



DEPARTMENT OF FAMILY MEDICINE

Intellectual and Developmental
Disabilities Program

Stories of Family Physicians' Experiences with Adults with Intellectual and Developmental Disabilities

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Presenter Disclosure

- **Faculty:** Meg Gemmill MD CCFP
- **Relationships with financial sponsors:**
 - I am faculty at Queen's University in the Department of Family Medicine
 - I have received honoraria for my participation in the development of the 2018 Canadian Consensus Guidelines for Primary Care of Adults with IDD.



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Objectives

1. Apply the 2018 Primary Care of Adults with Intellectual and Developmental Disabilities: Canadian Consensus Guidelines through a narrative medicine lens.
2. Integrate learning pearls in the care of adults with IDD from the experience of expert colleagues.
3. Reflect on experiences with patients with IDD to help develop narrative competence.



Outline

1. Review of the 2018 Primary Care of Adults with IDD: Canadian Consensus Guidelines
2. An introduction to narrative medicine
3. Expert reflections
4. Reflective exercise
5. Next steps in incorporating narrative medicine into care of adults with IDD



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Research Article | Practice

Primary care of adults with intellectual and developmental disabilities

2018 Canadian consensus guidelines

William F. Sullivan, Heidi Diepstra, John Heng, Shara Ally, Elspeth Bradley, Ian Casson, Brian Hennen, Maureen Kelly, Marika Korossy, Karen McNeil, Dara Abells, Khush Amaria, Kerry Boyd, Meg Gemmill, Elizabeth Grier, Natalie Kennie-Kaulbach, Mackenzie Ketchell, Jessica Ladouceur, Amanda Lepp, Yona Lunsky, Shirley McMillan, Ullanda Niel, Samantha Sacks, Sarah Shea, Katherine Stringer, Kyle Sue and Sandra Witherbee

Canadian Family Physician April 2018, 64 (4) 254-279;

[Article](#) [Figures & Data](#) [CFPlus](#) [eLetters](#) [Info & Metrics](#)



Abstract

Objective To update the 2011 Canadian guidelines for primary care of adults with intellectual and developmental disabilities (IDD).

Methods Family physicians and other health professionals experienced in the care of people with IDD reviewed and synthesized recent empirical, ecosystem, expert, and experiential knowledge. A system was developed to grade the strength of recommendations.

In this issue



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Vol. 64, Issue 4
1 Apr 2018

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Care of Adults with IDD: Canadian Consensus Guidelines (2018)

- Published in 2006, revised in 2011 & 2018
 - 32 guidelines
 - Over 100 evidence-based recommendations:
 - Approaches to care
 - Assessments and considerations important for all care
 - Physical health issues
 - Behavioural and mental health issues

