

## ORIGINAL RESEARCH

## Overcoming the challenges of translating mental health instruments into sign languages

Kate Moore<sup>1</sup>, Barry Wright<sup>2</sup>, Danielle Moore<sup>3</sup>, Richard Ogden<sup>3</sup>, Katie Rogers<sup>4</sup>

1. *Trainee Clinical Psychologist, University of Nottingham*

2. *Leeds and York Partnerships NHS foundation Trust*

3. *University of York*

4. *University of Manchester*

## ABSTRACT

In the United Kingdom (UK), the Strengths and Difficulties Questionnaire (SDQ) is widely used in Child and Adolescent Mental Health Services (CAMHS), and has been translated into over sixty spoken languages. It is used both as a screening measure of common mental health problems such as depression, anxiety, or anti-social behaviour, and also as an outcome measure within services. Clinical experience suggests that the SDQ has limited use within a Deaf mental health context due to linguistic and cultural differences arising. Translating diagnostic tools into British Sign Language (BSL) is important to provide valid assessment of common mental health problems in Deaf signing young people. In this paper the process of translating the SDQ from a written language (English) into a visual language (BSL) is reported, describing adaptations to the existing methodologies. The challenges of this process are discussed, with particular reference to the difficulties in translating for a population of signing Deaf young people, followed by suggestions of how these difficulties can be overcome.

## KEYWORDS

Deaf, British Sign Language, mental health, translation

### Introduction

Few widely used mental health instruments are available in a format that is culturally and linguistically relevant to the Deaf population<sup>1</sup>.<sup>1</sup> Based on the measures available, the prevalence of common mental health problems in d/Deaf children and young people is thought to be 2-3 times higher than their hearing counterparts<sup>2-5</sup>. However, the accuracy of these prevalence rates is uncertain due to the lack of available instruments that are culturally and linguistically appropriate for d/Deaf young people. As highlighted by Brauer, ‘inappropriate tests, unsatisfactory administration, and the unrealistic norm referencing of results’<sup>6(p294)</sup> remain the biggest challenges to overcome in mental health research with Deaf people.

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<sup>1</sup>Throughout this paper, an uppercase D is used to denote reference to individuals who are a culturally Deaf linguistic minority group.

Correspondence to Kate Moore  
Trainee Clinical Psychologist  
University of Nottingham  
Email: [lwzkamo@nottingham.ac.uk](mailto:lwzkamo@nottingham.ac.uk)

The SDQ is a multi-informant mental health questionnaire that can be used as a screening tool and a treatment evaluation measure. The 'informant rated' version of the SDQ can be used for children and young people aged 4-16, and is completed by either a parent or teacher; the 'self-report' version can be completed by young people aged 11-16<sup>7</sup>. Each version of the questionnaire comprises twenty five questions, each scored on a three point Likert scale, which can be divided into five subscales measuring emotional symptoms, conduct problems, hyperactivity-inattention, peer problems and positive social behaviour, resulting in a total difficulties score of overall psychological adjustment<sup>8</sup>. The SDQ has a satisfactory internal consistency (Cronbach alpha ranging from 0.80 to 0.87) and specificity and sensitivity ranging from 94-95% and 23-47% for each version (parent, teacher and child)<sup>8</sup>. In the UK, the measure is recommended for national use within NHS mental health services by the CAMHS Outcome Research Consortium (CORC) guidelines<sup>9</sup>.

The SDQ has previously been translated into over sixty spoken languages<sup>10-12</sup>. Although sign language versions have been produced previously, they have not been fully and rigorously translated or validated<sup>13-14</sup>. The methodology that this study has adapted was developed for translation of spoken and written languages, which outlines the process of translation/ back translation<sup>15</sup>. This methodology is widely used to translate mental health questionnaires by such organisations as the World Health Organisation (WHO). When applied to sign languages the translation process can result in questionnaires and screening tools that are more meaningful to Deaf participants as long as this is conducted rigorously and systematically<sup>16</sup>. To date, the authors are not aware of any study that attempts to translate mental health instruments into BSL for Deaf young people.

