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Introduction

Defining Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder (ASD) is a neurological developmental disorder, characterised by challenges with social interactions and repetitive or limited behavioural patterns¹. There are currently five different types of ASD, including;

- Autistic disorder
- Pervasive Developmental Disorder not otherwise specified (PDD-NOS)
- Rett syndrome
- Childhood Disintegrative Disorder (CDD) and
- Asperger's syndrome.²

According to the World Health Organisation, globally 1 in 160 children has ASD.³ This paper will focus on Autism Spectrum Disorder, a condition where the term "spectrum" describes the wide range of symptoms, skills, and degrees of disability that people with autism may experience. The spectrum can range from level 1, "requiring support", to level 3, "requiring very substantial support". A definitive diagnosis of autism is typically made between the ages of 3 and 4 years old as it relies on identifying distinct behavioural impairments that usually become apparent in the second year of a child's life. Even though autism can be diagnosed at a young age, its management can span one's lifetime, necessitating a comprehensive and multidisciplinary approach to care catering to the unique needs across the spectrum and throughout their lives.

The three functional levels of autism

ASD Level 1

Requiring support



- Difficulty initiating social interactions
- Organisation and planning problems can hamper independence

ASD Level 2

Requiring substantial support



- Social interactions limited to narrow special interests
- Frequent restricted/repetitive behaviours

ASD Level 3

Requiring very substantial support



- Severe deficits in verbal and nonverbal social communication skills
- Great distress/difficulty changing actions or focus

Research has shown that early detection of autism can lead to better prognosis, higher chances of rehabilitation and improved integration into society, as children transition into adulthood. This support must span across all sectors, including healthcare, education and employment, to ensure individuals reach their fullest potential and can be active members of society.⁴

This report explores autism in the Gulf Cooperation Council (GCC) region, examining its significance, prevalence as well as its social and economic influences on families. It draws insights from interviews with families caring for individuals with autism and healthcare professionals, as well as provides additional research to provide a comprehensive picture of the impact of autism on societies. The report also reviews recent initiatives related to autism in the region, and concludes with targeted recommendations to better support individuals with autism and build an inclusive society for all.



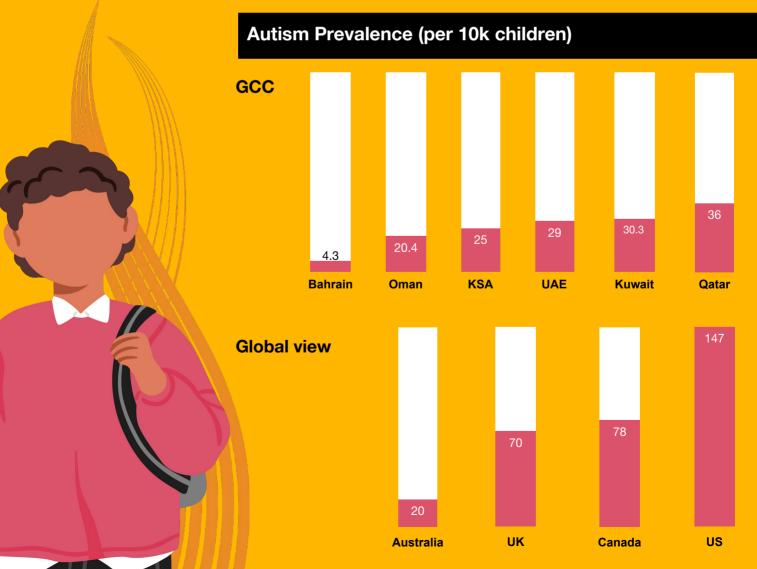
It's very humbling to be a parent to my son. It brought out hidden gems in me that I didn't know I was capable of. We often think that happiness has a single definition, but through parenting I've learned that children [with autism] see the world and happiness in a different way. Our way of happiness is not necessarily theirs.

The prevalence of autism in the GCC

The true prevalence of autism in the GCC is still uncertain, as conflicting studies suggest varying rates. Autism rates in Bahrain, for instance, are reported to be as low as 4.3 per 10,000 children while in Saudi Arabia, Oman and UAE these rates range between 20-29 per 10,000, and over 30 in Qatar and Kuwait.^{5,6,7,8} And specifically in the UAE, The Ministry of Community Development has indicated that autism represents 12% of all disabilities across the emirates.⁹

Differences in rates across the GCC, as well in comparison to global prevalence, have been identified. Some studies have shown that the lower reported prevalence does not necessarily reflect a true lower occurrence; instead, it could be due to diagnostic challenges, a lack of awareness of symptoms and the complexity of the spectrum, including how and when symptoms manifest. ¹⁰ This incompleteness of the available data makes it challenging to accurately understand the full scope and scale of autism across the region to inform effective healthcare planning and resource distribution for its care.

