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**SITUATION ANALYSIS OF CHILDREN
WITH DISABILITIES**
for the Development of an Inclusive Society
in the Republic of Kazakhstan

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Pictures on the cover: Day care facilities for children with disabilities: Astana's child medical-social institution and the 'Balam-ai' Child Development Centre.

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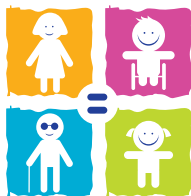
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The inclusive school, Astana



EXECUTIVE SUMMARY

This report provides a situation analysis of children with disabilities in the Republic of Kazakhstan. A holistic overview of the state of children with disabilities in Kazakhstan was constructed using a mixed-methods approach involving primary document review, focus group discussions, and in-depth interviews with teachers, parents of children with and without disabilities, children with and without disabilities, representatives of government institutions, and specialists working in non-governmental organisations. Analysis of primary and secondary data has revealed that the past two decades have been characterised by significant reform in the normative, legislative, and regulatory frameworks that address the rights of children with disabilities. These improvements reflect Kazakhstan's continued prioritisation of the protection and social inclusion of children with disabilities.

Continuing efforts to promote social inclusion and equity in Kazakhstan have resulted in the

development of several pieces of legislation that explicitly address children with disabilities. Specific legislation addresses rights to free education (to primary, secondary and professional training, as well as free higher education for those qualifying), specialised treatment in health care facilities, provision of services and material aid, and social support. Other legislation – such as that related to building codes and standards to promote accessibility – does not explicitly address children with disabilities but encompasses their needs indirectly. The laws and regulations introduced in the last two decades that address the rights of persons/children with disabilities not only provide a solid framework for the social protection of children with disabilities, but they also highlight the problems and special needs that such persons face while introducing the concept of social work to Kazakhstan. As a signal of their ongoing commitment to addressing the needs of persons and children with disabilities, Kazakhstan signed the UN Convention on the Rights of Persons with Disabilities on 11 December 2008.

In addition to developing a more cohesive and encompassing legislative framework, Kazakhstan has also introduced several regulatory changes that address children with disabilities. Kazakhstan has adopted new regulations that aid timely detection of disabilities from early stages of pregnancy. New regulations are in place for antenatal, perinatal, and neonatal screenings. A new method has also been introduced for the integrated management of childhood illnesses and early childhood development. Sectors like education, health and social protection have assumed new dimensions and roles in terms of identification, protection, inclusion and equity of children with disabilities. Pedagogical examinations in the education sector have helped in identifying developmental delays. Within the social sector, a child's degree of disability is assessed and, on the basis of the severity, prospects for social inclusion – which incorporates inclusion in the labour market – are also assessed. Efforts are integrated across sectors, and mass standardised screening of children has begun to identify developmental risks in early childhood, which aids in the development of life-long strategies for inclusion.

Monitoring the incidence of child disability also appears to have improved over the past decade. Between 2005 and 2012, the number of children with disabilities registered across the country increased, which reflects not only growth in both absolute and relative numbers of disabled children in Kazakhstan but also increased identification, registration, and subsequent protection of children

with disabilities. While there is some indication that the social stigma associated with disability has decreased, there is still some degree of undercounting of children with disabilities. There is some evidence that a substantial number of people have 'hidden disability', which are neither formally reported to the authorities nor linked to registration of disability. The distribution of children with disabilities across Kazakhstan follows larger population patterns, with the greatest absolute number of children with disabilities registered in the most populous regions (Karaganda, Almaty, Zhambyl and South Kazakhstan). Increased registration rates likely correspond to greater usage rates of state services and benefits: healthcare data indicates that 88.2% of all children under 16 years old with disabilities are registered in primary health care polyclinics, and more than 96% of children with disabilities benefit from state allowances. While these service take-up rates are impressive and represent a significant improvement over past years, they do indicate that a certain proportion of children do not make use of the benefits and services guaranteed to them by law. It is therefore important to continuously monitor the numbers of children with disabilities not benefiting from state allowances and identify on time the reasons that could lead to them not getting such benefits.

The educational inclusion and equity of children with disabilities is another area in which Kazakhstan has achieved mixed results. Based on the severity of the disability, children with disabilities can go to general, inclusive, or special pre-schools, primary schools, or social institutions. Many actors – including teachers, parents of children with and without disabilities, and government representatives – believe that inclusive classrooms provide the best educational environments for young pupils with disabilities. With that said, it is reported that inclusion of children with disabilities into general education requires more effort in terms of obligatory correctional, pedagogical and psychological assistance. At the same time it is difficult to assess specific improvements made in terms of inclusion of children with disabilities in general education given the absence of data and indicators of education participation. Secondary- and post-secondary education have seen some concrete improvements, however. Between 2002 and 2012, the number of children with limited abilities and disabilities attending technical and vocational education institutions increased. Although education for children with disabilities is free of charge, recent data indicate that only 85% of children with disabilities who applied for a scholarship received one in 2012. This signals that while

inclusion in tertiary education has increased, further efforts could be made to promote inclusion of children with disabilities in education.

Many of the trends signalled by statistics and document review were confirmed by participants in focus group discussions and in-depth interviews. Nine focus groups and 33 in-depth interviews were conducted in five regions (Astana, Almaty, Karaganda, Kyzylorda and East Kazakhstan) to investigate what gaps in protection still remain for children in Kazakhstan. Their insights suggest that there are some key areas of improvement children with disabilities have yet to experience.

In terms of educational inclusion, respondents discussed the following:

- 1) educational facilities need to be updated and refitted to accommodate children with disabilities;
- 2) more specialised personnel are needed in inclusive schools and classrooms, including teacher's aids, speech therapists, physical therapists, etc.;
- 3) lower student-teacher ratios would aid the success of educational inclusion;
- 4) tailored curricula, work plans, and education plans for children with disabilities are necessary for teachers to ensure that the pace of education is appropriate for both children with and without disabilities;
- 5) students and their parents need to be sensitised and prepared for the introduction of children with disabilities to the classroom.

Regarding healthcare, focus group and interview respondents noted three primary concerns:

- 1) accessibility of healthcare facilities;
- 2) availability of quality care, including appropriate antenatal screening and post-diagnostic counselling;
- 3) accessibility of social protection measures for health services.

In the domain of social participation, many respondents noted clear improvements in the treatment of people with disabilities in the past few years. Respondents suggested that children without disabilities are generally very receptive to children with disabilities, and what social stigma remains emanates largely from other parents or from state bodies that dismiss their children's potential to lead fulfilling lives.

Social protection was another area of social inclusion discussed by respondents. Parents and service providers discussed:

- 1) that care of children with disabilities is costly, and state benefits are thus essential;

- 2) despite generous benefit packages, many families still experience budgetary shortfalls because certain services or material needs of their children are not covered by existing benefits;

- 3) limited information is given by state bodies about how to access and make effective use of social protection provisions, which limits efficient benefit use.

Finally, respondents discussed the protection of the rights of children with disabilities through the elaboration of responsive legislative and regulatory frameworks. Respondents noted that substantial improvements have been made in the development of explicit frameworks, but implementation remains a challenge because:

- 1) the way disability is defined may exclude some children from social benefit access, as there is some indication that Kazakhstan's standards for designating a child as having a disability is more stringent than international standards;
- 2) monetary and human capital resources are still lacking in many parts of the country, particularly in rural areas where there is a distinct shortage of medical/educational specialists and equipment;
- 3) novel funding structures to support the expansion of service coverage (via, for instance, the subcontracting of NGOs by state bodies) need to be further refined and adjusted to ensure consistent and affordable service delivery.

Based on the information collected in the course of primary document review, focus groups, and in-depth interviews, several key areas for improvement in the social inclusion and equity of children with disabilities in the Republic of Kazakhstan can be identified. An abbreviated set of recommendations are provided below for how Kazakhstan can better promote the social inclusion and equity of children with disabilities.

Evolving Definitions

- 1) National standards should be brought into line with best international standards, particularly regarding minimum levels of impairment that a child must experience to be considered as having a disability.
- 2) Clear standards and criteria for distinguishing "limited ability" from "disability" should be elaborated to ensure that the designation is not made arbitrarily, denying children with more minor impairments access to needed state services and goods.
- 3) Words like "child-invalid", or "child with limited opportunities" should be changed or avoided from the legal terminology to make it free from stigmatisation and isolation.

Monitoring Tools

This report provides a technical annex with a list of indicators that would need to be periodically monitored with respect to domains like education, health care services, social services well-being and social benefits, accessibility, inclusion, equity and participation of children with disabilities.

Changing Attitudes

Awareness-raising and sensitisation campaigns could be conducted that increase the visibility of individuals with disabilities. Such campaigns could demonstrate that persons with disabilities have many of the same interests, capacities, and limitations as people without disabilities.

Promoting Ability

Trainings of medical practitioners, educators, and other agents of the social support system should be conducted to ensure that they are prepared to help children with disabilities and their families plan for a productive future.

Supporting Children and Their Families

1) Parents and other family members should be educated on the unique needs, challenges, and opportunities specific disabilities bring to children. This entails understanding a child's unique development trajectory and the implications this trajectory has for a child's opportunities to lead a fulfilling life.

2) Families could be empowered to share their experiences and knowledge with each other via the creation of knowledge networks; clinics, treatment centres, or education facilities could potentially act as a hub for these informal networks.

3) Following the diagnosis of an impairment which implies disability, families could be provided with a handbook or guide that outlines the steps they have to follow to register their children and receive social benefits.

Community-Based Rehabilitation and Support

1) Community-based networks of NGOs and service providers could be formed to share strategies and knowledge through "round-table" discussions and other public fora.

2) A case worker or other public agent could be assigned to each child with a disability. This person could act as a central focal point of knowledge and coordination, helping parents make decisions on the medical, social and educational needs of their children.

Inclusive Health

1) Protection of maternal health and the promotion of healthy lifestyles can help minimise the risk of the development of disabilities, thus public education programs could be offered to this end.

2) Medical personnel may need additional training to detect disability, both in the fetal and early-childhood stages.

3) Parents should be educated about activities they need to do with their children following the diagnosis of a disability to ensure that their children develop necessary cognitive, motor, and muscle skills, independently of rehabilitation or treatment centres.

4) Medical service formats – such as day-care facilities, home-care services, or mobile medical units – could be expanded to encourage parents to seek (ongoing) medical treatment for their children.

Inclusive Education

1) Education facilities must be updated to promote accessibility, which includes installing, for example, handrails and footpaths for the visually impaired, access ramps and lower door thresholds for children with limited mobility, etc.

2) Tailored education and skills trainings need to be offered to teachers who work with children with disabilities, as many educators are not prepared to manage inclusive classrooms.

3) Schools with inclusive classes need more (specialised) personnel, both to improve the student-teacher ratio and also to ensure that specialists such as speech therapists, teacher's aids, counsellors, etc. are available to aid both students and teachers.

4) Personalised education plans should be created for children with disabilities to help ensure that the curriculum meets their needs, which should help to achieve a classroom pace that is appropriate for children both with and without disabilities.

5) Job and career counselling should be offered to children with disabilities, and where possible, tailored career training programs should be offered that help such children reach realistic future productivity goals.

6) Schools introducing inclusive education should prepare staff, students, and student's parents for the changes such a transition may bring.



'Assyl Bobek' specialized kindergarten for children, Astana

I. INTRODUCTION AND CONCEPTUAL FRAMEWORK

1.1. The main objectives of the report

The main aim of this report is to perform a situation analysis of children with disabilities in the Republic of Kazakhstan in order to assist the development of an inclusive society. The report is based on a holistic understanding of the inclusion and equity of children with disabilities and at the same time tries to identify areas for further improvements within the existing social policy, legislation, systems and resources provided to them. The analysis builds on the best practices and examples for education of children with disabilities, trying to develop policy recommendations for the Republic of Kazakhstan. Specific tools and indicators that will help to implement and measure social inclusion and equity of children with disabilities are developed based on the results of this report.

This report uses a mixed-method approach to explore the barriers and successes of the social

inclusion and equity of children with disabilities by combining desk review analysis with in-depth interviews and focus group discussions. The in-depth interviews and focus group discussions were carried out in five regions: Astana, Almaty, Karaganda, Kyzylorda and East Kazakhstan. Children, parents, teachers, government officials, and other key stakeholders were involved in the data collection process, providing a diversity of insights on how social inclusion and equity can be fostered across different domains such as education, health care, social participation, social protection, and protection of rights. The mixed-method approach was chosen to compare the official trends and figures with different actors' perceptions of children with disabilities and how they function within Kazakh society. Findings from both parts of the analysis can complement or contradict each other, and in doing so each provides unique insights into the present achievements and future challenges for the equitable treatment of children with disabilities. The desk review analysis reports on aspects of the formal, institutionalised context, such as the legislative environment and the spatial distribution of services. The qualitative analysis, in contrast, reports on perceptions and experiences of individuals within that institutionalised structure. Differences between the results of these two forms of analysis play an important role in helping to identify persistent protection gaps that can be addressed.

The remainder of this first chapter provides the conceptual framework of disability and the approaches our societies have adapted during the years in dealing with disability. The chapter continues further with reviewing the definitions of child disability in Kazakhstan, as well as presenting the situation and challenges faced by children with disabilities in the country. Chapter 2 presents a situation analysis of child disability in Kazakhstan, giving the latest statistics as well as identifying the main challenges and barriers for children with disabilities in Kazakhstan. The situation analysis is performed from the perspective of the legislative framework, institutional framework, the financing of programs and benefits, as well as the delivery of social services. Chapter 3 presents the findings from the qualitative analysis on the barriers and achievements for successful inclusion of children with disabilities. The analysis focuses on education, health care services, social participation, non-discrimination and family care, adequate standard of living and social protection, and the legislative and normative environment. The report concludes in chapter 4 with a summary of the main findings and policy recommendations.

1.2. The international conceptual framework on disability

Disability is a concept that has changed over time in our societies. This change has affected the ways societies define disability and consequently the role they adopt for integration of people with disabilities and their families. During the last decades, the move from the 'medical' model towards the 'social' model (see also Box 1) has greatly affected the way social responsibility for disability is transferred from the individuals to the society as a whole. The 'medical' model of disability (adopted especially after World War II) considered physical or psychological disabilities as a domain of medicine or psychology. Disability in children or adults was seen as a consequence of a physiological or psychological impairment related to a disease or other damages and was predominantly thought of as a 'condition' that required 'treatment'. In fact, the 'medical' term used for this model originated from the World Health Organization (WHO) debate on the usage of terms like 'handicap', 'impairment' and 'disability' when defining disability (Llewellyn & Hogan, 2000). The medical model sees the individual as flexible and 'alterable' (and therefore vulnerable and at the same time adaptable to disabilities) while society is more "fixed". Children or adults with impairments under this model are considered automatically as handicapped and often their families are considered in the same way. The fact that such a model requires people with disabilities and their families to change into more 'normal' beings, while society mainly offers a 'medical' treatment, was one of the essential critiques that led to the rejection of this model. Over the last decades social scientists and disability activists have increasingly regarded disability as closely linked with social context and have pointed to consequences like social exclusion and other disadvantages closely linked with this (Shakespeare, 2006). Furthermore, social scientists have argued that the source of disability lies within society and have emphasised the role that social circumstances have in influencing the level of observed disability (Llewellyn & Hogan, 2000). Therefore, the social model of disability requires the problem to be brought back to the society, which in turn should take a more responsible role. This would presumably take back part of the emphasis that was put on people with disabilities and their families by the medical model. In light of the social model, disability is considered as part of

the society and people with disabilities (and their families) benefit from civil and political rights (voting, freedom of expression) as well as economic, social and cultural rights (health, education, etc.).

When dealing with people living with disabilities the literature suggests switching to the social model instead of the medical model (Fougeyrollas 2008). This will mean switching from policies that provide exclusively financial assistance for people with disabilities to policies that provide an inclusive environment with medical and social support for people with disabilities. The inclusion of individuals with disabilities should start immediately at the early stage of their life. This means that significant assistance should be provided to children's parents, to the upbringing and education of the children as well as to the prevention of social institutionalisation (UNDP, 2009).

From a policy perspective, when choosing the social model over the medical model, countries should be careful in shifting the focus from the health issues of an individual to the list of barriers that need to be identified in society in order to allow full access and inclusion of services, facilities and participation. Such barriers have to do with the legislative framework (e.g. the way that individuals/children with disabilities are defined, or the protection and services provided), the inclusiveness of the various service systems (e.g. health or education), as well as the creation of a generally inclusive environment and mentality for people with disabilities (and their families) in society.

Disability in children or in people in general and especially the social and integration aspects related to disability has become a challenge all over the world. About one billion people around the world were living with disabilities in 2012, and 110 to 190 million were living with significant difficulties in functioning. Out of all persons living with disabilities about 150 million were children under the age of five. More than 400 million people with disabilities were living in lower income countries and under the poverty line (Lansdown 2012; UNICEF-WHO, 2012). Moreover, disability numbers may be even more serious than reported due to limitations of comparative or global studies. Such limitations relate to the failure to identify persons with disabilities because of differences in definitions, limitation of censuses and surveys, and the wide range of methodologies that are used to identify and measure disabilities (Schneider, Loeb et al 2001; UNICEF, University of Wisconsin, 2008).



Home Care Centre for Children with Disabilities, Astana



Box 1. Theoretical models in approaching disability

The term disability cannot be generalised to a population group, as people with disabilities are diverse and heterogeneous, coming from different gender, age, socioeconomic, ethnicity or cultural backgrounds. Moreover, not all disabilities are equal (WHO-World Bank, 2011). In the World Report on Disability, the World Health Organization (WHO) defines disability as a human condition that almost everyone will experience either temporarily or permanently at some point in life (WHO-World Bank, 2011). On the other hand, disability can also be described as impairments that can occur at three levels: in body function, in activity or in participation. Such impairments can occur separately or simultaneously (UNICEF-WHO, 2012).

During the past decades, disability has been broadly categorised by two main models: the medical and social models (Palmer and David, 2011). The medical model considered disability as a consequence of a physiological or psychological impairment related to a disease or other damages and was more thought of as a 'condition' that required 'treatment'. Therefore medicine or psychology was seen as the main 'cure' for disability. Children or adults with impairments under this model are considered automatically as handicapped and often their families are considered in the same way. Medical experts, based on diagnosis, decided upon solutions to the disability problem and the focus was on eliminating or curing disability (or the so called "normalization"). This included aspects like pre-natal genetic testing & selective abortion. The medical model requires people with disabilities and their families to change into more 'normal' beings while society mainly offers a 'medical' treatment.

The social model of disability defines disability in a social rather than an individual context. As such, it focuses more on the discourse of social accommodation and social change as primary remedies for disability. This approach was in fact a transition from the individual medical model to a structural social perspective. From a social model point of view people are being disabled by society rather than by their body. This model has been successful in de-individualising and de-medicalising disability (Palmer and David, 2011; WHO-World Bank, 2011). However, social scientists argue that the social model may fail to address impairment and the experiences of people living with disabilities (Thomas, 2002). People with disabilities could have troubles arising from their health condition as well as challenges they face in a society that is not accommodating (WHO-World Bank, 2011).

At the international policy level, the human rights approach to disability (based on the social model of disability) has shifted the focus from the limitations in children (due to impairments) to the barriers within society (preventing the child from having access to basic social services). Two international conventions provide the necessary background for promoting this approach: (i) the Convention on the Rights of the Child (CRC) that recognises the human rights of all children (including those with disabilities); and (ii) the Convention on the Rights of Persons with Disabilities (CRPD) (adopted in December 2006 by the United Nations General Assembly). Both conventions have laid the foundations for the inclusion of children with disabilities into society. Inclusion relates to the "recognition of all children as full members of society and the respect of all of their rights, regardless of age, gender, ethnicity, language, poverty or impairment". Moreover, "inclusion involves the removal of barriers that might prevent the enjoyment of these rights, and requires the creation of appropriate supportive and protective environments" (UNICEF & Innocenti Research Center, 2006).

From an international perspective, various international conventions address the rights of children and in particular of children with disabilities. The Convention on the Rights of the Child (CRC) was the first treaty that provided explicit provisions on children with disabilities (articles 2 and 23 of the CRC). Most importantly article 23 of the CRC states, children with disabilities "...should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community". However, the drafting of the CRC was taking place during the 1980s, and, as such, disability was considered a problem that resides within the individual (UN, 2011; Lansdown, 2012). The Convention on the Rights of Persons with Disabilities (CRPD) focuses exclusively on the rights of people with disabilities. The convention came into force in 2008 and by September 2013, 114 countries had ratified it (out of 156 countries that had already signed it). Article 1 of the convention defines persons with disabilities as: "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." The above definition has been criticised for restricting the definition to 'long term' and only to those with impairments (Palmer and David, 2011). Nevertheless, the convention is referring to disability as an "evolving concept" in its general principles under article 3 (WHO-World Bank, 2011).

Various other definitions try to define disability but in general they distinguish between three levels through which individuals experience the disability: impairment, functional limitations and restricted participation (Susser, 1990; UNICEF, 2008). It is important to note that the last level implies that disability may be experienced (or enhanced) from factors that have to do with the context like mobility limitations (due to non-accessible buildings or lack of transportation means), social exclusion (due to stigma-related factors or due to policy-related factors, i.e., excluding people with disabilities from accessing regular education programs, etc.). It is also important to note that in general there is a difference between the definitions of disability in children and adults. Child disabilities or developmental disabilities have been defined as limitations in mental, social, and/or physical function relative to age-specific norms (Durkin, 2001; UNICEF, 2008). Such disabilities can be a result of development disorders of the nervous system and can be present before birth, during birth or after birth. The consequences of such disabilities

can be on functional domains such as cognition, movement, speech and language, hearing, vision and behaviour (Davidson et al., 2003).

Apart from the general socio-economic, cultural, environmental factors that all children may be affected by, children with disabilities could be exposed to additional risks and mistreatment by virtue of their impairments. In the meantime, some children with disabilities could be even more exposed to exclusion and disadvantage due to their gender, different socioeconomic background, having multiple impairments, being in a remote geographic location, living in rural areas, living in conflict zones or belonging to minority groups. Around the world children with disabilities and their families are faced with discrimination, poverty and social exclusion, and other forms of abuse and violence compared with children without disabilities (social isolation, stigma and powerlessness are some of the reasons leading to abuse among children with disabilities). Institutionalisation is another important issue that children with disabilities are faced with. They have a higher risk of missing vaccinations, malnutrition, and mortality rate, as well as starting school at an older age and remaining in school for more years. Adolescents with disabilities face more challenges in accessing services and in getting information regarding sexual and reproductive health (UN 2001; Lansdown 2012; UNICEF-WHO 2012). Often parents have limited access to information that could help them provide appropriate support to their children and, in general, they suffer from lack of social support (UN, 2001; Lansdown, 2012; UNICEF-WHO, 2012).

Despite the recent legal actions, the integration and social inclusion of persons with disabilities, especially children, remains one of the big challenges in most countries of the world. This can only be achieved by adapting society to the differences of people with disabilities and not by isolating them. The provision of education for children with special needs, professional training for young individuals, providing job opportunities, free health services, social benefits, and a proper infrastructure will make life easier for both persons with disabilities and their families. To this end, differences between integrated and inclusive education programs should be taken into account. For example integrated education programs for children with disabilities tend to place more emphasis on attendance rates, while inclusive education programs put an increasing emphasis on the educational outcomes of these children. Inclusive programs do not look exclusively at children but

also at teachers and schools and how they are able to adapt educational programs to the needs of children with disabilities (Ram and Poja, 2009). The philosophy of the inclusive programs should be to ensure equity between children with and without disabilities.

Reports on the issues that are faced by persons with disabilities in most Commonwealth of Independent States (CIS) countries show that the majority of provisions (both legal and financial) deal only with the social benefits. As such, other challenges that relate to integration and equity of children with disabilities into society still need to be tackled (UN, 2011).

1.3. Defining child disability in Kazakhstan

Disability in the CIS countries during the communist regime was mostly approached using the older models of disability. People with disabilities were seen as a deviation from ‘normality’ that had to be cured (or otherwise hidden from the official statistics). Statements like “There are no invalids in the USSR!” were not uncommon (Fefelov, 1986). In fact, this strong assertion exemplifies how persons with physical and mental disabilities have been stigmatised and made invisible from society (Dunn and Dunn, 1989) throughout the Former Soviet Union (FSU). Yet, even after independence from the Soviet Union individuals with disabilities in most of the CIS countries remain an “unknown population” (Poloziuk, 2005). Most of the CIS countries have either signed or ratified the Convention on the Rights of Persons with Disabilities (except for Belarus and Kyrgyzstan). This convention gives individuals with disabilities the opportunity to become ‘visible’ and not to be treated as an ‘object’ of charity, needing only medical treatment and social protection, but as ‘subjects’ of rights and dignity (UN, 2008).

The Ministry of Labour and Social Protection is designated as the focal institution for disability issues in Kazakhstan. However, depending on the particular piece of legislation in place, there can be differences in how disability is defined by different institutions. Hence, the law “On Social Protection of Disabled Persons in the Republic of Kazakhstan” (Law no. 39-III, dated April 13, 2005) defines a ‘disabled person’ as “... a person who has health problems with a persistent disorder of body functions, caused by diseases, injuries, and their consequences, defects, leading to a physical dysfunction and the need for his/her social

Box 2. Definitions used for children with disabilities in other CIS countries and the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY)

The Republic of Uzbekistan

The official definition of child disability in the Republic of Uzbekistan is provided in the law ‘On guarantees of the rights of the child’ stating that a child with disabilities “because of limited vital functions in consequence physical, mental, sensor and / or psychic impairments needs social assistance, protection and is recognized disabled in accordance with the procedures stipulated by law”. Moreover, the law ‘On social protection of people with disabilities in the Republic of Uzbekistan’ defines a person with disability as a person “who due to the limitation of vital functions as a result of physical, mental, psychological and sensor disorders was recognized as a person with disability in the order established by the law and is in need of social protection and assistance”. Finally, the same law defines that “limitation of vital functions is a full and partial loss by a person of a capacity or possibility to carry out self-service, movement, orientation, communication, control of behaviour as well as possibility to study or to work”.

Turkmenistan

According to the Code of Turkmenistan ‘On social protection of the population’, a person with disability is a “person with long-term physical, mental, intellectual or sensory impairments as a result of which he or she has limited opportunities for full and effective participation in society”.

The same definition also applies to children with disabilities. According to the law on ‘Protection of the health of the Population’ children with disabilities are defined as “children with defects of physical and psychological development as well as children with consistent health conditions”. Finally, the law on ‘Education’ defines children with disabilities as “citizens with limited health, i.e., those who have physical and psychological disabilities”.

protection”. Furthermore the same law defines a ‘disabled child’ as “... a person under the age of eighteen years old, with health problems with a persistent disorder of body functions, caused by diseases, injuries, and their consequences, defects, leading to physical dysfunction and the need for his/her social protection”. Yet, there exist other definitions in other laws, as for example when it comes to medical services for children with disabilities. The law “On social and health care and pedagogical correctional support for the children with limited capabilities” (Law no. 343-II dated July 11, 2002) defines children with limited abilities as “... a child(ren) under the age of eighteen years old with physical and (or) mental defects who experiences restrictions in vital functions caused by congenital, hereditary, acquired diseases or trauma consequences, confirmed in accordance with due procedures”.

Such definitions seem to be a bit outdated, especially in light of the social model of disability. The term ‘disabled person’ or ‘disabled child’ references back to the medical model of disability. In fact, chapter 2 of the law on Social Protection of Disabled Persons in the Republic of Kazakhstan states that the state’s policy on social protection of ‘invalids’ concentrates on: (i) prevention of disability; (ii) social protection, including rehabilitation of ‘invalids’ and (iii) integration of ‘invalids’ into society. While this is positive in defining the responsibilities of the state regarding persons/children with disabilities, it also brings up some of the issues that still exist in using terminology related to the stigmatisation and isolation of persons/children with disabilities. More specifically, such language still stresses the ‘correction’ of disability, which in itself refers back to the medical model. Kazakhstan, along with other CIS countries, has committed to transitioning from a medical to a human rights approach to disability in line with the social model promoted in Article 1 of the CRPD (UNICEF, 2013). In terms of legislation this would mean reviewing the terminology to make it free from stigmatisation and isolation, by changing or avoiding the words

The Kyrgyz Republic

The Kyrgyz Republic has recently replaced the references to ‘a disabled person’ with ‘person with limited abilities in health’. Such provisions are described in the new law ‘On the rights and guarantees of persons with disabilities’ in Kyrgyzstan, recognising the need to consider the person first and the disability last. At the same time, other legislative regulations use a large variation of terminology and definitions. For example, the Child Code (new version of 2012) defines children with disabilities in the following way: “with limited health possibilities as children with functional impairments caused by disease, trauma or deficiencies that cause disabilities as a result of physical and (or) mental shortcomings and requires social protection for the child”. The regulations of medical and social expert commissions define persons with disabilities as “incapable citizens – minors under 16 years and disabled citizens recognized as incapable, as well as citizens who reached pension age”.

The Republic of Tajikistan

The law on ‘Social Protection of People with Disabilities’ in Tajikistan defines disability as “the degree of limitation of life activities of a person due to impairment of health and reduction of functions of the body”; “disabled is a person with health deficiencies that reduce his/her bodily functioning due to sickness, injuries, physical or mental disabilities, which limit his/her daily activities and puts him/her in need of social protection; a child with disabilities is a person with disabilities up to 18 years old.”

International Classification of Functioning, Disability and Health for Children and Youth

The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY, 2007) is based on the WHO’s ICF and is considered a step forward in incorporating the social dimension in children’s disability definition. The WHO’s International Classification of Functioning, Disability and Health (ICF) is a classification of health and health-related domains. This framework is known for considering health and disability from a wider context of social barriers. Countries could rely on such a framework for improving local definitions of disability by stressing the social model of disability instead of the medical model. In fact, the ICF-CY incorporates both the aspect of children’s impairment and the effect of this impairment on functioning and participation in the environment (UNICEF, 2013). It covers four main areas: body structures (e.g., organs, limbs), body functions (e.g., listening, remembering), limitations on activity (e.g., walking, dressing) and restrictions on participation (e.g., playing with other children, performing simple chores).

Reference: UNICEF, 2013; ICF-CY, 2007

‘invalids’ or ‘children with limited opportunities’. In this respect the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) would help in acting as a benchmark to approach disability from the perspective of the social model. The ICF-CY is based on WHO’s ICF classification (see Box 2) which goes beyond the medical model by regarding disability in two main ways: in terms of the body’s structure and functions, and in terms of the person’s activity and participation. Disability, as defined by the ICF, is an ordinary part of human existence – every person can experience some degree of it (UNICEF, 2013). The most important feature of the ICF is that it recognises that functioning and disability occur in the social context. This is an important factor underpinning why an effective definition of disability should not only address body functioning but consider this in conjunction with societal and environmental factors.

1.4. Children with disabilities in Kazakhstan

In Kazakhstan 1.33 percent of children under 18 years old were living with disabilities in 2012 (Ministry of Labour and Social Protection, 2012). This is relatively higher if compared to the other CIS countries in the region. In countries like Tajikistan 0.80 percent of children under 18 years old were living with disabilities in 2012, in Turkmenistan 0.55 percent (in 2005), in Kyrgyzstan 1.25 percent (in 2012) and in the Russian Federation 1.88 percent (in 2010) (Transmonee, 2013). Global indicators (WHO-World Bank, 2011) show that these rates are below the global average when both moderate and severe disability rates are considered (5.20 percent at the global level for children 0-14 years old), but the rates are above the average if only severe disability is considered (0.70 percent at the global level for children 0-14 years old). In its efforts to comply with the international standards for protection and inclusion of persons and children with disabilities, Kazakhstan signed the UN Convention on the Rights of Persons with Disabilities on 11 December 2008. In addition, the legislation of Kazakhstan guarantees children with disabilities rights to social care, provision of specialised institutions, free education (to primary, secondary and professional training, as well as free higher education for those qualifying), specialised treatment in health care facilities, etc. The numerous laws regulating the rights of persons/children with disabilities during the past two decades did not only help in providing a

solid framework for the social protection of children with disabilities, they also helped in bringing forward the problems and specific needs that they face. It should be mentioned that such problems and needs were previously under-discussed and under-addressed.

Despite the legislation that is already in place, children living with disabilities are still reported to face difficulties in their daily life. Seitenova and Becker (2008) have concluded that there are a substantial number of people with hidden disability (disability that is not reported formally to the authorities and/or not registered as such). This is largely because of two main reasons: i) the barriers to applying for disability benefits have increased, making it more difficult to apply for them, and ii) there are frequent experiences of discrimination against disability and barriers to participation in society for people with disabilities (UN, 2009). Parents of children born with disabilities may be reluctant to report the disabilities as the family may face social stigma and exclusion (OECD, 2009).

The education challenges faced by children with disabilities and their families in Kazakhstan are reported to be similar to the other CIS countries. Some of the other factors impeding the achievement of high quality education for children with special needs in Kazakhstan are: lack of appropriate textbooks, poverty among families with children with disabilities, inequality in access to education facilities between urban/rural areas, insufficient schools and/or trained teachers, and lack of an appropriate education model for these students (i.e. individualised approaches are missing) (OECD, 2009).

Integration outside educational institutions also remains difficult for children living with disabilities in Kazakhstan. For example, children who have to stay with their families have limited chances for conducting a normal life. Most of the buildings, streets and facilities are not adapted to be disability-friendly (OECD, 2009). Infrastructure is another challenge that children with disabilities have to face in the Republic of Kazakhstan. Transportation, access to public buildings like schools, medical clinics, etc., often limit children with disabilities from having access. Lack of transportation and often an inability to get out of their apartments has resulted in the abandonment of schools and exclusion from normal life. Most of the education facilities for children with disabilities are reported to be state-owned and poorly maintained (OECD, 2009). In situations where transportation is not possible, boarding schools

or home schooling (where available) may remain the only chances for attending education (OECD, 2009).

Poverty among families of children with disabilities, and the lack of proper inclusive conditions are identified as underlying causes of the higher number of children with disabilities living in institutions. For example, the large number of children living in institutions is sometimes attributed to the provision of food and clothing, which parents could not afford (OECD, 2009). Similarly, single parents of children with disabilities cannot work unless their children are in institutions. As a result, many children are abandoned in orphanages at birth (OECD, 2009). According to UNICEF, Kazakhstan is one of the countries with high per capita rates of institutionalisation of children in the CEE/CIS Region –out of the 5 million children in Kazakhstan, more than 30,022 children are living in state-run residential institutions, including boarding schools for children (Transmonee, 2013).

In fact, reports show that disability is one of the main reasons why parents in Kazakhstan abandoned children in statutory establishments, preventing them from realising their rights to grow up in the family environment (Golomolzina et. al., 2011). A report from Golomolzina et al. (2011) shows, that almost 32% of the abandoned children had diseases and congenital pathologies. At the same time, research has shown that living in institutionalised care settings may hinder the development of children with disabilities. This is especially true when considering the psychological, social, physical and emotional dimensions of health and well-being of the children.

Different institutions are governed by different governmental bodies in the Republic of Kazakhstan. Infant homes are currently under the supervision of the Ministry of Health while the Ministry of Labour and Social Protection is responsible for the supervision of institutions for children with psycho-neurological and muscular-skeleton disabilities. The Ministry of Education is responsible for residential institutions for children with disabilities (Haarr, 2011).

A statutory establishment for children with disabilities is not considered the optimal solution. This is because it often lacks completely the integration aspects for children with disabilities and excludes the role of their families or of the society, as in the medical model. Moreover, the existing violence between children and at the same time the violence of staff against children (51-56% of

staff in the different types of institutions reported witnessing other staff using violence against children in the institutions), shows that children with disabilities are still marginalised in these institutions. Violence is also present in specialised institutions for children with psycho-neurological/severe disabilities (Haarr, 2011). It is reported that in facilities for children with disabilities, the children often have no access to education (Haarr, 2011).

The government of Kazakhstan has started developing and implementing incentives that will encourage the use of alternative modes of care. Such incentives include receiving benefits for children with disabilities. A further step in this direction is the initiative to start giving care allowances for caregivers of children with disabilities, which began in 2010.



II. SITUATION ANALYSIS OF CHILDREN WITH DISABILITIES IN KAZAKHSTAN

The number of children under 18 years old living with disabilities in Kazakhstan reaches about 1.33 percent of the total number of children of this age group (Ministry of Labour and Social Protection, 2012). The government claims that social integration of people living with disabilities, and in particular children, is at the top of the political agenda. In his words in addressing the “Strategy Kazakhstan-2050: A new political course of the established state”, the President of the Republic of Kazakhstan has emphasised the importance of providing protection to children as “the most vulnerable and unprotected part of our society (that) should not be deprived of their rights”. He has further highlighted the importance of social guarantees in providing “inclusion of education and healthcare items for better socialization of these categories”.

In its efforts to provide more complete protection and offer better inclusion and equity for persons and children with disabilities, Kazakhstan signed the UN Convention on the Rights of Persons with Disabilities on 11 December 2008. This has again demonstrated the international commitment to go further with protecting and improving the lives of persons living with disabilities. Kazakhstan's legislation secures children with disabilities' rights to social care, provision of specialised institutions, free education (to primary, secondary and professional training, as well as free higher education for those qualifying), specialised treatment in health care facilities, etc. Yet, many challenges remain ahead and reports from the country show that there are many areas which need more integrated efforts. In 2012 the Ministry of Labour and Social Protection started the implementation of the 2012-2018 action plan for ensuring the rights and improving the quality of life of persons with disabilities. This action plan was devised as a response to the country's plan for the ratification of the UN Convention on the Rights of Persons with Disabilities and covers the needs of different groups of the population, including children (UNICEF TOR, 2012). But, the question is: How is Kazakhstan currently doing in terms of numbers of children with disabilities, legislation coverage,

institutional framework, financial protection and service delivery? This chapter explores these aspects of children with disabilities in order to give a better overview of the progress made and the future needs.

