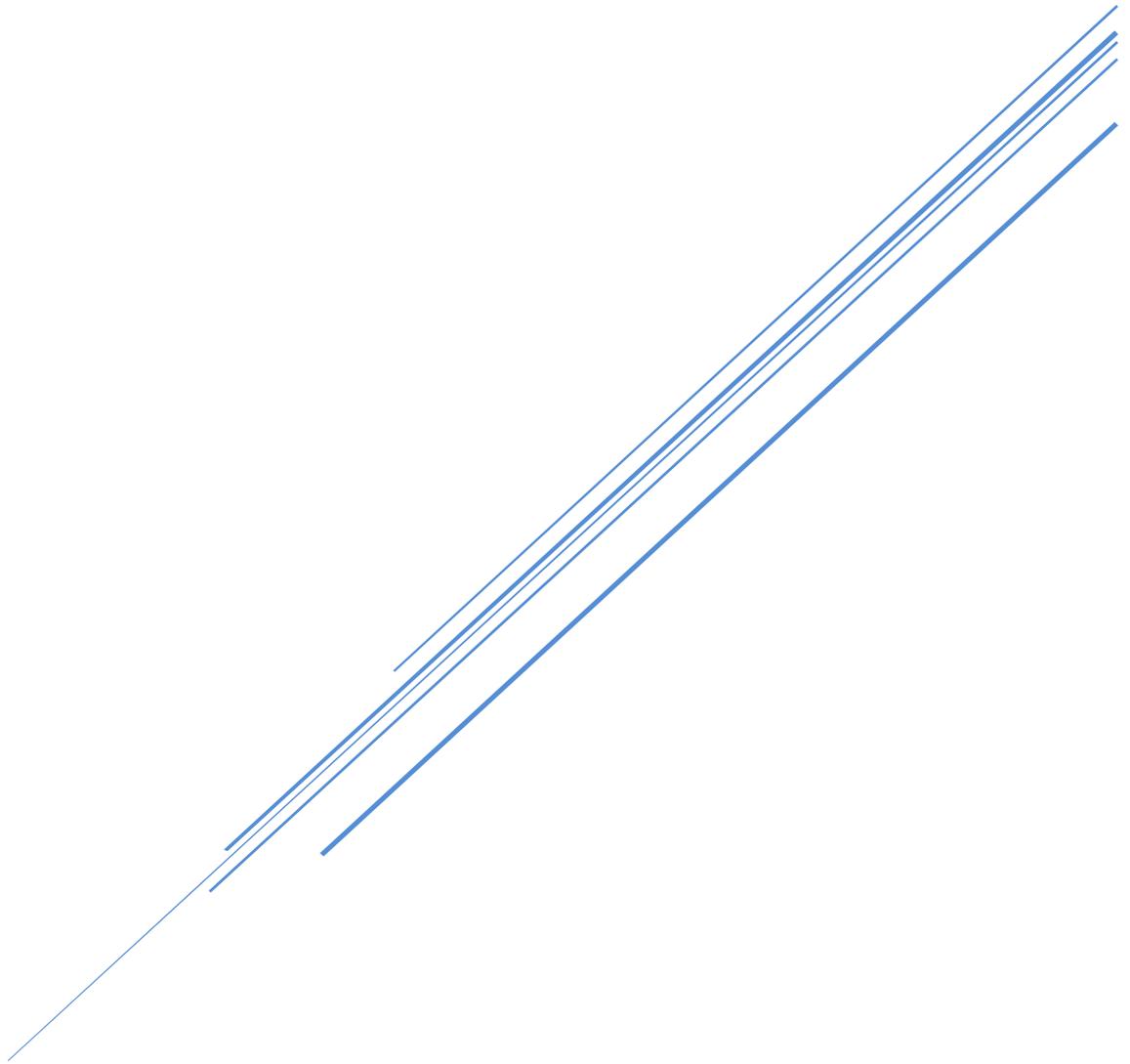# BETWEEN WORLDS

An investigation of the complex effects of acquired hearing loss based on first hand experiences from within

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Index:

A) Preliminaries

1. Introduction

People who lose the ability to hear often describe their situation as being 'between worlds'. In this study I intend to investigate that statement further by researching and evaluating the effects of acquired hearing loss in patients with Neurofibromatosis Type 2 (NF2). Most people affected by NF2 lose their ability to hear, this usually happens sometime during or after puberty.

This feeling of 'being between worlds' sums up all kinds of issues deafened people have to deal with such as identity doubts, psychological issues, linguistic challenges, but above all, the social and communicative challenges that hearing loss brings. Without giving away too much, we will see that many of those affected believe exchanging experience and feelings with other deafened people is a vital part of their lives, if not at the core. Based on first hand experiences by the participants I seek to evaluate these effects of acquired hearing loss and perhaps provide an educational piece that raises awarenes.

2. Goals & Objectives

I do not seek to draw conclusions or give judgements of the effects of hearing loss. Instead, respecting the many different ways of which people choose to cope – or struggle with coping, focus is on giving people a voice themselves and see whether there is a common, purely objective 'bigger picture' based on the findings.

My intention was to get an equal amount of participants from all the three countries of Great Britain, the United States of America and Germany and to see whether the replies match to some extent. Given the many replies this means that my research is quantitative, but also qualitative in terms of opportunities for the participants to express their experiences and opinions. This is also encouraged due to the format of the questionnaire with its division into subcategories and its many open questions.

