

Capstone Project

**TITLE: RAISING AUTISTIC TEENAGE GIRLS IN KAZAKHSTAN: A
PHENOMENOLOGICAL STUDY OF MATERNAL EXPERIENCES**

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DECLARATION

I hereby declare that the thesis is an original work, and I was supervised by Joseph Almazan and Paolo Colet in the conduct of the study. I have duly acknowledged all the sources of information which have been used in the thesis. This thesis has also not been submitted for any degree in any university previously.

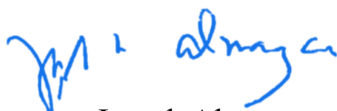
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ABSTRACT

Introduction: Autism Spectrum Disorder (ASD) is a lifelong condition affecting social communication, interaction, and behavior (American Psychiatric Association, 2022). Globally, it impacts approximately 62 million people, with higher prevalence in males than females (Santomauro et al., 2025). In Kazakhstan, childhood autism prevalence has risen significantly (Nukeshtayeva et al., 2025). Girls with autism often exhibit subtler social differences and masking behaviors, which can lead to anxiety, depression, and exhaustion (Hull et al., 2017; Gotham et al., 2012). Adolescence intensifies these challenges, requiring parents to support independence while managing complex emotional and behavioral needs (Lai et al., 2015; Galpin et al., 2018). In Kazakhstan, limited services, regional disparities, and cultural norms further shape caregiving experiences (Zakirova-Engstrand & Yakubova, 2023). This study explored the lived experiences of mothers raising autistic teenage girls, focusing on emotional, social and behavioral challenges and how caregiving is influenced by cultural and gender expectations, aiming to generate culturally grounded insights for support and policy development.

Aim: This study aims to explore how mothers of autistic teenage girls in Kazakhstan perceive and make sense of adolescence and caregiving, generating culturally grounded understandings of the emotional, social and behavioral meanings they ascribe to these experiences.

Methods: This study used a qualitative phenomenological design employing Interpretative Phenomenological Analysis (IPA) to explore the lived experiences of mothers raising autistic teenage girls in Kazakhstan. Seven mothers of girls aged 12-19 with a confirmed ASD diagnosis were recruited through purposive sampling. Data were collected via semi-structured interviews

lasting 30-50 minutes, conducted in participants' homes or another private location and audio-recorded for verbatim transcription. The study generated in-depth, culturally grounded insights into the emotional, social and behavioral challenges of parenting autistic teenage girls.

Results: Five main themes emerged from the analysis: (1) The Labyrinth of Recognition, highlighting the delayed and ambiguous diagnostic path obscured by the girls' masking behaviors; (2) Intensification during Adolescence, reflecting heightened emotional and physiological struggles during puberty; (3) The Burden of Invisible Disability, where the cultural construct of Uyat (shame) creates pressure for social conformity; (4) The Emotional Weight of Caregiving, characterised by chronic tension and a shift in family dynamics; and (5) Navigating the System, which involves a complex search for balance between managing deficient formal services and reclaiming personal time.

Conclusions: Maternal experiences in Kazakhstan reveal that late diagnosis is driven by girls' ability to mask social struggles, leaving mothers to bear the psychological and practical weight of systemic gaps. Rather than finding relief in the state system, mothers are forced to compensate for significant institutional gaps, bearing the full practical and emotional weight of care alone. While some mothers adopt advocacy roles, for others, the lack of support results in profound exhaustion and social isolation. The study concludes that maternal resilience is being used as a substitute for systemic responsibility. There is a need for gender-sensitive diagnostic tools and professional training in Kazakhstan to ensure that autism care transitions from an individual burden to a structured and public duty.

Keywords: Autism Spectrum Disorder, teenage girls, maternal experiences, caregiving, cultural context, Kazakhstan, emotional challenges, coping strategies

INTRODUCTION

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental condition characterised by persistent deficits in social communication and interaction across multiple contexts, together with restricted, repetitive patterns of behavior, interests, or activities that cause clinically significant impairment (American Psychiatric Association, 2022). Recent global estimates reveal that autism affects nearly 62 million people worldwide—approximately one in every 127 individuals is on the spectrum (Santomauro et al., 2025). In other words, in every 100 classrooms of children, at least one student is likely to have autism. The condition is also twice as common in males as in females, with 1 in 94 boys and 1 in 197 girls affected globally. In Kazakhstan, the prevalence of childhood autism has also increased significantly, rising from 14 per 100,000 children in 2016 to 59 per 100,000 children in 2022 (Nukeshtayeva et al., 2025). These numbers underscore that autism is not rare, but a major public health concern that requires early detection, understanding and comprehensive support (Santomauro et al., 2025). Around the world, autism diagnosis remains uneven, as diagnostic services, local healthcare systems, socioeconomic conditions and cultural attitudes vary from country to country. In countries such as Kazakhstan, these differences are further exacerbated by limited access to specialists and limited public awareness, influencing the ways parents navigate caregiving and support systems (Kurmanalina et al., 2025). Therefore, it is important to understand how the condition is experienced in diverse cultural and family contexts and how support systems can respond effectively.

While autism has long been recognized as a condition that affects both males and females, emerging evidence indicated significant gender disparities in autism recognition, which leads to substantial under recognition and delayed diagnosis (Halladay et al., 2015). Although often reported as 4:1, the male-to-female ratio for ASD is likely closer to 3:1, suggesting a diagnostic gender bias in which girls who meet criteria for ASD are disproportionately at risk of not receiving a clinical diagnosis (Loomes et al., 2017). In Kazakhstan, this gap is further exacerbated by a historical reliance on traditional psychiatric models and a nascent awareness of female-specific phenotypes. Consequently, girls with subtler social presentations often remain ‘invisible’ to state medical commissions until the social demands of adolescence exceed their coping capacities (Nukeshtayeva et al., 2025). One of the main reasons for this misconception is that autism in girls often manifests differently. Many girls with autism demonstrate more subtle social differences and engage in masking or camouflaging their behavior by consciously/unconsciously imitating their peers, thereby suppressing repetitive behavior, which reduces the visibility of the considered “core” autistic traits (Hull et al., 2017). However, masking only provides short-term results, as it leads to significant emotional costs and leads to internal struggles including anxiety, depressive symptoms and exhaustion (Gotham et al., 2012; Lai et al., 2015). However, it is critical to note that existing masking literature relies heavily on Western, predominantly White cohorts. In Kazakhstan, where social conformity and emotional restraint are culturally normative expectations for females, behaviors identified as ‘masking’ may overlap with culturally ingrained comportment rather than being a specific autistic trait. This study acknowledges these complexities and therefore interprets mothers' narratives as shaped by the intersection of neurodivergence and Kazakhstani gender expectations. This highlights the

importance of studying autism in girls as a separate phenomenon, rather than as a variant of the male presentation.

This intersection becomes particularly acute during adolescence. Adolescence is the period of life between the ages of 10 and 19, which represents the transition from childhood to adulthood, accompanied by physical, psychological and social changes (World Health Organization [WHO], 2022). Adolescents with ASD experience significant changes in social adaptation, communication, emotional regulation and self-identity, often requiring specialized support and an interdisciplinary approach (American Psychiatric Association, 2022). For mothers in Kazakhstan, observing their daughters struggle with increased sensory sensitivity and the pressure to meet feminine social ideals can be profoundly distressing. These maternal experiences are not merely about managing clinical symptoms. Girls with autism may experience increased sensory sensitivity, emotional instability and the effort required to meet complex social expectations during adolescence (Lai et al., 2015). Many girls devote considerable mental and emotional energy to appear socially appropriate, which can mask deep internal conflicts and create additional demands on their family. Therefore, mothers need to adapt their caregiving and support strategies. For mothers, observing these experiences can be both emotionally taxing and confusing. They often try to calm frustration, manage emotional swings and attempt to understand a world that may seem overwhelming to their daughters (Galpin et al., 2018). Thus, the adolescent life of Kazakh girls with autism is not simply a set of clinical symptoms, but rather real experiences that profoundly affect the everyday reality of parenting.

Because navigating these complex adolescent transitions requires intense parental involvement, raising a teenager with ASD places a significant burden on caregivers, including higher levels of parental stress, greater risk of negative psychological and emotional

consequences and significant financial losses or reduced working hours (Galpin et al., 2018).

These factors further increase the burden on parents caring for children, limiting families' access to a high-quality life. In addition, increased stress and reduced well-being among caregivers lead to poorer treatment outcomes for children with ASD (Kiami & Goodgold, 2017). These relationships show that effective treatment of autism requires attention not only to the individual child but also to the family system as a whole.

In accordance with these concerns, studies have shown that there's a lot of unmet service needs among families of children with ASD. Farmer et al. (2014) reported that 63% of families surveyed had at least one unmet service need, including behavioral therapy, communication aids or devices, occupational and physical therapy, speech therapy and mental health support. These challenges are particularly acute for caregivers, predominantly mothers, who often bear the primary responsibility for navigating fragmented service landscapes. Mirroring findings from the US, caregivers in Kazakhstan also face difficulties in accessing services specifically designed for children with autism, such as applied behavior analysis and services from professionals trained in caring for children with ASD (Abdi et al., 2020). According to Pallathra et al. (2019), as children move into adolescence and adulthood, mothers identify additional unmet needs such as occupational training, transition planning, sexual health education and relationship counseling. However, treatment options for adolescents remain more limited than those available for children. In the Kazakhstani context, this global service gap is further complicated by geographical disparities and a shortage of specialists trained in adolescent-specific autism care, placing an even greater emotional and logistical burden on mothers. Consequently, these unmet needs exacerbate maternal stress and undermine the overall quality of life for the family system

The increased maternal stress, as well as the increased mental distress of siblings, undermine family well-being and quality of life, which in turn can exacerbate behavioral and emotional problems in children or adolescents with ASD (Kiami & Goodgold, 2017). Because family dynamics and caregiver functioning are so closely linked to child development outcomes, there is a growing argument in the literature for a shift from child-centered to family-centered models of care. Family-centered approaches recognize that effective support for the child requires direct attention to the needs of caregivers, family traditions, mental health and social support systems (Galpin et al., 2018). Therefore, research identifies the critical support needs of children and families to help develop holistic services that consider the interests of both children and families and eventually contribute to effective caregiving practices.