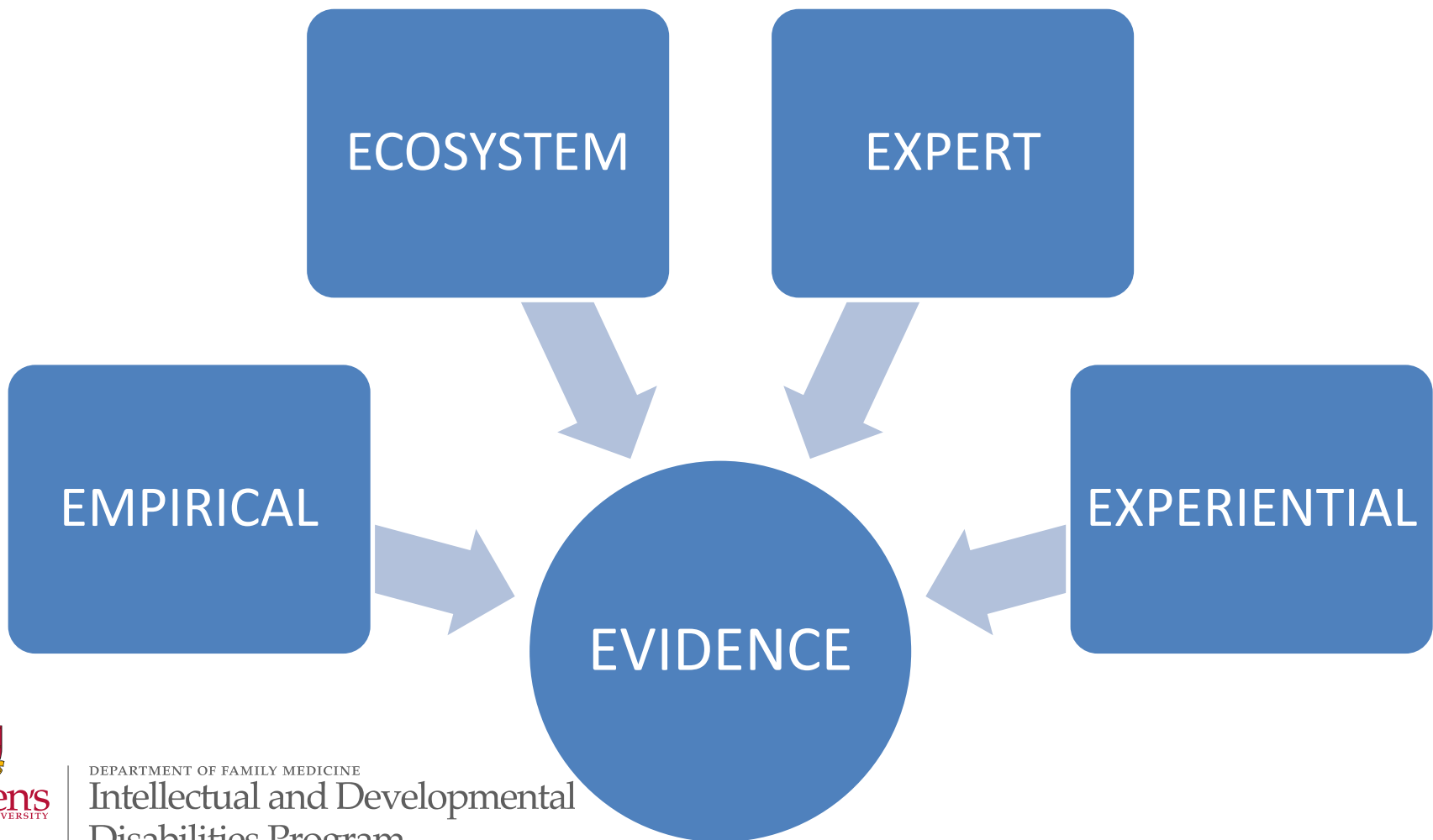
ddprimarycare.surreyplace.ca



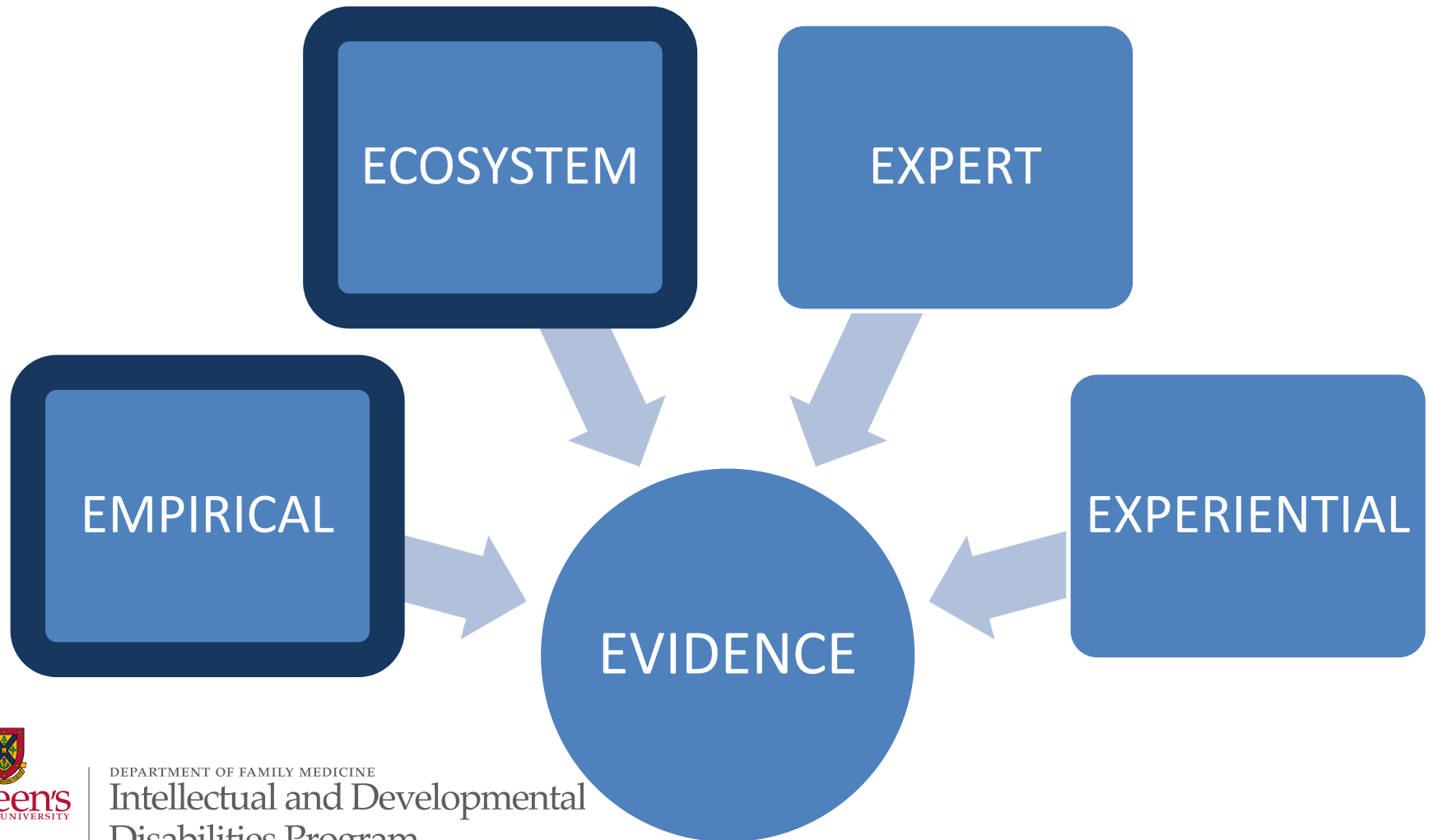