Sign languages have been increasingly recognised as official languages over time across the world, with the same essential features of language as spoken languages<sup>17</sup>. In 2003, British Sign Language (BSL) was officially recognised as a language by the UK Government. BSL has a linguistic structure that is significantly different to English<sup>18</sup>.

In practice interpreters may be called upon to do on-the-spot translations of diagnostic and screening instruments, but this process can be problematic. Interpreters make a linguistic and conceptual leap based on the experience of a Deaf person to relay information that is contextually relevant to a hearing mental health professional<sup>19</sup>. Each interpreter will bring something different to this interaction, based on their own experiences, backgrounds, or training, and as such the information given may not be

consistently expressed. By working with interpreters, variability in the translation and meaning of questionnaires is inevitable.

The inconsistency could be overcome by using a validated instrument. Arguably the best way of achieving culturally sensitive instruments is to develop them empirically from first principles. However, this process is expensive and time consuming. An alternative solution is to translate existing instruments into BSL, but the current evidence base outlining best practice is small. Rogers and colleagues gave an in-depth account of the issues regarding translation of standardised mental health assessments into BSL<sup>20</sup>. These issues included: the direction of the signing; influence of modality; emotional state in BSL; confirmation of statements; and statements in a social context. Cornes and colleagues have noted that pencil/ paper tests tend to underestimate prevalence of common mental health difficulties in d/Deaf people, particularly emotional problems. This is partly due to the written language deprivation often present in d/Deaf people in hearing environments<sup>21</sup>. Linguistic deficits, particularly in younger children, may invalidate standardised instruments validated for their hearing peers. For clinicians this presents additional difficulties, particularly those who have little knowledge of deafness or Deaf culture in assessment and diagnosis. The consequences of this may be that many d/Deaf young people may not receive appropriate treatment or they may develop more complex, long-term difficulties.

The need for questionnaires and screening tools to be appropriate to the Deaf community is echoed in UK government legislation. The Department of Health has emphasised the need for better access to services and service provision for this group<sup>22</sup>. Provision of instruments that are accessible to Deaf people to elicit accurate self-report data will play an important part in establishing prevalence rates, public health and needs assessment data, and is important in building therapeutic relationships between Deaf patients and their practitioners<sup>23</sup>. As such, it is imperative that any measure used to collect this type of data is meaningful to its population, and is both accurate and valid.

Previous research has highlighted the difficulties translating into sign languages,<sup>20(p5),24-26</sup> but few studies give detailed descriptions of the translation process from English to sign language, and its challenges. The aim of this paper is to describe the

process employed in translating the SDQ into BSL. It is hoped that this model will provide guidelines for future researchers attempting translation from a spoken to a sign language, particularly with reference for d/Deaf young people.

## Methodology

This study followed the translation model provided by Beaton and colleagues, which provides guidance for written translations<sup>5(p3187)</sup>. However there are issues that make the current evidence base on translation less well-equipped for sign languages; this is not to say that sign language itself is a problem rather that the problem is that the guidance outlined by Beaton and colleagues is designed for written languages. Examples of issues are that BSL is a language with its own syntax, morphology and prosodic features. Additionally, the difference in using visual media (ie videos), means that the respondent will be watching an actual person on the screen and the questions are being signed which can have potential implications on understanding to whom the question is referring. In the written questionnaire, the questions will not involve having an actual person to read out the question. Finally, as BSL is a visual language, this means that substantial modifications need to be made to the standard model of translating for written languages. These differences are well illustrated through the use of words in the English version of the SDQ which represent aspects of frequency: words like 'often' and 'frequently', or verb forms which express regularity such as simple present tense forms (steals, shares) are most naturally expressed in BSL through inflections to manual signs, such as repetition of the sign or aspects of its articulation. Therefore what is expressed by separate words in English is often expressed through prosodic features in BSL, as part of a complex morphological system that expresses meanings differently from English<sup>19 (p431)</sup>.

To overcome these challenges the translation of the SDQ involved three phases. This study was reviewed and approved by Leeds West Ethics Committee on 7<sup>th</sup> of March 2011.

