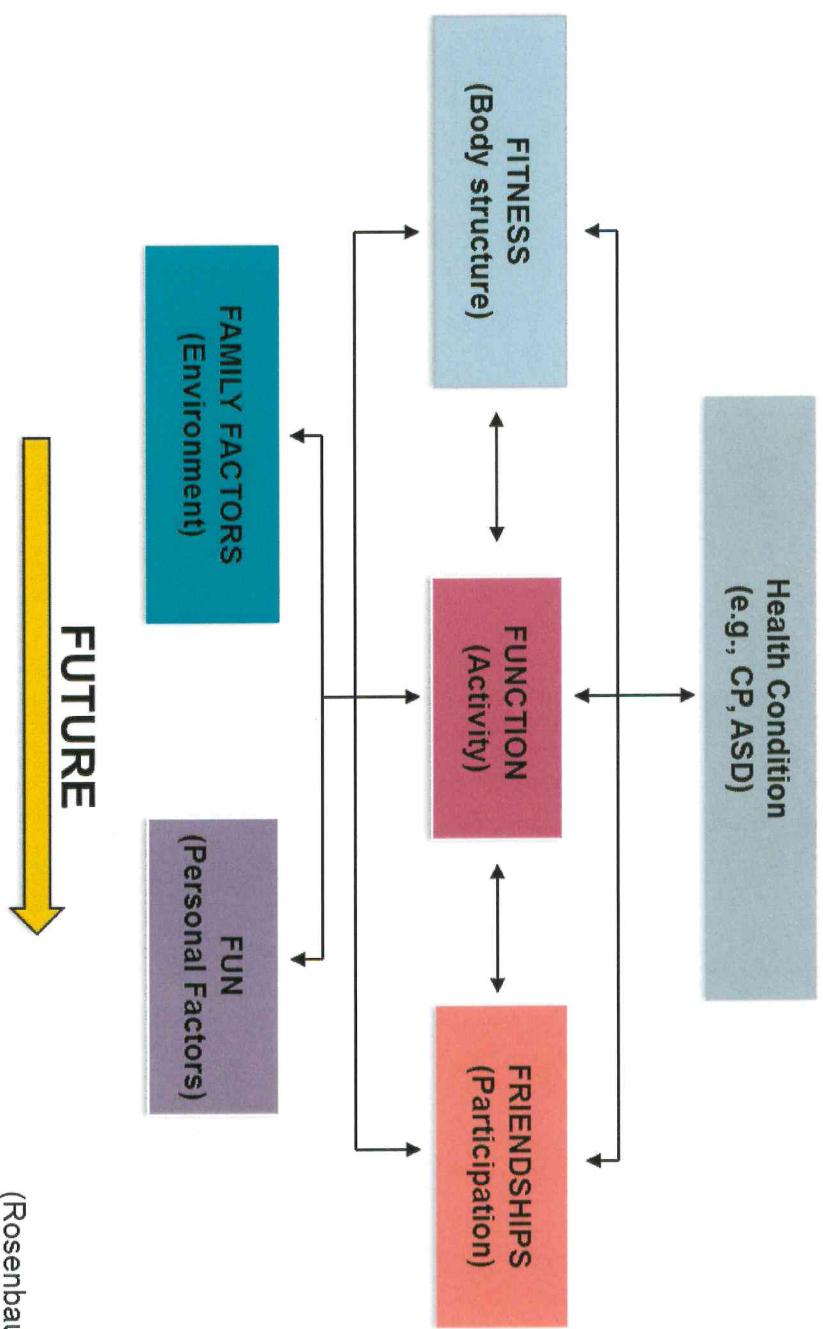


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The F-Words



(Rosenbaum & Gorter,
2012)



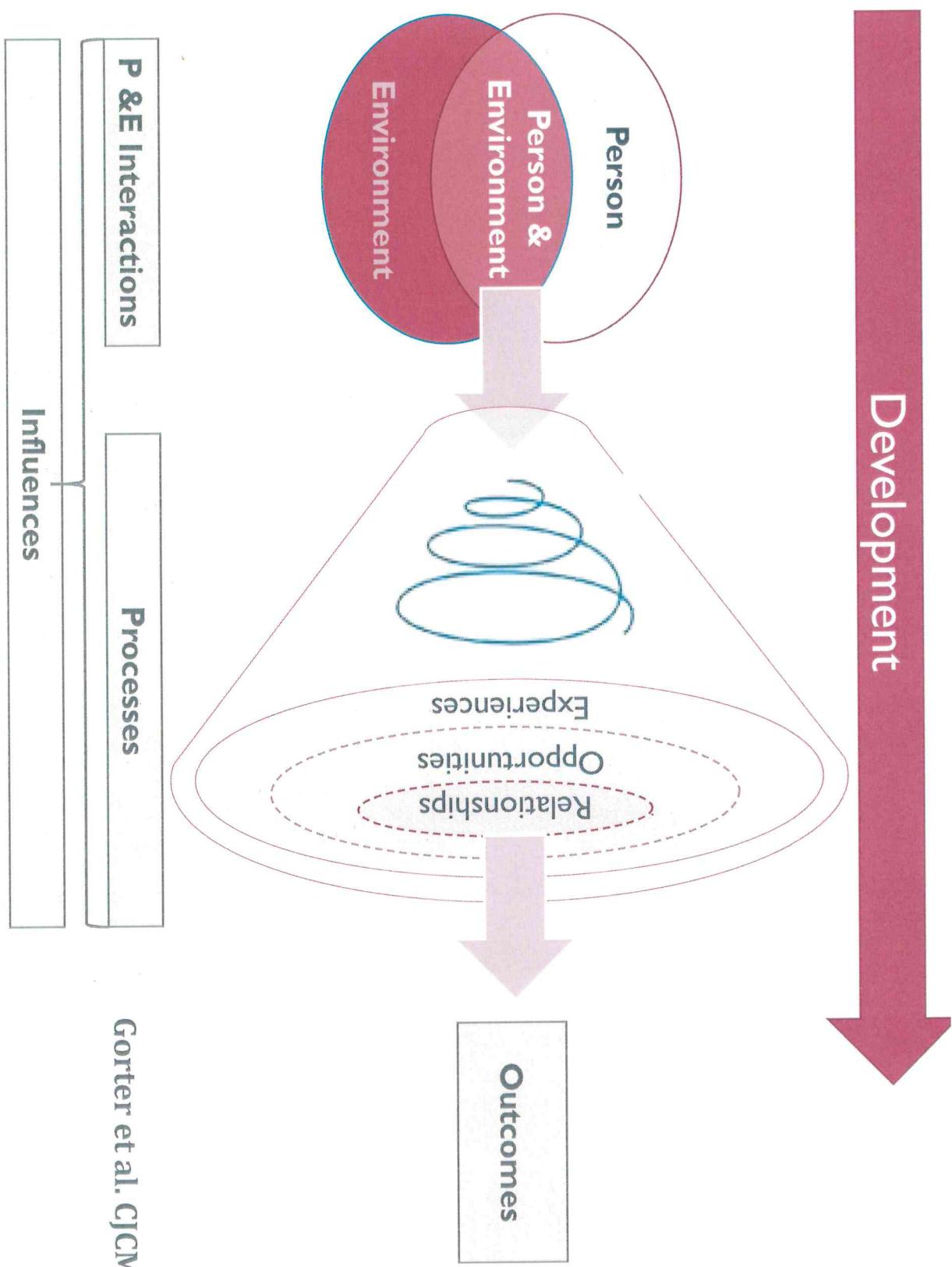
For more information: <https://canchild.ca/en/research-in-practice/f-words-in-childhood-disability>



