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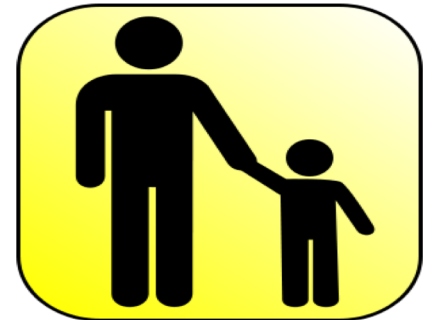
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# Giving voice to person-anchored outcomes in preschool children attending SLP services

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# Disclosure

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## **Financial relationships:**

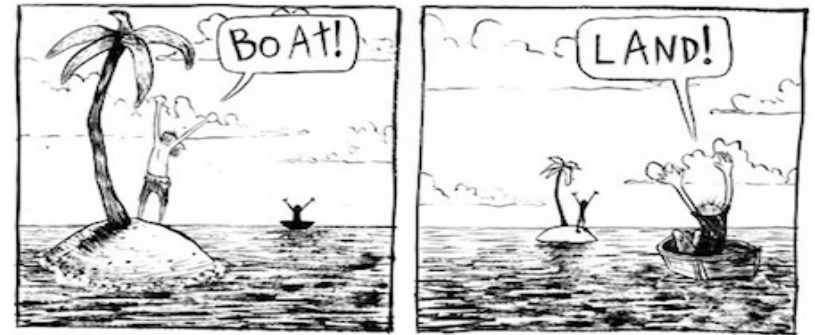
- <sup>1</sup>Employed at Trinity College Dublin (TCD) Ireland
- TCD part funded the research and my travel here (conference allowance)
- <sup>2</sup>Employed by Health Services Executive (HSE) Ireland

## **Nonfinancial relationships:**

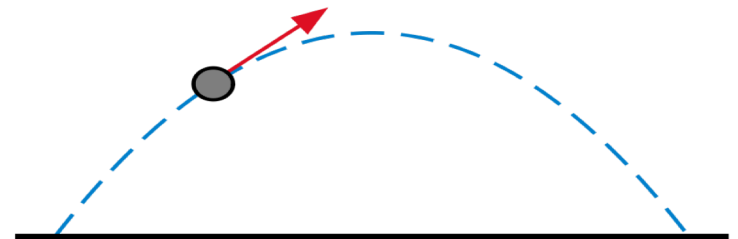
- We received no financial gain from this research or this presentation
- <sup>1</sup>International Affiliate - ASHA member

**Aim:** to show how parental accounts of experience of SLP with their child can align with the following propositions

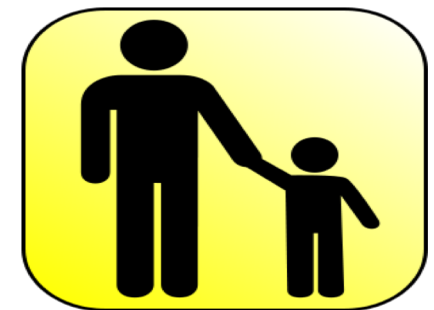
# 1. **Outcomes are a matter of contextualized, analytic focus** - What looks like progress from one frame of reference does not necessarily look like progress from another frame of reference



#2. **Person anchored outcomes** – not end states but processes, trajectories



# 3 **Client's voice as anchor**- can be informed by others' perspectives; objective and subjective measures



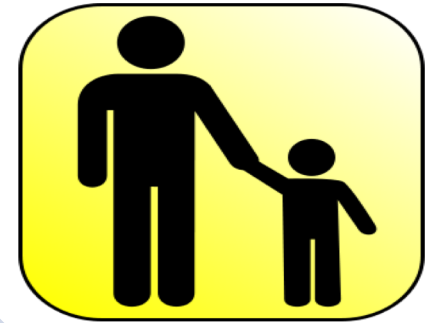
# Background 1

- In the domain of preschool developmental communication disorders, ‘patient-centered outcome’ *de facto* **includes** the parent or family in the equation



