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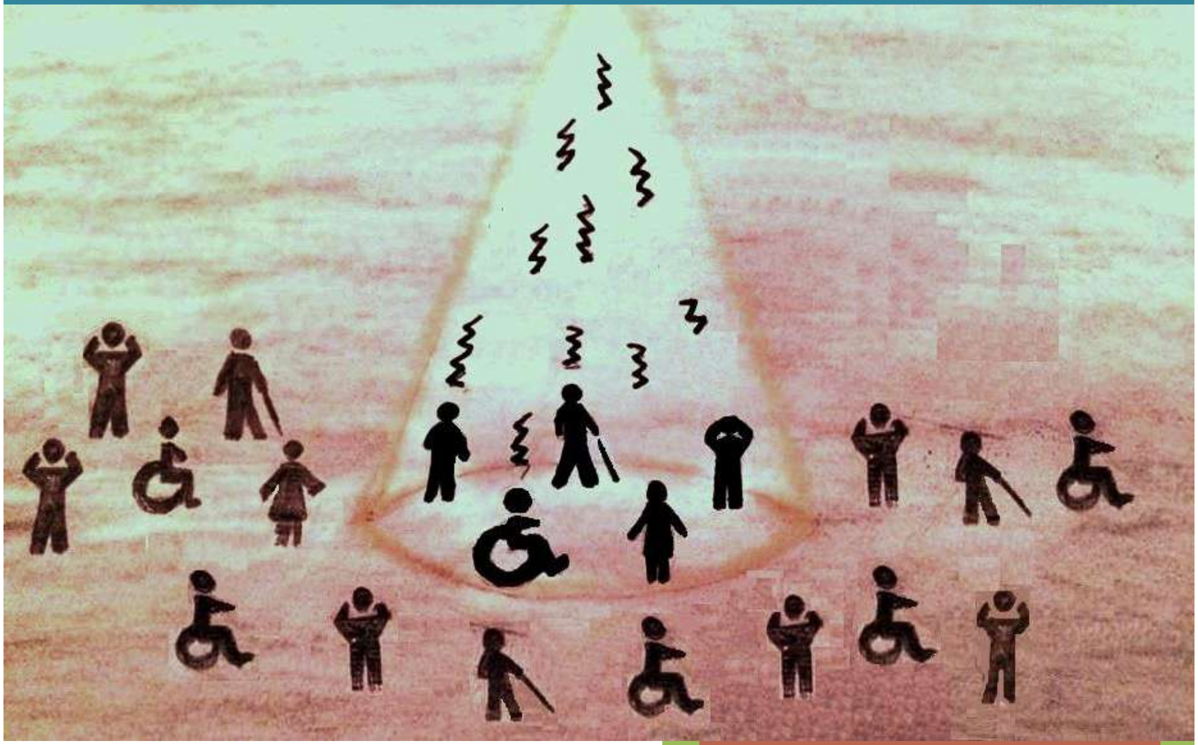
# Understanding the Situation of Children with Disabilities in Kosovo through Their Own Voice



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Shoqata e të Verbërve të Kosovës
Kosova Association of the Blind
Udruzenje Slepih Kosova

Forumi Kosovar i Aftësisë së Kufizuar
Kosovski Forum Invalidnosti
Kosovo Disability Forum

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## Abbreviations

KDF – Kosovo Disability Forum

DPO – Disability Persons Organization

ChwDs- Children with Disabilities

PwDs- Persons with Disabilities

UNICEF - United Nations Children's Fund

CRPD – Convention for the Rights of Persons with Disability

WHO – World Health Organization

## Abstract

The purpose of the current research is to generate data and impressions from children with disabilities in Kosovo in order to get a deeper understanding for their general situation and daily life in our country. Data were collected qualitatively through semi-structured interviews. In total 10 children with disabilities participated in the research; out of which 6 girls and 4 boys. Participant's age varied from 7 to 17 years old, representing three types of disabilities: physical, sensory and intellectual disability. The main findings of the research are the following: Children with disabilities are active interpreters of their personal experiences; Children with disabilities develop positive self-perception when their interactions rely only in family bases; Children with disabilities, develop negative self-perception when their social interactions rely beyond the family. Parents tend to develop inappropriate supportive strategies towards their children with disabilities; Children with disabilities face access difficulties; Mainly, children with disabilities hold non-positive perception towards school; Violence is not reported to be a common phenomenon among participants of the research; The current research has its limits; however, future advanced methodologies are recommended to be designed in purpose of generating more objective results.

Key words: Children with Disabilities; Barriers; Challenges; Self-Perception; Family; Education; Physical Access; Access on Information; Violence.

