Parental Perspectives of Barriers and Facilitators to Accessing Early Intervention Services for Children With Autism Spectrum Disorder

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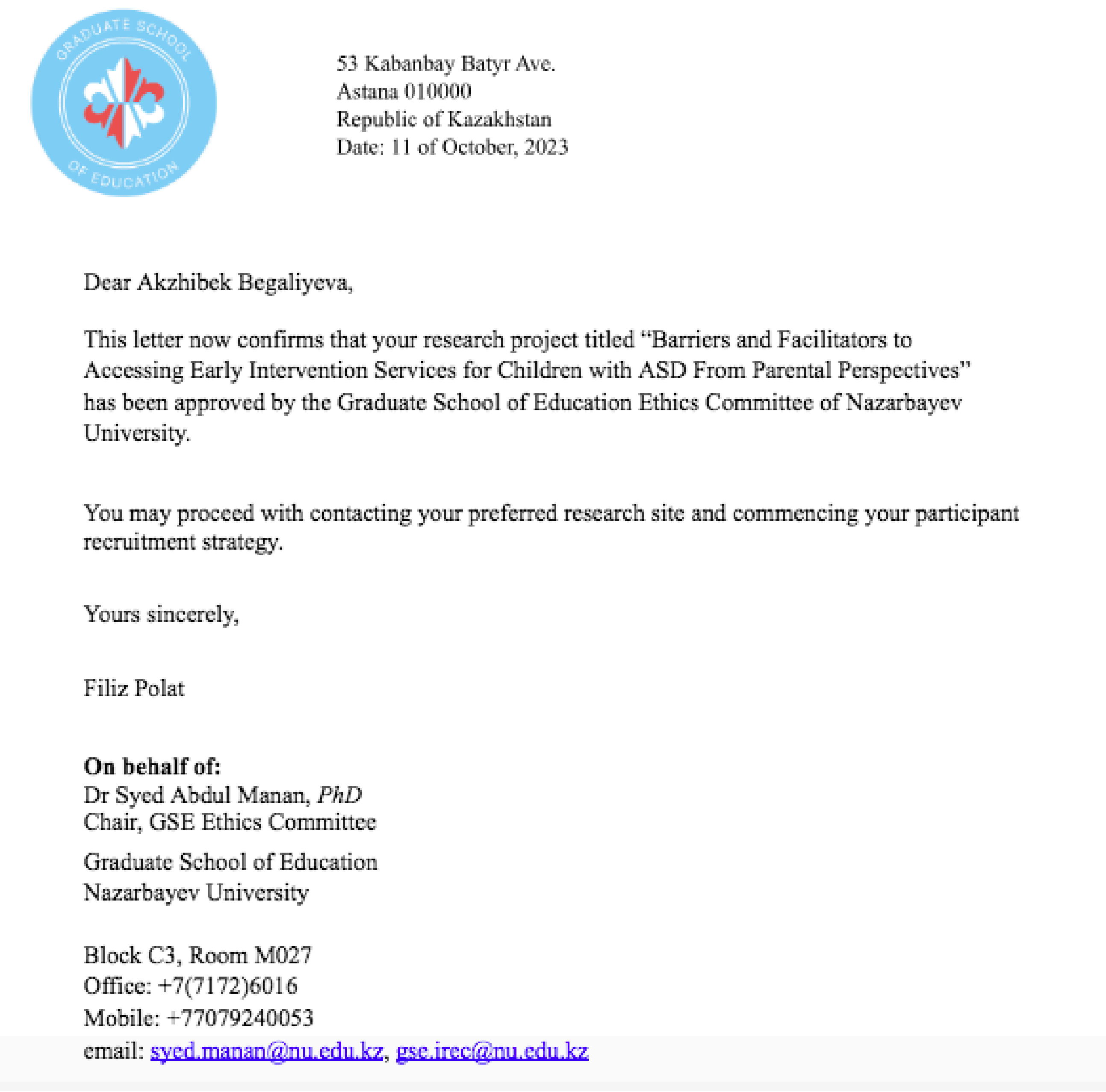

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Date: 11 of October, 2023

Dear Akzhibek Begaliyeva,

This letter now confirms that your research project titled "Barriers and Facilitators to Accessing Early Intervention Services for Children with ASD From Parental Perspectives" has been approved by the Graduate School of Education Ethics Committee of Nazarbayev University.

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

Yours sincerely,

Filiz Polat

On behalf of:
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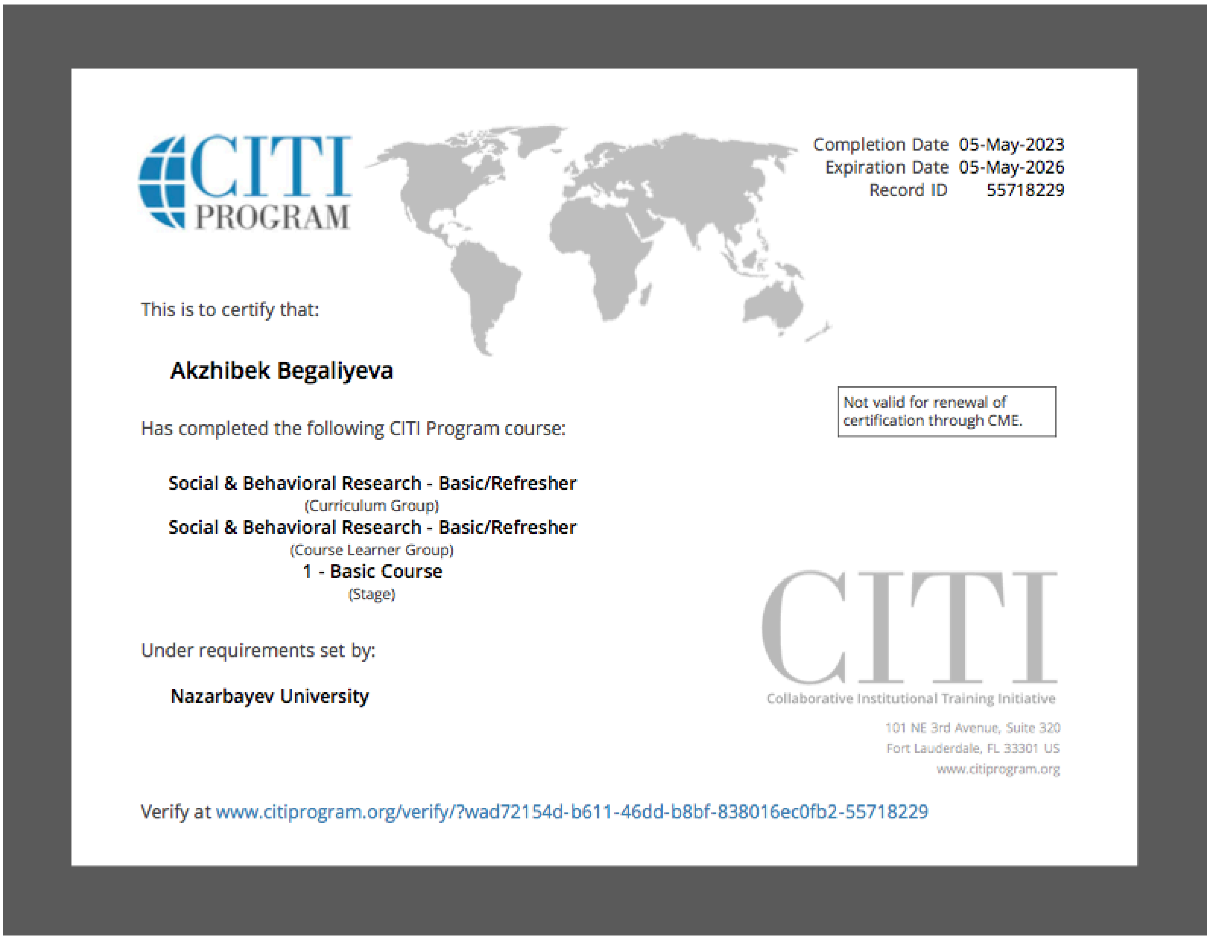

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ABSTRACT

Parental Perspectives of Barriers and Facilitators to Accessing Early Intervention Services for Children With Autism Spectrum Disorder

Accessing early intervention (EI) services is paramount for children with Autism Spectrum Disorder (ASD) to support their developmental needs. However, navigating the process of accessing these services presents numerous challenges for parents. This qualitative study aims to investigate the barriers and facilitators experienced by parents seeking EI services for their children with ASD in Kazakhstan. Data were collected through in-depth interviews with five parents of children with ASD, allowing for a comprehensive exploration of their experiences. Thematic analysis revealed several key findings. Parents described bureaucratic and administrative difficulties, including lengthy wait times, bureaucratic red tape, a lack of clarity regarding resource availability, a lack of qualified specialists, awareness and knowledge, limited resources, logistical difficulties, and cultural and social stigma surrounding autism. Additionally, challenges in obtaining disability certificates and accessing rehabilitation centers were highlighted, reflecting systemic deficiencies in the healthcare and social support systems. Despite these barriers, parents identified personal networks, persistence, and advocacy as key facilitators in accessing EI services. Support from organizations and the government was also acknowledged, albeit with limitations. The findings underscore the need for systemic changes to provide access to EI services for children with ASD in Kazakhstan. The findings have implications for policymakers, healthcare providers, and researchers in improving the accessibility and quality of EI services for children with ASD in Kazakhstan and similar contexts.

Keywords: early intervention services, autism spectrum disorder, barriers, facilitators, Kazakhstan

Аңдатпа

Ата-Аналардың Көзқарасы Бойынша Аутизм Спектрі Бар Балаларға Ерте Араласу Қызметтеріне Қол Жеткізудегі Кедергілер мен Фасилитаторлар

Аутизм спектрінің бұзылуы (АСБ) бар балалар үшін олардың даму қажеттіліктерін қанағаттандыруға ерте араласу қызметтеріне қол жеткізу өте маңызды. Дегенмен, осы қызметтерге қол жеткізу процесі ата-аналар үшін көптеген қиындықтарды тудырады. Бұл сапалы зерттеу Қазақстанда АСБ бар балаларына ерте араласу қызметтерін қолдануда ата-аналардың кездестіретін кедергілері мен фасилитаторларын зерттеуге бағытталған. Деректер бес АСБ бар балалардың ата-анасымен терең сұхбаттасу арқылы жиналды. Бұл олардың тәжірибесін жан-жақты зерттеуге мүмкіндік берді. Тақырыптық талдау бірнеше негізгі нәтижелерді анықтады. Ата-аналар бюрократиялық және әкімшілік қиындықтарды, соның ішінде ұзақ күту уақытын, бюрократиялық әуре-сарсаңды, ресурстардың қолжетімділігіне қатысты анықтықтың жоқтығын, білікті мамандардың жетіспеушілігін, хабардарлық пен білімнің жетіспеушілігін, ресурстардың шектеулілігін, логистикалық қиындықтарды және аутизм айналасындағы мәдени және әлеуметтік стигматизацияны сипаттады. Сонымен қатар, денсаулық сақтау және әлеуметтік қолдау жүйелеріндегі жүйелік кемшіліктерді көрсететін мүгедектік туралы анықтама алу және оңалту орталықтарына жолдама алу мәселелері атап өтілді. Осы кедергілерге қарамастан, ата-аналар жеке байланыс, табандылық және адвокатураны ерте араласу қызметтеріне қол жеткізудегі негізгі фасилитаторлар ретінде анықтады. Ұйымдар мен үкіметтің қолдауы шектеулі болса да, сұхбатта көрсетілді. Нәтижелер Қазақстанда АСБ бар балалардың ерте араласу қызметтеріне қолжетімділігін қамтамасыз ету үшін жүйелі өзгерістер енгізу қажеттілігін көрсетеді. Нәтижелер директивалық органдарға, медициналық қызмет көрсетушілерге және зерттеушілерге Қазақстанда және осыған ұқсас контексттерде АСБ бар балаларға ерте араласу қызметтерінің қолжетімділігі мен сапасын жақсартуға әсер етеді.

Түйін сөздер: ерте араласу қызметтері, аутизм спектрінің бұзылуы, кедергілер, фасилитаторлар, Қазақстан

Аннотация

Барьеры и Фасилитаторы, Препятствующие Доступу к Услугам Раннего Вмешательства для Детей с Расстройсвом Аутистического Спектра с Точки Зрения Родителей

Доступ к услугам раннего вмешательства имеет первостепенное значение для детей с расстройствами аутистического спектра (РАС), чтобы поддержать их потребности в развитии. Однако процесс получения доступа к этим услугам сопряжен с многочисленными трудностями для родителей. Это качественное исследование направлено на изучение барьеров и фасилитаторов, с которыми сталкиваются родители, обращающиеся за помощью в сфере раннего вмешательства для своих детей с РАС в Казахстане. Данные были собраны в ходе углубленных интервью с пятью родителями детей с РАС, что позволило всесторонне изучить их опыт. Тематический анализ позволил сделать несколько ключевых выводов. Родители описывали бюрократические и административные трудности, включая длительное время ожидания, бюрократическую волокиту, отсутствие ясности в отношении доступности ресурсов, нехватку квалифицированных специалистов, осведомленности и знаний, ограниченные ресурсы, логистические трудности и культурную и социальную стигматизацию, связанную с аутизмом. Кроме того, были отмечены проблемы с получением справок об инвалидности и доступом в реабилитационные центры, что отражает системные недостатки в системах здравоохранения и социальной поддержки. Несмотря на эти препятствия, родители определили личные связи, настойчивость и адвокацию в качестве ключевых факторов, способствующих доступу к услугам раннего вмешательсва. Также была отмечена поддержка со стороны организаций и правительства, хотя и с некоторыми ограничениями. Полученные данные подчеркивают необходимость системных изменений для обеспечения доступа к услугам раннего вмешательства для детей с РАС в Казахстане. Полученные данные имеют значение для политиков, медицинских работников и исследователей в плане повышения доступности и качества услуг раннего вмешательства для детей с РАС в Казахстане и аналогичных условиях.

