

# Patient Engagement: New Field and Contested Territory

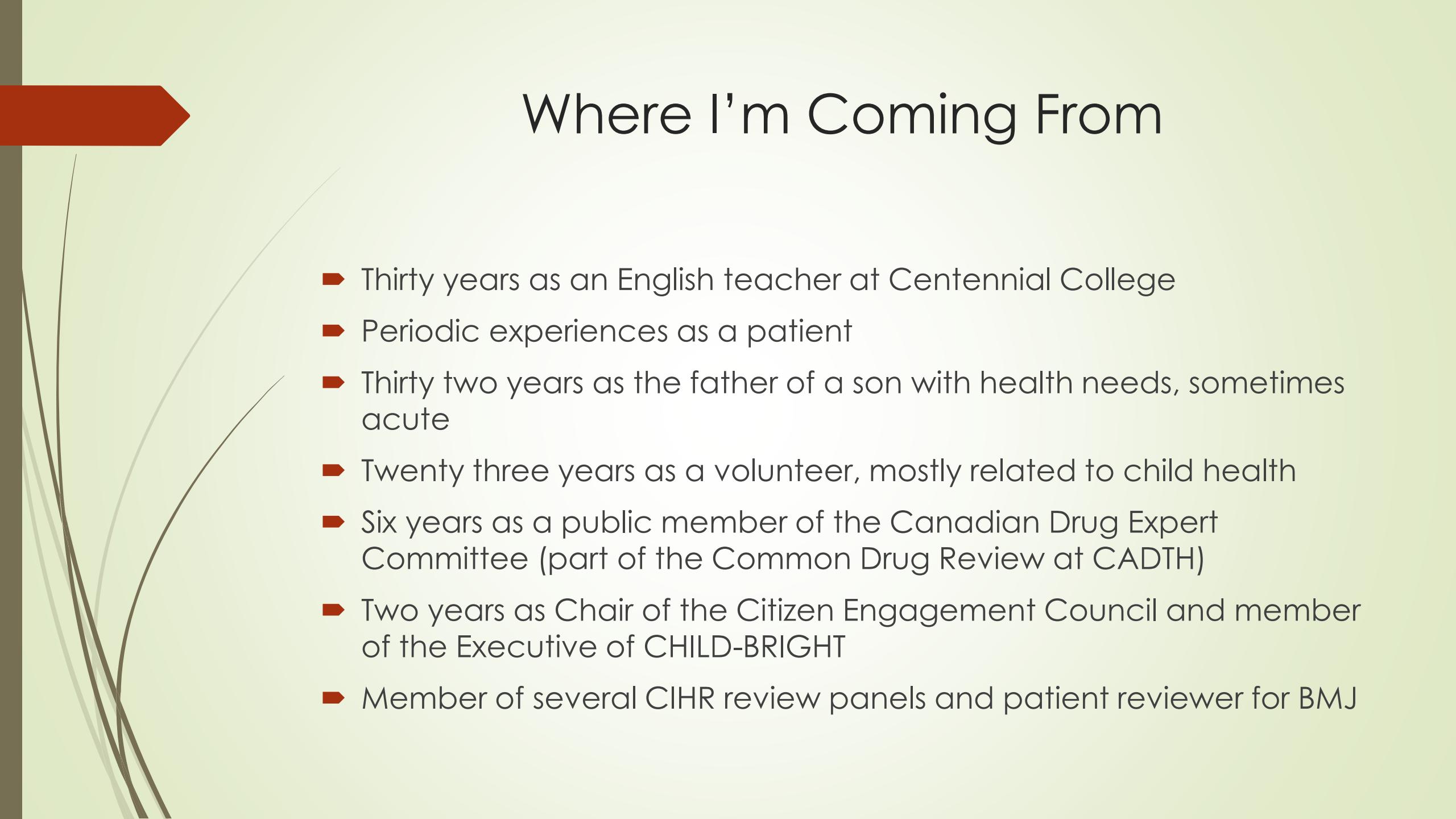
Frank Gavin

Chair, CHILD-BRIGHT Citizen Engagement Council



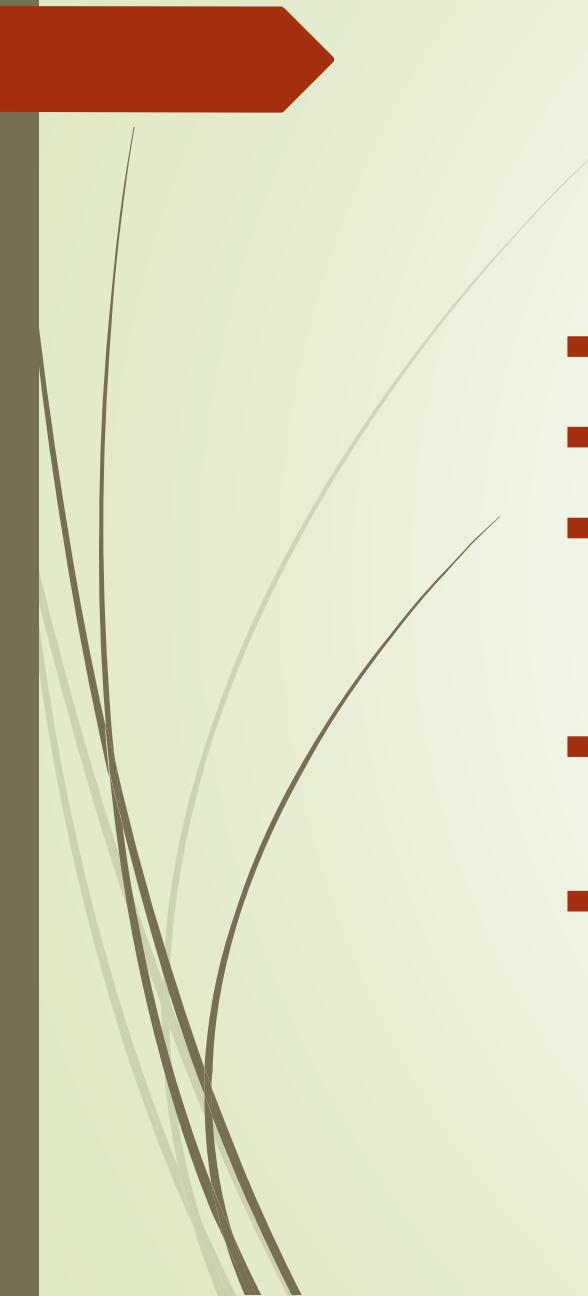
# Questions To Be Addressed

- ▶ Why are “patient” and “engagement” increasingly contested terms?
- ▶ What are the implications of different definitions/understandings of “patient” and of new models of engagement for knowledge translation and research?
- ▶ Are patients, by virtue of their experience or training, experts, and what are the consequences of their claims to expertise and of their being regarded as experts?
- ▶ What is and should be the place of patient stories in KT and in research, especially in relation to their status as evidence?



# Where I'm Coming From

- ▶ Thirty years as an English teacher at Centennial College
- ▶ Periodic experiences as a patient
- ▶ Thirty two years as the father of a son with health needs, sometimes acute
- ▶ Twenty three years as a volunteer, mostly related to child health
- ▶ Six years as a public member of the Canadian Drug Expert Committee (part of the Common Drug Review at CADTH)
- ▶ Two years as Chair of the Citizen Engagement Council and member of the Executive of CHILD-BRIGHT
- ▶ Member of several CIHR review panels and patient reviewer for BMJ



# Who is a patient?

- ▶ “Patient” no longer an episodic identity—this is quite new.
