

Investigating how families experience informed choice and perceive the impact of information they receive on their decision making about language and communication for their child in Scotland

Report for the UK National Deaf Children's Society

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1) Introduction

“Informed choice means that families can make knowledgeable decisions, which reflect their own cultures, values and views. This should be based on full access to comprehensive, unbiased and evidence-based information, about the full range of options” (Young et al, 2006)

This project was commissioned by the UK National Deaf Children’s Society with the stated aim being “to investigate how families experience informed choice and perceive the impact of information they receive on their decision making about language and communication for their child” in Scotland, and in doing so, to address four main questions:

- What reflections do parents of deaf children have on the information and advice they receive or have received around language and communication?
- In what contexts do families receive information and how might these affect their attitudes, feelings and decisions around language and communication?
- What specific messages, practices and/or professionals (if any) are perceived to have helped or supported families to make decisions around language and communication that met their needs of their child at that time, identifying factors which may have been especially helpful, empowering or influential, or conversely, found to be less helpful, restrictive or discouraging?
- What implications do the experiences of families have for professional practice and communication with families?

2) Background and Context

Choice and decision making has been remarked upon as “an enduring experience of parenting a deaf child” (DesGeorges, 2003), with decisions about communication choices – alongside for many families, consideration of cochlear implantation – being of considerable significance and challenge for parents (Harris, 2021). In the now-routine context of early identification of hearing loss, parents are faced with these complex decisions very early in their child’s life and also in their own parenting journey with their deaf child, within a short timeframe and, for hearing parents, in the context of having little or no prior knowledge about deafness. Parents experience a pathway in which they encounter screening, audiology, ENT, medical, therapy and educational personnel who may all play influential and consequential

roles in helping to shape the circumstances for informed decision making. For parents whose deaf child is later identified, decision making can also assume some urgency as they perceive the need to 'make up for lost time' in their child's language and communication development, and although the pathway may differ, the professionals involved can play a significant part in informing them and enabling consideration of their options to meet their child's communication needs.

According to the latest published (2023) Consortium for Research in Deaf Education (CRIDE) report for Scotland, based on a 97% return with 29 out of 31 local authority areas responding, there are at least 3,418 deaf children and young people aged 0-19 in Scotland (whereas the Independent Review of Audiology Services in Scotland 2023 estimates 3,600). Although CRIDE survey authors advise that data are used with caution owing to difficulties extracting data about deaf children in some areas, it reports:

- 14% of children being of pre-school age
- 42% of children being of primary school age
- 89% of the total 0-19 population communicating using spoken language*
- 3% of the total 0-19 population communicating using British Sign Language (BSL)*
- 5% of the total 0-19 population using Spoken English with sign support*

(* figures relate primarily to use of language / communication mode in education settings and may not reflect home language use or child preferences)

The report indicates that the vast majority of children receive services within their own local authority areas. These vary significantly in size, with the smallest number of deaf children reported by a service being 11 and the largest 352. Such huge variation is evidently likely to affect parent choice in terms of both availability and access to resources to support some options.

Despite historical tensions in relation to language and communication methodology for deaf children (either from a Rights perspective or in relation to beliefs about 'best' outcomes) which have been experienced across countries and continents over many years, informed choice as a principle, widely researched over the past two decades, is now well understood and generally supported in policy terms. Implementing informed choice in practice however can be challenging. Although the reported experiences of parents may suggest that some policy initiatives do not sufficiently recognise or address the specific needs of deaf children and families within the wider, universal context, the climate for facilitating informed choice and decision making about language and communication for deaf children and families in

Scotland is overall, however, a very positive one, with several important initiatives, developments and influences which can support its enablement:

- The See Hear strategy, launched in 2014, providing commitment to and a framework for 'structured, co-ordinated, person-centred service delivery and support' which can reduce uncertainties for parents in their pathway from early identification to intervention and beyond.
- The Scottish Standards for Deaf Children 0-3: Families and Professionals working together to improve services document (2011), which emphasises the importance of an informed choice approach in professional practice as well as recognising the essential elements of effective information sharing and support from parent peers and those with lived experience of deafness.
- The BSL Scotland Act (2015) and the British Sign Language National Plan 2023-2029, providing both strong legislative support, and commitment to increasing and enabling accessibility.
- The Education (Additional Support for Learning) (Scotland) Act 2004 and the Additional Support for Learning Statutory Guidance 2017.
- The Getting It Right for Every Child (GIRFEC) policy, focusing on wellbeing, with guiding values and beliefs which include promotion of choice and the importance of recognising child and family support needs.
- The Hearing Impaired Network for Children and Young People (HINCYP), established in 2019, enabling a multi-disciplinary forum to drive improvements and developments to "support services and families to achieve the best possible outcomes for children and young people in Scotland with bilateral severe or profound hearing loss".
- The Scottish Sensory Centre and Moray House, University of Edinburgh, centres of significant experience and expertise.
- Strong, pro-active third-sector organisations providing advocacy, information, and support for families with deaf children and for deaf children and young people themselves.

- The British Academy of Audiology Quality Standards in Paediatric Audiology (2022) which acknowledge the contribution of previous country-specific Quality Standards including Scotland's (2009), together with the Independent Review of Audiology Services in Scotland (2023). Although the Review identifies some significant concerns and recognises some key constraints in services, it also highlights areas of good practice and opportunities for development which will positively contribute to enabling and enacting informed choice for parents.

3) Approach / Methodology

As directed by the National Deaf Children's Society, the investigator has engaged throughout the project with the Hearing Impairment Network for Children and Young People (HINCYP), via the Chair and substantially with the Clinical Lead, whose full support for and active involvement and participation in the project, particularly in relation to the professionals' input, has been crucial for its successful delivery.

The project has involved:

- A desktop review of published and publicly accessible information relating to informed choice and language and communication in the Scottish context.
- An online questionnaire in both written English and in BSL, hosted and promoted to families by the National Deaf Children's Society in Scotland.
- In-depth interviews with parents of deaf children either online via Teams or Zoom or by telephone.
- Exploring the perceptions and practice of professionals involved across the care pathway through focus groups and telephone interviews.

The online questionnaire was developed by the lead investigator in conjunction with National Deaf Children's Society personnel, to address the priority areas of enquiry. Prior to launch on the National Deaf Children's Society website, it was tested for face validity with cognitive and simulation testing with a small group of teachers of the deaf and families of deaf children in England. The questionnaire comprised three sections under the headings: 'Demographic information', 'Information and support', and 'Making choices'.

51 parents (35 mothers, 13 fathers and 3 not specifying gender), living in 24 of Scotland's local authority areas, completed the questionnaire. Parents predominantly are typically hearing, with 2 parents reporting having a hearing loss themselves. 44 parents report their home language as English (with some also citing Scottish), with one family having spoken

language other than English and the remainder reporting English together with another spoken language. Of the 52 children / young people from the contributing families (28 male, 24 female):

- 13 are aged 0-4 years of age; 21 are aged 5-11 years; 9 are aged 12-18 years; and 9 are over 18 years of age with 4 being over the age of 25.
- 45 have their ethnicity reported as 'White British', with one reported as 'White Other'; one as 'Black, African, Caribbean or Black British'; and 3 as belonging to 'Mixed or multiple ethnic groups'.
- 11 of the total group are reported to have additional needs or other disability, with uncertainty for 4 others.
- 37 of the total group are reported to communicate using listening and spoken language, with 6 using British Sign Language. One is reported as sign bilingual, whilst others are reported to use a combination of speech and sign or, for 6 children, total communication.
- In terms of their position in the family, the deaf child / young person is reported as the only child in 13 of the families. There is a mix of elder / eldest, middle or younger / youngest in the other participating families.
- All the children / young people are reported to have permanent hearing loss, with 4 being unilateral. Degree of hearing loss ranges from mild to profound.
- 12 children / young people have cochlear implants, whilst 3 wear no amplification and the remainder wear hearing aids (inclusive of bone anchored hearing devices).
- 33 of the children had their hearing loss identified following referral from newborn screening, with 26 of those having hearing loss confirmed under the age of 3 months and a further 4 by 6 months of age. 22 children / young people were diagnosed over 12 months of age, including 8 in the 5-12 age group.

All parents completing the questionnaire were offered the opportunity to take part in a focus group or, if preferred, to have an individual interview. 10 parents / families (one with hearing loss), with children in the early years, primary and secondary age ranges, with and without additional needs, expressed willingness and consented to being interviewed, and represent experience with a range of services across a variety of local authority areas, both urban and rural.