Ключевые слова: услуги раннего вмешательства, расстройство аутистического спектра, барьеры, фасилитаторы, Казахстан

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Chapter 1: Introduction

1.1 Background of the Study

The latest version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) categorizes Autism Spectrum Disorder (ASD) as a complex neurodevelopmental disorder marked by communication, social interaction, and behavioral difficulties (American Psychiatric Association (APA, 2013). ASD is a heterogeneous condition that covers a wide array of symptoms, particularly in less severe cases, and the degree of core impairments can vary significantly among individuals (Lord et al., 2018; Stanković et al., 2012). The importance of early intervention (EI) for ASD is widely acknowledged, as it can significantly improve the developmental trajectory and quality of life for affected children (Dawson & Burner, 2011; Maglione et al., 2012; Warren et al., 2011). These interventions differ in their underlying principles, intensity, duration, settings, and professionals involved, contributing significantly to the overall costs associated with autism (Maglione et al., 2012). The significance of EI is underscored in various international guidelines and recommendations, such as those from the World Health Organization (WHO) and the American Academy of Pediatrics (AAP).

A rising trend in ASD diagnoses has been noted worldwide, emphasizing the need to examine the various aspects of ASD and the families who serve as the primary source of support for these individuals (Zeidan et al., 2022). The WHO estimates that approximately one in 100 children have ASD (WHO, 2021). In Kazakhstan, for instance, the number of officially diagnosed ASD cases among children has doubled in recent years, increasing from 6771 in 2020 to about 12087 in 2022 (Yazykova, 2023). However, research is scarce on parents' experiences accessing early intervention services for their children with ASD in Kazakhstan. Gaining insights into the challenges and facilitators from the parents' perspective is vital for developing targeted policies, programs, and support systems that align with the local context.

Parental perspectives play a critical role in shaping the trajectory of early intervention for children with ASD. Their experiences navigating the healthcare system and interacting with healthcare professionals significantly influence their ability to access timely and appropriate interventions for their children.

This research seeks to fill a gap in the existing literature by investigating the barriers and facilitators parents encounter when accessing early intervention services for children with ASD in Kazakhstan. By exploring parental perspectives, the study aims to provide a comprehensive understanding of the challenges and opportunities faced by families in the country. The insights from this research can inform policymakers, healthcare professionals, and advocacy groups in devising strategies to enhance the accessibility and effectiveness of early intervention services for children with ASD in Kazakhstan.

1.2 Statement of the Problem

Studies indicate that timely identification and early interventions for autism are associated with significant long-term benefits in symptom management and developing future skills (Charman, 1999; Helt et al., 2008; Reichow & Wolery, 2008). The optimal timing for early intervention is neurologically significant for children with diverse disabilities. Similar groups of children with autism, matched in severity, were assessed at 30 months and again at six years of age. The children who received early intervention showed significantly lower levels of restrictive and repetitive behaviors and significantly higher adaptive behavior scores compared to those in the community-intervention-as-usual group (Estes et al., 2015). Interventions that occur during the early years, from as young as two or three years old, are considered effective (Zwaigenbaum et al., 2015). During the initial three years of life, neural circuits crucial for learning, behavior, and overall health exhibit the highest level of flexibility or "plasticity." As time progresses, these neural circuits become increasingly resistant to change, making early intervention during this critical period particularly impactful. Due to this malleability, treatments during this time are more likely to produce lasting effects (Zwaigenbaum et al., 2015).

Despite the recognized significance of early interventions, numerous challenges persist in ensuring that children with ASD receive timely and appropriate support. Parental perspectives play a crucial role in understanding the barriers that impede access to these services and the factors that facilitate a smoother process.

In Kazakhstan, where the prevalence of ASD is growing (Yazykova, 2023), early interventions have gained prominence in the healthcare and education systems. The Republic's commitment to inclusive policies and its recognition of children's rights to quality education and support is evident in its legislative framework, such as the "Law on Education" (Ministry of Education and Science, 2007) and the State Program for Education development (Ministry of Education and Science, 2010). However, the extent to which these policies translate into practical and accessible services for children with ASD remains a significant concern.

This research aims to address this critical gap in knowledge by investigating the barriers and facilitators encountered by parents of children with ASD when seeking early intervention services in Kazakhstan. By exploring parental perspectives, this study seeks to identify the challenges faced by families in accessing services and the resources or strategies that enhance their access. Such insights are essential for developing targeted interventions, policy recommendations, and support systems that align with the needs and experiences of parents and their children with ASD.

The study's findings may contribute to developing culturally sensitive interventions, awareness campaigns, and policy recommendations to reduce barriers and maximize facilitators for accessing early intervention services. Ultimately, the findings of this study have the potential to inform the development of more effective and accessible pathways for parents to access the vital early intervention services their children need for optimal development and improved quality of life.

1.3 Purpose of the Study

The purpose of the study is to examine the barriers and facilitators parents of children with ASD encounter when attempting to access early intervention services in Kazakhstan. This study aims to contribute to the broader understanding of the challenges and opportunities within the Kazakhstani context. The findings of this research can inform policymakers, healthcare providers, educators, and advocacy groups about the specific needs and experiences of parents and children with ASD. Through a comprehensive exploration of parental perspectives, the study ultimately strives to inform the development of targeted interventions, policy recommendations, and support systems that align with the realities families face in Kazakhstan.

1.4 Research Questions

To examine the barriers and facilitators parents of children with ASD encounter when attempting to access early intervention services in Kazakhstan, the following two research questions were posed in this research:

1. What primary barriers do parents of children with ASD in Kazakhstan encounter when seeking early intervention services?
2. What are the key facilitators that enable parents of children with ASD in Kazakhstan to access early intervention services effectively?

1.5 Definition of the Central Phenomena

This section aims to define and contextualize the central phenomena of the study. It lays the foundation for a comprehensive understanding of the research focus by clarifying the terminology and concepts related to this study.

1. *Early Intervention (EI)* is a comprehensive term covering various strategies to foster optimal child development. These strategies include targeted interventions designed to enhance both child and family outcomes and regular engagement with support services, such as education, health, and social care, during the early years (Akhmetzyanova, 2016).

2. *Early Intervention Services:* Early intervention services refer to a range of coordinated and specialized interventions designed to address the developmental needs of children with ASD at a young age. These services encompass therapeutic, educational, and supportive interventions that enhance children's social, communication, cognitive, and adaptive skills during their critical early developmental years (Dawson et al., 2010).

3. *Autism Spectrum Disorder (ASD)*: ASD is a complex neurodevelopmental disorder characterized by difficulties in social communication and interaction, along with restricted and repetitive patterns of behavior, interests, or activities (APA, 2013). ASD is recognized as a spectrum disorder, implying significant variability in its manifestations and severity levels across individuals (Lai et al., 2014).

4. *Barriers:* Barriers refer to obstacles, challenges, or impediments that hinder or restrict parents' ability to access early intervention services for their children with ASD. These obstacles can encompass financial limitations, geographical distance to service providers, lack of awareness, social stigma, and logistical complexities (Magaña et al., 2012).

5. *Facilitators:* Facilitators denote factors or conditions that support and enhance parents' ability to access early intervention services for their children with ASD. These may

include support networks, informed healthcare professionals, effective government policies, and educational programs that promote awareness and inclusion (Martínez-Rico et al., 2022).

1.6 Significance of the Study

This section outlines the significance of the study, emphasizing its potential to contribute to both academic knowledge and practical improvements in the field. By examining barriers and facilitators, this research aims to clear up a critical area with implications for policy, practice, and the well-being of children and families.

This study addresses a notable gap in the current literature by focusing on parents' experiences seeking early intervention services for children with ASD in Kazakhstan. While research on ASD and early interventions is abundant, a limited understanding exists regarding parents' specific challenges in the Kazakhstani context. By exploring these challenges comprehensively, the study contributes to a deeper understanding of the nuanced barriers that impact parental decisions and actions.

The practical implications of this study extend to various stakeholders involved in the well-being of children with ASD in Kazakhstan. By identifying barriers, policymakers and service providers can gain insights into areas requiring attention, such as addressing financial constraints, improving awareness campaigns, and enhancing the overall availability of services. Understanding parental perspectives on facilitators, such as support networks and effective communication with healthcare professionals, can inform strategies to optimize service delivery.

Moreover, the findings of this research hold the potential for informing the development of targeted interventions and resources for parents. By acknowledging parents' challenges, educators and healthcare professionals can design training programs and support systems that are responsive to the diverse needs and experiences of families navigating the early intervention landscape.

1.7 Summary

The introduction chapter sets the groundwork for the research study by framing the research problem, establishing the significance of the study, and outlining the potential contributions it aims to make. It provides a clear overview of the context, challenges, and central research question, guiding the reader into the subsequent chapters that will delve deeper into the complexities of accessing early intervention services for children with ASD in Kazakhstan from the perspectives of parents.

1.8 Outline of the Thesis

The first chapter introduces the main subject under research, outlines the purpose of the study, frames the research questions, clarifies the relevant terminology, and highlights the importance of the research topic. The following chapter describes Bronfenbrenner's Ecological Theory and the Health Belief Model, which serve as the theoretical framework for the study. It also includes a comprehensive review of the existing literature. Chapter three explains the chosen research methodology, justifies the selected research design, describes the research approach, and discusses the ethical considerations considered during the study. The next chapter provides the primary findings of the research, derived from the analysis of interview data. Chapter five offers an in-depth discussion of the research findings, supported by relevant literature that either corroborates or contradicts the study's outcomes. The last chapter concludes the study by providing recommendations, summarizing the key findings, and suggesting potential areas for future research by other scholars.

Chapter 2: Literature Review

2.1 Introduction

Early intervention services are crucial for children with developmental disabilities (DD), including ASD, as they can significantly enhance their cognitive, social, and communication skills and reduce the severity of ASD symptoms (Warren et al., 2011). However, accessing EI services can be challenging for many families due to various barriers, such as lack of awareness, long waiting lists, high costs, and stigma (Sapiets et al., 2020). Understanding the factors influencing parents' decisions to access EI services for their children with ASD is essential for developing effective and equitable policies and practices to improve the quality and availability of EI services. This chapter reviews the literature on the barriers and facilitators to accessing EI services for children with ASD, using Bronfenbrenner's Ecology Theory and Health Belief Model as frameworks.

2.2 Barriers to Accessing EI services

Despite Kazakhstan's significant progress in early childhood development and education services, which have improved child health, nutrition, development, and early learning outcomes (UNICEF, 2022), seemingly, no research examines barriers to accessing EI services for children with ASD from parental perspectives. This is concerning, given that parents of children with ASD in many countries often encounter obstacles such as fragmented service systems, extended waiting periods, financial constraints, limited knowledge, societal prejudices, and a lack of diversity in available support services (Stahmer et al., 2019). Therefore, it is essential to investigate whether these barriers also exist in Kazakhstan to ensure that children with ASD receive the necessary EI services to support their development.

The scoping review on barriers to the early detection of ASD and its timely intervention by Bivarchi et al. (2021) identified five main barriers that hinder the early diagnosis and intervention of children with ASD, including lack of knowledge, social stigma, dismissal of parents' initial concerns by healthcare providers, barriers to ASD screening, and challenges in accessing ASD services. These barriers contribute to delayed diagnoses, leading to missed opportunities for early intervention and improved long-term outcomes for children with ASD. While parents of children with various DD may encounter similar challenges, parents of children with ASD tend to report higher levels of parenting stress and lower satisfaction with the support services they receive compared to others (Amireh, 2018; Bitterman et al., 2008; Hayes & Watson, 2013; Picardi et al., 2018; as cited in Wallace-Watkin et al., 2023). This highlights the need for targeted support and interventions to address the challenges faced by parents of children with ASD. In this regard, parents have identified several factors that help them access and engage in autism support services, including readily available information and education about autism and support services, trusting relationships with providers, support in navigating service systems, peer support, and clear communication about the cost of support services (Birkin et al., 2008; Pearson & Meadan, 2018; Stahmer et al., 2019; Wilson et al., 2021; as cited in Wallace-Watkin et al., 2023).

2.3 Bronfenbrenner's Ecology Theory

The person and context are two fundamental concepts in Urie Bronfenbrenner's theory, highlighting the significance of both the individual and their environment in shaping developmental outcomes. In the context of early intervention services, which involve multiple systems such as the family, healthcare, and service provision systems, a comprehensive framework is essential to account for this complexity. By considering the interplay between the individual and their environment, as well as the various systems involved, we can better understand the barriers and facilitators to accessing EI services for children with ASD and other DD. This holistic approach can inform the development of effective policies and practices aimed at improving the quality and availability of EI services, ultimately enhancing the outcomes for children and their families.

