Inclusive education for children and young people with disabilities in Uzbekistan: The perspectives and experiences of key players

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Abstract

This thesis explored the educational conditions for children with disabilities in Uzbekistan and the current development stage of inclusive education there. Of particular interest was how various groups perceived and understood the concept of inclusive education, what they saw as the critical issues in introducing inclusive practices, and how their experiences informed its better provision. These groups included parents of children with disabilities, teachers in general and specialised schools, non-governmental disability organisations (NGOs), and the government. The research is of importance as little has been written about inclusive education in Uzbekistan. It offers a platform for academics, policy-makers, and practitioners to further the agenda of equity in education in and beyond this setting through research, policy, and practice.

The research used phenomenology as a research methodology to explore the experiences and perspectives of the participants. Within this study, the social model of disability and the human rights treaties were utilised as a theoretical framework. A mixed-methods approach was applied to collect data. Semi-structured interviews were employed for parents, teachers, and government officials and an on-line questionnaire was completed by representatives of non-governmental bodies. In total, 23 interviews were conducted and six questionnaire responses were received.

The findings from the study suggest that inclusive education was mainly perceived as providing equal opportunity for children with disabilities to study in neighbourhood general schools, in age-appropriate classes, and with the necessary support to develop their skills and realise their potential. Children's social development was considered by many participants to be the most important aspect of inclusion. Yet, children with intellectual disabilities were considered as unsuitable to attend general schools.

Multiple challenges in the enactment of inclusive education were identified, such as the absence of individualised support in inclusive classrooms that made parents function as teacher aides, a lack of qualified teachers and their poor working conditions, inadequate provision of infrastructure, the absence of enabling legislation on inclusive education, and strong attitudinal barriers. Parental involvement was considered to be one of the most important prerequisites for successful inclusion. Nevertheless, teachers claimed that there was little effective collaboration between schools and parents due to a lack of parental responsibility for the lives and education of their children. The social partnership in disability-inclusive development between the government and NGOs appeared not to have been established yet, although NGOs have enough expertise and willingness to contribute to inclusion.

Four major implications emerged from the findings of the study. First, they suggest that inclusive education addresses the diverse needs of *all* students, not only those who have disabilities. Within a disability context, as stated by the human rights instruments, inclusive schools should accommodate students regardless of their conditions. They do not exclude students with intellectual disabilities. Second, the study indicates that teachers of mainstream schools, who participated in the study, feel more professionally prepared to practice inclusion when provided with in-service training and adequate working conditions, such as small size classes and a higher salary. Third, the study suggests that the capacity of parents of children with disabilities to cope with disability-related issues can be increased if they are provided with support services and a better financial provision to cover a disability cost. Finally, NGOs support children with disabilities and their families and promote inclusion more effectively when involved in decision-making processes and given more trust and freedom with organising and conducting their activities.

On this basis, recommendations for academics, researchers, and policy-makers were developed. Recommendations for academics and researchers primarily include supporting disability research and communicating research findings with policy-makers. Recommendations for policy-makers, in turn, outline the ways of how they could support children with disabilities, their parents, teachers, and non-governmental agencies. Furthermore, the study provides recommendations for further research. It would be useful to explore the inclusion of children with intellectual disabilities in a general school system in Uzbekistan, the transition of students with disabilities from high school or college to the workforce, and the impact of cultural beliefs about disability on social and educational inclusion.

Dedication

In the hope that this thesis may in some way contribute to the educational inclusion and equity of children and young people with disabilities in Uzbekistan, it is dedicated to them and their parents.

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Guide to Acronyms

ADB - Asian Development Bank

ASD - Autism Spectrum Disorder

ATA - Alberta Teachers' Association

CBR - Community-based Rehabilitation

CIS - Commonwealth of Independent States

CEE - Central and Eastern Europe

CWD - Child with a Disability

DDA- Disability Discrimination Act

DPO - Disabled People's Organisation

ECA – Europe and Central Asia

EFA - Education for All

EU - European Union

ICF - International Classification of Functioning

ICNL - International Center for Non-for-Profit Law

IDD - Intellectual and Developmental Disability

IEP - Individualised Education Plan/Programme

GONGO – Government-Organised Non-Governmental Organisation

JICA - Japan International Cooperation Agency

LSA - Learning Support Assistant

VTEK - Medical and Labour Expert Commission. The Russian abbreviation VTEK (**V**rachebno-**T**rudovaya **E**kspertnaya **K**omissiya, Врачебно-трудовая экспертная комиссия) is frequently used in the international literature.

MPPC - Medico-Psychological-Pedagogical Committee

NAP - EFA - National Action Plan on Education for All

NGO - Non-Governmental Organisation

NNO - Non-Governmental Non-commercial Organisation

OECD - Organisation for Economic Co-operation and Development

RCSAC - Republican Centre of Social Adaptation of Children

SEN - Special Education Needs

SEN CoP - Special Education Needs Code of Practice

SNA - Special Needs Assistant

UBHRRL - Uzbek Bureau on Human Rights and Rule of Law

UN - United Nations

UNCRC - United Nations Convention on the Rights of the Child

UNCRPD - United Nations Convention on the Rights of Persons with Disabilities

UNDP - United Nations Development Programme

UNESCO - United Nations Educational, Scientific, and Cultural Organization

UNICEF - United Nations Children’s Fund

USAID - United States Agency for International Development

USD – the United States dollar

USSR – the Union of Soviet Socialist Republics

UZS – Uzbekistani so’m (the currency of Uzbekistan)

WHO - World Health Organization

CHAPTER ONE
INTRODUCTION

> *When the subject of inclusive education is introduced one cannot help thinking of its demands and all it calls for, it seems like raising an umbrella against a storm… Developing countries cannot afford an overnight change of attitude or position on inclusive education. Policy endeavours must evolve grassroots participation so that all stakeholders are well informed and in order for the process to enjoy the support of the majority of teachers, parents, children, the community and those who are generally involved in education.*
>
> *(Charema, 2010, p. 1).*

1.1 The Challenge of Inclusive Education in Uzbekistan

In 1994, the Salamanca World Conference on Special Needs Education endorsed the idea of inclusion suggesting that inclusive schools should "provide an effective education for the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system" (UNESCO & Ministry of Education and Science of Spain, 1994, p. ix). Since then, inclusive education has been a major goal as well as the biggest challenge for educational systems of both developed and developing countries. In Uzbekistan, the concept of inclusive education was first introduced in 1996 within the framework of a project jointly enacted by the Republican Centre of Education and UNESCO (Akhunova, 2007). To support the rights of people with disabilities, including their rights to education, Uzbekistan has signed and ratified several international human rights treaties. Further, the Uzbek government has attempted to revise legislation from the perspective of inclusion and undertaken pilot inclusive education projects with the support of international aid organisations.

Despite these efforts, education for children with disabilities continues to have a strong focus on institutionalisation as it was during the Soviet period (UNICEF, 2012). Phillips (2009) notes that many post-Soviet countries still have "important legacies of the socialist era that have shaped current disability policy" (para 5). The majority of children with disabilities in Uzbekistan are either enrolled in home-based schooling or attend specialised institutions (Uzbek Society of Disabled People, 2014). The special education system in Uzbekistan is represented by the following institutions: special kindergartens and schools; special boarding schools; and Mercy houses for children with disabilities without parental care. Children who are placed in any of these institutions are often not provided with essential services and resources to receive appropriate education (UNICEF, 2013). Their situation is often worsened by other problems: “children with disabilities confront additional challenges as a result of their impairments and the many barriers that society throws in their way” (UNICEF, 2013, p. 1). These include poverty, inadequate living conditions, and societal discrimination.

According to UNICEF (2011), the Uzbek government often cannot support inclusive education initiatives even though it was committed to it. Uzbekistan was not the only country that made a start towards inclusive education but did not remain committed to its agenda. Inclusive education remains a confusing field for the majority of economically poorer countries and, therefore, difficult to enact. Mitchell (2005) states, “While many countries seem committed to inclusive education in their rhetoric, and even in their legislation and policies, practices often fall short” (p. 11). They struggle with financial constraints, a shortage of qualified human resources, large classes, cultural prejudices, unclarity of legislation, the lack of awareness of what inclusion is, and more (Charema, 2010). The aim of this research is to contribute to a better understanding of these challenges in the context of Uzbekistan.

1.2 The Place of the Researcher

Personal and professional biography usually influence any topic selected by researchers (Berger, 2015). Bogdan and Biklen (2003) state, “no matter how much you try, you cannot divorce your research and writing from your past experience, who you are, what you believe, and what you value. Being a clean slate is neither possible nor desirable” (p. 38). Similarly, Kacen and Chaitin (2006) note that a researcher’s background and worldview affects how he/she uses the language, raises questions, filters the collected information, and consequently shapes and presents findings.

It is, therefore, important to declare aspects of my background experience relevant to this study.

At the beginning of my teaching career, I did not think about working with children with disabilities. However, when I took up a position in a school as a Teacher of English at the beginning of the 2000s, I was assigned to teach such children, although I was not trained as a special education professional. These students were primarily receiving home-based education and school teachers had to work with them after regular working hours. Additional support services had to be provided to students studying at home. In practice, they did not receive any support from the school in the form of a logopedist [speech therapist], psychologist, or a tutor.

Many of the children I worked with were born with disabilities and some were victims of the Chernobyl disaster and were severely struggling with the consequences of radiation. By that time, there was a threefold rise in congenital anomaly prevalence as a result of the Chernobyl nuclear accident (World Health Organization, n.d.). Over the time I worked with these children I observed that regardless of the causes of disabilities, the children were experiencing the devastating effects of isolation, such as demotivation to study, low self-esteem, and personal insecurity. The financial issues, families faced, and the tremendous emotional distress of nearly all parents worsened their situations. It was the first time I started thinking about the importance of inclusive education.

Later I worked as a volunteer in the disability sector and participated in national and international projects aimed at integrating children with disabilities into regular schools. I was also involved in establishing an occupational training centre for young people with disabilities from rural areas. Whilst working on social inclusion through education and employment, I realised the importance of inclusion of people with disabilities in Uzbekistan’s national policy.

1.3 Research Aims

The study aims to identify how the concept of inclusive education is perceived and understood by parents of children and young people with disabilities, teachers of general and specialised schools, non-governmental disability-related organisations, and government officials. The study aims to explore what they see as the critical issues in introducing inclusive education practices, and how their experiences could potentially inform its better provision. If there are disparities in their understanding and perceptions, then the study will investigate how an effective collaborative approach might be developed in the future. In the absence of any substantive research on inclusion in Uzbekistan, the study also aims to inform policy development and provision needed to build the environment for inclusive education. A further aim of this research is to explore the educational conditions for children with disabilities and the current development stage of inclusive education in Uzbekistan.

1.4 Research Questions

The overarching question for this study is:

> How do participants understand the notion of inclusive education and how might this understanding either promote or hinder the development of the full inclusion of students with disabilities in regular classroom settings in Uzbekistan?

The following supplementary research questions are also investigated:

1. What have been the experiences of parents of children with disabilities, teachers, and non-governmental bodies in supporting inclusive education initiatives?

2. How do their experiences inform the better provision of inclusive education policy and practices in Uzbekistan?

3. What is the role of the government in the enactment of inclusive education?

4. How can the key players contribute to the development of a partnership amongst themselves to create an inclusive education environment?

5. How does international research and practice inform the development of inclusive practices in Uzbekistan?

1.5 Rationale for the Study

It is anticipated that the findings from this study will contribute to a developing body of knowledge that has the potential to lead to improvements for children with disabilities in

Uzbekistan. It will offer those with an interest and or involvement in the education of these children and young people, insights into the experiences of key players and how different groups conceptualise inclusive education and how each views its enactment in Uzbekistan. The study will also contribute to the existing literature on inclusive education in Uzbekistan and elsewhere. Although there is a growing body of literature on inclusion in other countries, little has been written regarding the development of inclusive education in Uzbekistan. In the opinion of Walker (2010), the lack of research on problems related to enabling inclusion faced by developing countries, as well as possible ways to solve those problems, seriously impedes that process.

Further, the research can potentially promote producing reliable data. It could be useful for relevant data collection agencies willing to build new knowledge for the development and enactment of inclusive education across the country. According to Article 31 of the Convention on the Rights of Persons with Disabilities (2006), all states have to collect appropriate statistical data to initiate policies supporting people with disabilities. Yet, in Uzbekistan, there are still no reliable statistics on adults or children with disabilities. Different agencies often provide different information. For instance, the Human Dynamics (2015) that enacted the Inclusive Education Project in Uzbekistan reported 150,000 children with disabilities. The World Bank (2018) notes that in 2016, there were 110,000 legally recognised children with disabilities. According to United Nations (2019a), the current number of children with disabilities is 100,827 that comprises 15 percent of the disability population in Uzbekistan. I will address the issues relating to disability statistics in Uzbekistan in subsequent chapters. Gevorgianiene and Sumskiene (2017) state that in many former Soviet Union countries, information on the number of people with disabilities and the quality of services they receive either does not exist or is not trustworthy.

1.6 Context of the Study

1.6.1 Country overview

Not many people outside of Uzbekistan (officially the Republic of Uzbekistan) know much about it, or about the life of people with disabilities living there. Before discussing inclusive education and disability issues in Uzbekistan, I will provide a brief country overview**,** including key facts about the country’s location, ethnic groups, economy, and education.

Uzbekistan is a landlocked country located in Central Asia with an area of 447,400 km^2. It is a secular, unitary, constitutional republic that consists of 12 regions and Karakalpakstan Autonomous Republic. The population of Uzbekistan is more than 30 million people (United Nations Statistics Division, 2016). The population is represented by more than 125 different ethnicities. The ethnic groups include Uzbeks (80 percent), Russians (5.5 percent), Tajiks (5 percent), Kazakhs (3 percent), Karakalpaks (2.5 percent), Tatars (1.5 percent), Ukrainians, Jews and others (UNESCO, 2012).

Until 1991, Uzbekistan was one of the Soviet Socialist Republics. After the disintegration of the Union of Soviet Socialist Republics (USSR), the country became independent. The path of transition for Uzbekistan was economically troublesome. Uzbekistan was able to maintain economic stability thanks to the policies based on import substitution (Bendini, 2013). The country also increased exports of gas, copper, uranium, and gold that helped to generate revenue and to finance large investments (World Bank, 2015). Agricultural production has always been significant for the Uzbekistan’s economy. Annually the country produces millions of tons of grains, fodder crops, fruits, and vegetables. Yet, cotton (often called “white gold”) remains the main agricultural product. Nowadays, Uzbekistan is the fifth-largest producer of cotton in the world (World Fact Book of the United States Central Intelligence Agency, 2016). Despite this, Uzbekistan is classified as a low-income country due to the inefficiency of economic management, low labour productivity, and the lack of food processing (World Bank, 2015).

Under the presidency of Shavkat Mirziyoyev, Uzbekistan has started new transformational economic reforms. Currently, Uzbekistan is enacting the reforms in economic development and liberalisation, with a focus on the modernisation of agriculture and industry. The reforms are also oriented towards making Uzbek products and services more competitive in the world market. New economic reforms have been assessed positively by reputable international institutions, such as the International Monetary Fund (IMF) (Tsereteli, 2018). It would seem that the beginning of these reforms was encouraging but it is too early to talk about their effectiveness at the initial stage of their enactment.

1.6.2 General education

Since independence, the Uzbekistan education system has undergone significant transformation due to changes of ideology, language, and orientation. Many positive changes have been made in its structure and content. Nevertheless, there are still serious problems in the present educational system. The most widespread problems in primary and secondary schools are overcrowded classes, a lack of material resources, and a shortage of qualified teachers. Teachers lacking the relevant skills and experience appears more prevalent in schools in rural areas (Education encyclopedia, n.d.). Due to teacher shortages, employing unqualified teachers is a common practice. In rural schools, the rate of teachers with relevant education is only 65 percent, while at schools in the cities it is almost 96 percent (UNESCO, 2012).

The main issue for secondary professional and higher education is a lack of practical education. Programmes at colleges and universities tend to focus on theory rather than practice. Thus, after graduation, young professionals do not have the essential practical skills and are less competitive in the labour market (Kasimova, 2011; World Bank, 2017). In addition, limited access to higher educational institutions makes enrolment extremely competitive. According to the World Bank (2014), the total tertiary enrolment rate in Uzbekistan is around nine percent, which is the lowest in the world. The growing number of international universities in the country is likely to change this situation. However, only one percent of entrants attend local branches of foreign universities in Uzbekistan (World Bank, 2014).

1.6.3 Special education

As mentioned previously, in Uzbekistan, education for children with disabilities is predominantly segregated. The majority attend specialised institutions and are treated according to the science defectology. Defectology is a branch of science that studies the principles and characteristics of the development of children with disabilities, problems related to their upbringing, and methods to teach them (The Great Soviet Encyclopedia, 1970-1979). Defectology is based on the assumption that children with disabilities cannot improve; they need special conditions and a special curricular. Its purpose, therefore, is not to help children develop their skills and knowledge but to correct their defects. According to UNICEF (2011), this is especially the case for Central Eastern

Europe/Commonwealth of Independent States (CEE/CIS) because there is a long-established tradition based on the philosophy of defectology that leads to placing children with disabilities in residential institutions, where they remain isolated from the rest of society.

The medical model of disability is pervasive in Uzbekistan. The model views disability as a limitation or a health condition and, therefore, focuses on finding a cure to make disabled people “normal” (Katsui, 2005). This approach is often ineffective because ‘correcting’ a disability is not possible. Many people with disabilities are affected by those models. When not cured, they are labeled “abnormal” which automatically excludes them from participation in social life. Rialland (2006) states that such a paternalistic approach “concentrates on "care" and ultimately provides justification for institutionalization and segregation” (para 10). A charity-based legacy exists in many countries and determines the attitude to people with disabilities (UNICEF, 2007b). Shakespeare (2017) notes that to solve the challenges of people living with disabilities, they have to be given rights and opportunities but not care and pity. Exclusion from social life also leads to many other problems, for instance, unemployment (Gallagher, Connor, & Ferri, 2014).

The social model of disability, in contrast, promotes more equity and critiques barriers developed by society for people with disabilities. According to Hughes and Paterson (1997), the model is based on the assumption that disability is an outcome of social organisation, not of physical pathology. Under the social model, disability is viewed as “a culturally and historically specific phenomenon, not a universal and unchanging essence” (Shakespeare, 2017, p. 197). Therefore, the application of the social model of disability is very critical to creating an inclusive education environment for children with disabilities. When children’s special needs are identified, the model considers their social and emotional needs in contrast to the medical model. Such an approach also helps professionals working with children with disabilities gain a better understanding of them as individuals (Department for Education and Skills, 2001).

1.6.4 International human rights treaties and inclusion

Inclusive education is based on human rights, which provide the inspiration as well as the foundation to create an inclusive society for all children, regardless of their gender, age, ethnicity, social status, or impairments (UNICEF, 2007b). Inclusive education works largely to ensure that people with disabilities have access to quality education. The widely accepted human rights treaties - the UN Convention of the Rights of the Child (CRC) and the UN Convention on the Rights of Persons with Disabilities (CRPD) - will be briefly discussed from the perspective of inclusive education.

The CRC has encouraged countries to protect the rights of children and provide all possible opportunities for their development. The Convention contains 54 articles, which describe civil, political, and social rights related to children. According to some researchers, the focus of the CRC is more on social rights (Coady, 2008; Quennerstedt, 2010). However, Article 28 declares the right to education and Article 29 outlines the fundamental values on which education has to be based (Harcourt & Hägglund, 2013). Article 23 precisely addresses the right of disabled children to education that promotes their full social inclusion. It also obliges governments to enable children with disabilities to access education.

Within the CRPD, people with disabilities are also viewed as active members of society who have rights and are capable to claim these rights; they are not objects of charity and mercy any longer. In its preamble, the CRPD emphasises the importance of equality, non-discrimination, and human dignity in relation to people with disabilities in all socio-economic spheres. The Convention recognises inclusive education as a fundamental human right (Ngwena, 2013). According to Article 24 of the Convention on the Rights of Persons with Disabilities (2006), all children with disabilities have a right to free quality inclusive education on an equal basis with students without disabilities. The Article states that students with disabilities have to be provided with individualised support to succeed within general education. The Article also emphasises the importance of professional preparation of teachers working with students with disabilities and requires governments to take responsibility for that.

1.7 Disability Categories

In this research, the following general disability categories are included under the term ‘disability’: physical disability, mental disability, cognitive and learning disability, sensory disability, chronic illness, and psychological disorder. These categories (with sub-categories) were created and proposed by the International Classification of

Functioning, Disability and Health (ICF), which provides a framework for the description of health conditions (World Health Organization, 2001).

1.8 Note on Terminology

1.8.1 Person first language

The language we use reflects our attitude towards the people around us. Therefore, using a respectful language while working with the disability community is very important. For some people, it is more appropriate to use the term ‘disabled people’ rather than ‘people with disabilities’. For instance, Cameron (2014), when describing the social model of disability, which the Disability Rights Movement is based on, states that the word ‘disability’ strongly emphasises not the impairments disabled people have but the barriers they encounter living in the society. According to Cameron (2014), disability is not what people have (they are not people with disabilities) but how society responds (or does not respond) to people who have certain conditions.

The social model of disability is used as a framework for my research. However, when it comes to the terminology, I believe that when we speak about a person with a disability, we should refer to a person first. Such a reference places the importance on a person rather than on his/her disabilities. It distinguishes the person from the disability and makes the person’s abilities central (National Center on Disability and Journalism, 2017). Therefore, throughout the thesis, I used the term ‘children with disabilities’ instead of ‘disabled children’ (the only exceptions are cited articles and legal documents where writers themselves use the term ‘disabled people/children’).

The philosophy of ‘person-first’ language was adopted first by the Association for Persons with Severe Handicaps and then subsequently used by many international human rights and disability-related organisations. Moreover, there are organisations that not only use the ‘person-first’ language but also encourage others to do that. Some American advocacy coalitions, for instance, the United Cerebral Palsy Association, educate families, who have relatives with disabilities about the philosophy and encourage them to use it (Blaska, 2003).

Tobin (2011) emphasises our responsibility, as professionals working with children with and without disabilities, to use person-first language. He believes that by setting a good example for typically developing children we can influence their knowledge and reshape attitudes towards people with disabilities. Children who have disabilities in their turn also need to hear that they are referred in a positive way (Blaska, 2003). Tobin (2011) continues:

> Attitudes of school staff towards persons with disabilities are translated primarily through the language used. Also, the degree to which children can perceive themselves as competent and worthy, or the opposite, is heavily influenced by the verbalizations used by their teachers. (p. 26)

Thus, people working with children should be aware of disability bias in language.

1.8.2 Other inclusive education and disability-related terms

In this study, the terms ‘general’ and ‘mainstream’ education are used interchangeably to refer to regular schools attended by most children. Within the context of inclusive education, these schools should become inclusive settings for children with disabilities. The terms ‘students/children with disabilities’ and ‘students/children with special educational needs’ are used in this research. The Salamanca Statement and Framework for Action on Special Needs Education notes that special educational needs may be acquired by “disabled and gifted children, street and working children, children from remote or nomadic populations, children from linguistic, ethnic or cultural minorities and children from disadvantaged or marginalised areas or groups” (UNESCO & Ministry of Education and Science of Spain, 1994). Therefore, in many cases, the term ‘special needs’ refers to “children who are “different” due to their disability, their behaviour, or their social vulnerability (e.g. being unprotected and weak within the society)” (Save the Children, 2012, p. 22). However, since the focus of this study is on education for children with disabilities, the term ‘students/children with special needs’ primarily refers to those who have learning disabilities, physical disabilities, intellectual disabilities, and other disabling conditions.

The term ‘intellectual disability’ is widely used in this research. According to the American Association on Intellectual and Developmental Disabilities (American Association of Intellectual and Developmental Disabilities (AAIDD), n.d.), ‘intellectual disability’ is an umbrella term for disabilities characterised by limitations in intellectual functioning and adaptive behaviour. It could be argued that this is a narrow biomedical understanding of intellectual disability, which is not compliant with human rights. Yet, due to the difficulty in finding a more comprehensive and rights-based definition, it was decided to refer to the definition approved by the AAIDD. In the context of the present study, this term also encompasses children in segregated institutions who acquired developmental delays and psychological problems due to a lack of a nurturing environment needed for their healthy growth and development.

1.9 Organisation of the Thesis

The thesis consists of five chapters. Chapter One outlines the development of inclusive education in Uzbekistan and provides the aims and purposes of the study, its rationale, country information, my previous background, concepts that form the foundation for inclusive education, and explanation of the terminology used throughout this research. Chapter Two reviews literature primarily related to the problems in the enactment of inclusive education in developing countries. Chapter Three explores the methodological approach to this study, the data collection instruments, the data analysis process, some information about the participating groups, and ethical considerations. Chapters Four-Six present the findings and discussion of these findings. Chapter Four reports on participants' perceptions of inclusive education and the way they see the enactment of inclusive education in Uzbekistan that are followed by discussion. Chapter Five presents and discusses the major challenges of realising inclusive education, including the absence of individualised support for students with disabilities, resulted in their parents being teacher aides; a lack of school and city infrastructures; a shortage of qualified teachers and their poor working conditions; the absence of inclusive education legislation; and disability stigma and discrimination. Chapter Six provides a comprehensive overview and a discussion of the importance of parental involvement; support from the Uzbek government; and the medicalisation of disability prevalent in Uzbekistan. Chapter Seven draws conclusions and implications of the findings, generates recommendations for academics, researchers, and policy-makers, presents research limitations, and gives recommendations for further research.

CHAPTER TWO
LITERATURE REVIEW

2.1 Overview

As stated in Chapter One, the main focus of this study is to identify how the concept of inclusive education is perceived by key players in Uzbekistan, whether there is a common view and understanding among them, and the implications of adopting an inclusive policy and practices in Uzbekistan. There are many reports on educational provision for vulnerable groups of children in the region published by UNICEF, the World Bank, and other international organisations. To date, there is little research literature available on disability issues and national inclusive education initiatives in Uzbekistan. The Japan International Cooperation Agency (JICA) (2002, p. 6) reports, “It is difficult to understand the situation of persons with disabilities in Uzbekistan, as there are almost no available statistics and research”. It is important to note that recently the Uzbek government has begun to take steps to include people with disabilities in the national policy, but issues related to disability and inclusion remain underresearched. In this context it is hoped that my study will help to fill a gap in the literature about inclusive policy and practice in Uzbekistan.

Given the current lack of literature about inclusive practices in Uzbekistan, I needed to draw upon international literature that offers insights into the challenges faced by other developing countries trying to progress inclusive education. I have also included research on disability issues and inclusion undertaken in the developed countries, at the time these countries were at the beginning of their journey towards inclusion. Literature on the development of inclusive education in former Soviet Union countries, including Soviet Central Asia has been reviewed as well. Even though all former Soviet republics have been independent for almost three decades, their sociopolitical situations and approach to education for children with disabilities inherited from the Soviet Union are very similar and continue to be influential.

This chapter consists of nine sections. The first section provides an overview of prevailing discourses around inclusive education. The second section describes the education for children with disabilities in Uzbekistan in the context of the Soviet legacy. Most of the remaining sections discuss challenges in the process of achieving inclusive education.

These include teachers lacking the relevant skills and professional training, barriers to parental involvement, the role of disability-related agencies and the difficulties they face, the effect of stigma on the attainment of inclusive education, a lack of reliable disability data, and the relationships between disability and poverty. The final section summarises the literature and outlines the relevance of the research.

2.2 Understanding of Inclusive Education

This section presents definitions of inclusive education from different perspectives, including interpretations of policy-makers and practitioners, and the major discourses of inclusion in education. The discourses include the human rights approach to education, rooted in international treaties, and inclusive education as a global agenda or as a continuum of special education. I also examine basic assumptions about special education and what the advocates of inclusive education think about these assumptions.

Even though inclusive education has become a more accepted notion in both developed and developing countries in recent years, it is still a complex and controversial topic (Hegarty, 2001). It is difficult to define the term ‘inclusive education’ because it has many different cultural and social meanings. Miles (2000) recommends using the definition of inclusive education proposed by the Salamanca Statement as a reference point. This scholar contends that the main inclusive education document reasserts the right of every child to receive quality education regardless of his/her differences, as stated by the Universal Declaration of Human Rights in 1948. According to the Salamanca Statement, inclusive education means:

> Schools should accommodate all children regardless of their physical, intellectual, social, emotional, linguistic or other conditions. This should include disabled and gifted children, street and working children, children from remote or nomadic populations, children from linguistic, ethnic or cultural minorities and children from other disadvantaged or marginalised areas of groups. (p. 6)

Meijer and Watkins (2016) also note the difficulty of finding a common definition of the term ‘Inclusion’ and the related terminology. They suggest four key aspects to defining ‘Inclusion’: language, legislation, conceptions of policy-makers, and conceptions of practitioners. The language used in a country that attempts to enact inclusive education is very critical. In cases, where terminology related to inclusive education has no direct translation into English, international professionals may refer to the same concept but have different understandings of it. Moreover, according to Peters (2007), policy theorists may deconstruct the language when they interpret and explain something in the policy document. The legislation is also crucial because inclusive education is led by general and special education systems, which is a case for many countries. Both systems need to be examined to understand inclusion and obstacles that could potentially prevent from its successful enactment. Hence, an inclusive education policy must be considered within the wider legislation reforms in any country. Conceptions of policymakers are important because they may vary from country to country significantly. Policymakers' interpretations of inclusion and other related concepts depend on their understanding of special education needs and disability itself. For example, translation and interpretation of the term 'disability' depend on what model of disability is prevailing in a particular country – medical or social. For Meijer and Watkins (2016) conceptions of practitioners are of no less importance. The concept of inclusion has been constantly developing. To understand it, practitioners should be familiar with the ideology associated with the concept of inclusive education and discuss it with other stakeholders. Otherwise, there might be too many terms used with no little overall impact on policy and practice. Meijer and Watkins (2016) argue that several factors should be taken into consideration while defining inclusion and that they all could be grouped around those four concerns; it would help avoid difficulties with the definition.

Due to the prevalence of the medical model in Eastern European countries and former Soviet states, many practitioners who work with children with disabilities in those countries use the terminology that is not consistent with the philosophy of inclusion (Stepaniuk, 2019). Makoelle (2020) analysed the terminology used in Kazakhstan by educators and medical professionals and found that they still used the language perpetuating stereotypes about people with disabilities. They extensively use words, such as 'invalid', 'defective', 'deficit', and 'correction'. Mittler (2000) believes that such a language is "offensive inappropriate" and "can be considered to be as unacceptable as sexist or racist language, which creates stereotypes based on the assumption of common characteristics attached to a label" (p. 8). In Uzbekistan, professionals often use the same disability language reflected in legislation. As noted by United Nations (2019a), the exclusive terminology is commonly used in Uzbek disability-related legislation. At the same time, some of the fundamental concepts utilised in the CRPD, for instance, ‘independent living’ and ‘inclusion and involvement’ are not mentioned in national legislation.

Ainscow et al. (2006) suggest that the concept of inclusion has both a broad definition and a narrow one. A broad definition is more about diversity as such, while a narrow definition refers to educating a specific group of students. The term ‘inclusion’ was introduced first to describe the quality of education for students with special needs. Later, inclusion was defined as an educational system for all students regardless of their gender, race, ethnicity, social status, religion and abilities. Based on that definition, students with disabilities fall under the UNESCO Policy “Education for All” (EFA), which is committed to ensuring that all children, young people, and adults receive basic quality education (Armstrong, Armstrong, & Spandagou, 2011). This commitment is based on human rights as well as the general belief that education is an essential prerequisite for well-being and development (Miles & Singal, 2010). Rouse and Lapham (2013) note that there is a strong link between inclusive education and EFA, although EFA does not mention children and young people with disabilities specifically. These researchers continue that there are many children and youth with disabilities around the world and EFA will not be able to reach its goals without inclusive education.

In the former Soviet Union states, inclusive education is still seen as an educational opportunity for children with disabilities only (Rouse & Lapham, 2013). For instance, in Armenia, the understanding of inclusive education is different from that of the international community: “Local interpretation is narrowed down to the educational rights of disabled persons” (Anapiosyan, Hayrapetyan, & Hovsepyan, 2014, p. 5). This could be explained by the fact that children with disabilities were excluded from general education institutions during the Soviet Union times. Anapiosyan et al. (2014) also note that international organisations, working in the region, keep trying to change the perception of inclusion by actively advocating for inclusive education as a human right and social justice matter.

It is argued by Farrel (2000) that inclusive education is the only type of education solely based on human rights. He asks why/how placing children with disabilities at special educational institutions contradicts human rights. Gordon (2013) raises similar questions: why teaching *all* students in *one* class is a human right and whether educating students with disabilities in segregated institutions is a human rights violation. Gordon (2013) presents the four historical developmental stages of the process from exclusion to inclusion: students with disabilities receive no education; students with disabilities receive segregated education; students with disabilities receive integrated education; and students with disabilities receive inclusive education. Although Gordon (2013) agrees that the denial of the right to education for children with disabilities is a serious violation of human rights, he does not agree with the fourth stage because in his opinion education cannot include *all* students. Gordon (2013) believes that it may be unrealistic to include students with different types of disabilities in one class, for instance, deaf students and students with intellectual disabilities. This author continues some children with severe disabilities also cannot be placed in the class with all other students. On the contrary, putting children with severe disabilities in a general class may violate these children's human rights. Additionally, Gordon (2013) believes that making inclusive education the only option for students with disabilities is paternalistic. They and their parents have to be given the freedom to choose the type of education they think is more suitable for them.

Both Farrel (2000) and Gordon (2013) agree that inclusive education definitely has benefits, such as empowerment, diversity, and autonomy. They however believe there are no empirical reasons why human rights cannot be attained if children are taught at specialised schools. Farrel (2000) points out that when inclusion is perceived as a good thing and exclusion as something bad, there is a risk that the needs of students with special needs may be overlooked because "people get swept along on the 'inclusion bandwagon' " (p. 154). Therefore, to avoid this, it is important to consider all possible arguments for and against inclusion when planning approaches to students with special needs. Further research on evidence for and against the practice is proposed.

Hockenbury, Kauffman, and Hallahan (2000), strong advocates for special education, state that it is often misinterpreted. They consider several erroneous assumptions about special education. One of them is that it stigmatises and labels students with disabilities. They maintain that every student within an educational institution should be somehow identified. If that student has special needs, he/she should be identified as a student with such needs. Furthermore, Hockenbury et al. (2000) state that proper labels communicate important information about the disabilities children have. Another assumption is that special education has no effective teaching methods and could be replaced by general education. Hockenbury et al. (2000) point out that general education cannot meet the needs of all students, “as some students have learning characteristics that are markedly different from the normative or general case” (p. 6). They believe that special education has a wide range of methods that provide quality instruction to students with disabilities. A further assumption is that special education is a separate system, which needs to be integrated into a general education system. Hockenbury et al. (2000) argue that special education *is* integrated into public education as one of the subsystems, at least in the USA. If special education was not integrated, it would have its own separate identity, boundaries, authorities, budget, and others. Kauffman and Hallahan (1995) also point out that both education systems, special and general, can be merged in a way to form inclusive education. They view inclusion as a “bandwagon that offers an attractive platform for the merging of special and general education into a seamless and supple system that will support all students adequately in general schools” (p. 98).

This point raises another conflicted discourse - whether inclusion is a global agenda or a continuum of special education. Many educators think that they are practicing inclusion when, in reality, they are practicing revised special education rhetoric. By doing so, they contribute more to exclusion rather than to the inclusion of students with disabilities (Slee, 2001, as cited in Purdue, 2006). Slee and Allan (2001, p. 177) state that inclusive education is not just “a linear progression” of special education. It should be acknowledged as a radical social movement against exclusion and discrimination in regular schools. Similarly, Lipsky and Gartner (1997) believe that children with disabilities have an absolute right to receive quality education in inclusive classrooms and, therefore, inclusive education is a response to segregated education, which has not been effective enough for many of them. Connor and Ferri (2007) mention another fundamental difference between special and inclusive education. According to them, inclusive education is not simply services for children with disabilities but a way of living with others based on shared beliefs that each person is valued.

Similarly, Kenworthy and Whittaker (2000) speak strongly against segregated educational institutions, “These special places have become twentieth century gulags, where the collective fear of children who are seen as different is assuaged and their segregation from other children is reconstructed as ‘special’ treatment in a ‘safe’ environment” (p. 291). That belief is supported by certain assumptions about how the concept of rights affect segregation. Some of them are segregated children are exposed to discrimination, people supporting segregation promote injustice because they accept discriminatory codes and practices, and that children's rights are obvious and do not need to be proved.

It is pointed out by Connor and Ferri (2007) that "the greatest paradox of special education is that is both a service and a disservice" (p. 74). Even though special education genuinely seeks to contribute to the development of children with disabilities, it brings many disadvantages to them, such as poor academic knowledge due to lower expectations associated with a disability, lack of self-esteem, and isolation. Many scholars consider segregated education as an archaic practice and state that as long as segregated institutions exist as an optional place to study for children with special needs, education authorities will find reasons to send children there (Connor & Ferri, 2007; Gallagher, Heshusins, Iano, & Skrtic, 2004; Kenworthy & Whittaker, 2000). Many of those that hold such views would argue that to fully realise the idea of inclusive education, segregated education as such has to be eradicated.

However, even if children with disabilities are placed in general schools, this is not the end of the problem. Kenworthy and Whittaker (2000) and Wang (2009) note that one of the most significant issues with inclusion relates to various forms of equality. Wang (2009) identifies the main principles of equality in inclusive settings. They are students with special needs have to be treated in the same way as other students; purposes of education have to be the same for all students; the evaluation processes have to be the same for all students; and parents of students with disabilities and students themselves have to be involved in the decision-making process. These principles are based on legislations formulated by the United Nations. For example, as mentioned in Chapter One, Article 2 of the Convention on the Rights of the Child (1989) states that all rights have to be applied equally to all children without discrimination, including children with disabilities.

Although inclusion promotes the full participation of students with special education needs with their peers in school life, many schools still create segregation and foster competition (Lloyd, 2008). For instance, in many general schools, children with special needs have to study separately from others to meet the national assessment standards. It prevents this group of students from enjoying real opportunities to participate fully in school activities. Lloyd (2008) calls such requirements exclusionary practices that "are legitimized within a policy of inclusion" (p. 227). Similarly, Wilson (2000) points out that even though inclusive classes have to be community-based, barrier-free, collaborative, and equal, they are still selective:

> Certain parts of the school … are not accessible to all …, some parts of the curriculum will not be accessible to those without the ability to access them …, and there will be private ‘methods of communication’ (between teachers, for instance) not open to all pupils. (p. 298)

Further, Wilson (2000) discusses some conceptual problems of inclusion trying to find a rational and practical frame for human values, such as justice and compassion.

In sum, many scholars and practitioners acknowledge that inclusive education is still an area in conflict. Ainscow and César (2006) note that “it is necessary to recognise that the field itself is riddled with uncertainties, disputes and contradictions” (p. 236). They note there are many different issues with the enacting of inclusive education in both developing and developed countries. In developing nations, many vulnerable children have never even been taught in schools while in wealthier countries, many students from marginalised groups have an opportunity to study but leave schools without adequate academic knowledge and social skills, despite the availability of resources. However, Ainscow and César (2006) point out that in spite of challenges and contradictions, many countries around the world attempt to provide quality education for all children regardless of their conditions, as required by the Salamanca Statement. Oliver (1996) argues that inclusive education is a continuous process and all weaknesses and issues related to its enactment are unavoidable in the process of its development. This researcher points out that inclusion is not a destination but a process, which requires commitment and changes: in policy, curriculum, values, and attitudes. This scholar concludes that the development of inclusive education is a complex process and it often requires struggle.

2.3 Inclusive Education in Uzbekistan

During the Soviet times, children with disabilities almost always received formal education in specialised institutions that practised medico-pedagogical approaches (Gevorgianiene & Sumskiene, 2017; Oreshkina & Lester, 2013; Phillips, 2009). Educating children with disabilities in a general education setting was not considered because education was standardised through the curriculum and was not suitable for children with disabilities (Phillips, 2009). Oreshkina and Lester (2013) cite one of the Russian special education experts in their work: “Good quality education for children with disabilities is education that takes into consideration their characteristics based on specially developed and proven curriculum and this is what is done in special education schools" (p. 695).

At specialised Soviet institutions, children with disabilities were taught in accordance with the science defectology that incorporated the fundamentals of several sciences: medicine, pedagogy, and psychology. Lev Vygotsky, the founder of defectology, promoted a comprehensive approach to education where all aspects of a child's development - physiological, psychological, and social - were considered. The Soviet version of defectology however was reduced to medical and physiological aspects only, putting more emphasis on children's limitations rather than their potential (Phillips, 2011). In other words, Soviet defectology viewed children with disabilities as deficient and in need of treatment. Bilson and Markova (2007) who researched child abandonment and social inclusion issues in Eastern Europe and Central Asia state that the treatment of children with disabilities was "exclusively a medical issue" (p. 60) and they continued to be institutionalised.

Uzbekistan, being a part of the Soviet bloc for almost 70 years, had segregation practices shaped by the former system that still have their effects (Katsui, 2005). Specialised educational institutions in Uzbekistan play an important role in the process of educating marginalised groups of children. The current special education system in Uzbekistan is presented by 28 Mercy Houses (orphanages), 109 boarding schools for children with different types of disabilities (86 specialised schools for children with impairments and 23 boarding schools with extended care facilities where children study and take treatment), and 122 specialised pre-schools for children with physical disabilities. According to Akhunova (2007), a former Head of Children Social Support and Rehabilitation Department under the Ministry of Education of Uzbekistan, the national Act of Education made provisions for establishing specialised schools for children with special needs. She noted that the Law of the Republic of Uzbekistan "About Education" (1997) fully supports establishing specialised schools which are seen to meet the needs and demands of children with special needs. Indeed, Article 23 'Education of children and adolescents with deviations in physical or psychiatric development' of the Law states: "For education… of children and adolescents with deviations in physical and psychiatric development… special education institutions are established".

Children with disabilities are categorised and assigned to different institutions based on the severity of a disability. According to the Decree of the Cabinet of Ministers on approving the normative and legal acts on state specialised educational institutions for children with disabilities (paragraph 23), children with mild or moderate intellectual or physical disabilities are transferred to residential institutions called "Mehribonlik" under the Ministry of Public Education. For those who have severe forms of disabilities, regulations are different. As stated in Paragraph 25 of the Decree, they are referred to either residential institutions called "Muruvvat" under the Ministry of Health or are assigned to home-based education (Lex.uz, 2011). There is no information on whether children staying in a "Muruvvat" receive educational provision. In the former Soviet Union, children with severe or multiple disabilities were categorised as "uneducable" and excluded from the special education system. They were sent to closed institutions where they were given care and medical treatment only (Oreshkina, Lester, & Judge, 2014). It is evident that the Uzbek system of special education has not been changed significantly since that time.

Nevertheless, with the development of inclusive education as a global agenda, the Uzbek government could not stand aside. It has signed and ratified several major international treaties, such as the Universal Declaration of Human Rights (signed in 1991); the United Nations Convention on the Rights of the Child (ratified in 1994), the Dakar Framework for Action (signed in 2000), and the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (signed in 2009). The government also started working on the national normative acts and resolutions to support inclusion but none of them were included in the national educational policy.

There have been some practical initiatives to enact inclusive education as well. Uzbekistan has expanded its cooperation with international aid organisations and some of them work specifically in the field of disability. The UNICEF initiated the project "Implementation of a Child Friendly Attitude through Inclusive Education" (2005-2006). At the same time, the Japan International Cooperation Agency (JICA) organised, free of charge, computer courses for people who were deaf or had hearing impairments to increase their employability. The Asian Development Bank (ADB) enacted the project "Basic Education for Children with Special Needs (formerly Improving Access and Quality of Basic Education to Disadvantaged Children)" (2006-2009). The USAID project “Equalization of Educational Opportunities for Children with Disabilities in Uzbekistan” (2009-2010) also attempted to improve access to education for children with disabilities. Recently, the European Union has founded a project “Inclusive Education for Children with Special Needs in Uzbekistan” (2014-2016). Currently, this project is being administered by the Republican Centre for Social Adaptation of Children (RCSAC).

Overall, it can be seen that there have been some efforts made by the Uzbek Government to develop inclusive education. Yet, practices of educational inclusion in Uzbekistan seem to be unsustainable. Although the government has committed to supporting inclusive education initiatives, it often fails to do so (UNICEF, 2011). As Mitchell (2005) argues, “While many countries seem committed to inclusive education in their rhetoric, and even in their legislation and policies, practices often fall short” (p. 11). There are many reasons for the gap between policy aspirations and enactment, such as economic; cultural; lack of teachers’ expertise in mainstream classrooms; poor school infrastructure; and lack of parental involvement. Some of these problems are discussed in the following sections.

2.4 Lack of Teachers’ Expertise

Teachers play a critical role in the development of inclusive practices (Forlin & Chambers, 2011; Jordan, Schwartz, & McGhie-Richmond, 2009). Ideally, they should provide holistic support to students with disabilities in their classes and serve as a liaison between the school officials and students and their parents (Ahsan, Sharma, & Deppeler, 2011; Mastropieri & Scruggs, 2010). Yet, in less developed countries, many teachers are not able to respond to the needs of students with disabilities and, therefore, are reluctant to have them in their classes (Sharma, Forlin, Deppeler, & Guang-xue, 2013). There are many reasons for that. One of the most significant arises because teachers do not have adequate qualification to meet the needs of their students with disabilities (Avramidis & Kalyva, 2007; Eleweke & Rodda, 2002; Florian & Becirevic, 2011). The situation is also worsened by a lack of resources at schools, overcrowded classes, inflexible exam-oriented curriculum, inadequate infrastructure, and lack of support from school administration and public agencies (Chong, Forlin, & Lan, 2007; Ghergut, 2010; Sharma, Moore, & Sonawane, 2009; Tyagi, 2016).

A shortage of well-trained teaching staff who can meet the needs of children with disabilities and a lack of in-service training is one of the major problems in many former Soviet Union countries. Institutes of Defectology are often the only institutions that conduct professional training for teachers working with children with disabilities (Florian & Becirevic, 2011). In Uzbekistan, the quality of existing training is also low because it is not practice-oriented (Education Sector Plan for 2013-2017, 2013). Yet, research has shown that practical experience is an essential component for teachers' training programmes because it helps teachers feel more confident and positive about teaching students with diverse needs (Brownlee & Carrington, 2000).

According to Rouse and Lapham (2013), pre-service training courses in the Central Asian region are not designed for inclusive education practices. Most pedagogical universities do not prepare their students for inclusion and departments of defectology still prepare specialists to work in segregated institutions. Rouse and Lapham (2013) also maintain that there are no professionals who could prepare pre-service teachers for the transition from specialised schools to mainstream ones. Some Central Asian countries have attempted to reform pedagogical universities. For instance, Kazakhstan has launched a new large-scale professional development programme for school teachers. In general, nevertheless, the current curriculum at teacher training colleges and universities in the region does not significantly differ from the curriculum used during the Soviet times except for Marxist-Leninist content (Papieva, 2006).

Florian and Becirevic (2011) state that although there were some educational reforms in the region that targeted teachers' professional development, none of them has led to systematic changes at universities and "teachers are still prepared according to their specialization in traditional subjects" (p. 372). They continue that university study programmes are highly academic and do not pay enough attention to diverse learning needs and student-centred methodology. After pre-service teachers graduate, they often do not know how to respond to students' diversity issues and consequently might have negative attitudes towards inclusive education initiatives. Thus, issues of teacher preparation programmes need to be addressed to prepare educators to meet challenges of a diverse classroom (Ahsan et al., 2011; UNICEF, 2010).

In Romania, also a post-Communist country, teachers' attitudes towards inclusion of students with disabilities in regular school is also one of the biggest obstacles to inclusive education practice (Ghergut, 2010; Unianu, 2012). Unianu (2012) notes that teachers' attitudes are influenced by different factors, such as the nature of students' disabilities, the degrees of disability, teachers' readiness to work with this group of students, and their belief in their professional capacities. Based on the questionnaire responses of 112 Romanian teachers, it was found out that many of them did not feel competent to work with those who had disabilities. Teachers stated that they did not have enough professional training to gain more knowledge and improve their skills to teach students with disabilities. Unsurprisingly, this affects their attitude towards what they do. Several other studies have found that training courses for teachers are critical because they contribute to positive attitudes towards teaching students with special needs (Lancaster & Bain, 2010; Loreman, Earle, Sharma, & Forlin, 2007).

In Pakistan, the main issues in the enactment of inclusive education are a lack of teacher training and a shortage of financial resources (Ghouri, Abrar, & Baloch, 2010). These researchers found that teachers from four schools in Karachi did not feel adequately trained to teach children with disabilities in their classes and were, therefore, not willing to do so. Ghouri et al. (2010) recommend the government generate more funds for professional opportunities for teachers working with students with disabilities. Moreover, they contend that government officials should think of professional incentives to stimulate teachers. Pasha (2012), who explored the readiness of primary school teachers from 75 public primary schools in Lahore to work in an inclusive setting, noted that many of them were not ready for that, although they might not be opposed to inclusion as such. Pasha (2012) argues that one of the main reasons for that is a lack of professional development opportunities where teachers and school administrators could receive knowledge about current inclusive education research. "In-service training is an important pillar of professional development" (Pasha, 2012, p. 123). This researcher concludes that only trained teachers and other stakeholders can promote inclusive education effectively.

