



## Empowering Lives: Navigating the Landscape of Down Syndrome Support in Saudi Arabia

Shahida Parveen<sup>1</sup>, Ajaz Ahmad<sup>2,\*</sup> and Aijaz Ahmad Reshi<sup>3,\*</sup>

<sup>1</sup>Department of Nursing, College of Pharmacy and Applied Medical Sciences, Dar Al Uloom University, Riyadh, Saudi Arabia

<sup>2</sup>Department of Clinical Pharmacy, College of Pharmacy, King Saud University, Riyadh 11451, Saudi Arabia

<sup>3</sup>Department of Computer Science, College of Computer Science and Engineering, Taibah University, Al Madinah Al Munawarah, Saudi Arabia

Correspondence to:

Ajaz Ahmad\*, e-mail: [ajukash@gmail.com](mailto:ajukash@gmail.com), Tel.: +966-11-4670765

Aijaz Ahmad Reshi\*, e-mail: [ajazonnet@gmail.com](mailto:ajazonnet@gmail.com), Tel.: +966-14-861888

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### ABSTRACT

This study offers an in-depth analysis of Down syndrome (DS) in Saudi Arabia, encompassing healthcare, societal integration, and policy frameworks. It assesses DS prevalence within the Saudi population against global rates and underscores the progress in prenatal diagnostics and screening for early detection. The significance of neonatal care and early intervention programs in the comprehensive development of children with DS is highlighted. The paper explores societal perceptions and efforts to increase public awareness and reduce stigma, with a particular focus on media and educational initiatives. It reviews the educational landscape for individuals with DS, touching on inclusive policies and specialized programs, and evaluates the effectiveness and obstacles of these approaches. The study also compares Saudi policies and legal protections for individuals with DS to international standards, illustrating the country's advancements toward global norms. It examines support systems, including contributions from nonprofits, community programs, and family services, and concludes with an identification of ongoing challenges and recommendations for future enhancements. This comprehensive overview underlines the importance of a multifaceted approach to supporting individuals with DS in Saudi Arabia, aiming to enhance their quality of life and ensure their full integration into society.

### KEYWORDS

Down syndrome, Saudi Arabia, inclusive education, healthcare policy, societal integration

## INTRODUCTION

Down syndrome (DS), medically termed as trisomy 21, represents a chromosomal condition resulting from the presence of an entire or partial extra copy of chromosome 21 (Roizen and Patterson, 2003; Antonarakis et al., 2020). This genetic anomaly, one of the most prevalent chromosomal disorders, manifests in approximately 1 in every 700 to 1000 births worldwide (Queremel Milani and Tadi, 2024). The condition was first documented by the British physician John Langdon Down in 1866, and the chromosomal nature of the disorder was identified in 1959 by the French geneticist Jérôme Lejeune (Megarbane et al., 2009). Individuals with DS typically exhibit a range of physical and cognitive characteristics (Martin et al., 2009). These may include distinct facial features, such as a flat facial profile and an upward slant to the eyes, and varying degrees of intellectual disability (Bull, 2011). The condition also predisposes individuals to a variety of health issues, including heart defects, respiratory and hearing problems, and a higher risk of certain diseases like

leukemia and thyroid conditions (Chistiakov et al., 2013; Tariq and Bora, 2024). Additionally, there is an increased likelihood of developing Alzheimer's disease later in life (Salehi et al., 2016; Head and Ances, 2020). The severity of these health issues and the intellectual disability can vary significantly among individuals with DS (Bhattacharyya et al., 2010). Modern healthcare and early intervention programs have been instrumental in improving the quality of life and life expectancy of individuals with DS (Hendrix et al., 2021; Ijezie et al., 2023). With proper medical care, educational support, and social inclusion, many individuals with DS live into their 60s and beyond (Hendrix et al., 2021; Ijezie et al., 2023).

Understanding DS within the Saudi Arabian context is imperative due to the unique interplay of cultural, religious, and social dynamics in the region (Al-Aoufi et al., 2012). These factors significantly influence societal attitudes, healthcare provisions, and the overall quality of life for individuals with DS. In Saudi Arabian culture, the prevailing religious