31 professionals, also from both urban and rural areas with different geographies and population densities, working clinically, in homes, and in educational settings, participated in the project through a combination of semi-structured focus groups and telephone interviews.

They represent a variety of professional roles across the health, early intervention and educational support pathways for deaf children and families including Audiology, ENT, Speech and Language Therapy (both at local level and within the national Cochlear Implant team), Educational Audiology, and Deaf Education (both peripatetic and special school based teachers of the deaf).

All interviews and focus groups (both parent and professional) were, with assurance of confidentiality, audio-recorded with participants' permission, verbatim transcribed and analysed using an Inductive Content Analysis approach.

4) Outcomes

4a) Desktop review

The desktop review, aiming to identify published, available, and accessible literature of relevance to both professional practice and to parents seeking information, was undertaken substantively via internet search, together with review of materials identified and/or supplied by professionals participating in the project. The online search utilised a wide range of search terms relating to informed choice, informed decision making, language and communication options, and speech and language or educational support for deaf children both in the early years and at school, and sought information specific to individual health boards and local authority specialist educational services as well as more general, nationally oriented information.

From a national perspective, the most significant available resource which relates specifically to the principles and practice of informed choice is the Scottish Sensory Centre's publication 'Scottish Standards for Deaf Children 0-3: Families and professionals working together to improve services'. This thorough and comprehensive document, developed collaboratively with a number of agencies in Scotland and incorporating consultation with and review by national organisations, provides an excellent framework for early intervention and partnership with families, in which facilitating informed choice and sharing information without bias are core elements. It also provides a Quality Rating Tool for services to self-audit against the standards. The Royal College of Speech and Language Therapists also has a publicly available statement about its services in Scotland which makes explicit reference to providing "clear and unbiased information on various communication methods to allow parents to make an informed choice" and to providing appropriate support for families, and the British

Association of Teachers of the Deaf (BATOD), although not Scotland-specific, also provides accessible information about communication modes and methods. These information sources are not the most readily locatable however for parents searching for information about language and communication options and support in the Scottish context.

Perhaps not unexpectedly, given the recent consultation and subsequent publication of the BSL National Plan 2023-2029, building on the BSL Scotland Act (2015) and the previous BSL National Plan (2017-2023), BSL resources do appear to have greater prominence in internet search results relating to language and communication options and support for deaf children which parents may therefore locate, both from the Scottish government, and from third sector organisations which have a strong and positive presence in Scotland. Education Scotland also has an excellent, high quality resource, 'Good Practice in working with deaf learners, their parents and families', which is focused on BSL and although aimed at professionals, is easily locatable in general searching. There does not however appear to be a similar resource relating to good practice in spoken language support or using other approaches to fostering language and communication with deaf children and supporting families who choose other options.

Dominating the search results relating to language and communication and deaf children from a national perspective are information pages and resources from the UK National Deaf Children's Society. The website is also generally well signposted from various Scotland Health Board and Local Authority web resources. The National Deaf Children's Society's beliefs and values in relation to informed choice are well known, and are articulated in the Position Statement for external audiences (accessible to both parents and professionals), clearly detailing not only what informed choice involves, but also the implications for governments and service providers. The website's information and support pages offer clear, accessible and unbiased information for families about the full range of language and communication approaches, along with guidance for families to help them understand the options and questions to ask both themselves and their service providers in considering potential choices. The information includes signposting to resources and contacts for further information across the UK, including specific to Scotland. Although not detailing communication approaches available in local authority areas, online 'maps' enable parents to contact their local education services for deaf children via the website, to seek area-specific information.

Despite the unbiased and balanced information across the National Deaf Children's Society website's many pages addressing language and communication however, searching with a

Scotland-specific focus tends to highlight resources mainly connected to BSL, with emphasis on Family Sign Language and the two National Deaf Children's Society Scotland publications 'British Sign Language (BSL) in Scotland', one aimed at families and the other at professionals. These high quality resources both clearly espouse the principles of informed choice and reference a continuum of language and communication approaches (including links to excellent video clips – 'Professional Profiles' – and links to websites of a wide range of organisations some of which specifically promote spoken language or other approaches) but the overall impression may tend to be one of emphasis and promotion of BSL within the Scottish context.

In terms of local and regional information, there is generally a paucity of readily accessible published information specific to language and communication for deaf children, especially in the form of communication policies or detail about different options and how they may be supported. Local Authorities' general information in relation to the education of children with Additional Learning Needs references services and teams to support deaf children and families both in the early years and in school education, but this is often well embedded amongst more general information. Some make specific reference to providing a range of communication supports dependent on needs and providing information to enable "an informed communication choice for families", but often little further detail is apparent. NHS Health Boards' Speech and Language Therapy services generally make more reference to the promotion of communication and language for deaf children and reference spoken and sign approaches, but appear to offer limited detailed explanatory or evaluative information. Both Health and Education do however have local BSL plans which are easily locatable, with many specifying intention to ensure families of deaf children receive information, guidance, support and access in relation to BSL.

The fullest readily accessible information appears to be that offered via the websites of the Schools for the Deaf and their associated outreach and early years services. Published Communication Plans or information pages on communication, even where the approach of the school itself may be within a particular communication methodology, clearly recognise individual needs and preferences and a continuum of approaches, respecting and supporting informed choice. Mainstream schools with resourced or enhanced provision for deaf children and young people also reference communication support but focus more on the support provided within their stated communication approach rather than detailing the policy itself. Overall however, unless directed to the National Deaf Children's Society website or to the websites of the Schools for the Deaf, it would seem that parents independently seeking

detailed information about communication choices with deaf children may find it somewhat challenging to do so.

4b) Professionals' experience and perspectives

All participants were positively committed to the principle of informed choice and responded to the invitation to contribute to the project not only willing to share and openly discuss their own views, experience and practices, but also expressing interest in learning from and exploring practical issues with colleagues from across Scotland in a multi-disciplinary context. Discussions were loosely structured around four general areas of focus: perceived main influences on parental decision making, primarily in the context of early identification; the impact or effects of professionals' own beliefs about language and communication and the effects of system and service structures on opportunity for informed choice and decision making; perceived barriers and enablers for informed choice and decision making; and thoughts and suggestions about what is 'most effective' practice to support informed choice and the optimum circumstances for enabling and enhancing it.

Data analysis of the verbatim transcripts of the discussions identified five primary content categories across the areas of focus (several of which are interconnected or show overlap, and each of which contains a number of sub-categories):

- Belief in family-centredness and professional responsiveness.
- Assumptions and unconscious bias.
- Variability or selectivity in information sharing and signposting and the effects of available / unavailable provisions or resources.
- Reliance on independent sources - and significantly, the National Deaf Children's Society - for information to support parental choice and decision making.
- Perceived challenges and possibilities within the national context in relation to informed choice.

Belief in family-centredness and professional responsiveness

Professionals across the care pathway acknowledged the significance of their roles in informing, supporting and guiding families and spoke about the importance of recognising the uniqueness of each child and family, highlighting the need to "meet the family where they are" and being sensitive and responsive to individual family needs and wishes. They spoke of it being a privilege to work with and support a family in the early stages of their parenting

journey with their deaf child and the desire to be open minded and to come to joint decisions in partnership with families, “wanting to get that right”. The importance of, and their commitment to, engendering mutual trust was emphasised, as was establishing a relationship in which professionals actively listen to families. Some professionals expressed a strong commitment to having a fluid approach towards language and communication considerations and encouraging families to be flexible, acknowledging that informed choice making is a process and that initial decisions and support may need to evolve in light of a child’s developing strengths and needs and as families gain more knowledge and experience. Others voiced some concern that families may easily get ‘pigeonholed’ into their first choice without being supported to reevaluate when their child’s progress may indicate that an alternative approach may better suit their child’s strengths and needs. Professionals spoke too about the influence of families whose own experience had been ‘inspirational’ in respect of pursuing and widening opportunity for informed choices for their children.

Effective multi-disciplinary working was also identified as a key contributor to family-centredness and responsiveness and is viewed as an important enabler or facilitator for supporting families to have and make informed choices. Professionals articulated that the different perspectives of colleagues from other parts of the care pathway to their own enriches their knowledge and understanding of both language and communication and of the wider context for families, and enables them to question and challenge any biases they may have held. This was caveated with the recognition that it is important that multi-disciplinary teams work collaboratively so that families do not receive conflicting advice or information from different professionals who may hold specific views, and cited examples of where families had had this experience. The fact that families engage with different services at different times was thought to increase this possibility, reinforcing the need for multi-disciplinary co-ordination as well as collaboration and the development of shared knowledge and understanding of the pathway and network of services.

