

# Childhood Disability: Who is the 'Patient', and Why Does it Matter?

**(and these ideas apply to ALL our work with families!)**

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# An Overview of My Ideas

- We work with **parents** (families)... **they** are the 'patients'
- Parents are the world's experts on **their** child!
- We must listen to, and answer, the concerns and questions they are **really** asking!
- There are evidence-based ways to **enhance parents' sense of empowerment and confidence** when raising a child with a developmental impairment.

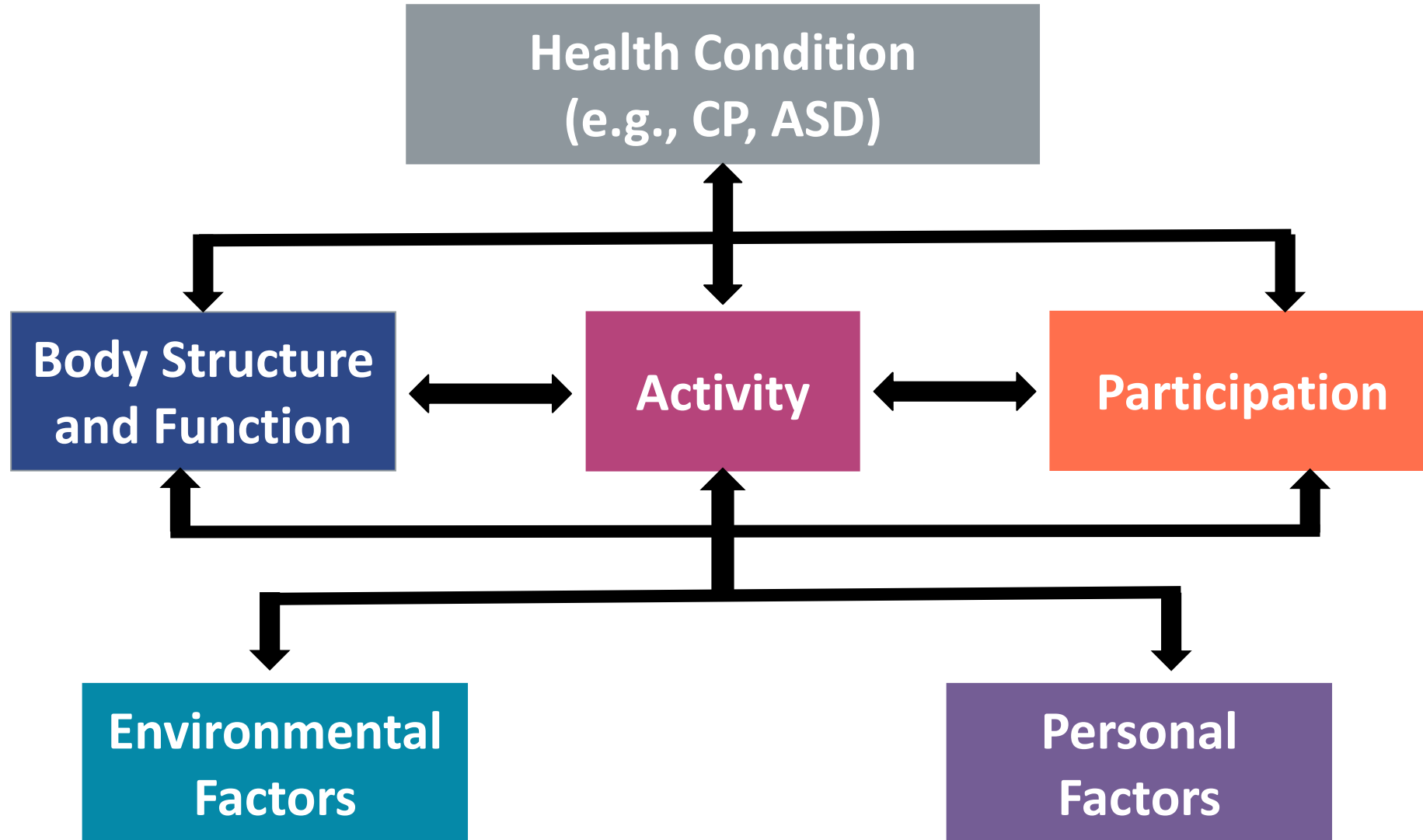


# My Assumptions about our Field

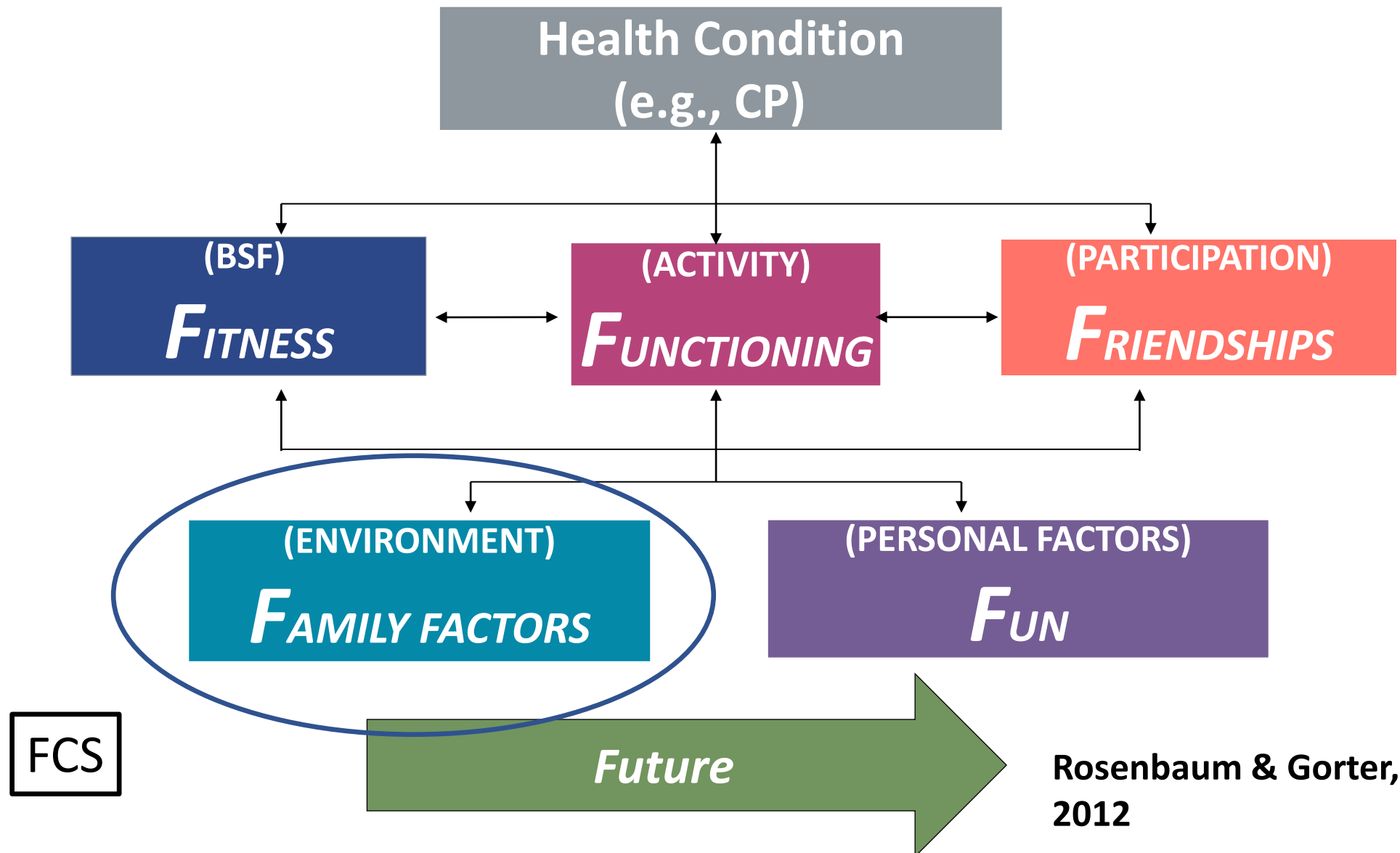
- We like and use WHO's ICF Framework for Health...
- This integrated set of ideas brings together the medical, the psychological, and the social aspects of people's lives in a very interesting interconnected way.
- We will look very briefly now and say more later
- Let us also see the way our 'F-words' bring these ideas to life.



