

Assessing Cognitive Ability and Adaptive Behaviour with Culturally Deaf Adults: A

Review

Kathryn Roscoe; Hannah Merdian; Kevin Baker;

David M. Gresswell; Louise Braham & Mike Berry

Abstract

Assessing deaf adults' cognitive ability and adaptive behaviour is complex due to confounding factors such as language deprivation, the influence of deaf-cultural norms, and the need to adapt assessment measures, impacting on their validity and reliability. This systematic literature review investigated the types of assessments currently used for deaf people, their common adaptations, and the implications for clinical practice. There appears to be little academic agreement on these issues, and an associated lack of methodological rigour in the literature. The review highlighted a need to further develop valid, psychometrically sound assessment tools for this population, and provides suggested best-practice guidelines for the assessment of this population.

Keywords: Deaf, cognitive ability, adaptive behaviour, assessment, standardisation.

INTRODUCTION

In this paper, we review the issues surrounding the assessment of Intellectual Disability (ID) in deaf adults. Identifying ID involves the assessment of both *cognitive* and *adaptive* behaviour, along with evidence that these deficits started within the developmental period (American Psychiatric Association, 2013).

In the UK, around 10 million people have some form of hearing loss. Around 800,000 of this group are severely or profoundly deaf (Action on Hearing Loss, 2011). Often, British Sign Language (BSL) is the preferred form of communication, a language that is reportedly being used by between 15,000 (Office for National Statistics, 2011) and 156,000 (British Deaf Association, 2013) people. Some deaf people identify as a cultural and linguistic minority group. While prevalence data suggest that hearing loss may be associated with a greater prevalence of (a diagnosis of) ID (e.g., Gallaudet Research Institute, 2008), the assessment of behavioural and psychiatric problems in deaf populations is often confounded by difficulties in undertaking and interpreting assessments, including differing opinions on what constitutes reasonable adaptations to testing and unfamiliarity with issues associated with deafness (Reesman et. al., 2014).

Cognitive Assessment and Deaf People

The methodological complexities of assessing cognitive abilities with deaf people have frequently been discussed (e.g., Baker & Baker, 2011; Pollard et. al., 2005). Few cognitive assessments provide formal guidance on their use for deaf adults; and common adaptations, such as use of an interpreter or translation of the items into BSL, impact on the linguistic and cultural validity of the items (Dean et al., 2009; Reesman et al., 2014). As approximately 90% of deaf children are born to hearing parents (Herman & Roy, 2006; Mitchell & Karchmer, 2004), they often experience significant difficulties in developing language skills because the parents have little experience of signing or the cognitive development of deaf children and are

exposed to fewer opportunities for incidental learning (e.g., overheard conversations; Moores, 2001), impacting on the development of verbal, social, and cognitive skills.

Adaptive Behaviour Assessment and Deaf People

The second aspect of ID, adaptive behaviour, requires the assessor to determine whether differences in adaptive behaviour are indeed a consequence of lower intellectual functioning as opposed to other factors, such as growing up deaf or language deprived. Some scales do not recognise that they are orientated to activities that deaf individuals do not have real-life experience of or have a different real-life experience of (e.g., Gross, 2003). Indeed, as Jones (2002) pointed out, some assessments of adaptive behaviour may simply highlight that a deaf person does not engage fully in mainstream hearing culture.

Developing psychometrically sound assessments for ID in deaf adults is complicated by the above-described methodological, developmental, and ethical issues. The difficulty in providing clinical guidelines for assessment is indicative of the paucity of research discussing the practical or conceptual issues of conducting psychological assessments with deaf people (Gutman, 2002). Consequently, deaf people may be disadvantaged in the assessment process.

