Narratives of hopes fears and expectations: Young people with cochlear implants

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ABSTRACT

Introduction: Research including cochlear implant users is slowly developing since their introduction in the treatment of deafness. Current gaps in research point to the inclusion of young people who have received paediatric cochlear implants.

Method: This qualitative study sought to collect the perspectives of young people (aged 16-18) with cochlear implants in relation to their hopes, fears and expectations for the future. The eight participants were of equal gender mix (four females, four males) and were on average 17 years old; they had been using a cochlear implant for an average of 14 years.

Data was gathered via one-to-one topic focused interviews with holistic narratives being analysed for content, form, and performative elements.

Results: Overall narratives of hopes were thicker than those of fears and especially those of expectations. Narratives of hopes included: achievement through education/career; acceptance of deafness from self and others; a greater desire for fluidity between communication partners and improvements in cochlear implant technology. Interestingly how participants framed fears seemed to vary; yet this pointed to concerns over the visibility of deafness and non-acceptance from others (i.e. friendships and relationships), particularly with hearing people. Expectations, linked with narratives of hopes, however were framed in more vague terms.

Conclusion: The study highlighted commonalities and disparities in the participants' future narratives. To conceptualise the psychological consequences of being a young person with a cochlear implant, models of adjustment and life transition were used. The study calls for a greater awareness of deaf issues within professional settings and the wider society. Through their practice, Clinical Psychologists ought to be deaf aware and take a critical stance towards negative social narratives of competence. Through research, Clinical Psychologists should aim to represent the idiosyncrasies of deaf lives. The study supports a paradigm shift towards a fluid sense of identity in promoting a greater sense of acceptance.

CONTENTS

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DEDICATION

This thesis is dedicated to the loving memory of my beautiful, bold and beaming, friend and colleague, Vera Azarova. Starting out on this journey together, I could not help but be allured by her infectious enthusiasm and determination. Having her in my heart and knowing she watches over me, has given me the strength to continue on this journey. She will forever be in my heart and in my thoughts, inspiring me to share the love of life and learning, she so graciously oozed; I will strive to continue her legacy.

PROLOGUE

This psychology research project approaches the topic of deafness, where audiological research is abundant and psychological research, underdeveloped. Of the psychological research available, much has focused on the global development of the deaf child, often comparing deaf children to their hearing peers.

Since the introduction of cochlear implantation, a form of treatment for deafness, candidacy criteria have evolved to include children, even those with congenital deafness. Cochlear implant research mirrors the trends in wider deaf research, yet is proportionally fewer. Furthermore, it has until recently been difficult to include young people who use cochlear implants in research, due to their small population size; therefore research with this population group is particularly thin. This means that little is known about the psychological consequences this unique population face.

A call for research in this area is further perpetuated by the key debates in deaf literature. This is due to cochlear implants being depicted as a barrier towards the development of a cultural Deaf identity and membership with the Deaf community (a group collectively affected by Deafness, whose rhetoric is: “we’re normal just not able to hear”). This is particularly striking given that these issues are synonymous with adolescent development (i.e. identity and group affiliation), and yet this is an area that is particularly underdeveloped. Therefore this study aims to gather the perspectives of young people who have received paediatric cochlear implants, to better understand the psychological consequences this population group face at this point in their lives. The study is particularly interested in the psychological consequences given that research in this area is novel, and to create a stringent focus, on identity for example, may not be the most poignant issue for these young people.

The subsequent sections will give an overview of the deaf research, funnelling to the research questions and rationale for the approach taken.

1. INTRODUCTION

When compiling this literature review, the following terms, in all combinations, were searched in EBSCO: cochlear implants, deafness, young people, adolescence, hopes, fears and expectations, outcomes and psychological.

1.1. Overview

For the purposes of this paper, I will firstly define deafness and outline types of hearing loss, including how these are identified, current hearing loss treatments and their ethical implications. I will present an overview of deaf research and a subsection focussing on cochlear implants; paying particular attention to those with a psychological focus.

1.2. Types of Hearing Loss

Hearing loss is classified as either conductive or sensorineural (MacKay, 2010). Conductive hearing loss occurs as a result of disease of the external or middle ear; hearing loss is said to fluctuate. Whereas sensorineural hearing loss is often caused by damage to the inner ear (cochlea), or to the nerve pathways between the inner ear and the brain; this hearing loss is permanent.

A child can either be born with deafness[1], i.e. congenitally deaf, or acquire deafness before or after acquisition of speech and language, through, for example, the contraction of meningitis. Deafness is often described in relation to language development at hearing loss onset, i.e. pre- or post-lingual, meaning the onset of deafness occurred before or after the acquisition of language respectively (NICE, 2009). This differentiation is made to offer a basis of standardisation, as the acquisition of language and speech varies within normative groups. Pre-lingual deaf children, have quite a different task in learning to use hearing aid technologies, such as cochlear implants (CI), as they must develop an auditory based language, from exposure to input with fewer distinctions (Spencer & Marschark, 2003).

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[1] Cultural 'Deafness' is distinguished using a "D", "d" represents 'deafness' as a condition requiring treatment, this will later be expounded. This will be applied throughout the document; however, when referring to both groups "deaf/ deafness" will be used.

1.3. Deafness and Levels of Deafness

A widely accepted definition of deafness, and the one that will be used in this paper, is put forward by NICE (2009): only hearing sounds louder than 90 dB HL at frequencies of 2-4 kHz without hearing aids. This definition refers to the extent of hearing loss, which is usually graded into severity levels, defined by Action on Hearing Loss (2013) as: ‘mild deafness’ hearing sounds within the range of 25-39 decibels; meaning one may have difficulty following speech in social situations. ‘Moderate deafness’, hearing sounds between 40 and 69 decibels, which may require one to wear hearing aids. ‘Severe deafness’, often grouped with ‘profound deafness’ are defined as hearing sounds between 70-94 and over 95 decibels, respectively. Of these two, the former may benefit from hearing aids as well as use sign language to communicate; the latter are likely to only use sign language.

2. NARRATIVES OF DEAFNESS

2.1. Deaf Culture: a Sociocultural Narrative

Historically, perspectives of Deafness had been largely misunderstood. Since the time of Aristotle, Deaf people were thought to lack intelligence (Bender, 1981). It was then, that lack of speech implied lack of language and, therefore, the inability to think (MacDougall, 1991). However, what has more recently come to light, especially since the campaign to make British Sign Language (BSL) an official language, is the sociocultural narrative of Deafness, including Deaf culture and the Deaf community.

Deaf culture describes the history, social beliefs and values of some individuals who are collectively affected by Deafness; together they form the Deaf community. Those aligning with the Deaf community conform to the rhetoric: “I’m normal, I’m just not able to hear” (Power, 2005) and assert that they, like anyone else, are able to live ‘normal’ family, social and work lives via sign language (Hyde & Power, 1992). The Deaf community’s view on Deafness is not as a disability but a human variation (Butler, Skelton & Valentine, 2001), one that is to be cherished and celebrated. Therefore, most members of the Deaf community tend not to ‘treat’ their Deafness with the use of hearing aid technologies, especially CIs, and prefer to communicate with sign language (e.g., BSL). These sociocultural narratives of Deafness in the wider hearing community, and especially within the health care system, are thin, as Hyde, Punch and Komesaroff (2010:163) acknowledge: “despite the large amount of information parents may encounter, most hearing parents are exposed largely to a medical model of deafness and may not be presented with information about the social, cultural and linguistic life of the Deaf community”.

2.2. A Medical Narrative

In contrast, the medical model sees deafness as a ‘deficit’ (Butler et al., 2001) that can be treated with hearing aids and CIs, so people born deaf can live within the hearing world (Jones, 2002). This narrative is positioned within a model of disability from which the person seeks relief, if available. The medical perspective of deafness is prevalent in many audiology services and other healthcare contexts (Hyde et al., 2010), and dominates the media and lay views (Power, 2005). However, NICE (2009:21) concludes:

> *“Most children who are deaf have families who are hearing and who have no access to 'Deaf culture'. In addition, it is unlikely that adults who become deaf will become proficient users of sign language and integrate into the 'Deaf community'. The Committee concluded that for many people ‘deafness’ would have a significant adverse impact on their quality of life, and that it was appropriate to consider cochlear implants as a means of reducing this impact.”*

Thus, opposing positions of whether to ‘treat’ deafness or not, mirror the existing narratives of deafness (Blume, 1999), i.e. deafness versus Deafness.

3. IDENTIFICATION OF HEARING LOSS AND DEAFNESS

The need for a health care pathway that sets out to identify hearing loss in young infants has been accelerated by research over the last few decades, indicating an impact on the holistic developmental of a deaf child; for example developmental delays have been suggested in 30-40% of children with varying degrees of hearing loss (Karchmer & Allen, 1999). Furthermore, NICE (2009:6) suggests: “deafness may have significant consequences for linguistic, cognitive, emotional, educational and social development”.

The accumulation of such research, highlighted the need for early detection pathways and brought about the introduction of the universal newborn screening programme, implemented in the UK, in March 2006 (WHO, 2010). Through this initiative, each year around 370 children are detected to be born with permanent ‘severe’ to ‘profound’ deafness in England and Wales (NICE, 2009); early identification enables appropriate support, such as special educational programmes (Alpiner & McCarthy, 2000).

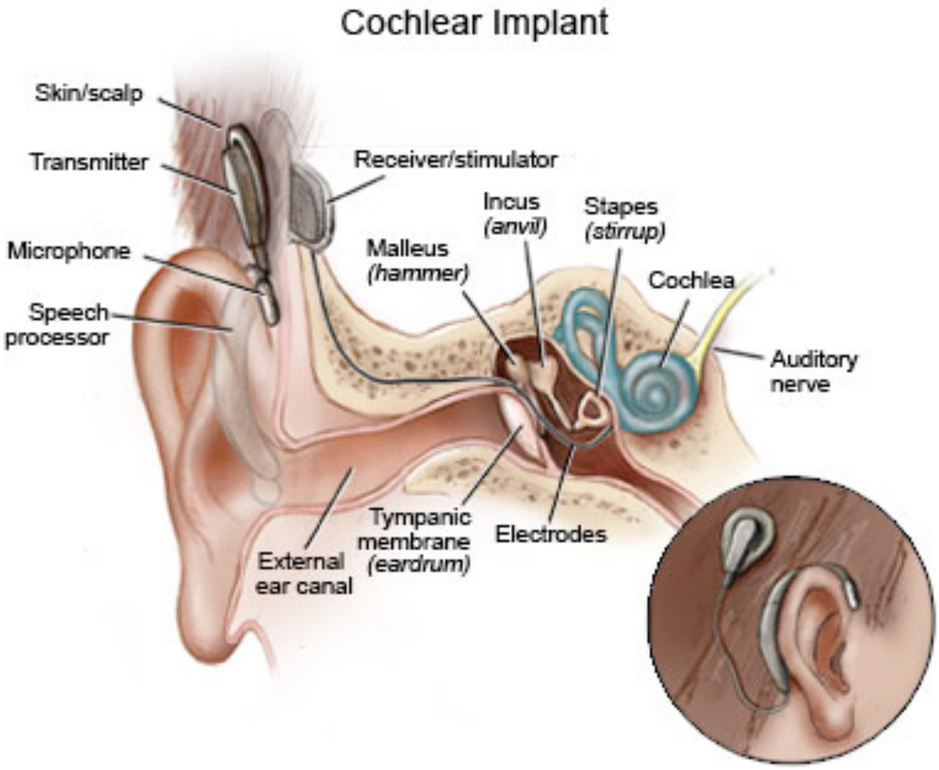
3.1. ‘Treating’ Hearing Loss

After screening, children who are suspected of having hearing difficulties are referred to audiology services, where the type and severity of the hearing loss are established. Audiologists assess both the audiological and functional deafness (i.e. their ability to hear speech in quiet conditions with acoustic hearings aids) (NICE, 2009). The type of hearing loss determines the possible treatment pathway, for instance some children with conductive hearing loss may be referred for hearing aids, but would not be eligible for CIs. For children with sensorineural hearing loss, it is recommended that they receive hearing aids within two months of being diagnosed with hearing loss (NICE, 2009). For some people with sensorineural hearing loss, adequate benefit is derived from hearing aids, however, as these are essentially amplifiers, their benefits are inversely related to the degree of hearing loss (Spencer & Marschark, 2003). In concordance with NICE guidelines (2009), those who derive no benefit from hearing aids should be considered for cochlear implantation.

3.2. A Cochlear Implant (CI)

In brief, a cochlear implant (diagram 1) is a device that has several external components and one surgically fitted internal component. It is given to people with sensorineural hearing loss to enable them to hear and interpret sounds. It works by capturing external sounds via the external receiver (microphone), which, in turn sends an electric current through the other components finally reaching, and thus, stimulating the auditory nerve (Copeland & Pillsbury, 2004). Although this produces the sensation of hearing, it does not restore hearing (MacKay, 2010). Furthermore, children must develop speech perception (Svirsky et al., 2001), meaning children need to learn to interpret the signal the CI produces; thus, learning how to listen.

Diagram 1. A Cochlear Implant (Kidshealth, 1995-2015).



3.3. UK Figures of Cochlear Implantation

The British Cochlear Implant Group (BCIG) (2015) published a report outlining the statistics of annual cochlear implantation between April 2013 and March 2014. This report documented a total of 638 adults were fitted with CIs in this time; child implantation equated to 523. As recorded in this report, since their introduction, and up until March 2014, 7,254 adults and 5,049 children had been implanted.

3.4. Cochlear Implantation Healthcare Pathway

Patients are considered for cochlear implantation through a formalised Multi-Disciplinary Team (MDT) assessment that ought to occur within one year of diagnosis, according to NICE (2009). In this assessment, audiological and functional hearing are assessed and candidacy factors reviewed: suitability for surgery, structure of the cochlea, presence of a functioning auditory nerve, and the likely ability that one would derive benefit from the stimuli produced (NICE, 2009). For those undergoing cochlear implantation, a period of rehabilitation time is required to gain maximum benefit from the implants (Meyer, Svirsky, Kirk & Miyamoto, 1998).

Originally, candidacy criteria only allowed for the implantation of deafened adults; however, over the years, the candidacy criteria have widened to include children, even those who are congenitally deaf (Waltzman & Shapiro, 1999). Implantation can occur in infants as young as 6-months-old or younger (Birman, 2009; Holt & Svirsky, 2008). The first paediatric cochlear implantation in the UK took place in 1989 (Wheeler Archbold, Gregory & Skipp, 2007).

4. CI ‘OUTCOMES’ IN CHILDREN AND YOUNG PEOPLE

Over the years the support of paediatric implantation has accumulated, partly due to the widening of developmental courses it is said to allow (Geers, Brenner, Nicholas, Tye-Murray & Tobey, 2003). Evidence suggests that implantation in younger children is far more beneficial than in older children (Geers et al., 2003; Wass, Hallgren, Ibertsson, Larsby, & Sahlen, 2007; Pisoni et al., 2009), for example, vocabulary outcomes and spoken language development (Connor, Craig, Raudenbush, Keavner & Zwolan, 2006; Nicholas & Geers, 2007). Furthermore, evidence suggests that implantation in infants as young as two-years-old, go on to acquire the auditory skills near to that of their hearing peers (Britz, Fry & Owston, 2010). These findings are attributed to the greater plasticity of younger children’s auditory systems (Robinson, 1998).

Several factors are said to affect the ‘outcomes’ associated with paediatric cochlear implantation (e.g. social economic status of the family and the presence of other difficulties). Some research points to higher familial social economic status, and belonging to a smaller family, as predicting higher performance in speech and language domains (Geers et al., 2002; Schorr, Roth & Fox, 2008; Tobey, Geers, Brenner, Altuna & Gabbert, 2003). However, evidence appears inconclusive, as other studies, have not confirmed these findings (Hyde, Punch & Grimbeek, 2011). Other factors that affect CI effectiveness include length of hearing aid use, with shorter periods of use being associated with less benefit from implants (Dowell, Blamey & Clark, 1997). Also, for children who experience multiple difficulties, less positive outcomes in several domains have been found (Hyde et al., 2011). However, having said this, variability in audiological outcomes are widely noted (Hawker et al., 2008) and as demonstrated, evidence is rarely conclusive; thus, suggestive of a complex multifaceted relationship, between idiosyncratic factors affecting post-implantation outcomes.

Qualitative outcome data from both parents and young people, concluded positive results from CI use (Chmiel, Sutton & Jenkins, 2000), with young people reporting greater access to a variety of activities and a sense of enjoying being able to hear. However on balance, they also reported some sounds to be troublesome. In another qualitative study seeking only to gather parent's perspectives, Christiansen and Leigh (2002) reported parents noticing that their children were happier, more independent and self-confident after implantation.

4.1. Unilateral and Bilateral Implantation

Now that cochlear implantation procedures are established with a thriving momentum, research in this area has been able to compare the utility of unilateral and bilateral implantation. Bilateral implantation, according to Brown and Balkany (2007), is indicative of improved speech recognition in noise and sound localisation. Research findings such as these have influenced the most recent clinical guidelines for cochlear implantation, NICE (2009); which recommends simultaneous implantation (i.e. implantation in both ears at the same time, should both ears meet criteria). Sequential bilateral implantation (i.e. receiving one implant then some time after receiving a contralateral implant) is no longer recommended by NICE. Further, those who have previously received a unilateral implant should, according to NICE (2009), be considered for a sequential implant.

4.2. Longer-term Outcomes

According to Luckner (2002), language and communication difficulties extend into adulthood, as demonstrated by lower attendance in further education and lower income. Therefore, Punch and Hyde (2011) emphasise the importance of appropriate career guidance in high school, to help deaf young people manage the barriers they might encounter and to maximise career opportunities.

Until fairly recently, research has been unable to examine the longer-term outcomes of young adults who were implanted as infants. One US study has reviewed longer-term educational and employment ‘outcomes’ (Spencer, Tomblin & Gantz, 2012). The average age of the 61 participants was 21.9. For 34% of participants, their highest level of education was high school, 32% university; two participants did not finish high school. These percentages, as highlighted by the authors, were above the general population figures: 27% and 24% respectively (figures for the general population who did not finish high school were not recorded).

5. COCHLEAR IMPLANTATIONS: IMPORTANT CONSIDERATIONS

5.1. Medical Risks

Cochlear implantation surgery, like any other, has associated risks, although reported to be “infrequent” (Johnston et al., 2009) these may include: facial nerve paralysis, vestibular problems and infections (Fayad, Wanna, Micheletto & Parisier, 2003; Fina et al., 2003; Gysin, Papsin, Daya & Nedzelski, 2000).

5.2. Ethical debate

Since the introduction of hearing technologies, but more specifically, cochlear implantation in children, controversy and debate has erupted between the opposing views of deafness: sociocultural narratives of Deafness are around a “life to be lived”, whereas the medical narrative “as a condition to be cured” (Hyde & Power, 2005). The main ethical debates are centred on informed consent, risk/ benefit analysis, and cultural orientation; in many instances these debates raise more questions than they answer. It is beyond the scope of this paper, and may be considered to be naïve, to be able to work towards a resolution of the contentious dilemmas that arise as a result of paediatric cochlear implantation, yet one must acknowledge the opposing narratives and the debates they create.

5.2.1. Informed Consent

It is accepted that legally and ethically a parent can consent to treatment procedures on behalf of their child. This is contentious in any context, but when considering deafness, the issues become multifaceted and complex (Hyde & Power, 2000; Young et al., 2006). Human rights legislation, specifically the

United Nations' Convention on the Rights of the Child (CROC; United Nations General Assembly, 1989) offers provision whereby children have a right to participate in all decisions, and their view taken into account; involvement in such decisions is relative to maturity and age. Given that candidates of CIs are often very young, the issue related to the "participation rule" (articles 5 and 18) seldom arises and, therefore, a best interest decision is often made.

What tends to complicate the CI decision-making process from an ethical viewpoint are the hearing statuses of the deaf children's parents; 95% of deaf children have at least one hearing parent (Bond et al., 2009). This complicates the decision making process, as hearing parents of deaf children are unaware of the experience of hearing loss themselves (Northern & Downs, 1991) and, therefore, may be positioned to see life without hearing as deviating from the norm and perhaps to be less "viable" (Hyde & Power, 2005). According to Hyde et al. (2010) the likelihood of receiving information about the sociocultural narratives of Deafness is low. Hence, it is argued that without information about the potential futures of their children, parents are unable to make a fully informed decision (Berg, Ip, Hurst & Herb, 2007).

However, for hearing parents who may be aware of the sociocultural narratives of Deafness, and who chose to reject implantation for their child, implications are still plentiful. For instance, if parents decide to reject CI for their child and embrace Deaf culture, the family would likely receive little to no input due to their child's young age. Furthermore, such a decision would have a wider systemic impact for the family, in relation to communicative methods, as they themselves would be choosing for their family to embrace the Deaf culture and become bilingual (i.e. also BSL users).

Nevertheless, regardless of whether the sociocultural narratives are presented or not, the decision parents are faced with is complex and difficult (Burger et al., 2005).

5.2.2. Benefit/ Risk

The key benefit/ risk debate is outlined by Hyde and Power (2005); the central question being if the benefits of implantation outweigh the risks. In a review of CI programmes protocols and procedures, Hyde and Power (2005) found there to be an emphasis on audiological outcomes, such as speech perception (as previously presented, chapter 4). Yet, taking a more holistic stance, considering the cultural and social benefits and risks is essential. This, Hyde and Power (2005) note, has been given some consideration by virtue of wider cultural and social contextual factors being taken into account, i.e. cultural positioning.

5.2.3. Cultural positioning: hearing or Deaf Community?

As before, the main arguments come from the opposing positions: medical and sociocultural narratives. A eugenics perspective argues that implantation threatens the sociocultural community of Deaf people (Lane & Grodin, 1997): interfering with a child's development of a Deaf identity, as well as learning communication skills that enable integration within the Deaf community (Lane & Bahan, 1998). In response, some have argued that this view privileges the needs of the group, at the expense of the individuals (Balkany, Hodges & Goodman, 1996). 'Best interest' questions arise, as to who has the right to decide, with assertions being made that only the parents are in a position to make this decision and not the Deaf community (Balkany et al., 1996). This, Sparrow (2005) argues, endangers the cultural identity of deaf children, as there is a risk of depriving children a membership of any culture in being "between cultures". However, Most, Wiesel and Blizter (2007) highlight the complexity of cultural alignment, pointing to multiple characteristics that influence the development of cultural identity. These are outlined by Head, Cusack-Long and Stern (1991) and Israelite, Ower and Goldstein (2002) to include: degree of hearing loss, age of onset of hearing loss, type of sensory aid used, preferred mode of communication, hearing status of parents, education and social experiences.

In an attempt to compromise the seemingly opposing positions, Lane and Bahan (1998) suggest, the best outcome for the individual may be cultural competence and affiliations with both hearing and Deaf communities, thus, adopting a 'both/and' position (Burnham, 1992). Carrying on from this, McIlroy and Storbeck (2011) advocate for a paradigm shift in the consideration of deaf identity, from that of a binary concept, towards understanding deaf identity as a fluid phenomenon. It is also noteworthy that in some educational establishments (i.e. 'Hearing Impaired Units', HIU, or schools for children with 'hearing impairment'), Deaf awareness and Deaf culture lessons are taught, bridging the gap between the dichotomous positions.

Furthermore, a child may in the future exercise their right to choose to distance themselves away from aspects of their implantation, i.e. chose not to wear their processor or explore Deaf culture (Hyde & Power, 2005); thus, the CI creates flexibility in this sense.

In revisiting Bond et al.'s (2009) statistic: 95% of deaf children have at least one hearing parent; we may also consider this in the context of cultural alignment and making the decision of implantation. Firstly, it may be assumed that the parent may be unaware of other Deaf narratives (Hyde et al., 2010) to decide on any other cultural group than that of their own. Secondly, given their own status and positioning in the hearing community, is it viable to choose a community and culture for your child with whom you not a part of?

6. PARENTS' DECISIONS TO IMPLANT THEIR CHILDREN

Upon agreement by the professionals in the healthcare pathway that a particular child is suitable for cochlear implantation, it is the parents who have the final decision. They are positioned to make very important decisions about cochlear implantation at a time that is difficult and stressful (Burger et al., 2005). Yet, as described, this decision extends beyond the options of no surgery and hearing aids with minimal benefit, or surgery/ cochlear implantation. Parents must also decide how they wish to interact with their child (Johnston et al., 2009); aspects of socialisation and, thus, cognitive development opportunities afforded to them (Simonsen, Kristoffersen, Hyde and Hjulstad, 2009) and the culture and community in which their child will be brought up (Freeman, 1995). These complex decisions are influenced by the parents' beliefs, values and attitudes and the information that is available to them (Li, Bain & Steinberg, 2004).

It has been argued that the introduction of the CI has meant that parents now face the prospect of deciding between three options of cultural identity for their child. The existing options for hearing parents of deaf children were to either raise their child in the Deaf community, a community and culture inherently separate from their own, or to be raised in a hearing world, which allowed the child to remain in their parents' culture and community, but posed considerable challenges for communication. The introduction of the CI allowed for a third option: facilitating access to spoken language (Spencer & Tomblin, 2005).

6.1. Making a Decision

For parents who placed greater importance on their child learning to talk and participate in the hearing community, their decision was less difficult than those seemingly having knowledge of the sociocultural narrative of Deafness, and who worried about the cultural positioning of their child, i.e. hearing or Deaf community (Archbold, Sach, O'Neil, Lutman & Gregory, 2006).

Studies have examined the reasons why parents chose cochlear implantation for their child. The parents in several studies seemed to suggest that they were driven by a motivation to 'normalise' their child for them to speak (Power, 2005; Williams, 2003; Christiansen & Leigh, 2002) and to function as a hearing child (Kluwin & Stewart, 2000). One parent described how she imagined her child living "a lonely life in her head" as a deaf child (Devlin, 2003:33). It is therefore likely, according to MacKay (2010), that parents will chose feasible options of technology and/or surgery for their children and not other possibilities such as integration into the Deaf community and culture.

7. EXISTING DEAF RESEARCH

Research in the area of deafness has mostly focused on the paediatric population, and taken a biomedical/ audiological perspective (Penaranda et al., 2011); it aims to assess functional audiological outcomes. Psychological research is proportionally scarcer and tends to focus on the developmental trajectories of deaf children, often comparing them to hearing peers.

CI research accounts for a small proportion of the overall deafness research, given its relatively recent emergence in the UK (Wheeler et al., 2007). However, it is slowly gaining momentum, especially with the paediatric population of CI users. Again, there is a biomedical and audiological focus, with psychological research being under represented (Mance & Edwards, 2012). Given that the children who were first implanted in the UK are reaching adolescence and early adulthood, this represents a gap within the existing research base (Wheeler et al., 2007).

Overall, of the deaf research that has taken a psychological approach, the focus has considered aspects of child and adolescent development; an overview of this will now be presented.

7.1. Deaf Child Development

Hearing loss and deafness is said to impact on most areas of development (Geers, Tobey, Moog & Brenner, 2008); as a result, this has been a dominant focus of existing research, particularly the scrutiny of language development in deaf children. Proportionately fewer studies have focused on psychosocial and socio-emotional development in children and young people. Of these, given the deaf narratives and the ethical debates that emerge, the identity of deaf young people has been of interest for researchers in this area.

7.1.1. Language development

Theories of language acquisition map on to the nature nurture debate, with key theorists arguing for innate mechanisms (e.g. Chomsky, 1957) and theorists such as Skinner (1985) explaining language acquisition through operant conditioning principles. The ‘Language Acquisition Support System’ (LASS) put forward by Bruner (1983) offers an integrative perspective that emphasises a dialogical partnership in both the ‘active adult’ and the ‘active child’.

Language development in deafness, as noted, has been researched with a particular gaze towards comparative developmental trajectories of both deaf and hearing children; this in itself remains controversial, given the cultural perspective of Deafness and not seeing this as a deficit to be compared against (Lane, Hoffmeister & Behan, 1996). However, these studies typically suggest a myriad of factors, which may mediate language success for deaf children. In a review of these, Hyde et al. (2011), summarise these to be: age of identification; receipt of support (from professionals, other families, and other individuals with hearing loss); ability for family members to learn sign language; access to professional services; parental involvement; access to good quality early childhood education; and social economic status. Considering these layers of contexts, it is no wonder that predicting language development trajectories for deaf children is not simple or linear.

Exploring the language modes available to deaf children and their families (sign language, simultaneous signing and speaking, and spoken language; the latter, usually with the assistance of hearing aids or cochlear implants), Lederberg, Schick and Spencer (2012) reviewed the evidence of language development in each modality. They concluded that being deaf does not inevitably lead to language deficit and recommended that naturally occurring interactions in whatever mode of communication be introduced to deaf children as early as possible.

7.1.2. Socio-emotional Development

Competencies that make up ‘socio-emotional’ skills are outlined by Greenberg and Kusche (1993) as: good communication skills; having the ability to think independently; good self-direction and self-control; understanding own/ others’ feelings; flexibly approaching situations; being relied upon and reliant on others; understanding of own/ others’ cultures; and maintaining healthy relationships. It is argued that these competencies are also applicable in realising one’s own academic and vocational potential (Feuerstein, 1980). It has been suggested that deaf children demonstrate reduced mastery in many of these competencies and, thus, may be at risk of low academic achievement, under employment and psychological distress (Greenberg & Kusche, 1989). However Calderon (2000) moves away from a negative deterministic view of deafness and considers systemic factors, which may encourage socio-emotional development; including: the quality of the family environment, parental adaptation to deafness, family coping, school and communication resources, and child characteristics. Other findings support this (e.g. Bodner-Johnson, 1986).

7.1.2.1. Social-emotional Development: Children and Young People CIs users: Psychological research has more recently included children and young people who use CIs. One study focused on social-emotional development of this population group, and found there to be social-emotional difficulties in young people who use CIs (Pans et al., 2006); further research is needed to either support or refute these claims.

7.2. Psychosocial Development

Psychosocial development is a concept usually associated with general wellbeing (Martikainen, Bartley & Lahelma, 2002); to be free of psychosocial difficulties is to feel good about oneself, comfortable around others, in control of tensions and anxieties and able to achieve goals (Dammeyer, 2009).

