

Inclusive Urbanism

Accounting for the Vulnerabilities of Persons with Invisible Disabilities



Realising
Community
Living in the
City for
Persons with
Intellectual
Disability

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I. Introduction

The 'Inclusive Urbanism' working paper series is an attempt to engage with the question of accessibility to urban space from the perspective of less visible, often overlooked, and invisible disabilities. The first working paper¹ in the series performs a context-setting exercise by detailing the background and key considerations to be covered in relation to how and why urban spaces are inaccessible for persons with invisible disabilities. The next set of working papers separately and specifically look at accessibility to cities from the perspective of those with mental illness and psychosocial disabilities; those with intellectual disabilities and persons with autism spectrum disorder ('ASD'). In doing so, the working papers draw attention to the role of the urban environment in enabling better mental health, overall well-being, and quality of life for persons with these specific invisible disabilities, as well as for the larger set of urban residents.

This working paper attempts to detail what inclusive urban spaces would look like for persons with intellectual disabilities. India is reported to have one of the highest absolute numbers of persons with intellectual disability in the world.² Research estimates that 2.6 crore people have intellectual disabilities in India, out of which more than 1.5 crore are under the age of 10 years.³ This is a sizable number despite the likelihood that most persons in this category are underrepresented and have not been formally identified.⁴ It was not long ago that persons with intellectual disability were cared for in settings quite separate and isolated and were deprived of full integration into their communities. Their sheer number, and yet their exclusion from and invisibility in cities, begs consideration of measures needed to improve their social inclusion and quality of life in these urban settings. The Covid-19 pandemic has also generated large-scale realisation of the need for better access to resources, meaningful social

inclusion and community-based interaction and support to all regardless of their specific needs and capabilities.

This working paper attempts to highlight how a social dimension to considerations of 'accessibility' is often missing from the imagination of law and policy frameworks. It explores the role of social inclusion and community living, which can maximise opportunities for integration and interaction of persons with intellectual disabilities with their larger social and urban environment. In doing so, this paper draws attention to how many of the prominent barriers to such access and inclusion stem from negative attitudes and stigma of people and communities—barriers which are also invisible and lead to the exclusion and isolation of persons with disabilities, and which ultimately hinder their access to social equality.⁵ This paper argues that a 'right to community living' enshrined in national and international legal frameworks is a crucial gateway through which this social dimension of accessibility can be developed.

II. Methodology and Structure of the Working Paper

The research for this working paper is based on a review of published literature and policy documents about initiatives to change attitudes towards persons with intellectual disabilities and measures to promote their social inclusion and provide appropriate avenues for community support. Reliance is also placed on one-on-one stakeholder consultations held in the form of semi-structured interviews with a variety of stakeholders including persons with intellectual disability, their caregivers, disabled people's organisations ('DPOs'), disability scholars and accessibility consultants, doctors, psychologists, therapists as well as architects and urban planners.

Given the nascent discussion of this topic, especially in India, the consultations with stakeholders were very useful in highlighting lived experiences, and in bringing out a better understanding of on-ground issues and measures needed to boost access to and inclusion of persons with disabilities within urban spaces.

In this working paper, relevant and applicable legal and policy frameworks at various levels have also been enumerated and explained, and with a focus, where relevant, on Karnataka, notably Bengaluru. This includes the United Nations Convention on the Rights of Persons with Disabilities ('UNCRPD'), the Rights of Persons with Disabilities Act, 2016 ('RPWD Act') and its subordinate framework, including the Karnataka Rights of Persons with Disabilities Rules, 2019 ('Karnataka RPWD Rules'); the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 ('National Trust Act') as well as local laws and policies in Karnataka, including the Karnataka Municipal Corporation Act, 1976 ('Karnataka Municipal Corporation Act') the Karnataka Municipalities Act, 1964 ('Karnataka Municipalities Act') and the Bruhat Bengaluru Mahanagara Palike ('BBMP') Act, 2020.

The working paper is structured such that it first lays out the scope and understanding of intellectual disability and then details approaches based on social inclusion and community living that are beneficial in providing an improved standard of access and quality of life for persons with intellectual disability, as they conduct their lives in cities and urban spaces. The working paper provides an overview of the prominent legal frameworks which govern disability rights, details measures and gaps in them, towards social inclusion and implementing a right to community living for persons with intellectual disability. Finally, the working paper details a forward-looking agenda to help promote social inclusion and implement a right to community living thereby facilitating

larger inclusion and access for persons with intellectual disabilities within urban spaces. The working paper also contains an annexure which brings out case studies that try to address the barriers to social inclusion, and that provide means of achieving better community living and inclusion for persons with intellectual disability.

