An Investigation Into Pre-School Family Support Groups for Children Who are d/Deaf and Their Families

Report by Helen Nelson
Commissioned by the National Deaf Children's Society

April 2025

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Definition of Terms

Pre-School Family Support Group (PSFSG)

Within the context of this research, this term refers to groups which specifically cater for, and are attended by, pre-school age d/Deaf children and their families and are facilitated by a Specialist Support Service in the UK. These groups may have a range of individual titles, and the nature and context of these groups may vary from area to area.

Mutual Support Group

In the context of this research, this term refers to support groups for families that are parent-led as opposed to professionally led.

Pre-school d/Deaf Children

This term refers to children aged 0–5 years old, prior to formal school entry, who have a diagnosis of deafness. The term d/Deaf refers to children with all levels of deafness from mild to profound, including unilateral losses, and includes those who identify as deaf or Deaf.

Families of Pre-School Age d/Deaf Children

This term refers to both the immediate and wider family of the young d/Deaf child and acknowledges the varied composition of individual families and the diversity of families' cultural backgrounds. It may also include others who are not related to the young d/Deaf child but are directly involved in their ongoing care and development e.g., family friends.

Specialist Support Services

This term refers to Support Services for d/Deaf children and their families that are provided by Education as opposed to Health or Social Care Services within the UK. These services are typically staffed by Qualified Teachers of the Deaf (QToDs), Specialist Teaching Assistants (STAs) and/or Communication Support Workers (CSWs) and may also include other staff members such as Educational Audiologists and Deaf Role Models. Many services also meet the needs of children who have vision impairment, but within the context of this study, only the support for children who are d/Deaf is under consideration. These teams are typically led by a Head of Support Service, who may be a QToD or may have an alternative professional background. Within the UK, most of these teams are based within the Local Educational Authority, although other organisational arrangements exist (CRIDE 2022).

Introduction

Within the UK, most infants diagnosed with deafness are born to hearing parents (Karchmer & Mitchell, 2004). These parents will typically have no previous experience or knowledge of deafness, and the diagnosis is likely to be unexpected. The impact of the diagnosis of infant deafness upon parental stress and coping resources is well-documented (Bosteels et al., 2012; Calderon & Greenberg, 1999; Jackson et al., 2008; Wood Jackson & Turnbull, 2004). It is recognised that the diagnosis of deafness impacts key domains of family life, including family interaction, family resources, parenting and support for the child (Wood Jackson & Turnbull, 2004). As a result, there is a clear need for effective, tailored early intervention to support families within the early years and to optimise outcomes for their young d/Deaf children (Desgeorges, 2003; Moeller et al., 2024**;** Moeller, 2000; Moeller et al., 2013; Yoshinaga-Itano, 2003).

Within the UK, early support is typically provided by Qualified Teachers of the Deaf (QToDs) and takes place within the home and/or pre-school setting (CRIDE, Consortium for Research into Deaf Education, 2022). This study seeks to explore a specific component of early intervention provision for families of d/Deaf children within the UK, namely the role of Pre-School Family Support groups (PSFSGs). It is understood that many UK Specialist Support Services provide support groups for pre-school children who are d/Deaf and their families. However, to date, there is no UK-based research evidence to evaluate the impact or efficacy of these groups, either from the perspective of the families who attend these groups or the professionals who provide this service. This accords with the findings of Wright et al. (2021:1) who highlight the current 'lack of clarity around which specific family support interventions are most helpful.' In addition, there are no models of good practice to inform the practice of local service providers when setting up, delivering, and evaluating this type of provision.

Current Knowledge About Provision

Within the UK, anecdotal evidence indicates that many Specialist Support Services/Schools for the Deaf include access to a PSFSG as part of the package of provision they offer to families. However, there is currently no data, either country-specific or for the UK as a whole, which indicates either how widespread this type of provision is or what proportion of Specialist Support Services/Schools for the Deaf offer groups of this type. The most recent UK-wide figures (CRIDE, 2022) indicate that there are approximately 5,750 young deaf children of pre-school age supported by Specialist Support Services for d/Deaf children (either within the home or early years settings). It is likely that, as part of their provision package, many of these children and their families attend a PSFSG run by the local Specialist Support Team; however, there is currently no robust evidence to confirm that this is the case. These children and their families may also potentially have access to Family Support Groups facilitated by other agencies, e.g., the voluntary sector. Again, the availability and extent of this type of provision are unknown.

Types of Support for Pre-school d/Deaf Children and Their Families

Responses to the thematic questions within the CRIDE nation-specific reports (CRIDE 2020a, b, c) indicate that a range of types of support is being offered to families by Specialist Support Services within England, Wales and Scotland (see Table 1) n.b. no data was available for Northern Ireland within the 2020 survey due to the COVID pandemic.

Table 1: Support Provided or Facilitated for Families of Deaf Children 0–4 years *(adapted from CRIDE Surveys for England, Scotland and Wales 2020, Table 3, Part 4)*

Information and Advice on hearing and hearing technology
Opportunities to meet other parents of deaf children
Opportunities to meet deaf adults/role models
Supporting families with their deaf children's spoken language
Supporting families with their deaf children's sign language
Information and advice on child development
General advice on the social and emotional well-being of deaf children
Specific programme, course or intervention on social and emotional development of deaf children
Behavioural management advice
Counselling or targeted support for the emotional well-being of parents/carers
Support for deaf children transitioning into early years settings/school

It is probable that some or many of these aspects of support are being facilitated within the context of a PSFSG, in addition to the intervention provided by the Service within the home or pre-school setting. Analysis of the responses within the Report for England (CRIDE, 2020a), indicates that group sessions for pre-school children are either already established or that Services desire to establish support groups of this type. This is indicated by the fact that the responses include reference to difficulty establishing groups due to low numbers of referrals, transport issues for parents impacting upon access to groups and family engagement in under 5s sessions.

The systematic scoping review of early interventions of deaf children (Wright et al., 2021) noted that early interventions for parents were reported in both group (i.e. potentially in PSFSGs) and individual contexts; however, as the authors highlight, there were only a few UK-based studies, and these were not necessarily of good quality. In common with some of the areas identified within Table 1, interventions tended to focus upon four key areas.

Table 2: Focus of Early Interventions for Parents of Deaf Infants (Wright et al., 2021:1)

Area of Focus
1. Language and Communication
2. Parental Knowledge and Skill
3. Parental well-being and empowerment
4. Parent/Child Relationships

Legislation and Guidance

At present early intervention within the UK is governed by a range of legislation and guidance as outlined below.

International Guidance

The key principles governing early intervention with families of young deaf children were established within *Best Practices in Family-Centred Early Intervention with Children who are Deaf or Hard of Hearing: An International Consensus Statement* (Moeller et al., 2013). These were revised in 2024, and the resulting expanded principles (see Table 3) were presented within a series of eight papers (Moeller et al., 2024a,b,c; Moodie et al., 2024; Sass-Lehrer, 2024; Swarkowski et al., 2024a,b,c). Neither the original statement in 2013 or the 2024 revision make explicit reference to specific provision/contexts; however, it is likely that a PSFSG could provide a means to facilitate many of the values, principles and behaviours outlined.

Table 3: Foundational Principles (Moeller et al., 2024c)

Principle Number	Best Practice Principle
1	**Early Identification (EI) following identification:** Early, timely and equitable access to services
2	**Family-EI Provider relationships**: Partnership, engagement, capacity building and reflection
3	**Family Support:** Basic Needs, strengths, challenges and connections
4	**Child Well-being:** Infant/child Development, positive social and emotional functioning, child welfare and safeguarding
5	**Language and Communication:** Early and consistent access, approaches and opportunities, and language-rich environments
6	**Use of assistive technologies and supporting means of communication**
7	**Trained Family-Centred Early Intervention (FCEI)-DHH providers:** Dispositions and Competencies
8	**Teamwork amongst Professionals:** Composition, collaboration and responsibilities of teams
9	**Developmental assessment:** Purpose, approaches, skilled assessors and interventions
10	**Programme Monitoring:** Relevance, effectiveness, and tracking DHH programmes/services and outcomes

The 2024 expanded principles concur with the Infant Hearing Position statement (2019), which emphasises the need for individualised support and information for families in relation to language and communication, leading to high-quality interactions within the home. The Position Statement, similarly, emphasises the importance of promotion of the social, cognitive and linguistic development of the child and refers to the fact that early intervention may take place in the home or maybe centre or community-based (or a combination of these), which would encompass provision within a PSFSG.

UK-based Legislation and Guidance

Provision for Special Education Needs and Disability within the UK is governed by nation-specific guidance as follows:

Wales

Special Educational Needs Code of Practice for Wales

(Welsh Assembly Government, 2013)

England

Code of Practice for Special Educational Needs and Disability (Department for Education/Department for Health, 2015)

Scotland

Getting it Right for Every Child (GIRFEC) (Scottish Government, 2006 onwards)

Supporting Children's Learning: Statutory Guidance on the Education (Additional Support for Learning) Scotland Act 2004 (as amended) Code of Practice (Third Edition) (Scottish Government, 2017)

Northern Ireland

Department for Education Northern Ireland: The draft code – Section 6 – Children under Compulsory School Age – Services, Assessment and Statements (Department for Education Northern Ireland,2020)

Supplement to the Code of Practice on the Identification and Assessment of Special Educational Needs (Department for Education Northern Ireland,2005)

Code of Practice on the Identification and Assessment of Special Educational Needs (Department for Education Northern Ireland, 1996)

Each Code of Practice has sections explicitly outlining the regulations for those under statutory school age. Within the respective codes, there is a commonality of themes with reference to factors such as the importance of working in partnership with parents, the provision of flexible support for children and families, the need for effective early intervention, and coordinated multi-disciplinary working. There is no direct reference to the provision of PSFSGs; however, in section 1.14, the Welsh Code of Practice refers to the need for training and support groups to be accessible to both Welsh and English-speaking families. Good practice guidance is also in existence in the form of Quality Standards (NDCS, 2016) which embody the principles of the International Consensus Statement (Moeller et al., 2013).