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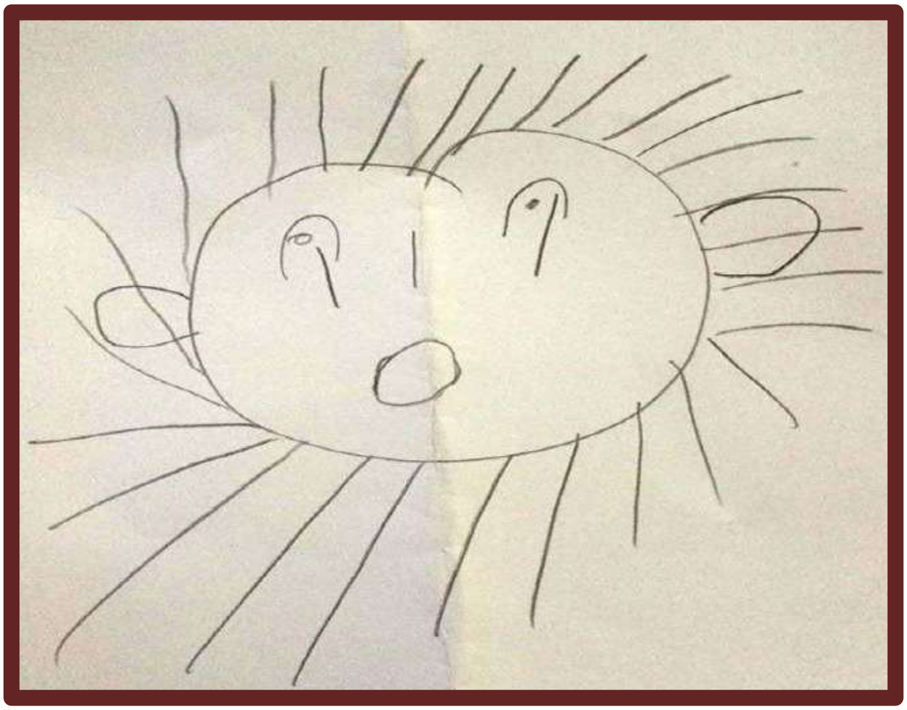
# Introduction



*(Pictured by a child with disability)*

*Because of the communication difficulties, a child with disability was unable to respond to the questions for Self-perception. Therefore, the child was asked to picture his self. He started smoothly… picturing and associating each move with hardly articulated words: "face… eyes… noose…mouth…hairs…" and just as this naturally "…tears..."*

*Why should tears be a natural part of self-conception of a child with disability?*

***If all people in the world would be listening to you right now, what would you ask them to do for you and other children like you?***

***"To learn some of our language"***

The voice of children with disabilities has been widely ignored in the field of researches. Numerous studies and analysis in regard to the situation of children with disabilities has been conducted in the regional and international level;  although, only few of them followed the child-centered approach. Usually researchers have been oriented in the perspective of parents or teachers of children with disabilities rather than in their direct perspective. However, recently growing body literature suggests that children with disabilities should be closely consulted when trying to analyze their situation. Their voice within a research is valuable, useful and shows us vividly what means to be a child with disabilities in our society.

As Davis (1998) suggested, UN Convention on Rights of Children acknowledges "that children have the right to express their opinions for the issues affecting them", regardless of "any kind irrespective of race, color, language, religion, national, ethnic or social origin, disability or other status" (Lewis & Lindsay, 2000). Therefore, children with disabilities should not be excluded from the researches that analyze issues who directly impact them and their situation. Consulting directly children with disabilities might not be an easy process, considering the eventual lack of communication or cognitive abilities; even though, it should not be considered as impracticable. Appropriate mechanisms should be designed in purpose of obtaining children's voice within a research (Dickinson, 2004).

The current research follows a completely child-centered approach and aims to initiate further studies and researches which analyze the situation of children with disabilities in Kosovo. The literature concerning the situation of children with disabilities in our country is deeply limited; albeit, even the actual research is unable to present a completed picture of such situation in the actual context. However, it might serve as a useful starting point for emphasizing the significance of such researches in Kosovo, and also for initiating future ones. Findings of this research should not be considered as incontestable or absolute; instead, advanced methodologies should be designed in the future, on purpose of generating more objective and generalized results.

## Definition

According to UNICEF (2013), nearly 93 million children in the world under the age of 14, live with some kind of disability; enough to make their daily functioning harder. Even though, in the same report UNICEF (2013), puts in question the reliability of these data, considering the fact that the meaning of the term “disability” differs from place to place. According to the Convention on the Rights of Persons with Disabilities (CRPD), these latter are defined as “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’’. In the other hand, World Health Organization (2011), segregates five types of disability, such as the following: 1) Physical Disability, 2) Sensory Disability, 3) Intellectual Disability, 4) Emotional and Mental Health Disability, 5) Developmental Disability.

## Literature review

“Challenge” is the most correlative word with the position of children with disabilities in the world. Historically, children with disabilities faced social stigma, stereotypes and prejudices. Every day, we walk nearby children with disabilities, and usually we tend to ignore their needs concerns and barriers. Just recently, society at large has started to accept its responsibilities towards children with disabilities. However, the situation of these latter continues to be truly unfavorable. People with disabilities and especially children are often excluded from all parameters of social functioning. Children with disabilities face difficulties to adapt within the family, school and beyond, and society should pay close attention to such difficulties.

## Adapting within the family

When a child with disability is born, everything in the family begins unusually. Parents, siblings and the community at large, tend to develop an exceptional emotional respond towards the new member. Parents face the challenge of accepting and adapting to the situation. In the very beginning they may develop feelings of stress, anger or disappointment (Kandel & Merrick, 2003). The birth of a child with disability can be considered as a traumatic event for the family, and especially for parents (O'Neill, 2005). Therefore, obviously that is not the best "welcome in the family" to be received at the beginning of the child's life.