Some evidence points towards a greater degree of social problems in deaf and 'hard of hearing' children and young people (Fellinger, Holzinger, Beilel, Laucht & Goldberg, 2008), including greater difficulties in peer relationships amongst deaf young people, comparative to their hearing peers (Remine & Brown, 2010). Research examining the impact of the extent of hearing loss on psychosocial development in children is inconclusive. For example, Polat (2003) found an association between greater degree of hearing loss and more psychosocial difficulties, whereas Sinkkonen (1994) and Hintermair (2007) did not. When considering the type of educational establishment a deaf child attends, greater social difficulties and a greater sense of loneliness have been reported in HIUs and mainstream classrooms (Byrnes & Sigafoos, 2001; Charlson, Strong & Gold, 1992).

On the other hand, systemic factors can promote development and dissipate any milestone-achievement differences between deaf and hearing peers. For example, Bodner-Johnson (1986) and Calderon (2000) suggested that parent attitudes, parent involvement, social support, expectations and problems solving skills, influenced the academic and social development of deaf children. Individual factors that promote the child's psychosocial development and wellbeing are positive affect, optimism, resilience, and peer acceptance (Oberle, Schonert-Reichl & Thomson, 2010). Peer acceptance was noted in those who were confident, outgoing and friendly towards their peers (Punch & Hyde, 2011).

7.2.1. Psychosocial Development and Wellbeing of CI Users

On the one hand, deaf children with and without CIs have been found to have a greater extent of psychosocial difficulties, as rated on standardised measures completed by their teachers (Dammeyer, 2010). However, other studies have indicated no difference between the social wellbeing of CI users and their hearing peers (Loy, Warner-Czyz, Tong, Tobey & Roland, 2010; Percy-Smith, Caye-Tomasen, Gudman, Jensen & Thomsen, 2008; Schorr, 2006; Warner-Czyz, Loy, Roland, Tong & Tobey, 2009).

Research examining the psychosocial development of children and young people who use CIs is also inconclusive (Dammeyer, 2009); the variability in audiological outcomes may account for the differences (Bat-Chava, Martin, Kosciw, 2005). However, even those with good spoken language development still encounter difficulties in social situations (Punch & Hyde, 2011). Findings such as these support the concept of ‘social deafness’, a term coined by Vonen (2007) to describe the social disadvantage deaf children, with or without hearing aids/CIs, have in following conversations in social situations.

7.3. Deaf Adolescent Development

7.3.1. Individual Identity

It is through interactions with social structures that one comes to understand their own individual identity and sense of who they are as a person (Hogg, Terry & White, 1995). In childhood, Shulman, Seiffge-Krenke and Samet (1987) depict parents as the most influential in identity formation through direct or indirect processes: determining the family climate and the nature of their social interactions, and influencing where interactions may occur (such as choosing a particular educational establishment for their child). It is acknowledged that in adolescence the extent of parental influence diminishes, whilst peer influence markedly increases (Shulman et al., 1987). In this way, identity formation is a socially constructed process in which one relates their past and present experiences into ones identity (Hadjikakou & Nikolaraizi, 2006). Thus, our identity is shaped and constructed in the narratives we form and the stories we tell others (Sikes & Gale, 2006). It is therefore interesting that although parents may have established certain social structures for their child, as a young person they may choose to deviate from them as they gain independence.

During adolescence, young people are also establishing their worldviews and a sense of who they are as person. Identity formation in adolescence is described by Erikson (1968). He suggests that at each stage of development a person must face a personal dilemma in which they need to overcome; it is through overcoming these sustained efforts that identity is acquired. He highlights key stages of development and their challenges: 12-18 years-old ‘early adolescence’, here the challenge is ‘group identity versus alienation’; then adolescence, 19-22 years-old, were the challenge is “identity versus role confusion’. It is in these stages that the person questions where they came from, who they are and what they will become.

Identity, as is understood and conceptualised in the present study, is inherent in the stories individuals tell, about who they are (Yuval-Davis, 2007) (and who they are not, Denis-Constant, 1995). In this way identity is seen as a "fluid, dynamic and shifting process" (Benwell & Stokoe, 2006: p 34) thus enabling self-identities to be assembled and dissembled, accepted and contested (Holstein & Gubrium, 2000). A narrator can draw upon edited versions or, preferred selves; presenting these in different contexts, for different audiences, thus making certain aspects of identity more salient at different times (Georgakopoulou, 2002).

7.3.2. Identity and Deafness

The identity of deaf children has long been noted as an important issue, given the debates previously outlined (section 5.3). In an attempt to depict the identities of deaf young people, Weinberg and Sterritt (1986) developed and utilised the Deaf Identity Scale (DIS). Cultural alignment was determined from which identity subscale received the highest rating: 'hearing', 'dual identity' and Deaf. Drawing on ideas of social acceptance it was hypothesised that more young people would align with a hearing status, as to be seen as "able-bodied" was to increase a child's chances of succeeding in life (i.e. establishing relationships and obtaining jobs) (Wright, 1983). However, this was not the case: 58% of participants identified as having a dual identity, 24% a Deaf identity and 18% hearing identity (Weinberg & Sterritt, 1986). Explaining their finding, they hypothesised that participants had a sense of "inferiority" when aligning with hearing peers.

It was later proposed that there are four static deaf identities: deaf, Deaf, negative/ambiguous identity, and bicultural identity (Bat-Chava, 2000). In a move towards a greater sense of fluidity, Ohna (2004) suggests there to be four phases of Deaf identity development (in order): "taken for granted", "alienation", "affiliation" and the bicultural "deaf in my own way[2]". Critiquing 'first wave deaf identity politics' (Davis, 2002) that assume only two static identities for deaf people: Deaf or deaf, thus, presenting an either/or category, McIlroy and Storbeck advocate for a paradigm shift in how deaf identity is conceptualised.

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[2] A person centred construction allowing one to enable a self-reflective stance coexisting in and between hearing and Deaf worlds.

They note the presence of this problematic binary (McIlroy & Storbeck, 2011) between the medical and sociocultural models in deaf research and deaf education (Davis, 2002). Thus, they defend the need to understand deaf identity as a fluid concept, including the concept of a DeaF[3] identity. In this way, identity is based upon a self-reflective co-existence between hearing and Deaf worlds, thus, an identity that is comfortable in both worlds. In moving towards identity as a fluid concept, in this 'second wave deaf identity politics', marginalised narratives are celebrated (Corker, 2000). Further, Fernandes and Myers (2010) advocate for the complexity of deaf lives, such as this, to be represented within deaf education and research.

7.3.3. Identity of Cochlear Implant Users

Young people who use CIs consider aspects of their deafness and their implant when establishing their sense of cultural and community belonging (Wheeler et al., 2007). In this way, young people who use CI might be described as "living between spaces" (Brueggemann, 2009:495), meaning that in the hearing community, with whom their parents mostly align with (Bond et al., 2009), they may have a sense of feeling 'different'; yet they may not feel a sense of belonging in the Deaf community either, given their oral communication (Leigh, 1999, 2009). It is these "in-between" states, that "frames identity as a quest for belonging instead of a narrow quest for self-definition…" (McIlroy & Storbeck, 2011:495) and may, in turn, create greater conflict for deaf young people using CIs.

Given this, Punch and Hyde (2011) argued that identity formation in young people who use CI face a time of understandable 'struggle'. More specifically, this struggle may entail: feelings of self-consciousness about their deafness, the visibility of the CI device and the sound of their speech; furthermore, they may have concerns around friendships, dating and their future plans in the world.

Some studies have explored cultural alignment of young people with CIs, using the DIS, developed by Weinberg and Sterritt (1986), and the Deaf Identity Development Scale (DIDS) developed by Glickman and Carey (1993) (e.g. Most et al., 2007; Wald & Knutson, 2000; Wheeler et al., 2007). These studies

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[3] An identity "which represents the cultural space from which they [deaf people] transition within and between both the Deaf and the hearing community" p.497 (McIlroy, 2010)

conclude that most individuals endorsed a dual identity, meaning they felt comfortable with Deaf individuals as well as hearing individuals.

Dual identity, such as this, has been suggestive of better outcomes in relation to academic placement, social relationships, personal adjustment and perceived family acceptance, than the endorsement of a hearing or Deaf identity (Weinberg & Sterritt, 1986). From their study, Weinberg and Sterritt (1986) hypothesised that children and young people with a hearing identity may have difficulties accepting their hearing impairment. They went on to suggest that these children and young people may grow up feeling less accepted by their parents, having a sense that their hearing difficulties should be hidden, and also when around others with hearing difficulties there is a sense of an uncomfortable experience. This, McIlroy and Storbeck (2011) would suggest, is due to the construction of identity around a person’s hearing loss; that when seeing deafness through only the lens of the medical model, hearing loss is seen as something to be overcome.

8. PSYCHOLOGICAL WELLBEING AMONG CI USERS: CHILDREN AND YOUNG PEOPLE

Previous research has indicated that deaf children and young people are at greater risk of psychological difficulties than their hearing peers (Farrugia & Austin, 1980; Hindley, Hill, McGuigan & Kitson, 1994; Hintermair, 2007; Fellinger et al., 2009). More specifically, low self-esteem is more prevalent amongst those who are not exposed to sign language and those who have hearing parents, whether or not they sign (Sacks, 1989). In this context, Bat-Chava (1993) highlights the acceptance of sign language as a vehicle towards accepting ones deafness, in turn, leading to higher self-esteem.

Research has attempted to demystify the factors affecting psychological wellbeing in deaf children and young people. In a study comparing mainstream and segregated educational establishments, no significant differences were found between the self-esteem of deaf young children in either site (Kluwin, Stinson & Cicerini, 2002). Yet, communication difficulties are said to be the main contributor of alienation from hearing peers, leading to marginalisation, ambivalence and isolation, which is said to lower self-esteem amongst deaf young people (Bat-Chava et al., 2005; Leigh & Stinson, 1991). Studies have also examined ‘relatedness’, which refers to emotional security in relationships with significant others, highlighting the greater sense of relatedness among deaf young people when they were with their deaf peers, as opposed to their hearing peers (Stinson, Whitmire & Kluwin, 1996; Stinson & Whitmire, 1991). Given this, young people may struggle in situations where there are few deaf peers to relate to.

There have been concerns regarding psychological consequences of paediatric cochlear implantation, particularly the psychological wellbeing of children and young people (Lane, 1992; Evans, 1989). However, recent research has concluded that deaf children with CI are no more likely to experience psychological difficulties than those who are not implanted (Dammeyer, 2010; Leigh, Maxwell-McCaw, Bat-Chava & Christiansen, 2009). Furthermore when comparing deaf CI users to their hearing peers, again self-esteem was rated fairly equally between the two groups (Percy-Smith et al., 2008).

Expanding on this, Mance and Edwards (2012) set out to examine the self-perceptions and psychological wellbeing of young people who use CIs. They hypothesised that those who perceive themselves to be closer to their ideal selves would have fewer psychological difficulties. In their study, having a hearing status was associated with higher levels of psychological wellbeing. Although being cautious of causality in this relationship, Mance and Edwards (2012) understood this in the context of rehabilitation aims from cochlear implants: to talk.

Having presented the existing research, a short summary of the trends in this area will be outlined, followed by a summary of the existing gaps in published research.

9. EXISTING RESEARCH: IDENTIFICATION OF GAPS

As demonstrated, deaf research taking a psychological perspective has assessed the development of deaf children, and compared them to their hearing peers. When including children and young people it has often taken an observational approach or quantative approach.

For those who have received paediatric implants, there has been a short-term outcome focus (i.e. infancy and childhood), with longer-term ‘outcomes’ (i.e. adolescence and early adulthood), particularly in the UK, being significantly underdeveloped (Christiansen & Leigh, 2002; Lane, 1992; Reagan, 2002). Meaning that, research including young people who have received paediatric implants is significantly underdeveloped (Mance & Edwards, 2012) and underrepresented in various research disciplines (Wheeler et al., 2007). Of the published research to date that has been able to include young people with cochlear implants, studies have again been predominantly observational and quantitative; qualitative research has tended to seek the perspectives of parents or professionals.

Therefore, in summary, the current gaps in research are identified as: directly including young people who have received paediatric cochlear implants as a means of assessing longer-term paediatric cochlear implantation; and seeking to gather the qualitative perspectives of young people who use CIs.

It must also be highlighted that there has been no research which has focused on the future perspectives of this population group, which again, adds a longer-term focus. Furthermore, no research has sought to gather the hopes, fears and expectations of paediatrically implanted young people.

This study aims to explore the gaps in research, by including paediatrically implanted young people, in seeking to gather their future-focused qualitative perspectives of hopes, fears and expectations. This will expounded in the next chapter.

10. THE PRESENT STUDY

10.1. Relevance to Clinical Psychology

This study aims to capture previously unknown perspectives from young people with CIs at a crucial stage in their lives that is, so far, under-developed in research. In exploring the narratives of young people, we may be better informed of some of the unique psychological consequences of being a CI user at this particular life stage.

This understanding may have implications for how professionals (including Clinical Psychologists, CP) work with young people with CIs. It may inform policy or suggest areas of wider societal change.

10.2. Aims and research question

The aim of this study was to consider the current gaps in research by directly including young people and seeking their perspectives; by virtue of this, this study aimed to have a longer-term focus on the outcomes of paediatric cochlear implantation. Furthermore, the future-focused research question also enabled a consideration of longer-term outcomes. Ultimately, this study aimed to explore the psychological consequences young people with CIs might face at this stage in their lives.

10.3. Research Question

> What are the narratives of young people with cochlear implants about their hopes, fears and expectations for the future?

11. METHOD

This chapter outlines the rationale and method for this narrative analysis study; it details the design, methodology and ethical procedures undertaken.

11.1. Rationale for chosen approach

Given that research that seeks to include the perspectives of young people with CIs is underdeveloped, little is available to generate research hypotheses and guide a particular focus. Furthermore, in defining a stringent focus, participants may not be able to draw upon issues pertinent to them (Kou, Shipp & Nedzelski, 1994). Therefore, an exploratory approach with deliberately broad research aims was appropriate to generate rich data; thus a qualitative approach was adopted, which is welcomed in CI research (Rembar, Lind, Arnesen & Helvik, 2009).

The literature review identified some gaps in current research (Chapter 9) which in turn informed the research question, to seek longer-term and future orientated perspectives of young people who received paediatric CIs. Therefore an approach that offered potential to explore longer-term/future perspectives was appropriate.

A range of qualitative methods were considered in the context of deaf research and the present study's research question. For instance, a thematic analysis was considered and deemed not to be appropriate, as representing the data in collapsed themes risked decontextualizing the tellings, of the complexities found in deaf people's lives, and the wider deaf literature (i.e. the debates of the opposing narratives of deafness). Similarly, a discourse analysis was considered, and again deemed not to be the most appropriate approach for this study, as it didn't speak directly to the research question. In discourse analysis, understanding 'how' participants use discursive resources is the main area of enquiry. Whereas in the present study, although some attention was given to how participants narrated their story, this was an adjunct to the main area of inquiry, which, was to understand 'what' the perspectives were. The research question was formulated in this way given that research in this area is novel.

The chosen approach for this study, was narrative analysis, a form of qualitative research; the rationale for its use was twofold. Firstly, narratives enable us to understand our experiences over time (Holloway & Freshwater, 2007) allowing us to interpret our past, articulate our present and guide our futures (Baillie, Novato, Johnson & Kalaw, 2005). This lent itself well, as it allowed for future perspectives to emerge. Secondly, a narrative approach was considered particularly poignant given the role narratives play in the construction and maintenance of self-identities (Hiles & Cermak, 2008) and the importance of identity issues among deaf young people (Wheeler et al., 2007).

11.2. Narrative Analysis

Central to narrative research, which is also referred to as Narrative Analysis (NA), is the idea that we make sense of, and communicate our experiences through narratives (Bruner, 1986). It "aims to produce knowledge about how people weave their experiences into meaningful stories and about some of the (psychological and social) consequences of this" (Silver, 2013:152).

Furthermore, it is considered a human interaction (Denzin, 2001), a relationship between the teller and the listener (Pinnegar & Daynes, 2007) whereby an audience can witness the performance of self and society (Denzin, 2001). Its use in health and illness research, is frequent (e.g. Riessman, 2002; Frank, 2006) and enables the narrator to perform preferred identities of themselves for a given audience (Benwell & Stokoe, 2006).

11.3. Epistemology

The present study takes a material-discursive epistemological stance, acknowledging the ‘material’ and physical feature of deafness and cochlear implant as a treatment of hearing loss; intertwined with the ‘discursive’ contribution; recognising how human experience is mediated by social and linguistic influences (Yardley, 1997). As argued by Yardley,

> “*We are intrinsically social and embodied beings, the material dimension of human lives is always socialised, meditated by language and consciousness and modified by social activity. While the discursive dimension is inevitably physically manifested, in our speech, behaviour, institutions and technology*” (1997, p.15).

A material-discursive position avoids being trapped between limiting dichotomies such as mind-body, deafness and Deafness. The material discursive position reconceptualises embodiment, from a culturally informed perspective, meaning the body is understood as an organism that is immersed within a culture, rather than being neutral of cultural influences. Therefore, it posits that the body is both materially and discursively produced (Bordo, 1993).

11.4. Reflexivity

Given that this study analysed ‘performative’[4] elements of the narratives, it is important to outline certain characteristics of the researcher. The researcher is of hearing status, however, has recently been diagnosed with moderate sensorineural hearing loss and wears a hearing aid. She has had a long-standing interest in deaf and Deaf issues, and learns BSL. In wearing a hearing aid she may be considered to align herself with the medical narrative of deafness; and yet on the other hand she is immersed within the Deaf

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[4] The influence of the narrator upon the observer (Goffman, 1959).

community through her learning of BSL. It may therefore be argued that she straddles and sees the merits in both social narratives.

11.5. Participants

This study recruited eight young people between the ages of 16 and 18 who use CIs and had being using a CI for a minimum of seven years; which, referred to continuous use from the date the CI was switched on. This was important as the study wanted to capture the perspectives of young people at this particular life stage and not experiences of adjustment, or being new to, CIs. Research suggests that children can take 4-6 years to adjust to CIs (Nicholas & Geers, 2003); therefore to account for this, use of CI, in this study, was set at seven years, in fact the average use of a CI for the present study was 13 years and 4 months[5].

All participants communicated through verbal language (English), which was a requirement of participation. The average age of participants was 17years-old[6]. There was an equal gender mix; four female, four male. Participant ethnicity and cultural affiliations, including family structure and hearing statuses were not collected in this study, as they were not recruitment factors.

The study excluded those who were in current receipt of support from mental health services. This was an ethical dilemma, however there was a small risk of distress being exacerbated during the interview process. Therefore, it seemed ethically reasonable to exclude participants on these grounds.

11.6. Recruitment

In this study there were two recruitment stages of purposeful sampling. Initially, participants were to be recruited from a NHS-based CI service, Great Ormond Street Hospital (GOSH), however, as only one participant was recruited, a second recruitment stage was added. These recruitment stages will be referred to as ‘recruitment stage one’ (NHS-GOSH) and ‘recruitment stage two’ (non-NHS based recruitment i.e. charities and other organisations).

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[5] Calculated from switch on date to 1st November 2014, the time of recruitment.

[6] Actual value=16.875, this was rounded up to the nearest whole year.

11.7. Procedure

Recruitment for this study began in October 2014 and ended in December 2014. Given that the two recruitment processes (i.e. recruitment stage one and two) came under differing ethical boards, NHS-GOSH and University ethics boards respectively, the methodological procedures differed somewhat (see appendix 1).

11.7.1. Ethics and Registration: Recruitment Stage One

Relevant university procedures were followed, in applying for (appendix 2) and gaining ethical approval (appendix 3). Subsequent to this, NHS-GOSH procedures were followed and ethical approval was granted (appendix 4).

11.7.2. Ethics and Registration: Recruitment Stage Two

As the original ethics application only covered NHS-based recruitment a re-application was submitted (appendix 5&6) and subsequently approved (appendix 7).

11.7.3. Recruitment Stage One: Initial Procedures

Potential participants were identified from an existing electronic database cross-referencing the inclusion and exclusion criteria for the study. From this, a GOSH staff member distributed 23 letters to potential participants (appendices 8, 9 & 10) and their parents/ guardians (appendix 8 & 11).

Letters to the young people were amended as per ‘language age’; which is routinely collected in the service up to five years post implant. For those whom ‘language age’ may have been considered to be ‘out of date’ consultation between the distributor of correspondence and a member of GOSH CI staff, who knew the potential participant well, occurred.

A period of around 3 weeks was given for potential participants to respond to the written request; as there were no spontaneous responses, a GOSH staff member made contact with non-respondents via telephone. This was to ensure they had received the written correspondence, and answer any questions they had about the study. Given that some participants would have struggled with using the telephone especially with unfamiliar voices, the GOSH staff member followed their usual department protocol in requesting to speak with the young person. If the parent explained that the young person was not able to speak on the phone, the GOSH staff member advised them regarding the purpose of the phone call; in these cases the parent relayed information to the participant. This generated two potential participants, who the researcher attempted to contact; from this, contact was only established with one participant.

11.7.4. Recruitment Stage Two: Initial Procedures

After approval for the second UEL ethics application was received (appendix 7) relevant organisations were contacted and advertisements for the study were published on social media (appendix, 12). From this, one charity organisation agreed to assist with the recruitment for this study, and made contact with potential participants, for whom they had the details on an existing database. Those who agreed to participate were sent an information pack, including: an invitation letter (appendix 13), information sheets for the young person and their parent(s) (appendices 14 &15, respectively), and consent forms for the young person and their parent(s) (appendix 16 & 17, respectively). The details of those who agreed to participate were given to the researcher, who then initiated contact to arrange an interview. Thirteen potential participants were identified; contact was made with ten (three were not contactable). Of these, one person was excluded due to receiving active support from mental health services; one person, after agreeing an interview date, withdrew from the study due to family circumstances; for another potential participant, an agreed interview date was not established.

11.7.5. Interviews

Data were collected through one-to-one topic-focused narrative interviews (Hiles & Cermak, 2008). All but one of the interviews was conducted in face-to-face meetings at the participant’s home, this was where the participant felt most comfortable and had better control of the hearing environment. One interview took place over Skype, due to geographical location; this was how the participant often communicated with their family. All interviews were audio recorded and transcribed as per the transcription convention (appendix 18) based on transcription guidelines as proposed by Parker (2005). Given the attention to performative aspects of the co-constructed narrative both voices were represented within the transcripts. Other utterances and sounds that enable the reader to understand the research encounter were also provided (e.g. laughter) as proposed by Parker (2005).

Six of the interviews were conducted with only the researcher and young person present; one young person's parent was present briefly at the start of the interview, another young person's parent was present throughout.

Prior to commencing the interview, the young person (and parent, where applicable) was reminded of the aims of the study and the research question being asked. Participants were reminded that interviews would be audio recorded. Prior to the interview commencing, consent forms were collected and participants were verbally reminded about the terms of confidentiality, and the storage of personal information, audio files, and transcripts. To emulate transparency the participants were informed of the style of interviewing, which is connoted for being less structured than some other approaches. This was put to the participant as enabling them to have greater control in the telling of their story (Kellas & Manusov, 2003). Yet, if they found it difficult, the researcher would make use of some prompts, which had been co-constructed with a psychologist in a CI service (appendix 19).

The eight interviews took place in one encounter and ranged from 29 to 57 minutes long, with an overall average of 44 minutes per interview.

All participants were given a copy of the relevant 'support information' corresponding with their recruitment stage (appendix 19 & 20, recruitment stage one and two, respectively) for their information. Further, it was explained to participants that the interviewer would contact each interviewee to seek their input from the proposed analysis of their data; all participants agreed and gave the researcher a corresponding email contact.

11.8. Analytic procedure

11.8.1. Overview and rationale

It is acknowledged that there are many ways to analyse narratives, therefore, what constitutes NA, is often contested (Riessman, 2003). However, all forms of NA are concerned with the content of the narrative (Riessman, 2008) and should ultimately seek to understand the structure of a narrative, its function and its social and psychological implications (Willig, 2013). Analysing narratives in multiple ways and deviating from a prescriptive formula of NA, is advocated for by Riessman (2008). In the present study holistic narratives are analysed for their content, linguistic features and performative enactments.

Focussing on the holistic narrative took place, so that the narrator remains central to what they say (Riessman, 1993). It also allowed for a clear consideration of social and cultural contexts for each participant, as issues previously identified had highlighted the relevancy of considering wider contextual factors (chapter 2). Furthermore, collapsing the data into themes across participants may have de-contextualised the data.

Analysing the content of the narratives was important due to the research being novel in this area. Further, it was especially relevant to the study's research question (section 10.3). The researcher thus sought to gather narrative content pertaining to hopes, fears and expectations, as well as considering other emergent stories.

Linguistic features, as outlined by Lieblich, Tuval-Mashiach and Zilber (1998) add depth to the telling and aid the reading of the narrative encounter. Moreover, they captured attempts to persuade the listener, which in turn complimented the performative enactment this study was also interested in.

The performative enactment was particularly of interest as it offers to contextualise the telling and allows for analytic possibilities to emerge (Langellier & Peterson, 2004). Furthermore, given the differing contexts the listener and teller were potentially acting out of, it was considered crucial to capture this aspect of the co-constructed narrative. Taking a performative stance, according to Patterson (2002) enables the narrators to take a privileged position, as they negotiate what they want the audience to know about them, thus they 'perform' a sense of preferred identity. This has been demonstrated in studies analysing illness narratives, whereby an author can select from a multiplicity of selves to perform in the telling (Harre & Van Langenhove, 1999).

11.8.2. Level 1: Content (fabula)

As described, this study focussed on the narrative content pertaining to hopes, fears and expectations, as well as considering other emergent stories from the holistic narrative (Paget, 1983). It did so by identifying sub-narratives in accordance to Labov's (1972, 1982) framework, including the following elements: abstract, orientation, complicating action, resolution and coda. The abstract refers to a summary or overall point of the story and orientation serves to inform the listener of the setting, time and place of the story. Complicating action encompasses sequential aspects in the telling, such as aspects that allow for the plot and sequence to unfold. This also refers to aspects of the narrative that appear to represent a crisis or critical turning point within the sub-narrative. Resolution refers to concluding elements of the sub-narrative, which serve to summarise the outcome of the plot; representing the end of the sub-narrative, the coda serves to bring attention to the present.

11.8.3. Level 2: Sjuzet part one: Performative analysis

To examine aspects of performative enactments this study drew upon Frank's (2006) performative analysis framework. At the level of the telling, the research explored:

- What multiple voices can be heard in the text?
- What resources were used to shape how the story is told?
- What other narrative resources may have been available and what prevented these from emerging?
- What was at stake? How did the teller hold their own?
- How does the story teach people who they are and how people tell stories to explore who they might become?

In considering the investigators influence the research asked:

- What resources shaped how listeners comprehend the story?
- What influence did the listener have on the production of the narrative and its interpretation?
- How is the story co-produced in a complex choreography in space between the teller and the listener, including power dynamics?

Wider contextual factors are also influential; Frank (2006) proposes that research examines:

- How the story co-produced in a complex choreography in space between the speaker and the setting, speaker and culture.
- Who will be affiliated into a group that shares a common understanding.

- Who does the story render external or other.

In this study, ‘setting’ referred to aspects of the tellers life, including family, the hospital/CI service, the CI charity (were most participants were recruited from), friends and social networks, as well as, the wider society. ‘Culture’ considered the social narratives of deafness as previously outlined (sections 2 & 7.3): deaf, Deaf and hearing; as well as other aspects of societal culture.

11.8.4. Level 2: Sjuzet part two: Linguistic features

As an adjunct to thicken the analysis linguistic features were also considered. This drew upon Lieblich et al. (1998) framework, which aimed to examine how the teller attempts to persuade the listener. In this, the researcher systematically examined the holistic narratives for: adverbs, mental verbs, denotations of time, intensifiers and repetitions.

These levels of analysis were merged to form an idiosyncratic analytic framework for this study, which evolved during the analytic process (appendix 21). Although it appears to artificially separate concepts (i.e. aspects of content and performance), in reality, this was a more fluid process. The framework was developed to ensure that a systematic enquiry of each narrative occurred.

11.9. Supervision

Supervision was provided by both UEL and GOSH. This provided opportunity for potential research bias to be examined through the course of personal and professional reflection.

11.10. Ethical Considerations

Appropriate procedures were adhered to in collecting ethical approval from the corresponding institutions: UEL and NHS-GOSH research committees. As noted, the procedures differed between recruitment stages due to differing recommendations from each institution (appendix 1); therefore, some of the ethical considerations differ.

11.10.1. Informed Consent

Potential participants from ‘recruitment stage one’ were firstly contacted by letter and then followed-up with a telephone call. As previously described (section 11.7.3), potential participants were sent an information pack consisting of appendices 8-10; their parents received a separate letter informing them of what their child had been invited to participate in, this included appendices 8 and 11. Both the young people and parents were given the mobile contact details of the researcher, in case they had any questions (call/text). Agreement to participate meant that the invitee gave the researcher the contact details of the potential participants.

In ‘recruitment stage two’ the researcher advertised the study on social media and contacted relevant organisations (appendix 12). The researcher sent information packs (see 11.7.4) to the relevant organisations to distribute to potential participants (appendices 13-17). A charity organisation aided the contact with the majority of the participants, as discussed. They made verbal contact with the potential participants’ parents firstly and sent written correspondence (information packs) upon their agreement. Contact details of those interested in participation were given to the researcher.

In both recruitment stages, the researcher made contact, as preferred (telephone, email or text). Contact was mostly with the parents due to communication difficulties over the telephone with unfamiliar voices for most CI users. In this phone call, the researcher reiterated the details and ethical considerations of the study to relay to the young person and gave them and the young person the opportunity to ask questions (via their parents or text).

All participants received an information pack in advance of the interview to ensure they had time to read the relevant information. They were given the contact details (research mobile telephone/ email) in case they wanted to contact the researcher before meeting. They were given a copy of the information sheet to keep (appendix 9 & 11, recruitment stage one; appendix 14 & 15, recruitment stage two).

On the day of the interview, prior to the interview commencing, the researcher verbally reiterated aspects of the ethical considerations and checked the understanding of the consent forms; these were then collected from the participants, and parents, where necessary. Written participant consent was obtained from all participants.

