

Standard paragraphs for Positive Support project

For individual researcher's presentations:

This work is being carried out as part of the 'Positive Support in the Lives of Deaf Children and their Families' project; a collaboration between the University of Manchester and University College London, in partnership with Deafness Research UK (the Hearing Research Trust) and the National Deaf Children's Society. The project is funded by the National Lottery through the Big Lottery Fund.

When talking about the project as a whole:

This project is a collaboration between the University of Manchester and University College London, in partnership with Deafness Research UK (the Hearing Research Trust) and the National Deaf Children's Society. The project is funded by the National Lottery through the Big Lottery Fund.

For use in charity literature in the absence of specific news or results:

The ongoing study, supported by the National Lottery through Big Lottery Fund, into 'Positive Support in the Lives of Deaf Children and their Families' is a partnership between Deafness Research UK (the Hearing Research Trust), the National Deaf Children's Society, the University of Manchester and University College London. For up to date information, go to www.positivesupport.info/click here (as appropriate).

Information for Participating Professionals
Heads of Services, Teachers of the Deaf, other Support Services and
Audiology services

Introduction

This is an exciting time for important new research to be conducted with babies that have been newly identified as having a hearing loss and their families. New and substantial changes in Health, Education and Social Care policy concerning services for deaf children and their families have been effected and implementation of these policies is well advanced, led by the introduction of the Newborn Hearing Screening Programme (NHSP), the Modernising Children's Hearing Aid Services (MCHAS) and the DfES funded programme 'Early Support' (ES). This is giving rise to significantly earlier identification of deaf children than ever before, followed by early support initiatives for babies, infants and their families.

However, we do not currently have a full understanding of the links between what happens after identification of deafness and outcomes in later life; that is, we do not have a robust evidence base upon which to make recommendations to families and their support services about the type and extent of support which works best for individual deaf children.

To address this, the Big Lottery Fund has given a £500,000 grant to a group of organisations for the "Positive support in the lives of deaf children and their families" research project. The research group is a collaboration between the University of Manchester, University College London (UCL), the National Deaf Children's Society (NDCS) and Deafness Research UK (the Hearing Research Trust).

A unique opportunity exists to capitalise on the current implementation of the NHSP to monitor key outcomes for deaf children in the first few years of life and their families and to relate these to the details of specific interventions.

The key outcomes to be monitored are language, communication, play and social behaviour and motor and physical development, using the parent-led Monitoring Protocol (ESMP) developed as part of the DfES programme 'Early Support'. Also, the study will measure the type and extent of support and intervention, including family functioning, and relate these to outcomes. From this we hope to be able to disseminate more robust information upon which parents may make informed choices and services may base their improvements in provision so that early development is likely to be optimal and the social exclusion of deaf children reduced. It is also possible that the research will lead to the later development of a national database of outcomes for deaf children and their families that can be used as a valuable resource for families and professionals.

What data will be collected in this study?

The research consists of three strands.

1. Children's development will be assessed with regard to language, communication, play and social behaviour, motor and physical development and other developmental milestones. All parents will use the Early Support Monitoring Protocol to chart their child's development. We will collect copies of the summative information sheet from this tool at six monthly intervals. In addition, families using BSL will be asked to complete a standardised BSL version of the MacArthur-Bates Communicative Development Inventory, developed by the project team.
2. More detailed studies will be carried out with a subset of approximately 40 of these families. These include interviews, semi-structured questionnaires and scale rating techniques. From these we will be able to i) understand families' own definitions and understanding of what counts as quality intervention for them; and ii) explore parents' changing perceptions of desired and expected outcomes for their deaf

children. This evaluation will be carried out on an annual basis during home visits made by members of the research team.

