

Defining and Measuring Adaptive Behaviour in Deaf Adults

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Abstract

Assessing adaptive behaviour for deaf people is particularly complicated due to confounding cultural, linguistic, and methodological issues. A thematic analysis of expert comments yielded a potential new working definition of adaptive behaviour and initial guidelines for assessing adaptive behaviour accordingly.

Around 10 million people in the UK have some form of hearing loss: around 800,000 of this group are severely or profoundly deaf (Action on Hearing Loss, 2011). Some deaf people perceive themselves as a cultural and linguistic minority group, using British Sign Language

(BSL) as a preferred form of communication and although specific figures are inconsistently reported, this group could comprise between 15,000 (Office for National Statistics, 2011) and 156,000 (British Deaf Association, 2013) people. Currently, there are no established standardised assessments of adaptive behaviour for a d/Deaf population, highlighting a significant gap in the field.

Adaptive behaviour describes a *“collection of conceptual, social, and practical skills that people have learned to be able to function in their daily lives”* (Schalock et al., 2010, p. 15). Adaptive behaviour is assessed in order to identify educational and rehabilitative interventions for individuals (Tassé et al., 2012) and significant deficits in adaptive behaviour are a criterion for the diagnosis of Intellectual Disability (Department of Health, 2001). However, ‘adaptive behaviour lacks a unifying theoretical foundation’ (National Research Council et al., 2002, p. 150) and measures have been criticised for their focus on low-level skills, for example, self-care (National Research Council et al., 2002). These limitations create a particular challenge when assessing individuals with additional needs, such as deafness.

The different terminology used in the context of deafness is important in conveying meaning: deaf, Deaf, hearing impaired, and hard-of-hearing all describe the medical condition of not being able to hear, but denote different underlying assumptions (Roberts & Hindley, 1999). Lower-case ‘deaf’ refers to a medical conceptualisation of deafness, referring to hearing impairment, often used in the context of people who have acquired deafness later in life or are deaf but do not consider themselves part of the Deaf community, using spoken language and hearing technologies as preferred forms of communication (Ladd, 2003). Upper-case ‘Deaf’ refers to those who consider themselves part of a cultural community and linguistic minority who are usually deafened pre-lingually and use sign language as their first or preferred language (Meadow-Orlans & Erting 2000).

Given the above, current measures of adaptive behaviour may fail to accurately discriminate between outcomes related to cognitive impairment and those linked to deafness or concomitant factors, such as spoken and signed language exposure (Szatmari et. al., 1995). In addition, there are considerable differences in adaptations made to testing of a d/Deaf client which typically rely on translating test instructions or test materials (British Psychological Society, 2010), or excluding measures that may introduce confounding variables, such as omission of verbal comprehension scales (Baker & Baker, 2011). These adaptations may be made idiosyncratically and are often not reported, further confounding the validity and reliability of assessments.

Given the limited literature and theoretical basis, the current research aimed to develop an understanding of the assessment of adaptive behaviour in d/Deaf people, by developing:

1. A working definition of adaptive behaviour for d/Deaf people through the collation of existing theory and expert input.
2. Empirically derived guidelines for standardised practice in the assessment of adaptive behaviour in d/Deaf people.

Methodology

Procedure and Materials

Delphi procedures are designed to build agreement between professionals on a specific topic over a number of set rounds, by independently polling and intermittently feeding back to participants (Herdman et al., 2002). For the current study, participants were initially sent the study materials, consisting of a working definition of adaptive behaviour, example items from

existing measures of adaptability (details can be provided on request), and space to provide qualitative comments. In the second Delphi round, the interim results were presented to participants for further feedback.

Participants

Registered members of a Special Interest Group for psychologists working with d/Deaf people were invited to participate in this research. Sixty-three emails were sent to potential participants; 12 emails were undeliverable, or the prospective participant was unavailable. A total of 13 participants consented to take part (25% of the remaining population of 51; see Table 1). Retention across the Delphi consensus fell in the second round, with only four of the original 13 participants providing additional comments.

<Insert Table 1 about here>

Data Analysis

In accordance with the guidelines for Thematic Analysis (Braun & Clarke, 2006), participants' comments ($n = 204$) were collated and coded to identify common themes. Each comment was given equal weighting during the coding process, and reflections were noted. The themes and labels were reviewed and ordered by the research team and summarised in a thematic map. Based on the findings, a working definition of adaptive behaviour in d/Deaf populations was formulated.

