A Participatory Research Approach to Explore the Experiences of Children of Deaf Adults (CODAs)

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Abstract

Children of deaf adults (CODAs) are a unique group representing a relatively invisible linguistic and cultural minority. Research on CODAs is scarce, and little is known about their lived experience and how they view their identity, especially in a United Kingdom (UK) context. The current study aimed to break free from traditional research and instead adopted a participatory research (PR) approach, which aims to hand over the power to those closest to the matter. Consequently, two enthusiastic and driven female CODAs, aged 19 and 20, adopted the roles of co-researcher and participant.

The co-researchers' aims were both exploratory and emancipatory as they were interested in exploring how the experiences of CODAs shaped their identity and gaining an understanding of what support is currently available for CODA families and what can be modified. The data was collected using virtual semi-structured interviews, artefacts, and diary entries. The data was analysed using an interpretative phenomenological (IPA) approach. The IPA process encouraged the co-researchers to explore their individual views first before identifying four general experiential themes: increased responsibility, the importance of being part of a CODA community, being empowered by your CODA identity, and supporting CODAs.

The findings were discussed in relation to the critical theory, social identity theory, and intersectionality theory, which underpin the current research. The PR findings have implications for educational psychologists and school practitioners in supporting CODA families and making them feel included, with a particular focus on deaf parents. There is a need for future PR in the UK that focuses on empowering diverse groups of CODAs aged 18 and under.

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List of Abbreviations

APA	American Psychological Association
BPS	British Psychological Society
BSL	British Sign Language
CASP	Critical Appraisal Skills Programme
CODA	Child of Deaf Adult
CYP	Children and Young People
EP	Educational Psychologist
GETs	Group Experiential Themes
HCPC	Health and Care Professions Council
IPA	Interpretative Phenomenological Analysis
PR	Participatory Research
PETs	Personal Experiential Themes
RF	Research Facilitator
SPIDER	Sample, Phenomenon of Interest, Design, Evaluation, and Research
TEP	Trainee Educational Psychologist
UK	United Kingdom
UEL	University of East London

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Chapter One: Introduction

Overview

This chapter provides the background and context for the current study, which explores the experiences of children of deaf adults and their identity. Firstly, the term child of deaf adults (CODA) is defined before introducing the research facilitator's (RF) reflexive position and rationale, followed by the participatory research (PR) approach of the current research. Next, the intersection of the hearing and deaf worlds is discussed. The RF recognises that to understand CODAs, it is first necessary to understand their parents' deaf history and cultural identity (Filer & Filer, 2000). Therefore, this chapter briefly describes the terminology and different models of deafness before outlining the theoretical underpinnings of this research.

Background to the Study

Defining Child of Deaf Adults

A CODA is a hearing child born to one or two deaf parents (Preston, 1995a). There are many terms for CODAs, such as kid of deaf adult, hearing child of deaf parent/mother/father, and deaf and heritage signers (Napier, 2021). The current research has adopted 'CODA' as it seems to be the term most used in the literature, as epitomised in Chapter Two.

The Research Facilitator's Reflexive Position and Rationale

This research project has evolved from my upbringing and connection to the deaf community. I am a white, neurodivergent female of dual heritage, British and French. I am also a grandchild of deaf adults (GODA); I have had the opportunity to be part of the deaf, hearing and CODA worlds. My French grandparents were deaf and non-verbal; therefore, my mother is a CODA. I first heard the term CODA after searching the internet for groups for hearing children with deaf parents for my mother. In doing so, I came across the CODA UK and Ireland organisation, a community created by, and for CODAs. This discovery was a true revelation and reinforced the current research.

My mother often shared the hardships that she experienced and how isolated she sometimes felt having two deaf and non-verbal parents. However, she also shared how incredibly proud she is to be a CODA and her admiration for her parents, who, despite their differences, managed to navigate a hearing world. Consequently, she did her best to immerse my siblings and me into the deaf world by accompanying my grandparents to their deaf clubs, where we could practise our French signing. Furthermore, we attended a secondary school for deaf and hearing students, where I proudly completed my levels one, two and pre-level three British Sign Language (BSL). I am eternally grateful to have experienced the deaf world through my grandparents' lens and the CODA world through my mother's lens, as it reinforced my GODA identity and influenced my passion for the current research.

However, my experience and understanding of CODAs are mainly based on my mother's worldview, as opposed to my own. Therefore, I only have access to one unique perspective, and I am conscious that this is not representative of all CODAs' stories. Furthermore, I have a connection to the deaf community through my grandparents and have only recently started to identify as a GODA. Thus, I recognise that I come with assumptions and biases that would inevitably influence my decisions in the research. The thought of misinterpreting a CODA's voice based on my lived experience was uncomfortable, especially as my perspective was clouded by the difficulties and challenges associated with CODA families. For this reason, I was eager to explore alternative ways of conducting research.

Research Facilitator Axiology

Creswell and Creswell (2017) posited that a researcher's acknowledgement and understanding of how their values and biases inevitably shape and influence the research is paramount. This is also referred to as the researcher's axiology (Saunders et al., 2015). My values of social justice, beneficence, and empowerment influence my daily practice as a trainee educational psychologist (TEP). I actively seek to involve children and young people (CYP) in decision-making in all matters that affect them, and I aim to reduce power imbalances between the systems involved. Article 12 of the United Nations Conventions on the Rights of the Child (The United Nations, 1989) also highlights CYP's rights to express their views freely and to have their opinions considered. The Children and Families Act 2014 and the Special Educational Needs and Disability Code of Practice (Department for Education & Department of Health, 2015) emphasise that the CYP's views should inform decisions affecting their lives. Therefore, CYP advocacy and empowerment are paramount to EP practice, including research (Fox, 2016).

Bagnoli and Clark (2010) suggest that EP research should take an increasingly participatory focus and consider the issues of power and control within traditional research, especially between researchers and the researched. My lived experience, values and practice undoubtedly influenced my decision to move away from a 'traditional researcher' role, instead adopting the role of RF, and to seek to empower those most impacted by the matter in question, also known as PR (Aldridge, 2017a).

Participatory Research

Rivera (2022) claimed that there has been a momentous shift towards greater collaboration in research. PR aims to empower and emancipate individuals, especially CYP, who are usually at the bottom of the hierarchical chain. CODAs are a unique minority group that deserves research recognition (Preston, 1995a). Previous research indicates that very few studies focus on CODAs, especially in the UK, as the research is more focused on the experience of deaf parents (Buchino, 1988; Filer & Filer, 2000). Therefore, the research available on CODAs is scarce, and little is known of CODAs' perspectives and lived experiences (Bishop & Hicks, 2005).

EPs play a valuable role in supporting and empowering children, parents, and school staff, thus including deaf-parented families (British Psychological Society, 2018). It was therefore deemed necessary to seek the voices of CODAs through PR to better help guide how EPs can support CODA families and provide implications from those closest to the matter. Hart (1992) identified that for research to meet PR aims, the researcher must collaboratively involve the community in all aspects of the study, from the design stage to the dissemination. Throughout this study, the co-researchers were invited to be 'active researchers', moving away from 'tokenistic' approaches, adult manipulation, and unequal power relations and instead "becoming agents of their own transformation" (Fielding, 2004, p. 306). Ultimately, it was important that the CODA co-researchers' voices were prioritised. PR will be further discussed in Chapter Three.

The Intersection of the Hearing and Deaf Worlds

Globally, it is estimated that 90% of all children born to deaf parents are hearing (Hadjikakou et al., 2009). CODAs are in a unique and interesting position as they grow up in a bicultural and bilingual family (Frank, 2019). Bishop and Hicks (2005) suggest that CODAs are culturally deaf as they inherit social, communication and cultural norms and behaviours from their deaf parents, and this sets them out as different to hearing peers. For instance, CODAs might stamp on the floor, wave, or point to get people's attention. This can be intuitively picked up on and misunderstood or misinterpreted by the hearing world (Knight, 2018). However, CODAs are also exposed to the hearing world and, therefore, are uniquely positioned to view the world through two different lenses (Knight, 2018). This can be challenging for CODAs as they try to mediate between the hearing and deaf worlds (Preston, 1996), and therefore, to better understand this, it is necessary first to have some awareness of deafness, including the historical and current context and culture (Filer & Filer, 2000).

An Introduction to Models of Deafness

Any meaningful dialogue and attempt to understand the lived experiences of CODAs must first recognise the deaf historical context, including models of deafness (Wood, 2016). Henderson and Hendershott (1991) highlighted that deafness does not just belong to the individual but to the entire family. Therefore, understanding how the world views deafness is vital, as this influences the different narratives on what it means to be CODA. In the following section, the terminology around deafness will be discussed before outlining the models of deafness.

Defining 'Deaf' and the d/D Distinction

It is important to define the term, deaf, as it refers to various medical and cultural meanings (Fracchia & Theofilatou, 1993; Hindley, 2005; Pudans-Smith et al., 2019). Within the medical sense, the term 'deaf' describes individuals within multiple levels of hearing loss: 'mild', 'moderate', 'severe' or 'profound' (Denmark, 1994).

Deaf people also have different forms of communication; this entails those who are verbal and non-verbal, those who use BSL (a language with its grammatical structure and syntax different to English), sign-supported English (based on spoken English) and lipreading (Karas & Laud, 2014). Within a cultural sense, deaf refers to the unique language, beliefs, values, norms and customs different from hearing culture (Ladd, 2003).

There is still an ongoing debate regarding the d/D distinction. Upper case ‘D’ is used for those who use sign language and are members of the deaf community; however, the lower case ‘d’ generally refers to a person with hearing loss who uses different forms of communication and is not necessarily part of the deaf community (Zárate, 2021). Pudans-Smith et al. (2019) found that the d/D distinction creates a divide within the community, adding that it is important to recognise all deaf people, to remain curious, and to respect and use a person’s preferred naming conventions. For the current study, the term ‘deaf’ will be used as an umbrella term to refer both to those with hearing loss who do not identify with the deaf community, and to those who identify within the deaf community. This supports the terminology outlined by The Consortium for Research in Deaf Education (2023).

The Medical Model

Throughout history, the deaf community has been stigmatised, marginalised, and discriminated against by hearing people (Corker, 1998; Eckert & Rowley, 2013; Ladd, 2003). Within the medical model, deafness is viewed as a personal tragedy holding a ‘within-person’ attitude, placing the responsibility of deafness onto the deaf individual, with any language or social barriers that they face being due to their functional limitations (Byrd et al., 2011; Knight, 2015). Before 1970, there was a strong emphasis on the medical pathological view of deafness, which focused on deafness as a physical deficit that required a diagnosis, intervention, medical cures and treatments, and assistive technology to enable deaf people to become ‘normal’ hearing people; thus, ‘fixing’ them (Glickman, 2008). Feu and Fergusson (2003) argue that the modern development of paediatric cochlear implants and hearing aids reinforces the medial problem and normalises ‘fixing’.

Furthermore, Fracchia and Theofilatou (1993) argue that until the early 1990s, in medical circles, there was a link between deafness and psychopathology, with the mental condition known as surdophrenia (meaning ‘deaf mind’). Deaf people were seen as emotionally immature individuals who lacked empathy and had explosive natures (Carvill, 2001). More recently, Hindley (2005) found that ‘severely’ to ‘profoundly’ deaf children are more vulnerable to mental health problems and physical illnesses than their hearing peers; thus, the link is still prevalent.

Suppression of British Sign Language

The medical focus on cure and interventions led to the suppression of BSL, deaf culture, and the deaf community (Ladd, 2007). Deaf people were treated with paternalistic attitudes based on the view that they lacked verbal communication skills. There was a notion of ‘phonocentrism’, which is the assumption among the hearing world that sound and speech are superior to BSL, as BSL was considered a simple collection of gestures and not a language with its own grammatical structure (Corker, 1998; De Meulder, 2016). Consequently, deaf people were deemed less intelligent and were taught poorly alongside hearing students in schools and, at times, misdiagnosed as being mentally ill (Lang, 2011). In school, deaf children were discouraged and even punished for signing and forced to learn lip reading, which was believed to be more successful (Kyle & Pullen, 1988).

Notably, the medical model has been used to oppress and disempower deaf people, as it suggests that hearing is the norm and alienates deafness, referring to it as an abnormal state (Kelly-Corless, 2022). Researchers argue that the medical model is far too reductionist as it fails to account for the linguistic, social, and psychological dimensions of deafness (Kelly-Corless, 2022; Ladd, 2003; Shakespeare, 2006). The medical model was challenged by the disabled community, who offered the social model of disability instead (Shakespeare, 2006).

The Social Model

Berghs et al. (2019) state that the social model challenges social discrimination and normative assumptions and has significantly impacted United Kingdom legislation. It was foundational to the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) and the Disability Discrimination Act 1995, which made it unlawful to discriminate against the disabled concerning employment, the provisions of goods and services, education, and transport. The Disability Discrimination Act 1995 was later replaced by the Equality Act 2010, which further improved protection for deaf individuals against direct and indirect discrimination (Bellei, 2019).

The social model recognises that disability is an evolving concept and distinguishes between individuals' impairments and disability. It views disability as a social construct where the individual is disabled by the obstacles created by society; thus, it considers the structures and attitudes of society to be the cause of disability (Shakespeare, 2006). The social model focuses on how society fails to adapt to enable full integration and participation (Corker, 1998). For instance, Lesch et al. (2019) found that the lack of sign language interpreters in health care and education systems leads to misunderstanding, missed opportunities, and poor outcomes for the deaf community. Thus, in this model, deaf people are disabled by unequal barriers posed by society, not by their impairment or differences (Shakespeare, 2013).

Nonetheless, although the social model has had a prominent influence on legislation, it is not without its limitations, as it undermines the cultural and linguistic status of deaf people and inhibits further progress (Brennan, 2003). The social model's goal is to normalise deafness so that deaf people can fit into broader society; however, societies have different views, expectations, beliefs, and values of 'normality', and not everyone aspires to the same 'norms' (Brennan, 2003). Furthermore, the terms 'impaired' and 'disability' are strongly contested by the deaf community; many members of the deaf community do not see themselves as having a disability or their deafness as a problem (Lane, 2002). Instead, they consider themselves "happily diverse and different" (Zárate, 2021, p. 22).

The Cultural Linguistic Minority Model

"A central dilemma for hearing children of deaf parents: It is hearing people who make deafness problematic" (Preston, 1995a, p. 52). The cultural, linguistic minority model believes in the beauty of being deaf and rejects the emphasis on deafness as a disability; instead, it focuses on how it is a natural deviation of human identity with their own language and culture (Ladd & Lane, 2013). Thus, the term, deaf, is viewed as a cultural-linguistic identifier that derives from the shared life experiences of deaf people based on their collective shared history, language, and cultural ways of being (Brennan, 2003). The cultural linguistic minority model not only challenges the assumption that hearing and auditory speech are superior to deafness and sign language, referred to as 'audism' (Humphries, 1977), but also redefines deaf people and provides them with an opportunity for empowerment and self-actualisation (Carol & Humphries, 2005).

The Current National Context

The different models of deafness are useful in definition; however, they are not mutually exclusive nor do they hold equal weight in the hearing world (Young & Hunt, 2011). Kelly-Corless (2022) emphasised that although the Equality Act 2010 represents an increase in rights for the deaf community and aligns with the social model, other aspects of the Act have been contested by the deaf community, perpetuating problematic narratives which support the medical model. The Act's definition of disability, "A physical or mental impairment . . . [that] has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities" (Equality Act, 2010: 6.1), denies the deaf community of their deaf culture and language, and positions them instead in the disability category; thus, dismissing the cultural linguistic minority model (Wilks, 2019).

Nonetheless, a cultural and political shift appears to be happening due to an increased representation and awareness of the deaf community in media (Wootten, 2021). Most recently, BSL has been recognised in law as a language of Great Britain and, from September 2025, it will be taught in secondary schools (BSL Act, 2022; The Education Hub, 2023). As part of GCSEs, pupils will be taught 750 signs, focusing on how to communicate effectively with other signers in social, academic, and work settings, and an introduction to the history of BSL and how it evolved into the language it is today. Although this appears to be a significant step towards equality, GCSE in BSL will be optional and not part of the national curriculum. Therefore, it is crucial to remain critical, to question whether this is a tokenistic act and whether it will positively impact deaf and CODA families.

Theoretical Perspectives Underpinning the Research

There are different lenses through which the phenomenon of being a CODA can be viewed; however, for the purpose of the current research, the following theories will be adopted as they align with the current PR and paradigms (to be introduced in Chapter Three): Critical psychology (Parker, 2015), social identity theory (Tajfel & Turner, 1979), and intersectionality theory (Crenshaw, 1991), which incorporates social GGRRAAACCEEESSS (Burnham, 2018). Chapter Three will also introduce additional theoretical frameworks underpinning data analysis.

Critical Psychology

A critical perspective is reflected throughout the introduction, especially when exploring the models of deafness, as they each come with limitations. Critical psychology challenges traditional models and studies of disability and raises concerns about deficit or pathologically oriented ways of understanding the world; thus, the medical approach (Mills, 2015). Corcoran (2022) argues that EPs still engage in traditional models as they examine and compare people living with disabilities to the 'idealized physical, psychological and developmental norm'. For example, many EPs may use a standardised test comparing CYP to the supposed norm. However, the critical perspective opposes such comparison, noting that this is an explicit form of ableism and demanding alternative approaches (Corcoran, 2022; Slee et al., 2019).

It could be argued that the social model acts as one alternative approach and fits with the critical perspective, as both contribute a non-pathologising and non-disabling view. The social model draws people's attention towards the barriers in the environment that prevent 'disabled people' from full participation in society and, instead, focuses on emancipating individuals living with a disability (Slee et al., 2019).

Previous literature notes that CODAs can experience the oppression and discrimination felt by their deaf parents from hearing society (Hindley, 2005). However, when barriers in society are dismantled so that their deaf parents have the same access as hearing parents, this benefits CODAs, too, as they can focus on the positives associated with being CODA (Mand et al., 2009; Moroe & de Andrade, 2018a).

Furthermore, Parker (2015), a co-founder of critical psychology, argues that psychologists should look at different contexts and relations to understand how people experience the world in their particular way. The critical EP perspective aligns with the current study as it seeks to level the professional and CYP relationship. It positions them as the experts of their lived experience, finding ways to honour and explore this rather than compare (Beal, 2015; Corcoran, 2022). This study empowered CODAs to share their lived experience as “To speak for the deaf, you must be deaf” (Preston, 1995a, p. 200) and therefore, to speak for CODAs, you must be a CODA.

Social Identity Theory

Tajfel’s and Turner’s (1979) social identity theory proposed that individuals' self-identity derives from social categories in which there are three cognitive processes relevant to being part of an in-group or out-group (Tajfel & Turner, 1979):

1. Social categorisation: individuals categorise themselves and others into groups based on characteristics such as religion, gender, and race.
2. Social identification: people identify as members of particular social groups and adopt the associated values, behaviours and norms.

3. Social comparison. Individuals compare their ‘in-group’ with other ‘out-groups’, often favouring their group and seeking to enhance its power and status.

This theory argues that the groups that individuals belong to are essential sources of pride, self-esteem, and purpose, and increase a person’s understanding of themselves and their identity (Tajfel, 2010). Furthermore, the theory asserts that people naturally view their ‘in-group’ through a positive lens while being neutral or negative towards ‘out-groups’. Tajfel and Turner (1979) suggest that categorising people into groups increases the risk of a ‘them and us mentality’ and can help explain bias, prejudices, and discrimination.

Previous research suggests that CODAs identify with two different worlds and thus lead two different lives (Tajfel & Turner, 1979). They are “a population who are both outsiders and insiders” (Preston, 1995a, p. 1461). Therefore, this theory can help explain the social conditions and cognitive processes underlying CODAs’ experiences of being part of the deaf and hearing worlds, and of their identity.

Intersectionality Theory

Intersectionality is an analytical framework for understanding that an individual’s identity is multi-faceted and intertwined by social markers such as race, gender, class, language, and education (Crenshaw, 1991). The intersectionality wheel of power and privilege (Appendix A, Duckworth, 2020, adapted from Crenshaw, 1991) does not explicitly use the term ‘deaf’; instead, it accounts for able bodies vs ableism. Therefore, ‘deaf individuals’ are viewed as oppressed, and this framework is a helpful reminder of the oppression and marginalisation that deaf people have faced and, arguably, still encounter (Corker, 1998; Lane, 2005).

Furthermore, while CODAs may share the same ‘label’, it does not mean that all CODAs have experienced life in the same way (Preston, 1995a). Considering a

CODA's characteristics, one might experience multiple forms of oppression at the same time, for example, deafness together with racial discrimination (Rivera, 2022). This research encouraged the co-researchers to reflect on their characteristics using the social GGRRAAACCEEESSS model while promoting reflection on differences, diversity and power dynamics (Burnham, 2018). Additionally, it aims to draw on the theory of intersectionality to help consider the multiple, and often overlapping layers of the participant's identity as part of the discussion in Chapter Five.

Chapter Summary

This chapter outlined the RF's reflexive position and rationale and introduced the PR approach to this research. The key focus of this PR, CODAs, is elaborated on by discussing the intersection of the hearing and deaf worlds before describing different models of deafness. Fundamental theories that underpin the current research have been presented. The following chapter explores the available literature on 'What is known about the experiences of CODAs?'.

Chapter Two: Literature Review

Overview

This chapter will critically review the literature concerning what is known about the experiences of CODAs. Firstly, this chapter outlines the systematic research literature review question and the systematic literature search methodology. The chapter then describes the thematic synthesis undertaken to identify themes and subthemes in the final articles. The main body of the chapter outlines the four themes identified through the literature's synthesis: ‘bicultural identity’, bilingual identity’, ‘protection’, and ‘a high level of responsibility’. These four themes have subthemes that help the reader to better understand what is known about the experiences of CODAs. Finally, this chapter ends with a summary of the literature review, outlines the limitations of the available research, and reinforces the need for current PR.

Systematic Literature Review Research Question

A literature review “is a systematic, explicit, and reproducible method for identifying, evaluating, and synthesising the existing body of completed and recorded words produced by researchers, scholars, and practitioners” (Fink, 2019, p. 6). The literature review question, ‘What is known about the experiences of CODAs?’, was intentionally kept broad to fit the PR approach and maximise findings. It is important to note that although the literature review does not inform the PR, as the co-researchers will discuss and agree on the research direction, it aims to understand what is currently known about CODAs' experiences and examine how CODAs’ views have been represented in the literature, with a particular interest in finding PR studies.

The Systematic Literature Review Process

The Databases

A systematic literature search was conducted in October 2022, for the research proposal, and reviewed in March 2023 to check for new research. The Booth et al. (2012) search, appraisal, synthesis and analysis framework was adopted to guide the process and provide an appropriate structure for the review. The search engine, EBSCO Host, was used to complete the systematic search within the following databases: American Psychological Association (APA) PsycInfo and Scopus. These two databases were chosen because they provide comprehensive and authoritative psychology-related articles. The RF also identified studies through citation searching and exploring academic articles on the CODA UK & Ireland website (https://www.codaukireland.co.uk). The research literature review question: ‘What is known about the experiences of CODAs?’ informed the search terms.

Search Terms

Initially, the thesaurus function was used to identify synonyms for the main search terms ‘CODA’ and ‘experience’. However, after multiple unsuccessful attempts, the RF consulted with CODA experts, who helped identify appropriate and valid synonyms for the niche term, CODA. Guidance was also sought from the specialist librarian from the School of Psychology at the University of East London (UEL). Consequently, free-text searching was adopted, enabling the RF to use recognised and precise synonyms for CODA. Table 1 highlights the final search terms from APA PsycInfo and Scopus. The RF applied suitable Boolean operators (‘AND’ and ‘OR’) and truncation (*) to help mitigate the drawbacks of using a free-text searching approach and broaden the search, whilst keeping it focused on CODAs’ experiences (Booth et al., 2012). Furthermore, filters such as ‘subject terms’ and ‘English language only’ were used to increase the specificity and relatedness of the research generated (Hart, 1998) (Table 1).

Table 1

Key Terms using Elements of a Sample, Phenomenon of Interest, Design, Evaluation, Research Type

Sample	Evaluation	Filters Applied	Final Key Terms and Justification
Terms related to Child of deaf adults (CODA) Synonyms **APA PsycInfo** Child* of deaf adult* Kid of deaf adult* Deaf parent* Hearing child* of deaf parent* **Scopus** “Child* of deaf adult*” “Kid of deaf adult*” “Hearing child of deaf parent*"	Terms related to Experience Synonyms **APA PsycInfo** perspective view perception attitude feelings views viewpoint opinions **Scopus** Additional search terms yielded irrelevant findings.	**APA PsycInfo** SU English language only **Scopus** SU English language only (The research facilitator is only fluent in written English language, and there was no additional funding for translators)	**APA PsycInfo** SU (SU "child* of deaf adult*" OR SU "kid of deaf adult*" OR SU "deaf parent*" OR SU "hearing child* of deaf adult*") AND ((experience OR perspective OR view OR perception OR attitude OR feelings OR views OR viewpoint OR opinions)) **Scopus** TITLE-ABS-KEY (“child* of deaf adult*" OR "kid of deaf adult*" OR "hearing child of deaf parent*") AND (LIMIT-TO (LANGUAGE, "English") SU: more relevance when it was a main area of the research

Note: SU looks for the subject terms, * = captures terms associated/related to the word, () = keeps it separate from the search, AND = combines different concepts, narrowing the search, OR = combines terms within the same concept.
Due to the niche area of interest, the research question was broad; therefore, not all elements of the SPIDER were utilised.

Eligibility Criteria

The sample, phenomenon of interest, design, evaluation, and research type (SPIDER) tool was adopted to inform the inclusion and exclusion criteria (Cooke et al., 2012) (Appendix B). Other tools, such as population, intervention, comparison, and outcome, were considered (Booth et al., 2012). However, SPIDER ensured that searches were relevant to the qualitative literature review question, ‘What is known about the experiences of CODAs?’, as it focused on the how and why of individual experiences and participants' attitudes and views (Cooke et al., 2012). For these reasons, quantitative-only papers were excluded, as although they allow participants to share their views, the reductive nature of numeric measures does not enable them to give detailed and rich accounts of their lived experiences (Booth et al., 2012).

Due to a lack of primary and peer-reviewed literature, grey literature, such as dissertations and bibliographies, were included at this stage. This is because the chosen grey literature was highly relevant and innovative. Paez (2017) supports using grey literature as it reduces publication bias and offers the most recent, balanced, and broader picture of the evidence available. This fits well with the literature review question. Nonetheless, a thorough quality appraisal later found their lack of credibility, so they were excluded. However, the RF continued to have access to them and referred to them in Chapters One and Five.

The Preferred Reporting Items for Systematic Review and Meta-Analyses

A preferred reporting item for systematic review and meta-analyses (PRISMA) was utilised to illustrate the complete account of the systematic literature search methodology (Page et al., 2021) (Appendix C). A total of 130 papers yielded from the search. From skim-reading the titles and abstracts, they notably seemed more relevant than the initial scoping search using the thesaurus. Thus, it confirmed that free-text searching was a more successful approach. From the yielded 130 papers, there were 5 duplications across the 2 databases, and 8 articles were ineligible. This led to the exclusion of 13 studies. Subsequently, 117 titles and abstracts were screened further for relevance to the literature review question. All the studies which did not meet the SPIDER inclusion criteria, but instead met the exclusion criteria, were removed leading to a reduction of a further 83 papers. A total of 34 papers met the criteria; however, 17 were then excluded as the RF could not retrieve the full text and, therefore, could not examine the full quality of those studies.

Quality Assessment of Articles

Although other quality appraisal tools, such as the critical appraisal of a qualitative paper (Shenton, 2004), were considered, the ten-item Critical Appraisal Skills Programme (CASP) (CASP, 2023) was chosen. It is a user-friendly checklist for novice qualitative researchers, and the RF had previous successful experience using this tool to help them make sense of their qualitative papers (Booth et al., 2012). CASP (2023) enabled the RF to assess the papers' quality and relevance to the current research. This provided a richer understanding of the papers and enabled the RF to systematically assess the trustworthiness, relevance, and findings.

The CASP ratings for each paper are presented in Appendix D. A total of 17 articles were assessed for eligibility; however, due to a lack of ethical consideration (n=1), lack of sufficient rigour (n=4) and a lack of evidence for valuable findings (n=3), 8 articles were excluded. Therefore, 9 articles met the CASP criteria. As mentioned, the RF also used citation searching and academic papers from the CODA UK & Ireland website (https://www.codaukireland.co.uk). Booth et al.’s (2012) exact systematic literature process was applied due to high duplication with APA PsycInfo and Scopus, this added only 5 studies to the database data. Finally, a total of 14 papers satisfied the quality criteria.

Characteristics of the Papers Identified

The final 14 identified papers were either qualitative or mixed methods studies (Appendix E). Most of the data collection methods used were in-depth semi-structured interviews with open-ended questions. Notably, two papers adopted a participatory approach in which the co-researchers had the autonomy to decide on the research matter (Hale, 2001; Knight, 2018). However, the co-researchers in these studies were not invited to take the role of participant; thus, they did not have the opportunity to share their views. The majority of views gained in the 14 papers were from adult CODAs aged 18 years and above; only three studies gained the views of children and adolescents between the ages of 9 and 17 years (Buchino, 1988; Knight, 2018; Schleif, 2006).

There was a diverse cultural and geographical spread across the papers. The majority were from the United States of America (Buchino, 1988; Frank, 2019; Hale, 2001; Knight, 2018; Preston, 1994; Schleif, 2006; Wood, 2016), and South Africa (Harrison & Watermeyer, 2019; Moroe & Andrade, 2018a; Moroe, 2019; Moroe & Andrade, 2018b). However, the remaining papers were from New Zealand (Harrison & Watermeyer, 2019), the Czech Republic (Klimentová et al., 2017), Australia (Mand et al., 2009), and Cyprus (Hadjikakou et al., 2009). This international perspective is valuable and enables a diverse range of voices. Interestingly, none of the final studies were conducted in the UK, emphasising the value of the current research as there seems to be a lack of CODA representation in UK literature.

Thematic Synthesis of the Literature Review Findings

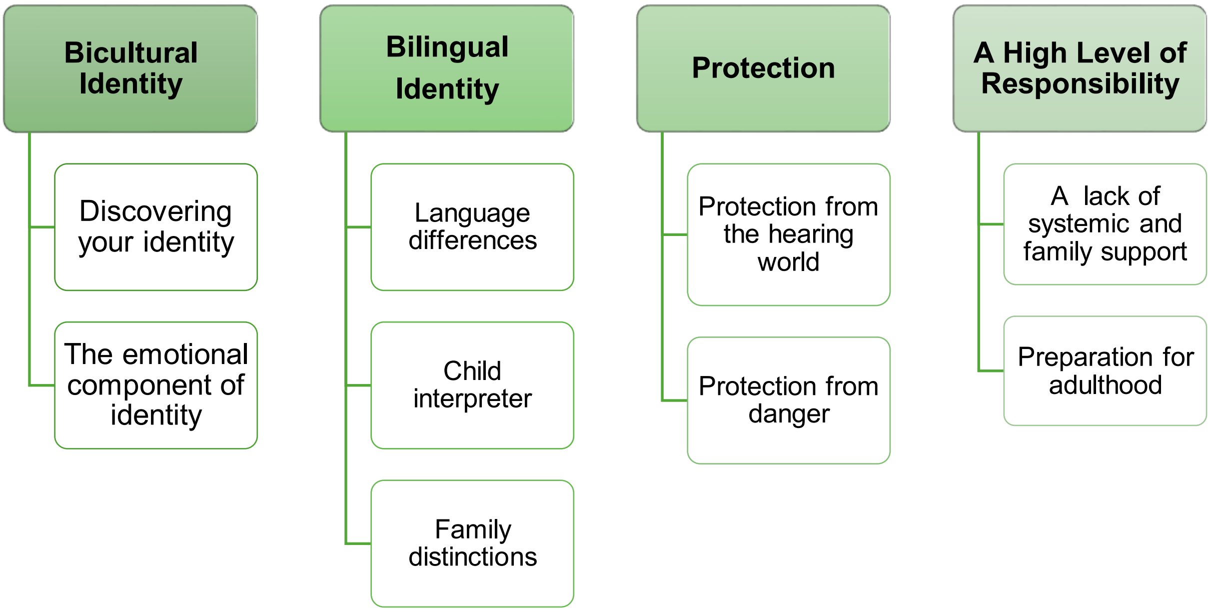
The RF used elements from the thematic synthesis method (Thomas & Harden, 2008) as general guidance to help identify themes in the final 14 papers linked to the literature review question: ‘What is known about the experiences of CODAs?’. Thomas and Harden (2008) state that a thematic synthesis consolidates qualitative research findings. It allows researchers to develop initial codes for descriptive and analytical themes: ‘descriptive themes’ remain ‘close’ to the primary studies, and ‘analytical themes welcome interpretation.

According to Thomas and Harden (2008), third-order interpretation, ‘interpretations of interpretations of interpretations of experiences’, should occur when the yielded literature stems from a broad literature review question, thus aligning with this research. The RF was most concerned with ‘going beyond’ the primary studies and generating new interpretative constructs aligned with the broad literature review question. Thus, there was an emphasis on analytical themes and third-order interpretation.

Firstly, the RF developed descriptive themes based on the final 14 papers, thus staying close to the original findings. The descriptive themes were then considered through the current research systematic literature review question. From this, analytical themes emerged, from which the RF went beyond the primary studies and applied third-order interpretation (Thomas & Harden, 2008). Based on the RF's connection with the CODA community, referred to in Chapter One, they adopted a self-reflexive approach to increase transparency, examining how thoughts, feelings and actions influenced their thinking (Appendix F). It is important to note that this current research adopts a critical realist and transformative paradigm, and accepts that the analytical themes depend on the RF's constructs, experiences, and social history (Robson & McCartan, 2017). The RF identified 4 main themes and 9 subthemes in the final 14 papers (Figure 2.1). The themes are in temporal order below, as the RF wanted to emphasise the timeline in which they might occur. These are reviewed and critically considered below.

Figure 2.1

The Final Four Themes and Nine Subthemes



Theme One: Bicultural Identity

The first theme to be explored was bicultural identity. Interestingly, CODAs' upbringing consists of two worlds—the deaf world of their immediate family and the hearing world outside of this. Therefore, CODAs are unique, as they are immersed in both the hearing and deaf cultures and must learn to manage and mediate between them (Preston, 1994). The subthemes provide a rich and complex picture of CODAs developing an identity and the emotional component of identity.

Subtheme One: Discovering Your Identity

Preston's (1995) research focused on the cultural identity of CODAs, "a population who are both outsiders and insiders" (p. 1461). He interviewed 150 CODAs of adult age throughout the United States; 141 of them had two deaf parents. The informants shared their journeys of discovering their identity, which involved exploring three different cultures: the deaf, hearing, and CODA cultures. He noticed that the age at which CODAs discovered their identity differed. For example, many informants recalled that it was not until school age that they realised they were hearing, and that deaf people were ‘abnormal’ and hearing people were ‘normal’. Yet, informants also shared experiences of discovering their identity much later.

Preston (1995b, p. 1647, as cited in Moroe, 2019) captured this example:

> When I turned 18, my father took me aside. He pointed out the window and said (“The time is coming. Soon you must go. That’s your world out there. The Hearing world. You belong there.”) For 18 years, I had grown up Deaf, and now all of a sudden, I’m supposed to be hearing. I looked at him and said, (“What do I know about the hearing world? I hear, yes. I speak, yes. But I thought I was Deaf”).

This reinforces the idea of two worlds, the hearing and the deaf worlds. It also suggests that CODAs toil with their identity; they are on a journey of self-discovery, and in this case, the participant’s father influenced them to choose the hearing world.

However, Moroe's (2019) phenomenological qualitative research design used semi-structured interviews to explore the experiences of 10 CODAs, aged 21- 40, their sense of belonging, and affiliation to the deaf and hearing communities. The findings revealed that most CODAs (60%) viewed themselves as belonging to both cultures but having a clear preference and cultural bias for the deaf community. CODAs also reported finding it challenging to balance the two worlds and had to be reminded of the different expectations and rituals between the two cultures. This acceptance of bicultural identity tends to happen once CODAs encounter similar people to their demographic, usually occurring in early adulthood (Knight, 2018).

Despite the CODA’s age, Preston (1995) emphasises that there is a dilemma of identity, in which CODAs are neither deaf nor hearing. Instead, they are both deaf and hearing and, therefore, must eventually either accept the norms of the majority hearing community and culture, often causing conflicts with their deaf family's way of being, or align themselves with their deaf parents and remain outsiders. This 'in-between stage' has been described as "living on the border" (Hoffmeister, 2008, p. 189). This intersection of two worlds can lead CODAs to question where they belong throughout childhood and can lead to self-conflict and confusion, which education professionals should consider carefully (Moroe & Andrade, 2018a).

Subtheme Two: The Emotional Component of Identity

Knight (2018) used a qualitative study where she trained 3 CODAs, young hearing children of deaf parents, to interview 11 other CODAs aged 11-17 (referred to as kids of deaf adults or KODAs throughout their study). The open-ended interviews explored the CODAs' social identities, and the findings revealed an emotional component of social identification. The CODAs appeared pessimistic about hearing people, and avoided expressing their deaf identity in schools as they felt pressured to educate others and obliged to answer sensitive questions on deafness. This often left them feeling uncomfortable, awkward, and embarrassed.

However, CODAs also expressed appreciation and positive feelings of belonging, pride, responsibility, bilingualism, and biculturalism. They noted that the summer camp, a safe place for CODAs to come together and spend time with others who have shared lived experiences, was a significant place for them to establish and strengthen their identity as CODAs. Here, they found that being around others like them boosted their self-esteem and sense of self. Despite this, most CODAs preferred the deaf world, and only four chose the CODA world, that is, the deaf and hearing world, yet all participants identified themselves as a CODA.

Knight's (2018) study is not without its limitations. The researcher openly shared their researcher bias towards CODAs, as they are deaf and are mother to four CODAs. However, for this reason, they trained non-family related CODAs to conduct the interviews. Furthermore, those CODA participants who attended CODA camps shared more in-depth stories and anecdotes about being CODA than those who did not attend CODA camps; therefore, equality and voice representation is in question.

Theme Two: Bilingual Identity

For many CODAs, sign language is their first language; spoken language is secondary and something that they learn from individuals outside their immediate family (Bishop & Hicks, 2005). The experience of CODAs' bilingual identity is a prominent theme across the literature review. The RF has broken it down into three subthemes: language differences, sign language interpreting, brokering, and family distinctions, such as birth order and gender.

Subtheme One: Language Differences.

Frank (2019) used a hermeneutic phenomenological study to explore the experiences of 13 CODAs aged 18-40 who were the only hearing person in their family. The participants reported that, initially, when starting school, they struggled with their speech as it was their first full-time experience of spoken language, 'the hearing world'. This finding aligned with Frank's (2019) literature review, which highlighted that CODAs found it challenging to socialise in school and had difficulties with their expressive spoken language. Consequently, they were often labelled as having a speech delay or learning difficulty (Bishop & Hicks, 2005). Additionally, Bull (2005) notes that CODAs are typically visual learners and, therefore, can find it challenging to process information orally within a hearing classroom environment.

Frank (2019) strongly suggests that teachers should consider the communication differences between CODAs and hearing children of hearing parents, and make necessary adjustments to their teaching and learning environment.

Similar to Frank's (2019) study, Knight (2018) identified how communication influences social identification in CODAs. The CODAs shared that, due to growing up in a deaf home environment in which they used sign language and attended deaf events, they initially adopted deaf culture and communication norms. This was evident in their facial expressions, eye contact, and behaviour. Consequently, when starting education, the CODAs expressed worries about learning and assimilating to hearing culture, such as knowing how to regulate their voice.

Harrison and Watermeyer (2019) used an auto-ethnographic study that explored the life of a South African, black, female CODA who reported similar concerns about adjusting to the hearing culture. The CODA shared her reflections on school, saying, “I could hardly answer any questions in class for fear of mispronunciation or lisping, and I often found it difficult to express myself” (p. 5). She emphasised that spoken language was not expressive enough: “Like a painter expressing, I need my audience to see what I am saying” (p. 5), thus feeling paranoid and restricted in a hearing environment. Notably, as CODAs share the language of the majority, they eventually learn to assimilate into the hearing world and frequently adopt the role of interpreter for their parents (Harrison & Watermeyer, 2019).

Subtheme Two: Child Interpreter.

Preston (1995) describes sign language interpreting as “conceptually organising what is being said as well as putting oneself in the place of the speaker and the listener” (p. 143). However, he notes that an important distinction for CODAs is that they not only translate the words, but also have an element of cultural mediation. The literature also uses the term ‘child language brokering’, an informal act of CYP assisting their parents with communication, as different to interpreting (Napier, 2021). Thus, CODAs often replace professional paid interpreters as they are made to start ‘language brokering’ for their parents from a very young age (Napier, 2021; Preston, 1996).

Klimentová et al.'s (2017) empirical research found that CODAs as young as five and six were interpreting for their deaf parents in situations for which they lacked the life experience required, and were ultimately too young. For example, they make big purchases and interpret at a doctor or state appointment: “When I was a kid, I dealt with my parents’ problems, although I didn’t understand them at all” (p. 848). Preston (1995) described this as the ‘chameleon effect’: “I could be any role; I was the mechanic, the teacher, the car salesman” (p. 218). However, further research found that CODAs have memories of interpreting for their parents from an even younger age, that is, ages one to five: “I started school when I was four, and I remember interpreting phone calls before I went to school” (Wood, 2016a, p. 66).

Wood (2016) used a qualitative phenomenological study to explore the reflections of 12 CODAs who acted as linguistic and cultural brokers for their parents throughout their childhood. Their findings reveal that all 12 participants felt they had parental roles, and 11 of the 12 participants felt they had no choice in their interpreting and cultural brokering responsibilities. Regardless of their age, they recall events of interpreting for their parents in matters such as paying bills, mortgage closing, doctors’ appointments, and mental health interventions. Most participants expressed being unaware of what they did not know, and being concerned about what damage that could have caused. However, all participants recognised that this influenced their personal development and made them who they are today.

It is essential to recognise that Wood's (2016) sample of 12 American signing CODAs is a snapshot of their lived experience and, therefore, does not account for the lived experiences and views of the CODA community. Furthermore, this study was a recollection of memories. Thus, despite Wood (2016) facilitating in-depth interviews, the reflective accounts would have been somewhat distorted and naturally influenced by their adult processing overlay.

Subtheme Three: Family Distinctions.

The additional interpreter role is also referred to as ‘parentification or role reversal’, that is, adopting the responsibility of an adult and caretaker of their parents (Buchino, 1993). A growing consensus is that CODAs’ level of parentification is determined by their gender and birth order (Schiff-Myers & Klein, 1985). The findings of Hadjikakou et al. (2009) revealed that, usually, the firstborn or eldest CODA had more duties as an interpreter than their younger siblings: “I was the firstborn child in my family. I’ve been interpreting for my parents since I was 5 to 6 years old” (p. 493). The participants reported that this additional responsibility was tiring and stressful, as it hindered their childhood and was an extra burden for them to carry. Nonetheless, they could not do otherwise, as there was no alternative.

More recent qualitative research, by Moroe and Andrade (2018a), argues that there has been a shift as older children now pass on the interpreter role to their younger siblings. Five of the ten participants were last born in their family, and they all adopted the interpreter role: “I’m the last born at home, and I have no idea how I ended up being an interpreter at home” (p. 7). They noted that the firstborn in their family did not want the role, which they believed was mainly due to personality differences: "My older sister was an introvert, and she did not like interpreting” (p. 7). This meant that the younger siblings were often left to interpret matters exceeding their comprehension, thus not age-appropriate and contradicting Hadjikakou et al.'s (2009) study.

Moroe and Andrade (2018a) also found that, although there was no formal assignment of the interpreter role, female CODAs were much more likely to interpret for their parents than male CODAs. This correlates with Preston's (1994) analysis, which revealed that the interpreter role would often fall to the eldest female, despite their sign language ability, and even when there was an older brother in the family. However, it is essential to note that the female CODAs describe their interpreting role as an honourable duty that helps build independence and autonomy (Preston 1994). Thus, they embraced this role and deemed it an admirable life skill.

Theme Three: Protection

A recurring narrative shared in the literature was CODAs’ responsibility to protect their parents. Nine of the fourteen studies identified two primary forms of protection. Firstly, CODAs have the responsibility to protect their deaf parents from negative and prejudiced comments from the hearing world (Hadjikakou et al., 2009; Morales & Hanson, 2005). Secondly, CODAs have feelings of responsibility to protect their family from potential danger and hazards (Frank, 2019). The studies also suggest that CODAs are positioned by their parents as the ‘protector’ due to their ‘gift of hearing’.

Subtheme One: Protection From the Hearing World.

Moroe and Andrade (2018b) used a phenomenological, qualitative, non-experimental research design to explore the views of ten CODAs reflecting on their childhood experiences of language brokering for their deaf parents. Their findings illustrated that all CODAs reminisced about times when they felt the need to protect their parents from insensitive and offensive comments from the hearing world: “Should I tell him? Should I not tell him? Should I tell him or protect his feelings?” (Moroe & Andrade, 2018b, p. 76). CODAs’ position to protect their parents is an interesting dilemma as the parent-child relationships become blurred, and the child seems to take on parental responsibility. Moroe and Andrade (2018b) noted that CODAs did not necessarily want to belittle their parents by making decisions on their behalf; however, they equally wanted to shield their parents from hurtful comments.

More recently, Frank's (2019) hermeneutic phenomenological study identified ‘being responsible or protective’ as a main theme. This theme illustrated that 8 of the 13 CODAs interviewed shared experiences of protecting their deaf parents from prejudice and stereotypical comments from the ‘hearing world’. Interestingly, the CODAs also felt that they had to protect and defend their younger deaf siblings: “I just expected it would be the same for my brother as well” and “I definitely took on the role as a second mother to my brother. I was very protective of him” (Frank, 2019, p. 11). CODAs were the only ones who could hear, becoming their family’s ‘ears’.

Furthermore, Harrison and Watermeyer's (2019) auto-ethnographic study introduces a racial element when exploring the life of a black, female CODA living in South Africa during apartheid. This explores protection through an intersectional lens as the CODA shared her experience of responding to apartheid’s structural racism: “In protecting my mother from the humiliations of disablist othering, I was also holding, for her, vulnerabilities to do with racism” (p. 7). In this case, the participant had to protect her parent from multiple layers of harmful comments. Harrison and Watermeyer (2019) conclude that life as a black, female CODA living in South Africa is complicated and multidimensional. It is also a crucial reminder that oppression and discrimination can manifest differently; this CODA’s story was influenced by the intersection of her visible blackness and invisible characteristics as a CODA.

Subtheme Two: Protection From Danger.

Another facet of the CODAs’ family role as the ‘protectors’ is their responsibility to be alert to any possible danger that a hearing person would foresee coming or notice before a deaf person. Hadjikakou et al. (2009) shared experiences of CODAs who would be awoken by strange noises and had to warn their parents of any potential danger and emergencies at home, like house fires, vehicles approaching or burglary. Additional research highlights the extent of CODAs' worries and paranoia of potential danger: “If I heard something break the window, my parents couldn’t hear it so that they would get killed” and “I did always have problems with sleeping because I was paranoid.” (Frank, 2019, p. 12). The findings suggest that deaf families depend on CODAs as the ‘protector’. Therefore, when it comes to leaving home, CODAs feel anxious and worried about its impact on their parents, as they are the sole communicators.

However, Wood's (2016) findings demonstrate that deaf parents experience feelings of protection from potential dangers, too. For example, a deaf parent shared that they often had trouble sleeping as they were afraid of not hearing their baby cry or recognise if they were in discomfort or danger. Thus, they depended on tying a ribbon to their baby to notice them moving. Overall, Wood’s (2016) results indicate that CODAs and their deaf parents feel protective over one another, shifting the narrative that the burden is solely on CODAs.

Theme Four: A High Level of Responsibility

Moroe and Andrade (2018b) state that CODAs are their parents’ ‘ears and mouths’. This comes with a high level of responsibility and appears to result from the lack of systemic support the CODA community can access (Hale, 2001; Klimentová et al., 2017). The final theme provides a deeper understanding of this by first adopting a critical lens to explore a lack of systemic and family support and giving suggestions for supporting CODA families, before reviewing how obtaining a high level of responsibility can positively impact CODAs.

Subtheme One: A Lack of Systemic and Family Support.

Klimentová et al.'s (2017) empirical research used semi-structured interviews to explore the experiences of 14 CODAs in their role as native interpreters of sign language during their childhood. A key theme identified in this study was a lack of social support. The participants pointed out that their role as mediators between deaf parents and the hearing world was perpetuated by the lack of systemic support, especially from the interpretation services: “There was always a lack of social support . . . no one was really surprised, and no one ever helped me” (p. 849). This initiated isolation and pressure: “When I was a kid, I dealt with my parents’ problems, although I didn’t understand them at all” (p. 848). The participants strongly criticised the system, especially the lack of accessible interpreters. They felt they were overlooked by the system and were left with disproportionate responsibility, which did not match their age: “When I was six, I bought my parents a washing machine on instalments” (p. 848).

