




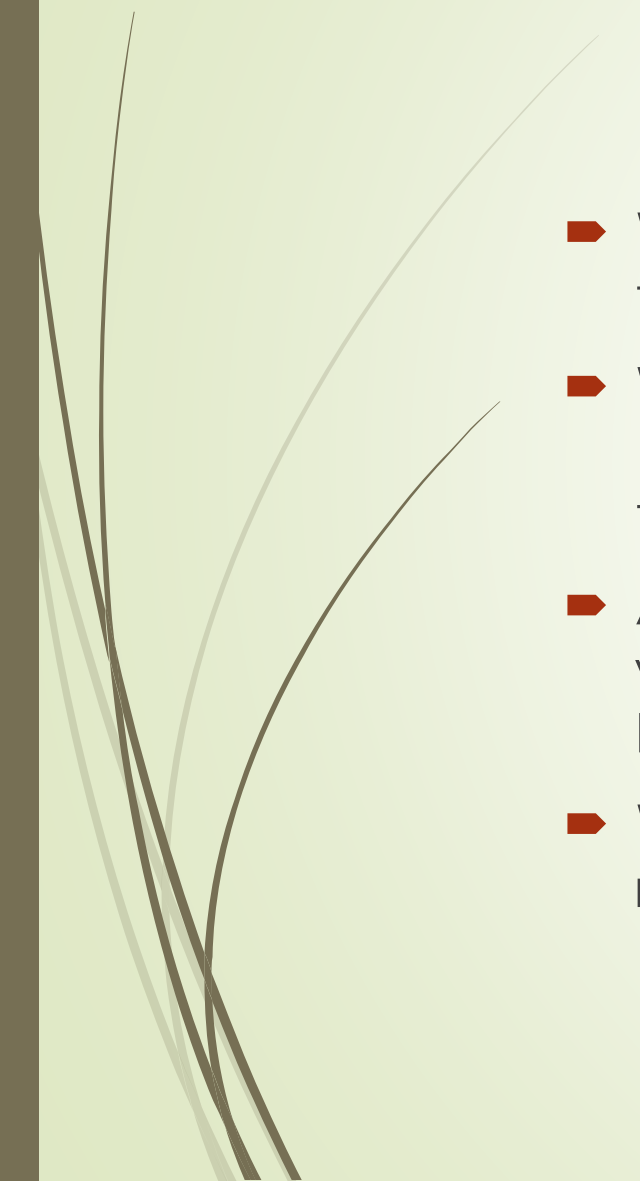
Patient Engagement: New Field and Contested Territory

