

Conducting a Demographic Survey on a Deaf Population: A Case Study



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Conducting a Demographic Survey on a Deaf Population: A Case Study

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FOREWORD

Florjan Rojba, Executive Director, Albanian National Association of the Deaf, ANAD

Our co-operation with the Finnish Association of the Deaf (FAD) started at the beginning of the 2000's, which also marks the launch of ANAD's operations. The Finnish Association of the Deaf provided us with support and guidance for running an organisation, as well as tools for strengthening our linguistic and cultural identities and empowerment as a community. We started to spread knowledge about the importance of sign language to deaf people's mental and cognitive growth among the deaf people in Albania. As deaf people, we understood that we should have the opportunity to live and function on equal terms with hearing people, however we still faced a number of obstacles in reaching this goal.

In order to work towards equality, we needed to create a policy. In 2013 ANAD began to design one, as until then we had not had any such policy because our operations were completely unorganised. The deaf community had no connections to the so-called hearing society as we lacked a common language, an opportunity for interaction. However, with determined efforts, we eventually succeeded in establishing functioning connections with the state administration.

The state administration, however, did not have information in place about the special linguistic needs of a group like us. That is why we needed research and documentation to communicate the importance of using sign language. Inkeri Lahtinen, representative of our international cooperation partner the Finnish Association of the Deaf contacted

Päivi Rainò at the Finnish Humak University of Applied Studies for this purpose, to set forth such research. We used a similar survey published in Kosovo as a starting point, which involved deaf people in carrying out the work. The survey helped to highlight the linguistic barriers that deaf people face in different interaction situations. We wished to carry out a similar survey in Albania so as to be able to communicate the actual situation among deaf people in our country to our state administration in a reliable and extensive manner. The survey described in this publication is the result of ANAD's longstanding cooperation with our cooperation partner Päivi Rainò.

Päivi Rainò, Senior Researcher, Humak University of Applied Sciences

The aim of the survey was to obtain information on the everyday life of deaf people in Albania in regard to interaction, language and inclusion, particularly in light of the articles in the Convention on the Rights of People with Disabilities concerning deaf people and sign language. We needed documentation on how deaf people interact with other people in their own living environment. What kind of education have they been able to attain, and what are their chances of employment? How do they access different kinds of information and knowledge? How do they manage handling their personal matters? We planned everything together with ANAD and representatives from the Finnish Association of the Deaf, from the survey's aims and questions, data collection methods and field work documentation, to describing and presenting the results to both the state administration and the Albanian deaf community.

To our knowledge, no such study has yet been conducted anywhere else in the world, with deaf people having been involved in carrying out a demographic study of this scale.

I am grateful to all the deaf people who contributed to this survey, to the team who travelled around Albania to collect data from 434 people, to those who guided the fieldwork team to meet deaf people in even the most remote areas, to all interviewees who gave up their time and informed the fieldwork team about their lives, as well as their families and relatives, who supported the team in many ways to help conduct the survey. This demanding multilingual study, which encompassed the whole spectrum of interaction, was only made possible by working together with all of you.

***Inkeri Lahtinen, Project Manager,
Desk Officer, Finnish Association of
the Deaf***

The Albanian government officially recognised sign language in 2014, preceded by lengthy advocacy efforts. In addition to the recognition of sign language, we needed to gain concrete research evidence to identify the barriers hindering linguistic equality: What does it mean to know sign language? What is complete or partial languagelessness? Why are the literacy and writing skills at such a low level among deaf people who have received a basic education? Based on the results, ANAD would be able to launch concrete measures to promote access to information in sign language and organise bilingual education for the deaf, interpreter training and interpreter services in Albania.

With this publication, we wish to demonstrate to national associations for the deaf operating all over the world as well as to

other key people that a qualitative and statistically valid deaf-specific study can be conducted in an inclusive manner by deaf people themselves. We also want to encourage them to collaborate with statistics authorities and advocate reliable and up-to-date research into how the linguistic rights of deaf people are being fulfilled.

