

CAREGIVER EMPOWERMENT THROUGH TRAINING AT MCMASTER UNIVERSITY AND CONTINUING EDUCATION



Donna Thomson

The Family Engagement in Research Certificate of Completion (Microcredential)

- An online (30 hours + assessment) program
- Run in partnership between KBHN, CanChild, and McMaster Centre for Continuing Education

“I think the course definitely gave me more confidence in how to how to be engaged as a family because it also identified and highlighted some ways to do it.... I learned some actual steps in what it takes to do that, so knowing how to do it gives you the confidence on how to ask for it.” – Parent



Why is training needed?

- **Lack of training, yet desire and need to engage being driven by research funders and parent community**
- Families want to influence both WHAT is researched and HOW it is researched in order to influence health care experiences
- *FOR MEANINGFUL PARTNERSHIP TO OCCUR, ALL PARTIES MUST BE TRAINED (together as co-learners) IN BOTH THE THEORY AND THE PRACTICE OF RESEARCH ENGAGEMENT ("flattened hierarchies").*

Course Goals

- Create a cohort of *family members and researchers* who are:
 - Invested in contributing to and ready to engage in neurodevelopmental research
 - Knowledgeable about the research process and can make informed decisions with regards to partnering on a research project
 - Capable and confident to engage with each other at various levels of the research process.

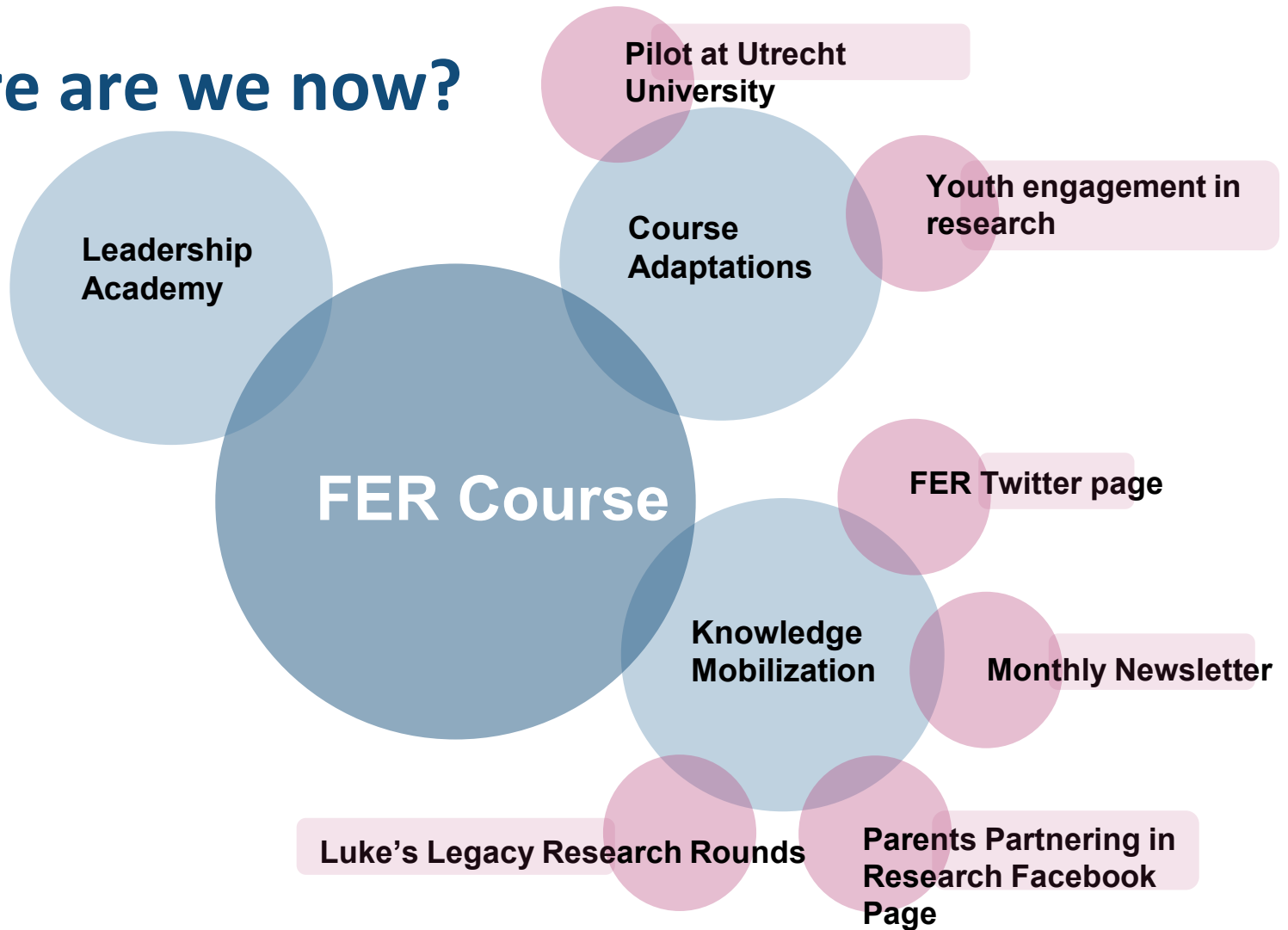
Course Graduates

- 224 Grads (108 family member; 116 researcher) - 27 family members identified that they also had a researcher role (e.g., 'both').
- 196 from Canada and 28 international from 12 countries.
- 61 KT Tools on the CanChild website

Course Schedule

Week	Topic
Week 1	Family Engagement in Research: What do we really mean?
Week 2	Family Engagement in Research: Why is it important?
Week 3	Building an integrated research team: How can we find each other?
Week 4	Building an integrated research team: How can we work together?
Week 5	Roles and responsibilities of families and researchers
Week 6	Ethics of family engagement in research
Week 7	Barriers and facilitators to family engagement
Week 8	Evaluation of family engagement activities
Week 9	Family engagement tools & resources
Week 10	Next Steps: Building a community for family-researcher partnerships

Where are we now?



CONTACT: Fer@McMaster.ca

End Note: Caregiving Essentials, McMaster Continuing Education

- Free Online Training Course for Family Caregivers (with microcredential)
- Approx. 1/3 of participants are front line health care providers – some are "Double-Duty" caregivers

Double-Duty Caregivers

- *“In the past four years, I have learned a lot about dementia... I am interested in building my knowledge and skills as a caregiver so that I can support other family caregivers who have decided to place their loved ones into Long-Term Care.” [participant 00E]*
- *- Hosseini et al, 2022*