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# Everyday Life of Children with Intellectual and Developmental Disabilities in Albania

May 2021





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Childhood Studies

Submission date: May 2021

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# Abstract

The focus of this master's thesis is children with Intellectual and Developmental Disabilities (IDDs) in Albania. It is exploratory research about the everyday lives and personal experiences of childhood and disability. The research took place in a private multi-functional daycare centre in Tirana. The primary participants were children with IDDs whereas the secondary participants were their parents, teacher and therapist who worked with them in the centre.

This research draws on theories, concepts and models from interdisciplinary fields of research including childhood studies, disability studies, disabled children's childhood studies and intersectionality theory. The central value that guided the data collection process and analysis is the acknowledgement that children with IDDs are participants and active agents worthy of contributing to the co-creation of knowledge about their own lives. Utilising the mosaic approach and inspired by ethnographic and participatory methodology, I designed an inclusive, child-focused methodology for this research. I conducted participatory observation and activity-based interviews with the children, as well as semi-structured interviews with parents and professionals.

The main contribution of this research is that it reveals the social construction of childhood disability by painting a more nuanced picture of the uniqueness of the experience of the participants' lives at the intersection of age, ability, gender, culture and socio-economic status. The findings of the study are threefold. First, whereas children with IDDs are very different from one another, they experience some similar challenges and share some basic needs. They enjoy going to school and being included in regular classrooms which allows them to make friends and socialise. However, they often struggle with receiving quality and consistent education that matches their lived realities. Second, the issues present in the healthcare services should be improved to comply with the demands stipulated by law. Raising a child with disabilities is a joyful and extraordinary experience but it is also difficult at times and presents many challenges for families. Caring for children with IDDs in Albania is influenced by the family's support from their relatives, their economic status, the geographic location and proximity to services and many other factors. Third, oftentimes children with IDDs become targets of stigma and prejudice based on a construction of disability as a 'misfortune' or problem informed by the normalcy and development paradigm. These findings have important social policy implications for supporting families and children with IDDs in Albania and beyond.

# Abbreviations

ABA - Applied Behaviour Analysis

IACC - Interagency Autism Coordinating Committee

ICF - The International Classification of Functioning, Disability and Health

IDD - Intellectual and Developmental Disabilities

IEP - Individualised Education Plan

UNCRPD - The Convention on the Rights of Persons with Disabilities

UNCRC -The United Nations Convention on the Rights of the Child

WCAC - Work Capability Assessment Commission

WHO - World Health Organisation

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# Introduction

This master's thesis aims to explore the everyday lives and challenges of children with intellectual and developmental disabilities (IDDs) in the context of Albania. The main motivation behind conducting this research is to further the exploration of the childhoods of children with disabilities and identifying the uniqueness of their experiences. It aims to set a positive precedent in participatory, child-centred research in Albania which is a new and mostly unknown research paradigm. Through the active participation of children in research and the weight that is granted to their perspective and testimonies of their own lives, it attempts to prove that research 'with' children with disabilities can be successfully achieved, despite the challenges presented due to the children's impairments or special needs.

Theoretically, this research is positioned within the field of disabled children's childhood studies. It draws inspiration from both the theoretical perspectives of childhood studies and disability studies to explore the lives of children with disabilities. The main perspectives employed from childhood studies are the constructionist and actor-oriented branches. Social constructionism provides a lens for the exploration of social and cultural influences that shape childhood in a specific context. Whereas, the actor-oriented approach allows for the consideration of children as active agents in society. It aids the fieldwork process and design of methods in order to promote children's active participation as well as the analysis process with the identification of children's acts of agency in different contexts in their everyday life. From the disability studies, the main theoretical stances that were utilised in this research are the disability models and the debates surrounding their utility and ethical grounds. The medical, social and bio-psycho-social models have been reviewed due to their influence in Albanian law, policy and the work of NGOs. However, the social and cultural models have been selected as guiding models for this research.

Furthermore, the intersectionality theory has been employed as a means of exploring the intersections between economic status, gender, age, ethnicity and disability. The research itself is positioned in the intersection of age, disability and ethnicity because it focuses on childhood and disability as social categories and it is situated in Albania by drawing connections between culture and the constructions of disability and childhood.

The methodology of this research is built upon the Mosaic approach which aims to create a mosaic of data received from various participants that are organised into themes by identifying the uniting and differentiating elements. The methods employed are a combination of ethnography and participatory methods designed to be child-centred and reflexive towards the needs and modes of communication of each of the participants.

The main participants in this project are the children themselves who contributed to the data collection stage in two phases. They engaged in participatory observation where they were able to meet the researcher and interact with them through casual conversations and joint activities. Due to the position I took in the research which is 'the least adult role', children were treated and considered as equal and they were able to challenge the traditional relations of power between them and adults. In the second stage, the child participants were given the opportunity to engage in activity-based interviews where we explored together different topics inspired by the main research questions such as daily life and routine, their experiences in school, their social relationships, etc.

The secondary participants of the research are the parents and professionals who are the people who have a very close relationship with the children and are able to disclose a lot of details regarding the children's lives and experiences. The semi-structured interviews with parents and therapists offered insight into the experiences of parenting and caring for a child with IDD, as well as the challenges faced with the education and healthcare system. These interviews provided a clear background to the factors that influence and shape disabled childhoods in Albania, including the effects of the paradigms of normalcy and development which are quite prominent in the Albanian context. Furthermore, the conversations with adults who live with children with IDDs provide a clear picture of the social constructions of disability and childhood in the Albanian society.

## **1.1 The gap in research 'with' children with disabilities**

Children with disabilities are a highly researched group, who receive attention from many fields such as medicine, psychology and social work. The most researched topics regarding children with disabilities revolve around the impact of their condition on their development and the evaluation of services and needs (Runswick-Cole, Curran, & Liddiard, 2017). Most of the international research has focused on the medical and developmental aspects of the IDDs and less on the social life of children with IDDs. Furthermore, in sociological research children have been positioned as objects rather than participants and the data has been gathered based on the testimonies of their caregivers and the perspective of the family (Hodapp, Fidler, & Depta, 2016). They

may be excluded from research because their agency is not duly recognised due to the portrayal of disability, they are difficult to recruit and less visible than other children and lastly, they present a challenge in communication and methodology (Wickenden & Kembhavi-Tam, 2014). Based on the prejudice on their competencies and abilities they are not regarded as legitimate research participants, to the extent of undermining their right to participation based on the justification of their lack of ability to participate and contribute valuable data on their own lives. This leads to misrepresentation and misunderstanding of their perspective and their lived experiences. (Stafford, 2017).

There is a tradition of researching caregivers and family members of children with disabilities, both as informers about children's lives and as subjects. A large amount of research internationally has focused on the adversities and stresses of raising a child with disabilities for their families, caregiver and parents in particular. (Neely-Barnes & Dia, 2008). Research on the impact of children with IDD in their family, parents or communities portrays these children as a burden rather than as individuals with equal rights and equal opportunities. (Runswick-Cole & Hodge, 2009); (Perry, 2004); (Seltzer, Krauss, Orsmond, & Vestal, 2000).

Increasingly, researchers are starting to acknowledge the fact that children with disabilities have the right to participate in research, however, they don't pay any special attention towards using participatory methodology that is tailored to the needs and abilities of their participants. Wickenden & Kembhavi-Tam (2014), point out that despite being included in research, children with disabilities are rarely asked about general topics such as everyday life, friendships or citizenship. Their participation is only seen as relevant in topics that relate to their disability.

The main focus of research on topics of disability in the Albanian context is on issues of education and access to public services as it is seen from the legal and governmental perspective and reported by important international NGOs such as Save the Children. (Voko, Kulla, & Mactaggart, 2018); (Cuko, Kulla, & Kasapi, 2013). Because of the difficulties in communication with children with IDDs and the general disregard for children as active participants in research, most researchers gather data from the children's caregivers and other stakeholders. The goal of these studies is to provide information and recommendations on how the children's lives can be improved and how their rights can be met. However, by disregarding children's own opinions on the matters that affect their lives directly or indirectly, their rights for participation and self-determination are not being considered (Skivenes & Strandbu, 2006).

Increasingly, researchers are exploring everyday life and children's own views by increasing their participation and "power" over the research process, especially within fields like Childhood and Disability studies (Hedegaard, Aronsson, Højholt, & Ulvik, 2018), (C. Gray & Winter, 2011), (P. Christensen & James, 2017), (Asbjørnslett, Helseth, & Engelsrud, 2014). There is a growing body of participatory methods and tools being designed and implemented to involve children as much as possible in the process of research. Nevertheless, there is a long way to go for disabled children's voices to be duly represented in research. There is a gap in the knowledge about children's lived

experiences of childhood and disability contextualised and connected with intersecting factors such as culture, socio-economic status and geopolitical location. In response to the lack of research on children with IDD's experiences in Albania, I attempted to challenge the traditional approaches utilised so far and implemented a participatory and child-focused research design.

## **1.2 Purpose Statement-the Rationale of the Research**

The main purpose of this research is to present an alternative way of conducting research with children with disabilities. Moving away from research about children with disabilities based on the views of their caregivers and placing more emphasis on education and development towards conducting child-focused research on the topics that matter the most to children themselves in order to acknowledge them as experts in their own lives and give their opinions due weight in research.

The research employs an innovative approach both theoretically and methodologically which comes as a challenge to traditional forms of conducting research in Albania. Furthermore, the data that will be constructed through the active participation of children and their caregivers can be used to draft recommendations and propose solutions to issues and challenges that children with IDD's are facing in Albania.

### **1.2.1 Research Objective**

The main objectives of this research project can be divided into two main contributions. Firstly, this research intends to explore and gather information in order to critically examine topics such as everyday life, education, healthcare and social life from different viewpoints. Secondly, this project aims to achieve a methodological contribution to the field of research with children with disabilities. The methodology implemented with the children in this research can be described as participatory, inclusive and child-focused. Despite the necessary inclusion of other participant groups such as parents and professionals, children's voice has been given due weight and it is valued as the core contribution of this research. The successful inclusion of children with disabilities as participants in research aims to serve as a positive precedent and basis for further research in Albania with children as participants.

### **1.2.2 Research Questions**

In what follows I will elaborate on the main research questions that will be addressed in this thesis.

1. What does a day in the life of a child with IDD's look like in Tirana? The exploration of the child's daily life and routine, at home, in school and other places that they

visit. The aim of this research question is to be able to gather an insider's perspective on lived experiences of children with IDD in Albania, to understand what is most important for the children themselves, their aspirations for the future as well as their reflections on their own needs. The second reason for documenting a detailed account of their everyday life is to be able to make children with IDDs and their daily struggles visible in the society from which they are mostly hidden.

2. What are the social constructions of childhood and disability in the Albanian society? How do the normalcy and development paradigm affect children's lives? This question aims to examine the intersections between various social categories such as disability, childhood, economic status and gender.
3. How do children with IDDs experience their community's un/acceptance? Do children with IDDs face discrimination, stigma and unfair treatment in society, in school or in governmental levels? The focus of this research question will be education and healthcare, as two of the most influential factors in their life.
4. How is the relationship of children with IDDs with the adults in their life (parents, extended family, teachers, therapists, caregivers) and with peers? This question will contribute insights into the limited knowledge on the perception and the relationship of children themselves with other people in their life.

### **1.3 Scope of the Study and Its Limitations**

This research project is conducted in the city of Tirana, Albania in a daycare centre which children with IDDs attend. The fieldwork consists of three stages according to the methods used, namely the participant-observation stage, the child interview stage and the adults' interview stage. The data gathered from different tools and methods will be incorporated and analysed using the Mosaic Approach in order to co-create knowledge about children with IDDs and their life-worlds in Albania. The findings will serve as guidance to compile recommendations for possible changes and improvements that can be implemented by government institutions, NGOs and researchers.

#### **Children with IDDs**

According to the International Classification of Functioning, Disability and Health (ICF), a multipurpose classification tool designed by WHO, disability is defined as: "The negative aspects of the interaction (impairment, activity limitation, or participation restriction) between an individual (with a health condition) and that individual's contextual factors (personal and environmental factors) Problems with human functioning are categorised in three inter-connected areas: impairments are problems in body function or alterations in body structure – for example, paralysis or blindness; activity limitations

are difficulties in executing activities – for example, walking or eating; participation restrictions are problems with involvement in any area of life – for example, facing discrimination in employment or transportation. Disability refers to difficulties encountered in any or all three areas of functioning.” (World Health Organization, 2011, p.5) . This umbrella term promotes the understanding of disability under the lenses of the social model and represents the interaction between the individual and the context in which they live (Leonardi, Bickenbach, Ustun, Kostanjsek, & Chatterji, 2006).

Each person with a disability has a unique experience, comprised of the interaction of biological, personal and environmental factors together with differences in gender, age, socioeconomic status, sexuality, ethnicity, or culture. Thus, any generalisation done on the basis of their diagnosis alone would be misleading (World Health Organization, 2011). Nonetheless, in order to conduct a meaningful, precise and applicable research there is a need to specify the group of participants and the criteria for their inclusion or exclusion. Based on the common terminology and grouping used in many research articles, international organisations and international health facilities and scientific journals such as the “American Journal on Intellectual and Developmental Disabilities (AJIDD)”, in this thesis I have decided to use the term Children with Intellectual and Developmental Disabilities (IDDs) (Okyere, Aldersey, & Lysaght, 2019); (N. N. Singh, 2016); (Wehmeyer & Garner, 2003).

### **Research Limitations**

Being a small-scale qualitative research, the number of participants is relatively small and it was purposefully selected. One of the main limitations of this research is the sample, which might not be representative of the whole population. The difference between the lives of children in Tirana compared to other cities is not illustrated in this research due to limited opportunities to expand the reach of the research. Therefore, the issues and life experiences described in this research might not be the same for children who live in other parts of Albania, due to the inequalities between cities and villages compared to the capital. Secondly, the space where the research was conducted inevitably affects the research findings and the category of children that I was able to access. One example of the influence of place, is the inability to interview and reach the perspective of children who do not attend therapy or day-care centres and who might experience isolation and exclusion. Being a private centre, the families of children who went there were economically capable of paying for such an expense. Consequently, the perspectives of families who are unable to provide private services and rely on the state were not included.

## **1.4 The Structure of the Thesis**

This thesis is divided into seven chapters. The first chapter is the introduction, in which I present the rationale and motivation behind my research topics. Furthermore, I describe the main contents and contributions of the thesis, emphasising the importance of methodology and participation of the research subjects. Additionally, the chapter contains the research objectives and questions which provide the framework of the data collection and analysis. The chapter also discusses the scope and limitations of the research project.

The second chapter constitutes the background of the research. It presents an overview of the lives of children with disabilities in Albania, exploring healthcare and education as well as social and cultural factors that influence it. In addition, it delves into the history of child disability in Albania to explore how the conception of disability has changed throughout the years. This chapter also discusses the concept of inclusion and its implementation in international and Albanian contexts, bringing forward the positive contributions and the problematic aspects of the new paradigm in disability policy.

The third chapter explores the theoretical perspectives that serve as the framework of the research and help to give shape and meaning to research findings. There are three main fields of research presented which were relevant for this research, namely childhood studies, disability studies and disabled children's childhood studies. Moreover, there is a brief account of intersectionality theory which serves as a guide to explore the intersections between age, disability, gender, culture and socio-economic status.

The fourth chapter discusses the methodology of the research. In this part, I compile a detailed account of the methods and tools I designed to answer the research questions and fulfil the objectives. The process of fieldwork from gaining access, entering the field, getting to know the participants, conducting interviews and handling ethical dilemmas is described and illustrated with examples. Lastly, it presents the ethical principles of the research and their practical implementation.

Chapter five and six represent a combined account of the research finding and discussion in connection to previous research. The analysis chapters are organised based on a few main themes which correspond with the initial research questions and attempt to provide answers for them. The main themes that are highlighted in this part are the daily life of children with IDD, education, healthcare, parenting and the constructions of disability in Albania.

The final chapter presents the main conclusions and most important findings of the research. It creates a cohesive connection between methodology and theory. It concludes with recommendations for the improvement of the lives of children with IDDs and suggestions for further research.



# Background

## 2.1 Introduction

This chapter commences with a general account of child disability in Albania, focusing on issues such as assessment, diagnosis, cultural and social understandings as well as a historical account of the developments in the field of disability throughout the years. The second section highlights important arguments regarding the discourses and practices of inclusion of children with disabilities in Albania and internationally.

## 2.2 An Overview of Child Disability in Albania

In Albania, the term disability has a broad and inclusive meaning. It is used to refer to persons who have a born or acquired impairment. The "Law for Social Assistance and Social Welfare" specifies that disabled persons are considered only those who were born or have acquired the impairment before the age of 21 (Ekonomi, 2002). When referring to children, the official term is "children with disabilities" however, in the recent year it is being replaced by a more sensitive terminology such as "children with special needs" or "differently-abled children"

The lives of children with disabilities in Albania are affected by theoretical and practical understandings of disability that influence health, education, work, social life and most importantly; the perception of people with disabilities by society and themselves (Smart, 2009). Each person with a disability has a unique experience, comprised of the interaction of biological, personal and environmental factors together with differences in gender, age, socioeconomic status, sexuality, ethnicity, or culture. Whereas when it comes to the understanding of disability within families research concludes that disability is a complex matter that requires constant exploration and learning. Diagnoses and labels are seen as tool utilised only in the professional or medical spheres, whereas caregivers understand disability through daily interactions and behaviour (Canary, 2008).

One of the most pervasive issues that impacts the lives of children with disabilities in

Albania is poverty and the lack of social support to make up for it. Proper healthcare and therapy are very expensive. The majority of families that struggle to meet basic needs, cannot pay for the care of their children. An estimated 66% of families with children with disabilities report to having low income that does not cover all the necessary costs to provide a good life for their children (Rogers & Sammon, 2018). Moreover, there is large disparity between the opportunities and services children obtain in the capital, Tirana, compared to other cities, towns or villages. Tirana has most of the facilities that service children with disabilities, such as hospitals, clinics, therapeutic centres and special schools. The lack of infrastructure and development presents another challenge for families who need to travel to Tirana to get help for their children (Closs, Nano, & Ikonomi, 2003).

On the other hand, Albanian society and culture impacts children with disabilities positively by offering support and solidarity. Due to modernisation and the inclusion of women in the workforce, the structure of the typical Albanian family started to resemble the nuclear family. Despite these developments, the extended family remains one of the main sources of support for vulnerable members, such as children (Closs et al., 2003). Parents continue to rely on their respective families for help with taking care of their children especially with children with disabilities who need more care and attention. Furthermore, families in less developed areas of the country are bigger and maintain the traditional structure of the Albanian family, where the sons and their families continue to live with their parents in their home all together. Another positive development for children with disabilities has been the increased mobility and opportunities for emigration of Albanian people in Europe and America which has given children the possibility of receiving more specialised therapies and assessments in more developed countries.

Children with disabilities are becoming more included and accepted in communities. Stigma and discrimination has progressively lowered as people have more knowledge about disability and are more aware of their challenges. However, parents still report a level of isolation and separation that is not common for other children proving that there is a lot to be done for the genuine inclusion of children with disabilities in society (Rogers & Sammon, 2018).

### **2.2.1 The process of assessment and diagnosis in Albania**

The assessment and diagnosis process for disability is one of the most crucial events in the life of children with disabilities. Early identification and correct assessment provides children with the opportunity to receive early intervention programs and services which have been proven to have major positive outcome in the optimal development of children with Intellectual and Developmental Disabilities (IDDs) as well as in the quality of their life (Scherzer, Chhagan, Kauchali, & Susser, 2012), (Guralnick, 2005). In the context of Albania, there is a disparity between the legal provisions and the reality of

the process of assessment and diagnosis for children with disabilities. The Law "For the inclusion and accessibility of persons with disabilities" (93/2014) stipulates that the assessment of disability ought to be performed by a multidisciplinary team based on the bio-psycho-social model of understanding disability and international criteria.

In practice, there are two types of assessments children can receive: the medical assessment conducted by the Work Capability Assessment Commission (WCAC) and the educational assessment for children with learning difficulties. The evaluation by WCAC is the primary document that provides children with a formally accepted diagnosis and the right to access public services specialised for children with disabilities. Whereas, the assessment of special educational needs conducted by the Regional Directorate of Education. It provides children with the right to have an assistant teacher and an Individual Education Program (IEP) (Voko & Fortuzi, 2014).

The medical assessment is conducted by a team of 5 doctors specialised in various fields of medicine, although this does not include mental health professionals. It is based on two documents: the criteria for the assessment of the capability to work and the medical criteria for the evaluation of disabilities. These criteria make up a list of 387 medical diagnosis, thus treating disability as a purely medical condition rather than as bio-psycho-social condition as defined in the law (*Law "For the inclusion and accessibility of persons with disabilities, 2014*). This method presents many problems, such as using the the same diagnostic criteria for children as for adults despite the crucial differences between adult and child diagnoses and the exclusion of children with light and moderate disabilities who are not diagnosed as such by these criteria, leading to their lack of access to services and specialised care (Rogers & Sammon, 2018).

There is a disparity in the quality of service children receive based on their family's economic status. There are a few private facilities that offer a more professional and adequate assessment and therapy. However, they are very expensive compared to the economic level of Albania and only a privileged few can afford them. There is also a discrepancy based on location. Most private services are located in Tirana, the capital of Albania where most people live. For the families that live in other cities or towns these services are even more unreachable because of the added cost of travel and because the salaries and economic opportunities outside the capital are much lower. (See Fig 1.1 in the Appendix 1) Lastly, there is a gap in education and information between the capital and other cities. People who live in the capital have a higher chance of being more educated and better informed on disability and possibilities of therapy.

In the sphere of education, there many barriers that prevent children with disabilities from receiving quality education. Apart from challenges related to teacher training, lack of infrastructure and assistant teachers, the process of assessment and diagnosis constitutes an issue. Based on the provisions of the Law of pre-university education (*Law of Pre-University Education no. 69, 2012*), each Education Directorate or Office should have a multi-disciplinary commission that assesses the educational needs of children with disabilities based on the bio-psycho-social model. However, this structure is lack-

ing in most of the country despite efforts made by international organisations and the government. The commissions in charge of the assessment have limited competences and the process itself is ineffective (Rama, 2016).

There are roughly around 18,000 children with disabilities in Albania as reported by the WCAC. Moreover, there is a large number of non-diagnosed children who experience challenges in education or in their daily life. The process of identification and referral of a child for a more specialised assessment, which is the first step towards receiving help from social services, is not currently functioning in an optimal way. The responsibility of identification lays with the caregivers and family members of a child as well as different actors in the social services such as the midwife, GP, nurses, paediatrician, educators, teachers, psychologists, social workers (CRPD, 2015). However, the biggest barrier of identification and diagnosis remains the parents' nonacceptance of their children's condition due to stigma, shame in addition to the conception of disability as a "personal tragedy" (Haegele & Hodge, 2016) and their lack of information on the procedures necessary to receive the status of disability (Voko & Fortuzi, 2014).

In 2018, The ministry of Health and Social Protection has undertaken a reform in the procedures and policy of the assessment of disability for children and adults in order to fulfil the obligations provided by law (*Law "For the inclusion and accessibility of persons with disabilities, 2014*). The main objectives of this reform are (a) to review the assessment criteria for disability by creating separate manuals for children and adults based on the international codified system used in the International Disability Classification which is based on the ability to perform basic life tasks in accordance with age; (b) to create, pilot and review a new assessment scheme, based on the bio-psycho-social criteria and ICD-10 (World Health Organization et al., 2019); (c) to create 28 multi-disciplinary commissions for the assessment of disability by 2024 in all the major cities in Albania (Ministry of Health and Social Protection, 2019). With the changes that this reform promises, the assessment and diagnosis process will be improved and consequently it will become easier for children with disabilities to receive public services and the care they need, both in the educational sphere and for their well-being in a whole.

### **2.2.2 The Social Constructions of Disability in Albania – A Historical Account**

During the communist regime in Albania (1946-1990) the first services for persons with disabilities were established. In this political system, people's needs and well being became a priority, which resulted in the identified necessity of care for persons with disabilities. The understanding of disability in Albania during this period was based on the medical model which views disability as the direct result of a physical or mental disease or impairment, excluding social or cultural factors (Haegele & Hodge, 2016). Disabled people were portrayed as dependent and incompetent who are in need of protection by society. The feelings of solidarity and pity towards persons, especially

children, with disabilities led the state to create a network of special institutions that would remain open despite the economic difficulties of the country. The main purpose of these residential institutions was the provision of medical care and fulfilment of basic needs by governmental facilities, thus removing the “burden of care” from the family (World Vision Organisation, 2012).