beliefs and practices significantly shape societal perceptions of disabilities (Al-Aoufi et al., 2012). Islam, which emphasizes compassion and care for the vulnerable, may foster supportive environments for individuals with DS (Bentley et al., 2021). However, societal stigmas and misconceptions surrounding disabilities might still pose challenges in terms of social acceptance and integration (Barbareschi et al., 2021). The Saudi healthcare system, which has experienced substantial advancements in recent years, plays a critical role in the early detection, intervention, and ongoing management of DS (Alasiri and Mohammed, 2022). This encompasses prenatal screening, neonatal care, and specialized services catering to the health needs of those with DS (Gosadi, 2019). Understanding how these healthcare services are accessed and utilized by families affected by DS is crucial in assessing the effectiveness of the healthcare system in addressing this condition (van den Driessen Mareeuw et al., 2020). Education and societal integration are other vital aspects (Kroh and Prechsl, 2023). The approach toward education for children with DS in Saudi Arabia, whether through inclusive education systems or specialized programs, greatly influences their developmental outcomes and integration into society (Alabri, 2023). It is essential to explore the educational opportunities, challenges, and resources available to these individuals. Moreover, policies and support services in Saudi Arabia concerning disabilities have a direct impact on the lives of individuals with DS (Alabri, 2023). Assessing these policies and the extent of support services available offers insights into the level of assistance and protection provided to them and their families. Finally, localized research and awareness campaigns in Saudi Arabia are key to tailoring healthcare strategies, educational programs, and support systems for individuals with DS (Abu-Alghayth, 2022). Such initiatives not only improve care and support but also contribute to a more inclusive society that embraces diversity and ensures equal opportunities for all its members. Understanding DS in the Saudi Arabian context is, therefore, not just about healthcare and education; it is about enriching the fabric of the community and enhancing the lives of all its members (Abu-Alghayth, 2022). The rationale for this study on the status of DS in Saudi Arabia stems from the need to understand and address the unique manifestations and challenges of this condition within the specific cultural and national context of the country. DS, a globally prevalent genetic disorder, exhibits varying characteristics and impacts across different cultures and regions (Antonarakis et al., 2020). Saudi Arabia, with its distinct cultural, religious, and social dynamics, presents a unique environment that significantly influences the experiences of individuals with DS and their families (Alabri, 2023). By focusing on this particular setting, the study aims to uncover the specific needs, challenges, and opportunities that exist for individuals with DS in Saudi Arabia. It seeks to evaluate the effectiveness of current healthcare approaches, from prenatal diagnosis to long-term care, and assesses how societal attitudes and awareness affect the lives of those with DS. Moreover, the study examines the educational landscape, scrutinizing the implementation and efficacy of inclusive education policies and special education programs. The investigation into the policy and legal frameworks provides insights into the country's commitment to the rights and welfare of individuals with DS. The study also highlights the role of support systems,

community engagement, and family support in enhancing the quality of life for those with DS. Understanding these aspects is crucial for developing targeted interventions, informing policy decisions, and fostering a more inclusive and supportive environment for individuals with DS in Saudi Arabia. This study, therefore, serves not only as an analysis of the current situation but also as a roadmap for future improvements and strategies to ensure that individuals with DS receive the support and opportunities they deserve.

## Search strategy

The search strategy employed for this review on DS in Saudi Arabia was comprehensive and multifaceted, designed to capture a broad spectrum of relevant information across various domains. It involved an extensive review of academic literature, including peer-reviewed journal articles, medical research studies, and health reports, specifically focusing on the prevalence, healthcare approaches, and educational strategies related to DS in the Saudi context.

## Prevalence

The prevalence of DS in Saudi Arabia, as in many parts of the world, is a subject of ongoing study and interest due to its implications for healthcare, social services, and public policy. Understanding the incidence rates in Saudi Arabia and comparing them with global trends is crucial for developing targeted health interventions, support systems, and inclusive policies. The exact prevalence rate of DS in Saudi Arabia is challenging to pinpoint due to varying factors such as geographical region, genetic influences, and reporting methodologies. However, several studies have attempted to shed light on this. For instance, a study indicated that DS occurs in approximately 1.8 in every 1000 live births in Saudi Arabia. This rate can fluctuate based on specific regions and populations within the country (Niazi et al., 1995). It is also important to consider the impact of prenatal screening and diagnostic practices on these incidence rates (Boys et al., 2008). With advancements in prenatal care and the availability of genetic testing, many cases of DS may be identified early in pregnancy. This can affect the live birth prevalence of the condition (Rudolf et al., 2017). Additionally, factors such as the high rate of consanguineous marriages (marriages between blood relatives) in Saudi Arabia could influence the incidence of genetic conditions like DS (El Mouzan et al., 2008; Khayat et al., 2024). Research into the genetic and environmental factors contributing to the prevalence of DS in the Saudi population is essential for a comprehensive understanding of the condition within the country (Morris, 2008; AlSalloum et al., 2015).

