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The Emotional Well-being of Deaf Children and Young People Final Report

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and Social Care Trust



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1.0 Introduction

All children and young people have the right to the enjoyment of the highest attainable standard of health that meets their needs (Article 24, United Nations Convention on the Rights of the Child ('UNCRC') (1989). This includes access to mental health information, support and specialist services. Such support should be provided to all children without any discrimination, including on the grounds of disability (Article 2, UNCRC). The United Nations Convention on the Rights of the Child (UNCRC) also makes it clear that the best interests of the child shall be a primary consideration in all actions concerning children (Article 3 UNCRC), and that children and young people have the right to express their views on all matters affecting them, with these views given due weight (Article 12 UNCRC). This right of children to express their views on 'all matters affecting them' extends to the nature and type of emotional well-being and mental health services that are being developed or provided.

These rights have been reaffirmed by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2007). The UNCRPD also makes it clear that health services must be accessible and that health professionals have a duty to provide care of the same quality to people with disabilities as to others (Article 25, UNCRPD). Measures taken to ensure accessibility should include the identification and elimination of obstacles and barriers to accessibility (Article 9, UNCRPD). In addition, 'all information and communication pertaining to the provision of health care should be accessible through sign language, Braille, accessible electronic formats, alternative script, as well as augmentative and alternative modes, means and formats of communication' (UN 2014, para 40). Adopting a rights-based approach also entails ensuring that emotional well-being and mental health services are available, accessible, adaptable and acceptable (UN CESCR 2000) to the needs of deaf children.

Existing research indicates that deaf children can be vulnerable to poorer outcomes in relation to emotional well-being and mental health compared to hearing children. For example, a 2015 study in England found 26% of signing deaf children evidencing a mental health condition (Roberts et al, 2015). This is in comparison to a 2017 NHS report that 13% of all children aged 5-19 had a mental health condition (NHS, 2017). This heightened vulnerability

is due to a myriad of factors. It is important to note that this is not necessarily due to the fact of being deaf, but rather tends to be due to the surrounding barriers that deaf children experience. For example, over 90% of deaf children are born to hearing families (Mitchell and Karchmer 2004). This can, in some cases, lead to challenges around: communication, identifying and accessing appropriate support, making decisions about suitable educational placement, and making connections with other deaf children and adults; all of which can have implications for a deaf child's subsequent emotional well-being (Wright 2015). Elsewhere, Polat et al (2003) report that using total communication¹ at home was associated with better self-image among deaf children in their study while Dammeyer (2009) report an association between lower language ability in deaf children and poorer emotional well-being. However, the National Deaf Children's Society (NDCS) (2020), in a review of studies on the prevalence of emotional well-being issues in deaf children and related factors, make a critical point when they note that 'broad categorisations concerning communication mode with no reference to language ability are likely to mask the effect of more subtle factors' (p.6). In short, attempts to identify factors impacting on the prevalence of emotional well-being issues in deaf children should not look at communication mode alone. Research also indicates that deaf children are more likely than their hearing peers to be isolated, bullied, and subject to prejudice or stigma (Wolters et al 2011). They are also more likely to experience sexual abuse (Kvam 2004).

It is estimated that there are approximately 1,417 deaf children in Northern Ireland (CRIDE 2019). The majority (78%) attend mainstream schools while 26% are recorded as having an additional special educational need (CRIDE 2019). In some cases, they may be the only deaf pupil in their school. However, there is an absence of reliable or recent data on the prevalence of emotional well-being issues in deaf children in Northern Ireland and a lack of research which examines the perspectives and experiences of deaf children and their parents with accessing emotional well-being services and/or the types of services they would find helpful or like to see developed. There is currently no specialist deaf Child and Adolescent Mental Health Service (CAMHS) in Northern Ireland.

¹ Total communication uses a combination of communication methods such as hearing aids, speech, lip-reading, finger spelling and Signed English.

1.1 Project Aim

This project aims to identify future service needs. Specifically, it aims to:

- Identify what kind of data is available on the mental health difficulties of deaf children across Northern Ireland Trusts.
- Scope existing health and social care services in each Trust and other sector provision regionally addressing deaf children's mental health and emotional well-being.
- Identify and evidence good practice (if any) in supporting good emotional well-being in deaf children.
- Explore experiences of parents of deaf children in accessing CAMHS in Northern Ireland.
- Consult with children and young people, and parents on what they want from a service and engage with them to co-produce recommendations.
- Develop recommendations for next steps.

For the purpose of this project, the term 'deaf' is intended to include all types and levels of deafness, whether augmented (by hearing aid, cochlear implant etc) or not, and regardless of the preferred methods of communication of the deaf child or young person.

'Children' refers to children and young people between the ages of 0 to 19.

2.0 Methodology

The study encompassed four distinct stages, which are elaborated upon in turn below:

1. Scoping of existing services for deaf children across health and social care trusts.
2. Identification of prevalence of emotional well-being issues among deaf children.
3. Engagement with deaf children.
4. Engagement with parents of deaf children.

An ethics application for the project was submitted to the School of Social Sciences, Education and Social Work (SSES) Ethics Committee at Queen's University Belfast (QUB). Full ethical approval was received on 25 March 2021, following confirmation from the QUB Governance, Ethics and Integrity Office, and the Trust Research Office Governance Department that the scoping of services element of the project could proceed as a service evaluation.

An information sheet (including an age-appropriate information sheet) outlining the aims of the study, methods of data collection, dissemination and ways in which anonymity and confidentiality would be respected (including possible limitations) was sent to potential participants. All participants were asked to give their active consent to participate by completing an individual consent letter or by recording verbal consent where appropriate due to social distancing restrictions which meant the majority of interviews were conducted online. Interviews and focus groups were conducted online using Microsoft Teams and were audio recorded and subsequently transcribed.

2.1 Scoping of existing services for deaf children

To identify existing health and social care services for deaf children across Trusts, the project team developed a ‘service provision information collation form’ (SPICF) (see Appendix 1) for completion by the appropriate Heads of Services (CAMHS) in each Trust. The aim of the SPICF was to collate information on whether and, if so, what types of general or specific services are available to support deaf children with their emotional wellbeing, the extent to which there has been engagement with deaf children within general CAMHS services, any

identifiable good practice, and any barriers to engagement. Through the SPICF we have also sought to identify what type of data is currently collected within each health and social care trust area on deaf children in this regard, the form any data is collected in, and the extent to which any data is disaggregated. The data from the SPICF was thematically analysed and aggregated to provide a broad overview of existing services and to identify gaps in data collection along with appropriate recommendations for Northern Ireland wide development.

2.2 Identification of prevalence of emotional wellbeing issues among deaf children

To investigate emotional well-being among deaf children, the current study utilized data taken from the Northern Ireland Youth Wellbeing Study which focused on identifying prevalence of mental health conditions. The study included 3,074 children and young people aged 2 to 19, of which 67 children and youth reported being deaf or having some hearing loss (see Appendix 2 for how this was measured by age groups). Young people aged 11 to 19 filled out their own surveys while guardians completed survey for children 10 years old and younger. In a small number of cases ($n=116$) guardians filled out the survey for youths 11-19 years old if they were unable to due to a disability. It important to note that this survey was not specifically designed to study deaf children; the sub-sample of 67 deaf children is a relatively small number that limits the robustness of the statistical tests. At the same time, this 2019 survey provides the first population level survey of children and young people in Northern Ireland on their mental health. Chi-square and t-test were executed to determine if differences between deaf and hearing children were statistically significant.

Additionally, the data scoping exercise included in the SPICF revealed that data on well-being issues among deaf children, is currently not routinely collected or reported in a way that could be analysed quantitatively. In section 6 the project team provides recommendations on next steps for collecting this type of data going forward, including the feasibility of undertaking a primary survey on the emotional well-being among deaf children.

2.3 Engagement with deaf children

Information about the study was shared with deaf children via Action Deaf Youth, NDCS and Jordanstown Schools.² One focus group was organised online with deaf children via Action Deaf Youth in May 2021. However only one young person was able to attend (with a youth worker) and so this became a semi-structured interview. A second young deaf person took part in a semi-structured interview alongside a parent.

Two focus groups were held with young deaf people via Jordanstown Schools in June 2021. The first group consisted of six young deaf people aged 16-19 (three girls and three boys). The second group consisted of three young deaf people aged 13-15 (three boys). A third focus group of six young deaf people was organised via Action Deaf Youth (2 girls 4 boys). This took place in person at a residential in July 2021.

The focus across each of the interviews and focus groups was to ask deaf children about the factors they thought might impact on deaf children's emotional well-being and to think about what a deaf-friendly CAMHS or emotional well-being services should look like if a deaf friend or young person they know felt they needed support. Due to the sensitive nature of the topic, we did not ask children to talk about their own experiences although many children did feel comfortable enough to talk about their own emotional well-being in various ways.

2.4 Engagement with parents

Semi-structured interviews were undertaken with parents of deaf children across Northern Ireland. The focus of the interviews was on parent perceptions of the availability, acceptability, adaptability and accessibility of emotional well-being and mental health services for deaf children in Northern Ireland. Their perceptions of key factors impacting on the emotional well-being of their deaf child and views on how services could be improved and/or what other services could be put in place were also explored.

² Action Deaf Youth is a Northern Ireland based charity which provides services and supports to deaf children including play sessions for children aged 0-8, play therapy for children aged 3-12+ and youth clubs for older deaf children. It also offers sign language classes for parents of deaf children.

The National Deaf Children's Society (NDCS) is a UK wide charity which provides advice and guidance to families and provides support to deaf children and young people and their families in Northern Ireland.

Parent participants for the study were recruited using a twin pronged approach. Information about the study was distributed to parents through Action Deaf Youth, NDCS and Jordanstown School for children who are deaf or have vision loss. Action Deaf Youth and NDCS also shared study information on social media as did the project team.

Semi-structured interviews were completed with eleven parents (nine mothers and two fathers) across Northern Ireland. All interviews were conducted online.

2.5 Analysis

All interviews and focus groups were audio recorded, with the permission of participants. An anonymised transcript of each interview/focus group recording was prepared. Data was subsequently coded and thematic analysis was applied, with emerging themes identified. To ensure anonymity of parents and children throughout, no names or identifiers are used alongside quotes.

3.0 Findings: Analysis of Northern Ireland Youth Well-being Study

To provide a useful window into understanding how deaf children might compare to their peers in regard to prevalence of mental health conditions, the NI Youth Well-being study was examined.

The following Table 1 presents the percent distribution of being deaf or having hearing loss by age with a total of 2.2% reporting some hearing loss.

Table 1. Percent distribution of deaf or has hearing loss by age groups

		Age Groups			
		2-4 (n=641)	5-10 (n=1134)	11-15 (n=670)	16-19 (n=629)
Deaf or has hearing loss	Yes	2.6	1.8	1.8	3.1
	No	97.5	98.2	98.2	97.0
Total		100	100	100	100

Table 2 shows the percent distribution by gender, which indicates no notable gender differences on hearing status.