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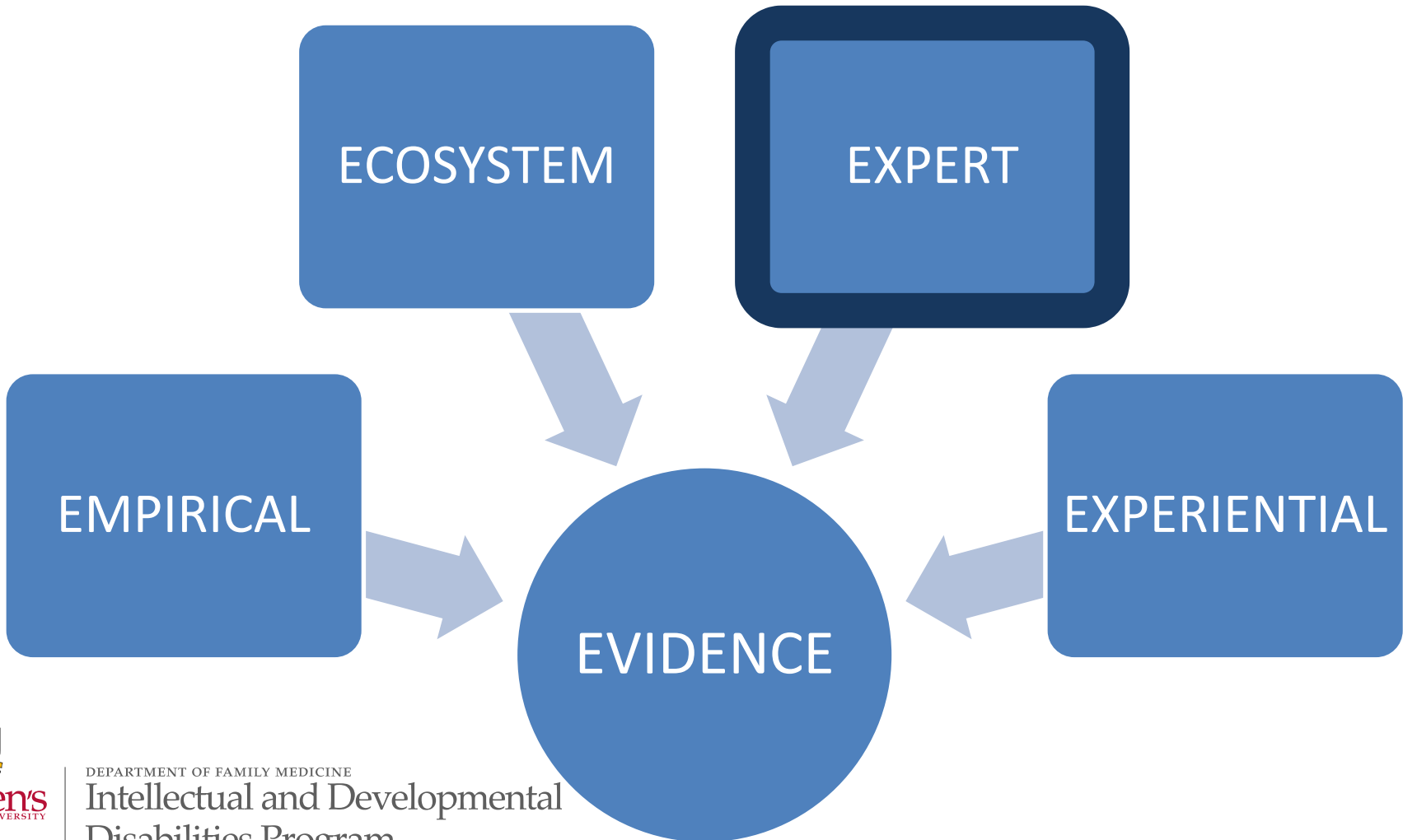
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