Assumptions and unconscious bias

Whilst professionals expressed full and explicit commitment to empowering parents to make informed decisions in respect of language and communication approaches, their perceptions about what are major influences on parents’ choice considerations following the early identification of their child’s hearing loss, revealed a number of assumptions: that parents “want what they know”; that families “naturally prefer spoken language”; that spoken language is or will be easier; and that spoken language will likely lead to ‘better’ outcomes.

In terms of parents wanting “what they know”, professionals expressed that in their experience, parents are mainly influenced by how they communicate themselves, generally preferring “what is known and familiar” and that “the language of the home will drive the language [choice]”. Some felt that there is parental expectation that if spoken language is used at home, then communicating orally will mean that the child will have the same language, enabling the family to “communicate freely”, and that the development of spoken language tends to be viewed as natural progression following the fitting and wearing of hearing aids. Some professionals reported that such assumptions can also be held and conveyed by parents.

Professionals’ assumptions do not in themselves imply that they consciously decide not to provide information about other options for language and communication development (and indeed in some instances, professionals reported their approach as one in which both sign and spoken language routes were clearly presented as choices for families) but they may influence the way in which information is framed and discussed. Professionals also spoke of their approach being one of commitment to being parent-led, guided by listening to parents and responding to their questions, which is of course core to family-centred practice. Yet without purposefully and fully informing families about different approaches to language and communication development for deaf children, and assuming that hearing families have a preference for spoken language without inviting them to explore the potential benefits and to deepen their understanding of the spectrum of potential alternatives, this can be a constraint on choice as parents are unlikely to ask questions outside of what they know.

It is perhaps important to recognise that professionals may themselves be influenced by their knowledge and experience of resource constraints for supporting some language and communication options, or indeed by their own potential lack of knowledge about or awareness of options or resources; however there are also some assumptions that a spoken language choice is ‘easier’ for parents. This appears so even in instances where services and individual practitioners clearly do share information about alternatives and resources to support them do exist. Professionals reported from their experience, their impressions of families feeling “daunted” about learning to sign, or that they “lacked confidence”, even when they had expressed interest in it or seemed keen to do so. Similarly it was felt that parents may find the “effort” of attending sign classes “a stumbling block” to realising their choice, with assumptions that, for some, family circumstances would make learning to sign “too challenging”, perhaps underestimating that a spoken language route also requires commitment and effort from families and also has its own resource requirements (both in skills and technology), especially in respect of a choice for cochlear implantation.

Possibly related to assumptions about parents having natural preferences for spoken language, its relative ease and familiarity, and the difficulties of opting to pursue sign language, is a supposition that a spoken language route will more likely lead to 'better' outcomes for children and families. This perception appears unrelated to issues of academic achievement, but more aligned to the framing of a spoken language choice as either a natural course for children with 'lesser' degrees of hearing loss, or as a facilitator for a less restrictive pathway to future opportunities, as well as meeting both a policy expectation and families' perceived preferences for mainstream education (which may potentially be viewed as less compatible with a choice for sign language). Although these assumptions may be shaped by professionals' practical experience, they may however also be indicative of some unconscious bias.

The potential for bias, whether unconscious or explicit, was additionally acknowledged in the recognition that families are also significantly influenced in respect of language and communication by the professionals they meet during and following early identification of hearing loss, most of whom, depending on the provision, have typical hearing themselves. Whilst some professionals with BSL knowledge and experience actively promote consideration of a signed approach to parents, given the predominantly medical context of the care pathway from (typically) hospital-based screening, onto audiological assessment and provision of amplification devices, together with medical consultations, prior to entering into early intervention and family support, it was acknowledged also that the system itself may represent implicit bias towards listening and spoken language, especially when discussions about communication may be heavily influenced by the audiological status of the child. Clinicians involved with audiological assessment and diagnosis recalled "We, as clinicians, can have a fixed idea of what we think might be the best outcome" but also, illustrative of an evolved perspective, commented "We definitely used to have a very fixed opinion about where we saw a set of test results and where we thought that was going, and that's evolved and changed over time". Another example was given in relation to cochlear implantation, with local speech and language therapists sharing that families would previously report being instructed not to sign with their children but that no longer being the case. Professionals pointed to a) multi-disciplinary collaboration and co-working with colleagues who are knowledgeable about different communication approaches, as well as collaboration with other organisations (including those with staff with lived experience of deafness) and b) their own experience with families, as being instrumental in helping them recognise and address any issues of personal or professional bias or assumption, and in deepening their understanding of how to support informed choice making in practice.

Variability or selectivity in information sharing and signposting and the effects of available / unavailable provisions or resources

Just as in other parts of the UK, there are significant variations in the types and structures of provision across the full care pathway for deaf children and young people and support for their families in Scotland, both in the early years following early identification of hearing loss and beyond, as children become of school age and progress through the system. Together with the large variation in numbers of deaf children and specialist staff within geographical / administrative areas, the variation in provision inevitably presents different challenges and enablers affecting the promotion and enactment of informed choice. The discussions revealed significant differences also in how professional teams and individual practitioners share information about language and communication approaches, whether it is written or verbal or both, its amount and breadth, the context in which they provide it, and how they signpost families to other resources or potential experiences and opportunities.

A number of pertinent factors were identified in this respect: the conceptualisation of informed choice as regards language and communication; perceptions of the impact of available or unavailable resources, together with those of professional boundaries; perceptions about families' readiness or ability to cope with information; the importance of knowledge and ongoing professional development; and efforts to address inconsistency and variability.

Whilst acknowledging a continuum of communication approaches for deaf children, and with the exception of specific providers or areas who have a clear policy of Total Communication within early intervention and educational services, there is a tendency to conceptualise informed choice primarily as a binary issue (i.e. spoken language and British Sign Language as distinct choices). Perhaps in part in an effort to overcome any inherent or historical bias towards any one approach (more often oral-aural), and with the increased focus on BSL initiatives in Scotland, communication choice can become framed in an 'either-or' context, and not inclusive of other approaches within the continuum. This may not only affect the scope of information given to parents about language and communication options, but in turn may also influence how parents go on to consider their choices and seek information and knowledge to inform them. Professionals supporting families following confirmation of hearing loss however were in agreement with an expressed view that it is essential "to debunk this idea that you have to choose one or the other" and acknowledged the possibility of 'both', yet even this does not convey the spectrum of approaches, or supports for approaches, which families could potentially explore. Some early support professionals, especially speech and language therapists, pointed to the need to emphasise the many elements contributing to the effective

development of early communication, especially in the weeks and months following diagnosis when parents may “rely heavily on professionals for advice” yet need time to explore what different options may mean for their child and family. The importance of families ideally experiencing a range of approaches to communication was well articulated by one participant, who advocated that “parents are exposed to different methods of communication and not one [of them] is kind of pushed onto a family”. Cautioning against “any presumption that they’ll fall into a particular method or mode, one pathway versus another pathway”, it was felt that “it’s not necessarily like a menu in the early stages.... it’s a sort of making sure everything is available” for families to experience. Another participant reinforced this, commenting that choices can be “what’s right at the time.... not saying to parents you’re making a choice and you can never go down another route.... that’s hugely important”.

All participants supported the view that ideally all parents should receive information and be able to gain experience about the full range of options, and want to be able to support parents to enact their choices. However, it is clear that in practice this can be challenging, and that the existence and availability of resources or otherwise, together with perceptions of professional boundaries, contribute to both variability in the information parents are given and selectivity in what and how much professionals choose or feel able to inform parents about communication approaches.

The availability or otherwise of provisions for deaf children in local areas appears to have a significant effect on the information families receive. Professionals reported feeling committed to and confident about informing families and discussing with them the full range of options available and accessible in their areas, something one participant described as “positive informed choice”, i.e. from the perspective of families’ choices being able to be supported. However, they reported feeling in somewhat of a difficult dilemma with regard to informing families about potential options that they know cannot be locally supported. Three main factors appear influential in this respect: a sense of there being ‘professional boundaries’ with hesitation, or even fearfulness, to share information which may be at odds with local provision or policy or even national guidance; feelings of concern about potentially ‘letting down’ families by raising awareness and expectations about options then telling them support is not available should they wish to choose them; or from an audiology perspective, consciousness of having insufficient knowledge of provisions which inhibits perceived ability to share information at the time of confirmation of hearing loss. Illustrating the issue of inhibition, one audiologist commented “most of us are actually a little nervous about bringing up sign because we are unsure of what provisions are available for families in our area.....so if a family brings it up to

us then we are very positive about it but we actually don't know what provisions are out there really".

