Appendices to –
An Evaluation of Specialist Mental Health Services for Deaf Children and Young People

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Appendix 1

Topic guides for interviews with staff

Topic guide for Time 1 interviews with staff based in the York and Dudley services

Topic guide for Time 2 interviews with staff based in the York and Dudley services

Topic guides for Time 1 interviews for staff (a & b) based in the London service

Topic guide for Time 2 interview with staff based in the London service

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Topic Guide for interviews with clinic staff (Dudley and York): Time 1

A. BACKGROUND INFORMATION

- Length of time in post

- Days/hours of NSCAG funded work

B. NATURE OF STAFF MEMBER'S INVOLVEMENT IN NSCAG PILOT PROJECT: BASIC INFORMATION ONLY AT THIS STAGE – ALMOST TREAT AS A CHECKLIST

- **Assessment**
  - own and/or other services in the network
- **Direct clinical work**

- **Post discharge support to children/families and/or referrers**
  - **own and/or other services in the network**

- **Supervision**
  - own and/or other services in the network

- **Case management**
  - own and/or other services in the network

- **Service management**
  - own service and/or the network
  - particular roles?

- **Any other roles**

- **Has their role/involvement changed over the period of the project**
  - How? Why?
  - Are these changes perceived as positive or negative

C. TEAM LEADERS ONLY - THE LOCAL SERVICE

- **How is the team organised and managed?**
  - *Probe:* leadership, use of team meetings, assigning cases, shared cases
  - Changes over time in terms of the way the team works
    - *Possible probes*: more skilled = autonomy, assuming more complex work, less reliant on head of team, other..
  - Any perceived gaps/deficiences in the team in terms of skills/experience?

D. CLINICAL WORK WITH THE CHILDREN, YOUNG PEOPLE AND THEIR FAMILIES

- Types of direct clinical work involved
  - type of cases seen;
  - therapeutic approaches used/ways of working with the child/family; group/individual (we don't need too much detail here)
  - where they work: clinic, schools, home
  - any restrictions on the types of cases they can see due to lack of skills/expertise
    - eg. communication; mental health and deafness; other
  - ways in which they communicate
    - how negotiated with child/family
    - issues/difficulties experienced

E. VIEWS ABOUT THEIR LOCAL SERVICE

- **What would be the alternatives sources of treatment/support for children and young people in this area if your service did not exist?**

- **Views on benefits of their specialist service to children and families compared to a *generic* CAMHS service.**

- **Are there any disadvantages or problems with the specialist service to children and families compared to a *generic* CAMHS service**

- **What do you think are the hall marks of a 'gold standard' mental health service for deaf children and their families**
  - *Probe:* staff skills and knowledge, access to service, discharge support, supporting other local services

- **Do you think your service 'falls short' of what a 'gold standard' mental health service for deaf children and young people should look like?**
    - In what ways does it fall short
        - *Possible probes*: staff skills and knowledge; families' access to service; discharge support; supporting other local services/institutions

- **DUDLEY ONLY: Has the quality of your service improved since the inception of the NSCAG pilot**
    - Describe improvements
    - Explore how the NSCAG pilot has facilitated an improvement
        - *Possible probes*: funding; access to London expertise; facilitating networking and sharing – joint meetings, telelink
    - Any non-NSCAG reasons behind improvements?

F. TELE-HEALTH AND VIDEOCONFERENCING

- **What do you use the video-conferencing equipment for?**
    - *Probe*: supervision, assessment/case management, direct clinical work, contact/support following discharge, network meetings, other

- **Has the way or purposes for which you have used the telelink changed over time?**
    - *Probe:* Increased use for certain purposes and decreased use for other?, Reasons behind those changes

- **Aside from direct clinical work, views about what the telelink has enabled them or their service to achieve which would not have happened otherwise**
    - *Probe:* Staff skills and training/development; expert input re case management, service development; support and supervision; other

- **How crucial is the telelink to the quality of the service they provide?**
    - *Probe*: reasons for response

- **How crucial is the telelink to the development and maintenance of the network?**
    - *Probe*: reasons for response

- **Views on how the telelink aspect of the service could be improved or developed?**

- **Any lessons learnt about using telelink that would share with other professionals working in mental health settings and/or with d/Deaf people.**

  - Things to avoid
  - Strategies to have in place
  - Things to beware of…

G. STAFF WHO HAVE USED THE EQUIPMENT FOR DIRECT CLINICAL WORK ONLY

- **What factors inform your decision to provide therapeutic input using the telelink as opposed to using staff within the local team?**
  - *Possible probes:* communication issues; nature/complexity of the case; characteristics of the individual child/young person; accessing even the local service is difficult; other ….

- **How do you find children respond to the idea of it?**
  - *Probe*: concerns; positive responses
  - Does this differ to how they respond in reality

- **What about parents' reactions? … and again how respond in reality.**

- **Uses of the telelink**
  - *Probe:* to access therapeutic input from a Deaf clinician; Remote therapeutic input/monitoring between non-Deaf clinician and child
  - Used with all children or just BSL?

- **How the telelink is used in an individual case**
  - Pre-determined by clinical team/and or negotiated with child/family
  - More 'suck it and see' approach - develops and changes
    - Child/family voice in this

- **Has the way you use telelink for clinical work changed since the pilot began?**
  - *Probe:* types of cases seen; the ways it's used; the use and timing of face to face sessions

- **In what ways does telelink changes the nature of the therapeutic encounter compared to face to face?**
  - For the child/family: Benefits/positives AND Problems/negatives
  - For yourself: Benefits/positives AND Problems/negatives

- **What have you found are the practical benefits and difficulties of using the telelink for direct clinical work?**
  - *Probe:* time/cost savings?; Frequency of contact; Flexibility/responsiveness? The technology – glitches etc.

- **In what ways have your feelings about using the telelink and your experiences of using it changed over the course of the pilot?**

H. THE NETWORK

- **How the network works? Any leadership/structure? Any protocols?**

- **Do individuals' assume specific roles?**
    - How/why?
    - Any changes re who does what over time?
        - Caused by changes in staff
        - Caused by staff becoming more skilled

- **Have you experienced any difficulties working with practitioners from the other teams. Describe and explore perceived reasons for…**
    - Probe: The telelink – miscommunication; different clinical approaches; Other

- **Perceived 'added value' of the network**
    - Development of professional skills,
    - Quality of care provided to children and families etc..
    - Meeting communication needs of clients
    - Other
    - Has this changed/developed over time

- **Views on the network as a model of providing specialist services to low prevalence, widely dispersed groups.**

- **Ways the effectiveness of the network could be improved.**

- **What impact has PH's departure had on the way the network works and the skills available?**

I. SUPPORT AND SKILLS OF STAFF MEMBERS

- **How have you acquired the skills you need to carry out your role?**
    - Acquired before NSCAG pilot
    - Through involvement in the NSCAG pilot: supervision, 'training', Work experience'
    - Other

- **How has the NSCAG project supported the development of skills?**
    - Being in a team
    - Access to specialist training
    - Supervision and contact within the Network, especially the London service

- **Do you feel there are any areas where you need to/or would like to further develop your skills or experience in working with deaf children and young people with mental health needs.**
    - Areas of skills/experience
    - Confidence re these training/development needs being met within the NSCAG project.

J. COLLABORATION WITH OTHER SERVICES/AGENCIES

- **Awareness of other local agencies/services about the service**
    - *Probe:* things they do to publicise the service; has awareness increased over the duration of the pilot

- **What kind of contact or support do you have with other agencies or services in the area (local CAMHS, school, social services, etc)?**
    - *Probe:* feelings re whether doing enough, over-burdened; ways they would like patterns of contact/support with local generic services to develop

- **Do you have ongoing contact with referrers (e.g. schools, professionals) after discharge?** (NB. we want to understand whether, if the referrers need help and advice concerning the patient, they can get in touch with the service)
    - How is this achieved/provided
    - Any difficulties/inadequacies re this
    - How could it be improved?

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Topic Guide (York and Dudley)

Staff Interviews Time 2

CONFIRM BASIC FACTS

- Staff role
- Length of time in post
- Days-hours of NSCAG-funded work
- Find out if any of these has changed

CHANGES/DEVELOPMENTS IN THE WAY MEMBER OF STAFF HAS WORKED OR THE SERVICE PROVIDED OVER THE PAST YEAR

- Type of children/families work with
    - Ask for description of change/development
    - Reasons for ….
    - Outcomes of this change/development in the service/way of working

- Type of therapeutic approach
    - Ask for description of change/development
    - Reasons for ….
    - Outcomes of this change/development in the service/way of working

- Aside from direct clinical work, other types of work undertaken
    - Ask for description of change/development
    - Reasons for ….
    - Outcomes of this change/development in the service/way of working

- Who/where take referrals from
    - Ask for description of change/development
    - Reasons for ….
    - Outcomes of this change/development in the service/way of working

- Role within the team
    - Ask for description of change/development
    - Reasons for ….
    - Outcomes of this change/development

- Nature of links with residential schools
    - Ask for description of change/development
    - Reasons for ….
    - Outcomes of this change/development in the service/way of working

CHANGES IN TEAM:

- Staffing – new staff, staff leaving…
    - Ask for description of change/development
    - Reasons for ….
    - Outcomes of this change/development in the way the team works/the service provided

- Management/leadership of the service
    - Ask for description of change/development
    - Reasons for ….
    - Outcomes of this change/development

USE OF TELELINK IN WORK WITH CHILDREN/YOUNG PEOPLE

- Use of the telelink over the past year in work with children and young people
- If they have used it: number of children who have used the telelink this year
- Reasons for using it/not using it with individual cases
- Has telelink been used only with S or for link-ups with local clinicians?
- New things they are understanding/realizing about using telelink with children
- New developments in implementing protocols for use
    - e.g. professional accompanying child
    - how to deal with drawings and printed materials

CHANGES IN USE OF TELELINK IN WORK WITH PROFESSIONALS

- Use of the telelink over the past year for meetings with teams/individuals in the network
- Views on the ways the use of the telelink has developed/changed over the past 12 months
    - Frequency of contact with other teams
    - Content of meetings
- Views on what has driven those changes

THE NETWORK

- Contacts/relationship with the other two services over the past year
- Current views on the usefulness of the network
- Leadership structure within the network - changes since one year ago
- Changes over the past year in management meetings among representatives of the 3 services
    - Where/how they take place (telelink or face to face or both)
    - Who participates
    - How often they meet
    - What they discuss

PREVENTATIVE WORK

- Does the service undertakes any preventative work
- Description of preventative work
  - Location (e.g. school, clinic)
  - Target group (e.g. teenagers)
  - Duration of intervention
  - Aims
  - Outcomes
  - Involvement of other professionals, within and outside of the team
- Views on the role/responsibility of the NSCAG service conducting prevention work
  - Limitations/boundaries?
  - Views on where responsibility should lie
  - Barriers to their service carrying out preventative work?

PART-TIMENESS

- Views on the ways that the part-timeness of the service presents problems
  - Team working
  - Referral process/waiting lists
  - Working with families
  - Working with other agencies

INTERPRETERS

- Number of interpreters they use routinely
- Choice of interpreter
  - Family able to choose which interpreter?
  - Is the same interpreter used with a family or different ones
    - Views on whether consistency of interpreter is important/makes a difference
- Training of interpreter to carry out this specific work
  - Their knowledge of mental health
  - ‘child-friendly’ language
- Quality control of interpreters (how do they know they are doing a good job)
- Views on whether the presence of the interpreter changes the therapeutic encounter
  - Ways in which it changes the encounter
  - Ways in which the clinician deals with or preempts any negative effects
- Things learnt about using/working with interpreters in these situations

DEAF STAFF ON THE TEAM

- Views on importance and value of having deaf staff on the team
  - To families
  - To the rest of the team
- Ask for examples of what their service has been able to provide because they have a deaf member of staff

- For Deaf Staff only:
    - How it has been- challenges/difficulties, positive things
    - What they like/dislike about their role
    - Extent to which feel skilled
        - How training needs have been met
        - Outstanding training needs
    - Working in a predominantly hearing environment
        - Any difficulties re communication outside the direct team
    - Any problems re the physical environment
    - Views on other improvements to make the workplace more deaf-friendly

INFORMATION PROVISION TO FAMILIES

- How do they go about keeping families informed about
    - What the service provides
    - Appointments
    - Treatment plans
    - How things are going
- Views on whether or not they are good at keeping families informed and providing them with information about the service
    - Things they do to ensure families are kept informed
    - Any things which are harder to keep families informed about?
    - Barriers to keeping families informed
- Views on whether they see it as their role to be a hub of information about other services (role in empowering families)
    - If yes, what they do to provide information to families

ENGAGING FAMILIES/FAMILIES WHO DNA

- Proportion of families who DNA
- Possible reasons why they DNA
- Views on whether this is a particular issue with deaf children/deaf parents or a more general problem experienced by CAMHS
- What the service typically does to engage them
- Views on other things they could do to improve this

