Childhood Disability in the 21st C.

CanChild's F-words for Child Development

Weaving Together Concepts to Change the Field!

EurlyAid and ISEI ECI Conference,

Lisbon, 2-5 September 2025

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Canada Research Chair in Childhood Disability Research (2001-14)
Co-Founder (1989), CanChild Centre
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A Brief Background ‘Context’…

- Like Dr. Dunst, I have been in the field for a long time!
- As a children’s disability doctor, I used to focus on specific ‘diagnoses’ and their ‘treatments…
- My evolution to the ideas presented today has been slow but steady…
- …and reflects my EXPANDED view of our field…
- Nothing I learned or did was ‘wrong’ – but I hope to share how today’s ideas are much more exciting…
- You can judge!

These ideas can be found (free!) at:

- Rosenbaum PL, Imms C, Miller L, Hughes, D, Cross A. (2024) Perspectives in Childhood-Onset Disability: Integrating 21st-Century Concepts to Expand our Horizons.
  Disabil and Rehabil. 2024 Aug 26:1-11.
  doi: 10.1080/09638288.2024.239464
  (open access)

This Talk Integrates CanChild's Ideas about 'Child-Onset Disability' (i)

1. Expanded Ideas about **Health**: **The W.H.O.'s framework and our 'F-words for Child Development'**
2. **Development**: A Universal Force in Childhood
3. **Parents and Family**: The Essential Environment for Children

This Talk Integrates Our Ideas about 'Child-Onset Disability' (ii)

4. Parenting: 'A Dance Led by the Children'

5. Life-Course Perspectives: Life beyond childhood

6. Knowledge Translation and Implementation:

How Do We Promote, Share, Apply New Ideas, and To Whom?

Before you ask… YES!

- I assume these ideas will sound familiar to you!
- So – you ask – what's new?
- I will try to answer with the following ideas:
  - The **EMPHASES** on these **CONCEPTS**
  - The **CONNECTEDNESS OF THESE IDEAS to one another**
  - The **ICF FRAMEWORK FOR HEALTH** that we believe brings coherence.
- This approach offers ways to help others understand US!
- Once again, YOU can judge!

Take-away Ideas – for Discussion!

- Thinking ***beyond*** our medical traditions in favour of efforts to promote child (and family) **development** and **functioning**.
- Recognizing how the **W.H.O.'s ideas about 'health',** in its ICF framework (and CanChild's animation – the F-words for Child Development) – open new opportunities for our work.
- As Dr. Dunst noted: promoting **FAMILY at the centre** in all our work, to provide 'early intervention' for parents.
- **Moving beyond 'fixing'** and **'normal'** as goals in our fields.
- Taking a **life-course approach** to our work right from the start.


I’ll try not to overfeed you!

FIRST: What do we see here? Depends!...

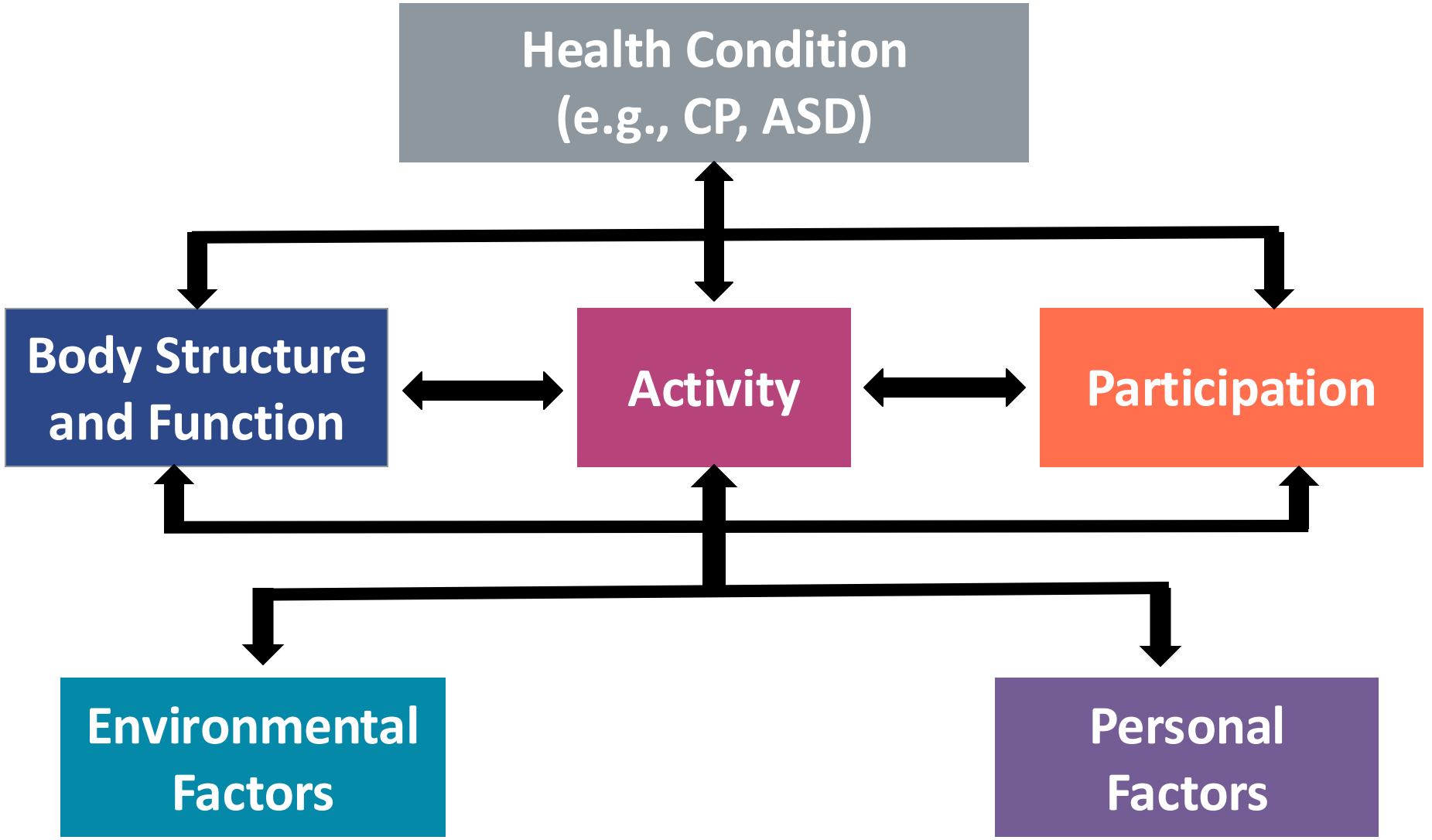
Do we focus on PROBLEMS & CANNOT?