Table 2. Percent distribution of deaf or have hearing loss by gender

		Gender	
		Male (n=1590)	Female (n=1477)
Deaf or has hearing loss	Yes	2.3	2.0
	No	97.7	98.0
Total		100	100

To investigate how well-being among deaf children compares to hearing children, Table 3 examines the percent distribution of having different types of mental health conditions by hearing status (see Appendix 3 for information on how the psychological conditions were measured.) Chi-Square tests were executed to determine if there were statistically significant

differences between deaf children compared to hearing children in the prevalence of any of psychological conditions. Due to the small sample size, the chi-square analysis should be interpreted with caution³, however it does reveal intriguing findings that suggests some differences exists between these groups.

The findings in Table 3 suggest that deaf children have statistically significant higher prevalence of Depression, Anxiety, Generalised Anxiety Disorder, OCD, Panic Disorder, Separation Anxiety Disorder and having any of the listed disorders compared to hearing children. In total, almost 21% of deaf children reported having at least one psychological condition compared to about 12% of hearing children. These findings are consistent with previous studies from other countries, which indicate that deaf children have a higher prevalence of emotional wellbeing issues compared to hearing children (see NDCS, 2020; Wright, 2021)

The condition with the highest prevalence among deaf children was Separation Anxiety Disorder at 16.1%. This condition also had the largest gap in prevalence between the two groups with only 4.9 % of hearing children reporting Separation Anxiety Disorder, a difference of over 11 percentage points. The next largest differences between the two groups were Generalised Anxiety Disorder and Anxiety with over 8 point differences. Over 1 in 10 deaf children reported having Generalised Anxiety Disorder or Anxiety, whereas slightly less than 1 in 20 hearing children reported Anxiety and 1 in 40 hearing children reported Generalised Anxiety Disorder. Furthermore, deaf children also had over double the prevalence of having Depression and having Panic Disorder compared to hearing children. In fact, deaf children showed a higher prevalence on all the conditions; however, the difference for Social Phobia Disorder was not statistically significant.

³ Chi-Square tests require expected cell size of n=5 or larger, due to the small cell size only any disorder meet the normal threshold and therefore should be interpreted with caution. A Yates' continuity correction is sometimes applied to 2x2 chi-square distributions; however it is generally considered to produce too conservative results and was not reported in Table 3. If Yates' correction is applied, depression, anxiety, generalised anxiety disorder, and separation anxiety disorder remain statistically significant and therefore may be more robust findings compared to OCD, panic disorder and any disorder.

Table 3. Percent Distribution of having psychological conditions by deaf or has hearing loss

		Deaf or has hearing loss		Chi-Square
		Yes	No	
Depression	Yes	11.3	4.9	$\chi^2(1) = 5.24, p= .022$ *
	No	88.7	95.1	
	Total	100.0	100.0	
Anxiety	Yes	13.1	4.8	$\chi^2(1) = 8.66, p= .003$ **
	No	86.9	95.2	
	Total	100.0	100.0	
Generalised Anxiety Disorder	Yes	11.3	2.5	$\chi^2(1) = 17.90, p= .000$ ***
	No	88.7	97.5	
	Total	100.0	100.0	
OCD	Yes	8.2	3.0	$\chi^2(1) = 5.37, p= .020$ *
	No	91.8	97.0	
	Total	100.0	100.0	
Panic Disorder	Yes	13.1	6.6	$\chi^2(1) = 3.99, p= .046$ *
	No	86.9	93.4	
	Total	100.0	100.0	
Separation Anxiety Disorder	Yes	16.1	4.9	$\chi^2(1) = 15.47, p= .000$ ***
	No	83.9	95.1	
	Total	100.0	100.0	
Social Phobia Disorder	Yes	4.9	3.7	$\chi^2(1) = .24, p= .628$
	No	95.1	96.3	
	Total	100.0	100.0	
Any disorder	Yes	20.9	12.3	$\chi^2(1) = 4.38, p= .036$ *
	No	79.1	87.7	
	Total	100.0	100.0	

Note: * p<.05; **p<.01; ***p<.001; Due to missing responses the sample size varies slightly across each condition: Depression 62/2871; Anxiety 61/2862; GAD 62/2875; OCD 61/2871; Panic Disorder 61/2867; SAD 62/2872; Any disorder 67/3007

The final analysis presented in Table 4 was based on a self-completed question among youths aged 11 to 19 that asked, "Please rate your quality of life on a scale of 1-5 from the 1 being the worst you can imagine to 5 being the best you can imagine." The results show that deaf children reported lower levels of quality of life reporting an average score of 3.85 compared to 4.24 among hearing children. This difference is statistically significant and suggests deaf children are demonstrating slightly lower emotional well-being on this measure.

Table 4. Means comparison of quality of life among youth aged 11-19 by deaf or hearing loss status (score ranges 1=Worst to 5= Best)

		N	Mean	Std. Deviation	T-test	Cohen's Effect Size
Deaf or has hearing loss	Yes	27	3.85	0.818	$t(1161)=277$ **	$d=.45$ medium effect **
	No	1136	4.24	0.733		

**p<.01

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Deaf or has hearing loss	Yes	27	3.85	0.818	$t(1161)=277$ **	$d=.45$ medium effect **
	No	1136	4.24	0.733		

**p<.01

The present quantitative findings suggest there is a substantial prevalence of emotional well-being issues among deaf children and that this prevalence is significantly higher when compared to hearing children. In particular, deaf children appear to be at higher risk of having emotional wellbeing issues related to anxiety. The project analysis had several strengths that provide a novel and important contribution on this topic. The data is recent, collected in 2019, providing a relatively up-to-date assessment of emotional well-being of children. Furthermore, the study includes prevalence estimates of specific psychological conditions. Most studies examining emotional well-being among deaf children use broader assessment scales that provide general overall scores on well-being but are not able to identify particular types of mental health diagnosis (Theunissen, 2014). Having estimates of specific psychological conditions, such as the notable prevalence of anxiety-related conditions among deaf children, could help shape more targeted policies and interventions to meet deaf children's needs. Another benefit to the current study was having a representative sample of all Northern Ireland children aged 2-19. This allowed for comparisons with hearing children, which is absent from most studies examining emotional well-being of deaf children (see NDCS, 2020). Moreover, the sampling strategy allowed for inclusion of a wide range of deaf children. Prevalence of emotional well-being among deaf children has been found to vary based on a number of characteristics including if deaf children attend a mainstream

school, if they are sign language users, and degree of hearing loss (see NDCS, 2020). At the same time, as the project used secondary data analysis that was not specifically designed for deaf children, there are some limitations. The relatively small sample size of 67 deaf children limits the robustness of statistical tests. Furthermore, we were unable to examine variations in emotional well-being among deaf children across some characteristics that have been found to matter in other studies. This was due to not having questions regarding those particular characteristics available in the general survey as well as the sample size being too small -for sub group analysis. A more targeted survey that included larger sample size of deaf children and included questions on areas previously found to affect emotional well-being among deaf children such as language and communication ability, presence of compounding additional disabilities, type of school attended, IQ, gender, age, use of hearing aids, and degree of hearing loss (see NDCS, 2020). It is important to consider deaf children as a diverse group since their emotional well-being could be shaped from a multitude of interlinked factors. At the same time, the current exploratory study provides novel information on the emotional well-being of deaf children living in Northern Ireland. Future research could include a larger representative sample of deaf children to determine the robustness of these findings. Nevertheless, the present results are highly suggestive that deaf children in Northern Ireland experience higher levels of emotional well-being issues compared to their peers. Moreover, the largest differences in emotional wellbeing were found in anxiety related conditions, which supports findings from the qualitative interviews.

4.0 Findings: Scoping of Existing Services Across Health and Social Care Trusts

The scoping exercise identified some similarities and some differences across the five Trusts in relation to the services provided, the number of deaf children using services, and training needs of staff. Overall, there were small numbers across all the Trusts (less than 5 in each trust). Reasons identified for the low numbers included being dependent on referrals of which there were low numbers and, unless the children are identified as deaf in the initial referral (which sometimes does not reference deafness), this information is not captured. Some Trusts expressed concern that some children will actively try not to disclose their deafness, which could make it more challenging to both identify deaf children in the referral process and provide them with tailored supports.

All Trusts stated that deaf children have access to the same services available to hearing children and that communication support would be provided as required to support deaf children in accessing any such service. Accessibility provisions included providing sign language interpreters, considering room layout/design to ‘reduce listening effort’, and providing clear facemasks for lip readers. Some of the Trusts highlighted having a practitioner with a specialist interest in deaf issues. For example, the Western Trust noted ‘Our referral coordinators discuss with this practitioner referrals in respect of deaf young people. There are times it is appropriate this practitioner works directly with the young person. However, it is important that the young people have access to all of professionals and services available.’

Other Trusts noted they had a Deaf CAMHS representative that can provide additional insight and coordination in setting up services for deaf children. It was noted that the Trust deaf CAMHS representative attends a regional Deaf CAMHS Special Interest Group along with representatives from other Trust areas, where they could share information or concerns both across Trust areas and with Dr Greer. This was noted as an important avenue for ensuring that deaf children were provided with the most appropriate support. Furthermore, Trusts mentioned having staff trained in several areas that, while not specifically about mental health of deaf children, could be applied to work with deaf children. For instance Belfast Trust mentioned having three staff trained in British Sign Language (Level 1) within Step 2 CAMHS, while six staff within Step 2 CAMHS have completed the training in

‘Healthy Minds’ as delivered by NDCS along with basic deaf awareness training. It was noted that this had been completed by two administrative staff from Step 3, while two nurses from Beechcroft inpatient Hospital had completed the training. Trusts highlighted the benefits of accessing additional group supervision or individual sessions to keyworkers as needed by Dr Greer.

The Trusts also identified a number of other gaps and challenges. In terms of Trust resources, it was also highlighted that additional training could be useful in terms of having more advanced sign language training for staff and more targeted training on the mental health needs of deaf children. It was suggested that training in mental health and deafness at university level would be most beneficial along with more advanced sign language training. It was mentioned that there was room for some practices to be expanded to better serve this group of children including more robust data collection, stronger partnerships between services, and a more accessible point of information of where to access supports for deaf children. For example, the Southern Trust suggested a Directory of Service Providers and what they offer for deaf children would be helpful. Trusts also mentioned that Covid-19 has added additional challenges for deaf children, specifically around communication needs at school such as facemasks.

5.0 Findings: Engagement with Deaf Children and Parents

The findings are broken into two broad sections. The first section sets out the views of deaf children and the second section sets out the views of parents of deaf children.

5.1 Findings from engagement with deaf children

The following section focuses on the key themes from engagement with deaf children as identified through data analysis:

1. Deaf children's perceptions and experiences of emotional well-being.
2. Deaf children's preferences for emotional well-being points of contact.
3. Deaf children's preferences for types of emotional well-being support.

5.1.1 Deaf children's perceptions and experiences of emotional well-being

Deaf children who took part in the study spoke of the importance of having positive well-being. This was something they were increasingly aware of, not least in the context of the pandemic and ensuing discussions in school with teachers on self-care and mental health.

Deaf children shared a range of things they enjoyed doing and were doing to develop their independence. Many of these can be understood as similar to the experiences of hearing children – for example, spending time with friends, playing sport, taking driving lessons and thinking about college or university. However, in the context of this study, there are experiences and perceptions that can be understood as specific to deaf children and which cannot be explored in isolation.