VIEWS ON THE NEED TO CASCADE SKILLS TO LOCAL CAMHS OR OTHER PROFESSIONALS (SOCIAL WORKERS, TEACHERS OF THE DEAF)

- Changes in past twelve months in terms of links with local CAMHS and other professionals/agencies/settings
    - Drivers behind those changes
- Views on the importance of making links and cascading skills
- Barriers to doing it

IMPROVING ACCESS

- Views on children who are likely to miss out on having access to the service (either not referred or not able to use the service):
    - Probe: mainstream vs special school
    - Probe: Minority ethnic groups
    - Probe: other groups 'at risk' of not being referred or not being able to use the service.
- What the service currently does to ensure equal access for all deaf children within current geographical boundaries
- Views on how could ensure children who might currently be missed are able to access the service
    - What their team should be doing
    - What people in other agencies should be doing

EXAMPLES OF POSITIVE AND NOT POSITIVE OUTCOMES ACHIEVED BY SERVICE

- Ask to give an example of a child they have seen who they feel is a good example of the service working at its best. Explore reasons why help offered led to a positive outcome
- An example of the opposite and reasons for help offered not leading to a positive outcome

THE NSCAG PROJECT

- Views on whether the NSCAG project has worked in terms of improving access to spec. mental health services for deaf children and their families
    - Things that have worked well
        - The network
        - Their local service
    - Things that haven't worked as well as hoped
        - The network
        - Their local service
    - In hindsight, anything done different
        - The network
        - Their locals service

    - Aside from more services like York and Dudley – what other changes would be need to happen to improve access to spec. mental health services for deaf children and their families

THE FUTURE OF THEIR SERVICE

- How they would like to see it develop
- Barriers to achieving that

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Topic Guide for interviews with clinic staff

London staff (a): Time 1

A. BACKGROUND INFORMATION

- **JOB TITLE**
- **Length of time in post**
- **Days/hours of NSCAG funded work**

B. NATURE OF STAFF MEMBER'S INVOLVEMENT IN NSCAG PILOT PROJECT: BASIC INFORMATION ONLY AT THIS STAGE – ALMOST TREAT AS A CHECKLIST

- **Assessment**
- **Direct clinical work**
- **Post discharge support to children/families and/or referrers**
- **Supervision**
- **Case management**

- How often, how much, how does each of those occur?
- Which areas do you feel York and Dudley need most input? Has that developed or changed over time?

- **Any other roles**

- **Has role/involvement of York and Dudley teams changed over the period of the project**
    - How? Why?
    - Are these changes perceived as positive or negative

C. CLINICAL WORK WITH THE CHILDREN, YOUNG PEOPLE AND THEIR FAMILIES

- **Types of direct NSCAG-related clinical work involved**
    - type of cases seen;
    - therapeutic approaches used/ways of working with the child/family; group/individual (we don't need too much detail here)
    - where they work: clinic, schools, home, over telelink
    - any restrictions on the types of cases they can see due to lack of skills/expertise

D. VIEWS ABOUT YORK AND DUDLEY SERVICES

- **Views on benefits of a specialist service to children and families compared to a *generic* CAMHS service.**

- **What do you think are the hall marks of a 'gold standard' mental health service for deaf children and their families**
    - *Probe:* staff skills and knowledge, access to service, discharge support, supporting other local services

- **Do you think the NSCAG funded York and Dudley services 'falls short' of what a 'gold standard' mental health service for deaf children and young people should look like?**
    - In what ways does it fall short
        - *Possible probes*: staff skills and knowledge; families' access to service; discharge support; supporting other local services/institutions

E. TELE-HEALTH AND VIDEOCONFERENCING

- **What do you use the video-conferencing equipment for?**

- **Has the way or purposes for which you have used the telelink changed over time?**
    - *Probe:* Increased use for certain purposes and decreased use for other?, Reasons behind those changes

- **Aside from direct clinical work, views about what the telelink has enabled the NSCAG-funded York and Dudley services to achieve which would not have happened otherwise**
    - *Probe:* Staff skills and training/development; expert input re case management, service development; support and supervision; other

- **How crucial is the telelink to the quality of the service York and Dudley provide?**
    - *Probe*: reasons for response

- **How crucial is the telelink to the development and maintenance of the network?**
    - *Probe*: reasons for response

- **Views on how the telelink aspect of the service could be improved or developed?**

- **Any lessons learnt about using telelink that would share with other professionals working in mental health settings and/or with d/Deaf people.**
    - Things to avoid
    - Strategies to have in place
    - Things to beware of …

F. STAFF WHO HAVE USED THE EQUIPMENT FOR DIRECT CLINICAL WORK ONLY

- **Views on factors informing York and Dudley's decision to use Sara as opposed to using staff within the local team?**
    - *Possible probes:* communication issues; nature/complexity of the case; characteristics of the individual child/young person; accessing even the local service is difficult; other ….

- **How do you find children respond to the idea of it?**
    - *Probe*: concerns; positive responses
    - Does this differ to how they respond in reality

- **How the telelink is used in an individual case**
    - Pre-determined by clinical team/and or negotiated with child/family
    - More 'suck it and see' approach - develops and changes
        - Child/family voice in this

- **Has the way you use telelink for clinical work changed since the pilot began?**
    - *Probe:* types of cases seen; the ways it's used; the use and timing of face to face sessions

- **In what ways does telelink changes the nature of the therapeutic encounter compared to face to face?**
    - For the child/family: Benefits/positives AND Problems/negatives

    - For yourself: Benefits/positives AND Problems/negatives

- **What have you found are the practical benefits and difficulties of using the telelink for direct clinical work?**
    - *Probe:* time/cost savings?; Frequency of contact; Flexibility/responsiveness? The technology – glitches etc.

- **In what ways have your feelings about using the telelink and your experiences of using it changed over the course of the pilot?**

G. THE NETWORK

- **How the network works? Any leadership/structure? Any protocols?**

- **Do individuals' assume specific roles?**
    - How/why?
    - Any changes re. who does what over time?
        - Caused by changes in staff
        - Caused by staff becoming more skilled

- **Have you experienced any difficulties working with practitioners from the other teams. Describe and explore perceived reasons for …**
    - Probe: The telelink – miscommunication; different clinical approaches; Other

- **Perceived 'added value' of the network**
    - Development of professional skills,
    - Quality of care provided to children and families etc..
    - Meeting communication needs of clients
    - Other
    - Has this changed/developed over time

- **Views on the network as a model of providing specialist services to low prevalence, widely dispersed groups.**

- **Ways the effectiveness of the network could be improved.**

- **What impact has PH's departure had on the way the network works and the skills available?**

H. COLLABORATION WITH OTHER SERVICES/AGENCIES

- **What kind of contact or support do you have with other agencies or services in York and Dudley (local CAMHS, school, social services, etc)?**
    - *Probe:* feelings re whether doing enough, over-burdened; ways they would like patterns of contact/support with local generic services to develop

- **Do you have ongoing contact with referrers (e.g. schools, professionals) after discharge?** (NB. we want to understand whether, if the referrers need help and advice concerning the patient, they can get in touch with the service)
    - How is this achieved/provided
    - Any difficulties/inadequacies re this
    - How could it be improved?

Topic Guide for interviews with clinic staff

London staff (b): Time 1

A. BACKGROUND INFORMATION

- **Length of time in post**
- **Days/hours of NSCAG funded work**

B. NATURE OF STAFF MEMBER'S INVOLVEMENT IN NSCAG PILOT PROJECT: BASIC INFORMATION ONLY AT THIS STAGE – ALMOST TREAT AS A CHECKLIST

- **Assessment**
    - own and/or other services in the network
- **Direct clinical work**

- **Post discharge support to children/families and/or referrers**
    - own and/or other services in the network

- **Supervision**
    - own and/or other services in the network

- **Case management**
    - own and/or other services in the network

- **Service management**
    - own service and/or the network
    - particular roles?

- **Any other roles**

- **Has their role/involvement changed over the period of the project**
    - How? Why?
    - Are these changes perceived as positive or negative

C. VIEWS ABOUT THEIR LOCAL SERVICE

- **Views on benefits of their specialist service to children and families compared to a *generic* CAMHS service.**

- **What do you think are the hall marks of a 'gold standard' mental health service for deaf children and their families**
  - *Probe:* staff skills and knowledge, access to service, discharge support, supporting other local services

- **Do you think York and Dudley services 'fall short' of what a 'gold standard' mental health service for deaf children and young people should look like?**
  - In what ways does it fall short
    - *Possible probes*: staff skills and knowledge; families' access to service; discharge support; supporting other local services/institutions

D. TELE-HEALTH AND VIDEOCONFERENCING

- **Aside from direct clinical work, views about what the telelink has enabled York and Dudley to achieve which would not have happened otherwise**
  - *Probe:* Staff skills and training/development; expert input re case management, service development; support and supervision; other

- **How crucial is the telelink to the quality of the service they provide?**
  - *Probe*: reasons for response

- **How crucial is the telelink to the development and maintenance of the network?**
  - *Probe*: reasons for response

- **Views on how the telelink aspect of the service could be improved or developed?**

- **Any lessons learnt about using telelink that would share with other professionals working in mental health settings and/or with d/Deaf people.**
  - Things to avoid
  - Strategies to have in place
  - Things to beware of …

E. THE NETWORK

- **How the network works? Any leadership/structure? Any protocols?**

  - **Do individuals' assume specific roles?**
    - How/why?
    - Any changes re. who does what over time?
      - Caused by changes in staff
      - Caused by staff becoming more skilled

  - **Have you experienced any difficulties working with practitioners from the other teams. Describe and explore perceived reasons for…**
    - Probe: The telelink – miscommunication; different clinical approaches; Other

- **Perceived 'added value' of the network**
    - Development of professional skills,
    - Quality of care provided to children and families etc..
    - Meeting communication needs of clients
    - Other
    - Has this changed/developed over time

- **Views on the network as a model of providing specialist services to low prevalence, widely dispersed groups.**

- **Ways the effectiveness of the network could be improved.**

- **What impact has PH's departure had on the way the network works and the skills available?**

Topic Guide London Service

Staff Interviews Time 2

CONFIRM BASIC FACTS

- Staff role
- Days-hours of NSCAG-funded work
- Find out if any of these has changed since last interview

CHANGES/DEVELOPMENTS IN MEMBER OF STAFF'S INVOLVEMENT IN NSCAG WORK OVER THE PAST YEAR

- Views about their role within the NSCAG project
    - Any changes in that role
    - Reasons for ….
    - Outcomes of this change/development

- How they have worked/been involved with the teams at York and Dudley
    - Providing support, advice, case discussions with/to staff in York and Dudley
    - Using York and/or Dudley for support, advice, discussing own case with staff in York and Dudley

- Views about changes in the way York and Dudley have been using the London team.
    - Ask for description of change/development
    - Reasons for ….
    - Outcomes of this change/development

- Views about changes in the way York and Dudley have been using the inpatient service: CornerHouse
    - Ask for description of change/development
    - Reasons for ….
    - Outcomes of this change/development

- Management and development of the network
    - Current role in terms of the management and development of the network
    - Has that changed over the past year
    - Reasons for those changes
    - Outcomes of this change/development

S. ONLY:

USE OF TELELINK IN WORK WITH CHILDREN/YOUNG PEOPLE USING THE YORK AND DUDLEY SERVICE

- Changes/developments in the way the telelink is being used for direct clinical work with children
    - By the two services (York and Dudley)
    - Type of child/young person
    - Nature of their problem
    - Frequency of face to face meeting
    - Other ...

- Views on how well the telelink works
    - Positive features/advantages
    - Negative features/concerns
    - Ways it could be improved
        - Barriers to improving

- New things they are understanding/realizing about using telelink with children

- Any developments in implementing protocols for use
    - e.g. professional accompanying child
    - how to deal with drawings and printed materials

S. ONLY:

EXAMPLES OF POSITIVE AND NOT POSITIVE OUTCOMES ACHIEVED WORKING WITH A CHILD USING THE TELELINK

- Ask to give an brief overview of a case which they feel is a good example of the telelink working at its best.
    - Why it worked well
- Ask for an example of where not as effective as had hoped
    - Explore reasons why outcome not as good as had hoped for.

CHANGES IN USE OF TELELINK FOR LINKING UP WITH YORK AND DUDLEY FOR NON-CLINICAL WORK

- Views on the ways the use of the telelink has developed/changed over the past 12 months
    - Frequency of contact with other teams
    - Content of meetings

- Views on what has driven those changes.

