The Perspectives of Parents Who Have a School-aged Child With Down Syndrome Towards Inclusive Education in Petropavlovsk

Aigul Kussainova

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53 Kabanbay Batyr Ave.
010000 Astana,
Republic of Kazakhstan

October 2019

Dear Aigul Kussainova

This letter now confirms that your research project entitled: The perspectives of parents who have school-aged children with Down syndrome towards inclusive education in Petropavlovsk
has been approved by the Graduate School of Education Ethics Committee of Nazarbayev University.

You may proceed with contacting your preferred research site and commencing your participant recruitment strategy.

Yours sincerely

Filiz Polat

On behalf of Elaine Sharplin
Chair of the GSE Research Committee
Professor
Graduate School of Education
Nazarbayev University

Block C3, Room 5006
Office: +7 (7172) 70 9371
Mobile: +7 777 1929961
email: elaine.sharplin@nu.edu.kz

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The Perspectives of Parents Who Have a School-aged Child With Down Syndrome Towards Inclusive Education in Petropavlovsk

Abstract

The development of inclusive education has become one of the priority directions of the national program of education in the Republic of Kazakhstan for 2011 – 2020. According to the State Program for Education Development of the Republic of Kazakhstan for 2011-2020, 70% of all Kazakhstani schools are expected to become inclusive and open their doors to children with special needs by 2020. On the contrary, children with special needs or disabilities are still educated in correctional schools or at home rather than in mainstream schools (OECD, 2015). It is believed that parents know their children best and can provide information about their children's strengths, weaknesses, preferences, disabilities, and needs. Logically, parents of children with disabilities should be considered as primary agents in the field of education. Nevertheless, parental views and experiences are disregarded, and it is proved by responses of parents in this study. The main purpose of the study is to explore the views of parents who have a school-aged child with Down syndrome towards inclusive education in Petropavlovsk. Additionally, the research aims to investigate what parents of school-aged children with Down syndrome feel about the inclusion of their children in mainstream schools in Petropavlovsk, to shed light on the factors that influence parental attitudes and beliefs, and find out whether parents advocate for the rights of their children with disabilities and how. Qualitative research method was used to conduct the study, with data collected through semi-structured interviews with six parents. The findings showed that parents of children with Down syndrome have a positive attitude towards inclusive education, but they feel negative about inclusion of their child in mainstream schools. Parents associate studying in mainstream schools with a number of barriers such as lack of properly qualified teachers and support service, social negative attitude and challenging curriculum.

Key words: inclusive education, views of parents, children with Down syndrome, Petropavlovsk

Петропавлда инклюзивті білім беру жолында Даун синдромы бар мектеп жасындағы балалар ата-аналарының болашағы

Аңдатпа

Инклюзивті білім беруді дамыту 2011-2020 жылдарға арналған Қазақстан Республикасында Мемлекеттік білім беру бағдарламасын дамытудың басым бағыттарының біріне айналды. 2011-2020 жылдарға арналған Қазақстан Республикасында білім беруді дамытудың мемлекеттік бағдарламасына сәйкес 2020 жылға қарай республикадағы барлық мектептердің 70% - ы инклюзивті мектептерге айналып, ерекше қажеттіліктері бар балалар үшін өз есіктерін ашады. Алайда, ерекше қажеттіліктері бар және мүмкіндігі шектеулі балалар түзеу мектептерінде немесе үйде білім алып жатыр (ЭЫДҰ, 2015). Ата-аналар өз балаларын өте жақсы біледі: олардың күшті және әлсіз жақтарын, қызығушылықтарын, мүмкіндіктері мен қажеттіліктерін. Демек, ерекше қажеттіліктері бар балалардың ата-аналары білім беру саласында жетекші рөлдердің бірін атқаруы қажет. Дегенмен, ата-аналардың тәжірибесі мен пікірі ескерілмейді және бұл осы зерттеудің нәтижелерімен дәлелденген. Бұл зерттеудің басты мақсаты – Даун синдромы бар мектеп жасындағы балалар ата-аналарының Петропавл қаласында инклюзивті білім беруге қатысты пікірін зерттеу. Сондай-ақ, зерттеу мақсаты ата-аналардың Петропавл қаласының жалпы білім беретін мектептерінде оқу туралы не ойлайтынын білу, ата-аналардың қарым-қатынасы мен нанымына әсер ететін факторларды айқындау және ата-аналардың ерекше қажеттіліктері бар өз балаларының құқығын қорғайтынын не қорғамайтынын және оны қалай іске асыратынын анықтау болып табылады. Бұл зерттеу үшін сапалы талдау әдісі қолданылды. Барлық деректер алты қатысушымен (респондентпен) сұхбат жүргізу арқылы жиналды. Зерттеу нәтижелері Даун синдромы бар балалардың ата-аналары инклюзивті білім беруге оң қарайтынын, алайда олар өз балаларының жалпы білім беретін мектепте оқуына қарсы болуын көрсетті. Ата-аналар білікті педагогтар мен қолдау қызметінің жетіспеушілігі, қоғам тарапынан теріс көзқарас және жалпы білім беретін мектептерде күрделенген білім беру бағдарламасы сияқты кедергілер мектепте оқуға кедергі келтіретін көрсетеді.

Түйінді сөздер: инклюзивті білім беру, ата-аналар пікірі, Даун синдромы бар балалар, Петропавл

Перспективы родителей детей школьного возраста с синдромом Дауна на пути к инклюзивному образованию в Петропавловске

Аннотация

Развитие инклюзивного образования стало одним из приоритетных направлений развития Государственной программы образования в Республике Казахстан на 2011-2020 годы. Согласно Государственной программе развития образования Республики Казахстан на 2011-2020 годы, к 2020 году 70% всех школ в республике станут инклюзивными и откроют свои двери для детей с особыми потребностями. Однако, дети с особыми потребностями и ограниченными возможностями получают образование в коррекционных школах или на дому (ОЭСР, 2015). Считается, что родители лучше всех знают своих детей: их сильные и слабые стороны, интересы, возможности и потребности. Следовательно, родителям детей с особыми потребностями следует играть одну из ведущих ролей в сфере образования. Тем не менее, опыт и мнение родителей не учитывается, и это доказано результатами данного исследования. Главная цель данного исследования - это исследовать мнение родителей детей школьного возраста с синдромом Дауна по отношению к инклюзивному образованию в городе Петропавловске. Также исследование преследует цель узнать, что родители думают по поводу обучения в общеобразовательных школах г. Петропавловска, выявить факторы, которые влияют на отношения и убеждения родителей, и выяснить защищают ли родители права своих детей с особыми потребности, и каким образом. Для данного исследования был использован качественный метод анализа. Все данные были собраны путем проведения интервью с шестью участниками (респондентами). Результаты данного исследования показали, что родители детей с синдромом Дауна положительно относятся к инклюзивному образованию, однако, они против того, чтобы их ребенок учился в общеобразовательной школе. Родители указывают на барьеры, которые препятствуют обучению в школе, такие как нехватка квалифицированных педагогов и службы поддержки, негативное отношение со стороны общества и усложненная образовательная программа в общеобразовательных школах.

Ключевые слова: инклюзивное образование, мнение родителей, дети с синдромом Дауна, Петропавловск

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Chapter One: Introduction

1.1 Introduction

The national education system of the Republic of Kazakhstan has experienced many paradigm shifts since the country became independent in 1991. One such educational development has been the introduction and promotion of inclusive practices. One of the actions taken in 2008 was signing the Convention on the Rights of Persons with Disabilities and its Optional Protocol to ensure education for people with disabilities (Tkachenko, 2015). The State Program for Education Development of the Republic of Kazakhstan for the years 2011-2020 expected that 70% of schools in Kazakhstan would be reformed to provide an inclusive environment for children by 2020 (The Ministry of Education and Science of the Republic of Kazakhstan, 2010). Denivarova and Abdresheva (2015) noted that many schools in Kazakhstan are inclusive; still, there are problems such as school buildings that cannot accommodate the needs of children with special needs, a lack of competence among teachers, and a lack of knowledge about the children's rights among parents.

Families may become important agents in the maintenance of inclusive education. Parents are a great source of information because they know about their children's strengths, weaknesses, preferences, disabilities, needs, and, as a result, they may play a crucial role in remodelling educational policies and determining their efficacy. Besides, they might provide recommendations that help to reduce barriers on the way to inclusive education. However, the opinions of parents who have children with special needs frequently are not considered, and it is justified by the responses of parents that will be discussed later.

1.2 Background of the Study

A considerable number of studies investigated parental views of children with special needs towards inclusive education (Al Neyadi, 2015; Boer, Pijl & Minnaert, 2010; Johnson, 2006; Leyser & Kirk, 2004). The review of the literature has shown that families have uncertain beliefs about inclusive education. Some parents support the view that the inclusion of children with special needs in mainstream schools provides an opportunity to socialise and achieve acceptance in society. Nevertheless, a lack of properly qualified teachers and reasonable facilities for children with diverse learning needs are considered the main barriers in mainstream schools.

The Organisation for Economic Co-operation and Development (OECD, 2015) School Resources Review highlighted the necessity "to shift towards providing education that promotes equity by recognising and meeting different educational needs" (p. 12). OECD highlighted that Kazakhstan is slow in meeting the needs of people with disabilities. According to the report, "Kazakhstan has a highly centralised top-down system that leaves little political, administrative and fiscal authority to lower levels of a clearly delineated hierarchy. This is reflected in the education system, which is characterised by an extensive system of planning and norms" (OECD, 2015, p. 29).

A large number of studies emphasised the necessity to advocate for the rights of children with special needs and empower parental roles (Bryant, 2015; Hess et al., 2006; Issakhanova, 2019; Mayrowetz & Weinstein, 1999, as cited in Rollan & Somerton, 2019; Shevlin, 2002). Parents in developed countries who had experienced transitioning their child on the path to inclusive education described it as a challenging journey (Bryant, 2015; Shevlin, 2002). Nevertheless, they are convinced that cooperation between families and schools is the key to the successful realisation of inclusive education.

Regarding Kazakhstan, the amount of literature in the area of inclusive education is increasing. Rollan and Somerton (2019) indicated the importance of parental position and experience by centering attention on their vital role in reforming education. The research by Issakhanova (2019) suggested that Non-Governmental Organizations (NGOs) play a significant role in the provision of educational support and empowerment of the position of parents. Khamidulina (2018) demonstrated the barriers in the way to developing inclusive education through parental lenses.

However, far too little attention has been paid to the parents of school-aged children with Down syndrome (DS) in small cities. The majority of research involved parents who have children with various special needs and disabilities; only one study has attempted to explore the perceptions of parents who have a kindergarten or school-aged child with DS (Issakhanova, 2019). While some studies have identified the factors (such as gender, parental education level, type and severity of a child's disability, socioeconomic and marital status) that influence parents' views and decisions, no studies have found which factors have an impact on Kazakhstani mothers and fathers. Therefore, this study makes a major contribution to research on inclusive education by demonstrating the position of parents who have a child with DS, and the factors that affect their feelings, expectations, and behavior.

1.3 Statement of the Problem

Meanwhile, the number of children born with DS worldwide and in Kazakhstan is increasing. The World Health Organization analysed the birth rate of children with DS in different countries. It revealed a surge in the birth rate of children with DS in Kazakhstan in 2006. In 2006 the birth rate ranged between 3-418 per 100 live births. In 2012 this number reached 722. The most recent data (2017) showed that the birth rate of children with DS is over 900. Thus, for the last 11-year period, the birth rate of children with the diagnosis of DS doubled in our country.

Although the national educational programmes emphasise the importance of developing inclusive education in Kazakhstan and take actions to implement it, children with DS are segregated from their peers, schools, and society. Human Rights Watch (HRW, 2019) reported that in Kazakhstan, parental opinion is disregarded and their children with special needs are marginalised. The report demonstrated that an approach to educating children with special needs is based on the medical approach. Children with special needs or disabilities are of serious concern in Kazakhstan because they are educated in correctional schools or at home rather than in mainstream schools (OECD, 2015). This study provides an important opportunity to advance the understanding of the parental views of children with DS towards inclusive education and make an original contribution to the Kazakhstani research field.