Frank Gavin

Chair, CHILD-BRIGHT Citizen Engagement Council

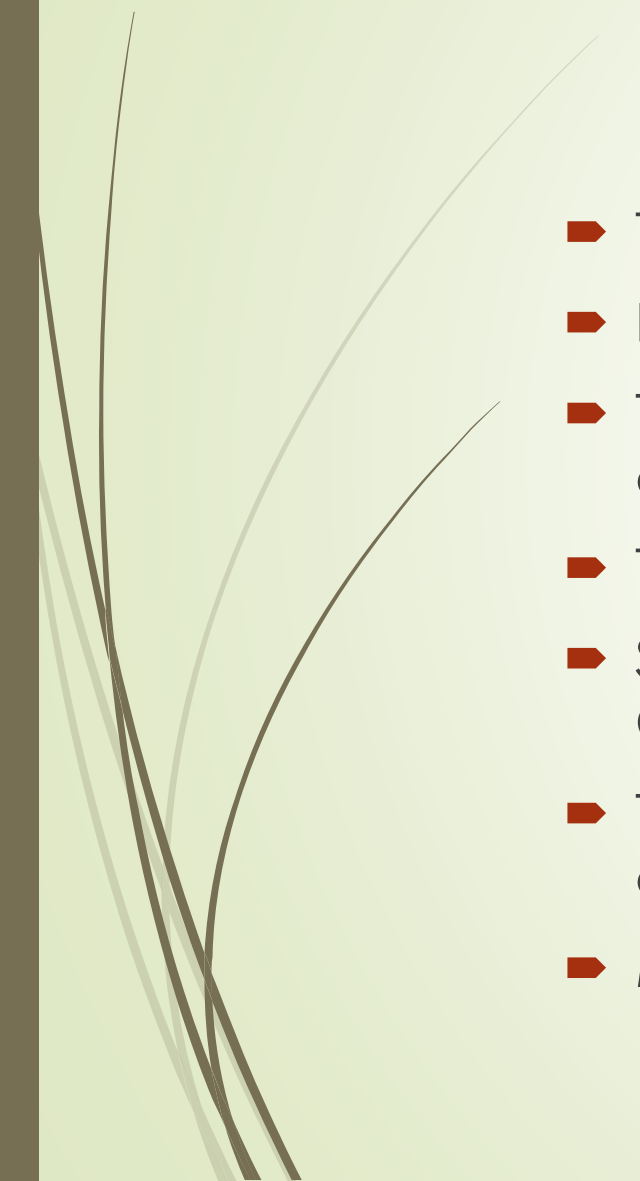


Questions To Be Addressed

- 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?
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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
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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?

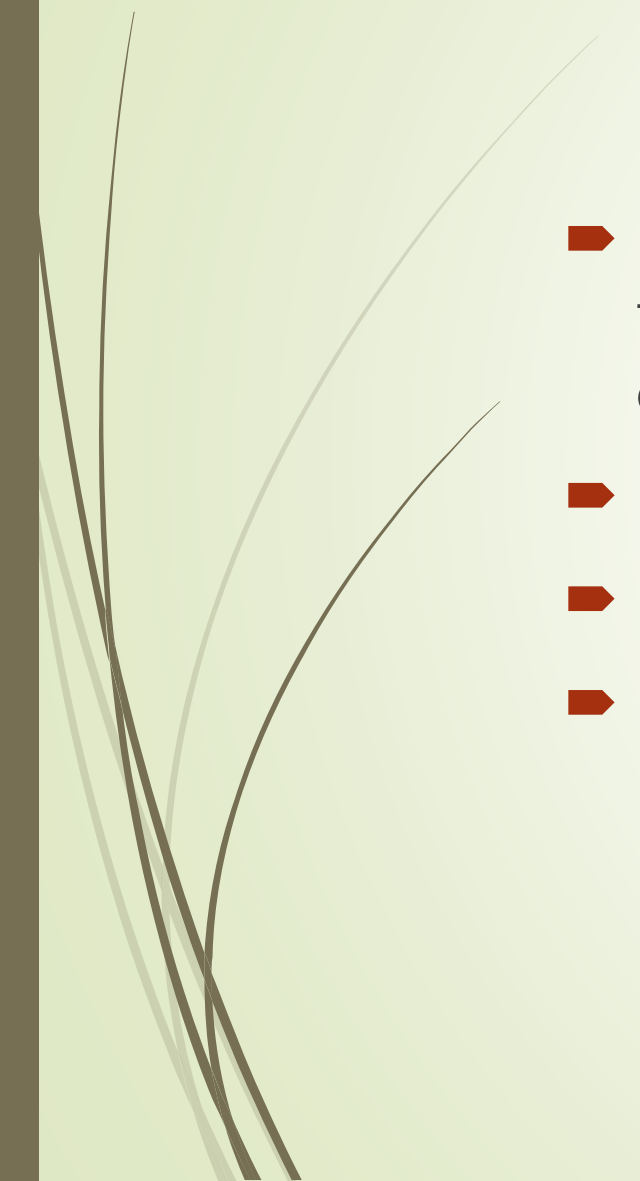
- ▶ “Some patients have the readiness to contribute as full members of research teams, while others may bring **expertise** in a certain area (e.g., ethics) or serve as knowledge brokers. Other patients bring the collective voice of a specific community. Their knowledge and **expertise** offers (sic) 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?