There are many similar examples in other developing countries too. According to Rahaman and Sutherland (2012), in Bangladesh, many general school teachers do not have enough knowledge and understanding of the needs of students with disabilities. It results in a lack of teachers' confidence to work with these children, which is one of the major barriers to including them in mainstream schools. Similarly, Singal (2006) states that in India, mainstream teachers do not have appropriate professional knowledge and skills to teach students with disabilities. They primarily have a college training that only “relies heavily on chalk-talk approaches, is isolated from schools, and has a focus on imparting theoretical knowledge” (p. 362). Singal (2006) continues that even though the Indian government supports inclusive education initiatives, teachers are not provided with relevant in-service disability-related training and experiences. According to Leung and Mak (2010), primary school teachers in Hong Kong experience the same difficulties, when they try to enact inclusive education in their general classrooms. They have limited training and insufficient knowledge about children with disabilities. As in Bangladesh, their lack of preparedness often prevents children with disabilities from going to mainstream schools.

Lack of teachers’ professional skills is not the only problem at school. The other major area of concern in developing countries is insufficient support personnel (Eleweke & Rodda, 2002; Giangreco, Suter, & Doyle, 2010). Learners with disabilities within inclusive schools must have not only special education teachers to help them succeed but also a wide range of other specialists who can assist with a referral, identification, diagnosis, and other services (Eleweke & Rodda, 2002). Lack of meaningful educational services negatively impacts both students and teachers. Students do not receive sufficient support and teachers, in turn, cannot work alone effectively and often experience stress.

Collaboration with paraprofessionals is an important aspect of educating children with disabilities at mainstream schools (Giangreco et al., 2010; Werts, Zigmond, & Leeper, 2001). Unlike education for typically developing children, education of children who have intellectual, emotional, or multiple disabilities cannot be considered supported without the involvement of trained and prepared paraprofessionals. Their involvement favourably affects the students’ performance because with their support, students are more academically engaged (Giangreco et al., 2010). Giangreco et al. (2010) state, “it was not surprising that when this support was moved away, they were less engaged” (p. 47). There is little doubt that many developing countries would point to a lack of paraprofessionals at mainstream schools due to financial constraints. In Uzbekistan, it can also be explained by the fact that historically education for children with disabilities was segregated and paraprofessionals were available only in specialised institutions. This practice is still widespread across the country and many children with disabilities who moved to general schools are often not provided with additional support except for a classroom teacher.

One more critical element for the success of students with disabilities at inclusive schools is Individualised Education Plans/Programmes (IEPs). IEPs adjusted in terms of pedagogy are necessary to meet the learning needs of children with disabilities in mainstream classes (Mitchell, 2005). According to Valentin (2007), the IEP is a document that includes specific learning needs of a student and certain ways to adapt the curriculum and physical environment to him/her. It also identifies the additional support services necessary for a student (Inclusion BC, n.d.). A typical IEP includes 1) information about students' current academic performances; 2) annual goals and objectives; 3) a schedule of when a student's progress will be measured; 4) a prescription of special instructions and services necessary for them (Musyoka & Clark, 2017). Drasgow, Yell, and Robinson (2001) believe that an IEP is a cornerstone in the education process of students with disabilities. Every school accommodating children with disabilities should follow all IEP requirements to ensure that they receive a quality education.

Goodman and Bond (1993) pose the question of what is meant by individual learning needs. In a general classroom, a student is defined by his/her age, which determines a grade placement and a relevant programme. Student's weaknesses, needs, and preferences may not always be considered. A child with different abilities needs another approach: his/her cognitive, social, motor and language skills are taken into account. Here, according to Goodman and Bond (1993), IEPs can help because they are designed to meet unique needs of students:

> Where goal areas are clearly defined this sort of individualization - equivalent to establishing expectations by subject matter for the older child - is not difficult to achieve under the current IEP mandate and indeed is encouraged by the various assessment instruments. (p. 417)

In Uzbekistan, IEPs are considered at neither a methodological nor legislative level. Students with special needs are expected to study based on the general curricular within the timeframe and to the extent required by the State Standards. Therefore, many students cannot succeed and children with intellectual disabilities are automatically excluded from such an "inclusive" system of education. Some measures have been taken to change the situation. The importance of IEPs has been presented to relevant ministries to generate governmental support. Subsequently, the training and recommendations on the development of IEPs have been offered to special education professionals from the Faculty of the Department of Defectology and some Ministry of Education officials (V. Artikova, personal communication, January 27, 2017). It will take time to disseminate the IEP practice but at least it has been initiated.

Inflexible school curricular are a further obstacle for successful inclusive education practices. The challenges faced by teachers in Singapore can be an example of that. Yeo, Chong, Neihart, and Huan (2016) conducted research on primary teachers' experience with inclusive education in Singapore and found that in general, they support inclusive education initiatives but at the same time experience many challenges. In addition to fear, anxiety, frustration, and inability to manage their students' challenging behaviour, teachers were stressed by large multilevel classes and pressure to meet curriculum and examination requirements.

Indeed, existing inflexible pedagogical practices are a big challenge for successful realization of inclusive education. For instance, in many developing countries, the examination system requires all students to meet the same criteria regardless of their abilities and knowledge. Tiwari, Das, and Sharma (2015) point out that "over-reliance on testing" in Indian high schools makes teachers get focused only on those who can pass exams successfully (Tiwari et al., 2015, p. 133). Those who are potentially not able to pass exams are not given enough attention. Law, Joughin, Kennedy, Tse, and Yu (2007) note that in the competitive world this system does not allow those who are studying at a slower pace to succeed. Within the exam-oriented education system, which is the same for all students, students with special needs are neglected (Deng & Poon-McBrayer, 2004). Sharma et al. (2013) point out that within a highly competitive school system, it will be very difficult to support inclusion for students with special needs because they will be less likely to achieve high results in numeracy, literacy, and science. They argue that it is an additional stressor for teachers because many of them are judged based on the results of their students.

For all the above reasons, teachers at mainstream schools often feel reluctant to work with students with disabilities. Their positive attitudes are central to supporting inclusion. They govern teachers' everyday practices and result in teaching strategies and activities they choose to work with students with disabilities. Positive attitudes towards inclusive education initiatives promote their success while negative attitudes ensure their failure

(Loreman, 2007). Therefore, both pre-service and in-service teacher training programmes, in-class support, and relevant conditions to work are critical (Florian & Linklater, 2010).

2.5 Lack of Parental Involvement

A lack of parental involvement in education of their children is often seen as a cornerstone of a child's education. According to Hill and Taylor (2004), parental involvement is the participation of parents in the educational activities of their children; these might include helping with homework, regular communication with school representatives, attending school meetings and conferences, or volunteering in school-related activities. Much has been written about the positive impact of parental involvement on the learning outcomes of their children (Garrick & Salend, 2000; Hornby, 2011; Newman & Wehlage, 1995). For instance, according to Fan and Williams (2010), students whose parents are actively engaged in their education process, generally achieve better grades and can better cope with academic challenges. There are also many social advantages of parental involvement: children usually have higher level of confidence, self-perception, self-discipline, and psychological well-being (Cripps & Zyromski, 2009; Hill & Taylor, 2004).

The involvement in their children’s education is even more important when it comes to children with disabilities. Ferrel (2012) emphasises that although the involvement of parents benefits all students, those who have disabilities need a greater degree of family support including advocacy than their able-bodied peers. It is also critical for parents because they are naturally more concerned about the development of their children (Blok, Peetsma, & Roede, 2007). The importance of family engagement in education of children with disabilities is based on the assumption that parents know their children like no one else: they know all about their capabilities, talents, and limitations (Andy, Black, & Bruce, 2015; UNESCO, 2002). Therefore, they can significantly contribute to the decision-making processes regarding education for their children. As Forlin and Hopewell (2006) point out, the expertise of parents should be acknowledged and utilised, especially when we talk about special needs children.

Chakuchichi, Chimedza, Chiinze, and Kaputa (2003) also argue that the involvement of parents in education is beneficial for both parents themselves and their children. Parents are empowered through close cooperation with teachers and then they contribute to changing the attitude towards their children at school and in society. Besides, teachers acquire greater cultural understanding through interaction with families of their students with special needs and schools, giving equal access to education for all children, establish a better reputation in the community (UNICEF, 2014c).

In developed countries, the involvement of parents in education of their children with special needs is generally strongly encouraged. If prior to the 1980s, parents were dependent on the support of professionals, now they are often accepted as equal partners whose experience is valuable (Spann, Kohler, & Soenksen, 2003). For example, in Canada, parental involvement it is not only encouraged but also supported by legislation (Lai & Vadeboncoeur, 2012). Parents are required to participate in the decision-making processes regarding their children’s education and assessment and to share their experiences.

The situation with parental involvement in developing countries is very different. Many of them are not involved in the lives of their children and often unaware of their rights and possibilities compared to parents from western countries (Engelbrecht, Oswald, Swart, Kitching, & Eloff, 2005). Bean and Thorburn (1995) explain this with references with factors, such as poverty, dependency, and cultural beliefs that eventually lead to “a crisis in parenting” (p. 3). These scholars discuss two rearing styles common for parents of children with disabilities in developing countries. One is focused on over-protection. It may occur because parents feel guilt for a disability their child has. Even though they may be loving parents, they tend not to participate in a child’s learning and training. An opposite rearing style is parental neglect and discrimination. It occurs particularly in families with other children and little resources. In such cases, parents often prefer to contribute to their able-bodied children leaving those with disabilities with little care. Such differentiation between children with disabilities and their non-disabled siblings also exists in families in Central Asian countries (Katsui, 2005).

Institutionalisation that was common during Soviet times is another reason why parents in Central Asia are often neither involved in the social life of their children nor in their education (Katsui, 2005; Phillips, 2009). In the Soviet Union, children with disabilities were often placed in segregated institutions and parental involvement was not needed. All responsibilities for their development were taken by medical practitioners and social workers. This is still a widespread practice in Uzbekistan: “Parents of children with disabilities believe that they ought to send their children to institutions… as this is the best place for children with disabilities to be taken care of" (Narolskaya, 2013, pp. 2-3).

In many developing countries, even when parents of children with disabilities are willing to participate in their children's education, teachers often regard them as a part of the problem and treat them with paternalism. For instance, in Jamaica, those parents who tried to speak up for their children were considered troublemakers (Bean & Thorburn, 1995). For the same reason, the special education legislation and teacher training programmes in Arab countries do not embrace parents. As a result, school personnel makes little or no efforts to encourage and support parental involvement and it is often "subject to the judgments and conditions of teachers" (Hadidi & Al Khateeb, 2015, p. 526). In Central Asian countries, including Uzbekistan, parents also have insufficient social power and capacity to act as advocates and partners. They are "typically passive" and unintentionally make their children's lives even worse (Katsui, 2005, p. 70).

Recently in Central Asia parents of children with disabilities have become more active in supporting their children. According to UNICEF (2013) (as cited in Nazarbayev University Writers Guild, 2015), 36 percent of Kazakh parents who participated in a sociological study of public opinion on creation of inclusive environments were familiar with the concept of inclusive education. However, 36 percent were not familiar with this term, 24 percent were somewhat familiar with it, and the remaining 4 percent did not answer. Although less than half of the parents were familiar with the concept of inclusion, according to Nazarbayev University Writers Guild (2015), it would be enough to start promoting the idea of inclusion within a wider community. Bridges (2014) concludes that in close collaboration with non-governmental organisations, these parents could significantly contribute to the development of inclusive education policies and practices in Kazakhstan.

There is limited official information on parental activism in Uzbekistan but there are some indications of its existence. A growing number of parents who have children with disabilities are trying to overcome social and educational barriers to ensure their children have equal rights. For instance, a mother of a child with Down syndrome regularly organises sports activities for other children with the same diagnosis. The woman believes that children with Down syndrome should have access to sport and recreation on an equal basis with other children (Nam, 2018). Additionally, some national and international

NGOs help parent activists organise support groups. Their purposes are to advocate for other families raising children with disabilities and provide information on medical, educational, and financial resources for their children (Uzbekistan Humanitarian Information, n. d.).

Rouse and Lapham (2013) state that despite the absence of the previous history of parental activism in post-Soviet Central Asia and many challenges parents have, they still try to help other families who are denied access to services and whose rights are violated. Some of them even “grew beyond support and service provision to become movements advocating for children’s rights” (p. 15). In addition to training and advocacy support, these parents, supported by school teachers and other professionals, work with parents of children without disabilities who do not welcome inclusive education to change their opinion.

Establishing cooperation is a complex process requiring the involvement of social, institutional, and interpersonal factors (UNICEF, 2014d). Additionally, parental involvement is a dynamic and constantly changing and developing phenomenon; it depends on the context, resources, and specific needs of each child and family (Xu & Filler, 2008). However, despite complexities, active family involvement, as stated above, is a significant prerequisite for the effective development of inclusive education. Xu and Filler (2008) state:

> When educational practices that support inclusion focus upon all systems with active family involvement as the focus of concern, we will be able to achieve the more important goal of education: to prepare our youth for a life that reflects an appreciation of the value and fundamental worth of each individual. (p. 68)

2.6 The Role of Non-Governmental Agencies in the Development of Inclusive Education and Issues They Face

Disability non-governmental organisations (NGOs) and Disabled People’s Organisations (DPOs) are another important group that promotes inclusion of people with disabilities. The term ‘non-governmental organisation’ can be applicable to many different types of organisations, ranging from large charities to small local self-help organisations. NGOs are usually private initiatives involved in a variety of development issues on a non-profit basis (Desai, 2014). In the developing world where countries have limited financial resources and their governance is not developed enough, NGOs are alternative forms of development. Banks and Hulme (2012) state, “Where states cannot provide sufficient goods, services or enabling environments that help citizens in securing livelihoods, or where disadvantaged groups are excluded from existing state institutions, alternative channels of service provision and/or holding governments to account must be found” (p. 1). For instance, in Russia, disability-related NGOs were formed as a response to the lack of social services (Thomson, 2006). By providing these services to people with disabilities, NGOs filled the gap of the state’s welfare system. The government, in return, supported NGOs financially. Globally, the non-governmental sector has played increasingly important roles in the development sector (Banks & Hulme, 2012; Murray & Overton, 2011; Thomson, 2006; Williams, 1990).

Unlike NGOs that can be organised by any person interested in change and development, DPOs are organisations that are founded, led, and controlled by persons with disabilities and/or their family members (Deepak, Santos, Griffo, Santana, & Bapu, 2013; Geiser, Ziegler, & Zurmuhl, 2011). The history of DPOs started in the late 1970s (Enns, n.d.). People with disabilities have always experienced barriers in different spheres of their lives, for instance, education, employment, family life, housing, and transportation. Eventually, following the Disability Rights Movement, they have established their own organisations in 100 countries (Enns, n.d.; Young, Reeve, & Grills, 2016). According to Driedger (1987), the first DPOs were specifically for blind or deaf people only. Latterly, multi-disability organisations were formed. In the developing world, DPOs evolved as a result of international initiatives. The majority of DPOs were established during the period from 1983 to 1992, a time right after the World Programme of Action Concerning Disabled Persons was adopted by the UN General Assembly.

By organising their agencies, people with disabilities have represented themselves as citizens with rights, not unequal to others anymore. For many years, the voices of people with disabilities were not heard. They were represented by other people, such as medical professionals and social workers. As Katsui (2005) stated, “Ignorance of the voices of disabled people reinforced the medically-oriented solution of their lives” (p. 24), while they wanted to be heard and represent themselves to the governmental and non-governmental agencies. They believed when people were united, they were much stronger: “Moving away from individual attempts to improve individual living conditions, persons with disabilities formed their own representative organizations” (Geiser et al., 2011, p.

12). Self-representation is not the only function fulfilled by DPOs. Other important functions of DPOs may include identifying and addressing the needs of people with disabilities and their families, providing advocacy and lobbying activities to support them, raising public disability awareness, and evaluating existing services. The functions of DPOs may vary markedly from organisation to organisation but they all have an overarching goal to improve the quality of lives for people with disabilities (Young et al., 2016).

There is a paucity of literature concerning the work of civil society organisations in Uzbekistan. After independence in 1991, civil society agencies faced serious regulatory barriers. Although there was a civil law to protect these organisations, they “frequently fell under suspicion and were subject to administrative measures” Bowyer (2018, p. 50). NGOs and DPOs were often limited in carrying out their activities and influencing decision-making and disability issues. Katsui (2005) gives an example of neglecting DPOs’ opinions and institutional power. In the early 2000s, DPOs were asked to contribute to the draft law on disability but their suggestions were not included in the final version.

In the mid 2010s, President Karimov formally acknowledged the role of non-governmental organisations in Uzbek society. The President eased registration procedures for NGOs, reduced registration fees, and provided financial assistance to enact initiatives. Legislation however for non-governmental agencies remained generally very restrictive (Bowyer, 2018; Katsui, 2005; Stevens, 2007). Despite challenges, many of them were actively supporting people with disabilities. These organisations were primarily involved in consulting, legal counselling, empowerment training, pre-vocational skills development, raising public awareness, and others.

As mentioned above, NGOs and DPOs particularly combat the exclusion of disadvantaged groups. In this regard, their roles in promoting deinstitutionalisation and inclusive education are crucial (Holland, 2008). According to Furuta and Thamburaj (2014), these organisations lead the enactment of inclusive education during an initial stage until the government takes over new functions and responsibilities. In this regard, disability-related agencies are considered very important stakeholders because of their expertise, flexibility, and proximity to people (United Nations, n.d.). There is little official information on the involvement of Uzbek NGOs and DPOs in inclusive education. Yet, there are many examples of non-governmental organisations' contributions to the inclusion of children with disabilities in general schools in other developing countries. Their work includes, but is not limited to, organising training for teachers and parents, providing advocacy for families with children with disabilities, reaching out to families living in remote areas, organising awareness-raising campaigns in the local communities, and assisting the government with data collection and policy development (Furuta & Thamburaj, 2014; Pillay, 2010).

Within inclusive education, cooperation between NGOs and families is of particular importance. Srivastava, de Boer, and Pijl (2015) mentioned several reports focused on "parents recognizing the importance of knowledge and information about disability, its management and available services" (p. 186). In their work, they referred to the study of Alur (2010) who described the initiatives of Indian NGOs to involve parents as equal partners in the education of their children. Similar initiatives were enacted in Cairo (Egypt) where both local and international NGOs involved community workers practicing a rights-based approach to inform parents and communities about disability issues (World Bank, 2005). In Malaysia, NGOs are also a good example of the support they can provide to children with disabilities. Many Malaysian NGOs are focused on a specific disability, for instance, Down syndrome. They are committed to the welfare of these children and to ensuring they receive appropriate education and disability support services (Jiar, Handayani, & Xi, 2014).

DPOs in many countries are also actively involved in inclusive education initiatives and building a partnership with the families of children with disabilities. For instance, ADEFIS, a Brazilian DPO, served as a focal point for parents of children with disabilities studying in mainstream schools to provide information on their children's rights. This DPO regularly organised workshops to educate the public about inclusive education and the barriers children with disabilities face on the way to it (Deepak et al., 2013). The contribution of Chinese DPOs to inclusive education is also significant. Leaders of many DPOs closely worked with local education experts to develop advocacy strategies aimed at the integration of children with disabilities. Moreover, DPOs, together with other stakeholders, actively participated in the process of developing a national inclusive education policy to support children with disabilities in mainstream schools in terms of funding and experts. The Chinese government released the national policy in 2012 (Zhang, 2017).

The participation of people with disabilities and their organisations in the development of laws, policies, and programmes is critical to promote disability inclusion to all people with disabilities. Hurst (1999) suggests that “One of the most important parts of a sound development strategy must be to ensure that policies are in place which recognise the need to include socially excluded groups in all stages of development work” (p. 32). If the unique experiences of people with disabilities are valued and taken into account, they are empowered. Empowerment leads to social change in the society and transforms cultural and institutional norms prevailing there (Hurst, 1999).

2.7 Social and Institutional Stigma

According to Susman (1999), stigma can be defined as an adverse reaction to the perception of a difference that is evaluated from a negative perspective. Disability stigma contributes to the discrimination and exclusion experienced by children with disabilities in all spheres of their lives, including education (Uba & Nwoga, 2016). It is necessary to gain a better understanding of the impact of stigma on the attainment of inclusive education in developing countries to identify barriers impeding inclusion and design appropriate interventions to enable it (Fakolade, Adeniyi, & Tella, 2009; Lloyd, 2008). With regard to this, misconceptions about the causes of disabilities that children are born with and wrong beliefs about the nature and abilities of these children should be considered as key factors contributing to their social and institutional exclusion (Al-Dababneh, Al-Zboon, & Baibers, 2017; Rohwerder, 2018).

In developing countries, many people believe that there are specific external causes of disability, such as punishment from God, bad actions of people with disabilities themselves, or the sin of their parents (Lamorey, 2002; Rohwerder, 2018; Stone-MacDonald & Butera, 2012). In some post-Soviet Central Asian countries, mothers of children with disabilities are often suspected of having sex with a man who is not the father of her child while pregnant. For instance, in Tajikistan, many traditional Tajiks believe that a child’s disability is a result of “the birth mother engaging in sexual relations outside of marriage or other behaviour considered ‘antisocial’ ” (Gatling & Juraeva, 2013, p. 24). It puts both a woman and her husband at risk of harm. A woman is blamed for behaving “antisocially” and her husband for losing control over his wife, which is perceived damaging for the Tajik concept of male honour (Harris, 2006, as cited in Gatling & Juraeva, 2013). In Kyrgyzstan, people have the same belief: a child with a sensory or intellectual disability is a result of a mother’s moral failing that “brought a punishment upon the family” (Hartblay & Ailchieva, 2013, p. 115). There is no official information about cultural and religious beliefs regarding disability prevailing in Uzbekistan. Nevertheless, many anecdotal pieces of evidence are circulating amongst people about mothers of children with disabilities who were being blamed for immoral actions in the past. It makes parents hide their children from everyone including extended family members and friends to protect their reputation and the reputation of other children in the family.

Negative attitudes towards children with disabilities, including denial, often start within a family and community and then spread to the wider society, including school systems (Oliver-Commey, 2001). Misconceptions that children with disabilities are not able to perform well at school alongside their non-disabled peers are one of “the drivers of disability stigma” (Rohwerder, 2018, p. 2). They create institutional barriers that prevent these children from enrolment and participation in inclusive education (Adera & Asimeng-Boahene, 2011). Institutional barriers include but are not limited to a lack of provision, support, and trained personnel. These barriers often seem natural and are hard to detect (Saar, Täht, & Roosalu, 2014). Children with disabilities may be blamed for difficulties to be a part of a mainstream environment. According to Gatling and Juraeva (2013), this is how a school principal in Tajikistan explained his reluctance to admit a child with cerebral palsy to the mainstream school:

> The school is a place for healthy children. If they are healthy, we’ll accept them. Our pedagogy is for healthy children, not for special children. Our teachers aren’t prepared to teach disabled children. They’ve been trained in standard pedagogy and psychology. It’s possible that we would accept other children, if they have documentation from doctors. (p. 25)

Markova and Sultanalieva (2013) note that in most cases, school principals have sound experience in managing educational institutions but only within the previous Soviet system, which isolated children with disabilities. Some of them understand that they should support inclusive education initiatives but the benefits are not clear to them. Those, who are reluctant to admit students with disabilities, ignore their needs and interests and do not provide the necessary support. Markova and Sultanalieva (2013) provide two examples. One school principal mentioned that even though she understood that parents wanted to keep their children with disabilities among “normal children” (p. 57), she was unwilling to accept them and did not seek cooperation with parents. Another principal did not want to take a risk with these children and preferred to transfer them either to private schools or to home-based education.

Erroneous beliefs about disability followed by discriminatory institutional practices are maintained by other developing societies too. For instance, a study conducted in Nigeria found that many people believe that children with physical disabilities are punishment from gods for the bad deeds of their parents, while children with intellectual disabilities are often believed to be possessed by demons (Uba & Nwoga, 2016). Segregated institutions are strongly recommended for these children because “societal misconceptions held about them may make them targets for exclusionary practices in mainstream schools” (Uba & Nwoga, 2016, p. 978). Those parents who do not want their children to be segregated either rely on private schools that have more qualified and committed teachers and better facilities, or place them in mainstream schools where they face discrimination from teachers and classmates. The majority of these students are more likely to drop out without transitioning to higher levels of education (Global Campaign for Education, 2014).

Similarly, in India and East Asian countries, children with disabilities and their family members often experience stigmatization due to traditional beliefs (Alur, 2001; Kayama, Haight, Ku, Cho, & Lee, 2017; Tait, Mundia, & Wong, 2014). The study of Alur (2001) found that in India, a child’s disability was perceived by parents as “karma, a result of past deeds, an individual responsibility” (p. 290). Disability services of voluntary organisations there were mainly based on charity and benevolence. These practices affected policy-makers who extensively supported segregated education. In China, people’s beliefs are mainly grounded in the concept of Confucianism. One of the core ethical principles of Confucian philosophy is filial piety: children have to take care of their parents when they grow old (Tait et al., 2014; Wee, 2014). Parents of children with Autism Spectrum Disorder (ASD) experience feelings of frustration, shame, and embarrassment because their children may not be capable to meet these family expectations. Besides, parents are afraid that their children may face discrimination in communities and particularly in mainstream educational settings based on academic criteria. Therefore, to avoid "discrimination such as exclusion from social activities, humiliation and neglect by teachers and the public" (Tait et al., 2014, p. 23), parents do not send their children to local general schools and often hide them even from close relatives.

There are many other examples of cultural and religious beliefs about disability resulting in children with disabilities being treated with superstition and neglect (Al-Dababneh et al., 2017; Riany, Cuskelly, & Meredith, 2016; Stone-MacDonald & Butera, 2012). As stated above, the stigmatisation of children with disabilities is often characterised by a lack of understanding and awareness regarding the causes and nature of the disability. Therefore, education interventions are an effective way to challenge the stigma held by many parents, teachers, and community members (Rüsch, Angermeyer, & Corrigan, 2005). Mostert (2016) notes that stigma-reduction measures are considered effective for combating disability-related beliefs when they are matched with local cultural particularities. Simply, teaching about the causes of disability from a biomedical perspective is not effective. Rohwerder (2018) proposes the following interventions to combat disability stigma: educational vignettes, university lectures, online films, and celebrations of disability-related events. At the same time, these efforts need to be reinforced by legislation prohibiting discriminatory practices against children with disabilities and their families (McConkey, Kahonde, & McKenzie, 2016).

2.8 Lack of Disability Data

Article 31 of the CRPD states, "States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention" (Convention on the Rights of Persons with Disabilities, 2006). Although the availability of relevant data is critical for the development of sound policies, many countries of the developing world still have no information on how many people with disabilities live there and what living conditions they have (Eide & Loeb, 2005; Fujiura, Park, & Rutkowski-Kmitta, 2005; Robson & Evans, 2003). As stated at the beginning of this chapter, currently, in Uzbekistan, there are also no reliable statistics on the total number of adults and children with disabilities, the nature of their disabilities, and their educational needs. There might be several reasons why there is no *reliable* data but below I will discuss three of these: the large number of unregistered people; bureaucratic procedures for receiving a disability status; and intentional distortion of facts by authorities.

In Uzbekistan, there are still many unregistered people with disabilities. According to the UNICEF (2004), this is a prevailing problem for rural areas where children with disabilities are often not registered at birth. Many families do not register their members with disabilities to hide them from the public eye so as not to be stigmatised, and by doing so make them unknown to services (Katsui, 2005). Schools, clinics, and other institutions must keep administrative records of the number of people receiving their services/benefits. If children were not registered, they do not have access to education, health care, and social services. According to official statistics, there were around 750,000 persons with disabilities in Uzbekistan, but disability rights activists suggest that there may be around three million (United States Department of State, 2014).

Bureaucratic barriers to becoming officially identified as a person with a disability are another reason for a lack of adequate data on their number. According to the Japan International Cooperation Agency (JICA) (2002), in Uzbekistan, neither people with congenital disabilities nor people with acquired disabilities can obtain a disability status automatically. These groups have to go through a long bureaucratic process to prove that they have disabilities. The process consists of two steps: first, people are placed in a hospital to receive treatment and an official diagnosis. Second, those people who have disabling conditions receive referrals to a Medical and Labour Expert Commission (VTEK), which determines a category/grade of a disability. D. Yusupov (2018) points out that administrative registers of VTEKs is the main source of information about the number of people with disabilities in Uzbekistan. Yet, the information provided by VTEKs is often not reliable. Many people with disabilities have either decided not to go through this exhausting process to receive a disability status, or their disabilities were not recognised by a VTEK.

A population census can be an effective instrument to collect trustworthy information about people with disabilities and their experiences. According to the UNICEF (2014b), censuses “are typically carried out every 10 years over the entire nation” (p. 11). In Uzbekistan, the latest census was conducted almost 30 years ago (Scott & Mete, 2008). Presumably, there were not enough human and financial resources to do it regularly. However, in February 2019, the President issued the Decree “About the approval of the concept of conducting a population census in the Republic of Uzbekistan in 2022”. The Presidential Decree also mentions vulnerable groups of people, including people with disabilities. It states that reliable statistical information on vulnerable population groups is necessary to enact effective social protection policies (Lex.uz, 2019).

A further reason for a lack of reliable data is intentional hiding or distortion of facts by authorities. Narolskaya (2013) notes that in Uzbekistan data collection on disability issues is a big problem and even ministries are reluctant to provide true data, as they do not want to be punished for releasing the information, which can somehow diminish the country’s prestige. This practice and attitude towards people with disabilities is inherited from the Soviet times. Phillips (2009) states that historically throughout the Soviet Union people with disabilities were invisible because the government tried to hide them to keep an image of a welfare state where all people were able-bodied and healthy. “The politics of exclusion and social distancing” characterised disability policy of that time (Phillips, 2009, para. 1).

Another reason why the Uzbek government intentionally reduced the official number of people with disabilities may be that there are not enough financial resources in the state budget to pay disability allowances. The government has changed disability registration criteria reducing the number of people eligible for social support (Zagirtdinova, 2005). Currently, the official number of people with disabilities in Uzbekistan constitutes 1.3% of the total population (Japan International Cooperation Agency (JICA), 2002; United Nations, 2015). This number is significantly lower than that in other countries, including the post-Soviet countries. According to the World Health Organization and World Bank (2011), the prevalence of disability in the world is about 10% and this number is growing primarily due to the rapid aging of the population and the spread of chronic diseases. Therefore, it is not likely that people with disabilities in Uzbekistan make up only 1.3% of the population.

On the other hand, with regard to inclusive education, the government reported the unrealistically high number of children with disabilities included in general schools in comparison with their number in specialised schools and being home schooled. According to the official data from the Ministry of Public Education, the number of children with disabilities in general schools is 28,890; in specialised schools 18,600; and assigned to home-based education approximately 10,000 (Education Sector Plan (ESP) of Uzbekistan 2019-2023, 2019). As we can see, the number of students with disabilities in general schools is significantly higher than that in segregated settings, which is questionable. First, due to the medical model of disability reflected in the national disability-related legislation, education for children with disabilities remains largely segregated, not inclusive (United Nations, 2019b). Second, these statistics seem not to have been updated for a long time. The same numbers were reported in 2014 by the Uzbek Society of Disabled People (2014), in 2013 by the Education Sector Plan for 2013-2017 (2013), and in 2004 by the Immigration and Refugee Board of Canada (2004).

The World Bank (2018) mentions the report of the Ministry of Health that provides even more unrealistic data. According to the Ministry of Health, 56 percent out of 110,000 school-age children with disabilities (61,600 students) study in general schools; 18 percent (19,800) receive home-based education; 12 percent (13,200) study in specialised schools; and 14 percent (15,400) are out of school. Based on this information, we can see that two key agencies responsible for children with disabilities and their education and wellbeing report different data at nearly the same time. Moreover, the Japan International Cooperation Agency (JICA) and Ministry of Health of the Republic of Uzbekistan (2014) jointly conducted a data collection survey on the health sector in Uzbekistan and provided significantly different information on the percentage of children with disabilities by various types of education: only 5,4 percent, representing around 1,600 to 1,700 students, studied in general schools; 33,7 percent received home-based education; and 60,9 percent attended specialised schools. Such a rapid increase from 5,4 percent to 56 percent in the country with a strong Soviet legacy of defectology that only recently started disability reforms seems hardly possible.

The data provided by other post-Soviet Central Asian countries seem more reliable. For instance, in Kazakhstan, the percentage of children with disabilities receiving education in a mainstream setting was 21 (UNICEF, 2014e). In Tajikistan and Kyrgyzstan, their number represented 12 percent (World Health Organization & Ministry of Health and Social Protection of the Population of the Republic of Tajikistan, 2015) and 0,9 percent, respectively (Ministry of Education and Science of the Kyrgyz Republic, cited in Cabar.asia, 2019). The relatively high percentage of children with disabilities included in general schools in Kazakhstan can be justified. Despite many challenges, Kazakhstan is arguably leading in the enactment of inclusive education practices in Central Asia because the country has prioritised inclusion since its independence (Makoelle, 2018). Another reason might be that Kazakhstan has a stronger socio-economic situation than that of other Central Asian states (Starr, Engvall, & Cornell, 2016). Therefore, the percentage of children with disabilities in general schools in Uzbekistan, which is more than two times higher than that in Kazakhstan, is highly questionable.

The World Bank (2018) posits the main reasons why in Uzbekistan, data on education in general and education for children with disabilities, in particular, are questionable. Amongst these is the legacy of central planning and control. During the Soviet times, all major decisions in education and other spheres, including data collection and utilisation, were the sole prerogative of Moscow. Therefore, “Uzbekistan’s education system lacks a data culture” (p. 96). Another identified reason is a lack of coordination between agencies responsible for data collection. Currently, seven major agencies collect data related to education. They collect data separately, using different methodologies, which leads to a lack of comparability and limited applicability of that data. Moreover, key indicators to measure educational efficiencies, such as dropout rate and completion rate, are not applied in Uzbekistan at all. These all lead to poor data quality, which significantly restricts any improvements towards the education of children with disabilities.

2.9 Disability and Poverty

Poverty amongst people with disabilities has been briefly referred to above. There are strong linkages between poverty and disability and that relationship has long been recognised (Abidi & Sharma, 2014; Banks, Kuper, & Polack, 2017; Groce, Kett, Lang, & Trani, 2011; Singal, 2011). The poor may become disabled through malnutrition, lack of relevant healthcare, and sanitation. Conversely, disability increases exposure to poverty due to high costs and limited access to the labour market and education (Emmett, 2005). Poverty and disability reinforce each other contributing to the greater exposure of vulnerable groups of people to suffering. Elwan (1999) suggests that people with disabilities comprise 15 to 20 percent of the total estimated population of poor people. Batavia and Beaulaurier (2001) states, “These individuals, who have virtually no financial reserves and extremely limited earning potential, have no financial ‘cushion’ to help absorb short-term shocks, are at high risk of poverty” (p. 140). Thus, the majority of them are more likely to live at or below the poverty line.

Research indicates that the cost of disability is a significant issue. The financial burden incurred by families who care for children with disabilities is very substantial (Loyalka, Liu, Chen, & Zheng, 2014; Parish & Cloud, 2006). Those families cannot maintain their standard of living and quality of life as households without them. There is a wide range of expenses associated with disability: medications, assistive technology, essential services, and transportation for some of them. Dobson and Middleton (1998) suggest the cost of taking care of a child with a disability is two or three times that of a child without a disability. They note, “Most parents cannot meet the levels of spending implied and for many the gap between the budgets and their weekly income is insurmountable” (p. 3). To cover the needs of a child with a disability, parents often either go into debt or cut their expenditures.

Another issue is that families who have children with disabilities often live on a single-income because one of the parents often stays at home with a child. Not many women can work. Based on the statistics provided by the HM Treasury (2004), only 3 percent of mothers with children with disabilities in Great Britain work full time and only 13 percent work part-time. Even when two parents work, at least one of them needs to work reduced hours to provide on-time care. If a child goes to school, many parents cannot afford afterschool care (Wynd, 2015). In rare cases, when they can find suitable childcare, it is usually more expensive than for children without disabilities (Dobson & Middleton, 1998). However, the costs associated with care, are often overlooked by national welfare policies (Anderson, Dumont, Jacobs, & Azzaria, 2007). These authors note that the costs and circumstances influencing these costs have to be understood from a policy perspective.

The Uzbek government allocates over 40 percent of the annual budget (which comprises 15 percent of the GDP) to support vulnerable people (Japan International Cooperation Agency (JICA), 2002). The Constitution of the Republic of Uzbekistan (1992) (Article 39) states that those who are not able to work are entitled to allowances that have to be at least equal to a minimum wage. In addition, children and adults with disabilities receive free medical services in state clinics and rehabilitation centres and tax exemption. Yuldashov (2012), a researcher at Tashkent State Institute of Law, argues that social welfare policy in the country aims to guarantee social and economic rights to people in need with a focus on “labor, education, health care, provision of necessary goods” (p.

186). Indeed, people with disabilities formally have access to 12 types of cash transfer and 28 benefits (United Nations, 2019a). This may seem to indicate that they are socially protected but it is far from their reality.

Disability allowances in Uzbekistan are unrealistically low (Japan International Cooperation Agency (JICA), 2002; Katsui, 2005). Therefore, many people with disabilities rely financially on relatives or simply struggle trying to make ends meet. One of the participants of a UNICEF study mentioned the support of other people, “My mom has to post requests in social media to raise funds. And also relatives and friends try to help, because they know about our situation. Without this help we would not be able to live, my disability allowance and father’s salary are not enough” (United Nations, 2019a, p. 113). Regular financial dependence leads to another problem: people with disabilities lose their self-worth. One of Katsui’s participant said, “I’m dependent on my parents and it’s very embarrassing at my age because my pension is enough only for the utility” (Katsui, 2005, p. 68). People with disabilities often blame themselves due to the fact that their families live in financial hardship because of them.

There is no official estimate of the optimal size of a disability allowance in Uzbekistan. Dobson and Middleton (1998) proposed that in the UK depending on a child’s age and type of disability he/she has, benefits should be increased by 20-50 percent. The situation in Central Asia countries and other developing nations would seem to be much worse. The participants of the above-mentioned research of Katsui (2005), argued that they needed 10 times of the amount of pension to cope with the disability-related costs in addition to basic daily expenses.

The integration of people with disabilities in economic activities is another major challenge. According to the United Nations (2007), in developing countries, 80 to 90 percent of people with disabilities (in the working-age group) remain unemployed; in developed countries, the figure is in the range of 50 – 70 percent. Limited employment opportunities for people with disabilities cause significant problems for both national economies and people themselves. If people with disabilities are not involved in the labour market, a country loses productivity gains and economic returns while at the same time it has to increase social benefits to support the people concerned (Fuchs, 2014).

The Uzbek legislature guarantees employment for people with disabilities. Article 37 of the Constitution of the Republic of Uzbekistan (1992) states, “Everyone has the right to work, to free choice of employment, to fair conditions of work and protection against unemployment in the procedure specified by law”. Amongst other measures undertaken to secure jobs for people with disabilities is tax exemption for enterprises owned by public associations of persons with disabilities. A job quota, requiring any company to employ at least 3 percent of people with disabilities if its workforce exceeds 20 people, has also been introduced. If companies violate this employment legislature, they are fined (Uzbek Society of Disabled People, 2014).

Despite these protective measures, many people with disabilities remain unemployed. The medical assessment system designed to determine the degree to which a person’s abilities to work are limited is one of the main reasons for that. A Medical-Labor Commission decides whether people with disabilities are capable, of limited capacity, or fully incapable of work (USAID, 2009). The system is very subjective because many medical professionals do not consider social factors and the professional skills of people. It is fully conceivable that even persons with significant physical disabilities, such as cerebral palsy, could make an important contribution to business, science, technology, etc. in today’s technological environment. Professor Stephen Hawking, an English theoretical physicist and cosmologist, has provided the world with a graphic example of this principle. Baldwin and Johnson (1994) also note that depending on a type of disability an individual can fulfill certain functions effectively: “A blind person might find it difficult to operate a crane but might face no productivity impediment as a phone operator” (p. 7). Following the Uzbek legislation, a medical-labor commission has to involve social workers and vocational rehabilitation professionals to make more objective decisions. However, it is practically impossible due to a lack of such specialists (Uzbek Society of Disabled People, 2014).

There are other reasons why many people with disabilities worldwide cannot work. Many such adults find it difficult because not all employers are ready to develop inclusive practices at their companies. Yeo and Moore (2003) state that employers often do not even consider people with disabilities as potential employees. They believe that employees with disabilities are less productive and need more support. They can be employed if there are some added incentives, for instance, acceptance of low salaries and fewer benefits. Groce et al. (2011) add that in developing countries people with disabilities are often self-employed or work in their households doing unpaid jobs, such as taking care of children or working in a family shop. In both cases, they are financially insecure: they do not receive welfare benefits or unemployment benefits.

People with disabilities, who are employed, still face barriers, such as inaccessible buildings and non-inclusive environments. They often experience the negative attitudes of co-workers at their workplace associated with fear, ignorance, misunderstanding, and stereotyping (Brostrand, 2006; Schur, Kruse, & Blanck, 2005). Such attitudes “affect the socialization of new employees with disabilities, and limit their ability to become fully accepted and well functioning insiders” (Schur et al., 2005, p. 11). Thus, employees with disabilities often feel unwanted and uncomfortable in their workplace. This might affect their willingness to work and reduce productivity.

Abidi and Sharma (2014) note that employment is directly linked to other key factors, such as education, accessibility, communication, and policies. It clear from numerous examples around the world the majority of people with disabilities can be employed but as the above writers note, education is a critical factor in employability. Clearly, they can only acquire this education if educational institutions are accessible and relevant information is available. Employment, education, and accessibility are possible only with appropriate policies. Therefore, a low employment rate amongst people with disabilities cannot be considered in isolation from other factors. However, Filmer (2008) notes that education is the most important factor. If the low educational attainment of people with disabilities can be addressed, they will not suffer from poverty any longer.

In Uzbekistan, as noted previously, the vast majority of children and young people with disabilities remain segregated throughout all levels of education, including vocational and higher education. According to the Uzbek Society of Disabled People (2014), children and young people with disabilities in Uzbekistan are denied equal opportunities for quality education. There are only four specialised colleges in Uzbekistan and these colleges offer a limited number of professions. If young people with disabilities aspire to another profession, they need to go to regular colleges, but this is often unrealistic for them. First, they have to enter colleges on a general basis, which is difficult for many of them because they cannot compete with their non-disabled peers academically. Second, as the Uzbek Society of Disabled People (2014) notes, there is no accessible infrastructure there. Those who want to study at higher educational institutions encounter the same obstacles, but the situation there is worse because of the high cost of education. Many children and young people with disabilities come from low-income and large families. In such families, the parents cannot afford to pay for the education of all their children. Due to these reasons, the number of educated young people with disabilities is decreasing every year in Uzbekistan and they are becoming less competitive for the labour market (Uzbek Society of Disabled People, 2014). These barriers affect prospects of these people for education and further employment and need to be addressed.

2.10 Summary

This chapter has presented an overview of international literature that lays the foundation for conceptualising inclusive education and forms a basis for the current research. The chapter has discussed interpretations of the term ‘inclusive education’ and related concepts that often vary from country to country, depending on their historical, cultural, and ideological contexts. The chapter has also explored numerous discourses circulating around the inclusion of children with disabilities in regular schools. Some scholars consider inclusive education both unrealistic due to a variety of students’ medical impairments and paternalistic due to being mandatory for those parents who prefer a specialised institution for their children. Other disability proponents believe that inclusive education is a social justice matter. Students with disabilities were excluded from equal educational opportunities for a long time and now they must have a right to be educated alongside their typically developing peers.

Even though inclusive education remains a contested area, many developing countries are attempting to enact this model of education and end discriminatory practices. Uzbekistan and other developing nations have accomplished several inclusive education projects and made certain attempts to prepare teachers, parents, and community members to support inclusive education initiatives. Despite these efforts, the vast majority of children with disabilities in these countries remain segregated. The chapter has offered a critical review of the major barriers to successful inclusion these nations have encountered. The common barriers include inadequate teacher preparation, the lack of parental involvement, the limited participation of NGOs in disability-related policies, social stigma, the absence of valid and reliable disability statistics, and poverty.

CHAPTER THREE
METHODOLOGY

The chapter outlines the research design of the study. In the first part of the chapter, an overview of qualitative research and exploration of phenomenology as the research methodology used for disability study are discussed. The theoretical framework that includes two critical notions of the social model of disability and human rights is presented. Further, the instruments, used in this research and the participant groups are outlined. This is followed by an explanation of the data gathering and analysis processes. The ethical considerations taken into account for this study are also presented.

3.1. Qualitative Research

3.1.1 Characteristics of qualitative research

Denzin and Lincoln (2005) define qualitative research as a multimethod with a naturalistic approach to the subject being researched. Qualitative research allows a researcher to become familiar with a problem or concept and possibly generate a hypothesis to be tested (Golafshani, 2003). It means that objects are studied in their natural settings, which allows a researcher to gain deeper insights into and understanding of phenomena under investigation. A natural setting also helps a researcher to interpret objects in relation to the meanings people bring to these objects.

The key characteristic of qualitative research is that all instruments for data collection have to be designed by the researcher. He/she cannot rely on instruments developed by others. Within a qualitative research framework researchers are the authors of their own research processes, starting from developing research questions and ending with writing a story (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). A further important characteristic of qualitative research is that it is inductive. When an inductive approach is taken, it is expected that a new line of abstraction should emerge from the data. This is also referred to as a “bottom up” principle, where a researcher organises “the data inductively into increasingly more abstract units of information” (Creswell, 2013, p. 45). Consideration of the possibility of obtaining a holistic account of the phenomena is another characteristic of qualitative research. Within a qualitative study, a larger picture of the issue is developed. To do so, multiple perspectives are involved. While analysing those perspectives, a researcher is not concerned about examining cause-and-effect relationships amongst them, but rather identifying complex interactions within and amongst the accounts gathered (Bogdan & Biklen, 2003; Creswell, 2013).

3.1.2 When is a qualitative research study useful?

Creswell (2013) suggests that qualitative research is suitable when a researcher needs "to study a group or population, identify variables that cannot be easily measured, or hear silenced voices" and when there is a need for "a complex, detailed understanding of the issue" (p. 48). This is very pertinent to my study because people with disabilities in Uzbekistan and other Central Asian countries have been an unseen/unheard population for a long time (Katsui, 2005). Therefore, their unique experiences, the struggles they have been through and the thoughts, feelings, and beliefs they had would be of particular value. While quantitative research has advantages over qualitative research in certain contexts, it is generally considered less effective in capturing the unique lived experiences of individuals. Brantlinger et al. (2005), who researched the use of the qualitative methods in special education, note that descriptive information in qualitative studies contributes to a better understanding of people with disabilities and those who are in relation to them, for instance, their family members, teachers, or colleagues. As these researchers remark "qualitative designs… can explore the nature and extent to which a practice has a constructive impact on individuals with disabilities, their families, or on settings where they tend to work, reside, or be educated" (p. 196). A qualitative research study helps to find answers to questions about the meaning and interpretations of the people's lives and, therefore, makes it a strong option to investigate disability issues (Hartley & Muhit, 2003).

Quantitative studies require numerical rather than descriptive information in the form of variables. This research does involve a small quantitative dimension, represented by six survey responses from major non-governmental organisations working in a disability field in Uzbekistan. Initially, individual semi-structured interviews were planned for these participants. At a later stage, it was decided to design a questionnaire for the NGO group to allocate more time for interviews with teachers, parents, and government officials. Survey questions were designed with an emphasis on the specifics of NGO practices. However, the design of this study is primarily qualitative.

Qualitative studies encompass different types of qualitative research designs, such as grounded theory, ethnography, case study, and phenomenology. Phenomenology has been chosen to study the social phenomenon that is inclusive education. What phenomenology means and how this notion is used for the purposes of this study is explored below.

3.2 Phenomenology

Phenomenology is a qualitative research method, which is popular in the social and health sciences (Borgatta & Borgatta, 1991; Creswell, 2013). According to Sokolowski (2000), “phenomenology is the study of human experience and of the ways things present themselves to us in and through such experience” (p. 2). It is based on the work of Edmund Husserl (1936-1970), a German philosopher and founder of this philosophical movement. He insisted that phenomenology should be based on consciousness rather than empirical evidence (Kockelmans, 1967). Thus phenomenology aims to investigate the nature of a phenomenon: not to explain it but describe as it appears in human consciousness (Aagaard, 2017).

A central issue raised by phenomenology is subjective (or existential) truth, which helps to understand individual phenomena (Bolton, 1979; Brown & Cordon, 2009; Koopman, 2015). Bolton (1979) states that we are very focused on objectivity, trying to collect “the information that lies outside the range of our personal concern” (p. 246). However, as he suggests, “subjective truth, on the contrary, has to do with the moral stance I am to take in the world in the light of what it means to be human” (p. 246). Two decades later, Lester (1999) notes that a phenomenological research study attempts to collect information and the perceptions of people through qualitative methods, and then to understand their subjective experiences by gaining insights into their actions. In this view conventional wisdom is put aside. More recently, Koopman (2015) points out that people taking part in research should be viewed as “subjective epistemological beings” whose experiences should be learned without presuppositions, existing beliefs, and judgemental knowledge (p. 3). Thus, subjective experience, the cornerstone of a phenomenological approach, is central to human existence but one that has been downplayed by objectivity and the prevalence of naturalistic approaches in modern sciences.

These ideas suggest that phenomenology is an effective research tool to investigate disability issues. According to Paterson and Hughes (1999), previous disability studies could not address issues experienced by people with disabilities because they presented an impaired body “as a passive recipient of social forces” (p. 597). Similarly, Oliver (1990) notes that throughout the twentieth century health professionals rarely perceived people with disabilities as ordinary people. They treated people with disabilities as less than human. Therefore, sociology of impairment is needed and “phenomenology seems to embody a stronger case than other theoretical candidates - notably post-structuralism - in the running to establish a sociological agenda for impairment” (Paterson & Hughes, 1999, p. 598). In phenomenology, the experiences of people with disabilities are viewed from the perspective of ‘a social life’ where cultural constructions of disability and impairment are considered through the body, and through the social actions, these constructions embody.