- **What are his Dx and GMFCS level?**
- **What can he NOT do?**
- **Does his seating need improvement?**
- **Does he need more therapy, better equipment, special school..?**
- **What is his long-term prognosis?**
  - **(He'll be back later!)**

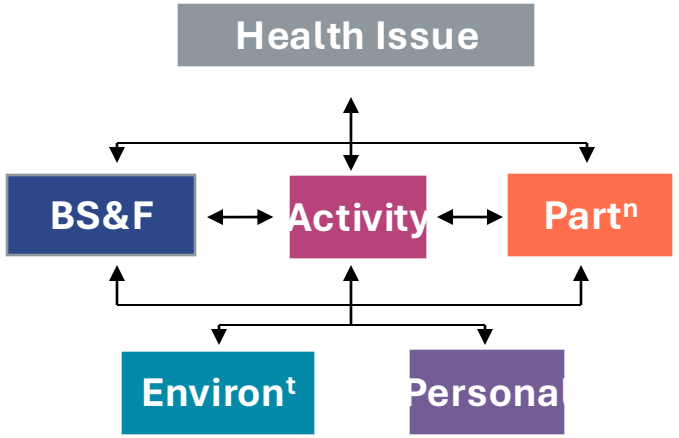
Theme 1: *Expanded Ideas About 'Health': W.H.O.'s 2001 ICF Framework*

- WHO's ideas about health were revised in 2001 to integrate three obvious concepts that affect health:
  - The ***biological/biomedical*** components
  - The ***psychological*** **(within-person)** components
  - The ***social*** **(environmental)** aspects of people's lives
- This **BIO-PSYCHO-SOCIAL** approach is valuable for all of us – we now MUST pay attention to them!

Theme 1: WHO's ICF Framework



Why do we like the ICF?



- It is a framework for **health** for **everyone**
- The words are '**neutral**'
- Everything is **interconnected**
- This is a '**dynamic system**', so *where* we start our interventions is less important than we used to think
- ICF focuses on **strengths** – what people **CAN do!**

Wait! Don't We Already Know This?

- **Yes**, and **No**!
- Many people **DO KNOW** these *words* and *ideas*…
- …but most of us **DO NOT APPLY** them well enough, as we think about and formulate our plans and implement management approaches!
- In other words, like much of what this talk presents – the ideas **MAKE SENSE**, so we THINK we *KNOW* and *DO* them!

Bringing the ICF to Life: The F-words for Child Development

Child: care, health and development

Review Article

doi:10.1111/j.1365-2214.2011.01338.x

The 'F-words' in childhood disability: I swear this is how we should think!

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†NetChild Network for Childhood Disability Research, Utrecht, the Netherlands

