



University of Zagreb

Faculty of Education and Rehabilitation Sciences

Sanja Tarczay

Meeting Challenges – Deafblind Interpreting From a User’s Perspective

DOCTORAL THESIS

Zagreb, 2014



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Supervisor:
Associate professor, Ljubica Pribanić Ph. D.

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Sveučilište u Zagrebu

Edukacijsko-rehabilitacijski fakultet

Sanja Tarczay

**Izazovi na sastancima –
korisnička perspektiva
prevoditelja gluhoslijevim osobama**

DOKTORSKI RAD

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Zagreb, 2014.

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CURRICULUM VITAE

Professional Preparation:

- 1998 – PhD – University of Zagreb, Faculty of Education and Rehabilitation Sciences
- 1991 – MS – University of Zagreb, Faculty of Education and Rehabilitation Sciences
- 1979 – BA – Teacher of the deaf; University of Zagreb, Faculty of Education and Rehabilitation Sciences
- 1979 – BA – Teacher of Croatian; University of Zagreb, Faculty of Philosophy - Croatian studies

Appointments:

2011	Associate professor
2000 - 2011	Assistant professor
2007 - 2011	Vice Dean for Students and Teaching
2006 - 2010	Head of the Unit for Hearing Impairments, Rehabilitation Center, FERS
2005 to present	Head of the Sign Language and Deaf Culture Laboratory (HZJ Lab)
2002 - 2003	Head of the Rehabilitation Center, Faculty of Education and Rehabilitation Sciences, University of Zagreb

Undergraduate lecturer:

University of Zagreb, Croatia
University of Tuzla, Bosna & Hercegovina (1997 - 2004)
Courses: Nonverbal communication, Methods of rehabilitation and education of deaf and hard of hearing children, Deafblindness

Graduate lecturer:

University of Zagreb, Croatia
Course: Language development of deaf and hard of hearing children

Postgraduate lecturer (doctoral study and specialization):

University of Zagreb, Croatia
University of Tuzla, Bosna & Hercegovina (2003/2004)
Courses: Language development of hearing impaired children, Early intervention in children with sensory impairments

Selected research projects:

- Evaluation of program and models of transformation of behavior disorders in children and youth with special needs, Supported by Croatian Ministry of Science and Technology (1986-1990) – collaborator
- Speech and language disorders in school-age children, Supported by Croatian Ministry of Science and Technology (1991-1996) – collaborator
- Senior consultant on the research project “The Basic Grammar of Croatian Sign Language” - bilateral USA () and Croatia project; Supported by National Science Foundation – Linguistic

program (PI Prof. Ronnie Wilbur, Purdue University, West Lafayette, IN, USA) (2004-2009)

- Prime investigator – project „The Basic Grammar of HZJ“– supported by Ministry of Science, Education and Sports of Croatia (2007-2009)

Selected publications:

- Pribanić, Lj. (2005): Učenik oštećena sluha u redovnoj osnovnoj školi (Hearing impaired pupil in regular primary school). *Napredak*, 146 (4), 477-487.
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- Chen Pichler, D., Schalber, K., Hochgesang, J., Milković, M., Wilbur, R., Pribanić, Lj., Vulje, M. (2008): Possession and existence in three sign languages. 9th. Theoretical Issues in Sign Language Research Conference, Florianopolis, Brazil, December 2006. R. M. de Quadros (ed.). Editora Arara Azul. Petrópolis/RJ. Brazil. 440-458.
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- Salaj, I., Pribanić, Lj. (2010): Model podrške za starije gluhoslijepe osobe – put prema kvalitetnijoj starosti (Support model for elderly deafblind persons – Providing high quality of life in old age). *Zbornik radova s 8. kongresa defektologa Hrvatske s međunarodnim sudjelovanjem*, Varaždin, 22.-24.4.2010., Društvo defektologa Hrvatske.
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- Milković, M. i Lj. Pribanić (2012): Što znamo nakon deset godina istraživanja gramatike HZJ (What do we know after ten years of Croatian Sign Language [HZJ] grammar research)? U Juriša, M. i J. Držaić (ur.): *Zbornik radova sa stručnih skupova, URIHO*, Zagreb, 15-20.
- Hrastinski, I., Pribanić, Lj., Degač, J. (2014): Razumijevanje poćitanog u ućenika s oštećenjem sluha (Reading comprehension in students with hearing loss). *Logopedija*, 4, 1, 10-18.
- Tarczay, S., Pribanić, Lj. (2014): Prevoditelji znakovnog jezika – kako ih vide korisnici usluge prevođenja (Sign language interpreters: How the service users see them). *Hrvatska revija za rehabilitacijska istraživanja*, 50, 2, 1-16.

DEDICATION

“Optimism is the faith that leads to achievement. Nothing can be done without hope and confidence.”

Helen Keller

I dedicate this doctoral thesis to my life mentor Đurđica Karlić, M.D., who complemented and spiritualised my path of life and encouraged me to face another life challenge, this time a scholarly one.

Thus the longest journey of my life began, with a lot of ups (optimism) and downs (doubts whether I really need all this and fear of rapid vision loss). I was not ready for such a big challenge and sometimes reaching the end of that road seemed almost impossible.

I would never have finished this journey without a great support and assistance that came primarily from my family, from my elder, deafblind sister Eli, from my deaf nephew Vanja and from my niece Tajana who is also a Sign Language interpreter, and from Chris, a deaf person himself, all of whom had a lot of understanding and patience travelling with me through beautiful and difficult moments, and from Missy who secured me an area of relaxation and peace in the most difficult moments.

And when I thought that I will never complete my journey, my deaf grandniece Isabel gave me a new motivation, ignited a fiercer flame of optimism because this work, although dedicated to the Deafblind, speaks about the need to ensure high quality interpreters, by which I want to establish the foundation for a happier growing up to small Isabel, but also to all deaf and deafblind children who will need high quality support to realise their potentials and dreams.

However, my family was not the only one to provide me with support. The main support came from my mentor, Ljubica Pribanić, Ph.D., who had confidence in me and let me work on the topic that is dear to me most of all.

The most significant support came precisely from the Croatian Association of Deafblind Persons *Dodir*, especially in terms of my personal interpreters Igor and Marina, as well as all the other employees who took care that the activities of Dodir were carried out without delay.

A special support was given to me by my deafblind, deaf and hard of hearing friends and colleagues from Croatia. I had also an unconditional support from my colleagues in the European Deafblind Union and the World Federation of the Deafblind.

I was provided with expert support by a number of professionals engaged in the field of interpreting: Ann, Kerstin, Karen, Maya, Rhonda, Deb, Kelli,... who were always pointing me into the direction of the literature I needed, but also managed to find the exact words of encouragement.

To all of you who have shared with me the moments of this exceptional experiential travel I want to say that I appreciate the support that you have given me and that I am thankful from the depths of my heart, because you helped me to never stop dreaming and to make those dreams come true.

Once again, to all of you, a big sincere THANK YOU!

SUMMARY

This thesis is dedicated to the relatively new field of science and practice, Deafblind interpreting, and is focused on one specific area – Deafblind interpreting at international meetings. One of the most important activities that leads deafblind people out of social isolation is participation in and leading of international organisations of the Deafblind, where they can make decisions and create policies to the benefit of deafblind persons. Because of the nature of dual visual and auditory impairment, the participation of deafblind persons is impossible without the use of Deafblind interpreting services. And it is the Deafblind who are the stakeholders of this research. The approach to a scientific research from the user's perspective by selecting the qualitative method of research and appropriate research material – a questionnaire with follow-up – allows an insight into what Deafblind users consider important and what they expect when using Deafblind interpreting services at meetings, as well as it creates new knowledge in the creation of guidelines in future scientific and practical work.

KEYWORDS

Deafblind users perspective, Deafblindness, Deafblind interpreting, interpreting at international meetings

SAŽETAK

Ova doktorska disertacija posvećena je relativno novom području u znanosti i praksi - prevođenju gluhoslijepim osobama te je usredotočena na njegovo specifično potpodručje – prevođenje gluhoslijepim osobama na međunarodnim sastancima. U ovom radu, s obzirom na dosadašnju relativnu nezastupljenost prevođenja gluhoslijepim osobama kao teme znanstvenih istraživanja, strogo se vodilo računa da bude pristupačan i razumljiv onima koji se još nisu susreli s gluhosljepošćom.

Autorica je kroz dvanaest zasebno obrađenih poglavlja pregledno strukturirala sve odgovarajuće relevantne informacije i činjenice. Svako je poglavlje koncipirano tako da može stajati samostalno, ali i tako da sva zajedno čine jednu značajnu cjelinu koja unosi novo svjetlo u razumijevanje specifičnih potreba gluhoslijepih osoba tijekom prevođenja na međunarodnim sastancima.

U uvodnom dijelu čitaoci se postupno uvode u pozadinu ovog istraživanja, odnosno u to kako je sve počelo. Slijedi opis istraživačkog interesa u kome je objašnjeno koji su razlozi potaknuli i vodili autoricu prema tom novom području istraživanja - međunarodnim sastancima u kojima sudjeluju gluhoslijepe osobe. Također se prikazuju dostignuća za budućnost.

U drugom dijelu, „Terminološka razjašnjenja”, daje se cjeloviti prikaz razumijevanja dva ključna termina koji su dio ove teze, „gluhošljepošće“ i „prevođenja gluhoslijepim osobama”. Korištenjem funkcionalne nordijske definicije gluhošljepošća se razumijeva kao heterogeni fenomen. Objašnjenjem termina „prevođenje gluhoslijepim osobama” postiže se značajna distinkcija od pojma prevođenja gluhima te u potpunosti opisuju sve sastavnice koje su obuhvaćene prevođenjem gluhoslijepim osobama. Terminološko razjašnjenje ova dva termina bilo je nužno jer bez potpunog uvida i razumijevanja neće se moći steći potpuna slika o stvarnim teškoćama i problemima s kojima se gluhoslijepe osobe suočavaju prilikom sudjelovanja na međunarodnim sastancima.

Treći dio posvećen je organizacijama gluhoslijepih osoba s kraćim povijesnim pregledom osnivanja svjetske ali i ostalih regionalnih organizacija gluhoslijepih osoba, koje pružaju mogućnost za jednakost u sudjelovanju u političkom i javnom životu. Jedna od najvažnijih aktivnosti koja gluhoslijepe osobe izvodi iz društvene izolacije jest upravo vođenje međunarodnih organizacija gluhoslijepih osoba i sudjelovanje na međunarodnim sastancima gdje mogu donositi vlastite odluke i kreirati politike u korist gluhoslijepih osoba.

Četvrti dio opisuje važnost prevođenja gluhoslijepim vođama prilikom sudjelovanja na međunarodnim sastancima. Zbog prirode dvostrukog oštećenja vida i sluha sudjelovanje gluhoslijepih osoba gotovo je nemoguće bez korištenja usluga prevođenja za gluhoslijepe te su upravo gluhoslijepe osobe nosioci ovog istraživanja.

Peto poglavlje nam daje dublji uvid u različite aspekte interakcije na međunarodnim sastancima na kojima sudjeluju gluhoslijepe osobe. Ovdje zapravo ulazimo u jedinstven svijet sastanaka na kojima gluhoslijepe osobe sudjeluju. Opisani su vidovi interakcije koji se mogu promatrati s aspekta gluhosljepoće, aspekta načina komunikacije, jezičnog i lingvističkog aspekta, kulturnog aspekta, edukacijskog aspekta i aspekta organizacije okoline na sastanku.

U šestom poglavlju, naslovljenom „Problem istraživanja”, opisana su početna polazišta prije samog istraživanja: problem istraživanja, korisnička perspektiva, svrha i cilj istraživanja, istraživačka pitanja i inicijalna očekivanja.

Nadalje, u poglavlju „Metode istraživanja” upoznajemo se s metodologijom istraživanja koja obuhvaća raspon od uvodnih napomena o istraživanju, jedinstvenog objašnjenja podrške u istraživanju, opis sudionika istraživanja, metode i tehnike prikupljanja podataka, te provođenje postupaka istraživanja, kao i opis metoda analize dobivenih podataka te etičke aspekte istraživanja.

Osmo poglavlje govori o odabranom uzorku sudionika u istraživanju, o strukturi tog uzorka s posebnim osvrtom na komunikacijske metode kojima se sudionici koriste. Odabrano je dvanaest (N=12) sudionika za ovo specifično istraživanje. Svi sudionici odabrani su prema trima kriterijima i to: uključenost u radu međunarodnih organizacija gluhoslijepih osoba (European Deafblind Union i World Federation of the Deafblind), iskustvo koje su stekli obnašajući neku od funkcija u odboru ili u nekom od tijela upravljanja navedenih organizacija te da su osobe sa stečenom gluhosljepoćom. Struktura uzoraka ravnomjerno je raspoređena po spolu gdje je prisutnost muških i ženskih sudionika gotovo izjednačena (muški sudionici 58%, ženski sudionici 42%). Analiza strukture sudionika prema kategorijama gluhosljepoće pokazuje da tri od četiri kategorije imaju sličnu zastupljenost po broju sudionika (slijep i gluhi, slijep i teže nagluhi, gluhi i teže slabovidni), dok je jedna imala izrazito manji broj sudionika (teže nagluhi i teže slabovidni). Struktura sudionika prema godinama iskustva pokazuje uključenost sudionika na obje strane kontinuma – neke sa puno godina iskustva, a neke sa vrlo malo iskustva što nam daje širi i raznoliki opis stavova, opcija i zahtjeva. Vezano uz komunikacijske metode kojima se služe sudionici istraživanja u davanju informacija služili su se ili znakovnim jezikom ili govorom, dok je velika različitost bila evidentna u primanju

informacija. Sudionici su naveli sljedeće komunikacijske metode u primanju informacija: znakovni jezik, jasan i glasan govor, taktilni znakovni jezik, znakovni jezik u okviru vidnog polja, taktilna abeceda uz korištenje haptičkih znakova, kombinacija prijenosa jasnog i glasnog govora i haptičkih znakova, prijenos govora na tekst uz kombinaciju Lorm abecede te prijenos govora na brajčni tekst.

Definicija kategorija u devetom poglavlju najvažniji je dio ove doktorske disertacije jer uključuje kategorije identificirane prilikom analize podataka, te je ono podijeljeno u trinaest zasebnih sekcija u kojima je svaka kategorija zasebno opisana i potkrijepljena iskazima sudionika iz upitnika, ali i grafičkim prikazima pojedinih kategorija. Izdvojene su sljedeće kategorije: naziv pružatelja usluge, odabiranje prevoditeljā, ograničeni izbor prevoditeljā, fizički izgled prevoditeljā, uloga prevoditelja, odnos prevoditelja i korisnika, teškoće u suradnji, organizacija, neovisnost, kompleksnost prioriteta, obrazovanje prevoditeljā gluhoslijepim osobama i privatnost. U ovom poglavlju čitatelj se upoznaje sa svime što sudionici smatraju važnim u prijevodnom procesu tijekom sudjelovanja na međunarodnim sastancima, ali istovremeno dobiva uvid u ono što sudionicima istraživanja jest ili nije zajedničko. Naziv pružatelja usluge kategorija je koja je pokazala da mnogi ispitanici sličnim nazivima oslovljavaju pružatelje usluga, ali iz različitih termina koji se koriste mogu proizaći nesporazumi oko očekivane uloge prevoditelja za gluhoslijepe osobe. Odabiranje prevoditelja kategorija je koja je proizašla iz opisa ispitanika kako izgleda proces odabira prevoditelja, što pri tom cijene i vrednuju, odnosno na čemu se zasniva njihov odabir. Ova kategorija usko je povezana sa sljedećom – ograničeni izbor prevoditelja, koja se pojavila kao rezultat sličnih teškoća u izboru prevoditelja kod mnogih ispitanika. Naime, zbog malog broja kvalificiranih prevoditelja za gluhoslijepe osobe, kao i zbog nerazvijenosti sustava za pružanje podrške gluhoslijepima u mnogim zemljama, brojni ispitanici opisali su ograničenu mogućnost izbora prevoditelja, koju su neki od njih doživjeli kao olakšanje zbog poznavanja prevoditelja, dok su drugi poželjeli imati veću slobodu izbora. Fizički izgled prevoditelja kategorija je koja se pojavila na temelju opisa ispitanika kako treba izgledati njihov prevoditelj. Velike razlike pojavile su se između onih koji imaju ostatke vida i onih sa sljepoćom, od kojih je većina rekla da im nije važno kako prevoditelj izgleda i kako je odjeven, budući da ga uopće ne vide. Osobe s ostacima vida iskazale su svoje potrebe za kontrastom između odjeće i ruku prevoditelja. Važan utjecaj na stav korisnika o izgledu prevoditelja ima i kultura, što se pokazalo značajno za neke ispitanike koji su opisali stupanj pokrivenosti tijela odjećom koji je prihvatljiv u njihovoj kulturi. Opis kategorije Uloga prevoditelja sastoji se od tri glavna dijela koja su prepoznata od strane svih ispitanika kao

sastavni dio posla prevoditelja za gluhoslijepe osobe – prevođenje, vođenje i opisivanje okoline. Svaki od njih opisan je kroz niz primjera iz života gluhoslijepih osoba, kao i kroz njihove ideje o tome kako bi dobra suradnja s prevoditeljem trebala izgledati. Na ovu kategoriju se nadovezuje kategorija Odnos prevoditelja i korisnika, koja opisuje detalje suradnje koji moraju biti definirani između korisnika i prevoditelja, kako ne bi došlo do nesporazuma i teškoća u suradnji. U ovoj kategoriji pojavile su se razlike od prijateljskog do formalnog odnosa koji korisnici očekuju s prevoditeljima. Teškoće u suradnji sljedeća je kategorija, koja se sastoji od opisa brojnih načina kako suradnja između korisnika i prevoditelja može biti ugrožena, ali uključuje i primjere strategija za rješavanje pojedinih problema. Kategorija Organizacija nastala je na temelju iskaza koji opisuju organizacijska pitanja prevođenja, od planiranja, dolaska na prevođenje, prikupljanja materijala i ostalih organizacijskih koraka koji moraju biti poduzeti kako bi prevođenje uopće moglo biti održano. Ovdje je važno naglasiti da su međunarodni sastanci situacija koja se razlikuje od prevođenja unutar neke zemlje, a zbog toga su iskazi gluhoslijepih osoba koje same organiziraju svoje sudjelovanje naročito vrijedni. Neovisnost je kategorija koja se odnosi na želju i nastojanje gluhoslijepih osoba koje sudjeluju na međunarodnim sastancima da očuvaju svoju neovisnost i donose svoje odluke, usprkos stalnoj ovisnosti o prevoditeljima kao komunikacijskim posrednicima i pružateljima informacija o okolini te vođenju s jednog na drugo mjesto. Privatnost je kategorija u kojoj se naglašava potreba gluhoslijepih osoba da očuvaju svoju privatnost, iako je ona često ugrožena zbog korištenja prevoditelja, koji neminovno imaju pristup i upoznati su s privatnim informacijama korisnika. U kategoriji Kompleksnost prioriteta opisuju se kompromisi kojih su gluhoslijepi korisnici svjesni te njihova razmišljanja o njima, uz mnoštvo primjera iz situacija u kojima na međunarodnim sastancima, oni moraju donositi odluke o tome što im je važnije, kako bi što bolje funkcionirali na sastancima na kojima ne mogu dobiti potpunu informaciju, ali moraju poduzeti nešto kako bi bili što bolje informirani i uključeni u procese donošenja odluka. Kategorija Obrazovanje prevoditelja govori o zahtjevima gluhoslijepih korisnika za prevoditeljima koji su formalno obrazovani i o načinu obrazovanja koji bi bio odgovarajući za dobivanje najveće moguće razine kvalitete prevođenja i suradnje na međunarodnim sastancima.

Utemeljena teorija prevođenja gluhoslijepim osobama na međunarodnim sastancima dana je u desetom poglavlju. Utemeljena teorija bazira se na podacima prikupljenima ovim istraživanjem, a izrađena je povezivanjem koncepata i prepoznavanjem njihovih međusobnih utjecaja. Detaljni opisi i vizualni prikazi olakšavaju praćenje i razumijevanje procesa

izgradnje utemeljene teorije. Glavni koncepti – *Zahtjevi* i *Svjesnost*, kao i njihov nadređeni pojam – *Zadovoljstvo* procesom prevođenja, opisuju se kroz kategorije i njihov utjecaj te preklapanja pojedinih kategorija, što zajedno čini jasniju sliku brojnih sastavnica međunarodnih sastanaka gluhoslijepih osoba i izazova s kojima se tamo suočavaju. Završetak poglavlja nudi objašnjenja kako se utemeljena teorija može iskoristiti za opisivanje svakog pojedinog korisničkog iskustva u situaciji prevođenja na međunarodnim skupovima.

Jedanaesto poglavlje odgovara na pitanja postavljena u šestom poglavlju. Odgovori na istraživačka pitanja su dani revizijom podataka prikupljenih u ovom istraživanju i rezultatima prikazanim u desetom poglavlju.

U dvanaestom poglavlju čitatelj dobiva zaključak izveden iz ovog istraživanja, a u skladu s odgovorima na postavljena pitanja. Uključena je i autoričina interpretacija rezultata istraživanja te općeniti zaključak je li ovo istraživanje ispunilo svoju svrhu. Na temelju informacija dobivenih od ispitanika i utemeljene teorije koja je iz njih proizašla, može se zaključiti da je cilj istraživanja postignut. Korisnička perspektiva omogućila je da iz iskaza gluhoslijepih korisnika prevoditeljskih usluga na međunarodnoj razini dobijemo informacije o brojnim aspektima prevođenja, na temelju čega se može stvoriti opis korisničkog iskustva.

Ovim istraživanjem je potvrđeno da je sve što gluhoslijepi korisnik zahtijeva od suradnje s prevoditeljima usmjereno prema postizanju zadovoljstva procesom prevođenja. Pritom su u prvi plan iskočila dva koncepta - *Zahtjevi* i *Svjesnost* kao vrlo važna za razumijevanje korisničke perspektive prevoditeljskog procesa. *Zadovoljstvo* procesom prevođenja sastoji se od ta dva pojma, jer se svako iskustvo sastoji od ta dva elementa - svjesnosti i zahtjeva. Ravnoteža između njih je ključ pozitivnog procesa prevođenja. Oba ta koncepta su izrazito individualna, te se mogu smatrati dobrim pokazateljima korisničkog iskustva, budući da omogućavaju da se korisnik prepozna na nekoj točki kontinuuma svakog od glavnih koncepata.

Ovo istraživanje baca novo svjetlo na ono što je važno za korisnike prevoditeljskih usluga na međunarodnoj razini. Dobivene informacije se mogu koristiti u procesu kreiranja kurikuluma za edukaciju prevoditelja za gluhoslijepe osobe.

KLJUČNE RIJEČI

Perspektiva gluhoslijepih korisnika, gluhosljepoća, prevođenje gluhoslijepim osobama, prevođenje na međunarodnim sastancima

CONTENT

1. INTRODUCTION	1
1.1. Research Background – How It All Began	1
1.2. Description of Research Interest – Reasons That Have Led to My Interest in Deafblind Meetings	9
1.3. Accomplishment for the Future – What Is This Research Supposed to Accomplish	12
1.4. The Outline of the Research – Guidelines	13
2. TERMINOLOGICAL CLARIFICATIONS.....	16
2.1. Deafblindness – a Heterogeneous Phenomenon	17
2.2. Deafblind Interpreting – Various Methods of Interpreting.....	25
2.2.1. Interpreting of Speech.....	29
2.2.2. Environment Description.....	30
2.2.3. Mobility Support.....	32
2.2.4. Interpreting Methods Specific to Deafblind Persons.....	33
3. ORGANISATIONS OF THE DEAFBLIND – AN OPPORTUNITY FOR EQUAL PARTICIPATION IN POLITICAL AND PUBLIC LIFE.....	40
4. THE IMPORTANCE OF DEAFBLIND INTERPRETING FOR LEADERS AT MEETINGS ON AN INTERNATIONAL LEVEL	50
5. WHAT DO WE KNOW ABOUT INTERACTION AT INTERNATIONAL DEAFBLIND MEETINGS – DIFFERENT ASPECTS OF INTERACTION.....	55
5.1. Aspects of Deafblindness.....	56
5.2. Aspects of Communication Modes	58
5.3. Linguistic Aspects of Interpreting.....	60
5.4. Cultural Aspects	63
5.5. Educational Aspects.....	67
5.6. Organisational-Environmental Aspects	70

6. RESEARCH PROBLEM	74
6.1. Research Problem.....	74
6.2. User's Perspective	75
6.3. Purpose and Objective of Research.....	76
6.4. Research Questions	77
6.5. Initial Expectations.....	78
7. RESEARCH METHODS	80
7.1. Introductory Remarks on the Research	80
7.2. Support in the Research Process	80
7.3. Participants in the Research	85
7.4. Methods and Techniques of Data Gathering.....	87
7.5. The Research Procedure.....	89
7.6. Methods of Data Analysis.....	90
7.7. The Ethical Aspects of the Research.....	93
8. DESCRIPTION OF THE SAMPLE OF PARTICIPANTS	97
8.1. Structure of Participants.....	97
8.2. Communication Method	100
9. DEFINITION OF CATEGORIES.....	105
9.1. Title of Service Provider	105
9.2. Selection of Interpreters	108
9.3. Limited Choice of Interpreters	113
9.4. Physical Appearance of Interpreters	117
9.5. Interpreter Role	120
9.6. Relationship Interpreter–User	125
9.7. Breakdowns.....	129
9.8. Organisation	133

9.9. Independence.....	137
9.10. Preferences	140
9.11. Complexity.....	147
9.12. Education of interpreters for the Deafblind	151
9.13. Privacy	155
10. GROUNDED THEORY ON DEAFBLIND INTERPRETING AT INTERNATIONAL MEETINGS	157
10.1. Introduction to the Grounded Theory on Deafblind Interpreting at International Meetings.....	157
10.2. Demands.....	160
10.3. Awareness	164
10.4. Dynamics – Demands, Awareness and Satisfaction	167
11. RESEARCH QUESTIONS ANSWERED.....	169
12. CONCLUSION	180
13. LITERATURE.....	182
APPENDIX A – STATEMENT OF COMPLIANCE WITH ETHICAL STANDARDS IN SCIENTIFIC RESEARCH	196
APPENDIX B – INFORMATION SHEET FOR PARTICIPANTS.....	199
APPENDIX C – PARTICIPANT CONSENT FORM	202
APPENDIX D – QUESTIONNAIRE	203
APPENDIX E – CATEGORIES	210
APPENDIX F – RELATIONAL CODING	217
BIOGRAPHY.....	218

1. INTRODUCTION

1.1. Research Background – How It All Began

International meetings of the Deafblind are a kind of platform where deafblind persons acquire the necessary information and share their knowledge, skills and abilities to advocate their needs and rights, and also where, over time, they became skilled negotiators and thus active stakeholders in all other meetings (working groups for legislation, forums, etc.) where decisions are made that affect their own lives. In this way, they continuously monitor the latest findings related to the various international documents that can help improve the quality of life of deafblind persons both in their own countries and at large. This is the main reason why international meetings of the Deafblind play such an important role in empowering deafblind persons in the exercise of their fundamental human rights and equal opportunities in their participation in political and public life.

The very dynamics of the meetings and the intensity and complexity of interactions confronts all Deafblind participants and their Deafblind interpreters with the responsibility to conduct the interaction, that is, the process of interpreting to deafblind persons in meetings, efficiently and effectively. Such meetings do not leave sighted and hearing persons, professionals and lay persons, who were in a position to follow or participate in such meetings together with the Deafblind, indifferent. According to Andreoli (1999), both deafblind persons and their interpreters manage to fully participate in discussions not only on the linguistic level but also at the environmental one.

The fact remains that the combined sight and hearing impairment with expressed difficulties in communication, access to information, mobility, and social interaction, places the Deafblind into the socially most susceptible and most marginalised group of persons with disabilities. Richard Howitt, a MEP from the UK said: “Deafblind persons are the most excluded population of persons with disabilities. They are excluded from the excluded.”

In spite of the imposed social exclusion and isolation, deafblind persons have devoted and still do dedicate great efforts to take the decision-making process affecting their lives and their future in their own hands. Some deafblind persons wanted to maintain the mission that was set in

motion in the nineteen-twenties in the USA by the deafblind author and Ph.D. Helen Keller (Lash 1984: I, 199, 239). Every day, more and more deafblind persons have their own visions and want to follow their own dreams. What they have in common is striving to turn the slogan “Nothing about us without us^{*}” into reality for deafblind persons as well.

My personal experience^{**} as well as the experiences of other deafblind persons, concerning our first participations at various meetings, whether ones attended mostly by persons without disabilities, or those attended mostly by other groups of persons with disabilities, were not always positive. Deafblind persons at such meetings were often “invisible” to other participants, not because of their passivity, but either because qualified Deafblind interpreters were unavailable to the Deafblind there, or because other participants at the meeting did not have sufficient knowledge on the specific needs and impediments of the deafblind persons, especially on those regarding communication. It was mostly because of this lack of knowledge that the deafblind participants at those meetings were ignored and that their “voice” was rarely heard. Even if the deafblind person managed to impose him/herself to the other participants on a more equal level, the quickness and dynamics of the meeting were often the cause that he/she was exhausted by the end of it. (Grandia 2013; Andreoli 1999) However, the rights of persons with deafblindness were rarely implemented in those days, partly due to the above described situation and partly due to the paucity of deafblind participants. This prompted some prominent deafblind individuals and a small group of like-minded deafblind persons, to whom Deafblind interpreters were available and who possessed good preconditions to affect the development of social services and professional interpreter services for

* Latin “Nihil de nobis, sine nobis” is a slogan used to communicate the idea that no policy should be decided by any representative without the full and direct participation of members the group(s) affected by that policy. This involves national, ethnic, disability-based, or other groups that are often thought to be marginalised from political, social, and economic opportunities.

The saying has its origins in Central European political traditions. It was the political motto that helped establish – and, loosely translated into Latin, provided the name for – Poland’s 1505 constitutional legislation, *Nihil novi*, which first transferred governing authority from the monarch to the parliament. It subsequently became a byword for democratic norms.

Info from Wikipedia, http://en.wikipedia.org/wiki/Nothing_About_Us_Without_Us, accessed on 7 March, 2014

** At first I was uncertain whether personal experiences constitute a valid argument in a scholarly work. However, the personal experiences quoted in Gullacksen et al. (2011) convinced me that such experiences are not uncommon, at least in the area of researches on deafblindness.

deafblind persons, to comprehend that in order to accomplish the exercise of their fundamental rights it was necessary for the Deafblind to have their own organisations, not only at a national level but also at regional and global ones. Those Deafblind enthusiasts (often leaders of their national organisations of the Deafblind) first ventured into the undertaking of founding a world organisation of deafblind persons, and soon afterwards encouraged the establishment of regional organisations. All of them were guided by a strong desire to provide better opportunities and develop Deafblind interpreting services and other support services in countries where they were unavailable to deafblind persons.

Even a perfunctory examination of historical facts on successful deafblind individuals discloses the apparent fact linking all of them: they all had significant support in communication. For instance, Helen Keller could have not participated in her many activities without Ann Sullivan. Initially, Ann Sullivan was her teacher, but she had a significant role throughout Helen's life as a supporter (Crow 2000, Herrmann 1998, and Kleege 2000, as quoted in Schneider 2006). Ann facilitated Helen's communication with others and acted as her mediator, her bond with the world. (The role and the manner in which Ann, as an intermediary in communication, allowed Helen Keller to establish a chain of communication with the world, but also to do the same for the world, vice-versa, is described in detail in Lash 1981). Her work represented a significant step forward in contemporary understanding of providing communication support to the Deafblind. Since then until the present day, the development of communication support, i.e. the development of attitudes toward Deafblind interpreting proceeded in a very similar or even identical manner as those toward Sign Language interpreters, where we can differentiate three main approaches to interpreting: the helper model, the conduct/telephone model, and the bilingual-bicultural mediator model (Tarczay 2009; Wilcox & Shaffer 2005).

In the early days of providing communication support "helper interpreters" were those who knew the deafblind person well, like family members, friends, members of religious communities, etc. Such an interpreter was, among others, Ann Sullivan, Helen Keller's teacher, interpreter and life companion. According to Tarczay (2009) "helper interpreters" were almost always the ones who decided what was best for the deafblind person, thus creating a false image of the Deafblind as passive and powerless. Helping was the "norm" in those days and, according to Tarczay (2009) and Frishberg (1986), "helper interpreters" did not attend any formal education on interpreting, nor did they receive any official interpreter fee (however, the deafblind persons could provide a financial or

otherwise compensation to them privately). As for many years many deafblind persons were exposed to the dominance of “helper interpreters,” they have often developed the wrong aptitude that they should be grateful for any help they got without regard to its quality. Since those days to the present one, the notion that deafblind persons need to become aware and be educated on how to use Deafblind support is present in examples of curricula for support providers like Nuccio & Smith (2010), where education is envisaged not only for the Support Service Providers (SSPs), but for Deafblind users as well. Such user education should make it clear why home and family helpers without formal interpreter education are not a good solution for communication support, as well as that good intentions can result in wrongdoings.

It took a really long time since the days of the original non-trained “helper interpreters” for today’s educated Deafblind interpreters to be recognised.

By recognising and defining the role of a Deafblind interpreter (Eriksson 2009) and with the development of the first guidelines as well as educational programmes for the education of Deafblind interpreters such as WASLI (*no date*), Hecker-Cain, Morgan Morrow & Frantz (2008), Nuccio & Smith (2010), or Dodir (2012), we can conclude that a relative consensus had been reached in understanding the role and responsibilities of a Deafblind interpreter. It became apparent that in order to conduct its own independent life and for a successful and effective communication in all formal situations, including meetings, a deafblind person requires a professional Deafblind interpreter and not some enthusiastic amateurs.

The Nordic countries have a long tradition of facilitating a better and dignified life for persons with disabilities, including those with deafblindness. Their organisations of the Deafblind are doyens among cognate European and World organisations: the Norwegian association (Foreningen Norges døvblinde – FNDB) was established in the distant 1957 (FNDB *no date*), the Swedish one (Förbundet Sveriges Dövblinda – FSDB) in 1959 (FSDB *no date*), the Finnish one (Suomen Kuurosokeat ry) in 1971 (Suomen Kuurosokeat ry *no date*), and the Danish one (Foreningen Danske DøvBlinde – FDDB) in 1987 (FDDB *no date*).

Due to the long tradition of available professional support provided to them, deafblind

persons in those countries have access to good quality social services and Deafblind interpreting services that enable them to live independently and thus fully participate not only in social life, but also in the political and public ones.

Therefore, it does not come as a surprise that the initiator and founder of the World Federation of the Deafblind (WFDB *no date*) was Stig Ohlson, a deafblind visionary from Sweden.

Among Stig Ohlson's merits is also the fact that the Deafblind in Sweden have attained such a level of rights to allow them to lead independent lives as it is possible for them today, and it is absolutely necessary to emphasise the fact that he was "responsible for the development of interpreting services for the Deafblind, as well as for the development of special technical equipment and its applications." (Tarczay 2004: 92). The idea that has been guiding Ohlson is also the fundamental vision and mission of the World Federation of the Deafblind: "The aim of WFDB is to improve the quality of life of deafblind persons world wide" (WFDB 2001), and one of the most important activities of WFDB is to locate the Deafblind, and to break through their isolation.

Stig Ohlson's enthusiasm and active involvement was not limited exclusively to Sweden and the WFDB, but it has enabled the expansion and strengthening of the movement of deafblind persons on regional levels as well.

Today there are three regional organisations existing along with the World Federation of the Deafblind: the European Deafblind Union (EDbU), the Latin American Federation of the Deafblind (Federación Latinoamericana de Sordociegos – FLASC) and the African Federation of the Deafblind (AFDB). All these organisations create a network of more than sixty national organisations of deafblind persons all around the world. The number of regional, national and local organisations is still growing worldwide.

In addition to international organisations *of* deafblind persons, there are also international organisations *for* deafblind persons. They bring together experts and professionals who work with the Deafblind. Although some deafblind persons can be found among them as well, the majority of members of such organisations are sighted and hearing persons. I will mention here two most

influential such organisations. Deafblind International (DbI) is the largest and oldest among them. Its roots go back to the 1950s, when a coordination was founded by teachers and educators working with Deafblind children. In 1976 this coordination evolved into International Association for the Education of the Deafblind (IAEDB), in the next decade it acquired a constitution, and in 1999 it was revitalised under the present name. Today, DbI represents programmes and services for thousands of people who are deafblind around the globe. (DbI *no date*). Another such organisation Sense International, a global charity supporting deafblind persons in Bangladesh, India, Kenya, Tanzania, Peru, Romania and Uganda, one of the world's leading international organisations working for deafblind persons and their families. However, Sense International is a fairly small charity with a big impact. (Sense International 2013)

In this paper, we will focus on the organisations *of the Deafblind* only, because they represent an authentic and powerful voice of deafblind persons and promote awareness of deafblindness as a unique disability on national, regional and global levels by disseminating information on how deafblindness affects every single person. Significant activities are directed to the recognition of deafblindness as a unique disability, because in many countries deafblindness still is not identified and recognised as a unique disability (Grandia 2013).

The failure to recognise deafblindness as a unique disability with individual needs in accessing information, communication, mobility and social interaction prevents the Deafblind to access the services they require to meet their needs. The Deafblind are often listed either as deaf persons with an additional visual impairment, or as a blind persons with an additional hearing impairment. However, neither the support for the Deaf nor the support for the Blind fully satisfies the needs of deafblind persons. Moreover, as deafblindness itself is not the sum of deafness and blindness, so support for deafblind persons cannot consist of the mere sum of support for the Deaf and support for the Blind. In addition, the organisations of the Deafblind undertake other activities aimed at the empowerment of deafblind persons and at the establishment of services for deafblind persons necessary to enable them to attain equal rights and opportunities in all aspects of social life.

Although the goal of the activities of Deafblind organisations is bringing deafblind persons out of isolation and improving the visibility of deafblindness, we must not ignore the crucial role as well as the entire reason for the existence of Deafblind organisations: lobbying with governments to

recognise deafblindness and for services like assistants, interpreters, technical aids in order to enable persons with deafblindness to participate in public and political life on equal terms with persons who do not have a disability.

One of the most important activities that deafblind persons had to take into their own hands was participation at meetings of executive committees of their own organisations, where important decisions were made and guidelines for policies concerning the Deafblind developed.

The challenge is even greater at meetings of international organisations, which are becoming increasingly complex, more numerous and with an increasing number of topics (a glance at the UN official Internet site, un.org, suffices to discern a large number of themes as diverse as peace and security, development, human rights, humanitarian affairs, and international law), meetings which deafblind persons still do not attend in appropriate numbers. At such meetings, deafblind persons face numerous difficulties, starting from the unavailability of a sufficient number of qualified Deafblind interpreters, especially those with a good knowledge of the English language (most of such meetings are in English) and a good knowledge of the specific topics discussed at the meeting, the lack of preparation time for the meeting for both the deafblind person and the Deafblind interpreter, the speed and dynamics of the meetings, and, last but not least, the process of Deafblind interpreting that is far more complex than traditional spoken language interpreting. Hearing and sighted participants at a meeting just put on their headphones and choose a language they want the meeting to be interpreted at. They watch the speaker and other participants and follow their reactions. However, it's the Deafblind interpreter who puts on headphones and chooses the language he listens to, not the deafblind person, thus adding one more step to the interpreting process. It's up to the Deafblind interpreter to interpret not only what has been said, but also who said and with what expression and/or gesture were the words accompanied. If a hearing and sighted participant wants to reply, all he/she has to do is raise the hand or press a button. The Deafblind participant, always a bit late in receiving the information, must often alert the others of his/her intentions to speak via interpreter. Meetings where many participants speak at the same time are a nightmare both for the deafblind person and for the Deafblind interpreter.

Even attending less important meetings at local level may pose a special challenge for a deafblind participant, as stressed by Aimee Chappelow Bader: "Being in a group setting is more

confusing and requires multi-tasking for the interpreter and even for us as Deaf-Blind because we're trying to mingle. It's harder than one-to-one interaction." (Jacobs 2009)

Most sighted and hearing persons attended a meeting of some sort, either a meeting of a governing body or a business meeting. Many textbooks (Parker 2009; Timm 1997) and handbooks (Weynton 2002) have been written on meetings, on communication at meetings, on the conduct of meetings and their effectiveness. However, all the collected knowledge becomes questionable when the circumstances and participants of meetings are so different and so diverse among themselves that the application of usual rules is not possible. If we try to imagine a meeting of several deafblind persons, it becomes obvious that the dynamics of such a meeting must be completely different, that such a meeting is entirely unlike a customary meeting attended by sighted and hearing persons.

We can ask ourselves what do we know about meetings involving the Deafblind. What do we know about Deafblind interpreting at international meetings? Virtually nothing, and the majority of sighted and hearing persons is not even aware that such meetings exist. Very few outsiders had the opportunity to attend a meeting of exclusively deafblind participants.

Almost no significance is given to the meetings of the Deafblind, although that is one of the vital activities of deafblind persons, where they make great efforts and work hard to make their own decisions. This situation is consistent with the fact that there is a lack of literature and research on this issue.

I want to shed more light on meetings attended by deafblind persons because they are really special ones that require our attention, and this is the reason it was them that were selected as the object of interest of this research.

I believe that the collected knowledge and experiences of deafblind persons are able to contribute to a better insight and understanding of the uniqueness of communicative interaction among them, and offer possible solutions to the problems that they meet in such an environment. We will deal with people with acquired deafblindness who represent their own organisations there. For more information about deafblindness and deafblind persons see chapter 2 *Terminological*

1.2. Description of Research Interest – Reasons That Have Led to My Interest in Deafblind Meetings

My personal, professional and research interests, as a deafblind person, are focused on the area of deafblindness, especially on the development of support services for the Deafblind.

My first “touch” of deafblindness began by accepting my own deafblindness in Leksand, Sweden, in 1992. Confronting deafblindness left a strong mark but also the desire to find ways to alleviate its effects. Then I made my first steps in the search for better solutions and ways for the Deafblind to lead a happier life. To possess one’s own experience and expertise is often not enough to fight for certain rights of the Deafblind. I strongly believe that science-based facts can easily and significantly affect the improvement of a certain situation.

My innate curiosity and constant hunger for new knowledge as well as myself being in constant search for better solutions have led me to this lifelong journey of mine into the world of deafblindness. After completing my education in Sweden and returning back to Croatia, I was faced with enormous obstacles concerning access to information and communication. But even greater obstacles were found in the complete ignorance of deafblindness as a unique disability. There were no support services for the Deafblind. There was nothing that could help me make deafblindness visible and understood. I needed help from abroad, and I first found it with Ann Thestrup, an educator when I met her as Lex Grandia’s spouse, today a Development Project Nepal coordinator at FDDDB (Danish Deafblind Association). Later, by her recommendation, I meet Richard Hawkes, then Chief Executive of Sense International, and today Chief Executive in Scope, a UK disability charity working with disabled people and their families in England and Wales.

