

# Focus on the future of participation

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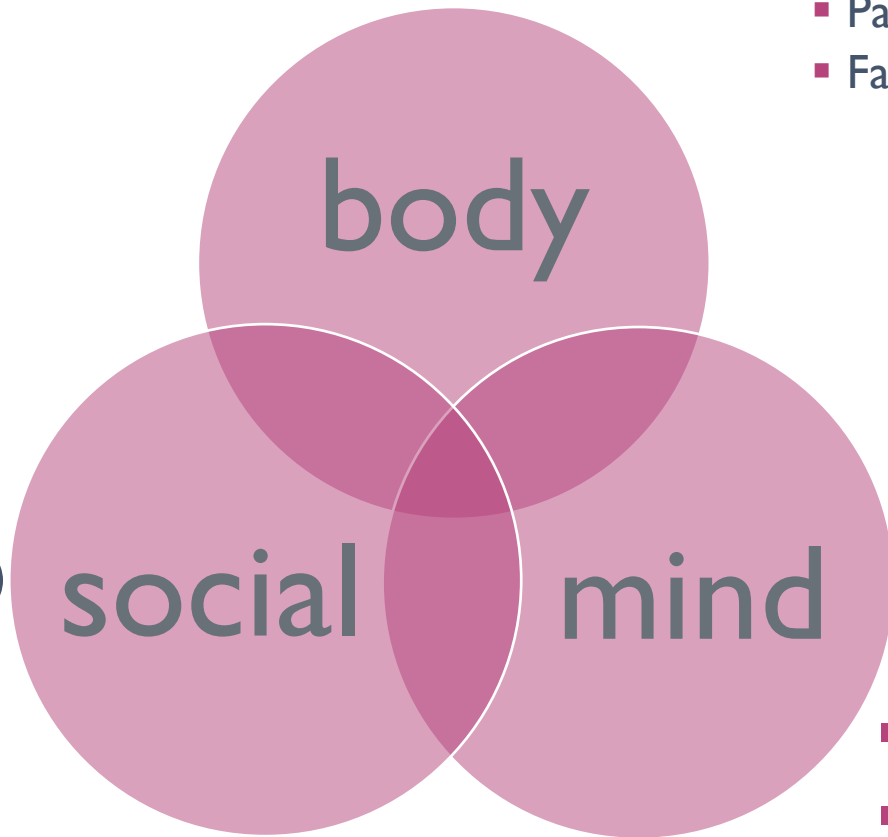
CAPA September 14, 2022

# Key questions in terms of future participation

- How children with a variety of developmental conditions develop
- How to identify children and families at risk based on their needs
- How to best support these children over the life course, in particular during health services transition points

# Adult Health Outcomes

- Living on your own (more with parents)
- Employment (lower rates)
- Relationships (fewer)



- Physical activity level (low)
- Pain
- Fatigue

- Anxiety
- Depression

# 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, Roebroek 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

# Recent data from Australia

## From the Victorian CP Register

- All adults with CP aged 18–25 years (n = 649) were invited
- 90 participants (response rate 16.9%).
- 57% male
- mean age 22.4 years (SD: 2.2) in 2020

## Living independently:

- 87.5% (compared to 48.2%) were living in their parental home

## Partner

- 3.4% (compared to 31.6%) were married or partnered

## Employment

- 32.6% (compared to 75.8%) were in paid work

79.8% had completed secondary school (compared to 83.2%)

While foundational education completion rates were similar to non-disabled peers, significant gaps in social outcomes remain, including residence in the parental home and single status.

Imms C, Reddihough D, Shepherd DA and Kavanagh A (2021) Social Outcomes of School Leavers With Cerebral Palsy Living in Victoria. *Front. Neurol.* 12:753921. doi: 10.3389/fneur.2021.753921

# Recen data from Sweden

## **Cross-sectional registry-based study** adults with CP in the Swedish CP follow-up programme

- 1,030 males/858 females
- median age 25 years (range 16–78 y)

### **Living independently:**

- under 20 years: 8,7%
- 25- to 29-year olds: 55.6%
- 40- to 49-year olds, 72.4%

### **Partner**

- One in eight adults with CP has a partner

### **Employment**

- One in six has competitive employment

Independent living was almost equal in adults at **GMFCS levels I (40.2%) and V (38.6%)**.