There was a consensus among the deaf children who took part in this study that this group as a whole were much more likely to be anxious and to have poorer emotional wellbeing overall compared to hearing young people. In short, it was argued that doing simple day to day activities were harder for deaf children. For example, one young person said:

It's just hard because the common things that wouldn't be a struggle to somebody else can be a massive thing.

This was predominantly put down to communication challenges and a lack of deaf awareness among hearing people and across services and facilities. There was also a perception that more deaf people should be accessing emotional well-being services but were not due to communication barriers:

I think the emotional help for a lot of deaf people...[they] should be getting more of it, because when, going into counselling if you need help for poor mental health, a lot of them aren't deaf-aware. So, when you talk about experiences with friends and having anxiety and depression, it's hard to relate to the counsellor, and the counsellor struggles to help you out, because they don't understand what it's like not to hear and not feeling included because there's a barrier between everyone.

Lots of varied reasons were presented for the poorer emotional well-being of deaf children. Bullying was cited as the key factor for poorer emotional well-being. One girl shared how a (hearing) young person in school took her hearing aid from her and put it in a bin while others spoke of being 'picked on' because of their speech. Another young person spoke of how they were constantly left feeling 'flustered' in shops or cafes when they tried to complete a transaction or place an order and ultimately in trying to develop their independence. One girl in the study explained how in the past her speech was very soft and others may have found it difficult to hear her and she felt very embarrassed and anxious by that each time she went out. Others spoke of the frustration they had if they mispronounced words in public and that this was frustrating and embarrassing for them. Three girls in the study shared how they tended to go to a specific shop assistant, and avoid others, in a local shop after school who knew a little bit of sign language and was deaf aware and that this helped them to feel more confident and at ease.

Ultimately, deaf children in the study shared their anxiety at being a teenager and the challenges in taking part in what would be perceived as 'normal' social activities. This meant always having to think about accessibility and whether or not any barriers would be in place before taking part or making plans. For example, going to the cinema was presented as difficult despite being an activity they enjoyed. This was because, even if subtitled screenings were scheduled and advertised, there were times when hearing people at the screening argued that this was distracting and asked for captions to be removed for the remainder of the

screening. Thus, there was a feeling of always have to ‘fight’ for their rights which was tiring.

Other deaf young people found it difficult to make friendships with hearing people in their local community. Despite making plans and taking part in, for example, football, they found that hearing young people also taking part spoke too fast and did not take time to explain things with the result that they felt ‘left out’ and isolated. One deaf boy discussed how he found boxing really helped him deal with frustrations and anxieties but, because it was a hearing boxing club, it brought its own separate anxieties because he found it difficult to communicate with others who attended the club. Deaf children who had friendships with other deaf children either through school or local deaf organisations said they found it easier to be with deaf people, that they could ‘relax’ and felt more included.

All said that school life was exhausting and very tiring and difficult to concentrate. One boy said that he did not see any friends outside school, and he preferred to be alone in the evenings as he felt so exhausted. Listening fatigue and struggles to concentrate in class whether using sign language interpreter or lipreading and/or using FM equipment was a recurring theme among deaf children in the study. This had a subsequent impact on how they felt:

Because I know when somebody says after three to four points, and if it’s really intense conversation and I don’t fully get it, I’m like my brain goes dead. I just can’t focus, I then get very emotional and then I’m just a big mess.

For those deaf children who attended mainstream school, there was a sense of awareness about the need to be more confident in certain situations to highlight when support needs were not being met or equipment was not being used properly. They felt the onus was on them to point this out, perhaps in front of a large class of children in a mainstream environment:

When using FM in class I find sometimes teachers forget how to use it, and maybe have it facing the opposite way round so it’s making it so I can’t hear them..., it’s hard to find the courage then to turn round and be like, in the middle of class, and it’s just, it makes you feel low because you can’t get your, you know, the things you want to say.

And then it's when you're struggling with certain things and you're getting overwhelmed it's hard to approach a teacher when they're already unapproachable. If they're in a bad mood, if you've interrupted them in the class, and if you're struggling with something it's really, really hard to address that you need that extra help in a certain area.

One group of deaf children who took part talked a lot about being the only deaf person in their family, and while they had developed means of communication with parents, few parents signed, meaning it was challenging and not always smooth or easy to communicate compared to deaf friends. One boy spoke of how his brother annoyed him by not communicating with him and he felt stressed and upset about this.

The anxieties of deaf children were compounded by recent lockdowns. The lockdowns and social restrictions appeared to exacerbate existing inequalities and inaccessibility in, for example, accessing important information:

From personal experience with like mental health, and especially through lockdown, it was a lot tougher on a lot of deaf people, because there wasn't the same access to everything. And especially the first round of lockdown where most people didn't know what was going to happen, they didn't have like the same access to subtitles and having, you know, the accessible stuff.

Young people expressed concern about stories they heard across social media. An example was shared of a man who was deaf but had no hearing aids and signed. The man had a stroke during lockdown. When the ambulance arrived, according to the young people, he kept trying to tell paramedics he was deaf, but they did not understand him, and it was not until he got to hospital that they realised he was deaf. For deaf young people in one of the groups, this contributed to their anxiety and worries about something similar happening to them in the future. It was suggested that social isolation during lockdown made especially difficult to keep up with education. One deaf girl said:

I find it hard to make friends, so I couldn't like, contact somebody to ask homework, because people just don't understand what it's like to be deaf.

The young people in the study shared worries about future transition to college, university or employment. While they were excited about becoming more independent, they had added worries about what the new environment might look like and whether or not they would be able to access the support they needed to succeed. One deaf girl who attended a specialist school and who had recently begun attending some classes at a mainstream school spoke of how shocked she was at the different ‘culture’ and the extent of background noise which was a contrast to the much quieter environment she was used to.

A deaf girl shared her experience of accessing support through mainstream CAMHS services due to high levels of anxiety. She told us:

I’d got help with my anxiety, because I had to leave class because it was just a mess. But yeah, yeah it’s just learning how to use them. I got help through Action for Children and just CAMHS as well, they helped. And it’s just having, knowing that certain things are normal, certain things I can deal with and certain things that I need help with. Like it’s knowing that when you’re about to vomit it’s not a normal thing. Yeah.

She managed to access support during the first lockdown. However, the counsellor did not appear to be deaf aware, and she had to ‘teach’ them how best to communicate with her before being able to proceed:

I had to kind of teach them a little bit, because they didn’t know how to approach me and it made me feel a bit iffy at the beginning. They did do well and, wearing masks at that stage, when masks were a thing, I just wore the mask and then they took it off, and it meant that I could communicate with them.

Another young person disclosed how they were accessing counselling via mainstream CAMHS due to a difficult home situation. They did so with the assistance of an interpreter. However, they did not find it helpful and said they did not want to share what was going on as did not want the issues to be ‘on record’ or to share via an interpreter.

A young person disclosed how they were meant to see a deaf counsellor and was happy with this but ended up seeing a hearing counsellor instead due to a long waiting list. He felt frustrated that his preferences were not ‘listened to’.

Others did not have direct experience of accessing CAMHS but were acutely aware of the importance of talking about emotions and of developing self-care strategies to build resilience. However, despite this, there was also a perception among some young people that while they knew what they *should* do, in practice they did not feel that they were able to do so. A group of young people in the study discussed how they felt unable to talk to their family and did not have anyone in their lives they felt they could trust enough to share how they felt. One young person spoke of the negative message conveyed by long waiting lists. Having been on a waiting list to see a counsellor for 18 months at the time of meeting, they said this made them feel ‘what is the point? They don’t care about deaf problems.’

There were some exceptions. A girl who attended a mainstream primary school felt her school PATHS childhood development programme had been very helpful for her, even though it was not deaf specific:

So PATHS is a programme that we have started in school, last year, and a person would come into us and talk to us about, all about PATHS, which is about your emotions and how you deal with your emotions. That all emotions are okay, but it’s how we deal with them emotions... It teaches you new ways to deal with things, and even if you feel a bit worried about something when there’s no one around you that you can confide in you can at least think of other things and try breathing exercises and things that help. Because we, lately we’ve been taught a few good breathing exercises..., and what to do if it’s not just emotions and there’s something more causing it. And you need to tell someone and not keep it to yourself.

Overall, it is clear that deaf children are experiencing a multitude of anxieties centring around communication and support. This was compounded by the social distancing regulations and recent lockdowns. While all children can find transition to a new environment difficult, for deaf children this could build on existing fears and concerns. There was a consensus that deaf children were more likely to experience poorer emotional well-being compared to hearing children and that available supports were not always easy to access.

5.1.2 Deaf children's preferences for emotional well-being points of contact

Deaf children in the study shared their preferences for key points of contact if they had concerns about their emotional well-being. The importance of both one-to-one support and peer support/networks were highlighted. For the majority of deaf children in the study, connecting with deaf peers were presented as the most important, irrespective of whether they attended a mainstream or specialist school. This was because they were perceived as being most likely to understand what they were going through:

PARTICIPANT 1: Would it be fair to say that [deaf friend] helps a lot... whenever you are both sad and face things together?

PARTICIPANT 2: Yes definitely, because we would definitely feel for each other. Because if something say happened to [deaf friend] then mummy told me, I would be angry and upset for her because I would totally understand. Then we may call each other and talk about that.

However, it was acknowledged that perhaps not all deaf children might have another deaf friend to draw on, especially if they were the only deaf child in a mainstream school. In this instance it was suggested that some capacity building among deaf friends would be helpful:

But you don't always have a fellow person. So, it would be good to make sure your friends know about your deafness, and know what they can do to help you and to support you. So definitely make sure that friend group would know and would definitely be associated so they would know what to do with situations like that.

Others emphasised the need to use online facilities that young people are already familiar with and would feel comfortable using as a way of expressing emotions. Some deaf children acknowledged that helplines for children were not necessarily accessible for those who were deaf and that they were effectively excluded from accessing support.

I think they should have like a website or a WhatsApp group for people, and if they are feeling low if they could just have that chance just to say to people about how they feel, through text message. And even if it was that they could FaceTime with somebody if they were really struggling with something, just that reassurance would make a massive

difference. Because all of those calls, stuff, they leave people [out] who can't go on the phone. And yeah sometimes people can't put into words how they feel, but if they message it, it becomes easier to say if they're feeling low, if they're struggling with friends, if they're struggling in school, or they're just needing someone to listen.

One young person had availed of a text messaging facility belonging to a mainstream helpline. She had found this helpful but was somewhat frustrated at the length of time it took to get a response to her message each time.

It was suggested that it was important to have someone in every school who is deaf aware and aware in particular of the additional anxieties that deaf children can experience:

Maybe, it would be handy if there was someone within every school that was deaf-aware and could, even just in general just awareness of different disabilities, and was able to have a one-to-one conversation with the likes of people who are deaf and be able to give them one-to-one support and that reassurance within school.

I think it would be helpful to have parts of it in school, so then you can go during your break and just ask, and, you know, it seems a bit more accessible for everyone.

However, it was also suggested that some deaf children might prefer emotional well-being support outside school, in the local community:

But I also think it would help by having a network where it isn't necessarily in school but is somewhere that you can approach maybe during the summer, before heading back to school, maybe when you're not in school.