DIFFICULTIES EXPERIENCED BY THE LONDON SERVICE OVER THE PAST COUPLE OF YEARS

- The current situation re
    - Staffing
    - Funding
    - Improvements in the situation over the past few months

- How they managed in terms of providing a service during the period when they had few staff
    - Changes in the type of service provided
    - Changes in who could access the service
    - Changes in the sorts of things staff did outside of direct clinical work (e.g. preventative work, consultancy)
    - Any other changes

- Impact of these difficulties on staff
    - Workload
    - Impact on individuals – stress/morale
    - Experiences of working in a vulnerable/uncertain environment

- Impact of ‘weakened’ service on families
    - Using the service
    - Trying to access the service

- Impact of ‘weakened’ service on key referrers

PREVENTATIVE WORK

- Does the service undertake any preventative work?

- Description of preventative work
    - Location (e.g. school, clinic)
    - Target group (e.g. teenagers)
    - Duration of intervention
    - Aims
    - Outcomes
    - Involvement of other professionals, within and outside of the team

- Views on the role/responsibility of their service to conducting preventative work
    - Limitations/boundaries?
    - Balance with other work
    - Views on where responsibility should lie

- Views on the sorts of preventative work their service should be/would like to be doing.
    - Barriers to their service carrying out preventative work?

IMPROVING ACCESS

- Views on children who are likely to miss out on having access to the service (either not referred or not able to use the service):
  - Probe: mainstream vs special school
  - Probe: oral/non BSL users
  - Probe: Minority ethnic groups
  - Probe: other groups ‘at risk’ of not being referred or not being able to use the service.

- Views on how could ensure children who might currently be missed are able to access the service
  - What their team should be doing
  - What people in other agencies should be doing

VIEWS ON THE NEED TO CASCADE SKILLS TO LOCAL CAMHS OR OTHER PROFESSIONALS (SOCIAL WORKERS, TEACHERS OF THE DEAF)

- Views on the importance of making links and cascading skills
  - Barriers to doing it

DEVELOPMENTS IN THE SERVICE

- Views on other ways they would like to see the London service develop
  - Barriers/ facilitators to those changes

- Views on the way they would like to see the current network develop (York, Dudley, London)
  - Ways of working
  - Supervision/support structures
  - Other

- More generally, their views on the way specialist mental health services for deaf children should develop across the country.
  - Priorities
  - ‘Wish list’
  - Barriers to achieving these things (exploring particularly barriers that aren’t just about funding).

THE NSCAG PROJECT

- Views on whether the NSCAG project has worked in terms of improving access to spec. mental health services for deaf children and their families across the country
  - Things that have worked well
  - Things that haven’t worked as well as hoped

CLOSE

- **Any other questions/comments; thanks**

Appendix 2

Content of proforma for routine data collection

Name of Child/young person ……………………………
Name of clinician ……………………………………… Date …………………………

1. PADDINGTON COMPLEXITY SCALE

Please circle the number that best describes the child/young person

PRIMARY PSYCHIATRIC CONDITION	
A psychiatric condition indicates a handicapping abnormality of emotions, behaviour and/or relationships. Circle one only	
a) None	0
b) Acute stress reaction/Adjustment disorder	1
c) Sleep and feeding disorders	2
d) Non-organic encopresis	2
e) Somatoform disorders	2
f) Anxiety disorders (OCD scores 3)	2
g) Mood (affective disorders)	2
h) Eating disorders	2
i) Oppositional defiant disorder	2
j) Hyperkinetic disorder (or ADHD)	3
k) Personality disorders	4
l) Conduct disorder (inc. mixed CED)	4
m) Schizophrenia	5
n) Pervasive development disorder	5
o) Other (please specify)	?
DURATION OF CONDITION	
a) Less than six months	0
b) Longer than six months	1
SEVERITY OF CONDITION	
a) Mild	1
b) Moderate	2
c) Severe	3
d) Extreme	4
SECONDARY PSYCHIATRIC CONDITION	
(please specify as under Primary Psychiatric Condition)	
	1
	1
CHRONIC PHYSICAL ILLNESS	
a) None	0
b) Present without brain involvement	1
c) Present with brain involvement	2
LEARNING DISABILITY	
a) None	0
b) Specific	1
c) Generalised - mild	2
d) Generalised - moderate	3
e) Generalised- severe	4

SCHOOLING	
a) Ordinary school	0
b) Ordinary school with special education provision	1
c) Special school	2
d) No school (excluded)	3
e) Not applicable	0
MAIN CARERS	
a) Both parents(natural or adoptive)	0
b) One parent (with/without partner)	1
c) Other relatives	2
d) Foster parents	3
e) Institution	4
CARERS ATTITUDE AND CO-OPERATION WITH ASSESSMENT AND TREATMENT	
a) Facilitative	0
b) Indifferent	1
c) Counterproductive	2
IS THIS THE PATIENT'S FIRST CONTACT WITH MENTAL HEALTH SERVICES?	
a) Yes	0
b) No	1
c) Not known	0
CURRENT INVOLVEMENT WITH OTHER AGENCIES (use several if appropriate)	
a) None	0
b) Paediatrics	1
c) Education (Authority, EWO, Ed. Psych, Counsellor)	1*
d) Social work	1
e) Other (please specify)	?
CURRENT CHILDREN ACT 1989 INVOLVEMENT (including being on the "at risk" register	
a) No	0
b) Yes	1
*** Score only if SCHOOLING score = 0**	
TOTAL	

2. ADDITIONAL INFORMATION

		Please tick (✓) when appropriate
Today's date		
Child's Age		
Gender M/F		
School		
Day pupil or residential		
Referral source	School liaison	
	Teacher of the Deaf	
	Health Professional	
	Education	
	Social Services	
	Other	
Child protection		
	Concerns	
	Registered cases	
	Specific work	
Hearing Loss		
	Mild	
	Moderate	
	Severe	
	Profound	
Hearing Aids		
	Cochlear implant	
	BE aids	
	Bone conductor	
	Cannot/will not wear aids	
Cause of deafness		
	Prematurity	
	Hereditary	
	Acquired	
	Not known	
	Ushers syndrome	
Visual impairment		
	Registered partially blind	
	Registered blind	
Communication		
	BSL	
	SSE	
	Lip reading and speech	
	Other	

Parents		
	Deaf	
	Hearing	
	Deaf and Hearing	
Communication at home		
	Speech	
	Sign	
	Family Specific mode	
Other agencies involved		
	Audiology	
	Paed	
	ENT	
	Social Services	
	Ed Psychologist	
	Local CAMHS	
Ethnic group		
	White	
	Black Caribbean	
	Black African	
	Black (other)	
	Indian	
	Pakistani	
	Bangladeshi	
	Chinese	
	Other ethnic group	
	Not known	
Date of closure:		

Appendix 3

Additional data collected routinely by the York and Dudley services

Additional information collected by services

1. Postcode

2. Date of referral

3. No of sessions attended

4. Clinician view on the outcome of the referral, rated as either:
    a. Family did not engage
    b. Child/family moved away
    c. Mutually agreed ending

5. Description of the presenting problem
    a. Behaviour issues
    b. Family and communication issues
    c. Emotional difficulties
    d. Self-harm
    e. Eating/sleeping difficulties
    f. ADHD
    g. Tourettes
    h. Psychosis
    i. Substance misuse
    j. Adjustment/post-abuse difficulties
    k. Empathy skills deficits
    l. Autistic spectrum disorders
    m. Court reports
    n. Other

6. Involvement of the inpatient service (yes/no)

7. Name of clinician (for queries with form only)

Appendix 4

The Strengths and Difficulties Questionnaire (parent version)

Strengths and Difficulties Questionnaire (P 4-16)

For each item, please mark the box for Not True, Somewhat True, or Certainly True. It would help us if you answered all items as best as you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behaviour *over the last six months*.

Child's name ______________________________
Date of Birth ______________________________
Male/Female

	Not true	**Somewhat True**	**Very True**
1) Considerate of other people's feelings	☐	☐	☐
2) Restless, overactive, cannot stay still for long	☐	☐	☐
3) Often complains of headaches, stomach-aches or sickness	☐	☐	☐
4) Shares readily with other children (treats, toys, pencils etc)	☐	☐	☐
5) Often has temper tantrums or hot tempers	☐	☐	☐
6) Rather solitary, tends to play alone	☐	☐	☐
7) Generally obedient, usually does what adults request	☐	☐	☐
8) Many worries, often seems worried	☐	☐	☐
9) Helpful if someone is hurt, upset or feeling ill	☐	☐	☐
10) Constantly fidgeting or squirming	☐	☐	☐
11) Has at least one good friend	☐	☐	☐
12) Often fights with other children or bullies them	☐	☐	☐
13) Often unhappy, down-hearted or tearful	☐	☐	☐

	Not true	**Somewhat True**	**Very True**
14) Generally liked by other children	☐	☐	☐
15) Easily distracted, concentration wanders	☐	☐	☐
16) Nervous or clingy in new situations, easily loses confidence	☐	☐	☐
17) Kind to younger children	☐	☐	☐
18) Often lies or cheats	☐	☐	☐
19) Picked on or bullied by other children	☐	☐	☐
20) Often volunteers to help others (parents, teachers, other children)	☐	☐	☐
21) Thinks things out before acting	☐	☐	☐
22) Steals from home, school, or elsewhere	☐	☐	☐
23) Gets on better with adults than with other children	☐	☐	☐
24) Many fears, easily scared	☐	☐	☐
25) Sees tasks through to the end, good attention span	☐	☐	☐

If possible, please answer these additional questions

26) Overall, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behaviour, or being able to get on with other people?

No	**Yes- minor difficulties**	**Yes- definite difficulties**	**Yes- severe difficulties**
☐	☐	☐	☐

27) If you have answered “Yes”, please answer the following questions about these difficulties:
How long have these difficulties been present?

Less than a month	**1-5 months**	**6-12 months**	**Over a year**
☐	☐	☐	☐

28) Do the difficulties upset or distress your child?

Not at all	**Only a little**	**Quite a lot**	**A great deal**
☐	☐	☐	☐

29) Do the difficulties interfere with your child’s everyday life in the following areas?

	Not at all	**Only a little**	**Quite a lot**	**A great deal**
1) Home life	☐	☐	☐	☐
2) Friendships	☐	☐	☐	☐
3) Classroom learning	☐	☐	☐	☐
4) Leisure activities	☐	☐	☐	☐

30) Do the difficulties put a burden on you or the family as a whole?

Not at all	**Only a little**	**Quite a lot**	**A great deal**
☐	☐	☐	☐

Signature of parent ………………………………..

Mother/Father/Other (please specify) ………………

Date ………………..

Thank you!

Appendix 5

The Child Global Assessment of Functioning Scale

Children’s Global Assessment of Functioning (GAF) Scale

(Please complete)

Name of Child/Young person……………………………………………….

Name of clinician………………………………………………………….

Date…………………………………………………………………………

C-GAS rating at time of child/young person’s assessment……………………..

Please rate the child/young person’s level of general functioning at the time of assessment on a scale between 1 and 100. Use intermediary numbers (e.g. 35, 58, 62) and rate actual functioning regardless of treatment or prognosis. The examples of behaviour provided are illustrative and are not required for a particular rating.

91-100
Superior functioning in all areas (at home, at school, and with peers); involved in a wide range of activities and has many interests (e.g. has hobbies or participates in extracurricular activities or belongs to an organized group such as Scouts, etc): likeable, confident; "everyday" worries never get out of hand; doing well in school; no symptoms

81-90
Good functioning in all areas; secure in family, school, and with peers; there may be transient difficulties and "everyday" worries that occasionally get out of hand (e.g. mild anxiety associated with an important exam, occasionally 'blowups" with siblings, parents, or peers)

71-80
No more than slight impairment in functioning at home, at school; or with peers; some disturbance of behaviour or emotional distress may be present in response to life stresses (e.g. parental separations, deaths, birth of a sib), but these are brief and interference with functioning is transient; such children are only minimally disturbing to others and are not considered deviant by those who know them

61-70
Some difficulty in a single area, but generally functioning rather well (e.g. sporadic or isolated antisocial acts, such as occasionally skipping school or petty theft; consistent minor difficulties with school work; mood changes of brief duration; fears and anxieties which do not lead to gross avoidance behaviour; self-doubts); has some meaningful interpersonal relationships; most people who do not know the child

well would not consider him/her deviant but those who do know him/her well might express concern

51-60
Variable functioning with sporadic difficulties or symptoms in several but not all social areas; disturbance would be apparent to those who encounter the child in a dysfunctional setting or time but not to those who see the child in other settings.

41-50
Moderate degree of interference in functioning in most social areas or severe impairment of functioning in one area, such as might result from, for example, suicidal preoccupations and ruminations, school refusal and other forms of anxiety, obsessive rituals, major conversion symptoms, frequent anxiety attacks, poor or inappropriate social skills, frequent episodes of aggressive or other antisocial behaviour with some preservation of meaningful social relationships.