## COMPARISON WITH GLOBAL PREVALENCE RATES

The occurrence of DS in Saudi Arabia, estimated at 1 in every 554 live births, is notably less frequent compared to

global figures. Nonetheless, the population of individuals diagnosed with DS within the kingdom is on an upward trend, influenced by a decline in mortality rates (Niazi et al., 1995). Globally, the prevalence of DS varies but is estimated at about 1 in every 700 to 1000 live births (CDC, 2023). This rate is influenced by various factors, including maternal age, healthcare access, and prenatal screening practices. For instance, in countries with widespread access to prenatal screening and diagnostic tests, the reported prevalence of DS at birth might be lower due to the higher rates of pregnancy termination following a diagnosis (Rudolf et al., 2017). Comparatively, Saudi Arabia's reported incidence rate appears to be within the global range, though specific factors unique to the Saudi population may influence these numbers (Niazi et al., 1995; Eltyeb et al., 2023). For instance, the younger average maternal age in Saudi Arabia might initially suggest a lower incidence rate, as the likelihood of having a child with DS increases with maternal age (AlSalloum et al., 2015). However, this could be counterbalanced by factors such as consanguinity and variations in prenatal screening practices. Studies highlight challenges faced by families, including exclusion and difficulty accessing services, and a prominent feature of obesity among Saudi children with DS, emphasizing the need for societal support and improved awareness. Overall, these findings emphasize the need for tailored health monitoring, educational initiatives, and supportive measures for individuals with DS and their families (Niazi et al., 1995; Al Husain, 2003; Samarkandy et al., 2012; Binjahlan et al., 2017; Sijeeni and Barnard, 2018).

## Healthcare approaches

In Saudi Arabia, the healthcare approach for DS encompasses various stages of care, each crucial for ensuring the well-being and development of individuals with this condition (AlSalloum et al., 2015; Alwhaibi et al., 2022). From prenatal diagnosis to long-term support, the healthcare system plays a vital role in managing DS (Hasina and Wang, 2022). Prenatal diagnosis and screening are essential in the early detection of DS, involving noninvasive tests like blood tests and ultrasounds during the first and second trimesters to assess the risk. These may include measuring blood hormones, proteins, and an ultrasound for nuchal translucency, followed by the quadruple test (Hasina and Wang, 2022). High-risk pregnancies may require more definitive diagnostic tests such as amniocentesis or chorionic villus sampling (CVS) to analyze fetal chromosomes for chromosomal abnormalities characteristic of DS. In Saudi Arabia, awareness and availability of these prenatal services are increasing (Alfirevic et al., 2017; Hasina and Wang, 2022). Additionally, the emerging integration of artificial intelligence (AI) in the diagnosis and management of DS promises significant advancements (Koul et al., 2023). AI can analyze genetic data and facial features with high accuracy, potentially enabling noninvasive, early detection, and personalized treatment plans. By identifying patterns and correlations in extensive datasets, AI technologies improve diagnostic techniques and enhance the understanding of DS complexities (Koul et al., 2023). However, the extent to which they are

utilized can vary across different regions and communities, influenced by factors like cultural beliefs and socioeconomic status (Gosadi, 2019). Following birth, immediate neonatal care becomes paramount, especially considering that children with DS may face health complications such as heart defects or respiratory issues (Seither et al., 2021). Hospitals in Saudi Arabia typically provide specialized neonatal care involving multidisciplinary teams to cater to these diverse health needs. Alongside this, early intervention programs are initiated to address developmental needs (Almalki et al., 2023). These programs, which might include services like physical therapy, speech therapy, and special education, are crucial in laying the foundation for the child's future development. The recognition of the importance of these early intervention services is increasing in Saudi Arabia, though the availability and quality can vary (Almalki et al., 2023).

Long-term healthcare support and services form the backbone of care for individuals with DS in Saudi Arabia. This involves regular health checkups to monitor and manage the myriad of health issues associated with DS, including cardiac conditions, hearing and vision problems, and thyroid dysfunctions. However, healthcare extends beyond physical well-being (Alhaddad et al., 2023). Educational support is essential to aid cognitive development and skill acquisition, while social support, including community integration and recreational activities, is vital for emotional and social well-being. Furthermore, supporting the families of individuals with DS is an integral part of this long-term care approach. This support encompasses counseling services, providing educational resources about DS, and facilitating support groups where families can share experiences (Ijezie et al., 2023). As individuals with DS transition into adulthood, the focus shifts to maintaining health and fostering independence. This transition from pediatric to adult healthcare services is crucial and involves continued health monitoring and support systems to ensure a high quality of life (Bray et al., 2022; Peters et al., 2022).

