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**Translation into British Sign Language and validation of the Strengths
and Difficulties Questionnaire**

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Background

Health Need: Mental health problems in Deaf children are vastly under-researched, with no well conducted systematic reviews. Evidence suggests that Deaf children have much higher rates of mental health problems than hearing children (Mejstad et al., 2009). However, the research shows large variations in rates across studies; in small samples; with inadequate measurement such as instruments that are not validated in Deaf children or that are inaccessible (e.g. in language delay or BSL users). The cost implications of education failure, unemployment and long term mental health service provision makes mental health in Deaf children and young people an important research area. However, the mapping of need is not accurate because at present, we do not have an appropriate tool to screen Deaf young people for mental health problems, nor are we able to evaluate whether the service provides positive outcomes for clients. Deaf children may communicate in a range of different ways. This includes oral English, sign supported English and British Sign Language. For those using oral English there are usually significant English language delays and therefore written communication needs to be plain uncomplicated English. Instruments need to be available in all these forms and this study focuses specifically on those young people who use BSL as their first or main language. We have set up a Clinical Research Group for child mental health and Deafness and have put in a larger Programme Grant to the NIHR take this agenda forward. The BSL questionnaire resulting from this research will support clinicians in making more accurate clinical screening and assessments. It will also enable future researchers to map out the prevalence of various mental health problems in Deaf young people, therefore allowing NHS services to target interventions and spending where it is most needed and most likely to be of benefit.

Expressed Need: Mental health is related to long term psychological morbidity, poor educational attainment, unemployment, and delayed social skill development (Huttunen & Sorri, 2001; Kluwin et al., 2002). As a result, many organisations have highlighted the need for better access to mental health services for this group. A National Audit of Families Support lists lack of support for mental health issues as one of the areas of most concern to Deaf children and their families (DFES, 2006). Standard 8 of the NSF for children requires all children to 'have equal access to CAMHS' (DFES & DOH, 2004b) and Towards Equity & Access (DOH, 2005) highlights the importance of improving provision and access to mental health services for Deaf people. The Human Rights Act and Disability Discrimination Acts mean such inaccessible services are hard to defend. Voluntary organisations such as the RNID, UK Council on Deafness (2004) and Social Policy Research Unit (Greco et al, 2009a; 2009b) have called for improved services and research in this group. The National Deaf Children's Society sees it as one of its priorities. Improving the screening instruments enables tier 1 professionals to have an adequate tool to identify such need.

Sustained Interest and intent: The newly established National Deaf Child & Adolescent Mental Health Service is a new clinical network that was launched in October 2009 to address the needs of Deaf children and young people with mental health problems. The outcome of this research will be a validated translated questionnaire, which will then be used both in practice for clinical screening and for future research to determine prevalence and types of psychiatric morbidity in Deaf young people. The development of this screening instrument for those whose first or main language is British Sign Language will become a routine part of the service's ability to screen for mental health problems and to monitor mental health outcomes. This will be part of a set of outcome measures that will meet the government's target that high quality services should have good measures that monitor outcome routinely.

Capacity to generate new knowledge: Previous screening and epidemiological studies in Deaf children have had to use interviews and reliance on parent/carer/teacher report instead of youth self report (e.g., Hindley et al., 1994), as researchers have found that written versions of questionnaires for Deaf children are not as sensitive as they are for hearing children (Cornes, Rohan, Napier, & Rey, 2006). However, this is not ideal as parent/carer report may differ from self-report. For example, Fellingner and colleagues (2008) found that parents/carers viewed their children's quality of life more positively than their Deaf children who reported higher levels of dissatisfaction, when using a self-report questionnaire in German and Austrian Sign Language. Ideally, any evaluation of Deaf services should be directly comparable to those of 'hearing' services, but the lack of suitable self report screening or evaluation tools prevents this. It is this problem which we wish to directly address in this research.

The reason for this gap is the difficulty in translating suitable instruments. The Deaf signing population in the UK not only have their own language, but have a unique Deaf culture. It is now recognised that questionnaires cannot simply be translated linguistically, but also need to be adapted culturally to maintain their content validity (Beaton et al., 2000). This is particularly important for British Sign Language because it is a visual and not a written language. It is not sufficient simply to have an interpreter present as this would not be true self report and the translator may change the meaning of the original question so that the content validity is reduced.