The first effort towards educating children with disabilities was the establishment of special schools. The first special boarding school was the Institute for Deaf and Blind children was established in 1963. After the year 1970, children with mental disabilities were no longer placed in hospital-like medical centres, but rather in special educational institutions. The first special school was opened in Tirana and later in other big cities such as Vlora, Elbasan, Shkodra, Durrës and Korça. These schools operated with a special curricula which also included vocational training that would provide students with employment opportunities. Students in the 7th and 8th grades – which were the final two years of compulsory education – attended training courses in public enterprises, assisted by their teachers. Once their education was complete, they were offered a job position in the enterprise and received a regular salary as any other worker there.

This program represents a major development in the field of education for children with disabilities as well as in the socio-cultural construction of disability (Dedja et al., 2003). Disabled children were no longer seen as a burden, but rather as people capable of learning and contributing economically and becoming functional members of society. These initiatives represent the first steps towards the acquisition of equal rights and integration for people with disabilities. Despite the positive outcomes of this system of education and institutional care, there were also many drawbacks. Children with disabilities lived a life disconnected from their families and the community. They lacked social interaction with children outside of the institutions where they lived and studied which lead to their social exclusion that lasted throughout their life (World Vision Organisation, 2012).

During the 90s’, Albania became a democratic country and underwent a series of positive changes with the influence and assistance of western European countries. The exposure to the western understanding of disability and education swayed the Albanian government into reforming the law for education and reviewing the rights of children and people with disabilities. International NGOs became a crucial actor that supported families and pressed the government to adhere to children’s right and to provide mainstream education opportunities for children with disabilities (Metani, 2003). Furthermore, movements and associations lobbied against discrimination with the aim of changing the way people with disabilities were perceived in the Albanian society. They worked towards the full integration of people with disabilities in many areas of social life such as education, work, socialisation and political engagement (World Vision Organisation, 2012).

Albania ratified the United Nations Convention on the Rights of the Child (UNCRC) in February, 1992 and included the right to education for all children in the Constitution.

The law for "Pre-University Education" (1995) envisioned the right for all children to attend public schools, including children with disabilities and special educational needs. The integration of children with disabilities in mainstream education was seen as an important process. However, this proved to be difficult due to economic restrictions, lack of public structures and lack of specialised teachers (Poni, 2013).

Meanwhile, international NGOs in collaboration with local NGOs ran a few pilot projects for the inclusion of children with disabilities in mainstream schools. An example of this type of initiative is the Prrenjas Elementary School project. In this school a special class for children with disabilities was created, giving them the opportunity to socialise with the rest of the pupils during school breaks in the common areas. Furthermore, the government incentivized teachers to include children with disabilities in regular classes by introducing additional pay for teachers who agreed to take on this responsibility (Radoman, Nano, & Closs, 2006).

The framework within which all of these measures were taken was that of integration, although they served as stepping stones in the process of creating an inclusive society. Integration in education refers to a classroom setting where students with disabilities learn alongside peers without disabilities. They receive extra support to assimilate the standard curriculum or study a special curriculum within the same classroom (Vislie, 2003). The analytical report on children with disabilities in 2002 recommends that the social protection of children should come from residential or non residential institutions and development centres suggesting that the concept of special institutionalised care pertained. It is reported that despite the legal obligation for children with disabilities to be educated in mainstream schools, those institutions were not prepared to receive such students. There were only 6 schools for special education, 3 residential care centres and 2 institutes for blind and deaf children in Albania at the time. The schools followed the mainstream curriculum, however it was adapted to the pupils' limited capacity and only applied for 2 hours per day (Ekonomi, 2002).

In contrast, inclusive education removes the emphasis off the disability and treats every student as a unique individual with different needs, abilities and learning styles. Thus, an inclusive education allows everyone equal access to the same curriculum by aiming to remove any barriers to education and learning (Vislie, 2003). The vision of the inclusive society is that of an equal society, in which the causes of exclusion are identified and addressed qualitatively. From this perspective, disability is the result of the interaction between an individual and their environment, as opposed to a feature of a person, thus the change needs to occur within the societal structures that hinder full and effective participation (World Health Organization, 2011).

## **2.3 The Inclusion of Children with Disabilities in Society - the Albanian and International Context**

### **2.3.1 Discourses of Inclusion in the International Setting**

The concept of the inclusion of people with disabilities stems from the Civil Rights movements in the 1960s. The struggle for equal rights and opportunities regardless of race, gender, ethnicity or disability led to a change in the way disability is understood and the way people with disability are treated in society (Hassanein & Elshabrawy, 2015). An inclusive society is defined by the civil participation of each citizen in matters that concern them, the fulfilment of human rights and responsibilities and equal access to public services and provisions. Other important dimensions of an inclusive society are equity in the distribution of wealth and resources, acceptance and appreciation of diversity and the existence of a strong civil society. Education plays a critical role in the process of creating an inclusive society. Education is seen as a tool that can empower marginalised groups and promote diversity and acceptance in the generations to come (UNDESA, 2009).

Many international organisations have developed initiatives to support the efforts towards the creation of an inclusive society. The UN Convention addresses the significant disadvantages that people with disabilities face in society by promoting inclusion, equality and solidarity based on the principal of fundamental human rights (Stein & Lord, 2009). In the World Report on Disability (World Health Organization, 2011) disability is framed as a human rights issue due to the inequalities people with disabilities experience as well as a development issues due to its two-directional link to poverty.

The World Conference in special education held in Salamanca, Spain in 1994 marked the beginning of the global movement towards the inclusion of persons with disabilities in society. The process of inclusion is viewed as a change in the social structures and actions that should be redesigned to include every citizen despite their needs and characteristics. This movement focused mainly on the education of children with disabilities moving from segregation and institutionalisation to inclusion in mainstream schools. By following an individualised, child-centred pedagogy, the schooling system must provide basic, quality education for all children despite their needs (Rodriguez & Garro-Gil, 2015). Furthermore, this movement served as an instigator of broader social acceptance of people with disabilities and their inclusion in all areas of social, economic, political and community life. The inclusion of children with disabilities in mainstream schools allows them to fully participate in society both as children and later as adults, given that providing opportunities for socialisation encourages younger generations to become more accepting of people with disabilities. (Hassanein & Elshabrawy, 2015).

### **2.3.2 Legal and Policy Frameworks for Inclusion of People with Disabilities in Albania**

In the recent years, inclusion and inclusive education have received increased attention from the Albanian government as well as NGOs and the civil society. From a legal perspective, there are a lot of positive developments in the sphere of education for children with disabilities. The Law for Pre-University Education, The National Strategy for Pre-university Education (MAS), the Action Plan for Children and the commitments to comply with signed international acts and efforts to meet the "Education for All" objective (which is a part of the Millennium Development Goals) are some positive indicators of the development of inclusive education in Albania. The legal framework for children with disabilities in Albania is founded and examined based on two important international conventions: The United Nations Convention on Rights of the Child (UNCRC, 1989) and the United Nations Convention of Rights of Persons with Disability (UNCRDP, 2006).

In 2005, the Albanian government in collaboration with the civil society established a 10-year national strategy for people with disabilities which focused on these main areas of intervention: inclusive and quality education, employment and economic development, access to public services, support for people with disabilities, fulfilment of their rights and the collection of data and information on people with disabilities (Cuko et al., 2013). Furthermore, in 2016 a new national action plan for people with disabilities was drafted (PKVPAK) which will last until 2020. This action plan proposes a framework with 8 strategic goals, one of which refers specifically to children with disabilities. The main issues underlined in this plan are related to education, social and health care and participation in social life (Rogers & Sammon, 2018). According to a recent report by World Vision Organisation, this action plan lacks sufficient objectives for children with disabilities, focusing more on their treatment and rehabilitation rather than prevention and early identification which has proven to be a problematic process in Albania (Voko et al., 2018).

In 2012, Albania approved the law for inclusive education based on the UNESCO Salamanca statement for Special Education and the Human Rights convention. Chapter XI of this law states that the principal of the education of children with disabilities should be the development of their full intellectual and physical potential and the improvement of their quality of life with the goal of their full integration in society and the job market. Children with disabilities must be included in regular kindergartens and schools of primary education must follow the normal curriculum with the assistance of a special teacher if needed (*Law of Pre-University Education no. 69, 2012*). According to a recent report on child disability conducted by World Vision and Save the Children, the new Albanian laws that affect children with disabilities are in full compliance with the principles and requirements of the UNCRC and the UNCRPD. There have been many improvements for the rights of children with disabilities, such as the right of non-discrimination and the right to participation and quality education. However, the



Albanian government needs to put more effort into realising Article 26 of the UNCRPD which requires guaranteed developmental and rehabilitation services for children with disabilities (Voko et al., 2018).

In spite of the progress that has been in legislation, there is still a lot of improvement to be made in the social perspective. Discrimination and stigma are widely researched when it comes to children with disabilities because it is seen as a barrier for access to public services and the fulfilment of their rights. Consequently these issues are subject of interventions and programs that aim to reduce negative attitudes towards them (Smythe, Adelson, & Polack, 2020). According to the report on child disability in Albania (Voko et al., 2018), 1 in 2 children with disabilities face discrimination in their community, in play with peers and in educational institutions. Similarly, 1 in 3 children face discrimination in public health and social services (ibid). The issues of inclusion have received a lot of attention from NGOs in Albania in the recent years, whose work has focused on raising public awareness in schools and communities about the rights and challenges of people with disabilities with the intent of removing one of the biggest barriers of inclusion and accessibility for persons with disability (Murillo, 2014).

Children with disabilities in Albania are mostly cared for by their family. The Albanian family is caring and supportive, however it does not allow children a certain level of independence and does not work towards their relative autonomy. Despite the changes in mentality and understanding of disability, families are not able to offer their children the necessary integration and rehabilitation as a result of poverty and an absence of sufficient support (The Network of Disability Organizations, 2019). Another disadvantage young people with disabilities experience, is the lack of prospects for the future. The employment rate of people with disabilities is very low (Shtino & Fortuzi, 2011), thus most youngsters remain at home for most of the time, which further increases depression and feelings of guilt and shame surrounding their disability (Ekonomi, 2002). The main obstacle for employment and integration is prejudice, stigma and discrimination not only from employers but also from the schooling system which reproduces discriminatory practices by creating unequal opportunities for education and professional training (Duraku, 2017).

### **2.3.3 Challenges of the Inclusive Practice and Barriers to Inclusion**

The discourse of inclusion has gained popularity in the recent years, nonetheless it is a highly contested and criticised practice. The theoretical and idealistic part of the movement fails to critically evaluate the realities of the schooling system and to propose concrete steps towards a reform in education as a whole by removing focus from special education (Armstrong, Armstrong, & Spandagou, 2011). When it comes to putting inclusive rhetoric into practice, professionals are faced with confusing and contradictory meanings. While legislation and policy demands the inclusion of children with disabilities in mainstream schools, structural factors such as budgets, resources, teacher

training, etc. become barriers of progress in the field of education (Lyons, 2013). Furthermore, the notion that mainstream schools are made for "regular" students is still embedded in the conception teachers, directors and academics have regarding schooling. Children with disabilities might be included but that doesn't inherently create inclusiveness. The ideals of inclusive education rely on the acceptance and accommodation of all pupils as individuals with diverse needs despite their differences in ability or development pattern (Graham & Slee, 2008).

There is a lot to be done in educational settings where exclusive practices continues to be an important issue. The term commonly used to refer to children with disabilities is pupils with "special educational needs" (Runswick-Cole & Hodge, 2009). Consequently, this categorisation of children by professionals reproduces discrimination and separation similar to the system of special education. Goodfellow (2012) uses participatory approaches to identify ways in which the school spaces can reproduce the exclusion of children with disability. The results point to the stigmatising effect of the "special education" label which indicates an inferior level of education compared to mainstream education. Children with disabilities perceive this differentiation in many small but important details of the school environment. The use of a label to indicate the pupils with special needs, the use of special learning materials that are different from the regular ones and the presence of a teaching assistant perpetuates exclusion by teacher and peers as well as self-exclusion. Hodgkinson, Ghajarieh and Salami (2018) state that raising awareness amongst non-disabled pupils is an important part of the process of inclusion. All children should be educated over the issues of disability, in order to be more accepting of their peers. By including this theme in textbooks of mainstream education, it may spark conversation in classes and help children with disabilities integrate more easily into regular schools.

In the context of Albania, the main barriers of inclusion relate to school staff (teachers, assistants and directors), parents, peers and children with disabilities themselves. Teachers in regular public schools lack the knowledge and training on inclusive practices. They manage large groups of pupils in classes of 30-40 children and they often suffer from burn-out due to the amount of work and stress the face in their workplace. Moreover, some teachers do not believe in the ideals of inclusion despite being forced to accept children with disabilities in their classes due to legislation. They are discouraged when it comes to teaching children with disabilities as they believe they are unable to benefit from mainstream education. On the other hand, low income, lack of infrastructure and support and general negative beliefs related to disability make the parents another obstruction in the pursuit of inclusion. Pupils without disabilities discriminate and judge their disabled peers due to lack of knowledge about disability, prejudice inherited from their community and family and the lack of communication channels with children with disabilities. Meanwhile, children with disabilities suffer from low self-esteem and social anxiety. They are unable to communicate and adapt to social environments with their peers because they lack practice and guidance. The experience of discrimination and bullying prevents them from trying to integrate in the

school environment (Cuko et al., 2013).

Social inclusion does not refer solely to the context of education. Children with disabilities in Albania are subject to inequalities when it comes to social, health, rehabilitation, and cultural services. It is reported that a quarter of children with disabilities, certified by the Disability Assessment Commission do not receive disability payments and three-quarters do not have access to social services. Community-based services for children with disabilities are still lacking both in quantity and variety. The public sector makes up for half of the social services provided and there is a persistent trend of foreign donors and NGOs withdrawing which will further reduce the amount of services children have access to (The Network of Disability Organizations, 2019).

## **2.4 Chapter's Summary**

The lives of children with disabilities in Albania are affected by a number of factors, namely economic and socio-cultural. Economic status and the location affect children's access to healthcare and educational services. Whereas, culture and social organisation affect the way they are regarded in society. The problematic process of assessment and diagnosis for children with disabilities is another impacting factor that promotes or hinders their chances of receiving the necessary care.

The historical account of child disability in Albania is a testimony that there has been many positive changes throughout the years both in social policy and law. Moreover, the discourse and conceptualisation of disability has progressed from segregation and isolation to inclusion and equality. The path towards building an inclusive society is a challenge for both the international and the Albanian context. There have been many steps forward with respect to the legislation, however there is a lot of work to be done in the practical application and implementation of the policies.

# Theoretical Perspectives

## 3.1 Introduction

The focus of this chapter is the theories and models that provide the theoretical framework for the research. The chapter introduces three distinct and interconnected fields of research, namely childhood studies, disability studies and disabled children's childhood studies. It briefly outlines the main theoretical contributions of these fields which are applicable for this research. From childhood studies, the main perspectives described are social constructionism and actor-oriented perspective. Whereas from disability studies, discussions on the models of disability are brought forth. Moreover, the chapter presents the intersectionality theory and its contributions to the research on children with disabilities.

## 3.2 Childhood Studies

Childhood studies emerged as a new paradigm in theorising and conceptualising childhood and children in research and the society at large. It started as a criticism of the dominant views on childhood and children, mainly shaped by developmental psychology and functionalist sociology which later progressed into a fully developed research approach and field. Childhood studies set out to critically review these concepts and give alternative understandings of children's position in society, their value as individuals and their agency.

Developmental psychology is embedded in the idea that childhood is a natural phenomenon that is characterised by physical and cognitive growth. Piaget advanced the theory of universal developmental stages which every child should progress through according to their age. Thus, childhood is seen as a period of apprenticeship that leads to becoming a rational, functional adult. This universal construction of childhood promoted the processes of standardisation and normalisation of children's lives, education, health, international policies and research (Jenks, 2004). The problematisation and critique of this paradigm gave way to the initial writings in Childhood studies.

James and Prout identified a few key features of the new paradigm in an attempt to give a defined shape to the new research field in 1990 (James & Prout, 1990). Firstly, childhood is a socially constructed concept, distinct from the biological features of life. Furthermore, childhood varies across time and space and it is influenced by other factors such as class, gender and ethnicity. Secondly, children are active agents in society that affect and are affected by social structures. Therefore they are worthy subjects to be studied in their own right, independent from adult perspectives. Thirdly, children should be given the right to participate in research using innovative and inclusive methodology like ethnography and participatory research.

The field of childhood studies is rapidly growing and gaining popularity. Christensen (Christensen James, 2017) identified three key strands of new research that should be further developed. In the theoretical aspect, the conceptualisation and definition of children and childhood in research and their relationship to research are still highly debatable. Moreover, researchers are attempting to link theory with practice and are investigating the consequences of the new child-centred approaches that childhood studies has developed. Lastly, the new developing topic of research is the use of media and the internet as a tool for communication and information.

There are three main branches in Childhood studies, although their boundaries are blurred, namely the actor-oriented, structuralist and constructionist perspective to discuss different aspects of children's lives. Hereinafter will be underlined the main debates and ideas from the constructionist and actor-oriented perspective, which are most relevant to this research.

### **3.2.1 The Socially Constructed Childhood**

The fundamental idea behind the social constructionist view of childhood is that childhood is a concept that is constructed by society. Therefore, it is fluid, variable depending on culture and time and it is heterogeneous. Theoretically, social constructionists focus on the discourses surrounding childhood and children. Discourses are "...sets of ideas which are rooted in historical, social and political context" (Montgomery, 2003, p. 47).

Originally social constructionists developed a critique concerning the construction of childhood in Psychology. The developmental paradigm that is present in social sciences as well as in the everyday understanding of childhood is termed as "a totalising concept". Childhood is a unifying experience that every individual can relate to and the constructions and ideas surrounding it are part of the everyday interactions. Constructionism rejects the idea of a universal concept of childhood. The meaning of childhood is culturally and historically dependent, therefore children should not be seen as a homogeneous group. Aries, the childhood historian, points out that the concept of childhood was created by society after the Middle Ages and since then it has changed and evolved to the concept we know today. Along with it, similar transformations have occurred to children's lives and child-care practices. Apart from time, childhoods vary according to

place. Cultural views and lifestyles affect the way children are perceived and treated in society. (Montgomery, 2003). Historically there has been a tendency in policy (such as UNCRC) as well as academia to universalise some aspects of childhood based on the western concept which is the most prominent in research (Anne Bentley, 2005). The growing numbers of research being conducted in childhood studies has served to highlight the vast variation in childhoods in different social, cultural, economic and political circumstances using innovative research methodologies such as ethnography or participatory research.

Childhood is a phenomenon that varies across all countries and societies as well as across time. To say that childhood is socially constructed requires an analysis of how concepts are built, how knowledge is produced and what the basic assumptions behind it are. Thus, the goal of the social constructionist approach is to identify what constitutes a child in different societies and how childhood is variable (Jenks, 1982). Moreover, social constructionists challenge the concept of scientific knowledge itself, arguing that all forms of knowledge are subjective because it is a product of human activity. Apart from the theoretical differences, social constructionists are also interested in exploring the practical consequences the different conceptions of childhood have on children in the real world.

The meanings attached to disabled childhood and the responses targeted towards children with IDDS, namely policies and the structure of institutions designed for them are culturally dependent. Consequently, I have selected the social constructionist theory in order to provide a lense for the analysis of the underlying influence of cultural and contextual factors in the way child disability is perceived. Constructionism is used to explore how the different constructions of disability, affect the everyday life of children with IDDs.

### **3.2.2 The Actor-oriented Approach - Debates on the Concept of Agency**

The actor-oriented approach is one of the central theories of childhood studies. One of the main concepts introduced in the field is the view that children are active subjects that use their agency to navigate and negotiate their social worlds. Conceptualising children as social agents signifies recognising their role in society and in the construction of their own lives (James, Jenks, & Prout, 1998). The main topics that are researched using the actor-oriented perspective are the concepts of agency, space and place in addition to children's culture.

Corsaro's studies in America and Italy on children's lives in kindergartens are good examples of how children live independent lives and develop their own peer cultures amid of the broader adult culture and society. He used the concept of interpretative reproduction to illustrate children's agency in cultural reproduction. When introduced with social norms, rules and traditions children do not simply absorb and internalise them. They consciously analyse them by taking elements and including them into their

own cultures. Children negotiate and use their social identities to their advantage and actively modify and change the culture over time. Corsaro noticed a representation of children's agency in the way children negotiated rules and gained control in the supervised environment of the kindergarten. He testified how children understood rules and made secondary adjustments, sometimes in secret to change them to fit their own desires. One example of this was children smuggling small objects into their pockets and showing them to their friends in secret, even though they were not allowed to bring anything from home. Children were also prone to being late or pretending that they had forgotten to do certain tasks such as cleaning that they didn't like to do. This phenomenon is viewed in many cultures and societies. Children in the Global South who are obligated to engage in labour may obey to such conditions, but they secretly resist by meeting up after work to some hidden locations or by integrating work and play (Corsaro & Eder, 1990).

The concept of agency has also received a lot of criticism in academic debates for being an unrealistic and simplistic concept. Agency was developed in opposition to the theory of socialisation and appears as a dualist view of reality. However, there are many alternative theoretical standpoints from which the concept of agency is conceptualised. In many articles, Abebe (Abebe, 2019), (Abebe, 2008) suggests the understanding of agency as interdependence. Children's agency is enacted in certain contexts and it is not an isolated phenomenon. One of the factors that highly influences children's agency is the relationship they have with the adults in their lives, such as their family members, teachers as well as the relationships they have with their siblings and peers. This perspective highlights the importance of researching agency within the social-cultural and political-economic contexts, paying attention to how they influence and co-construct each other.

Another standpoint of examining agency in the context of this research is the thick and thin agency suggested by Klocker (2007). This theory analyses the influences the context has on the expression of children's agency. The social structures children live in might encourage or constrain children's agency however, this does not make children inherently incompetent or dependant. Thick agency is present in an environment where children have a high level of freedom of action and choice, whereas the opposite can be said from thin agency. Children who live in authoritative and highly regulated environments or children who live in adverse situations are not presented with many choices, therefore they develop personal strategies to navigate their world.

Robson, et. al (2007) suggest the idea that agency is not only relational but it is also a continuum. The amount of agency an individual has in their life is ever-changing. Places and people influence children's expression of their agency in everyday life. When a child is at school they have to follow rules and respect the structure of the school, whereas when they are playing in their room the spectrum of their freedom and agency is much larger. This concept applies not only to children but to every individual who is part of a community. To further develop this idea, Payne (2012) brought forth the concept of everyday agency. She approached agency through common everyday

actions and decisions children make in normal circumstances. Guided by stories and experiences children shared in ethnographic research, she conveyed a picture of daily life from the perspective of children and young people.

Concerning children with disabilities, the discussion on agency has a special significance, as a result of the common belief surrounding disability. Children with disabilities are seen as incompetent in making decisions in their own lives, therefore they are denied agency and overshadowed by their caregivers, teachers, social workers or therapists. Holt (Holt, 2004), argues that this notion is flawed and demonstrates in her research the ways children with disabilities enact their agency by responding to opportunities and challenges even in the contexts where their power is limited. Researchers argue that children with disabilities should be seen as individuals worthy of studying in their own right and attention should be given to their own experiences and voice (Singh & Ghai, 2009) .

In this research, agency is seen as relational and interdependent. Children's agency is observed in relation to their family members, their teachers and peers. Relational agency helps analyse how children's agency unfolds in everyday encounters and relationships. Moreover, the ways agency is enacted is observed in different contexts and places such as at school, at the daycare centre and at home, based on Robson's (2007) continuum of agency.

### **3.3 Disability Studies- Theoretical Models of Disability**

Disability Studies arose as a response to the discriminatory and distorted approach of researching disability. Nowadays, this field has evolved from criticism and is formulating new ideas and theories using a socio-political-cultural model of disability along with an epistemology of inclusion (Linton, 1998). In Disability Studies, some authors are trying to develop a new model of researching children with disabilities. This new approach includes the participation of children with disabilities in the research project and allows for heterogeneity and variety of experiences. Watson (2012) further argues that the new paradigm in disability studies need to explore disability as a category and as a longitudinal process and that it should challenge disablement, oppression and exclusion where possible.

The concept of disability is highly disputed and debated, both in the academic environment as well as the socio-political environment. The term "model" itself, does not signify a fact or a real phenomenon, rather it is a type of theory that generates an explanation or hypothesis for research or helps to explain "real life" conditions (Llewellyn & Hogan, 2000). Furthermore, models are criticised for being a narrow one-size-fits all approach on real-life experiences of disability (Beaudry, 2016). Models of disability are not simply theoretical constructions, they hold power and determine a large part of



the life of people with disabilities, especially when it comes to children, whose agency is more restricted by societal structures and norms (Mitra, 2006).