The perspectives of mothers themselves are an invaluable source of knowledge. Qualitative phenomenological research is particularly well-suited to capturing the nuances of the real-life experiences of caregivers. Although awareness of ASD has increased in Kazakhstan in recent years, families often face limited specialized services, uneven distribution of professional knowledge across regions and social attitudes that can stigmatize developmental differences (Zakirova-Engstrand & Yakubova, 2023). Raising a daughter with ASD presents a distinct challenge because of the intersection of autism symptoms with the cultural expectations of female identity development. In societies where social reputation is highly valued, expectations regarding girls' behavior, such as modesty and emotional restraint, may influence how mothers interpret and manage autistic traits in their daughters. These cultural characteristics can shape childcare practices that differ from Western contexts, making it necessary to conduct research that takes local characteristics into account. This study therefore addresses an important gap by

seeking to understand how mothers in Kazakhstan experience the challenges of raising autistic teenage girls and how they respond within their cultural and social landscapes.

Aim:

This study aims to explore how mothers of autistic teenage girls in Kazakhstan perceive and make sense of adolescence and caregiving, generating culturally grounded understandings of the emotional, social and behavioral meanings they ascribe to these experiences.

Objectives:

1. To explore and describe the broader lived experiences, social challenges, and cultural expectations faced by mothers raising autistic teenage girls in Kazakhstan.
2. To explore how these mothers make sense of the emotional and psychological dimensions of their caregiving roles.

Research question:

How do mothers of autistic teenage girls in Kazakhstan perceive and make sense of their experiences of adolescence and caregiving?

METHODS

Design

This study used an explicitly interpretative stance. Using Interpretative Phenomenological Analysis (IPA), the research foregrounded parents' sense-making, focusing not merely on listing problems, but on how caregivers interpret, construct and communicate the meaning of adolescence and caregiving in their cultural context. IPA's double hermeneutic emphasises that participants were treated as meaning-makers who make sense of their world, and the researcher engaged in a second-order interpretation of those sense-making accounts. Analytic work therefore balanced fidelity to participants' idiographic accounts with reflexive interpretation that situates meanings within social and cultural frames (Smith et al., 2009).

Setting

The data were collected across Astana, Kazakhstan. Interviews were conducted in-person, either at participants' homes or other places based on participants' preferences and what they felt was most private and comfortable. This flexibility ensured that participants could choose a setting that balances privacy, convenience and emotional safety. These settings allowed for naturalistic, face-to-face interaction while respecting participants' preferences for convenience and confidentiality. Site-specific details were documented during the interviews.

Participants

Purposive sampling was used to recruit mothers who are able to provide rich, relevant perspectives of the phenomenon of interest. Maximum variation sampling was sought on key characteristics (age range of mothers, urban/peri-urban residence, socioeconomic background) in order to capture diverse perspectives while maintaining a purposive focus appropriate to IPA.

Sample size and justification.

IPA is grounded in an idiographic approach, meaning that the emphasis is on developing a detailed, case-by-case understanding of each participant's lived experience. The aim was not to reach numerical saturation but to gather rich, meaningful accounts that allowed for deep interpretative engagement. IPA therefore purposefully employs smaller, more focused samples to preserve the depth of analysis. Based on established guidance in IPA research, a sample of approximately 7-10 caregivers was planned for this study. This range was appropriate to support in-depth examination to individual narratives while still enabling the exploration the commonalities and differences between participants' experience. The final number of participants depended on the richness and completeness of the accounts collected.

Inclusion criteria:

- Primary caregiver (mother, father, or primary guardian) of a girl aged 12–19 with a formal ASD diagnosis.
- Able to communicate in Kazakh or Russian.
- Aged 18 years or older and able to provide informed written consent.

Exclusion criteria:

- Non-primary caregivers.
- Caregivers of girls with severe comorbid intellectual disability.
 - The impairment can significantly limit the caregiver's ability to describe the social, emotional, or behavioral experiences of the adolescent. This was determined based on the caregiver's report during initial screening.

Recruitment procedures

Recruitment was conducted via social media platforms, social media parent groups and snowball referrals. Recruitment materials were available in Kazakh and Russian. Interested participants contacted the research team by phone. Recruitment messages clearly emphasized voluntary participation, confidentiality and that choosing to participate or declining would not affect access to services or relationships with staff at the centers.

Data collection procedure

Interviewer and training. The researcher conducted all interviews. The interviewer was trained in qualitative interviewing techniques, trauma-sensitive approaches, cultural competency and safeguarding procedures. The interviewer was bilingual (Kazakh/Russian).

Reflexivity

The researcher acknowledged that their own background and perspective might influence both the interviews and how the data were interpreted. As a young nursing student and a non-parent with professional experience working with autistic individuals in educational and clinical settings, I recognized a significant generational and experiential gap between myself and the participants. During interviews, this manifested as a specific power dynamic: mothers, being older and experts in their daughters' lives, sometimes adopted a "pedagogical" tone. To mitigate this, I consciously positioned myself as an empathetic learner, allowing participants to move beyond "performing resilience" and share deeper vulnerabilities. My professional background in clinical settings created a risk of confirmation bias, where I might have looked for "textbook" symptoms of ASD. To counter this, I maintained a reflexive journal where I recorded my emotional reactions and assumptions. For instance, I noted how my Kazakhstani cultural identity facilitated immediate rapport regarding shared values like *uyat* (shame). However, I had to

remain vigilant not to assume I understood their specific meanings of these concepts, forcing myself to ask "naive" questions to ensure the findings remained grounded in their unique idiographic accounts rather than my cultural preconceptions.

Measures/ Instruments

Interview guide and pilot. A semi-structured interview guide was developed from the literature and was appropriate to the study objectives. Key domains included: the parenting journey through adolescence, daily caregiving challenges, emotional and psychological impacts, coping strategies, social and cultural influences and support needs. The guide was piloted with 1 caregiver (not included in the sample) to refine wording, pacing and cultural sensitivity.

Interview. Interviews lasted 30-50 minutes and were audio-recorded with participants' consent and transcribed verbatim for analysis. The researcher maintained trauma-sensitive practices throughout, remaining attuned to signs of distress and pausing or stopping interviews if needed. Reflexive field notes were taken during and immediately after each interview to capture contextual details, non-verbal cues and preliminary reflections that may support the interpretative analysis.

Demographic Sheet. Prior to interview, participants completed a brief demographic sheet capturing age, gender, relationship to child, child's age and household composition. This information assisted contextual interpretation but was not used for quantitative analysis.

Translation and Cultural Adaptation. Since the participants answered in Russian, the interview and the demographic questionnaire was translated following the Beaton et al. (2000) guidelines for cross-cultural adaptation. The process included 1) forward translation by two bilingual

experts, 2) synthesis of translation, 3) back translation into English by two independent translators, 4) review by an expert to ensure semantic, conceptual and cultural equivalence and 5) pilot testing with a small group of participants to confirm clarity and relevance. A copy of the original transcript was retained for reference.

Ethical Consideration

Before the data collection, ethical approval was obtained from the Institutional Review Board (IRB) of Nazarbayev University and from the administrations of the autism centers. All participants received detailed information about study's purpose, procedures, risks and benefits before agreeing to participate in the research. Written informed consent was obtained and participants were informed of their right to refuse or withdraw from the study at any stage without any consequences.

To maintain confidentiality, personal identifiers were not recorded in interview and questionnaire. All data were coded and only the researcher will have an access to it. Participants were informed that they may skip any question they are not comfortable with.

A distress protocol was implemented to support participants who might become upset or overwhelmed during the interview. If a participant showed signs of significant emotional distress, the researcher would pause or stop the interview, offer emotional support and provide contact information for local counseling and mental health services. The researcher ensured that participants felt safe and supported throughout the process.

The approved distress protocol did not explicitly anticipate disclosures of third-party child self-harm. When this occurred, the researcher followed the ethical principles of the protocol: pausing the interview, assessing existing support, and providing mental health

resources. The participant confirmed ongoing psychiatric care for her daughter and received written helpline information. No formal referral was made, as the family was already under professional care and Kazakhstani law does not mandate researcher reporting in this context. The researcher documented the incident and addressed this gap in future protocol revisions.

Data Analysis

The data analysis was done using the model of Interpretive Phenomenological Analysis as described by Smith et al. (2009). This approach was selected because it is applied to interpret how individuals make meaning of life events, hence relevant for understanding how parents of autistic teenage girls in Kazakhstan perceived and made meaning of the challenges posed by adolescence and childcare.

All interviews were audio-recorded, transcribed verbatim and translated into English. The researcher read and re-read each transcript to get a sense of familiarity and immerse themselves in the participant's narrative. The researcher carefully read and re-read all the data, including the transcriptions and field notes in order to get a sense of familiarity, immerse themselves in the participant's narrative and gain a comprehensive understanding of the data and considered its significance. As the research proceeded, the researcher asked themselves reflective questions such as “What is this participant saying?” and noted every idea that came to mind. Initial reflections were recorded on analytical notes to capture first impressions and possible meanings.

At the initial stage, detailed research notes were taken in the form of descriptive (content-focused), linguistic (language use), and conceptual (interpretive) notes to capture how participants described and made meaning of their experiences. These notes then helped develop emerging themes that summarize the essence of each participant's narrative. Attention was given

to emotion words, experiential claims and meaning-making narratives, capturing both explicit statements and subtle nuances in how participants describe their experiences.

The themes were grouped into themes through abstraction and comparison, highlighting relationships of experiences within and between the cases. A thematic table was developed for each participant before moving to cross-case analysis.

Reflexivity throughout the process was maintained by journaling as a means of acknowledging and managing researcher assumptions. All coding and thematic organization were documented systematically, manually using Microsoft Excel. To reinforce credibility, an analytic audit was conducted through discussions with peers or supervisors. This process ensured that the findings accurately reflected participants' experiences while maintaining transparency in the analytical decision-making.