1.4 Purpose of the Study

The purpose of the study is to explore parental attitudes of school-aged children with DS towards the inclusion of their children in mainstream schools in Petropavlovsk. First, the study aimed at exploring whether parents who have school-aged children with DS have a positive, negative, or neutral attitude towards inclusion. Second, this research indicated the factors that affected the opinion of parents who live in Petropavlovsk. Finally, this research investigated if and how parents take advocacy roles for the rights of their children with DS.

1.5 Research Questions

The research questions that guided this study were the following:

- What are the attitudes of parents of school-aged children with Down syndrome towards the inclusion of their children in mainstream schools in Petropavlovsk?
- What factors influence parental attitudes towards inclusive education?
- How do parents advocate for the rights of the children with Down syndrome to be included in mainstream schools in Petropavlovsk?

1.6 Definition of Key Terms

In this study, the acronym DS will be used. Down syndrome is a chromosomal disorder associated with mental retardation. Children with Down syndrome have a typical physical appearance that can include small head circumference, flattened face with a recessed bridge of the nose, upward slanting eyes, small ears and mouth, protruding tongue, short, broad hands and feet, stubby fingers, broad neck, and stocky appearance (Encyclopedia of Clinical Child and Pediatric Psychology, 2012).

One of the issues related to the research concerning the inclusion of children with disabilities or special needs in an educational setting is the terminology and the definition of inclusive education. Booth and Ainscow (1998) argued that inclusion is a process in which schools, communities, local authorities, and governments strive to reduce barriers to participation and learning for all citizens. For Council (2011), inclusion is a continuous process of increasing the presence, participation, and achievement of all learners in education establishments.

Two complementary definitions of inclusive education are suggested in Contemporary Issues in Special Educational Needs: Considering The Whole Child (Armstrong & Squires, 2012). The first defines inclusion as the relocation of children placed in special schools to a mainstream setting. The second definition refers less to the placement of children with special educational needs, but focuses on the quality of education they receive. This study will use a combination of these definitions.

1.7 Significance of the Study

First, this study will be significant for families of children who have DS because it provides an opportunity for them to reveal their opinion, express the worries, and share their experiences and expectations regarding inclusive education.

The findings should make an important contribution to the Kazakhstani context. It might raise awareness about the necessity to empower parents to advocate for themselves and on behalf of their children with special needs, not only on a personal level (by developing and enhancing their skills) but also on the legislative level. This research may lead to new research that would centre their attention on exploring the problem from the perspective of different stakeholders.

Policy-makers may benefit from the findings of this study because it offers some insights into the ways of reforming and evolving inclusive practices in mainstream schools for all children regardless of their special needs.

1.8 Organization of the Study

This study consists of six chapters. Chapter 1 (Introduction) provides the background of the study and states the problem. Additionally, it presents the research questions that frame the study and the importance of the research.

In chapter 2 (Literature Review), the review of the previous studies regarding the problem is presented. In addition, it explains the gap in the literature that is addressed in this study.

Chapter 3 (Methodology) comprises a description of the research design and sampling procedure with a detailed description and justification of selected procedures. Additionally, data collection instruments and data analysis procedures are discussed.

Chapters 4 (Discussion of Findings) presents the analysis findings collected through the interviews and critically discusses them with reference to the previous studies.

Chapter 5 (Conclusion) summarises the main conclusions arising from the discussion, which provide the final thought on the parental perspectives of school-aged children with DS towards inclusive education and answers the main research question. Besides, it includes recommendations and implications for future research.

Chapter Two: Literature review

2.1 Introduction

In the previous section, the purpose of the study, research questions and key terms were described. This chapter discusses the review of the literature that explored parental views and perspectives of children with special needs towards inclusive education. This chapter is structured in the following way. First, this chapter describes a theoretical framework. It then details the actions taken towards inclusive education by the Kazakhstani government. After that, this chapter examines the work of Psychological-Medical-Pedagogical Consultation (PMPC) in Kazakhstan. The next part is devoted to the necessity of raising awareness among families of children with special needs and demand for parental advocacy. The last part of this chapter demonstrates the findings of the studies that explored the current topic and identified the factors that had a significant impact on the opinion of mothers and fathers. The gaps in international and national research and rationale for the importance of this study are analysed in the final section of this chapter.

2.2 Theoretical Framework

To understand parental views and their perspectives towards the inclusion of children with DS in mainstream schools two theories – ecological systems theory and 3D model of attitude - were chosen. The theoretical framework represented by Bronfenbrenner suggested, "developing person is embedded in a series of environmental systems that interact with one another and with the person to influence development" (Shaffer & Kipp, 2010, p. 62). He concluded there to be five systems: microsystem, mesosystem, exosystem, macrosystem and chronosystem (see Appendix 3).

The microsystem is the inner layer of the whole system. When a child is born, he or she acts and interacts in their immediate family. The way children think, behave, and respond may affect parents and siblings who are in their surroundings. This system is a vital part of development because an individual both influences and is influenced by other people around them. Positive relationships between two members of the family are influenced by the behaviour and attitude of a third family member. Therefore, if there is a positive and emotionally healthy environment at home, parents are likely to interact with their child in a patient and sensitive manner. The research conducted by Durmaz, Cankaya, Durmaz, Vahabi, Gunduz, Cogulu, and Ozkinay (2011) indicated that families who have a child with DS encounter quarrels. This results in having a stressful life, difficult relationships with other children, and a hard life altogether.

In the mesosystem, Bronfenbrenner refers to the connections between homes, schools and peer groups. According to Bronfenbrenner, supportive links may enhance a child's development. Therefore, teachers should provide proper instruction to children with disabilities, and there should be cooperation between parents and teachers. Booth and Ainscow in the Index for Inclusion (2002) stated the fortification of respectful and collaborative relationships between parents and teaching staff. Several studies showed (Bryant, 2015; Hess et al., 2006; Shevlin, 2002) that partnership between parents and teachers is beneficial, and it maximises the chances of being inclusive. Parents in the study of Hess, Molina, and Kozleski (2006) perceived teachers' caring and openness to communication crucial to children's success rather than the teacher's level of expertise and years of experience.

The exosystem, according to Bronfenbrenner, is a series of social systems that children may not experience, but they may also have a huge impact on a child's development. Parental dissatisfaction with work or low family income might result in negative views and experiences. Balboni and Pedrabissi (2000), in their research, suggested that parents with low socioeconomic status (SES) are less favourable towards inclusive education in comparison to parents with high and average SES.

The macrosystem comprises of economic, social, legal, educational and political systems that determine the values and beliefs of a society. The experience that children with

DS have and the way they are treated at home, school, and other contexts may greatly affect them. Parents in the study of Issakhanova (2019) stated that society is biased towards disabled people, and the reason for that is a lack of accurate information about people with disabilities, especially among the younger generation. According to the experience of mothers, as soon as they learned about the diagnosis of their child after birth they felt depressed and wanted to commit suicide because their newborn child was treated as 'infectious' (Issakhanova, 2019, p. 66). Thus, parents had to overcome the diagnosis of their child, and they face a constant fight with society. Gilmore, Campbell, and Cuskelly (2003) suggested stereotypes that exist in society tend to lead people to focus on the disability than on the uniqueness of an individual.

According to ecological theory, "changes in the individual or the environment occur over time and influence the direction the development takes" (Shaffer & Kipp, 2010, p. 65). Thus, the younger a child is, the easier the process of including a child into inclusive surroundings can be. Kasari, Freeman, Bauminger, and Alkin (1999), in their study, revealed the impact of the age of a child on parental preference on the best educational setting for their children. The findings suggested that parents of younger children with DS are more positive about inclusion compared to parents of older children.

The 3D (Three-Dimension) model of attitude can also provide lenses through which parental perspectives of children with DS towards inclusive education can be examined. The model is based on combinations of Affect (Feeling), Behavior (Dealing), and Cognitive (Meaning) components of attitude. It is believed that all three components are significant. Each of these components can be positive or negative. When all three components combine, the overall attitude towards an object is constructed. The combinations refer to so-called triodes.

A considerable number of studies (Boer et al., 2010) show that parents have positive feelings towards inclusive education (Affect). However, only a minority of them take action to advocate for the rights of their child with DS (Bryant, 2015; Fox, 2016; Hess et al., 2006).

They strive to ensure equal access to quality education (Behavior). Still, the majority of parents cannot protect the rights of their children due to various reasons. First, parents have a lack of knowledge in the field of inclusive education (Hess et al., 2006). Second, parents may be afraid of being accused of having a child with DS that is associated with social stereotypes. Problems associated with family income may also be a reason for inaction (Abdina et al., 2018; Durmaz et al., 2011). These parents are affected by negative feedback and different factors that are reviewed later in this chapter. Additionally, they witness an environment that is not prepared to meet the needs of their children: a lack of qualified teachers and inadequate support services (Cognitive). As a result, parental beliefs dominate feelings and it results in unfavourable decisions.

These two theories explain that all parents develop their expectations about their child's education based on their experiences and information provided by schools, the availability of support services and interactions within the community. Their expectations are subjective predictions about the future. They originate from and can influence the behavior of people during social interaction.

2.3 Kazakhstan on the Path to Inclusive Education

Studies from the past (Donnellan & Miranda, 1984; Frohboese & Sales, 1980; Lipski, 1989; Nietupski & Hamre-Nietupski; 1987; Turnbull & Turnbull, 1980, as cited in Palmer, 1998) to present (Fox, 2016; Hess et al., 2006) have argued that the voice of parents should be taken into account in educational decision-making. Nevertheless, the Kazakhstani context contradicts this argument. Even though the government invests much into the development of education, many children with disabilities are segregated from schools and do not get a quality education. The State Program for Education Development of the Republic of Kazakhstan for the years 2011-2020 predicted that 70% of schools in Kazakhstan would be inclusive and would be available for children with disabilities by 2020 (Ministry of Education and Science of the Republic of Kazakhstan, 2010). It may seem ambitious because the proper introduction of a new phenomenon, formation in people's minds and distribution of the concept is a long-lasting process with many obstacles on its way. These days, the emphasis is on the discussion of the capacity of educational institutions and necessary facilities. However, recent developments in the area of inclusive education have heightened the need for hearing parental views and beliefs of children with special needs.

2.4 Psychological-Medical-Pedagogical Consultations: Recommendation or Verdict

The research showed (HRW, 2019) that there is a small number of children with disabilities who have an opportunity to go to a mainstream school, but the majority of them are still segregated being taught either at home, in a special school or separate classes. Those children, who study in primary and lower secondary schools, have minor or no chance to receive higher education and pursue a good job in the future. The process of shifting to inclusive education in our country seems contradictory. According to the Law of Education, everyone has a right to a quality education and "the accessibility of education at all levels, taking into account the intellectual development, psycho-physiological and individual characteristics of each person" is fundamental (HRW, 2019, p. 64). There is an educational institution Psychological-Medical-Pedagogical Consultation (PMPC) in our country. Their function is to assess children with disabilities and propose recommendations whether the child should attend a mainstream school or receive a home/special education. However, these recommendations are considered as the final decision at schools. The Ministry of Education and Science of the Republic of Kazakhstan and National Academy of Education (2015) reported that only 27% of children with special needs study in mainstream schools and 1% in higher institutions. Thus, a small number of children with disabilities in Kazakhstan attend mainstream schools, whereas a large percentage of children are prescribed homeschooling or segregated in special classes.

2.5 The Importance of Parental Awareness and the Need for Advocacy

The birth of a child with special needs influences the lives of families. As soon as parents reveal that their child has a disability, they enter the world with its own rules, terminology, and personnel. In addition to accepting the child's diagnosis and learning about their needs, parents have to play proactive roles for the rights of their child.

Recently, more attention has been focused on the importance of parental awareness about the rights and possible educational options for children with special needs. Bryant (2015) highlighted the significance of an advocacy role for their children on the way to inclusive education. Parental involvement is crucial since they are the people who are better informed about the needs, peculiarities, strengths and weaknesses of their child. In the study (Bryant, 2015), parents admitted that the road to inclusion was a difficult journey. Mothers and fathers, who completed a successful path to inclusion, strongly believed that it is important to stay positive and believe in their child, collaborate with educators, start the inclusion process earlier and, what is more important, to seek to advocate and be familiar with the laws related to the area of inclusive education.