## Social attitudes and awareness

In Saudi Arabia, societal attitudes and awareness about DS play a crucial role in shaping the lives of individuals with this condition. The public perception of DS is a complex mix influenced by cultural, religious, and educational factors. Traditionally, there may be a lack of understanding or misconceptions about DS, leading to stigma and social isolation for individuals with the condition and their families. However, this scenario is gradually changing as awareness grows and efforts to educate the public increase. Efforts to raise awareness and reduce stigma around DS have become more pronounced in recent years (Hendrix et al., 2021). These efforts are multifaceted, involving government initiatives, nonprofit organizations, and advocacy groups. Educational programs aimed at dispelling myths and providing accurate information about DS are crucial in this regard (Hendrix et al., 2021). These programs often focus on highlighting the abilities and potential of individuals with DS rather than just their limitations. By promoting a more inclusive view, they help to break down barriers and foster a supportive environment (Clement et al., 2013; Hendrix et al., 2021).

The role of media and educational campaigns in changing societal attitudes cannot be overstated. The media has a powerful influence in shaping public opinion and can be a potent tool in raising awareness about DS (Clement et al., 2013). Television programs, social media campaigns, and news articles that positively portray individuals with DS or highlight their achievements can have a significant impact on public perceptions. These media efforts, combined with educational campaigns in schools and communities, help in creating a more informed and accepting society (Clement et al., 2013). In schools, incorporating information about DS and other disabilities into the curriculum can be an effective way of educating the younger generation. This approach not only increases knowledge but also promotes empathy and inclusivity from a young age. Community-based awareness programs, including workshops and public events, further extend this education to the wider society (Hayes and Bulat, 2017). Another critical aspect of these awareness efforts is the involvement of individuals with DS and their families. Their firsthand experiences and stories are powerful tools in challenging stereotypes and showing the reality of living with DS. By giving them a platform to share their experiences, it not only empowers them but also provides the public with a more personal and relatable understanding of the condition (Alsem et al., 2014).

## EDUCATIONAL OPPORTUNITIES

Educational opportunities for individuals with DS in Saudi Arabia have seen significant developments, reflecting a growing recognition of the importance of inclusive education and specialized support (Alabri, 2023). The landscape of educational options for children with DS ranges from inclusive policies to dedicated special education programs, each playing a pivotal role in their development and integration into society (Alabri, 2023). Inclusive education policies in Saudi Arabia are designed to integrate children with DS into mainstream classrooms, where they can learn alongside their peers (Alhumaid et al., 2023). This approach is based on the understanding that inclusion benefits all students, not just those with disabilities. It fosters a sense of belonging and teaches empathy and diversity from a young age. Implementing these policies, however, comes with its own set of challenges, such as ensuring adequate training for teachers, adapting curricula to meet diverse needs, and providing the necessary classroom support. Despite these challenges, inclusive education remains a key goal and is increasingly being adopted in schools across the country (Alhumaid et al., 2023).

Parallel to inclusive education are special education programs specifically tailored to meet the unique needs of children with DS (Hunt, 2020). These programs often offer a more individualized educational approach, with curricula and teaching methods adapted to address the specific learning styles and capabilities of these students. Resources in special education programs can include speech therapy, occupational therapy, and physical therapy, all integral to the holistic development of a child with DS. Specialized schools and classrooms equipped with trained staff and appropriate

resources are essential in providing this level of support (Hunt, 2020). Success stories in both inclusive and special education settings are not uncommon in Saudi Arabia. There are instances of students with DS achieving significant milestones, excelling in certain subjects, or even participating in mainstream extracurricular activities. These successes highlight the potential of these individuals when given the appropriate support and opportunities (Daunhauer et al., 2014; Ijezie et al., 2023). However, the journey is not without its challenges. Inclusive education, while beneficial, requires a systemic shift in attitudes, resources, and training, which can be a gradual process. On the other hand, while special education programs provide necessary tailored support, they can also inadvertently lead to segregation or limited social interaction with peers without disabilities.

## POLICY AND LEGAL FRAMEWORK

The policy and legal framework in Saudi Arabia regarding individuals with DS reflect the country's growing commitment to the rights and well-being of people with disabilities (APD, n.d.). This framework is an essential aspect of providing support and ensuring equality for individuals with DS, encompassing government policies, legal rights, and protections. Government policies in Saudi Arabia have increasingly focused on supporting individuals with disabilities, including DS. These policies are aimed at ensuring access to healthcare, education, and social services. Key among these is the commitment to the principles of inclusivity in education and the workplace, recognizing the right of individuals with DS to learn and work in mainstream settings wherever possible. Additionally, there are specific healthcare policies aimed at providing comprehensive and accessible medical care for those with DS, covering everything from early intervention programs to ongoing health management (APD, n.d.).

