Lived Experiences of Parents Raising Children with Down Syndrome: A Phenomenological Study

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This letter now confirms that your research project titled:

Lived experiences of parents raising children with Down syndrome

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,

Janet Helmer

Associate Professor Janet Helmer

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ABSTRACT

In general, parenting can involve heightened levels of mental and physical strain (Sadziak et al., 2019), with stress being an almost inevitable consequence (Hsiao, 2017). However, parents of child(ren) with Down syndrome (DS) experience significantly higher levels of stress compared to parents of typically developing children (Dabrowska & Pisula, 2010). The complexity of parenting a child with DS has not received sufficient attention in Kazakhstan. Among a spectrum of possible stress-inducing challenges, it has been reported that children with with DS in Kazakhstan face challenges in gaining acceptance to mainstream schools (Human Rights Watch, 2019). Consequently, due to these obstacles, parents tend to opt for special education settings over inclusive environments (Kussainova, 2020). There is lack of research on the experiences, needs, and available support systems for parents navigating the journey of rearing a child with DS. Therefore, the present qualitative phenomenological research aimed to explore the lived experiences of parents, shedding light on educational journey of their children and the hurdles they face. Data was collected through interviews with eight parents of children with DS hailing from different regions of Kazakhstan. The Conceptual Model of Family Factors Relating to the Early Development of Children with Down syndrome (Van Hooste & Maes, 2003) guided the study. The parents in this study demonstrated remarkable resilience and adeptness in adjusting to the life changes associated with raising a child with DS. Nevertheless, parenting, especially when it comes to navigating the educational journey for their children, remained fraught with numerous challenges encompassing stages of diagnosis, birth, early childhood intervention services and schooling. Ultimately, in light of these challenges, diverse parental experiences simultaneously converged on parents serving as advocates for their children.

Keywords: children with Down syndrome, experiences of parents, Kazakhstan

Аңдатпа

Жалпы, барлық ата-аналар эмоционалды және физикалық шиеленістің жоғарылауын сезінуге бейім (Sadziak, Wilinski, & Wiekzorek, 2019), ал стресс-бұл көп жағдайда сөзсіз нәтиже (Hsiao, 2017). Дегенмен, Даун синдромы бар балалардың ата-аналары норматипикалық балалардың ата-аналарымен салыстырғанда стресстің айтарлықтай жоғары деңгейіне ие (Dabrowska & Pisula, 2010). Даун синдромы бар баланы тәрбиелеудің күрделілігіне Қазақстанда жеткілікті назар аударылған жоқ. Стрессті тудыруы мүмкін көптеген проблемалардың ішінде Қазақстанда Даун синдромы бар балалар қарапайым мектептерге қабылдану деңгейінде-ақ қиындықтарға тап болады (Human Rights Watch, 2019). Осы кедергілерге байланысты ата-аналар инклюзивті ортаның орнына арнайы білім беру мекемелерін таңдауға бейім (Kussainova, 2020). Даун синдромы бар баланың ата-аналардың жолы, қажеттіліктері және қол жетімді қолдау жүйелері туралы зерттеулер жетіспеушілікте. Сондықтан, осы феноменологиялық зерттеу ата-аналардың өмірлік тәжірибесін зерттеуге, әсіресе балаларының білім беру жолдары мен олардың алдында тұрған қиындықтарды білуге бағытталған. Деректер Қазақстанның әртүрлі аймақтарынан келген Даун синдромы бар балалардың сегіз ата-анасымен сұхбат арқылы жиналды. Даун синдромы бар балалардың ерте дамуына байланысты отбасылық факторлардың тұжырымдамалық моделі (Van Hooste & Maes, 2003) зерттеуге көмектесті. Бұл зерттеуде ата-аналар өмірлік өзгерістерге бейімделуде керемет төзімділік пен шеберлікті көрсетті. Дегенмен, ата-ана болу, әсіресе олардың балалары үшін білім беру жолын шарлау туралы айтатын болсақ, диагностика, баланы өмірге әкелу, ерте балалық шақтағы араласу қызметтері мен білім беру кезеңдерін қамтитын көптеген қиындықтарға толы болып қала береді. Сайып келгенде, осы қиындықтарды ескере отырып, ата-аналар балаларының құқықтарын қорғаушы ретінде әрекет етуге мәжбүр.

Түйінді сөздер: Даун синдромы бар балалар, ата-ана пікірі, Қазақстан

Аннотация

В целом, все родители склонны испытывать повышенные уровни эмоционального и физического напряжения (Sadziak, Wilinski, & Wiekzorek, 2019), и стресс является почти неизбежным следствием (Hsiao, 2017). Однако родители детей с синдромом Дауна (СД) испытывают значительно более высокие уровни стресса по сравнению с родителями детей с типичным развитием (Dabrowska & Pisula, 2010). Сложность воспитания ребенка с СД не получила достаточного внимания в Казахстане. Среди множества возможных вызывающих стресс проблем, отмечается, что дети с СД в Казахстане сталкиваются с проблемами в получении признания в обычных школах (Human Rights Watch, 2019). Следовательно, в связи с этими препятствиями, родители склонны выбирать специальные образовательные учреждения вместо инклюзивной среды (Kussainova, 2020). Существует недостаток исследований по опыту, потребностям и доступным системам поддержки для родителей ребенка с СД. Поэтому настоящее качественное феноменологическое исследование направлено на изучение жизненного опыта родителей, просвещая об образовательном пути их детей и трудности, с которыми они сталкиваются. Данные собирались через интервью с восемью родителями детей с СД из разных регионов Казахстана. Концептуальная модель семейных факторов, связанных с ранним развитием детей с синдромом Дауна (Van Hooste & Maes, 2003), помогла в исследовании. Родители в этом исследовании проявили замечательную устойчивость и мастерство в приспособлении к жизненным изменениям, связанным с воспитанием ребенка с СД. Тем не менее, родительство, особенно когда речь идет о навигации образовательного пути для их детей, остается насыщенным многочисленными трудностями, охватывающими этапы диагностики, рождения, услуг по раннему детскому вмешательству и образования. В конечном

итоге, в свете этих вызовов, родители вынуждены выступать в качестве защитников прав своих детей.

Ключевые слова: дети с синдромом Дауна, опыт родителей, Казахстан

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Lisr of Abbreviations

DS – Down Syndrome

ASD – Autism Spectrum Disorder

TD – Typically Developing

CHD – Congenital Heart Defect

NDD – Neurodevelopmental Disorders

IDD – Intellectual and Developmental Disabilities

SEN – Special Educational Needs

PMPC - Psychological Medical and Pedagogical Commission

TA – Teacher Assistant

1. Introduction

Introduction

The objective of this chapter is to lay the foundation for the study by first providing background information. Then, the chapter presents a problem statement which focuses on the phenomenon of parenting a child with Down syndrome (DS), specifically their challenges and needs, including the Kazakhstani context. Essentially, this section aims to develop an understanding of the parenting of children with DS, shedding light on why exploring parenting experiences of this group of parents was considered research worthy. The chapter also presents the research questions that will guide the study including a section that explains the study's purpose and significance. The chapter concludes with an outline of the thesis.

Background of the Study

Down syndrome is a chromosomal disorder caused by the presence of an extra copy of full or partial chromosome 21. The cells of the human body typically contain a complete set of genes arranged in the form of chromosomes. These chromosomes are inherited from both the mother and the father, with each contributing 23 pairs, totaling 46 chromosomes (Nugent, 2011). In the case of Down syndrome, error in cell division known as "nondisjunction" leads to the inheritance of an extra copy of chromosome 21 or a portion of it which results in one of the three types of DS - Trisomy 21, Mosaic or Translocation (Sherman et al., 2007; Kazemi et al., 2016). Its common physical features were first described by John Langdon Down in 1866, and the syndrome is currently named after the researcher (Nugent, 2011). While the incidence of Down syndrome is estimated to be one in 400-1500 births worldwide (Kazemi et al., 2016), there is no official statistical information on the annual number of children born with Down syndrome in Kazakhstan. Levin (2023), referencing the Ministry of Health, reports an estimated total of approximately three thousand

individuals with Down syndrome in the country. Specifically, there were 138 births of children with Down syndrome recorded in 2020 and 133 in 2019 (Levin, 2023).

Down syndrome is one of the most prominent neurodevelopmental disorders, causing intellectual disability and developmental delays (High, 2013). This genetic condition is also characterized by distinct physical features such as poor muscular tone, flattened facial features, high joint flexibility, and shorter limbs and stature (Centers for Disease Control and Prevention, 2023). Additionally, these individuals tend to have slanted eyes, a small chin, a short neck, and a small mouth, along with a larger tongue, resulting in a protruding tongue (Perkins, 2009). Moreover, DS is associated with a heightened risk of hospitalization, with one Tennessee study indicating that nearly half of children with Down syndrome require hospitalization within their first three years of life (So et al., 2007). Frequently documented health concerns include congenital heart defects (CHD), immune system irregularities, infectious diseases, gastrointestinal disorders, and leukemia. Apart from these mentioned conditions, individuals with Down syndrome are also prone to thyroid issues, hearing impairment, visual impairment, and early aging. Adults are at increased risk of developing dementia and Alzheimer disease. They also tend to suffer from obstructive sleep apnea (Hickey et al., 2012). To fully understand the unique needs of individuals with DS it is not only crucial to grasp the physical aspects of this condition, but it is just as vital to carefully examine the real-life experiences of parents of children with DS. While the majority of health concerns can be alleviated with the help of medical interventions, the latter remains to be an unexplored topic within Kazakhstani context.

Statement of the Problem

In general, all parents tend to experience heightened levels of mental and physical strain (Sadziak et al, 2019), with stress being almost inevitable (Hsiao, 2017). However, the challenges faced by parents of children with Down syndrome take on a different, more

heightened tone. As stated by Lawrence (2008, p.528) who studied experiences of parents of children with disabilities including one with Down syndrome, parenting involves "navigating public spaces that presume normalcy, managing the emotions of raising a non-typical child in a typical world…," as parents face changing dynamics on multiple levers including "school, medical community, social networks, and the larger community" (Nugent, 2011, p.10).

A number of researchers have attempted to assess the impact of raising a child with developmental and/or intellectual disabilities (IDD), and there is a unanimous agreement that these parents experience higher levels of parental stress (Gupta, 2007; Hoffman et al., 2009), anxiety, and depression (Olsson & Hwang, 2001; Zablotsky et al., 2013) compared to parents of typically developing (TD) children. These emotions are often accompanied by feelings of guilt, blame, and instability in mental and physical well-being (Reichman et al., 2007). Such an emotional response can be attributed to the heightened demands of caring for a child with a disability (Pillay et al., 2012). Parents may grapple with the challenge of accepting their child's disability, find other aspects of family life and its members being ignored, feel pressured with arranging specialized care and locating community resources, as well as planning for future caregiving responsibilities and managing associated financial obligations (Floyd et al., 1995; Parish et al., 2008; Reichman et al., 2007). On top of that, families may face child behavior issues (Meppelder et al., 2015), unpleasant experiences with specialists and schools (Blacher & Hatton, 2007), and absence of support (formal and informal) (Douma et al., 2006).

Down syndrome is, in a way, a unique diagnosis because of the availability of prenatal diagnostic procedures, with pregnancy termination rates being reported to be as high as 90-93 percent (Mansfield et al., 1999). While there is no available data specific to Kazakhstan, for a mother, the challenge starts with choosing to preserve the pregnancy or discovering the diagnosis post-birth and represents only a part of the possible spectrum of experiences, not to

mention the emotional stain of these early challenges. As a result, many quadian factors of the lives of these families, including "scheduling, prioritizing, amount and quality of relaxed family time, career or education take on increased complexity" (Nugent, 2011, p.35). Meanwhile, research indicates that parents of children with Down syndrome experience lower levels of depression, among many other indicators, compared to parents of children with other developmental disabilities (Blacher & McIntyre, 2006). However, higher levels of depression are reported among them in comparison to parents of typically developing children, (Sanders & Morgan, 1997), urging not to undermine the struggles of this demographic of parents, considering they can be at risk of being overlooked (Desimpelaere et al., 2024). Moreover, given that parental depression is recognized as one of the key extrinsic factors that directly impact developmental outcomes of a child with DS (Windsperger & Hoehl, 2021), by examining parents and their experiences at the intersection of their respective context, there is an opportunity to potentially enhance outcomes of children.

Purpose of the Study and Research Questions

This qualitative study aims to explore the multifaceted experiences of parents raising children with Down syndrome. Specifically, it seeks to understand the challenges they encounter, their role in their children's educational journey, and the needed support to navigate this unique path. In pursuit of this objective, the main question guiding this study is: "What are the lived experiences of parents of children with DS as they relate to education-related endeavors?" There are also three sub-questions:

- As parents of children with DS, what is their role in the educational journey of their children?
- As parents of children with DS, what are the main challenges they face in rearing and supporting the education pursuits of their children?
- As parents of children with DS, what areas of improvement do they suggest?

Significance of the Study

According to Windsperger & Hoehl (2021, p. 5), Down syndrome is "still one of the least understood genetic ID syndromes." The majority of studies addressing the parenting of children with disabilities have been conducted in Western countries, with the notable exception of studies such as Kussainova (2020) and Human Rights Watch (2019). While Kussainova's study exclusively examined the perspectives of parents regarding the schooling of their children with Down syndrome, the latter explored education-related challenges across various levels for children with disabilities, without a specific focus on Down syndrome. There is neither adequate research nor an understanding of the experiences, needs, and available support systems for parents navigating the complexities of raising a child with DS in Kazakhstan. Therefore, given the existing gap, it is crucial to investigate and shed light on the real-life experiences of Kazakhstani parents with particular attention to their obstacles, the resources or support services accessible to them, and education of their children. Centering on the firsthand perspectives of parents offers a unique opportunity to bridge a crucial knowledge gap regarding the impact of Down syndrome on families in Kazakhstan. Through this exploration, customized support can be developed to improve the well-being of these families, thereby fostering positive outcomes for both parents and children. By addressing existing gaps, there is a potential to positively influence social and educational achievements for children with Down syndrome in Kazakhstan.

Therefore, it is expected that the study will be instrumental for various stakeholders, including parents, educators, policymakers, and society as a whole. To start with, by gaining insights into parental perspectives and challenges, this study will aid in understanding how to better provide targeted support and interventions. Additionally, this study can contribute to promoting inclusive education in Kazakhstan by helping educators understand the strengths and points of support for children with DS. This knowledge can help educators develop

strategies such as differentiated curricula and support systems. Lastly, the study has the potential to raise awareness about the obstacles parents of children with DS encounter, with potential implications to combat stigmatization, misconceptions, and biases surrounding Down syndrome in Kazakhstan. As a consequence, there is a potential to create a society that is more inclusive where the rights of individuals with Down syndrome and their families are supported and conditions for such inclusion are created.

Summary

In conclusion, this chapter has explored the importance of understanding the experiences of parents raising a child with Down syndrome (DS). It is crucial to recognize that while Down syndrome, including aspects related to parenting, has been extensively researched in the West, there is a lack of studies exploring experiences of parents and their children with Down syndrome in Kazakhstan. The next chapter will delve into existing research on Down syndrome phenotype, challenges encountered by children and their families, and how parents navigate the challenges of raising a child with DS. This will involve presenting a conceptual framework and critically analyzing the research of various scholars.

Outline of the Thesis

This thesis is divided into six chapters. Chapter 1 serves as an introduction providing an overview of the study. In Chapter 2 the researcher presents the existing research and systemizes findings in the form of a literature review. Chapter 3 explains the methodology used in this study followed by Chapter 4 where the findings and outcomes of the conducted research are presented. The interpretation and discussion of these findings can be found in Chapter 5. Lastly, the conclusion is presented in Chapter 6 where the findings are summarized and suggestions for future researchers are offered.

2. Literature Review

Introduction

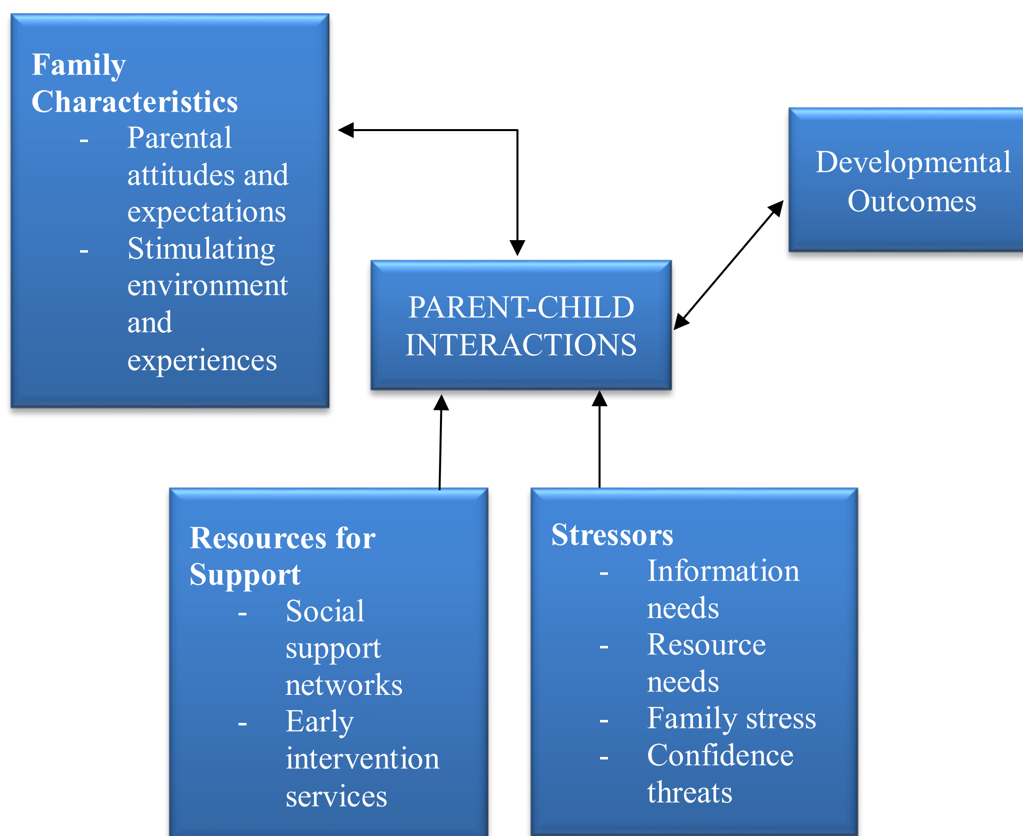
In the previous chapter, the groundwork in the form of background information, problem statement, study objectives, research questions, and research significance were presented. This section is dedicated to the review of the literature. More specifically, it presents the conceptual framework and a synthesis of studies on the following themes: Down syndrome, Down Syndrome and Education, Education of Children with DS in Kazakhstan, Challenges and Concerns Experienced by Primary Caregivers of Children with Down Syndrome, and Family Coping and Adaptation**.** Due to the paucity of research on this particular topic, much of the literature presented are quite dated, but are still relevant to this under-explored topic.

The Conceptual Framework

The conceptual framework that guided this study was the Conceptual Model of Family Factors Relating to the Early Development of Children with Down syndrome (see Figure 1) by Van Hooste and Maes (2003). Drawing from Guralnick's work (1998), at the core of the model lies a component named parent-child interactions. It is based on the premise that the quality of interactions between the child and parent have a direct relationship with developmental outcomes of child(ren) with Down syndrome. The authors contend that in light of individual child traits, some of which are characteristic of the Down syndrome phenotype, such as responsiveness, hypotonia, activity level, approach-avoidance tendencies, and distractibility, parent-child interactions should prioritize "sensitivity, responsiveness, and incorporate a moderately directive parenting approach" (p. 298) on the premises of reciprocity, warmth and affection in an a structured environment with elements of scaffolding. At the same time, the model notes that the quality of these interactions may be influenced by such factors as family characteristics, support resources, and stressors.

Figure 1

The Conceptual Model of Family Factors Relating to the Early Development of Children with Down syndrome



Note. Adopted from Van Hooste & Maes (2003).

The second component, family characteristics, comprises two sub-components: parental attitudes and expectations, and stimulating environment and experiences. Regarding the former, it is asserted that low parental expectations may result in the underestimation of abilities of children with DS (Cunningham, 1987, as cited in Van Hooste & Maes, 2003). Consequently, this can prompt parents to engage in behaviors that are not conducive to the development of the child (Marfo et al., 1998, as cited in Van Hooste & Maes, 2003). Various factors may cause low parental expectations, including negative perceptions from professionals regarding the capabilities of their children, associating intellectual disability of their child with notions like low cognitive ability, inactivity, and unfavorable long-term

developmental prospects (Marfo et al., 1998, as cited in Van Hooste & Maes, 2003), as well as a shortage of age-appropriate data on developmental milestones (Spiker, 1982, as cited in Van Hooste & Maes, 2003). Conversely, overly high expectations can also be harmful, particularly when they stem from parental refusal to accept the diagnosis, as noted by Marfo et al. (1998, as cited in Van Hooste & Maes, 2003). Nonetheless, it is known that, generally, parents are able to successfully identify their child's level of development, and adjust their parenting patterns accordingly (Berger, 1990, as cited in Van Hooste & Maes, 2003). Another significant family characteristic that can influence developmental outcomes is the presence of a stimulating family environment. This includes various elements such as the variety of toys and materials, the overall level of stimulation provided by the environment, and the frequency and quality of interactions with both adults and peers (Guralnick, 1998, as cited in Van Hooste & Maes, 2003). Therefore, the authors' synthesis of prior studies by Guralnick (1998), Spiker and Hopmann (1997), and Cunningham (1996) underscores that a stimulating and supportive family atmosphere, along with exposure of a child to other adults and children, significantly promote the positive development of children with Down syndrome.

Simultaneously, the model acknowledges that families raising a child with Down syndrome often face heightened levels of stress. Once again, adapting Guralnick's (1998, 1999) work, it delineates four sources of stress linked to the child's disability, which could potentially affect family dynamics and the child's development. The initial three stressors encompass the parental need for informational guidance regarding their child's health and development, interpersonal and familial strain, and the complexity of managing provision of support. Collectively, these stressors can culminate in a condition known as "confidence threat," representing the extent of parents' confidence in their perceived capability to ensure their child with education and care. The strain experienced by families can escalate into marital crisis, and parents may have concerns about potential adverse effects on their other

children, although there is no empirical evidence in support of the latter (Cuskelly, 1996, as cited in Van Hooste & Maes, 2003). According to the authors, managing these stressors depends on parents' capacity to access support resources and employ proactive problem-solving approaches.

