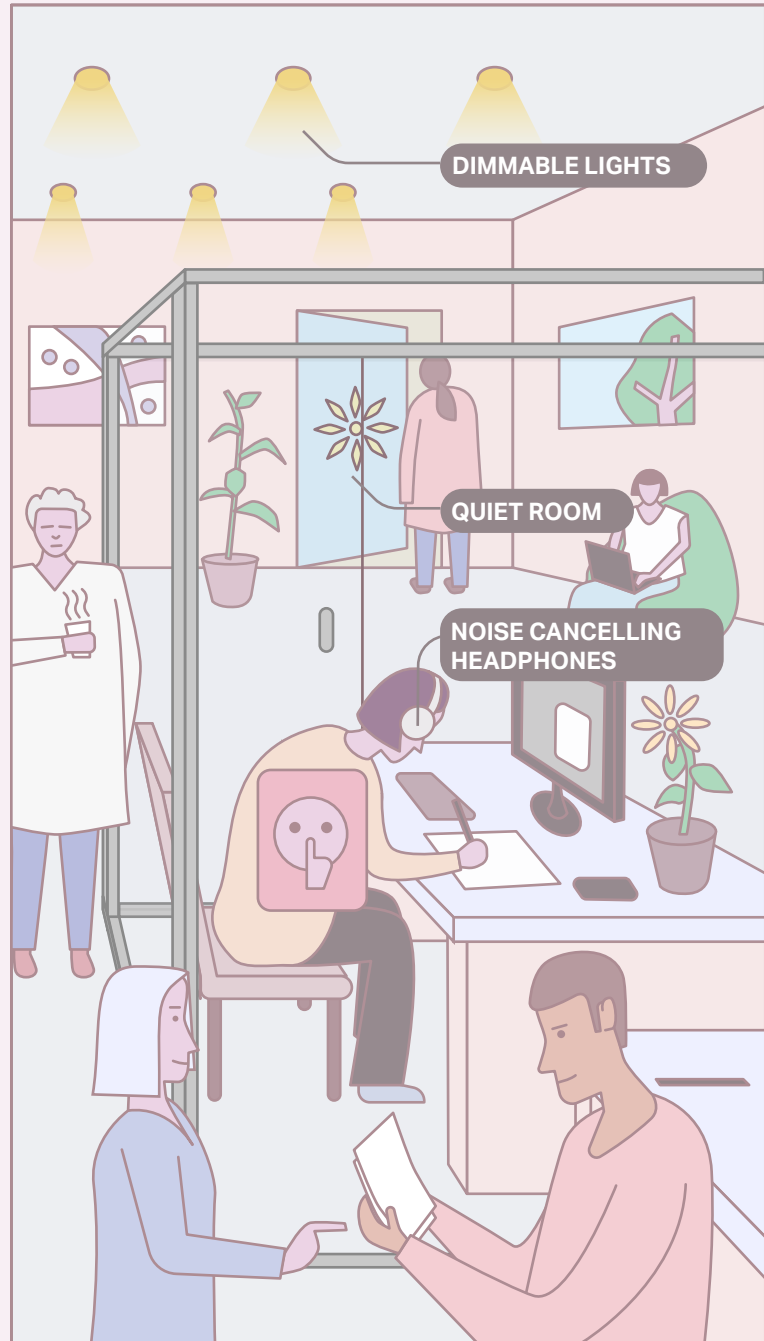


Inclusive Urbanism

Accounting for the Vulnerabilities of Persons with Invisible Disabilities



July 2023



Creating Sensitised Communities and Sensory-friendly Urban Spaces

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Acknowledgements

This research, as part of a working paper series on Inclusive Urbanism, has been made possible by the generous support provided by the H.T. Parekh Foundation.

We would like to extend our gratitude to Kavitha Krishnamoorthy (Kilikili), Dr. Nidhi Singhal, (Action for Autism), Rakshita Shekhar; Gopika Kapoor, Dr. Pratibha Karanth (DEALL Trust), Juhi Sardana, Reena Gupta (Ashoka University), Smita Pathak and Aditi Jha (Ummeed Child Development Center); Dr. Renu Addlakha (Centre for Women's Development Studies), Neha Trivedi (Spandan; Accessibility Consultant), Parul Kumtha (Architect - urban designer; Forum for Autism) and Neha Shigwan (Architect) for helping shape the research in profound ways with their insights and contributions.

We are grateful to Advaith Agrawal and Aarya Srivastava, interns at Vidhi for their assistance during this study and to Kunal Agnihotri for designing this document with care.

We are also grateful to Akhileshwari Reddy for peer reviewing this paper with patience and attention; to Damini Ghosh for her valuable insights and support through the course of this research, and to Alok Prasanna Kumar for his guidance in shaping this working paper series.