Bronfenbrenner's Ecological Theory, also known as bioecological theory, is a framework that explains human development as a product of the interaction between individuals and their environment (Bronfenbrenner, 1979). The theory is divided into several systems, including the microsystem, mesosystem, exosystem, macrosystem, and chronosystem. The microsystem refers to the immediate environment where the individual interacts directly, such as family and school. The microsystem, as defined by Bronfenbrenner, is the most vital level of context as it is the immediate environment where critical processes occur, allowing children to interact with others and engage in significant activities. Children are part of multiple microsystems, and Bronfenbrenner's term mesosystem refers to the connections between these microsystems. For instance, a child's home is a microsystem, but their grandparents' house can also be considered a different microsystem. The home environment is typically the most influential microsystem, as its organization can impact the child's transition to a new childcare center or school. Mesosystem analysis is crucial for understanding why a child from one type of home might struggle to adapt to a different classroom or center, and vice versa. However, Bronfenbrenner did not advocate for a perfect fit between different microsystems, as children can benefit from learning that different environments require different behaviors and can lead to the acquisition of new roles and ways of interacting (Bronfenbrenner, 1979). The exosystem represents a context where the focal individuals are not directly present but exert significant indirect influence. For example, a crucial exosystem for a child could be their parent's work environment or the circumstances in a teacher's home. The parents' educational experiences and current work environments, although not directly involving their children, can indirectly shape how they interact with their children at home. Likewise, suppose a teacher is experiencing personal challenges at home or lacks adequate rest due to a sick or restless child. In that case, this can impact the interactions and processes the teacher engages in with her students at school. While home-school dynamics are part of the mesosystem when focusing on the teacher, these indirect effects from the teacher's home life on proximal processes involving the children in her class are considered exosystem influences. The macrosystem, which, according to Bronfenbrenner, is analogous to culture. It encompasses an entire society or specific racial, ethnic, regional, or socioeconomic groups within a society. The macrosystem includes individuals who share common values, beliefs, customs, resources, and a sense of collective identity. For instance, individuals residing in Japan can be distinguished from those living in Kazakhstan, forming separate macrosystems. Within Kazakhstan, if distinct racial/ethnic, socioeconomic, or regional groups can be differentiated based on their values, beliefs, practices, and sense of identity, they are also considered separate macrosystems. Consequently, members of these unique macrosystems within Kazakhstan possess diverse child-rearing values, beliefs, and practices. The chronosystem is a dynamic and evolving aspect of human development that encloses the temporal dimension of an individual's life. It represents the cumulative impact of various environmental events, transitions, and historical contexts that occur over time, shaping the individual's developmental trajectory. The chronosystem interacts with and influences all other systems, providing a historical context for these systems. Examples of chronosystem factors include normative life transitions, such as graduating from school or marriage, and non-normative life transitions, such as an accident or a parental divorce. These events can profoundly impact an individual's psycho-social development, influencing their values, beliefs, practices, and sense of identity.

In the context of EI services for children with ASD, Bronfenbrenner's Ecological Theory can be applied to understand the various factors that influence access to these services. For instance, the microsystem involves the child, family, healthcare providers, and different specialists, directly impacting intervention access. The mesosystem highlights the importance of collaboration between these systems for effective service delivery and its quality. The exosystem considers external factors like work environments affecting parents' ability to access services. The macrosystem reflects cultural beliefs and societal attitudes towards ASD that may influence service utilization. Lastly, the chronosystem accounts for changes over time, such as evolving policies impacting service provision for children with ASD. Studies have applied Bronfenbrenner's Ecological Theory in international and intercultural education research, demonstrating its relevance in understanding the complex factors influencing access to early intervention services for children with ASD (Tong & An, 2023).

2.4 Health Belief Model

The HBM is a widely used model in health psychology that explains how individuals' perceptions of health risks and benefits affect their health-related behaviors (Rosenstock, 1974). The HBM was initially developed in the 1950s by social psychologists Hochbaum, Rosenstock, and Kegels to understand why people did not participate in disease prevention programs (Champion & Skinner, 2008). Since then, the HBM has been applied to various health issues, including chronic diseases, mental health, and health promotion (Champion & Skinner, 2008).

According to the HBM, four main components shape an individual's health-related behavior: perceived susceptibility, perceived severity, perceived benefits, and perceived barriers (Janz & Becker, 1984). These components are influenced by various factors, such as demographic characteristics, knowledge, cues to action, and self-efficacy (Champion & Skinner, 2008). In the context of EI services for children with ASD, these components can be defined as follows: (1) Perceived susceptibility: Parents' perception of their child's risk of having or developing ASD or other DD, (2) Perceived severity: Parents' perception of the impact of ASD or other DD on their child's development and well-being, (3) Perceived benefits: Parents' perception of the effectiveness and outcomes of EI services for their child with ASD or other DD, (4) Perceived barriers: Parents' perception of the obstacles or challenges that prevent or discourage them from accessing EI services for their child with ASD or other DD.

2.4.1 Perceived Susceptibility

Perceived susceptibility refers to parents' perception of their child's risk of having or developing ASD or other DD. This component is closely related to screening and diagnosis, which are essential steps for accessing EI services. However, many parents face challenges in recognizing the early signs of ASD or other DD in their child, obtaining a timely and accurate diagnosis, and accepting the diagnosis (Sapiets et al., 2020).

One of the challenges parents face is the lack of awareness or knowledge about the early signs of ASD or other DD in their child. Some parents may not notice any developmental concerns in their children or may attribute them to normal variation, temperament, or environmental factors (Braiden et al., 2010; Sapiets et al., 2020). Some parents may also have misconceptions or stereotypes about ASD or other DD, such as believing that they only affect boys, that vaccines cause them, or that they are associated with specific behaviors (e.g., lack of eye contact) (Braiden et al., 2010; Sapiets et al., 2020). These factors can delay parents' recognition of their child's developmental needs and their seeking of professional help.

Another challenge parents face is the difficulty of obtaining a timely and accurate diagnosis of ASD or other DD for their child. Many parents report long waiting lists, multiple assessments, inconsistent feedback, and a lack of coordination among professionals and agencies involved in the diagnostic process (Braiden et al., 2010; Sapiets et al., 2020). Some parents also report receiving a provisional or unclear diagnosis, such as "developmental delay" or "social communication disorder," which can create confusion and uncertainty about their child’s condition and eligibility for EI services (Braiden et al., 2016; Sapiets et al., 2020). Moreover, some parents report experiencing stigma, discrimination, or cultural barriers when seeking a diagnosis for their child, especially from minority or immigrant backgrounds (Braiden et al., 2010; Sapiets et al., 2020).

A further challenge that parents face is the difficulty of accepting the diagnosis of ASD or other DD for their child. Many parents report going through emotional reactions, such as shock, denial, anger, guilt, grief, or depression, after receiving the diagnosis for their child (Braiden et al., 2010; Sapiets et al., 2020). Some parents may also experience ambivalence, resistance, or rejection of the diagnosis, especially if they perceive it as a label, a stigma, or a threat to their child’s identity or potential (Braiden et al., 2010; Sapiets et al., 2020). These factors can affect parents’ readiness and willingness to access EI services for their children.

The literature on perceived susceptibility highlights the importance of raising awareness and providing education to parents about the early signs of ASD or other DD in their children, as well as the benefits of early detection and intervention. The literature also underscores the need for improving the screening and diagnostic processes for children with ASD or other DD by reducing waiting times, increasing coordination and communication among professionals and agencies, providing clear and consistent feedback, and addressing stigma and cultural barriers. Furthermore, the literature emphasizes the need to support parents emotionally and psychologically after receiving the diagnosis for their children by offering counseling, peer support groups, information resources, and advocacy services.

2.4.2 Perceived Severity

Perceived severity, one of the components of the HBM, refers to how individuals perceive the seriousness or impact of a health condition or problem. For parents of children with ASD, perceived severity may involve how they view their children's symptoms, behaviors, and outcomes.

ASD is a developmental disorder that affects communication, social interaction, and behavior. The term "spectrum" indicates a wide range of symptoms and severity among individuals with ASD (APA, 2013). The DSM-5 categorizes ASD into three levels based on the level of support needed: level 1 (requiring support), level 2 (requiring substantial support), and level 3 (requiring very substantial support) (APA, 2013; Weitlauf et al., 2013).

However, measuring autism severity is not straightforward, as there are different approaches and tools to assess the various aspects of ASD, such as cognitive abilities, adaptive skills, social functioning, repetitive behaviors, and sensory issues (Mehling & Tassé, 2016; Weitlauf et al., 2013). Moreover, autism severity may change over time and across contexts depending on the individual's development and environment (Mehling & Tassé, 2016; Weitlauf et al., 2013).

Therefore, parents may have different perceptions of the severity of their children's ASD depending on their knowledge, expectations, experiences, and resources. Perceived severity may influence how parents cope with the challenges and stressors associated with ASD, as well as how they seek and access EI services for their children.

2.4.3 Perceived Benefits

According to Sapiets et al. (2020), EI refers to "a range of services and supports provided to children with DD and their families from birth to school entry." These services may include assessment, diagnosis, therapy, education, family support, and care coordination. EI has been shown to positively affect children's cognitive, language, social, emotional, and adaptive skills, as well as parental stress, coping, and satisfaction (Sapiets et al., 2020).

However, accessing EI services is not always easy or straightforward for families of children with ASD. Sapiets et al. (2020) conducted a narrative review of the literature on the factors influencing access to EI for families of children with DD, including ASD. They identified three phases of the access process: recognition of need, identification or diagnosis, and EI provision or receipt. They also found several factors affecting access to EI at each phase, such as family characteristics, service availability and quality, family service interactions, and contextual influences. Some facilitators included early detection, referral, advocacy, information, support networks, collaboration, flexibility, and cultural competence (Sapiets et al., 2020).

2.4.4 Perceived Barriers

Some commonly perceived barriers to accessing EI for families of children with ASD are related to the availability, affordability, accessibility, and acceptability of the services. For example, some families may face long waiting lists, high costs, limited transportation options, or lack of insurance coverage for EI services (Sapiets et al., 2020). Some families may also encounter negative attitudes, stigma, discrimination, or cultural mismatch from service providers or other stakeholders (Sapiets et al., 2020; Zaidman-Zait et al., 2016). Additionally, some families may have low awareness, knowledge, or trust of EI services or experience denial, guilt, or fear about their child's diagnosis or prognosis (Sapiets et al., 2020).

Barriers to accessing EI can harm their child's development and well-being, as well as their own mental health and quality of life. Therefore, it is crucial to identify and address these barriers through various strategies, such as increasing public awareness and education, improving service coordination and delivery, enhancing family support and empowerment, and fostering cultural competence and diversity among service providers (Sapiets et al., 2020; Zaidman-Zait et al., 2016).

2.5. Summary

The chapter discussed the research on the barriers and facilitators to accessing EI services for children with ASD. It included the significance of parental perceptions of susceptibility, severity, benefits, and barriers to accessing EI services, the application of Bronfenbrenner's Ecological Theory to understand the complex systems involved, and the role of the Health Belief Model in shaping health-related behaviors. The next chapter details the methodology that was used in the study.

Chapter 3: Methodology

3.1 Research Design

To achieve the research objectives effectively, a qualitative research design was selected. Qualitative research is particularly suitable for exploring complex and nuanced phenomena, providing valuable insights into lived experiences and perspectives of individuals involved in the educational context (Creswell, 2014).

The decision to adopt a qualitative research approach stems from the acknowledgment that the experiences and perspectives of parents navigating the complexities of early intervention services for children with ASD cannot be adequately captured through quantitative means alone. Qualitative research offers the depth and flexibility necessary to explore the multifaceted, context-dependent, and often deeply personal aspects of the barriers and facilitators parents face in Kazakhstan.

The data collection process was conducted through semi-structured interviews with parents. According to Creswell (2014), a face-to-face interview is one of the widely used qualitative research designs, wherein the researcher engages with a single study participant at a time, asking questions and recording their responses. Kvale (1994, as cited in Cohen, 2018) defines interviews as a valuable exchange of perspectives on a mutually interesting topic, highlighting the significance of human interaction in generating knowledge and emphasizing the contextual nature of research data. Interviews, as discussed by Hochschild (2009, as cited in Cohen, 2018), offer unique advantages over surveys, enabling in-depth exploration of topics and understanding how individuals conceptualize their ideas. In line with Creswell's (2014) perspective, face-to-face interviews become particularly essential when participants cannot be observed physically, allowing them to share comprehensive personal information. In the context of this research, face-to-face interviews were instrumental in illuminating the research questions and unveiling significant research findings.

3.2 Research Sample

The target population for this study includes five parents of children with ASD in Kazakhstan. According to WHO (2021), the prevalence of ASD has been rising globally, including in Kazakhstan. This population is paramount as they navigate the challenges and opportunities of accessing early intervention services for their children.

Non-probability sampling methods are used to select participants who possess valuable insights into the research questions, specifically purposive sampling. As recommended by Patton (2015), purposive sampling allows for the deliberate selection of participants with relevant experiences and knowledge related to the research topic. In this case, parents with direct experience with early intervention services for their children with ASD are chosen purposefully to provide rich and in-depth insights. Additionally, snowball sampling is employed, as Creswell & Creswell (2017) recommended, allowing participants to refer us to other parents who may have valuable insights.

Each participant shares the commonality of being a parent of a child with ASD, ensuring their direct connection to early intervention services and the relevant experiences that inform the study.

3.3 Data Collection Procedures

For this study, semi-structured interviews with participants were chosen as the primary data collection method due to their flexibility and capacity to explore participant perspectives in-depth (Smith, 2018).

To ensure the accuracy of data capture, all interviews were audio-recorded with the participant's consent. The audio recording serves two critical purposes: it allows for the precise transcription of participant responses and ensures that no nuances or details are missed during the interview process. Audio recording is an industry-standard practice in qualitative research (Rubin & Rubin, 2011).

Interviews took place in a setting most convenient and comfortable for the participants. All five interviews were conducted through virtual platforms via video conferencing tools. The choice of setting aimed to accommodate participants' preferences and ensure they feel at ease during the interview, thereby promoting open and honest discussions.

A pilot interview was conducted with one participant to test the clarity and effectiveness of the interview questions. Feedback from the pilot study participant was carefully considered to refine and adjust the questions as needed. The pilot interview was a valuable step to ensure that the questions and prompts encourage participants to share their experiences comprehensively.

3.4 Data Analysis

Data analysis is promptly conducted right after data collection to ensure its quality. Creswell (2014) outlines a six-step process for qualitative data analysis, which includes preparing and organizing the data, coding the data, using the codes to generate a broader understanding of the data, presenting the findings through narratives and visuals, interpreting the meaning of the results, and employing strategies to validate the accuracy of the findings. On the other hand, Cohen (2018) argues that there is no singular or definitive approach to analyse and present qualitative data. The method chosen for analysis should be tailored to the specific research purpose and objectives.

This study addressed two research questions, which were answered through interviews. The interview responses were subsequently coded according to the specific research questions.

3.5 Ethical Issues

The research design for this study incorporates face-to-face interviews, which necessitates the careful consideration of ethical principles such as identifiability, anonymity, confidentiality, and privacy of the participants. Qualitative data can often be sensitive or personal, so the researcher must ensure that ethical criteria, including confidentiality, are upheld during any transcription process (Cohen, 2018).