The process of translating linguistically and culturally is long and costly (Beaton et al., 2000), and as a result there are currently no suitable screening questionnaires for the young Deaf signing population. The 'Strengths and Difficulties Questionnaire' (SDQ; Goodman, 1997) is used as an outcome measure in the national CAMHS Outcome Research Consortium (www.corc.uk.net), and has been translated into over 60 languages (www.sdqinfo.com) but not BSL. It is a self-report questionnaire, initially developed to improve the detection of child psychiatric disorders in the community (Goodman et al., 2003). There are three versions – one for children and young people, one for parents/carers and one for teachers. Together, the three SDQs show good sensitivity (63.3%) and specificity (94.6%) (Goodman et al, 2003). The SDQ can be completed at the beginning

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and end of treatment to assess how well the treatment has worked (Mathai et al., 2003) and is frequently used to evaluate Child and Adolescent Mental Health Services (e.g., Callaghan et al., 2004). A version in plain and uncomplicated English will need to be developed for those Deaf children with oral English (not the subject of this application), as well as a British Sign Language version (applied for here).

Organisational focus consistent with HSR mission: With more accurate estimates of the prevalence and types of psychiatric morbidity in Deaf young people, the organisation and delivery of CAMH services for Deaf young people can better reflect the needs of this population. This will enable the development of appropriate care pathways for Deaf children, which necessarily and appropriately involve professionals at tiers 1, 2, 3, and 4. Currently Deaf children find accessing mental health support difficult (Beresford et al., 2008), and more accurate mapping of mental health need will enable more appropriate targeting of services.

Generalisable findings and prospects for change: This research involves the collaboration of a comprehensive network of national centres (in four main centres and six outreach centres that map onto the 10 strategic health authorities in England). This will therefore allow us to screen children from across England. The research is therefore likely to be generalisable nationally. Once the prevalence of mental health problems in Deaf young people has been more accurately estimated NHS services can target interventions and spending where it is most needed and most likely to be of benefit. One of the National Deaf CAMHS aims is to improve accessibility of services to Deaf children and this will be a vital tool in furthering this aim.

Building on existing work: There is very little research in the area of mental health in Deaf children, partly because of the lack of any suitable screening measures. This research will provide a foundation on which further research studies can build.

Various studies across the world have suggested that the prevalence of mental health problems is higher in Deaf children than hearing children (Hindley et al, 1994; Hindley 1997; Meadow & Trybus, 1979; Mejstad et al, 2009; Van Eldik et al, 2004; Van Gent et al, 2007; Vostanis et al, 1997a). In studies using the parent/carer version of the Child Behaviour Check List in both Holland (n=238) (Van Eldik et al., 2004) and England (n=84) (Vostanis et al., 1997a) Deaf children and adolescents have between two and three times the rates of mental health problems (about 40% of the samples) compared to hearing children. 111 Swedish Deaf children also had higher levels of mental health problems (Mejstad et al., 2009) using the Strengths and Difficulties Questionnaire (Goodman, 1979) in written forms. Another English study using screening instruments followed by a structured diagnostic interview using a sign language interpreter found that 50.3% of 11-16 year old Deaf adolescents had a psychiatric disorder (42% of those in a Deaf school and 61% in a hearing impaired unit) (Hindley et al., 1994). Forty-one Deaf boys (aged 6-11 years) had more internalising and externalising problems compared to hearing counterparts (Van Eldik, 1994) and the younger boys

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had more behaviour problems. What all these studies have in common is that for the Deaf children whose first or main language is sign language the researchers do not use instruments developed for these languages. This may explain the wide differences in findings between studies. There is a clear need to carry out methodologically sound studies using appropriate and accessible instruments.

Aims and Objectives:

Aim: To create a valid British Sign Language (BSL) translation of the Strengths and Difficulties Questionnaire (SDQ) for children, parents/carers and teachers

Objectives:

1. To translate the Strengths and Difficulties Questionnaire into British Sign Language.
2. To use the BSL version of the translated SDQ with a cohort of BSL using Deaf children sampled across England and to validate it by comparing it to a gold standard to elicit true psychological morbidity.
3. To validate Deaf parent and Deaf teacher versions in the same way.

Research methods:

Objective 1: translation of the SDQ into BSL

Design and theoretical/conceptual framework

The SDQ will be translated using well-established guidelines laid down by Beaton et al (2000). This involves a strict translation and back translation methodology with reiterations until successful translation is achieved:

Translation/Back Translation Methodology

Following consultation with the author of the original SDQ, Robert Goodman, the translation process is as follows:

1. The SDQ is translated from written English into British Sign Language by three BSL users who have fluent English (including a mix of genders) who use BSL as their first language and who have experience of translation. The research group already has a network of BSL users who meet these criteria.
2. This BSL version of the SDQ is then translated back into written English by three different Deaf adult BSL users who have fluent English. They will not have seen the original English version.
3. Once translated back into written English a group independent of the translation process, including members of the research team, will discuss the translation and compare it to the original English Language SDQ to ensure the back translation is loyal to the original SDQ. Faithfully translated items will be 'banked' and unsuccessful items will go through the translation/back translation cycle again.

