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Disability statistics in Uzbekistan: bridging the gap for inclusive policies

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Accurate disability statistics are crucial for developing effective policies to improve the lives of individuals with disabilities. However, Uzbekistan faces considerable challenges in obtaining reliable data, resulting in the exclusion of individuals with disabilities from essential services and equality-driven policies (World Bank, 2018). This study explores the discrepancies between official disability statistics and estimates from international organizations and surveys, with a focus on inclusive education. It identifies key barriers, including outdated Soviet-era practices, procedural complexities, social and financial obstacles, and inadequate data collection methods. The study recommends several strategies to address these issues: using the Washington Group Short Set of Questions on Functioning to accurately identify individuals with disabilities, improving the Education Management Information System (EMIS), incorporating gender-disaggregated data, and involving individuals with disabilities in data collection. It also emphasizes the need to strengthen governmental capacity for inclusive disability data and combat social stigma. Implementing these recommendations, will enhance data accuracy, improve understanding of the population's needs, and support more effective policymaking, leading to more equitable development in education and other sectors.

Keywords: disability statistics; Uzbekistan; disaggregated data

Introduction

Located in Central Asia, the Republic of Uzbekistan (hereafter referred to as Uzbekistan) gained independence from the Soviet Union in 1991 and is now a member of the Commonwealth of Independent States (CIS) (CIS Legislation, n.d.). With a population of approximately 35.27 million, Uzbekistan is classified as a lower-middle-income economy and is currently transitioning from a planned to a market economy, having recorded a GDP per capita of $1,993.42 in 2021 (Data Commons, n.d.).

Uzbekistan's Soviet legacy has fostered a long-standing emphasis on institutionalization rather than social inclusion for individuals with disabilities (Phillips, 2009). This historical influence, enduring for over seven decades, has profoundly shaped societal attitudes, governmental policies, and educational approaches toward children with disabilities (Katsui, 2005). During the Soviet era, individuals with disabilities were often stigmatized and hidden from public view, making them largely excluded from society (Dunn & Dunn, 1989). Many remnants of this legacy persist today, with individuals still being categorized and confined to closed institutions based on the severity of their conditions. Within these institutions, a reductionist view of disability prevails, focusing on limitations and deficits while overlooking the strengths, capabilities, and diverse experiences of individuals (UNICEF, 2015).

Children who begin their education in segregated institutions often remain within these systems for life, transitioning to different facilities as they age. Buysse and Bailey (1993) emphasize the importance of promoting inclusivity during the preschool years, as children in specialized preschools are more likely to continue their education in segregated settings. Lipsky and Gartner (1997) address the same issue at a later stage, noting that after completing their schooling, many young people either move on to specialized colleges or face isolation at home. Although these authors examine this issue within the context of other countries, this pattern of lifelong segregation is similarly pronounced in Uzbekistan, where many students with disabilities remain confined to institutional settings and isolated from broader society.

Recent legislative reforms in Uzbekistan, such as the adoption of the Law ‘On the Rights of Persons with Disabilities’ in 2021 and the ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD), mark a significant shift toward advancing disability rights. This shift is also reflected in the evolution of the national institutional framework, which now includes the Agency for the Development of Medico-Social Services under the Cabinet of Ministers, the Interagency Disability Council, and various ministries dedicated to supporting the rights of individuals with disabilities. Additionally, the disability civil society in Uzbekistan is becoming increasingly active. The Association of Disabled People of Uzbekistan, a key player in the nation's efforts to support individuals with disabilities, has been instrumental in driving recent positive changes (UNICEF, 2021). In addition to this leading organization, numerous other non-governmental organizations (NGOs), including Disabled People’s Organizations (DPOs), are actively advancing disability rights in Uzbekistan. In 2017, 613 of these organizations were specifically focused on protecting the rights and interests of people with disabilities, out of a total of 9,205 registered NGOs in the country (NIMFOGO, 2018).

Yet, despite these extensive reforms, institutional changes, and the increased number of disability advocacy organizations, challenges continue across many disability domains, including the reliability of data. Historical practices of concealing or distorting information, combined with inadequate data collection systems and a lack of transparency in reporting, have created substantial data gaps. This study aims to address these issues by analysing the state of disability statistics and examining recent data collection practices to uncover deficiencies and inconsistencies. By providing a clearer understanding of these gaps, the study seeks to evaluate their broader impact on policy development and service delivery. Ultimately, it strives to support the development of more effective, evidence-based policies and programs that better meet the needs of individuals with disabilities, particularly children transitioning into inclusive educational settings.

