

## Appendix 1: Findings in detail

To be referred to when prompted in the dissertation

### About the participants

| <i>Country</i>   | <i>Overall</i> | ♂         | ♀         |
|------------------|----------------|-----------|-----------|
| <i>UK</i>        | 12             | 4         | 8         |
| <i>Germany</i>   | 15             | 5         | 10        |
| <i>USA</i>       | 9              | 2         | 7         |
| <i>Australia</i> | 1              | -         | 1         |
|                  | <b>37</b>      | <b>11</b> | <b>26</b> |

Median age: 45

Median age deafened: 28

*Question: Do you wear...?*

|                            |     |
|----------------------------|-----|
| Hearing aid                | 14% |
| Cochlear implant           | 16% |
| Auditory brainstem implant | 22% |
| Nothing                    | 46% |
| Other                      | 3%  |

*Question: If you can hear a bit still, are you able to understand speech without looking at the lips?*

|           |     |
|-----------|-----|
| Yes       | 0%  |
| No        | 46% |
| n/a       | 32% |
| Other     | 14% |
| No answer | 8%  |

## Area 1: Your Attitudes and those of others

Q3: *In terms of your self-perspective, do you think your personality has changed? If, so in which way? Make a list of which personality changes have you or close ones observed (feel free to ask them)*

| More...              | Less...        | From...to...and other   |
|----------------------|----------------|---|
| self-centred         | quick-witted   | from extrovert to introvert   |
| Angry                | self-confident | from shy and quiet to direct and open, outgoing                         |
| unsatisfied          | prone to anger | from being brave to avoiding  |
| Quiet                | Patient        | from happy-go-lucky, privileged to a more fighting, withstanding stance |
| self-critical        | self-conscious | self-conscious with deafness  |
| insecure             | self-involved  | anxious   |
| wary/sceptical       |                | stubborn  |
| reserved             |                | sometimes embittered  |
| supportive of others |                |   |
| assertive            |                |   |
| self-controlled      |                |   |
| serious              |                |   |
| patient              |                |   |
| isolated             |                |   |
| focussed             |                |   |
| spiritual            |                |   |
| socially withdrawn   |                |   |
| intense lifestyle    |                |   |

Q4: How did core family cope [with your hearing loss]?

|   | all | Most | a few | none |
|---|-----|------|-------|------|
| <b>stood by me</b>                          | 59% | 30%  | 14%   | 0%   |
| <b>turned away</b>                          | 0%  | 8%   | 24%   | 54%  |
| <b>Learned strategies for communication</b> | 19% | 22%  | 19%   | 11%  |

Q5: How did relatives and friends cope?

|   | all | most | a few | none |
|---|-----|------|-------|------|
| <b>stood by me</b>                          | 14% | 65%  | 24%   | 0%   |
| <b>turned away</b>                          | 0%  | 19%  | 54%   | 16%  |
| <b>Learned strategies for communication</b> | 0%  | 30%  | 46%   | 24%  |

Q6: How are you treated by strangers/the general public? People...

- ...don't know how to communicate: 84%
- ...are struck with helplessness: 73%
- ...don't bother to make effort: 60%
- ...underestimate the impact of hearing loss: 76%

Q7: How does this make you feel?

|              |     |
|--------------|-----|
| Isolated     | 51% |
| frustrated   | 57% |
| Angry        | 30% |
| not inclined | 30% |
| too tired    | 35% |
| Burden       | 30% |

- Pity
- Treated like I am dumb
- Frustrated with me so I get frustrated with them

- Ignored (speaking to hearing person next to him/her instead)
- Assuming me as rude/thick
- Feel the need to shout (making things worse)
- Patronising (sometimes intended, others not)
- Assuming deaf = speaks sign language
- Not bothering to make effort, not wanting to write
- Some apologise for my hearing loss
- Forgetting about the hearing impaired person
- Various examples of underestimation (“but you can lip-read?!” one or two sentences in slow speed, then normal again...)

## Area 2: language, communication and linguistic environment

Q8: Which strategies do you use for communication?

|                |     |
|----------------|-----|
| sign language  | 57% |
| fingerspelling | 81% |
| lip-reading    | 84% |
| write down!    | 73% |
| slowly!        | 78% |
| clearly!       | 81% |

Q9: How important do you think it is to learn ... when you are deafened?

|                | unimportant | low | neutral | important | Very imp. |
|----------------|-------------|-----|---------|-----------|-----------|
| lip-reading    | 0%          | 3%  | 11%     | 24%       | 65%       |
| sign language  | 3%          | 5%  | 27%     | 35%       | 32%       |
| fingerspelling | 0%          | 0%  | 8%      | 49%       | 46%       |

Q11: How important do you think it is for family and friends to learn....?