3. Service providers in health, education and social care who work with families of pre-school children will be asked to detail the type and extent of support provided to participating families. Services vary in the type of 'support' they provide to families and deaf children. For example, the support may include modelling strategies for parents by the Teacher of the Deaf interacting directly with the child, or centre on advising and discussing strategies. Time might be spent focused on a family's concerns in general, or be specifically directed to promoting the development of a child. Exactly what happens when a professional visits a family will be quantified and compared. This will help to give us a better understanding of sensitive family support.

What will service providers be asked to do?

Heads of LEA Sensory Support Services (or equivalent) will be asked to pass Project Information Packs (which the research team will supply) to the families of all children born after September 1st 2005 within the local authority and newly identified as having a 40dB or greater permanent bilateral hearing loss. It is important that the pack is given to all these families, since the aim is to recruit all deaf children born in England between 1.9.05 and 31.8.07 into the research. The information pack will contain details of the study and will explain to parents the issues surrounding consent and confidentiality. The pack will also explain what parents will be asked to do if they agree to take part. It will be made very clear to them what information will be collected about their child and from whom. A return slip will be included in the pack so that families who wish to take part can reply directly to the research team at the University of Manchester. It is only at this point that the research team will know the identity of those participating in the research.

LEA support services will be asked to encourage the families recruited to the study to use the ESMP. We will ask for copies of the completed summative ESMP information every six months. This process will require a copy of the summative sheet being sent to the research team by the professional in contact with the family. Any expenses incurred for this will be reimbursed.

LEA support services will also be asked to detail how much and what type of input is being given to each participating family including job descriptions, actual practice and responsiveness to family needs. The research team will seek audiological data from the child's audiology service and other relevant health and social care data from the appropriate services.

All aspects of the project will have the appropriate ethical approval.

What is the timescale of the study?

The recruitment process will start in February 2006 when information packs will be sent to Heads of Services. The information packs will be left unsealed to allow Heads of Services to see the contents and to add a covering letter if they so wish. Data will be collected at six monthly intervals at 6, 12, 18, 24 and 30 months of age, with no further babies being recruited after 31.8.07 and no further data being collected after August 2008 (unless the project is extended, as we hope it will be, but in that case it will be a 'new' study and new approvals would be sought).

How will language barriers be overcome and 'hard to reach' populations accessed?

It is essential that 'hard to reach' populations are accessed and recruited to this project. To help with this, the parent information, consent forms and all other recruitment materials will be available in community languages including BSL. Case study examples of how services are using the measurement tools with families for whom English is not the first language or have low literacy levels will be shared with all participating services.

How will the information collected be used in the future?

The results of this study will help us to understand the complex relationships between early development of deaf children and the interventions and support provided to the child and family, at a level of detail that has not been achieved previously. We hope that this understanding will enable services and families to make earlier, better informed choices and to predict with greater certainty 'what works for whom'. The information may help with service planning and allow professionals and families to feel confident that the support being provided is both justifiable and optimal. As outlined earlier, a long-term aim of this work is to develop an ongoing national database of outcomes for deaf children and their families and so it is hoped that the project will continue past the three years currently funded.

Summarised Information for Professionals

This is an exciting time for important new research to be conducted with babies that have been newly identified as having a hearing loss and their families. New and substantial changes in Health, Education and Social Care policy concerning services for deaf children and their families have been effected and implementation of these policies is well advanced, led by the introduction of the Newborn Hearing Screening Programme (NHSP), the Modernising Children's Hearing Aid Services (MCHAS) and the DfES funded programme 'Early Support' (ES). This is giving rise to significantly earlier identification of deaf children than ever before, followed by early support initiatives for babies, infants and their families.

However, we do not currently have a full understanding of the links between what happens after identification of deafness and outcomes in later life; that is, we do not have a robust evidence base upon which to make recommendations to families and their support services about the type and extent of support which works best for individual deaf children.

To address this, the Big Lottery Fund has given a £500,000 grant to a group of organisations for the "Positive support in the lives of deaf children and their families" research project. The research group is a collaboration between the University of Manchester, University College London (UCL), the National Deaf Children's Society (NDCS) and Deafness Research UK (the Hearing Research Trust).