Methodology

This study employs a theoretical approach to critically examine concerns related to disability statistics, with a particular emphasis on the inclusion of children with disabilities in mainstream educational settings. The analysis is grounded in a comprehensive literature review. Due to the scarcity of academic publications on disability statistics in Uzbekistan, the study relies significantly on reports from national agencies and international development donors. The review encompasses studies, reports, and policy papers published within the last five years to ensure relevance and currency. However, older materials were also utilized in some instances, as they remain pertinent given the slow pace of changes in disability issues within the region.
Information from the selected sources was systematically extracted and organized into key themes, including the current statistical situation of people with disabilities in Uzbekistan, inconsistent data on the number of children with disabilities in mainstream schools, factors affecting the reliability of disability statistics within the education system, and potential solutions to these issues. Following this categorization, a qualitative analysis was conducted to evaluate the reliability of the information and identify key concerns. This analysis involved comparing various sources to determine which were most aligned with the current situation, considering all relevant details. The synthesis of findings integrated insights from multiple sources, providing a thorough overview of disability statistics and educational practices in Uzbekistan.

Discrepancies in disability data and systemic barriers in Uzbekistan: overview

Uzbekistan faces considerable difficulties in accurately determining the overall number of individuals with disabilities, as evidenced by the disparities between official statistics and data from international organizations. In 2019, the State Committee of the Republic of Uzbekistan on Statistics (SCS) reported approximately 693,900 adults and 111,300 children with disabilities (World Bank, 2021). However, the United Nations (2020) presents a vastly different figure, estimating a total of 4.5 million people with disabilities, including 1.15 million severely disabled individuals. This stark inconsistency illustrates the challenges in precisely assessing the prevalence of disabilities in the country.

In response to this challenge, the World Bank (2021) conducted its first 'Listening to the Citizens of Uzbekistan (L2CU)' household survey in 2018. The survey aimed to provide a more comprehensive understanding of disability prevalence and its impact on households. The findings revealed that approximately 13.5% of the population aged 3 and above reported some degree of disability, with 3.5% experiencing severe forms of disability. Moreover, the survey highlighted that 45% of households included at least one member with a disability, while 14%

had a member with a significant disability.

Notably, in 2019, the officially reported percentage of people with disabilities in the country stood at 1.3% of the total population, substantially lagging behind global averages and those of other nations within the region (UNESCAP, 2019). That was the second-lowest rate of disability prevalence in Asia and the Pacific after Brunei Darussalam, where the disability rate is 1,1%. According to the latest statistics from the United Nations Development Programme (UNDP) (2021), Uzbekistan reports that 2.14% of the population are registered as persons with disabilities. However, this figure also remains considerably distant from reality. In comparison, data from the 2023 WHO report suggests a disability prevalence of approximately 16% globally. This figure reveals a significant proportion of individuals facing disabilities worldwide - 1 in 6 of us. This situation is further compounded by the accelerating rates of chronic diseases in low income countries, surpassing those in developed nations due to adverse economic conditions (WHO, 2023; WHO & World Bank, 2011). Thus, it is highly improbable that the proportion of individuals with disabilities in Uzbekistan is confined to merely 1.3% or even 2.14% of the population. The conspicuous difference between administrative data and survey findings on individuals with disabilities can be attributed to various factors discussed below.

Challenges in registration: procedural and legal, social, and financial

Procedural and legal barriers

The medical model of disability, a remnant of Soviet times, continues to be strongly prevalent in Uzbekistan. This model dramatically impacts the procedures for disability recognition and assessment. In Uzbekistan, individuals with disabilities face substantial barriers during the registration process, particularly when dealing with the Medical Consultative Commissions (MCC) and Medical Labor Expert Commissions (MLEC). Achieving recognition as a disabled person, involves a lengthy procedure. To initiate the application process with MLEC for disability status determination, applicants must provide all necessary medical documents, including a referral from a recognized healthcare institution for the initial disability assessment, along with their outpatient medical records. Based on a survey conducted by the United Nations in Uzbekistan, 42% of individuals with disabilities and their guardians/parents found the procedures for obtaining disability status to be complex and demanding (United Nations, 2019). Despite the unlikelihood of improvements in their disabilities over time, both adults and children undergo regular re-evaluations. Nam (2021) notes that even individuals with lifelong conditions such as amputated limbs and Down Syndrome were required to go through annual evaluations.