Throughout these stages, the double hermeneutic was clear: the researcher interpreted how participants themselves made sense of events, emotions and relationships. Interpretative moves and assumptions were documented through reflexive memos and a reflexive journal. Supervisor peer-debriefing and an analytic audit trail were used to check coherence between participant extracts and the researcher's interpretations.

Rigor and Trustworthiness

To ensure that the findings of this study were both meaningful and credible, several strategies were employed, based on Lincoln and Guba's (1985) framework for trustworthiness in qualitative research.

Credibility:

Establishing credibility began with building trust and maintaining open communication with

participants. After the interviews, participants had the opportunity to review and comment on the researcher's preliminary interpretations, a process known as member checking. This step helped confirm that their perspectives were accurately represented and prevented any misinterpretation of their experiences. The researcher also engaged deeply with the data through prolonged interaction and careful reflection, while peer debriefing with academic mentors helped challenge assumptions and refine interpretations.

Dependability:

To ensure that the research process is systematic and transparent, an audit trail was maintained throughout the study. This included detailed documentation of decisions made during data collection, coding and analysis, as well as notes on how themes evolved. By keeping this record, the researcher aimed to make the process replicable and open for external review.

Confirmability:

Because the researcher plays an interpretive role in phenomenological research, maintaining reflexivity is essential. A reflexive journal was kept to record personal reflections, reactions and evolving thoughts about the data. This practice helped minimize bias and make the influence of the researcher's own background and assumptions more transparent.

Transferability:

Although the study focused on parents in Kazakhstan, providing rich, detailed descriptions of their experiences and cultural contexts allowed readers to determine how the findings might apply to other families or societies. This included offering vivid narratives and direct quotes that convey not only what parents say but also how they feel about their experiences.

Authenticity:

Finally, the study sought to capture the full emotional depth of parents' experiences their

challenges, resilience, fears, and hopes. By incorporating their direct voices and presenting a balanced interpretation, the research aimed to reflect participants' realities as faithfully and respectfully as possible. The ultimate goal was to honor their stories and ensure they are heard within broader conversations on autism and caregiving in Kazakhstan.

RESULTS

A total of 7 parents participated in the study. Their demographic characteristics, as well as their daughters' ages, are presented in Table 1.

Participants	Age	Relationship to child	Marital Status	Highest qualification	Child's age
P1	39	Mother	Married	Diploma	14
P2	40	Mother	Married	Diploma	16
P3	35	Mother	Married	Diploma	14
P4	37	Mother	Divorced	Diploma	13
P5	50	Mother	Married	Diploma	12
P6	47	Mother	Married	Diploma	13
P7	51	Mother	Married	Diploma	18

Table 1. Characteristics of the participants

As shown in Table 1, all participants were mothers. Their ages ranged from 35 to 51 years. The majority were married and all had Diploma. Their daughters were aged between 12 and 18 years (14.3=mean).

To analyze the data, I followed the framework set out by Smith et al. (2009), which involved immersing myself in the participant's worlds. I conducted a meticulous and repeated review of the interview transcripts to ensure a comprehensive understanding of each mother's unique experience. This idiographic approach was essential for moving beyond surface-level descriptions to interpret the deeper meanings and nuances within their lived experience. Once each case was analyzed, I transitioned to a cross-case synthesis by comparing the insights gained from each participant. This rigorous, multi-layered process led to the development of five themes and seventeen sub-themes, as illustrated in Figure 1. The study reported that mothers of autistic girls face multiple caregiving challenges, including a long and unclear path to recognizing their daughters' difficulties, the intensification of emotional, social and sensory struggles during adolescence, the burden of invisible disability compounded by societal stigma and gender expectations, the profound emotional weight of caregiving, characterised by chronic tension, guilt and pride, and the mix of support, where peer support help while generic advice and systemic barriers fail. Below, each theme is presented with its sub-themes, supported by illustrative quotes from the interviews. To ensure the findings remain grounded in the original data, each theme is substantiated by verbatim excerpts from the participants. These quotes serve as representative evidence of broader coding patterns, providing a direct connection between theoretical analysis and authentic lived experiences of mothers.

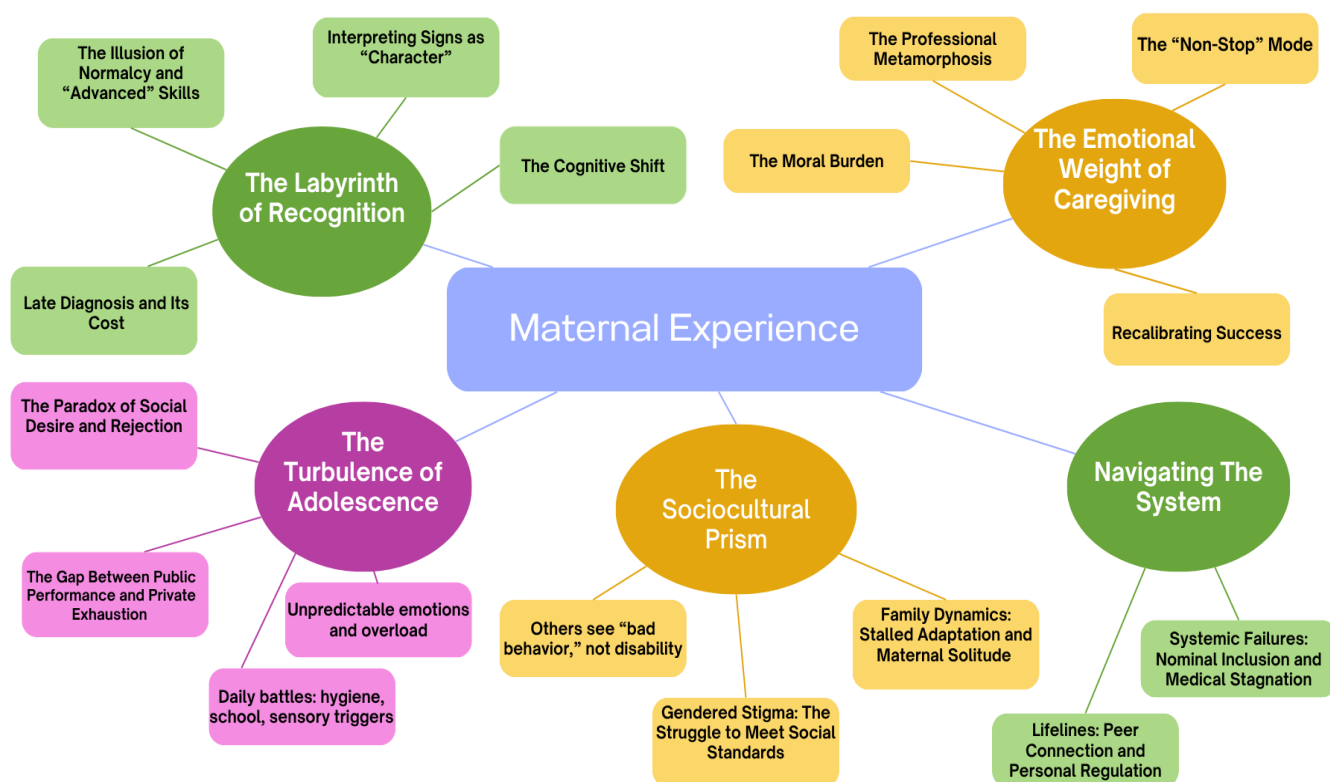


Figure 1. Thematic framework of parents' experiences

Theme 1: The Labyrinth of Recognition: From Character to Condition

All mothers described a prolonged and ambiguous path toward recognizing that their daughters have ASD. The manifestations during early childhood varied widely, and the majority were diagnosed late. Before the distinguishing the diagnosis, mothers moved from seeing their daughters' "different" behavior as intentional or character-based to understand them as signs of underlying condition.

1.1. The Illusion of Normalcy and “Advanced” Skills

Two mothers reported that their daughters initially showed academic or cognitive skills that exceeded those of typically developing peers, which masked the underlying autism and delayed recognition of difficulties. Two mothers reflected on how their daughters’ early achievements diverted any suspicion of a deeper underlying condition:

“She started speaking at two years old. At two and a half she was already speaking beautifully and learning poems...We would say them aloud together, and she would memorize them.”

“She taught herself to read at 5 years old. That is, nobody taught her...” (P3)

“Up to about age 7, she knew the curriculum very well... In some ways she was... how to put it...advanced for her age.” (P5)

One mother provided a striking account of this cognitive "blind spot", where even preserved intellectual functioning failed to lead to a timely understanding of the child’s needs:

“Her intellectual functioning is documented as preserved, but she is non-verbal... we never even suspected such a diagnosis because she knew everything appropriate for her age.” (P7)

The narratives reveal a shared phenomenological experience of "misleading competence." The "preserved" intelligence of these girls was not just a medical fact, but a barrier to visibility. For these mothers, the daughter's ability to memorize poems or master a curriculum became a source of pride that obscured the daughter's internal struggles with social communication. This suggests that in Kazakhstan, the "medical model" of autism often associated with intellectual disability leaves mothers of "advanced" girls in a state of confusion, where they must accept the child's brilliance with their growing developmental "difference."

1.2. Interpreting Signs as “Character”

Mothers initially normalized their daughters' atypical behaviors as personality traits rather than signs of autism. This normalization was often reinforced by cultural expectations in Kazakhstan, where specific female temperaments are socially praised. One mother recalled her daughter in early childhood as ordinary, active children's behavior.

"In childhood she was very active, even 'bright' ... she talked a lot, asked questions, could approach anyone and start a conversation. But at the same time... I realize now that the communication was a bit "superficial." She could talk, but she didn't always listen or pick up on the other person's reaction." (P2)

Another mother described her daughter as the opposite – a quiet child:

"Honestly, it was a long and... sometimes confusing path. In childhood she seemed like a 'convenient child' – calm, could play alone, didn't demand much attention. At the time that was even considered a plus, especially when you look at other children who constantly need attention."