2.1. National trends and statistical data on child disability in Kazakhstan

The total number of registered children with disabilities in the Republic of Kazakhstan has increased during the period between 2005 and 2012 (figure 1 and figure 2). According to the Ministry of Labour and Social Protection (MoLSP) the number of children with disabilities (0-17 years old) in 2012 was 65,844, or 31 percent higher compared to 45,118 children with disabilities registered in 2005. Part of this increase can be attributed to the increase in the total number of children in the Republic of Kazakhstan (the number of children aged 0-17 years old increased from 4.660 million in 2005 to 4.935 million in 2012). On the other hand, as we can observe from figure 1, children with disabilities also increased as a percentage of the total number of children (from 0.97 percent in 2005

Figure 1. Total number of children with disabilities compared with the total number of children for period 2005-2012 (in thousands)

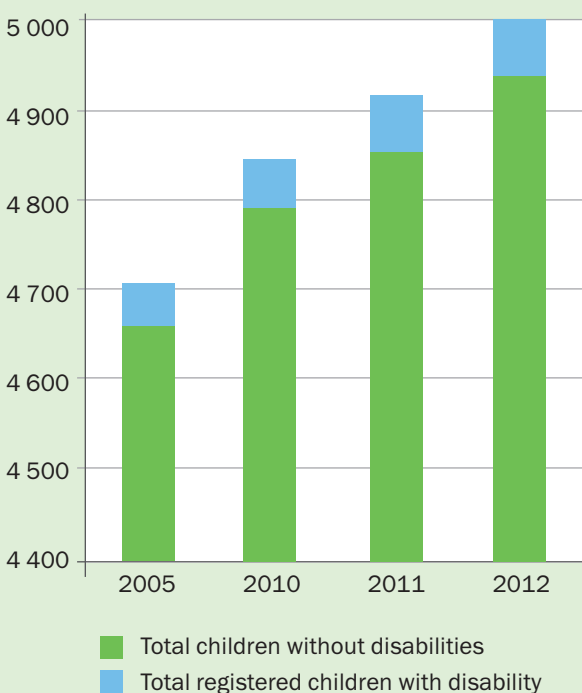
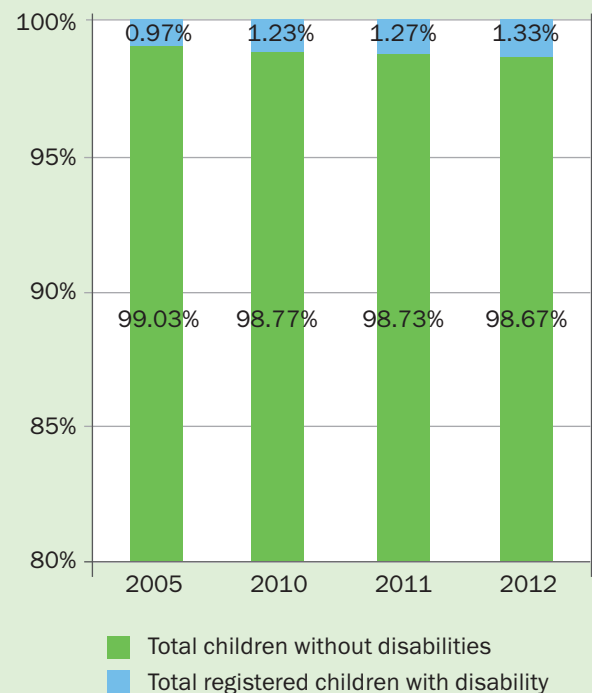


Figure 2. Total number of children with disabilities as a percentage over the total number of children (2005-2012)



Source: Own compilation based on data from the Ministry of Labour and Social Protection 2012; Transmonee 2013

| Table 1. Number of registered children with disabilities (0-17 years old) | | | | | | | |
|---|---------|---------|---------|---------|---------|---------|---------|
| Country | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 |
| Belarus | 28,895 | 28,403 | 27,662 | 26,632 | 25,867 | 25,562 | 25,737 |
| Moldova | - | - | - | 15,313 | 15,780 | 15,321 | 14,851 |
| Russian Federation | 561,881 | 556,907 | 527,126 | 506,636 | 495,378 | 495,330 | - |
| Ukraine | 122,640 | 85,564 | 50,671 | 39,516 | 157,474 | 165,121 | 166,164 |
| Armenia | 8,304 | 8,449 | 8,690 | 8,706 | 8,358 | 8,045 | 7,973 |
| Azerbaijan | 51,925 | 48,479 | 55,066 | 56,439 | 58,122 | 57,941 | 61,693 |
| Kyrgyzstan | 18,517 | 19,931 | 20,660 | 20,842 | 21,194 | 22,359 | 23,565 |
| Tajikistan | 16,963 | 19,101 | 15,319 | 18,612 | 20,348 | 24,013 | 29,144 |
| Kazakhstan* | 47,590 | 46,765 | 44,935 | 45,582 | 47,377 | 49,349 | 52,884 |

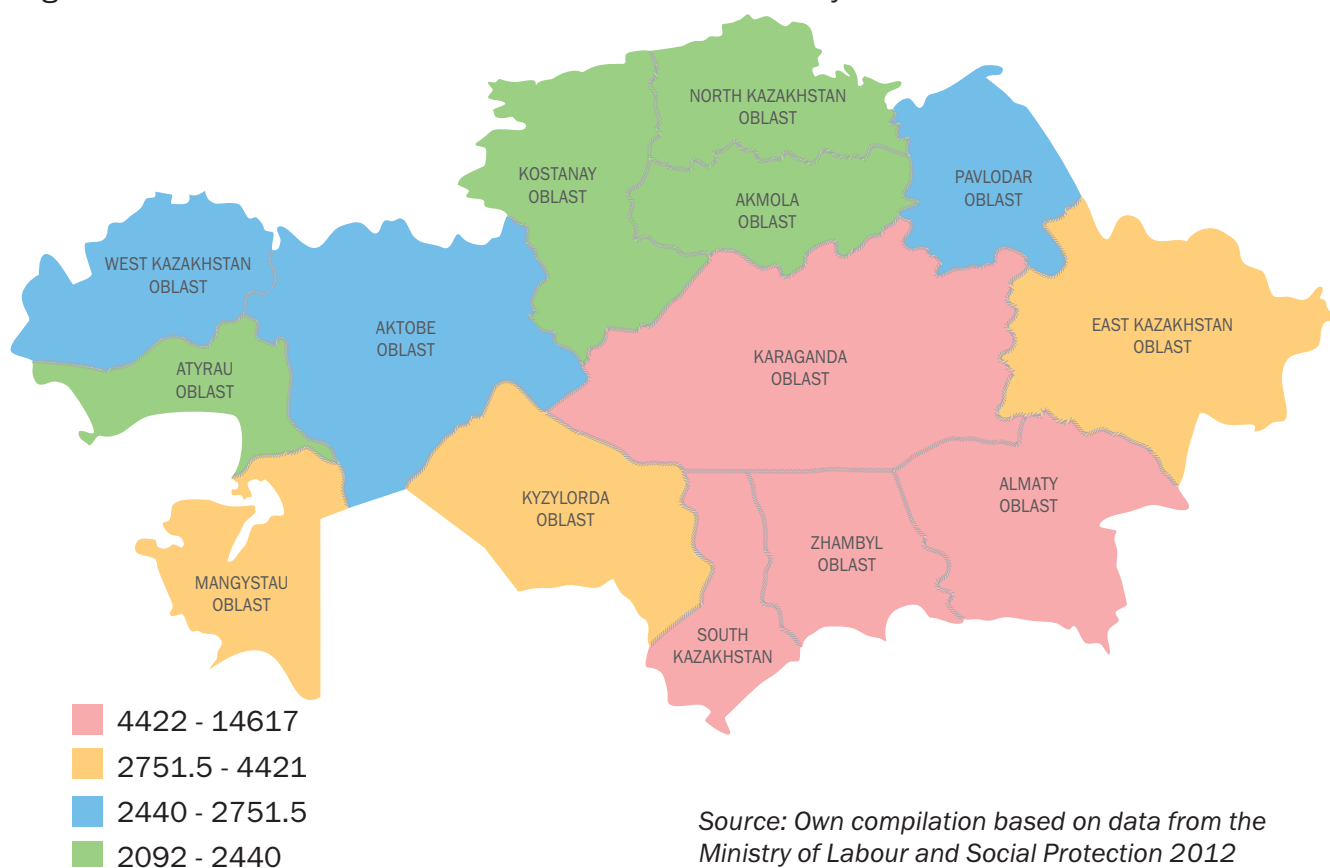
Source: Transmonee 2013

Note: *Children with disabilities aged 0-16 years receiving disability allowances.

to 1.33 percent in 2012). However, Seitenova and Becker (2008) have concluded that there are a substantial number of people with 'hidden disability' in the Republic of Kazakhstan (this is disability that is not reported formally to the authorities and/or not registered as such). It is possible to identify two main reasons for this: firstly, the barriers to apply for disability benefits (according to the figures of the Ministry of Labour and Social Protection 2012, 2093 registered children with disabilities are not taking disability benefit); and secondly, people with disabilities frequently

experience discrimination or barriers to participating in society (UN, 2009). Thus, parents of children born with disabilities may be reluctant to report the disabilities as the family may face social stigma and exclusion (OECD, 2009). Yet, it remains to be seen if the slowing down of economic growth (from 7.5 percent in 2011 to 5 percent in 2012) (World Bank, 2013) may influence the amount allocated to social programs and therefore create additional disincentives to report disabilities (and also increase vulnerability and social isolation for children with disabilities and their families).

Figure 3. The number of children with disabilities under 18 years

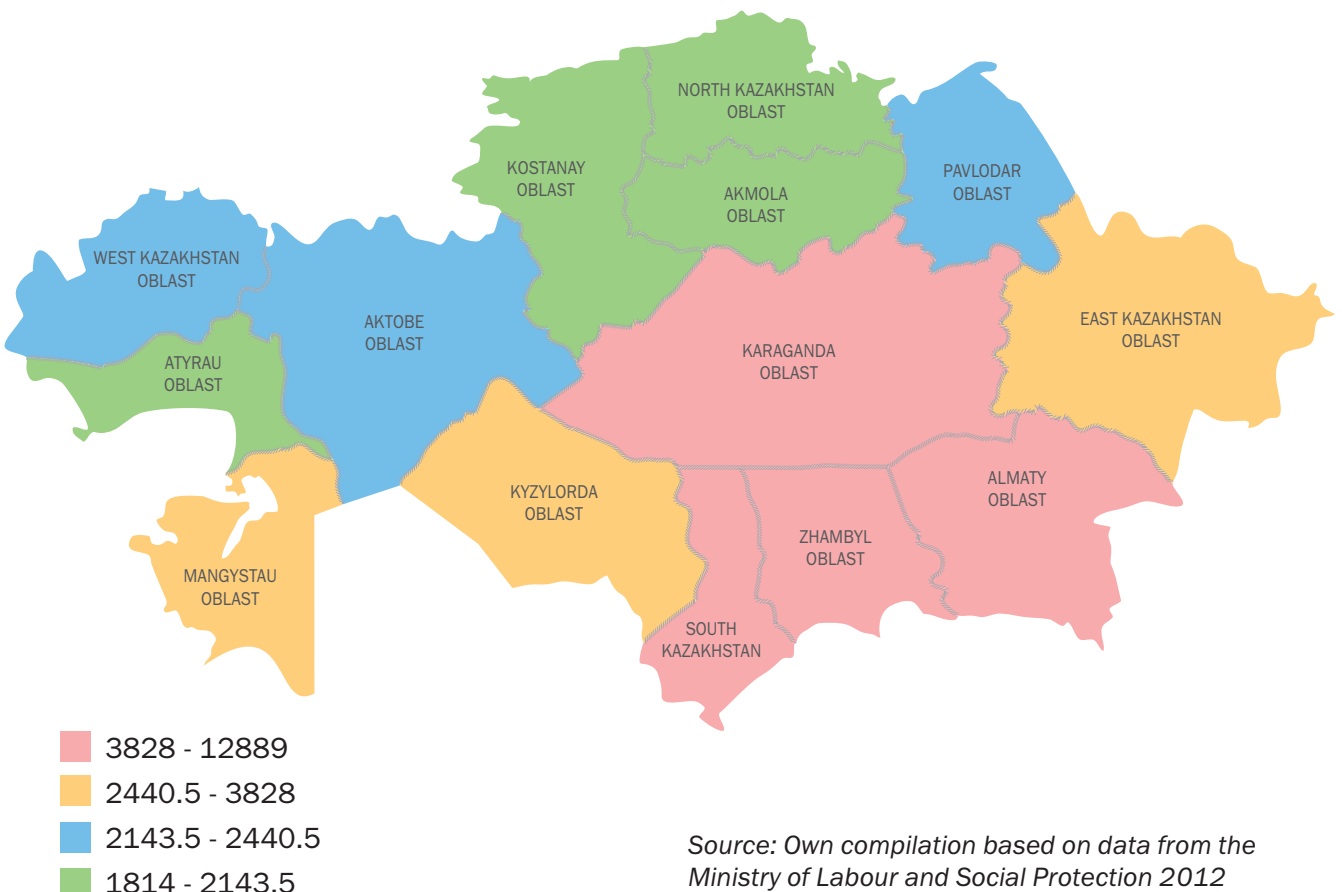


In fact, the data in table 1 show that in most ex-Soviet Union countries the absolute number of registered children with disabilities has increased between 2005 and 2011 (except for Moldova and Armenia). This increase may be a consequence of a changing climate towards children (and adults) with disabilities in each of these countries. Higher registration numbers of children with disabilities, due to a changing attitude towards these children and also better integration policies, may help in reducing the numbers of the 'hidden disability' in these countries.

Despite the increasing attention dedicated to children with disabilities in the Republic of Kazakhstan and the actions that have been undertaken for their inclusion into society, they are still reported to face difficulties in their daily life. The integration of children with disabilities into the general society continues to be reported as one of the outstanding issues for social policies in Kazakhstan. Aspects like inclusion and equity of children with disabilities into the general education system would need more efforts in terms of obligatory correctional, pedagogical and psychological assistance (UNDP, 2008).

Figure 3 above gives a map of the distribution of the total numbers of children with disabilities in 2012 in the Republic of Kazakhstan according to the main regions. In absolute numbers, children with disabilities are mostly concentrated in Karaganda, Almaty, Zhambyl and South Kazakhstan regions. This can be explained by the number of the population living in these regions (about 40 per cent of the population lives in these regions). Other regions with relatively high numbers of children with disabilities are also East Kazakhstan, Kyzylorda, Mangystau and Astana and Almaty cities, where the total number of children under 18 years old living with disabilities varies from 2752 to 4421. These are followed by Pavlodar, Aktobe and West Kazakhstan where the total number of children with disabilities varies from 2440 to 2752. Such variation may be explained by the structure of the population but also by other factors influencing the higher disability incidence, like the concentration of uranium in the region of South Kazakhstan or the consequences of 456 nuclear tests near Semey city (the Soviet Union operated the Semipalatinsk Test Site (STS) from the first explosion in 1949 until 1989).

Figure 4. Total number of children with disabilities (0 – 16 years old)



2.1.1. The national trends of children with disabilities by definitions used in social protection and health care sectors

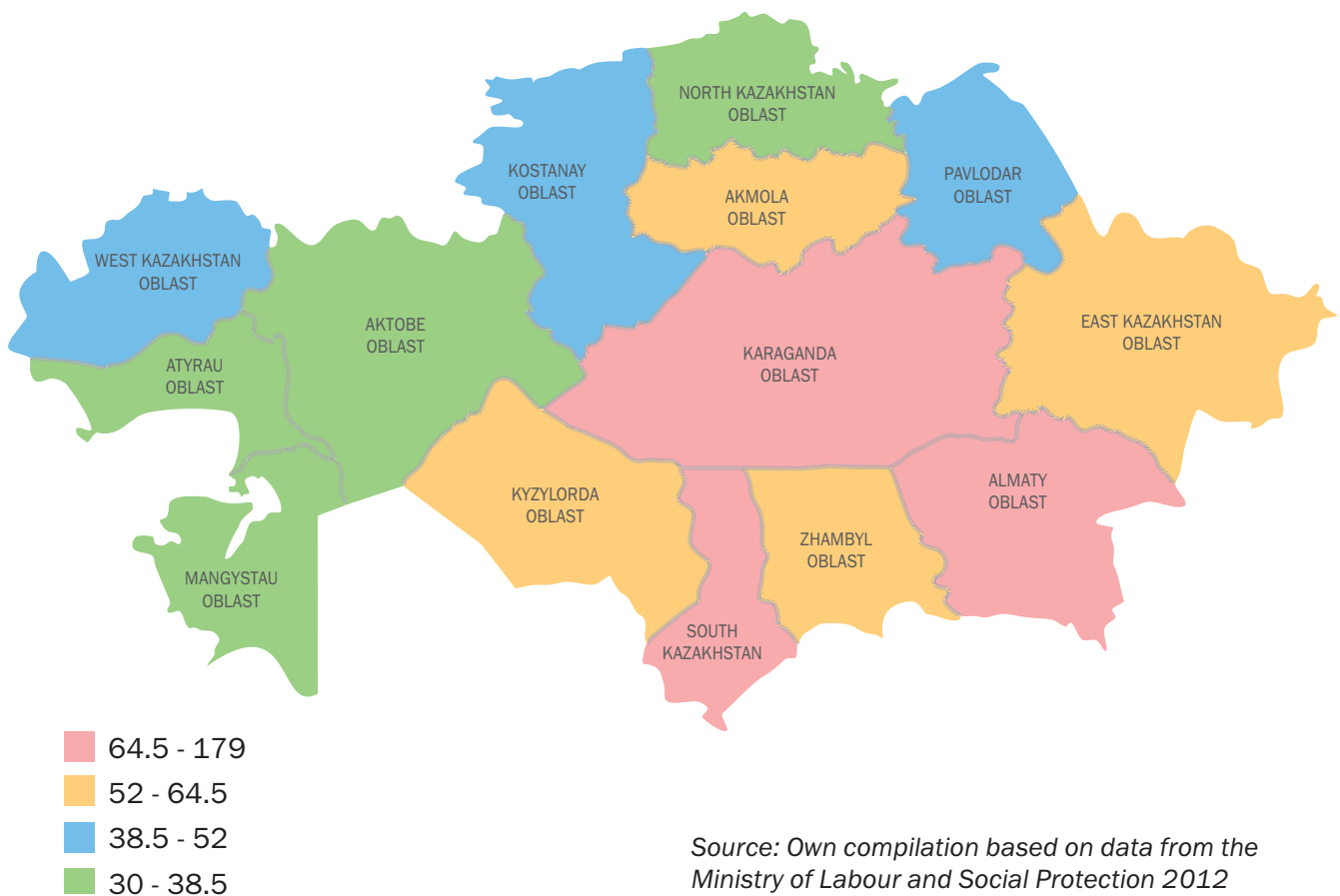
The law on social protection for persons with disabilities in the Republic of Kazakhstan states that the disability group shall be established starting from sixteen years old. Before this time, children with impaired functions are under monitoring within the time limits established by the Ministry of Health (a reassessment of their situation depends on the type of their impairment and complies with the rules for conducting medical-social expertise). The functional changes and pathological conditions in which disability is determined can be for a period of 6 months to 2 years, 2 years, 5 years, and up to 16 years. The determination of disability and monitoring during a periodic timeframe suggests the possibility of recovery or significant improvement of impaired functions, returning the persons to a full life. Above the age of 16 years, disability groups are established based on the classification of the fundamental body functions disorders and limitations on life activity. Box 3

gives more information on the criteria that a person living with disabilities should fulfil in order to qualify for a certain level of disability.

Figure 4 shows the distribution of children with disabilities under 16 years old between the administrative regions and the two big cities, while figures 5–7 show the division of children with disabilities (16-18 years old) according to three disability categories (1, 2, and 3). Similarly to the map in figure 3 above, figure 4 shows that in absolute numbers, children under 16 years old living with disabilities are mostly concentrated in Karaganda, Almaty, Zhambyl and South Kazakhstan regions. Figures 5-7 (on children with disabilities in categories 1, 2 and 3) show that the numbers of children with disabilities are higher in regions like East Kazakhstan, Almaty, Karaganda, South Kazakhstan and Zhambyl, following the same trends (and reasons) as mentioned above.

The data from the Ministry of Health shows that in 2012 only about 50,816 children with disabilities under 16 years old (or 88.2% of the total number of 57,627) were registered in primary health care polyclinics. This difference between the registered and the total number of children with disabilities

Figure 5. Total number of children with disabilities in Category I (16-18 years old)



Source: Own compilation based on data from the Ministry of Labour and Social Protection 2012

Figure 6. Total number of children with disabilities in Category II (16-18 years old)

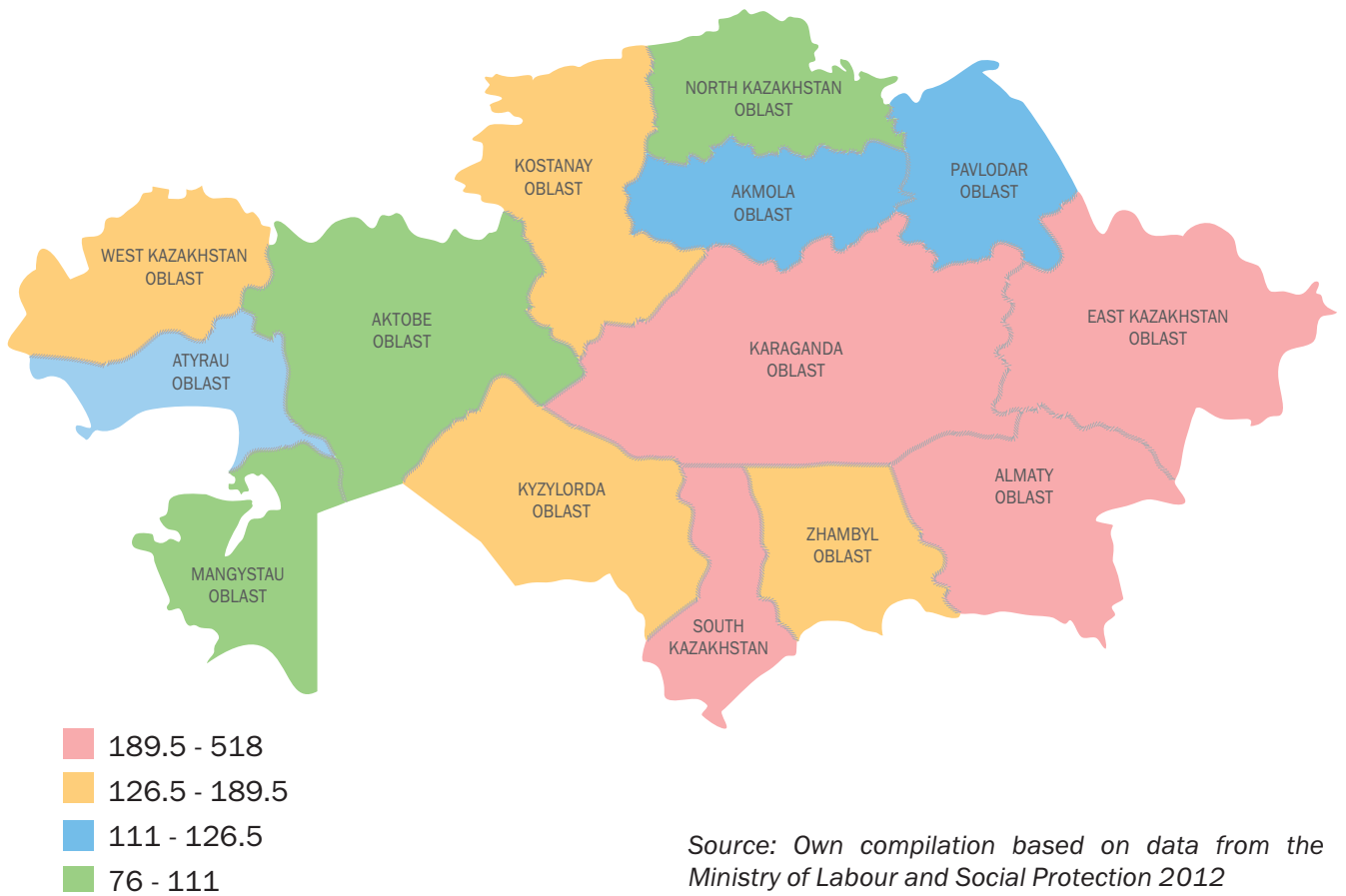
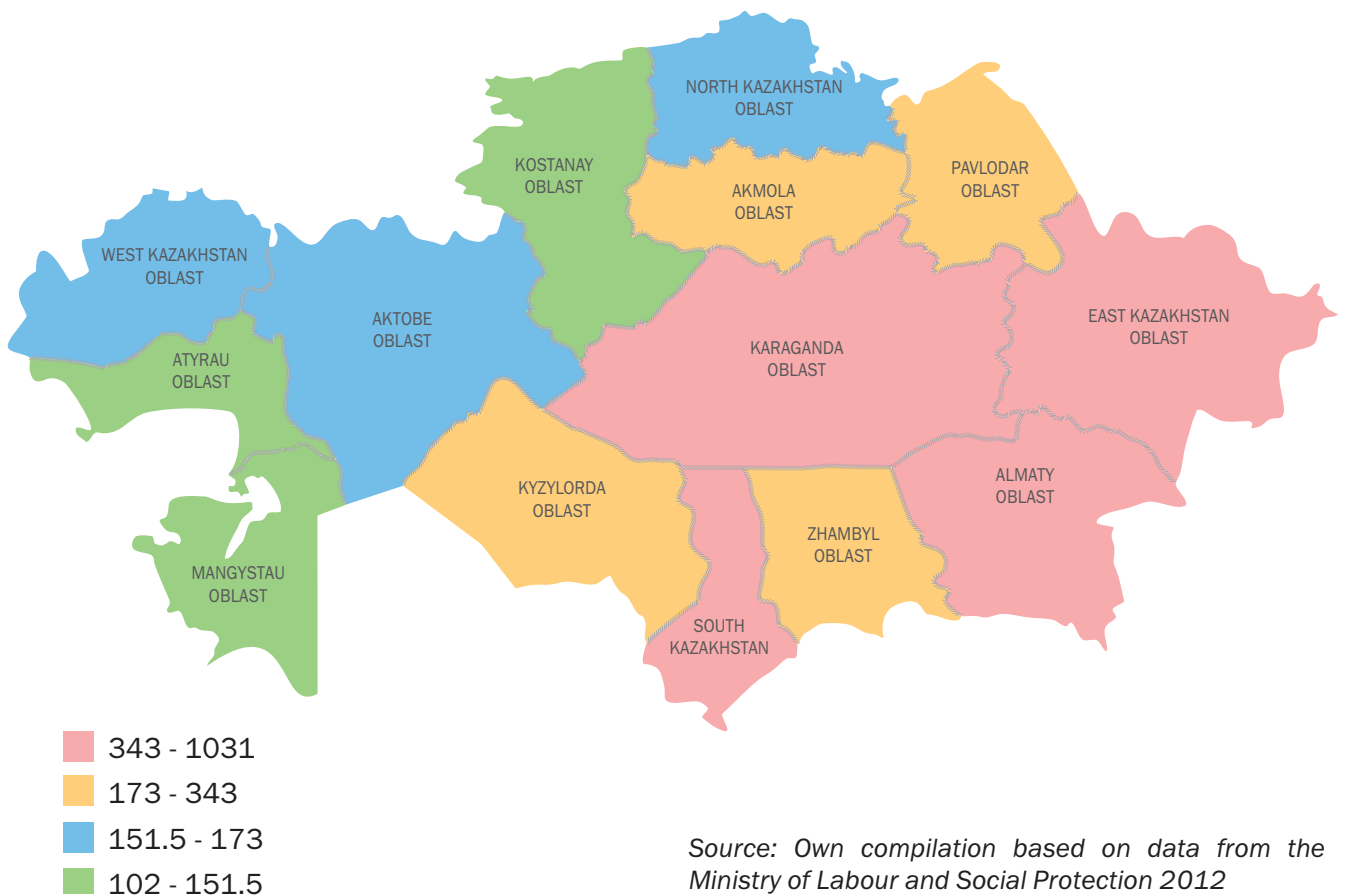


Figure 7. Total number of children with disabilities in Category III (16-18 years old)



Box 3. Classification of the fundamental body functions disorders and limitations of life activity

THE FIRST DEGREE

- ability to self-service using aids;
- ability to move independently, with spending a longer time and reduction of the distance;
- ability to learn in schools of a general type, with observance of a special regime of the educational process and / or with the use of aids, and / or help of other persons;
- ability to perform work subject to lower qualifications or reduced amount of industrial activity, inability to carry out the work by own profession;
- ability to orientate with the use of any additional equipment;
- ability to communicate, characterised by reduced speed, reduced amount of learned, received and transmitted information;
- a partial decrease in the ability to self-monitor own behaviour.

THE SECOND DEGREE

- ability to self-service using auxiliary aids and / or with help of other persons;
- ability to move independently, using auxiliary aids and / or with help of other persons;
- ability to learn only in special schools or by special programs at home;
- ability to perform work in a specific environment using auxiliary aids and / or a specially equipped work place, and / or with the help of other persons;
- ability to orientate, which requires the help of other persons;
- ability to communicate using auxiliary aids and / or with the help of other persons;
- ability to partially or completely control own behaviour just with the help of other persons.

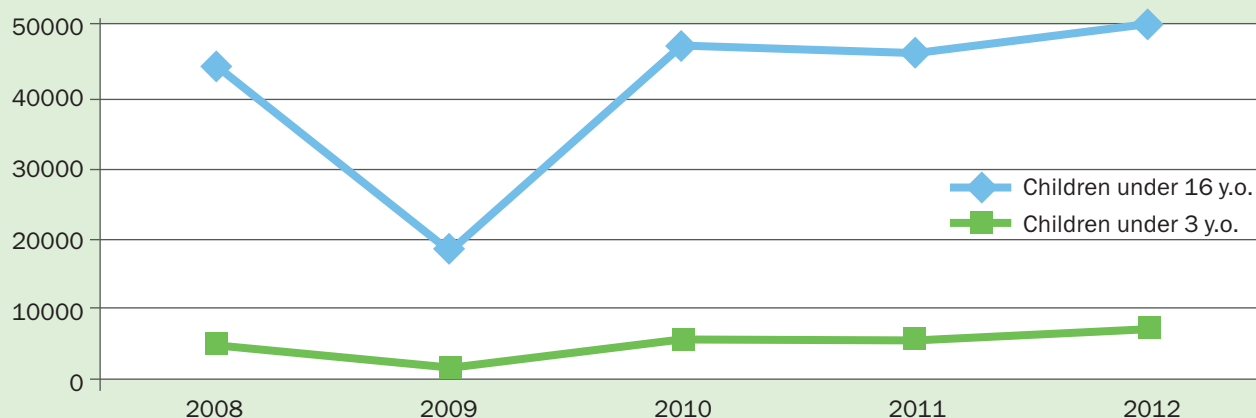
THE THIRD DEGREE

- inability to self-service and total dependence on others;
- inability to move independently and complete dependence on others;
- inability to learn;
- inability to work;
- inability to orientate (disorientation);
- inability to communicate;
- inability to control own behaviour.

may be the result of two factors. Firstly, a number of children with disabilities may be missing from the official statistics because of discrepancies between the official statistics and registration books at the primary health centres (but such discrepancies may also be a result of the different definitions of disability used in the health and social systems). Secondly, a certain number of children with disabilities may not be able to get access to primary health care and this could be due to system related factors, i.e. barriers to registration, as well as stigma related factors. Other factors like the distance to the health care centre, poor infrastructure, stigmatisation, or lack of parental time (e.g. because the mother may be working) can also contribute to fewer children with disabilities registering at health care centres. Unfortunately, the lack of quantitative data on such aspects prevents further detailing the extent of this problem and the weight that each of these factors may have in increasing the number of non-registered children with disabilities in primary health care centres. Figure 8 tries to give an overview of these numbers over the years (where data is available) starting from 2008. It should be noted that the particular drop observed in 2009 is a result of missing data for the regions of Almaty, Atyrau, WEST KAZAKHSTAN, Karaganda, Mangystau, North Kazakhstan, South-Kazakhstan and Almaty city. In addition, data for Atyrau are missing for 2011.

Trends in figure 8 show that, despite the differences between the total number of registered children and those registered in primary health care centres, the number of children with disabilities registered in the primary health facilities has increased during the years for both children with disabilities under 16 years old and between 0-3 years old. The data shows that except for a slight decrease in Zhambyl, in all the other regions the numbers have increased during the period 2008-2012. The region with the largest growth for the number of registered children under 0-3 years old is Mangystau, where numbers registered have grown almost six times (from 74 in 2008 to 456 in 2012). For a complete overview of the registered numbers by region refer to table A2 in Annex 2.

Figure 8. Number of children with disabilities (under 16 years old) registered in primary health care facilities between 2008 and 2012



Source: Own compilation based on data from the Ministry of Health 2012

Note: Data are missing for 2009 for Almaty, Atyrau, WEST KAZAKHSTAN, Karaganda, Mangystau, North Kazakhstan, South-Kazakhstan and Almaty city; and for 2011 for Atyrau.

2.2. The legislation covering people with disabilities in Kazakhstan

In general terms, the current social protection system for persons and children with disabilities in the Republic of Kazakhstan is based on a few fundamental laws, orders, codes and resolutions that were adopted in the early 2000s. Some of the most important laws and legislative acts passed during this period are given in Box 4:

The numerous laws regulating the rights of persons/children with disabilities during the past two decades helped in providing a solid framework for the social protection of these categories. In addition they also helped in bringing forward the problems and specific needs faced by children with disabilities and their families.

The main aim of the legislative framework is to support children with disabilities medically, legally, socially and economically. In accordance with the Law no. 345-II, dated August 8, 2002, "On the rights of the child in the Republic of Kazakhstan" children with disabilities hold the equal right to a full life in dignity, are entitled to education, choice of profession and participation in creative and public activities, as well as to health care and social assistance. The State shall support children with disabilities by integrated services that consist of medical, legal, social and economic services. As such, governmental and state bodies are to provide appropriate opportunities for their learning, professional training and employment.

Similarly, the Law no. 39-III dated April 13, 2005 "On social protection of the persons with disabilities in the Republic of Kazakhstan" entitles the persons with disabilities with all social, economic and personal rights and freedoms enshrined by the Constitution and other legislative acts. In addition, persons with disabilities are entitled to priority service in public and other organizations as well as support for creative skills. Their social protection is aimed at the creation of equal opportunities for participation in society with other citizens, and social assistance to them shall include payments. Starting at 16 years old, the respective disability group shall be determined through medical and social examination and a customised program of rehabilitation shall be developed. Medical rehabilitation of the persons with disabilities shall include rehabilitation therapy, reconstructive surgery, prosthetic and orthopaedic assistance. Sanatorium-resort therapy shall be provided according to the individual rehabilitation programs. Social rehabilitation of persons with disabilities shall include training in basic social skills, provision with technical subsidiary means of movement as well as legal assistance, social services at home and institutions, and a personal assistant or specialist in sign language, as needed. Social services at home and in the territorial centres for social care shall be carried out at the expense of the budget funds.

Moreover, the same law contends that the State shall provide persons with disabilities with access to information through provision of sign language interpretation. The persons with disabilities shall be guaranteed free primary, basic, and general

Box 4. Major laws and ministerial orders that relate to children (and persons) with disabilities in the Republic of Kazakhstan

- The Law no. 345-II dated August 8, 2002 “On the rights of the child in the Republic of Kazakhstan”.
- The Law no. 39-III dated April 13, 2005 “On social protection of the persons with disabilities in the Republic of Kazakhstan”.
- The Law no. 343-II dated July 11, 2002 “On social and health care and pedagogical correctional support for the children with limited capabilities”.
- The Law no. 126-I dated June 16, 1997 “On the public social benefits according to disability, loss of the breadwinner, and age in the Republic of Kazakhstan”.
- The Law no. 242-II dated July 16, 2001 “On the architectural, town-planning, and construction activities in the Republic of Kazakhstan”.
- The Law as amended and supplemented as of 07.10.2012 “On special social services”.
- The Resolution no. 719 dated May 15, 2000 “On approval of the Rules for use of the funds from sales of goods and services provided by boarding schools for mentally retarded children, psycho-neurological boarding schools, houses for the elderly and persons with disabilities of a general type”.
- The Order of the MoH no. 478 dated September 28, 2009 “On approval of the Rules for organization of screening and diagnostics of hearing disorders of the early age children”.
- The Order of the MoH no. 704 dated September 9, 2010 “On approval of the Rules for organization of screening”.
- The Order of the MoH no. 83 dated January 29, 2003 “On approval of the Rules for organization of screening of psychological and physical disorders of the early age children”.
- The Order of the MoLSP no. 286-p dated December 07, 2004 “On approval of the Rules for development of the individual rehabilitation program for the person with disabilities”.
- The Order of the MoE no. 712 dated September 3, 2004 “On the approval of the regulatory legal acts, governing the activities of the special education establishments”.
- The Order of the MoE no. 744 dated September 14, 2004 “On approval of the Rules about the order of organization of the activities of the psycho-medical-pedagogical consultation”.
- The Order of the MoE no. 166 dated March 2, 2004 “On approval of the Rules of the attestation practices of pupils”.

secondary education. Special kindergartens and other special correctional establishments shall be created or education at home provided as needed. The State shall be fully or partially responsible for the costs of maintenance of persons with disabilities in the period of their education. The local executive bodies shall ensure that architecture, urban planning, construction, housing and transportation infrastructure accommodate the needs of persons with disabilities. The local executive bodies shall provide persons with disabilities with the conditions for their access to cultural and spectacular events, as well as sporting facilities for physical culture and sports activities.

One important aspect of detecting disabilities in children, like the early examination of children with

disabilities, is regulated by a number of orders issued by the Minister of Health. The Order of the Minister of Health of the Republic of Kazakhstan “On approval of the Rules for organization of screening of psychological and physical disorders of the early age children” (dated January 29, 2003, No. 83 (as amended and supplemented as of 08.27.2009)) decrees that screening of mental and physical development shall consist of the implementation of five screening examinations, to be carried out in three phases. It regulates what to do in case of present risk factors and outlines next steps to be taken. The Order “On approval of the Rules for organization of screening and diagnostics of hearing disorders of the early age children” (dated September 28, 2009, No. 478) decrees

that screening and diagnostics of hearing disorders shall be carried out in the maternity hospital or delivery department for all the newborns after 2-3 days of their life. If positive, a profound audiological examination is to be followed. Another order of the Minister of Health “On approval of the Rules for organization of screening” (Kazakhstan dated September 9, 2010, No. 704) details all the technical prescriptions of how to organise pre and neonatal screenings in different levels and how to medically react to positive diagnosis of Folling disease or congenital hypothyroidism.

The State shall be fully or partially responsible for the maintenance costs of persons with disabilities during their education. Depending on the group of disability, these services are at the expense of the budget funds for either 50% or 100%.