Accessing peer support through an external organisation was viewed as being vital. It was argued that this would create a sense of community that deaf children could draw on and approach if they were struggling with their emotional well-being but did not necessarily need to access CAMHS or a counselling support:

But I also think it would be perfect if they had a group of people that felt the same way and being able to relate with some people. Because then you kind of feel that you're not

entirely on your own and that there's other people in the same boat and that you can talk to them as well, if maybe you don't need the counsellor but you just need like a friendly chat with a friend. I don't know. I think it would be nice to have like a mixture of different types of support, just kind of to fit everybody's kind of comforts.

It's just really having a place, if it was, that kind of helps support, like through Action Deaf Youth there's like a network of people and you feel that you're part of something bigger than yourself, and it just makes you feel included.

However, some young people expressed concern that existing support was not necessarily close to where they lived and meant they were only able to attend social activities on an irregular basis.

From the discussions with deaf children, it would appear that they would be more likely to access support if that source of support was deaf aware, deaf specific or part of a broader deaf network. The accessibility of emotional well-being services for all deaf children, whether a lipreader or signer must be acknowledged and existing services such as helplines for children and young people should be audited to ensure they can be accessed by deaf children when needed.

5.1.3 Deaf children's preferences for types of emotional well-being support

Lots of ideas were shared about the type of emotional well-being support that could be offered, both in terms of structure and content. In one group, discussion about what services they would like, led to one boy saying he would have a 'land' just for deaf people. While this was somewhat tongue in cheek, it relates to a broader idea of feeling part of a community, deaf identity, and being able to access services without having to think about barriers. He went on to say how he (and other deaf people) would design all services.

Deaf children across the study discussed the skills they felt was important for them in addressing barriers and subsequently alleviating anxieties and frustrations. For example, support with building confidence was seen as an essential skill for deaf children in lots of contexts:

I think, you know, having the confidence then to turn round and say to somebody, ‘look you’re not doing it correctly’ or, you know? And I think as well when needing the help, it’s knowing how to get it. It’s trying then to get the right help.

Developing a range of supportive techniques was presented as key. This was not just about general techniques to reduce anxiety or stress but understanding the need for deaf specific techniques tailored to particular situations. For example:

I just think very much knowing how to cope, because I would have quite bad anxiety and I would have panic attacks, those kind of things. And by having the techniques that I can use, like when I’m going to the shop maybe putting my hearing aids down just a little bit so that I’m not getting overwhelmed by all the noises and people. And having an FM system when it’s one-to-one with my mum if we’re in the shops, so I’m only focusing on one voice rather than a hundred, with everyone. It’s having the techniques, like the five minute rule, just kind of things that, even having, like being able to fiddle with a pen, being able to express yourself.

Some deaf children recognised that there was a variety of resources online that were available, and that increasing attention was being paid to these. However, it was argued that these did not always speak to their situation and were rarely deaf specific and age appropriate:

All the YouTube videos aren’t geared to anything with deafness. So they Google up something and it’s for general, hearing, everybody who’s hearing or doesn’t have a disability, it’s all geared to people like that. But if it was more geared to people that can use certain techniques, like using the hearing aid, putting it down a little bit in certain situations, having time set out during the day to take them off, to relax properly, and just having more time I think.

Deaf children in the study spoke about the need to have services and professionals that were ‘empathetic’ and ‘understanding’. They suggested that greater empathy would encourage more deaf children to seek help and share their worries, and subsequently to engage with support mechanisms:

And just kind of like knowing that people understand you makes a massive difference. That when you say something and somebody gets it you kind of feel then at least well now they understand it and they have ways of coping, then I can apply them. It's just knowing these things, I think, would help, because a lot of people don't know what to do in those situations.

[Being deaf] adds a lot of struggles when you're reaching out for help, because sometimes you don't realise you need help, because there's kind of normal stuff happening on a daily basis, where you can't communicate, you feel isolated, you feel stupid because you have to ask somebody to repeat again. It's just, I don't know, I think for a lot of deaf people it's getting that extra support and extra, just listening ears, just to understand what it's like.

There was some discussion around whether or not counsellors or emotional well-being professionals should be deaf themselves. There was a clear preference across the focus groups overall for a deaf counsellor or deaf professional associated with any service, and that this would encourage them to share issues or worries they might have. Suggestions included supporting or training more deaf people to become counsellors.

For some young people it was more important that a service be deaf specific, have expertise on deaf issues or be properly deaf aware:

I don't think it matters if they're hearing or deaf or if they're a counsellor or somebody who you see on a daily basis. I just think what would make more sense, if people who are in one of those things were deaf-aware and could have an idea of what it would be like. So then they can understand that bit better of how somebody feels when they're socially isolated from everyone. I don't know. It's kind of hard to put into words, of how that could be improved. I don't know.

Where training in deaf awareness had to be provided, one young person suggested that professionals should be given a 'deaf experience' to help them understand better what frustrations might emerge:

I think if they were given even like an experience of what it'd be like, even if they were taken to crossing a road or in a classroom setting, and if they had like [ear] moulds put in that they couldn't hear. It would make them maybe think, because they've experienced what it would be like.

Deaf awareness was highlighted time and time again – also the importance of everyone learning even basic sign language so they could communicate with deaf children. Another young person suggested that, as well as being deaf aware generally, it was important to be aware that deaf people are different from each other and have different needs, including different communication needs. In cases where a young person was a sign language user it was argued that the professional or counsellor should also be able to use sign language rather than having to go through a sign language interpreter who is effectively a third party. This brought up concerns around privacy and information protection, particularly given the relatively small size of the deaf population in Northern Ireland and where sign language interpreters may be known on a personal as well as professional basis. There was concern that having to use a sign language interpreter rather than communicating directly would put some deaf young people off from engaging with emotional well-being and mental health services:

I just think for other areas, and maybe for other people, it's just having those areas a bit more, 'okay this is what we do', and accommodating it to everyone, rather than just assuming, 'okay she's deaf. She can't hear,' but maybe she can hear certain things. Because everyone's deafness is different and everyone has a different spectrum of it, and sometimes some things are, you know, they could do with a sign interpreter. But instead of having to get somebody else to come in it should be done through the person, so it's a more one-to-one, rather than having it through two other people, which then makes it more awkward, and you feel that you have to explain the situation to two people and hope that they don't, you know, go home and say it to somebody else.

The set-up of any venue being used to provide emotional well-being services was also highlighted as important in making deaf children feel comfortable and at ease:

In general, I think those areas just need to be, okay having it that you're not put in a dark room, having it that it's not too bright and not having a person sitting too far or too close. Because when it's too close it's like claustrophobic, yeah.

In summary, deaf children across the study identified types of skills and techniques that would support them in managing their emotional well-being. The ability and willingness to engage with emotional and mental health support services was perceived to be contingent upon levels of deaf awareness within a service or among professionals. This included awareness around the diversity of deaf children's needs, the need for empathy, and the importance of an accessible venue and a safe, neutral space in which to meet professionals. Indeed, having deaf people as part of service delivery in some way was perceived as sending a strong message about the accessibility of a service and the value accorded to deaf people's emotional health and well-being.

5.2 Findings from engagement with parents

The parents section focuses on the following key themes identified through data analysis:

1. Parent perceptions on the emotional well-being of deaf children.
2. Experiences of accessing emotional well-being services and supports.
3. Best practice: play therapy.
4. Moving forward: the need for deaf specific services.

5.2.1 Parent perceptions on the emotional well-being of deaf children

There was consensus among parents who took part in the study that the emotional well-being of their deaf son or daughter was a 'huge, huge issue' (parent). The rationale for such a viewpoint ranged from current concerns about their child's emotional well-being to concerns about their child's emotional well-being in the future, for example, as a result of making the transition to primary school, secondary level education, or to college or university.

A number of parents spoke of how they had ongoing concerns about their child's emotional well-being, which manifested itself through different behaviours and frustrations. For example, one parent of an eight-year-old profoundly deaf boy explained how her child had been experiencing high levels of anxiety:

So I suppose around, I was trying to think back when it really started and I couldn't really tell you, but I would say around P2, P3 we started to notice a huge amount of anxiety. And, you know, I'd read up a lot about anxiety and deafness and the idea that, I think he's constantly worried that he might be missing something, you know, in class. And I suppose this came to a head in P3, last year... it was particularly bad. So his behaviour was just so, so poor, so challenging, and we just started to wonder what was going on.

A parent of a six-year-old profoundly deaf boy felt that factors impacting on her child's emotional well-being were not well understood. Rather there appeared to be an underlying assumption that once a hearing aid was provided and the child could then 'hear', there would be no further issues. But, in fact there were particular anxieties and frustrations that could arise due to trying to keep up with hearing peers:

So I think overall people just kind of think, 'oh he's got a hearing loss, do you know? He wears a BAHA⁴, do you know? He's brilliant, do you know?' No he's not, he's really, really struggling in school. Like he's really far behind in school, he's struggling to keep up with his peers, do you know? His anger, his anxieties in terms of that, he doesn't sleep well at night, it carries on. Yes, he's got a hearing loss, but that carries on throughout his whole entire life, and everything that kind of goes hand-in-hand with that.

'Missing out' and 'keeping up' were common themes identified throughout the interviews with parents as key factors impacting on emotional well-being. This was not just restricted to keeping up in the classroom but extended to developing and maintaining social relationships and friendships. A parent of a 17-year-old profoundly deaf girl expressed concern at the impact of trying to follow conversation on her daughter's well-being:

[H]er struggle would be with the social side. She finds keeping up in conversation really difficult, so that's sort of how she ended up going to CAMHS, was just that she struggles with making friends and interacting with people, because she finds it hard if more than one person's talking to follow a conversation.

⁴ BAHA – bone anchored hearing aids.

Concerns were expressed by a parent of a deaf child who was moving through the primary school years. In this instance the eight year old child found the (mainstream) school day very tiring as a result of maintaining concentration on lipreading and communication. The parent was further concerned that the child might be excluded from peer friendships, particularly as children get older and became more self-aware. The child in question was now becoming more aware that she ‘speaks differently to her hearing friends’ and, as parents, they could see ‘her wellness slowly being chipped away’. The parents were so worried about the potential impact of large class sizes and communication difficulties on their child’s confidence, self-esteem, and overall emotional well-being that they were contemplating moving her to a different school.

Parents who had connections with other parents of deaf children identified similar issues and were struggling to understand the reasons for this – whether it was simply due to the age of the children or whether it was borne out of frustrations around communication:

[A] lot of my friends whose children are deaf, are the same age as [son], they have really challenging behaviour. And I suppose an element of it is just they’re eight, you know? An element of it is, there’s some aspect of it is deafness. But then in your head you don’t know how to deal with it or how to respond to it, whether it’s just something that you’ve got to work through and it’s all going to come out fine, or is this something deeper that I’m not understanding here, you know? Is this a frustration? Has he missed half the conversation? Is he covering up at the dinner table because he’s missed half the conversation, and he’s acting out like this because he’s missed it? I don’t know.

A parent of a three year old child identified the source of her daughter’s frustration as not having the words to express her what she was feeling:

I’m having few behavioural problems with [child] at the moment and I know it is that transition period of her age, … I have a three-year-old niece who’s the same age, and the difference, because she can express herself and express her emotions and how she’s feeling. [Child’s] still learning those words.

