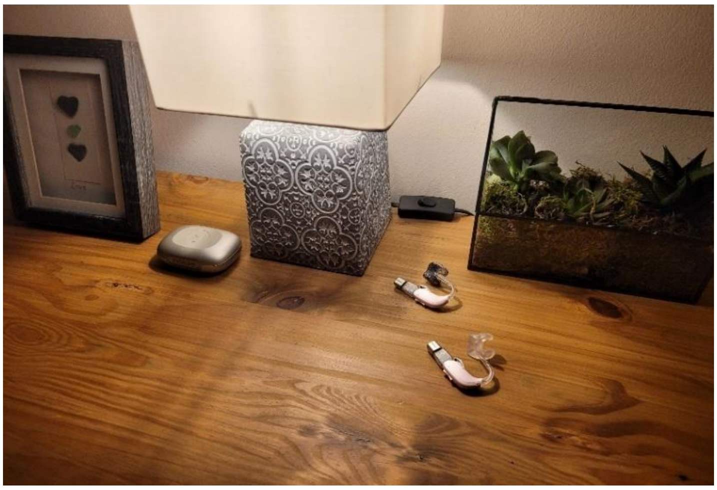
BRITISH DEAF ASSOCIATION NORTHERN IRELAND
THE FAMILY SIGNING IN THE HOME PROGRAMME 2024

An Independent Evaluation



15/07/24

Contents

“Fun, it’s fun.” (Deaf Child 2)

“I sign constantly. I sign to hearing people. I sign to the cat. Because I want it to be a normal natural thing in her life. That’s the way that it is in our house, we sign because it backs up speech and it helps with her understanding.” (Mother 2)

“I've been here five years. My family doesn't speak English. The children are quiet. They know, sign language.” (Father 2)

“Learning this language, I would say that this is the miracle that we can do this in this country.” (Grandmother 2)

“I never understood how much of signing is relied on your facial expressions and the movement of your lips with the words as well.” (Aunt)

“I knew that it (sign language) existed in the world, but I had never known that I would learn it. We're living here (NI) for two years.” (Sibling 1)

“I really look forward to the Tuesday night because she makes you feel really comfortable.” (Grandmother 2)

“It's lovely thanks to the signing at home M and TUTOR can hold a full conversation. It's beautiful to watch and watch her just progress.” (Mother 4)

“Only I understand everything” (Deaf Child 1)

1. Introduction

A decade ago, the British Deaf Association (BDA) in Northern Ireland (NI) introduced an innovative home-based sign language programme for families of children who are deaf. The Family Signing in the Home Programme (FSHP) is a bespoke programme tailored to the needs of each family and delivered by a team of tutors all of whom are deaf. The new FSHP commenced in November 2023 has been made available to 13 families across Northern Ireland (NI). Each family is offered an initial FSHP of 20 weeks duration with the option of an additional 10-week refresher course. In a significant development for the FSHP over half (53%) of families participating in the new FSHP are migrant populations for whom their first spoken language is not English. The first languages for these seven families are Arabic, Malayalam, Tetum, and Ukrainian. Evaluating the FSHP within the context of these families was a major focus of the evaluation.

The evaluation draws on the experience of six families three of whom were migrant families. One of the migrant families was visited at home, their session with tutor was observed and they were interviewed after. Fathers from the remaining two families were interviewed one by telephone and the other by Zoom. The three interviews were carried out with support from the Big Word telephone interpretating service. Interviews with these families served to shine a light on the severe social isolation that they experienced. Very appreciative of the FSHP the parents were hungry for more input and in all three cases, reflective of their lack of competency in English had asked for English classes as well.

A total of 16 people were interviewed as part of the evaluation. Two families were visited in their homes, two families were interviewed via zoom and two families were interviewed by telephone. As part of the evaluation a questionnaire has been developed that could be used with families at the beginning and end of the FSHP to capture expectations and learning. Feedback during the evaluation suggests that the questionnaire should be given to families when they register for the programme and by the tutor at the end of the programme.

Examining the FSHP within the wider research and policy context the evaluation demonstrates how the BDA programme recognises and promotes the rights of people who are deaf. Drawing on the experiences of parents the findings from the evaluation highlights how the FSHP addresses deficits in mainstream services provision. Parents described the anger and frustration they feel when receiving conflicting advice from health experts. They were also exasperated by the apparent ignorance in staff working in the health and education about needs of deaf and hard of hearing (DHH) children. By comparison they had only positive things to say about the FSHP. Fulsome in their praise for the tutors, parents emphasized how empowering it was for them to get to know adults who are deaf and see firsthand the full lives and successful careers that they had created for themselves. The location of classes in the home (in person or online) was deemed to be critical to the programme's success. The bespoke approach used with each family created a relaxed and fun environment. An overarching theme throughout the evaluation was the social isolation and loneliness that children who are deaf and by extension their families experience. The FSHP emerged as an effective intervention in promoting social inclusion.

Case studies of two families are used to demonstrate the impact of the FSHP for families. Case Study one describes the experience of Anne and John parents of Oliver a pre-school child who has no hearing. The second case study focuses on Amara and her family and serves to illuminate the major impact of the FSHP for migrant families.

In parallel with the evaluation, the BDA contracted a professional photographer[1] to capture the FSHP in action. These photographs are used throughout the report.

2. Aim and objectives.

2.1 Aim

To evaluate the BDA's 2023/4 Family Signing in the Home programme (FSHP)

2.2 Objectives

1. To develop a tool that will measure self-efficacy before and after the FSHP.

To identify:

2. The reasons why families engage with the FSHP.
3. The strengths of the FSHP the programme.
4. Impact of the FSHP on parents, siblings, and extended family.
5. Impact of the FSHP on the deaf Child.
6. Ways in which the FSHP could be improved.
7. The relevance of the FSHP for non-English speaking families

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[1] Joan Alexander https://joanalexander.net/info/

3. Context

The critical role of signing in enabling deaf and hard of hearing (DHH) children to grow, connect and make sense of the world around them has long been recognised.

> *"This early stimulation enables the child to gain confidence by knowing what is going on. The child learns where to look for visual cues, which makes communication meaningful and enables the child to feel that he or she is participating in a social relationship*." (Magnuson, 2000:14)

Feeling connected and part of the community is vital to human health and wellbeing. Social isolation is recognised as a major public health issue that results in higher rates of all-causes of mortality (Holt-Lunstad, 2017 & 2020; Leigh-Hunt, et. Al. 2017). Social isolation and loneliness in childhood has been shown to increase risk of depression and mental ill-health in adulthood (Almeida et al. 2021). People who are deaf or those people who are hearing-impaired are at high risk of being socially excluded. In a systematic review, albeit focused on older people, Shukla et al. (2020) found that hearing loss was: *"more consistently associated with social isolation than with loneliness*." (2020:7). People who are deaf do not have the same freedom or ease of opportunity to connect with people around them. Social isolation refers to the number of social contacts that a person has, and loneliness reflects a person's contentment with quality of relationships. In other words, someone could be surrounded by many people but the quality of those relationships id such that the person may feel lonely. Another person may not have many friends of family around them but feels content and happy. Socially isolated people are however more likely to experience loneliness and DHH people are more at risk of both.

> *"Most studies have reported higher prevalence of loneliness or social isolation in the hearing-impaired population compared to the hearing population. Twelve out of 20 (60%) articles that assessed the relationship between loneliness and hearing impairment found that loneliness was more prevalent in the hearing-impaired population. Similarly, 11 out of 17 (64.7%) articles found that social isolation was more prevalent in the hearing-impaired population. In a quantitative, controlled study, Majorano et al. uncovered that children and adolescents with cochlear implants were more likely to be isolated from peers and parents compared to their normal hearing counterparts."* (Patel et al. 2021: 1874)

In their study of social isolation and loneliness amongst people who are hearing impaired Patel et al. (2021) identified a number of protective factors including:

> *"the importance of having an attitude that hearing loss was not a barrier, having a robust hearing-impaired network, being extroverted, and being close to family."* (1873)

The importance of a supportive non-hearing network was also highlighted by Flowers et al (2022) in their study of parents of deaf children.

> "*Participants did not feel as though they can entirely trust professionals. As such, they placed a great deal of emphasis on encouraging parents of children with a newly identified hearing loss to identify appropriate sources of support outside of the professional realm, notably people with lived experience. Surrounding themselves with people they can relate to can in fact help them cope with the grief that follows the initial discovery of their child's hearing loss and feel more confident in their ability to make decisions. Overall, families with strong social support are better able to handle challenges"* (Flowers et al. 2022: 9)

Set against this context the authors identified the importance of nurturing trust for parents of deaf children. Trust in themselves as parents and trust in their child. In trusting in themselves they are advised to *"(1) trust your instincts, (2) educate yourself, and (3) exercise caution with regards to advice from others."* (2022:5). Trusting the child was characterised as supporting the child to make choices, enabling the child to know their own mind and express themselves. A central facet of this was recognising parents' responsibility to give their child a voice "*specifically when it comes to decisions regarding their preferred methods of communication*." (Flowers et al. 2022: 5)

Evaluation of the 2023 FSHP highlighted the importance of the first 1000 days of a child's life in terms of lifelong health and wellbeing.[2] Significantly, Magnuson (2000) emphasised the importance of early introduction of sign language in building children's capacity, confidence and understanding of the world in which they live.

> *"This early stimulation enables the child to gain confidence by knowing what is going on. The child learns where to look for visual cues, which makes communication meaningful and enables the child to feel that he or she is participating in a social relationship."*

In their study of exposure to 'visual language' Letteri et al. (2014) argue that children with early exposure to signing are more likely to develop better fluency and syntax in signing as adults. More recently Sümer, B. and Özyürek, A (2022) lend credence to this argument by revealing that delayed introduction of signing to deaf children has an adverse impact on fluency and level of sophistication in signing.