### PHASE 1 - Identifying Translation Teams

Phase one was built around the structure of translation/back-translation methodologies, requiring a forward translation team and a back translation team, independent of each other, and comprising three members each. The translation teams were made up of bilingual BSL/English professionals who had experience of translation work. Numerous factors affecting variation in BSL, or differences in BSL production, including: age, educational background, previous communicative and linguistic experiences, and family history of deafness<sup>27-29</sup>. BSL varies

dialectically across regions, much in the same way as spoken English. As there are questionnaire versions of the SDQ for young people, parents, and teachers, having a range of ages represented within the translation groups was essential.

Research has shown some important characteristics that translators should possess<sup>30</sup>. Most translation studies would involve at least two bilingual translators whose mother tongue is the target language in the forward translation team; the back translation team would be made up of at least two bilingual translators whose first language is the source language. However, building on previous research, consultation with professional Deaf researchers suggests that there is benefit of having Deaf translators on both teams as Deaf and hearing cultures are very different. As a result, a third translator was added to each team during Phase 1. Having translators from geographically diverse areas ensured a range of dialects were considered. It is recommended that researchers utilise the skills of native Deaf translators in that they can more readily discriminate sign meanings, which may be more useful for translation purposes.<sup>32</sup> This suggests that even skilled hearing interpreters may struggle to make culturally relevant, accurate decisions; moving images are likely not as easy to process by a hearing person as a native Deaf translator or respondent.

Beaton and colleagues<sup>15</sup> suggest that having a balance of expert and lay members on a translation team assists in retaining focus on both the academic aspects of translation (eg reliable knowledge of the constructs being measured) and the meaning of the language as it would be perceived by a wider population respectively. This was reflected in the construction of the translation teams, which comprised equal numbers of clinical psychologists and those experienced in translation work across the teams. Equally, members of an expert panel overseeing the translation process were selected on their ability to comment on the different psychological, linguistic, psychometric and cultural aspects of the translation. This group comprised the project leaders (two psychiatrists working in the field of deaf child mental health), a linguist with sign language expertise, and a range of Deaf professionals experienced in mental health, research and translation work.

The issue of agency was also considered by the team, in that a sign language has to be signed by someone, whereas a written questionnaire involves no other

person. This carries with it potential transference<sup>31</sup> issues that may resonate in terms of perceptions or feelings, and attributions or unconscious feelings about the signer. For example, a questionnaire signer that reminds a child of their critical mother may impact on responses and emotions. There may be a preference of adults/ young people for certain types of signers. Separate versions of the SDQ were filmed, presenting different characteristics of the signers (male/ female, younger/older, etc) with a final version favoured by focus groups of young people. A written test is neutral in this respect, and in clinical interviews a practitioner's gender is mitigated by the nature of their therapeutic relationship with the client. Alternatively, an unknown adult questioning the emotions and behaviour of a young person could be construed differently depending on various characteristics of that adult.

### PHASE 2 - *The Translation Process*

The translation process is illustrated in Table 1. Initially, three forward translation team members each filmed independent BSL translations of the SDQ materials, resulting in an initial unbiased signed translation. The translations were collated, presented and then discussed amongst the three forward translators as a group. The decision-making followed a systematic process of discussion, consideration of alternatives and appropriateness for the target audience (whether young person, parent or teacher). As a result, each item was re-filmed after agreement of the best version, by one of the translators at the meeting. These were passed to the back translation team.

The back translation team, who were blind to the original versions, produced individual English translations from each BSL item. The back translations were collated and presented to all three in group discussions, where the appropriateness of each English word and phrase selection was scrutinised, and a final version agreed. This differs slightly from the recommended process whereby independent back translations are used only as a validity check of 'gross inconsistencies'<sup>15(p3188)</sup>.

However, because sign languages are visual languages using the hands, face and body, it is possible for several meanings to be conveyed simultaneously<sup>32-33</sup>. Translating these meanings from signs into words is challenging because some elements that may be represented by words in spoken languages are expressed through timing, aspects of sign articulation, or facial expression in sign languages.