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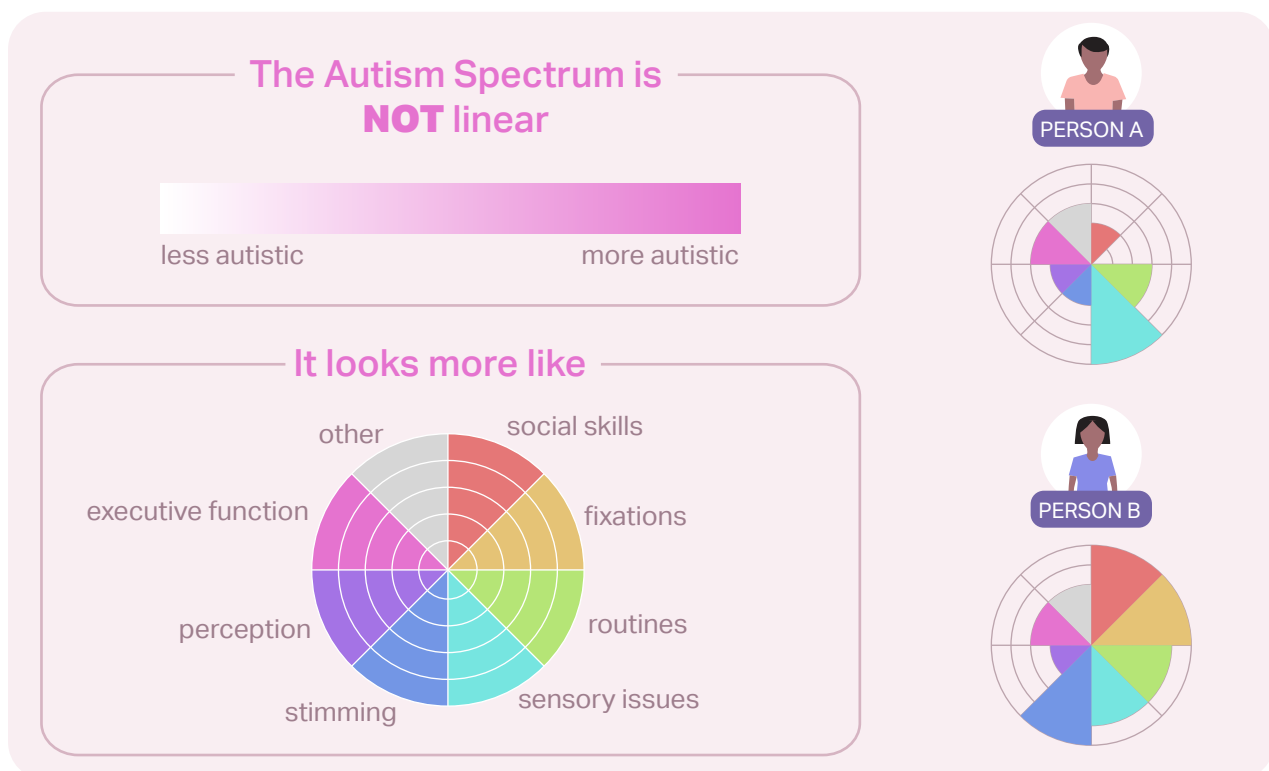
Preface

The working paper series on Inclusive Urbanism represents an endeavour to initiate discourse, raise awareness, and foster consideration of less visible or invisible disabilities within the realms of law and policy. Its overarching objective is to enhance the accessibility and liveability of cities and urban spaces for all individuals. The focus is on amplifying the voices of persons with invisible disabilities and their barriers to inclusion and access, which too are often invisible, characterised by stigma, misunderstandings, exclusionary attitudes, and lack of awareness.

This specific working paper focuses on securing inclusive urban spaces for persons with autism spectrum disorder. In recognition of the fact that no two people with autism are quite the same, this working paper attempts to amplify the myriad voices of individuals with lived experience and their caregivers, in the domain of law and policy. Vidhi, for its part, strives to add to conversation on the needs, understanding and kinds of interventions required to facilitate better access and inclusion in urban spaces for persons with autism. Through this working paper, Vidhi is attempting to gain an understanding of the necessary components for improved governance and legislation, based on the knowledge gained from continued dialogue and insights from stakeholders.

I. Introduction

Autism or autism spectrum disorder ('ASD') is a neurological developmental condition that affects social interaction, learning, communication, and behaviour.¹ It has largely come to be recognised as being distinct from both intellectual disability and mental illness.² The usage of the term "spectrum" is reflective of the wide variation in severity and symptoms,³ challenges and strengths possessed by each person with autism. It is representative of 'neurodiversity', the idea that throughout the human population different brain developments and structures exist.⁴ These differences are to be respected, and are not a deficiency to be 'repaired' or counteracted.⁵ The autism spectrum is often conceptualised or oversimplified as a linear concept with persons on the spectrum being attributed high-functioning or low-functioning labels, suggesting that individuals experience autism either mildly or severely.⁶ ASD is now better understood as a spectrum condition that primarily impacts aspects of language, sensory perception, executive function, social and motor skills, among others.⁷



The history of ASD discourse in India is nascent, with the oldest records being as recent as the 1960s.⁸ As highlighted in the first working paper,⁹ the early literature, like that of most invisible disabilities, mainly emphasised providing medical support and was characterised by initial sporadic endeavours in clinical description. This is representative of its initial understanding being through the lens of the medical model, which is rooted in the belief that a person's autonomy and ability to participate in society is limited due to their disability and contingent on medical professionals tasked with "rectifying" or "curing" the person and rehabilitating them.¹⁰ This medicalisation tends to be patronising and typecasts persons with ASD as 'sick' and dependent.¹¹ Although the law aims to address the inequalities,¹² disability legislation has tended to replicate this medicalisation, failing to transform attitudes and perpetuating the issue, by relying on the individual or medical model. Due to the self-advocacy of persons with ASD, families and activists, and inadequacy of the medical model, the social model came to be emphasised which views disability as a socially produced injustice that may be remedied through radical social change,¹³ and on society being the cause of the hindrances experienced by persons with disabilities, including ASD.¹⁴

In India, despite the growing incidence of autism - studies estimate that there are approximately 1.7 to 2 million people with ASD.¹⁵ - and the gradually enhancing visibility of ASD due to self-advocacy of families and persons with ASD,¹⁶ stigma, misinformation, stereotypes, and lack of sensitivity still hold sway among the masses at large. While there are many fundamental issues that confront persons with ASD in India (spanning the need for accurate and early diagnosis, access to education, employment, livelihood, and security); this working paper, in line with the larger theme of inclusive urbanism, looks at the extent and limits to the participation of persons with ASD in urban life and spaces. In line with the social model, this is premised

on the understanding that the ability of persons with ASD to autonomously engage with the built environment is frequently hindered or denied due to constraints arising from the mismatch between their specific spatial needs and the “built form”.¹⁷ By emphasising the need for inclusive and accessible design, this paper aims to promote inclusivity and accessibility in design practices that are suitable for a wide range of neurodiverse individuals.