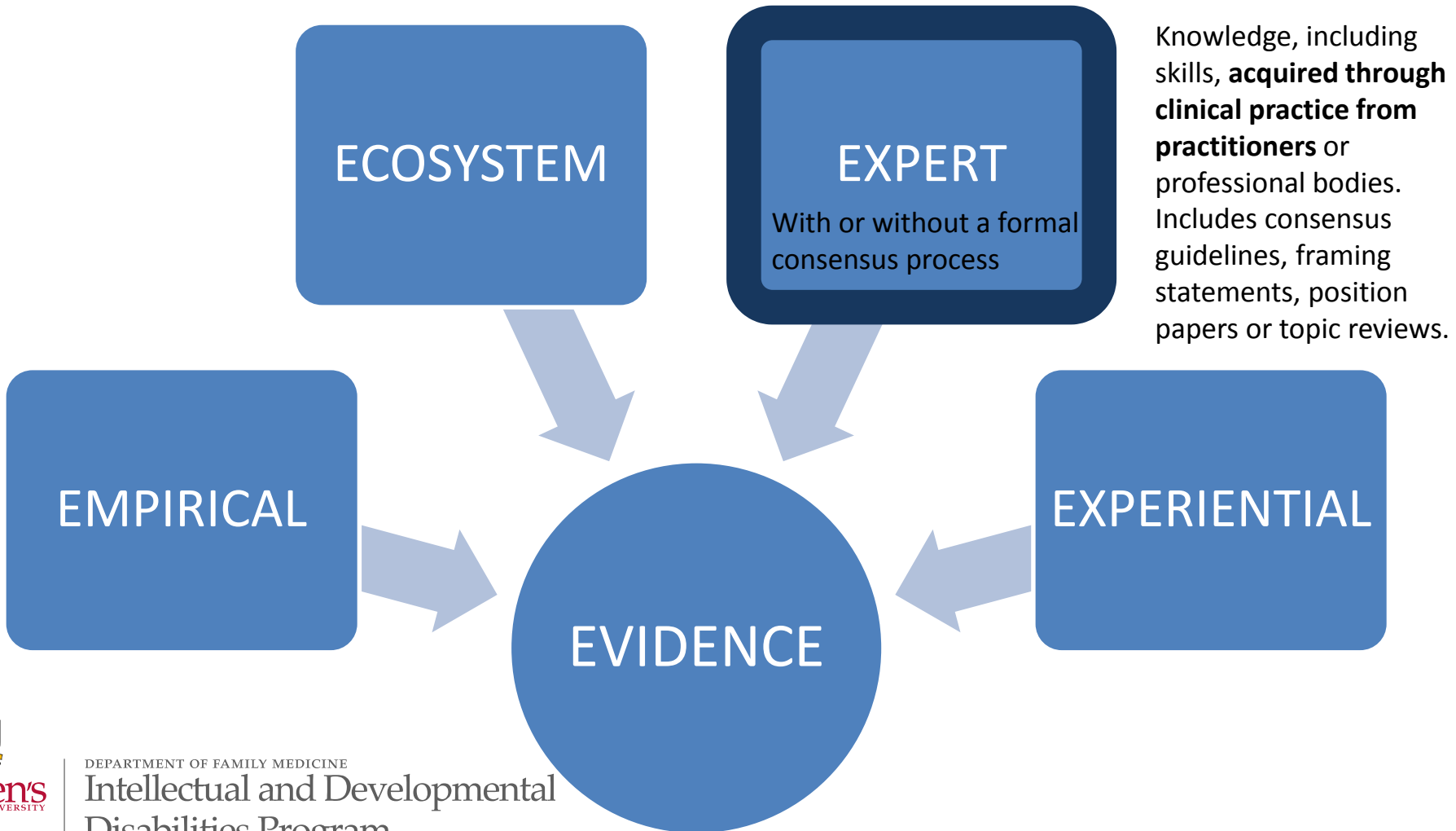
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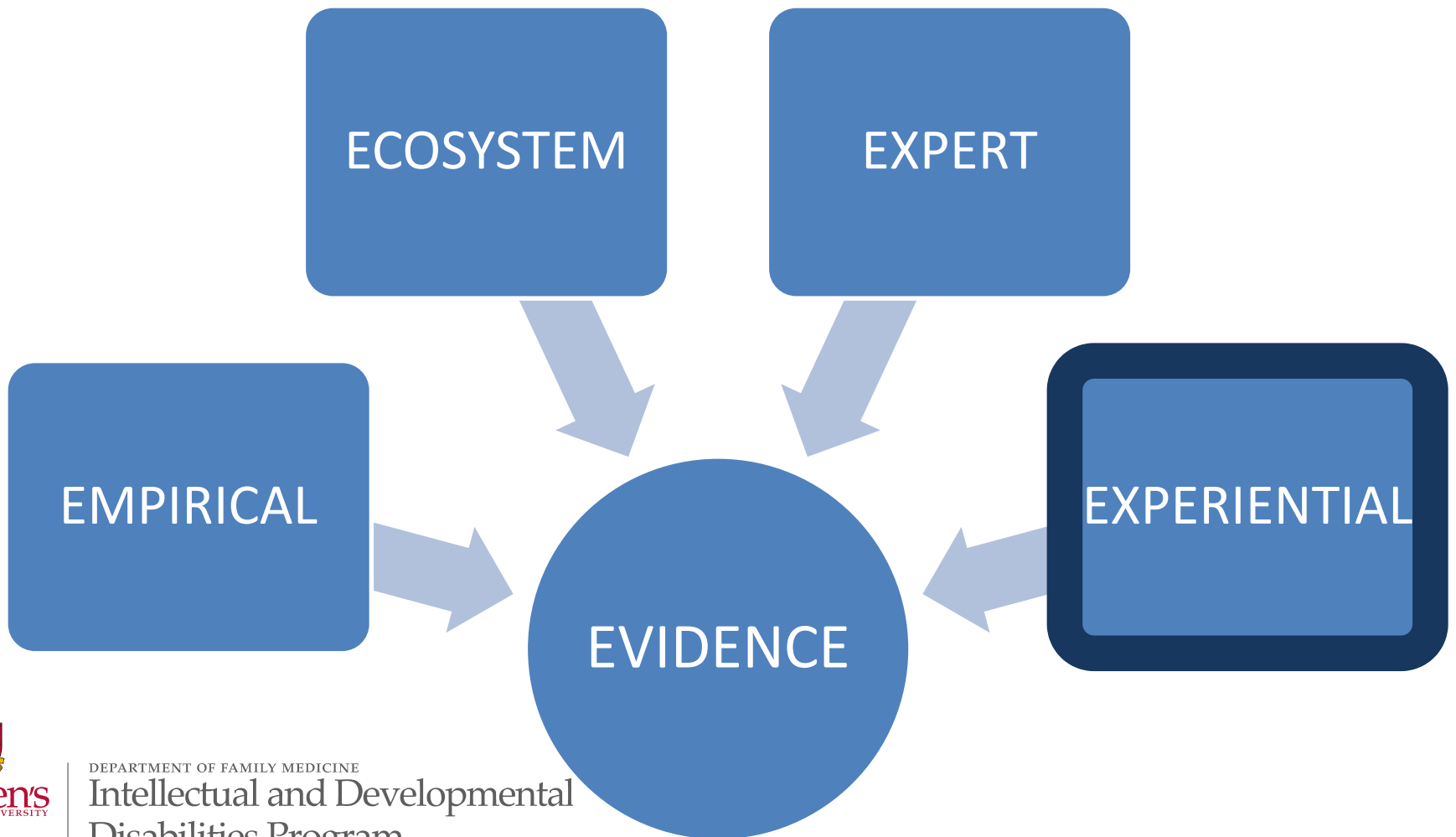