Eye voetbal (initiatief St. Rotterdamse Sporticonen)



Bron: Post van Nicole van de Dries op LinkedIn. <https://youtu.be/jAiflUtzkaYY>



Gorter et al. CJCMH 2014

Belang van samenwerking:

1. kinderen, jongeren, hun ouders/ gezin en onderzoekers
2. zorgverleners en onderzoekers
3. beleidsmakers en onderzoekers
4. onderzoekers en (industrie)partners
5. onderzoekers en onderzoekers.





Naar Canadees voorbeeld



➤ CanChild

Generating Knowledge
Transforming Lives

➤ Provinciaal:

➤ Ontario Brain Institute (OBI) CP-NET



➤ Federaal:

➤ Canadian Institute of Health Research (CIHR)



Network

CHILD-BRIGHT

➤ CanChild

CanChild's Onderzoek

■ Nieuwe kennis

- Meetinstrumenten (Outcome Research)
- Ontwikkelingstrajecten beschrijven en begrijpen (Longitudinaal onderzoek)
- Kwantitatief en kwalitatief onderzoek (mixed-methods)

■ Beter zorg

- Interventie onderzoek gericht op efficientere zorg (health services research)
- Instrumenten & informatie (website)

■ Beter toekomst

- Interventie onderzoek gericht op thema's zoals participatie en transitie

Succesfactoren

- Onderzoek & Praktijk gaan hand in hand
- Interdisciplinaire aanpak
- Niet-diagnose gebonden onderzoek
- “Integrated knowledge translation”
 - Betrokkenheid en participatie van stakeholders, met name kinderen, jongeren en gezinnen als partner van begin tot eind



CanChild



Meer weten over participatie?:

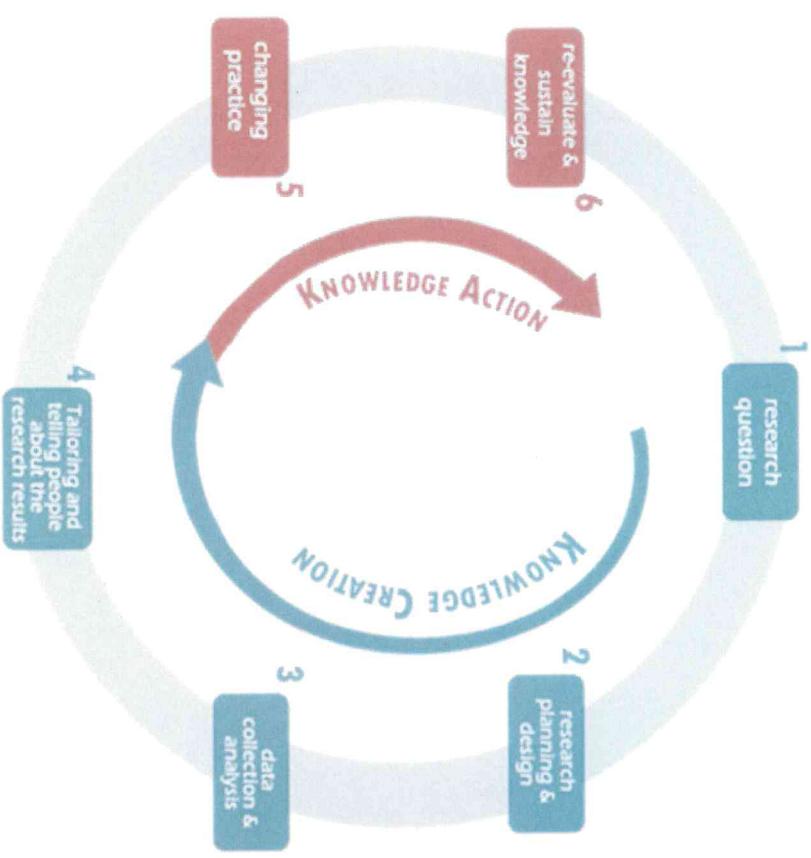
The screenshot shows a web browser displaying the CanChild website at <https://canchild.ca/en/research-in-practice/participation-knowledge-hub>. The page title is "Research In Practice". The main content area is titled "Participation Knowledge Hub" and features a large image of three children smiling. Below the image, the text reads "Participation: See What We Can Do!" followed by three smaller images of children in various settings. To the left of the main content, there is a sidebar with sections for "Support Us", "Share This Page", and "Stay In Touch". The "Share This Page" section includes links for Facebook, Twitter, and Google+. The "Stay In Touch" section includes links for Parents Participating in Research and Related Resources, which lists various icons representing different resources. The top navigation bar includes links for Home, Research In Practice, and Participation, along with a search bar and a menu icon.