Some parents spoke of how they tried to address their child's anxiety by preparing them before going into unfamiliar situations but also highlighted how this could be difficult to get right. However, there was a perception that new situations could be difficult as the deaf child may not be able to pick up on ongoing background conversations in the same way as hearing children. There was also recognition that different spaces could have different acoustic backgrounds and perhaps fewer soft furnishings which made it much harder for their child to engage compared to home spaces that had been adapted to suit their needs:

As a deaf child you try to prepare them what they're going into, but if you overprepared [child] that was a problem, but if you didn't prepare her that would be unfair because she's not getting, you know, just coincidental conversation. She wouldn't get bits and pieces, you know, she's going into a new situation that's easier for a hearing child that would take it all in their stride. But if you're going in somewhere as a deaf child and it's all different and it's a bit scary and it's a different sound in the room and, you know, it's not the same acoustics and it's, you know, anything can be scary for a deaf child.

There was concern that for some young children, frustration was already manifesting as anger or leading to self-isolation:

He's six years old now and I notice that there's elements of anger that I wouldn't like to see develop any more than what they are, do you know, in terms of like he would bang the table or I can see him clenching his fists. And I just wouldn't like it ever to progress to the fact that he would get physical with anybody else, do you know? And I think if we don't address these issues that are with him at the minute, I think eventually it will go down that route.

He is starting to make comments now such as 'I don't want to go and play, they don't understand me' or 'there's no point in going out to play' and stuff like that. And it's that kind of negative language towards his differences that I don't want to kind of creep in, do you know? I want him to have a good self-confidence and that identity of himself, I want it to be strong.

We notice with [child] she would get very angry very quickly, and even just in the way of tiredness throughout school she has to nearly isolate herself, because everything's amplified with the hearing aids and you have to concentrate so much harder. So we do notice that she would isolate herself quite a bit when she is tired.

The data suggests that deaf children's well-being has been exacerbated by the pandemic over the past year. While this has been an issue for all children and young people, deaf children have had particular experiences:

[Child] is not really keen on kind of the computer, sitting down and engaging via Zoom. It's something he finds really difficult. He relies quite heavily on lipreading, and when the screen is quite busy with a lot of different people, do you know, broke up he finds it just extremely difficult to focus on that. So he went from having quite a lot of support to basically nothing. So the last year's been very difficult.

She's always been incredibly independent, so this [pandemic] has sort of knocked her a bit, that she's back to relying on someone. Like for example going to, she went to [an appointment] today and I had to go with her because of the mask situation. She wouldn't be willing to go on her own because, you know, just, well she wouldn't know what questions they were asking her.

We found [three year old child] had very bad sleep. She didn't sleep at all some nights. I think, I counted it up and we had like three full nights' sleep in about six months, and I think it was because like Action Deaf Youth stopped, all the classes stopped that she went to, you know, we weren't really allowed outside as much. So, I think that didn't really help.

Transition from primary to secondary school and beyond were highlighted as critical junctures for deaf children's emotional well-being. Support that may have been consistent and familiar throughout primary school may not be replicated in secondary school or post-16 settings. There was a sense of uncertainty among parents as to what to expect and how this would be experienced by their son or daughter.

So where she is doing great at the moment and I've a very good relationship with school I know that's temporary and that will change when she goes to, all being well she wants to do her transfer and go to a grammar school. So I know that will change, so that's again that lead-on service I'm concerned about. I'm definitely a bit worried at this point, going 'okay will we now see problems? Will we now see changes happening?'.

You know, we're growing up, we're hormones, we're going possibly to either special school, a lot of them are going to mainstream school, maybe some of the children are going to the unit. There's such a change then from wherever they are, and they've got comfortable in their primary school. So yes, all children go through that transition, however it's not just so easy for deaf children, you know?

The impact of what could be perceived as increased attention on deaf children by the deaf child's siblings due to related support needs and appointments must also be considered. For example, one parent noted that their other child also began to struggle to 'find her place' and also required support:

Last year we noticed that she was very much struggling as well to kind of find her place. She was crying out for attention, her little behaviours started to rise, and we had reached out to Barnardo's at that stage and said like 'listen, this is the story of our family, and we just think that she needs a little bit of extra support with where she fits in'. And she went through that.

Across the course of the interviews, some key factors were identified by parents as contributing to positive or improved emotional well-being for deaf children. The most significant and recurrent of these was the positive impact of deaf children meeting up with each other in a safe space. In some instances, this required parents to be proactive in making links with other parents of deaf children in the area and developing opportunities to meet up, while in other instances parents were able to avail of opportunities for their deaf child to go along to events and youth clubs at local organisations such as Action Deaf Youth. This was perceived as providing their son or daughter with opportunities to meet other children who were like them, who communicated like them, had shared experiences and were in the process of trying to understand what 'being deaf' or having a 'deaf identity' meant for them.

For some children, going along to meet ups was the first time they had ever interacted with another deaf child:

But it really, you know, served a real purpose, of him knowing other deaf children, because there was one child in particular, walked in one day and, you know, the first thing he did was he pointed at his head, and he was like ‘oh he’s the same as me’. And it just really stood out to me, like that child had never seen another deaf child, you know, which was bonkers, you know? So he has a really positive, well I feel he has a really positive identity. He puts stickers on his ears and, you know, highlights them and, you know, does his presentations in school about deafness and sign language and teaching his friends and, you know? So it’s celebrated.

Interacting with other deaf children was viewed as taking on particular importance when a deaf child was attending a mainstream school and had few other opportunities to meet other deaf children who understood the challenges they were experiencing:

I think just having that safe space and having a similar peer group who, to share experiences with and to just, they just get on, they get on so well. It’s really amazing, do you know what I mean, to see, and it’s just something that I suppose we didn’t realise before they joined, how important it is when you are spending so much time in a mainstream education setting, do you know what I mean, where it can be difficult to navigate those friendships.

There were seventeen deaf children, and they were the happiest children. They were just, every one of them were deaf, they were just, and [child] loved it. It’s like a deaf club for her, we are very, very lucky that we have that in Belfast, where she can play with others without feeling insecure and thinking ‘oh am I speaking right?’

One parent noted that their deaf child felt a tension between the ‘deaf world’ and the ‘hearing world’, and perhaps not fully part of one or other but as overlapping both:

It’s really difficult because [deaf child] is in a hearing, like she’s in a hearing world but she’s in a deaf world, and she needs to embrace both of those, and it’s making sure that she has access to both of those things, do you know what I mean, to support her

emotional health and wellbeing, and so that she feels comfortable about her deaf identity.

In summary then, parents expressed concern that their deaf child was or could experience poorer emotional well-being compared to hearing children. This manifested primarily in the form of higher levels of anxiety or challenging behaviour. It was suggested that this was due, in part, to the challenges of communication, lack of deaf awareness, and difficulty of picking up on background conversations or noise which can be important sources of information. A majority of parents in the study highlighted the role of peer support and interaction with other deaf children as an important factor in supporting their child's emotional well-being.

5.2.2 Experiences of accessing emotional well-being services and support

A key challenge for parents who had concerns about their child's emotional well-being was what kinds of supports or services they could access and how they would be able to find information. There was a view among parents that excellent support was available for parents of very young deaf children of pre-school age from NDCS, including support with statements of special educational needs, equipment, and support with completing forms but very little beyond that around emotional well-being for deaf children. For example:

But in terms of services, we'll say like the NDCS does an amazing newly diagnosed weekend, and then that's kind of it, you know? And then Action Deaf Youth do great, the youth clubs I think are amazing at this age. But there's sort of a gap there in terms of behaviour and the challenges that that poses and self-esteem and things like that. You know, you really have to go looking for it.

Parents spoke of using google to try and access information about potential emotional well-being services that might be available. This appeared to be the case for specialist services such as deaf CAMHS. Other parents were also a key source of information:

And if we had a problem that would be my first port of call probably, would just be one of the other parents, do you know? And then we'd take it from there, you know, and see what people are recommending or what's available to us I suppose.

One parent who played an active role in a local support group for parents of deaf children highlighted that she is contacted on a regular basis by other parents asking about types of services that might be available to support their child. The parent suggested that it seems to be ‘almost like a secret, that [particular services] are available. I’m sure it’s not, but you have to go looking for it, you know?’ Across the study, three parents had some experience of accessing a deaf specialist in CAMHS while two had experience of accessing generic CAMHS services. Three parents had experience of accessing early intervention services in the form of deaf specific play therapy at Action Deaf Youth (this is discussed in a separate section below.)

There appeared to be a sense of resistance of going through a generic CAMHS service or a service that focused primarily on behavioural and emotional support. For one parent this resistance was based on a previous experience of accompanying their hearing child to CAMHS. They did not have a positive experience of the service they encountered. As such when a speech and language therapist suggested referring their deaf child to CAMHS they did not wish to avail of this service. In addition to what they had previously experienced, they were also concerned that if they took their deaf child there that the child would be assessed through a singular hearing lens. In other words, the child might be assessed as having autism or ADHD but the interaction between either of these conditions and the child’s deafness would not likely be considered:

So we’d been through all that before with my older boy, you know? And I said ‘to be honest I don’t want that because somebody who doesn’t understand deafness would automatically’, now I could be wrong Bronagh, but for me the person needs to understand deafness, and when you go to that service they don’t, and he would be diagnosed with ASD or ADHD or something else just on the basis of his behaviour, without an understanding of deafness.

Instead, they were referred to a deaf specialist in CAMHS. Following an initial conversation, and completion of relevant measures by parents and school, it was suggested that the deaf child did not have autism or ADHD and would benefit from an early intervention service in the form of deaf specific play therapy. The parent explained that while they may have had a similar outcome through completion of questionnaires at generic CAMHS, by going to a deaf

specific CAMHS specialist they ‘trusted’ the decision that was made because of the specialist’s expertise in deafness, the way they had considered the child’s deafness and the referral that was made to a deaf specific service:

And then the, we filled out all the questionnaires and the school filled out their questionnaires and [deaf specific play therapist] filled out hers and [CAMHS specialist] then gave us a call and said ‘look’, on the basis of our questionnaire as parents she felt that there may be like ADHD, but then on the basis of the school’s she didn’t, and then on the basis, you know, she really seems to be trusting [deaf specific play therapist] and what she thinks, and she doesn’t think there’s anything other than deafness, which is great, you know? And she just feels that whatever issues he’s working through are related to his deafness and that the play therapy will help that. So that’s kind of where we’re at, at the minute, so it’s sort of just ongoing.

The same parent suggested that some form of early intervention would have benefitted them before the stage of needing a referral to CAMHS and that this was ‘missing big-style for us.’ Another parent who accessed mainstream CAMHS with their child highlighted how there was an assumption that their deaf child should be assessed for autism or ADHD because of the way they behaved but that the impact of deafness on how the child might be feeling or behaving is rarely acknowledged:

[Child’s] hearing loss very rarely gets taken in as to his reasons, you know, why he would be feeling these emotions. A lot of time there’s questions such as ‘have you had him diagnosed with ADHD?’ or ‘are you sure he doesn’t have autism?’ Are you sure he doesn’t have this, that or the other?