2.2.1 Barriers and Problems Relating to the Implementation of Legislative Framework

Despite the comprehensive legislation framework providing protection for children with disabilities in the Republic of Kazakhstan, inclusion of children with disabilities remains a challenge. This is to a large extent driven by the ‘old approach’ i.e., predominantly considering the minimum resources necessary to provide rehabilitation and a social safety net. Consequently, people and children with disabilities are considered the vulnerable category of the population, who should receive a required level of public goods (most of the time rather limited) and are not considered as full members of society (UNDP, 2009).

Exclusion problems remain one of the most sensitive issues for children with disabilities despite the recent efforts of the Government in this regard. Kazakhstan is the only country in Central Asia that has introduced inclusive education in the Law “On Education” (2007) (UNICEF, 2013). The education model adopted by this law implies support for all children of school age regardless of their abilities, interests, opportunities and needs. In addition, the government is trying to move towards a more integrated system for social services. The integrated system combines management efforts in the field of social protection, health and education by also exploring new ways of social provision (Kovalevsky, 2012). Yet, in some cases such changes have been a source for denying services to children with disabilities. For example, a recent report by Kovalevsky (2012) states that the adoption of the Law “On Special Social Services” involved the redistribution of the population

groups obtaining social services through education, health and social protection. Responsibilities for the provision of special social services to children (including children with physical illnesses) were reshuffled between the education and the health sectors, while social work with such children was also re-conceptualised between the sectors (Kovalevsky, 2012). The report states that in some cases this may have been a cause for excluding certain groups of people with disabilities from getting such services. Such groups may have included children with certain physical disabilities who had indications for obtaining social services, children with disabilities of the third group, and a number of other categories. They may have been excluded from the system mostly because of a lack of clarity or understanding about how to implement the standards for delivering social services in education, health and social protection.

The problem of service coordination and delivery was also discussed by participants in focus groups and in-depth interviews. While the results of the qualitative research are discussed in greater depth in Section 3 below, it is worth mentioning here that many respondents reported that the implementation of legislation is an imperfect process that is riddled with gaps. While the adoption of legislation that specifically addresses the rights of children with disabilities represents an important and innovative step forward, coordinating implementation is an ongoing struggle. Some respondents reported, for instance, that implementation of legislation has not occurred evenly across all regions, with clear disparities emerging between rural and urban areas because of the higher availability of knowledge resources in urban areas. Other respondents noted that legislation guarantees rights that key service personnel lack the capacity and competency to protect. For instance, while legislation guarantees equal access to education for children with disabilities, there is a lack of trained teachers and pedagogical support staff who can meet the unique needs and challenges of inclusive classrooms. Given the lack of specialised training programs and degrees for teachers working with children with disabilities, there are few opportunities for those capacities to be developed. This leaves a major gap in the comprehensive implementation of legislation. The examples listed here are only a few of the practical challenges to implementation reported by respondents; in-depth analysis of the perceived challenges in implementation is provided in Section 3 below.

2.3. Institutional framework for children with disabilities in Kazakhstan

There are three main governmental bodies involved in protecting children with disabilities in Kazakhstan: Ministry of Health (MoH), Ministry of Education (MoE) and Ministry of Labour and Social Protection (MoLSP).

2.3.1 The Ministry of Health

The Ministry of Health of the Republic of Kazakhstan is responsible for offering quality health care to children with disabilities. In addition, health care institutions are also responsible for identification and categorisation of disabilities from the early stages of life. For this, the MoH has developed early development screening, involving checks from the first days. Medical institutions responsible for providing care to newborn infants (i.e. maternity health care centres) are also responsible for filling in the “Statistics form” directly after birth. The form is sent to the Ministry of Labour and Social Protection and helps to develop an individual plan for each child born with disability.

Health care centres that depend on the Ministry of Health are also responsible for defining and determining the degree of disability (mental/physical) in adults and children older than 16 years. This is based on the current legislative framework and administered through a series of ministerial acts and orders (see also Box 5).

All the policlinics that are regulated by MoH provide services and information to children with disabilities and can be involved in the early development of the child (with disability). All these policlinics have a separate room to counsel parents of children with disabilities and persons with disabilities.

Other institutions involved directly in delivering care and rehabilitation programs for children with disabilities are rehabilitation centres for children 0-18 years old. These rehabilitation centres are administered by the Ministry of Health and provide institutionalisation and education for children with disabilities.

2.3.2 The Ministry of Labour and Social Protection

The Ministry of Labour and Social Protection is one of the main governmental bodies involved directly in identifying, integrating, protecting and monitoring children with disabilities in the Republic of Kazakhstan. One of the first functions in this

Box 5. Orders issued by the Ministry of Health on the screening of children with disabilities

- The Order of the Minister of Health of the Republic of Kazakhstan “**On approval of the Rules for organization of screening of psychological and physical disorders of the early age children**” (dated January 29, 2003, No. 83 (as amended and supplemented as of 08.27.2009)).

This Order decrees that screening of mental and physical development shall consist of the implementation of five screening examinations, to be carried out in three phases. It regulates what to do in case of present risk factors and outlines next steps to be taken.

- The Order of the Acting Minister of Health of the Republic of Kazakhstan “**On approval of the Rules for organization of screening and diagnostics of hearing disorders of the early age children**” (dated September 28, 2009, No. 478)

Screening and diagnostics of hearing disorders shall be carried out in the maternity hospital or delivery department for all the newborns after 2-3 days of their life. If positive, a profound audiological examination is to follow.

- The Order of the Minister of Health of the Republic “**On approval of the Rules for organization of screening**” (Kazakhstan dated September 9, 2010, No. 704)

Article 2 of this Order contains a very technical prescription of how to organise pre- and neonatal screenings at different levels and how to medically react to positive diagnosis of Folling disease or congenital hypothyroidism.

Box 6. Legislative framework for special services and rehabilitative services

- The Law of the Republic of Kazakhstan “**On special social services**” (as amended and supplemented as of 07.10.2012)

Persons with disabilities are eligible for special social services. The so-called guaranteed scope of the special social services is provided at the expense of budgetary funds while paid special social services are rendered on a paid basis over the guaranteed scope.

- The Order of the Minister of Labour and Social Protection of the population of the Republic of Kazakhstan “**On approval of the Rules for development of the individual rehabilitation program for the persons with disabilities**” (dated December 07, 2004, No. 286-p (as amended and supplemented as of 06.11.2012))

The individual rehabilitation program shall be developed by the territorial division of the Committee on monitoring and social protection of the Ministry of Labour and Social Protection, for the period of identification of disability. The medical, social and professional parts of the individual rehabilitation program shall be developed depending on the results of the expert diagnostics carried out, and the needs of the person with disabilities in the rehabilitation activities. In a dynamic observance the effectiveness level, quality, and completeness of the implemented rehabilitation activities shall be evaluated. In case of availability of the medical indications, the territorial division shall carry out the correction of the individual rehabilitation program, either developing additional activities or resolving the issue of the need and advisability of further implementation of the rehabilitation activities.

respect is the (early) identification of disabilities. MoLSP, in collaboration with the MoH, establishes in which category of disabilities the children will be classified. The next aspect to decide upon is the amount of child benefits. Considering the social and economic conditions of a family (e.g. dependent on whether the parents are employed or unemployed), the MoLSP decides on the allowances and the type of help the child needs. Furthermore, plans for individual development are created. These plans are mainly based on factors like the type and severity of disability and the social conditions of the child (including the living conditions of the child). The need for specialised equipment is also assessed.

Social workers, who are based in departments at the Akimat level, work under the supervision of the Ministry of Labour and Social Protection. They work with parents in identifying the needs of children. There are about 12,000 social workers under the Ministry of Labour and Social Protection working with children with disabilities. However, their capacity differs as they are still not divided between the levels, i.e., divided between those doing individual assessment and those doing home visits. Specialised university courses for social worker graduates have been active since 2003, but the grants for social work were recently reduced.

Residential institutions such as the ‘Psychoneurological Institutions’ for children with

mental disabilities are also under the Ministry of Labour and Social Protection. There are 17 institutions for children with mental disabilities in the country and 4 institutions for children with physical disabilities. These are all residential institutions.

2.3.3 The Ministry of Education

The Law no. 345-II dated August 8, 2002 “On the rights of the child in the Republic of Kazakhstan” ensures the right to education, choice of occupation and profession and participation in creative and social activities for children with disabilities. The Ministry of Education is the governmental body responsible for offering children with disabilities the proper education in accordance with their needs. This is done through day care centres, pre-schools and schools. Some of the institutions offering education services to children with disabilities in the Republic of Kazakhstan are: general kindergartens, special kindergartens, day care centres, general schools, inclusive schools (mixed classes and/or separate classes) and special schools. Orphans and children with disabilities are also entitled to priorities in entering tertiary level education.

It is important to mention that the Ministry of Education in Kazakhstan does not accept the term ‘children with disabilities’. Instead the working definition for this group of children is ‘children with limited abilities in development’ or ‘children

Box 7. Legislative framework for education services provided to children with disabilities

- The Law of the Republic of Kazakhstan “**On education**” (as amended and supplemented as of 07.31.2012)

The State compensates maintenance costs for persons with disability during their education, grants preferential treatment in application procedures and provides them with special conditions, in the special education establishments, in general education schools, or at home.

- The Law of the Republic of Kazakhstan “**On social and health care and pedagogical correctional support for the children with limited capabilities**” dated July 11, 2002, No. 343-II (as amended and supplemented as of 07.24.2012)

The social and health care and pedagogical correctional support for the children with limited capabilities shall begin with the birth of the child up to the age of their majority. Special educational services for the children with limited capabilities shall be provided by special organisations, such as establishments of social protection of the population. Psycho-medical-pedagogical consultations shall be public establishments, sending the children with limited capabilities to the special correctional and other organisations only with the consent of their parents and other legal representatives. The children with limited capabilities can obtain pre-school upbringing and education from the age of three, primary and secondary education from the age of seven to ten. According to the psycho-medical-pedagogical consultations and individual education plan, the upbringing and education of the children with limited capabilities shall be carried out individually and for free at home. Social and health care and pedagogical correctional support shall be provided at the expense of the budget funds.

- The Resolution of the Government of the Republic of Kazakhstan “**On approval of the Rules for use of the funds from sales of goods and services provided by boarding schools for mentally retarded children, psychoneurological boarding schools, houses for the elderly and persons with disabilities of a general type**” (dated May 15, 2000 No. 719)

The funds from sales of goods and services, provided by boarding schools for children with mental impairments, psychoneurological boarding schools and houses for persons with disabilities, are to be used for the benefit of their clients.

- The Order of the Minister of Education and Science of the Republic of Kazakhstan “**On the approval of the regulatory legal acts, governing the activities of the special education establishments**” (dated September 3, 2004 No. 712)

Admission to special education establishments shall be carried out on the basis of the conclusion of the psycho-medical-pedagogical consultation and only with the consent of the parents or legal representatives. First this Order deals with the organisation of the activities of the special education establishments. With a view to the organisation of the education and upbringing process it stresses the importance of differentiated and individual approaches. The Order also addresses the composition of staff in special education establishments, stipulating that health care specialists and teachers shall work together closely and also involve the parents.

- The Order of the Minister of Education and Science of the Republic of Kazakhstan “**On approval of the Rules about the order of organization of the activities of the psycho-medical-pedagogical consultation**” (dated September 14, 2004, No. 744)

Article 2 details the main objectives of the psycho-medical-pedagogical consultation while Article 3 sets out the procedure leading up to said consultation as well as its order. The subsequent Article describes the main work scope of the psycho-medical-pedagogical consultation which performs the complex examination of the child leading up to a diagnosis and establishes the correctional and diagnostic classes. Furthermore the Order contains guidelines on the management of the consultation and the required documentation.

- The Order of the Minister of Education and Science of the Republic of Kazakhstan “**On approval of the Rules of the attestation practices of pupils**” (dated March 2, 2004 No. 166)

According to this order, it is not the task of the teacher of the supplementary school to provide all the children with even approximately identical knowledge, since their special conditions require a non-standard approach to the assessment of their knowledge and abilities. All the types of control of knowledge (oral, written, practical) are recommended to be estimated upon the traditional five-point scale only as the means of motivation for the activities and stimulation of the pupils. The teacher shall have the right to determine independently the individual educational program. Articles 3 and 4 specify how exactly examination of knowledge, abilities, and skills of the native language and mathematics respectively is to be executed and what each mark (1-5) stands for. Articles 5 through 9 explain how the performance of pupils with mental impairments pupils with visual impairments, hearing-impaired pupils and pupils with serious speech impairments, respectively, should be evaluated, allowing for lenience in comparison to standardised evaluation according to the pupils’ special requirements and conditions.

with special needs’. This latter group is larger and not all children have the disability status, however, they might have some special educational needs.

At the Akimat level, from an administrative perspective, there exist departments of education (in big cities) or divisions of education (in small cities). Such departments or divisions are in charge of deciding if children with disabilities should enter inclusive schools, attend mixed classes or attend separate classes. These decisions depend on the availability of money and on the recommendations coming from the offices for psychological and pedagogical issues.

The Ministry of Education also operates various offices like offices for psychological and pedagogical consultation, offices for correction rehabilitation, as well as offices for correction and inclusive education. The offices for psychological and pedagogical consultations define the development level in terms of education and can advise parents on which is the best education for their children (inclusive or special education). These offices also offer information and advice for parents with children without disabilities. Offices for correction and inclusive education are located inside the schools (parents are involved in inclusive programs together with teachers and children).

If parents do not want to send their children to special kindergartens, they can use day care centres that are usually included inside kindergartens. The difference between these care centres and kindergartens is that the number of hours children stay in the day centres is more limited. In villages, children can only attend the general kindergartens because they do not have other

possibilities and specific conditions for children with disabilities do not exist.

Depending on the conditions of the children with disabilities, distance learning and boarding schools are also available. Teachers spend four education hours/ per week on the distance learning programs. Children with disabilities are provided with a computer space at home. Computers are procured by the Ministry of Education (they do not remain children’s property).

One of the main objectives of the Ministry of Education is to bring all children with disabilities into schools. For this purpose, all-inclusive and special schools for children with disabilities offer special services like: social and pedagogical work with parents, psychological work with children, speech therapists (who are usually available in special and inclusive schools and work with children and parents), etc.

The State Education Development Program for 2020 aims to increase the number of inclusive schools to 70 percent and make it possible that 50 percent of the children with disabilities attend inclusive schools. Another objective of the same strategy states that at the tertiary education level every university has to open consultative practical centres to deal with disabilities. Moreover all universities have to provide different elements to facilitate the inclusion of students with disabilities, like: curricula, teachers trained for children with disabilities (inclusive) and training methodologies in a broader way for inclusive education.

Box 7 below includes more information on the legislative framework for providing education services to children with disabilities.

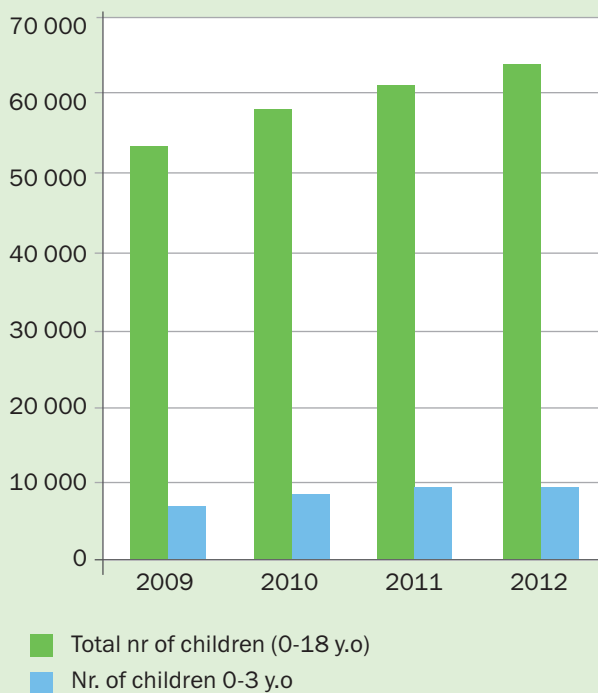
2.4. Financial benefits for children with disabilities in Kazakhstan

As mentioned earlier, the legislative framework in place guarantees children with disabilities free education, social and health services at the expense of the state budget funds.¹ This includes pre-primary, primary and secondary education, all the social and health care as well as pedagogical correctional support. In addition, state budget funds shall guarantee disability allowances and special social services for persons with disabilities.

2.4.1 The number of children with disabilities benefiting from social allowances

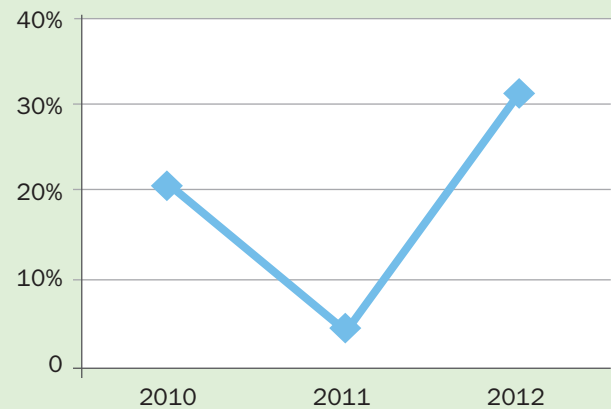
The data from the Ministry of Labour and Social Protection show that the number of children with disabilities (0-18 years old) benefiting from state social allowances has increased over the period from 2010 to 2012 (figure 9). However, figure 10

Figure 9. The number of children with disabilities benefiting from state social allowances in the Republic of Kazakhstan for the period 2010-2012



Source: Own compilation based on data from the Ministry of Labour and Social Protection 2012

Figure 10. Percentage of children with disabilities not getting any allowance over the total number of children with disabilities (0-18 years old)



Source: Own compilation based on data from the Ministry of Labour and Social Protection 2012

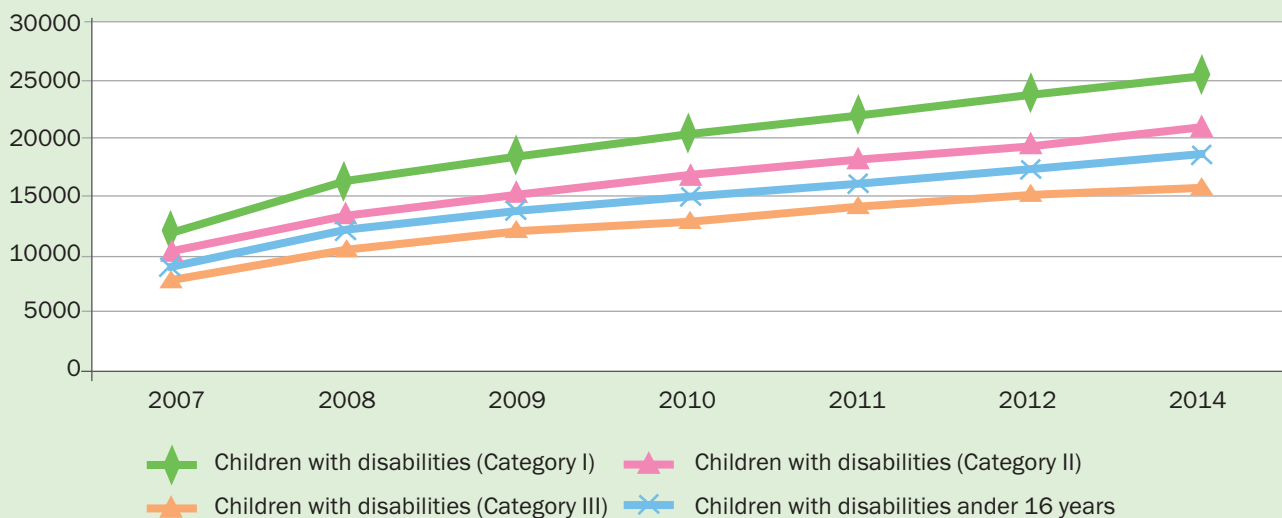
shows that 3.2 percent of children with disabilities did not benefit from state disability allowances in 2012, compared to 0.4 percent in 2011 and 2.1 percent in 2010.

There are no data, however, to investigate the reasons why children with disabilities (or their families) do not receive the benefits. As discussed in chapter three below, there are a number of possible explanations, such as the difficult bureaucratic procedures required to apply for disability allowances (e.g. the time and costs spent in collecting and presenting disability documents) as well as the lack of information on the eligibility rights for such allowances. While some of the barriers to accessing social benefits are discussed in the following section, it is important to monitor and collect hard data on benefit usage, barriers to benefit access, and means of eliminating any possible barriers.

The increase in the numbers of children with disabilities not benefiting from social allowances in 2012 may seem only marginal given the low percentage (only 3 percent of the total number of the children with disabilities). Yet, in absolute numbers, this concerns 2,093 children with disabilities (and their families) not getting the allowance. Most probably these families have the highest likelihood of falling under the poverty line. Evaluating the potential reasons and monitoring this number over time may be a good indicator for the government to prevent poverty among these categories.

¹ Laws "On social protection of the persons with disabilities in the Republic of Kazakhstan", "On social and health care and pedagogical correctional support for the children with limited capabilities" and "On special social services".

Figure 11. Monthly disability allowances for children with disabilities (in KZT) for the period 2007-2013



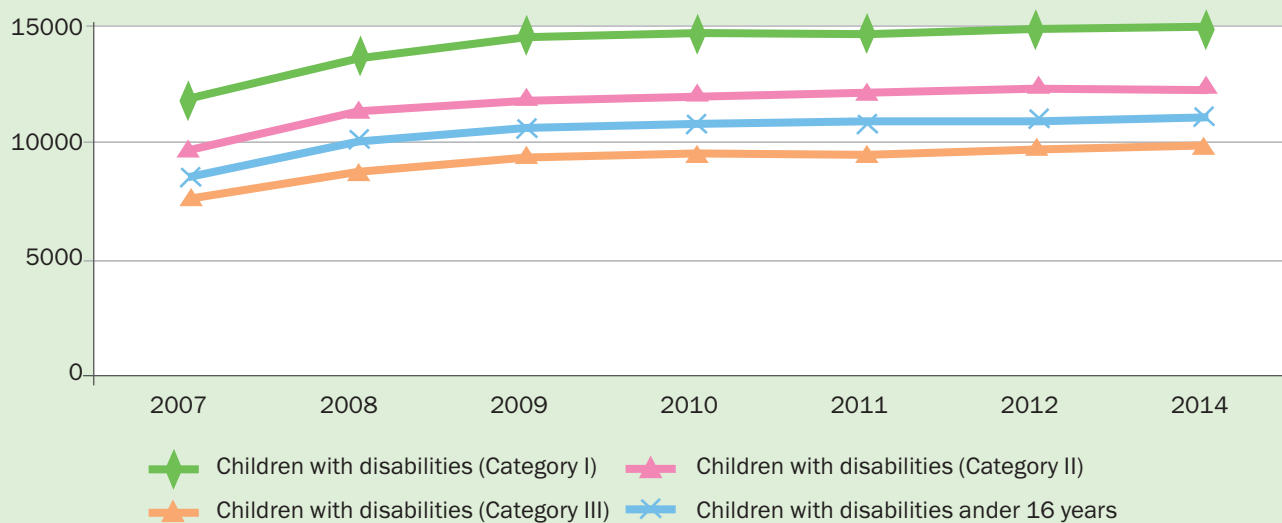
Source: Own compilation based on data from the Ministry of Labour and Social Protection 2012

2.4.2. The amount of financial allowances for children with disabilities

Children with disabilities in the Republic of Kazakhstan are entitled to monthly benefits in the range of 0.87 – 1.36 times the minimum subsistence level (i.e. from 15,103 KZT, which is equivalent to \$ 100, to 24,231 KZT, which is equivalent to \$161).² The benefit size is determined in accordance with the child’s age (until a maximum of 18 years old) and disability group. In addition,

parents of children with disabilities also benefit from an allowance in the amount of a minimum wage (about 18,660 KZT, equivalent to \$125) to provide care for their children (UNICEF, 2012). The level of benefits is comparable to that provided by other countries in Eastern Europe. The level of disability benefits in Albania is \$86 per month (an additional \$86 per month is received by the caregivers of children with disabilities enrolled in secondary or higher education) while child disability allowances in Ukraine are equal to 60-100% of the minimum subsistence level, which is around

Figure 12. Deflated monthly disability allowances for children with disabilities (CPI 2007=100)



Source: Own compilation based on data from the Ministry of Labour and Social Protection 2012

Note: Prior to January 1, 2006 state social allowances were set depending on the rate of monthly calculation index. From January 1, 2006 state social allowances were named to be the “base” social allowances and are set depending on the minimal subsistence rate (Law dated Dec 15, 2005 No 101).

² Law “On the public social benefits according to disability, loss of the breadwinner, and age in the Republic of Kazakhstan”.

\$113 per month (OPM, 2011). Other countries in the region have comparable benefit schemes for children with disabilities. Disability allowances in Turkmenistan range (depending on the disability group) from 1.6 to 3.3 times the minimum base amount of \$80 (UNICEF, 2013). Disability benefits in Uzbekistan equal the sum of two minimum wages for children with disabilities under 16 years old (UNICEF, 2013). Monthly social disability benefits in Kyrgyzstan are equivalent to \$63 and paid to families regardless of their income. This amount is significantly lower than in Kazakhstan.

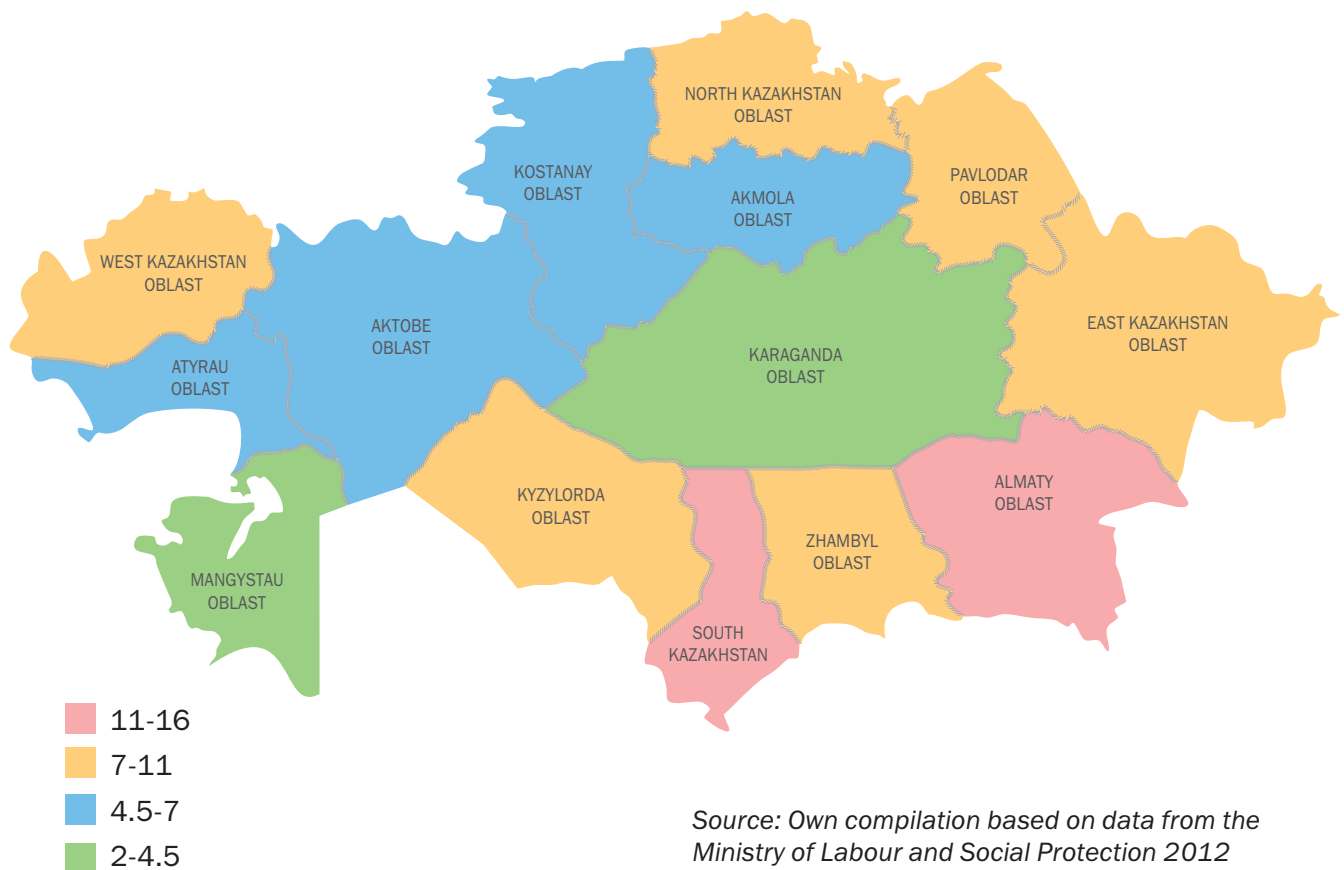
Data from the Ministry of Labour and Social Protection show that the state allowances for children with disabilities have increased during the period between 2006 and 2013. The amount of the allowance depends on the age of the child (under the age of 16 all children with disabilities get the same allowance) and on disability level (the disability group shall be established starting from 16 years old). The amount of the allowance for children with disabilities under 16 years old has increased over the years, though not at a constant rate. The highest increase in percentage to the preceding year is observed in 2008 (as compared with 2007) with an increase of 26 percent, and the lowest in 2012 and 2013 (compared with 2011 and 2012 respectively) with a 7 percent increase. However, figure 12 shows that the increase is somehow offset by the high inflation rate during that particular period. In fact, the figure shows that when deflating for the consumer price index (CPI) the increase in the level of allowances remains positive but not as high as in nominal terms. The amount of the allowances for the three disability groups differ from the benefits for children with disabilities under 16 years old with a factor of 1.36, 1.11 and 0.86 (respectively for the Categories I, II and III). Therefore any trends over the years are similar (curves are parallel to each other as observed in figure 11 and figure 12).

Most of the persons with disabilities in Kazakhstan are classified as poor given that they are in need of both state-provided care and support (Kazakhstan MDG Report, 2010). Other reports attest the fact that having a person with disability in the household increases the risk of poverty and social exclusion (UNDP, 2009). This is mainly due to the specific requests of persons with disabilities (who are less likely to work and need more informal care from other members of the family –who can leave work to care for them). In addition it is also evidenced that the financing for persons with disabilities is at times scarce as the allocated amount of benefits is not enough to cover arising additional needs due to disability (e.g. special health care needs, etc.) (Kazakhstan MDG Report, 2010).

2.4.3. Possible Barriers in Financing and Monitoring of the System

The analysis above showed that children with disabilities and their families in Kazakhstan are provided with relatively generous disability benefits (especially if compared to the other countries in the region like Kyrgyzstan). The increase of the disability allowances in real terms, despite being very low, is certainly a good signal showing that the government is committed to protecting this particular group of the population. On the other hand, despite the adoption of the various laws passed in the Republic of Kazakhstan, the system is still suffering from poor monitoring and evaluation mechanisms. Such mechanisms fail to detect and correct for inefficiencies and the lack of quality in delivering social care to the targeted population categories. A report from the country shows that some of these inefficiencies are also reflected by the relatively high differences in the costs of the social services delivered in various regions (Kovalevsky, 2012). For example, the government spent around 79.8 thousand tenge per service recipient per year in home-based care for children with disabilities and persons with disabilities over 18 years old with neuropsychiatric diseases in Atyrau region, while in the Almaty region this amounted to 217.7 thousand tenge. High differences are also observed for more standardised care, like the day care facilities (either in medical or social centres) where spending varies between 66.7 thousand tenge in the North Kazakhstan region and 5,174 thousand tenge in the West Kazakhstan region (a difference of about 78 times). Such differences in spending raise questions regarding the standards and quality of services offered in different regions and the effectiveness of the legislation in place.

Figure 13. The number of Psychological and pedagogical rooms in the Republic of Kazakhstan for 2012



2.5. State programs for children with disabilities in Kazakhstan

Programs for children with disabilities in Kazakhstan consist mainly of educative and rehabilitative activities. Social rehabilitation of children with disabilities is based on the Law of the Republic of Kazakhstan “On special social services” and provided by social organizations of the social protection system. At present the Republic of Kazakhstan relies on a sustainable network of social and education institutions in place for providing services to children with disabilities. Based on the severity of their disability children are assigned to general, inclusive or special pre-schools and schools, or to a social institution. The network of specialised institutions includes 4 home-internats for children with disabilities with disorders of the musculoskeletal system; 17 home-internats for children with psycho-neurological diseases, 16 rehabilitation centres, 29 day care facilities, 165 departments of social care at home for persons with disabilities including children with disabilities.

2.5.1 Psychological-pedagogical and logopedic services offered to children with disabilities

In order to support children with disabilities and their parents/foster parents, 129 psychological pedagogical corrections rooms are available across Kazakhstan. Figure 13, shows how psychological-pedagogical corrections rooms are distributed all over the country. The distribution of psychological-pedagogical corrections rooms is not always in accordance with the distribution of children with disabilities (cf. figure 3). The most under-served region is Karaganda with only three centres, while the number of children with disabilities in this region is the highest (4669 children with disabilities under 18 years old).

In 2012, 13,506 persons used the psychological-pedagogical corrections service (Ministry of Education 2012). The geographical distribution of this beneficiary population is shown in figure 14. The figure shows that except for the Almaty region (where the number of rooms follows the number of children served) in the other regions the situation is less favourable compared to the number of children in need. However, as the data on the

Figure 14. The distribution of children with disabilities taking services in psychological-pedagogical corrections rooms.