CanChild <https://canchild.ca/en/research-in-practice/participation-knowledge-hub>

Samenwerkings centraal

- Patient and Family Engagement

- Integrated knowledge translation.



www.pencru.org/research/whattodowemeanbyresearch/
Modified with permission © PENCRU

Visie en Missie



- CanChild is a world leader in the field of childhood disability research and a premier source for childhood disability information

- **Mission:** improving the lives of children and youth with disabilities / chronic conditions and their families



CanChild



CP-NET

The screenshot shows the homepage of the CP-NET website. At the top, there is a navigation bar with links for Home, About, Research, News, Events, and Contact. Below the navigation bar is a large banner featuring two young children, one in a wheelchair and one standing next to them, in a park-like setting. To the left of the banner, there is a sidebar with several links: Get involved in Research, Community Profiles, Watch CP-NET Webinars, and New F-twords Video! At the bottom of the page, there is a footer with social media icons for Facebook, Twitter, LinkedIn, YouTube, and Google+, along with a "Subscribe to our newsletter" button.



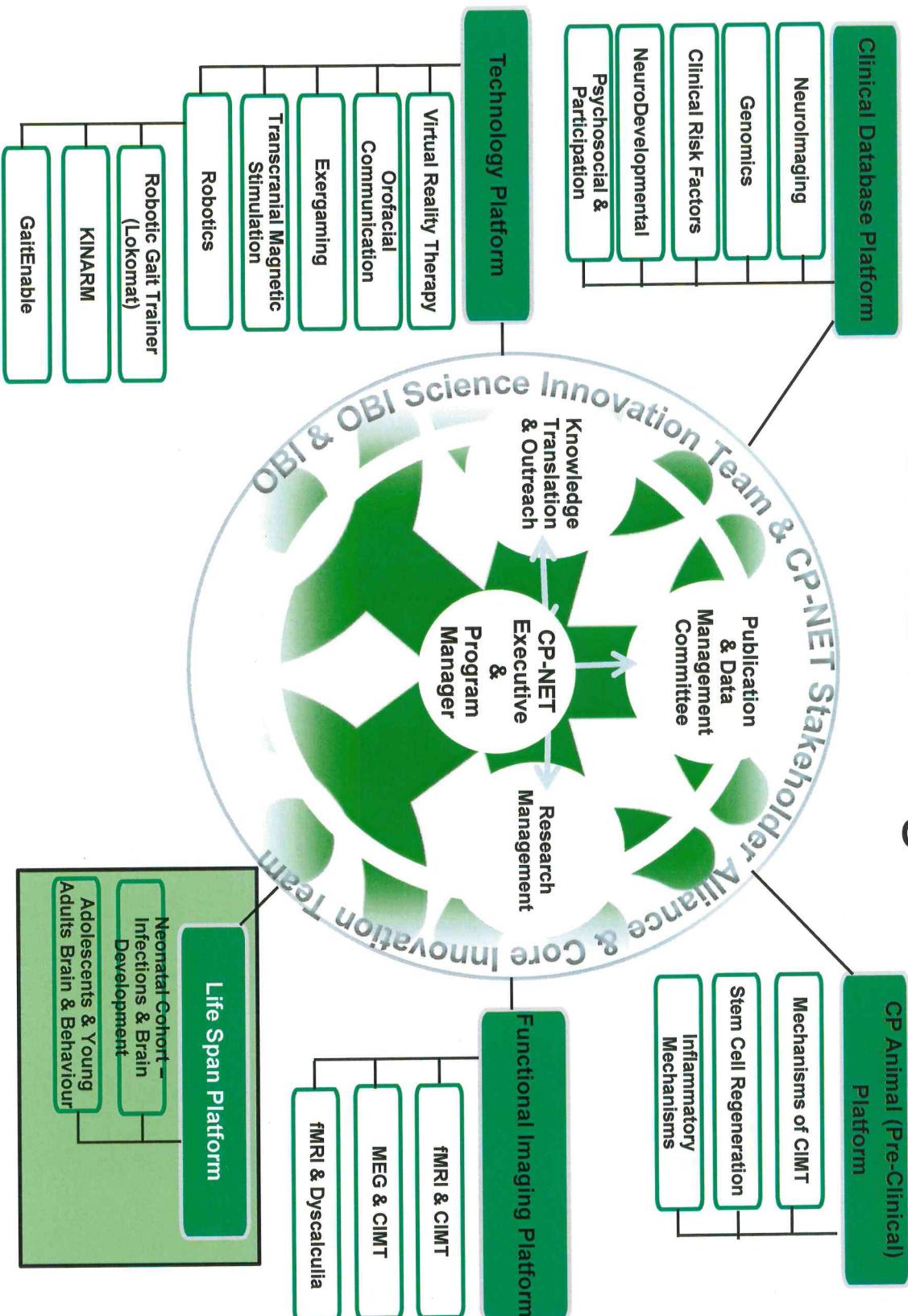
CP-NET
Childhood Cerebral Palsy
Neuroscience Discovery Network