Richard Hawkes taught me that meetings are very important and that I should attend them prepared. His immense patience in communicating with me, despite my “helper interpreter” only encouraged me more to always improve my own participation at meetings. I remember the words of William Green, a long-time President and now an honorary member of DbI, who, annoyed by my

uneducated “helper interpreter,” said: “I will talk to you only when you secure yourself a better interpreter!” All of this only encouraged and strengthened my desire to invest more effort and knowledge on the issues related to Deafblind interpreting and now to the topic of my dissertation research.

Before I became a deafblind person I was an active member of the Deaf community (I was born deaf and grew up in a Deaf family). When only 18, I was elected a member of the Executive Committee of the Zagreb Association of the Deaf and Hard of Hearing, so it was natural that I continued with my activities, only not in the field of deafness anymore, but that of deafblindness.

However, participation at Deaf meetings was far easier than at Deafblind ones due to the high heterogeneity of communication needs of deafblind persons and to them using many different communication methods. The situation at meetings was not improved by “helper interpreters.” Faced with such complex issues of participation at “regular meetings” of deafblind persons, I realised that it will be difficult for the Deafblind to fight for their rights if they are not provided with communication support. The most important thing for me then was to find a way to educate future interpreters and to provide good support services in order for the Deafblind to be able to be fully engaged at meetings.

It is therefore important that Deafblind interpreters, in addition to being competent in the usage of a wide range of communication methods, must also possess qualities, knowledge and skills that allow deafblind persons to be informed on what is happening at the meeting. Only in this way can deafblind persons make decisions that will heighten the quality of their lives based on real facts.

Deafblind participants should be provided with all the requirements needed for a meeting to take place smoothly and efficiently. They themselves know best what they need and what decisions should be made in the interest of the group whose rights they advocate. If equal opportunities are not secured for deafblind leaders, it will be hard for them to fight for the rights of the Deafblind, and they will not be able to empower other deafblind persons to actively engage in the fight for their rights.

By participating and making important decisions together with deafblind persons on national level, I became increasingly aware of the importance of active participation. In order to be able to keep track of everything that has been done and what has been state-of-the-art in the field of deafblindness, taking part in various international conferences, seminars and meetings was needed, where deafblind persons exchanged their experiences. Attending the founding assembly first of the World Federation of the Deafblind, and later of the European Deafblind Union followed up spontaneously. Being present at the “birth” of two organisations of the Deafblind only further increased the sense of the responsibility that I have taken. In the World Federation of the Deafblind, as a regional representative for Europe I was a member of the Executive Council for three consecutive terms (2001–2013). In addition to this, I have been and I still am the head of the Deafblind interpreting working group. I also had an active role in the European Deafblind Union, which resulted in me being elected President of the Executive Committee in 2013 in Bulgaria.

It was precisely my attendance and participation in those board meetings that prompted my thinking in the direction of taking active steps to alleviate at least a little bit the truly complex processes of communication and decision-making. Persons with disabilities are encouraged by social policies to participate in the decision-making process and to have the right to full participation in the political and public life. However, deafblind persons who wish to engage in decision-making processes are still coping with difficulties in meetings, but also in all the non-meeting activities connected with attending a meeting, each in his/her own way, almost without any guidelines from institutions, organisations and scientific research that could facilitate their equal participation at meetings.

The reasons for my research interest in Deafblind meetings mean much more than pure scientific research. They allow deafblindness to be viewed in a different light, in the light of its own perspective, but they also encourage the interest of other professionals and scientists that are interested in a hitherto neglected field, and most importantly they will make the problems of the Deafblind more visible.

This research is a step that is required for changes to be initiated in the first place, and for examples of good practice to be introduced in practice.

1.3. Accomplishment for the Future – What Is This Research Supposed to Accomplish

The expected accomplishment of this research is obtaining a clear insight into what Deafblind users consider important and what they expect when being provided with Deafblind interpreting during meetings on an international level. This description will provide us with better insight on differences both of the needs of the Deafblind and of adequate services for the Deafblind in various situations, especially focused on international meetings.

Having in mind that the body of literature on this matter, especially the one written from a user's perspective, is limited, the objective is to gather as many ideas and opinions from the participants in order to point out as many aspects as possible and raise questions that haven't been asked before. The user's perspective on everyday living, on difficulties, and on adaptations made by Deafblind users has been described in some works (Gullacksen 2011; Schneider 2006), but there is yet no literature available on the subject of Deafblind interpreting at meetings on an international level. The difference between those two situations – everyday living and international meetings – highlights the need for a separate research on each of those topics, in order to gain knowledge about Deafblind interpreting in general. Only by putting the pieces of a large puzzle together, we can see the whole picture that is Deafblind interpreting.

This research was designed as an examination of the actual needs of deafblind persons and their expectations related to Deafblind interpreting during international meetings. The knowledge gathered from the users themselves will represent framework guidelines needed to indispensably enhance the interactions among Deafblind participants as well as their interpreters during international meetings and it will be used for improving the quality of participation and decision-making of the Deafblind related to the implementation of their fundamental human rights.

The resulting knowledge and insights will complement the need for new guidelines in the creation of educational programmes and curricula in the field of Deafblind interpreting, by means of which the number of qualified Deafblind interpreters would increase, and the provided services would be consistent with the expectations of users and would enable effective and efficient

interpreting in various situations both in private life of the Deafblind and in the occupational, political and public one.

The intention of this research is to encourage the public interest, but also the narrowly scientific one, that would contribute to a change in the ways of relating to deafblind persons as a marginalised group. It will also enable the responsible institutions to assume greater sensitivity and be better informed in order to understand, recognise and support the special needs of deafblind persons and to enable them to participate in all aspects of life, especially in the political and public ones.

1.4. The Outline of the Research – Guidelines

In this thesis I endeavoured to structure clearly all relevant information and facts that can fully describe the issues that I was dealing with, taking into account the fact that the area of deafblindness is not a widely known topic. My desire is that this thesis be understandable and accessible to those who have not yet met deafblindness.

In the first chapter, *Introduction*, I introduce the readers step by step into how and why I chose to do this research. The background of this research is described in its first part, as well as how it all began, what reasons encouraged me and led me to a research interest in international meetings involving deafblind persons, and what is the intention of this dissertation.

In the second chapter, *Terminological clarification*, I give a complete review of understanding “deafblindness” as well as “Deafblind interpreting,” because without a comprehensive insight into these two key terms that are part of this thesis it would not be possible to acquire a full picture of the real difficulties and problems the Deafblind face when participating at international meetings.

The third chapter is dedicated to the organisations of the Deafblind, with a short historical overview of the establishment of regional and global organisations of the Deafblind without which it would be very difficult to implement the rights of deafblind persons.

In the fourth chapter, not less important, the importance of participation of persons with disabilities, in this case deafblind persons, in the political and public life is described, as well as the inability to participate at meetings without securing them equal access in the form of a Deafblind interpreter.

The fifth chapter is the key portion of this thesis – challenge meetings. Here, in fact, we enter the unique world of meetings attended by the Deafblind. A description of various interactions met by deafblind persons at these meetings is given, as well as of the importance of Deafblind interpreting at those meetings.

The sixth chapter describes the starting points before the research itself, the purpose and objective of the research, the research problem, as well as the initial research questions that guided it. In this chapter, the users' perspective is explained as the approach chosen to best describe the multiple aspects of the Deafblind interpreting process. Also, this chapter answers to why an intricate process of qualitative research was chosen as the best way to unveil Deafblind interpreting from the standpoint of Deafblind users.

In the seventh chapter we are introduced to the research methodology that comprises a range of research participants, methods and techniques of data collection, implementation of research procedures, as well as a description of research methods. A separate section is dedicated to the ethical aspects of the research.

The eighth chapter is dedicated to the description of the sample of participants involved in this research. This is the chapter where a bit of descriptive statistics will be presented, in order to achieve a clearer picture about who are the participants in this research. Personal general information about participants is represented in the first part of the chapter (*8.1. Structure of Participants*), while information on their communication methods is represented in its second part (*8.2 Communication method*). This type of data is separated from the data concerning feelings and attitudes, with the aim of separating these two kinds of information obtained from participants. Although both kinds were obtained through the same questionnaire, information regarding factual

data is represented in Chapter 8, while the data used to construct the grounded theory is separated and represented in the next chapter.

Chapter 9 is the most important one because it comprises the categories identified through data analysis. The chapter is divided into thirteen sections, each describing a separate category, together with excerpts from the participants' questionnaires and with graphical representations of categories. Through this chapter, a reader is acquainted with what the participants deemed important in the interpreting process at international meetings and what is it that they all have in common.

Chapter 10 gives the reader the complete grounded theory based on the data collected in this research. Its four sections guide the reader through the main concepts and their relations. The detailed descriptions and visual representations are provided to facilitate following and understanding the process of building the Grounded theory. The end of chapter 10 offers specific explanations how this grounded theory can be used to describe every user's experience in the situation of interpreting at international meetings.

Chapter 11 offers answers to research questions posed in chapter 6. Through revision of data gathered in this research and results presented in Chapter 10, research questions are answered.

Chapter 12 provides the reader with a conclusion to this research. In accordance to the answers to research questions, an overall conclusion is given. It includes the author's interpretation of the research results and a general conclusion to whether this research has fulfilled its purpose.

2. TERMINOLOGICAL CLARIFICATIONS

Since the world of the Deafblind is still a relatively new area of human knowledge and not nearly adequately described in the current research trends, it requires even more effort to clarify the terminology and introduce the relevant concepts. In this specific area terminological clarity is especially important because of the very different views and insights into the meanings hidden behind certain terms in this specialised terminology. This is the reason why it is important to make an extra effort in terminological clarification, it's because of the uneven and even different views and interpretations related to the meaning of certain terms in this specialised terminology such as person with deafblindness, deafblindness, Deafblind interpreting etc. "Terminological clarity is significant because not everyone understands the meanings conveyed by the terminology." (Evans & Whittaker 2010: chapter 1 What Are Sensory Needs?)

Only in this way can a reader become familiar with the material that will be explored and described. Currently, there are "many paths on the road toward becoming an interpreter skilled in working with people who are deaf-blind" (RID 2002).

A similar situation related to the disparity of terms and/or attitudes is recurring in many other areas of humanities, which is not a phenomenon to be despised, but appreciated and developed in many different directions. The outcome of such diversity is a better adjustment to real-life situations and a wider range of support services to users.

Since terms and definitions, as well as approaches to Deafblind interpreting, vary from state to state, from nation to nation, without a unique set of standards and a unique accepted view, the implementation of the fundamental rights of the Deafblind in many countries, as well as their access to Deafblind interpreting services, are hindered.

According to Tarczay (2004), a brief review of earlier terms in the professional and scientific literature, but also in the present ones, suffices to find a distinct variety of names like deaf-dumb and blind, and deaf and blind, that are not widely used. There are appellations that also applied medical specifications of each individual disability, such as practical deafness – severe visual

impairment, moderate hearing loss – practical blindness etc. all the way to some general terms applied within one country in this context, for instance United Kingdom: dual sensory loss (DSL), multi-sensory impairment (MSI), deafblindness (DB) (Evans & Whittaker 2010: chapter 1 What Are Sensory Needs?). Problems have occurred in written form as well, like Deaf-Blind, Deaf-blind, Deaf/blind.

To avoid all such inconsistencies in the use of terms denoting a person with dual impairment, Deafblind International (DbI), a world association promoting support services for deafblind persons, has already in 1991 decided to introduce the terms deafblindness and deafblind for persons with dual sight and hearing impairment.

Since in this study the emphasis is put on the principal terms “deafblindness” as well as “Deafblind interpreting,” their clarifications shall be based on generally accepted terms adopted by global, regional and most national organisations of deafblind persons. In addition to these organisations, the abovementioned terms are also used by the world and European organisations of Sign Language interpreters, as well as most of the national organisations of Sign Language interpreters.

In this chapter a brief comprehensive review and description of the most commonly used terms and definitions, as well as those used in this research, will be offered.

2.1. Deafblindness – a Heterogeneous Phenomenon

Deafblindness as a disability can be perceived from a variety of points of view. As a condition of an individual, deafblindness can be monitored either through functions which restrict the individual or through the level of support required to enable him/her to function as if there were no difficulties at all. Here we can already anticipate two opposed models, recognised by experts, but also by users – the medical and social ones. The former, called “medical model” or approach, is one that describes the impairment and focuses on the functional limitations of the individual (Oliver 2004). Such a definition of deafblindness is based on outcomes in functioning due to deafblindness,

and is often focused on the degree and type of disability that prevents a person to be functional in all aspects of his/her life.

In the United States, several definitions of deafblindness are available.

The federal definition of deafblindness, used in the school system for children with special needs, follows: “Deaf-blindness means concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programmes solely for children with deafness or children with blindness.” (National Consortium on Deaf-Blindness *no date*)

On the other hand, for infants and toddlers receiving Part C early intervention services, deafblindness is defined as: “Concomitant hearing and vision impairments or delays, the combination of which causes such severe communication and other developmental and intervention needs that specialised early intervention services are needed.” (Minnesota DeafBlind Project *no date*)

Finally, Texas Deafblind Project uses the Minnesota Rules/Department of Education in order to establish criteria for services from this project: “ ‘Deaf-blind’ means medically verified visual loss coupled with medically verified hearing loss, that, together, interfere with acquiring information or interacting in the environment. Both conditions need to be present simultaneously, and the pupil must meet the criteria for both visually impaired and deaf and hard of hearing to be eligible for special education and services under this category.” (Department of Education 2007)

Persons are considered deafblind if they have a high degree of combined sight and hearing impairments, resulting in problems in communication, access to information and mobility. (Deafblind Services Liaison Group – Working Party 1988: 6)

Significant dual sensory impairment will be recognised for a person in case when the combination of these two impairments prevents him/her to fully function both as a deaf or hard of hearing, and a blind or partially sighted person. (Hart 2003; Tarczay 2007).

The term “deafblindness” is used to describe a heterogeneous group of persons who may have varying degrees of visual and hearing impairment, sometimes in combination with learning disabilities and physical impairment, which can cause serious problems in communication, development and education. A precise description of the disability is difficult to devise because the degree of hearing or sight impairment in combination with varying degrees of other impairments is not always the same, and the educational needs of each person must be decided upon on an individual basis. (Hart 2003; Tarczay 2007)

In all the above mentioned definitions, we can clearly see an emphasis on the impairment, without stressing the opportunities and capabilities of the deafblind person. Such definitions would have been acceptable some decades ago, but in today’s society, where the *UN Convention on Rights of Persons with Disabilities* promotes equal rights and adjustments for persons with disabilities (UN 2006: article 4), new definitions need to be devised.

The progress in defining what deafblindness is can be seen in the following definitions. They represent a step towards the social model, in which, unlike the medical one, emphasise is put on social inclusion and fulfilling a person’s potential (Oliver 2004).

Deafblindness is a unique impairment which can be independent or in combination with other physical or mental disabilities. If a person is deafblind, regardless of his/her other impairments, he/she needs special programmes tailored to a unique style of learning and individualised support that would strengthen his/her independence and interaction with the environment. Programmes that meet the needs either of the visually impaired, or of the hearing impaired, or the physically impaired, do not meet the needs of deafblind persons. (McInnes & Treffry *no date*, according to Hart 2003; Tarczay 2007)

In this definition, there can still be found a medical “residue” of the definition, which is necessary to some degree in order for the definition to be precise and to limit the category only to persons who truly belong there. However, more and more attention is given to explanation of the persons’ needs and to the support services required for him/her to function in society. In recent years the majority of countries and organisations adopted a socio-functional definition of deafblindness, such as the following: “Guidance issued under the Local Authority Social Services Act 1970 under Section 7 defines persons as being deafblind if they have a severe degree of combined visual and auditory impairment resulting in problems with communication, information and mobility. The Act defines the four main groups of deafblind persons as: people born deafblind; people born deaf/Deaf and who later lose vision; people born blind; and who lose hearing and people with acquired deafblindness.” (Evans & Whittaker 2010)

Here we have the Nordic definition from 1980, revised in 2007:

“Deafblindness is a distinct disability.

Deafblindness is a combined vision and hearing disability. It limits activities of a person and restricts full participation in society to such a degree, that society is required to facilitate specific services, environmental alterations and/or technology.

These comments are a clarification to the definition of deafblindness:

1. Vision and hearing are central in getting information. Therefore a decrease in the function of these two senses that carry information from distance, increases the need to use senses that are confined to information within reach (tactile, kinaesthetic, haptic, smell and taste), as well as leaning on memory and deduction.
2. The need for specific alterations regarding environment and services depends on
 - the time of onset in relation to communicative development and language acquisition;
 - the degree of the hearing and vision disability, whether it is combined with other disabilities and whether it is stable or progressive.
3. A person with deafblindness may be more disabled in one activity and less disabled in another activity. Therefore each activity and participation in it needs to be assessed separately. Variation in functioning within each activity and participation in it may also be caused by environmental conditions and by internal personal factors.

4. Deafblindness causes varying needs for co-creating* alterations in all activities and especially in:

- all kinds of information;
- social interaction and communication;
- orientation and moving around freely;
- activities of daily life and effort demanding near-activities including reading and writing.

5. An interdisciplinary approach including specific know-how related to deafblindness is needed in service delivery and environmental alterations.” (Gullacksen et al. 2011: 13–14)

From the definitions quoted above it is quite evident that deafblind persons present an extremely heterogeneous group. (Göransson 2008).

Hitherto generally accepted categories of deafblindness will help us understand the differences between groups within deafblindness. The following categories of deafblindness are in accordance with the principles of the social and functional model, i.e. status of functioning of persons with disabilities because they facilitate the identification of potential needs and the type of support that is necessary for a person with deafblindness.

One of the most common older representation of those categories is the Coppersmith Matrix that enables understanding of diversity within deafblindness in such a way that it classifies it, in a simple way, into four basic groups of deafblindness based according to the current status of hearing and sight. To make the categorisation clearer, it is presented as a diagram, and is considered a good way of displaying four main categories of deafblind persons. The diagram is shown in Table 1.

* Co-creating means that the person with deafblindness and the environment are equally involved. The responsibility for this to occur lies on society.

[Original footnote from quoted text.]

Table 1. – Coppersmith Matrix. Diagram taken from Smith (1994)

	Hearing	Hard of Hearing	Deaf
Sighted	"Normal" Hearing "Normal" Vision	Hard of Hearing, "Normal" Vision	Deaf "Normal" Vision
Partially Sighted	"Normal" Hearing Partially Sighted	Hard of Hearing Partially Sighted	Deaf Partially Sighted
Blind	"Normal" Hearing Blind	Hard of Hearing Blind	Deaf Blind

In this diagram we can perceive two axes that represent the state of hearing ("normal" hearing, hard of hearing and deafness) and sight ("normal" sight, partially sighted and blindness), respectively. When a combination of hearing and vision condition is made, a category emerges. In the intersection of a particular state of hearing and a particular state of sight the category occurs in which an individual belongs. If a person is classified in a white field according to the status of her/his sight and hearing, it means that there is only one disability present. A single disability either of sight or of hearing does not classify a person as a deafblind one.

If a person is classified in a red field according to the status of her/his sight and hearing, it means that he/she has a simultaneous hearing and sight disability. It is this dual sight and hearing impairment that classifies the person into one of the categories of deafblindness. The diagram represents the four possible combinations of these two sensory impairments that classify the person as deafblind under the definitions adopted in this chapter. It can therefore be concluded that all deafblind persons can be classified into one of these categories, depending on the degree of impairment of their sight and hearing.

Another way of categorising the Deafblind is by the chronology of their vision and hearing impairment. Such categorisation is not in accordance with this research, since the latter is focused on the present functioning of the individual and the necessary level of support, without asking questions on when the disability occurred, which could derail the idea of this research in the

direction of the medical model, as well as on the individual's linguistic and cultural identity and is connected to the situation before the person became a deafblind one. "Deafblindness is significantly impacted by the time of life in which a person became deafblind. If a person was able to see and hear earlier in their life and later acquired deafblindness, it could mean that they had access to acquire speech and language skills, build a career and relationships." (Evans & Whittaker 2010) We can present the same this way:

- born deaf / hard of hearing and blind / visually impaired
- born hearing and blind / visually impaired ► became deafblind later in life
- born sighted and deaf / hard of hearing ► became deafblind later in life
- born hearing and sighted ► became deafblind later in life

In this classification the affiliation of a deafblind person to one of the above categories in the Coppersmith Matrix can be seen as well. However, what is significant in it is the linguistic and cultural status of the person before he/she became deafblind, because this greatly affects the choice of communication and consequently the use of certain types of support and of interpreting method. For instance, a person born deaf and sighted that became deafblind later in life typically will keep Sign Language as a means of communication but will use a different modality of it, e.g. Tactile Sign Language or Visual Frame Sign Language. The situation is similar within other categories where most individuals after becoming Deafblind find the best ways to communicate and thereby retain the original language and cultural identity.

To avoid possible conflicts in language expression in this research two forms of the term deafblind will be used. One begins with a lowercase letter "d" meaning the disability that characterises a person, e.g. person with deafblindness. On the other hand Deafblind with a capital "D" represents the identity of an individual as a person with deafblindness. Within the Deafblind world, there is a small group of individuals who were primarily Deaf and have their sight deteriorated later in life. When they accepted their deafblindness, they became Deafblind. On the other hand, the majority of deafblind persons, when they accept their deafblindness, become only deafblind, not Deafblind. As such identity on a linguistic and cultural basis differs little from a national one, capital initials are used in both cases. Such a distinction (deaf vs. Deaf) can be traced back to the world of the Deaf, as documented in Sachs (1991).

Besides, in this research, a study of Deafblind perspectives related to Deafblind interpreting at meetings on the international level, the Nordic definition of deafblindness shall be applied, since it represents the foundation for guidelines in all umbrella organisations of the Deafblind (World Federation of the Deafblind – WFDB, European Deafblind Union – EDbU), as well as of all umbrella organisations that include Deafblind interpreters (World Association of Sign Language Interpreters – WASLI, European Forum of Sign Language Interpreters – efsli). These organisations have adopted the Nordic definition of deafblindness and they use it in their work and in the creation of new documents and standards for good practice, as well as the definition of Deafblind interpreting, which will be explained in more detail in the next section.

2.2. Deafblind Interpreting – Various Methods of Interpreting

The simplest definition of interpreting is conveying the meaning of a message from one language (source language) to another language (target language) (Cokely, 1992). Interpreting is present in a range of various situations and exists since people from different language backgrounds first met. This is the reason why the interpreting profession and the corresponding area of human cognition have had time to evolve and to become an exhaustively described field of human knowledge. There are many areas within interpreting services that require description and definition, such as interpreting situations, methods of interpreting and users of interpreting services.

Some interpreting situations have been closely described, for instance conference interpreting, where we know that the greatest achievement of interpretation is to have “the same effect on the speaker as the original speech would... with special consideration taken for all nuances in the choice of words.” (Kurz 2001) Different circumstances require a different focus during interpreting, which is also a well-described fact, with examples like scholar gatherings, where technical accuracy is most appreciated; artistic settings, on the other hand, value the elegance of speech; in political assemblies a forcefulness of interpretation plays the principal role (Kurz 2001).

However, there are still parts of the interpreting profession that haven’t received such close attention and haven’t been described in detail. Human knowledge and standards of good

interpreting become significantly smaller when we undertake the task to interpret between languages with different modalities. Not all languages are spoken ones and not all of them can be described within the usual interpreting framework. Languages that differ in that segment are Sign Languages. It took a long time for society to accept them as equivalent languages and to start providing interpreting services between signed and spoken languages. The reason for this lies within the general marginalisation of the users of Sign Languages and their deprivation from rights and position in society, which should be one of equals.

The main difference between signed and spoken languages is the modality – the former are dominantly visual, and the latter auditive. This is the reason why it took such a long time for people even to consider that Sign Languages might be natural, complete languages, with a vocabulary and grammar of their own, capable of conveying every meaning necessary to their users (Emorrey 2002: 7). Once the status of “proper” languages has been confirmed for Sign Languages, research begun and the doors to an interpreting profession opened in that direction as well. It was then that definitions of Sign Language interpreters started to emerge.

It took some time for acceptable roles and duties of a Sign Language interpreter to be established, but there are still various approaches to this field of practice. Still many definitions are available, but only a brief overview will be given here. The simplest definition of a Sign Language interpreter is “the mediator in communication between people” (Solow 1981). However, such a definition leaves room for more detailed explanations, which include a description of what exactly interpreters do: “... practice of sign language interpreting involves complex communication processes requiring skilled professionals to execute optimally... signing what is spoken and speaking what is signed.” (Stewart et al. 2004: 13) Therefore, today’s attitude is that the interpreter has to have a firm grasp over languages he/she is interpreting, but also has to be trained and have a professional conduct in accordance with the profession, which includes a code of ethics and a demeanour that is suitable for the situation and acceptable to the users (Baumann 2011).

A type of interpreting resembling Sign Language interpreting is Deafblind interpreting. Their common characteristics are a different modality of language being interpreted and a relative novelty of the field. However, Deafblind interpreting has been significantly less described than Sign

Language interpreting, which makes it even more necessary to present a brief terminological clarification within that particular area.

When Deafblind interpreting emerged, there was no clear consensus on the interpreter's role in providing services for the deafblind person. There were different approaches to the profession of Deafblind interpreting, and they still exist, from providing speech interpreting services only to extending the role of interpreter to include features of a personal assistant for many different tasks (Wilcox & Shaffer 2005). Interpreting services for the Deafblind sometimes consisted, and still do, of more than one person as service provider. Sometimes there is a personal assistant who provides services of guiding and describing the environment, as well as note taking, organisation and various other tasks concerning the preparation of the meeting. In such a case the interpreter is the person responsible for language interpretation only, with no other tasks (Hassinen 1999). The lack of qualified interpreters working with Deafblind persons is widespread; it is not limited to a single country or region of the world. One way to address this lack is to increase the educational and training opportunities that lead to skilled and knowledgeable interpreters available to Deafblind communities. (WASLI *no date*)

Today efforts of many international organisations aim towards better defining Deafblind interpreting, which resulted in many definitions and in the creation of a consensus on the role of a Deafblind interpreter, accepted by the main organisations of the Deafblind. The effort to describe Deafblind interpreting was initiated by the users themselves, but also by service providers – interpreting organisations.

One of the recent breakthroughs in the field of Deafblind interpreting is the creation of a document entitled *WASLI Deafblind Interpreter Education Guidelines* in 2013. These guidelines were designed specifically for countries with existing signed language interpreter education programmes that seek to either add Deafblind interpreting to their curriculum or enhance their Deafblind interpreting curriculum offerings. (WASLI *no date*)

While working on this research, I had the opportunity to participate in the work of the World Association of Sign Language Interpreters (WASLI) – the organisation that is primarily focused on

Sign Language interpreting, but in late 2011 has established a Deafblind interpreting Committee, that took over the prior work of the WASLI Task Force on Education and Training. As part of the working group that had the task to devise standards of education for Deafblind interpreters, I had the opportunity to influence the making of this document and to detect current changes in the formation of policies concerning interpreting services. The expansion of the existing network of Sign Language interpreting services to Deafblind interpreting services is an effort worth mentioning, since it opens the doors to free communication for an even larger number of persons. The purpose of this document – *Draft of Deafblind Interpreter Education Guidelines* – is providing guidelines on education of Deafblind interpreters in order to increase the number of qualified Deafblind interpreters worldwide. (WASLI *no date*)

In this section we shall define what Deafblind interpreting actually is, and describe its four main components.

Unlike Sign Language interpreting, Deafblind interpreting is more complex and presents an additional challenge, which requires additional training as well. According to Tarczay (2009) and Hermansson (1999), education intended for Sign Language interpreters is not enough for one to become a Deafblind interpreter. Deafblind interpreters' education is much more than that. In addition to being fluent in Sign Language and to possess knowledge of and skills in linguistic interpreting, it also includes additional training in the areas of providing visual information (visual description), as well as in the area of mobility skills and knowledge on guiding a deafblind person (mobility support). To say nothing on education regarding other communication systems used by deafblind persons. We can conclude that education of Deafblind interpreters leads them into four main areas of learning, namely:

- a) interpreting of speech
- b) environment description,
- c) mobility support, and
- d) interpreting methods specific to deafblind persons.

Experienced and qualified Deafblind interpreters can simultaneously convey the speaker's message as well as the visual and auditory information, and the environmental information that

supplement the context of the interpreted message (RID 2002). In doing so, the deafblind person's preferences on what to be transmitted to him/her and what information he/she deems superfluous, should be respected.

A Deafblind interpreter is a good interpreter if his/her interpreting is appropriate for the occasion and to the extent that suits the needs and requirements of each deafblind person. Those differ from person to person and from occasion to occasion. Every deafblind person knows best in what occasions and to what extent he/she requires Deafblind interpreting. This applies not only to the degree of hearing and sight impairment, but also to the methods of communication and interpretation. If one or more Deafblind persons participate in a conversation, Deafblind interpreting may be needed for/to persons who are not deafblind as well. (Eriksson 2009)

“Deafblind interpreting is the provision via an intermediary of both visual and hearing impressions to persons with deafblindness.

This comes about through three fully integrated elements. These elements are: the interpreting of speech; environmental description; and guiding.” (Eriksson, 2009)

From these definitions we can conclude that the present efforts in educating Deafblind interpreters are directed towards training a person to be qualified in more than one area of expertise. In this way the interpreters are qualified not only for the interpreting of speech, but also for mobility support (in other words: guiding) and environment description. Such tendencies reduce the organisational and practical difficulties, especially when the number of professionals and the problem of defining their roles are considered.

2.2.1. Interpreting of Speech

At first glance, it might seem that a Sign Language interpreter and a Deafblind one have the same responsibilities and approaches considering speech interpreting. Although there are certain similarities between the two, there are also several differences, which we will outline in brief to enable a better understanding of the problem.

A Sign Language interpreter is focused exclusively on the interpretation of all auditory modalities into/from Sign Language. Sign language interpreters should be highly educated and possess interpreting skills, as well as the appropriate certificate (Berke 2009). Sign Language interpreters should be employed solely in order to facilitate communication between hearing and deaf users. (Rouse & Barrow 2009)

In some situations of interpreting to a number of deaf persons only one interpreter is needed, with the exception of interpreting events of longer duration, when it is necessary to employ at least two interpreters in order to enable them to take turns and thus maintain a high quality level of interpreting throughout. For example, at a seminar which lasts four hours and where there are twenty deaf persons present, usually two interpreters interpret taking turns every twenty minutes (efsli 2010).

Deafblind interpreting is usually provided on a one-to-one basis. Take the above example of a seminar which lasts four hours and where there are now twenty deafblind persons present. For such an event, it is necessary to provide forty interpreters if we wish to offer each deafblind person an equal opportunity to fully participate in the seminar at the same level that was provided for the deaf audience in the above case.

When it comes to Deafblind interpreting, the interpreter's models of interpreting have a wider range than those of a Sign Language interpreter. These models include:

- spoken to visual Sign Language interpreting;
- clear speech interpreting (with or without hearing aids);
- speech-to-text interpreting (with certain adaptations; with or without technical equipment such as computers, large screens and Braille displays);
- visual to tactile Sign Language interpreting. (Eriksson 2009)

In addition to what has been stated above, conveying the necessary visual context of spoken words is often included along the mere language or speech interpreting, which sometimes includes

writing down information relevant to the deafblind person. Other tasks can be added to this one, such as organisation of space in which to carry on the interpretation or providing mobility to the deafblind person (Smith 1994).

2.2.2. Environment Description

It is not possible to understand the course of a meeting attended by more persons without an access to the visual and auditory context of the event. A deafblind person to whom the interpreter provides only information on what has been said remains deprived of information who said that, what facial expression accompanied the words, how the other participants accepted the words, has someone stood up and walked away, or someone else come entered the room... (Sauerburger 1995) The inability of deafblind persons to perceive data by means of sight is compensated by the so-called visual interpreting, by transmitting visual information. (Göransson 2008).

According to Lahtinen et al. (2010: 12), “Environmental description makes things and activities in the environment clearer, which enables easier access to contexts; it aims to give a holistic view of the target, so that the receiver would master it better by being aware of what is happening around them. Environmental description complements a person’s sensory perceptions; it supports visual sensations about what has been seen and provides information for the support of tactile sensation. In addition, environmental description facilitates the person by enabling contacts with targets in the environment and within social situations.” The same authors list seven factors that influence description: personal history of the receiver, issues related to event and place, the describer’s choice, description mode, time reserved for description, ethics and proximity, and informing about description (Lahtinen et al. 2010: 30–36).

Some deafblind persons utilise haptic interpreting for the reception of visual information on the environment (Göransson 2008), which can be simply represented as drawing the physical context of events and its changes on the back of a deafblind person, while he/she receives information about the spoken words by sight or by touch. “The word haptic is Greek and means touch. Haptic signals are a number of signals, which are ‘drawn’ onto the body – typically on the upper part of the back or the upper part of the arm. They provide the possibility of a detailed visual

interpretation during communication.” (103 Haptic Signals – a reference book 2012) “Haptics are touch-related messages conveying onto the body. Haptics can be used to express behaviour, changes in the environment and events, describe spaces, produce social quick messages and describe competitions and arts. A shared action makes it possible to describe events and objects that are far away and not touchable. Since describing onto the body demands physical closeness, you have to agree on the methods to be used. It is possible to describe diversified information onto different parts of the body.”(Lahtinen et al. 2010: 30–36)

Some Sign Language interpreters deem such a description of the visual environment “unethical” (Smith 1994). However, there is nothing unethical about it. It is just a completely different situation than is the one with a Deaf user, whose vision can independently monitor what is going on around him/her. To a Deafblind user such a description is a necessity, for the describing of the environment contributes to the equalisation of opportunities of a deafblind person concerning the access to all the information – both its verbal and nonverbal modalities.

In addition to visual information, auditory information should be transmitted to the Deafblind user as well. Since hearing impairment prevents the person from accessing that information him/herself, it is the interpreter’s duty to make them accessible to the user. Such information do not include speech of persons present in the room only, but also non-speech auditory information, like slamming the door, alarm going off, noise of construction workers from the street etc. Oftentimes the information from the environment contributes greatly to the understanding of the context and to the building of comprehension at the meeting. The information acquired *en passant*, sometimes even by accident – such information can help make decisions based on real situations. In this way the Deafblind are put in the same position as the hearing and sighted persons – their opportunities to access all information are enabled. (Gaus & Kennedy 2002; Grassick 1999; Hassinen 1999)

In this manner the interpreter communicates to the deafblind person what Drena O’Malley calls “incidental information” (O’Malley 1999). These are all the data that can be gathered just by watching within the room in which we are and by listening to the situation in which we ourselves are not involved. All the information that the chairman or host of a meeting would not give in a formal and deliberate way are included here. Incidental information provide us with the basic data on emotions, habits, culture, partnership opportunities, and bring the so-much needed nuances to the

situation described. Depriving a deafblind person of such information results in his/her inability to read the situation. The absence of incidental information has a cumulative effect over time: the deafblind person finds coping with a given situation where he/she has no insight into the context of events, such as meetings where important decisions are made, harder and harder (O'Malley 1999)

2.2.3. Mobility Support

A Deafblind interpreter must also possess the mobility support skills. Deafblindness does not restrict the mobility of an individual in a physical way but in a sensory-informational one. Deafblind persons have all the motor skills needed to ambulate, but they lack the information on the environment that would make this ambulation safe.

Most deafblind persons manage well in familiar territory, regardless of whether the term applies to a room, an apartment, a house or some paths in the city. However, even in familiar areas there are unforeseen obstacles, often unperceivable to the Deafblind, into which they can bump or over which they can stumble.

As in most other activities, a deafblind person needs twice to three times more concentration, energy and time in mobility as well, to cross a certain distance, than a person who sees and hears. (Brown-Wollin & Nuccio 2006)

This leads to the increasing unwillingness of the deafblind person to embark on the adventure of going up unknown paths, which ultimately leads to physical isolation from the environment.

Providing mobility support to a deafblind person is not separated from communication, because an interpreter guiding a Deafblind must constantly communicate to his/her user all the information about the various obstacles they encounter, but also the events in the area they transect, which might interest the deafblind person (Tarczay 2003).

2.2.4. Interpreting Methods Specific to Deafblind Persons

The choice of interpreting method depends on the degree of hearing and vision impairment of the deafblind person, as well as on the communication methods the latter is using in the transmission and reception of data. The choice is left entirely to the deafblind person.

According to Eriksson (2009), the most frequently used methods are:

a) Tactile Interpreting (Hands-On Interpreting)

Tactile interpreting is generally used by those deafblind persons who knew Sign Language and used it before they became deafblind by suffering a visual impairment as well.

In the case that such interpreting is administered, the Deafblind interpreter interprets into Sign Language by putting his/her own hands under those of the deafblind user. The hands of the deafblind person gently grasp those of the signing interpreter, so that the former can perceive the signs by touch instead of by sight. Depending on the skills of each individual deafblind user, tactile interpreting can be performed by one hand only (one-handed) or with both hands (two-handed).

In her research, Mesh (2003) indicates that in tactile interpreting deafblind persons cannot “observe” the interpreter’s non-verbal facial expressions, common in Sign Language, which fact requires certain adjustments or changes in some signs, as well as in the grammatical structure of Sign Language. Such adjustments and changes are necessary if we want the deafblind person to fully understand the message that is being interpreted into tactile Sign Language for him/her.

b) Close Vision Interpreting

Close vision interpreting is actually Sign Language interpreting, but at a distance less than usual. It is mostly used by deafblind Sign Language users with low residual or blurred vision. The appropriate proximity of interpretation, i.e. the distance at which the interpreter should interpret, is

determined by the degree of visual impairment of the deafblind person. “This distance can vary greatly: a person with very close vision (e.g. optic atrophy, cataracts, glaucoma) might want an interpreter to sit extremely close while another individual with clear vision but a very restricted field of vision (e.g. Ushers Syndrome) might want the interpreter positioned farther away, perhaps even 20 feet.” (Petronio 2010)

It is important to emphasise that deafblind persons with low residual vision or blurred vision often have considerable difficulty in seeing signs clearly, and that they cannot fully follow the signs even when their interpreter is nearby. The mere proximity, therefore, is not sufficient for the deafblind person with residual vision to receive the full information in sign language, which makes it necessary to ensure the following factors that facilitate the interpretation: the interpreter should wear clothes that provide contrast to the colour of his/her skin, use a dark background to eliminate further distraction of visual attention, and provide additional lighting when needed. (Morgan 1998)

The interpreter must be able to assess the visual ability of the deafblind person, such as the distance to which he/she can identify objects or persons in the interpreting situation, and provide environmental information accordingly (the identity of the speaker, facial expressions, situations and relationships). To a Sign Language interpreter, accustomed to interpret for the Deaf, such interpreting can be a difficult, even a discomforting task indeed.

c) Visual Frame Interpreting

Visual Frame Interpreting is sometimes also called Reduced Peripheral Fields Interpreting and Restricted Vision Interpreting. For the purpose of this research the first term was chosen because the vision field might be impaired in its different sections, not only peripherally but it can also happen in its central area, and the selected term includes all kinds of impairments of the visual field.

Unlike classical Sign Language interpreting, with the upper and lower limits of the signing area located just above the top of the head and slightly below the waist, respectively, in this case the space in which the interpreter is signing to the deafblind person is much smaller. The size of the signing space depends on the size of the deafblind person’s residual vision field, or on the condition

of his peripheral vision. Such interpreting suits deafblind persons with Usher syndrome (pigmentary retinopathy / *retinitis pigmentosa* with hearing impairment). The size of the signing space depends on the remaining peripheral vision of the deafblind person: "... each Deaf-Blind individual differs in how much peripheral vision they have. This affects the size of the signing space an interpreter will use." (Petronio 2010)

We can define the optimum distance needed for the deafblind person's residual vision to better cover the signing space in the same way. "Depending on how much peripheral vision a Deaf-Blind person has, the distance they are from the interpreter also affects the size of the area they are able to see." (Petronio 2010)

The distance of the interpreter from the user, as well as the size of the signing space used in interpreting differs from person to person with Usher syndrome. Sign Language interpreters with no experience in visual frame interpreting often express insecurity regarding how small the signing space should be, and sometimes unintentionally neglect the interpreting conditions and start interpreting in the usual signing space. Some deafblind persons with very small residues of peripheral vision put their own hand on the interpreter's wrist and thus "correct" the signing space used by the interpreter in order to feel assured that no information will "escape" from their vision field. Sign language interpreters are not used to this kind of contact so they do not feel comfortable during interpreting.

In this type of interpreting adaptations of certain signs or letters are inevitable if they "escape" the vision field. For example, "how are you?" in Croatian Sign Language and the letter "Z" in Croatian two-handed manual alphabet are signed slightly modified to fit into the vision field of the deafblind person. Likewise, any pointing index finger sign (in Sign Language it is not considered rude, but a necessity) is not signed with an outstretched hand, as usual, but within the field of view.

d) Clear Speech Interpreting

Deafblind persons with residual hearing sufficient for the perception of speech usually choose this method of interpreting. Speech interpreting can be provided with or without the help of hearing

aids.

One of the aids is an individual closed loop system (a kind of individual inductive loop) consisting of a microphone with a transmitter and a receiver to be attached to the hearing aid. Interpreters interpret directly into a microphone, and the deafblind person individually adjusts the volume and tone to a suitable level. In this way he/she can fully hear only what his/her interpreter, whose voice he/she understands well, is speaking into the microphone.

Some deafblind persons using a hearing aid can switch onto an existing induction loop system. Such a system is installed into the room where the meeting takes place, and provides all users with a hearing aid to receive only the sounds coming through the microphone or to hear only the current speaker, and not the rest of the ambient noise. In this case no formal interpreting is needed.

In situations where the use of such technical support is not possible, interpreting is provided by speaking into the deafblind person's ear with less impaired hearing. Some persons that still have some residual vision accompanying their loss of hearing may want to combine their hearing ability with their skill of lip-reading. Depending on the degree of sight impairment, the user can request that the interpreter speaks either close to his/her ear or face-to-face. In this case, the deafblind person may or may not use his/her hearing aid. (Bradarić-Jončić & Mohr 2010: 60–61)

e) Interpreting by Finger Spelling or Manual Alphabet

Unlike the manual alphabet used by the Deaf community, which serves as a complement to Sign Language (Tarczay 2006), manual alphabet as a constant interpreting method is usually chosen by those deafblind persons who never acquired Sign Language, either because they were primarily blind, or due to them being hard-of-hearing, which used to allow them to draw on their residual hearing. This method consists of converting the written form of the word into a variety that deafblind persons can perceive tactilely and that includes several types of interpreting. In manual alphabet interpreting, it is important to emphasise a few key features that often go unnoticed. One of them is that manual alphabets rely on the written form of the word, representing each letter of the

word with a distinct hand shape that is conventional (once established, the connection between the hand-shape and the letter cannot be arbitrarily changed, and certainly cannot be done by an individual within the community; Škiljan 1994: 52), in order to enable the stability and recognisability of each individual letter. In a way, manual alphabets can be described as spelling the words, but with characteristic hand shapes that the users always recognise as corresponding letters of the alphabet. The other thing that often goes without saying, but should be mentioned here for greater clarification, is the problem of literacy. The user has to be literate to be able to use the manual alphabet as interpreting method. This means that the person has to know all the letters of the alphabet and to be able to connect them all together to form a meaningful word, which is a skill called phonologic awareness (Vernon & Ferreiro 1999). Besides that, the person has to have a grasp of the spoken language as well, with its vocabulary and grammar, in order to comprehend whole sentences and make meaning out of the string of words that is being presented in a manual form.