"But over time I began to notice that she didn't quite understand other children... it was hard for her to play together. She could stand nearby, watch them play, but not join in. Or if she joined, it was as if 'off topic' ... she would talk about her own things... not react to the rules of the game. Sometimes I thought maybe it's just her character... that she's an introvert. (P1)

These reveal how the "cultural" image of the ideal girl in Kazakhstan – one who is either "conveniently" quiet or politely "bright" creates an invisibility around autistic symptoms. For P1, the daughter's isolation was viewed as a "plus," suggesting that for Kazakhstani mothers, a girl's lack of social demand is often rewarded rather than questioned. This is where Goffman's (1963) concept of "normalization" is critical: mothers were not ignoring symptoms, but rather they were actively "reading" them through a cultural lens that prizes non-disruptive behavior in girls.

1.3. Late Diagnosis and Its Cost

Some mothers received the diagnosis later than they expected – at ages 8-12. Before that, many of them received multiple reassuring but misleading labels from local professionals, which delayed diagnosis. The specialists were claiming alternative explanations. Even when the diagnosis was confirmed, it was experienced as jarring because it contradicted prior advice and the mothers' own beliefs of autism. The same mother who described her daughter as a “convenient child” said:

“We were diagnosed only at age 8. Before that, I was told: ‘She’s just an introvert’, ‘she’ll outgrow it’, ‘girls are often calmer.’ And I... probably wanted to believe that.” (P2)

Another mother listed the versions she heard during her path to get the diagnosis:

“Before that there were different versions: ‘anxiety’, ‘behavioral problems’, ‘adolescence started early’.” (P1)

One mother explained that the child's strong early academic skills further delayed suspicion:

It’s not that we didn’t believe it – we never even suspected such a diagnosis. Because she knew everything appropriate for her age very well... it was only behavioral thing... (P5)

Additionally, inadequate local diagnostic services forced some families to turn to foreign specialists. One mother reported:

“Diagnostics in Kazakhstan right now are not very good... We saw a Russian child psychiatrist, and he diagnosed it.” (P3)

These labels used by professionals (such as “just an introvert”) represent institutionalized normalization. By reframing autistic traits as “typically feminine” qualities, the system effectively masked the true condition. This created a conflict between maternal intuition and professional authority, where P2's desire to “believe” the specialists led to suppressed own

suspicion. This highlights a systemic failure in Kazakhstan – the female phenotype of autism remains invisible.

1.4. The Cognitive Shift: From Blaming to Seeing Regulation Issues

Over the period, mothers changed how they perceive their daughters' behavior – moving from blaming the child to recognizing difficulties with regulation. This transition allowed mothers to move from a state of constant conflict to one of advocacy and mediation. Two mothers described the move from viewing behaviors as "intentional" or "manipulative" to seeing them as a failure of regulation:

"I used to see her behavior as... intentional. I thought she was arguing on purpose, purposefully "going against" me, and manipulating me. Now I understand that in most cases, it's not about her "character, but about difficulties with regulation of emotions, attention and reactions to stress." (P1)

"I used to think she was "being stubborn" or "lazy" ...or just "didn't want to." Especially when she refused to do something or reacted strongly. Now I realize that it's usually because she's overwhelmed or anxious. It's not that she "doesn't want to" but that she "can't right now." (P2)

"All these dreams – I will have a daughter, we will be fashionable together, I will teach her makeup – you have to part with them. It is a painful process, but you have to... and come to terms with the fact that your child is different. My daughter is no worse than others – she is just different." (P5)

This cognitive shift represents a move from trying to control to understand and support child's need. While P1 and P2 relabeled "laziness" or "manipulation" as "neurological overload," highlighted the emotional labor behind this change. The mother's initial "blame" was a defense against a reality that failed to meet the ideal image of a daughter. By letting go of the "good girl"

stereotype, P5 stopped measuring her child against impossible social standards. This shift is the pivotal moment where the daughter is no longer seen as a "problem to be fixed" but as a person who needs help in a complex sensory and emotional world.

Theme 2: The Turbulence of Adolescence: The Widening Gap

As daughters entered adolescence, mothers noticed a distinct intensification of difficulties. Mothers reported that mild and manageable delays in childhood became more prominent and disabling. Emotional reactions grew stronger, social desires ended with failures and daily activities require constant control. Mothers described the teenage years as the period of widening of gap between their daughters' internal capabilities and external expectations.

2.1. The Paradox of Social Desire and Rejection

The girls' desire for friendship grew over the teenage years but here is a painful paradox for mothers – the social demands of peer interaction also became more complex. Mothers described cases when their daughters wanted connection but rapidly experienced exclusion, misunderstanding or conflict.

"She wants to socialize and make friends, but conflicts often arise. She might say something too bluntly or fail to notice that it has hurt the other person's feelings." (P1)

"She was kicked out of the project group... may be because "she's hard to work with." (P1)

"My child has remained in childhood. She watches children's cartoons... she doesn't understand that to communicate with a person, you need to talk about topics that interest them. She doesn't have full-fledged communication with peers." (P6)

One mother pointed out that her daughter experienced “quiet bullying” and isolation, which culminated in a depressive episode and self-harm. This suggests that for autistic girls in Kazakhstan, the teenage years are a time of profound emotional vulnerability as they realize their "difference".

“The children didn't respond to her at all, and the only friend she had in the class also stopped communicating with her.” (P3)

One mother shared the pain of watching her daughter remain on “periphery” of social life:

“She was very autistic, very... it was only three years ago I realized I focused more on teaching and didn't think about her being happy. Now I am a significant person for her, but others—dad, brother—don't play a big role.” (P7)

The mothers are not just observing rejection, they are “co-suffering” with their daughters. The contrast between P6’s daughter and her seventh-grade classmates shows the difference in the development that breaks the mother’s heart. P7’s thoughts adds a layer of guilt that she focused on “rehabilitation”, the social-emotional happiness of the child was ignored. Therefore, the girl’s social circle shrank to her mother only, resulting in complete mutual dependency.

2.2. Unpredictable emotions and overload

Mothers reported that emotional instability became the most challenging aspect of adolescence. The girls’ reactions were described as intense and unpredictable. The girls’ inability to explain or understand their reactions makes it more difficult. One mother explained her daughter’s emotional reaction:

“It’s very unstable... some days everything is fine, but other days even the smallest thing can trigger a strong reaction. It’s very hard on her emotionally. She can suddenly go from being calm to getting irritated or breaking down in tears.” (P1)

“Sometimes she says afterward that she doesn’t understand why she reacted that way.” (P1)

I got very scared the first few times when she had such meltdowns. They happened periodically...She had such a really strong meltdown once, when she cried in class and left. ... She was banging her head against the wall in the bathroom and at some point, lay down on the floor. (P3)

“At 12.5 she had her first depressive episode, when an episode with self-harm, she cut her arms and said she didn’t want to go to school, lay down, couldn’t do anything. (P3)

Adolescence introduces a level of unpredictability. When the daughter herself cannot explain her emotional "explosions", the mother is left in a state of helplessness. The presence of self-harm and meltdowns shifts the maternal role from "support" to "emergency response". Witnessing a child’s self-directed pain causes a form of secondary trauma for the mother. This forces the mother into a state of chronic hypervigilance.

2.3. The Gap Between Public Performance and Private Exhaustion

Mothers observed a significant difference between how their daughters behave in a structured social environment and their actual emotional state. One mother described it as follows:

And then there are times when she seems to be “pretending” ... trying to copy other girls, their behavior, the way they talk... but then she gets really tired of it. (P1)

“Sometimes she tries to make friends, and I see that it matters to her... but then she comes home in tears, because she doesn’t understand what went wrong. She says: “I did everything like they did, but it still didn’t work.” (P1)

Two mothers highlighted that “appropriate” behavior in public often masks the true internal and “different” world or requires constant external support:

“They know how to behave in public places... And she knows the rules of behavior. [But] she is still like a little child. She still plays with bubbles...” (P6)

“I, essentially, supervised her there [at school] the whole time. ... She is non-verbal... if you saw her, it would be clear [that she has autism].” (P7)

The mothers are the only ones who see the “hidden” cost of constant supervision show that even when a girl is successful in a mainstream school or college, she remains internally vulnerable. Therefore, the home becomes a “safe zone” where they can express their true selves and stop performing, but this leads to constant management of resulting emotional “explosions”. This suggests that “appropriate behavior” of autistic girls in public is a highly valued trait in local culture and can be a misleading indicator of the girls’ actual well-being.

2.4. Daily battles: hygiene, school, sensory triggers

Mothers described daily life as a series of fights that one would not recognize as struggles. As girls required constant prompting and every “change” in usual activities triggered resistance.

Therefore organization, transitions and overall environment has to be constantly managed. One mother said:

“Mornings are always difficult. She takes a long time to get ready, gets distracted and might get fixated on one thing and forget about everything else. I have to constantly remind her and guide her.”

“School is also challenging...not so much because of the academic work, but because of social interactions and the workload. After school, she’s often “worn out” and can be irritable.

There are sensory issues. For example, she’s very sensitive to noise, especially in large rooms. After situations like that, she needs time to be alone.” (P1)

Another participant described puberty-specific hygiene challenges due to the sensory conflict:

“She absolutely refuses to use pads, so we use special underwear during her period. And she doesn’t change this underwear herself at the moment – I have to tell her every time that she needs to go change them.”

“She is used to sleeping without clothes at night, completely without underwear – apparently because she gets sensorially tired. So now we are facing the fact that she takes off her underwear at night even during her period.” (P5)

One mother mentioned the daily struggle that was defined by the loss of the daughter’s autonomy in basic tasks, requiring immense maternal control:

“In the morning, we have to wake her up 150 times, force her to brush her teeth, get dressed. In short, it irritates her and irritates us. Although I roughly know how to solve it, I don’t have enough resources for her. So, we probably need an additional specialist who will teach her to do this independently.” (P7)

Daily life of these mothers is a constant sensory and behavioral management. The mothers had to make considerable efforts daily to meet the girls’ sensory and hygiene needs. P7’s frustration with “150 reminders” highlights the mental load of giving instructions for her daughters. This suggests that for mothers of autistic girls, adolescence is not only about the child’s growing independence but also about the mother’s increasing exhaustion as she has to control physically maturing but mentally remaining fragile human being.