A number of other examples were given in respect of BSL. Some of these related to there being insufficient resources in some geographical areas, such as lack of availability and access to opportunity for parents to learn to sign, lack of existence of a BSL community, or insufficient early years professionals with BSL skills to support families. Other examples, which potentially relate to professionals' assumptions but are also informed by experience, involved reluctance to suggest BSL to families from a) areas where there are high levels of general language deprivation, out of concern about whether they would have the capacity to take on learning a new language, and b) different cultural communities where it is felt there is resistance to considering sign language as a positive option.

Further examples given referred to the influence of the education policy position of presumption of mainstream, when there may be no peer group available for deaf children unless at a specifically resourced school, and also to Auditory Verbal Therapy (AVT) where in the absence of qualified AV practitioners in the local area, professionals expressed reluctance to inform families about an approach they cannot resource. A practitioner from one area reinforced the issue of potential constraints on choice and being led primarily by families' expressed needs with the comment "We don't have AV practitioners [in the service]...we don't have those skills. And I've very rarely had a family ask me about those things that aren't on offer because I don't think we are explicit about what choices are available". Other practitioners expressed reluctance to inform families about AVT feeling that they were influenced by some previous "bad press", or that they are not well informed about it, or understood it to be only available privately, at a charge to the family.

Also contributing to issues of variability and selectivity are perceptions about families' 'readiness' for information or ability to 'cope' with it. Professionals tend to adopt an approach whereby they informally assess or judge parents 'readiness' for information. This is clearly motivated by their commitment to being family-centred in responding to individual needs, but it may also be related to assumptions, for example, that families "tend to still be grieving about the fact that their child is deaf" and that their ability to cope with information is consequently reduced. Professionals spoke about their information provision depending on "where the family is at" and that "some families want lots of information very quickly and some definitely don't". Others referred to gauging the families' level of knowledge and experience, as well as exploring their aspirations for their child, to avoid a "one-size-fits-all" approach. Acknowledging the potential difficulty of meeting all families' information needs and preferences, one project

participant appeared to sum up the generally agreed view, noting “They [families] all need the information but they’ll all need it at different times, and whether we can provide it at the time they need it is I think the challenge”. There is clear motivation amongst professionals to be responsive to individual family situations and contexts, however different professionals’ judgement about the pace and amount of information inevitably does add to variability and inconsistency which, in the absence of some instrument to help assess needs more objectively, may impede families’ opportunities to make informed choices.

The importance of knowledge was highlighted by professionals, who expressed a sense of responsibility to families to be as evidence-informed as possible in their information giving, advice and discussions. They commented that parents often want professionals to provide answers and to steer them towards a route in respect of language and communication choice, and that parents can “rely very very heavily on professionals and the advice they’re given”. In this context it was noted that it is important “to remain impartial and to be up to date with the most relevant research and what’s going on as regards communication, whether it be BSL or total communication or spoken English, whatever it may be”. The importance of disseminating new knowledge from training or professional development courses amongst colleagues was also noted in this respect, and gaining knowledge from other professional groups. Audiologists in particular spoke of the positive influence and value of their colleagues in the cochlear implant programme and their specialist speech and language therapy and teacher of the deaf colleagues, citing benefit of their breadth and depth of knowledge about communication in joint meetings with families. They commented that their own knowledge, particularly over the last few years, had become more scientific in its focus: “ABRs, and the science behind ABR, we’re having to peer review scientifically... and the verification of hearing aids is very scientific and it’s sometimes really difficult when you are having to do that in a very very emotional situation. So having the support of colleagues.... really makes a difference”. All audiologist participants emphasised the value of working with colleagues who support families in the home, to develop strong relationships to “get a better picture.... information to work more holistically”, concluding “that’s such a valuable experience”. Challenges were recognised however for practitioners who work in a more isolated capacity, whether in more remote geographical areas with few close colleagues in either their own discipline or from other disciplines, with low numbers of families, or in areas with less multi-disciplinary collaboration or more fragmented service structures.

Similarly challenging in more remote contexts is the issue of supporting families to gain more knowledge for themselves, which was also identified as a key enabler of informed choice making. In keeping with research into informed choice which identified the key relationship as being between *understanding* and choice, not simply *information* and choice (Young et al,

2006), professionals spoke about the importance of signposting parents to sources of peer support and groups where they can experience different approaches to communication in practice – both in pre-school settings and in BSL communities. By being able to experience first-hand how different families and D/deaf adults choose to communicate, ‘showing rather than telling’, families are perceived as having the benefit of seeing a model of “different things that work” so that they can bring some experience and knowledge to discussions and decisions rather than “the health professional or education professional coming in and telling them what to do”. This was also felt to be important for families who may feel their child isn’t thriving with their initial preference for an approach, providing an opportunity to see that it’s not a question of ‘failing’ but one of what best suits a child’s strengths and needs.

Practitioners recognise that there is notable variation in how they share information with parents in respect of language and communication and the need to address the significant differences in when, how and what information is provided. They acknowledge that even when practitioners are within the same team, whether they be audiologists, speech and language therapists or early years teachers of the deaf, there can be very different practices. Professionals report a mix of approaches, and whilst some services or teams have a clear framework – though not necessarily a written one – for how they approach information provision about language and communication, many rely on the evolved style and practice of individual practitioners rather than policy. Some good examples were given however of how local teams have recognised and are working to improve consistency and reduce selectivity, such as formalising closer links between audiology departments, teachers of the deaf and speech and language therapy teams, and ensuring joint understanding of the advice and information that has been given and when. Another positive example was shared by speech and language therapists who, acknowledging that “we all thought we were doing the same thing with all these little babies under one and it turned out we were all doing something slightly different”, and recognising that without some shared guidance there would inevitably be variability and inadvertent selectivity, developed an ‘information sharing pathway’ with an infographic to help assure consistency of approach to information giving irrespective of the individual therapist. A number of other local examples were given, demonstrating professionals’ commitment to improving opportunity for informed choice making and facilitating equity for families in receipt of their local services.

Reliance on independent sources, significantly the National Deaf Children’s Society, for information to support informed choice

In addition to some practitioners mentioning the benefits and their appreciation of having close

working links with named National Deaf Children's Society Scotland staff who work directly in support of families, most professionals spoke about the importance of the Society's information and resources in connection with supporting language and communication choice. There is clearly significant reliance on National Deaf Children's Society information, described as "probably some of the best researched" and deemed to be clear and balanced. Held in high regard, it appears to be the major resource in terms of presenting information about all approaches to language and communication and is routinely signposted to by professionals. Some practitioners report giving parents a print-off of the web pages about communication approaches to families at time of diagnosis and using it as a basis for discussion on the first home visit to families. Others signpost families to the information as they refer on to support agencies. Few practitioners reported providing their own locally contextualised information about language and communication options, so it is likely incumbent on families to follow through on the recommendation to contact the National Deaf Children's Society or to visit the website to access the information they need. Where families may experience some time between audiological assessment or confirmation of hearing loss and a first meeting with early intervention professionals, they may either be in an 'information vacuum' if they cannot or do not choose to access the Society's resources, or if they do, it may be the only information they have in that period, however short or long that may be. In this sense, and also in respect of being a key provider of Family Sign Language courses which are also signposted to by professionals, the National Deaf Children's Society may be seen as a core part of the information and support pathway in Scotland in respect of enabling parents' understanding of, and opportunities for, making informed choices about language and communication.

Perceived challenges and possibilities within the national context

In reflecting on their beliefs and practices, professionals were asked to identify what they thought are barriers and enablers in respect of enabling informed decision making, and also invited to consider, in an ideal world, what they would change or develop to improve informed choice in a national context, particularly in relation to families having full information about and support for all options. Their perceptions about barriers and enablers both overall and in their local contexts are reflected in preceding sections of this report, and in many ways, are two sides of the same coin: availability of and access to resources; knowledge, skills and understanding of practitioners; opportunity to work with and learn from colleagues in a multi-professional approach; access to opportunities for families to experience different options and to learn from other families and deaf people; and of course the impact of vastly different geographical areas on all of these factors which determine to a large extent whether they serve as barriers or enablers.