In the academic sphere, there are many theoretical models of disability, two of the main distinctions being the medical and social model. These models have been used as frameworks to create social programs, public services, legislation and to advocate for children with disabilities, making them relevant even in the socio-political sphere. Outlined below, there will be the models that influence the lives of the participants of this research and the models that are considered as a theoretical background in the research.

### **3.3.1 The Medical Model**

The medical model of disability perceives disability as a disease or impairment that needs to be corrected or treated, emphasising the biological aspect. It focuses on the limitations of the individual and ways to reduce them, by equalising the person with their impairment and by excluding the social and environmental factors. The medical model is mostly used in medicine and psychology where diagnosis is a very important part of treatment and the latter is seen as an eradication of the cause of disability. For the group of disabilities that cannot be fixed or improved, the only option is offering help and assistance by others.

Healthcare professionals are very important actors in the lives of people with disabilities as they are gatekeepers for access to public services (Haegele & Hodge, 2016). As a result, this model has been heavily criticised firstly by disability advocates and activists as well as researchers for the negative portrayal of people with disabilities and the disabling discourse it promotes. On the other hand, it should be noted that the process of moving towards more inclusive and ethical practices is lengthy and challenging, thus, the medical model still has a large impact on children with disabilities in Albania despite its limitations.

### **3.3.2 The Social Model**

In opposition to the medical model, the social model of disability interprets disability as a social construct imposed by external powers (e.g., medical, legal and governmental systems) which is caused by the way society is organised and its lack of accountability towards different needs of individuals and is unrelated to biological factors. Physical or mental impairment does not justify the unequal treatment, discrimination and oppression that people with disabilities face in interaction with society. This model proposes the removal of social barriers that act as oppressive structures for disabled people that prevent their full inclusion and participation in society (Holt, 2004).

The social model has helped Disability Studies and people with disabilities make a qualitative leap from the medical model towards a model that advocates for equal rights and opportunities. Despite sharing common grounds, the social model is not a singular

unified and universally accepted model, in fact, it varies in many countries and has been subjected to alterations, critiques and improvements.

On the one hand, it has been argued that the social model refuses to accept the causal link between impairment and disability by putting all the attention on the social and environmental factors and ignoring the fact that physical and mental impairment does create restrictions in various aspects of life (Thomas, 2004) . By denying impairment, it makes it difficult to respond to the needs of people with disabilities and examine discriminating structures. On the other hand, impairments are not a purely objective classification, they are influenced by social constructions of normalcy and the expectations on human functioning. It is futile to put the biological and social factors in opposition, seeing as they are interdependent and constantly evolving. Thus, each model should be considered valuable while being aware of its limitations and weaknesses (Wasserman, Asch, Blustein, & Putnam, 2011).

In Albania, the social model is popular among NGO projects and social activists and it is selected as a guiding model for this research as well because it removes the focus from the participants' impairments and instead centres around their experiences and perspective. This model also creates an inclusive research environment by actively removing barriers that could hinder the full participation of those who may face difficulties that stem from their impairments.

### **3.3.3 The Bio-Psycho-Social Model**

The internationally accepted model of disability is the the bio-psycho-social model which is the theoretical framework upon which the International Classification of Functioning, Disability and Health (ICF) is drafted. This model draws upon the official and most widespread definition of disability being the ICF , designed by WHO. The ICF takes a multi-factorial approach based on the bio-psycho-social model of understanding disability, by considering all the factors that influence the complex nature of disability (Shakespeare, 2017).

ICF defines disability as: "an umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)." (World Health Organization, 2001). It is mentioned as the guiding model in most research in Albania on children with disabilities (Rogers & Sammon, 2018), (Voko et al., 2018), (Rama, 2016). Moreover, the bio-psycho-social model informs the new assessment protocol designed to provide children with disabilities a formal diagnosis. As this diagnosis crucially influences the lives of children with disabilities, consequently this model does as well. The bio-psycho-social model is referenced in Albanian law and official documents referring to the definition, assessment and criteria of receiving social support for child disability (*Law "For the inclusion and accessibility of persons with disabilities, 2014*), (*Law of Pre-University Education no. 69, 2012*), (*Law on The Social Assistance in the Republic of Albania no. 57, 2019*).

### **3.3.4 The Cultural Model**

Disability is not determined only by medical or psychological diagnosis but it is also a cultural concept (Davis, 2005). Through expectations, social norms and values, societies construct the dichotomy of abled vs disabled body or mind. The meaning and understanding of impairment and disability evolve over time not only as a result of scientific advancements and theoretical debates but also as a result of policies, governance, social movements and emancipation (Goodley, 2016). The able-bodied standard is another measure that defines disability in society. The more a society focuses on reaching this standard, the less tolerant and inclusive they are towards alternative ways of being.

The cultural approach to disability argues that disability and normality are concepts constructed in society through comparison and differentiation. Disability does not represent the true nature of an individual, rather their categorisation in society. "Disabled" and "non-disabled" identities are interdependent and continuously evolving and changing (Waldschmidt, 2017). Human beings cannot be perfect, thus everyone has a limitation or impairment when compared to the ideal standard. Despite this, most people don't consider themselves disabled. Disability affects individuals to varying degrees and in different manners. Consequently, any kind of generalisation or categorisation of disability and people with disabilities is misleading (Shakespeare, 2017).

This model finds application in this research because it offers the space to explore the ties between the individual experience of children with disabilities and the cultural construction of disability in Albania.

## **3.4 Disabled Children's Childhood Studies**

Disability Studies and Childhood Studies have many intersections in discourses and principles. As researchers within Childhood Studies are advocating participation, agency and inclusion (Valentine, 2011), so are researchers within Disability Studies where the voices of people with disabilities are often excluded and misrepresented (Barton, 2005). Children with disabilities are twice marginalised from representation in academia, once as children and once as disabled, consequently research with children with disabilities can profit both fields of study.

In Childhood Studies research, children's voices have often been conceptualised as homogeneous in order to identify the common characteristics of childhood. It is equally important to point out the differences as well on the basis of social factors such as gender, age, class, ethnicity and disability in order to illustrate the variety of childhoods and the specificity of individuals between and within these classifications (James, 2007). Tisdall (2012) argues that research with children with disabilities is a challenging venture for researchers that not only benefits this specific field but serves as an exploration and amelioration of the practice of research in general. The par-

participation of children with disabilities prompts researchers to think constructively and reflexively about communication, research methods, the process of consent, the researcher/researched relationship and many other key concepts in qualitative research.

Disabled children's childhood studies draws from both of these approaches while aiming to create a distinct research field. It aims to explore the lives and perspectives of children with disabilities, moving the focus away from their impairment and diagnosis and towards their lived experiences and voice. It incorporates the ethical considerations and research design popularised by Childhood Studies and Anthropology, meanwhile focusing on challenging the concept of "normalcy" promoting the social model of disability (Curran & Runswick-Cole, 2014).

One of the tenets of this approach is the positioning of disabled childhoods in their geopolitical context, hence challenging the Western hegemony together with global norms around childhood and disability. Informed by the idea of a socially constructed childhoods, disability can also be studied in this light leading to a better understanding of what it means to be a child with disabilities in a certain context (Runswick-Cole, Curran, & Liddiard, 2018). There is a significant amount of research that explores the intersectionality of disability with race, class, gender, age, sexuality and nationality. Shakespeare and Watson argue that the multifaceted challenges children with disabilities encounter not caused by their impairments but rather by social structures and relationship, cultural representations and the set of beliefs and values surrounding disability (Shakespeare & Watson, 1998).

The second tenet focuses on deconstructing the concept of mental health and well-being. Authors in this field critique the psychologisation of the everyday life of children with disabilities, in education, healthcare and family environments. The notion of normality and the consequences it has on people's lives is one of the most debated topics in both Childhood and Disability Studies which unites these fields. Childhood studies criticises the theory of normal development of a child popularised by psychology and medicine. Age is another key concept with which development is measured based on a unified standard of what a child should be able to do depending on their age. Whereas, in Disability studies, normality is criticised as a measurement of what an individual should be able to do, based on which disability is defined in society (Franck, 2014). The ideology of normalisation informed by developmental psychology is reflected in the perceptions we have about disability nowadays and highly affects children's lives apart from being a theoretical concept (Holt, 2004).

Finally, there is an attempt to re-imagine research, policy and practices towards acknowledging the potential and active contributions of children with disabilities as active and equal actors in society (Runswick-Cole et al., 2018). In her editorial on researching the lives of disabled children and young people, Stalker (Stalker, 2012) identifies the key developments in this field. Firstly, the field is dominated by qualitative research which have used the Childhood and Disability Studies approach as a theoretical framework. Secondly, the topics of the research tend to focus on the aspect of support, constructing children with disabilities mainly as service users of specialised care and

support. There is a neglectful tendency to include children with disabilities in research about or with children in general, isolating them only in research pertaining to the topic of disability. Thirdly, disabled children who also belong to other disadvantaged groups such as minorities, refugees, children from low economic families or children with complex communication needs are further excluded from research (Stalker, 2012).

Scholars from both Childhood and Disability Studies are encouraged to engage more in-depth with issues of disabled childhoods and include all children with disabilities in research. There is a need for cross-sectional studies that highlight discussions and challenge hegemonic understandings of disability as well as childhoods and children (Franck, 2014). Given that this research incorporates theoretical stances from both the aforementioned fields and is focused on disabled childhood, it is positioned in this emerging field of research.

### **3.5 Intersectionality Theory**

Intersectionality originated within the field of gender studies in 1989 and has received widespread popularity in recent years encompassing other fields of social sciences such as childhood, disability, human rights and race studies. Intersectionality theory illustrates the connectedness of social constructs by proving that in order to understand one concept such as disability or childhood, it must be analysed in relation to the others. Social constructs such as race, class, gender, sexuality, age and (dis)ability intersect to create a person's identity and life-world. All these social constructs have their own history, contradictions and challenges while also being dependent on time and place. The cultural context represents the social space children live their lives. Nevertheless within any context, children's lives have a diversity of challenges, vulnerabilities or privileges. Intersectionality is a framework for analysing the ways in which multiple identities and social group memberships interact and overlap to produce to shape a person's life (McCall, 2005).

In order to research the lives of children in an inclusive way, researchers must theoretically and methodologically account for diversity based on social factors that affect them (Ghavami, Katsiaficas, & Rogers, 2016). Intersectionality theory offers an informative lens into the compound realities of children's lives however, it is still not regularly mentioned in relevant articles in this field (Alanen, 2016). Similarly, Keri Gray, the leader of a disability organisation, emphasises the importance of intersectionality in disability studies and advocacy. She criticises the common approach of identifying with a single identity, producing movements or conventions such as disability rights, children's rights or women's rights. She believes that in building a narrative of someone's life the intersections of all their multiple identities must be accounted for (Gray, 2020) .

Thorne (2004), calls for the necessity of theorising the concept of age. By utilising the intersectionality framework, researchers can go more in-depth in the analysis of

“age” in conjunction with other categories such as gender, class or race. In a research about children in the digital ages, the researcher gives an illustrative example of the practical use of intersectionality to understand children’s experience. He argues that a child with disabilities coming from a rich family experiences both privilege and oppression due to belonging to different social categories. The family is able to provide assistance and professional care for their child, however, this family is still at a disadvantage because it still faces systemic challenges of raising a child with disabilities. On the other hand, compared to a low-income family, it encounters fewer barriers. Despite the purely theoretical comparisons and description of a person’s life, this perspective is important because it sheds light on the different factors that influence a child’s life which are worthy of studying (Alper, Katz, & Clark, 2016).

Another researcher used intersectionality to study the experience of Nepali children during armed conflicts to counter the common homogenised view of the victims and their needs. There are also research in the field of disability exploring the diverse experiences of families who raise children with disabilities. Furthermore, Hodge argues that usually, the label of disability receives all the attention, leaving behind other aspects of children’s identities in their communities (Hodge, 2005).

In conclusion, the fundamental belief that these studies represent is that neither childhood nor disability can be studied as isolated phenomena. There needs to be an account of how other social factors influence or are influenced by childhood and disability. Arguably, this research is precisely positioned in the intersection of age and disability, the former being a transitory but universal identity, the latter being a permanent but specific identity.

### **3.6 Chapter’s Summary**

Childhood studies is a new research paradigm that changed the way children were conceptualised in research, by positioning them as participants rather than subjects. Children are seen as active members of society with an important voice in the research environment and society at large. There are three main perspectives in childhood studies, two of which were most important for this research. Social constructionism views childhood as a construction which is dependant on many social factors such as culture, geography, politics and economy. Whereas, the actor-oriented approach is concerned with research child agency and the various ways it is acknowledged and enacted in society.

Disability studies, on the other hand, researches and theorises the constructions of disability in research and society. The main models of disability examined in this chapter are the medical model, the social model, the bio-psycho-social model and the cultural model.

Disabled children’s childhood studies is an intersection between childhood and disability studies that researches the lives of disabled children in different contexts and

cultures. Intersectionality is a crucial theoretical standpoint for this research because it provides an interesting lense to analyse the relationships between different social factors such as age, disability, cultural background, economic status, etc.

# Methodology

## 4.1 Introduction

This chapter outlines the methodological approach followed to conduct participatory and ethical research with children with disabilities. Firstly, it discusses the conceptual basis of the methodology which is a combination of methods and principles of ethnographic and participatory research inspired by the Mosaic Approach. Secondly, the process of conducting fieldwork is described starting from the fieldwork site, field entry and reflections on positionality and reflexivity. Thirdly, the methods and tools used to explore the research questions are briefly explained and evaluated. The last section explores the ethical principles of inclusive and participatory research, focusing on informed consent, confidentiality and safety principles

## 4.2 The Methodological Approach

In Childhood Studies, children are recognised as active agents in society and have a right to participation and free expression, thus their position in the research project and the choice of methods is very important in ensuring their meaningful participation (P. Christensen & James, 2017). The design of this qualitative research is a combination of methodologies and approaches which were selected to achieve an authentic and realistic exploration of the everyday lives of children with IDD in Albania. The design of the methodology draws inspiration from ethnographic and participatory methods by incorporating them following the approach developed by Alison Clark and Peter Moss entitled "The Mosaic Approach" (Clark & Moss, 2011).

The Mosaic approach is a combination of verbal and visual tools that work as channels of communication between the researcher and the participants. By providing children with an array of choices, they are encouraged to pick the mode of communication they prefer and feel most comfortable using. This restores the power imbalance inherent in the researcher/participant relationship by giving the freedom of choice to children and using methods according to their strengths and needs. Instead of trying to make



children adjust to the methods the researcher imposes on them, the researcher has to adapt their research methodology to suit the participant (Clark, 2010).

The main concept behind this approach is presenting the participants with a large variety of methods from which they can select the ones that suit them the most. Each participant produces their "individual tile" and the researcher puts all these tiles together to create a mosaic of experiences and testimonies in order to construct a larger meaning with the participants.

The mosaic approach is an innovative framework that encompasses the principles of participatory methodology and addresses the issue of power and communication by using many methods and considering children as competent informers on the matters that concern them. This approach finds application mainly in research on the everyday lives of children and children's views on various topics.

Participatory research serves this project as a guiding principle in designing methods, engaging with participants, exploring concepts and theories as well as local culture and understandings of disability. The range of methods that were offered to children were participatory and child-focused. In participatory research, most of the methods are visual and task-based in order to be accessible and to facilitate communication (Beazley & Ennew, 2006), which is especially important in research with children with disabilities (Nind, 2008). Creative approaches make it feasible for children to understand the significance of their participation in research and the tasks that they will engage in, subsequently improving adults' understanding of the children's perspective and the authentic representation of their "voices". Therefore, the inclusion of creative methods which involve visuals can alleviate difficulties in communication between the participants and researcher and challenge existing power dynamics (Thomson, et.al,2020)

Apart from participatory methods, I also incorporated ethnographic methods and principles in order to get a fuller picture of the participants' lives and relationships within the fieldwork site as well as to build rapport and get to know the participants better. The ethnographic method that I utilised in my research was participant observation, which is a unique method of collecting data through observation while interacting with the participants (Jorgensen, 2015). It allowed me to explore the inter-subjectivity of children's lives through active participation and interaction. It is an interpretative approach that creates space for children's accounts to be voiced and places children in focus by allowing them to create meanings and interpret their reality.

Ethnographic methods take into consideration cultural differences and ways in which society shapes children's lives. Furthermore, they enable the concept of children as people who are worthy of being studied in their own right and facilitate access to children's true ideas and views, allowing the researcher to step into children's natural environment by using tools such as participant observation, unstructured interviews, casual conversation, etc. (James, 2001).

The combination of methods and tools inspired by participatory and ethnographic research using the mosaic approach is valuable and advantageous for this research

because it offers insights into childrens' lives and their authentic experiences captured through different perspectives and expressed in various ways. Due to the flexibility and creativeness of this approach, it proved to be highly inclusive because it allowed me to enable the participation of every child despite their impairments or challenges. Furthermore, it provided the triangulation of methods which makes the findings more valid and reliable, as well as increases the quality of the research by minimising the limitations of using a singular method (Harcourt, Perry, & Waller, 2011), (Flick, 2007).

### **4.3 The Fieldwork Process**

The fieldwork process was divided into three main stages. In the first stage, I joined some of the children's daily activities in the centres such as the kindergarten/daycare class, play time and lunch time. I took advantage of this time to familiarise myself with the structure of the centre and to build rapport with the children and staff. I used participant observation as the main method of collecting data. The participants in this stage were all the children and adults who attended the centre from 9:00 until 13:00. Even though the focus was on children with IDD, their interactions with other children and their teacher were very insightful to observe and experience as a researcher.

In the second stage, I conducted interviews with children. The main participants of this research were children aged from 6 to 13 years old with IDDs who attended the private centre. As there were only 6 children who fit these criteria in the centre, I attempted to include all of them in the second stage of the research.

In the third stage, I conducted interviews with adult stakeholders, such as the teacher, the therapist and some parents.

#### **4.3.1 The Fieldwork Site**

This research was conducted in a multi functional daycare centre. This private centre offered many services for children in the neighbourhood such as kindergarten, daycare, extra classes for children with special educational needs, English classes and therapy for children with disabilities. The distinctive feature of this centre which made it valuable for this research was its guiding principle of inclusion. Most centres for children with disabilities are specialised in one type of disability such as autism or Down syndrome or specialised in the sort of service they provide such as education or therapy. Meanwhile, this centre welcomed all children without discriminating based on their disability or any other factor.

The centre was organised in several classrooms where children could carry out different activities. The group that I joined was the kindergarten/ daycare. In this classroom, you could find children with or without disabilities attending kindergarten and some older children with disabilities who spent a few hours there after school while their parents were working and had no one to care for them. Apart from kindergarten

or daycare, children with disabilities attended a special private class they called "extra" to work on what they learned in school, do their homework and improve their academic skills. In addition, some of them also followed therapy with a psychologist.

There are many benefits to researching in a familiar environment for the child. Firstly, it helps to minimise distress and provide a safe environment where the child feels comfortable to interact with an unknown person (Seballos & Tanner, 2009). Secondly, it allows the researcher to observe the child in an environment where they routinely spend time in. These casual observations, conversations and interactions are valuable sources of insight into the lives and relationships of the participants.

### **4.3.2 Field Entry and Negotiating with Gatekeepers**

The process of entering the field and starting the project can be very challenging especially when doing research with children. In Albania, the concept of research in itself is not familiar for most people and it is met with a high amount of scepticism and suspicion. The initial impediment for my project was gaining access to an institution or private centre which children with IDD attended. Given the necessity for privacy and confidentiality, most of the places attended by children refuse to welcome researchers. I managed to get in contact with the director of the centre where I conducted my research through a friend who had previously worked there. Luckily the director was open-minded and positive towards my proposal and agreed that her centre participated in the project. After she was familiarised with the project information and the activities that would take place, we negotiated my intended plans with the rules and possibilities of the centre.

The second step was contacting parents and gaining their consent for their and the children's participation in the research. I visited the centre one day during the time when parents come to pick their children up and presented myself to them and the project. They also received a consent form which they read at home and returned the next day signed. Luckily, there were no parents who refused to let their children participate. However the parents were curious to see what the interviews with the children would be like. I briefly informed them on the topics we would talk about as well as showed them the activities that I was planning on using to assist the interview process. Most parents responded quite positively towards the activities and expressed their interest in exposing their children to opportunities like this.

Despite the overall positive experience in gaining access and consent to conduct my research, I had to negotiate a very important element of the research. Both the director of the centre and the parents were opposed to allowing me to record the audio during the interviews with the children. In order to respect their wishes and their right as participants and caregivers, I had to comply with their request. Instead of voice recordings, I took extensive notes during and right after the interviews in order to document everything that happened during the process.

### 4.3.3 Reflexively

In the process of conducting qualitative research, it is acknowledged that the researcher is not an objective observer of social phenomena. Rather, the researcher comes into the field with their own social, political and cultural values and ideas. These beliefs and positionings might potentially influence the research findings, analysis and interpretation processes. Therefore, it is crucial that the researcher evaluates their own influence continuously in the research process (Engward & Davis, 2015). Reflexivity is applicable to all the stages of research from the theoretical basis, methodology, fieldwork to data analysis and dissemination (Berger, 2015).

Prior to beginning the fieldwork, the researcher needs to reflexively address the main presumptions regarding the research questions, theories, concepts and social stereotypes that may affect the process of knowledge production (Lincoln, Lynham, Guba, et al., 2011). Some of the common conceptions that were challenged in this research, were the concepts of disability and childhood. People with disabilities are stereotyped as unable to actively participate in research due to their impairments. Traditionally they are left out of the research group and information about them is gathered through third parties such as family members or caregivers (Wickenden & Kembhavi-Tam, 2014). Similarly, children are also seen as a category that are researched about, rather than with. Most research on children does not include them as participants and does not give them a voice in matters that affect them. Conversely, I attempted to challenge the conception that children with disabilities are not capable of participating and sharing valuable and insightful information about their lives. Their inclusion informed the design, implementation and ethical principles of this research.

In the fieldwork stage, special attention should be paid to the process of self-reflection and the researcher's positionality should be constantly evaluated. The journey of self-reflexivity starts with the influence of the researcher's background (Ryan & Golden, 2006). I conducted my research in Tirana, which is my hometown where I lived for most of my life. My academic background is in Psychology and Childhood Studies. Furthermore, I had previous experience in working with children with disabilities and I am personally interested and involved in issues of advocacy and disability rights. My background influenced the encounters with participants and well as my perception and interpretation of them. I tried to remain objective during the observations and interviews, however, subjectivity is an inherent part of qualitative research, no researcher could be completely objective (Patnaik, 2013). Moreover, in the fieldwork process, reflexivity was prominent in the way the methodology was implemented. During the interviews with children and adults, the methods and tools were constantly adapting and evolving in each encounter with the participants. My goal was to create a space for the participants to express what is most important to them using tools that are shaped by their competencies and preferences.

#### **4.3.4 My Role as a Researcher**

The position of the researcher in relation to the participants has an influence on the process of data collection and analysis, therefore the awareness and examination of positionality is beneficial to the quality and validity of the research (McGarry, 2016). Positionality refers to the roles the researcher undertakes and the boundaries in the researcher-participant relationship (Fenge, Oakley, Taylor, & Beer, 2019). It is interesting to highlight similarities and differences between them and the participants and utilise these traits productively (Hopkins, 2007). The age and power difference between children and adult researchers are commonly seen as problematic in research that aims to empower children (Punch, 2002). However, if the researcher addresses this matter reflexively and uses methods that rely on children's competencies and encourage participation it can become a productive research relationship.

Another influential aspect of positionality is the insider/outsider perspectives in relation to the community and the topic that is being researched (Fenge et al., 2019). In many ways, I was positioned as an insider in the community I conducted the research. I share the same nationality and ethnicity as the participants. Furthermore, I am a psychologist and activist in the field of disability and I am familiar with the context and the experiences of children in Albania. On the other hand, I was considered an outsider in the centre and a stranger to the families I engaged with. With time and effort, I managed to negotiate my position as an outsider and gain access and build confidentiality with the participants.

Similarly to McGarry's (2016) research with young people, my role as a researcher and my social position in the children's group varied in each stage of the research and was a continuous negotiation with each participant (Solberg, 1996). Before entering the field, I was certain that the children would quickly understand what my role was in the centre, what I was doing there and why, and would treat me accordingly. Unfortunately, their first instinct was to approach me as another teacher or therapist and not as a friend or an unusual adult. Despite my effort to explain what research means and what I plan to do there, their unfamiliarity with these concepts did not permit them to fully understand it and created a bit of confusion around my presence. However, aided by the creative and collaborative nature of the methods that were selected for the research, children quickly picked up on the playful and unconstraining nature of the encounter. After the first few activities they began to act more freely and engage with me more naturally.