III. Scope and Understanding of Intellectual Disability

To understand the various approaches that have been used to promote the inclusion of persons with intellectual disabilities in cities and urban spaces, it is necessary to first sketch out a broad understanding of the term 'intellectual disability' and acknowledge the diversity of conditions and impairments that are brought within its fold.

What is Intellectual Disability?

Intellectual disability is widely understood as referring to a condition that involves limitations in cognitive ability, generally manifested during the developmental period, and accompanied by impairments in adaptive skills that are necessary for everyday living.⁶

Specifically, adaptive functioning is understood in terms of failure to meet developmental and sociocultural standards for personal independence and social responsibility.⁷ Numerous factors are thought to either facilitate or hinder adaptive functioning in daily life, such as communication, social participation, and independent living across multiple environments such as home, school, work and community.⁸ This understanding of intellectual disability puts significant emphasis on the ability to live independently, conduct daily communications and participate socially across various environments.

In India, the legal definition of intellectual disability places similar emphasis on everyday social and practical skills. The definition of a person with disability under the RWPD Act includes a person with long term intellectual impairment “which, in interaction with barriers, hinders his full and effective participation in society equally with others”,⁹ and the Schedule to this law which specifies the types of disabilities covered by it defines intellectual disability as, “a condition characterised by significant limitations both in intellectual functioning (reasoning, problem solving) and in adaptive behaviour which covers a range of every day, social and practical skills...”¹⁰

This working paper lays focus on these social and adaptive facets of intellectual disability to analyse the lack of ‘fit’ between a person with such disability and their socio-cultural community and environment that accepts only a fixed ‘normal’. It argues for promoting measures for social inclusion, participation, and community support, regardless of any difference in ability and explores methods to achieve the same in law, theory and practice.

Mental retardation

As mentioned in the first working paper, the term ‘mental retardation’ is now largely being replaced by the term ‘intellectual disability’¹¹ on account of the stigma it carries. There are several other terms used in literature to describe such disability—such as cognitive disability, intellectual impairment, intellectual developmental disorder, learning disability or developmental disability. While legal definitions and criteria for determining intellectual disability vary with prevailing law and jurisdiction, intellectual disability assessment typically involves the conduct of a standardised test of intelligence

quotient ('IQ test') and use of other standardised tests and assessments for adaptive behaviour, as well as clinical judgement.¹²

Since the publication of the World Health Organisation's International Classification of Diseases, 11th revision ('ICD-11'), the term has been now changed to "intellectual developmental disorders". While appreciated for moving away from its earlier use of the term 'mental retardation', it adds one more nomenclature to the already varied and complex terminology, while there remains sustained prejudice, discrimination and lack of understanding on intellectual disability.]

Terminology in this Working Paper

Within the larger understanding of intellectual disability, specific conditions are brought in as per diagnosis as well as constantly evolving understanding—such as down syndrome, autism spectrum disorder ('ASD'), specific learning disabilities such as dyslexia, attention deficit hyperactivity disorder, dyscalculia, etc.¹³ While the current definition under the RPWD Act follows an inclusive approach, it lists and defines only "specific learning disabilities" and "autism spectrum disorder"¹⁴ Given the broad understanding of intellectual disability, and informed by stakeholder consultation,¹⁵ it is apparent that there is no one constant definition of intellectual disability and limited consensus on which conditions fall within its scope. This working paper is not attempting to adopt any one interpretation or categorisation of intellectual disability over another. In line with the scope of this working paper series on 'Inclusive Urbanism', we will be placing specific focus on the social and adaptive skills and functioning that are observable in persons with intellectual disabilities, and which require a better understanding

and implementation of access measures involving social inclusion and community participation in cities and urban spaces. Towards this end, the working paper will be referring to the understanding of intellectual disability as per its definition in the RPWD Act.

IV. Social Inclusion and the Exclusion of Persons with Intellectual Disability in a City

Social inclusion, in relation to persons with disabilities involves their active participation and interaction in civil and community life¹⁶ It encompasses the nature of relationships and the feelings of belonging that a person can develop within the community they live in. This includes the development of interpersonal relationships such as friendships with members outside of one's own immediate family and paid caregivers, on account of sustained inclusion in everyday life of the community.¹⁷ Studies detail how an environment or space that encourages regular, sustained interactions for persons with intellectual disabilities is likely to have a more positive impact than environments that limit or create opportunities only for fleeting, infrequent interactions.¹⁸

Social exclusion, as a concept, expresses disadvantages and consequences in relation to certain norms of social, economic or political activity related to individuals, households, spatial areas or population groups.¹⁹ A study on persons with disabilities in India describes social exclusion as contributing to a sense of not belonging, diminished opportunities to participate and unequal access to resources and rights.²⁰ It details how the experience of stigma, discrimination and social exclusion impedes help-seeking, social participation and recovery of persons with disabilities. At the community level, social exclusion is described in relation to the degree of

participation or acceptance of persons in day-to-day life by other individuals, groups, and communities.