Deaf communities all around the world face similar challenges and barriers in terms of implementation of the linguistic rights stated in the CRPD. The questionnaire and the concrete measures proposed by ANAD in 2015 to national authorities in Albania to mitigate the challenges and barriers identified by the survey are presented in the survey report. We hope that other Deaf communities will find the presented method and the materials useful in their own advocacy for their linguistic rights in other parts of the world as well.

INTRODUCTION

Inkeri Lahtinen

The Finnish Association of the Deaf started co-operation with the Albanian National Association of the Deaf at the beginning of the 2000's. At the time, neither deaf people nor sign language had any official status in Albania, and there were no services available in sign language. The deaf community lacked linguistic rights in all aspects.

At the beginning of the collaboration, we focused on developing the community and the Albanian National Association of the Deaf as well as inclusive research and documentation of sign language. The compilation of a dictionary roused the linguistic awareness of the deaf community. The first dictionary of Albanian sign language was published in 2005 and it also served to establish to the authorities that the form of language used among the deaf was a fully-fledged language in its own right.

Albania ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2013. At the time, Albania was also in the process of applying to become an EU member state and was required to improve the status and legislation concerning people with disabilities. As ANAD grew to be more influential as an advocate, sign language was finally officially recognised in Albania in 2014.

Two years prior to the ratification of CRPD, in 2011, the Albanian Institute of Statistics –INSTAT– had conducted a census, in which they had also collected data on the possible limitations on citizens concerning mobility, vision, hearing, cognition and communication. These were identified using questions drawn up by the "Washington Group", a working

group set up under the UN Statistical Commission.

According to the census, there were 38,000 people with some or a lot of difficulties with hearing or who were completely unable to rely on their hearing. When INSTAT added further data on people who were both "completely unable to hear" and "completely unable to communicate", the total number was 5,300 people. In the light of this data, we can conclude that the number of deaf people and/or sign language users is somewhere between these figures.

Besides quantitative data, however, qualitative information on the living conditions of deaf people was also needed.

BACKGROUND

Inkeri Lahtinen

In 2013, ANAD and FAD put forward an initiative to the Albanian Ministry of Social Welfare on conducting a statistically valid qualitative survey on the deaf population in collaboration with the Albanian Institute of Statistics. We wanted to ensure that the survey would be conducted in extensive co-operation with the authorities and that it would be carried out solely by deaf interviewers. A written survey automatically excluded respondents with weak or no reading and writing skills. Even in a survey conducted with the help of (hearing) interpreters it was not possible to fully ensure that the respondents would understand the questions or that the interpreter would understand the respondents due to varied linguistic abilities caused by different growing environments and educational backgrounds.

(There are also only three interpreters available in Albania.)

FAD had previously conducted a survey in collaboration with the Kosovar Association of the Deaf, in which the living conditions and realisation of the linguistic rights of deaf adults were examined from the perspective of the CRPD articles. Our intentions were the same with the Albanian study, but we also wanted to refine the method further. FAD drew up a plan and invited an experienced signer and researcher from the Humak University of Applied Sciences to join the study.

The aim was to map out and analyse the mechanisms that contribute to linguistic inequality through the survey questions. The results should serve to provide a basis for concrete recommendations for policies and measures to improve the situation, as well as for co-operation between different authorities to develop services in sign language (e.g. teaching, access to information and interpreting services). The need for such data produced by deaf people themselves has also been stressed by the Disability Data Advocacy Toolkit published in 2020 by the International Disability Alliance & al.:

"Lack of data can be a large obstacle in disability-inclusive policymaking and programming. Lack of data on disability also increases marginalization and failure to address the challenges and discrimination encountered by persons with disabilities. Without data, we cannot know where a country stands concerning the implementation of the rights of persons with disabilities. We are not able to show where progress has been made and, equally, we are not able to show where gaps exist. Without data, we cannot compare countries against other countries or different different districts with each other to see how they are making progress on

implementing rights. If persons with disabilities are not counted, then they don't count. As a result, effective policymaking will suffer and persons with disabilities will fall off the statistical "map." Evidence-based data on persons with disabilities at the national and global levels is instrumental in identifying the policy gaps and challenges faced by persons with disabilities that can support policymakers to address these gaps and amend existing policies and regulations."