As Gilding (1991) suggests, usually parents are the experts in regard to the issues concerning their children. In contrast, when talking about parents of children with disabilities, numerous studies have found that these latter's views are not completely accepted (Case, 2000). Numerous programs have been developed widely, in purpose of supporting parents of children with disabilities, so they will be able to play an active role in the process of their children's integration (Kaczmareck, 2006).  However, these programs have had a limited use and only few parents of children with disabilities had the opportunity to benefit. Therefore, we can understand that the situation of children with disabilities might not be properly addressed, starting from the fundamental environment of the child's development – family.

In Kosovo, has been approved the Law No. 03 / L-022 on Material Support for Families of Children with Permanent Disabilities; which aims to facilitate the financial difficulties of the families of these latter. The aforementioned, is the only applicable Law in Kosovo concerning with the situation of the families of children with disabilities. However, as it is afore described, families of children with disabilities need much more than the financial support. Besides, they need to benefit from special programs that help them internalize best parenting approaches towards their children with disabilities. Consequently, these latter would face fewer difficulties while adapting in the family; and surely, also in the society at large in the long terms.

## Adapting within the school

After the family, school is the second environment when children develop their personal and social abilities. Numerous studies widely, have tried to compare different educational systems for children with disabilities. The aim of such comparisons is to understand advantages and disadvantages of such educational systems and suggest their implementation, depending on what they consider adequate. On the one hand “Inclusion is the philosophy that urges schools, neighborhoods, and communities to welcome and value everyone, regardless of differences. Central to the philosophy of inclusion are the beliefs that everyone belongs, diversity is valued, and we can all learn from each other" (Renzaglia, Karvonen, Drasgow & Stoxen, 2003). Inclusion is a juvenile education system comparing to the special one and in most cases, the overall impression of parents and teachers had initially been negative. Prerequisites exist to think that in inclusive classrooms, teachers would lose a great deal of time with children with disabilities, what would lead to non-qualitative education for other children. However, numerous studies have shown that these conclusions do not stand. Inclusive classrooms do not harm other children; instead, they have their obvious advantages comparing with special education system (Staub & Peck, 1995).

On the other hand, inclusive education has its positive impact also in the academic performance of children with disabilities. Moreover, findings indicate that inclusive education system demonstrated to have a positive impact in the overall development of social skills and self-esteem of a child with disability. According to Wagner, Newman, Cameto and Levine

(2006), the more time children with disabilities spend in the classroom, the more positive behaviors they will generate. Moreover, academic results and chances of getting employed after finishing school are increased for children with disabilities who followed inclusive education.

However, in order to make the inclusion work, there are some conditions that should be met and fulfilled. According to National Education Association (1992), the following are some prerequisites that make the inclusion work: "Regular teachers, special education teachers, and other specialists collaborate (e.g., co-teaching,); Teachers have the knowledge and skills needed to select and adapt curricula and instructional methods according to individual student needs; A variety of instructional arrangements are available; Appropriate policies and procedures for monitoring individual student progress, including grading and testing, are in place etc." However, the applicability of such conditions in the educative system is usually limited, since it requires budget implications which are often un-available. Therefore, children with disabilities continue to face their challenges of adapting within school environment.

## Methodology

### Participants

In total, 10 children with disabilities participated in the research, out of which 6 girls and 4 boys. Age of the participants varied from 7- 17 years old. It was noticed that besides the communication difficulties that some of the participants had, they all tried to actively express their experiences. Demographic features of all the participants are independently described in the following table:

| Participants | Disability | Age | Gender |
|---|---|---|---|
| 1 | Visually impaired | 12 | Girl |
| 2 | Visually impaired | 10 | Boy |
| 3 | Blind | 13 | Girl |

| | | | |
|---|---|---|---|
| 4 | Blind | 10 | Boy |
| 5 | Paraplegic | 15 | Girl |
| 6 | Paraplegic | 8 | Boy |
| 7 | Deaf | 7 | Girl |
| 8 | Autistic | 7 | Boy |
| 9 | Down Syndrome | 8 | Girl |
| 10 | Down Syndrome | 17 | Girl |

## Instrument

Data were collected through semi structured interviews which contained in total 25 open and closed questions. During the interviews, also other questions were applied accordingly to the context of interviews. The aim of the questions was to generate data from the perspective of the children with disabilities in regard to their situation and daily-functioning. Basic questions were uniform for all participants, while specific question were made depending on the course of the interviews and the individuality of the participants. Participants were asked to answer questions like: “what makes you different from others?’’ or ‘’what do you mostly like on school?’’ etc. in order to generate wide responses from first-hand experience. The interviews were foreseen to last approximately 30 minutes; even though, the shortest one lasted 15 minutes; while the longest one 40 minutes.

## Procedure

Initially, the instrument was formulated with questions relevant with the main objective of the research. Afterwards “Parental Permission for Child’s Participations in the Research’’ was drafted with the relevant information and instructions. Each parent was asked to read carefully the document and to sign it, in order to confirm their permission for the child’s participation on the research.

Secondly, the participants were identified with the help of Local Disability Person Organizations (DPO), member associations of Kosovo Disability Forum who provided the contacts. Parents of children with disabilities were contacted in order to inform them for the purpose of the research and also to arrange a meeting for the interviews. In general, parents had an open approach towards the idea of the research and expressed willingness to cooperate.