The development of a good and fruitful relationship with the participants takes time and effort, as well as an awareness of subtle signs that indicate children's perspective of it. Despite my initial intent to blend in with the children and become a member of their group, the conditions and the time frame of this project did not permit me to do so. Therefore, I decided that I would assume the least-adult role (Mandell, 1988) which means "...undertaking a responsive, interactive, fully involved participant observer role with the children in as least an adult manner as possible" (Mandell, 1988, p. 438). I

recognised my position as an adult amidst children and inherent power imbalance based on age (Punch, 2002) but did not take on similar behaviours and responsibilities as other adults. I did not try to direct or lead their activities, I did not offer help or guidance when they were learning new things in kindergarten and I tried to become part of their social group without interfering with it. Instead of focusing on the drawback that this role has in the nature and outcomes of the research, I decided to use "difference" to my advantage by viewing the interview relationship as an exploration of the relationships children develop with adults outside of their family. I used this relationship to explore issues of agency, independence, individuality, separation from the other, respect for the others personal space.

In addition to participants who were children, I also engaged with their parents and the professionals who worked in the centre where I conducted research. When it came to adult participants, a different approach was required. Upon the first encounter, I attempted to appear trustworthy and competent in order to gain their trust and gain access to the field. I presented my research project and what it entails for the participants and the community, as well as introduced myself and my prior experiences with working with children. Once they made sure that I was capable of engaging in a positive manner with the children, they felt more comfortable with my presence there and became more interested in the research. After confidentiality was built, the parents asked me many questions and advice about their children and what they could do to improve their situation. Even after the fieldwork was completed, I continued to be in contact with them and provided them with my help as a way of thanking them and giving back to the participants.

## **4.4 Methods and Tools**

The mosaic approach in this research is implemented by or put into practice in three different channels. Firstly, children were presented with a tool-box of diverse and creative methods which provided children with a choice to pick the ones that suited them the most. In order to challenge the common practice in education or therapy where children are obligated to complete the activity that is required from them, in the research setting they were given full agency to engage with whichever method that sparked interest in them. The methods were designed to be child-friendly, featuring colourful images, interesting objects such as play-dough, Lego, different utensils and everything that might make them curious and attentive.

Secondly, the researcher used multiple forms of communication such as speech, body language, facial expressions, drawing, showing signs and symbols, and play. The diversification and researcher's willingness to communicate with the child in the way that they find most comfortable is a crucial element of research with children with disabilities (Underwood, Chan, Koller, & Valeo, 2015).

Children with disabilities are a heterogeneous group both in intersecting categories

like gender, age, socio-economic background, etc. but also because of their impairment types and abilities. Designing research methods that employ multiple modes of communication empowers children with disabilities and gathers rich information from an interview (Gregorius, 2015). The aim of the researcher in the sphere of communication is to create ease and to allow the child to communicate as they would in their everyday life, in order to avoid creating a stressful environment for the child. As Christensen (2004) discovered in her ethnographic research, the best approach to create a fruitful relationship with children is to tune into their "culture of communication" and allow yourself to learn how to interact with children by putting yourself in their level. To ensure the inclusion of non-verbal children or children who struggle with verbal communication the researcher provided children with the option of using a Picture Exchange Communication System (PECS) (Bondy & Frost, 2011). which is a well known and commonly used system of visual communication in Albania (Ajodhia-Andrews & Berman, 2009).

Thirdly, the data was not collected only from children, even though they were the primary source of information. After the interaction with children was over, parents and professionals were also invited to share their thoughts and opinions on the topic. Their inclusion did not serve the purpose of undermining children's authority and expertise on their own lives, rather it was introduced as a way of creating a full picture and a holistic understanding of children's experiences and challenges. Parents and professionals have a close relationship and a special bond with the child, thus they were able to highlight important themes and ideas. Furthermore, their perceptions and approach on disability inform and greatly influences children's lives.

#### **4.4.1 Activity-based Interviews with Children**

The most essential method in this project was the interviews conducted with children, as it was the most elaborate and productive method which yielded the majority of the information from the primary participant group. An activity-based interview is a semi-structured interview that is aided by visual, art-based, participatory tools Each tool, activity or method designed for the interview process serve the purpose of facilitating and encouraging communication and exchange of ideas (Jenkin et al., 2015). These tools make conversation easier and more natural for children, by removing the element of the unknown and confusion which might bring unpleasant feelings for children.

The room I conducted the interviews was a common room where children would spend time playing and where they had lunch together. I selected this room because it was the most relaxing and unconstrained environment in the centre. It has big round tables, small chairs and many toys.

The process of interviewing commenced with a warm-up exercise which was a board game that was played with a die and contained simple questions. The purpose of this activity is to "break the ice" between the researcher and the child, to create a playful and entertaining environment and to encourage further engagement. The opening

interaction of the individual interviews was always rather uncomfortable as it was necessary to establish a new way of communication and to relate to each other, which was different from the interactions we had in a group.

By starting to present children with the game and explaining the rules it drew their attention towards it. They found it enjoyable to throw the die around and count the boxes that they had to move. The questions were very common and neutral, so most of them did not have any hesitation to answer. After a few throws, we learned a lot about each other and the children began to feel more at ease. Sometimes they would change the rules of the game and I would follow their lead. When the game was finished, they were always enthusiastic and motivated to carry on, especially if they had won.

The most interesting effect of this activity, was the shift in the power dynamic between myself and the child from before to after we engaged with it. When we went to a separate classroom and the teacher had left us alone, the child always appeared nervous and was eagerly awaiting to see what I would say or do. When the game was over, it was noticeable how the children started taking the lead. They took out some coloured pencils, changed the page to the next activity or even asked me if there was another game we could play.

After the warm-up, the interview activities started. The interview was divided into many themes which I found most interesting to explore including, self-introduction, daily routines, school, family, friends, activities. These themes were explored with various activities suitable for every mode of expression. Depending on their competencies and interests, children completed the activities with my help.

Midway through and towards the end of the interview, children were offered the chance to relax, take a break and simply play. They were presented with different sensory toys which helped to relax children with special needs, including colouring books, dolls and action figures, clay, bubbles and Lego. This part of the interview was designed as a break for the child, however, it turned out to be a great opportunity to build rapport and talk openly about whatever came up in the game.

Free play is such a powerful tool for understanding and connecting with children because it forms a space where children can talk about whatever they like without the researcher's guidance or questions. Even with my efforts to respect children's agency and encourage participation, I was still in charge of the process because I designed the methods and I decided on the general themes of this research. In play, children are fully enabled to do or say whatever they want and be in control of the activities we engage in. It is an accessible tool that engages children's minds, as well as their emotions (Greenstein, 2014).

The table below (Table 4.1) illustrates the whole list of tools and activities I utilised to explore topics of conversation with the children. The tools were presented in a form of a workbook that the children and I explored together while casually making conversation when possible. The activities were offered as a suggestion, but were not imposed on the children, therefore children had the decisive power over the way the interviews proceeded. While some children preferred to stick to the outline I had



prepared, some others changed the rules of the game and completed the activities or answered questions in the way that made more sense to them.

#### **4.4.2 Participant Observation**

Participant observation is a research method primarily used in ethnographic research in the field of anthropology, which has now been adopted by many other disciplines in social sciences (Montgomery, 2014). The method aims to gain access to a certain group or culture and actively engage with the participants of the research. As suggested in Corsaro and Molinary's (2017) ethnographic research, my approach to building rapport with the children and enter their culture was to let them interact with me. I joined children in their daily activities in the centre, in their playtime and during meals. I was introduced by the teacher as the new girl who will join their classes and activities. Their curiosity towards my unusual presence compelled them to come and talk to me and ask different questions. After the first few days, they were no longer shy or hesitant to talk to me but would interact with me whenever they could and ask me to join in their games and activities.

The length of my observation was relatively small compared to the typical ethnographic research. However, it proved to be a valuable tool and provided many advantages in gathering data and continuing with the next steps of the research. Firstly, it helped me build rapport with children and get to know them before the interviews. The observational data informed and shaped the tools and activities in the second stage to suit each child depending on their competencies, impairments and challenges. Secondly, it provided information on the interactions children with IDD's had with other children and adults in their social environments. Despite the questions and activities that explore the topic of social relations, it is more insightful to take part and observe such interactions.

The main advantage of using participant research is that it ensures the full inclusivity of all children regardless of their impairments (A. Cocks, 2008). In spite of my efforts to create an interview format that would be inclusive and utilise all forms of communication. One of the participants could not participate because he was fully non-verbal, therefore, his participation in this research was enabled by the use of participant observation.

#### **4.4.3 Interviews with Parents and Professionals**

In the third stage of the research, once the activities with the children were finished, I conducted interviews with the teacher and therapist who worked at the centre and some parents who were willing to participate in the project. The purpose of qualitative interviews is to understand the viewpoint of the participants and to co-construct

Tools and Activities	Conversation Topics and Aim
Naming activity - Who Am I?	The aim of this activity is for the participant to present themselves and give some basic information. It is a simple drawing activity that makes a good start for the interview
Daily Routine - My Day	This activity is used to explore children's daily routine by writing or drawing everything they did the day before the interview. The tool also contains a section where children can present who they were with during the day to explore social relations. Finally, the tool has a space where children can express how they felt during the daily activities with the help of emoji stickers
Complete the sentences (about School)	Children were presented with a picture of a school and some sentences they could complete to describe their experience in school
Pictures and questions	Children were presented with pictures containing: a classroom, two pupils sharing a desk, a teacher, a teacher asking a pupil a question in front of the blackboard. These pictures were used as props to encourage children to talk about their own classroom and how they feel about being there
Drawing OR Cut and Paste Activity - My friends	Children were asked to draw their friends. If they found drawing difficult they were offered to cut the shapes of the boys and girls and glue them in a blank page to represent their own friends. While they were doing this activity I asked questions about each friend to explore their relationship with them
Friendship High-5	An activity where children draw their own hand and, in each finger, write what they think makes a good friend.
Drawing OR Cut and Paste - My family	Children were asked to draw their family. If they found drawing difficult, they were offered the option of cutting the shapes of family members and glueing them in a blank page to represent their own family. While they were doing this activity, I asked questions about each family member to explore their relationship with them
Talking cards	Children were presented with a stack of cards. Each card contained an image of an activity, a setting or an object. Children were allowed to comment and share whatever they think about it. When the children didn't have anything to say they were asked encouraging questions such as what do you think is happening in the picture, who do you think these people are, what are they doing, what would they say or do? The purpose of these cards is to serve as props to start a conversation about different topics. It was very useful to explore children's realities and their thoughts and reactions towards different situations
My Healthy Day children's book	This book was taken from the child-friendly materials published by Save the Children Albania. This book displays pictures and some text about a common day in the life of a young boy. This book was used to start a conversation about a children daily life. It was used to explore topics such as their level of independence in performing everyday activities, their relationship with their caregivers and the range of activities they perform compared to the activities an average child in Albania is supposed to do as displayed in the book. This book was useful because children enjoyed reading it as an activity and it provided interesting information about their daily life. The book was given to the child to browse and most commonly they did not read it but only commented on the pictures as the latter take up most of the page.

Table 4.1: Table 4.1: Research tools and themes explored

knowledge on a topic through a professional conversation (Brinkmann & Kvale, 2015). Keeping in mind the participatory principles of research, I designed the interviews with the intention of allowing the participants the space to share what they assess as the most important information on their lives and experiences.

The semi-structured interviews were organised into general themes and talk points, however, these were not imposed on the participant. They were points that helped me guided the conversation if needed without pressuring the participant to answer them. The main themes were similar to those of the children's interviews, namely daily life, education, social life and healthcare.

In addition to the general topics of conversation, each participant contributed with their own stories, opinions and perceptions. Parents were mostly keen on sharing the challenges of raising a child with IDD in Albania, as well as their hopes and fears about the future. Whereas, the teacher and therapist preferred to talk about their experience of working with children with IDDs and their professional approach.

#### **4.4.4 The Practical Implications of the Mosaic Approach Unfolded in Real-world Research**

The Mosaic approach is a framework designed to listen to children through a range of tools and activities that enable communication and exchange of information. The research tools I selected and combined to conduct interviews with children, required constant adaption and improvement in the process of fieldwork. In the beginning, the tools were shaped by my initial meetings and familiarisation with the children during the first stage where I employed participant observation. Then, during each individual interview, the interview tools and activities were reshaped and redesigned by the children themselves in the way that they understood them.

By the end of the fieldwork, I gathered a wide range of data from children expressed in various ways. Because my methods were competence focused, each child had the opportunity to express themselves in the way that they chose. As a result, each participant produced a very unique "tile" of data unlike the others. Furthermore, I interviewed the children's parents as well who divulged plenty of information regarding their children. Due to the nature of the interview, they were also quite free to choose what they wanted to share and emphasise in their interviews. The goal of the mosaic approach is to collect individual tiles of data and incorporate them to create a full and diverse picture of the experiences of children with IDDs. Informed by the concept of heterogeneity of childhoods as well as heterogeneity within the group of children with disabilities, this approach helped me illustrate how each child experiences life differently and expresses themselves differently.

Moving further into a deeper understanding of the data and the information shared by the participants, it is valuable to shed light on the processes of co-constructing knowledge and meaning-making. Meaning plays an important role in social interactions. It can be defined as "culture, norms, understandings, social reality, and defini-

tions of the situation, typifications, ideology, beliefs, worldview, perspective or stereotypes" (Krauss, 2005, pg. 762). One of the purposes of qualitative research is to gain insight into the complex meanings of people's lives. In the process of participating in the everyday life and routine of children in the centre, I attempted to grasp the social meanings children attach to the world around them, to the activities they participate in and their relationships with others.

One of the key aspects of the meaning-making process is the awareness the researcher has of their own perspective and view on the topics they are researching (Hunter, Lusardi, Zucker, Jacelon, & Chandler, 2002). In my research, I strived to move away from my understanding and preconceived meanings in order to be open and receptive to the participants' reflections. When I entered the interview setting, I disregarded any expectation or idea of how it was going to proceed. I allowed the participants to lead the process of creating knowledge with the aid of the methods I had designed. The traditional participatory research tools were in a continuous process of adaption and change initiated by children in order to suit their understanding and meanings attached to them.

## **4.5 The Ethical Principles of Inclusive Research with Children**

In order to conduct ethical and right-based research, it is advised to compile and adhere to a list of guiding ethical principles (Beazley & Ennew, 2006). Inspired by the principles of an inclusive research with children with disabilities drafted by Jenkin, et.al (2015) and ethical guidelines founded in the children's right to be properly research manuals (Ennew et al., 2009), I compiled a list that applies to this research. These principles ensure not only the respect for children's right to be properly researched, but also the participatory nature of the research (Thomas & O'kane, 1998).

### **4.5.1 Respect for Human Rights**

Respect for the dignity of others including children is a core value of human rights and the UNCRC. Ethical rules and considerations in a research should be guided by principles of children's rights and the UNCRC. Based on the provisions of the UNCRC, researchers have developed guidelines for right-based ethical research with children. It translates the articles of the convention into a comprehensive guide to ethical research with children (Ennew et al., 2009). The UNCRC ensures children's involvement in matters that concern them, which includes research. This principle informs the design of the methodology and children's position as participants that are as important, if not more, as adult participants. Furthermore, respecting children's rights entails creating space for their participation without discrimination and barriers and allowing children

to speak freely and be heard.

#### **4.5.2 Informed Consent and Assent**

According to international and national ethical guidelines regarding gaining consent for children's inclusion in research, every participant under the age of 18 is legally considered a minor and the consent for their involvement is obtained by their legal guardian. In my project, I gained consent from two main gatekeepers, namely the director of the institution where I conducted the research and the parents of the children who participated. They received a written information letter describing the research aims and methodology as well as a consent form which they signed to signify their agreement.

In addition to receiving parental consent for the child's participation in research, participatory research should engage in a process of obtaining assent from the child as well to recognise their agency and right to participate or withdraw from research. (Jenkin et al., 2015). Obtaining formal consent is highly dependent on the participants demonstrating maturity and adult-centric communication skills, therefore in this study I attempted to seek assent from children informed by their competencies and abilities.

Cocks (2006) suggests that researchers need to move away from the idea of competence as a precondition of participation and agency. Incompetence and dependence should not be portrayed as an obstacle but should be critically and creatively addressed by designing appropriate methods and tools that respond to the needs of the participants. Through the use of visual and activity-based methodology, children can demonstrate their desire to participate by joining in the activities. Furthermore, this choice of methodology served the purpose of enabling the full engagement of the participants and creating a space for collaboration and co-creation. Using multiple tools and providing options for participation gives children the freedom of choice and asserts their voluntary and enthusiastic engagement (Farmer & Cepin, 2015).

Following the example of Harcourt, et.al's research (2011) children were informed about each step of the process to avoid overwhelming the child with information or being unclear about what their participation entails. Employing assent as a way to obtain children's agreement is an ongoing process that requires reflexive evaluation in each stage of the research. In the first stage, I was introduced to the entire group of participants and children were asked whether they agreed to let me join in their activities and sit with them in the common rooms. Whereas in the personal interview stage, children who were participating were also given information about the interview, in addition to being invited to have a look at the games and activities. These children were allowed to decide whether they wanted to engage with the games and activities or not.

The influence of the social space where the research is conducted is inevitable, therefore it needs to be considered and evaluated in the process of seeking assent (Barker & Weller, 2003). The centre where the research was conducted was formally structured

and learning-oriented. Children were used to following instructions from their teachers, carers or therapist and going through a regular schedule. When I stepped into the room to hold the individual interviews, children immediately perceived the space as a classroom where they were meant to learn something or perform some sort of task organised by the researcher. The culture of surveillance and compliance common to these kinds of settings may limit the choice of the participants to opt out of the research without feeling as if they are doing something wrong. Yet, by creating an inviting environment and employing participatory and creative methods I attempted to offset the negative influence of that space on the nature of the encounter. By paying attention to the children, I reflexively responded to their physical and emotional cues, by assuring them that participation is not compulsory they are entirely free to do as they please.

### **4.5.3 Privacy and Confidentiality**

The concept of confidentiality and privacy is one of the fundamental tenets of conducting ethical research with children. In general terms, confidentiality can be defined as the measures taken to ensure that the information the participants share remains private. This concept is operationalised in research through the process of anonymisation of the data so that the research findings cannot be linked to individuals (Einarsdóttir, 2007).

Regarding research with children, the researcher should aim to keep the things children share private from the public but also from parents or teachers who might be intrigued to know what they shared in private conversations (Wiles, Crow, Heath, & Charles, 2008). Children have the right to share their information privately and to be assured that it is handled with confidentiality. Anonymity was made possible since the beginning of the research. Children's names were changed and nicknames were used instead to identify children in my notes. I kept my notes and children's activity sheets with me the whole time and they were stored safely in my room. The data obtained throughout the research process was used solely for the purpose of this research. Furthermore, the private interviews were conducted in a separate room where no one apart from the participant and I were permitted to stay. All of the details that children shared were kept private regardless of the interest of parents or teachers to see what they had shared during the interviews.

The principle of protection and the child's best interest defines the boundaries of confidentiality in research with children (Williamson, Goodenough, Kent, & Ashcroft, 2005). The researcher has a legal obligation to report to the authorities if they have reason to believe that a child may be in danger or may be subject of violence or harassment, despite the agreement of confidentiality. In the duration of my fieldwork, I did not encounter cases of abuse that needed to be reported. However more subtle ethical dilemmas were presented regarding the privacy of the children's information. Some parents expressed interest in my opinion on the progress of their therapy and what actions they could take in order to improve the quality of life for the child. Taking into

consideration the best interest of the child, I gave parents some advice or insight based on the conversations and observations I shared with the children in order to let them know what they could do to help them. To illustrate the way I navigated this dilemma, I will present the case of Altin. In the private interviews we conducted together, he showed a big interest in drawing and illustrating. Altin was comfortable with answering my questions directly without the need of using the tools and methods I had prepared to conduct the task-based interview. However, he preferred to draw some cartoon figures for the entire duration of the interview. After learning about his interest and talent in drawing and his lack of space and time to practice it I felt the need to inform the parents about it. I shared my enthusiasm regarding his abilities and suggested they try to provide an art class for him.

In addition, when researching children with IDD, researchers should take into account that some children may need or feel safer at the presence of a caregiver or assistant and they should also have the right to receive needed support. Jenkin, et.al (2015) proposes that children's right to privacy and confidentiality should not be exercised at the expense of providing support. Informed by this consideration, children were asked before the interview if they were okay with their teacher or parent leaving the room so we could spend some time together. Due to the friendly rapport we had built throughout the days prior to the actual research, children felt comfortable with that option and did not require support during the private interviews.

The principles of privacy and confidentiality were duly respected even in the case of private interviews with the adults, where the same rules were followed.

#### **4.5.4 Ensuring Safety and Protection from Harm**

The tension between protection and participation is highlighted in the children's rights debates. The three main pillars of the UNCRC, commonly known as the 3Ps, are provision, protection and participation. Participation is conceptualised as children's right to actively contribute to decisions and knowledge production processes that affect them. On the other hand, every activity they are engaged in should be in their best interest and not subject them to any kind of harm. The dominant idea surrounding children with disabilities, is that of dependence and a higher need of protection and adult supervision. Consequently, children with disabilities are rarely included in decision-making in matters that concern them, which sometimes leads to more harm and abuse as a result of misinformation (Brady & Franklin, 2019).

Participants' safety and well-being during the research process is of paramount importance and should be ensured at all times. The process of interviewing may bring up uncomfortable conversations or negative emotions for both the children and the parents. Thus, the researcher needs to be aware of the participants emotional state during the interview and be responsive and empathetic (Brinkmann & Kvale, 2015). In order to address children's emotions and make them an important part of the process, in my research I implemented the "Feeling OK" tool developed by Beazley, et.al (2005)

in a research which explored a difficult and sensitive topic such as punishment. The purpose of this tool is not to collect data, but rather to account for children's safety and well-being. It proposes a series of steps the researcher can take to make certain that the child is feeling OK and that the interview is closed on a positive note.

Moreover, the researcher might face ethical dilemmas during fieldwork where positionality and principles, as well as personal choice, informs the decisions they make. In an ethnographic research with children with disabilities, the researcher witnessed an episode of bullying in the school halls which the teachers did not know about. The ethical dilemma that arose from this observation was to not engage with the situation, to inform the teacher by breaking the principle of confidentiality or to behave as an adult would and protect the child from bullying. In this case the researcher decided to give the decision power to the child and openly asked him if he would like the episode to be reported or not (McArthur, 2020). Inspired by this case study, in my research I followed a similar approach when presented with dilemmas concerning harm and confidentiality. Whenever I had a doubt, I always asked the child's opinion to make sure

## **4.6 Chapter's Summary**

The methodological approach selected for this research is the Mosaic Approach which brings together a combination of methods inspired by participatory and ethnographic research. The fieldwork was conducted in a daycare centre and was organised in three stages, with different methods employed in each stage. The most important method utilised was the activity-based interviews with children with IDD, which included a set of child-focused tools that aided the exploration of the research questions. Participant observation and interviews with parents and professionals complemented the child interviews and helped build a more complex understanding of the research questions.

Moreover, this chapter discusses issues of field entry and negotiations with parents and staff. It presents the importance of reflexivity in this research and my positionality as a researcher in relation to the participants.

The research was guided by a set of ethical principles which are explored in this chapter. The main principles that were applied are respect for human rights, informed consent, privacy and confidentiality and protection from harm. These principles were explored and illustrated with examples of their practical application in the fieldwork.



# **Analysis and Discussion of Key Research Findings I**

## **5.1 Introduction**

The current and the following chapters present and discuss the empirical findings from the fieldwork. The approach followed in the analysis chapters, is that of incorporating the research findings with the discussion, linking the conclusions drawn from the data with those of previous research and theory. Data is organised based on the main themes identified in the research questions and developed into sub-themes that were co-constructed with the participants. The topics of analysis covered in this chapter include children's everyday life and routines, children's main activities and special interests. Furthermore, this chapter delves into issues regarding education, exploring children's relationship with the school, teachers and peers. Lastly, it explores the challenges in accessing and receiving quality education.