- ▶ “Patient” becoming a primary identity—this too is new.
- ▶ CIHR: patient is an “overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends.” (**Who, then, is not a patient?**)
- ▶ PCORI (U.S.) includes all those CIHR does and adds “organizations that are representative of the populations of interest.”
- ▶ NICE (UK) has a Citizens Council and refers to “patients, service users, carers, and lay people.”



# Who is a real patient?

- ▶ Carolyn Thomas: “**We are all patients.**” **No you’re not** (<https://myheartsisters.org/2013/12/17/we-are-all-patients/>)
- ▶ Carolyn Thomas: Patients can be ranked as **1) high-risk patients, 2) rising-risk patients, and 3) low-risk patients**
- ▶ E-Patient Dave: “**Are there any actual sick people in the room?**”
- ▶ What about those using health services who reject being called patients and prefer to be called clients or people with lived experience or ...?



# When you hear “patient engagement,” who do you think ...

- ▶ initiates the engagement, i.e. Who's engaging whom?
- ▶ decides how many to engage and whom to include and exclude?
- ▶ decides its purpose?
- ▶ determines its scope?
- ▶ decides whether it's a success?
- ▶ decides when it begins and ends?

---

Can—**should**—engagement be two-way, even multi-directional, reciprocal?

What would have to change?