I have however also identified some possible blemishes in my research. Firstly, the questionnaire can be seen as a set of pre-chosen questions where there could be many more. This means that perhaps the findings give a slightly biased picture. This may also result in my very own position from within the community; however, it can

also be argued that this puts me in a very empowering position by knowing what is most relevant to ask. In either case the reader shall be reminded that none of the findings are my judgements but that they are based on what the participants had to say. Furthermore many questions are dependent on the situational circumstances because "there seems to be no hard-and fast way of doing things applicable to all situations" (The LINK Centre for Deafened people, 2005). I would like to add that the questionnaire is very long, emotionally challenging and thought-provoking.

3. Methodology

Many NF2 patients feel most confident in reading written words due to their communicative challenges with hearing loss. Moreover, geographical spread and limitations had to be considered. For these reasons, the core method of data collection was chosen to be via questionnaires. I created one as a fillable PDF file which I then distributed through various channels and websites. My scope were the three NF2 communities in Great Britain, America and Germany with one participant from Australia. As for the structure of the questionnaire I decided to subdivide my questions into six categories centralising a certain subject area to set the background of my questions. To assist with analysis some questions were in multiple choice format or based on grading systems. Since my aim was to let participants set the tone all of the questions allowed room for further comments and expression. Interestingly throughout analysis it became obvious that there are no clear patterns based on geographic location, much more it was the overall experience which provided patterns regardless of the 'whereabouts'.

Since it is an international project the questionnaires were designed in English. As a number of answers are from the German self-help group, the questionnaire was also translated from English to German.

Due to being a data-driven ethnographic research, the replies from the questionnaire act as my primary source. However, secondary literature has also been used to link and match my findings with those stated elsewhere.

B) Analysis and evaluation of findings

A key decision included the focus of the target group: In the questionnaire and in my outreach to the communities it was clearly stated that only people with five or more years of experience of complete acquired hearing loss could take part. Since hearing loss is a broad term those who still have useful hearing were denied to participate. People who were unsure whether they were eligible or not were invited to read the questions and see whether they were of relevance to them. For some they were not, so this measure resulted in a tighter concentration of the target group. Basic information about the participants can be found at the beginning of appendix 1. Throughout the next paragraphs I will make frequent reference to the detailed findings in appendix 1 which I suggest to consul when mentioned.

The deafened person's own attitudes and those of others

To begin with the subjects were asked if they feel more comfortable with their hearing loss now compared to when it started and how this changed.
The responses varied deeply, from 'not at all' to 'absolutely', with many different perspectives on the actual loss, from feelings of being freed to "like feeling in a plexiglas tube" and loss of hearing over night. However most participants didn't seem to feel "comfortable with it", as asked in the question. Instead, many emphasized the difference between "comfortable with it" and "now used to it" like this participant: "it took a long while before I became "comfortable" as such, if that's the right word? I would describe it as 'able to cope', rather than comfortable, particularly in the first few years." Some mentioned that becoming totally deaf was a sort of 'liberation', as a participant explains: "Although being totally deafened is very difficult at times I find it 'easier' than being hard of hearing as I can only lip-read or follow written/typed words. I no longer have to struggle to 'hear'".

The many different responses reveal a little about people's attitudes towards their acquired deafness, with most learning to cope with it: "I think I realised that I was stuck with being deaf so had better make the best of it". Not many addressed the question how this changed over time, perhaps because it did not change or was kind of incorporated into their whole answer. One participant said though that "the only way this has changed is that now I am used to being left out. " Overall there seems

to be a great acceptance of their fate: "Now, maybe the way I'm most comfortable thinking of my deafness is that it is simply a part of the whole me, like my height and weight and eye colour."

When asked if due to the hearing loss they had to give up their dreams and aspirations again this question spanned from "no, I am living my dreams" to "absolutely" and showed very mixed and diverse answers. Almost half report lost jobs or buried dreams. One participant said "oh of course – without doubt, I see my hearing sister, hearing kids being successful and often think where I would be if I wasn't deaf." Indeed, Richberg and Botnik in Jones also concluded in their research "that one could no longer become what one once wanted to become. (Lesley Jones, 1987)

Still though, the very phrase of "did not give up" was mentioned often; those replied they altered their career, or went a different route than intended, like a participant who had studied for a music degree with aspirations to work in the music industry and now volunteers at doing music therapy with children. Most said though that their hearing loss influenced their career path. If anything, it can be seen that giving up dreams and aspirations is hugely dependent on perspective/attitude and also especially the individual's dreams and aspirations themselves.

This brings us then to the interesting question how people perceive themselves and how they think their personality has changed, if it has at all. Participants were invited to make a list from their own observations and of those who are close to them. Some reported no changes in personality, some said "personality changes are normal over time" and many were unsure whether the hearing loss influenced their personality at all. Some went into detail of changes they and others observed and picked out a particular situation. Still two patterns seem to emerge in quite a number: The first is a kind of withdrawal and loss of self-confidence or self-consciousness or to explain in a participants observations: "I went through a period of total isolation and withdrawal from all group situations even though my natural personality is very outgoing. Whilst I have overcome this now to a certain degree I am aware I am not as outgoing as I would be if I did not have a hearing loss" or "I also was an extrovert and extremely friendly. Now you don't strike up a conversation because you know you won't be able to understand the answer". Interestingly, quite the opposite seems

to also have taken place in a few, meaning from being a more shy and quiet person, becoming a more confident one, perhaps because of the direct communicative effects of hearing loss: "Before deafness I was a very shy and quiet person. This had to change in order for me to understand what was happening. I am now much more confident and controlling due to a need to know what's going on." Indeed Orlans also reports this pattern which goes both ways: "either (1) to increase control (for example an introvert can become extrovert to try to dominate interaction) or (2) to withdraw from situations that threaten independence and control" (Orlans, 1985)