Another critical theme Klimentová et al. (2017) identified was the lack of security and support that CODAs felt from their parents. Numerous statements from the participants suggest feelings of insufficient academic support from their parents.

CODAs shared personal examples of their parents not being able to read to them, to help with homework or guide them in choosing future careers: “My parents never read with me, and I did my homework all by myself. They always just signed it, but never actually read it” (p. 849). The findings suggest that CODAs felt a lack of support from the system and their parents. They were also positioned to care for their parent's needs, making them feel isolated and lonesome. They concurred that the system should offer institutional support, such as free parenting classes and modern communication technology for deaf parents, to help reduce the pressure felt by CODAs.

Similarly, a dominant theme in Hadjikakou et al.'s (2009) study was the government’s role and responsibility. Participants argued that the state does not support their deaf parents: “I don’t think that the government should help the CODA. I believe that the government should help the deaf adults more than their hearing children” (p. 498). Most of the participants voiced that the state should empower deaf parents so that they are better placed to help their children, for example, through providing parent education training courses. Participants noted the significant role that extended family played in their success in life: “I am grateful to my parents, but my aunt was my main supporter” (p. 492). It was felt that extended hearing family replaced the support that the state could potentially offer. However, CODAs without supportive extended family were left alone. Therefore, the current study provides recommendations for schools to implement, such as homework clubs and interpreters for parent visits and meetings, to better support CODA families.

Subtheme Two: Preparation for Adulthood.

Nonetheless, despite the lack of systemic support and, consequently, the high level of responsibility that CODAs have, the literature also recognises that it taught them life skills and lessons, and prepared them for adulthood. Moroe and Andrade's (2018b) phenomenological study had a dedicated theme to ‘preparation for adulthood’ as they recognised that CODAs’ roles and responsibilities, at such a young age, affected their life positively and negatively. The participants proudly voiced the sense of autonomy and independence it exerted on them, too: “I think, you know, having sold my parent’s house at the age of six [. . .] made me a very responsible child” (p. 76) and “a lot of CODAs are intelligent . . . I also think that we, as CODAs, we became independent at a very young age.” (p. 77). The findings also suggest that this level of responsibility can increase confidence and maturity, among other positive qualities needed for adulting.

However, Moroe and Andrade (2018b) do not ignore that CODAs’ experiences of additional roles and responsibilities, especially as language brokers, had long-lasting adverse effects on their wellbeing. They further acknowledge their vulnerabilities as a minority community as CODAs are an overlooked group who, on the surface, do not seem to need any additional provision or support to safeguard their wellbeing in childhood. Therefore, they recommend that professionals working with deaf families make appropriate referrals for CODAs to other professionals, such as teachers, social workers, and psychologists, to ensure that they receive the psychological support needed. Similar to Hadjikakou et al.'s (2009) study, they also suggest more affordable and accessible interpreting services for deaf families to help mitigate the demands of language brokering.

Implications of the Literature Review for the Current Research

The systematic literature review provides an international perspective, from five different countries, of what is currently known about the experiences of CODAs. A diverse range of CODA voices was shared, with varying and unique interpretations of similar experiences. Notably, most of the literature on CODA experiences were adults' reflections on their CODA childhood, as there was a focus on long-term effects as opposed to current reflections and impact (Frank, 2019; Klimentová et al., 2017). Moroe and Andrade (2018a) recognised that their study highlighted adults' childhood recollections. Therefore, it could be a reconstruction or altered memory, in which the participant might not have accurately recalled their past as it occurred. The current research intends to explore CODAs' present experiences of their upbringing, instead of remembering events from their early life.

Furthermore, to the RF's knowledge, only two studies (Hale, 2001; Knight, 2018) took a participatory approach, and none had CODAs adopt the roles of both co-researcher and participant. This suggests that, although the CODA researchers had the autonomy to decide how CODAs' voices should be shared, they did not have the opportunity to share their own views. In conclusion, whilst some efforts have been made to explore the voices of CODAs via research, it is evident that this is still a niche area, and more needs to be done to empower CODAs to obtain autonomy and share their views through PR (Aldridge, 2017b; Frank, 2019).

Chapter Summary

This chapter has explained the systematic literature search that led to obtaining 14 papers for the focused review, from which the RF identified four main themes and nine subthemes, and critically analysed them. The findings highlighted the gaps in the literature and the need for additional PR investigating CODAs lived experiences, especially in the UK, which provide a basis for Chapter Three.

Chapter Three: Methodology

Overview

This chapter describes the researcher’s ontological and epistemological positions and how the RF’s worldview guides the research design. Next, PR's ethical, methodological, and practical challenges are introduced. The theoretical and conceptual frameworks underlying the research project are then discussed, including the philosophical underpinnings of the chosen data analysis. The remaining part of this chapter outlines the research procedure, including the recruitment process, introducing the co-researchers, and outlining their chosen research question, aims and methods. The chapter ends by outlining the data collection, the process of carrying out IPA and a review of the quality of the research. The current PR methodology is summarised in Appendix G.

Research Paradigm

Moore (2005) argues that it is an ethical duty for researchers to understand the paradigm underpinning their research so that they can engage in reflexivity and consider the impact of their position on their research. Guba and Lincoln (1994) define paradigms as “the basic belief system or worldview that guides the investigator” (p. 105). These beliefs “include assumptions about human knowledge (epistemological assumptions), about the realities you encounter in your research (ontological assumptions) and the extent and ways your values influence your research process (axiological assumptions)” (Saunders et al., 2015, p. 124). The RF’s axiology was introduced in Chapter One and will be referred to throughout, along with the co-researchers’ axiology.

Ontology

Ontology refers to “the study of being” (Crotty, 1998, p. 10). It asks, “What is the form and nature of reality and, therefore, what is there that can be known about it?” (Guba & Lincoln, 1994, p. 108). Paradigms are on a continuum: at one end is realism - “realities exist outside the mind” (Crotty, 1998, p. 10),therefore, humans should be studied in the same way as a natural scientist would research nature. At the other end is relativism, which considers humans different from physical phenomena as they create further depth in meanings and cannot be explored similarly (Alharahsheh & Pius, 2020).

Critical realism is positioned towards the middle of the continuum. Robson and McCartan (2017) state that it solves the ‘paradigm wars’ between positivists and constructionists. Roy Bhaskar introduced critical realism in the late twentieth century as a response to the positivist approach (Danermark et al., 2019). It mainly criticises positivism for reducing objects of knowledge to observable events, as constituted by facts and their conjunctions (Bhaskar, 2020). The ontology of the critical paradigm is realist (Guba & Lincoln, 1994), recognising that reality exists outside the mind and that social, political, cultural and economic aspects, such as one’s ethnicity and gender, shape one’s reality (Elshafie, 2013).

Critical realists claim that there are two steps to understanding the world (Saunders et al., 2015). Individuals experience ’the empirical’ through sensations and then through mental processing, described as ‘reasoning backwards’ (Reed, 2005). This means individuals experience reality differently depending on their constructs, experiences and social history (Robson & McCartan, 2017).

The Ontology within the Research.

The current study adopts the critical realist view that CODAs are a minority group that exists, and for this reason, there are communities set up by and for CODAs to aid connection, empowerment, and a sense of belonging (Children of Deaf Adults: CODA UK & Ireland CIC, n.d.; Moroe, 2019). However, how children of deaf adults relate to the term CODA differs and depends on their upbringing, interactions, and relationships (Preston, 1995a; Ward, 2009). Critical realists aim to bring positive change to improve the studied matter (Guba & Lincoln, 1994). Therefore, humans must move beyond simply understanding the world and, instead, focus on generating change (Bhaskar, 2020; Elshafie, 2013). This aligns with the RF's values, and the co-researchers' aim 'to explore the support received by CODAs and how this could be modified.'

Epistemology

Epistemology concerns "the nature of the relationship between the knower or would-be knower and what can be known?" (Guba & Lincoln, 1994, p. 108). "Epistemologically, objectivists seek to discover the truth about the social world, through the medium of observable, measurable facts, from which law-like generalisations can be drawn about the universal social reality" (Saunders et al., 2015, p. 128). However, the epistemologically subjectivist position believes that humans cannot be divided by their knowledge (Saunders et al., 2015). Therefore, a subjectivist researcher's role is to understand the different realities of the individuals involved and their motives, actions, and intentions (Alharahsheh & Pius, 2020).

The Epistemology within the Research.

Clark et al. (2021) state that the ontological position guides the epistemology. This research adopts a critical realist epistemological position. Critical realist epistemology is both transactional and subjective (Guba & Lincoln, 1994). It recognises that knowledge is developed through the interaction between the researcher and the participants; however, it is also influenced by the social and power relations in the community (Robson & McCartan, 2017; Scotland, 2012). Furthermore, critical realists rely heavily on the meaning participants give to their experiences and accept that all knowledge is value-laden (Pring, 2000).

The current research would seek to make sense of the world ‘through the eyes of CODAs’, and the RF would encourage the co-researchers to reflect on how their background, values, culture, and context would inevitably influence their decisions and the findings. Other epistemologies were considered, such as interpretivism, which also argues that “reality is subjective and differs from person to person” (Scotland, 2012, p. 11). However, the exception is that critical realists assert that knowledge is also influenced by power relations, such as the language associated with CODA families, which can be used to either empower or weaken them.

The Current Research Paradigms

To mitigate the limitations and barriers of being guided by one paradigm, the RF incorporated elements of two research paradigms (Reagan, 2004): the critical realist and transformative paradigms. The RF and co-researchers concurred, all being interested in social change, as it aligned with their values of respect, honesty, dedication, and trust.

Critical Realist Aspect

The critical realist paradigm addresses social justice and marginalisation; it recognises that humans can modify reality and, therefore, embraces the emancipatory function of knowledge (Scotland, 2012). This aligns with EP values

(Kelly et al., 2016; Wallace & Giles, 2019) and the current PR approach that aims to empower and emancipate CODAs. The RF invited the CODA community to be fully involved in the decision-making process for this research. Two CODAs enthusiastically adopted the role of co-researcher and participant. They hoped to contribute to social change, especially for CODA families in the education system.

However, it is important to consider that critical realists are criticised for having a political agenda, despite good intentions of improving the investigated context. “The disadvantage is that there are often hidden institutional sources of resistance to change, such as teacher and pupil ideologies, institutional structures, and so on, which may prevent the desired progress” (Ernest, 1994, p. 28). For this reason, the RF invited the co-researchers to think about disseminating their findings and how to reach those with power, thus being more likely to facilitate positive change, as covered in Chapter Five.

Transformative Aspect

According to Mertens (1999), researchers who question the positivist and post-positivist, constructionist and interpretivist approaches align with the transformative paradigm and embrace emancipation, participation, and inclusion. Mertens (2019) indicates that the transformative paradigm must involve the community most impacted by the research topic, and the researchers should position themselves side by side with the less powerful to bring about social change. This is consistent with the current PR approach. Similar to the critical realist paradigm, the transformative paradigm is change-orientated and addresses power structures at differing levels (Romm, 2015). This aligns with the current research population: CODAs, a minority group facing potential inequalities and increased responsibility due to discrimination experienced by their deaf parents (Harrison & Watermeyer, 2019; Preston, 1995a).

Research Design: Participatory Research

A fundamental difference between PR and other research methods lies in the location of power in the various stages of the research process (Cornwall & Jewkes, 1995). “PR engages those who are not necessarily trained in research but belong to or represent the interests of the people who are the focus of the research” (Vaughn & Jacquez, 2020, p. 1). Therefore, the value is placed on meaningful and genuine participation. Yet, how the participant contributes to the research and to what degree varies throughout the research process (Vaughn & Jacquez, 2020). The term ‘participation’ can be interpreted differently, and several PR models are used to guide research practice (Aldridge, 2017a; Cornwall & Jewkes, 1995; Hart, 2008; Shier, 2001; Vaughn & Jacquez, 2020). These are necessary to provide greater clarity and rigour to PR approaches (Aldridge, 2017b).

Participatory Model of the Current Study

The above PR models were presented to the co-researchers, who voiced a preference for two different models. Firstly, they related to the language in Aldridge's (2017a) participation model, particularly around ‘social change’. Secondly, the co-researchers felt that Vaughn and Jacquez's (2020) participation choice points in the research process encapsulated the current research's different stages within their Venn diagram. Hence, the RF created a PR model drawing on elements of the two, as demonstrated in Figure 3.1.

Figure 3.1

The Research Facilitators and Co-Researchers' Model of Participation

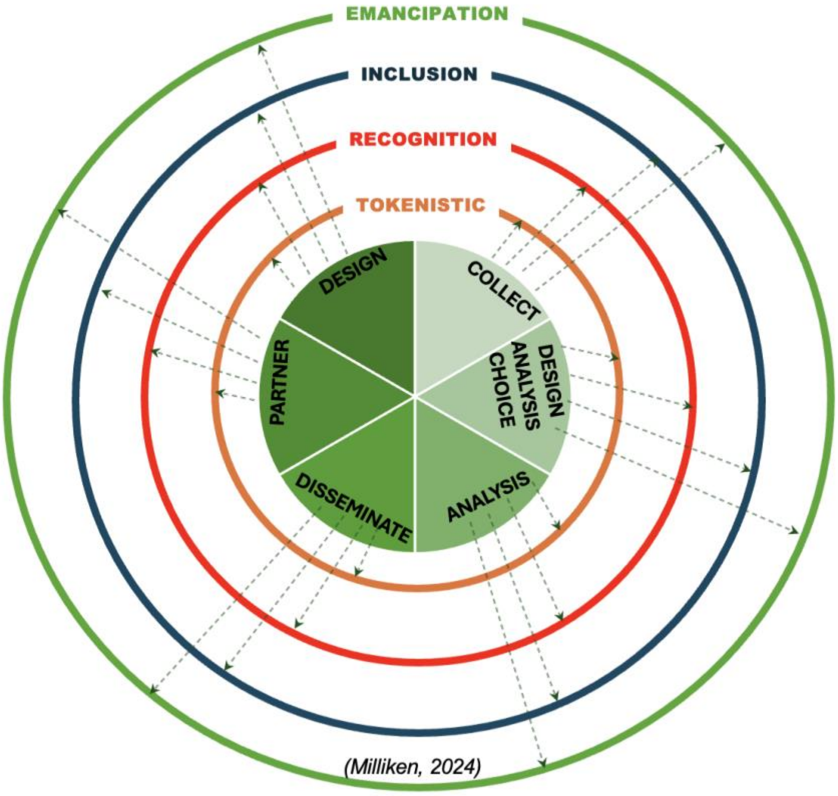


Figure 3.1 reflects the language used in Aldridge's (2017a) model and the visuals from Vaughn and Jacquez (2020). This newly created model was used to gain feedback from the co-researchers (outlined in Chapter Five). Figure 3.1 demonstrates the co-researchers' and RF's different options for their levels of participation throughout the PR process. 'Emancipation' is solely co-researcher-led, 'inclusion' involves more equal roles and relationships between the RF and co-researcher/participant, 'recognition' describes researcher-led but recognition of co-researcher/participants as individuals, and 'tokenistic' is solely RF-led. Appendix H further defines emancipation, inclusion, recognition, and tokenism and provides key descriptors for the terms inside the circle, such as 'partner and collect'.

The Purpose of the Research

The purpose of the current study was both exploratory and emancipatory. Exploratory research investigates novel and niche phenomena (Kirby et al., 2017). The current research focused on how the experiences of CODAs have shaped their identity. However, it also aimed to benefit the CODA co-researchers by handing over the power and control that traditional research usually holds and inviting them to share their stories and contribute to change by deciding the course of the current study. This aligns with the core principles of emancipatory research (Stone & Priestley, 1996).

The Methodological, Practical, and Ethical Challenges Associated with Participatory Research

Bradbury-Jones and Taylor (2015) highlight six methodological, practical, and ethical issues associated with PR. The RF considers them below and outlines pragmatic solutions and reflections before and during the research. This ensured that the duty of care to the co-researchers was paramount throughout the research.

One: Children and Young People Lack Research Competence

Lack of research competence, knowledge, and experience is a barrier to co-researcher involvement (Kellett, 2009). Lundy et al. (2011) observed that there is often the assumption that CYP lack the maturity and ability to share their views. However, previous research shows that when CYP are treated as equals, they take ownership and actively participate in the research process (Gray & Winter, 2011). Furthermore, Bradbury-Jones and Taylor (2015) state that to achieve meaningful engagement, the RF should ensure congruence between the co-researchers' level of competence and the selected methods. The RF accounted for this by facilitating workshops to support and complement the co-researchers' research skills and offer a safe space for them to practise and share their existing skills.

Two: An Extensive Training Programme is Needed

Wallace and Giles (2019) identify that a barrier to PR is that it is time-consuming, impractical, and unfeasible. This became increasingly evident when meeting with potential co-researchers for the current research (to be reviewed in Chapter Five). However, Coad and Evans (2008) found that committed co-researchers usually embrace the training, are eager to practise their skills and are empowered by the experience. Interestingly, this attitude was evident in the co-researchers of this study.

The RF prioritised the duty of care to the co-researchers by inviting them to decide on the dates and times of the workshops. In addition, during the workshops, the RF encouraged movement breaks and wellbeing check-ins. Furthermore, Bradbury-Jones and Taylor (2015) state that it would be unethical to not prepare the co-researchers properly for their role. Therefore, the RF considered the range of capabilities and learning styles and offered additional mentoring if needed. For example, a co-researcher requested clarification of IPA; thus, the RF met with them separately to answer specific questions.

Three: The Co-Researchers' Perspectives are Difficult to Balance

This research aimed to break free from the traditional hierarchy by inviting those closely related to the matter of study to be at the centre of the enquiry. Alderson (2001) highlights that a barrier to this is that the co-researchers may over-identify with one another and, therefore, view their experiences as homogenous. Consequently, the RF invited the co-researchers to engage in reflective and reflexive activities to help them identify any ‘soft spots’ whereby they could identify differences between themselves and similarities. (Sandeen et al., 2018).

Furthermore, the CODA co-researchers agreed that the current research should adopt critical realist and transformative paradigms. They argued that ‘CODA identity’ is a reality; however, how one experiences and interprets this differs depending on the individual and their social situation. The co-researchers embraced the emancipatory element of the study and were eager to activate change for other CODAs by participating in PR and sharing their views.

Four: Remuneration is Complicated

The matter of payment for CYP to participate in research has been deliberated for several years and is a sensitive and political issue (Alderson, 2001). Notably, many CYP take on the additional work associated with the research in their free time (Bergström et al., 2010). However, Schäfer and Yarwood (2008) found that the CYP co-researchers' motives for participating in PR were the chance to be upskilled through training and developing their communication and interaction skills in preparation for future job interviews. Therefore, they saw it as a form of ‘vocational preparation’ (Schäfer & Yarwood, 2008).

To optimise transparency and the co-researchers’ expectations of the current research, the recruitment advertisement did not offer payment but outlined the time needed for the research (Appendix I). Furthermore, the question-and-answer session highlighted the voluntary aspect before CODAs were asked to sign the consent form. The RF mitigated expenses and maximised autonomy over finances by offering virtual workshops and inviting the co-researchers to decide whether data collection should happen in person or online.

Five: Power Imbalances Must be Overcome

Gallacher and Gallagher (2008) highlighted that PR should not be viewed as a solution to the marginalisation of CYP. They emphasised the importance of being undistracted by the appeal of emancipation, empowerment, and agency. To mitigate power imbalances between the RF and co-researchers, the RF adopted a consultation approach, drawing on the principles of attuned interaction and remaining curious and compassionate throughout (Kennedy & Underdown, 2017; Wagner, 2008). During the decision-making, the RF ensured the co-researchers were treated fairly, with respect and dignity, and adopted a passive stance by muting their microphone and solely reflecting on the discussion and relationship between the co-researchers. Morrow (2008) states that CYP are often unable to challenge how research findings about them are presented. However, considering the PR nature of this research, the RF invited the co-researchers to decide how they would like to disseminate their findings.

Schäfer and Yarwood (2008) cautioned that power imbalances also happen between CYP co-researchers. James (2007) argues that PR does not remove power dynamics but instead changes their direction. Conolly (2008) notes that it is evident that CYP who hold experience and are training in social research are in an elevated position compared to other CYP. However, the co-researchers of this study are both university students of similar age and, therefore, academically able. Moreover, the RF invited the co-researchers to create a group agreement to encourage a safe and friendly atmosphere. Despite the critics, PR remains the sole research approach that aims to emancipate and empower CYP, “encouraging participants to ‘own’ the outcome by setting the goals and sharing in decisions about the most desirable process to be followed” (Everitt et al., 1992, p. 50).

Ethical Considerations

Before the research commenced, ethical approval was obtained from the UEL's Ethics Committee (Appendix I), along with the permission of the gatekeepers: CODA UK & Ireland (Appendix K) and the local authority (Appendix L). The RF made four ethical amendments, some of which are outlined in this chapter (Appendix M). The RF referred to relevant guidelines such as the British Psychological Society (BPS) Code of Ethics and Conduct (BPS, 2018), the BPS Code of Human Research (BPS, 2014), the Health and Care Professions Council (HCPC) Standards of Conduct, Performance and Ethics (HCPC, 2018) and UEL Code of Practice for Research Ethics (UEL, 2015). The RF also referred to the literature for specific ethical challenges associated with using CYP as researchers (Bergström et al., 2010; Porter et al., 2010). Informed consent, confidentiality, disclosure, emotional wellbeing, and duty of care are considered below (Dockett et al., 2009; Gibson, 2007).

Informed Consent

According to Flewitt (2005), it is difficult to obtain 'informed' consent from co-researchers as the development of the research is yet to be determined. Therefore, ongoing consent was sought throughout the co-researchers' involvement. To ensure transparency, the RF clearly outlined the time required from the co-researchers in the information sheet (Appendix N) and invited possible co-researchers to a question-and-answer session (Appendix O). Here, they could clarify any queries before signing the consent form. They were also reminded that they had the right to withdraw at any point without reason; however, after the analysis, the RF would obtain their pseudonymised data. The co-researchers were also the participants, and both were over 18, thus, their consent was sought directly.

Confidentiality and Anonymity

The RF followed the requirements set out by the Data Protection Act 2018, the General Data Protection Regulation (European Commission, 2018), and the Data Management Plan approved by the UEL. This entailed the consent form being uploaded and stored in UEL SharePoint and kept separate from any pseudonymised data, which only the RF and their Director of Studies can access.

Conolly (2008) argues that confidentiality is precarious when conducting PR with CYP, especially when co-researchers are part of the same social network. The current research were recruited from the same organisation, CODA UK & Ireland, following plan A (Appendix J). The co-researchers did not know one another before the research began, yet the fact that they were both the co-researcher and participant meant that discussions or data would not be anonymous. Therefore, in the first workshop, the RF emphasised the importance of confidentiality, anonymity and regulations concerning disclosures and safeguarding policies.

Furthermore, after data collection and at the point of transcription, the co-researchers chose pseudonyms, and all identifiable information was removed. The raw data was deleted immediately, and the pseudonymised data was stored safely in the UEL SharePoint, where it will remain for three years after research completion, complying with UEL policy.

Emotional Wellbeing and Duty of Care

The RF had a Disclosure and Barring Service check and completed a risk assessment before commencing the current research. This encouraged the RF to review and ensure that there was no anticipated physical harm, and all psychological harm would be mitigated. The CODA co-researchers recognised that they would be invited to share their views; thus, there was a slight possibility of resurfacing negative or upsetting emotions. Therefore, the RF took precautions to organise therapeutic support before starting the research, as agreed by the safeguarding representative and psychotherapist of CODA UK & Ireland (Appendix K). Furthermore, as reflection and taking time to debrief can help manage any potential stresses (Coad & Evans, 2008), each workshop entailed a reflective activity, and the co-researchers were debriefed and signposted to wellbeing services.

Research Data Analysis: Interpretative Phenomenological Analysis

IPA is an inductive, qualitative thematic research approach “committed to the examination of how people make sense of their major life experiences” (Smith et al., 2022, p. 1). Smith et al. (2022) stated that “IPA shares the views that human beings are sense-making creatures, and therefore the accounts which participants provide will reflect their attempts to make sense of their experience” (p. 4). For these reasons, Alase (2017) suggests that many researchers view IPA as the most ‘participant-orientated’ qualitative research approach, valuing respect and sensitivity whilst gathering ‘rich and in-depth’ data. The three key philosophical influences underpinning IPA are phenomenology, hermeneutics, and ideography (Smith et al., 2022).

Phenomenology

Smith et al. (2022) describe phenomenology as “a philosophical approach to the study of experience” (p. 5). Husserl (1931/2012) considers it the careful examination of human ‘lived experiences’ that involves depth and rigour and allows researchers to identify the essential qualities of that experience. He argued that researchers should “go back to the things themselves”: the ‘thing’ Husserl was referring to being one’s consciousness (Smith et al., 2022, p. 8).

There are two different phenomenological approaches: descriptive and interpretative phenomenology. Descriptive phenomenology intends to describe a lived experience without attempting to give meaning to it (Charlick et al., 2016). According to Husserl (1931/2012), researchers carrying out descriptive phenomenological research during the data collection and analysis phase should ‘bracket’ or put their previous experience, bias, and beliefs to one side and, instead, concentrate on their perceptions of that world. Other theorists expanded on phenomenology with a different focus, yet all agree that there is no knowledge outside of one’s interpretation, thus preventing researchers from participating in ‘bracketing’ (Smith et al., 2022). This is recognised as interpretative phenomenology and is most relevant to the current research.

Hermeneutics

The second key philosophical influence underpinning IPA derives from hermeneutics: the art of interpretation (Smith et al., 2022). Schleiermacher (1998) identified that interpretation involves grammatical (the objective textual meaning) and psychological interpretation (the individuality of the author). Heidegger (1962, as cited in Smith et al., 2022) highlighted the notion of ‘appearing’. This entails the researcher shining a light on the phenomenon and using detective work to reveal what is being said and then making sense and deriving meaning from it. Smith et al. (2022) suggest that reflexive practice is necessary as the reader cannot help but perceive any new stimulus in the light of their own prior experience. For this reason, the reflection and reflexivity of the RF and co-researchers are referred to throughout the thesis.

Similarly, Gadamer (1990, as cited in Smith et al., 2022) suggested that a person will only realise their preconceptions once the interpretation is underway, rather than putting their preconceptions upfront before the interpretation of the text. This means that the researcher cannot be separated from the researched because they are both engaged in the world, and the world is changing them (Smith et al., 2022). Consequently, researchers must be aware of their bias to ensure that, during the data analysis, the text can present itself in all its otherness and, thus, assert its truth against one’s fore-meaning (Smith et al., 2022).

The Hermeneutic Circle

Smith et al. (2022) suggest that to understand any part of an experience, the researcher must seek to understand the whole experience and vice versa. The hermeneutic circle encourages researchers to examine the whole in light of its parts, the parts in light of the whole, and the contexts in which they are embedded (Eatough & Smith, 2017). For example, the meaning of a word only becomes clear when read as part of a whole sentence. Yet, the sentence's meaning depends on the cumulative meanings of the individual words. This hermeneutic circle encouraged the co-researchers and RF to move back and forth when completing the analytical process.

Double Hermeneutic

The double hermeneutic is the process in which, firstly, the participant makes sense of their world, and, secondly, the researcher tries to decode that meaning to make sense of the participants’ meaning-making (Smith et al., 2022). This means that the researcher actively tries to understand an experience and world from the participant’s perspective, thus ‘what is it like to stand in their shoes’ (Pietkiewicz & Smith, 2014). IPA acknowledges that the researchers’ interpretations are influenced by their belief systems, values and experiences and, therefore, embraces reflexivity as part of the analysis (Smith et al., 2022).

Ideography

The third main philosophical influence of IPA is ideography, which is concerned with the particular (Smith et al., 2022). In contrast to other research methodologies concerned with making claims about a phenomenon at a group level, IPA is committed to examining a phenomenon at an individual level first. Each case is explored at the deepest level, generating rich and explicit themes before moving on to more general themes (Smith et al., 2022). To achieve this, IPA suggests undertaking a case study or small sample size that is reasonably homogenous and meaningfully selected. Smith et al. (2022) suggest that researchers should accept that the 'particular' and the general are not so different. The fact that IPA encourages the researcher to delve deeper into the 'particular' also brings us closer to the universal.

The Rationale for Using Interpretative Phenomenological Analysis

The decision to adopt IPA was intentionally RF-led. According to Alase (2017), IPA is well suited for novice researchers who aim to gather 'thick descriptive' data from a small sample. This meets the co-researchers' level of competency and the research aims. IPA empowers individuals to provide rich and detailed accounts of their experiences, encouraging them to describe personal experiences in their own words (Smith et al., 2022). This matched the CODA co-researchers' decision to conduct semi-structured interviews, in which they devised meaningful questions to encourage one another (the participants) to share their stories using their own words. Additionally, Creswell and Poth (2018) posited that "it is essential that all participants have experience of the phenomenon being studied" (p. 128). This reflects the CODA participants, who noticed similarities between their experiences.

Furthermore, IPA aligns with the research paradigms and PR. The critical realist and transformative paradigms both aim to emancipate the disempowered and encourage researchers to embrace their ideology as they recognise that “no research methodology is value-free” (Pring, 2000, p. 250). It acknowledges that knowledge production is subjective and relies upon the meaning participants give to their experiences. This is compatible with IPA hermeneutics: "The researcher is trying to make sense of the participant, who is trying to make sense of x” (Smith et al., 2022, p. 29).

Research Procedures

The present study was conducted between June 2022 and October 2023 (Appendix P). This section aims to outline and clearly justify the courses of action taken by the RF and co-researchers, which entail recruitment, workshops, data collection, data analysis, and assessment of the quality of the study.

Preliminary Work

Mellett (2016) identifies the CODA community as an unexplored and small minority group within the general population. Therefore, it was important that the preliminary work focused on building connections with the CODA community and investing time in gaining their views on the proposed research. This ensured that there was a direct and trustworthy link to aid recruitment before the RF committed to the study.

The RF contacted CODA UK & Ireland in June 2022 and consulted with their Welfare Director on several occasions. The consultations included reflections on the deaf and CODA identity and the available research on CODAs. The RF consulted with other members of this CODA organisation and participated in their monthly CODA newsletter (Appendix Q). Based on the connection established, the organisation agreed to support the RF with recruitment. This preliminary work reinforced the RF's passion for the current research and left them hopeful for the recruitment process. Thus, they decided to recruit exclusively through this organisation and not utilise their plan B, which was recruiting also from their local authority. This will be explained further in Chapter Five.

Co-Researcher Recruitment

The RF originally aimed to recruit six individuals, aged 15-22, to adopt the role of co-researcher and participant (Appendix J). CODA UK & Ireland shared the recruitment advertisement on their social media platforms in March 2023. However, the age range was later altered to 15-25, so the advertisement was changed to match the new eligibility criteria and shared again in April 2023.

The revised age range was determined firstly as there was limited research on CODA young people and the realisation that most people who initially showed interest in this research were between the ages of 20 and 25. Secondly, it aligned with the EP role, working with CYP to age 25, thus leading to invaluable implications. The adjusted criteria were:

- aged between 15 and 25 years
- be a CODA with one or more parent/carer who is deaf
- be willing to participate in doctoral-level research and share your story
  consider that this will take up to 15 hours (over several months, and dates and times will be collaboratively decided)
- you will be invited to a question-and-answer session
- if you are below the age of 16, you will need to be accompanied by a parent/carer

The PR approach guided the decision to invite CODAs to adopt roles as both co-researchers and participants. This would optimise their level of involvement, power and emancipation (Aldridge, 2017b; Kellett, 2009). Furthermore, an anthropologist who identifies as a CODA found that CODA informants were more willing and open to share their 'truth' with him because they felt he could relate to them: "Most people don't know this, but I know you do" (Preston, 1995a, p. 6). The RF hoped that the CODA co-researchers would find some commonalities and feel comfortable sharing their stories with another CODA.

Figure 3.2

The Recruitment Process of the Current Research

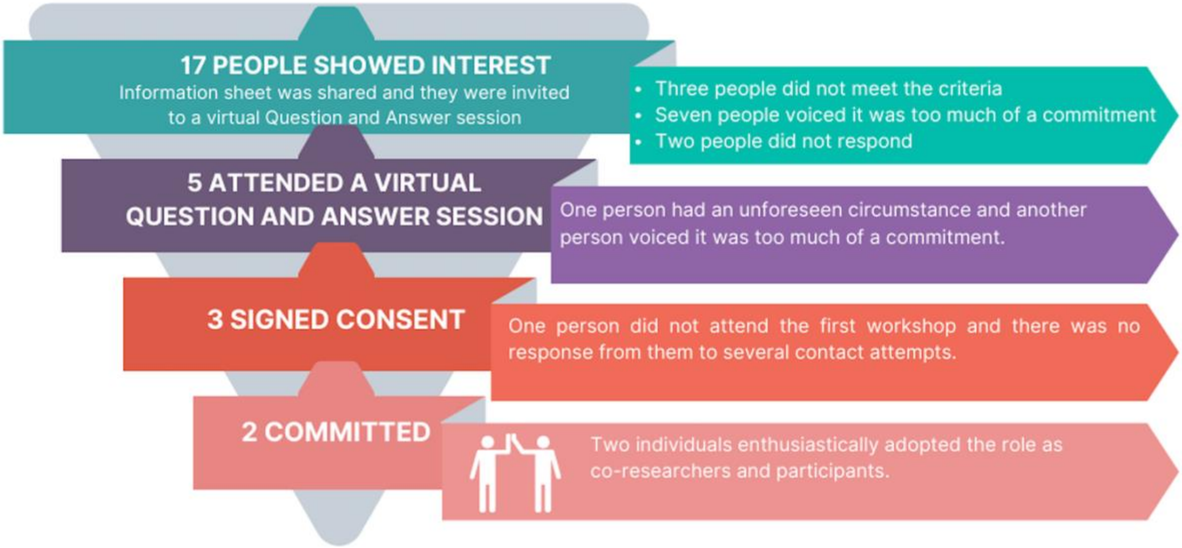


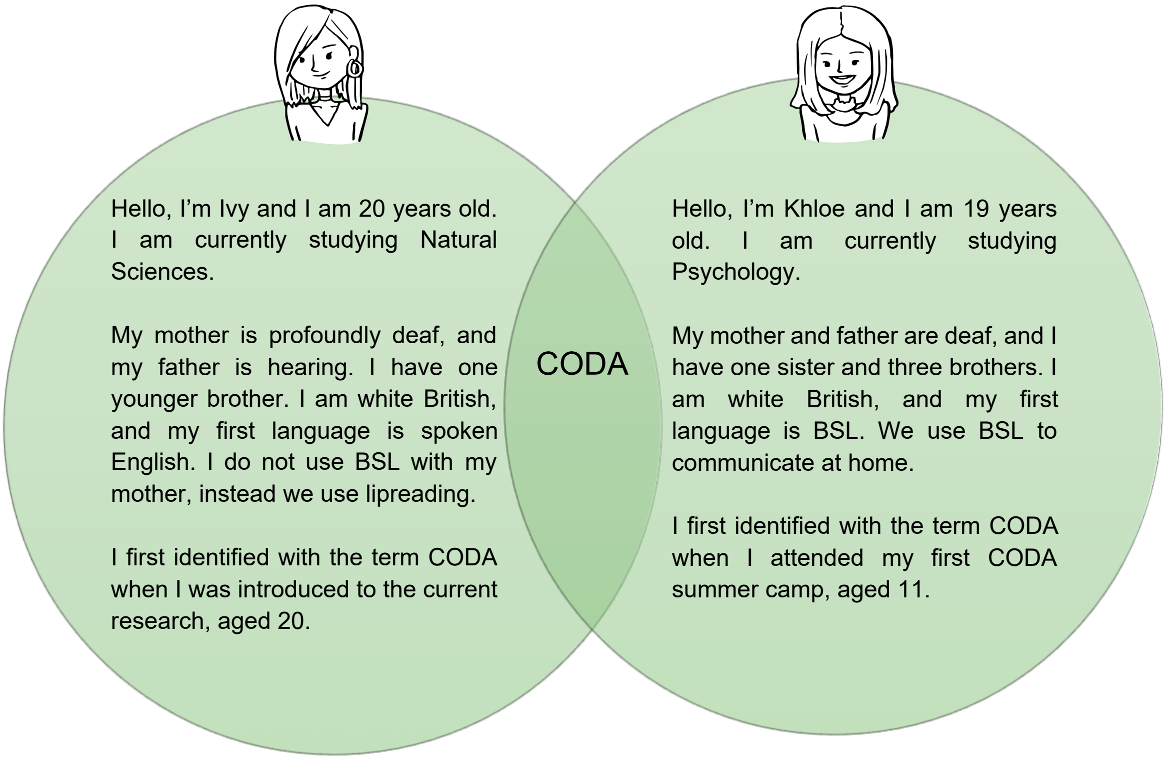
Figure 3.2 demonstrates that 17 individuals initially showed interest in the research. The recruitment process adopted a first-come-first-served basis. According to Robinson (2014), this is the fairest and most efficient approach. Following the initial email, the RF invited all 17 interested individuals to a Question-and-Answer session, which five individuals attended. This enabled the attendees to ask questions and better understand the commitment needed for doctoral research, thus maintaining

transparency (Appendix O). As a result, three CODAs signed the consent form. Finally, two individuals, Ivy, and Khloe, adopted the role of co-researcher and participant. These are pseudonyms chosen by the co-researchers to help humanise the research.

Introducing the Co-Researchers

Figure 3.3

The Co-Researchers' Biographies



Hello, I'm Ivy and I am 20 years old. I am currently studying Natural Sciences.

My mother is profoundly deaf, and my father is hearing. I have one younger brother. I am white British, and my first language is spoken English. I do not use BSL with my mother, instead we use lipreading.

I first identified with the term CODA when I was introduced to the current research, aged 20.

Hello, I'm Khloe and I am 19 years old. I am currently studying Psychology.

My mother and father are deaf, and I have one sister and three brothers. I am white British, and my first language is BSL. We use BSL to communicate at home.

I first identified with the term CODA when I attended my first CODA summer camp, aged 11.

The Aims of the Workshops

After recruitment, the RF's role was to support the co-researchers by facilitating virtual workshops. It was important that the co-researchers felt well-equipped to complete PR and that they had the chance to build a trusting relationship before collaborating and making important decisions together. Considering the co-researchers' academic abilities and lived experiences, the workshops were designed to activate their existing skills and maximise effective collaboration (Appadurai, 2006). The three aims of the research workshops were as follows:

- To formally introduce the research and encourage reflection and reflexivity throughout
- To use the co-researchers' existing skills to construct the research question’s aims and design
- To build the co-researchers' confidence by supporting and modelling the research analysis so that they would feel well-equipped to facilitate this

The Delivery of the Workshops

The co-researchers were invited to attend four virtual workshops. Appendix R highlights extracts from the workshops, and Appendix S outlines the timeline of the workshops. Three important matters were covered before commencing the research. Firstly, the RF and co-researchers reviewed the information sheet, whereby Ivy and Khloe were reminded of their right to withdraw (Appendix N). The co-researchers were then encouraged to compose a group agreement (Appendix R). Finally, they were asked to consider how they would like to proceed with the PR. Considering that the recruitment advertisement suggested that there would be six co-researchers, the RF wanted to ensure that the co-researchers had control over how to proceed with the research. Thus, they were presented with the following options:

- adopt the role of co-researcher and participant
- adopt the role of co-researcher and recruit another CODA as a participant
- adopt a case study approach and decide how they wished to share their views separately, and then come together for the analysis

The co-researchers preferred to remain with the original plan to adopt the role of co-researcher and participant, as they wanted the opportunity to lead the research and share their own story. Proceeding with this, the RF introduced a reflexive activity using the social GGRRAAACCEEESSS model (Burnham, 2018). This encouraged Ivy and Khloe to reflect on how their individual 'visible and invisible' characteristics would influence the research whilst also building a relationship (Griffiths et al., 2021). The co-researchers voiced that they found the exercise "interesting" as it highlighted that their CODA identity is invisible. This research would give them the opportunity to voice this identity to others.

The RF encouraged the co-researchers to summarise what they thought would be helpful for others to know about them for their biographies (Figure 3.3). This activity highlighted differences and similarities between the co-researchers. A significant difference was that Ivy only realised that there was a CODA community when her mother signposted her to this research. However, Khloe had attended CODA summer camps since the age of 11 and, therefore, already identified with the term, CODA.

Research Question and Aims

During the first workshop, the co-researchers generated the research question and aims. The choice of research question and aims is consistent with the research paradigms.

Research Question: How have the experiences of a child of deaf adults shaped their identity?

Aims

1. To explore the extent to which identity is shaped as a direct consequence of CODA experiences and upbringing.
2. To explore the support received by CODA individuals and how this can be modified.

3. To explore personal interactions and relationships with non-CODAs and how this has influenced CODA identity.

The Design Methods

The second workshop started by exploring the co-researchers' values; the RF used an online personal values test (https://personalvalu.es/personal-values-test) as it was a free, time-efficient, and accessible online test. This encouraged Ivy and Khloe to acknowledge their role as subjective researchers and reflect on how their values would influence the research process and outcomes (Etherington, 2007; Patton, 2014). They shared common values, such as ‘respect’ and ‘trust’: respect referred to listening to one another’s views without judgement, and trust was to be cautious of not over-identifying with one another. These values aligned well with the research paradigm and IPA.

Following this, the co-researchers were invited to decide on the research design. Ivy and Khloe were presented with different qualitative methods that would enable them to gain rich and detailed first-person accounts of their lived experiences (Smith et al., 2022). The RF also suggested using a combination of methods to support the study's trustworthiness and rigour (Given, 2008) (Appendix R). Ivy and Khloe deliberated for some time between the different qualitative methods, discussing the pros and cons of each. Their final decision was based on their limited experience with research methods and which method would encourage them to share their CODA story in depth, in a relaxed and comfortable way.

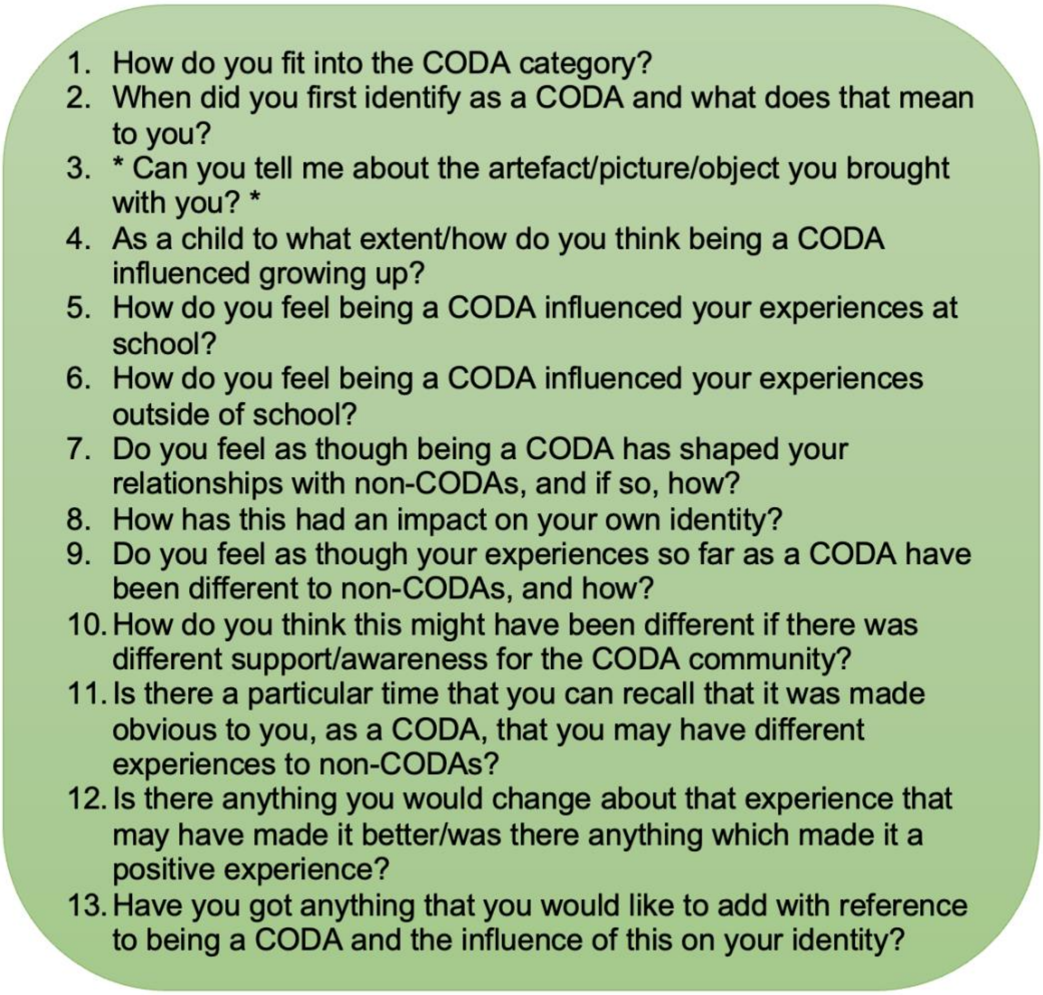
Designing the Semi-Structured Interview

Ivy and Khloe decided that using semi-structured interviews, artefacts, and an optional diary entry after the interview, with the phrase “what I wish I would have said” in mind, would enable them to gather rich and in-depth data. The purpose of the diary entry was to allow the co-researchers to reflect on the interview and add anything they ‘wish they had said’ after the interview. In line with the IPA recommendations, Ivy and Khloe were reminded that the interview should be at least one hour, and the questions should be open and expansive. Finally, the interview should reflect a meaningful conversation by being informed by the research question and aims (Smith et al., 2022).

Ivy and Khloe generated 13 questions (Figure 3.4). They prioritised a question for the artefact and agreed to ask follow-up questions as they believed it would enrich the data and allow for meaningful conversations. Throughout the planning, Ivy took notes on a shared screen, and both co-researchers contributed equally. After the 13 questions had been confirmed, the RF drew on their EP consultation skills, remaining genuine and curious (Wagner, 2008). They reflected on what they had heard to ensure that there was transparency and a shared understanding of how the questions linked to the research question and aims.

Figure 3.4

The Semi-Structured Schedule



1. How do you fit into the CODA category?
2. When did you first identify as a CODA and what does that mean to you?
3. * Can you tell me about the artefact/picture/object you brought with you? *
4. As a child to what extent/how do you think being a CODA influenced growing up?
5. How do you feel being a CODA influenced your experiences at school?
6. How do you feel being a CODA influenced your experiences outside of school?
7. Do you feel as though being a CODA has shaped your relationships with non-CODAs, and if so, how?
8. How has this had an impact on your own identity?
9. Do you feel as though your experiences so far as a CODA have been different to non-CODAs, and how?
10. How do you think this might have been different if there was different support/awareness for the CODA community?
11. Is there a particular time that you can recall that it was made obvious to you, as a CODA, that you may have different experiences to non-CODAs?
12. Is there anything you would change about that experience that may have made it better/was there anything which made it a positive experience?
13. Have you got anything that you would like to add with reference to being a CODA and the influence of this on your identity?

The co-researchers adopted the role of interviewer and interviewee (participant) and were advised to practise their interviewer skills by recording themselves and reading the questions out loud (Robson & McCartan, 2017; Smith et al., 2022). Ivy and Khloe also decided the day and time for each interview, both thinking it would be best to keep interviews on separate days. This was to avoid one story influencing the other, to consider the time the interviews would take and, therefore, their well-being, and to allow for time for reflection between the interviews.

The diary entries and a picture of the artefact were shared with the RF one week after the interviews.

Data Collection

The co-researchers decided that Ivy would interview Khloe first. This took place on 01.07.2023 and lasted 1 hour and 15 minutes. Following this, Khloe interviewed Ivy on 03.07.2023, lasting 1 hour and 24 minutes. Both participants shared an artefact and answered question three, ‘Can you tell me about the artefact/picture/object you brought with you?’ For this, Khloe brought her CODA camp t-shirt, and Ivy shared a letter her mother had written about being a deaf mother to a hearing child (consent was obtained from Ivy’s mother). However, only Ivy sent a diary entry as Khloe felt satisfied with what she shared in her interview. During the interviews, the RF had their camera and microphone turned off to mitigate any influence through potential non-verbal cues. Their only role was to support with technology and practicalities, if necessary.

The Co-Researchers’ Reflections on the Interview Experience

At the end of each interview, the co-researchers were encouraged to reflect on their roles and the experience. They recognised that working together beforehand had helped them build a relationship, so they felt more comfortable sharing their stories. Khloe noted that she would have been more reserved had it been the first time they had met. She also described the experience as ‘insightful’ as it resurfaced old family memories. Ivy described the experience as ‘empowering’: “it is cool to be a voice for CODAs, who don’t usually have a chance to share their story and realise how much you have experienced.”

The co-researchers also recognised the differences and similarities between their stories and reported “so much overlap”. Furthermore, designing the questions meant they knew what to expect and could reflect on their answers beforehand. This empowering and transparent process aligns with the study's PR principles and values. This reflective space was also used to check the co-researchers' wellbeing and remind them of the aftercare support available (Appendix K).