Support resources defined by the model include social support networks and early intervention services. Support networks can include "a spouse, partner, friends, kinship, and other personal network members of families and their children with Down syndrome" (p. 301). These social networks act as role models and source of valuable information, advice, and emotional support, thereby positively impacting coping strategies and fostering parental feelings of satisfaction and competence. Although it remains uncertain which type of support network, informal or formal, yields greater benefits, the authors assert that support is most effective when tailored to the specific needs of the family. When considering the significance of early intervention (EI), informed by the research of Guralnick (1991) and Cunningham (1987), the model proposes that commencing EI during infancy is advisable. It is contended that the purpose of EI programs are three-fold: 1) resource support (locating and coordinating all the necessary information about the array of services available); 2) social support (helping families to cope with negative external attention and personal reactions); 3) providing families with information and services (Guralnick, 1998, 1999, as cited in Van Hooste & Maes, 2003). Ultimately, EI not only benefits the child but also has a positive impact on the entire family. It leads to more favorable parental attitudes, enhanced family functioning, and improved parenting styles, all of which contribute to advancements in child development and behavior. According to the authors, for EI programs to be beneficial, several considerations must be in place. First, early intervention should be thorough and require a significant time commitment, commencing in the early stages of childhood and actively engaging both parents and children. Additional characteristics include a limited number of specialists per

family, and a balanced structure that both follows structure and is adaptable. Moreover, it should prioritize the enhancement of natural parent-child relationships and employ family-centered strategies.

By reviewing a number of research studies, particularly the work of Guralnick (1998, 1999), Van Hooste and Maes (2003) provided a comprehensive overview of significant family and environmental factors that can influence the development of children with Down syndrome, particularly at early stages. The model regards the quality of parent-child interaction as the cornerstone of a child's development, which is in agreement with a number of studies that report the deleterious effects of parental stress on child's wellbeing and development (Cabrera et al., 2011; Deater-Deckard, 2005). For example, the slower rate of reaching certain milestones, given the variability in developmental trajectories for these children, has been attributed to two factors: 1) medical comorbidities and following ramifications; 2) environmental factors such as exposure to interventions and home environment (Locatelli et al., 2021; Windsperger & Hoehl, 2021). In line with this, according to D'Souza et al. (2016), parental depression is linked to deficits in expressive language development of children with DS.

Although the precise extent of direct influence or moderating effects of other factors depicted in the framework remains unclear, the model has identified various environmental factors that can impact parent-child interactions. All of these factors - family characteristics, support resources, and stressors - can be analyzed within the context of Kazakhstan to identify areas for improvement in the current state of affairs.

What is Down Syndrome?

Initial epidemiological observations of Down syndrome were made during the mid-1800s by pioneering physicians such as Esquirol, Seguin, and John L. Down in 1866 (Sherman et al., 2007). Today, the syndrome bears the name of this latter researcher, whose

characterization of the traits associated with Down syndrome set it apart as a distinct category among other intellectual disabilities (Desai, 1997; Sherman et al., 2007).

Down syndrome is a genetic disorder caused by the presence of an additional chromosome 21 or part of it in a nucleus of a cell (Duranovic et al., 2017), resulting in a unique set of physical characteristics: a short stature, low muscle tone, and distinctive facial dysmorphia, such as almond-shaped eyes, extra fold of skin around eyes, a nasal bridge that appears flat, and a tongue that protrudes (Esquirol, 1838; Down, 1866; Seguin, 1846, 1856, as cited in Sherman et al., 2007; Asim et al., 2015). Aside from physical traits, Down syndrome is linked to health issues such as significantly increased occurrence of “cardiac, gastrointestinal, immunological, respiratory, sensory, and orthopedic” health concerns (Bittles et al., 2007, p. 222), vulnerability to developing leukemia (Asim et al., 2015), and being in a risk group for developing Alzheimer’s disease symptoms such as dementia (National Institute on Aging, 2020). In addition, Down syndrome is characterized by global developmental delays in “motor, language, cognitive, self-care, personal-social dimensions” (Jafri & Karman, 2020, p. 898). A distinct neurocognitive phenotype linked to Down syndrome is characterized by a pronounced array of challenges, notably in the realms of fine and gross motor skills (Canada’s Down Syndrome Magazine, 2023), cognition, speech and language, as well as verbal memory (Silverman, 2007). According to the National Down Syndrome Congress (2020), almost all children with Down syndrome achieve their developmental milestones, but they do so at a rate approximately 1.5 to 2 times slower than their typically developing peers. Moreover, in contrast to their early years, children with Down syndrome experience a deceleration in both linguistic and intellectual development, measured by IQ, as they progress into school-age and adolescence (Hodapp et al., 1999; Locatelli et al., 2021). Nevertheless, according to the National Down Syndrome Congress (2020), many individuals with Down syndrome lead fulfilling lives.

A Child with Down Syndrome in a Family

In times gone by, the birth of a child with Down syndrome was often viewed as a tragic event, and families being advised to institutionalize their children was a norm (Emde & Brown, 1978; Hodapp, 2001). However, a shift in perspective catalyzed by the 1954 report from the World Health Organization advocated for home care and emphasized the pivotal role of families in providing care (Emde & Brown, 1978). Research suggests that the majority of parents successfully adapt to the needs of their ‘new reality’ (Blacher & Baker, 2007; Cunningham, 1996; Van Riper, 1999). For instance, all three significant research programs investigating family adaptation to the birth of a child with Down syndrome, conducted in the United Kingdom (Cunningham, 1996; Gath, 1990) and the United States (Van Riper, 1999) during the 1970s and 1980s, provide evidence that adverse consequences are not unavoidable results of the heightened stress associated with raising a child with Down syndrome.

At the same time, in contrast to parents of children with other types of neurodevelopmental disabilities (NDDs) such as autism (ASD) (De Clerq et al., 2021; Dabrowska & Pisula, 2010), Prader-Willi syndrome (Lanfranchi et al., 2012), 22q11.2 deletion syndrome (Larkin et al., 2021), and other types of intellectual disabilities (ID) (Stores et al., 2002), studies observe lower levels of stress among parents of children with Down syndrome. That being said, it is reported that families of children with Down syndrome exhibit more positive outcomes, such as increased family cohesion, greater feelings of reward, reduced stress, and decreased caregiving burdens – a phenomenon described by Hodapp et al. (2001) as the Down syndrome ‘‘advantage.’’

Scholars have identified various factors that contribute to the phenomenon known as the "Down syndrome advantage." Chief among there is the behavioral phenotype of individuals with DS, encompassing traits such as heightened sociability (Kasari & Freeman, 2001; Pitcairn & Wishart, 1994), reduced occurrence of challenging behaviors (Ricci &

Hodapp, 2003), and a generally compliant, easy-going temperament (Adamson et al., 2009), plays a pivotal role in making them relatively easier to parent. From a different point of view, the reason lies not in child characteristics, but in parental demographics. It has been identified that compared to children with other types of intellectual disabilities, children with DS are often born to mothers with an average age higher than that of the general population, suggesting higher percentage of educated mothers (Stoneman, 2007), greater financial stability and richer life experiences (Hodapp et al., 2003). Other contributing factors include Down syndrome being a well understood diagnosis and with the presence of supportive systems for parents (Hodapp, 2002). Nonetheless, although parents of children with Down syndrome exhibit better well-being in comparison to parents of children with ASD, other psychiatric conditions, or other IDs, they still face higher stress levels when compared to parents of typically developing children of the same age (Dabrowska & Pisula, 2010; Gau et al., 2008; Hedov et al., 2002; Lam & Mackenzie, 2002; Olsson & Hwang, 2003; Roach et al.,1999; Scott et al., 1997).

Challenges

The journey of parenting a child with an intellectual or developmental disability is a mixture of both moments of happiness and instances of stress, negative emotions, and feelings of sorrow (Farkas et al., 2018; Marshak, 2019). Thus, the crisis and trauma of welcoming a child with Down syndrome cannot be overlooked. According to the study by Pillay et al. (2012) which explores the postnatal experiences of mothers in Australia, as a response to their children being diagnosed with DS, mothers go through a self-questioning process: “Why me?” and “What have I done to make things worse? What have we done to deserve this child?” Moreover, sadness, sorrow, and grief appear to be common pattern of reaction, as parents process the fact that their child is not as they imagined (Seligman & Darling, 2017). Once parents come to terms with the undeniable reality of their new life

situation, they may experience fear and guilt as they anticipate societal responses and grapple with uncertainty about the future (Mulcahy & Savage, 2016). In a study by Marshak (2015), parents described receiving unexpected news of their child having a disability as traumatic. The range of emotions experienced by parents include grief and chronic sorrow (Rueda et al., 2005), altered self-concept (Childs, 1985), decreased self-esteem (Sheldon et al., 2020), depression (Olsson & Hwang, 2001), social isolation (Seltzer et al., 2001), and severe emotional distress (Dabrowska & Pisula, 2010).

It is also known that the initial reaction of a family to the diagnosis or birth of a child with Down syndrome is shaped by the manner in which they receive the diagnosis (Van Riper & Choi, 2011). Sometimes, the content of information communicated to parents by medical professionals defines whether the pregnancy will continue or be terminated (Skotko et al., 2011). Parents express concerns about medical personnel exhibiting a lack of compassion, inadequate information provision, and a disproportionate emphasis on potential future difficulties or negative aspects of raising a child with DS (Nelson Goff et al., 2013; Skotko, 2005). One longitudinal study (Carr, 1988) was able to identify that even 21 years later, the words were used when mothers were told during diagnosis disclosure were ingrained in their memory with 82 percent accuracy. This highlights the enduring effect of information conveyed by medical professionals, including both its content and emotional resonance.

Therefore, numerous factors contribute to the heightened stress experienced by parents, including the unique healthcare, developmental, and educational needs of these children. Parents may contend with increased levels of behavior problems (Meppelder et al., 2015), the challenges of coordinating a range of specialized services (Reichman et al., 2008), and sometimes negative interactions with professionals (Blacher & Hatton, 2001). Additionally, the susceptibility of children with Down syndrome to various illnesses (Van

Allen et al., 1999) further adds to parental stress. Consequently, parents face heightened caregiving demands (Reichman et al., 2008) along with financial constraints and limited employment opportunities (Reichman et al., 2008; Parish et al., 2004). For example, according to Boulet et al. (2008), parents of children with DS spend 12-13 times more financial resources on their children's healthcare costs, as opposed to parents of other children, especially in the early years of life (Geelhoed et al., 2011). Hedov et al. (2002) suggest that mother of children with DS are more likely to have part-time employment when compared to mothers of typically developing (TD) children, indicative of parents having to reduce their work hours. Furthermore, parents report lack of informal and formal support (Douma et al., 2006), advocacy complexities (Blacher & Hatton, 2007), increased marital problems (Bristol et al., 1988), and pessimistic feelings about their maternal competency (Haldy & Hanzlik, 1990).

According to Kaliszewska (2018), parents typically experience an initial phase of depression following the birth and diagnosis of their child with Down syndrome, but their emotional well-being tends to improve up until the child reaches around 4 months of age. At this point, a second bout of depression emerges as parents observe the distinctive features of Down syndrome such as reduced responsiveness to external stimuli and fewer smiles compared to typically developing children. The preschool years may bring about additional episodes of depression, as parents become aware of their child's challenges in walking, speaking, using the toilet, and learning. These emotional struggles can also coincide with their child's adolescence and early adulthood. Therefore, intense emotional responses are a consistent aspect of the rearing of a child with Down syndrome at all stages of development (Zahn-Waxler et al., 2002).

Down Syndrome and Challenges Related to Education

While the challenges and concerns surrounding the birth of a child with Down syndrome paint a comprehensive picture of the emotional, social, and financial complexities that families navigate, a distinct set of hurdles emerge when we focus specifically on the realm of education. Addressing the intricate challenges associated with optimal learning environments for children with Down syndrome necessitates a thorough exploration of various key aspects. These include delving into the specific learning profile of individuals with DS, understanding the role of early intervention services, evaluating diverse schooling options, and examining opportunities beyond the school years.

Learning Profile

There is variability in cognitive characteristics among individuals with Down syndrome, and as such, they should not be collectively generalized under a singular "Down syndrome profile" (Davis, 2008). For example, research indicates that the age at which individuals with Down syndrome begin babbling can vary by as much as 10 months, with an average onset at 15 months. Similarly, sphincter control typically develops around 44 months of age, but this milestone can vary by up to 22 months between each child (Windsperger & Hoehl, 2021). Additionally, there are significant differences in both expressive and receptive language development delays experienced by individuals with Down syndrome, highlighting the diverse nature of their developmental trajectories.

Approximately 80 percent of individuals with Down syndrome display a moderate level of intellectual disability (Roizen, 2007, as cited in Martin et al., 2009), with mean IQ of 50, and mental age not exceeding the age of an 8 year old (Locatelli et al., 2021). Overall, the extent of disability can range from mild (IQ 50-69) to profound (IQ 20-35) (Slana et al., 2020; Windsperger & Hoehl, 2021), and the learning profile of people with DS encompasses strengths in certain areas on one hand and challenges on the other. Areas of relative strengths

include social functioning (Dykens & Kasari, 1997), non-verbal skills such as gesture use (Fidler, 2005), visual learning (Pinter et al., 2001), and receptive language, especially vocabulary (Martin et al., 2009; Pezzutti et al., 2018). On the contrary, there are notable weaknesses in motor skills (Bruni, 2006), the ability to process information, especially auditory information (Conners et al., 2007), and adaptive functioning (Windsperger & Hoehl, 2021). Additionally, there are observed deficiencies in intrinsic motivation, and a tendency to implement avoidance strategies (Wishart, 2002). Individuals with Down syndrome also face sensory processing difficulties (Bruni, 2016), challenges with executive functioning (Schmahmann, 2004), and issues with memory (Laws et al., 2000). Communication, language, and memory impairments manifest as obstacles in phonological development, syntactic comprehension, the production of grammatical structures (Chapman, 1997), and poor speech intelligibility (Jafri & Karman, 2020), with physical abnormalities such as hearing loss and hypotonia contributing to their difficulties in speech (Jafri & Karman, 2020).

Furthermore, Down syndrome is also associated with mental health diagnoses, intensifying challenges in cognitive, behavioral, and social functioning of these individuals (Davis, 2008). These encompass autism, prevalent in 5-18% of individuals with DS (Roizen & Patterson, 2003; Capone et al., 2005), disruptive behavior disorders such as attention deficit disorder and attention deficit hyperactivity disorder, affecting 9-34% of individuals with DS (Oxelgren et al., 2017), and obsessive-compulsive disorder (Evans & Gray, 2000). In comparison to typically developing peers, children with Down syndrome often demonstrate stubbornness in adhering to regulations and standards (Dykens et al., 2002). They may engage in frequent self-conversations and exhibit social withdrawal (Glenn & Cunningham, 2000). Additionally, they tend to participate in stereotypic and repetitive types of play, mostly initiated by others (Hines & Bennett, 1996). Therefore, although children with DS undergo the same developmental stages as typically developing children, the aforementioned

cognitive and behavioral characteristics pose unique challenges to a child's ability to acquire academic skills and participate fully in a classroom amongst peers (Merrick et al., 2004).

Early Intervention Services

In the initial stages of a child's development, early care plays a crucial role in minimizing the impact of disability and compensating for deficits (Slana et al., 2020). Therefore, the recommended route for children with Down syndrome typically is enrollment in early and intensive therapy such as physical, occupational, speech, and feeding (Bull & The Committee on Genetics, 2011) as early as possible, usually shortly after birth (Van Hooste & Maes, 2003). For example, seeking guidance from speech and language therapists may be necessary to address delays in speech and language development (Laws & Hall, 2014). Furthermore, in some cases individuals may not acquire speech at all, necessitating acquiring alternative communication methods by the family and child (Jackson et al., 2014) which also can be approached with the help of early intervention specialists (Kendall, 2017).

According to Tomris et al. (2022), early intervention is "a system of services designed to promote the overall development of young children birth to 5 years of age who have or are at risk for disabilities and/or developmental delays and provide support to their families" (p.120). On the other hand, Bowe (2004, as cited in Mohammed Nawi et al., 2013) defines early intervention as a service or specialized program designed to support children with developmental delays or those at risk, spanning from birth to the age of three. According to Spiker et al. (2011, p. 18), the array of services and supports may encompass:

> information about the child's disability; ongoing health monitoring to meet both routine and specialized medical needs; individualized one-to-one services and therapies targeted to promote specific skill acquisition and improvements in functioning; parent education and training that focuses on optimal responsivity to

promote the child's learning and participation in daily activities and routines; opportunities for interactions with peers in group settings.

The team involved in administering the necessary therapy usually consists of a number of specialists such as healthcare professionals, occupational therapists, speech and language therapists, and physiotherapists (Johnson, 2006). It is known that high-quality family-centered specialized interventions can significantly enhance the well-being of children with Down syndrome (Davis 2008; Fidler & Nadel, 2007).

To date, numerous studies have attempted to assess the effectiveness of early intervention programs. Guralnick and Bricker (1987), in their review of research assessing the influence of early intervention on the development of children with Down syndrome, discovered that early intervention played a crucial role in alleviating and preventing the usual decline in cognitive ability, as measured by IQ. While this measure remains stable throughout life for typically developing people, aging is associated with deceleration of IQ among DS population. All in all, research suggests a favorable impact of early intervention on educational outcomes for children with Down syndrome (Paige-Smith & Rix, 2006; Roberts et al., 2007): improvement in motor development (Clibbens et al., 2002), cognitive and adaptive functioning (Connolly, 1993; Clibbens et al., 2002), speech and language processing (Clibbens et al., 2002), and school performance (Irwin, 1989). Furthermore, literature indicates favorable outcomes of EI not only for children but for family members and especially mothers (Cuskelly et al., 2009), such as having more favorable views of their child and parenting situation, reduced distress levels, and feeling greater sense of support (Pelchat et al., 1999).

While early intervention is globally accessible, this must be considered in terms of the economic, political, cultural, and social contexts of different countries (Clibbens et al., 2002; Guralnick, 2019). Literature indicates that the services offered can fall short of fully meeting

the requirements of both the child and the family (Sarimski et al., 2013; Ziviani et al., 2011). Common obstacles encountered by parents include delays during the screening and diagnosis stages, along with challenges in accessing early intervention services (Bailey, 2021). In line with this, Kendall (2017), in an interview with parents of children with Down syndrome in England, unearthed issues related to a specific early intervention service. Parents expressed concerns over its limited accessibility across regions, leading them to incur personal expenses for specialized lessons. Furthermore, various problems emerged concerning speech and language therapy services, including lengthy waiting lists, insufficient contact with speech therapists, and the delegation of program delivery to non-specialists due to a shortage of speech experts. Similarly, Marshall et al. (2015), in their evaluation of available support services for parents in Northeast Florida, brought to light various challenges. These include insufficient insurance coverage for therapy services, inadequate information about accessible resources, rigid service schedules, and service providers lacking in sensitivity, knowledge, and care coordination. While early and intensive therapy is crucial for many children with Down syndrome, the availability of such services seems to hinge on a combination of factors. On one hand, it relies on the family's awareness, resources, and advocacy, and on the other, it is influenced by the responsiveness and flexibility of service systems and providers. Thus, families are often tasked with navigating through numerous medical and therapy services, often being solely responsible for coordinating their child's care (Lindeke et al., 2002; Nolan et al., 2007).

Furthermore, children with DS are more prone to having unmet healthcare needs compared to other children with special healthcare needs, particularly impacting families with low income or lacking insurance (McGrath et al. 2011; Nelson et al. 2011, as cited in Marshall et al., 2015; Mohammed Nawi et al. 2013). This circumstance can send parents over the edge, leading them to reduce hours or cease employment to attend to their child's care

(Phelps et al., 2012; Rogers & Hogan, 2003). On top of that, potential child behavior issues may compromise enrollment in childcare services, thereby affecting opportunities for parents to maintain employment (Rogers & Hogan, 2003). Although behavioral problems among children with DS are lower than those with other developmental disorders, they are higher in comparison to typically developing children (Dykens, 2007). Therefore, despite the shift towards inclusion, children with Down syndrome still face lower likelihoods of spending time at school with peers in general education settings (Turnbull et al., 2010) or participating in community recreational programs (Menear, 2007).

Schooling

Sheldon's (2020) examination of fathers' experiences resonates with the latter statement, revealing that challenges within systems, institutions, organizations, and bureaucracy prominently featured in responses, with a notable emphasis on schooling-related issues. A participant in the study poignantly expressed: "Getting the supports for school and education, it's an unending battle just to get her a fair opportunity" (Sheldon et al., 2020, p.7). Nearly 40 years ago, there was a prevailing belief that children with Down syndrome were incapable of learning such as acquiring reading skills due to perceived cognitive limitations (Buckley & Bird, 1993), with literature naming children with DS trainable but not educable (Spiker, 2011). However, contemporary research has dispelled this notion, revealing that the learning challenges faced by these children vary across a spectrum from mild to severe, and with adequate support they can excel both academically and socially in mainstream education (Buckley et al., 2006).

In the present day, mainstream schooling is a growing preference within families raising children with disabilities (Kasari et al., 1999). The study conducted by Kasari et al. (1999) revealed that 75 percent of parents of children with DS have positive views about inclusive education, simultaneously rejecting part-time placement in mainstream schools

(mainstreaming) as an option. Similarly, Kussainova (2020) explored the perspectives of parents raising children with DS regarding inclusive education in Kazakhstan. The findings revealed that parents perceived an inclusive environment as a valuable opportunity for their children to cultivate social competencies through learning from their typically developing peers. Yet, in practice, pragmatic choices of parents steered towards enrolling their children with DS in special schools.

Studies suggest that children with Down syndrome attending inclusive settings demonstrate improved academic achievement in domains of reading, numeracy, and writing skills (Beadman, 1997; de Graff et al., 2012; Sloper et al., 1990). In addition to improvements in literacy, they also demonstrate gaining benefits in expressive language development (Buckley et al., 2006; Couzens et al., 2011; Turner et al., 2008), behavior, and social development (Buckley et al., 2006) compared to their counterparts in special schools. On the other hand, Buckley et al. (2006) also noted that the advantages in academic and language development may come at the expense of social inclusion benefits such as developing friendships or having a boyfriend/girlfriend. Moreover, Laws et al. (2000) and Johnson (2006) highlighted a potential limitation of mainstream education in the lack of regular access to speech and language therapists. Other concerns voiced by parents include the choice and adaptations of the curriculum (Laws & Millard, 2001; Mullan et al., 2018), the abilities of teachers to tailor the curriculum and adjust their teaching methods (Laws & Millard, 2001), the level of organization of classroom support and available resources (Lightfoot & Bond, 2013), and the attitudes of teachers and staff (Laws & Millard, 2001), as well as fears of potential peer redicule (Gilmore et al., 2003). Consequently, parents may find that special schools offer advantages such as a tailored curriculum, consistent communication with educational staff, and opportunities for their children to socialize with peers facing similar challenges (Byrne, 2013). Nevertheless, according to Buckley et al. (2006), the ideal learning

environment for a child with Down syndrome can only be realized within an inclusive setting.