To address ethical concerns, strict adherence to all ethical guidelines was observed. The first step involved submitting an ethics review application to the Nazarbayev University Graduate School of Education Ethics Committee. After obtaining approval, interviews were scheduled. Before the interviews, participants were provided with informed consent forms to sign. Informed consent is based on the principle of autonomy, emphasizing the participant's right to freedom and self-determination (Cohen, 2018). Additionally, the participants were informed that their participation is voluntary, ensuring that all four elements of informed consent, including full information, comprehension, and competence, were met (Cohen, 2018).

The interviews were conducted via the Zoom platform, ensuring that participants were in a comfortable environment to encourage candid responses without distractions. Once the data was collected, it was carefully coded and securely stored on a personal computer with password protection to maintain its anonymity and confidentiality.

3.6 Summary

This chapter presents an overview of the research methodology used in the study. A qualitative design guides this study to understand participants' experiences. Semi-structured interviews were conducted via Zoom with five parents of children diagnosed with ASD. Data was analyzed thematically and all ethical guidelines were followed during the interviews by outlining the study's ethical considerations. The upcoming section presents the findings as personal accounts given by the participants.

Chapter 4: Findings

4.1 Introduction

The primary aim of this study is to find out the barriers and facilitators to accessing early intervention services from the perspective of parents of children with ASD. Through in-depth interviews, parents discussed their viewpoints, experiences, and difficulties acquiring the essential services.

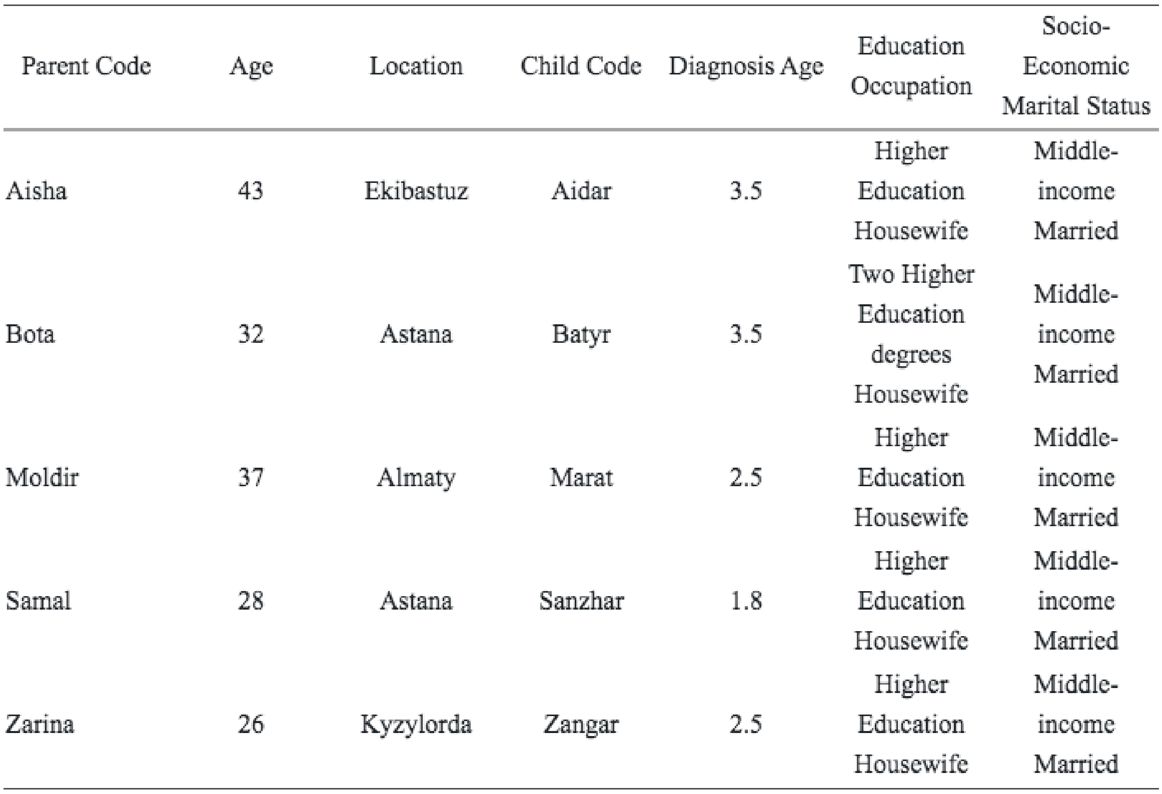
This chapter systematically organizes data under two overarching themes, each comprising sub-themes that provide a nuanced perspective of parents. The research questions guiding this study were: (1) What primary barriers do parents of children with ASD in Kazakhstan encounter when seeking early intervention services? (2) What are the key facilitators that enable parents of children with ASD in Kazakhstan to access early intervention services effectively?

4.2 Research Sample

The study involved five participants who were selected using the snowballing technique. The table below displays the background data of participants along with the assigned pseudonyms.

Table 1

Research Sample



Parent Code	Age	Location	Child Code	Diagnosis Age	Education Occupation	Socio-Economic Marital Status
Aisha	43	Ekibastuz	Aidar	3.5	Higher Education Housewife	Middle-income Married
Bota	32	Astana	Batyr	3.5	Two Higher Education degrees Housewife	Middle-income Married
Moldir	37	Almaty	Marat	2.5	Higher Education Housewife	Middle-income Married
Samal	28	Astana	Sanzhar	1.8	Higher Education Housewife	Middle-income Married
Zarina	26	Kyzylorda	Zangar	2.5	Higher Education Housewife	Middle-income Married

4.3 Primary Barriers Encountered by Parents of Children With ASD

To understand what barriers the parents encountered and how they hindered the process of accessing EI services, the parents were asked specific questions concerning their experiences and their thoughts on these experiences. The data analysis revealed six sub-themes: lack of qualified specialists, lack of awareness and knowledge, limited resources, logistical difficulties, cultural and social stigma, and bureaucratic and administrative difficulties.

4.3.1 Lack of Qualified Specialists

The lack of qualified specialists is one of the main obstacles parents mention. The first interviewee, Aisha, describes her interactions with specialists who propagate false information, pathologize autism, and work unprofessionally, all of which add to the anxiety and fears of parents.

> There is a very low awareness of specialists… Specialists who work with children with ASD of preschool age pathologize the topic of autism…Imagine a situation where the parent finds out about the child's diagnosis for the first time; the first person who encounters the parent and voices the diagnosis is these specialists. And when a specialist, absolutely not knowing what autism is, begins to tell the parent all sorts of tall tales and read various advertising articles, offering various obscure techniques and so on, imagine what is going on in the parent's head.

Additionally, she shared her experience with one psychologist, labeling her a pseudo-psychologist, meaning she considers that specialist incompetent.

> Allegedly trumping their experience, specialists say that these children have no future and so on. Once a pseudo-psychologist asked me, "Is your child sleeping with you?" I said, "No, he sleeps separately." Then she started telling me that autistic children have to sleep separately from their parents, saying "I have already had fifteen years of experience, you know, if you don't put them separately and you sleep together it could lead to incest." The psychologist had an experience where a mother was having sex and sleeping with her son. She thinks it's because autistic people do not know what it is, they do not feel pain at all. That is, it's like she means they are subhuman, the very last category of people... She was telling me different awful stories that autistics are not empathetic, that they live so long because they do not worry about anything, and they have no feeling of sympathy, and this may be my son's future life too... Was I ready to hear such things? The parent who had just learned about the diagnosis of the child, the parent who lost all hope for the future.

This incident shows that one specialist diminished parental confidence and faith in the healthcare system by sharing inappropriate narratives and making unjustified predictions about the child's future. Parental distress and their trust in seeking help and assistance have been compounded by instances of specialists violating professional boundaries and ignoring professional ethics. She also expressed her dissatisfaction with Kazakhstani specialists' and society's pathologization of autism.

Aisha's story of the specialist doubting her child's autism diagnosis because of stereotypes highlights the alarming lack of knowledge of specialists working with ASD. As Aisha points out, trained psychologists are essential in places like PMPC and correction rooms to help parents through the diagnosis and intervention process by offering them knowledgeable assistance and direction.

> These are the things those specialists say, especially in correction rooms, trumping their experience. That is, we see a gross violation of the personal boundaries of the parent, an absolute unwillingness to follow professional ethics. I'm not the only parent who listens to such horrors. Or when they said about my son, "he does not look autistic, is he really autistic? I thought autistics sit under the table." The topic of autism in Kazakhstan is too pathologized… The first places parents go to are PMPC and correctional rooms and it's fundamental to have professional psychologists here for a parent to accept and understand the diagnosis.

Moldir, another parent, also brought up instances in which specialists demonstrated a lack of knowledge regarding autism,

> Many parents of children with autism say that even if their children do not talk and are autistic, they are not given a disability certificate. Because of the fact that the child looks into the eyes. Or one specialist told me, 'Your child's ASD has passed, he looks into eyes, he already answers you, so it's not ASD at all, it's something else' and that's it.

Another parent, Bota, expressed her disappointment with neurologists at polyclinics:

> I think a neurologist in the clinic should at least do a pre-diagnosis…at the age of three and a half we went to a neurologist. She didn't understand anything, just wrote the PMPC numbers and contact numbers on a small piece of paper and that was it…at least she should have informed the parent beforehand, she should have at least given a pre-diagnosis, for example.

Additionally, Bota believes that professionals providing EI services, such as neurologists, speech therapists, and speech pathologists, have to be somewhat knowledgeable in psychology.

> ... to really understand the parent and the child, the specialist should understand a bit of psychology. There are not so many psychologists and mostly speech pathologists, and speech therapists. They are all different specialties and perceive work differently... I think if there is a psychologist in the center, then all other specialists might also understand how to work with this or that child and learn from a psychologist.

Moldir also noted the issue of unqualified specialists, expressing disappointment with her visit to the polyclinic neurologist.

> ... we need highly-qualified neurologists in polyclinics... This is either some old man or woman of the Soviet era sitting there, who has not even heard of ASD at all… He [the neurologist] prescribed a dosage for my 11-year-old son and for the newborns, the same dosage of the drug... The doctor himself was surprised with what we had [the characteristics of ASD]. This is a very big problem.

Samal's statement repeats a concern that many parents in Kazakhstan have about the level of help certain professionals offer to children with ASD. She emphasizes that her expectations are frequently not fulfilled and expresses disapproval of the services she received. Samal’s skepticism regarding the qualifications of specialists draws attention to issues with the knowledge of those working with children with ASD.

> I cannot say that the quality of services provided by certain specialists corresponds to some of my expectations. That is, I understand that I will not get a super result from these specialists. It’s just for a tick they do. I also have a huge doubt about their qualifications.

All in all, the experiences shared by parents highlight a lack of knowledge and comprehension among specialists working with children with ASD in Kazakhstan. These narratives reflect the troubling reality that parents must deal with when they come across specialists who misrepresent facts, pathologize autism, and demonstrate a worrisome lack of competence and compassion. Parents emphasized the critical role of psychologists in EI settings to provide accurate information, support parental acceptance of the diagnosis, and offer guidance on navigating the challenges associated with raising a child with ASD.

4.3.2 Lack of Information and Awareness

The lack of information and awareness regarding intervention services and resources for children with ASD is also a hindrance, according to parents. They do not know where to go and what to do since there is a lack of information about the services as Samal says, “There is minimal talk about intervention sites for children with ASD... it is tough to find out that we have such institutions in Kazakhstan because it is not covered anywhere.”

She expressed frustration regarding the lack of extensive media coverage of ASD and related therapies, as well as thorough educational activities, “Neither at the educational level nor in the mass media...you have to find out [about IE services] from your friends of friends, acquaintances of acquaintances.”

Parents said they wanted more people to know about autism and comprehend it. They advocated for outreach programs and more thorough education to foster acceptance and assistance for people with autism and their families.

> There is not enough enlightenment. You need to have conversations with teachers and parents, just educate them, for example, how to behave, how parents can help a neurotypical child understand an atypical child... Some parents don't understand. You just need to tell them peacefully and calmly… There are a lot of unpleasant moments. That's why we don't want to send our child to a general city school. This is our child and he may suffer some kind of psychological trauma, this would not be desirable, because it is already difficult and difficult for him in society. And such situations will make it worse. (Bota)

In addition, parents called for a change in equipping families with knowledge and resources to speak up for their children's needs and eliminate misconceptions and stereotypes. "Parents themselves are led to this; parents themselves pathologize their own children; they do not see the potential of their own children. They want to raise a convenient child" (Aisha). Improving outcomes and fostering a more inclusive and accepting society for autistic people will require addressing systemic issues not only within the healthcare system but also in society.

4.3.3 Limited Resources

The experiences of the participants demonstrated how difficult it is for children with ASD in Kazakhstan to access EI programs due to the scarcity of resources. The difficulties resulting from insufficient resources considerably impeded parents' ability to get adequate support for their children.

The sub-theme of limited resources was partly presented in the first sub-section, where parents shared their experiences with the specialists. Parents highlighted the lack of specialists in general. Also, the respondents' narratives underscore the need for more knowledge and comprehension among the existing specialists, which can make it more difficult for parents to use the system properly.

Another major obstacle to EI services for children with ASD in Kazakhstan is finances. The participants highlighted the long waiting lists for free or subsidized therapies as well as the high fees for private interventions. The financial load was described by Zarina, who said, "All our steps are money...If it's free, you have to wait for a long time, and you never know if your turn will come or not."

Moldir also highlights the financial burden that state-provided services place on families, saying, "There's a huge queue. So my son and I have been waiting for a whole year." This example shows the fact that families are forced to seek out private specialists, which is expensive and adds to financial burdens.

Samal also highlights the financial challenges associated with transportation, especially in winter when taxis cost more: "...especially in winter, when taxis cost 2,000 to 3,000 tenge in one direction. And our children need to be taken not to one, but to two, three, or more places…this all hits the pocket." Samal shares, "Financial barriers are the main issue since the free list of services leaves much to be desired. Since there is a huge queue. A parent can't just sit back." Because of the long queues they have to use private services.