Despite the very tentative pattern I have seen, I find deriving a conclusion from the data very daring - even more so in respect of the various degrees of hearing loss and many other factors, like preparedness to speak about one's own personality. For those reasons I invite the reader to look at the detailed findings in the appendix and make his/her own assumptions. (Appendix 1: Q3)

Moving on to attitudes of others, focus was now on the behaviour of the immediate family. When asked how core family reacted to the hearing loss almost 60% answered that they stood by them which makes up for almost two thirds. Still though a handful answered that only a few stood by them and 30% answered that most core family did. 8% replied that most had turned away, 24% said a few still did and 54% reported no experience of withdrawal by family members. When asked how many of the core family learned strategies for communication it must be noted that this hugely depends on the degree of hearing loss, the attitude of the affected and how important they view developing strategies. As will be seen in later questions, chosen methods for communication vary. 19% answered that the whole core family learned strategies for communication, 22% said most did, 19% said a few did and 11% said none did. Since core family mostly are known for years, the ability to lip-read them becomes much easier so that many do not find it necessary for them to learn for example sign language or other than the basic methods of speaking slowly and clearly. So, leaving many variables for interpretation, findings on this question must not be too heavily valued.

When asked about other reactions experienced by family members once again they vary hugely and they may not be a matter of fact but simply an interpretation of the affected individual; From fear of the family member of being affected themselves and thus avoiding a sibling, over "people think I am retarded" to changes in a role of family member: "I have changed from being as the oldest, a leader in my family whose opinions carried weight. Today I am ignored or 'cared for' and never asked for my opinion, seldom made aware of decisions that are made." or "I am definitely treated as a person with lower intellect than I had". Again though a pattern can be seen for many: That of sadness with core family and its helplessness, insecurity how to deal with the situation although many participants also seem to have chosen to not comment on anything perhaps suggesting that adjustments have been made over time or not, or possibly that it is a topic too emotionally challenging to talk about. (Appendix 1: Q4)

Extending the circle to relatives and friends then a similar question was asked. While again two thirds said they experienced loyalty from their friends, an equal number said that still a few decided to turn away. None of the participants ticked 'all' when asked if relatives and friends learned strategies for communication. 30% said that most did while the biggest number of 46% said 'a few' and still 24% said that no friends and relatives decided to learn any.

Conclusions drawn from here can only be speculative. However I think most would agree that it takes much effort for the deafened individual to make friends and relatives aware of their communicative needs and especially the need for developing strategies. Firstly deafened individuals need to adjust themselves and then comes core family - where already it can be seen that not all are prepared to learn anything. Again it must be noted though that 'learning strategies' is hugely dependent on a number of factors, however, this may explain why nobody ticked 'all'. When asked why they think that is (that relatives and friends decided to learn/not learn communicative strategies) this question was rather speculative and it was open to the participants on which aspect to focus. Many decided to focus on the 'stood by' part and others on the section about learning strategies where I was provided with interpretations on why relatives and friends did/did not learn any. As the replies show

there is a more even response between 'turned away' and 'stood by me' than with core family. Various explanations were given for the large proportion of withdrawal of 'friends', for example "they weren't (true) friends" or "I don't think they knew how to react so they withdrew". (Appendix 1: Q5)

When asked about strangers reactions there was a large proportion who ticked each of the suggestions with a rate of agreement between 60% and 84% for each suggested answer. (Appendix 1: Q6)

Many of those asked used the chance to say something in the 'other reactions' box where on the other hand many report of great efforts by strangers to make the communication work: "Some are very caring with my situation, try to integrate me into what's happening, search for strategies themselves in order to improve the communication".

The picture drawn becomes quite clear: Many people do not know how to treat a hearing impaired person, let alone a late deafened one. This seems quite logical many will not have come across a hearing impaired person and if so probably someone who was hard of hearing or a person deaf from birth. Many of the deafened have thus adopted the strategy to tell people what they need them to do. Unfortunately, like a participant says "some turn away if it doesn't go the way they are used to it" but most realised that the key to solving this problem lies within themselves; by building the larger part of the bridge as German counsellor Jochen Müller (Müller) suggests and helping those out who have no idea what to do and how to do it: "I find that most people are generally helpful but you need to 'break the ice' and tell them what to do!"

Of course these experiences can be emotionally distressing. 57% said these reactions are frustrating, 51% say they feel isolated about the kind of behaviour mostly displayed by the public, and 35% are too tired to explain their needs over and over again and 30% get angry and don't feel inclined to make effort or feel like a burden. This question allowed for mutiple ticks revealing that at least 39% can identify with at least one of these feelings.

Feelings are feelings and not necessarily negative unless decided to look at them this way. Thus, besides some other examples such as "disappointment", "feel like a spectacle", "bored", "less than equal", "helplessness", "embarrassment" or "lack of

independence" many stress the positivity and in turn say things like "I am pleased and surprised when someone makes a positive effort" or "if against all odds the communication works well, I'm happy". "As long as people accept you there is nothing to be unhappy about even if proper communication is not possible". One person said she "feels pity because they are so helpless" and another participant described his feeling like a useless fifth wheel when he cannot contribute his opinion into a group. This also confirms the public attitudes observed where "people often underestimate the serious effects and consequences of hearing loss" (The LINK Centre for Deafened people, 2005). One participant in particular had some very wise words: "I'm me and I have no reason to feel any of those. People's reactions have more to say about them than about me. […] If they choose to treat me otherwise, it's THEIR problem and loss." (Appendix 1: Q7)