When we talk about manual alphabets we usually refer to two-handed or one-handed alphabets. It is important to emphasise that manual alphabets are not the same worldwide and that each country has its own manual alphabet. Words can be spelled out either in a two-handed alphabet, which mimics the upper-case letters, or in a one-handed alphabet that mimics the lower-case letters. Both of them can be performed to be perceived both visually and tactilely. In some countries, the manual alphabet is identical to that used by the Deaf, while in others there are minimal adjustments of the letters of the alphabet so that the deafblind persons can easily perceive them in a tactile way.

Finger spelling, as opposed to manual alphabet, mainly uses the index or middle finger writing “capital letters” on the palm of the deafblind person’s hand. There are some other forms of finger spelling like Lorm or Malossi, which are used in certain countries.

A special type of this method is transferring Braille letters to the user, usually by using the three middle fingers of both hands of the deafblind person as keys of a Braille typewriter or to use the three middle fingertips of both interpreter’s hands as dots of a Braille letter, which are then pressed into the user’s palm.

f) Speech-to-Text Interpreting

This method involves a variety of options. It may be employed by writing capital letters with a thick, dark pen (like a black marker or felt-tip pen) on paper, but also by using a variety of technical aids.

One of the most common methods of such interpreting is using a typist, who types all the speech and all the background information (who speaks, is there laughter, what are the reactions of the audience, whether anyone leaves or enters the room...) into a computer and all typed text is simultaneously projected onto a large screen from which a deafblind person with sufficient residual vision, but interpreters as well, can read what was said and what was happening at the meeting. The projected text is most frequently enlarged and bolded. In order to facilitate reading, the display screen is usually slightly yellow or cream coloured.

A similar method is used when it comes to individual users. The typist writes all spoken and visual information, and the deafblind person reads that data from a computer screen in front of him/her. The font type, size, boldness and colour as well as the background colour are being adjusted to the needs of the deafblind individual.

Deafblind persons acquainted with Braille can use a similar way of interpreting, but in this case the screen is replaced by a Braille display, connected to the typist's keyboard. A Braille notebook connected to the typist's computer can be used too. The deafblind user fingertips lightly over the Braille display and reads the interpretation.

The communicator notebook for the Deafblind works in a similar way. The only difference is that it can be connected to a mobile phone device.

The advantage of these methods is that the typed text can be saved into a computer, and later be recalled and read again. It can be used as the minutes of the event too. Unfortunately, such devices are often not available to all deafblind users for financial reasons.

Conclusively, the term Deafblind interpreting, as used in this thesis, will encompass the task of mediating the complete auditory and visual information to a deafblind person about the meeting situation by a Deafblind interpreter. This mediating comprises three functions: language interpreting, mobility support, and conveying of visual data; all by using an interpreting method that matches the capabilities of the deafblind person. All these functions can be encompassed by a single interpreter's work or may be divided between an interpreter and another person, e.g. a contact person or a personal assistant.

3. ORGANISATIONS OF THE DEAFBLIND – AN OPPORTUNITY FOR EQUAL PARTICIPATION IN POLITICAL AND PUBLIC LIFE

The existence of both national and international organisations of deafblind persons is vital not only for the Deafblind themselves, but also for anyone who is in some way involved in the field of deafblindness (professionals of different profiles, employees of institutions, family members, spouses, friends of deafblind persons, even politicians and all those who just want to be informed). They are essential as a source of relevant information on deafblindness and for the fulfilment of the fundamental needs and rights of the Deafblind.

Such organisations of the Deafblind contribute to the recognition of this small and marginalised group of persons with disabilities and promote the rights of deafblind persons. They assist in the empowerment of the Deafblind and in the Deafblind themselves being more aware of their own situation, both those with acquired deafblindness as well as persons with congenital deafblindness. Such organisations strengthen the awareness of belonging to the Deafblind community and endeavour to encourage its members to mark 27 June, a day proposed as a UN International Day of Persons with Deafblindness (today Helen Keller Day) at the General Assembly of the WFDB and approved for on 26 October 2009 in Munyonyo, Uganda with 34 votes in favour, and 1 vote against, and to do so by organising various events to mark the occasion.

Apart from that opportunity, many national organisations of the Deafblind use a variety of events (open door days, holidays, cultural and sporting events of the Deafblind, etc.) to provide visibility for their organisations and to promote the identity of deafblind persons (as is the red and white cane they use), their inner diversity in communication methods (tactile sign language, tactile fingerspelling, communication aids, etc.).

Although the Deafblind had been aware of the importance and necessity of establishing their own national and international organisations for a long time, it was not always easy to actually initiate their founding because of specific problems connected with the double impairment of both vision and hearing. Enormous efforts had to be made and a lot of time invested to establish those organisations, and especially so for the formation of world and regional organisations of the

Deafblind as well.

We can demonstrate this in simple terms by comparing the data on the establishment of other international organisations of persons with disabilities, such as the World Federation of Deaf (WFD), which is most similar to or, more precisely, closely related to the Deafblind organisation due to communication difficulties faced by members of both organisations.

WFD was founded back in 1951 In Rome, Italy (WFD *no date*). On the other hand, the World Federation of Deafblind was finally born in 2001, after a long gestation period. It obviously took the Deafblind half a century longer to set up their own world organisation.

In the following text I will describe the growth of the World Federation of the Deafblind (WFDB), as well as that of other regional organisations of the Deafblind, the European Deafblind Union (EDbU), the Latin American Federation of the Deafblind (Federación Latinoamericana de Sordociegos – FLASC) and the African Federation of the Deafblind (AFDB). Moreover, I shall include important information about the origin of each individual organisation and present their main goals.

World Federation of the Deafblind (WFDB)

After many years of active labour in the field of deafblindness, some Deafblind enthusiasts (Lex Grandia from Denmark, Daniel Álvarez from Spain, Jeanette Scahill from New Zealand, etc.), under the guidance of Stig Ohlson from Sweden, and with the support of the organisations of the Deafblind that they represented, felt the time was right for the establishment of the World Federation of the Deafblind. Mr. Ohlson and Mr. Grandia did most of the groundwork on the new organisation's constitution with the assistance from some lawyers from the World Blind Union (WBU). The decision to establish a global umbrella organisation for the Deafblind was adopted at the Sixth Helen Keller World Conference organised by WBU in Paipa, Colombia, in September 1997. The establishment of such an organisation was perceived as a means to attain better networking between organisations of the Deafblind throughout the world, to strengthen the struggle for the identification and recognition of the rights of deafblind persons regardless of where they

live, and to raise the level of education and wider social inclusion of the Deafblind through awareness and public information. After the conference, it was decided that WFDB should be a non-profit and a non-governmental organisation. Four years of active work outlining and preparing the establishment of the future World Federation of the Deafblind followed, and the eventual founding of the World Federation of the Deafblind occurred on 11 October, 2001, in Auckland, New Zealand. The establishment of WFDB was welcomed by more than a thousand participants, and Stig Ohlson became the first president of WFDB.

The aim of WFDB is “to improve the quality of life of deafblind persons worldwide and one of the most important activities undertaken by WFDB is to identify deafblind persons in order to break their isolation. WFDB also aims at spreading information about deafblindness and about the kind of service deafblind persons need in order to live independent lives. In addition, WFDB strives to have deafblindness acknowledged internationally as a unique disability.” (WFDB 1997).

WFDB is governed by the Executive Council composed of Deafblind members elected by the General Assembly to be held quadrennially. At present, the Executive Council consists of ten deafblind persons, four of them elected officials, and six regional representatives from different parts of the world.

Although WFDB currently has sixty-two members, that figure is growing steadily as more and more national organisations of the Deafblind join the WFDB in order to help the work for the benefit of the Deafblind. In addition to the organisations, individuals can also become members of WFDB. (WFDB 1997)

European Deafblind Union (EDbU)

After the establishment of WFDB, traces of first regional activities of deafblind persons lead us not far from Mr. Ohlson’s Sweden, to neighbouring Denmark, where the former president of the Danish Association of the DeafBlind (Foreningen Danske DøvBlinde – FDDb) Ove Bejsnap dreamed of a “united Deafblind Europe.” His dream was to establish a large number of national organisations of the Deafblind across Europe, which would then associate and jointly advocate the

needs and rights of their members. In the act of founding an Interim Board on 3 September, 1999, in Finland Mr. Bejsnap was joined by his Nordic Deafblind colleagues.

From the founding of the Interim Board on 30 September, 1999, until the establishment of EDbU, its members were: Ove Bejsnap, Denmark (1999–2003, 4 years); Geir Jensen, Norway (1999–2003, 4 years); Seppo Jurvanen, Finland (1999–2002, 3 years); Jane Eriksen, Sweden (1999–2001, 2 years); Kristjana Gardarsdottir, Iceland (1999–2000, 1 year); Svanhildur Anna Sveinsdottir, Iceland (2000–2003, 3 years); Mona-Britt Broberg, Sweden (2001–2003, 2 years), and Ulla Kungas, Finland (2002–2003, 1 year) (EDbU 2003)

The Interim Board made an official announcement (EDbU 1999):

“We, the associations of the deafblind in the Nordic countries, have today, 3. September 1999, agreed to found the European Deafblind Union, EDbU.

The aim of the union is to develop cooperation between the associations of deafblind in all European countries, and at the same time to improve the quality of life for the deafblind.

Membership of the union is restricted to those associations of deafblind whose decisions are made by deafblind persons themselves.

An interim committee for the new organisation was also elected. Ove Bejsnap from Denmark was chosen as its chairman, and the following were elected as members of the committee; Kristjana Gardarsdottir (Iceland), Jane Eriksen (Sweden), Geir Jensen (Norway) and Seppo Jurvanen (Finland).

The first committee meeting of EDbU was held on the following day. Here it was decided, amongst other things, that the EDbU will hold its first congress in 2002.”

Mr. Bejsnap’s dream of establishing the European Deafblind Union (EDbU) became a reality four years after the founding of the Interim Board, on 22 October, 2003, in the city of Fredericia in his own native Denmark.

EDbU is a European organisation that connects all the Deafblind organisations from all over Europe. It is a non-governmental and non-profit organisation. Its main goal is to work on and

promote the equality of deafblind persons and their full participation in society in all European countries. The idea behind EDbU is the exchange of knowledge, experiences and information among organisations of deafblind persons, with the aim of establishing a greater solidarity between them.

EDbU holds its General Assemblies quadrennially, where members elect the Executive Committee for a period of four years. Currently the Executive Committee consists of nine elected members. There are also three new groups have been established within the EDbU: a group for young deafblind persons; a group for deafblind women; and a fundraising/PR group. A Deafblind Sport and Culture Organisation was also established, while the European Deafblind Holiday and the European Celebration of the Specific Capabilities of the Deafblind are already regular annual and quadrennial events, respectively. (Jensen 2014)

Deafblind organisations across Europe are encouraged to join EDbU, either as national members or as associate ones. National membership is limited to one Deafblind organisation per state, while other national organisations that are not national members are eligible to join as associate ones. Though it is the Executive Committee that makes its decision on the applications, once an application is accepted, the General Assembly is the one to vote on the respective membership. (EDbU 2008)

Latin American Federation of Deafblind persons (FLASC)

The initiative to establish an organisation that would represent the whole continent emerged in Latin America almost at the same time as in Europe. At the initiative of many Latin American countries (Argentina, Bolivia, Brazil, Colombia, Cuba, Dominican Republic, Ecuador, Guatemala, Honduras, Peru, Uruguay, and Venezuela), their national Deafblind organisations joined together to form a unique organisation. With deafblind leaders from the abovementioned countries along with support from the Association of the Swedish Deafblind (Förbundet Sveriges Dövblanda – FSDB), the Latin American Federation of the Deafblind (Federación Latinoamericana de sordociegos – FLASC) was founded in 2003.

The main issue that triggered the establishment of the Latin American organisation was the lack of care and programmes for education and quality living for adult deafblind persons. Before the creation of their own umbrella organisation, some of the Latin American countries had their national organisations of the Deafblind, but the majority of them depended on the help from FSDB and WFDB.

Throughout the newly-established Latin American organisation of the Deafblind, the main goals of deafblind persons could finally be carried out with more power and support. Those goals include advocacy for their rights, to become visible to the governments, and to participate in different activities that would improve the overall quality of life for the Deafblind in Latin America. (Villacrés 2011)

African Federation of the Deafblind (AFDB)

After long years of struggling to improve the position and status of deafblind persons in the societies of African countries, there came a point when a new, African organisation had to be established in order to empower the Deafblind and to give them a stronger voice to advocate for their rights. Even though the importance of having such an organisation existed from the year 2000, it was only in 2009 that the organisation could finally be established, with help from WFDB and SHIA (Solidarity Human Rights Inclusion Accessibility).

The initiative to establish the African Federation of the Deafblind was followed through with the help from existing organisations of the Deafblind. Support also came from The Secretariat of the African Decade of Persons with Disabilities, who joined WFDB in its backing of the establishment of an African Federation of the Deafblind.

In October 2009 during the Helen Keller World conference in Munyonyo, Uganda, AFDB was formed as a continental body. The delegates from different parts of Africa convened there and voted for and eventually established the Federation of all African national organisations of persons with deafblindness to be called African Federation of the Deafblind (AFDB). As a result an Interim Committee was elected and the constitution drafted.

Among the many persons actively involved in forming this organisation, three need to be mentioned because of their outstanding contribution: Ezekiel Kumwenda, the first president and founder of the organisation, Lex Grandia, President of the WFDB at the time, and Ann Thestrup, Financial Advisor of the WFDB. They were the three invaluable pillars that gave AFDB its shape and form. Their mentoring and guidance led the young organisation through periods of hardships and instability, only to emerge as a respectable organisation it is today, with 17 member organisations. (AFDB 2011)

Since the establishment of the first international organisation of the Deafblind – WFDB – twelve years now have passed, with three regional organisations being founded in this period, and the number of national organisations of the Deafblind increasing worldwide. With the constantly growing involvement of deafblind persons in decisions about themselves at the international level (as was the case with Lex Grandia concerning the UN Convention on the Rights of Persons with Disabilities) as well as with the increase of contacts with other, non-Deafblind organisations, the activities of the Deafblind are becoming more visible worldwide. Several organisations whose activities include support for deafblind persons became partners with organisations of the Deafblind in their pursuit of a better future for the Deafblind. So in April, 2008, the presidents of WFDB and DbI (Deafblind International), Mr. Lex Grandia and Mr. William Green respectively, signed a *Memorandum of Understanding* between the two organisations (WFDB–DbI 2008), while on 14 September, 2012, during efsli's (European Forum of Sign Language Interpreters) AGM in Vienna, Austria, a Memorandum of Understanding was signed between EDbU and efsli. (EDbU–efsli 2012). Finally, a similar document named a Join Statement was signed on 10. November 2013 in Manila, Philippines, between WFDB and WASLI (World Association of Sign Language Interpreters) (WFDB–WASLI 2013).

Since the organisations of the Deafblind are most often registered as non-governmental organisations or as humanitarian ones, they are required to coordinate a number of transparent activities in order to enable their vision and mission to become more visible to the general public, to the relevant decision-making institutions, and to potential donors. Their mission is also to be more accessible to the national Deafblind organisations as well as to individuals, deafblind persons,

members of their families, professionals who work with deafblind persons, and service providers for the Deafblind.

Although the abovementioned organisations of the Deafblind are relatively young, they still face some fundamental issues, such as the functioning of organisations, sustainability, and the still existing discrimination in both political and public settings.

When talking about the functioning of the organisations of the Deafblind, what is primarily on my mind is the basic functioning and the most vital activities such as participation in all meetings where decisions are made that concern not only the organisation itself, but the deafblind as well. Difficulties in maintaining the regularity of these meetings are always present, whether it is a Board meeting or a meeting of some other body. All these meetings are of crucial importance not only for the survival of organisations of the Deafblind, but also for the possibility of deafblind persons being able to represent themselves as well as to participate at other international meetings where important decisions or guidelines for persons with disabilities are made that can have a significant impact on the Deafblind as well.

The sustainability of Deafblind organisations, both at the national and international levels, becomes a problem if an opportunity is not provided for the Deafblind to actively participate in running the organisation and its participation at meetings. Therefore, it is not surprising that international organisations have considerable problems in their financial sustainability, which also means problems in human resources.

Discrimination against the Deafblind in relation to their participation in political and public life is still resiliently present in some countries in spite of the *UN Convention on the Rights of Persons with Disabilities*, of other international legally binding documents, and of the efforts of deafblind persons themselves to be actively involved in the work of their organisations. (See *The Story of John* and *The Story of Kathy* in Sauerburger 1995: 72–73, 74–75; Black 2013; DbI 2002; Macaskill 2011; RNID 2000) That discrimination against deafblind individuals is not a thing from the past, but can be clearly perceived from a recent series of articles about a deafblind man removed

from his seat he booked on a plane for “security reasons” in the *Citizen Online* (Citizen Online 2013_a, 2013_b, 2013_c).

The policy towards persons with disabilities proclaims equality and inclusion, but we are still witnessing the “traditional way” of treating persons with disabilities, including Deafblind persons, on an everyday basis. Although there is an increase in the number of educated deafblind persons, some of whom are themselves experts in the field, that still does not mean that they appear more frequently in places where decisions concerning them and their lives are made. Instead, it is persons without disabilities who continue to appear as the main authority, and it often occurs that their voice usually outvoices those of the Deafblind themselves. Besides, even if deafblind persons are involved in working bodies (working groups, committees, etc.), the purpose of this involvement might be constructing a Potemkin village, a farce with a fabricated image of their participation presented, while in reality their vote can by no means affect the decision.

Moreover, different rules apply to politicians who represent a state at an international event and Deafblind representatives of their countries in international political and public activities of persons with disabilities, although both are working, among others, to promote their country in the region and worldwide. Unlike politicians without disabilities, a deafblind person has no access to financial resources. Not only that he/she cannot cover his/her own attendance at international events financially, he/she cannot even cover the participation of his/her interpreters, a necessity required in order for the deafblind person to act at all. A positive image created by demonstrating examples of how some countries carry out the UN Convention and other European documents on the rights of persons with disabilities are often not the result of efforts made by the government, but the product of personal effort and resourcefulness of a deafblind person. Situations like this one actually represent the “parasitism” of the reputation of state authorities on the labours of individuals who are making great efforts to accomplish their own participation at such events.

It is also not uncommon that deafblind persons continue to be presented to the public with the false impression that they are helpless and in need of some representative from the ranks of persons without disabilities who would stand up for them and fight for their rights. On an international level, there are visible efforts by individuals without disabilities to be “the voice of deafblind persons” and also to become an icon of the struggle for their rights. Perhaps the reasons for this

could be found in the fact that most people often more easily and without hesitation accept persons without disability as the backbone of the struggle for the rights of the Deafblind or in the fact that there exists a relatively small number of persons with disabilities (deafblindness) who are able to fight for their own rights due to a still insufficient number of high quality interpreters for the Deafblind available.

International organisations of the Deafblind do not only struggle for the rights that the deafblind persons possess as persons with disabilities, but also for their rights as human beings, because, after all, the existence of the *UN Convention on the Rights of Persons with Disabilities* does not exclude the *UN Universal Declaration of Human Rights*. Persons with disabilities are still human beings. The Deafblind struggle for their equality with other members of the community and for their involvement in the community. Relying on the leading binding international documents, guidelines and charters, they can positively contribute to the rights of the Deafblind ceasing to be a dead letter, but also becoming a reality for deafblind persons.

It is clear that the opportunity to attend international meetings without Deafblind interpreters is inconceivable for deafblind persons. With the above description of the development of international organisations, it becomes conspicuous that the most active deafblind persons actually come from those countries that possess the best developed services for the Deafblind (Denmark, Finland, Norway, Sweden, and United States). However, there is still a significant number of states that have no available services of interpreters for deafblind persons, even though there are services of sign language interpreters for the Deaf. Besides, there is still an insufficient number of trained interpreters for deafblind persons and in particular there is also a lack of qualified interpreters for the Deafblind in the field of interpreting at international meetings.

So, with the advent of World and regional organisations deafblind persons are provided with a unique chance to attain equal opportunities in political and public life through participation in various international meetings, and in this paper the Deafblind will share their own perspective of their participation in the “meeting challenges.”

4. THE IMPORTANCE OF DEAFBLIND INTERPRETING FOR LEADERS AT MEETINGS ON AN INTERNATIONAL LEVEL

Since the very moment of accepting one's progressive sight and hearing deterioration and of the fact that this inevitably leads to a state called "deafblindness," the person is constantly facing great challenges, but so are the people who interact with that person too. Adaptation of the deafblind person to the newly acquired condition requires significant changes, modification of activities, shift of life priorities, reconsidering life goals and dreams, adaptation of communication habits, and most importantly, everyday struggle with personal limitations and difficulties (Smith 1994, Sauerburger 1995, Aitken 2002).

A combined vision and hearing disability presents a huge threat to all activities and to the ability to participate in everyday life (Gullacksen 2011). The focus of life of the deafblind person becomes how to participate in everyday life situations, how to access information, how to retain mobility and social interactions.

In addition to giant efforts to overcome personal restraints due to vision and hearing loss, a deafblind person is constantly travelling a road full of barriers that result from environmental influence and make the path even more difficult. According to a study conducted in 2010 (Edberg, Joge Johansson & Nylander 2010), the restrictive influence, or factors, are the services of interpreting, guiding and transport, which are not provided when necessary, the lack of general information, overall insufficient meeting with professionals etc.

Everything mentioned so far influences and makes profound impact on the deafblind person. The path from diagnosis to acceptance of deafblindness requires a longer period of adaptation (Birse 2004: 11–14). All of that leaves very little space to the deafblind person to decide on making additional changes, to change the course of their life even more. Very few of them decide to take active part in the political and public life, to advocate for the rights of the Deafblind. Some deafblind persons are aware that their active participation and human rights advocacy brings them closer to the realisation of the necessary services and education for the whole Deafblind community.

Their tendencies to materialise equal opportunities, as exercised by all other persons, in making the right decisions for the Deafblind are not always visible, but they do exist. Their efforts to achieve equal opportunities start with their own participation, but is then generalised to all deafblind persons and their opportunities in everyday life. This is the reason why international participation in political and public life is the new area where the Deafblind seek recognition.

Since this research is focused on meetings on an international level attended by deafblind persons, mainly Board members of the World Federation of the Deafblind and the European Deafblind Union, a short overview of the principal documents that deal with the importance of participation of persons with disabilities will be given. These documents are the *United Nations Convention on the Rights of Persons with Disabilities* (UN CRPD) and the *Recommendation CM/Rec(2011)14 of the Committee of Ministers to EU Member States on the Participation of Persons with Disabilities in Political and Public Life*.

The *United Nations Convention on the Rights of Persons with Disabilities* (UN CRPD), includes Article 29, entitled “Participation in Political and Public Life,” which explicitly states (UN 2006):

“States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake:

- a) To ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by:
 - i. Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;
 - ii. Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;

- iii. Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice;
- b) To promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:
 - i. Participation in non-governmental organisations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;
 - ii. Forming and joining organisations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.”

The Council of Europe issued the recommendations concerning political and public life of persons with disabilities in the Article 1 of *Recommendation CM/Rec(2011)14 of the Committee of Ministers to Member States on the Participation of Persons with Disabilities in Political and Public Life*, entitled “Equal Rights and Opportunities.” It also emphasises rights of persons with disabilities, as following:

“All persons with disabilities – men and women, including in certain circumstances children – have the right to participate in political and public life as citizens on an equal basis with others. Member states should secure for persons with disabilities equal rights and opportunities to participate in political and public life, and therefore prevent any possible discrimination by providing appropriate information and creating an environment which will enable persons with disabilities to participate fully in political and public life.

Persons with disabilities should be enabled, freely and without discrimination, particularly of a legal, environmental and/or financial nature, to:

- vote and stand for election at all levels;
- have access to communication, information, procedures and facilities related to their political rights;
- have equal access to public duties;
- meet, join or found associations;

- meet, join or found political parties;
- express their opinions;
- be closely consulted and actively included in the development and implementation of legislation and policies, and in other decision-making processes concerning issues that affect them.

In all the measures taken to facilitate the participation of persons with disabilities in political and public life, the authorities and other competent bodies should take into account the fact that persons with disabilities represent various groups in society. They can have a wide variety of impairments, very different personal characteristics and be in varying socio-economic situations.

The general principle of non-discrimination should form the basis of governmental policies geared to ensuring equal rights and opportunities for persons with disabilities through the removal of restrictions on legal capacity, the abolition of voting tests, the introduction of relevant legal provisions, specific forms of assistance, awareness raising and funding.

In the event of a violation of their rights, persons with disabilities shall have equal access to justice and enjoy the same level of legal protection as all other persons, in accordance with the *United Nations International Covenant on Civil and Political Rights* (1966) and, as appropriate, Article 13 of the *United Nations Convention on the Rights of Persons with Disabilities* (UN CRPD), as well as foreseen by the *Universal Declaration of Human Rights* (1948) and the provisions of Action Line No. 12 “Legal protection” of the Council of Europe Disability Action Plan 2006-2015 (Recommendation Rec(2006)5 on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015).” (Council of Europe 2011)

As we mentioned before, there are numerous factors, both internal and external, that prevent the deafblind person from achieving human rights to full extent in every aspect of life. From that it is evident that very few deafblind persons actively participate in work of organisations on European and World level.

It is no wonder that both international organisations mentioned above make securing human rights for all deafblind persons their priority. What makes their goal even more important is the insufficient level of recognition of deafblindness in many countries (Drescher & Lopez 2006; Danermark & Möller 2008). Even the basic human rights of the Deafblind are often neglected, especially in developing countries, where they are often overlooked.

Therefore, Deafblind leaders take on the great responsibility to lead and support the organisations of the deafblind and influence the authorities throughout the world in their struggle for the rights of the Deafblind, especially in providing services for the Deafblind, and for the recognition of Deafblind interpreting as the key factor in accessing their fundamental rights.

The precondition of enabling all the Deafblind to access proper services is to establish such services for Deafblind leaders at the meetings on international level. Only by achieving efficiency and proper functioning of such meetings changes can be brought about and the voice of the Deafblind can be heard. As we have seen in chapter 1 *Introduction* of this paper, the complexities of the meetings between deafblind persons are high, starting with language transmission of information and reaching the environmental contributors to the efficiency of the meeting.

We can conclude that the meetings at international level present a real challenge to the Deafblind and to Deafblind interpreters alike. What makes the difference in the success of their cooperation is the “better match between the needs and the environmental support given,” which can be better described as “the right support in the right place” (Gullacksen, 2011).

5. WHAT DO WE KNOW ABOUT INTERACTION AT INTERNATIONAL DEAFBLIND MEETINGS – DIFFERENT ASPECTS OF INTERACTION

In previous chapters, we were able to read that international meetings of the Deafblind really stand out among the majority of meetings we are accustomed to, and that they particularly differ in the richness and diversity of interactions that take place during them.

Unlike most meetings where hearing and sighted persons are present, at meetings of international organisations of the Deafblind there is a noticeable specific activity in communication when all present deafblind participants with the help of their Deafblind interpreters or other assistants who provide them communication support make great efforts together in order to make their meetings effective and successful. Both deafblind persons and their interpreters make a successful team that strives to overcome all difficulties and challenges to ensure high quality communication despite varying degrees of visual and hearing impairment of the Deafblind, despite different qualifications and backgrounds (knowledge, skills, abilities and experience) of the interpreters or assistants, despite different languages, communication methods, and interpreting methods.

At a superficial glance it might seem that deafblind persons fail to follow the proceeding of a meeting. However if we go beneath the surface, we could see that there is some dissatisfaction and dissent both by deafblind users and by their interpreters. The most frequent disagreements and objections are directed in the direction of the content of available information. For example: lack of information on the environment, lack of information on the conceptual level, which do not correspond to the reference frame of the deafblind person, complaints related to the small number of qualified Deafblind interpreters resulting in a lack of “negotiation” time as well as lack of preparation. (Andreoli 1999) Apart from the abovementioned disagreements and complaints, there are various other problems that are more or less repeated at each meeting. It became clear that among the biggest ones are the problems of slowness and lack of effectiveness. (Hicks 1997).

In this chapter I will exceptionally add my personal experiences as a deafblind person and as an active participant in international meetings of the Deafblind. I will describe examples of some of

the most common problems related to various aspects of interactions that have been encountered by me, but also by my deafblind colleagues, from the aspect of:

1. Deafblindness
2. Methods of communication
3. Linguistics of interpreting
4. Culture
5. Education
6. Organisation and environment

5.1. Aspects of Deafblindness

To avoid repeating myself, everything related to deafblindness can be found in Chapter 2 *Terminological Clarifications* under Deafblindness, while in the introductory part of chapter 4 *Importance of Deafblind Interpreting at Meetings on an International Level* the difficulties of persons faced with deafblindness are described, as well as constant adjustments they have to make at all levels of life. According to Schneider (2006) here we're not talking about a single specific adjustment, but about "a succession of adjustments" (Clark 2004: 7, according to Schneider 2006). Significant difficulties of the Deafblind are associated with constant adaptations to changes related to their hearing and vision, as well as the "emotional challenge of facing an uncertain future." Difficulties in communication and access to information lead to a gradual falling into loneliness and isolation. (Schneider 2006)

There are many factors that affect the limitations of the Deafblind, and one of the most important factors that influence it is the unavailability of support services for deafblind persons.

The words of the late President of WFDB describe the reality of the majority of deafblind persons: "Most persons with deafblindness live isolated in the family or an institution, isolated because of lack of communication, information, and mobility. Lack of education has made it impossible for persons with deafblindness to formulate their rights and needs to participate in

society. Most activities with or for persons with deafblindness were related to entertainment, not intended to get deafblind persons politically involved.” (Grandia 2013)

There is some very turbulent travelling on the path of a deafblind person. The time passed between the moment when he/she discovers deafblindness (upon diagnosis) to the moment when he/she needs to explore how to accept this new situation as a Deafblind can be a long one. This journey has significant emotional consequences for the person him/herself and usually does not leave enough room for other activities. Deafblindness limits the possibilities of the deafblind person in everyday life, therefore it does not come as a surprise that the number of experienced and active deafblind persons present at international meetings is limited. Because of too small a number of involved deafblind persons, it happens that some of the ones attending meetings are not up to its requirements. Patience and understanding and good support by other participants can help a person acquire the necessary knowledge, skills and abilities to participate in meetings and to make good decisions. Not all deafblind persons are able to acquire all the necessary experience to attend meetings, so it can happen that a deafblind person can hinder the interaction in a meeting due to his/her inexperience.

EXAMPLE: Most deafblind persons come to meetings almost unprepared. Since this is repeated at each meeting, extra explaining of what writes in the materials available beforehand consumes a lot of the time. When I asked some Deafblind what was the reason they have not done their “homework” the answer has always been that they did have not enough time, and the most common reason for that was that they have spent a lot of their time looking for sources of funding their travel and accommodation expenses. The second most common reason were their existing obligations in their own countries. What is more interesting for the issue of this research is their statement: “Deafblindness slows me down.” My deafblind colleague was explaining to me how easier it all was before, when he/she had had a better sight because he/she could had done a lot more things independently and that he/she felt that he/she needed more time for the same things than before. A deafblind person does need two or three times more time for the same activity than a hearing and sighted one (Brown-Wollin & Nuccio 2006). We must ask ourselves what is actually a greater challenge for the deafblind person: to find a way to come to a meeting or just to participate in it?

In brief, what contributes to the complexity of interactions of the Deafblind is the fact that the deafblind population is not homogeneous, but includes individuals with varying degrees of sight and hearing impairment. (Bar-Tzur 2008; Göransson 2008: 26–27; Gullacksen et al. 2011: 15; Aitken 2002: 4–6).

Apart from different degrees of sight and hearing impairment affecting the interaction itself, that is the pace, quickness of the meeting, there is the impact of the background of the occurrence of deafblindness also present, i.e. how a person became deafblind and how is he/she coping with it. The way in which someone “experienced deafblindness” certainly has an influence on the very interaction in meetings.

5.2. Aspects of Communication Modes

Even when we look at two deafblind persons with approximately equal degrees of sight and hearing impairment, we can notice that their communication methods are not always the same.

The use of certain methods of communication is most commonly associated with the ways the deafblind person was communicating before becoming deafblind. Some primarily blind deafblind persons, that have lost their hearing later in life, knew Braille alphabet from prior use, so it became the basis for the communication methods and techniques used once they have become deafblind. On the other hand, primarily deaf deafblind persons were used to use Sign Language and manual alphabets, and after becoming deafblind continued to use Sign Language with certain adjustments based on their visual impairment. If they have completely lost their sight they use Tactile Sign Language, and some with blurred vision or very little remains of sight use Close Vision Sign Language. Some individuals with a restricted field of vision (Usher syndrome) use Visual Frame Sign Language, etc. Deafblind persons with residual hearing can rely on it to understand loud and clear voice, whether conveyed by means of technology or without it. The deafblind persons can either rely on his/her residual vision either to read the speaker’s lips, or use another technique that relies on the visual modality, such as reading interpretations in different text forms adapted to the remnants of their sight. With such a diversity of communication methods available to deafblind persons, it is important to emphasise that the receiving and the transmitting of messages by the

same deafblind person does not have to take place within the same communication method, but a single person can use one method for receiving and another one for transmitting messages. There are deafblind persons who, when acquiring information use different methods depending on the situation in which they currently find themselves.

There are even other communication techniques that the Deafblind used to use in the past, but they were eventually abandoned because they were considered too invasive (Tadoma). (Eriksson 2009; AADB 2009; RID 2002) A detailed description of the most common communication methods can be found as part of interpreting methods in the chapter 2 *Terminological Clarifications* in the paragraph *Deafblind interpreting*.

Despite the numerous differences in the communication methods used by deafblind persons, they still manage to achieve successful communication interactions with their environment. Some deafblind persons know more than one communication method so they can manage on their own in interactions with each other before and after the meeting, during the meeting, as well as during the breaks. Some deafblind persons cannot establish interaction without the help of an interpreter. The methods we communicate in often determine the diversity and abundance of interactions.

EXAMPLE: I always thought it interesting to observe the mutual interaction of individual deafblind persons at international meetings. At one of these meetings in Finland one deafblind person from Denmark that used Danish Tactile Sign Language, had no difficulty in managing to establish good communication interaction with other deafblind persons who were familiar only with their own local Sign Language (Japanese, American, Greek, etc.). A smaller number of deafblind persons possessed the knowledge and skills of several Sign Languages simultaneously (e.g. British Sign Language and American Sign Language). Some of them used “International Sign Language” as well. As far as I was concerned, I knew my own Croatian Sign Language, and had a solid knowledge of Swedish as well as British Sign Languages.

All in all, a dozen of us, Deafblind Sign Language users, gathered and decided to taste a little bit of freedom and independence, and we literally “dismissed” our interpreters, or rather fled from them into an autonomous night out, to a pub. The one with best residual vision led the whole group of us holding to each other in a long single line. There were some accidents, but even more

laughter. One of the top priorities was how to strategically place ourselves around a table so that everyone is involved in the communication. The ones with Usher syndrome needed good lighting and those who were totally blind needed to be close to those who still have good enough residual vision to pass on what was happening at the table. The way we were supporting each other, ordered drinks, drank them, talked that night... we have not felt deafblind at all.

And that happened to be one of the best outings in my life!

Sometimes the way we communicate in determines the quality of the communication interactions. The more communication methods we know, the easier it is to communicate independently with others, even with those who do know nothing on some of the communication methods. Our communication methods and determine our “speed” because with some methods we communicate faster than with others.

We can conclude that the communication interaction itself depends on many different aspects: with whom we communicate, the way we communicate, whether we communicate with or without an intermediary (interpreter), where do we communicate, what we want to achieve with communication, etc.

5.3. Linguistic Aspects of Interpreting

At international meetings where there are people who speak different languages it is mandatory to indicate one (or more) official working language(s) for the sake of mutual understanding. Most often it is the English language, not always the native tongue neither of the participants of the meeting nor of the interpreters themselves. Since the entire interaction takes place in real time it is necessary to ensure high quality interpreting, that is high quality interpreters. “The role of the interpreter is to ensure full access to information to all the participants of an interaction.” (Napier 1998: 15, according to Hull 2002).

Deafblind interpreting is even more than that. It is in fact multipreting! (Jacobs 2009)

Just imagine ten deafblind persons speaking different languages and two interpreters per each Deafblind and you got thirty participants of an interaction during interpreting in a single meeting. Multinteraction!

I'll quote some examples of interpreting to provide a clearer insight into how complex the process of Deafblind interpreting is, so unlike interpreting at meetings where sighted and hearing persons are present. During meetings Deafblind interpreters seek to interpret from the source language into the target language with a smaller or greater time lag depending on whether the interpreting is done simultaneously or consecutively. However, the most common option during meetings is simultaneous interpreting. Consecutive interpreting is very rarely used exclusively, because it would prolong the meeting, and the Deafblind are slow enough in communication as they are.

Linguistically speaking, the interpreting situation is not a simple one because it is not dealing only with interpreting of a variety of spoken languages, but with interpreting of different Sign Languages as well.

Nevertheless, we sometimes have a simpler interpreting, in terms of languages, interpreting different languages in the same modality like when one spoken language (English) is interpreted into another one (Norwegian) and vice versa. Another case is when we interpret languages with two different modalities, such as when one spoken language (English) is interpreted into a Sign one (British Sign Language, hrvatski znakovni jezik or lingua italiana dei segni) or vice versa. I have even spotted a case when there is only one language in the interpreting process, but in two different modalities, e.g. spoken English into written English and vice versa.

At meetings I witnessed to more complex interpreting, such as when one Deafblind participant received the message after the (already interpreted) English one was first interpreted into the native tongue of the participant's country, and then re-interpreted into a combination of local Manual Alphabet and local Tactile Sign Language. Sometimes the same participant's words are

interpreted in a briefer proceeding: he/she speaks in his/her own native tongue and an interpreter interprets this into English (to be further re-interpreted).

As an exception, I can mention a remarkable deafblind person who has had significant residual hearing, as well as an excellent knowledge of English, so he/she could independently follow the progress of the meeting, without an interpreter. During the meeting, he/she used support by an assistant only occasionally, when in need to obtain additional information or when not hearing well something, as well as in the preparation of materials or finding some information in a particular documents, etc. The assistant was of greater help before and after the meeting when he/she needed guiding.

So far I have cited examples of interpreting with respect to language that I witnessed at Deafblind meetings. However, a lot more interesting Deafblind interpreting is found at WFDB and EDbU meetings. Here I will only describe some examples of such interactions during interpreting and for a more detailed view, see Chapter 2 *Terminological Clarifications*, section *Deafblind Interpreting*.

Sign-Language using deafblind persons use different methods of interpreting tailored to the degree of visual impairment of the individual Deafblind. For instance, a deafblind participant with Usher syndrome likes both his/her interpreters sitting somewhat farther in front of him/her it so that he/she can monitor both the course of the meeting and his/her interpreters as needed. With my low vision I prefer my Close Vision Sign Language interpreting, when both of my interpreters sit right in front of me. As my sight does not allow me to encompass what is going on, I usually sit with my face turned the other way when compared to other participants, to leave my interpreters the possibility of a better overview of the situation during meetings so that they can describe me what is going on. On the other hand, a deafblind participant who sees almost nothing and uses Tactile Sign Language interpreting has both his interpreters sitting next to him. There are also situations with Deafblind interpreters using technology in their interpreting, such as FM loop systems, interpreting into a microphone or such as a keyboard that projects the text onto a monitor screen or a Braille digital display.

Up to now I have been describing communication used by deafblind persons when receiving information. However, when the deafblind person wants to express him/herself, to transmit information, the process does not always look resemble the receiving process, but in reverse order. This means that a deafblind person can receive information in one way and provide it in another. For example, one participant uses Tactile Sign Language to receive information, but when giving information, it is done by speaking.

Besides, the Deafblind differ among themselves in the manner how they use interpreters. One or two interpreters may be used in order to receive information from spoken English into Sign Language, but when giving information he/she can speak English, no help from an interpreter is needed.

From the above examples it is evident that the interpreting processes have a very significant impact on the interactions during the meeting. Since the “concatenated” process can be time consuming, interpreting mistakes that can affect decisions might occur during it. As complex as the interpreting processes might be, they are very important for the interaction at meetings because without interpreting they could not be held and no decisions could be made.

5.4. Cultural aspects

At international meetings attended by persons from different countries, due to different cultural background/heritage, minor problems in understanding particular communication messages might arise or the way someone communicates something might be misinterpreted. For example, an interpreter with no previous knowledge of Bulgarian culture could interpret a nod of the Bulgarian interlocutors as “yes,” while in reality it means “no” (of course, if the Bulgarian interlocutor shakes his head, it means “yes”). Westerners often mistakenly interpret the posture of Japanese speakers as humility, which leaves a wrong impression of arrogance on the Japanese interlocutor. It is known that although the Americans and the British speak the same language (simply put), the Americans are prone to exaggerate their expressions, while to the British some restraint is inherent. (British firemen would probably say “We did not lose much time in coming,” while their American colleagues would put it “We ran like space rockets to the place.”) Such examples of cultural

approaches to communication can be found at meetings of the Deafblind as well. (Humphrey & Alcorn 2001)

EXAMPLE One speaker said to another “You smell like a smoked kipper,” the other smiled and nonchalantly replied “At least I will not become spoiled.” This exchange caused some confusion to me as well as to my interpreter because after several such statements both of us actually believed that these two speakers could not stand each other and were showing that publicly. A few years later we realised that they were actually very good friends. And even later we learned what “English humour” does mean.

Apart from these, many other cultural differences exist that should be kept in one’s mind, especially when we take into account the differences between cultures of sighted and hearing persons and the Deafblind one. The values that hearing and sighted persons place in voice and vision are reflected in their behaviour, as well as in their norms of decent and socially acceptable conduct. In contrast to the culture of the sighted and hearing persons, the culture of the Deaf community and of the majority of the Deafblind is focused on hands and touch, which creates different norms of conduct. Throwing objects in the air or putting one’s hands in pockets in the presence of a deaf or deafblind person is considered rude, since such behaviour carries the potential risk of injury to the eyes or reflects one’s refusal to participate in the interaction, respectively. (Humphrey & Alcorn 2001).

EXAMPLE: I said to a hearing interlocutor, a guest at a meeting of the Deafblind whom I had not seen for some time and I knew him before, “My god, look at you, what happened?” The response was neutral, but somewhat cold “Thank you, I’m fine, and how are you?” Later it was explained to me that I should not address anyone as directly as I was used to do in the Deaf and Deafblind communities. There, a direct comment comes before a greeting if a person has visibly changed. It took me a while to realise that I cannot be so straightforward with hearing and sighted persons.