Academic Literature

Deafness-specific Literature

There is no specific academic literature concerning PSFSGs for pre-school d/Deaf children and their families although family centre-based support does form part of the wider analysis of support available to this group, undertaken by Evans & Robinshaw (2000) and Robinshaw and Evans (2001). There are several studies which evaluate parent-to-parent support (Henderson et al., 2016; Henderson et al., 2014; Narr, 2015; Mehta et al., 2020). These are worthy of consideration as the facilitation of peer-to-peer support is likely to be one of the key functions of a PSFSG. Henderson et al. (2014) identify the central importance of parent-to-parent support, and this is reinforced by Calderon and Greenburg (1999), who emphasise the value of a social network (including both peers and professionals). This view is echoed in Jackson's (2011) study in which parents rated input from other parents of d/Deaf children as a very important source of support. Mehta et al's (2020) small-scale UK-based study of input from Parent Support workers (who were themselves parents of d/Deaf children) highlights the value to parents of input from those with shared experience. Henderson et al. (2014, 2016) establish a conceptual framework of parent-to-parent support comprising the three key components of well-being, knowledge and empowerment, and aspects of peer-to-peer support identified by other authors such as Wood Jackson and Turnbull (2004) would also fall into these broad categories.

Disability-Related Literature

Owing to the limited literature related to support groups for pre-school deaf children and their families, relevant papers related to support groups (either mutual support groups or professionally led groups) for families of infants with other disabilities such as Autism, Developmental Delay, Cerebral Palsy are also worthy of examination. In doing so it is recognised that 'Deafness is not a learning disability, although the impact it has on a baby or young child can be significant and wide-ranging' (NDCS, 2016:3) and the distinctly different impact of deafness in comparison to other disabilities is acknowledged. These studies are included on the basis that parents of infants with different special educational needs and disabilities often share similar experiences - such as the the emotional impact of receiving a diagnosis, the need for the family to adapt to their new circumstances, the development of strategies to support their child's development, and the challenges of navigating complex systems. It is also probable that the organisation and nature of some of these support groups are, to some extent, comparable to similar groups for families of d/Deaf pre-schoolers. Therefore, research related to support groups and peer-to-peer support for other disabilities is likely to add to the body of available knowledge, given the limited range of research which relates specifically to deafness.

Generic and Specific Disability-focussed Literature

When reviewing a selection of non-deafness-specific literature, several themes emerge, many of which are comparable to those emerging within the deafness-specific literature. Within the general disability-related literature, related to either mutual support groups parents reported increased control, agency and resilience (Jackson et al., 2018; Meltzer et al., 2020; Soloman et al., 2001). Support of this nature created a sense of belonging to a community, social interaction and friendship (Jackson et al., 2018; Meltzer et al. 2020; Prest et al., 2022; Soloman et al., 2001). Meltzer describes the relationship of parent-to-parent support as reciprocal in nature with the giving and receiving of information and support and this concept of reciprocity is also apparent in the deafness-specific work of Henderson et al. (2014, 2016). In addition, these support groups are reported to provide opportunities for self-change and personal development (Jackson et al., 2018; Meltzer et al., 2020; Soloman et al., 2001).

Parental Satisfaction

Measures of parental satisfaction in relation to the disability-based groups attended (both professionally led and mutual support groups) indicate good levels of parental satisfaction (Krstic, 2012; Jackson et al., 2018; Soloman, 2001; Prest et al.,2022). Soloman et al. (2001) note a correlation between the perceived usefulness of the sessions and parental satisfaction, and Krstic et al. (2021) report that feedback was initially positive with the caveat that more research is needed. However, in assessing these findings, one must be aware of the subjective nature of judgements of this type and, as Soloman et al. (2001) indicate, the social desirability of satisfaction.

Leadership of Support Groups

Within the available literature, an interesting issue emerges whether support groups should be parent- or professionally led. Within the UK, although there is no current empirical evidence, it is likely that such groups are mainly professionally led; however, there exists a range of opinions concerning whether this is the most appropriate model. Soloman et al. (2001) highlight the need for groups to be parent-led, with professionals undertaking a sign-posting role but not being directly involved. Within the deafness-specific literature, this view is supported by Henderson et al. (2014), who state that "parent-to-parent support is a central tenant of family-centred care ….it must be provided by experienced parents. It cannot be replicated by professionals". In comparison, Haggman-Laitila & Pietila (2009) report that parents appreciated the role of professionals in terms of planning/organisation and moderation of discussions. Similarly, the work of Robinshaw & Evans (2001) highlights the value parents place upon the opportunity to meet both other parents and professionals in the same location.

Cultural Issues

A small body of work considers the impact of cultural issues within parent-to-parent support. In Lusa's (2010) study of Chinese parents attending a specific support group for Chinese parents of children with disability, parents recognised the importance of their ability to meet with others from the same culture who understood their own culture and cultural pressures. Narr et al.'s (2015) deafness-specific study of support from Parent Mentors to Spanish-speaking and English-speaking parents found that Spanish-speaking mentors had more contact with fathers than English-speaking mentors, leading to the hypothesis that these fathers may be more confident to speak to another parent rather than a health or education professional. The study also identified greater issues of acceptance of the diagnosis of deafness from Spanish-speaking parents. These studies, whilst limited in number, highlight the importance of cultural considerations in relation to the provision of early intervention.

Summary

Whilst there is a range of literature, guidance and legislation related to early intervention with young children who are d/Deaf and their families, there is no available research which primarily concerns the role of PSFSGs. Studies related to parent-to-parent support indicate the value of support of this type to parents of both children who are d/Deaf and/or have other disabilities. However, in considering the role of PSFSGs the focus should not just be limited to the consideration of peer-to-peer support as it is likely that these groups fulfil many other functions deemed important to the parents of d/Deaf children as detailed in Tables 1, 2, and 3.

Methodology

Aims of Research

The study aims to answer three key questions:

1. What are the perceived benefits of attendance at a PSFSG, from the perspective of both the families who attend and the professionals who organise and deliver support group provision?
2. What do PSFSGs typically look like in practice within the UK?
3. Is it possible to establish models of good practice in relation to the content and delivery of PSFSGs, which could be adopted at a national level?

Research Methods

The study utilised a mixed methodological approach, involving the gathering of both qualitative and quantitative information. This approach was selected to study the topic more comprehensively via access to complementary data sets. Employment of different methodological approaches ensured that the relevant strengths and weaknesses of the different approaches were compensated for, and that greater validity could be achieved. (Denscombe, 2014; Cohen et al.,2011; Teddlie & Tashakkori, 2009.)

Overview of Research Process

The research process took place in three stages, as summarised below:

Stage 1:

- Literature Review
- Recruitment of Services/Schools for the Deaf
- Distribution and completion of Professional Questionnaire (see Appendix A)

Stage 2:

- Observational Visits to the PSFSGs
- Distribution and completion of the Family Member Questionnaire (see Appendix B)
- On-line semi-structured interviews with family members and professionals

Stage 3:

- Analysis of data
- Creation of final report and plain English synopsis
- Co-creation of potential models of good practice via family/professional panel

Literature Review

A literature review was undertaken to provide contextual and background information pertinent to the study. Recurrent themes within the literature were identified to form the basis of the subsequent research analysis.

The following databases formed the basis of the literature search:

- EBSCO Host
- ERIC
- Scopas
- PubMed

The following search terms were employed:

- *Support Groups and Disability*
- *Parent Support Groups and Disability*
- *Family Support Groups and Disability*
- *Support Groups and d/Deaf children*
- *Peer-to-Peer Support and d/Deaf children*
- *Peer-to-Peer family support and deafness/disability*
- *Early Intervention and Deafness/d/Deaf children/infants*

Sampling

To represent provision across the UK a sample of services/schools within Wales, Northern Ireland, Scotland and England was employed, to include at least one school/service from each of the four nations (England, Wales, Scotland, Northern Ireland). The study utilised an opportunity sample of services whose managers were known to the researcher(s) and who were willing to be involved in the study. Similarly, the parents/carers who were involved were self-selected and composed of parents attending the sessions visited who opted to take part in the study. Non-probability sampling is often used within small-scale research and has advantages in relation to cost and time. The limitation of this approach is that the sample cannot be claimed to be representative of the focus population as would be possible with a truly randomised sample. The research findings are, therefore, less generalisable, as in essence, as Cohen et al. (2013:155) state, the sample seeks to represent "instances of itself in a similar population" rather than being reflective of the population as a whole. It is, therefore, possible that the parents/carers and schools/services involved were composed of those more willing and able to engage in research, and as such, this may have influenced the findings.

Criteria for Inclusion in the Study

Professionals

Professionals involved in the study had to satisfy the following criteria, they had to be:

- Head of a Specialist Support Service or Head of a Special School catering for children and young people who are d/Deaf in England, Wales, Scotland or Northern Ireland.
  or
- Currently employed as a QToD within a Specialist Support Service/School for the Deaf in England, Wales, Scotland or Northern and having responsibility for planning and delivery of the PSFSG.

Family Members

Family Members had to meet the following criteria:

- To be part of the family (as defined earlier) of one or more child under the age of 5 years who is d/Deaf and attends a PSFSG involved in the study.

Recruitment

Heads of Specialist Support Services and Schools for the Deaf in the UK were contacted, and consent was requested for themselves or a QToD in their team to be included in the study. Information was provided via a Professional Participant Information Sheet (Appendix C). Parents/Carers were recruited during scheduled observation visits to the PSFSGs included in the study. Verbal information about the study was provided during the visit and further information was provided via the Family Member Participant Information sheet (Appendix D). All participants were aware that the information they provided was strictly confidential and that they could withdraw from the study at any point.

Questionnaire Design

Two questionnaires were developed for professionals and family members respectively (Appendix A and B), in addition an ethnicity/ethnic background questionnaire based on the recommended current nation-specific categorisation (Government Statistical Service (GSS), 2011) was developed for family members (see Appendix E).