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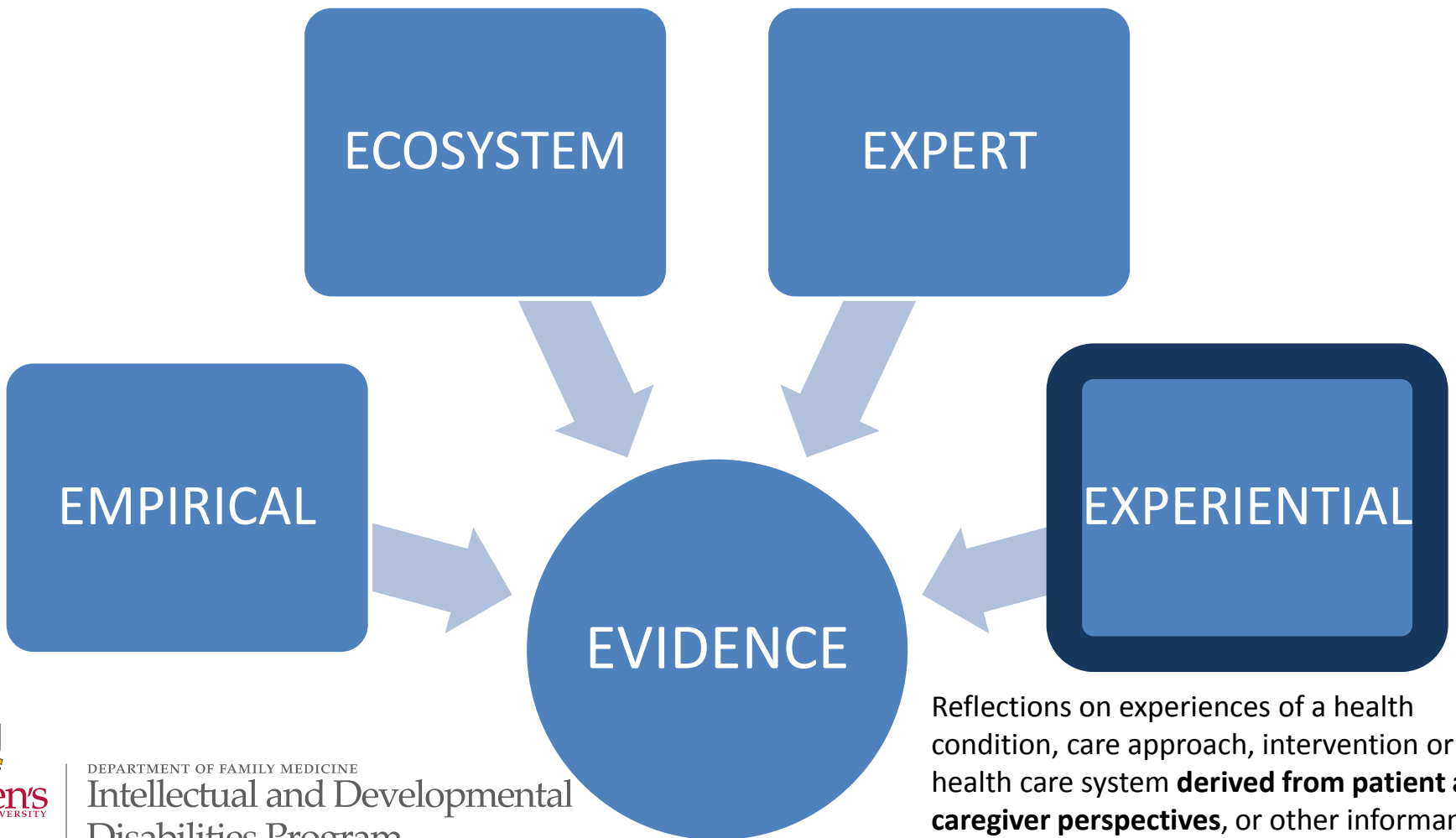
Care of Adults with IDD: Canadian Consensus Guidelines (2018)