Language, linguistic environment and communication

Next, participants were asked which strategies they use for communication as indeed "newly deafened people have to learn a set of communication skills." (The LINK Centre for Deafened people, 2005)
While sign language was the strategy chosen with the lowest numbers, still more than half use its help. The leading support most rely upon in communications seems to be lip-reading with 84%. The other suggested strategies such as speaking slowly, speaking clearly, finger spelling and letting people write down have a similar rate each of about 78 % agreement. (Appendix 1: Q8)
This question showed the varying strategies people use to aid communication. While some find combinations useful we can particularly see that it is dependent on the situation which will require a huge flexibility of the deafened person with preparedness to adopt to it: "I use the 'whatever works' method of communication." Other helpful strategies identified were positioning (i.e. not facing the light, sitting in corner, quiet place, etc.), social networking/technology, but especially focus on the facial expression and gesticulation of the communication partner. Several also said they are attentive and are proactive in making it work, for example by asking if not sure they understood or asking to rephrase.

On a scale from unimportant to very important people could rate the importance of the various communication methods. Already becoming obvious in the question above, participants said lip-reading was most important to them. Fingerspelling enjoyed an even density between important and very important mostly while sign language was still important or very important for a third for each option with 27% giving a neutral opinion, probably because sign was not known to them. (Appendix 1: Q9) Indeed, less than half said they had learned sign language, 35% said they only learned the basics while 22% didn't learn any sign at all.

Asking why participants chose to learn sign language or not revealed the dilemma many deafened individuals have to face when wanting to learn sign language. First of all, before willing to learn sign there needs to be a point of acceptance of one's own hearing loss. It also hugely depends on the degree of hearing loss whether or not there is the need to learn it. Moreover, there is also the factor of cost to be considered since in most countries the event of hearing loss does not automatically mean free access to a sign language course, so many would have to cover the costs involved themselves.

Linguistically, the term sign language actually describes two different sign languages: that of "full" sign language with its own features of a language, such as BSL (=British Sign Language) or DGS (=Deutsche Gebärdensprache). Ideally, deafened people would need to initially learn SSE (=Sign supported English) or LBG (=Lautsprachbegleitende Gebärden) which only use the signs of sign language but the grammar and word order of the spoken language of the wider linguistic community (e.g. English or German). The problem is these kind of courses are hardly offered, often resulting in a lack of motivation to learn the "full" sign language. All deafened people from the sample have spoken English (or German) as their first language, so having to learn a completely new language can be alienating. Thus, BSL, ASL or DGS being languages in their own right, like any language, learning them requires time and commitment and requires usage on a regular basis. Furthermore as Batia & Ritchie have observed "there is no language without the existence of a language community" (Batia & Ritchie, 2006)

For deafened people, problems arise: Since it is such a geographically spread group, there is no proper chance to practise the language and it is often left to the individual building such an environment. The timing here is of importance and also one's own attitude since learning sign properly would ideally also mean somewhat an immersion into Deaf culture, which we will see, hardly any deafened people can identify with. However the complications do not end here: Another important factor is that, while many still declare wanting to learn it in order to stay in touch with other hard of hearing or deafened people, signing is not primarily a necessity *for themselves* to speak, but it becomes one for friends and family to speak in order for the deafened individual to understand. However, in some families there is little realisation or need to learn it themselves. As a result of this sometime the deafened individual learns some sign language, but unused and not practised its knowledge withers. For individuals having no shared means of communication this as a result can have devastating psychological or emotional effects as we will see. There are a few though who stick with learning to sign and gladly rely on its benefits, building this needed community themselves by showing friends and family or by motivating them to learn. For many who learnt it to some degree it has become a relaxing method of interacting with one and another and they often see it as a sort of tool needed and therefore acquired with not as much attachment to the Deaf community "It (learning to sign) is the best choice I have made instead of sulking in sadness over the fact that I can no longer hear" where some have "come to appreciate the virtue of signing." (Orlans, 1985). Others say they had no other choice due to their chosen career paths, be it educational or work-related.

This introduces us into the complicated issue of learning sign language. Understandably, for many it becomes of no use and as seen it hugely depends on attitude and self-perspective along with the identity issues that acquired deafness brings. For others it has become a great enhancement of life quality. It is important to note here though, that while learning sign can be of utmost importance to an individual, it does not automatically count for everyone. Instead everyone must know for himself whether or not he wants/needs to learn it.

Similar to the question format above, I then asked about the deafened person's perception of importance of family and friends to learn sign language, fingerspelling and speaking slowly and clearly which almost all agreed with is of most importance.

As for fingerspelling, 40% said it is very important, 35% said it is important and 24 % gave a neutral answer. For Sign Language, only 8% said it's very important for friends and family to learn, 30% said it's important, 43% gave a neutral answer, 8% said there is a low importance and the same number said it is unimportant for them to learn. (Appendix: Q11) Asked about other strategies important for them to learn brought forth a number of ideas. However two were mentioned several times which is A) Patience and B) create awareness/tell them what to do and how.