Accepted for publication 18 September 2011

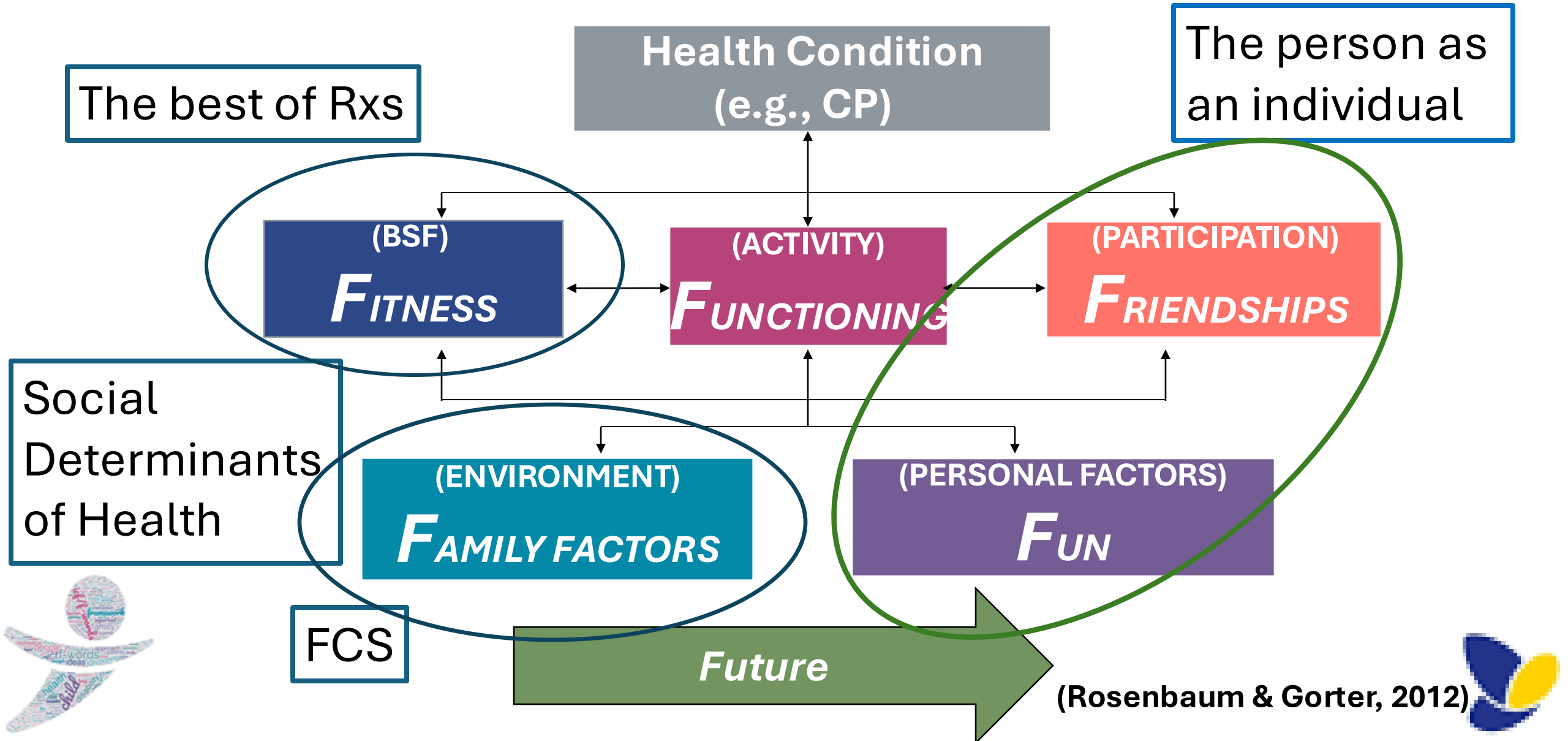
Downloaded **>92,000 times**
(since September 2011)
Cited **>830 times**

Presented **> 250 times**
locally & internationally

Shared around the world and translated into **>35 languages**

Free: https://canchild.ca/research-in-practice/f-words-in-childhood-disability/

“I See F-words” (ICF) in Child Development



(Rosenbaum & Gorter, 2012)

The ICF Framework[1] and the 'F-Words'[2]

Fitness

Everyone needs to stay fit and healthy, including me! Help me find ways to keep fit.

Functioning

I might do things differently but I CAN do them. How I do it is not important. Please let me try!

Friends

Having childhood friends is important. Please give me opportunities to make friends with my peers.

Body Structure and Function ↔ **Activity** ↔ **Participation**

Environmental Factors

Personal Factors

Family

They know me best and I trust them to do what's best for me. Listen to them. Talk to them. Hear them. Respect them.

Fun

Childhood is about having fun and play. This is how I learn and grow. Please help me do the activities that I find the most fun.

Future

For more information visit the F-words Knowledge Hub: canchild.ca/f-words

1) World Health Organization. (2001) *International Classification of Functioning, Disability and Health (ICF)*
2) Rosenbaum P & Gorter JW. (2012). The 'F-words' in childhood disability: I swear this is how we should think! *Child Care Health Dev*; 38.
*Photos shared with permission from World CP Day.

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IT'S IMPORTANT TO NOTE…

This approach is NOT

- … a new assessment measure!

This approach does NOT

- … challenge the roles of professionals!
- … challenge the importance of therapies!

What it DOES aim to do…

- … increase the roles of children, families and their voices!
- … emphasize family values and goals!
- … see the child as a person, in context (family & environment(s))!
- … change the dynamic of families and professionals!