Theme 3: The Sociocultural Prism

The social and cultural environment in Kazakhstan plays a significant role in shaping mothers’ lives. They often carry “double burden” – managing a complex disability that is often “invisible”

to the public, while simultaneously facing “visible” judgment for not meeting cultural and community standards of parenting and family life.

3.1. Others see “bad behavior,” not disability

Because the girls often have verbal skills and lack obvious physical markers of disability, the public frequently misinterprets their struggles as “bad behavior”. This places the mother in a position where she is constantly blamed for her child’s actions. The mothers shared their frustration:

“...people see it as “bad behavior.”. They think she’s just poorly raised or acting that way on purpose. But I know that’s not the case... though having to explain it all the time is hard.” (P1)

“... people often don’t see the difficulties because they aren’t “obvious.”

On the surface, it may seem like everything is fine—the child speaks, goes to school...

But inside, she may be experiencing a great deal of stress, anxiety, and struggle that simply aren’t visible.” (P2)

This creates a “ontological invisibility”. The mothers feel that their reality and struggles are being denied. Every public outing becomes a high-stakes negotiation where she must defend her daughter’s neurodivergence against a society that demands “good raising”.

3.2. Family Dynamics: Stalled Adaptation and Maternal Solitude

The diagnosis acts as a shock that reshapes the entire family architecture. The family often functions as a complex emotional environment where every member adapts at different speeds. While mothers quickly move to advocacy, other family members may experience a “slower adaptation”, struggling to reconcile the child’s neurodivergence with deeply rooted social expectations.

3.2.1. Parental Friction and the "Blame Game"

Mothers reported that their relationships with husbands become more strained. Disagreements about how to respond to daughter’s behavior were a source of conflict, and this tension affected the overall atmosphere of the family. One mother explained:

“There’s been more tension in the family... especially between my husband and me...”

“We react differently to her behavior. I tend to favor support and understanding, while he sometimes prefers a stricter approach. Sometimes this leads to arguments... and that also affects the atmosphere at home” (P1)

Another mother shared an even more painful situation – blame for the diagnosis itself.

“We did genetic tests... everything... There was even a time when my spouse and I blamed each other for her diagnosis. To this day, my husband still finds it painful...” (P4)

While some families experience blame and conflict, others find that the challenge brings them closer. One mother described how her husband became a true partner:

“We argued about it. But when we became a team with him, then it became easier, of course. The change is that I’ve come to appreciate him more. Perhaps before I didn’t notice it or took it for granted.” (P6)

3.2.2. The Sibling Shadow: The Guilt of Divided Attention

Mothers reported a painful "splitting" of their maternal self, as the autistic child's needs consumed so much time and energy that their other children received less attention.

"I have another child... He sometimes feels neglected, and I can see it... I try to make time for him, but I still feel guilty... as if I'm splitting myself in two." (P2)

"I cannot – even though they are the same sex – put them in one room... I have to separate them [to accommodate their different needs]." (P4)

For P4, the decision to give her daughters separate rooms is more than a just practical house accommodation. It is the physical personification of her care for her neurodivergent child. In phenomenological terms, the "separate room" acts as a physical barrier that protects the daughter's sensory world from outside triggers, even when that trigger is her own sister. However, this protection comes at a cost of disconnect within the sibling relationship. The mother is forced to physically separate her children, ensuring the comfort of one by fragmenting the shared family space. This highlights that, in this family, adaptation to autism happens through segregation rather than integration. This further intensifies the sense of "otherness" and isolation.

3.3. Gendered Stigma: The Struggle to Meet Social Standards

Cultural expectations in Kazakhstan where girls are socialized to be "calm" and "neat" create an additional layer of pressure.

"There's an expectation, especially among the older generation, that a girl should be calm, neat, easy to get along with," do well in school, and be sociable."

“But my daughter... she doesn’t always live up to those expectations. And because of that, we get comments from the school and relatives.” (P1)

“I think that in the 21st century it’s somehow stupid to conform to gender expectations. And it seems to me that this doesn’t affect me at all. I have two daughters, and I don’t think I should adapt them to society’s expectations...” (P4)

In Kazakhstan, there is a strong cultural “template” for how a girl should behave. For mothers of autistic girls, this creates a unique psychological struggle. This forces the mothers to make a difficult choice. She can either try to "force" her daughter to fit into these traditional boxes like P1 or she can reject these social rules like P4. By saying she won't adapt to society's expectations, the mother is performing an act of maternal bravery. She is essentially deciding that her daughter's comfort is more important than the family's reputation. This shift shows that accepting autism requires the mother to challenge the cultural definitions of what a "good girl" and a "good mother" should look like.

3.4. Emotional Resilience: The Mother as "Tank" and Mediator

While some describe the constant accommodation of the child's needs as unifying, the overwhelming reality is often one of profound exhaustion. Usually, mothers take on the exhausting role of a translator or a mediator—explaining their daughters to the outside world, and the outside world to their daughters. One mother explained:

“Sometimes I feel like I’m supposed to be... a sort of middle person between her and the world. Explaining people to her, and her to people. And it’s... really exhausting.” (P1)

“In our society, you have to be a 'tank.' If you are not a 'tank,' you will be crushed together with your child. I stopped caring about 'Uyat' long ago.” (P5)

However, mediation does not always have to be draining. One mother described a calmer, more confident approach:

If...she bothers someone, I see it, I calmly say, "Sorry, the child has autism. These are her vocalizations, this is stimming, she regulates and calms herself this way." (P4)

From a phenomenological perspective, this represents affective labor (emotional work). The mother is the "engine" of the family, but the way she powers that engine changes as she gains confidence. For P5, the "Tank" is a survival mechanism through which she is weaponized against "Uyat" (shame). Her resilience is built on a radical rejection of social judgment. For P4, she demonstrates a shift toward calm advocacy. By using clinical terms like "stimming" and "vocalizations" she is no longer just defending her child but educating the public and raising awareness.

Theme 4: The Emotional Weight of Caregiving: From Chronic Tension to Identity

Reconstruction

Mothers described their role as emotionally and psychologically demanding in ways that changes every aspect of their life. While some mothers successfully turn their struggle into a new professional identity, others remain in a state of total dedication where their personal life is completely replaced by the child's needs.

4.1. The "Non-Stop" Mode: Chronic Tension, Anxiety, And Regrets

Mothers reported a persistent, low-grade stress level that never disappeared even during calm moments of life.

“Honestly... it’s really exhausting... Sometimes I feel like... I’m constantly on edge, as if I have to be on high alert all the time, wondering what’s going to happen next, where a conflict might arise, how she’ll react.”

“There’s stress, yes... especially on those days when things don’t go “according to plan.” And anxiety... mostly about her future and how she’s coping right now.” (P1)

One mother described herself not as a woman, but as a caregiver whose entire existence revolved around her daughter:

“I don’t consider myself a woman at all. I consider myself support staff. Everything is for her. The whole world revolves around her. I understand that if I’m not there, who will take on these responsibilities?” (P5)

“Special needs parenting is a marathon...for special needs parents, this marathon never stops. That is, we lived in non-stop mode and we continue to live in non-stop mode.”(P6)

The metaphor of the "Marathon" (P6) highlights a unique phenomenological grief – unlike typical parenting where "sprints" of intense care end as the child matures, this race has no finish line. The description of being "support staff" (P5) reveals a profound self-erasure. The mother’s identity as a "woman" with her own needs is sacrificed to the functional necessity of the child's survival. This creates an existential state of indispensability, where the mother feels she cannot afford to "exist" outside of her daughter's life.

4.2. The Moral Burden: Guilt and Search for Connection

The mothers’ narratives reveal that the emotional weight of caregiving is often linked with feelings of guilt. This guilt does not stem from a single source but rather it appears as a

multifaceted burden that shifts depending on the situation. This guilt may arise from a momentary loss of patience or a long-term reflection on parenting choices.

“There’s a sense of guilt... especially after conflicts. Like... when I can’t take it anymore and raise my voice and then realize that she’s already having a hard time, and what she needed wasn’t strictness, but support...” (P1)

“I focused more on teaching and was less of a mother to her. I only realized my mistake three years ago, and since then I have completely changed. And now she is also changing, but slowly. I always tried to teach her, but I didn’t think about her being happy. That was also a huge mistake.” (P7)

“Despite my life experience, I think I am raising my child incorrectly. I think I overprotect her too much... I have made her not independent. My constant control... maybe it’s a mistake.” (P4)

These accounts highlight a persistent psychological "double-bind." The mothers feel personally responsible for every aspect of their daughter's development, leading to a state of constant self-doubt. Whether they are "too strict," "too focused on skills," or "too protective," any struggle the daughter faces is interpreted as a maternal failure. This leaves the mother to carry the heavy moral weight.

4.3. Recalibrating Success: Pride in daughter’s efforts

Despite the hardships, mothers find profound meaning in small victories that would go unnoticed in typical families.

“However, there are also moments of pride! For example, when she manages her emotions on her own or... tries to apologize after a conflict, that’s a big step for her.” (P1)

“The biggest achievement at her current age is that she is able to attend individual classes independently. Extracurricular activities, vocal lessons – she goes from home alone to the classes, they conduct the lessons with her, she returns independently, crosses roads, traffic lights, lets cars pass. She knows how to use WhatsApp. So at this moment, these are our successes.” (P6)

“I was always proud of her and never hid it.”

“She washes cucumbers, tomatoes, cuts them, makes a salad. ... She sews well on an industrial electric sewing machine.” (P7)

The feeling of pride is a recalibration of success. Mothers find joy in their daughters’ increasing autonomy. Acts like sewing or crossing the street are symbols of a future where the daughter might live without the "support staff." These moments are the emotional “fuel” needed to continue the journey.

4.4. The Professional Metamorphosis: Turning Pain into Agency

A striking finding was how mothers utilized their experience to build new careers, finding a way to balance their role as a parent with a meaningful professional life.

