**School of Psychology**

**Lived Experiences of Deaf Children’s Parents
Interview

Participant Information Sheet**

Thank you for your interest in this study. Before you decide whether to participate, please read the following information carefully. This information sheet is for you to keep. If you have any questions, please ask us. Our contact details are at the bottom.

**What is this research looking at?**
We are inviting parents of deaf child(ren) to take part in a study about Lived Experiences of Deaf Children's Parents. We’d like to invite you to participate in our study if you are a parent to a deaf child under the age of 18 years.

We use the term deaf to include children with moderate to profound hearing loss, from all kinds of backgrounds. This includes children congenitally deaf as well as those diagnosed at a later time. We acknowledge that there are many ways to identify individuals with any level of hearing loss and we use this term to try to include deaf children with varying backgrounds.

In this study, we want to gain better understanding of experiences of parents with deaf child(ren), including their access to information and support as well as the advice they receive from health professionals, education professionals, teachers of the Deaf and relevant charities (e.g. NDCS).

The study involves participation in an online interview. We are interested in finding out about parents’ primary and future needs for further information of deaf children’s development.

The results will guide the development of future projects to address questions you want to have answered, and will inform us as to how outcomes of our research can be made useful for practical informative materials.

Below, we describe what taking part in this study would involve for you.

**What will we do in this study and where is the study based?**
If you decide to take part, you will be invited to take part in an online interview, taking place via Microsoft Teams. During the session, we will ask questions about your experiences as a parent of a deaf child, what advice you received about your child’s development, and the accessibility of parenting-related information. The discussion will involve follow-on questions, but our aim is to keep to these central topics. We anticipate the session will take 1 hour of discussion with opportunities for participants to ask the researchers questions. The session will be recorded (audio only) for later transcription. This is for the purpose of analysis. We may use transcribed individual quotes from the session in presentations or write-ups, but these will always be anonymized (details for this process can be found under the subheading *Audio Recordings*). We will also ask for your permission to contact you via email to invite you to follow up research projects. **You can refuse to be contacted in the future but still take part in this study.**

**Do I have to take part?**Taking part in this study is your choice. If you decide to do so, you will be given this information sheet to keep, and we will ask you to sign a consent before the interview. You are free end the interview at any time, without giving a reason. This would not affect you in any way. You can also ask us to remove your data from the study up to one month after you have finished or stopped the study by contacting us by phone or email – our contact details can be found at the bottom of this information sheet. After that time anonymised data can no longer be removed from the study.

**What will happen if I agree to take part?**If you agree to take part we will invite you to an online interview via Microsoft teams. On the day you will participate in a session for up to 1 hour. The discussion will be recorded for later transcription and analysis. The questions we will ask will all centre on your experience as a parent of a deaf child. Our aim is to find out how new parents of a deaf child learn to support their child’s development, what provision of information materials/classes etc. is useful and where there is demand for more. We also aim specifically to find out what we as researchers could do to make sure our work is useful for parents and/or how to turn our findings into useful materials.

**Audio recordings**We will record the discussion using the record function on Microsoft teams. This is solely for the purpose of transcription and later analysis. Audio recordings will only be accessed by the researcher present during the interview. During transcription any identifying information such as placenames will be removed, before the transcriptions are shared with the wider research team. Transcriptions of individual utterances may, in anonymised form, be used in presentations or write-ups as journal articles or blog posts.

**Are there any problems associated with taking part?**Our study does not have any specific risks. It is possible that you may find some questions intrusive or sensitive. You will be under no obligation to answer any particular question or contribute to any particular part of the discussion. You do not have to explain why you don’t want to answer that question or contribute to that part of the discussion. As you will be required to spend 1 hour of your time being interviewed, we will compensate you £15 in vouchers for your time.

**Will it help me if I take part?**
While this study does not focus on helping participants, we hope that this study will help us, and other researchers, understand more about the experiences of parents of deaf children and their needs. Moreover, the knowledge from this study will be used for developing practical informative materials for parents of deaf children.

**Who is funding this study?**

This research study is funded by the UEA Associate Dean for Innovation Fund.

**How will you store the information that I give you?**

All information which you provide during the study will be stored in accordance with the 2018 General Data Protection Regulation and kept strictly confidential. The chief investigator Dr Nadja Althaus will be the custodian of the anonymous research data. All electronic data will be stored on secure, encrypted electronic drives. Only research team members will have access to these data. Anonymised results will be stored indefinitely in order to comply with open practice standards. We adhere to the ethics committee’s protocols on data storage. We will also share non-identifiable final data with the broader scientific community upon request, in line with open science practices. Data will only be shared with other researchers if they request it and enter into a data processing agreement - your data will not be stored or shared publicly. By final data, we refer to data that has been processed into final composite values that can be entered into analyses alongside demographic information. Demographic information refers to population characteristics such as gender, ethnicity, socioeconomic factors, languages used etc. Sharing non-identifiable data from studies is important for scientific transparency, integrity, and enabling reproducibility of results. We acknowledge data being non-identifiable is especially important for small populations in the UK and understand that not all participants will be comfortable with anonymous data sharing. For this reason, when signing the consent form to take part in this study, **you will be able to decide** whether you consent your non-identifiable data and demographic information being shared with other researchers (upon request and subject to a data processing agreement) or not. You will be given an option to indicate your preference in the consent form. Your response to this question does not impact your ability to take part in the study.

**How will the data be used?**The results of the study will be published or presented at conferences or elsewhere. If we write a report or article about this study or share the study data set with others, we will do so in such a way that you child cannot be directly identified.

**What happens if I agree to take part, but change my mind later?**

Taking part in this research is completely voluntary. If you consent to take part but change your mind during the interview or after, you have the option to remove any and all contributions you have made. If you wish to have your contributions removed, you have up to one month to contact the research team (contact details listed below), to request the removal of your data. After this time, we cannot guarantee the possibility of removing your data.

When you request the removal of your data you will be asked to provide the number assigned to you at the beginning of the session to help the researcher identify the specific data that needs to be removed.

**How do I know that this research is safe for me to take part in?**
All research in the University is looked at by an independent group of people called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This research was approved by the Psychology Research Ethics Committee at the University of East Anglia.

**Duty of care**Please note that we will disclose to the proper authority, information you share with us concerning child abuse, child sexual abuse, or harming yourself or others.

**You are under no obligation to agree** to take part in this research.
If you do agree you can **withdraw at any time without giving a reason.**

**Contact Details**

*If you have any questions or concerns about this research, you can contact:*

Dr Nadja Althaus (Principal Investigator):🖰N.Althaus@uea.ac.uk 🕿01603 592522
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