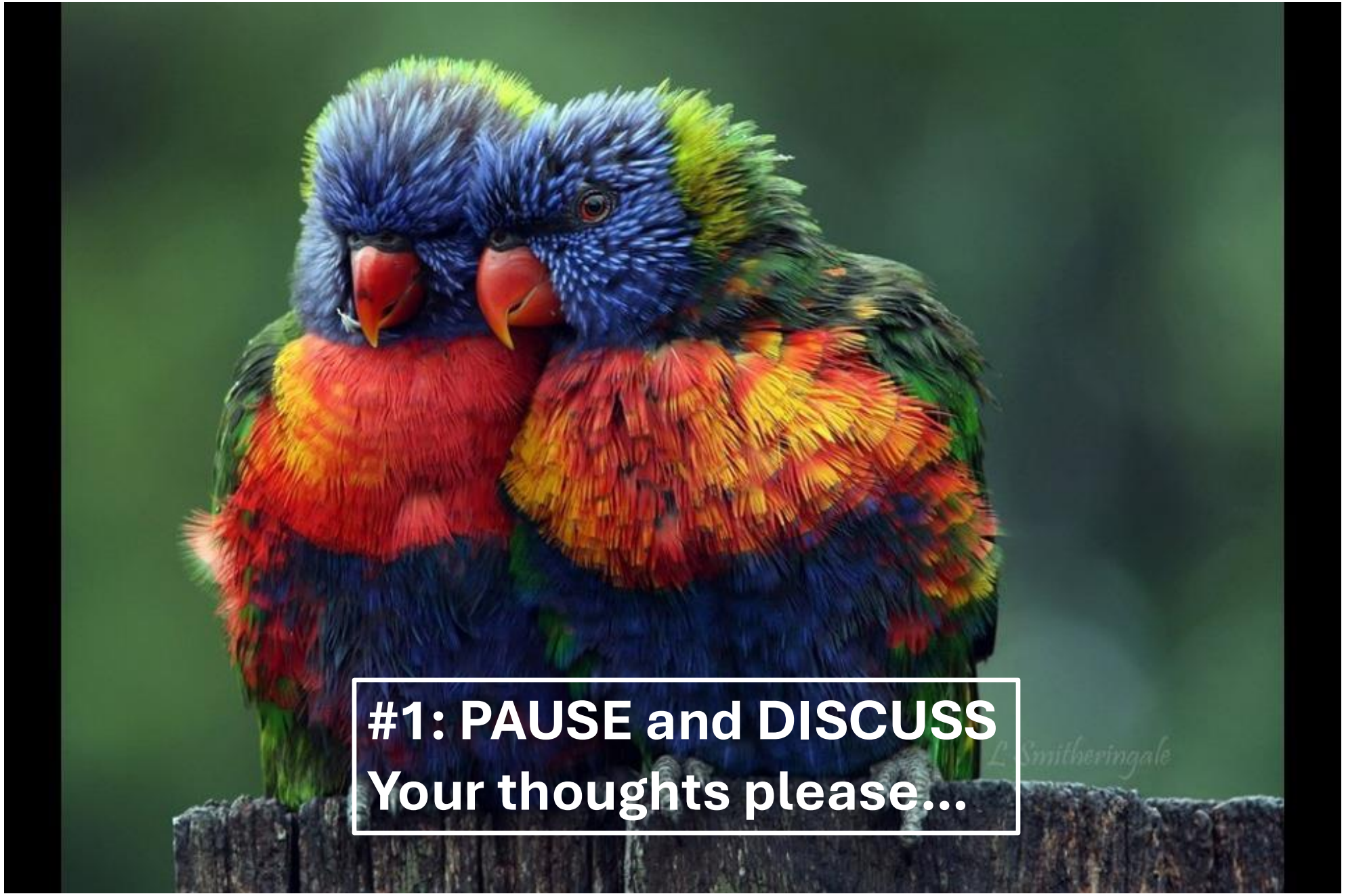
This Framework Serves Everyone!

- In the rest of this talk I hope to illustrate how this expanded view of our field allows us to cover ‘everything’.
- It should also be apparent that all these elements are interconnected and ‘transactional’, each influencing – and being influenced by – all the others!
- Presenting them as separate elements is merely an opportunity to highlight each individually
- Hear more ‘F-Words talk’ in the **Session P 9.12 C5.01 (3-4:15)** ***Implementing Favorite Words for Child Development: Bringing the Ideas to Life for Young Children and Their Families!***

Remember this Fellow?

We now focus on the CAN

- **He's a happy boy!**
- **He's going to SCHOOL!**
- **He has mobility!**
- **Rx: Ideas we need to promote: development, child/family strengths, achievement, being family-centred, life-course thinking**
- Ideas to **de-emphasize** ~~fixing~~, ~~normality~~, ~~disability~~


#1: PAUSE and DISCUSS
Your thoughts please...

Theme 2: *Development of Children & Families*

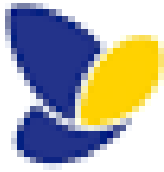
- Unlike adults, children's lives are rapidly and continually evolving and changing – they're a 'work-in-progress'
- Thus, any F-words 'profile' only reflects current status and must constantly be reviewed and revised to keep up with the changing child (and family!)
- The ICF does not include time as a dimension… the F-words creators added it to remind people of development

Isn’t this OBVIOUS?

- **Yes**… and **NO** **(sadly)**!
- Our field is often referred to as ‘Developmental Disability’…
  …and yet, we quickly forget, or ignore, the first word!
- A key idea for <u>all</u> aspects of our field is to ask this question:

WHAT IS THE *IMPACT* – ON (CHILD AND FAMILY)
<u>DEVELOPMENT</u> – OF ANY ‘IMPAIRMENT’?

- Considering this perspective takes us into new territory!



Note the Inclusion of **Family Development**

- Families, like children, are a constant ‘work-in-progress’
- All the individuals in the family change and evolve…
- So does the ‘system’ called ‘family’…
- Thus, each new encounter with ‘them’ – a changed system – is a new adventure for ‘us’ as service professionals!
- **Rx**: Always ask about their **current** thinking – strengths, questions, concerns…
- Rosenbaum PL. (2025). Viewpoint: Childhood Developmental Disability: Recognising the Primary Role of the Family. **BMJ Paediatrics Open 2025;0:1–2. Epub ahead of print: doi:10.1136/bmjpo-2025-003730**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#2: PAUSE and DISCUSS
Your thoughts please...

Theme 3: *Parents and Family: Children's Essential Environment*

- We ***never*** see children on their own!
- We believe that the unit of interest in all areas of child health and development must be **FAMILY**!
- This has implications for **WHAT** we do and **HOW** we do it!
- Both the **CONTENT** and **PROCESSES** of our services must respect parents' expertise.
- "You have textbooks, we have story books!"