On completion of a full translation/back translation cycle, the expert panel reviewed the equivalence of the back translations to the original English SDQ in terms of

meaning, linguistic structure, and cultural/experiential sensitivity<sup>24 (p317), 15(p3189)</sup>. Translations that were agreed by the team as faithful and appropriate were judged as accepted (or 'banked', meaning no further translation would be necessary at this stage in the process). Where there were disparities the questions were sent back to the forward translation group with comments on specific relevant issues. Versions of the items where the translation needed further iterations (the 'un-banked items') were re-produced to make the meaning clearer. The process was reiterated until all items were successfully banked.

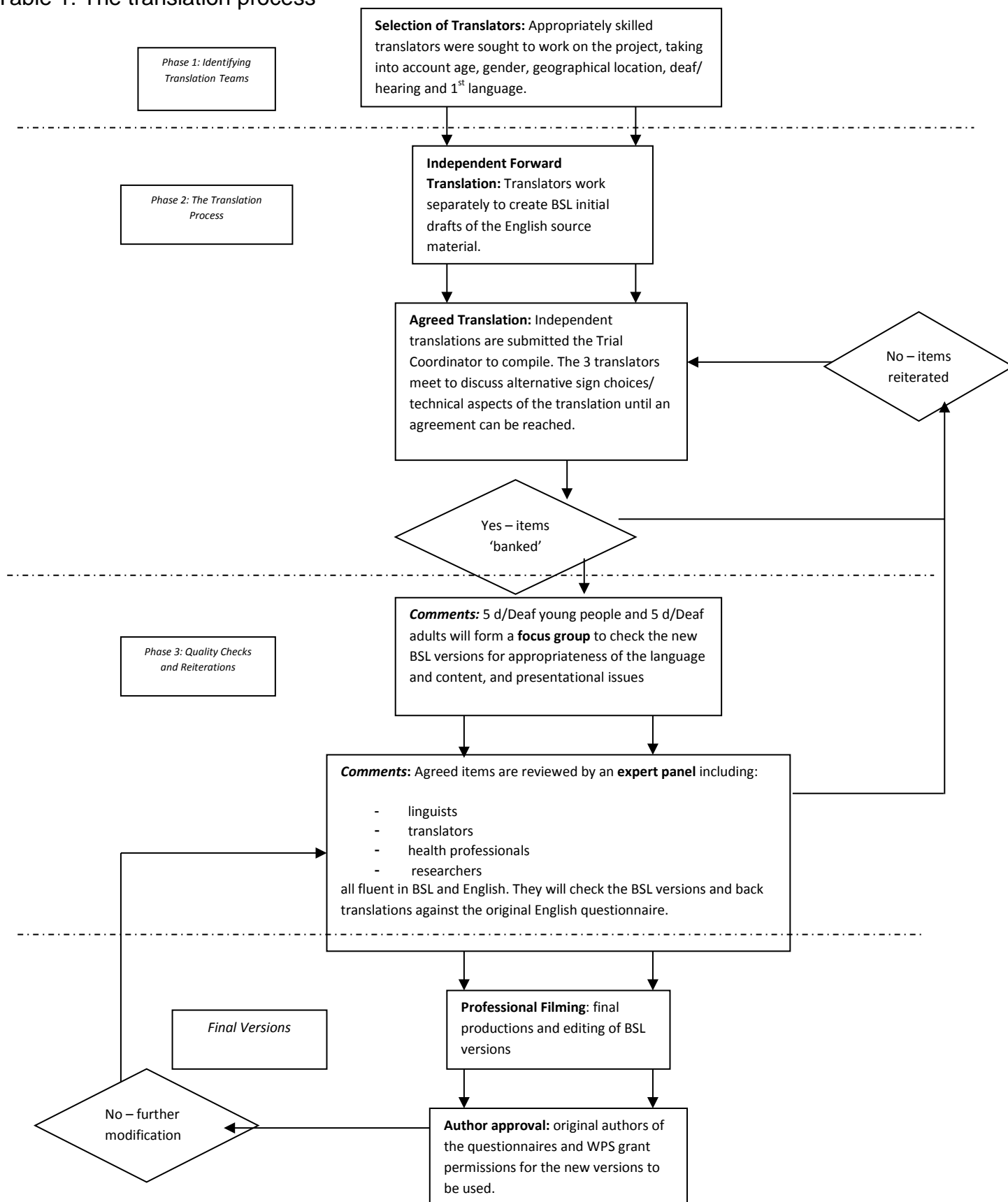
### PHASE 3 - *Quality Checks and Reiterations*