Interviews were held in different places such as: children’s home, schools or DPO’s offices. External factors during the interviews were carefully controlled and the interviews were made in appropriate conditions. All the interviews were conducted from the authorized administrators, excluding the cases when the help of an external assistant was necessary to generate data such as the case of a sign language interpreter or teacher assistant. These latter facilitated the process of the interviews which finished in total within a period of two weeks.

All the interviews were audio recorded. Once the process of the interviews was finished, demographic data of the participants were replaced with pseudonym codes. Afterwards, interviews were verbatim transcribed. Each transcript was closely consulted with the aim of identifying the themes which came out of the interviews. The themes that emerged are as following: Self Perception; General Mood; Intrapersonal Relations; Violence; Physical Access; Access on Information; School Perception and The Future. Once the themes were defined, each transcript was consulted with the aim of analyzing the data in terms of the identified themes. Subsequently, based on the participants reports, summarized result of the research were determined and discussed independently in the Discussion Section of this research paper.

## Design

Data were collected qualitatively, which is considered as a Phenomenological Approach and relies in the framework of Descriptive Studies. This research methodology is well known in Social Sciences, because it enables to get a deeper comprehending for a specified issue. Qualitative design was considered as the most appropriate form to achieve the research's objectives. Furthermore, this design allows identifying the most significant themes or topics for the participants, giving this way, a much crystalized picture of what they consider important and actual.

The participants were selected in collaboration with Member Associations of Kosovo Disability Forum. Such associations have access on the contacts of families of children with disabilities. Therefore, "Criteria Sampling" was chosen as a method for recruiting the participants. Criteria for selecting the participants were as following: The participant should have a type of disability; the participant's age can vary from 5 to 18; the participant should be resident of the Republic of Kosovo. It is important to emphasize that the results of the research can be considered representative only for the actual sample. Therefore, the findings should not be generalized among all children with disabilities in Kosovo. The aim of the research is to provide deep comprehending for the situation of children with disabilities in Kosovo, including their needs, barriers and challenges, and consequently to understand their situation.

## Ethical Considerations

Since the participants belonged to the minor age, parental permission for child's participation in the research was asked initially. On the one hand, parents and children were ensured for the confidentiality of the data obtained in the interviews and for the fact that their privacy will remain anonymous. The research was designed in a way that no psychological or physical harm was caused to the participants. Moreover, the questions were also controlled on terms of ethical consideration.

## Results

The current research generated data correlating with eight independent variables (themes) such as: Self Perception; General Mood; Intrapersonal Relations; Violence; Physical Access; Access on Information; School Perception and The Future. Such themes emerged after analyzing the transcribed interviews of each participant. Through such themes, the current research tends to assess and understand the general situation of children with disabilities in Kosovo through their own voice and perspective. Each of the themes will be presented with the corresponding data in the current section of the research; while summarized results are discussed in the Discussion Section.

### Self- Perception

The variable of self-perception was measured with the questions such as following: “What makes you different from others?”; “Are you happy with your life?”; “Do you like who you are?”; “If you would change something in yourself, what would it be?”; “What qualities do you think you have?” Some of the questions were designed priory; while some others were applied depending on the course of interviews. Based on the data generated from the interviews, different levels of self- perception were found among the participants. Mainly, children with disabilities expressed to have non-positive self-perception. In total 7 out of 10 children with disabilities reported to have non-positive self-perception while only 3 reported to have positive self– perception. For illustration, positive self-perception was expressed through the sentences such as the following: “Yes I like myself” or “I would change …nothing”. While on the other hand, non-positive self-perceptions was expressed through the following expressions: "I don't see, other people see, that is bad for me"; "I would change… to see"; "Since from the moment that I could not walk, I am not happy"; "I don't like who I am that much, I would like to be like others, able to walk and play"; "I don't know if I have good qualities or not…I know that I mess things up"; "I am different because I play, but not like others, I play with a ball with a bell; not football, because I am blind".

## General Mood

The variable of General Mood was measured with questions such as: "Are you happy with your life?"; "What is your mood in general?"; "Are you more happy or unhappy?" On the one hand, positive General Mood was expressed through the following sentences "Yes, I am happy with my life"; "I am more happy than unhappy"; "There are times when I am happy. But there are times when I get in trouble". On the other hand non- positive mood was expressed through the following sentences "I usually get bored"; "I am always complaining because I cannot play like my siblings"; "I stay alone most of the time, bored"; "I feel I am isolated".

## Interpersonal Relations

The variable of Interpersonal Relations was measured through different questions correlating with the following themes: Interpersonal relations with parents / siblings / friends/ teachers.

**Interpersonal relations with parents** - was measured through questions like: "How much time do you spent with your parents?"; "Do you feel like your parents are proud of you?"; "Do you feel like they support you?"; "Do you think your parents understand you?" Findings in general, show that children percept their intrapersonal relations with parents as positive. In this regard, participants expressed the following: "My mother supports me a lot, she said that I will be better”; “My dad usually tells me: Don’t worry- God took away the eyes from you and God will bring them back”; “My dad always told me: Once you are 15 you will have that intervention and I am sure you will walk again”; “ My mother is always worried for me – she can’t stop looking after me”; “Parents are my biggest support”; “ My mother feeds me and wears me, without me having to ask it”; “For everything, I have the help of my parents, I can’t do nothing without them; “I get all the information from my parents and family”

**Interpersonal relations with siblings** – was measured through questions like “How much time do you spent with your siblings?”; “What kind of problems do you have with your siblings, if any?”; “Do you feel you are a good sibling?” Positive interpersonal relations with siblings were reported among children with disabilities. Participants responded as following: “I do not have problems with my sister and brothers”; “I play with them”; “I would like to go to school with my twins, but I have a different school”; “They try to help me on my homework but they can’t since I use Braille and they do not know Braille”; “They play with me, and we sometimes get in trouble together”; “Me and my brother, mess our house and our parents get nervous”.