The next question gave people the opportunity to rate the importance (1-4) of lip-reading, sign language, fingerspelling and chat/e-mail with stating that they could only assign one number per medium. It was very difficult to answer since as seen this is hugely dependent on the situation. What becomes clear though is the importance of written text: It gives people confidence because it is the medium in which everything said can be followed without effort. When asked to explain their chosen order many decided to pick up on that point, e.g. "text/chat/e-mail is a wonderful thing for deaf people – it puts us on an equal footing with the rest of the world" though some rightly raise concerns about the emotional aspect: "In terms of getting feelings across that's not so great, so then something more intimate like sign language I think is better". A person who decided lip-reading is the best for them explained: "Lip reading is the easiest form of communication as long as I know and am familiar with the person's speech patterns. For example, I can speech-read my parents and friends perfectly. If a stranger were to approach me, however, 9 times out of ten, I would be utterly lost." Although fingerspelling alone is often disregarded as only method of communication, people seem to be aware of its support: "fingerspelling helps when stuck with a word" or "fingerspelling is a great support to lip-reading, i.e. when people can spell the first letter of the word they are speaking". This mehod often helps to facilitate and accelerate communication. Sign language then came last for many: "sign language to me is like a foreign language". Stressing the dependence on situation and other factors though it was said that it "obviously hugely matters whom I communicate with" (Appendix 1: Q12)

For many deafened people the needs for good communication are similar. Yet, dependent on one's own needs though the answers varied. However the picture of this question, if put into a short guide, the ideal situation although of course adaptable by each individual would look like this for many:

- ➢ Good light, deafened person not facing it
- ➢ Slowly and clearly speaking communication partner
- ➢ no groups or only small ones, if several people take turns, have discipline
- ➢ include deafened person in conversation if more than one
- ➢ Looking at the deafened person when speaking
- ➢ No facial hair, no covering face
- ➢ Awareness of the other, meaning being patient, tell the subject, awareness of the environment and needs of the hearing impaired person
- ➢ recognise the situations where lip-reading is impossible
- ➢ Stress-free, quiet, unhectic situation

Social Environment

In this area I began by asking subjects how their social environment has/had changed since they lost their hearing. The question allowed for a wide interpretation of the term 'social environment' thus answers varied greatly. There seems to be an even distribution between those who say their social environment has not changed, or who deny that it has anything to do with the hearing loss but other factors, for example time. Others reported a drastic change, e.g. one participant said: "My involvement with other late deaf people makes it clear that I am not alone in having pre-deafness friends and post-deafness friends that are largely different folks." Not many mentioned this though and again, attitude seems to play an important role. This results in partial withdrawal of, for example, going to the pub, dinner parties or clubbing and instead identifying the most comfortable social situations. For many this is a one-on-one interaction, rather than group gatherings (except with other deafened people).

For the next question some conceptual facts need to be explained here first in order to understand. Having never experienced hearing sensation prelingual Deaf people tend to have their own culture in which they grow into deeply based on sign language which is their mother's tongue. The deafened differ from this community in the respect that they were once able to hear and thus brought up orally through 'hearing' culture. For them the perception of hearing loss is often a different one than to the Deaf even though biologically it seems as if both are living the same thing.

They are not though and this may explain why many Deaf and deafened do not blend in with each other much, although the 32% who answered they indeed have Deaf friends also show the opposite is also true. So when asked to explain why they do or do not, besides the dilemma explained above, the tone of these answers is fairly unison and goes into two directions. Firstly it points to the cultural differences between the Deaf and deafened which is often stated as main reason for not mixing much socially with the Deaf.

Another major factor is once again that of geographical limitations where people explain for example: "I just haven't come across any [Deaf people]"

What the findings show us is that "Such 'deafened' people are in a totally different situation from those born deaf or who become deaf very early in childhood. Around 70,000 people in the UK grow up with deafness as a part of their lives. Deaf people are usually educated at schools or units in schools geared to their needs; they have deaf friends and peers and are part of a strong, recognisable community with their own language (signing) and culture. Deaf people, who have not incurred a sudden 'loss' in adult life, do not experience the adjustment issues faced by deafened people. (The LINK Centre for Deafened people, 2005)

Then I wanted to know what an ideal social environment for them would look like. Varying answers were expected and their distribution can be seen nicely with many stating that a mixture of the options given would be good for them. Answers show that sign language being spoken often does not constitute to that 'ideal social situation'. Other comments addressed for example that an ideal scenario would be where there are "hearing people who are proactive with communication" and "who understand my difficulties and particular challenges, who realise I do not always pick up immediately on things". (Appendix: Q16)

Participants were then asked when and how often they encounter their 'ideal social environment' and although there were some people who seem to have built their social lives pulsating around their ideal environment, e.g. "I encounter this environment daily and it makes me feel 'normal', when I manage and don't have to tell people about my deafness." most replied though that much too less they experience this 'ideal social environment', and the tone of answers suggest a longing for it: "It's rare to encounter such an environment. But when I do, I feel included."

"Maybe 2 or 3 times a year […] I am at my most happiest in this ideal environment - I am not alone."

Participants were then asked whether they make much of an effort to get to know strangers who don't know of the communicative needs of the deafened person on a scale from 'never' to 'always'. With most stating they do occasionally, a third chooses to 'rarely' and no single deafened individual ticked 'always' and one even 'never'. (Appendix: Q17)

So while for many hearing people this may not seem an issue, not needed to be thought about and encounters with strangers are a normal everyday situation, for most deafened people these encounters often have a different weight. Many times, depending on the deafened person's strategy and situational circumstances at some point in a conversation with a stranger the deafness is exposed. It is interesting then to see the different attitudes deafened people adopt, ranging from withdrawal to proactive methods, for example spreading deaf awareness. The hidden lives study states that "Faced with these obstacles every time the deafened person goes out, it is not surprising that many have given up trying to educate others about the use of appropriate communication tactics, and some avoid meeting new people altogether." (LINK centre for Deafened People, 2007). If you take for example a supermarket or other seemingly straightforward situations there is often no need to explain the hearing loss and many chose not to say anything. Simple questions such as "would you like a bag?" can be guessed, 'overheard' or indeed end in frustration. In public then we can understand how deafened people often describe their feeling as 'living in a vacuum'. "What often emerges is a story of frustration, anger and emotional stress that leaves many of the hearing-impaired with an intense feeling that very few hearing people understand their experience." (Lesley Jones, 1987). Approaches to strangers then and the individual's decision how to deal with these become much of a core experience of acquired hearing loss and further to the previous question I asked how people chose to react. Since replies vary I do not want to pick out just one or two and leave others unheard so I here present a few views expressed:

> ➤ I weigh whether or not the effort will be worth it. I decide if the person is just a brief encounter or if the person has the potential to be a friend.