Legal rights and protections for individuals with DS are enshrined in various Saudi laws and regulations. These legal frameworks are designed to safeguard the rights of people with disabilities, ensuring they are protected from discrimination and have equal opportunities in society (APD, n.d.). This includes the right to education, employment, and access to public spaces and services. The government has also ratified international conventions, such as the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which further reinforces its commitment to upholding the rights of individuals with DS. When comparing Saudi Arabia's policies and legal frameworks with international standards and practices, it is evident that the country is making strides in aligning with global norms. Many of its policies reflect a growing awareness and adoption of international best practices regarding the rights and support for individuals with disabilities. This includes efforts to integrate people with DS into mainstream society, provide specialized support where needed, and ensure their rights and dignity are respected (AlSalloum et al., 2015). However, as with any policy and legal framework, the effectiveness of these measures often comes down to implementation. While Saudi Arabia has established a solid foundation of policies

and laws, the challenge often lies in ensuring these are consistently applied and that resources are allocated appropriately to meet the needs of individuals with DS. This includes training for educators and healthcare professionals, public awareness campaigns to reduce stigma, and ensuring that legal protections are enforced (AlSalloum et al., 2015).

## SUPPORT SYSTEMS AND COMMUNITY ENGAGEMENT

In Saudi Arabia, the support systems and community engagement for individuals with DS play a crucial role in enhancing their quality of life (Asiri et al., 2023). Nonprofit organizations and support groups are at the forefront of this effort, providing resources, advocacy, and direct assistance to individuals and their families. These organizations often offer a range of services, including educational workshops, therapy sessions, and social activities, which are essential for the development and well-being of individuals with DS. They also serve as platforms for advocacy, raising awareness about the needs and rights of these individuals. Community-based programs and activities are another critical component. These programs aim to integrate individuals with DS into the community, promoting social interaction and inclusion. Activities can range from sports and arts to community service projects, all designed to foster a sense of belonging and participation (MacDonald et al., 2016). Such initiatives not only benefit individuals with DS but also enrich the broader community by fostering diversity and empathy. Family support and counseling services are equally important. Families of children with DS often face unique challenges and may require specialized support. Counseling services provide emotional support and guidance, while educational programs help families understand DS and how to support their child's development effectively. These services are vital in ensuring that families are equipped to provide the best possible care and advocacy for their loved ones (MacDonald et al., 2016).

## CHALLENGES AND FUTURE DIRECTIONS

Despite the progress made, there are several challenges in healthcare, education, and societal integration for individuals with DS in Saudi Arabia. In healthcare, while there are specialized programs and services, ensuring consistent and widespread access remains a challenge. Educationally, the full implementation of inclusive education and the availability of resources for special education need further development. Societal integration also presents challenges, as stereotypes and misconceptions about DS can lead to social exclusion (Almoghyrah, 2023). Looking to the future, there are several areas for improvement. In healthcare, a focus on training healthcare professionals and expanding specialized services across the country is crucial. In education, more resources need to be allocated to train teachers in inclusive education practices and develop specialized curricula for

students with DS. Societally, ongoing efforts to raise awareness and promote inclusion are essential in changing public perceptions and attitudes.

## CONCLUSION

The current study of DS in Saudi Arabia highlights a landscape of increasing awareness and support, while also pinpointing areas that require further attention and improvement. The insights gained underscore the necessity for more localized, in-depth research to better understand the interplay of genetic, environmental, and social factors in the incidence of DS. This knowledge is crucial for tailoring healthcare, education, and social support in a way that respects the unique cultural and social context of Saudi Arabia. The healthcare journey for managing DS in the country is multifaceted, spanning from prenatal care to adulthood, addressing not just medical needs but also educational, emotional, and social aspects. The progress in Saudi Arabia is also evident in the evolving educational landscape, where inclusive education and specialized programs reflect a commitment to meeting diverse learning needs. However, continuous effort is required to ensure that each individual with DS has access to empowering education. Additionally, the policy and legal framework in Saudi Arabia, aligned with international standards, shows a positive direction toward inclusivity and support for individuals with DS. Effective implementation of these policies is key to ensuring they receive the necessary opportunities to thrive.

Moreover, the role of support systems and community engagement has been pivotal in advocating for individuals with DS. Addressing challenges in healthcare, education, and societal integration remains critical for further progress. A comprehensive approach involving government support, community involvement, and family engagement is vital for effective support. This approach aligns with Saudi Arabia's Vision 2030, which emphasizes improving the quality of life for all citizens, including those with disabilities. By aligning with Vision 2030, efforts toward understanding and supporting DS not only contribute to the immediate needs of these individuals but also to building a more inclusive and empathetic society. The ongoing dedication to this cause is essential and holds the promise of better outcomes for individuals with DS and their families, ultimately contributing to a vibrant society, thriving economy, and an ambitious nation that accommodates the needs of all individuals, including those with special needs.