Transcription

The interviews were audio and video recorded via MS Teams. The recordings were stored on OneDrive according to the ethical requirements of the UEL (Appendix J). After both interviews had finished, the RF drew on the MS Teams transcription feature to help transcribe the raw data. This entailed correcting audio mistakes such as spelling and pseudonymising any identifiable information. However, as Smith et al. (2022) advised, long pauses and non-verbal utterances were not recorded, as the primary focus was on the meaning of the content of the participant's account. All identifiable information was anonymised, with pseudonyms Ivy and Khloe replacing their participant number, and dates were added. Finally, Ivy's diary entry was added to her transcript.

The Process of Carrying out the Analysis

Ivy and Khloe attended a virtual workshop led by the RF, where they were invited to follow the six-step process described by Smith et al. (2022). This workshop entailed a clear overview of the IPA steps, and the co-researchers had the opportunity to practise the process together using an example (Appendix R). The IPA process took place between July 2023 and October 2023, during which there were several co-researcher check-ins to aid transparency (Appendix S). The check-ins entailed the co-researchers reviewing and sharing their reflections with the RF to support their understanding. The RF took notes during the check-ins to ensure that they could reflect on them (Chapters Four and Five).

Step One: Reading and Re-Reading

The co-researchers were invited to decide whether they wanted to explore each case together, one by one, or explore one another's cases separately. Ivy and Khloe voiced a preference for analysing one another's stories separately and agreed to complete steps one to five independently (Smith et al., 2022). Ivy and Khloe were advised to immerse themselves in the data by visualising the interview and reflecting on their participant's responses when reading it through. Both co-researchers reported reading the data three times over.

Step Two: Exploratory Noting

Step two involved the co-researchers rereading the transcript for a fourth time whilst taking notes and highlighting anything that stood out to them. Ivy and Khloe were prompted to refer to the descriptive (content), linguistic (language) and conceptual (engagement and curiosity) elements of the transcript. During a virtual check-in, Khloe and Ivy shared that this process was more time-consuming than they had initially thought. They were concerned about overidentifying with the transcript and, therefore, 'whether they were doing it right'. As advised by Smith et al. (2022), the co-researchers were reminded to "work in depth and detail", "avoid an explanatory or formulatory focus", and "parse for meanings" (p. 86), ultimately, to stay focused on what was important to the interviewee.

Step Three: Constructing Experiential Statements

The next step of the IPA process involved going back to the notes and, from this, developing experiential statements. According to Smith et al. (2022), experiential statements are a "concise and pithy summary of what was important in the various notes attached to a piece of transcript" (p. 87). Therefore, they should reflect the participant's original words and the researcher's interpretation. This step also entailed adding the page number next to each experiential statement to make the corresponding quotes accessible.

Meaningful PR requires flexibility and the acknowledgement that co-researchers might not be able to be involved at every stage of the research (Kirby, 1999). Thus, it is important to note that, due to work commitments, Khloe required the RF to complete steps three, four and five of the IPA process (Figure 4.1, found in Chapter Four). This will be further discussed in Chapters Four and Five. Nonetheless, to ensure that Khloe's voice was still at the forefront of the research, the RF relied heavily on Khloe's exploratory notes, from step two, for guidance and consulted with her throughout. Furthermore, Khloe reviewed the RF's steps to ensure they aligned with her thinking before going on to complete step six with Ivy.

Step Four: Searching for Connections Across Experimental Statements

Step four entailed mapping out how the experiential statements fitted together. Throughout this step, the statements were treated with equal importance. The aim was to map out connections, interrelationships, and patterns between the experiential statements, and produce a structure representing the most important and interesting aspects of the participant's story (Smith et al., 2022). Ivy and the RF also started to consider names for these connections.

Ivy was invited to complete this, either on or off the computer, and was reminded to keep referring to the original transcript and the research question. Ivy and the RF chose to complete it on the computer for practical reasons. Khloe's interview transcript led to four connections, and Ivy's interview transcript led to six connections (Figures 4.3 and 4.5, found in Chapter Four). The next step involved naming the connections, also called personal experiential themes (PETs).

Step Five: Naming and Organising the Personal Experiential Themes

Step five involved naming the PETs and then dividing them into subthemes by referring to the experiential statements. Thus, each PET had subthemes and experiential statements that matched them. The RF also referred to page numbers of the experiential statements to return to the pseudonymised data to find appropriate quotes that matched each experiential statement. Ivy requested support in dividing the PETs into subthemes and finding the quotes that prompted the experiential statements. The RF's involvement at this stage will be further discussed in Chapters Five and Six.

Step Six: Working with Personal Experiential Themes to Develop Group Experiential Themes Across Cases

The final step entailed Ivy and Khloe coming together to review the PETs from both cases and to conduct a cross-case analysis. They started to look for patterns across the PETs to bring their voices together to create group experiential themes (GETs). Throughout this process, the co-researchers returned to the original transcripts.

The co-researchers began by highlighting the shared and unique PETs that stood out to them in both cases. From this, they devised four GETs and matched them with subthemes across cases before choosing experiential statements and quotes. The quotes had a page number linked to the raw data. This gave Ivy and Khloe easy access to the original exploratory notes and the wider transcript, which ensured that their interpretations were grounded in the data. Consequently, new quotes, which the co-researchers felt were significant, were added to the experiential themes. Throughout the process, the RF microphone was muted but the co-researchers were left with a list of reflective questions such as, “which PETs are most potent across the whole data set?” (Smith et al., 2022, p. 101).

The session ended with the notion that there would be continued member check-ins, especially if the RF made any slight adjustments to ensure their stories were coherent. Ivy and Khloe felt that, despite their differences, the final GETs equally contributed to, and represented their voices. A debrief form was shared with the co-researchers to remind them that they had access to wellbeing support (Appendix T).

Assessing the Quality of the Current Research

Trustworthiness

Trustworthiness in qualitative research refers to the quality and rigour of the study and the extent to which the practices are visible and, thus, auditable (Given, 2008). According to Smith et al. (2022), qualitative research should not be judged against quantitative research but instead evaluated in its own terms, replacing positivist language, such as validity, reliability, and objectivity. Instead, Yardley (2000) devised four ‘open-ended, flexible’ quality principles: “sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance” (p.219). Smith et al. (2022) identified that these four principles align well with the theoretical underpinnings of IPA. Therefore, the RF considered these four principles throughout the current research to achieve trustworthiness.

Sensitivity to Context

Yardley (2015) proposed that good quality research should show sensitivity to the context across all research areas including the relationships between the researcher and participants. For this, the RF first immersed themselves in relevant theoretical and empirical literature to better understand what is currently known about CODAs' experiences, outlined in Chapter Two. Chapter One also demonstrated a breadth of understanding of the socio-cultural context of deaf culture and history, and the impact of this on CODAs. In addition, extensive preliminary work was carried out to gain the current views of CODAs and ensure the proposed doctoral research was of interest and importance to the community in question.

The premise of the current research is based on breaking free from the traditional hierarchy in research, by inviting those closely related to the matter of study, CODAs, to be at the centre of the enquiry. Therefore, the RF positioned themselves to work alongside the co-researchers to help reduce power imbalances. Furthermore, the rationale behind adopting IPA for the current study was its commitment to idiographic principles, which focuses on examining the unique, rich, and detailed accounts of the people most concerned. The PR approach of this research also meant that the co-researchers independently led on elements of the six-step IPA process, enabling their voices to remain at the centre of the study. Of the parts that the co-researchers chose to hand over to the RF, the RF encouraged them to review and reflect on the interpretations offered, of which they had the opportunity to amend or change.

Commitment and Rigour

"The concept of commitment encompasses prolonged engagement with the research topic . . . the development of competence and skill in the methods used, and immersion in the relevant data"(Yardley, 2000, p. 221). The RF identifies as a GODA and thus has personal prolonged experience of the CODA culture and community. In addition, they support CODA families as part of their trainee EP role. Furthermore, the RF prioritised preliminary work and spent two months liaising and building connections and trust with CODA UK & Ireland before committing to the current research.

Rigour refers to the inclusion of a thorough research process (Yardley, 2000). To ensure rigour, the co-researchers were invited to use multiple methods of gathering data. Consequently, they decided on semi-structured interviews, artefacts, and an optional diary entry. Furthermore, the co-researchers were invited to review a random section of the transcript; however, due to other commitments, they asked the RF to complete this task. Thus, the RF reviewed a random sample of both transcripts. The co-researchers followed the six-step IPA process in a collaborative, comprehensive and systematic manner (Smith et al., 2022).

Transparency and Coherence

Yardley (2000) states that "at the level of presentation, the criteria of transparency and coherence relate to the clarity and cogency" of the research (p. 222). This chapter provides an account of the research methodology and data analysis process, including an insight into the co-researchers' decision-making. Due to the nature of this PR study, the RF had to account for transparency between themselves and the co-researchers to ensure that they could accurately represent the co-researchers’ decisions. For this, the RF gained the co-researchers' consent to record the workshops to ensure that the RF and co-researchers could review the teaching material and discussions surrounding the decision-making. The co-researchers demonstrated logic and consistency, as the research question and aims aligned well with their method. These decisions were also consistent with the RF's research position and analysis. Supervision and draft submissions have also contributed to the transparency and coherence of this process.

Yardley (2000) states that reflexivity helps ensure transparency. The RF believes that self-reflexivity should be a step-by-step descriptive and detailed journey of what it took to get to their destination rather than the casual exercise outlined in a thesis, as described by Alase (2017). For this reason, extracts of the RF’s reflexive diary are summarised in Appendix U and described in Chapter Five. The co-researchers were also encouraged to engage in reflection and reflexivity throughout, as outlined in the procedure above (Appendix R). This supported the co-researchers in making decisions systematically and thoroughly.

Furthermore, IPA explicitly incorporates reflexivity by recognising the significance of double hermeneutics; the co-researcher would interpret the participants' voices from a personal perspective, which can never be entirely avoided (Mauthner & Doucet, 2003). Therefore, a proactive evaluation of the self was required, as without it, the co-researchers might have been at risk of over-identifying, and the RF be at risk of representing the co-researchers' voices in a way that is dominated by their own characteristics and bias (Finlay & Gough, 2003).

Impact and Importance

The real validity of research relates to its impact and utility (Yardley, 2015). Yardley (2000) argues that “the decisive criterion by which any piece of research must be judged is, arguably, its impact and utility” (p.223). However, there are numerous variations in the usefulness and value of research (Yardley, 2000). Firstly, to the RF’s knowledge, this is the first CODA study to adopt a PR approach in the UK; thus, the research findings will offer a unique perspective and proudly contribute to PR. The RF hopes that the research will serve a socio-political purpose and have some positive social effects (Yardley, 2000). For this, the co-researchers were invited to contribute to the dissemination of the current PR, with a focus on how to reach a wider audience and those in power. The impact and importance are discussed further in Chapter Five.

Chapter Summary

This chapter provided an overview of the research paradigm, including the RF's ontological and epistemological positions. PR was reintroduced, with the RF focusing on the model of participation and the challenges associated with this approach. The RF justified the reasons for inviting the co-researchers to use IPA to analyse their data. The co-researchers, Ivy and Khloe, were introduced, and an outline of their research question, aims and research design provided. Finally, Chapter Three concluded with an explanation of the processes of data collection and carrying out IPA, and considerations of the trustworthiness of the study. The co-researchers' views of their CODA identity are shared in the next chapter.

Chapter Four: Findings

Introduction

This chapter provides an overview of the research findings. It starts by outlining who completed which parts of the six-step IPA process, before presenting the PETs for each participant. The remaining part of this chapter focuses on the final four common themes, GETs, that were devised by the co-researchers.

Development of Personal Experiential Themes

In the interest of identifying individual themes for each participant, the co-researchers and RF followed the IPA process recommended by Smith et al. (2022). The co-researchers and RF involvement in the six-step IPA process is outlined below.

1. The co-researchers, Ivy and Khloe, individually completed steps one and two in which they familiarised themselves with one another's transcripts and made exploratory notes (extracts of interview transcripts are outlined in Appendices V and W).
2. One co-researcher, Khloe, requested the RF's support with steps three, four and five. Therefore, these three steps were completed only by Ivy and the RF. This entailed developing themes and subthemes by exploring the lived experience of each of the participants (examples in Appendices V and W). Ivy requested the RF's support with step five.
3. Ivy and Khloe came together for step six, in which they explored connections and patterns across their cases to create the final four themes (summarised in Figure 4.1 below).

Figure 4.1

The Co-Researchers' and Research Facilitator's Involvement in the Six-Step Interpretative Phenomenological Analysis Process

Khloe Interviewed by Ivy

- Step one: Reading and re-reading (Ivy)
- Step two: Exploratory noting (Ivy)
- Step three: Constructing experiential statements (Ivy)
- Step four: Searching for connections across experimental statements (Ivy)
- Step five: Naming and organising the personal experiential themes (RF checked in with Ivy to see if she agreed)
- Step six: Working with personal experiential themes to develop group experiential themes across cases (Ivy and Khloe)

Ivy Interviewed by Khloe

- Step one: Reading and re-reading (Khloe)
- Step two: Exploratory noting (Khloe)
- Step three: Constructing experiential statements (RF)
- Step four: Searching for connections across experimental statements (RF)
- Step five: Naming and organising the personal experiential themes (RF, checked in with Khloe to see if she agreed)
- Step six: Working with personal experiential themes to develop group experiential themes across cases (Ivy and Khloe)

Multiple Hermeneutic

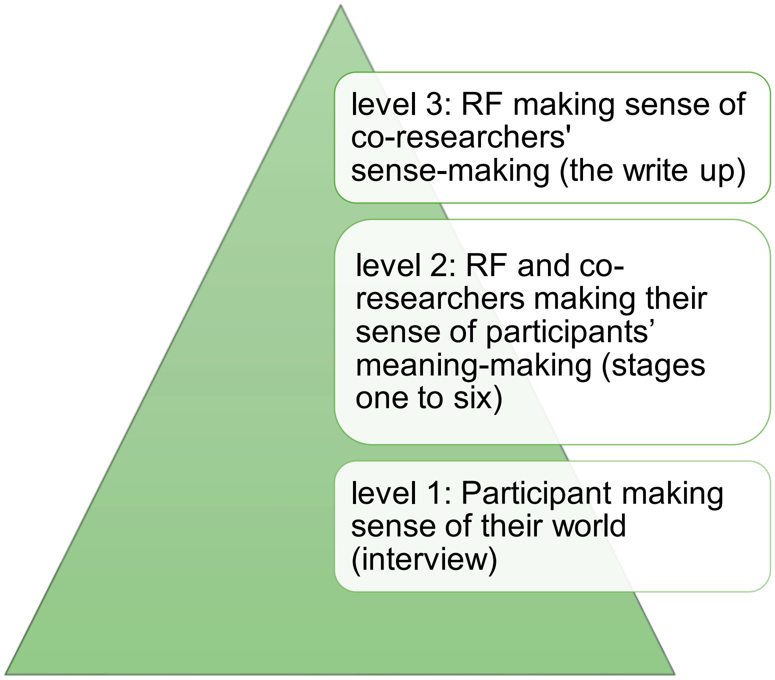
According to Montague et al. (2020), a further layer of complexity occurs when multiple researchers analyse data. Due to the PR approach, there were three individuals trying to make sense of the participants' CODA identities.

Figure 4.2 (below) represents the three levels of sense making and the stages at which they occurred. To increase the trustworthiness of the study, the RF honoured the co-researchers' narratives throughout by drawing on their experiential statements and exploratory notes (Appendix V and W). This means that the RF was constantly moving between 'parts' (words, sentences and paragraphs) to the 'whole' (participants' transcripts) as suggested by Smith et al. (2022). Furthermore, the co-researchers were sent a draft of the RF's interpretations of their individual findings

(PETs). A sample of this is provided in Appendices V and W, together with another draft of their common findings (GETs). This ensured that the co-researchers' voices were prioritised throughout.

Figure 4.2

The Three Levels of Sense-Making

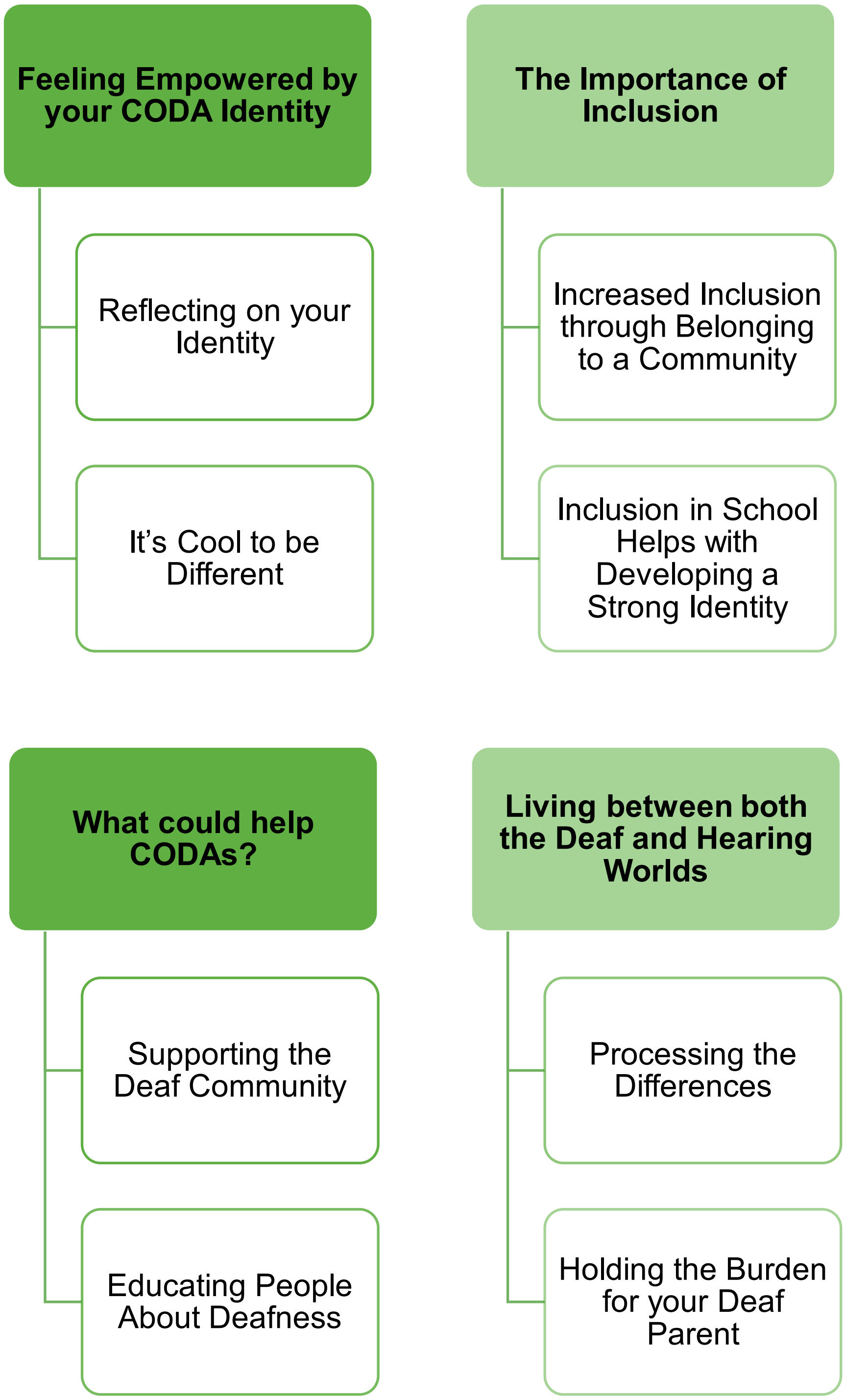


Khloe's Biography

Khloe is a 19-year-old woman studying psychology at university. She identifies as a White-British young person, and her mother and father are both deaf. Her first language is BSL, and at home, the family use BSL to communicate. Khloe first identified with the term CODA when she attended her first CODA summer camp at age 11. Interestingly, Khloe moved to Australia during the research process; however, she remained committed to her role as co-researcher and participant. Figure 4.3 (below) illustrates the four PETs identified by the RF and Ivy from Khloe's interview, and Appendix V highlights extracts of Khloe's transcript.

Figure 4.3

The Four Personal Experiential Themes Identified by Ivy and the Research Facilitator in Khloe's Interview



Personal Experiential Theme One: Feeling Empowered by your CODA Identity

The following themes were grouped together, by Khloe and the RF, as they highlight Khloe's feeling of empowerment when processing and reflecting on her CODA identity.

Subtheme One: Reflecting on her Identity

A significant message that came through to the RF and Ivy during Khloe's interview transcript was Khloe's emphasis on the importance of discussing identity with like-minded people. Throughout the interview, Khloe's approach to her CODA identity shifted, indicating that she was trying to make sense of it herself whilst reflecting on her childhood experiences. Furthermore, there appeared to be some discomfort and contradiction when using the term 'different', as though it implied 'less than'. Throughout the interview, Khloe associated the term 'different' with the positive "cool" and the negative idea that "agreeing with Ivy, the CODA co-researcher . . . it means that they are part of a minority group". Initially, Khloe noted that she did not view herself as different to non-CODAs:

> It's just a term, I don't know because I just think like I don't. I don't feel like too much different to say anyone who's not CODA in terms of like, just like what I do without my parents and things like that (p. 4).

However, Khloe later highlighted that she experienced an identity shift when she attended CODA camp for the first time. This opened her eyes to the world of CODAs and highlighted differences from non-CODAs:

> I feel like my kind of identity probably majorly changed then when I went to like this camp, this camp . . . called CODA camp . . . when I went there, I like met all other people that were like me . . . So, I feel like my identity like

> changed in the sense of like meeting other people kind of like, opened your eyes to like the whole different like world (pp. 5-6).

Before attending CODA camp, Khloe had only interacted with non-CODAs, therefore, was a CODA living in a hearing world. It seems that the experience of being in a CODA world, with “other people that were like me” (p. 6), was empowering and encouraged her to embrace her CODA identity on a deeper level. Thus, Khloe realised that she was not alone and there were other families like hers.

When Khloe was asked to share an artefact that represents her identity, she proudly shared her CODA camp T-shirt (Figure 4.4). It seems that the experience of attending a camp where everyone shared the same ‘label’ as hers increased her sense of pride and appreciation for her identity: “I literally remember in year 8, I used to wear it [T-shirt] like every day to school and people be like, what's that? ohh yeah. It's my CODA badge” (p. 9).

Figure 4.4

Artefact: Khloe’s T-Shirt from CODA Camp

Whilst holding up her T-shirt, smiling, Khloe seemed to have an ‘epiphany’ and noted that this must have been when she started to identify as a CODA: “So, I just brought that cause I feel like to me like . . . it was the first like time I ever like realised about CODA" (p. 9). From this, Khloe started to name positive 'differences' between herself and non-CODAs.

Subtheme Two: It's Cool to be Different

Khloe described how her experience at infant school was when she first realised that not everyone had deaf parents. From this, she recognised that the hearing world has little understanding of the deaf community:

> I first like really understood about like being a child with someone who is deaf, kind of when I was in like Infant School . . . I just remember cause my dad came into school and he read a book in sign language to my class, and I remember just sitting there and like everyone in my class is like . . . wow, this is so cool and I was like this is so like normal to me. . . . Nobody really knows like anything to do with sign language or . . . the deaf community (p. 3).

This quote also implies that her class peers viewed her CODA label as impressive. However, for Khloe, this is her norm, as it has always been part of her life. Khloe seemed to value this positive attention and it seems to have aided her self-acceptance and strong sense of identity: "I guess I think it's just like cool and unique. I just feel like it's something different and I always talk about it" (p. 5).

Khloe described her CODA label as "cool" multiple times throughout the interview. She seemed to value her identity hugely and appears to be a great advocate for the CODA community. This positive self-image seems to have been influenced by her primary school experience: "my primary school was very good . . . it was so fitting" (pp.17-18).

Personal Experiential Theme Two: The Importance of Inclusion

A key theme that the RF and Ivy identified in Khloe's interview was the importance of inclusion, and the impact that this had on Khloe developing a strong sense of self and a positive alliance to her CODA identity.

Subtheme One: Increased Inclusion Through Belonging to a Community

Khloe acknowledged that, prior to this PR project, she had spent little time reflecting on her CODA identity. However, in doing so, she was starting to understand how it has influenced her and shaped her as a person and therefore can now help her: "Maybe I can like help . . . my younger brothers" (p. 63). Reflecting on her identity also highlighted the influence that belonging to a CODA community had had on herself and her parents. She referred to her mother throughout the interview and reported that her favourite thing to come from CODA camp was seeing how confident and comfortable her mother was with other deaf parents, in her world, the deaf world:

> My favourite thing to come from it was when . . . our parents meet and my parents, can talk to their parents and I was like, this is weird because usually at home my mum can't really speak to my friends or like my friend's parents. I would have to like interpretate for them (p. 6).
>
> I think it was like the coolest thing ever. Just like see my mum like in a world of like deaf people . . . Mum would be like ohh I know her mum, like it's such a community where like everyone kind of knows (p. 63).

This implied that CODA camp provided not only a sense of belonging for Khloe but also for her mother. This was her mother's world, the deaf world, in which communication and cultural barriers were removed: "It was just nice, I guess for me to like see my mum, like, interact in a way that like she should be interacting anyways" (p. 63). It increased her mother's independence and minimised Khloe's responsibility and role as the interpreter, but instead acknowledged her role as the child: "It was like seeing my mum like be in her element and . . . like talk to people and I'm sat there like, I'm like that daughter who is like oh can we go, stop talking to your friends" (p. 64).

Furthermore, CODA camp was a place where 'cultural differences' became the 'cultural norms': "It's just so nice to just like to have . . . like other people who were also like in the same boat" (p. 64). Khloe seemed to appreciate the opportunity to share and hear similar experiences that she could relate to: "And everyone would just sit round the circle and be like, I remember when I did this and I was like, whoa, like, I had that too. Like, I experienced that as well" (p. 65).

Subtheme Two: Inclusion in School Helps with Developing a Strong Identity

Khloe described her infant school as "very good with my mum" (p. 17*).* She referred to numerous events where her school embraced and celebrated her CODA identity, by providing her parents with an inclusive space and encouraging the other children to do the same. This seems not only to have had a positive influence on her self-image as a CODA, but also to have had a long-lasting impact on her primary school: "kind of influenced like a lot of people" (p. 18).

> My primary school was very good with like my mum and things because, they still, have signs like around the school of like pictures of like sign language . . . we went there a couple of years ago and the head teacher had learnt sign language . . . from my mum (p. 17).
>
> I visited the school I think it was like some summer fair they were like talking to my mum and like my mum was like, they're all like signing to each other . . .

> like reception year one year two, they're all like being taught like some words as well (p. 18).

Notably, this nurturing environment had a positive impact on Khloe’s CODA identity. However, secondary school was different: “when I went to secondary school, no one's gonna whip out sign language . . . there's just too many kids to focus on parents” (pp. 18, 23). From this, Khloe implied that she could draw a comparison between attending an inclusive school and a non-inclusive school. Therefore, she was able to reflect on what could help or be improved for CODAs in school.

Personal Experiential Theme Three: What Could Help CODAs?

The second aim of this research was to ‘explore the support received by CODA individuals and how this could be modified’. Therefore, the co-researchers made sure that there was a direct interview question linked to this. When Ivy queried how things might have been different if there was different support or awareness for the CODA community, Khloe appeared certain that it was her deaf parents that required support and adaptations, not her directly.

Subtheme One: Supporting the Deaf Community

Khloe stated that the focus should be on supporting the deaf community, as by doing so it will support CODAs. She implied that she feels most comfortable and supported when her mum and the deaf community are supported. This would make her life, as a CODA, easier: “I feel like I never needed support like personally like me. But I feel like I was supported by the deaf community being supported” (p. 47).

Khloe drew on her primary school experiences and gave examples of her father coming in to read books in sign language, which helped raise awareness of the deaf community and supported them as a CODA family: “Making me think oh . . .

my parents cannot hear, but like, this doesn't matter cause this is educational" (p. 47). This further reinforced her belief that, to support CODAs, the hearing must support the deaf community first:

> I don't think like there's a way to support like CODA community, I think in a way it's kind of hard to . . . do that, but I think you can do it through just like supporting the deaf community and like learning (pp. 47-48).

Subtheme Two: Educating People About Deafness

Khloe implied that the priority should be on educating the hearing community about the deaf community and deaf culture. She felt that hearing people were unaware, or unsure of how to respond to deaf people, which further alienates them from society: "But I feel like if I just ask, like, a hearing person, like on the street like, a, do you know how to interact with the deaf person, they would probably go no!" (p. 59). Therefore, the aim of educating the hearing community would be to increase their understanding and awareness of how to interact and respond to deaf individuals. This, in turn, would increase their sense of inclusion and level of comfort and, consequently, support the CODA community too.

> If people were educated on it and things like that, like it would . . . maybe not like I don't think all my interactions are negative as such like . . . I think some people just don't know what to do and I think . . . like learning how to interact with deaf people can make like deaf people feel . . . less uncomfortable . . . smoother and like less awkward (p.55).
>
> I think it would make CODAs' lives easier to have people educated on it . . . It would just make experiences like positive for not only us, but like for deaf people just in general, which then would just make it positive for us (p. 60).

Overall, Khloe's advice for educating people about deafness reflected her personal experience and what she found was helpful whilst growing up in a CODA family.

Personal Experiential Theme Four: Living Between the Deaf and Hearing Worlds

Throughout the interview, Khloe was coming to terms with what her CODA identity means to her and, perhaps, how the deaf and hearing worlds have increased her awareness of 'differences': "The in between of like we can hear, we can sign" (p. 49). This was particularly prominent in her response to question 9: "Do you feel as though your experiences so far as a CODA have been different to non-CODAs, and how?" (p. 42).

Subtheme One: Processing the Differences

Khloe expressed that her CODA identity is more noticeable to those who do not experience the differences of the deaf world. It seems that she was processing the differences through the lens of the hearing community.

> They might look at . . . our lives and be like, ohh, wow, like that is so different to what I've ever had to do. To me it's like . . . I live with my parents, I live with my mum, so I know like this is just life (pp. 40-41).

Khloe seems to suggest that the CODA identity is mostly invisible; therefore, there was little opportunity for her to notice differences between her upbringing and those of her friends brought up in hearing families. Whilst reflecting on her childhood experiences, Khloe identified that, when differences became apparent, it was usually due to non-CODAs noticing and naming them:

> I think sometimes . . . we're not that different and then sometimes I think wow it is so different for me than it is to you. For example . . . when we're driving a

> car . . . in my friend's cars, like with their parents driving . . . the music will be like music that my friends don’t listen to or would be pretty quiet. Whereas if you get in my car . . . you're blasting like music that my brothers wanna listen to (p. 43).

Khloe implied that the hearing world’s expectations of a deaf or CODA family were different to her lived experiences: “Whenever they've [her friends] met my family, they just go wow like your family is so loud” (p. 44). This comparison of her world versus her non-CODA friends’ world seemed to have increased her awareness of her identity.

Subtheme Two: Holding the Burden for Your Deaf Parent

Khloe often addressed the feeling of putting herself in her mother’s shoes: What it might feel like to be a deaf person in a hearing world and the inequalities and burden this can come with. This seemed to have impacted her friendships. She seemed to value and appreciate friends who minimise treating her family as different. “You want the same respect that you give their parents to happen to you as well, even if it's like a brand new like thing for them” (p. 38).

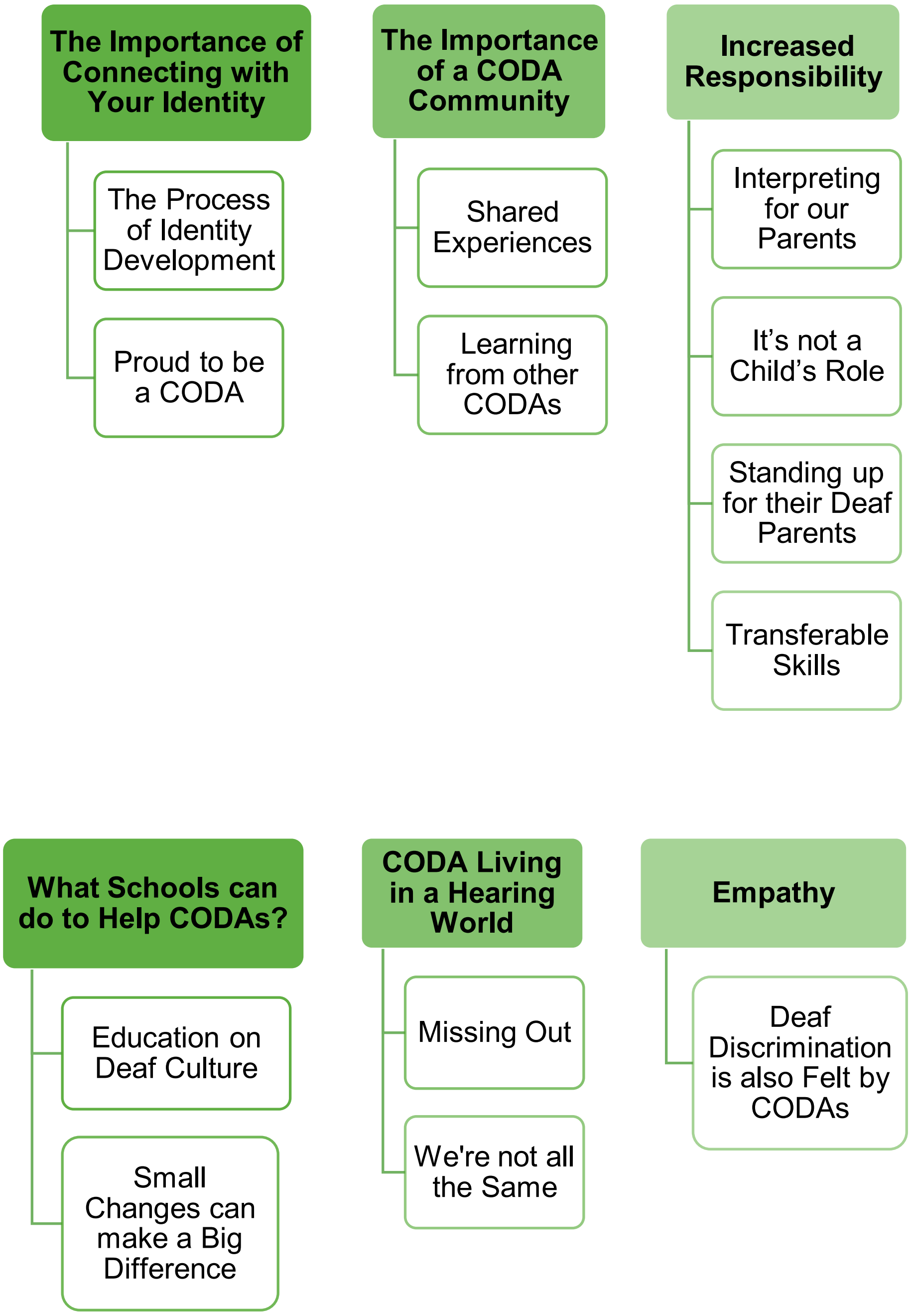
Khloe shared a recurring feeling that her difficulties or discomfort came from seeing her mother feel uncomfortable or excluded from society. Naturally, Khloe was extremely empathetic and emotive when reflecting on her mother’s struggles of being a deaf person in a hearing world. “I'm like ohh well, this makes me feel like upset and uncomfortable cause I'm like, I don't want my mum to feel like that” (p. 50).

Ivy’s Biography

Ivy is 20 years old and identifies as a White-British young person. Ivy is currently in her second year of university studying Natural Sciences. Ivy’s mother is profoundly deaf, and her father is hearing. Ivy’s first language is spoken English. She notes that she did not learn BSL and therefore does not use BSL with her mother; instead, the family uses lipreading. Ivy first identified with the term CODA, aged 20, when her mother shared the recruitment advert for the current research with her. Before this, Ivy was not aware of the term CODA, and had no connections with the CODA community. Figure 4.5 represents the Six PETs identified by the RF and Khloe from Ivy’s interview, and Appendix W highlights extracts from Ivy’s transcript.

Figure 4.5

The Six Personal Experiential Themes Identified by the Research Facilitator and Khloe, from Ivy's Interview



Personal Experiential Theme One: The Importance of Connecting With Your Identity

Ivy suggested that she had never previously considered her CODA identity until “this research” (p. 2). Throughout the interview she pondered on the word ‘different’, and whether this was a positive or negative term to be associated with. Two subordinate themes capture the importance of connecting with your identity, and the process and outcome that accompany this.

Subtheme One: The Process of Identity Development

Interestingly, Ivy seemed to value the time she had during her interview with Khloe to process her CODA identity for the first time. Although there was some appreciation of her CODA identity, she also seemed to question whether this meant that she was part of a ‘minority group’ and therefore different and “should be like disadvantaged” (p. 2). She continued,

> But I guess I am one. it kind of felt weird to start with or like even now still a bit I guess because it feels like a term like that is kind of like means you're like different, which I guess I am. . . . It feels like you're part of like a minority group, which I am, but it also feels like having like a label almost feels like I should be like disadvantaged (p. 2).

Nonetheless, Ivy also highlighted the positives of processing her CODA identity: “I think it kind of gives like more of a purpose I guess” (p. 49). Ivy also later emphasised, in her post interview diary entry, the importance of taking time to reflect on your identity:

> I feel as though I have really learnt a lot about myself during both interviews and I am looking forward to understanding more about the impact of my

> CODA identity moving forward, as well as how I can use this to help and better understand the deaf community (p. 55- diary entry).

Subtheme Two: Proud to be a CODA

Ivy explicitly said numerous times how proud she is to be a CODA. She suggested that it gave her the confidence to apply for certain roles and it was something unique and cool that she could talk about, especially in interviews.

> When it came to like applying for stuff in school like I applied like head girl in secondary school and stuff like that, it was something that I always mentioned . . . I think it's quite cool, like it's something that I'm proud of. . . . It's definitely like made me . . . me! (p. 27).

Personal Experiential Theme Two: The Importance of CODA Community

A close interpretation of Ivy’s transcript by the RF and Khloe (Appendix W) led to the formulation of superordinate theme two, ‘the importance of CODA community’. The two related subordinate themes highlight the significant impact that the current research has had on Ivy.

Subtheme One: Shared Experiences

Ivy commented on this interview being the first opportunity she had to discuss her CODA identity with another CODA. The experience seemed to enable her to profoundly connect and relate to it. However, Ivy also seemed to reflect that, although this experience was increasing her sense of self and appreciation for her identity, in retrospect, she seemed regretful that it had not happened sooner. Having a shared label, and therefore community, means that you are not alone.

> I've never really felt like part of, like a group of something like that before. And so that felt really nice, especially because I don't know anyone really That's also a CODA like before this, or at least like. I've never spoken to anyone

> about it, like the interview with you last week is like the first conversation I've ever had with another person who's a CODA about being a CODA (p. 3). Even the last few months, I felt more like a CODA, like been more aware of it, and I'd like enjoyed kind of appreciating it more and realising like it's a cool thing. . . . We've literally had the exact same issues come up and clearly, like anyone else that we would speak to, would probably say the same thing and so maybe if I realise like it wasn't just me that was being affected by that (pp. 48-50).

Subtheme Two: Learning from other CODAs

Ivy suggested that the essence of sharing similar experiences with another person who also shares your CODA identity, means that you have the opportunity to learn from one another. This left her feeling inspired to connect with the CODA community, after the current research. This was clearly elicited in her diary entry:

> I have found it really interesting to hear another CODA’s story for the first time and appreciate our similarities despite our differences. As someone who didn’t previously consider having a deaf parent to be something which may have impacted me day to day this in particular has really struck me . . . I hope to find other CODAs and understand more about my experiences through others too (pp. 54-55).

Personal Experiential Theme Three: Increased Responsibility

Ivy discussed in detail the increased responsibility that she felt being the eldest CODA in her family. She explained that “because my dad is mostly not at home” (p. 12), the responsibility fell onto her. The four subthemes related to responsibility were grouped together by the RF, with Khloe’s approval, as they describe the different responsibilities that Ivy adopted, what this taught her, and how it made her feel.

Subtheme One: Interpreting for our Parents

Ivy highlighted at the beginning of the interview that her family use lipreading as a form of communication. However, she still has the responsibility to ensure that her mother always feels included in conversations, in and out of their family home:

> We're just talking between ourselves and or, like, laughing at something and my mum will be like, what you laughing at? . . . I kind of have a lot more of a responsibility to make my mum feel more included (p. 6).

As aforementioned, although Ivy's mother uses lip-reading to communicate with the family, rather than BSL, Ivy suggested that the hearing world were still unable to communicate with her: "no one can lip read, so conversation is hard" (p. 6). Consequently, Ivy has the responsibility of interpreting for her mother, outside of their home:

> And then like when my like boyfriend comes around, he always goes like, what did she say? And I'm like, how do you not know what she's saying? . . . I think after the second time he was like Ivy I literally don't understand what she's saying, I feel really bad (pp.13-14).

Subtheme Two: It's not a Child's Role

A consistent feeling that Ivy shared during the interview was that CODAs are handed a role that is not theirs. She referred to herself as the "the in-between person", and made a poignant point that, "it's not our [CODAs] job" to be interpreting for them, "like especially in school" (p. 35).

> I guess kind of having to be that more mature like person for your mum while you're with your teachers, where you're the child is like a really weird place to

> be . . . we've been born into that role of like, we want to help our mum and everything, but it's not our job and like we shouldn't have to be put in these situations where we feel uncomfortable . . . we are still a child (p. 35).

Ivy proceeded to describe the pressure she felt as a child interpreting for her mother in school, describing it as a “weight shifted onto us” (p. 44). She continued to emphasise that it is not a child’s role, and implied that it is the school’s duty to ensure that this does not happen: “You shouldn't be the one who's interpreting like for your mum, it should be someone else . . . outside of school, I don't think it's ours” (pp. 35-36).

Subtheme Three: Standing Up for their Deaf Parents

Another responsibility that Ivy shared, was the experience of standing up for her mother and defending the deaf community. She implied that the hearing world seem to know very little about the deaf world, and therefore has misconceptions.

> One of the girls was talking about deaf people. And she was like, yeah, that's why like, no deaf people have jobs like, they just can't do it. And I was like my mum works . . . It's not like a life debilitating disease . . . that's how most people view it (p. 43).

Naturally, Ivy appeared frustrated at the lack of understanding in the hearing community and was very protective of her mother: “it's not really good enough” (p. 44). This ultimately led to conversations about what can be done to educate others, relating to subtheme four.

Subtheme Four: Transferable Skills

Ivy implied that despite her being “a lot quieter as a child” (p. 13), her CODA responsibilities gave her the confidence to take the lead and be in charge “when I needed to be” (p.13). This applied not only at home, but also in other social settings, such as with friends or in school: “Be in charge of the team or something. If we're doing stuff in school, so I don't know if that maybe has also come from being at home and having to” (p. 13). Ivy referred to this as “automatic” and “just kind of on autopilot”, as, at home, it was expected of her to occasionally “be in charge” when her mother was unable to. Consequently, she took on this role in other circumstances too.

Personal Experiential Theme Four: What Schools Can do to Help CODAs

The RF’s and Khloe’s interpretation of Ivy’s transcript led to the formation of the superordinate Theme Four, ‘What schools can do to help CODAs’. The following three subthemes, ‘Education about Deaf Culture, Small Changes, and Empower Young CODAs’, were taken from Ivy’s view on how to minimise responsibility for CODAs.

Subtheme One: Education about Deaf Culture

Ivy implied that educating the hearing world about deafness would support not only deaf people but also their hearing children, increasing inclusion and equity. Ivy suggests that educating people would also put hearing people at ease as they would know how to interact with deaf people. Furthermore, it would minimise segregation and the pressure that CODAs feel when mediating between the deaf and hearing worlds.

> And even like if there was something in school that would mean that my friends then would know or feel more comfortable in like, how to interact with like my mum. And it shouldn't even be like in school, it should just be where there is CODAs (p. 46).

Ivy emphasised that education on deafness would mean that everyone feels comfortable. “Because . . . my friends feel uncomfortable . . . my mum was uncomfortable. . . . It just causes her anxiety, which then causes me anxiety of like" (p. 47).

Subtheme Two: Small Changes Can Make a Big Difference

Ivy proudly advocated for equal treatment of the deaf community throughout, whilst sharing examples of how the smallest changes can make such a difference to the deaf community. She sadly shared numerous accounts of how her mother was excluded from school events, simply because there was a lack of awareness and consideration.

> It costs like a company that's running a concert like that, literally nothing. And there's other people, I'm sure that go to it that also have hearing problems or a hard of hearing that it would make a big difference for and so she also had a long process of trying to get them to make small changes (p. 7).
>
> They [school] made a video instead, but they actually didn't put captions on the video and I like got one of the awards and my mum was like really upset because obviously they were speaking about me, but she didn't know what they were saying. . . . Yeah, just like little things like that, like making sure like the captions are on videos so she knows what they're talking around, things like that, but yeah (p. 38).

This extract highlights the simple adaptations that can be made to ensure that deaf parents are able to access the hearing world and feel included, especially in their hearing child's life. Ivy implied that it is a school's duty to be curious, by "asking like genuine questions or like asking how they can speak to her best and stuff like that" (p. 41).

Personal Experiential Theme Five: CODA Living in a Hearing World

Ivy referred to being a CODA meaning that they are expected to live in two different worlds: the hearing world and the deaf world. The following two subordinate themes have been grouped together as they describe Ivy's experience of living in two different worlds. They include how this means decrying multiple ways in which CODAs can feel they are missing out yet emphasise that CODAs are not a homogenous group.

Subtheme One: Missing Out

Ivy referred to 'missing out' throughout her interview. She implied that being CODA means that she misses out in different ways and also how this made her feel envious.

> I kind of am very envious sometimes of like my friends who have hearing parents who friends can just pop round and like have a chat and like, especially at our age now like you almost like friends with the parents as well because my mum like doesn't have that with any of my friends maybe like (p. 21).

Ivy courageously shared her experience of 'missing out' when it came to parents' evenings and her position as interpreter, rather than student and daughter. This meant that there was a lack of transparency, and certain important conversations were avoided because of Ivy's presence and the communication barrier between teachers and her mother.

> One parents evening . . . my mental health wasn't 100% and like one of my teachers had kind of picked up on it and she obviously wanted to say something and she only very briefly, like touched on it, and I feel like because I was sat there, it definitely made a big difference because my mum also then

> didn't really push it and didn't really say anything. . . . I kind of needed that at the time and I didn't really get that because like I had to be sat there because the school wouldn't pay for an interpreter. Which, yeah, is obviously like. It's like negative for both me and my mum (p. 33).

Subtheme Two: We're Not All the Same

Throughout the interviews, Ivy and Khloe could relate to one another. Khloe, the interviewee, empathised with Ivy, and together they noticed similar experiences. However, differences were also evident. Ivy highlighted that not all deaf people and CODAs are the same. Therefore, one CODA’s experience should not be generalised. “Not all deaf people are like that it’s such a spectrum” (pp. 42-43).

Ivy was suggesting that not all deaf people are the same, therefore, not all CODAs have the same experience. Ivy also implied that this depends on the support system around you, for instance one of the differences between Ivy’s and Khloe’s stories was that Khloe's schooling experience was more inclusive.

> We've literally had the exact same issues come up and clearly, like anyone else that we would speak to, would probably say the same thing, and so maybe if I realise like it wasn't just me that was being affected by that or if I'd heard how your school did this, maybe I would have been more like ohh. Why isn't my school doing that? (p. 50).

Khloe and Ivy ended the interview agreeing that, although they both share the same identity as CODA, “we've not had the same upbringing” (p. 51).

Personal Experiential Theme Six: Empathy

An important and increasing theme throughout Ivy’s interview was her empathy for her deaf mother. This was particularly prominent when answering question three, ‘Can you tell me about the artefact/picture/object you brought with you?’ Ivy sought permission from her mother to share her diary entry (Figure 4.6 below, see Appendix X for transcribed version). This reflects her mother’s experience of being a deaf parent to a hearing child in a hearing world.

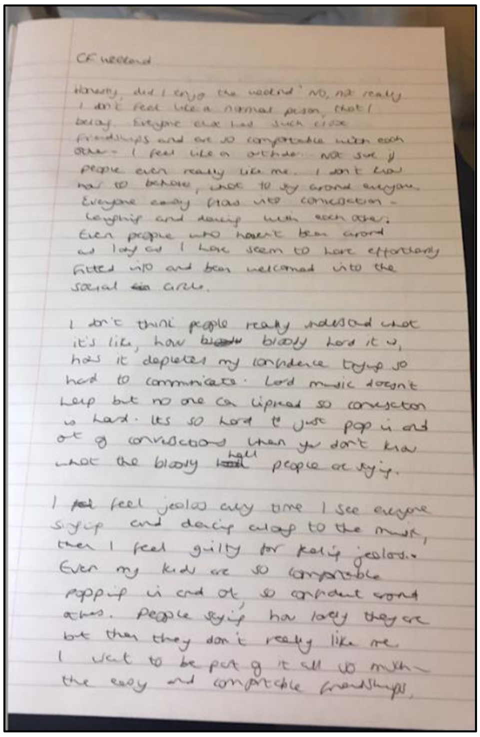
Subtheme One: Deaf Discrimination is Also Felt by CODAs

Ivy explained the emotional impact of witnessing her deaf mother face barriers and exclusion from hearing society:

> It made me like kind of tear up because I was like, I forget how much it impacts my mum and she doesn't ever complain about it . . . I don't think people really understand what it's like, how hard it is, how it's depleted, my confidence trying so hard to communicate (p. 4).