CO-OPERATION IN PREPARING THE SURVEY

Florjan Rojba

I shall describe here how we prepared the questions for the survey along with our project partner Inkeri Lahtinen of the Finnish Association for the Deaf and researcher Päivi Rainò from Humak University of Applied Sciences. We had lengthy conversations in Finland concerning the life and status of deaf people in my country. One example was naturally my personal life experiences as a deaf citizen born and raised in Albania. I was also involved in conducting a similar but a smaller scale survey in 2003, and based on this I already had a good overview and rough sense of the overall living conditions of deaf people in our country.

We then had a closer look at a similar study conducted among the deaf community in Kosovo. We did not want to repeat the Kosovo study, however, as there are differences between our countries and their histories and contexts. At this stage, the first draft of the survey form was designed by Päivi Rainò.

But how should the survey be carried out? Should the data be collected in the field using paper forms? At Rainò's initiative, we decided to utilise the electronic survey platform provided by Webropol, where answers would be automatically saved to the Finnish server. We would thus be able to save the survey answers with the push of a button and transfer them immediately via Internet to Finland to be processed and analysed by the researcher. In more remote areas, where there may not necessarily be locally functioning electronic Internet connections, the interviewers could rely on Internet connection via USB sticks, in addition to using traditional paper forms. – We went through different scenarios for fieldwork implementation. We also discussed the first draft of the survey form, which was based on the Kosovo survey, with Rainò here in Tirana, and brought up our own suggestions and additions. We went through the form several times, considering different aspects that should be added and deleted. We also discussed the phrasing of questions with several Albanian deaf people. After that, the researcher drew up the first version of the questions.

After my return to Albania, Päivi Rainò continued the work in Finland and bounced ideas off with our deaf Finnish foreign adviser Arttu Liikamaa as well. Once we had received a new set of questions in English for review, I carefully went through each one with my interpreter, Nikoleta Spahi, and Arttu Liikamaa. She interpreted the questions into Albanian sign language, and we fine-tuned them further based on my comments. There were 47 questions in total at this point. We once again discussed the online form with Inkeri Lahtinen and Päivi Rainò, after which Nikoleta Spahi translated the questions from English into Albanian.

TRAINING THE FIELDWORK TEAM

Florjan Rojba

We translated the 48 questions included in the question set into Albanian sign language, after which they were recorded on video. I was responsible for training a team of nine people (five men and four women representing different ages), who would carry out the fieldwork. They learned the questions in sign language off by heart and memorised each corresponding piece of text in written Albanian visually.

As the representative of ANAD I prepared a five-minute video presentation in sign language to be used for data collection, in which I described the survey and how the information collected by the survey was important in promoting the interests of the deaf: we needed examples of the barriers that the deaf people interviewed face in their everyday lives and which we strived to remove on our part through the advocacy efforts of the ANAD.

During the fieldwork team training, we carefully went through the survey questions along with the aims of the survey, both displayed on video screen in Albanian sign language. We also reflected on factors that are culturally sensitive in Albania. For example, the interviewer should preferably be of the same gender and age group as the interviewee, so that the interviewer can cover age or gender-sensitive topics in-depth, and the interaction can be as smooth as possible. We also rehearsed the fieldwork in practical situations and discussed how to open the interviews, for example that the interviewer should not begin asking the questions until each participant had seen the video

presentation in Albanian Sign Language which I had prepared. After seeing the video, the respondent could then decide whether they wanted to participate in the survey or not.

We also practised meeting people from different linguistic backgrounds: how to explain the survey's aims to those who do not know sign language but use fingerspelling only, or to people whose sole methods of communication are pointing and gesticulating, for example? They should also receive an unambiguous account of the aims of the survey, even if they were unable to understand the video presentation in Albanian sign language.