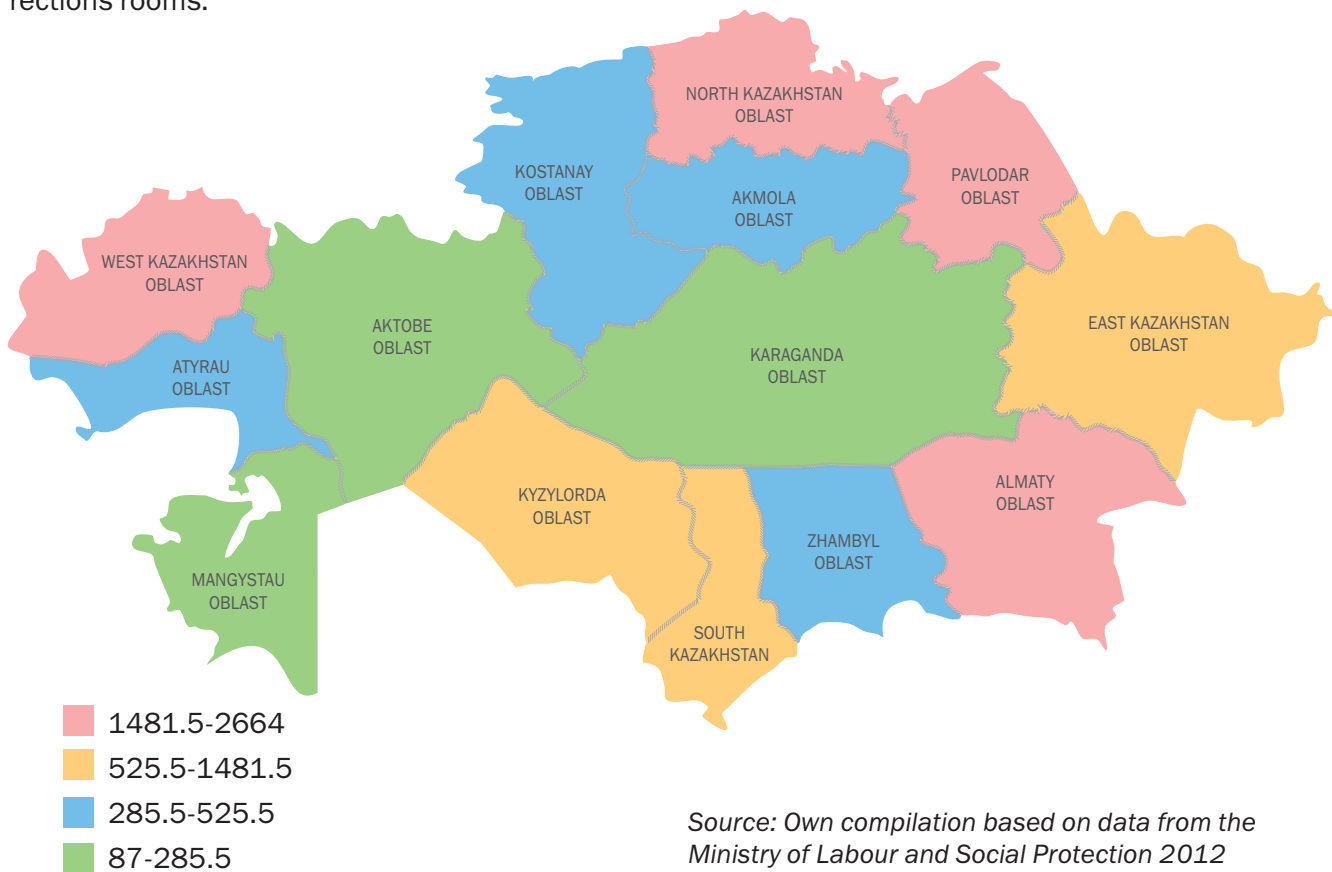


Figure 15. The distribution of Logopedic rooms all around the country for 2012

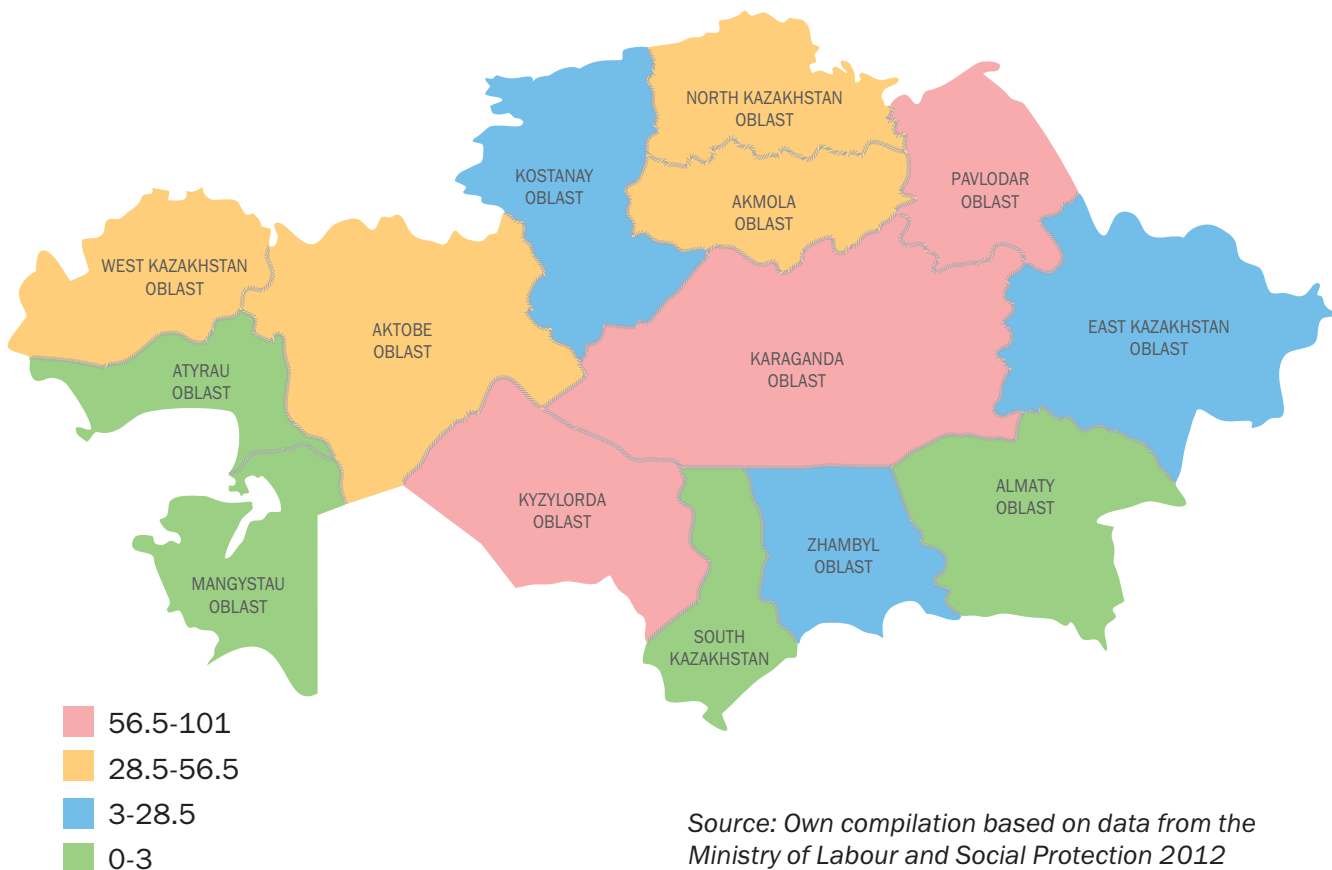
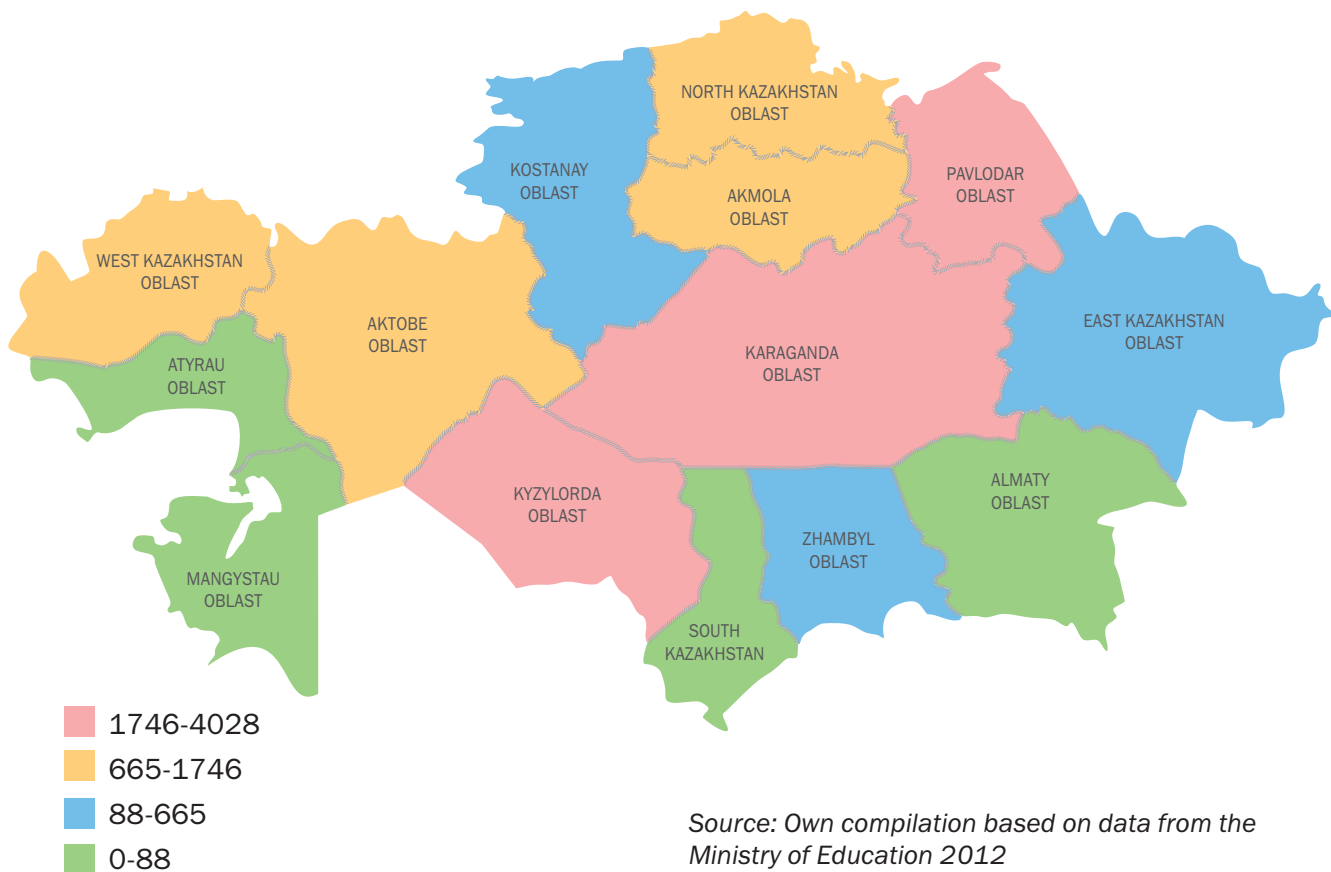


Figure 16. The distribution of children with disabilities taking services in Logopedic rooms for 2012



Source: Own compilation based on data from the Ministry of Education 2012

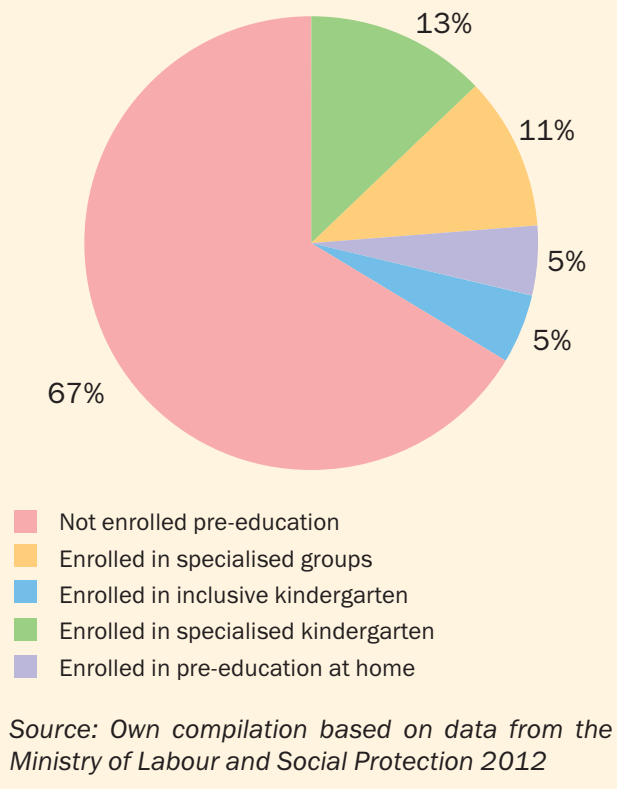
number of personnel serving in these rooms is not available we cannot say much about whether the ratio reflects the quality of services offered.

The Ministry of Education offers special educational services to children with disabilities for better inclusion in society. According to the data from the Ministry of Education, 558 Logopedic rooms (speech therapy) all over the country deliver services to 17,057 children with disabilities. The data show that the distribution of the Logopedic rooms and the number of children benefiting from this service are in line with each-other (figure 15 and 16).

2.5.2 Enrolment in pre-education and education systems for children with disabilities

According to the Ministry of Education, 152,370 children (0-18 years old) had “limited abilities in development” in 2012. The breakdown according to age shows that 5% of them are 0-3 years old, 23% of them are 3-6 years old and 72% of them are 7-18 years old. Figures 17 and 18 show the percentage of children with disabilities in education institutions (pre-schools and schools). As can

Figure 17. Data on children with limited abilities in development enrolled in the pre-education system (2012)



Source: Own compilation based on data from the Ministry of Labour and Social Protection 2012

be seen, 67 percent of children 3-6 years old 'with limited abilities in development' are not enrolled in pre-schools and 46 percent of children 7-18 years old 'with limited abilities in development' are not enrolled in schools. Only 5 and 21 percent of children 'with limited abilities in development' of the respective age groups are attending inclusive kindergartens and schools. Figures 19 and 20 show the regions with the highest number of children that are not enrolled in the pre-education and education system in 2012.

The country reports show that the number of children with disabilities in pre-school education (special and regular) has increased both in Kazakhstan and in other CIS countries. The number of children with disabilities in special pre-schools in Kazakhstan has increased with 8.8 percent in 2012 compared to 2005. This increase was even larger in countries like Kyrgyzstan and Uzbekistan (with respectively 80.0 and 25.6 percent increase in 2011 compared to 2005). The trends are more or less the same when comparing the number of children with disabilities in regular pre-school facilities. The number of children with disabilities in regular pre-school education in Kazakhstan has increased by 9.8 percent in 2012 compared to 2005, while for countries like Kyrgyzstan this increase was 132.2 percent. Even though the increase (in percentage

Figure 18. Data on children with limited abilities in development enrolled in the education system (2012)

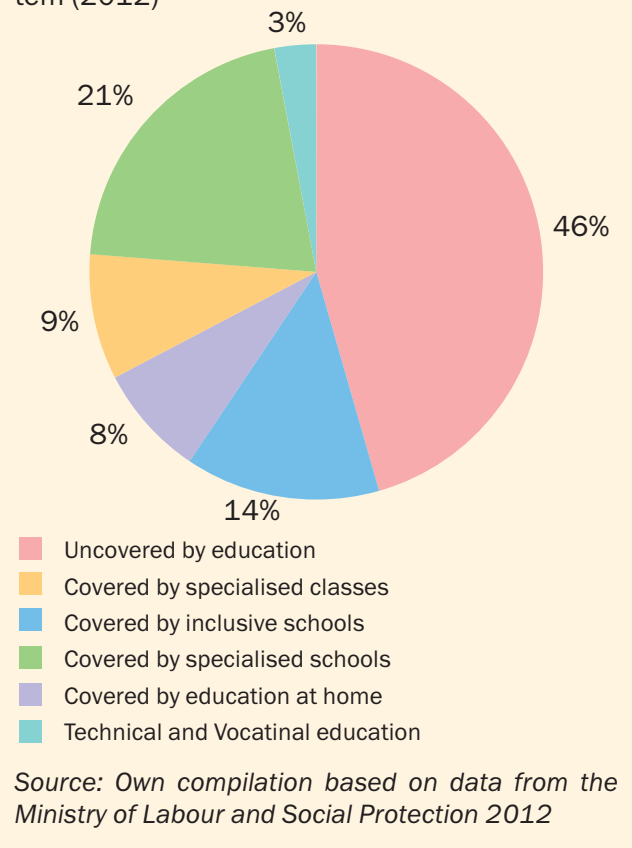


Figure 19. The percentage of children with disabilities not enrolled in the pre-education system

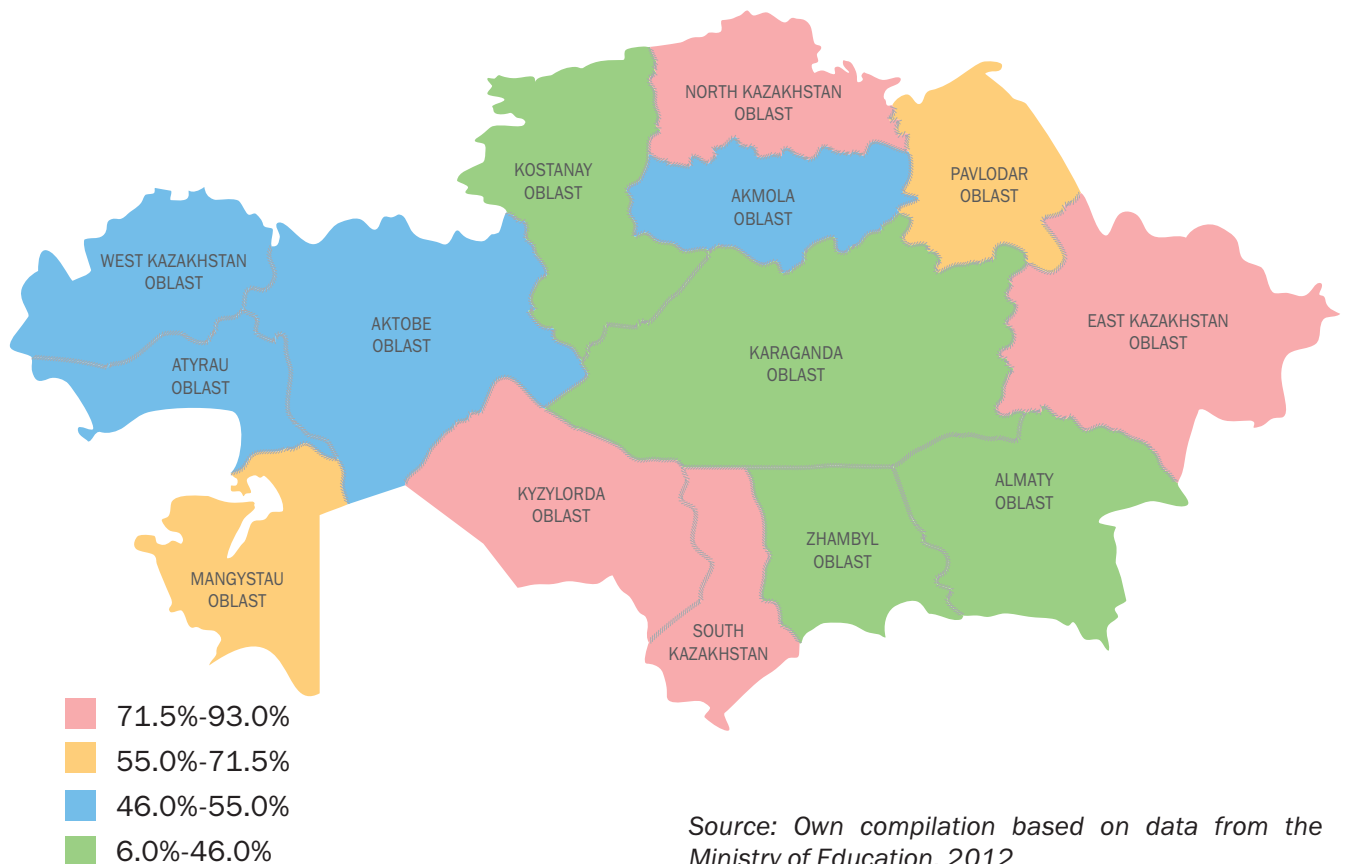


Figure 20. The percentage of children with disabilities not enrolled in the education system

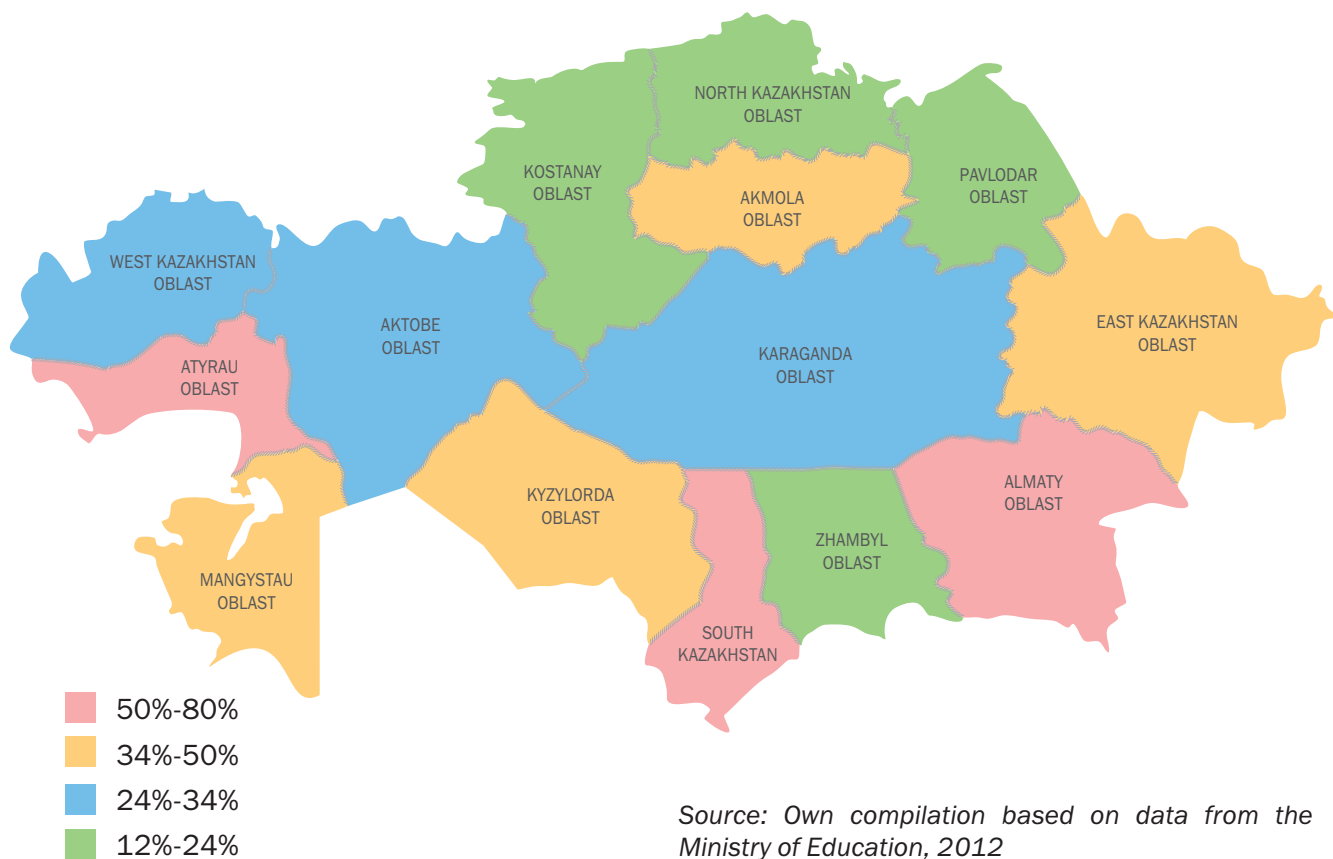


Figure 21. The distribution of children with disabilities in regular daily schools

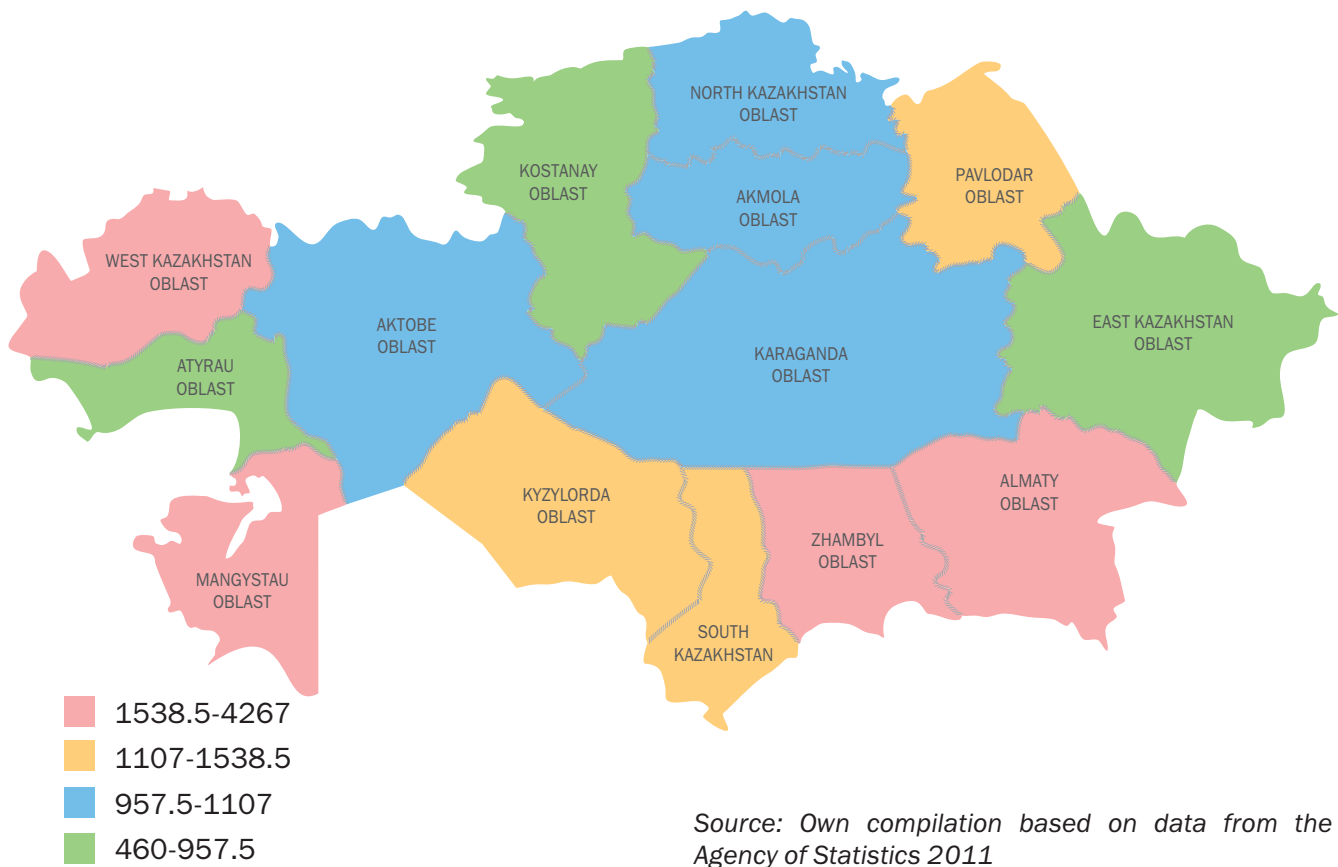
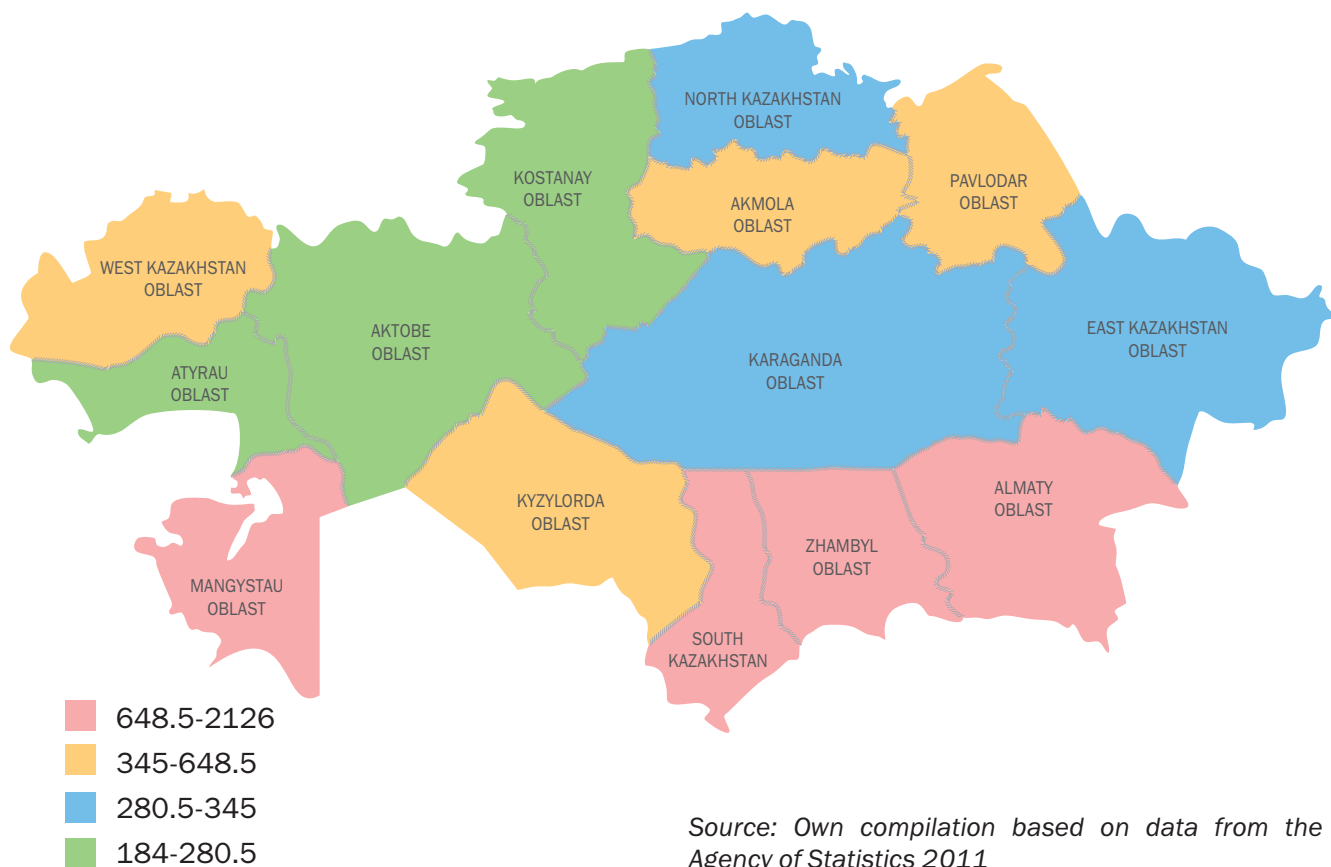


Figure 22. The distribution of children with disabilities supported by a tutor in regular daily schools



Source: Own compilation based on data from the Agency of Statistics 2011

over 2005) in Kazakhstan seems much lower than in other CIS countries this can be an indication of the higher number of children with disabilities already attending special or regular education in Kazakhstan in 2005. Moreover, this may also show that Kazakhstan is ahead in integrating children with disabilities into the education system compared to other countries.

2.5.3 Regular daily schools for children with disabilities

According to the Agency of Statistics, the total number of children with disabilities that studied in regular schools was 21,029 for 2012 (31 percent of total children with disabilities). The highest concentration was in Southern Kazakhstan (figure 21). The data shows that 42 percent of the children with disabilities who studied in regular schools were supported by a tutor (figure 22). From a comparative perspective, Kazakhstan is doing better in terms of inclusion of children with disabilities in regular schools compared to other CIS countries like Uzbekistan (where only 2 percent of children with disabilities are part of regular schools), but numbers are comparable to Kyrgyzstan, where 39 percent of children with disabilities are part of regular schools (UNICEF, 2013).

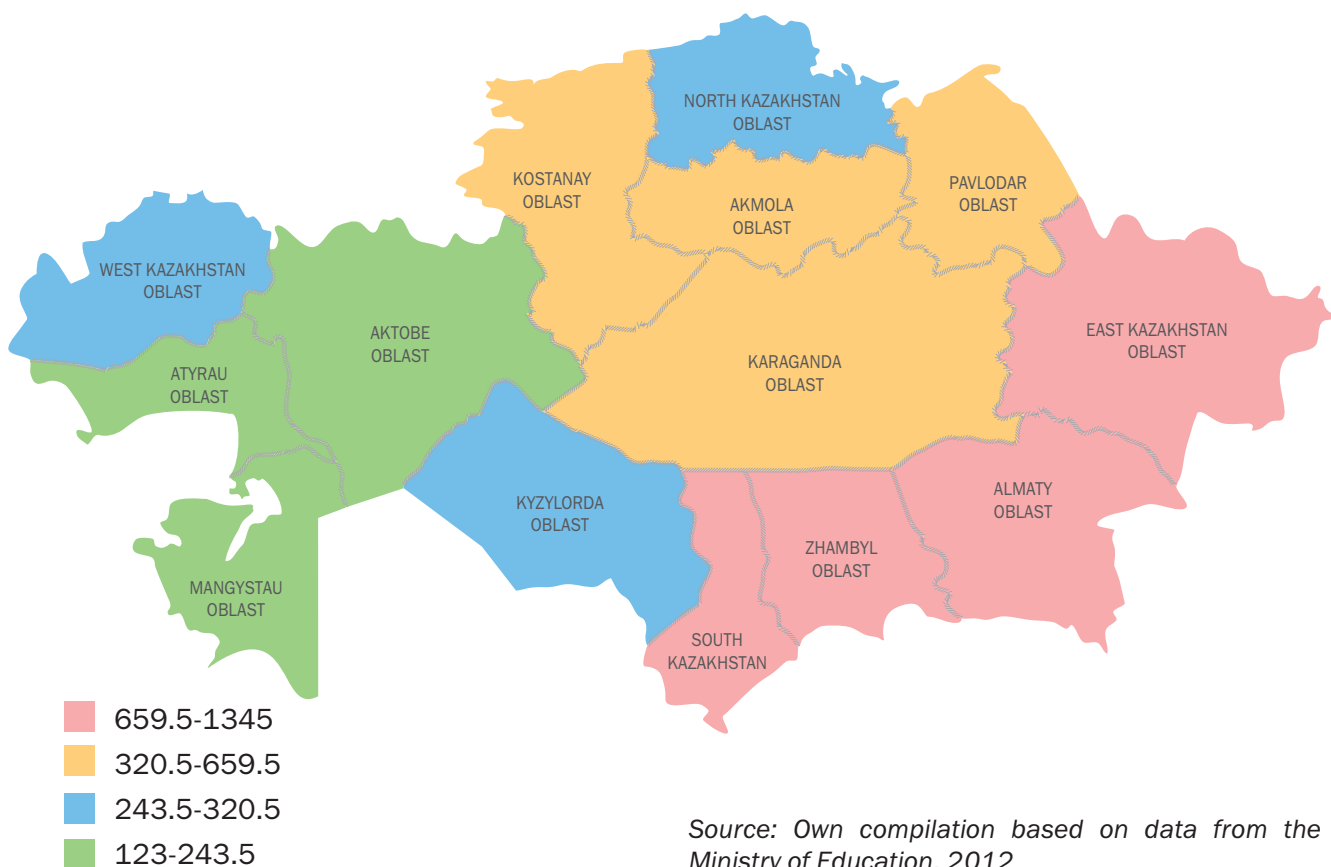
2.5.4 Home-based education for children with disabilities

Figure 23 shows that the regions with the highest number of children with disabilities receiving home-based education are south-east regions (South Kazakhstan, Zhambyl, Almaty and East Kazakhstan) followed by the central regions of the country. The highest percentage of children with disabilities receiving home-based education are in Almatinskaya (17%) followed by South Kazakhstan and Zhambyl (15 and 14% respectively). This distribution follows the same trend of the total number of children with disabilities in Kazakhstan (figure 3).

Data presented in figure 24 shows that regions with the highest shares of children with disabilities receiving home-based education in rural areas are in South Kazakhstan (87% of the total number of children receiving home-based education in this region live in rural areas), North Kazakhstan and Almatinskaya (75%) and Kyzylordinskaya (67%).

Official data on the total number of children with disabilities receiving home-based education in Kazakhstan can be contradictory. According to the Ministry of Education the total number of children receiving home-based education for 2012 was 7923 while in the country report for Kazakhstan

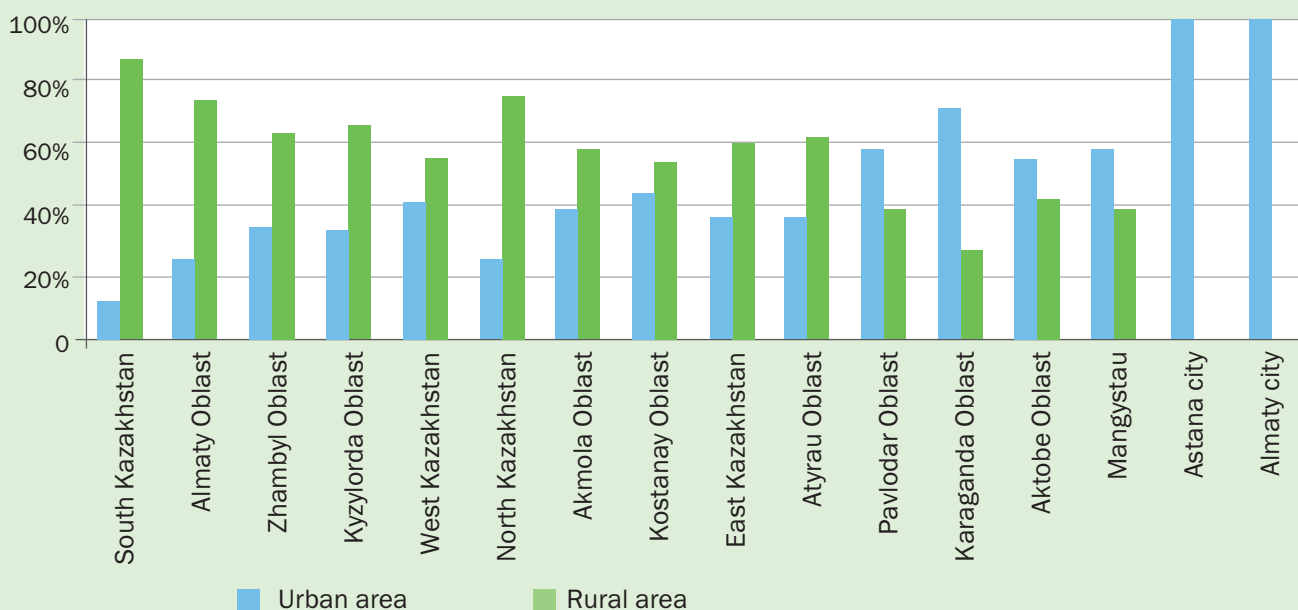
Figure 23. Number of children receiving home-based education (by regions)



this number was 8758 (10 percent higher) (UNICEF, 2013). The country report for Kazakhstan shows that the number of children with disabilities receiving home-based education for 2012 in Kazakhstan was 13 percent of the total number of children with disabilities (UNICEF, 2013). This

number compares well with Uzbekistan (where 13 percent of children with disabilities also receive home-based education) while it is much higher if compared with other countries like Kyrgyzstan (where 4 percent of children with disabilities receive home-based education).

Figure 24. The percentage of children with disabilities living in urban and rural areas receiving home-based education for each region



Box 8. Human Interest Story: Aisaule

“I’m a very happy mother!” says Nazira, aged 44. She’s now a mother of four, with two sons already grown, aged 22 and 23. She and her husband had always dreamt of having a daughter, so, 18 years after having their first two children, they decided to try again. This heralded the arrival of another lovely boy into their family.

“It brought us so much joy to see a little one running around the house again, and to our adult sons,” smiles Nazira. After another year or so, Nazira accidentally fell pregnant again and the doctors warned of the risks connected with her age. However, Nazira was not intimidated, being convinced that she was carrying a girl. She was right; as Nazira says, ‘a cutest girl’ came into the family’s life, bringing untold happiness.

Nazira admits, “During pregnancy, I was offered genetic screening because I was in the risk group, but I refused. If I’d accepted the screening, they probably would have told me that my daughter has Down Syndrome.” She is adamant that the knowledge wouldn’t have inspired her to have an abortion.

Aisaule is now 2.5 years old, with a sweet and beautiful nature: she can talk and walk, but still loves to be carried by her mother.

Nazira’s neighbors and friends advised her to abandon her daughter, but the idea seems odd to her and to her family. “We’re so happy to have her in our family!” says Nazira. “Kids like her are so warm and kind.”

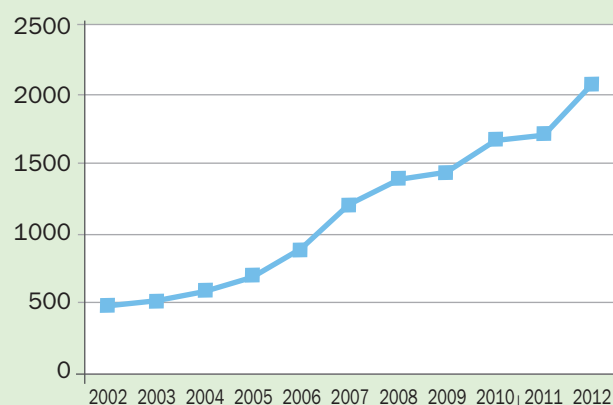
The Government provides Aisaule with a monthly allowance, social assistance, and rehabilitation treatment, including massage, physical training, and speech therapy. The only thing that worries Nazira now is her maternity leave, which will conclude once her daughter turns three. She wishes she could send Aisaule to a regular kindergarten. Nazira believes it most likely that she will stay at home with Aisaule but worries that this will interrupt her employment history and jeopardize her future pension. She admits, “I wish the government would formalize the job of staying at home as a housewife or mother as ‘regular work’.”

2.5.5 Technical and vocational education for children with disabilities

Participation in vocational training contributes towards the inclusion of children with disabilities in society as they will be a potential contingent for the labour market and as a result have the capacity to become quite independent from their family members. Based on data from the Ministry of Education, the number of children with limited abilities and disabilities increased in technical and vocational education institutions between 2002 and 2012 (figure 25).