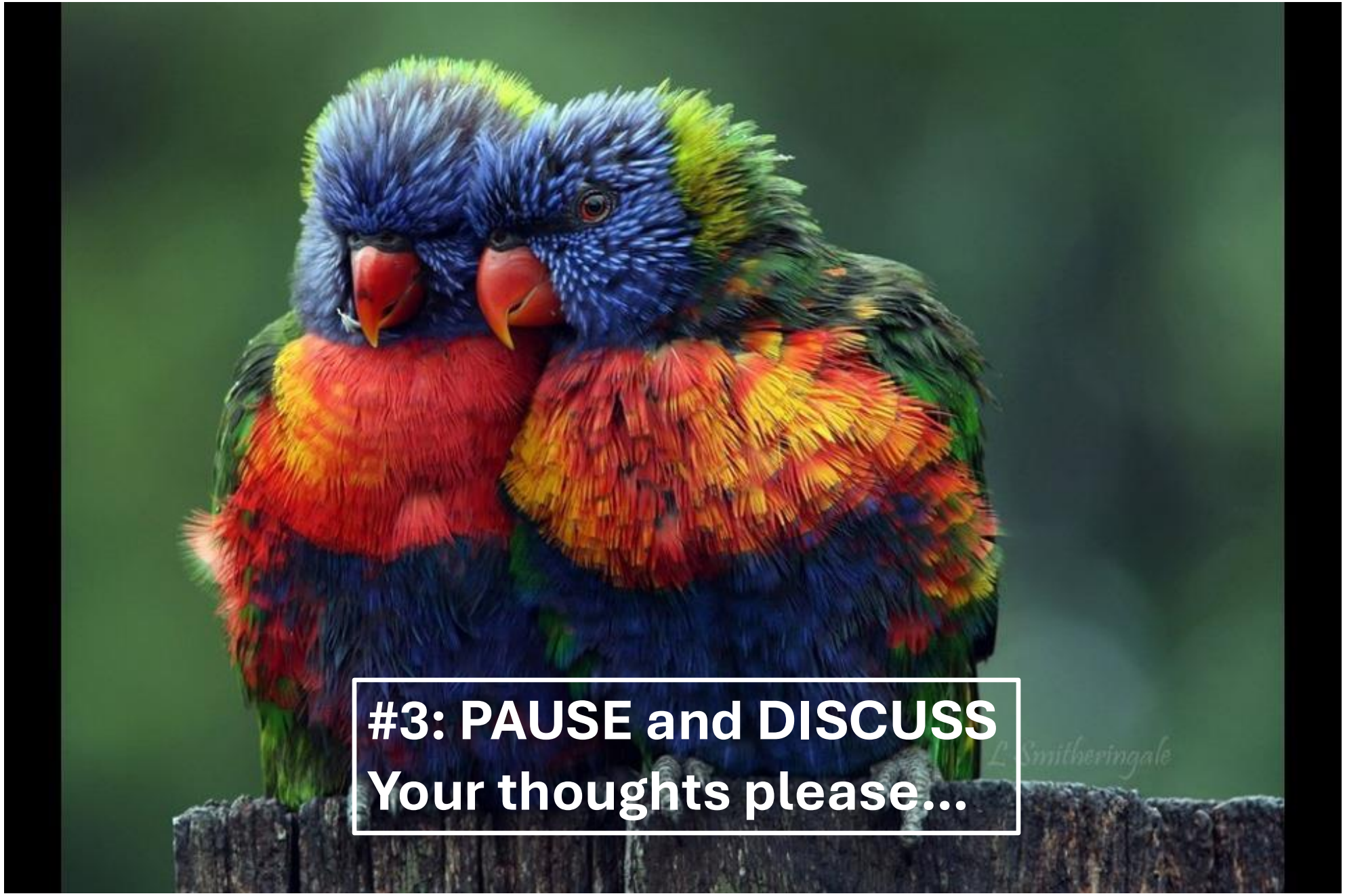
WHAT should we do?

- **Trust parents** as the world's expert on THEIR child.
- Remember, and respect: "You have textbooks, we have story books"
- PAPER: https://onlinelibrary.wiley.com/journal/14698749
- PODCAST: https://www.youtube.com/watch?v=E9NyZAUIqfA
- Speaks to the tight connections between OUR skills, perspectives, knowledge and experience, and THEIR skills, values, beliefs, knowledge and issues!


We need to avoid conflicts with ‘them’!

HOW should we do it?

- Be **FAMILY-CENTRED**! (as discussed by Dr. Carl Dunst!)
- Rx: **LISTEN, RESPECT, VALUE, check what we INTERPRET…**
- Understand that this is **THEIR CHILD & THEIR PREDICAMENT**
- Always ask: “How can I/we be helpful?”
- Ask about their ‘context’ – e.g., “What do the grandparents (and others in your orbit) think and advise?”
- Ask: “Would it be helpful for them to come with you to an appointment?”


#3: PAUSE and DISCUSS
Your thoughts please...

Theme 4: *Parenting*: ‘A Dance Led by the Children’

- Sameroff’s ‘transactional’ concept of child development recognizes the bidirectional IMPACT of child-on-parent-on-child…

  CHILD ↔ PARENT ↔ ***changed PARENT*** ↔ ***CHANGED CHILD…***

- In other words, parenting is a DYNAMIC process (a dance), and not ‘top-down’ as was traditionally believed.
- These ideas need to be shared with and illustrated to parents of children with NDDs.