According to a clinical psychologist who was interviewed: "The first signs [of autism] can include avoiding eye contact or speech delays. Parents often take their kids to a specialist who aligns with the signs they see (for example, an eye doctor). But such professionals may only test that specific area and do not see the bigger picture or think of referring the child for further assessments."



The importance of understanding autism

The complexity of autism emphasises the importance of understanding its varied presentation and functionality. This is especially crucial for governments, healthcare providers, and families caring for individuals living with autism. General practitioners and paediatricians, as the gatekeepers of care, must be able to recognise early symptoms and be aware of the referral process for suspected autism. Referral pathways for suspected cases of autism involve assessment, diagnosis, post-diagnosis support and intervention. Healthcare providers must also recognise the diversity of the spectrum and how best to support children and adults with autism based on their personalised needs. As one behavioural therapist shared: "currently it is not clear what happens once a child transitions into adulthood. Professionals need to also be trained for adult needs".



The earlier we start providing support for children and parents, the higher the chances are of improvement or rehabilitation for children on the spectrum.

-A clinical psychologist interviewee

Understanding the complexity of the disorder and the challenges individuals and families face in society will enable governments and decision makers to develop informed and inclusive policies to meet those challenges. Similarly, for families or caregivers, it is important that they fully understand the symptoms, capabilities and the support their loved ones need to be able to live a fulfilling life. Most importantly, a deeper understanding of autism and a holistic approach to policy making can significantly empower societies, enable tailored support and enhance self-advocacy among individuals living with autism themselves.

Currently there is not enough advocacy for parents or even adults with autism to be decision makers, sharing the insights of their lived experience.

- A clinical psychologist interviewee



Impact on families and society

Exploring the economic and social impacts of autism on families in the GCC



Raising a child with autism imposes significant emotional, social and financial¹⁴ strain on families. Extensive research and one-on-one interviews with families of children living with autism in the GCC revealed the main challenges and experiences they face.

The key themes derived from the interviews include:

- Limited access to care
- The financial burden
- Lack of community support

These collectively underscore the complex barriers faced by individuals and families in navigating care systems, pointing to the need for integrated solutions to improve accessibility and support.



Why did i feel lost? A lack of awareness, lack of proper guidelines - once you have this feeling that something is different about your child, there are no clear steps for the parents to take. You are in the dark.

Access to care: Availability of specialised professionals and services

The long-term care for those living with autism requires a multidisciplinary approach that includes, but is not limited to, professions such as speech language pathology, occupational therapy, geneticists, neurologists, and mental health. However, research shows that in the GCC, like in many parts of the world, there are challenges related to the availability of trained professionals in fields crucial for autism care due to limited educational programmes, increasing demand for services, and challenges in attracting and retaining talent.¹⁵ This shortage of trained specialised professionals can lead to long wait lists, delayed diagnosis and reduced access to care. As one of the interviewees shared, it can take up to three months to get an appointment for behavioural therapy in the UAE.¹⁶

The presence of mental health services is also critical in the care of individuals living with autism, as they play a vital role in addressing the complex emotional and psychological needs that accompany autism - not just for the person with autism but their family and carers as well. As one parent explained "I thought I could be [my son's] therapist but I couldn't. I needed therapy myself."

According to WHO Mental Health Atlas 2020, the Eastern Mediterranean Region (EMR) has notably fewer mental health workers than the European Region (EUR) and the Americas Region (AMR), with a stark contrast seen in the availability of psychologists - 1.0 per 100,000 in the EMR compared to 5.4 and 4.6 in the EUR and AMR, respectively.¹⁷ This disparity is significant for understanding and addressing mental health needs, particularly in autism care within the GCC.

This shortage of specialised skills means that healthcare institutions are often caught unprepared, and staff fail to respond adequately to the specific characteristics and needs of patients living with autism. Even simple tasks like taking a patient's vitals might prove challenging for healthcare providers who have not received basic training in caring for children with autism.