This process is reiterated until the English and BSL versions match. If the three bilingual raters can not agree they will film alternative versions and discuss the items to ensure linguistic fidelity with the original, following the methodology suggested by Beaton et al (2000). At the request of the translation triad experienced Deaf child mental health clinicians independent from the study can be consulted on the meaning and purpose of terms used within the SDQ. Professor Robert Goodman will also be asked for feedback on the translated SDQ at this point. Both groups will include at least one member who has experience translating BSL into different levels of linguistic complexity for different age groups.

This process will be carried out for the children and young people's SDQ, the parent's/carer's SDQ and the teacher's SDQ. The BSL questionnaires produced will be visual (e.g. available on a DVD and computer screen). The online computer version will include both the questionnaire and an online method of providing an answer to each question on the SDQ explained in BSL and inputted interactively. The DVD version will come with a paper 'fill in' corresponding to the visual display. Technicians will be recruited to do this and those involved in the translation will be consulted on the production of the visual questionnaire.

Following the process of translation and back translation, the newly translated SDQs will be given to a focus group made up of 5 Deaf young people, 5 Deaf adults (Deaf parents/carers and Deaf teachers) who all use BSL as their first language. These participants will be approached through existing networks within Deaf CAMHS sources throughout the county. This will ensure that a variety of dialects and level of BSL are included in the focus group.

They will review the translated SDQs to ensure that the language is comprehensible to them and carries the intended meaning. If there are translation issues with any of the questions, then the process of translation and back translation will be repeated. This will continue until the focus groups are able to understand the entire questionnaire. We will also ask about the accessibility and cultural sensitivity of the delivery of the SDQ. This may include presentational issues including characteristics of the presenter.

The questionnaires then need to be finally approved by Robert Goodman, the author of the SDQ. This will be based on the translation methodology used for the SDQ translation into 60 other languages (all of which we have incorporated in our methodology).

Setting/Context

The focus groups will be held at a geographically appropriate location at one of the National Deaf CAMH service bases and attendance from across the country have been costed in this proposal.

Objective 2: Validation

Design and theoretical/conceptual framework

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Following approval of the translated questionnaires, the research will proceed to a validation stage.

Sampling

A cohort of 138 Deaf children (aged 11-16), their parents/carers and teachers will be recruited using the links we have to the national Deaf service and through National groups of Teachers of the Deaf (who are involved in the lives of all BSL using Deaf children in school). Each child with a loss of more than 40 dB in the England will be referred to a teacher of the Deaf. Each locality keeps a register of such children. Using this, teachers will pass an information pack containing consent forms and an information about the study to children and their parents/carers. These information packs will be available in plain English and BSL on DVD.

Validation against a 'gold standard'

In order to ensure that the new questionnaires are successfully eliciting true psychological morbidity, the newly translated BSL versions of the SDQ must be validated by comparison to a 'gold standard' instrument. However there is no mental health screening measure validated for use with Deaf children in existence. The current 'gold standard' for the mental health screening of Deaf children is a clinical interview administered by experienced Deaf child mental health clinicians. This study will compare the findings of the new SDQs with those of the clinical interviews, and English SDQs and DAWBAs completed by hearing participants.

Validation of the young peoples (11-16) self-report SDQ

A cohort of 138 Deaf young people aged 11-16 will be recruited to complete the young persons self report questionnaire. Complete cohorts from teacher of the Deaf registers in at least four geographical locations will be invited. The parents and teachers of these young people will also complete their respective versions of the questionnaire.

80 randomly selected Deaf young people, their parents and teaching staff will be administered a structured clinical interview validation purposes.

Validation of the teachers (4-16) SDQ

We will then recruit a cohort of 80 Deaf teachers and teaching assistants (or as many as we can recruit) (40 teaching 4-10 year olds and 40 teaching 11-16 year olds) to complete the SDQ with respect to 40 children aged 5-10 and 40 young people aged 11-16. The parents of the young people will be asked to complete an SDQ and the 11-16 year olds will complete a self-report version. For validation purposes Deaf teachers, parents and young people will be administered a structured clinical interview, hearing participants will be administered the relevant sections of the Development and wellbeing assessment (DAWBA). The DAWBA is a semi-structured interview, taking into account the views of at least two informants (young person if 11 years old or over, parent/carer, teacher) to generate IDC-10 and DSM-IV diagnoses.