31-40
Major impairment in functioning in several areas and unable to function in one of these areas, e.g. disturbed at home, at school, with peers or in society at large, e.g., persistent aggression without clear instigation; markedly withdrawn and isolated behaviour due to either mood or thought disturbance, suicidal attempts with clear lethal intent: such children are likely to require special schooling and/or hospitalization or withdrawal from school (but this is not a sufficient criterion for inclusion in this category)

21-30
Unable to function in almost all areas, e.g., stays at home, in ward, or in bed all day without taking part in social activities or severe impairment in reality testing or serious impairment in communication (e.g., sometimes incoherent or inappropriate)

11-20
Needs considerable supervision to prevent hurting others or self (e.g. frequently violent, repeated suicide attempts) or to maintain personal hygiene or gross impairment in all forms of communication, e.g. severe abnormalities in verbal and gestural communication, marked social aloofness, stupor, etc.

0-10
Needs constant supervision (24-hr care) due to severely aggressive or destructive behaviour or gross impairment in reality testing, communication, cognition, affect, or personal hygiene

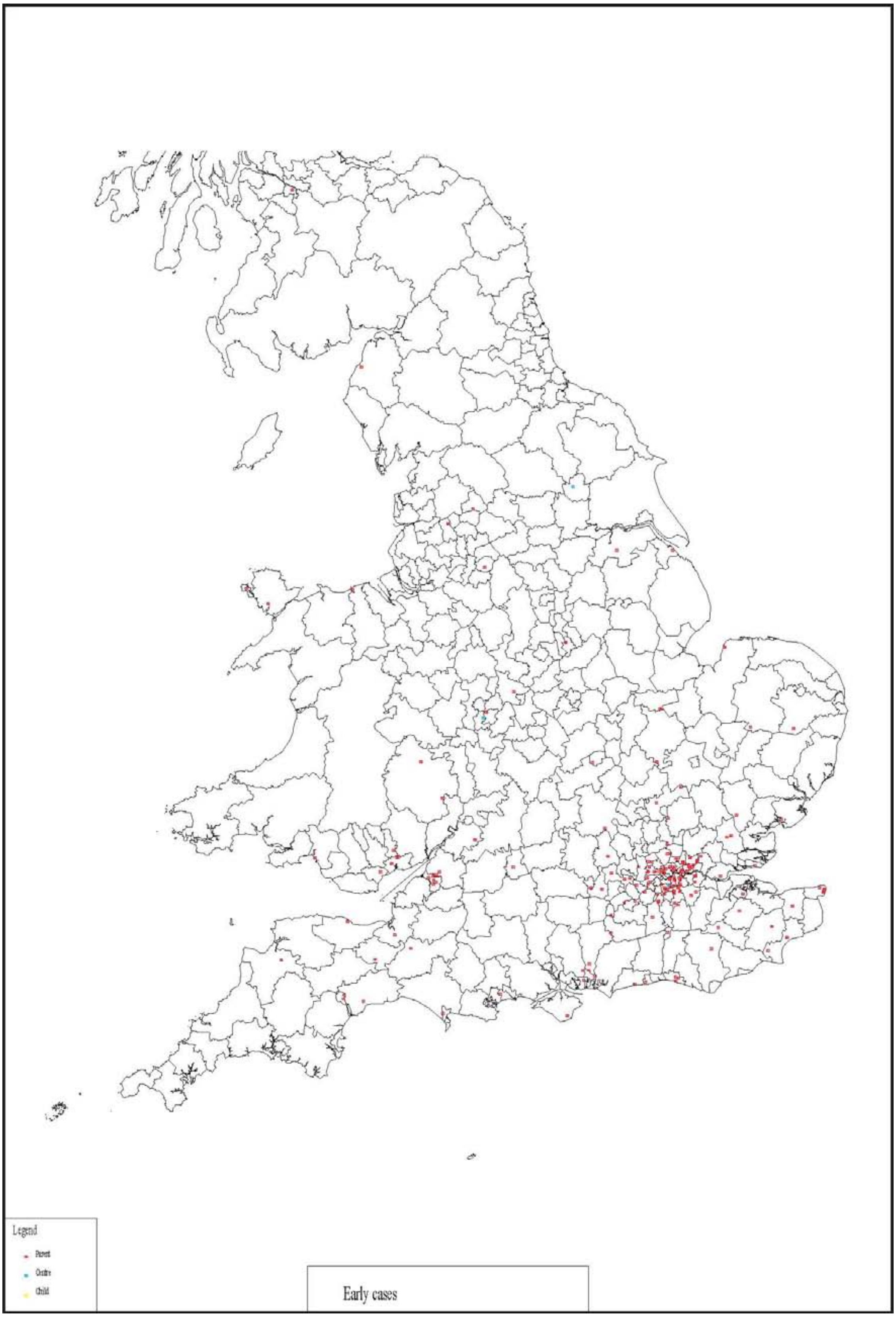
Appendix 6

Maps of locations of users' family homes

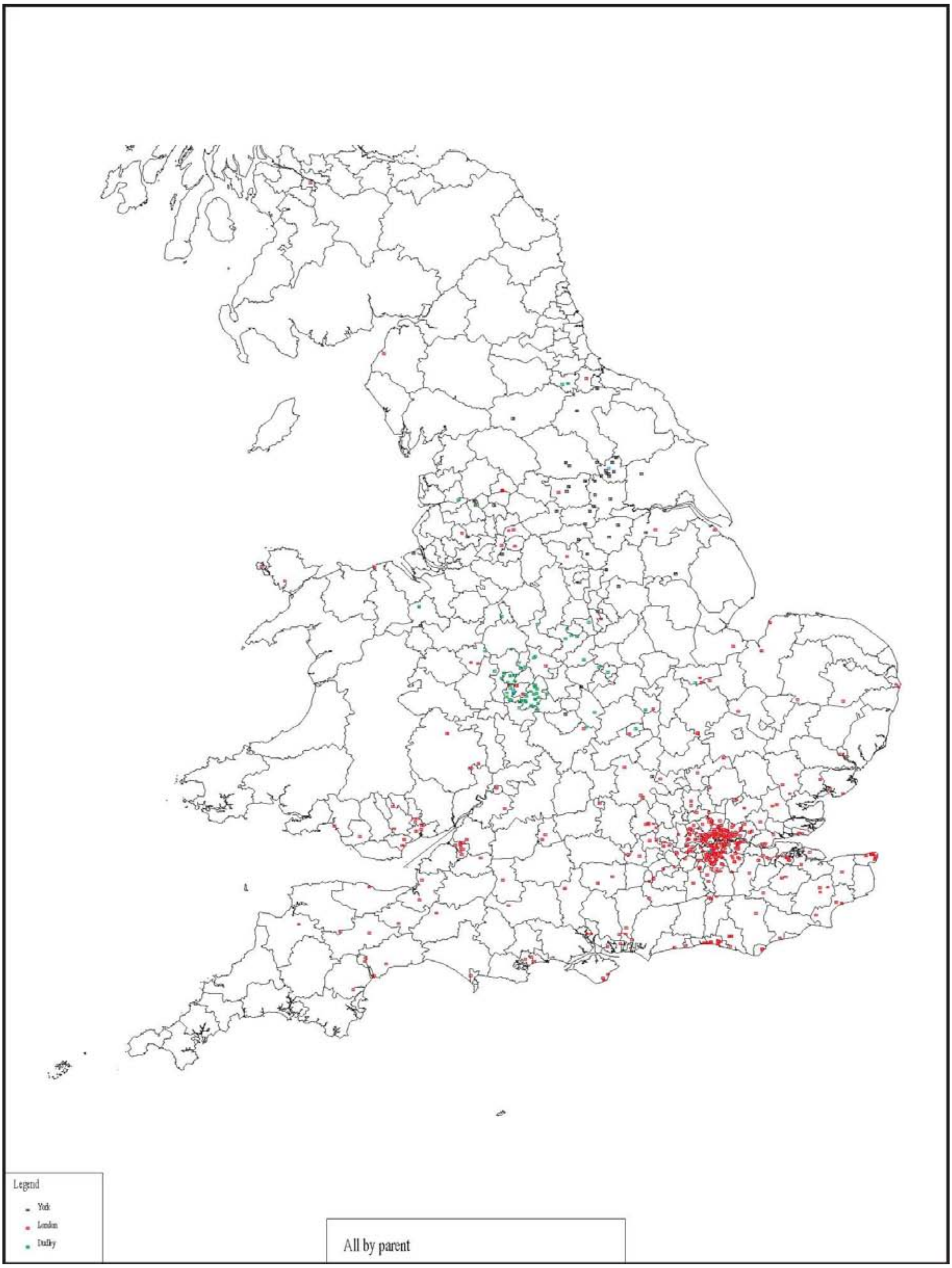
Family home location pre 2004

Family home location following setting up of the Dudley and York services (2004 onwards)

Family home location pre 2004



Family home location following setting up of the Dudley and York services (2004 onwards)



Appendix 7

Samples of recruitment materials for parents

Information sheet

Contact form

Consent form

THE UNIVERSITY of York

SPRU
SOCIAL POLICY RESEARCH UNIT

THE DEAF CHILD AND FAMILY SERVICE: A RESEARCH PROJECT ABOUT FAMILIES' EXPERIENCES OF A NATIONAL SPECIALIST SERVICE FOR DEAF CHILDREN

Information Sheet for Parents/Guardians

- The Deaf Child and Family Service is part of a national specialist service for deaf children and their families. The government's Department of Health wants to find out what families think of this service. They have asked us to carry out some research into the service.

- We are an independent research team based at the University of York. The research team includes people who use British Sign Language (BSL).

- The purpose of the research is to find out what families think about the Deaf Child and Family Service, what you find helpful, and what you think could be improved. The information you give us may help inform the future development of services to help deaf children, young people and their families.

- You are invited to take part in this research. This would involve talking to a member of the research team when your child starts seeing someone at the Deaf Child and Family Service, and then talking to us again six to eight months afterwards. People in the research team would also look at relevant sections of your child's notes. If possible, we would also like to talk to your child.

- All families who are using the Deaf Child and Family Service are being invited to take part in this research.

- You do not have to take part in this research project. It is entirely up to you. Whether or not you take part will not affect the service your child receives. You can also opt out of the research at any time.

- Someone from the Deaf Child and Family Service will talk to you about this research when you see them and you can ask them any questions you have. If you would like the research team to contact you and give you more information about the project, you can fill in a form so that we can contact you. On the next page, you will find more information about the research. Please take time to read the information carefully. Talk to others about the research if you wish.

Who is doing the research?

The research is being carried out by the Social Policy Research Unit at the University of York and is being conducted by Veronica Greco, Bryony Beresford, and Sue Clarke. We are not members of the clinic staff and we are independent from the Deaf Child and Family Service. The research is being funded by the Department of Health.

What will happen to me if I would like to take part in this research?

You will give permission for the research team to contact you. One of us will then contact you and arrange to visit you at your home or any other place you choose, at a date and time that would best suit you. If you use BSL, someone who uses BSL will visit you. We would like to ask about your views about going to the Deaf Child and Family Service and what you want to be achieved for your child. We expect that the interview will take about an hour. We would like to tape or video record the interview and we will ask you about this before we start. If you would prefer not to be recorded, we will take notes. We will also need the clinic staff to pass on some information from your child's notes. About six months after the interview, we would like to contact you again to follow up your experiences of going to the Deaf Child and Family Service and to ask you what could be done to improve it. If, by this time, you no longer wish to participate in the study, that is OK. When we visit we will also ask you to fill in a couple of short questionnaires.

Will my child be involved?

If your child is interested in taking part, we will also ask him or her to talk to us. If your child uses BSL, someone who uses BSL will visit them. We will use activities to make the interview more interesting for your child. If you would like to take part but your child does not wish to, or vice versa, that is OK. The information sheet for children and young people has more information about this.

Will what I say be confidential?

Yes. Any information you give us will not be communicated to anyone. We will make sure any notes and recordings we make are locked up safely and will only be used by the research team. We will destroy all our notes and recordings at the end of the project.

What will happen to the information?

When we have completed the research, we will produce a report. It will not be possible to identify you or anyone else who took part in the research in the project report. You will be sent a summary of the report. The report will also be sent to those who funded the research. We hope they will use our report to plan future help for children, young people and their families.

Any questions?

Please feel free to contact the research team at any time about this research. Our contact details are: Veronica Greco (Email: vg3@york.ac.uk) *or* Bryony Beresford (Email: bab3@york.ac.uk). Social Policy Research Unit, University of York, Heslington, York YO10 5DD. Telephone 01904 321950.

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THE DEAF CHILD AND FAMILY SERVICE: A RESEARCH PROJECT ABOUT FAMILIES' EXPERIENCES OF A NATIONAL SPECIALIST SERVICE FOR DEAF CHILDREN

Contact form

PARENT

I (*parent*) am willing for the research team to contact me with further information about the research

Signature ……………………………………………………..