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- ➤ If I want to have any semblance of a good time, I would need to step outside of my comfort zone and approach people who may or may not be understanding of my communicative needs.
- ➤ I think it is important to try to encourage others to see that we are not so different from them.
- ➤ It takes too much effort
- ➤ I find it exciting getting to know new people. Communicative needs can then be learned quite quickly.
- ➤ We are able to educate them and once they understand, usually they are prepared to make an effort. If not, I keep a distance.
- ➤ As a deafened person I have got to know more people than before as a hearing person.
- ➤ Whoever greets me with openness, in return receives openness from me.

If anything, what some of the answers show is the degree of control some chose to exercise not only in terms of communication, but also with regards to social relationships, even with strangers. Orlans observed that "one social technique of some deafened people is to monopolise or dominate conversation to reduce the need to understand other speakers. (Orlans, 1985)

Taken further, participants were asked how their motivation/effort changes when strangers do indeed make an effort to meet the communicative needs. Many replies show how even only a tiny bit of empathy by the other party means a lot emotionally and shows how this often gives the deafened individual a boost of confidence. "I wake up, that's how it feels, I become more enthusiastic and full of life." Or "If I am successfully able to hold a conversation with a stranger, I immediately afterwards feel gratified and triumphant. Many hearing people will take that for granted, but for a deaf person, or a hard of hearing person, taking the initiative to step outside of their comfort zone to approach a stranger with no knowledge of any communication needs feels like winning a marathon."

The deafened community

The next area was specifically designed for those who had experienced contact with other deafened people, the others were told to skip the area. Overall, 31 answered they had experienced it, which is 84% of the participants.

First asked was when they decided to get in touch with others in the same situation and what triggered them in the end to take that step. Although it is difficult to say what moved someone a set of answers emerges. Firstly those who mostly after going deaf sought contact with others initially through a variety of motivations, for example to obtain medical information such as on implant technology, curiosity or simply to share and learn about experiences of people in the same situation. Often this happened through a rehabilitation programme, either medical or run by an organisation or charity such as *Hearing Link* in the UK. A further UK community which concerns itself particularly with this, called 'Can you hear us?' is currently developing. The second set are those who first needed to go through a phase of acceptance before being ready to meet with other deafened people. A "trigger" expressed for example was „to end the feeling of isolation". Almost half answered that they didn't hesitate to make contact, while about a quarter answered they did. (Total of 29 replies). Asked about the reason for their hesitation of about ten answers the replies steered in a similar direction of feelings such as not being ready yet: "I needed to find myself as a deafened person first before I felt comfortable in my new world" or lack of acknowledgement of the situation, fear of the unknown, fear of rejection even to disbelief: "I wasn't prepared to accept that I would eventually go deaf". Of only 11 answers 6 said they did not regret they waited while 5 said they did.

The next few questions perhaps offered one of the most paramount findings of the whole project, for example when participants were asked if it changed something in them knowing others in the same situation. Of a total of 29 answers, only 7% said they did not benefit, 14% weren't sure and 83% said they found interaction with other deafened people beneficial. Asked about how it made them feel to come into contact with others for once a clear conclusion can be drawn: From the answers I cannot stress enough the importance of engaging with others in the same situation, as seen "once it emerges a sense of community with other deafened people can be

sustained by very little" (Orlans, 1985). Indeed, almost every answer agreed, stating in one way or another "not being alone anymore". Also common besides being able to share experiences, frustrations, strategies was the fact of mutual understanding: "The feeling of camaraderie and 'someone who understands' were huge". Unsurprisingly, 90% answered they had made friends from those encounters.

I then wanted to know whether their behaviour changes when among deafened people other than being around hearing/Deaf people and if so, why they think that is. Although a few people stated that they did not, the large majority mostly said the same thing: Since experiences particularly in terms of communication are shared among deafened people this takes away the pressure on both sides: "When around other deafened people I feel relaxed, and there is a sort of unspoken word, an internal understanding which feels like a relief, like I can breathe again. I find it strangely empowering and I usually leave the situation feeling happy." Communication may be a little slow, but there is a mutual understanding and patience. It hardly ever becomes an issue to talk about. As a result people become "more outgoing", their (self-)confidence is increased, and fear of being misunderstood or not understanding decreases, the whole situation becomes much more relaxed. And this already sums up why many deafened people enjoy the company of others in the same situation.

So what kind of treatment do people receive from the deafened community? Although many deafened people have had similar experiences, this does not necessarily mean all get on with each other perfectly. Deafened people, although sharing a common experience vary in their interests and so will personality, perceptions and opinions of things along with the degree of hearing loss, one's own attitude and the forms of communication (e.g. one feels most confident in sign language, the other in lip-reading).