Access to personal assistance is the single most important factor for independent living.

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**RESEARCH ARTICLE**

WILEY

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

Julia E. Hanes<sup>1</sup> | Oksana Hlyva<sup>1</sup> | Peter Rosenbaum<sup>1</sup>  | Matthew Freeman<sup>2</sup> |  
Tram Nguyen<sup>1</sup> | Robert J. Palisano<sup>3</sup> | Jan Willem Gorter<sup>1</sup> 

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

# Participants

- Sixteen individuals (across all GMFCS levels)
- Gender distribution included seven females and nine males.
- Age ranged from 17 to 29 years (Mean = 26; SD = 3).



## Theme: Meaningful participation

- Most participants chose to introduce themselves with the different activities in which they participate—including work, school, and recreational opportunities (as opposed to introductions based on diagnosis).
- It became obvious that participation was just as important, if not more so, as their underlying health condition.

## Theme: Meaningful participation (2)

- These various activities were imperative for the young adults to achieve “normality.”
- Participants did not talk about goals related to their CP (walking, achieving better gross or fine motor function, etc.); rather, they discussed goals related to sport, education, employment, and other recreation.

## Subtheme (ii): Goal setting

Goal setting was a notable subtheme of participation.

- Personal goals focused on educational and occupational issues, as well as those related to having a family and living independently.
- Because several were unemployed, underemployed, or volunteering, they were seeking more stable, higher level, or less physically demanding positions.

## Subtheme (ii): Goal setting

- Interestingly, some participants also shared a variety of social goals relevant to their collective identities. Those included increasing social support services for adults with CP, LGBTQ+ advocacy, making a more compassionate and understanding society, and improving accessibility in the community.
- Despite articulating a variety of personal and social life goals, only a few participants tied their goals explicitly to their CP.

## In summary, Future Participation...

- .. is part of (young) people's identity
- ..is determined by many factors; the diagnosis is only one of many
- .. is determined by the person-environment interaction

## Life course health development of individuals with neurodevelopmental conditions

ROBERT J PALISANO<sup>1,2</sup> | BRIANO DI REZZE<sup>2,3</sup> | DEBRA STEWART<sup>2,3</sup> | PETER L ROSENBAUM<sup>2,4</sup> | OKSANA HLYVA<sup>2</sup> | MATTHEW FREEMAN<sup>2,3</sup> | TRAM NGUYEN<sup>2,5</sup> | JAN WILLEM GORTER<sup>2,4</sup> 

