

# Perception of Stigma: Parents of Children with SEN in Mainstream Schools in Kazakhstan

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The ratification of the Child's Rights (1989) and the Rights of Persons with Disabilities Conventions (2006) in 1994 and 2015, respectively, reflects Kazakhstan's commitment to establishing a national inclusive policy for integrating children with special educational needs into general education. Despite the focus on policies and practices in national normative and strategic papers, social rejection and exclusion persist due to stigmatization and discrimination. This interview-based research with five parents of children with special needs in mainstream schools sheds light on the enduring stigma. Parents' experiences reveal stigmatized attitudes from both school administration and parents of typically developing children. The study underscores the need for effective anti-stigma strategies in general education to enhance inclusive practices. In particular, this is evidenced by how parents experience stigmatic attitudes from school administration and parents of typically developing children. The findings contribute significantly to national scientific discourse and suggest that inclusive education requires the development and incorporation of effective anti-stigma strategies into general education.

**Keywords:** inclusive education, children with special needs, stigma, parents' perception

## Introduction

The Soviet era's historical milestones significantly shaped Kazakhstan's political, economic, and cultural landscape before 1991. Even today, the country's political and economic conditions in the country are influenced by the post-Soviet state, with individuals characterized by upbringing processes aligning with specific roles in the present-day Kazakhstani society's value-oriented laws and norms. The perception of disability and impairments continues to be viewed through a medical paradigm, emphasizing obligatory health treatment both historically and presently (Makoelle, 2020).

During the Soviet era, specific ideologies permeated the cultures of nations, including Kazakhstan, resulting in the segregation and isolation of individuals with disabilities (Phillips, 2009). This legacy left social and cultural barriers across various spheres of life. The journey toward establishing an inclusive society in Kazakhstan began with the country's accession to the World Trade Organization (WTO), particularly between 1990 and 2000. During this period, the government-aligned national legislation with international standards. The pivotal moment came with the ratification of the 1989 United Nations Convention on the Child's Rights in 1994 emphasizing the right to "express views freely on all matters affecting the child." Another significant step was Kazakhstan's ratification of the United Nations Convention on the Rights of Persons with Disabilities in 2015, aligning with international law guidelines (UN, 2006; UNDP, 2023). Subsequent improvements in national inclusive policy occurred in the early 2000s,

marked by the adoption of core laws and regulations supporting inclusion. Despite efforts toward inclusive education in Kazakhstan, the special education approach inherited from the Soviet Union remains a significant barrier (Rouse & Lapham, 2013). Soviet ideologies, with an emphasis on an individual's labour contributions to society, continue to influence attitudes towards inclusion, creating a gap between theory and practice (Makoelle, 2020).

The concept of inclusive education in Kazakhstan began to take shape with the establishment of the 2011-2020 State Program of Education Development (SPED, 2010). Other state programs aimed at ensuring equal access to education and enhancing competitiveness further laid the groundwork. The signing of the Law on Inclusive Education by Tokayev in 2021 marked a significant milestone, promoting rights and access without discrimination for individuals with special education needs at all levels of education. This has triggered substantial review and changes in legislative acts and changes in legislative acts and state programs, signaling a paradigm shift toward developing a culture of inclusion. The new focus on creating an inclusive culture represents a turning point in educational relations, involving principals, teachers, students, and families to establish a common understanding of inclusive values. Researchers underscore the critical role of parents' views in the success of inclusive education (Francis et al., 2016; Loreman et al., 2009). Lack of awareness about the values of inclusive education among the population has been identified as another restricting factor (Zholtayeva et al.,

2013). As Kazakhstan moves towards a paradigm shift in favour of inclusion, understanding parental voices, attitudes, and perceptions regarding the transformation from exclusion in the past to inclusion at present becomes crucial. Research indicates that parents of children with disabilities have concerns about including them in mainstream education due to negative attitudes towards disability (Brydges & Mkandawire, 2020; Dimitrios et al., 2008; Hanssen & Erina, 2021; Loreman et al., 2009). The adverse effects of stigmatization, encompassing discrimination, social exclusion, and alienation, impact both children with disabilities and their families, hindering the formation of a tolerant consciousness towards persons with disabilities and impeding their social rehabilitation (Gray, 1993; Scourbys, 2019). These challenges generate frustration for parents of children with disabilities, forming an opposition that resists the introduction of inclusion in education (Zadorin et al., 2011).