Results and Discussion

Six main themes were identified from the data (see Figure 1). Two super-ordinate themes emerged, which divided the comments in terms of *structural factors* (e.g., those concerning

questionnaire development) and *content factors* (e.g., comments related to how adaptive behaviour may be conceptualised when applied to d/Deaf people).

<Insert Figure 1 about here>

Structural Factors

This theme comprised three sub-themes, namely Repetition, Language, and Assessment Issues. While these areas contained some important features, such as the need for language being accessible to respondents (e.g., references to plain English or avoidance of ambiguity), they were largely applicable to the design of any assessment. As the aims of the study were particularly focused on the assessment needs of d/Deaf people, these themes are not considered in greater detail here.

Content Factors

This overarching theme also comprised three sub-themes: Cultural Differences, Accessibility, and Developmental Factors.

Cultural Differences

Participants identified cultural differences as a core factor in defining the adaptive behaviour of d/Deaf people. This drew on the unique experiences of identifying with a Deaf community, the values and behavioural norms associated with Deaf culture, and the necessary negation needed to exist within mainstream hearing society. One participant suggested:

‘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)

Given that 90% of deaf children are born to hearing parents (Mitchell & Karchmer, 2004), unlike many other minority groups, Deaf people are also in a position where identifying as ‘Deaf’ is not necessarily shared by their family and therefore cultural membership may instead be learnt from peers or may shift throughout the lifespan (Jones, 2002).

Deaf people may also differ from hearing people in the type of strategies used to achieve goals. Many adaptive behaviour assessments require actions to be performed ‘independently’, yet in a d/Deaf context, working with a support worker or interpreter could be considered an adaptive solution to a range of interactions with the hearing world (Harrison & Oakland, 2015). However, one participant noted that many d/Deaf people may be discouraged from using compensatory strategies, possibly due to previous negative experiences:

‘Many deaf people don’t bother– too much trouble and learnt that it is too complex to book interpreter and the appointment. This happens across the range of adaptive abilities’ (Participant 12)

These comments highlighted the notion that adaptability is contextually bound, making it difficult to determine what course of action to consider adaptive due to the lack of a norm-reference group.

Accessibility

Participants explained that accessibility of opportunities may impact on the development of adaptive behaviour (Harrison & Boney, 2002). For example, individuals living in residential care may have relatively poorer access to community or leisure activities, thus limiting their opportunities to develop or display certain skills.

Many participants pointed out that communication barriers may stem from the cumulative impact of growing up language-deprived, and that the long-term impact of delayed language acquisition can affect both the development of 'everyday' skills (e.g., accessing transportation, shopping, and socialisation with others, with one comment suggesting: *'deaf people do not have same access to phone, internet, literacy on which a lot of these skills depend'*) as well as their assessment. For example, poor literacy was frequently felt to be an alternative explanation for not engaging with particular skills or problem-solving strategies, rather than a failure to perform the task itself.

'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).

Overall, the participants' comments demonstrated an important distinction to be made between measuring current levels of adaptability, and *potential* for adaptability. Whilst clinicians may be interested in an individual's capability (potential to acquire additional skills with adequate learning opportunities) in order to formulate and plan required support, adaptive behaviour measures are generally designed to measure *typically displayed*

behaviour. It is therefore a crucial task of the assessor to obtain a detailed developmental history and to differentiate between ability and capability (see Du Feu & Fergusson, 2003).

Developmental Factors

Participants reflected on the need to consider the *function* of specific skills; particularly, how behaving in a way that may not generally be regarded 'adaptive' could be considered so given an individual's developmental learning history. For example, while passivity would generally not be considered adaptive in current measures, in the context of negative early experiences and/or setbacks experienced by d/Deaf people, it can present a beneficial response to preserve the individual's energy:

'Deaf people generally give up making complaints – [the] 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)

In addition, participants highlighted that due to their differential developmental histories, certain skills are more difficult for d/Deaf people than for hearing people. For example, Participant 3 commented: *'journey by public transport is by default more complex for a deaf person'*. A lower-level adaptive skill for hearing people can present a relatively higher-order skill for d/Deaf people that requires greater planning, carrying with it greater risk of failure, and thus impacting on the choices people make.

