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

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Disclosure

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Financial relationships:

• 1Employed at Trinity College Dublin (TCD) Ireland
• TCD part funded the research and my travel here (conference allowance)
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• We received no financial gain from this research or this presentation
• 1International 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?
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.

<table>
<thead>
<tr>
<th>No. of Children with Disorder</th>
<th>Developmental Communication Disorder</th>
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<tbody>
<tr>
<td>1</td>
<td>Articulation difficulties secondary to cleft palate</td>
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<td>1</td>
<td>Stammer</td>
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<td>1</td>
<td>Speech and expressive language delay</td>
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<tr>
<td>2</td>
<td>Expressive Language delay</td>
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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).

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
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<tbody>
<tr>
<td>Stage 1</td>
<td>• Active Engagement with data</td>
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<tr>
<td></td>
<td>• Bracketing of preconceptions</td>
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<tr>
<td>Stage 2</td>
<td>• Notes on descriptive, linguistic and conceptual features</td>
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<td></td>
<td>• Notes must be directly linked to data</td>
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<tr>
<td>Stage 3</td>
<td>• Emergent themes identified</td>
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<tr>
<td>Stage 4</td>
<td>• Super-ordinate themes identified</td>
</tr>
<tr>
<td>Stage 5</td>
<td>• Initial four stages used for all other data sets</td>
</tr>
<tr>
<td>Stage 6</td>
<td>• Formation of master themes</td>
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</tbody>
</table>
Findings/ Main Conceptual Theme

‘Pain, Power & Progress’
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 | ‘as soon as he was interested in being corrected it worked and I think that was age 2’ [L666/667, P2]  
|                            | ‘too young’ [L409, P5] [P3]  
|                            | ‘failure’ because her child was assessed ‘according to his age not his experience’ [Line 785-786, P4] |
| Peers are benchmarks for development | **realisation / referral:** comparison of child’s communication abilities to ‘other children his age’ [L 63, P1] ; ‘must need some help’ [L 221/222, P3]  
|                             | **recovery:** ‘as good as’ [Line 714, P4] other children |
| Time is vital               | **-timing:** review x 3 months: ‘like a lifetime saying that to a parent’ [L526, P3]  
|                             | + **timing:** ‘so lucky we started so early’ [L319; P2] |
| Progress is a measure of effectiveness | **- progress:** ‘absolutely raging’ [L622, P3]  
|                               | + **progress:** ‘slow and steady’ [L86, P2]; sense of accomplishment for whole family [L93, P2] |
Theme 2 ‘mastering’
- the acknowledgement, development and utilisation of a skill set possessed by key stakeholders.

The Influence of the Maternal Instincts

Mastering

SLT as Expert

Parents as Developed and Emerging Experts

(Prop #2 outcomes not end states but process/ trajectories)
### Theme 2: ‘mastering’
(Prop #2 outcomes not end states but process/trajectories)

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

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.

John (2011; 38)
Discussion

Person anchored?

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

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

Conclusion
Thank You
Selected references


Selected references