Acutely aware of the challenges of variability and inconsistency, professionals cited their concern as one of the motivators to participate in the project, with one participant summing up the issue of information provision in relation to informed choice as “a huge thing for us to get right” and asserting that “we want to have consistency that all families are getting the right information because we are all from different areas... if we could do something to level that”. However, despite acknowledging the positive opportunities afforded by the BSL national plan and nationwide policy initiatives to support families of children with additional learning needs (including the promotion of choice for parents), together with the recommendations from the Independent Review of Audiology Services, the SSC Quality Standards and the leadership of HINCYP, professionals found it challenging to be aspirational. Having identified networking at local and regional levels as a key enabler for improving information about language and communication options and supporting informed choice making, greater and more systematic national networking (thought to be especially important for more isolated professionals) was suggested as a positive. Also deemed an opportunity is raising awareness of information resources which have been developed by different practitioners across the country and establishing a system by which to share them. Further suggestions included: better use of data and sharing data; greater involvement with D/deaf clubs and D/deaf communities; increased access to peer groups for children and families, especially early in their experience parenting their deaf child; and consideration of a charter or similar outlining what every deaf child should be entitled to, detailing their rights, with guidance about how to make entitlements to both information and resources (including technology) readily available and accessible in every locality.

Professionals identified more challenges though than opportunities in a national context, and wanted to be realistic in terms of what would be needed to effect real and positive change towards ensuring informed choice, pointing out that “the discourse around informed choice doesn’t always tease out the complexities”. Stressing their belief in and commitment to enabling informed choice and decision making for families, they identified the need for:

- recognition that in itself, multi-disciplinary co-ordination is only partly a solution and that joint training and professional development is needed to help practitioners recognise and address biases and properly embed the inherent values of informed choice within teams.
- engagement with the D/deaf community, especially in respect of widening BSL opportunities for families but also in providing role models for all communication options and preferences.

- recognition of the particular needs relating to deaf children and resource commitment from policy makers at national and local levels and from generic service managers to train specialist staff to an appropriately high level, with a properly developed workforce plan to meet the needs of deaf children using all modes of communication.
- consistency in approach to developing and delivering resources for families who choose sign, pointing out the challenges where 'Signalong' is seen as fulfilling parents' choice and may mislead families who wish to explore and enact their choice for their child to communicate in British Sign Language.
- ensuring that there is a policy and an equal commitment to resourcing for families who choose spoken language and that the focus does not become solely on sign access.
- making a smoother and more effective pathway for families with deaf children in which systems relate to each other, so that variability and inconsistency caused by system differences do not impede families' opportunity to enact their informed choices.
- mapping what is available across all areas so that there is a national picture of support for deaf children from birth onwards across health and education, not just of education settings but of the care pathways and resources (human, information and provisions) so that both families and professionals are aware of what is available nationally as well as locally.

4c) Parental reflections and experiences

It is important to acknowledge that this project has been carried out in a post-pandemic context and that families are recalling some experiences and impressions inevitably shaped by the support and services they received during a period of severe disruption to working practices in both healthcare and education as well as reduction of opportunities in wider social contexts. In terms of receiving information about language and communication, this is perhaps particularly significant for families with children in the 0-4 age group, whose earliest diagnostic experiences may have been negatively affected and for whom first-hand contact with their support professionals would not have been within the typical pattern of provision. Similarly for families of children in the 5-11 age group, for whom opportunities for pre-school experiences and early language development may have been impacted, or the period when they would be researching and choosing school provision for their children (when support for language and communication will have been high priority) adversely affected.

Parents were asked via the questionnaire about the type, amount, and sources of information and support they received at and around the time they learned about their child's hearing loss. Almost all parents of children and young people in all age groups recalled being given information about the level of their child's hearing loss and about amplification. Most parents in the 5-18 years groups recalled being informed about communicating with their child, but only ten parents recalled receiving any information about sign language, with only one parent out of thirteen in the 0-4 age group recalling receiving any information about it. Around half or fewer than half of all parents report receiving information about support services available to them, with similar numbers (slightly more in the 0-4 age group) reporting being given information about other sources of support such as the National Deaf Children's Society, either locally, nationally or both. The majority of information is reported to have been given verbally, with some parents recalling also receiving written information. For the family whose first language was not English, this was provided in their home language.

In response to which professionals or other people they encountered, audiologists were named by parents as being the most frequent contacts for information and support at and around the time of identification of hearing loss, followed by teachers of the deaf / educational audiologists, speech and language therapists and medical professionals (ENT and/or paediatrician). Health visitors were also noted for the 0-11 year old group, and particularly by families of children under 4 years of age. Only one family (in the 5-11 yrs group) reported contact with a social worker and only five from the whole age range noted their GP as a source of support and information around that time period. Audiologists, teachers of the deaf / educational audiologists and speech and language therapists were also reported as being the primary sources of information and support for parents, along with representatives from the National Deaf Children's Society and to a lesser extent, medical professionals. The internet was also a notable and frequent source of information for families with children in the 0-11 age group. Some parents additionally reported other families with a deaf child, their friends, other voluntary organisations and deaf or hard of hearing adults as being sources of information and support. In response to the question about the extent to which the amount of information and support they received from professional service providers met their needs, this was a mixed picture, with in hindsight twenty parents judging it to be about the right amount, thirty reporting that it was insufficient, and one reporting that it was too much or given too fast.

With regard to 'Making Choices' the questionnaire asked parents about
- the factors which were most important to them in choosing how to communicate with their child.

- whether they felt they were given the opportunity to explore different communication options.
- what information or experience was most helpful and /or influential in their considerations and decisions about which communication approach to use.
- whether they were able to make the choices they felt suited their and their child's needs and be supported in them.
- If they had made a change to their initial choice of communication approach for their child, what influenced them to make the change and how were they supported to do so.
- in making choices and decisions about what they want for their child and family, what or who had been the most helpful / useful and the most influential support, and whether they felt anything had hindered or been unhelpful to them, and if so what.

These same areas of focus were explored in some depth in the ten individual interviews with parents, in the context of their relating their and their child's journeys from the beginning to the point they were at now. In addition, interviewed parents were asked what if anything they may have liked to have been different in their experience, and what advice they would give to professionals providing the services and the systems and contexts in which they are provided.

Analysis of data from the questionnaire and the verbatim parent interview transcripts identified 4 primary content categories across the areas of focus, which, as with the professionals' data, show some interconnection or overlap, and contain a number of sub-categories:

- Aspirations and priorities in considering language and communication choice.
- Experiences of information provision.
- Availability of and access to support for language and communication choices.
- Reflections on experiences of pathways of care / systems of provision.

Aspirations and priorities in considering communication choice

Questionnaire responses highlighted some key factors which were significant to parents in this regard: thoughts about the future and the opportunities and possibilities which may be opened up or restricted for their child; perceptions of 'normalcy', 'inclusion' and 'acceptance'; and the importance of their child being understood and understanding others. The same or similar factors were expanded upon by parents taking part in individual interviews, some of whom, in recounting their experiences from the beginning of their journey with their deaf

child, also spoke of the impact of their screening experiences on their expectations and communication considerations, with concern that they had been over-reassured that their child was unlikely to have a hearing loss, leading to their feeling unprepared in terms of thinking about the potential implications, or conversely, made over-anxious so that they had fears about what the future may hold for their child.

Thoughts about their child's future, and what being deaf would mean for their child both in the shorter and longer term, were reported by many parents as being of appreciable significance in relation to considerations about communication. This was the case for families with both early and later diagnosed children, and those with children with additional needs or disabilities. Parents emphasised the importance of their child being able to enjoy "a full life" with as many opportunities as possible to make their own decisions in the future, and wanting to make "good choices" to help make that happen. They spoke also of wanting to make sure that their child would have a strong identity in terms of a positive sense of self, with confidence to fulfil their potential, "to thrive not just cope" and "to be the best they can be" as they go through life, and the importance of having the right support and guidance to support their child's emotional development.