In terms of communicative needs though, as just seen there seems to be a mutual understanding. For these reasons deafened people often treat each other respectfully. Above all though many deafened people tend to feel equal among each other and are "treated like a normal person". This is emphasized when asked how important the deafened community is, where almost two thirds stated that it is either important or very important to them. (Appendix 1: Q26)

Identity and psychological effects

In the next area participants when asked where they see themselves: Are they part of the hearing world, the Deaf one, both or neither or even something else? This was a difficult question to answer and it must be noted that some may not be aware of the Deaf world and its culture, due to never having chosen to venture inside it. Thus, the term "Deaf world" may sometimes have been thought of as "deafened" although as seen these are two very different concepts. However, as seen above a number have never even experienced the companionship of other deafened people. Attitude and self-perspective play a vital role too, so altogether drawing conclusions from the answers of this question seems highly ambiguous and I can only speculate. As stated above perhaps some understood the "Deaf world" as simply a world without hearing, not having the knowledge of the concept. This would explain the high number of people who ticked "both", while throughout the rest of the questionnaire it becomes clear that for many the "Deaf world" does not seem attractive. In retrospect this question perhaps should have provided more explanation and should have been asked in an alternative format. Still though it becomes clear from the answers that feelings of identity vary highly, In the 'Lost for words' study we can observe similar findings where "deafened people often themselves do not know they belong to a separate group" (LINK centre for Deafened People, 2007)

Asked if they were able to explain their decision many stated their feelings in a similar way: All had a hearing childhood, so have definitely had experience within the hearing world. Since going deaf some learn that there is the 'Deaf world', but largely due to cultural and linguistic differences it does not seem the right place either, unsurprisingly none expressed a Deaf identity. People frequently said things like "I often feel trapped between both worlds. I function as if I am in the hearing world but can't hear. And I can't sign fluently" or "I feel like an outsider looking in". Many answers of people stating "both" reveal as said above a misunderstanding of the concept of the 'Deaf world' when it comes to an explanation. This does not count for all though, some are well aware of these conceptual issues. This distribution with 32% deciding for "neither" shows a tendency goes towards being caught "between the stools" as Reverend George Firth already observed in 1966: "They fit in neither with the born-deaf nor with those hearing". (Firth, 1966)". (Appendix 1: Q27)

Asked about how they felt identity-wise when they deafened and how this has changed over time again the mere word of "identity" left lots of room for interpretation, thus answers vary and often elaborate either on the onset of deafness or on a largely individual narrative in terms of change in identity which makes analysis difficult. Many state their identity has not changed, some said it did like this participant "It took a really long time to feel comfortable in my own skin again. When I found myself 'between worlds' I didn't know who I should or could be. I now feel like myself again, just a little different with my form of communication". For some, changes in identity have been positive, for example leading a more intensive life after going deaf or put into the words of a participant: "I feel I have become much more of an identity since becoming deaf, a far more interesting and less shallow one."

Participants were then asked whether they could observe some kind of psychological processes after going deaf for which I gave some suggestions of phases and they were also invited to add their own. In addition to the suggestions of phases some mentioned a grieving process or a phase of isolation. Although of course highly dependent on the individual's path a pattern suggested by a participant resembles that of findings in literature: "1. Panicking 2. Retreating 3. Ignoring 4. Accepting 5. Developing strategies 6. Finally living again!" or summed up in a sentence: "Retreating whilst in denial of extent of deafness until after acceptance was the time for developing strategies." (Appendix: Q29) These findings confirm those identified by Becker:

1. Phase of 'not-wanting-it-to-be-true', shock
2. Phase of chaotic emotions: why me? Feelings of guilt, fear from life, fear of death, helplessness, despair, resignation, clarity over the mutilated body, sadness over the lost future
3. Phase of searching, finding and separating oneself, admitting loss towards oneself and those close.
4. New self-reflection and worldview, departing into life, finding a sense in it (Becker, 2003)

The time these phases occur seems to depend on the individual to a large extent, although Becker claims that "at some point every deafened person goes through a crisis of identity." (Becker, 2003)

Withdrawal often seemed to be initial: "withdrawal took place quite at the beginning of going deaf…just because I needed time for myself to accept and adjust first" Although sometimes assisted by an organisation or a self-help group it becomes clear that in the end every individual faces these phases by himself. Frequently participants mentioned an initial grieving process: "When I first lost my hearing, I grieved as I would as if I had lost a friend or a relative".

Answers to whether they feel isolated went into both directions with a slight majority saying they still feel isolated and many saying they do less now since they have become used to it. Many here state it is dependent on the situation and it seems to be an area where people make adjustments for themselves, e.g. by making use of developed strategies, so that the feeling of isolation is lessened. One participant explained it like this:

"I am more isolated, although not lonely. I need peace and quiet ...as having to make that constant effort is very tiring and often not enjoyable. But I have good friends who oversee my "isolation". But I do spend much more time on my own now." Almost two thirds have experienced depression or depressive episodes (Appendix 1: Q31). A slight majority of people have chosen to do counselling (Appendix 1: Q32) and most said it helped them but just as many said they were either not sure if it did or said they did not benefit from counselling. (Appendix 1: Q32.1) Findings elsewhere suggest that "Counselling can be extremely beneficial, especially in the early stages of adjusting to deafness, but few people obtain it – in part because there are so few professionals who are knowledgeable about acquired total deafness" (The LINK Centre for Deafened people, 2005)

Rounding off the section I asked how people feel psychologically now after all the years which displayed varying answers with some saying "still lonely, depressed, and isolated" or "I feel better, but still sad at times. Still feel like I'm on the sidelines of life". In many there seems to be a kind of compromise with themselves that life just isn't 100% anymore but there is acceptance of that: "I have learnt to cope, have

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learnt all the strategies and sometimes they work and other times they don't. I have accepted that, accepted who I am and accepted what I can't change". Life with its ups and downs seems to be a human consensus. For people who are deafened it can be argued that due to deafening they are psychologically even more prone to these changes and/or that they become intensified.