Bota emphasizes how the growth of daycare centers - which is frequently motivated by financial gain – and leads to a dearth of high-quality services, adding, "They all start saying that the child will start talking in three months, that there will be such results in six months, and so on. They immediately put pressure on the pain, mostly pursuing mainly entrepreneurial goals." It demonstrates how a profit-driven mindset can decrease the quality of services provided, leaving parents unhappy with the results for their kids.

Even when services were available for free, parents occasionally chose private services due to concerns about the quality of public services.

> Now almost every tenth family has such a child and there is no need to panic. It got down to business and people earn money in this regard. There are a lot of centers. I know that there are free places where I can go. But it's just not the quality of the services, but the specifics of their work. There may be some evidence-based techniques, but it does not suit our children at all. That is, their classes feel like when a child is given a chocolate bar, a candy bar, or his favorite thing - it looks like dog training. For example, the consequences of such activities, according to autistic adults, are not the best. [The experience] leaves psychological traumas. (Bota)

Parents who wanted to provide their children with timely and appropriate support faced several obstacles due to the high prices of interventions and their limited financial means. Samal highlighted this difficulty by saying, "We pay out of pocket... It's very expensive. One lesson at least starts from 7-8 thousand tenge." Moldir faced the same problem,

> There's a huge queue. So my son and I have been waiting for a whole year. And accordingly, like all parents, you start looking for private specialists. And most of them cost a lot of money. For each lesson, but at that time, we were paying 6,000 tenge. It was about 6 years ago... There are at least 3 to 6 such classes per week because a speech therapist has two classes at least, a psychologist, and a defectologist too.

Moldir claims that children are not eligible for a government allowance if children do not possess a disability certificate. "There is no financial assistance from the state. To receive financial assistance, you need to get an official disability certificate... Only free classes, and it's a miracle if you get to them." Moldir's report provides a glimpse into the financial strain that families with children with autism often endure.

> Well, it's good that my husband works, I worked part-time. I had a job as a courier. I used to deliver the orders in the evenings once my husband used to arrive home. Then it all went away [salary], 80% of the budget went to the rehabilitation of the child, to classes.

Zarina points out financial obstacles as well, "I didn't see any simplified resources [accessing the services is hard]. We are forced to seek private services. One lesson for such specialists as a defectologist, and psychologist costs from 6500 tenge. It is not always possible for parents to afford it."

All in all, these statements from parents' experiences collectively highlight the significant financial obstacles families in Kazakhstan must overcome to receive EI services for children with ASD. Long waiting lists force families to seek out private specialists at high prices and consequently, they incur additional transportation expenses. These are a few of the ways that families' inability to pay for necessary services adversely hinders access to EI services.

Zarina states that there are restrictions on entry to sanatoriums and rehabilitation facilities. Families can visit the sanatorium once a year for a month, which, she thinks, has little beneficial effect. She adds that the benefits for children with ASD could be significantly improved by increasing the number of sanatorium visits to two or three times a year. Second, lengthy queues make it difficult for children with ASD to receive care on time; their wait times are longer than those of children with other disabilities like cerebral palsy, as Zarina says. She suggests that this load could be reduced by speeding up the procedure and expanding the number of government rehabilitation facilities. Thirdly, Zarina says, there are not many clubs or centers that specifically cater to the requirements of kids with ASD, making it difficult for them to participate in essential leisure activities like sports. Sports are important for natural growth, according to all parents, and they believe that having specially qualified coaches at regular sports centers or creating specialized sports centers for children with ASD would be very helpful.

Samal emphasizes the barriers to having not enough correctional rooms. “A large flow of people. There are very, very few psychological, medical, and pedagogical consultation rooms considering the number of children with developmental delays.”

The parents’ experiences demonstrate the difficulty of accessing EI services due to barriers of a shortage of state-funded services and insufficient PMPC, rehabilitation centers, and correction rooms, which result in long waiting lists and wait times. These results highlight the importance of addressing the scarcity of resources to provide children with ASD in Kazakhstan with fair access to EI services.

4.3.4 Logistical Difficulties

Navigating the labyrinth of logistical barriers also presents a challenge for parents seeking EI services for their children with ASD in Kazakhstan.

The realization of transportation expenses clarifies the financial hardship of traveling to different service providers as well as the logistical obstacles presented by regional limitations. Moldir suggests, “It is necessary to open, for example, in every center or micro district so that there is a correction room where they can be near the house permanently.” Bota says they had problems reaching the first correctional room:

> ... it was on the edge of the city. At that time, there were practically no roads there. That was four years ago. At that time, I couldn’t physically carry them. It’s a two-hour drive. The child will be exhausted. To study with four specialists, the effect of which is also questionable, is not worth it.

She adds about the current situation, “I am a person without a personal car, for example, I drive from the village to the city for an hour and then another hour to the Paralympic center.” When responding to a question regarding logistical barriers, Moldir shared:

> For example, to take a child to the same correction room if there is no car, you will have to take a bus with transfers. And a child with autism can yell, and scream… Just taking a child somewhere is a whole quest. The fact that this is not within walking distance is a problem.

It highlights the special requirements of children with ASD and the difficulties they could encounter in public places, making the logistical obstacles parents confront much more severe. The parent’s narrative captures the significant challenges in obtaining EI programs, characterizing the process as a “whole quest.” Samal confirms the thoughts of Moldir, stating, “Our children travel on the bus, taking into account the psychological characteristics - a large crowd of people, causing them emotional outbursts and fears, and so on - it all makes it difficult to commute.” Parents report that it is logistically challenging for children with ASD to receive services due to their sensory sensitivities, especially while traveling via public transportation.

All narratives highlight the need for systemic changes to remove logistical obstacles and provide fair access to treatments.

4.3.5 Cultural and Social Stigma

The stigma associated with autism in Kazakhstani culture and society has a significant impact on the experiences of parents looking for EI services. In their interviews, parents discussed the widespread misconceptions and unfavorable attitudes they come across in their communities, which contribute to the difficulties they face.

Zarina said, “People do not understand his difference.” This sentiment captures the ignorance about ASD throughout society. Such ignorance frequently results in cruel statements and incorrect conclusions. As she put it,

> My relatives and acquaintances... think the child is just spoiled... or maybe his father used some drugs or it’s just because of our sins. They say a lot of nonsense. People are unaware of what autism is or any kind of differences.

This misinformation feeds negative stereotypes. As Aisha described an awful experience with a specialist we discussed earlier, “A pseudo-psychologist [she considers her incompetent]... started telling me... It was her prediction. Was I ready to hear such things?” That story highlights the harmful effects of misguided beliefs and emphasizes society’s need for more education and awareness.

Samal also experienced distress in public places, “More than once, when flying on a plane, when visiting a theater with a child, we were told, to put it mildly, to change our place so as not to disturb others.” She states further,

> I realized at that moment that the concept of inclusion and inclusive society does not exist in Kazakhstan. There is no understanding that there are atypical people, such as special children. Even representatives of such cultural institutions as Astana Opera Ballet do not get it.

Moldir narrates about social and cultural barriers,

> People shy away, take their children off the playgrounds, and say don’t play with him, he’s different. Even relatives, if a child runs around the table, say, ‘It is necessary to educate, it is necessary to take care of the child, it’s your fault, something was probably wrong with you.’ I don’t drink, I don’t smoke, and I didn’t have any health problems either. As many people say, ‘Well, autistic children are born to sinful people, or if mothers smoke, they have disabled children.’ No. Most women I have come

> across lead a healthy lifestyle and have higher education. It doesn't affect anything at all. People make all sorts of comments, which makes it disgusting. Relatives say 'You don't bring him up, you should beat him for such behavior' [screaming, crying, temper tantrums].

The statement made by Moldir again highlights the widespread stigma and false beliefs about autism in Kazakhstani society. The parents' story illustrates the prejudice and condemnation they encounter not just from strangers but even from family members who wrongfully believe that their child has autism due to their faulty actions. The claim made by Moldir about leading a healthy lifestyle and not having any health issues highlights the absurdity of linking parental behavior or lifestyle choices to autism. It also highlights the negative attitudes and ignorance that dominate society, as demonstrated by people avoiding their children and the false notion that autism is the product of bad parenting. Moreover, the recommendation made by family members to use physical punishment is indicative of deep-rooted problems, some of which are such as a lack of knowledge regarding autism and simply a lack of sympathy.

Moreover, administrative and bureaucratic barriers reinforce the social and cultural stigma associated with autism. Healthcare workers expressed doubt, according to parents who shared this experience. Zarina said, "Doctors... do not want to give a disability certificate because they see that the child walks with healthy limbs... I had to fight for that." These difficulties not only make it difficult to receive necessary services, but they also support the social norm that stigmatizes people with ASD. Once some doctors intimidated a parent, saying,

> Then, you know, they start scaring us that if we have a diagnosis of ASD, and by the age of eighteen, it will be schizophrenia. This is a lifelong monitoring. He won't be

> able to hold any normal positions, he won't be able to drive a car, he can't have property, and so on. Because he has a mental disability. (Moldir)

This claim highlights a worrisome misunderstanding and fearmongering about autism and its possible course. It adds to the stigma and false information surrounding neurodevelopmental divergence.

Moldir additionally touches on divorce cases that result from guilt and accusations. "When such a diagnosis was made, I slipped into depression... Many parents get divorced because accusations begin [from relatives] about who is to blame and so on. It would be good if psychological support for parents were provided."

By sharing their personal stories, parents draw attention to the critical need for public education, advocacy, and legislative changes to dispel myths and promote an environment that is more accepting and helpful to people with ASD and their families. There is also a need for mental health support and intervention during these difficult moments. Their statements emphasize how crucial it is to launch education and awareness campaigns to fight stigma and encourage acceptance of people with autism.

4.3.6 Bureaucratic and Administrative Difficulties

When seeking support for children with ASD, dealing with the bureaucratic and governmental setting can frequently feel like handling a maze that is full of difficulties and barriers. Every parent's journey is full of experiences with bureaucratic red tape, lengthy wait times, and a general lack of clarity regarding the availability of essential resources. Aisha says,

> There are a lot of bureaucratic delays…The availability of sanatorium treatment, the availability of leisure centers. In some centers, especially in my city, it is written directly in the recommendations that children with mental disorders are not allowed at certain attractions… It is very difficult to get to the rehabilitation center in Astana…

> If the child has only one diagnosis and there is no accompanying one, it will be difficult to get sanatorium treatment… That is, the child who has a mental disability [mental health issues of intellectual disability], does not have the right, it was in the 26th order that people with mental disabilities are not allowed for sanatorium treatment… Getting a disability certificate is a whole quest to this day. Getting additional services, such as sports, and clubs, is also an additional quest. For a child to enter a music school is also a whole epic.

Aisha draws attention to significant administrative barriers families face when trying to get their children access to necessary services. She also notes how difficult it is to register a disability and get further help, such as sanatorium treatment. Her story presents a depressing image of the bureaucratic environment, where accessing necessary services becomes a complex process loaded with difficulties at every turn.

Bota also shared the bureaucratic hurdles she had to overcome to receive EI services,

> I went there [correction room]. I was told there's a queue, there's a year to wait for a spot…I didn't go to the correction room after that because there was no point. Firstly, we had to wait a year... Probably, there is a shortage of correction rooms. But I don't agree with the work they do… quality and also at any time when I want to avail some kind of service, I will have to wait. It makes no sense for such children [with ASD] to wait. Neither the Ministry of Education nor other institutions understand the specifics of working with such children. We also have parents who believe that it will be too late later, and now a two-year-old child practically goes to specialists from morning to night, and he has almost no childhood. That is, the state seems to have no understanding of such children here. They have standard provisions, and they operate according to the standard provisions.

The parent's narrative demonstrates the dearth of correctional facilities. Bota also highlights the adverse effects of extended wait times on kids' growth paths and complains about the lack of specialized government assistance.

Moldir outlines several challenges in accessing EI services, including lengthy waiting lists and wait times, as she describes waiting for months without progress:

> Firstly, you wait in queue there [PMPC], sign up, and wait an average of a couple of months. For them, you need to collect documents, such as from a neurologist, an optometrist, an ENT, and so on. Accordingly, once more, you register for a polyclinic until you do so and until you receive a referral time goes… then contact the correction office with these documents. There's a huge queue as well. So my son and I have been waiting for a whole year…My son never got to physical therapy because his turn never came. We waited a year for the correction room at the republican PMPC… We studied there for three months with a speech therapist and then returned to the queue for six to twelve months. Also, in the summer, everyone goes on vacation there, and classes do not take place. This is very difficult… Then back to the queue, then the commission again. This is very difficult because there is no timely approach, like you are diagnosed, prescribed what to do, signed up, and started doing it... Because while you signed up for the PMPC, you collected the documents for the PMPC, went there [to PMPC], signed up, and then went to this correction room… The district of Almaty has almost a million people. They show a whole shelf with a folder with children in the queue and so they start calling, for example, if you can't start there on such and such a date because the child is ill, they send you back to the queue.

She also highlights the inconvenience of the rehabilitation schedule, emphasizing the difficulties caused by inconsistent and inconvenient scheduling: "Classes are very inconveniently arranged. For example, you may have a speech therapist Tuesday and

Thursday at nine in the morning, and on the same Tuesday and Thursday, you then have a speech pathologist at 6:00 pm."

Moreover, Moldir discusses the challenges linked to obtaining a disability certificate, which may keep a parent from receiving financial assistance from the government. "To receive financial assistance, you need to get an official disability registration. Disability registration is very difficult to get. For example, we did not get one for our son."

Lastly, she expresses concerns about child safety and well-being, particularly regarding the conditions of institutional care and the lack of viable alternatives:

> It was necessary to put the child in the central hospital for 20-30 days at least, alone [to get a disability certififcate]. When we took up this issue [receiving a disability certificate], he was already over three years old. Children over the age of 3 go to hospitals and government institutions separately from their parents. And the child himself can neither eat nor drink. He's in a diaper, he can't ask, he's not talking. How can you put a child somewhere in the hospital in such a case? And they said they would tie him up, "we have belts", so he would lie tied down... They said not to be afraid, they would put sedatives on. The child is 3 years old, what damn sedatives… Receiving disability certificates and other services are all very hard to get. And if disability is not registered, then you do not receive anything from the state. Only free classes, and it's a miracle if you get to them…We did not register, because we did not put the child in the Central hospital. And there were no other options at that time [2018].