At the same time, the realm of inclusion is not that straightforward and there are acknowledged impediments to the effective inclusion of children with Down syndrome, including unfavorable attitudes from both peers and teaching staff (Fox et al., 2004); inadequate support from educational staff due to limited knowledge and scarce professional development opportunities (Lyons et al., 2016; Mulholland & O'Connor, 2016); and prioritization of academic accountability mechanisms such as league tables and examination results (Bagley & Woods 1998; Hodkinson, 2010). Literature in recent years has been extensively focusing on necessary procedures for successful inclusion. Specific to Down syndrome, Fox et al. (2004) delineate key factors for successful inclusion: teachers assuming full responsibility for organizing the student's daily educational activities, the involvement of teaching assistants (TAs) and their effective collaboration with the lead teacher, strong communication between the school and parents, and an accessible curriculum that places the child at the core of the learning process.

However, Gold (2000) points out, "Over their school careers ... these children remain at the mercy of geography" (as cited in Johnson, 2006, p. 24), that is – there is uneven distribution of inclusive education opportunities, with some regions embracing inclusion while others lack such provisions. Moreover, a parental survey conducted by Hargreaves et al. (2021) indicates a lower likelihood of inclusion for secondary school students with Down syndrome (37%), compared to their primary school counterparts (80%), especially among male students. This aligns with the findings of Cuckle (1997) and Lightfoot & Bond (2013), the latter of whom noted that only 20-25% of secondary students with DS graduated from mainstream schools. At the same time, the theme of participation is crucial in the discourse on inclusion. Students need equal opportunities to engage in social and extracurricular

activities. Similarly, instructional approaches should be guided by an inclusive philosophy, considering whether students are taught alongside their peers, in small groups, or in segregated settings (Hargreaves et al., 2021). For example, Engevik et al. (2018) discovered in their study of Norwegian students with DS that schools included these students in activities like mealtime, music class, physical education, and social events but limited their participation in more academically focused classes such as mathematics and English. However, Hargreaves et al. (2021), in their exploration of students' experiences, did not find strong support for this observation. Nevertheless, the researchers revealed that the percentage of students participating in the social aspects of school was lower among secondary students in mainstream schools (69%-81%) compared to students in mainstream and special primary schools and special secondary schools (88%-95%). This nuanced finding adds an additional layer to understanding the experiences of parents and children, especially those who are older. Namely, the evidence for continued enrollment in mainstream schools is scant (Egan, 2001, as cited in Kenny et al., 2005), and significant variations exist depending on geographic location (Moorcroft-Cuckle, 1993, as cited in Kenny et al., 2005).

Post-secondary Education

As noted by Johnson (2006), one of the major worries of parents is the future of their children once they graduate from school: "There is no provision for children with special needs coming out of the mainstream. At school, the children are striving to achieve. At college, they have to fit in" (p. 27). According to Channell and Loveall (2018), within the realm of post-high school outcomes for individuals with DS, post-secondary education stands out as the least explored area in research. These scholars suggest that such scarcity of studies likely mirrors the limited opportunities available for their enrollment in post-secondary education, possibly negatively impacting opportunities for independence and employment (Carr, 2008; Steingass et al., 2011). According to Nelson Goff et al. (2016), parents of

adolescent and young adult children with DS have less resources, highlighting the need for the establishment of localized vocational, recreational, and supportive services and programs. In fact, there is evidence that parental caregiving responsibilities persist even after a child reaches the age of 18 (Crnic et al., 2009). The combination of challenging factors, such as the heightened susceptibility of children with Down syndrome to health issues, psychiatric concerns, and social challenges with age (Irving et al., 2008; Mahy et al., 2010; Steingass et al., 2011), combined with their transition out of many support services (Nelson Goff et al., 2016), and the aging of parents, can significantly compound the difficulties of parenting.

Parents raising children with DS encounter a multitude of challenges concerning their children's educational journey, spanning from the pursuit of early intervention therapies to navigating suitable school environments, and extending to concerns about their child's post-secondary education, adaptation in community, and employment.

Education of Children with DS in Kazakhstan

Children with disabilities in Kazakhstan, including those with Down syndrome, have the opportunity to receive education within either a special education setting or an inclusive environment, with the decision stemming from the diagnosis conducted by Psychological Medical and Pedagogical Commission (PMPC) (Makoelle, 2020). The special education known as defectology, present in the form of correctional schools, classrooms, and rehabilitation centers, bears the hallmarks of a Soviet-era legacy. It promotes a correctional philosophy rooted in the belief that students with disabilities thrive best in specialized schools with special curricula (Rollan & Somerton, 2019).

At the same time, inclusive education has been gaining prominence, and children with Down syndrome, today, have an opportunity to attend mainstream schools under the Bolashak program. With the ratification of international human rights treaties such as the International Convention on the Rights of Persons with Disabilities in 2015 (UNDP, 2023)

and the UNESCO Convention against Discrimination in Education in 2016 (UNESCO, 2016), one can assume that Kazakhstan has demonstrated a clear commitment to safeguarding the rights of individuals with disabilities, particularly their access to inclusive and high-quality education (Human Rights Watch, 2019). This dedication is further emphasized in the State Program for the Development of Education and Science of the Republic of Kazakhstan for 2020-2025. In particular, the government aims for all schools and kindergartens, as well as 70% of colleges and universities, to establish inclusive educational environment by 2025 (International news agency "Kazinform," 2021). Yet, Human Rights Watch ([HRW], 2019) reports that progress toward truly inclusive education has been sluggish. Parents in Kazakhstan cite such issues as a shortage of qualified teacher assistants, ineffective educational programs, and insufficient accommodation (Khamidulina, 2018). Moreover, there are instances when children are denied admission to mainstream schools for reasons such as the child not having a PMPC recommendation, the assumption that the child would be unable to study, the absence of professionals to assist students in the classroom, or biased assumptions that kids with disabilities will act out and keep the other kids from learning (HRW, 2019). As a result, a majority of disabled children receive their education at home, segregated from their peers with only infrequent visits from teachers, in special classrooms, or at special boarding schools that may be located far from their homes and communities (HRW, 2019). According to Makoelle (2020), drawbacks of Kazakhstani inclusive education include lack of reasonable accommodation, negative teacher attitudes towards children who exhibit challenging behavior, lack of adapted programs, and teachers who feel incompetent to teach children with SEN. In major cities such as Almaty and Astana, schools have the opportunity to employ specialized tutors to support children with disabilities. However, a contrasting situation emerges in other regions of the country (Bazhkenova, 2018; Panchenko, 2021). Moreover, concerns are being raised regarding the

PMPC practice. As revealed by Bazhkenova (2018) in her book about experiences of people with disabilities in Kazakhstan, “The choice is determined by the members of the PMPC commission. But how long do they see the child? Half an hour? The adaptation alone takes about an hour…He will then live with the stigma of being ‘mentally retarded’” (p. 108).

Thus, as of today, Kazakhstan primarily emphasizes a medical model when it comes to the education of children with disabilities (Human Rights Watch, 2019). Meanwhile, globally, the concept of disability has transformed over the years, from an emphasis on a deficit or medicalized model to an inclusive comprehension of a human characteristic known as a social model of disability (DePloy & Gilson, 2004, as cited in Farkas et al., 2018). According to this model, “people are not disabled by their impairments but by disabling barriers they face in society” (Oliver, 2013, p. 1024). Fortunately, there are several non-profit organizations such as Caritas Kazakhstan, Mama Pro, Kun bala that are actively involved in mitigating some of the aforementioned barriers by providing support to children with Down syndrome and their parents. Nonetheless, it is ultimately the responsibility of the state to ensure the provision of services for individuals with disabilities and their entitlement to quality education, however beneficial these organizations may prove to be (HRW, 2019).

Summary

Children with Down syndrome encounter a diverse range of developmental challenges, akin to a "valley and peak" learning profile. Despite difficulties, with appropriate support in place, they can thrive both academically and socially. The literature review has also explored various facets of parenting a child with Down syndrome, shedding light on the trials and triumphs experienced by parents across different contexts. It concluded an examination of the landscape of inclusive education in Kazakhstan. The importance of employing a conceptual framework in guiding research, particularly, the conceptual model of

Family Factors Relating to the Early Development of Children with Down syndrome by Van Hooste and Maes (2003), was presented.

3. Methodology

Introduction

The preceding chapter provided an overview of the subject, delving into the realm of parenting child(ren) with Down syndrome and highlighted the insights garnered from previous scholarly works. In the current chapter, the spotlight turns toward the methodology employed in this study. This chapter presents the research design and methodology, as well as important aspects such as research questions, sample size and selection, data-gathering techniques and the subsequent analysis. The chapter concludes with an exploration of ethical considerations.

Research Philosophy

As stated by Kawulich (2009), "One's philosophical and theoretical perspectives, both tacit and overt, drive one's approach to research…" (p. 39). The fundamental elements of philosophy consist of "ontology," which pertains to the fundamental beliefs regarding the nature of our reality, and "epistemology," which concerns our understanding or acquisition of knowledge about it (Leavy, 2014). The present research follows a philosophical approach named interpretive epistemology, rooted in the premise that the reality is subjective and contingent upon individual interpretation. In particular, the study adopts phenomenology, the inception of which dates back to the early 1900s with its initial formulation by Edmund Husserl (Leavy, 2014).

Phenomenology is based on the idea that our comprehension of the world originate from our personal experiences (Hein & Austin, 2001), and, thus, attempts to study these experiences, otherwise referred to as phenomena. According to Hein & Austin (2001, p. 6), the goal of the phenomenological researcher is to elucidate the "taken-for-grantedness" assumptions that underlie lived experiences of study participants. Therefore, researchers should refrain from assuming that they possess knowledge about the

interpretations individuals assign to particular phenomena. As explained by Leavy (2014), the researcher has a task of revealing the aspects of people's perceptions that they consider as given. To achieve this objective, one should steer away from assuming shared ‘standard’ thinking, and in attempt to do so, implement the concept of bracketing pre-conceived notions and personal biases (Hein & Austin, 2001).

The researcher involved in this study has prior experience working closely with a family raising a child with Down syndrome. While this experience has shaped a particular understanding of parental experiences and the support needs of children with DS, the present study was intentionally structured to avoid reinforcing any preconceived notions the researcher might hold. Each step, from participant interviews to data analysis, was meticulously approached with awareness of potential researcher biases to prevent any unintentional influence on the findings.

Research Design

The chosen procedure of inquiry is a qualitative design based on the premises of phenomenology which is defined by Creswell (2013, p.76) as a qualitative study that “describes the common meaning for several individuals of their lived experiences of a concept or a phenomenon.” According to Johnson and Christensen (2020), it is about acquiring a perspective into the study participants’ worlds and grasping their meanings. Such a strategy in many cases is used to delve into the lived experiences of people such as Lauterbach’s study (1993) of ‘living through’ experiences of mothers who lost a baby in late pregnancy or Nieswadomy’s study (1993) of a mother’s experience living with a teenage child dying from a cancer. Therefore, to understand parental experiences of rearing children with Down syndrome, the research employs a phenomenological method. Grounded in a constructivist worldview (Creswell, 2013), when following the phenomenological design, there will be a variety of truths and perspectives (Cohen et al., 2018). In the end, the goal is to

distill individual encounters with the phenomenon into the depiction of its universal essence (Creswell, 2013).

Research Questions

Research questions are the pivotal queries that guide the research to understand a phenomenon under investigation (Creswell, 2013). The main question guiding this study is: "What are the lived experiences of parents of children with DS as they relate to education-related endeavors?"

Additionally, there are also three sub-questions:

- As parents of children with DS, what is their role in the educational journey of their children?
- As parents of children with DS, what are the main challenges they face in rearing and supporting the education pursuits of their children?
- As parents of children with DS, what areas of improvement do they suggest?

Sample Selection

In a phenomenological study, the approximate number of participants is a minimum of five people. According to Polkinghorne (1989) researchers are recommended to interview from 5 to 25 individuals who have all experienced the phenomenon. In a phenomenographic study on parenting a child with Down syndrome, Berthelsen and Joosa (2006) included five people and classified it as a small sample. However, to combat an issue with the inability to generalize the results (Barkhuizen, 2014; Blaikie, 2018; Morse, 2000), the present study aimed to include a higher number of participants. According to Mason (2010), the number of participants in phenomenological studies vary from 6 to 10 while Guest et al. (2006) recommends using an indicator such as data saturation to guide the sample size. Therefore, the number of study participants in this study is eight.

Study participants are parents with at least one child diagnosed with Down syndrome. At the same time, participants were recruited based on snowball sampling. The researcher was familiar with one family who agreed to participate in the study and other participants were sought through personal connections of the first family, social media advertising, and word of mouth. This type of sampling wherein study participants are recruited among the researcher's network is known as snowball sampling (Dragan & Isaic-Maniu, 2013).

Instruments

The main data collection instrument is semi-structured interviews, and the questions were devised by adapting instruments developed by Baimukhanova (2020) and Billen et al. (2021). The former researcher focused her thesis on investigating parental perspectives towards inclusive education of their children with Down syndrome, and the latter conducting a comprehensive study about the phenomenon of parenting a child with disability. By merging the instruments of these two studies and modifying the outcome based on a conceptual model of Family Factors Relating to the Early Development of Children with Down syndrome (Van Hooste & Maes, 2003), the researcher developed an interview protocol (see Appendix D) with questions that can provide an in-depth understanding of parents' experience in navigating the emotional, social, and educational landscape of raising child(ren) with DS in Kazakhstan.

Data Collection Procedure

After acquiring approval from the Nazarbayev University Graduate School of Education (NUGSE) Ethics Committee, the researcher started the process of participant recruitment. Initially, the researcher reached out to a family with whom there was a professional relationship. Subsequently, the researcher turned to Instagram, a social media platform, to identify parents of children with Down syndrome to send out the recruitment

letter (see Appendix B). Furthermore, participants who expressed willingness to partake in an interview were encouraged to disseminate information among their own networks of parents.

After obtaining agreement from study participants, the researcher delivered the consent form via email or WhatsApp messenger. The consent form (see Appendix C) comprehensively outlined essential details of the study, including its topic and objectives, the research procedure, potential risks and benefits, participants' rights, and the researcher's contact information. This documentation process serves to protect the rights of participants throughout the entirety of the data collection process, as advocated by Creswell (2013). Upon securing participants' consent, appointments for interview meetings were scheduled based on their preferred date, time, and location. With the exception of one interview, all sessions were conducted via audio chat platforms such as Zoom or WhatsApp Call. No video of the chats was recorded.

Data Analysis

Analysis of qualitative data is concerned with how researchers progress from the facts to comprehending, explaining, and interpreting the phenomenon under investigation (Taylor & Gibbs, 2010, p. 1). The initial step involved transcribing interviews verbatim using the "Transkriptor" application. Subsequently, the transcribed data was translated from Russian to English. Following this, the coding process was initiated, which entails segmenting and labeling text to generate descriptions and broad themes within the data (Creswell, 2013). In this regard, the researcher utilized Saldana's (2013) recommendations on coding for new qualitative researchers who suggests starting out by using the following codes: attribute coding, structural coding, descriptive coding, and NVivo coding (see Appendix E). According to Saldana (2013), in many cases, it can be appropriate to use several coding methods at the same time. Therefore, the researcher made use of all the codes listed above, as well as versus coding and causation coding. After the first cycle of coding, the researcher

used focused coding, as it is a recommended approach when the researcher aims to develop categories or themes (Saldana, 2013). Following that, a list of codes was developed, and the similar data were merged under one category or subcategory. As a result of this arduous process, the researcher was able to come up with six themes that could answer the research questions of the current study.

Ethical Considerations

“Ethics are the principles and guidelines that help us uphold the things we value” (Johnson & Christensen, 2020, p. 370). Many different factors can give rise to ethical concerns, including the nature of the research project itself, the context in which the research is being conducted, the procedures that will be implemented, the methods of data collection, the participants involved, the type of data that will be collected, what will be done with the data, and how the data will be reported (Oliver, 2003).

To start with, all of the information that was acquired during the interview was de-identified to protect the participant’s privacy and confidentiality. After the research project, any data and information that could possibly identify the participants was removed in order to ensure that the data are confidential. Collected data is stored on the researcher’s laptop protected by a password. Also, as recommended by Nayar and Stanley (2014), transcription verification by study participants was conducted to ensure the trustworthiness of the data and ensure parent voices are being accurately represented.

At the same time, the research topic and questions might trigger potential negative memories or experiences when interviewing participants. In particular, questions under the "The First Reaction" in the interview protocol could appear sensitive. The researcher was prepared to anticipate any uncomfortable situations that may arise during the interview. According to Rogers et al. (2021), interview protocols should be designed in a manner that recognizes the delicate nature of the topic and the potential vulnerability of the participants.

While preparatory strategies were embedded into the interview protocol, including the possibility to withdraw from the interview or skip certain questions, the researcher was also familiar with tools and resources that can be used during the interview in case of unforeseen participant distress. In particular, according to Ahern (2012), in qualitative research, researchers may feel troubled when faced with ‘the emotional pain’ of participants. As a result, interviewers might become excessively emotionally engaged with the participant or excessively detached (Morse et al., 2008). Hence, the interview protocol also included a language/script for offering support, taking a break, or stopping an interview.

Furthermore, according to Moustakas (1994), a key challenge in phenomenological research lies in the researcher’s difficulty in separating their own experiences and understanding from the study due to its interpretive nature. To address this, researchers employed the strategy of ‘bracketing,’ where they openly discuss their own experiences, the context, and the situations that may have shaped those experiences. Creswell (2013) suggests that composing such a statement as part of a reflective process can ensure that the researcher’s personal assumptions and experiences do not unduly influence the research findings.

Summary

In conclusion, Chapter 3 has outlined the methodology that was employed in this study. This chapter introduced the research design, methodology, research questions, sample selection, instruments, data collection procedures, data analysis, and ethical considerations. The chosen research design is qualitative, specifically based on the phenomenological approach which aims to uncover the essence of the lived experiences of parents raising children with Down syndrome.

4. Findings

Introduction

The present qualitative phenomenological research aimed to explore the lived experiences of parents navigating the raising of children with Down syndrome, shedding light on educational journey their children and the hurdles they face. Data was collected until the point of saturation through interviews with eight parents of children with DS hailing from different regions of Kazakhstan. Throughout this chapter, direct quotes of interview participants are presented to better understand the phenomenon under discussion and the surrounding context. The chapter is structured around the themes derived through the process of coding the interview data, ultimately aiming to answer the central research question and its associated sub-questions.

Study Sample

Table 1 illustrates the composition of the study sample in terms of study participants' demographic information. A pseudonym was assigned to each participant and children. Participants originate from various regions in Kazakhstan, namely Almaty, Konaev, Astana, Pavlodar, Petropavlovsk, and Atyrau, with all but one residing in urban areas.

Table 1

Demographic Information of the Mothers.

N	Participant pseudonym	Child (age, gender)	Residence	City of residence
1.	Zhanerke	Son, 8y	Rural	Konaev
2.	Asem	Son, 3.5y	Urban	Almaty
3.	Venera	Son, 11y	Urban	Pavlodar

4.	Gulbarshin	Daughter, 6y	Urban	Atyrau
5.	Alena	Daughter, 9y	Urban	Petropavlovsk
6	Altynai	Son, 8y	Urban	Almaty
7	Tolkyn	Son, 8y	Urban	Almaty
8	Meruert	Daughter, 4.5y	Urban	Astana

Note. y = year(s)

As depicted in Table 2, the experience of parenting was discussed in the context of children aged 3.5 to 11 years old. Among the eight children are five boys and three girls. In terms of the educational profile, four children are enrolled in school, two in kindergarten, and two have not yet commenced their education in any institutional setting.

Table 2

Table 2. Characteristics of Study Participants' Children with DS.

Variables	Frequency
Age group (years)	
1-5	2
6-10	5
11- above	1
Sex	
Male	5
Female	3
Circumstances of diagnosis discovery	
After birth	7
At the pre-birth screening stage	1
Education profile	
Kindergarten	2
School	4
Not in school	2

Mean age ± SD = 7.25 ± 2.29, range = 11 – 3.5

Interview Response Analysis

After the stages of coding and categorizing (see Appendix F), six overarching themes and seventeen subthemes (see Table 3) emerged. These themes encapsulate diverse lived experiences of parents navigating the journey of raising children with Down syndrome in Kazakhstan. The main themes include: (1) Discovery of the diagnosis; (2) How birth of a child affected the family; (3) Coping and adaptation; (4) Educational pathway of children with DS in Kazakhstan; (5) Parental challenges and support needs; (6) The role of government. Each main theme was further divided into sub-themes, and these sub-themes were categorized to offer a detailed understanding of multifaceted participant experiences.

Table 3

The Study Themes and Subthemes.

Themes	Subthemes
1. Discovery of the diagnosis	• Circumstances and initial reaction of the family • The role of medical personnel
2. How birth of a child affected the family	• Birth of a child: Careers interrupted. • Birth of a child: Filtered out social circle • Birth of a child: Fear of socialization • Birth of a child: Shifting perspectives and mindsets
3. Coping and Adaptation	
4. Educational pathway of children with DS in Kazakhstan	• Child's development • Speech and communication • Child characteristics • Maternal roles: Multiple hats • Early childhood education • Schooling decision
5. Parental Challenges and Support Needs	• Parenting: A hedgehog in the fog • Parenting: Learning to meet unique child needs • Parenting: Resourcefulness

- Parenting: Societal attitude
- Parenting: Navigating between parenting styles

6. Role of government support

Note. DS = Down syndrome.

Discovery of the diagnosis

The first theme corresponds to the initial reaction of mothers and surrounding circumstances when they discovered they are either expecting or have birthed a child with Down syndrome. This process is individual for every family and is shaped by a number of factors. Therefore, this theme was divided into two sub themes to depict such aspects as circumstances, initial reaction, and interactions with medical personnel.