# And when you hear “knowledge translation” who do you think ...

- ▶ has the knowledge that needs translation?
  - ▶ decides what needs to be translated?
  - ▶ determines where and how it will be translated?
  - ▶ does the translating?
  - ▶ decides whether the translation has been successful?
  - ▶ **And** Who are the people usually referred to as “knowledge users”?
- 

Can—**should**—knowledge translation and exchange be two-way, multi-directional, and reciprocal?

What would have to change?



# Patients as Experts: A Welcome Development?

- ▶ “Some patients have the readiness to contribute as full members of research teams, while others may bring **expertise** in a certain area (e.g., ethics) or serve as knowledge brokers. Other patients bring the collective voice of a specific community. Their knowledge and **expertise** offers (sic) insights ...” (My emphases) <http://www.cihr-irsc.gc.ca/e/45851.html>
- ▶ Julia Hanigsberg (CEO of Holland Bloorview): “I am constantly reminded ... that the parents of the children we serve **have a PhD** in their own child ...”
- ▶ The Ontario SPOR Support Unit runs a “**masterclass**” in the conduct and use of patient-oriented research.

---

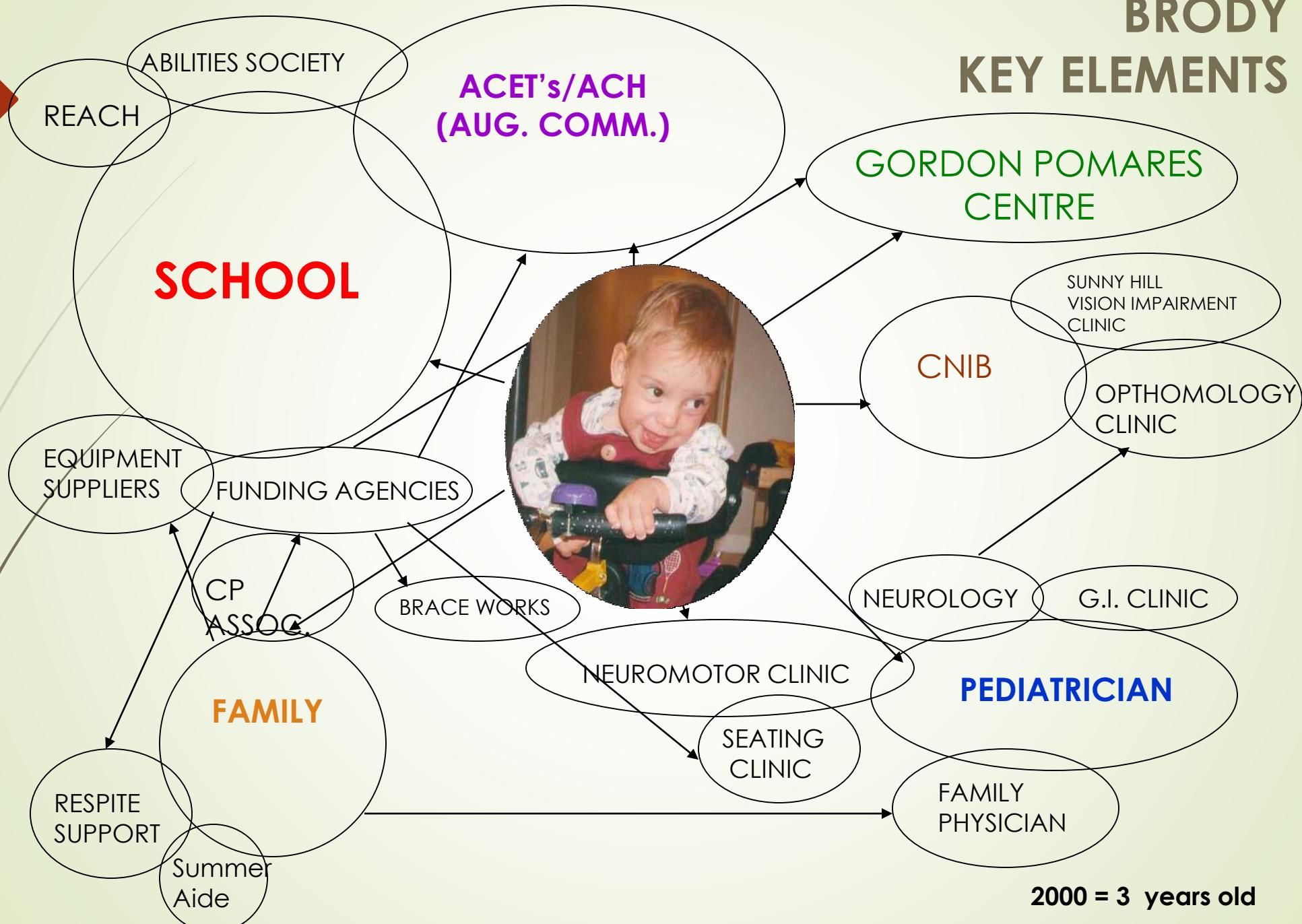
Why the desire/need to claim expertise and establish credentials?  
Whom does this help? Whom might it hurt? What are effects?