Parents who emphasised their concerns about their child having the opportunity to be "normal" did so in the context of not wanting them to be "singled out" or "different". Some parents explicitly stated that a choice for spoken language was driven by wanting their child to share the same way of communicating as the rest of the members of their own (hearing) families and also in light of perceiving spoken language as presenting fewer barriers for their child's future and giving them "the ability to have a mainstream life". These expressed priorities in relation to wanting their child to be 'normal' were seemingly unrelated to level of the child's hearing loss, but level of hearing loss and the impact of amplification on access to sound does appear to have been a notable influence on parents' early considerations and aspirations about communication mode. For some parents with children with mild or moderate, and in some cases severe, degrees of hearing loss, spoken language appears to be less of a conscious decision and more of an intrinsic expectation that with effective amplification, their child would be able to hear well enough to naturally develop speech and to be able to understand others' spoken language. Equally, for some parents with children with more severe or profound deafness, sign language was seen as a natural and preferred approach. For many families however, choice of communication mode was not necessarily related to level of hearing loss, and more a matter of what would "work best" for their child, also recognising that accessing different modes of communication could give the child the option of making their own choices for the future. Some embraced the positive consideration

of sign even when cochlear implantation was a potential way forward, as they saw the benefits of “having an alternative if it [the implant] didn’t work” or as it being advantageous for their child to be bilingual, able to play a part in both hearing and D/deaf communities.

Parents generally saw ‘inclusion’ and ‘acceptance’ in a somewhat broader context. Whilst, for some, inclusion was connected with hopes and preferences for mainstream education, for many it referred more to inclusion in society at large and to not being marginalised. Similarly with acceptance, with most parents framing this as a future in which their child is fully embedded in the family and also having peer groups in which they can be equals, able to communicate, to understand and be understood. This was equally important for parents whose children have additional needs, who commented that they felt that professionals tend to have lower expectations for their children. Parents also talked about their awareness of recent developments towards entitlements around BSL in Scotland, and the importance of having access to a D/deaf community and for their child to have role models (older children and adults), both hearing and D/deaf, with both spoken language and/or sign language being positive choices towards those aims.

Experiences of information provision

Parents described a range of experiences, both positive and negative, in relation to information provision and access, both at the time of identification of their child’s hearing loss and beyond as they encountered different services in the care pathway. They recalled how information about communication options, their ability to explore those options, and their access to information about resources to enact their choices affected those experiences. Factors identified included: the amount, nature and sources of information about communication options and the resources to meet them; the impact of key professionals; and the importance of contact with people with lived experience of deafness.

Although differing in their accounts of their diagnostic experiences, most parents looking back on the time when they learned their child had a hearing loss spoke about the audiologists’ sharing the news with them as being supportive with some noting audiologists’ manner as “kind” or “compassionate”. On the whole, parents recalled that audiologists took time to explain their test results with care, even though they felt it was a difficult time emotionally and the information was often challenging to process. They generally recalled that there was little focus on issues of language and communication however, with very little specific reference to sign language as an option within that. This perhaps accords to some extent with the feelings of participating audiologists who expressed being reticent to talk

about options of which they felt insufficiently knowledgeable or aware, or unsure about the possibility of being resourced. Alternatively however, it may indicate a narrower audiologist focus on the role of providing amplification with the purpose of enabling access to sound and by association, speech. Parents' apparent natural expectations of spoken language as an automatic or 'default' route may also have been influenced by audiologists' explanations of hearing test results, and the routine next steps to earmould impression taking and provision of hearing aids, all within a short time frame and when parents are only just learning about their child's deafness and the "new world" in which they perceive themselves to be. Some parents reported feeling that when they were assured that amplification would give effective access to sound, it was also implied or made explicit that their child "would not *need* to sign", revealing perhaps some level of bias, whether implicit or conscious. A similar feeling was reported in respect of an audiologist recommendation to consider cochlear implantation, where for one parent, opting for a cochlear implant was perceived as there consequently being no choice to be made about communication mode (the purpose of the implant being understood as to facilitate spoken language development and ruling out the option to sign). Whether this was as a result of professional information giving and advice or parental assumption is not clear.

Parents also recalled receiving different amounts of information from audiologists about the support pathway following diagnosis. All spoke about being given verbal information but with varying amounts of detail. Some parents reported being given "a leaflet" but not necessarily specific to their local context, and others reported having no written information provided about how their child's communication development would or could be supported, and although they were all aware that they would be referred on to a support agency, usually Speech and Language Therapy, they did not feel there was a timescale given for when to expect contact. The disparity in the amount and level of detail of information provided about next steps and follow up services specific to their child appears largely unrelated to geography in terms of rural or urban context or indeed to size or scope of local services. All parents however recollected being informed about and directed towards the National Deaf Children's Society as a source of information and support, particularly in relation to language and communication and help to understand the nature and level of their child's hearing loss. Being informed about the National Deaf Children's Society was said to be mainly verbal, with signposting to the website, but some parents recalled also receiving written materials, including in some instances about local groups. Parents spoke about how important the Society was to them in this early period, as a major source of knowledge and information.

Parents and professionals in the support pathway appear to have different perceptions about information provision about language and communication in the follow up to identification of a child's hearing loss. Whereas professionals report taking a responsive, 'family-led' approach to parents' information needs in relation to communication, wanting to be led by parents' questions, parents themselves reported wanting the information sharing initiative to be more professional-led, as they felt they had insufficient knowledge at the beginning of their experience to be able to "generate questions" or to ask the "right" ones. Several parents commented that although the professionals were responsive to any questions they did have, they felt that all options about language and communication should have been "laid out" for them so that they were aware of what existed, even if it couldn't be resourced. One parent's comment represented similar views from others in this respect: "I needed more, better information, telling me what I needed to know and I shouldn't have been left to find it myself. The thing is, I didn't even know what to ask". Other comments from parents reinforced the need for more extensive and balanced information, such as: "I worry about the people who didn't have the confidence to say to the professionals 'well no, it's not good enough'people need to be able to say 'I need more than you're giving me' to them" and "We were just left in a place where we needed, wanted, to make a decision but we just didn't have enough information.....just give people all the options and let them know that you can learn sign language as well as speech and it won't hinder them ". These perceptions of insufficient information to help parents be aware of and to understand communication options, with "not knowing what to ask" and "not knowing where to look" being commonly repeated sentiments in many of their accounts, were clearly felt to impede their abilities to make informed choices. Parents also reported being substantially reliant on National Deaf Children's Society information, both online and via the helpline, to help them with considering choices, calling it a "lifeline". They also spoke positively about in-person support from the Society's Scotland officers, but even then, many observed that they felt that it was important to have a local professional to take the lead in discussing communication issues with them in the context of their own child and family and with knowledge of resources they could access in their own areas and what was available elsewhere..

The importance of meeting "the right people" amongst professional service providers was also stressed by many parents, who recounted in some detail the impact of individual practitioners on their lives and their abilities to make choices for their child. How individuals had supported them in relation to learning about and considering communication options was significant to parents, who expressed strongly held views, both positive and negative, about those they had encountered. They spoke of feeling "lucky" or "unlucky" with regard to the professionals from whom they had received services, with some having taken steps

themselves to effect change when they felt they were not getting appropriate support. Many professionals – audiologists, medics, speech and language therapists and teachers of the deaf, from both local services (including schools for the deaf) and from the national Cochlear Implant programme - were frequently praised by parents for their balanced information and support in relation to language and communication and for their overall support for parents, with words such as “lifesaver”, “fantastic”, “amazing”, “important” and “empowering”. Many professionals were specifically mentioned by name, and those parents who had encountered professionals (from both statutory and voluntary services) who were deaf themselves particularly noted the overwhelmingly positive impact on their feelings of confidence about their child’s abilities to develop effective communication and to “do well”. Parent-professional relationships were also described as positive by many parents, with comments such as “deep and valuable” and “I know they are on my team”. Some parents however recalled the negative impact of certain individual service providers. They recounted receiving services from individuals who, despite being committed, helpful and “well-meaning”, had in their view insufficient specialist knowledge to be able to provide full and accurate information or couldn’t support them in their chosen communication approaches due to lack of skill or experience with deaf babies and families. Some also reported encountering individual service providers who held and shared explicitly biased opinions on communication options, especially in relation to sign language (both for and against) and to a lesser extent Auditory Verbal Therapy. The experience of overt bias in relation to communication approaches was mainly referred to by parents of older children but some parents of young children also reported a perception of bias in recent times. Conflicting views from different people in the same services or different professionals in the same area were also reported, which parents found unhelpful, especially when they felt they subsequently discovered information to be wrong or ill-informed in relation to their own situation. In these instances parents expressed feeling “let down” and spoke of relief and welcome change in their experiences on finding “the right people” which enabled them to have positive partnerships with service providers. Perceptions of the importance of “the right people” also included personnel at local authority level, especially when parents were seeking information about resources and potential placements, with parents frequently mentioning that there seemed to be a lack of knowledge or understanding about the needs of deaf children.