Figure 4.6

Artefact: Ivy’s Mother’s Diary



> And yeah, it made me feel really sad because I was like, I don't. I don't think I really appreciate how difficult it is for my mom and how much like that's her

> normal like feeling like that. And so yeah, it kind of made me feel like I should. Go out of my way a bit more to include her, especially cause sometimes like me and my brother would get. Like not frustrated (pp. 6-7).

Development of General Experiential Themes

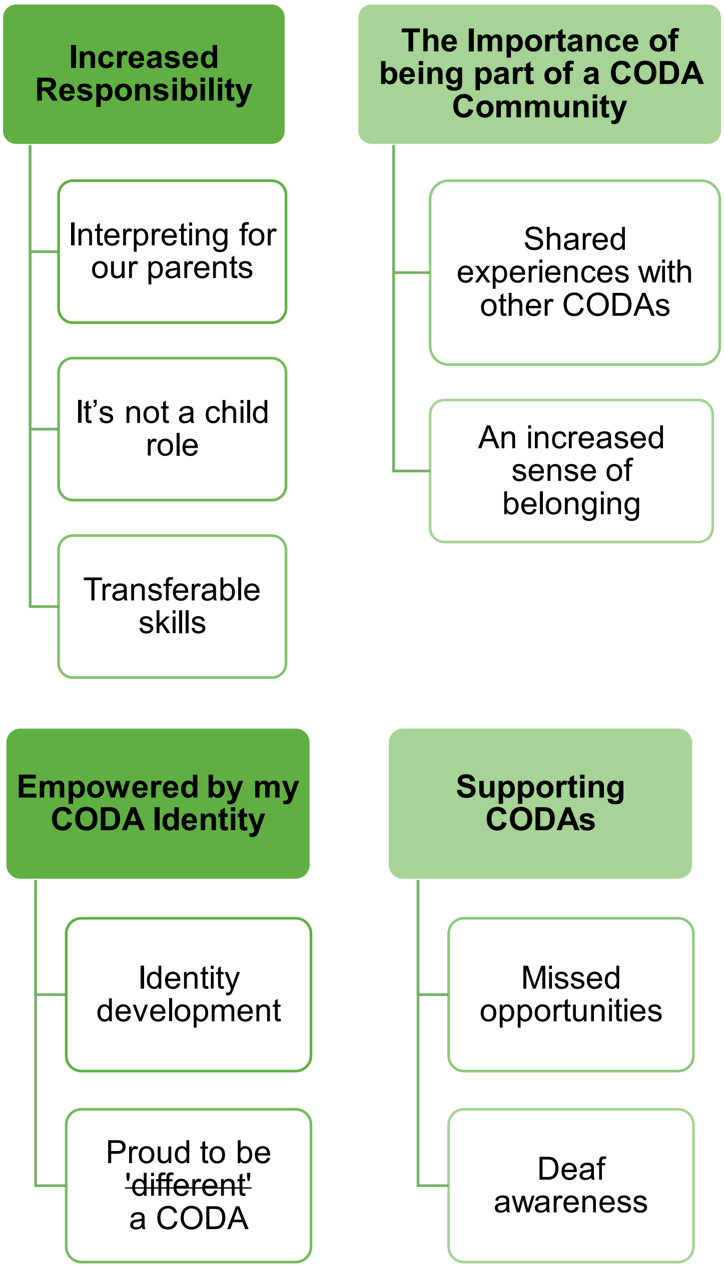
Following the case-by-case analysis, the co-researchers highlighted the shared and unique features of the experiences across both cases (Smith et al., 2022). Ivy and Khloe identified four GETs: Increased responsibility, the importance of being part of a CODA community, empowered by my CODA identity, and supporting CODAs (Figure 4.7). The RF honoured the co-researchers' final four GETs, and, notably, the themes related well to the research question and aims. This will be discussed further in Chapter Five.

As noted in Chapter Three, there were many common themes across both PETs; however, there were identifiable differences, which became more apparent in the subthemes. Naturally, based on Ivy’s and Khloe’s personal experiences, characteristics and values, some subthemes below align with one participant's voice more than the other. For example, 'It's not a child's role' aligns more with Ivy’s voice while 'Shared experiences with other CODAs' aligns more with Khloe’s voice.

Nonetheless, Khloe and Ivy felt that their voices were equally represented and wanted the hearing world to know that, despite having a 'shared identity', all CODAs have a unique upbringing, perspective, and experiences. Ivy and Khloe also chose to use some of the same wording from their PETs for their GETs, as they felt it suited; thus, there is some duplication.

Figure 4.7

The Final Four General Experiential Themes Identified by Khloe and Ivy



General Experiential Theme One: Increased Responsibility

This GET reflects the increased responsibility that Ivy and Khloe identified due to having deaf parents in a hearing world. A shared responsibility for both participants was their daily role as interpreter; thus, ensuring that the hearing world was accessible to their deaf parent.

Subtheme One: Interpreting for Our Parents

Ivy and Khloe shared daily experiences of interpreting for their parents: at home for their friends and family, at school for teachers and other parents, and for daily affairs, at the shops or booking appointments. This was their norm: “I was like this is so normal to me” (Khloe, p. 3). However, it appeared to be ‘hearing people’s’ lack of effort and understanding that led to their frustration.

Khloe seemed to focus on events in which she had to interpret for her mother when her friends came over. “At home my mum can't really speak to my friends or like my friend's parents. I would have to like interpretate for them” (Khloe, p. 6). As for Ivy, her sense of frustration came from being positioned as the interpreter at school: “I kind of wish that I didn't have to be this in-between person like especially in school” (Ivy, p. 35).

Subtheme Two: It’s Not a Child’s Role

Ivy and Khloe seem to share different views regarding their role as interpreter. This was particularly evident when discussing how they felt about interpreting at home, compared to at school. Both named interpreting for their parents in a school setting a nuisance, unnecessary, and unfair. However, Ivy made it clear that, in particular, “it’s not a child’s role”.

> It was like a big like faff, like obviously when you have an interpreter you need like longer time slots, but like cause there's so many kids, it's like we don't have time to give you more time. So, it was like up to me (Khloe, p. 23).
>
> You shouldn't be the one who's interpreting like for your mum, it should be someone else cause and then like I guess I outside of school, I don't think it's

> ours. . . . Like it's not really good enough. And yeah, it definitely means that then as CODAs is like we have some of that weight shifted onto us (Ivy, pp. 36, 44).

Although Ivy and Khloe both acknowledged that it was unfair and inequitable to have been positioned as the interpreter in school parents' meetings, they both agreed that Ivy shared an increased frustration, and was more vocal regarding this subject, throughout her interview.

Subtheme Three: Transferable Skills

Participants were asked during the interview to think about how being a CODA has influenced their experiences at school and growing up in general. Both participants felt that hearing people did not understand the amount of responsibility they had as a CODA, not only to interpret but also "to be in charge" and take on the parent role.

> My mum can't hear the fire alarm and my dad is mostly not at home and my brother's the younger one, so I remember being like, yeah, guys, I actually have to go through the fire if there's one, I'm in charge (Ivy, p. 12).
>
> I can do things, I can ring someone up and ask them for something, I can go into a shop . . . and be like, hey, can I have this? Where's this? Cause, that's just what I've done since I've like grown up (Khloe, p. 12).

Their increased responsibility as a CODA also meant that they tended to adopt leadership roles in school and, interestingly, they felt that they were perceived to be more mature by the hearing world: "I bet people when you were little . . . always like oh you're so mature for your age" (Ivy, p. 13 in Khloe's interview).

> Yeah, I'll do the signing for you, I'll interpret for you. Yeah, I'll get on the phone and ring someone. I was always like the go to . . . I guess it kind of helped me as I have like got older (Khloe, p. 12).

General Experiential Theme Two: The Importance of Being Part of a CODA Community

Khloe and Ivy shared many similarities; however, “even though like we share the same CODA title, we're still different” (Khloe, p. 62). Naturally, this was based on their individual characteristics and upbringing, as aforementioned in their biographies. A significant difference was their experience with the CODA community and the age at which they identified as CODA.

Subtheme One: Shared Experiences with Other CODAs

Khloe shared at length her experiences of attending CODA summer camp, a place where she could relate to, and connect with other CODAs. Here, she felt understood and no different to anyone else:

> I feel like my kind of identity probably majorly changed then. when I went to like this camp. . . . And everyone would just sit round the circle and be like, I remember when I did this and I was like, whoa, like, I had that too. Like, I experienced that as well (Khloe, pp. 5, 65).

An initial interpretation of these quotes is that being part of a CODA community seems to have strengthened Khloe's CODA identity. It reinforces the importance of being with other people “like you”, who share similar experiences. However, Ivy's story is relatively different. Before this PR, Ivy had never conversed with another CODA, and was not aware there was a CODA community. Instead, it was her deaf mother who had introduced her to CODA UK & Ireland and signposted her to this research.

"Even the last few months, I felt more like a CODA, like been more aware of it, and I like enjoyed kind of appreciating it more and realising like it's a cool thing, like to be able to say" (Ivy, p. 48). This highlights how significant it was for Ivy to share similar experiences with another CODA, and therefore find a new appreciation for her CODA identity. It seems that their similarity in age also helped with this relatedness.

Subtheme Two: An Increased Sense of Belonging

Khloe seemed to have an increased sense of belonging when attending CODA camp as it "opened your eyes to like the whole different like world" (Khloe, p. 6). This seems to have also had a positive impact on her mother's sense of belonging and was one of Khloe's favourite things to come from CODA camp.

> My favourite thing to come from it [CODA camp] was when our parents meet and my parents, can talk to their parents and I was like, this is weird because usually at home my mum can't really speak to my friends or like my friend's parents. I would have to like interpretate for them (Khloe, p. 6).
>
> I think it was like the coolest thing ever, just like to see my mum like in a world of like deaf people . . . mum would be like ohh I know her mum, like it's such a community where like everyone kind of knows (Khloe, p. 63).

It seems that seeing her mother feel so comfortable, and in her own world, reinforced Khloe's sense of belonging and appreciation for the CODA camp. As aforementioned, Ivy's experience was vastly different; however, she seemed to appreciate listening and learning from Khloe's experience and perhaps finding hope and inspiration in now belonging to the CODA community.

> I've never really felt like part of, like a group of something like that before and so this feels really nice, especially because I don't know anyone really that's

> also a CODA like before this, or at least like I've never spoken to anyone about it, like the interview with you last week is like the first conversation I've ever had with another person who's a CODA about being a CODA (Ivy, p. 3).

This subtheme emphasised the importance of being part of a community: an ‘in group’, with other people just ‘like you’ that share the same identity, and, thus, not feeling alone. Ivy noted, in her post interview diary entry, “I hope to find other CODAs and understand more about my experiences through others too” (Ivy, p. 55, diary entry). This suggests that the PR experience inspired her to continue connecting with the CODA community, so that she can also proceed to learn more about herself through connecting with CODAs. This infers that connecting with like-minded people also reinforces a sense of self and identity.

General Experiential Theme Three: Empowered by Your CODA Identity

This GET explores the influence that reflecting on one’s CODA identity had on Ivy and Khloe. Throughout their interviews, there was a sense of getting to know themselves through the eyes of a CODA. This appeared to have a profound and transformative impact on them both as it encouraged them to reflect on their upbringing and to explore the depths of their identity.

Subtheme One: Identity Development

Prior to the PR experience, Khloe identified as a CODA; thus, had time to familiarise herself and see her identity through CODA eyes. She expressed that at times she feels like “the in between of like we can hear, we can sign.” (Khloe, p. 49). There seems to be a sense that CODAs are constantly living in between two different worlds: the hearing world and the deaf world.

> I don't think about it as such until like I'm with my mum or I'm in a situation with her. So sometimes I feel like two, not two different people, but like two, like two separate like lives in a sort of way of life (Khloe, p. 27).

This also infers that her mother is a constant reminder of her CODA identity, especially when they are together in the hearing world. In contrast, Ivy was seeing her identity through a CODA lens for the first time. This was somewhat polarising, as her CODA identity was initially absent:

> But I guess I am one [CODA]. It kind of felt weird to start with or like even now still a bit I guess because it feels like a term like that is kind of means you're like different, which I guess I am (Ivy, pp. 3-4).

However, she appeared to embrace the process of self-discovery and felt empowered whilst doing so. “Yeah, I think it's probably shaped my identity more than I realised like in terms of who I am and how I react in situations and like I said, like the whole maturity thing.” (Ivy, p. 29). She later added, “I think it kind of gives like more of a purpose I guess” (Ivy, p. 49).

In Ivy’s diary entry, she mentioned the importance of taking time to reflect on your identity and how the PR experience had helped develop and strengthen her sense of self, both as Ivy and as a CODA.

> I feel as though I have really learnt a lot about myself during both interviews and I am looking forward to understanding more about the impact of my CODA identity moving forward, as well as how I can use this to help and better understand the deaf community. (Ivy, p. 55, diary entry).

Subtheme Two: Proud to be ‘~~Different~~’ Child of Deaf Adult

Throughout the interviews Ivy and Khloe reflected on what it meant to be a CODA. Despite choosing to use the term ‘different’ throughout their interview questions (questions 9, 10 and 11), they both appeared to struggle with the view that identifying as CODA meant they were ‘different’. Khloe and Ivy seemed to switch between proudly identifying themselves as ‘different’, to almost rejecting it. Hence, their decision was to use a strikethrough for the word ‘different’.

> I don't know, I didn't even think like, ohh, this [CODA] is something that's different about me. . . . When it came to like applying for stuff in school like I applied like head girl in secondary school and stuff like that, it was something that I always mentioned. . . . It is something that's different about you . . . I think it's quite cool. Like it's something that I'm proud of (Ivy, pp. 12,27).

> Well, I'm different like, not, I'm better than you, but like I have something that you don't . . . I don't think . . . like being a CODA is like a ginormous monumental thing where it means I'm completely different to my friends and we have all different experiences. (Khloe, pp. 26,39).

Nonetheless, although they were undecided about whether they were ‘different’, one consistency was how proud they felt to be a CODA. “Like I said, like interviews and stuff like that, it's always something that I mentioned because it's something that . . . I'm very proud of” (Ivy, p. 48). “I was like, this is like the coolest thing ever. Like, I'm so cool and I'm thinking I'll like no one else is like me and that's just cool” (Khloe, p. 19).

General Experiential Theme Four: Supporting Children of Deaf Adults

The final GET is in response to Khloe and Ivy’s second research aim: to ‘explore the support received by CODA individuals and how this could be modified’. Khloe and Ivy discussed the consequences they face due to the lack of support, understanding, and inclusion of deafness in the hearing world.

Subtheme One: Missed Opportunities

Ivy and Khloe both gave examples of ‘missing out’ as a CODA. Ivy shared the missed opportunities of communicating with her mother, in times that non-CODAs would be able to.

> I was thinking about like my relationship with my mum and how I've missed out on a lot of like time. Like . . . people would normally like chat to their mum whilst their driving, but like we can't do that (Ivy, p. 16).

Following this, she shared the ignorance of hearing people ‘not knowing’ what she misses out on as a CODA:

> Because yeah, I guess I missed out a lot . . . I've had so many times where I've had like a problem or I don't know literally anything and someone would be like just call your mum and I'm like, that's not actually an option like, I can't do that and so yeah, just things like that (Ivy, p. 17).

It seems that if hearing people were more educated about deafness, there might be an increased appreciation of what CODAs miss out on and consequently people may try to help mitigate this.

Notably, another difference between Ivy’s and Khloe’s upbringing was that Khloe seemed to have an extremely inclusive primary school experience. She shared many positive experiences of how the school celebrated her CODA identity and educated staff and children about deafness: “my primary school was very good with like . . . my mom and things because, they still, have signs like around the school of like pictures of like sign language” (Khloe, p. 17). This reduces the sense of ‘missing out’.

However, Khloe said that her secondary school experience was slightly different:

> I feel like you go to secondary and then there's just too many kids to focus on parents. . . . I think I did have parents evening once and everything else would just get sent like in letter form just cause it was too much hassle to do it . . . with an interpreter (Khloe, p. 23).

This suggests that there was a lack of commitment and equity, from the school, to provide an interpreter and ensure that Khloe’s mother received the same as the other parents.

During Ivy’s interview, Khloe reflected on Ivy’s experience of missing out and, in response, shared another experience of missed opportunities:

> At the end of year 13 . . . they made a video instead, but they actually didn't put captions on the video and I like got one of the awards and my mum was like really upset because obviously they were speaking about me, but she didn't know what they were saying (Khloe, p. 38) (seen in Ivy’s transcript).

This subtheme highlights how Ivy and Khloe missed out due to a lack of understanding of deafness and equity, whilst also providing examples of what the hearing world could do to ensure that CODAs are better supported.

Subtheme Two: Deaf Awareness

A common theme throughout Ivy’s and Khloe’s stories, was the emphasis they put on raising awareness of deafness, as it is deaf parents that need the support: “But I feel like I never needed support like personally like me, but I feel like I was supported by . . . the deaf community being supported” (Khloe, p. 47). Their views suggest that educating staff and children in schools would not only support the deaf community, but also their hearing children, and thus CODAs, too.

> And even like if there was something in school that would mean that my friends then would know or feel more comfortable in like, how to interact with

> like my mum and it shouldn't even be like in school where there is CODAs (Ivy, p. 46).
>
> It's easier to like do it when a child's younger, as in like if you like teach someone something when they're younger, it kind of sticks with them and they like, can kind of like grow up and then then teach their kids that, then teach their kids (Khloe, p. 33).

Raising deaf awareness, would help ease the pressure Ivy and Khloe felt to explain themselves and mediate between the deaf and hearing worlds. Khloe and Ivy also implied that it would make them feel more comfortable, as they would be reassured that hearing people know how to interact with the deaf community.

> If people were educated on it and things like that, like it would be maybe not like . . . I don't think all my interactions are negative as such like. . . . I think some people just don't know what to do and I think . . . like learning how to interact with deaf people can make like deaf people feel . . . less uncomfortable (Khloe, p. 55).

Furthermore, Ivy suggests that CODAs need to be educated too, especially about their rights as a child: “I feel like I definitely could have done more if someone had, like said to me like. This isn't okay or like. You're having to do a lot more than you should be doing” (Ivy, p. 39).

Khloe and Ivy implied that there are consequences for CODAs, depending on how society views and care for the deaf community. Khloe compared her CODA experience in an inclusive setting (primary school), versus her current context, which appears less inclusive of her deaf parents. “I read it out and signed it out in front of the whole like assembly hall, and like a bit embarrassing, I don't know how I did that I must have had, like, way more confidence back then” (Khloe, p. 22).

Ivy also shared how she felt in response to her mother’s letter (artefact) where she was expressing her negative experiences of the hearing community: “She [Ivy’s mother] was writing about how excluded, she felt, and it made me like kind of tear up because I was like, I forget how much it impacts my mum and she doesn't ever complain about it” (Ivy, p. 4). Therefore, it seems that it can either empower or disempower you as a CODA, which interestingly aligns with the current research paradigm of critical realists.

Chapter Summary

This chapter has presented the participants’ PETs, which were devised by the RF and the co-researchers as demonstrated in Figure 4.3 and 4.5. The chapter goes on to outline the overarching GETs, devised by the co-researchers (Figure 4.7). The next chapter ‘Discussion’ explores these findings in relation to the research question, the aims, psychological theory, and the literature review.

Chapter Five: Discussion

Overview

This chapter integrates the final four themes ,identified by the co-researchers relating to the current research question, with previous research and the underpinning theories of this piece of research. Following this, the strengths and limitations of the research will be critically discussed before outlining the proposed dissemination of the findings. The research implications concerning future research, EPs, and school practitioners will be addressed. Finally, the chapter will conclude with the research facilitator's reflexivity of the research process, followed by the conclusion.

Reviewing the Research Question and Aims

The co-researchers were interested in qualitatively exploring 'How have the experiences of CODAs shaped their identity?'. The co-researchers explicitly named how their findings aligned with their research question and aims in their final virtual session, as demonstrated in Figure 5.1 (below). Khloe's and Ivy's views on how their final themes fit with the research aims gave them a sense of satisfaction, as they felt that they had fulfilled their purpose. Although the RF will consider the co-researchers' reflections, when discussing the research question and previous literature regarding the four final themes, they recognise that this will be through third-level interpretation (Figure 4.2, in Chapter Four), that is, the RF will be making sense of co-researchers' sense-making.

Figure 5.1

The Co-Researchers' Views on How the Research Findings Aligned with their Aims

Theme one: **Increased Responsibility**	• Aim one: Explore the extent to which identity is shaped as a direct consequence of CODA experiences/upbringing. • Aim three: Explore personal interactions/relationships with non-CODAs and how this has influenced CODA identity.
Theme two: **The importance of having a CODA community**	• Aim one: Explore the extent to which identity is shaped as a direct consequence of CODA experiences/upbringing.
Theme three: **Empowered by my CODA identity**	• Aim one: Explore the extent to which identity is shaped as a direct consequence of CODA experiences/upbringing.
Theme four: **Supporting CODAs**	• Aim three: Explore the support received by CODA individuals and how this could be modified.

Findings Discussed in Relation to the Research Question and Previous Research

Increased Responsibility

The current study strongly features a CODA’s role as an interpreter. Ivy and Khloe shared daily examples of interpreting for their parents. The exception was that Khloe interpreted conversations for her parents using BSL to English and vice versa, whilst Ivy used lip reading to English and vice versa. A CODA’s interpreter role reflects the findings from the literature review. Preston (1995) found that CODAs view themselves as the primary interpreters for their parents. Moroe and de Andrade (2018a) highlighted that the role of CODAs as interpreters is influenced by their gender, age, and position in the family. Although not explicitly mentioned by participants, the implication was the same in this study. Khloe noted,

> I have like an older brother and younger sister and then two young brothers so . . . I felt I was always the one to be more like . . . Yeah, I'll do the signing for you, like I'll interpret for you” (pp. 11-12, Khloe).

Similarly, Ivy reported, “Because my dad is mostly not at home and my brother's the younger one. I would have to go and get my mum in that situation, and so . . . I'm in charge (p.12, Ivy).

According to Klimentová et al. (2017), CODAs are often given the role of interpreter and expected to interpret for their parents in situations where they are too young and lack adequate life experience. Consequently, CODAs experience a feeling of loss of a piece of childhood as they become premature adults (Klimentová et al., 2017). In the current study, Ivy shared that it is not a child’s role to interpret, especially in school settings. Ivy reminds the reader that CODAs are born into this role; thus, it is out of their control and implies that more should be done to support CODA families.

Nonetheless, Ivy and Khloe recognised how their role as interpreters taught them confidence and responsibility at a young age. Ivy and Khloe shared examples of how they applied these skills in school, such as adopting leadership roles. Ivy also noted that her CODA experiences influenced how non-CODAs viewed her as being mature for her age. This is similar to Moroe and Andrade's (2018b) study, which found that, despite the challenges associated with the interpreter role, CODA participants appreciated that it helped prepare them for adulthood.

Ultimately, the participants' CODA experiences in the current research included interpreting daily for their parents in both comfortable and uncomfortable situations. However, Ivy and Khloe implied that they had no choice and, therefore, learned to adapt and just take charge of the situations, as it was their ‘norm’, on ‘autopilot’. Ivy and Khloe suggested that their role as interpreters influenced how others viewed them as mature, independent, and responsible. Consequently, they naturally lived up to these expectations, which helped prepare them for adulthood.

The Importance of Being Part of a Child of Deaf Adult Community

An important message from this theme was how being part of a CODA community strengthens a CODA’s identity by encouraging them to embrace and celebrate their CODA identity and bringing about a sense of belonging. Khloe spoke about her personal experience of attending several CODA camps. On the contrary, Ivy noted that she had never referred to herself as CODA before this PR experience, as this was her first time connecting with another CODA. Despite their different upbringings, they agreed that being with others ‘like you’, with whom you share similar lived experiences and with whom you can easily relate and connect, can reinforce your CODA identity. Consequently, the conversations about being part of a CODA community inspired Ivy to continue meeting and staying connected with other CODAs.

These findings mirror Knight's (2018) study, which also named the benefits of attending CODA camps, thus being part of a CODA community. They described the CODA camp as a great place where CODAs discover others like them, in which they feel acceptance, belonging and comfort. This CODA camp experience ultimately encouraged them to find their identity and boosted their self-esteem. Interestingly, Knight (2018) found that CODAs who attended CODA camp were more likely to offer rich and detailed responses when discussing their identity compared to the CODAs who did not attend CODA camp. This was evident in the present PR. Ivy spoke in hindsight, as connecting to her CODA identity and community was new. However, Khloe shared at great lengths how her experiences of CODA camp, regarding the friendships she formed and the significant influence it had on seeing her mother 'fit in', such as being able to communicate with other deaf parents. This strengthened not only her CODA identity but also her sense of belonging.

The current study and existing research support the notion that having a CODA community, thus being with other CODAs, enhances and strengthens your identity. The participants implied that being with other CODAs serves as a safe space to share frustrations and stories, to reflect on emotions with others who understand and validate you and, therefore, prove that you are not alone. Knight (2018) further emphasises the importance of having a CODA community as it reinforces pride and acceptance to be yourself, which can be life-changing for CODAs.

Empowered by My Child of Deaf Adult Identity

Khloe and Ivy initially appeared dubious about what their CODA identity meant for them. They named feeling 'normal', and no different from non-CODAs. However, after further reflection and answering questions to explore potential differences (Figure 3.4 in Chapter Three), they noticed that their experiences did differ from those of non-CODAs. Ivy and Khloe also described this as feeling like 'the in-between person', referring to living in both the hearing and deaf worlds. Previous research labelled this as having a bicultural identity (Frank, 2019; Hadjikakou et al., 2009; Moroe, 2019; Preston, 1995; Wood, 2016).

The PR process encouraged Ivy and Khloe to reflect on their identity and differences. This proved to be a challenging task, as, initially, Ivy was conflicted: "It feels like you're part of like a minority group…a label almost feels like I should be like disadvantaged" (p. 2, Ivy). However, both participants concluded that being CODA was the coolest thing ever. According to Moroe (2019), CODAs often feel conflicted over their identity, “I am hearing, but psychologically, I am Deaf” (p. 501), and can also feel embarrassed as often their deaf parents were viewed as ‘stupid’ by the hearing world. Moroe’s (2019) quote is a helpful reminder that CODA is an invisible identity which they can choose to voice or not. Therefore, the context in which CODAs find themselves matters, as it seems to either empower or disempower them to share their identity, which is notably not the same case for their deaf parents.

Ivy and Khloe named the discomfort they felt when mediating between the hearing and deaf worlds. The ‘hardship’ for the CODA participants appeared to be caused by the incompetency of the hearing world rather than feeling embarrassed by their parents. The participants highlighted that they felt proud of their deaf parents, who continued to prosper and navigate through the hearing world despite the inequalities and lack of inclusion. Overall, this study emphasises how proud and empowered the participants were to be a CODA. Ultimately, the current research offers a positive perspective on the CODA identity.

Supporting Children of Deaf Adults

A key motivation of this study was to ‘explore the support received by CODA individuals and how this could be modified’, thus a focus on ‘social change’. Khloe and Ivy shared multiple examples of how their CODA family were supported in their primary school settings. They recognised that this influenced their primary school’s culture, as they embraced deafness. This seems to have strengthened their CODA identity, as they were encouraged to celebrate it.

However, there was a notable difference in their secondary school experience. Khloe noted that her secondary school teachers did not have time to provide additional support to her CODA family. Both participants were positioned as interpreters in secondary school, meaning there were fewer opportunities to celebrate their CODA identity, and instead, there was a ‘weight shifted onto them’. Furthermore, Ivy implied that there is a lack of recognition and ignorance from the hearing community on what she ‘misses out on’ as a CODA. This invalidated her experiences as a CODA and was disempowering.

‘A lack of systemic support’ was a key theme throughout the literature review. Klimentová et al. (2017) found no systemic support for CODA families, especially from the interpreting services; therefore, the duty falls onto the hearing children. There was a sense that CODAs lacked support from their deaf parents, too, such that they were unable to help them with their reading and homework. However, the current study participants did not explicitly mention their lack of support from their parents. Instead, they spoke about ‘missing out’. For example, they were positioned as interpreters at parent meetings rather than the student and daughter due to the lack of equity and inclusion in school. Furthermore, there were missed daily opportunities to converse and connect with their deaf parent, such as being unable to call their parents and to talk whilst driving.

Furthermore, Khloe and Ivy named the discomfort of repeatedly educating others on deaf culture and language. These experiences are consistent with previous CODA research, which found CODAs frequently need to educate and explain deafness to the hearing world. This is emotionally taxing and negatively impacts their well-being (Knight, 2018). Throughout the interview, Khloe and Ivy named and implied ways in which others can help mitigate CODAs’ discomfort and support CODA families. This will be further discussed in the implications below.

The participants expressed a significant view that there needs to be increased awareness and education on deafness in schools. In their research, Moroe and Andrade (2018b) identified CODAs as an overlooked group and reported that a multidisciplinary approach is required to support their emotional well-being, mental health, and development. For instance, health professionals regularly involved in the dynamic of deafness in a family should make appropriate referrals to other professionals, such as teachers, social workers, and psychologists.

Similarly, Frank (2019) emphasised the importance of schools and mental health agencies being aware of CODAs' daily challenges and the identity issues they might experience. Support services must be prepared and available to support CODAs (Frank, 2019). Ultimately, the current study reveals that when CODAs experience adequate support and inclusion, it helps to empower and strengthen their identity. However, when their CODA identity is not acknowledged, nor are their parents supported, this seems to disempower them. Thus, support is necessary but more so for their deaf parents.

Findings Discussed in Relation to the Theories Underpinning the Research

Critical Perspective

The participants challenged the ‘world view’ on deafness; in particular, Ivy voiced, “It's [deafness] not like a life debilitating disease . . . how most people view it” (p. 43, Ivy). Instead, the findings indicate that CODAs’ increased responsibilities and the inequalities and exclusion that their deaf parents face are attributed to the lack of resources, understanding, and knowledge from the hearing world. This suggests that the hearing world makes deafness problematic and coincides with the critical perspective. The critical perspective adopts a non-pathologising approach and seeks to challenge powerful institutions, discrimination, and exploitation (Corcoran, 2022), and it could be argued that the participants of the current research were eager to do the same.

Furthermore, the critical perspective seeks to empower CYP instead of ‘shifting weight, discomfort, and additional responsibility onto them’, as described by the CODAs of the current study. This would, therefore, involve ensuring that interpreters are available, and educating others on deafness. The critical perspective also aims to understand the individual and validate their lived experiences (Corcoran, 2022). Therefore, considering the current research findings, EPs and education professionals would first identify CODAs and then seek to support their parents by providing interpreters first before supporting CODAs directly.

Nonetheless, the participants also shared the positive impact that their education settings had on their CODA identity when they took the time to recognise and celebrate their ‘differences’. Khloe and Ivy implied that small contextual and relational changes, such as requesting that all staff learn a few BSL signs to welcome their parents, and asking that their deaf parents sign a story to the pupils, created a sense of belonging. This emphasises the need for change in the school environment and culture, to ensure that deaf people feel included. Ivy and Khloe shared examples of what this looks like, such as ensuring that there are subtitles in videos that the school shares and celebrating deaf culture in school through books, deaf guest speakers and BSL signs around the school. This perspective aligns with the critical perspective and, arguably, the social model of disability that moves away from ableism and empowers, recognises, and normalises differences (Shakespeare, 2006).

Social Identity Theory

Consistent with the social identity theory (Tajfel & Turner, 1979), the current study's findings identified ‘the importance of being part of a CODA community’. Although the participants never explicitly referred to the deaf, hearing or CODA world as ‘in-groups’ or ‘out-groups’, it was implied when naming feeling like the ‘in-between person’ and highlighting the importance of ‘connecting with others like you’. The three cognitive processes of the social identity theory are discussed concerning the findings of this study below.

Social Categorisation

Naturally, the current study participants had different CODA characteristics and experiences regarding their CODA identity development. Khloe and Ivy implied they spent most of their education with non-CODAs, whom they initially felt ‘no different’ from. The participants implied that CODAs living in a hearing world have little opportunity to connect with other CODAs. Therefore, CODAs seem to find alternative ways to fit in and categorise themselves based on non-CODA-related characteristics. This links with social categorisation, which states that individuals can categorise themselves based on multiple characteristics and belong to many groups throughout their lives (Tajfel & Turner, 1979). This suggests that individuals learn to adapt depending on the context and relations within the situation that they find themselves.

Social Identification

Khloe’s social identification as a CODA was influenced by her attending CODA camps and finding others who share the same label. In line with the social identity theory, Khloe’s increased understanding of her identity was an empowering experience and gave her a sense of belonging. This encouraged Khloe to proudly share her CODA identity badge with other non-CODAs (Figure 4.4 in Chapter Four). This implied that Khloe felt empowered to identify with her ‘in-group’ more overtly. Interestingly, whilst Khloe was with her ‘in-group’, she also witnessed her mother in her ‘in-group’ with other deaf parents. This appeared to give her a newfound appreciation for her ‘in-group’. Conversely, the findings revealed that Ivy’s identification as a CODA was influenced by the current PR, whereby she was connecting with another CODA for the first time.

Social Comparison

The findings revealed that Khloe and Ivy observed the inequalities that their CODA family faced, such as their increased responsibilities as interpreters. Interestingly, Khloe reported that attending the CODA camp amplified the ‘them vs us’ mentality as differences between CODAs and non-CODAs became more apparent. This also became evident for Ivy throughout the PR process. This initiated a sense of injustice and, therefore, a ‘them and us’ mentality. The social identity theory suggests that individuals are inclined to favour their ‘in-group’, which can lead to bias and prejudice towards ‘out-groups’ (Tajfel, 2010). However, despite the injustices, Khloe and Ivy remained relatively neutral when discussing ‘out-groups’. They mainly focused on the positives of having a unique identity.

Intersectionality Theory

The participants were encouraged to discuss their social GGRRAAACCEEESSS (Burnham, 2018) throughout the PR to encourage an intersectional lens. This led to Ivy and Khloe identifying characteristics that they had in common: white, university-educated, CODA females. Interestingly, both co-researchers noted that their social and economic status did not necessarily impact their CODA experiences or identity, yet the intersectionality wheel of power suggests that, to some extent, their characteristics reflect power and privilege (Appendix A, Duckworth, 2020, adapted from Crenshaw, 1991) However, the co-researchers’ findings also highlight how having deaf parents in a hearing world can lead to inequality and exclusion and, consequently, discomfort. Thus, it could be argued that they are ‘marginalised’ through having deaf parents, who are viewed as disabled by the hearing world.

Furthermore, the findings of this research highlight that the timing in which one adopts a CODA identity varies and depends on the intersection of various identities, personal experiences, and values; therefore, CODAs are not all the same. Instead, CODAs are individuals with different experiences despite sharing the same ‘label’. Notably, Khloe had been immersed in the CODA community at a much younger age, and this cultural capital empowered her CODA identity (Bourdieu, 2018). Nonetheless, both participants remained positive and proud of their CODA identity. The RF acknowledged that the lack of diversity meant that the study did not necessarily highlight how different forms of oppression can occur simultaneously. This will be discussed in the limitations below.

Critical Review of the Research

Research Strengths

A significant strength of the current research is that it was both exploratory, through the co-researchers’ research question and aims, and emancipatory, through the RF’s PR approach, giving voice to those closest to the matter (Aldridge, 2017a). CYP voices are usually neglected in research, being seen as ‘objects’ rather than ‘subjects’ (Kellett, 2011). Therefore, this research focused on authenticity and empowering CODA young people to become ‘active researchers’, to participate in meaningful ways, and to gain genuine first-hand perspectives (Aldridge, 2017a; Smith et al., 2002; Wurm & Napier, 2017). This is evident throughout the co-researchers’ feedback.

The RF took several approaches to gain feedback. As stated in Chapter Three, the RF asked the co-researchers to share a word describing each session.

Appendix Y highlights that the most commonly used words by the co-researchers were ‘empowering’ and ‘insightful’, which aligns with the PR aims and values (Aldridge, 2017a; Kellett, 2011). Next, the RF assembled a bespoke PR model, drawing on two existing models–Aldridge’s (2017a) participation model and Vaughn and Jacquez's (2020) participation choice points in the research–and influenced by the co-researchers’ views. Figure 5.2 outlines Khloe’s view, and Figure 5.3 describes Ivy’s view on their level of participation (Appendix H for descriptions).

Figure 5.2

Khloe’s View on her Level of Participation

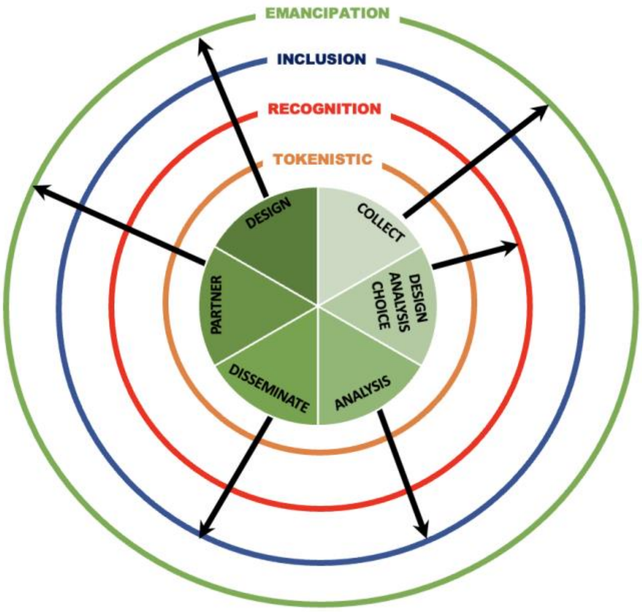
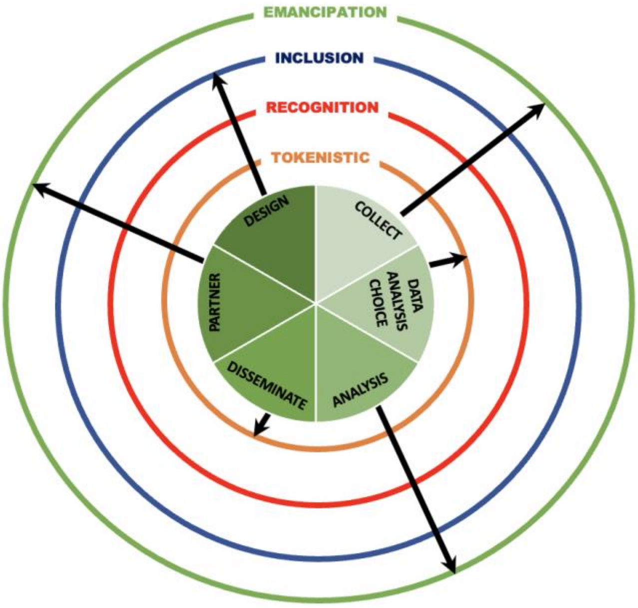


Figure 5.3

Ivy's View on her Level of Participation



Figures 5.2 and 5.3 highlight that Khloe and Ivy identified the research design, collect and analysis stages as emancipation and inclusion. This suggests they felt the research was mostly participant-led or that their voice was equal to the RFs. Appendix Z provides detailed feedback forms. Kellett (2011) notes that power differentials between peers should not be overlooked, as they could have implications on the PR process and findings. However, the co-researchers' feedback suggests they felt they were equal partners, and both contributed to the research: "I think we contributed very similarly" (Appendix Z, Ivy).

Furthermore, Ivy and Khloe were both meaningfully engaged in the PR; they were responsible and reliable and demonstrated considerable mastery of research skills. This shows a congruence between their level of competency and selected methods (Gray & Winter, 2011; Lundy et al., 2011). More notably, they explicitly named how their design methods and findings aligned with the research aims

(Figure 5.1), which undoubtedly guided the discussion. In addition, considering their ages, 19 and 20, there were no mediators or ‘gatekeepers’, such as parents, to intervene and make decisions about their PR on behalf of their children (Aldridge, 2017a).

Unique Contributions of the Research

As aforementioned in Chapters One and Two, none of the final studies from the systematic literature review were conducted in the UK, there was no EP perspective, and only two studies adopted a PR approach (Hale, 2001; Knight, 2018). Therefore, to the best of the RF’s knowledge, the current research will be the first CODA PR completed in the UK. This is important, as it offers two perspectives on what UK schools are doing to support CODA families and what more they can do, which will be discussed in the implications section.

Furthermore, the co-researchers had very different previous experiences regarding their connection with the CODA community. Therefore, IPA enabled them and the RF to first explore and analyse their individual stories, creating PETs. This allowed them to identify differences and similarities, and allowed Khloe and Ivy to have their personal stories heard before bringing them together, creating GETs (Smith et al., 2022).

Research Limitations

Whilst PR aims to break the limitations of more traditional research to avoid perpetuating dominant thinking, it is not without its limitations (Bradbury-Jones & Taylor, 2015). The RF acknowledged that PR is time-consuming and cognitively demanding for the co-researchers (Kellett, 2005). Figure 3.2 in Chapter Three highlights that 8 of the 17 CODAs who initially showed interest noted it was ‘too much of a commitment’. In addition, the current study is limited by the absence of a diverse population. Ivy and Khloe are both white, British females studying for a science-based degree at university, and aged between 19 and 20. Therefore, there is a lack of representation regarding race, age, gender, and education (Burnham, 2018). As such, the research is not representative of the CODA community.

Furthermore, after the preliminary work carried out by the RF, outlined in Chapter Three, and considering that 17 CODAs initially showed interest, the RF was confident that all six co-researchers/participants would be recruited using only CODA UK & Ireland. Thus, plan B of recruiting through their LA was not utilised (Appendix J). The RF also assumed that using the same organisation would mean the co-researchers would have something in common and, likely, already have established a CODA identity. This assumption and optimism bias limited the recruitment pool. Due to time constraints and the determination not to lose the interest of those already committed, the RF proceeded with two co-researchers.

Nonetheless, the RF and co-researchers embraced the rich and detailed data from having a small sample (Smith et al., 2022). The co-researchers seemed to appreciate this: “I enjoyed being a smaller group, which meant we could all get to know each other, and the atmosphere, in general, felt very warm and welcoming, and I felt very comfortable to ask any questions” (Appendix Z, Ivy). In addition, the RF assumption was incorrect, that co-researchers who were somehow connected to CODA UK & Ireland would identify with the CODA label, and that they probably would have attended CODA camp. On the contrary, initially, Ivy did not refer to herself as CODA, and it was her mother who had connections with the CODA organisation (Figure 3.3 in Chapter Three). Overall, this seemed to have a transformative impact on Ivy, as the experience of being with another CODA seemed to encourage an identity shift.

Dissemination of the Findings

To limit a tokenistic approach and maximise the impact of the current PR, the RF invited the co-researchers to decide how they would like to share their research findings (Aldridge, 2017a; Tarling, 2006). A significant view that Khloe and Ivy shared was that the findings should be accessible to the deaf community, CODAs, and educational professionals. For this reason, they welcomed the idea of a YouTube video in which a BSL interpreter should be present. The RF will present the key findings online, via YouTube, on the Educational Psychology Reach-out and CODA UK & Ireland channels, ensuring that a BSL interpreter is present, thus abiding by Ivy's and Khloe's hopes. It is important to note that the co-researchers agreed to be contacted regarding the opportunity to participate in co-delivering the online workshops.

An overview will be shared with CODA UK & Ireland as part of their monthly newsletter, accessed by over 500 CODA families. Moreover, the RF will share the PR findings with UEL TEPs during the doctoral research presentation day in July 2024. The RF wishes to publish the thesis and contribute to CODA peer-reviewed studies, hoping the study will reach a wider audience and thus raise awareness further.

Implications of the Research Findings

Throughout the research, the co-researchers seemed to prioritise 'social change'; they were eager to ensure that their findings had practical implications for the CODA community. This was evident in their second aim, 'to explore the support received by CODA individuals and how this could be modified', and in their semi-structured questions (Figure 3.4). This section will be divided into implications for future research, focusing on PR, and implications for EPs and school practitioners.

Implications for Future Research

PR approaches endeavour to address and reduce the power imbalances between the participant and the researcher (Vaughn & Jacquez, 2020). This research proudly contributes to PR and hopes to encourage other researchers, especially EPs, to do the same. Gersch et al. (2017) argue that all EP work can be likened to ‘research’ through collaborative investigations and data collection that aim to reach new and shared conclusions, albeit facilitated in natural environments. This illustrates the profession’s drive to increase the participation of all service users and suggests that EP research should take an increasingly PR focus (Bagnoli & Clark, 2010).

Considering that CODAs are a hidden population that is not easily identified and reached (Moroe, 2019), including CODA PR in the future would be beneficial. In the same manner as the current research, CODAs should be encouraged to adopt the role of co-researcher and participant. However, more consideration should be given to the time required for PR. According to Conolly (2008), the level of participation required for CYP to adopt the co-researcher role can be impractical and unfeasible and was a limitation of the current PR. Therefore, future PR with CODAs should offer a more flexible and accessible approach to participation, by which they have an optimal choice over their involvement.

Furthermore, the current study sought to recruit CODAs aged 15-25 to explore their everyday CYP experiences and reduce the risk of distorted memory recall, as suggested by previous researchers (Moroe & De Andrade, 2018a). However, the co-researchers of the current study were 19 and 20 years old. Although they reflected on recent everyday CODA experiences, they also reflected on childhood memories, which might have been somewhat distorted. Therefore, future studies should focus on empowering children aged 16 and below to explore current childhood memories.

In line with the current study's limitations, future researchers should consider keeping the recruitment process-wide, not limiting themselves to one organisation, to capture diverse experiences. Previous research would suggest that black and white CODA experiences are different. Black CODAs are subject to increased discrimination because of their race and were more hesitant, compared to white CODAs, to participate in research as they felt that their voice would not be ‘good enough’ and would go unheard over their white counterparts (Harrison & Watermeyer, 2019; Moroe, 2013; Rivera, 2022). Therefore, future research should consider the race and ethnicity of CODAs to increase representation and should aim to empower black CODAs by welcoming them to be involved in PR as opposed to traditional research. This would provide similarities and differences between the white and the black CODAs and, therefore, add a cultural and racial lens to CODA experiences and identity.

Implications for School Practitioners and Educational Psychologists in Supporting Children of Deaf Adults

This study has implications for EPs and school practitioners who play a pivotal role in supporting and educating all children, including CODAs. The literature states that there is a lack of awareness of CODA families within education settings (Hadjikakou et al., 2009; Harrison & Watermeyer, 2019) and, to the best of the RF’s knowledge, CODAs are an unknown group within the EP profession, thus emphasising the need for the current research. The RF hopes that effective dissemination, as outlined above, will help raise awareness of CODAs amongst EPs and school practitioners.

Raising Awareness of Children of Deaf Adult families.

The co-researcher's' views shared throughout the research influence the following implications. They shared that, to support CODAs, their deaf parents should be prioritised and supported first. Khloe and Ivy offered examples of celebrating deafness in school, therefore shifting the school's culture. This could entail welcoming deaf parents to share a story in BSL, providing whole school training on deaf culture and language, displaying BSL greetings, captions on videos, and CODA family representation in literature around the school.

It is also essential for EPs and school practitioners to have general guidance when working with CODA families, to reduce misunderstanding. For instance, CODAs may have been raised within a deaf cultural home, with BSL their first language, therefore adopting deaf mannerisms: stamping their feet to get their teacher's attention, and responding only to their BSL name rather than their English name. In addition, school practitioners and EPs should be culturally competent and able to interact with CODA families appropriately. Examples are ensuring your face is visible and well-lit, finding a quiet place to talk, reducing background noise, and using natural gestures and facial expressions to support your message. Most importantly, a BSL interpreter should be available for all parent meetings.

Increased Access to Interpreters.

CODAs act as a communication bridge between the deaf and hearing worlds (Hadjikakou et al., 2009; Harrison & Watermeyer, 2019; Moroe, 2019). Their role of interpreter appears to be part of CODAs' daily life; however, the co-researchers of the current study were adamant that this should not be expected of them, especially in a school setting: "It's not a child's role". CODAs should have the same experience as their peers with hearing parents. EPs and school practitioners are responsible for ensuring that this happens and that reasonable adjustments are made.

Despite CODA not being one of the nine protected characteristics (Equality Act, 2010), there is still legislation that advocates for children's rights and the rights of their deaf parents. In fact, the United Nations Convention on the Rights of the Child (1989) states, in Article 12, that children’s views should be respected and, therefore, if CODAs do not wish to interpret for their parents, this should be granted. Further, the Equality Act 2010 states that reasonable adjustments should be made for deaf individuals, such as changing the physical environment and providing extra aids and services to BSL interpreters. *Working with Interpreters* (BPS, 2017) clearly outlines the role of psychologists working with deaf families. It advises psychologists to check if the deaf person is fluent in BSL as they might have learned to speak orally and to lipread.

