Don't touch me! A child/young adult led approach to desensitisation.

This poster presents the outcomes of our desensitisation initiative, while also addressing the challenges faced. We hope to inspire audiologists to consider their advice on desensitisation & promote further consideration and research in this area.

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Seashell is an organisation aimed at providing education, care and health services for students with significantly complex needs. We decided to explore tactile desensitisation further after piloting the NHS England 'Hearing Checks for Residential Schools', and we found (despite proactive steps in place) that 50% of the students who were eligible to participate refused the hearing check. Feeling this was significant we set out to further explore a desensitisation programme ...

For this programme, students were recruited from the audiology caseload at Seashell who were unable to access audiology care due to their aversion to examination. A total of 7 students actively participated in the desensitisation programme.

Demographics:

1 Female / 6 Male. Age between: 13 - 22 years old. Mean age: 17.4 years old.

Diagnoses included: Sodicentric Chromosome 15 syndrome; Abnormal ABR Morphology; Mhyres Syndrome; Premature Birth; 23 Weeks; Ring chromosome 13; ASD/Severe Learning Difficulties; Corneliade-lange.

Outcomes:

Ethics and Consent

3 students achieved successful outcomes within the desensitisation programme.

2 students demonstrated progress during the programme, although the desired end goal was not fully achieved.

2 students showed little to no consistent progress throughout the duration of the programme.

Of note: the two younger participants were amongst those who achieved the goal. Whilst the sample size in this study was small, possible further studies could explore if age is a factor in determining the success of a desensitisation programme.



Ethical Considerations:

Prior to participation, students were given the opportunity to engage with the sessions based on their individual communication needs.

If any student declined participation in the sessions, their decision was respected and honored.

Mental Capacity Act (MCA):

The program highlighted the complex issue of obtaining consent while ensuring a balance with the principles of the MCA and the need to conduct assessments. This required a thoughtful and individualized approach to respecting each student's autonomy while considering their best interests.

Program Methodology:

The desensitisation programme employed a student-led approach tailored to the individual needs of each student. Key elements of the programme included:

- The use of consistent staff, visiting educational setting regularly and at the same time on each visit.
- Using methods consistent with those applied throughout Seashell. Typically a graded approach, incorporating familiar support staff, building rapport, and maintaining a consistent approach.
- The Seashell program, based on graded active support, was employed. This approach involved introducing equipment, allowing students to explore at their own pace, and gradually moving towards completing tasks.
- Communication with each student was adapted to their unique communication methods. For example, if a student responded well to social stories, a customised social story was created to support their participation in the audiology-led programme.

GAS goals were used in the absence of a standardised measuring tool. This measuring tool was chosen as it can be individualised to the specific goal of the student.

-2 = Baseline performance

-1= Progression made towards the goal

0 = Goal achieved

1 = Goal exceeded

2 = Exceeded beyond expectation

Considerations

Considerations in the desensitisation program included acknowledging and addressing challenges that students might face, which could impede their progress. These challenges included various aspects such as:

Health: Students' overall health status played a significant role in their progress, as medical conditions and physical well-being can impact their participation.

Individual Progress



Medication: The influence of medications on sensory sensitivities and cognitive function was taken into account, as it can affect a student's responsiveness during the program.

Mood: Emotional well-being and mood fluctuations were considered, recognizing that students may respond differently depending on their emotional state.

Challenges

Challenges faced during the program:

- Individual Differences: Each student had unique sensory challenges and communication needs, necessitating a bespoke approach for each participant.
- Reporting Progress: Accurately gauging progress for students with sensory challenges can be complex due to the diverse ways in which they respond to stimuli.
- Resource Allocation: Allocating sufficient resources, including trained staff and equipment, to meet the diverse needs of the participants proved challenging.
- Outcome Measurements: Difficulty choosing an appropriate outcome measuring tool, due to non-standardised approach
- Interdisciplinary Collaboration: Collaboration among various professionals, including audiologists, occupational therapists, and educators, was crucial for the program's success but required effective communication and coordination.

Conclusion

The desensitisation program aimed to provide a tailored approach to support students with sensory challenges to participate in an ear examination/hearing check; whilst acknowledging the individuality of their needs and the ethical considerations surrounding consent and autonomy. The goal of the intervention was varied and based on audiological presentation and need. The results reflect both successes and continuing challenges in this important area of audiology support. The approach used was successful for some of the students, but not all. Further research and exploration of this area would be useful. Insights gained from this program will be used to provide ongoing support and guidance to the participating and future students.

Discussion

Given the time and resources required to achieve the desensitisation goal, we asked ourselves: **Are audiologists in clinical settings offering enough information and support to parents/carers when it comes to desensitisation?** We felt the likely answer to this would be no, particularly given there is little research in this area, little training available for audiologists on this subject, and no obvious toolkit or outcomes measures that could be used. We suspect an approach led by the family, support staff, a ToD or school nurse could be more effective due to the consistency they could offer. Furthermore we considered that we did not establish, nor are we sure we would be able to define, the cause for the aversion to examination. We felt reasons could include anxiety, fear or sensory issues, however this was not explored and therefore we were unable to consider the question: **Does the reason for desensitisation programme?** Research in this area could help predict the success of a desensitisation programme?

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