Similarly, in another major study (Shevlin, 2002), parents described a road to inclusion as a struggle for them. Families had to play proactive roles in accessing the schools and necessary resources for transitioning to inclusion. In parental views, the positive attitude of teachers played a fundamental role and increased the chances to make the child with DS a full participant in the inclusive classroom. Other studies (Bender, Vial, & Scott, 1995; Buell, Hallam, Gamel-McCormick, & Scheer, 1999, as cited in Gilmore, 2003; Hess et al., 2006) agreed that the positive attitude of teachers is a key factor in the realisation of the successful inclusion process. Additionally, parents of children with DS expressed their preference for mainstreaming in early childhood.

In accordance with Hess et al. (2006), parental awareness and advocacy were developed and enforced due to the assistance provided. First, parents learned how to be advocates. Second, they were assigned with a family mentor who provided support. Parents agreed that studying helped them acquire knowledge about inclusive education. They interacted with parents who experienced special education and knew about the advantages and disadvantages of various options.

Similar findings were unveiled in the study by Fox (2016). According to parents, learning conferences and participation in parent support groups added to their knowledge about inclusive education. The findings indicated that even in developed countries parents may not be fully informed about inclusive education. Families shared that they regularly had to "battle to be heard among groups of professionals who often thought they knew more about their child than they as parents did" (Fox, 2016, p.73). They found it hard to be a parent and an advocate for a child experiencing disability. Although, they acknowledged that hope and belief for better things encouraged them to continue advocacy efforts.

Parents in the study by Kenny, Shevlin, Walsh, and McNeela (2005) encountered ignorance in the educational system, from the central administration to classroom teachers. According to parents, they moved from ignorance to knowledge, from fear to confidence for the rights of their children with special needs. To get the best for their children, parents invested "extraordinary levels of time, energy, and resources in their struggle" to ensure getting their children into mainstream schools (Kenny et al., 2005, p.17). On the contrary, in a recent study (Kendall, 2019), teaching staff in mainstream schools worked in collaboration with parents of children with DS and recognised the crucial role of parents in the education of children due to their expert knowledge in supporting their own children. As noted by McFadden (2014), a positive partnership between parents and teachers assisted children's learning, and it was a useful strategy for teachers to use.

In terms of the context of Kazakhstan, parents, particularly those who live in rural areas, are not well aware of the concept of inclusive education and the opportunities it provides. Fortunately, some active parents set up rehabilitation or care centres and Non-Governmental Organizations (NGOs) to accommodate the needs of children with special needs and raise awareness among other parents of children with special needs. Several case studies demonstrated that NGOs worldwide had played a significant role in the development of inclusive education reforms. Parents played a fundamental advocacy role in these organizations (Mayrowetz &Weinstein, 1999, as cited in Rollan & Somerton, 2019). Previous research (Rollan & Somerton, 2019) indicated the problem of a lack of awareness among parents. They emphasised the leading and helpful role of NGOs in informing parents about the options for their children. In addition, they took part in the policy-making process and "demonstrated a capacity to drive these reforms from a grassroots level" (Rollan & Somerton, 2019, p.14). The research findings showed that the cooperation of teachers with supporting staff, local officials, and parents was encouraged. Booth and Ainscow, in the Index for Inclusion (2002), associated inclusive education with the development of respectful and collaborative relationships between teachers, families, and local communities.

The research by Issakhanova (2019) detailed the beneficial outcomes that resulted from the cooperation between NGOs and parents of children with DS. Two NGOs that function in Nur-Sultan and Almaty created a special community where parents increased their self-esteem, developed skills, improved motivation, socialised and trained. Taking part in an empowerment program initiated by NGOs helped families to cope with stress, overcome the child's diagnosis, and look at the situation from a different angle. According to the responses of parents, they improved their competence on a personal level enabling them to demand services and proper education, still, they cannot make decisions on the legislative level and advocate for policy change.

2.6 Factors that Influence Parental Views

A growing body of literature has explored the factors that had impact on parental attitudes towards inclusive education.

In 1998, Palmer, Borthwick-Duffy, Widaman, and Best examined parental views and indicated that parents showed a positive attitude towards inclusive education, but they did not accept inclusive settings as a good option for their children with special needs. Longer experience with special education was a factor that influenced parental opinion. It meant that the longer their child was educated in a special school, the more negative attitudes parents had towards mainstreaming.

Stoiber, Gettinger, and Goetz (1998) investigated the opinions of parents of both children with and without special needs. The results of this study revealed that families of children with special needs had more positive attitudes towards inclusive education compared to parents of typically developing children. Moreover, parents of children with special needs who were poorly educated and had lower family incomes were less positive towards the regular setting. Parents who had one or two children demonstrated more positive beliefs towards inclusive education in comparison to those who nurtured four and more children. Another crucial factor was marital status. Subsequently, married parents proposed more favorable views than single ones.

In another study, Leyser and Kirk (2004) revealed that parents have a positive attitude towards inclusive education. However, the main concerns were related to a possible negative effect on the emotional well-being of the child and a lack of available services in regular schools. Parental education was defined as an important factor that influenced parental views. Hence, parents who had a higher educational level had more positive perspectives towards inclusive education than those who only finished high school. Leyser and Kirk (2004) also maintained that the level of a child's disability (mild, moderate, or severe) had a significant effect on parental attitudes. Thus, families who had a child with moderate and severe disabilities, were more likely to be negative towards regular school settings in comparison to those parents whose children had a mild disability.

By contrast, Downing and Peckham-Hardain et al. (2007, as cited in Al Neyadi, 2015) revealed that specifically, parents of children with moderate and severe disabilities did favour the inclusion. They argued that classmates in regular settings were a good role model for social and academic behaviour. According to parents, their children were "happier, more independent, and more motivated to go to school [and] participate in class" being enrolled in regular education classrooms (Downing & Peckham-Hardain et al., 2007, as cited in Al Neyadi, 2015, p.21).

Similarly, Kasari et al. (1999) explored whether families of children with DS regarded inclusion as a useful approach to improve a child's social skills. Parents stated that other children and their parents played an important role in the process. They considered that a peer could be a role model of appropriate behavior for their children. In addition, parents of younger children with DS were more supportive of inclusion compared to families with older children.

Peltier (1997, as cited in Hess et al., 2006) concludes that inclusive education promotes the social growth of learners and assures that it does not have a negative effect on the academic performance of typically developing children. Children with special needs demonstrate improved social competence in general education.

In the review of 27 studies, Graaf, Van Hove, and Heveman (2012) found out that children with DS who attended regular classes were appreciated by their classmates. However, they were not regarded as ‘best friends’. Therefore, it was recommended to model the social interactions between children with DS and typically developing children. The results revealed that regular placement leads to the development of social and academic skills. This view is supported by Shevlin (2002), who argued that regularly placed children developed social and communication skills better than in a special setting. Moreover, boys and girls who obtained support demonstrated higher academic achievements. The study (Gilmore et al., 2003) explored the attitudes of the community and teachers towards children with DS. They realised there are educational, social, and emotional benefits of inclusion both for children with and without disabilities. Additionally, typically developing children advanced better while interacting with children who have DS. They learned such significant qualities as tolerance and appreciation of diversity. The benefits of children participating and interacting with individuals in different activities at home, in school and community settings were highlighted in the findings of Lyons, Brennan, and Carroll (2016). The study showed children develop skills that are meaningful in real-life situations. Additionally, it was recognised that participation in everyday activities enhanced the psychological well-being and sense of belonging in children. In terms of barriers, parents indicated a child's current health status, communicative abilities, behavior, and the negative attitude of others.

The study of Rafferty, Boettcher, and Griffin (2001) explored the views of parents of children with and without disabilities who experienced so-called 'reverse inclusion'. The findings showed that parents of children with disabilities and non-disabled children indicated both risks and benefits for their children. Generally, parents agreed that inclusion is beneficial. According to their beliefs, it results in the acceptance of children with disabilities in the community. Participation with typically developing peers in various activities help children with disabilities learn considerably more, and it prepares them to function in real life. Nevertheless, parents expressed serious concerns associated with inclusive education. Parents claimed that the major risks for children with disabilities are the inability of education programmes to address the needs of the child, less qualified teaching staff, and limited support or individual instruction. Parents also find inclusion dangerous for their typically developing children. They may encounter behavioural problems that children with disabilities have.

Pace, Shin, and Rasmussen (2010) explored public perspectives on educational and occupational inclusion. It revealed that educating children with DS, together with typically developing children in one regular class, is distracting. In their view, the presence of people with this diagnosis in the workplace increases accidents.

Detailed examination of parental perspectives of children with special needs towards inclusive education by Dimitrios, Georgia, Eleni, and Asterios (2008) showed that the age of a child is an important strand that influenced parental opinion towards educational options. Parents of children under 18 years old were more interested in inclusive practices. Parents were concerned that peers would not accept their child with disabilities as a full participant in a regular class. Additionally, families were uncertain about the quality of the instruction and the availability of support services in regular schools. Nevertheless, parents listed the benefits that inclusive education has. They are the possibility for children with disabilities to take part in various class activities with typically developing children and to have the same rights as their peers.

In the study of Boer et al. (2010), parents of typically developing children expressed positive attitudes towards inclusion and recognised benefits their children acquire such as accepting diversity and sensitivity. In contrast, parents of children with disabilities did not consider inclusive settings as a good option. Their major concerns were associated with the child's emotional development, a lack of individual instruction and available resources in a mainstream setting. Parents supposed that their children with special needs may be rejected or bullied by peers (Salisbary, 1992, as cited in Boer et al., 2010).

In the study by Fox, Farrell, and Davis (2004), school staff, parents of children with and without special needs, and typically developing peers generally demonstrated a positive attitude towards children with DS in a regular class. Parents acknowledged the crucial role of teaching assistants in the effective inclusion of their children with special needs. Similarly, parents regarded teaching assistants alongside general teachers as a contributing factor that resulted in the effective inclusion of their children with DS into mainstream schools (Johnson, 2006). Even though parents indicated the academic progress of children in mainstream schools, teachers were concerned about possible difficulties due to the standard curriculum. Similarly, the curriculum was considered as a barrier in mainstream schools (Kendall, 2019). Teachers reported that the struggle of children with special needs to meet the learning objectives required by the curriculum negatively influenced the self-esteem and confidence of children. Cuckle (1999) suggested that it is highly important to differentiate the curriculum for children with DS because they have trouble in the area of language.

In an investigation into the lives of families who have a child with DS, Durmaz et al. (2011) found that the main problem associated with a child who has DS was a financial one. Even if mothers were more educated in comparison to fathers, there was a high rate of unemployment among mothers. The underrepresentation of mothers in Asian society is closely related to the traditional belief that mothers are the ones who look after a child in society, and fathers are more likely to contribute to family income. Additionally, the study revealed that mothers and fathers adjust to the child's disability differently, fathers of children with DS experience a lower level of stress in comparison to mothers.

Khamidulina (2018), in her study, investigated the parental views about inclusive education in Kazakhstan. Parents demonstrated a positive attitude towards inclusive education and agreed with the beneficial effects of inclusion. However, parents worried about the deficit of relevant facilities and underqualified teachers at regular schools. One more concern is associated with the lack of social understanding of what inclusive education is, and it results into difficulty with the acceptance of children with special needs in their environment. According to parents, society is not aware of the benefits that both children with special needs and their typically developing peers may gain when they study together.

The group of researchers (Abdina, Yeleussizova, Kakimzhanova, Turgaleyeva, Zhanarstanova and Kaskarbayeva, 2018) explored the views of parents who have children with special needs in North Kazakhstan. Families strongly believed that government, school and society are to support and provide educational services to their children. Parents support the view that financial and personal problems of families discourage meeting the needs of their children (Abdina et al., 2018).

2.7 Conclusion

To summarise, there are several gaps in the literature regarding the perspectives of parents who have a child with DS. Therefore, they were addressed in this study. Firstly, a large number of studies were conducted in the 20th century and may be considered as out-of-date. Secondly, the majority of studies were completed in Western developed countries, and studies in the Kazakhstani context are limited. National studies within inclusive education have just recently started to appear, and this study might contribute to the field within the Asian context. Third, the research studies have explored the parental views of children with a wide spectrum of disabilities. The purpose of this study is to explore the views and attitudes of parents of school-aged children with DS towards inclusive education in Petropavlovsk.