3.2.1 Bracketing

An important characteristic of phenomenology is bracketing. Bracketing refers to a methodological device requiring a researcher to put aside his/her beliefs and experiences related to the phenomenon being investigated (Carpenter, 2007). Ahern (1999) states that bracketing gives more validity to the data collection because it helps a researcher not to look at the phenomenon through their values, beliefs, and knowledge but describe only participants’ experiences. Moreover, Tufford and Newman (2010) point out that bracketing helps a researcher reach a deeper level of understanding of a phenomenon and reflection throughout the research process.

However, these scholars contend that the process, when bracketing is used, is not fully understood. In their work they discuss several major issues related to bracketing: the absence of a precise definition of bracketing and its elements; disagreement among scholars on when bracketing should be used; who should be involved in bracketing: a researcher, a participant, or both; and how to conduct bracketing. Each of these issues will be further discussed in more detail.

Researchers and philosophers define the term ‘bracketing’ differently, which can make the whole research process more complicated. For instance, according to Gearing (2004), bracketing is a “scientific process in which a researcher suspends or holds in abeyance his or her presuppositions, biases, assumptions, theories, or previous experiences to see and describe the phenomenon” (p. 1430). Fischer (2009) refers bracketing to “an investigator’s identification of vested interests, personal experience, cultural factors, assumptions, and hunches that could influence how he or she views the study's data" (p. 583). Drew (2004) defines 'bracketing' as "the task of sorting out the qualities that belong to the researcher's experience of the phenomenon" (p. 215). As seen from the above definitions, the term 'bracketing' includes different elements, such as beliefs, knowledge, experiences, assumptions, interests, values, and biases. With the lack of a precise definition for each of these elements, researchers may not distinguish them and consider all of them as one homogeneous group. Yet, the absence of a precise definition allows researchers to explore their own ways to identify their biases and preconceptions and to develop more suitable approaches to bracketing them (Starks & Trinidad, 2007).

Another issue is that scholars differ in their views at the point at which bracketing should take place. Some believe it should be limited to the analysis phase, not while interviewing participants (Giorgi, 1998). Others believe a researcher should use bracketing during the entire research process (Rolls & Relf, 2006). Those advocating for this practice point out that the different research stages are connected, and that any prejudices and biases arising at one stage will ultimately impact on the final results. Fischer (2009) also contends that in qualitative research bracketing should continue throughout the entire process. It allows a researcher to constantly identify assumptions and "check to see whether one is imposing meanings on the data to see what other meanings might appear" (Fischer, 2009, p. 584). The arguments here seem persuasive in maintaining that the use of bracketing as an ongoing process helps to avoid biases and to find opportunities to make important meanings more evident.

Who should bracket preconceptions: a researcher, participants, or both? This is another tension in phenomenology. Most of the literature indicates that it is a researcher's responsibility. However, Crotty (1996) states that bracketing should be done by a researcher as well as participants. This approach may constitute a problem because a researcher does not know when participants brackets their assumptions. Additionally, if participants bracket their preconceptions, they may not disclose their honest opinion knowing the focus of interview (Tufford & Newman, 2010). To avoid these issues, a researcher has to be very explicit about bracketing so others participating in research can understand all processes and its conditions and requirements. For that purpose, Crotty (1996) recommends including a clause about explicitness in a written form and making the whole process of bracketing transparent for everyone involved.

There are several methods to conduct bracketing. One is writing memos during the entire data collection process. Memos allow researchers to see their information in a useful visual way and reflect their feelings about research endeavours (Cutcliffe, 2003). Memos can be in the form of theoretical notes, methodological note or observational comments (Tufford & Newman, 2010). Memos are usually written out and put aside for a later examination of possible biases (Brink, 1998). Yet, Brink (1998) noted that that this method can be useful "only to the extent that the researcher can see his or her own biases" (p. 314). As biases are often unconscious, other methods can be used to seek out them.

Another method is reviewing the research data with other professionals, for instance a non-supervisor or research associate, who can listen to or read an interview and reveal and explain some hidden information in it (Brink, 1998; Tufford & Newman, 2010). It increases a researcher's clarity of a topic being studied and helps him/her better understand a phenomenon. Engaging with other professionals can be formalised through scheduling official meetings and offering payments. If outside sources are involved, a confidentiality agreement should be signed before information is disclosed.

Many experts recommend keeping a reflexive journal as one of the most effective ways to reflect on research steps (Ahern, 1999; Bagnato, Dimonte, & Garrino, 2013; Ortlipp, 2008; Watt, 2007). In a reflexive journal, a researcher can write down his/her reasons for undertaking research, assumptions, feelings, conflicts if any, and other relevant information important for a researcher. For instance, Watt (2007) states that journal entries made during a pilot study allowed her to see where she was and how she came to this stage and better understand connections between a theory and practice. Every researcher needs to decide what method is the most appropriate for his/her particular area of investigation. Of course, a researcher can combine the above-mentioned methods. These can complement each other and make data richer and more valuable.

3.2.2 Reflexivity

Even though a researcher may be committed to being non-judgemental, his/her social and cultural background is always present and affects an initial understanding of a situation (Padilla, 2003). In this case, reflexivity can be used as a tool to ensure the trustworthiness of research. According to Shacklock and Smyth (1998) reflexivity includes the revelation of researchers: "The conscious revelation of the role of the beliefs and values held by researchers in the selection of research methodology for the generation of knowledge and its production as a research account" (p. 7). Although the terms 'reflexivity' and 'reflection' are often used as interchangeable in academic literature, there is a significant difference between them. According to Finlay (2002), reflexivity is about a continuing and dynamic process while reflection is more about a distanced process that takes place after the event occurs. Another explanation is provided by Shaw (2010) who refers to Wooglar (1988) and his differentiation of these two concepts. From the perspective of Wooglar (1988) reflection is more concerned with process and verification to ensure that participants are represented "in their "true" light" (p. 234). Reflexivity involves evaluation of the self; it means that a researcher needs to reflect on his/her assumptions and preconceptions that may affect the results. However, reflexivity is the process of examining not only oneself as a researcher but also the research relationship. It examines the relationship of a researcher to a participant and how that relationship affects a participant's responses.

With the use of reflexivity a problem in research can be transformed into an opportunity. Researchers investigating disability-related topics should anticipate hearing many emotionally hard stories during their data collection process. Researchers are often "not immune to emotional experiences in the field" (Hubbard, Backett-Milburn, & Kemmer, 2001). They may feel that they cannot stop themselves from becoming involved by conveying empathy and understanding. It may help researchers build a rapport with the interviewees without losing objectivity. Hubbard et al. (2001) note that empathy and understanding are essential social skills and if used appropriately, they indicate respect in relation to respondents.

Yet, as Finlay (2002) states the process of reflexivity is complicated: "Taking the threatening path of personal disclosure, the researcher treads a cliff edge where it is all too easy to fall into an infinite regress of excessive self-analysis at the expense of focusing on the research participants" (p. 532). She contends that sometimes researchers can be overwhelmed with their thoughts and emotions. To manage emotions, a researcher should be aware that emotional distress is a natural part of research. A researcher should also have research fellows or friends with whom he/she can discuss what they emotionally go through (Hubbard et al., 2001). Keeping a personal diary can be a good medium to cope with emotions too. Putting thoughts and feelings on paper usually allow researchers not only to become more in tune with emotions but also to see a picture clearly and set further goals (Clarke, 2009). These two simple strategies (talking to a research fellow and keeping a diary) may help researchers avoid strong emotional distress and continuing reflexive analysis.

3.3 Theoretical Framework

3.3.1 Social model of disability and human rights

The human rights framework along with the social and medical models of disability have been outlined in the Introduction. These two models are most frequently mentioned in comparison to several other models that have been defined and practised over the last few years. The medical model is focused on disability as a physical defect of a person, while the social model is focused on how obstacles existing in the society view disability by preventing people having those disabilities from equal opportunities (Bøttcher & Dammeyer, 2012; Llewellyn & Hogan, 2000; Matthews, 2009; Oliver, 2013). Thus, the social model and human rights for children with disabilities - two important notions sharing fundamental similarities - are chosen as a conceptual framework for my research. Below I discuss these notions and their importance for the development of inclusive education.

The social model was theorised by Mike Oliver, a scholar with a disability. According to Oliver (2013), the idea of the social model of disability arose from the Fundamental Principles of Disability published in the 1970s and based on the assumption that disability is an outcome of social organisation, not of physical pathology. The purpose of the social model is to deconstruct the individual model of disability taking into account the experiences of people with disabilities and their understanding of disability. The social model is also aimed at addressing the issues of discrimination and marginalisation while promoting more equity and critiquing barriers developed by society for people with disabilities (Terzi, 2004).

In contrast, the medical model approaches problems from a perspective of individual deficit (Shakespeare, 2006). Disability according to the medical model is a serious problem to a person fully participating in social, economic, political, or cultural life. Siebers (2008) states that the idea of being defective comes from the environment, not from the body. The environment includes not only the physical environment but also cultural, economic, institutional, and educational practices. Degener (2016) shares the same point of view, “Even in a society without barriers and other forms of discrimination, people need social, economic, and cultural rights. People need shelter, education, employment or cultural participation” (p. 5). Thus, the social model views disability as a socially constituted phenomenon because all these factors make the life of people with disabilities meaningful.

Similar to other post-Soviet Central Asian countries, Uzbekistan has inherited the Soviet approach to adults and children with disabilities with a strong focus on medicalisation (Katsui, 2005; Rouse & Lapham, 2013). The United Nations (2019b) also notes that in Uzbekistan “Disability is defined using medical and charity models rather than the UNCRPD’s rights-based, enabling perspective” (p. 9). Children with disabling conditions are pitied but denied their rights to quality education in a mainstream setting, further employment, and social relationships. Many of them still face public prejudice, social rejection, and restrictive legislation. Therefore, the social model is considered a foundational principle for a rights-based approach to disability policies, including educational policy (Peters, 2007).

3.3.2 Social model of disability in education

Peters (2007) outlines four main assumptions of inclusive education that are consistent with the social model of disability: diverse needs of students; the responsibility of general schools to meet those needs; availability of relevant conditions (flexible curriculum, an accessible environment, qualified teachers); and a partnership between a general school and community to grow full-fledged members of the society. Therefore, adopting the social model of disability and applying it in the inclusive setting require educators to shift their focus from a deficit perspective to understanding and embracing differences to support a diverse range of students’ abilities (Department for Education and Skills, 2001).

The UK Special Educational Needs Code of Practice (SEN CoP) of the Department for Education and Skills (2001) also promotes the social model to support students with disabilities in general classes. The SEN CoP sets out the similar fundamental principles: children with special educational needs should have their needs met; children’s needs should be met in a mainstream setting; the views of children with special needs should be sought and taken into account; parents of special needs children should be recognised important in supporting their child’s education; children with special needs should have full access to relevant education, including appropriate curriculum. All these principles and factors help professionals working with children with disabilities gain a better understanding of them as individuals which would not be possible if the medical model of disability was informed by policy and practice. The document also considers key factors to help SEN students succeed, such as organising early intervention practices, allocating necessary resources, taking multidisciplinary approaches in problem-solving, conducting regular monitoring activities, and establishing partnerships with all other parties involved.

A collaborative approach plays an important role when the social model is practised in mainstream schools. School authorities, teachers, parents, medical practitioners, and representatives of social services should be involved in the learning and development processes of disabled children to meet their needs. Each of these stakeholders represents an important part of the whole mechanism to develop and promote a practice of inclusion. Yet, that partnerships can be successful only if all stakeholders have common values as a foundation and a clear understanding of shared objectives, their roles, and responsibilities (Department for Education and Skills, 2001).

3.3.3 Human rights for children with disabilities

It has been stated that children’s right to inclusive education has been increasingly recognised and supported by international law in recent years. As stated by UNICEF (2007b), the right to education is recognised without discrimination on any grounds, including ethnicity, gender, disability, social status, and other aspects of identity. The most widely ratified human rights treaties related to education for children with disabilities briefly mentioned in Chapter One are the UN Convention on the Rights of the Child (CRC) and the UN Convention on the Rights of Persons with Disabilities (CRPD).

The CRC became the first human rights treaty that included disability as a ground for protection from discrimination (Lansdown, 2012). The convention has been ratified by 191 countries including all CEE/CIS countries. The CRC encourages countries to protect the rights of children and provide all possible opportunities for their development. The treaty emphasises the right of the child to “the full and harmonious development of his/her personality, should grow up in a family environment, in an atmosphere of happiness, love and understanding" (Convention on the Rights of the Child, 1989, p. 1). The CRC contains 54 articles that are based on four main principles: children have to be treated without discrimination; government policies should determine and serve the best interests of children; children should develop to their full potential; and children's views are crucial and need to be heard. Some of these articles will be referred to throughout this research.

Two articles in particular, are relevant to children with disabilities and their education. Article 2 states that no child can be discriminated based on his/her "race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status". Article 23 precisely addresses the right of children with disabilities to education that promotes their full social inclusion. Recognizing the special needs of children with disabilities, they need to be provided with quality education, training, and other services needed for their development. The CRC emphasises the preparation of children for independent life in society. Therefore, the treaty requires the states to create conditions for children to prepare them for further employment and recreation opportunities in a manner that helps them reach social integration and personal development (Convention on the Rights of the Child, 1989).

The CRPD is an international disability treaty that recognises the rights of people with disabilities and embraces the idea of the social model of disability (Harpur, 2012). The CRPD is considered a framework for the development of policies to ensure and protect the rights and dignity of people with disabilities. The general principles of the Convention are respect for dignity, autonomy, and independence of people with disabilities; non-discrimination; participation and inclusion in the society; respect for difference; equality of opportunities; accessibility; equality between men and women; and respect for the capacities and rights of children (Convention on the Rights of Persons with Disabilities, 2006, Article 23). According to the UNICEF (2007a), the CRPD lay a totally new foundation to reconsider the situation with people with disabilities and creating opportunities for their inclusion in society.

Although Uzbekistan signed the CRPD more than 10 years ago, it has not ratified it yet. As the Equal Rights Trust (2016) notes, "Failure to ratify the CRPD… represents the most notable gap in Uzbekistan's international legal obligations related to equality" (p. 32). However, during the decade, the Convention and its significance have been introduced and promoted in Uzbekistan by the international development community through conferences and workshops. Recently, a lengthy procedure towards the ratification of the CRPD has been started following the new Presidential Decree (United Nations, 2019b). As the Uzbek government has initiated this important process, there is a need for more information and understanding of ways in which disability policies, including inclusive education policy and programmes, can be developed in full compliance with the treaty.

Inclusion within the CRPD promotes the transition from segregated schools to general schools with the provision of necessary support. The main principles of inclusion are accessibility, availability, acceptability, and adaptability (United Nations, n.d.). Accessibility means that general schools and programmes used there must be accessible for persons with disabilities, including both physical and economic access. Moreover, educational institutions and programmes have to be available, especially for those who live in distant areas. Acceptability is related to the special provision, for instance, studying materials and language of instructions. The concept of adaptability is about flexibility to meet the needs of students with disabilities. It mainly includes necessary support services and accommodation.

To initiate a better realisation of rights, the CRPD has introduced additional obligations for governments to ensure inclusive education at all levels and the removal of all barriers preventing children with disabilities from receiving quality education in a mainstream setting (Convention on the Rights of Persons with Disabilities, 2006, Article 24). According to Article 24, governments have to ensure that children with disabilities are not excluded from general schools, they can access inclusive quality education on an equal basis with others, they are provided with the necessary accommodation, and receive support at general schools to develop both academic and social skills. Governments are also responsible for taking measures to employ qualified teachers, including teachers with disabilities, and organise professional development training to improve their qualifications. Training should be focused on the development of educational techniques, materials, and communication means as well as the promotion of disability awareness (United Nations, n.d.).

Relying exclusively on either the CRC or CRPD would not be enough to remove discrimination against children with disabilities because these treaties have different focuses. The CRC provides an understanding of the holistic nature of the children’s rights without being focused on achieving equality in relation to another group of children whose rights are fulfilled. The CRC aims to establish recognition of the rights of *all* children, including those who have disabilities, and responsibility for their fulfillment. The CRPD is specifically focused on children with disabilities and elaborates detailed obligations for governments to ensure that they enjoy their rights without discrimination, on an equal basis to others (Lansdown, 2012). When combined, these Conventions are mutually reinforcing and can be effectively used to strengthen advocacy in respect of children with disabilities.

3.3.4 Differences between the social model of disability and CRPD

There is a difference between the social model of disability and the CRPD. While the social model explains disability, the human rights model promotes the values for the development of disability policies (Degener, 2016). This researcher states that "Only the human rights model can explain why human rights do not require absence of impairment" (Degener, 2016, p. 3). It means that there are no factors that can influence the human rights of a person, including his/her health conditions. The human rights can be called unconditional, i.e. they cannot be granted or taken away from an individual. This is the main idea of the CRPD. The social model of disability also acknowledges the rights; however, it is mainly based on social relations in society around disability and inequality (Finkelstein, 2007).

Another difference is identity politics. As it was mentioned above, the social model of disability has been criticised for not considering the identities of people with disabilities (Degener, 2016; Humphrey, 1999; Shakespeare, 1996). In this regard, the human rights model provides a bigger space for minorities. Degener (2016) states that identity in the context of disability plays an important role. In addition to gender, race, age, religion, etc., identity relates to categories or types of disabilities, for instance, deaf people have their own culture, which can hardly be understood by those who are outside the deaf community (Ladd, 2003). Humphrey (1999) also emphasises the significance of identity within a larger social unit: "At the level of the community, groups of people self-defining as disabled or gay are likely to adorn themselves with the mantle of ethnicity, as they carve out their own social institutions, elaborate their own cultural artefacts, celebrate different ways of being, doing and relating, and socialise newcomers into such traditions" (p. 182).

There is a further difference between the human rights model and the social model. The human rights model recognises the factors experienced by people with disabilities, such as pain, early death, and worse life qualities due to their impairments (Degener, 2016). These factors have to be considered when social justice theories are developed or used. According to Morris (1991), the social model does not acknowledge these and insists that all these factors are socially constructed. Morris (1991) does not deny the importance of considering social barriers in the context of disability but she insists that limitations caused by impairments have to be taken into account because they are a part of human diversity. Oliver (1996), however, states that the social model does not ignore personal impairments. It attempts to find solutions through reconsidering social factors rather than simply using medical treatment.

All these differences demonstrate the essence and importance of the CRPD. According to Harpur (2012), the CRPD provides a new framework for Disabled People’s Organisations (DPOs) to empower them by involving them in a convention process. Before this treaty, people with disabilities were protected by other human rights conventions. However, they were mainly nominal. The CRPD creates a new rights discourse, empowers civil society organisations, and makes human rights more obtainable for people with disabilities than they were in the past (Harpur, 2012).

The exclusion of children with disabilities from education is often justified because their abilities to participate in the educational process and benefits from it are questioned. Such attitudes create wrong assumptions and beliefs among people, including those who are directly related to children with disabilities, namely educators and parents. It significantly hinders the enactment of inclusive education. Therefore, the social model of disability and human rights are critical for the development of inclusive education as they both are focused on eliminating barriers and prejudice around people with disabilities as well as enforcing their rights (United Nations, n.d.).

3.4 Methods

A questionnaire and individual semi-structured interviews were the two methods employed in the data collection for this study. Step one involved a web-based questionnaire for representatives of major disability-related organisations. Step two involved interviews with parents of children with disabilities, teachers working with students with disabilities, and government officials. I also planned to involve step three - a focus group for children and young people with disabilities based on a trigger material (a video). My purpose was to obtain insights into what they know and think about inclusive education through discussion and debate. However, I was not able to do this, although I found potential participants for a focus group through out-of-school clubs and organisations offering extra-curricular activities for children with disabilities. The problem occurred with obtaining parental consent forms that I was legally required to collect from parents or guardians of children and young people under 18 years old (see Appendix C). Parents might have avoided the direct involvement of their children in a group discussion because disability remains a sensitive issue in Uzbek society. Another reason could be that people are mainly unfamiliar with informed consent and lack trust. In Uzbekistan, interviews and surveys are usually conducted by either journalists or government-affiliated organisations. Individuals conducting interviews are a rare occasion and, therefore, may seem highly suspicious.

3.4.1 Questionnaire

To collect information from representatives of major disability-related organisations I employed a web-based questionnaire (I used google forms). Online questionnaires have certain advantages. A major one being that it provides greater ease for participants when sensitive questions are discussed (Nicholas, Lach, & King, 2010). This is especially the case for underrepresented groups who may experience barriers to offline research options to express their opinions freely. For instance, people with disabilities may feel uncomfortable to talk about certain issues in person and/or face physical barriers (Heath, Brooks, Cleaver, & Ireland, 2009; Wright, 2005). Data collection via the internet also allows respondents more time and space flexibility that makes the whole process of responding convenient for them (Creswell, 2013). Other advantages include cost-efficiency: using online surveys significantly reduces administrative costs (Jones, Murphy, Edwards, & James, 2008). A researcher does not need to allocate resources for paper, printing, and postage. These key advantages of using online surveys are appealing to both participants and a researcher.

As a researcher, I was also aware of the disadvantages of online questionnaires. A major limitation of this method is the lack of contact between a researcher and participants, which may result in low response rates. Jones et al. (2008) maintain that a lack of personal contacts can be solved with the use of advanced technologies offered by internet. For instance, a researcher can provide a detailed description of a study on the instructional page accompanying the questionnaire. A researcher can also include embedded images, short movie clips, and/or hyperlinks to his/her e-mail so that respondents can have more information. I included the project information in the introductory part of the questionnaire and provided my e-mail addresses as well as the contact details of the Supervisory team in case respondents had questions or needed additional information (see Appendix A). Another limitation is a questionnaire contains ready-made questions and respondents have limited flexibility to present their views on an issue (Marshall, 2005). I added several open-ended questions so that they could have the opportunity to express their own thoughts and opinions.

There were seven steps involved in the development of a questionnaire:

1. *Identifying the purpose of a questionnaire*. At this stage, I referred to my research questions and identified what information was being sought from organisations in response. The purpose of a questionnaire was to collect information from representatives of NGOs and DPOs on their broad understanding of the concept 'inclusive education' and possible ways they could promote the inclusion of children with disabilities in a general school system in Uzbekistan.

2. *Selecting question types*. Different question types were employed to ensure richness and quality of data. Multiple-choice questions were considered to collect demographic information, such as the size of an organisation, how long an organisation has been working in a disability field, a respondent's position within an organisation, etc. Scale/rank questions were suitable because I needed information related to the attitudes and opinions of organisations about inclusive education. Although the ranking of questions requires a higher level of attention and more time to rank the options on a list of related items, they may lead to higher data quality (Alwin & Krosnick, 1985). Open-ended questions, as noted above, were necessary to allow respondents to answer in open text format and share their opinions freely in their own words. These were also used to gather additional information that could potentially help me gain a better understanding of a topic being researched. The questionnaire contained a total of 18 questions: four multiple-choice questions, eight scale/rank questions, and six open-ended questions (see Appendix D).

3. *Developing questions*. I generated a preliminary topic list that eventually was converted into more explicit questions. They were focused on their current and/or previous experiences in the disability area; the nature of the support they received from the government to promote their activities and their ideas about its adequacy; their understanding of inclusive education; what they thought about advantages and disadvantages of inclusive education; their possible contribution to the development of inclusive education in the country, etc.

4. *Improving the questionnaire layout*. The questionnaire layout was also considered. Dr Mira Peter, a Senior Research Fellow at the University of Waikato, gave her recommendations for improving a cover page of the questionnaire, instructions to guide respondents through the questionnaire, the use of sub-headings, and the questionnaire length.

5. *Testing questions for reliability and validity*. The questionnaire was revised by the Supervisory team and Mr M. Turdiev. Mr M. Turdiev is a Doctoral Researcher and Consultant on the Rights of Persons with Disabilities with substantial national and international experiences, who helped me considerably with recruiting research participants. I made amendments based on their recommendations. These recommendations allowed me to identify whether all questions were clear and appropriate and what information needed to be added to cover different aspects of the work of NGOs.

6. *Distributing a questionnaire*. Mr M. Turdiev sent links to the questionnaire to all NGO and DPO representatives via his e-mail (see Appendix E). He had established professional relationships with all of them and, therefore, it was assumed that a professional acquaintance would increase a participation rate. The questionnaire was developed in three languages: Uzbek, Russian, and English so that respondents could select the language they preferred.

7. *Sending a reminder*. Ten days after sending an initial e-mail invitation, Mr M. Turdiev sent a follow-up e-mail to the same contacts with the aim of increasing the number of responses (see Appendix E).

3.4.2 Interviews

As stated above, semi-structured interviews were designed for parents of children with disabilities, teachers, and government officials. Semi-structured interviews are a key qualitative data collection method for social research (Galletta, 2013). Among the advantages of these interviews is that they enlist reciprocity between an interviewer and an interviewee and allow the former to decide what question should be asked next, depending on a participant’s response (Kallio, Pietilä, Johnson, & Kangasniemi, 2016). This method also allows a researcher to determine the validity of interviewees’ responses by observing their non-verbal communication (Barriball & While, 1994). These scholars point out that non-verbal behaviour supplements participants’ verbal responses and may include facial expressions, voice, intonation, body language, and the nature of words used by a participant. Similarly, Denham and Onwuegbuzie (2013) consider non-verbal communication important and refer to it as “a formidable source of information as well as the complement to the study of verbal behaviors of humans” (p. 671). A further advantage is as a questionnaire and an interview are often used together, an interview can potentially overcome a poor response rate from a questionnaire and provide a better understanding of a complex phenomenon (Austin, 1981).

This method does contain some potential disadvantages. Time-constrain is one of the major limitations of interviews. The entire process, including preparation for interviews, undertaking interviews, transcribing, and analysing, requires much time. Another limitation of this method is it may be difficult for a novice researcher. As Adams (2015) notes, “Interviewers need to be smart, sensitive, poised, and nimble, as well as knowledgeable about the relevant substantive issues” (p. 493). However, even novice researchers can conduct an interview successfully if they prepare carefully for it. They are recommended to conduct at least one pilot or test interview before they start actual data collection. While practicing an interview with a colleague or a volunteer, novice researchers have an opportunity to explore language, test the appropriateness of questions, develop active listening, and see where they could fail (Fassinger, 2005; McGrath, Palmgren, & Liljedahl, 2019; Teijlingen & Hundley, 2002).

Below is the process I followed to prepare and conduct the interviews:

1. *Identifying the purpose of interviews*. The purpose of the interviews was connected to the purpose of the study. The interviews were focused on how all involved viewed the inclusion of children with disabilities in general schools, what problems they experienced, and what they could do to shift from segregation to mainstream education as standard policy.

2. *Preparing an interview guide*. An interview guide included a list of open-ended questions, focused on the issues that needed to be explored. I developed a set of suggestive questions for each group but they were used only as a guide (see Appendix F). When unexpected but relevant areas emerged during the interviews, I modified these questions or added new questions.

3. *Designing an appropriate communication method*. The language to communicate with an interviewee is critical because it helps a researcher establish more expressive communication and to elicit more accurate information (Cortazzi, Pilcher, & Jin, 2011). In Uzbekistan, predominantly Uzbek and Russian languages are spoken. It was planned that the information would be conveyed in either Uzbek or Russian (depending on a participant's preference) to assure that he/she understood a question being discussed. In the actual interviews, all participants, except for one, spoke and understood Russian.

4. *Piloting the interviews*. As mentioned above, conducting pilot interviews is critical for an inexperienced researcher. During the pilot process, I tested the appropriateness of the questions and obtained a general feeling of how the interviews were conducted. These interviews also prepared me to build rapport with the interviewees and to address different responses. In other words, practicing the pilot interviews allowed me to make necessary improvements for the actual interviews.

5. *Conducting a preliminary meeting with interviewees.* Prior to the interviews, an introductory session focused on the research was conducted with participants, primarily parents. This gave me the opportunity to explain the purpose of the study and to make sure respondents had sufficient understanding of the topic being researched. At this stage, some parents provided brief insights into their own experiences. This helped me generate some additional questions to be asked later. Moreover, since we already knew each other a little, both the interviewer and the interviewee felt more comfortable during the actual interviews.

6. *Conducting interviews*. To conduct the actual interviews, I followed the phases proposed by Whiting (2008). According to this author, each interview involves several phases: building rapport, apprehension, exploration, cooperation, participation, and concluding. Building rapport occurs throughout all phases of an interview (Whiting, 2008) but it should be developed most at the initial phase by dressing appropriately, avoiding jargon, listening attentively, and showing respect (DeJonckheere & Vaughn, 2019). The apprehensive phase is critical to building trust and openness with an interviewee. At this phase, I had a short conversation with each participant to reduce his/her discomfort and generate some openness. During the exploration phase, participants were involved in a more in-depth discussion. I continued using the open-ended questions and added some probing questions. This helped me generate more information. At the cooperative phase, participants typically feel more comfortable, trustful, and confident. I used this stage to ask more sensitive questions. During the participation phase, when the greatest rapport was established and mutual openness and trust were achieved, I continued active conversation. At the final stage, I expressed my gratitude to interviewees for their time and active participation.

3.5 Identifying and Recruiting Participants

The following participant groups were involved in this research:

1. *Representatives of disability-related organisations*. The NGOs and DPOs to be part of this research were identified before data collection. As previously noted, I discussed the possibility of contacting major organisations currently operating in Uzbekistan with Mr Mirjakhon Turdiev. The NGOs and DPOs for potential involvement were identified based on two criteria: 1) Active participation in social, economic, and political events related to disability issues and 2) Experience of working in a disability field.

Table 1: Suggested organisations

#	NGO/ DPO	Main activity
1.	Educational centre ‘Umnichka’	Early intervention for children with Down syndrome
2.	‘Millennium’	Working with the youth with disabilities

3.	‘Opa Singillar’	Social adaptation of children with disabilities and supporting family members of persons with disabilities
4.	‘Sharoit Plus’	Disability inclusion & disability equality trainings
5.	‘Special Olympics’	Organising sports training and competition for children and adults with intellectual disabilities
6.	‘Status’	Disability rights
7.	The Uzbek Society of People with Disabilities	Disability rights
8.	The Republican Centre for Social Adaptation of Children (RCSAC)	Comprehensive support for children with disabilities and children from other vulnerable groups
9.	The Society of the Blind	Social adaptation
10.	The Society of the Deaf	Social adaptation
11.	‘Umidvorlik’	Social adaptation
12.	UNICEF	Children’s rights

2. *Parents/caregivers of children with disabilities*. Parents of children with disabilities were also contacted before data collection. They were identified and accessed through the non-governmental organisations working with children with disabilities included in the above table. The educational NGO “Umnichka”, working with children with Down syndrome, the Support Centre for Children and Young People with Disabilities “Umidvorlik”, specialising in organising vocational training for children and young people with disabilities, and the Republican Centre of Social Adaptation of Children (RCSAC) were especially helpful in this regard. These organisations have established the Parents’ Associations and work quite closely with parents. I sent a research information letter to the organisations so that they could distribute it to potential interviewees. When

I arrived in Uzbekistan, I, as noted above, organised an introductory session with parents and scheduled the interviews.

3. *Teachers working with students with disabilities*. The teachers were identified during the data collection process. When I met with representatives of the NGOs and parents for the interviews, I asked them to share contacts of teachers working with students with disabilities if they had any. I also considered teachers who were not working at that moment but had worked with such students in the past. I contacted teachers to see whether they were interested in sharing their thoughts. I met with those who expressed their initial interest, to inform about the study in more detail. If the teachers agreed to participate in the interviews, I organised a schedule to meet with them.

4. *Government representatives*. I was not able to interview any government officials during my data collection field trip. I contacted some of them by e-mail but they did not reply. It could be explained by the fact that disability is still a very sensitive topic in Uzbekistan and authorities were not willing to talk openly about it. However, at a later stage, the former officials from the Ministry of Labour and Social Protection of Population, who were in charge of disability issues, agreed to participate in interviews.

3.6 Data Analysis

The approach used is this study is based on a six-step guide for a thematic analysis offered by Braun and Clarke (2006):

1. *Getting familiar with the original data*. At this stage, I immersed myself in reading the interviews to get a sense of participants' stories. I listened to the audio recordings and read each individual transcript several times. Each listening and reading provided me with additional insights. When I listened to or read the interviews for the first time, typically only the most striking points took my attention. After re-listening to recordings and re-reading the transcripts, I paid attention to these initial observations but less obvious ideas came into view.

2. *Generating initial codes*. After being reviewed, all data were coded. Coding helped me organise data in a meaningful way by reducing the information into small segments. I used colour coding to identify the parts of a text, concepts, and categories each potentially belonged to. As Bianco, Gasparini, and Schettini (2014) state, "The use of color for

encoding information can greatly improve the observer's understanding of the information depicted by image and his/her capacity for remembering it" (p. 85). I worked through each interview transcript to develop a list of codes that seemed to be relevant to my research questions.

3. *Searching for themes*. I organised all codes into broader categories and made a tentative list of themes that emerged from the transcripts. Each theme seemed to be significant or relevant in terms of research questions. Braun and Clarke (2006) recommend researchers to use visual displays, such as tables or mind-maps, so that they can easily organise codes into themes. Dey (1993) also notes that visual representations are helpful tools for a researcher to find connections between different pieces of relevant information. In my case, I used tables that gave me a better chance to detect patterns while analysing large amounts of information.

4. *Reviewing themes.* At this stage, a researcher should review and modify all themes to see whether they make sense. I consolidated all codes of each particular theme to a separate Excel sheet to see whether they supported a theme. Then I considered how the themes worked across the entire data set. I tried to see whether I could cluster them based on conceptual similarities. Some themes naturally clustered together, while others were disconnected.

5. *Defining and naming themes*. This is the final stage for a researcher to refine all themes. By defining and refining theme, Braun and Clarke (2006) mean "identifying the 'essence' of what each theme is about (as well as the themes overall), and determining what aspect of the data each theme captures" (p. 92). As a part of a refining process, I aimed to see whether I needed to develop sub-themes. Two themes were quite complex; therefore, I developed several sub-themes for each of them.

6. *Producing the report*. Here, the task for a researcher is to write up a thematic analysis in a way that could convince a reader of the validity and reliability of analysis. I aimed to produce a logical and concise story supported by illustrative extracts from the interviews and followed by sufficient discussion.

3.7 Ethical Considerations

Strict following of ethics is crucial in any research to minimise the potential harm for those who are participating in it. Ethics also underpins the core values necessary for collaboration: integrity, trust, mutual respect, and accountability. Moreover, ethical norms in research are essential to protect authorship, such as copyright and disclosure of data. All these characteristics of ethics are important. However, I would like to focus on ethical considerations in conducting research involving people with disabilities and their family members. I also provide the brief history of disability research with a focus on human experimentation that violated the ethical principles of research.

3.7.1 History of disability research

Historically, during the 19th and 20th centuries, people with disabilities and other vulnerable groups have been used as “convenient research participants” for medical research (Bryen, 2016, p. 53). The purpose of research was to prove or disprove certain medical assumptions without considering the adverse consequences on the wellbeing and dignity of these people. Unethical human experimentation was justified by the advancement of scientific knowledge and the ethics of conducting medical research, involving human subjects with disability, was not given much attention (Bryen, 2016; Iacono & Carling-Jenkins, 2012).

Bryen (2016) provides some historical examples where the rights of people with disabilities have been severely violated. For instance, in 1952, in the USA, Jonas Salk conducted a medical experiment where he injected the children with intellectual disabilities for the D.T. Watson Home for Crippled Children and the Polk State School to test his Poliovirus vaccine. Another example is medical studies on hepatitis conducted on children with disabilities at Willowbrook State School in New York between 1963 and 1966. To test the effects of gamma globulin, these children were intentionally infected with the virus, which caused them to contract a serious disease. The school was closed only in 1987. These are only two examples of serious violations of the rights, wellbeing, and dignity of children with disabilities by researchers. They reflected an era where people with disabilities were not even considered a *vulnerable* group. The vulnerable groups included only: “(a) fetuses, pregnant women, and human *in vitro* sterilization; (b) prisoners; and (c) children” (Bryen, 2016, p. 55). Consequently, individuals with disabilities were not covered by research ethics that adequately protected their rights and welfare.

Carlson (2013) states that in the wake of these historical examples, much attention should be drawn to protecting people with disabilities participating in research, especially to those who have intellectual disabilities. Individuals with intellectual disabilities continue to be subject to various forms of ethical violations, such as exploitation or breaching the principles of autonomy and informed consent (Bryen, 2016; Carlson, 2013). Carlson (2013) recommends researchers consider potential risks and benefits to which human subjects may be exposed. It is important to remember that the expected benefits of research must never be at the cost of wellbeing and respect of participants: "Willowbrook rightly serves as a reminder of how grotesquely distorted the aims and justifications of research can become" (Carlson, 2013, p. 313). Further, Carlson (2013) notes that disability perspectives enhancing the voices of people with disabilities should inform and govern ethical research practices involving them as research subjects.

3.7.2 Research ethics

Ethical approval was needed to conduct the study, as it involved human participants subjected to survey and interview processes. The Division of Education Human Research Ethics Committee has thoroughly reviewed the application to ensure this research complied with the ethical standards, such as minimising the risk of harm to participants, obtaining informed and voluntary consent, protecting confidentiality and anonymity, and providing the right to withdraw. Within the wider research ethics, I also had to comply with ethical standards for disability research, which include equality, autonomy and dignity, respect for difference, and accessibility (National Disability Authority, 2009).

Minimising the risk of harm to participants. This study itself was sensitive as it involved children with disabilities and their family members. Therefore, as a researcher, I had to ensure that participants did not experience serious psychological strain as a result of their participation in interviews. Since it was difficult to predict whether interviews would bring traumatic memories back and cause adverse emotional reactions, I tried to ensure appropriate counselling was readily available during the entire interview processes.

Participants' autonomy and dignity had to be upheld throughout the research process. Respecting the autonomy of all research participants means giving the right to every individual to make his/her own decisions regarding their participation in research (National Disability Authority, 2009). As a researcher, I also had to show respect for human dignity by having my participants feel that this research was for them, not on them. The National Disability Authority (2009) states that people with disabilities should be respected and involved in research as active participants, not as passive objects. As stated above, respect for the dignity of participants also means that their interests and integrity cannot be ignored in research to achieve a better understanding of a topic being researched.

Obtaining informed and voluntary consent. Participation in this research was voluntary and, therefore, the informed consent of participants was essential. As a researcher, I needed to ensure that every participant consented willingly to participate in the process. Before enlisting participants, I met with each of them individually to discuss the consent procedures so that they were informed about the matters related to their involvement, such as the purpose of the study, the procedures, the potential risks and benefits of their participation. Participants were given an information sheet (see Appendix A) containing brief information about the project and two copies of the consent form (see Appendix B): one to be signed and returned to me, and the other to be kept by the participant.

Protecting confidentiality and anonymity. According to Wiles, Charles, Crow, and Heath (2004), confidentiality in research means that identifiable information about participants and information they provide cannot be disclosed unless there is permission for that. In this context, confidentiality means not discussing the provided information with others, except for those involved in the supervision of research, and presenting findings in a way that ensures participants remain unidentifiable.

Ethical guidelines indicate that a researcher should anonymise his/her research participants (Wiles et al., 2004). All participants of my research were distinguished by numbers for data coding and reporting on the study findings. Nevertheless, it was explained to them that even though all measures would be taken to protect their identities, in qualitative research confidentiality could not be 100 percent guaranteed (Van den Hoonard, 2002). It should be noted that two participants stated explicitly that they did not want to be anonymised. Both wanted more visibility to promote the social and educational inclusion of children with disabilities. However, to avoid potential risks and harm to these participants that might be especially pertinent in the context of disability-related research, it was decided to preserve their anonymity.

Providing the right to withdraw. Participants had a right to withdraw completely from the study and to withdraw their contribution. Participants were explained that in case they chose to withdraw from the research process, they would not be stopped in any way from withdrawing. In case they decided to withdraw data, they would have to inform me about that no later than three weeks after receiving transcripts. They would not be required to give me any reasons for their withdrawal.

All principles of research ethics have to be followed during *the entire* research process. Rolph (1998) states that getting permission from the Ethics Committee to conduct research is only the beginning. A researcher has to be very mindful and considerate in relation to participants during the research process. Wiles et al. (2004) note that ethical issues may arise at any stage of research and a researcher should be ready to deal with them. Those issues may include the needs of research participants, their distressing emotions, which may relate to their experiences in the past, and/or unexpected disclosure.

3.8 Summary

This chapter presented the description of the research process followed in the study. The chapter discussed the qualitative approach that guided this research; methodology; theoretical framework; research instrument; selection of research participants; data analysis; and ethical considerations. The chosen qualitative research methodology was found to be relevant and suitable to examine participants’ experiences, beliefs, and assumptions about disability, equity, and inclusion of children with disabilities in regular classrooms.

CHAPTER FOUR
FINDINGS & DISCUSSION

Participants' Perceptions of Inclusive Education

4.1 Introduction

Having outlined the research design, the thesis now turns to the findings of the study. The combined approach that discusses the findings immediately after presenting them is used for this section. The findings emerged from the information of both the online questionnaire and semi-structured interviews. In total, I have formulated five major themes. The research questions and the existing literature provide the primary lens through which these themes are discussed.

The quotations of questionnaire respondents and interview participants in Russian have been translated into English. It was decided to provide all quotations in their original language in the annex to maintain the trustworthiness and credibility of the collected data. All quotations in English included in the findings sections were numbered. These quotations in Russian can be found in the annex under the same number.

4.2 Participants

Representatives of both national and international NGOs and DPOs were invited to participate in the online questionnaire. This questionnaire was developed in three languages: Uzbek, Russian, and English. In total, six responses were returned: two in Russian and four in English. No responses were received in Uzbek.

Four groups were invited to participate in the interviews: 1) parents of children with disabilities coming from different socio-cultural backgrounds; 2) teachers of both general and specialised schools and defectologists; 3) representatives of NGOs (who did not participate in the questionnaire); 4) government official. Some participants represented both groups, for example, they are parents who are also NGO or DPO leaders. In total, I interviewed 23 people. The demographic characteristics of non-governmental organisations and profiles of interview participants are presented in the tables below.

4.2.1 Questionnaire participants

Table 2: Size of the organisation

Scale	No. of responses
Less than 10 employees	1
From 10 to 50 employees	1
From 50 to 100 employees	--
More than 100 employees	3

Table 3: Disability fields the organisations work in

Scale	No. of responses
Education	1
Disability rights	1
Rehabilitation services	--
Social adaptation	1
Inclusion and Equality Training	2
In all above	1

Table 4: The period an organisation has been involved in the field

Scale	No. of responses
Less than 1 year	--
From 1 to 5 years	--
From 5 to 10 years	1

More than 10 years	4

Table 5: The position of the NGO representative within the organisation

Scale	No. of responses
High-level position	3
Medium level position	3
Entry-level position	--

4.2.2 Interview participants

Table 6: Group I - Parents

#	Group	Child's disability	Child's age	Educational institution
1	Parent	Down syndrome	13	Private general school
2	Parent	Down syndrome	3	General kindergarten
3	Parent	Down syndrome	4	General kindergarten
4	Parent with a leading role in the non-governmental educational centre for children with Down syndrome	Down syndrome	11	Specialised school
5	Parent	Down syndrome	11	General school - pilot inclusive class
6	Parent	Autism spectrum disorder	12	Home-based education

7	Parent & NGO leader	Cerebral palsy	28	Integrated class in general school (in the past)
8	Parent & DPO leader	Muscular dystrophy	26	General school (in the past)
9	Parent	Cerebral palsy	22	Specialised boarding school (in the past)

Table 7: Group II - Teachers

#	Group	Institution	Subject
10	Trainer with a leading role in the Centre of Adaptive Sport for Children with Intellectual Disabilities	Specialised school for children with intellectual disabilities	Physical training and mountaineering
11	Teacher	Specialised school for children with physical disabilities	Math
12	Head Teacher	Specialised school for children with intellectual disabilities	Russian language
13	Teacher	Specialised school for children with intellectual disabilities	Uzbek language
14	Teacher & NGO leader	Regional specialised school for children with intellectual disabilities	Russian language
15	Teacher	Non-governmental inclusive educational centre for children with Down syndrome	Early intervention practice
16	Logopedist	Non-governmental inclusive educational	Speech therapy

		centre for children with Down syndrome	
17	Principal	Specialised school for children with intellectual disabilities	--

Table 8: Group III - NGOs & DPOs

#	Group	Field
18	International development organisation	Rights of children
19	NGO	Inclusive theatre
20	Government-organised NGO	Social adaptation of children/law
21	Government-organised NGO	Social adaptation of children/defectology
22	Uzbek Society of Persons with Disabilities.	Inclusive education

Table 9: Group IV - Government officials

#	Group	Field
23	Ministry of Labor and Social Protection of Population of the Republic of Uzbekistan	Social protection

4.3 Inclusive Education

The theme “Inclusive Education” contains three sub-themes: an understanding of inclusive education and its enactment; the importance of socialisation; and no inclusion for children with intellectual disabilities. The participants generally supported the concept of inclusive education and saw it as an equal educational opportunity for children with disabilities. Some of the participants had substantial experience in inclusion, for instance, parents whose children studied in an inclusive classroom or NGO representatives who participated in the Inclusive Education Project. Some of the participants had only heard about inclusive education. However, regardless of their experiences they all offered a definition of inclusive education and readily identified a number of positive aspects of inclusion where socialisation was viewed as the most significant one. Inclusion of students with intellectual disabilities in a general school was one of the most often mentioned topics. These three sub-themes are discussed below.

4.3.1 Understanding of inclusive education and its enactment

Both the questionnaire and interview participants were asked to share their understanding of inclusive education. Their definitions of inclusive education were observed to be similar. They were about respecting the difference, acceptance, access, equity, quality, and justice.

In total, five survey participants responded to the question “How do you define the term ‘Inclusive Education’?”. Their responses are quoted below:

> 1. The open education for different categories of people regardless of the fact that they might have special needs.
>
> 2. A process of removing barriers to students' participation and learning in a regular classroom and school on an equal basis with other children.
>
> 3. Equal learning opportunities for all children, including those with disabilities, in the same classroom and with the provision of support that is required to meet the specific educational needs of each child.
>
> 4. Equal opportunities to receive quality education[1].
>
> 5. Creating conditions and possibilities for everyone to receive education at any educational institution[2].

The interview participants also shared how they understood the term ‘inclusive education’. They understood inclusive education as an educational model that encompassed children with disabilities only. One of them said that inclusive education was about equality and acceptance:

> Inclusive education is what I wanted. It means applying equal rights and having equal attitude towards them [children with disabilities]. Inclusive education is good because other people can see these children, not to fear them, and accept them as they are. Within inclusive education parents [of typically developing

> children] should not protect their children from ours and take their children out of the class saying, “Oh, this child has a disability”. This is my understanding of inclusive education. Yet, the approach to every child has to be different[3]. (P1)

Similarly, two other participants while talking about what inclusive education was, emphasised that students with disabilities had to study alongside their non-disabled peers in schools. They said, “I think inclusive education means that a child is not separated based on his category and diagnosis”[4] (P4) and “Inclusive education means that children with additional needs can study together with typically developing children”[5] (P16). Other research participants expressed similar views.

What was interesting is the respondents seemed to move very quickly from their own definitions of inclusive education to how it was enacted. Several participants expressed their opinions about the misinterpretation of inclusion by local schools. Schools placed students with disabilities in general classrooms but were not able to provide proper conditions and services to them. One of the participants who has extensive experience in inclusive education shared his view of what inclusion was and expressed his disagreement with how inclusive education was being enacted in the country:

> Let’s talk about how inclusive education is being enacted here if you don’t mind… First, we have the inconsistent concepts. A new concept ‘inclusive classroom’ has been created though it does not exist anywhere in the world. I said that there was no such concept. Only school can be inclusive [not a classroom]. A couple of children with disabilities were placed in a general classroom and that’s all. It is not inclusion. School starts at the entrance. The entrance, classes, gyms, toilets – everything has to be inclusive and accessible… They cannot build inclusive schools; it is easier to say, “We opened inclusive classes”[6]. (P22)

He claimed that many international development organisations tried to carry out inclusive education projects but none of them was successful. In his opinion, all these projects were about training only and he believed it was a misuse of available resources.

Participant 4 stated that many specialists in the country used the terms ‘inclusive education’ and ‘integrated education’ interchangeably, although, as she pointed out, there was a substantial difference between them. Similar to the previous participant, she also said that not *all* children with disabilities were accepted into general schools, “Nowadays, even leading specialists in the country mean integration by the term ‘inclusion’. Simply, those children who have physical disabilities but not intellectual ones are included in regular schools. It is not inclusion”[7]. The participant supposed that genuine inclusion was not being enacted in the country due to a shortage of financial resources.

Another participant shared a story about the unsuccessful attempt to integrate students with hearing loss into a mainstream school:

> She [a project organiser] offered to include deaf and hearing impaired students from specialised schools in the studying process [at the general school]. However, neither teachers nor children and their parents were ready for that. The preparatory work, as we organised within the framework of the EU project, had not been conducted there. Then, children are children: the deaf children were on their own and typically developing children were on their own. Inclusion as such did not happen[8]. (P21)

Two other interview participants expressed their doubts that it would be possible to enact inclusive education in Uzbekistan. One of them said, “I have seen inclusive schools in other countries: in the United States, Lithuania, and Hungary. What I saw makes me feel unsure that it will be possible to do the same here”[9] (P8). When I asked the participant why she held that view, she replied, “Both financial resources and understanding are needed for that. And not only parents but also the government has to understand that children need to study”[10]. In a similar vein, another participant said that she was not sure that it would be possible to enact inclusive education in the country because the way it was being enacted in Uzbekistan was far from how it had to be (P1).