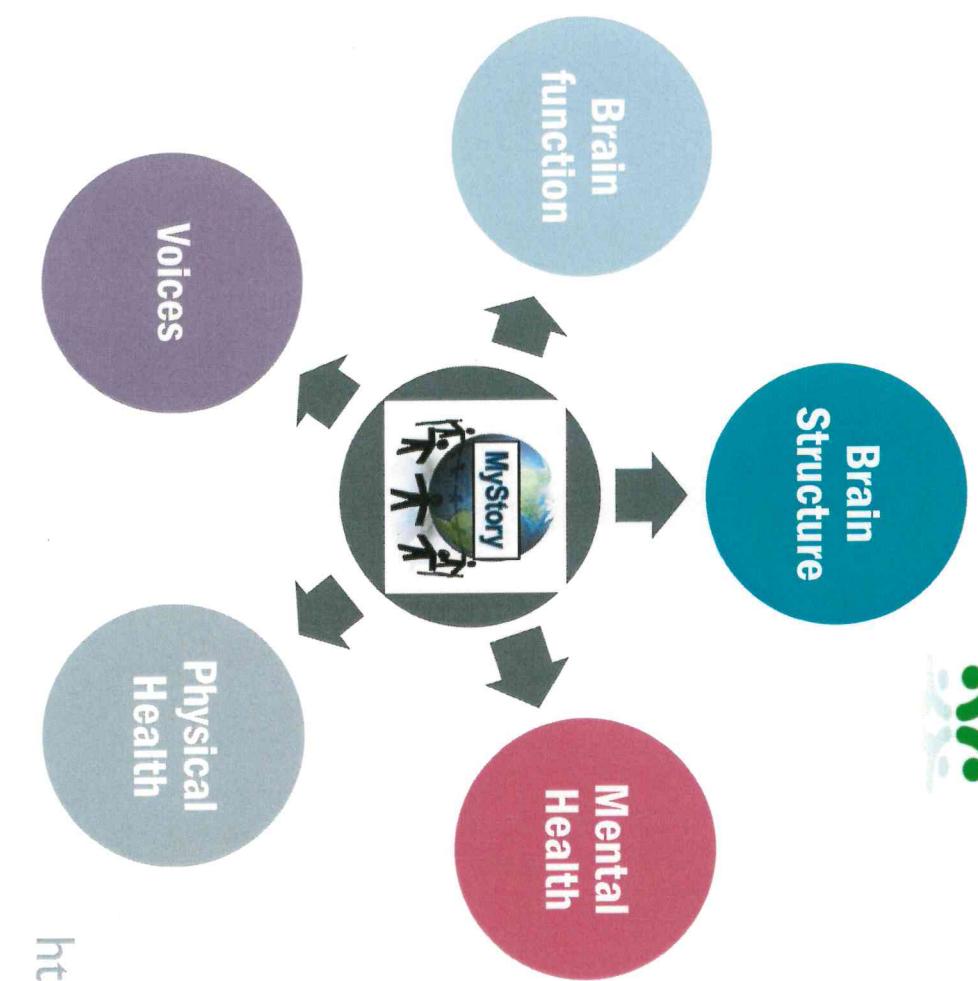
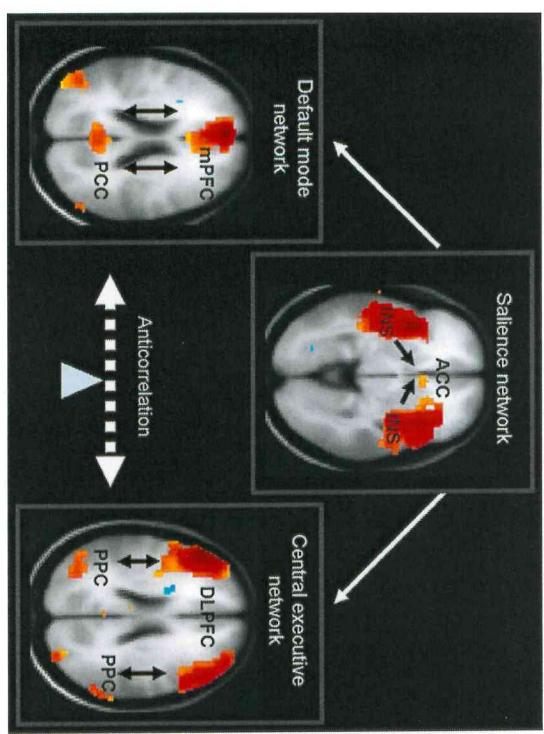
ONTARIO
BRAIN
INSTITUT