“I became a specialist in ABA, one of the best in the Russian-speaking space. ... I believe that I now bring so much benefit, and it feels like I found myself thanks to her.” (P7)

“Thanks to the fact that I have a daughter with special needs, I studied thoroughly ... and as a result, I became a special education psychologist, a play therapist, and an inclusive education specialist. And this helps me fulfill myself, as a person, so as not to sink completely into special needs parenting.” (P6)

“Not everyone wants to run a blog ... but I speak openly about it and explain.” (P5)

This transformation is the form of Meaning-Making. By becoming ABA specialists or bloggers, these mothers move from being "victims of a diagnosis" to "active agents of systemic change." This professionalization is a strategy to "not sink", and it allows the mother to maintain a "self" that is separate from her child.

Theme 5: Navigating The System: Helpful and Unhelpful Support

Mothers identified peer support and taking "pauses" as essential survival strategies. Finding "time for oneself" was described not as a luxury but as a critical psychological "reboot" to maintain their own well-being.

5.1. Lifelines: Peer Connection and Personal Regulation

Mothers identified peer support and intentional "pauses" as essential survival strategies.

"Sometimes it helps to just take a break... step outside, get some fresh air and clear your head. I didn't used to do that and I'd burn out faster." (P1)

"I also found some online groups for moms... that's probably the biggest source of support...at some moments. Because you don't have to explain the basics there... people already get it. Sometimes just reading other people's stories helps. You are always welcome to ask or share anything you would like to. It makes you realize you're not alone." (P2)

"The only thing that fills me up is talking with other mums like me. We heal each other, we help each other, women helping women." (P4)

"Not everyone wants to run a blog... but I speak openly about it and explain." (P5)

For these mothers, self-care is a vital act of self-preservation and "refilling resources". Peer communities act as a "safe zone" where mothers are exempt from the labor of "translating" their

lives. There, the Uyat (Shame) non-existent because experience is shared. Whether through sensory relief like "stepping outside," communal healing or transforming a private struggle into a public voice through blogging, these strategies function as psychological anchors.

5.2. Systemic Failures: Nominal Inclusion and Medical Stagnation

Mothers reported profound frustration with state-level support, which they perceive as outdated and insufficient for the needs of autistic girls

We need more correctional schools... There are only three in the whole country – that’s a disgrace. You can’t get into them – it’s simply impossible. Waiting lists for years... (P4)

“Inclusion” in schools is purely nominal, it’s just for show... it’s completely non-functional. For mild children – those with very mild autism – okay. But for those with moderate-severe autism, it doesn’t work at all. (P4)

“There are very few competent doctors – psychiatrists, neurologists – so that we finally switch to ICD-11, as the whole world has switched... For there to be more child psychiatrists, competent ones, ... so that medications in state psychiatric centers and hospitals are the latest, as in the rest of the world, and not old neuroleptics that have a bunch of side effects and are no longer used in normal countries.” (P4)

The term "nominal inclusion" means a form of institutional gaslighting, where the state claims to provide support that does not exist. The "old neuroleptics" and the lack of schools create a sense of being left behind by the global medical standards.

DISCUSSIONS

The present study aimed to explore and describe how mothers of autistic adolescent girls in Kazakhstan perceive and make sense of their caregiving experiences. By employing a qualitative phenomenological approach, this research captured the intricate emotional, social and cultural moments of caregiving process during the period of adolescence. IPA's double hermeneutic – the researcher's interpretation of participants' interpretations of their world – requires not just thematic description, but a deeper psychological and cultural reading of what these accounts disclose (Smith et al., 2009). The following discussion therefore moves beyond summary to interpret how these mothers' narratives reveal the structure of diagnostic delay, the weight of cultural stigma, the transformation of maternal time and the limits of resilience in Kazakhstan.

The Phenomenology of Diagnostic Delay

A profound temporal gap between maternal intuition and diagnostic confirmation anchors all subsequent themes. Mothers did not simply report that they had late diagnosis they described a lived experience of being caught between two incompatible interpretations of their daughters. On the one hand, the daughter presented herself as "advanced," "bright," "conveniently quiet", a child who fit culturally valued images of feminine competence. On the other hand, mothers noticed something unnameable, a "superficial" quality to social interaction or a fragility masked by precocious reading. This is not merely delayed identification, but rather it is a crisis of phenomenological validation. The whole outside world – teachers, relatives, even specialists told mothers their daughter is "just an introvert" or "she'll outgrow it" while their own experience told them otherwise.

IPA captures such moments of dissonance because it attends to how individuals negotiate conflicting meaning-systems (Smith et al., 2009). Mothers were caught between a medical viewpoint that saw no pathology and a maternal viewpoint that saw “internal” suffering. The “advanced skills” reported by P3, P5, and P7 acted not as protective factors but as obstacles. Females with ASD often exhibit stronger superficial social skills than males, bypassing male-centric screening tools (Schuck et al., 2019), and are frequently misdiagnosed due to less stereotypical presentations (Green et al., 2019).

These skills become interpreted by others as evidence of neurotypicality, not simply camouflage. Tubío-Fungueiriño et al. (2021) note that masking is associated with internalising symptoms such as anxiety and depression, but strikingly, the mother often detects the cost of masking before the clinician does. Mothers described daughters who “pretended” at school and collapsed at home. One mother said: “And then there are times when she seems to be ‘pretending’ ... trying to copy other girls, their behavior, the way they talk... but then she gets really tired of it” (P1). The mother's phenomenological dilemma – “how can my brilliant daughter also be struggling so much?” – is not resolved until she learns to see autism not as intellectual deficit but as a different way of experiencing the social world.

This shift from “she is difficult” to “she cannot regulate” restructures perception. Christou and Bacopoulou (2025) note that reframing behavior as dysregulation – rather than opposition – aids co-regulation, but what is deeper is that the mother learns to trust her own embodied knowledge over expert authority. P1's words – “I used to see her behavior as intentional... now I understand it's about difficulties with regulation” – show her reclaiming interpretive authority after years of being told they were wrong. This is a phenomenological resistance against institutional gaslighting.

Cultural Invisibility and the Double Burden of Gendered Stigma

The findings reveal that autism in girls is not merely medically under-recognised but culturally incomprehensible. In Kazakhstan, *uyat* (shame) regulates family reputation, and a girl's behavior reflects on the entire family. Mothers described being judged for poor parenting, withdrawing from neighbors and hiding the diagnosis from relatives. This is a social mechanism that forces families into secrecy. One mother said: "Her father didn't take her out for a long time, we didn't play on playgrounds, we avoided neighbors."

This phenomenon is not unique to Kazakhstan. Cross-cultural studies report that stigma surrounding developmental disabilities is pervasive (Mitter et al., 2019). IPA's commitment to idiographic details allows us to see how *uyat* affects mothers' feelings. The mothers are not simply "experiencing stigma", but they are living a contradiction between their maternal love for their daughter and the social demand to raise a "normal" girl. When a Kazakhstani girl fails to meet expectations of calmness, neatness and pleasantness, the mother becomes the target of judgment. As Hull et al. (2017) found, autistic girls' difficulties are judged more harshly because they violate feminine ideals. However, the Kazakh context adds a collectivist dimension: the violation is not just individual failure but familial.

However, some mothers actively reject this cultural framework. P4 stated: "I think that in the 21st century it's somehow stupid to conform to gender expectations." This is not just a strong claim, but it is a conscious act of cultural resistance. The mother who refuses *uyat* is not just protecting her daughter, she is acting on what it means to be a good mother. By publicly naming autism and refusing shame, she challenges the social judgment.

To understand this better, Goffman's (1963) distinction between different forms of stigma is useful. Enacted stigma is open discrimination – neighbors avoiding the family, relatives making harsh comments, schools excluding the child. Mothers described all of these. Courtesy stigma (or associative stigma) is the shame experienced by family members because of their a disabled family member – mothers being blamed for their daughter's behavior, fathers withdrawing from public spaces. Felt stigma (or internalised shame) is the fear of being judged, which leads to withdrawal and hiding the diagnosis. The mother who said “we didn't play on playgrounds, we avoided neighbors” is not only facing stigma but also anticipating it.

However, not all shame comes from outside. Some of the shame may be internalised through a medical view of disability that sees ASD as a defect to hide. In post-Soviet contexts, where disability has been associated with medical pathology and institutionalisation, mothers may learn to feel that their daughter's autism is their fault. This distinction matters for intervention: public campaigns fight enacted stigma, while peer support and counselling help with internalised shame. The mothers who reject uyat openly, like P4, were resisting not only community judgment but also unlearning internalized shame.

Maternal Burden as Existential Condition: The Never-Ending Marathon

The description of caregiving for an autistic child as a "marathon" that never ends, in contrast to the "sprint" of typical motherhood, points to a fundamental alteration in the structure of maternal time. For typical parents, the arc of caregiving is predictable – intense early years followed by gradual independence. For these mothers, relief is absent, only continued vigilance. P5's statement – "I don't consider myself a woman at all. I consider myself support staff" – is not hyperbole. Her identity has been absorbed into her function.

This finding aligns with extensive literature showing that mothers of autistic children experience elevated stress and depressive symptoms compared to parents of typically developing children (Lai et al., 2015). But IPA reveals what quantitative scales miss: the felt quality of this burden. It is not simply "high stress", but it is a state of being in a state of constant hypervigilance. Kiami and Goodgold (2017) have shown that increased stress among caregivers leads to poorer treatment outcomes for children with ASD. The mothers in this study are not just managing a child's disability. They are managing a system without a break.

Nevertheless, mothers expressed profound pride in their daughters' small victories – completing a morning routine, crossing a street independently, sewing on a machine. These moments of pride play a key role in maternal identity. They are the evidence that the marathon is worth running. From an IPA perspective, pride functions as a narrative anchor, because it allows to see the progress and meaning, even when daily life feels chaotic. Zhang et al. (2013) have documented positive reappraisal and post-traumatic growth among mothers of autistic children. This study suggests that pride is not simply an outcome of coping, but something that enables mothers to continue coping. However, celebrating maternal resilience without questioning the conditions that demand it risks romanticizing survival under unacceptable circumstances. In critical disability studies and feminist care ethics, resilience displayed under systemic neglect is understood as a response to structural violence, not a personal virtue. The mothers in this study are not resilient because they possess some inner trait. They are resilient because the state has abandoned them.