Moldir clearly illustrates the administrative challenges and bureaucratic obstacles families face when trying to get support. Even with recommendations for early intervention, getting timely and complete care is still very difficult, and long wait times mean that essential interventions are missed. The parent’s story highlights the shortcomings of the healthcare system, where obtaining disability registration comes with high costs.

Getting a disability certificate is challenging. Zarina's story also illuminates the obstacles parents encounter while attempting to receive disability certificates. Her story demonstrates the lack of knowledge displayed by certain medical specialists who ignore the complex demands related to ASD in favor of making diagnoses based only on outwardly apparent physical deficiencies. Zarina’s reference to “fighting and scaring them with the television” underscores the lengths to which parents must go to advocate for their children’s rights and access to essential services. This narrative highlights the structural difficulties in the disability certification procedure as well as the necessity for healthcare professionals to be more sensitive to and aware of the varied requirements of people with ASD.

> Often, doctors do not want to give a disability certificate because they see that the child walks with healthy limbs. I had to go there a lot of times. We received it through fighting and scaring them with the television [inviting the journalists]. (Zarina)

Additionally, Zarina’s description of the documentation process as a “quest” highlights how difficult and drawn out navigating the system is, which exacerbates the difficulties Kazakhstani families with children with ASD face.

> Also, there are a lot of queues for specialists, and doctors, we have to visit them often to get reports, and referrals. Everything is difficult and unclear. Without papers, you can’t get anything from the government, but getting those papers is a whole quest and is always difficult and a long way.

Samal’s story emphasizes how, despite efforts to shift procedures online, families still encounter difficulties getting necessary consultations and rehabilitation assistance. She draws attention to the lack of PMPC and correction rooms, which causes long wait times for referrals as well as consultations.

> Now, in my opinion, if I'm not mistaken, they did it online [registration to consultations], but unfortunately, this did not solve the problems with the queue…Critically, there are very few of these offices [PMPC]. Therefore, such a huge queue is created, and you just have to wait for months to get to a consultation.

The stories from the parents highlight the widespread problem of long wait times and long lines to obtain necessary medical consultations and to enter rehabilitation facilities. In addition, the need for more rehabilitation centers worsens matters, creating a backlog of appointments and lengthy wait times that can last for months.

Samal further explains the challenging procedure of seeking Invotaxi service, which is another bureaucratic barrier. They were legally entitled to this service, but the local polyclinic refused to provide it, citing incorrect interpretations of the legislation. This experience highlights the lack of consistency and clarity in how regulations are applied across various healthcare facilities, forcing parents to use persistence and advocacy to navigate a bureaucratic maze.

> ... based on our diagnosis and disability, we are entitled to use the Invotaxi service. This taxi is provided to all disabled children and all people with disabilities who have certain physiological characteristics, including our children with mental disabilities… This taxi provides an opportunity to travel free of charge to the correctional center, medical institutions, and government agencies…And our children need to be taken not to one but to two, three, or more places…this all hits the pocket...I applied to the local polyclinic at my place of residence, and I was refused this service. In the report itself, they specifically prescribed that my son, with a diagnosis of ASD, which is here [Kazakhstan] a mental disorder, is not supposed to take the service, allegedly

> according to the law. Although law 859 from the Ministry of Transport does not specifically state that children with autism are not allowed. It says to children with disabilities who are experiencing physiological difficulties or difficulties in moving alone. Our children travel on the bus, taking into account the psychological characteristics - a large crowd of people, causing them emotional outbursts and fears, and so on - it all makes it difficult to move. Our children cannot move on their own, they are constantly running away or something else. Listing all these, our child fits the characteristics… Then we transferred to another clinic and received it. The rules are supposedly the same for everyone and other clinics follow them, but for some reason, our previous clinic refuses… There are no roadmaps and instructions for how to access organizations, etc. I had to achieve everything by swearing and demanding what was entitled for my child.

In conclusion, the parent narratives reflected the multifaceted bureaucratic and administrative hurdles families encounter, including lengthy waiting lists, complicated administrative procedures, and a general lack of clarity and consistency in accessing essential services. These stories underscore the structural challenges families face, from obtaining disability certificates to accessing rehabilitation centers and specialized care, ultimately highlighting the systemic deficiencies in the healthcare and social support systems for children with ASD in Kazakhstan.

4.4 Key Facilitators That Enable Parents of Children With ASD

It is necessary to examine the facilitators that enabled parents to receive EI programs for children with ASD to comprehend the process thoroughly. The participants' collective voices paint a picture of their varied experiences, highlighting that none of them could confidently mention key facilitators; they hesitated to remember the cases where they obtained assistance, which was easy. There was little talk regarding facilitators because there were no obvious ones. Nevertheless, parents attempted to respond and provided some points.

4.4.1 Personal Networks, Persistence, and Advocacy

Despite the myriad challenges faced by parents, the importance of support networks and advocacy emerged as key facilitators in accessing early intervention services for children with ASD. Parents emphasized the value of peer support from other parents of children with ASD, who provided guidance, advice, and emotional support throughout their journey. Samal highlighted the role of support networks, stating, “Only word of mouth from the moms...I had to achieve everything by swearing and demanding what was entitled for my child.”

Moreover, parents demonstrated resilience and advocacy in persistently advocating for their children’s needs, whether through challenging healthcare providers or demanding improved services from authorities. Zarina said, “I received it by fighting and scaring them with the television.”

Parents concluded that informal connections and personal networks provided support when navigating the EI services. When asked what specific resources or factors had made it easier for her to obtain her child EI services, Aisha said, “There are no such factors. Only personal experiences and qualities, personal communication.” She emphasized the importance of interpersonal skills and communication in overcoming obstacles, stating that even in the absence of official support, peer support was a crucial source of help. Samal also underlined the value of parents helping parents, showing that peer support is essential for overcoming the challenges.

Parents mentioned that access to EI services was made easier by individual advocacy efforts. Moldir described how, despite institutional restraints and bureaucratic obstacles, they persisted in requesting aid, filing complaints, and speaking out for their child’s needs.

> No. And what will you do? Just write complaints. I wrote to the Ministry, but still. Well, for example, with my daughter, her epiactivity was revealed, and we needed an epileptologist's observation every six months. Well, again, an epileptologist admission costs 25-30.000 tenge. But the clinic did not give it. So I was constantly writing and complaining and so on.

Similarly, Bota overcame obstacles to access by using her initiative and persistence to work her way through the system, highlighting the value of individual advocacy.

4.4.2 Assistance From Organizations

Even while there may not have been much help from the government, some parents received support from organizations. Moldir noted that the non-profit Asyl-Miras was a valuable source of counsel, education, and direction.

> Asyl-Miras has a program that you can sign up for. There was also a queue; at that time, it had been half a year. There's free testing. They have a psychiatrist there. Malinovsky, a psychiatrist, who left the center now, is a fairly adequate person. He could advise, say, "Look, your child has been tested now, the commission has decided these," to say what to do with him, and so on. And so he could give advice. That's what made life easier. They were the ones who gave advice. Plus, then a series of classes. There were classes for parents and children. They explained something to you, things that you don't know.

Zarina on other organizations: "There are funds opened on behalf of entrepreneurs in the oil industry. There are only 2-3 funds in Kazakhstan, but huge queues exist. 2 times a week for half an hour." Bota remembered that they went to adaptive skating once. "The financing was from the World Bank. For 10 days, the child went to the mountains in Almaty and went skiing there."

4.4.3 Governmental Support and Resources

Parents acknowledged the role of governmental support and resources, albeit limited, in facilitating access to EI services. State-funded programs and resources, such as disability registration and rehabilitation centers, provided crucial support to families, albeit with room for improvement. Bota highlighted the importance of governmental support, stating, “There are state funds...It is not always possible for parents to afford it.”

Aisha shared, “No, I haven’t. (remembered) There were social workers, we have social services at home, and they somehow facilitated it. I don’t want to devalue their work.” Bota reflected on facilitators accessing EI services:

> I don’t know. All I know is from the PMPC. Everything that was said there, that’s what I’m guided by... I found out about some of the operating centers and I was looking for sports centers. I know that we can take a child to the pool for free but without a coach.

There is a state allowance for children with ASD, but a child has to have a disability officially registered, which is not an easy task. However, if it is official, an allowance is issued.

> It turns out that I pay for all the services that we receive from private specialists with an allowance. We were issued an official disability status. The last time they prolonged it up to 16 years old. With this allowance, I pay for almost everything for him. (Bota)

Moldir was categorical in her opinion on facilitators implying corruption in the system. “If they are state-owned, then no. If only to pay something. To get something somewhere, you have to pay accordingly.”

Parents also noted challenges such as limited availability, bureaucratic hurdles, and lengthy wait times for state-funded services, indicating a need for greater investment and expansion of governmental support initiatives.

4.5 Parents′ Suggestions

Parents of children with ASD in Kazakhstan have provided valuable insights and suggestions on how to improve access to EI services. One parent emphasized the importance of sports that promote natural development and neural connections, recommending activities like swimming and adaptive skiing. Another stressed the need for inclusive education, suggesting systematic teacher training and ongoing support for parents. High-quality specialists in polyclinics were highlighted as essential, along with permanent correction rooms in every polyclinic or micro-district for easy access to services. The need for psychological support for parents, simplified disability registration, and clear legislative guidelines were also emphasized. Additionally, expanding rehabilitation centers, reducing wait times, and establishing more sports facilities for children with special needs were proposed as key initiatives to enhance EI services. The urge that Samal expressed depicts a picture of what most parents wish:

> Specifically, it is necessary at the legislative level to create a roadmap. A list of all available free assistance organizations and clear step-by-step manual instructions where the parent will be guided on what to follow to gain access to certain organizations. This manual should be available on all social platforms as well as on the Egov site. And also make disability registration open, as in Malaysia, for example, that is, everything in one place. You have a disability diagnosed with autism, and you immediately have access to a free taxi, an automatic allowance, free diapers, the choice and appointment of a social center, and rehabilitation services in medical

> centers. So that with one registration everything becomes immediately available, and you don’t have to go through 10001 circles of bureaucratic hell for each step.

4.6 Summary

In conclusion, the findings of this study underscore the multifaceted challenges faced by parents of children with ASD in Kazakhstan when seeking EI services. From limited resources and logistical barriers to cultural stigma and bureaucratic hurdles, parents navigate a complex system full of obstacles. However, amidst these challenges, the importance of support networks, advocacy, governmental support, and professional assistance cannot be overstated. By addressing these barriers and utilizing facilitators, policymakers, healthcare providers, and communities can work together to enhance access to EI services and improve outcomes for children with ASD in Kazakhstan. The next chapter presents a discussion of the findings. The next chapter presents a discussion of the findings.

5. Discussion

5.1 Introduction

The preceding chapter presents the main findings from the qualitative data gathered from the five parent participants' narratives. The following research questions were created to fulfill the aim of the current study, which is to examine the barriers and facilitators to receiving early intervention services from the viewpoint of parents of children with ASD: (1) What primary barriers do parents of children with ASD in Kazakhstan encounter when seeking early intervention services? (2) What are the key facilitators that enable parents of children with ASD in Kazakhstan to access early intervention services effectively? The current chapter includes a discussion of the parental perspectives on barriers and facilitators in relation to relevant literature. The discussions chapter has been organized thematically to examine the findings of the study, focusing on primary barriers such as scarcity of qualified specialists and misinformation, financial and logistical challenges, cultural and social stigma, and bureaucratic and administrative difficulties, as well as key facilitators like personal networks, persistence, advocacy, assistance from organizations, and governmental support and resources.

The parents were asked 10 guiding questions about their experiences with early intervention for their children with autism. Prior to this, preliminary questions were asked to get background information and information on the process of the child's diagnosis with autism.

5.2 Barriers to Access

5.2.1 Scarcity of Qualified Specialists and Misinformation

The study's findings reinforce the Ecological Systems Theory, illustrating the profound influence of various environmental systems on parents' ability to secure essential services for their children with ASD. A critical challenge identified is the lack of qualified specialists, a gap within the microsystem where children with ASD and their families interact with healthcare providers. The WHO has recognized the global shortage of trained professionals for ASD and other developmental disorders, which is a barrier to early diagnosis and intervention, particularly in low and middle-income countries (WHO, 2013). This shortage can lead to misinformation, inappropriate treatment recommendations, delayed diagnosis and intervention.

Previous studies in Kazakhstan likewise show a significant need for autism-specific training for all specialists involved in diagnosing children with autism in Kazakhstan (Pather et al., 2020; Somerton et al., 2021). Somerton et al. (2021) highlight that there are significant misconceptions and uncertainties among participants regarding the developmental, cognitive, and emotional aspects of autism, which can lead to inaccurate and uncertain diagnoses, potentially resulting in misdiagnosis or underdiagnosis. There are various paths to diagnosing ASD in Kazakhstan, but in most cases, these paths are lengthy and complicated (An et al., 2018). One example of a mesosystem issue is the lack of communication and collaboration between healthcare and education professionals in providing comprehensive support for children with ASD. This can lead to gaps in service delivery and inadequate care for these children. Communication and coordination should be improved between these subsystems through joint training programs, shared resources, and regular meetings to discuss individual cases and develop integrated care plans. In another research, An et al. (2020) discovered that parents resort to utilizing complementary and alternative medicine (CAM) due to the insufficient accessibility of professional care alternatives for their children with ASD. These parents are hopeful that their children's condition would improve through CAM interventions.