<https://vimeo.com/185356507>

The CP-NET Program



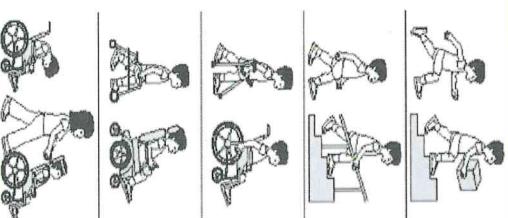
MyStory project



<http://cp-net.org>

CanChild

Clinical Database Platforms

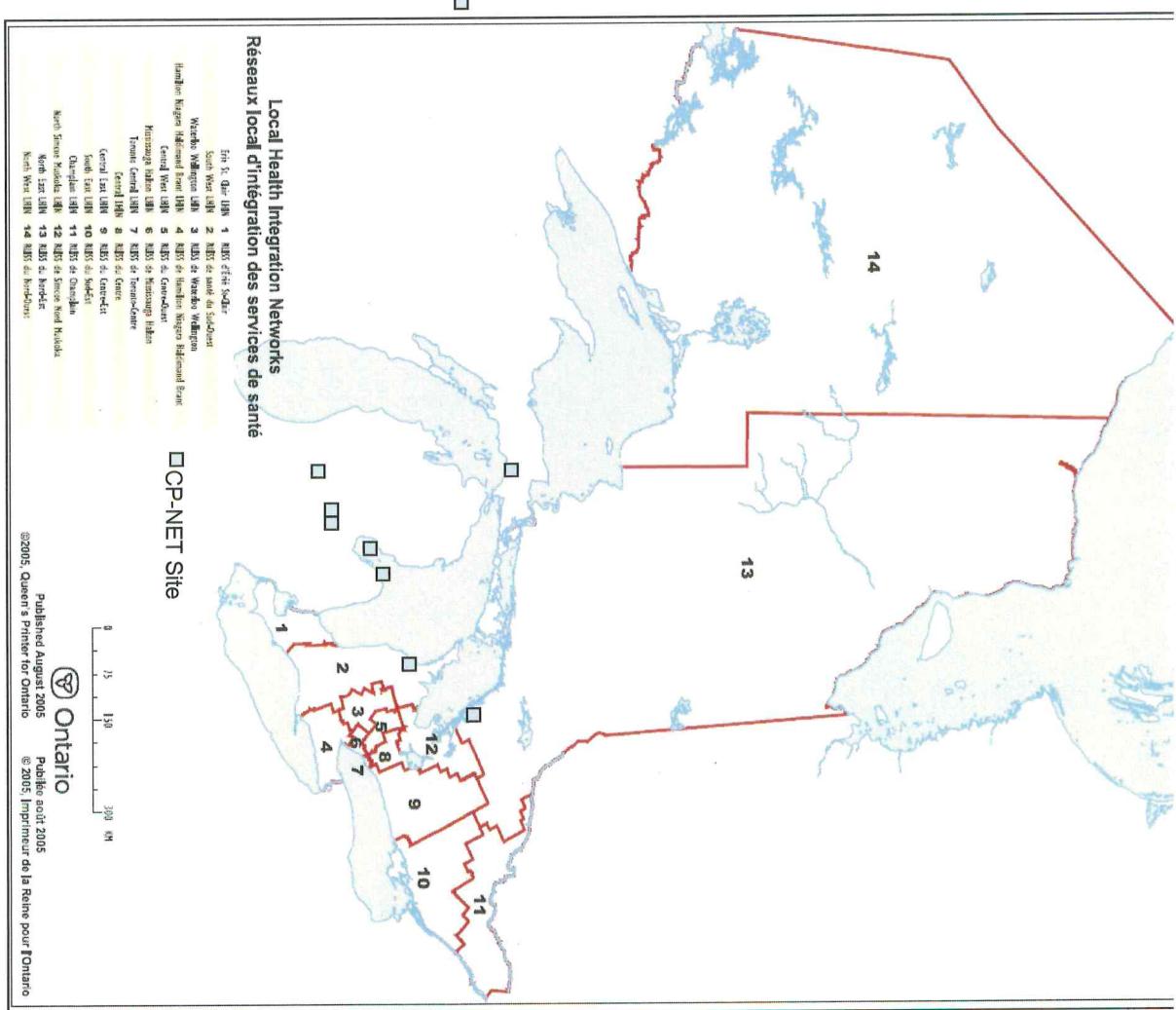
Clinical Risk Factors	Neuro-imaging	Genomics	Neuro-developmental	Psychosocial & Participation
Medical Chart Review & Parent Interview	Classification of Clinically-Acquired Images (MRIs)	Population-based DNA Database	Functioning, co-morbidities, pain, and standardized neurologic examination	Psychosocial markers, child & family health related quality of life, self-esteem, behaviour, sleep and participation
				



CP-NET
Childhood Cerebral Palsy
Neuroscience Discovery Network

Geographical Areas Involved in CP-NET for Data Collection

- Holland Bloorview Kids Rehabilitation Hospital, Toronto
- Children's Treatment Network of Simcoe York, York Region
- McMaster Children's Hospital, Hamilton
- Child Development Centre, Hotel Dieu Hospital, Kingston
- Children's Treatment Centre, Health Sciences North, Sudbury
- Grandview Children's Centre, Oshawa
- ErinoakKids Centre for Treatment and Development, Mississauga
- Ottawa Children's Treatment Centre, Children's Hospital of Eastern Ontario, Ottawa
- Thames Valley Children's Centre, Lawson Health Research Institute, London

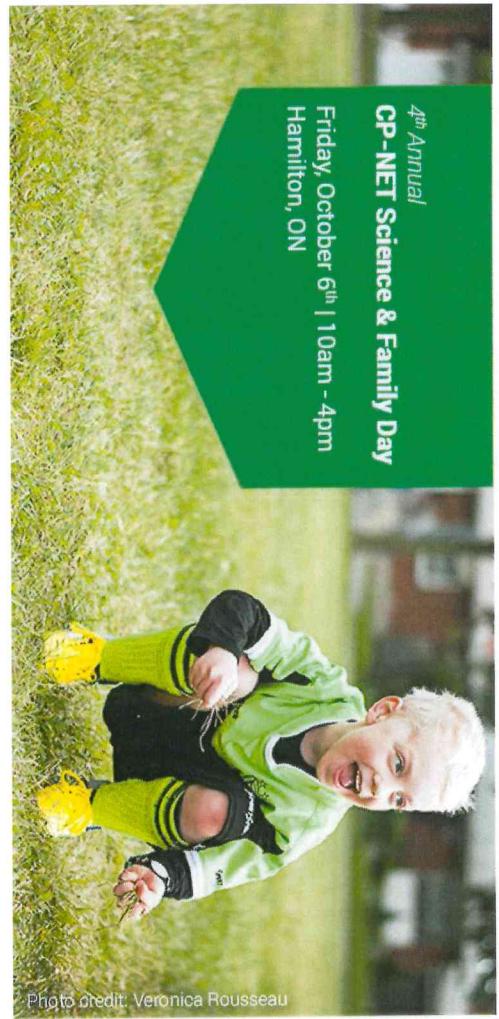


ONTARIO
BRAIN
INSTITUTE



CP-NET
Childhood Cerebral Palsy
Neuroscience Discovery Network

Knowledge Translation – Family Engagement



4th Annual
CP-NET Science & Family Day

Friday, October 6th | 10am - 4pm
Hamilton, ON





CHILD-BRIGHT Network

Réseau BRILLEnfant



BRILLEnfant

The screenshot shows a Windows desktop environment. A browser window is open to the CHILD-BRIGHT Network website at https://www.child-bright.ca/. The page features a large background image of a child's face. At the top, there is a navigation bar with links for Home, About Us, Programs, Projects, News & Events, Contact Us, and Search. A prominent orange sidebar on the right contains the text "Your voice is the one that matters! Sign up to receive our news by clicking here". The status bar at the bottom of the browser shows the URL https://www.child-bright.ca/ and the date 3/13/2018.