- *‘Family-Centred Practice is a philosophy of care that strongly encourages and values parental involvement’* (Washington, Thomas-Stonell, McLeod & Warr-Leeper, 2012, p 335) includes:
  - Involving the parents in decision making
  - Focusing on the family, not only the child
  - Formation of positive relations between therapist and family

# Background 2: Desired outcomes



adults/adolescents/  
school age children  
able to express their  
desired outcomes from  
SLP (e.g. Kagan et al.,  
2008; Fourie, 2009;  
Lyons & Roulstone,  
2018)

preschool children  
unable to voice  
such outcomes

parent/carer  
appropriates that  
voice

Outcomes based  
on others'  
perspectives of  
preschool child  
*person anchored*  
*e.g. parent*

*e.g. **FOCUS** - 50 Item validated clinical  
tool - measure change in communication  
participation; SLP & /or parent completion  
(e.g. Thomas-Stonell et al., 2013)  
-see also **Communication Function  
Classification System (CFCS)** (Hidecker et al.,  
2017)*

# Research Question

From which the data is drawn



*To hear that parental voice...*

**What is the lived experience of parents whose children with developmental communication disorders have attended SLP in a community setting?**



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# Methodology

- **In-depth interviews** with a purposive sample of 5 parents of preschool children (<6 yrs); talk about their experiences of attending SLP services with their child.

No. of Children with Disorder	Developmental Communication Disorder
1	Articulation difficulties secondary to cleft palate
1	Stammer
1	Speech and expressive language delay
2	Expressive Language delay



# Method



- All interviews took place in the parents' homes; lasted between 30-45 minutes
- Audio recorded and then transcribed verbatim & sent to participants for member checking
- Reflecting on involvement in SLP in general with their preschool child (see probes)
- Data later looked at again for evidence of voicing of desired outcomes as 'anchored' to their child





## Interview Schedule

1. Tell me about your child before he/she was referred to speech and language therapy.
  - a. Tell me more.
2. Tell me about your child being referred to speech and language therapy for example who referred him/her to speech and language therapy.
  - a. Tell me more.
3. Tell me about your expectations for speech and language therapy.
  - a. Tell me more.
4. What services did your child get? E.g. assessment, individual therapy, parent training.
  - a. Tell me more.
  - b. Was this what you had expected from speech and language therapy?
- 5. How is your child's communication now?
  - a. Tell me more
  - b. Is he/she still involved with speech and language therapy?
- 6. What impact has the way speech and language therapy services had on you and your child?
  - a. Tell me more.
7. If you could choose the way speech and language therapy services in Ireland were delivered what would they look like?
  - a. Tell me more.



# Analytic Methodology: Interpretative Phenomenological Analysis (IPA)

- **Phenomenon**= parental experience of SLP with their child
- “**Describe, understand and interpret** participants’ experiences” (Tuohy, Cooney, Dowling, Murphy, & Sixsmith, 2013).
- “Access to experience is always dependent on what participants **tell us** about that experience, and that the researcher then needs **to interpret** that account from the participant **in order to understand** their **experience** (Smith, Flowers, & Larkin, 2009).

Stage	Description
Stage 1	<ul style="list-style-type: none"><li>• Active Engagement with data</li><li>• Bracketing of preconceptions</li></ul>
Stage 2	<ul style="list-style-type: none"><li>• Notes on <b>descriptive, linguistic and conceptual</b> features</li><li>• Notes must be directly linked to data</li></ul>
Stage 3	<ul style="list-style-type: none"><li>• Emergent themes identified</li></ul>
Stage 4	<ul style="list-style-type: none"><li>• Super-ordinate themes identified</li></ul>
Stage 5	<ul style="list-style-type: none"><li>• Initial four stages used for all other data sets</li></ul>
Stage 6	<ul style="list-style-type: none"><li>• Formation of master themes</li></ul>