Circumstances and Initial Reaction

Study participants reported a range of intense emotions triggered by the discovery of the DS diagnosis, including shock, lack of understanding, self-blaming, panic, despair, a sense of helplessness, resentment, pain, a state of numbness, and fear about the future. Nearly all the mothers, with the exception of one (Alena), received the news of the diagnosis after their child was born. Zhanerke candidly expressed her initial confusion upon learning about her child's Down syndrome, questioning its implications: "What is Down syndrome? Why is he considered disabled if his arms and legs are intact, nothing is paralyzed anywhere, thank God, without any defects?" Then, as Zhanerke explains, when she was told that her child has an intellectual disability, a new set of questions arose, such as "How will everything be? Will I be able to provide him with what he needs? What if I can't?" These were the questions that came with her initial fear because as she explained, she felt like she was alone. Gulbarshin revealed that upon learning of her child's diagnosis, she grappled with distressing thoughts, contemplating, "Why didn't you die?" Now she describes those thoughts as terrible, and after

seeking guidance from a psychologist, she learned that such thoughts were a normal and protective reaction that anyone might experience. Zhanerke and Gulbarshin also shared that discovery of the diagnosis was associated with fears that their husband would leave the family. To her surprise, when the situation ended up being the opposite, Zhanerke recalls feeling relief: "I cried a lot from the relief that things weren't as scary as I had assumed."

A poignant narrative unfolded from Alena who discovered the diagnosis during prenatal assessment, providing an additional layer to the complex decision-making process of mothers who choose to proceed with the pregnancy. Her choice was met with a conflict stirred by disagreements with her spouse and pressure from medical personnel. According to her:

> On one hand, it was easier to know in advance so that we could prepare. On the other hand, it was more challenging if you decide to keep the child. It was as if there was a choice. For me, there was no choice, but for him [her husband], there was.

Furthermore, adding to her distress, she and several other study participants (Zhanerke, Asem, & Tolkyn) indicated a negative and unprofessional attitude of medical personnel.

Role of Medical Personnel

The study findings highlight not only the emotional turmoil faced by mothers upon receiving the disturbing news but also shed light on the unprofessionalism exhibited by certain medical personnel. Several mothers recalled unsettling interactions with doctors that subjected them to pressure and fear and lacked compassion during delivery of the diagnosis. Alena vividly recounts the pressure to terminate the pregnancy, and how she endured a critical moment:

> At that moment, there was a lot of pressure [from doctors], such as she won't move, she won't walk, she'll be a vegetable, she won't understand anything. 'Why do you need this? Your husband will leave, and no one will pay for this operation.'

Zhanerke shares a similarly distressing experience, revealing the deep shock caused by a nurse who persistently visited her maternity ward over four consecutive days, attempting to persuade her to give up her child:

> She tells me, 'You're young, you'll have more children, why burden yourself? It will tie your hands and feet; you won't be able to go anywhere.' On the fourth day, I said, 'Leave me alone already… Why are you so persistently trying to get me to give up on him?' And she tells me, 'You know, there are children born with one healthy kidney, and we need such children for organ transplants.'

Asem also shared an unsettling encounter with a neonatologist when she sought an examination to ascertain whether the earlier risk of Down syndrome given would be confirmed. Recounting the incident, she expressed, "I told him they raised a suspicion, look, something's wrong with the baby. He responded, 'Google what Down syndrome is. Read about it,' turned around, and left." Nevertheless, despite the negative encounters with certain medical staff, participants (Zhanerke, Asem, & Gulbarshin) also recounted instances when guidance from genetics specialists proved invaluable. Gulbarshin shared, "I had a wonderful doctor who told me, 'Children like these develop very well; it's just a matter of teaching them, simply putting in the effort."

How the Birth of a Child With DS Affected the Family

In essence, the birth of a child with Down syndrome had a profound impact on the lives of these mothers, reshaping various aspects of their lifestyle. Specifically, the birth of

their child and the subsequent adjustments to their parenting roles resulted in changes to their careers, social circles, and led to a mindset shift in them and their families.

Birth of a Child with DS: Careers Interrupted

When asked about the changes in their lives post-childbirth, three mothers (Asem, Venera, Meruert) revealed that they had to halt their careers to prioritize the care of their child with DS. Venera articulates this transformation, stating:

> I used to work as a foreign language teacher, and I also have a law school degree. I took maternity leave from my notarial job when Aibar was born. Although I had a successful career with good earnings, all of that, of course, pales in comparison to the importance of a child’s health and development.

Birth of a Child with DS: Filtered Out Social Circle

Zhanerke and Tolkyn employed the term "filter" as a euphemism to depict the significant shrinking of their social circles following the birth of their child. Portraying her initial pain when such a realization occurred in her life, Zhanerke stated:

> People from whom I expected support just, you know, everyone turned away. Some had their own concerns, someone forgot to even ask on WhatsApp how we were doing. No one called…, sorry [sarcastic tone], even a small message wouldn’t cost much.

Tolkyn who almost discontinued her PhD studies but was persuaded to continue by her husband, also expressed that the situation described by Zhanerke is a common one, and asserted that rather than succumbing to disappointment, mothers should embrace this transformation: “… Rejoice. Unnecessary people, ill-wishers, have filtered themselves out.”

Birth of a Child with DS: Fear of Socialization

Zhanerke highlighted that the birth of a child with DS affected her personality. Despite her always being a highly communicative extroverted person, currently she struggles building relationships with others:

> Living in the countryside, there was a time when I started to stutter and forget words, for real. It turns out I just lacked live communication. I have no friends; everyone turned away, as I mentioned. Just sitting with the child and chatting with him- that's all communication. Diapers, potty training, and blankets - that's it.

Birth of a Child with DS: Shifting Perspectives and Mindsets

Mothers also contemplated on how the birth of a child with DS changed both their and their family's mindset, creating a clear contrast between perspectives before and after. Asem shared that her outlook on life as well as her attitude towards people with special needs, underwent a transformation. Gulbarshin conveyed adopting a 'special' mindset, and shared: "I see myself as marked and blessed. Who is entrusted with special children? Special individuals. This is my way of self-comforting." She further revealed that two of her stepsons, who had previously used 'Down syndrome' in a derogatory manner during conversations with friends, underwent a shift in attitude after the birth of their sister and began actively educating their friends about DS. Venera expressed that her son taught her to perceive life in a completely different light. As she explains, everything is relative, and she now recognizes aspects where a child with DS can thrive:

> When I entered the world of children with disabilities, I thanked the Almighty that my child has a lot. That his mind works, he understands (though it may sound blunt, but that's how it is), that he can walk on his own, that he comprehends, that he speaks, that I can somehow help him in life, and this assistance will be realized and will yield results.

Such a mentality of understanding that everything is relative seems to be common among mothers. Asem highlighted this mindset, mentioning that medical specialists have tried to console her by suggesting she be thankful for the Down syndrome diagnosis. They conveyed that if it were a condition like cerebral palsy or something more severe, coping would be significantly more challenging.

Coping and Adaptation

The preceding subsections, linked to the family stress component of the conceptual framework (Van Hooste & Maes, 2003), aimed to portray the initial emotions that mothers experience following such a life-altering experience of giving birth to a child with Down syndrome. It not only presented the spectrum of emotions but also explored the contributing factors to this upheaval, including the circumstances surrounding the diagnosis, discovery, subsequent childbirth, and role of medical staff. Additionally, the sections touched upon transformations that mothers underwent in various aspects of their lives. The following subsection will discuss the process of coping and adaptation personal to each mother.

The aspect of coping and adaptation appears to be deeply personal for each mother, and is linked to the social networks component under the resources for support of the conceptual model. Alena articulated her experience, stating, "After the birth, it was complete acceptance. I just rejoiced that my child survived despite all the horror stories people had told me, saying that everything would be bad, that she would be born dead, and so on." Conversely, Venera reveals, "For probably 2 years I could not accept this diagnosis… I was fixated on the idea that it was most likely a mistake."

All in all, each mother, regardless of the duration of the process, managed to successfully adapt to the new life circumstances, and underscored the importance of seeking support from various avenues during the emotionally challenging period following the birth of a child. This support network included family members, spouses, close friends, other

mothers of children with Down syndrome, and faith. Moreover, mothers employed diverse coping strategies. Interacting with other parents of children with Down syndrome was highlighted by a number of participants (Zhanerke, Tolkyn, Gulbarshin, Alena). Zhanerke indicated that engaging with other parents and seeking their advice served as a remedy for self-blame, while Tolkyn emphasized that observing other parents with their children during swimming classes helped her spouse overcome his barriers. As a result, he is now actively involved in the child's development. In terms of witnessing child progress, participants (Gulbarshin & Altynai) indicated a child's initial victories such as being able to sit and crawl as a source of motivation. For a couple of parents (Gulbarshin & Alena) observing other children with DS emerged as a crucial element in their coping process as they recognized the potential and capabilities of such children. Social media played a crucial role in the coping process of Gulbarshin and Tolkyn by serving as a tool for correct representation of parenting a child with DS: "The environment felt that we were happy, that we could handle such a child perfectly. They understood, and through the prism of Instagram, they also began to accept him" (Tolkyn). Proactively seeking information, highlighted by Gulbarshin and Alena, also played an important role in parental adaptation: "The fact that I didn't isolate myself and began seeking information played a crucial role" (Alena). Finally, coping through religion was emphasized by Zhanerke, Venera, and Alena. Venera firmly believes that God is the source of her strength, stating, "There are no moments that we haven't overcome: if we are given this. It's not a trial; it's probably a great happiness."

In summary, this process is individual for every family, from initial diagnosis discovery to the process of adaptation. Some discover in advance, others after the birth of a child; some experience conflicts with their spouse and pressure from medical personnel; some go through a lengthy process before accepting the diagnosis. However, one constant aspect is that this period of life is described as causing one much emotional turmoil.

Nevertheless, each mother successfully navigated the adaptation process, resulting in profound transformations and personal revelations.

Educational Pathway of Children with DS in Kazakhstan

The second theme covers the overarching topic of the educational journey of children with DS in Kazakhstan. It is a subject that requires consideration of multiple factors, including key areas demanding attention in a child's development, the strategies parents employ to foster their child's development, considerations surrounding early childhood education, decisions regarding schooling environments (inclusive versus corrective), encountered challenges, and the pivotal role of the Psychological Medical Pedagogical Commission (PMPC). Collectively, these factors are associated with the stimulating environment and experiences within the family characteristics component of the conceptual model.

Child's Development

The discussion of education for children with Down syndrome is closely intertwined with medical considerations, given that children with DS frequently contend with additional complications alongside the primary diagnosis, which also impacts their education, as depicted in Table 4.

Table 4

Health-related Complications of Study Participants' Children with DS.

Names	Health-related complications
Zhasulan	Myeloblastic leukemia diagnosed at the age of 3
Dauren	Underwent surgery at the age of 1.3 years, and up until that point, remained confined to a bed
Rinat	Eye condition, Astigmatism; selective hearing

Dina	Might need a surgery because of a hearing problem
Vaselissa	Underwent a heart surgery, and has hypothyroidism
Mukhtar	No significant health issues were mentioned
Anuar	Heart and respiratory failure at birth
Kanagat	Vision impairment

Mentioned health issues significantly influence the child's development. As explained by Gulbarshin, "This extra 47th chromosome significantly impacts development, creating hindrances in various aspects." Asem whose son was confined to a bed prior to surgery at the age of 1.3 years elaborated, stating:

> We will be in the developmental stage throughout our entire lives... So, in terms of his current development, we started our development only after the surgery… Currently, his developmental age is probably around two years, well, if we compare it to typically developing peers.

Mothers shared that their children need support in various aspects of development. In particular, Meruert conveyed her response in an all-encompassing way:

> Assistance is needed in all aspects of life, as children with Down syndrome essentially require instruction in virtually every aspect: to foster thinking, communication skills, the ability to play and interact with peers and adults, speech, reading, writing, numeracy, self-care skills (eating, toileting, dressing, undressing), comprehension of spoken language, awareness of the surroundings, household tasks, i.e., understanding processes and participation (cleaning, laundry, cooking).

In other words, children with DS need comprehensive support – "to monitor health, to develop physically and to develop both emotionally and mentally" (Alena).

Speech and Communication

Altynai emphasized that one of the primary challenges her son faces is related to speech and communication. She shared that her child puts in effort by using gestures to explain things, but when she struggles to comprehend his intentions, he becomes irritated. Zhanerke has an identical situation with her son. According to her, their current situation feels like a dead end with even speech therapists reluctant to help her child:

> An experienced speech therapist, whom almost the whole city visits, said she couldn't help. When I asked why, she explained that, in his case, building a vocabulary is crucial in teaching him to speak. Since he doesn't know any words, it's challenging to work on anything.

In general, speech and communication challenges of their children have been (Venera, Alena, & Tolkyn), or continue to be (Zhanerke, Asem, Gulbarshin, Altynai, & Meruert) a common issue among all participants which ultimately impacts their education (see Table 5).

Table 5

Speech & Communication Status of Study Participants' Children.

Child	**Age**	**Speech & Communication Status**
Arman	8 y	Pronounces vowels but no consonants, knows a few words like "deda" (grandpa), "pupu" (grandma), "ap" for bread, "appa" for thank you, "tyutyu" for don't want, or "chuchu" for want, "papa," and "mama."
Ilyas	3.5 y	Speech has not developed yet
Danelya	6 y	Has about 10-15 active words, such as mom, dad, give, no, yes.
Malik	8 y	Does not speak, but tries to recognize certain phrases and letters. Mother assumes that in another 2 years he will start speaking.

Amina	4.5 y	Actively pronounces words and uses ASL to communicate

Note. y = year(s); ASL – American Sign Language

Strategies Implemented to Foster Speech Development. Mothers were asked about the strategies they have used to foster speech development in their children. Various approaches were mentioned, including seeking out the help of speech therapists, defectologists, and tutors, establishing an environment conducive to development at home, and leveraging on the inclination of children with DS to imitate others, particularly their siblings. Tolkyn elaborated: “Somewhere around 70-80%, I can say that my younger children influenced his speech development. Maybe 25% of the speech development came through the specialists and the surrounding environment, but 70-80% were our younger children. They strongly motivated him to start pronouncing some words.” Overall, all of the mothers support the latter sentiment that not everything depends on the specialists alone. As Gulbarshin states, “The specialist provides a certain push, a certain foundation. But afterward it’s up to the parents. Parents, with their desire and direct assistance, play a crucial role in helping the child.” Similarly, Alena articulated that although they participated in various rehabilitation programs, home activities were more beneficial: “It helped that we were constantly studying at home, there was always this developing environment.”.

Child Characteristics

While each child has their own distinct traits and personalities, there were some common characteristics in the way participants described their children. Zhanerke and Tolkyn pointed out traits such as laziness and slowness. Several participants (Zhanerke, Altynai, Tolkyn) also noted their children’s inclination to run away. Furthermore, Zhanerke highlighted seasonal behavior issues (discussed more comprehensively in the sections that follow). Mothers also highlighted their active involvement in addressing the mentioned behavioral traits by employing patience, promoting self-help skills, and engaging in at-home

occupational therapy. These parenting experiences, reflecting the behavioral phenotype of children with Down syndrome, carry implications not only from the parenting perspective but also for educators and related service providers.

Maternal Roles: Multiple Hats

Mothers, in addition to the role of a caregiver, also assume the roles of teachers, doctors, nutritionists, and many more: "One could say that we are probably becoming the doctors, nutritionists, and speech therapists for our own children" (Gulbarshin). For example, Zhanerke took on the responsibility of homeschooling her son until he commenced formal schooling this year. Venera played a pivotal part in advancing her son's speech by crafting home activities, acquainting him with the letters of the alphabet, and teaching him to read. Meruert is keen on working on her daughter's physical development by using equipment such as treadmill, vibro platform, balancers, orthopedic carpets, and other equipment. Alena acknowledges not only the influence of the home environment but also attributes her daughter's motivation to speak to her older son. Tolkyn, having a degree in teaching, devoted substantial effort to her son's intellectual development by implementing strategies of Glenn Doman and Romena Augustova, commonly implemented by speech therapists in Kazakhstan to teach children with DS to read and write. Meruert fosters speech development of her child by integrating American Sign Language (ASL) into their home life. However, it is important to note that integrating such educational elements into the mother-child dynamic is not universal. For Gulbarshin and Altynai, who are working mothers, juggling both work and development needs of their children has been a challenge. Altynai disclosed that her son is currently unable to attend any speech therapy sessions due to the extensive commute and her commitment to working full-time:

> As working mother and father, kids are being taken care of by their grandmother, so we're not going anywhere at the moment. We are working on his speech at home. We have logopedic books, Zhukov's alphabet for our home activities.

Gulbarshin, also, despite understanding the role parents play in promoting child's development, expressed challenges she faces in reality:

> Sometimes, you know, I blame myself. It's a feeling of guilt – thinking, "Is it really so hard to spare half an hour?" But when you come home from work, you are already tired, and you think, "I don't want to do anything." In reality, it's just half an hour, play, do something… however, there should be a system, and there isn't.

She also expressed that, essentially, she has no idea of how to develop her child's speech and mostly relies on speech therapist: "I'm placing a significant emphasis on the speech therapist because, right now, I don't even know how to kickstart that. If there were some kind of algorithm, I'm sure everyone would know." In this regard, Meruert shared that she learned all of the vital information, including how to design a program for her daughter's development, from specialists in the USA.

Early Childhood Education

While each child follows their own distinctive trajectory of development with early childhood education activities tailored to the individual needs of every child, study findings indicate that these efforts are centered on addressing common issues faced by children with DS such as speech and global developmental delay. As Table 6 illustrates, each child either currently attends or has participated in specialized services.

Table 6

Activities Study Participants' Children Were Engaged in at the Time of the Study.

Activity	Zhasulan	Dauren	Rinat	Dina	Vaselissa	Mukhtar	Anuar	Kanagat
Speech therapist	X	X		X				X
Defectologist	X			X				
Physical therapy		X						
Home-based activities	X				X	X	X	X
Hydrotherapy		X		X		X	X	
Adaptive sports			X		X			
Sessions at Caritas foundation or parent-led local foundations		X		X	X			
Music/ Dance			X		X			X
Sign Language (ASL)								X

Note. ASL = American Sign Language

The early childhood development journey for children with Down syndrome can be illustrated through the experience of Alena, involving a combination of physical therapy and massages provided both at rehabilitation centers in hospitals and at home. Additionally, corrective education is incorporated, including a defectologist and speech therapist offered in correctional classrooms recommended by PMPC. These services are also offered by foundations such as Caritas, 'Solnechnyi Dom,' and 'Kunbala,' or parents may explore other avenues. Kanagat, for example, visits a speech therapist not associated with any of the aforementioned organizations and also undergoes therapy through an online application named 'Geminii.' On the other hand, Asem noted that her child engages in two 40-minute speech therapy sessions at the Kunbala Foundation, emphasizing the positive outcomes achieved through the consistency of these sessions. Altynai highlighted the effectiveness of going to a speech therapist at Kunbala compared to a correctional classroom recommended by PMPC. She elaborated, stating,

> The therapist at Kunbala (who is also a mother of a child with DS) was focused and dedicated, leaving no effort spared for the child. This, perhaps, was the most crucial aspect because others tend to make concessions, but a mother facing similar challenges doesn't allow such compromises.

Gulbarshin highlighted the beneficial role of the Caritas foundation; her child has been attending since age three: "Initially, we had sessions three times a week, and as the number of kids increased, we now have sessions twice a week for an hour each." Alena, one of the founding members of the 'Solnechnyi Dom' foundation, shared that her daughter actively participates in various activities organized by the foundation, including table tennis, dance, and group psychology sessions.

For many children, hydrotherapy such as swimming has proven to be beneficial. Additionally, in the case of Venera, adaptive sports serve as alternatives to traditional

physical therapy: “He engages in adaptive sports seven days a week. We participate in activities such as swimming, Boccia (a Paralympic sport), choreography, and pioneer ball. These diverse adaptive sports activities serve as substitutes for programs like therapeutic physical exercises, etc.”

Schooling Decision

With respect to schooling, participants were prompted to share their experiences related to their child’s schooling. For those participants with children not yet of school age, the inquiry revolved around their vision of an ideal educational environment: inclusive versus special/corrective.

Pre-school. Asem, Gulbarshin, Altynai, and Meruert indicated that their children are not yet of school age. Gulbarshin and Meruert have opted for mainstream kindergartens, while others were unable to enroll their children in kindergartens due to personal circumstances. For example, Asem mentioned that she has not even considered enrolling her child in kindergarten because he has not mastered skills of independence or toileting.

Gulbarshin explained that it was her principled stance not to enroll her child in any correctional group or correctional kindergarten, and she wishes for her child to attend a mainstream school. As she emphasized, “According to our legislation, until the age of 10, a child with special needs can enter the 1st grade. I suppose, around the age of 9, I want to enroll her in a regular school. But, again, it depends on whether they will accept her.” Similarly, Altynai is also planning for her child to attend a mainstream school alongside her younger child. Meruert, however, indicated that while her daughter attends a mainstream kindergarten, there are number of aspects that disappoint her:

> There is a lack of inclusive development centers where we would be welcomed and provided with personal assistance in the form of a tutor, so that the child doesn't feel

like an outsider, keeps up with the group, and is actively engaged in play and various activities - being a participant rather than a passive observer.

School. As illustrated in Table 7, half of the participants (Zhanerke, Venera, Allena, Tolkyn) have children currently enrolled in school. Specifically, Zhasulan started 1st grade at an inclusive school in the fall of last year; Rinat attended a special boarding school before transitioning to an inclusive school in 4th grade last year; while Vaselissa and Anuar are currently studying at special schools.

Table 7

School Choice for Children of Study Participants.

School type	Zhasulan	Rinat	Vaselissa	Anuar
Inclusive School	X	X		
Special School		X	X	X

The Choice: Inclusive School. Both Zhanerke and Venera are elated that their children are now attending inclusive schools. Describing her emotions upon Zhasulan successfully passing tests administered by the commission, Zhanerke exclaimed, "I felt such joy in my heart... it felt like wings were flying behind me." She explained that the source of her happiness is two-fold. Firstly, as prior to attending school, Zhasulan was homeschooled, she felt like everything she had taught proved to be adequate for his acceptance into 1st grade. Secondly, she believes that attending an inclusive school will help her son to be accepted in society and aid him in learning to live among ordinary people. At the same time, Zhanerke also revealed that merely 2 years ago she opposed the idea of sending her son to school, expressing:

> I was against sending him to school because in our schools, kids used to call each other 'Down – mentally retarded.' I thought that I won't be able to endure it if someone says something to my child; bullying and all that.

Similarly, Rinat's mother, Venera, expressed her initial apprehension over sending him in the 4th grade last year to an inclusive school with "28-30 children and only one teacher assistant." She also shared fears regarding potential ridicule her son might face, leading her to initially enroll him in a boarding school for the visually impaired. Although Venera did not regret the decision of enrolling Rinat in a special school, she clarified that she aspired for more for her child and felt like boarding school would not be enough.

Ultimately, both Zhanerke and Venera conveyed that the schooling experience for their children has been nothing short of positive. Zhanerke attributes this success to the homeroom teacher: Likewise, Venera noted: "…He genuinely wants to go to school. This speaks volumes. He participates in all the competitions; children include him in various activities, including sports events. My child is not deprived of anything."