What Do We Mean by the ‘Dance’?

- Remember the idea of **transactionality** – the constant back-and-forth of relationships in time and space.
- **Each CHILD** brings **unique** features to the relationship, as does each parent… so parenting formulas are way too simplistic.
- Evidence? Ask parents of twins or triplets whether they ‘parent’ all the children the same way! PARENTS get this idea of the ‘dance’ when it is pointed out.

Parents Want to PARENT!

- Remember back to **Themes 1** and **3**:
  - **Theme 1**: **WHO IS THE CHILD** (an **F-words profile** can tell us!)
  - **Theme 3**: What is important to **FAMILIES**?
- What CAN a child DO? What do they WANT to do?
- Remember **Theme 2**: **Development**… first we 'do', and then we improve with practice! Research supports this idea.
- How can we help parents support their child's development of **FUNCTIONING** (<u>however</u> things are done?)

Do We Talk About 'Parenting'?

- Not usually! We too easily see parents as 'extenders' of our (well-intentioned) therapies
- Thus, we **MISS** the opportunity to recognize – to seek to learn and celebrate – what the child brings to the dance!
- Learning happens best in natural environments.
- This **REINFORCES** the impairments (see Editorial in **Dev Med Child Neurol vol. 66, Issue 6, p. 676**: "Beyond fixing: Reconsidering assumptions about child-onset impairments")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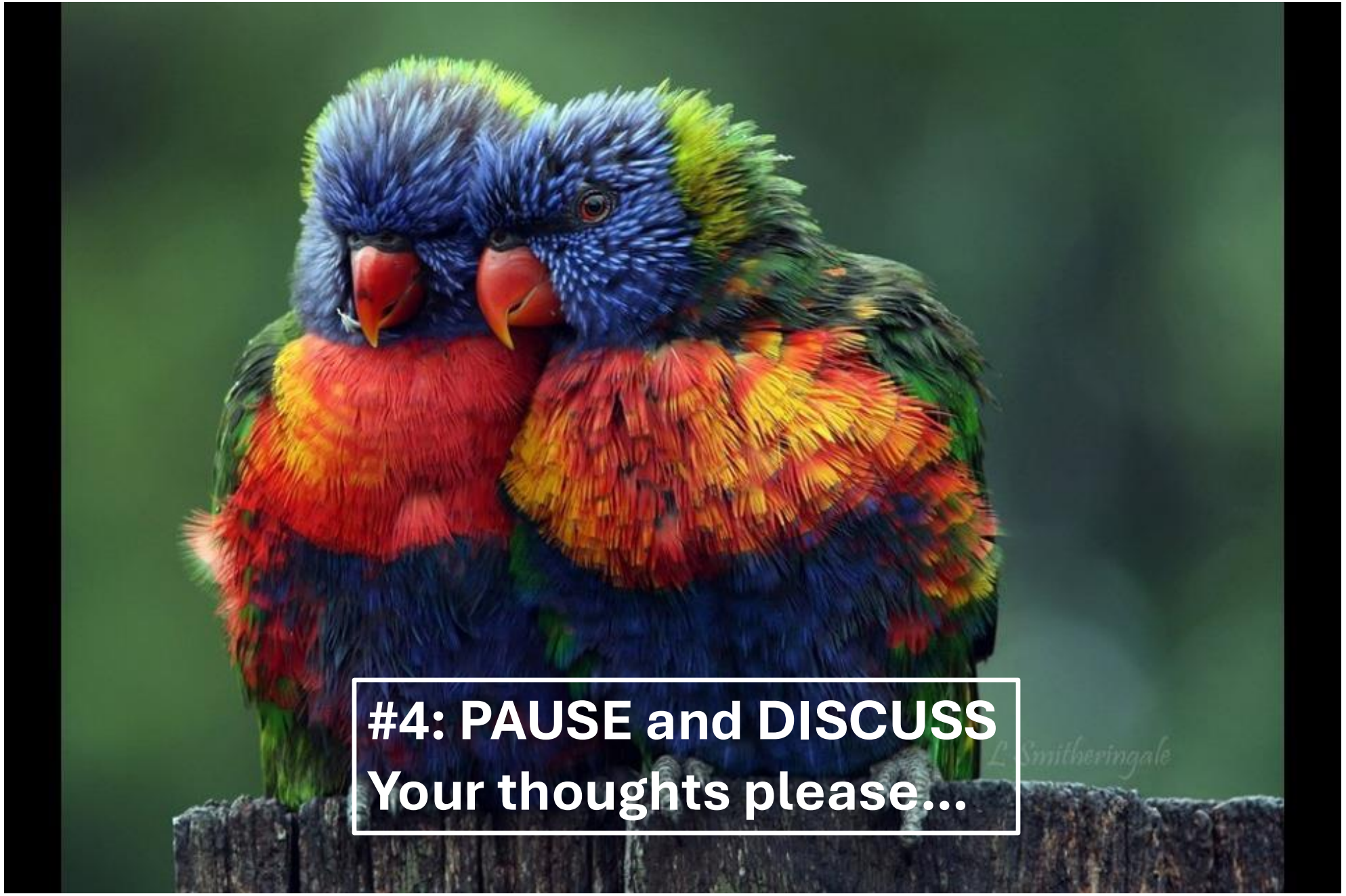
#4: PAUSE and DISCUSS
Your thoughts please...