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Findings/ Main Conceptual Theme

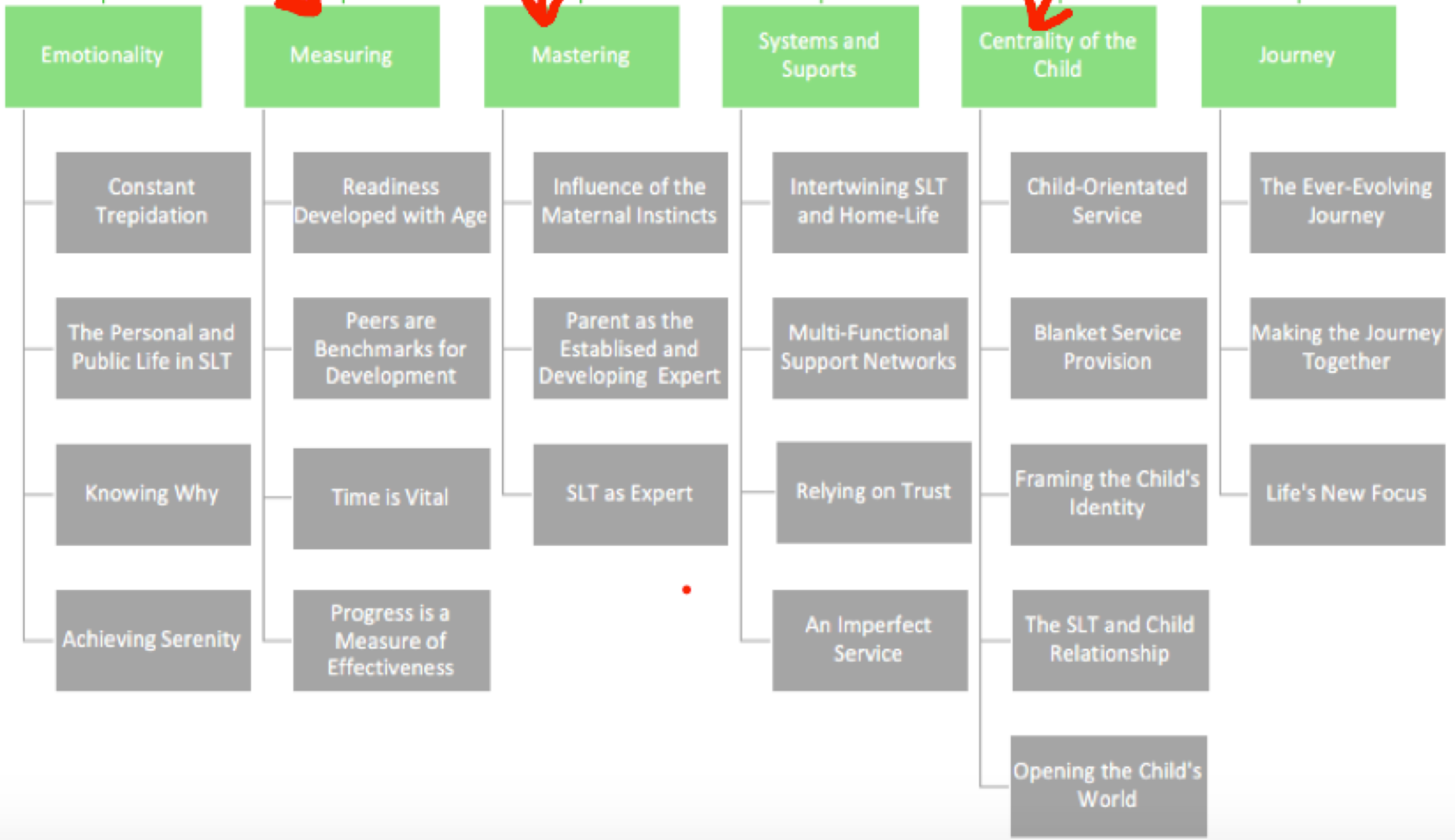
***‘Pain, Power & Progress’***

# Pain, Power and Progress

1

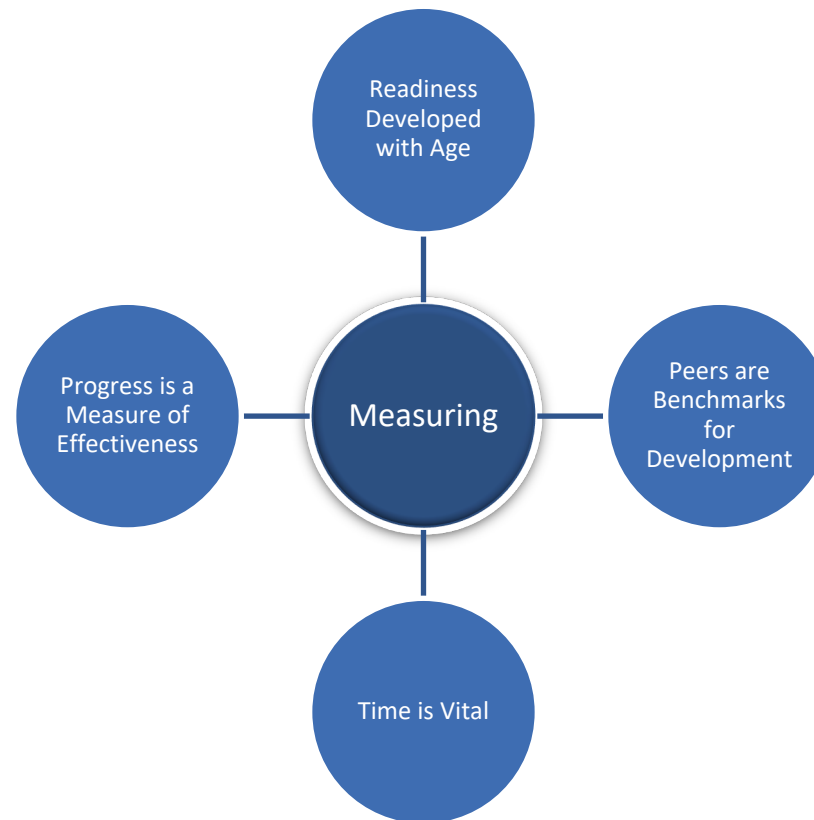
2

3



# Theme 1: 'measuring'

the focus on using definitive measurements, be they subjective or objective, during the participants' engagement in SLT services



(Prop #1: 'progress' viewed through different frames of reference)



# Theme 1: 'measuring'

(Prop #1. progress viewed through different frames of reference)

Readiness developed with age	<p><i>'as soon as he was interested in being corrected it worked and I think that was age 2'</i> [L666/667, P2]</p> <p><i>'too young'</i> [L409, P5] [P3]</p> <p><i>'failure' because her child was assessed 'according to his age not his experience'</i> [Line 785-786, P4]</p>
Peers are benchmarks for development	<p><b>realisation / referral:</b> comparison of child's communication abilities to <i>'other children his age'</i> [L 63, P1] ; <i>'must need some help'</i> [L 221/222, P3]</p> <p><b>recovery:</b> <i>'as good as'</i> [Line 714, P4] <i>other children</i></p>
Time is vital	<p><b>-timing :</b> review x 3 months: <i>'like a lifetime saying that to a parent'</i> [L526, P3]</p> <p><b>+ timing:</b> <i>'so lucky we started so early'</i> [L319; P2]</p>
Progress is a measure of effectiveness	<p><b>- progress :</b> <i>'absolutely raging'</i> [L622, P3]</p> <p><b>+ progress :</b> <i>'slow and steady'</i> [L86, P2]; sense of accomplishment for whole family [L93, P2]</p>