A nurse wouldn't take my kids vitals even though I insisted to follow the protocol and give the care he needs.





Such barriers can significantly impact the timely intervention and support that is critical for the development and well-being of individuals living with autism. Moreover, the availability of autism centres and autism-equipped schools is scarce across GCC countries, severely limiting access for many children with autism. Despite a recent policy in Dubai that requires schools to accept children with autism, most parents are finding that schools have limited capacity and resources to support more than a couple of students. Parents have also shared that inclusivity needs to be taught and understood better among all students at schools.



We can't expect that the child on the spectrum acknowledges and understands they are different, while other children are not taught to accept differences and learn about empathy.

- A parent interviewee



A study in Jeddah revealed there are also substantial gaps in home care, outreach programmes, and educational integration for individuals living with autism, with 57% of centres lacking essential services.²¹ While another study published in KSA found that only 31% of children on the autism spectrum could access nearby autism centres, and 72% have no access to private schools for autism in their area.²² As one parent explains, "you feel like you're begging for your child to get an education."



All parents fight for inclusion in the classroom, which is my fight too now.



Families face another challenge when trying to access care: navigating the complexity of the healthcare system. While a multidisciplinary approach is optimal for care, families often need to find the necessary healthcare professionals on their own. As a clinical psychologist shared, parents must navigate the "maze of professionals" to determine who to consult for specific concerns, ensuring each professional has access to their child's complete medical history, so that comprehensive support can be offered.²³

Parents have to navigate a very complex health system... a multidisciplinary approach is needed for individuals with autism and all these professions need to work together and collaborate.



- A clinical psychologist interviewee



And when care is available, it is not always up to the expected and necessary standards, as one parent shared: "We have had terrible experiences at different centres - I wish there was a place or regulation to keep the centres accountable. I once received an email that said they can't help my son or take him any more with no further explanation."



While there are more support groups now and centres, quality remains a problem because centres compromise in their training and recruitment. Parents pay a lot of money but are not getting the quality support.



- An educational psychologist interviewee

Financial burden

The financial impact associated with raising a child living with autism is significant, spanning various sectors within society. A study conducted in the United States revealed that autism leads to US\$3,020 higher healthcare costs and US\$14,006 higher aggregate non-healthcare costs, including US\$8,610 higher schooling expenses per year compared to those without autism.²⁴

The estimated lifetime expense for someone with autism can reach up to US\$2.2 million in the UK. and US\$2.2 million in the UK. A comprehensive study in 2020 estimated the average lifetime social cost of supporting an individual with Autism Spectrum Disorder at \$3,566,881, highlighting the extensive economic impact and the need for effective interventions and support systems across their lifespan. The economic impact of autism is similar to significant health issues like diabetes. However, autism stands out because it incurs higher indirect costs, such as non-medical needs. Additionally, comorbidities associated with autism significantly increase the overall societal and individual burden. Additionally burden.

This financial burden of autism care is also significant in the GCC, with families facing substantial costs for treatment and education. For instance, one family interviewed reported spending more than Dh1 million (approximately US\$272,200) on their seven-year-old's autism care and education over a period of four years.

Even the core diagnostic and therapeutic services for autism are high - ranging between Dh450 to Dh1,000 AED per hour in the UAE. Similarly, in KSA, fees for autism specialists range from SAR100 to SAR600 per appointment. Considering the multiple diagnostic tests and ongoing therapies required throughout one's lifetime, these healthcare costs can quickly escalate to around Dh/SAR8,000 per month.²⁸ When combined with other financial costs of autism, monthly expenses can reach up to Dh50,000 (US\$13,615) including therapy, school fees, speech/language services, and a shadow teacher, among other costs.²⁹



The Dubai Autism Centre has highlighted the critical need for support to help families manage these expenses. Treatment costs at the centre can exceed Dh120,000 per child per year. Although this cost is sometimes lowered due to donations, the high costs of care have led some families to significantly alter their living conditions to afford necessary treatments. 30 Interviews with families further emphasised these challenges. One parent detailed the emotional and financial strain of navigating expensive therapies and educational support, stating they often had to "choose certain therapeutic services over others" due to cost constraints. This has forced many parents to educate themselves through online programmes to provide crucial support for their children at home.



It's very very expensive...[especially] depending on how much intervention you want and need to do.