> *"Thus, effects of late language exposure or exposure to variation in input might become evident when signers are engaged in producing syntactically and semantically more complex*

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[2] House of Commons Health and Social Care Committee (2019) First 1000 days of life https://publications.parliament.uk/pa/cm201719/cmselect/cmhealth/1496/1496.pdf

> *utterances. Syntactic complexity was also observed to be a factor contributing to the differences in language productions of early versus late signers."(p.13)*

Moreover a 2023 study of literacy skills amongst deaf and hard of hearing children in Japan provides interesting indicators of the benefits of early signing in supporting reading ability. The authors use the evidence to advocate for an educational approach that recognises and supports DHH children as bimodal language users.

> *"For DHH children, the use of a signing system such as MCJ*[3] *in their early childhood provides them with a proper foundation for linguistic ability, as an easy-to-understand communication tool that facilitates communication with others. In addition, as our study suggests, the Japanese signing system serves as a gateway to reading Japanese. Consequently, Japanese-speaking DHH children who master language are not facing the alternative of a signing system, MCJ, or oral Japanese; rather, they should be regarded as bimodal language users who handle both visual and auditory information; this perspective contributes to their complete acquisition of Japanese-language reading ability. In other words, when we regard DHH children using a signing system as bimodal language users, such a perspective will help us to suggest more practical and suitable intervention strategies to help them acquire complete language-reading ability." (e130)*

A rights-based approach to service provision for DHH children has been advocated by Puyaltó et al. (2018). Drawing on examples like accessing routine consultations they emphasise the gross inequities that exist for DHH children vis-à-vis their hearing peers. They refer to the *"long and exhausting struggles to receive the necessary services that could support the development of their DHH child." (p.7).* Elaborating they describe consultations with specialists who do not understand what it means to be deaf and who don't have specialist knowledge. These inequalities are shown to be even more stark for DHH children and their families who live in rural areas for whom access to services is more sporadic or necessitates long journeys.

In a related study of deaf-accessible parenting classes in Wales Foltz et al (2022) highlight the lack of understanding of deaf culture and how well-meaning experts and practitioners try to fit deaf people into a hearing-based system. Drawing on the experience of deaf parents Foltz et al. illustrate how existing services are grounded in a deficit view of what it means to be deaf and are therefore shaped around interpreting services. They advocate that

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[3] Manually Coded Japanese

this dependency model be replaced by a rights based approach, which enables deaf people to participate as equal partners in a position to influence and shape service delivery.

> *"This all-too-common mindset often leads to hearing educators and trainers having either a lack of awareness or a lack of interest in the needs and/or preferences and cultural and linguistic identities of Deaf students or participants. This, in turn, diminishes or altogether denies the voice, agency, and role of the Deaf community and thus blocks them from informing and helping to shape both the content and mode of delivery in community based, local education and training programs. We believe that only by recognizing and incorporating the language and culture of the Deaf community, and seeing it as an important resource and an asset, can community-based education and training programs hope to achieve a meaningful degree of social participation and engagement by the participants or constituents that they serve."* (Foltz et al. 2022:13-14)

The focus on rights and promotion of equitable opportunity is explored in-depth by Young (2016). Positioning deaf people as a minority group Young is explicit in her description of the inevitable discrimination that they will face.

> *"Being d/Deaf implies being in a minority, whether considered from the viewpoint of a cultural linguistic minority in the case of sign language users or in terms of disability—where to be deaf is not a majority characteristic of the human race. All minorities are more likely to experience inequalities and discrimination; d/Deaf people are no exception. Some of this might be direct discrimination in the form of actions (and words) with the intention to oppress or abuse. Some might be indirect discrimination in the form of structures, organizational practices, laws, and policies whose unintended consequences create unequal opportunities."* (Young, 2016: 65)

Parents of deaf children usually come from a world that is constructed around hearing and the spoken word. As such these parents have little understanding of how to best meet the needs of their child or of deaf culture generally. In other words, they are on a steep learning curve.

> *"Returning to hearing families with deaf children, a fundamental journey is to understand what it means to be d/Deaf both in the abstract and the specific of an individual child who is part of a family. Th is focus on the individual child in the family (rather than deaf children in general) is important because families are vitally interested in transmitting their values, culture, and traditions to the next generation*." (Young, 2016: 60)

4. Methodology

The evaluation drew on a variety of data sources including internal monitoring data with regards to number of participants in the programme, observation of FSHP in action and interviews with 16 participants.

The evaluator worked in collaboration with the BDA coordinator in Northern Ireland to identify participants and plan fieldwork.

The evaluator worked in collaboration with the BDA coordinator in Northern Ireland to identify participants and plan fieldwork. Ten families were invited to participate in the evaluation. Eight of whom consented but unfortunately, due unforeseen circumstance and illness two families[4] cancelled scheduled interviews. Interviews were carried out with six families and a total of 16 people were interviewed.

Home based face-face interviews were carried out with two families (11 people), one of who was a migrant family. Co-ordination with the FSHP tutor enabled observation of the teaching sessions immediately prior to the interviews. In both of these families the child who is deaf was post primary school age and participated in the interview. In one family there were four people present and in the other, there were seven people.

Two interviews were carried out via Zoom. One interview was with parents of a pre-school child and the other was with the father of little girl, this interview was supported by Big Word interpreter. The final two interviews were conducted via telephone, one of which included a big Word interpreter.

As a service evaluation the study did not require ethical approval it did however adhere to best research practice. Informed consent was obtained for all interviews and contributions from participants have been anonymised. All interviews were transcribed, and thematic analysis carried out. Transcribing interviews conducted with the interpreting service was a complex, labour intensive and time-consuming task. The translated responses tended to be short and had the tone of an abridged or précised version of what had been said. As a result, it is highly likely that the quality of telephone based interpreting did not do justice to the actual content of the interviews.

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[4] One of these families participated in the photoshoot

5. Findings

5.1 Overview

The 2023 FSHP provided a 20 week home based tutoring programme for 13 families across Northern Ireland. In a new development for the programme over half of the families were from migrant communities, for whom English was not the first spoken language in the family. Analysis of data gleaned from interviews and observations is examined under two main headings. Firstly, the experience of parenting a child who is deaf. Within this section the challenges encountered in navigating statutory services are highlighted these include conflicting advice and ignorance about deafness amongst health professionals. The pivotal role of the teachers of the deaf is identified and finally the need to better preparation of teachers and schools to support children who are deaf. The second major heading is the FSHP. This section focuses on identification of the defining elements of the programme. These include location of the programme in the home, raising awareness and promoting understanding of deaf culture, the importance of having tutors who are deaf, impacts of the FSHP on children and the ways in which the programme could be improved. The section concludes with two illustrative case-studies which serve to illuminate the impact of the FSHP on a family with a preschool child and a migrant family.

5.2 Participants in Family Signing at Home Programme

Thirteen families participated in the FSHP in 2023/4. The age range of deaf children is set out in figure one. Four children were pre-school age, four primary school and the remaining five were aged between 11 and 15 years. Three of the children were girls (figure 2).