Within Deafblind culture touch is the main element of the culture pattern. According to Chappelow and Pope (Jacobs 2009) the main components that form part of the Deafblind culture

are touch, time, social interaction, communication and Support Service Providers. For instance, touch can be the principal or additional source of information for deafblind persons because they cannot fully use their sight and hearing. If you would like to draw the attention of a deafblind individual, you will neither call (because you won't be heard), nor wave (because you won't be seen), but you will approach the person and pat gently his/her shoulder or arm.

EXAMPLE: Deafblind persons who have very poor eyesight or cannot see at all almost always have a constant need for touch. We can observe that even when there is no interpreting going on the Deafblind will keep his/her hand on his/her interpreter, or at least occasionally touch him/her just to be sure that he/she is still beside him/her.

My deafblind colleagues often complain on the lack of knowledge of Tactile Sign Language by their interlocutors, as well as about new inexperienced interpreters who while interpreting often hold the hand of the deafblind person, which is not necessary. "As if I were trapped," they say, or "It's as frustrating as when someone keeps your eyes closed while you're trying to watch."

There are situations in which the interpreter can take some of the information for granted, but if that information is not conveyed to the deafblind person, it can lead to erroneous perception and inappropriate actions. Here is an example from the experience of Monica Hermansson: "One problem I have met is that we, as sighted people, consider some things so natural we don't think to describe them! I have one example from a conference where a man from South Africa participated. He had a Dutch name so for me it was so obvious that he was white! I never gave this information and neither did my colleague. When we went home we talked about this man and when I mentioned his sensitive type of skin the deafblind person reacted, 'What... Wasn't he black??' " (Hermansson, 1999)

EXAMPLE: Something similar happened to me when my interpreter left out something which was obvious to everyone but me. The interpreter thought that it was "visible" enough to me that my interlocutor is gay that it needed no more explanation. It took me a couple of meetings and a year or so that another interpreter mentions that fact so obvious to others, by saying: "You know he behaves like a gay." I was told that right after a conversation with the person in question, and that

alarmed me to check whether the person is acting like a gay or is in fact gay. After I learned about the person's orientation, it was easier for me to establish good contact with that person, who today is one of my very good friends.

Depending on cultural traditions, Deafblind interpreters are usually prone to omit information that they themselves find uncomfortable. In such cases, deafblind persons are missing information due to a conceptual level which does not fit the frame of reference of the deafblind person concerned, or missing information concerning the environment. (Andreoli 1999)

Deprivation of information associated with a certain cultural pattern of individual interpreters often leads the deafblind users themselves into an awkward situation because deafblind persons cannot know whether the person they are talking with is actually occupied with some other things (and it is possible that the interlocutor has even fallen asleep in the meantime): "It is more convenient to give the visual information to a person who uses a tactile method! You don't have to embarrass people around you while giving the information, for example if someone falls asleep during a meeting you don't want to embarrass him by giving this information in a loud voice. The group of deafblind persons who receive information aurally will often get less information because the reason mentioned above! That is to say that the interpreter may leave out embarrassing information." (Hermansson 1999) When the interpreter tries to avoid a situation that is unpleasant for him, this would probably put the deafblind person into an even more awkward situation.

EXAMPLE: I was always fascinated by those interpreters of my Deafblind colleagues who did not hesitate to interpret all behaviours, even my own naughty behaviour while looking straight at me. They also used to copy various other behaviours either when someone was angry or when someone was happy. On the faces of the Deafblind there was an evident interest while their interpreter interpreted such extreme environmental information.

Problems arise when due to lack of Deafblind interpreters deafblind persons have to address Deaf interpreters for assistance. Great problems are caused by the belief that Deaf interpreting culture is completely valid for interpreting to the Deafblind. However, in practice we most commonly encounter the dissatisfaction of the Deafblind since a Deaf interpreter does not

understand the different approaches to and needs in interpreting, differing from deafblind person to deafblind person. Moreover, the same deafblind person may in different situations ask for different ways to describe the environment, etc. Some Deafblind prefer literal interpreting of spoken language in a given situation, summary interpreting of language and a lot of environmental interpreting in another one, and even some combination of different interpreting methods in a third one.

According to Andreoli (1999), we should distinguish between Deaf interpreting culture and the developing culture of interpreting for the Deafblind.

5.5. Educational Aspects

The extent of involvement of a deafblind person in a meeting depends greatly on the interpreter he/she disposes of. The more qualified the interpreter, the more involved the deafblind person is.

EXAMPLE: I have to admit that in the beginnings of my participation in meetings, a bit out of ignorance, but also because of my inexperience, I have long avoided a certain deafblind person, because it seemed to me that there is nothing interesting to talk about with the person. Other deafblind persons seemed to share that impression of mine when we talked about that person one evening. A negative impression was left even on my interpreter. We fervently tried not to sit near that person at lunch or during breaks. Such an opinion of the person lasted until at one encounters the person appeared with a new interpreter. It was only then that we realised what we had missed before. The person we had so zealously tried to avoid turned up to be very interesting and knew a lot of interesting things, so that I was so sorry that I missed the opportunity to socialise with that person before. In fact, the whole negative impression was just a reflection of that person's inadequate interpreter.

It is clear that the key role in ensuring good and effective communication is played by intermediaries in communication, i.e. professional and qualified Deafblind interpreters. The legal system of the United States asserts: "the term interpreter for individuals who are deaf-blind means 'a qualified professional who uses tactile or other manual language or fingerspelling modes, as

appropriate to the needs of individuals who are deaf-blind, to facilitate communication between individuals who are deaf-blind and other individuals.’ ” (US Legal *no date*)

If Deafblind persons were provided with qualified Deafblind interpreters, situations that are common at international meetings when the interpreter does not know the terminology well could be avoided. Moreover, cases when a deafblind person is provided with an interpreter who has only graduated from high school are not infrequent, thus making situations like the one from the following example really inevitable.

EXAMPLE: At a meeting we had a lecture on “The Octagon – a Tool for the Assessment of Strengths and Weaknesses in NGOs,” where the presenter at one point mentioned the term “discriminative analysis” and the interpreter at the same time signed “discrimination” instead of “discriminative analysis.” Such a Sign Language interpreting was confusing because “discrimination” could not fit into the context of the whole presentation, so afterward I went to check with the interpreter what kind of discrimination was that about. I later realised that the interpreter did not know what “discriminative analysis” means so the most similar word to that was used, and that was “discrimination.”

A Deafblind colleague of mine complained that children of deaf parents are often employed as interpreters, without the necessary education on interpreting, and sometimes only a high school education behind them, and that it is almost impossible that a deafblind person with a higher degree of education could get accurate and complete information at some important meeting where special terminology is used. This happened to that deafblind person at a scientific meeting. Such examples are not just isolated cases, but this is not the subject of this scientific research. However, this issue may be left open to a future research.

There are also examples of how some interpreters value their job differently. By chance I had the opportunity to meet an interpreter at a meeting where he/she interpreted to a deafblind person. The meeting was held at a state level, in a ministry setting where the interpreter was at the height of the task. However, interpreting to another deafblind person at a Deafblind meeting, it was evident that the interpreter was “having fun” and behaving almost casually. During the meeting he would

often tell jokes related to what had been said to his interpreter colleagues but also to other interpreters who were near. Later I learned that some deafblind participants received information from their interpreters of a “disturbance” during the meeting, but only after the meeting was over and nothing could be done anymore. Some other deafblind persons did not even know that there were any “disturbances.”

EXAMPLE: A different evaluation: A professional interpreter was always telling me that in educating interpreters I need to pay attention to preparedness in order to avoid errors in interpreting, how important the interpreters’ physical fitness and health is and that interpreters should not be exposed to fatigue, etc. in the eve of important interpreting duties. Can you imagine how I felt when the evening before an important meeting, where significant discussions and essential decisions should be made, both my interpreters went to a party until the wee hours? At that particular meeting, I had great difficulty in establishing normal interactions with other participants because my interpreters (probably because of weariness) confused all the terms and abbreviations whenever I got involved in the conversation. The situation was so bad that it created uncertainty about what I actually wanted to say. Sensing that things were not going right, I decided to rely upon my own bad English and express alone what I wanted and then the conversation took a much better course. Otherwise my interpreters were not prone to such omissions in interpreting, perhaps because they never went out until the wee hours before. The responsibility of the interpreters in the described situation failed.

In section 2 *Terminological Clarifications*, section *Deafblind Interpreters*, I described the situation with the development of programmes for the education of interpreters.

However, talking about the training of interpreters only does not suffice, education should also focus on the Deafblind. To many deafblind persons access to education is not available. As noticed by Andreoli (1999), there is a wide range among active deafblind persons who have experience with interpreters and who often participate at meetings, seminars, conferences, unlike the majority of deafblind persons he meets. This also explicates us why the number of deafblind persons interacting in the international arena is relatively small. Mainly, it’s always the same persons appearing at international events.

I will mention an example to ask ourselves who really needs education, the interpreter or the deafblind person? Or maybe both of them? We had a situation where a deafblind person explained an issue at length in his/her native language, while all the participants' eyes were on his/her English interpreter to find out what is being said because it was a case of consecutive interpreting. As the speech went on and on, the interpreter was becoming more and more nervous and it was apparent on her (eye-rolling, puffing, etc.) while the deafblind person did not feel that his/her speech went on too long nor anyone signalled him/her that it should cut the long story short. And when the person finally ended with the speech, the interpretation into English was much shorter than the original. It was obvious that a lot of vital information was omitted. Later, I asked the same interpreter why he/she had not talked to the deafblind person about that, since the same situation was recurring constantly. The interpreter told me that it was because of ethics. Her answer puzzled me because the interpreter's face during the speech was anything but ethical. The dilemma remains whether this was really an issue of ethical nature or it just needed a negotiation on the relationship between the interpreter and the deafblind person.

If neither the interpreter nor the deafblind person possess basic training on what is the role and responsibility of the interpreter, mutual relationships can become complicated, which can directly affect not only their reciprocal interaction, but it can also be spread to all the present participants at a meeting.

5.6. Organisational-environmental aspects

There are many circumstances that contribute to the success and feasibility of meetings and affect them:

- securing financial resources to participate at meetings
- the number of available professional Deafblind interpreters
- rules at meetings (warming up, organisation of breaks, etc.)
- adequate room (lighting, temperature, seating, etc.)
- availability of materials in different modalities (large print, digital form, Braille)
- availability of technical support (FM loops, large screens)

- Interpreter–user relationship

The organisational and environmental aspects in securing good interactions may not have the crucial importance of directly affecting the ensuring of efficient and effective interaction at meetings, but eventually, it certainly has an indirect impact on the very interaction at meetings.

Seven groups of organisational-environmental factors were mentioned, but each of them has a lot of subgroups. Here I will take a look just at several examples which are not to be ignored if we wish to get a broader view on the problems faced at Deafblind meetings.

Most deafblind persons spend a lot of time and effort in trying to secure funding for participation at international meetings. Now and again, the Deafblind must find creative ways to raise funds for their participation, which means that from the very start they lose a lot of energy which should be focused on issues and decisions that should be made at the meetings. I do not have to repeat how slow and hard-labouring the process of seeking funds is due to the Deafblind's double sensory impairment, to say nothing of the uncertainty that the deafblind person goes through while waiting for the decision whether his journey shall be funded or not. It is not uncommon to receive the decision at the last minute and only then the fuss about seeking available interpreters and affordable travel options begins. Only a small number of states enables the deafblind person as well as his/her interpreters to participate at meetings by providing them with financial security, covering travel expenses, accommodation expenses, meals, interpreters' fees, etc.

However, not only the search for funds to cover travel expenses is exhausting, but it is also the looking for funds to cover the interpreter fees.

What to say then about the search for qualified interpreters for international meetings? Some deafblind persons sometimes cannot find an interpreter for them. Some have only one. Some manage to secure three interpreters or two interpreters and an assistant. However, the established rule is that each deafblind person should have at least two Deafblind interpreters.

However, when a deafblind person uses two interpreters, the complexity and extensiveness of interpreting are often inconsistent which can also affect the interaction itself.

For instance, some deafblind persons have two interpreters who interpret alternating all day long. They take turns every 20 to 30 minutes, as is the case with my interpreters, while one interprets into Croatian Sign Language the other is “resting.” But in the absence of qualified interpreters occurrences of a deafblind person with two interpreters that are both constantly interpreting without the possibility of taking turns are not rare, just like in the already mentioned case when one interpreter interprets from English into his spoken native tongue and the other interprets from the spoken native tongue into Tactile Sign Language, and do so all day long without a rest. Occasionally when the deafblind person wants to say something then interpreters use to work as a team, one of them being the “voice” of the Deafblind (interpreting into English as the deafblind person speaks) and the other being the “eyes and ears” of the Deafblind (while the deafblind person is talking, the interpreter uses haptic signals to describe the situation in the room, how participants are acting, sitting, etc. or interprets when someone wants to ask something).

At the meetings themselves certain standards of conduct are adhered to, but not always. One of the major problems is the speed or pace of the meeting. “One wish I could not formulate well was to have the right to do things at our own speed (an action against the speedy society). I finished the message saying: ‘and now I am tired, can you understand??’ ” (Grandia 2013)

The possibility of following meetings in real time and taking turn at meetings with a comment or question is taken for granted by the majority of persons. When it comes to active participation in a meeting with one’s own comments and questions, it is of the utmost importance to do it at the right time, which is a real challenge for deafblind persons. There are many testimonies of deafblind persons who oftentimes failed to get the floor in meetings, either because the interpreting process slowed the reception of information, or because of cultural differences that affected the tendency of interpreters and the deafblind person to interrupt other speakers and speak freely at meetings. (Jacobs 2009)

According to Schneider (2006) “McNamara described frustrating personal experience such as attending meetings where communication rules were not established or where the pace of proceedings prohibited her full participation.”

At meetings of sighted and hearing persons there is a rule that the participants gather before or after the meeting and talk to each other, either on private or on business matters. Deafblind persons invest even more effort to use the time before and after meetings for personal and/or business talks. However, such talks are often hindered either by the necessary preparations related to the meeting or due to the participants’ exhaustion after a long meeting.

Even if we follow all the norms or rules of conduct during meetings, it is also necessary to ensure the technical requirements for good communication as well as good environmental conditions in the room where the meeting takes place (good lighting, cosy atmosphere, well-set temperature, airy environment, good seating etc.), and the availability of materials in a proper format used by the deafblind person (large print, Braille, audio materials, etc.). All the materials should also be available to interpreters which is not always possible because the majority of written materials are often delivered in the last minute.

We could list all these organisational and environmental facts one by one and describe every instance. I’m sure that such an inventory would be quite a long one, but this is not necessary for this doctoral thesis. However, this remains an open field for further research of each of these aspects that affect the interaction.

Even a superficial reading of this chapter makes it evident that the interaction at meetings is an extremely rich and complex one and that we should better appreciate the efforts of each deafblind person who makes an outstanding effort and invests time in order to be a part of it, but we should never forget the efforts made by the Deafblind interpreters.

6. RESEARCH PROBLEM

6.1. Research Problem

In the last couple of decades we are moving towards a social model of disability, towards the equalisation of opportunities for persons with disabilities, to empower them and direct them to self-advocacy, as we mentioned already in the chapter 1 *The Importance of Deafblind Interpreting for Deafblind Leaders at Meetings on an International Level*. All these changes are a long anticipated improvement of quality of life for persons with disabilities, but there are still parts of the puzzle missing. Without the definition of support and agreed standards of good practice, there can be no successful integration of persons with disabilities in society.

Although official documents (UN 2006; Council of Europe 2011; etc.) express good intentions, without proper services, social inclusion cannot be achieved and the documents remain just a theory, without practice.

The situation becomes even more complicated when dealing with persons with disabilities whose needs haven't been well described in literature and there is even less opportunity to provide them with adequate support. One such population are deafblind persons, for whom scientific interest has only started to emerge. This is why there are no widely accepted standards of good practice and why there are significant gaps in knowledge necessary to provide them with proper support.

So far, we have apprehended the importance and particularities of the needs of the Deafblind during meetings. Generally speaking, the problem of Deafblind interpreting is inadequately known and relatively insufficiently studied. A review of available literature demonstrates an increasing number of representation of expert papers when compared to research papers on the issue. Expert and research perspectives on the subject do not yet provide a clear theoretical framework of what Deafblind interpreting is, although increasing interest for the field does open further opportunities for research, such as defining Deafblind interpreting (Gaus & Kennedy 2002; Eriksson 2009; Brenner et al. 1996), education guidelines for training interpreters for the Deafblind (Pribanić &

Tarczay 2006; Baumann 2011), code of ethics of interpreters (Timm 2000; Trabing 2003).

Professional papers, although well written, cannot have the same impact as scientific papers, which is the reason why the area of research needs to be more represented. The body of literature providing some insight into that area is growing (Göransson 2008; Eriksson 2009), but is still relatively small, which is why this research was initiated.

The gap between the necessity of providing services and the competence to do so was the key motivator for this research. As long as we don't have a clearer picture on what the services for the Deafblind should be like, we won't be able to provide them with support they need to fully function as equal members of the society. Since the field of Deafblind interpreting is very wide, covering a range of different users, all with different needs, only one specific set of deafblind individuals was chosen to be researched in this paper – the Deafblind leaders. A model of a successful and effective Deafblind leader can positively influence but also empower and encourage many deafblind persons to participate in the exercise of their rights: However, even to be provided with such a leader, proper services have to be established first.

As I have already mentioned, insufficient knowledge on what kind of services are considered appropriate and necessary are characteristic both for Deafblind leaders and all Deafblind citizens of every country.

6.2. User's perspective

Insufficient knowledge about the specific features of Deafblind interpreting, precisely from a user's perspective, locates the Deafblind in a marginal position, a position of a member of an oppressed group. This research is suitable to empower Deafblind leaders to express their experiences, thoughts and needs through a user's perspective.

Why exactly a user's perspective? According to Marković (2008), the features of contemporary culture are reflected in a way of thinking, characterised by a moral imperative to listen the voices of marginalised groups, including those of persons with disabilities, which in this case means the Deafblind.

This research is focused on the perspective of the user, that is, on the perspective of Deafblind leaders. In this research I will examine what is the user's perspective of Deafblind leaders regarding the area of interest – Deafblind interpreting at meetings on an international level – following the policy that no scientific results can be implemented in practice without considering the user's perspective and no quality standards can be implemented without science and practice combined (Duncan & Harrop 2006).

The approach used in this research reflects my genuine interest for the user's perspective and for gaining knowledge on areas of practice that haven't been described before. Although current literature has been consulted and included in this research, only after considering the user's perspective can there be new guidelines given and alternative perspectives opened, which is a more and more present way of information gathering and using in social context (Branfield & Beresford 2010).

Since this is the first time that the user's perspective of Deafblind interpreting during meetings at an international level will be researched, the methodology had to be devised in a way that would both respect the user's perspective and the pilot nature of this research.

6.3. Purpose and Objective of Research

The purpose of this research is to raise the level of knowledge on Deafblind interpreting by describing in detail the user's perspective of the process of interpretation during meetings at the international level. With this research, the interpretation of Deafblind interpreting by the users themselves was to be revealed. The purpose was going to be achieved through achieving three main objectives of this research:

1. Reveal and describe the characteristics of the interpreting process at international meetings that deafblind users deem important in obtaining complete and clear information from interpreters.

2. Explore and determine expectations, opinions and ideas, with establishing the contribution of the user's perspective of deafblind users of interpreting services, in order to understand the need for specialised education for Deafblind interpreting at international meetings
3. Offer a theory about the characteristics of interpreting and interpreters for deafblind persons at international meetings, based on their own perspective

Perspectives revealed in this research can subsequently be used to make further research and to better focus on areas of interest. The pilot nature of this user's experience gathering process makes its outcomes valuable as indicators of important issues to be considered in future research.

I believe that this research will provide a special contribution to science because it will open up opportunities for a number of other researches in this insufficiently explored area, and because it will encourage fellow researchers to engage in further studies in this specific field.

6.4. Research questions

What is to be accomplished with this research is to obtain an insight from the deafblind participants on four main areas – communication methods of the Deafblind, language interpreting, mobility support and environment description, covered by the following research questions:

1. How do deafblind users describe their positive experiences with deafblind interpreters at international meetings?
2. What are the expectations of deafblind users from interpreting process at international meetings, in all aspects of receiving interpreting service (language interpreting, mobility support and environment description)?
3. What specific expectations do deafblind users have when it comes to cooperation with interpreters at international meetings?

4. How do deafblind users describe the key difficulties that occur at international meetings they attend with their interpreters?
5. How do deafblind users describe the additional environmental impacts needed in order for an interpreting situation to be possible at all and to be as effective as possible?
6. What are the expectations of deafblind users when it comes to the organisation of international meetings?
7. What insights obtained from this study can be used as a basis for further scientific research?

6.5. Initial Expectations

My initial expectations from this research stemmed from my natural curiosity, many years of active participation in the field of deafblindness and even more deafblind persons whom I have met and had an opportunity to work with. This is why my expectations can be regarded in three ways – my expectations as a deafblind person, my expectations as a researcher and general expectations.

As a deafblind person, I expected to find glimpses into other deafblind persons' minds, their perspectives on the process both they and I are going through each single day, their thoughts and feelings that were hidden from me, and possibly from the world, because there is a chance that nobody bothered to ask them. Because I can relate to them, I believed that in reading their stories, I would find much of what had already happened to me, or was still happening to me during interpreting at international meetings. I hoped that for some deafblind persons in this research, my questions would provide an onset of a more critical consideration of the interpreting process and delving deeper into their own perception of the interpreting process. It could have meant that for some, their role in this process could change from passive to active and assertive in receiving the kind of support they require, thus changing their lives for the better, at least in this one segment of their lives.

As a researcher, I was aware that my personal expectations could somewhat influence my approach in reading the participants answers, but I was also prepared to have my expectations changed according to the data collected, just as it should be in the qualitative research (Jeđud 2008). As a researcher, I expected to find areas of vast differences and ones where participants would be more similar. One important area where there would be vast differences between participants was relationship with interpreters. From what I have seen and heard through the eyes and ears of my interpreters over the years, I expected that there would be deafblind persons who wanted a quite formal relationship, but there would also be others, whose interpreters were also their friends. In contrast, one area of the interpreting process organisation could be common to many participants. This would be financing of their participation and that of their interpreters. From my experience, financing was often a factor that prevented deafblind persons from participating in meetings and less formal gatherings alike. I believed that the situation in Croatia was similar to the situation in other countries, with few exceptions in developed countries where interpreting services existed for longer periods and there were more opportunities for covering the costs for participation of deafblind persons and their interpreters.

The general initial expectation was that by focusing on the user's perspective of deafblind leaders and by using the qualitative methodology, as well as by the application of qualitative methods for collecting and analysing data, obtaining of new and specific insights about the characteristics of the Deafblind interpreting process at international meetings would be enabled.

7. RESEARCH METHODS

7.1. Introductory Remarks on the Research

In this scientific research, the need for selecting a qualitative methodology, rather than the quantitative one, was imposed by the specificity of the research problem (Maxwell, 2009). Given the objective and the issue of this research, it was decided that the best data access can be achieved through an appropriate research methodology – a questionnaire with feedback (follow-up). Moreover, such an approach to research allows for a detailed description of the user's perspective with the smallest possible influence on him/her. The user's perspective in this research is a key factor in the gathering of actual guidelines for the development of new standards, since the research participants themselves are stakeholders of the process that takes place at international meetings. The specifics of the research will be described in more detail in this chapter.

7.2. Support in the Research Process

In this section I would like to share with you the details of a special kind of approach to a research process. I consider this important in order to encourage other people with similar disabilities to become researchers and not to give up their dreams, despite the restraints they face. Furthermore, I wanted to raise awareness in other researchers without disabilities about the tremendous effort and time it takes for persons with disabilities (in this context: persons with deafblindness) to do everyday chores, let alone complex tasks, such as writing a doctoral thesis and doing research.

According to some researchers, it takes a deafblind person three times more time to perform an ordinary task, in comparison to persons without disabilities (Smith 1994). If we apply this rule to the process of studying and finishing a doctoral thesis, it should have taken me three times longer to succeed at doing that. Since this was not an option due to administrative reasons, I was forced to assess all my restraints and possibilities.

Guided by my previous experience in working on my masters thesis, with the addition of new adaptations in reading and writing process due to my progressive vision loss, I was making estimates about how long would it take me to complete the doctoral thesis and could I even succeed at doing this. The deteriorating state of my vision forced me to learn new ways, methods and techniques of reading and writing, which was not an easy and quick process. These changes in the way I perform such necessary tasks required a lot of my time, energy and effort.

To be honest, the deadline I was given seemed an impossible dream, considering the state of my vision and my pace of reading and writing with new technology and techniques. I was looking for a way to make up for the obstacles I was facing, but to remain independent, despite my dependence on the support from other people. After consulting several professors from the University of Zagreb, who gave me examples of other students using assistants during their studies at all levels of education, I decided to consider this option as well. It seemed as the best way to solve my problems that were related to my vision loss.

To meet the standards of ethics required in the scientific research, my personal assistant had to sign a Statement of privacy of information. This way I could guarantee protection of personal information of every participant in this research.

Below I will give a description and examples of using personal assistance in working on this doctoral thesis. Two key segments of work will be described – one is the approach to the scientific literature and the other is the process of gathering and analyzing the data received from participants. It is important to emphasise that without support from a personal assistant, this research probably would not be possible.

Access to scientific literature and studying the field of science that is of interest to the topic of the research are one of the basic activities in scientific practice. To me, they are almost entirely inaccessible, due to my vision loss and inability to read larger quantities of text from a computer screen. Only by modifying scientific literature in some way I was able to read the publications relevant to my research. Ordinary people without vision loss might not even be aware of this tremendous effort and time that is hidden behind the last few pages of this thesis that contain the list

of bibliography used in this research.

Before the actual reading of scientific literature, it had to be modified technically, so that all the text was printed in a way that was most compliant to my remaining vision. The font used was Helvetica, size 22 pt, using bold letters and alignment to the left of the page, so as to avoid the unnaturally large spacing of words that is created automatically when paragraphs are aligned to both margins. The spacing between the lines was that of one empty line, in order not to create disturbances in the peripheral vision field, that would set off my nystagmus. In comparison to ordinary print, text formatted in the way that suits my needs is two and a half times longer pagewise. This means that the piles of paper are higher and it is more difficult to go through such large amounts of literature, not to even think about moving them or reading outside my office or my home, since they are quite heavy to carry around.

Literature available online was usually quite easy to manipulate with computer programmes for text processing. By copying and pasting in a text editor programme, such as Microsoft Office Word, the text became open for formatting. What presented real problems were documents in protected forms, such as PDF formats, that required additional creativity on behalf of my assistant, so that even those documents would become accessible to me. In handling such formats, errors occurred during transformations from PDF to text processing programmes. Usually, those errors include misplacement of paragraphs and sentences, automatic insertion of spacing, substitution of similar letters or groups of letters which sometimes renders the word incomprehensible. This meant that the assistant had an uneasy task of formatting and then checking the whole document for errors, which had to be corrected.

Concerning books and other printed documents that I had access to, I had trouble reading them without special technical equipment. Books had to be scanned first, after which the images were put through the computer programme for optical character recognition (OCR). In this way they became accessible as text that could be formatted differently. Text obtained in this way is seldom without mistakes. Once again, the role of assistant has proven irreplaceable, since the comparison with the original had to be done by someone with good eyesight and understanding of the problem. Computer programmes for correction grammatical errors and spelling checkers are of some use, but they lack the capability to judge the whole paragraph and the context. Because of

such situations, modification of literature still cannot be a fully automatised process, but requires some human guidance and control, which I had in a form of an assistant.

There are other details that had to be accounted for when modifying literature, such as footnotes and references. In order to make them accessible for me, they too had to be reformatted to the same size as the rest of the text and somehow included in the text, so that they do not disturb the course of reading and to stay connected to the right place in the text.

When the process of formatting was done, the document or a book was printed and bound. Shorter articles could be stapled, but longer texts or books needed to be bound like real books, to prevent falling apart and misplacing parts of the document (this could easily happen because although the pages were numbered, there was no headline on each page, like there would be in a book or in an article). Books in large print often have to be bound in more than one volume, due to their sheer size. This presents a task that is time consuming, costs money, but there also has to be previous experience to create a large print book that is not too thick to obstruct the pages from turning easily, to create a cover and contents for each volume of the book and to do it in a relatively short time.

Besides the printed materials, I had at my disposal electronic devices, such as a computer with a large screen and an electronic magnifier with optical character recognition. However, I could not use them for prolonged reading because they caused fatigue of my eyes and triggered episodes of nystagmus, which made reading entirely impossible.

The second part of the story about using assistance in my work concerns the gathering and analyzing of data. To even begin with the process of collecting data from participants, my own materials had to be formatted so that they are easily received and reformatted by other deafblind persons, whom I invited to take part in my research. This meant that all my written materials, sketches of questionnaires and documents in electronic form had to be formatted by my assistant. That is how a questionnaire was made, with help of the assistant, which saved me a lot of time and effort in dealing with technical details, which I could not monitor and correct by myself.

For purposes of this research, a special e-mail address was created, which I also needed help with. I believe that it is hard to imagine that a task so simple as creating an e-mail address could be so demanding, but this is a place to raise awareness about that also. There is a growing trend of creating web pages accessible to everybody, regardless of their disabilities, but the number of pages that are accordant to such principles is still scarce. In reality, persons with vision loss still struggle to find all the blanks they have to fill out, the buttons to press are too small, the colours are either distracting or indiscernible, the font cannot be enlarged, which is not even the complete list of visual obstacles that prevented me from creating an e-mail address by myself.

The process of sending out questionnaires was also done with my assistant's help. Sending them to the right address and checking the names were processes that would take me too long, but with assistance they took only a few hours. What took longer was the process of collecting questionnaires that were filled out and returned to me. They all had to be standardised and systematised, which are the processes described in greater detail in the Section 7.5. *Method of data analysis*.

When all questionnaires were printed out in large font, I had to devise a plan how to collect the relevant data from them and make them easier to re-read afterwards. One way was to use different colours to mark different themes, which would later be recognised as categories and subcategories. When the questionnaires were read through and highlighted with different colours, I could continue with data analysis. I used thick black markers to write and draw categories and relations between them. However, when my work was done, I had to rely on my assistant's help once more to create electronic versions of my paper drawings. Since it would be impossible for me to create electronic images according to my drawings, I provided guidance and feedback to my assistant, so that the final pictures matched those I envisioned in my mind. When those images were enlarged and printed out for me to check them, I could approve them and compare them to my drawings, together with my assistant. But when it came to putting them in the text, where they ultimately belonged, they became almost invisible to me because of their fine lines and small font. To maintain control over what is represented where, I had to keep my own record and refer to my own large print copies of them, otherwise I would keep losing track.

Putting the whole thesis together was also a task for my assistant. With my state of vision, it

would be very difficult for me to keep all the written material in one document. Instead, I wrote it section by section and kept them in separate documents in the computer. Together with writing the sections, I created a list of contents, which would later be used in assembling the parts. When all the chapters and sections were complete, the assistant used the table of contents and inserted the separate documents into the large document that would become the complete thesis.

7.3. Participants in the Research

Participants in qualitative research are usually chosen in accordance with their characteristics in order to obtain the best possible picture of their perspective on a specific topic or on a specific problem. The fact that the total number of respondents in this research could not be a large one was determined by the specificity and limitations of the group involved in it. This was consistent with the structure and methods of qualitative research conducting , as well as with methods of data processing (Flick, 2009a).

Due to the relative youth of both organisations of the Deafblind (WFDB and EDbU), deafblind persons have only recently begun to occupy leading positions in international and regional organisations and other positions in international organisations. The overall organisation and functioning mechanisms are still in the process of creation, customisation and development. This process is slow, and the greatest effect on it is by the Deafblind themselves, since they occupy the leading functions that require competent action and implementation of their duties in making correct and far-reaching decisions. However, simultaneously they are users of interpreting services without which such meetings would be inconceivable. This is the main reason why an insight into the awareness, opinions and expectations of the users is necessary in order to enable organising meetings at which an efficient and effective communication takes place.

The relative novelty of the possibility for the Deafblind to be personally involved into meetings and decision-making in their own organisations at international level determines the relatively small number of deafblind persons involved in this level of partaking and decision-making. Therefore, the anticipated number of participants in this research was twelve. The anticipated number represents the upper limit of the number of participants, due to restraints in

accessibility of more participants who meet the criteria for inclusion in this research. Moreover, the number of participants was adapted to the four groups of deafblind persons (described in chapter 1 *Introduction*), so that three participants per group be included, which gives a total of twelve participants.

The participant selection process was enabled by the fact that they all shared some common characteristics (Maxwell, 2009), which placed them in a class corresponding to the research problem, but also kept as diverse as possible in order to obtain a wider range of responses and insights into the problem.

Three criteria were selected in this research by means of which participants have been selected in order to best describe the group of interest. These criteria were as follows: involvement in the work of international organisations, holding positions in management bodies of those organisations, and deafblindness.

The first criterion common to all the participants of this research was previous experience in the boards or bodies of both international organisations of the Deafblind – the European Deafblind Union and the World Federation of the Deafblind. These two organisations have been selected as the base from which participants were recruited. The reasons for this choice were their greater availability, the longest tradition of meetings on an international level and the fact that the official language of these meetings is English. These reasons became very important when the work of other organisations of the Deafblind is considered, such as FLASC of Latin America or the African Federation of the Deafblind (AFDB), whose traditions go back only a few years. That made them less experienced, and their meetings still haven't gone through all the stages of development and fine tuning, like EDbU's and WFDB's. Also, the official language of FLASC meetings is Spanish, which tells us that those meetings are international, but for the vast majority of the representatives and their interpreters the official language of the meetings is not a foreign one. However, when their representatives participate at meetings on the worldwide level, they also use interpreters when participating in decision-making process concerning the Deafblind world. What makes the meetings truly international and erases the language barriers and difficulties in understanding is the participation of a great number of different representatives, with just a few whose primary language is English.

The second common criterion was that all the participants in the research had held a function in these international organisations, or held it at the moment, either in their second or third term or in their first one. Alternatively, the participants were board members or representatives in the bodies of these two organisations. This way, an international sample of deafblind persons was obtained, that would be able to provide an insight into the real situation after the research.

When international meetings of the Deafblind are referred to in this research, they concern board meetings of WFDB (World Federation of the Deafblind) and EDbU (European Deafblind Union), attended by board members (President, Vice President, Secretary General, Treasurer and other members), including other committees, such as the monitoring, election, scientific, organisational one, or other members of working groups at various international organisations.

The third common criterion to all participants was that they were persons with acquired deafblindness, although they differed according to the aetiology and time of occurrence of hearing and/or sight impairment. The participants belonged to one of the four groups of persons with deafblindness, as described in the chapter 2 *Terminological Clarifications* (Smith 1994):

- 1) hard of hearing and partially sighted,
- 2) hard of hearing and blind,
- 3) deaf and partially sighted,
- 4) deaf and blind.

The Deafblind community is by and large very heterogeneous, and so was the group of participants in this research too. In this way the research was to reflect the true image of the Deafblind community, and its results could be considered valid because they were not created by an artificial selection of just a specific, narrowly delimited group. An additional advantage of the heterogeneous sample was the subsequent possibility of grouping responses into categories, or clusters, which demonstrated which responses occur more frequently, and which one did it more rarely. (Flick, 2007)

7.4. Methods and Techniques of Data Gathering

The basic method of data collection was a questionnaire with feedback, conducted by means of questions focused on user views and expectations concerning participation at international meetings and the use of interpreting services for the Deafblind.

In order to make the questions in the questionnaire as compliant as possible with the actual interests and thoughts of the Deafblind, the participants in this study, first an interview with an expert, an “expert interview” was conducted (Flick 2009b) with a single deafblind person, who fitted into the sample of research participants with his/her characteristics. The interview was open-ended, and the research questions were guidelines in the interview. The purpose of this procedure was to gain insight into what the users consider important and to establish a possible starting point for creating questions for the questionnaire. Thus a combination of inductive and deductive approaches was used in order to branch out the questions and categories put in advance, but also to accept new categories if the participant brought them forth. In this way a higher level of importance of the questions for the participants was achieved than would be the one of those compiled by the interviewer. The interview was conducted live, led by the author of this research. The interview respected the privacy of the participants, and an opportunity was given to the participant to later supplement his/her answers if subsequent reflections brought new thoughts relevant for the investigation. The interview with the initial participant was processed and became the basis for creating questions that formed the questionnaire for the participants of this research.

The questionnaire was constructed in the form of open questions to which participants were able to make unlimited long answers. Questions were organised into three groups. In addition, it was emphasised to the participants that they can add comments, especially if they considered that the questionnaire did not cover all the questions that they would like to provide comments to.

In the first part of the questionnaire – General Personal Data – all data about the informant relevant for the research problem were collected (age, gender, level of vision and hearing impairment, communication method used, experience related to the use of interpreters and interpretation, education, experience of participation at international meetings, etc.). Thus collected

data provided us with an insight of each deafblind person into his/her own deafblindness and the range of his/her own needs.

From the second part – Data on Deafblind Interpreting – user's perspectives were collected from the participants' answers on the main areas of research:

- 1) interpreting of speech
- 2) environment description
- 3) mobility support
- 4) interpreting methods specific to deafblind persons

Each category consisted of several descriptive questions, which could be expanded as needed and according to the preferences of the participants.

In the third part – concerning the organisational arrangements necessary to make interpretation most efficient – questions related to specific areas of research were included:

1. Accessibility of the meeting
2. Planning and organising the meeting
3. Environment arrangements
4. Recommendations from the users

7.5. The Research Procedure

The research was conducted in several stages, with an emphasis on the thoroughness of approach and of the interpretation of results. Before carrying out the interviews, the existing literature had been consulted systematically and current insights in the field of interest for this study had been referred to. As part of the preparation for conducting the research, the readiness of potential participants to take part in the study had been tested. In addition, during international meetings in the period from January 2011 to September 2012 observations had been made on casual

meetings and data had been collected that could be used as a starting point for a more systematic data collecting from participants in the meetings.

Due to the specificity of the groups of deafblind persons participating in this research, a questioning procedure was selected that corresponds to their best functioning. The questionnaire, written in a form corresponding to the participants, has been distributed to respondents via e-mail. In this way the respondents received information in a way that suits them, and when answering the questions, they were given a possibility to use as much time as they needed. Thus, maximum sincerity was achieved, without time pressure and without possible hesitation when giving answers.

After completing and sending back the questionnaire, each participant was contacted again after a week, to give him/her an opportunity to expand his/her answers with some afterthought or piece of information not provided when first answering the questionnaire. Since the participants in the qualitative research were considered co-creators of the research, each additional contribution of information was appreciated, and it was my anticipation that the participants would continue pondering on the questions answered in the interim between the research and the second contact, so that potential new answers could be collected. This is the reason that this questionnaire was considered a questionnaire with follow-up (Creswell 2007).

The participants have filled out the questionnaire by e-mail. They received it as an attachment to the main text containing a short explanation of the purpose of research, and detailed instructions for completing the form. Added to the questionnaire was a written consent that they had to sign after reading it and attach it to the response, sent back to the e-mail address of the research, in order to be stored in the database as a proof of voluntary consent to participate in research. The importance of honest answers to questions was emphasised to all participants in the research, with a stress on descriptive answers and detailed descriptions of their views and thoughts. Completed questionnaires were returned to me to a special e-mail address formed specifically for the purposes of this research, and the responses were stored in the research database.

7.6. Methods of data analysis

In accordance with the methodology of qualitative research, the data on individual experiences of deafblind persons during meetings at an international level gathered in this research was analysed following the steps appropriate to the nature of the research. Before the data could be analysed, a preparation of the material was carried out.

The initial stage of the processing of data was the preparation for analysis. This preparation consisted of standardisation and systematisation of questionnaires. The goal of standardisation was to make all questionnaires look similar, while systematisation was aimed at removing identity revealing data.

To standardise all the questionnaires collected on the specifically created e-mail address, the computer programme Microsoft Office Word was used. Although nowadays there are many possibilities to create online questionnaires, they were avoided because they tend not to be easily adjusted to the individual needs of each deafblind person. Instead, a plain document created in Microsoft Office Word was sent to participants, so that they could easily adjust it according to their visual impairment. Because of the individual differences between deafblind persons, each of the participants in the research returned the questionnaire in the form that was best suited to their communication method. Some of them used black or dark blue background with white or yellow letters, because their vision impairment doesn't allow them to read regularly formatted documents. Others, visually impaired as well, used large and bold fonts. Participants who used Braille-based systems for reading and writing on computer, returned the questionnaire re-formatted, so it lacked the original table and the font was plain, with no large print or coloured backgrounds. Since the respondents gave their answers in writing, they were considered the original transcripts.

Then a process of systematisation was carried out, removing all personal information that could disclose the identity of the participant and come into conflict with ethical principles. Each questionnaire was printed out with a participant's number and time details when the test was conducted on its front page. Data obtained by the follow-up contact with the participants was attached to each questionnaire as an appendix that was also included in the data processing.

Gathered data was processed by means of qualitative analysis of the text. The organisation of collected empirical data in this research was carried out in several steps, each of them described in this chapter, as following paragraphs. The data was put through the process of open coding (Mesec 1998).

The first step was underlining responses relevant to the research problem. The underlining served the purpose of highlighting the important answers, which enabled faster re-reading and going through each questionnaire several times.

The underlined sentences were units of coding. Since the method of obtaining answers from participants was a questionnaire that was filled out and sent via e-mail, there was no way to influence the participants' answers. This is the reason why in some questionnaires one answer to a question was already a unit of coding, while in other questionnaires the answer to a question was longer and could be divided into several units of coding. For some participants providing answers to questions was a process that triggered longer answers, sometimes even going off topic of a question, but still relevant to the research purpose. For other participants, providing answers to questions posed a greater challenge, sometimes with difficulties to understand the question and to give a more detailed answer relevant to the research problem.

The second step of the open coding process was the extraction of units of coding. The units of coding were copied to a separate document and printed out. They were then read again and the third step – the process of finding categories – could begin. The same sheets of paper were re-read many times over and over again, and I devoted myself to thinking about what connects the units of coding into categories and which categories would that be. The task was to obtain more abstract categories from the participants' answers, which were distinct and specific. After some time, categories and subcategories started to emerge.

The fourth step of the data analysis was listing of all the categories. All categories and subcategories that were identified in the process of text analysis were written down on a separate sheet of paper. This was done by using thick black markers, to facilitate re-reading and future

sorting out of the categories, due to my vision impairment. These sheets of paper were photographed and are included in this thesis as Appendix E.

The fifth step was to provide a description of each category, together with excerpts from the participants' questionnaires. Each category and subcategory was defined and described in a separate paragraph in this thesis. For each of them, a detailed description was provided with quotes from the questionnaires.