A parent interviewee

While there has been an effort to expand insurance coverage across the GCC, significant gaps in alleviating the financial burden on families still remain. Universal coverage is limited in the GCC with public health services covering only assessment and diagnostic services.³¹ Many families discover that private insurance plans do not fully cover essential autism treatments required over an individual's lifetime. 32 Such financial burdens underscore the critical importance of expanding support and funding for families affected by autism, ensuring that all individuals can access the care and education they need without placing an unsustainable burden on families.

Not all insurances cover special needs, and you need a lot of different therapy services.

A parent interviewee



Applied behavioural analysis is the most common technique used for children with autism, and countries like Kuwait have put in a lot of effort to increase the number of ABA-certified therapists over the past few years. However, these services remain very expensive. A lot of families that access these services have to do so through employer insurance to afford them.

A behavioural therapist interviewee

Community support and awareness

Families navigating the complexities of autism care face numerous challenges, including accessing specialised care, educational support, and managing the emotional and financial strains associated with providing the best quality of life for their child. Community support such as support groups provide a platform for parents to exchange insights on therapies, share personal journeys, and offer practical advice for interacting with professionals. These groups also serve as a safe space for expressing frustrations, ensuring parents feel heard and supported.³³ Insights from interviews with families reveal a desperate need for more comprehensive community support to help alleviate some of these challenges and offer a network of resources, guidance, and emotional sustenance so they feel less isolated in their journey.



The most difficult thing was not knowing who to turn to and who to ask.

- A parent interviewee

Moreover, interviewees emphasised the critical role of public awareness campaigns in increasing societal understanding and acceptance of autism. Community-based initiatives, such as Learn Autism, created by a group of parents and experts exemplifies the power of community-driven resources in providing hope and understanding, and highlights the necessity of embracing and accommodating the needs of these individuals in all areas of life.³⁴ This initiative facilitates the identification of constructive pathways forward, leveraging community support to improve social skills, simplify parenting methods, encourage fun interactions, and promote educational involvement. It is carried out through a web application that provides training via video content and podcasts.

In the Middle East, the awareness is not where it should be. Parents need to do their part to raise the awareness and help get standards to where they should be.

- A parent interviewee



Community support and inclusion are crucial for the overall well-being and quality of life of people living with autism, especially as they transition into adulthood. Holistic integration into the community enables individuals to strengthen their social skills, forge connections, and actively contribute to society. This, in turn, fosters independence, enhances potential employability skills, and helps reduce isolation by connecting people living with autism with others.³⁵



I see that the most important thing is to help my child be happy, help her get there, and understand that she sees the world differently. I want her to be happy not in my own way, but in her own way of how she perceives the world.

Recent initiatives to support autism in the GCC



The uncertainties in the true prevalence of autism in the GCC and the challenges faced by families suggest a pressing need for more inclusive strategies and effective screening to ensure early diagnosis and intervention. Recognising this, the GCC countries have launched a number of important initiatives aimed at supporting individuals living with autism. They also underpin the social wellbeing and healthcare transformation aspects of the various guiding national visions.



Whenever a child is diagnosed on the spectrum, the family should have a social worker to give them a plan and guide them, teach them what the next steps are, and which healthcare professionals to visit and help them throughout their journey.



Legislative advances and policy



UAE

The UAE has shown a strong commitment to supporting individuals with special needs, notably through the establishment of the National Policy for Empowering People with Determination³⁶, which officially adopted the term "People of Determination" in place of "special needs", and implemented comprehensive policies aimed at empowerment and integration of people of determination into society. This was also extended to the launch of the National Autism Policy, which is dedicated to enhancing the well-being of individuals with autism, with a specific focus on offering support to caregivers, and improving the expertise of staff at autism centres.³⁷

Saudi Arabia

KSA is actively enhancing support and services for individuals with autism, focusing on both urban and underserved areas, through initiatives like the Prince Mohammed Bin Salman Program for Autism and the digital autism disorder card, aimed at standardising care and improving healthcare accessibility and convenience.³⁸



Qatar is committed to improving the lives of individuals with disabilities through global collaboration and inclusive policies, as demonstrated by the launch of the "Doha Declaration" in 2019 and initiatives to support individuals with autism, aimed at developing motor skills for about 120 people. 40



Kuwait's efforts, aligned with Vision 2035, aim to enhance inclusivity and empowerment for people with disabilities. The United Nations Development Programme has dedicated a full project to supporting the country's Public Authority for Disabled Affairs (PADA) by creating supportive environments, ensuring access to necessary services, and improving the quality of life for people with disabilities in Kuwait.⁴¹