This was similar to the fears of other parents that their child might be assessed as having another condition if they went to a generic CAMHS service when really the anxiety or challenging behaviour might be due to issues relating to deafness or barriers the deaf child might be experiencing in a hearing world. The second parent who had been referred by a teacher of the deaf to the deaf specialist in CAMHS for their child had done so as their child was experiencing high levels of anxiety and had difficulties with social interactions. The parent noted that they had been on a waiting list for some time and when their appointment finally came, that lockdown had begun so alternative ways of meeting had to be found. In this

instance they were able to meet the deaf specialist in the grounds of the clinic so that masks did not have to be worn. The parent highlighted the awareness of the deaf specific CAMHS specialist in terms of communication and contact as a positive aspect that was missing from the generic CAMHS that they subsequently accessed. However, in this instance the parent felt that their daughter should have had the opportunity to speak to the specialist on their own without the parent present:

She got referred to CAMHS. It was this time last year she started. She had been, there was like a programme that she got referred to through school and it was for deaf CAMHS. So she had one appointment at that and nothing after that. I think that was just like a chat more with the doctor and whoever the other person was that was there. They referred her down to [mainstream] CAMHS just. She would have a lot of anxiety and that. So she went to CAMHS over lockdown, which was not easy at the start. Everything was done sort of outdoors through walks and stuff. But they signed her off, there's not really anything that they could do really for her.

In this instance the parent would also have liked to have seen some follow-on support that was deaf specific and felt that while the staff in the generic CAMHS service were ‘lovely’, that they did not fully understand the interaction between deafness and anxiety:

And that if we needed anything we just have to get referred again right through. But to be honest I don't think that it was really beneficial hearing-wise. It was good for her to chat and just, you know, chat generally about things that were going on, but I don't think it was specific to any of the anxiety that she might have around her hearing, especially now with COVID and all these extra restrictions and, you know, that she's become less independent because of masks and things that other people wouldn't consider it to be an issue.

As noted above, the challenges experienced by a deaf child can have a knock-on effect on the wider family, including hearing siblings. In one case, a parent had to access additional support for their hearing child. The service that was accessed did not have particular expertise in deafness and it was suggested that this should have been a key issue that was discussed, yet it remained invisible:

I just felt it was never acknowledged that there's any kind of deafness that goes on within the household. Whereas I could very clearly see that that was at the root of the problem, but I just felt the counsellor from the other side of things was like 'okay how do we cope with things like this?' as opposed to 'let's talk about your brother being deaf. How do you feel about this?'

The parent argued that even if the child in question is not deaf, if there is a deaf member of the family, that the impact of this on everyone in the family should be acknowledged:

So, for services I just think that if there's somebody deaf within the family, that it needs to be identified throughout the whole family, do you know, because it does have that knock-on effect. It doesn't just affect that one deaf person within the household, it affects everybody within the house. So ideal world that's something that I would like, is just that more level of understanding, do you know?

The concern with generic CAMHS and mainstream emotional well-being services was a common theme across all parents in the study. Parents argued that deaf specific organisations such as NDCS and Action Deaf Youth offered the best support for both the family and the child. This included support with parenting, residential weekends for families with a newly diagnosed child, sign language courses as well as children's and youth clubs. Indeed, it was suggested that these organisations would be a natural 'home' for early intervention services and that it was important parents were made aware of what was on offer in a systematic way. However, while the support offered was extensive, at times more specialist child and adolescent mental health support could be required. This was perceived as a gap that needed to be urgently addressed. In particular, because:

All other professionals, once you mention hearing loss, they don't take that in as a factor. I don't think their understanding as to what hearing loss can affect, in terms of everything else. I mean for people who maybe don't have understanding on it, I think hearing loss, 'oh they can't hear' and that's just it. But it goes an awful lot further than that, you know, it's kind of, it's extended into every part of [child's] world.

Some parents were concerned that their child could be misdiagnosed with other conditions such as ADHD when what might have helped was adjusting or using equipment in the classroom more effectively:

You know, there's nothing untoward or anything that would suggest that he really needed to go into CAMHS. And that's what I'm trying to, still, to this day, to say to professionals, is simple things, and that's what all them [deaf specific] experts are saying, the simple things make the difference. Not ADHD medication ... they're looking at ADHD medication but they won't lift the radio aid up and use it to help [child].

One deaf child whose parent took part in the study had been diagnosed with ADHD alongside other health conditions, however expressed concern that the consultant they met had no experience of deaf children and that the treatment plan was made without taking the child's deafness into account. In this instance the child was able to subsequently avail of deaf specific play therapy and had found out about this because their child was attending Action Deaf Youth.

5.2.3 Best practice: Play Therapy

Across the interviews there were clear examples from parents of what they regarded as best practice in supporting the emotional well-being of deaf children. This took the form of early intervention via Action Deaf Youth – both generally and specifically via deaf specific play therapy provided by the organisation. Some children in the study attended the age-specific youth clubs provided by Action Deaf Youth such as Play Pack and Superstars; others had or were attending play therapy at Action Deaf Youth. Parents felt that the services provided by Action Deaf Youth to both parents and children, and the fact that many members of staff are deaf themselves, meant it felt like a safe environment that supported the whole family:

The staff down at Action Deaf Youth, they're like a family, do you know? And they're so open and welcoming, and they're not judgemental at all. Like I could go in with any question that's deaf-related and I can get an honest answer, do you know?

It was clear that deaf children enjoyed attending the activity sessions and looked forward to it:

So the Sunday sessions down in Play Pack, I just, I can't get enough of them, do you know? We just run down, every Sunday [deaf child] jumps up out of bed, like he just absolutely loves going down to it

[Action Deaf Youth] was setting up a group called Play Pack and asked if we would like to come along, and we did. And again [crying] it has been fantastic. We couldn't manage without it. The support again as a family and for [deaf child], and the friendships she's made, my goodness the social life.

The benefits for the deaf child and the family emanated from the understanding that staff at Action Deaf Youth had of children's social and emotional development and well-being. Parents provided examples of where activities had made a difference and enabled them to support their child when they were experiencing anger or frustration. For example:

I would stress about [deaf child] being quite behind in school, and then [Action Deaf Youth] had arranged, there was a lady called Kate from England and she had done a session teaching deaf children to read and supporting phonics. To be able to go on and listen to a deaf adult say 'it's normal. It's normal for deaf children not to understand rhyme' or 'it's normal for them not to listen to phonics' or it's, just to hear somebody say that it's normal, as a parent it really settles me. And then I'm more confident in terms of saying to [deaf child], 'it's fine, don't stress out about it', you know, 'let's not get angry about this because there's a reason behind it', do you know? So it's quite nice to have that, and it's definitely something that the services of Action Deaf Youth have provided us with, is those positive deaf role models, and just a bit of like compassion and understanding and saying 'you guys, everything will be okay, you know, it's fine'.

For very young children of pre-school age, taking part in Action Deaf Youth activities had enabled them to develop their independence. For example, two parents of two deaf children aged three noted:

The independence that ADY [Action Deaf Youth] have for her, like she goes and gets her bread and butters her bread, she goes into the fridge and takes out her ham and makes her ham sandwich and she cuts it, puts it in her bag. She gets her orange, she gets her yoghurt and she goes and puts it in her bag, and she stands and waits at the door.

[Child's] independence even has really improved with Action Deaf Youth because she goes on a Friday and I leave her there. Like she goes half nine to half twelve or something like that, and, you know, she like, you know, gets her own snack and she knows to get her coat and she does her hand sanitising when she goes in, and it just helps her be more independent. Whereas maybe at home I'd probably baby her a little bit more

There was also a perception from parents that children who attended Action Deaf Youth were given the space and support generally for their emotional development. For example:

We were going from a wee girl who said very little and did a lot of watching and yes she did a bit of hand flapping and stimming and stuff like through excitement, and we then went to a little girl whose speech was coming on, and she was, her emotions I think were maturing.

[Action Deaf Youth] let [child] be [child], which I think is really important, and they let her sort of find a way to be her own person if that makes sense, which is good for her confidence as well.

There was some concern however that access to services could be reduced or halted due to funding cuts in the aftermath of Brexit and Covid. One parent shared how their hearing children had been able to benefit from attending sign language classes for siblings which helped them to learn more about the communication needs of their deaf brother or sister and had a role in supporting the emotional well-being of both the hearing and deaf child in the family. However, due to limited funding this service was no longer being offered. Some parents however expressed a desire for more activities to be held outside of Belfast as they lived in a rural area or in the Northwest, and it was not easy for them to travel to Belfast every week. One parent was not able to attend any services at all due to living some distance

away, close on the border, but felt their child would benefit from attending Action Deaf Youth.

Three parents in the study had experience of engaging with deaf specific play therapy within Action Deaf Youth. One parent had been referred to the service by the deaf specialist in CAMHS and had not previously engaged with Action Deaf Youth. They felt that while their child was enjoying attending Action Deaf Youth as a whole, that the play therapy required time. This had, however, been somewhat disrupted by Covid and lockdowns but was now continuing:

He absolutely loves going, and he really enjoys his time in there, but we were in contact with [Action Deaf Youth] before Christmas because his behaviour was getting worse and worse and worse every week. And she was saying to us that that's actually part of the process of therapy, that it will get worse and then it'll get better, that he's actually working through things. And then unfortunately we had lockdown, you know, so it meant that he didn't get to complete the process. So he's still there, and I think it's very much a work in progress, you know?

A second parent was aware of deaf specific play therapy having already been attending Action Deaf Youth and so was able to self-refer to the service following concerns about her deaf son's behaviour:

We noticed that he's quite, he finds it difficult to kind of regulate his behaviour, and we think that's a lot to do with the communication skills and just the anger that he feels in terms of expressing himself. So we had six weeks of that with [deaf specific play therapist], and it's definitely something that we would like to avail of again, you know, it was very, very beneficial.

The benefits for the deaf child of attending deaf specific play therapy sessions over six weeks and the positive impact on their emotional well-being were clear:

Out of this world helpful. Really, really beneficial. The techniques, obviously I wasn't involved and I wasn't in the room for the therapy sessions, but we noticed a big

difference in [deaf child], the coping strategies that he was using in terms of his emotions and feeling those big emotions.

In this case the parents had been supported to help their child at home by learning sign language; in particular, the signs for various emotions that they could use when communicating with their child to help them express their feelings in a safe and familiar space outside of the play therapy sessions. The techniques learned at play therapy meant that the child was able to remove himself from situations whenever he was starting to feel overwhelmed or finding difficulty coping with a particular situation.

Play therapy had been recommended to the third parent by a mainstream CAMHS service. However, this was not a deaf specific service and was not available on the NHS. The parent subsequently found out about deaf specific play therapy via their teacher of the deaf and a visit from Action Deaf Youth to their child's school:

[Deaf child] actually had play therapy I think over a course of two years. We were so lucky, you know, she was able to get as many sessions as really she needed, and [deaf specific play therapist] was amazing with her. And really we'd such a change in her. it basically helped her mature. We saw, her teacher would agree, a huge change in her concentration.

This parent also spoke of how their child was able to 'bring herself back a wee bit' compared to before accessing the service where 'you couldn't have brought her back' and where:

If, what she thought was going to happen wasn't happening she just could not cope with that. Whereas now you can see her, nearly her processing system seems to, you can almost see her wee brain ticking over.