II. Methodology and Structure of the Working Paper

This paper relies on a mix of research methods, including literature review and stakeholder consultations in the form of semi-structured interviews with persons with ASD, parents and caregivers of persons with ASD, Disabled People’s Organisations (‘DPOs’) working in the field of autism, as well as disability studies scholars, accessibility consultants and practitioners in the field of law, medicine, urban planning, design and architecture. The primary objective of the consultations was to bring the narratives of people with lived experiences, particularly those with ASD to the forefront.

The consultations helped in understanding, uncovering and highlighting issues and gaps that come in the way of realising the accessibility needs and steps towards inclusion of persons with ASD, indicating where law and policy frameworks need amendments for securing inclusive and accessible urban spaces.

Further, the literature review encompassed assessing relevant and applicable law and policy, spanning the Rights of Persons with Disabilities Act, 2016 (‘RPWD Act’), the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities

Act, 1999 ('National Trust Act') and various schemes and missions pertaining to ASD like Sahyogi-Caregiver Training Scheme and the Badhte Kadam-Awareness, Community Interaction and Innovation Project. Reference is also made to the Harmonised Guidelines and Standards for Universal Accessibility, 2021, the Accessible India Campaign, and the Atal Mission for Rejuvenation and Urban Transformation.

III. ASD and Inclusivity of Urban Spaces

A point that came up repeatedly in stakeholder consultations was that 'inclusion' often felt like it was the sole burden of persons with ASD to 'fit in'.¹⁸ For e.g., as one stakeholder put it, "People with autism often have to mask their true selves in order to fit into the neurotypical world and appear normal."¹⁹ This is known as autism masking or camouflaging, and is a fallout of internalised ableism and a hostile, unsafe environment. Persons with ASD often mask to avoid stigma, which can be socially exhausting; cause anxiety and contribute to the late diagnosis of ASD.²⁰ It entails mimicking neurotypical (or what is considered 'normal' in society) behaviours in social settings to feel more accepted (for e.g., suppression of authentic autistic behaviours like stimming; forced eye contact even when it can feel uncomfortable or overwhelming).²¹

Research suggests autism tends to be under-diagnosed in females as a result of greater instances of masking.²² It is suggested that the actual occurrence of autism in females might be higher than currently estimated due to biases in diagnosis and variations in how autism manifests in females versus males.²³ Diagnostic procedures are less likely and effective in identifying autism in females, especially when unaccompanied by intellectual disability. This can be attributed to behavioural criteria for diagnosis, which were derived from predominantly male autistic populations previously identified as autistic, leading to possible misdiagnosis of broader developmental disorders rather than identification of autism in females.²⁴

Modern life in a city is overtly stimulating. It tends to be more stressful as compared to rural life, with higher expectations of productivity within a fast-paced urban environment.²⁵ Non-autistic individuals tend to deal with the exceedingly stimulating city environments by adopting a manner of perceived indifference or as renowned sociologist Georg Simmel called it, a 'blasè' outlook', by means of a defensive response.²⁶ He argued that without this adaptive ability, human beings would feel fragmented and disoriented by the excessive stimulation.²⁷

In contrast, persons with ASD often face difficulties with processing sensory information or stimuli,²⁸ which could manifest as either hyper or hypo reactivity to sensory stimuli in the surrounding environment.²⁹ As per a stakeholder consultation, new places, accompanied by new sounds, people, etc. may overwhelm a person with ASD, while non-autistic persons can largely filter out such aspects and focus on conversations.

While persons with ASD have their strengths and unique abilities, some of them may struggle with social interaction, communication and behaviour, and experience delayed social development in identifying and using facial expressions, body language and relating to feelings and emotions.³⁰ This can create many hurdles for independent living for persons with ASD in coping with urban life and can exacerbate social isolation.³¹

A young adult with ASD, Mr. X, who is a voracious reader and is considered smart and talkative by most people in his vicinity, experiences extreme discomfort in group situations. The classroom setting with its varied, numerous, simultaneous stimuli is both overbearing and overwhelming for him, to the extent that it can trigger a meltdown. On one occasion, when he found himself in a classroom environment, he experienced a meltdown which those around him later described as “uncontrollable screaming”.³²

People not in the known oftentimes tend to take meltdowns for a tantrum. While the former is a deliberate emotional outburst with a specific goal, meltdowns are an involuntary response to nervous system overload.³³ Individuals experiencing meltdowns typically cannot respond to standard behavioural calming cues or techniques. Meltdowns are the physical expression of neurobiological chaos triggered by a perceived life-threatening situation.³⁴

Because persons with ASD can feel sensorily overwhelmed in certain situations, for expressing themselves or self-soothing, some may engage in stimming – or self-stimulatory behaviour that may be repetitive noises or body movements such as jumping, rocking vigorously, hand-flapping,

humming, or finger-flicking. These movements may sometimes even manifest as unintentional self-harm.³⁵ These assistive strategies tend to help restore a sense of order to an over-stimulating and chaotic sensory environment. However, for most non-autistic persons, such behaviours may come across as odd or awkward and evoke discomfort and judgement.³⁶

As Doctor Stephen Shore, an ASD advocate put it, “If you’ve met one person with autism, you’ve met only one person with autism.”³⁷ This diversity among those with ASD poses a challenge in imagining what an inclusive urban space would even look like. This is largely exacerbated by improper diagnosis and ignorance and lack of awareness of those tasked with policy-making and urban-planning.