Overcoming, Coping

In this area the participants had the chance to reflect their overall way of coping with some suggestions of strategies which could be ticked, still allowing for a wide interpretation between them. (Appendix: Q34)

The varying answers again prove to what degree individual methods differ from another and how people chose their own way of coping rather than following a typical pattern. Indeed Stone in Jones found that "much depends upon how the stressor (hearing loss) is perceived and what the response to it is. When a major life crisis is seen as a challenge, coping is within reach. When the same life event is perceived as a blow, helplessness and depression negate effective coping." (Lesley Jones, 1987) Still, more than 80% chose to tick "learn lip-reading" or "learn about assistive technology available". Of the 31 who experienced the company of other deafened people, it cannot be said how many of those who did not take part in area 4 ticked the option "get in touch with other deafened people". Assuming not many of those did and thus a number around 31 to which this question was applicable amount to an assumed percentage of 90% who chose to tick the suggestion. This also underlines findings in area four, which is the importance of being around those in the same situation. About 68% gave the suggestion of learning sign language, while previously less than half stated they had learned it. This discrepancy proves the dilemma and inaccessibility to sign language mentioned before. This number show that there is indeed interest to learn it. While only 24% recommended the immersion into Deaf culture, over 70% recommend "going online for communication". The same number suggest "facing a few communicative challenges" or "avoiding frustration in communicative challenges" opposed to only one person suggesting "facing every challenge". When asked how people face "telling communicative needs" there is an even split between the two possibilities of either "touching needs

slightly" and "explain needs at length". Many used the opportunity to add to the list. These answers can be seen in Appendix 1 under Question 34.1.

Lastly participants were invited to answer a 'bonus question' and were asked which thing/aspect they miss the most if they had to decide on one.
This is the list of replies in order of frequency mentioned:

1. Music
2. Hearing close ones, family, kids, babies, partners speaking and their voices
3. Telephone conversations
4. Spontaneous, free-flowing conversation
5. Environmental sounds, e.g. animals and nature
6. Sing and dance together with others

Other answers:

➢ Following along with a joke while the other person is laughing
➢ Small talk
➢ Dialect
➢ Being able to make out speech while not looking
➢ Female voices
➢ Telling the atmosphere by hearing, i.e. pick up carols at mass, hearing crowd roar at sporting events
➢ Rather have the peace of deafness

C) The 'big picture'

In summary I would here like to offer a condensed overview of the findings. In most areas we can see that hearing loss results in a very diverse mix of experiences, perceptions and attitudes and relies on a number of factors. Although a common experience is shared on the linguistic side of it, people chose to cope in different ways, for example by identifying communicative methods which work best for them. Although indeed many have found sign language to be of value to them we can see

that given all the issues surrounding its acquisition, it by no means it is a simple issue, leaving many deprived of the opportunities it brings. The way of life in society people chose to live shows us the dilemma people face, being between the worlds. It shows us that finding an ideal spot is a difficult task with regards to all areas, perhaps identity in particular. It largely comes down to people's attitudes what to do with the situation.

This brings us to probably the most prominent finding which is the importance of sharing common experiences with fellow deafened individuals. Here people are treated 'normally', here many feel comfortable in their skin, here is their culture and perhaps a home.

In terms of identity and psychological effects we can also observe a pattern, which is that of phases deafened individuals go through in the course of acquired deafness with many required to battle their way through staying positive.

Lastly and interestingly, many participants seemed to have developed sets of strategies for coping in daily life which work for them. The many other suggestions in addition to the ones given show a strong belief in their ways and that it is truly an individual matter how those affected choose to cope and find their very own way of coping. Going through acquired deafness is a tremendous act and I want to thank all participants for sharing their inspirational insights. To conclude I want to emphasize the importance of supporting each other, perhaps with a quote by O. Wilde: "Nothing can cure the soul but the senses, just as nothing can cure the senses but the soul."

Bibliography

Batia, T. K., & Ritchie, W. C. (2006). *The Handbook of Bilingualism.* Oxford: Blackwell Publishing Ltd.

Becker, M. (2003). *Hörverlust und Identitätskrise.* Dortmund.

Firth, G. C. (1966). *The plate glass prison.* London: Royal Instutute of the Deaf.

Hindley, P., & Kitson, N. (2000). *Mental Health and Deafness.* London: Whurr Publishers Ltd.

HS Luey, L. G. (1995). Hard-of-hearing or deaf: issues of ears, language, culture, and identity. *Social Work*.

Lesley Jones, J. K. (1987). *Words apart. Losing your hearing as an adult.* Padstow: Travistock Publications.

LINK centre for Deafened People. (2007). *Lost for words.* Greenwich: The University of Greenwich.

Müller, J. (n.d.). Retrieved February 23, 2014, from http://www.jochen-mueller.org/New%20Site/startseite.html

Orlans, H. (1985). *Adjustments to hearing loss.* San Diego: Gallaudet College.

R. Hallam, P. A. (2006). Acquired profound hearing loss: mental health and other characteristics of a large sample. *International Journal of audiology*.

Sacks, O. (1989). *Seeing Voices.* Vintage Books.

The LINK Centre for Deafened people. (2005). *Hidden lives.* Seaford: Tansley Printers.

Bibliography