Oman is dedicated to improving the lives of people with disabilities through a comprehensive approach that includes accessible healthcare, education, and employment, underpinned by the Oman Vision 2040. This commitment is further exemplified by a collaborative strategy for autism, developed with UNICEF and the University of Northampton, focusing on health, education, and rehabilitation. It includes the pioneering work of Dr. Sharifa Al-Lawati who developed autism screening tools in the region, mandating evaluations for children at 18 months.⁴²



Bahrain is working on an executive plan for 2023-2027 as part of a broader strategy to empower and integrate people with disabilities into Bahraini society. This strategy is comprehensive, involving coordination across government, private, and civil sectors, aiming to build an inclusive community where persons with disabilities can exercise their rights fairly and equally.⁴³



Specialised support centres

The GCC countries are taking significant strides towards improving autism care through community engagement, comprehensive services, specialised programmes and autism research. The UAE has made strides in supporting individuals with autism and their families by establishing specialised centres, such as the Emirates Autism Center in Abu Dhabi, the Dubai Autism Center and the Sharjah Autism Centre. 44,45,46

Aligning with Saudi Vision 2030 and the Health Sector Transformation Programme to promote healthcare, social inclusion, and empowerment, Saudi Arabia has also launched centres such as The Center for Autism Research (CFAR) and the Center of Excellence for Autism which provide rehabilitation services as well as conduct Autism research.⁴⁷

Other GCC countries, such as Qatar, Kuwait, and Bahrain, are taking equally significant strides towards improving autism care. For example, the Qatar Foundation actively promotes Autism awareness through annual events at Oxygen Park, engaging the community and fostering understanding and inclusion, while the Autism Program by Hamad Medical Corporation provides comprehensive services for children with autism.

In Bahrain the REACH Behaviour and Development Center offers comprehensive support for children with autism and other developmental challenges,⁵⁰ providing Applied Behaviour Analysis (ABA) therapy, occupational therapy, speech and language therapy, and social skills training.

Finally, the Kuwait Centre for Autism (KCA) is the first autism centre to receive international accreditation in the Middle East⁵¹, emphasising the "REACH" approach, with a focus on relationship-building, creating a supportive environment, engaging activities, and effective communication.

These initiatives, aligning with a broader regional trend, focus on creating a more inclusive, supportive environment for individuals with autism and their families.

Global best practices

Globally, efforts to support individuals with autism are diverse and impactful, with countries such as Canada, the United Kingdom, and Australia leading with unique initiatives. Canada champions inclusive education for students with Autism, creating environments where they can learn alongside their peers, supported by tailored strategies like Individualised Education Plans (IEPs).



Additionally, Canada provides specialised schools and programs for these students, offering smaller classes, unique teaching methods, and therapeutic support. Transition programs for adolescents focus on life skills and preparation for independence and employment, frequently in collaboration with vocational training centres. ⁵² The United Kingdom's National Autistic Society advocates for the rights of individuals with autism and promotes awareness and acceptance through community engagement and educational resources. ⁵³

Australia implements the National Disability Insurance Scheme (NDIS) to provide financial support for therapeutic services, including speech therapy, occupational therapy, physiotherapy, psychological services, and early childhood interventions, offering relief to families and ensuring comprehensive care across different sectors.⁵⁴

Several technology based innovations are also being implemented around the world. For instance, in the United States, an innovative initiative, the VOISS (Virtual Reality Opportunities to Implement Social Skills) program has been launched to use virtual reality technology to help students with high-functioning Autism and learning disabilities to develop social skills.⁵⁵ Meanwhile, Luxembourg has developed QTrobot, a robot designed to help children with autism enhance their social interaction abilities, utilising a curriculum focused on improving communication skills.⁵⁶

Recommendations

The complexity of autism emphasises the importance for a holistic, multidisciplinary and cross-sectoral approach to care, rehabilitation and support. This support and resourcing needs to be identified and started as early as possible to maximise the potential benefits, and a clear pathway needs to be established starting in childhood and into adulthood to ensure that those living with autism can enjoy whole and fulfilling lives, including employment opportunities, entertainment and social integration.

While the GCC has taken significant steps to increase provision and access to care and community support for individuals living with autism and their families, several gaps persist. Reflecting on these, alongside global best practice initiatives, we have identified several key areas where action is needed.