It was learnt from various stakeholder consultations that different individuals on the spectrum have different triggers. Break in routine, commotion, crowds, bright lights, loud sounds, and other such sensory stimuli are among the most common triggers that might result in meltdowns.³⁸ For e.g., many individuals with ASD prefer to take the same route every day³⁹ or use headphones to turn down sensory stimuli. These ‘microplanning’ behaviours tend to serve as a way to cope with their environment and reduce anxiety⁴⁰ as they provide a sense of predictability, comfort and reduce the anxiety associated with unfamiliar surroundings. In addition to seeking familiarity, individuals with ASD often look for ways to reduce sensory overload. They may prefer to use app-based transportation services, such as ride-sharing or public transit applications, as these allow them to plan and control their journeys more effectively. Provisions for noise-cancelling headphones, dimmer lights, quiet rooms and similar initiatives in public and private spaces tend

to offer more enabling experiences and help enhance accessibility for persons with autism.

Non-autistic people need to become more aware and accommodative of such measures that are sometimes relied on by some persons with ASD, including sensory and inclusive design. This involves creating environments that cater to the needs of individuals with diverse sensory sensitivities, including autistic persons. This approach encompasses various elements such as controlling acoustics, utilising natural light while carefully managing it, organising spaces to facilitate smooth transitions, providing private spaces for retreat, and separating areas for quiet and more active engagements. The goal is to make spaces comfortable and accessible for everyone, irrespective of their sensory differences.⁴¹ However, given such negotiations of urban spaces are largely invisible, there is still a need to generate better understanding and awareness to ensure acceptance of such diversity and to further inclusion and transformation of urban spaces.⁴²

IV. Issues: Socio-legal Barriers to Inclusive Urban Spaces

The working paper relies on examples from stakeholder consultations and research on cities as spaces that largely cater to non-autistic or 'neurotypical' persons to indicate the main issues faced by persons with ASD in accessing urban spaces and being included in them. The following barriers stand out most prominently -

a) Stigma, Lack of Awareness and Sensitisation

The RPWD Act mandates the Central and State governments to conduct awareness campaigns and sensitisation programmes to promote values of inclusion, tolerance, empathy, and respect for diversity.⁴³ However,

the biggest challenge to inclusion in the current Indian context is the lack of awareness and sensitisation about ASD and the corresponding stigma this generates. While recent years have witnessed enhanced awareness, there is still a long way to go as reports of exclusion, misunderstanding and violence against persons with ASD remain commonplace.⁴⁴

In January 2023, a 23 year old was ill-treated and asked to exit one of Bengaluru's metro stations by the metro staff and security while he was travelling home from his vocational training institute, as co-passengers complained about what were perhaps self-soothing behaviours, and instead perceived and labelled as "odd" and "unusual" behaviour.⁴⁵ In another instance, several adults with autism were prevented from entering a private swimming pool in Dehradun owing to 'discomfort' of other swimmers, even after paying the fee and despite multiple attempts to communicate with and address the concerns of the pool owner.⁴⁶

Attitudinal barriers towards ASD start early. Upon consultation, several parents complained that schools deny children with ASD admission stating they do not have the resources to provide the necessary support to 'such' students.⁴⁷ Even where they do attend mainstream schools, children with ASD tend to get left out of school programmes, functions, and social events.⁴⁸ Most individuals therefore grow up without ever learning to accommodate or understand the specific needs of a person with ASD. This later informs exclusionary workplace cultures, policies, and etiquette.

This lack of sensitisation and awareness, despite a relatively vocal and active autism community is also reflected in how long it took for the recognition of ASD

as a separate category of disability in the law, warranting its own attention and consideration. ASD did not find any mention amongst the 7 categories of disabilities that were recognised under the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 ('1995 Act'). This is stated to be on account of the relative paucity of information, due to which ASD was mistaken or clubbed within the scope of "mental retardation" or "mental illness."⁴⁹ It was only under the National Trust Act, enacted in 1999, where 'autism' was separately defined as "a condition of uneven skill development primarily affecting the communication and social abilities of a person, marked by repetitive and ritualistic behaviour".⁵⁰

It was only as recently as in 2016 that ASD was recognised as a separate disability warranting provision of a 'disability certificate'.⁵¹ This came about after long-standing demands made by parents and ASD advocates for an official disability certificate on ASD, on the same lines as for other recognised disabilities.⁵² And yet, in complete ignorance of the nature of ASD as a lifelong condition, there is a validity period for the certification, based on whether the disability is 'temporary or permanent', with the certificate being valid only for 5 years "for those whose disability is temporary and are below the age 18 years."⁵³

Having detailed the above, it stands emphasised by various stakeholders that often, to include people with ASD, major structural changes are not needed. To begin with, people who are aware, empathetic, and willing to help can play a huge role in creating a culture of change.

b) Lack of Progressiveness and Specificity in Law and Policy Guidelines

The RPWD Act recognises 21 categories of disabilities (with the possibility of inclusion of more categories

by government notification) and clubs ASD within the definition and scope of 'intellectual disability'.⁵⁴ Even though the 2016 notification (framing guidelines for assessment and disability certification of ASD)⁵⁵, defined ASD to state that it "may or may not be accompanied by intellectual impairment", a fallout of the bucketing exercise performed by the RPWD Act, is perhaps reflected in the dearth of ASD-specific schemes and measures implemented under it.⁵⁶

Legal and policy measures in India exhibit little to no efforts for inclusion of persons with disabilities in the larger social environment, let alone measures specific to urban spaces and community settings.⁵⁷ Even though the RPWD Act provides for a broader definition of disability, accounting for social barriers, it is schemes under the National Trust Act (which specifically caters to persons with autism, cerebral palsy, mental retardation and multiple disabilities) that continue to hold fort in so far as awareness and social inclusion of persons with ASD is concerned. For e.g. The 'Badhte Kadam' scheme under the National Trust Act aims at generating community awareness, sensitisation of community stakeholders, social integration and mainstreaming of persons with ASD in all aspects of life.⁵⁸ However, the scheme (along with others) is also not well promoted through advertisements or posters, and stakeholders do not cite or recall them when asked about measures implemented by the Government. Additionally, other measures, such as the 'Autism-The Facts' booklet published by the National Trust⁵⁹ are still rooted in the medical model and fail to capture the legal and social dimensions.

