

CURRENT PROBLEMS OF INCLUSIVE AND SPECIAL EDUCATION

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SITUATIONAL ANALYSIS OF INTERSECTORAL CARE FOR CHILDREN WITH AUTISM SPECTRUM DISORDER

Abstract

This article presents a situational analysis of intersectoral care for children with Autism Spectrum Disorder (ASD) in Kazakhstan. The study analyzed legal documents from the healthcare, education, and social service sectors spanning 2017 to 2023. It focuses on recent developments in providing comprehensive care for children with ASD, examining approaches, challenges in implementing these regulations, and assessing potential benefits for patients. The results were deliberated by the project team, which includes parents of children with ASD and specialists from the inclusive services field. The research found that recent legal changes have shifted from a medical to a socio-pedagogical model, concentrating on creating conditions for the development of children with special educational needs. Notable initiatives and improvements in health regulations concerning ASD have been observed. The analysis also identified some challenges and opportunities for enhancing the intersectoral care system for children with ASD in Kazakhstan.

Keywords: ASD, education, inclusive, preventive health care, social assistance.

Introduction. Autism Spectrum Disorder (ASD) is a group of different conditions caused by a neurological developmental disorder (Chiarotti et al., 2020). This disease in children leads to a persistent lack of communication and support for social interaction with others. In addition, the child may exhibit limited interest and repetitive behavior (Lord et al., 2018). Over the last decade, there has been an a noticeable rise in the prevalence of ASD in all countries. In a systematic review and meta-analysis, the authors determined the global prevalence of ASD to be 0.6% (Salari et al., 2022), aligning closely with the World Health Organization data, which estimated 0.76%, and it was determined to represent approximately 16% of the world's child population (Baxter et al., 2015).

However, in subgroup analysis, the largest numbers were in Australia (1.7%), the Americas, and Africa by 1.0%, Europe (0.5%) and Asia (0.4%) (Salari et al., 2022). In America, ASD prevalence data vary between The Centers for

Disease Control and Prevention, which found 1.68%, and parent-reported data at 2.5% (Kogan et al., 2018). Men are most commonly affected compared to women, where the mean ratio is 4.2, and mental retardation was a common comorbid condition at 33.0% (Zeidan et al., 2022).

Management of care for children with ASD is provided by primary health care professionals who regularly assess and monitor health status. In addition, help from social services is important (Ip et al., 2019). Frequently, children diagnosed with Autism Spectrum Disorder (ASD) require personalized intervention, encompassing the formulation of specialized educational programs. These programs may include components such as speech-language therapy, occupational therapy, and other tailored approaches (Ontario Association for Behaviour Analysis, 2017; Charman et al., 2014). Proper multidisciplinary care approaches have the potential to enhance the well-being of individuals with ASD and their caregivers or parents (Frye et al., 2022).

The objective of our study is to conduct the regulatory documents analysis related to the care of children with ASD from three ministries of Kazakhstan.

Materials and Methods. We conducted an analysis of legal documents spanning the healthcare, education, and social service sectors in the Republic of Kazakhstan from 2017 to 2023. The focus of the document analysis was on recent developments in providing comprehensive care for children with Autism Spectrum Disorder (ASD), examining approaches and challenges in implementing these regulations, and assessing potential benefits for the patients.

The information examined encompassed decrees, guidelines, and the roadmap titled “Improvement of Comprehensive Assistance to Children with Disabilities in the Republic of Kazakhstan for 2021-2023.” These documents were sourced from the official websites of three ministries, the legal portal “Adilet,” and the National Center for Health Development, which regulates health system processes. Search keywords included combinations of terms such as “ASD, education, inclusive, preventive health care, social assistance, children, Psychological Medical and Pedagogical Consultation (PMPC), and others.”

The results obtained were deliberated upon by the project team “Integrating Children with Autism Spectrum Disorder into the Social and Educational Environment Based on Comprehensive Support: Challenges and Benefits.” This team comprises specialists from inclusive services and parents of children with ASD.