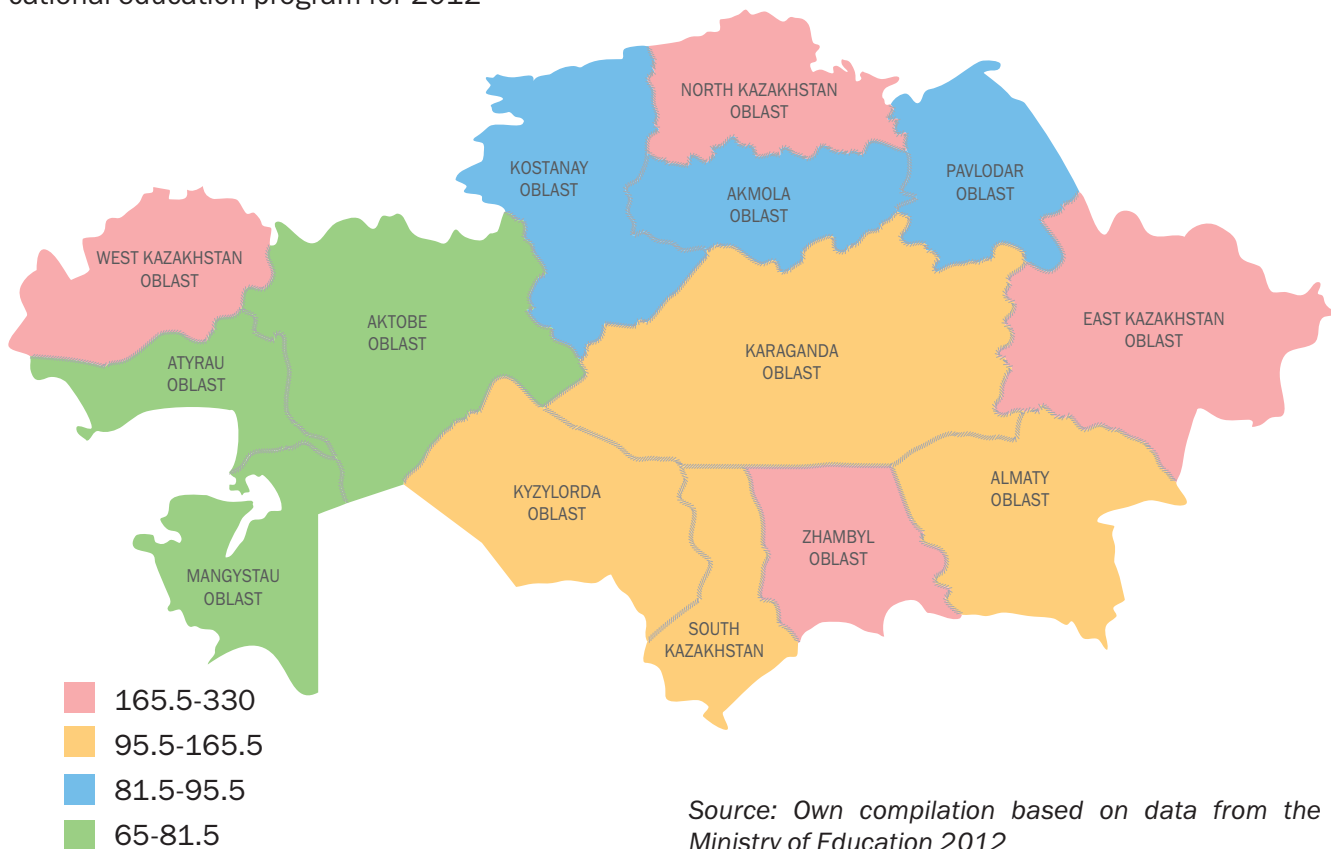
The regions with the highest number of children attending technical and vocational education are East, North and West Kazakhstan and Almaty city (figure 26). The data show that the total number of attendees is 2061 in 2012. This represents a 20 percent increase if compared to the total number of attendees in 2011.

Figure 25. Data on education of children and youth with disabilities and with limited abilities in Technical and vocational education organisations, 2002-2012



Source: Own compilation based on data from the Ministry of Education 2012

Figure 26. The distribution of children with disabilities and limited abilities attending technical and vocational education program for 2012



Source: Own compilation based on data from the Ministry of Education 2012

2.5.6 Rehabilitation centres and Medical social institutions for children with disabilities

As mentioned above, the severity of disability is a key factor in determining whether a child with disability can stay in a rehabilitation centre which is under the Ministry of Education. These residential rehabilitation centres are for children from 0 to 18 years old, where children undergo a personal rehabilitation program. The number of existing rehabilitation centres is 20 (but some sources only mention 16), serving 2386 children with disabilities in 2012 (Ministry of Education, 2012). Figure 27 shows the distribution of these centres throughout the country. These rehabilitation centres are mostly concentrated in the West Kazakhstan and Kostanay regions (3 centres for each region) followed by East Kazakhstan and Almaty region, while the highest concentration of numbers of children are in Kostanay, Karaganda and Zhambyl regions. As the data on the number of personnel serving in these centres is again missing, we cannot investigate whether the differences between the distribution of centres and the numbers of people can influence the quality of services offered in the rehabilitation centres.

Data from the Agency of Statistics 2011 show that there are 27 medical social institutions, for

children with psychoneurological disabilities and muscular-skeleton disorders, all over the country in 2011 (figure 29 and 31). The graph in figure 29 shows that the number of medical social institutions has increased in 2010 compared to the 2006-2009 period. The number of children with disabilities based in these institutions decreased in 2006 compared with 2005 (it went from 2457 to 2047). The main reason for this was that the number of functioning medical social institutions also decreased from 28 (in 2005) to 20 (in 2006). The number of children with disabilities based in these institutions continued to decrease until 2009 (2398 children), but this number increased again after 2009 and in 2011 there were 2901 children in the medical social institutions.

One of the main problems faced by the institutions for children with disabilities (especially in countries in transitions) is the transition period when children aged 18 years or older need to leave such institutions. The Ministry of Labour and Social Protection of Kazakhstan specifies that persons with disabilities aged 18 years or older have to reside in different types of institutions for adults. However, sometimes the transition period may take time and persons 18 years and older may still reside in these institutions. Data from the Agency of Statistics in Kazakhstan for the period

Figure 27. The distribution of rehabilitation centres

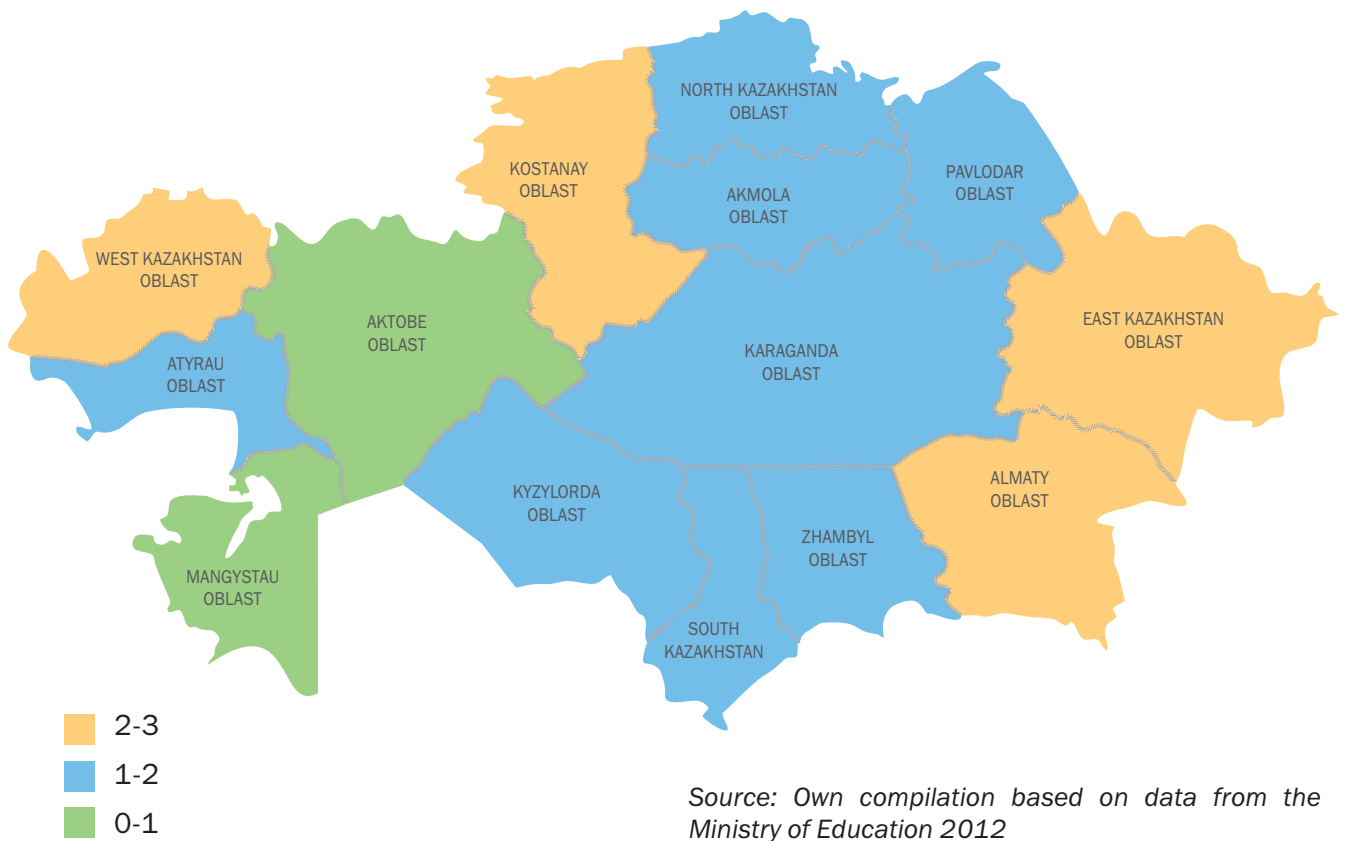


Figure 28. The number of children with disabilities in rehabilitation centres

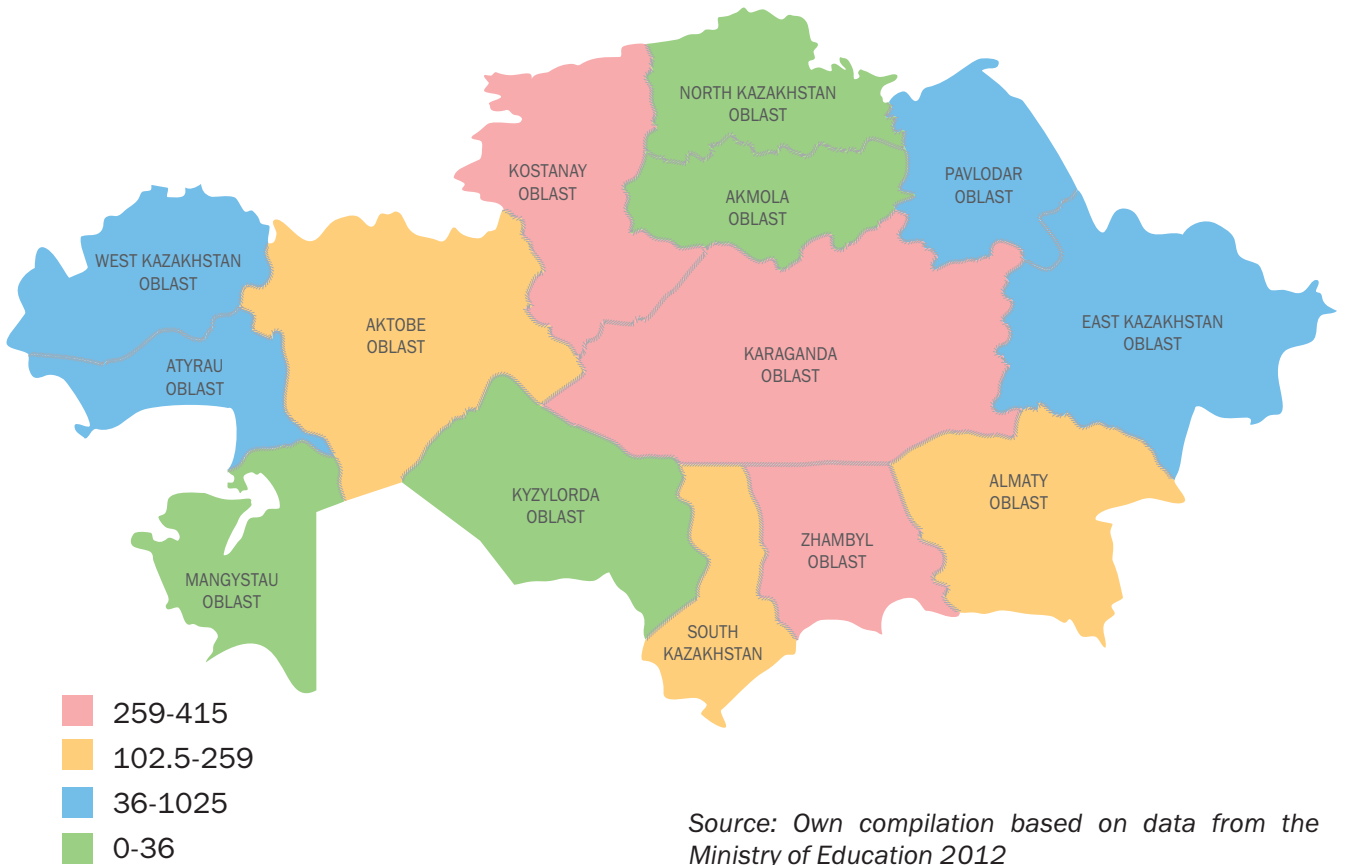
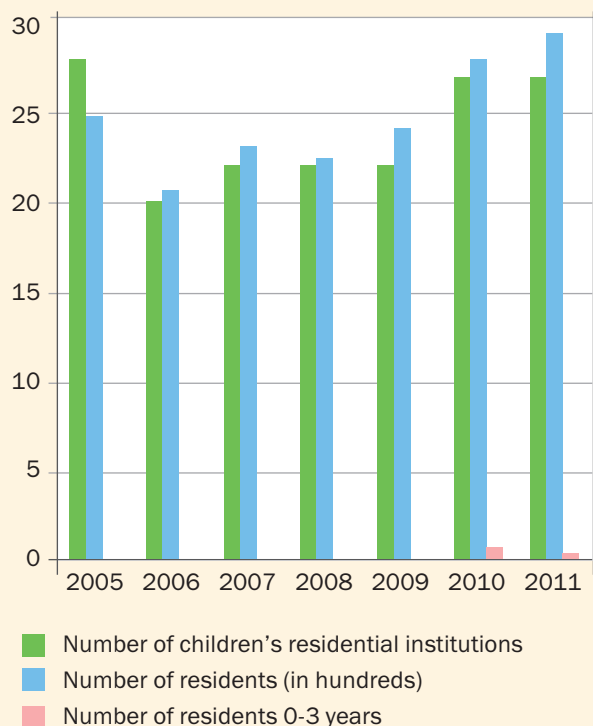


Figure 29. The total number of medical social institutions, number of residents under 18 and 0-3 years old for the period 2005-2011 (number of residents in hundreds)



Source: Own compilation based on data from the Agency of Statistics 2011

2005-2011 shows that these numbers have decreased dramatically over the years (from 2922 in 2005 to 136 in 2011) figure 30.

The reported number of medical social institutions may change depending on the source of reference. Hence, the Ministry of Labour and Social Protection reports 21 medical social institutions for 2012

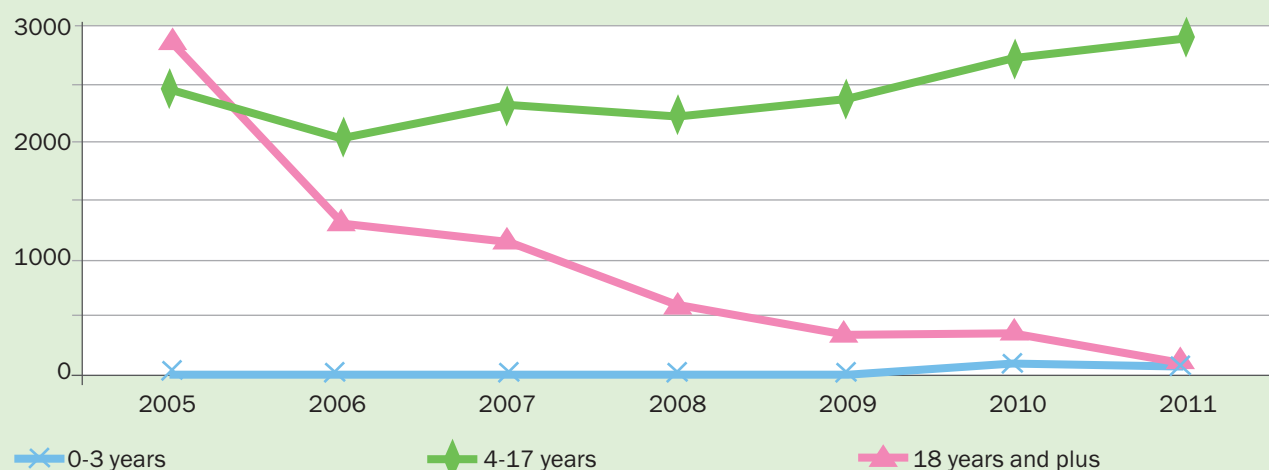
(17 institutions for children with psychoneurological disabilities and 4 institutions for children with muscular-skeleton disorders). This lower number of medical social institutions can be a consequence of transferring most of these services to the community level. The de-institutionalisation of children with disabilities is strongly associated with their inclusion in society, as this will include their participation in society and reduce discrimination.

Another possible explanation for the difference between the numbers reported from the Agency of Statistics and from the Ministry of Labour and Social Protection could be the methodology, the definitions used, the discrepancies in the numbers reported, etc. The differences between the reported statistics coming from agencies of statistics and line ministries is a known phenomena not only in Kazakhstan but also in other countries, especially where differences exist in the ways they are reported or in the definitions used.

The reason why the number of children in residential institutions has increased since 2009 (figure 30) can be linked to the fact that more children with disabilities were identified during this period and more attention was paid to these children since the adoption of the law "On specialized social services in 2008". The residential centres also included day care departments, which could be a positive reform change that attracted more home-based children.

The Transmonee (2013) data show that the number of children with disabilities in public residential care (all types of institutions) has decreased for most of the CIS during the period 2000-2011. Table 2 shows that the country with the highest decrease was Belarus (1.32 times less children

Figure 30. The total number of residents under and upper 18 years old in children's residential institutions for persons with disabilities for the period 2005-2011



Source: Own compilation based on data from the Agency of Statistics 2011

Table 2. Number of children with disabilities in public residential care (all types of institutions), for the period 2000-2011

| Country | 2000 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 |
|--------------------|---------|---------|---------|---------|---------|---------|---------|
| Belarus | 13,880 | 8,808 | 7,807 | 7,162 | 6,712 | 6,275 | 5,976 |
| Moldova | 4,788 | 4,974 | 4,674 | 4,460 | 4,272 | 3,655 | 3,288 |
| Russian Federation | 183,976 | 149,409 | 141,848 | 138,899 | 137,963 | 139,402 | 138,114 |
| Ukraine | 7,977 | 7,304 | 7,158 | 7,125 | 6,937 | 6,879 | - |
| Armenia | 4,875 | 1,935 | 1,707 | 1,588 | 2,671 | 2,667 | 2,484 |
| Azerbaijan | 2,979 | 3,051 | 4,290 | 2,810 | 2,939 | 2,804 | 2,459 |
| Kazakhstan | 16,010 | 15,477 | 15,282 | 14,761 | 14,424 | 14,341 | 14,118 |
| Kyrgyzstan | 3,923 | 3,492 | 3,446 | 3,334 | 3,362 | 3,326 | 3,483 |
| Tajikistan | 1,537 | 2,140 | 1,774 | 2,005 | 1,666 | 2,309 | 2,315 |
| Turkmenistan | 2,775 | 2,568 | - | - | - | - | - |
| Uzbekistan | 16,961 | 16,694 | - | - | - | - | - |

Source: Transmonee 2013

with disabilities lived in residential public care in 2011 compared to 2000), followed by Armenia (0.96 times less in 2011 compared to 2000). Only in Tajikistan the data show an increased number of children with disabilities (34 percent) living in public residential care in 2011 compared to 2000.

Despite the decrease in the total number of children with disabilities in public residential care it seems that the composition of children in these institutions has changed to the disadvantage of children with disabilities. Country reports show

that the percentage of children with disabilities in residential care over the total number of children in these institutions has increased between the years 2005-2012 for some of the CIS countries (Table 3). This could be a consequence of the increasing (economic or social) difficulties in caring for these children at home (e.g. employment difficulties for parents, insufficiency of economic means, but also discrimination and isolation from the community). Another reason for these higher percentages of children with disabilities could

Figure 31. The distribution of the medical social institutions for children with disabilities

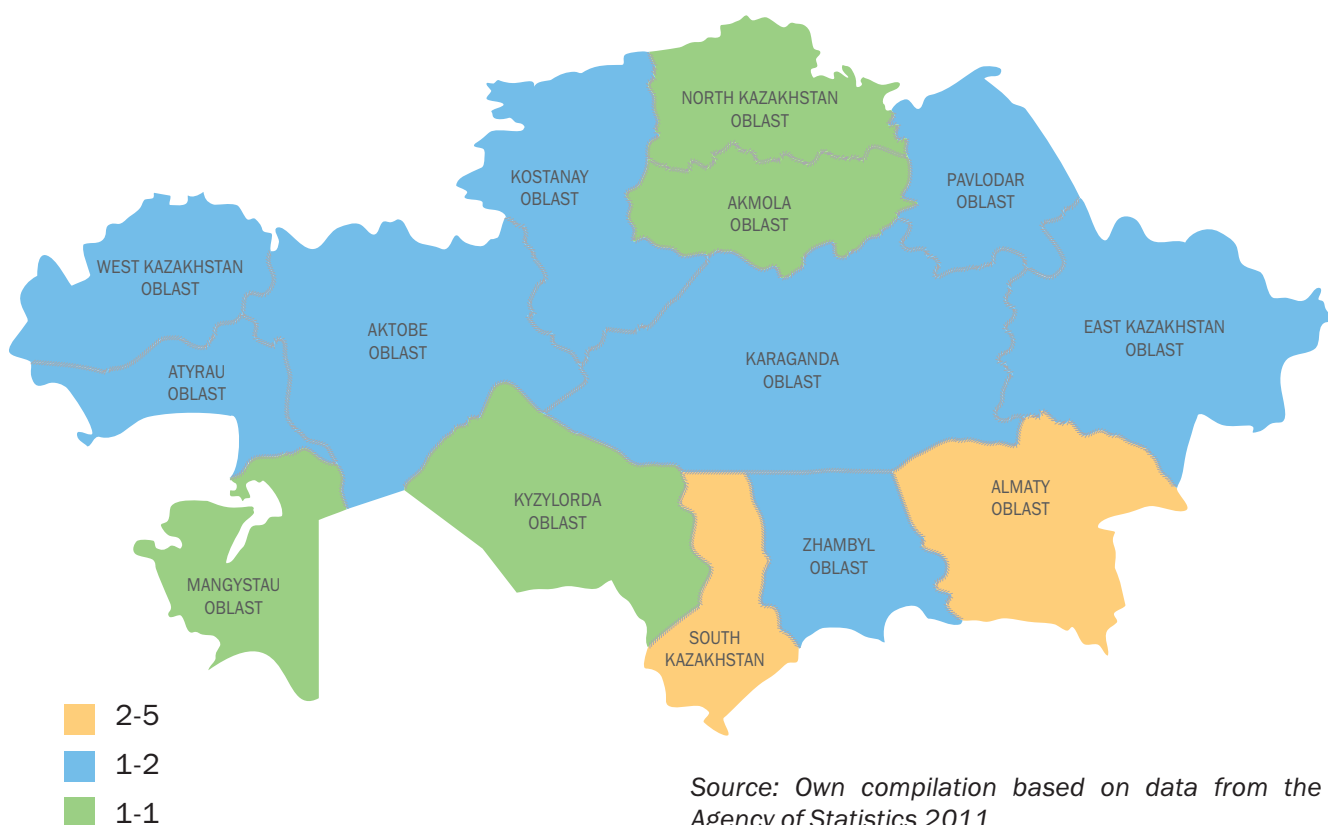
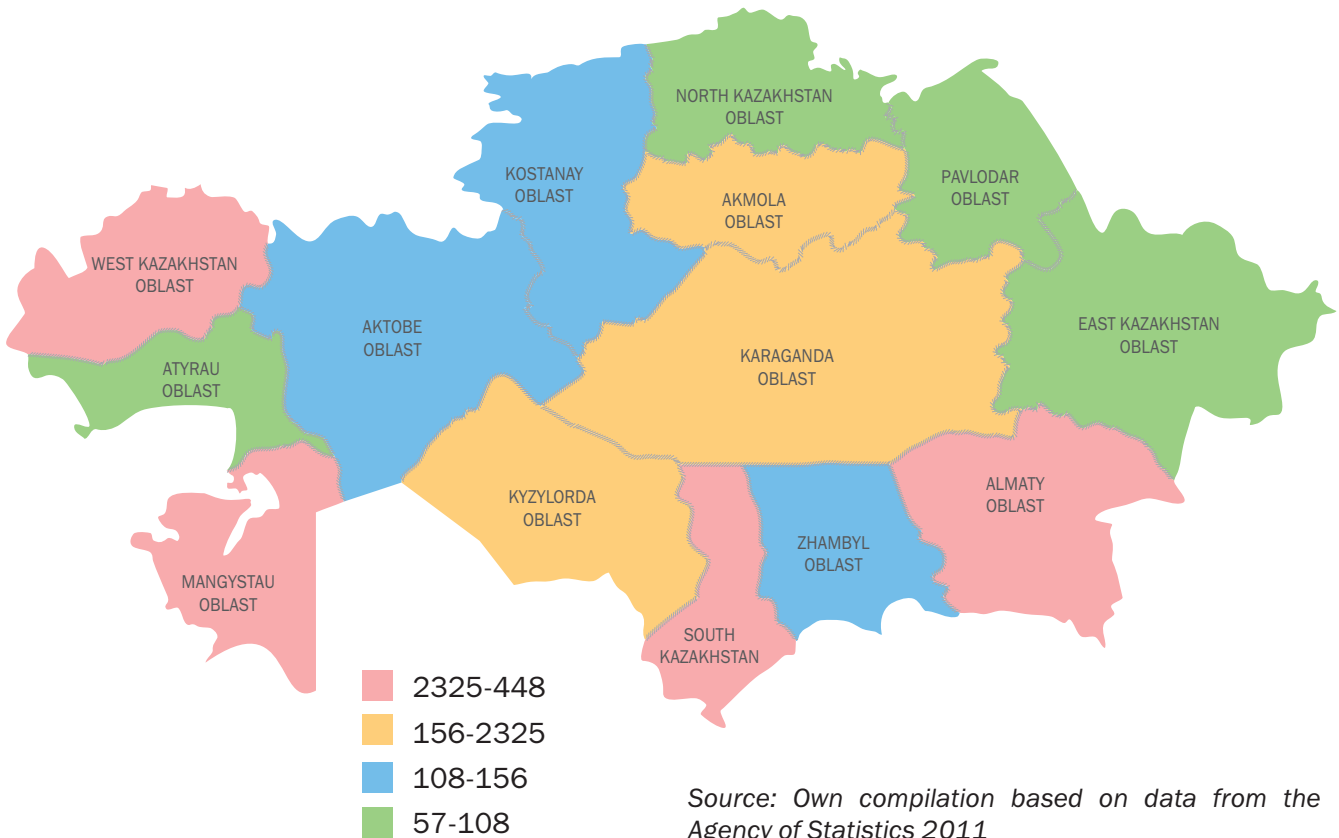


Figure 32. The number of children with disabilities in medical social institutions



Source: Own compilation based on data from the Agency of Statistics 2011

Table 3. The percentage of children with disabilities in residential care over the total number of children in residential care (18 years old)

| Country | 2005 | 2010 | 2011 | 2012 |
|--------------|-------|-------|-------|-------|
| Kazakhstan | - | 29.6% | 30.9% | 39.6% |
| Kyrgyzstan | 34.2% | 32.8% | 32.4% | 32.2% |
| Tajikistan | 16.5% | 20.8% | 17.8% | - |
| Turkmenistan | 83.5% | 84.1% | 85.3% | 86.7% |

Reference: Kazakhstan 2012, country profile; Kyrgyzstan 2012, country profile; Tajikistan 2012, country profile; Turkmenistan 2012, country profile; Uzbekistan 2012, country profile

also be a lower preference among potential foster parents to adopt a child with disability.

While figure 31 shows the distribution of these medical social institutions, figures 32 and 33 show the distribution of children and personnel serving in these institutions. The figures show that these institutions are mostly concentrated in Almaty and in South Kazakhstan regions. The total number of children with disabilities (under 18 years old) served in 2011 was 2901, while the total number of personnel serving in these centres was 4240. This shows us that the average child/personnel ratio are less than 1 and we can observe it for all the regions in the country. However, it should be noted that as the information regarding the background

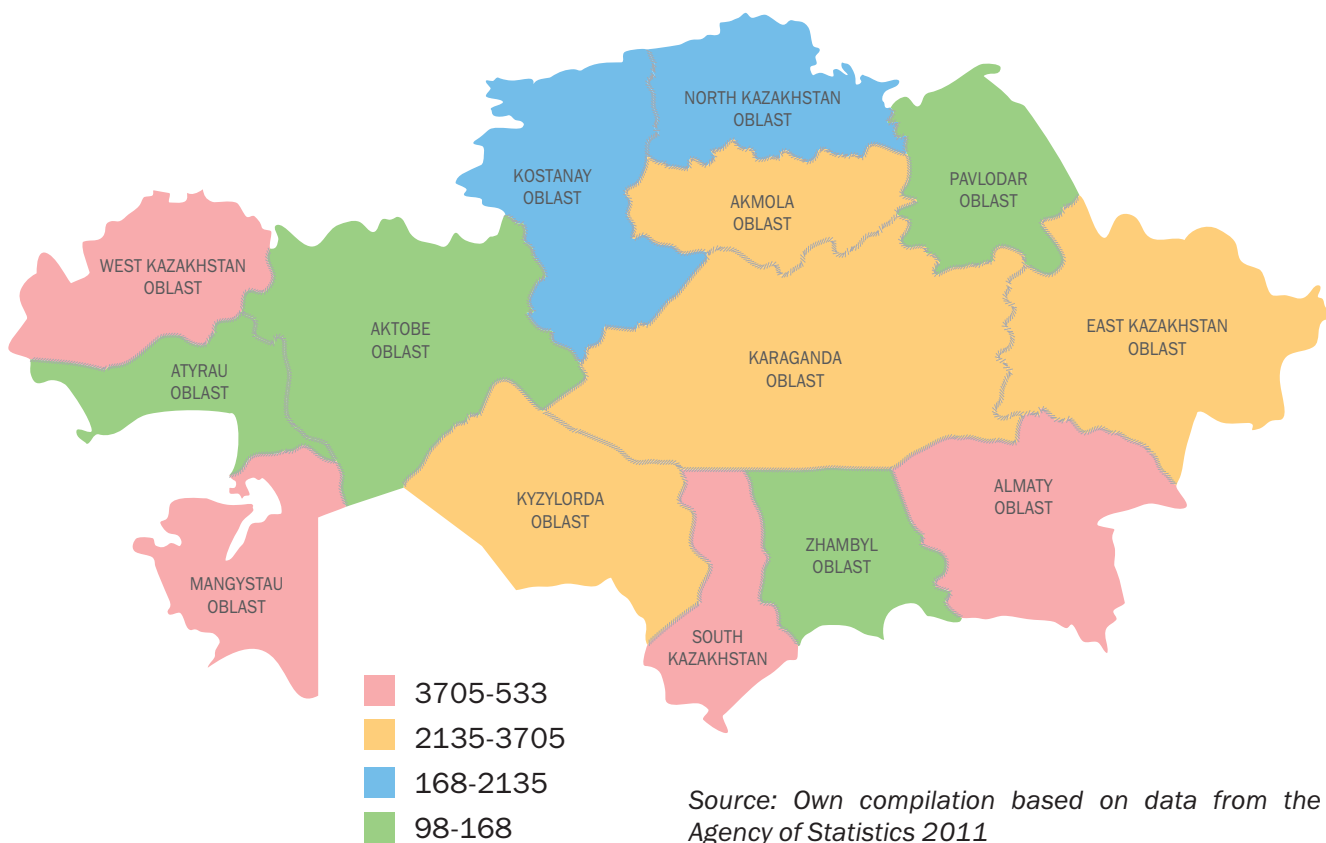
and the profile of the personnel is missing the ratio child/personnel may not accurately reflect the personnel assigned to a single child.

2.5.7 Higher education scholarships programs for children with disabilities

Even though education for children with disabilities is free of charge and they are prioritised for entering tertiary education, not all children with disabilities who have applied for a scholarship have actually received it. Figure 34 shows the percentage of children with disabilities that have received scholarships for tertiary education (as a percentage to those that have applied). Only 85% of children with disabilities who applied for a scholarship received one in 2012.

The distribution of children with disabilities across Kazakhstan follows larger population patterns, with the greatest absolute number of children with disabilities registered in the most populous regions (Karaganda, Almaty, Zhambyl and South Kazakhstan). Increased registration rates likely correspond to greater usage rates of state services and benefits: healthcare data indicate that 88.2% of all children under 16 years old with disabilities are registered in primary health care polyclinics, and more than 96% of children with disabilities benefit from state allowances. While these service

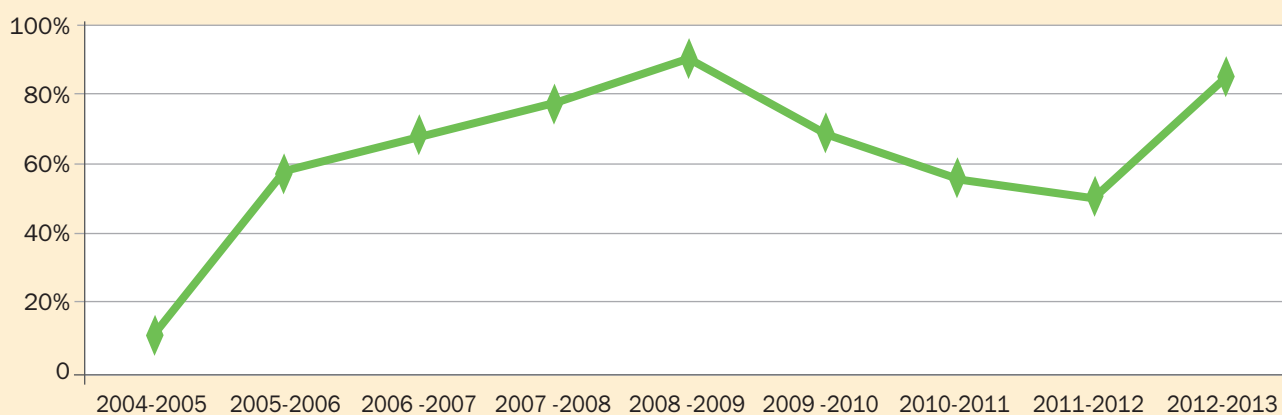
Figure 33. The number of serving personnel on medical social institutions for persons with disabilities



take-up rates are impressive and represent a significant improvement over past years, they do indicate that a certain proportion of children do not make use of the benefits and services guaranteed to them by law. It is therefore important to continuously monitor the numbers of children with disabilities not benefiting from state allowances and identify on time the reasons that could lead to them not getting such benefits. The educational inclusion of children is another area in which Kazakhstan has achieved mixed results. Based on the severity of the disability, children with disabilities can go to general, inclusive, or special pre-schools,

primary schools, or social institutions. Secondary- and post-secondary education has seen some concrete improvements, however. Between 2002 and 2012, the number of children with limited abilities and disabilities attending technical and vocational education institutions increased. Although education for children with disabilities is free of charge, recent data indicate that only 85% of children with disabilities who applied for a scholarship received one in 2012. This signals that while inclusion in tertiary education has increased, further efforts could be made to promote the inclusion of children with disabilities in education.

Figure 34. The percentage of children with disabilities that have received scholarships for the period 2004-2012



Source: Own compilation based on data from the Ministry of Education 2012



At the 'Community Buddy Bears' International Art Exhibition, in Astana

III. BARRIERS TO SOCIAL INCLUSION OF CHILDREN WITH DISABILITIES: STAKEHOLDER PERCEPTIONS

The prior sections detailed the institutionalised efforts Kazakhstan has made to ensure the equity of children with disabilities, providing a sense of the scope and scale of ongoing efforts to ensure equality of opportunity among children with disabilities. While Kazakhstan has undoubtedly made important strides forward in the protection of the rights of children with disabilities, such changes may not carry over to the daily experiences of children with disabilities and their families.

In order to better understand the situation of children with disabilities and the barriers they experience to fully participate in society, a series of in-depth interviews and focus group discussions with various stakeholders were conducted in five regions: Astana, Almaty, Karaganda, Kyzylorda and East Kazakhstan. The information collected through in-depth interviews and focus groups provides first-hand information on both barriers and achievements in the area of social inclusion and equity of children with disabilities. Different stakeholders yield different insights: children themselves provide first-hand accounts of how existing systems have failed them, parents of children without disabilities reveal their reservations about supporting inclusive education given concerns for their own children’s education, and policy practitioners reflect on the practical limitations faced in implementing regulations that will require significant reform. The diverse group of stakeholders provides an excellent range of insights into how social inclusion and equity can be fostered across different domains by identifying the circumstances and structures that can lead to the systematic denial of the rights of children with disabilities. This chapter summarises the findings from the discussions, focusing on key “domains” of a child’s life necessary to ensure “a full and decent life”, namely: education, health care services, social participation, adequate standard of living and social protection, and the legislative and normative environment.

3.1. Data and Methodology

In-depth interviews and focus group discussions were conducted in five regions: Astana, Almaty, Karaganda, Kyzylorda and East Kazakhstan. In-depth, semi-structured interviews were conducted with government officials (at both central and local levels), directors of schools (some of which had implemented curricula for children with disabilities), education staff, medical doctors and experts of the medical commissions, and representatives of national and international NGOs that are working with children with disabilities. Table 4 below provides an overview of the interview sample distribution by respondent type; the list of interviews and focus groups with type of respondent is provided in Table A6 in the Annex.