The aim of this research is, having monitored key outcomes for deaf children and families, to relate these to specific interventions. Families of children identified by the NHSP as having a 40dB or greater bilateral hearing loss will be invited to participate. The key outcomes to be monitored are language, communication, play and social behaviour and motor and physical development, using the parent-led Monitoring Protocol (ESMP), developed as

part of the DfES funded programme 'Early Support'. Also, the study will measure the type and extent of support and intervention, including family functioning and relate these to outcomes. From this it will be possible to disseminate more robust information upon which parents may make informed choices and services may base their improvements in provision so that early outcomes are likely to be improved and the social exclusion of deaf children reduced. It is also possible that the research will lead to the later development of a national database of outcomes for deaf children and their families that can be used as a valuable resource for families and professionals.

In summary, the research consists of three strands:

1. *Children's Development* will be assessed using the ESMP and a standardised BSL version of the MacArthur-Bates Communicative Development Inventory for families using BSL.
2. *Family Functioning* will involve an assessment of a subset of 40 of the families to evaluate various aspects of home life in finer detail. This will be conducted via questionnaires and semi-structured interviews during home visits by a research team member.
3. *Services* will be asked to provide details about the input they give to each of the families in the study.

This is an exciting project and we will be keeping all involved parties regularly updated about it. The project website contains further details about the project and the extent to which services will be asked to become involved and, over the next few months, information about the project's progress, events that are taking place, and how you can get involved. The website is at www.positivesupport.info

Positive support in the lives of deaf children

This is an exciting time for deaf children, their families and other people who work with them. Because of the Newborn Hearing Screening Programme (NHSP), deaf babies are now being identified at around 8 weeks of age rather than at an average of 22 months before the screening was started. Other changes have happened recently such as:

- the Modernising Children's Hearing Aid Services programme and the introduction of digital hearing aids
- the Early Support programme
- official recognition of British Sign Language (BSL)

All this makes it an ideal time to try and find out what is best to help individual deaf children to develop.

Permanent deafness from birth can cause problems with language, communication and literacy. These can affect a child's behaviour, quality of life and achievement at school. There can also be effects on the life of the whole family. A new project has recently started that will help us to have a better understanding of what kind of early support enables deaf children to do well.

The Big Lottery Fund has awarded a grant to a group of organisations to look at what can lead to a better quality of life for individual deaf children and their families. The organisations working on it are the National Deaf Children's Society (NDCS) and Deafness Research UK (the Hearing Research Trust) with the University of Manchester and University College London (UCL).

The main aim is to look at the relationships between '*interventions*', such as

- fitting of hearing aids
- support given by education
- how individual families work

and '*outcomes*', including:

- language development
- being involved in society
- quality of family life

When we have a better understanding of what works best for individual deaf children, it will be possible to use this for the benefit of families and services all over the UK. Hopefully, the end result will be that all deaf children can reach their full potential in life.

All families living in England whose child is identified as being deaf following newborn screening over the next two years will be invited to take part in the study. There will also be discussion groups that families of deaf children can take part in.

There are different parts to this three-year project:

- 1) To look at the language (spoken and signed), communication, play, social and physical development of deaf children identified by the screening programme
- 2) To find out from families about life with a deaf child and the effect on their family
- 3) To collect information about what help the family and the child receives from a wide range of support services.

There are two areas that are most important for the first year of the study:

- a) To develop information for families about the project and about taking part

For this part of the project, NDCS will be inviting parents to come to discussion groups around the country. Parents will be asked to tell us what information they want to know about the study and how they want it presented. Families of deaf children are the key part of this project.

b) To develop a way of checking how the language of young deaf children who use BSL is developing

At the moment the only tests that check language development in children look at spoken language. One of the most often used tests is the “MacArthur Communicative Development Inventory (CDI)”. To measure the language development of all deaf children better, the MacArthur CDI needs to be extended so that it can also be used with children who use BSL. This will involve work with a number of children whose parents are deaf and use BSL at home.

