

Evaluating the effectiveness and cost effectiveness of BSL (British Sign Language) IAPT (Improving Access to Psychological Therapies): an exploratory study

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Scientific summary

Background:

This exploratory, mixed methods study is focussed on adults who are Deaf, who use British Sign Language (BSL) as their first, preferred or strongest language, and who experience anxiety and/or depression. BSL is a fully grammatical visual language separate from English. Its users (Deaf people) are formally recognised as a cultural-linguistic community in the UK and distinguished from the larger number of deaf people who use spoken language. Deaf adults experience poorer mental health than the general population and face significant barriers to accessing mental health services. Poor treatment outcomes are related, in part, to late access to preventative and primary mental health services. IAPT (Improving Access to Psychological Therapies) services deliver approved psychological interventions to address anxiety and depressive disorders, in primary care settings and follow the NICE approved stepped care model. IAPT has been adapted for Deaf people and delivered by Deaf therapists using BSL in some parts of England (BSL-IAPT). Elsewhere, Deaf people usually access Standard IAPT through an interpreter.

This study both carries out preliminary effectiveness and cost-effectiveness evaluations of the two approaches to psychological therapies for Deaf people and lays the groundwork for a potential large scale study through addressing deficiencies in instrumentation, population profiling and outcome data, service modelling and patient involvement in research design.

Objectives:

1. To explore:
 - a) Is BSL-IAPT more effective than Standard IAPT for Deaf people with anxiety and/or depression?
 - b) Is any additional benefit from BSL-IAPT worth any additional cost to provide it?

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2. To establish relevant BSL versions of assessment tools and methods to answer research questions a) and b)
3. To gauge the feasibility of a larger scale definitive study and inform its future design

Methods:

- i. *The acceptability of randomisation and trial-related terminology in BSL* were explored through four Deaf-led focus groups with Deaf community members (n=19) who met on two occasions. Participants were aged 18 or above, BSL users and were not receiving support through the IAPT programme. BSL data were kept in source language and subjected to a phenomenological approach to qualitative analysis (Objective 3).
- ii. *The clinical cut-offs for the PHQ-9 in BSL and GAD-7 in BSL* were determined through secondary analysis of two datasets. Dataset one (n=502) comprised Deaf users of the BSL-IAPT service who met caseness and on which at least one score on the PHQ-9 BSL and/or GAD-7 BSL had been recorded. Dataset two (n=85) comprised Deaf BSL users who were not users of the IAPT and who had no reported mental health difficulties in the past 12 months and who had completed the PHQ-9 BSL and GAD-7 BSL. Parameter estimates, including the AUC value, sensitivity, positive predicted value (ppv) and negative predicted value (npv), were used in the calculation of the clinical cut offs of PHQ-9 BSL and GAD-7 BSL (Objectives 1 and 2).
- iii. *Comparison of Deaf users of BSL-IAPT and Standard IAPT characteristic and clinical outcomes.* Secondary data analysis of routinely recorded client data obtained from Standard IAPT services that had provided a service to Deaf individuals (n=116) compared with client data and outcomes from the cohort of Deaf people who had used BSL-IAPT (n= 429). Characteristics and outcomes of clients were compared descriptively by IAPT group. Independent-samples t-tests were used to compare mean scores for the PHQ-9 and GAD-7 by group. The prevalence of anxiety and/or depression, recovery and reliable recovery were compared by group using Pearson's χ^2 test; reliable improvement was compared by group

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using the χ^2 test for trend. Because of their skewness, waiting times were compared by group using the Mann-Whitney U test (Objectives 1 and 3).

iv. *Mixed methods modelling of Standard IAPT services accessed by Deaf people and BSL-IAPT.* A sequential mixed methods study design was used. Initially, self-selecting IAPT practitioners completed a survey consisting of closed and open questions in order to capture a broad range of views and experiences (n=118). This was followed by semi-structured individual interviews with a sub-group of purposefully sampled IAPT practitioners (n= 32) to explore in greater depth topics identified from the survey responses that warranted further enquiry. Qualitative data were analysed using a Realist Inquiry approach into which the descriptive statistical results of the survey were included (Objective 3).