Nine focus group discussions (FDG) were organised with the participation of teachers from inclusive schools, parents of children with and without disabilities, and children with and without disabilities. The selection of stakeholders for the FDGs was

Table 4. Characteristics of Interview and Focus Group Respondents

| Characteristic | Number |
|---|------------------------------|
| In-Depth Interviews | |
| <i>Type of Agency Represented</i> | |
| Public Health & Education Services | 8 |
| Non-governmental/ International Organizations | 6 |
| Central Government Agency | 5 |
| Local-Level Government Agency | 14 |
| Focus Groups | |
| <i>Type of Respondents</i> | |
| Children with Disabilities | 1 group; 9 participants |
| Children without Disabilities | 2 groups; 19 participants |
| Parents of Children with Disabilities | 2 groups; 15 participants |
| Parents of Children without Disabilities | 2 groups; 17 participants |
| Teachers | 2 groups; 23 participants |

guided by their diverse individual characteristics and potentially diverse opinions. The allocation of the FGDs across the five regions provides scope for regional disparities to be accounted for, as well as making the findings more generalisable at country level. The groups of parents were chosen to best encompass differing parental perceptions of disability and how the inclusion of children with disabilities should be promoted, with parents of children studying in general, inclusive, and special schools included. Three focus group discussions were organised with the participation of children; two of these included children without disabilities, and one was organised with children from a residential school for those with visual impairment, to assess what problems children with disabilities face on a daily basis. Two other focus groups were conducted with children without disabilities to better understand their perceptions of disabilities and their friends with disabilities, one of which was organised in an inclusive school and one in a general school. In total 83 persons participated in the FGDs, of which 28 were children (9 children with disabilities and 19 children without disabilities), 23 teachers, and 32 parents (15 parents of children with disabilities and 17 parents of children without disabilities). The age of the participating children varied from 7 to 13 years. Data collection was carried out using a local consultancy company “BRIF” in collaboration with the international experts.

3.2 Education

Over time the systematic social exclusion of children with different forms of disabilities can lead to two forms of inequality that are equally destructive to social development: inequality of life chances or opportunities, and inequality of outcomes. The effects of both forms of inequality can be especially harmful to children in the domain of education, where inequity can carry over to later-life social mobility. Given the strong overlap between educational attainment and aspects of a child's well-being such as health and future life opportunities (which are, in turn, correlated to poverty), it is especially imperative to understand the barriers that children face to social inclusion in education as well as the positive factors that facilitate their inclusion in mainstream education.

Respondents to semi-structured interviews and participants in the focus groups identified several clear areas in which general educational facilities were failing children with disabilities. These barriers exist on several levels such as access to educational facilities, physical school structure, quality of education provided, lack of tailored education approaches, etc. While some barriers applied to all children—even, in some cases, to children without disabilities—children with different forms of disabilities face unique, specific barriers. Given the highly heterogeneous nature of “children with disabilities” as a group, it is essential to assess the needs and constraints of children with different disabilities.

3.2.1 Facilities & Classroom Structure

An easy example of the need to recognise the heterogeneity among children with disabilities is in school facilities and classroom structure. Child focus group participants noted that one of the major disadvantages to general education schools is the large class size. This is a problem that also affects the educational outcomes of children without disabilities because it implies higher student-teacher ratios and less personalised educational guidance, but for children with disabilities these inadequacies can easily become grounds for exclusion. Children from a special school for the visually impaired noted that blackboard visibility was very low in general schools because of the class size. As one child remarked: “...they can put you on the back school desk, and nothing can be seen from there” (Child 3; FG1). Another added: “They put you on the back school desk. And how do you see from there? Do they say “you can approach” [the

blackboard]? They will say no, sit at your school desk.” (Child 5; FG1). The last quote highlights different structural inadequacies that can curtail learning: while the seating arrangement made it difficult for the child to see the front of the room, the inflexibility of teachers to allow children to approach the board made it difficult for a solution to be reached. Parents also recognise this limitation. A parent of a child without disabilities attending an inclusive school stated that:

“For example I think that for a teacher who has thirty children at school, it will be difficult to pay special attention to a child who has bad sight. Not because it doesn't matter for him, but it would be difficult even to calm him/her down if needed.”(Parent 2; FG7)

Another parent added: “Yes, a teacher needs specialised education” (Parent 4; FG7). Parents of children without disabilities expressed further concern that the presence of children with disabilities would detract from the overall quality of education: “Yes, these children will not be able to keep pace with our kids and it will affect our children's academic performance” (Parent 5; FG8). While this was not a commonly-held view by the parents of children without disabilities, some parents did express displeasure with the engagement of children with disabilities.

Facilities are an obvious area in which specialised schools offer a distinct advantage over general and inclusive schools. All respondents stated that school facilities are seldom built to accommodate special-needs students, particularly those who make use of a wheel-chair and cannot use the stairs. The coordinator of an inclusive education program provided a poignant example: “One girl with cerebral palsy studied here, her father teaches technology at our school... He came, he carried her from one lesson to another, he himself carried her with the wheelchair, and boys helped him. And imagine if they will be two, three. What to do? The teachers, of course, will not be able. That is, we have no conditions to receive such disabled children.” (Teacher; IN12). A teacher at a different school stated that major reconstruction would be necessary for full inclusion to take place:

“...we do not have ramps. The school was built for healthy children, and before we open the doors of our school to children with disabilities, we need to change many things; it would be better to build a new school, which would be fully equipped for a relaxing and independent movement of children with disabilities.” (Teacher 4; FG9)



Specialized Children's Home
(for those aged 0 to 3 years),
Astana

Many respondents emphasised that the school building and its equipment were relics of the Soviet period, and there have been few resources to update them. Doorways are generally too narrow and thresholds too high to accommodate wheelchairs. Desks are too narrow and unbalanced, and there are no lifts or ramps between floors. No reflective strips or rails are installed to guide those with visual impairments. One respondent felt that educators themselves could play a strong advocacy role in encouraging infrastructure updates:

"...we are stuck with this wheelchair. They think that children can just stay on the first floor. I always wonder why they can stay only on the first floor. Why do we need the second and the third floors then? It is for students, they say. And isn't this person a student? He is the same student as the other ones. Why does he have no right and no access either to the second, or to the third floor? There are classrooms for chemistry, physics on the second floor. On the

third floor children study history and geography. Maybe this student is some future historian or geographer? Why did the authorities decide that this student does not need to access these rooms? Just because they are adults and they can just forbid access to these rooms? It is in our hands. We just have to want this to happen." (Director; IN3)

The respondent clearly felt that inadequate infrastructure was used to rationalise the exclusion of students with disabilities. The lack of responsiveness about the mobility needs of children with disabilities seemed like a reflection of general apathy about their inclusion. This suggests clear room for improvement, but it is an area that requires significant financing and support from the state.

3.2.2 Curriculum Development & Specialised Personnel

Curriculum development is another area in which general and inclusive schools may not meet the unique needs of children with disabilities as well. Some parents of children without disabilities felt that the pace of learning would be too fast in general schools for most children with disabilities:

"A training program for these children should be made a bit easier. If they experience difficulties asking for bubble gum in a store, I doubt he will be able to learn a verse or the multiplication table." (Parent 5; FG8)

"This child will fall short of the school curriculum, the teacher will not provide special explanations for him, she will give a common task for the entire class for 25 students, and she will not devote even 5 minutes to this child." (Parent 6; FG8)

The issue of classroom size was once again raised as a factor that could limit access to education for a child with disabilities. Teachers themselves also recognised that pacing could be a problem. The solution that many proposed was not a move to specialised schools but to tailored classes. Several teachers provide specific examples:

"If in regular classes it is necessary to have 5 hours of Russian language a week, for children with disabilities it would be 1 or 1.5 hours." (Teacher 8; FG9)

"There is individual work. The knowledge that we teach, even based on the facilitated program, corresponds to the regular curriculum." (Teacher 12; FG9)

“There are children who cannot sit still or get tired. Our lesson lasts 45 minutes, and for a child with a disability, 35 minutes. At the elementary school 35 minutes are kept, and for senior classes at home our teachers conduct a 35 minutes class and a 45 minutes class at the school... This all depends on their diagnosis.” (Teacher 11; FG9)

Teachers discussed the use of “facilitated programs”, standardised curricula adapted to children with disabilities, as a means of ensuring that even children with disabilities learn the national standard. The appropriateness of this approach depends on the specific disability and severity, however. The director of an educational centre for children with disabilities noted that classes are designed around the severity of disability rather than age to ensure that children are in the right cohort with the appropriate learning goals. Another respondent —the founder and director of an integrated rehabilitation centre— suggested that even tailoring curricula according to the severity of disability is not enough. Individual work plans need to be designed for each child:

“...everybody should work in situ [within the unique local context], taking into account individual needs of a child. So there are no two children with similar problems. They are all different, even having a similar diagnosis, children have different conditions... we need to develop an individual working plan for each child... unfortunately, the state institutions do not pay significant attention to this problem... For us this is like the passport of Kazakhstan’s citizen –the individual working plan should be the passport for individual child development. We should trace, monitor and see the dynamics of development. Or vice versa, if a child has no results, it is necessary to reconsider the methods of development.” (Director; IN4)

While such tailoring may be possible in the context of a rehabilitation centre, where greater emphasis can be placed on individualised learning, the same level of personalisation may not be possible in general schools. While capacity may be a problem, the joint development of individual work plans by both teachers and parents may provide a better framework for guiding the education of children with disabilities. Teachers may then have better orientation in how to adapt the curricula for specific children. Other respondents also discussed how the degree of disability determines the appropriateness of the curriculum for the student. One teacher from a school with inclusive classes

noted that children with disabilities followed the same curricula as other children. In this case the curricula did not need to be adapted to the students because the form of disability —congenital or acquired hearing loss— did not significantly affect their learning ability, and the specific disability could be better treated by non-classroom therapy, like working with a speech therapist. At the same time, the respondent recognised that the situation would likely be different for children with other forms of disabilities, for whom more intensive supervision may be needed:

“That will be a bit more difficult as we will need a special teacher. Somebody needs to accompany a child to the blackboard, to the school canteen. Our state did not consider those issues yet. Who is going to pay for this? This is an additional teacher. How can the class supervisor cope with the problem alone? He will either stay with the other children in the classroom or accompany that child to the restroom. This has to be discussed at the state level.”(Teacher 1; FG4)

The respondent noted the complexity of inclusion, particularly for schools lacking specialised personnel. General and inclusive schools may not have enough staff to support more intensive supervision needs of children with disabilities, may not have staff knowledgeable in how to reconcile the different needs of children with and without disabilities learning in the same classroom, or may not have staff knowledgeable about different forms of disabilities, such as cerebral palsy. On a more basic level, teachers may be completely unprepared for handling children with special needs. One parent provided a particularly poignant example:

“Once I saw that the teacher slapped him [my son]. I was furious and asked the teacher what she was doing to my child, because my kid would not tell me that some nanny yelled at him. And this third time I came there and my child was sitting in the corner with his eyes twitching.” (Parent 1; FG6)

The fact that a teacher resorts to physical violence is never acceptable, but it may be a problem faced more often by children with disabilities, as teachers may be particularly ill-equipped to understand and address them appropriately. As another respondent notes: *“In any case, our children need specialists. A simple nanny cannot cope with them” (Parent 6; FG6)*. It is clear that for inclusive education to work, teachers and other support staff need to be trained on how to handle children with disabilities. Teachers themselves also recognised this. Teachers expressed a desire



In the Almaty pool used for working with children with disabilities

to have special training courses to better prepare for inclusive classes. They also stated a need for additional, specialised staff:

“In our school there are two nurses. One is from the local hospital, the other one for the students of the school. But we need a speech therapist for children, we really need a staff of speech therapists.” (Teacher 8; FG9)

“This [inclusive classes] requires an additional class teacher or caretaker in each class who will watch over these children, so that nothing happens to them, or so that no-one offends them, or even just to help them.” (Teacher 1; FG9)

“We lack specialists that would work particularly with these children, and that specialist would have not twenty students per person, but a maximum of five.” (Teacher 11; FG10)

The interviewed teachers seemed willing to help and include children with disabilities, but they clearly need the resources to do so. This was recognised by other respondents as well, such as the director of an NGO. When asked about the progress made in the past two or three years for children with disabilities, the respondent noted that lack of qualified personnel was an ongoing problem:

“The specific specialists, pedagogues, who render social services, should render social services to children with disabilities... they don’t have sufficient qualifications, didn’t re-train, and have no professional experience for rendering such social services. These specialists just now began undergoing training at the local level.” (Director; IN6)

The lack of specialists is a cross-sectoral problem that spans beyond the educational system. According to one respondent, training of people who work with children with disabilities is extremely poor: *“... the category of the teachers not only from our centre, but special education teachers in general, is not improving. There is virtually no advancement training courses. This is a very crucial problem... We [must] work on our own in order to improve.” (Manager; IN21)* The lack of training for specialised staff is very concerning, particularly given recent reforms that seek to adjust teacher’s wages to reflect the advanced courses they have followed. According to this respondent, teachers are incentivised to follow specialised courses but are not facilitated to do so. While specialised courses are lacking, so, too, are full educational programs to train specialists:

“Unfortunately, today in Kazakhstan there is practically no training [of certain categories of

specialists]. All these professions are taught within training courses. But as for the opportunity for a person to get a university degree and study purposefully for those professions, unfortunately, there is not much to boast of, though we all know that it is needed not only for our social protection system, but for the education system as a whole.” (Respondent; IN22)

The state could thus do more to establish full educational programs and training courses specifically for individuals who work with children with disabilities. The state could also build these training courses into existing teacher training programs, as well as offer them to institutions where staff have built up practical skill despite not necessarily having the educational background.

So far the inclusion of children with disabilities in education has been discussed in terms of either inclusive education or specialised schools, but respondents also noted a third alternative: home schooling. While the promotion of inclusive schools and classrooms is perhaps a preferred method for ensuring a child’s educational as well as social inclusion and development, the degree of disability may preclude physical presence in a classroom. Rather than withdrawing educational services from such children, home schooling may provide a valuable alternative:

“When a child is home-schooled, the teacher comes on schedule and keeps a record of studies. Parents, mothers or grandmothers sign the paper that the teacher actually came and taught a lesson. There is also the psychological, medical and pedagogical committee. They go from house to house, talk to these kids and these parents, check the level at which everything is done, whether training of children is conducted, how the program is fulfilled, this kind of control.” (Director; IN11)

The well-developed protocol for providing home-based education and social support may ensure that children who would normally be unable to attend an educational facility do not fall through the cracks of the educational system.

3.2.3 Preparation of Children for the Future

The same flexibility would be helpful in preparing children with disabilities for future careers. While several respondents from inclusive schools noted that pupils with minor disabilities, such as hearing loss, applied for and were admitted to post-secondary education at the same rates as the cohort of children without disabilities, other respondents recognised that the level of disability influences a child’s future prospects. Rather than preparing



At the ‘Different-Equal’ national competition

children for the same future educational paths, some schools have integrated more dynamic future training programs into the school curriculum. One school has used sponsor funding to purchase a hair-dressing salon setup, for instance: *“For those children [those using a wheel-chair] we have pre-professional training. They, you know, study manicure and pedicure...”* (IN17) Another respondent gave several examples of the way children with disabilities were being prepared for potential future careers at their institution:

“There are special colleges for such children. Deaf children are taught to be cooks. For children with delays in psychological development, there are professional schools... [that] offer mainly the simplest professions like a plasterer, shoemaker. Blind children are trained to become masseurs because their fingers are so sensitive they can feel even a nerve coming under the skin.” (Administrator; IN24)

Such an example highlights potentially positive and negative aspects. While it is positive that children with disabilities are encouraged to pursue skills training and education that is adapted to their unique disabilities, the development of specific institutions may inadvertently encourage the educational segregation of children with disabilities. Regardless, the development of alternative training possibilities is valuable not only for children with disabilities, but such programs have a clear benefit for children who may otherwise have bleak future planning prospects.

Another aspect of inclusion is, of course, whether children with disabilities are systematically excluded from registration in non-specialised schools. One parent stated that *“there is no chance of getting enrolled in a secondary school”* (Parent 4; FG5), and another lamented that *“I would like him to go to a school where similar children are because they will not enrol my child in a regular school. There I will be told that my child is sick and has nothing to do in their school”* (Parent 7; FG5).

The process of enrolment could prevent children from being enrolled in school altogether. The diagnoses the children receive can play a role in preventing their educational inclusion. One parent stated that her daughter had initially been diagnosed only with cerebral palsy; a few years later, she was diagnosed with hearing impairment, and the cerebral palsy was considered “solved”. These diagnoses led to the following situation:

“It turns out there is a rehabilitation centre for children in Almaty. There’s a new department

for hearing-impaired children. Normally, we should be able to go there. We have a statement that she has a bilateral sensorineural hearing loss... We need to be admitted to this centre. But they do not take us there, because our child has not yet been operated on to get the implant. And they haven’t done it yet, because her emotional state is unbalanced, there is a bit of mental retardation... The neurology department in Karaganda refuses to accept us, because the CP [cerebral palsy] was removed. As for deafness, they told us the same thing: we should wear the device or have an implant. That’s the whole story. We run around with our child looking for a solution. We are looking for a way out. At this point, the child is eight and she is not attending any school. The school for mentally retarded children will not enrol her. They tell us that she only suffers from deafness. The boarding school for the deaf says that she has a mental retardation. In short, it is a vicious circle.” (Parent 6; FG6)

The conundrum this mother was placed in prevented her child from being engaged in any form of education. The strong determining role that diagnoses play in enabling care —both in terms of education and in health, as discussed below— can be problematic. One potential solution is to support the promotion of diagnostic standards. This would likely be a multistep process involving the education of medical personnel, expansion of pre- and post-natal screening, and promotion of information dissemination for parents.

3.2.4 Promotion of Social Cohesion

While respondents made clear where general schools had failed children with disabilities, their discussions of the beneficial components of “special schools” and inclusive schools also highlighted unique characteristics that could promote the success of children with disabilities in general education. One such component is the promotion of social cohesion by fostering a sense of co-responsibility with other students. Children attending a residential educational institution, for instance, noted that:

“Everybody here is like a sibling to each other... Although we are all different, but at heart we’re like one family. Although we all have different characters.” (Child 5)

“At the school you know everybody. At the school we all are as one family, one team.” (Child 1).

While part of that feeling likely stems from the fact

that many of the children live in the facility much of the week, the school has also actively promoted social cohesion by providing a sort of mentorship program. One child noted that: *“There are counsellors from the first to the fourth grade. Further, if we will receive the first-graders, we will act in seventh, eighth grade as counsellors for some children.”* (Child 3). The fact that older children take responsibility for the younger children likely promotes social interaction among age cohorts while also increasing the school’s monitoring capabilities. General or inclusive schools could also promote the social and educational inclusion of children with disabilities by matching them with mentors who can help them navigate the school environment.

Positive examples of social cohesion were also expressed by both children with and without disabilities in inclusive schools. Children without disabilities noted the important role they can play in creating an open and friendly environment simply by not fixating on the disability. As one child from an inclusive school illustrated:

“We have a girl in class, who was then unable to walk. And when she came back to school, we were prepared for the meeting. We were told that it is nice not to ask questions about her health. That is, we should just talk to her.” (Child 1; FG3)

Another child stated it simply: *“...make them feel that they are the same guys, just like us”* (Child 8; FG3). This is a potential advantage of non-specialised schools, at least according to some children without disabilities. One stated that: *“Specialised schools have special equipment. And our schools offer interaction with people and feeling like a fully functional person”* (Child 12; FG3). The mutual interaction between children with and without disabilities provides an appropriate venue for exchange that can help a child with disabilities feel like “a fully functional person”. This is a unique advantage of non-specialised schools that a number of stakeholders recognised. Parents of children with disabilities noted that they want their children to attend general schools *“to be like everyone else and to grow up surrounded by normal children”* (Parent 2; FG5) so that “there will be an incentive to grow. Our child will see healthy children and will believe that tomorrow will be the same too” (Parent 6; FG5). The importance of interaction with children without disabilities was also emphasised because: *“... they will start communicating with their peers, teachers, and will try to reach them and develop...”* (Parent 7; FG5).

Parents of children without disabilities expressed similar ideas:

“In general, it is a good idea to educate those children in general education school. Because if these kids are educated separately, they will become even more avoidant. We will develop their inferiority complex from childhood, so we will separate them from society from childhood, and, of course, they will be indifferent, they will be afraid of society, because we have rejected them, we pretend that we don’t see them.” (Parent 9; FG8)

“If such children are educated in school, there will be communication with children, with teachers. And if they are trained at home, what will they see? A couple of times a week a teacher visits him at home and she teaches him. All the time the child is surrounded by four walls in his home. And at the school different competitions, events are held on a regular basis. We should undertake appropriate measures in order to ensure an active involvement of this kid in all events despite his illness. This is the support that we can provide to him. And in such a manner the child will make progress every day.” (Parent 4; FG8)

Teachers were also positive about having both children with and without disabilities in the same class. Several emphasised that inclusion in education would promote the future social participation of children with disabilities and help avoid feelings of marginalisation: *“If there are specialised schools, parents may think that we are detaching children with disabilities from the society. And if you open special classes in secondary schools, it would be all right for everyone”* (Teacher 7; FG9). The director of a school advocated strongly for the inclusion of children with disabilities in general education:

“It is obviously better in secondary schools. First of all, it is their social environment in which they [children with disabilities] will continue to live. They develop and learn faster in order to live in this world. I just know it because of my child. Had I sent my child, as they told me, to a special school, he would have never become the way he is now. He would have been unsociable, and would spend time only in those surroundings. And he went to an ordinary school. He graduated, having studied for 10 years. True, he was not good at all subjects. But then, communication between a healthy child and a child with disabilities is extremely important.” (Director; IN3)

The success of mixed classes does depend on preparation, however, as well as the age of the children involved. The director of an inclusive school stated that part of the process of creating a successful, inclusive environment involves bringing children together at an early age: *“..we take children from the first class. The earlier that they are accepted to our school, the better. The most interesting thing is that the children did not even notice that some children with special needs have come to them.”* (Director; IN17). Other respondents emphasised that everyone needs to be informed about the potential changes a classroom could experience when a child with disabilities is introduced:

“It is necessary to prepare children for this and not just in the class, but also in the whole school. I think if you constantly conduct educational work with children, then at least some of them will understand what we want from them, and will behave.” (Teacher 3; FG9)

“First, you need to prepare classmates for this, and only then bring a child with a disability.” (Teacher 11; FG9)

One educator mentioned that a sort of “sensitisation campaign” for children without disabilities could help them to understand better the challenges of disability. This in turn could ease social interaction:

“...when we conduct those ‘kindness lessons’, we always blindfold our children. They should try to find what they need by means of touch. We close their ears. Then I ask them if they can hear me. They say they can’t. I would ask them ‘Do you want to say anything, do you want to tell me something?’. Then I would tie up one leg like that, and let the child try to jump on one leg. Let’s see what happens then. Or we just put them in a wheelchair. We ask children if they can roll in someone’s wheelchair. They even try to go to the toilet in a wheelchair on their own. Can they do that? Then the children start thinking. ‘Yes, indeed, it is difficult’. Now, if all of these moments were acceptable everywhere in schools and day care centres, starting from kindergarten...we demonstrate already at this point that children should be kinder and help each other somehow.” (Director; IN3)

Preparation should not be limited to pupils, however. Parents could also be better engaged to help prepare their children for having a classmate with disabilities:

“Children are open, and parents are also open.” (Teacher 3; FG10), *“And that’s because we talked with parents of children without disabilities and had outreach seminars with them that they [the disabled] are also children and have the right to learn with other children.”* (Teacher 9; FG10)



At the medical-social institution’s day care department for children with disabilities, Astana

“It is necessary to work with children’s parents. It is necessary to develop some method or an intelligible way, together with psychologists, so that the children’s parents understand and support the idea, and then tell their children about this. Parents should understand, then tell their children at home... we, at school, and the children, will all be ready for this.” (Teacher 9; FG9)

The teachers highlighted the importance of engaging not only children but also their parents in promoting the harmonious inclusion of children with disabilities. Such quotes demonstrate the importance that multiple stakeholder groups attach to promoting inclusive education, but with exceptions. Many parents note that those children with more severe disabilities should attend specialised schools where they have access to smaller class sizes and more prepared teachers. Teachers themselves also recognise the limitations conventional education can pose for children with disabilities, but most seem dedicated to finding a common solution beyond either homeschooling or specialised education.

Based on the insights of educators, parents, and children themselves, several critical aspects/barriers emerged relating to inclusion in education:

1. The degree of a child’s disability is an important factor in determining their success in an

inclusive classroom. While children with (minor) physical disabilities were regarded as very easy to engage in inclusive classes, children with more severe mental impairments require more supervision and different class setups;

2. Related to the first point, inclusive education was favoured by all respondents. None were explicitly in favour of isolating children with disabilities in special schools, except for in the case where severe disabilities would require intensive, specialised care. Most respondents would rather see special or remedial classes developed in general schools;

3. Small class sizes would better help pupils —both with and without disabilities— as well as teachers to promote a healthy learning environment;

4. Increased teacher-to-student ratios would also help ensure the success of students with disabilities, as would the hiring of specialists such as speech therapists and teacher’s aids. Teachers and specialists also need access to ongoing education and training to help them foster the most productive learning environments for both children with and without disabilities. To facilitate this, the state could provide more specialised training courses as well as a university-level study specifically for education of children with disabilities;



At the medical-social institution’s day care department for children with disabilities, Astana

5. Children with different forms of disabilities have very different needs, and even children with the same form of disability have unique approaches and needs. To this end some respondents recommended developing personalised education plans that would tailor the curriculum to the individual child's pace;

6. Children with different forms of disabilities should also be prepared for future productivity possibilities according to their interests and capacities. Job and career counselling should be offered to children with disabilities, and where possible, tailored career training programs should be offered;

7. Preparation is key to ensuring a smooth transition into inclusive education. Disability needs to be discussed openly and honestly with both children and parents so that they do not regard children with disabilities with fear or dislike. Part of ensuring social inclusion in the classroom involves dispelling stigma, and an important way to do this is to sensitise children and parents to the challenges faced by those with disabilities.

Many of the barriers that challenge social inclusion in education can be seen in other “domains” of rights as well. The next section evaluates how well social inclusion in healthcare has been achieved.

3.3 Health Care Services

Access to healthcare is another aspect of child well-being that is a cornerstone for the social inclusion of children with disabilities. The right to life, survival, and development—one of the CRC's core principles—is reflected in the provision of timely and quality healthcare, a component of well-being that is especially important for children with disabilities.

A number of interviews noted the barriers that children with disabilities faced in receiving adequate healthcare. Several focus group participants, who are parents of children with disabilities, noted that their children's health has been negatively affected by the poor provision of healthcare. This stemmed from two main problems: limited access to healthcare facilities and poor quality healthcare.

3.3.1 Healthcare Facilities

Healthcare facilities appear to be concentrated in more urban areas, necessitating that parents of children with disabilities either travel long distances or move away from rural locales to receive medical care for their children. Different levels of

care are found in different locales, however, with basic care offered in rural areas and specialised care offered only in specific regional centres, the highest level of which is in Astana. While higher service levels are largely concentrated in urban areas, attempts have been made to increase service provision on a community level. A representative of a state health service noted that mobile teams are used to ensure vaccination of children in rural areas. This means that children with severe disabilities who cannot be transported to a clinic for vaccinations can still receive them: “... *there are seriously ill, disabled, lying cases, and if there are no adverse conditions for vaccination then they are vaccinated, and the team visits them at home.*” (IN27). The use of medical personnel who can visit children at home can provide an essential service for immobile populations.

Another respondent from a government agency noted that social healthcare institutions are being made available in more areas: in his region, there are two such institutions for children with musculoskeletal and psychoneurological disorders, and there are five day care facilities for children with disabilities throughout the region. Home care is also increasingly being made available, which may increase receipt of medical and social care by not only reducing physical distance between the child and the care provider but also by reducing parental discomfort with having their children at a distance. One respondent from Karaganda stated:

“We have an increased number of those willing to go to the day time [facility]. That is an alternative form of service provision. That is, we are meeting the wishes of our people in this way. The reason lies mainly in the fact that people do not want to leave their children... far from them. And there is another factor that influences their choice —disability benefits, child care, they do not want to lose that money.” (Respondent; IN8)

According to the respondent, some parents may be reluctant to leave their children at treatment facilities, making alternative service provision like day-care centres or home treatment valuable additions.

3.3.2 Qualification of Medical Personnel

A potentially more serious problem than the physical location of facilities may be the lack of quality healthcare due to medical personnel's limited level of knowledge and limited guidance on treatment of disability. One parent in a focus group discussion noted that:

“They said that our child has cerebral palsy and that’s it. Nothing more. We were not told where to go for treatment, what to do and not to do to be cured. Here, you have a diagnosis of cerebral palsy and that’s it.” (Parent 1; FG5)

Lack of consultation was identified as a problem for ensuring proper medical care for the child, which could clearly contribute to poor medical outcomes and further inability of children to participate fully in society. Other respondents expressed the feeling that medical personnel did not necessarily have the right level of training or information to suggest a proper course of treatment, particularly when they could not identify the problem at an early stage. Several parents shared similar experiences:

“Many doctors do not know. One day they tell you that your child has such a disease. The next day there is another problem. ‘Either one leg works or the other one does not’, ‘Your child has a heart disease, no, your child is healthy’... ‘We can operate on your child and then again, no, we can’t’. Can this really be true? It happens constantly. They send you to one hospital and then to another. It is not easy to run around with a child like this.” (Parent 1; FG5)

“I was told that everything is fine with the kid. ‘It is a healthy child’, so we were sent home and discharged from the hospital. Then we came home, the child had a fever of 38-39 degrees. Then we were admitted to the hospital and were told that the child has a malignant heart disease, pneumonia...” (Parent 4; FG5)

“The baby was born and was crying. The mother was doing everything. She went to many doctors and complained that her son has insomnia. ‘Oh, your son is doing well. He is fine’, she was told. The mother was suffering, sitting days and nights next to her child, not knowing what to do.” (Caregiver 6; FG5)

“At the age of 4-5 months when we were examined at the hospital, the doctors did not find anything and we were told that everything is fine. Had they revealed it then, then surely it would have been easier now, and we would have avoided all those sleepless nights in tears with our child.” (Parent 5; FG5)

The last quotation is illustrative of a shared feeling among many of the respondents, who felt that the prognosis for their children would have been easier to manage had they been informed earlier of the disability. While it is unclear if medical personnel really lacked the knowledge to make an early

diagnosis, it is apparent that parents felt as if the medical establishment was not as responsive as it could be to the particular constraints posed by their children’s conditions. Other respondents noted that parents can also respond to a diagnosis too late to significantly improve their children’s health. While it may be a doctor’s responsibility to make the initial diagnosis, parents are responsible for acting on that diagnosis. Acting on the diagnosis requires parents to educate themselves and seek help in the early stages of a child’s disability. One respondent from an educational facility provided several illustrations of the importance:

“We can tell parents, give them some advice, some training sessions. But they also have to do a lot themselves, at home with their child.... For instance, I’m talking about children with CP [cerebral palsy], who spent ten, twelve years at home, and their parents want them to start walking. How is it possible? I always say that one can still do something up to three years old. There is still some hope from three to five years old. One can change something from zero to three years old, and up to five years old. At five years old, it is almost impossible. It is practically impossible to put the child on their feet so that it starts walking. Sometimes people ask me why I think that it is not possible anymore. I say that certain motor skills, mental capacities are formed in very early childhood. Motor skills are developed when our body remembers what to do... And if this is not done, well, how can a child walk if it does not know, if the leg does not know how to move, where it should be placed, and the brain has never controlled it?” (Director; IN3)

The respondent emphasised the need for parents to encourage their children’s development early on. For this to occur, parents need to be given better information on how the specific disability can be managed throughout the child’s life. This is a particularly challenging issue for parents and medical practitioners alike. Different disabilities require different interventions, some of which require greater levels of medical care, palliative care, or psychological coaching. The medical, educational, and social benefit systems are not necessarily as responsive to these differential needs as would be desired. As one obstetrician explained:

“Rehabilitation is required urgently. Now we have put rehabilitation children’s beds in each in-patient facility, so that mother will not have to travel much every day... women can bring children, a child will be there the whole day long, he will be provided with massage, gymnastics,



At the 'Different-Equal' national competition

exercise therapy, cold water treatment, physio procedures. That is, a child will receive two-week rehabilitation treatment. Today we have very few kindergartens. For instance, some kindergarten has one group for hearing-impaired children, or for cecutient children, logopedic groups. And they try to open such groups in each district.” (Physician; IN15)

The development of disability-specific treatment programs and educational opportunities —while certainly a necessary component of potential social inclusion— can be challenging given limited budgets and lack of specialised personnel. The development of treatment and education regimes for children with different types of disabilities must both be responsive to the specific type of disability while still being feasible (in terms of financial and human capital resources), and without isolating children with disabilities from the cohort of children without disabilities.

3.3.3 Provision of Medical Services

Changes in funding structures may also inadvertently contribute to the way that health care services are delivered to children with disabilities. The director of a rehabilitation centre discussed how the introduction of government standards for the treatment of children with disabilities changed the way care is provided:

“...assistance has been directed to medical-social institutions and partially to services procurement from non-governmental organisations, i.e. these funds have not been allocated for families, but, of course, the families have obtained definite support... Parents, who are addressed to the public institutions, obtain services free of charge. The law stipulates that there should be services rendered both on a free basis and on a payment basis. We, for example, as a social organisation, take membership duties... And from another side – how should we survive? Our services are partially paid by parents. As of today this is 55% of the cost for child maintenance within day-time conditions. The residual part we should find by ourselves... It is very difficult! I can truly say that for the non-governmental sector it is very difficult to survive and render services.” (Director; IN4)

The respondent went on to state that the government “buys” the centre’s services, but in exchange 100% of the money must pay directly for the care of children. Grant monies cannot be spent on building maintenance, for instance, which makes it difficult for such a centre to keep providing low- or no-cost services. Children with disabilities may bear the consequences of this funding structure. While the respondent did not note any decrease in the quality of care, it can be assumed that care provision hinges on the ability to do so within the limitations of funding.

Adequate healthcare does not begin with treatment of disability, however: it begins with mothers and adequate prenatal care. An essential component of both maternal and fetal health is maternal education, which includes promoting healthy lifestyles in general. As explained by the staff member of a polyclinic:

"It is advisable not to broadcast commercials of some alcoholic beverage, but more videos or movies advocating healthy lifestyle... Tell people that pregnancy has some nuances. That a woman needs to get ready for that. The things that we say – they are only part... To get them a little ready, so that they know that it is necessary to turn to an obstetrician-gynaecologist as a minimum, then, to a therapist and a family doctor." (Staff; IN13)

Several respondents noted that mothers have the first responsibility for ensuring a healthy pregnancy, which they often do not bear well: "...mothers do not focus attention particularly on their health... it is necessary to prepare for pregnancy. We have no right, for example, to tell the mothers what to do... we cannot force her to do anything in particular." (Staff; IN10) A mother's responsibility includes not only taking care of her own health but also registering herself for antenatal screenings, which include both ultrasound and genetic tests. These screenings are imperative for the early detection of potential disabilities and the exploration of potential treatment paths. As one physician illustrated:

"Originally when we had made examinations before there were cases when they have already missed the right time [for early detection], which resulted in the birth of children with abnormalities.... We recommend taking analyses and making examinations in early pregnancy... At the end of 2011 we had one mortal case, i.e. the death of a child with Down's Syndrome. It was a planned pregnancy, but his mother was registered too late and didn't have the screening. As usual, ultrasonography doesn't show it, but genetic screening [would have], which she had missed because she was too busy...." (Physician; IN14)

Several physicians explained that the regime of medical screenings is thorough and specifically-timed: after registration, which should ideally occur no later than week 12 of the pregnancy, a woman should undergo five screenings. Two genetic screenings are performed (between weeks 11-14 and weeks 15-16), and three ultrasound examinations are conducted (between weeks

12-14, weeks 19-21, and weeks 32-34). These screenings attempt to detect different potential problems such as chromosomal abnormalities, congenital abnormalities, and late-state problems such as hypoxia. As these screenings attempt to detect different abnormalities, it is essential for a woman to receive as many as possible and at the earliest times possible.

Another respondent explained the value of preventative healthcare and pre-natal care. She felt that social inclusion of children with disabilities should begin with better maternal healthcare and education. She also emphasised the need for better education of doctors and more timely provision of care:

"... doctors sometimes are offended at me when I tell them that it is first of all their fault that the child does not speak. Children are disabled. Why? Because a pregnant woman... did not seek social protection, she did not visit any education authorities, but she has come to see a doctor. Already at the early stages doctors must determine the development of the fetus, identify the incidence of a child's illness, study the mother's medical history. Doctors should conduct preventive activities with the future mother. Going further... What maternity care do we have today? If they see that a woman cannot give birth on her own, doctors should do a cesarean section. Nowadays it's easy. Those doctors initiate the birth, when the child is already stuck somewhere and suffocating, it got a hematoma while going through the birth canal, and then the child comes out with asphyxia, with the umbilical cord wrapped around it, it is cyanotic, it cannot breathe and all of this. If the child got a hematoma, the consequence would be either a mental complication or cerebral palsy. Further on, if the baby is lying and the presentation is pelvic, the childbirth happens through the pelvis. What do those doctors do? They simply pull it out of the mother, and the child already has some pathology... Although there are plenty of other methods for a proper childbirth ... So, the child was born. Yes, the doctors gave it life... The child lives with a disability." (Director; IN3)

This quote reflects the frustration of the respondent, as the medical establishment could clearly do more to prevent the incidence of birth-related disabilities. This suggests a clear area for improvement that could aid the inclusion of children — namely by reducing the incidence of disability in total.