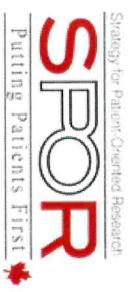
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<https://www.child-bright.ca/>



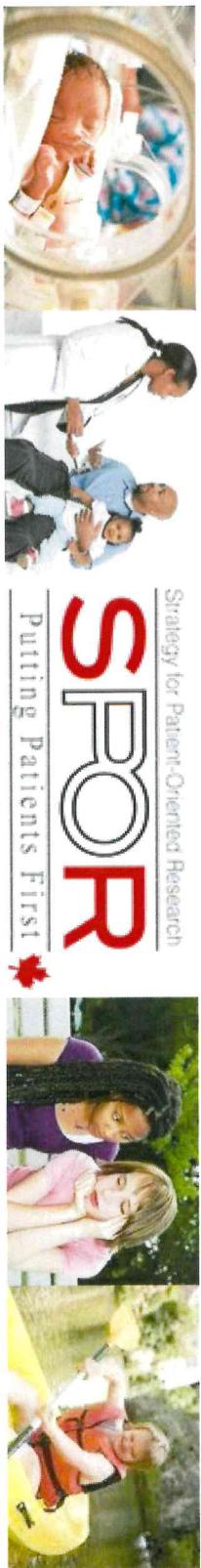
Strategy for patient-oriented research: What is it?

- Patient-oriented research refers to a continuum of research that
 - engages patients as partners
 - focuses on patient-identified priorities and
 - improves patient outcomes
- In partnership with relevant stakeholders (iKT)
 - aims to apply the knowledge generated to improve healthcare systems and practices



CHILD-BRIGHT Network

- 3 Co-directors, 15 PIs
- 160 co-applicants (all stakeholder groups)
- 37 collaborators (child health organizations)
- 27 funding partners (children's hospitals)



CHILD-BRIGHT
Network
Réseau
BRILLEnfant

Our vision

Achieving **BRIGHTer** futures for children with developmental disabilities and their families, across the life course, by:

- 1) promoting healthy outcomes through optimizing brain development,
- 2) creating novel interventions, and
- 3) providing responsive and supportive services



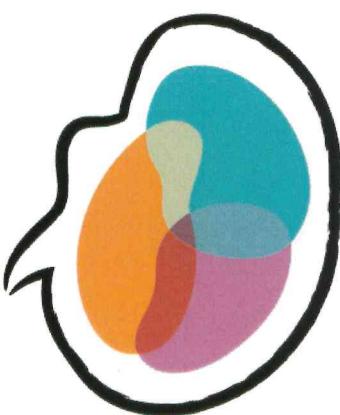
Programs and services

PATIENT-ORIENTED RESEARCH

Our research program consists of 12 patient-oriented research projects to be conducted across Canada

KNOWLEDGE TRANSLATION

We promote better ways to share credible information



PATIENT-ORIENTED TRAINING

We will train stakeholders about patient-oriented research

CITIZEN ENGAGEMENT

With our Citizen Engagement Council, we will engage patients as partners, focus on patient-oriented priorities, and improve patient outcomes

CHILD-BRIGHT
Network
Réseau
BRILLEnfant



Research themes



To develop and test effective interventions that will improve:



- The child's **brain plasticity**, developmental trajectory



- Child and family **mental health** and well-being



- The patient/family **experience** within the Canadian **healthcare system**



To implement KT that empowers children and families for
BRIGHTer futures

CHILD-BRIGHT
Network

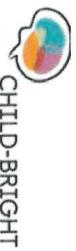


Réseau
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Child-Bright – READYorNOT study

Bright Futures

Projects that will redesign health care services to be more responsive to family needs



'READYorNOT' MOVING AHEAD WITH Transition Of care from ADOLESCENCE TO ADULTHOOD (16–18 years)

Principal Investigators: Dr. Ariane Marelli (McGill University Health Centre), Dr. Jan Willem Gorter (McMaster University), and Dr. Khush Amaria (SickKids)



Youth with brain-based developmental disabilities require seamless transition from the pediatric to adult health care systems. This transition can be disruptive for youth and their families and have a negative impact on a patient's health. In the majority of pediatric centres, there are no dedicated resources for transition of care. With the 'READYorNot' (READYness in Youth for Transition Out of pediatric Care) project, we are developing and evaluating e-health aids to help patients and families take charge of this transition.

www.child-bright.ca

<https://www.child-bright.ca/readyornot-moving-ahead-with-transition-of-care-from-adolescence-to-adulthood/>