## **5.2 Everyday Life and Routine of Children with Intellectual and Developmental Disabilities (IDDs)**

The everyday life of children with IDD is similar to the life of every other child in Tirana. Their day starts early in the morning when they wake up and get ready to go to school. They follow a regular morning routine of getting dressed, having breakfast and making their way to school. They spend a few hours at school, depending on the grade they are in and they are finished by 12 or 1 pm. After school, some of the children I interviewed would come to the daycare centre to spend the afternoon hours. Younger children spent their time together with the kindergarten group whereas the older children would follow special classes. Some children followed 'extra' classes where they would individually study the lessons they did at school for the day and do their homework under the supervision of a teacher specialised in teaching children with

IDDs. Some children came to the centre to follow the English lessons and some also had therapy sessions with the centre's therapist. After their activities were over, their parents came to pick them up from the centre and they went back home. At home they would mostly rest, play or watch TV until it was time to go to bed.

In one of the recall interviews I held with Sindi, an 8-year-old girl, she briefly described her routine as follows:

*Sindi: In the morning I went to school, my mother walked me there after I had breakfast. Then the driver with the mini-van came to pick me up from school and took me here, in the centre. Here I learned English and played with my friends with Legos. At 7, my mother came and we went home together.*

*Interviewer: Did you enjoy the day yesterday?*

*Sindi: Yes I had a lot of fun.*

Children seem to be aware of their routine and the most important things that they do during a normal day. They generally report to being happy and content with their daily life and most of the activities appear to be enjoyable for them.

The activities that children with IDD engage in during a normal day are very similar to those of other children. Typically activities can be categorised into education-oriented activities, family activities and leisure activities. Education-oriented activities include everything children engage in at school or in the educational centres and activities that revolve around learning. Family activities are things children do together with their family members. Leisure activities is a category that includes free playtime and special interests or hobbies. Each of these activities is presented and discussed below.

### **5.2.1 Education-oriented Activities**

Based on the data gathered using the tool entitled "My Day", where children list everything they did during the day, it is evident that they spend most of their time engaged in education-focused activities. These activities are a crucial facet of the week days that they spend in school, which ranges from 3 to 6 hours per day. After school, the children I interviewed attend the centre's activities which are also education-focused. On the days that they return home straight from school rather than attending the centre, they tend to do the same with the help of their parents. The afternoons are spent completing homework and revisiting the lessons they had at school. Due to the challenges in learning and cognition, often children with IDD require more time to absorb the school material. On the other hand, they sometimes struggle with attention and concentration on a specific task, especially when it is difficult and generally not entertaining. Therefore, the amount of effort they dedicate towards learning together with their parents is larger than other children.

Furthermore, informed by the hegemonic discourse of child development, children with IDD are categorised as a group of children who need to take part in activities

focused on the development of cognitive, physical, social skills in compliance with the stages and milestones that they need to reach in accordance with their age. In therapy and the educational sessions that they complete at home with the aid of their families, children have to complete a lot of rigorous extra activities in order to demonstrate development that is considered standard for their age. Parents and the professionals at the centre often talked about the "work" that they need to do with the children for them to develop properly or to achieve their highest potential. Children with IDD are constantly challenged to learn and acquire new skills. Parents are very conscious and attentive to their cognitive development.

### **5.2.2 Family Activities**

The main family activities include meal preparation, family mealtimes, household chores, playtime with siblings, visiting relatives, etc. At home, parents dedicate a large amount of time to teaching their children how to take care of themselves and be self-sufficient around the house. For children with IDDs, it is very challenging to take care of themselves without the assistance or supervision of an adult. For most children, activities such as brushing their teeth, showering, preparing simple meals like breakfast and dinner, getting dressed, waking up in the morning, getting ready to go to school are tasks that they complete on their own without the help of their parents. However, children with disabilities often require help therefore parents put a lot of effort into helping their children learn how to complete these tasks on their own. Moreover, parents encourage their children to participate in household chores and home-based activities in order to promote engagement and skill acquisition (Law et al., 2013). Everyday activities as mentioned before become an opportunity for learning and development as perceived by the parents. From the children's point of view, these everyday tasks and small responsibilities are not perceived as difficult or challenging. In fact, they enjoy some small household chores like watering the plants or cleaning their room.

Siblings play a very important part in the life of children with IDDs. The social roles assumed by siblings are diverse and dependant on age difference, gender and personal characteristics (Moore, Howard, & McLaughlin, 2002). In the interviews children and parents talk about the large amount of time siblings tend to spend together in the household, engaging in various leisure activities and playing games. When they are in a similar age, they become friends and playmates. Whereas, in the case of older siblings, their roles tend to be different. They assume a caregiving role and try to "parent" their sibling with IDDs, especially noted with girls. Older siblings often invest in their sibling's with IDDs social integration and the development of social skills. This section of the interview on family relationships indicates the special bond that can be developed between siblings.

Toni: Every weekend my sister and I go out and do something together. Last

week we went to have lunch at a fast food restaurant. Sometimes, we go to the cinema or to the park.

I: Do you enjoy time with her?

Toni: Yes, it is my favourite day. She is very nice and I have a lot of fun.

Another influential factor is the type of disability children have. For instance, children with Down Syndrome, despite their developmental specifics, are very social and easy to be around. However, children with autism might exhibit behavioural issues that might be difficult to manage by their siblings (Roper, Allred, Mandleco, Freeborn, & Dyches, 2014). Despite, individual differences sibling relationships tend to be positive and an important source of emotional and social support for children with IDD.

One of the activities that children enjoy the most is spending time with their relatives. Most of the children mentioned in interviews that during the weekend one significant part of their routine is to go and visit their relatives with their family. For some children it is also common to spend holidays with their relatives who live in different cities or villages in Albania. Sindi often told me several stories of visiting her grandmother's house in the village. During the summer months, her parents take her there and she spends a few weeks living with her grandmother. She's very impressed by life in the village surrounded by nature and animals and in many instances she mentions all the things that she does there are very different from her life in the city. She explains that in the village she has more freedom to do what she likes without the constant supervision of adults. Due to the structure of life in the village as opposed to the city, children are allowed to spend more time on their own and play together in bigger groups.

Relatives are an important support system for families and children with IDDs. They assist parents with the care of their children by looking after them when parents are occupied and help to ease the pressure off their daily life. Raising a child with disabilities is perceived as a difficult task, therefore the members of the extended family are mobilised to help and support the nuclear family. In one of the caregiver interviews that was conducted with the child's aunt instead of their parents. It is interesting although uncommon the dedication and affectionate relationship developed between the aunt and the child.

Most families rely on their extended family, commonly grandparents, to care for their children while they are working or busy. Whereas for children themselves, they are a source of affection and companionship. In Albania, as in most countries, grandparents are highly involved in the lives of their grandchildren. Depending on factors such as proximity, their relationship with the family and their understanding of the child's specific needs, they play an important role in children's life (Lee & Gardner, 2010).

### **5.2.3 Special Interests of Children with IDDs**

Playtime is one of the most important and enjoyable moments of the day for children, especially at a younger age (Glenn, Knight, Holt, & Spence, 2013). Most children

expressed an increased preference in playing electronic games on their computers or smartphones. They are highly interested and fascinated by technology and love to spend time playing. Research suggests that the increased interest in online games and virtual worlds is a significant feature of the childhoods of the modern days affecting the cultural and social spheres of the young generations (Marsh, 2010). This is also the case for children with IDD in my study.

For parents screen time that children with IDD spend is seen as problematic because it can easily become addictive which may lead to self-isolation and loss of interest in other activities. It is also believed to affect the cognitive and social skills of the children with IDD as it might contribute to deepen the challenges experienced in these areas. Children with IDD are prone to use technology as a means of escaping uncomfortable social situations, which makes it harder for them to develop social skills. Furthermore, as it happens with children in general, technology distracts children from learning and educational activities such as homework, therefore impeding their cognitive development. Parents try to limit children's time using technology and encourage more playtime away from technology. Despite the awareness of the negative consequences of technology, there is also a pattern in using screen time as a method of positive reinforcement for good behaviour or task completion.

In one instance, I was a witness to this practice when I conducted an interview with the parents of one of the children. The four of us were sitting together in one row and the child was very impatient and did not want to wait for their parents to give an interview with me. The mother handed her smartphone over to her child and promised that he could play his favourite game on the device if he was quiet and allowed us to talk for a few minutes. The child agreed to this deal and started playing on the phone. I observed that he was very engaged with the game and did not show any curiosity about what was going on around him. He was very focused on the mobile game and did not seem to be listening to our conversation or showing any interest or engagement with us. Normally he was considered to be a very curious child, however, the mobile game captured all of his attention and interest. This story illustrates how indispensable technology is to children with IDD.

When it comes to technology, there is an international debate between protecting children from the harm that it might cause, in contrast to giving them agency to spend as much time as they like using technology and have access to information. The 2017 UNICEF report (Third, Bellerose, De Oliveira, Lala, & Theakstone, 2017) offers insight into the perspectives of parents and children regarding technology. Parents' central issue is concern over the negative consequences that the overuse of technology might have on their health, school performance or social life. The authors view children as fragile and 'ignorant' of the dangers of the online world, therefore they undermine children's capacity to act responsibly and be aware of the risks. Whereas, children are often concerned about cyberbullying, discrimination and inappropriate content. Moreover, they highlight issues surrounding inequality of access to the internet and technology depending on economic status and location.

When it comes to children with disabilities, issues of vulnerability, support, and safety are in need of examination with regards to child and disability rights. Alper and Goggin (Alper et al., 2016), call for an intersectional framework when discussing digital rights, as a result of the conflicting factors that influence children access and participation in the digital age. The main factor that highly influences the usage of technology is socio-economic status. Children's access to technology is dependent on the family's capacity to provide resources such as internet services and digital devices like phones and computers. In Albania, access to technology and the internet is not considered as a basic need. Therefore less affluent families are not inclined to provide children with their own devices. Most children are allowed to use their parents' smartphones or computers but they don't have ownership of them. On the other hand, it is more common for affluent families to give smartphones or tablets as presents to their children, consequently providing them with greater access opportunities to the internet.

Some children during the interviews or casual interactions shared with me their special interests or hobbies that they enjoyed the most. In our interview about school, Kris told me about his favourite class, which is Physical Education (PE). In this class, boys spend their time mostly playing sports and exercising. Kris's favourite sport is football and he is especially enthusiastic in the class when he is selected to be captain of the team.

*Kris: Once I got to be captain of the team and I had a lot of fun.*

*I: What was it like? What does the captain do?*

*Kris: The captain is the leader of the team and he needs to plan how the game. Once I designed a game plan for my team so we could win and I shared it with the others.*

*I: Are you often the captain of the team?*

*Kris: No, everyone is captain, we take turns.*

*I: Is football your favourite sport?*

*Kris: Yes. I also like basketball and volleyball, My dad also like football and sometimes we watch games in TV when I finish my homework.*

Many children attested to enjoying participation in sporting activities at school. Florian said he also attends private basketball sessions on Saturdays and plays with his friends. It is very common for parents to send their children to private sports classes as a way of encouraging an active lifestyle and providing opportunities for socialisation outside of school. However, there is a gender disparity in the opportunities of participation in sports, because girls are not commonly taken to sports lessons and do not mention playing sports at school.

Sports are very beneficial for children with IDD because they provide opportunity for learning, improvement of skills and socialisation with peers in a friendly setting. Research suggests that the effects of exercise and sport in children with IDD is associated with improved physical health as well as psycho-social functioning. Sports

are an effective way of promoting inclusion amongst children (Murphy, Carbone, et al., 2008). Furthermore, it is a positive influence in developing healthy and productive lifestyles and increasing the general well being of children (Wilson & Clayton, 2010). Children with IDD's particularly enjoy the sense of accomplishment and self-efficacy (Wickman, Nordlund, & Holm, 2018) they experience when they successfully participate in games, especially if they win. Moreover, they enjoy the company of their peers and the fulfilment of being part of a team.

There are children with IDD's, especially those with autism who find great enjoyment in hobbies or special interests. Tina says her biggest passion is music and she loves playing the piano. Her interest in music, prompted her parents to attempt to get her registered in the artistic lyceum in Tirana. This is a special school where children follow intensive, specialised art classes and a reduced load of the general subjects. She was in the second year of high school now and her excitement and pride over her accomplishments was so apparent when she showed me videos of her performances on the piano. Altin was another child who was passionate about art. He had a talent in drawing detailed pictures of the characters of the games he played on his phone. He was only 10, but his drawing skills were fascinating together with his unique style of drawing and perceiving the characters. Art provides children with IDD's with an outlet for expression and creativity that doesn't require verbal communication or interaction. Art is an activity that does not require guidance or supervision from an adult and therefore it enables children to express themselves freely and creatively, without having to partake in adult-lead structured activities. Artistic practices and free play are activities that empower children and acknowledge them as experts and active agents.

#### **5.2.4 The Importance of Place in Everyday Life**

The significance of place in the socio-cultural perspective plays a formative role in a child's life and experience of disability. The "place" a child lives determines the community's social norms and beliefs, the services and interventions provided for children with IDD's, the family circumstances and many other contextual factors (Skinner & Weisner, 2007). Place influences a child's life particularly in terms of their social inclusion into meaningful life. A place built upon values of equality, democracy and inclusion has a positive effect on the child's life there and in general. A place that gives children a sense of safety and acceptance can easily become the central thing in their life. Tina's favourite part of the interview was when we talked about her school. She loves going to school and is very attached to her friends and teachers there. She was always excited to go to school and her mother claims it's the only reason for which she is willing to wake up early in the morning. She has many friends there, which she mentioned by name and she loves her teacher because she takes good care of her. Her favourite days are when she gets to practice the piano and learn new tunes. For Tina, school is the only place where she can freely interact with peers and be active the whole time. At home she often gets bored because she doesn't have much to do. She shares her

bedroom with her sister and she has to be quiet in the afternoon so that she can study.

Children's life in Tirana has become mostly situated in indoor spaces, commonly structured and supervised by adults. Most of their time is spent going from one institution to another and following the required schedule and rules of those places. They spend a few hours at school, followed by attendance in day centres, therapy sessions or extra lessons. Young adults with IDD's spend a larger amount of time at home, compared to their peers. They commonly lack independence and the privilege of going outside unsupervised or visiting friends' homes which is common for most young people in Albania.

### **5.3 Education**

A systematic review on children's participation in school (Maciver et al., 2019) identified the mechanisms, contexts and processes that enhance or inhibit participation. The three key factors that were common in most research were the child's identity, their competencies and their experience of their own mind and body which includes impairments and other symptoms. Regarding the characteristics of the school environment that facilitate children's participation, there are five interrelated areas that were identified from most of the research which are the organisation of the school, the social relationships with peers and adults and the space and objects of the school. This systematic review serves as a conceptual framework for further research in school participation as well as a guiding system for practitioners and policymakers I will use this framework suggested by the systematic review of the research in order to analyse the data and experiences that children shared regarding their participation in school in Albania.

Starting with the psycho-social factors, participation is affected by individual identity and the approach towards coping with their impairments. This is a factor which is different for every child therefore it is impossible to make generalisations based on the data from this research or any other quantitative or qualitative study. Every child has a unique relationship with school, which shapes the way that they experience education and learning. For some children school is a place where they spend the most important and active part of their day, in which they partake in activities or events that they typically enjoy. Children enjoy the idea of being with peers and being present in an environment where they receive attention and care from their teachers. By doing different activities, they stimulate their curiosity and sense of learning, in turn, aiding in their development. For some other children, school presents a place where they do not experience many positive emotions, in fact, they harbour a lot of negative emotions. They might experience anxiety, fear of the unknown and unpredictable situations as well as difficulty or challenges in concentration and understanding of what happens in the space of the classroom. Children with autism usually feel uncomfortable in these environments, with excessive sensory stimulation, so consequently they do not enjoy



being in public schools in Albania where classrooms are overcrowded and commonly noisy. They also don't enjoy increased levels of socialising encounters with other children or their teachers. They prefer to sit alone at their desk and they mostly prefer to complete tasks by themselves. Despite these challenges they still like going to school and have an overall positive experience of schooling in Albania.

### **5.3.1 Children's Relationships with Teachers and Other Adults**

Regarding their relationships with their teachers, most children have a positive yet not very intimate relationship with their teacher. Due to the fact that most children with disabilities have an assistant teacher who spends most of the day with them they feel more attached to this teacher rather than the main teacher of their classroom. They do not have a lot of interaction with other teachers apart from assistant and most of the learning is done through the latter. They develop a special bond with this teacher as it is a less formal, more intimate interaction than what other children have with the teacher that is responsible for the classroom. Therefore children view this teacher as more of a friend rather than an authoritative figure which is the other teacher in the classroom. One of the children referred to the assistant teacher as their "best friend at school" which clearly illustrates their close and friendly connection.

As is noted in research about social interactions of children with disabilities at school (Richardson, 2002), children with IDD have more interactions with adults rather than peers. Due to the difficulties in engaging with their friends or schoolmates, the assistant teacher accompanies the child even during free time activities, whereas other children are generally unsupervised and free to do as they please. The presence of adults has both positive and negative consequences for children with IDDs. The positive outcome is that it gives a sense of support and security to children who might feel socially anxious or fear unpredictable social settings at school, however it may also prevent children from learning to make new friends in the real world, which could hinder their social skills in the future. There is an underlying discussion of protection and the notion of making sure that the child feels safe and secure, but this tends to come at the cost of a lack of effort and intention to challenge the child. These challenges are vital in order for the child to progress and learn valuable life skills which will be very useful for them in the future and may help them integrate in society more easily.

### **5.3.2 Children's Relationship with Their Peers**

The relationship children with IDDs develop with their peers is crucial to their inclusion in the classroom setting. The peer attitudes towards them varies depending on many factors. One of the contrasting factors that influences peers' approach towards children or youth with IDDs is age. Firstly, younger children are less aware of the differences between each other. Their friendships and social connections are more fluid and flexible than friendships in older children or youngsters. It was evident from my research

findings that younger children with IDD found it much easier to form friendships and had a high number of peers that they considered friends. Whereas older children and young people found it much more complicated. Older children are able to better understand the differences between them and their peers with disabilities, therefore they are more prone to discrimination and prejudice. In many cases older children or young people are friendly and nice, they even exhibit helping behaviours, however they would not consider their peers with disabilities as their friends.

Secondly, research suggests that the longer and the earlier children with IDD are included in social environments such as school, the more accepted and included they are in society (Webster & Carter, 2007). When children learn from a young age that people with disabilities should be respected and cherished as contributing actors in society, they become more accepting of them in later stages and are able to form real friendships and bonds. As a result, the age of the participants determined their inclusion in the sense that younger children have been part of inclusive practices in education since the beginning of their schooling years. Whereas older children have not had the same opportunities of being included when they were younger. Their schooling and inclusion has been more gradual and has only become a reality in later years.

The case of Florian reflects this reality in the Albanian context. At the age of 8 Florian was registered in a private school in the first grade in order to take lessons together with his peers. After only a few weeks, the parents of the other children expressed their concern towards his presence in the classroom. They did not believe he belonged there and did not want their children to attend the same class as him. Therefore, Florian was obligated to abandon school and continue his education at home with the help of his parents and private teachers. Years later, he was finally able to attend school at the age of 12. However, he found it more challenging to fit in and develop social relations because he was not given the right space and opportunity to do so.

Apart from the influence of settings and children's age, many researchers conclude that individual characteristic of children has effects on the quantity and quality of friendships they form. The type and the severity of the disability children have is highly influential. Most of the social interactions between people are built upon communication. Therefore an impairment of the ability to communicate with others can become a barrier to forming friendships or social interactions.

One of the children at the centre, was unable to speak, but as mentioned before, his participation in the research was realised in the form of participant observation and casual interactions. Based on the findings extracted from my observations, it is clear Lukas' interactions with others were very limited. The only person he noticed and expressed motivation to interact with was his therapist. With respect to his peers he showed no interest, as if he didn't notice their presence. Other children did not particularly dislike him, but they also did not show any interest towards him. One of the girls expressed this approach when I asked her about Lukas

*We don't hate Lukas. He just prefers to be alone. The teacher told us that*

*we shouldn't bother Lukas if he does not want to play. He is nice but we are not friends. My friends are Bora and Liza.*

Another research that resonates with my findings reports that children with autism have few friends and the quality of their friendships are poorer than those of their non-autistic peers (Bauminger & Kasari, 2000). One of the influencing factors might be their tendency to engage in activities that do not provide opportunities for social interaction. Most of children with autism prefer to engage in solitary play or hobbies. They spend a lot of time playing games on the phone or computer, they like drawing, building with Lego's, etc. Arguably, their specific type of disability can be a barrier of forming friendships.

### **5.3.3 The Influence of Structural Organisation in Children's Experience of the Educational Settings**

An important aspect mentioned in the systematic review is the structural organisation of the school and the overall context in which children find themselves. In this research, I had the opportunity to draw a comparison between the setting of the kindergarten/daycare centre where I conducted the research and children's own account of their classrooms and school environments. Younger children do not have a very good understanding of the structure and system of their school. Nonetheless, they are generally express positive emotions towards talking about the classroom, where they sit in the class and their favourite places within the school. In contrast, older children have a better understanding of the way that the school is organised and give a better description of their classroom. Some children expressed a preference to sit in the back of the classroom as it is quieter and more secluded, however, parents explained that most of the time children with disabilities are seated in the front of the class so that they can be more attentive and closer to the teacher. But when the assistant teacher is in the classroom with them they are obligated to sit in the back with her so as not to bother the other pupils.

The environment in the daycare centre where children follow some lessons and activities is organised in a more inclusive and less traditional way. Instead of having desks of two students set up in rows as it is common in schools, children are seated at round tables that seat five or six children. they are allowed to sit wherever they choose to. It is common in Albanian schools that the teacher decides on where the children sit in the classroom and they are not free to change their seats during the day or even during the year. On the contrary, in the daycare centre they are allowed to sit wherever they choose to and they are free to move around the classroom. The system of the classroom in the centre is consciously set up this way in order to have a positive effect on children's perception of the space.

## 5.4 Challenges in accessing and receiving quality education

According to the Albanian law of Inclusive Education (*Law "For the inclusion and accessibility of persons with disabilities, 2014*), all children with IDD, who are enrolled in a general public school are entitled to an assistant teacher and an Individualised Education Plan (IEP). The role of the assistant teacher is to assist the pupil during the learning process both inside and outside the classroom to enable their full participation in all classes and other necessary school activities. The IEP is a plan designed specifically for a pupil with special educational needs so that they can learn alongside their peers with the same curriculum adapted to their abilities (Goepel, 2009). The legal procedure for assigning an assistant teacher involves the multidisciplinary commission that evaluates disability and the school board. The commission makes an assessment of the special educational needs of the child with IDD. They determine the amount of hours that the child requires the presence of the assistant teacher. This can range from assistance in exams to full-time assistance. Based on this report, the school board assigns the assistant teacher to the children with IDD in their school. The teacher is in charge of designing and implementing the IEP and following the progress of the pupil (Cuko et al., 2013).

In most of the interviews with the parents they report the challenges they experienced in obtaining the education services for their children. The first challenge they experience is in registering their children in public schools. Tina's mother shares a story of struggle with the faulty system in her attempts to register her daughter in the artistic lyceum.

*Tina's mother: It was very difficult to register her in the lyceum. I had to insist for months in order to get her in. They said that they don't have the capability to include my daughter, but I'm not certain if it was a matter of possibility or reluctance to accept someone with autism in the school. I am aware that Tina is not as skilful as her peers, but she is enthusiastic and willing to learn. That should be enough to accept anyone in school.*

One of the major challenges in educating children with IDD is the lack of assistant teachers. Children with IDD need constant support in school in order to learn. Without the assistant teachers, their integration in the classrooms becomes impossible. It is not enough to simply allow them to be in class. Inclusive education means that every child learns the same curriculum but in a way that is responsive to their needs and abilities. Therefore, the school is responsible for providing quality education and a productive learning experience for every pupil despite their specific needs. Parents who can afford it, pay for private teachers to accompany their children to school, but other families who cannot afford this service, depend on the state to provide it for them as required by law.

Another parent mentioned that it was also difficult to get an assistant teacher to spend enough time with her child at school. Some schools do not have enough teachers to cover all the pupils with disabilities in a school, therefore the time they spend with each child is very limited and it affects the child's ability to learn and follow up with the class very negatively. The therapist in the centre explained the negative consequences it had on Ani, who was following extra classes in the centre after school.