Additionally, the pathologization of autism, where individuals with ASD are viewed through a lens of deficits rather than differences, can lead to stigmatization and harm. A study by Schuck et al. (2021) highlights the adverse effects of using pathologizing language and focusing on the negative aspects of autism by clinicians providing autism diagnoses. The study argues for a shift towards a neurodiversity framework that aligns with the goals of respecting and supporting the autistic “way of being” rather than pathologizing it. Parents' narratives reveal encounters with specialists who not only lack understanding of ASD but also perpetuate harmful myths. Misinformation can lead to recommendations for inappropriate or harmful treatments, diverging from evidence-based practices and potentially harming the child (Lord et al., 2018). Such gaps in knowledge can delay diagnosis and the initiation of early intervention services, which are crucial during the early developmental years (Zwaigenbaum et al., 2015).

The research underscores the transformative impact of early intervention and support on children with ASD, highlighting the urgency of dispelling damaging myths and advocating for timely and appropriate interventions (Hyman et al., 2020; Estes et al., 2015). When families encounter misinformation from specialists, they can lose trust in healthcare providers, which may deter them from seeking necessary medical care in the future (Muskat et al., 2014). Aisha's story, in which a professional described autistic people as lacking empathy, is another instance of pathologization. It violates the dignity of people with autism and disseminates misleading information about ASD. Research by Kapp et al. (2013) emphasizes the importance of moving away from deficit-focused perspectives toward understanding and supporting the strengths and abilities of individuals with ASD. Moldir's account of a specialist claiming that a child's ASD had “passed” because he made eye contact illustrates a misunderstanding of autistic behaviors. Autism is a spectrum, and individuals with ASD can exhibit a wide range of behaviors. Zarina also mentioned the reluctance of doctors to provide a disability certificate due to stigmatizing beliefs about ASD: “Doctors... do not want to give a disability certificate because they see that the child walks with healthy limbs.” It reflects how stigma can affect the recognition of ASD as a legitimate condition that requires support and services. Encountering misinformation can exacerbate stress and anxiety for parents who are already navigating the challenges of raising a child with ASD. It can impact the mental health and well-being of the entire family (Karst & Van Hecke, 2012; Zaidman-Zait et al., 2016). The study by Alibekova et al. (2022) conducted in Kazakhstan to determine the prevalence of anxiety, depression, and stress in parents of children with ASD showed a high prevalence of stress (38.2%), anxiety (47.8%), and depression (37.5%) among them. The lack of awareness and understanding among healthcare professionals, as evidenced by Bota's encounter with a neurologist who failed to recognize signs of ASD, underscores the critical need for education and training.

5.2.2 Financial and Logistical Barriers

The financial barriers and logistical challenges identified in the study as obstacles are indeed barriers at both the microsystem and exosystem levels. Montes and Halterman (2008) found that the financial burden associated with ASD services can be substantial for families. This is consistent with parents' experiences, who discussed the high costs of private services and long waiting lists for subsidized therapies. Zarina mentioned, “All our steps are money...If it's free, you have to wait for a long time, and you never know if your turn will come or not.” It illustrates the dilemma faced by many parents who must choose between long waiting lists for subsidized therapies or expensive private services. A study by Kozhageldiyeva et al. (2023) revealed that parents acknowledged receiving some government assistance but, due to a long waiting list from the government, sought alternative services such as Applied Behavior Analysis (ABA) therapy, consultations with neurologists, and corrective training. These services require out-of-pocket payments. The financial strain of paying for therapies, coupled with the logistical difficulties of traveling to appointments, can increase stress levels within the family. Samal shared, “We pay out of pocket... It's very expensive. One lesson at least starts from 7-8 thousand tenge.” This highlights the significant financial burden placed on families seeking private intervention services due to the inadequacy or unavailability of state-funded options. Sharpe and Baker (2007) and Parish et al. (2015) highlight the significant financial burdens faced by families of children with autism. They corroborate the financial challenges identified in parents' experiences, emphasizing the universal financial strain encountered across different studies and geographical locations. Parents may need to reduce their work hours or leave employment altogether to care for their child with ASD, as in the case of Moldir, further exacerbating financial difficulties and impacting the family's overall quality of life (Lavelle et al., 2014). Addressing these financial and logistical barriers is crucial for improving the quality of life for families with children with ASD. This can involve policy changes to increase funding for ASD services, creating more local service options to reduce travel burdens, and providing financial assistance to families to offset the high care costs.

5.2.3 Cultural and Social Stigma

Cultural and social stigma significantly impacts individuals with autism and their families, often stemming from a lack of understanding about the condition. Gray’s study in 2002 highlighted the emotional distress and social isolation that parents of children with autism frequently experience due to societal stigma and misconceptions. Within the Ecological Systems Theory framework, this stigma operates across various levels of the individual’s environment, from immediate interactions to broader societal attitudes. At the microsystem level, individuals with autism and their families face direct stigma through personal interactions. For example, Zarina’s account highlights societal ignorance and misconceptions about autism, where behaviors of children with autism are misattributed to poor parenting or even parental sins. Such misconceptions can lead to blame and shame, significantly affecting the family’s social dynamics and emotional well-being. This finding is corroborated by the research conducted by Guler et al. (2017), which revealed that members of the community held parents responsible for their children's actions. Friends and relatives perceived the children as being "mischievous" or believed that the parents had not adequately instructed their children in proper behavior. Likewise, a study by Gona et al. (2016) observed that caregivers of individuals with ASD experienced emotions of seclusion and embarrassment when others incorrectly labeled their children as misbehaving. Hebert and Koulouglioti (2010) noted that societal attitudes could deter families from seeking necessary help and support services. Aisha’s experience with a specialist doubting her child’s autism diagnosis based on stereotypes further illustrates how stigma can lead to misunderstandings and misdiagnosis, impacting the quality of care and support received. Moldir’s account of social isolation and the suggestion that her child should not play with other children because of being different underscores the damaging effects of stigma on the child’s development and the family’s social support network. Additionally, the fearmongering by doctors about ASD leading to schizophrenia or other severe limitations illustrates how misinformation can cause unnecessary anxiety and stress for families. At the macrosystem level, cultural stigma and societal attitudes towards ASD can significantly impact the experiences of individuals with ASD and their families.

Research indicates that cultural factors can significantly influence stigma, with varying levels of understanding and acceptance of autism across different cultures. For instance, in some cultures, autism may be attributed to supernatural phenomena or seen as a karmic demerit, leading to significant stigma and social exclusion (Turnock et al., 2022). Some parents may resort to shamanic rituals or spiritual healers due to beliefs that autism is a spiritual punishment for crimes or sins committed by ancestors (An et al., 2020). Specifically, autism has been attributed to supernatural phenomena in parts of Africa, and in Vietnam, autism has been variously conceptualized as a disease, a “family problem,” and a karmic demerit. These cultural beliefs can lead to significant stigma, such as autistic children being asked to leave public transport or families being unable to rent accommodation due to the misconceptions surrounding autism (Turnock et al., 2022). Education campaigns, inclusive policies, and support for families can help reduce stigma and improve the quality of life for individuals with ASD and their families, as suggested by Kinnear et al. (2015).

The study by Anessova and Konkasheva (2017) analyzed the current government policies in Kazakhstan related to disability care, specifically focusing on programs and support for children with ASD. The study found that there is a need for government support for children with ASD in Kazakhstan, including early diagnosis, access to specialized education, and support for families. The study also highlights the importance of addressing the stigma and discrimination faced by children with ASD and their families, as well as the need for more research and data on the prevalence and needs of individuals with ASD in Kazakhstan.

A study by Kozhageldiyeva et al. (2024), in terms of perceptions of ASD among the general population in Kazakhstan, found that there is a lack of willingness to fully accept a child with ASD, regardless of residence. Fear and curiosity were noted as high responses when simulating the situation of a child with ASD on the street, and there were gaps in knowledge of helping children with ASD. Despite a high level of willingness to help families, there was reluctance among the population to attend schools with neurotypical children, make friends with them, and even live in the same neighborhoods. This highlights the need for activities to raise awareness and train the population in helping families with ASD.

5.2.4 Bureaucratic and Administrative Difficulties

The experiences shared by parents in the study also reflect the bureaucratic and administrative difficulties, highlighting the systemic barriers at the microsystem and exosystem levels. Administrative processes often intersect with financial barriers, as families may need to navigate complex systems to obtain funding or reimbursement for services. The financial strain of out-of-pocket expenses for private services when public services are unavailable or inadequate can be significant. A typical administrative burden is the lack of clear, accessible information about available services, eligibility criteria, and application processes. The necessity of having a disability certificate to access certain services and financial assistance, coupled with the challenges in obtaining one, exemplifies the systemic barriers within the healthcare and social support systems. As mentioned by parents, obtaining a disability certificate is often described as a “whole quest.” The need for extensive documentation to prove disability status, apply for services, or qualify for financial assistance can overwhelm families. This complexity can delay receiving services or lead to outright denial if paperwork is not completed correctly.

Aisha mentions the difficulty in accessing sanatorium treatment and leisure centers due to bureaucratic delays and restrictions, such as those that exclude children with mental disorders from certain attractions. The process of assessing children with special needs in Kazakhstan involves the PMPC, which plays a crucial role in determining a child's life path. Parents face challenges with the city PMPC, where specialists may rush assessments, neglect parental input, and favor segregation over inclusive education (Lapham et al., 2013). Moldir's experience of waiting for a year to access a correction room at the republican PMPC highlights the issue of long waiting lists for essential services. The lengthy wait times for receiving EI services, exacerbated by the shortage of available resources and facilities, reflect the inefficiencies within the system. Moldir also points out the inconvenience caused by scheduling rehabilitation services, where sessions with different specialists are spread out throughout the day. This logistical challenge burdens families, making it difficult to manage appointments and access continuous care.

Discrepancies in how policies are implemented across different regions or institutions can create confusion and inconsistency in service provision. Samal's account of the challenges faced in accessing the Invotaxi service, despite being legally entitled to it, highlights the need for more clarity in applying regulations across healthcare facilities. The studies highlight the significant impact of bureaucratic and administrative difficulties on accessing EI services for children with ASD (Brookman-Frazee et al., 2011; Magaña et al., 2013; Thomas et al. 2007; Zuckerman et al., 2015). They underscore the need for systemic reforms to simplify processes, improve service coordination, and ensure that policies and structures support rather than hinder access to care.

5.3 Facilitators to Access

Despite these challenges, specific facilitators were highlighted, such as the importance of personal networks, persistence, advocacy, assistance from organizations, and some governmental support and resources.

One of the primary facilitators identified by parents was the importance of personal networks, persistence, and advocacy. Samal emphasized the critical role of support networks, stating how peer support from other parents of children with ASD provided invaluable guidance, advice, and emotional support. A study by Shilling et al. (2013) found that support groups and networks can provide parents with the emotional support, information, and resources they need to navigate the complex service system for children with ASD. This aligns with Samal's statement about the importance of word-of-mouth from other parents and her advocacy efforts. The assistance from non-profit organization Asyl-Miras was highlighted by Moldir, who appreciated the counsel, education, and direction provided. Governmental support, though often limited, is a crucial facilitator for accessing services. A study by Thomas et al. (2007) highlights the impact of state-funded programs and resources on the accessibility of services for children with ASD. Bota's mention of state funds and the importance of governmental support reflects this finding, emphasizing the need for more comprehensive and accessible government initiatives. Brookman-Frazee et al. (2006), Ryan and Runswick-Cole (2008), and Solomon et al. (2001) underscore the critical role of support networks, advocacy, and persistence for parents of children with ASD. These elements are essential in securing services and navigating the complexities of the healthcare system.

5.4 Health Belief Model Perspective

The HBM offers a helpful framework for analyzing the challenges encountered by parents. In this study, parents expressed concerns about the quality of services available for their children, with some preferring private services due to concerns about the quality of public services. This suggests that the parents perceive their children as susceptible to the adverse effects of low-quality services. The HBM suggests that cues to action, such as information and reminders, can trigger behavior change. In the context of the study, the parents' experiences with bureaucratic and administrative barriers and logistical difficulties suggest a need for cues to action to facilitate access to EI services. This could include providing clear information about the availability and location of EI services, as well as streamlining administrative processes to reduce wait times and logistical barriers. The HBM implies that interventions should be tailored to the individual's beliefs and attitudes. In the context of the study, the parents' persistence and advocacy indicate that interventions should be designed to support and empower parents in their efforts to access EI services for their children. By emphasizing personal susceptibility and the seriousness of not making a change, outlining the costs of unhealthy behaviors and the benefits of change, and providing information as a cue or catalyst to those who are already contemplating change, interventions can be designed to support and empower parents in their efforts to access EI services for their children.

5.5 Summary

The discussion chapter is organized thematically, addressing primary barriers such as scarcity of qualified specialists and misinformation, financial and logistical challenges, cultural and social stigma, and bureaucratic and administrative difficulties. Additionally, the chapter explores key facilitators, including personal networks, persistence, advocacy, assistance from organizations, and governmental support and resources.

The scarcity of qualified specialists and misinformation is a significant challenge, with a global shortage of trained professionals for ASD and other developmental disorders. This shortage can lead to misinformation, inappropriate treatment recommendations, delayed diagnosis, and intervention. Financial and logistical barriers are also identified, with families facing substantial costs for private services and long waiting lists for subsidized therapies. Cultural and social stigma significantly impacts individuals with autism and their families, often stemming from a lack of understanding about the condition. Bureaucratic and administrative difficulties further complicate access to EI services, with complex systems, lack of clear information, and extensive documentation requirements posing significant challenges.

Despite these challenges, specific facilitators are highlighted, such as the importance of personal networks, persistence, advocacy, assistance from organizations, and some governmental support and resources. These facilitators play a crucial role in securing services and navigating the complexities of the healthcare system. The next chapter presents the conclusions, limitations, and recommendations of the study.

Chapter 6: Conclusion

6.1 Introduction

In the previous chapter, the study's findings were interpreted and supported by relevant literature. This chapter concludes the study's findings. Based on participants' lived experiences and perceived challenges, recommendations were made for improving access to EI services for children with ASD. Furthermore, this chapter outlines the study's limitations and suggests future research.

6.2 Summary of the Study

The purpose of this study was to identify the barriers and facilitators that parents of children with ASD encounter when accessing EI services in Kazakhstan. To achieve this goal, qualitative semi-structured interviews were conducted, and two main research questions guided the study. They were: (1) What primary barriers do parents of children with ASD in Kazakhstan encounter when seeking early intervention services? (2) What are the key facilitators that enable parents of children with ASD in Kazakhstan to access early intervention services effectively?