People’s perceptions of inclusive education are of critical importance for the successful enactment of inclusive education. It seems that in the disability context, the participants had a close familiarity with the term ‘inclusive education’. Their definitions closely align with the CRPD that stresses that inclusive education is a fundamental right for children with disabilities (Convention on the Rights of Persons with Disabilities, 2006). However, many participants perceived inclusive education as an educational opportunity for this group of children only. Other marginalised groups, such as ethnic, linguistic, religious, and other minorities, were not considered. This issue has already been mentioned in Chapter Two where I referred to Florian and Becirevic (2011) and Rouse and Lapham (2013) who argued that such a perception of inclusive education was common for former Soviet republics due to the extensive segregation of children with disabilities during the Soviet Union era. Therefore, it is important to re-conceptualise inclusive education from the perspective of “widening participation” (Makoelle, 2020, p. 7). This author notes that inclusion should be based on pedagogy advocating education for all rather than on a special needs pedagogy designed exclusively for children with disabilities.

Further, based on the participants' responses there seemed to be a teachers' misunderstanding of the concepts 'integration' and 'inclusion'. Artikova, an independent consultant on Public Health and Disability in Uzbekistan, also noted that many local educators, including Professors of defectology, did not understand the difference between those two concepts well enough to enact inclusive education initiatives successfully (personal communication, January 27, 2017). Yet, there is a substantial difference between them. The term 'integration' refers to the "placement of a student with disabilities into an ordinary school environment and regular curriculum, usually without the curriculum being modified to any great extent" (Chhabra et al., 2010, p. 219). Inclusion is a more radical concept and "implies not only the integration of children with disabilities in mainstream schools but also the curricula adjustment" (Unianu, 2013, p. 1237). Sanagi (2016) notes that teachers' confusion about what inclusion actually means may lead to the creation of a segregated environment for students with special needs in a mainstream setting. We can see it if we refer back to the participant's example of the integration of children with hearing impairments into a regular school.

Santos (2010) argues that integration and inclusion are integral parts of a historical process towards the humanisation of education. In this regard, these concepts represent different stages countries go through towards realisation of the right to Education for All. Santos (2010) states:

> As much as we need to learn to respect the different learning rhythms of our students in order to promote inclusion, we also need, in order to promote it internationally, to take account of the countries' rhythms of understanding and absorption of new paradigms, as well as their timing to adjust themselves within their own history (p. 897).

Sharma, Forlin, and Loreman (2007) also note that many countries have chosen integrated education as an interim model on the way from segregation to inclusion. From this perspective, it might seem that Uzbekistan and many other developing nations that started this worldwide movement in the 1980s and the 1990s are heading in the right direction. However, when an interim approach is taken, the focus is on "the student to fit the system rather than the system to adapt to meet the educational needs of a student" (Sharma & Deppeler, 2005, p. para 2). Based on the early history of educating children with special needs in some western societies, we can see that integrated education as a transition phase was hardly a successful way to move towards inclusion.

In the 1970s, in Quebec, Canada, the government recognised that segregated schools had deprived children of quality education and closed the majority of those schools. Children with special needs were placed in “a special section of an ordinary school, with an independent entrance and little mixing of the students” (Thomazet, 2009, p. 554). Even though those children attended mainstream schools, they were often still isolated and not involved in a learning process with all other students. In the 1960s and 1970s, many European countries also formulated and introduced integration “as a programmatic principle for a new societal practice and for institutional reforms” (Vislie, 2003, p. 18). The effectiveness of new reforms varied from country to country in Europe but in general, the quality of integrative practices was questioned. Vislie (2003) notes that the integration provision was primarily focused on reshaping the special education system, not on adjustments of teaching practice and learning. They were not comprehensive enough to meet the needs of diverse learners that resulted in limited participation of children with special needs in academic and social activities with others.

Due to different historical legacies and practices of segregation, developing countries may need more time and effort to shift from segregation to inclusion. Inclusion in the developing world is more concerned with access to schooling, while in developed countries, it is more concerned with access to a non-segregated education environment (Bines & Lei, 2011). Most developing nations do not have enough qualified personnel who would be able to teach students with disabilities enrolled in general schools, “Unlike countries where compulsory education has long been in place, many schools in the Global South simultaneously face increased student enrolment and teacher shortages” (Franck & Joshi, 2017, p. 348). Sharma and Deppeler (2005), when describing early integration practices in India, note that the situation is often worsened by the non-availability of resources.

It cannot be denied that financial resources are critical to develop and sustain inclusive education. International literature contains many examples of meaningful programmes failed due to insufficient resources. For instance, in India, the government launched a nationwide scheme called Integrated Education for Disabled Children (IEDC) (Chadha, 2000). However, only about 60,000 of the estimated 30 million children were enrolled under this scheme. In South Africa, the government also was not able to support inclusive education as it lacked adequate financial provision (Walton, 2011). This author notes that since 2001, only eight state schools across the country have had the necessary services and resources to meet the needs of students with disabilities. Uzbekistan is no exception in this regard. Based on the participants' responses, due to insufficient budget allocation, the Uzbek government, in cooperation with donors, established inclusive classes as a lower cost option instead of inclusive schools and ran small-scale integrated education projects.

However, even with all these challenges in mind, the concept of inclusion "may replace the one of the integration of children with special needs" if it becomes *an education priority* (Unianu, 2012, p. 900). The Salamanca Statement, therefore, committed all countries to "give the highest policy and budgetary priority to improve their educational systems to enable them to include all children" (UNESCO & Ministry of Education and Science of Spain, 1994, p. ix). Whether to make inclusion a priority or not depends on governments. According to the Education Sector Plan (ESP) of Uzbekistan 2019-2023 (2019), "33.6% of the national budget (and 62% of the social sector expenditures) goes to education expenditures" (p. 64). This allocation is higher than that in the Europe and Central Asia (ECA) region and other OECD countries at approximately 11 and 13 percent, respectively. In 2016, 1,5 percent (199 billion UZS) was spent on education for children with special needs. Although these expenditures are significant, the government still seems to prioritise segregation. For instance, in 2018, the Mercy house for children with disabilities in Karshi city (Kashkadarya region, Uzbekistan) was completely renovated. Its renovation was organised in the framework of a charity project and cost more than 22 billion UZS (approximately 2,3 mln USD) (Vesti.uz, 2018). According to Mariga, McConkey, and Myezma (2014), many other developing countries also use available resources to create or maintain segregation, "Even when money is available, it is mostly directed towards the specialised schools and units" (p. 22). It is apparent that as long as segregated education is imposed and reinforced by the governments, inclusive education initiatives will not be adequately funded, and preference will be given to integrated education as a cheaper option.

Santiso (2007) points out that "the budget is a political process, rather than a purely technical one" (p. 3), and a major reason for low budget allocations is a lack of political will. Halachev (2015) considers "the willingness of decision makers to support the transition from *segregating* settings to an *inclusive* mainstream educational system" a key element to facilitate inclusive education (para 7). A deficit of political will affects not only resource allocation but also policies. According to Artikova (personal communication, January 27, 2017), many educators in Uzbekistan are not familiar with the concepts of integration and inclusion because the Government's education policy neither provides a clear definition of these concepts nor a differentiation between them. It implies that with adequate resources and a clear policy backed up by political will, it is possible to transfer from *exclusion* to *inclusion* without wasting time and effort on an integrated stage.

4.3.2 The importance of socialisation

The development of social competencies of children with disabilities was found to be one of the major advantages of inclusive education. Four out of six survey respondents strongly believed that a mainstream setting contributed significantly to students' social skills.

Many of the parents interviewed mentioned that developing social competencies was the main reason why they wanted their children to study in inclusive classrooms. They said that growing in a "natural" environment amongst all other children and interacting with them were the most important aspects of inclusion:

> There are many advantages of inclusive education. First, a child is in a natural environment. There are no similar children in the class; they all are different. It means the child is in that particular environment where he is supposed to be according to his age[11]. (P4)

Another participant emphasised that studying in a general classroom was more about the development of social skills rather than academic knowledge:

> Any education is first of all communication with others, development of social competencies, and involvement in community life. Not all people who finished schools are necessarily very intelligent. The main purpose of inclusive education is to help children be included in the society[12]. (P8)

She added that she had realistic expectations of her child and fully realised that the majority of children with disabilities would not be able to reach the same level of development as children without disabilities. Yet, their social skills could improve if they studied amongst their typically developing peers and established social relationships with them.

However, some parents of children with intellectual disabilities believed that their children did not need to be in a general school to develop social competence. These parents considered that their children had sufficient opportunities for socialisation within their specialised schools. For instance, one of them said that not all students in a specialised school, where his son was studying, had severe intellectual disabilities; some children had very mild disabilities. He referred to them as “almost typically developing children” who were sociable and friendly and who his son could build relationships with:

> In our school, there are children with severe disabilities, but there are also children from the category F-70 [mild mental retardation code (World Health Organization, 2006)]. They have mental disorders but they are mild. Good children, they can socialise… There are different children there, for example, with Down syndrome. When we come there with my son, they hug him. They could cover our minuses [he means the inability to socialise with others common for people with ASD]. It would be good for our children[13]. (P6)

He continued to say that his child was mainly studying at home because he was not able to bear loud noises. The main obstacle for his son to be at school was a school bell; it scared him. The parent said he realised that the school could not cancel it only because of his son. However, the child was not completely isolated, he regularly went to school to take certain classes.

The parent of the child with muscular dystrophy raised her concerns about home-based education. After having studied in an integrated class for four years, her son was assigned to home-based schooling:

> I had been sitting with him in the class for about four years because he had a very complicated form of hyperkinesia if you understand cerebral palsy… First, he could hardly speak. Then, he needed help when he wrote or held something in his hands. I was functioning as a resource teacher for him. After four years, he was assigned to home-based education. Teachers from general school came home to teach him until grade 9… However, at the end of the 90s – the beginning of the 2000s teachers worked [with him] on a voluntary basis. The system as such did not already exist… Based on the opinions of other parents, even though home-based education exists along with general and specialised education, it is… better than nothing[14]. (P7)

The parent added that in her view, the main problem of home-based education was a lack of socialisation. She stated that children who received long-term home-based education were isolated from their peers and society broadly. She sacrificed her career to take care of her son and contribute to his growth and development. The parent said, “His health condition became my profession”[15]. She established a disability-related NGO aimed at socialisation of children and young people with disabilities. Young people with disabilities learned there how to cook, knit, or make/repair small pieces of furniture. It was an opportunity for them and their family members to socialise.

The teachers working at specialised schools for children with intellectual disabilities supported the view that students could develop social skills being at school. For that purpose, their school introduced a subject called ‘Social Orientation’. Students were taught how to wash clothes, do shopping, write basic letters, pay bills, and other essential things they would need to make in their regular life in the future. They were also offered extracurricular activities, such as knitting, art classes, and sports clubs (basketball, table tennis, etc.).

One of the teachers said that although their students studied at a specialised school, they were not isolated from the rest of the world. They regularly met and participated in joint activities with students from a neighboring regular school. In response to my question of whether their students ever experienced discrimination of any kind on the basis of their disabilities while socializing with typically developing students, the teachers said they had never observed that, “Because we might have got used to them [students from a general school]: we visit them, they visit us. They come to us on special occasions to show what they can: dancing or singing, whatever they can do”[16] (P12).

The teachers also mentioned that the school often organised extracurricular activities for the students:

> We try to take them to the theatre, circus, zoo, and museums because their parents will never do that. We have very good relationships with the Art Museum. The museum organises special themed exhibits and invites us. The students draw there, communicate with others, they are explained something[17]. (P12)

However, when I asked the parent whose child was studying at a specialised school about socialisation, she had a different opinion. She said that although the school organised events for students’ social integration, they were not enough to prepare them for adulthood, “They will anyway leave their school. Life out of school is very diverse… It is very difficult for them to live further”[18] (P4).

The parent added that her son was very sociable and could engage with people easily, despite being non-verbal. She believed it was her family members who contributed to the development of the child’s social skills, not the school. The parents and elder siblings regularly took him to different social events, and by doing so, they increased his comfort level to meet and communicate with other people.

The NGO representative concurred and stated that after finishing a specialised school young people would not be able to engage in society because they had never really been there:

> We explain to parents that socialisation is possible only if he [a child] has been amongst his typically developing peers since his early years, which is the most important concept of inclusive education. If he has studied with similar children for 17 years and then left his school, we cannot expect him to be socially developed - this is a problem. He will not be able to socialise[19]. (P21)

The participant, whose child was in general school, also supported the idea that a child develops his/her social skills better in an inclusive education setting than in a segregated one. She believed that even though her child did not develop academically, she definitely gained social competencies, built relationships, and improved her behaviour being amongst other children, “Many acquaintances and friends paid attention to my child’s behaviour; it changed drastically. Her worldview and behaviour became better. She behaves better amongst typically developing children”[20] (P1).

Similarly, another parent held the view that children with disabilities acquire the skills and knowledge necessary for interacting with others better when they are together with all other children. “I can only see advantages in both children's academic performance and social development. If all children had an opportunity to study at inclusive schools, we would have fewer socially underdeveloped children. They should be given this chance”[21] (P5).

The opinions of many participants indicate that socialisation is an integral part of children’s development, and ideally, school is a place where they can develop their social skills. This is consistent with numerous studies emphasizing the critical role of schools in developing the social competencies of students with disabilities. Simeonsson, Carlson, Huntington, McMillen, and Brent (2001) define school as “a primary environment for the education and socialisation of children and youth” (p. 49). According to these writers, active engagement of children with disabilities in school life leads to many positive outcomes. Amongst them are lower delinquency rates and active social participation during early adulthood. Vaughn et al. (2003) identified critical stages when children with disabilities develop their social skills. These scholars maintain that during the first three years socialisation mainly depends on their parents; for pre-school children it depends on play and interaction with other group-mates; and for school-age children, it is contingent on “developing peer relations by initiating and maintaining conversations, greeting, and joining groups” (p. 2). Thus, schools are of particular importance for the development of social skills of children with disabilities and making them more experienced in social engagement.

However, there is still a controversy amongst scholars and practitioners concerning what setting is better for children with disabilities to be socially integrated: a general school or a specialised one. Kassah, Kassah, and Phillips (2018) support the idea of “inclusion on their premises” (p. 349), which is widely practised by segregated schools for students with intellectual disabilities in Uzbekistan. These researchers believe that inviting students from mainstream schools to participate in “drawing and painting, skipping out of the loop, sports, whatever” (p. 349) can develop the social skills of students with disabilities studying at specialised schools. Kassah et al. (2018) state, “special schools should remain as the initial socialization arena, where teachers groom children with intellectual disabilities to meet the expectations of the mainstream schools” (p. 348). It would be the case if most students with disabilities continue their education in general educational institutions. According to some studies, their segregation may often be permanent (Buysse & Bailey, 1993; Kunk, 1992; Lipsky & Gartner, 1997). Buysse and Bailey (1993) point out that inclusive education should be actively promoted during preschool years because children placed in specialised preschool institutions tend to continue their education in specialised schools. Lipsky and Gartner (1997) also note that after leaving schools, young people either continue their education in specialised colleges or simply stay isolated at home, which is often the case for students in Uzbekistan.

Some studies on enhancing the social functioning of children and young people with disabilities also indicate that to develop their social skills, they need to experience different situations in a diverse setting, which a segregated environment cannot provide anyway (Fisher & Meyer, 2002; Solish, Perry, & Minnes, 2010; Vaughn et al., 2003). For example, in a two-year study by Fisher and Meyer (2002), students with severe disabilities were placed in two different programmes to examine their social relationships: in an inclusive programme and a self-contained one. The results of the study indicated that those students who were enrolled in the inclusive programme developed better social competencies than those who were studying in a segregated setting: the inclusive group gained 9.5 points when their social competences were measured, while the segregated group gained only 3.8 points. Fisher and Meyer (2002) conclude, "Moving instruction into inclusive environments, rather than providing instruction in isolation from normalized learning opportunities (provided in social contexts) seems to be beneficial for individual child learning outcomes" (p. 172). This resonates with the opinions of almost all participants of this study, who stated that children and young people with disabilities could gain stronger social competencies if they were placed in a mainstream setting.

In considering the first-hand experiences of the participants and the prevailing views of experts and researchers, it would seem that extracurricular activities for students studying in specialised institutions should be organised in a different, diverse setting. Being involved in extracurricular activities in a segregated setting, children may develop certain skills, for instance, photography skills, but not their social competencies. Participant 14 provided an example of an alternative opportunity for social skill acquisition. She received a grant from the government and organised Inclusive Clubs as an after-school activity for both children with special needs studying at specialised and boarding schools and typically developing children from general schools. The purpose of the Clubs is the social inclusion of children with disabilities. The participant added that she had been observing for many years how the children's engagement in social activities helped them form peer relationships.

Modell, Rider, and Menchetti (1997) also point out that meaningful relationships between children with and without disabilities are usually formed in inclusive settings where they can interact and participate in activities *together*. Therefore, "it is reasonable to assume that those children who attend segregated classes during the school day would benefit socially from participation in inclusive recreation and leisure" (p. 701). These authors continue that the majority of young people with disabilities leave their institutions and enter adulthood with poor social skills. It results in high unemployment rates, a lack of meaningful relationships, non-participation in community life, and low socioeconomic status. Given these adverse effects experienced by individuals with disabilities, there should be more opportunities to facilitate their social interaction and integration during their school years.

4.3.3 No inclusion for children with intellectual disabilities

When the teachers of both regular and specialised schools were asked whether children with intellectual disabilities could be included in general education, almost all of them replied negatively. The following statement represents the views of many other interviewees:

> Children with vision impairments or hearing loss can somehow be included [into regular schools] because they have intact intellect… I have been fighting against the inclusion of children with intellectual disabilities since the inclusive education movement started. These children will not be able to study in regular schools[22]. (P13)

To support her view, she provided some examples from her teaching practice, where students with intellectual disabilities came to a specialised school after they had struggled for several years at a regular school:

> Many years ago, inclusive classes were opened at some general schools, but only primary classes. After that, students were transferred to our school because general schools did not have workshops as we did. That transition was very hard for both parents and students: a child was studying at one school and then suddenly was transferred to another… Both children and their parents were not ready for that[23]. (P13)

She added that in a specialised school, students attended an adapted education programme with lower standards: for nine years of study in a specialised school they learned a programme that was equal to four years of study in a regular school. If they were placed at regular schools with other children, they would not be able to study based on their programme, “We do not have such subjects as Physics, Chemistry, foreign languages, and Algebra. We only have Math, natural science, Geography, and History but even these subjects are adapted”[24] (P13).

The other teacher from the same type of school expressed an opposing view on the adapted programme. He said that the programme of specialised schools was insufficient to equip students with the necessary knowledge, "In fact, this is a zero level taking into account students' progress… Students themselves protest… They feel it and say, "We do not want to study at this school". But do they have a choice?"[25] (P10).

Participants 12 and 13 still believed that specialised institutions were a better option for those who had intellectual disabilities, primarily because they would not be accepted by others at general schools:

> Inclusive education was introduced so that children [with disabilities] did not differ from others… However, those who have mental retardations are different anyway. They should be in this school. Here, they all are at the same level. In other words, they are like fish in the water here[26]. (P12)

The teacher from a specialised school for children with physical disabilities also said that inclusion could be possible only for those who had mental capacity. She was also concerned about large class sizes, "For those who have intellectual disabilities, I think it [inclusive education] is unreal. Then, how can we enact inclusion if there are 40 students in the class?"[27] (P11). One of the parents expressed the same concern, "Look at this education, there are 50 students in the class. How can we talk about inclusion of children with special needs? Therefore, I do not know whether we have any chance at all to enact inclusive education"[28] (P7).

The most surprising aspect of data is that the representatives of some NGO organisations, previously involved in inclusive education projects, also shared the same view. For example, Participant 21 explained that regular schools had certain educational standards that students with intellectual disabilities would not be able to achieve. This is the reason why schools accept only those students who have visual impairments, hearing impairments, and musculoskeletal disorders. In some cases, schools can accept those who have cognitive impairments, but these have to be mild.

The parent and a disability NGO leader, who actively promoted inclusive education in the country in the past, said:

> We talk about equal rights, about the inclusion of all children in general schools. However, what if a child cannot be corrected, and he screams during the entire lesson? It is ok if it lasts one day, two or three. But what if it lasts years? If he disrupts a learning process every day, we cannot talk about his inclusion. I am absolutely sure of that[29]. (P7)

A few participants were more optimistic. One of them indicated that if children with intellectual disabilities were given a chance to study in general schools, society would change its negative perceptions:

> You know, it [inclusive education] is not widespread here yet. There are such children in some schools, but not in all schools. However, if we open pilot kindergartens and schools in every district and send these children there, society will accept them[30]. (P16)

Another participant stated that we had to move from paternalism to dignity in relation to children with intellectual disabilities, "It should not be a paternalistic approach to these children. They have to be treated equally, like all others, with no discrimination"[31] (P14).

This participant continued to say that a reductionist view was dominating in the Uzbek society. She said she often observed how people from the neighbourhood brought some food and clothes to students. They tried to help children by doing so, but they did not even realise that these children needed acceptance and opportunities for development but not pity.

UNICEF (2015a) also emphasises the negative effects of the reductionist view of disability, formed by the existing social norms and excessively practised in educational institutions, "In the region, children with disabilities have been viewed as intrinsically 'defective', in need of life-long care, shelter, and pity' " (p. 3). The society does not recognise them as its full members due to their 'defects' which seem to be more influential than their abilities. Zagirtdinova (2005) also claims that the philosophy of "guardianship over weaker citizens" (p. 216) in Uzbek society has more disadvantages than advantages for people with disabilities. In the society practising such beliefs and standards, people with disabilities are viewed as defective and restricted "in their quest for independence" (p. 216). Similarly, Katsui (2005) points out that such a guardianship makes people with disabilities very passive because they live in a world where "dependency is the only way to 'exist' but not to 'live' " (p. 70).

The literature on stigmatizing attitudes towards people with intellectual disabilities in Uzbekistan is scarce, although there is sufficient information on this problem in other developing countries. In China, for instance, people keep secrets about the mental health issues of their family members to save a "face" (Mak & Cheung, 2008, p. 533). The findings of Ciftci (1999) also revealed the same tendency amongst Turkish families that had children with intellectual disabilities. This strong intention not to diminish a social status leads to creating barriers in the official registration of children with disabilities and their access to relevant medical, social, and educational services (Ciftci, 1999). In Egypt, sisters of children with intellectual disabilities did not have many chances to get married because of "the repetition of genetic norm in families with a history of births of babies with any intellectual disabilities, especially those with the more obvious ones such as Down's syndrome" (Gaad, 2004, p. 315). This is also the case for Uzbekistan: in Uzbek culture, marriages are often pre-arranged and prior to marriage, families want to know more about genealogy trees. If parents find out there is a child with a disability in a family of a bride or a groom, they most probably will not make/reject a marriage proposal.

Gaad (2004) states that attitudes towards the inclusion of children with intellectual disabilities are affected by cultural attitudes towards these people prevailing in a society: "Attitudes drive our behaviour. As individuals and as groups, what we believe and how we feel about matter largely determines what we do with respect to it. Human behaviour further reinforces our beliefs and feelings" (pp. 313-314). According to (Gaad, 2004), people lack an appreciation of the capabilities of children with intellectual disabilities and, therefore, have low expectations of how much they can achieve. Wilson (2011) notes that many people believe that even if these children are provided with proper educational conditions and services, they "may not be able to "give back" to society in ways deemed valuable by most (i.e., economically)" (p. 7). For this reason, education for children with intellectual disabilities is considered a waste of resources, which are already limited in developing countries.

In many former Soviet republics, children with intellectual disabilities face greater stigma than children with physical disabilities do. For instance, a UNICEF study revealed that in Armenia, the vast majority of respondents believe that children with physical disabilities can be integrated into society but children with intellectual disabilities should be isolated from society (UNICEF, 2014a). One of the significant reasons why these children are stigmatised is connected to a socialist legacy. Petrea (2012) states:

> For decades, the image of mental health in Soviet countries has been associated with political abuses in psychiatry and stigmatising attitudes and discriminating practices against people with any form of disability or, what in the Soviet society was viewed as a 'defect and burden'. (p. 2)

Uzbekistan was a part of the Soviet Union for almost 70 years and, therefore, the mentality and attitude of the society towards people with intellectual disabilities, shaped by the former system, still have their effects. One of the participants shared her childhood memories:

> It was the 1960s, the years of my childhood... The only person with an intellectual disability we saw was my friend's little brother. He was roaming around our village aimlessly, and no one paid any attention to him, no one talked to him... He was like an alien, who never entered the life zone of other people. He was something we could not comprehend, and how could we communicate with the incomprehensible?[32]. (P19)

Based on the participants' responses, attitudes towards children with intellectual disabilities by the community and school members have not changed significantly since the Soviet era. For example, participants expressed their concerns that many parents of typically developing children still do not want them to be together in one class/school with such children. Participant 6 said that at one point, a neighbourhood regular school could not organise a summer camp for its students. Parents of regular school students were informed that a summer camp for their children would be organised on the premises of the specialised school located nearby. As soon as they were informed, they came together and protested against that decision. Many parents still believe their children without disabilities can get 'infected' from those who have disabilities.

The cultural beliefs and values of teachers also play an important role in the inclusion process (Beacham & Rouse, 2012; Sharma, Forlin, & Loreman, 2008; Singal, 2005). Such a negative attitude towards the concept of inclusive education for children with intellectual disabilities is a significant barrier for its enactment (Malki & Einat, 2018; Singal, 2005). Ojok and Wormnæs (2013) state that the attitudes of primary teachers in Uganda towards the inclusion of children with intellectual disabilities are less positive than to the inclusion of children with other disabilities. The study found that even those teachers, who in general supported the idea of educational inclusion, had limited willingness to teach students with intellectual disabilities because they did not have the knowledge and skills for that.

The above-mentioned study of Gaad (2004) also revealed the negative attitudes of general school teachers in Egypt and the United Arab Emirates (UAE) towards the inclusion of students with intellectual disabilities. Almost all teachers in the study were against their inclusion. They said that these children had to be sent to special schools, “that’s what special schools are for” (p. 319). Downing (2010) notes that many general school teachers do not know how to provide teaching instructions to students with intellectual disabilities. Similarly, many teacher participants made false presumptions that students with intellectual disabilities needed special instructions and could only be taught based on the special education curriculum with a major focus on functional life skills.

With increasing numbers of students with intellectual disabilities in inclusive classrooms, however, it becomes clear that they can be taught on the general education curriculum if it is adapted (Kurth & Keegan, 2014; Lee, Wehmeyer, Soukup, & Palmer, 2010). Neary, Halvorsen, Kronberg, and Kelly (1992) note that curriculum adaptations largely determine the success of inclusive education because they allow teachers to create a more accessible learning environment for those who cannot comprehend and perform at the regular curriculum’s level. Lee et al. (2010) provide the following explanation of curriculum adaptations:

> Curriculum adaptations refer to efforts to modify the ways in which content is represented or presented or in which students engage with and respond to the curriculum, including the incorporation of features of Universal Design for Learning (e.g., graphics, lower-level reading material, assistive technology). (p. 3)

Drake and Sherin (2006) discuss different types of adaptation: changing terminology, changing time spent on a task, omitting or substituting particular tasks, changing the participant structures, simplifying concepts, changing the materials, and increasing teacher control over activities. One of the basic examples of curriculum adaptation that teachers used to accommodate the academic needs of students with intellectual disabilities was giving these students shorter assignments and allowing them more time for completion (Franck & Joshi, 2017). By using this type of accommodation, students with intellectual disabilities can acquire the same knowledge and move on to the next step in their learning with all other students.

Clayton, Burdge, Denham, Kleinert, and Kearns (2006) describe a four-step learning strategy to enable students with significant cognitive disabilities to have access to the general school curriculum. The strategy helps teachers align their instructions to the content standard and ensure that learning is matched to the objectives set in the students’ IEPs. The first step identifies how the content standard is linked to the curriculum and instructions. The second step defines the outcomes of instructions and specifies the learning outcomes for each instructional unit. The third step identifies the instructional activities to ensure that students with cognitive disabilities have equitable access to the general curriculum. The final step ensures that specific objectives from the IEPs are achieved.

The study of Lee et al. (2010) indicates that an adaptation of the curriculum contributes to greater students' academic engagement and more successful classroom management. Kurth and Keegan (2014) also report improved students' on-task behaviour and their less disruptive behaviour. Arguably, the greatest advantage of curriculum adaptations is they allow students with intellectual disabilities to participate in the learning process together with other classmates. Kurth and Keegan (2014) note, "the adaptations provided to students were tied to the general education activity and did not promote removal of students from that setting" (p. 200), which is the ultimate goal of inclusion.

It is also often presumed that a general school cannot provide specialist support for students with intellectual disabilities. For this reason, Goodley (2011) considers a special school "a more suitable context for the needs of disabled children to be met" (p. 139). Similarly, Kassah et al. (2018) argue that special schools are better equipped with personnel, who are trained to work with this population of students, in comparison to general schools. As stated in Chapter Two, successful inclusion involves a wide range of educational professionals; therefore, it may be wrong to think that in inclusive classrooms students with intellectual disabilities are taught by a general education teacher only. Downing (2010) states that it should be a team of "general educators, special educators, paraprofessionals, related service providers" (p. 6). This entails that with relevant specialist support, these children can be efficiently taught in a mainstream setting.

4.3.4 Summary

All research participants understood inclusive education as a model where all children study together regardless of their skills and abilities and are treated equally. Yet, they were concerned about the educators' misunderstanding of inclusive education that relates to considering integration and inclusion to be synonyms. According to the participants, it resulted in inclusive education projects being carried out ineffectively. Children with disabilities were placed in general schools, where there were no relevant conditions for them. In many cases, students felt isolated and needed to adapt to the existing conditions if they wanted to be educated alongside their non-disabled peers. The literature pertaining to integrated and inclusive education provides clear differentiation between these two concepts. It also suggests that the enactment of integrated education as an interim model is ineffective and unnecessary if inclusive initiatives are supported by strong political will.

The participants were generally of the view that socialisation with same age peers is one of the major benefits of inclusive education. They believed that social skills are necessary for their children's successful integration into community life in the future. A large body of international literature has also shown that children with disabilities who attend mainstream schools develop stronger social skills rather than those who are placed in segregated institutions. Despite that, some teachers of specialised schools held an opinion that their students could acquire social competencies being in a self-contained setting and periodically meeting with their typically developing peers at social events. However, as studies have demonstrated, the full social integration of children with disabilities is only possible when they are in a diverse environment regularly.

Another concern expressed by many participants was the inclusion of children with intellectual disabilities in regular schools. Both educators and disability advocates believed that they had better study in specialised institutions due to their lack of intellectual capacity. The evidence from the literature suggests that society, which does not accept people with intellectual disabilities, is highly unlikely to support their inclusion in regular schools. In Uzbekistan and other post-socialist societies, this attitude has been primarily formed by Soviet disability history. Yet, according to international studies, the inclusion of children with intellectual disabilities is possible. Its success is determined by different factors, but two of them, adjusting the existing general education curriculum and the availability of qualified manpower, are critical.

CHAPTER FIVE
FINDINGS & DISCUSSION
Challenges in Inclusive Education

5.1 Introduction

Chapter Five explores the various challenges in the enactment of inclusive education. Some of these challenges are common across almost all developing countries, while others are specific to Uzbekistan. The challenges include the difficulties of being a parent substituting a teacher aide, inaccessible infrastructure, a lack of teaching qualifications and teachers' poor working conditions, the absence of inclusive education legislation, and attitudinal barriers.

5.1.1 Lack of individualised support: Parents substituting teacher aides

Specialists providing paraprofessional support to students with special needs may have several different titles. According to Giangreco and Doyle (2006), these vary from country to country:

> The personnel hired by a school to assist classroom teachers and special educators in their efforts to educate students with disabilities are known by a variety of names such as a teaching assistant, learning support assistant (LSA), teacher aide, paraprofessional, paraeducator, and special needs assistant (SNA). (p. 429)

In Uzbekistan, these professionals are called tutors or resource teachers. According to participants of this study, there are no tutors available for children with disabilities placed in regular classes in the country at the moment. It is one of the most significant issues for supporting these students in a mainstream setting. In many cases, parents of students function as tutors for their children. However, these participants found being a parent and tutor at the same time very exhausting.

> Imagine, from morning until evening I am at school with him. Then we come back from school, I need to do homework with him - this is very hard. From 8 am until 6 pm, I am a teacher for him. At the same time, I need to cook, wash clothes, clean up… Everything happens at the same time, I am very tired. My brain never rests[33]. (P5)

As most participants stated, the situation is worsened by the fact that children with disabilities are often placed in over-crowded classes. Both teachers and non-disabled students are often not informed about how to treat these students. In many cases, parents stay in a class not to help their children learn but to protect them from others:

> Nothing is ready to include them [autistic children] in regular classes. In spite of that, many of them still place their children into inclusive classes. I have visited these classes. Can you imagine him [an autistic child] amongst 30 other students? They all scream, touch him… Therefore, parents need to stay with their children in the classes. They wish they could leave but how?[34]. (P6)

For this reason, when this parent received an offer to place his son in an inclusive classroom, he declined it. He also added that when he was participating in a conference, organised by the EU project, he raised all these issues and offered some ideas for the inclusion of children with ASD but his suggestions were not taken into consideration. However, he tried to understand the situation, "You know I am not fighting to end inclusion because they need to start from somewhere. I understand these are just pilot projects"[35].

The parent continued to say that being a teacher for your own child was not appropriate because a child would never accept his/her parent as a teacher. He shared a story about another parent who was interested in being trained as a tutor for her son with autism. She expressed her interest when she participated in an inclusive education conference organised by Israeli specialists. An expert from the Israeli Delegation said, "I am absolutely against that. You are Mum for your child. You wash clothes for him and you wipe him after he goes to a toilet… He will never accept you as a teacher"[36].

For some parents it might be difficult to have a professional attitude towards their children. One of the parents commented that a mother-child relationship did not allow her to function as a tutor effectively. Even insignificant failures and misbehavior of her son made her very upset, "Therefore, if a qualified specialist was there, everything would be different. First, he/she would take a professional approach to my son. I, as Mum, overreact and it affects the child"[37] (P5).

The parents tried to support their children with disabilities as much as they could. Yet, these parents said they still needed a qualified tutor to ensure students with disabilities have access to learning and participation:

> Look, the second rule of inclusive education, you know it better than I do, is the availability of a resource teacher. We do not have them… When we talked to the Ministry of Finance, we asked to open vacancies for resource teachers at schools.

> But they do not do that… How can we enact inclusive education without a resource teacher? How? Do you know? I do not…[38]. (P22)

This lack of support resulted in many parents being exhausted and frustrated. To illustrate that a participant shared a story:

> I have a friend Aliya. A year ago, she was obsessed with an idea to place her son in an inclusive class. She did that. However, now she is so exhausted that ready to give up. This is such a heavy workload… If any of the students in a class says something loudly, she covers her son's ears. If her son starts screaming [when he has a meltdown], they need to leave a class. If teachers give homework and he cannot do it, she does it for him. If he cannot draw a picture, she draws it for him…[39]. (P6)

Other interview participants agreed that children with disabilities needed resource teachers when included in mainstream education. Participant 20, an NGO representative, who is actively involved in the EU Project "Inclusive Education for Children with Special Needs in Uzbekistan", stated that in Uzbekistan, due to limited financial resources schools could not afford to hire them. She emphasised that for this reason only children with mild disabilities had been involved in inclusive classrooms. She said, "Today we cannot talk about opening vacancies for resource teachers at schools, because we are still in the development stage but we will come to that"[40].

This participant noted that involving parents or other family members as tutors was taken as a temporary measure. According to this participant, some other options have also been considered to assist in teaching students with moderate disabilities in inclusive classrooms. For example, in Samarkand (one of the cities in Uzbekistan), volunteers assisted in the class. In Urgench (also the city in Uzbekistan), students of the Pedagogical University were involved in inclusive classrooms as tutors during their teaching practicum:

> So far, we [the Project "Inclusive Education for Children with Special Needs in Uzbekistan"] have these three options. If a teacher encounters difficulties while working with students with special needs, we offer these options and mechanisms to enact inclusion. Of course, they cannot replace a tutor; we will be working on that. When we are ready to include children with severe disabilities, we will need tutors. It will be very difficult without them. When we were in Austria, we saw a child who was legally blind and could not move. A tutor worked with him. However, we have to be prepared for that. Tutors have to get paid; they have to be school staff members. (P20)

According to Tews and Lupart (2008), the services provided by teacher aides include assisting a classroom teacher with delivering academic instructions, managing students' challenging behaviour, facilitating peer interaction, collecting and managing data about students, assisting with personal care, and others. It is widely assumed that the participation of these professionals in a learning process of students with disabilities greatly contributes to students' increased engagement in academic activities, improved behaviour, and more effective communication with peers (Webster et al., 2010). Yet, as noted by Sharma and Salend (2016), teacher aides are increasingly employed in many *developed* countries across the world. Very little is known about teacher aides and the substituting for teacher aides by parents/guardians in the context of developing countries.

The participants' experiences suggest that the usefulness of this practice is highly debatable. First, many parents are probably already overwhelmed by being a parent of a child with a disability. They almost certainly face many other challenges related to raising such a child. Heiman (2002), who researched the resilience and coping of parents of children with disabilities states, "Parents of children with disabilities experience greater stress and a larger number of caregiving challenges, such as more health problems, greater feelings of restriction, and higher levels of parental depression than parents of nondisabled children" (p. 160). They often feel powerlessness and disappointment and can experience social isolation (Risdal & Singer, 2004). It is apparent that in addition to all the issues parents of children with disabilities deal with, being a teacher aide for one's own child might be a heavy load.

Second, as stated above, the nature of teacher aides' work is complex and demanding. According to Rutherford (2011), it includes many different functions: "academic, social, behavioral, health-related, and personal support for students in one-to-one or small group contexts" (p. 96). It is fairly clear that the majority of parents may not know how to provide this range of functions unless they were trained for that. In some cases, schools may consider the involvement of parents of students with disabilities as "natural support" (Giangreco & Doyle, 2002, p. 6). Given the expertise these parents have, they may provide invaluable assistance to classroom teachers. However, Giangreco and Doyle (2002) note that in such instances, parents are viewed as "*alternatives* to paraprofessional proximity" (p. 6). Unlike the participants in this study, they cooperate with an existing team of specialists and function as volunteers on a case-by-case basis.

Teachers working in inclusive classrooms also experience challenges and often feel overwhelmed by new responsibilities (Bourke, 2008). They need support in the class and ideally it should be provided “by employing more paraprofessionals (teacher aides) to help with the implementation of compensatory intervention strategies, and to help students with disabilities to integrate into school environments” (p. 19). Similarly, Grebennikova (2015) maintains that in an inclusive classroom a child with special needs has to be accompanied and supported by a teacher aide. A teacher aide acts as a conductor for a child, who supports him/her with studying, facilitates socialisation, and at the same time controls his/her health condition.

However, when inexperienced and exhausted parents function as teacher aides, teachers often do not receive help in terms of supporting students’ learning. Based on participants’ examples, some of them do perform effectively in spite of limited or no support but they still need professional help from teacher aides. They often cannot even leave a class for a few minutes when there is no another professional who could provide the necessary cover in their absence. One of the interview participants shared a story that when a teacher left the class there was a fight between students and a child with a disability was hurt. The parent, who was in the class at that moment, was not able to control the situation and then blamed the teacher saying that she did not have a right to leave her class. Another parent said that she did not really help her son learn in a class. She was more focused on protecting him from his classmates who misbehaved. These examples help to get a better understanding of possible problems arising in a class where parents are substituting teacher aides.

One thing comes clearly from the participants’ responses: neither students nor teachers benefit from engaging parents in tutoring. With no paraprofessional support, students with disabilities are less likely to succeed in their learning. According to the Alberta Teachers' Association (ATA) (2000), “The skills and expertise that educational assistants bring to their jobs often enable students who would not otherwise be able to attend school to do so” (p. 1). With the further advancement of inclusive education, the demand for paraprofessional support for students with special needs in general classes will be increasing. This is especially the case for children with moderate and severe disabilities who are highly dependent on the support of a teacher aide (Downing, Ryndak, & Clark, 2000).

Many countries have already recognised that a different service needs to be provided to students with disabilities to help them succeed in inclusive schools. For example, Russia has attempted to introduce additional support for students with special needs, although it is also at the beginning of the inclusive education reforms (Grebennikova, 2015). In Uzbekistan, the enactors of inclusive education discussed the necessity of individual paraprofessional support for students with disabilities in general schools with government officials. Recently, the Cabinet of Ministers has decided to introduce a teacher aide position with a salary rate equal to 0.75 percent of that of a regular classroom teacher (Governmental portal of the Republic of Uzbekistan, 2019). Schools and the current enactors believe that with the development of inclusion, teacher aides will be introduced as official school personnel soon. This process however may take time and for many parents functioning as teacher aides now the idea of having adequate support for their children in mainstream schools is slowly fading away.

5.1.2 Inadequate provision of infrastructure

Inadequate school infrastructure is another serious challenge impeding inclusion in Uzbekistan. Accessibility of a physical environment is often a decisive factor for children with mobility impairments and their families when they choose a school. The following is a story shared by one participant. The mother and her daughter with muscular dystrophy spent much time trying to find an educational institution with access to the main entrance:

> We were going from one lyceum to another to see whether there were stairs at the entrance or not… It was very hard for her to go upstairs. She wanted to study at the Lyceum of Foreign Languages. However, when we came there, she saw the stairs and said, ‘No’… ”[42]. (P8)

Finally, they managed to find the lyceum with no stairs but then another problem occurred: some classes were conducted on the 2nd, 3rd, and 4th floors. After a week of stair climbing, the girl felt unwell and could not come to the lyceum. Her mother approached the principal of the lyceum and asked her to organise classes for her daughter’s class on the first floor. However, the principal refused; she said to the parent to take her daughter and go to the neighbouring college for children with intellectual disabilities. The girl did not have an intellectual disability; on the contrary, she had a high level of intelligence. Fortunately, that parent knew her rights because she was leading a DPO and helped other people with disabilities solve similar problems.

Another participant added that even pilot inclusive education schools did not always have a physically accessible environment. Students with mobility impairments at these schools encountered many difficulties when moving:

> It is very complicated to include children with cerebral palsy in an elementary school because there is no proper infrastructure. There are ramps in some schools but classes may be conducted on the 2nd and 3rd floors. At one of our pilot schools, first-year students had classes on the 2nd floor. How can he [the child with cerebral palsy] go upstairs? Then his parent took him out of that school… The child could not go upstairs. So, his father took him upstairs and then downstairs after classes. He had enough intellectual capacities to study there but he could not get to the 2nd floor. We still encounter problems because there is no proper infrastructure[43]. (P21)

When I asked the enactor of the current Inclusive Education Project to comment on that, she said that building fundamental facilities at regular schools was one of the country's highest priorities, "Nowadays, by order of the President, all preschool educational institutions are being reconstructed. Schools will also be reconstructed; they have to be accessible for all students with special needs regardless of their disabilities"[44] (P20). She contended that after practical changes took place at schools, more children with disabilities would be included there.

Some participants were concerned that children are often unable to travel over long distances to schools or colleges. Girls with disabilities living in remote areas, in particular, struggle to get access to education:

> Young women are isolated. Girls who finished this school stay at home. They have nowhere further to go. There is a specialised college… again specialised… it is located out of the city. It provides good conditions: children can learn there how to sew, how to make shoes. Nevertheless, parents do not send girls to study there. First, they need to be taken there, and if they do not stay there for a night, they need to be brought back. If there is a regular college nearby, children are not admitted there because they have certificates of specialised schools. It is written there [that a child finished a specialised school][45]. (P14)

Participant 7 also said that many children with disabilities, especially from remote areas, cannot commute to schools. She offered two reasons for this. First, public transport is not affordable. The participant explained that the price for commuting to and from school is equal to the price for two loaves of bread, and needy families would rather buy bread than send a child to school. Families from remote areas without children with disabilities also face financial issues but the situation for families with children with disabilities is more severe due to their extra disability-related expenses. Second, public transport is not accessible for many individuals with mobility impairments. Buses and vans often do not have wheelchair ramps fitted to allow access for wheelchair users:

> Recently, the Decree prohibiting buying buses not adjusted [to wheelchairs] has been adopted. But again, Mercedes buses – yes, they are adjusted. Yesterday I saw a woman who had got on that bus with a stroller. However, locally produced buses are not adjusted: you yourself will not be able to get on it, let alone with a stroller[46]. (P7)

According to the participants, the problem of inaccessibility goes beyond schools and transportation. The infrastructure in the capital city (Tashkent) also does not allow people with mobility impairments to access places they need:

> These ramps, for example. They are a weapon for suicide – they were built under 45 degrees! How could the government build such ramps?! It is better not to build them at all than do it like this[47]. (P7)

When asked about why the government neglected a wheelchair ramp building process, she responded she did not know because there were specific accessibility standards in place and ramps had to be built accordingly.

As we seen in the examples above, children with limited mobility often face physical barriers. As stated in Chapter One, Article 24 of the CRPD mentions explicitly the provision of reasonable accommodation to students with disabilities (Convention on the Rights of Persons with Disabilities, 2006). Some scholars also suggest that schools should create an environment intended to ensure equality of opportunities. For instance, Yasin, Toran, Tahar, and Bari (2010) note that to make children with disabilities feel comfortable and safe at school, barrier-free facilities, which is one of the basic conditions, should be provided. Similarly, Madan and Sharma (2013) point out that general schools have to be adequately prepared in many aspects before they accept students with special needs and infrastructure is one of them. The researchers state, “Based on the type of disabilities the school is likely to admit, the school must make some basic infrastructural changes. Building of ramps, railings, disability friendly toilets, and magnified sign boards may be some of these” (p. 12).

However, the current school infrastructure in Uzbekistan seems not to comply with these requirements. Moreover, attitudinal barriers often contribute to creating physical barriers. It corroborates the idea of Sahu and Sahu (2015) who state that physical or other barriers are not because of certain conditions of a person but because of attitudes held by other people in relation to that person. Attitudinal barriers are rooted in people's stereotypes, fears, and misconceptions and are the most difficult to change (Ali, Mustapha, & Jelas, 2006). Sahu and Sahu (2015) note, "Negative attitudes often result in denying human and civil rights afforded to other members of their community" (p. 2). They also state that such an attitude towards people with disabilities causes illegal discrimination. It was exactly the situation cited above, where the lyceum principal refused to provide appropriate modifications and conditions to a student with a mobility impairment.

Inaccessible environments contribute to even greater isolation of children with disabilities. According to a report of the Uzbek Society of Disabled People (2014), the majority of educational institutions in Uzbekistan, including colleges and universities, are not accessible. There are no ramps, lifts, or accessible toilets. These conditions make effective education for many children and young people with disabilities impossible. Students who enter regular educational institutions often drop out of their schools due to inaccessible physical infrastructure. The participants of this research also mentioned that such cases occurred very often. The report of the Uzbek Society of Disabled People (2014) concludes that current conditions contradict the Uzbek legislation that requires both government and private organisations to ensure that their buildings are physically accessible for people with mobility impairments. This is an example of unenforced laws that practically have no effect on the lives of people with disabilities.

As mentioned above, in Uzbekistan even specialised institutions intended for children with mobility impairments have no facilities for them. This is what Katsui (2005) stated, "When I visited one boarding school meant for physically disabled children, no children in a wheelchair were studying there. Teachers explained this is due to the lack of the facility" (p. 72). After these children leave schools, they face similar problems at the post-secondary level too. The Uzbek Society of Disabled People (2014) noted that there is not even any higher education institution in the country that could be fully equipped to meet the needs of people with disabilities.

As the participants stated, the situation is worsened by inaccessible city infrastructure. The current infrastructure in the capital city was not adjusted to wheelchair users and visually impaired people because accessibility standards had not been followed when it was being built. Pivik (2010), when discussing inclusive environmental assessment, states that accessibility standards are not based on research and, therefore, very rarely address the needs of people with disabilities. Similarly, Venter et al. (2002) note that even though many countries have developed national accessibility standards, it is not clear how precisely they are followed when infrastructure is developed. It would seem that not only accessibility standards are often not followed, but laws in general. According to the United States Department of State (2016), in Uzbekistan, organisations can be fined if their buildings do not comply with accessibility requirements and during the year there were approximately 2,500 such cases.

Transportation is another significant issue for persons with mobility impairments. In 2014, in Tashkent, there were only four buses with low floors designed for people who used wheelchairs, while there were 46,617 people with limited mobility registered there (Equal Rights Trust, 2016). It was obvious that the likelihood of getting on an accessible bus was extremely low. There were some attempts to change the situation. For instance, in 2015 the National Human Rights Centre and other international organisations working in Uzbekistan proposed a number of measures to improve the level of accessibility of transport for people with mobility impairments. Two of these measures were to develop a draft Resolution of the Cabinet of Ministers on the accessible environment and to establish a Public Council within the Ministry of Labour and Social Protection to monitor the provision of the Law “On social protection of people with disabilities” (United Nations Development Programme (UNDP), 2015). Little is known whether these measures were taken and what effects they had. According to the research participants, public transportation in Uzbekistan is still not accessible.

Appropriate transportation to and from school is necessary to ensure that children with mobility impairments can fully participate in education. However, millions of children with disabilities in developing countries cannot access schools because of the lack of adequate transportation (Access Exchange International - San Francisco, 2017). Roberts and Babinard (2004) note that while many parents find transportation inaccessible and unaffordable, governments often do not consider a barrier-free transportation system a priority. This results in financial resources not being allocated to make transportation more accessible and affordable for people with mobility impairments.

5.1.3 Factors hindering the success of teachers in inclusive classrooms

Based on the participants' responses, teachers working in inclusive classrooms may not always have the essential knowledge to work effectively with students with disabilities. Many participants were concerned about the way children were taught and treated in general schools. One of them, who had considerable experience in working with educational institutions, stated, "Teachers do not know what to do with these children. They are afraid of them"[48] (P8).