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Validation of the parents (4-16) SDQ

To validate the parent's version of the SDQ we will recruit 80 Deaf parents of 4– 10 year olds, and 80 Deaf parents of 11-16 year olds. The teachers of these children and young people will also be asked to complete the SDQ and the 11-16 year olds will complete a self-report. Deaf parents, teaching staff and young people will be administered a structured clinical interview, their hearing counterparts will be administered the relevant sections of the DAWBA.

Feasibility of recruitment

Based on the sample size for this study, we anticipate that we will be able to recruit enough children, young people, parents and teachers to meet the numbers required in power calculation estimates. However should this not be the case we will work with service users, such as BATOD and the National Deaf Children's Society, to explore other routes of recruitment.

Inclusion/exclusion criteria

We will recruit Deaf young people aged 11-16 who are native BSL users. Parents/carers and teachers of the recruited young people, who are native BSL users will be given the BSL version of the SDQ and an interview in BSL. Any participants who use English as their preferred language will be given the English version of the SDQ and the DAWBA. Deaf parents and teachers of 5-10 year olds (hearing or Deaf) will also be recruited. Children aged 5-10 will not be directly involved in the study. Families in which neither English nor BSL is a first language will be excluded.

Procedure

Once consent has been obtained young people, parent/carer and teacher will be asked to complete the SDQ. Young people will be asked to complete the BSL online version or the BSL DVD version with paper fill in. Parents/carers and teachers will be able to choose between the standard version of the SDQ and the BSL online version or the BSL DVD version with paper fill in. Where necessary a clinician or researcher fluent in BSL will be available for support.

The questionnaires will be completed by participants and returned to sites pre-arranged by the research co-ordinators (NDCAMHS bases).

Once the participants have completed the SDQ a random sub-sample (remotely randomised by the department of health sciences at the university of York, by age band, gender, location and SDQ score) will be administered a clinical interview (if Deaf) or semi-structured interview called the DAWBA (if hearing). The DAWBA combines a semi-structured interview and questionnaires, which include a systematic review of emotional and behavioural symptoms and information such as social aptitude, friendships and development. It involves interviewing both parent/carer and young person and collects information from teachers. It is used to generate ICD-10 and

DSM IV psychiatric diagnoses in children and young people up to 17 years old.

National Deaf CAMHS has trained researchers and clinicians including BSL using Deaf staff and BSL using hearing staff who will undertake the clinical interview with Deaf young people and their Deaf parents/carers. Hearing parents and teachers will be administered the DAWBA.

65 participants will take part in an evaluation of test-retest reliability for all three versions of the SDQ. There will be an interval of one to two weeks between SDQ completion.

Proposed sample size:

Power calculations suggest that to have data that is comparable with normative data in the general population we would require at least 138 young people aged (11-16) to participate. This is based on estimating the mean within a 95% confidence limit of ± 1.0 . This calculation is based on the SD of 6 found in a normative population using the SDQ (<http://www.sdqinfo.com/bb1.html>).

In England, 17,500 0-18 year olds are moderately to profoundly Deaf. Since we are studying 11-16 year olds there would be approximately 5850 young people available to screen. In practice if we were able to screen only 40% of the target population, as with a recent epidemiological study of mental health in Sweden (Mejstadt, 2009) we would still have more than enough participants. We will recruit sequentially in geographical areas rolling out recruitment until full recruitment has occurred. We will recruit in each geographical area by approaching all known Deaf people with a loss of 40dB or above in the target age range, being careful not to miss any out. We will record percentage ascertainment in each locality.

With respect to the validation of the BSL teacher's version of the SDQ we are aware that the sample size is small, this is because we are constrained by a limited number of Deaf teaching staff in England.

With regard to the DAWBA a sample size of 80 in each category (i.e in the validation of the parents SDQ: 80 parents of 4-10year olds, and 80 parents of 11-16year olds) achieves 80% power to detect a difference of 0.20 between the null hypothesis correlation of 0.70 and the alternative hypothesis correlation of 0.50 using a two-sided hypothesis test with a significance level of 0.05.

Data Analysis

We will statistically analyse the data obtained from the young person, parent/carer and teacher versions of the SDQ by cross-correlating the three SDQs to check that similar scores are obtained from young person, parent/carer, and teacher versions.

The testing of reliability will comprise three parts:

1. A Person Separation Index derived from the Rasch analysis of the responses to the set of items in each subscale of the questionnaire.
2. Internal consistency reliability (Cronbach's Alpha) for the scores for the items in the questionnaire
3. Intra Class correlation coefficient to provide the test-retest reliability in a sample of 50% of the children chosen randomly to complete the questionnaire on two occasions. (A sample size of 65 subjects with 2 observations per subject within three weeks achieves 81% power to detect an intraclass correlation of 0.70 under the alternative hypothesis when the intraclass correlation under the null hypothesis is 0.50 using an F-test with a significance level of 0.050.)