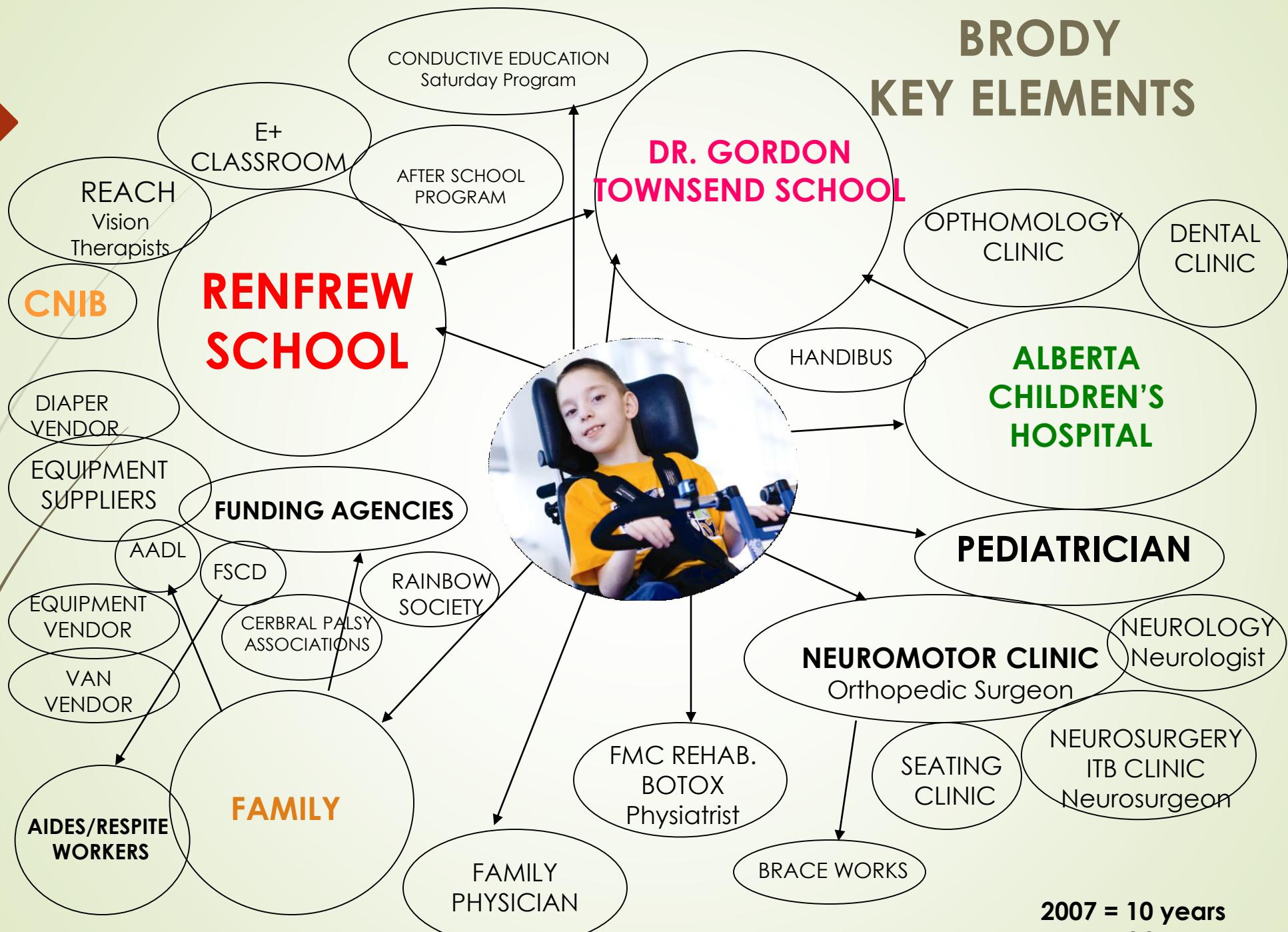
# Expertise or Deep Knowledge?

- ▶ Is the person who created the two care maps that follow (Joanne Ganton in Calgary) necessarily an expert?
- ▶ If she is an expert, about what/whom is she an expert?
- ▶ Does she have knowledge that needs to be shared?
- ▶ Is she a capable knowledge-sharer, even translator?