Theme 5: *Life-Course Perspectives*: Seeing Life Beyond Childhood

- Once again, TIME and DEVELOPMENT are recognized.
- Children with NDDs grow up to become… ADULTS with their child-onset NDDs!
- After starting Rx in early childhood, they eventually ‘fall off the cliff’ and are not well served by the ‘adult’ world.
- Their needs are beyond ‘medical’: i.e., social, vocational, housing, recreational, relationships…
- These needs are largely unmet in most places.

The ICF Framework[1] and the 'F-Words'[2]

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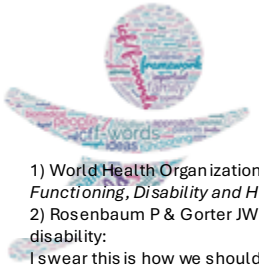

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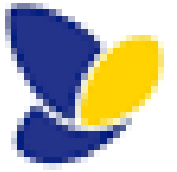
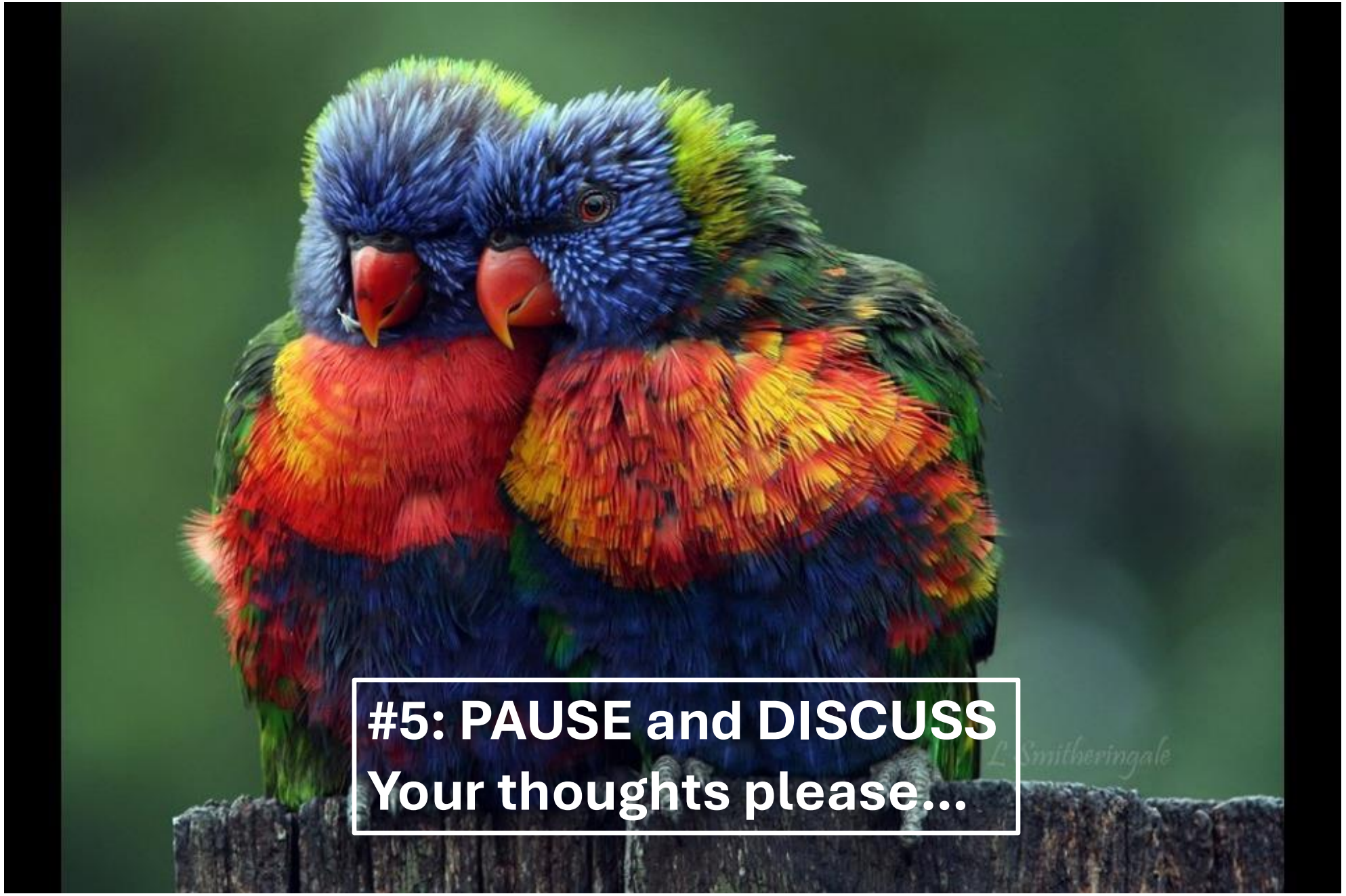
Can We Think and Plan Ahead?

- Traditional approaches to EI have focused on promoting kids' 'normal' function, and on addressing their impairments.
- We assume better function will follow… an adult 'rehab' idea.
- Rx: Things we can easily do…
  - Think about – and promote – **FUNCTIONING,** however it is done.
  - Promote/encourage/strive for/allow **INDEPENDENCE**.
  - Aim to create a sense of **COMPETENCE**, **SELF-CONFIDENCE**, and an "**I CAN**" attitude in kids from a young age.
  - **AVOID** the tyranny of 'normal' – a silly idea!




Please: stop talking about ‘Normal’!


#5: PAUSE and DISCUSS
Your thoughts please...