Your name ……………………………………………………………………………..
Home address ……………………………………………………………………………..
……………………………………………………………………………..
……………………………………………………………………………..
Telephone number …………………………………………………………………….….
Email ……………………………………………………………………………..

Are you (parent) deaf?

☐ Yes ☐ No

If yes, how do you prefer to communicate? (please tick)

☐ BSL ☐ Sign Supported English ☐ English
☐ Other (please explain) ………………………………………………………………….

Do you prefer to use a spoken language other than English? (e.g. Gujarati, Urdu etc.)

☐ Yes ☐ No

If yes, please tell us which language you prefer to use ………………………………….

Please return this form to clinic staff. If your child is <u>over 16</u> and wants to participate in this research please ask them to fill in the other side of this form. Thank you.

YOUNG PERSON (to be completed by child/young person **ONLY if over 16**)

I (*young person*) am willing for the research team to contact me with further information about the research

Signature **………………………………………………..**

Your name …………………………………………………………………………

Age ………………………

How do you want us to get in touch with you? (please tick ✓)

☐ Email - (write your email address here) ……………………………………………

☐ Text message - (write your mobile phone number here) ……………………………

☐ Letter - (write your address here) ………...………………

…………………………………………………………………………………………

…………………………………………………………………………………………

☐ Through your parents - (parents' address here) ……………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

☐ Through school (write the name of your school here) ……………………………

…………………………………………………………………………………………

How do you prefer to communicate? (please tick)

☐ BSL ☐ Sign Supported English ☐ English

☐ Other (please explain) ……………………………………………………………..

Thank you!

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SOCIAL POLICY RESEARCH UNIT

THE DEAF CHILD AND FAMILY SERVICE: A RESEARCH PROJECT ABOUT FAMILIES' EXPERIENCES OF A NATIONAL SPECIALIST SERVICE FOR DEAF CHILDREN

Consent Form for Parents/Guardians

I have read the research information leaflet and understand what is involved.	Yes ☐	No ☐
I have talked to a staff member at the Deaf Child and Family Service about this research.	Yes ☐	No ☐
I understand that relevant sections of my child's clinic notes will be passed onto the research team.	Yes ☐	No ☐
I understand that the information collected about my child and about me, including notes and recordings, will only be seen by members of the research team. It will be stored securely and will be destroyed at the end of the project.	Yes ☐	No ☐
I understand that my child and I will not be identifiable in the research reports.	Yes ☐	No ☐
I understand that taking part in the research is voluntary and I can withdraw from the research at any time without giving a reason.	Yes ☐	No ☐
I am willing to take part in this research	Yes ☐	No ☐

Parent signature: ……………………..……………………………………………………

Parent name: ……………………………………………………………………………

Child's name: ……………..……….……………… **Date:** ………………………

Researcher's signature: ……………………………………………………………………

If your child is under 16 years and/or has difficulties with learning we also need to know whether you agree to him or her taking part. Please turn over to complete a form about your child taking part in this research.

Cont'd…

Parent consent form – continued

These statements are about your child taking part:

I have read the research information leaflet and understand what is involved if my child takes part.	Yes ☐	No ☐
I understand that what my child says to the research team will be kept confidential.	Yes ☐	No ☐
I understand that any notes or recordings made of my child will only be seen by members of the research team. They will be stored securely and will be destroyed at the end of the project.	Yes ☐	No ☐
I am willing for my child to take part in this research	Yes ☐	No ☐

Parent signature: ……………………..……………………………………………….

Parent name: ………………………………………………………………………….

Researcher's signature: ……………………………………………………………….

Appendix 8

Topic guide for Time 1 interviews with parents

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Time 1 Interviews with Parents

Check they have seen the information sheet and get them to sign consent form.

1) Background information

- Name of child
- Age of child
- Does family have other children? How many?
- Age of other children
- Does partner live at home?
- Child's schooling history *(try to keep this brief or leave until later)*
    - What school does child attend?
    - How long have they attended the school for?
    - Has child always attended the same school or different schools?
    - Any issues/difficulties concerning school? (briefly)
- Family history of deafness
    - Any history of deafness in the family? If yes, please explain
- Child's history of deafness
    - At what age was child diagnosed?
- Parent's views on child's linguistic, reading and cognitive abilities
    - How is child doing in school compared to other children?
    - How does child communicate? (BSL etc.)
    - Probe about child's communication and language skills

2) History of child's mental health problems

- Description of past and current symptoms/issues
    - What kind of issues or problems has he/she been experiencing?
    - Timing of issues/difficulties experienced
- Mental health services already used
    - Is this child's first experience of using mental health services?
        - If not, explain
    - Experiences of using generic CAMHS services, if applicable
    - Route accessing generic CAMHS services, if applicable

3) The referral to specialist mental health service

- Things that lead up to the referral being made (e.g. things getting worse, becoming aware of the service, discussions with school/other professionals etc...)
- Route of referral
    - Who referred child to the service?

    - Any problems getting a referral? (eg. professionals not aware/reluctant to refer)
    - Any problems getting access to the service (eg. funding arrangements)
- The referral process – timing, information etc.
    - When was (child) referred?
    - How long between referral and the first appointment?
    - Did you receive enough information about the service at the time of referral?
    - How did you feel about being referred to the service? (e.g. Relieved, happy, or maybe didn't think referral was necessary)
    - How did child feel about being referred to the service? (e.g. worried about the stigma, anxious, happy etc)
    - Following your/your child's first appointment with the service, did you understand what would happen next?

4) Expectations with respect to the service

- What are their expectations of the service? e.g. they expect their child's difficulties will decrease, they expect their life to become less stressful etc.
- What are their desired outcomes for their child?
- What do they want out of the service for themselves?
        - Information, advice, support
        - In terms of being a parent of a deaf child in general
        - Supporting/facilitating their child's recovery
        - Their own feelings/adjustment

- What do they want out of the service for whole family (in terms of relationships within the family)
- What do they want out of the service re siblings (eg. relationship with deaf brother/sister)
- Do they think this service will make a difference?
    - Probe reasons for confidence/lack of confidence in the service
- Any concerns/reservations about using the service
    - Stigma
    - Privacy/confidentiality
    - Child's engagement or engagement of other family members
    - Communication problems
    - Telelink
    - Therapeutic approach

Travel and logistics

- How do they get to the appointments?
- Time and cost of travel
- Time out of school
- Time off work
- Managing other commitments/siblings

- From what they have experienced of the service so far, what are their impressions?
- From what they have experienced so far, what is the difference between this service and other services they have used?

Close

- Any questions or further comments
- Confirm that the child wishes to be interviewed. Confirm details concerning communication with child during interview. If applicable, tell parent which researcher will get in touch with the child or with them to set up the interview.
- Remind about re-interviewing in 6-8 months.

Appendix 9

Samples of recruitment materials for children and young people

Older and younger versions of covering letter

Older and younger versions of information sheets

Consent and assent forms

Sample of letter sent confirming interview

THE UNIVERSITY of York
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COVERING LETTER – OLDER VERSION

Hello,

We are a group of researchers who work at the University of York. We are doing a research project on families' experiences of going to see Dr. Walker and his team. The people in charge of Dr. Walker's team want to know what children and parents think about them and how they could help you more.

We are inviting everyone who goes to see Dr. Walker to take part in the research. Taking part would mean telling one of us about what you like and dislike about going to see Dr. Walker and his team.

The sheet attached to this letter explains more about the research and how you can take part. You do not have to take part, it is up to you.

When you go to visit Dr. Walker, the staff there will talk to you about this research, and you can decide then whether or not you want to take part.

Thank you for reading this.

Veronica Greco
Bryony Beresford
Sue Clarke

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COVERING LETTER – YOUNGER VERSION

Hello!

Our names are Veronica, Bryony and Sue. We are doing a project about Dr. Walker and his team.

The people in charge of Dr. Walker's team want to know what children and parents think about it. They have asked us to find out. We don't work for Dr. Walker. *Our* offices are at the University of York.

We are asking everyone who goes to see Dr. Walker to join in our research project.

The next page of this letter tells you more about taking part. Someone from Dr. Walker's team will talk to you and your parents about it too. Then you can decide if you want to take part.

Thanks for reading this!

Veronica Greco
Bryony Beresford
Sue Clarke

THE UNIVERSITY *of York*

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A RESEARCH PROJECT ABOUT *GOING TO SEE DR.WALKER AND HIS TEAM*

- People in charge of Dr. Walker’s team want to know if they are doing a good job at helping deaf children and young people and their families.

- They have asked us to do a project on what families think about going to visit them. We are researchers based at the University of York.

- Because you are seeing Dr. Walker or someone in his team, we would like to invite you to take part in this research project. We would like to visit you and talk to you. We would like to ask you what you think about the help Dr. Walker and his team give you and how they could help you more. We would like to visit when you first start going to see Dr. Walker and when you stop going.

- To help us understand how Dr. Walker’s team helps you we would also like to look at some parts of your clinic notes.

- You do not have to take part in this project if you don’t want to. It’s up to you.

- No-one will be told what you have said to us if you don’t want them to.

- On the next page you can find more information about the research project. Take time to read it. Talk to others about taking part if you want.

What's the point?

This research project wants to find out about children and young people's (and their parents') experiences of going to see Dr. Walker. This is because the people in charge of Dr. Walker's team and other similar places in London and York want to know how well they are doing at helping deaf children and young people. They also want to know how they could improve what they are doing.

What will I have to do?

If you decide to take part in the project one of us will arrange to visit you. If you like, this can be someone who uses British Sign Language. You can also choose to have someone with you (perhaps a parent, teacher, friend, brother or sister) when we visit. We will ask you about what you find helpful about going to see Dr. Walker and his team and your ideas of what they could do to help you more. We think our visit will last between 30 and 45 minutes. It helps us if we can record our discussion using an audio or video tape. But if you do not want us to use audio or video we will make notes instead. When you have finished going to the clinic we would like to visit you again to ask you about how it has been. When we make that visit we would like to ask you to fill in a short questionnaire.

We would also like to be able to look at parts of your clinic notes. This will help us understand how Dr. Walker and his team are trying to help you.

We will make sure any notes and recordings we make are locked up safely and will only be used by the research team. We will destroy all our notes and recordings at the end of the project.

Will anyone be told about what I say?

No, everything we discuss is private. We will not tell anyone what you say without your permission.

Do I have to take part in the project?

No, you do not have to take part. It is up to you.

What happens next?

When you go for your next appointment, someone will talk to you and your family about the research project. Your mother, father, or guardian may want to take part too. If you want to take part in the project, the staff will give you a form to fill in (get some help if you need it). If you are under 16, don't forget to get one of your parents to sign it too. People in Dr. Walker's team will send us that form and we will contact you. When we get in touch we will answer any questions you have. We will also make a time to visit. We will write a report of what we find out. We will send you a short report too. When we write the report we will make sure people won't be able to tell who took part in the project.

Any questions?

If you have any questions about the project please contact us:
Veronica Greco (email: vg3@york.ac.uk) *or* Bryony Beresford (email bab3@york.ac.uk)
Social Policy Research Unit, University of York, York, Y010 5DD. Tel: 01904 32150

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A PROJECT ABOUT GOING TO SEE DR. WALKER'S TEAM

- The people in charge of Dr. Walker's team want to know if they are doing a good job at helping deaf children and young people and their families.

- They have asked us to do a project about what families think about going to visit them.

- We work at the University of York. Our names are Veronica, Bryony, and Sue.

- We are asking families who are seeing Dr. Walker or one of his team to take part in our project. You do not have to if you don't want to.

- We want to know what you find helpful, what you don't like about it, and what people in Dr. Walker's team could do to help you more.

- On the next page, you can find out more about our research project. Please take time to read it. Talk to others about it if you want.

Who is writing to me?

We are Veronica, Bryony and Sue. We work at the University of York.

Veronica Greco

Sue Clarke

Bryony Beresford

What are you trying to find out?

We want to find out what children, young people and their families like or don't like about going to see Dr. Walker and his team. We are doing this so that they can do a better job at helping children and young people.

What will I have to do?

If you would like to take part in our project one of us will come and visit you. If you like the person can be someone who uses British Sign Language. You can also choose to have someone with you (perhaps a parent, teacher, friend, brother or sister) when we visit. We will ask you about the good and bad things about going to see Dr. Walker and your ideas of how things could be made better. We think our visit will last about half an hour. We won't tell anyone what you have said if you don't want us to. We would also like to visit you again when you stop visiting Dr. Walker and his team to find out how it has been.

Do I have to take part in the project?

No, you do not have to take part. It is up to you.

What happens next?

When you visit Dr. Walker or one of his team, someone will talk to you about this research project. If you decide to take part we will get in touch with you and your parents. When we get in touch we will answer any questions you have. We will also make a time to visit.

Any questions?