Both contained mainly closed questions to obtain quantitative data. Questionnaires were developed using Survey Monkey (Survey Monkey Inc., 2024) which was selected in relation to ease of distribution, collation and analysis. The professional questionnaire was distributed via an email link to the QToDs or HoSS in each area to gather empirical information about the service and the PSFSG in advance of the observational visit. The parental questionnaire was developed to obtain basic demographic data about the attendees and their children/ren and served to recruit parents/carers for the later stages of the research.

This questionnaire was distributed in paper form to parents attending the parent group on the date of the planned observation; to maximise opportunities for parents to ask questions they may have about the study whilst the researcher was on-site. Care was taken in the formation of the specific questions included to avoid bias and ambiguity to ensure the validity of the responses provided (Bell & Waters ,2014, Denscombe, 2014 and Cohen et al., 2013). Closed questions were included as a means of generating empirical data about the individuals completing the survey and/or the nature of the parent group they were engaged in. Closed questions with a limited range of responses were deemed most appropriate to capture most of this data, and the responses were subsequently easier to code and analyse. In some instances, some open-ended questions were included where responses were likely to be more varied e.g. main language used in the home.

Observational Visits to PSFSGs

An in-person observation visit was made to each of the participating PSFSGs. All observational visits were carried out by the same two researchers, both of whom were experienced QTODs with additional qualifications and professional experience in Early Years and Deafness. The Observational Schedule (Appendix F) was developed by the two researchers based on their professional understanding of activities which might typically take place within the context of a PSFSG. As the classification of activities involved a subjective element, the first visit was jointly attended by both researchers and post-visit moderation took place to ensure that similar activities had been consistently classified within the schedule.

Semi-Structured Interviews

In acknowledgement of the limitations of the nature of the initial questionnaires, semi-structured interviews were also included in Phase 2 to provide a more comprehensive and in-depth qualitative analysis of the topic. As Denscombe (2014) states, interviews are an appropriate tool to explore complex issues, subjective aspects such as viewpoints, and to access information from key informants. Semi-structured interviews were selected in preference to structured or unstructured interviews to allow for a degree of specificity and consistency in the topics covered, whilst retaining the flexibility to focus on particular responses and issues highlighted by respondents in more depth (Denscombe, 2014). All interviews took place on-line via Zoom (Barbu,C.M., 2014), this format was selected as interviewees were based in a variety of locations and it allowed interviews to take place at the most convenient time for the individual. The facility to record interviews and utilise the transcription service within Zoom also provided greater efficiency in relation to researcher time. All interviewees were able to request support for the interview via BSL interpretation, closed captions or translation into home languages if required.

Analysis of Data from Phase 2

The interview responses were subject to thematic analysis to identify a series of primary and secondary themes, and a comparison was made between the themes emerging from the responses of professional and family members. Triangulation of data from the questionnaires, observation schedules and interviews were undertaken, to assess the validity of responses, overcome the inherent weaknesses associated with individual research methods and to develop a more in-depth understanding of the issues (Cohen et al., 2013; Denscombe, 2014).

Report Production

The findings were summarised by the lead researcher into a final report and a plain English synopsis was produced.

A focus group was then established to look at the possibility of developing the research findings into a set of good practice guidance to support schools, services and families in assessing what good practice in this area should look like. The group comprised family members and professionals, taking care to ensure that there was an equal balance of individuals from each group. An initial draft was produced by the lead researcher, which was then distributed to members of the group for comment, discussion and further refinement prior to publication.

Presentation of Findings and Discussion of Results

Sampling

A total of 12 Services/Schools for Deaf were invited to take part in the study, and of these eight services chose to take part in the research. Geographically, these included services within the North, Midlands, South of England, Wales and Northern Ireland and covered a range of inner city, urban and rural areas.

Of the 12 services initially approached, seven chose to be involved in all components of data gathering. One service took part in the professional interview stage only, as the provision of the PSFSG was temporarily on hold in the academic year 2023-24. This service was still included in the professional interview stage to support coverage of the research across the individual nations of the UK. It was not possible to include a service from Scotland or a School for the Deaf within the time frame for the study. As a result, the findings only include responses from Specialist Support Services in England, Wales, and Northern Ireland.

Demographic Information: Services

Numbers of Pre-school Children (0–5 Years) on Caseload of Respective Services

Reported numbers of pre-school children (0–5 years) on the caseload of the services/schools involved ranged from 18 to 119. This is likely to relate to differences in the overall size of the population covered by each service and variation in average service size within the individual nations of the UK, as average numbers of d/Deaf children per service are higher in England than in Wales and Scotland (CRIDE UK-wide Report, 2022).

Proportions of Pre-school Children on Caseload Attending the PSFSG

School/service estimations indicate that the numbers of pre-school children and their families regularly attended the PSFSG are lower than the overall pre-school caseload numbers for each school/service with most services/schools (62.5%) reporting approximately 0–9 regular pre-school child attendees and fewer (37.5%) reporting 0–19 attendees. The professionals involved felt that this was likely to relate to several factors including, competing demands on family time related to the diagnosis of deafness, work commitments, nursery attendance and parental choice. Professional interviewees also noted that despite being invited, families of children with mild, moderate, unilateral or more transitory deafness were less likely to attend than those with severe or profound deafness.

Demographic Information: Parents/Carers

This data was gathered from parents/carers who attended the PSFSG on the day of the researchers' visit and who chose to complete a questionnaire. Therefore, this data presents a snapshot of those in attendance on those dates but may not fully represent the nature of the families who regularly attend the PSFSGs.

Of the 51 family members who were in attendance when the researchers visited, 40 chose to complete the questionnaire.

Table 4: Family Member Relationship to the d/Deaf Child/ren (Questionnaire)

Self-described relationship to the d/Deaf child/children	Total number
Mother/Mum	26
Father/Dad	8
Grandparent	5
Auntie	1

Whilst most of the attendees were mothers, there were also several fathers and grandparents present. The demographic data reflects the numbers of grandparents undertaking a significant childcare role (Age UK, 2017, Statham, J, 2011, Department for Work and Pensions (DWP), 2017) and highlights the importance of support and guidance for these grandparents, who are significant figures in the development of their d/Deaf grandchild.

Hearing Status of Parents (Questionnaire)

Most family members described themselves as hearing 91.89%, 8.11% as d/Deaf, with the remainder choosing the ‘prefer not to say’ option. These figures reflect the fact that most d/Deaf infants are born to hearing parents (Mitchell & Karchmer, 2004). The low number of respondents identifying themselves as d/Deaf means that the overall findings may not reflect the views of d/Deaf family members.

Ethnic Group/Background

Questionnaire responses indicated that most family members in attendance described their ethnic background/group as White (British/English/Scottish/Northern Irish/Welsh), and a range of other ethnic backgrounds were also indicated, as demonstrated in Table 5.

Table 5: Ethnic Group/Background of Family Members (Questionnaire)

(based on GSS (2011) descriptors)

Ethnic Group/Background	
White: English / Welsh / Scottish / Northern Irish / British	22
White: Any other White background	3 Total (2 Polish, 1 Latino)
Mixed Multiple Ethnic Groups: White and Black Caribbean	1
Mixed Multiple Ethnic Groups: White and Asian	1
Asian/Asian British: Pakistani	3
Asian/Asian British: Chinese	1
Black/African/ Caribbean/ Black British: African	2
Other Ethnic Group	1 (Arab)

Demographic Information: Family Members Who Engaged in Semi-structured Interviews

In total 10 family members undertook semi-structured interviews comprised of:

Table 6: Family Member Relationship to the d/Deaf Child/ren (Interviewees)

Self-described relationship to the d/Deaf child/children	**Total number**
Mother/Mum	6
Father/Dad	1
Grandparent	3

Table 7: Ethnic Group/Background (Interviewees)

Ethnic Group/Background	
White: English / Welsh / Scottish / Northern Irish / British	7
Mixed Multiple Ethnic Groups: White and Black Caribbean	1
Asian/Asian British: Pakistani	2

Hearing Status (Interviewees)

All the family members who took part in interviews described themselves as hearing.

Nature of Provision: Frequency and Location

Frequency of Sessions

Most Services/Schools surveyed provided a weekly or fortnightly PSFSG, with others offering a monthly or termly group.

Nature of Sessions: Face-to-face vs On-Line

Sessions were primarily delivered face-to-face, except for one service, which offered a combination of face-to-face and on-line provision. Many respondents reported that provision had been solely online during the COVID-19 pandemic and that since the lockdown, they had returned to face-to-face meetings, as this was the preferred option for both the families attending and themselves as providers. In the case of the service providing both face-to-face and on-line sessions, the on-line sessions had a more distinct information-based focus, covering topics such as audiology and language development.

Location of Sessions

A range of locations were being utilised for sessions, including specifically designed provision for this age group, such as Children's Centres and School-based Nurseries, as well as other community-based facilities, for example, church halls and community centres, with one group meeting at the local Deaf Centre.

Rationale for Choice of Venue

The reported factors governing the choice of venue were varied and included:

a. **Financial considerations**: venues had been selected as use was either without cost or low-cost.
b. **Accessibility**: venues had been selected due to central location within the geographical area covered by the service, existence of good road and public transport links and availability of car parking.
c. **Availability of resources/ability to store resources:** several venues were selected as they were already designed to cater for pre-school children and contained a range of age-appropriate equipment. Some other venues were employed as there was an opportunity for the service to store resources on-site in between sessions.
d. **Availability of regular and consistent time-slots**: several respondents cited the ability of a venue to offer the same time-slot on the same day each week/month as a very important factor in assisting families plan and to fit other commitments around attendance.
e. **Room acoustics**: in some cases, this was specifically cited as a reason for selection.
f. **Other**: in one case, a local Deaf Centre was selected to facilitate links with the local Deaf community.

Nature of Provision: Content

Most Services (87.5%) reported that they had a structured programme of events for each session. The findings from the observed sessions and professional questionnaires indicate that there was a high degree of commonality in relation to content across the PSFSGs involved. Whilst these PSFSGs represent a small sample of UK-wide provision, and therefore any over-generalisation of findings should be avoided, the level of consistency between these groups does seem to indicate that the activities noted in Table 6 represent content which could be regarded as typical.