11.10.2. Parental consent

In ‘recruitment stage one’ the NHS-GOSH ethics committee instructed that parental consent was not required for 16-17 year olds because they would be deemed as competent (‘Gillick Competent’[7]; House of Lords, 1985) and 18 year olds are legally adults. However, in ‘recruitment stage two’ parental consent was sought from parents of those who were 16-17 years old, as instructed by the UEL ethics board. All participants were advised in writing to discuss participation with their parent and/or guardian.

11.10.3. Withdrawal

Participants were advised of their right to withdraw from the research study, without having to give a reason, and with no detriment to their affiliations with the organisation they were recruited from. It was explained (in writing and verbally) that withdrawal from the study was not possible once analysis had begun. Participants were informed of the approximate time frames of this and were contacted when the analyses commenced.

11.10.4. Confidentiality and Anonymity

Participants were advised (in writing and verbally) of the terms of confidentiality. For example, only the researcher would have access to their personal information; audio recordings would only be listened to by the researcher; and during the transcription process, all data would be anonymised and pseudonyms given. They were advised that supervisors of the study may also read the transcriptions, but details would have been changed so that they remain anonymous and are not identifiable. All files pertaining to the study, i.e. audio file and transcripts were stored separately, each being password-protected with a different password. Each file was stored in a password-protected folder, stored on a password-protected computer, kept in a locked environment. Back-ups of the files were stored on an encrypted USB and stored similarly, i.e. separate password protected files and folders. Participants were advised, in writing and verbally, that confidentiality would be broken if the participant was to say something which indicated they, or someone else, was at risk of harm.

Audio recordings and personal information will be deleted/ destroyed when the research project has been passed by the UEL examining board; transcripts

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[7] Demonstrates sufficient maturity and comprehends the nature and implications of decisions

destroyed after three years to allow for possible dissemination of findings.

12. ANALYSIS AND DISCUSSION

This chapter outlines aspects of holistic narratives performed by each participant, integrating the multiple layers of analysis: differing analytic considerations will be drawn out and made explicit. Where applicable, analyses will be linked with literature previously mentioned, or emergent and relevant.

Interjections in the excerpts, such as utterances of encouragement (e.g. uh-huh, yeah, hm) will be replaced with ellipses (i.e. "…"), to aid the flow of the narrative. Contributions from the listener are signified in bold font, to distinguish them clearly from the teller's narrative; square brackets signify line numbering, so as not be confused with the parentheses used for pauses as described in the transcription convention (appendix 18).

Biographical portraits of the participants can be found in appendix 22.

12.1. Tom

Tom's holistic narrative centres on capability. His hopes and fears are interconnected throughout his narrative.

12.1.1. Fears and Hopes: Achieving at College

As is seemingly his highest level of context (Cronen & Pearce, 1982) Tom opens his narrative by describing his fears of "staying another year" [19] at college if he did not "get the grades" [22-23] he wanted. He also describes wanting to "go straight to uni" [28]. Returning to contextualise his fear, Tom states:

> [33-39] "The reason why I fear that is because I don't wanna be left behind a year… and er also my family they've all managed put-- to get into uni within er the first time so I don't wanna let them down…as well as myself".

The idea of being "left behind" [34-35] conjures up a persuasive image, which may initially serve to encourage empathy from the listener. Holding an element of responsibility, Tom states “not working hard enough” [41] will hold him back from obtaining his hopes. It seems more tolerable for Tom to discuss what he will do and what he is enabled to do in the context of his “good school [that] provide[s] good education for the deaf” [48-49]. By virtue of this, perhaps Tom performs a desire not to engage in ‘problem saturated’ (White & Epston, 1990) narrative. However, Tom returns to a narrative of fear thus performing a sense of uncertainty even if his efforts bear the desired results. He solidifies his concerns with examples:

> [238-242] “…what my brother went through I watched him what he went through…in the summer ( ) he er missed out by a grade to get into uni”.
>
> [250-253] “If I do get grades er ( ) sometimes uni still doesn’t let you in…cos that happened to my cousin as well”.

These examples, serve to persuade Tom and thus the listener, that failure is possible; despite this, they seem divergent from the depiction of family norms, Tom is aiming to keep up with. Further, his family’s struggles do not seem to have normalised his experience, in fact it seems to have solidified its possibility, or create an increased degree of uncertainty. Any difficulties Tom might have faced, do not feature in this sub-narrative, seemingly as holding his own as ‘keeping up’ with his hearing family. He thus preserves his alignment to his family, perhaps striving to align with those whom he associates with success (Wright, 1983).

12.1.2. Educational Support: “I didn’t need all that help” [309]

Tom appears to perform a preferred future identity of capability, continuing with this integral aspect of his current and past identity:

> [305-312] “If I don’t get that all round support it wouldn’t really bother me cos it let me learn to be more in—independent… er also I’ve always thought that I didn’t need all the help at the school I am cos I can hear so well talk so well…er so yeah I can kind of manage on my own”.

This narrative speaks to the predominance of a hearing society, hearing being privileged (Power, 2005) and therefore advantageous for learning. Informing this may include: the family hearing status, schools encouragement of audiological gains, the emphasis of medical services to promote audiological gains (Hyde et al., 2010; Mance & Edwards, 2012) and the wider society seeing hearing as the ‘norm’ (Power, 2005). This narrative appears to subjugate the sociocultural narrative of Deafness and Deaf identity; it portrays an alignment further towards a hearing identity. This was solidified through examples of Tom going to “mainstream school” [314]: “I was sitting in back of classroom I could still hear the teacher well…nothing went wrong” [317-320]. Again, this maybe a feature of social acceptance and an alignment with those considered successful (Wright, 1983).

12.1.3. Going to University: “I’m more excited” [325]

Tom explicitly notes his deafness as a factor to be excited about in going to university. From the context of his deaf school, where he states: “we’re all the same” [349], it might be hypothesised that Tom sees himself as being separate from hearing people at university and to be excited about their curiosity:

> [322-330] “Going into uni with me being deaf doesn’t really bother me actually am…I would say I’m more exciting cos I will be different compared to everyone else there…who actually go who are hearing I’d be like the deaf one there and it’d be pretty cool”.

Tom’s excitement about going to university is centred on the assumption that most people there will be of hearing status and there will be a difference in which: “they’ll probably be asking me loads questions” [333]. Tom’s sense of emotional security in his relationships seems to oppose social relatedness hypotheses put forward by Stinson et al. (1996), and Stinson and Whitmere (1991), given that Tom acknowledges his commonality to his deaf peers and yet eagerly wants to relate to his hearing peers at university. Performing his preferred identity of being inspirational figure, he states “the fact that er that it’s an amazing achievement [to go to university] ah God if he’s deaf and he can do it why can’t I so I’ll be…a bit of an inspiration” [334-337].

Here, Tom positions himself as having overcome struggles to be of equal status to his hearing peers, perhaps this emulates empowerment and wanting to hold power the hearing have. In line with this, Tom also performs a sense of independence when outlining his expectation for the future, to "live by myself" [531-532]. Given the hearing status of the listener, perhaps Tom is seeking to inspire the listener in the research encounter. However, he is certainly drawing upon linguistic resources to solidify and persuade of this preferred future event, especially through the use of multiple voices. For example, this message seems to have been reinforced by Tom reflecting on a professional footballers achievements: "cos er ( ) him being 19 and getting an England call up makes me think if I'm 19 maybe I can achieve this…it doesn't matter if I'm deaf" [773 - 778]. Here, Tom speaks directly to a sense of identity and emulates a position of acceptance of deafness. Perhaps Tom's optimism and resilience here, promotes a greater sense of psychosocial wellbeing (Oberle et al., 2010).

12.1.4. What it Means to be Deaf

Seemingly, Tom appears to separate from some aspects of deafness, particularly the sociocultural narrative:

> [373-377] "I'm more adapted for the hearing world cos I'm the only deaf person in my family…and I've been brought up hearing just talk ( ) fully oral".
>
> [384-386] "I've been brought up to actually (3) er (3) it's hard to put in words er ( ) understand er: at the same levels so hearing kids would".
>
> [402-403] "I spoke so early ( ) and now I've got a voice".

Implicit through linguistic features and explicit in the content, is Tom's unease in speaking about the differing worlds within his context: hearing and Deaf. This may be driven by the duality of his loyalty, in that his family are hearing and he mainly has deaf friends; this maps on to the previously described debate in deafness (section 2.2; e.g. Blume, 1999) and perhaps, a sense of Tom not wanting to be stuck 'between' cultures (Sparrow, 2005; Brueggemann, 2009). Speaking to a preference for good (oral) communication, the rhetoric of the medical model and CI services (Mance & Edwards, 2012), Tom positions himself as adapted for the hearing world, yet his narrative doesn't capture what has enabled this; his CI is invisible in the entire narrative. Preventing this narrative resource may be Tom's developmental stage or perhaps Tom is somewhat self-conscious about his appearance (Punch & Hyde, 2011) in the encounter. Furthermore, given the listeners hearing status and the powerful position she holds, does Tom's preference lend itself to social desirability within the research encounter and the multiple contexts (hearing family and society) in which Tom finds himself?

Linguistic features within the narrative, particularly denotations of time (Lieblich et al., 1998), signify Tom's past perspective of Deaf people as different from himself, which he orientates at the opening of the narrative "Deaf people [background noise] are not bad" [409-410], further, he states:

> [412-417] "Before I didn't really see myself getting on with Deaf kids [background noise stops] I thought it'd just be signing…all that ( ) but its more half signers half oral".

> [420-423] "I thought it wasn't (2) erm (3) I thought kids signing wasn't right for me…. I thought it was weird to see that".

This appears to support the notion being uncomfortable among other deaf peers, as previously noted by Weinberg and Sterritt (1986). However, subsequently, a newfound opinion emerges:

> [425-429] "One of my good friends he taught me how to sign fluent in school…and er how to sign it's quite <u>interesting</u> signing to kids".

> [432-434] "…their lives are very interesting because er the way they're brought up maybe because their family are also Deaf".

Interestingly, he draws upon a historical social narrative of Deaf people who are mute having no/minimal intelligence because of absence of spoken language (Bender, 1981; MacDougall, 1991); suggesting the dominant narrative remains within (a hearing) society (Vernon, 2005). It may be hypothesised that Tom's previous perception of Deaf people's intelligence, prevented a greater alignment to sociocultural Deafness; and his venture in learning sign language may, as Bat-Chava's (1993) suggests, represent a vehicle towards accepting aspects of his deafness.

> [447-453] "Some Deaf kids are actually pretty smart…and I thought they wouldn't I wouldn't say they were dumb but I would say they were average but there's some Deaf kids who are just very smart actually".

This, Tom admits had challenged his view of other Deaf people. As his narrative evolved, Tom seemed to have greater alignment with the Deaf culture, and perhaps lends itself to a DeaF identity (McIlroy & Storbeck, 2011). With this, Tom explains his interest in other Deaf people and Deaf ways; his deafness appears embraced. Perhaps enacted here is a sense of social relatedness to his peers (Stinson et al., 1996; Stinson & Whitmere, 1991), especially given his developmental stage having a greater influence on identity formation (Shulman et al., 1987). The listener's implicit interest of Deaf issues may have made it more possible for Tom to include this shift within his telling.

On balance, Tom also presents aspects of his view that have changed "that are bad" [484] he explains: "with Deaf in the Deaf world there's a lot of drama and a lot of gossip and rumours…which can be quite heart-breaking humiliating" [484-489]. He explicitly compares this to his hearing friends who "never kick up sort of drama" [496] he adds "that's why sometimes I prefer hearing friends" [499]. Here, through Tom's social groups he performs a connection with both hearing and Deaf friends, demonstrating his mastery in choosing a friendship group he prefers. This duality, as previously described, offers a sense of relatedness to both communities (Lane & Bahan, 1998) and opposes a sense of being stuck between cultures (Sparrow, 2005; Brueggemann, 2009) and non-acceptance from either culture (Lane & Bahan, 1998). It might be hypothesised that conceptualising deafness identity fluidly (e.g. McIlroy & Storbeck, 2011), enables this bi-cultural relatedness.

Tom, overall, performs confidence and competence. He views his deafness as something to set him apart from the rest, seeking to inspire those who he comes into contact with.

12.2. Sinead

Sinead's holistic narrative considers aspects of acceptance, particularly from herself and others.

12.2.1. Hopes and Fears

Sinead speaks of her ambitions in the future "to become an artist" [46] and is quick to acknowledge her related fears: "but er: I'm terrified that I won't be able to achieve that…" [51-52]. Attempting to normalise her fears, she states: "I erm (2) I expect a lot of things in life but I mean everyone does, everyone has hopes and dreams but not everyone can get them" [74-76].

Her hopes and expectations are intertwined; she appears to persuade the listener in forming an alignment with "everyone" [75], possibly from a position of power in numbers. Sinead depicts her sense of self-expression through her art:

> [68-73] "Its hard because I try to not make it about me being deaf I try to make it about me being person personally who I am…I don't e—ever think about being deaf I just think we're all normal people (3)".

Sinead refers to a holistic identity that rejects a position of deafness being all of who she is. Here, her identity is, arguably, formed as a result of her past and present experiences (Hadjikakou & Nikolaraizi, 2006); she performs both who she is and who she is not (Yuval-Davis, 2007; Denis-Constant, 1995). Further, she challenges wider societal assumptions of 'normality' through rhetoric of humanity and equality, performing her resistance (Foucault, 1970) of the identities imposed on her by powerful others (Philip, 1985).

Through her hoped for career, Sinead describes wanting to "meet a lot of famous people" [92], she appears to romanticise about their lives: "I'm thinking are their lives like ours or are they different? ...Do they have those expectations do they have those dreams that…that we once did?" [93-99]. It may be hypothesised that this refers to those in power within society, and interestingly leads to wonderings about the depiction of deaf people within popular media. Given we see predominantly hearing people through the media (Jankowski, 1997), is this a romanticised view of hearing people? Sinead appears to align with others by using “ours” and “we”, which could refer to those who are not famous; not in a position of power; friends/ family; perhaps, the Deaf community, or even the listener and herself in the research encounter. Nonetheless, Sinead performs her curiosity and a desire to connect with those she sees as different from herself; perhaps this serves to bridge the gap between the ‘problematic binary’ depicted in deaf identities, i.e. deaf or Deaf (McIlroy & Storbeck, 2011) and achieve a greater sense of acceptance from others.

12.2.2. Overcoming: ‘I was too stuck’ [305-306]

Sinead’s story points to a journey of overcoming; she starts by considering her relatedness to her friends:

> [290-294] “A lot of my friends were very depressed because they didn’t like who they were, they didn’t like being deaf, they didn’t like (3) who they were ( ) and er it kind of brought me down it, kind of made me think about myself”.

Here, there is a sense of collective depression[8], emphasised in her repetition, amongst Sinead and her friends from which she possibly wanted to break free, perhaps this maps on to Sinead’s individual identity development in facing the challenge Erikson (1968) depicts as ‘group identity versus alienation’. Inherent in this narrative is a sense of negative self-evaluations, which Harter (2006) associates with a sense of low ‘self-esteem’. Perhaps seeking to understand this collective depression and alluding to a sense of rejection she may have felt from the predominant hearing society, Sinead moves to consider societal narratives: “Society changed a lot and people really make you think of who you are and…make you think what your disabilities are and what your weaknesses” [298-302]. This maps on to rhetoric of ‘normalcy’, which Foucault (1970) purports is created by ‘the human sciences’; it is through rhetoric, Jankowski (1997) argues, that the legitimisation of the ‘normal person’ and, thus, exclusion of the deaf person, occurs.

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[8] A sense of depression felt by a number of people or a community

Mirroring the findings previously put forward by Weinberg and Sterritt (1986), Sinead describes her deafness as needing to be hidden: “I was too stuck in the area ( ) and the people I surrounded by…and for being deaf it was like (3) you should never mention it” [305-309]. Speaking from a past position and yet using the present tense for the narrative to be vivid and perhaps betraying that acceptance is an on-going task, she reflects: “I just like I need to move on and I need to ( ) app--appreciate who I am, I need to be a person that (2) who will love myself and know it’s okay being deaf” [309-312]. Here, Sinead appears to want to prioritise her own self-acceptance. Further, she alludes to a systemic and multifaceted understanding from others; perhaps there is a hoped for outcome that she is also able to embody this understanding, or for it to be part of her everyday life: “People now understand about being deaf, they understand about cochlear implants” [312-314]. This systemic understanding Calderon (2000) would hypothesise may lead to increased socio-emotional skills.

Sinead then moves to a past position: “in my primary [school] I was alone I was isolated ( ) I was treated like a (5) dumb deaf person” [337-339]. Sinead’s description of her experiences at her mainstream primary school supports Byrnes and Sigafoos (2001) and Charlson et al. (1992) findings of loneliness in these settings. Further, she relates her sense of rejection to a historical social narrative of Deafness in which the absence of a spoken language was synonymous with lack of intelligence (Bender, 1981; MacDougall, 1991). Those who are rejected, Diamantopoulou, Rydell and Henricsson (2008) argue, tend to strive for greater social acceptance. Perhaps aligning with this notion, Sinead speaks of a desire for less of a division between those with hearing and deaf statuses in society:

> [344-346] “It shouldn’t be about hearing or why you’re deaf, it should be about who you are ( ) what’s your personality like ( ) it shouldn’t be just because you’re deaf”.
>
> [375-377] “...and now I think who cares you’re deaf, so what () you can still talk, you can still talk to people, you have hopes you have dreams, follow them”.

Sinead speaks directly to a sense of overcoming and acceptance when reflecting on her journey; she focuses on what she is able to do and seems to value her ability to communicate and dream. Sinead, performs her quandary, particularly using the present and past tense, perhaps suggesting the struggle for acceptance remains current: “but I think I’m stuck feeling there ( ) I can’t think like that…and my friends try to encourage me to try to think like that …but it was hard” [379-385]. Perhaps, depicted in Sinead’s telling are her ‘phases’ towards a Deaf identity (Ohna, 2004) reflecting on ‘alienation’ she felt and the ‘affiliation’ she seeks.

12.2.3. Abandonment

Sinead spoke of a distinctive mainstream view in society, she explains: “mainstream thinking is er we have to vote ( ) we are London… we like David Cameron ( ) we don’t like disability people (2) men are sometimes upon us” [779-783]. In giving an example of disability, it is unclear whether she conceptualises deafness as a disability (Butler et al., 2001), perhaps if she did, her following example may represent a more tolerable position from which to speak; she chooses to speak of a “down syndrome kid” [836]. She continues: “just because it’s disabled doesn’t mean you should give it away, you should keep it and show that you love it” [858-860]. The narrative resources, which serve to de-personalise the child in her example (i.e. “it”), may signal an unconscious or conscious defence against the emotionality she feels. Aligning with the fear of abandonment, yet not on the basis of her deafness, she states: “I’m scared of being ( ) abandoned and won’t be able to cope to be in a place I want to be…Er (2) be in a position that I don’t want to be in” [902-907]. Sinead reflects that this may be around her life choices being different from the wishes or expectations others have of her, again speaking to a sense of desired for social acceptance, which may have been accelerated by her past experiences of exclusion (Diamantopoulou et al., 2008).

12.2.4. “Okay in the End” [1018-1019]

Sinead returns to a sense of self-acceptance as a hoped for outcome for the future, in her hope to “be okay in the end” [1018-1019]. Thus, “being able to express my stuff ( ) and not being so scared about expressing it, people knowing a little bit too much” [1013-1015]. The mystery remains regarding who she refers to here, however, this seems to be on the basis of others not fully understanding her views; perhaps she refers to those whom she is close with and unable to open up to, or even members of a collective society made up of predominantly hearing people (De Klerk, 1998).

Following a narrative of self-expression, an exploration of a preferred future identity occurred:

> [1058-1067] “To be the same person…to still have the state of mind and think it’s okay ( ) to be like this it’s okay not to er cover myself…and so it’s not okay when I keep covering myself because I’m an adult I will be surrounded by hearing people, and I will cover myself more and more, but I don’t wanna be like that I want to be open’.

This particular narrative speaks implicitly of the visibility of deafness by virtue of wearing a CI, which ought to be hidden. This is in line with previous findings, which suggest a desire to hide aspects of deafness amongst hearing people (Weinberg & Sterritt, 1986). Further, perhaps elements of mystery in Sinead’s narrative serve to ‘cover’ certain things from the hearing listener. Moreover, ‘covering’ appears both visual and metaphorical as she later elaborates covering to mean: “Like er I’m not deaf I’m like, it’s really hard, it’s er like I’m not deaf I’m covering myself ( ) as in I’m normal to what you want me to be…I’m okay like I’m in mainstream mind” [1071-1076]. Hiding deafness in this way is suggestive of non-acceptance of deafness (Weinberg & Sterritt, 1986); Sinead’s desire to be ‘open’ links with her sub-narrative of wanting to overcome a sense of being ‘stuck’. If she were to view her hoped for identity as far from her current identity, psychological difficulties might emerge (Mance & Edwards, 2012).

Overall, Sinead distinguishes herself as deaf, set apart from hearing people. She holds her own (Frank, 2006) in performing her determination of wanting to integrate with hearing people, or for there to be an absence of a distinction between hearing and deaf people, and therefore greater acceptance. It might be hypothesised that what permits this, is a sense of valuing CIs and what they enable for Sinead.

12.3. Paul

Paul's holistic narrative centres on a desire to "succeed" [16].

12.3.1. Hopes, Fears and Expectations

Paul approaches the research question methodically capturing both his hopes and expectations:

> [20-23] "My most immediate hope would have to be succeeding at school, at my A levels so I can go to a u-- a good university".
>
> [34-35] "...and then the furthest hope would be to then go on to do a career in er biochemical engineering".

His hopes are portrayed along a time line allowing for them to become vivid; thus persuading the listener of his ambition and thoughtfulness about his future. Paul depicts his hope in "making friends" [48] in the future, and reflects the sense of ease he has previously encountered: "one of my abilities that I'm proud of is ( ) a er (2) an ability to make friends really easily which I don't quite know how I got" [49-51]. This speaks to a sense of resourcefulness and is portrayed almost as a gift given to him, not something that he has learnt. However this ability seems not to extend towards having romantic relationships: "another hope would probably have to be (7) girls…yeah (2) er I can make friends with girls but I just can't get beyond that" [60-64]. These concerns are likely among adolescent CI users (Punch & Hyde, 2011).

In Paul's methodical approach to the research question, Paul proceeds to depict his fears, which link with his hopes:

> [75-76] "One of my fears of my future that I don't find anyone."
>
> [82-87] "My other fear would probably have to be failing my exams… cos I just I dunno what I'd do with my life because ( ) yeah I would have no idea for where to go next."

Interestingly, at the start of the research encounter Paul reports his "biggest fear" [104] to not having a "plan B" [135]; however, what emerges at the end of the holistic narrative is a possible "plan B" [135]: "travelling" [1007]. Perhaps, initially commenting on the absence of a 'plan B' Paul was attempting to persuade the listener of his determination and absolute desire for his main hope, his career in biochemical engineering.

Paul's expectations map onto his hopes and fears, however, these seem somewhat vague, he describes: "er expectations I would have to say (2) there goes hand-in-hand with my hopes…I expect to get somewhere ( ) in life through science" [110-114]. Perhaps, Paul's vagueness serves to reduce his fear or demonstrates aspects of socio-emotional skills, which link with realising ones vocational potential (Feuerstein, 1980) and emulating flexibility in certain situations (Greenberg & Kusche, 1993).

12.3.2. Fear: "I don't have much success with girls" [547-548]

Paul's fear of not finding a girlfriend seems to be exacerbated by the presence of social comparison amongst his peers (Festinger, 1954): "all my friends have ( ) either had or still have girlfriends and so ( ) I just feel like kind of left out… cos I'm the only one who hasn't" [70-74]. Specifically comparing himself to a peer, who Paul may relate to in some ways (Wood, 1989), Paul states: "I can't help but compare myself to him" [577-578]. Paul, in seeking to understand his position, acknowledges deafness for the first time in his narrative, it had seemingly been invisible until he stated: "I just don't know what it is ( ) because like girls have assured me that it's nothing to do with me being ( ) deaf" [586-588]. He reflects on girls being "considerate" [607] and enabling him to "feel included" [620]. However, despite reassurance he receives: "some people say that you shouldn't worry because you-- you'll meet someone when you're older" [556-558], this seems not to ease his quandary: "I just can't help but wonder ( ) whether it's something to do with being deaf or just something completely different" [593-595].

Implicit within this sub-narrative are the hearing statuses of his peers and although Paul is included in one sense (as a friend) he is excluded in another (i.e. from having a girlfriend). This may represent a pressured position for Paul, especially as intimacy at this time, for people of his age, is increasing (Eder & Nenga, 2003). Paul positions his peer, with whom he compares himself, as “confident” [575]; he attempts to persuade the listener purporting: “everyone agrees he’s not that good looking” [574]. Perhaps here, Paul firstly makes an ‘upward comparison’ (Festinger, 1954), followed closely by an equalising statement to lessen the impact on Paul’s self-regard (Tesser, Millar & Moore, 1988). Interestingly, it positions his peer, as having something Paul does not have as opposed to something Paul has not got. The subtlety in this, may suggest Paul thinks he is better looking than his friend, yet his friend has more confidence. Furthermore, it may be hypothesised to represent his peer’s hearing status as no other differences emerge within the narrative; yet, explicitly verbalising this may be intolerable for Paul. This seems to oppose findings that suggest deaf young people actively protect themselves from social comparisons with hearing peers (Van Gent, Goedhart & Treffers, 2011).

12.3.3. Self-consciousness

Paul described being: “self-conscious about my appearance” [615-616], initially questioning: “I don’t know whether it’s, well, related to being deaf at all” [627]. Yet, later in this sub-narrative Paul reflects: “I suppose it’s kind of related, [to] the ( ) processor, the ( ) cochlear implant in being deaf” [639-640]. This confirmation is in line with the findings from Punch and Hyde (2011), who highlighted areas of struggle in young people with CIs, however instead of a sense of hiding his deafness he describes needing to “compensate” [654] or “detract” [685], “in every other way possible I try to ( ) look as good as possible” [643-44]. This leads him to directly questioning: “what would happen if I wasn’t deaf” [656], “would I be more successful with girls or not” [660].

Here, Paul seems to perform his efforts in wanting to be desirable to others and perhaps wanting to fit in with his peers (Punch & Hyde, 2011). Perhaps, this depicts Paul’s desire to align with those who he associates with greater success, his hearing peers (Wright, 1983); or sees himself further aligned with a hearing acculturation style (Hintermair, 2008). He suggests the processor makes visible his deafness, and the undesirability he narrates this to bring perhaps suggests the unattractiveness of deafness for him. Indeed, rejection of hearing aid technologies on the grounds of cosmetic appearance and peer acceptance has been reported among young people who use hearing aids (Cameron et al., 2008; Cienkowski & Pimentel, 2001) and more recently, CIs (Punch & Hyde, 2011). Congruent with Weinberg and Sterritt (1986) and opposing Van Gent et al. (2011), it may be also hypothesised that alongside this rejection, Paul has feelings of inferiority when he compares himself with his hearing peers.

However, Paul also questions whether “being deaf has enabled” [701] certain possibilities in his life: such as getting “extra time in exams” [703], “extra help” [704] at school and, thus, the friends he has made that are “an integral part” [732] of his life. Paul places value in the achievements and friendships at his mainstream school, perhaps suggesting a value for what Paul perceives as ‘normality’ whilst concurrently rejecting a Deaf identity. This is in line with findings that suggest greater contact with hearing peers equates to less association with the Deaf community (Jambor & Elliot, 2005) and a greater sense of hearing acculturation (Hintermair, 2008). He describes other “perks” [710] of which his “friends are so jealous” [764], such as being able to sleep after a “party” [767], at a “sleepover” [768] or when “camping” [768]. He describes a trade-off: “I just wonder if I wasn’t deaf ( ) would it be worth ( ) like maybe being able to be successful with girls but then not do so well in exams” [704-706].

The context in which Paul is in, determines his acceptance of deafness and happiness: “recently I’ve come to, like question my acceptance of being deaf” [754], he states: “at home I’m completely happy with it” [763], however:

> [773-777] “It’s more when I go out like when I’m at school ( ) it’s always kind of annoying at the start of a new school year ( ) because the year sevens are usually ( ) they know nothing about it so to them it’s strange ( ) and so they tend to stare”.

Although Paul states: “I like the attention that it gives me” [780-781], this is not the case when stares are “for the wrong reason” [784]. He succinctly elaborates:

> [789-792] “I wear good clothes and try and look good, so that I can kind of convince myself that they’re looking ( ) it’s due to the fact that I ( ) look good rather than to being deaf”.

This desire to convince himself, suggests Paul may have a strong belief the stares are because of the CI. Paul goes on to stipulate the conditions of the stares: “if my left side is to them and they’re staring then I automatically assume it’s because of my cochlear implant” [850-851]. This is congruent with concerns related to self-image being present in CI users (e.g. Punch and Hyde, 2011; Emond, Moore, Tjornby & Kentish, 2013).

12.3.4. “Break the illusion” [934]

Paul spoke directly to identity and affiliation when stating:

> [888-889] “I suppose I kinda don’t really want to associate myself with other deaf people”.

> [891-892] “I’ve just ( ) tried to (3) lose all-- to cut all ties with my deaf side”.

Paul spoke of how he had connections with other deaf people previously and described a deaf youth camp he attended, however, he notes: “when I came to tell my friends about it I just said it was a youth camp I mentioned nothing about it being deaf” [894-898]. Paul then states: “they wouldn’t mind” [901]. Elaborating, he describes that it was more about: “reminding me that I am deaf, cos like sometimes I have such fun with them, ah sometimes I even forget I’m deaf” [916-918]. He alludes to being different to his friends: “I fit in so well that I kind of like ( ) forget that I was ever deaf” [930-931]. Holding his own in distancing himself from a Deaf affiliation (Hintermair, 2008) he asserts, it “wouldn’t make me feel good about myself” [927] and would “break the illusion” [934]. This fits with a concluding statement of an earlier narrative: “if I had the option ( ) I would definitely choose to not be deaf” [696-697]. For Paul, if he were to remind himself of his deafness, which would not make him feel good about himself, psychosocial difficulties might eventuate (Dammeyer, 2009), thus he protects his wellbeing by maintaining the ‘illusion’.