Chapter Three: Methodology

3.1 Introduction

The previous chapter showed what is already known about the parental perspectives of children with special needs towards inclusive education. This chapter describes the methodology used in the study. Specifically, this chapter provides information about the rationale of the qualitative research method adopted in the research. Moreover, it details the characteristics of the sample and site. Besides, the chapter describes the process of data collection and data analysis. Lastly, the limitations and ethical concerns of the research are outlined.

3.2 Research Design and Rationale

This part describes the research design used in the study and provides reasons why a particular method was applied. There are three types of research design: qualitative, quantitative and mixed methods. Each of them has its own features and advantages. Quantitative research focuses on the exploration of the relationships between different occurrences and relies on the numbers. In contrast, qualitative research deals with the words and provides an in-depth understanding of the issue or phenomenon. As Muijs stated, qualitative research helps the researcher "to really get under the skin of a phenomenon" (2004, p. 9). Another major reason for using a qualitative approach in this study is that it explores a sensitive topic (Skovdal & Cornish, 2015).

Previous studies (Fox, 2016; Hess et al., 2006) have shown that parental views of children with special needs are not taken into account in the decision-making process. Skovdal and Cornish (2015) pointed out that the qualitative approach is an effective way to give voice to those whose opinion is usually not considered. Therefore, it is rational to employ the qualitative research method in which the researcher seeks to listen to the participants and build an understanding of what is heard (Creswell, 2013). Moreover, the researcher explores how parental experiences, expertise, and other factors influence their behaviour and attitude towards the phenomenon (Maxwell, 2008).

Qualitative research is associated with the term 'umbrella' because it includes a variety of research methods such as observations, interviews, case studies, and ethnographic research (Muijs, 2004). For this study, the qualitative case study was chosen in order to get insights into parental perspectives and attitudes towards inclusive education. It was indicated that case studies provide a 'thick description' of what participants experienced in their lives, what concerns and expectations they have towards the issue (Geertz, 1973, as cited in Cohen et al., 2007, p. 254). Skovdal and Cornish (2015) suggested that issue-focused research helps the researcher to develop a better understanding of the problem and its effect on the group of people. Six case studies of families who have school-aged children with DS were investigated in the current study.

With the focus on exploring parental experiences, the nature of inquiry justifies using a phenomenological design. By referring to the phenomenological-based inquiry, the researcher seeks to listen to participants about their lived experiences about a phenomenon (Creswell, 2013).

3.3 Research Site

All six semi-structured interviews were conducted in Petropavlovsk and took place at the scheduled time and location suggested by participants for their convenience. Two interviews took place at the same location, to be precise, in the foundation 'Sunny Children'. A detailed description of the foundation is provided later. The next two interviews were held at the respondents' houses, and a further two interviews were conducted via telephone. Although the last two respondents initially agreed to participate in face-to-face interviews, difficulties meeting in person due to the spread of COVID-19 resulted in a decision to provide interviews via telephone.

The foundation 'Sunny Children' was established in Petropavlovsk over five years ago and was initiated by two mothers who have children with DS. Respondent 1 said that via the Internet, they had known about foundations run in Russia and they were inspired by their successful experience in the area of inclusive education. Thus, two mothers of children with DS came up with the idea to create their own organisation 'Sunny Children' that aimed to support mothers who have children with DS and their children in Petropavlovsk. Once a week, children and their parents gather and their children communicate with each other, draw, dance, play, and engage in other leisure activities. In the first four years, parents were required to raise funds to ensure the functioning of the foundation. During that period, children learned to sew toys from felt which were sold at different exhibitions. Currently, the foundation has official sponsors.

According to Respondent 1, the children who attend this foundation are the only children with DS who have gone on stage and danced in Kazakhstan. The mother believes that it is thanks to the hard work of their dance teacher, who teaches children with DS to dance despite their problems with balance and spatial orientation. Also, children have been engaged in drawing classes from 2017. One self-educated student comes and teaches boys and girls to draw pictures. Some children have won prizes in different competitions. Additionally, they perform doll performances accompanied by music. In her interview respondent 1 said that mothers initiated various classes and craft projects to help their children with DS to develop and interact with their peers.

3.4 Sample and Sampling Procedure

Purposeful sampling and snowball strategies were adopted for selecting participants for the current study. The main feature of the qualitative approach is the purposeful sampling that was used to explore the experiences of parents who have children with DS and their views towards inclusive education. The strategy in which particular participants, in this case - parents of school-aged children with DS, were chosen because they could provide important information that other resources cannot provide (Maxwell, 2008). Parents of children who are aged 7-16 were regarded as 'knowledgeable people' as they have in-depth knowledge about the problem and they shared their experience and expertise in the area of inclusive education (Cohen et al., 2007, p.97).

The researcher selected one participant who has a school-aged child with the diagnosis of DS and founded the organisation 'Sunny Children' in Petropavlovsk. Then the snowball strategy was applied in the study. The first respondent was as an informer who identified, and helped the researcher to contact the other five respondents who have similar characteristics and interest in the topic. As Cohen et al. wrote, the snowball sampling is "useful for sampling a population where access is difficult, maybe the topic is sensitive" (Cohen et al., 2007, p.116). Thus, the remaining five participants were selected through the snowball strategy. In total, six participants took part in the interviews. According to Creswell (2013), the sample size depends on what research design was adopted by the researcher. From the review of various qualitative studies, Creswell (2013) indicated that case studies include from four to five respondents, whereas the sample size in phenomenology ranges from three to ten respondents.

A purposeful sampling strategy perfectly fitted into this small-scale study and was used to involve participants of different ages and status. Criteria for selecting the subjects for this study were as follows: 1. Be a parent of a child with Down syndrome, 2. Have a school-aged child, 3. Live in Petropavlovsk.

Table 1 details information about the participants. This information will be useful in data analysis. The codes shown in Table 1 will be used throughout the paper instead of participants' names to maintain their confidentiality.

Table 1. General Information about Respondents

Participants	Gender	Respondents' age	Child's age	Marital status	Number of	Membership in the Foundation

					children in family	'Sunny Children'
Participant 1	Female	34	14	Married	2	Yes
Participant 2	Female	43	11	Married	2	Yes
Participant 3	Female		9	Widow	3	No
Participant 4	Female	51	10	Divorced	1	Yes
Participant 5	Female	39	16	Married	1	Yes
Participant 6	Female	44	7	Single	3	No

As can be seen in Table 1, respondents can be divided into two categories: those parents who are the members of the foundation 'Sunny Children' and those who are not. The data in Table 1 shows that respondents of different ages and marital status took part in the interviews. In order to gain a better understanding of parental experiences and perspectives, the section below provides detailed information about each participant.

Participant 1 is a 34 year old female. She raises two children with her husband. Her daughters are 14 and 4 years old. The eldest daughter is diagnosed with DS. She attended regular pre-school classes, and then, she studied in 1-4 classes in a correctional school, now she gets homeschooled. The respondent's husband runs his own business. Respondent has higher education. She had been working as a psychologist at a school for 9 years. Currently, she is on maternity leave, but she runs private practices and focuses specifically on children with DS.

She is also one of the founders of the organisation 'Sunny children'. The socioeconomic status of the family is average.

Participant 2 is a 43 year old female. She is married. The respondent did not reveal her educational level. It is known that she is a housewife and her husband works at a factory. Based on the story of the mother, their family frequently has financial issues. The family has two children: a son (14 years old) and a daughter (11 years old). The daughter has DS. She attends a correctional school.

Participant 3 is female. She did not reveal her age or education. Her husband died, so she raises three daughters alone – they are 17, 16, and 9 years old. Her 9-years-old daughter has DS. The daughter studies in a correctional school. The family moved from the village to the city where they rent a flat. The respondent does not work at present because her daughter with DS needs care and support.

Participant 4 is a 51 year old female. She has only one child. Her daughter is 10 and attends a correctional school. The birth of a child with DS influenced her marriage. Her ex-husband left the family after the child's birth, and the child did not get any financial support during the first few years. Currently the respondent is a businessperson. Their socio-economic status is above average. According to the respondent, they have plans to move to Astana.

Participant 5 is a 39 year old female. She is married. They raise a 16 year old daughter diagnosed with DS who attends a correctional school. The respondent has a degree in higher education. Her area of specialisation is teaching foreign languages. According to the respondent, it was hard to keep a balance between work at university and caring for a child with special needs. As a result, she left her workplace and is a housewife at present. It can be seen from the responses that the mother is very educated and well informed about the experience of foreign countries in the area of inclusive education due to her professional skills; she knows such foreign languages as German and English and it helps her to get access to international literature.

Participant 6 is a 44 year old female. She refused to share much information about her family. From her responses, it is clear that she raises her children alone. She has three sons, and the third boy, who is 7 years old, has DS. He is homeschooled. Currently, the respondent is a housewife, but she worked as a teacher.

As shown in Table 1, only the first respondent's child had one year of experience of studying in a pre-school regular setting. The children of the other five respondents study in correctional schools or receive homeschooling.

3.5 Data Collection Instruments

Semi-structured face-to-face interviews were considered as an effective instrument for data collection. According to Creswell (2014), interviews are characterised by a high response rate because they are scheduled in advance, and "sample participants typically feel obliged to complete the interview" (p.384). The interview protocol (see Appendix 1) comprised open-ended questions that were designed to address the research question and guided by the literature review. Cohen et al. (2007) defined a number of advantages of open-ended questions. One of them is flexibility. The participants talked on the research topic in their own way and led to unexpected findings. Secondly, it enabled the researcher to ask additional questions to gain a deeper understanding of the response or resolve a misunderstanding. In addition, it helped the researcher test the expertise and opinions of respondents.

The interviews were conducted in two ways. Four participants had face-to-face interviews, while two parents responded to the interview questions via phone. When doing the telephone interviews, the researcher scheduled the phone calls at a time when respondents were available and had sufficient time to think over questions and provide full answers. Muijs (2004) argued that in comparison to face-to-face interviews, telephone interviews are easier in terms of confidentiality and result in more sincere responses. However, the disadvantage of telephone interviews is that the researcher cannot see the respondents' gestures, posture and mimes during the conversation (Creswell, 2014).

3.6 Data Collection Procedures

As soon as the Nazarbayev Universty Graduate School of Education (NUGSE) Ethics Committee sent approval to conduct the study, the researcher contacted the participants via telephone and sent an informed consent form via WhatsApp messenger. The consent detailed the main features of the study: its topic and purpose, expected duration of the interview, the risks and benefits, the rights of participants, and contact information in case participants have any questions, concerns or complaints about the interview (see Appendix 2). The informed consent forms are important because, as Cohen et al. (2007) defined, the information included in the consent form influences the decision of participants whether to participate in the research or not. After reviewing the consent forms and agreeing to take part in the interviews, the participants were contacted again to schedule a convenient day, time, and place to be interviewed.

Prior to the interview, each respondent signed two copies of the consent form and returned one copy to the researcher. Before the interview, the participants were reminded about the purpose of the research; the measures taken to ensure anonymity and confidentiality of the interviewee, and that interviews would be recorded.

Each interview was conducted individually in the places preferred by the participants for their convenience and comfort. The interviews were audio-recorded All interviewees preferred to converse in Russian. Along with recording, the researcher took notes in the provided spaces in the interview protocol. Following the interview, the respondents were shown these notes to ensure their reliability. The participants interviewed via telephone followed the same procedure as described. The researcher used a Cube ACR recorder on a smartphone to record the telephone interview.

All audio-recorded interviews were transcribed. Two of them were transcribed using online software Trint and Sonix, while the researcher transcribed the remaining four manually. Then the transcribed data was translated into English for further data analysis.

3.7 Data Analysis Methods

The names of all participants were coded to ensure the anonymity of respondents (Respondent 1 – Respondent 6). The data was saved on the personal computer of the researcher protected by a password.

The researcher reviewed each data document separately and noted meaningful segments or topics in each document by underlining the words, phrases or sentences. When these topics were identified in all data documents, the researcher made a table that comprised all the topics on the same sheet. Each column of the table represented a certain data document. Thus, the table had six columns. Afterward, the researcher highlighted similar topics with the same colors across the different columns. Similar topics were coded and categorised in relation to emerging themes.

The researcher did not use any computer data analysis program, the data was coded manually even though the process took considerable time (Creswell, 2013).