Those parents who had not accessed deaf specific play therapy but who attended Action Deaf Youth activities spoke of how they felt reassured by knowing the service is there should they need it in the future if their child was struggling with their emotional well-being. However, they did highlight how they felt the service was not widely known about outside of those who were already engaged with Action Deaf Youth:

There could be other parents who don't know that that exists until they speak to somebody, do you know what I mean, and say 'oh we've accessed this'. That's kind of my point, it's all a bit trial and error, do you know what I mean? It's only when you really are in the depths of 'oh I need something' or 'I need help' that you really find these things. They're not necessarily signposted in advance to prevent you getting to that point, if that helps?

Overall, the interviews with parents who had engaged with Action Deaf Youth both generally and specifically for play therapy felt that this was hugely beneficial in supporting their deaf child's emotional well-being. The extent of deaf specific knowledge, expertise and awareness makes the service distinctive and it was suggested that this was a critical early intervention which should be open for all deaf children.

5.2.4 Moving forward: the need for deaf specific services

While there was a range of services currently available for parents to access on behalf of their child, this was largely restricted to provision of physical equipment or education related support. There was a perception that there was little or no support provided around emotional well-being for deaf children from statutory services and any that was available was being provided by overstretched and underfunded community and voluntary services.

When [deaf child] was five years old and he got handed a BAHA on the soft band, and he was sat down and told 'you need to look after this. This is very expensive, you don't break this', and I was like 'he's five years old', you know? So yes they provide equipment, but in terms of emotional support, wellbeing, social development, anything like that, we have had to receive that from a charity as opposed to the NHS. And I think that needs noted, you know, it's not good enough, in terms of a service that's meant to provide us as a community. And I mean we all pay our taxes, like it's our service, and we should be receiving more from that.

All parents in the study were adamant of the need for a deaf specific service to support the emotional well-being of deaf children, both in terms of early intervention and access to a deaf specific CAMHS service. While not all parents who took part had experience of CAMHS,

they still felt that they would prefer that this was deaf specific with professionals who had in-depth knowledge of deafness and deaf culture.

They have to be clued into the specific needs of deafness to understand, to be able to, how to meet the needs that that child will have, which is so different. Like whether that's feeling alienated because they're missing out with their peers or whether it's accepting their deafness or whatever it is. It has to be, in my opinion, very much specific to deaf, one hundred per cent.

I mean if I had a preference definitely a deaf specialist, one hundred per cent, without a doubt. But that isn't something that's been mentioned to me at all.

Parents were somewhat torn between the need to, at times, access support because of concerns around their child's behaviour and not knowing whether or not this was indicative of another health condition such as autism or ADHD. There was a worry that if they went to mainstream CAMHS services that the professional would not have a good understanding of the nuances of deafness and the relationship between deafness, communication difficulties and possible negative behaviours, or of the intersection between autism or ADHD and deafness and the implications of this for subsequent treatment and supports.

Some of the behaviours that come out as kind of the frustrations of dealing with kind of the issues relating to deafness, they can almost be seen as negative behaviours. And, you know, it's maybe like 'oh she's bold' or 'is there something else wrong?' or, you know, 'have you thought about those things?' Whereas a lot of the conversations I would've had with [Action Deaf Youth] and other people are that they're just the frustrations from a deaf child. They're not necessarily signposts that there's a further behavioural problem that you're not dealing with, do you know? They're just, they happen to be similar. So I think that deaf-specific services mean you don't necessarily get misdiagnosed or tarred with the brush that maybe there's something else wrong, and not fully understanding the causes and effects of deafness on the child.

Part of this was associated with providing deaf children with the means to express their feelings thus providing a healthier outlet for negative emotions.

The earliest intervention that could help, especially for the frustration. So we could, if we were taught as parents and then we could teach our children, ‘look if you’re angry this is [sign]. If you’re happy you can [sign], if you’re cross or if you’re feeling sad this is what the feeling is, this is the sign’. Even for the basic signs, ‘this is the sign’, so we can help and try and figure that out

Deaf awareness across emotional well-being services was understood to be key:

So for me the biggest thing would be to have, as you have mentioned there, so the likes of your early intervention or your CAMHS teams to be more aware of hearing impairment and deafness, and how that affects everything.

It doesn’t really matter what service it is, you need to have someone across the board that has deaf awareness and experience.

It actually pains me to know that these people are coming out and they’re making recommendations and they’re putting everything in place, and they have no experience of, like most of them have no experience of a deaf child.

Such deaf awareness should include things like being ‘aware of face-to-face… sitting at a certain distance, checking if the person lipreads and just being aware of things that will affect someone with a hearing loss, rather than the person having to tell them.’ Meaning the emphasis should be on the professional already having that awareness rather than relying on the deaf child to tell them, particularly those who may already be struggling with confidence and self-esteem. It was also suggested that generic and deaf specific CAMHS services should be able to signpost families to other deaf-specific services in the local area. There was, however, concern that vital services would be lost if permanent funding was not secured:

I think the foundations are definitely there with an organisation like Action Deaf Youth and the work that they’re doing is brilliant, you know? … They’re relying on government funding and charitable funding, so maybe some permanent funding for organisations like that so that they can further develop their programmes.

Finally, there were suggestions that there needed to be more preventative work undertaken with deaf children, particularly for those children in mainstream school in rural areas who may not have the same access to opportunities to meet with deaf peers.

And should we be doing them preventatively? You know, is it something that's worthwhile doing every now and again just as a kind of a checkpoint to make sure that we're not missing anything and there isn't underlying anxieties and worries there that we haven't thought about?

More broadly there were suggestions that the emotional well-being of deaf children and young people in Northern Ireland could be better supported if all children and their families, including siblings, had access to sign language classes as early as possible. It was argued that, ideally, this should be part of the school curriculum and would provide a means of promoting great social inclusion for deaf children and young people. Overall, there was a strong consensus among parents of the needs for more considered and bespoke support to be provided to deaf children and their families relating to emotional well-being. Early intervention, clear information and programmes to support well-being, and a deaf specific service grounded in experience, holistic understanding and knowledge appear to be core elements of any emotional well-being provision for deaf children and young people across Northern Ireland.

6.0 Conclusions and Recommendations

6.1 Conclusions

Adopting a rights-based approach entails ensuring that emotional well-being and mental health services are available, accessible, adaptable and acceptable to the needs of deaf children (UN CESCR 2000). Findings from the NI Youth Wellbeing survey presented in this report suggest that deaf children have statistically significant higher prevalence of Depression, Anxiety, Generalised Anxiety Disorder, OCD, Panic Disorder, Separation Anxiety Disorder and having any of the listed disorders compared to hearing children. In total, almost 21% of deaf children reported having at least one psychological condition compared to about 12% of hearing children. These findings are consistent with previous studies from other countries, which indicate that deaf children have a higher prevalence of emotional wellbeing issues compared to hearing children. This also aligns to the findings from the qualitative data in this study which illustrate the myriad of anxieties and frustrations that deaf children are experiencing. The data presented in this report provide important insight into some of the reasons why deaf children may be at higher risk of having emotional well-being issues. These factors are rooted in environmental, structural, social and cultural issues, which interact with a child's deafness to produce distinct barriers and challenges. There was also a perception that more deaf people should be accessing emotional well-being services but were not due to communication barriers.

The views of deaf children and parents of deaf children have shaped the recommendations which are set out below. At the time of writing, it is clear that there is preference across the board for emotional well-being services, including CAMHS, that are deaf specific and grounded in clear deaf awareness and expertise. Parent experiences would suggest that they would 'trust', feel reassured and understood by a deaf specific CAMHS services while deaf children have indicated they would be more likely to engage in services that are tailored to their support needs and explicitly recognise that they are not simply a 'child' but a 'deaf child'.

Consideration must also be given to early intervention services that are also deaf specific and that provide opportunities for deaf children to interact, learn from, and support each other. The services provided by Action Deaf Youth for deaf children is an example of best practice

that both deaf children and parents of deaf children have highlighted. The benefits of deaf specific play therapy provided by Action Deaf Youth cannot be understated – these are to be found not just in the play therapy element of the provision but the combination of this with deaf specific knowledge and expertise.

6.2 Recommendations

Based on the findings from this study the following recommendations are made:

Data collection and monitoring

1. The higher prevalence of mental health issues among deaf children compared to hearing children point to the need for a Northern Ireland wide deaf specific CAMHS service.
2. Further rollouts of the NI Youth Wellbeing survey could include a larger representative sample of deaf children to determine the robustness of the survey.
3. The sub-sample of deaf children from future iterations of the NI Youth Wellbeing survey could be analysed, allowing comparisons to be made on an ongoing basis.
4. A more targeted survey could be developed, building on the main variables in the NI Youth Wellbeing survey, to include larger sample size of deaf children and questions on areas previously found to affect emotional well-being among deaf children such as language and communication ability, presence of compounding additional disabilities, type of school attended, gender, age, use of hearing and other aids, and degree of hearing loss.
5. Any survey should be co-designed with deaf children.
6. Data on referral of deaf children across Trusts should be systematically collected and monitored in a way that allows for cross NI comparison. This could take the form of recording whether or not a child has a disability, including hearing loss, on an initial referral form. Monitoring of NI wide data could be undertaken by a centralised deaf CAMHS service.

Peer Support

7. Provision of one-to-one support and peer support/networks to promote positive emotional well-being and to support deaf children experiencing difficulties. Connecting with deaf peers could provide deaf children with a sense of community and of being understood,

particularly for those children attending mainstream school with little or no contact with deaf peers.

Emotional Well-Being Programme

8. While services targeted at deaf children already exist, there could be more service provision explicitly focused on emotional well-being. This could take the form of an emotional well-being programme designed specifically for deaf children that is age appropriate and accessible. Such a programme could include confidence building, techniques and tips to address or reduce deaf specific anxiety around communication issues, developing the self-confidence and skills to make others aware when they are not communicating properly or when they are misusing equipment, how to deal with listening fatigue or sensory overload, and support to express feelings. Any such programme should be co-designed with deaf children themselves.
9. The transition of deaf children to primary, post-primary and post-16 provision are critical juncture points impacting on a child's emotional well-being. Deaf children are likely to have additional or heightened concerns and anxieties. Tailored support and/or resources could be provided at these key points for deaf children and their families as a form of early intervention.

Accessibility of existing information and supports

10. An audit of emotional wellbeing helplines and resources (e.g online resources or videos) that are for children and young people to help identify and address any accessibility issues. Consideration should be given to piloting an accessible online helpline service with and for deaf children.
11. Deaf specific information about accessible and age appropriate well-being supports should be provided to all deaf children – in a single source if possible (for example, a Directory of Well-Being Supports and Services). This should be available in both written and BSL/ISL formats. Deaf specific information (e.g. short online videos) could be provided on topics such as anxiety, self-esteem, depression etc. These should reflect the lived experiences of deaf children.
12. Information about available deaf specific supports and/or other accessible and age appropriate supports should be provided to all families of deaf children.
13. Information should be provided to parents on the emotional wellbeing issues that can impact on deaf children.