Results. Medical services. Childhood is one of the priority areas of the Government of the Republic of Kazakhstan (RK), consequently medical care is regulated by many legal decrees. Screening and further management of ASD symptoms are one of the recent areas where the new initiatives and improvements in health care regulations are noted. According to the hierarchy of laws, we focus on Constitution, Constitutional Laws and other regulatory documents issued by the Ministry of Health (MoH) RK. As stated by clause 27 7 of the Constitution all children are under Governmental support and clause 29 states that all children are covered by State Guarantee Benefit Package for medical health. The law of the RK dated July 11, 2002 No. 343 “On

social and medical and pedagogical correctional support for children with disabilities” defines two groups of children: children at risk and children with disabilities. Children at risk are the category aged 0-3 that are having a high probability of lagging behind in physical and (or) mental development in the absence of early intervention and the provision of social and medical and pedagogical correctional assistance. Children with disabilities refer to individuals below 18 years old experiencing physical and/or mental impairments, resulting from congenital, hereditary, acquired conditions, or injury aftermath, confirmed according to specified procedures. The above-mentioned legislation outlines the following objectives for healthcare:

- 1) early (from birth) diagnosis of congenital and hereditary diseases, deviations from normal development;
- 2) prevention of retardation and disorders in the development of children, prevention of severe forms of disability;
- 3) reducing the level of child disability;
- 4) compensation or restoration of the physical, mental and other abilities of children with disabilities, the realization of their social rights, the promotion of their most complete social adaptation.

To implement the goal 1 and 2 of the MoH, screening of children for the risks of developing ASD is described in the legal act of the Minister of Health dated as of March 15, 2022 No. 25 “Standard for the organization of pediatric care in the Republic of Kazakhstan” and outlines methods to evaluate the progress of the development of autism risks in children. The TABLE attached to regulatory act #704 highlights home visits for early diagnosis of developmental risks. In total, there are 10 home-visits that could be possible ways to evaluate the risk of ASD symptoms in children.

The Pediatric Standard also defines the M-CHART tool as one of the screening tools for use at the outpatient level (Attached to this document). This is a tool used by health practitioners in the form of asking questions to parents/ caregivers and identifying the risk of ASD. The M-Chart tool was approved by MoH only in 2022 and included in clinical protocols as a tool to use by the nurse at primary care level.

In the Decree 704 “On Approval of the Rules for Organizing Screening”, visits to children to

assess the neuro- psychological development of children aged 0 -5 years. It also defines the tool that is called as Scale for neuro-psychological development and includes such domains as Sensitive area and speech and Social sphere. Both domains contain questions according to the age, whereas the assessment of neuro-psychological development should be done once in two months until age 1. Consequently, there are several opportunities at the primary care level to identify the risk of ASD that would be a proper base for early interventions.

Once a child is diagnosed with ASD, the primary care nurse or the nurse of the Child development room recommends to undergo the Psychological medical and pedagogical consultation to identify the educational needs of a child. PMPC is a structure that belongs to the Ministry of The process of the Psychological medical and pedagogical consultation is described at the chapter below. The data later are gathered from PMPC and the local health department goes to the Republican health institutes and MoH.

Early intervention services concerning primary care rehabilitation are available at centers where a multidisciplinary team, comprising psychologists, defectologists (speech pathologists, and rehabilitation specialists), administers care. This process is regulated by the legal act “On approval of the Rules for the provision of medical rehabilitation” dated

October 7, 2020 of the Ministry of Health. The rehabilitation of ASD is coded as F. 84, including subcodes (codes).

The most recent changes in clinical practice guidelines in the world are also reflected in Kazakhstani clinical protocols and the status of clinical protocols shifted from jurisdictional to recommendation character. The clinical protocols on “Childhood Autism “, “Asperger’s Syndrome”, “Atypical Autism”, “Hyperactive Disorder” are developed in 2021 by the Republican Center for Psychological health.