Professional Metamorphosis: Turning Trauma into Agency

The most unexpected finding is the phenomenon of professional transformation. Several mothers retrained as ABA therapists, special education psychologists, play therapists and inclusive education specialists. One mother became "one of the best in the Russian-speaking space" in ABA and opened her own school. This is not just a "finding a job," but a big transformation in response to crisis. The mother who becomes a therapist transforms her daughter's diagnosis from a source of suffering into a source of meaning.

This phenomenon can be understood through the lens of post-traumatic growth (PTG). Zhang et al. (2013) found that mothers of autistic children can experience positive psychological changes following adversity, including greater appreciation of life, new possibilities and personal strength. From an IPA perspective, it is not just growth, but also a regained sense of agency.

These mothers stopped being passive recipients of a failing system and became active participants in shaping it. By acquiring professional credentials, they gained a voice in the institutions that excluded them. As P7 said: "I believe that I now bring so much benefit, and it feels like I found myself thanks to her."

In a context where systemic support is weak, these mothers are building the infrastructure of autism care themselves. They are not just waiting for the state to act. Instead, they are taking those roles that are usually expected from the state. From a critical perspective, this professional transformation is not a success story about individual agency. It is an indictment of a system that forces mothers to become experts because no one else will. This is heroic but also problematic; the creation of an inclusive society should not rest on the shoulders of mothers already exhausted by caregiving. The very fact that professional metamorphosis emerged as a theme is a sign of systemic failure, not a celebration of individual resilience alone.

Family Dynamics: Togetherness and Fragmentation

The impact of raising an autistic adolescent girl had impact not only on the mother but entire family system. Marital relationships became strained, with disagreements about discipline escalating into arguments. Hartley et al. (2018) demonstrated bidirectional spillover between parenting stress and marital interactions – days with more negative marital interactions were associated with higher parenting stress and vice versa. The mothers in this study described it as: "We react differently to her behavior. I tend to favour support and understanding, while he sometimes prefers a stricter approach. Sometimes this leads to arguments" (P1). In one case, the parents blamed each other for the diagnosis itself, which threatens the very foundation of the family.

Siblings also experienced adverse effects. Mothers report that their other children received less attention and felt neglected. One mother described "maternal fragmentation" to attend to both children. This finding is consistent with research showing that siblings of autistic children can experience emotional difficulties and reduced parental attention (Kiami & Goodgold, 2017).

From an IPA perspective, the sibling's experience is largely absent from these accounts because the mother's attention is so consumed by the autistic child. The sibling becomes a "shadow" figure, being present but unseen.

However, some couples reported that the challenge united them and fostered a teamwork. As one mother said: "When we became a team with him, then it became easier." This aligns with Walsh's (1996) family resilience framework, which emphasises shared beliefs, flexible organisation and collaborative problem-solving as key to positive adaptation. Research on couples raising a child with ASD has similarly found that a "we are together" mindset

characterised by shared beliefs, teamwork and shared experiences, serves as a source of resilience (Sim et al., 2019). The difference between families that thrive and those that struggle may lie not in the presence of stress but in the meaning that couples make of that stress. Those who build a shared sense of purpose and partnership cope better than those who become isolated and blame others.

Another striking feature of this study is not only what mothers reported, but who was absent. Despite recruiting for primary caregivers of any gender, only mothers participated. This absence is not a sampling limitation – it is a finding. In post-Soviet countries, disability caregiving falls disproportionately on women due to the legacy of Soviet state-family models (Phillips et al., 2023). Some mothers described husbands who were absent from daily care, blamed them for the diagnosis or disagreed with supportive approaches. This absence has material, emotional and professional costs: mothers lose income, sleep and their own identity – “I don't consider myself a woman at all” (P5). The question is not whether mothers are capable, but why fathers are not equally responsible. In Kazakhstan, autism care remains deeply gendered and future research must ask not only about mothers' experiences, but also about the fathers’.

Systemic Failures: The Limits of Resilience

Finally, the mothers' accounts make clear that individual resilience has limits. Personal strength cannot compensate for absent correctional schools, waiting lists measured in years, nominal "inclusion" that excludes and outdated medications with severe side effects. One mother called Kazakhstan's "inclusion" purely nominal – "just for show". This finding aligns with previous research on autism care in post-Soviet Kazakhstan, which has documented delayed detection, challenges accessing healthcare, obstacles to special education, limited public benefits and low

public awareness (An et al., 2019; Zakirova-Engstrand & Yakubova, 2023). The World Health Organization (2025) recommends early diagnosis, evidence-based interventions and community-based support for autism, but implementation remains weak in many post-Soviet countries, including Kazakhstan.

From an IPA perspective, these systemic failures are not just contextual problems. They are experienced by the mothers as something lacking. They experience the lack as a form of institutional neglect. When P4 says, "There are only three correctional schools in the whole country – that's a disgrace. You can't get into them. it's simply impossible" she is not reporting a statistic, but expressing a moral injury. The state's failure to provide care is experienced as a betrayal of the mothers. This is why the mother's call for state action – "If not for me, nothing would be done. State work is needed" – is so profoundly affecting.

Implications of the Study

The findings of this study have a number of implications for nursing practice, education, leadership, and management, as well as for the healthcare system as a whole, particularly in Kazakhstan and similar post-Soviet contexts.

Nursing practice:

Nurses working in school health services and child psychiatry should receive training on the female autism phenotype. Many autistic girls appear “simply shy,” leading to missed or delayed diagnoses. Nurses can play a key role in early detection by avoiding gender bias and paying attention to difficulties with social communication, sensory sensitivity, and exhaustion from masking. In addition, nurses should regularly assess the caregiving burden on mothers of autistic

adolescents using brief screening tools to identify caregiver strain. Nurses should actively involve fathers in consultations to challenge gendered care norms and reduce maternal burden.

Nursing education.

Undergraduate and graduate curricula must include content on autism spectrum disorders, with a particular focus on female-specific manifestations. Training based on clinical cases of “hidden autism” will improve diagnostic skills. Training should also address cultural and gender-based expectations that reinforce stigma, so that nurses can support autistic girls and their families without judgment.

Leadership and Management in Nursing.

Managers and clinical leaders should advocate for the creation of multidisciplinary diagnostic teams that include autism specialists and for reducing wait times for evaluations. The formal establishment of hospital- or clinic-based parent support groups, modeled after the online communities that study participants described as highly valuable, is a feasible and cost-effective intervention. Leaders should also develop clear protocols for school nurses to identify and support autistic girls.

Recommendations

The following recommendations are derived from the lived experiences of parents in Kazakhstan and aim to address the systemic, cultural, and clinical gaps identified in this study.

1. Healthcare system

- **Implement gender-sensitive screening.** In Kazakhstan, current screening tools and clinical training predominantly reflect male-centric autism phenotypes. The Ministry of Health should adopt and validate instruments that capture camouflaging, subtle social

differences and behavioral symptoms in girls. This means updating the national clinical guidelines to align with ICD-11 criteria.

- **Standardize access to local diagnostic services.** To reduce the need for families to seek expensive foreign specialists, Kazakhstan should implement standardized, internationally recognized diagnostic tools across all regions, not just in major cities.

2. Educational reform

- **Educate teachers on neurodiversity:** Educators require training to understand that academic competence does not preclude the need for social and sensory accommodations.
- **Increase the number of specialized correctional schools and reduce waiting lists.** Due to the lack of correctional schools across Kazakhstan, waiting lists extend for years. Immediate expansion of public and public-private facilities is required.
- **Moving Beyond 'Nominal Inclusion'.** The ministry of education should enforce standards for inclusive education, by reducing class sizes, training special education teachers, on-site speech and occupational therapists and individualized learning plans. Additionally, parental feedback systems should be established.

3. Cultural Awareness

- **Launch public awareness campaigns.** The campaigns should aim to destigmatize ASD, specifically focusing on the fact that autism is a spectrum and can look like "personality" rather than "disability" or "parenting failure". Real stories of parents and autistic individuals themselves should be central.

4. Family-Centered Support

- **Develop parental mental health services.** The government must provide state-funded counseling to mitigate the chronic tension, focusing on guilt management, cognitive reframing and stress reduction.
- **Develop peer support groups.** Formalize and fund parent-to-parent support groups. The government could co-fund those groups, providing training, moderation and connecting them with professional consultants.
- **Develop transition planning for adolescents.** Develop specialized services focused on the transition to adulthood, including vocational training, sexual health education and relationship counseling.

5. Future Research

- **Include father's perspectives.** While this study focused on primary caregivers (all mothers), exploring the role and perceptions of fathers in the Kazakhstani context would provide a more holistic view of family dynamics.

Limitations of the Study

It is important to note a number of limitations. First, the sample consisted exclusively of mothers who voluntarily chose to participate in the study. The study did not take into account the perspectives of fathers and the experiences of fathers, grandparents or other primary caregivers remain unknown. The response to this inquiry would be more comprehensive if other individuals were included, as their experiences may differ significantly and contribute to a more complete understanding of the overall dynamics of the process.

Second, the sample size was small, which is typical for interpretive phenomenological analysis. Although thematic saturation was achieved, the results are not intended for statistical generalization. Third, the study did not collect clinical data on the severity of autism or comorbid conditions that might influence care requirements. Fourth, interviews were conducted in Russian, and despite careful back-translation, some cultural and linguistic nuances may have been lost. Despite these limitations, the study provides rich, contextualized insights into an under-researched population and lays the groundwork for future research.

CONCLUSIONS

This study explores how mothers of autistic teenage girls in Kazakhstan experience caregiving. The findings point to three interconnected interpretive claims about autism, gender and the state. First, the study described a prolonged and ambiguous path to diagnosis. For some, this path was extended because their daughters could imitate social behavior. For others, their daughters were simply seen as "quiet" or "shy". What all mothers had in common was that external signs of well-being – good academic performance, absence of disruptive behavior – delayed the moment when professionals began to suspect autism. In other words, a girl who does not cause trouble in class or who does well in early grades is not seen as needing help. Her struggles become visible only when the social demands of adolescence exceed her ability to cope.