When I asked Participant 20 to comment on the statement made by Participant 8, she said that all teachers in pilot schools had been trained before students with disabilities joined their classes. Moreover, pilot resource centres had been established. The main purpose of these centres was to provide methodological and technical support to teachers of regular schools working with students with disabilities. However, the specialist for the Republican Centre for Social Adaptation of Children (RCSAC) said they understood parents' concerns because many trained teachers had left their jobs. New teachers came as replacements, but they also needed to be trained. To solve this problem the Centre was organising more training sessions throughout a year.

The participants complained that the problem went beyond teachers: specialists of support services at schools often also did not know how to work with children with disabilities:

> There are a defectologist and a psychologist at school. I approached the defectologist last year but it was a waste of time. She said, "This is such a complicated case. He cannot do this and that… However, this is her profession. How can defectologists here [at the RCSAC] work with him? How can they make him interested?[49]. (P5)

The parent participants continued to say that children who did not go to *pilot* schools/kindergartens faced even more serious issues. Stories of these children were very similar: they did not participate in the learning process alongside their non-disabled peers. One of the parents said that her child was taken out of the classroom in a kindergarten while other children were studying:

> He was isolated; he was not allowed to be with others. If it was winter, he was kept in the bedroom. If it was spring or summer, he was sent for a walk. While all the children were studying, he was walking outside. It irritated him, he felt offended. Therefore, when he came back, he could spoil the artworks of other children. Then, their parents complained to the kindergarten principal about him[50]. (P4)

The kindergarten principal phoned this parent and asked her to keep the child at home, at least for some time until parents of other children calmed down. After this incident, the parent decided to transfer her child to another kindergarten. Another participant stated such situations were common:

> Sometimes parents put much effort to place a child into a regular kindergarten. This is a big achievement for them. Then, parents [of typically developing children] are informed about a child with a disability joining their children and they give the principal an ultimatum: either you will take this child out the group or we all will leave this kindergarten. The principal has no option other than to remove the child and say, "You do not fit us". You know it is so stressful for both a child and his Mum[51]. (P2)

Parent 4 added, "I wish teachers treated him with understanding and loyalty. I wish teachers wanted to teach children but not just to make money"[52]. She also shared her concerns about the absence of Individualised Education Plans (IEPs), "I would like IEPs to be introduced and our teachers to understand that every child develops individually. Even if children have the same diagnosis, their needs and levels of development are different"[53].

Similarly, another participant started experiencing problems from her daughter's early years. First, the participant enrolled her child in a specialised kindergarten. After some time, she was recommended a regular pre-school because the level of her daughter's development was high in comparison to that of other children. However, the principal of a regular kindergarten did not want to admit the child, "It was hard because her diagnosis was mentioned everywhere [in all documents] and it scared everyone. Honestly, we were begging the principal to try and see how our girl would be doing amongst typical children"[54] (P1).

After that kindergarten, the girl spent five years in a specialised school but according to her mother, she did not gain any knowledge there, "She did not even know the alphabet"[55]. Later, the parent chose a private regular school, hoping that conditions there would be more appropriate than at a public school. However, she was very disappointed, "Teachers do not give her homework, they do not pay attention to her, they do not work with her. She simply does not exist"[56]. The participant complained that the girl had lost her interest to study.

Another parent, whose son is currently in an inclusive class, shared her experience of when he was in a kindergarten:

> Teachers need to be trained that these children are equal to others. They have the same rights. I had many conflicts when he was in a kindergarten. I was told, "What do you expect from him? He will not develop further[57]. (P5)

One of the questionnaire respondents also emphasised the importance of training for educators:

> It is necessary to empower general teachers by training and by giving them a responsibility to lead and promote inclusion in regular schools and challenge segregated settings to promote a social model of inclusion in society. We need to change the attitudes of professionals and society towards children with disabilities.

Most teacher participants viewed their lack of knowledge related to teaching students with disabilities as a major barrier to the enactment of inclusive programmes in their schools. Teachers also expressed their concerns about inadequate working conditions that influenced their performance and motivation. By inadequate conditions, they meant a high workload, overcrowded classes, and low salaries. They stated that under those conditions, it was hardly possible to meet even the basic requirements of inclusion.

In reporting the participants' views on the subject of factors hindering the teachers' success, two themes emerged. The first of these related to concerns about a lack of skilled and qualified teachers. The second related to their working conditions. As the participants mentioned, teachers did not want to involve children with disabilities in a learning process because they did not know how to do that. Many studies show that the ability to teach special needs students and a willingness to do it are interrelated (Agbenyega, 2007; Ali et al., 2006; Avramidis, Bayliss, & Burden, 2000; Gal, Schreur, & Engel-Yeger, 2010; MacFarlane & Woolfson, 2013; Savolainen, Engelbrecht, Nel, & Malinen, 2012). According to these authors, many teachers often have negative attitudes towards inclusive schooling when they have a lack of knowledge about children with disabilities and limited experience in working with them.

However, teachers' attitudes have nothing to do with ideology; they are based on practical concerns about how educational inclusion will work in real life (Savolainen et al., 2012). Practical concerns include teachers' attitudes towards inclusive education and their feelings of self-efficacy in the process of its enactment. Teachers may change their attitudes if they gain professional knowledge to teach students with disabilities effectively. By professional knowledge, Shah, Das, Desai, and Tiwari (2016) mainly mean “knowledge of disabling conditions, procedures required in developing and implementing individualised education programs (IEPs), and government policies and programmes for children with disabilities” (p. 36). The knowledge of inclusive pedagogy should be also added to this list as it is crucial to enhance teaching while working with learners whose abilities and skills vary significantly (Florian & Linklater, 2010). According to Spratt and Florian (2015), “Inclusive pedagogy is a pedagogical approach that responds to learner diversity in ways that avoid the marginalization of some learners in the community of the classroom” (p. 90). In other words, inclusive pedagogy creates an environment where a child’s uniqueness is supported and fostered, but at the same time avoids the stigma associated with a child’s difference.

The success of inclusive education practices at schools depends largely on pre-service teacher preparation programmes (Lancaster & Bain, 2010; Sharma, Forlin, Loreman, & Earle, 2006; Taylor & Ringlaben, 2012). However, in Uzbekistan, current pre-service teacher programmes in teacher training institutions do not include even the basics of inclusive education. Consequently, pre-service teachers have no or little understanding of inclusive education practices and disability issues. According to Participant 21, an enactor of the Inclusive Education Project, recently, the RCSAC has started conducting a survey at Pedagogical Higher Education Institutions. The purpose of a survey was to explore pre-service teachers’ attitudes towards inclusive education. The Centre has completed the first survey at Djizakh State Pedagogical Institute that was distributed amongst 141 teacher candidates. The survey revealed that 82 percent of them were not familiar with the concept of inclusive education and approximately 62 percent of those who were familiar with this concept, were against the idea of inclusion. Currently, the RCSAC is negotiating with the Ministry of Public Education to incorporate a 24-hour inclusion program into the teacher-training curriculum. The Ministry generally appears to be reluctant to make changes in the existing study programme. Yet, there is a hope the programme will be reconsidered from the perspective of inclusion, given a marked increase of the importance of inclusive education worldwide.

Professional development courses to raise in-service teachers’ knowledge of the concept of inclusion are no less important (Pijl, 2010; Savolainen et al., 2012). However, as indicated in Chapter Two, in many former Soviet Union countries training courses for in-service teachers are still mainly administered by Institutes of Defectology, which have not made “appropriate paradigmatic changes towards an inclusive philosophy” (UNICEF, 2011, p. 12). The Open Society Institute (2002) also notes that the content of re-training courses has not changed significantly since the Soviet times. In many cases, they do not equip teachers with student-centred and interactive teaching methods, curriculum planning, and assessment strategies.

In Uzbekistan, in-service teachers working with students with disabilities have to attend special sessions once every five years (in total 40 hours) to improve their professional skills (Education Sector Plan for 2013-2017, 2013). Providing all teachers with professional development opportunities even once every five years is not realistic for the government. According to the Open Society Institute (2002), in Uzbekistan, “the capacity of teacher training institutions allows enrolment of only 60-65% of teachers every five years” (p. 18). Another problem is that teachers from remote rural areas have fewer chances for professional training than their peers from urban areas do. In-service training institutions are mainly located in the capital city and not convenient and affordable for rural teachers due to travel and accommodation costs. To address this situation, the Asian Development Bank (ADB) offered to decentralise the delivery of teacher training to increase the number of rural teachers attending training courses (Asian Development Bank (ADB), 2010).

In the last few years, the situation does not seem to have changed much. At the end of 2019, the Ministry of Public Education conducted teachers’ assessment competence amongst 12,261 general school teachers and principals in one of the regions in Uzbekistan. The assessment revealed that professional knowledge of 66 percent of them was unsatisfactory (Gazeta.uz, 2019). There is no information on assessment criteria used for teachers’ evaluation. Yet, these results do not seem surprising given the overall situation with the quality of teacher training and retraining programmes mentioned by research participants and representatives from international development organisations.

As noted by the participants, international donors that carried out inclusive education projects in Uzbekistan organised a number of short-term courses for teachers of pilot inclusive schools. Participant 20 stated that recently, the RCSAC had organised teacher-training courses within the framework of the Inclusive Education Project. The RCSAC invited not only school and kindergarten teachers but also specialists of the Department of Public Education, lecturers of the Pedagogical University, and specialists of the Institute of Improvement of Teachers' Qualification. In addition, the RCSAC worked closely with specialists of the Diagnostic Centre. In total, in 2017, the Centre trained around 75 educators and 25 medical professionals. According to this participant, trainees primarily learned about the principles of inclusive education, classroom methodologies to teach students with special needs in an inclusive setting, and non-discriminatory language. Developing IEPs to support students with disabilities was also given considerable attention during the courses.

Based on this information and earlier statements, it seems that training courses for in-service teachers remain largely dependent on donor organisations. Although donors contribute to capacity building, teacher-training programmes are often not sustainable. There may not be the long-term sustainability of training courses due to the high rate of teacher attrition. As maintained by Participant 20, many trained teachers, who were expected to continue teaching and to share their experiences with other colleagues, left their profession. It could be argued that inadequate working conditions contribute to teachers' apparent reluctance to teach students with disabilities and their high turnover rate.

Besides professional development opportunities, teachers need to be provided with relevant conditions, such as small-size classrooms (Pedder, 2006) and financial incentives (Tehseen & Hadi, 2015). There are many examples in research where a lack of these components affected teachers' performance. For instance, the study of Talmor, Reiter, and Feigin (2005) identified that large class size is a major environmental factor contributing to teacher burnout. These researchers state that in Israel, there are usually up to 40 students in regular classes, and the presence of one or more students with special needs often leads to teacher's emotional and physical exhaustion. The study also revealed that those teachers who had high expectations for inclusion experienced a greater degree of exhaustion than those who had fewer expectations.

According to Pedder (2006), in large-sized classes, teachers do not have the flexibility to use a variety of teaching activities, for example, monitoring and giving feedback. It is also much more difficult to observe and control students' behaviour in overcrowded classes. Zarghami and Schnellert (2004) note that small classes significantly affect students' academic achievements as well as their integration, especially in the early years.

These authors refer to McCrea (1996), who recommends the maximum student-teacher ratio 15:1. This ratio would seem very desirable; however, it may be unrealistic for many countries, especially developing ones. In Uzbekistan, a situation with class sizes is far from this. One of the participants of this study stated that with the current high number of students in a class, schools could only try to come up with a 25:1 ratio. Zarghami and Schnellert (2004) emphasise that class size reduction cannot be effective by itself without qualified teachers. To improve the academic achievement of students with disabilities, class size reduction policies should be combined with hiring qualified school personnel.

Meagre salaries are an additional stressor for teachers (Engelbrecht, Oswald, Swart, & Eloff, 2003). Narolskaya (2013) notes that in Uzbekistan, most teachers who work with students with disabilities appear not to be motivated and would like to have less pressure from school administration and higher salaries. This is in complete agreement with what participants of this study have stated. To address this issue, the Uzbek government has attempted to increase teachers' salaries several times. Between 2004 and 2006, there was an increase of approximately 185 percent. However, teachers' wages are still significantly below the average wage by 30 to 47 percent (Steiner-Khamsi, Harris-Van Keuren, Silova, & Chachkhiani, 2008). Barmby (2006) points out that low remuneration strongly discourages professionals and affects the quality of their work.

5.1.4 The absence of enabling legislation on inclusive education and a lack of law enforcement mechanisms

Several participants made reference to the absence of inclusive education legislation in the country to facilitate the development of a more inclusive educational system. This statement of one of the participants reflects the views of many others:

> The official document, registered at the Ministry of Justice, does not exist… You may ask, "What about the Law on Education?" but it does not have the word "inclusion" in it. The Law on Social Protection of People with Disabilities also does not have it. By the way, that Law is not compliant with the UN Convention on the Rights of Persons with Disabilities[58]. (P22)

Four out of six questionnaire respondents also mentioned that inclusive education had to be brought to the legislative level for it to be successfully enacted. Some participants said no law meant no binding obligation for school officials to include learners with special needs. They believed that if there had been appropriate legislation, the government would have been more committed to supporting inclusion. However, participant 20, an enactor of the Inclusive Education Project, stated that the existing national legislation was enough to move towards inclusion:

> As a lawyer, I can say that the current legislative framework is good enough. It allows us to enact inclusive education practices. There are no legal obstacles to include students with mild special needs in regular schools[59]. (P20)

She provided a list of the normative legal acts for the enactment of inclusive education, recently developed by the Ministry of Public Education and Ministry of Health. The list includes the:

> - Resolution of the Ministries of Public Education, Health, Labour and Social Protection of Population No. 2519 dated 24.10.2013 'On the approval of the provision on the Psychological-Medical and Pedagogical Committee (PMPC) for referring children to specialised institutions (schools, boarding schools)'. The document also mentions the PMPC gives recommendations on a transfer of a child from one specialised institution to another specialised institution or a general educational institution for education in inclusive settings (Chapter II, para 7).
>
> - Order of the Minister of Public Education No. 2685 dated 17.06.2015 'On the approval of the regulations to transfer students with physical or intellectual disabilities from one specialised educational institution to another specialised educational institution or a general educational institution for teaching them in an inclusive (integrated) setting (para. 5 chapter Vl)'. It is indicated in the parentheses: mental retardation, mild intellectual disabilities, hearing impairments, visual impairments, cerebral palsy, etc.
>
> - Resolution of the Ministries of Public Education and Health No. 2691 dated 30.06.2015 'On the approval of the regulations on organising home-based education for children with physical or intellectual disabilities and those who need a long-term treatment', which also includes the regulations for organising inclusive education (Chapter IV, para 30).
>
> - According to Item 266 of the State Program- 2017 'Year of Dialogue with the People and Human Interests', the Draft Resolution on organising inclusive education in the Republic of Uzbekistan has been developed.

However, the majority of parents and some NGO representatives believed that even though there was a legislative foundation for supporting education for children with disabilities, it was not enforced. They explained that a lack of law enforcement had serious implications for education as well as the welfare of people with disabilities. For example, one of the participants, who was a parent and an NGO leader at the same time, mentioned that there were two programmes for people with disabilities officially existing: for their rehabilitation and individual patronage. Yet, neither of these had been enforced:

> I think if there were state mechanisms to enact the programme of individual rehabilitation and there were people responsible for it, they would do what they were supposed to do and look after their wards… The same problem was with the programme of individual patronage. It does not really bring benefits to people with disabilities and seems to be very vague… For example, my child is a young man. He received everything possible from the family. He may have better social skills than a typically developing child does. However, he is a citizen, he is an adult, and he has rights to certain guarantees from the government[60]. (P7)

In addition, some interviewees shared their thoughts about the Decree of the President on Support of Persons with Disabilities, which had been issued by the President on December 1, 2017. The decree outlines several spheres to improve the state support system for people with disabilities and inclusive education is one of them. Many participants believed that the Decree would help to make significant changes for people with disabilities. For instance, Participant 20 stated that the Decree would support the enactment of inclusive education in the country. Other participants (mainly parents and NGO and DPO leaders) said that they had read it but they did not think it could be beneficial for their children or for their organisations. They did not appear to have high expectations for the recently issued Decree, arguably because the government had enacted certain laws and regulations to protect people with disabilities in the past but none of them seemed to be effective. When I asked Participant 23, a government official, how he would respond to these concerns, he said there might be many different factors affecting the enactment and enforcement of laws, such as the availability of financial and human resources. One of the NGO representatives also pointed out that laws were ineffective because there were no government officials assigned to monitor law enforcement.

According to Eleweke (1998), mandatory legislation related to inclusive education is essential for its effective enactment. It is expected to provide guidelines for services for children with disabilities, timelines, consequences for non-compliance, accountability, financing, and evaluation and monitoring of a development process. This supports the participants' views who stated that legislation on inclusive education was necessary because it would call on the government to commit to its enactment. Other participants, currently carrying out the Inclusive Education Project, argued there was no need for specific legislation to develop inclusion - the existing normative foundation was enough for that. Yet, the legal-normative acts outlined above seem to be vague. ‘An inclusive setting’ is mentioned there but these acts do not seem to be oriented towards inclusive education. In addition to inclusive schooling, the documents consider other educational settings for children with disabilities – specialised schools, boarding schools, and home-based education. As long as these alternatives exist, inclusion is unlikely to happen in practice. Therefore, in Uzbekistan and other countries, where the majority of children with disabilities receive education in segregated settings, “consideration should be given to the introduction of specific legislation backed up by policies and services to underpin the ending of institutional care” (UNICEF, 2014c).

Previously, the Uzbek government has made certain attempts to revise the national normative-legislative base from the perspective of inclusion. In the early 2000s, the following legislative proposals were drafted: a Bill on alterations and amends to the Uzbek Disability Convention; a Normative document on acceptance of children with disabilities in colleges and lyceums; an Act on inclusive education; and a Law on specialised educational foundations aimed at children with disabilities. Although some of these documents were adopted on their first reading (Akhunova, 2007), none of them have been promulgated.

Later on, the government introduced three Articles into the Law of the Republic of Uzbekistan "About Guarantees of the Rights of the Child" (2008) (Articles 24, 25 and 29), added an Article “On inclusive education” to the draft of the revision to the law ‘On Education’, and approved the regulation “About continuous inclusive education for children and teenagers with special needs”. In 2011, the Government adopted the Resolution of the Cabinet of Ministers “About regulatory-legislative acts on state special education institutions for children with limited abilities” and the Annex to the Resolution “Regulation on state special education institutions for children with deviations of physical or psychiatric development”. These documents include regulations on transferring students with special needs from specialised institutions to mainstream ones, there may have not been many such cases. Yet, based on the participants’ responses and reports of international organisations, there have not been many such cases.

Currently, high expectations are placed upon the new Law ‘On Education’, which the Uzbek government is planning to enact soon (Education Sector Plan (ESP) of Uzbekistan 2019-2023, 2019). It is promised that the pending Law will be more focused on education for children with special needs. The Law will define inclusive education in compliance with international human rights standards. First, education will be considered inclusive if it does not discriminate children by their gender, abilities, ethnicity, social status, or another basis. Second, inclusive education will specifically address the needs of children with physical and mental disabilities. However, similar to the acts mentioned by participants, the new Law will still promote and protect "a right for children to be educated at home should they not be able to attend regular or specialised schools" and allow medical practitioners to recommend specialised schools, "based on the interests of the child" (Education Sector Plan (ESP) of Uzbekistan 2019-2023, 2019, p. 52). Legislations that seemingly protect the right of children to study in a mainstream setting are not effective. Taking into account the prevalence of the medical model of disability in Uzbekistan, the way the law is formulated may be very convenient for medical commissions and schools to justify their decisions for a segregated environment.

It seems apparent that the Law 'On Education' cannot replace legislation on inclusive education. Although the new law will support the idea of inclusion in general, no policies will specifically commit the government to developing inclusive education and ensuring the provision of relevant services, flexible curriculum, individualised support, and necessary means of communication for children with disabilities as stated in Article 24 of the CRPD. Mutepfa, Mpofu, and Chataika (2007) argue that "In the absence of any mandatory order stipulating the services to be provided, and by whom, how, when, and where, there could be no meaningful educational services for learners with disabilities" (p. 343). Thus, there is still a pressing need for a separate legal provision to ensure the meaningful realisation of inclusive education.

Other former Soviet Central Asian states should also have appropriate legislation and explicit policies in place to ensure that children with disabilities are included in mainstream institutions. The Open Society Institute (2009) provides two examples of issues related to inclusive education legislation in Central Asia. In Tajikistan, the concept of inclusive education was a part of the National Poverty Reduction Plan. There was no specific legislation stating that children with special needs had to be included in regular schools. As a result, there were no funds allocated for the enactment of inclusive education and there was no control of the enactment process. Another example is Kazakhstan. Even though the country has signed the CRPD, which provides a framework to include children with disabilities in regular schools and developed legislation, the local and national legislations were not always consistent. This resulted in a poor financial provision for inclusive education initiatives (Open Society Institute, 2009).

Based on the participants' responses, another serious obstacle to successful inclusion is the absence of proper law enforcement mechanisms. There are some examples in the history of disability where legislation made little difference for people with disabilities due to a lack of enforcement mechanisms. One of these is the Disability Discrimination Act (DDA) in Great Britain. According to Barnes, Mercer, and Shakespeare (1999), the DDA was not effective and one of the reasons is that it was not monitored "the Act is toothless because there is no enforcement mechanism whatsoever. This means that disabled individuals must challenge unfair discrimination themselves" (p. 90). Another example is the Individuals with Disabilities Education Act (IDEA) in the United States. Even though more than seven million students with disabilities across the country received special education services thanks to the IDEA, the Act was not enforced effectively enough at both federal and state levels (Wakelin, 2008). It had a particular impact on minority students from low-income communities. Taking into account that in some districts, African-American males represented 41 percent of special education students who experienced "educational disenfranchisement" (Wakelin, 2008, p. 264), we can see the extent of the problem caused by a lack of enforcement. A similar situation appears to occur in Uzbekistan. Regardless of a country's level of development, the consequences of the law enforcement problems are the same: people with disabilities are not provided with services intended to support them.

All these examples indicate that the enactment of inclusive education is less likely to be successful without appropriate mandatory legislation and adequate mechanisms for its enforcement. Of course, the success of inclusive education practices does not depend on legislation alone. There are many other requirements for that. However, legislation consistent with the human rights standards is an important prerequisite that forms the basis for meaningful inclusion. As Baquer and Sharma (1997) state, "Although legislation cannot alone radically change the fabric of a society in a short span of time, it can nevertheless, increase accessibility of the disabled to education and employment" (p. 274). Finally and importantly, legislation and policies on inclusive education foster changes in societal attitudes towards children with disabilities. Negative attitudes have a profound impact on their access to education. “They can lead parents and teachers to believe that children with disabilities are not capable of learning” (UNICEF, 2014c, p. 17). Therefore, laws and policies encourage society to start thinking about the idea of including children with disabilities in regular schools and raise questions about the beliefs and practices related to disability prevailing in society.

5.1.5 Attitudinal barriers

According to the majority of participants, people with disabilities face multiple barriers every day but of these, attitudinal barriers are the most pervasive. Much has been written and discussed about the serious issues children with disabilities experience as a result of societal attitudes. This section is focused on the stigma coming from family members and potential employers.

A common view amongst the interviewees was that inclusion should start within families, but many families still tried to hide their children born with disabilities to avoid social stigma. One of the participants, who volunteered for the Society of the Blind, stated that in the Tashkent region alone, 20 unregistered children with visual loss had been identified recently, “They are isolated. No one knows about them: what their names are, who they are. They do not even have birth certificates and passports. You know there are many such places in rural areas”[61] (P22). The participant added that the Society of the Blind had searched children with visual impairments only. The number of hidden children would have been much higher if they had expanded their search and included children with other disabilities.

Participants 12 and 13 had a similar view. They stated that many parents felt ashamed to have such children and kept them at home. Parents often did not have high expectations for them and, therefore, did not want to invest in their education and life in general. Participant 11 shared her story. A new student was assigned to her class. His parents kept the boy at home until he was 16 and then sent him to a specialised school but the participant said the school administration did not know how to work with him. The student was placed in a class according to his age, but he was not able to catch up to his classmates academically or socially. One of the participants noted that many families tried to hide their little children with disabilities but that they could not do it for their children’s entire lives:

> Many families are still hiding their children. However, thanks to God, the situation has been changing from year to year… Well, they can hide him while he is little but then when he is in grades 2, 3, 4, they need to come out. There are some parents like that, but this is our mentality…[62]. (P6)

He continued:

> Even our relatives avoid us. Sometimes they invite my parents for family events. If they invite me, they always ask not to take my son to the event. I would not take him anyway, but they remind me, and it is very painful. They often say, "He is mentally retarded. Why do you keep him at home? He is a torture for everyone"[63]. (P6)

Other participants also experienced pressure from close relatives after they had given birth to children with Down syndrome:

> The first six months I was thinking, "Why?! What did I do wrong in my life?" My husband's relatives said to me, "There must be something", although I was a good daughter-in-law and tried to please my husband's family[64]. (P2)
>
> My mother-in-law did not want a child with a disability. My husband did not know what to do. He did not know whom to support - his Mum or me. It was a very difficult time… It is our mentality: Uzbek families do not accept children with disabilities. My mother-in-law asked, "How did it happen? How could my healthy son have an unhealthy baby?". That was a problem for her and she told me to exchange the child [for a healthy one]… I was going from one maternity hospital to another, trying to find an abandoned girl. She had to look like us… I spent four months on that… Honestly, I was shocked, and I did not realise what I was doing. I did not realise how I could abandon my own child and adopt another one… I did what my mother-in-law told me to do because I wanted to keep our family… We found another child and went through the adoption process. Then we brought the child home and that moment I realised that I would not be able to live without my child. I was breastfeeding and taking care of her for four months and then exchanged her. I was crying and crying. My husband was also crying. We were crying together… Then I came to my husband and told him about my decision: "If you cannot accept her, we can go for a divorce". He supported me, he said, "We will do what you decide". Then I got my child back[65]. (P1)

According to the participants, there was a strong disability stigma in employment too. Participant 12 stated that employers did not want to employ graduates from specialised institutions. Institutions for children with intellectual disabilities were of particular concern. Their graduates were usually not employed even though they had been trained for certain specialisations. Participant 17 stated that the employment of graduates was one of the most serious challenges for parents and their children, but she did not see any solutions. To avoid the problem, many parents preferred keeping their children in general schools, although there were no proper conditions for them in those schools.

One of the parents felt very uncertain about the future of her daughter:

> My only problem is the future of this child. Well, now she goes to school but what will she do after that? What will be her future in our country with our mentality? I am very concerned, and I have no idea… We [parents of children with disabilities] are trying to develop their vocational skills and contact authorities for help but they are not interested[66]. (P1)

She added that if parents wanted their children to be employed, they had to create job opportunities for them themselves. She and other parents were thinking about opening a cafe or a small shop for their children when they grew up.

Another parent was also concerned, “They [young people with disabilities] are not competitive. With the current condition at the labour market who will employ them?”[67] (P7).

When I raised this issue during the interview with Participant 23, he referred to a disability employment quota introduced to improve the employment prospects for people with disabilities:

> In Uzbekistan, decent employment is not an easy task not only for people with disabilities! Surely, you have heard about the Law of the Republic of Uzbekistan "On the social protection of people with disabilities" (a new bill is being prepared now). It states that depending on the number of vacancies, employers have an obligation to hire people with disabilities in compliance with an employment quota and the Inspection Department under the Ministry of Labor must control the availability of these vacancies for people with disabilities. Violation of this requirement is punished by the same law[68]! (P23)

However, some other participants raised the problem of non-compliance with a disability quota. One of them shared a story about a dance teacher with a hearing impairment:

> One of the school teachers organised a dance studio for students. They are amazing dancers. However, the school could not employ him officially. You know, there was no vacancy for him, although nobody at school could dance better than he could. He graduated from the circus school and that was not easy for him. Even though there is an employment quota system for people with disabilities and he has the second disability category, the school could hardly keep him. Our legislation is so… In the past, people who had the first or second disability categories were allowed to work but when the Medical and Labor

> Expert Commission came under the jurisdiction of the Ministry of Finance, they were no longer allowed to work[69]. (P7)

When I asked the reason for this, she said that those who were entitled to disability allowances were not allowed to work. She noted that a three-percent employment quota for people with disabilities did not work in reality. She concluded that if a person with a disability managed to get a job, it would be his/her accomplishment only.

Similarly, Participant 22 said that the disability employment quota was not helpful because there was no effective system to monitor the employment of persons with disabilities. He stated that several years ago organisations that employed people with disabilities had been given tax-exempt status. Then, the government stopped that practice because many organisations had hired people with disabilities only to avoid paying taxes. Since that time, only those organisations that were registered under the Society of People with Disabilities and hired more than 50 percent of persons with disabilities could get tax-exempt status.

The cultural reasons why children with disabilities remain unregistered have been examined at the beginning of this section. According to the participants of this study, families are reluctant to report their children's disabilities as they fear of social stigma. Lacking official recognition, these children do not receive relevant social services nor the legal protections that are critical to their survival and development. Arguably, the situation has not been addressed properly, although the CRC, ratified by Uzbekistan in 1994, states explicitly that every child has to be registered immediately after birth and has the right to a name, a nationality, and being cared for by his/her parents (Convention on the Rights of the Child, 1989, Article 7). Article 18 of the CRPD restates the same provision but for children with disabilities in particular (Convention on the Rights of Persons with Disabilities, 2006). Mute (2018) explains that the need for a specific provision concerning children with disabilities arises because cultural and religious practices often undermine their right to registration.

Similarly, Katsui (2005) states that in Central Asian countries, cultural prejudices prevailing in societies strongly influence the attitude of families towards their children with disabilities. In many cases, "When a disabled baby is born, the unfortunate story quite frequently begins already" (Katsui, 2005, p. 64). This resonates with the participants' experiences of being stigmatised because of giving birth to a child with a disability. Even if a child stays in a family, he/she is often treated differently from their typically developing siblings and is not given the same opportunities as their sisters and brothers. Katsui (2005) notes that some Uzbek mothers said in front of their children with disabilities, “There is only hope left for the daughters (her son is disabled)” and “It’s pity to see him all day like this” (p. 65).

A recent UNICEF study revealed that in Uzbekistan, parents of children with disabilities were one of the main factors why their children never attended a school or dropped out of it (United Nations, 2019b). “My parents did not want me to study” was one of the most frequent answer choices indicated by participants in the study. Katsui (2005) also points out that in many cases parents feel guilty and ashamed for giving birth to children with disabilities and try to hide them at home. When their children grow, they force them to stay at home with no access to education. This researcher concludes that this tends to occur more frequently in Uzbekistan than in other Central Asian countries.

It would seem that women bear a strong social stigma once they give birth to a child with a disability. These women often follow cultural values and rules imposed by society. The participation of Uzbek women in family decision-making and in society generally, is limited by gender stereotypes (Mee, 2001). Arguably, due to the role attributed to women in traditional Uzbek society, they are not always willing to fight against discrimination and, therefore, tend to hide their children at home or institutionalise them. Previous studies have shown that the oppression of mothers of children with disabilities occurs frequently. For instance, Gaad (2004) notes that when a Egyptian mother of a girl with an intellectual disability was asked why she had placed her daughter at a segregated school, she replied “that was how society placed and categorized her” (p. 317). The woman made that choice because any other person from her community in her situation would do the same, although personally she was against marginalising the child.

Other studies also revealed that mothers of children with disabilities were strongly influenced by traditional beliefs. In many cases, similar to the participants of this study, these women were discriminated against by family members and relatives. For instance, in a study by Kalyanpur and Gowramma (2007), some mothers reported that due to disabilities of their children, in-laws significantly restricted their social interactions. These authors noted that some women were frequently blamed for having a child with a disability and were humiliated. This even led them to thinking about committing suicide.

In some cultures, the influence of a mother-in-law is very strong. A study of Maloni et al. (2010) found that Bangladeshi mothers stated that they felt obligated to follow their mothers-in-law wills, even if they went against their own desires and beliefs. One woman said, “My mother in law believes in traditional healers very much. I don’t, but if she tells me, then I have to go there” (p. 849). It seems apparent that stigmatizing attitudes towards mothers of children with disabilities are prevalent in many developing nations.

Maloni et al. (2010) suggest that education and peer support networks provided to family members, especially to elder ones, play an important role in addressing these issues. If family members have a biomedical understanding of disability and treatment, they will most probably change their attitude towards children and their mothers. The researchers state, “such an understanding may translate into improved social and educational opportunities for CWD” (p. 845). Similarly, Danseco (1997) notes that understanding beliefs and the culture where those beliefs are formed is critical for professionals to develop appropriate intervention services for children with disabilities and their families.

Discrimination of people with disabilities continues in the employment sector as well, although Article 27 of the Convention on the Rights of Persons with Disabilities (2006) precisely states about their right to work on an equal basis with other people. Research indicates that young people with disabilities are especially disadvantaged in the labour market (Bassett, Lloyd, & Bassett, 2001; Carter, Austin, & Trainor, 2012; Lindstrom, Doren, & Miesch, 2011). One of the most significant barriers to unemployment amongst people with disabilities in both developed and developing countries is social stigma (Bassett et al., 2001). Employers often have a negative attitude towards hiring people with disabilities, especially those who have intellectual disabilities. Such attitudes often lead to the reluctance of employers not just to give a job to a person with a disability but also to support his/her professional development if that person is hired (Bassett et al., 2001).

Similarly, Lindsay (2011) notes that individuals with disabilities often face many issues at the workplace, such as “non-accommodating environments, inadequate income support, lack of opportunities and little political influence” (p. 1341). They also experience discrimination in the types of jobs they receive. They are primarily employed in lower-status and lower-paying positions. Temporary employment and part-time jobs are also higher amongst people with disabilities, compared to those who do not have disabilities. In her study, Lindsay (2011) explored the barriers experienced by young people with disabilities (aged 15-24) when seeking employment. They experience different barriers to employment: social isolation, discrimination coming from other employees, inaccessible transportation, and being given less responsibility at the workplace. Lindsay (2011) concludes that restrictions on employment are often a result of barriers and discrimination in society. According to Groce (2004), in the developed world, the total number of adolescents and young adults with disabilities is about 30 million, while in the developing nations this number is much higher - 150 million. Given these numbers, we can see the scale of the global unemployment crisis amongst youth with disabilities.

Although there is a lack of official statistics related to the employment of young people with disabilities in Uzbekistan, the majority of them are known to be unemployed. As stated by Uzbek Society of Disabled People (2014), there are many reasons for that. Some of them are stigmatisation of people with disabilities at their workplaces; the absence of professional development services for people with disabilities; a lack of viable tools to enforce labour rights; and many others. Government legislation supports the provision of jobs for people with disabilities and prohibits any form of discrimination in employment. The participant drew attention to the law stating that each company’s workforce must include at least 3 percent of people with disabilities. Companies whose workforce consists of 50 percent of people with disabilities are exempt from income tax. Yet, these measures do not change an employment situation for people with disabilities significantly. For instance, according to Japan International Cooperation Agency (JICA) (2002), in 2000, 43,924 jobs were opened for people with disabilities but only 2,914 of them were employed. The rest remained unemployed due to low wages and poor work conditions. Currently, the employment rate for people with disabilities still remains very low at five percent (United Nations, 2019a).

The United Nations Development Programme (UNDP) (2012) conducted a study in three Uzbek cities to identify social attitudes towards the employment of young people with disabilities. The study included in-depth interviews with 160 participants and analysis of 175 articles. The results showed that people with disabilities experienced social stigma not only from the community they live in but also from their families. As previously mentioned, families often avoid the negative attitudes of society by hiding their children. They simply do not allow them to attend vocational colleges or work. According to United Nations Development Programme (UNDP) (2012), there is also a cultural belief that a *respectable* family would never allow their child with a disability to work. To keep face in front of others, families prevent their children from being employed. It turns out that families experience stigma coming from society and then this, in their turn, affects their children. There is also a perception amongst employers that people with disabilities may take sick leaves too often. However, the attendance rate of employees with disabilities is high enough and they do not take sick leaves more often than employees without disabilities do (United Nations Development Programme (UNDP), 2012).

The United Nations Development Programme (UNDP) (2012) involved local DPOs in assisting young people with disabilities with employment. It was very advantageous because DPOs have both high motivation towards a more inclusive society and a strong understanding of issues that are important to people with disabilities. There were some initiatives taken by DPOs in Uzbekistan. For instance, the DPOs “Millenium”, “Opa-Singillar”, and the Association of Business Women with Disabilities helped 203 people get employment. These organisations also actively raised awareness about their rights and helped them confront the prejudice and discrimination they frequently encountered. The UN recommends that more specialised vocational colleges should be established throughout the country. These institutions are considered helpful because they provide training for different industries including “the modelling and manufacturing of garments, the repair and maintenance of radio and TV equipment, the operation of show-making businesses and the production of knitted garments” (p. 12). As the United Nations Development Programme (UNDP) (2012) states, these colleges will contribute to the development of certain professional skills of youth with disabilities.

A significant increase in specialised colleges across the country might be helpful. However, it cannot improve graduates’ chances of getting a job because this issue is much more complex. According to the findings of this study, the problem is not a lack of professional skills of young people with disabilities but attitudinal barriers existing in society. Even with a qualification, people with disabilities are not hired because of the employer's fear and prejudice. Furthermore, a focus on segregated institutions appears to be in contradiction with the idea of inclusion. Deinstitutionalisation has to be pursued at all levels of the educational system, including vocational colleges. Papay and Griffin (2013), who discuss the importance of post-secondary education for people with intellectual and developmental disabilities (IDD), state there should be advocacy for inclusive post-secondary education that will lead to innovative opportunities for people with IDD to access colleges with their non-disabled peers.

Another issue raised by parent participants was lack of support from government agencies with employment of their children. Preparing students with disabilities for the workforce has to be a concern of different agencies and organisations, including relevant Ministries. Educational institutions and families may not be able to address this complex issue by themselves. There are a number of studies and practical guidelines recommending bringing together government officials, teachers, psychologists, social services, potential employers, community representatives, and students' families in order to increase the employment of young people with disabilities (Center for Youth and Communities, 2015; Park, 2008; Sabbatino & Macrine, 2007). Sabbatino and Macrine (2007) note that collaboration amongst all stakeholders can foster a socially relevant programme and the development of an effective transition system within special education.

However, transition services are not mandatory in the majority of developing countries, although the Convention on the Rights of the Child (1989, p. Article 23) commits them to recognise the special needs of children and ensure their access to preparation for employment. As maintained by the participants of this study, in Uzbekistan, there are neither transition programmes, nor supported employment services for students with disabilities at schools. It is one of the major reasons for unemployment amongst these people. Some developing countries, where transition services are not supported by legislation, still attempted to increase employment opportunities for school graduates with disabilities. For example, in Malaysia, a number of NGOs were involved in assisting young people to obtain employment and maintain it. NGOs have provided job-related training and organised support services particularly for those who have severe disabilities (Abdullah, Mey, Eng, Othman, & Omar, 2013).

Participation in employment for young people with disabilities is critical. It offers "income, social relationships, social status, daily rhythms and often meaning in life" (Lindsay, 2011, p. 1340). Therefore, barriers to their employment need to be addressed. Other issues that arise in the process of development of an inclusive environment also need to be considered and resolved. With inclusion in place, young people with disabilities will be given equal opportunities to receive education and get employment as their able-bodied peers. Inclusion will make them more successful throughout their lifetime and, hence, our society will receive intellectually developed and civic-minded citizens.

5.1.6 Summary

Participants' insights and analysis of the existing literature demonstrate that Uzbekistan, as one of many developing countries, faces many challenges in the enactment of inclusive education. One of them is the non-availability of teacher aides in general schools. Effective inclusive practices are hardly possible if students with disabilities are "supported" by their parents, who function as teacher aides with no professional expertise for that. Many parents, who ideally support inclusion and want their children to study in mainstream settings, seem to be reluctant to place them in inclusive classes due to lack of professional support.

Inaccessible infrastructure is another serious issue mentioned by participants and international organisations. Many children with mobility impairments who started their education in general schools either leave because they cannot access classrooms and toilets or heavily depend on their peers or parents for that. Others do not even consider institutions where there are no ramps, special lifts for wheelchairs, and assisted toilets. According to participants, currently, the government is reconsidering the school and public infrastructure to make these institutions more accessible. However, in many cases, technical requirements are not followed when infrastructure and facilities for people with physical disabilities are built. For example, the gradients of ramps built in cities are too steep for people using wheelchairs and in such cases, they still need assistance to enter buildings.

The shortage of qualified teachers appears to be one of the greatest challenges for the enactment of inclusive education. In Uzbekistan, many teachers in mainstream schools are not sufficiently trained and motivated to work with students with disabilities. To develop teachers' skills and confidence, they need to learn more about inclusion during both pre-service and in-service training. In addition, to achieve significant change requires reconsidering the working conditions of teachers. Currently, many of them work in large multi-level classes with limited resources. As noted by teacher participants, with these issues, it is hardly realistic to require them to work with students with disabilities and expect them to be successful. It implies that they will most likely be willing to accept responsibility for these students and become agents for educational inclusion if given proper support.

The absence of a law pertaining to inclusive education, consistent with international human rights policies, would seem to be one more challenge hindering the inclusion process. Even though the Uzbek government is working on the new law ‘On Education’, there is no specific national legislation on inclusive education. After reviewing international literature on enhancing inclusive education in developing countries, it is apparent there is a need for an appropriate legislative framework. It would support the government at both the national and local levels to move towards inclusion having a common vision and a consistent approach (UNICEF, 2014c).

Another pervasive barrier to creating social and educational inclusion is the attitude of society towards people with disabilities. They are often treated as different and sometimes as a threat. According to the results obtained, many parents try to hide their children to avoid negative public attitudes. They purposely do not request official social support and medical help, and at a later stage do not send children to schools. While growing, children with disabilities are discriminated at all stages of their life: kindergartens, schools, and workplaces. Discrimination causes the devastating consequences for children and often their families: social isolation, lack of developmental opportunities, feeling of worthlessness, and low self-esteem.

CHAPTER SIX
FINDINGS & DISCUSSION

Parental Involvement, Support from the Government, and Medicalisation of Disability

6.1 Introduction

The remaining three themes are put in one chapter, as they have no significant sub-themes that emerged from the respondents' ideas. The themes are: the importance of parental involvement; support and cooperation with the government and other agencies; and the medical model of disability and the legacy of defectology. These themes provide critical analysis of the experiences of parents, teachers, NGOs, and the government in supporting children with disabilities and describe the relationships amongst these key groups for creating an inclusive education environment.

6.2 The Importance of Parental Involvement

The vital importance of parents' participation in the upbringing and education of children with special needs was raised by all teachers and many NGO and DPO representatives. They were very clear that parental involvement and attitudes, and the quality of child-parent relationships, were critical in the development of any child but particularly of a child with a disability. However, the teachers who participated in this research stated that parents often struggled in a number of ways and were not fully involved in the upbringing and development of their children. The participants noted the following issues: a lack of financial resources to support children, child neglect, and a lack of parent advocacy skills.

According to the teachers, many students with disabilities come from financially insecure families. A participant working with children with intellectual disabilities said, "Our students mainly come from low-income families. The surroundings affect their cognitive as well as physical development"[70] (P12). When I asked her how exactly the surroundings affected child development, she responded that many parents spent much time trying to make some money to survive. They often had neither opportunities nor time to contribute to their children.

Another participant, working with students with physical disabilities had a similar view:

> If we analyze family situations of these children, we will see that two students out of 12 come from relatively financially secure families. The rest of them come from needy families, incomplete families, or families living in remote areas. All these factors affect children[71]. (P12)

Some participants noted that a low level of parental education was one more reason why they could not help their children with disabilities to develop:

> Not all our parents could contribute to the development of their children… Not many of them can work day after day for that. It takes so much effort. There are not many such parents. Many parents left their children at specialised institutions. I cannot say they left them there because there do not want them but because they do not have knowledge and information, and because they cannot read. Due to their low level of education, they cannot find the information and contribute to the child's development. They think, "He differs from others. He cannot read and write". They try once or twice and if there are no results, they give up and send their children to boarding schools[72]. (P15)

Another research participant said that in addition to financial problems, some families raising children with disabilities had problematic behaviour, for instance, excessive alcohol drinking, and did not take responsibility for their children. His opinion was reflected in the views of many other participants:

> We inherit this problem because society or the system does not give any chances to children from vulnerable families. Why? Because they are born in such families - families that already have histories; their histories are bad initially. They have weak social positions, low earnings, and bad habits. Children for them are just by-products of their sexual activities. If it had been possible not to have these children, they would not have had them. However, they were born and they had to do something with them. Therefore, they have somehow adjusted [by sending their children to a boarding school]... Many of these parents are from here [a boarding school for children with intellectual disabilities]; even children's grandparents are from here[73]. (P10)

This participant continued to say that a better patronage system was needed to take those children out of their families and place them in other families who could take care of them. He believed that it would be a better option for them than staying in boarding schools, which was "similar to being in prison"[74]. The participant said, "They do not see a family here, they do not see family relationships, and they do not see those things that will be essential for them in their further life"[75].

Participant 13 stated that many of her students came from very problematic families and, therefore, the school had to fulfill some responsibilities that were supposed to be taken by their parents: feeding these children, helping them with hygiene procedures, and entertaining them (e.g. taking to a theatre or circus).

Another participant shared her positive experiences where parents had supported their children and contributed to their development. She told about a boy with a physical disability who studied well at school and was able to enter a very prestigious university, "His family supports him. They support him emotionally first, "You are not worse than others. You are equal to all of us"[76] (P11).

She maintained that such an attitude empowered the boy and made him more confident. That participant, who has a disability herself, shared a personal example. She emphasised that she had achieved a lot in her life thanks to the support of her parents. She shared a story about her neighbour with a physical disability whose relatives believed she did not deserve to have her own life:

> My Mum told me, "I do not want you to be like our neighbour"… We had a neighbour who was barely able to drag her leg behind her and could not bend her arm. She got old, taking care of her little brothers, then children of brothers, then grandchildren of brothers, and then she died[77]. (P11)

The participant said this was a widespread attitude towards females with disabilities, whose situation was even worse than that of males with disabilities. She continued that females with disabilities faced double discrimination due to disabilities they had and the prevalence of traditional gender roles in the Uzbek culture. In many cases, they face even greater social rejection in terms of education, employment, and marriage than males with disabilities do.

Another participant mentioned the importance of early intervention programmes and considered that passive parenting could cause much harm to children. She said that the first three years of a child's life were critical for his/her further development, and parents should not miss that time:

> Now, when I see older people [with Down syndrome] – 20, 25, 30-year olds, I see that they have the same conditions as described in books: they are sedentary, demonstrate tongue protrusion, cannot control a salivary flow… eyes, hands. Their parents have missed their development in the early years. They did not lay the foundation for the future of their children[78]. (P4)

She added:

> Every parent, whose child is diagnosed with a disability, should be given the wings [supported and inspired]. Psychological support is very important for parents… A child needs to be developed regardless of his/her disability. Parents should start it right after a child is born or after he/she is diagnosed[79].

A number of other participants also shared their views about the importance of active parental involvement in a child's development. They stated that parents should be more active and dedicated to their children with special needs, even though it requires a lot of effort and time. One of the parents said that activism was a major part of her experience of being a parent of a child with a disability, "Parental activism is similar to citizen activism"[80]. (P7)

Participant 7 believed that some years ago parents had been more engaged. They were contributors before but now they act more as consumers, "If 15 years ago families came to us because they wanted their children to socialise, go to school, develop certain skills, now they call us and ask, 'How can you help?', 'Do you give money?' "[81].

However, some participants stated that a lack of motivation amongst parents of children with disabilities could be explained by their financial hardships. One parent stated:

> Parents of children with special needs have to pay twice as much as others because their children are "special". Even these limited opportunities that exist for us are more business-oriented. Forty minutes of swimming costs 50,000 [UZS, approximately 5,0 USD]. I think it is unrealistically expensive[82]. (P4)

The parent explained:

> On average, one lesson with a logopedist costs 5-10 dollars [USD]. I would understand if it was just articulation but these children have to spend years to develop their speech. To pay 10 dollars for one lesson for many years is very expensive[83].

Similarly, Participant 5 stated several times during the interview that she could not afford a logopedist for her son. She was sure if her son had been supported, he would have made better progress in his speech. Participant 7, raising a child with cerebral palsy, also said that development opportunities for children with disabilities were often not affordable. She added that many families did not even have money to commute with their children to and from school, let alone access to other learning opportunities.

Another identified problem associated with parenting a child with special needs was a lack of parent advocacy skills and a general knowledge of the relevant law. The majority of NGO and DPO representatives working with parents of children with disabilities emphasised that parents were often not familiar with the existing laws and did not participate actively in their child's life. This is what one interviewee participant said:

> Recently, a woman has seen the Constitution for the first time, "Such a good book. Give it to me to read". Eventually, she got what she wanted when she demanded [her son's] constitutional rights. She simply said, "Is my child a citizen? He is… It means he has these rights"[84]. (P8)

Many parents encountered issues when their children had to go through the Medical-Psychological-Pedagogical Committee (MPPC), which made a decision where to place a child: into a specialised institution or a general one. In many cases, the Committee sent a child to a specialised kindergarten/school without considering a parent's opinion. Many parents mentioned that their children had been directly sent to specialised schools. One of the parents said, "It was out of the question, no one even tried to talk to a child"[85] (P1).

Some parents admitted that they had put pressure on members of the Committee to make them release official permission for their children to study at the general school/kindergarten. For instance, one of the participant's husband was an influential person. The Committee members told her, "We respect him [her husband] a lot and, therefore, we will give you permission with no questions, but then you do everything by yourself [no longer rely on us]"[86] (P4). According to the participants, they were also aware of instances of bribery. In such instances, money helped them induce medical officials to give recommendations for general educational institutions.

Participant 20, a lawyer and an enactor of the Inclusive Education Project, was asked to respond to this issue. She said, "They are official guardians of their children and according to the law, *they* make decisions… The decision made by the Committee should not stop them. If they do not agree with it, they should go further"[87] (P20). She also emphasised that the RCSAC offered consulting services for parents. Parents regularly receive legal assistance in addition to psychological, pedagogical, social, and medical support.