However, interviews also revealed a number of challenges that participants experienced in the educational journey of their children. First of all, as Zhanerke shared, she was not initially informed that she was supposed to take her son to the PMPC as they spent a lot of time in the hospital due to Zhasulan's oncological illness: "A social worker mentioned almost incidentally that apparently, we should have been taking him there. No one had ever told us that before." In other words, the mother faced challenges due to a lack of appropriate communication. She further elaborated:

> And at the age of 6, they directed us to the correctional center. You attend for 3 months, then have 9 months off, waiting for your turn. So, by the time Zhasulan turned 7, he had only attended for 3 months. The next year, when he turned 7, they

informed us, 'We're expelling your child because he has reached school age.' However, they didn't provide any guidance on where to go next or what to do.

Secondly, after the PMPC had referred her son to enroll in an inclusive school as part of a pilot inclusive education legislation, the mother encountered a challenge in securing acceptance for her child to study at the school:

> I went to the school where my other children are studying... and I came with this paper to the principal. She said, 'I don't have space. I won't accept you. Go to another school.'

As a result, Zhanerke had to take a proactive approach and inform the school principal that she would file a complaint with the Department of Education. Following that, another challenge emerged once her son was accepted, namely the lack of tutors: "Initially, we sat through the first week without an assistant for one subject… Then, in the second week, we attended two lessons, and in the third week, they found an assistant for us." According to Zhanerke, she was told that the tutor position is not attractive for potential job-seekers: "They told me that there are four children in the school with cerebral palsy, and none of them have assistants." Furthermore, according to Zhanerke, challenges are still present. She mentioned that Zhasulan receives two sessions a week with a speech therapist and defectologist, each lasting 20 minutes. While she does acknowledge that having these sessions is better than having none, she also elaborated that the number of sessions with a speech therapist and defectologist are insufficient:

> Now, at the moment, I'm going through this period [of worry] again… he attends two lessons, and in addition, he has sessions with a speech therapist, a defectologist. It's not enough because a lot of time is lost due to the illness.

The Choice: Special School. Both Alena and Tolkyn maintain a positive outlook on inclusive education and have chosen an inclusive environment for the preschool years of their

children. Alena stated, "Initially, when my child was born, I was solely focused on inclusion, advocating for it in every aspect... So, it did end up being a typical developmental center, a regular kindergarten – everything was ordinary." Similarly, Tolkyn emphasized that her child attended a regular preschool for four years where changes started to take place after her son joined the class as he was the only child with special needs. However, she emphasized that her child's acceptance into the kindergarten came with a condition:

> They said, 'Let's see how he progresses, and if things go well, he can stay. However, if not, dear mother, please don't be upset; you will need to take your child back.' Under these conditions, they reluctantly admitted my child to this kindergarten although I knew that, according to all the rules and the law, they must accept my child.

Tolkyn further stated that she had wanted for her child to attend a regular school: "When he started going to a regular kindergarten, I had a dream that my child would go to a regular school, be in a regular environment." Nevertheless, both Alena and Tolkyn, weighing all the pros and cons, made a personal decision in favor of special education although PMPC provided an option to attend an inclusive school.

Both mothers enumerated reasons that factored in their decision favoring special school. According to Alena, an individualized approach is essential for children with Down syndrome. Therefore, it was imperative to have a small class size, an experienced teacher with a developmental approach to children with special needs, and a program that reasonably corresponds to the child's level without being overly difficult. In a similar vein, Tolkyn highlighted that, based on experiences with her younger children, even typically developing children often struggle with the school curriculum. Consequently, she chose a corrective environment because she believes it caters to individual needs of a child: "I look at the class my middle son is in, where 35 children study. There, he would have only 2 hours a day,

maybe a maximum of 3 hours. What can Anuar learn in this class?" That is, whereas her son with DS would have 2-3 hours of schooling at a mainstream school, a special school provides more extensive learning opportunities. Tolkyn clarified that Anuar remains at the school until 3-4 pm. In school, various activities are offered beyond the main school program, which concludes before lunch. Following lunch, there is a nap time, sessions with a defectologist, sessions with a speech therapist, art, sports activities, etc. Altynai, who intends to enroll her child in an inclusive school, also elaborated that many children with DS in inclusive schools follow a specific schooling schedule: three days at school and two days at home. Similarly, Alena contrasts the expectations at mainstream and special schools. Specifically, she explained that while writing in capital letters poses a challenge for her child, it is an expectation in regular schools for children in the first grade, further elaborating:

> I had a realistic understanding of her abilities. Yes, she's well developed; she reads, writes poems, comprehends and can speak. However, if you can't keep up with the regular program in a regular school, it becomes a special program. Who will handle that?

In addition to the academic concerns, Alena voiced her worries related to discipline:

> Even now, with only 9 students in the class, she manages to move around, play, draw something, eat some clay, excuse me [chuckles]. Well, in a regular class, I think they would quickly expel us if no one attended to her.

Moreover, in her opinion, it is challenging to envision a scenario in a class of 30 students where the teacher has to somehow multitask–providing a child with special needs a personalized program while the rest follow the regular curriculum. Even in the presence of a tutor, Alena has a low-level of belief in the effectiveness of such a learning environment: "Even if she sits with a tutor, how can they incorporate additional activities during the lesson

following her program? I believe, at this point, it seems like the child is merely present, engaged in unproductive activities, just sitting there."

Therefore, at present, Alena deems the corrective school as the most suitable educational environment for her child. She clarified that the primary indicator is her child's progress and ongoing development: "For instance, when we started, we couldn't mentally add numbers (we relied on numicon for that). Now, we've advanced to two-digit numbers, and she can almost do it in her head. So, it's evident progress." Tolkyn is also content with the current situation: "Anuar has fully adapted to the new environment. He genuinely enjoys being there. Even on weekends, he asks, 'Mom, let's go to school, I'm ready.'" However, she also clarified that while the plan for her son is to continue attending a special school, at least for the initial grades, if her son will progress well with speech development and will be able to handle the school curriculum, they do not rule out the possibility of transitioning to an inclusive school.

The Role of PMPC. Within the discussion of school choice, participants were asked about the role of PMPC in terms of these choices. Tolkyn and Alena made the decision themselves, amidst recommendations they were given to enroll their children in mainstream schools. As Alena explained,

> It was like they gave us a choice – either a regular school or a correctional school. I made this choice myself because I couldn't imagine my child in the zero grade at the age of 6… I have no complaints about the choices offered; however, nothing is organized for my child there. It turns out she's like a guinea pig.

Both mothers claim that the main reason behind their choice is the unprepared state of mainstream schools to accommodate children with special needs. Tolkyn explained that when she visited a regular school located in her neighborhood, the deputy head of the primary grades was not supportive. She further elaborated: "The PMPC, of course, they help parents

in general, through consultations. I don’t know, maybe I turned to them at the wrong time when there were no places in inclusive schools, and so on.” Alena shares the opinion of Tolkyn, stating: “Specifically, when it came to school, I began to realize that none of this is developed at all for us, in Kazakhstan, in Petropavlovsk, in particular.”

Interviews with Alena and Tolkyn did not uncover significant challenges with special schools, as both mothers expressed satisfaction with their current schooling situation. Nevertheless, Tolkyn highlighted the limited number of correctional schools in Almaty and a long commute to their current school. Alena pinpointed the problem of double-standards:

> If a child is not keeping up with this program, they are transferred to a class for moderate intellectual disability, which I really wouldn’t want. These are double standards, if he sits in a regular class, he can follow his individual program, but if he is in a class for mild intellectual disability, sorry, if you can’t keep up, go to another class.

In addition, an interview with Venera whose son attended a special school until 4th grade unveiled issues with schools that PMPC recommends for children. As Venera recounted, initially, the PMPC directed them to a school that has many children with Down syndrome which was found to be unsuitable:

> I requested the same boarding school to have a teacher assess Rinat’s skills. After assessing him, the teacher advised against bringing him there. She said that ‘you want progress but with us, he will regress. They won’t work with him because of his diagnosis, I’ll be honest with you.’

This subsection was dedicated to portraying parental experiences concerning their children's educational journey, encompassing both preschool and school stages. It delved into parental decision-making regarding schooling options, including both inclusive and special

education, and provided insights into the rationale behind each choice. Furthermore, the section addressed perceived drawbacks associated with each educational arrangement.

Parental Challenges and Support Needs

Upcoming subsections, linked to the information needs stress, resource needs stress, and family stress components of the conceptual model, discuss various aspects of parenting. These include dealing with uncertainty, worrying about the child's future and concerns about their adaptation in society, absence of guidance, lack of government support, inadequate medical care and provision of support services, shortage of specialists, facing negative societal attitudes, learning to meet unique child needs, and navigating different parenting styles between a child with DS and other children. Meruert emphasized that this journey is especially daunting when parents are not young, and the child with Down syndrome is the only child in the family. Following the exploration of parenting challenges, participants were further asked about support requirements for parents raising children with Down syndrome. Within this context, parents pointed out areas that could be improved, alongside reflecting on the role of the government.

Parenting: A Hedgehog in the Fog

All participants unanimously acknowledged grappling with the challenge of uncertainty, coupled with an inherent need for guidance. According to the conceptual model, this is linked to one of the prominent stressors – information needs. Venera specifically highlighted the lack of information and resources available to mothers from the very beginning, as they become parents of a child with Down syndrome:

> To be honest, no one in the maternity hospital explained the problems or what to do. Despite having genetic results indicated in the medical records after examinations with the pediatrician, it consistently stated 'healthy.' There was no counseling, and no one engaged in a conversation with me. I confronted the issue of being left alone.

Alena also highlighted this distinctive challenge, emphasizing that while the developmental path for a typical child is generally predictable, the same cannot be said for a child with special needs:

> When an ordinary child is born, you roughly know, like, okay, at the age of 1, they'll start talking, and become somewhat independent by 2. Then maybe they'll go to daycare, followed by school. It's somewhat clear, a structured life. With a special needs child, nothing is clear. You don't know when something will happen to them; all the norms are shifted, and everything is unclear, both regarding daycare and schools.

Alena further elaborated that when a child with special needs is born, parents are compelled to independently seek and navigate everything, ranging from daycare to schools. In the absence of adequate support organizations and individuals to consult, parents find themselves having to discover and pursue every aspect on their own. As she explained, "When something is unclear, that's what you fear."

Emotional Support. Among mothers, a recurring theme underscored the significance of emotional support. Participants emphasized the necessity for psychological assistance, beginning from the maternity hospital and extending throughout the journey of motherhood and as stated by Zhanerke, psychological support is still a need, even after 8 years. Gulbarshin shared her observation that not all parents actively seek communication; many tend to isolate themselves, feeling as though they are grappling with the "problem of the century." Hence, she emphasized the crucial need for parents to receive accurate information right from maternity hospitals, "approached with understanding, not necessarily sympathy but understanding."

Informational Support. The dire need for clear and accessible informational support was discussed extensively by Alena: "There should be support at all levels. That is, when a

child is born, they should fully explain what to do regarding medical issues, rehabilitation and other issues." According to the Alena, currently parents are the ones who explain everything to each other. The interview with Gulbarshin also reflects this narrative. She recounted an encounter with a mother whose child began walking only at the age of 4.5:

> I know a child who started walking only at 4.5 years old; he crawled before that. When I asked them, 'Have you checked vitamin D and microelements?' They said, 'No.' At that moment, the mother had no information at all. I advised her, 'Get urgent tests done,' and surprisingly, the vitamin D level was catastrophically low… Naturally, I advised her to consult a therapist, who would prescribe everything. About six months later, the child slowly started walking.

She further expressed her opinion on this matter the following way: "It would be great if there were doctors who understand the specifics because, mostly, doctors work in a standard way, yet these children have their own specific needs."

Furthermore, Alena specifically underscored that parents are not even guided through the benefits they are entitled to receive: "Later, we find out about it from someone else." An interview with Asem reflects the latter statement. She noted that while her child receives disability benefits, she was not instructed to apply for IRP (Individual Rehabilitation Plan) that is needed to receive diapers: "They didn't tell us that we need to apply for IRP. And since then, somehow, I neglected it, and we didn't apply, and we don't receive diapers. So, we buy them ourselves."

As Alena concluded, mothers need genuine participation from various stakeholders, "I would like more participation in life, just human participation. When you go to a pediatrician, they don't tell you anything as if you came with an ordinary child, without mentioning any complications. We mostly operate this way at this stage."

Support Organizations. As a result, parents often find themselves navigating the

quest for essential information on their own. To cope with this challenge, they have taken on the initiative to connect, forming group chats and foundations for mutual support. For instance, Gulbarshin initiated a group chat for mothers of children with DS in Atyrau. Meanwhile, Alena holds a prominent role as a founding member of a foundation dedicated to supporting children and mothers in Petropavlovsk. Additionally, Tolkyn previously served as the chief assistant to the founder of the 'Mama Pro' foundation, which extends support to mothers through training and self-development programs. Meruert highlighted that government should financially support such organizations.

On the other hand, Zhanerke highlighted that there are no such organization in her place of residence, Konaev city: "In Kapchagay [now Konaev], where I live, there are no fellow moms with whom I can really engage in open conversations like the one we are having now." Thus, the absence of such organizations where parents could seek guidance from is a palpable issue: "I think that parents are helped by funds like Caritas. If there are such funds that can provide support, advice, and guidance, I believe it would help parents."

Parenting: Learning to Meet Unique Child Needs

The interview with Venera revealed that parents might find it challenging to overcome overprotection:

> I fed him with a spoon until he was 3. You know, there was a moment of fear: What if he burns himself? What if something happens? When we started attending corrective classes, a teacher asked if Rinat could eat on his own. I said I don't know. They asked if he was my first child. I said no. So, these moments probably require giving more independence.

She also pointed out that parenting a child with DS involves a significant amount of patience due to the need for repetition: "Even with great love, without immense patience, it's hard to achieve something. Everything won't happen all at once."

Behavior Issues. Zhanerke, Altynai, and Tolkyn indicated child behavior problems as one of the challenging aspects of parenting. Specifically, they mentioned such issues as running away and children displaying such behaviors as nervousness, agitation, and irritation. Zhanerke is worried about her child's behavior outbursts, and the absence of trustable specialists to guide her through this period exacerbates the situation. As she explained, "I understand that there are good specialists, but after such professionals [referring to the past negative experience], I really don't want to trust anyone. It feels like they are not interested in helping the child but rather worsening the situation."

Shortage of Specialists. Within the discussion of early childhood education, the role of specialists and the challenges associated with finding high-quality professionals emerged as a salient theme. However, paradoxically, some parents also asserted that locating good-quality specialists has not posed a challenge for them.

Zhanerke, Venera, and Meruert expressed their disappointment with the scarcity of reliable specialists. Zhanerke is struggling with finding a psychiatrist, whom she could consult when her son experiences periods of anxiety. The one time they consulted a specialist, her child was recommended for referral to a psychiatric hospital. She recounted her experience, saying,

> She harassed me for an hour, mentally pressing me, making me question my sanity because he didn't grasp her words and commands (find the red pen, the green pen). Maybe not on the first attempt in some instances: where's the big one, where's the small one; he may not distinguish all of that yet. Not on the first try, but he did respond. I couldn't fathom how she concluded from these moments that he is mentally abnormal.

Furthermore, Zhanerke expressed her disappointment with a specialized development center tailored for children with Down syndrome. Overall, she pinpointed several issues with

development centers, including the lack of safety regulations, insufficient staffing to adequately care for a group of children, and the perception that these institutions prioritize financial gains over the well-being of the children. As Zhanerke explained,

> It might seem like we are sitting here so confidently choosing, 'I want to go there, I won't go there.' No, not really. You just feel the difference between where there is genuine interest in results and where it's just about money.

In a similar vein, Venera shared that in her experience many specialists fail to see beyond the diagnosis and acknowledge the child's individuality, noting: "Here, perhaps, the commercial and financial side plays a bigger role." Meruert also stated that the lack of quality specialists is a considerable issue: "Very, very difficult. I would say they simply don't exist. Our only specialist who truly helps our daughter is our tutor from Nazarbayev University."

Furthering the discussion on the scarcity of good quality specialists, Altynai offered insights into their experience attending a correctional classroom recommended by PMPC. For one, she noted that the commission directed them to a correctional class which entailed a 40-minute commute. Moreover, she expressed disappointment, stating, "I didn't observe any significant effects; it felt more like attending for the sake of it." In addition, Tolkyn highlighted the problem of finding Kazakh-speaking speech therapists and Gulbarshin identified the shortage of Kazakh-speaking healthcare providers familiar with the nuances of the Down syndrome.

From another perspective, Alena emphasized that finding high-quality specialists has not been challenging for both her child and the foundation 'Solnechnyi Dom' where she is a founding member. However, she notes that her positive experience is because of her child's relatively high level of development. Gulbarshin also asserts that finding high-quality specialists has not been a challenge.

Parenting: Resourcefulness

Alena summarized the experiences of many mothers by stating that a lot of mothers have to live in an alert mode all the time, describing the mothering experience with the expression – "to be buttoned up on all buttons." She explained that it is very difficult to be always anticipating some catch and thinking, "'Oh, how can I add something, where else to take her, what doctor to see, whose opinion to seek out.'" According to her, parental concerns encompass various aspects, including situations where a child does not walk for an extended period or fails to speak by the age of 4-5 years. Thus, acquiring the ability to effectively allocate personal resources becomes a crucial skill for parents.

Along the lines of learning to be resourceful, encouraging mothers to self-actualize was identified as an urgent theme by Tolkyn: "It is not necessarily about earning a lot, but it's essential for a person to be in society." This realization is drawn from her personal experience as a mother of three children within relatively close ages. She further explains: "For 5-6 years, I was on maternity leave, and you should understand that it's very challenging. But I have a profession that allows me to work occasionally. I sometimes had part-time jobs, and it helped me a lot. Plus, I was also studying for a doctorate at that time." Therefore, reflecting on her experience, Tolkyn stated that despite various developmental needs of the child, "parents should remain individuals; they should not merge with the child."

Parenting: Societal Attitude

Zhanerke and Alena discussed the role of societal support, particularly lack of it, as one of the sources of serious challenge. Zhanerke mentioned that even with professionals to help, she is not fully reassured that society would adequately react to possible displays of reactive behavior of her child. She articulated: "He is in society; if someone suddenly provokes him and he reacts, and then they say, "My child is wild." On the matter of societal acceptance, Alena identified the challenge of facing society with exclusive notions,

particularly the non-acceptance of people with disabilities. She expressed that this non-acceptance poses a challenge, affecting child's development as parents often encounter difficulties enrolling their children in daycare centers and schools compared to typically developing children. Based on her personal experience, this process is not straightforward, requiring negotiation. As Alena elaborated, "The child, of course, doesn't understand; they just want to go to painting class. But for the mother, it's painful to realize this."

As put forth by Gulbarshin, there is a necessity for society to hear, understand, and acknowledge children with special needs: "Then there will be a different attitude towards these children, and it will be a big help for parents." Furthermore, Tolkyn also elaborated that it is essential for people to learn to use the right words, not asking unnecessary and uneducated questions: "Always approach with curiosity rather than pity… It's important to challenge the notion that having healthy children makes someone superior or grants more rights."

Parenting: Navigating between Parenting Styles

During the interviews, some of the participants discussed their parenting style when it comes to children with DS and their siblings. Most participants emphasized that they try to treat all their children equally. Nonetheless, citing the words of Tolkyn, parenting approaches can differ due to distinct child characteristics: "The approach varies for all three of my children. Their temperaments are different, and their characters are distinct." Within this narrative, Altynai shared, "I confess that despite my intentions, I still allow him certain things that I wouldn't permit the younger one."

At the same time, mothers acknowledged that the experience of raising a child with DS is inherently 'special.' According to Zhanerke, the most profound joy was experienced when her son with DS began attending school, even though she has older and younger children who also attend school. In this regard, Gulbarshin expressed a sentiment that, at

times, she finds herself having a deeper affection for her child with Down Syndrome compared to her eldest daughter. However, she acknowledged that this perception might be influenced by the fact that her daughter with DS is the youngest in the family.

In addition, insights from the interview with Tolkyn shed light on the complexities parents face in navigating their parenting approaches. She expressed concerns about her middle child possibly developing specific complexes:

> Anuar used to have a penchant for running away, a common trait in many children with Down syndrome… Although we've managed to minimize this behavior through concerted efforts, the impact of his past inclination to run away lingers. The constant reminders to stay close, 'stay with me,' have inadvertently influenced my second son negatively. He, in turn, is now inclined to stick closely to me, understanding the fear associated with getting lost. What I consistently communicated to Anuar, my second son has taken personally.

Role of Government Support

Participants were also questioned about their assessment of the government's role, leading to diverse opinions. Generally, mothers advocate for the notion that more should be done by the government. As expressed by Venera, "A lot, of course, depends on us mothers, but it also depends on our government, our legislative system." Asem emphasized that the primary support received is in the form of disability benefits. Within the conversation of financial support, dual perspectives emerged: some parents find the current state of support sufficient while others indicated that it is not enough to cover all the necessary expenses:

> You know, the state also helps us very well. We receive allowances. Right now, I consider it enough; we receive 134,000 tenge. At least it's good for covering some activities like swimming or speech therapy (Gulbarshin).

> We receive 130,000 tenge. Considering that we go to the pool, speech therapy, and therapeutic exercises, besides taking various vitamins… Sometimes we need orthopedic shoes, and the amount we receive is not enough. Definitely not enough, especially if you also use the services of a nanny, the kindergarten, and various classes (Asem).

Tolkyn highlighted that while she does not imply that the government should intervene, parents do need more financial support. Additionally, concerning financial support, Alena discussed one of the challenges encountered by non-profit organizations in raising funds to send children to competitions. Recently, her foundation sent children to a competition in Turkey and had to secure 1,200,000 tenge within a month. Although they refrained from approaching the Sports Committee due to uncertainty about receiving assistance, Alena outlined the ideal scenario: "We would like to approach, declare the amount, and be told, 'Guys, we will support you." Aside from the financial aspect of disability benefits, an overall evaluation of the current state of affairs can be described by the statement provided by Asem:

> Rehabilitative sessions or activities are free of charge, but navigating through bureaucratic obstacles takes months. Recently, we were offered rehabilitation at a medical center. Although we attended, I'm not overly enthusiastic about it; the sessions are brief, lasting only 10-15 minutes and involving a psychologist, speech therapist, and massage. We'll attend periodically when time allows, not consistently—perhaps for a month. I believe the sessions we arrange independently are more beneficial.