The CODAs of this research were assertive in stating that their rights as a child, and their parents’ rights to interpreters, should have been explicitly shared with them in school. EPs should aim to empower CODA families by sharing their rights in workshops, interventions, and consultations. Furthermore, it could be argued that the sensitivity required for CODAs is also essential for other CYP, such as CYP who have English as an additional language, as research suggests they also experience additional roles and responsibilities, and exclusion, vicariously, through their parents (Dyson, 2022; Ruzane, 2013). Therefore, EPs and education professionals should consider applying the implications outlined above with CYP who have English as an additional language.

Reflection and Self-Reflexivity

The following subsection will be written in the first person to encourage authenticity and transparency. Firstly, I will reflect on my role and position in relation to the chosen paradigms and methodology, followed by my role as a novice RF, before outlining how my GODA identity developed and strengthened throughout the PR. Appendix U expands on this.

Role and Position in Relation to the Paradigms and Methodology

The critical and transformative paradigm and PR often label participants as vulnerable and marginalised (Aldridge, 2017a; Scotland, 2012). This aligns with previous research which names CODAs as a minority group who experience inequalities and discrimination vicariously through their deaf parents (Harrison & Watermeyer, 2019; Preston, 1995a). Thus, it could be argued that CODAs are vulnerable. Steel (2005) notes that vulnerability is socially constructed and contextual. Therefore, although this reflected my lived experience of CODAs, I was conscious that the CODAs of this study might not share the same perception and, consequently, I should not let my biases influence the PR. For this, I remained neutral and curious throughout, kept a reflexive diary and explored this with my director of studies. Most importantly, I provided a safe space by focusing on relationship-building and drawing on the principles of attunement (Kennedy & Landor, 2015) to empower the CODAs to share their truths.

My values, social justice, beneficence, and empowerment underpinned this PR and focused on researching "'with' people and not 'on' or 'for' people". (Chevalier & Buckles, 2019, p. 2). I endeavoured to empower and emancipate the co-researchers by giving them full access to the decision-making. However, I hesitantly learnt that full involvement is not guaranteed, as how one views this differs. To illustrate, as reflected in the co-researchers' feedback (Figures 5.2 and 5.3), there was a significant disparity between how the co-researchers' viewed their level of participation in 'disseminating the findings'. Figure 5.3 states that Ivy felt that this was RF-led; thus, Khloe considered there to be more equal participation and, therefore, she felt more involved. Consequently, I wonder if this reflects their understanding or intention of future involvement.

Furthermore, despite good intentions, some elements of the PR were intentionally tokenistic, such as choosing the data analysis approach for the co-researchers. During the PR, I felt a sense of guilt and frustration as it conflicted with my values. However, on reflection, it would have been more beneficial to practice self-compassion and accept that, as a novice to PR, 'getting the balance right' between knowing when to activate and compensate the co-researchers was a learning curve.

Role and Position in Relation to Being a Novice Research Facilitator

As a novice to PR, I felt optimistic and empowered to find a research approach that aligned closely with my professional values. However, I was conscious that adopting the role of RF would challenge my values of 'security, inner strength, consistency' and, as expected, at times the PR process was anxiety-inducing. Notably, my values of 'inner strength and security' were confronted during the recruitment process, as it was hard to accept that, though many CODAs showed interest, they could not commit. In addition, due to the nature of PR, control and power were shifted to the co-researchers. This proved incredibly challenging when a co-researcher moved to Australia mid-way through the PR process.

Nonetheless, I was comforted and reassured by the co-researchers' enthusiasm for the research, their punctuality throughout, and the belief that with friction comes growth. Ultimately, this PR experience changed my narrative as I learnt to be comfortable with feeling uncomfortable and to trust the process. Most importantly, I had faith in the co-researchers, and consequently, Ivy and Khloe felt emancipated and included (Figures 5.2 and 5.3). I hope that I have represented their views well and made them proud.

Role and Position in Relation to Being a Grandchild of Deaf Adults

As a GODA, I feel a huge sense of responsibility to represent the CODA community meaningfully, especially considering the niche research available. I recognise that I was embarking on this PR journey with preconceptions and biases about what it means to be a CODA. The current PR created a cognitive dissonance, challenging my schema of CODAs. On occasion, it was difficult to process how different Ivy's and Khloe's CODA lived experiences were from my mother's. However, it was helpful to adopt a critical realist lens and reflect on how society's social and power relations influence an individual's experience and, thus, their perception. For my mother, this meant growing up in a society that viewed her deaf parents as people who needed 'fixing' and less capable than hearing people. This ignited a new sense of empathy for the hardships that my deaf grandparents and mother experienced due to the lack of inclusion.

Furthermore, the PR unexpectedly had a profound impact on my GODA identity. It allowed me to reflect on my GODA identity and encouraged me to connect with other GODAs. This has reinforced and strengthened my GODA identity and given me a new leaf of pride. Interestingly, this reflects the co-researchers' findings and highlights the importance of reflecting on your identity with others 'like you'.

Final Conclusions

This is the first study in the UK to use a PR approach to focus on the lived experiences of CODAs and their identity. This study contributes to an emerging body of CODA research by empowering them to share their story while also leading the research. The current study recognises that the themes generated and explored do not represent all CODAs' experiences and identities; however, it does represent how Ivy and Khloe felt during this research. The findings highlight the increased responsibilities CODAs have as primary interpreters for their parents. This theme was most congruent with the previous literature and reinforced CODAs' lack of control in this role. However, the findings also recognise the 'positive' influence the interpreter role had on the participants in preparing them for adulthood.

A key finding was the importance of having a CODA community. Overall, there was a consensus that being 'with others like you' supports self-acceptance and pride and emphasises the differences between yourself as a CODA and others who are non-CODA. Additionally, the findings highlight the conflict the CODA participants experienced when reflecting on what it meant to be a CODA, both moving between 'normal' to 'different'. However, overall, the participants felt empowered by their CODA identity. This study presents implications for EPs and school practitioners, which reflects the research findings which focus on supporting the social inclusion of CODAs by first helping their deaf parents. The implications primarily focused on better informing the hearing community about raising CODA families and, most importantly, increasing their access to interpreters.

In conclusion, Ivy and Khloe appreciated the protected time to reflect on how their CODA experiences influenced their identity, in which they emphasised how proud they were of their CODA identity. This PR experience encouraged Ivy to explore her

CODA identity and influenced her to connect with the CODA community. On the other hand, it inspired Khloe to help other CODAs connect and reflect on their CODA identity. Ultimately, the study hopes to inspire other researchers who retain ‘power’ to adopt a PR approach and further contribute to the CODA research field.

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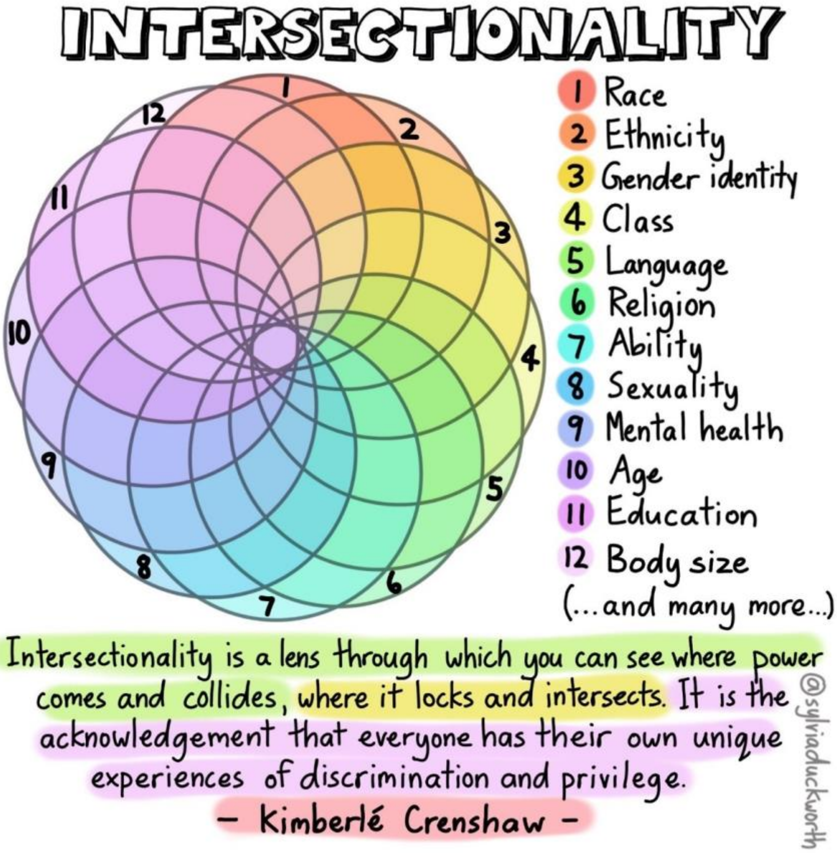
Appendices

Appendix A

The Intersectionality Wheel of Power and Privilege



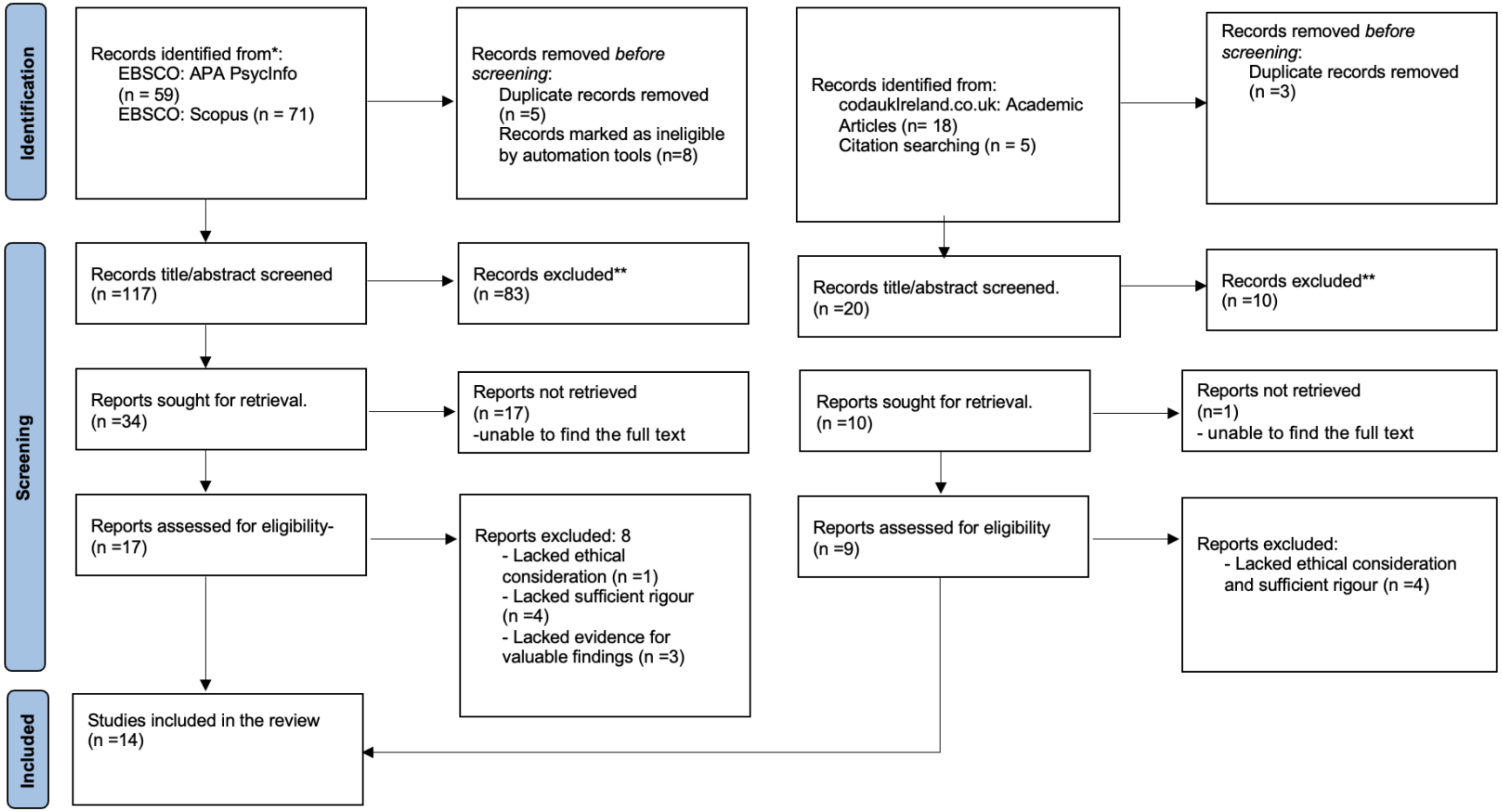
Appendix B

The Inclusion and Exclusion Criteria using the Sample, Phenomenon of Interest, Design, Evaluation, and Research type

	Inclusion	Exclusion	Justification
Sample	Small samples must be collated to ensure the data is rich, detailed, and aligned with qualitative data. This research is interested in CODAs with a range of social GGRRAAACCEEESSS (Burnham, 2018). It would be beneficial if the sample included children and young people aged 0-25 years, as EPs work with this age range.	Adults' views only (26 years of age plus). However, there are two exceptions. 1) adult accounts and memoirs of CODA upbringing and early childhood experiences are accepted. 2) The research was also accepted if the age range starts within 0-25. For example: (Hadjikakou et al., 2009; Wood, 2016)	This research will be facilitated by a trainee educational psychologist who works with children and young people aged 0-25. The researcher would like to find as broad and diverse a range of literature as possible to get an overall sense of CODAs' experiences and be able to extract common themes from this.
Phenomenon of interest	Hearing CODAs only – therefore, hearing children of one or more deaf adults. CODAs that sign (all sign languages accepted) and CODAs that don't sign use other means to communicate with their parent. CODAs whose parents are part of / not part of Deaf culture	Children who are deaf or have mild to moderate hearing loss. Hearing parents Perceptions of anyone other than CODAs, for example, parents, professionals, or university students	This is a niche area of research and thus has been under-represented and under-researched. Therefore, we would like to provide this space for CODAS only and, consequently, a hearing child with one or more deaf parents. Hearing CODAs only, as it aligned with the recruitment criteria. Furthermore, the researcher has a personal interest and attachment to this research area due to her grandchild of deaf adults' identity.
Design	Qualitative methods: interviews, observations, case studies, focus groups, MOSAIC approach, narrative approaches, etc… In mixed methods, however, the Qualitative element must be valuable.	Quantitative design methods only: closed-ended questionnaire, etc..	The literature review question is only interested in the experiences of CODAs, thus most fitting with the qualitative method and designs.
Evaluation	Views, experiences, narratives, and opinions of CODAs	Standardised data only	This aligns with the research title and aims.
Research type	Qualitative and mixed methods Grey literature, including third-sector and government reports and briefings, educational theses, and conference proceedings.	Quantitative data only	This research is interested in gathering rich and detailed qualitative data. Due to a lack of primary and peer-reviewed literature, dissertation bibliographies were included at this stage, as they were the most recent versions of research on this topic.

Appendix C

The Preferred Reporting Item for Systematic Review and Meta-Analyses



Appendix D

The Ten-Item Critical Appraisal Skills Programme

Authors & Publication **Scopus and APA PsycInfo**	**Clear statement of research aims?**	**Is a qualitative methodology appropriate?**	**Was the research design appropriate to address research aims?**	**Was the recruitment strategy suitable to the aims of the research?**	**Was the data collected in a way that addressed the research issue?**	**Has the relationship between researcher and participants been adequately considered?**	**Has ethical issues been considered?**	**Was the data analysis sufficiently rigorous?**	**Is there a clear statement of findings?**	**How valuable is the research?**	**Total score (>8 is high, 6–8 is moderate, ≤5 is low)**
Harrison & Watermeyer (2019)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	0.5 (Can't tell)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	**9.5** **(High)**
Moroe & Andrade (2018) **Gender**	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	0.5 (Can't tell)	1 (Yes)	1 (Yes)	1 (Yes)	0.5 (Can't tell)	**9** **(High)**
Moroe & Andrade (2018) **Brokering**	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	1 (Yes)	1 (Yes)	**8.5** **(High)**
Buchino, (1993)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	0.5 (Can't tell)	0.5 (Can't tell)	1 (Yes)	1 (Yes)	1 (Yes)	**9** **(High)**

Hadjikakou et al., (2009)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	0.5 (Can't tell)	0.5 (Can't tell)	1 (Yes)	1 (Yes)	0.5 (Can't tell)	**8.5** **(High)**
Wood, (2016)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	**10** **(High)**
Schleif (2006)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	0.5 (Can't tell)	0.5 (Can't tell)	1 (Yes)	1 (Yes)	0.5 (Can't tell)	**8.5** **(High)**
Fox (2018)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0 (No)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	**5** **(Medium)**
Miller (2007)	0 (No)	0 (No)	0 (No)	0 (No)	0 (No)	0 (No)	0 (No)	0 (No)	0.5 (Can't tell)	0 (No)	**0.5** **(Low)** **Autobiography**
Buchino (1988)	1 (Yes)	1 (Yes)	1 (Yes)	0.5 (Can't tell)	1 (Yes)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	1 (Yes)	0.5 (Can't tell)	**7.5** **(Medium)**
Blatt (2007)	1 (Yes)	1 (Yes)	1 (Yes)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	1 (Yes)	0.5 (Can't tell)	**7** **(Medium)**

Preston, (1995) article	1 (Yes)	1 (Yes)	1 (Yes)	0.5 (Can't tell)	0.5 (Can't tell)	1 (Yes)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	1 (Yes)	**7.5** **(Medium)**
Mand et al. (2009)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	**10** **(High)**
Filer (2000)	1 (Yes)	1 (Yes)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	**6** **(Medium)**
Moroe (2019)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	0.5 (Can't tell)	0.5 (Can't tell)	1 (Yes)	1 (Yes)	1 (Yes)	**9** **(High)**
Hale (2002)	1 (Yes)	1 (Yes)	1 (Yes)	0.5 (Can't tell)	1 (Yes)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	1 (Yes)	0.5 (Can't tell)	**7.5** **(Medium)**
Buchino (1988)	1 (Yes)	1 (Yes)	1 (Yes)	0.5 (Can't tell)	1 (Yes)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	1 (Yes)	0.5 (Can't tell)	**7.5** **(Medium)**

***Note: 1= 'Yes', 0= 'No' 0.5= 'Can't tell'* (>8 is high, 6–8 is Moderate, <5 is Low).**

Only Articles >8 (High) were included in the final.

Authors & Publication **CODA UK & Ireland and citations**	**Clear statement of research aims?**	**Is a qualitative methodology appropriate?**	**Was the research design appropriate to address research aims?**	**Was the recruitment strategy suitable to the aims of the research?**	**Was the data collected in a way that addressed the research issue?**	**Has the relationship between researcher and participants been adequately considered?**	**Have ethical issues been considered?**	**Was the data analysis sufficiently rigorous?**	**Is there a clear statement of findings?**	**How valuable is the research?**	**Total score (>8 is high, 6–8 is moderate, ≤5 is low).**
Ward (2009)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	1 (Yes)	**7.5 (Medium)**
Bull (2005)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	**5 (Medium) Autobiography**
Preston (1995) Book	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	1 (Yes)	**8.5 (High)**
Napier (2012)	1 (Yes)	1 (Yes)	1 (Yes)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	0.5 (Can't tell)	1 (Yes)	0.5 (Can't tell)	**7 (Medium)**
Hale (2001)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	**10 (High)**

Klimentová et al. (2017)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	0.5 (Can’t tell)	0.5 (Can’t tell)	0.5 (Can’t tell)	1 (Yes)	1 (Yes)	**8.5 (High)**
Knight (2018)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	0.5 (Can’t tell)	0.5 (Can’t tell)	1 (Yes)	1 (Yes)	1 (Yes)	**9 (High)**
Frank (2019)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	1 (Yes)	0.5 (Can’t tell)	0.5 (Can’t tell)	1 (Yes)	1 (Yes)	1 (Yes)	**9 (High)**

***Note: 1= ‘Yes’,0= ‘No’ 0.5= ‘Can’t tell’* (>8 is high, 6–8 is moderate, <5 is low).**

Only Articles >8 high were included in the final.

Appendix E

The Final 14 Articles

9 papers from EBSCO HOST: APA PsycInfo and SCOPUS

Study title, Author(s), Year, Source origin and country of origin	Research Purpose and Aims	Context and Participants Sample and Characteristics	Design and Methodology	Strengths and Limitations	Main Findings, Conclusions and Recommendations
1. Genetic selection for deafness: the views of hearing children of deaf adults **(Mand et al., 2009)** **APA PsycInfo** **Australian – University of Melbourne**	This study is the first of its kind to examine the vies of CODAs towards preimplantation genetic diagnosis and prenatal diagnosis to select for or against deafness. CODAs are widely known in the deaf community straddling both the deaf and hearing worlds, and this dual view makes them ideally placed to add to the academic discourse concerning the use of genetic selection for or against deafness.	66 CODAs – women and men (18-29 years) The thirties (30-39 years) Middle Age (40-64 years) Aged (65 years & older) USA, Australia, Europe Canada	Mixed methods This study features two complementary phases: interviews and a survey. Participation in both phases was restricted to hearing CODAs over the age of 18 years who had one or both parents who could not hear. Semi-structured interviews with key informants (CODAs and health professionals) to guide the subsequent development of an electronic survey, completed anonymously by 66 individuals.	Reasonably large sample – with the representation of ages – 18 – 65 years plus Participants were from worldwide, including the USA, Australia, Europe, and Canada. Therefore, this study could be argued to be generalisable.	The participants shared many of the same views as deaf people in the deaf community. participants described a variety of experiences related to growing up as a CODA. Four broad themes emerged: (1) a negative experience either (a) because of identity confusion or (b) because of increased responsibility of acting as an interpreter for parents, with an associated loss of childhood; (2) a positive experience; (3) mixed feelings surrounding personal experience and (4) a neutral experience. The similarities extended to their opinions regarding deafness not being a disability (45.5% believed deafness was a distinct culture rather than a disability), their ambivalence towards having hearing or deaf CYP (72.3% indicated no preference) and their general disapproval of the use of genetic technologies to select either for or against deafness (60% believed that reproductive technologies, when used to determine for or against deafness, should not be available to the community).

2. Perceptions of the oldest hearing child of deaf parents: on interpreting, communication, feelings, and role reversal **(Buchino, 1993)** **APA PsycInfo** **USA**	To explore the views of CODAS positioning in the family and how this influences their roles and responsibilities.	(birth-12 years) School Age (6-12 years) Adolescence (13-17 years) 16 CODAS and 16 hearing children of hearing parents – with a range of SES, country of origin, age, gender, and level of education	Mixed methods questionnaire and a structured interview with 16 1st-born hearing CYP (aged 9–15 years) of deaf parents and 16 1st-born matched hearing CYP of hearing parents investigate the issues of feelings toward parents' communication with parents, interpreting, and role reversal.	Generalisability – includes both CODA and hearing children with hearing parents – a comparative study	The two groups had no significant differences in feelings, communication, and role-reversal scales. A significant difference was found between groups on the interpreting scale and in the responses to interview situations. Ss' ages and the degree to which the parents relied on them to interpret appeared to strongly influence the Ss' feelings toward parents, communication with parents and views on role reversal. Older children of deaf children were more likely to have negative feelings toward interpreting than were younger Ss, although most Ss identified positive and negative results of interpreting.
3. The experience of Cypriot hearing adults with deaf parents in family, school, and society **(Hadjikakou et al., 2009)** **APA PsycInfo** **Cyprus**	This paper investigates hearing adults' experiences with signing deaf parents in their families, schools, and society. This paper aimed to explore, for the first time in Cyprus, the personal descriptions of memories and experiences of adult-hearing people with Deaf parents in family, school, and society.	18-29 years The thirties (30-39 years) (Different age, occupation, sex, and educational background) Cyprus only	Mixed methods in-depth semi-structured interviews were conducted with 10 Cypriot CODAs between the ages of 21 and 30 years with different occupations, sex, and educational background.	Limitation: In this retrospective study, participants were asked to recount stories of their childhood regarding their communication experiences. Even though this retelling may involve certain risks (e.g., restructuring memory), several researchers have employed similar methods. Lack of generalisability	It was found that most participants developed a bicultural identity undertook the role of interpreter and protector in their family and interacted well with their parents despite the lack of in-depth communication they noted. The positive role of the extended family was acknowledged. The prejudices of Cypriot hearing people against the deaf people were identified, as well as the lack of state support toward the deaf community.
4. Physiologically, I'm hearing, but psychologically, I am	This study aimed to explore CODAs experiences of	Respondents consisted of two males and eight females between the ages of 21 and 40.	A phenomenological qualitative research design.	Limitation: In South Africa, the Deaf community is	Most CODAs affiliate with both cultures and prefer the deaf community. They attributed their preference for the deaf community to a

deaf. Identity: lived experiences of hearing children born in families with deafness in South Africa (Moroe, 2019b) **APA PsycInfo South Africa**	belonging and affiliation within the deaf and hearing community	who were recruited through purposive and snowball sampling. Six were white, and four were black.	The participants completed semi-structured interviews using open-ended questions on their experiences of belonging and affiliation within the deaf culture. Thematic analysis of the data revealed two broad themes: (i) being torn between two worlds and (ii) stigma and feelings of embarrassment	small. As a result, this study had a small sample of hearing children of Deaf parents in Gauteng. Consequently, the findings cannot be seen to be representative of all hearing children born to Deaf parents. And across provinces.	sense of family and deaf language learning. Their sense of embarrassment appeared to be from the stigma attached to having deaf parents as well as using sign language in public. Programs for promoting biculturalism of CODAs may enhance their self-acceptance and identity development. In conclusion, this study highlighted the difficulties faced by CODAs in terms of identity formation and affiliation with both cultures.
5. Survey of hearing children with deaf parents regarding their role as sociolinguistic agents (Wood, 2016) **APA PsycInfo** **USA**	This qualitative phenomenological study explored the research question: What is the lived experience of CODAs who acted as language and cultural conduits for their parents during their formative years?	12 participants 18 years & older – women and men Both parents are deaf Part of Deaf culture	Qualitative: Open-ended questions stimulated self-directed responses to interviewees' perceptions of desirable and challenging experiences.	Limitations: This study examined recollected experiences and perceptions specifically for indicators of the subject's perceived impact on their development resulting from serving as cultural and linguistic brokers for their parents. Qualitative research enabled acknowledging complexity, uncertainty, and vitality in human singularities.	Composite themes included: being CODA is a privilege; parental interpreting expectations/preferences were influenced by era, sibling chronology, gender, personality, fluency, and technology; language brokering dynamics beyond the child's level of comfort or understanding; transient resistance to signing during one's tween/teen years; influence on one's parenting style; personal identity development within the deaf and Hearing cultural milieu; pride and appreciation for their parents' achievements; and overt certainty that personal career choices directly stemmed from being a Coda. A complete 100% of participants indicated that, while growing up, Coda significantly influenced personality traits and personal development, contributing to who they are today.
6. Exploring emotion development of hearing children with deaf parents: a qualitative study	This research explored the emotional development of hearing individuals with deaf parents	Ten hearing individuals with deaf parents between the ages of 13 and 39	Qualitative: The ten participants were interviewed to learn about emotion regulation, attachment and interactions	Limitation: room for interpretation	Seven significant themes and twelve minor themes emerged from the data. The major themes included Self-confidence, a High Level of Responsibility as a child, and Positives and Negatives About Being. A CODA, Permissive parenting style and

(Schleif, 2006) **APA PsycInfo** **USA**			with parents and social interactions. Interviews were analysed according to Maykut & Morehouse's (1994) constant comparative method.		Getting My Way, Games or Camping with Family, Needs Met Outside of parents Emotional Unavailability.
7. Views from the borderline: extracts from my Life as a coloured child of deaf adults, growing up in apartheid South Africa (Harrison & Watermeyer, 2019) **Scopus** **South Africa**	This study used auto-ethnography to explore the socialisation of a female-coloured CODA during the height of South Africa's apartheid era to shed light on intersectional influences on identity and selfhood.	This article accounts for part of the life experiences of a female-hearing child born and raised by her Deaf parents in apartheid South Africa in the 1980s. Objectives: This study used auto-ethnography to explore the socialisation of a female-coloured CODA during the height of South Africa's apartheid era to shed light on intersectional influences on identity and selfhood.	Methods: auto-ethnography under a qualitative research paradigm. A self-reflexive analysis – thoughts, observations and reflections are represented in the first person.	Strengths: An intersectional representation of CODA experiences. Limitations: difficulty in checking validity.	A thematic analysis approach was used to analyse data, and the themes that emerged are (1) CODAs as language brokers, (2) being bilingual and trilingual, (3) being bicultural, (4) role reversal and parentification and (5) issues of identity. Discussing these themes is interwoven with the literature to provide a rich and robust analysis that contributes to the body of knowledge.
8. Hearing children of deaf parents: gender and birth order in the delegation of the interpreter role in culturally deaf families (Moroe & Andrade, 2018) **Scopus** **South Africa**	Objective: This study sought to investigate the roles of children of Deaf adults (CODAs) as interpreters in Deaf-parented families, specifically, the influence of gender and birth order in language brokering.	Method: Two male and eight female participants between the ages of 21 and 40 were recruited through purposive and snowball sampling strategies.	A qualitative design was employed, and data were collected using a semi-structured, open-ended interview format.	Strengths: contributes to a diverse range of voices in the CODA community. Limitations: A recollection of events might be distorted, and it might be an interpretation of what the participants think they remember.	Results: The findings indicated that there was no formal assignment of the interpreter role; however, female children tended to assume the role of interpreter more often than male children. Also, it appeared that the older children shifted the responsibility for interpreting to younger siblings. The participants in this study indicated that they interpreted situations where they felt they were not developmentally or emotionally ready or in cases where they thought they were better suited for older siblings or siblings of another gender.
9. We were our parents' ears and mouths reflecting on the	To reflect on the childhood experiences of language brokering	Methods. Two male and eight female participants (21-40 years), identified through purposive and snowball	A phenomenological, qualitative approach was employed using semi-	Strengths: it gives an insight into CODA experiences and	The findings indicate that the interviewed CODAs acted as language brokers and interpreters between their families and the hearing community from a young age. As

language-brokering experience of hearing children born to deaf parents (Moroe & Andrade, 2018) **Scopus** **South Africa**	in deaf-parented families.	sampling, participated in this study.	structured, open-ended interviews.	reinforces previous findings. Limitations: it did not account for CODAs' race or socioeconomic status.	children, they were placed in demanding situations for which they were not developmentally ready. CODAs found balancing the demands of both communities emotionally draining, especially at a young age. Conclusion: A multidisciplinary approach is suggested to address young CODAs' mental health, well-being, and development.

5 papers from CODA UK & Ireland and citations

Study title, Author(s), Year, Source origin and country of origin	Research purpose/ aims	Context and Participants sample and characteristics	Design and methodology	Strengths and limitations	Main findings and conclusions/recommendations
1. Mother, father deaf: living between sound and silence (Preston, 1995a) **CODA UK & Ireland** **USA – 24 states**	This book focuses on the cultural identity and affiliation of CODAs. It gives the reader a better understanding of CODA's living experience between sound and silence.	150 (men and women) 141 participants whose parents were deaf, and 9 had one parent who was deaf. 18-79 years old from diverse geographic, educational and family backgrounds 43 were part / associated with a CODA organisation. The majority were European whites, with	One-to-one semi-structured interviews and life histories narrative approach	Limitation: lack of rigour in terms of the data analysis – subjective. Strength: large population – generalisability	Many quotes were used as part of the narrative approach – it takes the reader on a journey of identity and development/ experiences attached. Although there were some shared experiences, they were also unique to the individual and family. The informants are a debate between two competing worldviews. Among characteristics and values frequently dichotomized as either Deaf or Hearing, CODAs have dual, often polarized interpretations of the meaning of deafness.

		decreasing numbers of African Americans, Hispanics, Asians and Native Americans.			
2. The conflictual experiences of hearing African American children of deaf parents (Hale, 2001) **The Union Institute** **USA**	This study aimed to answer the question, "What conflicts do hearing African American children of deaf parents experience between childhood and adulthood?" phenomenological research,	Five hearing African American children of deaf parents – co-researchers	Participatory research Interviews using open-ended questions. Phenomenological method	Strengths: autonomy – empowerment Limitations: adult's experiences – reflecting on CODA upbringing	Some commonalities throughout the research study were the barrier of communication and the burdensome responsibility often placed on them as children, resulting in rebellious behaviour.
3. Hearing children of deaf parents–a new social work client group? (Klimentová at al., 2017) **European Journal of Social Work,** **Czech Republic, Vala skom i sko and Olo- moucko.**	The goal was to determine the personal experience of the respondents with the attributed social role of the native interpreters in sign language during their childhood. They were exploring hearing children of deaf experiences of their position as a native interpreter.	Ten women and four men were between 18 and 41 years old.	The instruments were semi-structured interviews using open-ended questions. Longitudinal: over a year The 'snowball' method for recruitment was used.	Strengths: practical tips for deaf parents of hearing children Direct quotes from participants There are Implications for social workers. Limitation: snowball: lack of control and representation	The empirical research resulted in some fascinating issues, for example, how an inappropriate form of the burden placed on a child's shoulders by the parents and formal institutions can relate to the state of the parent's education. The themes are illustrated below. They were interpreting for parents in situations where children were too young and lacked the required life experience. There is a lack of social support for children as a mediator between deaf parents and the hearing world. The lack of a sense of security and support from parents A feeling of loss of a piece of childhood – premature adulthood A childhood spent in a cohesive community of deaf people. The life of a hearing child of deaf parents entails the need for the child to learn how to live in a bilingual and often bicultural world.
4. Social identity in hearing youth who	This research study aims to describe the perspectives of young	The researcher recruited 11 participants who were	This qualitative study used semi-structured,	Strengths: implications for practice	The researcher found major themes in three components of Tajfel's social identity theory.

have deaf parents: A qualitative study (Knight, 2013) **Lamar University-Beaumont** **USA**	children of deaf adults regarding their linguistic and cultural identity. This research study used the phenomenological qualitative research method to conclude the social identity of Kodas by having their "voice" heard and documented in this dissertation.	Kodas themselves, aged 11 to 17 years old. Koda interviewed codas (almost participatory) The researcher trained three Coda young adults (aged 18 to 20 years) who interviewed the 11-17-year-old codas.	open-ended interviews to capture the Koda participants' viewpoints and how they formed their Koda social identity. Purposeful and snowball sampling methods were used to recruit eleven Kodas to participate in the study.	Limitation: One fundamental limitation of this study was the researcher's bias towards the Kodas since the researcher is Deaf and a mother of four Kodas. Another limitation is the requirement of parental consent to allow Kodas to participate. This may influence the self-selection of interested participants.	Cognitive Component of Social Identification Evaluative component of social self-identification The emotional part of social identification Overall, participants in the current study have a positive social identity as a Koda. More in-depth studies are needed about KODA camps describing how and in what ways they successfully assist the young Koda in their identity as a member of both worlds: hearing and Deaf.
5. The identity development of the only hearing child in an all-deaf family **(Frank, 2019)** **USA**	To fill the gap in the literature regarding CODA research: None of the limited literature on hearing children of deaf parents It focuses on the experiences of hearing children who grow up as the only hearing person in their families. according to the participants, deaf parents, mental health and school professionals did not appreciate the unique needs of Hearing children from all-deaf families. They also stated that neither parents Nor did professionals recognise that this group had special needs.	All participants grew up in the Deaf culture and used ASL. They ranged in age from eighteen to forty and came from eight states. Snowball sampling	In a hermeneutic phenomenological study, the author conducted face-to-face interviews using open-ended questions. 1. How do individuals who are the only hearing members of all-deaf Families describe their experiences. 2. How did growing up in an all-deaf family affect hearing individuals' identity	Strength: diverse location Filled a gap in the literature. Recommendations and actions are available to professionals working with CODAs. Limitations: snowball sampling – lack of control and representation?	1. Recognizing distinctions from the rest of the family{n=10) 2. Identity (w=13) 3. Being Responsible or Protective{n=8) 4. Interpreting for the Family{n=10) 5. No Distinctions («=7) 6. Lack of Interpreters{n=10) Conclusion: Obstacles within systems and with parents can be avoided if schools and agencies are aware of how much Obstacles affect hearing children. In this study, the findings were that schools And agencies might not know how to work effectively with deaf parents, Given that interpreters were typically not provided.

Appendix F

The Thematic Synthesis

Title of Research	Descriptive Themes and Description (Thomas & Harden, 2008)	Analytical Themes Considering the Research Systematic Literature Review Question: 'What is known about the experiences of CODAs?'	Self-reflexivity (Burnham, 2018; Sandeen et al., 2018)
1. The mother and father deaf: living between Sound and silence (Preston, 1995b)	Many quotes were used as part of the narrative approach – it takes the reader on a journey of identity and development/ experiences attached. Although there were some shared experiences, they were also unique to the individual and family. The informants are a debate between two competing worldviews. Among characteristics and values frequently dichotomized as either Deaf or Hearing, CODAs have dual, often polarized interpretations of the meaning of deafness. • Hearing world • Deaf world • CODA world The informants are a debate between two competing worldviews. Among characteristics and values frequently dichotomized as either Deaf or Hearing, CODAs have dual, often polarized interpretations of the meaning of deafness.	• Bicultural identity – a lot of CODAs expressed feeling part of the hearing and deaf. • Protection – CODAs spoke of caring for their parents and protecting them from harmful comments. • High level of responsibility – systemic support – interpreting for their parents daily- more than a language – culture to mediate between and interpret too.	150 different accounts of CODA experience. This highlighted many blind spots as CODAs shared views and attitudes that I had never considered, based on my own GODA experience and hearing my mother's CODA experience. For example, a CODA views themselves as deaf until the age of 18, before leaving home. Thus, being so immersed in deaf culture and proud, despite your hearing side.
2. The conflictual experiences of hearing African American children of deaf parents (Hale, 2001)	First organised in 17 descriptive nouns: for example, burden, viewpoint, culturally sensitive, learning, responsibilities, dependency, wisdom, support, expectation, rejection, role, control, mission, disadvantage rebellion, secret Synthesis: the six themes were revealed based on the co-researchers' lived experiences: -position: within the family – depending on their birth order – also took on the role of interpreter, liaison, educator,	• Bilingual identity is linked with birth order and gender. • Bicultural identity – linked with shame and embarrassment. • High level of responsibility: burdensome because there was no social support.	I understand the 'position' theme that illustrates that birth order will determine your level of involvement with supporting deaf parents. As the second oldest and female, I would often adopt the role of interpreting for my grandparents. This is the same for my auntie, the second eldest in the family, who has taken on supporting her deaf parents. Due to this high level of responsibility, she often reflects on the lack of

	adapter, and supporter, as they fluctuate between the deaf and hearing world. Identity: the identity of self and identity of culture – living between silence and sound – two cultures – hearing and deaf culture conflicting with the coda culture. Relationships: difficulties in relationships and overwhelming responsibilities secrets: kept hidden from others, based on shame and embarrassment: Coda had to fight once word got around school that the co-researcher had a deaf parent. Rebellion: the feeling of anger - a communication barrier and the burdensome responsibility placed on children resulting in rebellious behaviour. Examples of coding are below: The communication barrier is the primary conflict that supports various incidences of isolation, rebellion, and role reversal. CODA is often excused from school or restricted from play to negotiate with bill collectors or social support systems.	• Protection: fight for their CODA identity.	family and LA support and seems to rebel against the system. Reflecting on my GODA and my mum's CODA identities, I recognise that we wouldn't want our additional roles or differences to be deemed harmful. Therefore, I have used roles and responsibilities as the theme to summarise the interpreter role. Shame and Paranoia evoke sadness; I recall feeling the same with my deaf and non-verbal grandparents in hearing communities. The feeling of others looking at and judging our differences as a family 'elephant in the room'.
3. Hearing children of deaf parents–a new social work client group? (Klimentová et al., 2017)	The overall arching theme was Parentification/Roles and Responsibilities: five subthemes related to this. They were interpreting for parents in situations where children were too young and lacked the required life experience. Respondents agreed in all cases that they interpreted for their deaf parents, from television to doctor and court appointments, approximately when they were five or six. Lack of social support: for CODA in the position of a mediator between deaf parents and the hearing world. No professional or external help – especially when it comes to interpreting. A feeling of isolation and loneliness. The lack of a sense of security and support from parents. A feeling of insufficient support from their parents during childhood (homework, reading, parent meetings). A feeling of loss of a piece of childhood – premature adulthood. They had to grow up hastily and lost part of their carefree childhood and adolescence. Lack of hearing experience/culture: A childhood spent in a cohesive community of deaf people. Discontent in the family was mentioned, where parents favoured deaf friends over their hearing children:	• Bilingual identity: interpreting. • Bicultural identity • High level of responsibility – systemic support – additional role of caring for siblings and managing house chores.	Negative approach/interpretation. Based on my mother's narrative of being CODA, I could relate to some of the points—primarily the high responsibility, a feeling of loneliness/ lack of support and loss of childhood. I recall feeling somewhat anxious when alone with my deaf grandparents as I knew they could support me and a hearing person if I felt ill or was in danger due to our communication barrier and accessibility to a phone.

4. Social identity in hearing youth who have deaf parents: A qualitative study. Lamar University-Beaumont (Knight, 2013)	The researcher found major themes in three components of Tajfel's social identity theory. Cognitive Component of Social Identification: Kodas expressed they adopted many social norms of the Deaf community, such as using a loud voice, eye contact, facial expressions, hugging, and, in the case of three participants, functioning as interpreters for their Deaf parents. Kodas used to sign or sign with a voice in their home environment with their Deaf parents. Evaluative component of social self-identification: appreciation to their Deaf parents, feelings of belonging, confidence, responsibility, sensitivity, and a sense of freedom, as well as bilingualism and biculturalism. Kodas expressed similarities with other Kodas, such as having similar identities and experiences, being loud, relating to other Koda, feeling intensely connected with other Kodas, and bicultural. The emotional component of social identification: Kodas were pessimistic about hearing people. Kodas avoided expressing their Koda identity announcements in school. They noted they sometimes felt awkward in public. "There are others like me," and they were able to share experiences. They indicated the Koda camp was a great place to find their identity and Koda support to boost their self-esteem and kindred spirit.	• Bicultural identity – them and us mentality. • Protection- harmful comments.	Positive experience from connecting with others like you. This evokes sadness, as my mother never knew any codas, so I wanted to do this research and raise awareness for others like her. I also want to immerse myself within the Coda culture to solidify my identity as a GODA and give back/ make Papie proud of me.
5. The identity development of the only hearing child in an all-deaf family (Frank, 2019)	1. Recognizing distinctions from the rest of the family{n=10): not being aware that you're hearing until you go to school. You realise another part of your identity later (around age 4/5), initially struggling with speech and social skills with other hearing pupils – previous experience based on deaf social interactions. 2. Identity (w=13): finding your identity and relating to hearing, deaf, coda or bicultural. 3. Being Responsible or Protective{n=8): being the ears for your family and the need to protect them from hostility from the hearing community. 4. Interpreting for the Family{n=10): most CODAs detested this obligation to interpret for their family. This was based	• Bilingual identity • Bicultural identity • High level of responsibility – systemic support: linked with no interpreters and no distinction. • Protection	Fax: I recall using this to speak with my grandparents in France. Auntie dedicated her life to her parents – to interpret for them, protect them and give them the best life possible. I often felt guilty for not learning French sign language to a standard where I could not have entire conversations or interpret them in all contexts. My mother shared the lack of support available to her and her siblings when growing up. I had to count on myself.

	on demographics, SES, educational backgrounds and lack of technology. 5. No Distinctions («=7): parents expected their coda children to be okay and not need guidance and supervision. High pressure – you're hearing you can do anything. They were linked to survivor guilt. 6. Lack of Interpreters{n=10): lack of cultural and technological awareness despite the advent of communication technologies and telecommunications		
6. Genetic selection for deafness: the views of hearing children of deaf adults (Mand et al., 2009)	(1) a negative experience either (a) because of identity confusion or (b) because of the increased responsibility of acting as an interpreter for parents, with an associated loss of childhood. (2) A positive experience: the sense of pride: a very positive reward as being empowered to access things, which usually others would never see as fun. (3) mixed feelings surrounding personal experience: joyous childhood and adolescence had left them ill-prepared for adulthood. I struggle as an adult trying to fit in within both worlds. I don't feel like I ever quite fit in in either world. It's challenging, and I try too hard to ''fit in''. (4) a neutral experience: We felt that we were completely normal and that having deaf parents was not a big deal. It freaks hearing people out more than it is.	• Roles and responsibilities: linked to negative and positive experiences. • Bicultural identity: fitting into both worlds – linked with mixed experience.	This reminds me of Lewin's equation B = (p + e), as depending on this, it will be how you interpret having deaf parents. Intersectionality also helps me reflect on the different interpretations of codas. I recognise that my mother's CODA experience would align with mixed feelings; however, at the time, it was a negative experience' because of feelings of shame, loneliness, and high responsibility. I often reflect on how this might influence my role as a research facilitator, which is why I decided to conduct participatory research.
7. Perceptions of the oldest hearing child of deaf parents: on interpreting, communication, feelings, and role reversal (Buchino, 1993)	The theme was based on feelings, communication, and role-reversal scales – related to birth order. A significant difference was found between groups on the interpreting scale and in the responses to interview situations. Ss' ages and the degree to which the **parents** relied on them to interpret appeared to strongly influence the Ss' feelings toward **parents**, communication with **parents** and **views** on role reversal. Mixed feelings: Older **children** of **deaf parents** were more likely to have negative feelings toward interpreting than younger children, although most Ss identified positive and negative results from another lysis.	• Bilingual identity: related to birth order and gender-linked with a degree of responsibility and burden.	This aligns well with my mother's, auntie's, and uncle's experiences and perceptions: my auntie, the eldest female, has taken on most of the responsibilities. However, she shows no bitterness or resentment.

8. The experience of Cypriot hearing adults with deaf parents in family, school and society (Hadjikakou et al,. 2009)	Family experiences: communication- extended family - protection had to protect their parents from hearing people’s comments, looks, and other challenging conditions. -leaving home (guilt)- interpreting -interactions school experience: parent's communication with school – homework – teachers – friendships – hearing parents Deaf world: identity – Cypriot sign language – deaf community – deaf vs the hearing world society: hearing people’s attitudes – state roles and responsibilities -	• Bicultural identity – linked with interactions - • High level of responsibility – systemic support: linked Most participants referred to the vital role of some extended family members to succeed later in life – as there was a lack of systemic/professional support. • Protection- linked to family experiences. Survivor guilt: linked with leaving home	Feelings of leaving Mamie and Papie (French deaf and non-verbal grandparents) alone after long summers of supporting them. Mothers shared experiences of no one showing up to parent meetings at school as they hadn’t been informed or did not have an interpreter. The school communicates with her hearing auntie instead, and messages are lost.
9. Physiologically, I’m hearing, but psychologically, I am deaf. Identity: lived experiences of hearing children born in families with deafness in South Africa (Moroe, 2019)	Theme 1. Torn between two worlds- I live in two worlds. The hearing world and the Deaf world. Some things are the norm in a Deaf world, which are not- “I am half hearing and half Deaf. That is my identity.” Theme 2. Stigma and embarrassment: being stigmatised by the hearing community for being from a Deaf community and the shame of using a manual language.	• Bicultural identity- living between two worlds. • Roles and responsibilities • Protection- around hearing people’s stigmas	I identify as hearing and have never thought about placing as GODA until now. Although immersed in the deaf and CODA culture, I always separated myself from that. I hope this research might somewhat change this and reinforce my GODA identity.
10. Survey of hearing children with deaf parents regarding their role as sociolinguistic agents (Wood, 2016)	Composite themes included: being a Child of Deaf Adults (Coda) is a privilege; parental interpreting expectations/preferences were influenced by era, sibling chronology, gender, personality, fluency, and technology. Language brokering dynamics beyond the child’s level of comfort or understanding; transient resistance to signing during one’s tween/teen years; influence on one’s parenting style; personal identity development within the Deaf and Hearing cultural milieu; pride and appreciation for their parents’ achievements; and overt certainty that personal career choices directly stemmed from being a CODA.	• Bicultural identity • Bilingual identity: linked to choices around interpreting- based on gender and birth order - language brokering. • Protection	Feelings of frustration that CODAs still must interpret for their parents in situations beyond their understanding – relate to times when I stayed with my deaf and non-verbal grandparents as a child and had to interpret for them when we were stopped by the police for having a broken car headlight. Soft spot: Personal identity development: I only realised that I was. GODA, aged 27. Before that, I was just a child with grandparents who were deaf and non-verbal; however, knowing that there is a term/label and a whole community with similar lived experiences is invigorating.