Similarly, despite the progressive mandate of the RPWD Act, specific measures for ASD, where provided for, are couched in terms of reservations in employment for certified 'benchmark disabilities' constituting 40% or greater 'impairment'.⁶⁰ These entitlements are conditional on a 'Disability Certificate' that must state the 'percentage'

of disability. However, this tends to run into practical difficulties in matters of implementation as unlike the common misconception, 'spectrum' in ASD refers to diversity or variety and not 'gradient', which pertains to the severity of something. 'Spectrum' in the context of autism is specifically related to the wide range of diverse autistic characteristics and the various combinations thereof that can be observed across different domains.⁶¹ The prevalent reliance on quantification is representative of the pervasive and continued adoption of a medical and charity-based approach in the implementation of the RPWD Act. State policy has also been provider-centric, geared more towards ensuring reservation in employment, distribution of aids and appliances, inclusion in schools, etc,⁶² as opposed to identifying comprehensive measures for reasonable accommodation. While the state continues to neglect detailed and decentralised welfare measures and interventions for persons with disabilities, studies instead locate a trend of increased dependence on NGOs for envisioning disability-specific measures to guarantee a better quality of life for persons with disabilities.⁶³

c) Lack of Measures for Caregivers

Parents of children with ASD face unique challenges - not just in adequately and appropriately facilitating and responding to the diagnosis of their child, but also in the quality of support from family, the ensuing stigma and reduction of social life.

Persons with ASD experience a lot of society through their parents - their parents open up their environment and enable the realisation of a lot of their access and inclusion needs.⁶⁴ At the same time, stakeholders' consultations reveal that on many occasions, parents may curtail their and their child's social life, as they feel discomfort and unease when taking their child to public spaces, such as parks, restaurants or family functions.⁶⁵ There is fear that their 'autistic child' won't be accepted, would be stared at

and judged, especially if they display disruptive behaviour, such as meltdowns, or even stimming responses.⁶⁶

A stakeholder parent described⁶⁷ that soon after her child's ASD diagnosis, the doctor asked her to not search for answers on the internet. However, given the lack of clear information and support, she did just that and was overwhelmed with videos and online forums suggesting certain diets, going to a shaman, or trying past life regression therapy. While the journey was overwhelming and emotional, she went on to find a lot of support from other parents of children with ASD and benefited also from the involvement of people in her local community (such as a watchful security guard and helpful neighbours).

Where there is a shortage of trained professionals and high costs are involved in obtaining their service (as is largely the case in India⁶⁸), parents take on a lot of responsibilities as caregivers. Caregivers of persons with ASD encounter various challenges that have a profound impact on their lives. These include not only the initial process of accepting and responding to the diagnosis, but also difficulties in accessing appropriate support services and facing societal stigma. Additionally, family dynamics may be strained, and parents may experience 'caregiver burnout'. Burnout often arises from inadequate support and attempting to do more than one can handle physically or financially.⁶⁹

Stakeholders who are parents of a person with ASD repeatedly mentioned during the consultations about caregivers' fatigue - how caregiving can be overwhelming and how there is a need for a support system of caregivers who can respond to the situation, emulate the parents' concerns and provide them some time

and quietude to decompress and rejuvenate.⁷⁰ During Covid-19, parents had to take on a lot of the therapeutic and rehabilitative care of children with ASD at home.⁷¹ Studies document higher levels of stress and depressive symptoms among parents of children with ASD, which were exacerbated during the COVID-19 outbreak.⁷² Despite the commonplace nature of the issue, caregivers tend to be relegated to the background with there being no discourse on their issues or needs.

While the Mental Healthcare Act, 2017 ('MHCA') takes into consideration, at least to a certain extent, the significant role of families and caregivers, the same does not hold true in case of RPWD Act. Section 18(4)(c), MHCA provides for "mental health services to support family of person with mental illness or home-based rehabilitation". This provision acknowledges the role of a family member or caregiver of a person with 'mental illness' or a person requiring 'home-based rehabilitation'; and the various implications attending circumstances may have on the mental health and well-being of such a family member or caregiver. However, there is no similar or corresponding provision in the RPWD Act.

Both stakeholders and research indicate there is a paucity of mechanisms for local community members and barefoot workers in India (such as Accredited Social Health Activists ("ASHAs") and Anganwadi Centre Workers("ACWs")) to observe, step in, provide early intervention, therapy, stimulation, etc.⁷³ There is also a dearth of schemes and support by the government, with ASD-specific measures being carried out more prominently under the National Trust Act, instead of the more recent RPWD Act, as mentioned above. For e.g. the Sahyogi Scheme under the National Trust Act, provides

caregiver training by setting up 'Caregiver Cells' and seeks to create a skilled workforce to support persons with ASD and their families.⁷⁴ Even though this scheme exists on paper, it suffers from lack of publicity and reach, given the paucity of information about its state-specific implementation and availability, and also in light of the fact that the stakeholders consulted relied on support from NGOs more than this specific or any such government schemes.⁷⁵

d) Barriers in the Built Environment

As mentioned above, urban life is chaotic. The din of traffic, loud construction noises, crowded streets, uneven footpaths, noisy restaurants, and disorganised markets can make any person feel anxious and disoriented. Stakeholders tell us that persons with ASD thrive on predictability and structure in their daily routines.⁷⁶ However, many aspects of everyday life in India are neither automated, structured, or routine. Some of the prominent issues that make urban spaces inaccessible for persons with ASD are as follows -