Recent reforms, such as a November 2021 presidential decree, aimed to improve the effectiveness of medical commissions and streamline the disability assessment framework (Uzbekistan National News Agency, 2021). As per the enacted decree, individuals with explicit indications of disability and anatomical conditions have their disability status conferred indefinitely, irrespective of their direct involvement. However, it is important to acknowledge that individuals with disabilities that are not immediately apparent, such as sensory or neurological disabilities, chronic illnesses and so on, still endure a lengthy assessment process. This reflects a common issue in many low-income countries, where disability statistics are largely limited to impairment-based measures, often identifying only a small portion of the disabled population - primarily those with visible or severe impairments (Eide & Loeb, 2016). In addition to these procedural challenges, the legal framework's narrow definition of disability further complicates the situation. This definition often reduces disability to an incapacity to work due to illness, mirroring the legacy of the Soviet era, where disability was largely determined by an individual's loss of working capacity, and state interventions were focused on restoring employability (UNPRPD, 2022). This perspective emphasizes the capacity to work while neglecting other crucial factors such as social participation and access to education (World Bank, 2021). As a result, the stringent criteria for disability recognition often led to the underreporting of individuals with invisible or non-severe disabilities, causing official statistics to fail to reflect the true extent of disability.

Yusupov and Abdukhalilov (2022) raise similar concerns in their study on barriers to disability-inclusive employment in Uzbekistan. The study reveals that some participants who are deaf were not formally registered as having a disability and were denied disability benefits because they could speak. For example, one participant who developed a hearing impairment in 2005 was initially granted temporary second-degree disability status for two to three years. However, after this period, their disability status was revoked, leaving them without official recognition and support. Although speaking does not compensate for hearing loss, the criteria for benefits have overly focused on specific functional abilities, such as those related to work or daily life. This narrow focus has contributed to the mistaken belief that hearing impairments have minimal impact on employability and overall functioning. This case highlights how such restrictive criteria for disability recognition can not only deny individuals the financial aid they need but also contribute to the distortion of disability data.

Social barriers

The actual number of children with disabilities in Uzbekistan is significantly higher than reported due to under-registration, especially in remote areas. Reports from various years, including those by the Asian Development Bank (2006), Schulze and Kabir (2013), and the World Bank (2021), highlight this issue. Families often avoid registering their children with disabilities at birth to shield them from societal stigma, a common practice across Central Asia. Schulze and Kabir (2013) also point out that traditional beliefs about disability complicate the collection of accurate data, as parents may be reluctant to engage with official registration processes.

This issue is further emphasized by Nam (2021), who observes that many families continue to hide children with disabilities to avoid social stigma. A volunteer from the Society of the Blind, involved in Nam's study, reported finding 20 unregistered children with visual impairments in the Tashkent region alone during a project aimed at uncovering previously unrecorded cases. These children, lacking essential identification documents such as birth certificates and passports, were deprived of access to social services. The volunteer noted that the Society of the Blind had only searched for children with visual impairments, suggesting that the actual number of hidden children would be considerably higher if the search had included those with other types of disabilities.

This concealment is deeply rooted in the cultural context of Central Asia. Katsui (2005) illustrates how cultural prejudices shape family attitudes toward children with disabilities, leading to feelings of shame and guilt. Many parents, facing societal pressure, hide their children with disabilities, which limits their access to education and other opportunities. Additionally, Katsui (2005) notes that in Uzbekistan, families often allocate more resources to their typically developing children rather than to those with disabilities, due to the higher perceived return on investment. This focus on resource distribution further intensifies the marginalization of children with disabilities. Together, these practices distort the true extent of disability and significantly restrict these children’s access to essential services.

Financial barriers

Furthermore, these issues are compounded by financial constraints. The World Bank (2021) points out that the costs associated with the registration process, including transportation to and from medical facilities, impose substantial financial burdens, especially on individuals living in areas with limited access to public transportation. UNPRPD (2022) also notes that individuals with disabilities are often required to undergo four to six months of medical treatment at significant additional costs, including treatment expenses and transportation. When combined with restrictive legal criteria and societal stigma, these financial obstacles contribute to the underrepresentation of people with disabilities in official statistics. Addressing these multifaceted challenges requires comprehensive reforms to ensure accurate disability registration and improve support for individuals with disabilities in Uzbekistan.