Despite the largely negative discussions of the medical system, some respondents also highlighted its successes. A gynaecologist and obstetrician, for instance, discussed the types of screenings pregnant mothers undergo. The respondent noted that after a fetal congenital abnormality is detected, a council evaluates the case to better advise the parents:

“A council of physicians is conducted on any case of detected abnormality. I am always at the council, because it is held in our department, the ultrasonographer who has detected the abnormality, surely, a geneticist, and if needed, the specialist according to the case where the abnormality is found. Let us suppose, if the abnormality is of the nervous system, we call a neonatal neurosurgeon, if it is of the gastrointestinal system we call a neonatal surgeon. What abnormality is detected, we surely involve the specialist regarding it. All this matter is discussed jointly (is it curable or not, can we help or not, taking into consideration the mortality percentage of those infants). Then we talk to the woman, her relatives, explaining the situation.” (Medical personnel; IN5)

The early detection of congenital abnormalities in itself represents one of the key areas where medical care could make a difference. The involvement of specialists in making a preliminary action plan

can also help parents prepare from the very beginning an understanding of how they will handle a potentially disabled child. A physician at a polyclinic further emphasised the importance of discussing the diagnosis with the family:

“[After abnormalities are detected] we hold an explanatory discussion, then refer her to a geneticist who talks with her too. Also, we inform and hold discussions with the husband, parents, and most people become aware of the responsibility. That’s why we recommend making diagnostics and an examination in early pregnancy... we render psycho-emotional support because each woman has a gross stress... we refer them to psychologists who hold a discussion.” (Physician; IN14)

The respondent seems to feel that potential mothers of children with disabilities and their families need to understand the responsibilities for decisions they make. Medical facilities can play a strong role in this process by not only informing the woman and her family of the medical implications of this decision but the psychological consequences as well. The efficacy of these services naturally relies on parents using them. From this perspective educating parents on the necessity of neo-natal care can play a key role.

The identification of challenges to accessing healthcare services highlights how social inclusion



‘Assyl Bobek’ specialized kindergarten for children, Astana

in this domain can be encouraged. The following barriers emerged from discussions of healthcare:

1. Even prior to birth, a child's future social inclusion can be promoted through protection of maternal health. The provision of pre- and post-natal screenings can help ensure early detection of disabilities, which will help parents better plan for their children's future;
2. Medical personnel may need additional training to detect disability in early childhood. Early diagnosis can ensure timely treatment and the establishment of an appropriate treatment or rehabilitation plan, but medical practitioners need to be competent to design and communicate such plans;
3. A child's health can be severely limited by lack of knowledge about what a child with disabilities needs to manage or improve his/her disability. Parents need to be explicitly advised about the steps they should take to manage their children's

conditions following diagnosis. Medical staff need to be knowledgeable enough to provide relevant information related not only to the condition but to the social benefit system available to aid children with disabilities;

4. Parents play a key role in managing a disability. They cannot expect that care and rehabilitation centres will supplement their own activities with a child at home. Parents need to be educated about home care needs from the beginning so that a child will develop the necessary motor and cognitive skills required to facilitate their functioning in later life;

5. A diversity of medical service formats can encourage parents to seek (ongoing) treatment for their children. Rather than offering services exclusively through day-care or residential facilities, for instance, the provision of care through home visits may help encourage compliance with medical and social treatment regimes.

Box 9. Human Interest Story: Dias

Dias, aged 5, attends an inclusive kindergarten, alongside his peers. He is not the only one with cerebral palsy there: a condition affecting co-ordination, balance and speech. Some children with cerebral palsy also live with mental impairment. His kindergarten welcomes children with and without disabilities: they study together, play, eat, recite poems, and sing – feeling equal rather than focusing on their differences.

Dias was born healthy but, three days after leaving the maternity hospital, developed convulsions. An ambulance transported him to intensive care but it took some time to diagnose his difficulty, and the necessary treatment. Later, they discovered that he was suffering continuous damage to his brain, which resulted in his cerebral palsy.

Dias' parents, Samal and Dauren, spent several years trying desperately to formalize their son's disability status, in order to receive free medical treatment: vital in his early years. He was 3 before he was officially classed as having disabilities, although his medical certificate was provided much earlier. "All this time, while I was applying for disability status for my son, the members of the commission accused me of presenting a healthy child as handicapped," says the mother of four, with resentment.

Thanks to his disability status, Dias now attends the Republican Rehabilitation Centre twice annually; his mother is convinced that treatment is bringing progress, helping Dias to speak and talk more confidently. "We wouldn't be able to afford such treatment, as it's very expensive: 500,000 Tenge per course!" say Samal and Dauren. Meanwhile, his inclusive kindergarten is staffed with highly qualified specialists.

Thanks to specialists at the Rehabilitation Centre and at the kindergarten, Dias is beginning to communicate more easily, overcoming his shyness. He has found a common language with his peers, learned his colours and how to assemble Meccano construction toys. His posture and fluidity of walking has improved thanks to hydrotherapy and hippotherapy (provided by the Department of Social Protection of Astana City Akimat).

Dias is set to attend regular primary school but Samal is concerned that their boy's fine motor skills remain underdeveloped. Other issues no longer bother Dias' grateful parents, due to the support they've received, but they wish they had known earlier of the existence of the many organizations ready to offer help.

3.4 Social Participation, Non-Discrimination, & Family Care

In addition to aspects of child social inclusion such as education and healthcare, social participation and the ability to enjoy social relationships is another important component of a child's life wherein children with disabilities may face inequities. As these rights are ensured in the CRPD (in Articles 19, 29, and 30), it is imperative that children with disabilities are able to participate fully in public life. Throughout interviews many respondents and participants discussed perceptions of disability and how those perceptions hindered or helped the social participation of children with disabilities.

As noted previously, many children in inclusive schools felt that children with disabilities should be made to feel normal and equal, without great distinction made between them and their classmates. While among individual children it may be possible to foster a sense of belonging and normalcy, some respondents recognised that disability still carries a certain social stigma that has to be battled. When asked if they or their children had ever faced stigmatisation because of the disability, two respondents reported:

"...I remember some girlfriends advising me to send the child to an orphanage in the beginning, but I cannot do that, it's my baby." (Parent 4; FG5)

"Yes, we experienced that. We were advised to put our kid into an orphanage. But how can I leave my own child that I gave birth to in the orphanage? I would not leave him even for a couple of hours with my friends, saying nothing about giving him up!" (Parent 3; FG5)

Despite these reports that friends and acquaintances advised against the parents keeping their children with disabilities, many respondents reported that their immediate families were supportive. There is some recognition that families could become even more supportive if they were also instructed about child care and given access to psychological support. When asked what kind of services are extended to the families of babies born with disabilities, one physician noted: "As to the father, it's just [left to] the individual work of a psychologist... we do not know in what family what is being done, but the social workers try to identify [needs] and provide

assistance." (Physician; IN10) The respondent had noted earlier in the interview that prevention and management of childhood disability begins with the mother, who should prepare for her pregnancy by eating well and taking care of her own health. Engaging other family members in this process could help women do so, just as providing counselling and psychological support to family members following the birth of a child with disabilities can help increase the supportiveness of the family as a social unit.

While most respondents felt that they had supportive social networks, some reported facing harsh attitudes by official state bodies that dismissed the potential of their children to lead normal and fulfilling lives. As one mother illustrates:

"The director [of the psychological, medical and pedagogical committee] told me that I have two choices, either to sit with her at home until she grows up, develops mentally, or dies. Or send her to... our local orphanage. There she will be cared for round the clock. At the moment this is what bothers me that there is such a committee, and this director.... When you come in, they say 'Oh my God, it's the same girl, take her away, take her away, she has not changed, go away'" (Parent 6; FG6)

Some respondents seemed to feel as if the medical and state professionals providing them advice were not providing reasonable alternatives because they perceived the children as simply being burdens. Many respondents expressed the feeling that children with disabilities were not valued, reflecting persistent stigma and discomfort with individuals with disabilities.

The attitudes of different stakeholder groups reveal potential barriers to the full social participation of children with disabilities, particularly in the classroom. One potential problem with social participation of children with disabilities is bullying from children without disabilities. While children themselves did not bring this up, parents of children without disabilities mentioned the potential risks:

"I would like to say, they are children. Children usually taunt each other. This happens in life... If you listen to the youth of today, oh, it's just terrifying. I don't object that handicapped children study with full-fledged children, but it is necessary to take into account that children are young. Let's assume that the children from the first to the fourth grade do not have the right understanding. If someone falls down,

they're not going to help him to get up, they start to jeer and laugh at him.” (Parent 2; FG8)

“I agree with all the parents. We can teach our children, but they are still children and they tend to forget the things they were taught, [they] play, bully. Therefore, for their own safety we should keep them [children with disabilities] away from that.” (Parent 3; FG8)



‘Balam-ai’ Child Development Centre, Astana

Increased vigilance of teachers could help curtail bullying, but the problem may remain that children with disabilities are simply too distinct from other members of their cohort. Parents of children without disabilities expressed mixed feelings about whether inclusive education was appropriate:

“Simply... integrated schools must be established. Notably, why should they be isolated?” (Parent 4; FG7)

“If the child is adequate, why doesn't it study in a normal class with normal children? Vice versa, it will grow somehow and will feel absolutely as the same child. But if a child is not adequate, then it must study where it is due, so that specialists should deal with it.” (Parent 5; FG7)

“Depending on the kind of disability. In my opinion, it is also of great importance. Indeed, any nervous patients in the class distract. For example, we had such situations: when we had come in the class and one boy had an unhealthy state of mind. He throws everything. I was shocked at this situation, to say nothing of the children. Some restrictions must be available.” (Parent 2; FG7)

Many parents agreed that the degree of disability should be a determinant of whether a child should be included in general schools. At the same time some parents of children without disabilities expressed some resentment about the greater energy directed to children with disabilities. One mother states:

“Well, these children are still paid more attention to. Look, we're all mothers here today because of three [disabled] children. Not because of our children, but because of these three children. Constantly some demonstration classes are arranged... not to our children, but to those children. Those children, of course, are given more attention than our children.”(Parent 3; FG7)

These feelings may be reflected in parents' attitudes toward friendship between children with and without disabilities. Most parents —both of children with and without disabilities— note that the children with disabilities seldom have close friendships with the children without disabilities. While none provided concrete explanations for why, the attitudes of parents may play a role.

At the same time, there is some indication that the taboo and stigma associated with children

with disabilities is decreasing. The provision of state services and the visibility of children with disabilities were cited by several respondents as reasons for this. Just as teachers discussed the need for preparation to ease the social cohesion of children in the classroom, other respondents mentioned social service expansion as a way in which social acceptance of disability can increase:

“Maybe the social condition has improved a little; they began to work with the children, day hospitals opened, the children began to get services at home. Earlier the children, you know... there is a definition “ineducatable children” [who] used to stay at home, they could not go to regular school and actually were cooped up indoors. Now, social workers work with these children, there is already some kind of communication. They go to the day-care centre, it is some kind of kindergarten... Now a lot of work is being conducted concerning the introduction of inclusive education in Kazakhstan, that is, the children with disabilities will be taught at regular schools with healthy children.”(Representative of government office; IN26)

While children with disabilities surely continue to face exclusion, the terminology change (away from “ineducatable children”) signals a shift in public attitudes toward disability. The discussion among children without disabilities about the need to make children with disabilities feel “normal” is hopefully also a symptom of changing attitudes. A deputy director of a government office also indicated that the attitudes of parents themselves affect the potential for children with disabilities to be socially included:

“...it was difficult to get parents to work with these children due to the prevailing mentality, the parents were hiding those children... That is, they were living in a closed circle. But today the parents have got the right understanding, they go out and are having fun. First, they find like-minded people and this is a big plus.”(Deputy Director; IN7)

The ability of parents of children with disabilities to seek each other out and engage with one another may serve the important function of reducing taboos by encouraging the development of a supportive community. As the opportunities for children with disabilities to participate in public life increase, parents may have better venues for communication and exchange with each other. This could decrease the sense of stigma and

isolation that both children and parents have, thus perpetuating more holistic social participation among children and their families.

The insights shared by focus group and interview participants suggest that several factors could increase the social participation of children with disabilities:

1. While the social stigma and taboo surrounding disability appears to be decreasing, it is important for state and civil-society institutions to continue raising awareness about disability. This awareness-raising could consist of sensitisation and education campaigns that explicitly express:

- a. That children with disabilities are still children, in need of the same inputs as children without disabilities. While their introduction into a classroom may present some challenges, education is guaranteed to them, just as it would be to any other child. The inclusion of children with disabilities in a classroom can also provide valuable learning opportunities for all children;
- b. That children with disabilities can be productive members of society. Children with disabilities can lead productive future lives, but for this to occur, a long-term plan for each child should be made so that their options and opportunities for the future are known. Medical practitioners, educators, and other agents of the social support system are key actors in this planning process. Their advocacy is essential.

2. Parents and other family members of children with disabilities should be prepared from the very beginning of a child’s life for the types of challenges and opportunities they and their child may face. The more family members understand about the disability, the easier it will be for them to advocate for their child and to navigate their own feelings about the disability. The extension of psychological and life-planning counselling to members of a child’s family may help them work together to promote the future social participation of their child;

3. The social participation of the families of children with disabilities should also be promoted, as their inclusion will likely correspond to greater social participation of their children. Greater empowerment of families to create supportive community platforms may play an important role in this process. Clinics and schools, for instance, could provide the venue for parents of children with disabilities to meet each other and exchange information.

3.5 Adequate Standard of Living and Social Protection

Within the Convention of the Rights of the Child and the Convention on the Rights of Persons with Disabilities, the state's responsibility to ensure that children with mental or physical disabilities receive special care and necessary social assistance to ensure a "full and decent life" is clear³. A "full and decent life" can be interpreted as one in which a child is socially included, and provision of assistance by the state can play a clear role in this process.

Different stakeholder groups recognised that proper care of children with disabilities can be a costly venture, one which many families are not able to bear independently. Social benefits — particularly for families that cannot afford external care and forego wage employment for the person who stays to care for the child— become an essential resource for families. Parents of children with disabilities who participated in one focus group noted that despite the social allowances provided by the government, many expenses still had to be paid out of pocket. As one parent notes: *"I have to spend all the money on medicine"* (Parent 1; FG5). Another adds: *"While staying in the hospital, all treatment is free of charge, but once you are discharged, you have to buy all the medicine yourself"* (Parent 5; FG5). While many necessary expenditures can be paid for by monetary benefits or equipment/services provided by the state, many respondents expressed that the money does not cover all categories of expenditures, such as medicine and preventative (rather than palliative) care.

3.5.1 Process of Receiving Social Benefits

Many respondents note the essential role social benefits play and are thankful that they are delivered, but the process of receiving social benefits can be somewhat problematic. The first problem expressed by one parent is that she was not even made aware of the social benefits and how they could be accessed:

"I did not know about all this. The doctors did not say anything. If the mother is quick, then she will hear about something, will grab it or

make a necessary call. And if not, she will have no clue what to do." (Parent 4; FG5)

Other respondents noted that even when they know about the benefits, the process of receiving them can be a drawn-out and complicated process. The child must first be recognised as having a disability, which involves an evaluation by a medical consultative board. As one respondent explained, this is just the first step in a process that involves multiple agencies:

"Physical disability is... defined by the medical and social expert commissions (MSEC), which belongs to the Social Security Department at the Ministry of Labour. They define it on the basis of the medical consultative board conclusion and make a personal development program (PDP), and on the basis of PDP we give some recommendations." (Respondent; IN8)

After a child is recognised as disabled and is provided with a personal development program, paperwork requesting benefits needs to be submitted. The benefit claim process can hinder provision of health care, particularly when access to needed care or equipment is stymied because of delays in the processing of social benefit requests. Parents in one focus group discussed how the inefficiency in the quota processing system can result in improper aid provision:

"Even diapers, for example. It would be fine if they just gave them like this. But we never receive the size that we need. For example, I need size number five, but she is growing, and in order, for example, to be able to get number six, I have to collect all these documents again to get number six because number five is too small for her." (Parent 3; FG6)

"The child grows a bit more until you gather all the documents." (Parent 6; FG6)

"Having waited that long, you do not need size five anymore." (Parent 2; FG6)

For some parents the social benefit system does not keep pace with the needs of their children.

Part of this may be related to the structure of benefit provision itself. As one representative of a government agency noted, children with disabilities have sometimes faced unduly long wait times before receiving goods due to procurement requirements: *"until present prosthetic and orthopaedic appliances have been procured in compliance with the Law on state purchases. However,*

³ Refer to Article 23 of the CRC.

Kazakhstan has only one entity that provides such services, making the tender procedure needless to follow.” (Deputy Director; IN9) While the process has since been adjusted, the example highlights the way in which existing legal frameworks may not be fully aligned with the needs of the population of concern.

Requesting and receiving social benefits in a timely manner requires comprehensive understanding of how the system works from the first step through the last. One respondent from an NGO highlighted how poor information exchange can limit access to social benefits at different stages of the request process:

“Those parents, whose children gain disability status, have no problems related to receiving benefits and generally all kinds of social assistance. The problem is that not all children gain the disability status. And, as a rule, public servants closed any information distribution channels for open, positive dialogue with parents who have disabled children. And at the advanced stage of disease of the child it is defined, that this child has the right to obtain disability status and all those social benefits which are allocated by the state for that. The problem resides in the insufficient number of channels, information absence, and of course in the low civic engagement of the population...” (Director; IN6)

3.5.2 Information & Education About Social Benefits

The limited information and education provided to the public about social assistance channels made it especially difficult for parents to even register their children as disabled. Clear effort needs to be made to increase channels of information exchange and dissemination. This may be especially true in rural areas, where access to medical screenings is more limited and disabilities may not be identified in a timely manner, if at all:

“In the rural areas, of course, the number of children with disabilities is a little less; we are diagnosing them now because they are insufficiently examined... their hospitals do not have all highly specialised doctors, not all examinations are conducted; diagnostic testing is also not enough, or it is outdated. Therefore I think that the rate is lower there. Generally, our urban people are more “equipped” and more educated regarding the matters of social services, social protection, and they have their children examined more.” (Doctor; IN19)

The limited number of specialised staff and the outdated technologies or procedures used in screening are a problem in rural areas that other respondents also recognised. It is clear that improvements can be made in rural areas regarding detection of disability. As the identified problems



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reflect limited financial and human capital, which are longer-term problems, however, other small-scale solutions could be considered. Greater education of parents on early-warning signs of development abnormality is one possibility, for instance. As most of the help extended by the state to children with disabilities relies on registration of a child as disabled, focus should be placed on boosting detection and registration of disabilities in rural areas.

Social benefits are just one part of the important role the state can play in ensuring social inclusion. Teachers emphasised that full social inclusion is desired by society at large, but achieving it requires a proper system that can guide children with disabilities and their parents throughout their lives. One teacher who works with pupils with disabilities provided the following assessment:

“We see that abroad people with disabilities have equal rights in the society, just like all healthy people. They study, enter universities, regularly attend classes, even though they have a problem with movement, they come in wheelchairs. I think that it could be possible in our country as well, but every disabled person should be assigned to one person from the state, so that the person can always help them - at school, if they have any questions or simply if they cannot enter the building. There should also be a car that can pick them up and bring

them home. For all this, we need a certain body that would be responsible strictly for that and would control the situation. Then the disabled persons will feel comfortable in the society, and they will not feel left out. But we do not have it all yet.” (Teacher 11; FG9)

The respondent suggested an intensive and tailored approach to caring for children with disabilities. Teachers seem willing to include children with disabilities in the classroom, but they need help to learn how social inclusion of children with disabilities can be mainstreamed into curricula and teacher training. There is a stated need for a central coordinating body that would take the lead in aiding children with severe disabilities. This may be challenging given the dispersion of responsible agencies, however. The different agencies and structures available to aid a child with disabilities at different stages of his or her life are not clear. Difficulties in having a child recognised and registered as disabled is just one example. An additional hurdle then comes in requesting and receiving a good or service. As mentioned prior, the state has decentralised some care to NGOs. The mix of state- and non-state actors could further complicate care provision. Enrolling a child in proper education is then an additional possible problem. Such examples are peppered throughout the respondent discussions, highlighting the complexity of social inclusion of children with disabilities.



During sports events organized by UNICEF and the Special Olympics, in Semey

Respondent discussions have made clear that the state assistance system could improve in the following ways:

1. The process of diagnosing and registering a child as disabled to receive social assistance should be streamlined and standardised. Parents should be informed about this immediately after diagnosis so they can apply for benefits expeditiously;
2. The disability detection process relies on adequate health care facilities, which includes not only medical equipment but knowledgeable personnel. In rural areas in particular, attempts should be made to ensure that disabilities can be detected in a timely manner so that affected children can be registered for social benefits;
3. Once a child and parent are eligible to receive social benefits, the types of benefits for which they are eligible should be made clear. The process of applying for specific goods and services should be streamlined to avoid long wait times;
4. The state could consider assigning a case worker or other central figure who can act as an advocate for children with severe disabilities. This could also aid parents in making informed decisions regarding a child's medical care, enrolment in education, participation in treatment or rehabilitation programs, etc.

3.6 Legislative and Normative Environment

The prior sections highlighted the barriers faced by children with disabilities in specific “domains” of rights such as education, healthcare, and social participation. The overarching legal and normative structure in which the rights of children with disabilities are protected is important to understand as well, however.

3.6.1 Defining Disability

A starting point may be the way disability itself is defined and determined. According to a representative of a medical social expert, the rules for conducting a medical-social examination to determine disability are clearly established in the 2005 decree “On the approval of the rules for conducting medical social examinations”. Within this decree an individual can be recognised as disabled if three criteria are met: 1) health deterioration occurs as the result of persistent bodily disorders; 2) life activity is restricted in at least one of seven categories of abilities (self-service,

self-propulsion, self-orientation, communication, behavioural control, ability to learn, and ability to perform work activities), and; 3) the individual requires social protection. These criteria provide clear guidelines for the assessment of children with disabilities, which may in turn facilitate the granting of disabled status to affected children. With that said, the criteria can fall short in specific ways, as illustrated by this respondent, an educational specialist:

“... the classification criteria of the disabled are also wrong. If, for example, the World Health Organization considers a hearing loss of 25 to 35 decibels a disability, for us it is 70 decibels. And this is a severe degree of deafness. And if a child does not have these 70 decibels, they generally do not get any support. In fact, a lot of things make no sense in this regard. That is, in terms of providing hearing aids, prevention, the hearing disability was not included in the guaranteed scope of free medical care... hearing-impaired children who attend special boarding schools do not have [cochlear] implants either, they have no hearing aids because they are not considered to be disabled. Their parents cannot buy these devices for them because they have no money...” (Specialist; IN21)

If what the respondent states is correct, there is clearly also a gap between the international standards for defining disability and the standards adopted by the Republic of Kazakhstan. The classification of a child as having a disability can clearly be flawed, which can lead to exclusion from needed social benefits and, potentially, the exclusion from essential medical and educational services. The problem may lie in the differentiation between children with disabilities and children with limited abilities. According to a respondent from a government agency:

“A disabled person... has an established permanent disability, i.e. the degree of impairment that limits his activity... As for the children with limited abilities, let's say a hearing/visually impaired child, there is an opportunity for such a child to recover the lost function, or acquired loss of vision, with the help of glasses, special exercise etc. In other words, limited ability can be temporary, but the concept of disablement is permanent. Disablement is a permanent impairment that allows rehabilitation but not full recovery of functions.” (Representative; IN22)

While the distinction between a child with a disability and a child with limited abilities may be necessary in terms of resource planning, the needs

of these two groups may strongly overlap. Care should thus be made to ensure that the designation of “limited ability” versus “disability” is not made on an arbitrary basis, as the designation implies what forms of state support a child is eligible for. Two modifications could also be considered: the definition of disability could be made more inclusive of children with limited abilities, or the system of state support for children with limited abilities could be expanded to cover essential medical and educational support services.

The definition and determination of disability — and its type and severity— are essential not only to ensure access to state services but also to help families and educators tailor life-long development approaches for children with disabilities. A respondent from a medical-social expert board explained the importance of doing so:

“Disabled children need different care. They need the establishment and development of an individual program of rehabilitation; the individual rehabilitation program determines the exact amount and types of needs for the medical, social and vocational rehabilitation of the disabled person.” (Doctor; IN19)

Another respondent from a medical and social assessment (MSA) office added:

“In addition to disability, we also determine the needs in social protection measures. An individual program of rehabilitation is developed for each child. The Paediatric Department of MSA is working closely with Psychological, Medical and Pedagogic Consultation. If a child is over the age of 14 years, it is necessary to undertake a preliminary vocational orientation. What profession he/she will receive, what profession is suitable for him/her by the state of health, which one is impossible.” (Department head; IN20)

The identification of the specific needs of children with different types of disabilities is key to developing a responsive system of state help, which carries important implications for all forms of social inclusion.

3.6.2 Regulatory & Legal Frameworks

Many respondents noted significant progress on the protection of rights in the past years, at least in terms of explicit regulatory and legal frameworks. Several key pieces of legislation were highlighted

by different respondents for the changes they introduced. The “Law on Social, Medical, and Pedagogical Support for Children” was particularly identified by one respondent as enabling the establishment of a network of rehabilitation and educational facilities. According to one NGO representative, the following institutions were established after the introduction of the law:

- 17 Rehabilitation centres within the educational system
- 200+ Offices of psychological and special education
- 200+ Schools promoting inclusive education
- 58 Psychological, medical, and pedagogical counselling (PMPC) centres (established with a ratio of one centre per 60,000 children)
- A network of special pre-schools for children with specific impairments (i.e., hearing, vision, speech disorders, etc.)
- A network of 8 schools for children with different categories of impairments
- 103 special schools for children with specific impairments

The respondent noted that the geographic scope of these services has increased over the years, with most offices available in every regional centre and throughout other hubs in the regions — with the exception of Almaty. As the respondent stated: *“... Almaty, where the attitude toward children with disabilities is the worst. It is a huge city, but almost nothing is done with this issue. You should make a note of that because it's nonsense!” (Manager; IN21)* The significant progress achieved in addressing the needs of children with disabilities belies the progress yet to be made. As this respondent noted, the implementation of laws and the provision of services has not occurred evenly throughout the country. Furthermore, while the number of centres of rehabilitation and counselling has exploded in the past years, the number is still insufficient to serve the demand.⁴ Psychological, medical, and pedagogical counselling centres are in particularly short supply, with some serving far more than the population for which they are equipped. As one respondent explained: *“Generally, one PMPC is designed for 60,000... we have more than 80,000 children only in the city... the children of [different] districts come to us, though they are assigned to another PMPC. It is far for them to travel to their PMPC... it*

⁴ Refer to Table A7 in Annex 2 regarding projected shortfalls in PMPC centres across the country, as provided by the respondent from interview 21.

is easier for them to get here, to the city, and we won't refuse them when they bring their ill child on such a frosty day, shaking." (Director; IN26) As PMPCs provide such an indispensable service, it is essential that they are accessible. A single PMPC should also not be overburdened —an excess of 20,000 children falling under the auspices of a single centre can severely strain resources and potentially compromise service quality.

Further, despite advancements in the legal and normative frameworks concerning children with disabilities, important revisions need to be made to bring national norms up to international standards. Further, the actual implementation of principles remains a challenge:

"If the whole talk [is] about the legislation in general, it is definitely very weak. It is necessary to amend the law on social, medical and pedagogical support for children with disabilities. It should be particularly amended as part of the ratification of the Convention on the Rights of Persons with Disabilities." (Specialist; IN21)

"...the legal framework and normative legal documents are sufficiently presented in Kazakhstan. The problem resides in the absence of any mechanism on their execution. One of the problems is the absence of feedback, and the second problem is that the beneficiaries have no access to information on their rights, and accordingly, no mechanisms for protection of children and parents' rights in the social sphere are made." (Director; IN6)

As in the discussion of medical care, it appears that limited access to information is a major barrier to children being fully included in terms of rights protection. Another respondent noted that implementation of the "Law on Special Social Services" was challenging at first due to lack of by-laws, resulting in difficulties with licensing of care facilities. While licensing requirements have since been changed, other problems remain: *"the main challenge in the countryside is certainly a shortage of specialists." (Deputy Director; IN7)*

A range of respondents from different perspectives weighed in on problems with implementation of legal norms or frameworks. For instance, one respondent noted that there are currently around 20 documents on civil-structural engineering relating to building accessibility for persons with limited mobility, which includes elderly persons with mobility problems, pregnant women, and individuals with disabilities. While these construction norms and regulations apply to all facilities,

they are more effective for new buildings. For older buildings, significant retrofitting and redesign often must occur. According to one respondent: *"Today there is no access [to public buildings] at all, not only for children, but also for persons with disabilities in particular." (Deputy Director; IN7).* In response to this limited access of public buildings to persons with disabilities, the East Kazakhstan oblast has evaluated existing facilities and established a priority list of facilities that should be updated to accommodate access by individuals with disabilities. Facilities rated as high priority include divisions of the state centre of pension and benefit payment, healthcare institutions and pharmacies, education facilities, and libraries. A similar exercise has been conducted in Kyzylorda, which resulted in an interesting finding: *"There was an inspection of about 4,000 facilities and of those only 7% could provide access to physically-disabled people in terms of building codes." (Deputy Director, IN9).* Based on this assessment, a budget quote is now being prepared for how much it would cost to bring frequently-visited facilities up to a minimum standard of accessibility. While the legal framework is helpful in establishing minimum standards and expectations, such standards imply the mobilisation of significant resources to ensure adherence. A recent World Bank brief on the cost of accessibility noted that ensuring accessibility in newly-built schools is generally less than one percent of the total construction costs, which is far cheaper than retrofitting buildings after construction (World Bank, 2005). As the goal now is to ensure that frequently-visited buildings are made accessible, significant costs are likely to be involved; in the future, mainstreaming accessibility into building planning would be a much more cost-effective solution.

While most respondents regarded the state as a helpful partner in development of services for children with disabilities, some respondents were less positive. One respondent in particular seemed to regard the state and the legislative environment it has cultivated as essentially uninterested in the treatment of children with disabilities:

"For the whole period of our work I have not turned to the state structures. Yes, I notify [them] that some activity is being carried out, [but] most often they would not come because they are not interested. If they came, this means a meeting with some people, [raising] some issues, and they cannot answer these... there are many questions, for which an official cannot assume responsibility... I know through my experience in the Department. I had worked

for three years there. And that was why I left, because I understood that nobody will help these children.” (Director; IN24)

The respondent —the director of an NGO— further noted that official state structures are inefficient because the state has no real interest in service provision. Given the level of apathy, the devolution of certain services to NGOs can only be a benefit. While this respondent’s opinion was not echoed strongly by other respondents, it is interesting to note the strong perception of the state. Another respondent, a chairman of an NGO, said that the state will not hold itself accountable if they fail to provide the protection guaranteed by law. Parents themselves need to hold the state accountable: “I always tell parents to demand from the state, because the state should help. There is a law, according to which government should help, and all the rest that they do not give, parents should claim. Here I am, going around nervous, but why don’t you do the same?” (Chairman; IN28) The respondent seems to feel that parents need to take more of an initiative to advocate for their children, particularly if the state withholds services or benefits codified in law.

While there are doubtless gaps that still remain in the protection of children with disabilities, increased acknowledgement of their needs —and

the dedication of specific funding to meeting those needs— seems to have increased in recent years. An obstetrician noted that the framework for addressing the needs of children with disabilities has improved greatly over the past few years, particularly as state services have become more empowered to register and monitor children with disabilities:

“There was a report on TV, showing a family that was ashamed of a disabled child, and the child lived in a cowshed. But we don’t have such cases... We have great financing. And now, [with] this per capita financing – each medical care provider visits apartments and makes a list for each building. Each medical care provider wants to have a real picture of how many people she/he has within the site... there are no cases that a child would be unregistered as disabled.” (Physician; IN15)

The greater ability of the oblast administration to reach out to the families of children with disabilities seems to have played a role in reducing the shame and taboo associated with having a child with disabilities. While not all oblasts may have the same budgetary freedom as expressed by the prior participant, the creation of a strong monitoring framework can play a strong role in ensuring the social inclusion of children with disabilities.



‘Balam-ai’ Child Development Centre, Astana

3.6.3 Coverage of Services

When looking at how well the rights of children with disabilities are protected, one important aspect is the coverage of services that should be extended to them. In-depth interviews with both government and civic-society representatives highlighted the number of bodies within the

Republic of Kazakhstan that address the needs of children with disabilities in some capacity. Table 5 below provides an abbreviated overview of the agencies that address concerns related to childhood disability. This list is certainly not exhaustive but provides a sense of the agencies with varying competencies that have a mandate that encompasses children with disabilities.

| Table 5. Bodies with Mandate to Address Concerns of Children with Disabilities | |
|---|--|
| Agency | Competencies Relating to Children with Disabilities |
| Ministry of Labour and Social Protection | Organisation of state policy for social protection of children with disabilities. |
| | Development of state programs related to persons with disabilities (including disability status determination, rehabilitation, employment, etc.) and request for corresponding financing for state programs. |
| Departments of Employment and Social Programs Coordination | Development of construction norms to enhance facility access for persons with disabilities and limited mobility. |
| | Development of normative technical documents for construction. |
| | Development and approval of regulatory documents on construction. |
| Управления занятости и социальных программ | Coordination of activities of subordinate medical and social institutions. |
| | Coordination of home-based social services. |
| | Purchase of supplementary multiple-unit items for persons with disabilities. |
| | Development of measures to provide employment to citizens, including the disabled. |
| | Coordination of training activities to facilitate employment based on market demand. |
| | Evaluation and certification of facilities to determine needed improvements to enhance access. |
| | Elaboration of methodology to determine facility accessibility. |
| National Research Centre for Special Needs Education (NRCSNE) of the Ministry of Education and Science | Psychological, medical and pedagogical examination of children and teenagers to establish medical, psychological, & pedagogical diagnosis & treatment conditions, training and education. |
| | Identification of special needs of a child & establishment of their rights to receive health care, special education, & social services. |
| | Organisation & delivery of health care, psychological, social and educational services for children with developmental disabilities from 0 to 16 years old. |
| | Provision of comprehensive psychological, medical & educational assistance in form of psychological, pedagogical adaptation, & rehabilitation of children & teenagers. |
| | Development of scientific, educational & methodical provision of special and inclusive institutions for children with mental and physical disabilities. |
| | Development, testing & implementation of new teaching technologies. |
| | Counselling & training of parents/guardians on education of children with developmental disabilities within the family. |
| | Guidance & assistance for teachers of general education & special (correctional) educational institutions on working with children with disabilities. |
| | Organisation of international cooperation on diagnostics, correction, training, & education of persons with disabilities. |
| | Development of scientific, methodological, & technological support for the institution of social work regarding children with special needs. |
| Performing scientific research on organisational, psychological, & pedagogical questions, mass media and legal issues of special education for children with special needs. | |

These bodies do not function in isolation; there is a high level of cooperation among different government agencies at different levels. As explained by a representative of a medical expert board, their department coordinates heavily with many other agencies to ensure delivery of social protection. After the medical expert board determines a disability, goods and services the child is eligible for are delivered through different agencies: for instance, the Department of Employment Coordination and Social Programs addresses the need for goods such as diapers, walkers, wheelchairs, hearing aids, etc. The medical expert board —through a specific psychological medical pedagogical commission (PMPC)— makes recommendations to the Department of Education on the type and level of education that would be most appropriate for a child.

Several respondents also discussed the increasing level of coordination between state bodies, international organisations (such as UNICEF and UNDP), and NGOs. Legislation introduced in 2009 saw the establishment of a fund to help state bodies cooperate with NGOs to provide day-patient units and homecare services. According to one respondent⁴, 1.4 billion tenge was allocated to this “state social order” between 2009 and 2012. One representative of a government body noted that their agency has begun working with NGOs —nine to date— to increase home-care and day-care service provision. State agencies in different regions have engaged in similar arrangements with NGOs through state social orders. One respondent said that their agency presently has three projects that are jointly run with NGOs: one relates to the provision of special social services at a day stay hospital, one to the provision of home-based care for children, and the other one provides medical and social services to the elderly and to persons with disabilities. Another respondent reported that the funding provided through the state social order expanded service provision:

“... until 2010 social services were provided only by subordinate state medical and social institutions and in-home care service units under the district and municipal departments. From 2010 we have been inviting NGOs... A network of day patient facilities for disabled children only was established in 2010, covering Aral, Zhala-agash districts and Kyzylorda city; [it] has now been expanded to include two more districts - Kazaly and Chilik. The number of NGOs increased threefold from 2010 to

2012... From year to year we attempt to enlarge the number of disabled children to whom we provide special social services.” (Deputy Director; IN9)

The provision of state budget to fund NGO cooperation seems to have been successful in diversifying the services state bodies are able to provide. The state’s recent emphasis on expanding the relationship between government and non-government bodies has also resulted in increasing opportunities for consultation and communication. As explained by a pediatrician:

“Now a lot of attention is paid by the state to the relationship between other organisations - governmental and non-governmental. In this regard, we have conducted a variety of “round-table” conferences... Once or twice a year... we gather - state agencies and non-governmental organisations that deal with people with disabilities. We are solving a very wide range of issues. There are meetings with mothers of children with disabilities. In particular, last year I was on such a round table conference. Once we had a talk show dedicated to these children. We work very closely with them.” (Physician; IN20)

The round-table sessions provide a potentially valuable platform for feedback and evaluation, not only from organisations working with childhood disability but also from families affected by childhood disability.

While most respondents felt that the state social order system had helped to increase the scope and efficacy of services, the new funding tactic may have negative consequences. A respondent from an NGO noted that NGOs are often not exclusively funded by the state but also seek funding from international sources. Funders often look for program features that do not necessarily contribute to the lasting development of children: “Each fund is interested that there is a final and instant result. This will not work with these children... I am more than sure, if now I propose a program to [a funder] with the objectives of training of trainers, it will not be supported.” (Director; IN23) This could lead to a lop-sided provision of services on behalf of NGOs that are encouraged by international funders to offer short-term rehabilitation services. At the same time, the gradual segue away from state-run services to NGO-run services could leave children with the most severe forms of disabilities without meaningful, long-term development assistance.

5 IN22

Throughout the focus group and interview discussions, respondents credited the state for making positive steps forward in promoting the social inclusion of children with disabilities. Compared to the situation ten years ago, the legislative environment now has become much more responsive to the needs of individuals with disabilities. The important progress that has already been made does not signal an end to the struggle of protecting the rights of children with disabilities, however. Respondents highlighted the following remaining concerns that the legislative environment should address:

1. The definition of disability, and the criteria against which disability is measured, may not appropriately encompass children with varying levels of disability. The criteria may inadvertently exclude children from receiving the disability designation because it is not explicit enough or not fully in line with international norms and standards. Two specific issues have been identified in this regard:
 - a. The level of impairment a child must experience to be considered disabled is much higher than that defined in World Health Organization standards. Where possible, national standards should be brought into line with international standards;
 - b. Children with certain types or levels of disabilities may not receive the designation of “disability” but may instead be considered as having

“limited ability”. Clear standards and criteria distinguishing the two should be available.