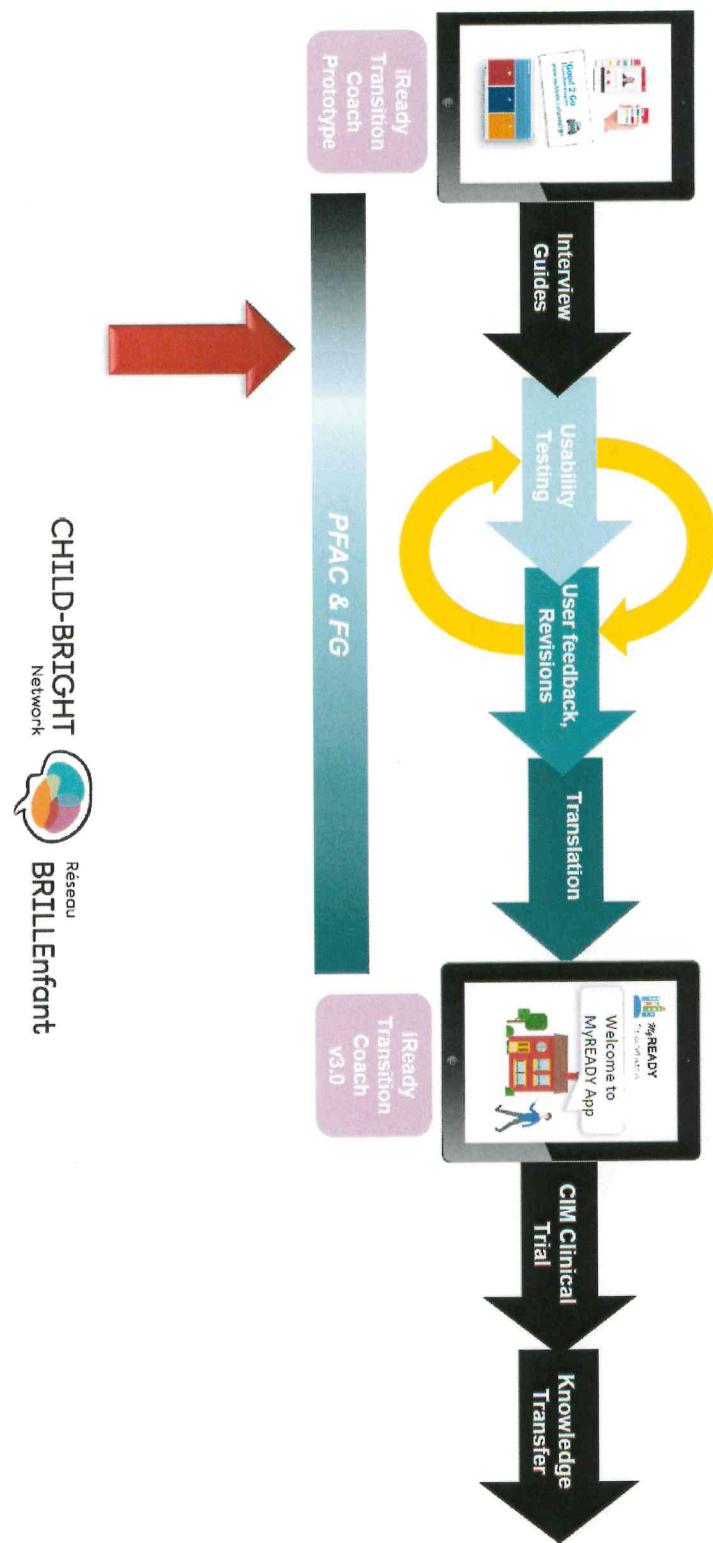


McMaster Children's Hospital
HAMILTON HEALTH SCIENCES
Hamilton Health Sciences
RESEARCH

Project plan -development

Project 3.3: Phase I (1-18 months)

Phase II (19-60 months)



CHILD-BRIGHT
Network
Réseau
BRILLEnfant

Co-Creation - Partnership



Project Plan – Clinical Trial

READYorNot Phase 2 RCT

Hypothesis: Youth who are between age 15 and 17 years of age who use the iREADY intervention will have higher change scores in terms of self-management over a 6-month period compared with youth receiving usual care.

Sample:

- 264 participants with brain-based disabilities
 - 132 intervention group and 132 control (usual care) group
- Within each of the 4 recruitment regions
 - 33 per arm for a total of 66 per region





Waar staan we over 5 jaar?

GO Rapport (1997)

Fragmentatie

Verdeeld

Gebrek aan capaciteit

L2M

en andere projecten

Samenwerking

Voor 2000

2000-2008

2008-2018

2018 - 2023

Toekomst

Le Programma
Revalidatieonderzoek

???