*Ani is a very special case. We worked a lot with him to be able to take him to a general school because it was very difficult for him to follow what was happening in class. It is necessary for him to have a teacher nearby to explain to him what he needs to do specifically. He understands everything, but he finds it challenging to follow commands if not explained personally to him. So on the days that the assistant teacher is not there, he is unable to understand and follow the lessons. This makes it very difficult for him to catch up in the following days. Luckily, he follows some extra classes during the week and we try to help him learn as much as possible.*

Apart from school, parents experience difficulties in registering their children in kindergarten as well. The main reasons that create this impediment are the lack of the proper capacities and resources, and the negative reactions of other parents towards children with disabilities, especially in private kindergartens. Kindergarten is not mandatory for children in Albania, although attendance is highly recommended to parents. Similarly to obligatory education, the state has the responsibility of proving inclusivity for all children in public kindergartens. However, there is a higher incidence of parents enrolling their children in private kindergartens or daycare centres.

Kindergartens find it very difficult to support children with disabilities because they don't have enough specialised staff to take care of them and they do not have the conditions of time and space to pay enough attention to them. The number of children per group in public kindergartens is very high compared to the number of teachers or assistants. The professionals at kindergartens perceive children with IDD as challenging and in need of specialised help and they are reluctant to take the responsibility of caring for them.

Another underlying factor that inhibits children with IDD's participation in kindergarten is the negative reactions of the parents of other children who attend the kindergarten. They don't want their children to be in the same group as children with IDD because they think that it will affect their children negatively. They have a strange perception that their "normal" children might learn inappropriate behaviour from children with IDD just by being in the same kindergarten group.

The parents perceive school in a very pragmatic way. From their perspective the main benefit children receive from going to school has less to do with education and learning and more to do with socialising with other children, learning to behave in a social setting and spending a part of their day doing something pleasurable outside the house. They always express concern that their children are passive and they don't

have much to do in their daily life. Therefore, school is a good alternative to staying at home. Moreover, taking children to school provides parents with more free time to do other activities and complete tasks.

## **5.5 Chapter's Summary**

The daily life of children with IDD is reported in three distinct categories. Children spend most of their time on education-oriented activities like going to school, completing homework and learning new skills. However, their favourite time of day is time they spend with their families or doing activities they are interested in such as sports, playing an instrument or drawing.

In the school environment, children with IDD are part of many social interactions. They develop a close and friendly relationship with their assistant teacher and spend a large portion of time in their company. Their relationship with peers is slightly more complicated and it is dependant on a set of factors. Their experience is also affected by the approach the institution they attend has towards children with IDD. A place that follows the principles of inclusion and acceptance is more favourable for children with IDD.

The parents' opinions and accounts of the challenges children experience with respect to education revealed many interesting themes. Parents mostly shared the difficulties they face in acquiring quality education for their children such as the struggle of getting them registered in school or kindergarten, the lack of assistant teachers and the stigma experienced from the community.

# Analysis and Discussion of Key Research Findings II

## 6.1 Introduction

The second chapter of the analysis, explores three main topics. Firstly, it presents the data gathered on the topic of healthcare, including diagnosis, therapy and treatment, as well as the challenges of raising a child with IDD. Secondly, it explores the intersection between disability and economic status, by highlighting the detrimental effects of poverty. Lastly, the chapter includes a discussion on the constructions of disability and the normalcy paradigm.

## 6.2 Healthcare

Public healthcare services are free for all children in Albania. Children with IDDs seek the general healthcare services just like every other child. However, apart from these services they require specialised services as well. The main specialised services children with IDDs seek are diagnostics, counselling and developmental and speech therapy, all focused on mental health and development.

In the field of mental health, there are a lot of drawbacks regarding the services offered for children. Firstly, there is still no university programme that specialises professionals such as psychologists or therapists to work with children. Child psychology is studied under the general Clinical Psychology master which allows for a very small part of the lectures to focus on children. Most professionals working with children have followed training courses offered by private therapy centres, whose quality and viability is not evaluated by any higher institution. The most common therapy that is followed in Albania with children with IDDs is Applied Behavioural Analysis (ABA) therapy, which is a highly contested and problematic therapeutic approach (Kirkham, 2017), (Chapman & Bovell, n.d.) . The centres that offer this therapy for children, also offer training for young professionals who are looking to be employed as therapists.

Secondly, due to stigma regarding mental health, parents refrain from seeking treatment for their children. There is a general distrust regarding the quality and reliability of services offered, especially when it comes to public services. Parents claim that most services are only formally offered but their quality is very low and they are inconsistent. Especially when it comes to therapy, there is a lack of infrastructure, necessary tools and most importantly a lack of human resources. As a result of the general unsatisfactory quality of the services provided in Albania, parents tend to lose trust and experience disappointment, which leads to a decrease in health-care seeking behaviour in account of their children.

### **6.2.1 Diagnosis**

The parents' interview data reveals that the process of assessment and diagnosis is very difficult for the families of children with IDD. Depending on the impairment type, the diagnosis is proceeded differently. In the case of congenital disabilities such as Down Syndrome, parents know from the beginning that their child has special needs. Increasingly mothers are undergoing screening tests during their pregnancy to check for any health conditions that might affect the baby. Although these tests are only done in private healthcare centres and are not included in the free public healthcare hospitals and are somewhat costly, more and more parents are informed about existing conditions even before the child is brought into the world.

There is no research on the decision making process of keeping or deciding for a termination of the pregnancy in Albania but it is interesting to bring in debates from other countries where the screening tests are more widespread. In developed countries such as Scandinavian countries where these tests are free, the number of babies born with Down Syndrome is rapidly decreasing. There is even public discussion on a potential extinction of people with Down Syndrome in the country (Norup, 1997). Whereas, in the U.S. where the topic of disability-selective abortion is very controversial. While the statistics show a decrease in birthrates for children with Down Syndrome or other conditions, there is still discussion on the morality of this choice (Fox & Griffin Jr, 2009). Disability rights advocates are arguing against genetic screening and counselling, deeming it an unethical action towards people with disabilities. This practice reinforces the construction of disability as something unwanted in society, making it even more challenging for parents to raise children with disabilities in communities that promote disability-selective abortions (Reingold & Gostin, 2018).

When it comes to disabilities that develop during a child's life, the main challenge Albanian parents face is acceptance. In my research, I was first introduced to the concept of acceptance of diagnosis by the therapist working in the centre. She claims that one of the biggest challenges in working with children with disabilities, is managing the problematic behaviours of their parents. Due to stigma and general negative conceptions of disability in Albania, parents find it really difficult to accept that their child has a disability.



*Toni's mother talks about her experience of her child's diagnosis. In the beginning, he was just like every other child. We didn't notice anything particular about him, we were just happy to have him in our lives. When he first entered kindergarten, we started to compare him to other children in his group. At first we noticed a few things that were different, but we didn't want to accept it. It took us a year to be convinced to take our child for an assessment and a lot more to accept his diagnosis. Now we regret that we were so sad and negative about it, because we still love our child the same, if not more than the first day he was born.*

The therapist argued that the main barrier to the children's development and improvement is their parents' approach to raising a child with disabilities. There are parents that persistently deny their child's diagnosis, therefore preventing them from receiving the help they need. They are reluctant to take them to therapy and even deny the fact that their child experiences difficulties at school or kindergarten. They are so fixated on the idea that their child should be normal that they ignore the pressing needs of their child in the present time. This level of parental denial is an observable direct consequence and a clear indicator of the stigma and discrimination that surrounds disability in Albania. The data suggests that there might be a connection between the parents' educational level and their approach towards their child's disability, as it is closely related to information and knowledge regarding disability.

Based on the findings of this research, there are typically two main types of approaches for raising children with disabilities. Some families choose denial and neglect to address the complex needs of their children hoping that they will grow out of their impairments. Other families are completely invested in giving their children the best chance they have at a happy life given the individual and social conditions. Every family knows it is not easy to raise a child with disabilities in Albania, due to the multi-faceted challenges. However, some families choose to hope for the best and have faith in the potential of their children.

### **6.2.2 Treatment Abroad**

Due to the shortcomings of the Albanian healthcare systems, both public and private, many parents seek treatment abroad for their children. Some families, depending on their economic and social conditions, attempt to go abroad to receive specialised services that are impossible or lack in quality in Albania. Depending on the type of impairment children have, they might need specialised diagnostic services, surgeries, medical advice or intensive therapies. Most families attempt to go only for a short amount of time, whereas some a few families try to move to another country entirely.

Kris' parents told the story of such an endeavour when they sought treatment in Germany. After two years of receiving a formal diagnosis from the doctors in Albania, they decided to attempt moving to a small city in Germany and build a new life there in

order to provide the best chances for their son. When they arrived there, Kris underwent a process of tests and diagnosis once again in order to receive services depending on his needs. After this process, Kris was placed in a special school where he received intensive therapy to help him make progress and reach important milestones for his age and type of disability. He had a lot of unmet needs for which the therapy and increased specialised attention he received in the centre, helped him overcome the lack of support he suffered in Albania. His parents admitted to being unaware of the multi-fold challenges he was going through. Kris' inability to express himself and their lack of knowledge and information about his impairments and needs lead to many difficulties and adversities for the child. In Germany, the parents learned a lot about their child's condition and also received instructions on how to care for him properly at home. The progress Kris proved to be crucial for his life afterwards and his parents claim that he had changed a lot after the first year there. Unfortunately, living in a foreign country is an arduous process due to the policies regarding Albanian citizens. Kris' parents did not manage to fulfil the necessary conditions and the whole family was forced to move back to Albania after over a year. The difference in Kris' life in Germany compared to Albania was vast. It was very challenging for him to readapt to living in his hometown, to the loss of support and the lack of therapy.

### **6.3 Joys and challenges of raising children with disabilities**

Although raising a child with IDD presents many negative or difficult experiences, it is also a source of positive impact. Children with IDDs and their parents form a very special bond with each other, strengthened by the amount of time they spend together, which does not diminish over time as with other children, and their interdependence.

Evidently, most international research on the parents of children with IDDs revolve around the themes of stress, depression, difficulties of adjustment and quality of life. Their quality of life is reported to be lower than normally developing children (Vasilopoulou & Nisbet, 2016) and the caregiving burden is significantly bigger, especially because it does not reduce as the child gets older. Due to the financial, social and personal strains of raising a child with IDDs, parents are at a higher risk of suffering from depression and anxiety (Scherer, Verhey, & Kuper, 2019).

*The nurses told me that there was something wrong with my child. They noticed the main physical characteristics of children with Down Syndrome. When I took the child from the hospital, the nurse told me these children don't live for very long and the expectations were very low.*

The lack of information and the negative expectations suggested by doctors, increases parents' fear about the future of their child. The information about Down

syndrome in Albania is mostly based on myths rather than facts. One of the common myths that is perpetuated by doctors and general talk is that people with Down Syndrome have a much shorter life expectancy than others. This concerning myth is particularly hurtful and hard to accept for parents especially in the beginning. Family members have a hard time coping with the news that their child has a disability and find it hard to accept it in the beginning. Part of this problem is the way doctors handle the process of diagnosis and informing the family. At first they tend to hold out the news, especially if it is a young mother, because they don't want to upset them. However, it leads to a general disbelief and scepticism about the healthcare system and doctors.

The most common reaction families have upon learning about their child's disability is sadness, desperation and fear for the future. The way that the information is shared with them is crucial, because it might help to alleviate some of the traumatic reactions they have. Most parents claim that they were so sad in the beginning because they did not know what to expect for their child, so they assumed the worst. If they had received a much more objective and empathetic information, they wouldn't experience it so badly. Despite the challenging start of the experience of having a child with IDD, parents always conclude by saying that no matter what, they are grateful for having their child. The love and special connection they form with their child is much bigger than any challenge that is presented to them. Parents share their perspective by saying that raising a child with disabilities is equally difficult as it is rewarding.

### **6.3.1 Mothering a Child with IDDs in Albania**

The majority of Albanian families follow a patriarchal model, although a modern one. Therefore, the larger part of the responsibility of child raising is with the mother. Mothers tend to dedicate their lives to their children especially if they have a disability. Most of them are obligated to quit working and stay at home to follow the routine and fulfil the needs of their child.

It is interesting to observe the multi-functions mothers take when raising a child with IDDs. Because of the special needs and lack of support they receive from other instances, mothers are inclined to provide the best care possible themselves. At the same time, they become a parent, a teacher, a therapist and a doctor. They are obligated to learn and read a lot about their children's disability and work hard with them in order to help them progress and integrate in society. It requires a big sacrifice and a lot of energy and hard work. Nonetheless, mothers are motivated by the love they have for their children and the hope and conviction that they will achieve more than is expected or predicted.

However, it is also common in Albania for relatives, especially grandparents to take care of children a few hours per day when parents are working. When it comes to children with IDDs, some relatives are highly supportive and give a valuable contribution towards taking care and educating children, on the other hand some are hesitant to take the responsibility of looking after a child with IDDs because they perceive them

as difficult and in need of specialised care.

One of the mothers, expresses her gratitude towards her husband's sister who has been a major help in their family with respect of caring for their child who was diagnosed with autism at the age of 3. When they found out about their son, his aunt offered to take care of him for a few hours every day. Being an elementary teacher, she started working with him engaging in games and educative activities. After many years, their relationship grew stronger. The aunt provided invaluable help for the family, while teaching her nephew and helping him progress.

## **6.4 Influence of Poverty**

Children with IDD have many financial considerations that need to be accounted for (Houtrow, Okumura, Hilton, & Rehm, 2011). Starting from healthcare and treatments, they often require physiotherapy and developmental therapy, apart from the usual care that children require in regard to their health. The public healthcare system in Albania is free for all people, however, there are many hidden costs of healthcare especially for children with disabilities. Many children with disabilities are in dire need of additional services to care for their conditions, whether it be a physical or mental condition. These are services that are not typically covered by the public healthcare system in Albania, or if they are available they are rather limited in their capacity to offer sufficient support.

The government offers very basic mental health services, such as therapy sessions in mental health clinics or day centres for children with disabilities. These services are free, but the standard and quality of these options are low, to the extent that they often fail to have a positive impact or influence on the child. The most common choice for families in need of these services is to seek assistance via private practices. The primary difficulty that families face when pursuing this option is that the cost for the service is typically substantial when considering the average income of an Albanian family. This finding resonates with the "Child Disability in Albania" report (Voko et al., 2018), that states that the main reason parents are reluctant to seek specialised healthcare services for their children, is not being able to afford the financial costs. Furthermore, parents claim that their children require special foods and diet, clothing and accessibility devices that all contribute to an increase in the costs of having a child with disabilities.

In relation to the spheres of education and leisure, children with disabilities are assigned assistant teachers by the state in public schools, however, parents are obligated to hire tutors specialised in teaching children with IDD privately as well. As mentioned before, many children also follow extra curricular classes or activities which contribute to the monthly expenses of the child.

Another economic aspect that is less prominent in the debates on the effects of child disabilities in families in Albania, is the loss of productivity and income. When a family is presented with the news that their child has a disability, they tend to put all their efforts

towards obtaining the best diagnostic visits, treatments and therapies. The increased attention that is poured over the child, usually comes at the cost of losing work and income. In the majority of the cases, mothers abandon their jobs in order to care for their child with IDD full time. They dedicate their whole lives to their children and their lack of employment results in less income for the household. Thus, the economic burden falls solely on the other parent. Legally, every child with disabilities receives a disability payment from the state and is entitled to a legal caregiver who also receives a payment for caring for the child during the day. In most cases, the caregiver is the mother but it could be another member of the family. Despite this, the sum of the financial support the families are entitled to is very low compared to the monthly expenses they have.

From a larger perspective, the economic situation in Albania is very difficult. The salaries are very low compared to the cost of living especially in the capital. Over the past few years has been a trend of a steady increase in the prices of goods and services, principally in the capital, Tirana, despite wages remaining stagnant during these years. Until January of 2021, the minimum monthly salary was 26,000 Lek (210 Euros) and now it is 30,000 Lek (240 Euros), and the average salary is 52,000 Lek (420 Euros) (INSTAT, 2021). Finding employment is another issue people face in Albania, with unemployment rates raising throughout the years. For families who were already in poverty before the birth of a child with IDDs, life becomes extremely difficult. They have to make many sacrifices in order to provide care for their child, sometimes in the expense of their other children as well. International research suggests that even in rich countries, families of children with disabilities are at risk of poverty due to higher costs of care and expenses. Furthermore, the experience of poverty is linked to poor health and well-being for children and their parents (Emerson, 2004).

## **6.5 Constructions of Disability**

Disability is not determined only by medical or psychological diagnosis but it is also a cultural concept (Davis, 2005). Through expectations, social norms and values, societies construct the dichotomy of abled vs disabled body or mind. The meaning and understanding of impairment and disability evolve over time not only as a result of scientific advancements but also as a result of policies, governance, social movements and emancipation (Goodley, 2016). Knowledge about disability is commonly reproduced through the exchange of beliefs and opinions between generations, from adults to children.

Disability in the Albanian society is constructed as an inability to function as everyone else in all the aspects of personal and social life. It is a restriction of the ability to act and interact with the world. The official Albanian term for a person with disabilities is "person me aftësi të kufizuara" which is translated to "a person with limited capabilities". Although NGOs argue for a more inclusive language, most people still use this term as

it seems to reflect their own understanding of what disability is.

The able-bodied standard is a measure that defines disability in society. The more a society focuses on reaching this standard, the less tolerant and inclusive they are towards alternative ways of being. The cultural approach to disability argues that disability and normality are concepts constructed in society through comparison and differentiation. Disability does not represent the true nature of an individual, rather their categorisation in society. "Disabled" and "non-disabled" identities are interdependent and continuously evolving and changing (Waldschmidt, 2017). The understanding of disability in Albania is a reflection of the normalcy and development discourses. A "normal" child is expected to follow the rules and norms of society. They should be able to successfully follow the school curriculum according to their age; they should be able to socialise with their peers, interact with them to complete certain tasks and create social relations within and outside their family; they should understand and respect the moral and social rules of society. A child with disabilities is defined as a child who is unable to achieve one or some of the aforementioned tasks assigned by society.

A uniting quality of Albanian childhoods is the high parental expectations, notably regarding education. Children are pressured into being the best students and the most successful at school and are always expected to have high grades. In contrast to most children, society holds very low expectations towards children with IDD. The general belief surrounding disability leads people to believe that they are not capable of being productive members of society. Once parents learned and accepted their child's disability, they admit that their expectations shifted and changed regarding academic achievements.

Children with IDDs are often compared to typically developing children despite them having different abilities and limitations. This system of standardised evaluation and judgement of a "normal" child reinforces discrimination and affects children's self-esteem. This conception of disability as opposed to normality connected to an normal-ideal child who cannot exist in reality. Human beings cannot be perfect, thus everyone has a limitation or impairment when compared to the ideal standard. Despite this, most people don't consider themselves disabled. Disability affects individuals in different degrees and manners. As a result any kind of generalisation or categorisation of disability and people with disabilities is misleading and discriminatory (Shakespeare, 2017).

Despite this social and relational sphere of defining disability the mainstream consensus remains that disability is an objective and measurable condition, diagnosed and proven by medical experts (Davis, 2005). Regarding the development paradigm, it is mostly noticed in the discourse of professionals. When talking about children with disabilities, they always refer to their development and their progress towards certain goals. Depending on their age, children are expected to be able to perform certain tasks and have certain abilities. For most professionals this model of development is the guiding principle of identifying children who might have a disability.

### **6.5.1 The Effects of Normalcy and Development Paradigm**

The birth of a disabled child has lasting effects on the family. The perceptions the family members have about such an event are embedded in the cultural conceptions as well as pathologising discourses of medicine and psychology. One of the first discriminating sentences parents hear about their children usually is "Your child is not normal". Nurses and doctors use this label when they start to notice signs of a certain impairment or syndrome. Another statement is that your child will not develop as other children, they will have a slower or limited development. Thus, parents become concerned about their child's health and development, informed by the constructions of normalcy and disability in society. Another negative effect of this way of thinking about disability and the pronounced lack of information about disability in Albania, leads to stigma and discrimination towards children with IDD.

Parents talk about challenges of registering their child in school. They often attempt to register their children in private schools as the number of pupils per class is much smaller and there is a better chance for the child to receive special attention. However, the biggest barrier of their inclusion is the negative reaction of other parents who refuse to have their child in the same classroom as a child with IDD. This negative approach has often been the cause of the dropout of children with IDDs.

Parents often talk about people in public spaces staring at their children with a sense of pity and judgement. The pity that people might feel or unknowingly express towards children with disabilities is really hurtful to their parents and to the children themselves. Parents want their children to be seen and treated as any other child, they do not want differentiation even if it is for a positive reason. They believe their children are not to be pitied because there is nothing wrong with them. Parents often feel uncomfortable taking their children in public spaces where they can be a victim of different kinds of reactions from people. Children themselves are harshly affected by the discriminating and stigmatic approach people have towards disability. Even though they might lack the verbal capacities to express their emotions and thoughts, they suffer from lack of self-esteem and isolation and come to internalise societal understandings of their impairments.

In a broader picture, NGOs and governmental intuitions prioritise raising awareness and spreading out correct information regarding child disability. Activities that are targeted to the community have a very positive effect because the personal contact and relatedness with children with disabilities spark feelings of compassion and understanding towards them. Most people have prejudice against children with IDDs because they have not had opportunities to interact with them and acknowledge their value as members of the society. The integration and inclusion of people with disabilities in social gatherings should become a priority for communities.

## 6.6 Chapter's Summary

The first part of the chapter discusses the challenges and drawbacks of the healthcare system in Albania and the ways it influences the children's and families' lives. The process of conducting an assessment and receiving a formal diagnosis for children with impairments is long and costly. Diagnosis is crucial because it provides the gateway to receiving proper social services from education, to therapy and monetary assistance. Despite the free public healthcare policy, there are many hidden costs to raising and caring for a child with IDD. Thus, there is a visible disparity in quality of care and quality of life for children based on their family's economic level.

Caring for a child with disabilities is a difficult experience for families, especially mothers, as well as rewarding and unique. Due to stigma and social constructions of disability, families struggle with the acceptance of their child's disability. The process of moving from denial and isolation to social integration and acceptance requires time and effort from the side of the parents. In Albanian families commonly the 'burden' of care falls on the mothers, who sacrifice a lot for the well-being of their children. They assume many roles towards their child with IDDs, from caring to teaching them and being their playmate.

The social construction of disability in Albania is widely based on the hegemonic theories of child development and the notion of 'normality'. The social stigma and disadvantageous constructions of a disabled child, directly affect children's lives making it more difficult for them to be included and fully integrated in society. People's perceptions and behaviour towards them might affect their chances of receiving quality education, opportunities for socialisation and the chance of their developing their potentials.



# Conclusions and Recommendations

## 7.1 Introduction

This chapter presents the conclusion and recommendations. The first section summarises the key research findings as an attempt to compile conclusive answers to the initial research questions. In the second section, some methodological reflections are expanded upon in order to fulfil one of the objectives of the research to serve as a methodological contribution to future research. Finally, the chapter contains some proposals and recommendations for possible positive changes that can be made to improve the lives of children with IDD.

## 7.2 A Summary of Key Findings of This Research

### 7.2.1 Everyday Life

Children with IDD lead a similar daily life as any other child in Albania. Their daily routine consists of self-care activities, education-oriented activities, family activities and leisure activities. The results of the daily recall tool suggest that most of their day is spent engaging in activities focused on education. Children with IDD spend much more time and effort on learning than other children. Most of the children with IDD struggle with comprehension and maintaining concentration, therefore they require more effort to absorb the same information as their peers in school. Furthermore, they not only spend time going to school and completing homework, but they also practise learning practical skills with the help of their parents. As the consequence of constructing child growth on the basis of the development paradigm, parents and professionals who work with children with IDD are more concerned with their progress compared to development milestones, rather than their inclusion, emotional and social well-being.

Despite their busy schedule, children with IDD enact their agency and personal preferences in their leisure time. Playtime is a crucial component of a child's life. This is a space where they are fully free to express themselves and engage in activities that spark their interest and make them happy, as opposed to the structured adult-led activities they engage in during most of the day. When children were asked about their hobbies and favourite games, they were very enthusiastic and happy to talk about them longer. Some children are interested in painting or music, some others are more passionate about sports. Almost all of the children expressed interest in electronic games and watching different TV shows. Free time provides a wonderful opportunity for children to socialise and interact with their siblings. Their relationship is strengthened by playing together. However, not all children enjoy the company of others all the time. Some children prefer to play alone and to be left in their own world without being asked to have numerous social interactions during the day, which they might find exhausting.

### **7.2.2 Education**

In general, children find school a pleasurable yet challenging experience. They enjoy going to school because it provides opportunities for socialisation, spending time with peers and being engaged in interesting activities. Children with IDD are entitled to have an assistant teacher to help them understand what is being taught in class, who is additionally responsible for preparing a program that is tailored to the needs and capabilities of the child. Children's relationships with their assistant teachers are very special and friendly. They spend a lot of time together and the teacher provides additional care and support for them in uncomfortable situations. The assistant teacher might accompany the child even during recess in order to help them with the interactions with peers.