If you have any questions about taking part please get in touch with Veronica (email: vg3@york.ac.uk) or Bryony (email bab3@york.ac.uk). Social Policy Research Unit, University of York, York, Y010 5DD. Telephone: 01904 321950

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A RESEARCH PROJECT ABOUT

GOING TO VISIT DR. WALKER'S TEAM

Consent Form for Young People over 16 years

I have read the information leaflet and understand what it says.

☐ Yes ☐ No

I have talked to someone from Dr. Walker's team about this research.

☐ Yes ☐ No

I understand that what I say to the researchers will be private and my name will not be mentioned in the research report.

☐ Yes ☐ No

I understand that it is my choice to take part in the research and I can leave whenever I want.

☐ Yes ☐ No

I am willing to take part in this research

☐ Yes ☐ No

Name ……………………………… Signature …………………………

Date ………………………………

Name of staff member ……………………..… Signature …………………

Date …………………………………………

A PROJECT ABOUT GOING TO SEE DR. WALKER'S TEAM

Assent Form for Children and Young People

(Note: the parental consent form has to be completed too)

Please tick (✓) either Yes or No

Do you understand what this project is about?

☐ Yes ☐ No

Have you asked all the questions you want?

☐ Yes ☐ No

Do you understand it's OK to stop taking part at any time?

☐ Yes ☐ No

Are you happy to take part?

☐ Yes ☐ No

Your name…………………………………… Date………………………….

The professional who explained this project to you must sign their name here.

Print name……………………………… Signature…………………………..

Date……………………………..

Hello!

My name is Hilary. This is my photo.

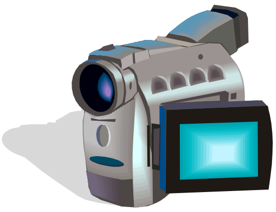
I am deaf too.

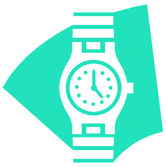
I am coming to see you on ____.

I want to find out what you think about going to the York Deaf Child and Family Service (YDCAF).

We will do a little bit of writing or drawing and play some games with cards. There are no right or wrong answers. When I visit it's OK to ask to stop, or to have a break.

I will bring a video camera but we don't need to use it if you don't want to.





My visit will be about 30 minutes.

I am looking forward to meeting you.

From

Hilary

Appendix 10

Topic guides for interviews with children and young people

Topic guide for Time 1 interview

Topic guide for Time 2 interview

TOPIC GUIDE FOR INTERVIEWS WITH CHILDREN AND YOUNG PEOPLE – TIME 1

1. CONSENT

- Check child has seen a copy of the information sheet. (Have a copy to give to them, if necessary).
- Check to see if they have any questions about taking part.
- Ask if the child is still happy to be interviewed.
- If yes, complete the consent form with them.

2. HOW TO SAY STOP OR I DON'T WANT TO ANSWER THAT QUESTION

- Explain it's OK to stop the interview or not answer a question.
- Give the child the 'Stop' and 'No thanks!' cards. Explain they can use the 'Stop' card to end the interview, and the 'No thanks!' card to show they don't want to answer a particular question.
- Rehearse with child how to use them.

3. WARM-UP: MAKING A MAP OF PEOPLE WHO HELP THEM

- Ask child to draw a **picture of themselves or write their name** in the middle of a piece of paper.

- Then ask them to **add to the sheet the names of people who help them when they are having a bad day, when they're feeling upset etc...** (This could include parents, brothers/sisters, friends, teachers, other school staff, *possibly* the person at the clinic they are attending).

- **If the child prefers you can do the writing/drawing for them.**
- **This is just a warm up exercise – you don't have to spend long on it.**
- **There is an example of what a 'map' might look like in your file.**

4. BASIC QUESTIONS ABOUT USING THE SERVICE

- **Find out about …**
    - Name of clinician they see (usually just one person but may be more).
    - Where they see the clinician (home; school/college; at the service).
    - When they started seeing the person
    - How they communicate with each other
    - Mum and/or dad's involvement
    - Do they use the telelink? (York and Dudley only)

- There is a **sheet with different shapes** on it which you/the child can use to record their answers. (You could use that sheet as prompt later in the interview.)
- You have **photos** of the staff and building to use here.
- It doesn't matter if they can't answer these questions accurately. The main purpose is to warm up to talking about using the service.

5. EARLY EXPERIENCES OF USING THE SERVICE

- **We want to find out about the child's experiences so far of using the service. The sorts of things we are interested in hearing about are:**
  - Feelings about going to clinic/seeing the clinician for the first time
  - Understanding of why they are using the service
  - What typically happens when they see the clinician.
  - Feelings about the clinician: Do they like them? Will they be able to help? etc..
  - What's the place/room like? (e.g. comfortable, relaxing, private)
  - Good things so far?
  - Bad things/things not enjoyed?

- We expect children to differ a lot in their understanding of why they have been referred to the service.
- Some children you interview might only have had one or two appointments, others might have had a few more sessions.
- Children will differ in how much they want to tell you.
- Some children might enjoy telling their story to the camera ('Big Brother' style!)
- You might want to use the **photos** and the '**service sheet**' they filled in topic 4 to prompt your conversation.

6. THE CHANGES THE CHILD WANTS TO HAPPEN AS A RESULT OF USING THE SPECIALIST MENTAL HEALTH SERVICE.

- This is an exercise to show the changes the child wants to happen as a result of using the specialist mental health service, and whether they think the service will be able to help them. It uses cards with statements about feelings.

- **Instructions:**
  - **Lay the cards out** in front of the child, including some blank cards and **check they understand them.**

  - **Ask child to choose cards which show the changes they want to happen to them** (as a result of using the specialist mental health service).

  - If they have **other problems/concerns, write them on the blank cards.**

  - **For each card** the child has chosen (and any blank cards they have added):
    - **Explore** why they have chosen the cards.
    - Ask if they think the clinician **will be able to help** make these things happen?
    - Ask **why** child thinks the clinician will/will not be able to help them.

- At the end of the interview record the cards the child chose on the **Interview Record.**

7. WHAT IS IMPORTANT ABOUT THE PEOPLE & PLACES THAT HELP DEAF CHILDREN AND YOUNG PEOPLE?

- Here we want to find out their views on an 'ideal' service. This might not necessarily be their experience at the moment. We use a card sorting exercise to help the children and young people think about this.

Instructions

- **Warm up:** You might want to begin this with asking the child to briefly describe their ideal playground, sports centre, shopping centre, bedroom etc. etc... This might help them to understand that we want to find out their ideas about an ideal service.

- Ask the child to **imagine a new centre to help deaf children/young people was being set up.** The people running the centre wanted to know what it should be like.

- Using the three labelled circles, ask child to **sort the cards into three piles:** 'very important', 'not important', 'not sure'.

- Ask if the child wants to **add any more ideas about what is needed to make an excellent service for deaf children and young people** – use the blank cards.

- Make sure the child understands **we want to know their ideas about an ideal service. This might not be their current experience.**
- At the end of the interview record how the child sorted the cards on the **Interview Record.**

8. 'Cool down'

- That's the end of my questions.
- It's been great to find out what you think.
- Have they enjoyed the interview? Any bit of the interview they've particularly liked or found difficult?
- Would like to come back to see them again in a few months time to find out how things are going? OK?
- Do they have any questions?
- Thanks!

Materials
Topic guide
Information sheet
Consent form

‘Stop!’ and ‘No thanks!’ cards
A3 paper for ‘people who help me’ map
A4 ‘service’ sheet
‘What I want to happen’ cards
‘Ideal service’ cards
Three coloured circles (‘very important’, ‘not important’, ‘not sure’)

Felt tips
Pencils
Rubber
Pencil sharpner

Interview Record

Camera
Tripod
DVDs
Timer

TOPIC GUIDE FOR INTERVIEWS WITH CHILDREN AND YOUNG PEOPLE – TIME 2

BEFORE THE INTERVIEW

- **Read the notes/summary** of the first interview to remind yourself of what the child talked about. In particular, their feelings about going and what they wanted out of going.
- **Take to the interview a list of their responses** to items 6 of the Time 1 topic guide (the changes the child wants to happen as a result of using the specialist mental health service) – these were recorded on the interview record.

THE INTERVIEW

As with the first interview, please feel free to adapt the topic guide and depth of questioning to the child's abilities.

1. Consent etc…

- **Remind** that the project is about finding out how families find going to see *Dr …../use XX service*. This is because the doctors and other people want to make sure they give deaf children and young people the sort of help and support they want.
- **Explain** this will be your last visit.
- **Remind** that what the child tells you will be private and you won't tell anyone. But it's OK if they want to tell someone what the interview was about.
- **Ask** if the child is still happy to be interviewed.
- If yes, **complete** the consent form with them.

2. How to say stop or I don't want to answer that question

- **Explain it's OK** to stop the interview or not answer a question.
- Give the child the 'Stop' and 'No thanks!' cards. Explain they can use the 'Stop' card to end the interview, and the 'No thanks!' card to show they don't want to answer a particular question.
- **Rehearse** with child how to use them.

3. How they have used/are using the service

- **Remind** the child about how they were using the service when you last visited them. Use the photos of staff and the sheet with shapes they filled in at the last interview.

  An example script: "Last time I came to visit you told me you were seeing (clinician) every week (e.g.) on Thursday. You saw him at (place). Also, your mum and dad would come with you. You would communicate with an interpreter. I asked you talked about what it was like to go to see (name of clinician) and whether you liked seeing (clinician) from (service name)."
- **Ask** if there have been any changes in how they use the service or who they see. You could use the photos to check who they have seen.

- **Record** any changes on the ‘service sheet’ using a different colour pen (or some other way of showing the information is new).
- If applicable, **ask** if child knows why things changed (for example, the reason why seeing another person from the team etc.)

4. Views about the people they see

- **Show the photograph(s)** of the people in the team they see
- **For each person explore the following:**
  - **Ask how many marks** they would give the person out of ten (in terms of how good at their job).
  - **Ask why** they gave that score
    - Positive things:
      - What did you like about him/her? Ask for examples (e.g. behaviour, appearance, attitude, skills)
      - What they were good at? Ask for examples
    - Negative/ not-so-good things:
      - What didn’t you like about him/her? Ask for examples.
      - Any things they were not so good at? Ask for examples

5. Feelings about using the service

Some children told us about how they felt when they started using the service – remind them what they told you at the first interview. Otherwise ask if they can remember how they felt (e.g. nervous, worried, embarassed etc).

- Feelings about going now.
  - If their feelings have changed, what has helped to change that feeling? (Note: this could be a positive or negative change). For example: things the person has done to make them feel relaxed; just getting used to it? OR, if more negative, things the person has said/done etc.

6. Outcomes: things they wanted to change

At the first interview we used a set of cards which showed possible changes children might want to make in their lives or how they were feeling. We asked the children to choose the cards that were true for them. We used blank cards if there was not an appropriate card.

- Show the child the cards he/she chose one year ago.
- In the **“How I Feel Now” booklet,** stick one of the card on a page:
  - Ask child to mark on the scale how they are feeling now compared to when they started using *the service/seeing Dr XX*.
  - If <u>not feeling better</u>:
    - Ask **why** child thinks the service/person did not/could not help them
  - If <u>feeling better</u>:

        - Ask **how** the person helped them (e.g. having someone to tell about problems, getting the right medicine, giving ideas how to manage difficult situations or how to deal with their feelings etc…)
        - If the child is seeing more than one person from the team, check if just one if the people or both have helped them.
        - For those not yet discharged: ask if they think they will continue to get better the longer you keep seeing the person/using the service?
    - **Repeat this process for all the cards** the child chose at the Time 1 interview.

7. Unexpected positive changes

- Show the child the remaining cards.
- Ask if there have been **other things shown on the remaining cards** where the person/using the service has helped.
- If the child chooses some new cards stick them in the "How I Feel Now" booklet too
    - Ask how the person helped them and how they are feeling now compared to when they started seeing *Dr X/using the service*.
    - If the child is seeing more than one person from the team, check if just one of the people or both have helped them.

- Check if **any other positive changes not shown on the cards:**
    - any other **good things which have happened** because they have been seeing the person/using the service.
    - **anything else they like** about using the service/seeing the person

8. Negative effects of using the service

- Ask if there have been any not-so-good things about seeing person/using the service.
- If child says yes: ask them to describe/give examples. (E.g. missing school; being teased at school for using the service; child or parents feel upset because the sessions bring up memories/emotions, etc)

9. Communication

a) Method of communication

- Ask how child most prefers to communicate.
- Ask child how they communicated with people in the service, including any changes over the course of using the service?
- Is this the way they wanted to communicate in this particular situation?
- If not, ask how they would have preferred to communicate?
- Ask who chose or decided how they would communicate (eg. child, professional, shared decision.