The findings unveiled six sub-themes that hinder the accessibility of EI services for children with ASD in Kazakhstan. They include a need for qualified specialists, more awareness and knowledge, limited resources, logistical difficulties, cultural and social stigma, and bureaucratic and administrative difficulties. The participants' collective narratives reveal a complex picture of their varied experiences, with none readily recalling key facilitators. They hesitated to remember instances where obtaining assistance was easy due to the lack of apparent facilitators. Nevertheless, parents provided some points, including personal networks, persistence, advocacy, and assistance from organizations and government.

Unexpected and contradictory findings from the study reveal the complexity of parental experiences in accessing EI services for children with ASD. Some parents reported receiving governmental support, while others faced bureaucratic challenges, suggesting variations in regional policies or that socioeconomic factors might influence these experiences. Parents had mixed experiences with support organizations, which could be due to differences in service quality or organizational capacity. Service utilization patterns also varied, with some parents engaging more with services than others, potentially due to differences in knowledge, socio-economic status, or beliefs about intervention effectiveness.

6.3 Limitations and Strengths

Several limitations should be acknowledged when interpreting the results of this study. The experiences of a small, geographically limited group of parents may not fully represent the broader population of parents of children with ASD in Kazakhstan. Additionally, potential biases in self-reporting may skew the data towards more vocal or engaged parents, possibly overlooking the silent struggles of others. This study alleviates Kazakhstan's specific context, contributing to a broader understanding of the global challenges faced by families of children with ASD in accessing EI services.

6.4 Research Implications

These findings underscore the need for further research to understand the multifaceted factors affecting parental experiences and to develop targeted support programs that address these complexities. Future research could explore the factors influencing parents' decisions regarding service utilization and preferences for specific types of interventions. Longitudinal studies could examine how service utilization patterns change over time and identify strategies to improve access to services for underserved populations. Comparative studies between regions within Kazakhstan or between Kazakhstan and other countries could provide further insights into practical strategies for improving access to services.

6.5 Recommendations

The study's findings highlight the need for a concerted effort to address the barriers to accessing EI services for children with ASD in Kazakhstan. It is crucial to implement mandatory ASD-specific training for all professionals involved in EI services, ensuring they are equipped with the necessary knowledge and skills to support children with ASD effectively. Increasing funding for EI services and ensuring equitable distribution across regions is also essential. This can be complemented by creating more correction rooms and rehabilitation centers in every district, which would help reduce wait times and make services more geographically accessible. Simplifying the process of obtaining disability certificates and ensuring families have easy access to state allowances and services would reduce bureaucratic hurdles. Community education programs are vital for combating the cultural and social stigma associated with ASD. Furthermore, facilitating the formation of parent support groups and networks can provide invaluable guidance and emotional support, empowering parents in their advocacy and caregiving roles. Legislative support is needed to review and amend existing policies to support better the needs of children with ASD and their families, ensuring a more streamlined and supportive system for accessing necessary services.

6.6 Conclusion

The study's findings highlight the urgent need for a coordinated and comprehensive approach to addressing the challenges faced by parents of children with ASD in accessing EI services. By improving public awareness, expanding governmental support and resources, promoting inclusive education, improving the availability and quality of specialized services, and simplifying disability registration processes, we can create a more supportive environment for children with ASD and their families. It is crucial to involve all stakeholders, including parents, healthcare providers, educators, policymakers, and community members, in the development and implementation of strategies to improve access to EI services for children.

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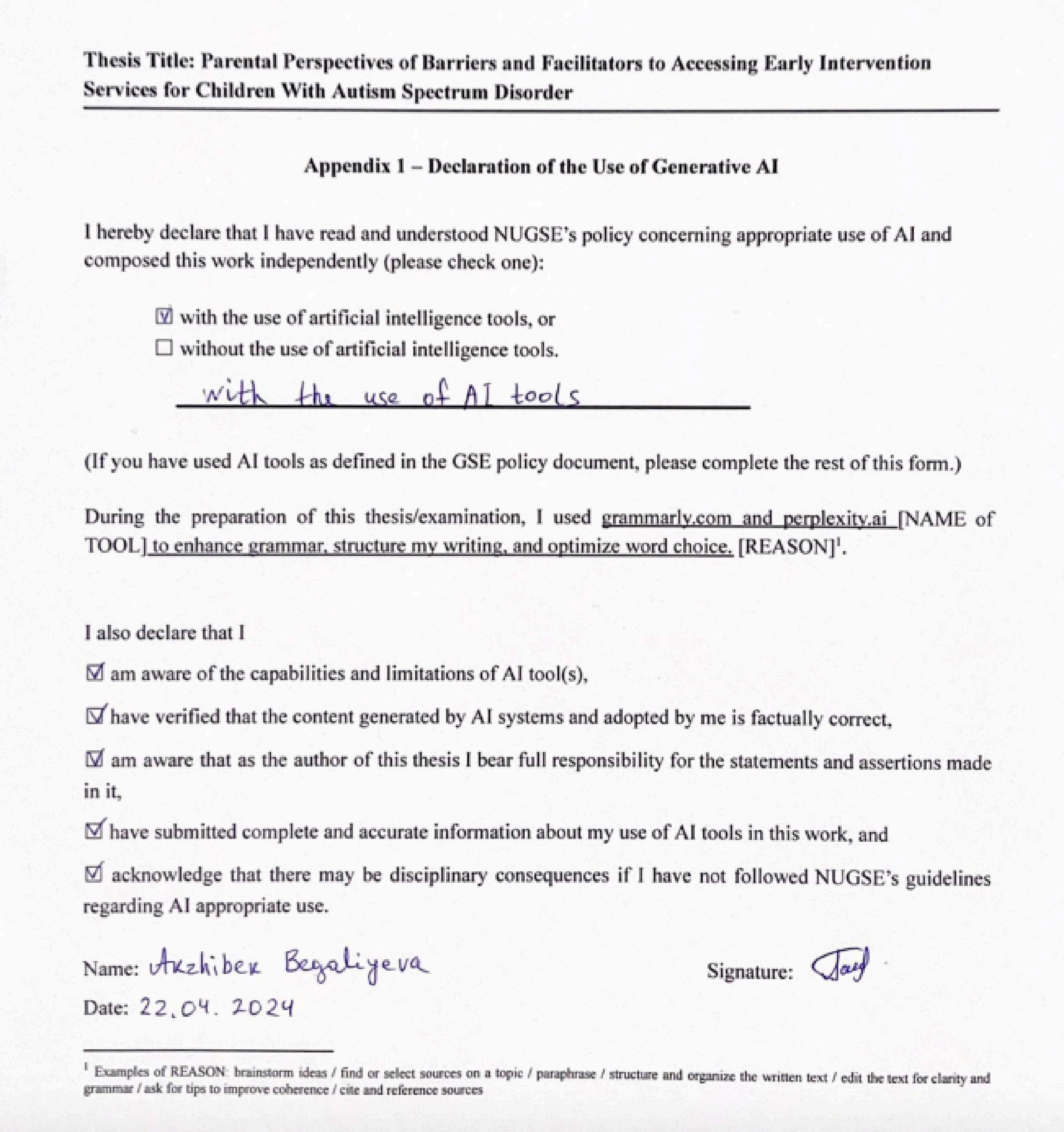
APPENDIX A



Thesis Title: Parental Perspectives of Barriers and Facilitators to Accessing Early Intervention Services for Children With Autism Spectrum Disorder

Appendix 1 – 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.

with the use of AI 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 grammarly.com and perplexity.ai [NAME of TOOL] to enhance grammar, structure my writing, and optimize word choice. [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: Akzhibek Begaliyeva
Signature:
Date: 22.04.2024

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[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 Letter

Subject: Seeking Assistance for Research on Autism Spectrum Disorder (ASD) in Kazakhstan

Dear _______ ,

I hope this message finds you well. My name is Akzhibek, and I am currently pursuing a Master's program at Nazarbayev University. As part of my academic journey, I am conducting research aimed at comprehensively understanding the challenges faced by parents of children with Autism Spectrum Disorder (ASD) in accessing early intervention services in Kazakhstan. I am reaching out to introduce my research and kindly request your assistance in recruiting parents who may be willing to participate.

Research Overview:
The primary focus of my research is to explore the barriers and facilitators that parents encounter when seeking early intervention services for their children with ASD. By learning parental perspectives, I aim to find out the specific challenges they face. Additionally, I seek to identify the factors that enable successful access, including support networks, informed healthcare professionals, and government initiatives. Through this comprehensive examination, I hope to contribute valuable insights to our understanding of the ASD landscape in Kazakhstan and inform the development of targeted interventions and support systems.

Request for Assistance:
I am reaching out to your organization/you with a request for assistance. If your organization is in contact with parents of children with ASD in Kazakhstan, I would greatly appreciate your support in connecting me with potential participants. Their invaluable perspectives will be instrumental in advancing our understanding of this critical issue.

How You Can Help:
If you are aware of parents who may be willing to participate in this research, kindly introduce them to me or provide their contact information.
If your organization has a newsletter or communication platform, sharing information about my research and the importance of parental participation would be immensely helpful.
Any guidance or advice on how best to engage with potential participants or organizations working in the field of ASD would be highly appreciated.
I understand the importance of respecting privacy and confidentiality, and I assure you that all research procedures will strictly adhere to ethical standards, ensuring the protection of participants' identities and information.
Your support in this endeavor would be of immense value, not only in advancing academic research but also in making a meaningful impact on the lives of children with ASD and their families in Kazakhstan.
Should you have any questions, require further information, or wish to discuss this request in more detail, please feel free to reach out to me.
Thank you very much for considering my request, and I look forward to the possibility of collaborating with your organization on this important research.

Warm regards,
Akzhibek
Nazarbayev University Master's Program Student

APPENDIX C

INFORMED CONSENT FORM

Parental Perspectives of Barriers and Facilitators to Accessing Early Intervention Services for Children With Autism Spectrum Disorder

Description: You are invited to participate in **a research study** on understanding the challenges and opportunities faced by parents of children with ASD in accessing early intervention services.

Time Involvement: Your participation will take approximately 20 to 40 minutes.

Risks and Benefits: We do not expect any risks or discomfort associated with this research study. However, if you feel uncomfortable, you can stop the interview at any time without giving me any explanation.

The insights from this research can inform policymakers, healthcare professionals, and advocacy groups in devising strategies to enhance the accessibility and effectiveness of early intervention services for children with ASD in Kazakhstan.

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

Contact Information:

Questions*:* If you have any questions, concerns, or complaints about this research, its procedures, risks, or benefits, contact my supervisor via email address or phone number

Email: filiz.polat@nu.edu.kz

Phone number:

Independent Contact*:* If you are not satisfied with how this study is being conducted or if you have any concerns, complaints, or general questions about the research or your rights as a participant, please contact the NUGSE Research Committee at resethics@nu.edu.kz

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

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

Signature: ________________________ ______ Date: ____________________

APPENDIX D

INTERVIEW PROTOCOL

Hello! My name is Akzhibek, and I'm conducting interviews as part of a research study focusing on the experiences of parents in accessing early intervention services for children with Autism Spectrum Disorder (ASD). Your insights are invaluable in helping us understand the barriers and facilitators you've encountered in this process.
The goal of this interview is to explore your experiences and perspectives regarding the challenges and opportunities you've faced while seeking early intervention services for your child with ASD. We're particularly interested in understanding how various factors have either facilitated or hindered your access to these essential services.

Before we begin, I want to ensure that you have received and reviewed the introductory letter and consent form. If you have any questions or concerns regarding your participation in this interview, please feel free to ask them at any time. Your participation is entirely voluntary, and you may choose to withdraw from the interview at any point without any consequences. Your responses will be kept strictly confidential, and any information you provide will be anonymized in the research findings.

Did you bring your consent letter? If not, I have some here for you. (Copies distributed). Do you have any questions?

If there are no further questions, let’s get started with the first question.

Section 1: Barriers to Accessing Early Intervention Services (Research Question 1)

These questions aim to understand the primary barriers parents encounter when seeking early intervention services for children with ASD in Kazakhstan.

Question 1.1: Can you describe any specific challenges or difficulties you faced while attempting to access early intervention services for your child with ASD in Kazakhstan?

Question 1.2: Were there any financial barriers that you encountered when seeking early intervention services? How did these financial challenges impact your ability to access these services?

Question 1.3: Did you encounter any logistical or geographical barriers that made it challenging to access early intervention services for your child? How did you address these challenges?

Question 1.4: Have you experienced any barriers related to cultural or societal perceptions of ASD in Kazakhstan? How did these perceptions affect your efforts to access services for your child?

Question 1.5: Were there any bureaucratic or administrative hurdles that you had to overcome in accessing early intervention services for your child with ASD? Can you provide specific examples?

Section 2: Facilitators in Accessing Early Intervention Services (Research Question 2)

These questions aim to explore the key factors that have enabled parents to effectively access early intervention services for their children with ASD in Kazakhstan.

Question 2.1: What specific factors or resources have facilitated your ability to access early intervention services for your child with ASD in Kazakhstan?

Question 2.2: Have you received support or assistance from any organizations, professionals, or support networks that played a significant role in facilitating your access to early intervention services?
Question 2.3: Can you describe any positive experiences or strategies you employed that made accessing early intervention services more manageable and effective?
Question 2.4: Have you noticed any differences in the availability and effectiveness of early intervention services in urban versus rural areas of Kazakhstan? Please provide examples.

Thank you for sharing your experiences and insights regarding the barriers and facilitators you've encountered when seeking early intervention services for your child. Your input is invaluable in discovering the challenges parents face and the factors that contribute to successful access to these services. If you have any additional thoughts or comments, please feel free to share them. Your participation is greatly appreciated.

Contact Information: If you have any further questions or would like to follow up on any aspect of this interview, please do not hesitate to contact me at akzhibek.begaliyeva@nu.edu.kz.