Figure: (1) Age Profile of Children 2023/4 FSHP

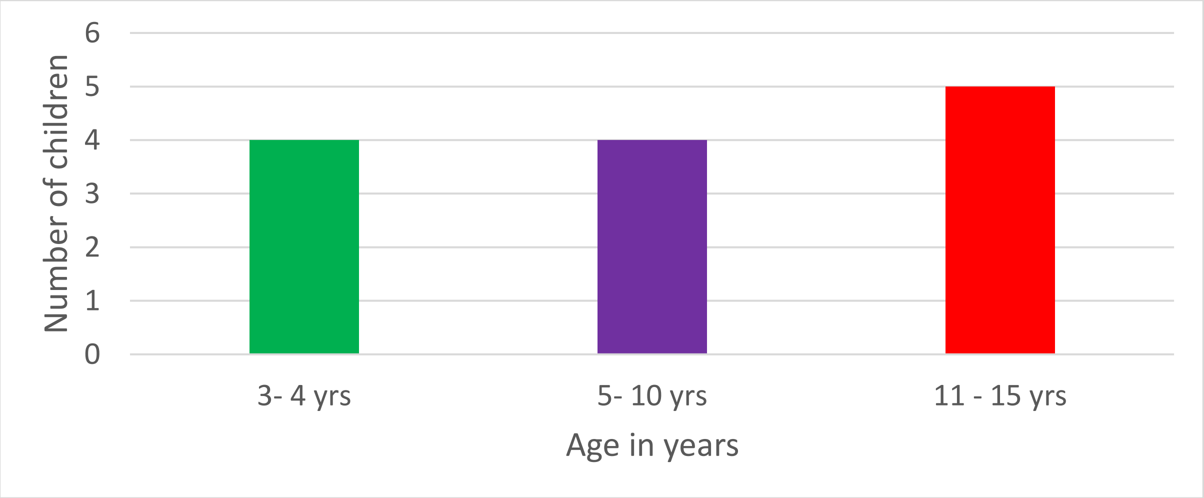
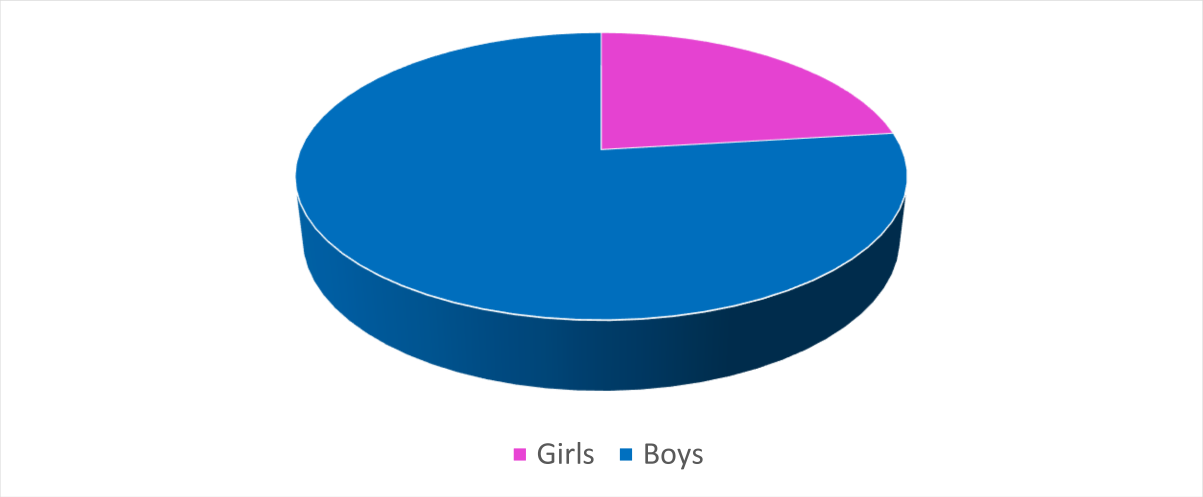
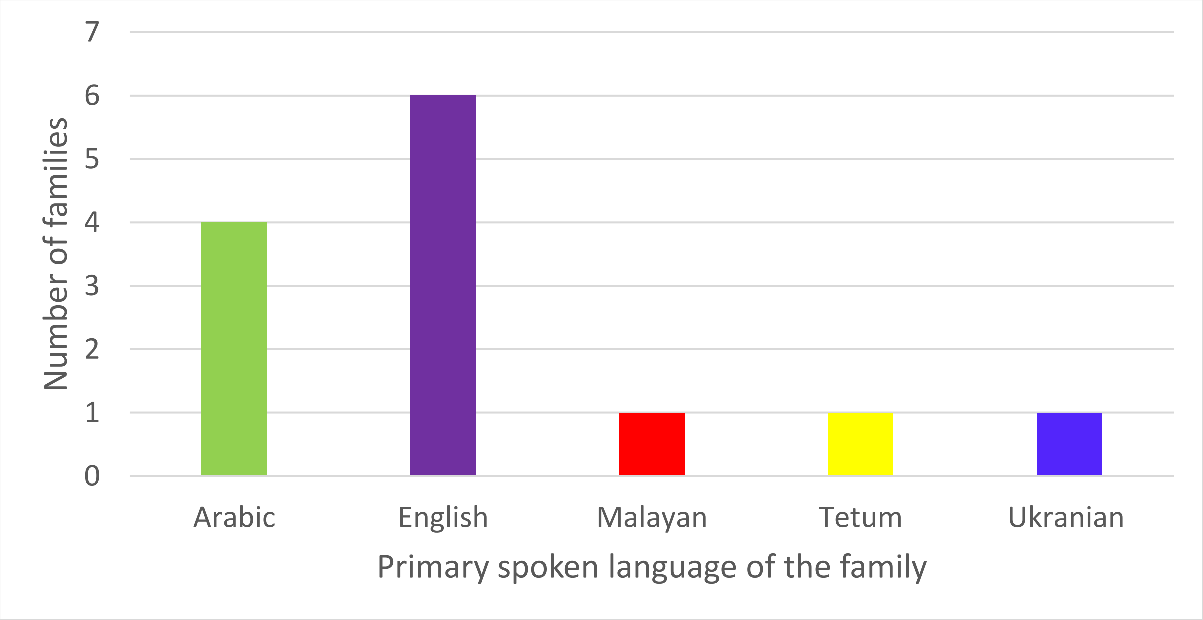


Figure: (2) Gender profile of children 2023/4 FSHP



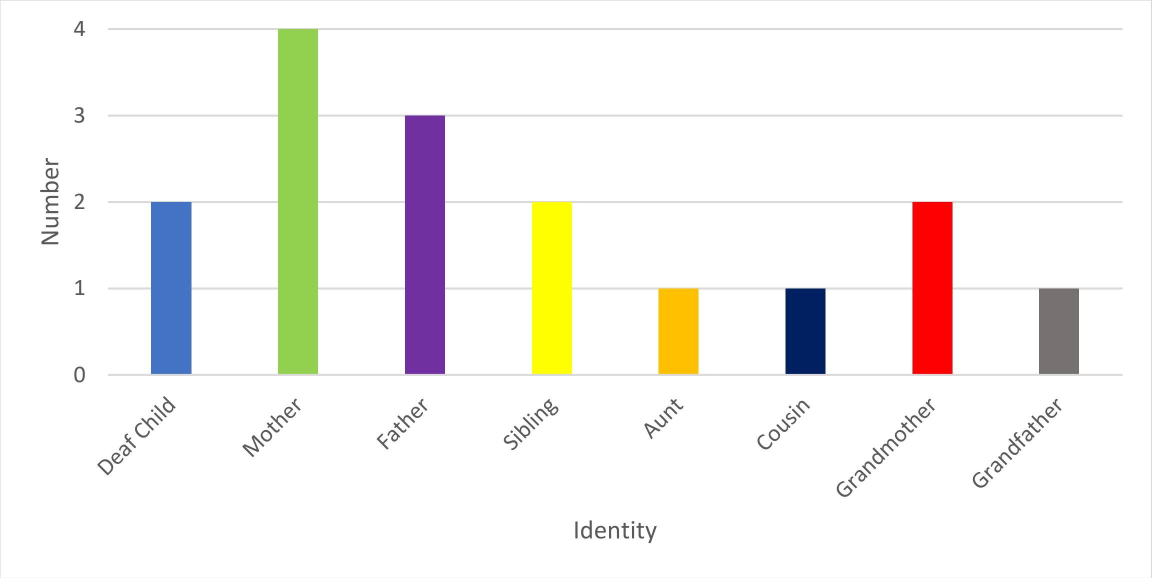
The primary spoken languages of all families participating in the FSHP are set out in figure three. English was the primary language for six families. Arabic was the primary spoken language for four families. Malayan, Tetum and Ukrainian being the primary spoken languages for the remaining three families.

Figure: (3) Primary spoken language of families participating in the FSHP



The characteristics of the sixteen people interviewed as part of the evaluation is set out in figure four.

Figure: (4) People interviewed as part of the evaluation FSHP



5.3 Deaf child in the family

The focus of interviews with families was the FSHP, however, it was impossible to explore the impact of the programme without understanding people's experiences of having a deaf child in the family. There was strong coherence between the families' experiences and four major themes emerged (1) deafness of statutory services with regards to the needs of children who are deaf. (2) Conflicting advice from experts and health professional and resistance against use of BSL is highlighted as a major source of frustration and stress for parents. (3) The teachers of the deaf and tutors on the FSHP are trusted and powerful source of support. (4) Schools and teachers appear to have little to no understanding of the needs and challenges that children who are deaf face. An understanding of these factors is important in understanding the overall context for the FSHP.

5.3.1 Deafness of statutory services

Being told that a child is deaf is a life changing moment for parents. Not surprisingly that moment is writ large in parents' memories. How that information was communicated was universally described in ways that failed to promote the dignity of parents or their child. Laughing sardonically Mother (2) recalled the journey that she had from the neonatal screening test to finally learning that her child was deaf.

> *"When she had her newborn screening, they said that 'You know, she's probably just needs to dry out and it should be fine'. That was on day two and then we back in a couple of weeks and they were like, 'she probably just hasn't dried out yet'. I just believed the professionals*

that everything would be fine. And then at eight weeks we went for another test, and I went on my own because everyone told me that it would be fine. It was the brain scan you know where they connect things to her scalp when she is sleeping. And I said to the audiologist 'can she hear?' and they said, 'I can't tell you anything' and I just said, 'please tell me is she deaf or is she not, can she hear?' and she just shook her head. She wasn't allowed to say whether she was deaf or not she had to let the consultant do that. But I could tell by her face." (Mother 2)

Alone and unprepared for the news that her baby was deaf, mother (2) explained that when she did meet with the consultant that he was very helpful and signposted her to various sources of support.

"The consultant was brilliant and connected us to useful groups. He directed us towards, the NDCS and the BDA and Chime and lots of deaf groups we have been really lucky." (Mother 2)

Although the experience with the consultant was very positive it would never change the shock and aloneness, that mother felt in the moment that she discovered that her child was deaf.

Discussion of diagnosis was a major theme during a visit with on the families. Mother (4) described having had concerns and worries for years about her child's ability to hear. But was always reassured by numerous experts (doctors, health visitors and teachers) that –

"–she is fine, she's just not concentrating she's not listening" –

As a result neither she nor the child's father were overly concerned when an appointment arrived for an audiology assessment. Both parents were working, on the day of the appointment and working on the assumption that it was just a routine test that would– *"–confirm what everyone had told us".* They gladly accepted an aunt's offer to take the six-year-old child to the audiology appointment. The aunt described the perfunctory way in which the consultant informed her that the child would be fitted for hearing aids. There was no actual explanation that the child was deaf. The aunt described how shocked and lost she felt and wondered how she was going to break this life changing news to her sister, the child's mother.

"So, I said I'd take her time it's fine it's only a routine thing here. And then they did the assessment and everything else and we went back into the waiting room and then the consultant came in and it was just like "so we'll get her fitted for her hearing aids today."

And I said "what?". You know they never actually even said OK we have detected this. No, it was just 'ok so we're fitting her for hearing aids.' It is a massive diagnosis to process, and I was sitting trying to process it and thinking that I had to go home and tell my sister that her daughter had 'something wrong with her that was life changing and would impact every day of the rest of her life. Obviously, we knew nobody who was deaf. I was thinking what this means? she can talk now but will she lose the ability to talk. It was just so huge to try and process." (aunt)

The irony of the 'shock' diagnosis was not lost on mother (4). For years she had been telling health professionals and teachers that she was worried about her child's hearing. Falling on deaf ears her concerns were greeted with platitudes about the child's lack of concentration and listening skills. An observation from the child's grandmother served to illuminate the unnecessary disability that the child had lived with.