# WHO (2001) ICF Framework



# “I See F-words” – ICF – in Child Development



FCS

Rosenbaum & Gorter,  
2012



I hope this is interesting!



# Reflections on Families

- How can we be helpful to PARENTS when their *children* have the developmental challenges?
- The purpose of these ideas is to shine the spotlight on areas of our work we (sort of) know but don't discuss as much as I believe would be helpful.
- Let us consider three interconnected ideas:  
**WHAT?... SO WHAT?... NOW WHAT?**





**1. WHAT is this about?**





# WHAT? My Basic Premises

- Consistent evidence shows that parents raising children with chronic issues of development, health, or functioning have more physical and mental health challenges than other parents.
- We believe that some of that health impact is potentially preventable when WE provide *processes* and *content* of service that address **parents'** needs and wellbeing.
- For this reason – parents should be considered our 'patients!





## 2. SO WHAT? What's this issue?



# Idea #1: Parents are our 'Patients'?

Q: What do **we** do when **we** have, e.g., **back pain**?

A: We see our health professional.

Q: How do **professionals** the situation?

A: Take a 'history' ("Tell me about it." "How do you think it started?")

A: Examine us...

A: Perhaps order some tests to understand what is going on...

Q: What happens next?

A: Explanation of the situation, as they see it, +/- diagnosis

A: Recommended management

A: Follow-up



# *Idea #1: Parents are our ‘Patients’*

## *Look again – see the parallel!*

- **“What concerns you about your child?”** (‘back pain’!)
- How does the health professional **assess** the situation:
  - Take a ‘history’ (“Tell me about **your child’s** functioning...”)
  - Examine **your child**...
  - Perhaps order some tests to understand what is going on...
- What happens next?
  - Explanation of the situation as they see it, +/- diagnosis
  - Recommended management
  - Follow-up





Oh, NOW I get it!

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# *Idea #2: We never see a child alone!*

- **Concerns** about a child  $\simeq$  concerns about ‘back pain’!
- The **child does not seek help on their own** about behaviour, motor development, language delay, etc.!
- The ‘**story**’ – the history – comes from... the parents...
- The ‘**explanation**’/interpretation/worries come from... the parents!
- We interact with both, but the *parent is the ‘patient’*



# *Idea #3: Parents are the world's experts... on their child!*

- A parent said to me: “You have textbooks; we have story books”. (Disability as perceived by professionals and parents.)
- **Reference:** DMCN June 2020;62(6):660. doi: 10.1111/dm cn.14491.
- **Podcast:**  
<https://www.youtube.com/watch?v=E9NyZAUIqfA>



# *Idea #4: FCS – Respecting Parents!*

- Being ‘family-centred’ means several things:
  - Listening to parents’ voices about their worries...
  - Hearing their many perspectives on their child...
  - Asking about their interpretation of ‘what’s going on?’
  - Taking it all seriously...
- Offering our interpretation of the parents’ concerns
  - Reassuring where appropriate
  - Taking action where appropriate







**3. NOW WHAT? What to do?**



# How Can WE be Helpful?

Let's think of our *traditional* views... NOT WRONG, but perhaps TOO FOCUSED?

- We saw the CHILD as the patient...
  - So we asked about, assessed, and tested... THE CHILD!
- We have/had a 'medical' view of the issues...
- We have offered interventions – for the CHILD! – often 'early', as is very appropriate... but...
- We have been less focused on parents' knowledge or wellbeing



# A Parent's Challenge...

- To see their child with an impairment as a whole person, when our traditional views have been on limitations, disabilities, 'cannots', and 'abnormality'
- We often disbelieve parents' optimistic reports about their child
- 'Success' is often judged by the child's progress... and lack of progress can too easily lead to parental self-blame (or indeed, in the past, blame by us!)