Care of Adults with IDD: Canadian Consensus Guidelines (2018)



Care of Adults with IDD: Canadian Consensus Guidelines (2018)



Reflections on experiences of a health condition, care approach, intervention or health care system **derived from patient and caregiver perspectives**, or other informants.

2018 Canadian Consensus Guidelines

“The quality of primary care experienced by adults with IDD is correlated not only with *what* their family physicians know medically, but also with *how* they relate to their patients and caregivers.”¹



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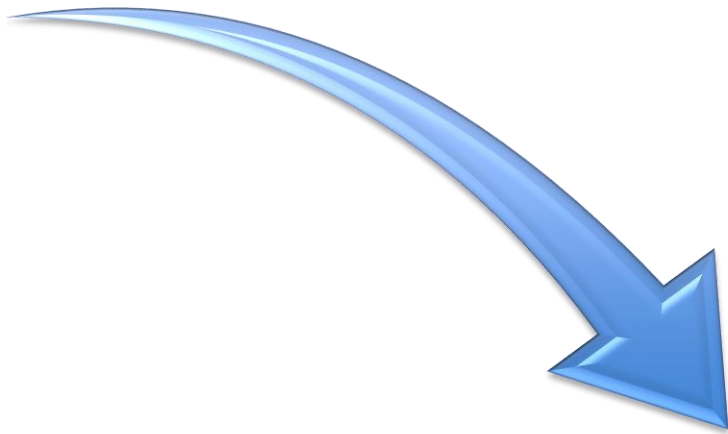
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Narrative Medicine

- A fundamental tool to acquire, comprehend and integrate the different points of view of all the participants having a role in the illness experience¹.

Narrative Medicine

PROBLEM
SOLVING



UNDERSTANDING





storytelling
exploring
understanding
bridging curiosity listening
story doctor emotions
empathy conversation
context patient belief
connection concern
person interest change
feelings validation fear
physician divide
meaning
experience

What is narrative medicine?