1. **Sensory Overload and Inflexible Design:** Most urban spaces comprising both closed and open environments like movie theatres, restaurants, parks, malls, airports, etc., are often not designed keeping in mind the requirements of persons with disabilities, let alone the specific sensory requirements of persons with ASD. These environments often lack flexibility in design and are rarely adjustable to suit a diversity of needs.⁷⁷ Even where there is recognition of measures to reduce sensory overload through urban design, there is no appropriate detailing of the specific components to facilitate implementation. For e.g. The Harmonised Guidelines mention the need for designing 'quiet areas' or 'silent zones', "for persons with neuro diverse conditions, feeding mothers or others" in waiting spaces in areas open to the public.⁷⁸ However, there

is no explanation of what such quiet areas could comprise - such as adjustable or fluorescent lighting; non-jarring colours on the walls and furniture, etc. that could offer visual and sensory comfort to help provide a calming environment. Stakeholders in the realm of urban planning report this lack of detail as being the reason for why there is no local level translation of such measures.⁷⁹

2. Lack of easy-to-understand visual signages: Persons with ASD, and indeed, most users of urban spaces face difficulty in navigation and wayfinding in public spaces.⁸⁰ A stakeholder indicated that ASD may cause a higher sense of spatial anxiety when it comes to accessing new or unknown spaces.⁸¹ There is a need for orderly environments with wayfinding support and easy to understand signage. A case in point is public transport systems with their long queues, overcrowded nature and unpredictable wait times. This can cause such transport to feel unreliable, overwhelming, and disorderly. Studies suggest that visual support in the form of pictorial representations, signs, videos and photographs can provide assistance but is often not used in public spaces as standard wayfinding aides.⁸² Most public spaces in India tend to lack any signage or wayfinding aides or have only written signs and not much else; or rely on jarring loudspeaker announcements.
3. Lack of Green Spaces and Playgrounds: Even though it is well documented that parks can help provide a calming environment beneficial not just to persons with ASD, but also the larger set of urban residents, many cities lack such spaces.⁸³ In many Indian cities, the per capita green space available is less than the optimal 9 metre square per person across several cities.⁸⁴ The creation of parks and playgrounds usually lie at the discretion of local municipal authorities. With there being no periodic accessibility assessment, this aspect of city living also remains largely overlooked.

In Karnataka, laws such as the Karnataka Government Parks (Preservation) Act, 1975, the Karnataka Parks, Play-fields, and Open Spaces (Preservation and Regulation) Act, 1985 are dated and do not incorporate basic access measures for persons with disabilities, such as provision of ramps or tactile paving. Thus, even where playgrounds and parks exist, they are not equipped for the needs of persons with disabilities. Some stakeholders explained that many children with ASD are known to retreat unexpectedly and suddenly from crowded spaces to decompress and to avoid a meltdown due to sensory overwhelm.⁸⁵ Therefore, design strategies that make such spaces easy to navigate, provide quiet spaces to decompress and manage sensory overload from overstimulation - like providing private "escape spaces," which provide a neutral sensory environment with minimal stimulation to retreat to are needed.⁸⁶ However, such parks and public spaces are not only rare but are also not designed to include specific elements that could help persons with ASD. These elements may include measures for compartmentalisation (segregated functional spaces), safety measures (avoiding sharp edges and corners), sensory zoning (grouping spaces into 'high-stimulus' and 'low-stimulus' areas), and inclusion of transition spaces (spatial sequencing to facilitate sensory recalibration like distinct nodes, sensory rooms) which can help persons with ASD take a break and cope with sensory challenges and overwhelm during movement between different stimulus levels⁸⁷.

In any case, it must be ensured that these measures do not remain tokenistic or standalone. So far, it appears that most efforts at inclusion are only geared at one-

measure, small-scale attempts at accommodation (such as installing ramps for wheelchair access and calling a space fully accessible) and are rarely aimed at centring the needs of persons with disabilities, let alone less visible disabilities such as ASD in the design of spaces, initiatives, or programmes. This tends to result in access to only selective, separate, specially designed spaces while leaving the majority of spaces unchanged and non-accommodative. As a mother of two boys with ASD pointed out, instead of focusing on one-off measures, “we want reasonable accommodation within existing spaces and not always a separate que or a separate school.”⁸⁸

V. Way Forward

There is a long way to go in better understanding and implementing measures towards realising inclusive and accessible urban spaces for persons with ASD. A first step is for non-disabled and non-autistic stakeholders to understand the social, attitudinal, and physical barriers within ‘disablist’ urban environments that impede participation in everyday life for persons with ASD. As a stakeholder explained, ‘the starting point for inclusion is one’s own awareness and behaviour which in turn influences whether a person with ASD feels included or not.’⁸⁹

The following sections put forward measures that should be practised and implemented through intervention of stakeholders like appropriate governments, local authorities, and municipal bodies, DPOs, caregivers, civil society organisations and self-advocates. These are based on the issues and measures pointed out in stakeholder consultations. They also rely on existing precedents that have shown value and positive effect in improving access to urban spaces for persons with ASD.

a) Measures for Dispelling Stigma and Awareness Generation

As mentioned above, insufficient awareness, misinformation, and lack of sensitivity amongst individuals, communities and society are perhaps the most onerous impediments to inclusion. Various stakeholders, including individuals with autism, their families, professionals, and advocacy groups, have been sharing their experiences and knowledge online⁹⁰ in the last few years. This has, to an extent, aided in dispelling myths, stigma, creating awareness and sensitising large groups of people. Along with these efforts, a mix of institutional and collaborative efforts (as detailed below), should be adopted to boost awareness and sensitisation at a wide scale, and amongst several stakeholders and communities in urban spaces -

Sensitisation and Training Efforts: There needs to be greater emphasis on ASD-specific sensitisation, training and awareness efforts amongst stakeholders that are responsible for making a city accessible and inclusive - spanning government officers, law enforcement agencies, local bodies and municipal authorities, architects and urban planners. Many of them are oblivious to the barriers faced by persons with ASD and are hence unaware of how to include and support them. Government authorities should take strong initiative in implementing training programmes, targeted workshops and other such capacity building efforts that bring disability and ASD-specific considerations and awareness to the forefront for these stakeholders.