# BRODY KEY ELEMENTS



# BRODY KEY ELEMENTS



# Questions Arising from the Care Maps

- ▶ What purposes do or can the care maps serve?
- ▶ Which of the elements of care identified in the bubbles is most important? (Such maps/contributions as antidotes to what Kahneman calls “the focusing illusion”)
- ▶ Who decides which is most important?
- ▶ What's not included in the care maps?
- ▶ What do the care maps not tell us?

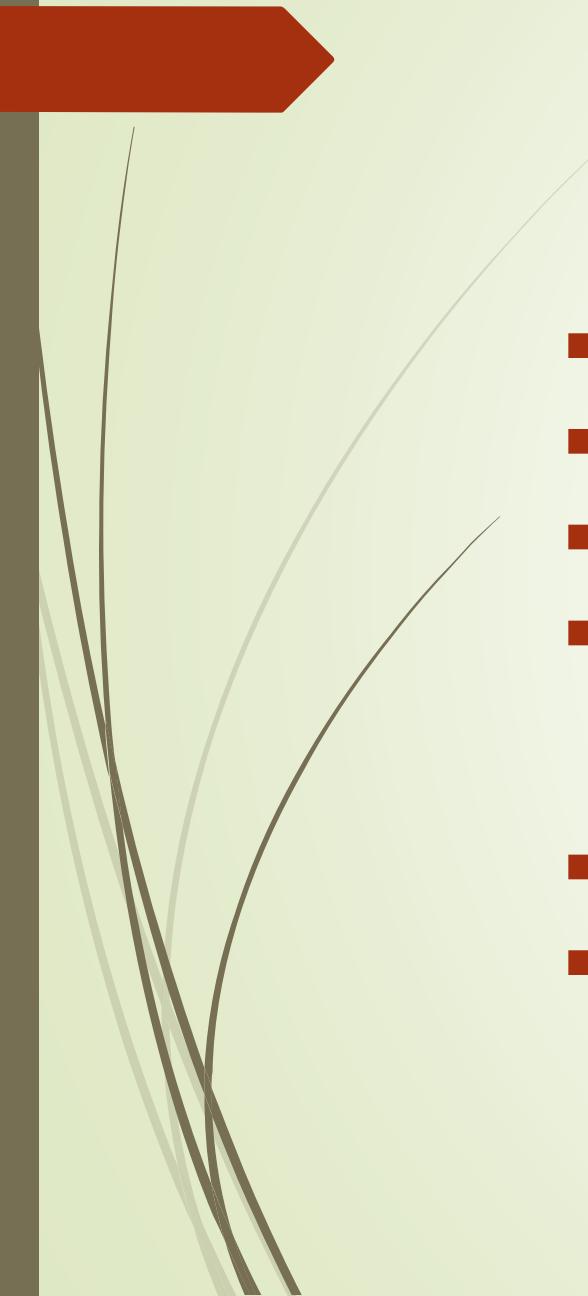
Care map by Joanne Ganton included in Gavin F. An imaginative partnership: parents and the doctors who care for their children. *Paediatrics and Child Health* 2009; 14: 295-7. See also Adams S. et al. Care maps for children with medical complexity *Dev Med & Child Neurology DOI:10.1111/dmcn.13576*



# Lived Experience and Stories: Not the Same

- ▶ Lived experience is a given: we own it and can choose to share it.
  - ▶ Stories are created / produced.
  - ▶ Stories emerge from experience and from other stories (Why are so many healthcare stories called journeys?)
  - ▶ The receivers of a story (listeners, readers, and viewers) are as free and often as capable as the story's creator to determine the meaning of a story.
  - ▶ The problem with advocacy stories in research.
  - ▶ Stories can “emplot” a future. (Frank: *Letting Stories Breathe*)
- 

Can—**should**—stories be regarded as evidence—or as sources of insight into evidence? Can stories be harmful? How best to use stories in KT/KE?



# Sharing What Matters: in Healthcare and in Life

- ▶ Some examples from my own experience
- ▶ The examples from Atul Gawande's *Being Mortal*?
- ▶ Your examples?
- ▶ What else (beside knowledge) was exchanged and what had to be established for the exchange 1) to happen and 2) to be effective?
- ▶ What skill(s) and attitudes were necessary?
- ▶ Can we apply what we know and move from different territories to common ground?



# Thank You!

I'm happy to respond to questions and to provide a list of resources about patient/public engagement.

[frankgavin@rogers.com](mailto:frankgavin@rogers.com)