In order to test the face validity, presentation, and understandability of the new BSL version of the SDQ that had been produced, a focus group of five d/Deaf young people and a focus group of five Deaf adults were organised to test the individual versions of the SDQ (eg young person and parent/ teacher). The purpose of this was to address the needs of both sets of non-expert users of the test. The young person's group comprised both community and clinical samples, whilst the adult group were parents and teachers of young people within the right age range (4-16) to be responding to the SDQ.

The study team felt that it was important to film the focus groups in order to capture the full extent of the discussions and be able to refer to these at a later date. Participants in the focus groups completed the BSL SDQ as a small pre-pilot of the questionnaire, and subsequently discussed each individual item. A Deaf facilitator interviewed each participant to check what they had interpreted as the meaning of the question and whether they understood the content. All discussions were filmed and transcribed, and notes were taken throughout the day. This was fed back to the expert panel for potential further iterations of the translations.

The emphasis on service user involvement is highly important in the context of translation work; although efforts were made in order to balance the translation teams, the translators may not be representative of the population as a whole. Their linguistic ability in both BSL and English may mean they selected signs from a wider and more complex vocabulary than the average Deaf person. In particular, this applies to young Deaf people, whose exposure to sign language is likely to be limited compared to the exposure of a hearing English young person's exposure to English.

Table 1: The translation process



As many Deaf young people are born to hearing families, their exposure to fluent sign language may be delayed, and potentially restricted<sup>34</sup>.

Feedback from the focus groups highlighted a range of issues reflecting diversity of needs in the Deaf community. Whereas in spoken language translations, questionnaires would be piloted in the native speaking population, d/Deaf young people often grow up with a mixture of language experiences, and may use many multi-modal strategies in order to gain maximal information from messages. Though the native signers amongst the young person's focus groups understood the items with relative ease, those from oral English families found this more difficult, despite using signed language as their main mode of communication. Despite 'successful' back-translation prior to the focus groups, it became apparent that the focus group did not understand some of the more complex BSL constructions in the questionnaire. This led the team to believe that the level of language was inappropriate for this group, and therefore some BSL items were reiterated to lower the register of the signing.

The author of the SDQ, Robert Goodman, was available to consult with the meaning of specific items, and reviewed the questionnaire translations prior to his final approval<sup>35</sup>.

## Results

The translation process posed many unique challenges, which had to be overcome to ensure valid translation. These are discussed below, with suggestions of clear strategies in which to overcome the issues that arise in sign language translations.

### *Signer Characteristics*

In Phase 1, the characteristics of the signer were considered by the focus groups and expert panel. It had been hypothesised that a male signer would elicit lower response rates for emotional disorders, where a female signer might cause a young person to respond to questions about conduct or aggression less readily. Despite our initial belief that there may be preferences or biases in this area, both the young people and adult groups stated that as long as the presenter was comfortable and clear in their signing, age and gender were irrelevant to them. It is the content of what is being said that is of most relevance.

### *Register*

A major point of discussion during the initial filming and reiteration of the young person informant version of the SDQ was around the level of signing in 11-17 year olds. The discussion group was carried out with d/Deaf young people, where the level of signing ability varied within the group. The translation strategy used to overcome this was

to pre-pilot the SDQ in focus groups of young people. This allowed a 'road test' of the BSL SDQ, highlighting issues in inappropriate vocabulary choice and structure of sentences. By including native Deaf signers as well as two psychologists on the forward translation team, the translators were able to adjust to an appropriate register as they had an understanding of the types of language that young people use in real-world environments.