- <u>If child uses BSL:</u> How many marks out of ten for signing would you give the person/people you saw?

b) How well it worked

- Where there ever any problems/difficulties with understanding each other?
    - Ask if child can give example(s).
- What would have made communication better or easier.

c) Experience of using interpreters (if applicable)

- Overall, was having an interpreter a good thing or a bad thing? Ask for reasons (or examples) for response.
- Any ways using an interpreter could be improved?
    - E.g. interpreter skills, using the same interpreter, seating/room layout

10. Involvement of parents

a) Deciding about parental involvement

- Ask whether child saw the person alone or with parents.
- Who was involved in deciding whether or not parent(s) were present:
- Did the child want to have a choice?
    - If child not involved in making decision about parents' involvement, ask what child would have preferred (i.e. mum/dad present or seeing person alone).

b) Experiences

- <u>If mum/dad was present</u>
    - What was good about having mum/dad there
        - If possible, ask for examples
    - What wasn't so good about having mum/dad there? Were there times when child wished mum/dad wasn't there?
        - If possible, ask for examples.

- <u>If mum/dad NOT present</u>
    - What was good about seeing the person without mum/dad being there?
        - If possible, ask for examples.
    - What wasn't so good about not having mum/dad there? Were there times when child wished mum/dad were there?
        - If possible, ask for examples).

11. Experience of Service Questionnaire

- Ask the child to fill in the questionnaire.
- It's OK to help them with it if they don't understand the questions.

- It is not necessary to ask the reasons for each response, **BUT** do ask the reason why a child chose a particular answer if the question concerns an issue that you haven’t already covered in the interview.
- If the child has been seeing more than one child ask if they would complete a second questionnaire (but only the questions that refer to the person, not the general questions about the service).

12. Conclusion

Was this interview OK?
Check whether they have any questions.
Was there a part you enjoyed more?
Was there a part you did not enjoy?
Thank you and remind that this is your last visit.
Remind that in the autumn we will send them a short report of what our research found out.
Check again whether they have any questions and thanks again.

Appendix 11

Sample of modified version of the Experience of Service Questionnaire for completion by children and young people

The person I see...

My name…………………………..

Date………………………

Please tick (✓)

	All the time	Sometimes	Never	Not sure
1) Is it easy to tell ________ about how you feel?	🙂	😐	🙁	**?**
2) Do you think ________ knows how to help you?	🙂	😐	🙁	**?**
3) Can you talk to ______ without feeling embarrassed?	🙂	😐	🙁	**?**
4) Do you think ________ keeps private what you tell him?	🙂	😐	🙁	**?**
5) Does _______ pay attention to you or does he pay attention only to your mum or dad?	🙂	😐	🙁	**I see Peter without Mum /☐d (✓)**

	Yes	A little	Not at all	Not sure
6) Did ________ explain how he was going to help you?	🙂	😐	🙁	**?**
7) Do you like the room/building where you meet ________?	🙂	😐	🙁	**?**
8) Are you happy with the time of the appointment when you usually see ________?	🙂	😐	🙁	**?**
9) Has Peter _______ helped you?	🙂	😐	🙁	**?**
10) Do you think ______ understands about deaf children and young people?	🙂	😐	🙁	**?**
11) I see Peter _______ at Home/Clinic/School (✓ the correct one) This is the best place to see him.	**Yes** 🙂		**No** 🙁	**?**
12) If a friend needed the same sort of help you needed, do you think they should see someone like ________?	**Yes** 🙂		**No** 🙁	**?**

Thank you!

Appendix 12

Topic guide for interviews with young people who had used the telelink

Topic guide for Telelink children and young people

Basic factual information

Give the young person a summary from Sara (e.g. dates used, frequency of telelink and face to face sessions etc.) and then they would pick up telling us about a typical session.

Make sure you cover:

- What happened between the moment they were collected by school staff to go to the telelink room and the actual link-up?
- Presence of staff
    - When did school staff leave the telelink room?
    - Were they waiting outside/nearby?
- How did the session with Sara typically start off?
- At the end of the session
    - How did the session finish?
    - Leaving the room and going back to other activities
        - Procedures
        - How did they feel when the session ended?

Procedures and experiences

- Recollection of decision process
    - Was a choice offered between the hearing clinician and Sara?
        - If yes, how did this occur?
    - If they were offered choice, what were the reasons for choosing the Deaf clinician?
    - In hindsight, are they happy with that decision?
        - If yes, investigate why?
        - If not, investigate why not?

- What preparation and/or information did they receive prior to the first session?
    - Were they satisfied with the information?
    - Do they have any ideas or suggestions regarding improvements?

- Expectations
    - What did they expect it to be like?
    - Was the telelink better or worse than expected?
    - Why?
- Initial/first impressions
    - What were their first impressions about the telelink after their first appointment?
- Getting used to it
    - Was there anything about the telelink sessions that was difficult to get used to?
    - Was there anything Sara did that helped them get used to it?
    - How many sessions before it felt natural and they were not inhibited by the screen?
    - Would anything else have helped them get used to the telelink?
    - Need for additional support from service or school staff
        - Was it ever an issue?
        - How this was dealt with
        - Ideas/suggestions about improving this part of the process
- Experiences of technology
    - Quality of picture
    - ‘Freezing’ of picture
    - Control over the technology: zooming in or out, managing when it froze
- Dealing with distress
    - Were they ever highly distressed during a telelink session?
    - How was it dealt with?
    - Were they happy about how this was dealt with?

Views/opinions

- Positive things about using the telelink
    - E.g. access to a Deaf clinician, access to expertise, ‘distance’ helped with being able to open up
- Difficulties experienced
    - E.g. relationship hard to establish, communication difficult (e.g. seeing facial expression, etc.), hard to feel relaxed, inhibiting
    - Ideas/suggestions about how to overcome these difficulties
- Comparison between telelink and face to face sessions
    - Which do they prefer?
        - Why?

    - Explore differences between telelink and face to face meetings (e.g. in terms of what the session covered/dealt with, how it felt during and after the session, quality of the relationship with Sara)
    - How decisions are made regarding timing and frequency of face to face sessions
    - Were they satisfied with the frequency of telelink versus face to face sessions?
- How could the telelink be improved?

Conclusion

- Would you use the telelink again?
- Would you recommend it to a friend?
    - If yes: What would you say to persuade them and what would you warn them about?

Appendix 13

Topic guide for Time 2 interviews with parents

TIME 2 INTERVIEWS WITH PARENTS

1. Preliminaries

- Consent process
- Remind re purpose of interview

2. Current situation re the specialist service

- Therapy on-going or discharge
    - If ongoing: do they know how much longer their child will be using the service?
    - **When were they discharged (if applicable)**

3. Review of how used service

- Confirm staff they worked with
- How the service worked with the family (e.g. joint sessions with child, sessions alone with clinician, mainly only child saw clinician etc.)
- Where family/child saw the clinician
- Any changes re this over time?

4. Involvement of parents in sessions

- Who was involved in deciding whether or not parent(s) were present during session?
    - If parent not involved in making decision about involvement, ask what parent would have preferred (i.e. involved / not involved)
    - Views on whether their level of involvement was appropriate and worked well
    - Any ways would have wanted to change how much involved

Note: responses to this section will guide you as to which of the following sections are relevant.

5. The journey to the appointment

- How far did they have to travel to attend appointments?
    - How did they get there?
    - How long did it take to get there and back
- Difficulties encountered making those journeys
- Estimate of travel costs.
- Other costs: time off work, child care etc …
- Suggestions of how this aspect of using the service could be improved

6. Appointment times

- Views on the frequency **and** length appointments
    - Suggestions re improving
- Did you ever miss appointments or forget?
    - If yes explore why
- Could anything be done to prevent missed appointments?

7. Communication

- How was communication **managed?** (note, this might be because of child/parent using BSL and/or family not speaking English)

- **Satisfaction re ensuring the child/the parent fully involved**
  - **If happy, what did the clinician/interpreters do to make it work**
  - **If not happy, what were the problems**
  - **Things they could have done better?**

- If used **an interpreter….?**
  - Did parent mind having the interpreter there?
  - Did they find the interpreter's presence influence the session?
  - Any problems with the interpreter?
    - Continuity (i.e. a different interpreter each time – is that an issue?)
    - Interpreter skills re understanding/communicating
    - Interpreter showed lack of understanding of mental health issues.

- Any views on whether all **staff** should be fluent in BSL and hence remove the need for interpreters

- Any views on how the use of interpreters could **be improved?**

8. Review of desired outcomes held at time of referral

- Summarize **parents' desired outcomes** from Time 1 interviews for child, self and other family members

- Taking each in turn, **were these desired outcomes achieved?**
  - If yes, **how achieved?**
    - Contribution/input of service/clinician
    - Other factors leading to an improvement

  - If not, views on **why weren't they met?**
    - Service/clinician factors (e.g. skills/competencies),
    - Other factors meaning outcomes weren't achieved (for example, unrealistic expectations, non-compliance)

9. Other outcomes

- Were there any **unexpected positive outcomes/things they found helpful** about using the service for themselves, child or other family members? (for example, other issues resolved, improvements in other areas of child's life, parental knowledge/understanding/skills)

- Any **negative**, **unexpected outcomes** of using the service for themselves, child or other family members?

- Any **unmet needs** (for self, child or other family member) which feel the service could have helped with?

10. Satisfaction with the service

- Views about **the clinician**
    - Did they like him or her
        - Positive things (ask for examples)
        - Any thing didn't like (ask for examples)
        - Did their view of the person change over time

- **Confidence** in clinician's ability to help the child/family
        - **What made them feel confident/not confident**

- **Whether parent felt listened** to and believed
        - Views on why/why not (ask for examples)
        - for time alone with the clinician

- **Views on how their experience of attending** the service could be improved**.**

11. Views on child's experience

- Does the **child tell parent** about using the service
    - What sorts of things?

- Did their child appear to **like going** to clinic/seeing clinic staff?
    - Any views on why/ why not?

- Anything particular to tell us about **how child was** before or after sessions?
    - Views on reasons for child's reactions.

- Views on whether child was properly involved in sessions, felt **listened to etc.**

- Suggestions re how child's experience of using the service could be **improved.**

12. Information

- Views on the **quality of information** provided by the service about……
    - The service
    - Appointment times etc..
    - How the child was being helped / what the clinician was doing with the child
    - Their child's progress
    - What, if anything, they should be doing to support the therapeutic process
    - If discharged, the timing of that and post discharge support
    - Any suggestions re improving information and keeping parents informed?

13. Liaison with other services involved with child

- Parents views on whether the service has liaised with other services (e.g. health, education/school, social care, voluntary organisations) involved with the child
    - Details of service(s) liaised with
        - Satisfaction re how the liaison has worked out
    - Any services parent thinks should have been liaised with but hasn't happened
        - Views on why liaison is important

- Further views on how the service could improve liaison/joint working with other services which support the child.

14. Where the child/family saw the professional(s)

- Views on **suitability** of the room for the sessions
    - Good aspects
    - Problems
    - How could be improved

- The general environment at Hightrees/The Elms/Limetrees
    - Pleasant/unpleasant waiting area?
    - Child / deaf friendly
    - Reception staff
    - Views on how could be **improved**

15. Use of family support worker (if not already covered)

- In addition to therapist, did they meet or work with the family support worker (Emma or Peter)?
    - In what role
    - **Effect** of working with family support worker for the parent, child, the family as a whole
    - Views on how to **improve** this aspect of the service

16. Post-discharge history and support (if they have already been discharged)

- Were they happy about the timing of the discharge?
- Satisfaction re how the discharge was handled?
- Support provided on discharge – to child/family, school etc.
- Any changes in child's condition post discharge/have improvements been maintained?
- Understanding about re-accessing the service (e.g. fast track, re-referral, awareness of how long would have to wait)
- Views on how discharge process could be improved

17. Comparison with other places/services they have gone for help or support for themselves or their child

- How does this service compare to other support services you have used?
    - What extra does it/ does it not offer

18. Improving the service or extending what the service offers families

- Anything more to say about the service you would change or do better?
- Anything else you think the service should provide to help children and families?

19. Ask parent to complete ‘Experiences of Service’ and Strength and Difficulties questionnaire.

20. Close

- Any questions/further comments
- Thanks
- Remind that summary of research findings will be sent to all participants

Appendix 14

Experiences of Service Questionnaire (parent version)

CHI
COMMISSION FOR HEALTH IMPROVEMENT

EXPERIENCE OF SERVICE QUESTIONNAIRE

Day services (Parent or Carer)

Please think about the appointments you, your child and/or your family have had at this service or clinic.

For each item, please tick the box that best describes what you think or feel about the service (e.g. ☑).