Educational data and inclusivity challenges for children with disabilities

Assessing gaps and inconsistencies in disability education data

The situation regarding officially recorded children with disabilities in Uzbekistan reveals substantial gaps and inconsistencies in disability education data. The World Bank (2018) highlights a lack of reliable statistics, sourced from internal agencies, on the causes and types of disabilities, living conditions, and educational achievements of these children. Additionally, while other Central Asian countries provide comprehensive data on prostheses, cash benefits, and school attendance, such detailed information is notably absent from Uzbekistan's data. This dual absence of crucial data sets further aggravates concerns about the overall reliability and validity of the information available. The United Nations (2019) also reports that the data on the education of children with disabilities provided by the State Committee of the Republic of Uzbekistan on Statistics (SCS) is fragmented and fails to present a complete picture.

Moreover, not only is there a lack of comprehensive data, but the existing figures are often unrealistic. In the Education Sector Plan for 2019–2023 (2019), the Uzbek government presented overly optimistic statistics regarding the educational participation of children with disabilities. The report claims that 28,890 children with disabilities are enrolled in general schools, 18,600 are accommodated in specialized educational institutions, and approximately 10,000 are engaged in home-based learning programs. Remarkably, the enrolment of children with disabilities in mainstream educational establishments exceeds that in segregated institutions, a trend that seems improbable when considering practical realities.

This optimistic portrayal contrasts sharply with the underlying issues in Uzbekistan's educational framework. The country's education and disability legislation are heavily influenced by the medical model of disability, which remains entrenched in national policies (United Nations, 2019; UNPRPD, 2022). While the legal-normative framework claims to support education for children with disabilities, it does not effectively prioritize inclusive education. Despite references to inclusive settings, the endorsement of alternative educational modalities- such as specialized schools, boarding facilities, and home-based education- continues to reinforce institutional practices rather than fostering true inclusivity (Nam, 2021). The information on disability and education provided by the Ministry of Health should be interpreted with even more caution. According to the Ministry's records from 2015, 61,600 school-age children with disabilities were purportedly studying in mainstream settings, constituting 56% of the total 110,000 children with disabilities (World Bank, 2018). However, the validity of such a high enrolment figure raises questions, particularly given the absence of sustainable inclusive education practices. Interestingly, a survey conducted by the Ministry of Health in collaboration with the Japan International Cooperation Agency (JICA) just a year prior yielded markedly different results. This survey reported that only 1,600 to 1,700 students, or 5.4% of children with disabilities, were enrolled in general schools (JICA & Ministry of Health of the Republic of Uzbekistan, 2014). This disparity may be ascribed to the utilization of more reliable and internationally comparable standards for measuring disability-inclusive education by the JICA. The Ministry of Health's explanation, if any, for the rapid escalation from 5.4% to 56% within a brief timeframe remains undisclosed.

Furthermore, there is a scarcity of statistical data concerning the population of out-of-school children with disabilities, a matter of major concern for the global community. According to Sankar (2019), in Uzbekistan, 26% of primary school-aged children with disabilities and 25% of secondary school-aged children with disabilities are not enrolled in any educational institution. Nevertheless, governmental sources tend to disregard these children, even in light of Resolution #256 of the Cabinet of Ministers of the Republic of Uzbekistan, issued on 13 September 2011. This resolution delineates a group of children considered ineligible for admission to educational facilities, including specialized ones, due to the degree of their disabilities. This group includes individuals with conditions such as deafblindness, severe intellectual disabilities, severe mobility impairments, behavioral disturbances, frequent seizures, or neurological urinary and faecal incontinence (Uzbekistan Government, 2011). These children are directed to a 'Muruvvat' (a 'Mercy House'), overseen by the Ministry of Public Health. Together with the unregistered children mentioned previously, this cohort represents a significant proportion of all children with disabilities who are not receiving formal education.