The testing of validity will comprise four parts:

- (i) Structural validity by fit of data to the subscales of the questionnaire through a Confirmatory Factor Analysis using a polychoric matrix as a base.
- (ii) Structural validity, and invariance properties (e.g. by gender) by fit of data to the Rasch measurement model.
- (iii) External validity by testing the BSL SDQ version against a clinical interview administered in BSL by a clinician from National Deaf CAMHS, which is the 'gold standard' for assessment of mental health morbidity, or the DAWBA (in the case of hearing participants) blind to the SDQ rating. This is well validated in a hearing population and was used to validate the original SDQ (Goodman et al, 2001). (A sample size of 130 achieves 80% power to detect a difference of 0.15000 between the null hypothesis correlation of 0.70000 and the alternative hypothesis correlation of 0.55000 using a two-sided hypothesis test with a significance level of 0.05000.)
- (iv) We will also compare child, parent/carers and teacher versions to test equivalence of correlations with versions of the SDQ used in the hearing population.

Contribution to collective research effort and research utilisation:

Once this instrument is developed it will be systematically used by the National Deaf CAMHS for screening and monitoring outcome in BSL using Deaf children and young people.

It will be presented at national Deaf CAMHS conferences, within the Clinical Research Group convened by Dr Sophie Roberts and Dr Barry Wright and at conferences run by the British Society of Mental Health and Deafness and the European Society of Mental Health and Deafness.

Plan of investigation and timetable

Months 0 to 3: Gain ethical approval.

Months 4 to 12: Process of translation and back translation

Months 8 to 12: Focus groups and repeated translation and back translation

Months 11 to 13: Filming and production of visual versions of BSL SDQ

Months 13 to 20: Recruitment and validation

Months 21 to 24: Statistical analysis and dissemination

Ethical Issues

We will gain full ethical permission from the local ethics committee before the study commences. We gained R & D permission on the 21st December 2010.

We will stress to young people, parents and teaching staff approached to take part in the study, that participation in no way implies that the young person has or may have mental health problems, and that this study aims to address the needs of a wider group of young people. Fully informed consent will be obtained from the young person, family, and teacher before either involvement in the focus groups in stage one or recruitment into stage two of the study. Consent forms and information leaflets will be produced using the current guidelines for researchers on writing information sheets and consent forms.

All study documentation received by participants will be available in three forms; standard English, plain English, and BSL, in DVD format translated by a National Deaf CAMHS staff, fluent in BSL.

We are aware that screening for mental health problems in Deaf children may result in the identification of young people with needs that may have not been previously addressed. Current studies using SDQ (Fellinger et al., 2008) report 36% of children are above 'borderline or abnormal' scores with 3.4% being thought to require specialist services at any one time (Hindley et al., 1994). This would mean that if we screen 138 young people, and 160 children of Deaf parents, 72 may have some milder mental health problems with seven who might require specialist CAMHS input.

Since there are more than 1060 CAMHS teams in England this means a maximum of one extra referral to every fourteen CAMHS teams in the country. We believe that this additional work is manageable given that existing CAMHS have a remit to provide interventions and support to any child with mental health problems. In addition, the new NDCAMHS has four main centres and six outreach centres with the capacity to see 400 new children each year. We believe we will easily be able to see 7 new children and young people in one year, and indeed would feel it our duty to do so. We feel that identifying such children in this way will allow us to offer appropriate support in a sensitive way. Our experience is that parents are actually relieved to be offered support when it has not previously been readily available. Working together these systems will be able to provide services for any newly identified child.

Should the findings of the clinical interview or DAWBA clinical assessment give cause for concern the clinician involved will give advice and information

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to the young person and their parent/carer, referring as necessary to an appropriate service which may include child mental health services. Serious adverse events/reactions will be recorded and reported to the IDMC, trial sponsor and ethics committee immediately.

Data Protection/Confidentiality

All participant information will be stored in accordance with the Data Protection Act 1998. Participant personal identifiable information will be stored in a locked filing cabinet. All participant data will be anonymised through allocation of ID numbers. Anonymised participant data will be saved on a password-protected secure computer drive, accessible only to members of the research team. Participant personal identifiable data will be stored in a separate location to anonymised participant data. All data will be maintained by the Research Co-ordinator.

We will follow good clinical practice in monitoring any young person of parent concerns or requests during all encounters with study participants. Any concerns raised will be discussed with an appropriate clinical member of the research team and if necessary referred to services as per usual practice. Parents/guardians of young people will be provided with a service number to call or text if they have any concerns. All such calls will be reported to the Independent Data Monitoring Committee (IDMC). Any reported serious adverse events or serious breach of the protocol will be urgently discussed with the IDMC and the Trial Steering Committee and/or the Sponsor.