Paul’s holistic narrative and the key issues raised mirror the findings put forward by Punch and Hyde (2011), in that young people with CIs face challenges around feelings of self-consciousness and wanting to fit in with hearing peers, often questioning their deafness.

12.4. Susie

Susie’s holistic narrative speaks to a sense transition from followership to potential leadership.

12.4.1. Hopes, Fears and Expectations

Susie begins her narrative attending to the research question, offering an overview of her hopes, fears and expectations for the future:

> [8-18] “My hopes are to pass all my GCSE exams which are taken ( ) next year and… And just to get good decent grades in them [both laugh] so I can go onto college and hopefully university…er my fears are moving on from my school because it’s a very small school”.
>
> [38-40] “My expectations are just to er (2) go through education…and work well [laughs]”.
>
> [44-45] “I’m also a swimmer so ( ) and just to expect to continue swimming”.

Like Tom, Susie relates her hopes, fears and expectations to an educational setting, performing her highest level of context (Cronen & Pearce, 1982) and her consideration for her academic potential (Feuerstein, 1980). She touches upon the implication of moving to a larger educational establishment, which she elaborates on later in her holistic narrative. She is keen to integrate her hobby early in her narrative, suggesting this to be an integral part of her identity that she wishes to perform in the research encounter.

12.4.2. Followership to Potential Leadership

There is a sense of connectedness and aspiration to follow in her siblings' paths:

> [70-74] “Er er I always enjoyed swimming and I took it up after my sisters, because when I was in year three I wanted to join the swimming squad team and er ( ) yeah and then I didn't get in, so then I joined a club and I got in and now I swim for Great Britain Deaf swimming club so”.

This may speak to a sense of wanting to fit in (Punch & Hyde, 2011), which could be due to peer influence gaining momentum at this life stage (Shulman et al., 1987). Yet, interestingly, Susie does not seem to perform a preference in aligning with others on the basis of similar hearing statuses, contrary to previous findings (e.g. Stinson et al., 1996). The sense of being rejected by the initial swimming club denotes a turning point in her narrative (Labov, 1972, 1982), as after which Susie seemingly performs resilience by joining another team. Not touching upon the emotionality of rejection, Susie appears to be holding her own as independent and determined.

Distinguished as “separate” [129], Susie described being integrated into both “mainstream” [108] and Deaf swimming clubs. Perhaps she is enabled to straddle this division by the CI and/or a more fluid DeaF identity, as pointed out by McIlroy and Storbeck (2011). Susie speaks of her experience of coaching: “I used to do swimming coaching at my old swimming club but then I moved so I've stopped [laughs]” [452-453]. Susie describes a desire to take up this leadership role in the future: “hopefully I'll go back into it at my new club” [482], yet hesitantly, she states: “but it's er it's higher up in a league so they might need older like people…so like yeah they might need more, I don't know what, they're c-- like older coaches” [484-488].

12.4.3. From Fear to Excitement

Susie describes “meeting new people” [284] as a fear initially in her holistic narrative. She explains what makes this “**a bit scary**” [299-300]: “just really find out about the deafness but like, it's fine, like I explain at [school], it's fine, they don’t mind [laughs]” [301-303]. What is striking here, is Susie’s externalisation of her deafness as almost separate from her; when stating “they don’t mind”, Susie seems to suggest she is concerned by others thoughts about her deafness and almost seeks their approval and acceptance. Individual factors that support peer acceptance centre on being friendly, confident and outgoing (Punch & Hyde, 2011), which Susie may have drawn upon in previous experiences and within the research encounter through her use of laughter.

In offering reassurance to herself and appearing to perform her competence to the listener, Susie recalls previous experiences describing others as understanding and “interested” [308] in her deafness. Further, Susie’s sense of ease with her deafness may be aided by the integration of these positive experiences into her sense of identity (Hadjikakou & Nikolaraizi, 2006). She solidifies this with an example, thus persuading the listener: “cos I’ve just moved swimming clubs and they’re all really interested to know how it works but I don’t really remember how it works myself [laughs]” [310-312]. Further, her narrative normalises her original fear: “Well everyone’s scared of meeting new people for the first time, so just that meeting new people yeah [laughs] getting to know them” [328-330].

Susie takes this further, by way of reframing her fear as excitement:

> [362-370] “I’m quite excited because I’ll be see-- I’ve been in the small group since I was 6 years old but I used to go to a state school before…and then I moved cos my older sisters moved…so I think I’ve just got put in there [laughs] but I--I like the school and so ( ) yeah it’s just er yeah”.

It seems Susie is excited now she is of an age where she is able to have more mastery over her choices and decisions, as signified by the increased sense of independence often noted for young people at this developmental stage (Erikson, 1968). She considers her present setting at school where: “everyone ( ) knows I’m deaf…Yeah they just they know [laughs]” [545-548], in comparison to her future educational establishment: “but people in my class will know as well cos they will see and I’ll probably tell them so yeah” [553-554]. This appeals to the visibility of her deafness by virtue of the processors[9], however, unlike previous research (e.g. Punch and Hyde, 2011), no sense of self-consciousness or hiding deafness (Weinberg & Sterritt, 1986) is described, suggesting this is not an area of concern for Susie. Further, she states: “Er I’m quite confident at telling people…cos I think it’s better to tell people sooner rather than, you know, later [laughs]” [557-560]. Although there is an element of Susie perhaps demonstrating a degree of unease in her use of laughter, this may also be framed as wanting to join with the listener and capture or persuade her.

12.4.4. Setting: Family and Friends

It emerged from the co-constructed narrative that Susie was the only deaf person in her family. This is unsurprising given the predominance of deaf children born to hearing families (Bond et al., 1999), however, it might be hypothesised that this is linked to a sense of questioning her deafness (Punch & Hyde, 2011). Susie stated: “well my granddad is deaf but that’s not passed on from him, he di-- his deteriorated… his was old age I think” [526-530]. Despite Susie being the only deaf person in her family and at her school, she affirms: “I’ve got er quite a lot of deaf friends” [652] her reflection on this later is that “it’s good” [659]. Susie’s sense of this being ‘good’, might point to the notion of social relatedness on the basis of hearing status (e.g. Stinson & Whitmire, 1991). Asked what her experience of being amongst other deaf people, Susie states: “Er (3) I don’t know, fine [laughs]” [662]. Perhaps for Susie this seems a strange question, as she does not distinguish people by their hearing status. However, she answers in relation to communication types:

> [664-671] “Well it depends which one I’m with, ‘cause some of them sign and so I have to sign if they don’t understand in noise-- like a shopping place…but some of them can just speak, it’s good I’ve got a mixture of signing and ( ) yeah [laughs] speaking one’s”.

---

[9] An externally-worn part of the cochlear implant which is responsible for taking sound from the microphone and converting it to digital information.

She alludes to the notion of ‘social deafness’ (Vonen, 2007) depicting, for her and her friends, a sense of social disadvantage in following conversations in social situations or difficult hearing environments. This supports the finding that, despite oral language skills, difficulties still emerge for CI users in oral social situations (Punch & Hyde, 2011). To overcome these obstacles, Susie draws upon her skills in sign language to adapt to difficult hearing environments; her communication skills may or may not extend towards a sense of DeaF identity (McIlroy & Storbeck, 2011). On this, Susie notes her preference to speak, which emulates the audiological gains emphasised and sought after in CI services (e.g. Mance & Edwards, 2012).

When considering the wider context of communicative preferences, she states:

> [676-681] “Yeah I wasn’t, some of them are taught to sign from a young age…and I don’t know, our council didn’t allow that, speaking’s better, but as I’ve got older I’ve said I wanted to start to sign, so I have, yeah [laughs]”.

This rather telling narrative suggests a wider societal preference for audiological gains (Power, 2005) and the oppression of the sociocultural narrative in powerful institutions. Susie describes her recent venture to learning sign language, which she states, “is good” [700], seemingly representing an act of resistance against powerful institutions (Foucault, 1970). Exercising her right to explore aspects of Deaf culture (e.g. Hyde & Power, 2005) perhaps signifies her independence and an aspect of her identity she is proud of. This seems to support the assertion put forward by Bat-Chava (1993), who highlights sign language as a vehicle towards accepting deafness; without simplifying the process of acceptance, which is arguably multifactorial and complex.

Overall, Susie’s narrative goes beyond a sense of acceptance to that of almost celebrating her deafness, especially through her extra-curricular activities and her initiative in taking up sign language.

12.5. Bella

Central to Bella’s holistic narrative is a sense of not wanting to miss out. Her hopes, fears and expectations weave throughout her telling.

12.5.1. Hopes and Concerns

Bella begins her narrative, briefly capturing some hopes, including wanting to go into “fashion management” [11] and “be really rich” [18-19], she then steps back in her timeline to a more immediate hope: “I just want to er get into my university” [22-23]. Flowing fluidly on from this, Bella speaks of a “concern” [29] in not wanting: “to go away to university”, she reasons this with:

> [33-35] “Not that I’m not going to hear anyone but ( ) I’m gonna have to have all these sort of set up for me like you know like a deaf doorbell or a deaf fire alarm”.

It seems more fitting, or arguably more tolerable, for Bella to frame this as a “concern” [29] as opposed to a fear. Positioning herself as ‘different’ (Leigh, 1999, 2009) she depicts an active sense of isolation in stating: “I feel like I’m very much a person that gets scared that they’re being ( ) in-- like individualised and like being struck out from everyone else” [40-42]. This may relate to a sense of loneliness found to be prevalent in deaf children in mainstream schools (e.g. Byrnes and Sigafoos, 2001).

Bella speaks directly to her expectations of concealing deafness when speaking of being “self–conscious about putting my hair up” [56-57], she acknowledges: “processors will get smaller and smaller, that’s my expectations” [57-58]. However she notes:

> [61-66] “But…you know I still think there’s always gonna be a little part of me that thinks in public places oh my processors showing, is everyone staring at them”.

Hiding, in this way is prominent among young people who wear CIs (Weinberg & Sterritt, 1986), and may result from unwanted attention the processors attract (Emond et al., 2013).

12.5.2. Fear: Missing Out

Her subsequent “fear” [84] speaks to a sense of “missing out”; this appears peppered throughout her holistic narrative. Firstly, she orientates whilst concurrently persuading the listener: “cos obviously fashion very high and like fast pace and high intensity” [85-88]. She then states:

> [88-93] “I’m worried you know like that I might miss something like because I couldn’t hear what they were saying on the phone call… but I was too embarrassed to ask”.

Implicit within this are preferred audiological gains in a setting, which is established and predominated by hearing peers; seemingly pointing to the barriers she may face. Similar barriers have also been reported for young people when considering employment situations (Punch & Hyde, 2011) and may also be attributed to difficult hearing environments, i.e. those compounded by background noise (Kerber & Seeber, 2011). In a hope to diminish this barrier, Bella hopes that “technology advances in a way that we don’t need to make phone calls anymore like we can just sort of text it to each other” [97-99]. Representing a step towards equality she purports: “I feel it make me feel less responsible for the mistakes [laughs]” [114-115]. Perhaps this commonality in communication styles would enable Bella to have a sense of inclusion and not different or ‘struck out’ from others (Leigh, 1999, 2009).

12.5.3. Deaf Awareness: Hope

Emergent from Bella’s narrative is her “hope that, you know, that more people become aware of deafness” [180-181]. She affirms: “we aren’t taught enough about it in schools” [185-186]. She notes how it would “be nice” [193] to be taught about “how not to patronise a person with deafness” [197-198]. Drawing upon her own experience she describes how her teachers had asked if she wanted them to sign, affirming her autonomy she states: "I’m like no I can…speak I can lip-read I’m fine I don’t need you to sign for me’ [203-206]. Stepping out of the narrative to offer her evaluation to the listener (Labov, 1972, 1982), she follows: “cos that’s what they think, deafness entails sign language” [206-207] but “not every deaf person’s the same they shouldn’t stereotype” [213-214]. This seems to support the view that conceptualising deafness as either cultural or non-cultural is problematic (McIlroy & Storbeck, 2011). In purporting the idiosyncrasies of all deaf people and rejecting identities imposed upon her (Philip, 1985), Bella seemingly advocates for a dominant DeaF identity in society (McIlroy & Storbeck, 2011). She challenges social narratives of deafness in her succinct and vivid example: “when I say to people like I’m deaf and they’re like I don’t believe you, you can hear me right now…but I can hear you that doesn’t mean I’m not deaf” [217-221]. Bella’s passion and determination can be heard when her hope at the start of this sub-narrative: “that more people become aware of deafness” [181] evolves to “an expectation” [226] that this happens in the future.

In an imagined curriculum to teach others deaf awareness, Bella describes the content: “number one I’d like to teach them about cochlear implants” [257-258] given that most assume her processors are “hearing aids” [264], then “number two sign language” [269], including what distinguishes BSL from Makaton, for example. Speaking to audiological gains within CI services, she describes the possibility of delivering speeches herself to “show that I’m well hopefully a successful er deaf person that I’d have I’ve got a good oral speech” [281-282]. Further, Bella alludes to the seemingly historic social narrative of lack of spoken language implying lack of intelligence (e.g. MacDougall, 1991):

> [283-285] “The next person might not have as good oral speech but still have that intelligence but ( ) people will think they’re stupid because they can’t convey it in a way I can”.

Although seemingly aligning with a preference of audiological gains, she shows solidarity in deaf issues across the spectrum stating: “so many statements that need to be eradicated and ( ) corrected” [320-321], ostensibly advocating for a DeaF identity to be socially recognised she asserts: “there’s so many different ways to embrace…a deaf human being and I think people need to be fully aware of that” [390-394]. Acknowledging the powerful positions in society being instrumental in change and perhaps fantasising about holding such a position she states: “when I’m prime minster I’ll do it [laughs]” [398-399].

12.5.4. Missing Out: Romantic Relationships

Like Paul, Bella speaks of a sense of missing out, when describing her imagined happiness, although this includes “a nice flat” she quickly highlights “I-- I would never have a flat by myself” [695] due to “being deaf” [696]. Her fears are performed for the listener through vivid examples: “is there a-- there a murderer in my kitchen but I didn't hear it because I was in the shower and I took my processors off" [701-703]. Due to this, she would prefer to share a flat with "a boyfriend or with a friend" [709-710]. However, when considering romantic relationships Bella states: "I'm not ( ) maybe ( ) a boyfriend but [sighs] not very likely [laughs]" [727-729]. Apparent in her telling are her hesitancy and false starts, suggesting a sense of being uncomfortable or the emotionality of the topic for her. She, like other young people who wear CIs (e.g. Punch & Hyde, 2011), directly relates this to her deafness: "I always (2) I always get a bit scared that you know like no one will ever love me because I'm deaf" [733-735]. She summarises: "I just I don't want my deafness to stop me from being…in love" [739-742]. Expanding on this, she explores the implications of being a deaf mother: "what about if my you know my baby cries and I can't hear it" [760-761], "what about if my husband doesn't, like, will he wake me up" [762-763], "I don't want, ever want them to think, like, oh I wish I didn't have a deaf mum" [773-775]. Implicit within this is the hearing status of her husband and children, to being hearing. Further, this speaks to a societal image of 'normalcy' and traditional family structures, inclusive of the gender roles and expectations of women to marry and make a family (Weiss, Freund & Wiese, 2012).

12.5.5. Identity: "I don't want the deaf label" [938]

Serving to summarise and speaking directly to her sense of identity, Bella states: "I just have so many hopes…that I don't want one little thing to push me back (2) and, but I don't want people to be like, oh wow she's great 'cause she's deaf" [916-920]; further, she states: "I shouldn't be defined by my deafness I should be defined because I'm a person" [927-928]. Reflecting on wider societal narratives, Bella stipulates: "I just feel like (2) labelling is still very ( ) prominent in this society and I don't want the deaf label" [935-938]. In seeking to capture Bella's preferred identity, she again rejects an identity enforced upon her (Philip, 1985) and suggests she'd like to be known for being "interesting, quite strong willed, opinionated, but not like opinionated in a bad way, just like she knows what she wants, like she's got good opinions" [962-964], as well as, "kind ( ) and willing to go that extra mile" [965-966]. Succinctly, she affirms: "I want people to define me by my characteristics not by my, you know, biological factors" [974-978]. Therefore, Bella assimilates aspects of her identity that are important to her (Georgakopoulou, 2002).

Throughout Bella’s narrative she holds her own in cumulatively purporting her sense of identity as something determined by her personal characteristics, and not something put on her by powerful others (Philip, 1985). Her concerns extend beyond a sense of self-consciousness, as suggested by Punch and Hyde (2011), to consider independence and parenthood as a deaf mum.

12.6. Alice

Central to Alice’s narrative is a sense of having been inspired by others and hoping she goes on to be successful and inspire others through her career and hobby. Alice speaks predominantly of her hopes; she alludes to some concerns without framing these as fears. Her expectations are omitted in the telling of her narrative, feasibly these may be held within her hopes, or perhaps due to the greater sense of certainty that expectations require (Schumacher, 2003), a difficulty emerged in narrating these during the telling.

12.6.1. Hoped for Career

Alice’s chosen area of study at university was “psychology” [8], she performs hesitancy: “since I’ve kind of like had a bit more of an idea of what I want to do er I don’t know er but I quite like to work with deaf people and working with deaf children” [13-16]. As Alice had recently set out on her journey, perhaps her hesitancy was performing her wish to keep her possibilities open. She offers what seems is a generalised hope for her future: “just be successful in life really” [19-20].

Speaking of her desired work with deaf children she describes her hope to “help them” [24] stemming from knowing “what it’s like to be deaf” [24]. This empathic position may also relate to a sense of social relatedness on the basis of deafness (e.g. Stinson et al., 1996). Apparent in Alice’s narrative about the advice she would like to impart on deaf children is “how to be successful” [65-66], something Alice seems to value. Furthermore, it might be hypothesised that this is based on rhetoric of low academic achievement, under employment and psychological distress in deaf people (Greenberg & Kusche, 1989); thus, Alice performs wanting to be active in promoting equality and aligns with the importance of career guidance being supported for deaf young people (Punch & Hyde, 2011).

Emergent from Alice's narrative was a sense of wanting to teach and promote deaf awareness along her career journey. Speaking of this, she starts:

> [120-128] "It's tricky…er 'cause it happens-- it happens in everyday life and it's quite frustrating especially because, like with deaf people, we're like, we understand each other really well and it annoys us all the time, like it happens all the time so, you know, we need to do something about it so we can ( ) like yeah (2) do you know what I mean".

Implicit within this is the reference to hearing people generally not having an understanding of the communication needs of deaf people. She appears to align with other deaf people perhaps due to social relatedness, performing solidarity. Further, her coda here ("do you know what I mean" [127-128]) almost serves to request a sense of understanding and perhaps alignment with the listener. Being aware of the hearing status of the listener, perhaps here, it is a more tolerable position for Alice to take more of a listening role.

During the co-construction there seems to be a clear sense of social action in promoting deaf awareness, in line with the Deaf social movement (Jankowski, 1997), to which Alice appoints herself as "the President of the deaf people" [156-157]. This narrative was thickened with the desire to do: "national campaigns speeches and stuff… like Obama and stuff" [166-169]. Perhaps this represents a preferred identity for Alice (Georgakopoulou, 2002); however, she strips herself of this powerful position and distances herself from this stating: "bit ambitious but yeah" [171].

Alice reflects on her experience of teachers of the deaf: "they kind of like inspired me a little bit so yeah" [190-191], then offers: "they have just so much impact on my life" [194-195]. Alice positions the teachers of the deaf as influential in all she has been able to achieve:

> [198-201] ‘Like I came out of school with like really good grades and I went off to sixth form and er and now I’m here at uni and er ( ) yeah, given me more opportunities to think about my er career choices”.

Alice speaks implicitly to the audiological gains emphasised in CI services (Mance & Edwards, 2012), and how technology and “equipment” [215] had enabled her independence, for example: “cos I can just take notes” [221]. Perhaps in promoting independence, this enabled her socio-emotional development (Greenberg & Kusche, 1993) allowing her to feel affiliated with her hearing peers (Wright, 1983).

12.6.2. Deaf Awareness

In supporting her affirmations of promoting deaf awareness, Alice offers an example to solidify her concerns, and performs the difficulty deaf people face to the hearing listener. Firstly, she gives a hypothetical example: “most people probably [inaudible] by say oh sorry, I’m deaf and then they don’t do anything about it, they just carry on talking” [277-279]. Seeking to persuade, Alice follows with:

> [281-286] “Some people just talk really quick or have really big accents and I asked them oh sorry I didn’t understand what you said cos I’m deaf and then (2) they wouldn’t change the tone of their voice or anything, so it’s just really annoying if you were to tell them oh can you slow down or can you sign to me”.

This speaks to an alignment with deaf others and a Deaf identity, placing hearing others as unaware of deaf communication needs and the difficulties in a predominant hearing society (De Klerk, 1998) (e.g. the notion of social deafness). However, the use of sign language here seems not to embody Deaf culture, but as a way to lessen communication difficulties in difficult hearing situations and perhaps, speaks to the adjustments that are made in other settings in Alice’s life (home/school). Familial adaptations, such as these, enable greater socio-emotional development (Calderon, 2000). Further, it might be argued her narrative speaks to a DeaF or dual identity (McIlroy & Storbeck, 2011).

In seeking to further understand Alice's thoughts of deaf awareness promotion, the listener asks who should promote this, Alice responds:

> [315-320] "Me [both laugh] I'm kidding, no, someone like, inspirational and ( ) someone <u>who</u> understands the whole situation and is someone, can listen to ( ) do you know what I mean?".

This suggests that Alice does not see herself as inspirational enough to take up such a role. What may have prevented this, may have been the power dynamic between Alice and the listener, which may have meant Alice felt disempowered, to not confidently embody this role entirely. Externalising this inspirational role on to an other may have been a more tolerable position for Alice. Again, Alice ends by seemingly inviting the listener to side with her; this may have been compounded by the research encounter taking place over Skype.

12.6.3. Swimming

Alice's other hopes for the future extend towards relationships and family life, and her involvement in swimming. The latter is given a thicker narrative initially, which perhaps suggests this is her preferred topic to explore. In speaking of her interest in swimming for which Alice is a member of a Deaf swimming club she states: "I never realised that I'd like get this far to international swimming" [457-458]. For the future she states: "I'd liked to do a bit of swimming coaching" [464-465], like Susie. She speaks to persuade the listener from her position of experience and confidence:

> [487-488] "Er you know obviously, I know swimming I've got loads of experiences of it"
>
> [490-492] I thought like coaching be a good idea to like show my experience to others swimming, especially deaf swimmers".

Here, Alice, agreed that she wanted to go on to inspire others, just as others had inspired her. In speaking of her experience, she appears thankful and humble:

> [533-536] “It’s been amazing, like I’ve done things that I would never thought I’d be able to do, I mean not many people get to do like swimming internationally for your country”

> [536-538] “I’m quite grateful that I got that opportunity and ( ) yeah it makes me feel really really lucky”

12.6.4. Marriage and Children

In speaking to a sense of normalcy often depicted in society, Alice states:

> [584-589] “Er obviously I want to get married to a man [laughs]…a nice man who will love me for who I am er have little children, I think I want just specifically two girls and one boy [laughs]”.

Further she describes hoping to have: “a big house” [593] and “a lot of money” [595-596]. Perhaps in marrying, Alice alludes to being accepted with her deafness, thus, implicitly positioning herself as different in some way to her hoped for partner. His implicit hearing status is further verified when she states: “he’s got to be deaf aware” [610]. Furthermore, when Alice stipulates her hopes to be a mother, she implicitly connotes her children and her husband as hearing: “if I had a husband he’s probably nudge me and go and get the baby or something” [663-664]. Specifically on being a ‘deaf mum’ she states:

> [621-624] “It would be quite weird actually, cos I don’t really know many people who are deaf mums, so I don’t know really what their experience is like ( ) I think it would probably quite difficult at times”.

Not knowing how she, as a deaf person, would find being a mother seems to refer to the predominance of hearing mothers surrounding Alice, or within a predominant hearing society (De Klerk, 1998). She explains her difficulty in relation to functional hearing and highlights the difficulties that remain in some situations, for example, children having “sweet voices” [626] and are, therefore, difficult to “understand” [626]. Perhaps given Alice’s limited exposure to deaf mums, the unknown of what this experience might be like may represent another fear, although framing it in this way may be intolerable because of her desire to be a mum.

Overall, Alice seems to embody inspiration and holds her own in advocating for a sense of social action in promoting deaf awareness. She describes herself as deaf, and draws upon some aspects of Deaf culture, specifically, the use of sign language. This may signify a communication skill or an alignment with a bicultural identity or DeaF identity.

12.7. Jack

Within Jack's holistic narrative is a sense of overcoming.

12.7.1. Hopes and Expectations

Jack is quick to highlight his hopes to achieve in his future, specifically he describes wanting get a job "with ICT" [14]. He performs from a position of competence and confidence: "I'm really good at computers and technology and stuff like that" [16-17]. Jack then moves swiftly onto his expectations: "I would like to live in a flat or in a house with my, with my mates ( ) and then I would like to get married and have children" [32-36]. His expectations seem parallel to the expectation often depicted in society, lending itself to a sense of 'normalcy'. In considering the path Jack would need to take to achieve his hopes, he recognises a more immediate hope to "pass the exam" [79] at college.

Interestingly, Jack does not bring into his narrative any fears he may have. Perhaps Jack does not relate to the question or wishes not to speak of his fears to the listener at this time in the research encounter.

12.7.2. Hopes and Expectations: Own Family

Jack firstly describes his hope to have children, then continues: "I would like to get married (2) to (2) to (4) to a female ( ) or a male or whatever" [283-285]. This suggests a desire for intimacy, which Eder and Nenga (2003), describe as pertinent for young people of this age group. Attending to the linguistic features in this sub-narrative, a sense of hesitancy emerges, perhaps due to discussing intimately private matters with the listener.

When the listener asks Jack to describe his “**future partner”** [305]. Jack follows with: “my future partner I would like him if he was kind, a gentleman ( ) er (4) that he’s always been there for me whenever I need help” [307-309]. Interestingly Jack performed this confidently, with minimal hesitation, perhaps feeling somewhat comfortable in the encounter following the permission implicit in “partner”.

In the research encounter, the listener is the first to allude to deafness by directly asking Jack about whether he had a preference of his future partner wearing a CI or not. Given this omission in Jack’s narrative, this may suggest deafness is not an integral part of his identity (Sikes & Gale, 2006). In the listener introducing this, it may have opened up and given permission to talk about deafness, as Jack responded: “If he wears cochlear implants or or none I don’t mind” [331]. This implies, for Jack there does not need to be mutuality in him and his partner both wearing CIs, however, Jack depicted earlier in his narrative, aspects of mutual interests that are important including going to the “gym” [311]. This implies relatedness on the basis of interests and not deafness, thus opposing the hypotheses previously described by Stinson et al. (1996).

12.7.3. CI: Before and After Implantation

Reflecting on Jack’s experience of receiving his implant, Jack starts by orientating the listener to when he was “a baby” [342] and before he got his first implant, he reflects:

> [344-348] “I wasn’t be able to hear anything, which-- which made me-- which made me not feel, like I’d not be able to fit into a group of friends that I have, cos I wouldn’t be able to hear them talking and listen them conversations and things like that”.

Jack alludes to a sense of loneliness in his narrative, he speaks of his experience of this as a direct feeling at that time and not a reflection of how he might have felt, in doing so perhaps Jack attempts to persuade the listener of the extent to which, Jack and his family, value what the CI has enabled. Also, here, there is a sense of oral communication being preferred in order to engage with others in a predominantly hearing society and his hearing family (Bond et al., 1999). Thus, there is a sense of distancing from the sociocultural narrative of Deafness (Hintermair, 2008), which Jambor and Elliot (2005) would hypothesise is due to Jack's greater amount of contact with hearing people.

Following this, Jack speaks directly of the Great Ormond Street Hospital (GOSH) and the process of having a sequential implant, he notes GOSH to have thought "it would be really good if I had two ( ) so I could hear more and I can know where this sound or direction is coming from" [372-374]. The sense of improvement in Jack's functional hearing is captured when he goes back to what it was like before: "I couldn't quite get the sound of direction" [376-377]. Further, he captures the listener by bringing her into his life: "so for an example if you were in the kitchen and if I was in my bedroom and you said, then you said 'Jack', and then I would be able to hear you from the kitchen" [380-383]. His noted improvements are also reported in research, in that bilateral implantation is indicative of greater speech recognition and also sound localisation (e.g. Brown & Balkany, 2007).

Speaking from a position of what he was unable to do prior to the implantation, Jack demonstrates him valuing integration into the hearing world and aspects that had "changed [his family's] lives" [397]:

> [397-405] "I could be able to talk and I could be able to listen to people…er and listen to music and lis-- and have a social life and listen people what they're talking about…join in conversations with them".

Jack's sense of appreciation of the CI in being able to engage with his family has also been found in research (e.g. Wheeler et al., 2007). Jack goes on to say: "when I was not able to talk what me and my parents and my family had to do was do signing language" [411-412]. After his implant, their use of sign language ceased; he performs his family to be supportive and inclusive in their using sign language as a communication aid, not with an immersed sense of Deaf identity. Jack's narrative speaks to a preference for oral communication, central to the aims of CI services (Mance & Edwards, 2012).

12.7.4. ‘Arch Enemy’ [526]

Jack also spontaneously told a moving story centred on overcoming. He describes having an “arch enemy” [526] at primary school, depicting this boy in this way conjures a powerful image, letting the listener into Jack’s longstanding, and difficult battle. Jack continued his story after being prompted by the listener **“I’m hoping that it stopped”** [550]. He made use of multiple voices to bring the listener into a meeting their parents attended: “his parents said…to my parents and teachers, you know what, that’s it, I’m taking out that school if going to start bullying that boy again” [555-559]. The resolution to Jack’s narrative captured a powerful sense of relief: “when he left I was so happy that finally I could get freedom” [561-562], almost suggesting Jack felt prisoner to this boy and these experiences. In continuing this sense of overcoming into the future, Jack captures his learning from this difficult situation and performs a sense of resilience in questioning: “If I had any fear that that would happen in the future I would just say to-- if I like if I had enemy in the future I would just say to them, just knock it off I don’t care” [589-591]; further “I would just go and report it” [595-596].