The sixth step in data processing could then begin, establishing relations between categories; in other words – relational coding. In this way the categories became connected. The connections brought more meaning to categories and subcategories in a way that they could be put in hierarchical order. At the beginning of relational coding, the relations were only ideas in my mind, with no tangible connections. First relations were drawn on a large piece of paper, using thick black marker pens. As was the case with the previous work done manually, these sheets of paper were also photographed and added to the thesis as Appendix F. This was the only way I would be able to see them and represent how I visualised the connections between categories. The process of connecting all categories and subcategories was laborious and time consuming, with many errors and re-doings of the connections. Many attempts later, a clearer picture started to form. When the relational coding was finished, the product was a large piece of paper with a graphic visualisation of the relations among categories, drawn and written by hand. The hierarchical order of categories and subcategories was then represented graphically by using computer programmes. This order was represented visually, by using graphic representations, popularly known as “flow charts,” which is included in the text regarding grounded theory in Chapter 10.

The seventh step was providing the written description of the result of relational coding. This was the grounded theory, valid for this group of participants (Glaser & Strauss 2012, Flick 2009c). The grounded theory was explained in a separate chapter, together with its visual representation and a legend that facilitates following and understanding.

7.7. The Ethical Aspects of the Research

Special attention was paid to the protection of the participants and this will represent a part of this doctoral dissertation as a separate unit. It is to be presumed that the compliance with relevant international and national laws and regulations on the protection of participants will be required from researchers and institutions in which the research was conducted.

In doing so all four major components of privacy protection were covered in the best possible way, namely:

(1) Voluntary participation of all the respondents

To all potential participants copies of Participant Data sheets were made available. Each participant was able to freely choose whether or not to join this research before he/she was informed on the nature of the research and on the role he/she should have in it. Each participant agreed to participate in the study in writing by willingly signing the Participant Consent Form. Written Consent Forms thus obtained were stored in the research database for at least ten years, according to the rules of scientific integrity.

(2) Confidentiality

Privacy protection was guaranteed to all the participants. This is particularly important in the context of a limited group of deafblind persons and their interpreters who attend meetings at an international level. As already stated, mutual acquaintance in a restricted circle of persons active in meetings presumed an increased need for data protection in order not to undermine the dynamics of international meetings and professional relationships among Deafblind participants of such meetings.

(3) Anonymity of respondents

Since the study was approached from a context in which it is impossible to avoid personal contact and invasion of privacy, data protection could be made only after the data were collected.

All participants were presented with numeric codes. In the course of transcription and storing data concerning each participant, his/her name was exchanged with a code number, to be used in the further processing of data. The original copies of a participant's data were stored in the research database and protected from opening by any other person but myself, as the researcher.

(4) A wellbeing/risk ratio favourable for the respondents

All the participants were acquainted with the research problems and protection against abuse of data obtained in this investigation was guaranteed to all of them. In this way a more open participation in the interview was enabled, which was necessary in order for the persons to express their opinions without hesitation and without fear that the data would affect their future participation in meetings at the international level.

8. DESCRIPTION OF THE SAMPLE OF PARTICIPANTS

8.1. Structure of participants

In order to obtain a clearer picture about the structure of participants in this research, a bit of descriptive statistics will be used. This serves the purpose of showing who participated and which groups of deafblind persons were included.

There were twelve deafblind persons involved in this research. More deafblind persons had been invited and offered an opportunity to participate, because it was expected that not all of them would agree to participate. Also, there was a possibility that the number be increased if the diversity of answers from respondents requires gathering more different accounts and experiences. During data analysis the final number of respondents was set to twelve, where there was approximately equal distribution of male and female respondents. The almost equal representation of male and female participants in this research could indicate that there is also approximately equal presence of male and female deafblind persons in the world or international deafblind organisations. Since this is the place where decisions are made, we can cautiously assume that women are also entitled to making decisions about the future of the Deafblind. If this would be indeed true for the whole deafblind population, it would mean that there is no gender discrimination. Table 2 represents structure of participants according to gender.

Table 2. – Gender of Participants

Gender	Male	Female
Number of participants	7	5
Percent	58%	42%

The next description of respondents in this research is concerned with categories of deafblindness. All participants were required to fill in the initial part of the questionnaire, which consisted of questions about their hearing and vision impairment. Categorisation of deafblind persons was used, the one that divides all deafblind persons into four categories (Smith, 1994). The analysis of structure of participants shows that three of the four categories were represented similarly, while only one category was represented with a slightly smaller number of participants – hard of hearing and partially sighted deafblind persons (Table 3). This could be due to various reasons, first of them being the possibility that they haven't yet fully embraced their identity as deafblind persons. Their remaining sight and hearing may seem sufficient to perform the majority of everyday tasks, with difficulties only in more demanding errands, which they are more inclined to avoid than to try to solve them by using interpreters. The other reasons why a group of hard of hearing and partially sighted deafblind persons was under-represented could be their busy schedules or inability of deafblind respondents to have an deafblind interpreter who can interpret to and from English for filling out the questionnaire. Another possible reason could be that they were not yet used to the idea of using deafblind interpreters for tasks like this, but that they are only learning how to work with interpreters and using their services in everyday life.

Table 3. – Category of Deafblindness

Category of deafblindness	Number of participants	Percent
Hard of hearing + Partially sighted	1	9%
Hard of hearing + Blind	4	33%
Deaf + Partially sighted	3	25%
Deaf + Blind	4	33%

The participation in this research was voluntary. What was important in the structure of participants was that all categories were represented. Also, interpretation of data gathered showed that participants had offered very different accounts and had shared very diverse experience. This

was also evidence that participants were heterogeneous, just as the population of the deafblind is (Göransson 2008).

Table 4. – Years of Experience

Number of participants	Participant code	Years of experience with international meetings
1.	8429	20
2.	7479	13
3.	7295	6
4.	5585	12
5.	4494	5
6.	4664	21
7.	4325	24
8.	3629	10
9.	3378	20
10.	3376	1
11.	3344	13
12.	2228	N/A
Average		13,18

The objective of this research was focused on interpreting at international meetings, which was why the respondents had to have some experience in such meetings. They were asked about duration of their experience at international meetings in the initial part of the questionnaire. Their answers are represented in the Table 4. The mean number of years of experience at international meetings is 13.18. Some of the participants had up to 24 years of experience, while others were relatively new to this field. Such wide spectrum of participants contributed to a diverse experience and different perspectives. Also, in data analysis it was useful to have participants from both sides of the continuum – the ones with much experience and the ones with little, so that all their opinions

and perceived needs were described in the research. To include only one group of participants, either the ones with much or the ones with little experience, would mean that the research would not be able to provide a wider description of attitudes, opinions and demands, but would only encompass the group of similar respondents, which could not represent the whole group of deafblind persons who attend international meetings.

8.2. Communication method

All the data gathered from the participants regarding their communication method is represented in Figure 1. The main goal of asking each participant to describe his/her communication method was to demonstrate the diversity of deafblind persons and their needs. Their communication methods were directly reflected in the way their interpreters worked with them, in the way they conveyed the information to them and how they received the information from them, in order to establish a good communication between the deafblind person and environment.

The data describing the communication method wasn't exactly qualitative, but descriptive. This is why it was separated from the true qualitative data that dealt with respondents' perceptions, opinions and experiences. However, the communication method data was presented in a similar way as qualitative data, but with the addition of a little descriptive statistics. Descriptive statistics here served the purpose of painting a clearer picture on what was the structure of respondents regarding their communication method. Also, it would demonstrate how rare some communication methods are, and accordingly, how difficult it is to find an interpreter who is skilled at them.

From what can be seen in Figure 1, this sample of participants managed to cover the entire range of communication methods used by the deafblind persons. As mentioned in the introductory and theoretical parts of this research, there are many communication methods available, and each of them was used by at least one of my participants in this research. This showed that the structure of participants reflected the deafblind population and no communication method was skipped. Each participant contributed with his/her experience and gave a bit more insight into the real situations of using Deafblind interpreting services. This way all users had a chance to describe their own

communication method, their requirements and issues with the communication method and/or interpreters.

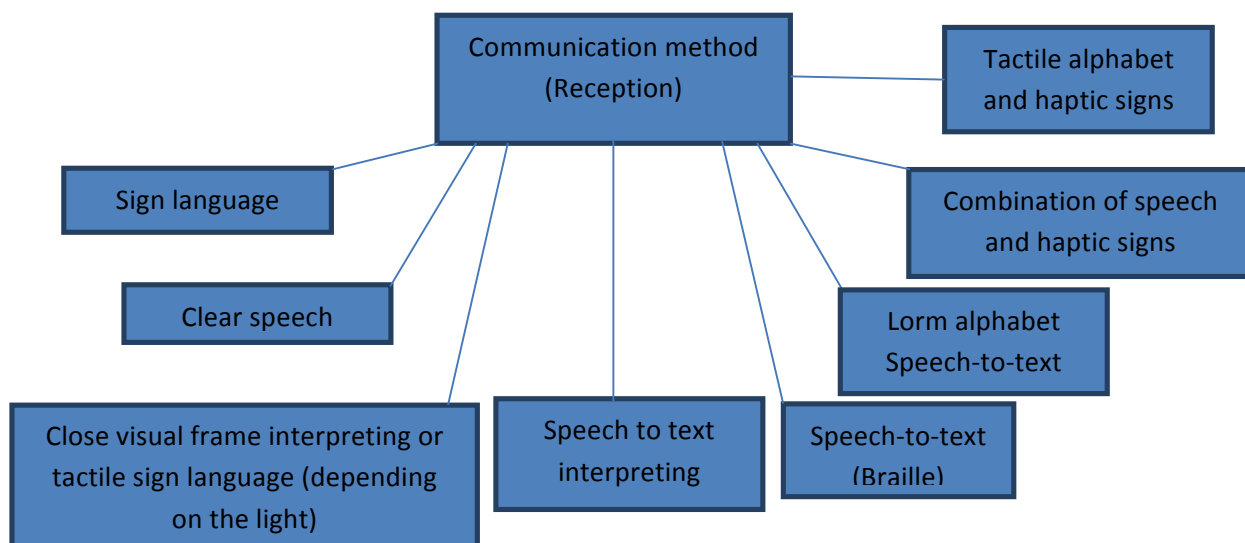


Figure 1. – Communication Method - Reception

The great diversity was evident in the communication method used to receive information. Due to different background of each deafblind person, different configuration of hearing and vision loss and different time of onset of hearing and vision loss, there were many communication methods used. For some, communication method differed considering the background and light conditions, ranging from close vision interpreting to tactile interpreting, when there was not enough light for the person to distinguish hand shapes and signs. Also, some rare communication methods emerged, like the Lorm communication method, which is can be classified in a group of finger spelling systems. This goes to show that persons with similar hearing and vision loss can differ significantly in communication method they use. For example, three persons with total blindness and profound deafness used three different communication methods: Lorm, Malossi and Speech-to-text interpreting. Each person described their method as the one they felt most comfortable with using. It is important to note that all of these three persons acquired deafblindness later in their lives, after receiving primary education and becoming literate. This is why all of their methods rely on letters and require the person to be literate. However, there is a cultural and historic background to choosing a communication method. Per example, Lorm and Malossi are two communication systems that use the same technique for transferring the information to the deafblind person – they use the palm of the hand to represent letters of the alphabet, with letters always in the same place, to

enable precise recognition of each letter. The interpreter uses his/her index finger to “type in” the letters, according to the previously learned position of each letter. Each letter is “typed” in succession and the deafblind person connects the letters the same way he/she would read the text written on paper. The difference between Lorm and Malossi is in the way letters are represented. The tradition of using Lorm is more typical for the Czech Republic and Hungary and neighbouring countries, while Malossi is typical for Italy. The participants in my research demonstrated that this was indeed true, at least for one of them. The one who was using Malossi was Italian, while the other, using Lorm was from Belgium, which was a less typical choice of communication method, but was a very valuable find that served as a reminder that there was great variety in communication methods and their distribution, despite the expectations based on usual finds.

One important find was that two of the respondents reported a significant change in the communication method used to receive information. They were both profoundly deaf and blind, which, by their own account, made their communication very difficult and forced them to receive all information via tactile communication. One of them used Tactile Sign Language, while the other used Tactile Alphabet, assisted with internally used manual tactile signs. The difference in communication method can be explained with their different backgrounds. While one was hearing impaired from childhood and used sign language from early age, the other acquired hearing impairment later in life and never got to learn Sign Language. Also, his/her environment was not consisted of people using Sign Language. He/she described the circumstances that led to his/her choice of communication method like this:

“No sign language, only alphabet. I never learned sign language because I didn’t live in that environment. And if you don’t live in an environment where you can use sign language every day, you have no chance to learn it actually. On the other hand, the alphabet was so simple to my family and easy to learn it then. The nearest relatives so I can keep in touch with them, communication...”

Participant 7479

He/she also described his/her custom of using made up signs for words that were difficult or long to spell via tactile manual alphabet. Also, he/she mentioned the difficulties he/she faced when these signs were presented to regular Sign Language interpreters, not the ones usually working with him/her. Here, a great importance of arbitrary signs emerged and brought to mind how important it

is to acknowledge the language status of Sign Languages. The words in Sign Language are arbitrary and stable, where internally made signs are also arbitrary, but only among a limited number of people, which makes them impossible to use amongst Sign Language users.

“Interpreters I have worked a lot together, they started to use signs differently. Certain signs in different situations. Speeds up a little. But I cannot use it together with sign interpreters because even if they only use a few signs, they will use different signs. Instead of knowing five of them, I will have to know a hundred of them. It doesn’t work. It’s easier when you work together for a week, for instance, and then we can adapt to each other. And we try to because many words with ten, fifteen syllables, it takes time to spell. If you can make a single sign for it, it’s easier. Sometimes, we make signs for very long and frequent words.”

Participant 7479

Using assistive communication systems, like haptic communication, emerged as a very common practice among the Deafblind in this research. Although haptic communication first started to be used on a regular basis in Nordic countries, it gradually spread and reached all parts of Europe. Haptic communication is used by both the users of Sign-Language-based communication methods and by those who use speech as their primary way of getting information. The robust nature and universal acceptedness of haptic communication makes it easy to use and practical to fill in the missing information from the environment. This is especially true in the meetings, as some participants emphasised – there is little time to interpret both the spoken information and the environmental information. This is where haptic communication takes over – it adds information, simultaneously with the interpretation process, it doesn’t disturb the flow of information from the interpreter and it is discreet enough not to disturb the course of the meeting. It is important to say that deafblind users who use haptic communication know that it is only an assistive method. Also, they know exactly which kind of information they receive through haptic communication – reactions of the people they are talking to, simple events like walking in or out, pouring water into the glass, the shape of the room etc. This means that the Deafblind are in charge of the information they are receiving and can monitor the effectiveness and quality of the information received.

The differences decrease when it comes to communication method for expressing oneself. Since deafblind persons communicate with their interpreters, who are (generally) sighted and

hearing persons, there are less constants in the communication methods they can use. Most of the deafblind persons continue to use the same communication method they were using before their hearing and vision loss. The two communication methods used to for expression were speech and Sign Language. Both communication methods were based on the deafblind person's primary communication method, prior to becoming a deafblind person. Some of the respondents were able to use both communication methods – speech and Sign Language, according to the situation and the person they are talking to. Whichever communication they were using, it seemed that deafblind persons did not report the need for modification of communication method, like they did in the receptive part of communication process.

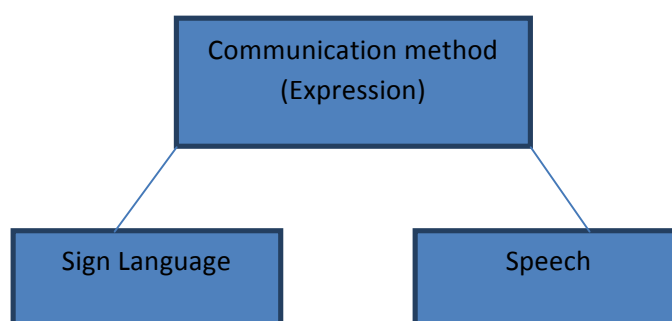


Figure 2. – Communication Method – Expression

The part of communication where they are conveying information to the interpreter didn't seem to be problematic to the participants of this research, or at least they didn't mention any specific problems in this area. While they talked a great deal about communication breakdowns and difficulties with missing or partly understood information, they didn't mention having problems expressing themselves. It seems that most of them were quite competent in using speech and sign language, so that their interpreters were not showing signs of problems with interpreting. It would be a bold and incorrect assumption to make that the interpreters were not having any trouble receiving information from the deafblind person because in this research no interpreters were interviewed. If there were communication breakdowns in the transfer of information from the user to the interpreter, they could be detected and described if interpreters were a part of the research. It would show a different perspective and maybe open doors to new discoveries. Also, it would most likely unveil an even greater complexity of the interpretation process

9. DEFINITION OF CATEGORIES

9.1. Title of Service Provider

The answers gathered from participants that describe the name of the person who provides services to the deafblind person are presented in Figure 3. It is evident that all of the participants indeed have one or more persons that provide them services, but they don't call him/her the same name. Since the respondents are from different countries and different socio-cultural background, this should be of no surprise and it shouldn't be of concern.

As mentioned before in literature overview, only recent years have started to bring formation of working groups focused on setting unified standards in Deafblind interpreting. Setting standards includes agreeing upon one name by which a service providers should be called. Until this is done, there will be different names, depending on many factors. Sometimes even state policy influences the way the service provider is called, by issuing tenders with fixed categories and names of service providers, which then become frequently used and people get accustomed with. The need to have an understanding on how to call the service provider for the Deafblind is a result of growing awareness that every deafblind person needs some kind of support. When deciding what kind of support and to which extent, the name of the service provider also influences how people perceive this person and what is their attitude towards them.

A significant find is that all of the participants had a name for their service providers, regardless of how different they were. One possible interpretation is that all of them think about their service providers and consider their job important enough to give it a name. However, not all of them explained why they use precisely this or that name. This is why there is no way of determining how did they come across it and what influences them to use it.

There is an old expression “nomen est omen,” which can be applied in the case of Deafblind interpreting too. The way deafblind persons call their service providers in a way determines their expectations from this person and reflects how much thought do they give to the importance of the profession of these service providers. Giving a name to the profession is a step towards recognition

and respect for the persons who are doing it. Some of the respondents are using names that include a part of the description of the role of the service provider. Those call him/her “guide-interpreter” or “interpreter-guide,” which makes it easier to determine their expectations – to receive interpretation and guiding services. It is more difficult to determine the expected role from the title if a person is using the term “interpreter.” Another way of specifying the service provider is naming him/her “Deafblind interpreter” or “interpreter for the Deafblind.” In this way a clear distinction is achieved and a target group of users is identified in the title of the service provider. However, to know what is the expected role of the interpreter, one has to have knowledge on what Deafblind interpreting is and who are the persons doing it. With growing awareness and more and more deafblind persons and experts involved in making standards for Deafblind interpreting, there is a growing number of people using this term correctly. It is the official stand of the leading organisations of and for the Deafblind (World Federation of the Deafblind – WFDB, European Deafblind Union – EDbU, Deafblind International – DbI) that the term “Deafblind interpreting” should be used in the context of service providers for the Deafblind. Also, the World Association of Sign Language Interpreters (WASLI) and the European Forum of Sign Language Interpreters (efsli) promote the usage of the same term, to make a distinction from Sign Language interpreters for the Deaf and from oral language interpreters. The effort to promote the use of the same term and to create guidelines for education and standards of good practice will eventually lead to a better understanding both within the profession of interpreters and outside it. This way the *nomen* will truly be *omen* and more people will better understand what Deafblind interpreting means and what it includes.

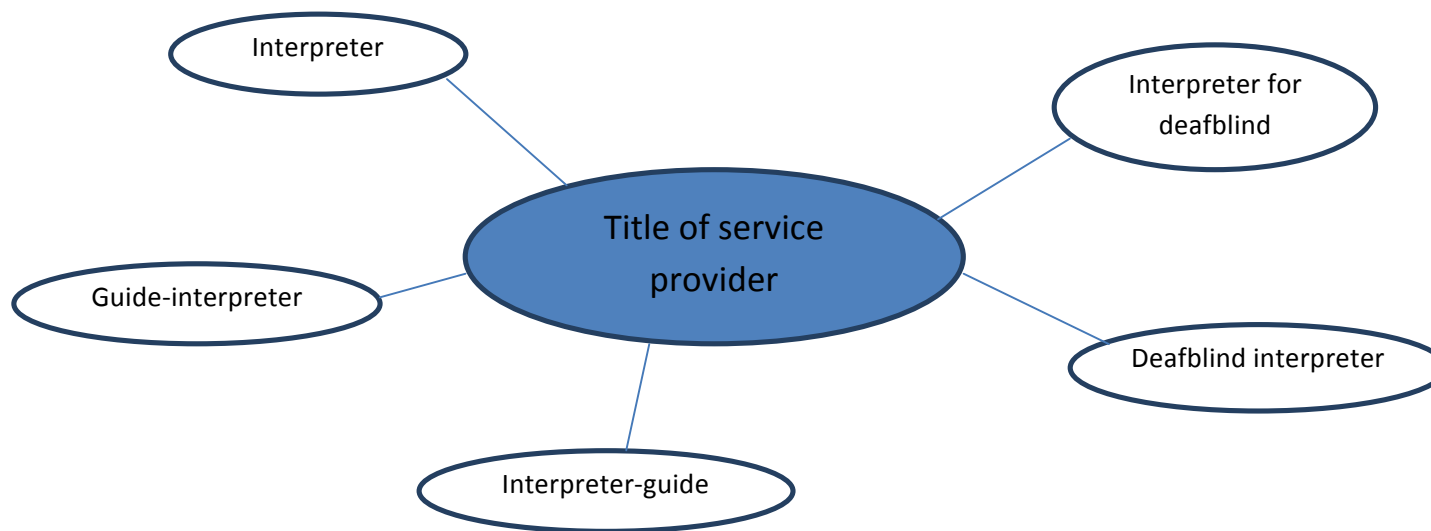


Figure 3. – Title of Service Providers

9.2. Selection of interpreters

Selection of interpreters emerged as an important category, showing that deafblind users have some criteria that they consider important in selecting interpreters. Through a number of questions, respondents described what they deem important when selecting interpreters, or with what kind of interpreter they would be satisfied with. They described what characteristics should an interpreter have to match their needs and the job requirements.

Most of the participants emphasised that a previous knowledge of the topic(s) of a meeting is very important. In their own words, “it makes the interpretation easier and quicker” (Participant 3378), “more accurate” (Participant 3344), “there is less misunderstandings” (Participant 5585)... The participants said that the interpreters with previous experience of similar meetings functioned better because they were accustomed to the terminology, the other participants and their interpreters and were able to better grasp the essence of the meeting. With such starting point, the interpretation process is easier for them because there are more things to anticipate and more familiarities. On the other hand, some of the participants complained about the low level of experience and knowledge of the topic(s), which makes the interpreting process slower and less reliable, because there is a greater chance that the interpreter him/herself won’t understand something, which leads to the inability to interpret it correctly. There is also a factor of a specific language used at international meetings. Some participants described the ideal interpreter as one with experience with similar meetings because of the “specific jargon, signs and words” (Participant 3378). It is a factor that determines language competence of an interpreter, regardless of being introduced to the topic(s) and other participants. Therefore, there are two main reasons why the users prefer interpreters with previous experience with international meetings: a better grasp over matter and participants and language competence.

There are other factors in the selection of interpreters, one of which is formal education. Most of the respondents in the research stated that they prefer interpreters with formal education. They consider that the profession of Deafblind interpreting requires a serious approach, with the need of formal education for interpreters, to convey all the necessary knowledge they require to be able to perform their duties on an acceptable level.

In the process of selecting an interpreter for the task, most respondents prefer when they have a group of interpreters that they can choose from. They describe this as “selecting from several interpreters they usually cooperate with and they know” (Participant 3376). This is also a criterion in selecting interpreters that most of the respondents stated – knowing their interpreter previously and/or in advance. They explained that this gives them assurance that the cooperation will be successful and that they will establish a good working relationship from the beginning. The interpreter who has previous experience interpreting for an individual is already accustomed to his/her communication method and there is a greater chance that he/she will be successful in the interpretation process.

Many participants described the way selection of interpreters affects them in an emotional manner. It became evident that the selected, or given, interpreter affects the way they feel during the meeting. When participants described a meeting where they had a positive experience with interpreters, it was connected to satisfaction with the selection of interpreters. In other words, if the selection of interpreters was in accordance to their needs, they felt better during a meeting and they felt successful with their participation at the meeting. One respondent described the experience of having the right interpreter for the meeting and the way it is supposed to feel:

“It’s always good with a good interpreter, but if I have an interpreter with a special, a special... Who’s especially easy to read and who knows about errand we are discussing, [he/she] can make small contractions without disturbing the information, then I feel it’s floating in oil and it feels good. And I stop to think about the interpreter, it’s just working. And if I have two, the same type, after an hour I don’t know which is which, it’s same thing you know, it’s floating on. Then everything feels very good.”

Participant 7479

From what we can read, it is evident that the emotional factor in working with the interpreter is great. It is also the factor that cannot be described very accurately and cannot be quantified. Some factors that contribute to good experience can be described, thus making a process of selecting an interpreter easier. However, the complete picture and the way it feels cannot be predicted from mere facts about interpreter and user. It is a much more complex phenomenon – achieving a good fit between user and interpreter. But once it is done and accomplished, it makes a tremendous

difference in experience of working with interpreters. In the world of the Deafblind, where one is dependent on a person of interpreter to be able to communicate with the world, it is very significant that the user feels good working with interpreter. It is, therefore, important that the user has a chance to select interpreters that are appropriate for the task at hand.

Some of the participants stated that they prefer working with always the same interpreters. This contributes to their satisfaction with their cooperation and the outcome of the whole event the deafblind person is participating. Some of the answers from respondents described why it is important to continue the cooperation with the interpreter with whom they have positive experience from before:

“If I go at a place like this [international deafblind conference], I need an interpreter that has been around with me before, because if I say: ‘I want to see Sanja’, my interpreter must know who Sanja is. And if there is something which is needed by someone, the interpreters must tell me who is this person coming.”

Participant 7479

When they were describing the feeling of not having the same interpreter, some of the deafblind users expressed their unease. It is also important that such feelings be noted and described because deafblind persons often face situations where they cannot change interpreters. They are put in a situation where they have to manage to work successfully with an interpreter they do not know. Below is a short statement from one participant, describing the feeling of being forced to work with a new interpreter, with whom they have not been working before:

“I do not feel at ease, I prefer working with interpreters that I already know.”

Participant 8429

Their feelings affect the relationship and outcome of the interpreting process, by making it harder or easier. Although it is not always possible to provide a deafblind person with an interpreter to their liking, this should be given a thought in the process of assigning an interpreter to a

deafblind person for a certain situation. Also, this tendency of some deafblind persons to prefer the same interpreters should be mentioned during Deafblind interpreting training. It is important that future interpreters be aware that their professional career could be linked to a limited number of users, which can also have an effect on their feelings, development of attachment to the user and it certainly will trigger the issues of boundaries and nature of a relationship between a deafblind person and interpreter.

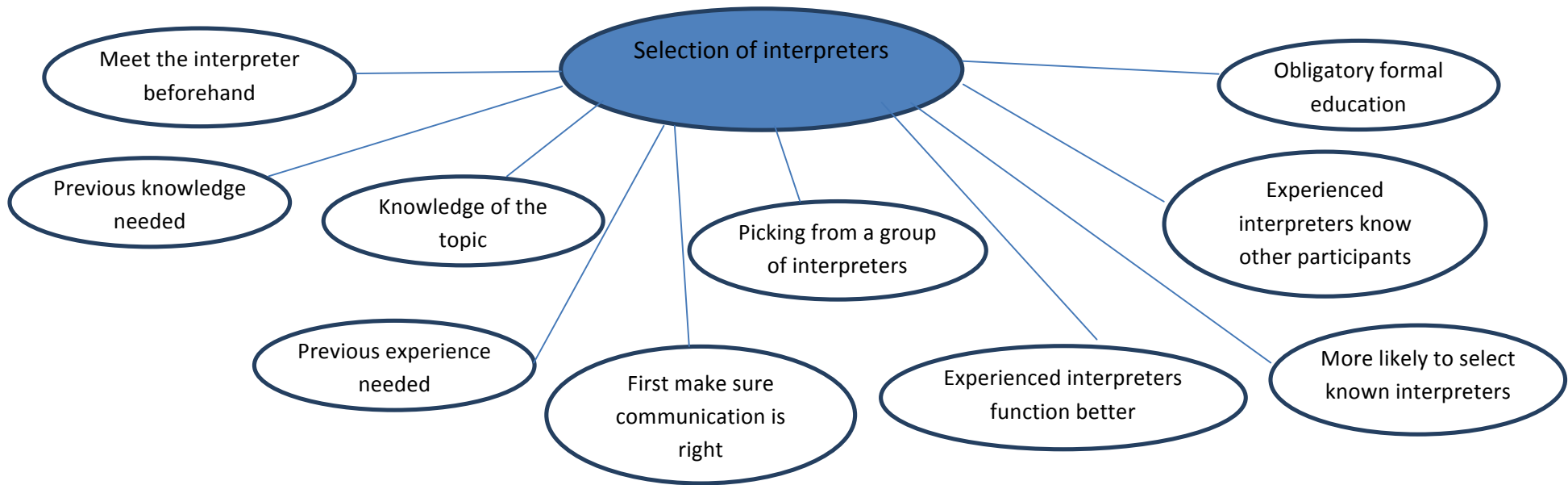


Figure 4. – Selection of interpreters

9.3. Limited choice of interpreters

Although deafblind users have a clear picture on what kind of interpreters they want, for some of them there is a gap between the desired situation and reality. The selection of interpreters doesn't always go according to plan, and for some there is no selection, but making do with what they can get.

The most common restraints in selecting interpreters are difficulties in finding the person who is qualified enough for the task. Sometimes the qualifications in question are basic ones for being a deafblind interpreter, but sometimes there is a specific lack of qualifications. One example is a limited number of deafblind interpreters who are competent users and interpreters of English, which is a very important factor when participating in international meetings. Some of the participants are faced with a limited number of interpreters whose level of English is sufficient to enable them to participate fully in a meeting, which is why they are forced to use an additional interpreter, just to cross this (spoken) language barrier. For some, the limited number of interpreters competent in English makes them use the same interpreters for the international meetings over and over again. Although the respondents are not unhappy with this situation, they are aware that it presents a risk of being left without interpreter when they need one. Some of the respondents said it would be better to have more competent interpreters to choose from, so they wouldn't have to rely on a very small number of interpreters and risk not being able to attend the meeting if they are all unable to interpret for him/her there.

There are ways of dealing with the lack of qualified interpreters and a limited choice. Some of the users turn to their friends who act as interpreters. This situation is described in the paragraph talking about interpreter role, too. The other way of finding an interpreter when there are no qualified ones available is using volunteers as interpreters. The users are aware that the level of competence of volunteers is usually lower and there is a question of meeting the volunteer beforehand. Since volunteers can't be given proper wages, the deafblind users are reluctant to demand the same standards from them as they would from proper, certified interpreters. The situation of having to use volunteers at international meetings is described as less desirable one:

“Sometime I used volunteers, namely when there were no other possibility.”

Participant 4325

However, not all participants of this research face the same problems with finding the appropriate interpreters. In countries with a developed network of service providers, deafblind persons have a greater opportunity of receiving adequate interpreting services. One participant described his/her usual process of applying for interpreters at international meeting:

“Usually I use the same interpreters. There is interpreter company in [the my home country] we all use and they have about forty interpreters. At least ten of them I know real well. So they give me the right interpreter for the right occasion.”

Participant 7479

This can be interpreted as a good experience with a limited number of respondents. In his/her case, this is not a bad thing, but quite the opposite. He/she describes that he/she is aware that he/she knows only ten of them and he/she is confident that the agency will choose the interpreter among these ten that he/she knows. Also, from his/her account, it is evident that there is a great level of trust between him/her and the agency, because he/she is confident that he/she will be given a right interpreter. This person has obviously had a lot of positive experience with this particular agency, which is why he/she confides in their making the right choice of interpreter for him/her and for the occasion he/she needs one for. The level of awareness of the complexity of interpreting situations makes this respondent even more active in using interpreting services and contemplating all the aspects of it. His/her awareness that not all interpreters are competent to perform in all situations, makes his/her trust in the agency's choice even greater. This relationship between the user and the agency is truly a remarkable example of good cooperation and well-established services. It is also the only example of such a positive account of a process of receiving interpreting services in this research. It shows that only some countries have developed reliable and well-functioning services.

However, many countries are in the process of establishing such services and their efforts may not be evident in the level of services given today, but it will show results many years later. Such is the example of a country one respondent came from, where there are unparalleled services for the

deafblind today. My amazement with the described situation in that country led me to inquire more about how they managed to accomplish this. The participant was more than willing to share his/her story, which is also the story of many deaf and deafblind persons there, whose efforts led them to a great victory for their right to communication, information and participation.

“I don’t think there’s any general solution to that. You must have the same aim to have interpreters many enough, skilled enough. And interpreters you can use when you want them, without problems. Then it depends on how country’s built up. In [my country], we had the opportunity to work politically from the beginning. Going up the departments and talk to the ministers and others and we were active in training. We were together with organisations for the deaf and organisations of the hard of hearing. And together we became such a large group so we could put pressure on the government. But it started in 1974. And it didn’t work until, you may say, ten years ago, the way it does. So, thirty years of work, step by step. But you must... In [my country], we had to work politically. And practically at the same time. And engage all organisations in a very deep way. It did one thing that been standing high on agenda, even since. And it would have to be. Because if we don’t continue to push, the service would wither. Because it cost money. And if it costs money, they tend to cut away a bit now and then. If you don’t observe. But it’s so essential in a life of deafblind. If we have interpreters, we can do almost everything. If we don’t have interpreters, there is really not much you can do outside your own apartment.”

Participant 7479

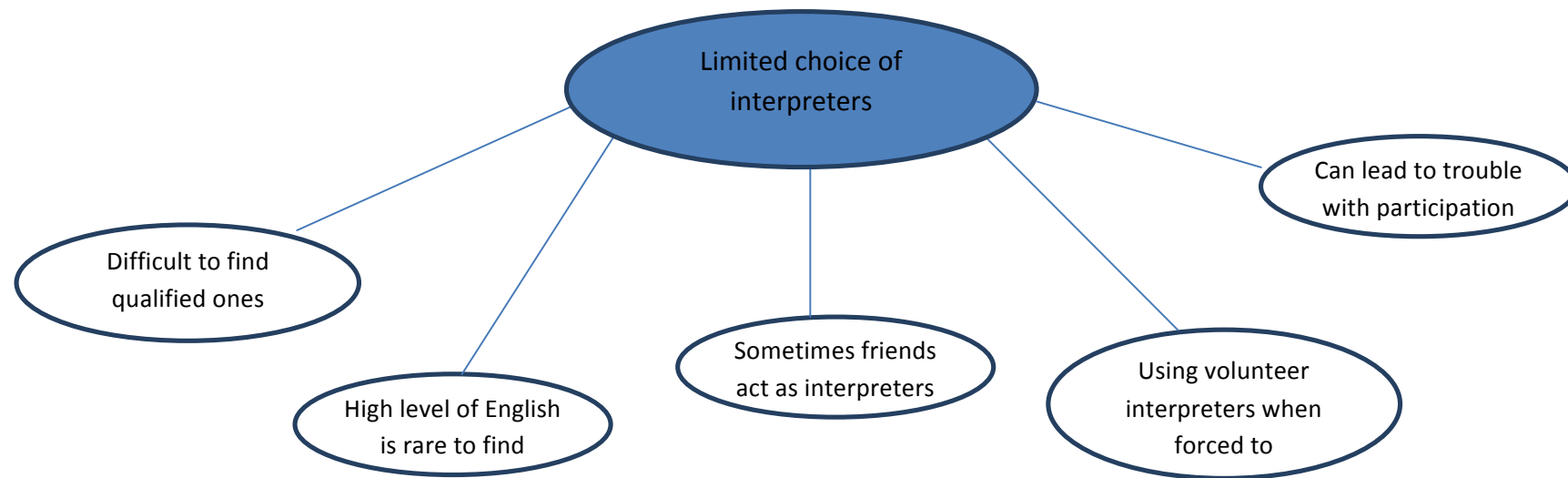


Figure 5. – Limited choice of interpreters

9.4. Physical Appearance of Interpreters

The attitude of participants towards the physical appearance of interpreters varied greatly. From those who stated that they don't care at all to total opposites, who required an interpreter with a strict dress code. Many respondents stated that the dress code of the interpreter is of no importance to them as long as the interpreter feels comfortable and is able to perform his/her job without obstructions. This reflects the general attitude of many respondents – they care about their interpreters and want them to feel comfortable in doing their job. It also shows that the users are aware that the profession of Deafblind interpreters is not a simple one, but requires a lot of dedication, hard work and can be very tiring. Therefore, it is evident that they wouldn't impose any more restraints and make their job even more difficult to perform.

Of course, there are situations that require a dress code that is appropriate for the occasion. Just like some of them stated – an interpreter has to fit in the environment, without attracting unwanted attention to him/herself and without breaking social norms and expectations. There is a strong cultural factor, which is also evident in some of the answers. For example, one participant stated that the dress code has to be moderate, so that “...it covers everything” (Participant 2228). Such preference is something that differs between cultures and has to be respected by both the user and the interpreter. There were also participants who described the desired attire of an interpreter as “well-dressed, but not attracting the attention of the public – neutral” (Participant 8429). This is also much influenced by the culture and norms of a particular community, country and continent. Moreover, what exactly is considered as “well-dressed” is also a matter of personal opinion. This could be seen as a source of disagreement between a user and an interpreter. If such a thing is not discussed prior to the interpreting situation, with detailed description of what is considered “well” and “neutral,” both the user and the interpreter can end up dissatisfied.

Between not caring at all about the interpreters' appearance and culturally determined preferences, there is a group of users whose limitations in visual perception influence the way their interpreter should look. Within the group of respondents with partial sight, the majority stated that they prefer their interpreter wearing black or very dark coloured clothes. They explained that the most important reason why they insist on dark clothes is the contrast. Their requirements depend on the remaining vision, which relies greatly on the environment and the structure of what is being

seen. What matters the most to them is the contrast, which enables them to see a clearer picture and to locate the hands of interpreters faster. Black or dark clothes enable them to perceive the signs made by their interpreter. If the clothes were of a light colour, or with patterns, it would be difficult to them to spot the exact position and hand shape of the interpreter. (Conversely, for African interpreters white or light coloured clothes would be the norm.)

The interdependence of remaining vision and the requirements for the physical appearance of interpreters is reflected also in the group of users with no residual sight. There is a clear distinction in the way they approach the topic of physical appearance and requirements regarding the dress code for interpreters. No respondent with total blindness had requirements for dark clothes for interpreters. They did want their interpreters to be dressed “appropriately” and to be “covered,” but some of them even declared that they do not see the interpreter, so it doesn’t have to be in accordance with their vision loss. From answers like those it is evident that their attitude is governed by some outside criteria and beliefs they shared, but it is not an internally perceived need. On the other hand, sign language users with partial blindness knew that their wishes were determined by visual restraints and a need for contrast.

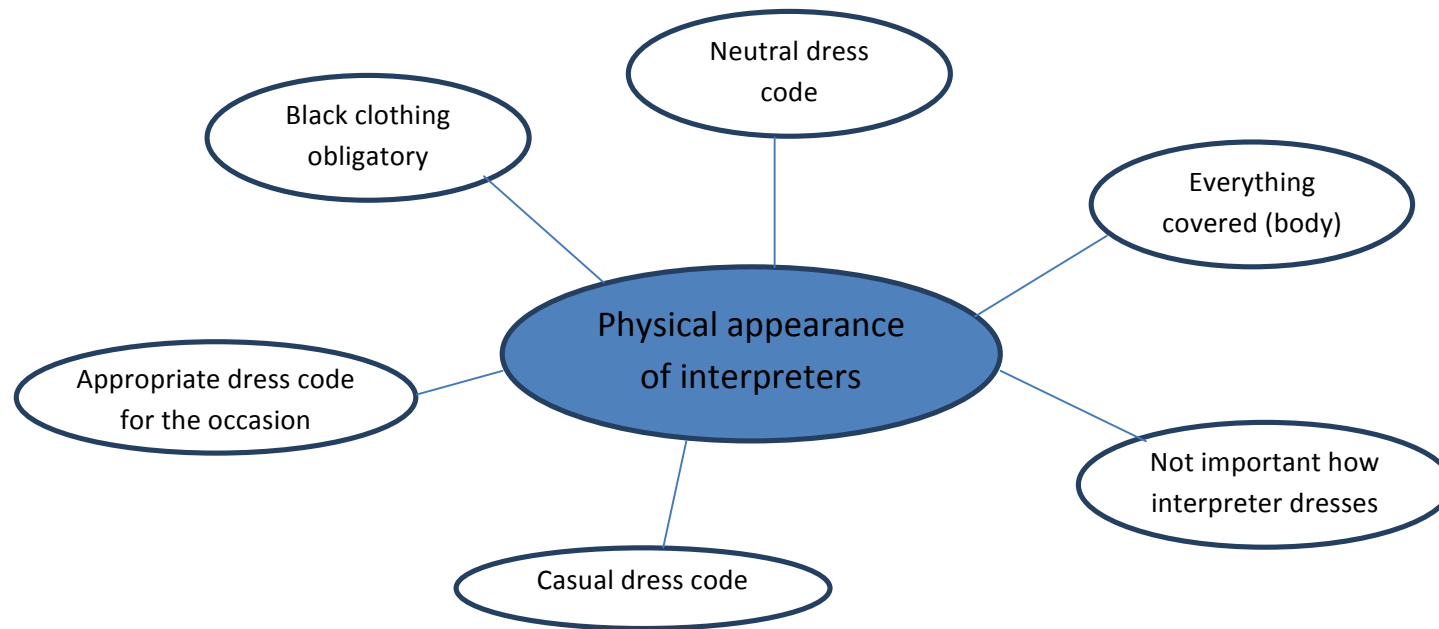


Figure 6. – Physical Appearance of Interpreters

9.5. Interpreter Role

The answers from participants are shown in Figure 7. They have been chosen as the ones that describe the desired role of the interpreter and thus can be coded as “Interpreter role.” The expected role of the interpreter is usually a rough description of the areas in which the interpreter should be providing support to the deafblind person. The description is not a detailed job description, but an overview of the areas the interpreter should be qualified for.

The most general description of an interpreter role is conveying information to the deafblind person. Although this is accurate, it does not provide us with details what kind of information should be conveyed and in which situations is it necessary. More detailed description provides us with an explanation – it is expected that the interpreter conveys verbal information, environment description and provides services of mobility support (in other words – guiding) for the deafblind person. This is also a general consensus of experts working in the field of Deafblind interpreting. The fact that the users of services also recognised the same three areas is significant because it shows there are no major discrepancies in services required and services recommended by experts. The detailed answers regarding the three main areas of interpreter’s work are represented in the Figures 8 through 10.

With the exception of the main areas of interpreting, there is a few other tasks deafblind users expect from their interpreters to perform – taking notes and writing down names of other persons during meetings. However, not all of the respondents have stated this, so it is not a generally recognised need of the deafblind users.

When describing a role of the interpreter, a few of the participants said quite a similar thing – they don’t want their interpreter to be involved and to participate in the meeting with his/her own words. This is also a part of the description of the role of the interpreter – what they should not do.