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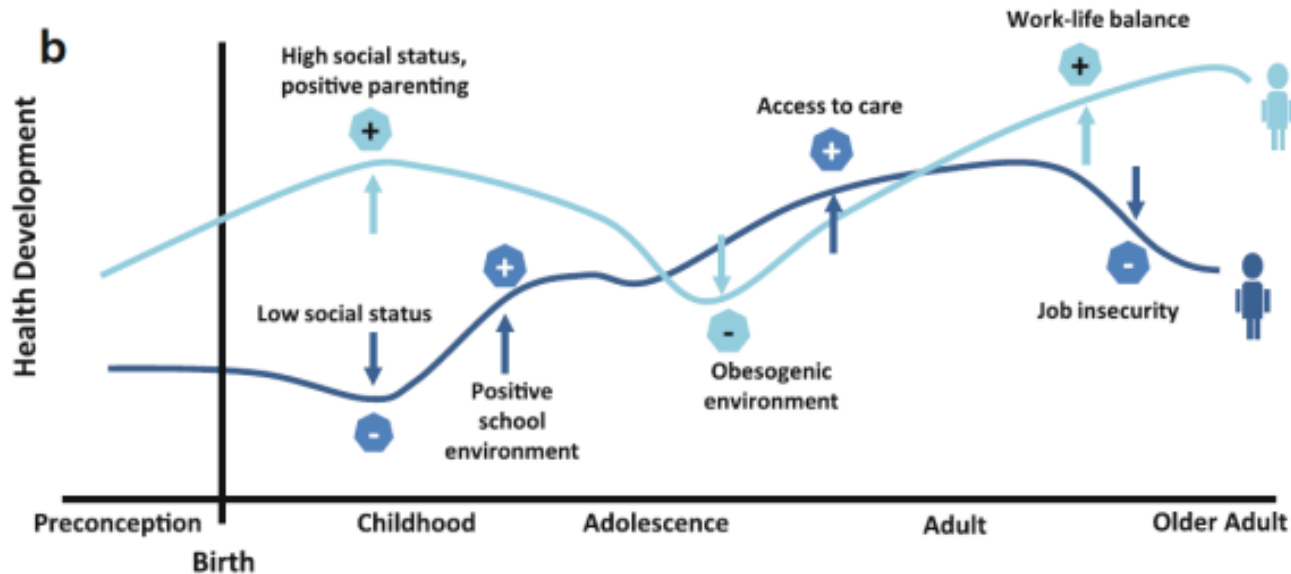
Correspondence to Robert J Palisano at Department of Physical Therapy and Rehabilitation Sciences, Drexel University, 1601 Cherry Street, MS 7502, Philadelphia, PA 19102, USA.  
E-mail: robert.j.palisano@drexel.edu

Dev Med Child Neurol. (2017)

# Health Capacity

- We propose that **the concept of participation** has important application to LCHD of individuals with neurodevelopmental conditions.
- In LCHD, **health capacity** represents an individual's potential for healthy development as they interact or adapt to environmental conditions.
- We have interpreted health capacity (as defined in LCHD) as **the potential for participation**, while participation (as defined in the ICF) is the actual involvement in a life situation.
- **Meaningful participation**, therefore, is a desired outcome of LCHD.

# Lifecourse Health Development



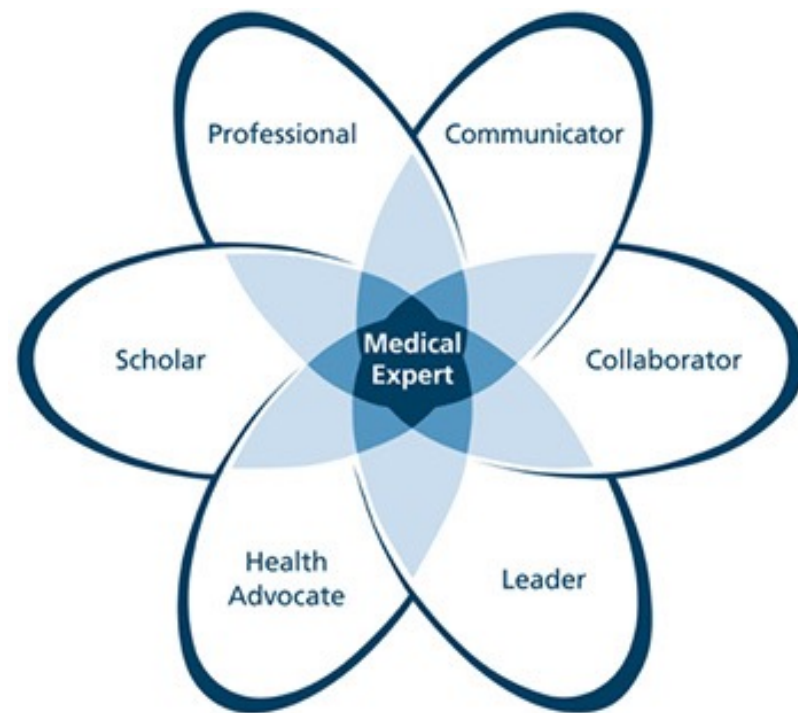
Halfon et al. Lifecourse Health Development: Past, Present and Future. *Matern Child Health J* (2014)