Jack, throughout his narrative, performs a sense of confidence and competence, which may contribute to the greater sense of affiliation to a hearing identity (Wright, 1983).

12.8. Mark

Aspects of Mark’s holistic narrative speak to a hoped acceptance from others. Mark initially denotes issues and concerns, later moving towards the depiction of fears; his expectations omitted in his telling.

12.8.1. Hopes: Career

Mark begins his narrative by capturing aspects of his preferred future career, hoping “to do something to do with computers” [6-7], this comes from a sense of expertise: “I’m quite experienced at it” [18]. Mark notes how he had previously “wanted to do car mechanics” [41-42], however, it was “a bit harder than I expected” [45-46]. Here, he affirms his preference for independent working: “I work better when I’m doing it myself” [49-50]. Mark suggested this was “a bit to do with communication" [71], seeking to encourage Mark, his parent asks him to "explain that in car mechanics you worked as a part of a group on a car" [77-78], Mark agrees and then pauses: "Yeah er" [79]. Mark describes it to be "a noisy environment", elaborating: "if they tell me to do something and I don't hear it" [89-90].

Mark's experience may relate to the notion of 'social deafness' (Vonen, 2007) when alluding to aspects of 'functional hearing' (NICE, 2009) in difficult hearing environments. Mark seems, initially somewhat hesitant in continuing his sub-narrative, however he goes on to describe past experiences of being in groups: "Er well maybe at school and we're in groups we had to like talk do a discussions…I wasn't very good at r-that really ( ) I just let everyone else do the talking really" [105-109]. This seems to portray Mark to be passive within groups, particularly of hearing peers, recreating a sense of exclusion he may feel. This further points to the notion of 'social deafness' for CI users as difficulties remain despite oral language skills (Punch & Hyde, 2011).

12.8.2. Hopes: "part-time job" [245]

After college, Mark described how he would: "try and get an apprenticeship or I'd try and get a job, a part-time job" [242-245]. Although he stated: "I haven't really thought about it that much" [250-251] he affirms he did not want to work in an office environment: "No no, I don't want to be in an office working in an office" [253-254]. A contributing factor to this was that it would be "quite noisy" [258-259]; when asked if this was a "**concern**" [261] Mark responds: "it's an issue really, background noise er it's hard to hear you with lots of background noise" [262-263]. This seems to, again, point to the notions of 'functional hearing' and 'social deafness', highlighting the difficulties in challenging hearing environments, despite oral language skills. Framing this as "an issue" [262], might be hypothesised to be a difficulty Mark faces in many different environments that have background noise within a predominant hearing society, which are extensively reported in research (e.g. Kerber & Seeber, 2011).

12.8.3. Confidence

Mark's preference for independence extends beyond his hoped for career to include activities of interest he also engages in, in particular cycling. Speaking of the sounds he hears whilst cycling he describes: “looking forward” [474] to his CI being upgraded, stating: “hopefully it will be ( ) a bit better than this one cause it’ll be more like splash proof ( ) and wind proof ( ) and you hear more sounds so hopefully it will be better” [474-479]. Again speaking to a sense of functional hearing he states:

> [482-489] “Yeah hopefully it will hear better in background noises…so that ma-might make a bit of an improvement…maybe I’ll become more confident or something”.

The hoped for improvements from the upgrade speak to a sense of having greater functional hearing (NICE, 2009) when in difficult hearing environments, thus, lessening the barriers and obstacles he has encountered. Mark appears to align with research suggesting greater confidence may equate to opportunities for peer acceptance to occur (e.g. Punch & Hyde, 2011). Speaking specifically to a sense of inclusion, Mark states: “Yeah, might feel more confident to be more involved with other people” [531-532]. Here, Mark speaks implicitly of hearing people and having a greater sense of connectivity through the preference of audiological gains (Wright, 1983).

12.8.4. “I use my vision rather than my sound” [663-664]

Speaking of football enables a narrative of strength to emerge. Mark, firstly draws on an example of his father’s opinion: “Er (3) my dad says I’ve got vision ( ) so I can like [see] when there’s like an opportunity” [636-637]. He follows with further skills: “er I’ve got good control of the ball er I’m good at shooting ( ) I shoot quite hard” [642-644]. Mark firstly outlines a communication difficulty, then moves back to his vision being one of his strengths: “Er well that can be quite hard cos lots of people are like shouting, so it’s hard to know who’s like wanting the ball or something ( ) so I--I use my vision quite a lot, I see like their hand in the air if they want the ball” [658-661].

12.8.5. “Having a second implant” [691]

Mark speaks of the possibility of “having a second implant” [691] when asked what might help the difficulty he experiences with background noise. However, he states “but I’m not ready at the moment for it” [693-694]. Orientating the listener he describes the second implant requiring “a lot of work” [699], seemingly alluding to the period of rehabilitation for maximum benefit of a sequential implant (Meyer et al., 1998). Perhaps performing from a pressured position, Mark considers the financial implications services enforce, in describing: “they pay for free for you to have it ( ) until 19…so if you’re older you can’t have it for free you have to pay privately” [708-712]. Reflecting on the prospective advantages, Mark’s narrative aligns with research suggestive of improved speech recognition and sound localisation (Brown & Balkany, 2007). Considering the disadvantages, Mark notes: “I think what’s putting me off a bit is the looks” [733-734], he then states: “I’m quite self-con-- conscious really…so I do care about how I look” [735-738].

Mark’s reason to possibly not have a sequential implantation speaks to a sense of self-consciousness (Punch & Hyde, 2011). For example, Cameron et al. (2008) have found young people to reject hearing aid technologies on the basis of cosmetic appearance and peer acceptance; this has similarly been found for young people with CIs.

12.8.6. Friendships and acceptance

Speaking of Mark’s hoped for friendships in the future, he speaks directly to a sense of deaf identity, integration and acceptance by hearing peers: “Er maybe they’ll accept me for who I am, not who they want me to or what they expect me to be ( ) er ( ) hopefully they won’t care about ( ) the fact that I’m deaf or the way I look” [836-841]. Drawing on Diamantopoulou et al. (2008), Mark’s future desire to have friendships may have been accelerated by previous experiences of exclusion. Further, Mark’s suggestion that romantic relationships might be “a problem” [850] maps onto challenges young people with CIs face (Punch & Hyde, 2011).

12.8.7. Identity and communication

Mark reports being comfortable in hearing settings; he performs competence and ability in not needing people to “talk slower” [938-939], this, he explains, has been enabled by attending a “hearing primary school” [956]; he purports: “I’m more in the hearing world than ( ) the Deaf world” [961-962]. By this, Mark refers to those with whom he spends most of his time, perhaps alluding to his hearing family or the predominant hearing society. Despite feeling comfortable in the hearing world, Mark suggests he is: “Er ( ) probably more confident ( ) with Deaf people than hearing people” [989-990], this is due to it being “easier to communicate with Deaf people ( ) like if I have to sign ( ) then I’ll sign so they can understand” [993-994]. This captures Mark’s communication skills with both hearing and Deaf communities. This may be a solely communication preferences or extend to dual or fluid DeaF identity (McIlroy & Storbeck, 2011).

For Mark it seems the concern of being in between communities, previously highlighted (e.g. Sparrow, 2005), is not an issue, he negotiates both communities with his oral and signed communication skills; Lane and Bahan (1998) suggest this is a helpful outcome.

13. FURTHER DISCUSSION

13.1. Summary of Findings

The findings highlight the commonalities and distinctions across and between the young people’s stories, philosophies and identities, which this section attempts to summarise, before moving on to critically evaluate and consider research implications.

Rather strikingly, across all participants, narratives of hope were more plentiful than narratives of fears, and especially, expectations. However, the extent to which participants were able to conceive the future ahead, varied considerably.

13.2. Comparisons and contrasts

13.2.1. Hopes

13.2.1.1. Education/career: For most participants, educational attainment was the highest level of context (Cronen & Pearce, 1982). It is feasible to suggest that this may be due to the life stage of the participants of this study.

13.2.1.2. Acceptance: A sense of hope for acceptance, at the level of self (as captured in Sinead’s story), as well as, both proximal (Mark’s story) and distal levels (Alice's and Bella's stories) emerged. The binary, in being between cultures (Lane & Bahan, 1998; Sparrow, 2005), was less apparent in the present study, with a hoped for acceptance seemingly only from a hearing community. On an interpersonal level, this was seen in the hope for acceptance of friends and romantic partners, who, rather strikingly were depicted to be of hearing status. This may be due an affiliation to a Deaf community not being preferred, already having a sense of being affiliated with a Deaf identity by virtue of own deafness, or performing tenacity in an embodied fluid DeaF identity i.e. portraying to the listener the importance of conceptualising a DeaF identity as a fluid concept (e.g. McIlroy & Storbeck, 2011). Drivers toward a hearing affiliation seemed influenced by: familial factors (Bond et al., 1999), the preference for oral communication within CI services (Mance & Edwards, 2012), and the predominance of a hearing community (De Klerk, 1998). For some of the participants, a deterrent from affiliating with a Deaf community was the presence of a supposedly historic social narrative, of lack of spoken language meaning minimal intelligence (Bender, 1981; MacDougall, 1991).

13.2.1.3. Communication: A preference for oral communication is both implicit and explicit from the findings of this study, which is unsurprising, given that this study recruited those who communicated through verbal language (English). However, diversity in communication needs emerged. Whereas some suggest no need for additional support at school (Tom), and not needing for people to speak slower (Mark) or sign (Bella), there was a hope for greater deaf awareness in society (Alice and Bella) due to difficulties in challenging hearing environments, for example those with background noise (Kerber & Seeber, 2011). This lends itself to the notion of social deafness (Vonen, 2007). This concept is supported by other studies (e.g. Hyde and Punch, 2010a) and is perhaps influenced by the fewer distinctions the CI gives the user (Spencer & Marschark, 2009).

13.2.1.4. Technology: Speaking explicitly to CI services, a hoped for improved CI technology is captured in the narratives of Bella and Mark. Although Mark alludes to the visibility of the CI and his processors, Bella is explicit in her hope for the aesthetics of the processors to improve, specifically, to get smaller over time. For some participants their CI was absent in their narratives, it is reasonable to suggest that perhaps, for these young people, their CI is not something they see as part of themselves, or a salient aspect of their identity (Georgakopoulou, 2002).

13.2.2. Fears

Interestingly, only Jack did not narrate fears for the future. Furthermore, in some instances participants chose not to use the term “fear”, instead describing “concerns”. This may have simply represented a preference in language or an illustration of the degree of their worry. As previously depicted, often the tellers’ hopes would also speak to their fears, this was particularly so for educational attainment, hoped for careers and romantic relationships, in that they feared they would not achieve what they had hoped for.

13.2.2.1. Motherhood: Another commonality emerged: Bella and Alice alluded to becoming mums in the future, which maps on to traditional gender role ideology, of women becoming wives and mothers (Weiss et al., 2012). Through this, Bella and Alice purport the ability to live a ‘normal’ life, however, for them, this is not through the use of sign language, delineating somewhat from the suggestion put forward by Hyde and Power (1992). Perhaps in considering the implications of their deafness on becoming mothers, they hope for a sense of normalcy in aligning with traditional societal norms. Somewhat divergent in the extent of their concerns, Alice hypothesises that the experience would be “weird”, whereas Bella describes the possibility of not hearing her child, or them wishing they did not have a deaf mum, as a “fear”.

13.2.2.2. Visibility of deafness: The visibility of deafness by virtue of external processors was alluded to as a concern by Bella, Mark, Sinead and Paul. With this, came an explicit fear of judgements (for Mark), as well as stares from others (Paul), with an overall sense of being self-conscious. This is in support of other research, which has suggested an increased sense of self-consciousness or concerns relating to self-image in CI users (e.g. Punch & Hyde, 2011; Emond et al., 2013).

13.2.2.3. Being among hearing peers: Sinead, Paul, Susie, Bella, Jack and Mark narrated being among hearing peers as a difficult experience at times, particularly when having a sense of wanting to fit in (Punch & Hyde, 2011). Conversely, for Susie, although framed initially as a fear in meeting new people, this was reframed later in the narrative to be a source of excitement. Through her self-compassion, she offers herself reassurance, by drawing upon past experiences of others' understanding and interest in her deafness (section 12.4.3). It has been suggested that affording oneself such compassion and reassurance is indicative of greater psychological adjustment and wellbeing (Troop, Chilcot, Hutchings & Varnaite, 2013). Similarly, Tom shared his experience of being excited about standing out from hearing people in going to university, almost as an inspirational figure in having overcome obstacles. This may in part, serve to challenge the predominant lay view of minimal intelligence (Vernon, 2005) and the rhetoric of underachievement amongst deaf people (Greenberg & Kusche, 1989).

13.2.3. Expectations

Expectations were often omitted in the telling of the stories, and were sometimes not followed-up by the listener, as it was not always apparent these had not been raised until transcribing the interview, highlighting a drawback of the study. The future expectations for some participants related to their hopes, for which they gave descriptive and vivid examples; however, they depicted their expectations using more generalised statements. Perhaps the notion of 'expectations' welcomed a vague depiction given its need for a greater degree of certainty (Schumacher, 2003).

13.3. Researcher Influence

13.3.1. Production

It was hoped that, in adopting an open approach in the interviews, analytic possibilities would become more plentiful. However, some participants often required encouragement and thus, the researcher appeared more present than had been anticipated or hoped. This mirrors other research with this population, which may be affected by self-consciousness with a hearing communication partner, or a presentation alluding to their respective life stage (e.g. Bassett, Beagan, Ristovski-Slijepcevic & Chapman, 2008; Preisler, Tvingstedt & Ahlstrom, 2005). Moreover, verbal feedback suggested that a more questioning approach would be helpful to guide the thinking of the teller, yet I wanted to ensure the encounter was guided by the teller and my views were not privileged (Mishler, 1986).

Given the general privileging of audiological gains in CI services (Mance & Edwards, 2012; Bond et al., 1999), and the listeners hearing status, what the teller was, and was not able to narrate in the encounter, would have been influenced, especially when alluding to delicate deaf issues. Furthermore, the listener, being a hearing aid user may have further complicated this. Some, if aware, may have felt a greater sense of affiliation in sharing a degree of hearing difficulty, or conversely, minimal affiliation given the disparity in the extent of hearing loss and use of differing technologies, as Bella particularly noted (12.5.3).

13.3.2. Interpretations

Interpretations offered, although tentative, were of course seen through an idiosyncratic lens, impacted by my own layers of context, as is the case for all qualitative research (Riessman, 1993). Areas of significance here may have been: my professional status particularly embedded within mental health settings and relative power position (Patel, 2003), and my own awareness and integration into both the Deaf and hearing worlds, including my own journey of deafness. My professional training may have meant that I readily conceptualised the psychological consequences of experiences. My awareness and integration in both deaf/Deaf worlds, enabled me to conceptualise the possibility of differing deaf identities.

14. CRITICAL REVIEW AND LIMITATIONS

In narrative research, predetermined standards to which a research project is compared are not advocated. Instead, validity and ethical considerations are the basis of the evaluative process (Riessman, 2008).

14.1. Validity

14.1.1. Fostering Trustworthiness and Transparency

Evaluating the validity of stories occurs through assessing the ‘trustworthiness’ of the stories told and the analytic re-telling of these stories (Riessman, 2008).

The perspective taken, as outlined previously (section 11.3), recognises experiences being discursively moderated, creating opportunities for multiple ‘truths’ to eventuate. Therefore, the co-construction of the telling is in itself one ‘truth’ (Riessman, 2008).

To demonstrate ‘trustworthiness’, I have attempted to clearly outline the systematic research process undertaken. I have transparently documented the processes of recruitment, data collection and data analysis (appendix 23). I have, explicitly outlined my own influence on the study, by considering reflexivity, i.e. being transparent about my own biases in devising and carrying out the research project. Aligning with Plummer’s (2001) view, I acknowledge that it is not possible to nullify aspects of bias, especially as they are characteristic of all qualitative research (Willig, 2013). Instead, I have explicitly placed myself within the co-construction of the narratives, thus, systematically considering my influence on both the production of the narrative in the research encounter, and the analysis of the data and re-telling.

14.1.2. External validity

Although sharing the interpretations of NA is debated amongst narrative researchers (Josselson, 2007), this step was taken to strengthen the trustworthiness and credibility of this research, as suggested by Riessman (2008). This was to establish whether the narratives resonated with the participants, whether the reconstructions were adequate representations of their telling (Lincoln & Guba, 1985), and to ensure anonymity requirements were fulfilled. However, as Riessman (2008) outlines, interpretations may not be meaningful to ‘non-social scientists’. In the process of sharing my interpretations some ethical considerations were raised (discussed later).

14.2. Correspondence-Feedback from participants

Due to the re-telling of performative enactments being potentially exposing for participants, and sharing aspects of my own views (through my interpretations), exposing for me, I was concerned about the process of collecting the feedback.

Where possible, feedback was sought directly from each participant, for reasons of confidentiality and relevance; three participants offered their feedback. Given the time constraints of this doctoral thesis, it was not possible to include the remaining feedback, which will be sought and included in any future publication of this research. Among other possibilities, minimal response may have been influenced by: educational commitments at the time of request (i.e. time of exams), research commitment coming more from parents than the young people (see section 14.3 below), the short turn-around (due to submission deadline), or the written communication style being difficult to understand.

One participant thought the analysis had captured her narrative and “was well balanced”; she thought it inherently raised deaf awareness. Another participant described having “enjoyed” reading the analysis and thought her “relevant fears and goals had been highlighted”. An aspect she was particularly pleased with was the thoughtfulness given to her view on deaf awareness and the empathic position that was adopted by the researcher, especially in “not making assumptions about deaf people”.

A request for feedback, which had to be sent via the parents contact details, returned as a joint evaluation from both the young person and parent. This highlighted how different positions can reveal different truths (Riessman, 2008) and brought about difficulties in obtaining autonomous feedback from the young person. After carefully considering the feedback, in consultation with both supervisors, feedback from both the young person and parent was taken on board, with the young person’s feedback incorporated into the analysis, where possible. Parental feedback informed some of the ethical considerations of both language use in NA and the use of interpretations, similar ethical concerns have also been raised (e.g. Josselson, 2007).

14.3. Power and autonomy of participants

As this study was predominantly interested in the views of young people, it privileged the young person’s feedback in the analyses; not to do so would have privileged other powerful voices, particularly the researchers and, where supplied, the parents. Inherent in this study was the assumption that the young people were autonomous and would not have needed their parents support in the interview or processing/understanding the analyses. However, as highlighted, some young people were reported by their parents to feel more comfortable with a family member present for either the entirety of the interview or for the beginning of the interview, bringing into question the young person's level autonomy. This consideration was not previously envisaged, although research has suggested that families of deaf children face understandable struggle in promoting independence and autonomy (Marschark, 1993; Schlesinger & Meadow, 1972). This may stem from a desire to protect (Marschark, 1993), guide and assist their children (Schlesinger & Meadow, 1972). This should not discourage research with young people alone, however, consideration should be given to the young person within their system and how they can be supported to engage in relevant research studies, should they themselves wish to. Allowing young people to determine the extent of their parental involvement, may serve as one solution. However, other ways that may support young people to engage in research may include: online interviewing via instant messaging (Mann & Stewart, 2002), focus groups (Eder & Fingerson, 2002) or peer-led studies (Kellett, 2009).

14.4. Language use in NA

In the present study, the researcher was cautious by carefully describing the use of "perform" in the analyses, given that this may be negatively connoted and considered to be a fabrication or something put-on. Plummer (1995) also recognises the risk in talking about 'stories', again, as something fabricated or fictional. Nonetheless, the feedback might suggest that this is not a preferred style of analysis.

14.5. Sharing interpretations

The receipt of feedback highlighted the debate around sharing interpretations (Josselson, 2007), especially as these are fundamentally researchers' report on "what the text says to us" (Gadamer, 1955: vxiii) and, therefore, our meaning making of it (Josselson, 2007). This is not to say that "anything goes" (Plummer, 1995: 157), thus, the analytic framework was founded in research and considered relevant. Further, I have been explicit about my own areas of bias. Learning from this, in future I will make explicit to participants the levels of analysis systematically applied to each narrative. Moreover, as Josselson (2007:550) suggests, I will outline to participants that although "participants may expect to find an exact mirror of the self they thought they presented to us, or the self whom they feel themselves to be at the time of the reading", the analysis provided is not intended as a literal truth.

Through this process, I have been reminded of the importance to be vigilant. Captured succinctly, Josselson (2007: 553-554) summarises: "If we underestimate our power, we may harm, if we overestimate it, we risk paralysis or the cessation of narrative research. Finding this balance is the challenge".

14.6. Methodological issues

14.6.1. Recruitment

14.6.1.1. Communication preferences and identity: By virtue of recruiting young people who communicate through verbal language and use English as their first language, this study implicitly privileged identities with greater distance from those associated with Deaf culture. Therefore, the study's results around identity alignment may not be that surprising.

Furthermore, the use of sign language for some participants may be conceptualised as aligning further towards a Deaf identity; however, for others this may solely represent a communication preference that enables systemic relations, particularly in difficult hearing environments. Identity questions were not explicitly asked and, therefore, only captured in as part of the analytic process (appendix 21).

14.6.1.2. Participants: As with any research, biases occur in who chooses to participate. In this particular study, an ethical issue emerged when following-up non-respondents. As is usual in most CI services, correspondence occurred via a parent due to the young person's communication difficulties with unfamiliar voices over the telephone. Hence, participation may have unwittingly privileged the parent's desires. Additionally, given that this study recruited from organisations, it might be hypothesised that those who chose to participate were those who had good relations with the respective services.

14.6.1.3. Adjustment and sequential implants: A poignant issue emerged in the consideration of sequential implants. This highlighted a methodological flaw of the present study. The young people were, on average, given their first implant 13 years ago. However, given changes in policy, simultaneous bilateral implantations are now recommended (section 4.1; NICE, 2009). Therefore, those who had received a unilateral implant under the previous guidelines (including those involved in this study) are to be considered for a sequential bilateral implant. For participants this has meant that sequential implantation has recently occurred or is being considered.

Six participants had had bilateral implants for on average 3 years and 3 months, although two of these participants do not use their sequential implant. It might be hypothesised that less benefit was derived from the sequential implant, compounded by multiple factors (e.g. Dowell et al., 1997), which led to non-use. However, interestingly, those who choose not to wear CIs on both sides, referred to a sense of self-consciousness of the visibility of the processor. Recently in the UK, Emond et al. (2013) audited non-use of sequential implants. In this, physical appearance of the processor was the main reason for non-use, with young people reasoning this with the unwanted attention the sequential implant brought to their deafness. This suggests the relevancy of adjustment to sequential implants, and therefore highlights that this study did not totally eliminate for adjustment to CI use. This may also relate to acceptance, as Emond et al. (2013) found that, some young people were happy to use the first implant as their peers were aware of it, however the second, challenged their sense of self and identity; some challenged the notion of needing to adjust to the second implant at all.

Furthermore, when considering how this study accounted for adjustment, although derived from research (Nicholas & Geers, 2003), in retrospect it seemed somewhat naïve and reductionist to minimise a complex process to a numerical value.

14.6.2. Interview process

It is acknowledged that the data, which informs the findings of this study, was captured from one research encounter with each participant. Given that narratives change over time and contexts (Riessman, 2008), consideration of this notion should be exercised when interpreting these re-tellings.

15. RESEARCH IMPLICATIONS AND RECOMMENDATIONS

This study does not claim that the participants involved are representative of all young people with CIs, however, it does highlight some of the issues some young people with CIs face, particularly the psychological consequences of being a young person who uses a CI. Therefore, it highlights some key considerations for service policy, clinical psychology and wider societal narratives. This section will firstly outline areas in need of development, including those in which this study has highlighted: policy and societal change. Subsequently, considering the role of psychology in influencing such change.

15.1. Policy- Health Service Policy

The duties of services and its stakeholders (including CPs) are captured in human rights legislation. For example, article 24 of the United Nations Convention of the Rights of the Child (United Nations General Assembly, 1989), stipulates that every child has the right to the best possible health care; furthermore, article 26 of the United Nations convention on the Rights of Persons with Disabilities[10] (United Nations General Assembly, 2007), states the rights of disabled people to be independent and be fully included in society.

Currently, services are falling short of ensuring this right for deaf young people, given that access to services remains challenging (National Deaf Children Society, NDCS, 2013); thus, having implications on independence and social inclusion. The NDCS (2015: 3) call “on MPs to promote the importance of deaf awareness in their local health settings”, and educational systems. The findings of the present study are in support of this, as there was a call from participants for there to be a greater understanding of deaf communication needs and greater promotion of deaf awareness, including, what it means to be a deaf person.

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[10] It is acknowledged not every deaf person frames his or her deafness as a disability however this seems predominant view of hearing society.

15.2. Societal Level- Deaf Awareness

Expanding upon the recommendation of greater deaf awareness within health settings (NDCS, 2015), this study goes further to recommend that deaf awareness is promoted at the wider societal level. Rather surprisingly, the individual stories demonstrated the presence of a supposedly historic narrative associated with Deafness and the assumptions of intelligence (Bender, 1981; MacDougall, 1991). It is hypothesised that this social narrative, as Leigh (2009) alludes to, may have implications for feelings of acceptance and identity formation, and thus, ought to be challenged.

This study has demonstrated the heterogeneity of deaf young people and their hopes, fears and expectations for the future through the use of narration of future possibilities. This supports the assertion that the complexity and extent of idiosyncrasies among deaf people ought to be represented in deaf education and research (Fernandes & Myers, 2010). Yet additionally, they also ought to be represented in deaf awareness programmes. Abandoning the problematic binary (McIlroy & Storbeck, 2011) at a societal level may lead to a greater sense of acceptance for those who view deafness as a salient aspect of their overall identity.

15.3. Clinical Psychology

Overall, CPs, should themselves be aware of the variety of communication needs deaf people require, and the idiosyncratic depictions of deaf identities; CPs should adopt an approach that welcomes the complexities and richness in deaf people’s lives. Further, CPs ought to take a stance of curiosity and challenge assumptions, particularly those associated with deafness and intelligence.

CPs are well placed, in their leadership roles, to contribute to representing the complexities of deaf people’s lives in our work with individuals and systems, development of policy and research (British Psychological Society, BPS, 2010). The subsequent subsections will consider previously identified areas of change (sections 15.1 and 15.2) and the role psychology can take in influencing these changes, namely policy development and wider societal change, through social action. Then, discussing the role of CPs with deaf people more generally (research and clinical practice).

15.3.1. Policy Development

To ensure that services are meeting the needs of deaf young people and therefore their human rights, current policies, in particular, those that govern access to services, ought to be challenged. CPs in their leadership roles are able to influence current policy (BPS, 2010) through their research, audit and service improvement skills. Furthermore, in working collaboratively with, young people for example, we may be better informed of some of the barriers this population face in accessing services.

The findings of the present study might suggest that communication between service provider and young person is one of these barriers. This may be especially so, given the extent of services relying heavily on telephone contact and the difficulties CI users and Deaf people have with these communicative methods. Through the narratives in the present study, a possible remedy spontaneously emerged; namely the use of text messaging or, technologies which allow for other non-oral communication methods. It could be argued that in presenting, research findings such as these, highlights to service providers and policy developers the implications for deaf people in accessing their service; this may subsequently promote change. By virtue of this, CPs can influence service policy both indirectly and directly: through conducting research and disseminating its findings to policy developers and/or through leadership opportunities in developing new policies.

15.3.2. Wider Societal Change: Social Action

As alluded to in the previous section (15.3.1), psychological research, such as the present study, can often be a platform for social action. In the present study there was an explicit call for greater deaf awareness in wider society, with some participants noting their wish to spread their message through presentations and talks (see section 12.5.3 and 12.6.1). Ideas such as these, primarily come from the community, however CPs can potentially have a peripheral role in facilitating projects being established. Furthermore, projects such as these may concurrently challenge the social narratives that assumes minimal intelligence amongst deaf people, as suggested by one participant (Bella,12.5.3).

15.3.3. Research

It could be argued that comparative approaches to deaf research are perhaps built on negative assumptions, which may perpetuate negative social narratives of deafness (i.e. deafness being synonymous with minimal intelligence). This may in turn negatively impact the psychological consequences for deaf people, for example the implications of adjusting to, and acceptance of, deafness and any chosen treatments (i.e. CIs). Furthermore, as demonstrated in the literature review of this study, comparative research approaches are largely inconclusive. Therefore this study supports the abandonment of binary comparisons, often depicted in deaf research (section 7.1.1; Lane et al., 1996), given that they have very limited utility, if any. Going beyond this, the present study supports the depiction of complexities in deaf lives, in particular, the notion of a fluid deaf identity (e.g. DeaF). This may then enable the diversity of human experiences to be better represented.

15.3.4. Clinical Practice

Participants experiencing psychological difficulties were not included in this study. Nonetheless, psychological consequences emerged, which are also relevant to clinical psychologists' practice, although they are understandable issues for these young people.

This study has helpfully depicted the complexities in deaf young people's lives, which in itself recommends person-centred and idiosyncratic practices in our clinical work. A narrative approach, which was used in the present study, is also well established in therapeutic work, (e.g. White & Epston, 1990).

Highlighted through the narratives of the participants was the supposedly historic narrative of deafness being synonymous with minimal intelligence. Therefore through clinical practice CPs ought to be aware of the implications this may have in relation to individual and systemic adjustment to deafness, depiction of identity and understandable struggles with identity formation and feelings of self-consciousness. CPs should allow for idiosyncratic depictions of identity, not making assumptions about identity or the person's level of ability.

This study has perhaps solidified the poignancy of self-consciousness among young people who use CIs, at this particular life stage and looking forward to the future. It is essential for CPs to be mindful of the powerful positions they hold and to conceptualise these areas of understandable struggles in a non-pathologising approach.

Feelings of self-consciousness and the notion of acceptance point to key psychological consequences young deaf people with CIs face at this time in their lives. In drawing upon models to formulate in clinical practice, yet capture this complexity, Brennan's (2004) social-cognitive model of adjustment may be of utility. It represents one way of conceptualising the multiple influences in adjustment processes (e.g. social narratives, medical narratives, family narratives, financial resources and social support). These influences, inform our expectations of future events, which if disconfirmed may eventuate in psychological distress. Therefore, understanding the narratives that inform our expectations, may lead to re-storying our preferred futures; by virtue of challenging and deconstructing some of the societal narratives put upon deaf young people. Additionally, in our work with families, the family life cycle (Carter & McGoldrick, 1989) may offer a way of conceptualising adjustment to life transitions for young people and their families, especially given the systemic impact deafness can have.