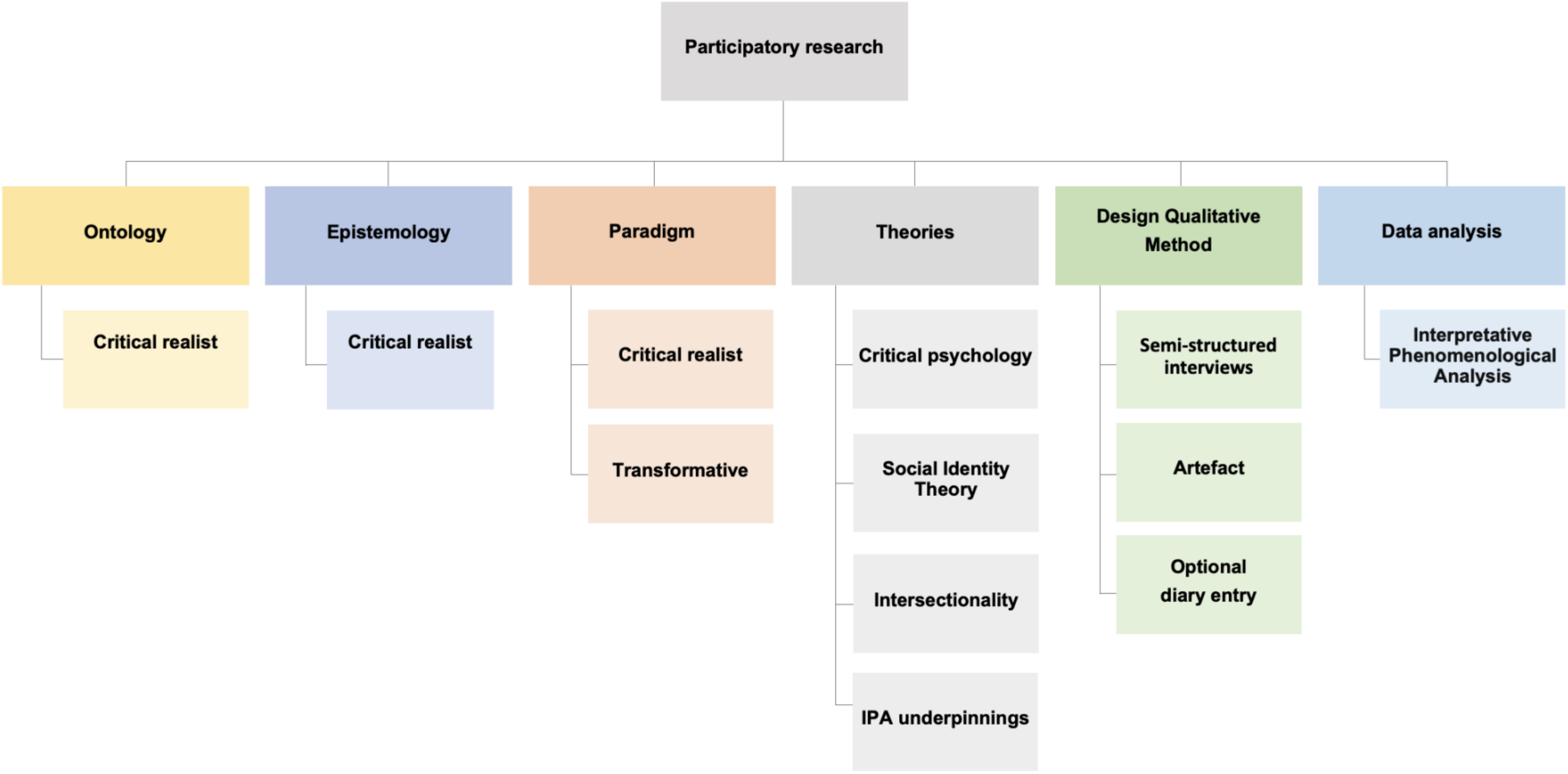
11. Exploring emotion development of hearing children with deaf parents: a qualitative study (Schleif, 2006)	Seven significant themes and twelve minor themes emerged from the data. The major themes include Self-confidence, a High Level of Responsibility as a **Child**, Positives and Negatives About Being a CODA, Permissive **Parenting** Style and Getting My Way, Games or Camping with Family, Needs Met Outside of **Parents**, **Parent** Emotional Unavailability	- High level of responsibility – systemic support	Soft spot: **Parent's** Emotional Unavailability – my mother would often share stories of where her parents were unable to support her emotionally. Permissive parenting style is not a theme I can relate to; thus, it is a blind spot. I grew up in a Christian household, where there were many rules to follow and a strong emphasis on right and wrong, not always getting my way – it was the same for my mother, CODA.
12. Views from the borderline: Extracts from my life as a coloured child of Deaf adults growing up in apartheid South Africa. African Journal of Disability (Harrison and Watermeyer, 2019)	(1) CODAs as language brokers: I was assuming the very familiar role of an interpreter and language broker, bridging a linguistic and cultural divide between the Deaf and hearing worlds, a position that I have played since my early childhood. Preston's analysis of gendered roles in CODAs identified that it is most often the eldest female child who takes on the role and responsibility of family interpreter. (2) being bilingual and trilingual: Hearing children born to Deaf parents are considered bilingual and bicultural, as they potentially share the language and culture of their Deaf parents—difficulties with speech and pronunciation. (3) being bicultural: 'bicultural' positioning as a CODA, I have had to recognise that I am not Deaf, but I am also not hearing. Awareness of coda identity might happen in later adulthood once you've met with other codas – bringing about a sense of belonging. 4) role reversal and parentification: CODA must accompany their parents wherever they go – therefore, living through them is opposed to their life/finding who they are. (5) issues of identity. Being exposed to the politics and practices of both worlds. I often say, 'Mother, father Deaf, me hearing' to gain acceptance.	- Roles and responsibilities- linked to CODAs as language brokers. - Bicultural identity is linked to issues of identity. - Protection: linked with being bicultural. - Survivor guilt – linked to issues with identity.	Soft spot: I know how they feel; while growing up, others referred to my grandparents as 'deaf and dumb' and would give them horrible stares as if they were 'alien'; therefore, I understand the need to protect the deaf community. I also understand my white privilege and did not have to protect my grandparents from racist comments.
13. Hearing children of deaf parents: gender and birth order in the	Results: The findings indicated that there was no formal assignment of the interpreter role; however, female children tended to assume the role of interpreter more	- Roles and responsibilities: linked with the birth order and gender subthemes.	The female role is to take the lead in supporting parents. This relates to my and my auntie's reality (the eldest female CODA). However, she did not

delegation of the interpreter role in culturally deaf families (Moroe and Andrade,2018a)	often than male children. Also, it appeared that the older children shifted the responsibility for interpreting to younger siblings. The participants in this study indicated that they solved situations where they felt they were not developmentally or emotionally ready or in cases where they thought they were better suited for older siblings or siblings of another gender. Role of interpreter Subtheme: Birth order older children shifted the responsibility of interpreting to the younger siblings as they moved home, therefore passing the commitment to the younger children. However, other participants indicated that the older children passed that responsibility on to younger ones, regardless of whether the older siblings lived in the house. The younger children had to engage in difficult conversations. Subtheme: Gender: female children tended to assume the role of interpreter more than the male children in their families. Her brother did not interpret for the family and, more specifically, it seemed to her that he was embarrassed about having Deaf parents: female participants felt that because the female CODAs often assume the interpreting role, they found themselves having to discuss topics which they, as females, found difficult to interpret with their fathers.	• High level of responsibility – systemic support	shift the responsibility onto my mother (younger sibling) but embraced it. Feelings: unfair and inequitable.
14. We were our parents' ears and mouths reflecting on the language-brokering experience of hearing children born to deaf parents (Moroe and Andrade, 2018b)	The findings indicate that the interviewed CODAs acted as language brokers and interpreters between their families and the hearing community from a young age. As children, they were placed in demanding situations for which they were not developmentally ready. CODAs found balancing the demands of both communities emotionally draining, especially at a young age. Experiences of frustration due to language brokering: CYP felt psychosocially and emotionally unprepared but also was unfamiliar with the sensitive, adult vocabulary used. Role reversal and protection: CYP felt they were taking on their parents' duties. Participants reported that they had the	• Roles and responsibilities • Protection • High level of responsibility – systemic support	Parentification and role reversal are heavy topics and somewhat controversial. They appear negative; however, it depends on the person's perspective and characteristics. For example, my CODA auntie embraced her 'mother' role, caring for her younger siblings (my mother and uncle) and deaf parents. Thus, I was conscious of this not blurring my vision when reading stories of CODAs that weren't so eager to adopt these roles.

	challenging and taxing responsibility of protecting their parents from insensitive comments from the hearing community. Parents had no choice but to rely on their children as language brokers. CYP need to be shielded from situations that are not psychosocially and emotionally appropriate, and the responsibilities placed on hearing CODAs must be reduced. Preparation for adulthood: interpreting responsibilities taught them to be responsible and independent from a young age. Findings have suggested that CODAs and language brokers generally have increased confidence, independence, and maturity, among other qualities.		

Appendix G

Research Overview



Appendix H

Key for the Descriptors for the Participatory Model

Stages of the Research Process	**Description**
Design	Regarding the development of the research question, aims and method used.
Collect	Regarding data collection and participant voice.
Data Analysis Choice	Regarding the choice and type of data analysis used (Interpretative Phenomenological Analysis).
Analysis	Regarding the completion of the data analysis- Interpretative Phenomenological Analysis: steps 1-6.
Disseminate	Regarding the telling and showing of the research findings.
Partner	Regarding the relationship between co-researchers and individual contribution to the research.
Level of Participation	**Description**
EMANCIPATION: social change and transformation	• This is co-researcher/participant led. • A bottom-up approach and emancipatory methods are used. The community most concerned leads the research and the voices of co-researchers/participants are prioritised.
INCLUSION: active participant as actor	• More equal roles and relationships between the RF and co-researcher/participant.

	• There are social change outcomes. However, the voice of the co-researcher/participants is not always prioritised.
RECOGNITION: active - participant as subject	• Researcher-led but recognition of co-researcher/participants as individuals. • Social change outcomes are not based on consultation with participants. • Information is obtained from the community most concerned.
TOKENISTIC: passive - Participant as an object	• Researcher-led • Limited opportunities for social change, and information is provided to the co-researcher/participant.

Appendix I

Recruitment Advertisement

CALLING CHILDREN OF DEAF ADULTS (CODAs) FOR RESEARCH

Who am I ?

My name is Naomi Milliken, and I'm a Trainee Educational Psychologist at the University of East London. As a grandchild of deaf adults (GODA), I have always been interested in my mother's CODA identity. This has strongly influenced my doctoral thesis.

Research title: A participatory research approach to explore the experiences of CODAs

What is participatory research?

Participatory research aims to empower young people by inviting them to become actively involved in the research.

This means that you will be one of six co-researchers, and you will be invited to decide on the research design, data collection, data analysis and dissemination of the research. Naomi will take the role of the research facilitator and support you throughout.

Are you eligible?

- You must be aged between 15 years - 25 years
- You must be a hearing CODA, with one or more parent/carer who is deaf
- You must also be willing to participate in doctoral level research and share your story.
- You must consider that this will take up to 15 hours (over several months and dates and times will be collaboratively decided).

What are your next steps?

If you are interested, please email me using the email address below.

- Recruitment will be on a first-come-first-served basis
- You will be invited to a virtual Question and Answer session
- If you are below the age of 16, you will need to be accompanied by a parent/carer

email: u2190383@uel.ac.uk

Appendix J

University East London Ethical Approval

School of Psychology Ethics Committee

NOTICE OF ETHICS REVIEW DECISION LETTER

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

Reviewer: Please complete sections in **blue** | **Student:** Please complete/read sections in **orange**

Details

Reviewer:	**Deborah Lee**
Supervisor:	**Janet Rowley**
Student:	**Naomi Milliken**
Course:	**Professional Doctorate in Child & Educational Psychology**
Title of proposed study:	A participatory research approach to explore the experiences of Children of Deaf Adults (CODAs)

Checklist

(Optional)

	YES	NO	N/A
Concerns regarding study aims (e.g., ethically/morally questionable, unsuitable topic area for level of study, etc.)	☐	☐	☐
Detailed account of participants, including inclusion and exclusion criteria	☐	☐	☐
Concerns regarding participants/target sample	☐	☐	☐
Detailed account of recruitment strategy	☐	☐	☐
Concerns regarding recruitment strategy	☐	☐	☐

All relevant study materials attached (e.g., freely available questionnaires, interview schedules, tests, etc.)	☐	☐	☐
Study materials (e.g., questionnaires, tests, etc.) are appropriate for target sample	☐	☐	☐
Clear and detailed outline of data collection	☐	☐	☐
Data collection appropriate for target sample	☐	☐	☐
If deception being used, rationale provided, and appropriate steps followed to communicate study aims at a later point	☐	☐	☐
If data collection is not anonymous, appropriate steps taken at later stages to ensure participant anonymity (e.g., data analysis, dissemination, etc.) – anonymisation, pseudonymisation	☐	☐	☐
Concerns regarding data storage (e.g., location, type of data, etc.)	☐	☐	☐
Concerns regarding data sharing (e.g., who will have access and how)	☐	☐	☐
Concerns regarding data retention (e.g., unspecified length of time, unclear why data will be retained/who will have access/where stored)	☐	☐	☐
If required, General Risk Assessment form attached	☐	☐	☐
Any physical/psychological risks/burdens to participants have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
Any physical/psychological risks to the researcher have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
If required, Country-Specific Risk Assessment form attached	☐	☐	☐
If required, a DBS or equivalent certificate number/information provided	☐	☐	☐
If required, permissions from recruiting organisations attached (e.g., school, charity organisation, etc.)	☐	☐	☐
All relevant information included in the participant information sheet (PIS)	☐	☐	☐
Information in the PIS is study specific	☐	☐	☐
Language used in the PIS is appropriate for the target audience	☐	☐	☐
All issues specific to the study are covered in the consent form	☐	☐	☐
Language used in the consent form is appropriate for the target audience	☐	☐	☐
All necessary information included in the participant debrief sheet	☐	☐	☐
Language used in the debrief sheet is appropriate for the target audience	☐	☐	☐
Study advertisement included	☐	☐	☐
Content of study advertisement is appropriate (e.g., researcher's personal contact details are not shared, appropriate language/visual material used, etc.)	☐	☐	☐

Decision options

APPROVED	Ethics approval for the above-named research study has been granted from the date of approval (see end of this notice), to the date it is submitted for assessment.
APPROVED - BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES	In this circumstance, the student must confirm with their supervisor that all minor amendments have been made **before** the research commences. Students are to do this by filling in the confirmation box at the end of this form once all amendments have been attended to and emailing a copy of this decision notice to the supervisor. The supervisor will then forward the student's confirmation to the School for its records. **Minor amendments guidance:** typically involve clarifying/amending information presented to participants (e.g., in the PIS, instructions), further detailing of how data will be securely handled/stored, and/or ensuring consistency in information presented across materials.
NOT APPROVED - MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED	In this circumstance, a revised ethics application **must** be submitted and approved **before** any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application. **Major amendments guidance:** typically insufficient information has been provided, insufficient consideration given to several key aspects, there are serious concerns regarding any aspect of the project, and/or serious concerns in the candidate's ability to ethically, safely and sensitively execute the study.

Decision on the above-named proposed research study

Please indicate the decision:	**APPROVED - MINOR AMENDMENTS ARE REQUIRED** **BEFORE THE RESEARCH COMMENCES**

Minor amendments

Please clearly detail the amendments the student is required to make

4.8 both yes and no are ticked – amend this to show which response is correct here

No: The pseudonymised data will not be made available for use in future research by other researchers.

5.2 says that you will 'ensure as much objectivity as possible' - yet 'objectivity', which often appears as a requirement of 'good research', is not possible from anyone – I'd suggest that what contributes to the work being ethical is being clear about insider status, being reflexive, one's decision-making being clear, so that readers can decide for themselves how far, if at all, they agree with us – this isn't an amendment as such, but something to consider as part of ongoing ethical explorations

The RF identifies as a grandchild of deaf adults (GODA) naturally, this comes with emotional attachment and assumptions. Therefore, it will be important for her to check in regularly with Dr Rowley (Director of studies) to reflect on any apparent blind, hot or soft spots that might be influencing the research. Ms Milliken will also keep a reflexive diary and will have access to therapeutic support from Mr Shrine and the UEL well-being team if needed.

P19 – I wasn't clear, in a 20 hour commitment project, over a stretch of time, what withdrawing after data collection means in relation to use of your material – does it mean if you leave after 10 hours you've already contributed to data collection and so cannot withdraw your data, even though you can withdraw from the final 10 hours of the project? I thought this needs to be clearer. People are usually given a space of time in which they can reflect on if they want their data to be part of a project at all. I wondered if a space after each of the events needed to be in

place – there could be circumstances where a participant shares something that impacts them emotionally and they don't want that as part of a project, but having said it, it seems, it's too late, and all they can do now is withdraw entirely. This may be a misreading of mine, but if it is not, it is something to consider carefully before proceeding.

Co-researcher Information sheet

Can I change my mind?
Yes, you can change your mind at any time and withdraw without explanation, disadvantage, or consequence. However, please note that if you wish to withdraw after the data collection, you will need to let Ms Milliken know before the data analysis session. There will be a minimum of 2 days between data collection and the data analysis session to allow for reflection. Post data analysis workshop you can still choose to withdraw however, your pseudonymised data will be used towards the analysis and findings. All identifiable data will be pseudonymised.

Parent Information sheet
Can your child change their mind?
Yes, they can change their minds at any time and withdraw without explanation, disadvantage, or consequence. However, please note that if they wish to withdraw after the data collection, they will need to let Ms Milliken know before the data analysis session. There will be a minimum of 2 days between data collection and the data analysis session to allow for reflection. Post data analysis workshop you they can still choose to withdraw however, their pseudonymised data will be used towards the analysis and findings. All identifiable data will be pseudonymised.

CHANGES FROM 13.04.2023
3.5: **Participants:**
Include all relevant information including inclusion and exclusion criteria.
This research hopes to recruit six co-researchers aged 15-25 years old.
Inclusion:

- They should have one or more parent / carer who is deaf.
- The CODAs co-researchers can entail those who sign and those who don't sign.
- The CODA must be hearing.

Exclusion: non-CODA, that is, this research will exclude young people who do not have one or more deaf parent or carer.

The RF has decided to change the age of her co-researchers because most of the interest has come from CODA's aged 22 and above. Considering that EP work with children and young people aged 0-25, it still fits the EP role and implications.

3.7: **Measures, materials or equipment:**
Provide detailed information, e.g., for measures, include scoring instructions, psychometric properties, if freely available, permissions required, etc.

The RF has also adjusted the time needed from co-researchers. This has been changed from 20 hours to a maximum of 15hours. From meeting with protentional co-researchers, 15 hours seemed more pragmatic to ensure commitment and support their wellbeing.

In total, with the four workshops, one data collection day (1 hour), data analysis (6 hours – across two days) and dissemination, the co-researchers will be required to take part over 15 hours in total This will be over a few months and the dates/times will be decided collaboratively by the co-researchers and RF. This will be clearly advertised on the recruitment advert and the information sheet.

Major amendments

Please clearly detail the amendments the student is required to make

Assessment of risk to researcher

Has an adequate risk assessment been offered in the application form?	**YES** ☒	**NO** ☐
	If no, please request resubmission with an **adequate risk assessment.**	

If the proposed research could expose the researcher to any kind of emotional, physical or health and safety hazard, please rate the degree of risk:		
HIGH	Please **do not approve a high-risk** application. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not be approved on this basis. If unsure, please refer to the Chair of Ethics.	☐
MEDIUM	Approve but include appropriate recommendations in the below box.	☒
LOW	Approve and if necessary, include any recommendations in the below box.	☐
Reviewer recommendations in relation to risk (if any):	**Considered carefully – only reservation is about withdrawal times for the co-researchers**	

Reviewer's signature

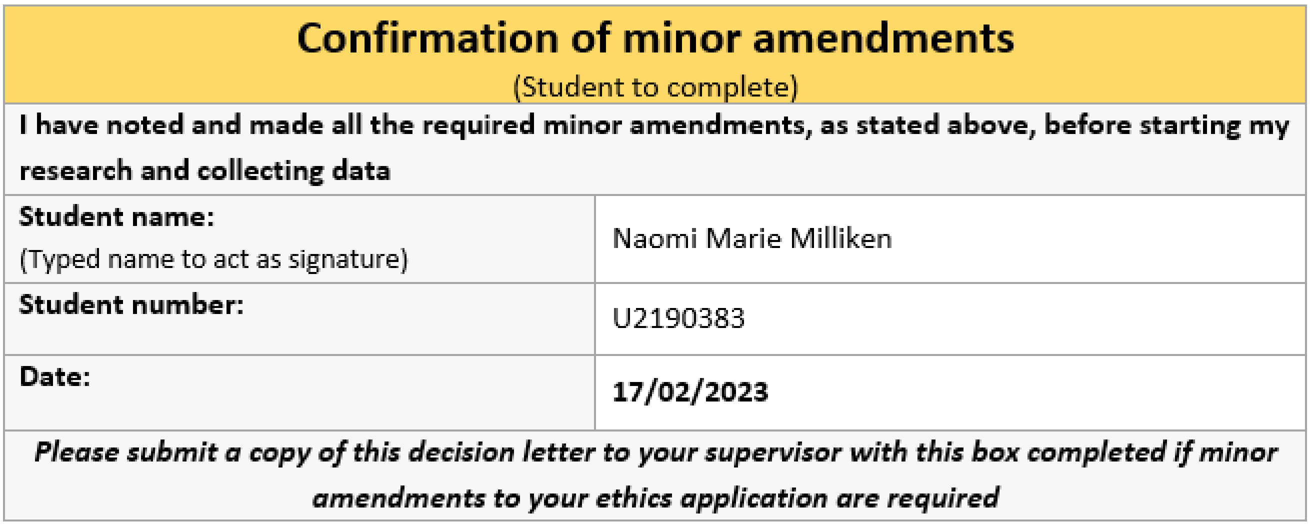
Reviewer: (Typed name to act as signature)	**DA Lee**

Date:	**12/02/2023**
This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Ethics Committee	

RESEARCHER PLEASE NOTE

For the researcher and participants involved in the above-named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UEL's Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard.



Confirmation of minor amendments

(Student to complete)

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data	
Student name: (Typed name to act as signature)	Naomi Marie Milliken
Student number:	U2190383
Date:	**17/02/2023**
Please submit a copy of this decision letter to your supervisor with this box completed if minor amendments to your ethics application are required	

Appendix K

CODA UK & Ireland Organisation Ethical Statement

Date: 9th October 2022
Organisation: CODA UK & Ireland CIC
Key Contact: Matthew Shrine (Welfare Director)
Email: Matt@codaukireland.co.uk
Business address: Lytchett House, 13 Freeland Park, Wareham Road, Poole, Dorset, BH16 6FA
Correspondents address: 61 Hawne Lane, Halesowen Birmingham B633RW

To whom it may concern,

I am writing on behalf of CODA UK & Ireland CIC to confirm support for Naomi Marie Milliken's Doctorate in Child and Educational Psychology research proposal working title: A participatory research approach exploring the experiences of children of deaf adults (CODAs). As an organisation we have been in direct contact with Ms Milliken in discussing her proposed research project. We feel that her suggested research would greatly benefit both individual CODAs and the wider CODA community as a whole through raising awareness of the unique lived experiences and social barriers. We feel that it would be able to significantly contributing to the resource and information base in this area, which is currently incredibly lacking.

We will work with Ms Milliken to ensure that all participants are recruited ethically and consent is gained for participation. We see no reason why there would be any difficulties in recruitment of participants and have supported other successful research projects in this manner previously. We have access to a large organisation membership which consists of adult and child CODAs and their families, organisations and professionals. We deliver regular workshops, social events and an annual CODA camp. We are in regular contact with our membership through our existing networks: our newsletter, and social media accounts as well as our word-of-mouth network. We feel that there would be a wide variety of CODAs that would be keen to participate in the project.

We have agreed to support Ms Milliken throughout her research in any way that we can to ensure that the project is able to gain enough useful data to make the project a success. More specifically we will support her in being able to recruit participants from the CODA community, we will support the project with:

- Finding CODA individuals who are interested in forming a part of the participatory research team.
- Organising/hosting online and if necessary, face to face research groups with CODA children.
- Providing aftercare mental health support, facilitated by one of our board members who is himself a qualified counsellor (*see below for more information).
- We also have access to a room we can use in Birmingham city centre where it would be possible to host a face-to-face session with participants.
- We have a professional business account with Zoom which ensures encryption and provides video calls up to 150 participants, that Ms Milliken can use to conduct her research groups with the CODA children. This includes the option of using a number of features including: presentations, recording meetings (stored on secure cloud storage), chat function, etc. This will ensure that it is safe, secure and confidential.
- In addition to this we have a professional Otter.ai account (Otter.ai is an auto captions/transcription tool) that integrates with zoom video conferencing software. We can use this to create an auto transcript of any video calls to be used in the research project. It will do automatic transcript in real time and can also be used afterwards to transcribe any recordings either video or audio.
- Given the stated age group of potential participants we would be able to provide adult volunteers to be involved in any of the groups to ensure we are in line with required ratios of adults: children. All of our volunteers are vetted to ensure they are safe to work with children and hold Enhanced DBS certificates.
- Following completion of the research project we will support Ms Milliken will creating and distributing the findings and presentation from her research in BSL, either through a recorded video, or a live presentation session. To ensure that CODAs and Deaf people would be able to understand the research and engage with the results.

*One of our board members; Matthew Shrine is a fully qualified psychodynamic psychotherapist; holds a MA degree from the University of Leicester in Psychodynamic Psychotherapy, as well as a higher education diploma in: Solution Focused Brief Therapy. He has been working full time as a therapist for over 7 years, including working in private practice and as part of the NHS Improved Access to Psychological therapies (IAPT) service. He

Business Address: CODA UK & Ireland CIC, Lytchett House, 13 Freeland Park, Wareham Road, Poole, Dorset, BH16 6FA**Company reg:** 08284194
Website: www.CODAukireland.co.uk **Email:** info@codaukireland.co.uk

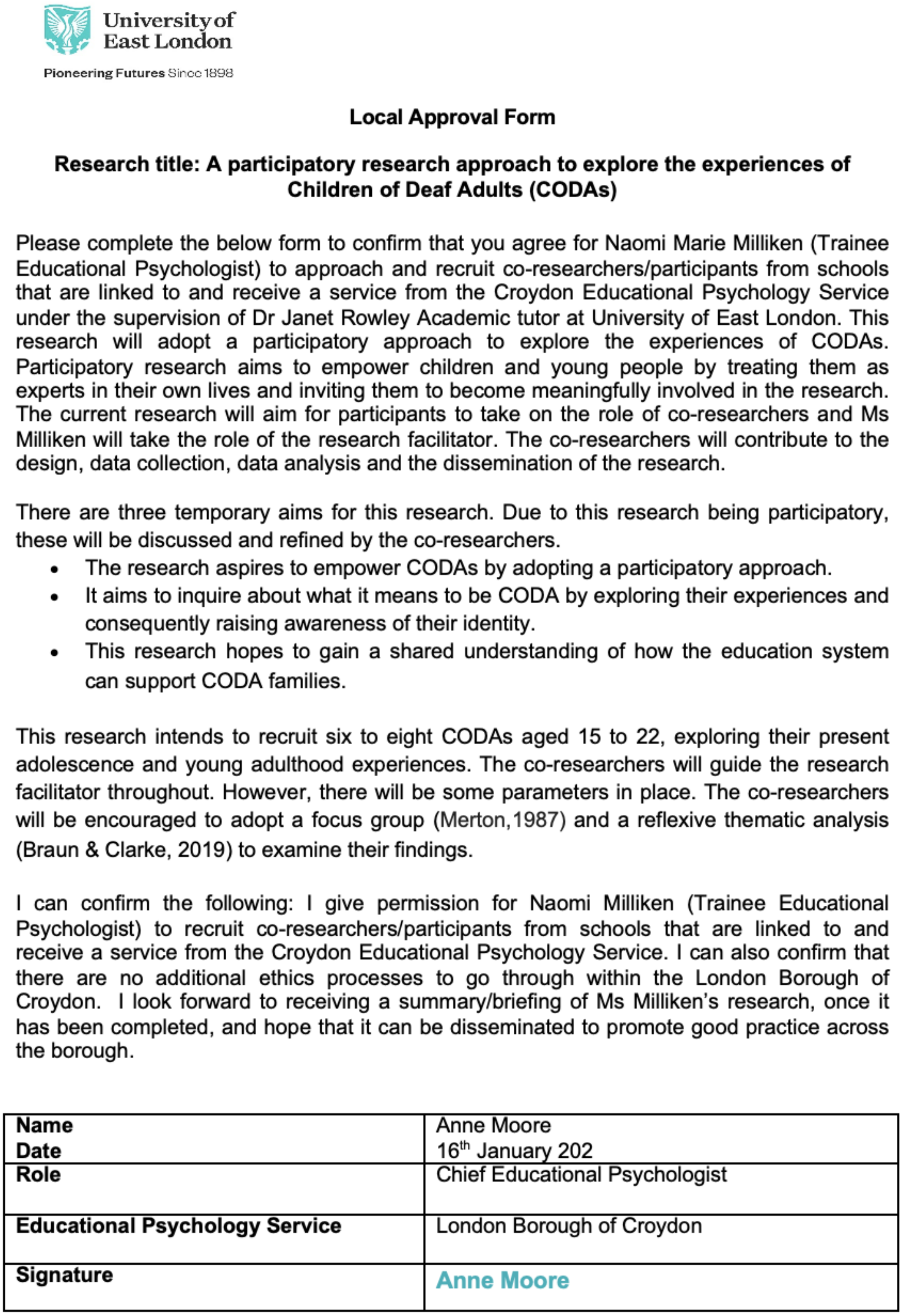
himself is a CODA, and has extensive experience of working with CODA clients (both adults & children), he runs a CODA specialist psychotherapy service in conjunction with Deaf4Deaf counselling service and delivers CPD training to other professionals around working with CODAs. He has also recently qualified as a supervisor; completing a higher education certificate through WPF Therapy. He is very supportive of the research and has offered to provide follow up sessions for any of the participants that want additional support.

If you require any further information or wish to speak to me regarding our organisation or the project, please do not hesitate to contact me.

Matthew Shrine
MBACP Psychodynamic Psychotherapist
(*Welfare Director) On behalf of the Board of Directors*

Appendix L

Local Authority Ethical Statement



University of East London
Pioneering Futures Since 1898

Local Approval Form

Research title: A participatory research approach to explore the experiences of Children of Deaf Adults (CODAs)

Please complete the below form to confirm that you agree for Naomi Marie Milliken (Trainee Educational Psychologist) to approach and recruit co-researchers/participants from schools that are linked to and receive a service from the Croydon Educational Psychology Service under the supervision of Dr Janet Rowley Academic tutor at University of East London. This research will adopt a participatory approach to explore the experiences of CODAs. Participatory research aims to empower children and young people by treating them as experts in their own lives and inviting them to become meaningfully involved in the research. The current research will aim for participants to take on the role of co-researchers and Ms Milliken will take the role of the research facilitator. The co-researchers will contribute to the design, data collection, data analysis and the dissemination of the research.

There are three temporary aims for this research. Due to this research being participatory, these will be discussed and refined by the co-researchers.

- The research aspires to empower CODAs by adopting a participatory approach.
- It aims to inquire about what it means to be CODA by exploring their experiences and consequently raising awareness of their identity.
- This research hopes to gain a shared understanding of how the education system can support CODA families.

This research intends to recruit six to eight CODAs aged 15 to 22, exploring their present adolescence and young adulthood experiences. The co-researchers will guide the research facilitator throughout. However, there will be some parameters in place. The co-researchers will be encouraged to adopt a focus group (Merton,1987) and a reflexive thematic analysis (Braun & Clarke, 2019) to examine their findings.

I can confirm the following: I give permission for Naomi Milliken (Trainee Educational Psychologist) to recruit co-researchers/participants from schools that are linked to and receive a service from the Croydon Educational Psychology Service. I can also confirm that there are no additional ethics processes to go through within the London Borough of Croydon. I look forward to receiving a summary/briefing of Ms Milliken's research, once it has been completed, and hope that it can be disseminated to promote good practice across the borough.

Name **Date**	Anne Moore 16th January 202
Role	Chief Educational Psychologist
Educational Psychology Service	London Borough of Croydon
Signature	Anne Moore

Appendix M

Final Ethical Amendment letter

School of Psychology Ethics Committee

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

For BSc, MSc/MA and 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 impact on ethical protocol. If you are not sure as to whether your proposed amendment warrants approval, consult your supervisor or contact Dr Trishna Patel (Chair of School Ethics Committee).

	How to complete and submit the request
1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	When submitting this request form, ensure that all necessary documents are attached (see below).
4	Using your UEL email address, email the completed request form along with associated documents to Dr Trishna Patel: t.patel@uel.ac.uk
5	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.
6	Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

Required documents	
A copy of your previously approved ethics application with proposed amendment(s) added with track changes.	**YES** ☒

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

Details	
Name of applicant:	NAOMI MARIE MILLIKEN
Programme of study:	Professional Doctorate in Child and Educational Psychology
Title of research:	A participatory research approach to explore the experiences of Children of Deaf Adults (CODAs)
Name of supervisor:	Dr Janet Rowley

Proposed amendment(s)

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

Proposed amendment	**Rationale**
3.7: materials and 3.8 data collection: I will create a feedback form. One based on the training experience and the other based on participatory research. This will be anonymous and used to reflect on in the discussion and the feedback forms will be added to the appendix.	3:7 and 3:8 – it is vital to ensure that the co-researchers have been given the opportunity to feedback on their experience of the training and the participatory research approach. This will act as evidence of how emancipatory the research was.
3.8: data collection: Artefact – regarding the co-researcher's mother's diary entry.	3.8: one of the co-researchers has asked whether she can use her mother's diary entry which entails her experience of being a deaf

	mother to a hearing child as her artefact. The co-researcher would talk about this in her semi-structured interview and a picture/photograph of the artefact would be used in the appendix – with the mother's consent and ethical consent. Therefore, the raw data will not be analysed, however the way in which the co-researcher chooses to talk about it will be analysed and kept anonymous throughout. If Signed consent is required, then Ms Milliken will share a form with the co-researcher and invite her mother to sign it.

Confirmation		
Is your supervisor aware of your proposed amendment(s) and have they agreed to these changes?	**YES** ☒	**NO** ☐

Student's signature	
Student: (Typed name to act as signature)	**NAOMI MARIE MILLIKEN**
Date:	**02/08/2023**

Reviewer's decision		
Amendment(s) approved:	**YES** ☒	**NO** ☐

Reviewer: (Typed name to act as signature)	**Miles Thomas**
Date:	**03/08/2023**

Appendix N

Information Sheet

Title: A participatory research approach to explore the experiences of Children of Deaf Adults (CODAs)

Research Question: What are Children of Deaf Adults' experiences of their identity?

Contact person: Naomi Marie Milliken
Email: u2190383@uel.ac.uk

You are invited to participate in a research study. Before you decide whether to take part or not, please carefully read through the following information which outlines what your participation would involve. Feel free to talk with others about this before making your decision. If anything is unclear or you have any questions, please do not hesitate to contact me, using the email above.

Who am I?

My name is Naomi Milliken. I am a postgraduate student in the School of Psychology at the University of East London (UEL) and am studying for a Professional Doctorate in Educational and Child Psychology. As part of my studies, I am conducting the research in which you are being invited to participate.

What is the purpose of the research?

This research will adopt a participatory approach to explore the experiences of hearing CODAs. Participatory research aims to empower children and young people by treating them as experts in their own lives and inviting them to become meaningfully and actively involved in the research. This means, that participants will also take on the role of co-researchers and Ms Milliken will take the role of the research facilitator.

What are the current aims of the research?

The current aims for this research will be discussed and refined by the co-researchers.

- **To empower CODAs by adopting a participatory approach in which they will be co-researchers.**
- **To explore CODAS' experiences of their identity.**
- **To explore with CODAs how the education system can support CODA families.**

Why have I been invited to take part?
As a Grandchild of deaf adults (GODA), I recognise that my journey comes with assumptions of the deaf and CODA community, and I anticipate that this research will reconsolidate my understanding and reinforce my GODA identity. Therefore, you have been invited to participate in this research, firstly because **you are a hearing CODA aged between 15 and 25 years old.** Secondly, you wish to take an active role in doctoral level research whilst also having the opportunity to share your story with others and be heard.

It is entirely up to you whether you take part or not, participation is voluntary and **please consider that this will take up to 15 hours of your free time.** This includes the four virtual workshops, the data collection day, the data analysis, and the celebration/ dissemination session.

What will I be asked to do if I agree to take part?
Firstly, you will be invited to a virtual Question and Answer Session (date and time will be confirmed via email). If you are <16 years old, you will need to attend with a parent/carer. There will be a BSL interpreter available.

Following on from the Question-and-Answer session, if you are still happy to take part, you will be one of six co-researchers and together you will contribute to the design, data collection, data analysis and dissemination of the research. This means you will discuss and refine the research title, question and aims. Following this, you will be invited to decide on a qualitative method, for example: interviews, open-ended surveys, artefacts, or focus groups, using open-ended questions. Finally, you will use a reflexive thematic analysis to find themes in your data.

Ms Milliken will be there to guide and support you as a co-researcher, she will facilitate virtual workshops that encourage learning, reflection, and discussion. The dates of these will be negotiated and agreed upon by you and the co-researchers.

Most of the research journey will happen virtually, however, you and the co-researchers will decide if the data collection day happens in person or online.

Can I change my mind?

Yes, you can change your mind at any time and withdraw without explanation, disadvantage, or consequence. However, please note that if you wish to withdraw after the data collection, you will need to let Ms Milliken know before the data analysis session. There will be a minimum of 2 days between data collection and the data analysis session to allow for reflection. Post data analysis workshop you can still choose to withdraw however, your pseudonymised data will be used towards the analysis and findings. All identifiable data will be pseudonymised.

Are there any disadvantages to taking part?

- I understand that sharing your CODA story, could be a vulnerable and exposing experience. However, there are highly thought-out measures in place, to ensure that you feel safe. For example, Ms Milliken will follow the General Data Protection Regulation (confidentiality) and the co-researchers will have access to additional mentoring, well-being, and therapy support.
- I hope that this research will be an enriching and valuable experience, in which you will learn new research skills and grow in self-confidence. However, I recognise that this will take up to 20 hours of time (over several months). Therefore, there is a risk of fatigue. Please be reassured that Ms Milliken will negotiate and come to an agreement for the dates and times, that suit you and all the co-researchers.
- If you and the co-researchers decide for the data collection day to happen in person, then travel and food expenses will be your responsibility. I understand that this could be a disadvantage for some.

How will the information I provide be kept secure and confidential?

- The co-researcher's consent forms will be securely stored and only Ms Milliken and Dr Rowley will have access to it.
- Ms Milliken will pseudonymise all identifiable information, for example, pseudo-names will be used for the co-researchers/participants.
- The co-researchers will not have access to the raw data. This will be deleted once pseudonymised.
- The co-researchers will use their encrypted shared Microsoft Teams channel/ SharePoint to communicate and share documents, such as the transcripts, workshops and excel spreadsheets.
- The Research Facilitator (Ms Milliken their supervisor (Dr Janet Rowley) and the co-researchers will have access to the pseudonymised data.
- Personal contact details will not be stored after the end of the project.
- Safeguarding: Confidentiality will only need to be broken in cases where we believe that there is a risk to yourself or others.

For the purposes of data protection, the University of East London is the Data Controller for the personal information processed as part of this research project. The University processes this information under the ‘public task’ condition contained in the General Data Protection Regulation (GDPR). Where the University processes particularly sensitive data (known as ‘special category data’ in the GDPR), it does so because the processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. For more information about how the University processes personal data please see www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection

What will happen to the results of the research?

The results of the research will be included in Ms Milliken's Thesis, Viva presentation and a poster for other students and staff at UEL. However, the co-researchers will decide on how else to disseminate their findings. For example, they may wish to create a video, in which British sign language is used to interpret their findings.

The research may also be used for publication later. In all material produced, your identity will remain pseudonymous, in that, it will not be possible to identify you personally. You will be given the option to receive a summary of the research findings once the study has been completed for which relevant contact details will need to be provided.

Pseudonymised research data will be securely stored by Dr Rowley (Ms Milliken's research supervisor) for a maximum of three years since completion to allow for dissemination activities (e.g., publication), following which all data will be deleted.

Who has reviewed the research?

The research has been approved by the School of Psychology Research Ethics Committee. This means that the Committee’s evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

Who can I contact if I have any questions/concerns?

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Naomi Milliken
u2190383@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor Dr Janet Rowley. School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: j.e.rowley@uel.ac.uk

or

Chair of School Research Ethics Committee: Dr Trishna Patel, School of Psychology,
University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

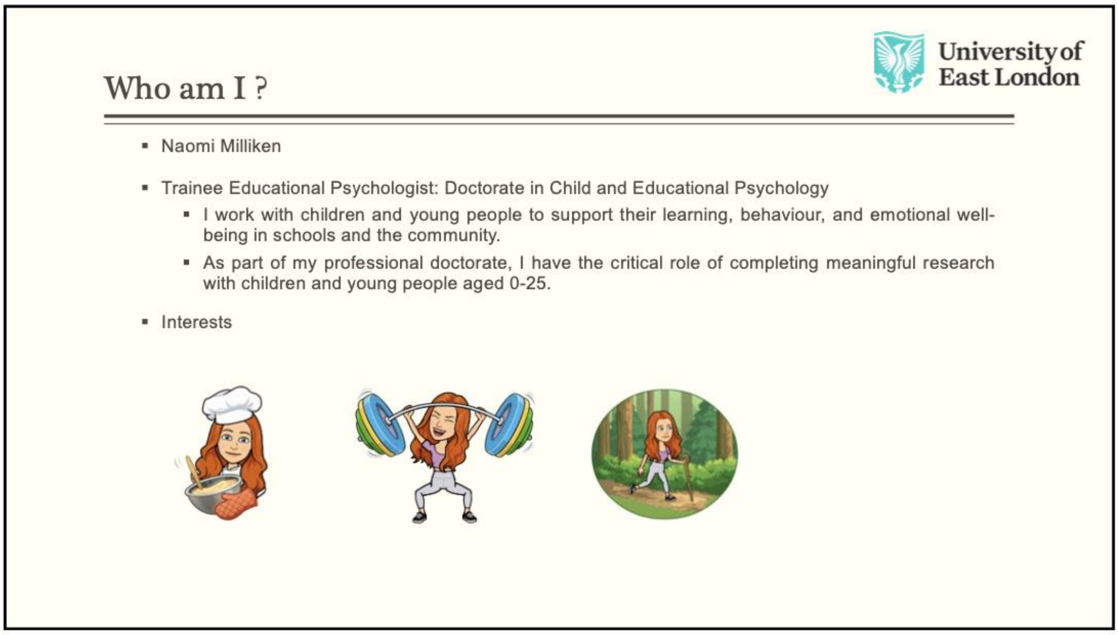
Thank you for taking the time to read this information sheet.

Appendix O

Extracts from the Question-and-Answer Session

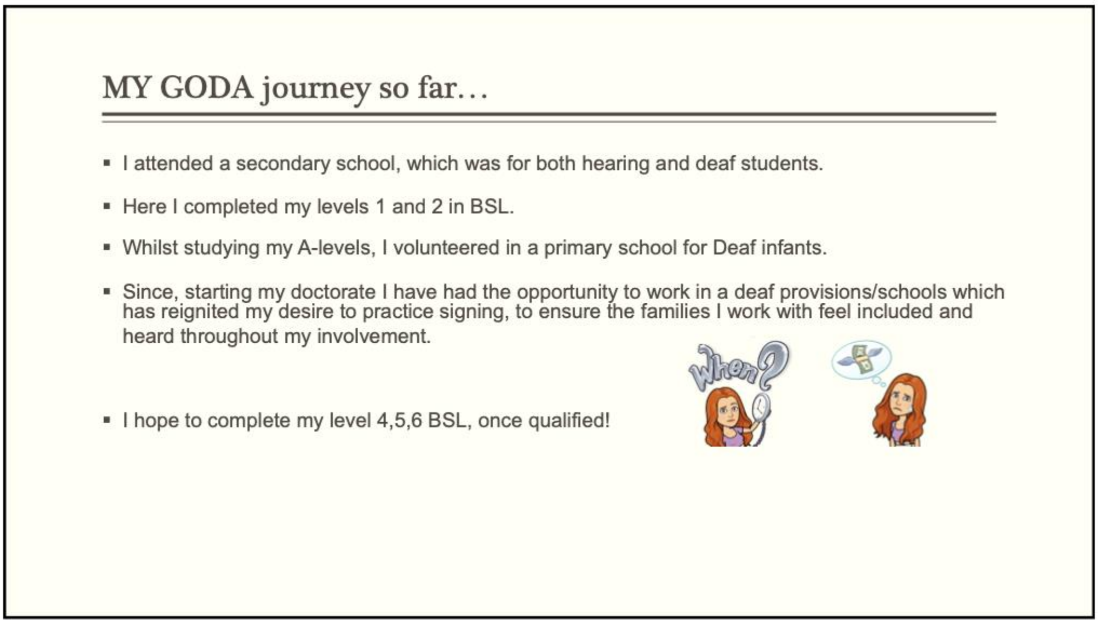
A PARTICIPATORY RESEARCH APPROACH TO EXPLORE THE EXPERIENCES OF CHILDREN OF DEAF ADULTS (CODAS)

Welcome to the Question & Answer Forum



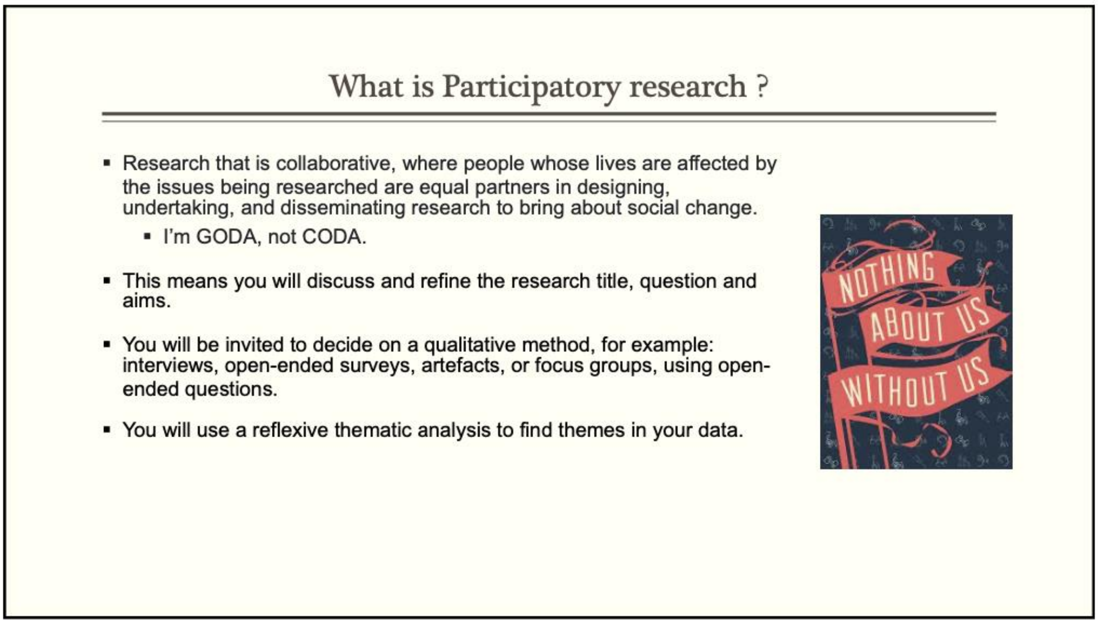
Who am I ?