An inconsistency also emerges regarding the number of general schools accommodating students with disabilities aged 6-16. As per the Concept of Development of Inclusive Education for 2020-2025, 13,000 students with disabilities are reportedly enrolled in 3,200 general schools nationwide (Uzbekistan Government, 2020). Conversely, the Education Sector Plan for 2019-2023 (2019: 52) suggests that 'only 60.7% of schools currently include SEN children'. Given that there were reportedly 10,090 general schools across the country at the start of the 2019-2020 academic year (Kun.uz, 2023), 'only' 60.7% would equate to approximately 6,126 schools. However, in 2022, according to Egamberdieva, the UNICEF Communication Officer, the number of general schools enrolling children with disabilities was dramatically lower, totalling 225.

Both the Concept of Development of Inclusive Education for 2020-2025 and the Education Sector Plan for 2019-2023 serve as fundamental frameworks for guiding educational reforms and initiatives in Uzbekistan. They outline specific goals, objectives, and strategies aimed at promoting inclusive education and ensuring equal opportunities for all students, including those with disabilities. However, discrepancies in the data presented within these documents raise concerns about the validity of the information used to inform policy decisions. Therefore, while numerous instances of questionable data exist, it is crucial to examine the root causes behind these issues to ensure that policymaking is based on accurate information.

Factors affecting the reliability of disability statistics in education

The World Bank (2018) sought to uncover the factors contributing to the questionable nature of education data in Uzbekistan, with a focus on data on children with disabilities. One of the primary reasons identified is the lack of coordination among agencies tasked with data collection. There are seven agencies responsible for gathering education data. Working in collaboration with the SCS, these agencies determine the specific data to be collected. Additionally, the SCS gathers data from educational institutions and conducts household surveys. While the collected data appears comprehensive, the issue arises from the fact that each agency collects information independently, resulting in duplication (State Committee of the Republic of Uzbekistan on Statistics & World Bank, 2019). Moreover, the use of varying methodologies during data collection further compounds the problem, leading to a lack of comparability and restricted applicability of the data obtained.

The World Bank (2018) further highlights that key indicators used to assess educational efficiencies, such as dropout and completion rates, are not utilized in Uzbekistan. These indicators are crucial for evaluating educational attainment among students with disabilities. Even if some students with disabilities are enrolled in general schools, their academic progress and graduation rates are not systematically monitored. In line with this, UNESCO (2018) emphasizes the significance of completion rates, disaggregated by both disability and gender, as children with disabilities are less likely to complete primary education compared to their non-disabled peers. For example, in five countries - Cambodia, Colombia, Gambia, Maldives, and Uganda - the completion rate for primary and lower secondary education was 73% for children without disabilities, contrasting with only 56% for children with disabilities. However, similar information for Uzbekistan, as observed earlier, is unavailable.

Another factor contributing to the poor quality of education-related data is the legacy of central planning and control, inherited from the Soviet Union era. During that time, all major decisions, including data collection and utilization, were exclusively the responsibility of the central government, with Uzbekistan and other republics subordinate to officials in Moscow. As noted by the World Bank (2018: 96), ‘Uzbekistan’s education system lacks a data culture explained by the legacy of heavily controlled managerial practices, which also led to challenges with evidence-based decision-making processes’. Even after the disintegration of the Soviet Union, remnants of this centralized control persist, hindering the development of a more flexible and responsive education system.

Additionally, a practice inherited from the Soviet era involves the intentional concealment or distortion of disability-related information by authorities. As highlighted by Phillips (2009), the Soviet government historically sought to hide both individuals with disabilities and any pertinent information to maintain the image of a welfare state where all citizens were portrayed as healthy. Narolskaya (2013) also discusses this phenomenon in the context of Uzbekistan, suggesting that state agencies are reluctant to release accurate data due to concerns about potential repercussions that could undermine the country's prestige on both national and international levels. While there is a gradual shift in attitude toward people with disabilities, evidenced by the development of supportive legislation, the influence of the Soviet legacy remains pronounced in the country. This dichotomy, combined with the challenge of obtaining reliable disability statistics, highlights the complex evolution of societal attitudes and governmental approaches, particularly concerning children with disabilities.

Recommendations

Conducting a comprehensive census with the Washington Group Short Set of Questions

To bridge the gap in disability data collection, Uzbekistan should prioritize the inclusion of people with disabilities in all future population censuses. The last national census was conducted in 1989 (Scott & Mete, 2008), despite the global norm of conducting censuses every ten years (UNICEF, 2014). This irregularity is likely due to financial and human resource constraints. Recognizing the need for accurate population statistics, the President issued a Decree in February 2019, outlining the 2022 population census and highlighting the significance of reliable data for the effective implementation of social protection policies (Uzbekistan Government, 2019).