Early detection and intervention

Launch universal screening with systemic support:

Introduce universal early screening for autism within paediatric care across the GCC, utilising culturally sensitive tools to ensure early detection. Parallel to this, strategically scale up support systems and resources to accommodate the expected increase in diagnoses. This includes enhancing professional training, support services, and creating guided pathways for families post-diagnosis, carefully balancing the expansion with the system's capacity to prevent overburdening it.

Implement comprehensive awareness campaigns:

Launch national awareness campaigns to educate the public about autism, symptoms, acceptance, and the importance of early intervention. Extend these educational efforts to all healthcare professionals, including those in non-specialised fields, to ensure individuals with Autism receive empathetic and informed care across all healthcare encounters.



Access to care

Implement comprehensive insurance coverage for autism services:

Enact policies ensuring that health insurance, both public and private, covers a comprehensive range of autism services, including diagnostic assessments, behavioural therapies, and ongoing support services.

Expand training programmes for specialised care providers:

Increase the availability of specialised training programmes for professionals in speech-language pathology, occupational therapy, and mental health services, addressing the critical shortage of specialised care providers and improving access to essential therapies and supports for individuals with autism and their families.

Enhance accessibility and capacity of autism centres:

Support the expansion and development of autism centres to increase their capacity and accessibility, including in underserved areas. This effort ensures families have comprehensive care and support services readily available, reducing wait times and travel burdens for ongoing therapy and support.



Community support

Strengthen support networks for carers:

Develop and fund programmes that provide education, respite care, and emotional support for carers of individuals with autism, alleviating the emotional and logistical challenges faced, promoting mental health and wellbeing, and enabling better care for individuals with autism.

Develop specialised programs for lifelong support and integration for adults living with autism:

While early detection and intervention is key, those with autism should not feel abandoned when approaching adulthood. Specialised programs and pathways need to be established to support those with autism throughout their life, enabling them to have fulfilling lives with employability skills, social empowerment and holistic wellbeing.



Policy and financial support

Implement comprehensive insurance coverage for autism services:

Enact policies ensuring that health insurance, both public and private, covers a comprehensive range of Autism services, including diagnostic assessments, behavioural therapies, and ongoing support services.

Expand training programmes for specialised care providers:

Increase the availability of specialised training programmes for professionals in speech-language pathology, occupational therapy, and mental health services, addressing the critical shortage of specialised care providers and improving access to essential therapies and supports for individuals with autism and their families.



Research and digital innovation

Conduct a comprehensive study on autism across the GCC:

Commit to a dual approach of funding focused research to map the prevalence, impacts, and effective interventions for autism, while also conducting a comprehensive study on the autism care landscape, family experiences, and individual needs across the GCC. These combined efforts will pinpoint system gaps, highlight effective practices, and guide a strategic overhaul of autism care. making it more accessible, proactive, and inclusive. Results will shape policies, care strategies, and educational initiatives, fully accounting for regional nuances and leveraging the latest research to empower individuals with autism to reach their fullest potential.

Incorporate advanced technologies in autism care:

GCC governments and healthcare providers should invest in exploring and adopting new and innovative technologies that support diagnosis, therapy, and intervention for individuals with autism. This includes, but is not limited to, artificial intelligence (AI) for personalised learning and therapy programs, virtual reality (VR) for social skills training, wearable technology for monitoring physiological responses and promoting self-regulation, and mobile applications for communication and daily living skills. This approach aims to make therapeutic interventions more personalised, engaging, and widely accessible.

Develop digital community platforms:

Leverage technology to build a digital community platform providing training material and resources, and a collaborative space for families and caregivers, as well as children and adults living with autism. This approach fosters an inclusive, supportive online environment where individuals can share experiences, access specialised learning tools, and find emotional support, facilitating a deeper sense of community and connection.





In order to successfully and sustainably implement these recommendations, governments must take a multidisciplinary approach involving key stakeholders from all sectors, healthcare providers, researchers, and families and caregivers of people with autism. It is crucial for the success of new initiatives to also include the voices of individuals living with autism in the decision-making process. This will allow governments to understand the lived experiences of society and develop relevant and inclusive initiatives and policies that start in childhood and continue to empower and enrich lives throughout adulthood.

We have a voice. If we escalate our needs, our voice will be heard.

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