While Kazakhstani scholars have extensively researched inclusive policy and practice dimensions, the cultural aspect of stigmatic attitudes among parents, siblings, and family relatives caring for disabled children daily is poorly developed by national academicians. Consequently, parents, family members, and children with disabilities are still neglected by society.

This research builds directly on Aitbayeva's (2020) investigation into cultural dimensions of stigmatization in Kazakhstani educational contexts. This study, which forms part of a broader research thesis, aims to explore parents' perception of the stigma associated with having children with special educational needs in several inclusive mainstream schools in Nur-Sultan (hereinafter referred to as Astana). By focusing on the cultural aspects of stigmatic attitudes, the research seeks to understand how parents of children with special educational needs perceive and experience stigma and to identify factors contributing to this stigmatization from parents' perspective. The central research question is: "How do parents perceive stigma related to children with special educational needs within a general school setting in Astana?"

### Literature review

Stigma, socio-cultural prejudices, and acts of discrimination have evolved over hundreds of years, deeply rooted in religion and culture. Historical records indicate that stigmatizing attitudes characterized society since its early development (Stiker et al., 2019). Theoretical frameworks on stigma, however, are relatively new and emerged in the mid-twentieth century. Attitudes towards

disability historically conformed to the traditions and customs of the region in which the child was born (Munyi, 2012; Safford & Safford, 1996). Ancient communities imposed strict rules, behaviors, and rituals, with deviations resulting in severe punishment or expulsion from society. Traditions and rituals had strong links with the rules that guided generations in the past (Kapitonova, 2012). Children born with mental and physical disabilities were particularly vulnerable, sometimes facing dire consequences if any signs of poor health or disability were evident. Ancient Greece and Rome employed specific terminology to describe the exclusion of disabled children (Grubbs & Parkin, 2013), with philosophers like Aristotle (1983) expressing negative views, deeming them a burden to society. The concept of stigma was introduced by American sociologist Goffman (1963).

His research revealed that stigma is a societal phenomenon rather than limited to small groups or individuals. Goffman identified three types of stigma: "abomination of the body," "blemishes of individual character," and "tribal stigma of race, nation, and religion" (Goffman, 1963). Goffman's work laid the foundation for subsequent researchers, expanding the understanding of stigma. Katz (1981) distinguished visible and hidden stigma, focusing on visibility, threat, sympathy, and perceived responsibility. Another conceptual model by Bos et al. (2013) discussed four types of stigmatization: public, self-stigma, association, and structural. People with self-stigma tend to have negative beliefs and hide their shortcomings, resulting in a feeling of being an inferior member of society. Self-stigma affects the social and psychological aspects of an individual's life. The association with the stigmatized person, and attitudes towards other members of society associated with the stigmatized person, are reflected in the individual's social responsibility and behaviors and imply stigma by association (Xhaferri, 2015).

The theoretical framework of stigmatization, based on available evidence, extends beyond the mere development and improvement of political, economic, and social spheres when striving to build inclusive societies. However, significant emphasis has been placed, both in theory and practice, on thoroughly studying all aspects of stigma and its profound influence on disabled individuals and their families. Nevertheless, many contentious issues remain unresolved concerning the self-identification of persons with disabilities and society's attitudes towards them and their families. The barriers in transitioning towards the social model of disability have