- Naomi Milliken
- Trainee Educational Psychologist: Doctorate in Child and Educational Psychology
    - I work with children and young people to support their learning, behaviour, and emotional well-being in schools and the community.
    - As part of my professional doctorate, I have the critical role of completing meaningful research with children and young people aged 0-25.
- Interests



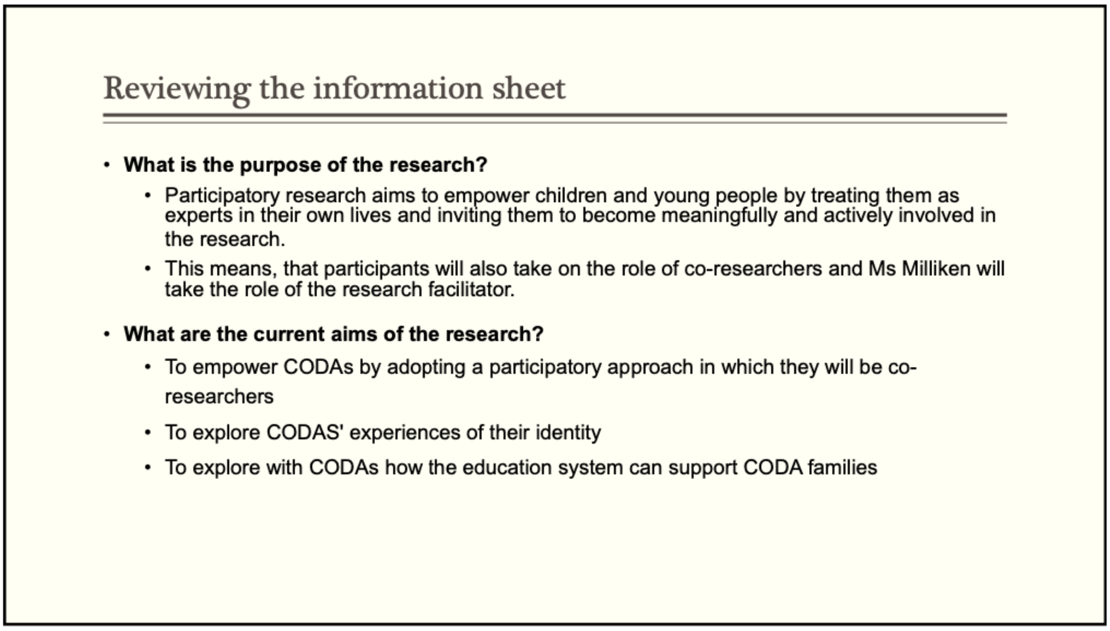
MY GODA journey so far…

- I attended a secondary school, which was for both hearing and deaf students.
- Here I completed my levels 1 and 2 in BSL.
- Whilst studying my A-levels, I volunteered in a primary school for Deaf infants.
- Since, starting my doctorate I have had the opportunity to work in a deaf provisions/schools which has reignited my desire to practice signing, to ensure the families I work with feel included and heard throughout my involvement.
- I hope to complete my level 4,5,6 BSL, once qualified!



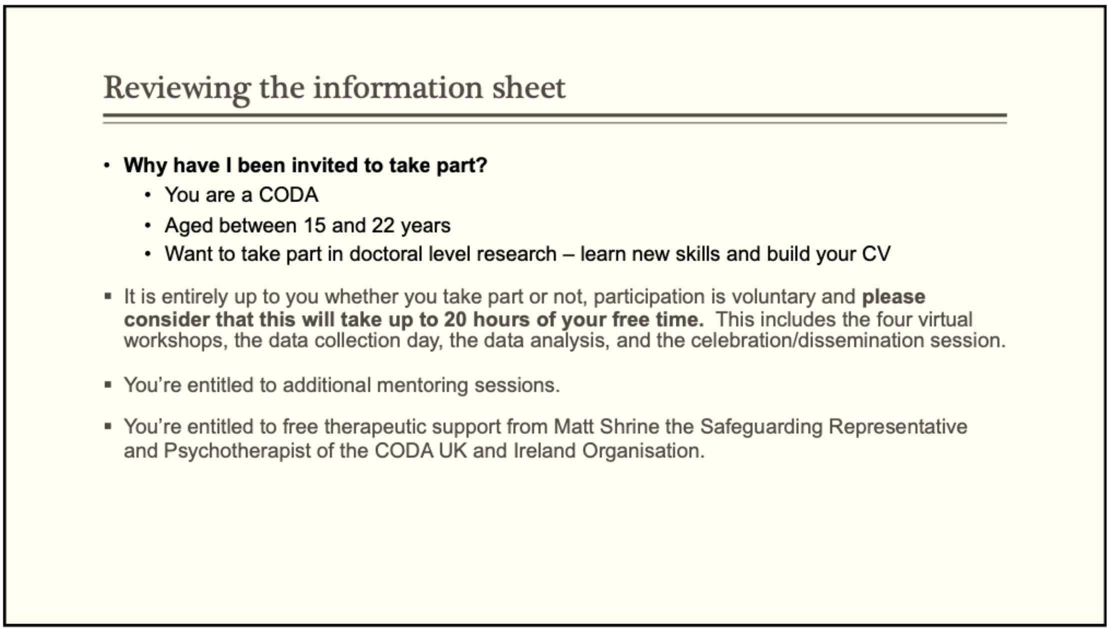
What is Participatory research ?

- Research that is collaborative, where people whose lives are affected by the issues being researched are equal partners in designing, undertaking, and disseminating research to bring about social change.
  - I'm GODA, not CODA.
- This means you will discuss and refine the research title, question and aims.
- You will be invited to decide on a qualitative method, for example: interviews, open-ended surveys, artefacts, or focus groups, using open-ended questions.
- You will use a reflexive thematic analysis to find themes in your data.



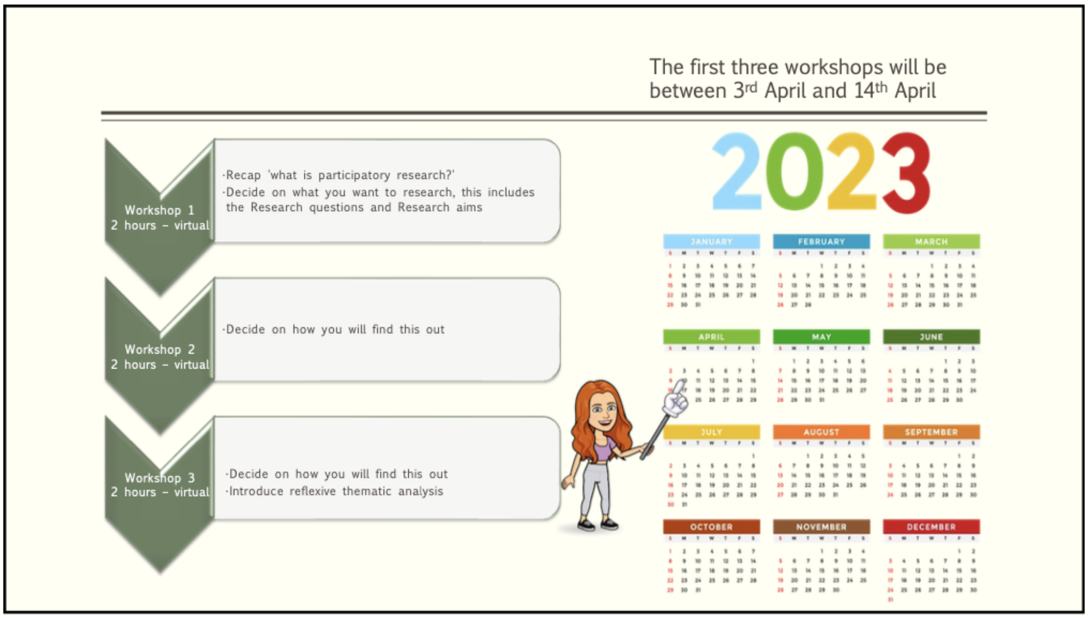
Reviewing the information sheet

- **What is the purpose of the research?**
  - Participatory research aims to empower children and young people by treating them as experts in their own lives and inviting them to become meaningfully and actively involved in the research.
  - This means, that participants will also take on the role of co-researchers and Ms Milliken will take the role of the research facilitator.
- **What are the current aims of the research?**
  - To empower CODAs by adopting a participatory approach in which they will be co-researchers
  - To explore CODAS' experiences of their identity
  - To explore with CODAs how the education system can support CODA families



Reviewing the information sheet

- **Why have I been invited to take part?**
  - You are a CODA
  - Aged between 15 and 22 years
  - Want to take part in doctoral level research – learn new skills and build your CV
- It is entirely up to you whether you take part or not, participation is voluntary and **please consider that this will take up to 20 hours of your free time.** This includes the four virtual workshops, the data collection day, the data analysis, and the celebration/dissemination session.
- You're entitled to additional mentoring sessions.
- You're entitled to free therapeutic support from Matt Shrine the Safeguarding Representative and Psychotherapist of the CODA UK and Ireland Organisation.



The first three workshops will be between 3rd April and 14th April

Workshop 1
2 hours – virtual

- Recap 'what is participatory research?'
- Decide on what you want to research, this includes the Research questions and Research aims

Workshop 2
2 hours – virtual

- Decide on how you will find this out

Workshop 3
2 hours – virtual

- Decide on how you will find this out
- Introduce reflexive thematic analysis

9

Appendix P

Research Timeline

June 2022-
December 2022

Preliminary work

December 2022-
April 2023

Ethics approved on 12.02.2023. A further four ethical amendments were approved.

March 2023-
April 2023

Recruitment

May 2023-
October 2023

First to final workshop, including data collection and analysis.

Appendix Q

Preliminary Work: CODA newsletter

Hello CODA UK and Ireland families,

My name is Naomi Milliken, and I'm a Trainee Educational Psychologist at the University of East London. I work with children and young people to support their learning, behaviour, and emotional well-being in schools and the community. As part of my professional doctorate, I have the critical role of completing meaningful research with children and young people aged 0-25.

As a GODA (grandchild of deaf parents), I have always been interested in my mother's CODA identity. We have spent many hours reflecting on the strengths and difficulties that she faced having parents who were both Deaf and non-verbal. My mother is incredibly proud of her CODA identity and tried her best to immerse my siblings and me in Deaf culture, for which I am very grateful. We attended a secondary school for Deaf and hearing students. Therefore, I had the privilege of completing levels 1 and 2 in BSL, which meant I could later volunteer in a primary school for Deaf infants.

France (2004): my auntie and I (aged 9) signing a Christmas song for my grandparents (French sign language).

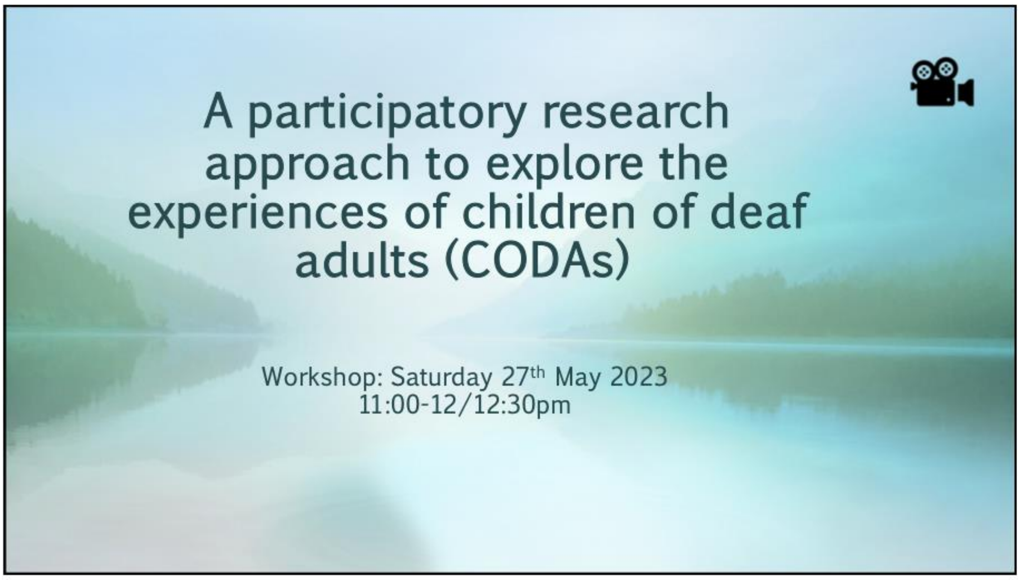
My identity and shared experiences have influenced my Doctoral research proposal in working with CODAs. I hope to take a participatory approach to empower children and young people by involving them in research decision-making. For example, I shall ask them, 'what do we want to find out? How do we want to find this out?'. I am in the early stages of the research process and have yet to receive ethical approval. However, I was eager to introduce myself, and hopefully, some of you will be keen to join me on my research journey.

If you are interested, please look out for the recruitment information sheets that I will share with you all in January / February 2023; however, if you have any questions before then, I would love to hear from you: u2190383@uel.ac.uk

I appreciate your time. Best wishes, Naomi Milliken

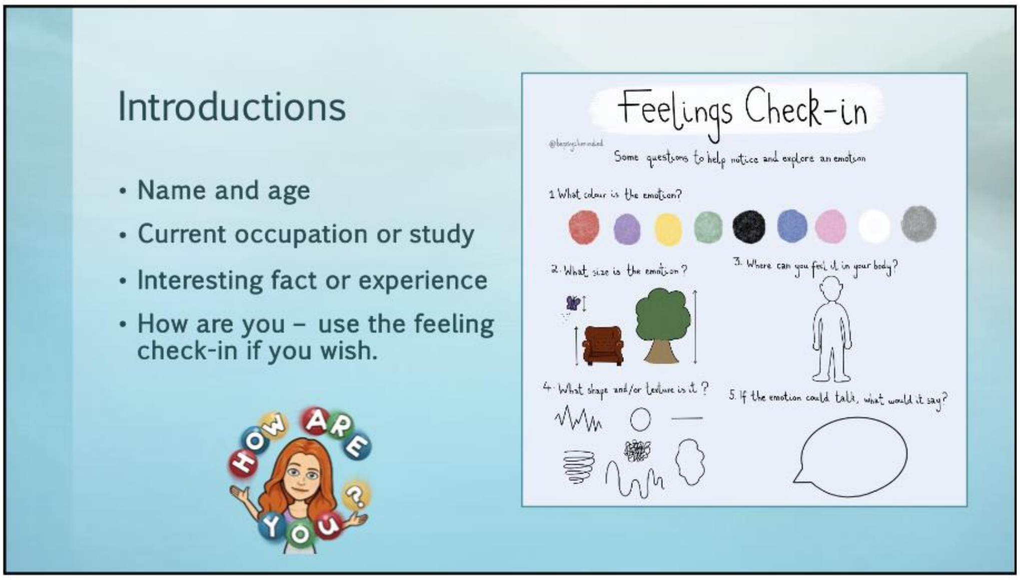
Appendix R

Extracts from the Virtual Workshops



A participatory research approach to explore the experiences of children of deaf adults (CODAs)

Workshop: Saturday 27th May 2023
11:00-12/12:30pm



Introductions

- Name and age
- Current occupation or study
- Interesting fact or experience
- How are you – use the feeling check-in if you wish.

Feelings Check-in

Some questions to help notice and explore an emotion

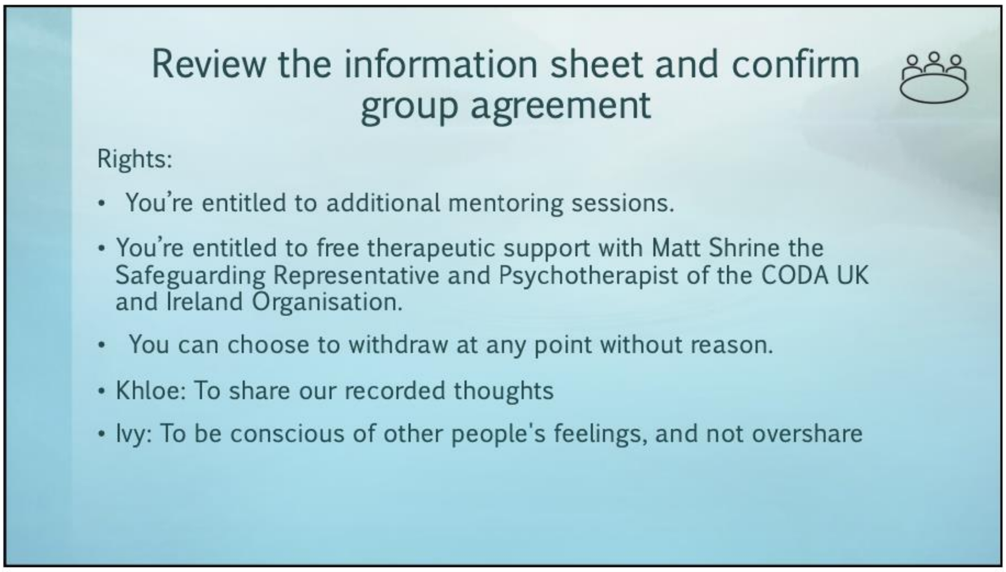
1. What colour is the emotion?

2. What size is the emotion?

3. Where can you feel it in your body?

4. What shape and/or texture is it?

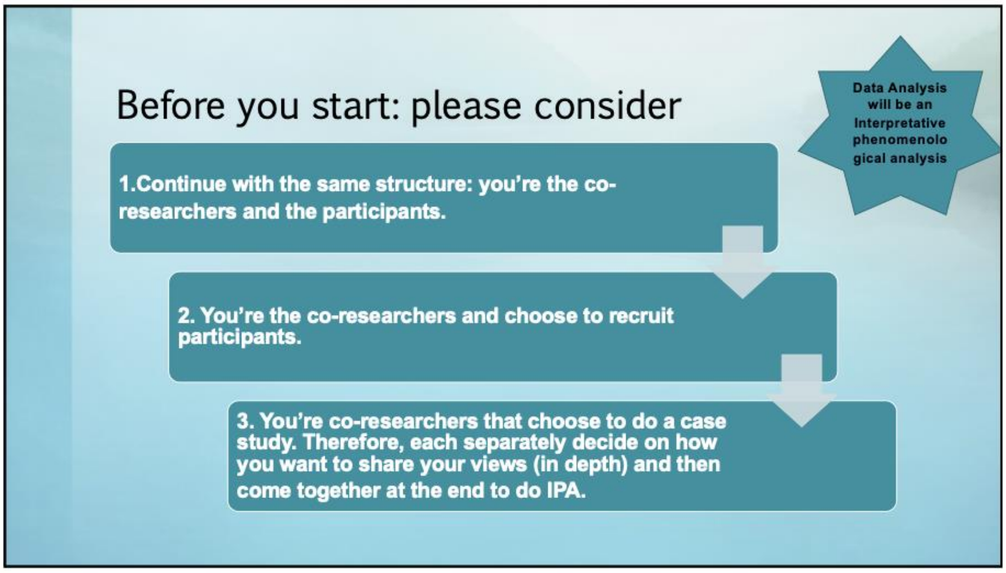
5. If the emotion could talk, what would it say?



Review the information sheet and confirm group agreement

Rights:

- You’re entitled to additional mentoring sessions.
- You’re entitled to free therapeutic support with Matt Shrine the Safeguarding Representative and Psychotherapist of the CODA UK and Ireland Organisation.
- You can choose to withdraw at any point without reason.
- Khloe: To share our recorded thoughts
- Ivy: To be conscious of other people's feelings, and not overshare



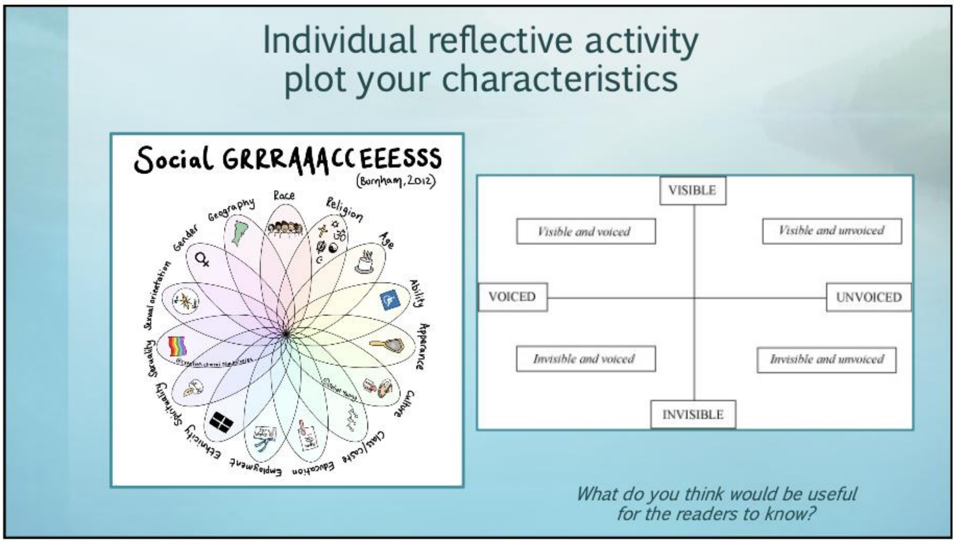
Before you start: please consider

1.Continue with the same structure: you’re the co-researchers and the participants.

2. You’re the co-researchers and choose to recruit participants.

3. You’re co-researchers that choose to do a case study. Therefore, each separately decide on how you want to share your views (in depth) and then come together at the end to do IPA.

Data Analysis will be an Interpretative phenomenological analysis



Individual reflective activity plot your characteristics

VISIBLE

Visible and voiced

Visible and unvoiced

VOICED

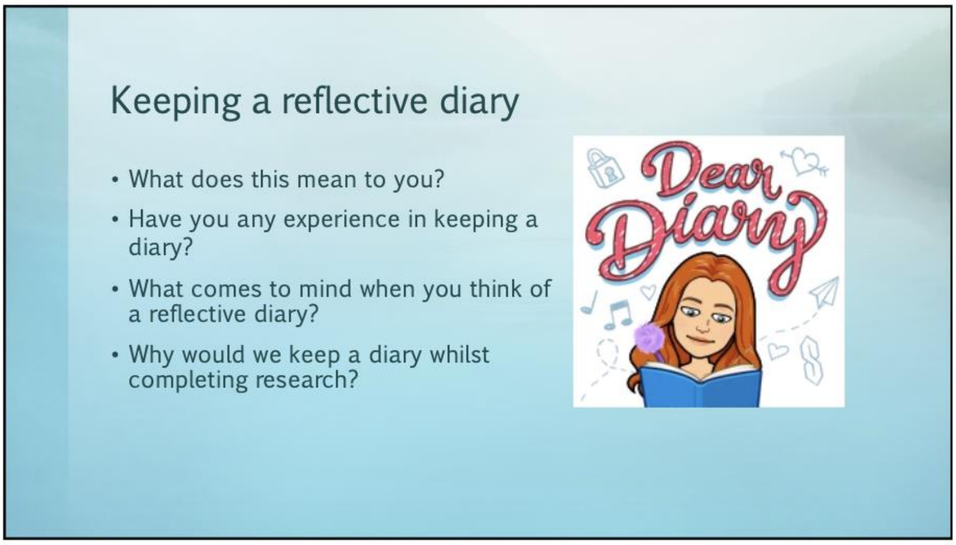
UNVOICED

Invisible and voiced

Invisible and unvoiced

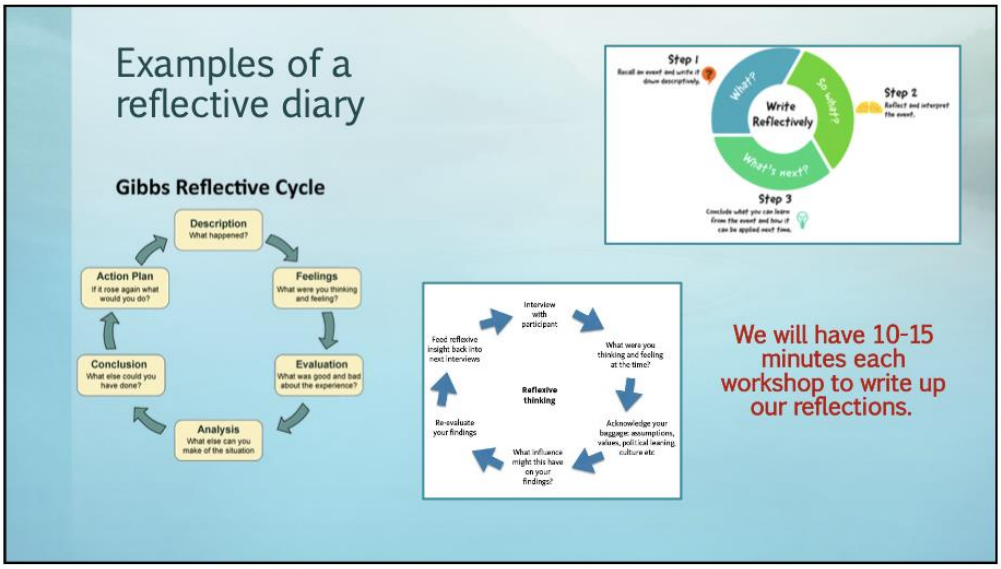
INVISIBLE

What do you think would be useful for the readers to know?



Keeping a reflective diary

- What does this mean to you?
- Have you any experience in keeping a diary?
- What comes to mind when you think of a reflective diary?
- Why would we keep a diary whilst completing research?



Examples of a reflective diary

Gibbs Reflective Cycle

Description
What happened?

Feelings
What were you thinking and feeling?

Evaluation
What was good and bad about the experience?

Analysis
What else can you make of the situation

Conclusion
What else could you have done?

Action Plan
If it rose again what would you do?

Write Reflectively

What?

So what?

What's next?

Step 1
Recall an event and write it down descriptively.

Step 2
Reflect and interpret the event.

Step 3
Conclude what you can learn from the event and how it can be applied next time.

Reflexive thinking

Interview with participant

What were you thinking and feeling at the time?

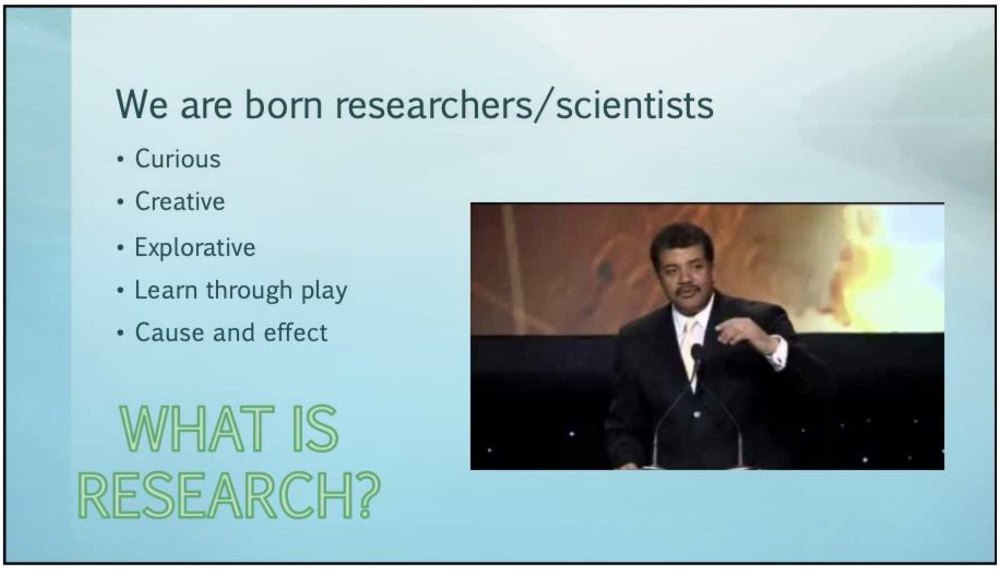
Acknowledge your baggage: assumptions, values, political leaning, culture etc

What influence might this have on your findings?

Re-evaluate your findings

Feed reflexive insight back into next interviews

We will have 10-15 minutes each workshop to write up our reflections.



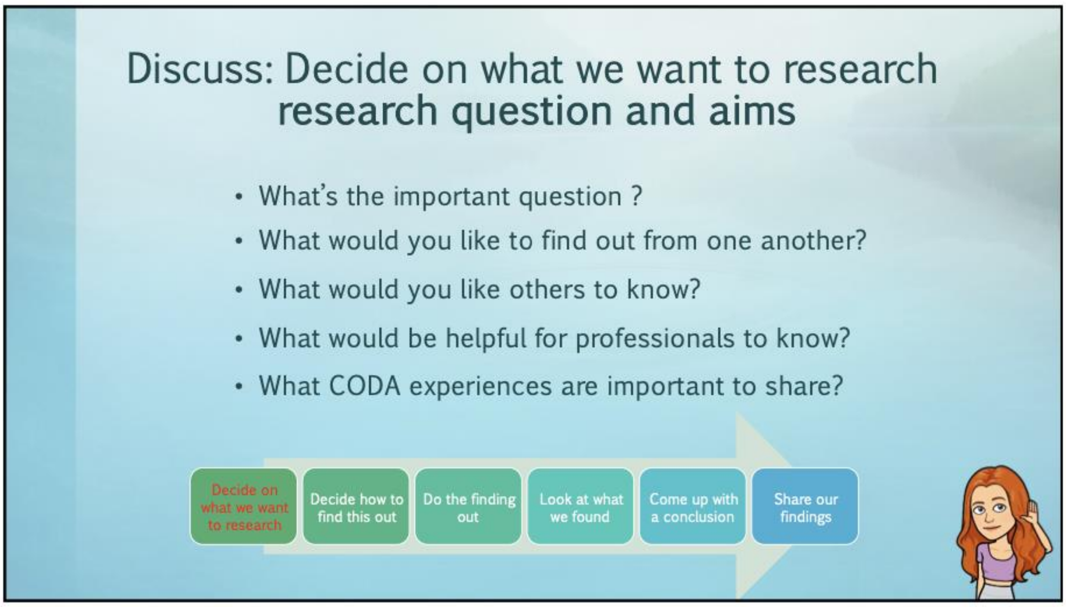
We are born researchers/scientists

- Curious
- Creative
- Explorative
- Learn through play
- Cause and effect

WHAT IS RESEARCH?

How do we do research?

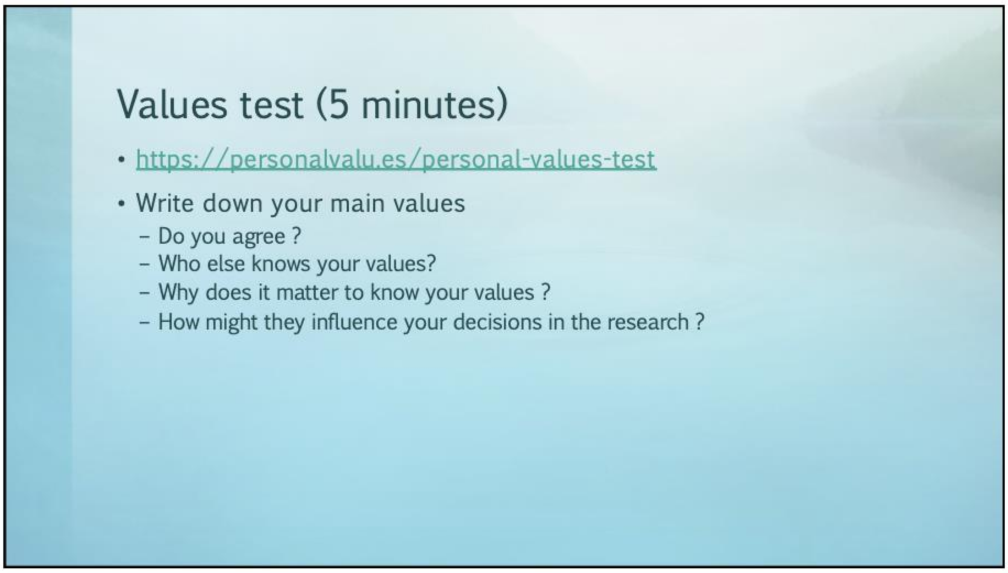
- Decide on what we want to research
- Decide how to find this out
- Do the finding out
- Look at what we found
- Come up with a conclusion
- Share our findings



Discuss: Decide on what we want to research research question and aims

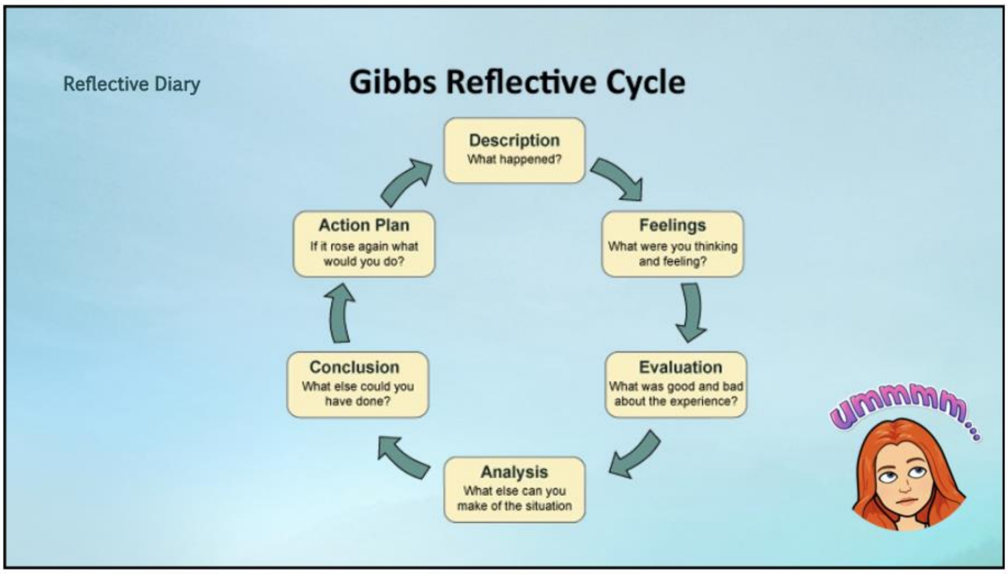
- What's the important question ?
- What would you like to find out from one another?
- What would you like others to know?
- What would be helpful for professionals to know?
- What CODA experiences are important to share?

- Decide on what we want to research
- Decide how to find this out
- Do the finding out
- Look at what we found
- Come up with a conclusion
- Share our findings



Values test (5 minutes)

- https://personalvalu.es/personal-values-test
- Write down your main values
  - Do you agree ?
  - Who else knows your values?
  - Why does it matter to know your values ?
  - How might they influence your decisions in the research ?



Reflective Diary

Gibbs Reflective Cycle

Description
What happened?

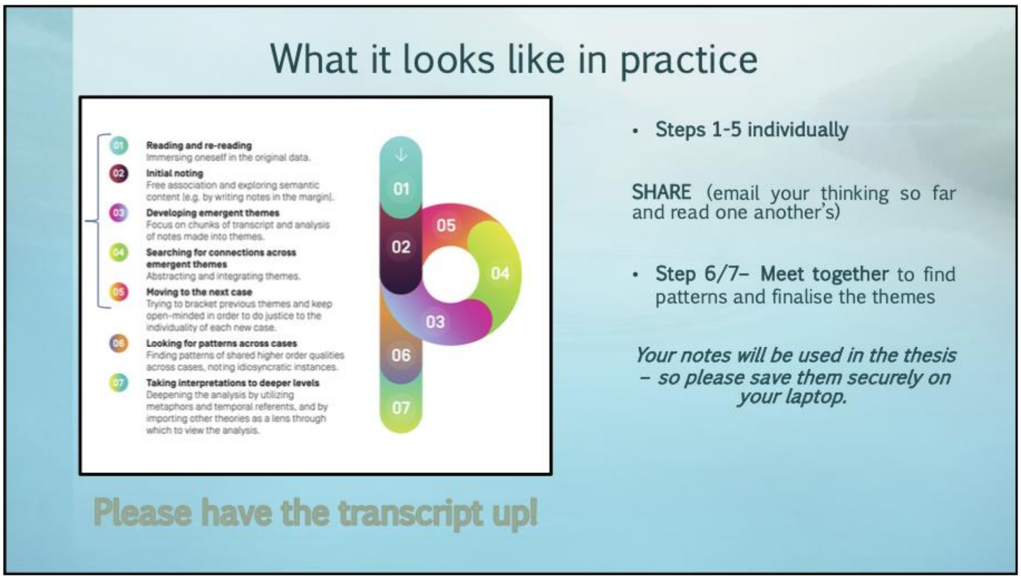
Feelings
What were you thinking and feeling?

Evaluation
What was good and bad about the experience?

Analysis
What else can you make of the situation

Conclusion
What else could you have done?

Action Plan
If it rose again what would you do?



What it looks like in practice

- 01 **Reading and re-reading**
  Immersing oneself in the original data.
- 02 **Initial noting**
  Free association and exploring semantic content (e.g. by writing notes in the margin).
- 03 **Developing emergent themes**
  Focus on chunks of transcript and analysis of notes made into themes.
- 04 **Searching for connections across emergent themes**
  Abstracting and integrating themes.
- 05 **Moving to the next case**
  Trying to bracket previous themes and keep open-minded in order to do justice to the individuality of each new case.
- 06 **Looking for patterns across cases**
  Finding patterns of shared higher order qualities across cases, noting idiosyncratic instances.
- 07 **Taking interpretations to deeper levels**
  Deepening the analysis by utilizing metaphors and temporal referents, and by importing other theories as a lens through which to view the analysis.

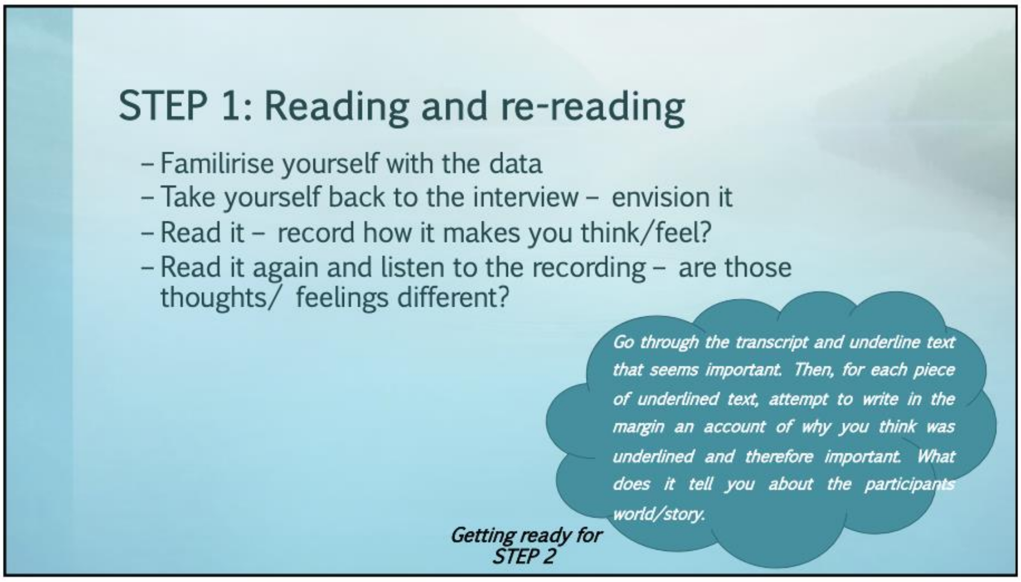
- **Steps 1-5 individually**

SHARE (email your thinking so far and read one another's)

- **Step 6/7– Meet together** to find patterns and finalise the themes

Your notes will be used in the thesis – so please save them securely on your laptop.

Please have the transcript up!



STEP 1: Reading and re-reading

- Familirise yourself with the data
- Take yourself back to the interview – envision it
- Read it – record how it makes you think/feel?
- Read it again and listen to the recording – are those thoughts/ feelings different?

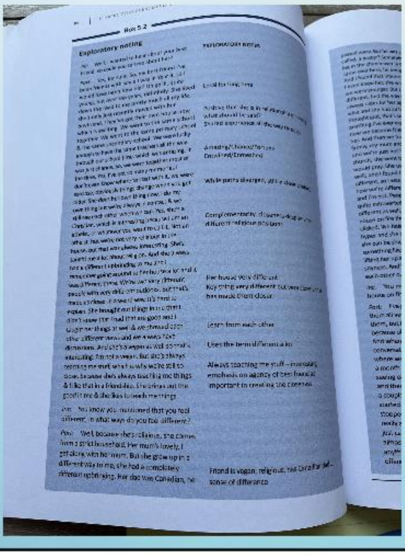
Go through the transcript and underline text that seems important. Then, for each piece of underlined text, attempt to write in the margin an account of why you think was underlined and therefore important. What does it tell you about the participants world/story.

Getting ready for STEP 2

STEP 2: Exploratory noting

- Once you're familiar with the data, read it again whilst taking notes of anything that stands out to you / interests you / sparks emotions
- Your aim is to produce a comprehensive and detailed set of notes and comments.
- This is participant led / participant orientated
- Immerse yourself in the participants shoes – what are they thinking/feeling/ what is important to them – make notes of this.

1. **Descriptive** (focusing on the content of what the participant said or the subject discussed),
2. **Linguist** (commenting on the way language was used by the participant) and
3. **Conceptual** (engaging with the data by questioning concepts and ideas by taking an interrogative approach).

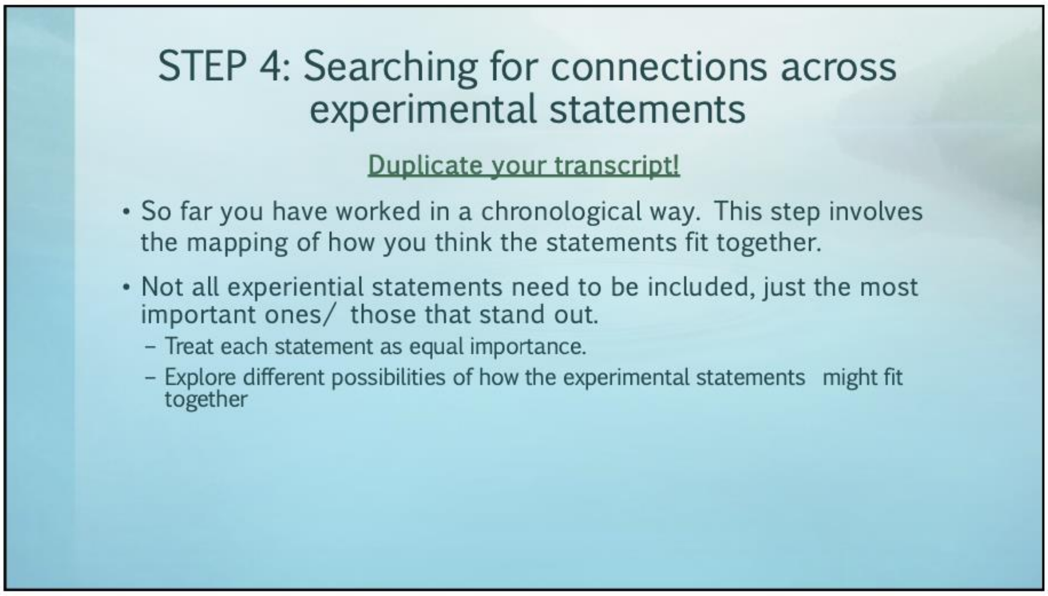


'Local for a long time'. This simple exploratory note is serving to summaries the main thrust of what is coming across in the first lines of the response.

'Amazing/chance/fortune'. The exploratory note focuses on some of the language of the participant highlighting an appreciative affective response.

'Her house very different'. There is a thing that matters to the participant.

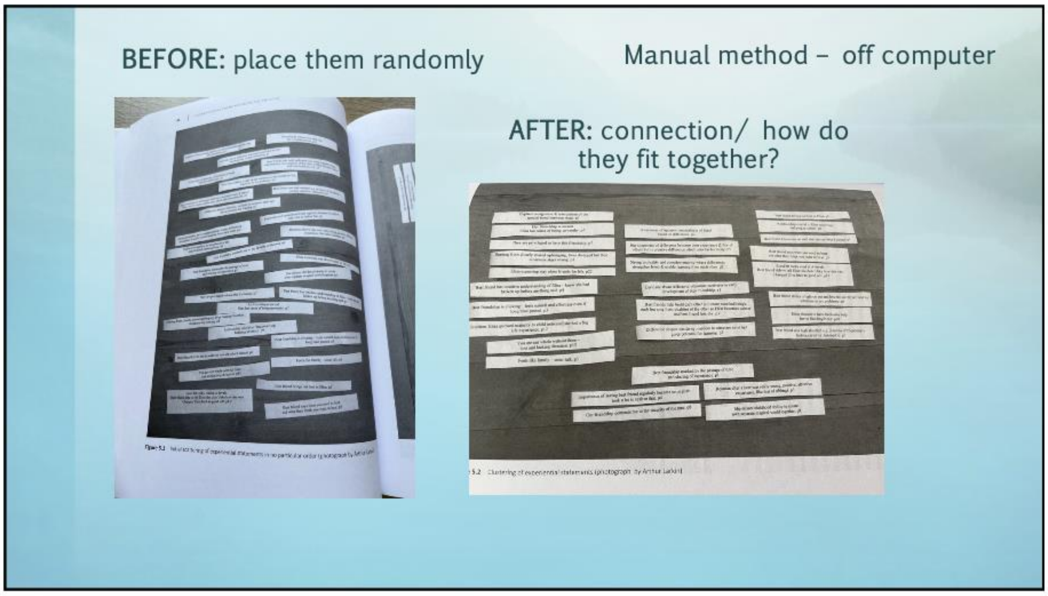
This is participant led / participant orientated. First person (use their words).



STEP 4: Searching for connections across experimental statements

Duplicate your transcript!

- So far you have worked in a chronological way. This step involves the mapping of how you think the statements fit together.
- Not all experiential statements need to be included, just the most important ones/ those that stand out.
  - Treat each statement as equal importance.
  - Explore different possibilities of how the experimental statements might fit together



BEFORE: place them randomly

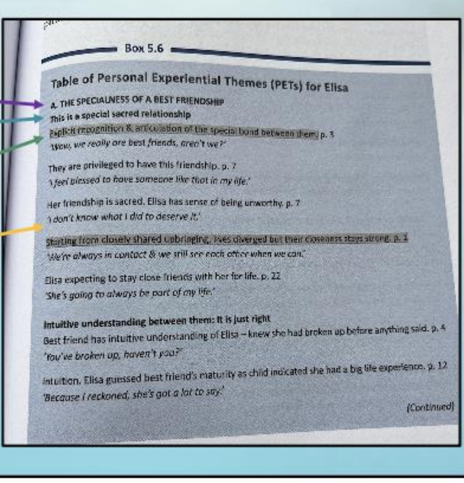
Manual method – off computer

AFTER: connection/ how do they fit together?

STEP 5: The clusters/connections become PETs.

Four distinct parts to PETs

- 1) Main Theme
- 2) Subthemes
- 3) Experiential statements
- 4) Quotes



Box 5.6

Table of Personal Experiential Themes (PETs) for Elisa

A. THE SPECIALNESS OF A BEST FRIENDSHIP

This is a special sacred relationship

Explicit recognition & articulation of the special bond between them. p. 3

'Wow, we really are best friends, aren't we?'

They are privileged to have this friendship. p. 7

'I feel blessed to have someone like that in my life.'

Her friendship is sacred. Elisa has sense of being unworthy. p. 7

'I don't know what I did to deserve it.'

Starting from closely shared upbringing, lives diverged but their closeness stays strong. p. 1

'We're always in contact & we still see each other when we can.'

Elisa expecting to stay close friends with her for life. p. 22

'She's going to always be part of my life.'

Intuitive understanding between them: It is just right

Best friend has intuitive understanding of Elisa – knew she had broken up before anything said. p. 4

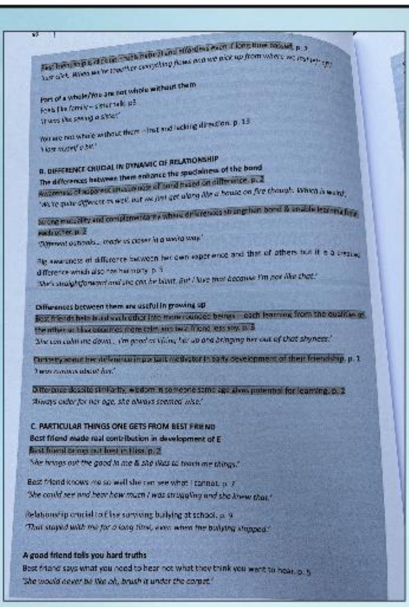
'You've broken up, haven't you?'

Intuition. Elisa guessed best friend's maturity as child indicated she had a big life experience. p. 12

'Because I reckoned, she's got a lot to say.'

(Continued)

This is what you will end up with.



[illegible] p. 3

'Just click. When we're together everything flows and we pick up from where we left off.'

Part of a whole/You are not whole without them

Feels like family – sister talk. p3

'It was like seeing a sister.'

You are not whole without them – lost and lacking direction. p. 13

'[illegible]'

B. DIFFERENCE CRUCIAL IN DYNAMIC OF RELATIONSHIP

The differences between them enhance the specialness of the bond

[illegible] of bond based on difference. p. 2

'We're quite different as well, but we just get along like a house on fire though. Which is weird.'

Strong mutuality and complementarity where differences strengthen bond & enable learning from each other. p. 2

'Different outlooks... made us closer in a weird way.'

Big awareness of difference between her own experience and that of others but it is a [illegible] difference which also has harmony. p. 5

'She's straightforward and she can be blunt. But I love that because I'm not like that.'

Differences between them are useful in growing up

Best friends help build each other into more rounded beings – each learning from the qualities of the other as Elisa becomes more calm and best friend less shy. p. 5

'She can calm me down... I'm good at lifting her up and bringing her out of that shyness.'

Curiosity about her difference important motivator in early development of their friendship. p. 1

'I was curious about her.'

Difference despite similarity, wisdom in someone same age gives potential for learning. p. 2

'Always older for her age, she always seemed wise.'

C. PARTICULAR THINGS ONE GETS FROM BEST FRIEND

Best friend made real contribution in development of E

Best friend brings out best in Elisa. p. 2

'She brings out the good in me & she likes to teach me things.'

Best friend knows me so well she can see what I cannot. p. 7

'She could see and hear how much I was struggling and she knew that.'