In addition to wanting full and unbiased information from professionals, parents also spoke about the value and importance of being able to see communication approaches ‘in action’, by meeting other children and deaf adults with different types of amplification, including cochlear implants, and using a range of communication methods. They commented that having support from other parents who shared their experiences of making choices for their

own families, and learning from deaf adults, including contact with members of the Deaf community, was “overwhelmingly positive” and “a game-changer”. They felt these experiences helped both to contextualise the information they had received from professionals or had accessed online themselves and to deepen their understanding of potential choices. Most parents learned of these opportunities via the National Deaf Children’s Society or from the schools for the deaf if they were aware of one in their area. They commented that being told about the importance and value of meeting parent peers (especially those with children of similar age to their own and slightly older) and deaf people, and how to access opportunities to do this, should form part of professionals’ routine information provision.

Beyond the initial period, parents also reported some difficulty in accessing information about language and communication support in educational settings (both schools and pre-school settings) for deaf children in Scotland. Whilst this was particularly the case for parents who were moving into an area having had their early provision elsewhere, a number reported it being very difficult to find information online about the type of supports offered, what communication approaches were supported, or provisions made in various areas, with one parent describing the experience of seeking information on government or local authority websites as “trying to navigatewith only little nuggets of information....you don’t know what you are meant to be searching for”, and several commenting on the need for better information online which is easier and more coordinated to access.

Availability of and access to support for language and communication choices

Availability and access to resources to further inform and support choices about language and communication, both in the time following identification of their child’s hearing loss and beyond into school years were highlighted by parents as a key concern, affecting both their initial decision making and also their experience in endeavouring to ensure that their child’s needs were met to enable them to fulfil their potential for the future. Whilst information about language and communication options appears to some extent, but by no means wholly, influenced by where they live, the availability of and ability to access resources appears to be of far greater significance in terms of geography.

Even when parents had reached informed decisions about their preferences for language and communication approaches, they reported that their abilities to pursue them were impacted by both availability and access to resources. In relation to BSL specifically, a number of factors were identified: existence of opportunities for parents to learn to sign;

funding; the variability in approach; access to and support from the D/deaf community; and access to educational opportunities and peer groups for children. Depending on availability in local and/or neighbouring areas, these issues act as both barriers and enablers to parents' choices. In relation to both BSL and to spoken communication, availability and access to settings with appropriate understanding of the needs of deaf children and to specialist staff, particularly in mainstream placements, appears similarly impactful.

Parents were positive and appreciative of the National Deaf Children's Society's Family Sign Language initiatives. As regards opportunities to access formal BSL classes within their local areas however, parents reported variable experiences. Some reported good access and received Local Authority funding to attend, whilst others found classes both difficult to access and prohibitively costly, having to self-fund them. When parents discovered, usually from other parents, that arrangements differed from area to area, they felt strongly that this inequity was "unfair" and "unreasonable". Also frustrating for parents is their experience of different providers of BSL classes, with some reporting that the two major providers, SQA and Signature, appear not to accept each other's qualifications when going from one level to the next. This created some logistical access issues for families.

In terms of wider support for BSL, parents who live in areas in which there is a school for the deaf generally spoke of greater opportunity to meet other parents whose children were signing, and very much appreciated increased opportunities to access pre-school opportunities for their children alongside others developing language and communication through sign. All parents who had chosen to use sign, whether BSL as a primary mode of communication, Sign Supported Spoken English (SSSE), informal sign to support oral approaches, or Total Communication, emphasised the importance of accessing Deaf clubs to help increase not only their signing skills but also to learn about the Deaf community.

Parents who wished for a mainstream education for their children but who also wished for BSL recounted experiencing difficulty in accessing support for this, citing both a lack of teachers who are significantly competent in BSL and also some attitudinal issues in the schools themselves. It was observed by one parent that "parents' choices are limited by what a school can or wants to provide", whilst another described the impact of a lack of a signing peer group for her child in mainstream school, where although the child communicated in both sign and speech, they "just kind of stopped using it because there was nobody to sign with and they were embarrassed to be the only one". Signing peer groups and a whole school commitment to embracing sign was felt to be invaluable by those parents for whom it was a reality and a failing for those who did not have that experience.

Not being informed about Auditory Verbal Therapy was also an issue for some parents who wished to pursue a spoken language choice for their children. Not only did these parents feel that information had been omitted by professionals who perhaps were reticent about being able to provide it (finding out about it from other parents), they were concerned to find that in some areas it was routinely available yet in others it needed to be self-funded. Some perception of withholding opportunity to access some choices were also reported by parents of children with Additional Learning Needs. Connected to the perception of being insufficiently informed about potential options due to low expectations of their children or lack of understanding of deafness within the context of other needs or disabilities, where “hearing gets put on the back burner”, parents of children with ALN perceived they had not been enabled to have access to cochlear implant assessment or to developing BSL within their (non-deaf) specialist schools, who mainly advocated Makaton.

What is clear across all interviews and through the questionnaire responses however is the resourcefulness and proactiveness of parents who expressed a strong sense of responsibility to seek out information and to pursue access to the language and communication opportunities they wanted for their children when they felt that these were not being made available. Although some reported feeling “overwhelmed” by thoughts about how deafness might imply “life restrictions” for their child in the early period following diagnosis, they also expressed positivity about deafness, with high aspirations for their children. Finding out about the perceived large differences between what was routinely available and accessible to some families but not others depending on different geographies, (especially when this reportedly often happened by chance in meeting other families or through their own research), presented as a significant issue for parents, who expressed strong feelings about there being equitable provision in respect of meeting language and communication choices, not only for their child and family but for others too.

Reflections on experiences of pathways of care / system(s) of provision

Informed choice means that the effectiveness of the information parents receive about language and communication is closely related to their ability to act on it and to navigate the system networks which enable access to support their choices. Even where parents were appreciative of the individual practitioners and teams or departments they had encountered along the pathway from diagnosis onwards or from whom they currently receive services, they expressed frustration with how the overall system functions and how different parts of it relate to each other. Lack of contact and communication about and within the care pathway,

expectations about timeliness; lack of accessible printed information about provisions and access to provisions (including online) and the content of that information in relation to how the overall system works both within and across Health Boards and Local Authorities were highlighted as contributing to this.

One parent expressed the reported feelings of many in describing the experience following identification of their child's hearing loss as "a journey of uncertainty", and commented on the added stress of navigating different supports in the context of not knowing what to expect. They spoke about not understanding the roles and responsibilities of different professionals and the lack of written information to clarify this. Some parents were unclear, for example, about the differences in support and interventions between speech and language therapists and teachers of the deaf in particular, whilst others did not understand why medical investigations were undertaken. They commented that a lack of co-ordinated information from the range of involved professionals affected their ability to understand the bigger picture and to make informed choices about language and communication, which included considerations of the implications for later educational placement.

Parents understood that the Covid-19 pandemic and its inevitable constraints on in-person contact affected their experiences in relation to how they received both information and support. The impact of this period seems to have been most keenly felt by parents of children who were diagnosed during or just prior to the pandemic, or by those whose children were at key points of transition, although parents of older children also reported a significant impact on communication with education and healthcare providers during that time.

Although not the experience of all parents involved in the project, lack of timely or co-ordinated contact (whether in-person or by other means) following their child's identification with hearing loss was cited by many however, describing it as both frustrating and/or an emotionally difficult time. They reported being told that various professionals "would be in touch" but frequently with no indication of when that would be or what to do if it didn't happen, and in the absence of information about expected timescales, felt that they couldn't judge if they had "fallen through the net", were on a waiting list, or whether the time interval between diagnosis and next steps being implemented was normal or typical. Parents spoke about this period of not being in contact with professionals as being one in which they felt they lacked support to help them adjust to their new situation and to begin to think about language and communication, with one parent commenting "So there we were with our 6 week old baby and we didn't know what her future was going to be like.....thinking what do we do if she can't hear us, how will we communicate?". Others referred to the lack of specific

emotional support within the system both around the time of and in the period following diagnosis, when decisions need to be made but parents may feel emotionally unready, commenting that support for parental wellbeing should be prioritised, either by having specialist professionals or by ensuring that professionals who are currently part of the system have training or qualifications in supporting families' emotional needs.