CURRENT RESEARCH

We conducted a systematic literature review to provide an overview of issues concerning psychometrically sound assessment of cognitive ability and adaptive behaviour in deaf adults. Of the 106 reviewed papers, only nine were suitable for inclusion in the review. Our review identified a number of different measures employed to assess cognitive ability and/or adaptive behaviours. Researchers tended to use the *WAIS-IV* non-verbal subtests, the *Wechsler Memory Scale* visual reproduction tasks, or the *Mini-Mental State Exam*. Dean et al. (2009) suggested that there is a systematic measurement error in the latter which yields lower results in the assessment of deaf clients than would otherwise be expected (e.g., difficulty in translating test instructions leading to misunderstanding of the task). Some

measures were developed specifically for deaf people (e.g., the ‘Signed Paired Associates Test’, Pollard et al., 2005; the ‘American Sign Language Stories Test’, Pollard et al., 2007). In these studies, care was taken to ensure that the tests were: designed and produced in language accessible to deaf people; that they were consulted (albeit self-selected and well educated) in the test development; and that rigorous translation and piloting procedures were applied throughout the process.

Regarding the assessment of adaptive behaviour in deaf adults, the authors of the papers included in this review repeatedly noted the difficulties in administering and interpreting data from tests that had not been validated for use with the deaf community. For example, Werngern-Elgström et al. (2013) highlight that for deaf people, items intended to assess independence (such as ability to use public transport) may inadvertently assess the ability to communicate effectively with hearing people. O’Reilly et al. (2014) provided deaf group norms that differed from hearing population norms, therefore challenging the applicability of existing scales.

The review also highlighted that there is no standardised approach to adapting assessments for deaf adults. Whilst some (e.g., Baker & Baker, 2011; Chamberlain & Mayberry, 2008) delivered only non-verbal segments of tests as a way of eliminating language deprivation factors from measurement, others used sign language translations; however, some translated only test instructions (e.g., Hauser et al., 2007), whilst others (e.g., Pollard et al., 2005, 2007) used rigorous translation methods for all their materials. Many of the papers reviewed urged caution in interpreting results of assessments that have been translated into sign language. Until methodological issues have been addressed and a clear standard for testing has been developed, inconsistencies in findings are likely to remain. Our review concluded: 1) adaptations are likely to be needed to ensure that culturally deaf individuals understand task demands and are able to engage with the testing process; and 2) adaptations are likely to affect

the psychometric properties of the measures being used and should be interpreted tentatively by clinicians familiar with deafness.

DISCUSSION

Four key discussion points emerged from this review:

- **Lack of methodological rigor:** While the reviewed papers showed a good standard of reporting the test procedures and adaptations, only one paper was rated “good” regarding their method. Possible solutions include addressing the psychometric properties of the test, developing norms for deaf sub-populations, and piloting different administration techniques such as working with an interpreter rather than a sign-fluent clinician.
- **Limited applicability of findings:** The findings of this review are dominated by research on the American deaf community and many of the studies recruited only well-educated, motivated, and geographically convenient volunteers, limiting the conclusions that can be drawn from results. More work is needed to facilitate impartial testing of deaf adults compared to their hearing peers, and the need for increased awareness of testing standards by clinicians and researcher, such as the work driven by the Social Research with Deaf people group (<https://sites.manchester.ac.uk/sord/resources/>).
- **Ethical considerations:** Assessments of deaf individuals bring ethical challenges, such as the use of translators, or the knowledge / professional background requirements of the translator. Non-standard translations of highly complex and carefully worded psychological assessments are likely to impact on the validity of the data collected (Leigh & Pollard, 2003). The practice of administering any ability test to an individual where the validity of the test is questionable can be considered unethical in itself due to the social and psychological impact of test results on an individual (Maller, 2003).
- **Biases in the presented literature:** It should be noted that we are hearing, therefore possibly introducing a source of bias in the interpretation of results. While the current study

excluded grey literature due to the quality criteria, future research may wish to include such literature in order to gain a fuller, culturally-orientated, perspective on the issues that pervade this area. The field of deafness and intellectual ability is still under-researched. There may be a problematic bias in the types of studies into deafness that are funded and published. In addition, this limits the possibility to conduct (and appropriately interpret) rigorous research methods, such as systematic reviews or meta-analyses.