## KEY HIGHLIGHTS

1. The Kingdom of Saudi Arabia is advancing in providing aid to those with DS, emphasizing improvements in medical care, educational strategies, and efforts to integrate them into society.
2. Cultural, religious, and societal dynamics in Saudi Arabia play a crucial role in shaping the experiences and support available to individuals with DS.

3. Early intervention, specialized healthcare services, and inclusive education are key to enhancing the quality of life for individuals with DS.
4. There is a growing awareness and effort in Saudi Arabia to challenge societal stigmas and foster a supportive and inclusive environment for individuals with DS.
5. Continuous improvement and adaptation of support systems, policies, and community engagement are essential to meet the evolving needs of the DS community in Saudi Arabia.

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## REFERENCES

- Abu-Alghayth K. (2022). Teachers' use of assistive technology in Saudi special education schools: a mixed-methods enquiry. *Int. J. Dev. Disabil.*, 68(4), 547-557.
- Al Husain M. (2003). Growth charts for children with Down's syndrome in Saudi Arabia: birth to 5 years. *Int. J. Clin. Pract.*, 57(3), 170-174.
- Alabri W. (2023). Maternal perspectives: the needs of Saudi families of children with Down's syndrome. *J. Intellect. Disabil.*, 27(1), 221-237.
- Al-Aoufi H., Al-Zyoud N. and Shahminan N. (2012). Islam and the cultural conceptualisation of disability. *Int. J. Adolesc. Youth*, 17(4), 205-219.
- Alasiri A.A. and Mohammed V. (2022). Healthcare transformation in Saudi Arabia: an overview since the launch of vision 2030. *Health Serv. Insights*, 15, 11786329221121214.
- Alfirevic Z., Navaratnam K. and Mujezinovic F. (2017). Amniocentesis and chorionic villus sampling for prenatal diagnosis. *Cochrane Database Syst. Rev.*, 9(9), CD003252.
- Alhaddad F.A., Alkhushi N.A., Alharbi A.M., Al Talib S.A., Sultan S.M. and Bahawi Y.O. (2023). Quality of life among Down syndrome patients with and without congenital heart disease at King Abdulaziz University Hospital, Jeddah, Saudi Arabia. *Cureus*, 15(1), e33553.
- Alhumaid M.M., Alfazan S.K., Alobaid M.A., AlNajjar N.A., Althikr Allah B.A. and Said M.A. (2023). Effects of disability type, prior contact, and school setting on attitudes toward peers with disabilities among Saudi female students aged 7 to 12 years. *PLoS One*, 18(9), e0291274.
- Almalki N.S., Arrushaid O.M., Farah Bakhiet S. and Alkathiri S. (2023). Examining the current practices of the individualized family services plan with young children with disabilities in Saudi Arabia. *Int. J. Dev. Disabil.*, 69(2), 163-178.
- Almoghyrah H. (2023). The challenges of implementing individualised education plans with children with Down syndrome at Mainstream Schools in Riyadh, Saudi Arabia: teachers' perspectives. *Int. J. Disabil. Dev. Ed.*, 70(3), 291-313.
- AlSalloum A., El Mouzan M.I., AlHerbish A., AlOmer A. and Qurashi M. (2015). Prevalence of selected congenital anomalies in Saudi children: a community-based study. *Ann. Saudi Med.*, 35(2), 107-110.
- Alsem M.W., Siebes R.C., Gorter J.W., Jongmans M.J., Nijhuis B.G.J. and Ketelaar M. (2014). Assessment of family needs in children with physical disabilities: development of a family needs inventory. *Child Care Health Dev.*, 40(4), 498-506.