Palisano RJ, Di Rezze B, Stewart D, Rosenbaum PL, Hlyva O, Freeman M, Nguyen T, Gorter JW. Life course health development of individuals with neurodevelopmental conditions. *Dev Med Child Neurol*. (2017)



# What we can we do?

- Medical Expert (the integrating role)
- Communicator
- Collaborator
- Leader
- Health Advocate
- Scholar
- Professional



CANMEDS

<http://www.royalcollege.ca/rcsite/canmeds/canmeds-framework-e>

# Growing up is hard to do

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

## NOUR





[https://youtu.be/Sv5\\_c0EaAhE](https://youtu.be/Sv5_c0EaAhE)

Twitter: TransitionDoctor @Dr\_Gorter

# Autonomy = Self-regulation

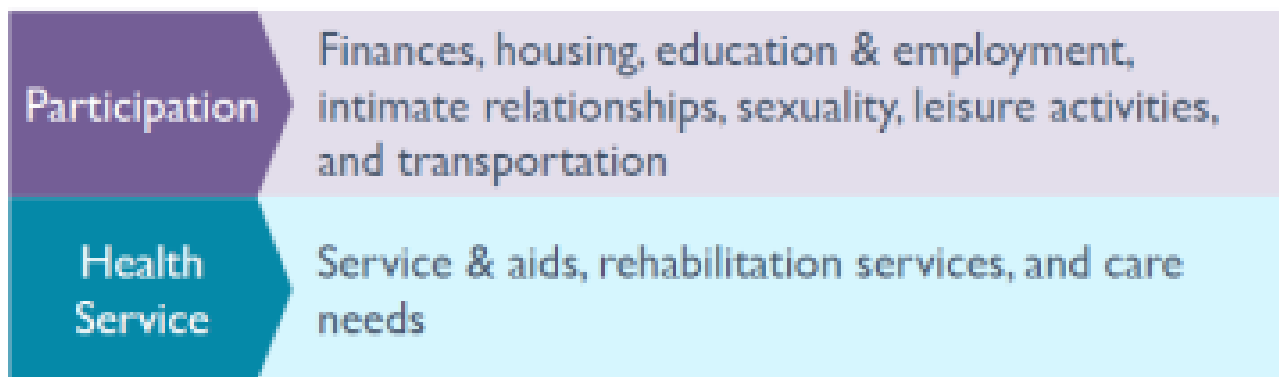
Dependency

Relationship

Early Adolescence (10-13)	Largely dependent	Hierarchical
Middle Adolescence (14-15)		
Late Adolescence (16-19)	Relatively independent	Equivalent relationship

## *Description of the RTP*

- The RTP classifies an individual's developmental stage for domains of participation and health service.