Educational services: In recent years, awareness and understanding of the challenges associated with autism have increased in Kazakhstan, leading to more comprehensive support for children with Autism Spectrum Disorder (ASD) and their families in the realm of education. During the study period of 2017-2023, positive changes have been observed in the policy of inclusive education. The education of children with ASD is considered within the context of inclusive education.

The law “On Education,” dated July 27, 2007, No. 319-III, underwent changes during the period 2017-2023, which included the formulation of the concept of inclusive education. Notably, for the first time, subparagraphs addressing psychological and pedagogical support and the assessment of special educational needs (SEN) were incorporated (refer to Table 1).

Table 1. *Amendments to the Law of the Republic of Kazakhstan “On Education” dated June 26, 2021*

The specific clause, article of law	The early version of the Law of the Republic of Kazakhstan «On Education»	The corresponding amendments to the Law of the Republic of Kazakhstan «On Education» dated June 26, 2021
Paragraph 11, Article 5	Previously, there were no subparagraphs given in the amendments	Supplemented with the following subparagraphs 11-3) develop and approve rules of psychological and pedagogical support in educational institutions; 11-4) develop and approve rules for assessing special educational needs;
Paragraph 1, Article 31	1. Children attaining the age of six are eligible for enrollment into the 1st grade	1. Children from the age of six are admitted to study in the 1st grade. For children with disabilities, admission to educational organizations for receiving secondary education is permitted between the ages of six and ten. The education of children with disabilities is conducted with due consideration to the assessment of their special educational needs. Concurrently, the duration of acquiring primary and basic secondary education through educational programs is mandated to be a minimum of ten years.

According to Article 49 of the Law on Education, the right to choose the educational institution lies exclusively with the parents or legal representatives of the child. When applying to a kindergarten or general education school for children with Special Educational Needs (SEN), there is no requirement for the conclusion of the PMPC. However, if a parent opts for a special kindergarten or school, the decision of the PMPC is necessary before admission.

In the Law of the Republic of Kazakhstan dated July 11, 2002, No. 343, titled ‘On Social and Medical and Pedagogical Correctional Support for Children with Disabilities,’ changes were made during the study period concerning the functioning of the PMPC (refer to Table 2).

As evident from the table, the primary role of the PMPC is now to assess the Special Educational Needs (SEN) of children with disabilities. Prior to 2021, children with disabilities were directed to schools based on a medical diagnosis, and they had to adapt to general education programs. Following the changes outlined in Table 2, the PMPC’s activities now take on a socio-pedagogical character. This signifies a shift from a medical model to a socio-pedagogical one, where SEN assessment is conducted to create

conducive conditions for a child’s development at school.

For instance, whereas previous PMPC conclusions specified a medical diagnosis such as childhood autism or ASD, today, socio-pedagogical classification of children with SEN is employed (refer to paragraph 133, chapter 3, paragraph 8 of the Order of the Minister of Education of the Republic of Kazakhstan dated August 31, 2022, No. 385, titled ‘Model Rules for the Activities of Organizations of Preschool, Primary, Basic Secondary, General Secondary, Technical and Vocational, Post-Secondary Education, Specialized, Special, Educational Organizations for Orphans and Children Left Without Parental Care, Organizations of Additional Education for Children and Adults’). For example, it might be expressed as difficulties or impairments in communication and social interaction or a lack of independent mobility, necessitating individual care. This more accessible terminology aids teachers in educational organizations, as highlighted in an interview with the director of PMPC in the Karaganda region. This shift aims to facilitate the creation of conditions tailored to the child’s characteristics and the adaptation of the curriculum to meet their needs.