The pathways of care and systems of provision themselves were reported as hard to find out about and hard to understand, with parents feeling that whilst individual elements of the care pathway supported them well, with "hardworking and highly motivated professionals", generally there was a lack of cohesiveness. The perceived lack of co-ordination and integration between the different elements of provision led one parent to observe "the system is only giving what is asked of it but we don't know what to ask" and another to comment on the lack of expected contact and the perceived need to take the initiative, saying "If I'm perfectly honest all the contact has been because I have pursued it". It was suggested that there needs to be some co-ordination with perhaps "a single point of entry" and "an eco-system and networking amongst professionals so there is systemic understanding".

As well as commenting about the systems of care and provision in their specific home areas, both in relation to considering language and communication options and the impact of choices on educational opportunities and how and to what extent those choices can be supported locally, families spoke about wanting to know about the bigger Scotland-wide picture. They wanted to be aware of the systems of support in other geographical areas and how they differed from their own areas, whether children in some areas were getting different opportunities or different levels of support for language and communication development, or whether other parents were having greater amounts of support (both resource and financial) to enact their choices. One parent summed up the views of several with the comment "It [the national picture] needs more integration especially for deaf children".

Reflections on the system, and indeed parents' views on the various aspects of provision of information and resources relating to supporting informed choice for language and communication, were reiterated in their responses to the question asking what they might have liked to be different in their own experiences and what advice they would want to give to service providers and policy makers. The variability in parents' experiences is summed up by the responses of two different parents, with one saying "That's a difficult one, because I've not really had the support so I don't really know what's out there. I guess the answer is that I really should have known about it all", and another expressing "Overall, a positive experience really... and we've had some great people in our corner". Based on their experience of both

limiting and enabling factors affecting their ability to make and enact informed choices, parental perceptions of need for both now and in the future included:

- Information about all options – “Tell us everything” – with the opportunity to discuss them and make decisions supported by knowledgeable but impartial professionals.
- More and better information about the system and how it works, with greater recognition of the needs and provisions for deaf children within the overall ALN focus.
- Greater knowledge about the needs of deaf children at Local Authority / Council levels.
- Better co-ordination of services, with information about what to expect and when.
- Easier and more equitable access to resources for learning BSL, including financial support.
- Access to the expertise of specialists within the schools for the deaf, even when out of area, and resourced early years provisions.
- Greater contact with and support from knowledgeable professionals, especially experienced Speech and Language Therapists or Teachers of the Deaf with BSL skills as well as competence to support spoken language development.
- Early and facilitated access to support from parent peers, other deaf children, and D/deaf people using a range of communication approaches - “so we can learn from others with experience”.
- More recognition of the emotional needs of parents and the importance of support for emotional needs at a time when parents are faced with what they describe as an important but challenging time for adjustment and decision-making.
- Greater understanding of the needs of deaf children in mainstream schools.
- More opportunities “to be listened to” and to be able to influence provision from a position of having their abilities to be ‘parent leaders’ acknowledged and valued.

5) Conclusions and Recommendations

In many respects, parents and professionals recognise the same or similar issues as both barriers and enablers in respect of informed choice, but from the different perspectives of providers and receivers of services and support. Barriers and enablers exist at both systems and service practice levels, and can vary markedly both between and within geographical areas, leading to inequity for parents and their deaf children.

Parental reflections on the information and advice they receive or have received around language and communication reveal significant variations in their experiences. How, when, and from whom they receive information, its breadth and depth, and how they are supported to understand and contextualise it, is clearly impactful and affects both their feelings and aspirations and their ability to make informed decisions about language and communication for their children. Access to high quality and comprehensive information both verbal and written, presented by supportive professionals in an unbiased yet open and honest way, together with access to the support they need to enable their informed choices to be resourced, is of key importance to parents.

The National Deaf Children's Society plays a significant part in the information picture for both professionals and for families, with service providers routinely signposting to the website (in addition to some audiology services giving out the Society's leaflet following identification of hearing loss) as the main source of information on language and communication options. The reliance on the National Deaf Children's Society for information about communication approaches in many ways makes it a core element of the support and information provision pathway. Professionals hold the information in high regard and parents clearly value and depend on its comprehensiveness. They are proactive in using the information to inform their considerations, but they also point to the need to have impartial personal input and knowledgeable advice to help them consider the information in the context of their own child and family, and to support decision making.

Parents have positive views about sign language for their children, either as a primary mode of communication or alongside or in support of their children's spoken language development. Like professionals, they welcome the new BSL National Plan, and express hope and expectation that there are sufficient skilled resources and appropriate funding to support its full and equitable implementation. Parents choosing spoken language as the primary communication approach also wish for the same purposeful focus on ensuring high quality support, both in the early years and in educational provisions, with access to appropriate skilled intervention and technology and a favourable environment (both physical and philosophical) for developing listening and spoken language.

It is interesting to note that whilst professionals may have a tendency to conceptualise informed choice in relation to language and communication approach as somewhat of a binary issue, this does not appear to be the case with parents, whose expressed desire is to ensure the best possible language and communication development for and with their child,

whether that be through sign language, spoken language or both, and to experience the necessary range of opportunities to inform their choices.

In terms of the messages, practices and provisions which are helpful or unhelpful in the context of supporting parents to make informed choices about language and communication, the bullet-pointed summaries of the reflections of both parents (page 34) and professionals (pages 20,21) both stand in themselves as recommendations from this report and inform the further recommendations detailed below. Some of the recommendations relate to professional practices at individual, team and service delivery levels. As such they may be addressed by committed practitioners across both health and education sectors networking and collaborating to share their expertise and experience and the information resources they have developed. Others, however, relate to factors which present as a result of how systems operate and the impact of national strategies and policies on deaf children and families. Addressing these will require the collaborative engagement of key stakeholders such as the National Deaf Children's Society with the Scottish Government and with Local Authorities and Health Boards, drawing on the expert input of HINCYP and other important stakeholders such as the Scottish Sensory Centre at the University of Edinburgh, professional associations in both Health and Education, and potentially other third sector organisations. There are also some recommendations which relate specifically to the National Deaf Children's Society itself. Across all recommendations, the principles of co-production should underpin actions taken.

Recommendations:

- Raise the profile of the existing 'Scottish Standards for Deaf Children 0-3' amongst service planners and policy makers, professionals in the health and education care pathways, and parents, and use them to assess current service provision to support further service development on a national basis. This should lead to clear national consensus on the provision of early years language and communication support pathways for both signed and spoken language, which adhere to the principles of informed choice and are in accord with the latest international evidence on family-centred practice.
- Ensure that the developed pathways are recognised, aligned with, and embedded within wider Scottish government policy frameworks and initiatives, including GIRFEC and ASL.

- Either through the HINCYP, The National Deaf Children's Society, or both, look to ways in which Local Authorities / Policy Makers may become more informed about the needs of deaf children and make information more explicit within their general information on Additional Support Needs.
- Formalise the role of the National Deaf Children's Society in the language and communication information and support pathways for families following identification of their child's hearing loss, underpinned by a commitment to informed choice.
- Ensure that the support pathway for newly identified children and their families has systematic involvement of a) people with lived experience of deafness and b) experience of parenting a deaf child, who have had appropriate training in family support, underpinned by a commitment to informed choice.
- Undertake a review or audit of all the provisions available in all areas, including information about language and communication approaches that are supported and make it available to both professionals and parents.
- Undertake an audit or compile a contributory list of resources to help inform parents about language and communication which have been developed by various professionals in their local context, so that they can be shared nationally amongst service providers.
- Undertake a workforce review, involving the identification of the expertises in different support services across areas so that there is a national picture, with a view to ensuring sufficient expertise continues through training and development of qualified staff now and into the future.
- Develop an assessment instrument or guide, or adapt an existing one in use in the field of early intervention support, to assess parents' needs and priorities for information post-diagnosis, or develop some standardised checklists, to support individual practitioner judgements of parents' 'readiness' or capacity for information.

- Develop materials at local/regional level to ensure that parents understand the pathway, its timelines and the services/professionals involved so that they are clear what support to expect after confirmation of their child's hearing loss.
- Ensure that all professionals supporting families around and following the period of identification of hearing loss have had appropriate training in sharing information without bias and can inform families about all potential options for language and communication development

For the National Deaf Children's Society specifically:

- Review the balance of information specific to Scotland across all its platforms in terms of language and communication, to ensure there is no perception of bias and that there are clear routes for Scottish families to access this information.
- Review whether it may be helpful or appropriate to include information about language and communication options within the current online 'maps' (such as that made available by 'Aussiedeafkids' in the Australian context).
- Consider steps to ensure that Advice and Guidance Officers or other personnel are well equipped and have appropriate training to help parents to contextualise and evaluate their options in support of informed choice making.

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