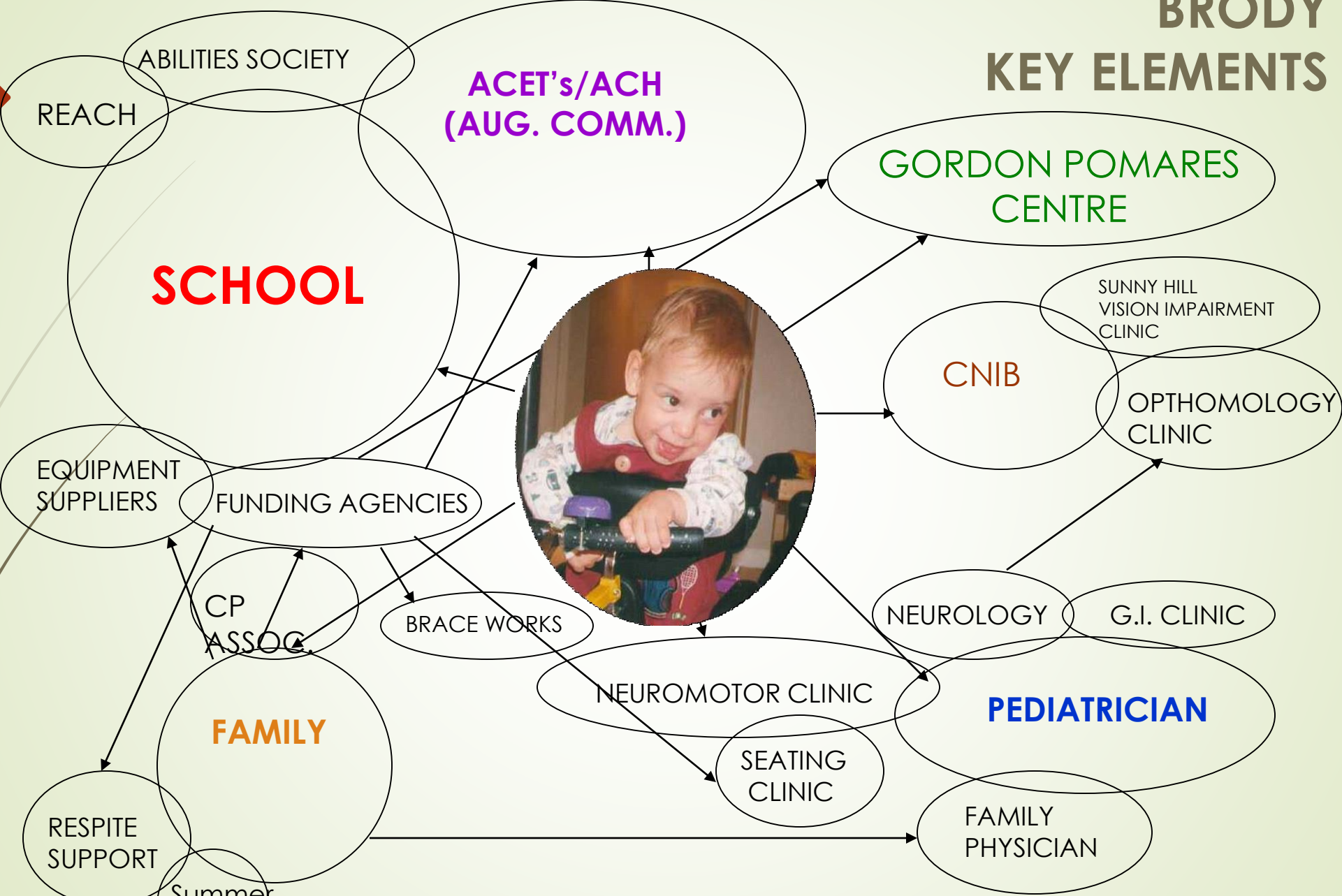
Whom does this help? Whom might it hurt? What are effects?



Expertise or Deep Knowledge?