3.8 Ethical Concerns and Risks of Research

This section describes the measures taken to ensure research ethics. Following approval from the NUGSE Ethics Committee, the participants received consent forms that highlighted the voluntary nature of the participation in the current research. Apart from the indication of the research topic, its purpose, risks, and benefits, the consent form informed the participants about the right to withdraw at any moment or refuse to answer certain questions during the interview. Additionally, the researcher ensured that the names of participants and all the names mentioned in the interview would be coded to keep them anonymous. When all participants agreed to take part in the interviews, they signed two copies of the consent form and one of the copies was given back to the researcher.

3.9 Limitations

This section provides information about the limitations of the current study that should be addressed in future research.

The first limitation of the study is associated with the lack of representativeness of the sample. All six respondents in the current study were mothers of school-aged children with DS. In order to address this limitation, it is recommended that future research should involve both mothers and fathers because previous studies (Balboni & Pedrabissi, 2000; Durmaz et al., 2011) showed that sometimes fathers have different views and perspectives compared to mothers.

The second limitation of the study relates to the small number of participants. Therefore, the results of the study cannot be generalised.

Despite the fact that telephone interviews have some benefits, it is recommended to conduct interviews face-to-face in further research because it is important to both hear voices and see the body language of the respondents.

3.10 Conclusion

The methodology chapter provides an overview and the rationale for the research design, the sample, the instruments, the data collection procedure, and the data analysis methods adopted in the current study. The interview was recognised as an effective tool to use and explore the perspectives of parents who have school-aged children with DS towards inclusive education. By applying the purposeful sampling alongside the snowball strategy, the researcher recruited six participants in the present study who provided in-depth knowledge about their experiences and expertise in the research problem and shared their worries and expectations about inclusive education.

Chapter Four: Findings and Discussion

4.1 Introduction

This chapter focuses on the findings that emerged from the collected data and discusses the research findings in terms of exploring the views of parents who have a school-aged child with DS towards inclusive education in Petropavlovsk. In addition to the main purpose of the study, the research aimed to investigate what parents of school-aged children with DS feel about the inclusion of their children in mainstream schools in Petropavlovsk. It will shed light on the factors that have a considerable influence on parental attitudes and beliefs, and find out whether and how parents advocate for the rights of their children with DS.

The following research questions were addressed in the study:

- What are the attitudes of parents of school-aged children with Down syndrome towards the inclusion of their children in mainstream schools in Petropavlovsk?
- What factors influence parental attitudes towards inclusive education?
- How do parents advocate for the rights of their children with Down syndrome to be included in mainstream schools in Petropavlovsk?

In order to answer these research questions and obtain more insightful answers from the participants, a qualitative research design, more precisely, semi-structured interviews were employed.

The chapter is divided into three parts and is aligned with the research questions of the study. The first part provides an answer to the first research question and shows whether parents support the inclusion of their child who has DS in a mainstream school or not. The second part is devoted to the second question and demonstrates the factors that influence how parents feel towards inclusive education. The last part aims to answer the third question and reveals if parents make efforts to fight for the rights of their children who have DS and the ways in which they advocate for them.

4.2 Attitudes of Parents of School-aged Children with Down Syndrome Towards the Inclusion of Their Children in Mainstream Schools.

In order to answer research question one, the Respondents were asked whether they are familiar with the term 'inclusive education' and how they perceive it. Hence, in response to the question 'Have you ever heard about the term 'inclusion'?' only four out of six mothers reported that they have heard about the term 'inclusive education'. In contrast, Respondent 2 has heard the term, but does not have a clear understanding of what it is and how it will be implemented. The remaining Respondent, number 3 stated that she has no idea what it is. However, Respondent 3 became interested and asked the interviewer to explain the concept of 'inclusive education'. The resulting explanation on what inclusive education meant helped her to answer the subsequent questions. She did not respond to some interview questions because they were difficult to answer due to her limited knowledge. Nevertheless, she proposed the benefits and possible challenges that would emerge on the way to inclusive education.

There are similarities between the attitudes of parents of children with DS in the current study and those described by Al Neyadi (2015), Boer et al. (2010), Khamidulina (2018), Leyser and Kirk (2004), and Palmer et al. (1998). The majority of parents have a positive attitude towards inclusive education. Although all respondents indicated the possible challenges on the way to developing inclusive education, five out of six respondents acknowledged the importance of including a child with DS in a mainstream setting. This study has been unable to match those observed in the previous research (Stoiber et al., 1998) that demonstrated that single parents and families with more than three children have a negative impact on parental views towards inclusive education.

Regarding the question: 'What benefits can your child acquire from a regular school?' responses corroborate the ideas of parents in the studies by Al Neyadi (2015), Kasari et al. (1999), Rafferty et al. (2001), Shevlin (2002), who indicated that children with special needs can improve social skills, academic behaviour and become prepared for the future.

Table 2. Benefits that Chidren Acquire from Regular Schools

Themes	Number of Respondents
Role modelling of behaviour	5 (Respondents 1, 2, 4, 5 & 6)
Development of social skills	3 (Respondents 1, 4 & 5)
Realisation of their potential	2 (Respondents 1 & 5)
Adaptation to society and preparation for real life	1 (Respondent 3)

It is evident from Table 2, that modelling of behavior by peers, development of a child's social skills, the opportunity for a child to reach their full potential, a chance to adapt to society and prepare for their future life are the main benefits that were indicated by the respondents.

4.2.1. Role modelling of behavior.

The majority of respondents claimed that the inclusion of their children alongside their typically developing peers could have a positive influence on the behavior of their child. This finding is in agreement with Kasari et al. (1999) conclusions. In their study, they revealed that parents of children with DS were 69% more likely to regard their children's peers as an advantage of regular schooling because they are role models for their children with special needs. According to Respondent 1, it is a stereotype that children with DS have difficulties in remembering and repeating gestures due to problems with the vestibular apparatus and problems with memory. On the contrary, Respondents 1,2,4,5 and 6 argued that their children can mime and copy gestures they see. Respondent 1, who founded the organisation 'Sunny Children' said that the performance of their children in annual dance competitions contradicts the myth that children with DS cannot reproduce the gestures or body postures they see.

> *We have a dance teacher who has worked with our children in the foundation these last five years. She admits that it was hard to organise the children at the beginning because they could not even stand straight. Weekly dancing training, and the teacher's love and dedication helped her to organise the children and turn them into the dancers they are. Believe it or not, in April our children participated in the Republican*

> *Festival 'Zhuldyzai' and they were the only children with the diagnosis of Down syndrome in Kazakhstan who danced on the stage (Respondent 1).*

Therefore, parents assume that looking at the behavior of typically developing peers and interacting with them provides an opportunity for children with DS to see, and then model behavioural norms. This assumption matches those observed in an earlier study. In this previous study, parents agreed that children with DS 'benefitted tremendously' from being in a mainstream setting, especially leading to an improvement in their behaviour and social skills (Bryant, 2015, p.10). Respondents 2 and 6, who have more than one child in their families, stated that typically developing siblings are role models for their child with DS at home and have a positive effect on the behavior of their child.

> *As I told you, I have three sons. The youngest one is diagnosed with Down syndrome. But I see that my two older sons provide a model for their behaviour, and their friends come to us and treat the younger son as a little brother (Respondent 6).*

Respondents 4 and 5 also indicated modelling as one of the benefits that children may acquire from a regular setting, and this affects their experiences and the achievements of their children in various social activities.

> *I do not expect improvements in academic performance, but if we talk about children with Down syndrome, they are imitators. Sometimes they are called copiers. My daughter easily copies my gestures, blinking, fingers moving, whatever. Such children are like sponges that absorb every object they see around them. If she is in an environment where children demonstrate disadvantageous behavior, she will repeat that and behave badly (Respondent 5).*

There was an interesting assumption indicated by Respondent 4, who associated role modelling with the academic improvement of her child.

> *My child might learn better. For example, typically developing children start writing in the lesson. My child, looking at them, would start doing the same but at a slow pace. (Respondent 4)*

This finding seems to be consistent with other research that found parents of children with special needs indicated that typically developing children act as role models for social and academic behavior (Downing & Peckham-Hardain et al., 2007, as cited in Al Neyadi, 2015).

4.2.2. Development of social skills.

Three out of six respondents indicated that their children with DS could develop communication skills through interaction with their typically developing peers. Respondents 1, 4, and 5 emphasised the importance of their children acquiring social skills to enable those children with DS to communicate, ask for help, obtain what they need, protect themselves, get along with people, make friends and develop healthy relationships.

It was the initiative of respondent 1 to create a foundation in Petropavlovsk that pursues two main goals. First, it aims to support mothers who have a child with DS. Second, it strives to create a community for children with DS to interact with each other and develop social skills. Respondent 1 suggested that it is necessary to provide an environment where children with DS are encouraged to learn to speak and socialise, and she agreed that a regular setting is a better place for children with DS to acquire and develop social skills. Respondent 4 reported that her daughter has difficulties in building relationships with children and she hopes that a regular setting may help to overcome this problem. In her story, she reported that when her child went to a correctional group in kindergarten, she persuaded the administration to allow her child to go for a walk with typically developing children three times a week and interact with them during outdoor activities. She did this because she strongly believes that inclusion would have a positive effect on the development of her child's communication skills and interaction with peers. In accordance with the present finding, a previous study (Bryant, 2015) demonstrated that an inclusive environment leads to positive changes in a child's relationships with friends and teachers. Respondent 5 is convinced that it is crucial to provide a regular environment for children to learn how to socialise. In addition to participation in social activities organised by the foundation for children with DS, this mother took the initiative. Hence, they go to a club in the city library every Saturday to ensure that her child communicates with typically developing peers, and both mother and child are pleased with this opportunity. It is encouraging to compare the benefit indicated by parents with that found by Graaf et al. (2012). They indicated that regularly placed children with Down syndrome developed their speech and language skills better than specially placed ones.

4.2.3. Realisation of a child's potential.

Respondents 1 and 5 suggested that regular schools might provide more opportunities for their child to realise their potential. These responses can be associated with the high educational level of respondents 1 and 5 and their awareness of the achievements of other countries in the area of inclusive education. This study confirms that parental education and competence in the area of inclusive education influence the perspectives and opinions of parents (Leyser & Kirk, 2004; Stoiber et al., 1998). According to respondent 1, children have wider opportunities in regular schools compared to correctional ones. Mainstream schools provide more possibilities for children to have access to computers, visit museums and theaters, and participate in various contests. It is her belief that these opportunities might broaden a child's mind and discover hidden talents that could be significant in a child's future. Respondent 5 is convinced that children with DS have great potential, can achieve a great amount in their lives and strongly believes that DS children could reach their full potential in mainstream schools.

4.2.4. Adaptation to society and preparation for real life.

When respondent 3 received an explanation of what inclusive education is, she proposed that a regular setting might help children with DS adapt to society. Still, it is necessary to ensure that the adults and children involved accept her child. This mother was sincere when she expressed her fears about the future. This result may be explained by the fact that this woman is raising three children alone. When their primary income provider died, the family moved to the city and had to rent a flat. The Respondent worries about how her child with special needs will live in the future after she passes away. Therefore, she considers that studying with typically developing people might prepare her child for the future. This finding mirrors those of a previous study that examined the perspectives of parents of children with and without disabilities towards inclusion (Rafferty et al., 2001). Rafferty and her colleagues (2001) found that almost all parents agreed that inclusion enables children with disabilities to participate in a wide range of activities and prepare them to function in the real world. Additionally, it leads to the acceptance of children with disabilities in the community.

4.3 Factors that Influence Parental Attitudes Towards Inclusive Education

Of the six parents who answered the question 'How do you feel about inclusion for your child?' the responses of five were negative. These findings further support the idea of Boer et al. (2010) who showed that, in the views of parents, the inclusive setting is not a good option for their children with disabilities. Parental concerns were associated mainly with the lack of available resources and individual instruction in regular schools.

The most striking result that emerged from the data is that only respondent 5 felt positive about the inclusion of her 16 year old child. However, this finding in the current study does not support previous research. In the study by Palmer et al. (1998), it was indicated that the more years a child spends in a special class, the more negative parents are about inclusive education. Returning to the current study, Respondent 5's responses can be associated with the mild level of severity of the child's diagnosis and the area of this respondent's specialisation. She supports the idea of inclusive education for her child only in the case of mainstream schools providing a tutor and a curriculum that is suitable to the learning style and needs of her child.

In their interviews, respondents proposed possible challenges that may emerge in mainstream schools.