deep historical roots in stigmatization, which often predominates over the medical model of disability due to the complex nature of stigma, the varying levels and degrees of its influence, and the heterogeneity in its manifestations (Aitbayeva, 2022). In the context of inclusive social development, researchers have used theoretical frameworks on stigmatization and stereotypes to explore the perceptions and experiences of parents of children with disabilities concerning stigma. They concur that these parents encounter stigma due to their association with the stigmatized individual family members (Bos et al., 2013; Goffman, 1963). Gray (2002) investigated the distinction between felt and enacted stigma in a study involving 53 parents of children with Autism Spectrum Disorder (ASD) in Australia. The findings revealed that both mothers and fathers experienced two types of stigma. Parents reported encountering both hostile and discriminatory attitudes from others, while also experiencing self-blamed, embarrassment, and shame, related to their inability to manage their child's behavioral issues. Parents felt particularly stigmatized in public spaces such as schools and shopping centers. Gray (2002) identified enacted stigma as the most significant factor impacting parents' psychological well-being, and noted that over time, parents tend to accept the stigma imposed on them (Gray (1993; 2002). Kalyva et al. (2007) investigated the attitudes of parents with primary school children without special educational needs (SEN) toward the inclusion of SEN students in Greek primary schools. Utilizing an anonymous questionnaire with eight yes/no questions, the study surveyed 338 parents from randomly selected urban schools. The results revealed that parents of typically developing children generally held favorable views on the inclusion of SEN students, especially regarding teaching quality, learning outcomes, and the right of SEN students to receive education in mainstream settings. However, there was a notable division in opinions: mothers of children without SEN showed a greater willingness than fathers to engage in various out-of-school activities with SEN children, such as playing with them or hosting them at home. Conversely, fathers exhibited more positive attitudes than mothers toward forming friendships with parents of SEN children. A major study on the self-stigma of parents of children who have mental disorders was carried out in Australia and New Zealand. Eaton et al. (2019) examined a model of self-stigma model involving 424 parents of children with mental health issues, finding that stigma awareness predicted their self-doubt regarding parenting, which subsequently predicted self-stigma and emotional distress. The results revealed a strong link between self-doubt and self-stigma with self-stigma potentially lead-

ing to psychological difficulties.

No significant differences were observed based on demographic factors, such as the child's age, parents' age, educational background, or the diagnosis and treatment type concerning the parents' emotional distress. Marital status emerged as a negative factor affecting parental beliefs, with single or divorced parents of children with mental disabilities experiencing greater emotional distress compared to married parents.

Although research on educational stigmatization is limited, several academic articles have documented stigma against children with disabilities in Kazakhstani schools. Kauffman and Popova (2013) performed a qualitative case study in an inclusive mainstream school in Petropavlovsk. The findings demonstrated the effective implementation of inclusive education through physical access, a suitable learning environment, and extracurricular activities for children with disabilities. Nonetheless, the school encountered various cultural barriers and challenges related to stigma. Interviews revealed negative attitudes from parents of non-disabled children towards the inclusion of disabled children in mainstream schools, leading some parents to withdraw their children out of concern. Conversely, teachers showed compassion but at the same time hesitated to assign low grades to special-needs students, reflecting a complex dynamic in the classroom. Lapham and Rouse (2013) made a significant contribution to understanding inclusive policy development and implementation in Kazakhstan. Their 20-year analysis of inclusion policies in Kazakhstan indicated that while the country adopted supportive inclusive policies, some aspects remained ambiguous and contradictory. The study noted that a medical-based approach persisted in inclusive practices, focusing on "disability and "correction" to normalize and adapt children to their environment (p. 446).

Additionally, evidence showed that parents in rural areas concealed their children due to stigma fears. Parents also avoided enrolling their children in state organizations due to the shame associated with their children's disability identification (p. 447). These findings offer insights into the potential for inclusive policy development in Kazakhstan but highlight a gap in understanding cultural stigmatization in education. Overall, the studies emphasize that stigma and discrimination are key factors impacting the psychological well-being of parents and their children with disabilities, thereby hindering full social inclusion and affecting the progress of inclusion educational policies.

## Methodology

This study employed narrative inquiry, a qualitative approach aimed at exploring the perceptions of parents of schools with school-aged children who have special educational needs regarding stigma. Narrative research is recognized as a method for documenting or recording life experiences (Creswell et al., 2007, p.243). Denzin (1989) supports the use of narrative studies for examining personal experiences and contexts, while Creswell (2014) describes narrative inquiry as a method that involves exploring a problem through understanding individual experiences. In this study, the focus was on examining the stigma perceptions among parents of children with disabilities. Moreover, qualitative methods proved advantageous for acquiring insights into phenomena with limited knowledge established (Creswell, 2014). According to Cohen et al. (2011), a non-probability sample, particularly purposive sampling, is considered a crucial “feature of qualitative research” (p.114). This choice proves suitable when making a qualitative selection of a small-scale group of participants with shared characteristics. Professional contacts of the researcher with different Non-Governmental Organizations (NGOs) supporting parents and children with disabilities in Astana helped find two parents of children with SEN purposefully. Another method of sampling – snowball sampling was also used by the researcher. The snowball sampling allowed the researcher to simplify the procedure when the first participant would recommend other participants with the same features and characteristics they acquired (Cohen et al., 2011; Creswell, 2012).