"Do you remember the day M got her hearing aids she went round the house asking what's that sound? It was the clock. The ticking of the clock. It was amazing. All those years she'd never heard it." (Grandmother 1)

The lack of preparation for dealing with the needs of deaf children and their parents was a recurring theme in interviews. Case Study one describes in detail the experience of mother (1) and her partner. Having learnt that their child was deaf the mother described the frustration that she felt when she asked health professionals for advice and guidance about toys that she could get to help her son.

"Oh, we don't know because we would advise sound to get them to use devices." (Mother 1)

Parents recalled how in the beginning that they had assumed that experts would know best. They quickly discovered that there is widespread lack of understanding of what being deaf means. As a result, advocacy is a key part of their role as a parent. Mother (4) described how her 10-year-old child had been wearing hearing aids for four years. The hearing aids were so critical to the child's functioning that they were affectionately known as "her ears". Despite wearing the hearing aids full time in school, the child wasn't achieving her full potential. The mother described her frustration at the lack of adaptation in the school environment and in primary seven proposed that the school install a Frequency Modulated (FM) system. The positive impact of the FM system was dramatic and instantaneous.

"She was four years with nothing, bar her ears, and then in primary seven I queried the FM system. The P7 teacher had her in September and October. The FM system went in and in

November he pulled me aside and he could not believe the difference in her work just by the FM system you know." (Mother 4)

5.3.2 Conflicting advice

Parents described the challenges they faced in trying to find the best way to support their child. The lack of consistency between health professionals and experts was frustrating and bewildering.

> *"a lot of medics were saying you could teach him sign language, but some others were saying use Makaton at home, and some were saying oh no use Pecs instead and some were like, 'oh, no, don't listen to that person, listen to me'."* (Father 3)

Eventually parents learnt to listen to their 'gut' and decide what they thought would be best for their child. It was evident from the neonatal screening test that Mother two's child was deaf. In the absence of any specialist advice, she decided to learn 'baby sign' when her child was four months old.

> *"I just thought well this is a deaf child, what do you do? You learn sign."* (Mother 2)

The baby sign programme is designed for parents of all children as a way of enhancing babies' communication skills. There are various community-based classes for infants across NI that use forms of signing to promote communication. These include sing and sign, tiny talk and sign2music. Although not designed for babies who are deaf Mother (2) explained how useful she found it to be. Elaborating she explained that no one had suggested that she learn to sign. The National Deaf Children's (NDCS) organisation would subsequently discuss the importance of signing but never a health professional.

> *"NDCS would have talked about signing and the importance of it, but never a professional."* (Mother 2)

Case study one highlights the challenges that most parents experience with speech and language therapists (SALT) actively discouraging the use of BSL. Mother (2) was the exception in this regard. The SALT supporting mother (2) had studies BSL to level three and incorporated signing into the consultation. Unfortunately, there were very few sessions with SALT and as a consequence the service was of limited value.

> *"The Speech and language therapist that she had actually has level three herself. Level three sign. She was a wonderful speech therapist. And used little bits of sign in her classes and it*

was brilliant. So that was never a problem there. But speech therapy was so scarce, so she *doesn't receive much."* (Mother 2)

5.3.3 Teachers of the deaf is the 'trusted expert'.

Parents' experiences with teachers of the deaf and tutors on the FSHP were described in positive ways. These practitioners were the 'trusted experts' that families relied on to navigate their way through the system.

> *"It was the teacher of the deaf who got us signed up for our first sign language course."* Father (3)

It was evident from the warm and enthusiastic way that parents talked about them that the teachers of the deaf helped instil a sense of confidence.

> **"**I *think … you should be told your child is deaf and here is your teacher. Here is the person who is going to guide you through signs, if that's what you want. That would be an ideal world."* (Mother 2)

5.3.4 Teachers/schools need to be educated about deafness

Parents were very conscious of the lack of understanding and awareness of what it means to be deaf in mainstream education and how that impacts negatively on children's capacity for learning. A recent accident in school involving teenage pupils served to highlight the need for education of teachers with regards to the needs of children who are deaf.

> *"I think this*[5] *should be rolled out to schools, even if it was just to the SEN teachers. There was an incident in school a few weeks ago and her hearing aids were damaged in the incident. But the teachers don't fully grasp the magnitude that has on a non-hearing child. She was left with one partially working hearing aid. It was the incident in school that they were more focussed on. But that's not the point. The fact that the incident was just a school accident is neither here or there, but the fact that she was going into school and trying her best to focus and listen, that's twice the workload in her brain trying to process what's going on. And there was no consideration given to that element of her learning, so I don't think there's enough understanding."* (Aunt)

In primary school setting the situation was equally challenging. Conscious of her child's needs mother (2) described going into school every week to teach her child's classroom assistant sign language. Her thinly disguised frustration was evident as she explained that it is only now after six years in primary school that a classroom assistant has agreed to learn to sign.

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[5] FSHP

> *"She has an assistant for 20 hours a week. But it has taken from nursery to now for the assistant to learn sign. So, I would have gone into school and taught the assistant to sign every week, but it's only now that there's an assistant in place who has agreed to learn sign and she's the one in P6 she'll be going into P7 cos we held her back a year. And it has taken all this time for the assistant to learn sign. (Mother 2)*

5.4 The Family Signing at Home Programme

In contrast to the challenges and frustrations that parents recounted in describing experience of navigating mainstream services. The FSHP was universally viewed in a positive light. Families talked enthusiastically and passionately about how much they enjoyed it. Location in their home was deemed to be vital. Characterised as being very enjoyable the classes were described as relaxed and fun. In addition to learning how to sign families placed great value on the powerful insight that they gained into deaf culture. The FSHP also provided a much-valued opportunity for parents to see their child flourish.

> *"It's lovely thanks to the signing at home M and TUTOR can hold a full conversation. It's beautiful to watch and watch her just progress."* (Mother 4)

5.4.1 Location in the family home

Location of the FSHP in the home was cited by all families as the primary strength of the programme. The reasons included a more relaxed atmosphere, ease of access and flexibility around timing.

Families described how the location in their own home helped people feel relaxed. They didn't feel judged. This non-judgemental aspect was vital in encouraging extended family to participate.

> *"Nobody is judging you in here. If I was out somewhere else, I'd feel that everybody was judging me, and I wouldn't want to do it."* (Grandmother 1)

The non-judgemental was deemed vital in promoting participation of the more those family members who were more nervous and dubious about their ability to understand and learn signing.

> ***"****We're all together, we do it together it's a much more family-based approach, we're all in the comfort of our own home. And A is not out of her own surroundings, it just makes it more family focussed, more fun and easier to learn. The kids don't feel judged. They're not being judged by their peers. They're not embarrassed because it's only us there."* (Mother 2)

It was evident from the experiences families shared that the tutors adopt a very bespoke approach to sessions. One mother recounted how the previous day it had been only her daughter and her at the session. The tutor used it to focus on the child's spelling homework. Clearly expert in reading the room the tutors were universally described as creating an atmosphere that brought the best out in everyone

"What's good about being a small group and everyone here in the house with C. She makes everyone take their turn. Nobody gets to slide into the background. She gets that my kids are young and are sometimes tired at this time of the evening and she gets that. She reads the situation really well and includes them when they are ready or interested. And mum she would tend to hide behind everyone else and miss her turn, but here you can't do that." (laughing) (Aunt)

The relaxed atmosphere was credited with overcoming diffidence and whetting appetites of extended family members to engage with the classes. One of the grandmothers took great delight in recounting how, despite initial resistance, her husband (child's grandfather) became actively involved with the sessions.

"He said: 'I'm only going to sit and watch'.
And then the next he was making his way from there to here to sit on the arm of the chair.
C (tutor) asked if he wanted a chair.
And he said: 'No, no, no, I'm only just watching'
and then before he knew where he was. He was he was totally involved, and he was telling these ones to move up." (Grandmother 1)

All of the parents had participated in other signing programmes all of which were in group setting in person and online. The FSHP was compared very favourably to the other programmes. Reflecting on the advantages a father highlighted the opportunity to communicate directly with the tutor and in the process develop more sophisticated communication skills. Comparing the FSHP to another programme that was run online for people across the four countries of the UK he highlighted how the online programme focused only on signs and all communication with the tutor mediated through an interpreter.

"You have less kind of one-on-one time to actually communicate. You actually don't really talk to the tutor it's all done through the interpreter. So, you literally only get to go through your signs." (Father 3)

Four of the six families[6] interviewed lived in towns approximately 40 – 60 mins drive from Belfast. Most specialist services for children who are deaf are concentrated in and around the city. For those families living in more rural areas having access to FHSP in their own home was a major benefit.

"The fact that it's in your own home. In the past we've had the travel. When I was doing my different levels in sign language. I had to travel to Belfast twice a week. So that was taken away from family time." (Mother 2)

Two of the three migrant families who participated in the evaluation live in Belfast. Despite their geographical proximity to services the families were very socially isolated. Case study two focuses on the experience of one of these families and highlights the added social isolation and loneliness that these families face. Having the tutors visit their homes was deemed vital in forging links with the wider community. The father from another migrant family where there are three deaf children painted a graphic description of the isolation and loneliness that they endure.

"I feel suffocated because I cannot go out. Because I don't speak the language and my children are deaf. They can't talk. It is too difficult. It is suffocating." (Father 2)

5.4.2 Deaf culture

Families constantly referred to how much they learnt about deaf culture through FSHP. This appeared to a surprising and very welcome added bonus. Prior to the FSHP parents and extended family members appear to have viewed sign language in a fairly perfunctory way replacing spoken words with signs.