There is an intersection between age and children's relationship with peers at school. For younger children, it is much easier to socialise because young children are unaware of what disability signifies and are not fully exposed to society's prejudice and constructions of children with disabilities. They tend to be caring and open towards their friends with IDD in their school or their community. Despite this, socialisation and friendship tends to be more difficult for young people with IDD as their peers exhibit more discriminatory behaviour because they are willing to be friendly but they are reluctant to develop a close relationship with a person with IDD.

### **7.2.3 Healthcare**

Receiving quality healthcare is one of the most crucial needs for a child with IDD. Apart from basic services that every child receives, children with IDD require specialised services, such as diagnosis, therapy and treatment for physical conditions.

The quality and the accessibility of these services in Albania has shown to be quite unsatisfactory for the participants of the research, particularly the parents. They tes-

tified of the difficulties they faced while receiving a formal diagnosis for their child's disability. The lack of information and professionalism commonly lead parents to feel concerned for the future of their child. There is a disparity in the quality of treatment children receive based on the economic conditions of their family. Parents who can afford it usually pay for private services for their children, sometimes even abroad.

#### **7.2.4 Constructions of Disability**

An analysis of childhood as a cultural concept has shown that in Albania childhood is a construction heavily influenced by the development and normalcy paradigms. Children are expected to develop following a certain pathway and every childhood that doesn't follow the norm is seen as problematic. Children are expected to be able to perform certain tasks according to their age which constitutes the able-bodied standard. This way of framing normality and disability is very limiting and discriminating for children with disabilities.

The constructions and conceptions of child disability in a society has direct effects on children's lives. Various findings have illustrated how the parents change their expectations and perspectives on the future of their child upon learning about their disability. Very little is expected of children with IDD, due to the underlying belief that they are incapable of integrating and being productive members of society.

### **7.3 Methodological Reflections and Contributions**

One of the main purposes of this research was to conduct research with children with disabilities in Albania by including them as participants in research and create a space for them to express their opinions and views on topics that concern them. Previous research in Albania on children with disabilities has constructed them as objects of research and gathered data from their parents, teachers or other community members without including their 'voice'. Moreover, there is a common disbelief reflected in disability studies research that children with IDDs are capable of participating in research due to their impairments and difficulties in communication. This research aims to be a positive example that proves that children with IDDs are as capable as any other child to participate in research if the methods employed are suited to their needs and abilities.

The most important 'tool' in research is the researcher. Their abilities to reflexively address issues of communication and gathering data from children with IDDs, as well as their awareness of the 'traps' of interpreting data and the representation of authentic voices are the most important indicators of a productive and ethical research. The process of gathering data from children is different from adults on many levels. Firstly, it is demanding and time-consuming to create a tool box of methods and tools to research different topics because each tool must be designed with the participants in

mind. There is cannot one-size-fits-all approach or method because every child has their own personality, impairment type and communication method.

Secondly, no matter how much planning the researcher does before the fieldwork, the ways their plan will be implemented in practice is very unpredictable. Along with unexpected challenges the researcher is also presented with continuous ethical dilemmas. In order to cope with these challenges, the researcher must be well prepared but also willing to improvise and adjust to the demands of the participants. Regarding ethical considerations, it is wise to prepare ahead of fieldwork a list of ethical principles to which the researcher will adhere to.

Thirdly, reflexivity is a core skill of a good researcher because it promotes the examination of each situation in the field in order to produce data with high quality and empower the participants through positive inclusion. Furthermore, reflexivity aids the researcher to examine their own presumptions and stereotypes on the topic that is being researched beforehand, as well as their positionality in the fieldwork and power dynamics between the researcher and children.

## **7.4 Recommendations**

### **7.4.1 Specialised Services for Children with IDD**

There is an international debate between the inclusion of children with IDD in regular schools versus their education in special schools. Albanian law and policy reforms indicate that the government supports the full inclusion of children with IDD in mainstream education. However, in practice it has proven to be more complicated than simply locating children with IDD in regular schools. Professionals and parents in Albania as well as internationally are very sceptic towards the new inclusion paradigm because they have experienced first-hand the challenges of its implementation and its shortcomings (Cole, 2008).

Children who attend mainstreams schools and kindergarten require more attention and specialised care than they are currently receiving in order to fulfil their potentials and have a positive experience in these institutions. Children with IDD require therapy sessions to work on behavioural and psycho-social difficulties as well as extra classes to work on learning and absorbing the academic material. There are two methods that may be applied to deliver these services to them.

One solution might be the integration of special classes and therapy sessions within the structure of the school. This may be achieved by strengthening and expanding the structure of the psycho-social staff which is already existing in most schools. Every school is required to have a psychologist who is in charge of caring for the mental health of the pupils and running different programs. If the staff is expanded with a therapist and a social work as well as trained in the field of disability, they should be capable of assisting children with IDD at school.

Another solution, which is more costly but also more productive is the creation of specialised centres. These centres typically offer a wide range of services for children with disabilities and their families. They have the advantage of creating a community and being able to receive help in many aspects from one unified place. The range of services the centres should provide include assessment, catch-up classes, various therapies, leisure activities, consultations with specialised medical and mental health staff. Although the creation of these centres requires a lot of time, resources and funds I believe it should be an aspiration and possibility of the near future for children in Albania.

#### **7.4.2 Training for Professionals Working with Children with IDD**

There are a number of professionals who work with children with IDD throughout their lifetime. Starting with the paediatrician who is the first to be in contact with the child and whose help is crucial in the process of diagnosis and initial treatment. After the child receives a formal diagnosis and is registered in kindergarten, he is followed by the kindergarten teachers and psychologist. When they attend school, the professionals in charge of caring for children with IDD are the assistant teacher, the other teachers and the school psychologist. Moreover, most children follow therapy sessions either in private or public centres.

All these professionals who work with children with IDD are in need of training and specialisation. As mentioned in the second analysis chapter, the education and formal knowledge available for young therapists and psychologists is very limited. Furthermore, not only the professionals specialised in working with children with disabilities are in need of training, but also the medical staff, the mainstream school teachers and kindergarten teachers who lack information about disabilities and how to care for children with IDD. The government and NGOs should put immediate attention to develop the capacities of the staff in order to ensure that children are receiving quality services and are not being harmed by the lack of information or skills.

#### **7.4.3 Sources of Support for Parents**

Parents are the most important source of support for children with IDD. As proven by the testimonies of parents who participated in this research, raising a child with IDD requires extraordinary effort from parents, who are obligated to assume many roles. Most parents had no information about their child's disability prior to their birth and diagnosis. The realisation of being the parent of a child with IDD is faced with feelings of fear, insecurity and many questions.

Therefore, a crucial service that should be widely available should be dedicated to the support and assistance of the parents of children with IDD. The creation of support groups for parents of children with IDD can be a life-changing solution for most

families who feel isolated and alone in the task of raising their children. The group can be used as a space to share experiences, receive advice and provide hope and encouragement for new parents. It may also be a space where parents are able to consult with professionals in order to receive information regarding disabilities, parenting and the management of difficult situations or behavioural issues with their child.

# References

- Abebe, T. (2008). Ethiopian childhoods: A case study of the lives of orphans and working children.
- Abebe, T. (2019). Reconceptualising children's agency as continuum and interdependence. *Social Sciences*, 8(3), 81.
- Ajodhia-Andrews, A., & Berman, R. (2009). Exploring school life from the lens of a child who does not use speech to communicate. *Qualitative Inquiry*, 15(5), 931–951.
- Alanen, L. (2016). *'intersectionality' and other challenges to theorizing childhood*. SAGE Publications Sage UK: London, England.
- Alper, M., Katz, V. S., & Clark, L. S. (2016). Researching children, intersectionality, and diversity in the digital age. *Journal of Children and Media*, 10(1), 107–114.
- Anne Bentley, K. (2005). Can there be any universal children's rights? *The International Journal of Human Rights*, 9(1), 107–123.
- Armstrong, D., Armstrong, A. C., & Spandagou, I. (2011). Inclusion: By choice or by chance? *International journal of inclusive education*, 15(1), 29–39.
- Asbjørnslett, M., Helseth, S., & Engelsrud, G. H. (2014). 'being an ordinary kid'—demands of everyday life when labelled with disability. *Scandinavian Journal of Disability Research*, 16(4), 364–376.
- Barker, J., & Weller, S. (2003). Emerald article: "is it fun?" developing children centred research methods. *International journal of sociology and social policy*, 23(1), 33–58.
- Barton, L. (2005). Emancipatory research and disabled people: Some observations and questions. *Educational review*, 57(3), 317–327.
- Bauminger, N., & Kasari, C. (2000). Loneliness and friendship in high-functioning children with autism. *Child development*, 71(2), 447–456.
- Beaudry, J.-S. (2016). Beyond (models of) disability? In *The journal of medicine and philosophy: A forum for bioethics and philosophy of medicine* (Vol. 41, pp. 210–228).
- Beazley, H., Bessell, S., Ennew, J., & Wateson, R. (2005). Comparative research on physical and emotional punishment of children in southeast asia and the pacific: 2005 regional protocol.
- Beazley, H., & Ennew, J. (2006). Participatory methods and approaches: Tackling the

- two tyrannies. *Doing development research*, 189–199.
- Berger, R. (2015). Now i see it, now i don't: Researcher's position and reflexivity in qualitative research. *Qualitative research*, 15(2), 219–234.
- Bondy, A., & Frost, L. (2011). *A picture's worth: Pecs and other visual communication strategies in autism*. Woodbine House.
- Brady, G., & Franklin, A. (2019). Challenging dominant notions of participation and protection through a co-led disabled young researcher study. *Journal of Children's Services*.
- Brinkmann, S., & Kvale, S. (2015). *Interviews: Learning the craft of qualitative research interviewing* (Vol. 3). Sage Thousand Oaks, CA.
- Canary, H. E. (2008). Negotiating dis/ability in families: Constructions and contradictions. *Journal of Applied Communication Research*, 36(4), 437–458.
- Chapman, R., & Bovell, V. (n.d.). Neurodiversity, advocacy, anti-therapy.
- Christensen, P., & James, A. (2017). Researching children and childhood: cultures of communication. In *Research with children: Perspectives and practices*. Routledge.
- Christensen, P. H. (2004). Children's participation in ethnographic research: Issues of power and representation. *Children & society*, 18(2), 165–176.
- Clark, A. (2010). Young children as protagonists and the role of participatory, visual methods in engaging multiple perspectives. *American journal of community psychology*, 46(1-2), 115–123.
- Clark, A., & Moss, P. (2011). *Listening to young children: The mosaic approach*. Jessica Kingsley Publishers.
- Closs, A., Nano, V., & Ikonomi, E. (2003). I am like you. an investigation into the position of children with disabilities in Albania. *Save the Children, Albania Programme*.
- Cocks, A. (2008). Researching the lives of disabled children: The process of participant observation in seeking inclusivity. *Qualitative Social Work*, 7(2), 163–180.
- Cocks, A. J. (2006). The ethical maze: Finding an inclusive path towards gaining children's agreement to research participation. *Childhood*, 13(2), 247–266.
- Cole, K. (2008). Between a rock and a hard place: Parents attitudes to the inclusion of children with special educational needs in mainstream and special school. *British Journal of special education*, 35(3), 173–179.
- Corsaro, W. A., & Eder, D. (1990). Children's peer cultures. *Annual review of sociology*, 16(1), 197–220.
- Corsaro, W. A., & Molinari, L. (2017). Entering and observing in children's worlds: A reflection on a longitudinal ethnography of early education in Italy. In *Research with children* (pp. 23–42). Routledge.
- CRPD. (2015). Initial report submitted by Albania under article 35 of the Convention, due in 2014. *UN*.
- Cuko, O., Kulla, F., & Kasapi, E. (2013). *Inclusive education in Albania. An analytical study*. Tirana: Save the Children.



- Curran, T., & Runswick-Cole, K. (2014). Disabled children's childhood studies: a distinct approach? *Disability & Society*, 29(10), 1617–1630.
- Davis, N. A. (2005). Invisible disability. *Ethics*, 116(1), 153–213.
- Dedja, B., Ceka, N., Myzyri, H., Kashari, Q., Osmani, S., & Gogaj, I. (2003). History of Albanian education and pedagogical thought. In (p. 123 - 178). Tirana: Education and Science Ministry.
- Duraku, Z. H. (2017). *Jetesa e pavarur dhe përfshirja në komunitet. Perspektivë nga personat me aftësi të kufizuar intelektuale, familjet e tyre dhe ofruesit e shërbimeve në komunitet*. Shoqata Ndihmoni Jeten. (Independent living and community inclusion. The perspective of people with intellectual disabilities, their families and service providers in the community)
- Einarsdóttir, J. (2007). Research with children: Methodological and ethical challenges. *European early childhood education research journal*, 15(2), 197–211.
- Ekonomi, M. (2002). Children and Disability in Albania. MONEE Country Analytical Report. *UNICEF Innocenti Research Centre*.
- Emerson, E. (2004). Poverty and children with intellectual disabilities in the world's richer countries. *Journal of Intellectual and Developmental Disability*, 29(4), 319–338.
- Engward, H., & Davis, G. (2015). Being reflexive in qualitative grounded theory: discussion and application of a model of reflexivity. *Journal of advanced nursing*, 71(7), 1530–1538.
- Ennew, J., Abebe, T., Bangyai, R., Karapituck, P., Kjørholt, A. T., Noonsup, T., ... Waterson, R. (2009). *The right to be properly researched: ten manuals for scientific research with children*. Bangkok: Black on White Publications, Norwegian Centre for Child Research and World Vision International.
- Farmer, D., & Cepin, J. (2015). Creative visual methods in research with children and young people. *Methodological Approaches. Geographies of Children and Young People*, 2, 303–333.
- Fenge, L. A., Oakley, L., Taylor, B., & Beer, S. (2019). The impact of sensitive research on the researcher: Preparedness and positionality. *International Journal of Qualitative Methods*, 18, 1609406919893161.
- Flick, U. (2007). Concepts of triangulation. *Managing quality in qualitative research*, 38–54.
- Fox, D., & Griffin Jr, C. L. (2009). Disability-selective abortion and the americans with disabilities act. *Utah L. Rev.*, 845.
- Franck, K. (2014). Contributions of disability studies and childhood studies to understanding the construction of "normality" and "disability" in day-care settings. *BARN-Forskning om barn og barndom i Norden*, 32(1).
- Ghavami, N., Katsiaficas, D., & Rogers, L. O. (2016). Toward an intersectional approach in developmental science: The role of race, gender, sexual orientation, and immigrant status. *Advances in child development and behavior*, 50, 31–73.

- Glenn, N. M., Knight, C. J., Holt, N. L., & Spence, J. C. (2013). Meanings of play among children. *Childhood, 20*(2), 185–199.
- Goepel, J. (2009). Constructing the individual education plan: confusion or collaboration? *Support for learning, 24*(3), 126–132.
- Goodfellow, A. (2012). Looking through the learning disability lens: inclusive education and the learning disability embodiment. *Children's Geographies, 10*(1), 67–81.
- Goodley, D. (2016). *Disability studies: An interdisciplinary introduction*. London: Sage.
- Graham, L. J., & Slee, R. (2008). An illusory interiority: Interrogating the discourse/s of inclusion. *Educational philosophy and theory, 40*(2), 277–293.
- Gray, C., & Winter, E. (2011). Hearing voices: participatory research with preschool children with and without disabilities. *European Early Childhood Education Research Journal, 19*(3), 309–320.
- Gray, K. (24 July 2020). *Intersectionality & Disability, ft Keri Gray, the Keri Gray Group DisabilityDemandsJustice*. Youtube. Retrieved from <https://www.youtube.com/watch?v=p2XNOCQazr0>
- Greenstein, A. (2014). Today's learning objective is to have a party: playing research with students in a secondary school special needs unit. *Journal of research in special educational needs, 14*(2), 71–81.
- Gregorius, S. (2015). Combining multiple qualitative methods in research on young disabled people in the global south.
- Guralnick, M. J. (2005). Early intervention for children with intellectual disabilities: Current knowledge and future prospects. *Journal of Applied Research in Intellectual Disabilities, 18*(4), 313–324.
- Haegele, J. A., & Hodge, S. (2016). Disability discourse: Overview and critiques of the medical and social models. *Quest, 68*(2), 193–206.
- Harcourt, D., Perry, B., & Waller, T. (2011). *Researching young children's perspectives: Debating the ethics and dilemmas of educational research with children*. Taylor & Francis.
- Hassanein, E., & Elshabrawy, A. (2015). Perspectives of disability and inclusion. In *Inclusion, disability and culture* (pp. 23–43). Springer.
- Hedegaard, M., Aronsson, K., Højholt, C., & Ulvik, O. S. (2018). *Children, childhood, and everyday life: Children's perspectives*. IAP.
- Hodapp, R. M., Fidler, D. J., & Depta, E. (2016). Blurring boundaries, continuing change: The next 50 years of research in intellectual and developmental disabilities. In *International review of research in developmental disabilities* (Vol. 50, pp. 1–31). Elsevier.
- Hodge, N. (2005). Reflections on diagnosing autism spectrum disorders. *Disability & Society, 20*(3), 345–349.
- Hodkinson, A., Ghajarieh, A., & Salami, A. (2018). An analysis of the cultural representation of disability in school textbooks in iran and england. *Education 3-13, 46*(1), 27–36.

- Holt, L. (2004). Children with mind–body differences: performing disability in primary school classrooms. *Children's Geographies*, 2(2), 219–236.
- Hopkins, P. E. (2007). Positionalities and knowledge: Negotiating ethics in practice. *ACME: an international journal for critical geographies*, 6(3), 386–394.
- Houtrow, A. J., Okumura, M. J., Hilton, J. F., & Rehm, R. S. (2011). Profiling health and health-related services for children with special health care needs with and without disabilities. *Academic pediatrics*, 11(6), 508–516.
- Hunter, A., Lusardi, P., Zucker, D., Jacelon, C., & Chandler, G. (2002). Making meaning: The creative component in qualitative research. *Qualitative health research*, 12(3), 388–398.
- INSTAT. (2021). *Tregu i punes dhe te dhenat e pagave (the job market and salaries' statistics*. Retrieved from
- James, A. (2001). Ethnography in the study of children. *Handbook of ethnography*, 246.
- James, A. (2007). Giving voice to children's voices: Practices and problems, pitfalls and potentials. *American anthropologist*, 109(2), 261–272.
- James, A., Jenks, C., & Prout, A. (1998). Theorizing childhood. *New York*.
- James, A., & Prout, A. (1990). Constructing and reconstructing childhood.
- Jenkin, E., Wilson, E., Murfitt, K., Clarke, M., Campaign, R., & Stockman, L. (2015). Inclusive practice for research with children with disability: A guide. *Melbourne: Deakin University*.
- Jenks, C. (1982). Introduction: constituting the child. *The sociology of childhood: Essential readings*. London: Batsford, 9–24.
- Jenks, C. (2004). Constructing childhood sociologically. *An introduction to childhood studies*, 77–95.
- Jorgensen, D. L. (2015). Participant observation. *Emerging trends in the social and behavioral sciences: An interdisciplinary, searchable, and linkable resource*, 1–15.
- Kirkham, P. (2017). 'the line between intervention and abuse'–autism and applied behaviour analysis. *History of the human sciences*, 30(2), 107–126.
- Klocker, N. (2007). *An example of 'thin' agency: Child domestic workers in Tanzania*. London: Routledge.
- Krauss, S. E. (2005). Research paradigms and meaning making: A primer. *The qualitative report*, 10(4), 758–770.
- Law, M., Anaby, D., Teplicky, R., Khetani, M. A., Coster, W., & Bedell, G. (2013). Participation in the home environment among children and youth with and without disabilities. *British Journal of Occupational Therapy*, 76(2), 58–66.
- Law "For the inclusion and accessibility of persons with disabilities. (2014). Republic of Albania.
- Law of Pre-University Education no. 69. (2012). Republic of Albania.
- Law on The Social Assistance in the Republic of Albania no. 57. (2019). Republic of Albania.

- Lee, M., & Gardner, J. E. (2010). Grandparents' involvement and support in families with children with disabilities. *Educational Gerontology, 36*(6), 467–499.
- Leonardi, M., Bickenbach, J., Ustun, T. B., Kostanjsek, N., & Chatterji, S. (2006). The definition of disability: what is in a name? *The Lancet, 368*(9543), 1219–1221.
- Lincoln, Y. S., Lynham, S. A., Guba, E. G., et al. (2011). Paradigmatic controversies, contradictions, and emerging confluences, revisited. *The Sage handbook of qualitative research, 4*, 97–128.
- Linton, S. (1998). Disability studies/not disability studies. *Disability & Society, 13*(4), 525–539.
- Llewellyn, A., & Hogan, K. (2000). The use and abuse of models of disability. *Disability & Society, 15*(1), 157–165.
- Lyons, L. (2013). Transformed understanding or enlightened ableism? the gap between policy and practice for children with disabilities in aotearoa new zealand. *International Journal of Early Childhood, 45*(2), 237–249.
- Maciver, D., Rutherford, M., Arakelyan, S., Kramer, J. M., Richmond, J., Todorova, L., ... others (2019). Participation of children with disabilities in school: A realist systematic review of psychosocial and environmental factors. *PloS one, 14*(1), e0210511.
- Mandell, N. (1988). The least-adult role in studying children. *Journal of contemporary ethnography, 16*(4), 433–467.
- Marsh, J. (2010). Young children's play in online virtual worlds. *Journal of early childhood research, 8*(1), 23–39.
- McArthur, J. (2020). Dilemmas at school: How and when to support the inclusion of students with disability. *Ethical Research involving children*. Retrieved from <https://childethics.com/case-studies/dilemmas-at-school-how-and-when-to-support-the-inclusion-of-students-with-disability-by-jude-macarthur/>
- McCall, L. (2005). The complexity of intersectionality. *Signs: Journal of women in culture and society, 30*(3), 1771–1800.
- McGarry, O. (2016). Repositioning the research encounter: exploring power dynamics and positionality in youth research. *International Journal of Social Research Methodology, 19*(3), 339–354.
- Metani, I. (2003). Transforming education: The Albanian experience. In (p. 21-25). Tirana: Nova Science Publishers.
- Ministry of Health and Social Protection. (2019). Reforma e vlerësimit të aftësisë së kufizuar në sistemin e mbrojtjes sociale.
- Mitra, S. (2006). The capability approach and disability. *Journal of disability policy studies, 16*(4), 236–247.
- Montgomery, H. (2003). Childhood in time and place. *Understanding childhood: An interdisciplinary approach, 45–84*.
- Montgomery, H. (2014). Participant observation. *Understanding research with children and young people, 122–135*.

- Moore, M., Howard, V., & McLaughlin, T. (2002). Siblings of children with disabilities: A review and analysis. *Int. J. Spec. Educ*, 17, 48–64.
- Murillo, L. (2014). Perspectives on disability and community engagement in Albania: Developing mutual understanding through the sharing of individual narratives.
- Murphy, N. A., Carbone, P. S., et al. (2008). Promoting the participation of children with disabilities in sports, recreation, and physical activities. *Pediatrics*, 121(5), 1057–1061.
- Neely-Barnes, S. L., & Dia, D. A. (2008). Families of children with disabilities: A review of literature and recommendations for interventions.
- Nind, M. (2008). Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges.
- Norup, M. (1997). Attitudes towards abortion in the danish population. *Bioethics*, 11(5), 439–449.
- Okyere, C., Aldersey, H. M., & Lysaght, R. (2019). The experiences of children with intellectual and developmental disabilities in inclusive schools in accra, ghana. *African Journal of Disability (Online)*, 8, 1–11.
- Patnaik, E. (2013). Reflexivity: Situating the researcher in qualitative research. *Humanities and Social Science Studies*, 2(2), 98–106.
- Payne, R. (2012). 'extraordinary survivors' or 'ordinary lives'? embracing 'everyday agency' in social interventions with child-headed households in zambia. *Children's Geographies*, 10(4), 399–411.
- Perry, A. (2004). A model of stress in families of children with developmental disabilities: Clinical and research applications. *Journal on developmental disabilities*, 11(1), 1–16.
- Poni, M. (2013). Inclusion of children with disabilities in mainstream education in Albania: lessons from three regions..
- Punch, S. (2002). Research with children: The same or different from research with adults? *Childhood*, 9(3), 321–341.
- Radoman, V., Nano, V., & Closs, A. (2006). Prospects for inclusive education in European countries emerging from economic and other trauma: Serbia and Albania. *European journal of special needs education*, 21(2), 151–166.
- Rama, R. (2016). Situation analysis of services for children with disabilities in Albania. *Save the Children*.
- Reingold, R. B., & Gostin, L. O. (2018). Banning abortion in cases of down syndrome: important lessons for advances in genetic diagnosis. *Jama*, 319(23), 2375–2376.
- Richardson, P. K. (2002). The school as social context: Social interaction patterns of children with physical disabilities. *American Journal of Occupational Therapy*, 56(3), 296–304.
- Robson, E., Bell, S., & Klocker, N. (2007). *Conceptualising agency in the lives and actions of rural young people*. London: Routledge.
- Rodriguez, C. C., & Garro-Gil, N. (2015). Inclusion and integration on special education. *Procedia-Social and Behavioral Sciences*, 191, 1323–1327.