15.3.5. Future research

Procedures that serve to privilege the stories of marginalised populations are required, whilst being mindful of the contentions and dilemmas identified in deaf issues. It is important, therefore, that future research attempts to capture the idiosyncrasies of deaf people. With this population, it may be helpful to relay research findings in a face-to-face meeting to aid communication both ways.

Through the process of carrying out this research, a potential future direction is highlighted by the opposing positions the young people took, in considering the visibility of the CI, and extent of self-consciousness. Future studies should explore what influences the extent of their self-consciousness. Furthermore, exploring how young people story their identity, and whether the concept of a DeaF identity, resonates with them or allows for a greater sense of acceptance, would be useful. As some participants storied their futures of being deaf parents, exploring this significantly underdeveloped area is suggested, particularly parents who themselves have received paediatric implants.

16. CONCLUSION

This study sought to collect the previously unknown perspectives of young people when narrating their hopes, fears and expectations for the future. The data collected, represented both commonalities and disparities in some of the key aspects of future lives for young people who use CIs. Hopes centred on their seemingly highest level of context: education and future career, whilst their fears centred on the visibility of their deafness and self-consciousness. Some fears spoke to hopes, in a call for greater acceptance, and a sense of fitting in. Future expectations were less pronounced, although some participants called for greater deaf awareness and continued improvements in CI technology. Identity featured explicitly and implicitly in the narrations, with most young people describing their deafness at an audiological level, however, at a cultural level, a sense of fluidity in identity was hypothesised.

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18. APPENDICES

18.1. Appendix 1: A Summary of the Ethical Considerations and Protocols for Each Recruitment Stage.

Ethical considerations and protocols: the differences between ‘recruitment stage one’ and ‘recruitment stage two’.

The institutions differed in their recommendations made. This equated to two key procedural differences:

1. Parental consent: Although in both recruitment stages, all parents were given information pertaining to the study, in ‘recruitment stage one’, parental consent was not required for any participant. However, in ‘recruitment stage two’, parents were asked to consent to their child participating in the study. However, participants aged 18 in both recruitment stages were not asked to obtain parental consent.
2. Prize incentive: ‘recruitment stage two’, included a prize incentive for participation, namely three cash prizes of Amazon e-vouchers. In ‘recruitment stage one’ it was assumed that an interview would presumably take place at the hospital grounds on a date when they were already attending the hospital for a routine appointment. In ‘recruitment stage two’, this was not applicable and, therefore, participants may have faced inconvenience in attending for an interview. To compensate for this an incentive for participation was added.

18.2. Appendix 2: UEL Application for Ethics Approval (First Submission)

UNIVERSITY OF EAST LONDON

School of Psychology

APPLICATION FOR RESEARCH ETHICS APPROVAL

FOR RESEARCH INVOLVING HUMAN PARTICIPANTS

FOR PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

Students on the Professional Doctorate in Occupational & Organisational Psychology and PhD candidates should apply for research ethics approval through *Quality Assurance & Enhancement* at UEL and NOT use this form. Go to: http://www.uel.ac.uk/qa/research/index.htm

Before completing this form please familiarise yourself with the latest *Code of Ethics and Conduct* produced by the British Psychological Society (BPS) in August 2009. This can be found in the Professional Doctorate Ethics folder on the Psychology Noticeboard (UEL Plus) and also on the BPS website www.bps.org.uk under *Ethics & Standards.* Please pay particular attention to the broad ethical principles of respect and responsibility.

HOW TO COMPLETE & SUBMIT THE APPLICATION

1. Complete this application form electronically, fully and accurately.
2. Type your name in the 'student's signature' section (5.1).
3. Include copies of all necessary attachments in the **ONE DOCUMENT** SAVED AS. doc. See page 2
4. Email your supervisor (Director of Studies) the completed application and all attachments as **ONE DOCUMENT**. INDICATE 'ETHICS SUBMISSION' IN THE SUBJECT FIELD OF THIS EMAIL so your supervisor can readily identity its content. Your supervisor will then look over your application.
5. If your application satisfies ethical protocol, your supervisor will type in his/her name in the 'supervisor's signature' section (5.2) and email your application to the Helpdesk for processing. You will be copied into this email so that you know your application has been submitted. It is the responsibility of students to check this. Students are not able to email applications directly to the Helpdesk themselves.
6. Your supervisor will let you know the outcome of your application. Recruitment and data collection are **NOT** to commence until your UEL

ethics application has been approved, along with other research ethics approvals that may be necessary (See 4.1)

MANDATORY ATTACHMENTS

1. A copy of the invitation letter or text that you intend giving to potential participants.

2. A copy of the consent form or text that you intend giving to participants.

OTHER ATTACHMENTS AS APPROPRIATE

- A copy of original tests and questionnaire(s) and test(s) that you intend to use. Please note that copies of copyrighted (or pre-validated) questionnaires and tests do NOT need to be attached to this application. Only provide copies of questionnaires, tests and other stimuli that are original (i.e. ones you have written or made yourself). If you are using pre-validated questionnaires and tests and other copyrighted stimuli (e.g. visual material), make sure that these are suitable for the age group of your intended participants.

- A copy of the kinds of interview questions you intend to ask participants.

- A copy of ethical clearance from an external organisation if you need one, and have one (e.g. NHS ethical clearance). Note that your UEL ethics application can be submitted and approved before ethical approval is obtained from another organisation, if you need this (see 4.1). Please confirm with your supervisor when you have external ethical clearance, if you need it.

- CRB clearance is necessary if your research involves ‘children’ (anyone under 18 years of age) or ‘vulnerable’ adults (see 4.2 for a broad definition of this). Because all students registered on doctorate programmes in clinical, counselling or educational psychology have obtained a CRB certificate through UEL, or had one verified by UEL, when registering on a programme, this CRB clearance will be accepted for the purpose of your research ethics application. You are therefore not required to attach a copy of a CRB certificate to this application.

* IF SCANNING ATTACHMENTS IS NESSASARY BUT NOT *AT ALL* POSSIBLE, SUBMIT TWO HARDCOPIES OF YOUR APPLICATION (INCLUDING ALL ATTACHMENTS) DIRECTLY TO THE HELPDESK. HARDCOPY APPLICATIONS ARE TO BE SIGNED BY YOU AND YOUR SUPERVISOR AND DELIVERED TO THE HELPDESK BY YOU

N.B: ELECTRONIC SUBMISSION IS REQUIRED WHERE AT ALL POSSIBLE AS HARDCOPY SUBMISSION WILL SLOW DOWN THE APPROVAL PROCESS

REMEMBER TO INCLUDE ALL NECESSARY ATTACHMENTS IN THE ONE APPLICATION DOCUMENT AND EMAIL THE COMPLETE APPLICATION AS ONE DOCUMENT (.doc) TO YOUR SUPERVISOR WITH 'ETHICS SUBMISSION' IN THE SUBJECT FIELD OF YOUR EMAIL

1. Initial details

1.1. Title of Professional Doctorate programme:

Professional Doctorate in Clinical Psychology (ClinPsyD).

1.2. Registered title of thesis: (This can be a working title if one is not yet registered)

Narratives of hope, fear and expectations: young people with cochlear implants.

2. About the research

2.1. Aim of the research:

To capture the narratives of a selection of young people who use cochlear implants; specifically the research aims to capture future narratives in relation to how the young person a) see's themselves b) life in general (this may include work/education, relationships) and c) the prospect of transitioning from paediatric to adult services (in the context of cochlear implant services).

2.2. Likely duration of the data collection/fieldwork from starting to finishing date:

01 April 2014- 31 August 2015

Methods

2.3. Design of the research:

The study will use the qualitative methodology of Narrative Analysis.

This will involve topic focused, unstructured face-to-face interviews; asking participants about their hopes, fears and expectations about the future (in relation to identity, life in general and transitioning in services). Prompts will be used (see appendix 1) as necessary to encourage their narrative, but ordinarily in Narrative Analysis a prescriptive interview schedule is not used. Interviews will be about 45-60 minutes in duration.

2.4. Data Sources or Participants:

Data will be captured from interview sessions for young people currently receiving treatment from a Cochlear Implant service which will be ending in the coming years/months/ weeks or having recently left (this is dependent on whether there are sufficient participant number in the former category, should there be insufficient participants, the latter will also be invited to participate within the study). The interviews will take place on a hospital site, UEL campus or at another agreed location, where privacy and safety can be ensured.

In this study there will be approximately five to eight participants who communicate through verbal language, ranging in different genders, ethnicities and social economic status' and other demographic variables; all will be between 16-18 years old and be using a cochlear implant (unilaterally and bilaterally) which was fitted more than 7 years ago (i.e. those who have had their cochlear implant fitted within the last 6 years will be excluded from this study, as the aim of this study is to focus on the experiences of those young people who are considered to be adjusted to their implant).

Potential participants will be contacted through the service in which they receive/ received treatment; this correspondence will be through letter. Included in this will be information sheet(s) (appendix 2 &3), and consent form(s) (appendix 4&5) for the young person and their parents, respectively.

2.5. Measures, Materials or Equipment:

An audio recorder will be used to record interviews and facilitate transcription onto a password-protected computer, which will be used to store the transcriptions. A duplicate copy of this transcription will also be saved onto an encrypted storage device and stored in a locked cupboard.

An interview schedule will not be used, as the researcher will follow the narrative of the participant. The researcher will, however, ask the main research questions and use prompts (appendix 1) to encourage the telling of the narrative.

2.6. Outline of procedure, giving sufficient detail about what is involved in the research:

The procedure involves:

- Potential participants will be invited to participate in the study via a ‘language age’ appropriate letter. In this correspondence they will be given an information sheet about the study and consent form for them and their parents. They will also have the contact details of the researcher, via a pay-as-you-go mobile phone (number, yet to be arranged) in which they can contact to discuss any questions about the study.
- Should there be minimal response via letter, a hospital staff member will contact the potential participants by phone to establish whether they are interested in participating in the study and answer any questions they may have about the study. They will also be given the opportunity to talk to the researcher if they consent to their details being handed over to the researcher.
- The interviews will be arranged at an appropriate time for both the participant and the researcher. They will take place on the hospital site, UEL interview rooms or another agreed location. This location will be considered for noise levels and confidentiality. Should the agreed place be the participant’s home, the researcher will inform one of the supervisors (GOSH and UEL) of the location of the interview and the expected start and end time. The researcher will telephone a supervisor at the beginning and end of the interview and will have their mobile telephone with them, with credit and full battery charge.
- Interviews will last around 45-60 minutes and will be audio recorded for transcription within 4-6 months.
- The first participant that takes part within this study will be asked to give verbal feedback about the study; it’s questions and the

interview process. Their feedback will be considered in advance of subsequent interviews.

3. Ethical considerations

Please describe briefly how each of the ethical considerations below will be addressed.

3.1. Obtaining fully informed consent:

At initial contact, each potential participant will be given an information sheet (appendix 2&3) regarding the research study and consent forms for them (appendix 4) and their parents (appendix 5) (if necessary) to be signed. Should the parent(s)/ guardian(s) not consent to the study, the young person (considering that they are 16-18 years old) may still be able to participate in the study provided the service deems them Gillick competent (House of Lords, 1985). This refers to a child being legally able to consent and make decisions without the consent or permission of their parents, e.g. decisions about treatment etc.

3.2. Engaging in deception, if relevant:

The proposed research involves no deception.

3.3. Right of withdrawal:

Participants will be advised of their right to withdraw from the research study without disadvantage to them and without being obliged to give any reason. It will be made clear that their treatment at GOSH will in no way be effected should they wish to withdraw from the study. This will be made clear to participants on the information sheet (appendix 2&3) and consent forms (appendix 4&5).

Should a participant withdraw from the study prior to data analysis, (which will approximately begin in December 2014/January 2015) the researcher will delete all audio recordings and interview transcripts; however, after this time, data will be used in the final thesis project. This will be made clear to participants in the information sheets and consent forms.

3.4. Anonymity & confidentiality:

After the participant has expressed an interest in taking part within the study the researcher will be given the details of the participants (e.g. name, date of birth and contact details) from the service. Participants' details will be kept in a locked environment and not shared with anyone else. These details will not be included on the interview transcripts.

To protect confidentiality of participants, pseudonyms will be used in transcripts, the final thesis and any subsequent publications. Audio recordings will be stored on a password-protected computer and a duplicate copy on an encrypted storage device; these will be stored within a locked environment. Only the researcher will have access to these files. Transcripts will also be stored in this way, however the researcher and supervisors will have access to these. Audio recordings will be deleted when the research project has been passed by the UEL examining board, transcripts will be kept for three years after the completion of the study and then they will be destroyed.

Participants will be informed that confidentiality will be broken if they say anything that gives the researcher concern for their safety from others, to others or to them self. Participants will be notified of this in the information sheets and at the start of the interviews (appendix 2).

3.5. Protection of participants:
There are no potential hazards or risks of injury or accident to the participants. The participants may during the course of the interview become distressed or upset. The researcher will look for sign of this and check with the participant what they would like to do, i.e. whether they would like to proceed with the interview. The researcher will have details of support agencies in which the participant can contact should they wish to.

3.6. Will medical after-care be necessary? NO

3.7. Protection of the researcher:
There are no specific risks to the researcher.

Interviews will be carried out on either hospital premises, UEL campus or another agreed location. Should the interview take place on the hospital premises the on-site supervisor will be aware of the time and specific location of this interview. Should the interview take place on UEL premises, a UEL member of staff will be aware of the room and expected time of the interview. Lastly, should the interview take place elsewhere (i.e. at an alternative agreed location) a supervisor will be aware of the time and place of the interview. The researcher will call a supervisor before and after the interview and will have access to a fully charged mobile phone with credit.

3.8. Debriefing:
Participants will be reminded at the start of the interview the nature of the study. Participants will be given time to ask any questions at the end of the interview. Participants will be reminded of what will then happen with the data, if they are still willing to proceed.
No deception is involved in this study.

3.9. Will participants be paid? NO
3.10. Other: None

4. Other permissions and clearances

4.1. Is ethical clearance required from any other ethics committee?
YES
If YES, please give the name and address of the organisation:
NHS and Great Ormond Street Hospital.
Has such ethical clearance been obtained yet?
Currently in the process of writing and submitting relevant ethics forms.

PLEASE NOTE: UEL ethical approval can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by UEL and other ethics committees as may be necessary. Please let your supervisor know when you have obtained ethics approval from another organisation, if you need one.

4.2. Will your research involve working with children or vulnerable adults?*
YES

If YES, please tick here to confirm that you obtained a CRB certificate through UEL, or had one verified by UEL, when you registered on your Professional Doctorate programme.

YES

If your research involves young people between the ages of 16 and 18 will parental/guardian consent be obtained.

YES

5. Signatures

ELECTRONICALLY TYPED NAMES WILL BE ACCEPTED AS SIGNATURES BUT ONLY IF THE APPLICATION IS EMAILED TO THE HELPDESK BY YOUR SUPERVISOR

5.1. Declaration by student:

I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor(s).

I undertake to abide by accepted ethical principles and appropriate code of conduct in carrying out this proposed research. Personal data will be treated in the strictest confidence and participants will be fully informed about the nature of the research, what will happen to their data, and any possible risks to them.

Participants will be informed that they are in no way obliged to volunteer, should not feel coerced, and that they may withdraw from the study without disadvantage to themselves and without being obliged to give any reason.

.

Student's name: u1236184/ Gillian Wright

Student's signature: Gillian Wright

Student's number: u1236184 Date:

5.2. Declaration by supervisor:

I confirm that, in my opinion, the proposed study constitutes a suitable test of the research question and is both feasible and ethical.

Supervisor's name:

Supervisor's signature: Date:

**Accompanying this application was the interview prompts (appendix 19) as well as the information sheets and consent forms for the young people and their parents. These have been omitted as they are presented subsequently and are slightly different in each of the recruitment stages.

18.3. Appendix 3: Ethical Approval (First Submission)

ETHICAL PRACTICE CHECKLIST (Professional Doctorates)

SUPERVISOR: Maria Castro	**ASSESSOR:** Ho Chung Law
STUDENT: Gillian Wright	**DATE (sent to assessor):** 13/03/2014

Proposed research topic: Narratives of hope, fear and expectations: young people with cochlear implants.

Course: Professional Doctorate in Clinical Psychology

1. Will free and informed consent of participants be obtained? YES

2. If there is any deception is it justified? N/A

3. Will information obtained remain confidential? YES

4. Will participants be made aware of their right to withdraw at any time? YES

5. Will participants be adequately debriefed? YES

6. If this study involves observation does it respect participants' privacy? NA

7. If the proposal involves participants whose free and informed consent may be in question (e.g. for reasons of age, mental or emotional incapacity), are they treated ethically? YES

8. Is procedure that might cause distress to participants ethical? YES

9. If there are inducements to take part in the project is this ethical? NA
10. If there are any other ethical issues involved, are they a problem? NO

APPROVED

	YES, PENDING MINOR CONDITIONS	

MINOR CONDITIONS:

- **The parent/guardian also needs to be asked to consent to this under the Data Protection Act.**
- **Each individual file needs to be password protected (not just the computer).**
- **The information sheets for parents/guardians and young people need to be clearer and more concise (they are too long and have some jargon in them, e.g. some people may not understand what 'anonymised' means; try to reduce to two sides of A4).**
- **The sheet for young people needs to be in much simpler / child-friendly language.**

- **The researcher will also hand out a list of local support and emergency services available to each participant / their parent / guardian in an unlikely case that they become distressed following the interview at a later date.**

REASONS FOR NON APPROVAL:

Assessor initials: HC Date: 23 March 2014

RESEARCHER RISK ASSESSMENT CHECKLIST (BSc/MSc/MA)

SUPERVISOR: Maria Castro **ASSESSOR:** Ho Chung Law

STUDENT: Gillian Wright **DATE (sent to assessor):** 13/03/2014

Proposed research topic: Narratives of hope, fear and expectations: young people with cochlear implants.

Course: Professional Doctorate in Clinical Psychology
Would the proposed project expose the researcher to any of the following kinds of hazard?

1	Emotional	YES
2.	Physical	YES
3.	Other (e.g. health & safety issues)	NO

If you've answered YES to any of the above please estimate the chance of the researcher being harmed as: LOW

APPROVED

	YES, PENDING MINOR CONDITIONS	

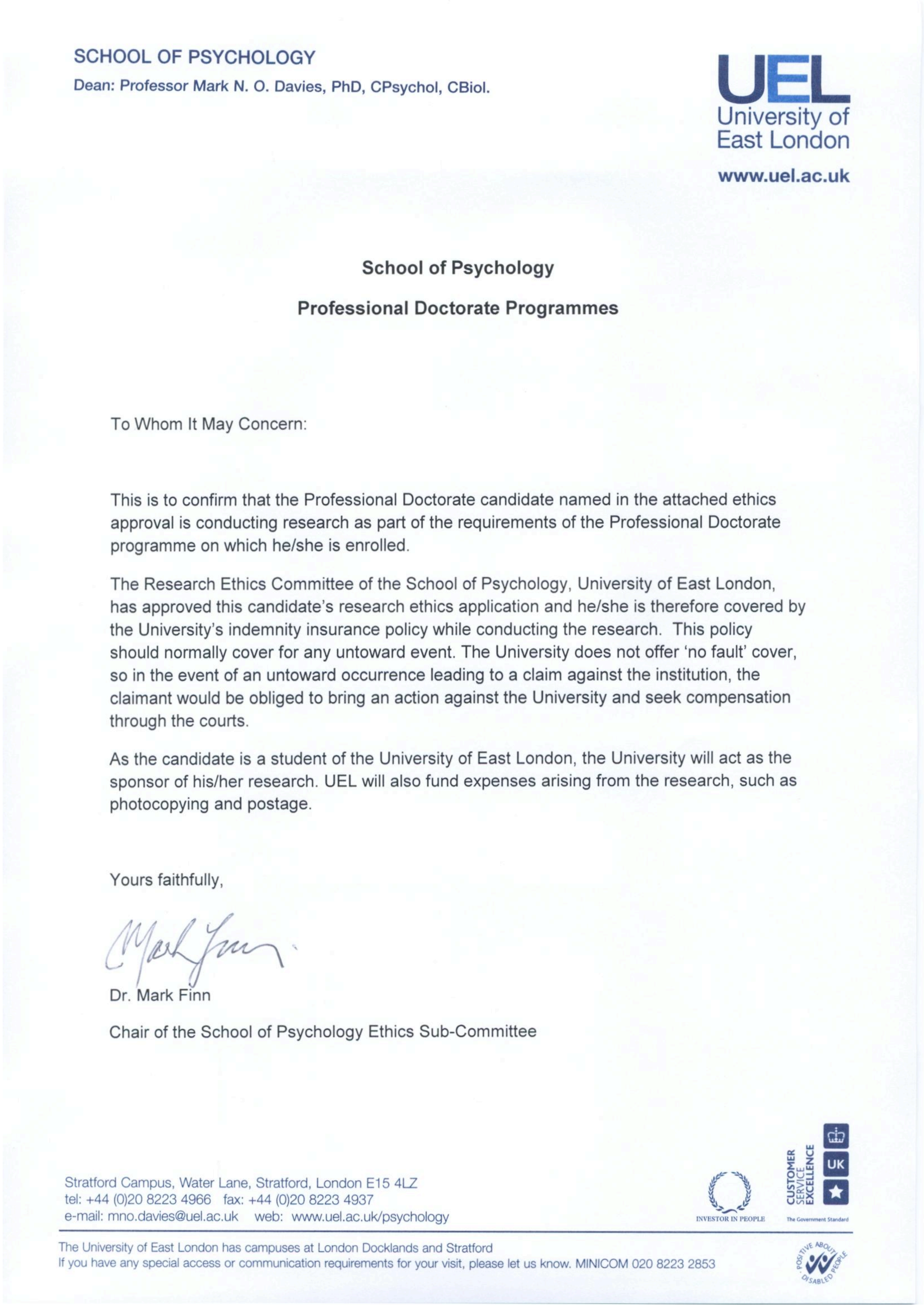
MINOR CONDITIONS:

- **Apart from informing the clinical supervisor about the location and times of the interviews, there needs to be an agreed procedure of what to do. For example: if there was a problem – what would you do? What would you want your supervisor/others to do?**

REASONS FOR NON APPROVAL:

Assessor initials: HC Date: 23 March 2014

For the attention of the assessor: Please return the completed checklists by e-mail to ethics.applications@uel.ac.uk within 1 week.



SCHOOL OF PSYCHOLOGY
Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.

UEL
University of
East London
www.uel.ac.uk

School of Psychology

Professional Doctorate Programmes

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

Mark Finn

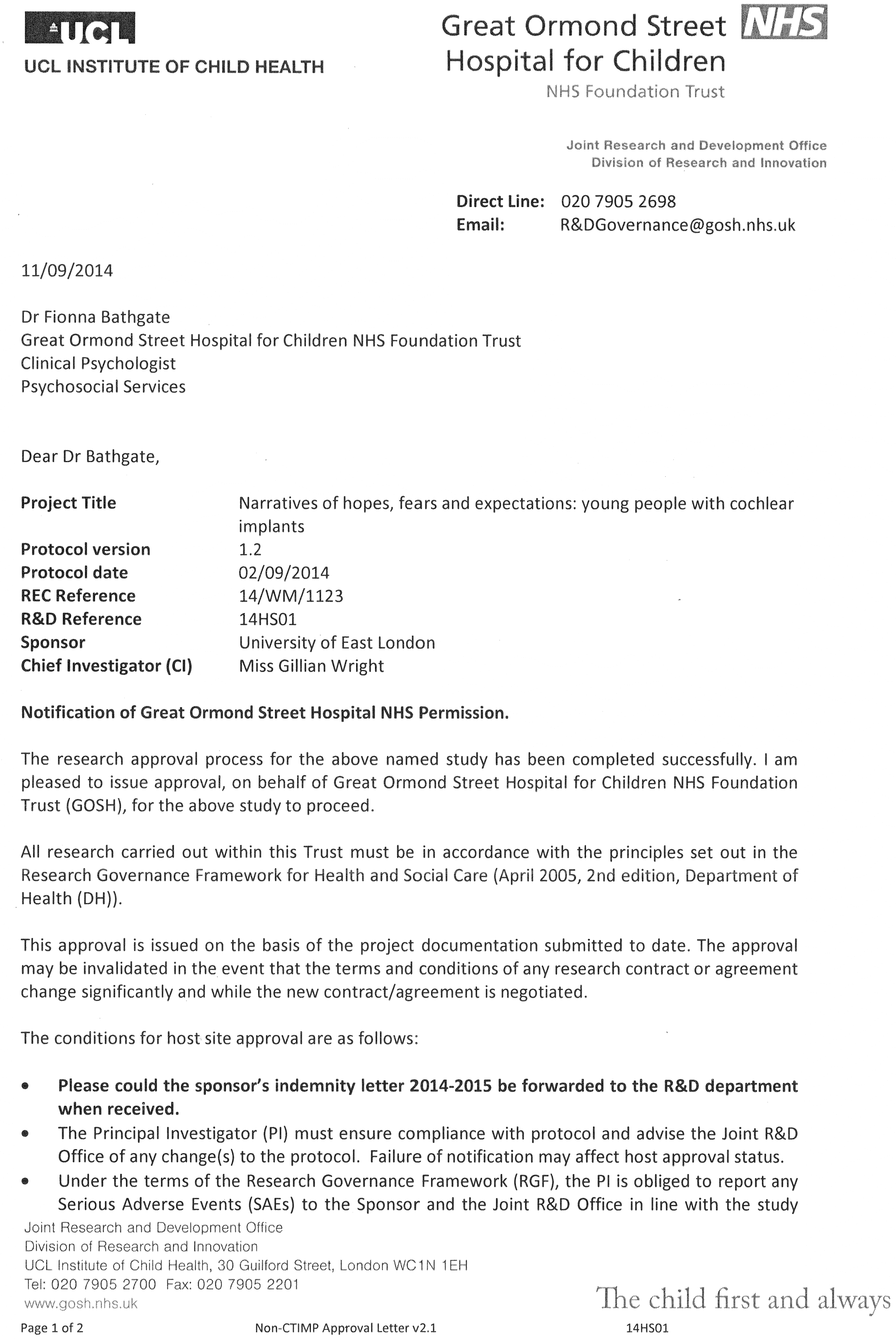
Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

Stratford Campus, Water Lane, Stratford, London E15 4LZ
tel: +44 (0)20 8223 4966 fax: +44 (0)20 8223 4937
e-mail: mno.davies@uel.ac.uk web: www.uel.ac.uk/psychology

The University of East London has campuses at London Docklands and Stratford
If you have any special access or communication requirements for your visit, please let us know. MINICOM 020 8223 2853

18.4. Appendix 4: NHS Ethics Approval



UCL INSTITUTE OF CHILD HEALTH

Great Ormond Street Hospital for Children
NHS Foundation Trust

Joint Research and Development Office
Division of Research and Innovation

Direct Line: 020 7905 2698
Email: R&DGovernance@gosh.nhs.uk

11/09/2014

Dr Fionna Bathgate
Great Ormond Street Hospital for Children NHS Foundation Trust
Clinical Psychologist
Psychosocial Services

Dear Dr Bathgate,

Project Title	Narratives of hopes, fears and expectations: young people with cochlear implants
Protocol version	1.2
Protocol date	02/09/2014
REC Reference	14/WM/1123
R&D Reference	14HS01
Sponsor	University of East London
Chief Investigator (CI)	Miss Gillian Wright

Notification of Great Ormond Street Hospital NHS Permission.

The research approval process for the above named study has been completed successfully. I am pleased to issue approval, on behalf of Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH), for the above study to proceed.

All research carried out within this Trust must be in accordance with the principles set out in the Research Governance Framework for Health and Social Care (April 2005, 2nd edition, Department of Health (DH)).

This approval is issued on the basis of the project documentation submitted to date. The approval may be invalidated in the event that the terms and conditions of any research contract or agreement change significantly and while the new contract/agreement is negotiated.

The conditions for host site approval are as follows:

- **Please could the sponsor's indemnity letter 2014-2015 be forwarded to the R&D department when received.**
- The Principal Investigator (PI) must ensure compliance with protocol and advise the Joint R&D Office of any change(s) to the protocol. Failure of notification may affect host approval status.
- Under the terms of the Research Governance Framework (RGF), the PI is obliged to report any Serious Adverse Events (SAEs) to the Sponsor and the Joint R&D Office in line with the study

protocol and Sponsor requirements. Adverse Incidents (AEs) must also be reported in accordance with the Trust Adverse Incident Reporting Policy & Procedures.

- The PI must ensure appropriate procedures are in place to action urgent safety measures.
- The PI is responsible for the set up and maintenance of the Investigator Site File (ISF) generated to store all documentation relating to this project.
- The PI must ensure that all named staff are compliant with the Data Protection Act (DPA) 1998, Human Tissue Act (HTA) 2005, Mental Capacity Act (MCA) 2005 and all other applicable statutory guidance and legislation.
- The PI must allow monitoring and auditing by the Sponsor and the Joint R&D Office.
- The PI must report any cases of suspected research misconduct and fraud to the Joint R&D Office.
- The PI must provide an annual report to the Joint R&D Office for all research involving NHS patients, staff and/or resources. The PI must notify the Joint R&D Office of any presentations of such research at scientific or professional meetings, or on the event of papers being published and any direct or indirect impacts on patient care.

Failure to comply with the above conditions and regulations will result in the suspension of the research project.

Please contact the Joint R&D Office if you require any further guidance or information on any matter mentioned above. We wish you every success in your research.