Persons with intellectual disabilities have historically been excluded from most public and community settings, as they have been stigmatised, subjected to a history of institutionalisation, involuntary sterilisation,²¹ and various other forms of segregation and discrimination.²² The inclusion and acceptance of persons with intellectual disabilities further declined with the rise in industrialism²³ as they were considered incapable of making any productive contribution, excluded from access to most opportunities, and instead considered to be non-essential to society and a burden on its limited resources.²⁴ The process of exclusion and stigmatisation thus represents the rejection of groups that are considered as a burden to society.

Women and girls with intellectual disabilities have faced greater instances of violence, exclusion, and institutionalisation²⁵ compared to non-disabled persons, due to the compounded effect of their disability and gender. There are reports from around the world of forcible institutionalisation where women and girls with intellectual and psychosocial disability are subject to appalling living conditions.²⁶ In India, the conditions in the Asha Kiran complex which houses persons with mental illness and intellectual disability garnered much attention, as it was reported to be overburdened with housing over 900 children, when intended to house only 350,²⁷ and as news reports carried distressing information of the living conditions and a staggering death toll of over 600 since 2001.²⁸

The rise of deinstitutionalization efforts²⁹ led to the movement of persons with intellectual disabilities into community settings. While there is now a growing understanding and concerted effort to ensure that persons with intellectual disabilities are not

institutionalised and excluded from society, where their adaptive and social functions further deteriorate,³⁰ in the absence of measures for social acceptance and community integration, persons with intellectual disabilities continue to confront social isolation and discrimination. The lack of social support such as through participation in community life, provision of sufficient integrated and affordable living options; healthcare and support from community workers means that persons with intellectual disability also face increased homelessness, poverty, and social exclusion.³¹

Owing to the scarcity of such support services and community resources,³² and perhaps also on account of Indian socio-cultural practice, persons with intellectual disability in India predominantly live with their families and are supported by their familial social networks.³³ Despite the strong involvement of family and kinship in providing support and caregiving for persons with intellectual disabilities, the need for other pillars of support, as mentioned above, is acute, given the growing nuclearisation of families and erosion in larger family support in recent years. One of the common negative outcomes of this, reported by both stakeholders and secondary research is that there are many instances of under stimulation and overprotection of children and adults with intellectual disability, leading to worsening social and adaptive skills and undesirable behaviours.³⁴

In urban areas, the lack of support for persons with intellectual disabilities and negative attitudes are much more pronounced given that urban communities stress on specific aspects of productivity in their fast-paced lives, and do not see persons with intellectual disabilities as active contributors to such spaces. In contrast, rural areas are described as less stressful and impose lower expectations on the kind of work and contribution persons with intellectual disabilities need to do there.³⁵

Even with progress in the understanding, various rights and protections afforded to persons with disability, they are regularly mistreated, stigmatised and denied basic human dignity. This in turn impacts their ability to access the prospects, privileges, and resources they need to achieve their full potential. Thus, despite social inclusion being a significant contributor of well-being for people, for persons with intellectual disability, it remains something that many rarely experience in the broader community.³⁶

V. Approaches to Foster Social Inclusion and Community Living

Consultation with various stakeholders makes it quite clear that social inclusion and access can have different meanings for different persons with intellectual disabilities.³⁷ For example, while people with milder intellectual disabilities may be able to conform to the social and cultural norms and expectations of their communities, those with severe intellectual disability are not as able or willing to participate in neurotypical social activities like work and recreation.³⁸ There is a growing understanding that public attitudes and behaviour—both relatively invisible indicators and measures for inclusion—have a huge role to play in the social and community integration of persons with intellectual disability.³⁹

Measures and avenues for community living are beginning to be understood and pursued for realising the community integration and social dimension of accessibility for persons with disabilities. Community living in this context, refers to measures by which persons with disabilities are able to live in their local communities as equal citizens, with the support that they need to participate in everyday life. This includes living in their own homes or with their families, going to work, going to school and taking part in community activities.⁴⁰