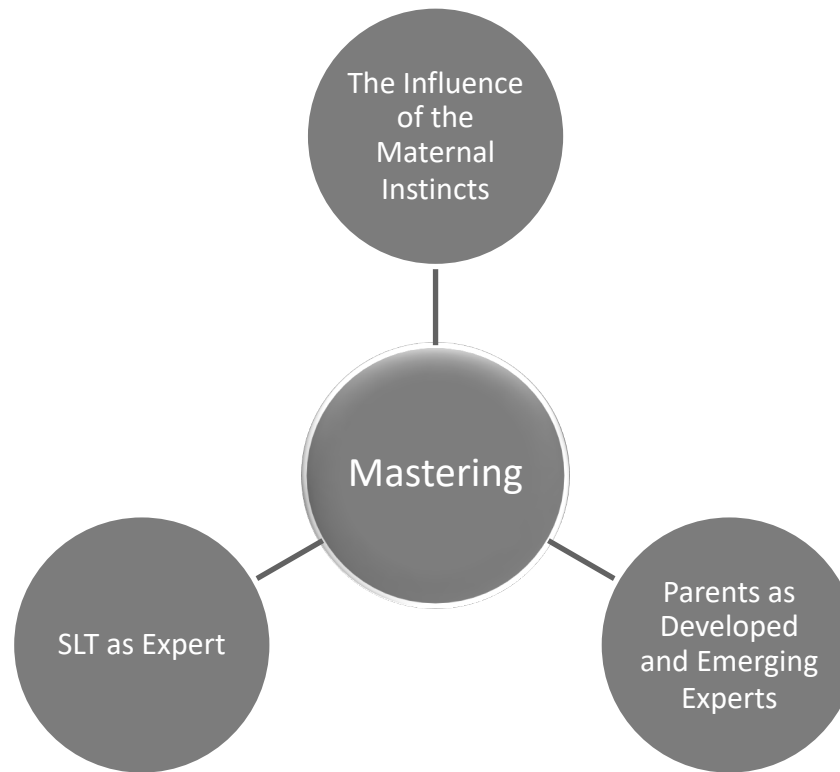
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# Theme 2 'mastering'

- the acknowledgement, development and utilisation of a skill set possessed by key stakeholders.



(Prop #2 outcomes not end states but process/ trajectories)



# Theme 2: ‘mastering’

(Prop #2 outcomes not end states but process/ trajectories)

<i>Influence of Maternal Instincts</i>	<p><i>‘nobody besides me felt it was a thing’ [L 721/722, P1];</i> <i>GP ‘humouring me’ [L 727/728, P1]</i></p> <p><i>‘started worrying’ [L699, P5]</i> Self-assertion regarding referrals P1, 4 &amp; 5</p>
<i>Parents as the Developed &amp; Emerging Expert</i>	<p>needing to <i>‘bridge that gap’</i> in her child’s communication and <i>‘needed help with that’</i> [L 24- 246, P4] &amp; [P3] <i>“ I was showing her what I was doing and she goes ‘ that’s exactly what I’d be doing with him in the class’”</i> [P3 236-237] <i>‘it was strange’</i> because <i>‘you don’t think about language, you just use words’</i> [L 452/453, P4] guided <i>‘to teach him’</i></p>
<i>SLT as Expert</i>	<p><i>‘just going with what I was suggested’</i> [L363, P2]. <b><i>‘they said’ ‘ they reviewed’ ‘they gave him..’</i></b>[L257-265,P3] <i>‘didn’t have the awareness’ ‘pointers to where I needed to work on with him you know’</i> [410-417, P4]</p>