Relationship crucial to Elisa surviving bullying at school. p. 9

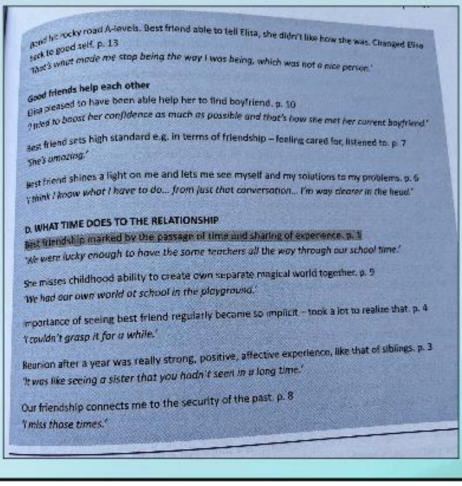
'That stayed with me for a long time, even when the bullying stopped.'

A good friend tells you hard truths

Best friend says what you need to hear not what they think you want to hear. p. 5

'She would never be like oh, brush it under the carpet.'

OVER TO YOU – Spot the FOUR parts of PETs



Bond hit rocky road A-levels. Best friend able to tell Elisa, she didn't like how she was. Changed Elisa back to good self. p. 13

'That's what made me stop being the way I was being, which was not a nice person.'

Good friends help each other

Elisa pleased to have been able help her to find boyfriend. p. 10

'I tried to boost her confidence as much as possible and that's how she met her current boyfriend.'

Best friend sets high standard e.g. in terms of friendship – feeling cared for, listened to. p. 7

'She's amazing.'

Best friend shines a light on me and lets me see myself and my solutions to my problems. p. 6

'I think I know what I have to do... from just that conversation... I'm way clearer in the head.'

D. WHAT TIME DOES TO THE RELATIONSHIP

Best friendship marked by the passage of time and sharing of experience. p. 1

'We were lucky enough to have the same teachers all the way through our school time.'

She misses childhood ability to create own separate magical world together. p. 9

'We had our own world at school in the playground.'

Importance of seeing best friend regularly became so implicit – took a lot to realize that. p. 4

'I couldn't grasp it for a while.'

Reunion after a year was really strong, positive, affective experience, like that of siblings. p. 3

'It was like seeing a sister that you hadn't seen in a long time.'

Our friendship connects me to the security of the past. p. 8

'I miss those times.'

Appendix S

The Co-Researchers Workshops and Contact Hours

Workshop one: Research questions and aims

date: 27.05.23	time: 1 hour 8 minutes

Workshop two: Research design

date: 12.06.23	time: 59 minutes

Interview one (P1)

date: 01.07.23	time: 1 hour 15 minutes (Khloe)

Interview two (P2)

date: 03.07.23	time: 1 hour 24 minutes (Ivy)

Workshop three: Research analysis

date: 26.07.23	time: 1 hour 03 minutes

IPA member-check in

date: 26.08.23	date: 01.09.23	time: 1 hour per session

Workshop four: Research analysis and dissemination

date: 22.10.23	time: 1 hour 13 minutes

Dissemination of the research: Youtube video

date: to be confirmed	time: to be confirmed

Appendix T

Co-Researcher Debrief Form

CO-RESEARCHERS DEBRIEF SHEET
Title: A participatory research approach to explore the experiences of Children of Deaf Adults (CODAs)

Research Question: How have the experiences of CODAs shaped their identity?
Aims

1. To explore the extent to which identity is shaped as a direct consequence of CODA experiences/upbringing.
2. To explore the support received by CODA individuals and how this could be modified.
3. To explore personal interactions/relationships with non-CODAs and how this has influenced CODA identity.

Contact person: Naomi Milliken
Email: u2190383@uel.ac.uk

Thank you for having an active role in co-facilitating this participatory research. This document offers information that may be relevant now you have taken part.

How will my data be managed?
The University of East London is the Data Controller for the personal information processed as part of this research project. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. More detailed information is available in the Participant Information Sheet, which you received when you agreed to take part in the research.

What will happen to the results of the research?
The results of the research will be included in Ms Milliken's Thesis, Viva presentation and a poster for other students and staff at UEL. However, the co-researchers will decide on how else to disseminate their findings. For example, they may wish to create a video, in which British Sign Language is used to interpret their findings.

The research may also be used for publication later. In all material produced, your identity will remain pseudonymous, in that, it will not be possible to identify you personally. You will be given the option to receive a summary of the research findings once the study has been completed for which relevant contact details will need to be provided.

Pseudonymised research data will be securely stored by Dr Rowley (Ms Milliken's Director of Studies) for a maximum of three years since completion to allow for dissemination activities (e.g., publication), following which all data will be deleted.

In the case that a co-researcher wants to be identified, they will be known as a co-author and an additional consent form will need to be completed.

What if I been adversely affected by taking part?
It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise distress or harm of any kind. Nevertheless, it is possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways, you may find the following resources/services helpful in relation to obtaining information and support:

Mind – For mental health and wellbeing support:
https://www.mind.org.uk/information-support/

HelpGuide – Support for managing stress at work:
https://www.helpguide.org/articles/stress/stress-in-the-workplace.htm

Health and Safety Executive (HSE) – Support for managing stress at work:
https://www.hse.gov.uk/stress/

Able Futures - Providing support for mental health at work:
https://able-futures.co.uk/

Health and Care Professionals Council (HCPC) – Additional advice and support:
https://www.hcpc-uk.org/standards/meeting-our-standards/scope-of-practice/medicines-and-prescribing-rights/additional-advice-and-support/

British Psychological Society – Support for professionals in the coronavirus pandemic:
https://www.bps.org.uk/news-and-policy/supporting-psychological-wellbeing-healthcare-staff-key-pandemic-recovery

As mentioned in the information sheet, you also have access to therapeutic support from Mr Shrine (Welfare Director at the CODA UK and Ireland organisation). Please contact Matt@codaukireland.co.uk for more information.

Who can I contact if I have any questions/concerns?
If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Contact person: Naomi Milliken
Email: u2190383@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor Janet Rowley, School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: j.e.rowley@uel.ac.uk
or
Chair of School Research Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

Thank you for taking part in my study.

Appendix U

Extracts From the Research Facilitator's Reflexive Diary

Gibbs reflective cycle (Gibbs, 2005) ▪ What happened? ▪ Feelings ▪ Evaluation ▪ Analysis ▪ Conclusions ▪ Action plan	**Values:** Professional values: empowerment – beneficence – social justice Personal values: consistency – security – inner strength	**Blind spot:** *Unaware of relevant cultural information due to unexamined assumptions of one's own background.* **Soft spot:** *Holding unexamined assumptions which lead to deviations from usual practice.* **Hot spots:** *Those who have experienced powerlessness in aspects of their lives and understandably have strong emotions associated with that dimension.* **(**Sandeen et al., 2018b) Social GGRRAAACCEEESSS Model (Burnham, 2018)
Workshop one: Research questions and aims Establishing a group agreement: I felt slightly uncomfortable as the co-researchers were quietly thinking for a while. This led to me guiding them more than I set out to, by offering examples. Next time, I would have practiced being comfortable with silences, as they eventually did offer ideas.	Throughout the session, I saw my role as the facilitator, therefore, I remained curious, genuine, and transparent. Empowerment: I put myself on mute and was passive throughout their deliberation of putting the aims/RQ together. However, I question how much they were guided by the information sheet, which had some suggested aims and RQ. My values of consistency and security were challenged as the third co-researcher did not show, despite signing the consent form, furthermore after emailing them, there was no response. I question whether they felt comfortable enough to share that they no-longer wanted to participate? In the future I would take a more relaxed approach and invite the ci-researchers to take part in as much or as litter. Perhaps send out a question, regarding what areas they could/were able to participate in. my values of consistency took over, as I was fearful that people would drop out at different stages, therefore the PR would be inconsistent and difficult to manage.	During this session I encouraged the co-researchers to think about their visible and invisible social GGRRAAACCEEESSS Model (Burnham, 2018). A shared reflection was that out CODA/GODA identity was invisible. Naturally, this was a hot spot. The girls spoke about social class as an invisible factor, however, did not feel it was essential to put into their bio. This challenged my core belief that social economic status does matter and, in my view, would influence your CODA upbringing/experience. However, due to the nature of the PR, I abided with their truths. Therefore, avoiding a soft spot.
Workshop two: Research design PR: there was a physical barrier (muted) so even if I had the urge to prompt or say something – I would need to unmute myself therefore gave me more thinking time – to not act on my impulses – responsive rather than reactive. I question how this might have been different in person.	The coresearchers were enthusiastic, punctual, and reflective – this was highly reassuring/comforting as a RF and aligned with my personal values – security and consistency. Beneficence and empowering: this PR experience appeared to be doing good, as the girls shared words of 'insightful and empowering' at the end of the session. They also voiced feeling excited to interview one another.	Education and ability – being in a position of knowing more and therefore teaching others, however still handing over the power. For this I utilised my interpersonal skills.

Technology: facilitating this PR virtually was a significant risk, as we were relying on technology to work. However, something I had not anticipated was the co-researchers' restrictions to MS teams. Unfortunately, as their email addresses were not recognised by the university, there were certain functions they did not have access to, like a shared white board. Therefore, alternative ways were used – sharing screen and one co-researcher typing, rather than both having control- which would have distributed the power. Research Design decision: It was challenging to get the balance right between teaching/guiding them on what qualitative research looks like and sharing examples of different methods and allowing them to self-educate. For example, the co-researchers thought of 13 questions to ask one another which to me, seemed like too many and I questioned how much time they would talk about each question in great depth. Furthermore, they started discussing questions some and some of their CODA experiences were shared I had to promptly pause them, as I did not want any important messaged to be lost/unheard.	In preparation I asked the co-researchers to practice reading the semi-structured questions and encouraged them to treat the experience as a conversation, rather than I structured interview… questions might not necessarily be asked in the exact order (Kellett, 2011). This aimed to empower them and reduce any nerves that they might have in adopting the role as interviewer. Interestingly the co-researchers decided not to interview one another on the same day as they were afraid that their answers/views would influence one another. They seemed to be adopting my language and felt empowered to make decisions . One of the co-researchers informed us that she was moving to Australia. This challenged my values of security as I predicted that this would make it increasingly more difficult to meet up. However, ultimately, it showed that you can complete research with people from around the world. As the CODA was eager to continue to participate and make it work. I was keen for the co-researchers to adopt an more than one form of data collection method, as the literature suggests that it increases trustworthiness and rigour (Given, 2008). Therefore, I emphasised the strength and opportunities that came with using more than one model – I question whether this was empowering or disempowering and somewhat taking control.	
Interview Process Ivy interviewed Khloe on 01.07.2023. Khloe interviewed Ivy on 03.07.2023. Both appeared comfortable in their different roles. The interview process felt more like a conversation, where they connected to one another's shared experiences. During the interviews, I remained on mute and had my camera off; this ensured that my body language had no influence on the participants.	The participants shared how empowering it was to have the opportunity to reflect on their CODA identity. They were grateful to be able to share this with another CODA, who they could relate too and spot similarities and differences. There was a sense of connection between the participants – beneficence. Which seemed to do good. This was apparent in their interpersonal skills, (smiles, laughs), and how they summarised the sessions.	**Blind spots**: the co-researchers shared experience in which I could relate to, there were also examples that surprised me and were foreign. My mother CODA, experience was incredibly different to theirs and appeared more challenging. The participants seemed to benefit from having a supportive systems and characteristics that enabled them to view their experience as CODA differently to that of my mothers. This encouraged thoughts regarding a nature/nurture. **Hot spots**: I later adopted the same 13 questions to interview my mother, a CODA informally, this increased my awareness

Listening to their stories elicited feelings of Compassion, gratitude, and happiness. However, I could not help but think about how different their CODA experience was to my mothers. This led to feelings of sadness. I was also nervous and conscious of the technology. There appeared to be equal power when the co-researchers interviewed one another, this was achieved through their effective interpersonal skills.	Affirmation and empathy. This would have been notably different if I, as a GODA, had interviewed them. I would have been able first to hand connect with their stories, or even share a different stance through my own experience. Inner strength: hearing their views elicited a sense of inner peace and reassurance that my decision to adopt a PR approach with CODAs, was the right one.	of her upbringing and gave me a new sense of empathy for her hardships and what she missed as a CODA. Hot spot: the co-researchers shared experiences of hardship and difficulty, this was raw and emotive and resonated with my mother's experience. Following this there was a wellbeing check in.
Workshop three: Research analysis In this session, I introduced IPA to the co-researchers; however, prior to this, we explored our values. Khloe: dedication and respect And Ivy: Trust and honesty Also confirmed the title of the CODA thesis. IPA: this is a lot to take in, and this was reflected in the co-researchers' feedback. On reflection, I would offer the opportunity, rather than set it as an expectation, but given them opportunity to ask for my help… I started going through the theory – next time, I would ask whether this is something the co-researcher is interested in, as at the time it felt uncomfortable. However, the co-researchers feedback suggests that they would have wanted more on the theory behind IPA. What went well: Kept to the time - Shared files in advance - Had examples ready – to showcase how to do this on the computer.	**Empowerment**: This session placed me as the expert, as it was the only workshop that was RF-led and where I was teaching the co-researchers how to conduct IPA. The co-researchers' level of involvement here was at its lowest as I was sharing. My view on IPA and how I would facilitate it as an example to aid their understanding. **Beneficence:** I offered to support and meet with them separately. Perhaps I could have this clear and encouraged the co-researchers to hand over any task that they found overwhelming. **Security:** My Level of trust as a RF, was tested. On a scale of 0 (none) -10 (fully trust) – I feel like a 6.5/7. I know that they are able; however, because their initial examples of steps 2 and 3 were not what I was expecting, it made me question it. Furthermore, they suggested that they would be able to complete steps 1-5 in 3 days – I would need longer, therefore making me question their level of intensity and understanding.	**Blind spot:** Gave them the opportunity to practice, as this is something I would have liked. However, although they found it helpful, they also found it uncomfortable. They noted things that they didn't quite like seeing – such as they way they ask questions and the repeated words that they use. Naturally this was a blind spot for me.
Workshop four: Research analysis and dissemination This was the final session, whereby Khloe and Ivy came together to finalise the GETs; they also shared ideas on how their finding should be disseminated. Both made the significant point that there should be a BSL interpreter present. Feeling: hopeful, reassured, inspired, and encouraged.		.

RF's involvement in IPA Many different feelings: excitement, engagement, eagerness however conscientious and responsible. I was aware that I would now be influencing the results – even if I wasn't finalising the GETS, I would have influenced it in some way. This was slightly disappointing at first, as I wanted to reduce my involvement. However, it was in line with PR, as it was the co-researchers' decision to invite me in.	Third level interpretation – questioned empowerment	**Soft spot:** I questioned throughout how my soft spots and my idea of CODAs would influence my input of the IPA…this was challenging, and I had to keep reminding myself of the participant's voice – by re-watching and reading the interview to avoid my soft spot intruding on the analysis.
Co-researchers' check-ins This was optional and for the co-researchers to activate if they felt it would be helpful. Both co-researchers requested support and guidance at different points. Therefore, it was a good idea to offer this. This also gave me the opportunity to review /clarify their thinking so that could draw on this in the results and discussion section, keeping their thoughts/reflections in mind.	Be flexible. Be available to the co-researchers.	**Soft spot / Hot spot**: Projection, because the situation was out of my control, I wonder if any of my own worries and anxieties showed. Furthermore, there was a feeling of being removed and wanting to ensure that although I was not in full 'control' of the IPA, I was aware of some of their thinking and reflections throughout that I could still represent their views as accurately as possible.

Appendix V

Extracts From Khloe’s Interview Transcripts and Interpretative Phenomenological Analysis Process

Research Question: How have the experiences of CODAs shaped their identity?
Aims

1. To explore the extent to which identity is shaped as a direct consequence of CODA experiences/upbringing.
2. To explore the support received by CODA individuals and how this could be modified.
3. To explore personal interactions/relationships with non-CODAs and how this has influenced CODA identity.

Step 3: Constructing experimental statements	**Original transcript (step 1: reading and re-reading)**	**Step 2: Exploratory notes /initial noting**
	Question 1: How do you fit into the CODA category? **Co-researcher:** So the first question is just about how you fit into the coda category like what allows you to identify as a coda. **Participant 1** To me, it's both. My parents are both. My parents are fully deaf. And I'm not sure. **Co-researcher** Were they born fully deaf Or did they become deaf? **Participant 1** Ohh, I'm pretty sure. Yeah. Both of them were born deaf. **Co-researcher** So your whole life they've been … **Participant 1** Yeah, whole life they’ve been deaf	

Research Question: How have the experiences of CODAs shaped their identity?

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No view of herself as different to anyone else but appreciates that she fits into this category. Wouldn't consider her daily life to differ much because of the Coda label. Appreciates it means she is different and has different experiences from other people	Co-researcher So. **Question 2: When did you first identify as a CODA and what does that mean to you?** Co-researcher Being a coda and that kind of term, what does that mean to you and has you said about how you may be first in? Like know that term has. Um, you're like identity as a coda as well, and the meaning of that change as you've got older? Co-researcher Hmm. Participant 1 Yes, I I just answer the first bit it said like just being a coda to me, I just I feel like in a way it's like. *It's just a Term*, I don't know because I just think like I don't. *I don't feel like.* *Too much different to say anyone who's not coda* in terms of like, just like what I do without my parents and things like that. But then when my parents like involved and things like that, like if we're going out for dinner, I'm doing anything with them, I feel like I kind of feel.	Feels no different to other people – just another term.

Research Question: How have the experiences of CODAs shaped their identity?

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around her. Proud of these differences but again doesn't view herself as that different from day to day as other non-Codas.	I I guess *I think it's just like cool and unique. I just feel like it's something different and I I always talk about it in my like.* whenever I can, I just talk about it. Ohh yeah. Like my parents are Deaf, it's like kinda cool. Like I can sign. I can do this. And people who you talk to are like, Wow. That's cool. Like whatever like.	Feels different from people around her.
Positive association with the Coda term; other people view her Coda label as something impressive but Khloe just sees itas something which has always been a part of her life.	So I feel like. I don't know. I just feel like it's my. It's like my parents, my mom, really. I feel like it means like. *It means that I can communicate with her* and she like has a community around her who knows how to sign, how to talk to her and etc... And I guess as I like grew up, I feel like. I think when I was younger, I was like. I'd let my dad come into school and sign, and then when I grew up I was like, no. **Co-researcher** Yeah.	Personal significance of CODA term.
Coda camp allowed her to find other people in her upbringing which changed her views towards being a Coda	**Participant 1** I feel like that's just an ageing thing. Like you don't want your parents, right? Things. But then *I feel like my kind of identity probably majorly changed then.* when I went to like this camp because I never really.	Identifies a change in association with the Coda label

Research Question: How have the experiences of CODAs shaped their identity?
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2. To explore the support received by CODA individuals and how this could be modified.
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Pride; not embarrassed that her parents are deaf – would wear her Coda badge and enjoy people asking about it. Perhaps some of this pride came from having such a positive experiences at the camp and feeling more secure in the label and what that meant for her.	I use to have a …. They gave us like a wristband as well Um, which had like coda camp and then like the year on it. Co-researcher Ohh. That's good, yeah. Participant 1 And I literally remember in year 8, *I use to wear it like every day to school and people be like, what's that? That was like, ohh yeah. It's my coda badge.* And things like the family even. Yeah. So I just bought that cause I feel like to me like a lot of like the first like time I ever like realised about coda. All of that kind of came from like this, this comp that I went to so.That's that was my artefact, yeah. **Co-researcher** That's cool. are you still in touch with anyone like that? You went on the coda camp Was it like the same people every year or? Participant 1 Yes, the first year I went I met like three of my friends and then the year after two more girls we met two more girls who kind of joined our like group or whatever. Um. And then the year after another girl joined. And then I think, I think I went three times or four times. I still, I still keep in touch. Yeah, I am.	Coda camp memorabilia lasted much longer the camp and she would wear it outside of this a lot.

Research Question: How have the experiences of CODAs shaped their identity?
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Almost burden-like to be a Coda. Less spoken about and felt much more overlooked. Left out of basic education expectations because of the 'effort' it would take to be inclusive. Felt as though being a Coda meant extra work for everyone around her and it was a nuisance.	Co-researcher That's so good. Yeah. Participant 1 Like, not her, but so that she was like involved as well. Like she's not just like this is fine. And they had like interpreters and like everything. So I mean, obviously. That all of the stuff that she would come to like, they'd be something there. And then I feel like you go to secondary school and then there's just *too many kids to focus on parents*. Idon't know. Like, I feel like.It was like known about me, but like. Co-researcher Yeah. Participant 1 We never, *I don't think we ever did like… I think I did parents evening once. And everything else would just get sent like in letter form just cause it was too much hassle to do it, jn, Like with an interpreter,* cause I think when we did it. Co-researcher Yeah. Participant 1 It was like *a big like fath*, like obviously when you have an interpreter you need like longer time slots, but like cause there's so many kids, it's like we don't have time to give you	Less personal relationship with staff at secondary school. No parents evenings at secondary school; was written out instead. Hassle of needing an interpreter at parents evening.

Khloe’s PETs

PET 1: feeling Empowered by your CODA identity

Subtheme 1. Reflecting/establishing on your identity

Pride; not embarrassed that her parents are deaf – would wear her Coda badge and enjoy people asking about it. Perhaps some of this pride came from having such a positive experience at the camp and feeling more secure in the label and what that meant for her.
“I literally remember in year 8, I use to wear it like every day to school and people be like, what's that? That was like, ohh yeah. It's my coda badge.” (p. 9)

No view of herself as different to anyone else but appreciates that she fits into this category.
“*It's just a Term*, I don't know because I just think like I don't. *I don't feel like.* t*oo much different to say anyone who's not coda* in terms of like, just like what I do without my parents and things like that. (p. 4).

Coda camp opened her eyes to the world of CODAs. Perhaps this highlighted differences with non-Codas as she has only had interactions with them to compare with previously. *“this camp called coda camp. Really. And then when I went there, I, like, met all other people that were like me…So I feel like my identity Like changed in the sense of like meeting other people kind of like, opened your eyes to like the whole different like. World.” (p. 6).*

Subtheme 2: it’s cool to be different

Realisation that not everyone has a deaf parents and sees this as a positive difference
” I first like really understood about like being a child with someone who is deaf kind of when I was in like Infant School…I just remember cause my dad came into school and he read a book in sign language to my class, and I remember just sitting there and like everyone in my class is like so like wow, this is so cool. And I was like this is so like normal to me.” (p. 3).

Getting to explain her differences to her peers and having a positive responses to this furthered her pride and appreciation for her Coda label and reinforced it as a positive association within her identity.
“ I was like, this is like the coolest thing ever. Like, I'm so-cool and I'm thinking I'll like no one else is like me. And that's just cool.”(p.19)

Positive association with the Coda term; other people view her Coda label as something impressive but Khloe just sees it as something which has always been a part of her life
“I guess I think it's just like cool and unique. I just feel like it's something different and I I always talk about it in my like.” (p. 5)

Bold: experimental statements
Not bold : Quotes

Khloe’s PETs

PET 2: the importance of inclusion

Subtheme1 : increased inclusion through belonging to a community

Inclusivity again, feeling like part of a community and no different from anyone else, feeling understood, accepted
“And everyone would just sit round the circle and be like, I remember when I did this and I was like, whoa, like, I had that too. Like, I experienced that as well.” (p.65)
“my favourite thing to come from it was when… *Our parents meet and my parents, can talk to their parents and I was like, this is weird because usually at home my Mum can't really speak to my friends or like my friend's parents. I would have to like interpretate for them.” (p. 6).*

Coda camp was extremely positive again and made her feel very proud to have different experience as a Coda, feelings of inclusivity and pride as a result,with those feelings towards both herself and seeing her Mum there too. “I think it was like the coolest thing ever. Just like see my mom like in a world of like deaf people…Mum would be like ohh I know her mum, like its such a community where like everyone kind of knows.” **(**p. 63).

Subtheme 2: inclusion in school helps with developing a strong identity

Primary school was extremely inclusive and went out of their way to appreciate her differences and make the other children appreciate these too; feelings of acceptance and understanding.
“my primary school was very good with like My mom and things because, they still, have signs like around the school of like pictures of like sign language and things like how do you like wash your hands in the toilets or things like that?” (p.17).
“The head teacher had learnt sign language like from that like from my mom.” (p.17)

“visited the school I think it was like some summer fair. they were like talking to my mom and like my mum was like, they're all like signing to each other… like reception year one year two, they're all like being taught like some words as well.” (p.18)

Perhaps her strong pride helped her to achieve this. Now she says she would find it much more challenging; maybe because the nurturing environment of primary school has gone.
“I think she (mum) never felt out of the loop because our school was doing something to like include her and like Mother's Day would come on and they would have, like, everyone would sign, like songs on Mother's Day.” (P. 22)

Appendix W

Extracts From Ivy’s Interview Transcripts and Interpretative Phenomenological Analysis Process

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Research Question: How have the experiences of CODAs shaped their identity?
Aims
1. To explore the extent to which identity is shaped as a direct consequence of CODA experiences/upbringing.
2. To explore the support received by CODA individuals and how this could be modified.
3. To explore personal interactions/relationships with non-CODAs and how this has influenced CODA identity.

Step 3: Constructing experimental statements	Original transcript (step 1: reading and re-reading)	Step 2: Exploratory notes /initial noting
	Question 1: How do you fit into the CODA category? Co-researcher So we will just kind start with like how do you fit into the coda category? Participant 2 So my mum is deaf and she's profoundly deaf and she's been deaf since she was 3 and my dad is fully hearing. But he worked abroad most of my childhood so. It was mostly my mum that was at home. So yeah, that's what I'm a coda. Co-researcher Okay. Wait, so does your dad know sign language? Participant 2 No. No. **Question 2: When did you first identify as a CODA and what does that mean to you?** Co-researcher	

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Research Questio **:** How have the experiences of CODAs shaped their identity?

Aims

1. To explore the extent to which identity is shaped as a direct consequence of CODA experiences/upbringing.
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The emotional impact of a coda hearing her deaf mother's difficulties (p. 4). The emotional impact on being a deaf parent to a hearing child (p.4). The importance of inclusion and power in education (p.5)	Has like made me who I am, but since learning it and I'd like thought about that more, I definitely. Know that like it is quite a big part of my life and so it's quite nice to be able to. Yeah, like, have a label for it, **n**guess. **Questio 3: *Can you tell me about the artefact/picture/object you brought with you?*** Co-researcher Yeah, that is quite nice. Did you bring like an object or artifact or picture or anything ? Participant 2 Yeah, I brought a picture and it's kind of a bit depressing no going to lie. I basically I was trying to think of artifact, especially because I've not thought myself as a coda, I didn't really. Like I was like ohh, I definitely wouldn't have anything like but I was trying to think about something that. Kind of really hit me of how my mum's deafness has impacted her and me and. This was like a few years ago now it was. I didn't know when it was, but probably like five or six years ago. Um, I found I was looking for paper and I found like an old school book and I was flicking through it and at the back my mum had written like. A diary entry kind of thing, I guess, like kind of ranting. Um, and it's about we have near ours like a family festival thing, and it just been that weekend and she was writing about how excluded, she felt, and it made me like kind of tear up because I was like, I forget how much it impacts my mum and she doesn't ever complain about it. But yeah, it's literally just, I don't know if you can see it. It's like writing.	learn more about herself It's still quite new to her A raw and emotional thing to talk about- she really cares about the effect on her mum

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deaf parent who is excluded (p.6 and 7).	I was already aware of like how I'm sure she felt sometimes, but the fact that, like, she felt compelled to write it down. Yeah, it was like just kind of sad to me.	
	Co-researcher Was it like addressed to, like the school and things? Or was it just?	
Small changes can make a big difference to the deaf community (p.7).	Participant 2 No, it was. I think it was literally just her, like ranting because yeah, this like event is basically like it's like a concert at the in the evening. And I guess also like in the build up to it there was a lot of. My mum has sent so many emails of like can I have a list of like what songs it's gonna be so I can look at the lyrics before or like she emailed them to get like a free ticket for her friend who could interpret for her and like signed to the music because she was like, it makes such a big difference and it doesn't. It costs like a company that's running a concert like that, literally nothing. And there's other people, I'm sure that go to it that also have hearing problems or a hard of hearing.	Small changes can make a big difference
The importance of educating the hearing world about	that it would make a big difference for and so she also had a long process of trying to get them to make small changes. and Also, her friends obviously are good and like, speak to her, but most of them are other parents that she's met through school, like none of them. Um, that live locally are deaf as well, and so. A lot of them are good at like make sure they face her and everything like that. But as soon as they've been like drinking or whatever, it like goes out the window and also my mum can't ever drink as much because she relies on lip reading and she can't do it if she's like had more to drink. So yeah, there's like so many different factors that just kind of made me. Feel like I understood it a lot more and understood like the impact or appreciated the impact a bit more.	

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**Research Questio : **How have the experiences of CODAs shaped their identity?

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Increased responsibility as a CODA and the impact this has on their deaf parent. (p.12) The emotional impact of being deaf and how this impacted Ivy and her mum. Made them who they are today. (p.12).	Because I think like you kind of have to be. I'm the oldest sibling. It's just me and my brother, so. And I guess like girl versus boy, the girl is always like a bit more mature and. Like in charge of things I suppose. Especially cause my dad wasn't at home. I remember. Actually, we had the fire brigade come in and do like a fire safety talk. And I remember feeling really cool because they were saying how, like, if there was a fire, you have to just get yourself out first. Everyone else will get themselves out and they're like, is there anyone who, like at any of you think that doesn't apply to you? And I like, go to my hand up. And I was like, well, actually, my mum can't hear the fire alarm and. Because my dad is mostly not at home and my brother's the younger one. I would have to go and get my mum in that situation and so I remember being like, yeah, guys, I actually have to go through the fire. If there's one like, I'm in charge. But yeah, I don't think it really influenced. Me and terms of like. I don't know. I just didn't think about it. I didn't even think like, ohh, this is something that's different about me. But yeah, I guess. I think it probably influenced me in terms of like. It's made my mum who she is and who my mum is has made me who I am like. I think I said before like she's quite shy again. This is something I've only really realised in the last few years but she doesn't. She's not that confident. Especially like meeting new people and stuff. She gets very worried about people not understanding her is like quite self-conscious about it because.	Pride of being mature Impact of parents Notices the impact on her mum Influences her mum had on her

Ivy’s pets

PETS theme 1. The importance of connecting with your identity / having a strong sense of identity

Subtheme 1. The process of Identity development

Processing her identity has increased her sense of self (p.3,4).
“But I guess I am one. it kind of felt weird to start with or like even now still a bit I guess because it feels like a term like that is kind of like. Means you're like different, which I guess I am.”

Having a CODA identity has increased her sense of purpose “I think it kind of gives like more of a purpose I guess.” (p.49).

The importance of taking time to reflect on your identity (p.55)
“I feel as though I have really learnt a lot about myself during both interviews and I am looking forward to understanding more about the impact of my CODA identity moving forward, as well as how I can use this to help and better understand the deaf community” – (diary entry)

Subtheme 2.
Proud to be CODA

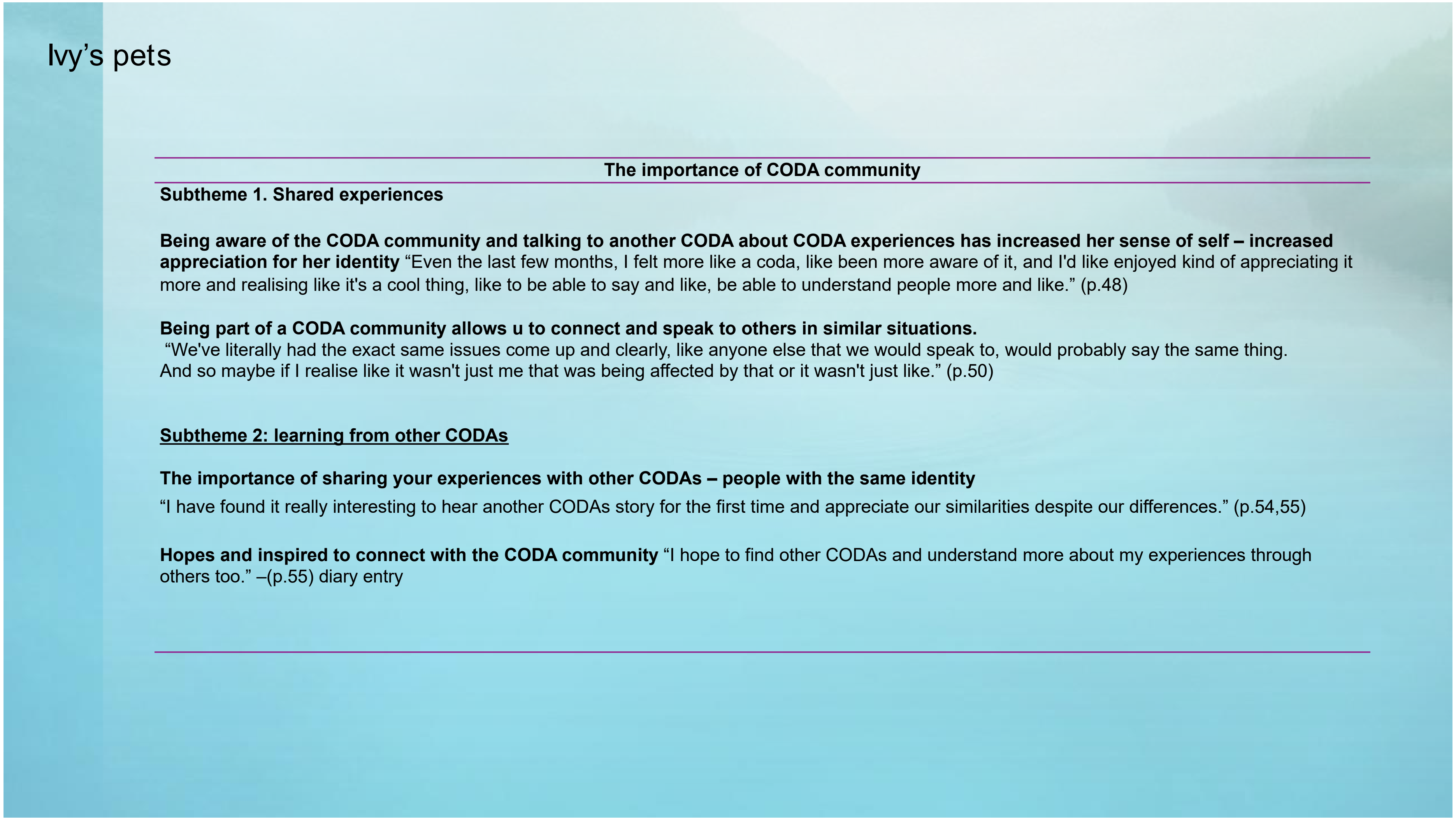
Proud to be a CODA “Like I said, like interviews and stuff like that, it's always something that I mentioned because it's something that I'm like proud of and I'm very proud of, like my mum and how she is able to, like, cope completely fine.” (p.48)

Being CODA is unique and cool “When it came to like applying for stuff in school like I applied like head Girl in secondary school and stuff like that, it was something that I always mentioned… It is something that's different about you… I think it's quite cool. Like it's something that I'm proud of” (p.27)

Subtheme 3.
Identity labels don’t have to be negative

Labels make people feel part of a minority group and realise their differences.
“It feels like you're part of like a minority group, which I am, but it also feels like having like a label almost feels like I should be like.
Disadvantaged or like there should be something.” (p.2)

Bold: experimental statements
Not bold : Quotes



Ivy’s pets

The importance of CODA community

Subtheme 1. Shared experiences

Being aware of the CODA community and talking to another CODA about CODA experiences has increased her sense of self – increased appreciation for her identity “Even the last few months, I felt more like a coda, like been more aware of it, and I'd like enjoyed kind of appreciating it more and realising like it's a cool thing, like to be able to say and like, be able to understand people more and like.” (p.48)

Being part of a CODA community allows u to connect and speak to others in similar situations.
“We've literally had the exact same issues come up and clearly, like anyone else that we would speak to, would probably say the same thing. And so maybe if I realise like it wasn't just me that was being affected by that or it wasn't just like.” (p.50)

Subtheme 2: learning from other CODAs

The importance of sharing your experiences with other CODAs – people with the same identity

“I have found it really interesting to hear another CODAs story for the first time and appreciate our similarities despite our differences.” (p.54,55)

Hopes and inspired to connect with the CODA community “I hope to find other CODAs and understand more about my experiences through others too.” –(p.55) diary entry

Appendix X

Transcript of Ivy's Mother's Diary

"Honestly, did I enjoy the weekend, no not really. I didn't feel like a normal person, that I deaf. Everyone else has such close friendships and are so comfortable with each other. I feel like an outsider. Not sure if people even really like me. I don't know how . . . to behave, what to say around everyone. Everyone easily falls into conversation – laughing and dancing with each other, even people who haven't been around as long as I have seem to have effortlessly social circle. I don't think people really understand what it's like, how bloody hard it is, has it depleted my confident, try so hard to communicate. Loud music doesn't help. But no one can lipread, so conversation is hard. It's so hard to just pop in and out of a conversation when you don't know what the bloody hell people are saying. I feel jealous every time I see everyone singing and dancing a lot to the music then I feel guilty for feeling jealous. Even my kids are so comfortable popping in and out so confident with people saying how lovely they are but they don't really like me I want to be part of it all so much – the easy and comfortable friendship."

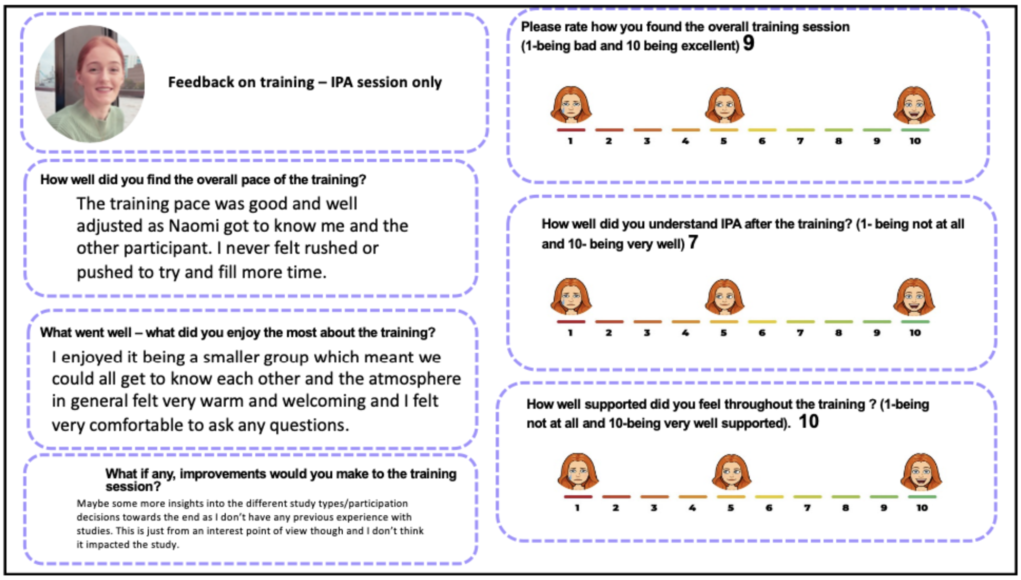
Appendix Y

The Co-Researchers Word Cloud

Appendix Z

Detailed Feedback Forms from the Co-Researchers

Ivy's Feedback



Feedback on training – IPA session only

How well did you find the overall pace of the training?

The training pace was good and well adjusted as Naomi got to know me and the other participant. I never felt rushed or pushed to try and fill more time.

What went well – what did you enjoy the most about the training?

I enjoyed it being a smaller group which meant we could all get to know each other and the atmosphere in general felt very warm and welcoming and I felt very comfortable to ask any questions.

What if any, improvements would you make to the training session?

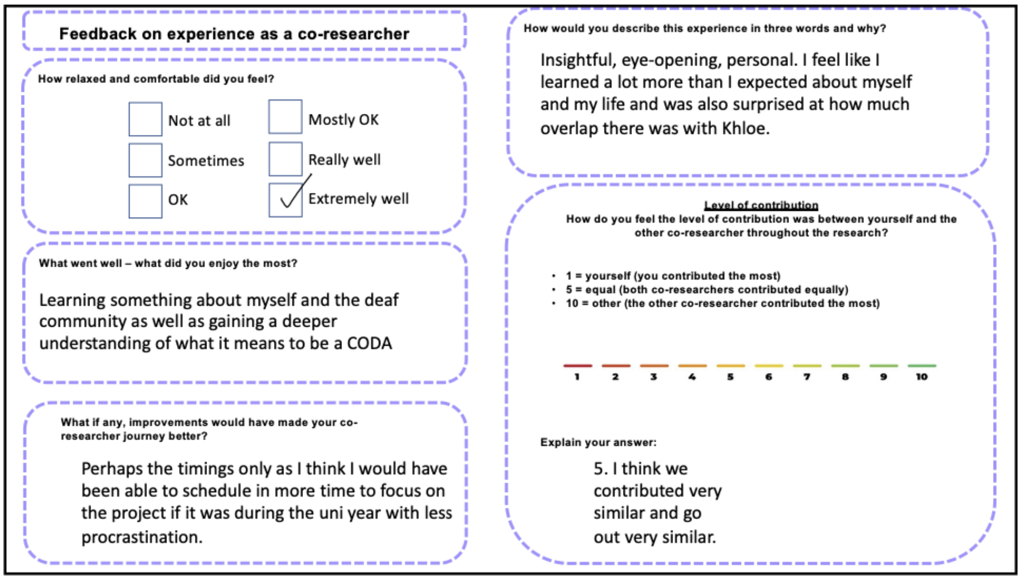
Maybe some more insights into the different study types/participation decisions towards the end as I don't have any previous experience with studies. This is just from an interest point of view though and I don't think it impacted the study.

Please rate how you found the overall training session (1-being bad and 10 being excellent) 9

How well did you understand IPA after the training? (1- being not at all and 10- being very well) 7

How well supported did you feel throughout the training ? (1-being not at all and 10-being very well supported). 10

1



Feedback on experience as a co-researcher

How relaxed and comfortable did you feel?

☐ Not at all
☐ Sometimes
☐ OK
☐ Mostly OK
☐ Really well
☑ Extremely well

What went well – what did you enjoy the most?

Learning something about myself and the deaf community as well as gaining a deeper understanding of what it means to be a CODA

What if any, improvements would have made your co-researcher journey better?

Perhaps the timings only as I think I would have been able to schedule in more time to focus on the project if it was during the uni year with less procrastination.

How would you describe this experience in three words and why?

Insightful, eye-opening, personal. I feel like I learned a lot more than I expected about myself and my life and was also surprised at how much overlap there was with Khloe.

Level of contribution

How do you feel the level of contribution was between yourself and the other co-researcher throughout the research?

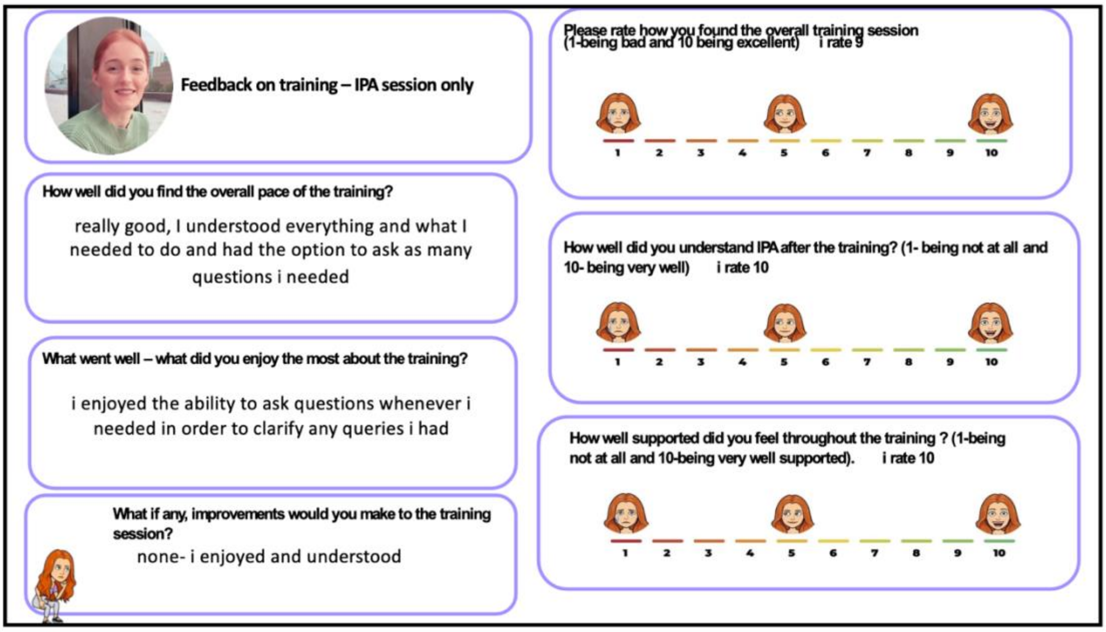
- 1 = yourself (you contributed the most)
- 5 = equal (both co-researchers contributed equally)
- 10 = other (the other co-researcher contributed the most)

Explain your answer:

5. I think we contributed very similar and go out very similar.

2

Khloe's Feedback



Feedback on training – IPA session only

How well did you find the overall pace of the training?

really good, I understood everything and what I needed to do and had the option to ask as many questions i needed

What went well – what did you enjoy the most about the training?

i enjoyed the ability to ask questions whenever i needed in order to clarify any queries i had

What if any, improvements would you make to the training session?

none- i enjoyed and understood

Please rate how you found the overall training session (1-being bad and 10 being excellent) i rate 9

1 2 3 4 5 6 7 8 9 10

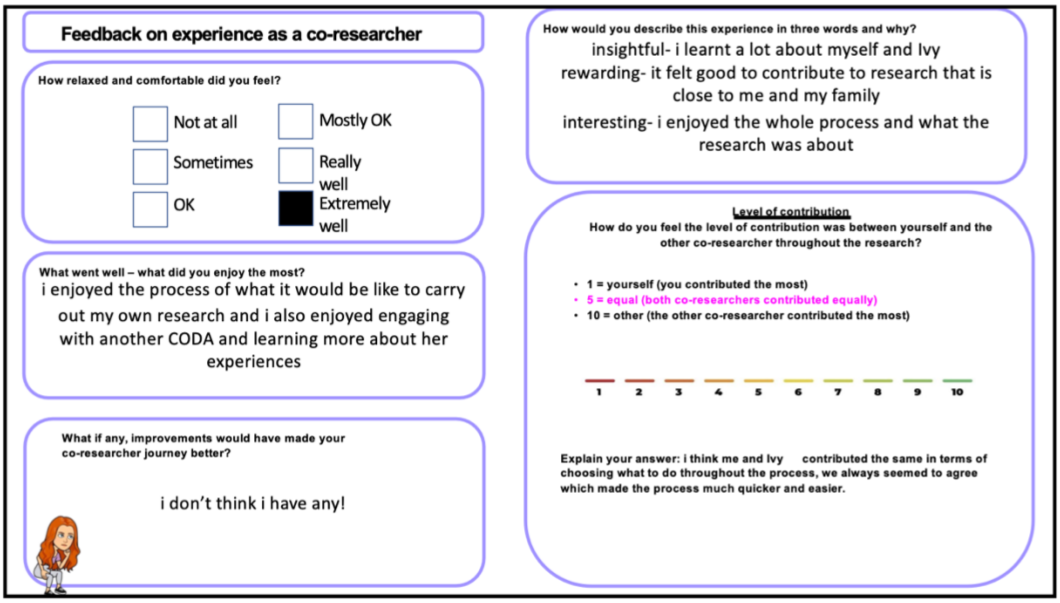
How well did you understand IPA after the training? (1- being not at all and 10- being very well) i rate 10

1 2 3 4 5 6 7 8 9 10

How well supported did you feel throughout the training ? (1-being not at all and 10-being very well supported). i rate 10

1 2 3 4 5 6 7 8 9 10

1



Feedback on experience as a co-researcher

How relaxed and comfortable did you feel?

☐ Not at all
☐ Sometimes
☐ OK
☐ Mostly OK
☐ Really well
☒ Extremely well

What went well – what did you enjoy the most?

i enjoyed the process of what it would be like to carry out my own research and i also enjoyed engaging with another CODA and learning more about her experiences

What if any, improvements would have made your co-researcher journey better?

i don't think i have any!

How would you describe this experience in three words and why?

insightful- i learnt a lot about myself and Ivy
rewarding- it felt good to contribute to research that is close to me and my family
interesting- i enjoyed the whole process and what the research was about

Level of contribution

How do you feel the level of contribution was between yourself and the other co-researcher throughout the research?

- 1 = yourself (you contributed the most)
- 5 = equal (both co-researchers contributed equally)
- 10 = other (the other co-researcher contributed the most)

1 2 3 4 5 6 7 8 9 10

Explain your answer: i think me and Ivy contributed the same in terms of choosing what to do throughout the process, we always seemed to agree which made the process much quicker and easier.

2