# Rotterdam Transition profile

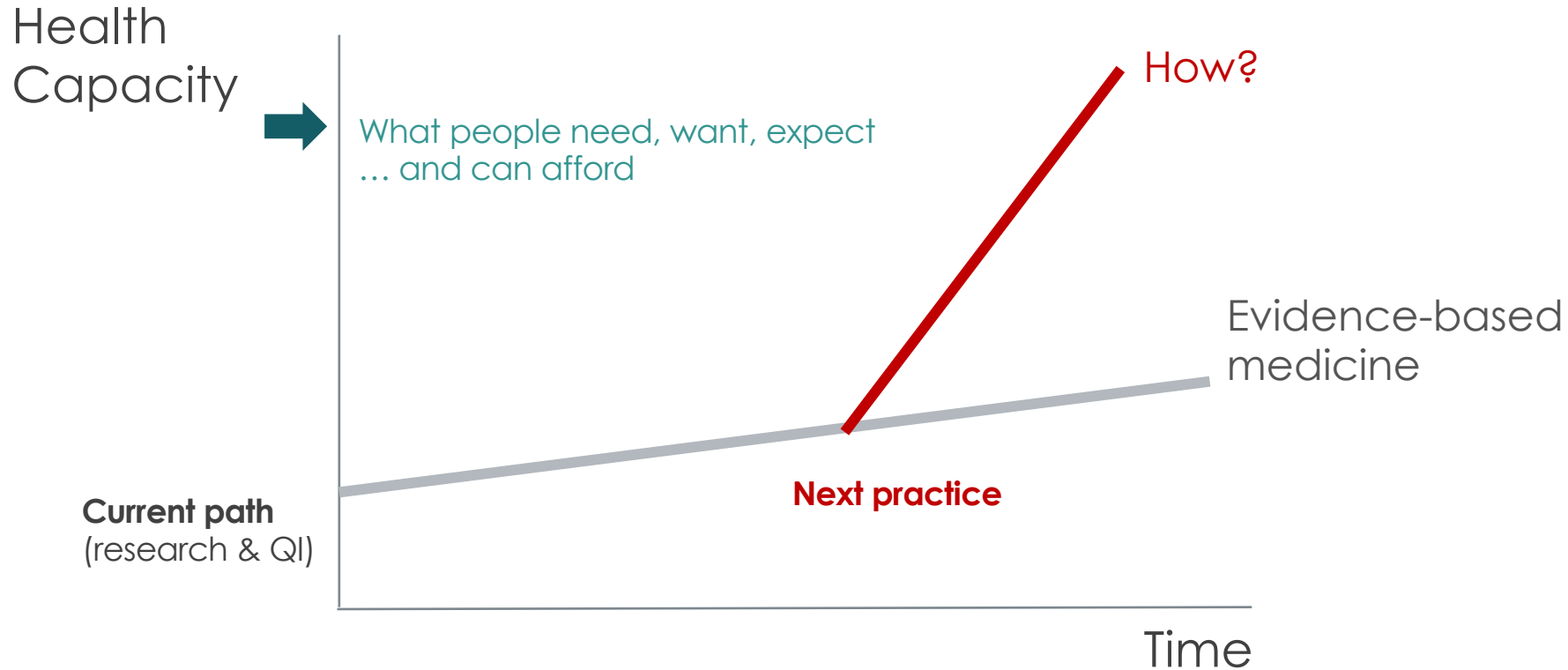
[www.erasmusmc.nl/revalidatie/research/transition](http://www.erasmusmc.nl/revalidatie/research/transition)

For each item below, please check off the one statement that best describes your current situation.

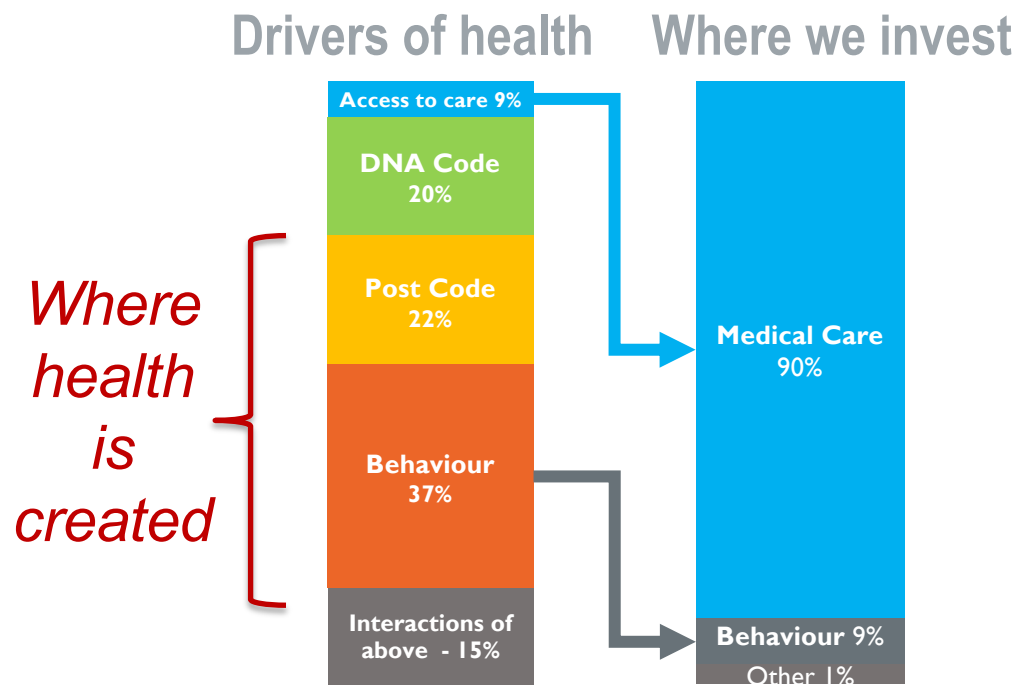
1. Education and employment
2. Finances
3. Housing
4. Intimate Relationships
5. Transportation
6. Leisure / social activities