Recent research is coming up with specific approaches to encourage social inclusion and participation of persons with disabilities.⁴¹ While the 2030 Agenda for the Sustainable Development Goals emphasises on inclusive development and stresses on 'leaving no one behind', the New Urban Agenda or Habitat III specifically recognises the potential that harnessing the transformative nature of urbanisation provides in terms of ensuring that no one is left behind.⁴² When it comes to an assessment of the living conditions and well-being in cities, many recent studies are emphasising on the "quality of urban life". This is a recognition of the fact that while cities, being centres of innovation and technology, may offer employment, higher education and specialised services, they however, struggle for social cohesion and suffer from problems of social inequality, environmental degradation, crime, etc.⁴³ There is a perceptible and growing recognition of the need for identifying measures that promote a better quality of urban life.

The following paragraphs seek to highlight approaches that help increase participation and decrease exclusion of persons with intellectual disabilities from mainstream settings and communities. Instead of exploring changes that specifically promote their productive contribution, such as what skills, employment and other livelihood opportunities persons with intellectual disabilities should be equipped with, this working paper will talk about how cities, neighbourhoods and communities can be brought closer to persons with intellectual disabilities. Accordingly, this working paper is highlighting studies and approaches⁴⁴ that focus on inclusion as a responsibility of communities, thus lifting the focus on and responsibility of inclusion from being the isolated concern of persons with intellectual disabilities themselves.

a) Understanding 'Access' for Persons with Intellectual Disability

For persons with intellectual disability, the barriers to accessing public spaces in the city is qualitatively different from a person with a sensory and/or physical disability. As noted above, persons with intellectual disability often experience reduced independence, and need varying degrees of person-based, family and community support in order to be able to access various urban spaces such as parks, schools, airports, restaurants, malls etc.⁴⁵ Further, complete dependence on family and paid caregivers leaves persons with intellectual disability vulnerable in situations where their primary caregivers may pass away or are otherwise indisposed.

This reliance on family and community networks necessitates attitudinal shifts among the non-disabled. It is not the responsibility of persons with invisible disability to change to be included. Rather, inclusion is the collective responsibility of communities at a localised level.⁴⁶ To ensure that access remains consistent and long-term, practices that support the creation of inclusive neighbourhood communities and a sense of social cohesion need to become a policy priority. In other words, the concept of access itself must be expanded to necessarily include a social dimension.

Stakeholder consultations inform us that even where measures are implemented to provide a better standard of living for persons with intellectual disability, such as by provision of alternative accommodations, they would not be implemented in a manner so as to facilitate integration within the community: this was so in cases where shelter homes for persons with intellectual disabilities were not even located within city spaces, but built on the outskirts.⁴⁷ This feeling of exclusion, of not being a part of their communities, further pushes people with intellectual

disability to the margins of society and impedes their access to urban life and all that it has to offer.

Thus, to imagine access, we need to move beyond its spatial and physical dimension and incorporate a social dimension. The social dimension is not simply a question of where one lives but also the nature of relationships and a sense of belonging a person with intellectual disability is able to develop within the community that they live in. A broader understanding of access is also one that promotes the quality of life of a person with intellectual disability. A key pillar of this quality of life approach⁴⁸ is facilitating social inclusion through community engagement. High levels of appropriate and inclusive community engagement, such as through daily interactions with community members, or through activities in sports and recreation, or in support groups; lead directly to an improvement in the quality of life by enhancing social well-being, and happiness. Being a part of one's community also provides for many more opportunities of choice, control, independence, and self-determination⁴⁹—all of which are essential for better access to one's city and urban space.

b) Realising Community Living for Persons with Intellectual Disability

The understanding and need of, and entitlement to community living, is only developing in recent years. Much work remains in understanding what components of community involvement matter, in identifying how to enhance these opportunities, in understanding how to increase community acceptance, and in ensuring that persons with disabilities experience the full range of community immersion experiences.⁵⁰

Disability experts identify three key pillars to evaluate the quality of community participation by a person with disability.⁵¹ These are:

1. The type of activity a person with disability participates in;
2. The nature of the environment that they are a part of; and
3. The degree of involvement they experience within these spaces.