"All the tutors are fantastic. They're passionate because this is their life, you know, this is what they've had to do for their whole lives. They teach you the culture as well as the signs what's acceptable, what's not acceptable. And it was really, really informative and interesting. We didn't realise that there were limitations for deaf people in day-to-day activities that they don't have access to things. And it was a very it was a big learning curve, getting into the sign, to be honest, because you realise, oh God, that's actually difficult for them to communicate in these situations." (Mother 1)

The FSHP helped people understand the nuances and complexities of deaf culture.

"It's even putting things into the concepts. The very first class that we learnt how to say our names and I would say to you what is your name. But in signing it is name you what and it is

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[6] The two families living in Belfast had migrated into NI and had Arabic as a primary spoken language.

putting the context all around that. It is a completely different way of learning and thinking and that is why I think that it is so important for us to start signing with M. While yes M is partially hearing we have no idea what the future will hold for that. The fact that she spends so much of her time negotiating and translating a hearing world. Where we are trying to figure out and how to negotiate a non-hearing world." (Mother 4)

The focus on non-verbal communication and eye-contact was remarked on by all of the extended families' members.

"I never understood how much of signing is relied on your facial expressions and the movement of your lips with the words as well." (Aunt)

Elaborating further the aunt remarked how participating in the FSHP had helped her own 'hearing' children's concentration. She described how the focus on eye contact and facial expression had helped her children develop their listening and communication skills.

"We practice when they're doing their normal school spelling during the week, you know their homework, and they'll use finger spelling as well. And she did her end of term test last week and she did far better than she has ever done previously. That added layer of concentration for signing has done well for her." (Aunt)

Gaining insights and understanding about the meaning of behaviours in deaf culture and what is acceptable touch was a welcome revelation.

"S*omething that we would think are rude in hearing culture are actually polite you know like pointing or flicking the light on and off to get their attention and learning where to tap them so you're not scaring them, you know I was thinking oh this is great because this is good for me to know for my son."* (Mother 1)

Although the children in the migrant families had all been diagnosed as deaf before their arrival in NI, none had previous experience of signing. For those families the opportunity to learn sign language was seen as a very precious opportunity. A grandmother in one family, refugees from the war in Ukraine, characterised the FSHP as a miracle.

"Learning this language, I would say that this is the miracle that we can do this in this country. Taking into account that we have these difficult circumstances, how we got here and what we had to do to get here. In Ukraine, we were not even offered to learn sign language. And so, we didn't even have the chance to do it. And here I am right now. And I'm very happy that through my grandchild. We were able to learn this wonderful language, and I'm really respecting this language. I can say, and that our whole family of four people came through and finished all the classes, I am just very happy about that." (Grandmother 2)

The teenage sibling of a deaf child explained that they were aware the sign language existed but never imagined that they would one day have the opportunity to learn it.

> *"I knew that it (sign language) existed in the world, but I had never known that I would learn it. We're living here (NI) for two years. My mother decided that we needed to learn and so we started the classes. I myself don't have any visual or hearing defects but I still learn it. Maybe at some moment in the future I will know it and be able to communicate with my brother using this language."* (Sibling 1)

Unable to speak English father (2) described how his children (all deaf) have learnt to sign at Jordanstown school for the deaf. Participating in the FSHP has enable the father and his wife to understand his children and to be able to communicate with them.

> *"I don't speak English. I've been here five years. My family doesn't speak English. The children are quiet. They know, sign language."* (Father 2)

Observing the FSHP sessions provided a powerful insight into the rich reality of deaf culture, something that hearing community would not usually be aware of.

> *"What a lovely fun evening. Lots of smiling, laughter and intense eye contact. The hour flew by with animated conversation about a range of topics. I was struck by the silence and realised that this was the first time that I had properly experience deaf culture."* (Evaluator, notes)

For those parents with younger children the FSHP helped them visualise a future in which their child would have a sense of belonging and be part of a community that understands them. The mother of a very young child took great comfort in knowing that her child would have access to community where he could be totally himself and not have to constantly adapt.

> *"It's really lovely to open your eyes and say, oh my God, you know, he's not going to have to just, you know, adapt to other people… I just want him to be accepted and comfortable with people and he will be with hearing people. But it's also nice to have that little avenue to go down and see other deaf people you know."* (Mother 1)

5.4.3 Tutors who are deaf as a vehicle for empowerment

All of the FSHP tutors are deaf, and signing is their first language. This factor was cited by all families as being a major strength of the programme and the positive impact of tutors is highlighted in case study one. Experts in their field the tutors acted as a powerful antidote to prejudiced ideas of what it means to be deaf. Parents were conscious that ignorance about what it means to be deaf results in images of people who are intellectually challenged. Reflecting on the time when her child was first diagnosed, one mother recalled how her own mother used to try and console her by reminding her that a deaf person they knew could drive.

"My mum used to say to me. You know, your second cousin is def and she can drive." (Mother 2)

Parents talked about how empowering it was to get to know someone who is deaf and for whom BSL is their first language.

"*She's amazing too, absolutely fantastic as well. She has no speech at all. She doesn't use any speech. And very rarely I think she even wears her device. She prefers to just sign. And again, she was sending us photos via WhatsApp of like, facial expressions. Whatever we were learning, she had like colourful resources for us. And again, she was very kind, very nice. When we finished the course, we drove down and gave her flowers and got to meet her and it was very, very nice." (Mother 1)*

The flexible nature and conversational style of FSHP mean that families learn about the tutor's life and often find that they have much in common. For example, the grandparents in one family bonded with the tutor over a shared love of caravaning.

"We have a campervan, and she has a caravan and she kind of knows a wee bit about the family and you build on that. I really look forward to the Tuesday night because she makes you feel really comfortable." (Grandmother 1)

5.4.4 Impacts on the children

Parents described how the FSHP impacted positively on their children. Parents of younger children described how as they gained confidence and competence in signing their child's frustration decreased.

"She was a very frustrated little girl because she couldn't communicate. Yes. And until she started to learn signs, she would have banged her head on the floor. She would have, you know, had massive tantrums because she couldn't tell me what she needed and what she wanted. And then once we started to have more sign and she understood more sign, that alleviated so much and she's a much happier, little girl." (Mother 2)

Parents of older children recognised the mental and physical exhaustion that comes from using hearing aids all day in school. They described how once in the door the hearing aids come out.

> *"She comes in from school and hearing aids are straight off. All that visualisation and focus all day on her is exhausting and draining on her."* (Mother 4)

Once the hearing aids come out children are dependent on signing to communicate. Functioning in this environment is enriched greatly when other family members can sign. The discussion in box one followed observation of one of the FSHP sessions. It was obvious through body language, smiles and giggles that the deaf child was taking great delight in being the expert in the room.

Box (1) Discussion between evaluator, deaf child and mother

Evaluator: *"I got the sense that you were really enjoying being the expert in the group this evening."*

Deaf Child 2: Smiles and laughs sheepishly and then added *"fun, it's fun."*

Mother 4: *A hundred percent she loves lording over everyone else. It's lovely her and C* (the tutor) *can hold a full conversation and it's beautiful to watch. To watched her just progressing."*

Whereas deaf child two was timid and shy about her signing ability. Deaf child one was much more forthcoming about his prowess and expertise vis-à-vis other family members. Smiling broadly, he happily declared that he was the only one who understood everything.

> "*Only I understand everything*" (Deaf Child 1)

One of the Arabic speaking fathers described how through the FSHP he was able to see his child as 'the expert'. He took great delight in recounting how his eight-year-old child corrects him when he gets signs wrong.

> ***"****C starts correcting me showing me the correct way to make the sign for a certain word. I'm sometimes just joking with her or testing her, and she's able to correct me."* (Father 1)

5.4.5 Ways FSHP could be improved

Very positive in their description of the FSHP families had to be encouraged to identify ways in which the programme could be improved. The five issues identified were (1) raising awareness of the rights of deaf children to learn sign, (2) better advertising of the FSHP, (3) duration of the programme, (4) continuity of tutor is important, and (5) migrant families need support to learn English too. Issues one and five are not directly related to delivery of the FSHP but may inform advocacy and lobbying carried out be BDA.

The mother of a child identified as being deaf as a young infant described how she wasn't given any advice or guidance on signing. On her own volition she was proactive and sought out various ways to learn signing. Drawing on that experience she was vociferous in describing learning to sign as a right and called for access to signing to be made universally available to families in their home.

> *"It's part of A's rights as a deaf person to learn sign. And to learn it on her terms. Yes. It's really beneficial to learn in her home environment. Makes it natural, makes it not oh, this is something we have to do because I'm a bit different to other kids. This is something that happens in my home and it's part of my whole life*." (Mother 2)

In a similar vein families talked about the importance of raising awareness of and skills in sign language within the wider community. Teaching sign language within schools was advocated as a positive life skill for all children to have.

> *"In the course of either of my kids' lives, walking up our main street what is the chance that they're going to randomly bump into a German who's going to ask them for directions greater than the chance that they're going to bump into a deaf person asking for directions? Probably not. In the general remit of the world or in their future workplaces. Sign is going to be a far better benefit to them. If they went into schooling or the health care system at all, police or pharmacy. If you go to the dentist, you need to convey this information to someone. So, what is going to be more benefit to them? To me it would be sign language over learning another language."* (Aunt)

Parents decried the lack of support generally for them to learn BSL. Courses are usually paid for and expensive. The FSHP is available free of charge to parents and as such was viewed as an exceptional opportunity. The programme is oversubscribed. Despite its obvious popularity parents felt that the FSHP could be better advertised. They talked about how difficult it was to learn about FSHP and the availability of BSL courses generally.

> *"I think the only like comment I can make, I don't know if it's relevant, is. I wouldn't really know. I can't even remember how we got in touch with BDA, but I don't think it was, like, easy to access. I don't know how you access those courses. I think I just got like a text once or something, but I wouldn't know how to actively go and look for that."* (Mother 1)

The twenty-week duration was deemed to be ideal, although one father suggested that it be run in two blocks of 10 weeks to allow for short period of consolidation.