However, the State Committee on Statistics announced in 2020 that people with disabilities would be excluded from the census due to a lack of understanding on how to integrate disability data (Gazeta.uz, 2020). While integrating data on individuals with disabilities into national statistics is challenging, it is not insurmountable. With proper training and the adoption of internationally recognized methodologies, data collection can be successfully conducted. The Washington Group Short Set of Questions on Functioning, recommended by the UN, is one such tool that can enable the accurate identification of individuals with disabilities, ensuring that their social participation and barriers are effectively captured (Madans, et al., 2011). This tool aligns with the International Classification of Functioning, Disability and Health (ICF) framework, which provides a robust foundation for understanding and measuring disability.

The previously discussed survey, ‘Listening to the Citizens of Uzbekistan (L2CU)’, conducted by the World Bank in 2018, utilized this specific set of questions (World Bank, 2021). As a result, the survey produced significantly more accurate findings. By adopting a rights-based approach and integrating these methodologies, the Uzbek government can re-examine its policies, ensuring that people with disabilities are better represented and more actively included in social and economic life.

Enhancing Education Management Information System (EMIS)

Ensuring the comparability of data on disability, education, and related areas, both nationally and internationally, is crucial. This requires compiling and standardizing information obtained through data-collection instruments (UNESCO, 2018). To address the challenge of non-comparable education data, international donors introduced a unified EMIS to relevant ministries (State Committee of the Republic of Uzbekistan on Statistics & World Bank, 2019).

The aim was to facilitate digital data collection, integration, processing, and dissemination, providing education leaders with comprehensive and timely datasets. Initially, the implementation of the EMIS faced challenges such as high software adaptation costs and personnel training (World Bank, 2018). However, a few years later, the EMIS has been integrated into several agencies and currently collects data on students at the preschool, primary, and secondary education levels, including details on disabilities and functional challenges (UNICEF, 2023). Yet, certain crucial pieces of information remain unaddressed within the current EMIS framework.

In preschool education, the EMIS focuses on key metrics such as enrolment, attendance, absences, and the identification of students requiring special education interventions. However, these essential educational metrics are absent from the EMIS at the primary and secondary education levels. This absence of data can have several significant impacts. Without accurate enrolment data, education authorities may struggle to effectively allocate resources such as teachers, classrooms, and educational materials to meet students' needs. Additionally, the lack of data on attendance and absences makes it challenging to identify and address issues related to student retention. This is particularly critical in the context of disability, where high absenteeism rates may indicate underlying issues such as accessibility barriers, health-related challenges, socio-economic factors, and unmet educational support needs. Without such data, it becomes difficult to implement targeted interventions to improve attendance and reduce dropout rates for students with disabilities. Moreover, the absence of data on students requiring special education services hampers the provision of necessary support and accommodations, potentially leading to academic underachievement. To address these issues and ensure equitable access to quality education, it is recommended that the EMIS be enhanced to include comprehensive educational metrics across all levels. This integration is crucial for providing a complete and accurate picture of the education system.

Another significant issue is that formal EMIS training is currently available only for primary and secondary education, leaving a critical gap at the preschool level. This training covers crucial areas such as data needs assessment, collection, processing, analysis, and dissemination (UNICEF, 2023). The lack of equivalent training for preschool education risks reducing capacity and expertise in preschool settings, potentially resulting in inconsistencies in data collection and management. Such inconsistencies can undermine effective educational planning and policymaking, as reliable data is essential for evaluating early student needs and progress. To rectify this situation, it is vital to extend formal EMIS training to encompass preschool education. By doing so, we would build essential capacity, ensure consistency and reliability in data management, and support a smoother transition for students throughout the education system.

Additionally, while the budget for EMIS operations is specifically allocated to Ministries and government agencies for primary and secondary education, organizations involved in preschool education often rely on non-earmarked funds (UNICEF, 2023). This dependency can lead to underfunding or inefficient resource use, compromising the quality and consistency of EMIS data at the preschool level. To tackle this challenge, it is recommended that a dedicated budget for EMIS operations in pre-primary education be established. Allocating specific funds for this purpose would ensure that adequate resources are available for high-quality data collection and management. A designated budget would also support the development of tailored data systems that meet the unique needs of preschool education, enhance staff training, and facilitate the regular maintenance and upgrading of the EMIS infrastructure.