Study sponsorship

The trial has received sponsorship approval from the North and East Yorkshire Research and Development Committee (approval dated 21st December 2010 code: NYY-P01807).

Research governance and the conduct of the study

The study will be conducted to protect the human rights and dignity of the participant as reflected in the 1996 version of the Helsinki Declaration. Patients will not receive any financial inducement to participate. In order to protect the study participants we will following will apply:

- the study has been designed to minimise pain, discomfort and fear
- the study has been designed to minimise any foreseeable risk in relation to the intervention involved (administration of the translated SDQ)
- the explicit wishes of the participants will be respected including the right to withdraw from the study at any time,
- the interest of the patient will prevail over those of science and society
- provision will be made for indemnity by the investigator and sponsor

- contact details for further information will be provided.

Trial steering committee (TSC)

A Trial Steering Committee will be set up and will include at least two independent members, along with the lead investigator and the other study collaborators. They will meet twice a year.

Independent Data Monitoring Committee (IDMC)

Our data will be independently monitored by a committee with an independent chair, a statistician and the local research monitoring officer (appointed by the sponsor/R&D department). This group will meet 6 monthly but will be able to convene rapidly if any notable events need discussing. This group will report to the trial steering committee. The monitoring officer will visit the York site twice and the Taunton, Dudley and London sites once during the course of this study and will report back to the IDMC.

Project Management

The project will be overseen by the co-chief investigators, Dr Sophie Roberts and Dr Barry Wright. Lead clinicians in the four main National Deaf CAMHS are involved with the project and will oversee recruitment and validation stages at their sites. This will be discussed at regular steering group meetings which will occur immediately after the existing National Deaf CAMHS Clinical Coordinating Group meetings. The London, Dudley, and York NDCAMHS sites will each be responsible for three strategic health authorities and the Taunton site will be responsible for the South West strategic health authority. These regular meetings will ensure good communications across all sites. Televideo conferencing facilities are in place at each of these sites to facilitate some steering group meetings and ad-hoc meetings as required. The day to day project management, including obtaining ethical and governance permissions, will be overseen by four research assistants, who will be employed as part of this research. Each research assistant will be based within the local main NDCAMHS and will be responsible for maintaining recruitment at each site. The research assistant based in York will be employed for the duration of the trial and will be part of a team of research assistants and clinical studies officers working on a wider child mental health research agenda. They will assist with analysis and dissemination. Co-applicants in London, Dudley and Taunton have been costed in to support the research. Co-applicants have a wealth of expertise in overseeing health services research and we are confident that we can meet the milestones set out in our plan of investigation.

Service users/public involvement

Service users have been involved from the outset of this funding application. Service users are a part of the steering group and will provide insight into appropriate methods of recruitment and dissemination. We have already identified Deaf young people, parents/carers and teachers who will form part of the focus group. Additional service users will be involved in the design of

information leaflets for the study. We will also ask Deaf young people and their parents/carers to help present the findings of our study at relevant conferences. Further detail regarding service user involvement is detailed throughout this application. The National Deaf Children's Society which is run by parents/carers of Deaf children and advocates on their behalf has a strong record of supporting emotional and social care issues. They have been involved in the development of this protocol from the outset and support this application and will be members of the steering group.

Expertise and justification of support required

We have a strong team of multi disciplinary researchers, clinicians and user representation to complete this programme of research. The research team (many of whom are BSL/English bilinguals) has a wide range of research skills and expertise.

1i. Co CI Dr Barry Wright: Dr Barry Wright (ND CAMHS clinical lead, York) has considerable research experience within a clinical setting and in a range of health services research including children's medicines randomised controlled trials. He has held multiple research grants, is chief investigator on two other national portfolio studies and currently supervises two clinically based research assistants. His recent research has been into causes of autism as well as both medical and programme based interventions.

1ii. Co CI Dr Sophie Roberts:

Dr Sophie Roberts is a consultant child and adolescent psychiatrist within the National Deaf CAMHS. She has considerable clinical experience working with Deaf children and children with learning disabilities. She has been integrally involved with the development of child mental health services for Deaf children across the country.