	Certainly True	Partly True	Not True	Don't know	
I feel that the people who have seen my child listened to me	☐	☐	☐	?	1
It was easy to talk to the people who have seen my child	☐	☐	☐	?	2
I was treated well by the people who have seen my child	☐	☐	☐	?	3
My views and worries were taken seriously	☐	☐	☐	?	4
I feel the people here know how to help with the problem I came for	☐	☐	☐	?	5
I have been given enough explanation about the help available here	☐	☐	☐	?	6
I feel that the people who have seen my child are working together to help with the problem(s)	☐	☐	☐	?	7
The facilities here are comfortable (e.g. waiting area)	☐	☐	☐	?	8
The appointments are usually at a convenient time (e.g. don't interfere with work, school)	☐	☐	☐	?	9
It is quite easy to get to the place where the appointments are	☐	☐	☐	?	10
If a friend needed similar help, I would recommend that he or she come here	☐	☐	☐	?	11
Overall, the help I have received here is good	☐	☐	☐	?	12

PLEASE TURN OVER...

What was really good about your care? 13

Was there anything you didn't like or anything that needs improving? 14

Is there anything else you want to tell us about the service you received? 15

Child's age: ____________ Child's gender: Female ☐ Male ☐

Child's ethnicity: White ☐ Black/Black British ☐ Asian/Asian British ☐

Mixed ☐ Other ☐

Is your child registered disabled (e.g. hearing-impaired)? No ☐ Yes ☐

If you don't want to take part, please tick this box ☐ and return the blank questionnaire in the envelope provided.

THANK YOU FOR YOUR HELP

Now place this form in the envelope provided and put it in the box marked CHI in the reception

For administration purposes

Trust: ______________________________

Service: ____________________ Code: __________

Tier: __________________ DB No: ______________

Appendix 15

Topic guide for interviews with key referrers

Interview schedule for key referrers

Background of interviewee

Name
Job title
Name of institution where they work
How long they have been working there
How long they have been making referrals to the service
Have they made referrals since before or after 2002 (inception of NSCAG pilot project)?
How many children have they referred to the service?

Referral to the service- procedure

Procedure for referral
Time frame for referral
Do any glitches/problems occur during/after referral? (e.g. hard to make contact with parents, parents don't consent to child's treatment, parents hesitate to consent due to stigma, etc.)
How does contact with parents occur? (e.g. telephone parents, arrange an appointment to visit them, see them in person etc.)
Have any children they referred to the service been discharged yet?
Does the service accept every referral or are some not appropriate?
If some are not appropriate, ask to give examples
What happens if a case is not appropriate? (e.g. directed to another service etc)

Contact with service staff

Within their school/agency is there a room allocated to visits by service staff? If yes, ask to describe
Do they have regular meetings with the service staff?
If not, explain nature of contact with service staff
If yes, how often do meetings occur? Ask to elaborate on nature of meetings, frequency and location

Training and interventions with staff and parents

Do service staff conduct interventions with parents? (e.g. training and educating parents about deafness?)
If yes, ask to describe.

Do service staff conduct interventions to train up staff in the school/workplace of interviewee?

Effects of the service on the children

Have you seen a difference in the children since referring them to the service?
What would happen to these children if this service didn't exist?
Before this service was available, what mechanisms were in place to deal with these children? (e.g. educational psychologist, social worker for the deaf)
In hindsight, were those mechanisms satisfactory?

Effects of the service on their practice

Effects of the mental health service on the school/service/agency they work for (e.g. behaviour of the children has improved, staff are less stressed because they know they can count on the service, etc.)
Has contact with the service changed your practice in any way?

Interviewee's evaluation of the service

What are the advantages of this service compared to generic CAMHS? (e.g. communication skills, expertise, knowledge, etc)
How satisfied are you with the service?
Have you encountered any problems with the service?
What are your views about the skills/expertise of the staff members?
What improvements do you think should take place in this service?
If they have made referrals to the service since before 2002, what difference have they seen in the service since before and after the inception of the NSCAG pilot project? (Prompts: speed of referral, accepting more complex referrals, wider geographical spread, provision of more interventions, BSL staff, skills and expertise, better outcomes for children and young people)

Future of the mental health service

How do you see the service developing in the future?

Appendix 16

Materials used in survey of referrers

Questionnaire used in survey of referrers

Covering letter

Information sheet

THE UNIVERSITY of York

SPRU
SOCIAL POLICY RESEARCH UNIT

QUESTIONNAIRE FOR PROFESSIONALS REFERRING TO THE WEST MIDLANDS DEAF CHILD AND FAMILY SERVICE

This questionnaire concerns your experiences of referring one or more children to the West Midlands Deaf Child and Family Service which is led by Dr Rob Walker and based at The Elms Health Centre, Dudley. If you have referred more than one child to this service, and/or have been referring over a number of years, please report your overall impressions of the service. There are opportunities in the questionnaire to report on the consistency of the service, and any changes you have observed over the period in which you have used the service. Please use continuation sheets if insufficient space is provided on the questionnaire.

1. About you

Your name: __________________________ Profession: ______________________

Place of work: ____

2. In what ways have you used the West Midlands Deaf Child and Family Service?

☐ Referral of individual children/families for assessment only

☐ Referral of individual children/families for assessment and therapeutic work

☐ Preventative work with children/families

☐ Consultation/advice with regard to you/ your organisation's own practice

☐ Staff training

☐ Other (please state):

____

____

____

3. What have been your reason(s) for referring a child/family to the service?

☐ Family relationship problems

☐ Other (please state):

☐ Emotional/behavioural problems

____

☐ Mental health problems

____

☐ Child protection issues

____

☐ Educational assessment

☐ Diagnosis of other conditions (e.g. autism)

4. **Do you refer deaf children with mental health problems to any other services?** ☐ Yes ☐ No

If yes, please tell us which services you also refer to:

____

____

_____

5. **These statements are about your experiences of using the West Midlands Deaf Child and Family Service. Use the scale to indicate your view. Please circle not applicable (n/a) if a statement is not applicable to your experience of using the service.**

I know the sorts of children/difficulties that are appropriate to refer to West Midlands Deaf Child and Family Service.	*Agree* **1 2 3 4 5** *Disagree*	n/a
The period of time between referral and assessment is/was acceptable.	*Agree* **1 2 3 4 5** *Disagree*	n/a
The period of time between appointments is/was appropriate.	*Agree* **1 2 3 4 5** *Disagree*	n/a
The service is/was flexible in terms of where children/families can be seen.	*Agree* **1 2 3 4 5** *Disagree*	n/a
Children/families find travelling to appointments difficult.	*Agree* **1 2 3 4 5** *Disagree*	n/a
Staff value(d) my expertise and knowledge of the child(ren)/family(ies) I refer(red).	*Agree* **1 2 3 4 5** *Disagree*	n/a
It is/was easy to contact staff to discuss possible referrals or on-going cases.	*Agree* **1 2 3 4 5** *Disagree*	n/a
Staff work/ed hard to engage families.	*Agree* **1 2 3 4 5** *Disagree*	n/a
I am/was happy about the amount and quality of information staff pass(ed) on to me about progress with/outcomes of a case(s).	*Agree* **1 2 3 4 5** *Disagree*	n/a

At discharge, the service ensures/d that support or other resources are/were in place to maintain the changes or improvements achieved.	*Agree* **1 2 3 4 5** *Disagree*	n/a
The service is able to provide an appropriate range of therapies/interventions.	*Agree* **1 2 3 4 5** *Disagree*	n/a
The West Midlands Deaf Child and Family team is made up of an appropriate mix of different professional groups.	*Agree* **1 2 3 4 5** *Disagree*	n/a
The presence of deaf staff is an important feature of the service.	*Agree* **1 2 3 4 5** *Disagree*	n/a
Generic CAMHS are not equipped to meet the mental health needs of deaf children and young people.	*Agree* **1 2 3 4 5** *Disagree*	n/a

6. These statements are about the skills/expertise of staff working at the West Midlands Deaf Child & Family Service. Use the scale to indicate your view.

Ability to communicate with a child using their preferred method of communication.	*All staff competent* **1 2 3 4 5** *No staff competent*
Understanding of the cognitive & socio-emotional development of deaf children.	*All staff competent* **1 2 3 4 5** *No staff competent*
Understanding of the way deafness may affect language/communication development.	*All staff competent* **1 2 3 4 5** *No staff competent*
Understanding of the psychological/psychiatric issues associated with deafness.	*All staff competent* **1 2 3 4 5** *No staff competent*
Understanding of Deaf culture.	*All staff competent* **1 2 3 4 5** *No staff competent*

7. For the children/young people you have referred to the West Midlands Deaf Child and Family Service, how satisfied have you been with the outcomes of them using the service?

Very satisfied **1 2 3 4 5** *Very dissatisfied*

8. What factors do you think most influenced these outcomes? (Please tell us about both positive and negative features of the service.)

Positive:

Negative:

9. **If you have referred more than one child/young person to the West Midlands Deaf Child and Family Service, has the quality of the service been consistent across all the children/young people?**

Quality consistent **1 2 3 4 5** *Quality inconsistent*

Comments:

10. **Has the quality of the service changed over the period of time you have been referring to it?**

☐ Improved ☐ No change ☐ Deteriorated

Comments:

11. **Has your contact with the West Midlands Deaf Child and Family Service changed or influenced your/your organisation's practice in any way?**

☐ Yes *(please describe in the box below)* ☐ No

12. Finally, what would you recommend in terms of improving or developing this service, and mental health services for deaf children in general?

Improvements or developments to the West Midlands Deaf Child and Family Service:

Improving or developing mental health services for deaf children in general.

Thank you very much for taking the time to complete this questionnaire.
Please return this questionnaire in the s.a.e. envelope provided.

Veronica Greco (vg3@york.ac.uk) SPRU, University of York, York YO10 5DD

THE UNIVERSITY of York

S|P|R|U

Address

30 January 2007

Dear

The Department of Health is currently funding the University of York to conduct a research project to evaluate specialist mental health services for deaf children. The West Midlands Deaf Child and Family Service led by Dr Rob Walker and based at The Elms Health Centre, Dudley is part of this evaluation. An information sheet about the project is enclosed

One of the main purposes of this project is to inform future developments of specialist mental health services for deaf children and young people.

Your name has been passed onto us by the West Midlands Deaf Child and Family Service as one of the professionals who has referred to this service. We are asking everyone who has made a referral to this service to complete a questionnaire about their views and experiences of using this service.

A copy of this questionnaire is enclosed. We would be grateful if you would take the time to complete it. It should take no longer than 15-20 minutes to complete. If you would prefer to complete it electronically, please email Teresa Frank (tjf3@york.ac.uk).

[*Please note:* we are asking that just one questionnaire is completed per organisation. If several people within your organisation are involved in referring children to this service, please nominate one person to complete it. It is, however, quite acceptable for them to consult with others about the responses entered onto the questionnaire.]

We look forward to hearing from you.

Thank you.

Yours sincerely

Dr Bryony Beresford
(Senior Research Fellow)

Dr Veronica Greco
(Research Fellow)

Sue Clarke

THE UNIVERSITY of York

SPRU
SOCIAL POLICY RESEARCH UNIT

AN EVALUATION OF THE NATIONAL SPECIALIST MENTAL HEALTH SERVICE FOR DEAF CHILDREN

What is the project about?

Prior to 2004 the only centre providing specialist mental health services to deaf children and young people was the Corner House service in London. This obviously posed considerable problems with regard to access to this service by families living outside the London area. In response to this, in 2004, the National Specialist Commissioning Advisory Group (NSCAG) of the Department of Health set up a pilot project to extend specialist mental health services for deaf children by establishing two ‘satellite’ services in York and Dudley. One of the key features of this extended service is the use of video-conferencing. This is used to allow deaf children who use BSL direct access to clinicians who are highly skilled in BSL, and to provide clinical supervision to the teams working in the satellite services as they developed their skills in working with deaf children and their families. This evaluation aims to assess the impact and effectiveness of this pilot project and will draw on the views and experiences of all stakeholders.

Who is doing the study and how is it funded?

The study is being conducted at the Social Policy Research Unit at the University of York, by Veronica Greco, Bryony Beresford, and Sue Clarke. It is funded by the Department of Health.

Why do you want me to help?

The project seeks to explore the ideas and experiences of professionals, children, and parents. We are asking all professionals who have referred children to the service to complete a questionnaire.

What would I have to do?

Please fill in the enclosed questionnaire. It should take you no longer than 20 minutes to fill in. The questionnaire covers: your awareness of and views about what the service can provide; experiences of accessing the service; views about the impact of the service on service users and on your own practice; comparisons of the service with other services; suggestions as to how the service could be changed or improved. The completed questionnaire can be returned to us using the enclosed pre-paid envelope.

Do I have to take part?

You do not have to take part. Participation in this research is entirely voluntary.

What will happen to the information?

All information will be treated in confidence. No names or identifying information will be used in any reports of the study. The information from staff, children and parents will be collated together in a report documenting the findings of this evaluation. You will receive a summary of the report.

Further Information

If you would like further information on the study, please contact Veronica Greco (vg3@york.ac.uk,) or Bryony Beresford (bab3@york.ac.uk) at the Social Policy Research Unit, University of York, Heslington, York YO10 5DD. Telephone: 01904 321950.