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What is Narrative Medicine?

*“Narrative medicine provides healthcare professionals with practical wisdom in comprehending what **patients** endure in **illness** and what **physicians** themselves undergo in the care of the sick.” – Rita Charon*



Evidence for Narrative Medicine

“Narrative Medicine is a useful tool to assess the patients’ experience of illness and could be implemented in daily medical practice to enrich general clinical information focused on the needs and the critical aspects of patients’ lives.”

Fioretti *et al.* (2016)



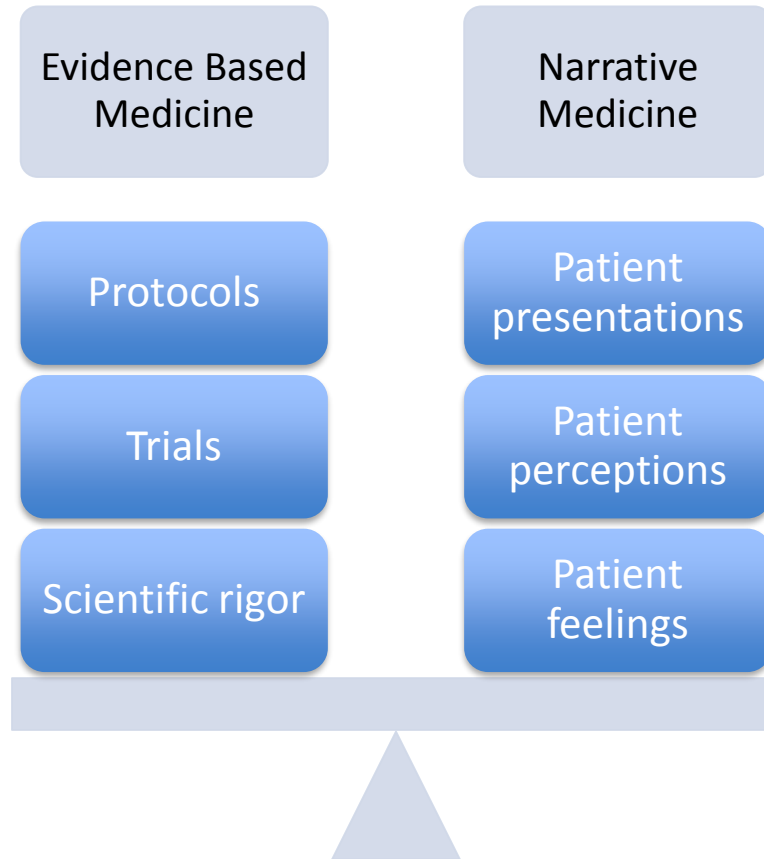
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Evidence for Narrative Medicine

- Examples of benefit to the patient
 - Increased patient wellbeing
 - Reduces cancer pain
 - Reduces disease activity in rheumatoid arthritis
 - Improves lung function in asthma
- Examples of benefit to the physician
 - Greater concern for self-care and resilience
 - Greater understanding of one's own feelings and experiences





Benefits of Narrative Medicine⁵

- Improved communication
- Improved medical information
- **Understanding how evidence can be interpreted in different ways**
- Exposing fears and prejudices in the clinician
- Improving and enriching the doctor-patient relationship
- Fostering shared decision making
- Understanding how medical errors are made and how they can be avoided
- Improving relationships with colleagues
- Enhancing work satisfaction

Narrative Medicine in Patients with IDD

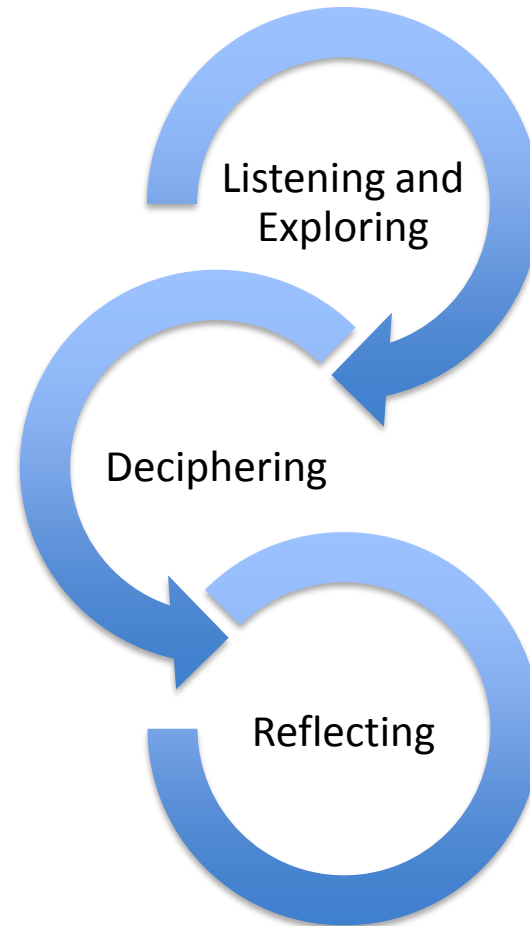
- People with IDD are often medically complex
 - This makes EBM less useful
- Evidence-based medicine is problematic in patients with IDD
- Patients with IDD and their families usually have a long duration of dealing with their illness or disability
- Family physicians are making decisions under conditions of ambiguity and uncertainty