v. *Translation and validation of the EQ-5D-5L in BSL.* Five stage translation protocol in collaboration with assessment originators including forward/back translation with independent translation teams and respondent testing resulting in a final fourth draft for testing with a general population self-selecting sample of Deaf BSL users (n=92) hosted via an online secure portal. Participants completed a short demographic survey and the BSL versions of EQ-5D-5L, CORE-10 BSL and CORE-6D BSL, through the online platform. They were asked to take part in the retest of the EQ-5D-5L BSL approximately one week later and 74 did so. A sample size of 51 allows a 95 % confidence interval for an ICC of 0.75 to be estimated to within plus or minus 0.1. The psychometric properties of the EQ-5D-5L BSL were examined. The analyses included: content validity (assessed by interviewing a small sample of Deaf people), internal consistency of the items and test-retest were assessed for its reliability (using Cronbach's alpha values and weighted kappa scores), and convergent validity was assessed by determining how well EQ-5D-5L BSL correlates with CORE-10 BSL and CORE-6D BSL (using Kendall's tau) (Objectives 1 and 2).

vi. *Calculating utility values for the Deaf population.* Secondary data analysis. Descriptive statistics were used to summarise the responses of Deaf people to the population norms for the EQ-5D domains (percent reporting no problems) and EQ-5D utility weights (mean,

standard deviation (SD)) and to compare these to population norms. Deaf participants' (n=92) EQ-5D-5L scores and utility values were compared with published norms from the hearing population, identified via the EurQoL website. Linear regression was used to establish whether participants' socio-demographic characteristics were associated with Deaf participants' health and EQ-5D-5L utility weights. The analysis was also used, with descriptive statistics to assess whether utility values differed between people with and without depression. In line with clinical cut-offs from the hearing population a CORE-10 score of 13 or greater was used to identify participants with and without depression (note that cut-off values specific to the Deaf population are not available) (Objectives 1 and 2).

vii *Exploratory Economic Evaluation.* The economic evaluation used a two part economic model to synthesise data from the IAPT databases and published literature. The overall perspective or decision maker viewpoint used to determine the range of costs is that of health and social care providers. The economic model focuses on Deaf BSL adults referred to IAPT for a low or high-intensity intervention to treat depression and/or anxiety. The intervention is the BSL-IAPT specialist service, which is compared to Standard IAPT services. The economic model estimates the costs and quality adjusted life years (QALYs) for one year after a person's first contact with the service. Depression and anxiety are long term conditions, so the economic model also explored the costs and QALYs over longer time periods. The price year is 2015 and costs are presented in UK pounds sterling (£).

Results:

i. *The acceptability of randomisation and trial-related terminology in BSL.* The four main influences on the acceptability of randomisation were: (i) whether participation would benefit Deaf people as a whole, rather than the individual per se; (ii) if perceived as another example of imposed choice in Deaf people's lives it would be resisted; (iii) whether it implies linguistic needs will not be met or respected; (iv) if it implicitly or explicitly denies the value of Deaf people's point of view and life experiences.

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ii. *The clinical cut-offs for the PHQ-9 in BSL and GAD-7 in BSL are 8 and 6 respectively.*

This compares with the original English version cut-offs in the hearing population of 10 and 8 respectively meaning that a lower score is required to reach caseness in the BSL versions of the assessments. The three different statistical choices for calculating clinical cut-offs (Equalising, Maximising and Prioritising FN:FP= \sim 1:2) all showed a lower clinical cut-off for the Deaf population with respect to the PHQ-9 BSL and GAD-7 BSL with the exception of the Maximising criteria when used with the PHQ-9 BSL. The primary limitation on this result is the design did not include a gold standard clinical interview.

iii. *Comparison of Deaf users of BSL-IAPT and Standard IAPT characteristics and clinical outcomes.*

There was no significant difference between Deaf clients of Standard IAPT and BSL-IAPT in reliable improvement (63.5% v 66.8%, $p = 0.917$) and no difference in reliable recovery (40.0% v 40.4%, $p = 0.946$), based on attending a minimum of two therapeutic appointments as the definition of treatment completion. Using the tighter definition of completed therapy reliable improvement in Deaf clients attending BSL-IAPT services was 76.5% while reliable recovery was 54.0%. These results compare favourably with recent national IAPT statistics which report reliable improvement as 61.5% and reliable recovery as 43.1%. However results should be treated with considerable caution because of the small number of Deaf users of Standard IAPT on which they are based ($n=89$) and small number of Standard IAPT services ($n=21$) most of whom had seen fewer than four Deaf clients.

iv. *Mixed methods modelling of Standard IAPT services accessed by Deaf people and BSL-IAPT.* Problematic issues in Standard IAPT provision for Deaf people included: self-referral and general access arrangements that were heavily biased toward use of written English; little understanding of the impact of interpreter use on the therapeutic encounter; lack of use of the IAPT assessments in BSL; poor background understanding of Deaf client's knowledge needs in order to engage in therapy; low cultural competence; lack of robust systems of equality impact monitoring. Key components of BSL-IAPT included: direct not indirect therapeutic experience; cultural and linguistic compatibility of therapist; choice of therapist; structural components that supported a culture of quality improvement and monitoring in