Table 3. Challenges That May Emerge in Mainstream Schools

Theme	Number of Respondents	Respondents
Child's problems with health	5	Respondents 1, 2, 3, 4 & 6
Negative attitude towards children with Down syndrome	6	Respondents 1, 2, 3, 4, 5 & 6
Lack of learning resources and adequate service	4	Respondents 1, 4, 5 & 6
Psychological-Medical-Pedagogical Consultation	5	Respondents 1, 2, 3, 4 & 6

Table 3 displays the various factors that influenced the opinions of the respondents. The child's health problems, negative attitude towards children with DS based on stereotypes, PMPC, a lack of resources and inadequate services were identified by respondents as the main barriers to inclusive education.

4.3.1. Children's health-related issues.

The majority of respondents defined their child's health issues as one of the main barriers to inclusive education. A possible explanation for this might be the level of severity of a child's disability. It is known that children with DS have common health issues like heart disease, problems with their vestibular apparatus and thyroid. Each respondent shared their own story in the interview and revealed the emerging problems related to their child's health, which prevented parents from accepting the idea of inclusion for their child.

According to respondent 1, her child started walking and speaking as a typically developing child in her early years. They lived the experience of going to regular kindergarten and pre-school. Nevertheless, these parents did not favour a regular school as an option for their child. The mother's concerns were related to her child's short attention span that required an individual approach that was not accommodated in the regular school. Respondent 2 is convinced that her child's speech impairments decrease the opportunity for that child to study in mainstream schools because she would not have been able to express herself and communicate verbally with peers and teachers. Respondents 3 and 4 assumed that mainstream school would not be a good educational setting for their children because of their phonophobia. According to Respondent 3, her child went to a regular mini-center for children when they lived in a village, which was a stressful experience. Her child started to panic and hid under the table when the other children became noisy in the room. Similarly, Respondent 4 defined her child's fear of noise as one of the issues; additionally, it is difficult for her child to self-care; she always needs someone to help her use the toilet or get dressed, for instance. Respondent 6 strongly believes that neither correctional nor mainstream schools are a safe place for her child with DS. According to her response, her child might be in danger at school because he can hardly walk upstairs. She supposes that schools cannot provide proper care and attention for her child. Her child's problems with body coordination and chewing were indicated as the main barriers to his studying at a mainstream school.

These findings are in line with the findings of another study (Lyons et al., 2016) in which parents indicated a child's current health status, communicative abilities and behaviour as the major barriers for children with DS to attend a regular setting.

4.3.2. Negative attitude towards children with Down syndrome.

All respondents were concerned that in a regular setting, parents, children, and teachers may harbour negative attitudes towards children with DS based on stereotypes and superstitions. The responses are associated with the gender of respondents and negative experiences that have influenced their views. Table 1 shows that all respondents are mothers. During the interviews, these mothers sincerely expressed their fears and concerns about how their child may be treated in society. In order to have a better understanding of this challenge, a further analysis based on the following sub-themes was conducted: (1) Attitudes of typically developing children, (2) Attitudes of parents of typically developing children.

Sub-theme 1: The attitudes of typically developing children. Respondent 6 worried that her child might face negative attitudes from his peers in mainstream settings. As a recommendation, she suggested that peers should be either older (in order to treat her child as a little brother) or 2-3 years younger. The mother is convinced that teachers are in charge of building positive relationships and a welcoming atmosphere to ensure the acceptance of a child with DS as a full participant in the class by typically developing children. This finding matches those observed in the earlier study by Shevlin (2002). Respondent 5 considered that children in regular school might tease and offend her child. This mother`s belief was based on a childhood experience when she and her classmates made fun of a classmate with developmental disabilities. Therefore, she admits that her child may encounter a similar negative attitude from her peers in class. This finding corresponds to the study by Salisbary (1992, as cited in Boer et al., 2010) in which parents of children with special needs were concerned about the risk of bullying. Respondent 4 was also convinced that a mainstream school is a dangerous place for her child in terms of her psychological and emotional well-being. She is afraid that children in schools may insult her child, mainly due to her distinctive physical characteristics, which places her child in a vulnerable position. According to the mother, if children in mainstream schools treat her child negatively, it may result in psychological pain for her daughter. This finding accords with the earlier study (Leyser & Kirk, 2004), which revealed a number of parental concerns towards mainstreaming, mainly that of the emotional well-being of their children. In accordance with the views of parents who have children with special needs, mainstream settings may negatively influence the emotional development of their children.

Difficulties in building relationships with typically developing children in mainstream schools was mentioned by Respondent 3 in her interview. In her opinion, in order for other children to form a positive attitude towards her child, it would better that they have younger peers.

Sub-theme 2: The attitudes of parents of typically developing children. Respondent 1 often mentioned the word 'stereotypes' in her interview and emphasised that these over-generalised beliefs form social attitudes towards children with DS. This finding is congruent with the previous research (Gilmore et al., 2003) that explored both the community's and the teachers' attitudes towards children with DS. The study has shown that stereotypes tend to lead people to focus on the syndrome rather than on the uniqueness of each child.

In response to the question 'What challenges would emerge on the way to inclusion?’ Respondent 1 was anxious that her child could be regarded as aggressive and unstable by parents who believe in these fixed stereotypes. She considers that if typically developing children offend or cause her physical pain, and she dares to protect herself and fight back, her behavior will be considered as aggressive and lacking control. Respondent 2 expressed serious concerns about possible negative attitudes towards her child in a regular setting. It is linked to an experience that the family had in a correctional school. According to the respondent, she had to advocate for her child's right to study in a correctional school when the family of a child with a mental impairment stated that her child was aggressive and dangerous to the other children in the class. This incident shows that parents of typically developing children may have negative attitudes towards children with DS based on these stereotypes, and they could turn their own child against another child with a disability. As a result, this unpleasant story had a negative influence on both mother's and the child's health and well-being.

Similarly, Respondent 3 had negative experiences that influenced her opinion. She supports the view that due to stereotypes, parents might be against placing children with disabilities in an educational setting with their non-disabled children. This mother recalled the period when her child went to kindergarten in the village. Parents of typically developing children were opposed to her child because they believed that she was aggressive and their children were under threat. She admits that parents may put pressure on teachers and the school administration, which might have a negative influence on the school community. Respondent 5, who is highly qualified in the area of education, associates attitude formation with upbringing. In her opinion, in the process of growing up, children's opinions are formed by their parents and society; thus, their relationship to the world around them depends on adults. In most cases it is evident that children behave, act, and think the way their parents do. The older children get, the more difficult it becomes not to notice that all people are different. Young kids, on the other hand, do not make any judgements between children with special needs and those without them. Based on her personal experience, Respondent 5 discussed a situation whereby parents of typically developing children complained that their children play together with her child in the playground. The point is that parents of typically developing children impose their opinions on their children. This finding can be interpreted through the lens of the ecological systems theory introduced by Bronfenbrenner (Shaffer & Kipp, 2010). According to Bronfenbrenner, the microsystem is the inner layer of the whole system where the child grows up and interacts with the immediate family. Thus, parents have a vital impact on the development and attitude of their child.

4.3.3. Lack of learning resources and adequate services.

It is apparent from Table 3 that the majority of respondents indicated a lack of learning resources and adequate services in mainstream schools as the main pitfall to the development of inclusive education. This study produced results that corroborate the findings of a great deal of the previous work in this field (Boer et al., 2010; Dimitrios et al., 2008; Khamidulina, 2018; Leyser & Kirk, 2004; Rafferty et al., 2001).

In order to gain a better understanding of this challenge, further analysis is based on the following sub-themes: (1) Underqualified teachers, (2) Lack of teaching assistants, (3) Challenging school curricula in mainstream schools. These responses can be associated with the higher educational level of respondents and their experience.

Sub-theme 1: Underqualified teachers. Respondents 1 and 5 defined inadequately qualified teachers in mainstream schools as a challenge that prevents the implementation of inclusive education. These responses are related to the personal experiences of the respondents and their knowledge of international developments.

Respondent 1 was convinced that teachers in mainstream schools could not meet the needs of children with DS. This is associated with her personal experience. According to the interviewee, her child studied in pre-school with typically developing peers. At the end of the academic year, specialists recognised that her child had not acquired any skills throughout the school year. It was evident for the mother that teachers were not ready to accommodate the needs of her child in regular settings due to their lack of competence and unwillingness to do so. This result is in line with the finding of the study by Abdina et al. (2018) where they found that teachers working in an inclusive setting were underqualified. The authors' reflection on the findings were that firstly, teachers opt for teaching positions because they have no other employment opportunities. Second, the courses that teachers undertake are mainly focused on theory rather than on practice. The third reason is the high workload of certified teachers in inclusive schools. Respondent 5 seemed to have a good grasp of the American and Canadian educational system where children with disabilities are welcomed in mainstream schools as full participants. Additionally, the respondent appeared to be knowledgeable about local regulations and laws. According to her, there must be individual educational plans (IEP’s) that should be designed by PMPC specialists in Kazakhstan for teaching children with special needs to enable children with disabilities to study in mainstream schools. It presupposes that children study those subjects that are prescribed by an IEP with specially trained teachers, who, in the respondent's belief, do not currently work in regular schools.

Sub-theme 2: Lack of teaching assistants in mainstream schools. Half of the respondents consider that having a tutor or teaching assistant in class is crucial to ensure an inclusive and safe environment for their children. These responses are associated with personal experiences and knowledge about inclusive education.

Based on her experience working as a psychologist in a regular school, respondent 1 knows that it is difficult for one teacher to meet the needs of thirty children in one class. In her opinion, the school can be regarded as inclusive if there is additional support for children with disabilities. Therefore, she is convinced that tutors should be present in the regular class and assist children with special needs. Knowing about inclusive education in the USA, respondent 5 agreed with the opinion of respondent 1 and considered that tutors for special students may play a significant role in a regular setting. Respondent 5 would have agreed for her child to study in a mainstream school if the school could have provided a tutor for children with disabilities. Similarly, Respondent 6 has a positive attitude towards inclusive education in the case of regular schools ensure tutoring services for children with DS. Taking into account the specialisation of the respondent, who worked as a schoolteacher, she emphasised that tutors should provide quality service in mainstream schools that is more than ‘just for show’. The study confirms that teaching assistants are associated with the effective learning of children with DS in regular classes (Fox et al., 2004; Johnson, 2006).

Sub-theme 3: Challenging school curriculum in mainstream schools. Two respondents indicated that curriculum in mainstream schools posed a challenge along the path to inclusive education. Mainstream schools offer a standard curriculum, and, in the opinions of respondents 4 and 5, if their children could have studied in a mainstream school, they might have found the standard curriculum challenging. With regard to this issue, respondent 5 said that the individual approach of teaching with differentiated tasks designed and then assigned in accordance with the level of a child's development, and the presence of a tutor are key factors in ensuring successful academic performance of children with special needs in mainstream schools. Her response is linked to her teaching experience and awareness of inclusive practices in other countries. The findings of the current study are consistent with those of Johnson (2006) and Kendall (2019) who discovered that curricula in mainstream schools are not relevant for children with DS. This is in agreement with Cuckle's (1999) findings, which emphasised the importance of differentiation to ensure the access of children with DS to education. As respondent 4 stated, PMPC specialists suggested her child study in an inclusive school. However, she refused this option. Knowing the weaknesses of her child, the respondent believed that her daughter would not have met the requirements of the standard school curriculum. It is difficult to explain this response, but it might be related to the divorced marital status of the mother; consequently, she feels a high degree of responsibility for the well-being of her only child.

4.3.4. Psychological-Medical-Pedagogical Consultation (PMPC).

Sixty-six per cent of those who were interviewed indicated PMPC as a barrier for their children with DS to be included in inclusive settings. It seems possible that these results are due to the personal experience of the respondents. Respondents 1, 2, 4 and 5 have negative views about PMPC. This most noteworthy finding, which extends the results of the previous study (HRW, 2019) on the role of PMPC in education, is consistent with the parental responses of children with special needs in the large cities of Kazakhstan such as Almaty, Nur-Sultan, Kostanay, Kyzylorda, Shymkent and Taldykorgan.