- Alwhaibi R.M., Omer A.B., Khan R., Albashir F., Alkwait N. and Alhazmi R. (2022). Assessment of the correlation between the levels of physical activity and technology usage among children with Down syndrome in the Riyadh Region. *Int. J. Environ. Res. Public Health*, 19(17), 10958.
- Antonarakis S.E., Skotko B.G., Rafii M.S., Strydom A., Pape S.E., Bianchi D.W., et al. (2020). Down syndrome. *Nat. Rev. Dis. Primers*, 6(1), 9.
- APD. (n.d.) Overview of the Rights of Persons with Disabilities in the Kingdom of Saudi Arabia. <https://apd.gov.sa/web/content/15711?unique=0d23ee619dbb470672c2272b00c697106093f858>. Accessed 15 February 2024.
- Asiri F., Tedla J., Sangadala D., Alshahrani M., Gular K., Dixit S., et al. (2023). Quality of life among caregivers of children with disabilities in the Kingdom of Saudi Arabia: a systematic review. *J. Disabil. Res.*, 2(2), 8-17.
- Barbareschi G., Carew M.T., Johnson E.A., Kopi N. and Holloway C. (2021). "When they see a wheelchair, they've not even seen me"-factors shaping the experience of disability stigma and discrimination in Kenya. *Int. J. Environ. Res. Public Health*, 18(8), 4272.
- Bentley J.A., Feeny N.C., Dolezal M.L., Klein A., Marks L.H., Graham B., et al. (2021). Islamic trauma healing: integrating faith and empirically supported principles in a community-based program. *Cogn. Behav. Pract.*, 28(2), 167-192.
- Bhattacharyya R., Sanyal D., Roy K. and Bhattacharyya S. (2010). Correlation between physical anomaly and behavioral abnormalities in Down syndrome. *J. Pediatr. Neurosci.*, 5(2), 105-110.
- Binjahlan Y., Binjahlan M., Alqurashi A., Alqurashi G., Zirari M., Alturkistani F., et al. (2017). Assessment of knowledge, attitude and practice toward Down syndrome in Jeddah city, Saudi Arabia 2016. *Egypt. J. Hosp. Med.*, 66, 146-151.
- Boys C., Cunningham C., McKenna D., Robertson P., Weeks D.J. and Wishart J. (2008). Prenatal screening for Down's syndrome: editorial responsibilities. *Lancet*, 372(9652), 1789-1791.
- Bray E.A., Salamonsen Y., Everett B., George A., Chapman I.A. and Ramjan L. (2022). Transitioning between paediatric and adult healthcare services: a qualitative study of the experiences of young people with spinal cord injuries and parents/caregivers. *BMJ Open*, 12(11), e065718.
- Bull M.J.; Committee on Genetics. (2011). Health supervision for children with Down syndrome. *Pediatrics*, 128(2), 393-406.
- CDC. (2023). Data and statistics on Down syndrome. <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html>.
- Chistiakov I.S., Medvedev A.P. and Pichugin V.V. (2013). [Features of the perioperative management of patients with congenital heart disease complicated by infectious endocarditis]. *Khirurgiia (Mosk)*, (12), 78-81.
- Clement S., Lassman F., Barley E., Evans-Lacko S., Williams P., Yamaguchi S., et al. (2013). Mass media interventions for reducing mental health-related stigma. *Cochrane Database Syst. Rev.*, 2013(7), CD009453.
- Daunhauer L.A., Fidler D.J. and Will E. (2014). School function in students with Down syndrome. *Am. J. Occup. Ther.*, 68(2), 167-176.
- El Mouzan M.I., Al Salloum A.A., Al Herbish A.S., Qurachi M.M. and Al Omar A.A. (2008). Consanguinity and major genetic disorders in