Table 8: Type of Activity Taking Place During Observational Visits

Activity type	**Additional information from observations**
Welcome/Greeting activity	Most observed sessions contained a welcome activity/song and some also included a good-bye song/activity to conclude the session.
Songs/Musical Activity	All sessions involved songs and musical activities. These included combinations of: • Use of recorded song/music audio materials, some of which was specifically designed for children who are d/Deaf • Singing of well-known songs for pre-school children • Singing, signing and playing of instruments by staff, parents and children • Songs supported by BSL, gesture and props • Song/Music activities designed to develop early listening skills e.g. changes in loudness, tempo, pitch, awareness of sound vs no sound, recognition of own name • Development of early sign/spoken vocabulary through song e.g. animal names and sounds • Development of early concepts through song e.g. high/low, number skills • Development of early turn-taking skills within song/music activities • Welcome and Good-bye songs
Free play	All sessions involved free play with age/stage appropriate toys and materials, some of which involved informal adult interaction and modelling.
Activity led by professional	All sessions involved activities led by the professionals involved, including music/song sessions, art/craft activities, snack-time session etc.
Activity modelled by professional for parents	All sessions included modelling of activities/language for parents. In most instances this took place incidentally/informally during free play. In some cases, modelling was more explicit with additional explanation for parents of the strategies employed.

Opportunity for parents/carers to talk to each other (peer led activity/discussions)	All sessions involved opportunity for parents/carers to talk to each other. In some instances, this occurred spontaneously and informally, in others it was supported by staff who initiated discussion of issues relevant to the parents in attendance.
Opportunity for parents/carers to talk to professionals	This was noted within all the observed sessions with professionals circulating to ensure that there was opportunity for discussion with all families in attendance.
Visiting speaker/s	This was not observed during any of the researcher visits, but all but one of the services stated within the questionnaire that this was a feature of their provision.
Input from Audiological services	One observed session contained advice and input (including earmould impression taking) from the local clinical audiologist. Many services reported in the questionnaire that input from a clinical or educational audiologist took place sometimes within the sessions and two services responded that this was never included. A common feature of all observations was discussion with QToDs and parents/carers about audiological issues e.g. hearing aid management, assessment for cochlear implantation and hands on assistance with hearing equipment.
Activity with d/Deaf adult	Within the observed sessions input from a d/Deaf adult formed part of the provision in the minority of sessions and in one service a d/Deaf adult, employed as a Total Communication Tutor, was the lead member of staff in relation to organising and leading the PSFSGs.
Activity involving BSL/Early sign	In most cases, BSL or early sign was incorporated into song-based or free play sessions. The consistency of use/modelling BSL/individual signs was varied. In a minority of settings use was consistent and in others use of BSL/sign was more ad hoc and included a combination of recognisable signs and gesture.
Snack activity	Many of the sessions included a snack session/refreshment for the adults and children attending. In most cases this was an informal part of the session. In a limited number of sessions, the snack-time was more structured and used as a basis for language development, turn-taking and modelling of key words/signs.

Discussion/advice re use of activities at home	This was observed in a minority of sessions, and one group had a take-home activity for the families involved to try at home.
Curricular activities	The most common curricular activities related to early number and concepts and took place informally within free play/songs.
BSL tuition for parents	This largely took place informally within the context of songs/free play. In one session teaching of key signs relevant to specific family members was included and in this session family members were also pro-active in requesting demonstration of signs they wished to use at home. In one session, in addition to the use of sign within the group, families were also signposted to additional BSL tuition provided by the service.
Other activities	Some groups provided a library of pre-school books. Story sacks (a collection of items in a bag or container that can be used to support and extend the telling of a story) for families to loan.

Within the sessions observed, the main activities catered more for young children than specifically for babies. It may be that more bespoke activities/intervention is needed for these younger attendees.

Nature of Provision: Professional Roles

Table 9: Professional Roles (As Noted During Observational Visit)

Group	QTOD	STA/CSW	Speech and Language Therapist (SaLT)	Deaf Adult	Clinical/Educational Audiologist	Other
Group 1: Visit	2 (including 1 HoSS)	1	1	Absent due to illness	1 (also HoSS)	0
Group 2: Visit	4	0	0	0	0	0
Group 3: Visit	2	0	0	0	0	0
Group 4: Visit	2 (including 1 HoSS)	4	0	0	0	0
Group 5: Visit	3 (including 1 HoSS)	1	0	0	1	0
Group 6: Visit	2	2	0	1	0	0
Group 7: Visit	1	2	0	1	0	0

A visit to Group 8 was not possible as the group was suspended temporarily

Table 10: Professional Roles (As Noted in Professional Questionnaire)

Professional Role	QTOD	STA/CSW	SaLT	Deaf Role Model	Clinical/Educational Audiologist	Other
Total	8	6	1	3	1	0

The findings of the observational visits and professional interviews indicate that all groups were attended by QToDS (some of whom were also HoSS). In most services, the planning and delivery of the sessions were assigned to specific QToDS, and in one service, this lead role was undertaken by a CSW. Other QToDs tended to attend if the families they were working with – in the home/pre-school setting – were also coming along to the Family Support Group. In some groups, TAs and CSWs were also part of the core team and were involved in the planning and delivery of the sessions. Only one group had regular input from a Specialist SaLT, and similarly, only one group had regular input from both a clinical and educational audiologist. In 50% of the responses to the initial professional questionnaire, a d/Deaf adult was reported to form part of the PSFSG provision. However, a d/Deaf adult was involved in a minority of the sessions observed, with a d/Deaf adult present in only two sessions. In these instances, the d/Deaf adult was an existing employee of the service undertaking the role of QToD, STA/CSW, Deaf Instructor and/or Deaf Role Model. One of the services reported that they had identified that this was a gap in their provision and that they were seeking to appoint a d/Deaf individual in the capacity of a Deaf Role Model. Some of the groups were regularly attended by the HoSS or a QToD in a senior leadership role, which reflects the recognition amongst senior management of the importance of this provision.

Itinerant Visitors

In addition to the regular staffing, 85% of professional questionnaire respondents indicated that additional input was provided by several professionals/organisations on a less regular basis. These included staff from Health, Education and Social Care, e.g. SaLT, Educational Psychologist, Paediatrician, Audiology Staff, Dental Service, Health Visitor, organisations relevant to early years, such as Book Start and deafness-specific charities, e.g. Deafness Support Network, National Deaf Children's Society and Hearing Dogs for the Deaf. These visitors were not apparent during the observational visits, which may reflect the fact that these visitors are a less-frequent component of the PSFSGs, as indicated in the questionnaire responses, or that observational visits did not coincide with input from visiting speakers. It was interesting to note that several respondents reported that both regular and less frequent input from other professionals/organisations had been well-established prior to the COVID-19 epidemic and had either not been as successfully re-instated post-pandemic or was still in the process of being re-established.

Impact of PSFSG Attendance on Overall Allocation of Support

Within the initial questionnaire, two services reported that the provision of the PSFSG replaced a home visit, therefore potentially impacting on the equity of provision for those who were unable to/chose not to attend. However, in the interim, these policies had been reviewed, and within the professional interviews, all services reported that attendance at the PSFSG was additional to regular support visits in the home/pre-school setting.

Perceived Benefits of Attendance

Thematic analysis of the semi-structured interviews with family members and professionals indicated a number of main and secondary themes, as follows:

Perceived Benefits of Attendance for Families (Professional Views)

Thematic analysis of professional responses to questions related to the aims of the group highlighted 3 key themes which were consistent across all interviewees.

Primary Themes

1. **Family-to-Family Contact:** All interviewees stated that one of the main aims of the provision was to provide an opportunity for families to be in contact with other families in the same situation as themselves in order to promote mutual support and sharing of experiences and to lessen feelings of isolation. Accounts of the development of strong and ongoing relationships between the family members who attend were reported.
2. **Information/Advice:** All interviewees also perceived the PSFSG to be a forum for providing information and advice to families. The PSFSG was seen as an effective means to provide information/advice to several families at the same time, and this, in addition, created opportunities for parents to contribute and share experiences related to the topic under discussion.
3. **Modelling/Coaching:** All respondents reported that one of the main functions of the group was to provide opportunities for coaching and modelling within the session with the aim of encouraging families to develop effective strategies to support key aspects of child development such as language development and listening skills.

Secondary Themes

1. **Socialisation for the d/Deaf child:** Professionals considered that the Family Support Group provided important socialisation opportunities for the d/Deaf children because of the opportunity to interact with their d/Deaf peers in a context that was different from the home or nursery setting.
2. **Opportunity to have contact with the Wider Team:** The PSFSG was regarded as an important opportunity for families and children to have contact with and input from other members of the service who may work with the family at some point in the future. This was regarded as facilitating and supporting smoother future transitions, as the other staff members were already known to the family and had knowledge of the child prior to beginning to work with them.

3. **Opportunity for multi-disciplinary working:** As the PSFSG provides opportunities for other professionals to attend, the respondents felt that this provided opportunities for multi-disciplinary working, facilitating aspects of practice such as liaison, joint observations, and informal joint meetings with the family members as per Foundation Principle 8, Moeller et al. (2024c), B5 & D3 Quality Standards Early Years, NDCS, 2016.
4. **Opportunity to see the d/Deaf child in a different context:** The respondents felt that the PSFSG provided the members of their team/visiting professionals with opportunities to observe the child in a context which was different to the one where they usually undertook their visits.
5. **Audiological input and maintenance of equipment:** One service, which had regular input from educational and clinical audiologists, stated that this was a key component of their group and that the provision of ear mould impression-taking was a strong driver in encouraging families to attend.

Perceived Benefits of Attendance for Families (Family Member Views)

Thematic analysis of family member responses to questions related to the aims of the group highlighted 3 key themes which were consistent across all interviewees as well as a number of secondary themes.