> *"I think ten weeks would be a good length for you to, so that you can kind of, like, learn the stuff that you've been taught." (Father 3)*

All but one family had the same tutor for 20 weeks. Reflective of the challenge in finding tutors to work with families in rural and isolated areas and unforeseen circumstance one family had three different tutors. The lack of continuity impacted negatively on the learning experience.

> "*Definitely affected our progress. It definitely has because the first session is always getting to know each other. And then what do you want out of it.*" (Mother 2)

Interviews with all of the migrant families were conducted via a 'big word' interpreter. It was evident that the three families are very socially isolated. As parents of children who are Deaf these families are already isolated, learning to sign is enhancing their capacity to communicate effectively with their children. However, to meet the needs of their children effectively they need to be more integrated into the local community. It is significant that despite living in NI for between two and five years none of the migrant families had friends from the local community, or people with whom they could practice their English, or from who they could ask for advice/support.

> *"I need to learn English it would be better than sign language for me. My light went out I needed to buy a bulb, but I didn't know how to do that." (Father 2)*

5.5 Illustrative Case study (1) Pre School-Child

Case study one draws on a zoom-based interview with Anne and John parents of Oliver[7]. aged 4 years. Oliver has no hearing and is not suitable for cochlear implant. The case study serves to highlight the challenges that the parents have faced and the hugely positive impact the FSHP has had on their lives.

Although still in their early twenties, Anne and John have been together over 10 years. They have two children, aged 9 months and 4 years. The elder child Oliver is deaf. Anne was a student when she became pregnant. She has put studies on hold for the present and is a fulltime mother and carer for Oliver. John is currently undertaking a PhD.

> *"I'm 24 and I had Oliver when I was 19. It was a total surprise. It wasn't anything planned, but we were very happy. We went for a private scan just to find out the gender and get a 4D scan, just because we were so excited, and then we found out that he had a cleft lip."*

Elaborating Anne described how the pregnancy was a lovely surprise and although there were a few abnormalities detected during the pregnancy it wasn't until after the birth that hearing loss was detected.

Oliver was born by emergency caesarean section and was admitted to special care baby unit (SCBU). Due to complications associated with the birth Anne was unable to visit her son until he was three days old. Recalling this time, she described the numerous visits that she received from medical staff advising her of each new complication and problem that they had discovered. The final piece of news was that Oliver had failed his neonatal hearing test.

> *"All the consultants kept coming into my room and saying, well, we found this, and we found that, and he has failed his first hearing test. And they were saying, you know, he's got a very hard road. He's very sick."*

Anne had chosen not to see photos of Oliver wanting to meet him in person and she described being happily surprised. The image that she had of a very sick baby did not fit with the beautiful big boy that she met in the SCBU. By way of explanation John described how Oliver looked out of place surrounded by very premature babies.

> *"All the other babies that were around him were premature babies."* (John)

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[7] Pseudonyms are used to protect the family's identity.

In retrospect Oliver’s healthy size may have belied the seriousness of his condition. The first year of life was dominated by issues related to his cleft palate and heart. The cleft palate meant that he had to be fed by a nasogastric tube and ultimately via a tube in his abdomen. With a great sense of awe and admiration Oliver’s parents talked about how his resilience, courage and good humour shone through at ever stage of the challenging journey.

> *“From the beginning, no matter what has been thrown at him. You know, he's been in ICU with bronchiolitis on a ventilator. His heart failed. He was waiting for emergency surgery for months in the ward without leaving. And I mean, he never stopped smiling. He was always full of energy. He was obviously struggling to breathe with the heart and stuff, but he really was so strong. And he's carried that through with every operation, with every day. He is a happy little chap like you wouldn't know. You know, people say, oh well, God love him and all that. And I said, yeah, but he is literally the happiest little man.”*

Set against this backdrop of critical medical issues it is worthy of note that Oliver has a very rare condition that means he has absolutely no hearing. His parents described meeting a teacher of the deaf for the first time when Oliver was six-month-old. The meeting with teacher of the deaf was described as a wonderful revelation. Finally, someone who understood what it meant to be deaf. Prior to this point the health professionals that they had contact with did not appear to have any specialist knowledge about what it means to be deaf or how to support deaf children. Anne described feeling angry and frustrated in encounters with staff who clearly didn’t have experience working with deaf children and did not appear open to engaging with Anne and learning about Oliver’s interests, abilities and needs.

> “E*specially with like, speech and language staff and OTs. I think they think when you go into that room, they're the professional. It doesn't matter that you're trying to tell them ‘You don't know deaf children’ because I've asked, and they haven't got any other deaf children on their caseload. And they're saying to me, you know, ‘we need to do that, you need to do this’. And I just said, oh, yeah.”*

Expanding on her observation regarding the lack of awareness of the needs of deaf children Anne gave the example of how her son was ‘marked down’ in assessment of cognitive development because he wasn’t banging toys of each other. Anne explained that unlike hearing children Oliver wasn’t getting any sound stimulus from this action and therefore unlikely to repeat it. It was clear throughout the interview that the lack of awareness and attention given to Oliver needs was omnipresent in consultations with specialist services. Anne described frequently attending appointments with speech and language therapists who hadn’t taken the time to read Oliver’s noters in advance of the consultation and as a result didn’t even know that Oliver was deaf.

“I go into that room and I'm not a nurse and I’m not a speech and language therapist, but I know my child. I'm with him 24 hours a day. I know my son. They have his notes. They see him every six weeks. And they come in and they're talking at him, and they don't know he's deaf. And it's highlighted on the front of his notes. I don't understand. Nobody takes the time to remember to read that I know they see thousands of children. But I think it's a really important.”

It is credit to Anne and John’s desire to give their son the best chance in life that they have persevered with appointments, which at best appear to give lip service to involving and listening to parents. Anne describes how she will spend the first few minutes of health care appointments having to explain that Oliver has no hearing and that he depends on visual clues. Practitioners appear to listen and then descend into advice that is completely at odds with Oliver’s needs.

“It can be very frustrating because you feel like you're constantly having to go through the same thing. I don't mind repeating myself saying it when they come in, but then it's ten minutes later and then they're like, ‘oh, mommy, you're not, you're not. comforting him enough with your voice’. But I'm focusing on looking at him and feeling him. You know, when you kind of feel like they're judging you. They've got the title, and they think so I've been doing this for years. But I think it's really limited for deaf people if they don't, you know, try to understand. You know, as I say, that culture and stuff, like they might just go up and try and take his blood and that's terrifying for him.”

Set against this context of health-related appointments Anne highlighted the importance of health practitioners having good communication skills and an understanding of deaf culture.

“Just talk to him and say it's okay. And you know what it's like when he sees them first and then touch him. And so, I think it would be a really important tool for people to know.”

The frustration associated with mainstream services stands in stark relief to the hugely positive experience of the FSHP. Anne and John are participating in the FSHP for the second time and when they started to talk about the programme they relaxed, smiled more and talked fondly about their experience. Because of where they live and a lack of sign language tutors in the area Anne and John have accessed the FSHP via zoom. This has worked well for them. By doing two rounds of the programme Anne and John have gotten to know two tutors and spoke highly of both.

> *"She's so lovely – like her husband came on (zoom) one night and talked with us and she has sent us photos of her children's weddings and stuff like that and it's just really lovely. It's really, really nice that, you know, they have that life that we have, but just they have got sign and they've got a different kind of version, you know."*

It was evident that the couple have formed strong bonds with the tutors. In addition to the language skills the FSH tutors have provided the parents with practical tips and advice with regards to things like toilet training. Has helped them to understand deaf culture and the norms within it.

> *"All the tutors are fantastic. They're passionate because this is their life, you know, this is what they've had to do for their whole lives. They teach you the culture as well as the signs what's acceptable, what's not acceptable. And it was really, really informative and interesting."*

Reflective of the trust that has been built with the teachers of the deaf Anne and John have used knowledge and skills built through those networks to navigate mainstream services and have the confidence to trust in their own decision making.

> *"They were going against everything the teacher of the deaf said. But the teacher for the deaf for me, I thought within this one area I'm going to maybe just take on board mostly the advice from the people who deal with this every day. Okay, that was kind of how we narrowed it down and then just trust in our gut."*

The couple agreed that location in the home was vital as it created a relaxed environment that was focused specifically on their needs. In the first round of FSHP Anne and John had been joined by seven or eight extended family members. While this was a positive experience the couple felt that narrowing the focus to have a programme just for the two of them was much better. It was logistically easier than getting a time that suited 'everyone' and as it was just the two of them, they could go at a faster speed and work together on developing their signing skills.

> *"We're trying to really focus. It's hard when you have to do your course and then it's like a hundred new signs and trying to use them, because it's so natural for us to just forget to sign and talk, because that's what we've done our whole life. So, we're really trying to focus on it. So, for example if we go shopping, we're not allowed to talk to each other, we have to sign all the food items."*

Another strength highlighted in the FSHP was the focus on conversation skills. Elaborating Anne and John explained that the informal bespoke, small group dynamic was conducive to having normal everyday conversation. Having this experience was enabling them to develop comprehension of signs and gain greater fluency and confidence in use of them. Anne believed that this experience was preparing them to become more engaged with the deaf community and to support Oliver.

> *“Which is more like everyday life. When you're meeting deaf people, you hope that you can have a conversation. Because it's one thing learning one sign, but when a deaf person is communicating with me, they're quite fast and we're we are doing that all the time with her. So, it's becoming easier to understand. You know what, I think that will stand by us when we meet people and we're communicating with Oliver. We're kind of picking up the speed, reading, the lips, reading the facial expressions. She's absolutely fantastic. You can tell she just loves what she does. she really enjoys teaching families.”*

The tutors were commended for their creativity and the innovative approaches that they used to teach. The sharing of signs via video messages was particularly valued.