**Interpersonal relations with friends** – was measured through questions like: “How easy is for you to make friends?”; “With whom do you play?”; “Do you enjoy the time spent with your classmates?” Participants’ responses varied in regard to the interpersonal relations with friends. Children who attend special schools answered to have good relations with their classmates; even though they reported to not have other friends except classmates. In this regards, children expressed the following: “I play a lot with my friends”; “I have friends in my class and in my school”. On the other hand children who attend regular schools, responded as following: “I have friends but I don’t play with them”; “My friends visit me, but we don’t go out together”; “My friends hang out without me”; “We are not the same”; “I can’t play football with them, but I would like to”; “I don’t have friends at all”; “My friends like to play with each other more than with me". Children with disabilities reported to have friends; even though, special attention should be given while interpreting these reports; because, as studies suggest the term "friends" for children with disabilities may be based in other settings comparing from typically developing children (Evans, et al., 1992; Locke, Ishijima, Kasari, & London, 2010). Often they might concept "a friend" as a person who is just physically close or in the same environment; instead of, relying in the reciprocity, cooperation or trustfulness (Kuo, et al., 2011).

**Interpersonal relations with teachers** - were measured through the following questions: "Do you think that your teachers are satisfied with you?"; "Do you feel like your teacher likes you?"; "Does your teacher try to defend you?"; "Do you feel like teachers support you?". In regard to the actual variable participants responded as following: "My teacher stays with me during the half-breaks, since I do not have friends in the class"; "I don't know if my teacher likes me or not"; "I don't know, maybe not, I mess up things often"; "Yes, I think she likes me"; "We are a lot of children in the class, she does not have only me, maybe she likes us all".

## Violence

Violence was measured through questions "Do you ever make mistakes?"; "What do your parents do when you make mistakes?"; "Do they ever punish you, and how?"; "Did you ever forgot to do your homework; how did the teacher react?"; "Does your teacher ever punish you"; "Do you feel like other children bully you?"; "Do you siblings or friends make fun of you?". None of the participants reported to experience any kind of direct violence from their parents, siblings, teachers or friends. Participants responded through the following expressions: "No, my parents never punish me"; "My teacher forgives me when I do not do the homework, he does not punish me"; "My classmates don't bully me; but I get scared when I see them fighting with each other"; "My siblings never disturb me". From the responds, it can be noticed that direct violence is not a common phenomenon among children who participated in the research.

The sample of the research is not representative; therefore, we cannot conclude that violence is not a common phenomenon for all children with disabilities in Kosovo.

## Physical Access

One of the main problematic issues in regard to children with disability especially to children in the wheelchair and blind ones is Physical Access in the environment. Among other questions, this variable was measured also through the following “Do you like visiting places?”; “With whom do you usually go out and why?”; “What would you change in your city or school?” The answers, derived as the following: “I always go out with someone from my family”; “Even in school I go with my father; he helps me to climb the stairs and then takes my wheelchair up in my class”; “I would like to have an elevator in school so I could go alone in my class and back”; “I don’t go out very often”.

## Access on Information

Among others, access on information emerged as a theme from the interviews. “Do you read books?”; “Do you use the computer or the phone?”; “How do you communicate with other people?” were some of the questions who emerged answers related with the access on information of children with disabilities. Answers of these latter varied and non–surprisingly access on information was found to be a difficulty for deaf, blind and visually impaired children “ I read books in Braille, but I don’t have a lot of books, and Braille is difficult for me” ; “My sister or brother sometimes reads me fairytales”; “ I use sometimes my brother’s IPhone, he has the voice within it”; “ When I was not blind, I used to play on the phone, now I play the games by heart because I remember what should I press in the phone”; “ I get all the information from my parents because no one else speaks my language"; "I ask my parents for the things that I see but don't understand".

## School Perception

Among other questions, School Perception was also another variable of interest. "Do you like school?"; "What do you mostly like in school?"; "What you don't usually like in school?"; "What would you like to change in your school?" were some of the questions measuring the variable of School Perception. Participants' responses show that their general perception towards school is negative. "I don't go to school; I can't climb the stairs"; "My father helps me go to my classroom in the second floor, and he also comes to get me when the classes are over. But during the pauses, everyone gets out and I can't, my father can't stay in my school all day"; "I don't like to go in a different school from my siblings. At their school, teacher does not know Braille. Therefore, I have to go at my school where teacher knows Braille"; "I don't want to go in a special school, because it is so far from family, and I want to stay with my parents and twins"; "School is so hard"; "I can't learn"; "Braille machine is too hard for me to carry on every day from my home to school"; "I am the only pupil in my classroom and I cannot communicate with other children in school, since no one knows sign language".

## The Future

Apart of the actual situation of children with disabilities, some questions of the interviews were related to the children's perceptions toward their own future. "What is your biggest wish for the future?"; "How do you see yourself in the future?" were some of the questions measuring this variable. "To see" and "To walk again" were two of the most significant answers of the participants. On the other hand, the rest of the participants were unable to answer such question. They remained silent or expressed as "I don't know".