Zhang-Jiang, Sofía and Gorter, Jan Willem. "The use of the Rotterdam Transition Profile: 10 years in review"  
Journal of Transition Medicine, vol. 1, no. 1, 2019, pp. 20180002. <https://doi.org/10.1515/jtm-2018-0002>

# Meeting the participation needs of children, youth & adults



# (Reimbursement based) healthcare



Source: NEHI Analytics (2013)

Courtesy to Zyana Khayat @ZaynaKhayat



# Healthcare delivery

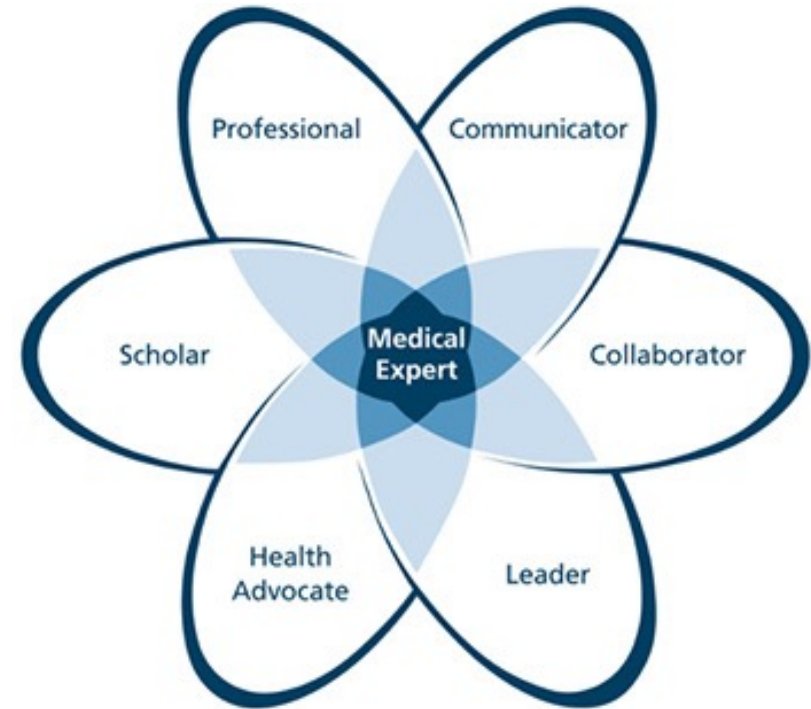
- Past: biomedical model
- Present: biopsychosocial model
- Future: Health development

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



# What could we do better?

- Medical Expert (the integrating role)
- Communicator
- Collaborator
- Leader
- Health Advocate
- Scholar
- Professional



CANMEDS

<http://www.royalcollege.ca/rcsite/canmeds/canmeds-framework-e>

# How to be a health advocate?

# Health Advocate

- As Health Advocates, [Healthcare Providers] **contribute their expertise and influence** as they work with communities or patient populations to improve health.
- They work with those they serve to determine and understand needs, speak on behalf of others when required, and support the mobilization of resources to effect change.