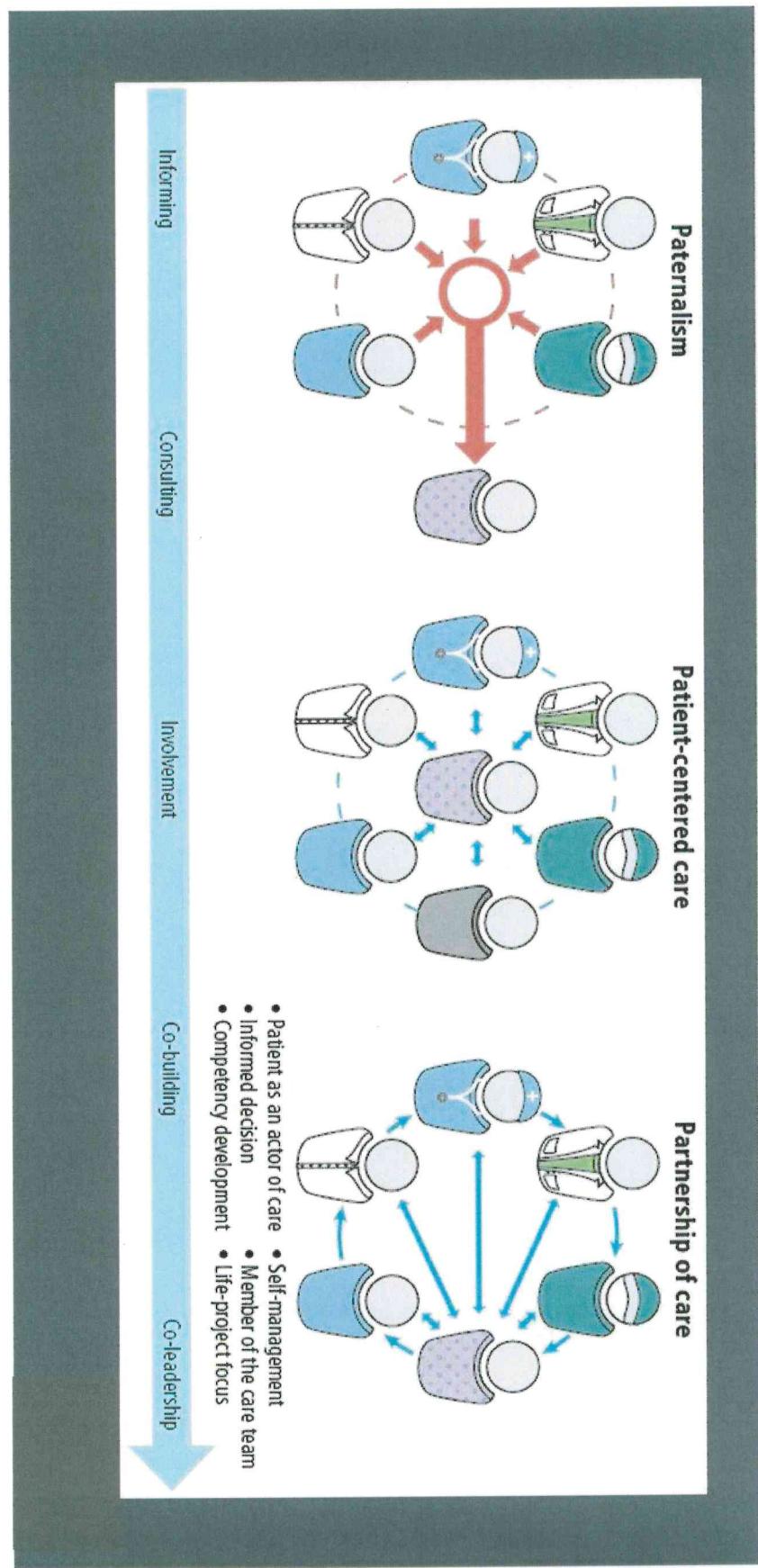
PERRIN



CanChild

Wat we ook doen – dit is mijn visie

Partnership



Source: LinkedIn

Samenwerken is....

- Een middel – geen doel in zich zelf: het begint met een visie!
- Denken in netwerken – de traditionele hierarchie voorbij
- Een werkwoord – het vraagt een inspanning
- Elkaar iets gunnen – samen is meer dan de som der delen
- Goede zorg en een betere toekomst!

"Sometimes the most ordinary things
could be made extraordinary, simply
by doing them with the right people."

Elizabeth Green



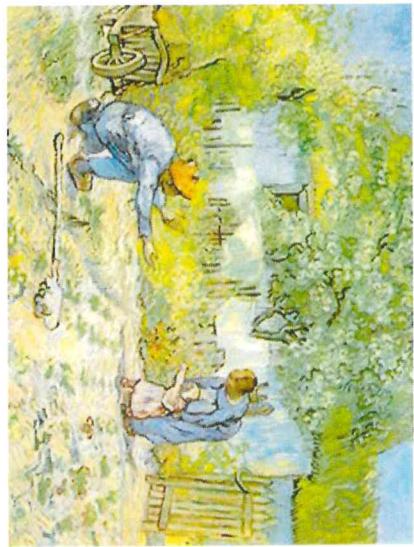
Terug naar het begin...

1) Te vertellen wat ik geleerd heb in Canada over samenwerking in onderzoek met als doel goede zorg en een betere toekomst voor kinderen met ontwikkelingsbeperkingen en hun gezinnen

2) Te dromen waar we over 5 jaar kunnen staan met samenwerking in de kindervalidatie in Nederland

3) Te horen wat samenwerken in de kindervalidatie voor een ieder betekent

Terug naar u....



TransitionDoctor
3,217 Tweets

Tweets & replies Media Likes



Profile picture



TransitionDoctor @Dr_Gorter · 2d

Graag ga ik na mijn keynote presentatie in gesprek met de deelnemers van het JKF/KFA congres over de vraag wat samenwerken in de kinderrevalidatie voor een ieder betekent.

JKF Kinderfonds @JKF_Kinderfonds

In de geschiedenis van de kinderfondsen
is de samenwerking tussen de verschillende
organisaties een belangrijke factor geweest.
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Profile picture



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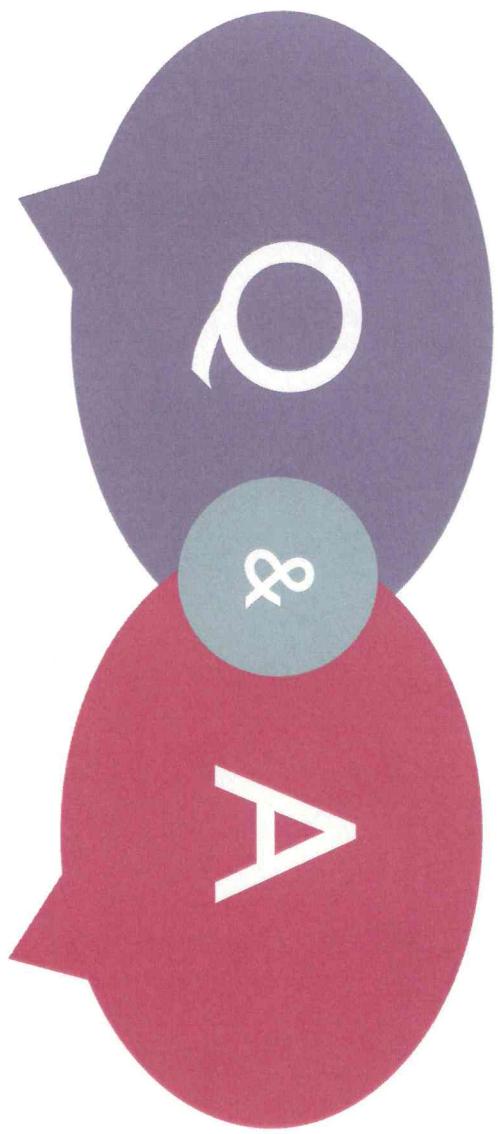


TransitionDoctor @Dr_Gorter · 4d
Excellent editorial with a call for
compassion for people living with
childhood onset condition over the

CanChild



Kinderrevalidatie Fonds Adriaanstichting



Hartelijk dank!