Barriers to Narrative Medicine

- Time
- Experience
- Patient preference
- Physician preference

Narrative Medicine Techniques

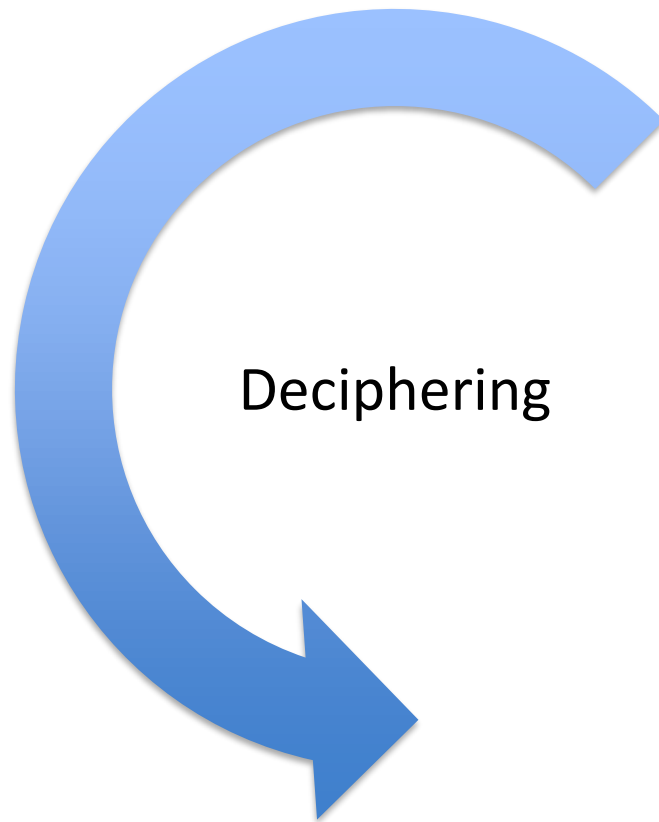


Narrative Medicine Techniques



- Ongoing over several appointments
- Neutrality
- Circular questioning

Narrative Medicine Techniques



- Hypothesizing
 - “how to you explain...”
 - “suppose...”
 - “what if...”

Narrative Medicine Techniques



- On oneself, the patient, and the interaction
- Solo or group
- Writing
 - Parallel Charts

Reflections from our Experts

- CFPC Developmental Disabilities Community of Practice Advisory Committee
- As you are reading the reflections, consider:
 - What do you think are the key learning points?
 - What do you think the physician was feeling?
 - Did anything surprise you?
 - Is there anything you agree or disagree with?
 - How does the reflection help you think about guideline recommendations?



Narrative Medicine Exercise

- Write about an encounter with a patient with IDD that moved you.

Conclusions

- Developing narrative competence takes time and practice but can have benefits to both the patient and the physician.
- There is a role for using narrative medicine to help gain the type of experiential and expert knowledge that has been used to create the most recent Primary Care Guidelines for Care of Adults with IDD



Conclusions

- Due to their medical complexity, and the often prolonged duration of their disability, patients with IDD would benefit from an approach that uses both narrative medicine techniques as well as evidence-based medicine.

Where to Start?

- Writing exercises
 - Parallel charts
- Reflective exercises
- Mainpro self-learning credit for the guidelines article in CFP
 - Submit a reflection to CFP
- Narrative Medicine courses



Resources

- 2018 Canadian Consensus Guidelines
 - www.cfp.ca/content/64/4/254
- Online Guidelines
 - ddprimarycare.surreyplace.ca
- 3-part series on Narrative-Based Medicine in the CFP (Dr. George Zaharias)
- Launer J. *Narrative-based primary care. A practical guide*. Abingdon, UK: Radcliffe Medical Press; 2002.



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1. Sullivan *et al.* Primary care of adults with intellectual and developmental disabilities: 2018 Canadian Consensus Guidelines. *CFP* 2018;64(4) 254-279.
2. Fioretti C *et al.* Research studies on patients' illness experience using the narrative medicine approach: a systematic review. *BMJ Open* 2016;6(7):e011220.
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Questions?



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