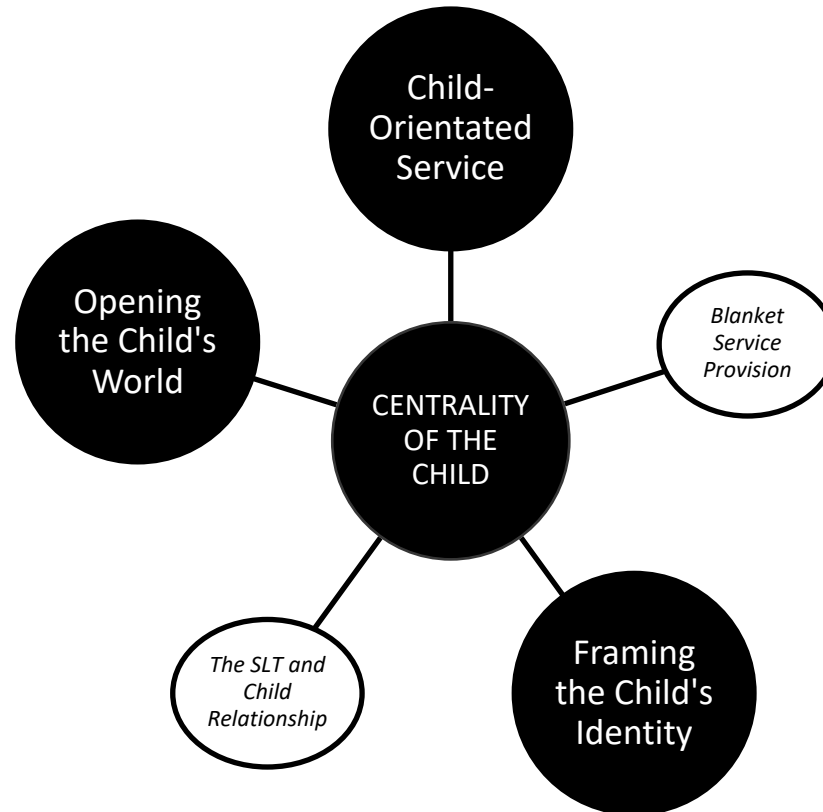
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# Theme 3 'centrality of child'

the abilities of key stakeholders to hold the child as the main focus within decision-making for all aspects of service provision



# Prop 3  
*Client's voice as anchor-*  
*informed by others'*  
perspectives;  
objective and  
subjective  
measures



# Theme 3: ‘centrality of the child ’

## (Prop #3 client’s voice as anchor)

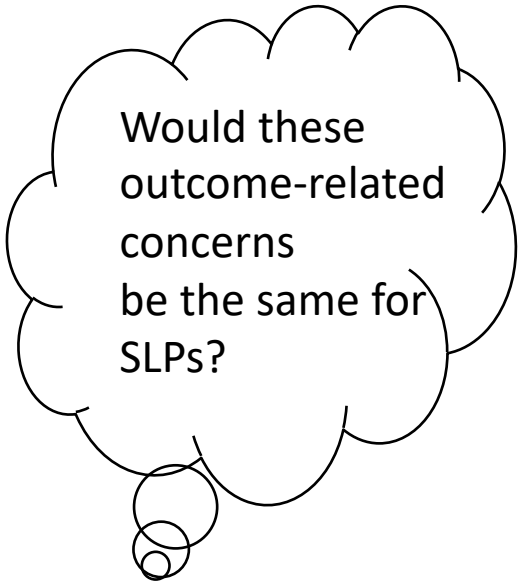
Child-orientated service	Flexible service delivery [P2] Child’s enjoyment [P1, P5] Reinforcement ‘loved getting the praise and everything’ L568-570 [P2] Following child’s needs [P2]
Framing the child’s identity	‘Normal’ “there was nothing wrong with him” [Lines 61/62, P5] “a much more emotional child” [Line 154, P1] “he’d be like that anyway he’s a bit of a perfectionist” [Line 669, P4]
Opening the child’s world	“he was flying” [Line 400, P3] “a happy, happy, outgoing, little ... man” [Line 22, P3] “definitely ready for it now” [Line 467, P1] “he was sorted” [Line 318, P2]