# Can We Change the Discourse?

- Obviously, I believe we can, and we must do so
- In the next few slides, I will outline some ideas about **'processes'** by which we can work with families... and **'content'** that refocuses on what parents want to share, and hear, and understand about their child, their roles, and our working relationship as service providers.



# *Processes of Providing Services*

- Practice in a ‘family-centred’ manner...
  - Easy to say, but what does this mean?
- Start by asking questions such as...
  - “What do you boast about concerning your child?”
  - “How can we be helpful...?”
- Recognize that **the PARENTS are our ‘patients’!**
- Build trusting relationships...
- Respect parents as the **world’s expert on their child**  
Accept that the child’s issues are theirs, not ours...



# *Processes of Providing Services*

- Be accessible...
- Be honest...
- Be collaborative...
- Use plain language...
- Answer their questions – again and again, as needed – because things change so fast and in so many ways !



# Modern *Content* of our Services

- Emphasize **WHAT IS** instead of what is **NOT**...
- **ICF and F-words-based concepts** – very popular around the world...
- **FUNCTIONING**... however it is done...
- **DEVELOPMENT**... the only constant in life! ('yet'!)
- **PARTICIPATION** – engagement in life...
- **PARENTS'** voices/values/preferences...
- **LIFE-COURSE** thinking – seeing beyond today!