Yours sincerely,

Dr Thomas Lewis
Research Management and Governance Officer
Joint Research and Development Office

cc: GOSH Finance
Sponsor contact

18.5. Appendix 5: UEL Application for Ethics Approval (Second Submission)

UNIVERSITY OF EAST LONDON

School of Psychology

APPLICATION FOR RESEARCH ETHICS APPROVAL

FOR RESEARCH INVOLVING HUMAN PARTICIPANTS

FOR PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

Students on the Professional Doctorate in Occupational & Organisational Psychology and PhD candidates should apply for research ethics approval through *Quality Assurance & Enhancement* at UEL and NOT use this form. Go to: http://www.uel.ac.uk/qa/research/index.htm

Before completing this form please familiarise yourself with the latest *Code of Ethics and Conduct* produced by the British Psychological Society (BPS) in August 2009. This can be found in the Professional Doctorate Ethics folder on the Psychology Noticeboard (UEL Plus) and also on the BPS website www.bps.org.uk under *Ethics & Standards.* Please pay particular attention to the broad ethical principles of respect and responsibility.

HOW TO COMPLETE & SUBMIT THE APPLICATION

7. Complete this application form electronically, fully and accurately.
8. Type your name in the 'student's signature' section (5.1).
9. Include copies of all necessary attachments in the **ONE DOCUMENT** SAVED AS **.doc**. See page 2
10. Email your supervisor (Director of Studies) the completed application and all attachments as **ONE DOCUMENT**. INDICATE 'ETHICS SUBMISSION' IN THE SUBJECT FIELD OF THIS EMAIL so your supervisor can readily identity its content. Your supervisor will then look

over your application.

11. If your application satisfies ethical protocol, your supervisor will type in his/her name in the 'supervisor's signature' section (5.2) and email your application to the Helpdesk for processing. You will be copied into this email so that you know your application has been submitted. It is the responsibility of students to check this. Students are not able to email applications directly to the Helpdesk themselves.
12. Your supervisor will let you know the outcome of your application. Recruitment and data collection are **NOT** to commence until your UEL ethics application has been approved, along with other research ethics approvals that may be necessary (See 4.1)

MANDATORY ATTACHMENTS

3. A copy of the invitation letter or text that you intend giving to potential participants.

4. A copy of the consent form or text that you intend giving to participants.

OTHER ATTACHMENTS AS APPROPRIATE

- A copy of original tests and questionnaire(s) and test(s) that you intend to use. Please note that copies of copyrighted (or pre-validated) questionnaires and tests do NOT need to be attached to this application. Only provide copies of questionnaires, tests and other stimuli that are original (i.e. ones you have written or made yourself). If you are using pre-validated questionnaires and tests and other copyrighted stimuli (e.g. visual material), make sure that these are suitable for the age group of your intended participants.

- A copy of the kinds of interview questions you intend to ask participants.

- A copy of ethical clearance from an external organisation if you need one, and have one (e.g. NHS ethical clearance). Note that your UEL ethics application can be submitted and approved before ethical approval is obtained from another organisation, if you need this (see 4.1). Please confirm with your supervisor when you have external ethical clearance, if you need it.

- CRB clearance is necessary if your research involves 'children' (anyone under 18 years of age) or 'vulnerable' adults (see 4.2 for a broad definition of this). Because all students registered on doctorate programmes in clinical, counselling or educational psychology have obtained a CRB certificate through UEL, or had one verified by UEL, when registering on a programme, this CRB clearance will be accepted for the purpose of your research ethics application. You are therefore not required to attach a copy of a CRB certificate to this application.

* IF SCANNING ATTACHMENTS IS NESSASARY BUT NOT *AT ALL* POSSIBLE, SUBMIT TWO HARDCOPIES OF YOUR APPLICATION (INCLUDING ALL ATTACHMENTS) DIRECTLY TO THE HELPDESK. HARDCOPY APPLICATIONS ARE TO BE SIGNED BY YOU AND YOUR SUPERVISOR AND DELIVERED TO THE HELPDESK BY YOU

N.B: ELECTRONIC SUBMISSION IS REQUIRED WHERE AT ALL POSSIBLE AS HARDCOPY SUBMISSION WILL SLOW DOWN THE APPROVAL PROCESS

REMEMBER TO INCLUDE ALL NECESSARY ATTACHMENTS IN THE ONE APPLICATION DOCUMENT AND EMAIL THE COMPLETE APPLICATION AS ONE DOCUMENT (.doc) TO YOUR SUPERVISOR WITH 'ETHICS SUBMISSION' IN THE SUBJECT FIELD OF YOUR EMAIL

1. Initial details

1.1. Title of Professional Doctorate programme:

Professional Doctorate in Clinical Psychology (ClinPsyD).

1.2. Registered title of thesis: (This can be a working title if one is not yet registered)

Narratives of hope, fear and expectations: young people with cochlear implants.

2. About the research

2.1. Aim of the research:

To capture the narratives of a selection of young people who use cochlear implants; specifically the research aims to capture future narratives in relation to how the young person a) see's themselves b) life in general (this may include work/education, relationships) and c) the prospect of transitioning from paediatric to adult services (in the context of cochlear implant services).

4.2. Likely duration of the data collection/fieldwork from starting to finishing date:

01 April 2014- 31 August 2015

Methods

2.3. Design of the research:

The study will use the qualitative methodology of Narrative Analysis.

This will involve topic focused data collection, by various collection methods such as face-to-face interviews, internet conferencing (Skype), written/video diaries, web-based communications and pictures. The topic of these communications will be focused on the young people's hopes, fears and expectations about the future (this may be in relation to identity, life in general and transitioning in services). Prompts will be used (see appendix 1) as necessary to encourage their narrative, but ordinarily in Narrative Analysis a prescriptive interview schedule is not used. Interviews conducted either face-to-face or via web-based communications will be about 45-60 minutes in duration, other means of data collection may not easily be quantifiable but the researcher will keep in mind the approximate time the participant has spent on each piece of communication, and for it to be around a similar time scale.

2.4. Data Sources or Participants:

Data will be collected via two sources, each representing different stages of the recruitment process. Stage 1 refers to potential participants who currently use or have recently used an NHS Cochlear Implant service; stage two, potential participants will be recruited from non-NHS based organisations (this may include charities, social groups or internet based social groups).

This study, is seeking to gain the narratives of 5-8 participants in total (i.e. from both recruitment stages). All participants will communicate through verbal language; they will be of any gender, ethnicity, social economic statuses or other demographic variables. All participants will be between 16-18 years old and be using a cochlear implant (unilaterally and bilaterally) which was fitted 7 or more years ago (i.e. those who have had their cochlear implant fitted within the last 6 years will be excluded from this study, as the aim of this study is to focus on the experiences of those young people who are considered to be adjusted to their implant).

Stage 1:
Data will be captured from interview sessions for young people currently receiving treatment from a Cochlear Implant service which will be ending in the coming years/months/ weeks or having recently left (this is dependent on whether there are sufficient participant number in the former category, should there be insufficient participants, the latter will also be invited to participate within the study). The interviews will take place on a hospital site, UEL campus or at another agreed location, where privacy and safety can be ensured.

Potential participants will be contacted through the service in which they receive/ received treatment; this correspondence will be through letter. Included in this will be information sheet(s) (appendix 3 &5), and consent form(s) (appendix 4&6) for the young person and their parents, respectively.

Stage 2:
The researcher will contact Cochlear implant organisations identified through internet searches, word of mouth or other means of information sharing. They will be contacted with by letter, email or telephone to give details about the research. Organisations will be given posters (appendix 13) and information packs for young people, this will include a letter from the researcher (appendix 2), an information sheet for the young person (appendix 8), a consent form for the young person (appendix 9), a ‘Parent/ Guardian information sheet’ (appendix 10), a Parent consent form (appendix 11) and an information sheet about organisations to contact in case of distress/crisis (appendix 12). Organisations will also be asked whether the researcher can attend their establishment to answer any questions potential participants, their families and the organisation may have about participating.

For participants who are 18, parental consent to participate is not required. For those ages 16-17 parental consent is required and will be sought before any data collection commences.

2.5. Measures, Materials or Equipment:

An audio recorder will be used to record interviews and facilitate transcription onto a password-protected computer, which will be used to store the transcriptions. A duplicate copy of this transcription will also be saved onto an encrypted storage device and stored in a locked cupboard. All files, computers and storage devices will be pass-word protect, each with a different password.

An interview schedule will not be used, as the researcher will follow the narrative of the participant. The researcher will, however, ask the main research questions and use prompts (appendix 1) to encourage the telling of the narrative.

2.6. Outline of procedure, giving sufficient detail about what is involved in the research:

Recruitment stage one involves:

- Potential participants will be invited to participate in the study via a ‘language age’ appropriate letter. In this correspondence they will be given an information sheet about the study and consent form for them and their parents. They will also have the contact details of the researcher, via a pay-as-you-go ‘research’ mobile phone, which they can contact to discuss any questions about the study.
- Should there be minimal response via letter, a hospital staff member will contact the potential participants by phone to establish whether they are interested in participating in the study and answer any questions they may have about the study. They will also be given the opportunity to communicate with the researcher if they consent to their details being handed over to the researcher.
- The interviews will be arranged at an appropriate time for both the participant and the researcher. They will take place on the hospital site, UEL interview rooms or another agreed location. This location will be considered for noise levels and confidentiality. Should the agreed place be the participant’s home, the researcher will inform one of the supervisors (GOSH and UEL) of the location

of the interview and the expected start and end time. The researcher will telephone a supervisor at the beginning and end of the interview and will have their mobile telephone with them, with credit and full battery charge. The researcher will be aware of localised health and safety procedures, including the use of personal panic alarms if provided. The researcher will arrange interviews so that she has quick access to escape should she need to and have the direct contact details of both supervisors whom she will contact. On-site staff may also be contacted in an emergency situation.

- Interviews will last around 45-60 minutes and will be audio recorded for transcription within 4-6 months.

Recruitment stage two will involve:

- The researcher will identify potential Cochlear implant organisations through internet searches, word of mouth and other means of information sharing. The researcher will make contact with these organisations via letter (appendix 2), email (copy of appendix 2), phone to explain the details of the study. The researcher will also offer to visit an organisation to discuss this.
- Organisations will be sent information sheets/ posters (appendix 13) as well as information packs for young people (appendix 8-12). In these information packs there will be: a letter from the researcher (appendix 2), an information sheet for the young person (appendix 8), a consent form for the young person (appendix 9), a ‘Parent/ Guardian information sheet’ (appendix 10), a Parent/Guardian consent form (for 16-17 year olds) (appendix 11) and a list of organisations to contact in case of distress/ crisis (appendix 12).
- In the letters the contact details of the researcher will be provided so that she can be contacted to discuss potential participation or general information about the study. Through this discussion the researcher will confirm that they meet the referral criteria of the study. If appropriate and the potential participant is willing to consent, they will be asked to provide the signed consent from before the data collection process takes place.

- Data collected from these participants may be through: one-to-one face-to-face interviews, video/ written diaries, pictorial information, web-based communications (including video conferencing). In the case of video medium these will not be visually recorded, however voice transcription will still take place.
- The first participant from either recruitment stage will be asked to give verbal feedback about the study; it's questions and the interview process. Their feedback will be considered in advance of subsequent interviews.

3. Ethical considerations

Please describe briefly how each of the ethical considerations below will be addressed.

3.1. Obtaining fully informed consent:

At initial contact, each potential participant will be given the relevant information according to the relevant recruitment stage. For recruitment stage one, potential participants will be given information sheets (appendix 3&5) regarding the research study and consent forms for them (appendix 4) and their parents (appendix 6) (if necessary) to be signed. For recruitment stage two, potential participants will be given an information pack containing an invitation letter (appendix 2), information sheets (appendices 3 &5), consent forms (appendices 4&6) and an information sheet of organisations to contact in case of crises (appendix 12).

Should the parent(s)/ guardian(s) not consent to the study, the young person (considering that they are 16-17 years old) may still be able to participate in the study provided they are deemed to be Gillick competent (House of Lords, 1985). This refers to a child being legally able to consent and make decisions without the consent or permission of their parents, e.g. decisions about treatment etc.

No parental consent is required for participants aged 18 years old.

All necessary consent forms will be collected prior to data collection.

3.2. Engaging in deception, if relevant:

The proposed research involves no deception.

3.3. Right of withdrawal:

Participants will be advised of their right to withdraw from the research study without disadvantage to them and without being obliged to give any reason. It will be made clear that their treatment at GOSH/ involvement at any other organisation will in no way be effected should they wish to withdraw from the study. This will be made clear to participants in the relevant information sheets (appendix 3&5) and consent forms (appendix 4&6).

Should a participant withdraw from the study prior to data analysis, (which will approximately begin in December 2014/January 2015) the researcher will delete all audio recordings and interview transcripts; however, after this time, data will be used in the final thesis project. This will be made clear to participants in the information sheets and consent forms.

3.4. Anonymity & confidentiality:

The researcher will either be given the details of participants who have expressed an interest in participating by their associated organisation or be provided with this by the potential participant themself. If after an initial conversation with the researcher the participant does not wish to be involved in the study their details will be deleted.

Participants' details will be kept in a locked environment and not shared with anyone else. These details will not be included on the interview transcripts.

To protect confidentiality of participants, pseudonyms will be used in transcripts, the final thesis and any subsequent publications. Audio recordings will be stored on a password-protected computer and a duplicate copy on an encrypted storage device; these will be stored within a locked environment. Only the researcher will have access to these files. Transcripts will also be stored in this way, however the researcher and supervisors will have access to these. Audio recordings will be deleted when the research project has been passed by the UEL examining board, transcripts will be kept for three years after the completion of the study and then they will be destroyed.

Participants will be informed that confidentiality will be broken if they say anything that gives the researcher concern for their safety from others, to others or to them self. Participants will be notified of this in the information sheets and at the start of the interviews. Participants will be informed that it will be necessary for the researcher to contact other people in cases where risk is identified. For those participants in stage one of recruitment, participants will be informed that a member of GOSH will be contacted. In stage two of the recruitment process, if the participant is recruited from a particular organisation, the organisation will be contacted and or their parent if they are 16-17 years old. All participants will be given an information sheet of organisations to contact in cases of distress/ crisis (appendix 7 & 12). Parents of those participants requiring parental consent will be asked for parental contact details in case of an emergency (appendix 11).

3.5. Protection of participants:

There are no potential hazards or risks of injury or accident to the participants. The participants may during the course of the interview become distressed or upset. The researcher will look for sign of this and check with the participant what they would like to do, i.e. whether they would like to proceed with the interview. The researcher will have details of support agencies in which the participant can contact should they wish to.

3.6. Will medical after-care be necessary? NO

3.7. Protection of the researcher:

There are no specific risks to the researcher.

Interviews will be carried out on either hospital premises (only for stage one participants), UEL campus or another agreed location. Should the interview take place on the hospital premises the on-site supervisor will be aware of the time and specific location of this interview. Should the interview take place on UEL premises, a UEL member of staff will be aware of the room and expected time of the interview. Lastly, should the interview take place elsewhere (i.e. at an alternative agreed location) a supervisor will be aware of the time and place of the interview (depending on whether the participant was recruited from stage one or stage two of the recruitment process). The researcher will call a supervisor before and after the interview and will have access to a fully charged mobile phone with credit.

3.8. Debriefing:

Participants will be reminded at the start of the interview the nature of the study.
Participants will be given time to ask any questions at the end of the interview.
Participants will be reminded of what will then happen with the data, if they are still willing to proceed.
No deception is involved in this study.

3.9. Will participants be paid? NO

3.10. Other: Participants will be entered into a prize draw for their participation. Upon successful completion of the study, they will be entered into a prize draw to win one of three prizes (shopping vouchers).

4. Other permissions and clearances

4.1. Is ethical clearance required from any other ethics committee?
YES
If YES, please give the name and address of the organisation:
NHS/ Great Ormond Street Hospital
Has such ethical clearance been obtained yet?
Granted for Recruitment stage one, not necessary for recruitment stage two.

PLEASE NOTE: UEL ethical approval can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by UEL and other ethics committees as may be necessary. Please let your supervisor know when you have obtained ethics approval from another organisation, if you need one.

4.2. Will your research involve working with children or vulnerable adults?*
YES

If YES, please tick here to confirm that you obtained a CRB certificate through UEL, or had one verified by UEL, when you registered on your Professional Doctorate programme.

YES

If your research involves young people between the ages of 16 and 18 will parental/guardian consent be obtained.

YES

5. Signatures

ELECTRONICALLY TYPED NAMES WILL BE ACCEPTED AS SIGNATURES BUT ONLY IF THE APPLICATION IS EMAILED TO THE HELPDESK BY YOUR SUPERVISOR

5.1. Declaration by student:

I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor(s).

I undertake to abide by accepted ethical principles and appropriate code of conduct in carrying out this proposed research. Personal data will be treated in the strictest confidence and participants will be fully informed about the nature of the research, what will happen to their data, and any possible risks to them. Participants will be informed that they are in no way obliged to volunteer, should not feel coerced, and that they may withdraw from the study without disadvantage to themselves and without being obliged to give any reason.

.

Student's name: u1236184/ Gillian Wright

Student's signature: Gillian Wright

Student's number: u1236184 Date:

5.2. Declaration by supervisor:

I confirm that, in my opinion, the proposed study constitutes a suitable test of the research question and is both feasible and ethical.

Supervisor's name:

Supervisor's signature: Date:

**accompanying this re-application were the following appendices7-16. These have not been re-presented as they're presented as stand alone appendices.

18.6. Appendix 6: UEL Request for Amendments to Ethics Application

UNIVERSITY OF EAST LONDON
School of Psychology

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology.

Note that approval must be given for significant change to research procedure that impacts on ethical protocol. If you are not sure about whether your proposed amendment warrants approval consult your supervisor or contact Dr Mark Finn (Chair of the School Research Ethics Committee).

HOW TO COMPLETE & SUBMIT THE REQUEST

13. Complete the request form electronically and accurately.
14. Type your name in the 'student's signature' section (page 2).
15. When submitting this request form, ensure that all necessary documents are attached (see below).
16. Using your UEL email address, email the completed request form along with associated documents to: Dr Mark Finn at m.finn@uel.ac.uk
17. Your request form will be returned to you via your UEL email address with reviewer's response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.
18. Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

REQUIRED DOCUMENTS

5. A copy of your previously approved ethics application with proposed amendments(s) added as tracked changes.

6. Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form etc.
7. A copy of the approval of your initial ethics application.

Name of applicant: Gillian Wright

Programme of study: Professional Doctorate in Clinical Psychology

Title of research: Narratives of hopes, fears and expectations: young people with cochlear implants.

Name of supervisor: Dr Maria Castro

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	Rationale
An additional recruitment stage to include potential participants from non-NHS organisations. These will be Cochlear Implant organisations (such as charities, social groups, including internet social groups) and will be contacted directly by the researcher. Snowball sampling may also be incorporated to generate sufficient potential participants.	Due to the first recruitment stage not generating sufficient potential participants, a second stage of recruitment is needed.
In addition to face-to-face one-to-one interviews, the researcher will also collect data through: web-based communications (email, Skype or other web communications), telephone contact (if the participant is able to use the phone given their hearing difficulties), written diaries or other written/pictorial forms of communication.	To account for communication difficulties and ease of participation the medium in which interviews will be collected will include more methods.
Introduction of a prize draw	To encourage participation.

Please tick	YES	NO
Is your supervisor aware of your proposed amendment(s) and agree to them?	Yes	

Student's signature (please type your name): Gillian Wright

Date: 22/10/2014

TO BE COMPLETED BY REVIEWER		
Amendment(s) approved	YES	NO
Comments		

Reviewer:

Date:

18.7. Appendix 7: UEL Request for Amendments to Ethics Application-Approval.

UNIVERSITY OF EAST LONDON
School of Psychology

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology.

Note that approval must be given for significant change to research procedure that impacts on ethical protocol. If you are not sure about whether your proposed amendment warrants approval consult your supervisor or contact Dr Mark Finn (Chair of the School Research Ethics Committee).

HOW TO COMPLETE & SUBMIT THE REQUEST

19. Complete the request form electronically and accurately.
20. Type your name in the ‘student’s signature’ section (page 2).
21. When submitting this request form, ensure that all necessary documents are attached (see below).
22. Using your UEL email address, email the completed request form along with associated documents to: Dr Mark Finn at m.finn@uel.ac.uk
23. Your request form will be returned to you via your UEL email address with reviewer’s response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.
24. Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

REQUIRED DOCUMENTS

8. A copy of your previously approved ethics application with proposed amendments(s) added as tracked changes.
9. Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form etc.
10. A copy of the approval of your initial ethics application.

Name of applicant: Gillian Wright
Programme of study: Professional Doctorate in Clinical Psychology
Title of research: Narratives of hopes, fears and expectations: young people with cochlear implants.
Name of supervisor: Dr Maria Castro

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	Rationale
An additional recruitment stage to include potential participants from non-NHS organisations. These will be Cochlear Implant organisations (such as charities, social groups, including internet social groups) and will be contacted directly by the researcher. Snowball sampling may also be incorporated to generate sufficient potential participants.	Due to the first recruitment stage not generating sufficient potential participants, a second stage of recruitment is needed.
In addition to face-to-face one-to-one interviews, the researcher will also collect data through: web-based communications (email, Skype or other web communications), telephone contact (if the participant is able to use the phone given their hearing difficulties), written diaries or other written/pictorial forms of communication.	To account for communication difficulties and ease of participation the medium in which interviews will be collected will include more methods.

Introduction of a prize draw	To encourage participation.

Please tick	YES	NO
Is your supervisor aware of your proposed amendment(s) and agree to them?	Yes	

Student's signature (please type your name): Gillian Wright

Date: 22/10/2014

TO BE COMPLETED BY REVIEWER		
Amendment(s) approved	YES	
Comments		

Reviewer: M Finn

Date: 29/10/14

18.8. Appendix 8: Recruitment Stage One: Invitation Letter

Great Ormond Street Hospital for Children NHS Foundation Trust

Cochlear Implant Programme
Great Ormond Street Hospital
London
WC1N 3HJ
Tel: 0207 405 9200
Tel No: 020 7813 8316
Fax No: 020 7829 7877
Email: cochlear@gosh.nhs.uk

[name]
[address]
[date]

Dear Young person/[Parent]

I am inviting you /[your child] to take part in a research study. Please read the enclosed information sheet.

[For parents: Your child is old enough to decide for themselves if they would like to take part, but we wanted to let you know that we had invited your child to take part, and in case they want to discuss it with you].

If you are happy to be contacted by the researcher please complete the form below and return it to me at the Cochlear Implant Programme, or you can email it directly to the researcher, Gillian Wright, at u1236184@uel.ac.uk

If you have any questions about the research, please do get in touch with either myself or the researcher directly.

Yours sincerely

Dr Fionna Bathgate Clinical Psychologist

Agreement to contact for research”

Young person’s name:

Age:

Phone number:

Email address:

Address:

Preferred contact (please select): Email Telephone

Signature (or printed name if emailing):

Parent/carer name [optional]:

Date:

18.9. Appendix 9: Recruitment Stage One: Participant Information Sheet

UEL
University of East London

Great Ormond Street Hospital for Children
NHS Foundation Trust

UNIVERSITY OF EAST LONDON
School of Psychology
Stratford Campus
Water Lane
London E15 4LZ

The Principal Investigator:
Gillian Wright
Trainee Clinical Psychologist

Consent to Participate in a Research Study

The purpose of this letter is to give you information so that you can decide if you want to take part in a research study for my Professional Doctorate in Clinical Psychology at the University of East London (UEL).

Project Title

Narratives of hope, fear and expectations: young people with cochlear implants.

What is it?

The aim of this project is to explore the hopes, fears and expectations young people with cochlear implants have about the future. The research aims to collect the views of young people in the hope that this will help services provide better experiences for young people with cochlear implants, especially in changing to adult services.

What does it involve?

The research involves me meeting with young people who receive help from Great Ormond Street Hospital (GOSH) or who have recently been discharged from GOSH. I will meet with young people on a one-to-one basis and will ask them some questions about their hopes, fears and expectations for the future. Each interview will be audio recorded (so I can remember our conversation) and will take about one hour.

What will happen to the information from the interview?

Each interview will be saved to an audio file, from this I will write up what we talked about in a transcript. Transcripts will be analysed and written up into an academic thesis and may be submitted to a journal for psychologists in the future.

Is it private?

Only I will listen to the audio files from our interviews. They will be saved in a password-protected file on both a password-protected computer and encrypted USB, both will be stored in a locked environment.

The transcripts may be read by my supervisors (at UEL and GOSH) and also the examiners who mark my work. No one else will read the transcripts. Transcripts will be saved in the same way as the audio files, but as separate documents. In the transcripts I will change all names so that you can't be identified.

The final project will be shared with some staff from GOSH, because of this I will change some of the information so you cannot be identified. You can have a copy of the final project also.

It is important for you to know, if you were to tell me something that makes me think that someone, including you, is at risk of harm I would need to speak to someone else about our conversation. If this happens, I would speak to you first.

What will happen with my information after the study?

After my examiners have marked my work I will delete the audio recordings. The written transcript will be kept for three years after the study and may be used to write the research up for a psychology journal.

Is it safe?

There are no risks or dangers in taking part, although you could get upset if you're talking about something difficult. I will give you information of organisations you can contact and/ or contact someone from the hospital for you to talk to if you felt you needed support.

Do my parents have to agree?

If you are aged 16 or over, your parents or legal guardians do not need to consent to you taking part in this study. However, if at all possible, I would encourage you to discuss this with them, as it is an important decision.

Where will the project take place?

GOSH, University of East London or another place, e.g. a public place that will be quiet, e.g. a quiet café or library. Unfortunately we are unable to reimburse your travel expenses.

Do I have to take part?

You do not have to take part in this study and should not feel under any pressure to do so. You are free to change your mind and withdraw from the study without giving a reason. If you choose to withdraw I will delete your files and they will not be included in the final project; this will not effect your care at GOSH. However, if you tell me you want to withdraw after data analysis has started (approx. December 2014) your data will be used in the final write-up of the study.

If you are happy to continue you will be asked to sign a consent form before you can take part. If you have any questions or concerns about how the study has

been carried out, please contact:

The study's supervisor: Dr Maria Castro, Professional Doctorate in Clinical Psychology, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 XXXX. Email: m.castro@uel.ac.uk)

Or

NRES Committee West Midlands - Coventry & Warwickshire The Old Chapel Royal Standard Place

Nottingham NG1 6FS Telephone: 0115 883 9440 Email: NRESCommittee. WestMidlands- CoventryandWarwick@nhs.net

For concerns relating to your care in the NHS/service, you can contact the Patient Advice and Liaison service on 02078297862 or email: pals@gosh.nhs.uk.

Thank you for considering taking part in this project. Yours sincerely,

Gillian Wright, Trainee Clinical Psychologist (Telephone: XXXXX)

18.10. Appendix 10: Recruitment Stage One: Participant Consent Form

UEL
University of East London

Great Ormond Street NHS
Hospital for Children
NHS Foundation Trust

Consent to participate in a research study

“Narratives of hope, fear and expectations: young people with cochlear implants.”

Please initial each box

1. I confirm that I have the read the information sheet, dated..........version...) about this research study and have been given a copy to keep. I have had the chance to discuss the details and ask questions about this information. I understand what it is I am being asked to take part in.

   ☐

2. I have been encouraged to speak to my parents or guardians about the research, if I wish to do so.

   ☐

3. I understand that my involvement in this study and any personal data from this research will remain strictly confidential, which means other people will not have access to this information or be able to see my personal details. Only the researchers involved in the study will have access to identifying information (e.g. name). It has been explained to me what will happen after the research study has been completed.

   ☐

I am aware that the interview will be recorded and I give my consent for this.

☐

4. By signing this consent form, I am showing that I freely and fully consent to participate in the study. I understand that even once I have given this consent I have the right to withdraw from the study without disadvantage to myself or my family and without needing to give any reason. I also understand that if I withdraw, the researcher may still use my data in the write-up of the study and in any further analysis done by the researcher.

☐

Participant's Signature ....Date:....................................

Name (BLOCK CAPITALS) ....

Researcher's Signature .... Date: ....

Name (BLOCK CAPITALS) ....

18.11. Appendix 11: Recruitment Stage One: Parent Information Sheet

Great Ormond Street Hospital for Children
NHS Foundation Trust

UNIVERSITY OF EAST LONDON
School of Psychology
Stratford Campus
Water Lane
London
E15 4LZ

The Principal Investigator:
Gillian Wright, Trainee Clinical Psychologist

Consent for my child to participate in a research study

The purpose of this letter is to give you information to decide whether you agree to your child taking part in a research study as part of my Professional Doctorate in Clinical Psychology at the University of East London (UEL). Your child has also been given a copy of this information.

Project Title

Narratives of hope, fear and expectations: young people with cochlear implants.

What is it?

The aim of this project is to explore the hopes, fears and expectations young people with cochlear implants have about the future with the aim of helping services provide better experiences for young people with cochlear implants.

What does it involve?

The research involves me meeting with young people who receive help from Great Ormond Street Hospital (GOSH) or have recently left the care of GOSH. I will meet with young people on a one-to-one basis and will ask them some questions about their hopes, fears and expectations for the future. Each interview will be audio recorded (so I can remember the conversations) and will take about one hour.

What will happen to the information from the interview?

Each interview will be saved to an audio file, from this I will write up what was said into a transcript. Transcripts will be analysed and written up into an academic thesis; and may be submitted to a psychology journal in the future.

Is it private?

Only I will listen to the audio files from the interviews. They will be saved in a password-protected file on both a password-protected computer and encrypted USB, both will be stored in a locked environment. The transcripts may be read by my supervisors (at UEL and GOSH) and also the examiners who mark my work. No one else will read the transcripts. Transcripts will be saved in the same way as the audio files, but as separate documents. In the transcripts I will change all names so that your child can't be identified.

The final thesis project will be shared with some staff from GOSH, because of this I will change some of the information so your child cannot be identified. The final write-up may be shared with you and your child if you wish.

In the interview with your child if they were to tell me something that makes me think that someone is at risk of harm, including your child, I would need to speak to someone else to support him or her in the most appropriate way. If this happens, I would let your child know before I did this.

What will happen with my child's information after the study?

After my examiners have marked my work I will delete the audio recordings. The transcripts will be kept for three years after the study and may be used to write the research up for a psychology journal.

Is it safe?

There are no risks or dangers in taking part, although there is a possibility that your child could get upset if they are talking about something difficult. I will give him/her information of organisations they can contact and/ or contact someone from the hospital for them to talk to.

Why am I being asked about this?