Below, we elaborate on each of these pillars.

i) Type of Activity

There are many different types of activities that constitute 'community life'. A non-exhaustive list of activities that take place within online and offline spaces are leisure activities, such as hobbies, arts, and sports; political and civic activities or organisations; productive activities, like employment or education; consumption or access to goods and services (e.g.: restaurants, shopping malls etc) and religious and cultural groups and activities. Thus, urban spaces like schools, offices, places of worship, recreational centres, restaurants, parks, malls, markets etc. are potential spaces for participating in community life.

ii) Nature of Environment

Each of the above-mentioned activities can take place within settings with varying degrees of integration. For instance, when persons with intellectual disability live in spaces where a majority of their interactions happen within the family or paid caregivers, such an environment can be described as segregated.⁵² A good example of this are some types of group homes or residential living facilities.⁵³ As mentioned above, many such facilities/homes are located far from the main city.⁵⁴ Even if a person with intellectual disability stays with their families, they tend to not have any relationships or interactions with anyone outside of their immediate family or paid caregivers.⁵⁵ This is because families of persons with intellectual disabilities often worry about the hostility and mistreatment they might encounter on exposure.⁵⁶ Such

spaces where the majority of social interactions take place within the family members and paid caregivers, the environment can be categorised as segregated.⁵⁷

An environment can be categorised as non-segregated if it offers a person with intellectual disability the opportunity to interact with non-disabled persons outside their families and paid caregivers.⁵⁸ This would include for instance, spaces like restaurants, cinema halls, parks situated within a local community. It may also include residential environments where non-disabled persons interact with persons with intellectual disability; for instance, where volunteers participate in some sort of leisure, cultural or entertainment programme organised within the group home. Cyber communities in the form of social media can also be a non-segregated environment. These activities are important opportunities for social interaction, developing confidence and building connections among persons with intellectual disability.⁵⁹

Levels of interaction and communication may differ across different environments. An environment or space that encourages regular, sustained interactions for persons with intellectual disabilities is likely to have a more positive impact than environments that limit or create opportunities only for fleeting, infrequent interactions.⁶⁰ For instance, one may think of the difference between visiting a mall versus a local library.

iii) Degree of Involvement

Along with the type of activity and environment, a third metric to assess the quality of community living is the degree of involvement experienced by a person with intellectual disability. This could either be experienced as presence, encounter, or participation.⁶¹

Presence refers to simply being physically or virtually present within a community (online or offline) but without

much personal interaction or contact with others within the community.⁶²

Encounter, on the other hand, means meetings between a person with intellectual disability and other community members that could either be fleeting or more sustained.⁶³ Many day-to-day encounters with shopkeepers, servers at a restaurant, etc. would fall under this category. Such encounters are important springboards for participation and connection.

Finally, participation in the everyday life of the community goes beyond daily encounters to mean the development of interpersonal relationships such as friendships with members outside of one's own immediate family and paid caregivers. Such relationships are developed when one typically can participate with others in a common activity or work towards a common goal.⁶⁴ For instance, this could include working in an office space, volunteering at a local community centre or even playing team sports. Such activities can give rise to a feeling of belonging and connection and provide space for developing mutual relationships within the community.⁶⁵ Some features of participation are equal membership status with other non-disabled persons, mutually rewarding and reciprocal relationships and working towards a common goal as part of the community.⁶⁶

Disability researchers have pointed out that friendships and peer relationships are an integral part of feeling included.⁶⁷ There is a need to move beyond presence and encounter towards participation by fostering more meaningful relationships within the community.

Having sketched the contours of access, inclusion and community living for persons with intellectual disability, next, we will bring out the role of the current legal framework, schemes, and local measures in incorporating and fostering the above approaches to promote access,

social inclusion and community living for persons with intellectual disabilities.

Finally, a way forward will help strategize and lay out the kinds of measures and forward-looking steps that need to be taken, both implemented and integrated with the legal and policy framework—to truly realise a better quality of life for persons with intellectual disability in cities and urban spaces.

VI. Role of Law and the Current Legal Framework

International Framework: UNCRPD and other prominent international efforts

There has been progressive recognition and understanding of the rights of persons with intellectual disabilities, gaining momentum with the international decade of disabled persons (1993-2003) and with the entering into force of the UNCRPD in 2008. The UNCRPD is today recognised as the cornerstone international framework instrumental in shifting the cultural narrative around disability, where, from being rooted in a medical approach, disability was understood as per a social approach, resulting from 'the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others'.⁶⁸ The UNCRPD is based on fundamental principles of non-discrimination, the need for full and effective participation and to facilitate better access for persons with disability, on an equal basis with others.