CONCLUSIONS.

Our findings have direct clinical relevance for the assessment of cognitive ability and adaptive behaviour in deaf populations, and indirect implications for clinical diagnosis and resource allocation and therapeutic support. The following conclusions can be drawn:

1) Which tests of cognitive ability or adaptive behaviour should be administered?

The review has highlighted that agreement is needed for best practice for cognitive or adaptive behaviour assessment in this population and that a variety of testing procedures are being employed.

2) What adaptations should be made to standard procedure?

It is difficult to extrapolate to cognitive testing of deaf adults for clinical purposes as most research in this area is focused on children and/or on academic achievement. It appears that researchers who have made attempts to assess deaf people accounting for cultural factors (such as language deprivation) have done so by either adapting existing tests or creating new measures. Of those who chose to adapt measures, adaptations have ranged from: using only parts of tests that do not load on verbal skills, translating test instructions and/or test materials a priori, to interpreting test instructions and/or test materials on the spot. The variety of methods used to adapt and re-standardise measures not designed for the testing population suggest that it is complex and points to difficulties in the validation of the adapted measure. As such, developing measures specific to the client group to be assessed is likely to be a more reliable

and valid means of testing.

3) What are the clinical implications?

Given the problem of assessing cognitive ability of deaf adults, combined with the under-representation of research investigating the assessment of the adaptive behaviour of deaf people, developing new measures is an appropriate first step to assist practitioners in disentangling the various languages, cultural, and cognitive factors underpinning a deaf person's functional ability. This review argues that a "one-size-fits-all" approach may not be suitable given the diverse presentations of deafness. For clinicians administering assessments, we propose to adopt a Scientist Practitioner stance:

- a. a thorough theoretical understanding of the impact of pre-lingual deafness, and/or growing up language-deprived, on cognitive development; the cultural context in which the adaptive behaviour is being assessed, including the demands that co-existing in both hearing and deaf communities can place on the deaf individual; and choices individuals may have to make in prioritizing the development of their skill set.
- b. The ability to formulate how the clients have been affected by their deafness - based on a holistic understanding of the individual's history, including the impact of signing or non-signing parents and their exposure to a signing community etc.
- c. A robust understanding of the principles of psychometric testing and the ability to set up testable hypotheses about how any adaptations to measures are likely to affect the psychometric properties of the test used (e.g., the consequences of changing verbal instructions to three-dimensional signing, the influence of translations and translators).
- d. The ability to taking account of both norm-referenced (the comparison sample) and criterion-referenced considerations (referring to the construct in question, e.g.,

consequences of language deprivation *vs.* cognitive impairment *vs.* adaptive behaviour deficits).

- e. a commitment to reporting the decision-making transparently, so that the methods used can be directly replicated, that gaps in the knowledge base are made explicit, and the narrative can be critically evaluated

Take home message

- There is a lack of standardisation in the assessment of intellectual ability of a deaf client, which usually consists of an assessment of cognitive ability and adaptive behaviour.
- In addition, this population has very specific needs for an assessment due to confounding factors such as language deprivation, the influence of deaf-cultural norms, and the need for translation into sign language.
- There is a need to develop psychometrically sound assessment tools specifically for deaf individuals rather edited/abridged hearing ones and to assesses how they can be interpreted in a valid way.
- For a more details on the systematic review and its relevance, please contact the authors of the paper.

Count: 2,093

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Kathryn Roscoe – Leicester Partnership NHS Trust.

Hannah Merdian – University of Lincoln.

Kevin Baker - National Deaf CAMHS, Dudley & Nottingham / St Andrews Hospital, Northampton.

David M Gresswell – University of Lincoln.

Louise Braham - Derbyshire Healthcare NHS Foundation Trust.

Mike Berry -- Consultant Clinical Forensic Psychologist.

contact Mark Gresswell mgresswell@lincoln.ac.uk.