### *Non-Manual Features*

Non-manual features can be problematic in terms of the kind of answer that they seek, altering how a person interprets a question. This was the case in one of the items on the SDQ, which asked 'do you take things that are not yours?' The first translation of this was produced with non-manual features for a question, but with a facial expression indicating that if the respondent were to choose 'certainly true', there would be a negative judgement made on the part of the person marking the questionnaire. It is important at all times for the signer to produce sentences in an attitudinally neutral and non-leading way using only obligatory grammatical features, and paralinguistic features should be avoided in order not to bias responses.

However, in the translation/ back translation process these features make it harder to obtain total linguistic fidelity. For example, the English SDQ response set for the main test items are on a scale of 'certainly true', 'somewhat true' and 'not true'. In BSL, the degree of truthfulness is expressed on a continuum by facial expressions. These represent degrees of certainty simultaneously articulated with the sign TRUE. Facial expression thus inflects the sign and alters its meaning in the way that the modifiers 'certainly', 'somewhat' and 'not' change meaning. Selecting a sign-for-word substitution, as in SSE, would also be to negate a natural linguistic feature of BSL production. Content-for-content translation is common in interpreting scenarios but this elaborative process means that psychometric properties of a standardised questionnaire may be compromised if not done with great care<sup>19(p430)</sup>.

In terms of finding suitable translations, we worked according to procedures outlined in previous research<sup>24 (p316)</sup>. Discussions about the exact meaning and context of each statement were considered by the expert panel and, where agreement could not be reached, the author was consulted in this process.

### *Statements as Questions*

The original English SDQ is formatted as a series of statements with which the respondent does or does not agree. In this way, the statement reads “I...”. As discussed earlier, in BSL the sentence must instead be produced in the second person, since the presenter and the respondent are not the same person. This therefore means that the sentence must also be interrogative, or something to be agreed or disagreed with, in order to elicit a response. This means that there are two key changes to the statement’s linguistic structure: a change of pronominal deixis, and a change of sentence format from declarative to interrogative.

Previously, sign language translation studies have made this reference to the self clear by using a technique of finishing each statement with the index finger pointing outward with head tilted to indicate questioning<sup>20(p5), 24(p332)</sup>. This might be glossed as ‘YOU WHAT?’ Using this second person singular pronoun denotes that the item is referenced to the test taker, rather than the person signing on-screen, and the sign glossed as WHAT makes it clear that the sentence is designed to elicit a response. Despite this, feedback from focus groups indicated that this format of questioning seemed unnecessary and was, in some cases, confusing.

Based on this, forward translators attempted to further clarify the distinction between the presenter and the respondent. For parent and teacher statements, asking about the child, ‘THIS CHILD’ was placed at the beginning of each statement. At the end of a sentence, an appropriate sign more related to the question was chosen (such as ‘YOU HAVE?’, ‘YOU BEEN?’ or ‘YOURS?’) rather than the more generic ‘YOU WHAT?’ Although it is not then standardised throughout the questionnaire, it fits more closely with the natural characteristics of BSL sentence structure.

#### *Placement*

The English version of the SDQ contains the item ‘nervous or clingy in new situations, easily loses confidence’. Signs in BSL often have to be located, and show for example where the subject or object of a verb is. This is known as placement. In translating ‘clingy’, the forward translators had to show that a young person might be clingy to a parent or guardian. In English this might be implicit, but in BSL needs to be referenced since the sign is visual and clinginess is directional towards somebody.

#### *Concreteness*

Having an understanding of Deaf culture within the core research team is highly important, in order to understand the functional ways in which BSL is commonly used. Category words or words with ambiguous meaning can be

extremely difficult to translate without further concrete explanation of what that word or concept might include (for example, in BSL the sign for ‘considerate of other people’s feelings’ might include noticing those feelings in others, thinking about them, and moderating one’s actions based on this observation). The SDQ tends to give examples where this has been felt to be necessary. Where examples are not given in the English version, the challenge is to not choose signs that narrow the options too greatly (eg considerate of a specific person’s feelings). Research has shown that this as a key problem for interpreting in mental health settings<sup>19(p430)</sup>. An additional complication here is that lack of access to situational cues and incidental learning may mean that Deaf young people may struggle to ‘get the gist’ or understand when context is general as opposed to specific. Without a certain degree of openness to the statement they may believe that the question only relates to a very specific context. To overcome this, translators must be aware of how they are contextualising situations in their sign choices and placements, and try to strike an appropriate balance between clarity and scope. Having psychology and psychiatric expertise within the research and translation teams allowed choices to be made based on the original intent behind each item.