Similarly, participants from the NGO group commented that they often provided juridical advice for parents of children with disabilities whose rights had been violated. These parents either did not even know about the violation of their rights or they knew but were not sure how to act in accordance with the law. According to the NGO representatives, parents need to have knowledge and skills to function effectively within their role to promote social change for children with disabilities. For this reason, many of these organisations provided support services and training to help parents to become advocates for their children. As this group of participants stated, many parents became advocates after experiencing distress related to the unfair treatment of their children. For instance, one of the NGO participants shared that a mother of a child with a mild disability came to an NGO to seek help because her child had been refused an opportunity to attend a general kindergarten. After the woman had been given support in the form of legal advice, she helped other parents who faced similar issues.

There were many similar examples provided of parents not only supporting their children but also helping others. Parent activists also raised awareness of disability issues. For instance, the parents of children with Down syndrome organised a fashion show with the participation of their children. Their purpose was to demonstrate to society that "these children can also develop, can be ordinary kids, can study"[88] (P2). Another example was an initiative of a father of a child with autism who regularly meets with students of a regular school to tell them about people with disabilities and their lives. The initiative was supported by the school administration as well as by students' parents. Many of the parents of children without disabilities noticed that their children had become more compassionate. These efforts of parents are very important and have direct relevance to the research question that focuses on parental contribution to creating an inclusive environment.

In reporting the participants' views related to parents of children with disabilities, three themes emerged. These were a lack of parental care and nurturance, shortage of financial resources, and lack of advocacy skills and a general knowledge of the relevant law. As mentioned previously, the literature focused on the lives of children with disabilities and their families in Uzbekistan is limited. Therefore, the following section is discussed in the context of international literature and where it is possible, drawing from studies considered more relevant to Uzbekistan.

Lack of parental care and nurturance. According to many participants, the development and well-being of children with disabilities, in many respects, is very dependent on their parents. Some of the parents support their children as much as they can, while others overlook their children and their needs. Myers et al. (2002) identify four types of neglect: physical, emotional, mental health, and educational. Physical neglect includes failure to provide basic physical support (shelter, food) and protect a child from harm. Emotional neglect is inattentiveness to a child's emotional well-being. Mental health neglect refers to a refusal to provide necessities to a child in accordance with medical procedures, for example, medications or therapies. Educational neglect is a failure to comply with the requirements for school attendance. Regardless of the type, child neglect has negative short- and long-term effects on children's cognitive, emotional, and physical development. Some of those effects are negative views of self, poor social adaptation, emotional instability, care-giving deficits, homelessness, poverty, and family breakup (Hildyard & Wolfe, 2002).

Sullivan and Knutson (2000), who assessed the prevalence of abuse and neglect amongst children with disabilities, found that they were neglected 3.76 times more than their peers without disabilities were. There are potentially a number of reasons for this but the teacher participants viewed bad habits of parents, such as drug addiction and alcoholism, as major ones. They stated that some parents of their students were prone to those troublesome habits that often led to family conflicts and marital disruption. The literature indicates that the incidence of alcoholism in families raising children with disabilities is not uncommon in the former Soviet Union countries. Hartblay (2006), in describing a situation of women raising children with disabilities in rural Siberia (Russia), states, "fathers often leave families of children with disabilities or become alcoholics, and the mothers must carry on with strength" (p. 92). Bilson and Markova (2007) call such parents asocial and note that they might be irresponsible and with a wide range of problems. Similarly, in the view of the participants in this research, parents in the study of these authors did not have a strong commitment to bringing up children. The participants also noted that these parents often experienced finance-related issues caused by their unstable employment histories.

It is too easy to oversimplify the above situation and to position the parents as being deliberately neglectful of their children. Dubowitz and Bennett (2007) point out that many parents who neglect children do not do so intentionally. They believe it is important to understand what emotional, psychological, physical, and financial challenges those families encounter while raising their children with disabilities. Hastings and Beck (2004) point out that parents experiencing high levels of stress and having mental health issues interact with children and react to their needs differently. If parents feel stressed, they may be engaged in different behaviour that negatively affect a child. I would suggest that poor supervision, physical punishment, and drug or alcohol abuse are some of that parenting behaviour.

Arguably, the absence of respite care in Uzbekistan and other services that could ameliorate parents' stress and improve the quality of their life significantly contributes to this problem. Social support services and programmes are essential for the mental health and well-being of families raising children with disabilities. Heiman (2002) notes that in many respects, the adaptation of families to their child's disability depends on support services. More than 93 percent of Heiman's research participants reported that they were able to cope with their child's disability and new lifestyle demands thanks to support services and the associated benefits. These included support groups, social workers, psychological services, psychiatric consultations, special education services, and support of voluntary organisations. Without proper support, not every family could remain strong enough to cope with all challenges related to the care of their child with a disability.

As suggested by a participant of this study and supported in the literature, neglect by parents of their children with disabilities has to be addressed. There are a number of immediate measures that need to be considered as a national response to this situation. UNICEF (2005b) provides recommendations for professionals in case of abuse of children with disabilities. First, national legislation has to be enforced to prosecute neglect and violence against children with disabilities. Second, relevant services, schools, and disability advocacy organisations have to oversee those families and work with parents regularly to protect children with disabilities living in families where there is evidence of suspected neglect. If children continue being neglected, enforcement mechanisms have to be applied to take those children out of their families and placed in conditions that are more appropriate.

The Uzbek legislation formally protects individuals with disabilities. Article 3 of the Law "On Social Protection of Persons with Disabilities in the Republic of Uzbekistan" states that all children and young people with disabilities "require social assistance and protection due to limited abilities because of physical, mental, psychiatric or sensorial impairments". Article 3 of the Law "On Guarantees of Child Rights" also emphasises the need for social support and protection, "A child with a disability is a child who needs social support, protection and is certified as disabled according to the existing regulations due to physical, mental, sensorial and (or) psychiatric impairments". However, as mentioned previously, there is little or no law enforcement. The Equal Rights Trust (2016), which addresses legal provisions designed to protect the marginalised population in Uzbekistan, states, "Although several laws declare the right to equality and non-discrimination, there is little provision for their implementation or enforcement" (p. 73).

Law enforcement measures to protect children with disabilities from parental neglect should be taken only when less extreme measures are ineffective. It should be first a joint effort of teachers and child welfare personnel to identify and support these children (Gore & Janssen, 2007). These researchers offer a table of common indicators of possible maltreatment of children with disabilities that teachers should know. The table includes the following indicators: chronic tardiness, chronic hunger, signs of physical abuse, aggressiveness, rejection, and others. Sobsey (2002) suggests that schools should enforce a mandatory attendance policy and monitor children's frequent absences. The role of child protection agencies is also critical. It is recommended that these agencies collaborate with schools to identify at-risk families and offer them intervention programmes (Fantuzzo, Stevenson, Weiss, Hampton, & Noone, 1997).

Yet, intervention programmes are currently unavailable in Uzbekistan. International organisations have attempted to develop some measures to strengthen child protection. For instance, the UNICEF reintegrated 364 young children to their biological parents and to alternative care to prevent their institutionalisation. The UNICEF, along with Tashkent Paediatric Medical Institute, also conducted training for medical specialists focused on the prevention of neglect and maltreatment of children (UNICEF, 2015b). These measures are effective, but they need to be translated into the national policy to be enhanced and systematic.

Shortage of financial resources. All parents who participated in this research also reported that raising a child with a disability was financially overwhelming. They stated they often did not have enough financial resources to cover all the needs of their children. The research indicates that families raising children with disabilities experience significantly greater financial pressures than families of typically developing children (Baldwin, 2015; Parish, Rose, Grinstein-Weiss, Richman, & Andrews, 2008). There are additional costs associated with a disability: medical services, medication, adaptive equipment, educational services (Parish & Cloud, 2006). It is estimated that families of children with disabilities spend three times as much as it costs for families of children without disabilities to raise a child (Social Finance, 2009).

In the context of Uzbekistan, the high expenditure faced by parents raising children with disabilities can be explained by a number of factors. According to many research participants, the main reason is an inadequate disability allowance. All children with disabilities under 16 years old receive a monthly allowance (Внебюджетный пенсионный фонд [Extra-budgetary Pension Fund], n.d.). Currently, a child disability allowance is 436,150 UZS (approximately $43 USD) for everyone regardless of the severity of a disability. People with disabilities over 16 years old receive an allowance depending on their disability categories. According to the Office of Retirement and Disability Policy (2014), people with disabilities are categorised into three groups: “Group I (total disability, incapacity for any work, and requires constant attendance), Group II (total disability, incapacity for any work, and does not require constant attendance), or Group III (partial disability and incapacity for usual work)” (p. 9). People with disabilities receive about $34-$74 USD monthly (Oddsdottir, 2014).

This disability allowance is definitely not financially sustainable for people with in Uzbekistan, especially taking into account that many will have additional expenditure related to health issues. This finding is consistent with the other studies. Katsui (2005) states that the amount of a disability allowance for children and adults with disabilities in Uzbekistan and other Central Asian countries is unrealistically low. According to Katsui’s participants, it should be ten times more to cover basic expenditures, such as rent, utilities, food, transportation, and medication. The situation has not changed since the early 2000s. One mother, who participated in the recent UNICEF study, reported that “she can only afford diapers for her daughter for one month by combining the allowance she gets for 2 children with disabilities for 2 months” (United Nations, 2019a, p. 95). All other health services remain unaffordable for these children, even though they are essential.

Another reason for the financial pressure experienced by parents of children with disabilities is the low quality of free services provided by state medical institutions. As the parent participants noted, they either referred to private clinics instead of pubic ones or bribed doctors at state institutions, if they wanted better health care services for their children. Based on these parents’ experiences and evidence from previous studies, when doctors are bribed, they demonstrate more willingness to help and provide medications.

Katsui (2005) notes that officially medical treatment in all Central Asian countries is free; however, in practice, people have to pay illegally for it. Those who cannot afford it, do not get proper medical treatment. This author also contended that government officials were satisfied with the existing services and did not consider the reality of people with disabilities. The existing medical policy and practice only increased their vulnerability.

The participants of this study complained that rehabilitation and social services are often inaccessible to many parents because their costs are very high. According to participant 20, the RCSAC and its two regional branches provide free good quality services for children with disabilities and their families. However, as Participant 2 said, her son could not be provided with services regularly because there were many other children with disabilities who also needed professional support. Therefore, those who have sufficient financial resources rely on private medical and rehabilitation centres; those who cannot afford it, have no other options except to leave their children with little or no support. Katsui (2005) calls the situation of Central Asian families who have children with disabilities “catastrophic” (p. 65).

In addition to the excessive expenditure, many parents of children with disabilities encounter difficulties with their employment. They often need to reduce their working hours to take care of their children. According to Bourke-Taylor, Howie, and Law (2010), in many cases, one of the parents stays at home with a child. These researchers state that in 94–98 percent of all cases, mothers are primary caregivers of children with disabilities. Porterfield (2002) states, “for families with children who have disabilities, the decision of one parent not to work may be more a necessity than a choice” (p. 972). Mothers, who are employed, often can work only part-time, as there are few services where they can leave a child until the evening. Based on the figures provided by UNICEF (2005a), in many former Soviet Union countries and Eastern Europe, 68 percent of women, taking care of their children with disabilities, cannot work overtime and 72 percent of women are not promoted because they are more focused on their children and cannot compete with others.

This employment situation also applies to the parents who participated in this study. Almost all of them (with one exception) were females. The majority of them left their jobs and relied financially on their husbands. A few women organised private disability-related agencies where they have a flexible schedule. None of them work for other governmental or non-governmental organisations because as they said, they needed more work flexibility to take care of their children. The male participant working for a non-government organisation, admitted that he often leaves his office for 2-3 hours when his autistic son has bouts of aggression.

The situation for single parents is potentially much worse because they often lack the immediate and ongoing support of another adult. This could be particularly relevant to Uzbekistan, where, as previously stated, men often abandon their wives after they have given birth to a child with a disability. Many women quit their jobs to take care of their children, relying on a disability allowance, which, as claimed, is inadequate (Katsui, 2005). In such situations, the majority of women have to either send their children to boarding schools to go to work or else live in extreme poverty. That is exactly the case of Participant 9, who institutionalised her son to start working after her husband had left her. While she was working, her son was being taken care of in a state-run institution for children with disabilities. Some years later, she withdrew him, but felt guilty for what she had done with him because she said that at the institution he had been neglected in terms of his social and academic development.

As shown above, many families raising children with disabilities face serious financial hardship due to the high cost of caring for them. The situation is worsened by the fact that many parents, primarily mothers, cannot work to take care of their children. Yet, none of their costs are supplemented through public funds, unless a child is institutionalised. If children are being cared at home, their families take full responsibility for the cost of their care. If families do not have a sustained income base or savings, which is often the case, their children have limited access to appropriate support needed for their health and development.

Lack of advocacy skills and a general knowledge of the relevant law. Many teachers and representatives of disability advocacy organisations, who participated in this study, stated that parents of children with disabilities often lacked appropriate advocacy skills. By advocacy skills, they meant the act of supporting a child by promoting and defending his/her rights. This problem has been briefly discussed in the previous Theme in the context of social stigma. It makes parents passive and leaves them unaware of their rights and services available for them and their children. In many cases, the situation is worsened by the fact that parents do not know how to get access to legislative documents and are not provided with any type of assistance with legal matters.

Rehm, Fisher, Fuentes-Afflick, and Chesla (2013) note that to be an advocate for one's own child, parents need to have a social position, financial security, knowledge of existing systems and organisations, negotiation skills, and time available for advocacy. These factors are crucial because parental advocacy requires advocating for services needed for their children, being an expert for their children, and protecting them from incompetent specialists. In other words, all those factors that are needed, the majority of parents in Uzbekistan do not have. Yet, Rehm et al. (2013) continue that these factors are needed ideally. If parents experience financial difficulties and do not have high social status and good education they still can advocate successfully for their children. For that, they need to be regularly engaged in the educational process of their children and establish a partnership with other parents who have strong advocacy skills. These researchers give an example of when a parent with no advocacy skills was supported by other parents who were strong advocates. With their support, she became familiar with the law related to special education and knew how to use it for the advantage of her child. The study corroborates the findings of this research related to parents supporting other parents to become advocates for their children. The parents, who were helped, were not educated and did not have high social status, but they were able to support their children with disabilities effectively.

It would seem that the majority of parents in Uzbekistan still need support, especially in the area of disability-related laws and rights. There appear to be several reasons why parents of children with disabilities are unfamiliar with the relevant laws and may be less effective in providing necessary support for their children. One is prejudice and social stigma. Another is obedience to authority that is quite common in Uzbek culture. It is difficult to imagine that in Uzbekistan, marginalised people protesting in front of those who have more power and higher status, and demanding what they must have according to the law. Similarly, Koszela (2013) notes that a hierarchical system in East Africa does not allow people with disabilities and their family members to advocate for their rights. They cannot do that because it is simply beyond their cultural norms. As a result, the needs of people with disabilities are easily overlooked, simply because there is no voice to represent them.

Regardless of the reason, consistent efforts should be taken to change the situation. Parent peer advocacy can be an effective way to respond to this issue. Bell, Fitzgerald, and Legge (2013) emphasise that parent peer advocacy is not simply taking other parents' problems and solving those problems for them but making sure that these parents are capable enough to advocate for their children themselves. These authors state, "A capability is developed in a parent who feels excluded on a particular issue so that the parent is able to see a way to move around an obstacle to meet their own needs" (p. 7). Bell et al. (2013) maintain that parent peer advocacy is critical and needs to be an unavoidable function for parents who have children with disabilities.

Similarly, Banach, Iudice, Conway, and Couse (2010) note that a support network can be a very effective way to empower parents and help them to become familiar with disability-related laws and other relevant information. These researchers note that it is necessary "to support families in advocating for themselves in schools and other service arenas" (p. 71). Support groups can provide information about available services and resources, share their experiences, and express encouragement. These authors offer this guidance with reference to parents of children with autism but this type of support can also be applicable to parents raising children with other disabilities. Currently, in Uzbekistan, there are several self-support groups, organised by parents of children with Down syndrome and parents of children with autism.

In Uzbekistan, some international organisations and national DPOs have made specific attempts to support parents. For instance, the Uzbekistan National Commission for UNESCO, in cooperation with the Republican Education Center and the Ministry of Public Education, has trained 50 parents from five different regions to strengthen their capacities for ensuring a dignified life for their children. Additionally, UNESCO published a manual that serves as a guide for parents to assist in their children's development (UNESCO, 2012). DPOs are also focused on service delivery with advocacy and lobbying activities to people with disabilities and their family members. Even though the situation is slowly improving thanks to these efforts, the number of participating parents is still small, particularly taking into account the total number of children with disabilities in the country.

6.2.1 Summary

There has been much discussion in this study about the importance of parental involvement in their children’s lives and education. The teacher participants tended to blame many parents for irresponsibility and non-engagement. The literature pertaining to parenting children with disabilities strongly suggests that these parents need to be understood and supported. Some parents can adapt flexibly to a child’s disability, while others may experience considerable distress and depression that can change their behaviour in relation to their children. Social service providers have been found critical for addressing this issue. They can support parents by providing various types of services, such as respite care, parental counselling, or child mental health care. In Uzbekistan, however, these services are mostly unavailable.

A number of participants have also recognised that many families of children with disabilities are more likely to experience financial problems. Besides regular needs that all children have, children with disabilities often require medication, medical and rehabilitation services, specialised equipment, etc. In addition, in these families, one of the parents often quit a job or work reduced hours to take care of a child because they do not have access to reliable and affordable childcare. In some cases, parents who have a child with a disability split up, leaving one of them, mostly mothers, to face financial strains alone. For these reasons, many of these families are at greater risk of living in poverty and their children do not have access to learning opportunities, and some of them not even to essential medical services.

According to the participants, many parents, regardless of their social and financial situations, do not have the knowledge of disability-related laws and regulations to advocate for their children effectively. In many cases, the legacy of the Socialist culture has made them passive and unwilling to confront injustice. NGOs and DPOs help parents who seek help by providing legal advice. Parent-activists also provide on-time moral support and information to families of children with disabilities and draw public attention to their challenges. However, there are not many disability activists amongst parents, and they cannot reach all families, for example, those who live in remote areas. In general, many parents of children with disabilities are very vulnerable. Therefore, they need to be supported, and the role of the government in that is crucial.

6.3 Support and Cooperation with the Government and Other Agencies

The absence of effective government support and provision to children with disabilities was of concern to all parents. The parents stated that they did not receive significant help from governmental agencies, except for a disability allowance. These parents were strongly in the opinion that a disability allowance, however, is not sufficient to cover essential expenses. What follows are some examples of statements from parents pointing out the inadequacy of this funding.

One parent said, "The child gets a disability allowance but honestly, it is not enough at all. For example, medications and development opportunities: logopedists, doctor's consultations… Everything is expensive"[89] (P1). Another parent stated that inadequate financial provision to children with disabilities could often lead to their institutionalisation. She said she had no other choice but to leave her son with cerebral palsy at a boarding school because she had to work:

> If the government had helped me… The government spends a lot of money on these [segregated] institutions. It would be better if it gave this money to families. If the government had helped parents, I would not have sent him there [a boarding school] under any circumstances[90]. (P9)

The parent who supported her son with Down syndrome and at the same time took care of her health because she had been diagnosed with cancer, asked a mahalla committee (community centre) for some help:

> I said, "You know what kind of a child I have but you have never offered help to me". Then they came and brought me some food. I said, "I do not need food. I need financial support to take care of my son. One course of treatment costs a million [Uzbek soms]. Medications are very expensive. Help me with that". They helped me a little and that is all. No help after that[91]. (P5)

This parent added that she would have never normally asked for help but it was hard for her to see how her husband struggled to financially cover both hers and her son's treatment.

NGO and DPO leaders also shared their experiences, both negative and positive, regarding the support from the government to organise social activities. One of their biggest concerns was the strict government's control over funds from international donors:

> We prepared a joint project with a European partner from Hungary to organise seminars for parents of children with disabilities. Our partner was the Hungarian religious organisation. The word 'religious' actually prevented us from realising the project[92]. (P8)

The participant explained that the Hungarian partner had transferred money for the planned seminars but the DPO had not been allowed to withdraw money received from the religious organisation. The government was suspicious that the DPO was planning to organise religious activities, which were strictly prohibited in the country.

The situation with national funding seems to be less complicated. The Uzbek government provides funding opportunities to non-governmental organisations to support their activities. For example, as mentioned in Chapter Four, one of the regional NGOs received grants to organise Inclusive Clubs for children with disabilities:

> These Clubs are unique because educating children with disabilities there does not require any special programmes. They learn art, meet new people, and make friends. The centres promote their integration[93]. (P14)

The participant reported that the organisation had been successfully receiving grants for five years.

Participant 8 identified another problem: to organise events, non-governmental organisations had to get approval from the Ministry of Justice. However, because of the short timeframes, this was not always possible. Sometimes she simply did not have enough time to make an application. As an example, she shared that she had recently been called by the director of a circus, who invited children with disabilities to the show. She had only one day to notify the Ministry of Justice and get its approval, and this was not enough time. The participant added she felt very frustrated and was thinking about closing the DPO.

Participant 14 noted that the government still did not accept non-governmental organisations as partners. When asked about the reasons, she said that there could be several, including a lack of trust and knowledge about the role of NGOs. It resonates with what the participants of the online questionnaire said. They stated that their organisations were not consulted and involved in activities related to disability issues. Almost all of them also complained that there was a lack of accountability and transparency when they dealt with governmental agencies. Yet, when I asked Participant 23, a government representative, about the role of NGOs in developing social and educational inclusion, he seemed to understand their importance and difficulties they experienced. He said that the role of non-governmental agencies was pivotal, but they could be effective only if they were actively involved in decision-making processes. He also added that such a complex process as inclusive education could not be organised by the government alone. It would require the involvement of many other parties.

The majority of participants, however, believed that the interests and opinions of NGOs were often disregarded in comparison with government-organised NGOs (GONGO). For instance, when it comes to the current Inclusive Education Project administered by the Republican Center for Social Adaptation of Children (RCSAC), the government is more cooperative arguably because the RCSAC is a government-organised NGO. Participant 20 said that the project had two key partners at the governmental level: the Ministry of Public Education and the Ministry of Health. At the time the interviews were conducted, the RCSAC was establishing a partnership with the Ministry of Preschool Education. The participant reported that the Center regularly invited partners from the Ministries to all events organised in the framework of the project and had productive negotiations with them. As this participant stated, all involved ministries had been supportive.

The same participant also emphasised a close collaboration between the RCSAC and NGOs, especially those working in rural areas. NGOs are considered strategic partners because people with disabilities living in villages are the most difficult to reach:

> We work with them [NGOs] not only in Tashkent [the capital] but also in remote areas… Many small NGOs are helping us in the territorial districts. We realise that families living there get more support from them rather than from us[94]. (P20)

This participant also said that regional NGOs were regularly invited to attend disability-related events and were provided with updated literature and materials so that they could work with rural families more effectively. In relation to including children with disabilities in regular schools from remote areas, she said,

> They [inclusive schools] are essential for remote areas because not all parents want to send their children to specialised schools [which are mainly located in cities]. They want their child to be with them [parents]. In that case, a child should go to a local school and it has to be ready for inclusive education[95]. (P20)

When I undertook the interviews with the representatives of the RCSAC, they said they were waiting when the Decree of the Cabinet of Ministers on Further Improvement of Inclusive Education came into force to start their activities in the regions.

I asked Participant 20 whether the current Inclusive Education Project worked with specialised institutions. She said that Project members worked with parents as well as teachers, logopedists, and psychologists from specialised educational institutions. She said, "If a child, depending on his/her needs, can receive general education, we offer him/her to transfer to a general school"[96]. She continued to say that in some cases, parents had agreed and transferred their children to a general school but in other cases, they preferred a specialised school.

When the head teacher of the specialised school was asked about cooperation with any governmental agencies, she stated there was no cooperation with NGOs, except for the Special Olympics, an international sporting organisation working with athletes with intellectual disabilities. The Special Olympics organised swimming classes for children with Down syndrome and trained gymnasts. In addition, the organisation occasionally supported families of young athletes by providing food products and holiday gifts.

Yet, the school received regular support from the government:

> The government takes care of our students a lot: free lunches at school… Every year they receive underwear sets and clothes: shoes, jackets, hats, mittens. Every year! Now the government provision has decreased a little but we still have been receiving it for all these years. Textbooks are free; we do not rent them. Many schools in our district are provided with free stationery[97]. (P12)

As seen from above, students of residential institutions and specialised schools in Uzbekistan receive a significant provision from the state. The participants' responses are supported by the information provided in a national report stating, "The students of Mekhribonlik [Mercy] homes and those of the boarding-schools are provided with textbooks and sets of school accessories for free. Annually, more than 500,000 pupils of those categories are provided with winter clothes (coat, footwear, headwear, and gloves)" (Education Sector Plan (ESP) of Uzbekistan 2019-2023, 2019, p. 54). In contrast, families receive very little financial support from the government, and, therefore, some of them cannot afford to take care of their children with disabilities and send them to a state-run institution. Arguably, it is a reflection of historical practices. Phillips (2009) states, "Care in internaty [residential institutions] was framed as a "right" accorded to vulnerable citizens by the beneficent Soviet state, and the collective care of people with disabilities in institutions designed especially for such purpose was considered optimal for their quality of life" (para 48). As indicated previously, during the Soviet era, parents, who took care of their children at home, did not have enough access to disability-related services because they were primarily based in segregated institutions.

Morrison (2004) points out that institutionalisation tends to occur when the state does not provide support and social services to families of children with disabilities. As has been previously reported in the literature, this was a case for the Soviet Union. Tobis (2000) states that the government of the Soviet Union contributed extensively to residential care, “These institutions absorb much of the limited governmental and nongovernmental resources that are needed to assist vulnerable groups” (p. 1). After the disintegration of the Soviet Union, the independent states continued the practice of institutionalisation (Gevorgianiene & Sumskiene, 2017). These authors note that it is paradoxical that former Soviet Union countries, which are not economically developed countries yet, choose to maintain residential institutions whereas community-based services are much more affordable.

In recent years, with increased international attention to human rights, deinstitutionalisation of people with disabilities has become a central issue. Deinstitutionalisation is defined as moving patients of hospitals or residents off institutions into small community residencies (United States Agency for International Development (USAID), 2013). Right after gaining independence, the government of Uzbekistan attempted to deinstitutionalise people suffering from mental disorders. According to the World Health Organization (WHO) and Ministry of Health of the Republic of Uzbekistan (2007), “the number of mental patient-beds was reduced by over 5,000 beds” (p. 9). The funds received from their deinstitutionalisation were supposed to be transferred to outpatient mental health facilities. Yet, instead, they were transferred to other fields of healthcare. This is an example of how a deinstitutionalisation initiative was unsuccessful due to the misappropriate distribution of funds. There is no official information on other attempts of the government to deinstitutionalise adults and children with disabilities. Even if some ideas were realised, they did not change a situation drastically: institutional care in the country is still the main alternative to community-based care.

In Uzbekistan, community-based interventions were first endorsed by international development organisations. In 2008-2010, a pilot CBR project was organised by World Vision International under the sponsorship of the Japan International Cooperation Agency

(JICA). The project was launched in five mahallas (residential neighbourhoods), located in the capital city, with a CBR working group in each. Although the project did not last long, it had a significant positive impact on the lives of people with disabilities, their families, and other community members. Many children with disabilities were identified, integrated into social life, and provided with occupational therapy and educational opportunities in community settings. Support networks were organised for their parents. Non-disabled members of mahallas also benefited from diverse communities that challenged their erroneous assumptions about disability (Turdiev, 2013). However, despite these changes, the government, represented by the Ministry of Labour and Social Protection of Population, did not support the integration of people with disabilities into mainstream community development programmes on a large scale.

Why did the Uzbek government appear to be reluctant to integrate people with disabilities into communities? Arguably, the government did not want foreign representatives to penetrate into local communities. A mahalla might have been considered a primary source of sensitive information that international organisations were not supposed to know. Having faced many challenges when carrying out the CBR project, the project experts proposed realising further CBR initiatives primarily through local NGOs. Although the capacity of NGOs is limited in Uzbekistan, they are less dependable on the government, less hierarchical, and more aware of disability issues than mahallas. Yet, mahallas are still expected to be key partners of NGOs. In this case, CBR programmes have the potential to be realised successfully in Uzbekistan (M. Turdiev, personal communication, December 19, 2019).

Disability allowance and category system. The parents complained about the inability of the government to pay adequate disability allowances. The determination of disability categories has been briefly mentioned above but it will be revisited in more detail in this section. In Uzbekistan, the amount of the disability allowance is dependent on the category of disability that people fit into. The more severe their disabilities are, the higher the allowance they receive. However, in reality, it is difficult for people to receive the right category based on the severity of their disabilities because the government has restricted disability-related benefits. In accordance with the Law on State Pensions (1993), those people who had categories I and II were given the lower disability status. Those who had category III (less severe forms of disabilities) were excluded from this form of social assistance (Equal Rights Trust, 2016).

As noted in Chapter Three, according to Zagirtdinova (2005), medical commissions in the country are reluctant to assign people to higher categories to save the state budget. This author argues, “The state budget cannot afford the social expenses promised by the government, that is; there are a lot of people needing social support and there is little money” (p. 215). Katsui (2005), when discussing disability categories in Central Asian countries, also notes that the states prioritise their financial needs over the rights of people with disabilities. According to Zagirtdinova (2005), the official explanation given by government representatives for reduction of the number of disability benefit claimants was they had changed the registration criteria, due to the increasing number of people who illegally used financial privileges intended for people with disabilities. At the same time, this measure significantly harmed those who were not able to receive adequate financial support under a new criterion, despite their impairments.

The determination of a disability status for adults and children is made by different medical commissions. A Medical Labour Expert Commission makes it for adults and a Medical-Psychological-Pedagogical Committee makes it for children and young people under 16 years old. Both commissions still follow very outdated disability measurements to identify a disability and its degree, which do not allow medical professionals to take an individual approach to people and their health problems. Diagnoses are made and disability categories are assigned based on very general principles without considering people’s specifics and needs (Uzbek Society of Disabled People, 2014). Thus, people with disabilities are often not able to receive the right category, especially in the case of severe disabilities. According to the Equal Rights Trust (2016), it often results in the current system of disability categories being corrupt, “Our research found that due to the complexities of obtaining a disability classification, in some cases, persons with severe disabilities resort to paying bribes in order for their medical certificates to be processed” (p. 230).

The category system also causes a practical difficulty for people with disabilities because their categories have to be renewed every year. This may be appropriate for those who have temporary health problems, but it seems inappropriate for those whose disabilities are permanent. For example, a person with an amputated limb still has to go through a renewal procedure regularly. Participants 2 and 22 mentioned that they had to renew their children’s disability category annually, even though their disabilities could not be changed/improved over time. Participant 2 said that she once had officially complained about the practice. She asked why her child with Down syndrome had to go through that exhausting procedure every year, given that Down syndrome could not be treated. It was explained that even if her child’s medical condition remained the same, medical specialists and social workers still needed to see the child once a year. This supposedly helps them to control his general health condition and see whether he is given appropriate care in the family. Although government officials somehow justified why children with disabilities had to renew their categories, the category situation with adults remains unclear. By making people with chronic conditions renew their disability categories frequently, the government reinforces “the label of abnormality” and reinforces the policy “equal treatment for all” instead of “equal opportunities for all” (Katsui, 2005, p. 53).

According to Kamerman and Gabel (2006), social protection benefits for children may include allowances, fee waivers, feeding programmes, social services, and others. Yet, in less developed countries, there are many problems related to social protection, such as the limited financial coverage, limited provision of social services, and failure to recognise economic benefits of social protection. This is likely to be the case for Uzbekistan. In reviewing the practice of allocating financial support based on the system of disability classification, and in considering the first-hand experiences of the participants, it seems appropriate to conclude that this is a flawed system. It arguably represents a disservice to those with disabilities, whatever the nature and severity of their specific disability and weakness of the current social protection approach.

McKinley and Handayani (2013) argue that the child welfare system in Uzbekistan is adequate, stating, “Uzbekistan offers a range of unconditional child welfare programs. These benefit over half of all children 14 years or younger and involve expenditures that represent a fifth of the government’s total social protection spending” (p. 5). This would be the case if the funding allocated to children with disabilities and other vulnerable groups was sufficient, at least enough to cover essential expenses, such as food and medications. McKinley and Handayani (2013) also note that certain allowances are allocated based on the decisions of mahalla committees. They believe that the distribution of funds through mahallas is very effective because these committees know how to identify beneficiaries better than centralised agencies. Similarly, Coudouel, Marnie, and Micklewright (1998) state that the Uzbek government developed a notable social assistance scheme by establishing mahallas, which should be adopted by other post-soviet states. According to these researchers, in Uzbekistan, in 1997, at least 1 out of 10 families received support from the scheme.

This is the opposite of what the participants of this research said. They argued that mahallas were inefficient in identifying needy families raising children with disabilities and responding to their needs. Stevens (2005) also points out that even though the Uzbek government imposed serious responsibilities on mahallas, there is little evidence that they fulfill these responsibilities effectively. According to this author, the main reasons are a weak institutional structure of mahallas, a low level of human capital available in mahalla committees, and a shortage of financial resources provided by the government to support vulnerable people in communities.

Civil society in the country. Civil society activism is a new phenomenon for post-communist countries (Holland, 2008; Ilkhamov, 2005; Jacobsson & Saxonberg, 2013). After the fall of communism at the end of the 1990s, all newly independent states started a transition policy towards democracy, and this created favorable conditions in the society for the emergence of the activist role. In the early 2000s, there were many newly-established political parties, NGOs, and religious organisations across the former Soviet bloc. In Uzbekistan alone, 3500 different NGOs were registered by 2004. Not all of these organisations were actually operating but many of them were successful (Ilkhamov, 2005).

However, as briefly mentioned in Chapter Two, all Uzbek NGOs were under the strict control of the government, which was suspicious of their activities. According to Babajanian, Freizer, and Stevens (2005), the government repressed the grassroots initiatives of civil society organisations and did not give enough freedom to them to operate. Lewis (2013) states, “Under contemporary authoritarian government, then, civil society organisations may be permitted to function in terms of self-organisation, but any initiatives to promote discursive public spheres are likely to provoke oppression of the state” (p. 333). Under these conditions, civil society organisations were not able to express alternative views and practices.

In 2008, the Uzbek government opened up space for civil society organisations to develop. It established the fund under the National Parliament to finance social initiatives of non-governmental agencies on a competitive basis. Between 2008 and 2011, the Fund distributed around 15.4 billion UZ sums (USD 8.6 million) (UNESCO, 2012). However, according to Bowyer (2018), one third of grants was received by government-organised NGOs (GONGOs), emerged as a counterweight to the independent civil society, and it "diluted the impact of this initiative" (Bowyer, 2018, p. 51). This demonstrates that government policies remained contradicting and hindered the development of civil society in the country.

At the same time, the government enacted two Laws to support NGOs: the Law "On Openness of Activities of Governmental Bodies" and the Law "On Social Partnership". Their purposes are to increase government transparency and public participation (International Center for Non-for-Profit Law (ICNL), 2018). Yet, certain regulatory measures were taken to increase restrictions on civil society organisations. On June 15, 2016, the Ministry of Justice (MoJ) approved the enactment of the Regulation on the Procedure of Coordination of Receipt of Monetary and Other Assets by Non-governmental Non-commercial Organisations (NNOs). According to this Regulation, all NNOs, including foreign NNOs, with registered offices in Uzbekistan, were required to obtain the MoJ's approval to receive assets from any foreign source. On April 25, 2016, the government adopted the Law on Introduction of Amendments to Some Legislative Acts. It requires all NGOs to notify the government about their planned trips to foreign countries (International Center for Non-for-Profit Law (ICNL), 2018, para 11-12).

Recently, the country's new President, Shavkat Mirziyoev, enacted several governance reforms to develop civil society organisations. He has adopted the Decree "On Measures to Fundamentally Enhance the Role of Civil Society Institutions in the Process of Democratic Renewal of the Country". Its purpose is to improve the regulatory environment for NGOs and DPOs in Uzbekistan and to establish a dialogue between these agencies and the state. According to S. Yusupov (2018), the Decree is a turning point in the development of socio-political and socio-economic reforms in the country and creates better conditions for civil society institutions.

The Decree is expected to solve the problems mentioned by Participant 8: receiving financial support from foreign partners and getting approvals from the Ministry of Justice to organise and conduct events. The Decree states that Civil Society Institutions will be permitted to receive grants from foreign sources to accounts opened with any bank (previously, they were allowed to receive grants only to accounts opened with the state-owned banks). In addition, organisations will no longer be required to obtain approval from the Ministry of Justice to conduct events. They will only be required to notify the Ministry of their plans. It is too early to talk about the effectiveness of the Decree but if enacted properly, it may enable social partnerships and address the issue identified earlier in this section of the thesis.

According to some participants, there are some signs of an improved partnership between DPOs and the government. Similarly, Bowyer (2018) points out that national DPOs, along with the Ministry of Labor and Social Protection of Population and members of the Uzbek Parliament, are developing strategies for the realisation of the CRPD. DPOs will also work with the Ministry of Health, Ministry of Public Education, Ministry of Higher and Secondary Education, and Ministry of Employment and Labor Relations to develop a plan on the improvement of lives of people with disabilities in Uzbekistan. Currently, there are 9,000 non-governmental agencies operating in Uzbekistan. However, despite these changes, many of them, especially from the human rights sector, continue to face barriers in their daily activities (Bowyer, 2018). Therefore, much still needs to be done to create a less repressive environment for civil society organisations to thrive.

Rollan and Somerton (2019) suggest that governments and schools should closely cooperate with civil society organisations because they are change-agents in the development process of inclusive education. One of the examples of the successful engagement of NGOs in facilitating inclusive education is Kazakhstan, a neighboring Central Asian country. Kazakhstani NGOs are actively involved in revising education policies, ensuring their enactment, provision of methodological support to teachers, raising awareness of children with disabilities, and changing the cultural perception of them. NGOs are also engaged in lobbying and advocating for children with disabilities. For instance, in Kazakhstan, children with intellectual disabilities were not allowed to study in mainstream schools. However, after NGOs conducted several round tables with officials, the government repealed the law prohibiting these children to attend mainstream schools (Rollan & Somerton, 2019). Thus, to enhance inclusive education reforms, civil society organisations should be acknowledged as equal partners and involved in developing, enacting, and monitoring educational policies.

6.3.1 Summary

Social protection policies can make a significant difference for adults and children and are one of the most effective instruments to tackle poverty amongst them and inequality. Yet, the research participants and most studies indicated the social protection system for people with disabilities in Uzbekistan does not provide equitable access to all people with disabilities and protect them against poverty. The Uzbek government allocates funds to support them, but they are not sufficient. It results in reliance of families of people with disabilities on institutionalisation. If children and adults with disabilities are institutionalised, they receive a full state-sponsored provision. Current practices are largely influenced by a long history of the placement of children with disabilities in residential institutions. Even though there is a growing understanding of the detrimental effects caused by institutionalisation, deinstitutionalisation practices in the country are not supported.

Disability-related NGOs usually take an active role in the process of deinstitutionalisation. However, at this stage, based on the information provided by the representatives of NGOs in this study and the international literature, there is no vibrant civil society in Uzbekistan. Until recently, all non-governmental agencies have been strictly controlled by the government and faced its oppressive policies. It resulted in a significant limitation of organisations' activities, despite their increasingly important role in providing social services. Currently, the civil society sector in Uzbekistan is transforming thanks to a different political approach of the new President. If a non-governmental sector is supported, Uzbekistan will most likely have a sustainable secular civil society that can engage with government officials around social problems, including disability issues and the enactment of inclusive education.

6.4 The Medical Model of Disability and the Legacy of Defectology

During the interviews, the parents reported that as soon as their children with disabilities were born, they became targets of interventions by medical practitioners. Almost all mothers having children with Down syndrome said that doctors in maternity hospitals strongly recommended that they abandon their children. Medical professionals explained that their children would never have a quality future due to their disabilities and they would be a burden to parents and other family members. The parents believed that the practice of abandonment was inherited from the Soviet Union when newborns with disabilities were often taken away from parents and assigned to residential care.

One participant shared, “Right after I had delivered a baby, my husband was informed… He was informed harshly that a child was not healthy, he was born with a certain diagnosis, and he had better abandon him”[98] (P2). However, her husband was supportive and refused to abandon their newborn son. Despite this, the doctors insisted and said that the child would not live long. Her husband was very determined, “Even if he lives for a day, I will still take him home”[99]. Yet, the participant added that her husband’s relatives were against his decision to bring such a child home.

Another participant stated:

> A geneticist examined my son and said that he had Down syndrome. It was very hard to accept a diagnosis; it was like a nightmare. I almost lost consciousness. The doctors said that he would be like a vegetable and I had better abandon him[100]. (P11)

She continued,

> By the way, my son knows how to use a computer very well, although the doctors said that he would never be able to use it. He even helps me to use a computer. He knows it because he often sits by his Dad when he works[101]. (P11)

Another participant was also told at the hospital that her daughter would be like a vegetable and would never be able to move and speak. The woman was given a piece of paper and a pen and with no explanation was asked to sign a refusal letter. The parent said, “I took a paper and a pen but I could not sign it… I could not”[102] (P1). She maintained that in many cases, unfortunately, women and their family members relied on doctors’ recommendations and abandoned their children born with disabilities. The medical authorities defended this by stating that it would be better for the child, who would be given professional care at the orphanage. They said it would be also better for the parents, who would not have the burden of raising such a child if they turned care over to the state. The participant continued that in a residential institution, her child would have been treated in accordance with the traditional medical model – with a focus on her biological dysfunction.

All parents maintained what they needed most at that moment was moral support and information about their child's disability. One participant said,

> You know I was luckier than others were. After spending two weeks in a maternity hospital, I came home. I had internet, I knew languages, and I started searching for information, both positive and negative... Negative information from old encyclopedias stated that they [children with Down syndrome] were hard to raise and hopeless. However, there was positive information as well. I knew languages and translated a lot of information. I understood that they could live a full life but, of course, after they overcame certain difficulties[103]. (P4)

Parents continued to experience problems at later stages too, because medical practitioners viewed disability as a serious obstacle for the child's development in general, and studying at mainstream school, in particular. Much has already been said above about the power of medical officials when it comes to selecting an educational institution for a child with disabilities. Here, I add the opinion of one participant who works at an inclusive educational centre with pre-school children with Down syndrome. It reflects the views of many other participants:

> We teach these children at our level, but when it comes to the further stages, for example, school, we cannot take responsibility for that and recommend a child [for a general school] because our opinion is not final, you know… Even if I give my recommendation that a child will be able to study in a general school, medical specialists may not always approve it[104]. (P15)

The parent said that doctors see a child's disability as the leading causes of *all* other health problems, "For example, when he has a problem with ears or something else, I bring the child to a paediatrician and again he refers to Down syndrome, "Children with Down syndrome always have problems with ears" "[105] (P4).

The same parent complained that medical specialists saw a diagnosis, not a child. They did not want to accept that Down syndrome was not a disease that could be treated. The parent also said that medical specialists had to understand a child still could develop even with that diagnosis. When asked about her perspectives on inclusion, she said that inclusive education was less likely to be developed in the country in the next 50 years because the medical approach continued to dominate.

NGOs and DPOs, participating in the questionnaire, also identified the prevalence of the medical model of disability as one of the most serious problems for a child's participation in regular school:

> The medical approach to disability known as 'defectology' is the biggest barrier to inclusion. It is important to understand that not only special teachers/educators should deal with children with disabilities.

Another questionnaire participant identified three main reasons for the over-medicalisation of children with disabilities:

> One reason is "Gatekeeping" mechanisms (e.g. provisions for the work of a Medical Psychological Pedagogical Commission). Another reason is the absence of continuum services. One more reason is the non-existence of early intervention services (despite new regulations and pilot services that have been established in some polyclinics in the capital city and some regions).

The participants, involved in the Inclusive Education Project, shared that in the framework of the Project they closely worked with medical specialists and tried to convince them to move from the medical model of disability to the social model. When asked whether they encountered resistance, one of the participants replied:

> We have many debates, but eventually, they agree that a decision where a child should study cannot be made based on his/her diagnosis. Let’s take two children with cerebral palsy or two children with Down syndrome. Despite the same diagnosis, they may have different educational needs. Medical professionals have to understand that. They make decisions to treat, treat, and treat a child. However, we explain that a child’s diagnosis cannot be treated. In some cases, a child’s conditions may improve but, in many cases, he will have that diagnosis for the entire life. However, our responsibility is to help that child to receive education, live in society, have a job, his home, his family, and his opinion[106]. (P20)

She added that the RCSAC would continue organizing training and round tables for medical professionals and representatives of the Ministry of Health.

The other representative of the same Project said:

> The Classification of Functioning, Disability and Health emphasises the social model [of disability] rather than the medical model. We select children for studying in an inclusive setting based on their potential, not their diagnosis… Their strengths first and only then their weaknesses. We develop an Individualised Education Plan considering both their potential and weaknesses. This is very important. The medical professionals, whom we trained, have changed their attitudes[107]. (P 21)

Some progress in changing the attitudes of medical authorities towards the development of children with disabilities is promising. However, based on the participants’ experiences, the medicalisation of disability in Uzbekistan still often relegates these children into a lower category of ‘defective’ in which they are exempt from equal educational opportunities. Given that many parents raised the issues of abandonment of newborns with disabilities and defectology, the following discussion is focused on these two themes.

Abandonment of newborns with disabilities and a lack of professional support. Carpenter (2000) states, “In our civilized society, the term “abandon” may seem inappropriate, but examples can still be found of situations where parents were put under pressure to relinquish responsibility for their children” (p. 135). Indeed, as seen from the participants’ statements above, in Uzbekistan, medical authorities often push parents to abandon their newborn children with disabilities to an institutional setting. The same practice also exists in other former Soviet Union countries. Iarskaia-Smirnova (1999) in her research examined the experiences of 12 Russian mothers of children with disabilities. When her participants were asked to share stories of their children’s birth, they all stated that medical officials had put pressure on them to abandon their newborns. They were told that their children would never develop, “It is hopeless, he will be an idiot, he will not even be able to move” (p. 73). When Dowling (2005) analyzed the findings of research on the understanding of a child’s disability by parents and service providers in former communist countries, he found the same tendency. The women in both studies stated that their children’s diagnoses were delivered in a very insensitive way and that there was a lack of dialogue with medical officials. Similarly, Carpenter (2000) concludes that the approaches of medical specialists to parents are often unprofessional; they do not provide any support during the first months after a child was born and diagnosed with a disability, and by doing so, they leave parents to struggle on their own.

In previous years, in some developed countries, for instance, in the United States, mothers of newborns with disabilities were treated similarly. Since 1964, Skotko (2005) had been examining how medical professionals delivered a postnatal diagnosis of Down syndrome to women. This researcher found that a diagnosis had often been delivered to mothers in a very tactless manner, and no professional support had been provided to them. The majority of his research participants reported feeling very anxious and frightened with a diagnosis. Skotko (2005) maintained that women needed more information about a child’s diagnosis and they expected pediatricians and neonatologists to provide that information. However, in many cases, the information they gave was incorrect and insensitive, for instance, the child “would never live on her own or hold a job” or the child “would be mentally retarded and never be able ‘to make change for the bus’ ” (p. 68).

Skotko (2005) reported that some women were also advised to institutionalise their children with Down syndrome. According to one of the Scotko's participants, the doctor said, "Just tell people he died and go on to have more children" (p. 68). Another participant had a similar experience, "In fact, he gave me a shot to dry up the milk and suggested that I never see the infant again" (p. 68). The author states that physician behaviour seems to have changed with time: they are no longer offer women to abandon their children. Yet, in Uzbekistan and many other former Soviet Union countries, the situation has been the same since the Soviet times. Health professionals still strongly recommend to parents that they place newborns with disabilities in infant homes (UNICEF, 2005a). Iarskaia-Smirnova (1999) points out that such "a situation of exclusion is produced through the relationships between the powerful and powerless" (p. 72).

Both the CRC and CRPD impose an obligation on states to respect the right of the child to live with a family. The CRC states that governments have to ensure that a child is not separated from his/her family unless separation is necessary for the child's best interests (Convention on the Rights of the Child, 1989, Article 9). To prevent abandonment of children with disabilities specifically, the CRPD obliges governments "to provide early and comprehensive information, services and support to children with disabilities and their families" (Convention on the Rights of Persons with Disabilities, 2006, Article 23, para 6). Nevertheless, the government fails to ensure adequate support for families of newborns with disabilities that results in their large number transferred from maternity homes to infant homes. In most cases, it is "a first step that leads to lifelong institutionalization" (UNICEF, 2005a, p. xvi).

Power of medical authorities and defectology. Humpage (2007) points out that although medical professionals have expertise in the diagnosis and treating diseases, they should not be given the power and authority over the lives of people with disabilities, especially in social and economic areas. In Uzbekistan, according to the participants, medical authorities are still considered important gatekeepers who have access to necessary resources and make decisions regarding different spheres of the lives of people with disabilities, including their education. Worthwhile support to children with disabilities and some forms of medical examination provided by medical specialists will always be necessary. However, when physicians decide where to place children to study, their focus should be more on individual characteristics of child development, not on their limitations.

Grigorenko (1998) describes an early diagnostic system in Russia that is still applied in Uzbekistan. Children cannot start primary school without a complete medical examination. A medical commission is composed of a pediatrician, a neuropsychologist, a defectologist, and a representative of a local authority. This committee has the responsibility for ensuring the early identification of children with disabilities and making a recommendation regarding an institution where children should study. In most cases, medical officials recommend specialised schools. Grigorenko (1998) states, "It would be an unusual parent who would defy such a formidable array of experts in order to keep his or her child in the ordinary school system" (p. 198). Katsui (2005) notes that even if parents express their wish to send their children to a mainstream school, a medical commission will often not allow them to do that.