In this regard, snowball sampling allowed access to other participants through informal channels of acquaintance (Cohen et al., 2011). The researcher recruited five parents of children with SEN whose children attended mainstream primary schools for the research. Then, the participants were provided with official forms and documents verifying the study and their rights and confirmed their readiness to participate.

The semi-structured interview format was deemed the most suitable method for gathering data on parents’ experiences. It was selected because it best aligned with the research problem and objectives and provided the flexibility for the researcher to guide the conversation and modify questions as needed (Creswell, 2012).

Given the increased precautions to prevent coronavirus transmission and ensure participants’ safety, online interviews were considered the most appropriate. Each interview lasted at least between 30 to 40 minutes, some ex-

tending to 60 to 70 minutes. Regardless of duration, participants were interviewed individually. All sessions were audio-recorded with the participant’s consent.

The researcher employed thematic analysis, a fitting approach for qualitative data analysis (Braun & Clarke, 2012). This method facilitated the organization of qualitative data through systematically coding and linking with broader concepts and theories (pp. 2-3).

The researcher engaged in a thorough coding process, leading to the development of coding categories that provided a detailed interpretation of the data, aligning with the study’s sub-questions and addressing the primary research questions effectively.

## Findings and Discussions

Three main research questions were formulated to address the study:

1. How do parents of school children with special needs experience stigma?
2. What factors have shaped parents of children with special needs’ perceptions of being stigmatized at school?
3. What are the parents of school children with special needs expectations from the school regarding the development of stigma preventive programs?

The data analysis resulted in five main categories of findings aligned with the research questions: parents’ experience of self-stigma of being a parent of a child with a disability; parents’ perception of stigma in family-school relations; parents’ perception of stigma in parent-parent relations at school; parents’ perception of stigma in child-child relations at school; and parents’ expectations from schools.

### Parents’ perceptions of being a parent of a child with a disability

The findings indicated that all five respondents faced psychological problems when confronted with a new reality. Common features included a sense of rejection and isolation from society. Once the child’s diagnosis was first confirmed Participant 5 described:

Of course, at first, when we found out about the diagnosis, there was shock, rejection, and all the stages.

The comment “and all the stages” from the quote aligns with the psychological framework of the Five Stages of Grief proposed by psychiatrist Elisabeth Kubler-Ross (1972). The parents’ emotional states progressed from denial to acceptance. Participant 4 expressed her percep-

tion with the following comment:

I blamed myself, I was depressed, I could not fall asleep, and I did not sleep for weeks. It's not easy to accept, you look at the baby, everything seems normal, but nothing is normal and there is no explanation.

Participant 3 stated:

We are still separated from society; our children cannot normally communicate with other children in the playground.

Over time, however, the prevailing theme shifted towards acceptance. Participant 1 highlighted: Now I treat her like a normal child, I have the same attitude as if she were a typically developing child, set the same requirements. I don't consider myself vulnerable. Yes, there are difficulties. Maybe, I even became stronger having my child. I used to have a humble character. Now, I am a fighter.

Despite obstacles, parents reclaimed normalcy. Their perception of self-stigma transformed from self-accusation and societal blame to an acceptance where disability became a matter of fact rather than a defect.

Parents experienced profound cognitive shifts as their attitudes and beliefs transformed upon recognizing differences in appearance and the presence of mental or behavioral disorders in a family member. This often resulted in experiences of depression, anxiety, and denial. According to Goffman (1963), families endure stigma associated with a stigmatized member. Gray (2000) and Bos et al. (2013) concurred that parents of children with disabilities face stigma. Additionally, other studies have suggested that having a family member with disability leads to psychological distress and diminished self-esteem among relatives (Link et al., 2001; Mak & Kwok, 2010).