On the matter of rehabilitation and other support services, Alena also shared her opinion: "What we have now, of course, is great—the existence of correctional classrooms,

rehabilitation facilities. But it's not always as it should be, as parents would like it." According to her, the current state mostly operates with a 'box-ticking' mindset: "I wish it was not just ticking a box and saying, 'Yes, we opened a rehabilitation, this many people attended." Furthermore, the problem of insufficient rehabilitation and correctional centers was brought to light by Venera. She revealed instances where she desired to enroll her child in speech therapy sessions but encountered obstacles due to both being a working mother and the unavailability of such services in close proximity. Therefore, she stated in the following way that this area requires attention:

> I think it would be great if they could provide services within the framework of the Psychological Medical Pedagogical Commission (PMPC). For example, even when we lived in Almaty, in one neighborhood, they directed us to a correctional school that required a 40- minute commute. So, what could be done right near home is lacking. There are many children who need speech therapists, but the number of correctional schools is very limited.

Tolkyn emphasized that there is a need for more active state involvement, particularly when it comes to inclusive education:

> Regarding state involvement, I don't particularly rely on the state either. I understand that it's my personal responsibility. He is needed primarily by us, not the state. I understand this perfectly, but in terms of how state policy is currently moving in the direction of inclusive education, I can't say anything. I think it's moving very slowly…

Nevertheless, Tolkyn mentioned that there is a visible progress in society and that society is moving in the right direction due to various social projects that are initiated by various parties, including state. However, she also added that there is a need for people in

higher ranks who have an innate desire to make positive changes in the lives of children with disabilities. All in all, she is hopeful about the future:

> We are at the forefront of these changes. Therefore, I think everything is ahead. Let the state move in the right direction, but current movement is a bit slower than one would like, of course. In the future, I would like decisions to be much more tactful and effective.

Alena supports narratives proposed by Tolkyn as she shared her perspective as a leader of the non-profit foundation. She summarized the current situation, stating

> When we approach them ourselves, they may or may not help, so to speak… Even with the opening of clubs, so that they also suggest something to us, not that we go looking for it. Well, this is idealizing, of course. Naturally, as long as there are no problems, no one pays attention to them.

Furthermore, interviews with Venera and Meruert revealed another urgent area of improvement – inclusive programs for secondary special education or colleges:

> I know that after finishing school, there are currently no specific programs available for our children… Currently, I see that they send older kids to construction sites, which is definitely not an option. Because there are safety regulations and physical abilities need to be taken into account, not to mention the additional accompanying conditions. (Venera)

Participants expressed that they are hopeful that the government will pay attention to this existing gap. Additionally, Venera highlighted the role of projects such as ‘World of Possibilities’ that offer opportunities for children with disabilities to participate in sports competitions: “I think that in the future, more projects like this would be a great support for the development of our children.” Furthermore, Alena highlighted one of the concerns faced

by parents of older children with Down syndrome—the classification into disability groups. According to her, when children with Down syndrome turn 18, they are automatically assigned to the 2nd disability group. This process was further explained by the participant:

> In my opinion, this classification should be done differentially based on the actual abilities of the child. Completion of school does not necessarily guarantee employment. However, the current system does not reflect this.

To finalize, as highlighted by Meruert, the recommendations for government include:

> To provide specialists, to make inclusion a reality rather than a mythical concept existing only on paper; to increase pensions for the care of children with disabilities and their guardians, to open centers for the physical, musical, and creative development of such children, to make secondary education and the job market accessible for people with disabilities.

Chapter Summary

This chapter presented study findings following the themes that were identified at the data analysis stage. Six themes and respective subthemes were extensively elaborated through the participants' voices. It resulted in the presentation of data on such matters of parenting as experiences of birth and diagnosis, coping and adaptation, choices of school, as well as challenges encountered along the way coupled with suggestions for improvement.

5. Discussion

Introduction

The purpose of this qualitative phenomenological study was to explore the lived experiences of Kazakhstani parents raising children with Down syndrome. The goal was to unveil the key aspects of parenting, specifically focusing on how participants navigate the educational journey of their children, ultimately gaining insights into the experiences of children with DS in Kazakhstan.

The initial three chapters introduced the problem to be researched, presented synthesis of existing literature concerning children with DS and parenting, and justified the selected methodology. The preceding chapter presented the study findings through the direct voices of participants. This chapter is dedicated to interpretation of the research findings and highlighting its implications. This will be achieved by addressing how the findings of the study relate to the research questions and demonstrating how the selected conceptual framework contributed to making sense of data.

The research questions guiding the study were as follows: "What are the lived experiences of parents of children with DS as they relate to education-related endeavors?" with three sub-questions

- As parents of children with DS, what is their role in the educational journey of their children?
- As parents of children with DS, what are the main challenges they face in rearing and supporting the education pursuits of their children?
- As parents of children with DS, what areas of improvement do they suggest?

Lived Experiences

The primary objective of this study was to delve into the firsthand experiences of parents raising children with Down syndrome, aiming to make sense of their realities to potentially be able to enhance the educational journeys of their children. As such, the main research question carries a broad meaning, necessitating subsequent, more focused inquiries to thoroughly represent the phenomenon under investigation. In essence, three sub-questions collectively addressed the overarching research inquiry: "What are the lived experiences of parents of children with DS as they relate to education-related endeavors?"

To address the research questions, the chapter was structured into sub-sections covering 1) Parental roles, 2) Challenges, and 3) Areas for improvement.

Parental Roles

The significance of parents in shaping their children's education is undeniable (Lendrum et al., 2015) with studies (Friend, 2011; Hess et al., 2006; Leyser & Kirk, 2011) highlight the growing importance of empowering parents and involving them actively in decision-making processes. This emphasis is intuitive, considering that parents are typically more invested in their children in terms of time and emotion compared to professionals or service providers (Johnson et al., 2002).

In the context of the current study, the experiences of mothers are particularly noteworthy. It was revealed that they often navigate a complex web of responsibilities that stretch across clinical, societal, workplace, and recreational domains, mutually influencing the development and education of their children. In the preceding chapter, the parenting experience was characterized as encompassing 'multiple hats,' juggling roles of teachers, therapists, and doctors. The findings of present study align with existing research, which suggests that parents and caregivers of children with special needs serve as "health coordinators, medical experts, systems advocates, and personal ambassadors and

representatives" for their children (Isgro, 2015, p. 66). These diverse experiences simultaneously converge on parents serving as advocates for their children.

Consistent with prior research (Coots, 2007; Friend & Bursuck, 2009; Hess et al., 2016; Isgro, 2015; Johnson et al., 2002; Lechtenberger & Mullins, 2004) parents exhibited advocacy in various ways. At the onset of their parenting journey, some mothers in this study encountered adversarial aspects of the condition, presented by clinical professionals in a hardhearted manner, resulting in feelings of isolation. In certain situations, mothers found themselves in conflicts with medical professionals, being persuaded to give up custody of their child. Particularly, when the diagnosis was discovered prenatally, the battle for parents focused on preserving the pregnancy itself. This recurring pattern of tension and strained relationships with service providers and specialists persists in the lives of mothers as they navigate rehabilitation services, early childhood education, and the transition to school. They consistently highlighted the necessity for ongoing negotiations to secure acceptance for their children in various educational settings, including developmental centers, kindergartens, and schools. On top of that, the concept of "doctor shopping" was frequently brought up by mothers. In their pursuit of best practices, compounded by the challenge of finding high-quality Kazakh-speaking specialists knowledgeable about Down syndrome, parents in Kazakhstan constantly find themselves in a state of an ongoing search. With the prevalence of outdated information, mothers find themselves tasked with the additional challenge of seeking reliable sources, often turning to Russian and American specialists and resources for assistance. To address the information asymmetry, mothers come together through online chat communities and establish foundations specifically created by and for parents. Additionally, participant interviews unveiled their proactive approach to educate their immediate circles through social media posts due to persisting stigma around Down syndrome. In order to realize these advocacy efforts, some mothers had to make significant

life adjustments, including the substantial step of interrupting or halting their careers which reflects the statement of Scott (2010) that balancing caregiving and work is intricate, sometimes appearing insurmountable.

Dialogues with mothers in this study resonate with findings from prior studies. In a study by Hess et al. (2006), parental advocacy displayed a range of expressions, from subtle support of their child to overcoming challenges to actively supporting other parents. Isgro's study (2015) encapsulated mothers' advocacy work as "one-on-one battles" that transpired in their children's daily lives. These endeavors involved negotiating with clinicians and educators to make them recognize the capabilities of their child, actively searching for healthcare providers proficient in addressing Down syndrome-related complications, engaging in written correspondence to educate others on DS, and organizing public activities. In a study by Johnson and Duffett (2002), which involved over 500 parents of children with special needs, it was found that participants viewed their role as holding schools accountable and ensuring the delivery of an adequate education for their child. Research by Coots (2007), Friend and Bursuck (2009), and Lechtenberger and Mullins (2004) emphasizes the pivotal role parents play in helping professionals understand the academic strengths and needs of their children.

While acts of advocacy on behalf of their children constitute a defining aspect of parental roles, they frequently stem from tensions and negative experiences prevalent in communities, institutions, and systems that shape the realities of parents (Ocasio-Stoutenburg, 2020). This connection will be further explored in the follwoing sections.

Challenges

Consistent with existing scholarly observations on stress and adaptation of families raising children with DS (Abery, 2006; Blacher & Baker, 2007; Van Riper, 2007), the parents in this study demonstrated remarkable resilience and adeptness in adjusting to the life

changes associated with raising a child with DS. Aligning with prevailing literature on parenting children with disabilities that identifies consequences such as difficulties in diagnosis acceptance (Blancher, 1984), social isolation (Seltzer et al., 2001), stigmatization (Gray, 1993), increased marital challenges (Hartley et al., 2010; Risdal & Singer, 2004), additional financial burden (Hedov, 2006; Holroyd & McArthur, 1976) and the need for mothers to interrupt their careers or compromise ambitions (Seltzer et al., 2001; Shearn & Todd, 2000; Marshak, 2019), the adaptation was marked by adjustments to lifestyle and a shift in perspective (King, et al., 2006). Resembling Marshak's (2018), King et al. (2000), and Lalvani (2008), experiences of mothers were equal parts transformative and painful, with dramatic statement of equating parenting a child with disability to learning to live with "an amputated limb" being present among participant responses. Congruent with Poehlmann et al. (2005), by leveraging positive coping strategies, encompassing seeking support from family and friends, relying on faith, connecting with a network of other mothers, as well as utilizing resources such as books, movies, and inspiring stories of famous individuals, mothers were able to reframe their experiences in a positive light. This enable them to reflect on their experiences through a positive lens, drawing strength from their character and personal values. Among the coping strategies observed, engaging in information-seeking (Gibson, 2016), socializing with other parents of children with Down syndrome (Nelson Goff et al., 2013; Ridge, 2013, as cited in Rose, 2021), and spirituality (Gibson, 2016) emerge as the most prevalent. However, in contrast to mothers in studies conducted by Isgro (2016) and Lalvani (2011), who rejected the idea of being viewed as "chosen by God" or "special," mothers in the current study embraced such beliefs as a means to cope.

Nevertheless, even with re-examination of their belief system, a shift in mindset and the presence of individual coping pathways, parenting, especially when it comes to navigating the educational journey for their children, remained fraught with numerous

challenges. Mothers indicated grappling with uncertainties, concerns about the child's future and adaptation in society, a lack of guidance, insufficient government support, inadequate medical care and support services, a shortage of specialists, negative societal attitudes, the learning curve of meeting unique child needs, and navigating parenting styles between a child with DS and other children. According to Gilmore and Cuskelly (2012), the demands of early childhood may encompass the time dedicated to early intervention therapies, challenges in accessing services, and decisions related to schooling.

As articulated by Vaseliisa, who likened the parenting journey to "being buttoned up on all buttons," the multifaceted experiences of mothers in Kazakhstan typically unfold in a manner that is predominantly challenging and not inherently positive.

Areas of Improvement

The aforementioned challenges encompassed a spectrum of concerns spanning stages of diagnosis, birth, early childhood intervention services and schooling. Furthermore, the responses offered insights into the emotional and psychological aspects of parenting children with Down syndrome, the navigation of which constitutes another facet of the challenges faced by parents.

The Beginning: Diagnosis and Birth

The widely-held assumption that clinical knowledge about Down syndrome is exhaustive, resulting in advancements in the health, education, and occupational outcomes for individuals with DS, stands in stark contrast to the enduring challenges confronted by parents in reality (Ocasio-Stoutenburg, 2020). The responses from participants in the present study resonate with findings from other studies (Buyukavci et al.,2019; Skotko, 2005), revealing that specialists advising parents of children with Down syndrome tend to overemphasize the negative aspects of the diagnosis. Therefore, parents in present study found themselves navigating a landscape marked by a lack of guidance, and specialists subjecting them to

disproportionately negative or outdated information, particularly during the crucial stage of diagnosis - discussed in the context of participants who by the most part received the diagnosis postpartum. Frequently, mothers pointed to the delivery of the diagnosis being conducted in a non-empathetic manner, causing fear, anger, and anxiety (Skotko, & Bedia, 2005). Additionally, one participant reported the burden of feeling pressured to relinquish her child, and another experiencing pressure to contemplate terminating the pregnancy. Moreover, even today, stigma appears to persist within the healthcare provider community, where dissemination of misinformation, such as the shortened life expectancy among individuals with DS, continues to affect parents. Resonating with Costigan's (2000) assertion that historically individuals with Down syndrome were stereotyped as vegetable-like, the recurring phrase in interviews with parents, describing their interactions with medical professionals, involved equating children with Down syndrome to vegetables.

At the same time, participants also highlighted positive interactions with healthcare providers, particularly genetics consultants. Although caution is warranted in generalizing mother-professional relationships, the identified gaps within the dyad make up a significant portion of parental experiences. As per Sheets' (2011) examination of the provision of information for parents of children with Down syndrome, encompassing perspectives from both genetics specialists and parents, there is indeed a discernible distinction in the delivery of information between prenatal and postnatal settings. In the prenatal stage, information primarily consists of clinical details, emphasizing the negative aspects of the diagnosis and addressing considerations like pregnancy termination or potential adoption arrangements (Sheets, 2011). However, in the postnatal phase, there is a shift towards a more comprehensive perspective, encompassing both negative aspects and positive elements, such as strategies for effective management. While mothers in the present study reported receiving similar diagnostic information content-wise, there was a significant disconnect between them

and professionals, stemming largely from the lack of communication skills and empathy exhibited by the professionals. According to Sheets (2011), essential information that parents should receive include the nature of the Down syndrome diagnosis, relevant medical consequences and necessary interventions, available therapeutic options to address intellectual development, and a spectrum of the potential outcomes. Furthermore, it is important to equip parents with updated informational materials, contact details of relevant specialists, and information about support groups and other families raising children with Down syndrome (Hodgson & Spriggs, 2005; Sheets, 2011; Skotko, 2005).

Societal Attitude

The persistent stigma associated with Down syndrome and hegemonic discourses surrounding it within our society is vividly illustrated as one of the parenting challenges. It has been well-established that individuals with intellectual disabilities (Ali et al., 2012) and students with special educational needs (SEN) exhibiting challenging behavior (Orsati & Causton-Theoharis, 2012) represent one of the most socially stigmatized groups. Extending beyond the medical realm, it affects adaptation of families (Huiracocha et al., 2017; Lam & Mackenzie, 2002). Also, Ali et al. (2012) identified that parents perceive negative attitudes as hindrances to their children's participation.

In the context of the current study, societal non-acceptance of children with disabilities notably impedes a child's acceptance into various settings alongside peers, such as a drawing class, as illustrated by the experience of Alena and her daughter. Moreover, a child's behavior outbursts add an extra layer of concern to the parenting experience, as parents must consider the potential societal reactions and the risk of their children being stigmatized as abnormal. Being pegged as abnormal is already taking place in interactions with specialists such as psychiatrists (Heflinger & Hinshaw, 2010; Moses, 2010), as in the case of Zhanerke, and, thus perpetuating "the otherness of children with Down syndrome"

(Lalvani, 2013, p.444) across various contexts. Hence, despite advancements in the scientific knowledge base about Down syndrome and comprehension of intellectual disabilities, stereotypes continue to shape experiences of individuals with Down syndrome in Kazakhstan (Gilmore et al., 2003).

Early Childhood Intervention Services

The conceptual model of family factors relating to the early development of children with Down syndrome (Van Hooste & Maes, 2003) recognizes personal social support networks and Early Intervention (EI) services as crucial sources of support. In this study, social support networks comprised family members and fellow mothers of children with Down syndrome, connected through online communities and parent-led foundations. When it comes to the reality of navigating Early Intervention (EI) service systems mirrors a prior evaluation by Human Rights Watch (2019) on state and medical service providers in Kazakhstan serving children with disabilities. The report highlighted issues such as parents lacking access to essential and accurate information about their children's disability, encountering problems with receiving diagnosis, and facing challenges in accessing high-quality EI and support services. In the context of the present study, two distinct aspects emerge for discussion: the quality and accessibility of state-provided services, and the provision of information to parents. Deficiencies are evident in both of these areas.

The Quality and Accessibility of Services. Children in present study actively participate in services aimed at targeting areas of challenges, which are specific for each child, focused on enhancing both physical development and speech. The former involves collaboration with developmental pediatricians, massage therapists, as well as participating in hydrotherapy, and adaptive sports, while the latter is addressed through the involvement of speech therapists and defectologists. While the majority of these services are available at Psychological-Pedagogical Remedial Offices, where children are referred by PMPCs, none of

the participants expressed satisfaction with the quality of services. They cited bureaucratic challenges such as lengthy waiting lists, concerns about the approaches of specialists, the short duration of therapies, and lack of correctional centers in close proximity. Furthermore, some participants indicated their participation in rehabilitation services meant being placed on a waiting-list for a period of a few months. Considering that Early Intervention (EI) programs covering the first five years of life, when comprehensive and time-intensive, are suggested to yield stable long-term effects, (Guralnick, 1998; Van Hooste & Maes, 2004), questions also arise about the overall effectiveness of such programs. Consequently, after participating in state-initiated EI for a brief period, ranging from 1 to 3 months, parents choose to enroll their children in services offered by parent-led foundations, organizations like Caritas, or other commercial entities, the latter choice introducing an additional financial burden for the families. Moreover, when exploring private avenues, in addition to incurring financial burden, parents consistently reported the challenge of finding high-quality specialists, preferably Kazakh-speaking, who understand the specific nuances of a Down syndrome diagnosis and do not adopt a “one-size-fits-all” approach.

While the shortcomings of the current system have been highlighted, supporting as well as expanding on existing literature, what needs to be acknowledged is - the responsibility squarely lies with the state to ensure that parents and children with Down syndrome have access to a comprehensive spectrum of support services (Human Rights Watch, 2019). Foundations established “by parents for parents” serve as an alternative source of support services and provide children with disabilities an avenue to connect with others, yet it is crucial to note that they cannot replace the imperative of “government-led inclusive education and social services” (Human Rights Watch, 2019, p. 58). For instance, Zhanerke highlighted a sense of isolation stemming from the absence of parent-support groups or foundations in her rural area; thus, capabilities of alternative support avenues are limited.

Information Provision. In light of the present state of affairs detailed in the preceding sub-section, parents are de facto service coordinators for their children. Asked about the problem of locating information, mothers revealed that they are the primary disseminators of all essential information, from medical intricacies related to the diagnosis to the state benefits they are entitled to receive - shared through group chats and parent-led support organizations. The lack of guidance and systematic information was especially apparent during discussions of speech development, a rocognized challenge for parents raising children with DS (Sheldon et al., 2020).

Language, Speech, and Communication Development. According to Buckley and Le Prevost (2002), speech and language therapy holds paramount importance among intervention services for children with Down syndrome, because of its direct influence on cognitive and social development (Moraleda-Sepúlveda, 2022) which consequently defines whether a child will be at an advantage or disadvantage when starting school. The progression of speech and language development, as any aspect of child's development, is individual to each child, and as such, some mothers in this study indicated that their children remain mostly non-verbal, while others observed comparatively advanced speech development in their children. Early intervention for children with Down syndrome is recommended to commence as early as possible, supported by studies such as Kasari et al. (1999), Paige-Smith and Rix (2006), and Roberts et al. (2007). For example, the initiation of teaching reading through sight words is advised to start between three to four years of age, as suggested by Buckley (1999). As highlighted by the same scholar, children with Down syndrome begin using gestures by 18 months, and around the same age, they utter their first words. On average, the acquisition of their initial 10 words occurs around 27 months, with a productive vocabulary of 50 words developing at an average age of 37 months. This typical profile of speech and language development contrasts the way mothers depicted the language

profile of their children in current study. Among eight children, five (aged between 3.5 and 8 years) are grappling with challenges in speech and communication, having developed from 10 to 15 words, and relying primarily on gestures. Mothers, actively involved in their children's development, have indicated encountering obstacles due to their children's prolonged illnesses, the absence of quality specialists, not being able to enroll their child in support services due to physical and financial constraints, and a lack of information and guidance. The amalgamation of these challenges places a child at a disadvantage, to the extent that even speech therapists refuse to provide assistance. As pointed out by Bazhkenova (2018, p. 168), tending to the unique needs of children with disabilities in Kazakhstan is encapsulated by the phrase 'too late': "Attention is given too late, consultation with specialists too late, diagnoses are made too late, treatments come too late, the commencement of education is too late," with the findings of present study supporting this sentiment.

According to Buckley and Le Prevost (2002, p.71), parents play a primary role as therapists for their children since language is acquired "all day every day." Consequently, the fact that parents in Kazakhstan are deprived of up-to-date information and guidance, creates conditions where they lag behind, directly impacting the child's development. At the same time, as illustrated by the conceptual model (Van Hooste & Maes, 2003), a parenting style that is moderately directive, coupled with "sensitive, responsive, and reciprocal interactions (p. 305)," within a broadly stimulating environment both at home and in the community, contributes positively to the child's development. Congruent with the model, mothers in the current study highlighted that stimulating home environments and interactions with typically developing siblings were significant factors influencing their children's development, particularly in terms of speech development. However, despite the mothers in this study demonstrating effective coping mechanisms and investing maximum effort in providing developmental environments for their children, their surroundings are fraught with stressors.

With regards to the model, experiences of mothers represent such stressors as lack of information about the child's abilities and developmental needs and inadequate support provision, collectively contributing to a condition termed "confidence threat," potentially disrupting the parents' sense of confidence and competence. Given the reciprocal relationship of parent-child interactions and developmental outcomes, such disturbances can adversely affect both of the parties.