## AUTHOR CONTRIBUTIONS

All authors have contributed equally and agreed to the publication of this manuscript.

## CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

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- Saudi children: a community-based cross-sectional study. *Ann. Saudi Med.*, 28(3), 169-173.
- Eltyeb E.E., Halawi M.H.A., Tashari T.B.M., Alharbi K., Alsayari O.S., Albarrak D.A., et al. (2023). Prevalence and pattern of birth defects in Saudi Arabia: a systematic review of observational studies. *Pediatric Rep.*, 15(3), 431-441.
- Gosadi I.M. (2019). National screening programs in Saudi Arabia: overview, outcomes, and effectiveness. *J. Infect. Public Health*, 12(5), 608-614.
- Hasina Z. and Wang C.C. (2022). Prenatal and postnatal therapies for Down's syndrome and associated developmental anomalies and degenerative deficits: a systematic review of guidelines and trials. *Front. Med. (Lausanne)*, 9, 910424.
- Hayes A.M. and Bulat J. (2017). *Disabilities Inclusive Education Systems and Policies Guide for Low- and Middle-Income Countries*, RTI Press, Research Triangle Park, NC.
- Head E. and Ances B. (2020). Biomarkers in Down syndrome can help us understand Alzheimer's disease. *Lancet*, 395(10242), 1951-1953.
- Hendrix J.A., Amon A., Abbeduto L., Agiovlaitis S., Alsaied T., Anderson H.A., et al. (2021). Opportunities, barriers, and recommendations in Down syndrome research. *Transl. Sci. Rare Dis.*, 5(3-4), 99-129.
- Hunt P. (2020). Inclusive education: children with disabilities: programme and meeting document: Global Education Monitoring Report Team [1052]. In: ED/GEMR/MRT/2020/P1/7 (ed.) p. 82.
- Ijezie O.A., Healy J., Davies P., Balaguer-Ballester E. and Heaslip V. (2023). Quality of life in adults with Down syndrome: a mixed methods systematic review. *PLoS One*, 18(5), e0280014.
- Khayat A., Alshareef B., Alharbi S., AlZahrani M., Alshangity B. and Tashkandi N. (2024). Consanguineous marriage and its association with genetic disorders in Saudi Arabia: a review. *Cures*, 16(2), e53888.
- Koul A.M., Ahmad F., Bhat A., Aein Q.U., Ahmad A., Reshi A.A., et al. (2023). Unraveling Down syndrome: from genetic anomaly to artificial intelligence-enhanced diagnosis. *Biomedicine*, 11(12), 3284.
- Kroh J. and Prechsl S. (2023). The intervening role of social integration in the effect of education on subjective mental health. *Res. Soc. Stratif. Mobil.*, 85(2023), 1.
- MacDonald M., Leichtman J., Esposito P., Cook N. and Ulrich D.A. (2016). The participation patterns of youth with Down syndrome. *Front. Public Health*, 4, 253.
- Martin G.E., Klusek J., Estigarribia B. and Roberts J.E. (2009). Language characteristics of individuals with Down syndrome. *Top. Lang. Disord.*, 29(2), 112-132.
- Megarbane A., Ravel A., Mircher C., Sturtz F., Grattau Y., Rethore M.O., et al. (2009). The 50<sup>th</sup> anniversary of the discovery of trisomy 21: the past, present, and future of research and treatment of Down syndrome. *Genet. Med.*, 11(9), 611-616.
- Morris K. (2008). Shift in priorities for Down's syndrome research needed. *Lancet*, 372(9641), 791-792.
- Niazi M.A., Al-Mazyad A.S., Al-Husain M.A., Al-Mofada S.M., Al-Zamil F.A. and Khashoggi T.Y. (1995). Down's syndrome in Saudi Arabia: incidence and cytogenetics. *Hum. Hered.*, 45(2), 65-69.
- Peters V.J.T., Bok L.A., de Beer L., van Rooij J.J.M., Meijboom B.R. and Bunt J.E.H. (2022). Destination unknown: parents and healthcare professionals' perspectives on transition from paediatric to adult care in Down syndrome. *J. Appl. Res. Intellect. Disabil.*, 35(5), 1208-1216.
- Queremel Milani D.A. and Tadi P. (2024). Genetics, chromosome abnormalities. In: *StatPearls*. Treasure Island (FL) with ineligible companies. Disclosure: Prasanna Tadi declares no relevant financial relationships with ineligible companies.
- Roizen N.J. and Patterson D. (2003). Down's syndrome. *Lancet*, 361(9365), 1281-1289.
- Rudolf G., Tul N., Verdenik I., Volk M., Brezigar A. and Kokalj Vokac N. (2017). Impact of prenatal screening on the prevalence of Down syndrome in Slovenia. *PLoS One*, 12(6), e0180348.
- Salehi A., Ashford J.W. and Mufson E.J. (2016). The link between Alzheimer's disease and Down syndrome. A historical perspective. *Curr. Alzheimer Res.*, 13(1), 2-6.
- Samarkandy M.M., Mohamed B.A. and Al-Hamdan A.A. (2012). Nutritional assessment and obesity in Down syndrome children and their siblings in Saudi Arabia. *Saudi Med. J.*, 33(11), 1216-1221.
- Seither K., Tabbah S., Tadesse D.G., Suhrie K.R. (2021). Neonatal complications of Down syndrome and factors necessitating intensive care. *Am. J. Med. Genet. A.*, 185(2), 336-343.
- Sijeeni A. and Barnard A. (2018). Caregiver experiences of caring for a Down syndrome child in Saudi Arabia. *Int. J. Nurs.*, 8, 76-86.
- Tariq A. and Bora V. (2024). Perioperative management of patients with congenital heart disease. In: *StatPearls*. Treasure Island (FL) ineligible companies. Disclosure: Vaibhav Bora declares no relevant financial relationships with ineligible companies.
- Van den Driessen Mareeuw F.A., Coppus A.M.W., Delnoij D.M.J. and de Vries E. (2020). Quality of health care according to people with Down syndrome, their parents and support staff-A qualitative exploration. *J. Appl. Res. Intellect. Disabil.*, 33(3), 496-514.