The survey would be conducted in pairs, so that one of the interviewers would write down their answers and the other one would ask the questions. The questions were to be asked in the given order without any changes to the content. The other member of the team could then provide support in case anything was forgotten and help with any problems, for example entering the answers correctly. Pair work was important in many respects.

COLLABORATION WITH THE INSTITUTE OF STATISTICS

Florjan Rojba

Next, I shall describe our co-operation with our Finnish partners Inkeri Lahtinen from the Finnish Association of the Deaf and researcher Päivi Rainò from Humak University of Applied Sciences as well as the Albanian Institute of Statistics INSTAT.

As the ANAD representative, I discussed the implementation of the survey with the Albanian state administration and INSTAT. At first, the representatives of INSTAT found the idea of having the survey conducted by a field-work team of deaf people almost impossible. However, after we met and discussed things a few times, they eventually understood the importance of utilising deaf people for the survey. There are no employees within INSTAT who know sign language, and if the survey were to be carried out by them, the deaf respondents would not be able to understand the questions posed in spoken language. If the questions were presented in sign language by deaf people and communicated visually, however, they would be fully understood by the respondents, which means that the answers they would provide would also be carefully considered. It would be completely impossible for hearing people to use spoken language to conduct a survey on deaf people, in particular due to linguistic barriers.

Once we had agreed on the survey method, we went through the questions with our Finnish partners and INSTAT, who then gave their approval to the questions. We had now reached an understanding on implementation of the survey as well as the survey itself.

But how would INSTAT be able to select the people to be interviewed for the survey from their databases based on the 2011? We solved this issue by disclosing the entirety of ANAD's membership to INSTAT. Based on the membership list, they would be able to select and suggest a statistically representative sample group for each geographical area. – In earlier negotiations, we had suggested that the number of interviewees should be about a hundred people, however, the INSTAT representatives considered this too small a group in terms of representativeness and

suggested increasing the number of interviewees to 400–500 people.

It was clear to us that this would increase the time spent collecting the data and the amount of work.

After INSTAT had gone through our membership and compared it with their own database, they constituted that we should aim at interviewing 522 people, with a 25% deviation at most. We settled on aiming to reach at least 437 people. I forwarded INSTAT's suggestion to our team of nine interviewers. We went through the goals for each region once again and reviewed the survey principles and methods and the questions recorded on video and in the electronic survey form.

My cooperation with the National Institute of Statistics proved productive. It was important for them to see and understand why we need deaf people specifically to carry out this kind of research: Only the deaf themselves are able to make themselves understood as well as to understand as perfectly as possible those respondents who use sign language, as opposed to hearing researchers who use spoken language. We had now also received approval for our suggested method from the National Institute of Statistics, and so the team of interviewers could head out to the field on the mandate received from INSTAT.

PLANNING THE FIELDWORK

Florjan Rojba

Nine people set out to conduct the interviews under my supervision. How was the work organised?

The interviewers visited each of the Albanian provinces and targeted the interviews to the groups specified by the Albanian Institute of Statistics.

With the team of interviewers, we went through the tasks, the provinces and the time frame available for us, and prepared the schedule and work plan. We also decided to rotate, so that the pairs would be switched regularly (weekly) to maintain cohesion within the teams that consisted of five men and four women, representing different ages. I would be supervising the work from ANAD. We planned the duration of the trips, which were mainly due to take three to four days – the number of days depended on the distance to be travelled and the number of interviewees in each province. The fieldwork team then decided which areas they would travel to in order to maintain the rotation simultaneously. There would be a local ANAD point of contact in each province and interview site ready to meet the data collection teams, and their task would be to take the interviewers to meet ANAD members as well as any deaf people who were not members of our association. As part of my role, I took responsibility for contacting active members of ANAD, or “local leaders” living in the provinces to inform them about the survey and the date of the interviews, and to give them the contact details of the interviewers.