Primary Themes

1. **Family-to-Family Contact:** All respondents perceived the PSFSG to be an opportunity to meet other families in the same situation as themselves and to see other children who were d/Deaf like their own child/ren. Many respondents recalled the first time they had attended the group. They reported that it had been very important to see other d/Deaf children wearing hearing aids or with Cochlear Implants who were engaging in activities and communicating. This opportunity seemed to have normalised their own child's diagnosis, also noted by Evans & Robinshaw (2001), and observing the other d/Deaf children reportedly made them more aware of how their own child may develop and progress in the future. The relationships with other families were seen as reciprocal, with some respondents who had attended for some time, being aware that they had benefitted from the support of other families earlier in their journey and that they were now able to provide that support to others. This aspect was particularly noticeable in the responses of family members with children who had cochlear implants; these respondents felt that having experienced the process, they were able and willing to offer advice and support to others. In observations of family members within the sessions and via interview responses, there was evidence of a strong community

engagement with families taking a keen interest in the development and progress of not just their own child but also the other children they had come to know in the group.

2. **Socialisation Opportunities for their d/Deaf Child:** Whilst acknowledging the young age and potentially limited awareness of their child, the respondents felt that it was very important for their child to be in a context where they can meet other children who are d/Deaf with Hearing Aids or Cochlear Implants like themselves. They felt it was important for their child to interact with other d/Deaf children, and many contrasted the PSFSG with other pre-school groups/ activities they attend where their child is the only child in attendance who is d/Deaf and therefore has no opportunity to meet other d/Deaf children. These findings accord with earlier research by Evans & Robinshaw (2001) in which parents attending family intervention, which was centre-based, noted improvements in their d/Deaf child's confidence, self-esteem and communication skills because of the opportunity to interact with their d/Deaf peers
3. **Contact with the QToD:** Respondents felt that contact with the QToD, in addition to their existing provision, was a major benefit of attending the group. This appeared to be particularly significant for families whose children were in nursery provision where the professional visits may be taking place within the setting rather than the home. The importance of contact with the QToD was also notable in the comments of respondents who were grandparents, undertaking a significant component of childcare. In these cases, the direct input from the QToD tended to involve the parents, and therefore, these grandparents welcomed the chance to speak to and receive advice from the QTODs during the PSFSG.

Secondary Themes

1. **Opportunity to meet the wider team/other professionals:** Family members welcomed the chance to meet other members of the Support Service within the context of the PSFSG. One respondent noted that this had made the change of key QToD for their child much easier, as the new QToD was already known to themselves and their child. In a setting where the SaLT was in regular attendance, a respondent reported that they found the opportunity to meet with the SaLT and discuss their child's progress very beneficial and regarded this as an important component of the PSFSG provision.
2. **Opportunity for Staff to see the child in a different context:** Several family members felt that attendance at the PSFSG gave the professionals working with their child the opportunity to see their child in a different context to those normally visited.
3. **Bespoke nature of Activities on Offer:** Some respondents referred to the bespoke nature of the activities on offer, noting that whilst the activities within the session were very typical activities for pre-school age children, what made them effective was the fact that they were specifically designed to cater for children who are d/Deaf. Some

respondents noted that their child engaged better in the activities at the Family Support Group than in other pre-school groups they had attended, which were not specifically catering for d/Deaf children. Some families also felt that their child focussed on or engaged better with specific activities in the group setting in comparison to the home.

Comparison of Parent/Professional Responses

When comparing the responses of professionals and family members, many similar themes were apparent. However, there are some notable differences between the themes identified within the responses of the two groups and in relation to the relative importance placed upon specific aspects of provision.

Table 11: Comparison of Themes Emerging from Professional and Family Member Interviews

Theme	Professionals	Family Members
Family-to-family contact	x	x
Information/advice	x	
Coaching/modelling	x	
Socialisation for the d/Deaf child	x	x
Contact with the wider team	x	x
Multi-disciplinary working	x	
Opportunity to see the child in a different context	x	x
Audiological input	x	
Contact with the QToD		x
Bespoke nature of provision		x
Different context for professionals to observe the child	x	x

Both groups stated that family-to-family contact was one of the key benefits of the PSFSG, which highlights the importance of peer-to-peer support for families of young d/Deaf children as identified in many other studies (Calderon & Greenburg, 1999; Evans & Robinshaw, 2001; Henderson et al., 2016; Henderson et al., 2014; Wood Jackson & Turnbull, 2004; Jackson et al.,2008; Jackson, 2011; Narr, 2015; Mehta et al., 2015). Professionals placed a strong emphasis on the provision of information, advice, modelling and coaching, whereas family member responses referred to contact with the QToD but tended not to expand upon the purpose of this. It may be that both groups are referring to the same aspects of QToD input, namely information, advice, modelling and coaching, but more exploration is needed. It is also possible that advice, information, coaching, and modelling were undertaken in a very naturalistic manner, and therefore, this was less identifiable to the families attending. Families also gave higher importance to socialisation opportunities for their child and the bespoke nature of the pre-school activities on offer. This is likely to reflect the fact that childhood deafness is a low-incidence disability (Fortnum et al., 2001); therefore, opportunities for d/Deaf children to interact with their d/Deaf peers are more limited, and as reported by several family members, that other pre-school groups cater less well for the needs of children who are d/Deaf. It is interesting to note that audiological input was a less common theme overall and was not noted in any of the responses of family members. This contrasts with the observation data, which indicated that discussion, advice and hands-on management related to audiology was a feature of all the sessions.

Parental Satisfaction

The families interviewed demonstrated high levels of satisfaction with the PSFSG they attended. When questioned about potential improvements to the group, these tended to be logistical, primarily relating to timing or location. It was clear from their responses that families felt that the professionals were doing their best to meet the needs of the range of families involved and they were appreciative of these efforts. This accords with the deafness-based research of Evans & Robinshaw 2000 and research related to non-deafness-specific disability groups (Krstic, 2012; Jackson et al., 2018; Soloman, 2001; Prest et al., 2022), which similarly noted good levels of parental satisfaction, indicative of positive parent- early intervention provider relationships (Principle 2: Moeller et al., 2024c).

Transferability of Activities to the Home Context

When questioned about the transferability of activities from the Family Support Group to the home context, professionals found this hard to assess, with some commenting that this was something they had not really considered. Most felt that this was difficult to assess and some commented that this is something which as a service they should perhaps begin to consider in more detail. Similarly, many family members found this a difficult question to answer, commenting that it was hard to judge as they tended to do very similar types of activities at home. A few respondents, notably grandparents, commented that they did try to incorporate ideas from the session into home activities, describing use of songs and incorporation of signs from the session into home activities with their grandchild. Many respondents did however comment that they did or had previously used music/songs from the sessions via the Baby Beats app (Advanced Bionics LLC, 2024) as suggested by their QToD.

Challenges

It was clear from professional responses that they faced several challenges in relation to the provision of an active and well-attended PSFSG.

Maintaining Numbers of Attendees

From the viewpoint of many of the professionals, maintaining a critical mass of attendees had presented a significant challenge. Many services reported that their numbers had fluctuated significantly over time, and several were taking active steps to improve or maintain numbers. Professionals appeared to be using a range of strategies to support and encourage attendance; however, they were aware that some families were less able/willing to come to the groups.

Interventions by Professionals to Support attendance included:

- Assistance with transport via encouragement of family lift-sharing or professionals supporting families to attend the initial visit to the group
- Open access to the group for all family members, including members of the wider family and siblings
- Use of phone calls, texts, social media and printed information to keep families informed of forthcoming meetings
- Running specific events for particular ethnic/cultural groups within the community to identify and overcome barriers to attendance
- Setting up satellite groups within specific local areas to increase ease of access

They recognised the importance of having enough regular attendees in relation to:

- Quality of experience of families: having enough other families to interact within the session and avoiding situations where the family members were outnumbered by professionals, family members also noted that this was not desirable.
- Staffing: most groups involved several members of staff, and some services were concerned about potential scrutiny of staffing numbers in relation to attendees.
- Balancing accessibility of location and numbers of attendees: in situations where services held the PSFSG in only one location professionals were aware that this created access issues for some families. To overcome this issue some services ran multiple

groups in different areas within their locality, but this was not practical for all areas due to low overall numbers which would make additional groups less viable.

Transport

Most services (75%) did not offer/were unable to offer any assistance with transport from the family home to the venue. Family members who volunteered to be interviewed did not report issues with transport, as most had their own transport. Many family member interviewees acknowledged that travel may be an issue for some families, although it was not a significant issue for themselves. This is likely to mean that the responses do not fully reflect the issues faced by families reliant upon public transport or the impact that this may have upon their attendance. Whilst the interviewed family members were able to travel to the venue some noted that this involved a long round trip, and this was particularly significant in more rural areas or areas of high congestion. During the observation visits, anecdotal comments from family members indicated that many of them undertook 1-2 hour round trips to attend the sessions. Services were creative in offering some support to families with examples including, encouraging family lift-sharing, accessing charitable support e.g. one service had managed to access support from the local volunteer hospital transport service or QToDs offering transport to families for the initial visit to the group. Whilst these initiatives are positive examples of effective problem solving, given the higher incidence of poverty in families which include a disabled child (Social Metrics Commission, 2023, Joseph Rowntree Fund, 2024), funding of transport is clearly an important issue to be addressed to achieve equality of access for all families.

Use of BSL

Within the observed sessions the quality of use and modelling of BSL was very varied. In some contexts, BSL was used consistently, key signs were demonstrated to families and family members had opportunity to request demonstration of signs which they wished to use within the home. In other sessions use of signing was more ad hoc and a combination of recognised signs and gesture was in use. This was recognised as an area of required development by some services, one service planned to improve BSL input by planning a schedule of new signs to be introduced each session, with supplementary handouts for families to use at home, another service was in the process of recruiting a Deaf Role Model with the intention that this individual would support the development of BSL within the PSFSG. In the family responses, only two family members referred to use of sign, one family member found modelling within the PSFSG useful to acquire signs to use in the home but commented that they were unsure if the signs used in the sessions were BSL or Makaton, another parent noted that this was an area where improvement was needed.