Similarly, Markova and Sultanalieva (2013) note that there is often a disagreement between doctors and parents. Many parents are not satisfied with the decisions of medical professionals because they spend too little time with children, do not allow children to adapt to a new environment, administer outdated tests, and then "rush to declare them 'retarded' " (p. 59). In contrast, medical practitioners believe that those parents who try to place their children in mainstream institutions are too ambitious and do not want to recognise that their children will not be able to study there. Markova and Sultanalieva (2013) note that it is not about a lack of professional skills or dedication of medical specialists but rather about a system they were trained under.

When placed in specialised institutions, children are treated in accordance with the science defectology (Phillips, 2009). Dowling (2005) notes that defectology became a professional discourse that separated children from their parents, and by doing so, it created two opposing camps. One comprised medical providers who believed that they served the best interests of children with disabilities by placing them in specialised institutions; the other camp comprised parents who believed that they were forced to relinquish children against their will.

Defectology refers to a person's characteristics related to abnormal psychology, learning disabilities, and special education, such as "sensory difficulties with hearing or speaking, motor impairments, and cognitive functioning below the normal range" (Smagorinsky, 2012, p. 2). On this basis, defectology employs clinical, psychological, physiological, and pedagogical approaches in relation to children with disabilities (Lubovsky, 1974). Defectology is linked with other medical sciences: neuropathology, psychiatry, pathophysiology, and genetics (Big Medical Encyclopedia, n.d.).

The founder of defectology is Lev S. Vygotsky, a Soviet psychologist and founder of Soviet cognitive developmental psychology (Knox & Stevens, 1993). According to Smagorinsky (2012), Vygotsky's works were influenced by his cultural experiences, Christian beliefs, and Marxist philosophy. As a Jew growing up in Byelorussia, Vygotsky experienced anti-Semitism, which made him think about how to integrate people with different views into society. As a Christian, he believed that people with any type of disabilities should be surrounded by support and humanity. He severely criticised those who advocated the importance of suffering as an integral part of Christianity. However, some people question that Vygotsky was a truly Marxist psychologist, as he was known as a dialectical materialist, applying the historical-materialist approach to pedagogy and psychology. Within the historical-materialist framework, his focus was on diversity and socialisation as essential prerequisites for children with disabilities to develop. Florian and Becirevic (2011) also note that the interaction of children with disabilities with their non-disabled peers was viewed by Vygotsky as an important socio-cultural condition. Smagorinsky (2012) states that due to the exclusion experienced by Vygotsky in his life, he developed educational approaches in defectology that supported inclusion and not separation.

Similarly, Daniels and Lunt (1993), when discussing the differences between the principles of Vygotsky's theory and how they were applied in the Soviet special education system, state that Vygotsky proposed a socially-driven model of the child's development. He believed that the goal of the development of children with disabilities should be the same as that for their non-disabled peers. The only difference was that children with disabilities needed a modified educational approach (Grigorenko, 1998). However, in the Soviet system, the social and emotional needs of children were ignored. The teaching content and methods were solely focused on "the correct identification, diagnosis and categorisation of pupils" (Daniels & Lunt, 1993, p. 82). Those who had disabilities caused by organic damage were treated differently from those who had developmental problems caused by social deprivation. Soviet defectology covered only children with developmental delays. It did not include those who had intellectual disabilities or other severe learning, sensory, and/or physical disabilities. It was the responsibility of the Soviet child psychiatry to treat these children (Grigorenko, 1998). This distinction in approach to children with special needs still prevails in the former Soviet Union countries. Vogt (2008), a practitioner who worked in Uzbekistan in the field of inclusive education, also states that defectology as a pedagogical framework is directed towards children with mild and moderate disabilities. Children with more severe disabilities are often declared uneducable and either sent to residential institutions with an emphasis on treatment and rehabilitation or stay with their families and with little or no access to education.

Thus, despite the advanced views of Vygotsky, defectology in the Soviet Union reflected a strictly medical approach to children with disabilities. Florian and Becirevic (2011) state, “though defectology began as a progressive development from Vygotsky’s teaching, it became a discipline that served as an ideological vehicle which, under the medical establishment, produced segregation in tune with the wishes of the communist party elite” (p. 375). That Soviet legacy has been so strong that the legislation related to disability in former Soviet Union countries is still based on medical concepts (Kozma & Illyes, 1993).

Changing views. Even though the medical model of disability is still widely practiced in Uzbekistan, it is possible to make a paradigm shift in the system of special education. Some former Communist nations are good examples of that. The Czech Republic was referred to in Theme Four as an example of a country trying to support the ideology and practice of deinstitutionalisation. In the Czech Republic, defectology was a predominant science to work with children with disabilities (Langer, 2017). Every child, who was diagnosed with a disability, was given a specific treatment and then sent to a specialised school. However, after the Velvet Revolution in 1989, the Republic reconsidered education for students with disabilities and started the enactment of inclusive education. Langer (2017) reports that currently, children with disabilities still receive medical diagnoses, but teachers in inclusive classrooms have a different approach to educating them. Previously, if students with disabilities did not meet the high expectations of a teacher in terms of their academic development and behaviour, they were immediately sent to a specialised school. The new approach insists that students with disabilities should be taught based on their Individualised Education Plans and assigned a teacher assistant (European Commission: DG Employment Social Affairs and Inclusion, 2016). Langer (2017) states, “Little by little, the rigid culture of communism has been breaking down” (p. 5). The societal attitude towards disability is changing and now the society recognises more that children with disabilities should be included in the general education system. There is also an understanding that all main stakeholders, for instance, parents and teachers, should be involved in that process.

Albania is also a former Socialist country with a long history of institutionalisation that actively attempts to promote inclusive education and children’s rights (Taraj, 2018). During the 50 years of Albanian dictatorship that lasted until the early 1990s, individuals with disabilities were isolated and there were no effective social policies to support them. They were placed in care institutions and treated through the medical model (Save the Children, 2012). In the mid of the 1990s, Albania went through the radical transformation towards democracy. The country reconsidered many of its social and educational approaches, including segregated education for children with disabilities. Many parents refused to enrol their children in specialised schools, demanding a right for their children to study alongside all other children. With the support of international donors, the government of Albania started its first integration practices. In many regards, these practices were successful due to the solidarity between the Albanian government, families of children with disabilities, and educators. Since 2000, the government of Albania has been enacting inclusive practices in education. Albania is facing many challenges in this process that need to be addressed, such as a lack of adequate training for teachers, a shortage of financial resources, and an inflexible school curriculum. Yet the country has made considerable progress towards the inclusion of children with disabilities into mainstream schools, even with a limited budget (Radoman, Nano, & Closs, 2006).

Both the Czech Republic and Albania are former countries with a communist regime that have a long history of the institutionalisation of adults and children with disabilities. When inclusive education became a global agenda, the countries reconsidered their approach to these children and started a gradual process of their integration into a general school system. In a mainstream setting, students with disabilities are provided with support services and taught based on IEPs with a strength-based orientation, not based on defectology any longer. The Czech Republic and Albania are at an early stage of the development of inclusive education. However, their experiences in eliminating the power of Soviet defectology and uniting families and schools to reach inclusion could be effectively utilised by other former socialist countries. These experiences are notable and related to the research question about how international experiences inform the better provision of inclusive education.

6.4.1 Summary

When the parents of children with disabilities were asked to reflect on their experiences of giving birth to a child with a disability, they all stated they had experienced strong distress. It primarily happened due to the pressure of paediatricians to abandon a child and a lack of communication with them regarding a child's diagnosis. The attitude towards children with disabilities is still largely determined by the medical model practised in many post-Soviet states. As reported by the participants and recent studies, parents continue to struggle at later stages too, when trying to place their children in general educational institutions. Parents are often confronted by medical practitioners who impose their opinions and send children to specialised kindergartens or schools.

When placed in specialised institutions, children with disabilities are treated based on defectology. A considerable body of literature shows that the Soviet defectology focuses on children's physical and/or intellectual limitations and tries to rehabilitate them, although the initial idea of Lev Vygotsky, a founder of defectology, was to support child's social learning in education and not to be focused on his/her disorder. Within Soviet defectology, which is still excessively practised in Uzbekistan and other former socialist states, people mistakenly assume that children with disabilities have no potential to learn and become self-sufficient. Such an attitude results in low expectations for these children and almost no investment in their development.

There are, however, some positive examples of former communist countries of Central and Eastern Europe that started the process of moving away from the medical model of disability, defectology particularly and initiated the idea of social and educational inclusion of children with disabilities. Although there are still many challenges and contradictions, the governments and people of these countries, who previously believed that children with disabilities had to be separated from their non-disabled peers and institutionalised, have changed their attitudes towards equal access to mainstream education.

CHAPTER SEVEN
CONCLUSION

In this chapter some concluding remarks are made, key implications identified, and recommendations for practical applications and further research offered. The conclusions and implications address the research questions, outlining stakeholders' understanding of inclusive education and their experiences and attitudes to the inclusion of children with disabilities into general schools. The first set of proposed recommendations is for academics and researchers involved in disability research. Other recommendations concern policymakers engaged in disability policy and the design of social services. The chapter next outlines the research limitations related to the methodology this study hinges on. Finally, the chapter suggests some areas for further investigation.

7.1 Main Conclusions and Implications

Although numerous conclusions and implications could be drawn from the discussion of the findings in the previous chapters, four stand out as being particularly relevant: the perceptions of different groups about inclusive education in Uzbekistan and its enactment; attitudes of teachers towards inclusive education; the lived experiences of parents of children with disabilities; and the experiences of national NGOs and DPOs in developing a more inclusive society. These groups raise a wide range of challenges related to inclusion that are discussed further.

7.1.1 Perception of inclusive education and how it is being enacted

As mentioned in Chapter Two, internationally, the concept of inclusive education is considered as education for all students regardless of their abilities, social classes, gender, race, ethnicity, and religion. International organisations often link inclusion to the UNESCO Policy "Education for All", which is committed to ensuring that *all* children, young people, and adults receive basic quality education (Armstrong et al., 2011). This commitment is based on human rights as well as the general belief that education is an essential prerequisite for well-being and development (Miles & Singal, 2010). Yet, the results of this study demonstrate that in Uzbekistan, inclusive education is primarily understood as an equal educational opportunity for children with disabilities only. The international literature suggests that inclusive education should be redefined from a broader perspective and advocated as a social justice matter that includes *all* students regardless of their identities.

In general, within the disability context, participants had a sound understanding of the concept of inclusive education. They might have this understanding because several inclusive education initiatives had been carried out in the country previously. In the late 1990s, international organisations, with the help of national disability activists, started promoting ideas of inclusive education. Even though not all attempts were successful, these helped to shape a certain understanding of inclusive education. However, participants' understanding did not necessarily mean they agreed that *all* children with disabilities should study in mainstream schools.

The staff of schools, non-governmental bodies, and parents appeared to be resistant to the idea of inclusion for those who have intellectual disabilities. Most of them believed that students with intellectual disabilities, excluding those who have mild intellectual disabilities, are not able to succeed in general schools. There are two reasons that were given to support the argument that children with intellectual disabilities need to stay in specialised educational institutions. First, such students are seen as not having "an intact intellect" to study and communicate with other students in a regular class. Second, they are viewed as disruptive to others.

According to the international literature, the attitudes towards people with intellectual disabilities are shaped by cultural norms prevailing in the society. This is also the case for Uzbekistan. Stigmatising attitudes were inherited from Soviet times when children and adults with intellectual disabilities were regarded as a non-existent population (Katsui, 2005; Petrea, 2012; Phillips, 2009). In Uzbekistan, stigma is partially related to the Soviet legacy, but at the same time, it might be very specific to the Uzbek culture, where many people are concerned about having a positive image amongst others. This study has shown that many Uzbek families purposely hide their children with disabilities to maintain a favourable image and avoid discriminatory public attitudes.

Given that stigmatizing attitudes towards children with intellectual disabilities are very strong in Uzbek society, it is not surprising that most of them are not deemed worthy of studying in a mainstream setting. The teachers of specialised schools said they were largely united against inclusion because some of their students had tried general schools but returned to specialised schools. These teachers, however, did not consider the fact that in general schools, these students were expected to study based on a general education curriculum with no individualised support. As stated in Chapter Four, students with intellectual disabilities can succeed if they are taught an adapted curriculum and provided with relevant support services. Support services include but are not limited to, speech therapy, occupational therapy, counselling, and educational skills training support (Datta, 2015). In Uzbekistan, some of these services are available in specialised institutions only.

Centralisation of educational and medical services in one place might seem appealing, but it leads to the medicalisation of special education (Iarskaia-Smirnova & Romanov, 2009). Based on the findings articulated in the previous chapters, students in specialised schools do not receive quality education because they are viewed as defective, with low intellectual functioning. A study programme for them is more focused on the development of occupational skills than academic skills, which significantly impedes their access to further education. A sole focus on occupational skills with no effective transition programmes does not help students find a job either. In general, specialised institutions more create a culture of ‘otherness’ around these students than prepare them for a dignified independent life.

The findings in this study have also indicated that many participants were not satisfied with the way inclusive education was being enacted in Uzbekistan. Their primary concern was that general schools are not ready to work with students with disabilities. There are too many barriers for them in current so-called “inclusive schools”: a lack of infrastructure, overcrowded classes, non-adjusted curriculum content and methodology, untrained personnel, and stigmatising attitudes. Therefore, many parents of children with disabilities felt frustrated and did not have a strong belief that it would be possible to develop inclusive education in the near decades.

Another reason why the research participants were concerned about the enactment of inclusive education was due to a view that many local educators did not see a clear distinction between integration and inclusion. They claimed that educators tended to see inclusive education as simply the placement of a child in a mainstream setting, although inclusion goes far beyond physical presence and involves the transformation of beliefs, cultures, policies, and practices and then a totally different pedagogical approach (UNICEF, 2011). Based on the participants’ experiences and international research, without adaptable teaching and learning environments, the majority of students with disabilities placed into a general education system cannot succeed.

This study suggests that inclusive education in Uzbekistan is not being satisfactorily enacted, despite the government's promise to uphold it. Current educational policies and practices are still based on a medical discourse that views disability as a pathological condition and applies a classification system of children with disabilities introduced during the Soviet era. As Peters (2007) states, "written policy provides a documented legal and moral framework as well as a critical lens for interpreting and understanding practical action/reaction in everyday practice" (p. 100). Supporting a traditional concept of education for children with disabilities has resulted in a lack of vision and awareness of the nature of inclusive education and challenges related to its enactment.

7.1.2 Attitudes of teachers towards inclusive education

In general, there was much agreement between the literature and the findings of this study about the attitudes of general school teachers towards teaching students with disabilities. Evidence from this study has shown that teachers in Uzbekistan typically do not welcome children with disabilities, referring them to specialised institutions. They do not mind working with those who have mild disabilities, for example, hearing or visual impairments, but not with those who have more severe or complex disabilities. Teachers often do not have adequate professional knowledge and skills to teach students with disabilities and their non-disabled peers in one classroom. As stated above, modifications to curricular materials and instructional practices to accommodate children with a wide range of educational needs are also not considered.

The research suggests that teachers face a range of other barriers that make them act against inclusive practices. They include but are not limited to a lack of resources, a lack of individualised support in a classroom, large classes, low pay, and the attitudes of society – namely, the views of parents of non-disabled students who strongly oppose the idea of inclusion. A particular concern here is that inclusive education cannot be enacted unless teachers, as primary stakeholders, hold positive attitudes towards its principles. Therefore, their attitudes, concerns, and expectations need to be further explored to shift inclusive education initiatives from rhetoric to practice.

7.1.3 The lived experiences of parents raising children with disabilities

According to the findings of this study, in Uzbekistan, many parents of children with disabilities are one of the most vulnerable groups, and their experiences are similar to those of parents in other developing countries. They face a myriad of problems at all stages of their children's lives: strong social stigma, financial constraints, the absence of respite care, a lack of disability-related information and services, and many others. Inadequate welfare benefits appeared to be one of the most serious issues encountered by parents. Their children's disability allowance is not enough to cover even essential needs, such as proper food and medical services. Thus, families either find alternative ways to finance their children's needs or continue to struggle. There are also many single mothers of children with disabilities amongst parents. By force of circumstances, some of these women have left their children in residential institutions to start working.

The study has shown that the support of family members and medical practitioners is also what parents need most. Women are often blamed by husbands' relatives for giving birth to children with disabilities and told to abandon them to a state-run institution. The social position of Uzbek women influenced by local traditions often does not allow them to confront their family members. Medical specialists could change this situation if they provided families with on-time information about the nature of a child's disability and effective types of interventions. However, doctors insist on relinquishing these children, explaining that it is a better option for both a child and a family. It results in many children being voluntarily relinquished to residential state care. Parents who decide to keep their children within families despite medical prognosis face many barriers, especially to their child's access to general education.

Regardless of a type of institution children are placed into, parents have many concerns about the quality of education and stigmatization that have a profound impact on children with disabilities throughout their school years. The fact that families and schools often do not maintain relationships worsens the situation. This study has found that there is no effective communication between parents and teachers. Consequently, they do not truly understand one another. Parents complained that teachers were not interested and qualified enough to work with children with disabilities, while teachers blamed parents for not being accountable for their children's lives and shifting their parental responsibilities onto school. Given the fact that most parents raising children with disabilities are in difficult circumstances, some recommendations to address this situation are tabled further in this chapter.

7.1.4 The experiences of national NGOs and DPOs

This study has found that national NGOs and DPOs primarily provide support and advocacy for people with disabilities and their families in the areas of disability rights, social adaptation, and rehabilitation. Since traditionally these organisations deal with legal, social, and medical issues, they are not heavily involved in education and, therefore, cannot advocate effectively for inclusive education. Officials responsible for the education policies in Uzbekistan do not recognise the knowledge and recommendations of NGOs and DPOs as trustworthy and valuable. The government mainly takes advice from defectologists, despite them not often having expertise in inclusive education.

Non-governmental bodies generally have the requisite knowledge and expertise to help the government with the development of inclusive education in Uzbekistan. Based on the survey responses, they have a clear view of what inclusive education is, what hinders its development, and what measures need to be taken to move it forward. Depending on their areas, non-governmental organisations could contribute to inclusive education by participating in policy development, collecting data, organising professional training for teachers of general schools, developing and enacting early intervention programmes for children with disabilities, and informing the society about the advantages of inclusive education. Yet, despite the sound knowledge and experiences of those organisations, they do not take an active part in the enactment of inclusive education.

In some cases, NGOs and DPOs work effectively in small or remote locations, which is difficult for large governmental agencies. The study has illustrated that NGOs and DPOs sometimes are used as a link between inclusive education enactors and rural families raising children with disabilities. For this purpose, organisations are invited to events and meetings to receive updated information and disseminate it amongst families in their villages. They also provide support to international organisations as local experts, for instance, UN agencies, working with and for people with disabilities. In other activities, non-governmental bodies function autonomously.

Due to their limited role and a lack of accessibility, NGOs and DPOs often do not have a partnership with educational institutions. Some international organisations, for instance, Special Olympics, collaborate with specialised schools, but national agencies remain largely uninvolved. There was also limited evidence of cooperation between non-governmental entities and the government itself. According to the NGO representatives who participated in this research, their organisations are not considered equal partners, despite their active participation in socio-political life in Uzbekistan. This study suggests that non-governmental bodies face two particular issues: they are often restricted in their activities, and due to the state monopoly over almost all spheres, they are not directly involved in decision-making processes related to people with disabilities.

7.2 Recommendations for Practice

7.2.1 Recommendations for the field of disability and education

Recommendations for academics and researchers include supporting research-based initiatives, engaging with policymakers, and hiring lecturers with disabilities to promote equity and challenge negative stereotypes and attitudes linked to disability. Recommendations for policymakers include imposing mechanisms for non-compliance with disability regulations, enacting legislation to end institutionalised practices, enacting inclusive education through community-based rehabilitation (CBR) programmes, supporting pre-service and in-service teachers, and supporting families of children with disabilities.

Supporting research. Disability research is critical because it has the potential to improve understanding of the diversity of human minds and bodies (Bolt, 2015). It is especially important in the context of Uzbekistan, where there is not enough research, if any, on disability as a social construct. Many people in the country still believe that disability is a strictly medical issue and can be studied exclusively by medical professionals, health providers, and rehabilitation specialists. Within scientific and non-scientific fields, researchers primarily use a deficit-based approach to disability that has very little influence on policies and consequently does not contribute efficiently to the lives of people with disabilities. Thus, it would be useful to initiate and support disability research in the humanities and social sciences. By doing so, academics and researchers would emphasise the importance of viewing disability as one of the aspects of human diversity, not as a problem in body function.

Another critical aspect of promoting disability research is the involvement of people with disabilities themselves. The current research on disability issues “is not representative of disabled peoples’ experiences” (Kitchin, 2000, p. 26). More substantial knowledge of disability issues could be built if people with disabilities were involved as researchers and co-researchers, not just as respondents or research subjects. As co-researchers, they could participate in a variety of project tasks: identifying a problem, conducting a literature review, data collection, analysis, and/or co-writing. In this instance, research would be based on the principles of participatory action research “conducted by insiders, people who are part of the phenomenon being studied” (Stahl & King, 2019, p. 26). The direct involvement of people with disabilities would produce authentic analysis and address their widespread exclusion from academic and institutional research.

Engaging with policymakers. Academics and researchers exploring disability issues throughout different disciplines need to promote their research beyond academia by communicating their findings to a policy audience. Research that adopts a rights-based approach should inform policymakers what policies could be designed to ensure a long-lasting impact on the lives of people with disabilities. Policymakers themselves may not have breadth of knowledge in the field of disability, and the views of researchers can potentially influence their decisions and, consequently, a policy itself. “By engaging with policy makers academics become involved in answering some of the most challenging questions…, and their ideas contribute to national policy” (Council for Science and Technology, 2008, p. 1).

Nevertheless, connections between academia and a government are often found to be weak (Sasse & Haddon, 2019). To ensure that academia is engaged with policy, certain measures need to be taken. Representatives of academia need to understand why and how they can influence public policies. To equip them with the necessary information, policy engagement training could be offered. Training programmes may include information about a process of policymaking, impact of academia on policies, techniques to bring government officials to universities and get them interested in research, and others. For instance, the University of Southampton, England, has organised a training programme with the involvement of former ministers on how to identify relevant policymakers and to write policy briefings (Sasse & Haddon, 2019). Such training opportunities could help researchers gain essential knowledge and lobby for policy change. Furthermore, developing a broad network with relevant ministries and other government institutions to promote research in terms of advocacy is necessary. It would allow academics and researchers to stay connected with policy experts working on disability issues and to develop long-standing professional relationships with them.

Hiring lecturers with disabilities. To reduce stereotypes related to people with disabilities, higher educational institutions also need to hire lecturers with disabilities. They could shape positive views of themselves by speaking about disability from a perspective of the social model, which is, as stated above, critical. It would be especially important for pre-service teachers, as many of them will work with students with disabilities. Carrington and Brownlee (2001) conducted a qualitative study with the participation of a teacher assistant with cerebral palsy during the training organised for pre-service teachers. During the semester, the teacher assistant interacted with students in-group tutorial discussions. The authors found that students' attitudes to people with disabilities and inclusive education had been significantly improved thanks to the involvement of the teacher assistant in their study.

Currently, in Uzbekistan, there are some restrictions to hiring teachers with visual impairments for primary and secondary specialised schools. According to the Decree of the Cabinet of Ministers on approving the normative and legal acts on state specialised educational institutions for children with disabilities (paragraphs 47 and 50), only sighted typhlitis teachers are allowed to teach students with visual impairments in grades I to IV. In specialised schools, visually impaired teachers may not comprise more than 30% of the total number of teachers. Visually impaired specialists are allowed to teach several subjects, such as native language, literature, foreign languages, history, social sciences (except for geography), math, and music while in specialised boarding schools, their teaching is limited to history, social sciences (except for geography), and music (Lex.uz, 2011). The act does not explain these restrictions and differences in their application.

There is no information on restrictions to hire teachers/lecturers with other disabilities and their number at educational institutions and, in particular, at universities. Yet, given attitudinal barriers and accessibility issues, there may not be many of them working at universities, if any. It would seem that a critical element in addressing this obvious underrepresentation would be for the government to change legislation imposing employment restrictions on teachers/lecturers with disabilities. As stated by UNICEF

(2014c), “This will necessitate the removal of any legislative or policy barriers that require candidates to fulfil specific medical eligibility criteria, as well as the provision of reasonable accommodations for their participation as teachers” (p. 16). This implies that the above-mentioned Decree should be completely reconsidered from the perspective of inclusion.

7.2.2 Recommendations for policymakers

Imposing measures for non-compliance with disability laws and regulations. The CRPD affirms that people with disabilities have the right to freedom from discrimination. The treaty requires governments to “prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds” (Convention on the Rights of the Child, 1989, Article 5, para 2). The Law of the Republic of Uzbekistan on the Social Protection of People with Disabilities nominally protects them against all forms of discrimination. Due to non-compliance with legislation, people with disabilities continue to face discriminatory attitudes in different spheres of their lives. The existing fines and penalties for non-compliance are either inadequate or not enforced. Therefore, there should be *effective* mechanisms to ensure regulatory compliance with laws and regulations to stop discrimination against people with disabilities.

A legally mandating behaviour change imposed by the government to force individuals and organisations to provide equal opportunities to people with disabilities could be an efficient measure. Bilz and Nadler (2014) note that laws are often effective “because they are backed by the threat of punitive enforcement. This threat prompts individuals to make judgments about risk and reward before deciding whether to engage in a prohibited activity” (p. 245). However, such measures are not only about punishment but also about changing the moral attitudes of citizens: when the law imposes punishment based on justice norms, people accept that law as a source of morality. It could be also a timely opportunity for others to learn that no one can be discriminated against on the basis of disability. It could change their perception of these people too. For this purpose, a focus should be made on formulating and enacting strict compliance measures to ensure the effective protection of people with disabilities.

Enacting legislation and policy framework to end school segregation and institutional care. The national disability policy appears to be more focused on increasing the number of segregated educational institutions and their provision, despite the government's formal commitment to inclusion. A very recent example of a segregation-oriented policy is the draft resolution “On measures for further improvement of the educational system for children with disabilities”. The document is primarily about the improvement of the existing special education approach. The measures outlined in the document include the reconstruction of specialised educational institutions, providing specialised institutions with medical equipment and technology, establishing specialised vocational colleges, recruitment of qualified personnel for specialised schools, and others (Governmental portal of the Republic of Uzbekistan, 2020). These legislative practices do not reflect a lack of concern for children with disabilities and their education and wellbeing but rather the perpetuation of previous practices based on insufficient understanding of what could best support children's development (UNICEF, 2014c).

Everything seems to indicate that a key component in addressing school segregation and institutionalisation would be for the government to follow the provisions of the CRPD and to develop legislation and policies that promote a more inclusive education system. First, this would necessitate that the government stops allocating funding to open segregated institutions. Second, this would require policymakers to develop deinstitutionalisation policies with a focus on community-based rehabilitation (CBR) programmes to reintegrate children with disabilities into society. The policy emphasis should be on developing community-based services for children with disabilities and their families. Given the scale of segregation of these children in Uzbekistan, it would also be critical to provide clear guidance and advice on procedures and timeframes to cease their admission to state-owned care institutions.

Enacting inclusive education through community-based rehabilitation (CBR). According to the UNESCO and Ministry of Education and Science of Spain (1994), CBR and inclusive education are interrelated and mutually supported in serving children and young people with disabilities, because they both are based on the principles of integrity, equality, and participation. CBR aims to equalise opportunities for people with disabilities and develop their social inclusion. Inclusive education aims to give children with disabilities full access to learning by including them in community educational settings. Within education, CBR programmes should be focused on establishing and maintaining links between communities, local mainstream schools, and families of children with disabilities and helping those children gain access to schools in their neighbourhoods.

For this purpose, parents, teachers, school authorities, and CBR workers should be trained and involved in supporting children with disabilities in local general schools. Non-governmental bodies could provide training and, at the same time, mobilise communities by educating them. Chavuta, Kimuli, and Ogot (2006) note that relationships between these groups should be based on mutual dependency and cooperation that would construct a shared sense of identity and purpose. For instance, CBR workers could identify children with disabilities and send them to local general schools, while teachers could refer their students to CBR workers for vocational training or other community services.

The main advantage of inclusive education organised in the framework of CBR programmes is it is initiated by internal efforts within the community, not by external ones. This is more effective because internal agencies are more familiar with the local needs, cultural aspects, and available resources. Pförtner (2014) points out that “it might be a good move to start inclusive education through CBR strategy in organised communities, with schools which are willing to collaborate and based on their resources and culture” (p. 80). The other advantage is that if inclusive education is enacted within a CBR programme, it takes a multi-faceted approach to community-based inclusive development, including disability awareness, engaging in early intervention programmes, rehabilitation, and equality training.

Providing professional support for pre-service and in-service teachers. As already mentioned several times in this study, the problem with many current teacher-training programmes is they are primarily based on the concept of defectology. This concept still has a strong influence on professional learning in former socialist countries and raises many issues for pre-service teacher programmes and in-service teacher professional development (Florian & Becirevic, 2011). As a part of overall education legislation, the government should introduce an inclusive education study programme for pre-service teachers. The focus of a programme should be on teaching that addresses issues of student diversity and reducing stereotypes and stigma in relation to people with disabilities.

Otherwise, with defectology being widely taught in teacher training institutions, there is a risk that graduates will reject any move towards inclusive education.

There have been some teacher training opportunities for in-service teachers organised by international and national inclusive education enactors. Yet, none of them was linked to general education reforms and, therefore, was not regular and consistent. To be effective, teacher training need to be conducted on a regular basis: one-shot sessions usually have no significant effect on teachers' practice and consequently on student learning. Another important factor is ongoing support for teachers who enact new practices after they attend training. Teachers may understand and agree with new ideas related to inclusive education, but they often need to be supported in their every-day practice. Ongoing support may be in the form of teaching and professional development resources, collaboration with other teachers and agencies/experts working in a disability field, and professional incentives. In many cases, the realisation of innovative ideas in a class does not lead to salary increases or promotion. If teachers cannot be stimulated financially for supporting new initiatives, certain professional rewards should be considered for them. It does not imply that rewards are essential to effect change, but they could keep teachers motivated.

Inadequate professional preparation and the challenging conditions teachers work in often result in their low motivation, poor performance, and absenteeism. If the government is serious about the introduction of inclusive education, it is imperative that teachers are acknowledged as catalysts for inclusive education practices, and their working conditions are made a priority. Even though government officials recognised the needs of teachers and tried to address them, the reality on the ground is teachers remain one of the most vulnerable professional groups in the country. Currently, the government is undertaking policies and programs to support teachers financially. However, much still needs to be done to address the most pressing of teachers' concerns which are related to the conditions they work in. New policies may require certain funds that are not easy to allocate in a low-income context. However, if teachers continue working in poor conditions, we cannot expect even the most dedicated ones to enact education reforms effectively.

Providing support and education for parents of children with disabilities. Different types of support should be considered for parents of children with disabilities. As the majority of participants stated, they are primarily surviving on their own. Even though there are some laws and regulations enacted to support children with disabilities and their families, they have no significant impact on their lives. Many parent participants have indicated that financial provision is their most urgent need. There should be financial assistance programmes for families in addition to their children's disability allowances, as many of them left jobs to take care of their children. These programmes need to be enhanced by proper monitoring and adequate law enforcement mechanisms. Otherwise, their effectiveness will remain highly questionable. There has been an unsuccessful practice before. In 1991, the government enacted the law on financial provision for parents whose children received home-based education for health reasons. However, the law has never been enforced since that time (Uzbek Society of Disabled People, 2014). After many years, it simply remains a long-lost legal formality. There have been some positive changes in this area. Recently, the President has issued a new Decree to support mothers of children with disabilities. From March 1, 2019, mothers of children born with disabilities with no work experience will be paid a social allowance upon reaching the retirement age (Norma. uz, 2019). It is a certain acknowledgment of their hard work. However, they need financial assistance most when their children are growing to provide them with all the necessary interventions at the right time.

Parents of children with disabilities should also receive appropriate social support. Many government-led social support services remain inadequate and unresponsive to the needs of children with disabilities and their families. Children with disabilities primarily receive informal care from family members and formal services from NGOs and DPOs. However, that support is often not enough for primary caregivers, especially those who have children with high or complex needs. Therefore, it would be useful to reconsider the work of government-organised social services. Respite childcare programmes, designed to provide a temporary break to parents, should be an essential part of that support. Taking time away from caregiving functions would leave caregivers refreshed and enable them to fulfill their duties more effectively.

According to the participants of this study, some parents cannot or do not want to take care of their children for different reasons. Some of them are a lack of responsible parenting and/or bad habits, for example, excessive alcohol use. Therefore, children are often denied adequate living conditions, proper food, and medical and/or rehabilitation services. Research participants recommend taking children out of their families and placing them temporarily with their close relatives, foster families, or other alternative places where they can be watched and protected. Respite care interventions have the potential to avoid this situation by decreasing parental burnout and stress, increasing their life satisfaction, and improving the parent-child relationships (Cohen, 1982).

Investing in the development of this service is, therefore, of particular importance. Even with the budget constraints, the relevant ministries should consider ways of using the existing funding to better support families with children with disabilities. Ministries, together with people with disabilities and disability support organisations, should consider possible respite options (in-home respite care, respite houses, and/or after school care) and develop a strategy that will set a direction for their establishment. As a part of that strategy, they also need to develop an action plan to train and retrain support workers responsive to the needs of people with disabilities. Only under these conditions, primary caregivers would be able to continue their caring role and maintain their wellbeing.

Parents also should be educated about specific skills their children's disabilities might require, in addition to the general knowledge they have. Besides, parents should know about the importance of early intervention practices to minimise the long-term effects of disabilities. These may include speech therapy, occupational therapy, and/or physiotherapy. Knowledge of disability laws and regulations is also essential for parents to act on behalf of their children effectively, especially in a situation where laws are not enforced. Yet, education should not be limited to only managing their children's lives. Parents should be also encouraged to participate in decision-making processes and supporting other families that could potentially facilitate parental activism.

7.3 Limitations of the Study

Limited number of participants from the regions. One of the limitations of my study is it was primarily conducted in the capital city of the country; only two regions out of 12 were involved in it. Participant 14, representing the region, mentioned there were no significant differences in a disability situation between the capital of the country and its regions, except for the fact that all legislation came into force in the regions later than in the capital. However, I do believe if data had been collected in some other regions, I, as a researcher, would possibly have had a more complete picture of disability issues in the country.

Limited involvement of government officials. Collecting very little data from government officials could also be considered a limitation. I was not able to involve many government representatives as research participants, although they are key players in the process of the enactment of inclusive education in the country. I attempted to contact current and former officials from the Ministry of Public Education and the Ministry of Labor and Social Protection of Population, but they were not willing to meet, except for one person. As indicated previously, although the government is more open now than it was previously, disability issues remain sensitive, and Ministry representatives might remain reluctant to release that information. Therefore, I could only consider what many of them seem to think about disability issues and inclusive education indirectly based on the statements provided by other research participants.

Non-involvement of children and young people with disabilities in the study. The non-involvement of children and youth with disabilities may be seen as a limitation because their participation could have provided additional valuable data for the study. As noted in Chapter Three, it was planned to involve children and young people with disabilities in this study as research participants to gain their insights into what they thought about inclusive education. Yet, the obtaining of consent forms from their parents was not possible. Parents were arguably reluctant to allow children to participate in a focus group due to their unfamiliarity with informed consent and, consequently, mistrust.

Lack of previous research. Given the lack of previous research on inclusive education in Uzbekistan, I had little literature to make reference to in this research. After searching the international databases extensively, I have found much literature on the enactment of inclusive education in other developing countries, including some of the former Soviet Union states, and used this material to inform my study. This literature helped me understand the enactment of inclusive education in the developing world better and laid the foundation for this study. Some problems discussed there are typical of all developing nations, for instance, a lack of professional knowledge and skills of teachers working with students with disabilities in mainstream classes or a shortage of financial resources to enact inclusive education. Nevertheless, there are still certain country-specific problems that with a wider scope and more time could have been explored more, such as cultural stigma and the complexity of rural contexts experienced by people with disabilities living in remote areas. I have attempted to discuss some disability issues typical for Uzbekistan where it was possible. Yet, the outcomes of the discussion are not conclusive. Thus, I proposed several areas that seemed critical to me for deeper investigation. They are outlined below.

7.4 Recommended Areas for Further Research

Inclusive education for children with intellectual disabilities. As stated above, many participants of this research believe that children with intellectual disabilities cannot be educated in a mainstream setting because their mental capacity is limited and cannot be improved over time. However, international research and practice suggest that children with intellectual disabilities can be successfully included into regular schools (Hallahan, Kauffman, & Pullen, 2019). Their success is largely attributed to the change in teachers' attitudes and the use of appropriate curriculum and special education services. Therefore, one of the proposed areas for research is teachers' attitudes and concerns about teaching students with intellectual disabilities. It would also be useful for researchers to explore best practices that have the potential to help students with intellectual disabilities to succeed in a mainstream setting.

Transition of students with disabilities into the workforce. The vocational transition for students with disabilities and employment barriers could be another study for further exploration. Based on the results of this study, we can conclude that in Uzbekistan there are no comprehensive transition processes for this group. Many young people with disabilities remain unemployed after leaving schools. Job opportunities for them remain a pressing concern for both parents and teachers. Specialised schools offer vocational training programmes, which have little effect in reality, due to strong prejudice towards people with disabilities in the workplace. It is important to emphasise cooperation between schools and potential employers. A successful transition into the workforce should require more than just schools to facilitate vocational rehabilitation programmes. It should also require employers to reconceptualise the employment of people with disabilities as potentially beneficial for society as a whole, and an organisation in particular. Other areas for research within this study may include a current understanding of transition processes of families, schools, and potential employers; transition issues faced by young people with disabilities and what could possibly be done to improve their transition outcomes; and evidence-based practices in transition programmes.

Cultural understanding of disability and its impact on the inclusion of children with disabilities into general schools. As the participants' experiences and literature revealed, traditional cultural values and beliefs shape our attitudes towards individuals with disabilities. In Uzbekistan, a legacy of disability labelling and cultural stigma appear to be severe and pervasive. Children with disabilities often experience discrimination and exclusion in every aspect of their lives, including education. More knowledge could be built if studies on cultural perspectives on disability in the Uzbek context were undertaken. The focus of proposed studies should be on investigating sociocultural beliefs about the causes of disability and what intervention strategies could be designed to combat these beliefs and include children with disabilities into local general schools.

7.5 Final Thoughts

Even though Uzbekistan has attempted to include children with disabilities in a general school system, inclusive education in the country remains elusive. Taking into account the long history of institutionalisation, it may be a very long way to go before we have truly inclusive schools. Charema (2010, p. 88) states, "Inclusion is a vision, a road to be traveled, but a road without ending since it is a process rather than a destination and a road with all kinds of barriers and obstacles, some of them invisible and some of them are in our own heads and hearts". Indeed, the development of inclusive education is a long journey with many barriers to overcome.

Nowadays, Uzbekistan is facing many obstacles in the process of enacting inclusive education in the country: attitudinal barriers, a lack of teachers' professional knowledge and skills, a lack of services for children with disabilities and their families, inaccessible school and public infrastructure, and many others. These problems cannot be solved overnight; they require time, effort, and resources. However, the development of inclusive education is not only about financial provision. In many respects, inclusive education is about attitudes, values, and political will. As briefly discussed in Chapter Four, the political willingness of decision-makers to support the development of inclusion is a determining factor. According to Halachev (2015), political will support pedagogical initiatives that will be aimed at "developing inclusive knowledge and skills among mainstream teachers, supporting peer learning programs, mentoring programs and minding the gap between the education system and the labour market" (para 7). The international literature offers many examples showing how low-income countries succeeded in promoting and fulfilling the right of children with disabilities to mainstream education because their politicians have a vested interest in inclusive education (Mariga et al., 2014).

The willingness and readiness of the government is critical but it is not the only factor for the successful enactment of inclusive education. Advocacy by parents of children with disabilities, teachers, Disabled People's Organisations, and other stakeholders plays a critical role in this process. There are many examples across the world of advocacy campaigns that pushed governments to launch inclusive education projects. For instance, in Lesotho in the 1980s, parents started to demand a better educational provision for their children (Khatleli, Mariga, Phachaka, & Stubbs, 1995). They initiated the disability movement and put pressure on the government to start pilot inclusive education projects that were further extended. The advocacy of people with disabilities themselves can also be a powerful instrument for creating a more inclusive society. In the United Kingdom, the British Council of Organisations of Disabled People (BCODP) encouraged other disability-related agencies to join forces and advocate for a new model of inclusive education that was supported by the government (Campbell & Oliver, 1996). These authors state, "disabled people themselves had come together in a collective sense at the heart of disability politics in Britain" (p. 89). Hence, the power of disability advocacy can radically shift policymakers' thinking and persuade them to recognise the rights of children with disabilities to study in general schools, with choices equal to others.

The success of inclusion also largely depends on cooperation amongst all stakeholders as none of them can effectively function in isolation. Uzbekistan will not need to develop new ways of creating a partnership to establish and sustain inclusive schools. Many countries have already gone through this process and their "successful experiences… can help [other countries] build a suitable foundation for effective partnerships with families, communities and social organizations and networks" (UNICEF, 2014d, p. 25). When adapted to the local context, existing expertise could be beneficial for Uzbekistan. I am convinced that tangible results in bringing children with disabilities back to communities and realising their right to receiving a quality education can only be produced through joint efforts.

Annex

Participants' statements in original (Russian) language

[1] Равные возможности в получении качественного образования.

[2] Создание условий и возможностей [для] получения образования для всех и в любом учебном заведении.

[3] Инклюзивное [образование] это то, что я хотела. Чтобы равные права были, равное отношение было, как к обычным детям. Инклюзивное образование хорошо тем, что оно открывает людям глаза на таких детей, чтобы они не боялись их, а воспринимали такими, какие они есть. Чтобы родители [нормотипичных детей] не ограждали, не забирали своих детей: «Ой, больной ребёнок». Я понимаю так инклюзивное образование. Ну, всё-таки подход разный должен быть к каждому ребёнку.

[4] Инклюзивное образование, мне кажется, это когда ребёнок не отделён согласно классам, категориям, не разбит по диагнозам.

[5] Инклюзивное образование это когда дети с ограниченными возможностями могут учиться с обычными детьми.

[6] Давайте поговорим о том, как у нас понимается инклюзивное образование, если Вы не против... Во первых, [у нас] несогласованность понятий. У нас создали новое понятие, которого нет нигде в мире – «Инклюзивный класс». Я говорил о том, что нет такого понятия, инклюзивной может быть школа. У нас посадили пару человек с инвалидностью в общий класс и всё. Это не есть инклюзивная школа. Школа начинается с ворот. Ворота, классы, спортзал, туалеты – всё должно быть инклюзивным, они должны быть доступными… Они не могут построить инклюзивную школу, им проще сказать: «Мы создали инклюзивные классы».

[7] На сегодняшний день ведущими специалистами страны под инклюзией понимается интеграция. Просто детей с нормальным интеллектом, но с [физической] инвалидностью включают в школу. Это не есть инклюзия.

[8] Она [организатор пректа] предложила взять учащихся из специализированных школ для глухих и включить в образовательный процесс [в общеобразовательной школе]. Т.е. утром автобус подходил туда, забирал детей и привозил в школу. Но здесь опять-таки не были подготовлены ни учителя, ни дети, ни родители. Т.е. подготовительной работы, которую мы потом проводили в проекте Евросоюза, не было. И потом, дети они же дети всё равно: глухие дети были сами по себе, а те [нормотипичные] сами по себе. Не было инклюзии как раз-таки, включённости не было.

[9] Я видела инклюзивные школы в других странах: в Америке, в Литве, в Венгрии. То, что я видела, не даёт мне уверенности, что это можно сделать у нас.

[10] И финансирование должно быть, и понимание должно быть. И не только понимание родителей, но и понимание власти, что детей надо учить.

[11] Плюсов [инклюзивного образования] много. Во первых, ребёнок в среде, [приближённой] к жизни. В классе дети ведь не на подбор - разные дети там. Он [ребёнок], получается, без отрыва от жизни находится в той возрастной среде, в которой он должен по жизни быть.

[12] Любое образование это, прежде всего, социальное общение, приобретение социальных навыков, включение в жизнь общества. Ведь даже люди, которые заканчивают общеобразовательные школы, не всегда грамотные. Мы не даром говорим, что это включение, а образование – это просто рычаг, один из элементов для включения в это общество.

[13] В нашей школе есть тяжёлые дети, но есть и дети категории Ф-70 [шифр умственной отсталости согласно Международной классификация болезней 10-го пересмотра (МКБ-10)]: [у них] есть умственная отсталость, но это пограничное состояние. Очень хорошие дети, идут на контакт… Там есть разные дети, например с синдромом Дауна. Я всегда хотел, чтобы в обычных классах были дети с синдромом Дауна, они же очень открытые. Когда мы приходим туда с сыном, дети с синдромом Дауна его обнимают. Они могли бы компенсировать наши минусы [имеется в виду отсутствие коммуникативных навыков, присущее людям с РАС]. И это было бы хорошо, наши дети привыкли бы к этому.

[14] Около четырёх лет я сидела с ним [в классе], у него очень сложная форма гиперкенеза, если Вы понимаете детский церебральный паралич. Во первых, он практически не говорит. Если что-то держит в руках, пишет - ему нужна непосредственная помощь. Я, получается, выполняла роль ресурсного педагога, потому что я сидела с ним. Потом, когда он четыре класса закончил, мы перешли на надомное обучение. Педагоги к нам ходили из общеобразовательной школы до девятого класса… Но в конце 90х - начале 2000х учителя [работали] на общественных началах. Как таковой системы уже не было. И судя по отзывам наших родителей, надомное обучение - хотя оно до сих пор существует, причём существует так же как и общеобразовательное, и вспомогательное типы обучения - ну, лучше чем ничего.

[15] Его состояние здоровья стало моей профессией.

[16] Может, потому что мы уже привыкли: то мы к ним, то они к нам. Иногда они приходят к нам на праздники показать своё искусство - танцы или пение - то, что они могут.

[17] Мы стараемся их выводить в театры, цирк, зоопарк, музеи, потому что родители их не поведут. У нас дружба с музеем искусств. Там даже какие-то циклы они проводят и мы в эти циклы включаемся. Ученики там рисуют, общаются, им что-то объясняют.

[18] Всё равно ведь они из этих спец. школ когда-нибудь выходят в жизнь. Там уже жизнь разнообразная… Дальше им сложно жить.

[19] Родителям начинаем объяснять, что социализация может быть только тогда, когда он будет в среде своих здоровых сверстников с раннего возраста - самая главная концепция инклюзивного образования. А когда он обучался среди подобных ему детей в течение 17 лет и потом его выпустили, мы не можем сказать, что он может социализироваться – вот где проблема вся. Он не может...

[20] Многие знакомые, родственники обратили внимание на то, что поведение кардинально изменилось у ребёнка. Мировоззрение, поведение изменились в лучшую сторону. Среди обычных детей она стала лучше себя вести.

[21] Я вижу только плюсы со всех сторон: и в учёбе, и в развитии отношений. Если бы все дети имели возможность ходить в инклюзивные школы, то у нас было бы меньше забитых. Нужно давать людям такой шанс.

[22] Дети, у которых слабое зрение или слух слабый, могут как-то быть включены [в общеобразовательные школы], потому что у них интеллект сохранный… Я всё время борюсь против инклюзии детей с интеллектуальной инвалидностью, как только это движение началось: не смогут такие дети присутствовать на уроке в общеобразовательной школе.

[23] Много-много лет назад на базе общеобразовательных школ открывались классы, но это только начальные классы были. Потом они переходили сюда, так как на базе массовых школ мастерских таких, как у нас, нет. Этот переход был тяжелее, морально тяжелее для родителей и для детей: ребёнок учился в одной школе и вдруг его переводят в другую… И ребёнок, и родители не были готовы.

[24] Физика, химия, иностранный язык, алгебра - нет у нас таких предметов. Только математика, естествознание, география, история, но это курс очень сокращённый.

[25] Фактически это нулевой уровень при таком прогрессе, развитии знаний… И у них у самих протест... Они чувствуют это и говорят: «Мы не хотим учиться в этой школе». А какой у них есть выбор?

[26] Инклюзивное обучение ввели для того, чтобы дети не отделялись от других… но у кого нарушен интеллект, он так и так будет отделяться. Лучше пусть в своей школе они все будут одинаковые. Они на одном уровне все. Грубо говоря, они как рыба в воде.

[27] С ментальными нарушениями, мне кажется, это [инклюзивное образование] тоже нереально. Потом, если инклюзию проводить, представляете, в школах у нас заполненность 40 человек [в классе].

[28] И если взять образование, у нас в классах по 50 человек. О каком включении особого ребёнка может идти речь? Поэтому я не знаю, насколько у нас перспектива с инклюзией вообще [есть].

[29] Мы говорим о равных правах, о включении всех детей в общеобразовательные школы. Но если ребёнка невозможно скорректировать и он кричит весь урок? Понятно, если день, два, три, а если это годами продолжается? Если это мешает учебному процессу ежедневно, то ни о какой инклюзии речи не должно быть. У меня убеждённость в этом.

[30] Знаете, у нас это [инклюзивное образование] ещё не так распространено. У нас, по-моему, в школах есть такие дети, но не во всех. Но если мы начнём в качестве экспериментальных школ: во всех районах по одному саду или по одной школе, [будем] отдавать туда детей и распространять это, общество это примет.

[31] Это не должно быть жалостливое отношение к этим детям, а отношение как к равным, как ко всем людям, без дискриминации.