2. National Deaf CAMHS clinical staff: At least one clinician from each of the four national teams would be involved in the detailed design of the research and recruitment of young people. These staff all have experience and expertise in the clinical assessment and management of Deaf young people with mental health problems. Several of the staff also have research experience. Dr Maria Gascon Ramos is now the clinical team manager in the Taunton service, but was previously part of the Manchester University Social Work division, and most recently worked on a project to evaluate early support packages for parents/carers of Deaf children. In her PhD she translated another measure of mental wellbeing into BSL, so she has experience in this area. Dr Sarah Kent is a clinical psychologist working with the National Deaf CAMHS based at Oxford. Sarah has previously worked as research tutor on the Clinical Psychology Doctorate at the Universities of Coventry and Warwick and has significant experience of supervising and conducting research at doctoral level. She researched self-awareness in children who are Deaf for her Clinical Psychology Doctorate and investigated self-awareness in children on the autistic spectrum for her PhD.

All of the National Deaf CAMHS staff are practising clinicians, and this obviously mitigates some of the ethical issues inherent in this project. Any young people who are picked up with clinically significant mental health issues during the epidemiological phase will be able to access further assessment and support from an experienced clinician.

3. Bryony Beresford: Bryony Beresford is the senior research fellow at the Social Policy Research Unit at the University of York. She is responsible for the Children and Family Team research programme. She has extensive experience in research into disability in children and has an interest in developing methodology for research with children as well as service development. The team at SPRU know the National Deaf CAMHS services well, as they undertook the external evaluation in 2007 (Beresford et al, 2008).

4. Professor Alan Tennant: Alan Tennant is Director of the Psychometric Laboratory in the Department of Rehabilitation Medicine at Leeds University. He is an experienced translation methodologist and an internationally renowned expert in psychometrics, statistics and RASCH analysis. He has wide experience of adapting scales into other languages, and other cultural settings and applying modern psychometric standards to those adaptations.

5. Katie Rogers: Katie Rogers is an NIHR doctoral research fellow, who is doing a follow up study of the well-being of the Deaf young people first carried out in 1988. She is familiar with the SDQ, having used it as part of her Masters degree project. Ms Rogers translated the SDQ, and other measures, into BSL (both youth and parental report) however the validity of these versions has not been checked. She is native BSL user and is bilingual in both BSL and English. Ms. Rogers have been involved in the translation procedure of the Trait Emotional Intelligence Questionnaire (TEIQue) project at the University of Manchester.

6. National Deaf Children's Society: Pauline Walker is the parent of a Deaf daughter and now works for the NDCS as the deputy director for the families section. She helps to organise the family weekends and has very strong links with families. She was on the steering group for the ND CAMHS service evaluation and has experience of prevalence research into the mental health problems of Deaf children within the NDCS.

7. Professor Simon Gilbody: Simon Gilbody is Professor of Health Services Research and Director of the York Mental Health Research Group. Prof Gilbody is an internationally renowned expert in diagnostic epidemiology and psychometrics in relation to common mental health problems (having completed an MRC Fellowship and PhD on these topics). He has published widely in this area and there are existing collaborations between Dr Wright, Prof Tennant and the York MHRG in relation to Deaf Children

In addition this bid will be supported by two CLRN/MHRN Clinical Studies Officers, Dr Liz Littlewood and Ms Danielle Moore, who will assist in the day to day running of each stage of the research

It is important that the SDQ is translated accurately in order to ensure both linguistic and cultural validity. This requires a rigorous translation process and adequate time needs to be allocated to this to ensure the translation meets the strict criteria set out by Robert Goodman, author of the SDQ.

This research is embedded within the National Deaf CAMHS network and as such we are well placed not only to recruit to target but also to disseminate the results of the research and role out a national programme of screening.

Planned or active related research grants

Co-applicant Wright has recently been awarded funding to convene and coordinate a Mental Health Research Network Clinical Research Group in Deaf CAMHS. This involves academics, researchers, and clinicians and members of voluntary organisations across the UK. He has also submitted recent applications to the Research for Patient Benefit Programme to investigate the use of computerised cognitive behavioural therapy for depression in adolescents and to the NIHR Programme Grants Programme for a programme of research on child mental health and Deafness.

Applicant Wright has also submitted a proposal for an NIHR Programme Grant investigating mental health in young people who are Deaf. A part of this research involves translating screening measures, including the SDQ, into formats accessible to Deaf children and young people. Accessible formats include translating the measures into plain English. In the current application we are only requesting funding to translate the SDQ into British Sign Language. Therefore, although these two research projects are similar, they do not overlap.