Schooling

In the current study, two participants chose special schools for their children, while two others opted for mainstream schools, with one participant having experience with both special and mainstream education. The types of special schools mentioned during interviews were corrective schools and auxiliary/boarding schools - portraying a comprehensive picture of choices available to parents. While parents expressed satisfaction with their choices, whether it be a special or inclusive school, those who opted for special schools did not do so out of a genuine preference for this type of education. Instead, their choice was influenced by barriers encountered during the enrollment process in mainstream schools, including an unwelcoming attitude from school principals, or perceived issues with the current state of inclusive education. Parents perceive that current inclusive education practices fall short in meeting the needs of children with Down syndrome, citing factors such as large class sizes, a challenging school program, and ineffective teaching and behavior management methods. The nature of these challenges are consistent with those reported by Human Rights Watch (2019) and Kussainova (2020), highlighting that parents in Kazakhstan frequently opt for special schools due to a lack of confidence in mainstream schools' ability to provide necessary support for their children or due to PMPC commissions directing their children to attend special schools. However, in the current study, the influence of PMPC was not as prominent as in the HRW report: all parents received recommendations to enroll their

children in mainstream schools, thus, the ultimate choice being placed on the shoulders of parents. Parents indicated that special schools offer more extensive educational opportunities, leading to noticeable progress in their child's development. Two participants highlighted that the educational arrangements for children with Down syndrome in mainstream schools involve restricted participation, such as being allowed to attend for only three hours of the educational day or attending school for only three days per week.

Nonetheless, issues within special education were also identified. Specifically, a prevalent problem is the existence of 'double standards.' While mainstream schools allow children who are lagging behind to study using a special program and remain in the same class, special schools require a child struggling with the program to be transferred from a class for mild intellectual disabilities to one for moderate intellectual disabilities.

At the same time, inclusive education, currently promoted by the government under the Bolashak program, is also in a state where parents are able to identify specific shortcomings. This pertains to both the challenges faced in persuading schools to accept their children and concerns regarding the school's ability to meet a child's needs, as well as the lack of communication from designated institutions during the transitional stage of starting school. Considering that the transitional phase of moving from preschool to school is a vulnerable time for children with SEN (McIntyre et al., 2006), a number of impediments at this stage are a significant source of stress. Specifically, it seems that children with Down syndrome who also face health complications and spend significant time in hospitals are deprived of continuous informational guidance, including the necessity of undergoing PMPC commission examinations. Then, upon receiving the recommendation to enroll in a mainstream school, parents encounter the challenges of finding schools that do not harbor outdated and stigmatized views of children with Down syndrome. Additionally, they face the task of advocating for the rights of their children in the face of rejection by school

administrators, both at primary and preprimary education levels. Furthermore, once children are enrolled, schools may or may not be prepared to accommodate a child with Down syndrome. Zhanerke highlighted obstacles such as a shortage of tutors and an insufficient number of sessions with speech therapists and defectologists, the latter being consistently recognized by parents as one of the drawbacks of mainstream education (Johnson, 2006).

Life After School

As highlighted by Venera and Alena, once children with Down syndrome complete their schooling, the opportunities for further education and employment become minimal. According to Venera, they are often directed to construction sites which is unsuitable due to health concerns of these individuals, and as mentioned by Alena, even in cases where individuals with Down syndrome attend sewing classes, securing employment is not guaranteed. This aspect of parenting aligns with Nelson Goff et al.'s statement (2016, p.1142) that, "this group of parents often face limited external resources and programs for an adult child with developmental disabilities," thus, necessitating "vocational, recreational, and other related services and programs." In this regard, it is important to voice Venera's hopes that the Kazakhstani government and its legislative system will acknowledge the needs of older children with Down syndrome.

Chapter Summary

In an effort to answer the research questions, a multitude of challenges were examined. This exploration has brought to the forefront various facets of parental experiences, illuminating the prevalent gaps in our communities, institutions, and policies, simultaneously paving the way for the discussion of areas necessitating improvement. The conceptual framework presented by Van Hooste and Maes (2003), which examines family factors impacting the early development of children with Down syndrome served as a means to elucidate the intricate web of interacting systems in the lives of parents.

6. Conclusions

The present study explored the experiences of parents raising children with Down syndrome in Kazakhstan, a topic that has received limited attention in previous research. Previously, Kussainova (2020) examined the attitudes of parents towards inclusive education for children with Down syndrome, while Human Rights Watch (2019) shed light on the educational experiences of children with disabilities in Kazakhstan, including cases involving children with Down syndrome as well. This study enriches the literature by offering a comprehensive depiction of parental voices regarding their experiences across different stages of their child's development. Specifically, it delves into the unique challenges and perspectives of parents regarding the birth, adaptation, early intervention, preschool, and school experiences of children with Down syndrome.

The Study Summary

The present qualitative phenomenological study aimed to explore the lived experiences of parents, shedding light on the educational journey of their children and the hurdles they face. Data was collected through semi-structured interviews with eight parents of children with DS hailing from different regions of Kazakhstan. The conceptual model of family factors relating to the early development of children with Down syndrome (Van Hooste & Maes, 2003) aided the study, with the research attempting to gauge parental experiences regarding the model components, namely the family characteristics, support resources, and stressors.

Overall, the parents in this study demonstrated remarkable resilience and adeptness in adjusting to the life changes associated with raising a child with DS. Nevertheless, parenting, especially when it comes to navigating the educational journey for their children, remained fraught with numerous challenges encompassing stages of diagnosis, birth, early childhood intervention services, and schooling. Ultimately, in light of these challenges, diverse parental

experiences simultaneously converged on parents serving as advocates for their children. As a result, a number of points for improvement covering the work of medical and other service providers, educational institutions, and state initiatives were postulated.

Implications for Future Research and Recommendations

In an effort to gain insight into the experience of parenting a child with Down syndrome, this study comprehensively examined various aspects of life, ranging from initial stages of birth and diagnosis to parental satisfaction with the state support. Future research can build on the findings of the current study by adopting a more targeted approach and a narrower focus. For instance, researchers could explore the experiences of parents whose children are receiving early intervention services or navigating pre-school and school years. Especially, it is recommended to include a diverse sample, including participants from varied backgrounds and demographics. Additionally, researchers are advised to study experiences of adolescent children with Down syndrome, as well as actively involve fathers in discussions. Despite potential limitations in generalizability, the findings of this study remain transferable and carry significant implications for practical application.

Practical Implications

As the study encompasses experiences of parents with children ranging from as young as 3.5 years to as old as 11 years, its findings carry implications for various stakeholders, including medical specialists and other service providers, educators, school leaders, and policymakers.

First and foremost, this research underscores the crucial role of medical professionals in determining whether parents' initial response and subsequent adaptation to becoming parents of a child with a disability will be characterized by positivity or fraught with negative emotions. The quality of the relationship between parents of children with DS and healthcare professionals plays a crucial role in shaping parental attitudes towards caring for their infant

and influences the duration it takes to establish attachment (Dent & Craey, 2006; Miles et al., 1999). Reiterating the best practices for interacting with parents of children diagnosed with Down syndrome, as outlined in the discussion chapter, it is crucial to provide parents with immediate, balanced, up-to-date factual information, communicate with sensitivity and compassion using language that respects individuals with Down syndrome, and refer parents and their family members to relevant support groups (Sheets et al., 2012; Skotko et al., 2009). It is plausible that medical professionals may not fully grasp how negative discourses can impact the social outcomes of families with Down syndrome (Thomas, 2016), highlighting the importance of disability cultural competency training as well as reflective practice to help professionals in identifying and reflecting on their own perceptions, attitudes, and implicit or explicit biases toward individuals with Down syndrome (Schön, 1983, as cited in James, 2022; Meredith et al., 2024).

Secondly, the study's findings illuminate critical issues within the practices of various professionals, including speech therapists, occupational therapists, physical therapists, and other service providers such as private art therapy centers. Specifically, the study highlights instances where professionals refuse to work with a child, exhibit insufficient understanding of Down syndrome diagnosis specifics, overlook the child's individuality in therapy approaches, and predominantly link DS diagnosis with intellectual disability, sometimes even stigmatizing the child as abnormal. These challenges manifest in the experiences of parents and their children with Down syndrome in a profound way and, therefore, specialists are advised to adopt a strength-based, affirmative approach rooted in the evidence-based learning profiles of individuals with Down syndrome instead of relying on normative expectations of development (Lemons, 2018; Pickard, 2019; Rickson, 2014). On top of that, embracing the social model of disability (Rapley, 2010) and educating oneself about Critical Disability Studies is crucial, as it encourages a shift away from historically deficit-based approaches

that may be potentially reductionist (Pickard, 2019). Instead, professionals should strive to embrace an "able identity" perspective (Magee, 2002, p.191), thereby creating a "maximally supporting learning environment" (Wishart, 2002, p.18) marked by enhanced participation and understanding of children with DS. These vital notions should also be introduced to aspiring specialists in pedagogical universities and colleges as well as programs for professional development to practicing professionals.

Thirdly, considering the robust empirical evidence supporting the advantages of inclusive education for children with Down syndrome, coupled with Kazakhstan's ambitious goals in this realm, the findings of the current study hold significant implications for educational institutions at the preschool and school levels, particularly for teachers, tutors, and educational leaders. While parents with children attending inclusive education expressed high satisfaction with their choice and attributed their positive experience to the homeroom teacher, they also mentioned certain impediments. Moreover, the decision of parents to opt for special education, driven by the realization that the needs of their children were unmet within a mainstream education system rather than being based on personal preference, speaks volumes. In some cases, parents express apprehension regarding the negative unwelcoming attitudes of school leadership, inadequate provision of necessary accommodations and tutors, and concerns about teachers' capabilities to effectively teach and manage challenging behaviors, highlighting the importance of addressing these aspects. At the grassroots level, schools must acknowledge the recommendations of the PMPC when children are referred to their institutions and adopt an inclusive mindset as the norm. The subsequent step involves ensuring the provision of the least restrictive environment and making child-specific adjustments such as introducing an IEP.

As Tolkyn expressed, "He [Anuar] is primarily needed by us, not the state. I understand this perfectly, but regarding the current direction of state policy towards inclusive

education, I can’t say much. I feel it’s progressing very slowly...” It’s evident that challenges related to providing optimal education for children with Down syndrome extend beyond school administration and teachers to encompass government policies and actions. Mothers emphasized the necessity of active state involvement across all facets of life, spanning from early intervention services and information provision to the organization of inclusive education and the availability of post-school programs. Within the scope of this study, the lives of mothers are characterized by a constant dichotomy: on the one hand, they must navigate the less-than-optimal current state of affairs, while on the other hand, they are tirelessly advocating for the rights and well-being of their children, simultaneously endeavoring to counterfeit institutional ableism. It is undeniably true that families raising children with Down syndrome often face greater challenges in life. However, these hardships are primarily due to societal prejudices and institutional barriers they encounter, rather than solely the presence of an extra chromosome in their child.

In addition to the implications mentioned earlier, anyone who reads the present study can hopefully glean points to take away. Despite the tumultuous and challenging journey, families raising children with Down syndrome managed to adapt successfully and discover moments of joy within their new reality. Individuals with Down syndrome are often type cast as joyful and happy, all while being stigmatized due to dominating narratives and imposed assumptions that reify intelligence and label them as inferior. The study invites readers to perceive individuals with Down syndrome as complete, acknowledging both their challenges in certain areas and strengths in others. These challenges and strengths should not limit their ability to comprehend and navigate all the ups and downs, and ins and outs of life, thereby instilling urgency to addressing issues outlined throughout the thesis.

Strengths and Limitations

Although this descriptive phenomenological study offers valuable insights into the parenting journey with significant implications for practice, it is important to acknowledge several limitations and boundaries. First, it is important to note that the oldest child included in this study is 11 years old (range = < 3.5-11 years-old). Consequently, the exploration of parental experiences is confined to those with children of younger ages. Given that parents of older children with Down syndrome face unique challenges and needs, there is an opportunity for future studies to explore this population of parents. Furthermore, although the study set out to investigate the lived experiences of parents, it is noteworthy that all participants in this study are mothers. In Kazakhstan, there is a traditional division of gender roles with mothers being the main caregivers of children. Thus, while some mothers shared stories involving their spouses, there is an absence of direct voices of fathers. A further limitation is that the researcher is educator who works with children with special educational needs and is professionally involved with one of the participants. The process of bracketing, or setting aside pre-conceived notions, is integral to descriptive phenomenology (Reiners, 2012). Hence, the researcher diligently worked to minimize the influence of personal bias by consciously engaging in this practice. Therefore, while the study enhances understanding of the complexities involved in supporting these families throughout various stages of their journey, there are notable limitations that should be addressed.

Final Reflections

Finally, I want to present my reflections that stem from the 10 month-journey of composing the present study. The decision to explore the experiences of parents and children with Down syndrome was inspired by a meaningful encounter with a family raising such a child. However, before embarking on this research endeavor, my understanding of the developmental trajectory of children with Down syndrome and the intricacies of parenting

children with developmental and intellectual disabilities in Kazakhstan was incomplete, revealing significant gaps in my epistemology. Therefore, the study is not only instrumental from a point of practice implications, but it also played a crucial role in my personal growth, both as a professional and as a researcher.

Being able to delineate the abstract construct of parenting into a universal experience, while acknowledging its individual twists and turns along the way, has fostered a heightened appreciation for qualitative methodologies, particularly the phenomenological inquiry. Identifying and justifying the research problem, strategizing the study design, recruiting participants, conducting interviews, analyzing data, and documenting findings represent merely a condensed enumeration of the skills I have developed, each carrying valuable learning opportunities. Ultimately, I became a more confident and objective researcher with a deeper understanding and sensitivity surrounding the phenomenon of rearing a child with Down syndrome.

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Appendices

Appendix A

Thesis Title: Lived Experiences of Parents Raising Children with Down syndrome: A Phenomenological Study

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Appendix A – Declaration of the Use of Generative AI

I hereby declare that I have read and understood NUGSE's policy concerning appropriate use of AI and composed this work independently (please check one):

☒ with the use of artificial intelligence tools, or
☐ without the use of artificial intelligence tools.

(If you have used AI tools as defined in the GSE policy document, please complete the rest of this form.)

During the preparation of this thesis/examination, I used Chat GPT [NAME of TOOL] to refine language, check punctuation, paraphrasing specific phrases [REASON][1].

I also declare that I

☒ am aware of the capabilities and limitations of AI tool(s),

☒ have verified that the content generated by AI systems and adopted by me is factually correct,

☒ am aware that as the author of this thesis I bear full responsibility for the statements and assertions made in it,

☒ have submitted complete and accurate information about my use of AI tools in this work, and

☒ acknowledge that there may be disciplinary consequences if I have not followed NUGSE's guidelines regarding AI appropriate use.

Name: Moldir Muratkhan Signature:

Date: 22.04.24

[1] Examples of REASON: brainstorm ideas / find or select sources on a topic / paraphrase / structure and organize the written text / edit the text for clarity and grammar / ask for tips to improve coherence / cite and reference sources

Appendix B

Recruitment Statement Addressed to Parents (in English)

Dear [Recipient's Name],

Greetings!

I hope this message finds you well. My name is Moldir Muratkhan, and I am currently pursuing my master's degree at Nazarbayev University. I am reaching out to you because I am conducting a research study, as part of my master's thesis, centered on the lived experiences of parents raising children with Down syndrome.

The aim of this study is to research the experiences of parents raising children with Down syndrome, focusing specifically on parental challenges, their role in their children's educational pursuits, and support needs. My interest in this topic stems from the fact that I interact with a family raising a child with Down syndrome, as a special educational needs tutor. Furthermore, I came to realize that this particular demographic of parents remain relatively underrepresented in scholarly discussions within Kazakhstan.

Participants in this study will be invited to take part in either a face-to-face (if located in Astana) or online interview, where they will be asked to share their experiences and perspectives on parenting a child with Down syndrome. Your participation is estimated to require approximately 45 minutes of your time. Please rest assured that there are no known risks associated with your involvement in this research. Any information you provide will be treated with utmost confidentiality and securely stored.

If you decide to participate, additional instructions will be provided in a separate message. Should you have any questions or require clarification on any aspect of this study, please feel free to contact me at your convenience.

Thank you for considering being part of my research project.

Warm regards,

Moldir Muratkhan

[Contact Information]

Recruitment Statement Addressed to Parents (in Russian)

[Имя Получателя],

Здравствуйте!
Меня зовут Муратхан Молдир. В настоящее я являюсь магистрантом университета Назарбаев. Обращаюсь к вам, так как провожу исследование, в рамках моей магистерской диссертации, посвященное жизненным опытам родителей, воспитывающих детей с синдромом Дауна.

Целью этого исследования является изучение опыта родителей, воспитывающих детей с синдромом Дауна, с акцентом на родительских трудностях, их роли в образовательном пути детей и потребностях в поддержке. Мой интерес к этой теме вызван тем, что я взаимодействую с семьей воспитывающей ребенка с синдромом Дауна в качестве тьютора. Так же я наблюдаю, что эта конкретная демографическая группа родителей остается относительно мало представлена в научных дискуссиях в Казахстане.

Участники этого исследования будут приглашены принять участие в личном (если находятся в Астане) или в онлайн-интервью, где им будет предложено поделиться своим опытом и взглядами на воспитание ребенка с синдромом Дауна. Участие займет примерно 45 минут вашего времени. Будьте уверены, что ваше участие в этом исследовании не несет рисков. Вся предоставленная вами информация будет обрабатываться с максимальной конфиденциальностью и сохранится в безопасности.

Если вы решите принять участие, дополнительные инструкции будут предоставлены в отдельном сообщении. Если у вас возникнут вопросы или потребуется уточнение какого-либо аспекта этого исследования, не стесняйтесь связаться со мной в удобное для вас время.

Благодарю вас за рассмотрение возможности стать частью моего исследовательского проекта.

С уважением,
Молдир Муратхан
[Контактная информация]

Recruitment Statement Addressed to Parents (in Kazakh)

[Хат қабылдаушының есімі],

Сәлеметсіз бе!

Менің есімім Мұратхан Мөлдір. Мен қазір Назарбаев университетінің магистрантымын. Сізбен хабарласып отырған себебім, мен Даун синдромы бар балаларды тәрбиелеп отырған ата-аналардың өмірлік тәжірибесі туралы магистрлік диссертациямның бөлігі ретінде зерттеу жүргізіп жатырмын.

Бұл зерттеудің мақсаты ата-аналық қиындықтарға, олардың балалардың білім алу жолындағы рөліне және қолдау қажеттіліктеріне назар аудара отырып, Даун синдромы бар балаларды тәрбиелеп отырған ата-аналардың тәжірибесін зерттеу болып табылады. Бұл тақырыпқа деген қызығушылығым Даун синдромы бар бала тәрбиелеп отырған отбасымен тьютор ретінде араласуыма байланысты. Мен сондай-ақ ата-аналардың бұл нақты демографиялық тобы Қазақстандағы ғылыми талқылауларда салыстырмалы түрде аз қамтылғанын байқаймын.

Бұл зерттеуге қатысушылар жеке (Астанада орналасқан болса) немесе онлайн сұхбатқа қатысуға шақырылады. Даун синдромы бар баланы тәрбиелеуге қатысты тәжірибелері мен көзқарастарымен бөлісу сұралады. Қатысу шамамен 45 минут уақытыңызды алады. Бұл зерттеуге қатысуыңыз үшін ешқандай қауіп жоқ екеніне сенімді болыңыз. Сіз берген барлық ақпарат барынша құпиялылықпен өңделеді және қауіпсіз сақталады.

Қатысуды ұйғарсаңыз, қосымша нұсқаулар бөлек хабарламада беріледі. Егер сізде қандай да бір сұрақтарыңыз болса немесе осы зерттеудің қандай да бір аспектілері бойынша түсініктеме қажет болса, маған ыңғайлы уақытта хабарласудан тартынбаңыз.

Менің зерттеу жобамның бір бөлігі болуды қарастырғаныңыз үшін рахмет!

Құрметпен,

Мөлдір Мұратхан

[Байланыс ақпараты]

Appendix C

Informed Consent Form For Parents (in English)

Study Title: Lived Experiences of Parents Raising Children with Down Syndrome: A Phenomenological Study

Description of the Study:
You are invited to participate in a research aimed at exploring the experiences of parents raising children with Down syndrome, focusing on parental challenges, their role in their children's educational journey, and support needs. Your participation will involve either a face-to-face or online interview during which you will share your insights and experiences regarding parenting a child with Down syndrome.
With your consent, the interview will be recorded for transcription purposes. The recorded material will be securely stored on the researcher's password-protected computer. All data will be retained for a period of three years following the submission of the thesis, after which it will be permanently deleted. Your anonymity and confidentiality will be strictly ensured, and any identifying information will be removed from the data prior to analysis and presentation in the Master's research thesis.

Time Involvement:
Your participation is estimated to require approximately 30-45 minutes.

Risks and Benefits:
Participating in this study entails minimal risks. Should any of the topics discussed during the interview cause discomfort, you have the option to refrain from answering specific questions or to withdraw from the study entirely at any point without penalty. Throughout the interview process, the researcher will ensure your well-being and address any concerns you may have. In the event that you choose to withdraw from the study post-interview, all data pertaining to you will be promptly deleted.
While there are no direct benefits to you for participating, your contribution to this study holds significant potential for societal impact. By sharing your experiences, you can facilitate a better understanding of the challenges and strengths inherent in raising a child with Down syndrome in Kazakhstan, thus aiding educators, policymakers, and society as a whole in fostering inclusive education practices. Additionally, your participation can help raise awareness and combat stigma surrounding Down syndrome, ultimately contributing to the creation of a more inclusive and supportive society for individuals with Down syndrome and their families.

Voluntary Nature of the Study:
Your participation in this study is entirely voluntary. You have the freedom to withdraw from the study or decline to answer specific questions without facing any repercussions.

Contacts and Questions:
If you have any questions, concerns, or complaints regarding this research study, its procedures, risks, or benefits, please feel free to contact the Master's Thesis Supervisor, Janet Helmer, at janet.helmer@nu.edu.kz.

For independent inquiries or concerns about the research process or your rights as a participant, you may contact the NUGSE Research Committee at gse_researchcommittee@nu.edu.kz.

Statement of Consent:
I have carefully reviewed and understood the information provided above. I willingly consent to participate in this study and permit the use of my data for research purposes.

Participant's Name:
[Participant's Name]

Participant's Signature:
[Participant's Signature]

Date:

Informed Consent Form for Parents (in Russian)

ФОРМА ИНФОРМАЦИОННОГО СОГЛАСИЯ ДЛЯ РОДИТЕЛЕЙ

Название Исследования:

Жизненный Опыт Родителей, Воспитывающих Детей с Синдромом Дауна: Феноменологическое Исследование*

Описание Исследования:

Приглашаем вас принять участие в исследовании, направленном на изучение опыта родителей, воспитывающих детей с синдромом Дауна, с акцентом на родительских трудностях, их роли в образовательном пути детей и потребностях в поддержке. Ваше участие предполагает проведение либо личного, либо онлайн интервью, в ходе которого вы поделитесь своими взглядами и опытом в воспитании ребенка с синдромом Дауна.