One stakeholder described how while travelling, she came across the mother of a child with ASD who was struggling to navigate the space and was hesitant to ask for help as she did not know who to approach and was also weary of the attention it would draw.⁹¹ A lot of the worry and inhibition

faced by persons with ASD and their caregivers, in travelling and interacting with various urban spaces can be mitigated by the deployment of sensitised personnel in such spaces, besides clear signages and guidance as to the appropriate channel for assistance and accessing the same. An informed society that doesn't judge or exclude, but instead supports and includes would also contribute to dismantling the narrative of alienation and creating cities that are easier to navigate without fear or hesitation.

Large-Scale Awareness Building: Existing resources published by the government towards awareness generation, especially specific to ASD, are limited, dated and mostly available under the aegis of the National Trust Act. There is a need for reliable, accurate, regularly updated, and scientifically grounded information that uses sensitised language, targeting not only the wider community but also parents, caregivers, and specialists. Towards this end, it is essential that the government regularly update the available resources, such as the 'Autism-The Facts'⁹² booklet published by the National Trust.⁹³ Central and state governments with their mass reach and financial resources must contemplate active collaboration with DPOs and civil society to develop large-scale awareness campaigns and for other similar initiatives and information dissemination activities to foster greater, widespread understanding and dispel misconceptions.

In 2018, to mark the 10th year of observance of World Autism Awareness Day, Qutub Minar in Delhi joined other global structures that were lit up with blue lights as part of the international #LightItUpBlue campaign to increase sensitisation and acceptance of autism in the society. The event

was organised through collaborative efforts of the Archaeological Survey of India (ASI), Ministry of Social Justice and Empowerment and Autism Centre for Excellence (ACE).⁹⁴

Participatory Policy Planning: The government has embarked upon and implemented various measures, such as the Smart Cities Mission⁹⁵ the Accessible India Campaign⁹⁶ or the Atal Mission for Rejuvenation and Urban Transformation ('AMRUT')⁹⁷ towards achieving better planned and accessible cities that improve residents' quality of life. These have empowered local bodies and municipalities to start working with innovative city plans geared towards better management of cities and also, to an extent, promote inclusion of persons with disabilities.⁹⁸ However, the inadequate representation and participation of the ASD community and its stakeholders in the planning process itself, results in a city that is designed only for a neurotypical population, despite efforts to upgrade urban spaces and ensure more inclusive environments. Policy making that is inclusive, sensitised, and aware will help translate these efforts into more comprehensive measures that address the accessibility and inclusion needs of persons with disabilities, particularly invisible disabilities - and persons with ASD.

b) Incorporating Specific Measures in Urban Spaces

With increased awareness of the needs and requirements of persons with ASD, there is new research and recommendations emerging relating to specific measures that can be undertaken, especially in relation to cities.⁹⁹

Some of the prominent measures include -

Inclusive Design Policy: Provision of more 'sensory sensitive' urban spaces as well as calm spaces or quiet rooms in areas that have high sensorial load - not just in

waiting spaces as detailed in the Harmonised Guidelines, but in a range of urban spaces that are identifiably crowded, bustling or overwhelming, such as in malls or airports. The same may be indicated in accessibility standards and guidelines, such as those pertaining to civil aviation. Research indicates that modulating the physical environment via careful attention to spatial arrangement, acoustics, lighting, furnishings, etc. can help persons with ASD relax and focus.¹⁰⁰

In India, there are a few examples of proactive effort to provide such sensory sensitive experiences that are inclusive of persons with ASD. This was observed in the case of cinema halls offering 'sensory friendly' movie screenings,¹⁰¹ or with stores offering a 'quiet hour' to encourage persons with disability to shop in comfort.¹⁰² In 2019, Big Bazaar, the prominent retail giant earmarked the opening hour on every Tuesday of the week as 'quiet hour' across select stores throughout the country. During this hour, the stores created a sensory-friendly environment by dimming the lights, minimising announcements, and switching off music across the store. Big Bazaar also provided a pictorial checklist to aid customers with navigating the store and locating products¹⁰³.

Provision of Green Spaces: The suggestion for calm spaces is often coupled with emphasis on the provision of abundant green and blue spaces given that they are reported to help ease the stress and anxiety of otherwise chaotic urban spaces,¹⁰⁴ and have a beneficial impact on physical and mental well-being.¹⁰⁵ Urban planning missions, including city and town planning efforts should contain specific provisions for green pockets in crowded and closed urban spaces such as airports, train

stations, healthcare establishments and office spaces besides educational institutions and residential areas. Stakeholders have suggested the equipping of spaces such as parks, playgrounds with toys and installations for sensory stimulation for making them more inclusive- a healthcare professional provided the example of parks such as the Garden of five senses in Delhi, which can provide “sensory integration therapy through pebbles, water, its various sights and sounds”.¹⁰⁶ The Government of Karnataka should follow suit, providing for measures for sensory stimulation as well as safety.

Sensory Gardens: Similar to, but building on the initiative by organisations like Kilikili,¹⁰⁷ a registered Trust established by parents of children with disability that endeavours to develop accessible, inclusive play spaces for all children, regardless of their abilities. Kilikili partnered with the Bruhat Bengaluru Mahanagara Palike between 2006-10 to construct multi-ability children’s parks, sensory gardens with tactile flooring, a sand pit, mini pond, sound instruments such as drums and bells, and a tactile panel wall have been developed in the cities of Pune, Mumbai and Vadodara.¹⁰⁸ Similar to Kilikili, these have largely emerged from private and collaborative efforts to provide inclusive play areas, including for children with ASD. These have been praised for providing stimulating environments for children that help engage their various senses, including sight, smell, sound, and touch. While they have helped aid children with ASD by creating spaces that offer appropriate sensory stimuli, Kilikili has also tried to incorporate calm or quiet corners in its parks to cater to the wide diversity of sensory needs of children with ASD.