When young people are asked to take part in research, a parent or guardian is also asked to consent to this as they are responsible for helping them to make important decisions. It is always encouraged that potential participation is discussed. However some young people who are deemed "competent" can consent without parental/ guardian consent.

Where will the project take place?

GOSH, University of East London or another place, e.g. a public place that will be quiet, e.g. a quiet café or library.

Do they have to take part?

Your child does not have to take part in this study and should not feel under any pressure to do so. He/she is free to change his/her mind and withdraw from the study without giving a reason. If they choose to withdraw I will delete their files and they will not be included in the final project; this will not effect their care at GOSH. However, if your child tells me they want to withdraw after analysis has started (approx. December 2014) their data will be used in the final thesis.

If you are happy to continue you will be asked to sign a consent form. If you have any questions or concerns about the study, please contact:

The study's supervisor: Dr Maria Castro, Professional Doctorate in Clinical Psychology, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 XXXX. Email: m.castro@uel.ac.uk)

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 4493. Email: m.finn@uel.ac.uk)

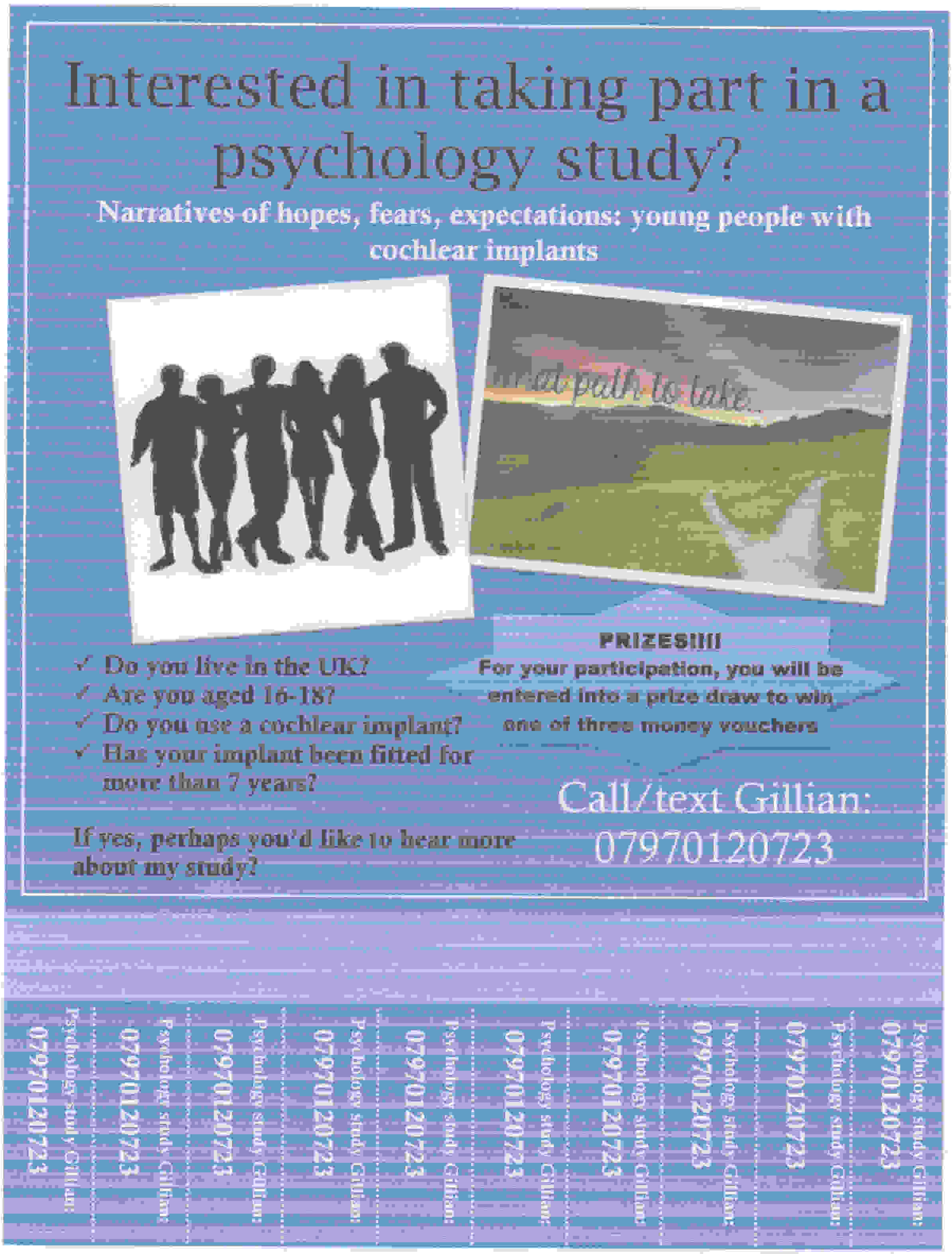
For concerns relating to your care in the NHS/service, you can contact the Patient Advice and Liaison service on 02078297862 or email: pals@gosh.nhs.uk.

Thank you for considering taking part in this project.

Yours sincerely,

Gillian Wright,
Trainee Clinical Psychologist
(Telephone: XXXXX)

18.12. Appendix 12: Recruitment Stage Two: Research Advertisement Poster



Interested in taking part in a psychology study?

Narratives of hopes, fears, expectations: young people with cochlear implants

- ✓ Do you live in the UK?
- ✓ Are you aged 16-18?
- ✓ Do you use a cochlear implant?
- ✓ Has your implant been fitted for more than 7 years?

If yes, perhaps you'd like to hear more about my study?

PRIZES!!!!

For your participation, you will be entered into a prize draw to win one of three money vouchers

Call/text Gillian:
07970120723

Psychology study Gillian:
07970120723

Psychology study Gillian:
07970120723

Psychology study Gillian:
07970120723

Psychology study Gillian:
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Psychology study Gillian:
07970120723

Psychology study Gillian:
07970120723

18.13. Appendix 13: Recruitment Stage Two: Invitation Letter

Name: Address:
Date:
Dear Young person/[Parent],

I am inviting you /[your child] to take part in a research study which is part of my University studies. Please read the enclosed information sheet.

[For parents: If your child is old enough (18 years old) to decide for themselves if they would like to take part, but we wanted to let you know that we had invited your child to take part, and in case they want to discuss it with you].

If you are happy to participate please complete the form below and return it to me at the University of East London, or you can email me directly, at u1236184@uel.ac.uk.

If you have any questions about the research, please do get in touch, you can reach me by email u1236184@uel.ac.uk or you can either call or text me on 07970120723.

Yours sincerely

Gillian Wright
Trainee Clinical Psychologist

Invitation letter *V1.0 28th October 2014*

18.14. Appendix 14: Recruitment Stage Two: Participant Information Sheet

UNIVERSITY OF EAST LONDON
School of Psychology
Stratford Campus
Water Lane
London E15 4LZ

The Principal Investigator:
Gillian Wright
Trainee Clinical Psychologist

Consent to Participate in a Research Study

The purpose of this letter is to give you information so that you can decide if you want to take part in a research study for my Professional Doctorate in Clinical Psychology at the University of East London (UEL).

Project Title

Narratives of hope, fear and expectations: young people with cochlear implants.

What is it?

The aim of this project is to explore the hopes, fears and expectations young people with cochlear implants have about the future. The research aims to collect the views of young people in the hope that this will help services provide better experiences for young people with cochlear implants, especially in changing to adult services.

What does it involve?

The research involves me asking young people with cochlear implants what they think about the future. This can be done through: meeting with me on a one-to-one basis for a conversation, a conversation through Skype, written or video diaries, email or phone calls etc. Each of these that involve us talking (not the written diaries and emails) will be audio recorded so I can remember our conversation (none of our interactions will be video recorded). Conversations may take about one hour.

What will happen to the information from the interview?

Each verbal interaction will be saved to an audio file, from this I will write up what was said into a transcript. For emails, pictures and any other written information, these will be analysed directly. For any videos, I will only record what you say with an audio recorder, I will not video record what you do. All transcripts and any written/drawn communication will be analysed and written up into an academic thesis; and may be submitted to a psychology journal in the future.

Is it private?

Only I will listen to the audio files from our interviews. They will be saved in a password-protected file on both a password-protected computer and encrypted USB, both will be stored in a locked environment.

The transcripts may be read by my supervisor (at UEL) and also the examiners who mark my work. No one else will read the transcripts. Transcripts will be saved in the same way as the audio files, but as separate documents. In the transcripts I will change all names so that you can't be identified.

The final project may be shared with Cochlear implant organisations, because of this I will change some of the information so you cannot be identified. You can have a copy of the final project also and I may contact you in the analysis period to check my understanding of what you said.

It is important for you to know, if you were to tell me something that makes me think that someone, including you, is at risk of harm I would need to speak to someone else about our conversation, this may be someone from the organisation you found about this study from, or in some cases a parent. If this happens, I would speak to you first.

What will happen with my information after the study?

After my examiners have marked my work I will delete the audio recordings. The written transcript will be kept for three years after the study and may be used to write the research up for a psychology journal.

Is it safe?

There are no risks or dangers in taking part, although you could get upset if you're talking about something difficult. I will give you information of organisations you can contact if you felt you needed support.

Do my parents have to agree?

If you are aged 16-17, we would ask that you get a parent or guardian to also consent to you participating in this study. We'd ask that you also provide their details so that we can contact them in the case of an emergency. However, if you are 18 years old, we do not require parental/guardian consent to participate, but we would encourage you to discuss this with them, if possible, as it is an important decision.

Where will the project take place?

Depending on how you decide you'd want to have our conversation, you may not need to travel to see me. However if you prefer to meet face-to-face we can have our conversation at the University of East London or another place, e.g. a public place that will be quiet, e.g. a quiet café or library. Unfortunately we are unable to reimburse your travel expenses but for your participation you will be entered into a prize draw to win one of three prizes.

Do I have to take part?

You do not have to take part in this study and should not feel under any pressure to do so. You are free to change your mind and withdraw from the study without giving a reason. If you choose to withdraw I will delete your files and they will not be included in the final project. However, if you tell me you want to withdraw after data analysis has started (approx. December 2014) your data will be used in the final write-up of the study.

If you are happy to continue you will be asked to sign a consent form before you can take part. If you have any questions or concerns about how the study has been carried out, please contact:

The study's supervisor: Dr Maria Castro, Professional Doctorate in Clinical Psychology, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 4422. Email: m.castro@uel.ac.uk)

Or

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 4493. Email: m.finn@uel.ac.uk)

Thank you for taking the time to read about my study.

Yours sincerely,

Gillian Wright,
Trainee Clinical Psychologist
(Telephone: 07970120723)

18.15. Appendix 15: Recruitment Stage Two: Parent Information Sheet

UNIVERSITY OF EAST LONDON
School of Psychology
Stratford Campus
Water Lane
London E15 4LZ

The Principal Investigator:
Gillian Wright
Trainee Clinical Psychologist

Consent for my child to participate in a research study

The purpose of this letter is to give you information about a research study you child has been invited to participate in. This study is part of my Professional Doctorate in Clinical Psychology at the University of East London (UEL). Your child has also been given a copy of this information.

Project Title

Narratives of hope, fear and expectations: young people with cochlear implants.

What is it?

The aim of this project is to explore the hopes, fears and expectations young people with cochlear implants have about the future with the aim of helping services provide better experiences for young people with cochlear implants.

What does it involve?

The research involves me asking young people with cochlear implants what they think about the future. This can be done through: meeting with me on a one-to-one basis for a conversation, a conversation through Skype, written or video diaries, email or phone calls etc. Each, that involve us talking (not the written diaries and emails) will be audio recorded so I can remember our conversation (none of the interactions will be video recorded). Conversations may take about one hour.

What will happen to the information from the interview?

Each conversation will be saved to an audio file, from this I will write up what was said into a transcript. Transcripts and any written/drawn communication will be analysed and written up into an academic thesis; and may be submitted to a psychology journal in the future.

Is it private?

Only I will listen to the audio files from the interviews. They will be saved in a password-protected file on both a password-protected computer and encrypted USB, both will be stored in a locked environment. The transcripts may be read by my supervisor (at UEL) and also the examiners who mark my work. No one else will read the transcripts. Transcripts will be saved in the same way as the audio files, but as separate documents. In the transcripts I will change all names so that your child can't be identified.

The final thesis project may be shared with Cochlear Implant organisations, because of this I will change some of the information so your child cannot be identified. The final write-up may be shared with you and your child if you wish.

In the interview with your child if they were to tell me something that makes me think that someone is at risk of harm, including your child, I would need to speak to someone else to support him or her in the most appropriate way. If this happens, I would let your child know before I did this.

What will happen with my child's information after the study?

After my examiners have marked my work I will delete the audio recordings. The transcripts will be kept for three years after the study and may be used to write the research up for a psychology journal.

Is it safe?

There are no risks or dangers in taking part, although there is a possibility that your child could get upset if they are talking about something difficult. I will give him/her information of organisations they can contact and/ or contact someone from the hospital for them to talk to.

Why am I being asked about this?

When young people are asked to take part in research, a parent or guardian is sometimes asked to consent to this as they are responsible for helping them to make important decisions. If your child is between the age of 16-17 we would need your consent for them to participate in this study, if your child is 18 we do not need your consent for them to participate. However some young people who are deemed “competent” can consent without parental/ guardian consent.

Where will the project take place?

Depending on how your child wants to communicate they may not need to travel to see me (i.e. Skype, email, written/video diaries). However if they prefer to meet face-to-face our conversation may take place at the University of East London or another place, e.g. a public place that will be quiet, e.g. a quiet café or library. Unfortunately we are unable to reimburse travel expenses but your child will be entered into a prize draw for participating.

Do they have to take part?

Your child does not have to take part in this study and should not feel under any pressure to do so. He/she is free to change his/her mind and withdraw from the study without giving a reason. If they choose to withdraw I will delete their files and they will not be included in the final project. However, if your child tells me they want to withdraw after analysis has started (approx. December 2014) their data will be used in the final thesis.

If you are required to consent (i.e. your child is 16-17 years old) and you are happy to continue you will be asked to sign a consent form. If you have any questions or concerns about the study, please contact:

The study's supervisor: Dr Maria Castro, Professional Doctorate in Clinical Psychology, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 4422. Email: m.castro@uel.ac.uk)

Or

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 4493. Email: m.finn@uel.ac.uk)

Thank you for taking the time to read about my study.

Yours sincerely,

Gillian Wright,
Trainee Clinical Psychologist
(Telephone: 07970120723)

18.16. Appendix 16: Recruitment Stage Two: Participant Consent Form

UEL
University of
East London

Consent to participate in a research study

“Narratives of hope, fear and expectations: young people with cochlear implants.”

Please initial each box

5. I confirm that I have the read the information sheet, dated..........version...) about this research study and have been given a copy to keep. I have had the chance to discuss the details and ask questions about this information. I understand what it is I am being asked to take part in.

☐

6. I have been encouraged to speak to my parents or guardians about the research, if I wish to do so.

☐

7. I understand that my involvement in this study and any personal data from this research will remain strictly confidential, which means other people will not have access to this information or be able to see my personal details. Only the researchers involved in the study will have access to identifying information (e.g. name). It has been explained to me what will happen after the research study has been completed.

☐

8. I am aware that my conversation(s) will be audio recorded and I give my consent for this.

☐

9. By signing this consent form, I am showing that I freely and fully consent to participate in the study. I understand that even once I have given this consent I have the right to withdraw from the study without disadvantage to myself or my family and without needing to give any reason. I also understand that if I withdraw, the researcher may still use my data in the write-up of the study and in any further analysis done by the researcher.

☐

Please state your age. I am ..... years old.

Please tell us where you found out about this study: ....

If you are 16-17 please give your Parent(s)/Guardian(s) details:

Name:...

Address..

Telephone number ....

Participant’s Signature ....

Date:...................................

Researcher’s Signature ....

Date: ....

Name (BLOCK CAPITALS) ....

Name (PRINT) ....

18.17. Appendix 17: Recruitment Stage Two: Parental Consent Form

Parental consent to participate in a research study for young people aged 16-17

"Narratives of hope, fear and expectations: young people with cochlear implants."

I have the read the information sheet about this research study and have been given a copy to keep. The researcher has explained to me why this research is being done and what it involves. I understand what it is my child is being asked to take part in. The researcher has also explained to me how my child will be involved and what he/she will be asked to do. I have had the chance to discuss the details and ask questions about this information. My child has also been given a copy of the information sheet to keep and asked to consent to taking part in the research.

I understand that my child's involvement in this study, and any personal data from this research, will remain strictly confidential, which means other people will not have access to this information or be able to see his/her personal details. Only the researchers involved in the study will have access to identifying information (e.g. name). It has been explained to me what will happen once the research study has been completed.

By signing this consent form, I am showing that I freely and fully consent to my child participating in the study, which has been fully explained to me. I understand that even once I have given this consent my child has the right to withdraw from the study without disadvantage to him/her, myself or my family and without needing to give any reason. I also understand that if my child withdraws, the researcher may still use my child's data in the write-up of the study and in any further analysis that may be carried out by the researcher.

Parent(s)/Guardian(s) Signature .... Date:..................

Parent(s)/Guardian(s) Name (PRINT)..

Contact details Address:..

Telephone:..

Researcher’s Signature Name (PRINT) ....Date: ....

18.18. Appendix 18: Transcription Convention

Emphasis- is underlined.

CAPITAL LETTERS- Increase in volume.

] utterance [- brief interruption.

Content followed by a full stop. – signifies a pause or end in speaking.

( ) brief interruption.

(2) a pause equating to the value in the brackets.

[laughter]- laughter in the narrative.

[inaudible]- speak that the listener is unable to comprehend.

[background noise]- background and it’s duration

Speech-- has false starts

Wan::ted- elongation, more colons depict a longer elongation.

18.19. Appendix 19: Interview Prompts

INTERVIEW QUESTIONS AND PROMPTS

For the interviews of young people with Cochlear implants GOSH.

Q. 1 Can you please tell me what your hopes, fears and expectations you have of yourself for the future? (E.g. how do you see yourself in the future? How would you describe yourself in 5, 10 years time? This could be what sort of person you'd want to be in the future?

Q. 2 Can you please tell me about your hopes, fears and expectation you have of your life in the future? (This could be in terms of whether you'll think you'll go onto further education and/ or work, what you're relationships would be life, where you see yourself in 5, 10 years time)

Q. 3 I'm interested to know a little about your hopes, fears and expectation you have in going on to adult services? Are there things you think might be different to GOSH, if so what does this difference look like? What would you hope or expect the support from adult services to look like? Have you got any fears of things that you think might challenge you?

18.20. Appendix 20: Recruitment Stage One: Support Services Information Sheet

SUPPORT SERVICES

- **National Deaf Children's society** The National Deaf Children's society is a leading deafness charity, dedicated to creating a barrier-free world for deaf children and young people. They offer information and support to families and young people through forums, helplines and specialist advisors. They also run activities for children and young people to learn new skills, gain confidence and meet other deaf children and young people.

You can see what the NDCS has to offer by looking at their website:

http://www.ndcs.org.uk/

Alternatively, contact their Free phone helpline: 0808 800 8880 (Monday-Thursday 9:30am-9:30pm, Friday's (9:30am-5pm).

- **The Buzz (NDCS)** The Buzz, in association through NDCS, offers information and advice on a range of topics, for example: identity, communication, friends and education.

Their website is:

http://youngpeople.ndcsbuzz.org.uk

- **Cochlear Implant Children's support** Offer advice and support for children, young people and their families, giving practical advice if needed, or linking with other services if appropriate. They also organise social events, to provide social support.

Their website is:

http://www.cicsgroup.org.uk/

Each region has a different contact representative, please see their website for more details.

Other support

For concerns relating to your care in the NHS/service, you can contact the Patient Advice and Liaison service on 02078297862 or email: pals@gosh.nhs.uk.

For information regarding any other concern, please contact your allocated key-worker, alternatively contact a member of the GOSH Cochlear Implant service.

18.21. Appendix 21: Recruitment Stage Two: Support Services Information Sheet.

SUPPORT SERVICES

☐ **National Deaf Children's society** The National Deaf Children's society is a leading deafness charity, dedicated to creating a barrier-free world for deaf children and young people. They offer information and support to families and young people through forums, helplines and specialist advisors. They also run activities for children and young people to learn new skills, gain confidence and meet other deaf children and young people.

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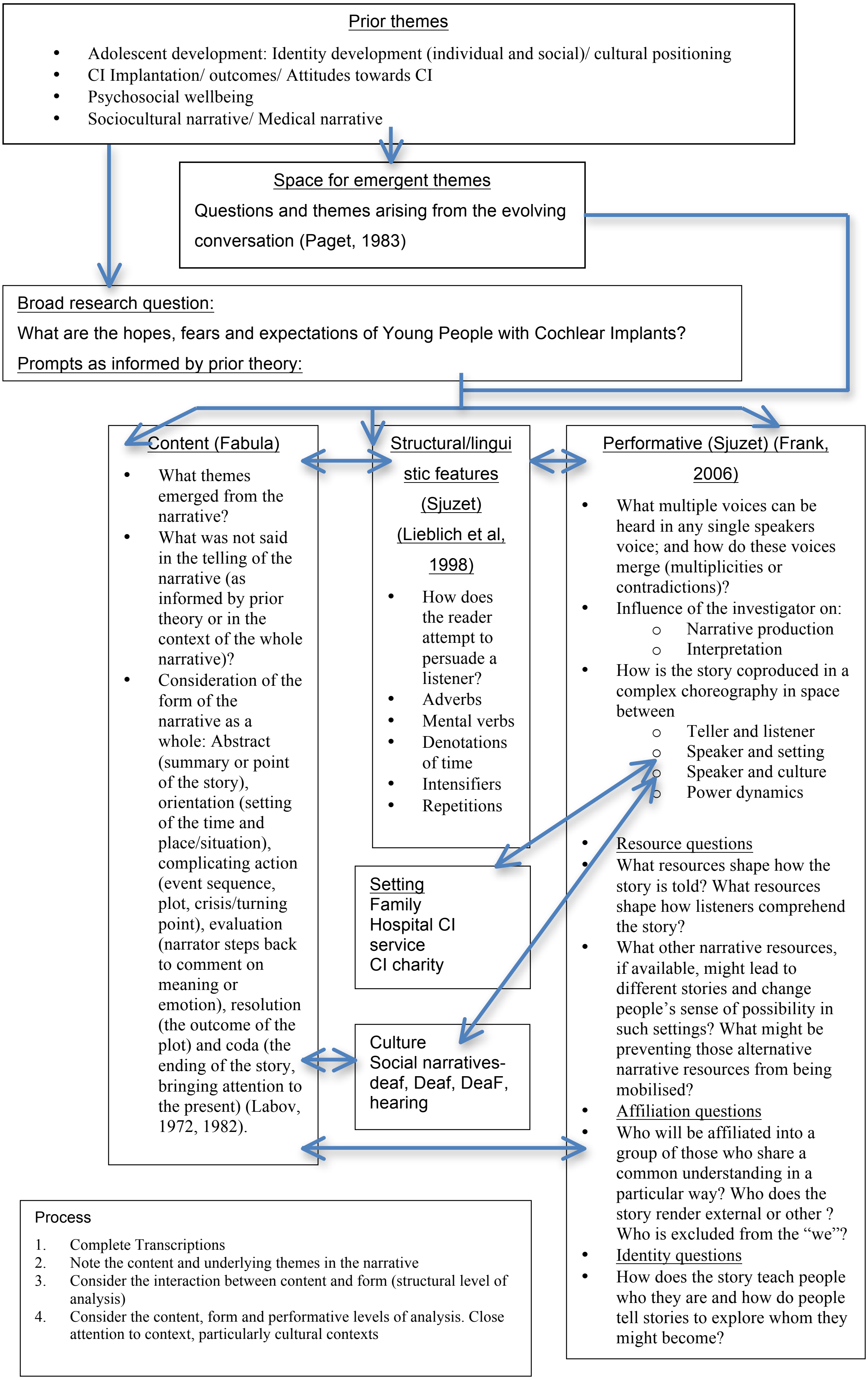
Their website is:

http://www.cicsgroup.org.uk/

Each region has a different contact representative, please see their website for more details.

18.22. Appendix 22: Analytic Framework



Prior themes

- Adolescent development: Identity development (individual and social)/ cultural positioning
- CI Implantation/ outcomes/ Attitudes towards CI
- Psychosocial wellbeing
- Sociocultural narrative/ Medical narrative

Space for emergent themes

Questions and themes arising from the evolving conversation (Paget, 1983)

Broad research question:

What are the hopes, fears and expectations of Young People with Cochlear Implants?

Prompts as informed by prior theory:

Content (Fabula)

- What themes emerged from the narrative?
- What was not said in the telling of the narrative (as informed by prior theory or in the context of the whole narrative)?
- Consideration of the form of the narrative as a whole: Abstract (summary or point of the story), orientation (setting of the time and place/situation), complicating action (event sequence, plot, crisis/turning point), evaluation (narrator steps back to comment on meaning or emotion), resolution (the outcome of the plot) and coda (the ending of the story, bringing attention to the present) (Labov, 1972, 1982).

Structural/linguistic features (Sjuzet) (Lieblich et al, 1998)

- How does the reader attempt to persuade a listener?
- Adverbs
- Mental verbs
- Denotations of time
- Intensifiers
- Repetitions

Setting
Family
Hospital CI service
CI charity

Culture
Social narratives- deaf, Deaf, DeaF, hearing

Performative (Sjuzet) (Frank, 2006)

- What multiple voices can be heard in any single speakers voice; and how do these voices merge (multiplicities or contradictions)?
- Influence of the investigator on:
    - Narrative production
    - Interpretation
- How is the story coproduced in a complex choreography in space between
    - Teller and listener
    - Speaker and setting
    - Speaker and culture
    - Power dynamics
- Resource questions
- What resources shape how the story is told? What resources shape how listeners comprehend the story?
- What other narrative resources, if available, might lead to different stories and change people's sense of possibility in such settings? What might be preventing those alternative narrative resources from being mobilised?
- Affiliation questions
- Who will be affiliated into a group of those who share a common understanding in a particular way? Who does the story render external or other ? Who is excluded from the "we"?
- Identity questions
- How does the story teach people who they are and how do people tell stories to explore whom they might become?

Process

1. Complete Transcriptions
2. Note the content and underlying themes in the narrative
3. Consider the interaction between content and form (structural level of analysis)
4. Consider the content, form and performative levels of analysis. Close attention to context, particularly cultural contexts

18.23. Appendix 23: Biographical Portraits

Tom: lives at home with his parents, his older brother has moved to university. He has recently started a part-time job, which he reports has enhanced his confidence, particularly in meeting new people. He has many hobbies, including various sports.

Sinead: is the only deaf person in her family, but has many deaf friends. She is approaching her last year at school.

Paul: lives at home with his family, he attends a mainstream school, where he has made many friends who are an integral part of his life. Paul’s passion is science.

Susie: attends a small mainstream school and is approaching her GCSE’s. She hopes to go to college to further pursue her interest in sports. He sports form her hobbies, whereby she swims for Deaf and hearing clubs.

Bella: attends a mainstream school and also has a part-time job. She lives at home with her family, and is the only deaf person in her family.

Alice: is at university, and lives away from home. She usually communicates with her family through Skype, and has equipment to help her to do so. She has an interest in swimming, and swims for a Deaf club.

Jack: lives at home with his parents and sibling, he attends college where he has a good social life. He see’s his culinary skills as skills for life as well as a way to spend time with his family.

Mark: lives at home with his parents, his sibling attends education away from the home. Mark has interests in individual and group sports. He has recently pursued membership of a deaf football club and also plays for a mainstream club, which he has done for many years.

18.24. Appendix 24: Analysed Excerpt

Key

Z= Listener/ researcher

P= Teller/ Participant

Linguistic features using blue font then marked with:

D= Denotation of time

MV= Mental verb

A= Adverb

I= Intensifiers

R= Repititions

Form of the narrative (black font with a pink highlighted letter following)

A=Abstract

O= Orientation

P= plot/sequence

TP= Turning point

E= Evaluation

Resolution

Co= Coda

Z: Er I wondered (D/MV) whether you could tell a little bit more you said that moving on from school and I wondered (D/MV) what your fears were about that? {A}
P: er just er meeting new people [{A}
Z:] mhm [
P:] 'cause I've (D) got used to used to (R) being very small school [
Z:] yeah [
P:] so like the [inaudible] at college is about a thousand in every year I think (D/MV) [{F}
Z:] right ok [
P:] so it's massive {E}[laughs] [
Z:] yeah [
P:] yeah.
Z: What's it been like before when you've met new people what are the things that [
P:] er [
Z:] that make that situation a bit scary [
P:] just really find out about the deafness but like it's fine {E} like I explain at [name of school] {P} it's fine {E} they don't mind {TP} [laughs] [
Z:] yeah [
P:] yeah [
Z:] so your experience so far has been that people actually just kind of understand it?
P: Yeah and like they they're quite interested as well {TP}[
Z:] Hm [
P:] 'cause I've (D) just moved swimming clubs and they're all really interested to know how it works but I don't (D) really remember how it works myself {TP} [laughs]
Z: What do you mean by how it works?
P: Just like er the computerised stuff {D}[laughs] [
Z:] okay like the actual fitting [

Comment [1]: Fear: meeting new people

Comment [2]: Teller and listener… laughter and "yeah" signifies a pause, perhaps demonstrating wanting guidance with another question?

Comment [3]: Fear people finding out about deafness. Reflection: what does the P fear most about this?

Turning point

Comment [4]: Teller and listener- teller externalises 'deafness' then reassures listener. Perhaps coming from a position of the listener not knowing how this experience feels, given the hearing status of the listener(?) Profession of the listener positions teller to perform she's not distressed(?) Anxious around the listener(?)

Teller and setting (society/friends/school): they don't mind, cares what others think about deafness(?) Approval(?)

Teller and culture: will I be accepted by my hearing peers(?) Will someone disapprove(?)

Comment [5]: Resource: despite presenting this as a fear, positive experiences are described. A competent person is perhaps performed? Not phased by meeting new people. What has enabled this? Hearing family and friends, previous positive experiences(?)

Teller and setting (friends/social groups): interested, positive experience.

Affiliation: with friends/ hearing friends.

Identity: hearing/dual/DeaF(?)

Interpretation: CI not specifically mentioned, presented as more of technological aid "computerised".