Table 2. *Amendments to the Law of the Republic of Kazakhstan dated July 11, 2002, N 343 “On social and medical and pedagogical correctional support for children with disabilities”*

The specific clause, article of law	Early revision until 2021	The corresponding amendments in the law of 06/26/2021
Article 10. Psychological-medical-pedagogical consultations	Psychological, medical, and pedagogical consultations function as state institutions responsible for diagnosing and conducting psychological, medical, and pedagogical assessments for children with disabilities. Their purpose is to identify criteria for social, medical, and pedagogical corrective support, ascertain the appropriate type and format of education, and formulate individual rehabilitation programs.	A Psychological-Medical-Pedagogical Consultation is an educational institution responsible for conducting examinations and providing counseling for children. It assesses special educational needs, identifies suitable conditions for education, determines educational programs, and directs specialized psychological and pedagogical support for children with disabilities.

According to subparagraph 11-4) of Article 5 of the Law of the Republic of Kazakhstan ‘On Education,’ the ‘Rules for Assessing Special

Educational Needs’ were initially approved by order of the Minister of Education and Science on January 12, 2022 (No. 4). As per these rules,

children with Autism Spectrum Disorder (ASD) are categorized within the first group of children with Special Educational Needs (SEN). The basis for addressing the identified SEN in children of the first group relies on the conclusions and recommendations of the PMPC, the decision of the psychological and pedagogical support service, and/or the pedagogical council of the educational organization (Rules for Assessing Special Educational Needs, 2023).

If a child enters an educational organization without a recommendation or conclusion from the PMPC, the responsibility of the organization is to identify the SEN of the child and develop an individual program for their education. This process involves the participation of psychological and pedagogical support and/or the pedagogical council of the organization. Consequently, the 'Rules for Psychological and Pedagogical Support in Educational Organizations' were initially approved by the Minister of Education and Science on January 12, 2022 (No. 6), following subparagraph 11-3) of Article 5 of the Law 'On Education.' As outlined in the rules, psychological and pedagogical support encompasses the identification and assessment of the special educational needs of individuals (children) with SEN (Rules for Psychological and Pedagogical Support in Educational Organizations, 2023).

The National Scientific and Practical Center for the Development of Special and Inclusive Education (NSPC DSIE) under the Ministry of Education of the Republic of Kazakhstan oversees the methodological guidance of regional and city PMPCs (paragraph 93, chapter 3, paragraph 8 of the Order of the Minister of Education dated August 31, 2022, No. [reference]). The conditions and methods for the psychological and pedagogical examination of a child with autism are outlined in paragraphs 131 and 132. Chapters 4 and 5 detail the procedures for the activities of psychological and pedagogical correction offices and rehabilitation centers, respectively. Chapter 6 focuses on the operations of the Center for Support of Children with Autism Spectrum Disorders (ASD). These measures signify positive strides towards inclusive education and reflect a comprehensive and compassionate approach to children with ASD.

Social services. The similar process of analysis of legal acts of the law portal "Adilet"

was conducted for regulatory documents in the social support area. The social support system in Kazakhstan is covering the children with disabilities with a state package of social support. This package includes financial, legal and other special social services. Autism has been recognized as a disease for social support quite recently and is regulated by the regulatory document #44 "On approval of the Rules for conducting medical and social expertise" dated as January 30, 2015. Once the child is registered with the status of a child with disability, the local authorities of medical-social expertise assign different status of disability according to the disease severity and categorize it to 3 groups. The recent changes in the categories as a child with disability from the birth has been changed to the category called "child with disability until age 7" and then prolongs with child with disabilities for the particular term. One of the recent changes in law is the changing the status of a parent/caregiver for a child with a disability of group 1 and providing them with work experience for the period of caring for a child. This experience enables people caring for a child with a disability of group 1, the right to appropriate retirement. Alongside financial aid, the Government covers children with disabilities with free special social services, where different types of care is provided. Children with disabilities can take day-care services with multidisciplinary team support, which in cases in children with ASD includes psychologists, speech pathologies, caregivers and other educational support team members. Visiting day-care centers does not influence the parents in terms of governmental financial aid.

Discussion. The analysis carried out by Michelle Somerton co-authors showed that in Kazakhstan there is a variability in the approaches of different specialists (psychiatrists, child neurologists, general practitioners and others) in understanding autism, which is often based on subjective indicators, and often excluding the latest scientific evidence (Somerton et al, 2022). This fact may be a barrier to the provision of quality, evidence-based care, which indicates the need for training among medical professionals.