Reading: <https://www.royalcollege.ca/rcsite/canmeds/framework/canmeds-role-health-advocate-e>

## Health Advocate - Practice Points

- To be competent health advocates, [healthcare providers] must understand the factors that create health inequities and recognize how they impact the lives of their patients
- Although it is clear that efforts to improve health of an individual or population must consider ‘upstream’ factors, how this is operationalized in medicine and medical education is controversial

Hubinette M, Dobson S, Scott I, Sherbino J. Health advocacy. Med Teach. 2017 Feb;39(2):128-135. doi: 10.1080/0142159X.2017.1245853.

## Health Advocate - Practice Points

- Health advocacy is both a **mind-set** and a **multifaceted set of skills** that includes ensuring access to care, navigating the health care system, mobilizing resources, addressing health inequities, influencing health policy and creating system change
- There is both an essential cognitive foundation and experiential/workplace learning component to teaching and learning health advocacy

Hubinette M, Dobson S, Scott I, Sherbino J. Health advocacy. Med Teach. 2017 Feb;39(2):128-135. doi: 10.1080/0142159X.2017.1245853.

## Reflective questions re future participation

- What does advocacy mean to you?
- What do you do in terms of advocacy re future participation?
- What do we (collectively) do?

## Reflective questions (2)

- Wat could we do to promote participation?
  
  
  
  
  
  
  
  
  
  
- What should we do to promote participation?

## Reflective questions (3)

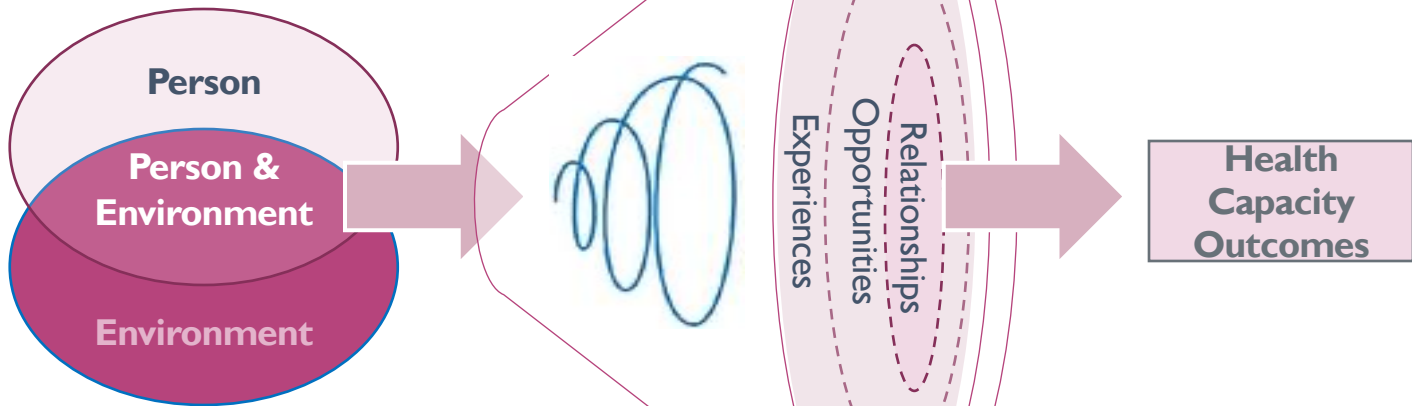
- What do we need to be effective in our advocacy?
- What would help us?
- What would hinder us?



## Back to my experiences with advocacy

- Knowledge synthesis for the Ministry of Child and Youth Services in Ontario
- One plan for all youth
- Insight in developmental trajectories, across conditions
- Conceptual developmental framework

# Development



**P & E Interactions**

**Processes**

**Influences**

Gorter et al.  
CJCMH 2014

## Key-messages for policy and decision makers

- Focus on participation, citizenship, community engagement, and other outcomes that are meaningful to youth with disabilities and their families
- Promote collaboration to provide person-centred planning at important transition points. This involves useful and relevant information for youth and families to help them make informed decisions for the future
- Ensure that adequate resources and supports are available to youth with disabilities and their families to maximize participation and inclusion in the community

Gorter et al. CJCMH 2014



Thank you for your attention!