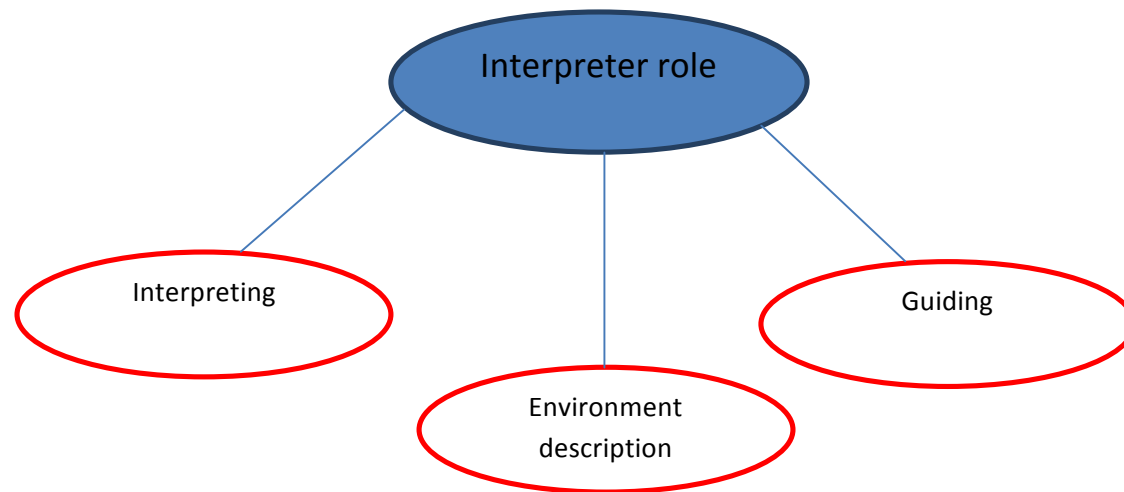


Figure 7. – Interpreter Role

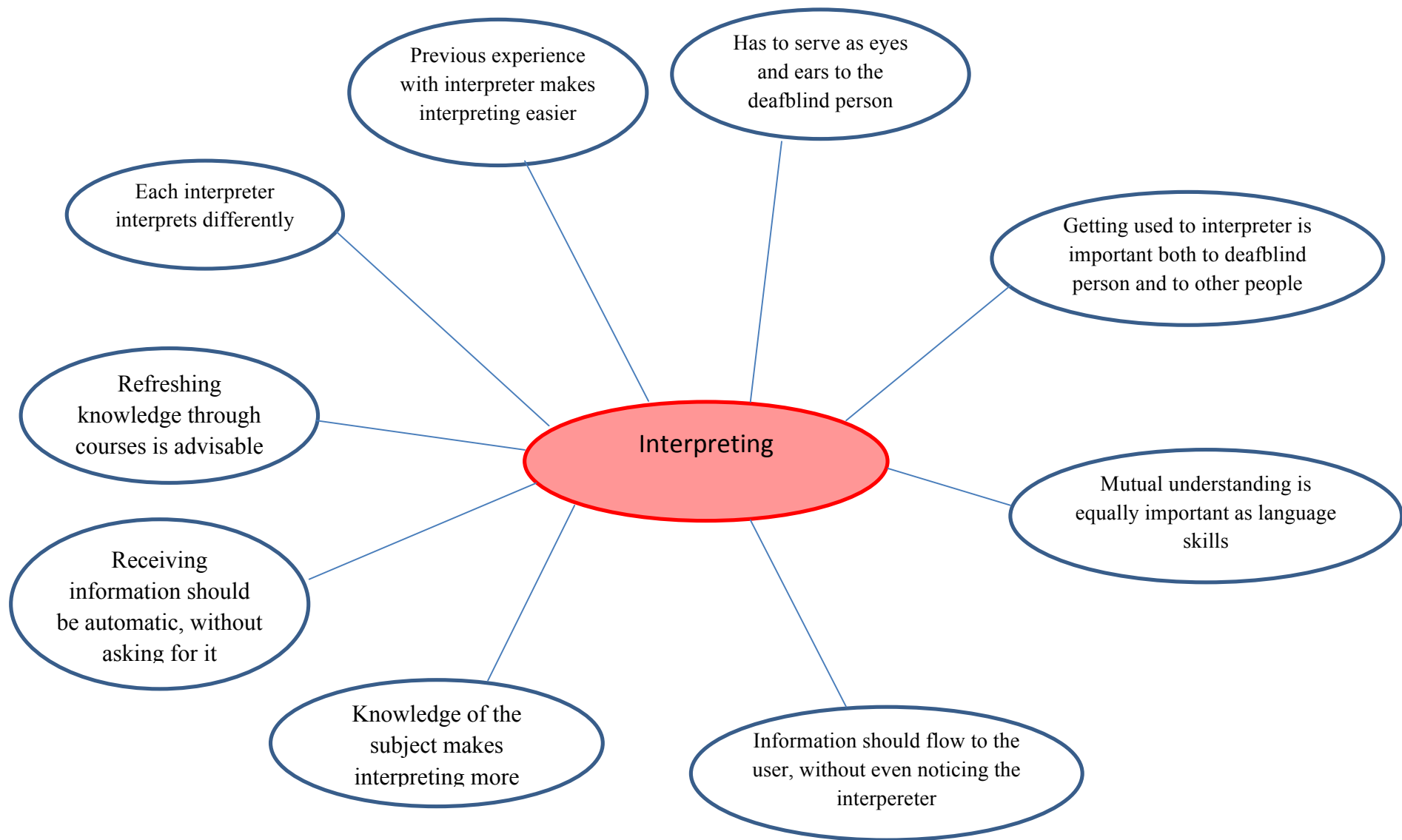


Figure 8. – Interpreter Role – Interpreting



Figure 9. – Interpreter Role – Guiding

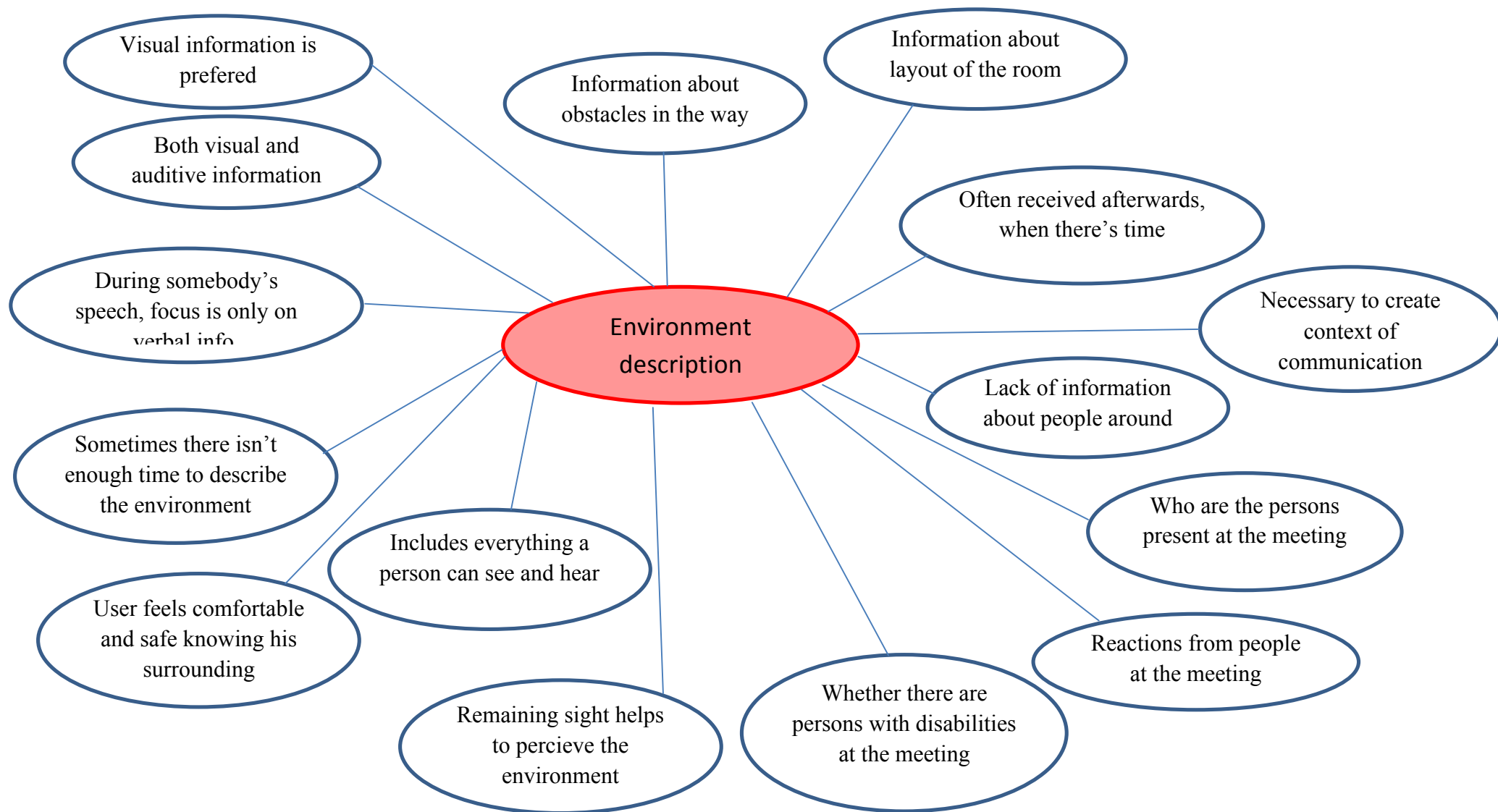


Figure 10. – Interpreter Role – Environment Description

9.6. Relationship Interpreter–User

Different participants described different types of relationships with their interpreters. Their answers were gathered from more than a single question, because this issue is reflected in many other areas of functioning with an interpreter. Even more information were gathered from the questions that didn't focus on the relationship, but describing a situation. However, the information they provided was also a description of their relationship with interpreters.

Some of the respondents don't have available services for the deafblind, so they are forced to use their friends as interpreters. They are aware that they are not qualified for the job and that their relationship is greatly influenced by the fact that they know each other outside work. It also influences the readiness of a user to complain and to insist on some things done differently. As they put it themselves, they “don't want to bother them [friends] too much” (Participant 7295)

On the other side of the continuum, there are users who are used to having professional interpreters for the Deafblind. They are the ones with formed attitudes and opinions on what the services should be like and what they consider a good relationship between a user and an interpreter. One of the participants stated that what annoys him/her most are “Interpreters who behave like nurses. A deafblind is not a patient/kid, just the customer.” (Participant 5585) From that answer, it is evident that a relationship affects the satisfaction of the user and it is a question that this particular user gave a lot of thought to. He/she also gave his/her opinion on what this relationship should be like: “Horse (interpreter) – Rider (Deafblind). A Deafblind must say clearly what he wants from an interpreter. An interpreter doesn't decide for a Deafblind (e.g. where to sit).” (Participant 5585)

A relationship between an interpreter and a user is also included in the role of the interpreter. This is so because there were different answers that described the ideal relationship, and all of the views influence the expectations from the interpreter. Some of the respondents claimed they wanted a professional, neutral relationship, while others preferred informal relationship with their interpreters. According to this, the interpreter has to modify his/her role to be compliant with the expectations of the deafblind person.

“Even if we are friend, they should still have the capability to stay as interpreters when it’s needed. Nothing else. Just like a guide dog, you know. When you put the harness on, [he/she]’s working, when you take the harness off, [he/she]’s a family member.”

Participant 7479

Other respondents described the desired relationship with interpreters as “neutral, mutual carefulness and respect, keeping within limits of each role” (Participant 8429). Similar description was given by several respondents, which clearly reflects that they wished for a relationship that isn’t private and that is limited mostly to cooperating during interpreting, without confusing the reason why these two persons (user and interpreter) are interacting.

Some of the participants described the relationship they wanted with interpreters as “informal... and good cooperation and understanding between us” (Participant 4664). However, the same participant stated that he/she prefers his/her interpreters to have additional education and to be qualified for the task of Deafblind interpreting. So, there shouldn’t be confusion of “informal” with “unprofessional.”

One respondent pointed out that a deafblind person and his/her interpreter should be a good match in terms of being compatible persons. Much like being a good match with any other person who you come in contact with, being a good match with your interpreter clearly means a lot to a person. Sometimes it is not easy to explain why some people are a good match and others are not, but there clearly exists an effect on their relationship and the way they will work together. Even when other factors seem ideal, sometimes it is hard to establish a good working relationship with a person who is not a good match to a deafblind person. One respondent described it in more detail:

“I think it’s the same like when you are together with any other people, you are not working on the same level, using the same signals. Well, you doesn’t work together, it happens. I had very skilled interpreters, but you never get the feeling like it’s going like in oil. It’s matching. It must happen even between interpreters and deafblind. It happens between two other people.”

Participant 7479

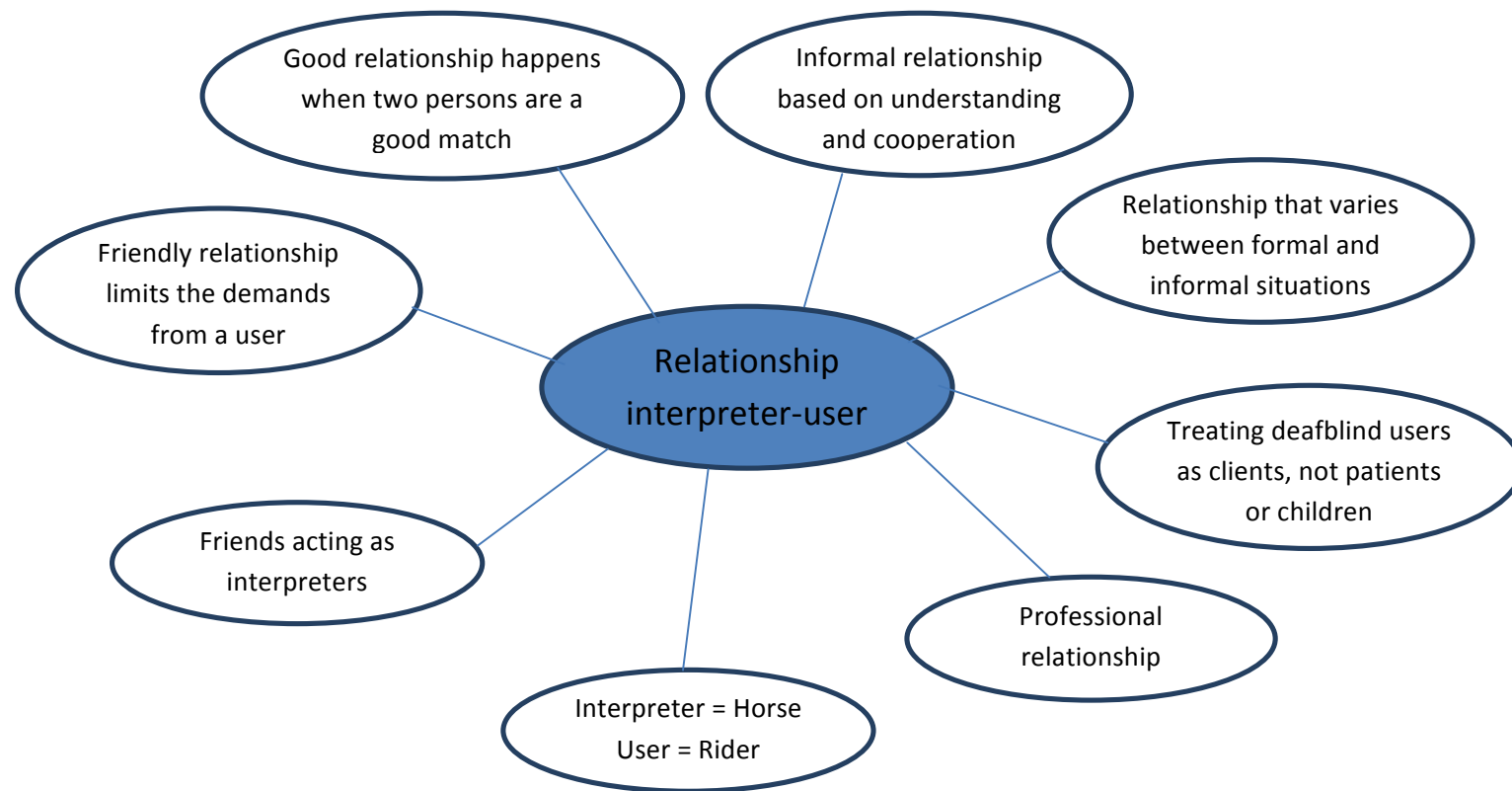


Figure 11. – Relationship Interpreter–User

9.7. Breakdowns

Much like every other part of human life, in interpreting there cannot be the good without the bad, functioning without malfunctioning, and harmony without breakdown. However, one shouldn't feel sad about those situations, but turn them to a good use. Participants in this research explained why some of the breakdowns in cooperation occur and what influence do they have on their satisfaction with interpreting process. Figure 12 represents the main complaints that emerged from reading the answers from the participants in this research.

Most of the respondents contributed with some description of breakdowns in cooperation, with only two participants who reported not to have had problems with interpreters. This indicates that in many hours spent working with interpreters there is bound to be some issues. This also shows that deafblind persons detect these breakdowns and that they ponder about what went wrong in a certain situation. However, not all of them are equally good at detecting the exact reason why their cooperation broke down or when and in what way it happened. The more detailed descriptions provided with more insight into the thoughts and feelings of deafblind persons at international meetings, where demands are high and the importance of good communication is paramount.

The most commonly repeated complaint about a breakdown in cooperation was explained by the respondents as the unprofessional behaviour of interpreters. However, not all of them have the same idea of what professional means in terms of being a deafblind interpreter. By collecting their accounts of what they deem unprofessional, we can gain knowledge about what should be taught to future deafblind interpreters as a code of professional behaviour.

Also, from these complaints, we can gain insight into what kind of attitude from the interpreter is leading to a breakdown in cooperation. For most users, it is the way of being treated as someone who needs constant attendance, somewhat like a child or an ill person. Keeping in mind that deafblind persons refuse to be treated as if they require a tutor or a nurse is helpful in establishing the proper relationship between an interpreter and a user. It can also be taught to future interpreters, so that they start working with deafblind persons with some knowledge and confidence into how they should treat their users.

Some respondents described the breakdowns as a normal part of interpreting process, without the tendency to offer solutions and without expressing too much worry or stress about them:

“I want my interpreters to be concentrated on the meeting. But sometimes you have to accept that even interpreters can be tired. And their thoughts may wander away. And nothing you can do about that.”

Participant 7479

Other participants expressed their annoyance with certain ways cooperation tends to break. They were more ready to show their emotions:

“What annoys me the most, is when my interpreter’s knowledge is too weak to interpret the issues in the meeting correctly.”

Participant 3376

Some respondents chose to make a list of unpleasant situations that happen to them during interpreting at international meetings. Although this list can seem inconsiderate towards the interpreter, it shows that this deafblind person is has gone through some very negative experience. Also, it shows that a lot of thought has been given to those breakdowns, which enabled this person to provide us with a very concise list of things that bothered him/her during interpreting process:

- “– the interpreter gives comments on the speakers, other than visual description.
- the interpreter says she doesn’t understand the speaker
- the interpreter wants to know in advance what I would like to say in the discussion
- interpreter says speaker speaks to quickly”

Participant 3629

When this person describes the faults of interpreters, it should be seen through the consequences of such situations on the user. For example, it could be seen as inconsiderate towards the interpreter to be bothered by his/her inability to hear or understand the speaker. But this has a consequence of leaving the deafblind person without information that can be relevant or even crucial, thus making his/her decision making impossible or at least not based on ongoing flow of information. These kind of situations are inevitable and they pose a challenge to a relationship between user and interpreter. It is also clear that attention should be given to ways of dealing with such situations, from both interpreter's and user's perspective.

From the last two quotes from users it can be seen that lack of knowledge or competence is a potential source of breakdowns in cooperation. It can be seen in the user's descriptions of interpreters who fail to interpret at a level desired by users. Also, wanting to know the user's speech in advance can be a sign of insecurity in his/her ability to interpret the user's speech simultaneously when first hearing it. Although users didn't exactly blame the interpreters for lacking the ability to work in the desired way, they did express dissatisfaction with such instances where this becomes evident and influences their work at the meeting.

This is closely related to another category that emerged in this research – education of interpreters. Although deafblind users cannot always choose the right interpreter for themselves and they cannot assure that their interpreter was given proper education, they recognise education as highly important factor in receiving their desired standard of interpreting.



Figure 12. – Breakdowns

9.8. Organisation

Category Organisation emerged from many technical details that the deafblind users were talking about. They all emphasised that without proper organisation, no meeting or interpreting can take place. This is also the reason why they wanted to share many opinions and experiences that concern organisational matters.

Many users discussed the quality of interpreting, which in their opinion depends greatly upon the number of interpreters and the opportunity for them to take turns. According to them, the ideal situation requires at least two interpreters for longer meetings. They should take turns, so that they can maintain high quality of interpreting. There were a few opinions on how long interpreter shifts should be. They range from 15 to 25 minutes, as can be seen in Figure 13. Not all participants in this research have the opportunity to follow these guidelines in practice. They talk about having only one interpreter due to financial restraints or unavailability of qualified interpreters. The example of a deafblind user who is aware of his/her restraints concerning interpreter shifts is following:

“... olala my interpreters mostly have not the luxe to switch or don’t like switch if they have break of ten minutes after fifty minutes of working.”

Participant 3629

Also, there have been great discrepancies between respondents. Their experiences vary – from requesting short shifts for interpreters to being able to receive good interpreting from one interpreter for longer hours before feeling the need to switch him/her with the other interpreter. Two radically different examples follow:

“It’s optimal that they [interpreters] switch every 30 minutes at regular [local] meetings [in my home country], but in international meetings they should switch more often; every 10–15 minutes.”

Participant 3376

“It always depends on the contents of the meeting and the situation, I would say that they should switch between them every two hours.”

Participant 8429

Respondents also discussed the necessary breaks for themselves. They explained them as a necessity to keep their concentration and to be able to follow the meeting. As is shown in the Figure 13, they require little breaks during the meeting, but also larger breaks after longer periods of time spent in the meeting. This is in accordance with literature that states that the process of following an interpretation is a laborious and tiring one. This is especially true for users of different communication methods, who have a very difficult task of constructing meaning from the input from interpreters. This means that high concentration is necessary, which can be achieved and maintained by using a few small breaks. Here is the quote by one participant, with explanation why breaks are necessary:

“5 min eye break every 1 half hours, straining to see and concentrate means if I don’t get a break, concentration gets worse.”

Participant 3378

Number of interpreters was also an issue addressed by some respondents. They emphasised the importance of maintaining standards of interpreting, which is reflected through the number of interpreters per meeting. This allows them to take turns, which means this issue is closely tied to the previous – interpreter shifts. Accounts from respondents vary – from having only one interpreter, to requesting three interpreters for international meetings. From this situation, we can see that their experiences will be dramatically different and will have different angles when talking about their needs. The two examples given below explain the differences in communication assistance necessary – where the first respondent needs extensive support, the second only needs limited support, which is enough when provided by only one interpreter:

“Because the interpreters should have pauses during the meetings, and should supply each other, there should be at least two interpreters in [local] meetings [in my home country], and three in international meetings.”

Participant 3376

“One since most of the time I also depend on clear speech and just need clarification if I have missed some.”

Participant 2228

Many details and seemingly irrelevant circumstances influence the organisation of a meeting. One can say that the whole is composed of such details, that ultimately make a picture complete – was the meeting a success, or was it a failure. The deafblind participants with experience in attending international meetings are aware of many technical details that influence the course of the meeting and their satisfaction with the meeting. Their remarks are shown in Figure 13 – they concern following schedules, preparing the documents, coordinating with environment, but also a few very important circumstances that determine whether or not they can attend the meeting. One such thing is financing. As it can be seen from Figure 13, there is no unified way financing is done for the deafblind. Some of them rely on funding from the government, for some the money comes from their organisation, but there are also ones who have to contribute with their own private money. Such situation clearly doesn't put all deafblind persons in similar conditions, but rather gives the opportunity to participate to some, but others have to fight hard and be very resourceful to be able to participate.

The participants also described the participation of other persons, who in their opinion contribute to the quality of the meeting. They are the chairman of the meeting and the coordinator of the meeting. Their role is to moderate the meeting in a way that it flows successfully. They also make sure that all participants can follow the course of the meeting. Besides them, one participant mentioned having a CEO of his/her organisation present at the meeting, with a role of monitoring the content of the meeting and its influence on the organisation.

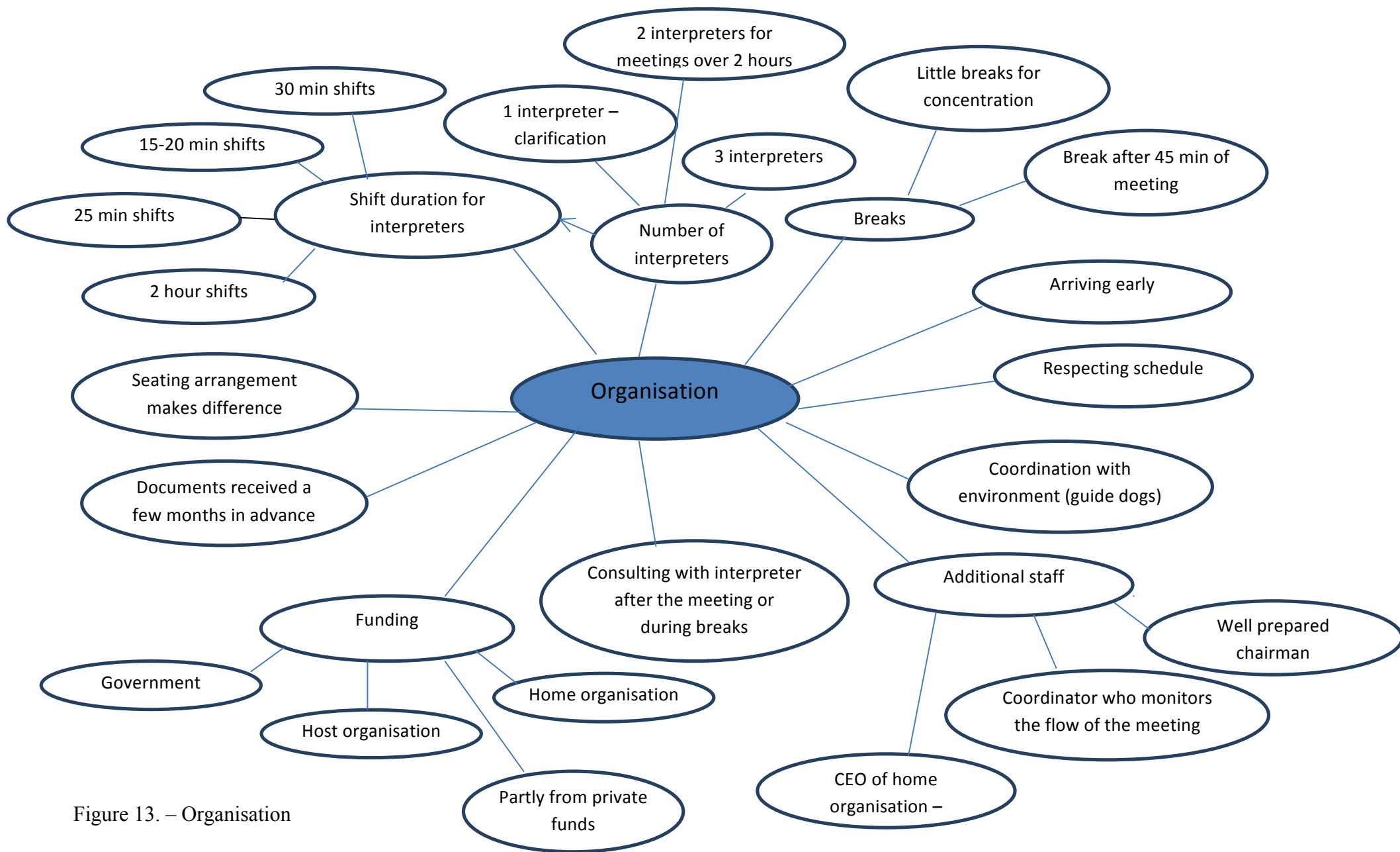


Figure 13. – Organisation

9.9. Independence

Achieving independence for some is a natural thing and often it goes without saying that a person is independent and responsible for his/her own actions. For the deafblind, more often than not, this is not the case. It is very difficult to achieve independence in all aspects of life, especially with all those people around them who are trying to help and provide support needed in life. This support often turns into doing things *instead* of the deafblind person, the motive for this being either good intentions (wanting the deafblind person to achieve as much as he/she can) or not believing that they can do much by themselves. This is the reason why for many deafblind persons, independence encompasses many little things in life that we wouldn't exactly call "acts of independence," but in reality, they are little proofs that deafblind persons can be taken seriously as individuals, and not only as persons with disabilities who need pity and compassion.

The Deafblind in this research described the ideal cooperation with the interpreter as one that gives them the ability to participate and to make their own decisions. The components of independence at international meetings are shown in the Figure 14. One important aspect of being independent is the ability to speak and be spoken to. This was well described by the respondents of this research. They described techniques they use to start speaking and to make themselves heard. A big part of that is the cooperation with the interpreter, who has to give the deafblind person a cue when exactly to start speaking, in order for other persons to be able to hear him/her, but the interpreter is also the one who has to make sure the raised hand from a deafblind person is noticed, so that he/she can be given floor to speak at the meeting. Also, the importance in giving independence is placed upon communicating directly. This means that the interpreter has to make sure that the communication is properly interpreted, so that there are no delays and no need for someone else to speak instead of the deafblind person. A great problem of the Deafblind is the tendency of people to address the interpreter, and not the deafblind person. Also, there is a problem with some interpreters who speak about the deafblind person in third person, which makes other people more prone to talk to interpreters, not the deafblind users. This is why such an emphasis is put on direct communication. The deafblind in this research have identified this as a major part of being independent in a meeting setting. They want to be addressed directly and they want to speak for themselves, when they want and about the topic that is relevant to them.

There are other components of independence, not less important, but none of them was mentioned as often as freedom of speech and communication. What deafblind users mentioned besides that was the responsibility to inform the interpreter about their expectations regarding his/her role in the interpreting process. This reflects their efforts to be the ones in charge of the cooperation process, since they are the receivers of the interpreting services. Also, taking care of quality of cooperation with the interpreter was stated as an ongoing process and responsibility of a deafblind person. Monitoring whether received information complies with their expectations and whether they can achieve the desired level of independence and inclusion is also a part of working with interpreters. Without the ability and readiness to communicate their expectations, there can be no successful cooperation. This can also lead to chronic dissatisfaction and aversion to working with interpreters.

The participants in this research were clear about what they wanted from interpreters and they even described their usual way of communicating their ideas on what the interpreter role should be and how the interpreting process should flow.

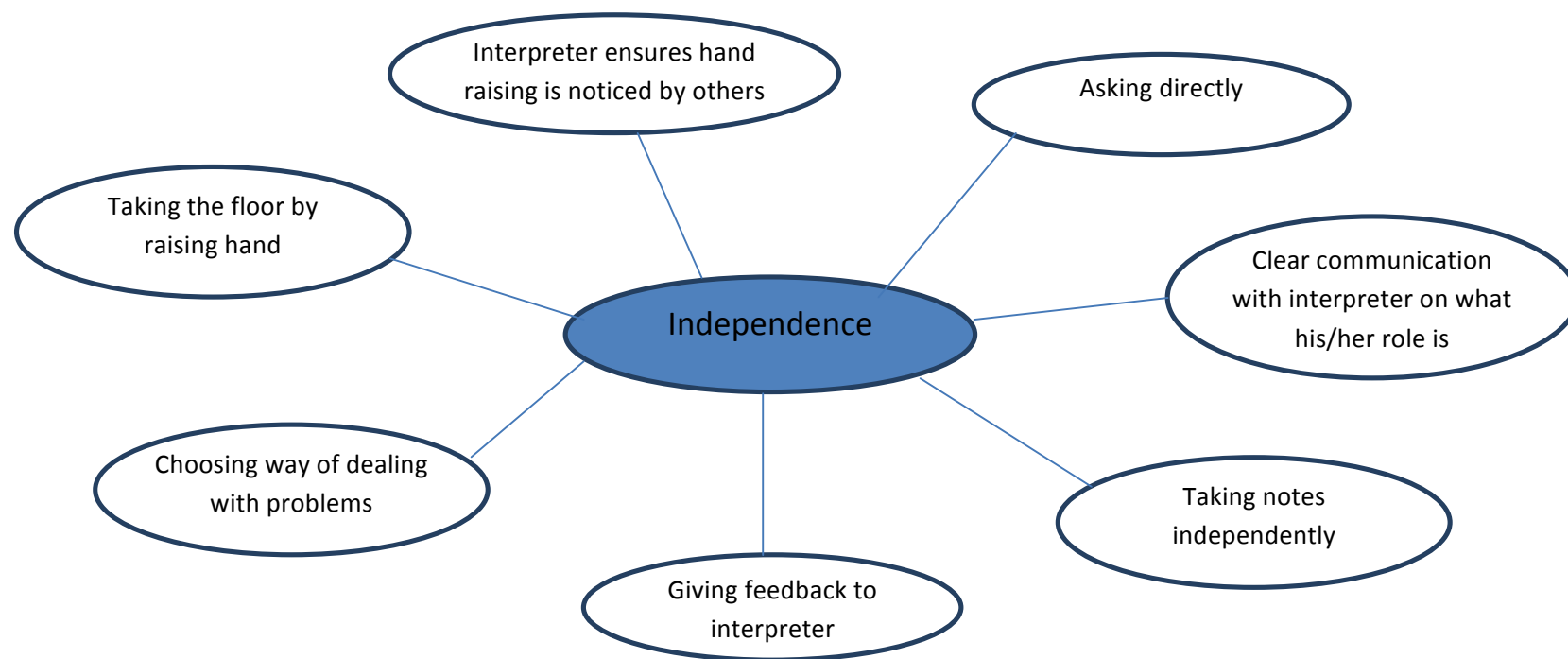


Figure 14. – Independence

9.10. Preferences

Throughout the filled out questionnaires, all of the respondents' answers were coloured by their attitudes and their reflection on different preferences. According to those preferences, the deafblind users tried to establish a cooperation with their interpreters that represents the closest resemblance to the one they envisioned as ideal and fitting to their needs.

It is very useful and informative to see the areas where the Deafblind have very different attitudes towards the interpreting process and standards of the interpreting profession. It can serve to demonstrate how diverse the population of deafblind users regarding the interpreting services is and how there is little or no consensus about the majority of those questions. However, attention should be paid to trying to set standards that would give answers to practical questions that arise from facing different users with different preferences. To what extent they should be respected and what is considered a reasonable adjustment of interpreter to the user are the issues that demand resolving.

Some of the participants showed vigour in stating their expectations, while others merely expressed their inclination to having things done in their preferred manner. This reflects the differences in character between users. They influence the cooperation between user and interpreter and make it more or less difficult to bridge the gap between a user's desired characteristics of the interpreting process and the real situation, in which they sometimes weren't the ones to choose all the variables. Below are several examples of different preferences of users on the same issue, that demonstrate how different they can be and how easy it is for problems to arise from the inability to always accommodate to their demands.

When it comes to areas that emerged as ones where the preferences are the strongest and produce the greatest differences between users, they are as follows: flexibility, giving power to interpreters, type of information, and gender. Accordingly, there were four sub-categories identified as belonging into the category Preferences. Each of them is described in more detail in the following paragraphs.

Gender

When it comes to working with interpreters, there is an obvious question of whether or not gender is important. Although reason tells us there should be no difference between male and female interpreters, my experience tells me that many deafblind persons tend to choose either male or female interpreters, according to their opinions and previous experience. In this research, the respondents gave similar answers to the question about gender of interpreters:

(Question: Is the gender of the interpreter important to you?)

“Yes since women are better interpreters than men. Women don’t get tired and board easily as compared to men”

Participant 2228

“Usually not. It depends on the participants and events. Sometimes a man’s voice gets somebody to wonder who is really talking.”

Participant 5585

“Not important, but in some situation I prefer interpreter-guide [of the same gender I am], for example going to the toilet or dressing room.”

Participant 4664

“Gender is not important. Interpretation, personal and professional skills are the main things.”

Participant 4494

Flexibility

When it comes to changing interpreters and meeting new ones, the question of flexibility is another sub-category recognised in the category Preferences. Through reading the participants' questionnaires, it became evident that being willing and able to work with different interpreters and possibly going through some rough patches in the beginning is a very distinctive preference for each respondent. There were some who were more flexible to changes in their usual team of interpreters, as opposed to ones who were quite adamant that they needed always the same person to do the interpreting work for them. Here are some quotes that illustrate the diversity in flexibility when it comes to working with different interpreters:

“I usually only use interpreters that I know and that knows me, to ensure that we communicate correctly.”

Participant 3376

“It is important to meet the person before the meeting to make sure the communication is right. That the interpreter can understand me and meet my requirements.”

Participant 3378

“If it is a training course I prefer the same interpreters, so that there is some continuity for both me and my students. If it is one off meetings, I have a group of interpreters I will ask who is available.”

Participant 3378

“As long as the interpreter fulfils all the requirements and if I have the chance to meet him/her in advance, I think that it should not be a problem to have different interpreters.”

Participant 4494

Type of information

Being deafblind means that for the person both visual and auditive information are necessarily incomplete or completely missing. This also means that the interpreter has a demanding task of channelling both visual and auditive information to the user, in order to give him/her enough information about the environment. However, more often than not, there is a time constraint that prevents the interpreter to transmit all of the information, as well as for the deafblind user to process and understand it all. Because of such situations, many deafblind persons acquire a preference to the type of information they rely more on – auditive or visual.

“It depends on the current situation. during a lecture or speech, the focus should be on the verbal auditive interpreting.”

Participant 3629

“I prefer visual information.”

Participant 4325

“It depends on the situation, but I normally like to have general information (both auditive and visual).”

Participant 4494

“I like both levels of description because they give me a real picture of the situation.”

Participant 8429

Giving power to interpreters

Working with interpreters always means that there has to be a consensus about how much power is an interpreter allowed to have. The role of interpreter often puts him/her in a position where they have the power to make decisions and even to influence the way a deafblind person is making decisions. For example, an interpreter can chose not to inform a deafblind person that there is a person who wants to speak to him/her, thus preventing the deafblind person from making social

or business contact. Also, the question of power is important when it comes to interpreting from Sign Language to speech. The interpreter has the power to change what the deafblind person is saying, whether deliberately or not, as well as to add or remove nuances from what the deafblind person is communicating to the audience or interlocutor. There is also a dilemma whether or not the interpreters should be allowed to make their own remarks. This implies a great deal of trust between a user and an interpreter, because in many situations, there is no way of preventing an interpreter from saying or doing what he/she wants. Moreover, there are users of interpreting services who would not even notice, due to their vision and hearing impairment, that their interpreter is acting as an independent interlocutor. Here are some quotations from participants in this research about their expected way of their interpreters' behaviour:

“The interpreter will not give suggestions or opinions. comments can be given if it leads to better understanding of the situation.”

Participant 3629

“Yes they should be allowed since some of them have a vast experience in the subject matter.”

Participant 2228

“I think that the interpreters can give their opinions if asked to by the deafblind because otherwise it might seem intrusive.”

Participant 3344

“I think that there are different profiles, an interpreter should only interpret; otherwise we could be talking about a secretary/assistant interpreter.”

Participant 4494

“They can make only technical suggestions which help their work.”

Participant 4664

“They can talk sometime to own customer, but cannot take a part in the meeting. They are interpreters, not participants in the meeting.”

Participant 5585



Figure 15. – Preferences

9.11. Complexity

The category Complexity emerged from the description of situations that respondents pointed out as especially demanding. These areas are the ones that, in the opinion of both respondents and in my opinion, require more attention and effort to resolve.

One of the issues typical for any international meeting are languages. Since in the greatest number of such meetings the official language is English, there is always a challenge to interpret from English to the deafblind person's native tongue, with communication method accounted for. Unlike interpreting in national settings, where interpreting is done in only one step – between the spoken source language and the target one, in the communication method preferred by the user, international meetings require one additional step – interpreting to and from English. While some deafblind participants have interpreters who are able to interpret in such situation by themselves, others need to have more than one person to do the job – one to interpret between English and the spoken national language of the country of the deafblind person's origin, and another one to interpret between that spoken language and the language used by the deafblind person when receiving information. Regardless of the number of steps in the process of interpreting, there is always more effort involved in such situation, for the interpreter as well as for the deafblind person. Here are some examples of how deafblind persons see this situation:

“The less stages the better. Not only to avoid problems but to lose less time. Sign language interpreters from different countries should have a common language (i.e. English) in order to make communication easier and faster.”

Participant 4494

“... yes there are problems. but I don't see a solution. except if the person is reading a text and the text is available in English.”

Participant 3629

“These problems are often only discovered and faced by the interpreters, and must therefore be solved by the interpreters themselves.”

Participant 3376

The issue of selection of information to be transmitted to the user about the environment is also an example of complexity of the process. The user explained some of his/her problems that arise from deliberately reducing information from the environment. He/she also admitted this to be his/her own decision and he/she, therefore, has no one but him/herself to blame when the information is too short:

“I cannot remember any specific situation, but it happens that I later wish that I asked for more information about the place. But it’s my own decision. I don’t want to know too much in the beginning. Because there are other things maybe more important to get informed about. But it happens. Also, you never have time to get all the information at once because it takes time to translate to me and things are happening fast.”

Participant 7479

Another participant also referred to the shortening of information in the interpreting process, but he/she approached it from different angle. He/she sees it as a necessary part of working with an interpreter and a valuable trait in an interpreter. The ability to shorten the information, in his/her opinion, stems from his/her background knowledge and this helps in the interpreting process.

(Question: Is it important to you that the interpreter has some general knowledge and understanding of the topic, themes and background of the meeting? Explain why.)

“Yes since it helps him/her to use all the necessary skills of shortening the interpretation i.e. information.”

Participant 2228

Complexity in interpreting process arises from deafblind persons not being able to use the same interpreting method in all situations. Some of them explained what forces them to use different communication methods and how that reflects on their ability to participate in the meeting. From their stories, it became evident that their backgrounds are very diverse and that they shape their way of functioning with interpreters and their way of perceiving the world. To be able to participate at international meetings, they have to achieve harmony with interpreters, which is sometimes quite a challenge. The example of such variety and complexity of communication options is below:

“As I lived as a hearing person for thirty-five years, it’s in my system. And will always be the easiest way to take communication. It will be easier to store the information I get before. I will not need so much energy to, to take the information. The manual will never be natural, I used to concentrate more. I need to concentrate more, which takes powers from my storing and using what I have. So I prefer today, I prefer hearing. Nine years ago, I had no choice, I had to take everything tactile. As long as I can hear, nothing can beat me. But if I have to take it tactile, of course, people who are using sign language are faster. That’s the nature of things. I try to hear as much as possible today. And when it’s not possible, I have to accept it and go back to tactile again. It also depends a little on the situation and which interpreter I have. If I can use my hearing, I do it. And my voice. If my interpreter has a good voice, she can speak clear. And she doesn’t have to speak so high. I prefer that. It’s faster. Otherwise I use the tactile, manual. In some situations you have to use the tactile, manual. In some situations, you have to use the tactile, manual because of the noise.”