- Rogers, J., & Sammon, E. M. (2018). *We all matter! Situation analysis of children with disabilities in Albania*. Tirana: Unicef.
- Roper, S. O., Allred, D. W., Mandleco, B., Freeborn, D., & Dyches, T. (2014). Caregiver burden and sibling relationships in families raising children with disabilities and typically developing children. *Families, Systems, & Health, 32*(2), 241.
- Runswick-Cole, K., Curran, T., & Liddiard, K. (2017). The everyday worlds of disabled children. *Disability, Normalcy and the Everyday, 41–61*.
- Runswick-Cole, K., Curran, T., & Liddiard, K. (2018). *The palgrave handbook of disabled children's childhood studies*. Springer.
- Runswick-Cole, K., & Hodge, N. (2009). Needs or rights? a challenge to the discourse of special education. *British Journal of Special Education, 36*(4), 198–203.
- Ryan, L., & Golden, A. (2006). 'tick the box please': A reflexive approach to doing quantitative social research. *Sociology, 40*(6), 1191–1200.
- Scherer, N., Verhey, I., & Kuper, H. (2019). Depression and anxiety in parents of children with intellectual and developmental disabilities: A systematic review and meta-analysis. *PloS one, 14*(7), e0219888.
- Scherzer, A. L., Chhagan, M., Kauchali, S., & Susser, E. (2012). Global perspective on early diagnosis and intervention for children with developmental delays and disabilities. *Developmental Medicine & Child Neurology, 54*(12), 1079–1084.
- Seballos, F., & Tanner, T. (2009). The importance of participatory child-centred research for climate adaptation.
- Seltzer, M. M., Krauss, M. W., Orsmond, G. I., & Vestal, C. (2000). Families of adolescents and adults with autism: Uncharted territory. In *International review of research in mental retardation* (Vol. 23, pp. 267–294). Elsevier.
- Shakespeare, T. (2017). *Disability: the basics*. New York: Routledge.
- Shakespeare, T., & Watson, N. (1998). Theoretical perspectives on research. *Growing up with disability, 34*, 13.
- Shtino, E., & Fortuzi, S. (2011). *The Employment of persons with disabilities in Albania. Study Report*. Tirana: ASDR & USAID.
- Singh, N. N. (2016). *Handbook of evidence-based practices in intellectual and developmental disabilities*. Springer.
- Singh, V., & Ghai, A. (2009). Notions of self: Lived realities of children with disabilities. *Disability & Society, 24*(2), 129–145.
- Skinner, D., & Weisner, T. S. (2007). Sociocultural studies of families of children with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(4), 302–312.
- Skivenes, M., & Strandbu, A. (2006). A child perspective and children's participation. *Children Youth and Environments, 16*(2), 10–27.
- Smart, J. F. (2009). The power of models of disability. *Journal of Rehabilitation, 75*(2).
- Smythe, T., Adelson, J. D., & Polack, S. (2020). Systematic review of interventions for reducing stigma experienced by children with disabilities and their families

- in low-and middle-income countries: state of the evidence. *Tropical Medicine & International Health*, 25(5), 508–524.
- Solberg, A. (1996). The challenge in child research from “being” to “doing”. *Children in families: Research and policy*, 1, 53–65.
- Stafford, L. (2017). ‘what about my voice’: emancipating the voices of children with disabilities through participant-centred methods. *Children’s Geographies*, 15(5), 600–613.
- Stalker, K. (2012). Researching the lives of disabled children and young people. *Children and Society*, 26(3), 173–180.
- Stein, M. A., & Lord, J. E. (2009). Future prospects for the united nations convention on the rights of persons with disabilities. In *The UN Convention on the Rights of Persons with Disabilities* (pp. 17–40).
- The Network of Disability Organizations. (2019). *Alternative report to the UN committee on the rights of persons with disabilities. On Albanian government’s initial report on the convention on the rights of persons with disabilities*. Albania.
- Third, A., Bellerose, D., De Oliveira, J. D., Lala, G., & Theakstone, G. (2017). Young and online: Children’s perspectives on life in the digital age (the state of the world’s children 2017 companion report).
- Thomas, C. (2004). How is disability understood? an examination of sociological approaches. *Disability & society*, 19(6), 569–583.
- Thomas, N., & O’kane, C. (1998). The ethics of participatory research with children. *Children & society*, 12(5), 336–348.
- Thompson, S., Cannon, M., Wickenden, M., Unicef, et al. (2020). *Exploring critical issues in the ethical involvement of children with disabilities in evidence generation and use* (Tech. Rep.).
- Thorne, B. (2004). *Theorizing age and other differences*. Sage Publications London, Thousand Oaks and New Delhi.
- Tisdall, E. K. M. (2012). The challenge and challenging of childhood studies? learning from disability studies and research with disabled children. *Children & society*, 26(3), 181–191.
- UNCRC. (1989). *Convention on Children’s Rights*. Retrieved from <https://www.unicef.org.uk/what-we-do/un-convention-child-rights/>
- UNCRDP. (2006). *Convention on the Rights of Persons with Disabilities and Optional Protocol*. Retrieved from <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>
- Underwood, K., Chan, C., Koller, D., & Valeo, A. (2015). Understanding young children’s capabilities: Approaches to interviews with young children experiencing disability. *Child Care in Practice*, 21(3), 220–237.
- UNDESA. (2009). Creating an inclusive society: Practical strategies to promote social integration. *United Nations*.
- Valentine, K. (2011). Accounting for agency. *Children & Society*, 25(5), 347–358.
- Vasilopoulou, E., & Nisbet, J. (2016). The quality of life of parents of children with

- autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders*, 23, 36–49.
- Vislie, L. (2003). From integration to inclusion: focusing global trends and changes in the western european societies. *European journal of special needs education*, 18(1), 17–35.
- Voko, K., & Fortuzi, S. (2014). Analizë e situatës së sistemit të vlerësimit të aftësisë së kufizuar në Shqipëri. *PNUD*. (Situational Analysis of the Disability Assessment system in Albania)
- Voko, K., Kulla, F., & Mactaggart, I. (2018). *Child disability in Albania : disability prevalence, access to services and quality of services : study report*. Tirana: World Vision. Retrieved from [https://www.wvi.org/sites/default/files/PV\\_FINALALB](https://www.wvi.org/sites/default/files/PV_FINALALB)
- Waldschmidt. (2017). Disability goes cultural: The cultural model of disability as an analytical tool. In A. Waldschmidt, H. Berressem, & M. Ingwersen (Eds.), *Culture–theory–disability: Encounters between disability studies and cultural studies* (p. 19-29). Germany: Transcript.
- Wasserman, D., Asch, A., Blustein, J., & Putnam, D. (2011). Disability: Definitions, models, experience.
- Watson, N. (2012). Theorising the lives of disabled children: How can disability theory help? *Children & Society*, 26(3), 192–202.
- Webster, A. A., & Carter, M. (2007). Social relationships and friendships of children with developmental disabilities: Implications for inclusive settings. a systematic review. *Journal of Intellectual and Developmental Disability*, 32(3), 200–213.
- Wehmeyer, M. L., & Garner, N. W. (2003). The impact of personal characteristics of people with intellectual and developmental disability on self-determination and autonomous functioning. *Journal of Applied Research in Intellectual Disabilities*, 16(4), 255–265.
- Wickenden, M., & Kembhavi-Tam, G. (2014). Ask us too! doing participatory research with disabled children in the global south. *Childhood*, 21(3), 400–417.
- Wickman, K., Nordlund, M., & Holm, C. (2018). The relationship between physical activity and self-efficacy in children with disabilities. *Sport in Society*, 21(1), 50–63.
- Wiles, R., Crow, G., Heath, S., & Charles, V. (2008). The management of confidentiality and anonymity in social research. *International journal of social research methodology*, 11(5), 417–428.
- Williamson, E., Goodenough, T., Kent, J., & Ashcroft, R. (2005). Conducting research with children: The limits of confidentiality and child protection protocols. *Children & Society*, 19(5), 397–409.
- Wilson, P. E., & Clayton, G. H. (2010). Sports and disability. *Pm&r*, 2(3), S46–S54.
- World Health Organization. (2001). International Classification of Functioning, Disability and Health (ICF).
- World Health Organization. (2011). *World report on disability 2011*. World Health Organization.



World Health Organization, et al. (2019). Icd-10 online versions. *Online: www. who. int.*(Access: 29.01. 2016).

World Vision Organisation. (2012, March). *The right to inclusive education for children with disabilities. analysis of the history of educational development of children with disabilities in Albania during 1945 -2011.* Retrieved from <https://www.wvi.org/albania/publication/right-inclusive-education-children-disabilities-analysis-history-educational>

# Appendices

## Appendix 1



**Fig 1.1** A map of Albania

Une jam ne klasen e 10.....

Mesuesi/sja ime i/e preferuar quhet DANIELA.....

Lenda ime e preferuar eshte MATEMATIKE.....

Shoku/shoqja ime quhet ANDI.....

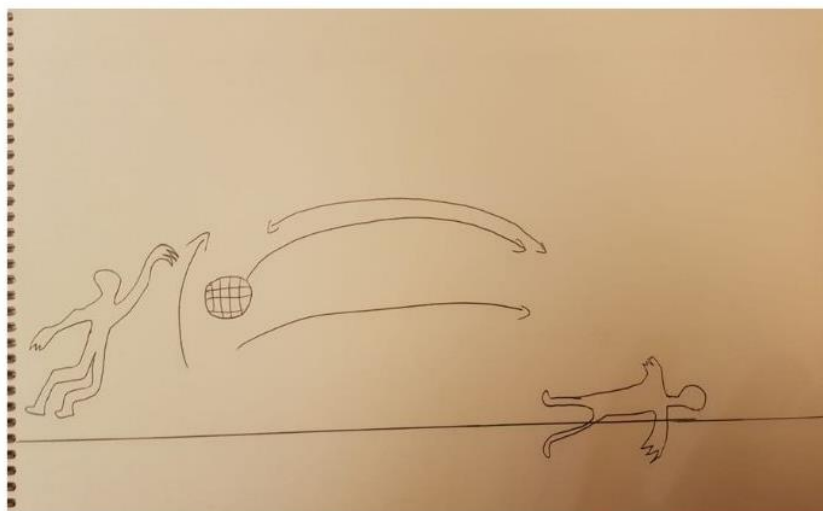
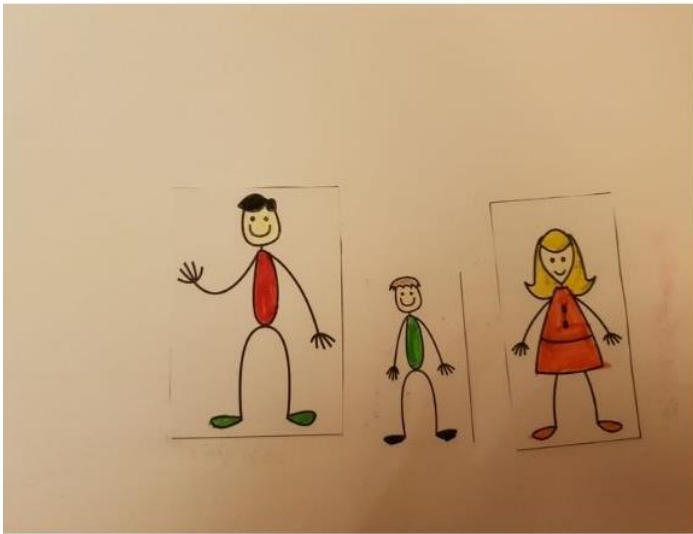
Ne banke une qendroj FUND.....

Kur shkoj ne shkolle ndihem LUMTUR.....

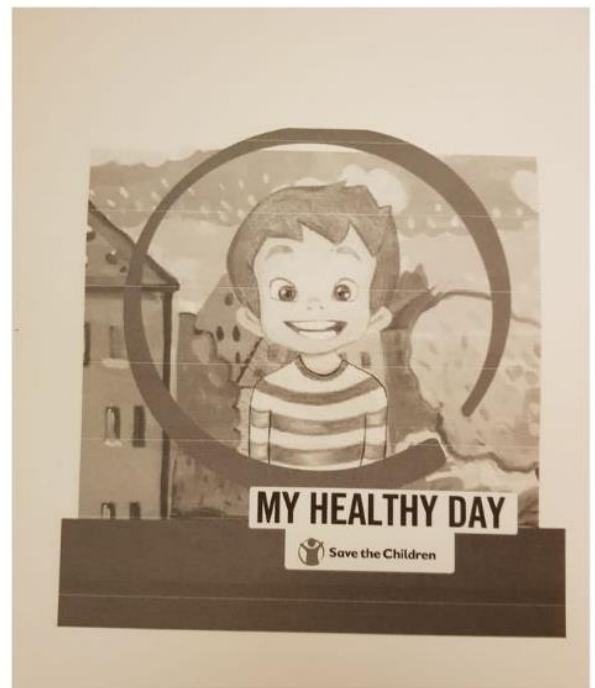
# KUSH JAM UNE?

Portreti im

Gjerat e mia te preferuara



FILLIMI	Si ? Quresh	Sa vjeç je?	Me kë jetom?	Ngjyra ime e preferuar	Dita ime e preferuar	A ke kafshë stëpiake?
Ku jetom? 	Ushqimi im, i preferuar	Filmi im, i preferuar	Shoku/Shoqja ime qubet 	Ke motër ose vëllë?	Superheroi i preferuar	Princesha e preferuar 
Si qubet mësuësja jote? 	Lojë e preferuar	Lodha që luam më shumë	Gfara të pëlqen më shumë të bësh	Me kë jetom?	Ngjyra ime e preferuar	Ushqimi i preferuar
Filmi i preferuar	Shoku/Shoqja ime qubet 	Dita ime e preferuar 	Ke motër ose vëllë?	Superheroi i preferuar	Ushqimi i preferuar	Superfugja ime
Kafshë e preferuar	Sa vjeç je?	Ku jetom 	Kun të ritim dua të bëhem	Superfugja ime	Si Quresh ?	FUNDI 



**Fig 1.2-1.9** Tools used in Activity-based interviews with children

## **Appendix 2**

### **Do you want to participate in the research project "Everyday lives of children with Intellectual and Developmental Disabilities in Albania"?**

This is a request for you to participate in a research project where the purpose is to explore the lives and shed light on the challenges of children with intellectual and developmental disabilities (IDDs) in the context of Albania. In this letter, we give you information about the goals of the project and what participation will mean for you.

#### **Purpose**

This project is part of my Master program titled "Childhood Studies" at NTNU. The main objective of this study is to gather information on the children's and families' perspective on aspects of the everyday life of children with disabilities and social interactions in their school, community, family and health-care facilities can help their caregivers, teachers, decision-makers and society at large gain insight on what their main needs are and how can they be met. This will be achieved by using ethnographic methods and encouraging the children's participation in the project to get a better understanding of the way they experience everyday life.

#### **Who is responsible for the research project?**

The institution responsible for this project is "Norwegian University of Science and Technology (NTNU). The supervisor of this project is Professor Randi Dyblie Nilsen.

#### **Why are you asked to participate?**

The participation of your family and your child is crucial to this project. This research is focused on children's perspective on the important aspects of their lives and the experience of families of raising a child with disabilities in Albania.

#### **What does it mean for you to participate?**

If you choose to participate in this project these are the activities that your child and your family will take part in:

- Participant Observation: An interaction and joint activities with the child. The researcher will accompany the child through some of their main daily activities and will talk to them about these activities and their feelings and opinions towards them.
- Different tasks: Children will engage with different tasks such as drawing, playing, telling stories, role playing as well as casual conversations with the researcher.
- The parents or the child's caregiver will be interviewed on the most important topics related to caring for a child with disabilities and their experiences. The focus will be education, health services and the social interactions of the child.

The interview and some conversations with the child may be recorded using a voice recorder and the researcher will take written notes. You may opt out of the recording if you wish.

You may see all the materials that will be used with the child beforehand.

#### **It is voluntary to participate**

It is voluntary to participate in the project. If you choose to participate and allow your child to participate, you or the child can withdraw your consent at any time without giving any reason. All your personal information will then be deleted. It will not have any negative consequences for you if you do not want to participate or later choose to withdraw.

### **Child's Informed Consent**

The child participant will be provided with a clear description of the project and the activities they will be asked to join. They will have the right and the space to ask questions and to decide if they want to participate or not. The informed consent will be in the form of a conversation or an activity assisted with pictures to make it easier for the child to fully understand what their participation means. Their consent will also be given in an oral form.

### **Your privacy - how we store and use your information**

We will only use the information about you for the purposes we have described in this article. We treat the information confidentially and in accordance with the privacy regulations.

- The data will be confidential and all personal information such as your name, the child's name, the school or health center they go to, etc. **will not be included.** The participants will not be recognizable in the publication of the research.
- The researcher and the supervisor are the only people who will have access to the data.

The information is anonymised since the beginning of the project and will be deleted when the project is completed and the assignment is approved, which according to the plan is in the end of May. The materials and the recordings that will be collected will be deleted.

### **Your rights**

As long as you can be identified in the data material, you have the right to:

- access to which personal information is registered about you, and to receive a copy of the information,
- to have personal information about you corrected,
- to have personal information about you deleted, and
- to send a complaint to the Data Inspectorate about the processing of your personal data.

### **What entitles us to process personal information about you?**

We process information about you based on your consent.

NSD - Norwegian Center for Research Data AS has assessed that the processing of personal data in this project is in accordance with the privacy regulations.

If you have questions about the study, or want to exercise your rights, please contact:

- The project supervisor: Prof. Randi Dyblie Nilsen ( [randi.dyblie.nilsen@ntnu.no](mailto:randi.dyblie.nilsen@ntnu.no) ).

If you have questions related to NSD's assessment of the project, you can contact:

- NSD - Norwegian Center for Research Data AS by email ([personverntjenester@nsd.no](mailto:personverntjenester@nsd.no)) or by phone: 55 58 21 17.

NTNUs data protection officer contact information:

- Thomas Helgesen ( [thomas.helgesen@ntnu.no](mailto:thomas.helgesen@ntnu.no) )

With best regards,

Anja Doksani.

## Consent Statement

I have received and understood information about the project "Everyday lives of children with disabilities in Albania" and have had the opportunity to ask questions. I agree to allow my child:

- to participate in participant observation
- to participate in task activities
- to have casual interactions and conversations with the researcher

I agree:

- to participate in the interview

I agree that my information will be processed until the project is completed

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(Signed by the legal guardian of the participant, date)

## **Appendix 3**

### **Interview Guide**

This interview format is a semi-structured interview that will address a few key areas of discussion while allowing the participant (the child's caregiver/parent) the space to express their opinions and experiences. The following questions should be used to guide the conversation but are not all mandatory. The participant should have independence and space to express themselves freely.

#### **Section 1: The child's everyday life**

Describe the average day of your child.

What are the main activities that he engages in daily?

Where do they spend most of their time (indoors or outdoors)?

What are the most pleasurable activities and what are the activities the child prefers to avoid?

Does the child have an active daily life?

#### **Section 2: Education**

What is your opinion on the educational system in Albania?

What is your opinion on the school your child attends?

How do you evaluate the quality of education your child receives?

Do you have any criticism or positive remarks on the school environment and teachers?

Do you think your child mostly enjoys school?

Is school a positive and enjoyable aspect of the child's life?

Do you want to share any other experience or comment?

#### **Section 3: Health Care**

How do you evaluate the overall quality of health care services your child receives?

Does your child follow therapy?

How do you evaluate the quality of service received in public health centers?

Do you face any challenges related to health care?

Do you want to share any other experience or comment?

#### **Section 4: Social Interaction**

With which people does the child interact the most?

How much time do you spend with them daily?

Who are the most important people in their life?

Do you think your child has a positive social life?

Is your child independent?

How easy or difficult is it for the child to meet up with friends or other family members?

Does your child use social media to communicate with friends?

Do you want to share any other experience or comment?

#### **Section 5: Recommendations**

What are the main areas that require improvement (health care, education, social life, other)?

What are the main challenges you face as a parent of a child with disabilities?

How do you think you could be helped by governmental and non-governmental institutions?

What do you think are the main challenge your child faces?

How do you think they could be helped by governmental and non-governmental institutions?

Do you have any last comments and experiences or recommendations you would like to share?



## Appendix 4

12/05/2021

Meldeskjema for behandling av personopplysninger



### NSD's assessment

#### Project title

Everyday lives of children with disabilities in Albania

#### Reference number

368557

#### Registered

27.07.2020 av Anja Doksani - anjadok@stud.ntnu.no

#### Data controller (institution responsible for the project)

Norges teknisk-naturvitenskapelige universitet / Fakultet for samfunns- og utdanningsvitenskap (SU) / Institutt for pedagogikk og livslang læring

#### Project leader (academic employee/supervisor or PhD candidate)

Randi Dyblie Nilsen, randi.dyblie.nilsen@ntnu.no, tlf: 4773596248

#### Type of project

Student project, Master's thesis

#### Contact information, student

Anja Doksani, anjadok@stud.ntnu.no, tlf: 4746747118

#### Project period

01.08.2020 - 01.08.2021

#### Status

07.09.2020 - Assessed

#### Assessment (1)

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##### 07.09.2020 - Assessed

Our assessment is that the processing of personal data in this project will comply with data protection legislation, so long as it is carried out in accordance with what is documented in the Notification Form and attachments, dated 7 September 2020, as well as in correspondence with NSD. Everything is in place for the processing to begin.

#### NOTIFY CHANGES

If you intend to make changes to the processing of personal data in this project it may be necessary to notify NSD. This is done by updating the Notification Form. On our website we explain which changes must be notified. Wait until you receive an answer from us before you carry out the changes.

#### TYPE OF DATA AND DURATION

The project will be processing special categories of personal data about health, and general categories of personal data, until 1 August 2021.

#### LEGAL BASIS

The project will gain consent from data subjects to process their personal data. We find that consent will meet the necessary requirements under art. 4 (11) and 7, in that it will be a freely given, specific, informed and unambiguous statement or action, which will be documented and can be withdrawn.

The legal basis for processing special categories of personal data is therefore explicit consent given by the data subject, cf. the General Data Protection Regulation art. 6.1 a), cf. art. 9.2 a), cf. the Personal Data Act § 10, cf. § 9 (2).

#### PRINCIPLES RELATING TO PROCESSING PERSONAL DATA

NSD finds that the planned processing of personal data will be in accordance with the principles under the General Data Protection Regulation regarding:

- lawfulness, fairness and transparency (art. 5.1 a), in that data subjects will receive sufficient information about the processing and will give their consent
- purpose limitation (art. 5.1 b), in that personal data will be collected for specified, explicit and legitimate purposes, and will not be processed for new, incompatible purposes
- data minimisation (art. 5.1 c), in that only personal data which are adequate, relevant and necessary for the purpose of the project will be processed
- storage limitation (art. 5.1 e), in that personal data will not be stored for longer than is necessary to fulfil the project's purpose

#### THE RIGHTS OF DATA SUBJECTS

Data subjects will have the following rights in this project: transparency (art. 12), information (art. 13), access (art. 15), rectification (art. 16), erasure (art. 17), restriction of processing (art. 18), notification (art. 19), data portability (art. 20). These rights apply so long as the data subject can be identified in the collected data.

NSD finds that the information that will be given to data subjects about the processing of their personal data will meet the legal requirements for form and content, cf. art. 12.1 and art. 13.

We remind you that if a data subject contacts you about their rights, the data controller has a duty to reply within a month.

#### FOLLOW YOUR INSTITUTION'S GUIDELINES

NSD presupposes that the project will meet the requirements of accuracy (art. 5.1 d), integrity and confidentiality (art. 5.1 f) and security (art. 32) when processing personal data.

To ensure that these requirements are met you must follow your institution's internal guidelines and/or consult with your institution (i.e. the institution responsible for the project).

#### FOLLOW-UP OF THE PROJECT

NSD will follow up the progress of the project at the planned end date in order to determine whether the processing of personal data has been concluded.

Good luck with the project!

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