# Summary

## Parents concerned with outcomes that are influenced by

- ✓ Readiness
- ✓ Timing & flexibility
- ✓ Progress & effectiveness; family owned
- ✓ What is 'normal' to them/ others
- ✓ Child Identity & how it is framed (by all)
- ✓ Meaning of success for family
- ✓ Acknowledgement of ability and parental instinct; emerging expertise 'knowing how'
- ✓ Meaning of 'recovery' (for them and for their child)

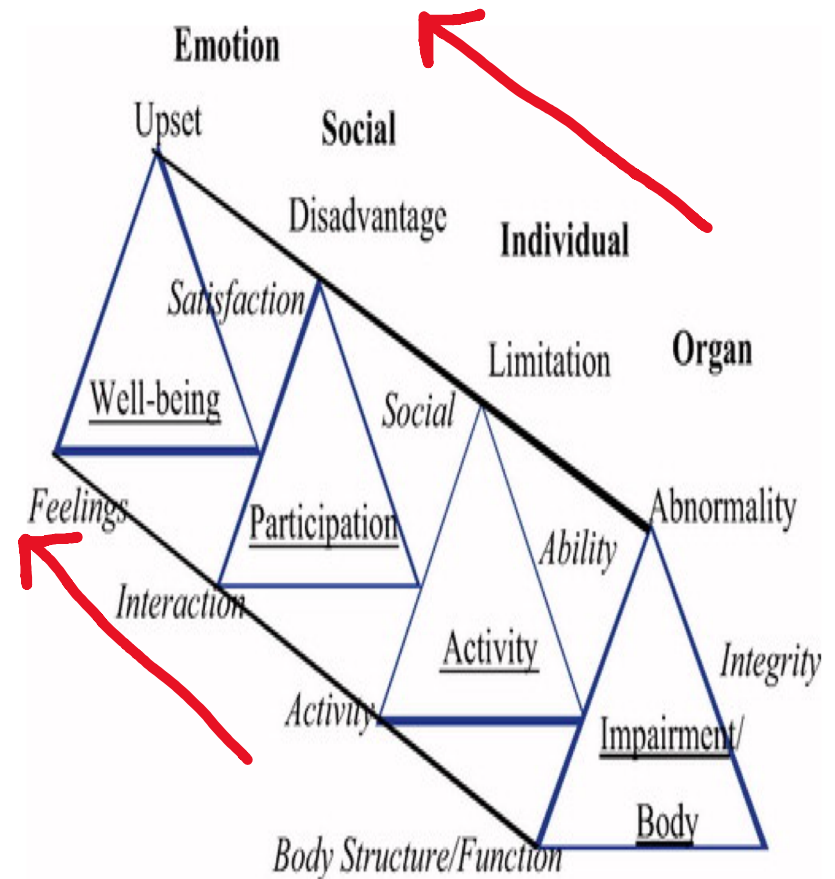


Would these outcome-related concerns be the same for SLPs?

# Discussion

- Support the move away from impairment based models (Baker & McLeod, 2011) and focus **on functional outcomes which parents value most** (Thomas-Stonell, et al., 2009)
- Exploring the **lived experience of parents** engaged with SLP services, supports the idea that the term '**person-anchored outcome**' is a more accurate term to use within this context...
- to **achieve meaningful and desirable outcomes**, collectively informed by their own concerns and those of others (e.g. preschool teachers) who make up that child's communication network.

Figure 1. Therapy outcome measure dimensions.



John (2011; 38)

Need to respect & authentically support parents/carers/others as co-interventionists

Person anchored?

Continue to add to the evidence for increased parental/carer involvement in formulation and articulation of desired & meaningful outcomes



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Thank You

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