> *“She absolutely loves being creative. She makes her own posters. She actually sends me a video of her repeating all the signs, and it's absolutely fantastic to have because it's so easy when you're. sends by WhatsApp.”*

A major impact of the FSHP for Anne and John was seeing the possibilities that lay in store for Oliver. Meeting the tutors and getting to know them and their lives, helped counteract the deficit narrative that was being forged around Oliver. Instead of seeing limitations associated with being deaf through the FSHP Anne and John were able to see for the first time that being deaf was not a barrier to living a full and happy life.

> *“When you have a child, it doesn't matter what they do in their life, you're going to be so proud of them. And I know Oliver I’m so proud of everything he's achieved. I’m not expecting him to go off and be this famous lawyer or anything, if he does that would be amazing. But I just want him to be happy and healthy. Seeing two people who are completely deaf, who have this brilliant career teaching other people, have families, have marriages. And showing us that there's actually there's so much out there for these people, it's really, really nice. And it just shows you that, you know, we're so lucky in the world we live in today that there's so much help out there and there's so much support. And they have just showed us how happy their lives are. Which is really nice as a parent, because you just want to make sure your child is involved, accepted, loved by as much as you love them and accept them. And seeing them* [tutors] *with their own kids. And their kids are actually both hearing. Both M and P have two hearing children each. Both they and their partners are completely deaf, but their children are hearing.”*

Anne and John have been on a rollercoaster of a journey over the past four years. Participating in the FSHP is characterised as a high point in that journey. They spoke very highly about the programme and how important it has been in helping them develop knowledge, confidence and skills that will enable them to support and care for their son.

Anne: *"That's why it's really important for us the Oliver can sign away to tell us what he thinks, what he needs, what he wants. You know, with him being sick all the time we just really want to get to a point where him to say, oh, mommy, I'm sore. Yes, you could be a doctor or something's wrong because."*

John: *"Just to be able to explain to Oscar if he's getting a scan or getting his bloods done or something. To be able to reassure him and tell him that it's going to be ok."*

In a final reflection Anne spoke with pride and gratitude about her son. She credited Oliver with opening her mind and helping her to see the world in a new way. A less judgemental way. In a way that celebrated diversity and focused on capacities rather than disabilities. In a way that helped her see and understand how amazing deaf children are.

"No amount of regret or worry or guilt. Nothing's going change that and to me he is absolutely perfect the way he is. And I also think obviously in a heartbeat I would take away all the pain. I also think Oliver has been the biggest learning experience of my life. He has taught me so much and I'm very grateful for that. Learning about people, you know, with abnormalities. He has really opened my eyes to be a lot more respectful, a lot more, understanding. I think in Ireland, I call us blissfully ignorant. They don't mean any ill will, but we're very much behind the times. There's a lot of comments like deaf and dumb and Hare's lip. I thought that was normal. I didn't think anything of that. And then whenever I had Oliver, I put myself out there into those communities and learned what's respectful. And I learnt how amazing these children are. I wouldn't have opened my mind before I had Oliver."

5.6 Illustrative Case study (2) Migrant Family[8]

This case study draws on the findings from a Zoom based interview with Karim the father of a child who is deaf. Reflective of the social isolation that the family experience despite living in Northern Ireland (NI) for five years Karim has very minimal English. The interview was conducted with the support of the Big Word interpreting service, Karim attempted to speak in English at times, but it was only possible to understand the occasional single word.

Along with his wife Carmen and daughter Angela, Karim moved to NI in 2019. When they arrived in Belfast Angela aged three years had already been diagnosed as being deaf and in need of cochlear implants.

"We have done all of the investigations. And before coming to Ireland, we learned that she was in need to have the surgical procedure for the cochlear implants."

Prior to arriving in Belfast Karim had no knowledge of sign language and explained that it was a hospital social worker who told him about BDA. He described how this introduction opened a new world for his daughter and that he started to realise what was possible.

"The journey of the treatment of my daughter started here."

Talking about his family's experience with FSHP there was a palpable change in Karim's demeanour. More animated and smiling as he shared experience of the FSHP.

"When we first arrived here, we have our first class in at home."

The FSHP is designed around the rhythms and needs of each family. The exchange below serves to provide insight into why the home base is important.

Father: *"It is very Important to have the teacher at home."*

Interviewer: *Why?*

Father: *"Because it allows the whole family to be there. It's after work hours. I can go and it's more relaxed more comfortable. Just family"*

Throughout the week Angela attends a school for the deaf. On Saturdays along with her mother she also attends a group with other children who are deaf. But due to his work commitments Karim is unable to participate in any of these activities. As a consequence the

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[8] Pseudonyms used to protect anonymity

FSHP sessions are regarded as a very precious way for Karim to develop his knowledge of signing and his understanding of his daughter’s world.

Karim and his wife had another baby 10months ago, this child is hearing. It was very evident from conversation that the family is very self-contained and socially isolated.

“*I don't have any family here*.”

With no other family in NI and unable to speak English they have limited social networks locally and described having contact with only one other family in Belfast. This contact was sporadic as the two families live on opposite sides of the city and neither has access to a car.

Karim explained that he was keen to learn English, and this was evidenced in his frequent attempts to use English during the interview. Determined to develop his language skills Karim is currently attending night classes to learn English.

“I try. I Study. I go to classes for two years and I will continue after that.”

It was evident that participating in the FSHP had opened a new and very welcome way for Karim to communicate with his child.

“Being able to communicate. That's number one. Number two, we have been able to learn new words. I mean, in sign language, of course.”

The delight that he found in using signs was evident. He talked about how they are also incorporating signs such as *“love, water, please”* in communicating with their youngest child.

Karim described how FSHP helped him see another side to his daughter. Elaborating he explained that Amara was very good at signing and that she looked happy and confident when using it. Smiling broadly, he recounted how he sometimes teases Amara by using the wrong sign or making a mistake, just to see the joy that she has in correcting him.

“*I make a certain sign mistakenly, so that I would allow her to correct me, and she says no, and she starts correcting me, knowing that I should know the correct way to make the sign for a certain word. But I'm just joking with her or testing her, and she's able to correct me.*”

Karim explained that he had been a little wary when the FSHP was starting. His unease stemmed from the fact that the tutor was deaf and neither he nor his wife could speak English. Anxieties quickly disappeared as they discovered that using sign language eliminated the need for comprehension of any spoken language.

“Instructor is deaf. No speaking. I don't have a problem.”

The passion and enthusiasm in Karim’s voice was evident when he talked about the FSFP. It was evident that the family enjoyed welcoming tutors into their home. Having the same person come for 20 weeks enabled them to build a strong and trusting relationship. The informal and participatory approach and use of visual aids by tutors was viewed to be a refreshing change from formal classroom setting.

“Same people coming to the house. They don’t have any books.”

When asked how the FSHP could be improved, without hesitation and clearly hungry to learn more Karim recommended more classes and for those classes to be held in their home.

“More courses

I’ve not had enough

To be able to get a new course at home”

6. Discussion

The Family Signing at Home Programme (FSHP) is delivering a much needed and highly valued service to the families of deaf children. The love and pride with which parents in the evaluation talked about their children was noticeable. The challenges which the children and their families face were described with stoic dignity. Struggling against a system that is not designed to support DHH children families described the social isolation, frustration and grief that they experienced. Set against this backdrop the FSHP was depicted as a bright light. In addition to enhancing communication the FSHP was described as building confidence, creating social connections and providing positive images of the full and rounded lives that people who are deaf can live.

In a study of deaf children and their families, Young (2018) highlighted how parents frequently describe their initial reaction to learning that their child is deaf in terms of pain, grief and loss. She argues that the negative discourse that surrounds deafness is a consequence of depictions of children who are deaf as being *"impaired versions of hearing children*" (p.61). Changing that mindset and focusing on capabilities is essential in ensuring that children who are deaf and their families achieve their full potential.

> *The challenge is how individual parents in their highly specific circumstances with idiosyncratic life histories take on that reconstruction of the narrative and forge new meanings coherent with their sense of self and family.* (Young, 2018:61)

All of the Families participating in the FSHP emphasised how important it was for them that the sign language tutors were deaf. Meeting an adult who is deaf and seeing that they have a career was a very empowering element of the FSHP. Parents and the deaf children talked with great enthusiasm about how much they appreciated getting to know the tutors as people and learning about the lives that they had created for themselves. It was noticeable how many people appeared surprised that a person who is deaf could be married, have children and in some cases grandchildren. These findings echo findings from evaluation of the 2023 FSHP. In that evaluation a ten-year boy who experienced bullying and isolation enthused about learning that his FSH tutor had a wife, a son and daughter.

The families for whom the FSHP has been designed are from the 'hearing' community and as such do not have a lived understanding of how to best support their child (Young, 2019). FSHP parents talked at length how the powerful role that tutors played in helping them gain invaluable understanding and awareness of deaf culture. Parents were conscious that this understanding of deaf culture is critical in enabling them to support their children to achieve their full potential. It is reflective of Young's (2018) emphasis on unique visual orientation of "*sign language peoples*". She argues that people who are deaf:

> *"…exploit aspects of what it is to be human that most hearing people are unable to access, yet these aspects are a capacity of what it is to be fully human."* (Young, 2000:61)

The deaf culture aspect of the FSHP was very evident during the observation visit. As a hearing person stepping into an environment structured around the needs of people who are deaf, I was immediately struck by the powerful sound of silence, the strong eye contact between participants, the smiles, laughter and fast flow of conversation. As someone with no prior experience of sign language I was surprised at how quickly I was able to start following the gist of conversation. Greater exposure of the general public to sign language would help broaden understanding and generate interest in learning it.

Reflective of research cited in the literature review it was very evident from parents that there is a worrying lack of understanding amongst statutory services of what it means to be deaf. DHH children have additional challenges to overcome with regards to developing communication skills and developing an understanding of how the world operates. In the interests of equity specialist services should be prioritised to enable parents develop communication skills and support the cognitive development of their child.