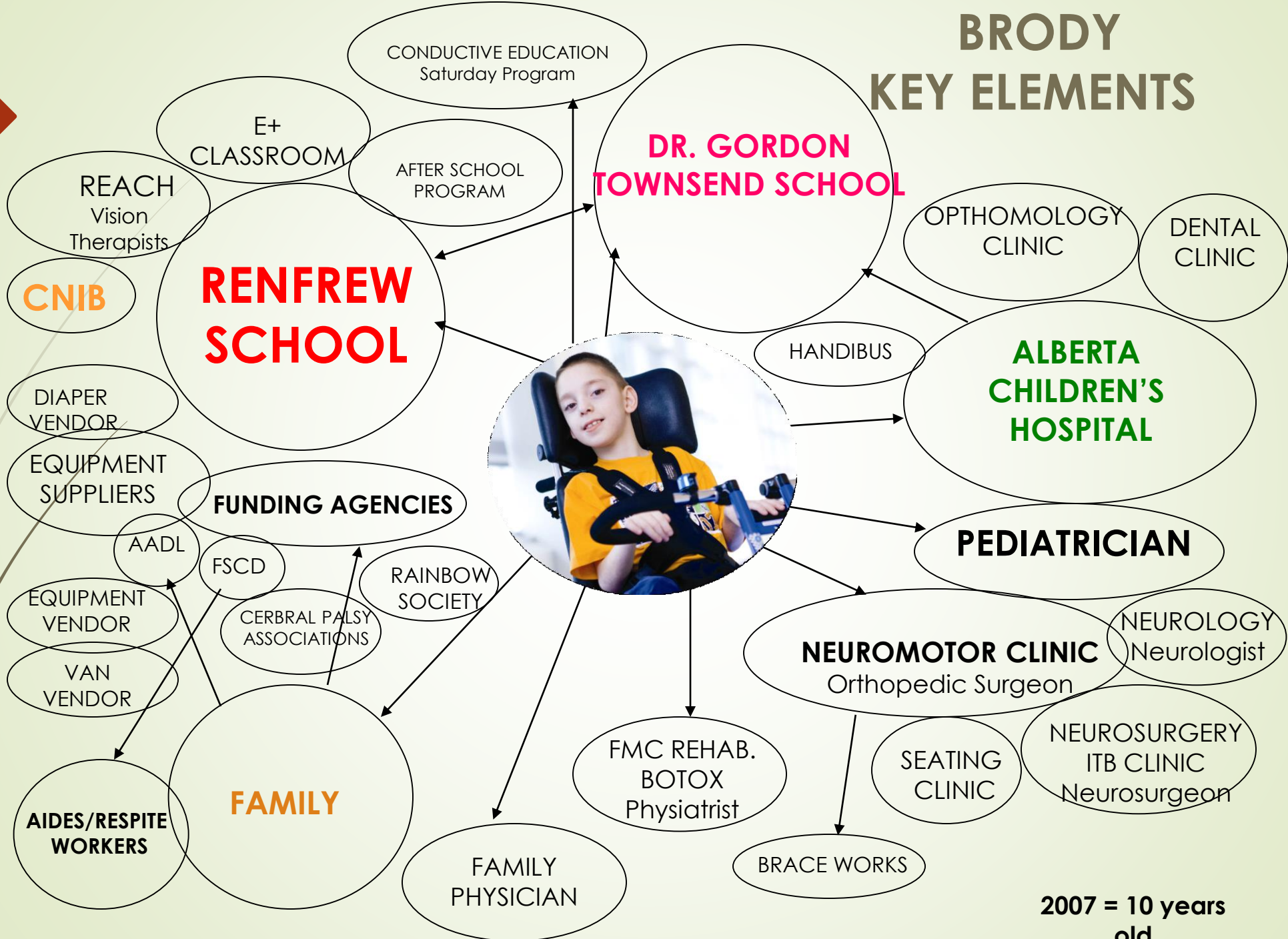
- ▶ Is the person who created the two care maps that follow (Joanne Ganton in Calgary) necessarily an expert?
 - ▶ If she is an expert, about what/whom is she an expert?
 - ▶ Does she have knowledge that needs to be shared?
 - ▶ Is she a capable knowledge-sharer, even translator?
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BRODY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



2000 = 3 years old

BRODY KEY ELEMENTS



2007 = 10 years old



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