The Sound Access Parent Outcome Instrument (SAPOI) for Children with Complex Needs

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Rationale for Instrument Development

- Necessity to justify investment of cochlear implantation regardless of medical system
- Desired/expected CI outcomes for typically-developing children usually focus on the development of spoken language – may not be valid for children with severe multiple disabilities.
  - We believed that parent identified outcomes would be the best insurance of content validity for such an instrument.
Rationale con’t

- Desire to avoid replication of other instruments in use but to formally capture outcomes parents report as important that are not currently captured.
- Desire to capture WITHIN child and family changes over time
Based on Phase One data, what items do the majority of participants agree on as important to themselves and their families?

Is there duplication between these items and items in instruments already in use?
• Are the items derived from Phase One data and the item selection process ratable and reliable?

• How does Clinical Specialist feedback impact SAPOI development and use?
Methods: Item Refinement

Judgement based evaluations were employed throughout the item selection and refinement process

• Parent participants in the Phase One study identified outcomes developed from Phase One interview data that they felt applied to their family and child. Items that had at least majority agreement were included in the Phase two study instrument

• To address the potential for duplication the item pool developed from the first step was compared to items from The IT-MAIS, the REEL-3, The Rosettis, and the Little Ears
Phase 2 Caregiver Participants

• In Phase Two, seven families whose children had been using amplification for at least one year filled out the SAPOI on two occasions, within one month apart, in order to establish ratability and test-retest reliability of the items.
### Characteristics of Phase 2 Caregiver Participants’ Children

<table>
<thead>
<tr>
<th>Participant</th>
<th>Child Age (in years)</th>
<th>Amplification Type (Hours Used Per Day)</th>
<th>Additional Diagnoses / Challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (M)</td>
<td>6</td>
<td>Cochlear Implant (12 hours)</td>
<td>Cerebral Palsy, Cognitive delay</td>
</tr>
<tr>
<td>2 (M)</td>
<td>6</td>
<td>Hearing Aids (all waking hours)</td>
<td>Charge syndrome</td>
</tr>
<tr>
<td>3 (F)</td>
<td>2</td>
<td>Hearing Aids (all waking hours)</td>
<td>Charge Syndrome, Tracheostomy,</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Born with one kidney</td>
</tr>
<tr>
<td>4 (M)</td>
<td>14</td>
<td>Hearing Aids (all waking hours)</td>
<td>Seizure disorder, Legally blind</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(left eye), Cerebral Palsy</td>
</tr>
<tr>
<td>5 (M)</td>
<td>17</td>
<td>Cochlear Implant (8-12 hours)</td>
<td>Autism, Cerebral Palsy</td>
</tr>
<tr>
<td>6 (M)</td>
<td>8</td>
<td>Cochlear Implant (12 hours)</td>
<td>Severe global developmental delay</td>
</tr>
<tr>
<td>7 (M)</td>
<td>3</td>
<td>Hearing Aids (10-12 hours)</td>
<td>Charge syndrome, Tracheostomy</td>
</tr>
</tbody>
</table>
Methods: Clinical Specialist Participants

- Five clinical specialists (Subject Matter Experts) invited to participate based on:
  - Known involvement with children using amplification who have severe multiple disabilities
  - Variety of clinical backgrounds (Educators of the Deaf and Hard of Hearing, Speech-Language Pathologists, Auditory-Verbal Therapists, Clinical Psychologist)
Clinical Specialist Participants

- Multi-national representation (Canada, US, Europe)
- No working affiliation with the authors
Phase 2 SAPOI Rating Scale

Rating Scale for each item:

- (Never) 0  1  2  3  4  5  6  7  8  9  10 (Always) NA
- A ten point scale allows for sufficient variance to capture small differences
- Each of four scales is scored independently from the other scales, without adding the scales to get a total score
Child Affect Due to Use of Amplification (4 items)

Child shows evidence of happiness and contentment by smiling, lack of agitation, laughing and/or use of happy voice quality.
Child Interaction (12 items)

Child enjoys interaction (has fun with) with parent in routine caretaking activities as evidenced by smiles, attentiveness, tone of voice and/or demonstration of anticipation.
Child wears device without removing it.
Parent/Caregiver Well Being (12 items)