COMMUNICATION BETWEEN THE FIELDWORK TEAM AND THE PROJECT PARTNERS

Florjan Rojba

Our nine-person team left for the data collection trip, while I stayed in Tirana to supervise the fieldwork. We set up a WhatsApp group for keeping in touch instead of using a text-based communication tool. Work teams all sent messages to this platform to inform each other how their work was progressing. Each pair would report on the number of interviews conducted per day. They were also able to ask for advice from other pairs during the interviews, for example on problems relating to the questions, or any other issues that arose. They could take a photo to illustrate the problem, and the group could discuss it together in sign language. If the group could not find a solution, the question came to me. I could then consult INSTAT or the Finnish researcher. Our signed communication and rapid exchange of ideas with other research parties proved to work very smoothly, which was a very positive experience. My task was also to maintain contact between the fieldwork team and the local contact people and solve any problems caused by communication problems, for example.

Later, field work reports produced by the team members were also translated from sign into a written form. Two examples of signed reports can be found here below.

Jetmir Dekovi

Ilirjana Jupa and I were accompanied by someone who was familiar with the Tropoja

area. We conducted five interviews with deaf people. Three of the interviewees were men and two were women. The difficulties we faced were as follows: In one house there was nobody home, whereas in the other house we waited for a while, but the man never came. The person who accompanied us said that there were more deaf people in the area, but he did not know where they lived.

Communication with the five interviewees was varied and difficult. It took us a long time to conduct interviews because several people communicated using gestures, and we had to mimic with our hands and provide a lot of examples. I would also mention the following points: One married couple had no home, and were living without legal permission in an old house from the Communist era, and they even had children there. They told us that they watch the news on Albanian Public Television, but they did not understand the news very well because sign language was used, and they only understood finger-spelling.

Eduard Ajas

I will make a report about the interview process in the district of Fier on 7-8 February 2015. Denis Plloça and I went to Patos and Libofsha, along with a deaf person who was helping us to find the addresses of the deaf people. We interviewed ten people, five men and five women.

During the interviews we encountered some problems: For an interview with two deaf-blind brothers, our coordinator Florjan Rojba insisted that we would carry out the interview despite their condition. I asked for the permission of the family to interview the brothers, as well as the wife of one of them, who

was deaf but not blind. The couple had an adult daughter who was able to hear. At first, the family did not approve of the interview, stating that they did not want it to be publicised in the media. We explained that we were ANAD representatives, and that the interviews were made in collaboration with IN-STAT and the Ministry of Social Welfare and Youth, and that all information would be confidential. After they agreed, we conducted the interview. Communication was difficult because they were blind but I, with my long experience, managed to communicate with them using fingerspelling on the palm, and tactile signing. Fortunately one of the brothers had previously attended the deaf school and knew some sign language.

The deaf wife told us about their very difficult situation. She was looking for a job, and had asked for help from the state for her husband and brother-in-law, who stayed at home as it was impossible for them to work. Their house was old and its roof was leaking. They had not yet received any assistance from the state for their living condition.

We conducted the other interview in a remote area of Libofsha, where we interviewed a married couple. They had three boys and the youngest (eight years old) was visually impaired. They had asked for assistance from the state due to their situation. Both in Fier and Patos, the deaf people had a huge number of problems. We kept records of everything they told us.

CONCLUSIONS AND LESSONS LEARNED

Florjan Rojba

The teams worked under my supervision according to the action plan that we designed by ourselves, from 21 January until 22 February 2015. During this time, we successfully interviewed 434 deaf people in our sample quota from all around Albania.

I myself am a deaf person, and have been deaf since birth. This was the first time that I had coordinated such an extensive survey process. However, the teams were very satisfied with our communication and with the way that problems were solved using sign language. It was extremely motivating to see how we were able to quickly solve acute problems that arose in the field, whether related to the study or in more everyday matters, both by ourselves and with the help of our project partners.

The major task of translating questions into sign language from a questionnaire written in a language unknown to the interviewers was naturally challenging. But having the questionnaire on the computer in both a written language and a signed language made it possible for us to overcome this.

Finding an adequate communication method when interviewing respondents proved to be a real challenge. The interviewers had to test and apply a variety of means of facilitating communication, including Albanian Sign Language, fingerspelling, gesticulation, pointing, and different combinations of all of these methods.