2. Existing legislative frameworks and specific pieces of legislation should better reflect international norms and standards. With the signing of the Convention on the Rights of Persons with Disabilities in 2008, some legislation should be updated to reflect the increased scope of state services;
3. The existing legal framework is fairly comprehensive, but mechanisms for its implementation are somewhat lacking. The level of state responsibility outlined in law requires the significant dedication of monetary and human capital resources that cannot be met across the country. The lack of qualified specialists in different domains has been consistently identified as one of the challenges to full implementation of law. This is one clear area in which the state could invest to boost adherence to legal standards;
4. In line with the prior point, the implementation of legal standards has not occurred evenly across the country. While respondents often mentioned problems faced in rural areas (because of large distances between these areas and regional centres, lack of personnel, etc.), Astana was mentioned as lacking appropriate services for children with disabilities. A likely contributor to this problem is, again, resources for service provision. One of the cornerstones of the state system for



Home Care Centre for Children with Disabilities, Astana

addressing the needs of children with disabilities are PMPCs, but it appears that there are significantly fewer centres across the country than is necessary given the population burden. Greater resources could be directed at increasing the geographical presence of essential agencies such as these;

5. Changes in state funding structures have both positive and negative implications for the provision and delivery of services for children with disabilities. The establishment of the state social order system in particular should be assessed and evaluated in terms of how its positive and negative aspects can be reconciled. The increased cooperation between and among state services, NGOs, and IOs was both applauded and criticised in interviews:

- a. Positive aspects: Contracting of NGOs to deliver certain services has enabled expansion of service provision, both in terms of geographical scope and population size. The system has promoted the dispersion of both cost and responsibilities, which can make service provision both more efficient and more effective. Non-governmental organisations are perceived as more passionate advocates of children's rights and their provision of services allows dedicated actors to address the needs of children with disabilities. The inclusion of NGOs engages more specialists in different aspects of disability and promotes the expansion of knowledge and support networks, which may in turn facilitate venues for exchange of knowledge and experience;
- b. Negative aspects: The dispersal of costs and responsibilities across a network of state services and NGOs can lead to decentralisation of authority and fragmentation of service delivery, particularly given the large number of actors involved at different stages of addressing disability. The funding transition places more pressure on NGOs to work in cooperation with state services, but the budgets provided by the state do not cover the needs of NGOs fully. To address budgetary needs, NGOs often turn to international funders, but such funders emphasise the funding of short-term programs and projects with immediate outcomes. This funding source may thus disincentivise NGOs to offer long-term counselling and rehabilitation services.



'Ocean Art' Creative Centre of Art Therapy, Astana



IV. MAIN FINDINGS AND POLICY RECOMMENDATIONS

4.1 Main findings

The protection of children with disabilities and their inclusion and equity in society remains one of the top priorities on Kazakhstan's political agenda. In its efforts to comply with international standards for the protection and inclusion of persons with disabilities, Kazakhstan signed the UN Convention on the Rights of Persons with Disabilities on 11 December, 2008. The legislation of Kazakhstan provides some security to children with disabilities by specifying rights to social care, provision of specialised services, free

education (to primary, secondary and professional training, as well as free higher education for those qualifying), specialised treatment in health care facilities, and a number of other services and benefits that uniquely address the needs of children with disabilities. The laws and regulations introduced in the last two decades that address the rights of persons/children with disabilities not only help provide a solid framework for the social protection of children with disabilities, but they also helped highlight the problems and special needs that these persons face while introducing the concept of social work into the country. These are all substantial achievements for the Republic of Kazakhstan, especially given the limited recognition and discussion of disability prior to the 1990s.

There are a number of achievements noteworthy in the last years regarding the treatment of children with disabilities in Kazakhstan. Kazakhstan has adopted new regulations that aid timely detection of disabilities from the early stages of pregnancy. New regulations are in place for antenatal, perinatal, and neonatal screenings. A new method has also been introduced for the integrated management of childhood illnesses and early childhood development. Sectors like education, health and social protection have assumed new dimensions and roles in terms of identification, protection, and inclusion of children with disabilities. Pedagogical examinations in the education sector have helped in identifying developmental delays. Within the social sector, a child's degree of disability is assessed; on the basis of the severity, prospects for social inclusion —encompassing inclusion in the Labour market— are assessed. Efforts are integrated across sectors, and mass standardised screening of children has begun to identify developmental risks in early childhood, which aids in the development of life-long strategies for inclusion and equity.

One of the outstanding issues raised in approaching disability in Kazakhstan is also how disability is formally defined in the country. The definition of disability should be the first indication of how 'inclusive' and non-discriminatory the entire system is. This report has identified two major differences between the definitions used in the laws of the Republic of Kazakhstan. Firstly, the law differentiates between 'disabled children' and 'children with limited capabilities' by giving the former the right to benefit from disability allowances and the latter can benefit from free medical care. Secondly, both definitions seem to be outdated, especially in light of the social model of disability.

Terms like 'disabled child' refer to the medical model of disability by stressing the 'correction' of disability. Kazakhstan should consider reviewing the legal terminology to free it from stigmatising and isolating connotations by changing or avoiding words like "invalids", or "children with limited opportunities". In this respect the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) would help in acting as a benchmark to approach disability from the perspective of the social model. The most important feature of the ICF-CY is that it recognises that functioning and disability occur within a social context, an important factor in why an effective definition of disability should not only address body functioning but consider this in conjunction with societal and environmental factors.

As the data analysed in this report has demonstrated, the total number of registered children with disabilities in the Republic of Kazakhstan has increased during the 2005-2012 period. Part of this increase can be attributed to the increase in the total number of children in the Republic of Kazakhstan, but the number of children with disabilities also increased as a relative proportion of all children. This is a positive trend in the sense that it signals that more children with disabilities are being identified and therefore protected by the system. Some evidence does suggest, however, that there are a substantial number of people with 'hidden disability'— disabilities that are not reported formally to the authorities and/or not registered as such. Possible reasons for this are barriers to applying for disability benefits and frequent experiences of discrimination against persons with disabilities. Moreover, integration of children with disabilities into general society is still one of the outstanding issues for social policies in Kazakhstan. It is reported that aspects like inclusion of children with disabilities into the general education require more efforts in terms of obligatory correctional, pedagogical and psychological assistance.

In terms of geographical distribution, Karaganda, Almaty, Zhambyl and South Kazakhstan are the regions with the highest (absolute) numbers of children with disabilities. This can be explained by the proportion of the population living in these regions (about 40 per cent of the population). East Kazakhstan, Kyzylorda, Mangystau and Astana and Almaty cities are also administrative regions with relatively high numbers of children with disabilities. The distribution of sub-categories of children with disabilities follows more or less the same trends.

Health care data show that 88.2% out of the total number of children under 16 years old with disabilities are registered in primary health care polyclinics. This shows that some proportion of children with disabilities may not be able to receive primary health care. Barriers here may be the distance to health care centres, poor infrastructure, stigmatisation, or lack of time for parents to bring children to clinics because they are working.

The legislative framework in place guarantees children with disabilities free primary education, basic secondary education, and all social, health care, and pedagogical correctional support. In addition, children with disabilities and their families receive special social services and are also provided with monthly benefits in the range of the minimum of the subsistence level. The number of children with disabilities benefiting from state social allowances has increased between 2009 and 2012, but about 3.28 percent of all children with disabilities do not benefit from state allowance, demonstrating persistent vulnerabilities among these groups.

Programs for children with disabilities in Kazakhstan consist mainly in educative and rehabilitative activities. At present the Republic of Kazakhstan relies on a sustainable network of social and education institutions for providing services to children with disabilities. Based on

the severity of the disability, children with disabilities can go to general, inclusive, or special preschools, primary schools, or social institutions. This report has found that the number of children with limited abilities and disabilities has increased in technical and vocational education institutions within the 2002-2012 period, which is certainly a positive trend. The regions with the highest number of children attending technical and vocational education are East, North, and West Kazakhstan, as well as Almaty city. More can be done, however, with regard to providing scholarships for children applying to enter tertiary education. Although education for children with disabilities is free of charge and such children are given priority in entering tertiary education, not all applicants for the scholarship have received it. Data for 2012 show, only 85% of children with disabilities who applied for a scholarship received one in 2012.

From an international perspective, Kazakhstan seems to perform well in comparison with other CIS countries like Uzbekistan, Kyrgyzstan or Turkmenistan regarding disability allowances, percentage of children with disabilities in residential care, inclusion of children with disabilities in general education, etc. However, such international comparisons should be considered with caution due to the high level of differences in defining children with disabilities or the other contextual changes.



A multiple winner of sporting events organized by the Special Olympics

This report used a mixed-method approach to explore the barriers and successes of the social inclusion of children with disabilities by combining desk review analysis with in-depth interviews and focus group discussions. The in-depth interviews and focus group discussions were carried out in Astana, Almaty, Karaganda, Kyzlorda, and East Kazakhstan. Children, parents, teachers, government officials, and other key stakeholders were involved in the data collection process. Across the sampled regions, 33 in-depth interviews and 9 focus group discussions were organised. The diverse stakeholder groups included in these interviews provided an excellent diversity of insights

on how social inclusion can be fostered across different domains such as education, health care, social participation, social protection, and protection of rights.

With regard to education, several critical aspects that may undermine (or alternatively help) inclusion efforts for children with disabilities were discussed by participants. Respondents discussed the need for educational facilities to be updated and refitted to accommodate children with limited mobility; only a small number of education facilities are considered accessible for children with impaired mobility and vision. Most respondents were in favour of inclusive classrooms, but determining factors of the success of such classrooms included tailored curricula for children with disabilities, training of specialised personnel, lower child-to-teacher ratios, and preparation of students and their parents for the inevitable (yet often minor) changes inclusion may bring. Respondents also emphasised the need to design tailored work and education plans for children with disabilities, which would not only help reduce teacher burden but also help children and their parents plan for their eventual post-education social inclusion (including in the Labour market).

In terms of healthcare, focus group and interview respondents noted three primary concerns: accessibility of healthcare facilities, availability of quality care, and accessibility of social protection measures for health services. While great efforts have been made over the past years to increase the presence of medical facilities for children with disabilities, more specialised medical facilities are generally only available in urban centres. When medical care is available, the quality of care is sometimes unsatisfactory. This occurs for several reasons such as lack of equipment (particularly for antenatal screenings), lack of specialised medical personnel (particularly those who can detect early childhood risk factors and early-warning symptoms), and limited provision of information on disabilities to parents with recently-diagnosed children. Some respondents also reported that delays in receiving social protection can hinder the provision of medical services, which could be offset by more transparent application procedures.

In the domain of social participation, many respondents noted that clear improvements have been made in the treatment of people with disabilities in the past few years. Some respondents attribute attitudinal changes to government-led awareness-raising campaigns that encourage people to register children with disabilities. While some respondents reported experiencing discrimination



At the 'Different-Equal' national competition

or judgment (from friends and strangers alike), most noted that their immediate social networks were positive and helpful. Respondents suggested that children without disabilities are generally very receptive to children with disabilities, and what social stigma remains emanates largely from other parents or from state bodies that are dismissive of their children's potential to lead fulfilling lives that can contribute to society at large.

Social protection was another area of social inclusion discussed by respondents. Parents and service providers alike recognised that care of children with disabilities can be a costly venture, and state benefits are thus essential. While the coverage of social benefits has increased over the last years, and the package of service and item provision can be generous, many families still experience budgetary shortfalls because certain services or material needs of their children are not covered within the existing benefit structure. Another problem highlighted by respondents is the limited information given about how to access and make effective use of social protection provisions. Many of the hiccups experienced by families relating to social protection could potentially be addressed by the assignment of a case worker or other individual who could act as a central contact point for a family regarding social protection provision for their children with disabilities.

In terms of protection of rights through the elaboration of responsive legislative and regulatory frameworks, respondents noted that significant progress has been made over the past few years. Substantial improvements have been made in the development of explicit frameworks, but implementation remains a challenge. One challenge relates to the way disability is defined, as the process of having a child evaluated and designated as having a disability determines the state services a child will be eligible for. Respondents suggested that more transparent standards for determining disability should be made, and that the distinction between "disability" and "limited ability" should be reduced to increase coverage for children with (relatively minor) impairments that still need access to state support. Another challenge in implementation relates to shortfalls in monetary and human capital resources, particularly in rural areas. Some of these shortfalls are being met by novel funding structures such as the contracting of NGOs for certain services, which has expanded service coverage and delivery while also decentralising some of the care from government to smaller organisations.

4.2 Policy recommendations

Based on the information collected in the course of primary document review, focus groups, and in-depth interviews, several key areas for improvement in the social inclusion of children with disabilities in the Republic of Kazakhstan can be identified.

Evolving definition -The definition of disability, and the criteria against which disability is measured, may not appropriately encompass children with varying levels of disability, leading to exclusion of children who still need state intervention for social inclusion to occur. The state could take the following actions in regard to this:

- National standards should be brought into line with international standards, particularly regarding minimum levels of impairment that a child must experience to be considered disabled.
- Clear standards and criteria for distinguishing "limited ability" from "disability" should be elaborated to ensure that the designation is not made arbitrarily, denying children with more minor impairments access to needed state services and goods.
- Words like "invalids", or "children with limited opportunities" should be changed or avoided from the legal terminology to make it free from stigmatisation and isolation.

Monitoring Tools –Having an updated picture of the current situation with respect to the rights and conditions of persons with disabilities will help in timely assessment of governmental objectives and the current progress made. Annex 1 of this report gives a detailed table of the main indicators that would need to be periodically monitored with respect to domains like education, health care services, social services well-being and social benefits, accessibility, inclusion, equity and participation of children with disabilities.

Changing Attitudes –Attitudes about disability are slowly changing, with the social stigma surrounding disability appearing to decrease. This positive trend can be encouraged by the following:

- Public perceptions about the cause of disabilities could be influenced by information campaigns that emphasise that disability is not anyone's "fault", which could help the parents of children with disabilities combat their own potential social exclusion.

- Awareness-raising and sensitisation campaigns could be conducted that increase the visibility of individuals with disabilities. A key aspect of these campaigns would be to demonstrate that persons with disabilities have many of the same interests, capacities, and limitations as people without disabilities.

Promoting Ability –A key aspect of any child’s social inclusion and equity is promotion of the attitude that each child deserves a fulfilling and meaningful life. Regardless of disability status, each child should be regarded as a person with abilities that are valuable. This promotion of ability can be encouraged through:

- Information campaigns emphasising that children with disabilities are still children, in need of the same inputs as children without disabilities. Their rights to healthcare, education, opinions, and a healthy future are guaranteed and should be equally enforced.
- Trainings of medical practitioners, educators, and other agents of the social support system, who are key actors in the process of helping children and their families plan for a productive future. As such personnel are often the first points of contact and interface between families and the state, it is essential that they act as advocates for children with disabilities by helping make long-term plans for treatment, rehabilitation, and inclusion of children with different needs.

Supporting Children and Their Families – Supporting the families of children with disabilities is an essential part of social inclusion, particularly as the family provides a key network for advocacy and distribution of resources. State and non-state actors alike could contribute to the resilience and functionality of families by:

- Educating parents and other family members on the unique needs, challenges, and opportunities specific disabilities bring to children. Each child will navigate each distinct disability in a unique way; families should be educated about specific disabilities to help in this process.
- Counselling can be extended to families as part of the education process, which can help them understand and process their own concerns and stresses relating to the disability.
- Families could be empowered to share their experiences and knowledge with each other via the creation of knowledge networks; clinics, treatment centres, or education facilities

could potentially act as a hub for these informal networks.

- Following the diagnosis of a disability, families could be provided with a handbook or guide that outlines the steps they have to follow to register their children and receive social benefits. Such a guide could also list requirements for receiving specific goods and services.

Community-Based Rehabilitation and Support

–The provision of services to families of children with disabilities has increased in the past year. The expansion in the coverage of services has been a particularly valuable improvement, but further improvements in service provision could be made by encouraging community-level interventions. This could be done by:

- Encouraging the establishment of service networks of local-level NGOs, both those that are directly contracted by the state and those that function independently. The promotion of “round-table” discussions and other public fora could further encourage the mutual cooperation and knowledge exchange of local-level actors.
- Assigning a focal point for each child with disabilities such as a case worker or other public agent who could act as a central source of knowledge and coordination. This could aid parents in making informed decisions regarding a child’s medical care, enrolment in education, participation in treatment or rehabilitation programs, etc. by providing one unified source of knowledge.

Inclusive Health –Children with disabilities may have specific medical needs that change throughout the course of their lives and disabilities. The following improvements in the provision of medical care could ensure social inclusion through promotion of health:

- Protection of maternal health and the promotion of healthy lifestyles can help minimise the risk of the development of disabilities. Different media (such as magazine articles and television programs) can help educate expecting mothers about how they can help ensure healthy fetal growth.
- Medical personnel may need additional training to detect disability. Equipment and knowledge about its use is also essential to ensure effective antenatal screenings.
- Parents play a key role in managing a disability. They should be educated about activities they need to do with their children following

the diagnosis of a disability to ensure that their children develop necessary cognitive, motor, and muscle skills.

- Medical service formats could be expanded to encourage parents to seek (ongoing) medical treatment for their children. Alternative services formats that could be pursued include day-care facilities, home-care services, or mobile medical units.

Inclusive Education –The educational system provides an essential venue for social inclusion of children, both by encouraging a child’s present social participation but also by giving children the knowledge and skills they need for later life. The inclusion of children with disabilities in education can be challenging, but several actions could improve their current level of inclusion:

- Facilities need to be updated before inclusion can be fully pursued; this includes aspects such as access ramps between floors for those using a wheelchair, handrails and footpaths for the visually impaired, lower door thresholds for children with physical (mobility) impairments, etc.
- Tailored education and skills trainings need to be offered to teachers who work with children with disabilities. Both short-term and periodic courses and University-level education could

be offered in this regard, which would help ensure that adequate specialists are available in schools.

- Schools with inclusive classes likely need more personnel, both to improve the student-teacher ratio and also to ensure that specialists such as speech therapists, teacher’s aids, counselors, etc. are available to aid both students and teachers.
- Educational coordinators and teachers should be encouraged and empowered to create personalised education plans with children with disabilities and their parents to help ensure that the curriculum is responsive to the specific disability.
- Job and career counselling should be offered to children with disabilities, and where possible, tailored career training programs should be offered that help such children reach realistic future productivity goals.
- Schools introducing inclusive education should prepare staff, students, and student’s parents for the changes such a transition may bring. This includes the need for open and honest discussion about disability, sensitising students and teachers, and informing teachers about new classroom management strategies.



School for children with special educational needs, Astana

ANNEX 1. DRAFT MONITORING TOOLS

Many states have now ratified The United Nations Convention on the Rights of Persons with Disabilities (CRPD) and have in place a complete package of legislations protecting children with disabilities and promoting their social inclusion. The Republic of Kazakhstan is on the way to ratification of the CRPD. However, beyond the ratification of conventions and passing laws there is a need for reporting on the current situation and to be able to undertake long-term tracking that shows if and how the situation is improving. Knowing the current situation with respect to the rights and conditions of persons with disabilities will help in having a longitudinal assessment of governmental objectives and the current progress made.

Monitoring involves the systematic collection and evaluation of evidence about the extent to which the current objectives are fulfilled in terms of providing the right protection and ensuring the social inclusion of children with disabilities.

| Table A1. Monitoring tools | | | |
|--|--|---|---|
| DOMAIN | OBJECTIVES | OBJECTIVE CHECKS | INDICATOR |
| EDUCATION | Getting 100% of the children with disabilities in education by 2020. | How many children are currently still out of pre-education and primary school? | What percentage of children with disabilities attending education have an individual program based on the pedagogical office? |
| | Having at least 50% of the children in education in inclusive schools by 2020. | Effectiveness of home-based education? | |
| | Increase attendance and participation of children with disabilities to 100%. | Are there reliable data on daily/regular school attendance? If so, what are the main patterns of attendance and which groups of children do not attend regularly? | Based on the severity of disability, what percentage of the total number of children with disabilities are: |
| | | | Out of pre-school |
| | | | Out of primary school |
| | | | Learn in general schools |
| | | | Learn in inclusive schools |
| | | | Attending home-based education |
| | | | What percentage of children with disabilities that need tutoring in general or inclusive schools have it? |
| | | | What percentage of children with disabilities are attending secondary education |
| What percentage of children with disabilities are attending vocational training | | | |
| What percentage of children with disabilities are attending university education | | | |
| What percentage of children with disabilities that attend university education have tuition fees subsidised? | | | |

| | | | |
|----------------------|--|--|--|
| HEALTH CARE SERVICES | Provide an effective surveillance system that would detect disabilities as early as possible. | How many cases of disability (in percentage over the total cases of those born with disability) are detected within the first month after birth? | What percentage of children with disabilities have had their disability diagnosed directly after birth (as a percentage of children born with disability that year)? |
| | Provide health care that covers all basic needs of children with disabilities | How many children with disabilities (in percentage over the total number of children with disabilities) are covered by the health care services? | <p>What percentage of children with disabilities have had their disability diagnosed in the first month after birth (as a percentage of children with disabilities being born that year)?</p> <p>What percentage of children with disabilities have been registered in polyclinics (as a percentage of children with disabilities being born that year)?</p> <p>What percentage of children with disabilities have visited the dentist (as a percentage of total number of children with disabilities in that year).</p> <p>How far is the polyclinic from each child with disabilities?</p> <p>What percentage of the specific service (like speech therapy, etc.) is covered by the state budget for each child?</p> |
| SOCIAL SERVICES | Provide quality social services for children with disabilities and their families throughout the entire country. | <p>What percentage of children with disabilities do not benefit from social services?</p> <p>What types of social services are offered and do they cover all the needs of children with disabilities and their families?</p> | <p>What percentage of children with disabilities is covered by social services? And, are there significant differences between the regions?</p> <p>At what level (or where) are these services offered (institutional level, community level or at home)?</p> <p>What needs do these services cover and do these include any of the needs of children with disabilities</p> <p>Are there social services for families with children with disabilities?</p> <p>What type of needs for families with children with disabilities are covered? What percentage of these families is covered? And, are there significant differences between the regions?</p> <p>How many social workers (per children with disabilities) are there in the country? And, are there significant differences between the regions?</p> <p>What percentage of the social workers is professionally trained? What percentage of medical equipment has to be paid for by their parents and other family members?</p> <p>How long does a child with disabilities have to wait on a waiting list for aids/appliances?</p> <p>How long does a child with disabilities have to wait on a waiting list for personal care?</p> <p>Percentage of children rehabilitated from disability?</p> |
| HOUSING/ RESIDENCE | To reduce the number of children with disabilities living in residential institutions. | What is the percentage of children with disabilities living in residential institutions? | <p>Proportion of children with disabilities 0-3 years old living in parental home/residential institutions.</p> <p>Proportion of children with disabilities 3-18 years old living in parental home/residential institutions.</p> |

| | | | |
|---|---|---|--|
| | | | <p>How many parents/caregivers of children with disabilities have been assisted in order to increase the number of children with disabilities residing in a family environment?</p> <p>Is the social assistance benefit offered to parents who may lose jobs because of caring for children with disabilities? Is this assistance enough to compensate?</p> <p>How many of the children residing at home (in percentage over the number of children living in residential institutions) attend general/specialised pre-education and education?</p> <p>How many of the parents/caregivers (in percentage over the total number of parents/caregivers of children with disabilities) have been offered the help of a social worker?</p> |
| SOCIAL BENEFITS | To reduce the risk of falling into poverty and provide sufficient financial means for families with children with disabilities. | What is the percentage of families with children with disabilities falling below the poverty line? | <p>How many children with disabilities (in percentage over the total number of children with disabilities) receive disability allowances?</p> <p>How many parents/caregivers of children with disabilities (in percentage over the total number of parents/caregivers of children with disabilities) receive disability allowances?</p> <p>How many households of children with disabilities (in percentage over the total number of households of children with disabilities) receive any social transfers?</p> <p>How often should parents of children with disabilities renew the documentation to benefit from disability allowance?</p> |
| ACCESSIBILITY | To increase the accessibility of children with disabilities to all public services and facilities, as well as facilitate their movement and transportation. | | <p>Proportion of footpaths which have been dished</p> <p>Proportion of public transport accessible for children with disabilities</p> <p>Proportion of public buildings, cinemas, libraries, supermarkets, etc., accessible for children with disabilities</p> <p>How many households of children with disabilities (in percentage over the total number of households of children with disabilities) have to move towards urban areas in order to have access to public services for children with disabilities?</p> |
| Inclusion of Children with disabilities in the National and Local Policies | To provide coverage for children with disabilities and their families in every aspect both at national and local levels. | <p>Do the national and local policies consider children with disabilities and their families?</p> <p>How do these policies help the inclusion and integration of children with disabilities and their families?</p> | <p>How many of the national and local policies include particular provisions for children with disabilities and their families?</p> <p>Do the official policies include any wording or terminology that otherwise would exclude/isolate or discriminate against children with disabilities and their families?</p> |
| PARTICIPATION | To increase the participation of children with disabilities and their families in all policy forums at both the central and local level. | Access to decision making and engagement in school participation | <p>How many children with disabilities or their parents/caregivers (in percentage over the total number of children with disabilities or their parents/caregivers) participate in policy forums at both the central and local level?</p> <p>How many people with disabilities (in percentage over the total number of people with disabilities) are employed either in the private or the public sector?</p> |

ANNEX 2.

STATISTICAL SNAPSHOTS

Table A2. Number of children with disabilities registered in primary health care services, 2008-2012

| Region/Year | Дети с инвалидностью в возрасте до 16 лет | | | | | Дети с инвалидностью в возрасте до 3-х лет | | | | |
|------------------------|---|--------|--------|--------|--------|--|------|------|------|------|
| | 2008 | 2009 | 2010 | 2011 | 2012 | 2008 | 2009 | 2010 | 2011 | 2012 |
| Aktobe | 1511 | - | 1727 | 1796 | 1965 | 123 | - | 203 | 245 | 280 |
| Akmola | 1725 | 1755 | 1898 | 1194 | 1332 | 125 | 114 | 132 | 118 | 147 |
| Almaty | 4182 | 4441 | 4819 | 4905 | 5358 | 347 | 394 | 499 | 522 | 754 |
| Atyrau | 2016 | - | 1926 | - | 2118 | 179 | - | 215 | - | 296 |
| Eastern Kazakhstan | 3705 | - | 3644 | 3616 | 3660 | 296 | - | 343 | 332 | 359 |
| Zhambyl | 3668 | 2900 | 3231 | 3504 | 3673 | 500 | 354 | 431 | 436 | 429 |
| West-Kazakhstan | 2092 | 2194 | 2108 | 2019 | 2083 | 98 | 174 | 165 | 192 | 198 |
| Karaganda | 3892 | - | 3783 | 3796 | 3885 | 350 | - | 340 | 367 | 407 |
| Kostanai | 1725 | 1765 | 1836 | 1914 | 1896 | 110 | 132 | 148 | 161 | 157 |
| Kyzylorda | 2278 | 2255 | 2380 | 2328 | 2560 | 172 | 138 | 276 | 239 | 372 |
| Mangistau | 1389 | - | 2118 | 2447 | 2486 | 74 | - | 190 | 341 | 456 |
| Pavlodar | 1994 | 1962 | 2000 | 2160 | 2190 | 211 | 217 | 244 | 313 | 346 |
| North-Kazakhstan | 1918 | - | 1951 | 1891 | 1856 | 180 | - | 270 | 162 | 163 |
| South-Kazakhstan | 9438 | - | 9877 | 10040 | 10533 | 1363 | - | 1640 | 1796 | 1618 |
| Astana city | 948 | 1151 | 1336 | 1781 | 2096 | 157 | 188 | 251 | 332 | 458 |
| Almaty city | 2093 | - | 2706 | 2974 | 3125 | 230 | - | 421 | 348 | 344 |
| Republic of Kazakhstan | 44 574 | 18 423 | 47 340 | 46 365 | 50 816 | 4515 | 1711 | 5768 | 5904 | 6784 |

Source: Based on the data from the Ministry of Health 2012

Таблица А 3. Данные Министерства труда и социальной защиты населения РК, 2012 г.

| Region | No. of persons with disabilities | No. of children with disabilities | No. of children with disabilities registered in health centres (0-16 years) | No of children with disabilities (group 1) | No of children with disabilities (group 2) | No of children with disabilities (group 3) | No. of rehabilitation centres | Total number of territorial divisions of medical and social assessment office | Medical and social institutions for children with disabilities with musculo-skeletal system disorders | Medical and social institutions for children with psychoneurological pathologies | No. of home-based social assistance departments |
|------------------------|----------------------------------|-----------------------------------|---|--|--|--|-------------------------------|---|---|--|---|
| Akmola | 28,193 | 2,434 | 2,085 | 53 | 122 | 174 | 0 | 8 | 0 | 2 | 6 |
| Aktobe | 21,451 | 2,502 | 2,189 | 33 | 108 | 172 | 0 | 6 | 0 | 0 | 3 |
| Almaty | 69,584 | 7,581 | 6,601 | 157 | 406 | 417 | 2 | 11 | 0 | 2 | 25 |
| Atyrau | 17,554 | 2,419 | 2,121 | 30 | 117 | 151 | 1 | 5 | 0 | 1 | 6 |
| Eastern Kazakhstan | 57,560 | 4,401 | 3,786 | 58 | 202 | 355 | 0 | 12 | 2 | 1 | 21 |
| Zhambyl | 38,375 | 4,441 | 3,870 | 61 | 179 | 331 | 2 | 9 | 0 | 1 | 12 |
| Western Kazakhstan | 25,019 | 2,525 | 2,166 | 46 | 161 | 152 | 0 | 6 | 0 | 1 | 8 |
| Karaganda | 61,704 | 4,669 | 4,009 | 65 | 200 | 395 | 0 | 12 | 0 | 1 | 23 |
| Kyzylorda | 26,517 | 3,823 | 3,319 | 64 | 131 | 309 | 2 | 6 | 0 | 1 | 3 |
| Kostanai | 26,310 | 2,275 | 1,932 | 42 | 166 | 135 | 1 | 8 | 0 | 1 | 8 |
| Mangistau | 17,440 | 2,813 | 2,523 | 35 | 107 | 148 | 1 | 4 | 0 | 1 | 0 |
| Pavlodar | 29,092 | 2,690 | 2,358 | 43 | 114 | 175 | 2 | 7 | 0 | 1 | 5 |
| Northern Kazakhstan | 29,117 | 2,092 | 1,814 | 31 | 76 | 171 | 1 | 7 | 1 | 1 | 1 |
| Southern Kazakhstan | 101,944 | 14,617 | 12,889 | 179 | 518 | 1031 | 2 | 15 | 1 | 1 | 26 |
| Almaty city | 42,607 | 4,116 | 3,760 | 82 | 114 | 160 | 2 | 8 | 0 | 1 | 15 |
| Astana city | 17,313 | 2,446 | 2,205 | 51 | 88 | 102 | 0 | 6 | 0 | 1 | 3 |
| Republic of Kazakhstan | 609,780 | 65,844 | 57,627 | 1,030 | 2,809 | 4,378 | 16 | 130 | 4 | 17 | 165 |

Source: Based on the data from the Ministry of Labour 2012

Table A4. Data from the Ministry of Education 2012

| Region | No. of rehabilitation centres | No. of children with disabilities in rehabilitation centre | No. of Psychological and Pedagogical Correction Rooms | No. of children with disabilities in Psychological and Pedagogical Correction Rooms | No. of Logopedic rooms | No. of children with disabilities in Logopedic rooms | Percentage of children with disabilities uncovered by pre-education | Percentage of children with disabilities not accessing education | Technical and vocational education organizations |
|------------------------|-------------------------------|--|---|---|------------------------|--|---|--|--|
| Akmola | 0 | 0 | 7 | 466 | 41 | 1,066 | 0.50 | 0.35 | 93 |
| Aktobe | 1 | 147 | 6 | 143 | 39 | 879 | 0.50 | 0.32 | 79 |
| Almaty | 2 | 105 | 15 | 1,666 | 0 | 0 | 0.06 | 0.61 | 98 |
| Atyrau | 1 | 80 | 7 | 317 | 1 | 35 | 0.52 | 0.56 | 71 |
| Eastern Kazakhstan | 2 | 90 | 11 | 766 | 18 | 353 | 0.77 | 0.39 | 268 |
| Zhambyl | 1 | 415 | 7 | 513 | 5 | 141 | 0.28 | 0.12 | 84 |
| Western Kazakhstan | 3 | 100 | 11 | 1924 | 50 | 1,443 | 0.47 | 0.33 | 171 |
| Karaganda | 1 | 281 | 3 | 145 | 82 | 4,028 | 0.45 | 0.28 | 160 |
| Kostanai | 0 | 0 | 11 | 734 | 101 | 2,650 | 0.89 | 0.41 | 99 |
| Kyzylorda | 3 | 399 | 6 | 326 | 13 | 269 | 0.32 | 0.24 | 93 |
| Mangistau | 1 | 22 | 2 | 87 | 0 | 0 | 0.65 | 0.48 | 65 |
| Pavlodar | 1 | 50 | 11 | 1,622 | 90 | 2,250 | 0.58 | 0.23 | 85 |
| North Kazakhstan | 0 | 0 | 11 | 2,664 | 49 | 1467 | 0.75 | 0.24 | 171 |
| South Kazakhstan | 1 | 159 | 16 | 1341 | 0 | 0 | 0.93 | 0.80 | 107 |
| Astana city | 2 | 301 | 2 | 254 | 6 | 451 | 0.68 | 0.52 | 68 |
| Almaty city | 1 | 237 | 3 | 538 | 63 | 2,025 | 0.65 | 0.22 | 330 |
| Republic of Kazakhstan | 19 | 2,149 | 126 | 12,968 | 495 | 15,032 | 0.67 | 0.46 | 2,042 |

Source: Based on the data from the Ministry of Education 2012

Table A5. Data from the Agency of Statistics 2011

| Region | No. of residential institutions for children with disabilities | No. of children with disabilities in residential institutions | No. of personnel in residential institutions | The ratio of personnel/child in residential institutions | No. of children with disabilities at day general education schools | No. of children with disabilities being tutored at day general education schools |
|------------------------|--|---|--|--|--|--|
| Akmola | 2 | 164 | 219 | 1.33 | 1,079 | 371 |
| Aktobe | 1 | 117 | 98 | 0.83 | 980 | 277 |
| Almaty | 5 | 448 | 533 | 1.18 | 1,654 | 868 |
| Atyrau | 1 | 89 | 161 | 1.80 | 460 | 223 |
| Eastern Kazakhstan | 1 | 100 | 214 | 2.14 | 956 | 301 |
| Zhambyl | 1 | 116 | 151 | 1.30 | 1,682 | 1,107 |
| Western Kazakhstan | 1 | 277 | 509 | 1.83 | 1,567 | 423 |
| Karaganda | 1 | 159 | 270 | 1.69 | 959 | 313 |
| Kostanai | 2 | 167 | 250 | 1.49 | 1,135 | 577 |
| Kyzylorda | 1 | 153 | 175 | 1.14 | 619 | 184 |
| Mangistau | 2 | 382 | 471 | 1.23 | 4,267 | 2126 |
| Pavlodar | 1 | 57 | 99 | 1.73 | 1,208 | 463 |
| North Kazakhstan | 2 | 100 | 213 | 2.13 | 975 | 319 |
| South Kazakhstan | 4 | 394 | 508 | 1.28 | 1,510 | 720 |
| Astana city | 1 | 188 | 188 | 1.00 | 505 | 202 |
| Almaty city | 1 | 126 | 181 | 1.43 | 1,473 | 284 |
| Republic of Kazakhstan | 27 | 3,037 | 4,240 | 1.47 | 21,029 | 8,758 |

Source: Based on the data from the Agency of Statistics 2011

Table A6. List of Interviews & Focus Groups

| Interview Code | Institution Represented/ Respondent Type | Interview Code | Institution Represented/ Respondent Type |
|----------------|--|----------------|--|
| IN1/2 | Government agency | IN 23 | NGO |
| IN 3 | NGO | IN 24 | Government agency |
| IN4 | NGO | IN 25 | Government agency |
| IN 5 | Government agency | IN 26 | Government agency |
| IN 6 | NGO | IN 27 | Government agency |
| IN 7 | Government agency | IN 28 | NGO |
| IN 8 | Government agency | IN 29 | School |
| IN 9 | Government agency | IN 30 | NGO |
| IN 10 | Government agency | IN 31 | Government agency |
| IN 11 | School | IN 32 | IO |
| IN 12 | School | IN 33 | School |
| IN 13 | Health clinic | FG1 | School: Children with disabilities |
| IN 14 | Health clinic | FG2 | School: Children without disabilities |
| IN 15 | Government agency | FG3 | School: Children without disabilities |
| IN 17 | School | FG4 | School: : Parents of children with disabilities |
| IN 18 | Government agency | FG5 | School: Parents of children with disabilities |
| IN 19 | Government agency | FG6 | School: : Parents of children without disabilities |
| IN 20 | Government agency | FG7 | School: : Parents of children without disabilities |
| IN 21 | Government agency & NGO | FG8 | School: Teachers in remedial classes |
| IN 22 | Government agency | FG9 | School: Teachers in inclusive classes |

Table A7. Existing network of PMPCs and Demand for Further Centres by Child and Teenage Population

| Region | Child and teenage population | Demand of child and teenage population on PMPCs (# per 60,000) | Existing PMPCs | Shortfall in Number of Needed PMPCs |
|------------------------|------------------------------|--|----------------|-------------------------------------|
| Akmola | 194.6 | 3 | 4 | - |
| Aktobe | 227.1 | 4 | 2 | 2 |
| Almaty | 589.7 | 10 | 7 | 3 |
| Atyrau | 185.1 | 3 | 2 | 1 |
| Eastern Kazakhstan | 336.3 | 6 | 6 | - |
| Zhambyl | 370.9 | 6 | 5 | 1 |
| Western Kazakhstan | 165.8 | 3 | 3 | - |
| Karaganda | 346.4 | 6 | 2 | 4 |
| Kostanai | 201.8 | 3 | 5 | - |
| Kyzylorda | 259.3 | 4 | 4 | - |
| Mangistau | 195.2 | 3 | 2 | 1 |
| Pavlodar | 178.8 | 3 | 4 | - |
| North Kazakhstan | 137.6 | 2 | 3 | - |
| South Kazakhstan | 103.6 | 17 | 2 | 15 |
| Astana city | 323.1 | 5 | 2 | 3 |
| Almaty city | 189.1 | 3 | 3 | - |
| Republic of Kazakhstan | - | - | 1 | - |
| Республика Казахстан | 4935.4 | 82 | 57 | 30 |

Source: Based on the data from the National Correctional Pedagogy Applied Research Centre of the Ministry of Education and Science of the RK, 2013

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