The distinguished types of stigma could overlap at individual, societal, or interpersonal levels, impacting parents' self-stigma and stigma by association (Bos et al., 2013; Xhaferri, 2015). Seeking help outside the family increased the negative impact on their emotional and psychological conditions. Thus, communicating with the local society, parents' self-stigma and stigma by association affected their social and psychological aspects of life.

Parents' perception of stigma in school-family relation  
All participants faced significant barriers during their

children's enrollment in mainstream schools, with the process being particularly challenging. Findings revealed stigmatic attitudes causing difficulties, such as rejection from kindergartens by the administration and aggression from parents of typically developing children. Some participants feared their children might never attend mainstream schools, encountering multiple rejections before eventual acceptance. Participant 3 shared,

I had a choice between a special school and a mainstream school with inclusive education. Initially, I applied for the special school, because I feared rejection from a regular school. Before deciding, we had gone through five schools.

During interviews, contradictory attitudes from the school administration emerged. One participant felt the school showed no concern for her child, while another highlighted the administration's positive contribution to inclusivity.

Teachers' attitudes also played a crucial role in parents' perception of stigma. Three opinions surfaced: one parent praised the class teacher's involvement, while two emphasized their proactive role in educating teachers about their children's needs. Interestingly, teachers openly expressed fear of teaching children with disabilities.

While three participants faced reluctance from principals due to a lack of necessary resources, none experienced open aggression or discrimination. Mainstream school administration recommended alternative options, reflecting inner psychological confrontations. This public stigma, developed by Pryor and Reeder (2011), suggests hidden negative perceptions towards stigmatized children.

In these particular situations, stigmatized factors were defined by the presence of various disorders among the children of the study participants, including ASD, Down syndrome, and mild mental disorders. These conditions significantly influenced the cognitive representations of school administrators, often triggering negative attitudes and feelings towards both the parents and their children who were perceived as stigmatized. This form of stigma is classified as public stigma in the scientific literature, a concept developed by Pryor and Reeder (2011). Public stigma refers to the negative perception and stereotypes that society assigns to individuals with certain conditions. Bos et al. (2013) further elaborated on this by discussing the characteristics people attribute to those with stigmatized conditions (p.2). Despite these pervasive

challenges, most children were ultimately admitted to schools, illustrating a degree of progress in overcoming stigma. Nonetheless, there was one case where a principal explicitly refused to enroll a child, underscoring the continued obstacles and discrimination that families with stigmatized conditions face within educational institutions.

### **Parents' perception of stigma in parent-parent relations at school**

This theme emerged from the findings on the interaction between parents of children with disabilities and those of typically developing children in mainstream education. Participants stressed the importance of collaboration, emphasizing its role in fostering mutual values of tolerance and trust. Positive parental attitudes were seen as influential, with Participant 1 sharing an example:

There was an example. We came to school once, we were a little late. There were a couple of other late children accompanied by their parents. My daughter wanted to go to class with one of the girls and she said: "I'll go with you". Her mother grabbed her daughter's hand and tried to escape as soon as possible so that not let her daughter go with my daughter. My child was ready to become friends with the girl, but her mother was obviously against it. She pushed her child away from my daughter as if she did not want her child to even touch mine.

While negative past experiences were common, participants observed a positive shift in parent-parent relations at school. Participant 3 noted:

I think the situation has improved now. For now, I have no such negative experiences. In general, the situation is changing. Parents are afraid to say something because all parents of children with ASD can sue them for infringement of their child's rights, and that's it. So they are afraid to say something bad because they know they will not be right.

This shift may be influenced by both changing societal attitudes and strengthening the legislative system that reinforces the rights of children with disabilities. The fear of legal consequences for parents of typically developing children contributed to a more positive environment.