|                        | unimp. | low | neutral | important | Very imp. |
|------------------------|--------|-----|---------|-----------|-----------|
| <b>finger spelling</b> | 0%     | 0%  | 24%     | 35%       | 41%       |
| <b>sign Lang</b>       | 8%     | 8%  | 43%     | 30%       | 8%        |
| <b>slowly/clearly</b>  | 0%     | 3%  | 5%      | 19%       | 76%       |

Q12: In which means of communication do you feel most comfortable? (Only one number per answer possible)

| Order:                | 1   | 2   | 3   | 4   |
|-----------------------|-----|-----|-----|-----|
| <b>lip-reading</b>    | 38% | 38% | 16% | 11% |
| <b>sign language</b>  | 14% | 27% | 14% | 43% |
| <b>Fingerspelling</b> | 8%  | 38% | 38% | 8%  |
| <b>text/e-mail</b>    | 81% | 16% | 3%  | 3%  |

### Area 3: Social Environment

Q16: Which would be the perfect social environment for you? Being around...

|                |     |
|----------------|-----|
| Fingerspelling | 30% |
| sign Lang      | 8%  |
| lip-reading    | 49% |
| Deafened       | 30% |
| Mixture        | 49% |

Q17: Do you make much effort getting to know people, e.g. strangers who don't know of your communicative needs?

| never | Rarely | occasionally | frequently | always |
|-------|--------|--------------|------------|--------|
| 3%    | 32%    | 51%          | 14%        | 0      |

#### Area 4: The deafened community

Q26: How important would you say is the deafened community to you?

| unimportant | Not so important | neutral | important | very important |
|-------------|------------------|---------|-----------|----------------|
| 0%          | 10%              | 22,5%   | 22,5%     | 45%            |

#### Area 5: Identity and psychological effects

Q27: I feel I am part of....

|               |     |
|---------------|-----|
| hearing world | 22% |
| Deaf world    | 0%  |
| Neither       | 32% |
| Both          | 32% |
| other:        | 14% |

Q29: Thinking back, after going deaf can you observe some kind of psychological processes? Tick any suggestions you sympathise with and add your own:

|                       |     |
|-----------------------|-----|
| Panicking             | 24% |
| Ignoring              | 24% |
| Retreating            | 62% |
| Accepting             | 54% |
| Developing strategies | 25% |

*Q31: Have you ever had depressive episodes or depression?*

|                     |       |
|---------------------|-------|
| depressive episodes | 30,3% |
| depression          | 33,4% |
| Neither             | 36,3% |

*Q32: Have you ever chosen to do counselling? Yes-no*

|        |     |
|--------|-----|
| Yes    | 44% |
| No     | 38% |
| other: | 18% |

*32.1 If so, do you think it helped you? Yes-no-not sure*

|          |     |
|----------|-----|
| Yes      | 52% |
| No       | 22% |
| not sure | 26% |

## Area 6: Overcoming, Coping

Q34: Tick any of the strategies for coping if you can sympathise and add your own recommendations for coping with acquired hearing loss:

|  |         |
|--|---------|
| learn lip-reading                                | 84%     |
| Learn about assistive technology available       | 81%     |
| Get in touch with other deafened people          | 73%/90% |
| go online for communication                      | 70%     |
| Face a few challenges, but not all               | 70%     |
| learn sign language                              | 68%     |
| avoid communicative stations which frustrate you | 68%     |
| Unfriend 'false friends'                         | 54%     |
| touch your needs slightly                        | 46%     |
| explain your needs at length                     | 43%     |
| Just behave 'normally' like the others           | 41%     |
| don't ignore/wait                                | 38%     |
| see a counsellor                                 | 35%     |
| Get involved in Deaf culture and its community   | 24%     |
| stay focussed on the hearing world               | 16%     |
| Don't say anything about your needs              | 3%      |
| Face every challenge                             | 3%      |

### Q34.1: Other suggestions

- try to find a balance between educating others and not wanting to be irritating
- try not to isolate yourself
- Tell and explain as soon as possible
- Do not pretend
- Ask for help
- Never apologise for having to ask someone to repeat something
- Never think it's your fault.
- Give yourself time to get used to it
- Recognise other people have problems too often much worse than deafness. Be as independent as possible which is good for self-esteem.
- Although not always easy - think positively
- be realistic about situations you can cope in, but don't ignore those situations which scare you, sometimes that is the learning process
- don't be too self-focussed, keep awareness of other people's feelings

- learn to be assertive, but not in an aggressive way
- try and find someone to confide in, be it a councillor, a family member or friend
- Accept what you cannot change. Keep your sense of humour
- Accept that you will not be able to understand everything. Enjoy what you can do rather than regret what you can no longer do
- Get people to write things down (a lot!)
- Avoid situations where you feel ill at ease
- Try to accept the deafness as part of your life
- Keep your self-esteem
- Search for new hobbies and set new goals in life
- Make the best of the situation
- Sometimes try to beat your weaker self and step out of your comfort zone
- Keep an eye out for self-help and support groups and networks