Succession Planning

Several professional respondents noted concern about the pre-school expertise of staff members in the future. Current good practice guidance emphasises the importance of training for those working with children and families in the early years, (Foundational Principle 7 (Moeller at al. 2024c), Domain 2: Quality Standards: Early years support for children with a hearing loss, aged 0 to 5 (England) NDCS (2016)) and many of the QToDs leading the PSFSGs involved had substantial experience and/or specialist additional qualifications in Early Years and Deafness. Concerns were expressed about the availability of and access to deafness-specific early years training for the staff who would replace them over time. This issue of provision of specific early years training for QToDs was noted by Robinshaw & Evans in their 2000 study, and whilst post-graduate and short courses in Early Years and Deafness have been available in the intervening period, many of these courses have now closed. Succession Planning is a significant issue as it is known that the population of QToDs is ageing with an estimated 48% aged 50 and over and due to retire within the next 10-15 years (CRIDE UK-wide Summary, 2023).

Other Emerging Themes

Decision-Making/Organisation of the PSFSG

When questioned about decision-making in relation to content of the PSFSG sessions all professionals and family members reported that this role was primarily undertaken by the professionals involved. Opportunity was provided for families to give feedback/make suggestions about potential content either formally via questionnaires or more informally through discussion, and examples were provided by both professionals and families about how these had been acted upon. The observations and interviews demonstrated an open and responsive relationship between professionals and the families involved, indicative of good family/early intervention provider relationships (Principle 2, Moeller et al. (2024c)). Families appeared happy with the status quo as per the findings of Haggman-Laitila & Pietila (2009), and there was no indication that families wished to take on more responsibility or have more control as advocated by Soloman et al. (2001).

Support Post 5 Years of Age

Two of the services involved had begun to establish a similar family group for families of children 5+ years, which met less frequently than the PSFSG at weekends or evenings. This initiative seems to offer good continuity to maintain connections made between families at the pre-school stage.

Social Media

In most of the PSFSGs social media provided a very effective means to maintain contact between families in-between sessions or to remind families of upcoming meetings.

Some Examples of Good Practice

This is not an exhaustive list and may include aspects of practice noted elsewhere in this report:

- Provision of on-line sessions in addition to face-to-face meetings
- Creative ways to support attendance e.g. lift sharing, accompanying initial visits etc.
- Use of Social Media to share information and encourage attendance
- Provision of input from audiology staff including provision of earmould impression taking
- Provision of input from SaLTs within the session
- Staff demonstrating flexibility and sensitivity to individual family needs
- Post session tasks to complete at home, encouraging family interaction beyond and between sessions
- Accessing local charitable funding to pay for additional aspects of provision e.g. snacks, input from pre-school music group
- Services demonstrating a culture of re-evaluation and ongoing development
- Sharing good practice via special interest groups attended by professionals involved in running the PSFSGs e.g. North West Early Years Group which facilitates sharing of ideas and activities to be included within PSFSGs
- Provision of a lending library with resources for families to use at home, such as BSL books, Story Sacks (a collection of items in a bag or container that can be used to support and extend the telling of a story), information leaflets for parents
- Provision of groups for school age children and families to maintain links established at pre-school age
- Provision of staff who are fluent users of the home languages of the families attending the PSFSG

Limitations of the Current Study

It is important to note that the family members and professionals involved were self-selected therefore the findings reflect the views of those who are more supportive of PSFSG provision and may not fully reflect the views of all family members or professionals. Whilst the study aimed to provide a snapshot of provision within all four nations of the UK, within the available time frame, inclusion of Scottish PSFSGs or those delivered by Schools for the Deaf were not possible. Similarly, some groups were under-represented in the data e.g. d/Deaf family members and the results may not fully reflect their views.

Conclusion

PSFSGs perform an important role in the overall package of early support provision available to families of d/Deaf children and provide a forum for the fulfilment of many aspects of good practice guidance. Within the study, professionals regarded the PSFSG as a significant component of their pre-school provision and demonstrated flexibility and sensitivity to the needs of families. The family members involved showed high levels of satisfaction with the PSFSG and identified many benefits to themselves and their children.

Many aspects highlighted in research on other similar deafness-specific and disability-based support groups were apparent, most notably the benefits and reciprocal nature of peer-to-peer support. It is important to recognise that whilst peer-to-peer support was a very important component of the PSFSG, it was not the only function. The PSFSG fulfils several other roles in relation to access to professional support and guidance for families and promotion of socialisation and early development for young d/Deaf children within a bespoke pre-school context, as well as opportunity for collaborative and multi-disciplinary working. These factors distinguish the PSFSG from other family/support groups which may be available for young deaf children and their families. The PSFSG has the potential to fulfil many of the requirements of current good practice guidance and as such provision of such groups should be encouraged and supported.

Recommendations

Whilst quality of provision and levels of family satisfaction were good there are several identifiable areas where improvement would be beneficial:

- Greater involvement of d/Deaf adults within the planning and delivery of the sessions due to the unique insights and support they can provide to families resulting from their lived experience (Moeller et al., 2024; Gale et al., 2021, Yoshinaga-Itano, C., 2015).
- Improved modelling and use of BSL within the context of the Family Support Group, to facilitate effective communication and provide a language-rich environment for the child, Principle 4, FCEI-DHH (Szarkowski et al., 2024 a).
- Provision of early years deafness-specific training for QToDs to develop the knowledge and skills required within an early years role, Principle 7 FCEI-DHH (Szarkowski et al., 2024a).
- Exploration of funding sources to improve access for some groups who currently may either find it difficult to attend or to fully access information within PSFSGs e.g. those

facing transport issues or those requiring interpreters to facilitate full access to the content of the session.

- Further exploration of the role of cultural factors which may impact upon family engagement (Narr et al., 2015; Lusa, 2010).
- Establishment/re-establishment of closer links with clinical audiology to provide audiological provision within the PSFSG setting i.e. for earmould/impression-taking.
- Development of more regional special interest groups for those involved in the provision of PSFSGs to facilitate the sharing of ideas and good practice.
- Consideration of support available to those grandparents and/or other family members who are undertaking significant regular childcare duties.
- Development of Family Group provision for families of children over the age of 5 years, to ensure continuity of access to the identified benefits of attendance.
- Consideration of the potential role of an on-line component to support some aspects of the PSFSG functions e.g. information sharing, and to provide access to those unable to access the face-to-face sessions.
- Improved recognition by those commissioning and funding provision for young d/Deaf children of the role and importance of PSFSGs in order to support the establishment and continuation of this provision across the UK to enable access to a PSFSG for all families of d/Deaf children.
- Further consideration of bespoke provision for those families attending with young babies.

Suggestions for Future Research

The current study provides a snapshot of the type of provision currently available in the UK and the views of the professionals and family members involved in these groups. Whilst the findings were very similar across the PSFSGs involved, a larger study utilising a random sample of PSFSGs would help to assess the extent to which the findings of this project can be fully generalised. This study did not attempt to evaluate the incidence of PSFSGs either within the UK as a whole or within the four nations specifically, and this is important data to obtain to assess the distribution of provision and equality of family access to these groups. Within the family members who opted to undertake the questionnaires and interviews, there is an under-representation of d/Deaf adults and those whose first language is not English therefore further research would be needed to fully capture the opinions of these groups. The impact of cultural factors upon engagement was touched on by some professionals but similarly this requires more in-depth exploration. In addition, future research which encapsulates responses from Scottish professionals and family members and involves PSFSGs run by Schools for the Deaf would be beneficial to complete the picture of types of provision across the UK. This research study did not attempt to evaluate the views of parents who opted not to attend a PSFSG, as a result further exploration of the reasons for this and assessment of how the needs of these families are being met would be an important area of future study.

Acknowledgements

This research could not have been undertaken without the commitment of the family members and professionals involved and their input was greatly appreciated and valued.

Thanks also go to Emma Fraser (NDCS) for her involvement in planning and undertaking observational visits to some of the PSFSGs and to Tanyel Oktar (NDCS) and Ian Noon (NDCS) for their input to the research process and final report.

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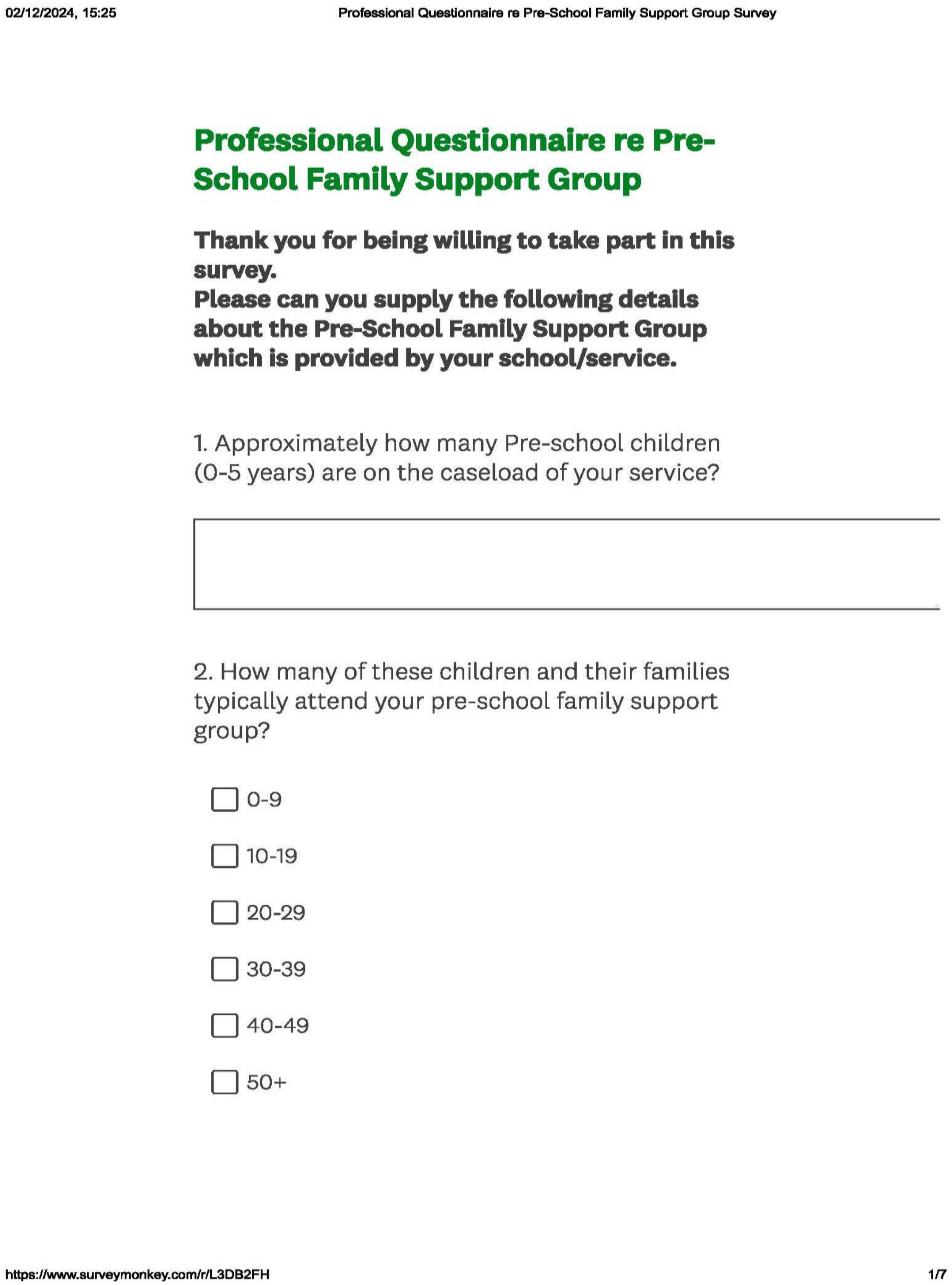
Appendices