The interviewers met deaf people in a variety of living conditions: some were totally isolated, some faced extreme poverty, and

others had no access to information or education. This had an emotional impact on the interviewers, who witnessed the hardships that deaf people deal with and have to overcome in their everyday lives in the provinces. This experience was an eye-opener for the interviewers, and it put the barriers and problems of their own lives into perspective. They now have a better understanding of the diversity of people's circumstances and the living conditions that the deaf population faces throughout Albania. Many members of the survey team encountered deaf-blind people for the first time in their lives. Nevertheless, they learned to communicate with them using tactile sign language. These meetings were empowering experiences for both parties.

It was also a wake-up call for many hearing family members to realise, that the deaf individuals who they considered to be "uneducated" are in fact able to self-reflect, and to see how important it would be for them to receive a better education.

It was a truly rewarding experience for me to work on this research with Inkeri Lahtinen and Päivi Rainò. In 2003, there were just two of us conducting a survey, travelling around Albania and sharing the burden of seeing the reality of the conditions that deaf people face in Albania. The results of this previous survey were also rather modest compared with our 2015 study, which I find to be qualitatively very valid. The nine deaf interviewers also learned a great deal from their work and from solving the problems that they faced along the way. They felt that they had gained a strong confidence that, regardless of the massive challenges that this kind of work brings, it is still possible to push it through successfully.

I would therefore like to express my grateful thanks to all those who participated in or furthered the study; both our Finnish partners Inkeri Lahtinen from The Finnish Association of the Deaf and Päivi Rainò from the Humak University of Applied Sciences, as well as the interpreters and translators. My special thanks go to our sign language interpreters in Albania: Nikoleta Spahi and Arttu Liikamaa, and Selman Hoti in Kosovo.

I also would like to extend sincere thanks to our nine-person team, who successfully completed the data collection and made this whole study possible. Only with the help of this type of research can the deaf community solve the problems they face in their daily lives and clearly show to administrative authorities where these issues lie, so that together, we can find solutions to achieve a higher quality of life.

I thank all of these people alongside me who participated in our research project, from the bottom of my heart.

ANALYSIS AND INTERPRETATION OF THE RESULT

Inkeri Lahtinen

The Deaf People in Albania 2015 study corroborated the linguistic deprivation and the mechanisms that produce such deprivation faced by deaf people at all stages of life.

Children born deaf or prelingually deaf are mainly born to hearing parents. In Albania, deaf children have grown almost languageless, which has had a grave effect on their opportunities for development. As their parents may not know sign language, they struggle to establish a common language with the child. Families may only be able to resort to rudimentary home signs.

The majority of the interviewees, 83%, had attended the Tirana Deaf Institute, while the rest of the interviewees had either attended a school for hearing children or been left without education altogether. At the institute for the deaf, teaching had been based on spoken language, gestures and finger-spelling. The hearing teachers did not know sign language and the children did not understand their spoken language, so there was actually no common language between the pupils and the teacher. The reading test included in the survey also showed that even amongst those deaf people who had attended basic education for 9 years, **97% were still functionally illiterate**. On the other hand, at the institute for the deaf, children were able to meet other deaf children for the first time and communicate with them in their free time in their own ways.

Due to weak literacy skills, level of knowledge and a lack of interpreting services, the deaf

had no chances of furthering their studies or becoming employed in anything other than very basic jobs. After finishing their education, in most cases the deaf youngsters had returned to their homes in different parts of Albania to a linguistically isolated life. The deaf community had only started to come together and Albanian sign language only began to emerge after ANAD had been activated with FAD's support.

The study thus showed that the interviewees had not learned sign language at school or before starting school, nor had they learned written Albanian in their basic education. They did not have sign language interpreters or bilingual people, who would know sign language, in their living environments. The deaf interviewees were not able to obtain information independently (from books, newspapers or television via subtitles, for example). Even as adults, they still had to rely on the fragmentary and unclear communication conveyed by their family members and were often also financially dependent on them.