This part of the project is being led by UCL and more information is available on www.ucl.ac.uk/HCS/research/EBSLD/ or by contacting Tyron Woolfe by minicom on +44 (0)20 7679 4094.

During the project, a project advisory group made up of parents, professionals and individuals who support deaf children, will regularly discuss the project’s progress with the project management team. This is a very important part of this project, making sure that parents of deaf children are at the heart of the work and regularly have an opportunity to have their say about it.

This is an exciting project and we will be keeping all families of deaf children regularly updated about it. Further details of our progress, events that are taking place and how you can take part are on our website at www.positivesupport.info

Positive support in the lives of deaf children

This is an exciting time for deaf children, their families and other people who work with them. There have been a large number of changes connected to services for them such as the Newborn Hearing Screening Programme (NHSP), the Modernising Children's Hearing Aid Services programme and the introduction of digital hearing aids, as well as the programme called Early Support. All this makes it an ideal time to try and find out what is best to help individual deaf children to develop to their full potential.

Permanent deafness from birth can cause problems with language, communication and literacy. These can affect a child's behaviour, quality of life and achievement at school. There can also be effects on the life of the whole family. A new project has recently started that will help us to have a better understanding of what kind of early support enables deaf children to do well.

The Big Lottery Fund has awarded a grant to a group of organisations to look at what can lead to a better quality of life for individual deaf children and their families. The organisations working together on this are the National Deaf Children's Society (NDCS) and Deafness Research UK (the Hearing Research Trust) with the University of Manchester and University College London (UCL).

The main aim is to look at the relationships between '*interventions*', such as

- fitting of hearing aids,
- support given by education, and
- how individual families work,

and '*outcomes*', including:

- language development,
- being involved in society and
- quality of family life.

When we have a better understanding of what works best for individual deaf children, it will be possible to use this for the benefit of families and services all over the UK. Hopefully, the end result will be that all deaf children can reach their full potential in life.

Over the next two years, all families living in England whose child is identified following newborn screening as having a hearing loss will be invited to take part in the study. There will also be discussion groups that families of deaf children can take part in.

There are different parts to this three-year project:

- 1) To look at the language (spoken and signed), communication, play, social and physical development of deaf children identified by the screening programme
- 2) To find out from families about life with a deaf child and the effect on their family
- 3) To collect information about what help the family receives from a wide range of support services

This is an exciting project and we will be keeping all families of deaf children regularly updated about it. Further details of our progress, events that are taking place and how you can take part are on our website at

www.positivesupport.info

PRESS RELEASE

Embargoed to 08.00 17 November 2005

Positive support in the lives of deaf children and their families

A pioneering study is set to help support the development of deaf children identified by the Newborn Hearing Screening Programme (NHSP).

The £500,000 study is funded by the National Lottery through the Big Lottery Fund and is a collaboration between the University of Manchester and University College London, in partnership with the National Deaf Children's Society and Deafness Research UK (the Hearing Research Trust). The project is called "Positive support in the lives of deaf children and their families".

Permanent deafness from birth can often lead to problems with language, communication and literacy. These in turn can affect a child's behaviour, quality of life, achievement at school and how the whole family interacts. The three-year project aims to explore how different interventions such as provision of hearing aids, the role of the family and professional support (including education and health services) can affect the development of a deaf child.

Vivienne Michael, Chief Executive of Deafness Research UK, said:

"Recent advances in the field of childhood deafness such as the Newborn Hearing Screening Programme, the Early Support programme and the introduction of digital hearing aids means this is the perfect time to examine what best supports the development of individual deaf children."

Gwen Carr, NDCS Deputy Chief Executive and Director UK Services, said:

"When we find out what leads to the best benefit for these young children we will then be able to establish this in practice all over the UK. This work will mean that we can provide evidence of how support services can really benefit

the development of deaf children and lead to them reaching their full potential in life.”

