Defining and measuring adaptive behaviour in deaf adults

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Overview

* Background/ aims
* Methods
* Results
* Discussions
* Conclusions
* Clinical implications
* Limitations
* Future research

Background

Adaptive behaviour – what is it?

* Used to identify intellectual disability (ID) and behavioural goals
* Different definitions of adaptive behaviour – evolving construct
* Lack of agreement about "unifying theoretical foundation"[1]
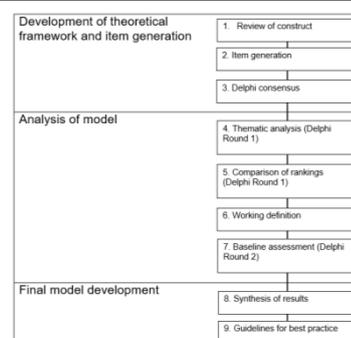* Culture under-emphasised in available measures

Background

Adaptive behaviour and deafness

* Deaf community as distinct cultural group with different behavioural norms[2,3]
* ID often associated with deafness due to concomitant causes[4]
* Biases in assessment make it hard to establish prevalence[5,6]
* Lack of consensus in how to appropriately adapt assessments[7]
* Guidance promoting importance of adaptive behaviour in ID assessment[8]

Aims

1. To develop a working definition, through collation of existing theory, generation of theoretically coherent items, and subsequent expert input, of adaptive behaviour for Deaf people

2. To develop empirically-derived guidelines for standardised practice in the assessment of adaptive behaviour in Deaf people

Development of theoretical framework and item generation
1. Review of construct
2. Item generation
3. Delphi consensus

Analysis of model
4. Thematic analysis (Delphi Round 1)
5. Comparison of rankings (Delphi Round 1)
6. Working definition
7. Baseline assessment (Delphi Round 2)

Final model development
8. Synthesis of results
9. Guidelines for best practice

Methods

* 13 expert participants consented (25.5% of overall sample)
* Rated 309 items on Likert scale and provided written feedback
* Very little consensus achieved
* Quality of written feedback so comprehensive TA was conducted
* Working definition constructed and feedback report provided
* Re-rating of items in terms of normative adaptive functioning in Deaf and hearing contexts
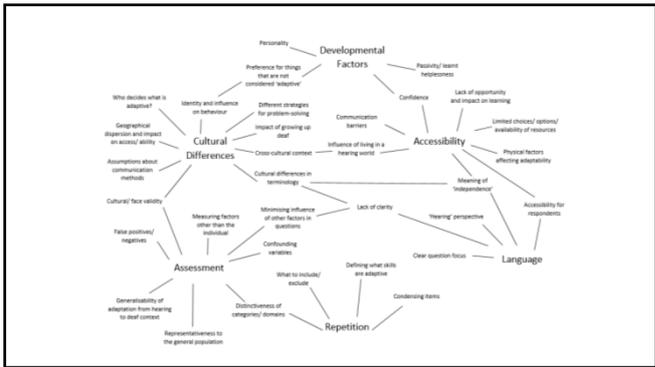
Results

Cultural differences

Negotiating balance: what is adaptive for deaf people and adherence to cultural norms vs hearing world

> *Capturing someone who tries to fit in with the hearing world and rejects deafness might be useful as this identity of attempting to 'pass' as a hearing person has been shown to be the least adaptive in various studies (participant 2)*

Strategies used to achieve goals (e.g., through working with interpreters)

> *'[Gives shop assistant the necessary amount of money when purchasing items] – if it can be seen on a visual display - most deaf people give larger denomination and get change as they can't hear how much the cashier is asking for.' (Participant 3)*

> *'[Ending conversations appropriately]… there are differences in hearing ways of doing this and deaf ways – might need examples' (Participant 12)*

Items lacking face validity

Results

Accessibility

Conflation of literacy with higher order skills

> *Literacy issues reflect educational opportunity and access rather than LD (participant 2)*

> *Deaf people do not have same access to phone, internet, literacy on which a lot of these skills depend (participant 12)*

Limitations in availability of resources and choice

> *'Never been given the opportunity to try different things, to then be able to choose for themselves what they would want to do when bored – follow the same pattern of being told what to do' (participant 13)*

Lack of opportunities impedes development

> *People often do not do things they 'could' do due to others doing it for them. Sometimes they 'can' but are not given the opportunity. Sometimes that lack of opportunity means they do not develop the skill and cannot (participant 9)*

Results

Developmental factors

Impact of early experiences and setbacks

> *Deaf people generally give up making complaints – process is usually hearing oriented and they soon learn not to bother. It is adaptive not to bother to complain as it takes up too much energy and doesn't change anything (participant 12)*

Confidence mediated by context – different behaviour with other deaf vs hearing people

> *Journey by public transport is by default more complex for a deaf person (participant 3)*

Requires more planning > greater risk if something goes wrong > impact on choices

A working definition

*'a collection of skills that are used day-to-day based upon a person's prior learnt knowledge and access to opportunities, enabling the individual to draw upon a variety of resources to achieve their full potential within both Deaf and hearing contexts, in a manner consistent with their values and identified cultural norms and appropriate to their age. **Any deficits in adaptive behaviour should be considered in light of cultural, accessibility, and developmental factors, and which cannot be better accounted for by other causes before making diagnostic determinations of ID**.'*

Clinical implications

Guidelines for practice:
* Selection of knowledgeable informants and triangulation
* Gathering developmental history
* Assess at multiple time points prior to diagnosis
* Language assessment (deaf-specific norms)
* Explore use of compensatory mechanisms

Clinical implications

* Use of working definition specific to Deaf people
* Assessment of both Deaf and hearing contexts
* Interim use of the ABAS-III
* Generation of Deaf-specific norms and culturally sensitive questionnaire development

Limitations

* No service-user involvement
* Small sample size
* Lack of consensus obtained
BUT
* Useful adaptation of Delphi process
* Draws together theory and contributes to development of working definition
* Development of guidelines for practice

Future Research

* Refinement of guidelines (case-based approach)
* Test hypotheses raised by guidelines
* Pursue further development of proposed items for assessment tool

Any questions?

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