According to respondent 1, mothers spend twenty-four hours, seven days a week with their children with DS and know their strengths and weaknesses, needs and interests, but her opinion was ignored by the commission; therefore, she interfered in the procedure and insisted on having test materials changed. She is convinced that PMPC specialists make hasty decisions without allowing the child to think over the given task. Respondent 2 associated PMPC with a negative and dreadful experience. In her opinion, the building and specialists do not provide a welcoming atmosphere for parents and their children with special needs. Similarly, PMPC is considered a stressful experience by respondent 4. Respondent 5 criticised the work of PMPC. According to her, specialists focus on children's disorders rather than on their individual needs.

4.4 Proactive Roles of Parents for the Rights of their Children with Down Syndrome.

In order to answer the third research question, Respondents were asked to indicate whether they have ever made an effort to fight for the rights of their child with DS and to share their experience about taking advocacy roles. One-third of the interviewees (Respondents 3 and 6) indicated that they had never had a situation when their child was offended and/or they had to protect their child's rights. These responses can be related to the age of their children with DS. These respondents' children are 7 and 9 years old. They are younger in comparison to the children of respondents 1, 2, 4 and 5.

It is evident that the birth of a child with special needs leads to changes in the lives of parents. As soon as a family finds out that their child has a disability, they enter a world with its own rules, terminology, and personnel. The majority of respondents shared their feelings as well as the changes that occurred in their families after the birth of a child that was diagnosed with DS.

The following extract from the interview with respondent 1 shows that due to the lack of knowledge among parents, the birth of a child with DS is regarded as a negative and destructive factor for the family.

> *When mothers give birth to a child with Down syndrome, we have 'zero' information. Mothers get into a vacuum with a lack of information. What we knew was only what our doctors had said. Doctors said that it is better to abandon a child because she will be like 'a plant', she will not recognize you and your husband, that my husband will leave the family and I will stay with this child alone (Respondent 1).*

Similarly, respondent 5 said that when her child was born, she was misinformed. According to this respondent, her child was made to study in a correctional organisation because it was regarded as the only educational option for children with special needs in Kazakhstan. After a while, she studied the phenomenon and found this to be false information.

The comment below shows that it was difficult for respondent 4 to accept the diagnosis of her child. What is more, the birth of her child negatively influenced her marriage. She divorced after a while and had no financial support. Although these results differ from the previous study by Durmaz et al. (2011), where parents stated that the birth of a child with DS did not influence the family integrity, they are consistent with those of Issakhanova (2019). In her study, parents admitted that they felt depressed where they were told the diagnosis of their child, and they wanted to commit suicide.

> *I knew about child's diagnosis 3 days after my child was born. I became hysterical at that moment. A psychologist helped me to overcome this stress. It was suggested that I leave my child with the diagnosis of Down syndrome at the hospital because, in the doctor's opinion, I would be ashamed of having such a child. They predicted that the child's ability to communicate verbally and to walk ranged from non-existent to minimal. They said that I was not ready to nurture such a child and she would be a burden on me in the future. There was a situation when I tried to commit suicide, but it was such an unconscious action. The first three years were tough. My husband and I got divorced. Whenever I went to the hospital and to the shop with my child – I burst into tears. Then I realised that she is my daughter, and I loved her (Respondent 4).*

A comparison of these parental responses reveals that these families accepted their child along with their needs and weaknesses. Parents were also thrown into the role of advocates for their children and they had to stand up for the rights of their child.

Table 4. Parental Proactive Roles

Themes	Respondents
Foundation initiatives	Respondents 1, 2, 4 & 5
Contribution to a child's development	Respondents 1 & 4
Parental self-study	Respondents 1 & 5
Advocacy role	Respondents 1, 2, 4 & 5
Early mainstreaming	Respondents 1, 3, 4 & 5

As can be seen in Table 4, five broad themes emerged from the analysis of parental responses. In accordance with the interviewees, they had to play a proactive role starting from the birth of their child. The majority of respondents became members of a foundation in Petropavlovsk. Thanks to the foundation, children with DS interact with their peers, develop art and dancing skills, participate in various competitions, and raise awareness about children with DS in society. Thus, it was the initiative of the parents to invite a speech pathologist from

Russia to share her experience and methodology of how to work with children with special needs. Two respondents mentioned that they contributed to the development of their children. One-third of the respondents demonstrated knowledge and expertise in the area of inclusive education in Kazakhstan and the international context. Over half of the interviewees mentioned PMPC and the Department of Education as places where they advocated for the rights of their children. The majority of the Respondents acknowledged the importance of early mainstreaming and that, according to the responses, this project has recently been realised in Petropavlovsk.

4.4.1 Foundation initiatives.

Respondents 1, 2, 4 and 5 consider the foundation as a platform for their children to socialise and develop skills. Dancing, drawing and handcrafting help children to develop basic skills and escape from rooted stereotypes. As a consequence, they promoted themselves on the local and national level when they participated in the 'Zhuldyzai' festival and achieved first place. Thus, they contradicted the myth that children with DS are incapable of coordinating their body, and remembering and repeating gestures. Additionally, the foundation helped to empower and improve the personal qualities of parents. This finding is in agreement with the previous research (Issakhanova, 2019), which states that non-governmental organisations unite mothers of shared interest and develop parental self-esteem and confidence.

4.4.2. Contribution to a child's development.

In their interviews, respondents 1 and 4 mentioned that they spent money on their child's development. According to respondent 1, there were 16 extracurricular clubs in the correctional school, but her child with DS was not allowed to attend them. Then the mother initiated extracurricular lessons of dance and art for her child and proved to the administration of the school that her child is not hopeless. Being one of the founders of the organisation 'Sunny Children' in Petropavlovsk, the mother said that parents contributed money for the development of the organisation during its first four years. That autumn, for example, the mothers in the foundation were looking to have a meeting with a speech pathologist from Russia whose seminar has already been paid by the foundation. As soon as her child was five years old, respondent 4 started consulting with various speech therapists and psychologists in the city with the aim of developing her child and preparing her for school. When her daughter started going to school, the mother controlled her child's achievement. She was dissatisfied with the school's curriculum and asked for the teacher to differentiate the tasks in the lesson according to the level of her child's development. The mother argued that it took her much time and money, and she expected results from the efforts.

Hence, the information gathered from these responses can be associated with the average socio-economic status of parents. In accordance with the present result, a previous study (Kenny et al., 2005) demonstrated that parents of children with special needs invested much time, energy and resources to get the best for their children.

4.4.3. Parental self-study.

In comparison to other participants, respondents 1 and 5 showed extensive knowledge in the area of inclusive education. This is connected with the higher educational level of these parents and awareness about inclusive policies and practices in other countries.

In her interview, respondent 1 appeared competent in her knowledge about Russia's experience in the area of inclusive education. She learned that Russian specialists had developed a methodological pack of books and workbooks for children with DS. In connection with this, the mother said that they keep in touch with the parents of three children with DS who, according to the decision of PMPC specialists, were excluded from the school. The families of these children left Kazakhstan to live in Russia. It was surprising for mothers in Petropavlovsk to discover that the children from these families went to mainstream schools in Russia and were welcomed in society. According to respondent 5, when her child was born, she was misinformed. She was told that in Kazakhstan children with special needs only have one option - to go to a correctional educational institution. The internet was not available for the family at that time, and the mother had to find information about the diagnosis from various sources. Later, she found out that no law in Kazakhstan mandates that children with DS must go to a correctional school and be registered at a psychiatric hospital. Respondent 5 seemed to have expertise in this area. She is in a more advantageous position because, due to her professional skills, she can read and understand English and German literature. She read about DS in international publications and explored the diagnosis from both biological and medical perspectives. She thus realised that foreign countries regard DS as a syndrome. In the mother's belief, in Kazakhstan they focus on a medical approach that originated in the Post-Soviet period, where DS is perceived as a disease. The respondent said that she read and consulted with her acquaintances before the interview. In conversations with her friends in the USA and Canada, she found out that children with DS study with typically developing children in regular schools. Concerning Kazakhstan, she recently suggested that PMPC specialists should design learning programmes that offer an individual approach in schools in Kazakhstan so that children with DS can attend regular classes together with their typically developing peers. In mother's responses, they should study those school subjects that are prescribed in the Individual Educational Plan (IEP) designed for children with special needs, but, unfortunately, they do not have such an option.

4.4.4. Advocacy role.

In response to the question 'Have you made an effort to advocate for the rights of your child?’ four out of six respondents answered that they have. Respondents 3 and 6 indicated that they had never had a situation when their child was offended and/or they had to protect the rights of their child. These responses are associated with the lack of experience because their children are younger (seven and nine years old) in comparison to the children of other interviewees, whereas respondents 1, 2, 4, and 5 played a proactive role in advocating for their children.

In her interview, respondent 1 shared information of a situation that occurred in PMPC that led her advocating for her child's rights.

> *Once they showed pictures of bad quality and asked my daughter to find mushrooms on them. I said that my child suffers from astigmatism. I insisted on changing to a picture that was of better quality, and she found everything on it. Then she was given a text to read and retell. While my child was thinking, one of the specialists started writing that my daughter does not understand instructions and has problems with reading comprehension. Here I had to fight for the rights of my child. I asked the commission to give more time for my child to think and paraphrase some of the instructions. Then my child managed to complete the tasks. I spend 24 hours, 7 days a week with my child. I know her strengths and weaknesses best, but people who work in PMPK ignore parental opinions.*

Respondent 1 knows that many mothers, due to their lack of knowledge and confidence, cannot defend the rights of their child. An increased necessity for advocacy in this study corroborates earlier findings. In their study, Hess et al. (2006) emphasised that parents should have access to information about all possible educational options for their children to fulfill "the need to assist families in learning to be advocates for their children through education, support and the use of family mentors" (p.156). Respondent 2 stated the following "Every time my child and I go to PMPC, there is a climate of fear. Instead of creating a welcoming environment, the commission starts asking questions. So, it is a stressful experience both for my child and me". Respondent 5 commented, "I have to read a lot before going to PMPC in order to advocate for the rights of my child. Otherwise, they prefer to ignore my presence". The necessity to seek out resources and study laws to educate themselves about inclusive education was also acknowledged by parents in the study by Bryant (2015). Respondent 4 advocated for her child's rights in schools, PMPC, and the Local Department of Education. According to her story, the mother started advocating for her child when they went to kindergarten. She went to PMPC and the Local Department of Education to enable her child to go to a regular kindergarten. In response to this request, the mother was told that her child was not allowed to go to the regular institution, and that it could lead to complaints among the parents of non-disabled children. When her daughter went to a correctional school, the mother monitored her child's learning process. The parent was persistent in her visits to the correctional school because she was dissatisfied with the curriculum in correctional schools. She argued that thanks to prior contributions to the development of her child and regular work with the child at home, her daughter is able to count to ten and read words consisting of four or five letters. She suggested that teachers should differentiate the tasks in their lessons by taking into account the individual needs of learners. However, according to the mother, the school did not provide an opportunity for her child to master these acquired skills due to the limitations of the curriculum in the school. Therefore, the respondent referred to PMPC and insisted on changing the school. However, another correctional school did not meet the mother's expectations either. In her interview, respondent 5 reported that she had been advocating for the rights of her child throughout the latter's life. She describes advocacy as 'the fight'. This finding is consistent with those in the study by Fox (2016), where parents of children with special needs described their advocacy role as a battle against professionals who considered that they knew the child better than the parents did. In this mother's opinion, it is important, first, to be knowledgeable about laws and regulations in order to advocate. According to her, she had to fight for the right to get a disability certificate. It took the family much time and effort to secure a place in the correctional kindergarten and school. This accords with the earlier study (Kenny et al., 2005), which showed that parents struggled at every stage – from preschool to primary school and from primary to secondary school.

> *When I went to the Department of Social Protection, I had to explain to them what they have to do. I need a document, but I cannot do it on my own; therefore, I have to explain and prove to the personnel who provide services there that I have a right to this (Respondent 5).*

In the comment above, the respondent expressed her doubts in the competency of some specialists. A possible explanation for this may be a general lack of awareness about children with special needs in the city. This finding corroborates the idea of Denivarova and Abdresheva (2015). They suggested that the right to quality education is not fully satisfied due to the insufficient awareness of people about the rights and services for people with special needs in the country.

4.4.5. Early mainstreaming.

A large number of those interviewed suggested that placing children with and without disabilities together in one setting should start in the kindergartens. This result is comparable to the findings of previous work. Shevlin (2002) and Bryant (2015) also revealed that parents expressed their preference for mainstreaming in early childhood.