### **Parents' perception of stigma in child-child relations at school**

While concerns about child-child relations were touched upon, a deeper exploration emerged from participants'

interviews. Two parents highlighted the negative attitudes of typically developing children toward their peers with disabilities. One participant expressed satisfaction that her child with ASD was in the same classroom as a typically developing child, even though there was no visible communication. Participant 5, a parent of a child with Down syndrome, mentioned:

She communicates with peers, my child walks from the class to the canteen, eats by herself, and communicates with other children. For example, the children look after my daughter, and they help her if she needs help.

This reveals a spectrum of experiences, from challenges in communication to hearing instances of understanding and support among typically developing peers.

### **Parents' expectations from schools regarding creating antistigma programs**

All participants emphasized that fostering an inclusive school environment depends on contextual, personal, and professional factors. They advocated for a preventive program on stigmatization involving all stakeholders – administration, teachers, parents, children, and their families (siblings, close friends). One participant even suggested that a program could "filter out expelling principals who refuse to accept children into regular school". Participant 4 expanded the idea:

So that teachers understand that society is for everyone. There are a lot of nuances here, all children are different. There needs to be basic awareness, the school doesn't understand, for example, what autism is. There is a stereotype that they live in their world. They saw a movie about a child with autism who is crazy, doesn't feel anything, and doesn't understand. But a child with ASD understands everything, he just cannot express his emotions.

In the findings of this study, participants unanimously agreed on incorporating anti-stigma preventive programs into school activities, with a particular emphasis on improving interpersonal communications. They stressed the need for a unified and systematic approach to situations related to children with special needs, extending beyond mainstream schools. There was resonance in the findings on the parents' expectations.

The resonating theme in parents' expectations focused on developing and disseminating awareness-raising information related to children's health conditions, their study abilities, and educational needs. Parents expressed

concerns about dispelling myths surrounding their children's disabilities and emphasized the importance of educating both adults and children on disability issues. This aligns with research by the National Academies of Sciences, Engineering, and Medicine (NASEM, 2016), identifying education as a core feature of stigma-preventive programs. Their suggestion of developing a public-stigma intervention program emphasizes presenting factual and accurate information about stigmatized issues, with a focus on the specific features of each mental or physical characteristic of stigmatized individuals.

### Conclusions and Recommendations

The study emphasizes the influential role of parents of children with special needs in implementing inclusive education in mainstream schools in Kazakhstan, particularly in Astana. It explored parents' perceptions of stigma and identified key factors contributing to stigmatization. The findings revealed that parents face self-stigma, experiencing depression, anxiety, and low self-esteem due to their children's disabilities. Stigmatization and stereotypes were observed in family-school relations, influencing school administrations' decisions on enrollment. Parents and their children facing refusals often change schools before finding inclusion in mainstream schools.

Teachers at mainstream schools contributed to stigma due to misinformation and misconceptions about children's abilities, leading to misunderstandings and tension with parents of typically developing children.

Child-to-child interaction also contributed to stigmatization, with typically developing peers stigmatizing children with special educational needs at school. The study underscored parents' awareness of the need for stigma-preventive programs in schools, advocating for cooperation, education, awareness, and positive behavior modeling among all stakeholders.

Recommendations include the adoption of a value-oriented inclusive school policy by administrations, aligning goals with the needs of children with special needs and their families. Closer cooperation and dialogue involving all stakeholders, including parents, are encouraged. The study suggests utilizing parents' experiences and knowledge to involve children with special needs in the learning process. Training teachers on fact-based profiles of children's special needs is proposed to reduce stigma. The study identified challenges related to personal disincentives among some school heads for enrolling children in mainstream schools in Astana, rec-

ommending a comprehensive study by national education authorities.

Despite valuable insights, the study acknowledged limitations, such as a small sample size and potential bias. The focus on parents of children with ASD and Down syndrome may not represent the experiences of parents with other categories of special needs. Future research should incorporate diverse perspectives from parents in different educational settings, including secondary and high schools, and consider regional variations, especially in rural areas. Furthermore, it should be acknowledged that limitations arise from a geographical perspective. All participants in this study are recruited from Astana city. Parents' perceptions of children with special needs regarding stigma in other regions, particularly rural areas, might differ. Parents from rural areas could encounter distinct types of stigma not identified in this study. Therefore, future research should aim to include parents of children with various special needs, providing a more comprehensive coverage of regions across the country.

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