Second, mothers bear the weight of this diagnostic and social failure. They are alone witness their daughters' exhaustion after pretending all day. They are blamed when a daughter does not fit the image of a "good girl". The system that offers nominal inclusion, outdated medication and years-long waiting lists was navigated. Over time, some mothers rebuild their entire identity around advocacy, becoming therapists or educators. This professional transformation is

remarkable, but it also reveals a deeper problem – the state has effectively outsourced the responsibility of autism care to mothers.

Third, the central argument of this manuscript is that maternal resilience cannot replace systemic responsibility. The mothers in this study are not asking for praise. They are asking for schools that include, doctors who recognise autistic girls and services that give them a break. When a mother says that without her efforts nothing would be done, she is not celebrating her strength but describing a failure of the state.

Therefore, the way forward is not to train mothers to cope better. It is to build a system that detects autism in girls early, supports families practically and stops treating inclusion as a show. Autism care in Kazakhstan must shift from an individual burden to a collective, public duty. Only then will autistic girls and their mothers be treated with the dignity they deserve.

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APPENDIX A

Invitation to Participate

We are looking for parents of autistic teenage girls in Kazakhstan to share their experiences of raising their daughters. This study aims to understand the daily challenges, emotions, and ways parents support their children.

Participation involves a **one-on-one interview lasting 30-50 minutes**, at a location you feel comfortable with. The interview will be confidential and voluntary, and you can stop at any time without affecting your access to services.

If you are interested or want more information, please contact:

Phone number: +7 700 271 93 06 Email: nuraiym.tleukabyl@nu.edu.kz

Your story can help improve support for families like yours!

APPENDIX B

Consent Form for Participation in Research Study

Study Title: *Raising Autistic Teenage Girls in Kazakhstan: A Phenomenological Study of Maternal Experiences*

Researcher: Nuraiym Tleukabyl.

Institution: Nazarbayev University School of Medicine

Purpose of the Study:

You are invited to participate in a study exploring the experiences of parents raising autistic teenage girls. The study aims to understand daily challenges, emotional experiences, and caregiving strategies within your cultural and social context.

Participation Involves:

- A one-on-one interview lasting 30-50 minutes, conducted at a location of your choice.
- The interview will be audio-recorded to accurately capture your experiences.
- You may be asked questions about your daily experiences, emotional challenges, and ways you support your daughter.

Voluntary Participation:

- Participation is completely voluntary.
- You may choose not to answer any question or withdraw at any time without any consequences or impact on your access to services.
- Your decision to participate or withdraw will not affect your access to any services, support, or programs for you or your child.

Confidentiality:

- Your identity will be kept confidential. No personal identifiers will appear in any reports or publications.
- Only the researcher had access to the recordings and transcripts.

Data Storage and Destruction:

- All audio recordings and transcripts will be securely stored on a password-protected computer and backed up in encrypted files.
- Data will be retained for **5 years** after the completion of the study.
- After this period, all digital and physical data will be permanently destroyed.

Potential Risks and Benefits:

- Some questions may evoke emotional responses. You may pause or stop the interview at any time. Support information will be provided if needed.
- While there is no direct benefit to you, your participation may help improve understanding and support for families of autistic girls in Kazakhstan.

Contact Information:

If you have questions about the study or your participation, you may contact:

Nuraiym, +7 700 271 93 06, email: nuraiym.tleukabyl@nu.edu.kz

Consent:

By signing below, you indicate that you:

- Have read and understood the information above
- Agree to participate voluntarily

- Understand that you may withdraw at any time without consequences

Participant Name: _____

Signature: _____

Date: _____

Researcher Name: _____

Signature: _____

Date: _____

APPENDIX C

Qualitative Interview Discussion Guide

Study: Raising Autistic Teenage Girls in Kazakhstan: A Phenomenological Study of Maternal Experiences

Updated: November 2025

Method: Semi-structured in-depth interview

Duration: 30-50 minutes

Objectives:

1. To explore and describe the broader lived experiences, social challenges, and cultural expectations faced by parents raising autistic teenage girls in Kazakhstan.
2. To explore how these parents make sense of the emotional and psychological dimensions of their caregiving roles.

Introduction:

(To be read aloud to participants)

1. **Welcome and build rapport:**

“Hello, my name is Nuraiym. I’m conducting research on the experiences of parents raising autistic teenage girls. Thank you so much for taking the time to meet with me.

This is an informal conversation, and I hope you feel comfortable sharing your thoughts and experiences.”

2. Project context:

“The study aims to better understand the day-to-day challenges parents face, how these affect your emotions and wellbeing, and what strategies or supports help you in parenting your daughter. Your experiences will help improve support programs and services for families in Kazakhstan.”

3. Data usage and confidentiality:

“With your permission, I would like to audio-record our conversation to ensure I capture your experiences accurately. The recording will be kept confidential, anonymized, and only I will have access. Your responses will not be shared outside of this research.”

4. Voluntary participation:

“Your participation is completely voluntary. You can skip any question, take breaks, or withdraw at any time without any consequences. Do you have any questions before we begin?”

5. Consent:

Confirm that the participant has read and signed the consent form and verbally reconfirm consent for recording.

Information collection / warm-up:

(Short, non-threatening questions to gather context and ease into discussion)

1. How did you hear about this study?

2. Can you briefly tell me about your daughter (age, diagnosis, school or support programs she attends)?
3. As a warm-up: Thinking back, what is one of your happiest memories with your daughter?

Main discussion questions:

Warm-up / Life story prompt

1. **Can you tell me, in your own words, about your journey as a parent of your daughter from childhood into adolescence?**

Probes: How would you describe her as a child / now as a teenager? What have been the main changes over time?

Experience of adolescence

2. **How has adolescence been for your daughter, from your perspective?**

Probes: What changes have you noticed (socially, emotionally, behaviorally)? Which moments stand out most? How did you respond?

Daily challenges & routines

3. **What are the main day-to-day challenges you face as a parent right now?**

Probes: Practical tasks (sleep, school, self-care), social situations, sensory issues, managing emotions, safety concerns. Which are most difficult and why?

Emotional and psychological impact on parent

4. How do these caregiving responsibilities affect you emotionally and psychologically?

Probes: Stress, worry, fatigue, guilt, pride, resilience. How do you notice these feelings in your daily life?

Meaning-making & interpretation

5. How do you make sense of your daughter's behaviors and needs?

Probes: What explanations have helped you? Has this meaning changed over time? Who or what influenced your understanding?

Coping strategies and supports

6. When things become difficult, what helps you cope?

Probes: Practical strategies, emotional supports (family, friends), professional supports, spiritual/religious practices, respite. Which supports are most/least helpful?

7. What kinds of formal services or informal supports have you used or tried to access? How did that go?

Probes: Therapy, medical, school supports, support groups, online resources. Barriers to access (cost, distance, waiting lists, stigma).

Cultural and gender expectations

8. In what ways do cultural beliefs or expectations about girls or family life influence how you parent or seek support?

Probes: Expectations about femininity, behavior, marriage prospects, family reputation. Pressure from relatives or community. Examples where culture helped or made things harder.

Relationship and family impact

**9. How has parenting your daughter affected relationships within your family—
partner, siblings, extended family?**

Probes: Changes in family routine, sibling experiences, partner support or conflict, wider family attitudes.

Hopes, needs and suggestions

10. Looking ahead, what do you most wish for your daughter?

Probes: Education, independence, mental health, relationships, work. What would need to change to support those hopes?

11. What practical changes or supports would make life easier for you and families like yours?

Probes: Services, information, community attitudes, policy changes, training for professionals, parent groups.

Reflective / closing prompts

12. Is there anything important about your experience that we haven't talked about but you would like to share?

13. If you could give one piece of advice to other parents of autistic teenage girls, what would it be?

Closing:

1. Thank the participant for sharing their time and experiences.
2. Reiterate confidentiality and voluntary nature.
3. Provide contact information and referral resources if needed.

4. Inform the participant that they may be contacted for a short summary of key themes
(optional member checking).
5. Allow final questions or reflections from the participant.

Notes for interviewer:

- Use open, empathetic, non-leading prompts.
- Allow silence to encourage reflection.
- Take field notes for contextual and non-verbal cues.
- Follow distress protocol if participants show signs of emotional difficulty.
- Pilot 1-2 interviews to refine language, pacing, and culturally sensitive phrasing.

APPENDIX D**AI Declaration Form**

Completing the AI declaration is compulsory for this course. Please declare how you have used any AI tool (e.g., ChatGPT, Bing, Bard, QuillBot) for any part of completing this coursework, including the approved usage in this module. This form should appear immediately after your cover page. The course instructor has provided an approved usage of AI tools for this coursework, as stated in the course documents.

Have you used any AI tool for this coursework (including the approved usage)?

☐ Yes

I acknowledge the use of ChatGPT (<https://chatgpt.com>) and FreeFiles.ai (<https://fireflies.ai>) to assist in transcribing primary interview data and refining the academic language of the final report.

I entered the following prompts on 05.03.2026, 30.03.2026, 8.04.2026, 14.04.2026:

- "Convert the attached audio file from the interview into a full text transcript".

The output from these prompts was used to the transcription output provided the raw data for thematic coding. The language suggestions were manually reviewed and edited to ensure the final text reflects my original analysis and voice.

I acknowledge the use of Gemini (<https://gemini.google.com/>) and Grammarly (<https://www.grammarly.com/>) to assist in proofreading the manuscript and refining the expression of ideas in English.

I entered the following prompts periodically during the drafting phase from January 2026 to April 2026:

- "Check the following paragraph for grammatical errors and punctuation."
- "How can I express this idea more clearly and formally in academic English? "
- "Improve the academic tone and vocabulary of this section while keeping my original text."

The output from these prompts was used to improve the linguistic quality and clarity of the research paper. Every suggestion was manually reviewed and further modified to ensure it accurately represents my own tone, style and research findings.

Name: Nuraiym Tleukabyl

Student Number: 202232064

Course: Capstone II: Evidence-Based Quality Improvement/Research Project Completion

Program: Bachelor of Science in Nursing

Signature:



Date: 22.04.2026