## Message for the world

In the end of the interviews all the participants were asked to answer the following question “If all the people in the world would be listening to you right now, what would you ask them to do for you and other children like you?.” This question was applied in purpose of understanding the biggest concerns that children percept as able to be changed by the society. Only few of the participants were able to respond to this question. Most of them were unprepared for an eventual respond; therefore, they expressed like “I don’t know”; “No idea for that” or they remained silent. While two of the participants, asked to answer the same question, replied as following: “to learn some of our language” and “to like us”.

## Summarized Results

Accordingly to the data generated from the interviews, based completely in the reports of personal experiences of children with disabilities, the following are the summarized results of the research:

- Children with disabilities are active interpreters of their personal experiences.
- Children with disabilities develop positive self-perception when their interactions rely only in family
- Children with disabilities, develop negative self-perception when their social interactions rely beyond the family
- Parents tend to develop inappropriate supportive strategies towards their children with disabilities
- Children with disabilities face access difficulties
- Mainly, children with disabilities hold non-positive perception towards school
- Violence is not reported to be a common phenomenon among participants of the research.

## Discussion

While in the Results Section, the findings of the research were only presented; the actual sections aims to interpret and discuss such findings. The summarized results that emerged from the identified variables in the interviews are discussed below, independently.

### Children with Disabilities are active interpreters of their experiences

Even though, a special approach is required when interviewing children with disabilities; it is important to emphasize that significant data can be generated and children with disabilities can interpret actively their experiences. Children with disabilities just like other children may feel shyness as a "hesitation when faced with an unfamiliar situation" (Coplan and Armer, 2007). Similarly, the process of interviewing may cause them feelings of discomfort. Therefore, the interviewer should have previous knowledge on the possible factors that may influence negatively the communication of a child. Consequently, the researcher should develop appropriate techniques to help the child overcome the feeling of discomfort. Creating a prior functional and empathic relation with a child with disabilities might be a complex process; although, it contributes directly in the data generated from the interviews. Special attention was given to this specific dimension of the interviewing process in the current research. Therefore, it can be considered that no major problems were faced during the interviewing process and children with disabilities provided significant data regarding to their perspective and experience.

### Correlation between the Dimension of Social Interactions and Self Perception

Based on the reports of the interviews, it was noticed that self-perception of children with disabilities varies. Therefore, specific attention was given to the possible factors that may influence these differences. Data indicated that children with disabilities, whose social interactions are based on their families, develop positive self-perception; while, children with disabilities whose social interaction rely beyond the family bases tend to develop negative self-perception.

Children with disabilities develop positive self-perception when their interactions rely only in the family bases. Interpreting the above statement, it can be implied that in such cases children with disabilities did not faced situations where they were perceived as inferior by the society, since most of the time they were accompanied only by family members who usually (as reported) support them and do not highlight their differences . On the other hand, children with disabilities, develop negative self- perceptions when their social interactions rely beyond the family bases.As the opposite of the above summarized result, when children with disabilities have a broader interaction with different groups within the community they live, they tend to develop negative self-perception. These findings imply that in such cases children with disabilities are faced with social stigma, stereotypes and prejudices which directly impact their self-perception and mislead them towards the feeling of "not-belonging" to the community.

***"My friends like to play with each other more than with me"***

There are different beliefs in regard to the correlation between disability and self-perception. Numerous researches were conducted widely in purpose of shedding light and analyzing this issue. However, the conclusions deriving from such researches, not always matched. According to a study of Chapman (1998), evidence was found that students with disability developed a higher self-perception when placed in non-academic areas. Further, segregated placements were associated with more positive self-perception among children with disabilities. These findings might be considered in line with the results of the current research; which, might be used as a hypothesis for future testing. Future researches may asses the correlation of the following independent variables "family based interactions" and "positive self-perception” of children with disabilities, in purpose of further understanding such issue.

### Inappropriate parental supportive strategies

Based on the data generated in the current research; in cases, parents use inappropriate supporting strategies towards their children with disabilities. Findings showed that parents use the following inappropriate mechanisms in purpose of supporting their children with disabilities:

> ***“My dad always told me: Once you are 15 you will have that intervention and I am sure you will walk again”***

**Disability as not permanent** - Accordingly to children’s responds, parent tend to make them believe that their disability is not permanent and they will improve in time. This kind of approach might increase the feelings of disappointment in long terms among children with disabilities. Consequently, children will not orient their mechanisms toward accepting themselves and adapting to their situation. Children with disabilities, will percept their condition as “something to be changed” instead of developing strategies to get used with it. In this regards, children will tend to develop hopes and expectations towards their future which may contribute on deeper disappointment for their actual situation.  Parents should try to use a complete different supportive approach towards their children with disabilities. Instead of giving them hopes that their condition will improve on time, parents should help their children internalize that their disability does not define them. Moreover, children should be encouraged to use their potential and perform at the best of their abilities despite their eventual limitations.

> ***“My dad usually tells me: Don’t worry- God took away the eyes from you and God will bring them back”***

**Overprotection**- Children reported to get lots of attention from their parents, especially from mothers. According to their responses, mothers tend to show their support through helping them with their daily barriers and challenges even without "having to ask". Such approach does not promote child's independence and actually generates more problems than it appears to solve. Independent skills are highly significant for all children and especially for those with disabilities, taking into account the fact that these latter are more likely to suffer from social exclusion, stigma and prejudices. As researches show (Craft, 2011; Quinn, 2016), parental overprotection correlates with underprepared children.