Appendix A Professional questionnaire



02/12/2024, 15:25 Professional Questionnaire re Pre-School Family Support Group Survey

Professional Questionnaire re Pre-School Family Support Group

Thank you for being willing to take part in this survey.
Please can you supply the following details about the Pre-School Family Support Group which is provided by your school/service.

1. Approximately how many Pre-school children (0-5 years) are on the caseload of your service?

2. How many of these children and their families typically attend your pre-school family support group?

- ☐ 0-9
- ☐ 10-19
- ☐ 20-29
- ☐ 30-39
- ☐ 40-49
- ☐ 50+

https://www.surveymonkey.com/r/L3DB2FH 1/7

3. Of these children and their families approximately how many have chosen not to attend your pre-school family support group?

☐ 0-9

☐ 10-19

☐ 20-29

☐ 30-39

☐ 40-49

☐ 50+

4. How often does your group meet?

☐ Weekly

☐ Fortnightly

☐ Monthly

☐ Other (please specify)

5. Does the group meet on-line or face-to-face?

☐ Meets face-to-face

☐ Meets on-line (please skip to question 9)

☐ Combination of face-to-face and on-line

6. If your meetings are face-to-face where does your group meet (please specify type of location e.g. village hall, children's centre, service HQ etc.)

7. Why was this location chosen?

8. Do you offer any assistance with transport to enable families to attend?

○ Yes

○ No

9. Is opportunity for families/carers to attend the pre-school group additional to normally scheduled QToD visits or does it replace a scheduled visit?

☐ Additional to scheduled visits

☐ Replaces scheduled visit

10. Which professionals who are employed by your service/school are
regularly involved in organising, facilitating and attending the sessions? (Please circle all that apply)

☐ QToD

☐ Teaching Assistant

☐ Communication Support Worker

☐ Educational Audiologist

☐ Deaf Role Model

☐ Other (please specify)

11. Do you have a structured programme of events for each session?

○ Yes

○ No

12. If you answered yes to question 11 is this something that your school/service would be willing to share as part of the research project?

○ Yes

○ No

13. Are opportunities to meet d/Deaf adults available within the sessions

○ Always

○ Sometimes

○ Never

14. Is opportunity for parents to develop skills in BSL included within the sessions?

○ Always

○ Sometimes

○ Never

15. Is audiological input from a clinical or educational audiologist included as part of your sessions?

○ Always

○ Sometimes

○ Never

16. Do you have input from other professionals and speakers who are not employed by your school/service in the sessions?

○ Yes

○ No

Please detail the types professionals/speakers who are involved:

17. I agree to a researcher undertaking an observational visit to the pre-school group as part of the study. I understand that the observational visit will be in person if our group meets face-to-face or virtually if the meeting is on-line.

○ Yes

○ No

18. Are you or an appropriate colleague (QToD) willing to take part in an on-line interview to discuss the support group in more detail?

○ Yes

○ No

19. At a future point would you or an appropriate colleague (QToD) be interested in being part of the Parent/professional panel to further develop and review good practice guidance in this area?

○ Yes

○ No

20. If you answered yes to questions 17 or 18 please can you provide your or your colleagues contact details below:

Name	
School/Service	

Address (of school/service) ☐

Address 2 ☐

City/Town ☐

County ☐

Postal Code ☐

Country ☐

Email Address ☐

Phone Number ☐

Done

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Family Member Questionnaire

1. How many children who are d/Deaf are attending the session with you today?

○ 1 child

○ 2 children

○ 3 children

○ 4 children

○ 5 children

○ More than 5 children

2. What is your relationship to the child/children you are attending the group with?

3. Would you describe your self as d/Deaf or hearing?

○ d/Deaf

○ Hearing

○ Prefer not to say

4. What is the main language and other languages used in your home?

Main

Other

Other

Other

5. How often do you attend the Pre-School group?

☐ all sessions

☐ most sessions

☐ some sessions

☐ rarely attend

☐ this is the first session I have been to

6. Would you be interested in telling us more about your pre-school group (*this will involve attending an online meeting of approximately 45 minutes)*.

○ Yes

○ No

7. Would you be interested in being part of the Parent/Professional Panel to further develop good practice guidance in this area?

○ Yes

○ No

8. If you answered **yes** to questions 6 or 7 would any additional support be helpful e.g. interpreters.

○ Yes

○ No

○ If yes please tell us what type of support you will need.

9. If you answered yes to questions 6 or 7 please can you supply your contact details below

Name

Email address

Phone number

Done

Appendix C: Professional Participant Information Sheet

PARTICIPANT INFORMATION SHEET (Professionals)

Title of study

An exploration of Pre-School Family Support Groups for Pre-School age d/Deaf children and their parents and carers.

Introduction

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the research that is being done and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask if anything is not clear or if you require any further information to help you make your decision. Please do take your time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of this study?

This study is funded by The National Deaf Children's Society and is aiming to find out more about Family Support Groups for pre-school aged d/Deaf children and their families. At present there is very little available research to help Support Services/schools and parents to know what good practice in this area should look like.

The study aims to find out:

What support groups of this type typically look like in different locations across the UK.

2. What both parents/carers and Teachers of the Deaf feel are the benefits for families of attending these groups.
3. To identity any aspects which parents/carers and Teachers of the Deaf feel are particularly effective and also any aspects that could be improved.
4. To see if it is possible to develop a model of Good Practice in relation to Family Support Groups, jointly developed by parents/carers and professionals, that could be used across the UK.

Do I have to take part?

It is completely up to you whether you decide to take part in this study. If you complete the initial questionnaire you have consented to take part in the first part of the study and the questionnaire will also ask you to give agreement to be involved in the later stages of the study if you wish to do so. You are free to withdraw at any stage without giving a reason. You are able to withdraw retrospectively and any data that has been collected from you will not be included in the study and will be destroyed/deleted.

Are there any restrictions that may prevent me from participating?

You will be able to participate in the study if you are Qualified Teacher of the Deaf (QToD) and/or Head of Support Service (HoSS) who is currently involved in the planning and delivery of a Family Support Group for pre-school aged d/Deaf children (0-5 Years) and their families.

How long will my part in the study take?

If you decide to take part in this study, you will be involved in it for a maximum of 12 months.

What will happen to me if I take part?

You will be invited to fill in a short on-line questionnaire which will request some basic anonymous information in relation to the number of pre-school children supported by the service/school you work for, and the nature of the Family Support Group your Service provides. A mutually convenient date will then be arranged for a researcher to visit your local Family Support Group. During the visit the researcher will observe and record the type of activities that take place during the session. The researcher will also invite the parents and carers in attendance to fill in a short questionnaire to provide some anonymous data about themselves and their d/Deaf child/ren. The parents/carers will also have the option to choose to be involved in the future stages of the research if they wish to do so and these aspects will take place on-line at a later date. You as a HoSS or QToD will be invited to an on-line or face-to-face interview in which you will have opportunity to engage in discuss aspects of the Family Support Group in more detail. An audio or video recording of the focus group will be made to enable the researcher to review the comments you have made and make a transcription and once transcribed the recording will be destroyed. You will be provided with a copy of the interview transcript to verify that the content is accurately reflects the content of the interview. You will be asked to give written consent to the interview and the use of video/audio recording. If you decide to take part in the final stage of the research, you will be invited to join an on-line panel to develop and review good practice guidance alongside other parents/carers, HoSS and QToDs.

What are the possible disadvantages, risks or side effects of taking part?

Involvement in the study will involve a short amount of your time involving up to 20 minutes for the questionnaire and up to 45 minutes for the interview. If you also decide to be involved in the 2nd focus group this will involve a further 1-2 hours of your time.

What are the possible benefits of taking part?

At present little is known about Family Support Groups for pre-school children who are d/Deaf and their families within the UK. You will be helping to develop knowledge about this area of practice and to generate guidance to improve the quality of support that families receive in the future.

How will my taking part in this study be kept confidential?

All responses via questionnaire and interview will be randomly coded and the participants will only be identifiable to the researcher/s. The study will not name or identify any individuals or services, and no information will be provided which will enable others to identify individuals or services. All participant responses will be strictly confidential, and individual responses will not be accessible to other participants involved in the survey.