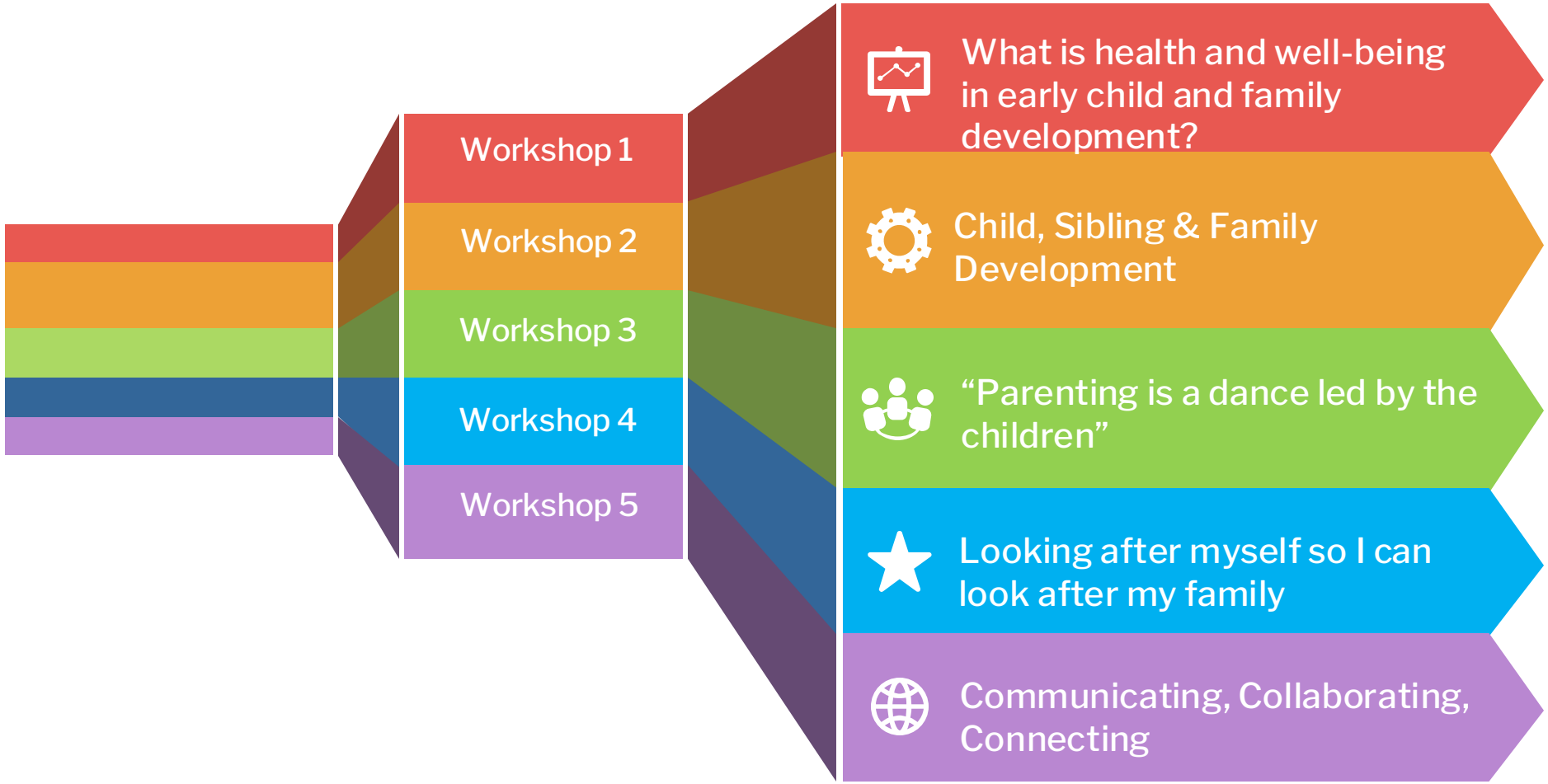
Theme 6: Knowledge Translation (KT): Promoting/Implementing These Ideas

- If you like them, these newer concepts need to be:
  - **Shared**… so people are aware of them
  - **Explained**… in context, so people understand them
  - **Taught and Discussed**… from early in training
  - **Implemented**… beyond people simply ‘knowing’ them
  - **Evaluated**… constantly tested and assessed
  - **Improved**!... as we learn more from the steps above
- There is research to be done on all these stages of KT
- This whole process is… TRANSACTIONAL!

An Example: The ENVISAGE Program

- A Canadian-Australian program, co-created and co-delivered by parents, researchers and service providers.
- Brings the ideas from this talk to parents of young kids with any neurodisabilities.
- A parent participant called this program ***'Early Intervention for Parents'!***
- We have created a parallel **ENVISAGE-SP** – data being analysed right now – also seems very POSITIVE.

The 5 ENVISAGE Workshops



The IMPACT of ENVISAGE-F?

- The next slide shows (some of) what we have learned so far, with findings that remain solid at 12-months
- The program has since been funded by Australia's Department of Social Services and is being offered to 2000 families across that country.
- We are in discussion with Ontario's MCCSS for their support to do this in our province of 14.5 m people.

Overall Findings of the pilot study with >60 families across Australia and Canada

Improved self-reported:

- Caregiver empowerment
- Caregiver sense of competence
- Caregiver wellbeing

These quantitative findings are strongly supported by interviews


It CAN be done


Thanks for listening...Now over to you!