Case study one provides powerful insights into the additional challenges and obstacles that babies who are deaf face. This little boy spent many months in special care baby units, having intrusive medical procedures. Although diagnosed as totally deaf his parents did not receive any specialist training or advice about communication until he was aged six months. With enormous eloquence and fortitude, the parents in case study one described the repeated affronts and dignity violation that they experienced in consultations with various health personnel. Practitioners who failed to even read the child's notes in preparation for the meeting and were therefore unaware that he is deaf. The fact that this experience was not isolated is an indictment on service provision. Parents and wider family described the apparent 'deafness' of experts in education and health. They described how experience of DHH children is not understood and the expertise and experience of their parents is not valued.

Social isolation is recognised as major public health issue which leads to higher rates of all causes of mortality (Holt-Lunstad, 2020). There is also a powerful causative link between social isolation, loneliness and mental health (Leigh-Hunt, et. Al 2017). Childhood experiences of loneliness are associated with greater risk of mental illness in adulthood (Almeida et al. 2021). Not surprisingly given the lack of service provision people who are deaf are recognised as being more susceptible to social isolation (Shukla et al. 2020). The FSHP is proving to be a powerful intervention for promoting social inclusion of children who are deaf and their families. This inclusion works in two ways. Firstly, the fact that tutors are going into the home provides an immediate connection for the family with someone else. At 20-weeks duration the FSHP allows the family and tutor time to get to know each other and build trusting relationships. The bespoke and conversational nature of the programme results in tutors and families learning much about each other lives and interests. In the process the FSHP is proving to be a powerful vehicle in building resilience and confidence for children who are deaf and their families. Patel (2021) emphasised the importance of a strong non-hearing network in supporting resilience and enabling families with children who are deaf to focus on capabilities instead of deficits.

The department of communities estimates there to be approximately 5,000 deaf adults living in NI. BSL is the first or preferred language of communication of approximately 3,500 members and Irish Sign Language (ISL) is language of choice for a further 1,500 people. The relationship with tutors and connection with BDA has enabled families to broaden their networks within the deaf community in Northern Ireland. These connections have proved vital for families.

The interviews with the three migrant families revealed the extremely isolated lives that these people are living. Case Study two provides an insight into the experience of one of these families. It also highlighted the additional challenges that these families face in accessing services and enabling their children to achieve their full capacity. Despite having lived here for three and five years none of the three families had developed friendship networks within the local populations. It is telling that the big word translation service was required for interviews with each of the three families. During the in-person interview with the migrant family the boy who is deaf and his sister tried to speak in English, but it was evident that their comprehension was much more advanced than their ability to speak

English. Similarly, it was evident during the zoom interview with one of the migrant fathers that his comprehension was good but ability to speak was not at a comparable level. Navigating a health care system and advocating for their children when they don't have English or understanding of local services is challenging. One of the families has three children who are deaf. Neither parent speaks English, and they have no social networks in NI. Due to languages barriers and working through a remote interpreter (Big Word) it was only possible to explore experience of migrant families in a very superficial way. Nevertheless, it was very evident that the FSHP was very highly valued by them. Perhaps reflective of their extremely isolated circumstances each of the families were very appreciative of the tutor 'coming into their home'. All of the migrant families liked the fact that the tutor was deaf and welcomed the positive vision that the tutor's deafness created with regards to the their children's potential. Nevertheless, a reflection of their personal desire and need to learn English they all talked about how helpful it would be to have someone there to translate the signs into English. The introduction of 'spoken' language in the FSHP would be a radical change to the current format. It is likely that parents desire to hear spoken English reflects their isolation and hunger to learn it. More detailed interviews would help explore this aspect and identify specific needs.

In the evaluation of the 2023 FSHP there was a conspicuous absence of voices/contributions from fathers. This evaluation includes contributions from three fathers and one grandfather. All of the men spoke positively about the programme and how much that they got from it. The flexible structure, timing of classes in the evening and location in the home were all cited as major positives, enabling men to participate after work and in a relaxed environment.

The FSHP is very relaxed but nevertheless over the course of an evening families learn many new signs and ways of communicating. Participants talked enthusiastically about ways in which they incorporated the new signs into their daily lives. A simple electronic questionnaire aimed at capturing impact of the FSHP on self-efficacy was piloted with families but failed to yield any responses. The reasons for this are unclear but likely due to trust and not knowing/understanding the purpose. Drawing on findings from the evaluation a new questionnaire has been developed for use with the next cohort of families before and after participation in the programme.

The photograph on the cover of this report was taken during one of the observational visits. Casually strewn on the hall table are the child's hearing aids, discarded like a pair of uncomfortable shoes as soon as she comes home from school. In many ways this photo captures the essence of the FSHP. Relaxed, comfortable and free to communicate without judgement or pressure. It is in such an environment that children are most likely to grow and flourish and are most likely to achieve their full potential.

The FSHP has been running in NI for over ten years but is still operating on a small scale. There were only 13 families involved in the programme this year. The small number of participants is not a reflection of demand but rather a reflection of limited resources. There are currently 7 families on a waiting list for the service. Despite its popularity amongst participants the FSHP does not appear to be very well known. Knowledge of the programme's existence appeared to be sporadic with most families learning about the programme by chance. The BDA is in an unenviable position and faced with an ethical dilemma. If the programme was proactively advertised the demand for places would increase and as it stands there are not sufficient resources to cope with current number of families. This conundrum points to the need for government investment and core funding. This funding would enable BDA to deliver the FSHP in an equitable way that upholds the rights of deaf children to be able to communicate and participate in society.

7. Recommendations

The recommendations below include ways in which the FSHP could be strengthened and issues that are beyond the responsibility and power of the BDA. Recommendations one to five are focused directly on FSHP. Recommendations six, seven and eight highlight issues that the BDA could lobby the NI Assembly and national government about on behalf of families.

(1) Duration: the twenty-week duration was deemed to be just right. With the option of undertaking a second course being deemed very valuable.

(2) Materials: there is currently great diversity in the materials used. Some tutors share videos of them signing via WhatsApp and others create posters and other visual aids. It was clear that all of the tutors are very creative in their approach. Families were keen to have some posters of signs that they could put up at home. A central online repository of videos made by tutors around specific topics could be a valuable resource for sustainability of the programme.

(3) Pre and post evaluation of self-efficacy: Informed by the findings in the evaluation a questionnaire has been designed to use with families in FSHP. To enhance response rates, it is proposed that the questionnaire be administered by the BDA administrator when families register for the programme and when they complete it. Given in the lack of response to the electronic questionnaire it is proposed that paper copies of the questionnaire be sent to families with stamped addressed envelopes for their return.

(4) Networking opportunities: there was a great deal of overlap in parents' experiences of having a child who is deaf and navigating education and health services. Creating opportunities for these parents to meet would help strength their networks and capacity to support their children. Initiatives such as an end of programme celebration and/or a focus group discussion with parents to explore their shared experiences could yield powerful insights. These events could take place in person or online.

(5) Migrant communities: the BDA is commended for extending the FSHP to include migrant families. The evaluation highlights how extremely social isolated these families are. Support with integration, including learning English needs to be prioritised to enable these families to support their children to achieve their maximum capacity. The research shows that deaf children are more isolated than their peers, this situation is exacerbated when they live in a family environment that is also isolated. The complexity of issues faced by migrant families with deaf children need to be further explored. Face to face interviews with an interpreter present would enable more effective exploration of their needs and the impact of the FSHP.

(6) Awareness raising/training for health and social care professional about the importance of connecting families with the deaf community: all of the families had similar experiences about the challenges inherent in navigating health and educational services. There appears to be an absence of 'joined-up' thinking and appreciation of how important it is for families to be connected with the wider deaf community. As soon as child is diagnosed as having hearing loss or as Deaf the family should be provided with information about and an introduction to the BDA and other resources. The number of people who are deaf in NI is relatively small and as a result the community is tight knit and supportive. It was evident that once families connected with teachers of the deaf their lives were transformed for the better. There can be no justification for delaying the introduction of parents to teachers of the deaf and the BDA.

(7) Specialist speech and language therapist (SALT) for children who are deaf: The apparent lack of understanding of what it means to be deaf is worrying. SALTs are the primary professional group employed to support children develop communication skills. The over reliance on spoken language is depriving children who are deaf of

vital learning opportunities. The early introduction of signs in conjunction with spoken language would maximise the infant and child's potential for understanding their environment and developing communication skills.

(8) The inclusion of some basic sign language skills in curricula of inter-alia SALTs, audiologists, children's nurses, health visitors, paediatricians and teachers would help create greater awareness of deaf culture and an environment that is more supportive of children who are deaf.

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About the evaluator

All work relating to the evaluation was carried out by Dr Una Lynch, Sonrisa Solutions Ltd

Una Lynch RGN, RM, RPHN, DMs, MSc, PGCUT, D.Gov.

A public health nurse Una worked in academia for over 20 years and has practiced across the island of Ireland, Latin America and in Ghana. Reflective of her interest in community development and in the relationships between policy and public health she worked with the World Health Organisation (WHO) in Copenhagen, led a national strategy on community nursing for the Irish Department of Health, accompanied members of the Northern Ireland Assembly during a study visit to Cuba. During the pandemic (2021/22) she managed the COVID-19 response on behalf of Nottinghamshire County Council.

Working closely with the Arts Council of Northern Ireland she has completed a series of evaluations examining the impact of Arts based interventions on alleviation of social isolation and promotion of wellbeing for older people, carers, and people affected by dementia. Other evaluation related work includes Cancer Focus NI (evaluation of programmes focused on men and older people), EastSide Arts in Belfast (evaluation of an intercultural arts programme focused on migrant arts), Head Injury Support (evaluation of lottery funded programme for people with acquired brain injury), the Crumlin Community Hub (evaluation of lottery funded health and social care project) and a report commissioned by The Baring Foundation celebrating creativity and ageing in Northern Ireland.

una@sonrisa-solutions.com