***"My mother feeds me and wears me, without me having to ask"***

## Children with disabilities face access difficulties

Two of the biggest challenges of children with disabilities can be determined as Physical Access and Access on Information. Such challenges are not uniform for all children with disabilities; instead, they differ dependently on the type of disability.

**Access on information** - is a particular challenge for deaf and blind children. Based on the information generated from the interview with the deaf child, it was implied that he faced problems on accessing significant information. Communication was not possible without the help of the family members which knew sign language.

***"I am the only pupil in my classroom and I cannot communicate with other children in school, since no one knows sign language"***

While for the blind child, access on standard writing books was impossible. Books in Braille, as the only alternative writing for blind individuals, was reported to be "lacking" and "difficult".

However, deaf children as well as blind ones are not born with the knowledge to use “sign language” or “Braille literacy” respectively. Both of these alternative settings should be toughed for these children, just like normal language and literacy for all other children in the world. Therefore, concrete steps should be taken in order to create teaching opportunities for all deaf and blind children in Kosovo so they would continuously benefit from “Braille literacy” and “Sing Language” special services.

***“I read books in Braille, but I don’t have a lot of books, and Braille is difficult for me”***

**Psychical Access** - is a particular challenge for blind and children in the wheelchair. These latter, report to be always accompanied by family members, in order have a facilitated physical access. Especially, physical access was reported to be a problem in school environment because of the lack of ramps and elevators. Moreover, based on the children’s reports, the problem with the physical access is one of the main reasons why they tend to develop negative perception towards school.

***“My father helps me go to my classroom in the second floor, and he also comes to get me when the classes are over. But during the pauses, everyone gets out and I can’t, my father can’t stay in my school all day”***

**Non-positive perception towards school**- Negative attitudes towards school emerged from the majority of the reports of the participants in the current research.

***“I don’t want to go to the special school, because it is so far from my family, and I want to stay with my parents and twins”***

Even though, in general children with disabilities reported to have non-positive perception towards school, it was implied that these attitudes are more related with "situational factors" within school, than directly with teachers, peers or education curricula. The following points illustrate these "situational factors":

- facing daily problems in accessing their classroom
- not attending school at all because of the lack of physical access
- being unsatisfied for attending school separately from their siblings
- being unsatisfied for attending a school far from their family
- facing difficulties while transferring physically the Braille machine from school to home and vice versa.
- being the only pupil in the classroom
- feeling disappointed for not having a peer who understands sing language
- feeling alone in the school environment

> ***"I don't like to go in a different school from my twins. At their school, the teacher does not know Braille. Therefore, I have to go at my school where teacher knows Braille"***

## Violence as not common phenomenon

Participants have not reported to experience direct violence in their daily functioning. However, it is important to point out that violence is a complex phenomenon extended in numerous dimensions; which are not always easy to define. According to World Health Organization, Violence is defined as the "intentional use of physical force or power, threatened or actual, against oneself, another person, or against a group or community, which either results in or has a high likelihood of resulting in injury, death, psychological harm, maldevelopment, or deprivation". Semi-structured interview contained only few questions regarding violence and could not generate satisfactory data on this regard. Since violence is a complex phenomenon, it is usually measured independently from other variables. In the current research, violence was measured among numerous other variables; what made it difficult to generate in depth data in regard to this phenomenon.

***"My teacher forgives me when I do not do the homework, he does not punish me"***

## Study Limits

In principle, all research methodologies have their strengths and weaknesses, advantages and disadvantages; although, in practice they all do find implementation. The methodology of a research is usually chosen accordingly to the main objectives set initially. In the actual research, qualitative design was chosen with the aim of collecting data and enabling a deeper understanding of the situation of children with disabilities in Kosovo.

**Lack of Similar Studies** - The first limit of the actual study is a consequence of the lack of similar studies in Kosovo. Researches or analysis regarding to the situation of children with disabilities in Kosovo are limited; therefore, the actual research finds it difficult to create a crystalized picture of the issue. In lack of satisfactory number of previous researches in this field, the actual research could not generate new hypothesis; therefore, its methodology was imposed. Consequently, qualitative design was chosen for data collection in the actual research, since it provides an illuminative approach towards non-straighten out issues.

**Non Representative Sample** - On the other hand, when using descriptive design on the research, the number of participants is usually lower comparing to quantitative studies. In the actual research also, low number of participants implies that the sample is not representative for the target group; therefore, the findings cannot be generalized. Although, it can be considered that the primary steps towards enlightening the issue has been taken. From the critics' point of view, qualitative design is also a good starting point, since it leads us to different topics which enable a deeper understanding of the situation and also generates new ideas or hypothesis for next studies. Although, future research on this field should aim to provide a larger number of the participants; a representative sample, so the data can be generalized. Moreover, another limit of the research can be considered the fact that not all types of disabilities were represented in the sample. Developmental Disability and Mental Disability were two types of disability which are not included in the sample of the actual research. This limit is due to lack of data of the children with such disabilities. Future research should try to include participants with such disabilities with the aim of providing a more representative sample for the target group of "children with disabilities".