CONCLUSIONS AND RECOMMENDATIONS, A CONCRETE ACTION PLAN

Inkeri Lahtinen

Since the study concerned only deaf adults, it was also important to gain information on the current state of education of deaf pupils. After the Deaf People in Albania 2015 study, the Albanian Ministry of Education launched a separate inquiry at the Tirana School for the Deaf at ANAD's initiative, on the languages used in teaching, as well as the learning outcomes in mathematics and the Albanian language at three different grades. ANAD participated in the study by testing the teachers' skills in sign language and analysing the learning outcomes. The inquiry revealed that the teaching method remained the same, and the teachers did not know sign language (except for one person, who also worked at ANAD). The school employed a heavily simplified curriculum, where learning aims had been lowered compared with those in mainstream education. Also, the grades on the graduation diplomas did not reflect the actual learning outcomes in comparison with those in mainstream education.

In addition to the survey results, the Deaf People in Albania 2015 survey report analysed the conformity of Albanian legislation with the obligations stated in the CRPD (regarding deaf people and sign language). While the fulfilment of rights regarding social welfare was not included in the survey as such, the interview reports showed that deaf adults were not considered legally eligible for disability benefits and services.

The most important part of the report was to draw up a concrete action plan regarding each theme included in the study, describing both short-term and long-term measures to be implemented in order to fulfil the rights of deaf people and use of sign language, in terms of the needs that arise at each stage of a deaf person's life (these stages being early intervention, basic education, upper secondary and higher education, employment, and access to information and interpreting services). These were also intended to serve as the framework of ANAD's future scheme for advocating the interests of deaf people.

By the time of this publication (2021), ANAD has been able to have an impact on various aspects of Albanian legislation. For example, the right to receive an education via sign language has been stated in the law regarding basic education, and sign language has been included as a subject in the curriculum of the institute for the deaf. The implementation of these statutes requires changes to teacher training, however, which is difficult. But vocational training for deaf sign language instructors is on the cusp of being launched, and the law on interpreting services is waiting to be approved. The task of promoting the linguistic rights of deaf people is a continuous and demanding process of co-operation with the authorities.

BIBLIOGRAPHY

Ferré, C., Galanxhi, E. & Dhono, O. 2015. Profile of the Disabled population in Albania. United Nations' Support to Social Inclusion in Albania Programme. Tirana: Institute of Statistics & Ministria e Mirëenies Social dhe Rinisë & United Nations Development Programme in Albania. <http://www.al.undp.org/content/albania/en/home/library/profile-of-the-disabled-population-in-albania.html> [accessed on 14 November 2021].

Kosovar Association of the Deaf & Finnish Association of the Deaf. 2010. Report of the status of Deaf people in Republic of Kosovo. <https://www.shksh.org/wp-content/uploads/2018/11/Raport-i-statusit-te%CC%88-personavete%CC%88-Shurdhe%CC%88-ri%CC%88-Republike%CC%88n-e-Kosove%CC%88s.pdf> [accessed on 14 November 2021].

Lahtinen, I., & Rainò, P. (Eds.). (2016). *Deaf people in Albania in 2015. A survey study*. Helsinki: Finnish Association of the Deaf. <http://urn.fi/URN:NBN:fi-fe2020061242912>

Lahtinen, I., & Rainò, P. (Red.). (2016). *Personat që nuk dëgjojnë në Shqipëri, 2015. Studim*. Helsinki: Finnish Association of the Deaf. <http://urn.fi/URN:NBN:fi-fe2020061242915>

Stakeholder Group of Persons with Disabilities, the International Disability Alliance, & CBM Global Disability Inclusion. (2020). Disability Data Advocacy toolkit. Author. <https://cbm-global.org/news/disability-data-toolkit/>

United Nations. (No date). Convention on the Rights of Persons with Disabilities (CRPD). UN Department of Economic and social Affairs; Disability. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

Washington Group on Disability Statistics. (2021). <https://www.washingtongroup-disability.com/>.

Washington Group on Disability Statistics. (2021). WG Short Set on Functioning (WG-SS). <https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/>