John Bamford, lead researcher on the project, said:

“Ultimately, this project could lead to possible policy changes necessary to offer families valuable and relevant support for their specific needs, ensuring a better quality of life for the deaf child and their family.”

“One of our hopes for this project is to involve and represent ALL families of deaf children which will include those from ethnic minority communities and families using BSL.”

The project team will be working with education services to recruit families with deaf children from across England. Parents will be asked to observe their child’s developmental behaviour and interviews will be conducted with some parents during home visits made by researchers. This will enable the team to assess the family dynamics, provision of education services and the effectiveness of this and other support for the family.

Regular project updates are available at www.positivesupport.info.

Notes to editors

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- Deafness Research UK (The Hearing Research Trust) is the medical charity for deaf and hard of hearing people. Since being founded in 1985, Deafness Research UK has secured many radical improvements in the prevention, diagnosis and the treatment of hearing difficulties, including supporting the development of the technique now used in newborn hearing screening.
- The NDCS, founded in 1944, is the UK's only charity solely dedicated to the welfare of all deaf children. NDCS provides immediate and on-going support, information, advice and advocacy on every aspect of childhood deafness. NDCS provides balanced information about all aspects of childhood deafness, including education, health welfare benefits and technology.
- Three babies are born deaf every day and 90% of deaf children are born to hearing parents with little experience of deafness.
- There are 35,000 deaf children in the UK.
- The roll-out of the Newborn Hearing Screening Programme (NHSP) is due to be completed across the UK early 2006.
- The introduction of the NHSP means the average age a child's deafness is identified has fallen to around eight weeks. Before screening was introduced it was sometimes as late as three years.



Informed Consent Form for Parents/Guardians of Project Participants

Project Title: Developing a British Sign Language Version of the MacArthur Communicative Development Inventory

I agree that my child , for whom I am a parent/guardian, and I will take part in the above City University research project. The project has been explained to me, and I have read the Explanatory Statement, which I understand I may keep for my records.

I understand that by agreeing to take part I am willing:

- For my child to be filmed interacting with me and with Dr Tyrone Woolfe (researcher) on dates to be mutually agreed
- To complete vocabulary checklists which will be sent to me on a quarterly basis over the next 3 years
- To meet with Dr Woolfe and be interviewed/observed in interaction should that be required

I have had an opportunity to see the explanatory statement in BSL.

I will be paid £20.00 at the end of the project for my co-operation. This will be pro-rated if I withdraw before the end.

Data Protection

This information will be held and processed for the following purposes:

- a) To develop a normative description of early development.
- b) To provide a database that will inform parents of future cohorts of deaf children and professionals about the developmental stages of BSL
- c) To allow further insights about the early developmental indicators of BSL.

I agree that data can be shared for the purposes of research with researchers at University College London, University of Manchester & Royal Holloway College, University of London. These organisations have made a written agreement with City University to abide by the Data Protection Principles.

I know that my participation is voluntary and that I may withdraw at any stage without any penalty, and without any effect on my child's participation in intervention programmes.

Signature

Date

Child's Name: (please print)

Child's date of birth:

Parent's/Guardian's Name

Your relationship to the child:

Signature of Parent/Guardian:

Date:

RE-USING DATA FOR FURTHER ANALYSIS

I understand that the researchers may wish to use the data in future research studies. I give permission for this and understand what this means from the Explanatory Statement.

Signature of Parent/Guardian:

Date:

I understand that the researchers may wish to use the recordings in future research studies. I give permission for this and understand what this means from the Explanatory Statement.

Signature of Parent/Guardian:

Date:

I understand that the researchers may wish to show excerpts from the recordings for teaching purposes. I give permission for this and understand what this means from the Explanatory Statement.

Signature of Parent/Guardian:

Date:

I understand that the researchers may wish to show excerpts from the recordings at conferences and workshops. I give permission for this and understand what this means from the Explanatory Statement.

Signature of Parent/Guardian:

Date: