



**Master Thesis**

**Exploring the Quality of Life of people with Acquired Deafblindness in Greece**

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October, 2022

Total number of words: 11.583

**Table of Contents**

Acknowledgments.....	p. 3
Abstract .....	p. 5
Introduction.....	p. 6
Previous Studies.....	p. 8
Research Purpose .....	p. 10
Method.....	p. 11
Results.....	p. 15
Discussion.....	p. 19
References.....	p. 25
Appendix A.....	p. 27
Appendix B.....	p. 30

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## Acknowledgments

I would like to express my gratitude towards the following people for helping me with this study.

First of all, I would particularly like to thank my first supervisor, Dr Saskia Damen, for dedicating precious time from her busy schedule to counsel and guide me through this process. Her feedback was of great value and of utmost importance and without her, the completion of my study would not be feasible.

Moving on, I want to thank my second supervisor, Johannes Westberg and my content supervisor, Dr Jude Nicholas, whose feedback was valuable and helped improve the study.

Moreover, I wish to thank all of the academic professionals of the Master program of Deafblindness for teaching me new things and helping me deepen my knowledge and understanding of such a complex disability like deafblindness.

In addition, I cannot omit to mention Mrs Maria Zeza, my internship supervisor. She has been an incredible mentor and a professional. She was understanding when needed and she offered me very useful insights in deafblindness. She also brought me in contact with the association of Deafblindness of Greece, "Iliotropio", where I recruited the participants from. Also, I want to thank Katerina Mpezerianou, a member of "Iliotropio" for bringing me in touch with the participants I interviewed and advised me on how to find Greek sign language interpreters.

I would like to mention my fellow colleagues for being willing to exchange opinions and offering me a sense of comfort and encouragement by knowing that we were all in this together.

Furthermore, I wish to thank the participants of my study for being so pleasant to work with and willing to help me with my study in any way they could. Their view and opinions

helped me complete my study but also, they helped me comprehend how it really is to be a person with deafblindness in Greece, beyond theory.

Last but not least, I want to thank my family for supporting me both financially and emotionally throughout this process and especially at periods of time when things got overwhelming and stressful for me.

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## Abstract

Deafblindness creates a specific condition more disabling than either deafness or blindness alone, as it combines both impairments to such profoundness, that it is not possible for them to counterbalance each other. Acquired deafblindness (ADB), which this research is focused on, is post-lingual deafblindness, meaning becoming aurally and visually impaired after the development of language. Apart from old age, the most common cause is found to be Usher Syndrome which accounts for approximately half of the people with acquired deafblindness. Acquiring both vision and hearing impairment can have an extensive impact on quality of life. According to Schalock and Keith (1993), Quality of Life can be defined through the four following domains: 1) personal life satisfaction, 2) competence and productivity, 3) empowerment and independence and 4) social belonging and community integration. There have been investigations conducted in several countries of the quality of life of people with Deafblindness as a result of Usher syndrome, which revealed variations in quality of life. Although research has illuminated quality of life of people with Usher, no study has examined this issue in Greece to date. Based on the four domains of Quality of life suggested by Schalok & Keith, three people with Usher Syndrome in Greece were interviewed in this study about quality of life. The results showed that the Greek participants perceived a lack of support provided by their state, necessary for participation and living a full life. However, they indicated that, they did experience having quality of life, as they truly enjoyed their lives and lived as independently as possible. It is discussed that their positive attitude, shows personal willpower and strength, and can also be explained as a type of coping strategy.

## **Introduction**

### **Background and Scientific Framework**

According to the Nordic Definition of Deafblindness (2018), “deafblindness is a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other” (Nordic Definition of Deafblindness, p.2, 2018). There are two categories of deafblindness, congenital and acquired. People afflicted with congenital deafblindness are both visually and aurally impaired from birth. Pre-lingual deafblindness refers to people who lose part of their hearing and vision early in life before the development of language. Subsequently, acquired deafblindness is post-lingual deafblindness, meaning becoming aurally and visually impaired after the development of language (Dammeyer, 2012). There are several causes for congenital deafblindness in the population. The most common causes are CHARGE syndrome, prematurity, meningitis, cytomegalovirus and, in countries without inoculation programs, congenital Rubella Syndrome (Dammeyer, 2010). Similarly, there are many causes for acquired deafblindness and if we exclude the elderly population, who are the majority of people with acquired deafblindness, the most common cause is found to be Usher Syndrome which accounts for approximately half of the people with acquired deafblindness (Möller, 2003). This study focuses on people with acquired deafblindness (hereafter ADB) caused by Usher Syndrome, which is a genetic condition that includes hearing loss, retinopathy, and vestibular areflexia with different entities and onset. Also, it is inherited in an autosomal recessive pattern and it is divided into three clinical subtypes (Type 1, 2 and 3), corresponding to different responsible genes (Castiglione, & Möller, 2022).

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People with ADB may use different means of communication on a daily basis. These include spoken languages, sign languages, tactile sign languages, deafblind manual alphabets, Tadoma, the deafblind block alphabet (Spartan) and finger Braille (Marion Hersh, 2013).

Despite the availability of alternative means of communication, ADB can have a major impact on a person's quality of life. The concept of quality of life is chosen as the framework of the study, because it is an all-embracing term that entails all aspects of one's life, whereas focusing only on life satisfaction for example, would be too specific and not enough to gather insights on a person's general well-being. In terms of definition, there is some ambiguity on what is meant by the term "quality of life", because there is a variety in what people deem important for having quality of life. According to Schalock and Keith (1993), Quality of Life can be defined through the four following domains; 1) personal life satisfaction, 2) competence and productivity, 3) empowerment and independence and 4) social belonging and community integration. Using the same assessment scale as Schalock and Keith, Verdugo and colleagues (2005) conducted a study on the concept of Quality of Life. They used questionnaires including forty questions, ten for each of the abovementioned domains. The data were taken from a sample of persons with visual disabilities. The results indicated that there are only three domains related to quality of life. The first of them, Competence/Productivity, concerns the perception of a person with respect to their ability, skills, development of competence, and economic, personal, and social advantages related to the area of work. The second domain, Satisfaction, concerns aspects related to overall or global satisfaction with life, comparing oneself to others, and satisfaction with specific aspects of life especially related to social relationships (family, friends). The third domain, Self-determination/Independence, concerns the perception of an individual of their opportunities to choose and decide different aspects of their life related to the carrying out of

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daily activities, using money, possessions, friends, and in relation to decision-taking in general (Verdugo et al., 2005).

### **Previous studies**

Over the years, several studies in different countries have investigated the quality of life of people with deafblindness. One study in 2013 examined the experiences of people with Usher Syndrome in England. The main focus of this study was to investigate how Usher Syndrome would impact one's life and how people with Usher syndrome would experience this disability. It was a qualitative study with semi-structured interviews. Based on the results, it was discovered that despite some indications of depression, there was also excitement, interest and anticipation (Ellis & Hodges, 2013), which correspond to Schalock's Satisfaction factor. "Having Usher did mean that these people had to do things differently, and perhaps to give some things up, but they had learned to manage, and they managed" (Ellis & Hodges, p.8, 2013). All in all, the conclusion was that people were doing the things they wanted to do. They claimed to be successful parents and competent employees, which adheres to Schalock's self-determination and independence and competence and productivity. The authors describe that the participants played music, they had friends and socialized with others, and took part in sports, which fall under the umbrella of Schalock's personal life satisfaction domain and social belonging and community integration domain. They had already accepted their disability. "Usher was obviously part of what was going on, but it was not all of it" (Ellis & Hodges, p. 217, 2013). In conclusion, people with ADB in the UK appeared to have quality of life.

In contrast, a recent study of Climens et al. (2020) showed less positive results when investigating the quality of life of people with Usher Syndrome Type I. A total of 18 patients



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(7 in the US; 11 in France)– 9 adults, 4 adolescents, and 5 children– and 9 mothers were interviewed.

With regard to ocular symptoms, photosensitivity and contrast sensitivity, eye pain, black spots, difficulty adjusting to light and following moving items, depth perception and general vision decline were mentioned. Balance issues, fatigue and headache were reported. In terms of mobility, patients hit things or people or even trip over objects and get bruises. They reported loss of mobility at night, incapacity to drive, difficulty in crowded places, using public transportation and crossing roads. So far, it is evident that they lacked two of Schalock's domains; competence and productivity and empowerment and independence. The lack of competence and productivity was also obvious at school or work, where the subjects struggled with following the course, doing homework or usual tasks and missed some days due to their disease. Additionally, struggling with using screens, reading subtitles and writing were commonly cited. Limitations on sports and other physical activities were present, too. Regarding emotional functioning, some patients expressed fear, worry, anxiety, frustration or even anger associated with certain situations due to their condition. Identity issues were expressed as well. All these led to feelings of sadness, depression or having ups and downs. Therefore, Schalock's satisfaction is not present either. About their cognitive function, difficulty with concentrating, recognizing and locating people was mentioned. Furthermore, social functioning was impacted, too. The participants faced difficulties discussing their disability. Less interaction, difficulty following conversations or being understood and difficulty shaking hands was reported by the patients, which indicates lack of Schalock's social belonging and community integration as well. Also, they got teased by classmates or coworkers. Longer-term impacts were the need to change career or location and having to stop working, which shows problems in Schalock's empowerment and independence. Lastly,

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people's finances were influenced due to the necessity to have special equipment (Climens et al, 2020).

Finally, Miner also carried out a qualitative study through interviews with thirty-two people with Usher Syndrome Type II in New York (1997). The participants reported problems with their communication and relationships with others, professional lives, mobility, hobbies and other pastimes. "What was previously simple...becomes a trial as their communication needs change and their visual limitations interfere" (Miner, p. 585, 1997). Furthermore, they expressed having real concerns about the future, about working, marriage and having children. Socially, other people see them as incompetent and that pity prevents them from being seen as real people. According to the author, the participants explained how their self-esteem is attacked on a daily basis and they feel isolated. Depression and sometimes suicidal ideation are also evident (Miner, 1997). Once again, connecting this study with Schalock and Keith's (1993) and the study in 2005, people with ADB in New York did not appear to have quality of life, as all domains seem to be missing.

The above-mentioned studies took place in the UK, France and the US. As far as we know, no study has been carried out that investigates the quality of life of people with deafblindness in Greece.

### **Research purpose and questions**

This research's purpose is to gain insights on the quality of life of people with deafblindness in Greece. This is important, because Greece, so far, is a country where deafblindness is not commonly known by society and the only people that know about this disability are the ones that actually have to deal with it in their lives. Therefore, gathering information about the quality of life of people with Usher's lives will help the readers get a better understanding of the situation in terms of living with such a disability in Greece. To

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that end, conducting a study that allows people with Usher who actually live in the country to discuss their experiences, would provide a clear picture as to whether they feel that they are competent and productive, satisfied and able to lead an independent life. In addition, by the end of the study, there will have been insights in the theory on quality of life. Specifically, the quandary of whether there are four domains that are relevant (Schalock & Keith, 1993) or only three (Verdugo et al., 2005) is to be answered.

One main question is to be answered through the master thesis:

What is the quality of life of people with Usher Syndrome in Greece?

In order for this question to be answered, more detailed and specific questions must be answered; 1) Do people with ADB with Usher in Greece feel competent in the areas of communication, orientation and mobility and daily living skills? 2) Are people with ADB with Usher of Greece able to determine the career they are going to pursue? 3) Do people with ADB with Usher in Greece truly enjoy their lives? 4) How do people with ADB with Usher of Greece feel about the way that society treats their disability?

### **Method**

This is a qualitative study. Personal interviews were scheduled with people with ADB that live in Greece. The interviews were carried out online, through Zoom. Interviews are the most commonly used qualitative data collection method (Olife et al., p.1, 2021).

Unfortunately, due to long distance, in-person meetings were not possible, therefore Zoom was the best alternative. A study of Olife et al. (2021) concluded that participants that were interviewed through zoom about partner relationships appreciated the use of Zoom, and seemed relaxed and spontaneous because they could do the interview at home. Furthermore, the authors mention the cost-effectiveness, as multi-site in-person interview studies entail

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significant costs and fatigue. Lastly, it seemed that Zoom interviews were strongly endorsed by participants because of their therapeutic value.

### **Participants and settings**

The participants were recruited through an association for people with deafblindness of Greece called “Iliotropio”. Three participants were included. Participant 1 was a man, aged 38 years old, who communicates using Greek sign language. He has partial vision and hearing loss and does not know what type of Usher he has (hereafter P1). Participant 2 was a woman, aged 54 years old, who communicates using Greek sign language. She recently got retinitis pigmentosa, she is partially impaired in vision and hearing and does not know the type of Usher she has (hereafter P2). Participant 3 was a man, aged 59 years old, with Usher Type 3. he has severe vision and hearing loss and he communicates through Greek sign language (hereafter P3). After contacting them and taking their consent to be interviewed, personal meetings were scheduled online, through Zoom.

### **Instruments**

The interviews were semi-structured and the questions were based on the four domains of the Quality of Life Scale of Schalock and the Quality of Life Questionnaire (Schalock, 1993): 1) empowerment and independence, 2) competence and productivity, 3) social belonging and community integration, 4) personal life satisfaction.

With reference to the semi-structured interviews, the opening question was standard for everyone and after that, there were some specific questions that needed to be answered, but this did not happen in a strictly question-answer pattern. Some answers were elicited from other responses and new questions arose during our conversation as well. The introductory question basically invited them to talk about themselves for a while (their name, age, who they live with, how long they have been deafblind for, any hobbies etc). The rest of the

information that was to be deduced from them concerned whether they can independently walk around in the city or if they need a guardian, who they socialize with, what working opportunities they have, whether the state facilitates their mobility with special infrastructure on the streets and pavements, whether they are given some sort of financial support, how they choose to entertain themselves inside and outside of the house, what dating or marriage opportunities they have, whether they are competent with everyday activities, like eating or going to the bathroom, how they feel about the way that they are treated by society: whether they feel marginalized and isolated or accepted and included, and finally, as a concluding question, if, overall, they feel satisfied and content with their life.

**Table 1**

*Overview of Interview Questions, Formulated for each of the Four Domains of Schalock*

Domains	Questions
Empowerment and Independence	What job do you do? What are the working opportunities for people with deafblindness? What are the working conditions? Does the state provide you with some sort of financial support?
Competence and Productivity	Do you walk around in the city alone or do you need a guardian? Does the state facilitate your mobility with special infrastructure on the streets and pavements? Do you do your everyday activities (cooking, cleaning, going to the bathroom etc) alone or do you need help?
Social Belonging and Community Integration	Who do you socialize with? Are your associates hearing people, deafblind

Domains	Questions
Personal Life Satisfaction	<p>people or both?</p> <p>What dating or marriage opportunities do you have as a person with deafblindness?</p> <p>Are hearing people accepting towards you, and people with deafblindness, in terms of dating and friendships?</p> <p>Do people in the street give you weird looks?</p> <p>How do you feel about the way that society treats you?</p> <p>Do you feel marginalized and isolated or accepted and included?</p> <p>What do you do for fun inside and outside of the house?</p> <p>Overall, with a brief answer, do you feel happy with your life?</p>

### Procedures

The interviews were carried out online video and audio-recorded by the researcher. The goal was to make the participants feel comfortable and create a sense of familiarity, as much as possible. For that reason, informal and everyday language was used and the questions were direct.

One thing that needs to be taken into consideration is the language used. The author was familiar with Greek Sign Language but there was an interpreter present to translate from spoken language to sign language and vice versa. The participants used Greek sign language and the interpreter translated it for the author into Greek spoken language. After having finished with the interviews and after having transcribed them, the information that was transferred in the master thesis was translated from Greek to English by the author.

### Data analysis

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As previously mentioned, the interviews were conducted online and recorded. Then, the information that was to be used in the thesis was coded using thematic coding. According to Gibbs (2007), thematic coding involves identifying one or more passages of data items that exemplify the same theoretical or descriptive idea, which is the code. The codes were based on the four domains of the Schalock and Keith questionnaire (1993) and were: a) empowerment and independence b) competence and productivity c) social belonging and community integration d) personal life satisfaction. Translated quotes of the participants were used to illustrate their stories.

## **Results**

### **Empowerment and Independence**

As all three participants stated, they all work. Their jobs vary. P1 is a permanent civil servant at the registry office. P2 is a teacher and P3 is working for the borough as a cleaner. According to them, employers are hesitant when it comes to hiring deafblind people and many of the deafblind who work were recruited through Greek legislation according to which, each person gathers points and the public sector hires them as public employees. P3 reported that it is very hard for deafblind people to find a job, while the other two who are less severely impaired in vision and hearing agreed that it was not that difficult for them because, they were hired through the public sector. Therefore, the results on the field of empowerment and independence are kind of mixed. According to these three people, there were many unemployed deafblind people, but there were also people that did not struggle with finding a job and P1 has actually gotten a University degree. However, it is worth mentioning that the working conditions may not be the most appropriate for a deafblind person. The public cleaner said that at midnight, the employer turns off the lights in the office and thus, he is made to use a flashlight when he is assigned to do office work. This, as he

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said, causes him extreme irritation and stress and the flashlight is also an extra cost added to his spending. Also, he mentioned that his employer has pushed him five times so far and during one of them, he actually hit his head. As he described, *“he pushed me and he scared me. It was like seeing a huge wolf with teeth...it is prohibited to do that to us. His behavior was awful”*. He carried on by saying that *“everyone at Universities and employers make huge mistakes because they don’t know...They have to be educated on deafblindness. It is essential for employers to know who they hire and all of them should have a degree related to people with disabilities”*. Moving on, the same person said that on December 3<sup>rd</sup>, on Disabled People’s Day, they ask for the day off but they keep getting rejected, even after taking the case to court. *“They all are incredibly stubborn”*, he said.

### **Competence and Productivity**

With regard to general mobility, all three mentioned that they walk around in the city without the assistance of a guide. P3 stated that he tries to walk around in the city alone, because most of the times, guides do not cooperate well with them. He said and I quote, *“having someone next to me, pushing me and taking me wherever they want is very hard and it is an issue for me and it really makes me feel awful...No one has been educated on appropriate behavior towards us. The result is that I get dragged around and it bothers me. So I walk alone slowly because it confuses me”*. In addition, as they said, the streets are not well equipped with special infrastructure to facilitate their mobility. Finally, when it comes to everyday activities, like cooking, cleaning, going to the bathroom etc, they all claimed that they are competent and do everything alone. Sometimes, they are offered help by relatives or friends, but it is not essential for them.



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## Social Belonging and Community Integration

When asked about their personal relationships and societal treatment, P1 and P2 responded that they grew up around hearing people and P1 said that he attended school with hearing people, but he just attended some specific subjects in a special class. Hence, their associations include hearing, blind and deafblind people. P3 answered that he has some hearing friends in his hometown and that he also has deafblind acquaintances. However, when it comes to romantic relationships, it was reported by two participants that hearing people are a little more hesitant regarding dating people with deafblindness. Nonetheless, they did mention that this does not happen on an extreme level, more like it depends on each person's standards. To be more specific, P1, when he was asked if hearing people immediately reject deafblind people, replied that *"Yes, unfortunately, this happens. In the past, I feel like there was some kind of racism against me. But, of course, I pay them no mind. I don't care at all"*. Couples of hearing and deafblind people, though, is not a non-existent occurrence, but as P2 said, *"it is up to each person's judgment"*. The third participant made the distinction between casual and serious relationships. According to him, there are hearing people that are open to casually date people with deafblindness for small periods of time without having to commit to one another. Getting rejected by a hearing person for a serious long-term relationship, though, is more frequently the case. Considering societal treatment, it was mentioned by P2 that *"in Greece, in comparison with other European countries, we are very far behind"*. She specifically named Sweden as a country to look up to because of the state's organization and inclusivity towards people with deafblindness. When asked about racism and marginalization in everyday life, she said *"it's not exactly racism, there is a bit of marginalization. Many people say that they are not interested in learning about it (deafblindness), many parents do not try to give the right education on what being a deafblind person means"*. About weird

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looks from people in the street, she specifically stated that *“the way that we look at a person with different and strange hair color or an eccentric person wearing eccentric clothes, is the exact same way one looks at a person with deafblindness”*. On a more optimistic note, however, she also stated that the two Greek deafblind associations (“Faros” and “Iliotropio”), *“try to show (the problem) in order for people to be informed, via Facebook and other social media, so that people understand and realize the problem and racism stops”*. *“I believe that through social media, deafblindness will slowly be discovered and understood by people, but it will take time because unfortunately we are still very far behind”*, she said. To conclude, she placed emphasis on the role of school and family, as two institutions that need to take up on educating children on disabilities, such as deafblindness, because otherwise, *“if there is not right education, deafblindness will most definitely, 100%, stay marginalized”*.

### **Personal Life Satisfaction**

The participants were asked about the ways they entertain themselves inside and outside of the house. P1’s and P2’s answers were quite similar to each other. They replied that they enjoy doing ordinary things like relaxing with friends in a house, going out for a walk, visiting coffee places, going to restaurants and traditional taverns with friends and in general, *“the same things as hearing people”*. P3, with severe hearing and vision loss, gave a slightly different answer. He said that he enjoys going for walks and especially enjoys going to the beach. He characteristically said that *“the sea refreshes me, helps my optic nerve and functions as music to my eye”*. However, he expressed frustration when he happens to be with friends at the beach. *“I try to go alone and be under an umbrella alone, peacefully...so I can stay healthy. If I turn my head and it is windy and sunny and someone talks to me from one side, someone talks to me from the other side, it is very difficult. Going alone is better”*.

Furthermore, as mentioned earlier, as a closing question, I asked from the participants to

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answer very briefly if they feel satisfied and content with their life. All three of them stated that yes, they do feel happy with their lives. In fact, the participant with the most severe impairments explicitly said that *“I really like life”* and *“I live my life...I go out, I flirt, I talk, I am happy. It is enough for me. A little bit of this, a little bit of that”*.

### **Discussion and Conclusions**

In order to be able to draw conclusions on how participants with deafblindness caused by Usher syndrome in Greece perceive their quality of life, we first have to consider Schalock's domains separately.

Firstly, we examined the domain of empowerment and independence. Participants stated that many people with deafblindness are unemployed, or they do not have the opportunity to determine their own career, the conditions they work under are inappropriate, or the jobs they are given are not tailored to their disability. Hence, the Greek participants with Usher syndrome in this study perceived a lack of empowerment and independence.

Considering the domain of competence and productivity, in general, all three participants stated that they walk alone and also do everyday activities alone. However, the participant with the most severe form of deafblindness stated that he does not walk alone because he does not necessarily need a guide, but because of the guides' bad manners. He explained that he has attempted to walk with a guide, but his experience was rather unpleasant. Hence, he started walking alone and as he said, he manages. In conclusion, the Greek participants with Usher syndrome in this study seemed to perceive sufficient competence and productivity.

The next domain is social belonging and community integration. Considering all the participants' replies, it is hard to set on a definitive answer. There were both positive and negative experiences mentioned. However, when considering the role of society and the Greek state and what is offered to include people with Deafblindness in society, the

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conclusion is that the Greek participants with Usher did not perceive sufficient social belonging and community integration.

Considering the domain of personal life satisfaction all three participants confidently answered affirmatively when they were asked if they feel content with their lives. Therefore, it can be concluded that the Greek participants with Usher syndrome perceived personal life satisfaction. The third participant's answer, which was quoted earlier, was particularly moving and inspiring.

Taking all things into consideration, and based on Schalock's domains, it can be concluded that the Greek participants with Usher syndrome do experience quality of life. All of the participants responded without a second thought that they do feel happy with their lives and most of the domains are present in their lives.

When interpreting the results of the study, it can be noticed that the perceived quality of life cannot be explained by inclusive laws or policies of the Greek government. The people that were interviewed described having quality of life, but this seems to be due to the fact that they fight for it and do not give up on life. They fight to work, to move around, and to enjoy life in general. In fact, this is a coping strategy. Coping strategies offer a means by which the impact of a disability is minimized, and help a person arrive at the psychological place in which the undeniable presence of a disability no longer dominates the person's mental and emotional state (Martz & Livneh, 2007). According to Martz and Livneh, coping can be growth-oriented, negative-weighted or it can encompass both forms simultaneously (2007). Evidently, the participants that were interviewed use growth-oriented coping. This involves strategies such as solving issues impeding one's functioning or thinking positively about the possibilities available in the future.

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The Greek state does not appear to play a role in enabling inclusion of the participants in this study. As P2 and P3 said, the financial support that is supposed to be given, is only given under specific circumstances that have to hold, like an age limit, or the person being unemployed for instance. Also, P2 and P3 discussed the bad situation of the pavements and the streets and the lack of special infrastructure such as special traffic lights etc. The fact that they are able to walk around without a guide is again thanks to their own effort. All in all, the participants gave the impression that they do experience quality of life, but only thanks to their own willpower and resilience. They all indicated having great fortitude by saying things like *“I am human, I want equality and I don’t wanna feel disadvantaged and that’s what I assert”*, *“I myself asserted it and managed to be where I am right now. This helped very much and this is why I have quality of life now”* and *“like Alexander the Great, we want to fight the stereotypes of society and move forward”*.

With some caution because of the sample, the results of the study, can be compared with studies in other countries. As described in the Introduction section, there have been studies that investigated the quality of life of people with Usher syndrome in England, in France and in the US. The results from the study in England, conducted by Ellis and Hodges (2013), displayed similarities to this study in Greece. People with Usher syndrome in England appeared to be competent in everyday activities, they expressed being successful parents and employees, they said they do sports, they have hobbies, and apparently, they genuinely enjoy their lives. All these are similar to the experiences described by the participants with Usher in Greece. However, perhaps, the situation of the working field in England might be more optimistic than the situation in Greece.

Climens et al conducted a study in 2020 with people in the US and in France. The participants had Usher Type 1 and they displayed loss of mobility, lack of competence and

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productivity at school or work, social dysfunctioning, feelings of anxiety, difficulty finding a job, and financial insecurity. It is very obvious, that they perceived their situation as much more pessimistic than the Greek participants that were interviewed in this study, as the Greek participants explained to be productive and generally competent.

Finally, Miner interviewed people with Usher Syndrom Type II in New York (1997). They reported having problems with communication, with personal relationships, with work, with mobility and with hobbies, which all led to feelings of depression and even suicide tendencies. Again, the difference to the findings in this study is clearly noticeable, as the Greek participants stated they do not face problems with mobility, communication, socializing, and most importantly, their psychology. Their only similarity lies in their difficulty in the field of work.

Notwithstanding, what should not be overlooked, is the fact that the differences mentioned above may not be explained by difference between countries alone. The factor of severity of vision and hearing loss or personal factors such as personality traits and coping strategies must by all means be taken into consideration, as they can have a huge influence on the way that one perceives their life.

### **Strengths and Limitations**

The study in question contains some strong points. First of all, the author interviewed the participants personally, by having face-to-face online meetings and thus, creating a comfortable atmosphere and not leaving much room for misunderstandings. Also, in contrast with a yes/no form of questioning, they had the opportunity to elaborate on their answers, give further and in-depth explanations and document their replies. This encouraged them to be more expressive and thus, give the author a better understanding of their situation. Finally,

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since they are people that actually live in Greece, they offered a realistic view of how it is to live in Greece as a person with deafblindness

However, the study has limitations, too. To begin with, the number of the participants is very small, which means that the results are not generalizable to the whole population of people with Usher syndrome, not even in Greece. In addition, two of the participants have a light form of Usher, which can result in having a more positive experience, not corresponding to people with Usher with a severe form of deafblindness.

Moreover, an important aspect to consider is the fact that there was an interpreter translating to the author. This means that the author did not receive information directly from the participants. In this way, the interpreters may have accidentally omitted some information, misunderstood something, or even let their personal opinions interfere with how they translated things to the author. Fortunately, since I -the author- am familiar with Greek sign language, I was able to ascertain that the information that was translated to me was in accord with the participants' answers. Lastly, as the author, I was alone in the process of coding. Without receiving feedback from a second party or hearing someone else's opinion, the process of coding is not immune to errors.

### **Recommendations**

Based on the results of the study, several recommendations can be made. Firstly, there is a need to raise awareness about deafblindness and to educate people on deafblindness and Usher syndrome. Family and school are institutions that are also responsible for properly upbringing children so that when they go out in society, they turn out to be citizens with empathy and sensitivity, especially when it comes to disabilities.

Further studies need to be conducted on different topics around deafblindness, too. First of all, it would be quite interesting to see more studies that investigate quality of life of people

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with Usher in Greece in a bigger sample, which will allow the opportunity to cross-examine the veracity of the results of this study.

Also, there are measures that could be taken by the Greek state to enable families that deal with deafblindness. Looking at Dimitra Nellopoulou's study on available services and awareness of congenital deafblindness in Greece (2021) offered great insights on this matter. The participants she interviewed suggested guiding families of people with deafblindness and informing them about the available support services, providing psychological support to all family members, upgrading the education options through early intervention services to children with deafblindness and offering specialized training to professionals in the field of education. The current study's author's addition is that the state should invest money in embedding special infrastructure in the streets to facilitate mobility, override limitations such as age or work when it comes to providing allowance for people with deafness or deafblindness and lastly, pass a law that would guarantee adjusted job positions for people with deafblindness.

Only if the world acquaints with deafblindness and disabilities, will societal inclusion be possible. Ethics need to be taught, so that people with disabilities do not feel alienated from the rest of the world. As a closing point, the author wants to stress that all this should not be viewed as a favor that people without disabilities do for people with disabilities, but as a moral obligation.



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## Appendices

### Appendix A

#### Informed Consent Letter



university of  
 groningen

faculty of behavioural  
 and social sciences

Dear parents, guardians or people with deafblindness,

In March 2022, I started a research on what Quality of Life Deafblind people have in Greece, in terms of the master program of Deafblindness of University of Groningen. In order to have a clear picture as to what the quality of life of deafblind people in Greece is, the way that these people experience their disability in the country needs to be known. To that end, as part of the study, deafblind people, relatives or guardians of deafblind people are asked to participate in personal interviews with the author via videocalls that will be recorded. The participants will be asked questions about their everyday life, opportunities they have and social-emotional aspects. This is the first time that quality of life of deafblind people is measured in Greece and hence, this research will offer unique insights on deafblind people's experiences in the country.

The following points are also important:

- A. The aim of this research is to have a view on what extend Greek deafblind people have quality of life.
- B. The interview will take approximately 30-60 minutes.
- C. The data obtained from this investigation will be treated confidentially: names will not be mentioned and if there is a need to, fictional names are going to be used. The data is reported anonymously and is only available to researchers. The data is going to be kept by the researcher until the end of the study's writing, which is estimated to be until October.

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- D. The researchers, Maria Rodoula Zografou and Dr Jude Nicholas, will answer any further questions about the interviews, now or during the course of the interviews.
- E. Contact details for University of Groningen:  
Tel: +31 50 363 9111  
E-mail: [communicatie@rug.nl](mailto:communicatie@rug.nl)
- F. The participants have the right to complain with the Data Protection Officer. The contact details are:  
Mr. A.R. (Arjen) Deenen ([a.r.deenen@rug.nl](mailto:a.r.deenen@rug.nl)) - University of Groningen  
Postal address: P.O. Box 72 9700 AB Groningen  
An. Central Privacy Desk  
E-mail: [privacy@rug.nl](mailto:privacy@rug.nl)

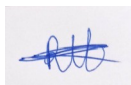
You should know that yours, your child's or your relative's participation in this study is entirely voluntary. You can terminate your cooperation at any time and have the data obtained from this investigation recovered, removed from the database or destroyed. At no time will the data be published on the internet.

**By completing and signing this form, you consent to you, your child or your relative participating in the study.**

Kind regards,

*Maria Rodoula Zografou*

[mariazwgrafou@outlook.com](mailto:mariazwgrafou@outlook.com)



I have agreed to take part in the study entitled: *Exploring the Quality of Life of People with Acquired Deafblindness in Greece* and I understand that my participation is entirely

voluntary. I understand that my responses will be kept strictly confidential and anonymous. I have the option to withdraw from this study at any time, without penalty, and I also have the right to request that my responses will not be used. The researcher is responsible for a safe storage of the data. For questions about privacy protection: mr. A.R. Deenen ([privacy@rug.nl](mailto:privacy@rug.nl), data protection officer of University of Groningen).

Date \_\_\_\_\_

Signature \_\_\_\_\_

<mailto:privacy@rug.nl>

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## Appendix B

### Interview Transcripts

Note: Only relevant and useful information for the thesis is transcribed. “...” means that at that point, the parties talked about something irrelevant to the theme of the thesis.

Where R=Researcher, P=Participant

#### **Interview with Participant 1, man, age 38, Type of usher unknown.**

<sup>1</sup> R: Can you tell me a bit about yourself? your name, age, percentage of hearing and vision

<sup>2</sup> P: Okay, my name is \*restricted information\*, I am 38 years old, I am deaf and I have a

<sup>3</sup> second condition, I have Usher Syndrome...I have a bachelor degree in Computer Science

<sup>4</sup> and I work as a permanent civil servant at the registry office in the protocol department...in

<sup>5</sup> general, at night I have difficulty in mobility I can't see well, but during the day everything

<sup>6</sup> is fine I don't have any problem...in my spare time I usually go fishing and take a walk in the

<sup>7</sup> mountain either with company or alone I don't mind and I travel as much as I can, I have

<sup>8</sup> visited different countries abroad and places in Greece.

<sup>9</sup> R: Great, so is the residual percentage of vision and hearing high?

<sup>10</sup> P: I have 80% deafness and 50% blindness, in total 87% disability.

<sup>11</sup> R: In general, outside, in the city, do you walk independently or do you need a guardian?

<sup>12</sup> P: Of course, at night I need help, but when it's daytime and there is light I have no

<sup>13</sup> problem, I walk independently. At night I need a guide.

<sup>14</sup> R: Is there any special infrastructure, pavements, traffic lights in the streets that facilitate

<sup>15</sup> transport?

<sup>16</sup> P: To be honest, here in the city I live, I know the area very well, it is very easy for me. If,

<sup>17</sup> for example, I go to a strange city, I believe it will be difficult for me. I know the place I

<sup>18</sup> live in very well, so I do not struggle.

<sup>19</sup> R: Good. Does the state provide you with any financial support?

<sup>20</sup> P: Yes, yes of course it does.

<sup>21</sup> R: Okay. When it comes to friendships and socializing, do you-and people with Usher in

<sup>22</sup> general-socialize only with people with deafblindness or hearing people as well? Are

<sup>23</sup> hearing people accepting?

<sup>24</sup> P: I grew up with hearing people because in school...I was in a special affiliation class that

<sup>25</sup> was part of a general education school. I attended some subjects like math and physics in

<sup>26</sup> the special affiliation class and the rest of the subjects in the general class. Therefore, I have

<sup>27</sup> many friends from there. I have friends who are deaf, who have Usher and hearing people.

<sup>28</sup> A few of every kind. Besides, I grew up among hearing people.

<sup>29</sup> R: Regarding romantic relationships and dating, what is the situation? Are hearing people

<sup>30</sup> open to date people with deafblindness or do they immediately reject them because it seems

<sup>31</sup> too strange to them?

<sup>32</sup> P: Yes, unfortunately, this happens. In the past, I feel like there was some kind of racism

<sup>33</sup> against me. But, of course, I pay them no mind. I don't care at all.

<sup>34</sup> R: So, could we say that deafblind people mostly date deafblind people?

<sup>35</sup> P: No, of course they may date hearing people as well. There are such cases. I have a

<sup>36</sup> hearing girl friend that is in a relationship with a guy with Usher, like me.

<sup>37</sup> R:...Regarding the work field, do employers hire deafblind people with Usher with ease, or

<sup>38</sup> do they avoid it?

<sup>39</sup> P: This is very hard for me to answer, because I am completely unfamiliar with the system.

<sup>40</sup> I have no idea how companies work and how employers hire disabled people, because I am

<sup>41</sup> a permanent civil servant, so I never had to look for a job. Of course, there are positions

<sup>42</sup> dedicated to people with disabilities, but these are not permanent. For example, an employer  
<sup>43</sup> could hire you for three or four years and then not renew the contract. That is the system of  
<sup>44</sup> Greece, which I am not very familiar with, so I can't give an answer. For example, I  
<sup>45</sup> applied for my current position 10 years ago and I waited for five years until they hired me.

<sup>46</sup> R: Okay I understand...Inside the house, I guess you do the cooking you go to the bathroom  
<sup>47</sup> etc alone?

<sup>48</sup> P: Yes. I can do everything alone. I can cook, I can clean, I can do my laundry, I can iron  
<sup>49</sup> my clothes, I don't have a problem. However, my parents live upstairs so they help me too.

<sup>50</sup> R: Great. How do you feel about the way that society treats you? Do you feel included and  
<sup>51</sup> accepted or do you feel marginalized and isolated?

<sup>52</sup> P: At first, yes, I felt very isolated. I struggled very much with integrating, but my best  
<sup>53</sup> friend is hearing and he helped me very much with my psychological state back then when I  
<sup>54</sup> was little. He gave me amazing fortitude and now, I don't have any issue at all. Whatever  
<sup>55</sup> happens, even if I have to deal with hearing people, even if they don't understand me or I  
<sup>56</sup> don't understand them, I pressure them to write it down. There is the Relay System, which  
<sup>57</sup> allows you to contact an interpreter from long distance. There is not a problem anymore. I  
<sup>58</sup> am human, I want equality and I don't wanna feel disadvantaged and that's what I assert.

<sup>59</sup> R: Good. Now, generally, with one word,...are you content with your life given that you  
<sup>60</sup> have this disability? Are you satisfied with the quality of your life let's say?

<sup>61</sup> P: Yes, of course.

<sup>62</sup> R: Wonderful. Inside and outside of the house, how do you entertain yourself?

<sup>63</sup> P: I hate sitting around in the house. I do drawings, crafts, fake fish for example, to use it as  
<sup>64</sup> bait when I go fishing. Then of course, my friends come over to my house. Unfortunately, I  
<sup>65</sup> am divorced with my wife, we have a daughter, so I have some acquaintances from them.



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<sup>66</sup> Outside of the house, for fun, I really enjoy going to traditional Greek taverns, coffee  
<sup>67</sup> places, going on walks, the usual...I forgot to tell you that I am also a volunteer  
<sup>68</sup> representative in a worldwide organization for the deafblind but unfortunately, we haven't  
<sup>69</sup> started doing any projects yet, because it's summer and people are away on vacation. But  
<sup>70</sup> I hope that we can start in September to help all people with Usher and improve our quality  
<sup>71</sup> of life...

<sup>72</sup> R:...you have been of great help, thank you very much, have a great day

<sup>73</sup> P:...thank you, I am more than happy to help. Bye.

**Table 2***Codes for Interview 1*

<b>Codes</b>	<b>Lines</b>
Empowerment and Independence	ll. 3-4, ll. 19-20, ll. 37-45, l. 58, ll. 67-71
Competence and Productivity	ll. 5-6, ll. 11-18, ll. 46-49
Social Belonging and Community Integration	ll. 21-36, ll. 50-57
Personal Life Satisfaction	ll. 6-8, ll. 59-67

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**Interview with participant 2, woman, age 54, type of Usher unknown.**

<sup>1</sup> R: Hello, can you tell me a bit about yourself? Name, age, profession?

<sup>2</sup> P: Well, my name is \*restricted information\*, I am 54 years old, I have been working as a  
<sup>3</sup> teacher...for 25 years

<sup>4</sup> R: What is your percentage of vision and hearing?

<sup>5</sup> P: Well, the vision impairment came up later. I will explain. Around the age of 2, I got  
<sup>6</sup> diagnosed with deafness. I spoke, I sang, then I stopped. My brother was deaf, because he  
<sup>7</sup> got meningitis when he was 4 months old, so we both got admitted in the hospital, we stayed  
<sup>8</sup> there for a month approximately, my brother suffered a lot...I wore a hearing aid and it  
<sup>9</sup> helped me hear some words, I tried, not 100% of course, I could hear about 10-20% of the  
<sup>10</sup> words around me. About my vision, it all started in 2010, I got labyrinth, I received  
<sup>11</sup> treatment for 8 months and in 2012 I started not seeing well, especially at night. I wore  
<sup>12</sup> myopia glasses, I went to see my eye doctor, I explained to him that I can't see very well at  
<sup>13</sup> night, I wondered if maybe my myopia increased, he examined  
<sup>14</sup> me, he gave me other glasses, but nothing changed. In 2014, I was wondering if I have  
<sup>15</sup> Usher, and eventually, I got officially diagnosed with Usher...

<sup>16</sup> R: Okay. Outside in the city, do you walk alone independently or do you need a guide?

<sup>17</sup> P: No no I walk alone independently...I just go slow because I am careful...

<sup>18</sup> R: Do you use a cane?

<sup>19</sup> P: No without a cane, alone, just with slow steps.

<sup>20</sup> R: Now, concerning socializing, do you personally-but also people with deafblindness in  
<sup>21</sup> general- socialize with hearing people as much as with deafblind people?

<sup>22</sup> P: I grew up among hearing people so I am used to being around hearing people. During the  
<sup>23</sup> last few years, I have been struggling with lip reading, but I do communicate, I have

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<sup>24</sup> informed the hearing people around me that this vision impairment has come up, so they  
<sup>25</sup> either turn on the lights for me, or they speak slowly to me, but I have to take the initiative  
<sup>26</sup> to inform them, which of <sup>24</sup> course is accepted by them.

<sup>27</sup> R: Regarding romantic relationships, is it a common occurrence for a deafblind person to  
<sup>28</sup> date a hearing person, or do they tend to date mostly deafblind people?

<sup>29</sup> P: Of course, it is up to each person's judgment. There are people that avoid us, there is  
<sup>30</sup> some kind of racism. Most people with Usher are able to and do have relationships...but  
<sup>31</sup> there are deafblind people and people with Usher that don't take initiative and they single-  
<sup>32</sup> handedly feel isolated and embarrassed. They don't participate in many social activities. It  
<sup>33</sup> is a personal issue and up to each person's character.

<sup>34</sup> R: Concerning the working field, do employers hire deafblind people with no special  
<sup>35</sup> hesitation, or do you struggle to find a job?

<sup>36</sup> P: No no no, it is extremely difficult. I haven't heard from a deafblind person that they have  
<sup>37</sup> been hired to a job, unfortunately.

<sup>38</sup> R: Does the Greek state give any allowance?

<sup>39</sup> P: Yes, yes. Deafblind people are prioritized because they receive two different allowances.  
<sup>40</sup> One as a deaf person and then as a blind person which totals almost the double amount of  
<sup>41</sup> money, because deafblindness is deemed as two different disabilities...Deaf people that only  
<sup>42</sup> have one disability have to be over the age of 65 to get the allowance for deafness. The  
<sup>43</sup> Hellenic Federation of the Deaf strives for deaf people to get the allowance before reaching  
<sup>44</sup> that age. There are too many expenses...for hearing aids, for special electric devices for the  
<sup>45</sup> house...even in order to have interpreters, because The Hellenic Federation of the Deaf only  
<sup>46</sup> covers 25 hours per week, so if anyone needs an interpreter outside of those hours, they  
<sup>47</sup> have to pay with their own money.

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<sup>48</sup> R: Outside in the street, has the state built infrastructure like traffic lights or special  
<sup>49</sup> pavements to facilitate mobility?

<sup>50</sup> P: No, no, no unfortunately. The Hellenic Federation of the Deaf has made a request for the  
<sup>51</sup> subway, to establish some facilities, the lighting to be brighter...in general, we are very far  
<sup>52</sup> behind in comparison with the rest of Europe. Image that in Sweden things are very  
<sup>53</sup> advanced...here compared to Sweden, unfortunately, I 'll say it, we are at zero.

<sup>54</sup> R: Okay. Do you use public transport with relative ease?

<sup>55</sup> P: Yes yes. Of course, I don't have a severe form of Usher and that's why I can do it with  
<sup>56</sup> ease. However, when it gets dark, I realize I have to do my best so that I can manage.

<sup>57</sup> R: Good. Inside the house, during the day and night, do you do your everyday activities -  
<sup>58</sup> like going to the bathroom, cooking, cleaning etc- alone?

<sup>59</sup> P: Yes yes yes just like before, normally. I am not incompetent, I do them as normal, like I  
<sup>60</sup> used to.

<sup>61</sup> R: Good, now as a general picture, how do you feel that Greek society treats people with  
<sup>62</sup> deafblindness? Is there marginalization, racism, isolation to this day? Or do you feel  
<sup>63</sup> included?

<sup>64</sup> P: I 'll tell you. In Greece, in comparison with other European countries, we are very far  
<sup>65</sup> behind. There is an organization called "Iliotropio" that has to do with deafblindness, and  
<sup>66</sup> "Faros". They are organizations that try to show in order for people to be informed, via  
<sup>67</sup> Facebook and other social media, so that people understand and realize the problem and  
<sup>68</sup> racism stops. I believe that through social media, deafblindness will slowly be discovered  
<sup>69</sup> and understood by people, but it will take time because unfortunately we are still very far  
<sup>70</sup> behind...It's not exactly racism, there is a bit of marginalization. Many people say that they  
<sup>71</sup> are not interested in learning about it, many parents do not try to give the right education

<sup>72</sup> on what being a deafblind person means, just like how things in America are. Parents and  
<sup>73</sup> teachers should work together so that people with deafblindness feel good about  
<sup>74</sup> themselves. It needs some spur from the parents...from family, from school, from people. If  
<sup>75</sup> there is not right education, deafblindness will most definitely, 100%, stay marginalized.

<sup>76</sup> R: Outside in the streets, are there any weird looks?

<sup>77</sup> P: Yes, there are. The way that we look at a person with different and strange hair color or  
<sup>78</sup> an eccentric person, wearing eccentric clothes, is the exact same way one looks at a person  
<sup>79</sup> with deafblindness...

<sup>80</sup> R: I see. Inside and outside of the house, how do you choose to entertain yourself?

<sup>81</sup> P: I invite people over in my house, we talk, we eat. If we don't want to stay inside, we  
<sup>82</sup> meet outside. There are days that I want to be alone to rest and enjoy the day by myself. We  
<sup>83</sup> do the same things as hearing people.

<sup>84</sup> R: And now, in general, with a brief answer, do you feel like you have quality of life?

<sup>85</sup> P: Yes, I do. I will tell you again, it's because I got used to it since I was little and I have  
<sup>86</sup> been independent all these years. I myself asserted it and managed to be where I am right  
<sup>87</sup> now. This helped very much and this is why I have quality of life now.

<sup>88</sup> R: Do you think this is also due to the fact that you don't have a severe form of Usher and  
<sup>89</sup> people with a more severe-

<sup>90</sup> P: Yes, yes, exactly. This is also very important. It is recent, it is not severe...(i have a  
<sup>91</sup> problem) only at night. Very often at night, If I am not careful and move hastily, I bump into  
<sup>92</sup> furniture because I haven't gotten used to it yet. I am careful and if I bump into someone I  
<sup>93</sup> apologize, but it is not that big of a deal.

<sup>94</sup> R: I see...thank you very much for your help...have a great summer...bye.

<sup>95</sup> P:...good luck with your thesis, bye.

**Table 3***Codes for Interview 2*

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<b>Codes</b>	<b>Lines</b>
Empowerment and Independence	ll. 2-3, ll. 34-47, ll. 86-87
Competence and Productivity	ll. 16-19, ll. 48-60, ll. 90-93
Social Belonging and Community Integration	ll. 20-33, ll. 61-79
Personal Life Satisfaction	ll. 80-86

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**Interview with participant 3, man, age 59, Usher Type 3.**

<sup>1</sup> R: ...Hello...can you tell me a bit about yourself? Name, age, profession, hobbies?

<sup>2</sup> P: I am \*restricted information\*, I work in the municipality of Athens as a cleaner...since

<sup>3</sup> 2003. I was born in Crete...we are seven siblings, two of us have Usher, one is hard of

<sup>4</sup> hearing and the rest are hearing.

<sup>5</sup> R: what is your age?

<sup>6</sup> P: 59.

<sup>7</sup> R: Great. Do you have any hobbies?

<sup>8</sup> P: I like going for walks, I really like life, joy, the sea helps me very much with my vision, I

<sup>9</sup> am alone, calm and with friends I get lost, it confuses me. Also, the sun irritates my optic

<sup>10</sup> nerve. I try to go alone and be under an umbrella alone, peacefully...so I can stay healthy. If

<sup>11</sup> I turn my head and it is windy and sunny and someone talks to me from one side, someone

<sup>12</sup> talks to me from the other side, it is very difficult. Going alone is better so I can look at one

<sup>13</sup> place and be consistent. The sea refreshes me, helps my optic nerve and functions as music

<sup>14</sup> to my eye...when I sit in the house, my eye sticks...the fact that my optic nerve closes is

<sup>15</sup> awful and brings me down psychologically. Therefore, I want to go outside...People with

<sup>16</sup> Usher around the world sit around in the house because...their parents can't accompany

<sup>17</sup> them everywhere. Their minds are a bit closed, their siblings have their own families, there

<sup>18</sup> is a bit of prejudice, so they leave them alone. It is like people with Usher live on the

<sup>19</sup> mountains. However I, and many others, want to do sports, workout, lift weights, like

<sup>20</sup> Alexander the Great, we want to fight the stereotypes of society and move forward.

<sup>21</sup> R: Good. Do you walk around in the city independently or do you need a guide?

<sup>22</sup> P: The streets in Athens are full of obstacles. They are not accessible, many parts are poorly

<sup>23</sup> constructed, my legs hurt because I accidentally hit them, my eyes, my brain, my back all

<sup>24</sup> get tired, there is a huge problem with this. There are rocks everywhere, the problem with  
<sup>25</sup> parking makes me hit my legs. It is extremely annoying, it causes me health problems. The  
<sup>26</sup> goal is to walk appropriately and it is very important...not to cause myself another  
<sup>27</sup> disability...Many times people see us walk and think we are drunk. I am not drunk, I am just  
<sup>28</sup> trying to find my way so that I don't hurt myself...It is because the city is incoherently  
<sup>29</sup> structured...If the streets and pavements were straight, it would be easy for me to walk...for  
<sup>30</sup> example, in the street, there is not enough lighting...we wait 5, 6 months, a year for  
<sup>31</sup> someone to change a light bulb. The situation is awful.

<sup>32</sup> R: So do you walk alone?

<sup>33</sup> P: Yes, alone. I try. I can't have a guide...having someone pressuring me is hard. Having  
<sup>34</sup> someone next to me, pushing me, taking me wherever they want is very hard and it is an  
<sup>35</sup> issue for me and it really makes me feel awful...no one has been educated on appropriate  
<sup>36</sup> behavior towards us. The result is that I get dragged around and it bothers me. So I walk  
<sup>37</sup> alone slowly because it confuses me when I get dragged around...exercising also helps me a  
<sup>38</sup> lot. At work, my boss has pushed me five times and made me hit my head...he pushed me  
<sup>39</sup> and he scared me. It was like seeing a huge wolf with teeth...it is prohibited to do that to us.  
<sup>40</sup> His behavior was awful...Everyone at Universities and employers make huge mistakes  
<sup>41</sup> because they don't know...They have to be educated on deafblindness. It is essential for  
<sup>42</sup> employers to know who they hire and all of them should have a degree related to people  
<sup>43</sup> with disabilities. On December 3<sup>rd</sup>, we ask for the day off and they don't allow it. It is  
<sup>44</sup> International Day of Persons with Disabilities and we have tried many times to take the case  
<sup>45</sup> to court...but they all are incredibly stubborn...We used to sign papers in the morning but the  
<sup>46</sup> program changed and now we have to do it at night...and they turn off the lights at



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<sup>47</sup> midnight...and this bothers me a lot, it makes my heart ache, it is stressful. We can't all turn  
<sup>48</sup> off the lights...and I have to use my own flashlight. It costs 20 euros and I keep making  
<sup>49</sup> expenses...

<sup>50</sup> R: Do you receive an allowance from the state?

<sup>51</sup> P: No no. Deafness with Usher is not considered as one disability...Deaf people with Usher  
<sup>52</sup> that receive the allowance for the blind have to report blindness as a second separate  
<sup>53</sup> disability which means that they have to be 100% blind...As a result, they do not receive an  
<sup>54</sup> allowance for blindness, they only receive the allowance for deafness. I receive nothing  
<sup>55</sup> because I work.

<sup>56</sup> R: Do you socialize with hearing people, deaf people, deafblind people or people of every  
<sup>57</sup> category?

<sup>58</sup> P:...in Greece, people with Usher are not all connected. We click with some people and  
<sup>59</sup> don't click with other people. Some people form romantic relationships and isolate  
<sup>60</sup> themselves. In Europe and worldwide, it is difficult to be friends with a person with Usher. I  
<sup>61</sup> used to hang out with deaf people...now and then I hang out with deaf people that know  
<sup>62</sup> about my condition. Most of them don't have much money though, so I have to pay and this  
<sup>63</sup> is difficult. Some are sneaky

<sup>64</sup> R: Do you have hearing friends?

<sup>65</sup> P: Yes in my hometown. They are nice, they help me. When I wear glasses and they talk, I  
<sup>66</sup> have a better connection with them. When I don't wear glasses, I struggle.

<sup>67</sup> R: Is it easy for you to find women to date?

<sup>68</sup> P: When a hearing woman sees us, she starts processing us...in Europe, there are people that  
<sup>69</sup> want to get intimate with us but it is harder in Greece, because women are afraid of bearing  
<sup>70</sup> a child with disabilities. Some women, though, accept it...there is physical contact...but not

<sup>71</sup> long term. They don't get married to them...I start seeing someone and when I start showing

<sup>72</sup> that I can't do many stuff, they leave me. So, I keep things casual because I am scared.

<sup>73</sup> R: How do you feel that society treats you? Is there marginalization or inclusion?

<sup>74</sup> P: Somewhere in between. There are some obstacles that slowly reduce. There needs to be

<sup>75</sup> education in order to be inclusion. In Europe, there is progress.

<sup>76</sup> R: Do employers hire deafblind people?

<sup>77</sup> P: There are some deaf people or deaf people with Usher that get hired. But at work, there

<sup>78</sup> is always a group of people that gossips and reports back to the boss. I stay out of this, I

<sup>79</sup> don't like it...Usually, they get hired through the public sector for jobs that are not adapted

<sup>80</sup> to their disability. Deafblindness is very far behind in Greece, it is only now getting

<sup>81</sup> discovered. Also, many employers don't want to take the responsibility for a deafblind

<sup>82</sup> person, maybe not even for a deaf person, because what would happen if, for example, they

<sup>83</sup> get hit by a car during work hours?

<sup>84</sup> R: Inside the house, do you do your activities alone? Like going to the bathroom, cooking

<sup>85</sup> cleaning

<sup>86</sup> P: Yes, I know how to do everything alone. I sweep, I clean, because maids may rob you.

<sup>87</sup> They took a small heart once and I stressed and panicked. Since then I do everything alone.

<sup>88</sup> R: With one sentence, do you feel satisfied with your life?

<sup>89</sup> P: Yes yes. I have managed to get by. When I came here it was very difficult for me, a

<sup>90</sup> village boy. But then, I gained experience and now I can go everywhere. Here I started

<sup>91</sup> bumping into people...I went to the gym, karate, weight lifting. Living in the mountain

<sup>92</sup> would have made me retarded. But here, things are better, I learn things. I started not

<sup>93</sup> bumping into people, I go to parties, I live my life, and I realize that this is life. I go out, I

<sup>94</sup> flirt, I talk, I am happy. It is enough for me. A little bit of this, a little bit of that. Do you

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<sup>95</sup> know how hard life was in my village?

<sup>96</sup> R: Yeah, I understand. Okay, I have a clear picture, that's all I wanted to ask. Thank you

<sup>97</sup> very much, have a great evening. Goodbye.

<sup>98</sup> P: Thank you, bye bye.

#### **Table 4**

##### *Codes for Interview 3*

<b>Codes</b>	<b>Lines</b>
Empowerment and Independence	l. 2, ll. 15-20, ll. 38-55, ll. 76-83
Competence and Productivity	ll. 9-15, ll. 14-15, ll. 21-37, ll. 84-87
Social Belonging and Community Integration	ll. 56-75
Personal Life Satisfaction	l. 8, l. 10, l. 13, l. 15, ll. 88-95