14. Particular consideration should be given to deaf children and their families living in rural areas.

Early Intervention and Best Practice

15. As noted above, there is a need for deaf specific services to support the emotional well-being of deaf children in terms of early intervention. The existing Play Therapy service provided by Action Deaf Youth is a best practice example of early intervention provision. It is critical that the service continues to be funded and offered to deaf children who would potentially benefit from it. This is clearly a service for which long term funding is required and opportunities for further possible development explored.
16. Families of deaf children should be made aware of the service and how referrals can be made.
17. Strong links should be made between a deaf specific CAMHS service and deaf specific early intervention programmes.

Deaf Specific CAMHS

18. The findings from this study suggest that there is a strong case to be made for a deaf specific CAMHS service to address the intersectionality between mental health support required by a deaf child because of their age and the mental health support required because of deafness. Across the interviews, deaf children and parents of deaf children stated that they would prefer a deaf specific CAMHS service rather than a generic CAMHS service. Indeed, interview participants indicated they would be more likely to engage with the former due to the specialist nature of the service and the desire for a service with indepth knowledge of deaf issues, deaf culture and accessible communication.
19. Professionals engaged in care of deaf children's emotional well-being should have indepth deaf awareness and experience of working with deaf children and their families. Ideally one or more professional within the service should be able to communicate in sign language.
20. The deaf specific CAMHS team could include appropriately qualified deaf people in a variety of roles. For example, a deaf CAMHS outreach officer could work with local organisations and teachers of the deaf to promote positive emotional well-being and/or develop deaf specific and age appropriate emotional well-being resources.
21. Support and funding could be provided for deaf people to become counsellors over time.

22. Information about deaf specific CAMHS should be provided to all families of deaf children and related organisations so they are aware of the existence of such a service.
23. A deaf specific CAMHS service should be deaf-friendly in terms of the environment, space, lighting, seating and acoustics. It should be a safe and neutral space.
24. A deaf specific CAMHS service could provide additional information and/or supports/signposting for parents and siblings of deaf children who may also be impacted.

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Appendices

Appendix 1: Service Provision Information Form for each Trust Area



**QUEEN'S
UNIVERSITY
BELFAST**

**CENTRE FOR
CHILDREN'S
RIGHTS**

Service Provision Information Collation Form

The Emotional Wellbeing of Deaf Children and Young People

Queen's University Belfast has been commissioned by the Northern Health and Social Care Trust to conduct a service evaluation relating to the emotional wellbeing of deaf children and young people across Northern Ireland. As part of this we are asking each Health and Social Care Trust to complete a 'Service Provision Information Collation Form'. This will allow the project team to map the availability of existing services and support for young deaf people across Northern Ireland. It will also provide an idea of the kind of data that is being collected on this population group in relation to their well-being.

The form will take around 20-30 minutes to complete. The information you provide will be confidential and the name of your organisation will not be included in the project report.

We would be grateful if you could complete and return this form to Dr Bronagh Byrne – 3044618@qub.net.uk by Monday 10 May 2021

If you are not currently in contact with any young people with hearing loss, or do not currently offer a service, we would appreciate if you could answer as many questions as you are able to and return the form to us. This will help us identify any difficulties that organisations may face.

1. Which HSCT are you based in?

2. What services do you offer to support the emotional well-being of children and young people generally in your Trust area (e.g. CAMHS)

3. What age range do these services cater for?
4. What geographical area do these services cater for?
5. To what extent are these services accessible to deaf children or young people? Please give examples.
6. Have these services received referrals on behalf of deaf children and young people?
7. If Yes, how many deaf children and young people have engaged with this service over the last year?
8. Has this number increased or decreased in the last five years? Please provide numbers if possible.
9. If yes, why do you think this is?
10. If possible, please provide a breakdown by communication type/level of hearing loss and age
11. Do you provide any specific services to support the emotional wellbeing of deaf children and young people? If yes, please tell us about this service(s)

12. If Yes, how many deaf children and young people have engaged with this service over the last year?

13. Has this number increased or decreased in the last five years? Please provide numbers if possible.

14. If yes, why do you think this is?

15. If possible, please provide a breakdown of by communication type/level of hearing loss

HEARING LOSS	NUMBER
Mild	
Moderate	
Severe	
Profound	
Don't know	

COMMUNICATION TYPE	NUMBER
Sign language	
Oral	
Mixed	
Don't know	

16. If you do not currently work with any deaf children or young people, why do you think this is the case?

17. Do you currently work with any young people who have a cochlear implant? If so, how many?

18. Have you and/or your staff had any training on working with deaf children and young people with hearing loss? Please provide details

19. Do you feel you and/or your staff have any additional training needs for working with deaf children and young people
20. What, in your experience, are the key challenges for deaf children and young people seeking to access support for their emotional wellbeing in your Trust area?
21. Do you perceive there to be any gaps in provision regarding support for deaf children and young people in relation to their emotional well-being? – if so, please provide details
22. Are there any examples of best practice you would like to share?

Data

23. Do you routinely collect data on deaf children and young people and their well-being in your Trust area?
24. Please tell us what types of data you collect in the box below
25. To what extent is this data disaggregated (i.e. able to see data about individual young people rather than total combined numbers from your practice)?
27. How is this data recorded (i.e. entered into a computer, photocopied uploads, handwritten files?)

Thank you for taking the time to complete this form. Please return to Dr Bronagh Byrne at
3044618@qub.net.uk

Appendix 2: How deafness or hearing loss was identified by age group in the Northern Ireland Youth Wellbeing Study

The Northern Ireland Youth Wellbeing Study had multiple questionnaires based on age of the child and if it was being filled out by the child or the guardian. The following table provides the questions used to determine if a child or youth was deaf or had hearing loss for each version of the questionnaire.

Type of Questionnaire	Questions Identifying Hearing Status
Completed by parent/carer about child	<p>Age 2-10: The following statements describe possible problems that your child may have. Read each statement carefully and tick the items, if any, that describe your child. Tick all that apply</p> <p>1. Hearing problems 9. Seems to have trouble hearing</p> <p>Age 2-10: B36 Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behaviour a few times, but he or she does not usually do it, then please answer no. Please tick yes or no for every question.</p> <p>2. Have you ever wondered if your child might be deaf?</p> <p>Age 2-15: B51 Here is another list of health problems or conditions which some children or young people may have. Please can you tick below whether your child has...</p> <p>Tick all that apply</p> <p>12. Hearing problems</p> <p>Age 2-15: B53 What are these other health problems? (open text)</p>

Type of Questionnaire	Questions Identifying Hearing Status
Self-completed by child/youth	<p>Age 11-15: C40 Do any of these conditions or illnesses affect you in any of the following areas? Tick all that apply</p> <p>2. Hearing (for example deafness or partial hearing)</p> <p>Age 16-19 B4 Here is another list of health problems or conditions which some children or young people may have. Please can you tell me whether you have... Tick all that apply</p> <p>12. Hearing problems</p> <p>Age 16-19: C40 Do you have any physical or mental health conditions or illnesses lasting or expected to last for 12 months or more? Y/N</p> <p>The purpose of this question is to establish the type of impairment(s) you experience currently as a result of your health condition or illness. In answer to this question, you should consider whether you are affected in any of these areas whilst receiving any treatment or medication or using devices to help you such as a hearing aid for example.</p> <p>C41 Do any of these conditions or illnesses affect you in any of the following areas?</p> <p>Select all that apply</p> <p>2. Hearing (for example deafness or partial hearing)</p>

Type of Questionnaire	Questions Identifying Hearing Status

Appendix 3: Operationalization of psychological conditions reported in section 2.3 Table 3

The Northern Ireland Youth Wellbeing Study project team provided the following description on how they measured psychological condition. Although the NI Youth Wellbeing project team provided most of the description, we included some minor additions for clarification purposes.

Most common mental health problems can be classified as mood or anxiety disorders. Mood disorders are characterised primarily by low mood (feeling sad or empty) or diminished interest and pleasure in normal activities or hobbies. Often other symptoms occur such as difficulty concentrating, feelings of worthlessness, feeling guilty, hopelessness, disturbed sleep, fatigue, and thoughts of death or suicide. Anxiety disorders are characterised primarily by feeling nervous, apprehensive, and excessive worry and these are often accompanied by feelings of restlessness, irritability, and a sense of foreboding. The mood and anxiety disorders that were assessed in this study were major depressive disorder, separation anxiety disorder, social phobia, generalized anxiety disorder, panic disorder, and obsessive compulsive disorder. The *Revised Children's Anxiety and Depression Scale (RCADS: Chorpita, Yim, Moffitt, Umemoto, & Francis, 2000)* was used to assess these disorders. The RCADS is a 47-item questionnaire, that can be self- or parent completed, and produces indications of clinically relevant levels of severity of the six disorders derived from the diagnostic criteria of the DSM-IV (American psychiatric Association, 2000). Children were categorised as having the psychological condition if they meet the clinical threshold on the number of reported RCADS items specific to each condition. The items and scoring are age-adjusted and standardised. The scale has shown good internal consistency, reliability, and validity (see Child Outcomes Research Consortium <https://www.corc.uk.net/outcome-experience-measures/revised-childrens-anxiety-and-depression-scale-and-subscales/>). The scale was originally designed for self-completion of children 8 -18 years old but there is a version to be filled out by parents for younger children. This parental version was designed for children age 4 years and older, however the Northern Ireland Youth Wellbeing Study made the decision to include children 2-3 in the analysis.

A description of these different disorders, and how the RCADS measures them, is presented in below.

Description and Sample Items for RCADS Disorders.

Disorder	
Description	Example RCADS Items
Major depressive Disorder	
Depressed mood and/or loss of interest or pleasure in life activities and symptoms that cause clinically significant impairment in social, work, or other important areas of functioning almost every day	<ul style="list-style-type: none"> • Has no energy for things • Feels sad or empty • Feels worthless • Feels nothing is much fun anymore
Separation anxiety disorder	
Developmentally inappropriate and excessive anxiety concerning separation from home or from those to whom the individual is attached.	<ul style="list-style-type: none"> • Scared to sleep alone • Fears being away from parents • Scared to sleep away from home • Fears being alone at home
Social phobia Disorder	
A marked and persistent fear of one or more social or performance situations in which the person is exposed to unfamiliar people or to possible scrutiny by others. The individual fears that he or she will act in a way that will be humiliating or embarrassing.	<ul style="list-style-type: none"> • Afraid of looking foolish in front of people • Worries might look foolish • Worries what others think • Afraid to talk in front of class
Generalized anxiety disorder	
Excessive anxiety and worry (apprehensive expectation), occurring more days than not for at least 6 months, about a number of events or activities.	<ul style="list-style-type: none"> • Worries something bad will happen • Thinks about death • Worries something awful will happen to family • Worries about things
Panic disorder	
Experience of panic attacks (discrete period of intense fear or discomfort which develops abruptly) and a concern about additional attacks, along with worry about the implications of the attack or its consequences.	<ul style="list-style-type: none"> • Heart suddenly beats too quickly for no reason • Suddenly trembles or shakes for no reason • Suddenly feels really scared for no reason • Suddenly has trouble breathing for no reason
Obsessive compulsive disorder	
Recurrent and persistent thoughts, impulses, or images that are experienced, at some time during the disturbance, as intrusive and inappropriate and that cause marked anxiety or distress.	<ul style="list-style-type: none"> • Has to do things over and over again • Has to do things just right to stop bad events • Keeps checking if things done right • Has to think special thoughts to stop bad events

Disorder