Parent feels connected to child through sound in meaningful and mutually enjoyable ways.
Inclusion of Caregiver Well Being

- We concluded, based on Phase One data, and research on family centered practice, that for this population, caregiver well being should be taken on par with child outcomes (not INSTEAD of!) in the determination of ‘success’ for this population.
Results

Test-Retest Reliability:

- Intraclass Co-efficients (ICC) using a pairwise exclusion rule showed ICCs in the strong to excellent range (.73 - .84) for each scale (Portney & Watkins, 2000)

- The marginal homogeneity test showed that the difference between item ratings between pre and post test was not significant (p<.05)
Clinical Specialist feedback re items:

- Suggestions for item rewording, inclusion of examples to enhance item clarity and suggestions for item additions
- A question re: music, singing
- A question about child safety, changes in self damaging behavior
Clinical Specialist Feedback re: utility

• It’s terrific – nothing like this exists

• This measure taps important dimensions of child functioning in this population

• Combining this tool with the IT-MAIS or Little Ears would take information to the next level
Results con’t

- Could be used pre and post implantation to assist parents in considering what they would consider benefit for their child

- It gives parents a legitimate [more formalized] voice

- The dimensions are those that, in our experience, are important to parents
Next Steps

• Based on participant and clinical specialist feedback, the Phase Three version of the SAPOI has been developed

• In process of developing data base that will allow research partners for Phase 3 to contribute SAPOI data

• Recruit research partners from larger centers to allow for enough data to perform strong item analyses to fine tune instrument
The authors wish to express their gratitude to:

- The parent and Clinical Specialist participants
- Alberta Health Services/ Glenrose Rehabilitation Hospital Depts. Of Communication Disorders and Audiology
- University of Alberta
- Brad Janvier for technical support
If Interested in Participating in Phase Three:

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3. Parent/caregiver can determine child’s emotional state from another room based on the child’s vocalizations.

4. Child reacts to music by smiling, movement associated with pleasure, focused attention and/or demonstration of anticipation.
3. Child enjoys interaction with adults, other than parents, in routine caretaking activities as evidenced by smiles, attentiveness, tone of voice and/or demonstration of anticipation.

4. Child enjoys interaction with adults, other than parents, in activities outside the home as evidenced by smiles, attentiveness, tone of voice and/or demonstration of anticipation.
5. Child enjoys interaction with peers, other than siblings, in routine activities at home as evidenced by smiles, attentiveness, tone of voice and/or demonstration of anticipation.

6. Child enjoys interaction with peers, other than siblings, in activities outside of the home as evidenced by smiles, attentiveness, tone of voice and/or demonstration of anticipation.
Child is able to tolerate new experiences as evidenced by lack of agitation and/or behavior indicating pleasure in:

Rate each:

7. Family gatherings.
8. Church, Synagogue, Mosque, other
9. Restaurants.
10. New experiences outside the home.
11. The child is “no longer alone in the room” (present but not connected to others in the room as evidenced by focus of attention and appropriate emotional reactivity).

12. People outside of the family’s close social circle interact verbally with child.
5. Child attempts to put the headpiece back on him/herself.

6. Child removes headpiece if device is not working properly.

Child removes headpiece to signal lack engagement or to request a change in activity. Rate each:

7. At home.

8. At school.

9. In other settings.
10. The parent/caregiver feels that a management of equipment requires minimal effort.
5. Parent/caregiver feels able to successfully include their child in activities outside the home (church, restaurants, shopping, etc.).

6. Parent/caregiver feels well supported by CI team.

7. Parent/caregiver feels able to meet the needs of other family members (siblings, spouse) without feeling overwhelmed.
8. Parent/caregiver feels own personal needs (emotional, intellectual, physical) are being met.

9. Parent/caregiver experiences joy in interacting with child who uses CI.

10. Parent/caregiver feels able to interact with child from a distance (5 feet or more).
11. Child’s behavior can be effectively managed through spoken direction/input.

12. Parent/caregiver feels family life is ‘normal’