This also links with an additional concern that any concrete explanation may be a judgement on behalf of the translator that goes beyond the meaning that is intended in the original. This is a particular concern between spoken and sign languages as some English words have a more general sense than their BSL equivalents. The SDQ has an item in the parent version; ‘Often complains of headaches, stomach-aches and sickness’. The word ‘sick’ in English can be translated into BSL with two different signs which can also be glossed as ‘VOMIT’ (which is more specific than ‘SICK’) or as ‘ILL’ (which refers to more general illness or malaise). The English word ‘sick(ness)’ is ambiguous between these two meanings, but in BSL, as in other languages, one is explicitly forced to make a choice because there is no sign that covers both meanings in the way that ‘sick’ does in English. Thus, it is highly important to consult with the authors of any questionnaire that is being translated, as well as mental health professionals, to understand how intended meaning is received; hence the need for culturally aware translation and focus groups. For example, there is a question in the self-report SDQ about ‘playing

alone'. This does not capture the fact that a Deaf child might play alone because they struggle to communicate with their peers, rather than playing alone because they don't have the necessary social skills to play with others. In this way they might play alone at a school where they only have hearing peers, but play quite happily with other deaf children with whom they can communicate in their home environment. This may have the effect of creating disparities between parent and teacher responses.

However, mental health questionnaires are designed to be understandable to the general population and in any questionnaire there may be some element of the respondent having to make a judgement as to what they understand by the items. The concept of 'decentring' in translation work, where the acknowledgement that concessions may be made in both languages, and that one is not more important than the other, should be adhered to at all times<sup>30(p186)</sup>.

Furthermore, common metaphors and abstract language in one language may be difficult to translate into another, especially where there are cultural differences as in the case of BSL. For example, our focus groups and translations were clear, that 'hot tempers' (in the English version) would make little sense if translated literally. A lengthy process led to signs for 'TEMPER' (very angry) and 'TANTRUM' being used.

#### *Structural Characteristics of the Questionnaire*

A key structural difference between a language presented in writing and one presented on film/video like BSL is that in responding to a written test, instructions are always present at the top of the page, and a respondent can keep checking back. However, with a visual questionnaire, this may need to be reiterated within the content or technical solutions sought to readily access instructions. Time frames, scales and instructions may need to be reinforced, and it may be necessary to give a specific contextual placement in each case rather than assuming that the information will be retained through several items. Previous translation work in signed languages indicates that adaptations and concessions during translation do not necessarily affect the psychometric properties of test items to a significant extent, but this will only become clear when we validate the new BSL SDQ<sup>36</sup>.

#### **Discussion and Conclusions**

There are relatively few large-scale studies focussing on translating into sign languages, and fewer still focussing on the additional difficulties this presents when applied to d/Deaf young people. There is a great need for further research in this area, and consideration of the impact of the circumstances of d/Deaf young people in undertaking translation work. As an inclusive process, it is imperative

to involve Deaf people in the construction and assessment of the translation. The UK population of signing Deaf people is comparatively small and tight knit, and encouraging Deaf people to lead in the development of the study and early on in the process can be important to the overall success of such a pursuit.

Deaf culture embraces information sharing, and international collaboration on sign language translation processes could improve the quality and efficacy of mental health questionnaires, allowing services to more accurately map the prevalence rates of mental health in this population. Equally, it will allow the National Deaf Children, Young People and Family Service, and their collaborators, to better understand the needs of deaf children and young people and to target interventions earlier and more effectively than by using English tests.

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