The regulatory documents do not sufficiently define the role of assistance to parents, in particular, psychological support. Parents or caregivers of ASD children in Kazakhstan had

high levels of stress and depression (Alibekova et al., 2022).

There significant developments are occurring within the implementation activities of a roadmap titled “Improvement of Comprehensive Assistance to Children with Disabilities in the Republic of Kazakhstan for 2021-2023”. The roadmap is being led by Aruzhan Sain, who holds the position of children’s ombudsman. The mention of “On approval of the Roadmap for improving the provision of comprehensive assistance to children with disabilities in the Republic of Kazakhstan for 2021-2023” suggests that this initiative has undergone an approval process. The roadmap encompasses four key chapters focused on comprehensive initiatives, including preventive measures, early interventions, enhancements to rehabilitation services, improvements in accounting systems, and the provision of special technical means and medical products. The primary objective of this roadmap is to bolster collaboration across health, education, and social support systems, fostering a multisectoral approach. The First President Foundation “Kamkorlyk” is instrumental in this initiative, establishing care centers within the health sector that offer a 21-day rehabilitation program for children with disabilities. This endeavor is expanding into the realm of social support, with the establishment of centers providing specialized services for children with disabilities, including those diagnosed with Autism Spectrum Disorder (ASD). The duration of stay at “Kamkorlyk” Centers offering special social services ranges from 6 to 12 months, involving a multidisciplinary team of diverse specialists. Despite concerted efforts from various stakeholders, early interventions face challenges due to legislative gaps in identifying children with ASD. Future initiatives should prioritize providing guidance for parental support from primary health care professionals to facilitate the timely identification of parents requiring assistance. In summary, the roadmap is designed to address multifaceted aspects of care for children with disabilities, with notable contributions from the “Kamkorlyk” Foundation, and highlights the need for targeted efforts in early intervention and parental support.

Despite significant changes in the practice of providing care to children with ASD, our opinion is consistent with the need for further

improvement in strengthening the system of professional care for children with autism (An et al., 2020) as well as given the situation as a COVID 19 pandemy (Amirova et al., 2022).

Despite significant coverage in the educational area, some pitfalls are important to note:

1. Even though the PMPC centers cover the entire territory of the Republic (a total of 92 institutions, on the website of the NSPC DSIE), however, even in the city of Almaty, there is a shortage of PMPC specialists and one specialist has a very large load, due to as a result, specialists cannot devote sufficient time to counseling each child.

2. Children at risk are screened en masse, and the healthcare organization sends information to the territorial PMPC. This can be shown through the interview with the director of PMPC in Karaganda region, the bridge between the two subordinate organizations is poorly established and information from the polyclinic is often not sent to the PMPC. Because of this, there is no timely intervention in child development.

3. If a parent (legal representative) brought a child with SEN to a kindergarten or a general education school, then the organization does not have the right to refuse admission. The absence of a PMPC conclusion is not grounds for refusal. The conclusion of the PMPC for parents (legal representatives) is advisory in nature, and for the organization of education, it is mandatory.

Conclusion. In conclusion, our analysis of legal documents pertaining to comprehensive care for children with Autism Spectrum Disorder (ASD) in the Republic of Kazakhstan has illuminated both strides forward and areas warranting improvement. While commendable efforts have been made to enhance the system of professional care for children with ASD, challenges persist in the healthcare sector. Notably, there exists a lack of standardized approaches among medical professionals, coupled with insufficient emphasis on providing psychological support for parents.

Within the education sector, despite the presence of PMPC centers across the entire territory of the Republic, challenges such as shortages of specialists and inadequate communication between organizations persist, leading to delayed interventions in child development. Addressing these issues necessitates further guidance and training for

healthcare, social, and education professionals. Additionally, an increased focus on psychological support for parents is imperative to foster a more holistic and supportive environment for children with ASD.

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