**Risk of Subjectivity** - Interview, on the other hand, as an instrument for collecting data has its limits. The results of the interviews can be presented either in a quantitative form or in a qualitative one. Regarding to this latter, the usual form for interpreting data generated from the research is to select specific sentences from the interview in order to highlight a point or a topic. This can be considered as one of the most transparent approach towards results presentations; but, it can also lead to subjective interpretation of the data. In the current research, special attention has been given to data interpretation. Findings were interpreted with the highest objectivity, tending to decrease the eventual probabilities for bias approach or subjectivity. Therefore, future research on this field should try to avoid even more such possible limits, with the aim of generating objective and representative findings.

## Recommendations

- Disability Persons Organizations in Kosovo should orient their advocacy towards improving the situation of children with disabilities in Kosovo.
- Special Family Supporting Services should be designed and delivered for families of children with disabilities in Kosovo.
- Concrete steps should be taken in purpose of functionalizing the inclusive education system in Kosovo.

## Recommendations for future researches

- Statistical data which provide an accurate number of children with disabilities in Kosovo should be collected.
- Advanced methodologies should be designed with the aim of deeply understanding the situation of children disabilities in Kosovo.
- The voice of children with disabilities in Kosovo should be actively consulted within the researches.
- Appropriate techniques should be designed with the aim of enabling data obtaining from children with communication difficulties.
- Future hypothesis recommended to be tested are as following:

  - Significant correlation exists between social interactions relying in family bases and positive self-perception of children with disabilities.

  -Significant correlation exists between wider social interaction and negative self-perception of children with disabilities.

  -Significant correlation exists between the inappropriate parental supportive strategies and increased feelings of disappointment of children with disabilities

- The situation of children with disabilities should be studied also independently for each type of disability.
- Violence – is recommended to be treated as an independent variable in future researches.

## Conclusion

The current research gives and overview of the situation of children with disabilities in Kosovo, consulting closely their own voice and perspective. Children with disabilities are the most accurate interpreters of their situation. Families, teachers, friends, community, and researchers should value what children with disabilities have to say. Their potential has been largely and widely undervalued, but fortunately, current research strongly demonstrates that children with disabilities are active interpreters of their personal experiences. No one can articulate more authentically then them, their feelings and impressions. Bringing alive the voice of children with disabilities enables us to get a deeper understanding of their real situation.

Based on the findings of the current research, it can be indicated that the situation of children with disabilities in Kosovo is truly unfavorable. Findings indicate that children with disabilities are not provided with the best parenting approaches as well as not with a functional inclusive education system. Family and school, as two of the most important environments for child's development, should continuously be empowered. Significant steps should be taken with the aim of creating a non-discriminatory environment for children with disabilities. Situation of children with disabilities in Kosovo should urgently be addressed by the relevant stake holders in front of institutions, so these children will be able to enjoy their human and legal rights guaranteed with the Constitution and Laws in Kosovo as well as with the Convention on the Rights of Children. Our society should finally start to recognize its moral and political responsibilities towards the situation of children with disabilities in Kosovo through seeking, defending and promoting their rights.

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## Annex 1 - Semi Structured Interview

Understanding the Situation of Children with Disabilities

1. Are you happy with your life?
2. What makes you different from others?
3. Do you like who you are?
4. If you would change something in yourself, what would it be?
5. How much time do you spent with your parents?
6. Do you feel like your parents are proud of you?
7. What do your parents do when you make mistakes?
8. Do they ever punish you, and how?
9. How much time do you spent with your siblings?
10. Do you feel you are a good sibling?
11. With whom do you play?
12. With whom do you usually go out and why?
13. Do you enjoy the time spent with your classmates?
14. Who are you friends?
15. Do you like visiting places?
16. Do you feel like your teacher likes you?
17. Do you think that your teachers are satisfied with you?
18. Did you ever forgot to do your homework; how the teacher reacted?
19. Do you read books?
20. Do you like school?
21. What do you mostly like in school?
22. What you don’t like in school?
23. What would you like to change in your school?
24. What is your biggest wish for the future?
25. If all the people in the world would be listening to you right now, what would you ask them to do for you and other children like you?

## Annex 2 – Parental Permission for Child's Participation in the Research

*Please read carefully the instructions and sign in the end of paper if you agree for participation of your child in the research*

Introduction– The current research is conducted in the framework of the project "Protecting Children from Violence and Promoting Social Inclusion of Children with Disabilities in the Western Balkans and Turkey" financed by European Union and co- financed by UNICEF, implemented by UNICEF and European Disability Forum and will be presented in the National Seminar "Empowering the Rights of Children with Disabilities in Kosovo" organized by Kosovo Association of the Blind.

Purpose – Is to directly consult children with disabilities in Kosovo in order to deeper understand their situation including their challenges, barriers and concerns.

Instrument – Semi structured interviews will be used to obtain data from children in regard to their situation. Children will answer questions such as "What makes you different from others?"; "What would you like to change in your school?" Interview contains 25 basic question; although, other questions might be added during the interview.

Confidentiality – Your child's privacy will remain completely anonymous and the data obtained from your child will be confidential and used only for the purpose of the research.

Administration – Interview will be administrated by Ilirjana Geci (School and Counseling Psychologist) or Trina Xheladini (School and Counseling Psychologist).

Name / Surname

____________________________

Signature

____________________________

Place and Date

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