Respondents 1, 2, 4, and 5 support the belief that an inclusive environment should be provided for both children with DS and non-disabled peers at an early period of their lives. These responses are associated with the foundations of grounding arguments. According to respondent 1, a special kindergarten in Petropavlovsk welcomes children with various special needs. Four years ago, parents claimed that their children did not progress in their development in this kindergarten. Thus, parents from the foundation 'Sunny Children' addressed this issue, reported it to the officials of the City and Regional Departments of Education, and convinced them to accept children with DS in a regular kindergarten. They argued that being in a regular setting at an early age enables their children to interact with non-disabled peers, which allows them to imitate their behavior and acquire social skills. Since the implementation of inclusive education is promoted throughout the country, in Petropavlovsk some kindergartens welcomed children with DS on an experimental level. Parents of younger children with DS were pleased that their children were accepted in regular kindergartens. In terms of young children with DS, who go to regular kindergarten now, respondent 2 noted that such pre-school placement provided opportunities for those children to develop a range of social skills, which are not accessible in special settings. In her interview, respondent 4 noticed that those children with DS whose parents opted for inclusive kindergartens have shown significant progress in their skills acquisition and behaviour due to their interactions with typically developing peers. According to respondent 5, a young child does not distinguish between typically developing children and those who have special needs. As the interviewee said: "young children lack knowledge about DS". Therefore, this requires a welcoming pre-school community with the necessary staff to encourage the acceptance of children with DS in regular groups and be role models for typically developing children to develop a positive and tolerant attitude towards children with disabilities. This finding is in agreement with the previous research (Graaf et al., 2012), which claims that pre-school educators need to model and foster social interactions between typically developing children and those with special needs. Thus, typically developing children who spend time with children with special needs in a regular setting may benefit significantly from their interactions, such as a greater willingness to accept diversity.

4.5 Conclusion

The purpose of this chapter is to present the findings collected through the interviews and analyse them with reference to previous studies. First, parental perspectives on inclusive education were analysed. All respondents showed a positive attitude towards inclusive education, but the mainstream school was not indicated as being the best option for their children with DS. The second part detailed the factors that influence parental opinion and beliefs. The last section was devoted to the representation of proactive roles that parents play in order to fight for the rights of their children.

Chapter Five: Conclusion

5.1 Introduction

This chapter outlines the main conclusions that provide the final thought on views and perspectives of parents who have a school-aged child with DS towards inclusive education in Petropavlovsk. It consists of three sections. The first section summarises the study and provides a general overview. The second section informs about the possible educational implications. The third section details the limitations of the present study and makes recommendations for further research.

5.2 Summary of the Study

This section provides a summary of the study, the main goal of which is to determine parental perspectives of school-aged children with DS towards inclusive education.

The qualitative research adopted case study and phenomenology designs to address three research questions: (1) What are the attitudes of parents of school-aged children with Down syndrome towards the inclusion of their children in mainstream schools in Petropavlovsk? (2) What factors influence parental attitudes towards inclusive education? (3) How do parents advocate for the rights of the children with Down syndrome to be included in mainstream schools in Petropavlovsk?

The study has shown that parents of school-aged children who have the diagnosis of DS and live in Petropavlovsk have a positive attitude towards inclusive education; nevertheless, the majority of respondents do not regard the mainstream school as a good setting for their children with special needs. Although many parents indicated the benefits that regular schools may provide, they hold a negative attitude towards the inclusion of their children with DS in a mainstream setting. The findings of this study suggest that a child's problems with health, a negative attitude towards children with DS, PMPC, a challenging curriculum, lack of teaching assistants and underqualified teachers in mainstream schools are the main barriers on the way to inclusive education. The results of this research support the idea that such factors as parental level of education, socio-economic status, personal experience, and expertise in the area of inclusive education have a significant impact on the perspectives, opinions, and behavior of parents. Another significant finding to emerge from this study is that the birth of a child with DS influences the families in different ways. Parental life can be associated with the 'battlefield' where mothers have to fight for the rights of their children with special needs.

5.3 Educational Implications of the research

This small-scale research has added to a growing body of literature in the context of Kazakhstan. Whilst the study took place in the city of Petropavlovsk and the findings cannot be generalised to the whole population of Kazakhstani parents who have a child with DS, several implications of the research can be indicated.

5.3.1 Implication for policy makers. Inclusive education is associated with the development of respectful and collaborative relationships between teaching staff, parents, and local communities (Booth & Ainscow, 2002). Parental voice is crucial because they play a primary role as caregivers, and they possess comprehensive knowledge of the child`s strengths, weaknesses, interests, and needs. It is highly important to expand the involvement of parents in the decision-making process. Therefore, one of the implications is to empower parents of children with DS on a personal and public level by taking part in various empowerment programmes. Thus, families may become confident and competent enough to make decisions, to protect the rights of children, to speak out on behalf of their children, and change legislation for the well-being of children with DS in the country.

Another implication is to explore the experience of countries in the Central Asia region and globally in the field of inclusive education and contribute to the development of methodology and learning materials for the quality teaching of children with DS. One more implication is to implement Individual Educational Plans that would accommodate the needs of children with DS in mainstream schools in collaboration with parents and teaching staff.

5.3.2 Implication for the Ministry of Education and Science. Based on the conclusions, a challenging curriculum and lack of qualified teachers are defined as one of the main pitfalls in mainstream schools. One of the implications is to stimulate internship programmes for graduates of Nazarbayev University Graduate School of Education, who obtain their Master's in the area of Inclusive Education, aimed to get experience and practice in international countries. Subsequently, these specialists could arrange courses for local teachers and teaching assistants to develop theoretical knowledge and master practical skills at school.

5.4 Limitations and Recommendations for Future Research

The findings in this thesis are subject to at least three limitations that should be addressed in future research. The most important limitation lies in the fact that this study lacks a representative variety of respondents. The current study has only explored the views and perspectives of mothers who have school-aged children with DS in Petropavlovsk. Further research is needed to account for the varying respondents and involving fathers in the study.

Another limitation of this study is that the number of respondents was relatively small. Future trials should involve a larger number of respondents.

Unfortunately, the researcher had to conduct two interviews with parents via the phone. It was an unexpected occurrence related to the rapid growth of COVID-19 cases in the country. In the case of similar situations emerging, it is recommended that interviews in further research be undertaken via Zoom or Skype to enable a researcher to hear and see the respondents.

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Appendices

Appendix 1: Interview Protocol

Interview Protocol

Project title: The perspectives of parents who have school-aged children with Down syndrome towards inclusive education in Petropavlovsk.

Time and date of the interview	
Place of the interview	
Interviewee	
Contact details	

After greeting and introducing yourself, the participants are told about the purpose of the research; the measures taken to ensure anonymity and confidentiality of the interviewee (all the names mentioned in the interview will be removed and the collected data will be used only for research purposes); and the approximate duration of the interview. The interviewees are given the consent form to read attentively and sign. The participants are reminded about audio recording while interviewing. The audio recorder is turned on.

Interview questions

1. To get started, could you tell me a bit about yourself and your family (age, place of living, workplace, etc.)?
2. Have you ever heard about the term ‘inclusion’? How do you perceive it?
3. Did/does your child with Down syndrome attend regular school?
    - If *yes*, what challenges did/ does your child and/or family encounter on the way to inclusion?
    - If *no*, in your opinion, what challenges would emerge on the way to inclusion?
4. How do you feel about inclusion for your child?

   Are there any fears? If *yes*, what are they?
5. What do you expect from teachers, school authority, other children and their parents in schools? What kind of support would you like your child to get in school?
6. Do you acknowledge the importance of including your child in mainstream setting?
    - If *yes*, what benefits can your child acquire from inclusion?

7. Have you made an effort to advocate for the rights of your child?
    - If *yes*, what activities have you engaged in for advocacy?
8. What recommendations would you give to ensure equal access to education and social acceptance of children with Down syndrome in mainstream schools?

Appendix 2: Informed Consent Form

CONSENT FORM

The perspectives of parents who have school-aged children with Down syndrome towards inclusive education in Petropavlovsk

DESCRIPTION: You are invited to participate in a research study on investigating parental attitudes of children with Down syndrome towards inclusive education in Petropavlovsk. You will be asked to take part in face-to-face interviews, which will be audio recorded in order to compile an accurate summary of the interview through transcription.

TIME INVOLVEMENT: Your participation will take approximately 30-40 minutes.

RISKS AND BENEFITS: The risks associated with this study are minimal. In case you may feel stressed and uncomfortable to answer the questions, it is within your right to refuse to answer any of the questions or being interviewed. The benefits which may reasonably be expected to result from this study are sharing what challenges and expectations you have towards inclusive education, which may lead to getting more quality education and support in educational setting.

PARTICIPANT'S RIGHTS: If you have read this form and have decided to participate in this project, please understand your participation is voluntary and you have the right to withdraw your consent or discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled. The alternative is not to participate. You have the right to refuse to answer particular questions. The results of this research study may be presented at scientific or professional meetings or published in scientific journals where the participants' anonymity will be ensured.

CONTACT INFORMATION:

Questions: If you have any questions, concerns or complaints about this research, its procedures, risks and benefits, contact the Master's Thesis Supervisor for this student work (Supervisor`s name, e-mail)

Independent Contact: If you are not satisfied with how this study is being conducted, or if you have any concerns, complaints, or general questions about the research or your rights as a participant, please, contact the NUGSE Research Committee to speak to someone independent of the research team. You can also write an email to the NUGSE Research Committee at gse_researchcommittee@nu.edu.kz

Please sign this consent from if you agree to participate in this study.

- I have carefully read the information provided;
- I have been given full information regarding the purpose and procedures of the study;
- I understand how the data collected will be used, and that any confidential information will be seen only by the researchers and will not be revealed to anyone else;
- I understand that I am free to withdraw from the study at any time without giving a reason;

- With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

Signature: ________________________ Date: _____________________________

ФОРМА ИНФОРМАЦИОННОГО СОГЛАСИЯ

Перспективы родителей детей школьного возраста с синдромом Дауна на пути к инклюзивному образованию в Петропавловске.

ОПИСАНИЕ: Вам предлагается принять участие в исследовательском работе, направленной на изучение отношения родителей детей школьного возраста с синдромом Дауна по отношению к инклюзивному образованию в Петропавловске. Вас попросят принять участие в личном интервью, которое продлится около часа и будет записано на аудио.

ВРЕМЯ УЧАСТИЯ: ваше участие займет около 30-40 минут.

РИСКИ И ПРЕИМУЩЕСТВА: риски, связанные с этим исследованием, минимальны. В случае если во время интревью Вы ощущаете стресс или некоторые вопросы покажутся вам неуместными, у Вас есть право не отвечать на вопрос или отказаться от участия в интервью. Преимуществом данного исследования,ожидаемого в результате, является возможность поделиться переживаниями и перспективами в рамках инклюзивного образования, которые сформируют качественное образование и поддержку в образовательной сфере.

ПРАВА УЧАСТНИКА: Если вы прочли эту форму, пожалуйста, поймите, что вы имеете право отозвать свое согласие или прекратить действие. право. Альтернативой является не участие. Вы имеете право отказаться отвечать на конкретные вопросы. Результаты этого исследования будут написаны в тезисе магистров. Они также могут быть представлены на научных или профессиональных собраниях или опубликованы в научных журналах.

КОНТАКТНАЯ ИНФОРМАЦИЯ:

Вопросы: Если у вас есть какие-либо вопросы, проблемы или жалобы на это исследование, его процедуры, риски и выгоды, свяжитесь руководителем этой работы (имя руководителя, контакты).

Независимый контакт: Если вас не устраивает то, как вы работаете, обратитесь в Исследовательский комитет NUGSE в gse_researchcommittee @ nu. edu.kz

Пожалуйста, подпишите это согласие.

- Я внимательно прочитал предоставленную информацию;
- Мне была предоставлена полная информация о цели исследования;
- Я понимаю, как будут собираться данные, и что любая конфиденциальная информация будет видна кому-либо еще;
- Я понимаю, что я могу свободно покинуть кабинет в любое время без объяснения причин;
- Имея полное знание обо всем этом, я согласен с моей собственной волей.

Подпись: ______________________________ Дата: ___________________

Appendix 3: The ecological systems theory