Participant 7479

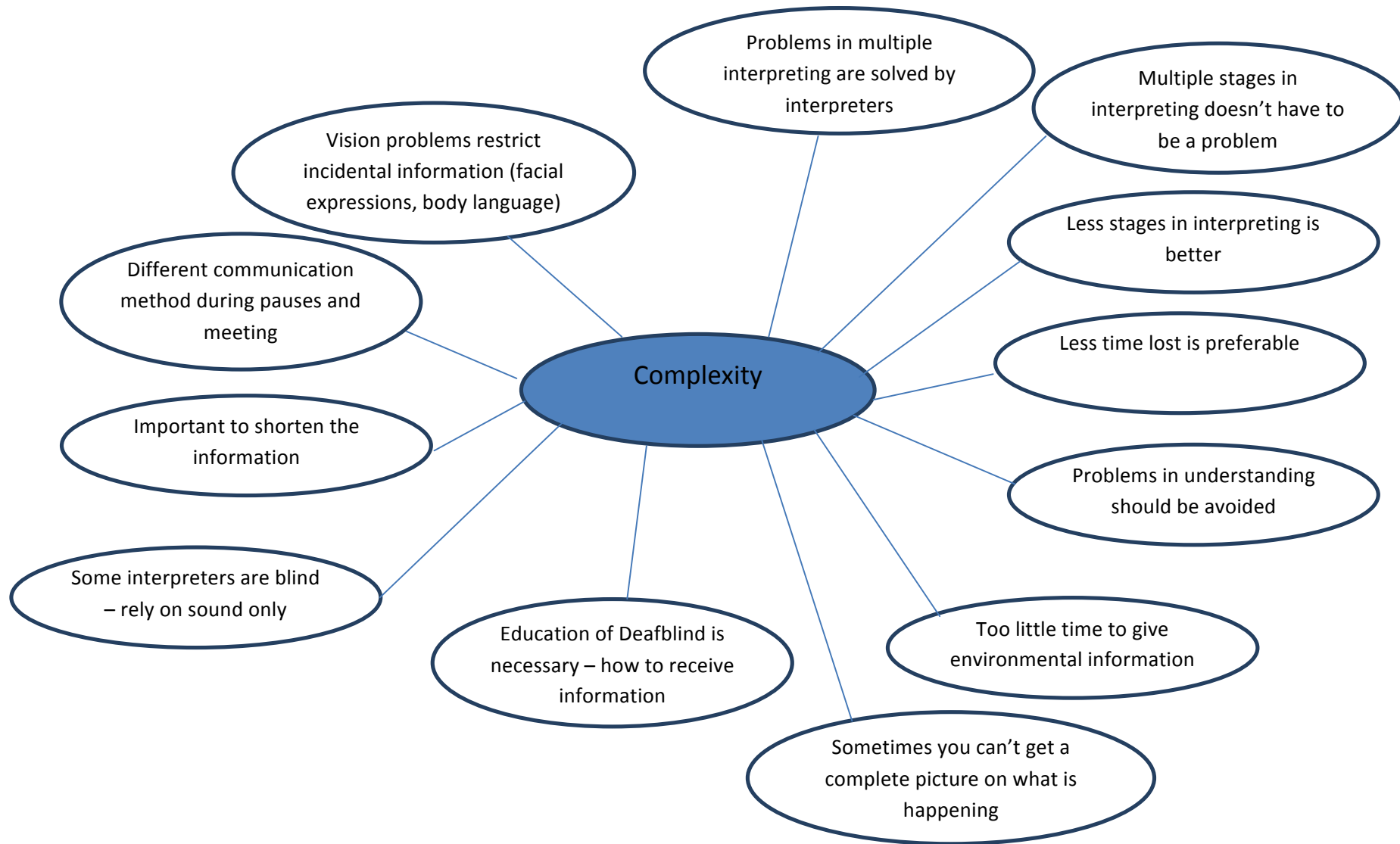


Figure 16. – Complexity

9.12. Education of interpreters for the Deafblind

The question of education of interpreters has been on my mind for years, but this was the first time that I had the opportunity to collect other people's opinions on this subject. It was reassuring to see that I was not the only one to pay close attention to this problem. Also, it became apparent that I am not the only one with high standards and beliefs about the level of education a Deafblind interpreter should have.

Many deafblind respondents stated that they prefer educated interpreters. They emphasised the importance of having special training for Deafblind interpreting, although not many of them described in detail of what it should consist. Part of the reason for that could be that in many countries there is still no college programme or official training course for Deafblind interpreters. However, training courses are provided in many European and other countries, which makes it easier for the Deafblind to receive proper interpreting services.

For some participants, there is a clear picture in their mind of how much formal education contributes to successful cooperation between a user and an interpreter. This participant values the training of interpreters and takes into account that they have to have an opportunity to train. He/she describes a positive practice of hiring an inexperienced interpreter in training, to enable him/her to gain experience and become an independent interpreter. An example is the following quotation:

“So, it's say, twenty, twenty-five percent is that they have right training, the right skills and that are used to work international. Sometimes I have new interpreters with me, then I have two skilled and one extra, you know. Just learning.”

Participant 7479

Here are more quotes from respondents saying that the optimal interpreter profile is the one of a formally educated person, who received specific training to become a Deafblind interpreter. Although not all of them specified the kind of training and education they require in their interpreters, they listed benefits they experience from having well-trained interpreters.

“Yes, based on the nature of the international meetings it is mandatory that the interpreters have a specific formal education, this to ensure that they have a better understanding of how the meetings are run, and eventually be able to interpret the progress in a more accurate way.”

Participant 3376

“All interpreters or volunteers should have formal training, specifically about their role.”

Participant 3378

“Formal education is necessary for professional interpreters, not only for international meetings but also for other services (doctor, lawyers...).”

Participant 4494

“The best if the interpreter has a specific education, especially for sign language interpreters, or they work with deafblind persons, but if a volunteer is good for the task, it is also enough.”

Participant 4664

There were more deafblind participants who were quite clear about their demands for educated and trained interpreters. From their quotes, some ideas can be drawn, especially when comparing their experiences with my own. From the following excerpt, it can be concluded that this deafblind person had the opportunity to cooperate with both educated and volunteering interpreters. Also, it is evident that those differed in quality and overall satisfaction, to the point that the participant links autonomy and self-respect to the level of education of the interpreter. It could be considered a strange connection, but after delving a little deeper in the problem, it becomes more evident why this is so. I myself have had the same opportunity to compare working with trained and volunteering interpreters and I can relate to the feeling expressed by this participant. While an educated and formally hired and paid interpreter is more competent in doing his or her job, a volunteer is almost always a person with less training and less experience in interpreting. This usually means that the educated interpreter is doing this as his/her profession, with more formal approach, more responsibility and with more skills necessary to provide requested services. When

an interpreter is not a professional, nor is he/she paid for the effort and time, the question of quality and dedication to the task becomes a great gamble. It would be rash to conclude that all volunteering and training interpreters are irresponsible and indifferent, but there may come situations where a deafblind person's autonomy is compromised. Often it is not done deliberately by an interpreter, such is my experience, but happens from lack of experience and/or failure to react in a proper way in a given situation. I believe this is, at least partly, the reason why the following deafblind person categorically states the need for a certain kind of interpreter, with specific skills and ways of behaviour. I strongly believe that such demands should not be overlooked or taken for granted, because a person's feelings are on the line and the way he or she is able to direct his or her life.

“I need someone who can type what is said correctly and give me the information I need to be able to participate successfully. the person should behave deontologically correct. is so, the person can be both volunteer or professional interpreter. but I think it is better to have a well educated and well paid interpreter. the deafblind should not lose his autonomy and pride and self-respect. a volunteer interpreter will cause limits, I think.”

Participant 3629

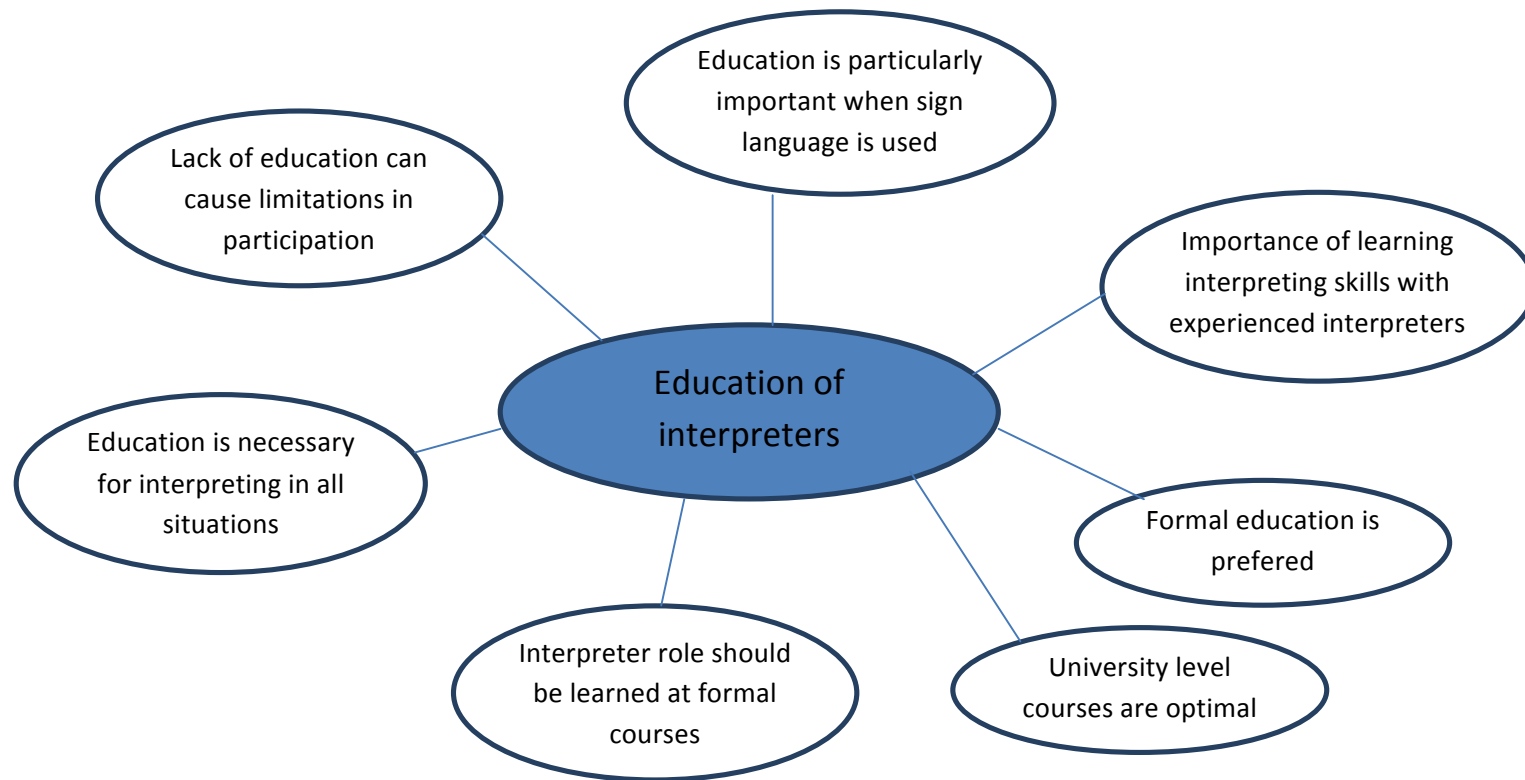


Figure 17. – Education of interpreters

9.13. Privacy

In comparison to other aspects of cooperation with interpreters, the matter of privacy of information was mentioned less often. Only a few of the respondents referred to it as being very important and a major part of a successful teamwork between a user and an interpreter. The reasons for a relatively seldom mentioning of matters of privacy could be several: lack of experience in working with interpreters, lack of theoretical and practical knowledge about the interpreting profession, and lower awareness about the importance of a code of ethics, among others. However, this category is important because it shows that some of the respondents do pay attention to this subject. Due to the tone in which some statements from respondents were expressed, I categorised Privacy under the larger category Demands. Here is an example of a deafblind person who demands a certain way of behaviour from an interpreter and mentions privacy of information as obligatory:

“To ensure a successful cooperation you need to know your interpreters well, and they need to know their user, and be prepared regarding the themes or issues discussed in the meeting. They should agree on what to be said out loud, and what to be private between the user and the interpreter.”

Participant 3376

However, the category Privacy was also put under the larger category Awareness, due to a relatively low number of participants who even mentioned it. It serves as an example of a lower awareness of such a thing being important and influencing the cooperation between interpreter and user, as well as user's personal and professional life.

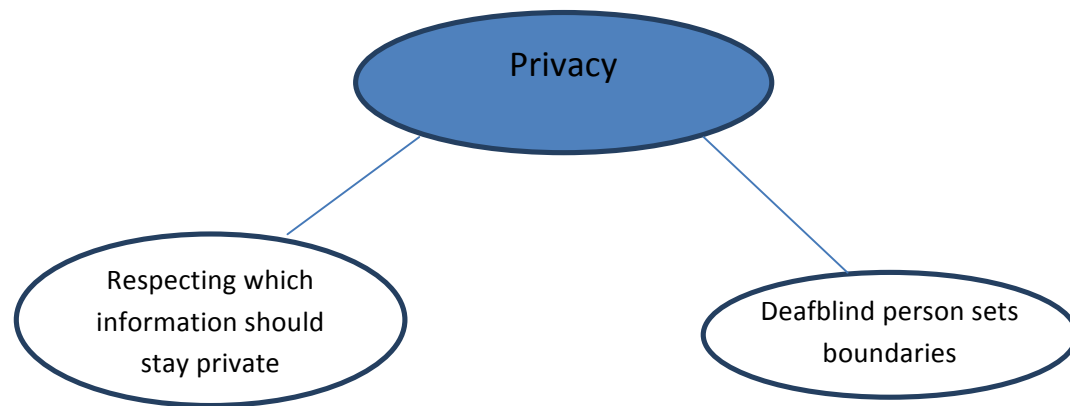


Figure 18. – Privacy

10. GROUNDED THEORY ON DEAFBLIND INTERPRETING AT INTERNATIONAL MEETINGS

10.1. Introduction to the Grounded theory on Deafblind interpreting at international meetings

The richness of data gathered from the respondents enabled the detailed description of categories that emerged in the process of open coding. The next step – relational coding, provided even more insights into what is the meaning and the relationship between the categories. The product of the relational coding is the grounded theory presented in this chapter – both visually and described in the text.

There is one main concept that emerged from the answers from participants in this research. This concept is considered the key factor in describing the experience and expectations from working with interpreters. It seems as though all factors contribute to a more detailed description of what exactly makes a satisfied user of interpreting services. This is why all other categories and categories are subordinate to the main concept – satisfaction with interpreting process.

The main concept and secondary concepts (or categories) are explained so that a clear picture emerges and an understanding of the users' perspective can be obtained. For the purposes of obtaining maximum visibility and clarity, only categories were shown, without the lower-level units of coding.

The users continually emphasised the importance of satisfaction with the interpreting process, which made it, naturally, the key concept. The way they described all the other circumstances implied that they were factors that contribute to the overall satisfaction. Functioning well with interpreters in a way that makes the deafblind user satisfied was the most common thing mentioned by the participants. This goes to say that the greatest part of their experience is centred around the question: were they satisfied with the services of Deafblind interpreting? This isn't surprising, because it reflects the importance of their subjective impression and their feelings throughout the interpreting process. When we consider the interpreting process as one where two persons cooperate

and are closely connected, their feelings and impressions start to receive a greater attention. The whole interpreting process is subject to personal factors that can generate inadequate cooperation and dissatisfaction with interpreting process. Also, the process of interpreting can generate dissatisfaction and accumulation of negative experience and bad impressions, both towards the person of interpreter and towards the interpreting process.

There are two major categories that influence user's satisfaction with interpreting process – Demands and Awareness. Category Demands can in brief be described as the demands of a deafblind user to interpreting services about various characteristics of his/her interpreter and the way he/she performs the job. Category Awareness comprises all the factors that influence the process, of which users may or may not be aware. This category shows that there are a lot of factors that ultimately contribute to their satisfaction with the interpreting process, whether they notice it or not. This is the main difference between Demands and Awareness – the component of being fully aware that you are making a demand (or a choice in preference) in the interpreting process, versus potentially not being aware of behaviours and events that are influencing your own satisfaction with the interpreting process. Between them, there are two categories that somehow unite the characteristics of both categories – Privacy and Relationship interpreter-user. They are in the middle and can be considered part of both main categories because of their specific nature. For my group of respondents, it became evident that they both have demands, but at the same time show various levels of awareness of both these categories.

The grounded theory that can be constructed on the basis of the data gathered in this research is graphically represented in Figure 17.

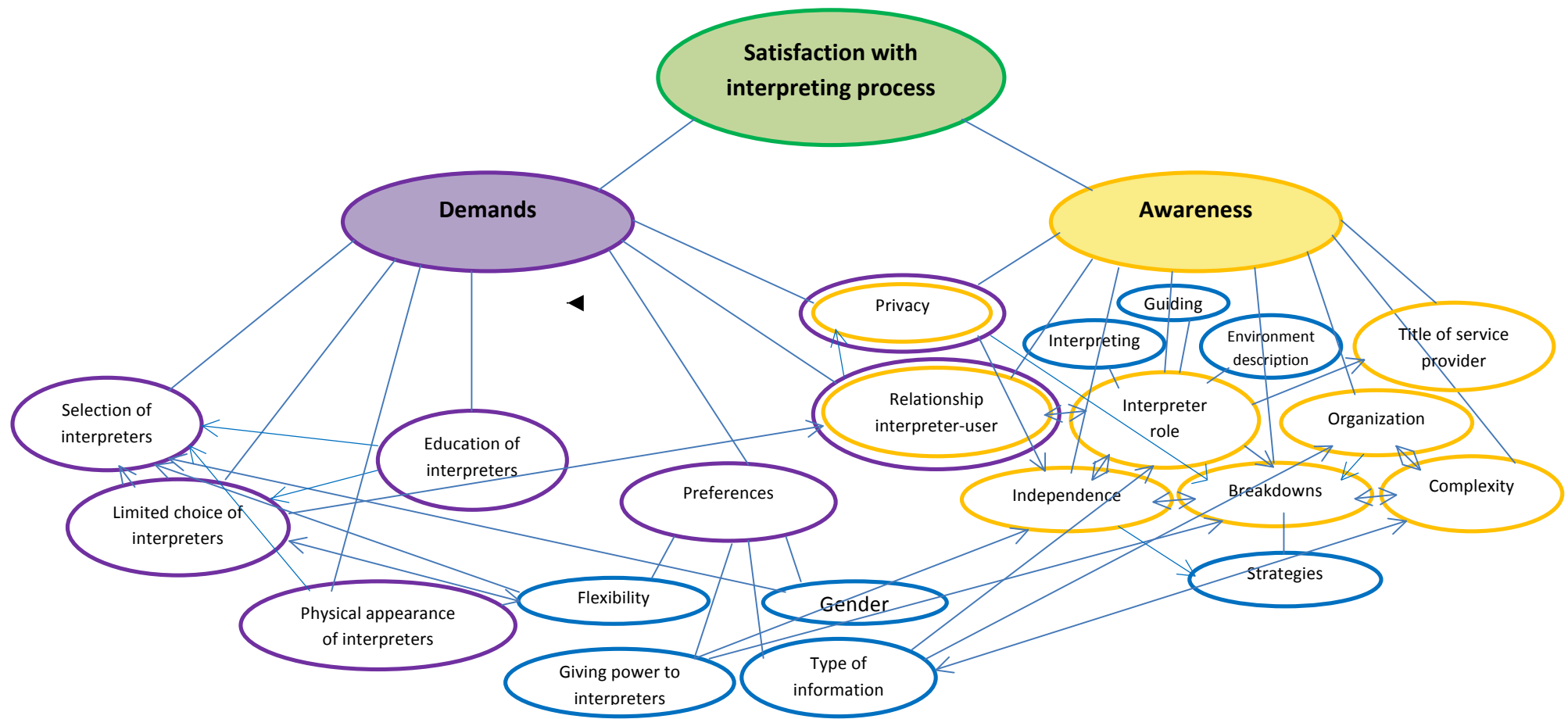


Figure 17. – Satisfaction with the Interpreting Process

10.2. Demands

One of the two main categories under the central category – Satisfaction with interpreting process – is Demands. The main category Demands consists of seven categories of lower rank – Selection of interpreters, Limited choice of interpreters, Education of interpreters, Physical appearance of interpreters, Preferences, Relationship interpreter-user and Privacy, of which the last two are shared with the main category Awareness. These seven categories influence each other, but also influence categories under the main category Awareness. Such influence can be regarded as natural, considering that we are observing a very elusive phenomenon of Deafblind interpreting at international meetings, where there can be no distinct boundaries between important factors. Also, there can be no strict dividing into (sub)categories, merely grouping where there will be overlapping and influencing between (sub)categories.

The category Selection of interpreters is an important part of the main category Demands. It is influenced by other categories, both directly and indirectly. Direct influence comes from categories Physical appearance, Limited choice of interpreters and subcategories Flexibility and Gender. All those categories and subcategories are concrete and illustrate what are the most important factors that influence the selection of interpreters of deafblind persons when it comes to participating at meetings at international level. Gender is the subcategory of the category Preferences, which together with the category Physical appearance of interpreters influences Selection of interpreters. These influences are most easily described because they are concrete and relatively straightforward. More complex influence comes from the category Limited choice of interpreters. It is fairly reasonable to establish this connection because our respondents in this research very often complained about the general lack of available interpreters for the task of international meetings interpreting. From that, it can easily be concluded that the selection of interpreters can exist only when there is a larger number of interpreters to choose from. Both direct and indirect influence to the Selection of interpreters comes from the category Education of interpreters, which also directly influences the category Limited choice of interpreters. Direct influence is evident in the reported tendency of participants of this research to choose more educated interpreters over those who are lacking in formal education to become interpreters for the deafblind. Indirect influence can be drawn from the reports of participants in this research that there is a limited and not too large a number of qualified interpreters for the Deafblind. The necessary outcome of such a situation is that there are not many qualified interpreters to choose from. The category that directly continues this

string of influence is Flexibility. It also influences the Selection of interpreters, but in more than one way. For some deafblind participants of this research it means that they are quite happy with selecting always the same interpreter or a few interpreters they already know, while for others the selection of interpreters is a process that can have various results – choice of different interpreters. This is the reason why categories Limited choice of interpreters and Flexibility are also connected, in a way that they make mutual influence.

The category Limited choice of interpreters influences the category Relationship Interpreter-User, that belongs to a different main category – Awareness. This means that for many deafblind users of interpreting services at international meetings, the limited number of available interpreters affects their relationship. For some it means that the lines are blurred due to previous friendship, while for others it means that they have started to become friends with their long term interpreters. The reason for the influence to bridge these main categories is that many deafblind respondents, and potentially deafblind persons that have not participated in this research, may not be aware of this influence taking place.

The category Preferences consists of four subcategories that are concrete and can be considered building blocks of their more abstract higher level category. Those subcategories are Gender, Flexibility, Type of information and Giving power to interpreters. The influence of subcategories Gender and Flexibility was described in the previous paragraph, but other subcategories are of influence, too. The subcategory Giving power to interpreters influences two categories from the other main category, Awareness – Independence and Breakdowns.

The category Independence is influenced by the subcategory Giving power to interpreters in such a way that too much power given to interpreters can significantly reduce a deafblind person's independence. Giving power to interpreters in this context refers to allowing interpreters to make their own remarks at meetings and making their own decisions in interpreting situations, which some participants of this research considered to be influential to their independence, while there were some who did not recognise this influence.

The subcategory Giving power to interpreters can also influence the category Breakdowns, which is sometimes overseen as the direct cause of a breakdown of cooperation between an interpreter and a user. Both of these influences are subtle and not many deafblind participants of this research recognised them, which confirms the importance of stating this relationship and making it more easily recognised.

Type of information is also a subcategory of the category Preferences. It influences three categories – Interpreter role, Organisation and Complexity. When we described the subcategory Type of information, we focused on the tendency to choose either visual or auditive information, which then in turn influences the role of an interpreter. It defines what his/her job is in terms of providing more visual or more auditive information to the user. However, some respondents claimed that they preferred both kinds of information, which necessarily influences the category Complexity, thus making the process of providing information more complex and elaborate. Type of information also influences the category Organisation, because the process of interpreting has to be organised in a special way, according to the type of information demanded from the user. Such influence is usually subtle, but more easily noticed by more experienced users of interpreting services. This was evident in the answers from participants in this research, where some of them appreciated the way the interpreting process has to be organised according to the type and the amount of information demanded from the user. Some of the participants seemed not to be aware of the factors of Complexity and Organisation that are necessary to make their ideal interpreting process happen. But there is also an influence to the subcategory Type of information by the category Complexity. The reason for such an influence are situations and complex ways of dealing with all the nuances of Deafblind interpreting, that require that the deafblind user choose between types of information in order to be able to follow a certain situation. This is why the researcher felt appropriate to make a connection between the demand of a certain type of information and interpreter role, organisation and complexity, as factors that not all deafblind persons are aware of. An example can be a deafblind person who demands both kinds of information interpreted – visual and auditive, without realising that it takes a lot of time and usually there has to be some reduction of information in order for him to be able to follow the pace of the speakers and meetings in general. In contrast, there are some who are aware of the lack of time to interpret both kinds of information, with a few of respondents who demand that the lacking information be given after the meeting, when there is no time pressure.

The category Relationship Interpreter-User is also a part of the main category Demands, due to relatively frequent descriptions of what deafblind users demand, in terms of how this relationship should look and feel like. This category is also grouped under the main category Awareness, because of the nuances in this kind of relationship that can elude the deafblind user and he/she may not be aware of the whole relationship and the implications it brings. The category Relationship interpreter-user influences Privacy, in a way that user's privacy depends on the nature of relationship with a chosen interpreter. When interpreters are chosen among the deafblind person's friends, there is inevitably a question of defining boundaries and ways of behaviour, in respect to information that ought to remain private and those that are open for sharing. Because of the difficulty to sometimes see this problem and act upon it, both of these categories are sorted in both main categories – Demands and Awareness. The category Relationship interpreter-user influences Interpreter role, because the sort of relationship established at the beginning of their cooperation can influence the behaviour of both the interpreter and the user, in terms of dividing responsibilities and expectations. An example was given by one participant in this research, who claimed that he/she cannot expect his/her interpreters to behave like professional ones, because his/hers are in fact his/her friends, whom he/she cannot make do things they cannot or will not do. Following the same subject is the influence of the category Limited choice of interpreters on the category Relationship interpreter-user. This means that the limited number of interpreters can play a determining role in the relationship they have with their users – especially when we take into consideration the extreme ends of the continuum, e.g. friends who act as interpreters and professional interpreters who switch between users daily.

The category Privacy makes influence on two categories of the main category Awareness – Independence and Breakdowns. It is important to acknowledge these influences because otherwise it wouldn't be possible to tie demands with implications that are often not easily perceivable and users of interpreting services may not be aware of them. Demands or lack of demands for privacy influence the feeling of independence of users, in a way that they may become overly dependent upon their interpreters if too much private information is given to them. Also, this puts an interpreter in the position of power over the user because he/she possesses knowledge about the user that wouldn't otherwise be accessible to other people. Demands for a certain amount of privacy can lead to breakdowns in cooperation because an interpreter may overstep the boundaries of privacy, either not knowingly or even with best intentions.

10.3. Awareness

The main category Awareness is comprised of six categories of lower rank – Interpreter role, Independence, Breakdowns, Organisation and Complexity, Title of Service Provider, with two additional categories shared with the other main category Demands – Privacy and Relationship Interpreter-User. The last two have been described in Chapter 10.2, which is why they will only be mentioned briefly in this chapter.

Independence is a category influenced by many other categories and subcategories, some of which come from a different main category. This can be interpreted as the result of some demands and preferences from users of interpreting services, whether or not they are aware of such influences. Giving power to interpreters is a subcategory of the category Preferences, that directly influences Independence, meaning that too much power given to an interpreter can have a detrimental effect on a deafblind person's independence. Independence is also influenced by Privacy, which can be described as the power of a deafblind person to keep his/her privacy and the independence that stems from that power. If a person can maintain a successful cooperation with the interpreter without sharing all of his/her private information, then he/she is able to lead an independent life, because interpreters are not involved in his/her private affairs, but are only hired to perform a task that enables a deafblind person to be included in the society with his/her own input and experience. Interpreter role is the category interdependent with the category Independence, in a way that it determines what an interpreter does during an interpreting session. Interpreter's role can sometimes include tasks with more responsibility, e.g. taking notes during a meeting, discussing meeting topics after the meeting, advising the user, but can also be limited to interpreting only. Not knowingly, the user can reduce his/her independence by placing important tasks in the hands of interpreters. This process has its opposite as well. When a deafblind person feels independent in his/her actions, then he/she can control and model the role of interpreter, so it fits his/her needs, thus preventing any future limitations or threats to his/her independence. Independence is also connected to Breakdowns – they have a mutual effect upon each other. When there are threats to a deafblind person's independence, there are likely to be breakdowns in cooperation with interpreters. This is also true for situations where no boundaries have been set in advance, which increases the risk of an interpreter or a user doing the unexpected thing and potentially going against what the other feels is an appropriate reaction or behaviour. Breakdowns then in turn influence a deafblind person's independence, in a way that he/she is driven into situations that are out of his/her hands and with

limited powers to handle those situations on his/her own. There is a long term influence of Breakdowns on a person's Independence, in a way that a continuous experience of malfunctioning cooperation can reduce the willingness of a deafblind person to engage in interpreting situations. This effect is particularly detrimental on deafblind persons, being at great risk of becoming isolated from society (Schneider 2006). It also presents a paradox, because interpreting services are the ones that should help the users break their isolation, but if not provided in a manner that suits their needs, they can also become risk factors for isolation.

Interpreter role is a category mutually influenced with the category Relationship Interpreter-User. Just like it was described in Chapter 9.5. *Relationship Interpreter-User*, there is a strong influence of the relationship between user and interpreter, which determines what a user can expect and to what extent he can modify the interpreter's behaviour. The example of a friend acting as an interpreter was given, which limits the extent to which a user can control the interpreter's role. The opposite influence is present when there is a professional relationship with an interpreter right from the beginning, which starts with defining the roles of the interpreter and leads to a relationship between user and interpreter that is determined by their professional relationship and working together. Interpreter role is interdependent with the category Independence. This one was described in the previous paragraph. There is also an influence of Interpreter role on the category Breakdowns. It can be explained as breakdowns in cooperation stemming from disregarding the agreed interpreter role, or a positive example of avoiding breakdowns when there is a respect of the agreed interpreter role. This influence was recognised on the basis of many accounts from respondents in this research that can be viewed as interpreters stepping out of their role or behaving in accordance to the roles of other kinds of interpreters, for example the interpreters for the Deaf.

The category Breakdowns consists of various accounts and examples of how cooperation between interpreters and users can go wrong, but there is also a subcategory that deals with Strategies of solving those Breakdowns. Breakdowns themselves were not grouped in a separate subcategory because they are self-explained and there was the need to separate them from Strategies. The mutual influence between Breakdowns and Independence was described in the previous paragraph. A mutual influence exists between Breakdowns and Complexity too. It can be regarded as the way the more complex situations can cause more breakdowns in cooperation to occur. On the other hand, more breakdowns that can be caused by other factors, like misunderstandings in the expected role of interpreter, can cause the interpreting situation to become

more complex and difficult to maintain successful. There is also a direct influence of the category of Organisation to the category Breakdowns. This is most evident when there is a problem with securing funding for appropriate interpreters or with the organisation of interpreter breaks due to not enough interpreters available to make the proper shifts, which can cause breakdowns due to tiredness of interpreters or the deafblind person. The subcategory Strategies is influenced by a deafblind person's Independence, which means that a more independent person will be able to come up with more strategies and more various ones to deal with breakdowns during interpreting at international meetings.

Organisation is the category that influences Breakdowns, as described in the previous paragraph. It is also connected by a mutual influence with the category Complexity. This is so because more complex situations require more elaborate organisation. Examples are easily given when we consider the various interpreting methods and all the tasks interpreters are required to perform in order to meet the user's needs in communication and participation in a meeting at international level. Also, there is an influence of Organisation on the category Complexity, which can be explained as various components of organisation that increase the complexity of the interpreting process. There is also an influence from the subcategory Type of information, from the main category Demands. Due to different demands for the type of information, there are obligatory accommodations in organisation, to be able to provide the information of the right kind and in the right amount to the user.

The category Complexity has mutual influence over Breakdowns and Organisation, both of which have already been explained in the previous paragraphs of this chapter. What remains to be explained is the influence from the subcategory Type of information on the category Complexity. The choice and demands for certain kind of information mean an increase of complexity. This is the influence that is sometimes overlooked, because one needs to consider what are the implications of making a request for a certain kind or amount of information. This is especially true for some participants who claimed to demand the complete picture, with visual and auditive information, without realising, or without reporting to realise, that this is a time-consuming and laborious effort from an interpreter, that increases the complexity of interpreting process.

The category Title of Service Provider is influenced by Interpreter role. This goes to show that generally deafblind users choose names to call their interpreters according to what they think their role is. However, that is not true for all respondents, because some of them are not aware of the relation between the title and the job description. This is the main reason for placing the category Title of Service Provider under the main category Awareness. Although it does not have extensive connections with other categories besides Interpreter role, it completes the picture of what it means to be aware of many aspects and nuances of working with interpreters.

10.4. Dynamics – Demands, Awareness and Satisfaction

Figure 17 represents the key areas relevant to all participants – Demands, Awareness and Satisfaction with interpreting process (or shorter – Satisfaction). They can be considered higher-level concepts because they encompass lower-level concepts and they explain them in a more abstract manner. What was previously considered as a factor or an influencing concept, can now be regarded in the light of other similar and related concepts. This is the way three key points were established – **Satisfaction**, **Awareness** and **Demands**. Awareness and Demands are concepts that emerged through careful consideration of categories that data analysis produced. They are intended as superordinate to the categories and necessary to gain a wider picture on deafblind persons' experience of Deafblind interpreting process AT international meetings, a picture that encompasses many categories and gives them a new and broader meaning. Satisfaction is the concept that is even higher in the hierarchy and encompasses the two main categories – Demands and Awareness. This makes the concept of Satisfaction with interpreting process the central one to this grounded theory.

This theory considers the user's experience through the central concept – Satisfaction with interpreting process. It is an abstract and very complex phenomenon, which can be regarded through its two main categories, thus making it more concrete and accessible to further explanation.

All the users' experiences can be viewed as continuums, whether we consider the central concept or its main categories. An example will be given – one person can be very demanding in his/her expectations and requests from an interpreter, while another person can have very few demands and be compliant with all kinds of services. In between, there are other people whose

demands vary and fall somewhere in the middle of that continuum. Also, a person can describe his/her demands in detail, but fail to describe his/her awareness about the implications of his/her demands or the factors that influence whether or not those demands can be met. Such a person would be described as one whose demands fall on the more demanding side of the continuum, while at the same time being on the lower awareness side. Many categories and subcategories that are offered to explain in detail what makes usual demands and what it is that a person can be aware of, make it easier to describe in which areas users manifest their characteristics and attitude. They serve to gain a better understanding of what makes a user's experience and what are the components that make each user different. The continuity of each part of the experience makes it suitable for describing it in terms of individual differences and variability of each part of the experience. It also enables the experience to be described separately in each part, but with an opportunity to tie all those parts together and gain a more complete understanding of the process as a whole.

11. RESEARCH QUESTIONS ANSWERED

1. How do deafblind users describe their positive experiences with deafblind interpreters at international meetings?

This question can be observed from more than one angle, which contributes to the diversity of information and new insights into the experiences of deafblind users of interpreting services.

One angle is to examine the data provided by the respondents which describe the components of a positive experience working with interpreters at an international meeting. This gives us a description of a positive experience in terms of everybody's roles, duties and circumstances in which the meeting is held.

A different angle provides us with a description of the deafblind persons' feelings during a positive experience with an interpreter. This can unveil what a positive experience means to a deafblind person and how do they differentiate between positive experiences and not so positive ones, on the basis of their internal experience and not according to the outside criteria. The value of this angle of giving answers is that it takes into account inner feelings that can sometimes be irrational and not in accordance with previously set criteria for a positive experience. A theoretical positive experience can be described through the characteristics of the interpreter, through the description of the right way the interpreting process should go, and through the characteristics of environment and organisational matters. However, this doesn't always have to match the experienced emotions during the interpreting process. This discrepancy between the expected experience and the real one is the reason why one should consider the emotional side of the cooperation between user and interpreter. In this research, there have been accounted a few cases of deafblind persons whose emotional experience of working with interpreters didn't match the expected experience. Although they did not always know the reason, they knew that their interpreter was a mismatch and they had a difficult time working with him/her. This goes to show that theoretical expectations and practical experience don't always match.

Even more insights can be gained if we consider the way participants described their positive experience with interpreters at international meetings. Their readiness to share details of such experience can serve as indicator of their own experience and their tendency to think about different experiences. Some of the respondents were not inclined to share the details of a positive experience, but described it only as one that is not negative. Their description of a positive experience was limited to describing what it should not consist of. There were other respondents who provided a rich insight into what kind of experience they consider a positive one. They described which outside factors contributed to their positive feeling, but they also tried to describe the intangible connection with an interpreter that makes an experience of working together a positive one.

The last insight into a description of a positive experience can be gained from acknowledging that there are deafblind persons whose every experience of working with an interpreter is a positive one because that is the only way they could accomplish any kind of participation at international meetings. This reflects the inaccessibility of interpreting services in some parts of the world, thus making deafblind persons quite non-selective to their interpreters because they are aware that they cannot afford to be too demanding. Such a situation, where every experience working with an interpreter is a positive one for the mere fact that they were given an opportunity to even have an interpreter, shows that interpreting services in some countries are quite difficult to arrange. The consequences are that deafblind persons do not get enough opportunities to contemplate upon the quality of services and their own feelings during the interpreting process. Unfortunately, this makes them less capable of influencing the quality of interpreting because they have very little experience to compare the interpreting process with. Also, this lack of critical thinking can lead them to a situation where they are not even aware that interpreting services can be better and more effective. This find, that there are deafblind persons who are not aware of the nuances in quality and standards of interpreting, is very important because it highlights the importance of training for deafblind persons, as well as for their interpreters. What should also be taught is the skill of assessing the quality of interpreting process, so that the deafblind person could be the one in control of the situation and his/her inclusion into society and important events where decisions are made.

2. What are the expectations of deafblind users from the interpreting process at international meetings, in all aspects of receiving interpreting service (language interpreting, mobility support and environment description)?

The way the deafblind participants in this research described their cooperation with interpreters at international meetings was concentrated on three different areas, as was expected. There were differences in description of those areas, but also many similarities between the participants.

The area where they were focused on the special circumstances of international meetings, as opposed to regular meetings in their home countries, was interpreting. All respondents were very focused on making clear the difference between language interpreting situation abroad and all the requirements that are different at international meetings. They were also very similar in describing the desired outcome and quality of interpreting. For most of the respondents, the interpreting part of the cooperation with interpreter was the most technical and least emotional part. It was also the one where they demanded the highest level of skills and professional behaviour.

Providing mobility support, or guiding, was the part where just a few participants gave detailed description on how it should be done and what were specific expectations in terms of being guided properly. Also, most of the participant didn't emphasise the difference between being guided in their home country and at international meetings. What most of the participants stated as important was the way they felt when being guided. It was the part of interpreting process that they mostly experienced through feelings of security and feeling safe about their movement. Although they used less detailed description of the interpreter's actions, they described how they should feel during guiding that fit to their needs, as opposed to describing language interpreting, where they focused on criteria and facts.

The third part of the interpreting process – environment description, was the part where the respondents showed to be the most diverse in their needs. While some described what they don't want interpreted, the others listed all the things they were interested in being informed about. Some described the desired outcome of the description, while others described the steps that

should ensure proper environment description. We can conclude that this part of the interpreter's role is the most dependent on the user and his/her preferences. Although we can consider an interpreter as being the eyes and ears of a deafblind person, the overwhelming amount of information contained in the environment makes it impossible to perform the task of environment description uniformly. The differences will and should occur, in respect to the deafblind user, to the environment and to the certain situation.

3. What specific expectations do deafblind users have when it comes to cooperation with interpreters at international meetings?

The specific expectations that can influence the cooperation between a deafblind person and an interpreter are those that vary greatly from person to person. In this research, several areas emerged where there were great differences in preferences from person to person. Especially because they originate in people's preferences, they represent a great challenge to explore and an even greater one to indulge in when it comes to working in practice. The areas where preferences influence the cooperation the most are connected to the person of interpreter, but also to the deafblind person and their surroundings.

One distinct preference is whether a deafblind person wishes to work with always the same interpreter. While some participants can allow for interpreters to change, others will insist on having the same person on most interpreting sessions. This is an expectation that can influence the way interpreting sessions are organised, but it also influences the way other deafblind persons in his/her town or region use interpreters. If a service provider, like an agency for interpreters, respects this person's wishes it will certainly lead to an uneven distribution of interpreters, because one will always be booked by the same person, which will not allow for the other interpreters to switch between users. An even bigger dilemma arises if more than one deafblind person insists on having the same interpreter – then every deafblind person would effectively have a personal interpreter. This is a very significant question that arises from this specific expectation of deafblind persons. It has to be further explored, with emphasis on the role of such interpreter. Also, professional behaviour and code of ethics have to be carefully considered and included into training courses and education of interpreters.

Another specific expectation that is closely related to the person of interpreter is the interpreter's gender. In order to achieve satisfaction with the assigned interpreter and his/her work, some of the respondents feel that the interpreter has to be of certain gender – for some, it is important that the interpreter is female, for others that the interpreter's gender has to match their own. Whether their preference is guided by some preconceived ideas about good interpreters or by their previous experience, some of them expressed their strong attitude towards being able to choose the interpreter according to their gender. There were other respondents who didn't have any preference towards the gender of their interpreters. This difference between users can create dissatisfaction with the interpreting process in some users, although all other factors are optimal for successful interpreting. In the process of selecting interpreters, this should be taken into account, since it can lead to problems in communication between user and interpreter, thus making it more difficult for a deafblind person to achieve his/her goal at the event he/she is attending. Also, one has to bear in mind the discomfort that such a situation can cause to both the interpreter and the user.

Specific expectations are dictated by interests and inclination towards specific kind of information. This means that deafblind persons differ when it comes to choosing auditive or visual information from the environment, they also demonstrate different levels of interest for the events in the environment, they have different opinions on whether they should be informed about the environment during being guided from one place to another... All these things influence the way they expect their interpreter to work. If their preferences are not clearly stated at the beginning of the cooperation, the interpreter might provide the deafblind person with different kind of interpretation, guiding or environment description. Although he/she might be well trained and experienced, he/she must be given an output about the way the services should be performed. This is also an issue that needs to be taught during education and training to become an interpreter – how to be sensitive to the user's needs and how to offer only those services that are required, in the form that is acceptable to the user.