Mandate for Inclusivity Information: Stakeholders suggest simple measures such as publishing information about which spaces are sensory friendly and likely accessible to persons with ASD, along with pictures of the same (as is done for restaurants by Zomato, but with disability information limited to that of wheelchair access), would be very helpful, given especially that persons with ASD tend to be uncomfortable with new environments.

These are simple and implementable measures that should be reflected in the Harmonised Guidelines, as well as in most urban planning legislations and municipal legal frameworks. Many stakeholders also recommend the provision of visual support and 'picture exchange communication systems' in crowded urban spaces.¹⁰⁹

Message boards and sign language are found to be better paths to communication and help substitute fully verbal communication.¹¹⁰ These measures have shown success in places like restaurants, stalls or booths, facilitating easier communication between persons with ASD, who can present a single picture of a desired item or action to a 'communicative partner' who immediately honours the exchange as a request.¹¹¹

The Delhi Metro serves as an exemplary model for standardising public spaces with its clear visual layout and how it incorporates easy to understand signage, with symbols and pictorial support, navigational strips, and timely transport. Implementing these measures would not pose a significant financial burden, can be accomplished effortlessly, and would ease the navigation barriers of persons with ASD significantly.¹¹²

Many stakeholders quote the example of the Delhi Metro and suggest it may be beneficial to equip other places of transport such as railway stations,

inter-state bus terminals, as well as crowded malls and marketplaces with similar visual signage and easy to read, coloured, navigational strips.¹¹³

The incorporation of such and other measures are becoming increasingly common in a growing number of countries as the awareness and incidence of multiple sensitivities and persons with ASD increases¹¹⁴ and India needs to follow suit.

c) Identifying Measures to Support Caregivers

To support caregivers in overcoming the barriers and challenges of including persons with ASD in various social and urban spaces, the following measures can be considered by DPOs, civil society organisations, local bodies, and other stakeholders to help caregivers, particularly family members and informal caregivers:

Community Caregiving Support: Parents and family members require caregiving support, not just in the form of services provided by trained specialists such as occupational and speech therapists and counsellors, but also in the form of local community support networks. State governments, in coordination with local level authorities, should train community workers such as ASHAs, Multi-purpose Workers (MPWs), ACWs, etc. in providing assistance and training to persons with ASD for performing day-to-day tasks and independent living. Along with support from barefoot community-level workers, community support groups should be organised by local governments (at the ward and municipality levels). This may be done in collaboration with local autism organisations, community centres, or as was done during the Covid-19 pandemic, via online platforms, allowing caregivers access to support from anywhere. Such measures provide a sense of community and offer a supportive and non-judgmental environment to connect,

share stories, exchange advice, and learn from one another.

Bookosmia, an online publishing platform, features a dedicated section on its website called 'Parents Speak' where parents of children on the autism spectrum share personal experiences through video content. 'Not That Different' Parent Club, a community of parents of children with ASD facilitates mutual learning and provides essential support through insight-sharing and experiential guidance. This helps parents and caregivers cope more effectively and provide enhanced care for their children with autism in a collaborative manner.¹¹⁵

Dedicated Training Programmes: Dedicated training programmes for caregiving support should be developed and offered by the State government, in conjunction with DPOs and local level authorities, roping in trained professionals, self-advocates and other service-providers. Such programmes will help caregivers understand the phenomenon, circumstances, needs, strengths, support needs which will enable them to perform their role in a manner that is not just conducive to their own well-being but also maximises requisite support to persons with autism. Moreover, trained parents can become a valuable source of information and support for others in their local communities, expanding the program's impact through a ripple effect.

Action For Autism offers a Parent Child Training Programme which aims to empower parents by helping them understand their child, their autism, and the unique learning style of children with autism. The programme helps the primary

caregivers effectively manage challenging situations and work with children on the spectrum from a place of acceptance and comprehension.¹¹⁶

Respite Care/Alternative supports for Caregivers: DPOs, civil society organisations and support groups can collaborate with trained professionals and train volunteers to offer 'respite care'. This is a form of temporary care provided to individuals with complex care needs, including children, in order to offer caregivers a temporary reprieve from their caregiving responsibilities.¹¹⁷ It can encompass various forms, such as a few hours of caregiving support at home or a brief period of stay in a nursing home or assisted living facility. State governments should coordinate with such organisations in the provision of such initiatives and boost the quality of services in alternative accommodation facilities such as nursing homes or assisted living facilities.¹¹⁸ The purpose is to provide caregivers with much-needed respite, allowing them to recharge and attend to their own needs before returning to their caregiving duties.

Employment Support Measures: In addition to the above point, the government (as well as private offices) should consider offering parents of children with ASD relaxation in working hours and accommodations like work from home to enable them to access therapy and other support services and to take care of the children in such terms as they consider adequate, without having to compromise on their own career.

In May 2023, the Kerala government announced relaxations in working hours for its employees who have children with ASD. The scheme allows one parent of a child with ASD who is a government employee to work for a maximum of 16 working

hours in a month.¹¹⁹ The Karnataka government may also consider such measures, starting at least with the provision of the same to their employees.

The impact of ASD-friendly spaces goes beyond individuals with ASD. The principles of inclusive design and neurodiversity consideration benefit a wider range of individuals, including those with anxiety disorders, sensory sensitivities, and other cognitive differences. They can also be appreciated by individuals who may temporarily experience heightened stress or sensory sensitivities, such as parents with young children, individuals with temporary disabilities, or older adults. By prioritising accessibility, predictability, and safety, these spaces foster a more inclusive and accommodating environment, contributing to the overall well-being and comfort of the community at large.

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