[32] Это были 60-е годы, годы моего детства... Единственного инвалида с умственной отсталостью, которого мы видели, был братишка моей подруги. Он шатался по нашему посёлку сам по себе и никто не обращал на него внимания, никто из встречных с ним не общался... Он был как инопланетянин, никогда не входил в зону жизни обычных людей. Это было что-то непонятное, а как общаться с непонятным?

[33] Представляете, с утра до вечера с ним в школе, потом приходим со школы, я с ним уроки делаю - это очень тяжело. Я с восьми утра до шести вечера как педагог. В это время я должна кушать сварить, постирать, убраться… Это всё в одно [время], очень устаёшь. У меня мозг вообще не отдыхает.

[34] Если их включать в инклюзивные классы, ничего не готово. Многие всё равно идут туда. Я ходил в эти классы. Представьте, 30 человек и он [ребёнок с аутизмом] там сидит. Они все кричат, его трогают... И родители вынуждены сидеть там. Они хотели бы оставить его и уйти, но как?

[35] Знаете, я не борюсь с тем, чтобы инклюзию закрывали. Им же надо с чего-то начинать. Я понимаю, это пилотные проекты.

[36] Я категорически против. Вы для него мама: Вы для него стираете, Вы ему попу подтираете… Он никогда не будет воспринимать Вас как учителя.

[37] Поэтому если бы с ним сидел специально подготовленный педагог, всё было бы по другому. Во первых, она бы подходила ко всему профессионально, а я переживаю сильно и ребёнка дергаю.

[38] Вот смотрите, второе правило инклюзивного образования, Вы лучше меня знаете, – наличие ресурсного педагога. Его нет. Мы когда разговаривали с Минфином, просили выделить штаты для должности ресурсного педагога. Но такие штаты никто не выделяет… Как можно внедрять инклюзивное образование без ресурсного педагога? Как? Вы знаете? Я нет…

[39] У меня есть знакомая Алия. Год назад она горела желанием, чтобы её ребёнок обучался в инклюзивном классе. Она добилась этого, но сейчас она настолько устала, что готова уйти оттуда. Это огромная нагрузка... Кто-то из детей что-то выкрикнет, она уши своему ребёнка закрывает. Если он начинает кричать, она его из класса выводит. Учителя дают задания и, если он не может, она сама делает за него. Он не может нарисовать, она рисует за него…

[40] Сегодня мы не можем говорить о создании штата таких педагогов в школах, потому что мы сейчас в процессе становления, но со временем это будет.

[41] Вот эти три варианта у нас [у проекта «Инклюзивное образование для детей с особыми потребностями в Узбекистане»] существуют. И если учителю трудно, мы предлагаем эти варианты и механизм их релизации. Но, конечно, [наличие] тьютора остаётся [актуальным], мы будем над этим работать. Когда мы будем готовы включить детей с тяжёлыми потребностями, тьюторы будут уже необходимы, без них будет сложно очень. Мы когда были в Австрии, видели ребёнка, который на сколько-то процентов не видел, он был неподвижен и отдельный тьютор сидел с этим ребёнком. Но мы к этому должны подготовиться: для этого необходим тьютор, у которого будет оплачиваемая работа со стороны школы. Он должен быть штатным работником этой школы.

[42] Мы с ней ездили от одного лицея к другому и смотрели есть ли ступеньки… Ей очень тяжело было по ступеням ходить. Она хотела в лицей ин. яза, мы подъехали туда, она ступеньки увидела и говорит: «Нет»...

[43] У нас в начальные классы детей с ДЦП очень сложно внедрять, потому что нет инфраструктуры. Есть пандусы во всех школах, но они же потом учатся на втором, на третьем этажах. В одной пилотной школе у нас первый класс на втором этаже. Как он [ребёнок с церебральным параличем] может подняться туда? Родитель потом забрал его… Он не может подняться, родитель его поднимал туда и потом, когда заканчивались уроки, уносил. Нет возможности на второй этаж подняться, а так он мог бы ментально [учиться]. Из-за такой неподготовленности инфраструктуры ещё есть сложности.

[44] Сегодня по распоряжению Президента идёт реконструкция во всех дошкольных образовательных учреждениях. В школьных образовательных учреждениях тоже будет такая реконструкция и школы должны быть готовы к тому, чтобы для любого ребёнка с потребностями, какие бы потребности он не имел, они были доступны.

[45] У молодых женщин затворнический образ жизни. Девочки, которые заканчивают эту школу, сидят дома. Дальше - всё, им некуда идти. У нас есть специализированный колледж, опять-таки специализированный… Он находится за городом. Там хорошие условия, обучают швейному делу, сапожному делу, но туда родители девочек, во всяком случае, не отдают. Во первых, туда надо отвезти и, если [девочка] не будет ночевать [там], вечером привезти. Если есть рядом с домом колледж, туда не берут, потому что аттестат не тот. Там написано [что ребёнок закончил специализированную школу].

[46] Сейчас, правда, вышло распоряжение, что нельзя закупать автобусы, не приспособленные [к коляскам]. Но опять-таки, Мерседесы - да, они ездят. Я вчера видела как мама с обычной коляской вошла и встала. Но наши автобусы узбекского производства [не приспособлены]: туда не то что с коляской, туда и сам не всегда поднимешься.

[47] А вот эти пандусы строят. Это же орудие для самоубийства – под 45 градусов. Я считаю, что это просто не порядочно со стороны государства, лучше вообще не надо строить, чем ради галочки.

[48] Учителя не знают что делать с такими детьми. Учителя их бояться.

[49] Логопед есть, психолог тоже есть. К логопеду я пошла в прошлом году, но, знаете, это была потеря времени. В начале она сказала: «Ой, какой тяжёлый ребёнок. Вот это он не делает, то не делает». Но это её профессия. Почему здесь [в РЦ САДе] логопеды справляются, как-то могут его заинтересовать?

[50] Его держали, не выпускали ко всем. Если это зима, то в спальне с ним отдельно сидели. Если это весна или лето, выходили на прогулку. Т.е. пока дети занимались, они там прогуливались. И это его очень сильно раздражало, обижало. Он приходил и мог что-то начертить на рисунках детей. И родители пошли жаловаться к заведующей, сказали, что он портит работы их детей.

[51] Иногда бывает, что родитель с таким трудом устраивает ребёнка в обычный сад. Для неё это показатель. Родителям [нормотипичных детей] говорят, что появился такой-то ребёнок в группе, но родители ставят ультиматум заведующей: уберите этого ребёнка или мы все уйдём из детского сада. И у заведующей не остаётся другого выбора, как убрать этого ребёнка, сказать «Вы нам не подходите». Знаете, какой это стресс и для ребёнка, и для мамы?

[52] Хотелось бы, конечно, чтобы педагоги относились с пониманием, лояльно. Хочется уже таких педагогов, которые хотят обучить чему-то детей, а не так, что пришли зарабатывать на жизнь.

[53] Хотелось бы, чтобы у нас внедрили индивидуальную программу развития ребёнка и чтобы наши педагоги понимали, что каждый ребёнок развивается индивидуально. Даже если диагноз одинаковый, потребности и уровень у каждого ребёнка разные.

[54] Очень сложно было, так как диагноз везде присутствует [упоминается во всех документах], все боятся этого диагноза. И мы, честно скажу, умоляли заведующую, чтобы она посмотрела на нашу девочку в окружении обычных детей.

[55] Даже элементарно весь алфавит она не знала.

[56] Учителя не задают ей домашних заданий, не обращают на неё внимания, не занимаются с ней - её просто нет.

[57] Педагогов надо обучать, что эти дети такие же, как и остальные. Они имеют такие же права. У меня были конфликты в саду, мне говорили: «Чего Вы хотите от него? Он дальше развиваться не будет!».

[58] Официального документа, зарегистрированного Министерством юстиции, нет... Вы можете сказать: «А Закон об образовании?», но там нет слова «Инклюзив». В Законе о социальной защите инвалидов этого тоже нет. Кстати, этот Закон не соответствует Конвенции ООН о правах инвалидов...

[59] Наше сегодняшнее законодательство, так как я юрист всё-таки, хочу сказать, очень хорошее. Оно допускает применение практики инклюзивного образования. Нет никакого законодательного препятствия для того, чтобы дети с легкими особыми потребностями обучались в общеобразовательных школах.

[60] Я считаю, если бы были государственные механизмы программы по поддержке индивидуальной реабилитации и с кого-то бы за неё спрашивали, люди бы этим занимались и за подопечными смотрели… То же самое произошло и с индивидуальным патронажем. Чем выше [закон] от благополучателей, тем более всё становится размытым… Например, мой ребёнок – молодой человек. В семье он получил всё, что возможно. Он, может, больше социализирован, чем обычный ребёнок в обычной семье. Но, тем не менее, он гражданин, он взрослый, он имеет право на получение каких-то гарантий от государства.

[61] Они изолированы. Про них никто ничего не знает: как их зовут, кто они. У них даже метрик и паспортов нет. Знаете, в кишлаках много таких мест.

[62] Многие всё равно прячут [детей с инвалидностью]. Но, Слава Богу, год то года ситуация меняется… Ну, ладно в первом классе он маленький, а потом во втором, третьем, четвёртом классах уже нужно будет открываться. Есть такие родители, конечно, но это уже менталитет. У нас считается, что это [аутизм] стыд, что в аутизме виноваты родители.

[63] Родственники от нас давно уже отвернулись. Они могут ещё родителей куда-то позвать [пригласить]. Если меня зовут, то просят сына не брать. Мне же обидно. Я им говорю, что я бы и так его не взял. Они лишний раз напоминают, а это больно.

Иногда они мне говорят: “Он умственно отсталый. Зачем ты его держишь? Всех мучаешь”.

[64] Первые шесть месяцев у меня было такое состояние: «За что?! Что я сделала не так в своей жизни?». Окружение со стороны мужа говорило: «За что-то», хотя я была очень хорошей невесткой, старалась во всём потакать семье мужа.

[65] Свекровь очень не хотела нездорового ребёнка. Муж был в замешательстве. Он не знал чью сторону принять: прислушаться к матери или ко мне. Это очень сложный период был… Это больше относится к нашему менталитету: не принимают узбекские семьи больного ребёнка. «Как так вышло: у меня здоровый сын и у моего здорового сына больной ребёнок родился?». Такая проблема у нас возникла и свекровь сказала мне, чтобы я поменяла ребёнка… Я по роддомам ездила, смотрела отказных девочек. По виду она должна была быть похожей [на нас]. Четыре месяца я искала ребёнка… Честно скажу, я в шоке была и ничего не соображала. Я не осознавала тяжесть потери собственного ребёнка и как я восприму чужого ребёнка… Чтобы сохранить семью, я шла на поводу у свекрови… Нашли ребёнка, оформили всё юридически. Потом привезли другого ребёнка домой и в этот момент я осознала, что я не могу без своего ребёнка. Я её грудью кормила, четыре месяца ухаживала за ней и вдруг поменять. Я плакала и плакала. И муж плакал. Мы обнимемся и плачем… Потом я к мужу подошла и сказала о своём решении: «Если не хотите, мы можем расстаться». Муж поддержал меня, сказал: «Как ты решишь, так и будет». И я поехала за своим ребёнком.

[66] Единственная моя проблема - будущее этого ребёнка. Школа, а что будет дальше? С нашим менталитетом, в нашем государстве как это вообще будет, будущее её? Меня это очень волнует и представления нет… Вот мы [родители детей с инвалидностью] пытаемся каким-то специальностям их обучать, обращаемся в инстанции, но нет желания у людей [у чиновников поддержать нас].

[67] Они не конкурентоспособные. В тех условиях на рынке труда кто их будет брать?

[68] Достойное трудоустройство нелёгкая задача в Узбекистане не только для инвалидов! Наверняка Вы знаете закон Республики Узбекистан "О социальной защищенности инвалидов" (сейчас готовится новый законопроект). Там указано, что в зависимости от количества рабочих мест работодатели должны создать квоту

рабочих мест для лиц с ограниченными возможностями и Инспекция при Министерстве труда должна контролировать наличие этих квотируемых рабочих мест для инвалидов. Нарушение этого требования карается тем же законом!

[69] В этой школе есть преподаватель, он создал студию из учеников. Они великолепно танцуют. Так вот, ему не могли найти единицу, которая бы оправдывала его работу в школе. Понимаете, его никак нельзя было назвать, хотя лучше его не было: он закончил цирковое училище, что тоже больших трудов стоило. Хотя существует квота и у него вторая группа инвалидности, его оставили с превеликом трудом в школе. У нас законодательная база очень такая… Если раньше как-то удавалось [людям] с первой и второй группой инвалидности работать, то когда ВТЭК перешла в ведение министерства финансов, им перестали разрешать работать.

[70] В основном, конечно, наши дети живут в малообеспеченных семьях. Окружение тоже накладывает свой отпечаток на их познавательную деятельность, на их общее физическое развитие.

[71] Потом, анализируя семейное положение этих детей, чаще всего из 12 учеников двое могут быть из более или менее обеспеченной семьи. Остальные малообеспеченные, либо из неполной семьи, либо отдалённые от цивилизованного района. Это тоже сказывается.

[72] У нас не все родители такие, которые могут [что-то] дать своему ребёнку…, которые изо дня в день работают, работают для этого. Это такой колоссальный труд. И таких родителей очень мало. Во многих специализированных школах как раз такие детки, у которых родители [бездействуют]. Не скажу, что от нежелания; больше от не знания, от дефицита информации, от того, что они не могут что-то прочитать. Уровень образованности не позволяет им найти полезную информацию и начать вкладывать в ребёнка. Они просто думают: «Он не такой, он не научится никогда читать, писать». Они раз попробуют – у них не получилось, два… они опускают руки и отдают детей в интернаты.

[73] Мы по наследству получаем эту проблему, потому что общество или система детям, которые из незащищённых семей, шансов практически не даёт. Почему? Потому что они рождаются в определённой семье, у этой семьи уже есть история,

история уже плохая изначально. У них слабые социальные позиции, у них слабые заработки, плохие привычки. Дети для них – это побочный продукт их сексуальной деятельности. Если бы это можно было как-то остановить, они бы не рожали детей. Но они рождаются и с ними надо что-то делать. Поэтому они приспособились… Многие из этих родителей сами отсюда, их бабушки отсюда...

[74] …подобие, сильно похожее на тюрьму.

[75] Они не видят здесь семьи, они не видят семейных отношений, они не видят того, что необходимо для их дальнейшей жизни.

[76] Семья болеет за него. Они поддерживают его именно в эмоциональном плане: «Ты не хуже других. Ты равный среди нас всех».

[77] Мне мама моя родная говорила: «Я не хочу, чтобы ты была, как наша соседка»… У нас соседка была, она ножку волокла, ручку не сгибала. Она так и состарилась, воспитывая сначала братишек, потом детей братишек, потом внуков братишек и так и умерла.

[78] Сейчас сталкиваясь с более взрослыми людьми - 20, 25, 30 лет - видишь, что они действительно такие, как описывают в книге: малоподвижные, с гипотонусом, язык высовывается, не могут контролировать выделение слюны… глаза, руки. Этот период [раннего вмешательства] упущен. Это запущенные дети. Родители не заложили будущее для своего ребёнка.

[79] Нужно каждому родителю, когда диагноз определяют ребёнку, крылья дать [поддержать и вдохновить]. Психологическая поддержка родителей очень важна… Не важно какой у ребёнка диагноз, с ним нужно заниматься. И заниматься нужно сразу, как только он родился или как только определили диагноз.

[80] Родительская активность должна быть, а это сродни гражданской активности.

[81] Если 15 лет назад к нам приходили семьи, чтобы ребёнок мог общаться, чтобы ребёнок мог пойти в школу, чтобы ребёнок что-то научился делать, то теперь звонки: “Вы чем можете помочь?”, “Вы деньги даёте?”.

[82] Родители особенных детей должны в два раза больше платить, потому что их ребёнок «особенный». Т.е. даже те возможности, которые есть, нацелены на бизнес. Пятьдесят тысяч [сумов] за 40 минут работы с ребёнком [плавание], мне кажется, это нереально дорого.

[83] В среднем, цена за одно занятие [с логопедом] от пяти до десяти долларов [США]. Я понимаю, если это звукопостановка, но эти дети должны годами ходить… чтобы их [речь] выровнять, годами нужно заниматься. И платить годами по 10 долларов за одно занятие очень дорого.

[84] Недавно женщина одна Конституцию впервые в глаза увидела: «Ой, какая книга хорошая. Дайте мне её почитать». В итоге она добилась своего на основе Конституции. Она просто говорила: «Мой ребёнок гражданин? Гражданин... Значит, у него есть вот такие права».

[85] Даже разговора не было, даже не пытались общаться с ребёнком.

[86] Мы очень сильно уважаем этого человека, что без вопросов даём направление, а дальше действуйте сами [больше не полагайтесь на нас].

[87] Они являются законными представителями своего ребёнка и по закону они принимают решения… Они не должны останавливаться на том заключении комиссии. Они должны идти дальше.

[88] Такие дети тоже могут развиваться, могут быть точно такими же обычными детьми, также учится.

[89] Ребёнок получает пенсию по инвалидности, но, честно говоря, её ни на что не хватает. Это лекарства, развитие ребёнка: логопеды, консультации врачей… всё дорого.

[90] Если бы государство оказало какую-то помощь... Сколько денег оно тратит на такие [закрытого типа] заведения. Если бы эти деньги «раскидать» на семьи, было бы лучше. Если бы оно [государство] помогало родителям, я бы в жизни его не сдала туда.

[91] Я сказала: “Вы видите какой у меня ребёнок, но ни разу не подошли и не предложили помощь». Они прибежали, принесли мне продукты. Я сказала: «Мне продукты не нужны. Мне нужна материальная помощь, чтобы я могла лечить его. Если я начинаю курс, у меня миллион уходит. Препараты очень дорогие. Вы мне в *этом* помогите». Немного помогли и всё. После этого никакой помощи нет.

[92] Мы писали совместный проект с Европейскими партнёрами из Венгрии о просвещении родителей, проведении для них семинаров, где мы даём всю эту информацию. Нашим партнёром была Венгерская церковная организация. Вот это слово «Церковная» помешала нам реализовать этот проект.

[93] Эти центры уникальны тем, что там не нужно особых программ. Дети обучаются творчеству, знакомятся друг с другом, дружат. Центры хорошо способствует [их] интеграции.

[94] Мы работаем с ними [ННО] не только в Ташкенте, но и в отдалённых районах… Есть много маленьких ННО, которые помогают именно в территориальных округах. Мы понимаем, что большая поддержка тем семьям ни от нас, а от них.

[95] В отдалённых районах они [инклюзивные школы] необходимы, потому что не все родители оттуда хотят оставить своих детей в специализированных школах [которые в основном находятся в городах]. Они хотят, чтобы ребёнок был с ними. В этом случае ребёнку будет лучше идти в территориальную школу, но эта школа должна быть готова к инклюзивному образованию.

[96] Если ребёнок может, исходя из своих потребностей, получать общее образование, мы предлагаем такому ребёнка перейти в общеобразовательную школу.

[97] Государство очень заботится о наших детях. Обед бесплатный. Комплект белья и одежды мы получаем каждый год: обувь, куртки, шапки, варежки. Каждый год! Сейчас немножко в этом плане сократилось, но все эти годы мы всё равно получаем [помощь]. Учебники бесплатно, никакой аренды у нас нет. Канцтоварами снабжают много школ нашего района.

[98] И когда я только родила и мужу сообщили… Сообщили, конечно, в жёсткой форме о том, что этот ребёнок родился нездоровым, такой-то диагноз и «лучше бы Вы оставили этого ребёнка».

[99] Даже если он проживёт всего день, я заберу его домой.

[100] Генетики осмотрели его и сказали, что у него синдром Дауна. Я восприняла это очень тяжело, это было как страшный сон, я чуть сознание не потеряла. Мне врачи сказали, что он будет как растение и я могу его оставить.

[101] Он, между прочим, очень хорошо компьютер знает, хотя говорили, что он не будет его знать. Он мне помогает найти папки, потому что часто сидит с папой за компьютером.

[102] Я взяла бумажку с ручкой, но не смогла подписать… не смогла.

[103] Вы знаете, наверное, мне повезло больше, чем остальным. Через две недели я пришла домой. У меня был интернет, я знала языки и я начала искать информацию. Информацию, как положительную, так и отрицательную… Отрицательная информация была из старых энциклопедий, что они [дети с синдромом Дауна] сложные и безнадёжные. Очень много положительного было, я знала языки и переводила много. Я поняла, что в принципе можно нормально жить, конечно, преодолев какие-то трудности.

[104] Мы обучаем детей на своём уровне, а то, что выше, например, поступление в школу, за это мы уже не несём ответственности и мы не можем направить ребёнка [в общеобразовательную школу] и наше слово не самое окончательное, понимаете… Даже если я дам заключение, что ребёнок может посещать обычную школу, не всегда моё мнение одобрят медицинские специалисты.

[105] Например, ухо заболело или что-то еще, приводите ребёнка к врачу и опять-таки всё списывают на синдром Дауна: «У этих детей всегда с ушами проблема»….

[106] Бывают очень сильные дебаты у нас, но в конце концов они соглашаются с нами, что не зависимо от диагноза ребёнка, он [диагноз] не должен быть основным компонентом, когда принимается решение касательно образования ребёнка. Мы можем взять двоих детей с ДЦП или двоих детей с синдромом Дауна, но у них могут быть разные образовательные потребности. И медики тоже должны видеть это. Бывает, что принимается решение ребёнка лечить, лечить, лечить. Но мы объясняем медикам, что лечением мы не уберём основной диагноз, он останется. Да, бывают моменты, когда состояние меняется, но если ребёнок инвалид с детства,

во многих случаях он останется им до конца жизни. Но наша задача помочь этому ребёнку жить такой жизнью, как у всех, т.е. чтобы он получил такое же образование, жил в социуме, имел свою работу, свой дом, свою семью, своё мнение.

[107] Есть функциональная классификация болезней, где больше внимания обращают на социальную модель [инвалидности] нежели на медицинскую модель. При включении детей в инклюзивное образование мы смотрим не столько на диагноз, сколько на их потенциальные возможности... Мы в начале стараемся определить их сильные стороны, а потом слабые стороны. И с учётом их потенциальных возможностей и слабых сторон мы разрабатываем индивидуальную программу. Это очень важный подход. Те медики, которых мы обучили, меняют своё отношение: они уже не столько внимания обращают на диагноз.

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Appendices

Appendix A: Information letter

Dear Prospective Participant,

My name is Galina Nam and I am a PhD candidate at the Faculty of Education, University of Waikato (New Zealand). I am conducting research as a requirement for my Doctoral Degree. The title of my research is “Policies for inclusive education for children and young people with disabilities in Uzbekistan: Relationships amongst schools, parents and children, disability-related organisations, and the government”. The research has been given ethical approval by the Faculty of Education Human Research Ethics Committee.

I am interested in how different groups with interest in and involvement with children and young people with disabilities understand the term ‘inclusive education’. I am also interested in exploring their perception how they see critical issues in introducing inclusive practices in Uzbekistan. To do this I propose to undertake a series of interviews that will be focused on experiences and perceptions of disability-related organisations, parents of children with disabilities, children, teachers working with students with disabilities, and government officials; and how their experiences inform the better provision of inclusive education.

All interview conditions are stated in the consent form.

If you need further information, or have questions, please contact me at namgalina@yahoo.com or gn15@students.waikato.ac.nz.

You may also contact my Supervisors: Professor Roger Moltzen at rim@waikato.ac.nz, Professor Martin Thrupp at thrupp@waikato.ac.nz, and Doctor Carol Hamilton at hamiltca@waikato.ac.nz.

Yours sincerely,
Galina Nam
PhD Candidate
Faculty of Education
University of Waikato

Appendix B: Consent for participation in a research interview

Institution: Faculty of Education, University of Waikato.
Research project title: Policies for inclusive education for children and young people with disabilities in Uzbekistan: Relationships amongst schools, parents and children, disability-related organisations, and the government.
Researcher: Galina Nam.

Thank you for agreeing to be interviewed as a part of the above research project. Ethical procedures for academic research undertaken from New Zealand tertiary institutions require that interviewees explicitly agree to be interviewed and understand how the information contained in their interview will be used. Therefore, I am asking you to read the following information to certify that you agree with these:

- The interview will be recorded and transcribed.
- You will be sent the interview transcript to review, and remove or amend any parts/material;
- If you decide to withdraw from the study, you will advise me of your intention no later than three weeks after receiving transcripts.
- The transcript of the interview will be analyzed and translated by me (Galina Nam) as the researcher.
- Access to the interview transcripts will be limited to myself and my Supervisory Panel.
- Any interview summary and/or direct quotations from the interview will be anonymised so that you cannot be identified.
- All necessary measures will be taken to protect your identities and keep the information your will provide confidential.
- The audio recordings will be kept for five years and then destroyed.

Quotation Agreement:
- I agree to be quoted directly if my real name is not disclosed and a pseudonym is used;
- I agree that the researcher may publish quotations from me.

By signing this consent form I agree that:
1. I am voluntarily taking part in this interview;
2. I understand that I can stop the interview or withdraw from it at any time;
3. The transcribed interview or extracts from it may be used as described above;
4. I will be provided with a copy of the transcript of my interview to make edits;
5. I understand that I am free to contact the researcher with any questions.

Printed Participant's Name ____
Participant's Signature ____
Participant's e-mail ____
Date: ___________________________________

Contact Information

If you have any further questions or concerns about this study, please contact:
Researcher: Galina Nam
Full address: 4/41 Cameron Rd, Hamilton East, Hamilton, 3216 New Zealand
Tel: +64226261534
E-mail: namgalina@yahoo.com, gn15@students.waikato.ac.nz

Appendix C: Parental consent for participation in a research interview

Institution: Faculty of Education, University of Waikato.
Research project title: Policies for inclusive education for children and young people with disabilities in Uzbekistan: Relationships amongst schools, parents and children, disability-related organisations, and the government.
Researcher: Galina Nam.

Your child has been invited to join the research study. Ethical procedures for academic research undertaken from New Zealand tertiary institutions require that interviewees explicitly agree to be interviewed and understand how the information contained in their interview will be used. Therefore, I am asking you to take whatever time you need to discuss the study with your family and friends, or anyone else you wish to. The decision to let you child join, or not to join, is up to you. Before you make a decision, please, read the following information carefully:

- The interview will be recorded and transcribed.
- Your child will be sent the interview transcript to review, and remove or amend any parts/material;
- If your child decides to withdraw from the study, he/she will advise me of his/her intention no later than three weeks after receiving transcripts.
- The transcript of the interview will be analyzed and translated by me (Galina Nam) as the researcher.
- Access to the interview transcripts will be limited to myself and my Supervisory Panel.
- Any interview summary and/or direct quotations from the interview will be anonymised so that your child cannot be identified.
- All necessary measures will be taken to protect your child's identities and keep the information he/she will provide confidential.
- The audio recordings will be kept for five years and then destroyed.

Quotation Agreement:
- I agree my child to be quoted directly if his/her real name is not disclosed and a pseudonym is used;
- I agree that the researcher may publish quotations from my child.

By signing this consent form I agree that:
1. My child is voluntarily taking part in this interview;
2. I understand that my child can stop the interview or withdraw from it at any time;
3. The transcribed interview or extracts from it may be used as described above;

4. My child will be provided with a copy of the transcript of his/her interview to make edits;
5. I understand that I am and/or my child is free to contact the researcher with any questions.

Printed Parent's Name ______________________________________
Parent's Signature ____
Parent's e-mail ____
Date: _________________________________

Contact Information

If you have any further questions or concerns about this study, please contact:
Researcher: Galina Nam
Full address: 4/41 Cameron Rd, Hamilton East, Hamilton, 3216 New Zealand
Tel: +64226261534
E-mail: namgalina@yahoo.com, gn15@students.waikato.ac.nz

Appendix D: Online questionnaire

Inclusive Education for Children & Young People with Disabilities in Uzbekistan

Dear Representative of the Disability-Related Organization,

My name is Galina Nam, I am a PhD candidate at the Faculty of Education, University of Waikato, New Zealand. I am conducting research as a requirement of my Doctoral Degree. As a researcher I am interested in exploring stakeholders' perceptions of the critical issues in introducing educational policies and practices for children and young people with disabilities in Uzbekistan.

Even if your organization is not directly involved in education of children and young people with disabilities, your completing this questionnaire would be still invaluable for this research.

The questionnaire should take about 20 minutes to complete. All information that you provide will be anonymous. The results of this study will be analysed and used only for scholarly purposes (e.g., conference presentations and publication in scholarly journals).

Completing and returning the questionnaire constitutes your consent to participate.

If you have any questions regarding the research, please contact me at gn15@students.waikato.ac.nz. You may also contact my Supervisors: Prof. Roger Moltzen (rim@waikato.ac.nz), Prof. Martin Thrupp (thrupp@waikato.ac.nz) or Dr. Carol Hamilton (hamiltca@waikato.ac.nz).

Thank you for your time and consideration.

Sincerely,
Galina Nam

*Please note the term 'DISABILITY' in this questionnaire is not limited to certain types of disabilities. It covers ALL EXISTING TYPES of DISABILITIES.

1. How big is your organization?
Mark only one oval.

○ Less than 10 employees
○ From 10 to 50 employees
○ From 50 to 100 employees
○ More than 100 employees

2. What disability field is your organization involved in?
Mark only one oval.

○ Education
○ Disability rights
○ Rehabilitation services
○ Social adaptation
○ Inclusion & Equality Trainings
○ Other: ____________________

3. How long has your organization been involved in that field?
Mark only one oval.

○ Less than 1 year
○ From 1 to 5 years
○ From 5 to 10 years
○ More than 10 years

4. What is your position within the organization?
Mark only one oval.

○ High level position
○ Medium level position
○ Entry level position
○ Other: ____________________

Please give your opinion for the following question:

5. How do you define the term "Inclusive education"?

Please rate the following on a scale of 1 to 5:

1 – NO conditions are met.
2 – VERY FEW conditions are met.
3 – SOME conditions are met.
4 – MANY conditions are met.
5 – MOST/ALL conditions are met.

6. The current educational conditions for children and young people with disabilities in Uzbekistan.
Mark only one oval.

1	2	3	4	5
○	○	○	○	○

7. Support for children and young people with disabilities studying at general schools, NOT at segregated institutions (relevant programmes and services).
Mark only one oval.

1	2	3	4	5
○	○	○	○	○

For each of the following please indicate how strongly you agree based on a scale of 1 to 5: 1- Strongly disagree, 2- Disagree, 3- No opinion, 4- Agree, 5- Strongly agree.

8. Inclusive education:

Mark only one oval per row.

	1	2	3	4	5
Develops academic skills of children and young people with disabilities.	○	○	○	○	○
Develops their social skills of children and young people with disabilities.	○	○	○	○	○
Develops an individual's strengths and talents.	○	○	○	○	○
Encourages the involvement of parents in education of their children.	○	○	○	○	○
Fosters a culture of respect and belonging.	○	○	○	○	○
Provides all children with opportunities to develop friendships with one another.	○	○	○	○	○
Allows children without disabilities to become more tolerant and accepting.	○	○	○	○	○

9. When inclusive education is introduced in a regular classroom:

Mark only one oval per row.

	1	2	3	4	5
It is often focused on the socialization part of education rather than on the academic part.	○	○	○	○	○
Children and young people with disabilities do not receive individual approach.	○	○	○	○	○
Children and young people with disabilities may have low self-esteem.	○	○	○	○	○
Children and young people with disabilities do not feel safe enough.	○	○	○	○	○
Some children and young people with disabilities can disrupt the learning environment.	○	○	○	○	○
Children without disabilities lag behind in their study because of children with disabilities in their classes.	○	○	○	○	○
Teachers have to take on extra work.	○	○	○	○	○

10. Problems hindering the implementation of inclusive education:

Mark only one oval per row.

	1	2	3	4	5
A lack of legislative clarity.	○	○	○	○	○
A lack of data related to disability.	○	○	○	○	○
A shortage of qualified staff.	○	○	○	○	○
A lack of infrastructure.	○	○	○	○	○
A shortage of financial resources.	○	○	○	○	○
The society does not think that children and young people with disabilities need to be educated.	○	○	○	○	○
There is a Socialist legacy that rejected the existence of people with disabilities in the country.	○	○	○	○	○
Other	○	○	○	○	○

If you selected "Other", please list up to the 3 most critical problems.

____

____

____

____

____

11. Government support:

Mark only one oval per row.

	1	2	3	4	5
The government is doing all that is needed for the development of inclusive education.	○	○	○	○	○
Our organization receives sufficient support from the government to promote activities related to disability issues.	○	○	○	○	○
Our organization is consulted and/or involved in different activities related to disability issues in general.	○	○	○	○	○
Our organization is consulted and/or involved in different activities related to education for children with disabilities.	○	○	○	○	○
Other	○	○	○	○	○

If you selected "Other", please list up to 3 kinds of the most sufficient support.

____

____

____

____

____

12. Possible problems experienced by your organization:
Mark only one oval per row.

	1	2	3	4	5
Limited legitimacy (e.g. problems related to official registration).	○	○	○	○	○
Lack of funding.	○	○	○	○	○
Networking difficulties.	○	○	○	○	○
Communication difficulties within the sector.	○	○	○	○	○
Lack of accountability and transparency when dealing with other governmental and non-governmental agencies.	○	○	○	○	○
Other	○	○	○	○	○

If you selected "Other", please list up to the 3 most critical problems.

For each of the following statements please give your view on a scale of 1 to 5: 1- Strongly disagree, 2- Disagree, 3- No opinion, 4- Agree, 5- Strongly agree.

13. How do you see inclusion within next 10 years?
Mark only one oval per row.

	1	2	3	4	5
Our organization will see inclusion as an important goal of our work in Uzbekistan.	○	○	○	○	○
Policy and practice in Uzbekistan will affirm the shift to an inclusive education framework.	○	○	○	○	○
Teachers will include students with disabilities in their classes as an integral part of their teaching practice.	○	○	○	○	○
Parents of children with disabilities will actively support the development of inclusive education.	○	○	○	○	○

For each of the following questions please give your opinion.

14. What steps are needed to make the idea of the full inclusion of students with disabilities in regular classroom settings a reality in Uzbekistan?

15. What are the main barriers to achieving the full inclusion of students with disabilities in regular classroom settings in Uzbekistan?

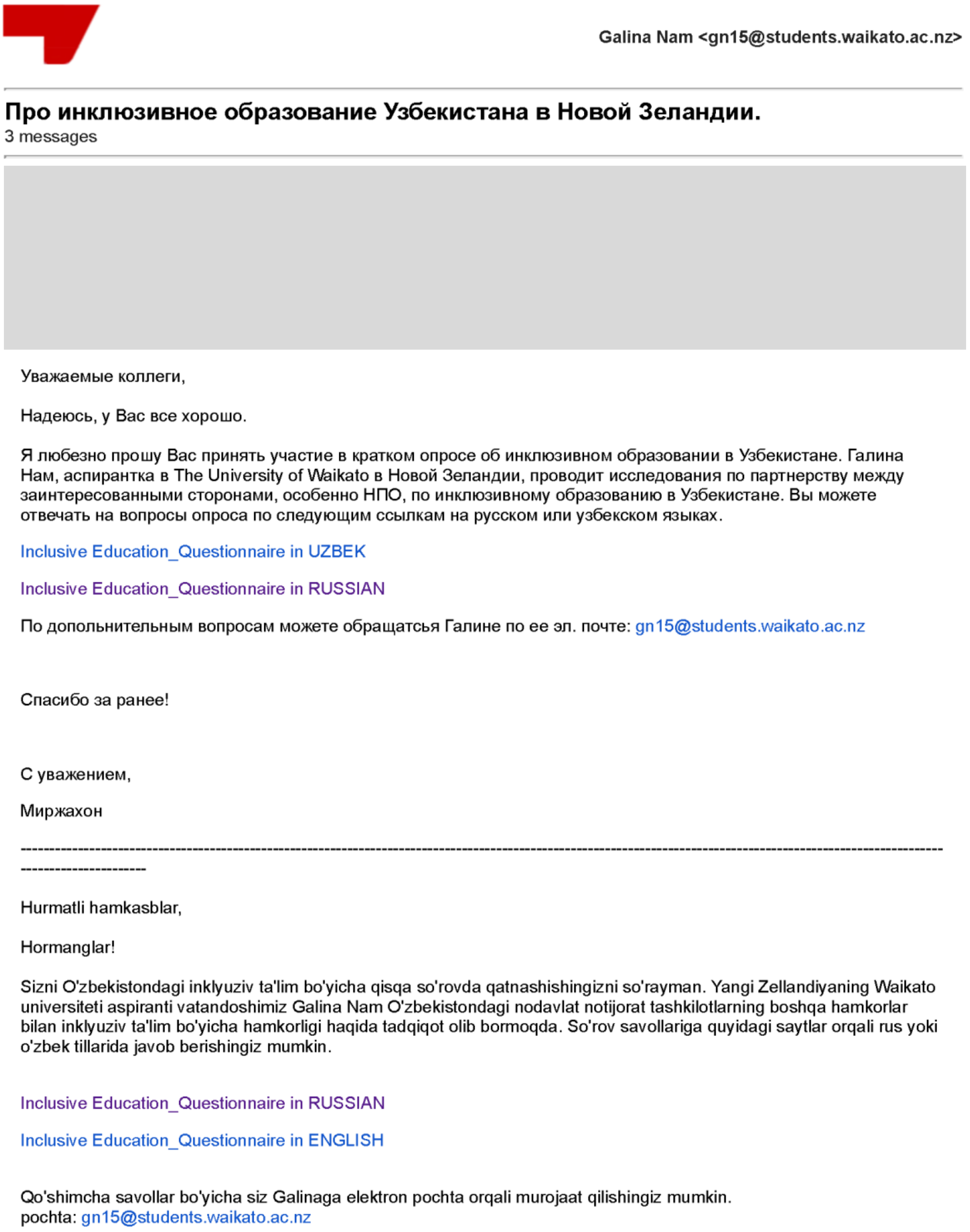
16. What changes might be needed to overcome these barriers?

17. How could your organization contribute further to the development of a partnership with other stakeholders (parents, schools, the government) to support inclusive education?

18. Additional comments:

Thank you for participation in the project!

Appendix E: Email notifications for potential questionnaire participants



Galina Nam <gn15@students.waikato.ac.nz>

Про инклюзивное образование Узбекистана в Новой Зеландии.
3 messages

[redacted]

Уважаемые коллеги,

Надеюсь, у Вас все хорошо.

Я любезно прошу Вас принять участие в кратком опросе об инклюзивном образовании в Узбекистане. Галина Нам, аспирантка в The University of Waikato в Новой Зеландии, проводит исследования по партнерству между заинтересованными сторонами, особенно НПО, по инклюзивному образованию в Узбекистане. Вы можете отвечать на вопросы опроса по следующим ссылкам на русском или узбекском языках.

Inclusive Education_Questionnaire in UZBEK

Inclusive Education_Questionnaire in RUSSIAN

По дополнительным вопросам можете обращатсья Галине по ее эл. почте: gn15@students.waikato.ac.nz

Спасибо за ранее!

С уважением,

Миржахон

Hurmatli hamkasblar,

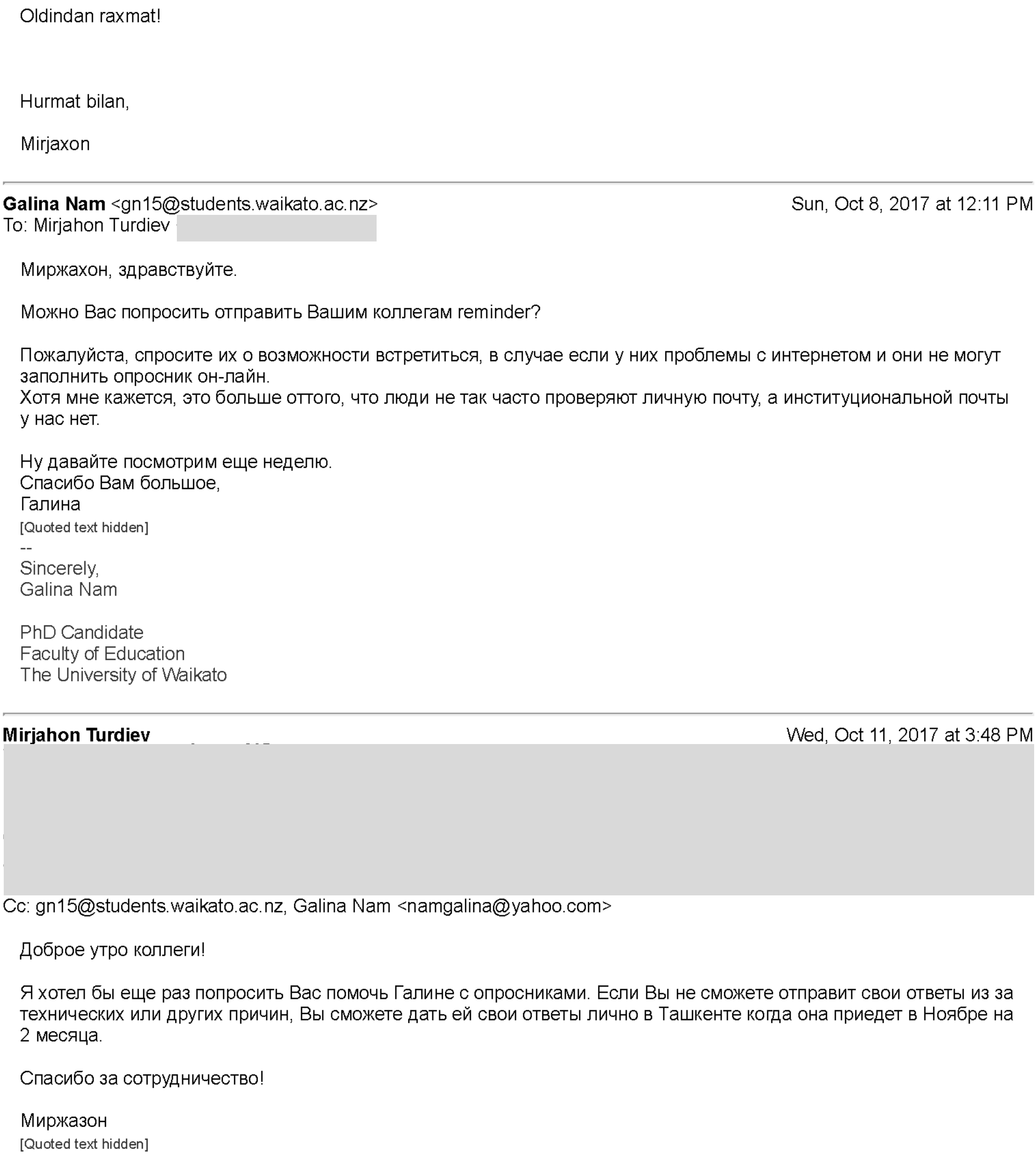
Hormanglar!

Sizni O'zbekistondagi inklyuziv ta'lim bo'yicha qisqa so'rovda qatnashishingizni so'rayman. Yangi Zellandiyaning Waikato universiteti aspiranti vatandoshimiz Galina Nam O'zbekistondagi nodavlat notijorat tashkilotlarning boshqa hamkorlar bilan inklyuziv ta'lim bo'yicha hamkorligi haqida tadqiqot olib bormoqda. So'rov savollariga quyidagi saytlar orqali rus yoki o'zbek tillarida javob berishingiz mumkin.

Inclusive Education_Questionnaire in RUSSIAN

Inclusive Education_Questionnaire in ENGLISH

Qo'shimcha savollar bo'yicha siz Galinaga elektron pochta orqali murojaat qilishingiz mumkin.
pochta: gn15@students.waikato.ac.nz



Oldindan raxmat!

Hurmat bilan,

Mirjaxon

Galina Nam <gn15@students.waikato.ac.nz> Sun, Oct 8, 2017 at 12:11 PM
To: Mirjahon Turdiev [redacted]

Миржахон, здравствуйте.

Можно Вас попросить отправить Вашим коллегам reminder?

Пожалуйста, спросите их о возможности встретиться, в случае если у них проблемы с интернетом и они не могут заполнить опросник он-лайн.
Хотя мне кажется, это больше оттого, что люди не так часто проверяют личную почту, а институциональной почты у нас нет.

Ну давайте посмотрим еще неделю.
Спасибо Вам большое,
Галина
[Quoted text hidden]
--
Sincerely,
Galina Nam

PhD Candidate
Faculty of Education
The University of Waikato

Mirjahon Turdiev Wed, Oct 11, 2017 at 3:48 PM
[redacted]
Cc: gn15@students.waikato.ac.nz, Galina Nam <namgalina@yahoo.com>

Доброе утро коллеги!

Я хотел бы еще раз попросить Вас помочь Галине с опросниками. Если Вы не сможете отправит свои ответы из за технических или других причин, Вы сможете дать ей свои ответы лично в Ташкенте когда она приедет в Ноябре на 2 месяца.

Спасибо за сотрудничество!

Миржазон
[Quoted text hidden]

Appendix F: List of lead questions for participants

Lead questions for parents:

Family Experiences

- Could you tell me about you child, his/her age, particular strengths and abilities?
- What kind of disability does he/she have?
- When did you find out that X had a disability?
- Could you tell me about what happened next?
- How did the family adjust?
- What has the family had to do differently to help X grown and develop?
- What do sisters and brothers think about disability?
- What support did the family (yourself) receive?
- What else would have been helpful?

Educational/School Experiences

1. Going to school:

- How difficult was it to find a school for X?
- If there were any problems, how did you solve them?

2. Being in school – participation, fitting in, friendships:

- How does X feel about going to school?
- Who are his/her friends?
- How is social interaction between X and classmates managed at the school?

3. Support in school:

- What specialist are involved in support?

- What is working? What isn't?
- What could be done differently?

4. <u>Parent-School relationships</u>:

- How is the school communicating with parents? Is this working – if not, why not?
- How are you involved in the education process of your child/ children?

5. <u>Previous schooling:</u>

- Tell me, please, about previous schooling of your child (pre-school, elementary school, etc.).
- Could you describe the support systems that existed for your child in his/her schooling? How did you find out about them and access these?
- Looking back, what could have been done differently in relation to your child's previous education?
- In what ways do you consider your child's education significantly different from that of a child without a disability at a regular school?

6. <u>Opinions about education in the future</u>:

- What do you understand by the term 'inclusive education'?
- What do you think might be possible advantages and disadvantages of inclusive education?
- How do you see the idea of inclusive education working in the future?
- In your opinion, how might inclusive education be implemented across the country?
- Can you possibly contribute to the development of a partnership with other stakeholders to support inclusive education? If yes, how?
- What needs to be changed so that every disabled child can attend school?
- Is there anything else you want to add?

Lead questions for teachers:

- Tell me about what a typical day looks like in your class
- How does having a disabled child/children in the class change your routine?
- What kind of assistance do you have?
- What kind of training/experience did you have to work with disabled children?
- Why did you choose to work with them?
- What do you think about the current educational conditions for children with disabilities?
- How are children with disabilities supported within the general school system (e.g. individualized programmes, relevant infrastructure, and assistive devices)?
- Could you tell me about some of the challenges you faced in supporting your students' education?
- What was experience of students with disabilities with peer relationships?
- Do you think students without disabilities benefit from being in one class with those who have disabilities? If yes, how?
- What do you need as a professional to work with children with disabilities effectively?
- How is/was your students' education significantly different from that of students without disabilities at a regular school?
- How do you view the concept of inclusive education?
- What do you think might be possible advantages and disadvantages of inclusive education?
- How do you see inclusive education in the future?
- In your opinion, how could inclusive education be implemented across the country?
- Can you possibly contribute to the development of a partnership with other stakeholders to support inclusive education? If yes, how?
- Is there anything else you would like to add?

Lead questions for logopedists/defectologists:

- In your opinion, to what extent are general schools ready to accept children with disabilities?
- How are teachers of general schools supported to teach students with disabilities?
- How are children with disabilities supported within the general school system (e.g. individualized programmes, relevant infrastructure, and assistive devices)?
- To what extent the qualification of a teacher is taken into account when he/she is hired?
- Please, tell me about a professional development programme for a teacher working with children with disabilities.
- Is it effective? Is there anything what needs to be changed (the content or/ and structure) to make it more effective? If yes, what exactly?
- Could you tell me about some of the challenges you faced in training teachers working with children with disabilities?
- To what extent has the approach to teaching children with disabilities been changed since the Soviet times?
- How do you view the concept of inclusive education?
- What do you think might be possible advantages and disadvantages of inclusive education?
- How do you see inclusive education in the future?
- In your opinion, how could inclusive education be implemented across the country?
- Can you possibly contribute to the development of a partnership with other stakeholders to support inclusive education? If yes, how?
- Is there anything else you would like to add?

Lead questions for government officials:

- Could you tell me briefly about the scope of your work at the Ministry of Labour and Social Protection?
- What do you think about the changes that the government is currently making in the field of disability?
- Many interview participants mentioned in the interview that the social support for people with disabilities and their families in our country remained very underdeveloped. What could you say about this?
- What are the prospects for changing social disability policies?
- There was also an opinion that the implementation of many disability-related laws and regulations in the area of social protection is not monitored. Therefore, they are ineffective. What could you say about this?
- School administration and parents of young people with disabilities, who are leaving specialised schools soon, are concerned about their future employment. As practice shows, employers are not willing to deal with graduates of specialised schools. How does the Ministry support or could support these young people with their employment?
- In your opinion, what is the role of NGOs in the development of disability inclusion in general ad inclusive education in particular?
- Does (or did) the Ministry cooperate with disability-related NGOs? If yes, could you tell me briefly about it?
- How do you view the concept of inclusive education?
- What do you think might be possible advantages and disadvantages of inclusive education?
- In your opinion, what are the biggest challenges we face in the implementation process of inclusive education?
- In your opinion, what is the role of the government in solving these problems?
- In your opinion, how can the Ministry possibly contribute to the development of a partnership with other stakeholders to support inclusive education?
- Is there anything else you would like to add?