There are specific expectations that arise from the inherent characteristics of a deafblind person, although they are not connected to preferences or attitudes, but to physical conditions. This includes the state of their vision, the remaining hearing, their ability to walk straight, their capacity to concentrate during a meeting and their endurance for long lasting interpreting sessions. These factors arose during this research and were detected as important because users

mentioned them very often and described in detail what were their expectations. Those factors can and must be accommodated by interpreters, who must gain enough knowledge and experience to be able to provide adequate services. Although, not everything can be learned in training, just the foundations on which an interpreter can build new knowledge and experience. This is especially true to making accommodations regarding the user's vision and hearing. An interpreter cannot know in advance how to use a communication method or to what extent does a deafblind person hear or see for him/herself. Also, an interpreter has to be in accordance with a deafblind person regarding periods of time spent in interpreting and time spent in breaks. This is largely dependent upon the situation and rules of a certain meeting, but a deafblind person also has a say in the matters of taking a break when he/she needs one. Distribution of breaks is essential to keep the concentration of a deafblind person and for him/her to be able to function and participate actively in the meeting. In the opinion of the participants of this research, an interpreter has to be sensitive of that. That is why an interpreter has to be taught special skills of assessment and adjustment to a deafblind person. This adjustment is a necessity to deafblind persons and they expect it from an interpreter, otherwise they cannot achieve proper communication with the world around them.

4. How do deafblind users describe the key difficulties that occur at international meetings they attend with their interpreters?

Respondents in this research described the issues they face during interpreting sessions and their answers can be seen from three angles. One is the way the difficulties are described. Some of the participants were emotional when they described instances of breakdowns in cooperation, while others were rational and provided a factual description, without colouring it emotionally.

The other angle is whether they regard the breakdowns as someone's fault or just as misfortunate events during interpreting sessions. Some of the participants are prone to blaming the interpreter, the environment or themselves for the breakdowns, while others spend less time thinking about who is to blame, but rather accept those breakdowns as a natural part of working with another person.

The third angle is whether they describe breakdowns in terms of offering a solution to them. Sometimes they describe a particular problematic situation to a great detail, which shows that they spent some amount of time thinking about what went wrong. Some respondents were prone to offering solutions to problems, while others merely gave descriptions. This shows that there are differences in the approach to breakdowns in cooperation – some users will be inclined to seek solutions, while others will accept the occasional breakdown and will not worry about it too much.

5. How do deafblind users describe the additional environmental impacts needed in order for an interpreting situation to be possible at all and to be as effective as possible?

We can focus our attention to two ways of describing environmental influences – one is the awareness of their existence and capability to detect and describe them and the other is the structure of these environmental factors.

Since no interpreting is done in vacuum, the environment plays a significant role in the success of an interpreting session; such is the opinion of some of the participants. Others were not so inclined to assign great power of influence to environment. Such difference in perceiving influences from the environment shows that the level of awareness varies between participants in this research, as probably does between all the other users of Deafblind interpreting services who were not a part of this research. This means that some users won't be able to give guidelines to improve the environmental influences, while others will be more demanding and clear about environmental factors that they think can influence the interpreting process.

From the answers given by respondents in this research, it is evident that they pay less attention to environmental factors and describe them in less detail than they do the direct factors that influence the success of interpreting – factors connected to the interpreter and their cooperation. Even though they acknowledge the existence of factors from the environment that can disturb or improve their ultimate level of functioning at a meeting, they consider them less potent and less subject to a change. It is either because they believe they do not have enough influence over

them, or because they think they are not of such relevance that they do not deem them as crucial in making their participation as successful as possible.

What is interesting is the fact that many completely deafblind persons expressed very little interest or worry in those environmental factors, as if the environment is detached from them and cannot influence them. Those respondents with remaining sight and hearing more often made complaints about the environment, especially in terms of inadequate lighting or noisy environments. They did describe such influences as deteriorating to their participation at a meeting and provided some solutions to the problems they are facing due to poor environment conditions.

When it comes to the way they described the environmental influences, they only referred to them when they perceived their influence as deteriorating, but they did not mention the way the environment can improve their functioning with interpreters at international meetings. Whether this is because they do not perceive the environment as a potential facilitator, or because their previous experience has only been negative, they are less inclined to pay attention to what kind of environmental influences they are exposed to. There is one more possible explanation of this lower level of awareness to environment – the reduced quantity of information regarding environment. This is because the only way of receiving such information is through the interpreter, who doesn't always manage to transfer all the information – both the spoken communication and description of environment. One possible outcome of this inability to include all information into interpreting process is that the deafblind person cannot detect environmental influences because they have not been brought to his/her attention. This would explain why those users who have some remaining vision and hearing are more prone to make remarks about environment, while those who are completely deafblind do not.

When we consider the most commonly stated influences, those are physical ones – light and positioning of interpreter and other participants of a meeting. Those factors are usually noticed by the deafblind persons, but some of the participants in this research are of the opinion that interpreters should also be able to notice them and act in the direction of improving them as much as possible. This means that they expect them to work together with users to improve the setting of interpreting session.

6. What are the expectations of deafblind users when it comes to the organisation of international meetings?

Expectations regarding the organisation of international meetings can be regarded in terms of control over the situation, making participation possible and making themselves as effective as they can be.

When it comes to control over situation, the respondents of this research showed that they consider themselves responsible for controlling their own understanding of information received from an interpreter, but when it comes to the larger picture and controlling the flow of the meeting, they expect the chairman of the meeting to be in control and guide the respondents through the meeting.

Participants also reflected upon the factors that contributed mostly to realisation of participation at international meetings. Two main factors emerged – one was the financial aspect and the other was having interpreters for a meeting abroad. This is a very valuable find because it emphasises two main problems of the Deafblind – restraints and difficulties in raising the funds for their participation and the complete inability to participate if the organisation doesn't include their interpreters.

The issue of making themselves as effective as they can be is very important to the deafblind participants in this research, which can be linked to their experience at international meetings, where they wanted to participate to achieve some goal, and not just to be a passive part of an event. Therefore, all of the participants in this research emphasised the necessity of having accessible all the written materials a long time before the actual meeting.

7. What insights obtained from this study can be used as a basis for further scientific research?

A few important subjects emerged in this research as an important starting point for further research that could lead to a better understanding of cooperation between interpreters and users, which can be used in education of interpreters and users.

Emotional attachment and questions of professional behaviour arose as important areas of research, especially when considering specific expectations from users that can place an emotional burden upon both the interpreter and the user. Knowing how interpreters and users handle emotions and behaviour is very important in providing input for future interpreters during education, but also for providing support to interpreters and users alike, to make them more competent in handling situations that could potentially be overwhelming and stressful to persons involved in the relationship.

Establishing a successful working relationship, where the interpreter knows which information to transmit and in what way, is a very important question that can be researched. There are no two deafblind users alike, which was also shown in this research, which means that no education can prepare the interpreter for the great diversity of users. This is why the attention has to be turned to the process of adjusting between the interpreter and the user, a process through which they achieve a functional relationship and mutual satisfaction.

A question of responsibilities emerged as a very delicate one, with quite diverse attitudes of respondents. This means that different users consider different things to be a responsibility of interpreters, which can create misunderstandings and breakdowns in cooperation. For this reason, there should be further research, to determine what is the general attitude of users and interpreters alike, on what should be the responsibility of the user and what should be the responsibility of the interpreter. Without such knowledge, there will be no consensus in education of interpreters and it will vary greatly, depending upon country.

Assigning interpreters is a question that can be researched in order to gain knowledge on how different countries and agencies approach this issue. Knowing that different users have distinct preferences about which interpreter they prefer or what kind of interpreter, it would be valuable to know to what extent are those preferences taken into account and to what extent do deafblind

users have influence on the assignment of interpreters. This question includes the deafblind person's demands regarding the gender of the interpreter, his/her preferences regarding the interpreter's clothing, or generally speaking, freedom of the deafblind person to choose his/her interpreter. This is closely related to the next question – personal interpreters.

From answers of respondents in this research, it has become evident that many of them describe an ideal cooperation with an interpreter as one where they in fact have a personal or designated interpreter. Whether that is done in practice, should be explored and reported. Also, the positive and negative sides to having a personal interpreter should be explored too, an interpreter who would always interpret for the same deafblind person, which many participants in this research consider ideal and desirable.

Finally, user satisfaction is a very important area for future research. A research should be made on components of the user's satisfaction and of the ways of measuring it, in order to devise a reliable instrument for measuring the user's satisfaction in real life situations. This would be a good way of monitoring the quality of cooperation between user and interpreter, through making sure that the user is satisfied with a service provided, which is ultimately a goal of interpreting services and work of deafblind interpreters.

12. CONCLUSION

In conclusion to this research, it can be stated that the objective of this research has been achieved. By answering the research questions, an insight into a new understanding of multiple aspects of the Deafblind interpreting process was offered. Seeing the process of interpreting through the eyes of the users has made me more prone to use their way of thinking and their values in assessing the components of the process. It is an approach that enables both me, as a researcher, and my readers to gain knowledge about what are the most important factors to the users and what is their way of assessing the success of an interpreting session at international meetings.

What was found in this research was the fact that everything the deafblind users required from the cooperation with interpreters was aimed in the direction of achieving satisfaction with the interpreting process. This concept is very robust and it can be seen in all of the answers from the respondents. It comprises factual data, with very easily described requirements, some of which can even be quantified and measured. But it also contains a lot of emotional experience, which cannot be easily quantified and sometimes it is hard to even explain it in terms of factors that contribute to it.

Two other concepts – demands and awareness, emerged in this research that are very important in understanding the user's perspective of interpreting process. Those two concepts make up the satisfaction with the interpreting process, in a way that every experience is comprised from those two elements – awareness and demands. This means that every deafblind person's satisfaction with the interpreting process stems from his/her demands and the awareness of many factors influencing the interpreting process. The balance between those two is one likely key to overall satisfaction with the interpreting process. Since both concepts – Demands and Awareness – are highly individual and depending upon the characteristics of a particular user, they can be truly considered as good indicators of the user's experience.

These abovementioned three concepts emerged as the most important ones in describing the user's perspective of Deafblind interpreting at international meetings. Each can be seen as a continuum, from high to low demands, awareness and satisfaction, and all of them coming together

to create a complete immersion into how deafblind users perceive the process of interpreting. By providing a description of each deafblind user's perspective through these three concepts, one can gain a very thorough insight into the inner experience of interpreting services by deafblind users. Moreover, explaining the user's experience through three concept-continuums – Satisfaction with interpreting process, Demands and Awareness, enables a depiction of individual experience, without compromising its diversity. This research enabled an even more detailed description of each of those concepts, through categories that were discovered in data processing. Concepts Demands and Awareness consist of five and six categories, respectively, with additional two categories that they share.

This research produced a new angle for considering what is important to the users of interpreting services at an international level. This information can now be used in the process of creating curricula for Deafblind interpreting training courses. Training courses can be enriched with the information on what are the sources of breakdowns in cooperation, which areas of the interpreting process are the sources of vast discrepancies between users, and most importantly – future Deafblind interpreters will be able to read this paper and see the process of interpreting from a standpoint of their user and hopefully become more emphatic and aware of the nuances that make up the user's satisfaction with the interpreting process. Moreover, the general idea of the user's experience being constructed from demands and awareness can help create systems and instruments for assessment of user satisfaction, specifically for deafblind users at international meetings.

My sincere hope is that this research will stir interest in other scientists, especially ones who are dedicated to the field of interpreting and deafblindness. The description of a user's perspective could be even richer and deeper if the same group of participants were examined again, after several months and more international meetings. I believe that that would yield even more detailed answers, because the group of deafblind persons included in this research was provoked to start thinking about questions raised in it. What would also be beneficial is a separate research, focused on interpreters and their perspective. Comparison of those two standpoints could bear even more answers and raise new questions, many of them worthy of further research.

13. LITERATURE

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STATEMENT OF COMPLIANCE WITH ETHICAL STANDARDS IN SCIENTIFIC RESEARCH

In accordance with the fundamental values and principles of the scientific-educational community, I hereby declare that I will approach this research as part of a doctoral dissertation in accordance with the highest ethical standards and with the responsible conduct of the research.

Since the qualitative research of the users' perspective involves a vulnerable group of persons with disabilities – deafblind persons – the scientific efforts and ethical behaviour shall be fully respected in accordance with the standards of the Code of Ethics of the Ethics Committee in Science and Higher Education (Odbor za etiku u znanosti i visokom obrazovanju 2006) as well as with the Code of Ethics of Psychological Practice (Hrvatska psihološka komora 2004).

The most important standards encompassed by the Code of Ethics shall be built in this scientific work as its inseparable part, and in accordance with that, ethical behaviour and responsibility shall include:

Scientific integrity, which presumes: (1) competence in the area of scientific work; (2) taking all reasonable steps to ensure the accuracy and veracity of the data; (3) that the original data will be saved, stored, processed, used and transferred in such a way to prevent their loss, destruction, access to them by uninvited personnel, disclosure of confidential or classified information or possible abuse, within reasonable limits, for at least 10 years from the completion of the research. After the publication of results, all of the original information must be made available on request, within reasonable limits; (4) that all processing of data resulting from this research shall be correct and in accordance with scientific methodology until proven otherwise; (5) that the presented results of the research shall consistently match the conducted research and that there shall not be any fabricated, falsified or plagiarised data, results, ideas, etc.

Collegiality, which presumes: (1) that the authors and co-authors of all scientific works, particularly scientific publications, meet the following criteria: active participation in (a) development of research ideas, development of concept and forms of research, (b) collection, processing, and interpretation of research results, and (c) writing and conception of a scientific paper or critical revision and approval of such a paper; (2) that the structurally superior function within the institution, financial or other support do not themselves present qualifications for appropriation; (3) mentoring relationship must be based on mutual understanding and respect of intellectual property rights and other rights generated through scientific research in the framework of that relationship, without exploiting the superiority of the mentoring position.

Special attention will be paid to the protection of the participants and this will represent a part of this doctoral dissertation as a separate unit. It is to be presumed that the compliance with relevant international and national laws and regulations on the protection of participants will be required from researchers and institutions in which the research shall be conducted.

In doing so all four major components of privacy protection shall be covered in the best possible way, namely:

(1) Voluntary participation of all the respondents

To all potential participants copies of Participant Information sheets will be made available. Each participant will be able to freely choose whether or not to join this research and before it will be informed on the nature of the research and on the role he/she should have in it. Each participant shall agree to participate in the study in writing by willingly signing the Participant Consent Form. Written Consent Forms thus obtained will be stored in the researcher's database for at least ten years, according to the rules of scientific integrity.

(2) Confidentiality

Privacy protection is guaranteed to all the participants. This is particularly important in the context

of a limited group of deafblind persons and their interpreters who attend meetings at the international level. As already stated, mutual acquaintance in a restricted circle of persons active in meetings presumes an increased need for data protection in order not to undermine the dynamics of international meetings and professional relationships among Deafblind participants of such meetings.

(3) Anonymity of respondents

Since the study is approached from a context in which it is impossible to avoid personal contact and invasion of privacy, data protection could be made only after the data were collected. All participants are presented with numeric codes. In the course of transcription and storing data concerning each participant, his/her name was exchanged with a code number, to be used in the further processing of data. The original copies of a participant's data are stored in the researcher's database and protected from opening by any other person but the researcher.

(4) A wellbeing/risk ratio favourable for the respondents

All the participants are acquainted with the research problems and protection against abuse of data obtained in this investigation is guaranteed to all of them. In this way a more open participation in the interview is enabled, which is necessary in order for the persons to express their opinions without hesitation and without fear that the information will affect their future participation in meetings at the international level.

I hereby also pledge all the participants in this research, including the author, mentor and co-mentor, to respect the same rights, duties and rules included in the abovementioned Codes.

INFORMATION SHEET FOR PARTICIPANTS

Meeting challenges – Deafblind interpreting From a User's Perspective

It is my pleasure to invite you to participate as an “experience expert” in this research – “Meeting challenges – Deafblind interpreting from a User's Perspective.” Your experience will contribute to widening the area of knowledge on Deafblind interpreting, especially in situations of international meetings. In this Information Sheet, you will find all the relevant information about this research. After reading this information sheet, you will be free to decide whether you want to give your own perspective on Deafblind interpreting in this research.

1. What is the research about?

The theme of this research is Deafblind interpreting for deafblind participants during meetings at an international level. The focus of this research is to explore your perspective as an “experienced expert” in the field of Deafblind interpreting during international meetings, in order to gain insights into the real expectations of deafblind persons in situations like these.

2. What is the purpose of this research?

The purpose of this research is to gain insights on user perspective of Deafblind participants on the subject of Deafblind interpreting during meetings on international level. This research is the first in this field of knowledge, which is why the results will be highly valuable. With your answers the area of knowledge on Deafblind interpreting will be widened and a more detailed description of deafblind participant's needs will be given. Also, with the new information available on Deafblind interpreting during meetings, there is the opportunity to improve the quality and efficiency of international meetings of the World Federation of the Deafblind (WFDB) and the European Deafblind Union (EDbU), as well as to improve the participation in all other international meetings where deafblind persons partake. This effort will encourage other deafblind persons to play a more active role in political and public life.

How will the participants be involved in the research?

Every potential participant in the research will be first given this Information Sheet. After reading about the importance and purpose of the research, he/she will be given a Consent Form, to sign if he/she chooses to participate in the research. After that, he/she will be sent the Questionnaire in

written form, via e-mail. Answering the questions is on a voluntary basis and all the participants are free to refuse to give answers or to withdraw from the research. All the Questionnaire data will be transcribed and used in research analysis.

What are the topics of the Questionnaire?

The topics are connected to the whole interpreting process, before, during and after the meetings on international level, with all the areas of Deafblind interpreting included – interpreting of speech, mobility support, describing of environment and choosing the right communication methods. Also, there will be questions about environmental conditions that influence the successfulness of the meetings of the Deafblind. The participants will be free to express experiences and opinions and to add everything they think is important.

Who are the participants of this research?

The participants will be persons with acquired deafblindness, who have experience with participating in meetings on an international level in the organisations European Deafblind Union (EDbU) and World Federation of the Deafblind (WFDB), whether as members of committees, working groups or other roles that demand international participation.

How will participants' privacy be protected?

Participants in this research will be granted protection of their personal information, as well as any other identity revealing information. All the Questionnaires will be transcribed with removing the data such as names and functions that could potentially reveal the identity of participants. The participants' data will be managed under numeric codes and the data itself will be archived in the researcher's database for a minimum of ten years.

Who is carrying out the research?

Sanja Tarczay, a postgraduate student at the Faculty of Education and Rehabilitation Sciences of the University of Zagreb, is carrying out this research to meet the requirements for the degree of Ph.D. Sanja Tarczay is mentored by researchers at the University of Zagreb, Ljubica Pribanić, Ph.D. in rehabilitation sciences.

What is the expected contribution of this research to the Deafblind?

By doing this research, I would like to achieve greater knowledge on the subject of Deafblind interpreting during meetings on an international level, that can be used to improve the current interpreting services, to facilitate arrangements necessary for successful participation in meetings

and to ensure that the Deafblind access their rights to participate in political and public life.

What is the expected overall contribution of this research for wider public?

The results of this research could be used as guidelines in making curricula for future interpreters, as well as a starting point for future research in the field of Deafblind interpreting. In this way, more information about Deafblind interpreting will be available, which will contribute to the overall improvement of quality of life for persons with disabilities. Also, service providers will benefit from results of this research, because they will have a clearer picture on what proper services for the Deafblind are.

APPENDIX C

PARTICIPANT CONSENT FORM

I confirm that I understand the intent of this research after having carefully read, or have been explained to me, all the information from the Information Sheet “Meeting challenges – Deafblind Interpreting From a User’s Perspective.”

I am fully aware and I agree with the procedure involved in this research, which will be via e-mail Questionnaire.

I understand that I am guaranteed complete confidentiality of information. Also, I understand that I can terminate my participation at any given moment.

I declare that my participation in this research is voluntary and I accept it with all the obligations that go with it.

Name:

Date:

APPENDIX D
QUESTIONNAIRE

PART 1: GENERAL INFORMATION			
Initials:		Gender:	
Age:		Nationality:	
Your level of education and your occupation:			
Vision loss:	1.	When did you lose your vision?	
	2.	What caused problems with your vision?	
Hearing loss:	1.	When did you lose your hearing?	
	2.	What caused your hearing loss?	
Category of deafblindness: (please select one of the following)	a)	Hard of hearing + Partially sighted	
	b)	Hard of hearing + Blind	
	c)	Deaf + Partially sighted	
	d)	Deaf + Blind	
Deafblind interpreting method preferred: (please select one or more of the following)	a)	Tactile interpreting (hands on interpreting)	
	b)	Close vision interpreting	
	c)	Visual frame interpreting	
	d)	Clear speech interpreting	
	e)	Interpreting by Finger Spelling or Manual Alphabet	
	f)	Speech-to-text interpreting	
	g)	Other method (please describe)	
Years of experience with international meetings:			
What was your function in international organisations and meetings:	a)	president	
	b)	vice-president	
	c)	secretary-general	
	d)	treasurer	
	e)	member of executive committee	
	f)	member of election committee	
	g)	auditor	
	h)	member of working groups	
	i)	other function	

Continue to PART 2 on the next page

PART 2: MAIN AREAS OF RESEARCH	
a) INTERPRETING	
1.	What do you call the person who transmits information to you and describe the tasks and role of that person.
2.	How many interpreters do you feel optimal for your meeting to be successful? Explain why.
3.	Is the gender of the interpreter important to you? Explain why.
4.	Is it important for you to meet the interpreter before the meeting and know more about him/her? Explain why.
5.	How do you feel about not having the same interpreter(s) at different meetings?
6.	What is your interpreter's ideal dress code that you would like him/her to wear at meetings? Explain why.
7.	Describe the method used for receiving information from the interpreter (<i>e.g. Sign Language, loop, Braille,...</i>). Describe the method used for transmitting information to the interpreter (<i>e.g. Sign Language, loop, Braille,...</i>).
8.	In your opinion, do problems occur during interpreting that is done in multiple stages (<i>e.g. national sign language to national spoken language, national spoken language to English, English to national spoken language, national spoken language to national sign language</i>), what these problems are, and how could they be solved?
9.	Is it important to you that the interpreter has some general knowledge and understanding of the topic, themes and background of the meeting? Explain why.
10.	If you find yourself in a situation during a meeting when you don't understand what is being interpreted to you, how would you describe the problem and what would be the preferred way to solve it?
11.	Describe how do you engage in a discussion? How do you ask for the floor? How do you interrupt the debate to express your opinion?
12.	Describe what would a relationship between a user and an interpreter at a meeting be like?
13.	What is the thing (or several things) that can annoy you most about your interpreter or other interpreters at a meeting?

14. Have you ever had situations when the interpreters were disturbing the course of the meeting with their behaviour? Can you describe them?
15. Has it ever happened to you that the interpreter was great at language interpreting, but didn't quite fit to your needs with his behaviour or some of his characteristics or that the interpreter's behaviour and/or some of his characteristics suit you perfectly, but didn't quite fit to your needs with language interpreting?
16. Considering that the meetings are dynamic, do you need to revisit some issues of the meeting with your interpreter after the meeting? Which ones usually?
17. How would you describe successful cooperation with interpreters during international meetings, what does everybody need to do, to be successful?
b) ENVIRONMENT DESCRIPTION
1. What general information are you interested in about the environment (not people) when you are at a meeting?
2. What general information are you interested in about people (participants and interpreters) when you are at a meeting?
3. During environment description, do you prefer auditive (<i>e.g. what are people talking about, environmental sounds</i>) or visual (<i>e.g. what do people look or act like, what is the room like</i>) information to be transmitted to you? Or do you like both kind of information to be interpreted? Does the choice depend on the current situation?
4. Do you often feel that some information from the environment are missing when at a meeting? If so, describe in which situations it happens.
5. In what way are the information from the environment helpful for your full participation at meetings?
6. Sometimes there is not enough time for both interpreted information and environment description to be transmitted to you. How do you solve the problem of getting the complete picture of the meeting in progress?
c) MOBILITY SUPPORT
1. Who is the person that in your opinion is responsible for guiding you when you are going to the meeting and for moving around during the meeting?
2. Describe the type of guiding that you are satisfied with.
3. Is it important for you to receive information about the environment during guiding/walking?
4. What would be an example of unsatisfactory guiding from your experience?

d) COMMUNICATION METHOD

- 1. Do you always use the same communication method regardless of the situation, or maybe you prefer some method over another in a certain situation?**
- 2. As a person with acquired deafblindness, you have probably changed your communication method as your disability progressed (*e.g. earlier close-up Sign Language, later Tactile Sign Language; earlier clear and loud speech, later loop system or Braille*). Has this change of communication method affected the quality of received information? Describe how.**
- 3. Does the place of the meeting (*e.g. open space with lot of noise or closed room with a loop system*) or the circumstances (*e.g. badly lit room, unsatisfactory sitting arrangement,...*) of the meeting affect the communication method being used?**
- 3. Do you feel sometimes that it is the communication methods that present a constraint at a meeting or the inexperience of the interpreter?**

Continue to PART 3 on the next page

PART 3:	SPECIFIC AREAS OF RESEARCH
a) ORGANISING AND PLANNING THE MEETING	
1. In your opinion, how much in advance do you need to receive information on the meeting (place, date, time) to be able to successfully organise your attendance there?	
2. How do you secure the funding for your travelling to and attending the meeting?	
3. In your country, how do you secure funds for your interpreter at the meeting (<i>for his travel, accommodation and fees</i>)?	
4. Do you have difficulties finding the appropriate interpreter for a meeting? If so, what are the difficulties (<i>knowledge of language, availability, fees,...</i>)?	
b) TIME AND PLACE ARRANGEMENTS	
1. Is sitting arrangement important to you at a meeting? Explain why.	
2. Are other circumstances of the meeting (<i>lighting, assistive devices,...</i>) important to you? If so, please list them and explain why.	
3. How often do you prefer your breaks during a meeting and how long each break should last?	
4. According to you experience, what is the optimal time for the interpreters to switch between them?	
c) PARTICIPATING IN THE MEETING	
1. Are you of the opinion that during a meeting someone should monitor that every participant is fully involved in and that they follow the meeting? Who should that person be?	
2. Do you have problems with starting to speak at the right moment during a meeting? If so, describe them.	
3. How do you feel about the interpreters' involvement in the meeting at a personal level? Should they be allowed to give suggestions, opinions, comments?	

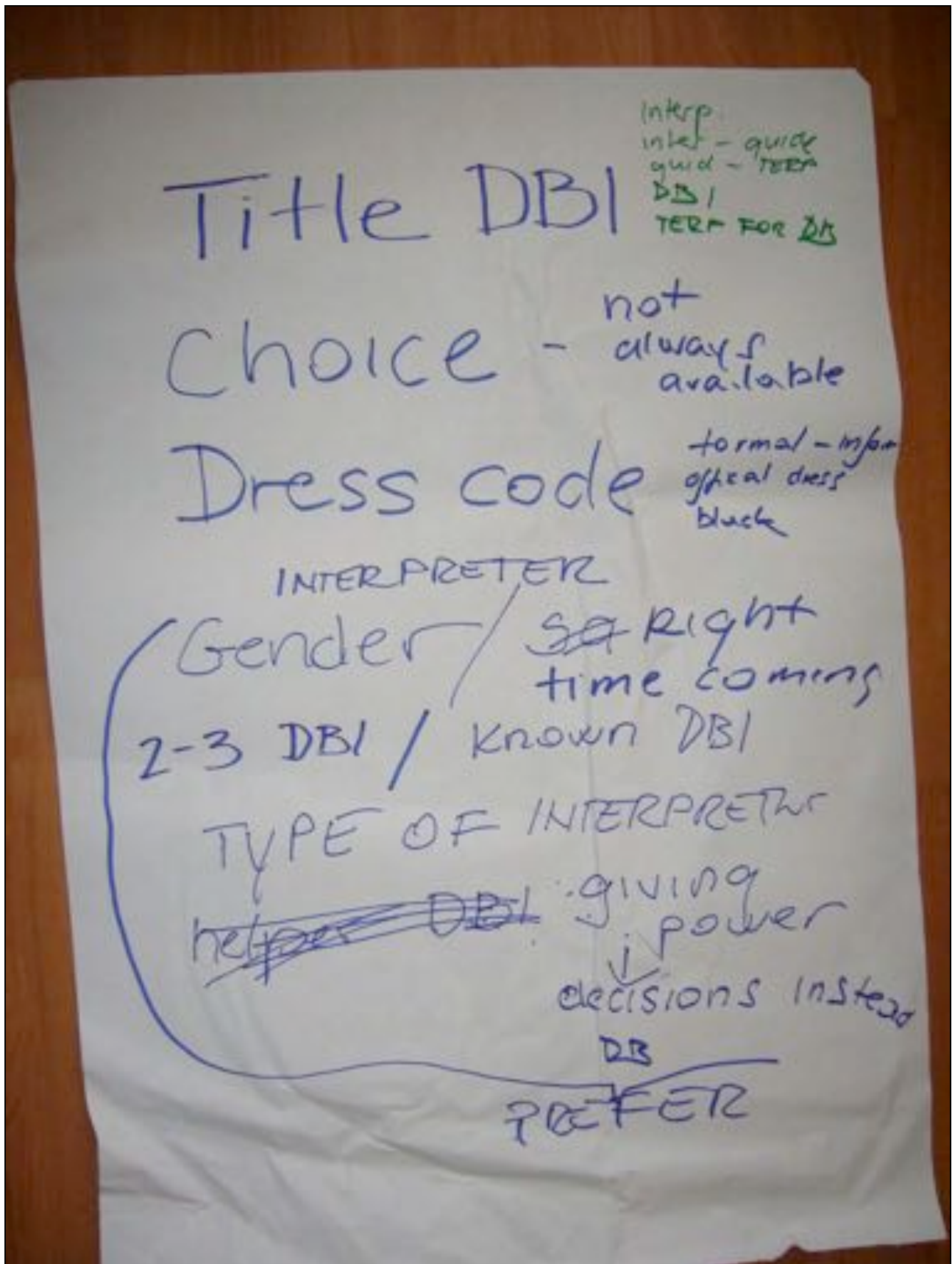
4. Do you need someone to take notes for you during the meeting? Who is the person usually doing it for you?
5. Do you need assistance of some kind other than interpreting on a meeting?
d) OVERALL EXPERIENCE
1. As a deafblind person and user of interpreter services, could you describe a positive experience that has improved the quality of a meeting?
2. As a deafblind person and user of interpreter services, what would be the most important difficulties you face during international meetings?
3. In your opinion, is it necessary for the interpreters at international meetings to have some specific formal education or is it possible to use volunteers for that task?

Continue to PART 4 on the next page

PART 4:

YOUR COMMENTS

CATEGORIES



PROBLEMS

no nursing / patronising
language limited / slow
interpreting / missing knowledge
concentration / (kidding in
process of interpreting) / dragging
using mob / attitude like DB is
DEAF / omitting info /
stuck with interpreting
(user use FTSY - DBI
hopeless)

OPTIONS TO SOLVE PRO

ask → chairman for help
→ DBI for explanation
stopping and repeating

Relation

official

strict

like guide dog

like ride horse

client
not child
not patient

appreciate

out of ^{norm} ~~norm~~

≠

friendly

friend = DSI

family member
volunteer

for relaxing

~~they~~ similar/same
taste

love long walk,
sports,

sport

non professional

Protecting info → Privacy

Interpreters Role

- Interpreting
- Guiding
- describing
- FLOWING PROCESS OF INTERP. ↑
LIKE NO TEXT
- AUTOMATICALLY GIVING INFO
- PREVIOUS EXPERIENCES WITH TS
 - INFERENCES IN INTERPRETIVE
 - NEW INTERP BOTHER ALL IF "BAD"
- MUST BE EYES AND EARS
- POINTS IN COMMON

B

understanding DA needs
in mobility

like dancing

be sure, confident

good ability for special situations

stairs / barrier /

contact - haptics signals

without contact - follow

informations giving < yes

no too much chatting < no

who

where

C

how many

in watch ~~in watch~~ events
- row, taught, discuss, etc

context ~~of watch~~

full pics

giving info < before
in process
after

Categories

Title of ~~Interpreters~~ ^{SERVICE PROVIDER}

Selection of interpreters

Limited choice OF INTERPRETERS

~~Dress code~~ ^{PHYSICAL APPEARANCE OF INTERPRETERS}

Interpreter role

Relationship ^{TERP - USER}

Problems ~~solutions~~ ^{BREKDOWN}

Organisations

Independence

~~Prefer~~ PREFERENCE !

Complexity

EDUCATION

QUALITY

Categories

Title of ~~Interpreters~~ ^{SERVICE PROVIDER}

Selection of interpreters

Limited choice OF INTERPRETERS

~~Dress code~~ ^{PHYSICAL APPEARANCE OF INTERPRETERS}

Interpreter role

Relationship ^{TERP-USER}

Problems ~~solutions~~ BREAKDOWNS

Organisations

Independence

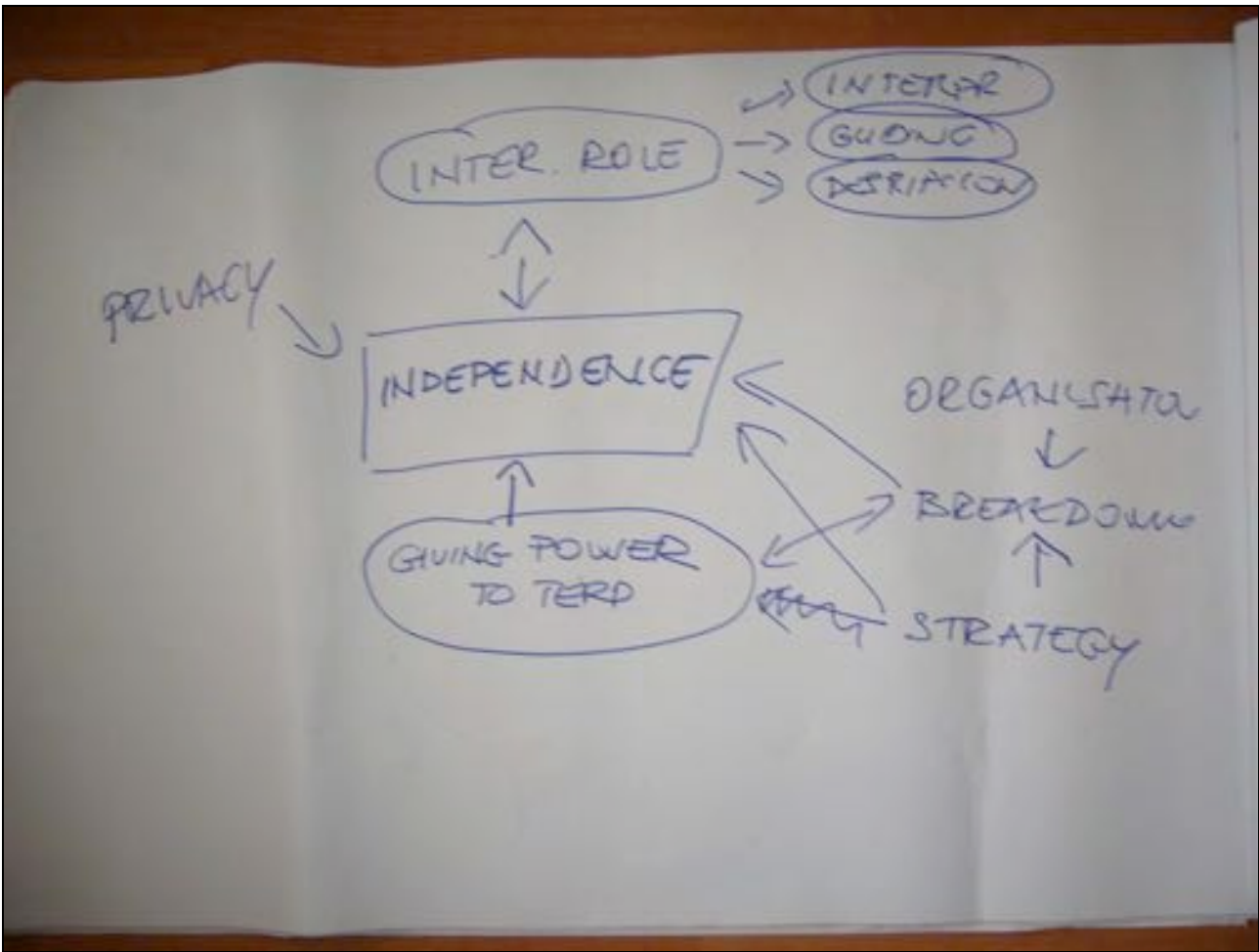
~~Prefer~~ PREFERENCE !

Complexity

EDUCATION

PRIVACY

RELATIONAL CODING



BIOGRAPHY

Sanja Tarczay was born on 17 October, 1966, in Zagreb, as a deaf child in a deaf family and is a native speaker of Croatian Sign Language. In addition, she is also fluent in British Sign Language (BSL). On her numerous journeys she uses International Sign Language (ISL), and also knows Swedish and American Sign Languages. She reads, writes and speaks English.

After graduating from Economics High School in Zagreb, she was employed at the Centre for the Accommodation of Mothers and Children “Josipovac” in Zagreb from 1986 to 1987, and at THE Association of the Deaf and Hard of Hearing of the City Of Zagreb from 1987 to 1992. In 1992 she started attending a two-year education at Vastanviks Folkhögskola in Leksand, Sweden, and obtained a certificate to have completed the training in the field of Sign Language linguistics, Deaf and Deafblind culture, planning programmes for Sign Language education, development of educational materials for the Deafblind, etc.

In Sweden in 1992, Sanja Tarczay faced with her deafblindness, and upon her return to Croatia in 1994, she established the Croatian Association of Deafblind Persons *Dodir*, whose president she is. She is also the creator of several important educational programmes: Croatian Sign Language course, courses for SSPs, and courses for Deafblind interpreters. She was also the initiator and founder of the Croatian Sign Language Interpreting Centre.

Together with her collaborators she devised what are still the only Croatian Sign Language textbooks with accompanying CD-ROMs, *Znak po znak 1, 2 and 3*.

Sanja Tarczay was the initiator of the first International Symposium “Sign Language and Deaf Culture,” held in 2001 in Zagreb.

Her long-time involvement in the promotion of Sign Language and the struggle for its recognition as a language of a minority community of deaf and deafblind persons, as well as her work on the organisation of a competent Sign Language interpreting service, have led to Sanja

Tarczay being recognised as a qualified person and to her being involved in numerous expert working groups, of the most important are: member of the Working Group for the Consideration of Issues of Persons with Disabilities of the Croatian Parliament Committee on Human and National Minority Rights (in 2004 and 2006), member of the Expert Working Group for the Draft Proposal on the Recognition of Croatian Sign Language of the Ministry of Social Policy and Youth (in 2012), member of the Working Group for the Pilot Implementation of Uniform Criteria for Determining Disability of the Ministry of Social Policy and Youth (in 2012), member of the Committee for Persons with Disabilities of the Government of the Republic of Croatia (in 2014), member of the Expert Working Group “Regional Support for Inclusive Education” for Primary Education of the Council of Europe in Regional Support for Inclusive Education Project (in 2014) among others.

However, the work of Sanja Tarczay in the fields of her interest did not remain unnoticed outside the Republic of Croatia and from 2001 to 2013 she was member of the Executive Council of the World Federation of the Deafblind – WFDB, as the Regional Representative for Europe (in three consecutive terms). In 2012, she was appointed head of the Deafblind Interpreting Working Group for the development of standards for Deafblind interpreting within WFDB. On behalf of the WFDB she cooperated with the World Association of Sign Language Interpreters (WASLI) and has participated in the development of the *Memorandum of Understanding between Deafblind International (DbI) and WFDB*, as well as being actively involved in drafting the WASLI *Deafblind Interpreter Education Guidelines*.

In 2013 she was elected President of the European Deafblind Union – EDbU. Along with her other duties within the EDbU Executive Committee she is also responsible for official contacts with the European Forum of Sign Language Interpreters (efsli). In 2009, Sanja Tarczay not only participated in the organisation of the efsli Summer School *Interpreting for People with Deafblindness*, but she was also one of two lecturers at the School. She also participated in drafting the *Memorandum of Understanding between EDbU and efsli*.

In 2000, she enrolled in the study of rehabilitation at the Faculty of Education and Rehabilitation Sciences, University of Zagreb, and graduated in 2004 with the thesis *Understanding Acquired Deafblindness*, thus obtaining the title of professor of rehabilitation. She earned her

Masters degree with the thesis *Preconditions of Professionalisation of Sign Language Interpreters for Deaf and Deafblind Persons* in 2009.

Since 2008 Sanja Tarczay is the head of exercises for the subject Deafblindness at the Faculty of Education and Rehabilitation Sciences, University of Zagreb, and lecturer on Sign Language at the University of Applied Health Studies in Zagreb. She also lectured at numerous other universities at home and abroad as a guest lecturer.

Since 2011, she is a collaborator at the research project *Continuous Professional Development of Teaching Staff Working in Schools for the Deaf – Enhancing teaching practices through Romanian Sign Language and ICT* for the development of educational materials for Sign Language interpreters at Babeş-Bolyai University in Cluj-Napoca in Romania.

She has published several expert and research papers, both as a sole contributor and as co-author. She participated in 40 conferences at home and abroad.

List of Works

Published Professional and Qualificational Papers

Tarczay, S. (2007), **Gluhosljepoća - jedinstveno oštećenje**. *Ljetopis socijalnog rada*, 2007, vol. 14, n. 1, pp. 143–152, UDK 3762/3. Zagreb : Pravni fakultet sveučilišta u Zagrebu, Studijski centar socijalnog rada

Pribanić, Lj. and Tarczay, S. (2006), **Služba prevoditelja – put do izjednačavanja mogućnosti gluhih / gluhoslijepih osoba**, *Zbornik radova međunarodnog znanstvenog i stručnog skupa Rehabilitacija – Stanje i perspektive djece s teškoćama u razvoju i osoba s invaliditetom*. Rijeka : Centar za rehabilitaciju Rijeka; pp. 284–291

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Bradarić-Jončić, S and Tarczay, S. (2004). **Sign language and education of the deaf in Croatia**. Zagreb : Faculty of Education and Rehabilitation Sciences, University of Zagreb; pp. 179–185

Tarczay, S., Pribanić, Lj. (2014): **Prevoditelji znakovnoga jezika – kako ih vide korisnici usluge prevođenja**, *Hrvatska revija za rehabilitacijska istraživanja*, 50,2 (in print)

Published Expert Individual and Collaborative Publications

Tarczay, S. et al.: (2007), **Znak po znak 3 – udžbenik za učenje hrvatskog znakovnog jezika**. Zagreb : Hrvatska udruga gluhoslijepih osoba Dodir

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