По вашему согласию, интервью будет записано для транскрибации. Записанный материал будет безопасно храниться на защищенном паролем компьютере исследователя. Все данные будут сохранены на протяжении трех лет после представления диссертации, после чего они будут безвозвратно удалены. Ваша анонимность и конфиденциальность будет строго соблюдены, и любая идентифицирующая информация будет удалена перед анализом и презентацией в магистерской диссертации.

Временные Затраты:

Ваше участие оценивается в примерно 30-45 минут.

Риски и Выгоды:

Участие в данном исследовании сопряжено с минимальными рисками. Если какие-либо обсуждаемые во время интервью темы вызовут дискомфорт, у вас есть возможность воздержаться от ответа на конкретные вопросы или отказаться от участия в исследовании в любой момент без последствий. В течение процесса интервью исследователь будет обеспечивать ваше благополучие и реагировать на любые возникающие вопросы. В случае отказа от участия в исследовании после интервью, все данные, относящиеся к вам, будут немедленно удалены.

Для вас участие в исследовании не предполагает прямой выгоды, однако ваш вклад может иметь значительное влияние на общество. Поделившись вашим опытом, вы можете способствовать лучшему пониманию вызовов связанных с воспитанием ребенка с синдромом Дауна в Казахстане, что поможет педагогам, законодателям и обществу в целом сформировать практики инклюзивного образования. Кроме того, ваше участие может способствовать повышению осведомленности и борьбе с стигматизацией вокруг синдрома Дауна, что в конечном итоге может привести к созданию более инклюзивного и поддерживающего общества для лиц с синдромом Дауна и их семей.

Добровольность Участия в Исследовании:

Ваше участие в данном исследовании является абсолютно добровольным. Вы вправе в любой момент отказаться от участия в исследовании или не отвечать на определенные вопросы без каких-либо последствий.

Контакты и Вопросы:

Если у вас возникнут вопросы, замечания или жалобы относительно данного исследования, его процедур, рисков или выгод, не стесняйтесь обращаться к руководителю магистерской диссертации, Джанет Хелмер, по адресу janet.helmer@nu.edu.kz.

По независимым вопросам или замечаниям о процессе исследования или ваших правах в качестве участника, вы можете связаться с Комитетом по исследованиям NUGSE по адресу gse_researchcommittee@nu.edu.kz.

Заявление о Согласии:

Я внимательно ознакомился(-ась) и понял(-а) предоставленную информацию выше. Я добровольно соглашаюсь участвовать в этом исследовании и разрешаю использование моих данных в исследовательских целях.

Имя Участника:

Подпись Участника:

Дата:

Informed Consent Form for Parents (in Kazakh)

ЗЕРТТЕУ ЖҰМЫСЫ КЕЛІСІМІНІҢ АҚПАРАТТЫҚ ФОРМАСЫ

Зерттеу тақырыбы: Даун синдромы бар балаларды тәрбиелеп отырған ата-аналардың өмірлік тәжірибесі: Феноменологиялық зерттеу

СИПАТТАМА:

Сізді Даун синдромы бар балаларды тәрбиелеп отырған ата-аналардың тәжірибесін және олардың балаларының академиялық жолындағы ата-ананың рөлін анықтауға арналған зерттеуге қатысуға шақырамыз. Сізден жеке сұхбатқа қатысу сұралады, оның барысында сізден Даун синдромы бар баланы тәрбиелеу тәжірибесі туралы сұрақтарға жауап беру сұралады.

Сіздің рұқсатыңызбен сұхбат аудиожазбаға алынады. Содан кейін аудиожазба транскрипцияланады және ол тек зерттеушінің пайдалануында болады. Деректер құпия сөзбен қорғалған зерттеушінің компьютерінде сақталады. Деректер диссертация тапсырылғаннан кейін үш жыл бойы сақталады, содан кейін барлық деректер жойылады. Деректер талданады және ғылыми диссертацияда ұсынылады және кез келген қатысушы сәйкестендіретін ақпарат жойылады.

ӨТКІЗІЛЕТІН УАҚЫТЫ: 30-45 минут

ЗЕРТТЕУ ЖҰМЫСЫНА ҚАТЫСУДЫҢ ҚАУІПТЕРІ МЕН АРТЫҚШЫЛЫҚТАРЫ:

Деректер жинау әрекеттері тек сұхбатты қамтиды. Егер тақырыптар сізді ыңғайсыздандырса немесе жайлылық шегінен асып кетсе, сіз зерттеудегі кез келген сұрақтарға жауап беруден бас тарта аласыз және қаласаңыз, қатысуыңызды кез келген уақытта тоқтата аласыз. Зерттеуші ретінде мен сұхбат барысында сізбен байланыста боламын және кез келген сұрақтарыңызға жауап беруге дайынмын. Ұсынған ақпаратпен танысқаннан кейін зерттеуге қатысуды тоқтатуды шешсеңіз, сізге қатысты барлық деректер жойылады.

Бұл зерттеуге қатысудың сізге ата-ана ретінде өз тәжірибеңізбен бөлісу мүмкіндігінен басқа ешқандай пайдасы жоқ. Дегенмен, Қазақстандағы Даун синдромы бар балалардың ата-аналарының тәжірибесін зерттеу әртүрлі мүдделі тараптарға, соның ішінде ата-аналарға, мұғалімдерге, заң шығарушыларға және жалпы қоғамға пайдалы болады деп күтілуде. Тәжірибеңізбен бөлісе отырып, сіз педагогтарға Даун синдромы бар балалардың артықшылық жақтары мен қажеттіліктерін түсінуге көмектесу арқылы Қазақстанда инклюзивті білім беруді дамытуға көмектесе аласыз. Ақырында, зерттеу Даун синдромы бар балалардың ата-аналары кездесетін қиындықтар туралы хабардарлықты арттыруға және сайып келгенде, Қазақстандағы Даун синдромына қарсы стигмамен күресуге мүмкіндік береді. Бұл Даун синдромы бар адамдар мен олардың отбасыларының құқықтарын қолдайтын неғұрлым инклюзивті қоғамға әкелуі мүмкін.

ЗЕРТТЕУГЕ ҚАТЫСУДЫҢ ЕРІКТІЛІГІ:

Сіздің осы зерттеуге қатысуыңыз толығымен ерікті. Кез келген уақытта ешқандай салдарсыз зерттеуге қатысудан бас тартуға немесе белгілі бір сұрақтарға жауап бермеуге құқығыңыз бар.

БАЙЛАНЫСТАР МЕН СҰРАҚТАР:

Осы зерттеуге қатысты сұрақтарыңыз, пікірлеріңіз немесе шағымдарыңыз болса, магистрлік диссертацияның кеңесшісі Джанет Хелмерге janet.helmer@nu.edu.kz мекенжайы бойынша хабарласыңыз.

Зерттеу процесі немесе қатысушы ретіндегі құқықтарыңыз туралы сұрақтар немесе түсініктемелер үшін gse_researchcommittee@nu.edu.kz мекенжайы бойынша NUGSE зерттеу комитетіне хабарласуға болады.

КЕЛІСІМ ТУРАЛЫ МӘЛІМДЕМЕ:

Мен жоғарыда келтірілген ақпаратты мұқият оқып шықтым және түсіндім. Мен осы зерттеуге қатысуға өз еркіммен келісемін және деректерімді зерттеу мақсатында пайдалануға рұқсат беремін.

Зерттеуге қатысушының аты-жөні:

Күні:

Қолы:

Appendix D

Interview Protocol (in English)

Dear Participant [Name],

Thank you for agreeing to participate in my research! My name is Moldir Muratkhan. I am a master's student at Nazarbayev University, and this research is being conducted as part of my thesis. The aim of the study is to understand experiences of parents raising children with Down syndrome, in particular, the role of parents in the educational path of children, challenges, and the support they need.

The data will be stored for three years after the submission of the dissertation, after which all data will be destroyed. The data will be analyzed and presented in the research thesis, while any identifying information will be deleted.

If any of the questions will cause you discomfort or exceed your comfortable limits, you can refuse to answer, and terminate your participation at any time, if you wish.

Let's start with the first question:

Part 1 - The first reaction

1. Please tell me about your child (age, gender)
2. What was your reaction when you found out that you were going to have a special child? How did people from your close circle react?
3. How did you cope with stress? What helped you? Where did you look for support?
4. What is the most difficult thing about parenting a child with Down syndrome?
5. Is there perhaps a story that has changed your mindset?

Part 2 - The Child

1. In what aspects did your child need or needs support?
2. How do you help the development of your child?
3. What is your typical day like? Do you attend any additional classes (speech therapist, speech pathologist, sports)? If so, how old were you when you started visiting specialists? Is it difficult to find high-quality specialists?

Part 3 - Education

1. Please share your experience regarding the education of your child. What difficulties do you encounter on your way?
2. What kind of educational environment would be ideal for your child?
3. How did you choose the current kindergarten/school?
4. How do you see the role of the state in supporting families raising children with Down syndrome?

Part 4 - The Future

1. What are your expectations now and for the future?
2. In your opinion, what kind of support do parents of children with Down syndrome need?

If a participant feels distressed during the discussion of sensitive topics, offer support and extend the opportunity to: 1) stop the interview; 2) regroup; 3) continue.

Интервью Протокол

Уважаемый участник исследования,

Спасибо что согласились участвовать в моем исследовании! Меня зовут Мұратхан Мөлдір. Я являюсь магистрантом Назарбаев Университета, и это исследование проводится в рамках моей магистерской диссертации. Цель исследования - понять опыт родителей воспитывающих детей с синдромом Дауна, в частности, роль родителей в образовательном пути детей, трудности, и поддержка в которой они нуждаются.

Данные будут сохранены в течение трех лет после представления диссертации, после чего все данные будут уничтожены. Данные будут проанализированы и представлены в исследовательской диссертации, при этом любая идентифицирующая информация будет удалена.

Если какой либо из вопросов причинит вам дискомфорт или превысит ваши комфортные границы, вы можете отказаться от ответа, и в любой момент завершить свое участие, если пожелаете.

Давайте начнем с первого вопроса:

Часть 1 - Первая реакция

1. Расскажите о вашем ребенке (возраст, пол)
2. Какая была ваша реакция, когда узнали, что у вас будет особенный ребенок? Как отреагировали ваши близкие?
3. Как вы справились со стрессом? Что вам помогло? Где вы искали поддержку?
4. Что самое сложное в родительстве ребенка с синдромом Дауна?
5. Возможно есть какая - нибудь история, которая изменила ваше мышление?

Часть 2 - Ребенок

1. В каких аспектах вашему ребенку нужна поддержка?
2. Как вы помогаете вашему ребенку в развитии?
3. Каков ваш обычный день?
4. Не сложно ли находить качественных специалистов?

Часть 3 - Образование

1. Расскажите о вашем опыте касательно образования. Какие сложности встречаются на вашем пути?
2. Какая образовательная среда была бы идеальна для вашего ребенка?
3. Как вы выбирали нынешний детсад/школу?
4. Как вы видите роль государства в поддержке семей воспитывающих детей с синдромом Дауна?

Часть 4 - Будущее

1. Какие у вас ожидания сейчас и на будущее?
2. По вашему мнению в какой поддержке нуждаются родители детей с синдромом Дауна?

Если участник чувствует себя расстроенным во время обсуждения деликатных тем, предложите поддержку и дайте ему возможность: 1) прекратить интервью; 2) перегруппироваться; 3) продолжить

Appendix E

Interview Transcript Excerpt

Interview 8	First Cycle Coding	Second Cycle Coding
1. Please, tell me about your child's age, gender I have a daughter. She is already [1]9 years old, she will be 10 in February. Her name is [name].	[1]Age [Attribute code]	
2. [2]What was your reaction when you found out that you were going to have a special child? How did your loved ones react? The first reaction was, of course, [3]shock and non-acceptance of this fact. [4]I found out in advance during the second ultrasound, which was around the 20th week of pregnancy, somewhere in the middle. The first ultrasound went well, everything was fine. Both screenings, the first and the second, were good, and my well-being and test results were excellent. However, during the second ultrasound, they started examining the heart threshold, the threshold of the brain, and some signs indicating Down syndrome. We were urgently referred for further examination to Astana. Initially, we consulted a geneticist, who then directed us for additional tests. [5]My close relatives, especially my mother, provided strong support during this period. My parents, both mom and dad, and my two older	[2]Initial reaction [Structural code] [3]"shock and non-acceptance"[Emotion code] [4]"Found out in advance" [5]Source of support: Relatives and mother	Finding out about the diagnosis: circumstances

sisters were very supportive. However, my [6]husband had a different stance at that time. [7]On one hand, it was easier to know in advance so that we could prepare. On the other hand, it was more challenging if you decided to keep the child. [7]It was as if there was a choice. [8]For me, there was no choice, but for him, there was. So, we had difficulty reaching an agreement. Eventually, the decision was mine – to keep the child. This period was [9]challenging for us because [10]immediately after the ultrasound, he said that if the diagnosis was confirmed, we should terminate the pregnancy. I said "no," I would not terminate it.	[6]"Husband had a different stance" [7]Knowing in advance to prepare VS. Knowing in advance to make a decision [Versus code] [8]"As if there was a choice" [9]"Challenging period" [10]"He said to terminate the pregnancy"	Finding out about the diagnosis: Conflict with a spouse
During the entire process (from going to Astana, undergoing additional tests, waiting for the results for about 10 days), and when the results arrived, we had to decide whether to terminate the pregnancy immediately or continue. By that time, it was already around 24-25 weeks of pregnancy, as far as I remember. We convened a perinatal council. I wrote a refusal, and [11]doctors pressured me heavily. To be honest, [12]my reaction was more related not to the diagnosis itself but to the difficult relationship with my husband at that moment and the intense pressure from medical personnel. It wasn't like I went there, signed, and left. I signed a refusal, and [13]they continued to insist that I was	[11]"Doctors pressured heavily" [12]Reacting to the difficult relationship w husband and medical personnel VS. reacting to the diagnosis [13]Pressure from medical personnel	Finding out about the diagnosis: Pressure from the medical personnel

foolish, that I didn't understand anything, and that my child would be disabled for life. Besides Down syndrome, there were [14]other life-compatible diagnoses that were uncertain in terms of their impact on the child because there was also [15]Dandy-Walker syndrome. This condition affects the brain, and its manifestation varies greatly among individuals. [16]I started reading about it on the internet. There are cases where a person doesn't know about it and lives until, for example, the age of 50, accidentally undergoes an MRI due to some incident, and discovers the condition. On the other hand, there are cases where the child is born with severe headaches, doesn't walk for a long time, or never walks. Apart from Down syndrome, there were other complications. They told me that she [17]wouldn't move, [18]wouldn't walk, would be a [19]vegetable, wouldn't understand anything. Why would I need that? I already [20]had an older child at that time; my son was almost 2 years old. At that moment, there were a lot of intimidations, such as "she won't move, she won't walk, she'll be a vegetable, [21]she won't understand anything. [22]Why do you need this? [23]Your husband will leave, and no one will pay for this operation." There were many such threats. However, [24]I chose to keep the child. I gave birth,	[14]medical conditions other than DS [15]“Dandy-Walker syndrome” [16]“Reading on the internet” [17]Intimidations: “Wouldn’t move” [18]Intimidations: “Wouldn’t walk” [19]Intimidations: “Would be a vegetable” [20]Other children [21]Intimidations: “She won’t understand anything” [22]Intimidations: Why do you need this?” [23]Intimidations: “Husband will leave” [24]“I chose to keep the child”	

although it was earlier than the due date. I don't know; maybe it was related to stress or just a complication of the pregnancy because I had placental insufficiency of the second degree. In general, it turned out that she asked for it ahead of time. At 35 weeks, I already gave birth to her.		
3. [25]How did you cope with stress, and what helped you? Where did you seek support? Well, first of all, as I mentioned before, my [26]family, especially my close relatives, played a significant role in supporting my decision and assured me of their ongoing support. It turned out that after the child was born, they	[25]Coping with stress and sources of support [26]Source of support: family	Coping strategies

continued to support me, whether it was [27]sitting with the baby, [28]accompanying me to the hospital, or [29]helping with my older child. There was always support. Another significant source of support for me was my [30]faith in God. I attended church, especially during my pregnancy, and it greatly helped me deal with the situation. [31]Otherwise, I felt like I would lose my mind because there was complete uncertainty about how these anomalies would affect the child. Some [32]internal acceptance and resignation, as much as possible at that moment, also helped me. Additionally, the fact that [33]I didn't isolate myself and began seeking information played a crucial role. I researched about children with Down syndrome, how they are supported here in the city, in [34]Petropavlovsk, or in Kazakhstan in general. I wanted to prepare in advance and accidentally shared this with a colleague I used to work with. I told a co-worker that I was expecting such a child, and she mentioned that there was another colleague from a different department who also had a child with Down syndrome. It turned out that this guy was married to a girl who went to the same school as me. Well, not that we knew each other personally, but we were in parallel classes. At that time, there was a [35]"My World" platform (social networking	[27]"Sitting with the baby" [28]"Accompanying to the hospital" [29]"Helping with older child" [30]Source of support: faith [31]Complete uncertainty about the effect of diagnosis > Lose my mind [Causation code] [32]Coping: "internal acceptance and resignation" [33]Coping: "Didn't isolate myself and began seeking information" [34]City [Attribute code] [35]Connecting w other parents online	

site). I remember writing to her with trembling hands, saying, "Hello, Katya, can we talk? I've been told that I'm expecting such a child. I heard that you also have a similar child (he was about three years old at that time)." She replied, "Yes, of course, let's talk." So, we quickly switched to informal communication, started talking on the phone. At first, [36]she spent about two hours telling me various things and providing strong support. Her mother, who was a neuropathologist at the perinatal center, also supported me. When I gave birth to [name], she came to me, brought some gifts, and simply offered support. Katya and I agreed to meet. At that time, there were only about five parents with children who communicated with each other. Even before I gave birth to [name], when I was pregnant, probably around the seventh or sixth month, [37]we met with parents and their children, sat in the children's room. I saw that there was nothing scary, [38]the children had some issues, but overall, they walked around, understood everything, reacted to everything, played. I thought, well, these mothers are quite adequate, and I figured [39]if they could cope, then I can too. I continued to search for some organizations. Unfortunately, there was [40]no specific organization for Down syndrome in Kazakhstan or	[36]Source of support: other parents [37]Meeting other parents during pregnancy [38]Positive observation of other children w DS [39]"If they can cope, then I can too" [40]Lack of DS organizations	Change of the mindset

Petropavlovsk 10 years ago. I found some adjacent organizations that supported all children and people with disabilities in general. I attended such an organization twice, just [41]observed the children attending classes. In general, I got used to the idea that I might have such a child, although there were no children with Down syndrome in that organization at that time. I watched children who attended classes, adapted to the thought, and gradually accepted it.	[41]Coping: Observing other children	

Appendix F

A List of Codes

Case attributes
Age: 10
City: Petropavlovsk

Category: FINDING OUT ABOUT THE DIAGNOSIS

Circumstances

- Discovery of the diagnosis pre-birth
- Conflict with a spouse: Keep the baby or not
- Pressure from the medical personnel

Category: COPING WITH STRESS, SOURCES OF SUPPORT, AND ADAPTATION

Sources of support
Family
Faith
Other parents

Coping strategies
“Internal acceptance and resignation”
“Not isolating oneself and seeking information”
Connecting with other parents online
Meeting other parents during pregnancy
Observations of other children with disabilities

Adaptation
Child survived > feeling rejoiced > complete acceptance after the birth

Category: HOW BIRTH OF A CHILD AFFECTED THE FAMILY

Change of the worldview
The change
    “DS children have great potential”
    “DS children need to be developed”

Factors that led to the change of the mindset
    Birth of a child
    Other parents
    Stories of famous people
    Stories and movies

Category: CHALLENGES OF PARENTING CHILDREN WITH DS

“Constant burnout”
Parenting a typical child VS. Parenting children with disabilities
“Uncertainty, the unknown”
Unclear developmental and educational path

Finding out and pursuing everything on your own

Absence of organizations
"Lack of people to ask"

Societal attitude: non-acceptance
Unequal educational opportunities
Exclusion on the basis of diagnosis

Living in an alert mode all the time
Parental activism as a result of faced challenges

CATEGORY: EARLY CHILD DEVELOPMENT

Areas of deficit that need to be addressed
Ways parents support development of their children
Types of therapies
Types of activities child engages in
Peculiarities in finding good quality specialists

CATEGORY: CHOSEN SCHOOLING OPTION. INCLUSIVE EDUCATION VS. SPECIAL EDUCATION

Inclusive education challenges
Ch: No precedents
Ch: Geographical factor
Ch: Can't keep up with the regular program in a regular school > Special program
Ch: Class sze
Ch: Tutor
Ch: Teacher attention
Ch: "No one to attend her > Quickly expel us"

Studying at the special school
Reason: "Individualized approach is very important"
Reason: Program that corresponds child's level
Reason: Small class size
Reason: "Didn't want to bite off more than I could chew"
Reason: Academic progress being made
Ch: "Double standards"

Category*:* **THE ROLE OF PMPC**

PMPC recommendation vs. personal choice

CATEGORY: THE LEVEL OF SATISFACTION WITH THE STATE SUPPORT

Current support
Ideal situation

Areas for improvement
Financial
Route when such child is born
Medical guidance

People who explain everything
Medical specialists being more informed about the diagnosis
Disability group classification

Category: AREAS OF SUPPORT FOR PARENTS

Psychological support
Physical support

A List of Themes

1) Theme: Discovery of the diagnosis
Sub-themes:
a) Circumstances
b) Initial reaction of family
c) The role of medical personnel

2) Theme: How the birth of a child with Down syndrome affected the family
Sub-theme:
Mindset shift

3) Theme: Coping and adaptation
Sub-themes:
a) Sources of support
b) Coping techniques
c) The mental shift

4) Theme: Educational pathway of children with DS in Kazakhstan
Sub-themes:
a) Areas of deficit that need to be addressed, and ways parents support development of their children
b) Early childhood education
c) Schooling decision
- Inclusive VS. Correctional environment: Reasons and challenges
- The role of PMPC

5) Theme: Challenges and support needs of parents
Sub-themes:
a) Current challenges parents face in rearing a child with DS
- Constant burnout
- Unclear developmental and educational path
- Lack of guidance
- Societal attitude

b) Areas of support
- Psychological
- Financial
- Providing clear route after birth of a child
- Medical guidance
- Supporting siblings

6) Theme: The role of government
Sub-themes:
a. Current state of support
b. Recommendations for improvement
    - Disability group classification
    - Financial support
    - Having more initiative
    - Participation in the lives of parents