The WHO, with the release of the first ever 'World Report on Disability' in 2011 also highlighted the importance

of disability inclusive development and the need for the removal of barriers that hinder the participation of persons with intellectual disabilities.⁶⁹ Similarly, the goals of larger inclusion and participation are also prominently reflected in the Sustainable Development Goals,⁷⁰ which not only focus on reducing inequalities for persons with disabilities, but also lay down specific targets for enabling and strengthening community participation and for equal opportunities for leadership and public life.⁷¹

Emphasis on Social Inclusion and Community Participation in the UNCRPD

With the UNCRPD, it was no longer enough to facilitate piecemeal measures for inclusion. Rather, a rights-based approach was required. Forwarding the social model of disability, the UNCRPD emphasises the responsibility of society to dismantle the physical and attitudinal barriers that exclude and stigmatise people based on their impairments or condition. This is evident from the principles enshrined in Article 3 of the UNCRPD which lays strong focus on the social and community aspects that promote a better quality of life for persons with disability, and which, at the same time identifies that the general public's attitude towards such persons can also act as one of the most prominent barriers. Article 9 is also important in how it envisions the need for social integration and mainstreaming, by stressing the right of persons with disabilities to participate fully in all aspects of society, and its call for the removal of barriers to inclusion.

The right to independent and community living is explicitly recognized under Article 19 of the UNCRPD and is central to the achievement of social inclusion. It mandates States to enable the inclusion and participation in society of persons with disabilities. The Article emphasises the right of persons with disabilities to live independently and the entitlement to be fully integrated into the community. This latter right entails the development of appropriate

services to facilitate the involvement of persons with disabilities in community life and activities.⁷² In promoting such a right to independent and community living, Article 19 presents a response to the history of segregation and institutionalisation of persons with disabilities. States that continue to rely on institutions as the preferred model of care deny Article 19, and do not conceptualise and bring forward measures for deinstitutionalisation; create alternative, less restrictive living facilities and social supports, fail to fulfil the rights and objectives of this provision. A quick glance at the General Comment on Article 19 reveals how such a right is envisioned and the consequent state obligations. These obligations are not merely civil-political in nature (such as the right not to be institutionalised against one's wish)' but also entails socio-economic obligations (making necessary budgetary allocations for community living arrangements, providing financial aid where required, enforcing standards of universal design and accessibility).

The Rights of Persons with Disabilities Act, 2016

In India, the ratification of the UNCRPD helped bring forward a paradigm shift in the disability discourse. The RPWD Act was enacted in 2016 and replaced the erstwhile Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 ('1995 Act') on disabilities. The new law was enacted to take cognizance of the changes in the understanding of disability since 1995, in addition to bringing it in line with the requirements of the UNCRPD, of which India is a signatory. In this manner, the RPWD Act brought to the forefront the UNCRPD-led concepts of diversity, equity, and inclusion.

In line with the UNCRPD, the RPWD Act brings in a shift towards a social, rights-based approach, replacing the earlier, more medical view of disability under the 1995 Act.⁷³ For example, in adopting a more progressive

definition of disability, and expanding the kinds of disability (the Schedule to the RPWD Act recognises 21 categories of disabilities as compared to the 7 categories previously identified under the 1995 Act), the RPWD Act pertinently includes intellectual and developmental disabilities such as ASD, specific learning disabilities and other disabilities such as Parkinson's disease and multiple disabilities.

Focus on social inclusion and community participation.

The RPWD Act's broader, social inclusion and rights-based mandate means that it recognises several social, economic, and political rights and freedoms of persons with disabilities.⁷⁴ There is a strong thread of recognition on the need for social inclusion and provision of a more fulfilling and participatory life for persons with disabilities. In its provision on non-discrimination,⁷⁵ the RPWD Act specifically mandates the appropriate government to ensure that persons with disabilities enjoy the right to equality, life with dignity, and respect for their own integrity equally with others, and the provision of reasonable accommodation.⁷⁶

In line with the UNCRPD, the Indian lawmakers also enshrined a right to live in a community in the RPWD Act.⁷⁷ Section 5(2) provides that a person with disability is not obliged to live in any living arrangement and has a right to a "range of in-house, residential and other community support services, including personal assistance necessary to support living with due regard to age and gender". Along with recognising the right to community life in Section 5, there is Section 9, which also recognizes the right of a person with disability to be placed in a 'family or community setting' and only in very exceptional cases in shelter homes, when the parents of the child are unable to take care of a child with disability. There are a few more sections which seek to implement corresponding and additional measures in relation to community living and

social inclusion. Provisions pertaining to the above under the RPwD Act are collectively enumerated in Table 1 below:

Section	Corresponding Welfare Measure
Section 5(2)	a person with disability is not obliged to live in any particular living arrangement and has a right to a "range of in-house, residential and other community support services, including personal assistance necessary to support living with due regard to age and gender"
Section 9	a person with disability has the right to be placed in a 'family or community setting' and only in very exceptional cases in shelter homes, when the parents of the child are unable to take care of a child with disability.