Improving gender-disaggregated data collection

Disaggregating data by various categories such as types of disabilities, age, gender, socioeconomic status, and geographic location is crucial for comprehensively understanding and tackling disparities within the education system. In alignment with the 2030 Agenda for Sustainable Development, effectively addressing discrimination and inequalities requires prioritizing the gathering and utilization of accurate and comprehensive data, disaggregated across various dimensions (United Nations, 2015). This approach allows policymakers, donors, community leaders, and beneficiaries to gain a comprehensive understanding of their challenges and opportunities, leading to more informed decision-making and equitable resource allocation. As a result, tailored and effective interventions can be developed, promoting fair outcomes for all community members across various aspects.

Gender-disaggregated data, emphasized by UNICEF (2020a), holds particular significance in the context of Uzbekistan. Many children with disabilities, particularly girls, often face marginalization within the education system due to deeply ingrained gender stereotypes prevalent in Uzbek society. This issue is widespread in low income countries, where 9 out of 10 children with disabilities are excluded from formal education, with the majority being girls (United Nations Girls’ Education Initiative, 2021). Consequently, the adult literacy rate among individuals with disabilities stands at only 3%, with women experiencing an even lower rate of just 1%. Gender-disaggregated data available in Uzbekistan is quite superficial (UNPRPD, 2022). The current EMIS collects basic demographic information, including gender, across all educational levels from preschool to secondary (UNICEF, 2023). However, it fails to capture crucial data on girls' academic achievements, the types of support they may need, or their retention rates. Filling these gaps in data collection is crucial for ensuring that the specific needs of girls are met effectively.

To confront these challenges effectively in Uzbekistan, it is essential to emphasise the collection and analysis of gender-disaggregated data, with a particular focus on the educational challenges faced by girls with disabilities. Given the high dropout rates among girls, especially in rural areas (European Training Foundation, 2023), it is crucial to gather comprehensive data on their learning outcomes, necessary resources, and retention rates. This detailed data collection will enable the development of targeted interventions that address both gender and disability-related barriers. By improving data on these aspects, Uzbekistan can better tackle societal stigmatization and work toward dismantling systemic inequalities, ensuring that all children, regardless of gender or disability, have equitable access to quality education and future opportunities.

Engaging people with disabilities and their organizations in data collection

Integrating individuals with disabilities and their organizations into data collection initiatives is essential but often overlooked in Uzbekistan. Despite recent reforms aimed at empowering NGOs and strengthening partnerships with state bodies (United Nations, 2022), policymakers frequently undervalue the insights and recommendations from people with disabilities and their organizations (Nam, 2021). This oversight is particularly concerning, as such participation is fundamental to a democratic society and is supported by human rights law and international agreements (McVeigh et al., 2021).

To address this gap, it is crucial to significantly enhance the involvement of individuals with disabilities and their organizations in data collection initiatives. Their perspectives should be integrated from the initial design phase to establish a well-informed and representative process. This involvement must extend throughout every stage of data collection to ensure effectiveness and accuracy (UNICEF, 2020b). Community-led initiatives, where individuals with disabilities actively gather data, are particularly effective in fostering trust, ownership, and cultural sensitivity, making the data collection process both inclusive and contextually relevant.

Special attention should be given to the role of individuals with disabilities in data analysis and interpretation. Including their perspectives at these stages improves the accuracy and relevance of the findings. Engaging them from the design phase through to analysis benefits the data collection process and helps foster commitment and buy-in from both individuals with disabilities and their representative organizations. This inclusive approach addresses the historical exclusion of people with disabilities from research and leads to more nuanced policies and interventions.

Strengthening governmental capacities and legal reforms for inclusive disability data

In Uzbekistan, authorities have made notable progress by partnering with international donors to enhance the reliability of disability statistics. Nevertheless, the enduring effects of the centralization system and the historical denial of the existence of disabled individuals-mechanisms inherited from state socialism that perpetuate injustice (Mladenov, 2017)-continue to pose significant challenges. Furthermore, a lack of knowledge and experience in managing disability statistics impedes further progress. To ensure a comprehensive and transparent approach to disability data, it is crucial to strengthen the capacities of relevant governmental agencies and implement legislative reforms.