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meeting Deaf clients requirements; boundary issues arising from Deaf community members in multiple roles.

v. *Translation and validation of the EQ-5D-5L in BSL.* The psychometric properties of the EQ-5D-5L BSL are good, indicating that it can be used to measure health status in the Deaf signing population in the UK. Convergent validity between EQ-5D-5L BSL and CORE-10 BSL and CORE-6D BSL is consistent, demonstrating that the BSL version of EQ-5D-5L is a good measure of the health status of an individual. The test-retest reliability of EQ-5D-5L BSL, for each dimension of health, was shown to have Cohen's kappa values of 0.47 to 0.61; these were in the range of moderate to good, and were therefore acceptable. This is the first time EQ-5D-5L has been translated into a signed language for use with Deaf people and validated and is a significant step forward towards conducting studies of health status and cost-effectiveness in this population.

vi. *Utility values and the Deaf population.* The utility values were 0.77 (SD 0.03; n=82) for Deaf study participants, which is lower than the published UK population norms (0.86; SD .23; n=3392). Results indicate that health status and associated utility norms published for the general population may not be generalisable to the Deaf population. The mean utility in this group was nearly 10% lower than the general population published norms. In addition depression and anxiety are shown to be more prevalent in this group. Statistical analysis indicated that, as may be expected, utility values for Deaf people with depression may be lower than for people without. Our results provide EQ-5D-5L utility values relevant to a Deaf population, which have previously been unavailable. However, there are some limitations. In particular, the study sample (n=92 overall; n=82 with complete utility data) is too small to draw strong conclusions.

vii. *Exploratory economic evaluation.* BSL-IAPT is associated with a net saving of £240 (SD 832; 95th percentiles -£2,303, £935). However, the 95th percentiles cross zero indicating uncertainty about whether BSL IAPT is associated with a net saving or net cost. The model predicts that BSL IAPT services are associated with a very small gain of 0.001 QALYs.

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Again the 95th percentiles cross zero indicating uncertainty about whether BSL IAPT is associated with a QALY gain or loss. The cost-effectiveness acceptability analysis suggests there is a 57% probability that BSL-IAPT is cost effective if decision makers are willing to pay £20,000 to gain one QALY. Most of the sensitivity analyses indicated that BSL IAPT was likely to be cost effective. Two exceptions were first, if the costs of an interpreter were excluded from the costs of the standard IAPT service, BSL IAPT was not likely to be cost effective. Second if the range of services provided by BSL IAPT included more high intensity treatment, standard IAPT was more likely to be cost effective than BSL IAPT. However, there were limited data and a high level of variance and uncertainty in the estimates of the costs and QALYs associated with the two services.

Conclusions:

This study has added the first evidence of the acceptability of randomisation and exploration of trial related terminology to be published with respect to sign language users anywhere in the world. It has established for the first time clinical cut offs for translated/validated standard instruments in BSL in clinical use in the UK with Deaf people. It has produced the first comparative outcome data on Deaf users of IAPT services (whether Standard or BSL-IAPT services) including reporting the largest verified clinical data set on Deaf people with anxiety and/or depression in the UK. It has established the first ever, validated version of the EQ-5D-5L in any sign language in the world and reported its operational characteristics. It has demonstrated that that health status and associated utility norms published for the general population may not be generalisable to the Deaf population.

However, the feasibility of recruiting large enough numbers to any future large scale study of effectiveness and costs effectiveness of BSL-IAPT Vs Standard IAPT is yet to be tested and clinical data recording in its current form has been shown to be unreliable. Small numbers have meant that the evidence base comparing reliable recovery and reliable improvement for Deaf users of BSL-IAPT and Standard IAPT is weak and it is not possible to produce good estimates of effect size.

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A carefully controlled large scale prospective observational study would enable greater recruitment of target population numbers, control of consistency and validity of clinical data recording and specification and standardisation of components of delivery of intervention to Deaf people whether within BSL-IAPT or Standard IAPT delivery structures. It would also enable investigation of the determinants of reliable recovery and reliable improvement in the Deaf clinical population in comparison with existing knowledge about the general population users of IAPT services. A larger prospective cohort study would also help to inform which socio-demographic and clinical characteristics are key influencers of utility, which would allow us to more fully investigate utility in the Deaf BSL population.

Finally, there is a dearth of epidemiological evidence on the Deaf population which severely hampers health research therefore some consideration should be given to establishing a Deaf mental health observatory in the UK which would benefit many studies in the future.