Conclusion: A working definition

The identified themes both challenged the validity of existing measures for d/Deaf individuals and highlighted a differential understanding of the construct of adaptive behaviour for this population. Our definition has been adapted from existing definitions (e.g., Schalock, 2004; Schalock et al., 2010) to emphasise the importance of cultural relativity and identity, which the participants' responses suggested may be particularly important facets of adaptability for d/Deaf people. We propose that Adaptive Behaviour refers to: *'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 differences in adaptive behaviour should be considered in light of cultural, accessibility, and developmental factors, and which cannot be better accounted for by other causes, such as intellectual disability, before identifying adaptive skills deficits.'*

Conclusion: Where to from here?

There is still a lack of suitably structured and normed measures that can be used in the assessment of a d/Deaf client. The current study highlighted the differential understanding of adaptive behaviour amongst professionals and drew attention to the considerable variation in their assessment practice. We thus translated the above findings into best Practice Guidelines for the Assessment of Adaptive Behaviour in Deaf Adults, based on six principles. We hope this presents a first step in the standardisation of professional practice when working with d/Deaf individuals, with the ultimate aim to work towards a standardised assessment tool of adaptive behaviour normed on d/Deaf populations.

1. Use a Shared Definition

The initial step to a comprehensive assessment is to be clear about the construct that is to be assessed. The literature and expert participants highlighted variability in the definitions of adaptive behaviour, and the need to differentiate it from cultural differences, accessibility, and developmental factors. We suggest the above working definition as a starting point to definitional alignment.

2. Engage in Information Triangulation and Selection of Knowledgeable Respondents

The participants recommended gathering information from various sources, including those knowledgeable about the person's current everyday behaviour, the developmental experiences of the individual, and d/Deaf cultural factors. It may be the case that different parties have a better understanding of each of these components and it will be important for clinicians to draw on the themes identified within this research in order to inform which individuals may be best placed to do this. For example, a parent may be able to most accurately reflect on relevant developmental experiences and how this may have shaped the individual's behaviour, but a Deaf support worker may be better placed to consider cultural differences and sign-language ability in some cases. Thus, triangulation of information will yield more comprehensive and reliable data.

3. Explore Use of Compensatory Mechanisms

Whilst most existing measures of adaptive behaviour do not consider behaviours that are performed with the assistance of others as adaptive, the findings of this research showed that expert participants considered the use of resources to achieve goals, including working with others, to be a good indicator of an individual's adaptability. This highlights not only

the importance of incorporating this into scoring matrices of existing tools, but actively assessing how a person uses alternative strategies for meeting goals if they are unable or unmotivated to do this independently. Hersh (2013) discusses the concept of 'interdependence' with deaf-blind adults, suggesting that considering self-determination is a meaningful and less infantilising way of assessing the support needs of these individuals.

4. Consider developmental history

In addition to exploration of cultural factors, specific assessment and information gathering with regards to the person's family background (e.g., history of deafness within the family, communication at home), identity, developmental history, language use, and cultural identification may also impact on the behaviour of the individual. Through explicitly considering these features within history-taking, clinicians can begin to develop hypotheses about how to define behaviour that is adaptive (i.e., culturally and developmentally normative). Because of the confounding nature of these variables and particularly due to the significant role of learning opportunities, it is important to specifically assess for these factors.

5. Assess at Multiple Occasions Prior to Diagnosis

The fundamental importance of establishing access to developmental opportunities was a theme arising throughout the research. As such, it is recommended to include an assessment of potential (e.g., through the teaching and retaining of new skills) before making firm determinations of causation.

6. Include an Assessment of Language and Literacy

Although literacy deficits are not inevitably linked to deafness, poor literacy and possible language deprivation influence any psychological assessment. An assessment of language should therefore be conducted due to its impact on a person's adaptability (National Research Council et al., 2002).

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Figure Legend

Figure 1. Thematic map of the themes and sub-themes derived from the thematic analysis process

Table 1: Participants' Demographic Information

Demographics	N (%)
<i>Role</i>	
Clinical Psychologist	8 (61.5)
Clinical Neuropsychologist	1 (7.6)
Assistant Psychologist	1 (7.6)
Trainee Clinical Psychologist	1 (7.6)
Psychological Therapist	1 (7.6)
Counselling Psychologist	1 (7.6)
Total Participants	13 (100)
<i>Hearing Status</i>	
Deaf	4 (30.7)
Hearing	9 (69.2)
<i>Experience of working in the field of deafness and mental health (years) [M(SD)]</i>	14.3 (8.9)