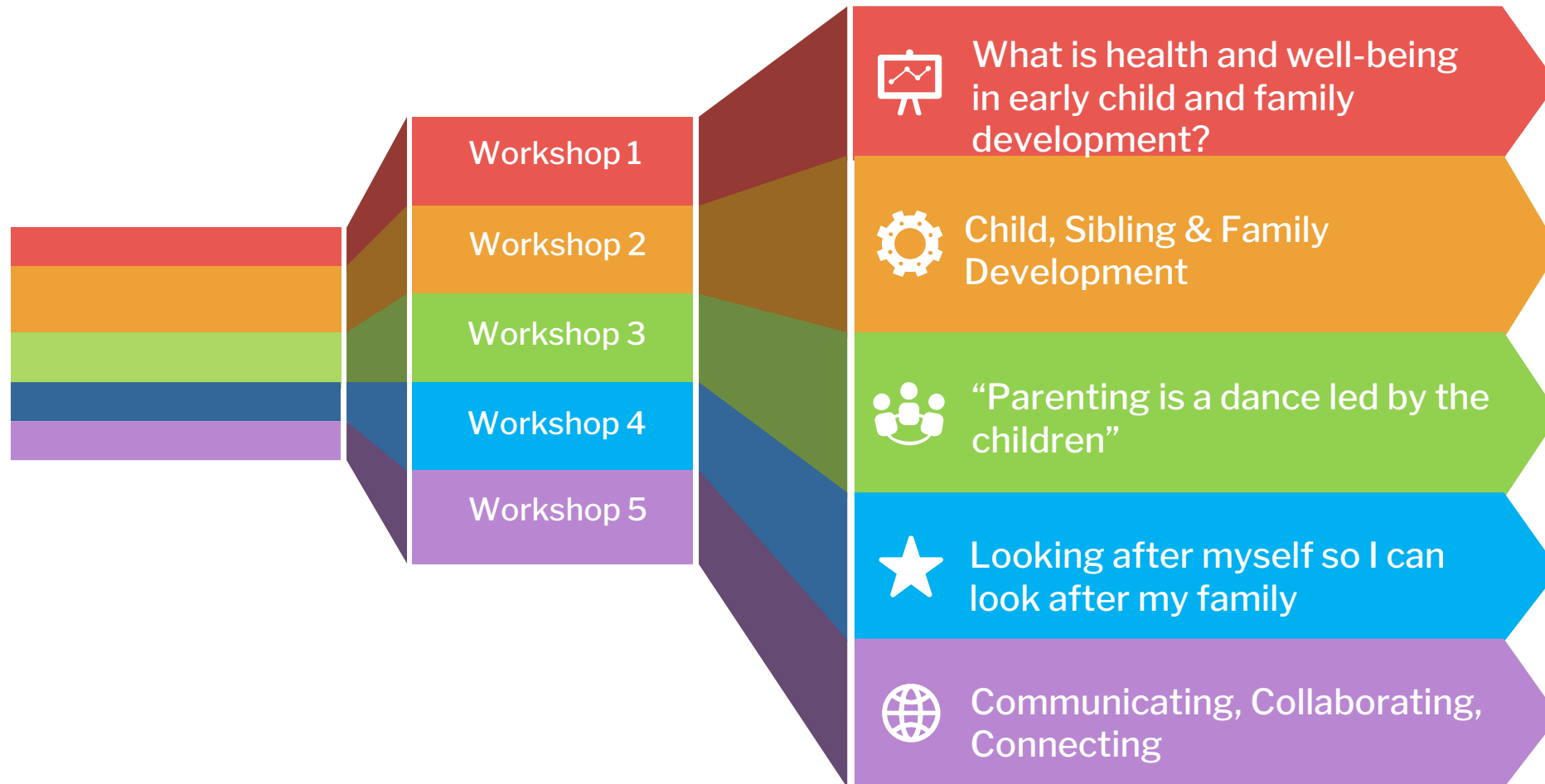
# *Content of our Services:* Example

- Our Canada/Australia ENVISAGE program has been called (by a parent!) ‘Early Intervention for Parents’
- It was designed – with parents – to bring these concepts to families, to promote parenting, and hopefully to prevent some of the distress we know that parents experience.
- Five co-led weekly interactive workshops present ideas like those I have outlined (see next slide)





# The 5 Workshops of Envysage~F



# The IMPACT of ENVISAGE-F?

- The next few slides show what we have learned so far, with findings that remain solid at 12-month follow-up
- The program has now been funded by Australia's Department of Social Services and is being offered to 2000 families across the country.
- We are in discussion with Ontario's MCCSS to get their support to do this in our province of 14.5 m people.



# The IMPACT of ENVISAGE-F?

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

Improved:

- ➔ •Caregiver empowerment
- ➔ •Caregiver sense of competence
- ➔ •Caregiver wellbeing



# My Ideas Once More...

- We work with *parents* (families)... *they* are the 'patients'
- Parents are the world's experts on *their* child!
- We must listen to, and answer, the concerns and questions they are *really* asking!
- There are evidence-based ways to *enhance parents' sense of empowerment and confidence* when raising a child with a developmental impairment.



# In Summary:

- Our field, and our ideas, continue to evolve
- We need to trust and respect **parents** as the people who seek our support and advice, and support THEM!
- The **PROCESSES** and **CONTENT** of our interactions can be tailored to parents!
- These ideas put a new perspective on all we do...
- They do not throw out the best of what we know!





**THANK YOU!**





**DISCUSSION!**





# Our World



I think, when your child is diagnosed with something, it's kind of like, here's your diagnosis, you're gonna (sic) need all these services.

Now off you go! And that's kind of how it feels. ...there isn't that support and you're just, you don't know what the expectation is, and you don't know what is actually required and you often don't even know what services

exist *Parent 31*

Yeah, the collage things, like how you would view your child, what are your values, how do you see wellbeing, all that type of stuff. And that's not stuff that you normally think about day to day. So, it was good to make the time to do and go through those questions and think about that. *Parent 45*

## **A room for reflection**



***“Early Intervention for parents”***

I really felt like I was like in the passenger seat, the way that I was...my son's life was being structured and now I don't. ...it's such a cliché to say I'm not the passenger. I am the driver. It sounds ridiculous but that's truly how I feel.

*Parent 35*



## **Shifting perspectives**

The central theme **A Change in Perspective** is nested inside two themes, **Room for Reflection** and **Our World**.

**Room for Reflection** subthemes (time, space, content, and reflective processes), occur in a context of **Our World and My World**.

Central to **A Change in Perspective** is a shift in **self-perception** (seeing myself differently) and **empowerment** (self-value, self-confidence, and self-care).

**Resetting relationships** and how things are done with others (family, friends, others who work with my child) comes with **A Change in Perspective**.