Improving the management of disability data in Uzbekistan requires enhancing the skills and knowledge of local state bodies. This involves providing comprehensive training for officials and researchers in modern statistical methods and advanced data management and analysis tools. Such training should align with international standards, including those established by the Washington Group on Disability Statistics and the UN Convention on the Rights of Persons with Disabilities (CRPD). Additionally, developing inclusive research methodologies is essential to ensure that data collection instruments are accessible to individuals with a diverse range of disabilities. According to UNICEF (2020b), these inclusive practices are crucial for eliminating discrimination and advancing global efforts towards inclusive programming. Engaging DPOs in the data collection process will also ensure that the insights and needs of individuals with disabilities are accurately reflected.

Equally important are legislative reforms mandating the collection and publication of comprehensive disability statistics, which should be central in ensuring data accuracy and transparency. Such reforms should establish standardized protocols for data collection, requiring all relevant institutions to adhere to uniform methods. These protocols must include clear definitions of disability that align with international standards, ensuring consistency in data collection across different regions and sectors. To enforce these guidelines, the legislation should create an independent oversight body responsible for monitoring compliance and conducting regular audits of data collection practices. This body should have the authority to impose penalties for non-compliance while also offering support and training to institutions facing challenges in meeting the standards. Additionally, the reforms should mandate that disability statistics be made publicly accessible, with regular updates published transparently. This approach will promote accountability and enable policymakers, researchers, and advocacy groups to use the data effectively to drive informed decision-making.

Combating social stigma and underreporting

A contributing factor to the underreporting of global disability statistics is the prevalence of negative cultural attitudes and prejudice (Loeb, 2013). As highlighted earlier, Uzbekistan mirrors this trend, where many families conceal children born with disabilities to avoid societal stigma, exacerbating underreporting. To tackle this issue, a comprehensive approach is required, starting with public awareness campaigns aimed at transforming negative cultural perceptions by promoting the inclusion and rights of individuals with disabilities. Utilizing diverse platforms such as local media, social media, and community outreach can help disseminate information and foster positive attitudes. Tailoring messages to various demographic groups and involving respected community leaders, religious figures, and influencers can enhance the impact of these efforts.

Direct engagement programs are another crucial strategy. These should facilitate open dialogues between families and disability professionals to address misconceptions and provide evidence-based information. Establishing support groups for families of children with disabilities is also essential. These groups can create networks for sharing experiences and emotional support, with peer mentoring offering personalized guidance to help new families manage disability stigma. Research indicates that such peer support can effectively reduce stigma and promote social inclusion (Smythe et al., 2020).

In addition, educational workshops play a vital role in confronting cultural beliefs and providing practical guidance. These workshops should focus on registration processes, clarify the benefits of registration, and explain disability rights. Complementing these workshops, counseling services are essential for managing cultural pressures and supporting informed decision-making about registration and accessing services. Together, these strategies create a comprehensive support system that empowers families and promotes greater inclusion and understanding.

Furthermore, promoting inclusive practices within local schools, healthcare facilities, and community centers can significantly enhance the effectiveness of these initiatives. Schools should adopt policies that value diversity and ensure equal access to education for all children, regardless of disability. Expanding community outreach to remote areas will ensure that even isolated families receive the necessary resources and support. By integrating awareness, education, emotional support, and inclusive practices into a comprehensive support system, Uzbekistan can substantially reduce underreporting and improve outcomes for children with disabilities**.**

Conclusion

These recommendations can only be realized if the Uzbek government, as a UN Member State, demonstrates strong political will to identify people with disabilities and equalize opportunities for them, which will ultimately be reflected in tangible policy changes. Given that Uzbekistan has recently initiated disability-inclusive development reforms in education and other spheres, it is imperative to recognize that their success hinges on the availability of reliable disability statistics. Comprehensive data will influence policies in several ways. For instance, by identifying children with disabilities who are at risk of social and educational exclusion, we can develop early intervention strategies to prevent them from dropping out of school. This approach will enable these children to access education and achieve greater success throughout their lives (Loeb, 2013). As Lamia Gurdleneck, an anagram of the renowned British statistician Maurice Kendall, once aptly stated, ‘It’s not the figures, but what you do with them that matters’ (Kendall and Stuart, 1967, cited in Fujiura et al., 2005: 299).

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