Section	Corresponding Welfare Measure
Section 24 (3a)	obligation on the Central and State Governments to formulate schemes and programmes so that persons with disability can live independently in a community setting
Section 24(3)(i)	obligation on the Central and State Governments to provide for care-giving allowance.
Section 29	Obligation of Government and local authorities to promote and protect the right to cultural life of persons with disabilities and secure their participation in recreational activities at par with all others.
Section 30	Obligation to secure effective participation of persons with disabilities in sporting activities.

Section	Corresponding Welfare Measure
Section 47	Mandate Rehabilitation Council of India and the Government to disseminate information through awareness campaigns, initiate capacity building measures on community life and independent living for families, persons with disability and other stakeholders.

Through these provisions on non-discrimination, equality, emphasis on community living and social participation, the RPWD Act seeks to limit mechanisms that cause the social exclusion and marginalisation of persons with disabilities. The express recognition and encoding of a legislative right to community living in the RPWD Act is worth much emphasis as well as understanding, to ensure it can become an implementable reality and not just a right that remains on paper.

It is worth noting here that when it comes to persons with benchmark disabilities, (referring to persons with over forty percent of a specified disability⁷⁸) the RPWD Act makes relatively more detailed provision for education, vocational training and reservation in employment.⁷⁹ Specific to persons with intellectual disability, the RPWD Act provides 1% reservation in government jobs, which is an improvement on the 1995 Act's provisions, which made reservations largely for the physically disabled. However, these measures indicate an understanding

that places greater emphasis on measures to bring into the mainstream and improve the productive capacity of persons with intellectual disabilities—whereas measures for social inclusion and community are framed in more general terms, and not given the same level of importance in terms of their specificity and content. Regardless, the RPWD Act has comprehensive provisions that recognize the rights of persons with intellectual disabilities to live independently, have access to education, employment, and other opportunities, and to be included in all aspects of society.

National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999

The National Trust Act was enacted to provide for the long-term support and care for persons with autism, cerebral palsy, 'mental retardation' and multiple disabilities. Though enacted much before the RPWD Act, in 1999 (and hence the use of the pejorative and now rejected term 'mental retardation'), it recognises the need for community living and capacity-building, so that persons with intellectual disabilities may be better assimilated in and contribute meaningfully to the society.⁸⁰ Its provisions have been praised for specifically looking after the interests of persons with intellectual disabilities, including autism, cerebral palsy and multiple disabilities given they are characterised by a greater degree of invisibility and discrimination, and given the Act's focus on shelter and community support for persons with such intellectual disability.⁸¹ For e.g., Section 10 of the National Trust Act lays down progressionist objectives to "enable and empower persons with disabilities to live as independently and possibly close to the community to which they belong". This is—at least in writing—an ambitious goal in a relatively older legislation, that reflects the pillars of appropriate social environments and robust

community involvement detailed above in the approaches to community living.

Pertinent to measures for independent and community living, many of the schemes relevant for persons with intellectual disabilities are operational under the National Trust Act. These range from Early Intervention programmes (Disha Early Intervention and School Readiness Scheme), day care residencies (Vikaas Day Care Scheme), educational support schemes (Gyan Prabha), marketing assistance (Prerna), aids and assistive devices (Sambhav) group home schemes (Gharaunda and Samarth Schemes), care associate training schemes (Sahyogi), a scheme on health insurance (Niramaya) and awareness programme schemes (Badhte Kadam).⁸² These initiatives are laudable and important. Schemes like Gharaunda offer a secure home for persons with intellectual disability and are an integral part of the care infrastructure of such persons. Such group homes encourage assisted but independent living. Similarly, the Sahyogi scheme provides much needed training in care work for families as well as paid caregivers.

Other Central Schemes and Policy Measures

Given that the broad definition of a 'person with disability' under the RPWD Act includes a person with intellectual disability, various schemes by the Government (such as the Accessible India Campaign, the Assistance to Disabled Persons for Purchase/Fitting of Aids/Appliances or the 'ADIP Scheme', technically cover persons with intellectual disability. However, given their invisible nature and specific barriers to access, as discussed above, this paper is bringing out a few schemes and measures which incorporate measures that refer to or benefit persons with intellectual disability, in the specific context of social inclusion and community support.