References:

- Beaton D, Bombardier C, Guillemin F & Bosi Ferraz M (2000) Guidelines for the Process of Cross-Cultural Adaptation of Self-Report Measures. *SPINE*, 25, 3186–3191.
- Beresford, B., Greco, V., Clarke, S., & Sutherland, H. (2008). *An Evaluation of Specialist Mental Health Services for deaf children and young people*. Working Paper No. DH 2259 05.08 Social Policy Research Unit. York: University of York; 2008. Available from: <http://www.york.ac.uk/inst/spru/pubs/pdf/tele.pdf>.
- Callaghan, J., Young, B., Pace, F., & Vostanis, P. (2004). Evaluation of a new Mental Health Service for looked after children. *Clinical Child Psychology & Psychiatry*, 9, 130-148.
- Cornes, A., Rohan, M. J., Napier, J., & Rey, J. M. (2006). Reading the signs: impact of signed versus written questionnaires on the prevalence of psychopathology among deaf adolescents. *Australian and New Zealand Journal of Psychiatry*, 40, 8, 665-673.
- Department for Education and Skills. (2006). *National Audit of Support Services and Provision for Children with Low Incidence Needs*. Editor Peter Gray. Research Report RR729. DFES Publications: Nottingham.
- Department for Education and Skills Department of Health. (2004b). *National Service Framework for Children, Young People and Maternity Services*. Standard 8. Disabled children and young people and those with complex health needs. London: Department of Health.
- Department of Health. (2005). *Mental Health and Deafness - Towards Equity and Access : Best Practice Guidance*. Gateway reference 4054. Department of Health. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4103995
- Fellinger, J., Holzinger, D., Sattel, H., & Laucht, M. (2008). Mental health and quality of life in deaf pupils. *European Child & Adolescent Psychiatry*, 17, 7, 414-423.
- Goodman, R. (1979). The strengths and difficulties questionnaire: a research note. *Journal of Child Psychology and Psychiatry*, 38, 581-586.
- Goodman, R., Ford, T., Simmons, H., Gatward, R., & Meltzer, H. (2003). Using the Strengths and Difficulties Questionnaire (SDQ) to screen for child psychiatric disorders in a community sample. *International Review of Psychiatry*, 15, 1-2, 166-172.
- Greco, V., Beresford, B., & Sutherland, H. (in press, 2009a). Deaf children and young people's experiences of using specialist mental health services. *Children and Society*.
- Greco, V., Beresford, B., Clarke, S. (in press, 2009b). Parents' Evaluation of Specialist Mental Health Services for Deaf Children and Their Families. *Clinical Child Psychology and Psychiatry*.
- Hindley, P. (1997). Psychiatric aspects of hearing impairments. *Journal of Psychology and Psychiatry*, 38, 101-107.

- Hindley, P. A., Hill, P. D., McGuigan, S., Kitons, N. (1994). Psychiatric disorder in deaf and hearing impaired children and young people: a prevalence study. *Journal of Child Psychology and Psychiatry*, 35, 917-934.
- Huttunen, K. H., & Sorri, M. J. (2001). Long-term outcome of early childhood hearing impairments in northern Finland. *Scandinavian Audiology*, 30, 106-108.
- Kluwin, T. N., Stinson, T. S., & Colarossi, G. M. (2002). Social processes and outcomes of in-school contact between deaf and hearing peers. *Journal of Deaf Studies and Deaf Education*, 7, 200-213.
- Mathai, J., Anderson, P., & Bourne, A. (2003). Use of the Strengths and Difficulties Questionnaire as an outcome measure in a child and adolescent mental health service. *Australasian Psychiatry*, 11, 3, 334-337.
- Meadow, K. P., & Trybus, R. J. (1979). Behavioral and emotional problems of deaf children: an overview. In L. Bradford & W. Harding (Eds.), *Hearing and hearing impairment* (pp. 395-403). New York: Grune and Stratton.
- Mejstad, L., Heiling, K., & Svedin, C. G. (2009). Mental health and self image among deaf and hard of hearing children. Project MUSE. *American Annals of the Deaf*, 153, 504-515.
- Royal National Institute for the Deaf and the UK Council on Deafness. (2003). *A Simple Cure. A national report of deaf and hard of hearing people's experiences of the National Health Service*. RNID & UK Council on Deafness: London.
- Van Eldik, T. (1994). Behavior problems with deaf Dutch boys. *American Annals of the Deaf*, 139, 394-399.
- Van Eldik, T., Treffers, P. D. A., Veerman, J. W., Verhulst, F. C. (2004). Mental health problems of deaf Dutch children as indicated by parent's responses to the Child Behaviour Checklist. *American Annals of the Deaf*, 148, 390-395.
- Van Gent, T., Goedhart, A. W., Hindley, P. A., & Treffers, P. D. A. (2007). Prevalence and correlates of psychopathology in a sample of deaf adolescents. *Journal of Child Psychology and Psychiatry*, 48, 950-958.
- Vostanis, P., Hayes, M., Du Feu, M. (1997a). Behavioural and emotional problems in hearing impaired children: a preliminary study of teacher and parent ratings. *European Journal of Special Needs Education*, 12, 239-246.

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