The information will be stored on a password protected computer or in a locked filing cabinet to which only the researcher/s undertaking the study have access.

What will happen to the data collected within this study?

The survey data collected will be deleted/destroyed once the research is complete. The video/audio clips of the interviews will be deleted as soon as the content information has been transcribed. No information will be retained beyond the completion of the study for any purpose.

Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with me by email helennelsonconsultancy@outlook.com

Appendix D: Family Member Participant Information Sheet

PARTICIPANT INFORMATION SHEET (Family Members)

Title of study

An exploration of Pre-School Family Support Groups for Pre-School age d/Deaf children and their parents and carers.

Introduction

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the research that is being done and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask if anything is not clear or if you require any further information to help you make your decision. Please do take your time to decide whether you wish to take part.

Thank you for reading this.

What is the purpose of this study?

This study is funded by The National Deaf Children's Society and is aiming to find out more about Family Support Groups for pre-school aged d/Deaf children and their families. At present there is very little available research to help Support Services/schools and parents to know what good practice in this area should look like.

The study aims to find out:

What support groups of this type typically look like in different locations across the UK.

2. What both parents/carers and Teachers of the Deaf feel are the benefits for families of attending these groups.
3. To identity any aspects which parents/carers and Teachers of the Deaf feel are particularly effective and also any aspects that could be improved.
4. To see if it is possible to develop a model of Good Practice in relation to Family Support Groups, jointly developed by parents/carers and professionals, that could be used across the UK.

Do I have to take part?

It is completely up to you whether you decide to take part in this study. If you complete the initial questionnaire you have consented to take part in the first part of the study and the questionnaire will also ask you to give agreement to be involved in the later stages of the study if you wish to do so. You are free to withdraw at any stage without giving a reason. You can withdraw retrospectively and any data that has been collected from you will not be included in the study and will be destroyed/deleted.

Are there any restrictions that may prevent me from participating?

You will be able to participate if you are the parent or carer of a pre-school (0-5years) aged child who is d/Deaf and if you attend one of the family support groups which is involved in the study.

How long will my part in the study take?

If you decide to take part in this study, you will be involved in it for a maximum of 12 months.

What will happen to me if I take part?

A researcher will visit the Pre-School Family Support Group which you attend to observe and record the type of activities that take place during the session. You will be invited to fill in a short questionnaire which will request some basic anonymous information about yourself and your child/children.

The questionnaire will ask you if you are willing to take part in an on-line interview to discuss your experiences of attending the group in more detail. If you would like to do this, you will be asked to provide your contact details, and the researcher will contact you to arrange a convenient time for the interview. An audio or video recording of the interview will be made to enable the researcher to review the comments you have made and make a transcription, once transcribed the recording will be destroyed. You will be provided with a copy of the interview transcript to verify that the content accurately reflects the content of the interview. You will be asked to give written consent to the interview and the use of video/audio recording. If you decide to take part in the final stage of the research, you will be invited to join an on-line panel to develop and review good practice guidance alongside other parents/carers, Heads of Service/Schools and Teachers of the Deaf**.**

What are the possible disadvantages, risks or side effects of taking part?

Involvement in the study will involve a short amount of your time of up to 10 minutes for the questionnaire and up to 45 minutes for the interview. If you also decide to be involved in the 2nd focus group, this will involve a further 1-2 hours of your time.

What are the possible benefits of taking part?

At present little is known about Family Support Groups for pre-school children who are d/Deaf and their families within the UK. You will be helping to develop knowledge about this area of practice and to generate guidance to improve the quality of support that families receive in the future.

How will my taking part in this study be kept confidential?

All responses via questionnaire and interview will be randomly coded and the participants will only be identifiable to the researcher/s. The study will not name or identify any individuals or services, and no information will be provided which will enable others to identify individuals or services. All participant responses will be strictly confidential, and individual responses will not be accessible to other participants involved in the survey.

The information will be stored on a password protected computer or in a locked filing cabinet to which only the researcher/s undertaking the study have access**.**

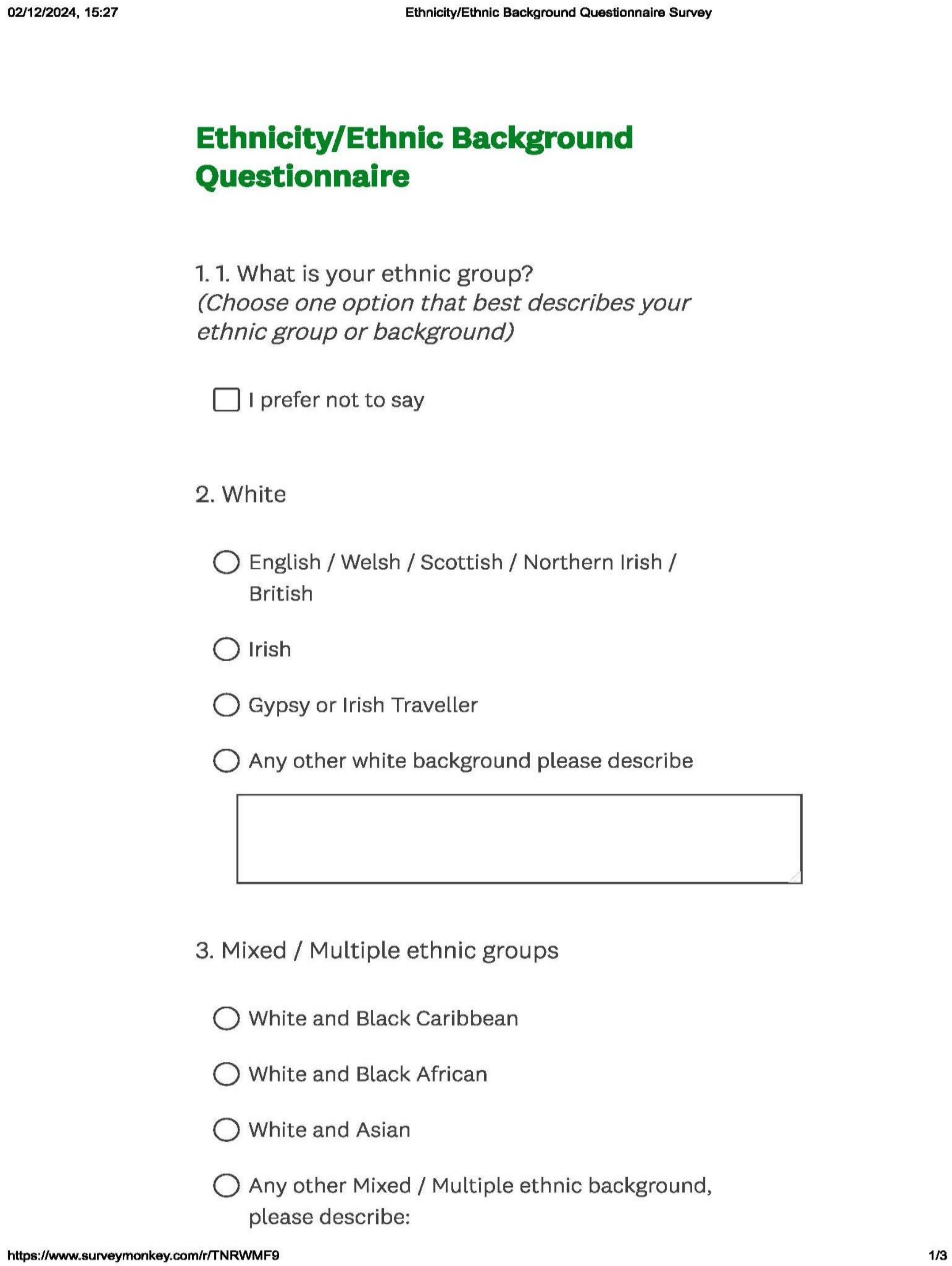
What will happen to the data collected within this study?

The survey data collected will be deleted/destroyed once the research is complete. The video/audio clips of the interviews will be deleted as soon as the content information has been transcribed. No information will be retained beyond the completion of the study for any purpose.

Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with me by email: helennelsonconsultancy@outlook.com

Appendix E: Ethnicity/Ethnic Background Survey



02/12/2024, 15:27 Ethnicity/Ethnic Background Questionnaire Survey

Ethnicity/Ethnic Background Questionnaire

1. 1. What is your ethnic group?
(Choose one option that best describes your ethnic group or background)

☐ I prefer not to say

2. White

○ English / Welsh / Scottish / Northern Irish / British

○ Irish

○ Gypsy or Irish Traveller

○ Any other white background please describe

3. Mixed / Multiple ethnic groups

○ White and Black Caribbean

○ White and Black African

○ White and Asian

○ Any other Mixed / Multiple ethnic background, please describe:

https://www.surveymonkey.com/r/TNRWMF9 1/3

4. Asian/Asian British

○ Indian

○ Pakistani

○ Bangladeshi

○ Chinese

○ Any other Asian background, please describe

5. Black / African / Caribbean / Black British

○ African

○ Caribbean

○ Any other Black / African / Caribbean background, please describe

6. Other ethnic group

○ Arab

○ Any other ethnic group, please describe

Done

Appendix F: Observational Schedule

Observation Schedule: Visits to Pre-School Group

Please categorise activities into the following areas and provide more detail in the notes section:

Overall length of session:

Number of Parents/Carers:

Number of d/Deaf children:

Number of hearing children:

Number of staff including roles:

Activity Type (including approx. timings e.g. 5 mins)	**Notes** *(also note suggested focus e.g. development of shared attention, listening skills, turn-taking, vocalisation, imitation of actions/signs)*
Welcome/greeting activity	
Songs/musical activity	
Free play	
Activity led by professional	
Activity modelled by professional for parents	
Opportunity for parents/carers to talk to each other (peer led activity/discussions)	
Opportunity for parents/carers to talk to professionals	

Visiting speaker	
Audiological services	
Activity with d/Deaf adult	
Activity involving BSL/Early sign	
Snack activity	
Discussion/advice re use of activities at home	
Curricular activities	
BSL tuition for parents	
Other activities	
Additional comments	