- a. The Deendayal Disabled Rehabilitation ('DDRS') Scheme, implemented by the Department of Empowerment of Persons with Disabilities under the Ministry of Social Justice and Empowerment, focuses on providing comprehensive rehabilitation services to persons with disabilities, including those with intellectual disabilities. It offers assistance for early intervention, special education, vocational training, assistive devices, and accessibility modifications. It also supports the creation of community-based rehabilitation centres and promotes the inclusion of persons with disabilities in mainstream society.⁸³
- b. The Scheme for Implementation of the Rights of Persons with Disabilities Act, 2016 ('SIPDA'), which provides financial assistance for undertaking various activities under the RPWD Act is very broad in its scope and includes the provision of financial assistance for building of recreational facilities, support for sporting events, and setting up of resource centres which will help provide information, counselling and support services to persons with disability.⁸⁴
- c. In addition to the above schemes, the National Institute for the Empowerment of Persons with Intellectual Disabilities ('NIEPID') under the DEPWD also offers vocational training workshops for persons with intellectual disability, including skill development programmes, long-term courses on special education and diploma training in vocational rehabilitation for persons with mental retardation.⁸⁵

Despite the evident progress in the legal and policy framework, significant challenges remain in addressing the deep-rooted societal, cultural, and legal barriers that have historically led to the exclusion of persons with intellectual disabilities in India.

VII. State and Local Level Measures in Karnataka

State Level Efforts

In Karnataka, the Department for the Empowerment of Differently Abled and Senior Citizens, Government of Karnataka ('Karnataka State Department') provides certain social security schemes. Relevant to this paper is the scheme providing for 'Social Service Complexes', which aim to provide "protection and shelter with health care and rehabilitation to the destitute aged and infirm disabled persons."⁸⁶ Interestingly, this also includes an incentive scheme providing financial incentives to otherwise able persons marrying "differently abled men and women".⁸⁷

The Karnataka State Department has also issued rules under the RPWD Act to ensure state-level compliance: these rules contain substantive provisions, some of which are relevant to the well-being of persons with intellectual disability. These pertain to education,⁸⁸ employment opportunities⁸⁹ and notifying vacancies in government posts.⁹⁰ They also clarify the functions of the district level committee⁹¹ and the role of the State Commissioner of Disabilities⁹²—authorities responsible for implementing the RPWD Act.

These measures to further the inclusion of persons with disabilities are not only very limited, but also extremely mandate based—such limited implementation has only contributed to the exclusion and segregation of persons with disabilities from mainstream society into special schools, sheltered workshops and housing. They do not sufficiently address the very cause of the segregation and isolation of persons with intellectual disabilities; promote understanding of the choice, equality, and agency that persons with intellectual disabilities should enjoy and take

steps to conceive programmes that actually foster social connectedness and integration. The dearth of meaningful policy and legislation establishes that till date, persons with intellectual disabilities are not seen as autonomous humans with a full set of social and legal rights, but merely as objects of welfare and charity programmes.

Local level Urban Governance Efforts

So far as urban governance is concerned, local municipality laws (Karnataka Municipal Corporation Act and the Karnataka Municipalities Act) contain discretionary provisions⁹³ that facilitate the maintenance and establishment of homes for “disabled and destitute persons”.⁹⁴ In Bangalore specifically, the BBMP Act, 2020 enables the city municipal corporation, i.e., the BBMP to implement schemes for urban development and social justice on matters related to urban planning and infrastructure.⁹⁵ Such provisions could be used favourably for the welfare of persons with disabilities.

Despite this, persons with intellectual disabilities still face significant barriers to full inclusion and participation in many areas of society, be it going to the movies or a park, shopping at a mall or using public transport services. It was learnt from our stakeholder interaction that parents of children with intellectual disabilities feel uncomfortable taking their children outside the house, even to family functions. This apprehension is particularly enhanced with respect to public spaces like parks and movie theatres. They are apprehensive in exposing the children to uncertain conditions and prefer a more controlled environment that is offered inside the house. There is a need for efforts and reimagination of frameworks to ensure social inclusion, better quality of life, access, and liveability of cities for persons with intellectual disabilities. Relying on the approaches towards social inclusion and community living highlighted above, there is a need to assess the law and the schemes such that one goes

beyond examining whether basic needs of sustenance are met (food, shelter, and safety) but also whether the need for a sense of belongingness and support in the form of adequate social infrastructure are fulfilled. Viewed through this lens, the issues in the law and policy framework are brought out in the following section.

VIII. Issues in Realising a Right to Community Living

a) Need for Realising Social Inclusion as a Dimension of Access

Our assessment of laws and policies from the perspective of persons with intellectual disabilities has revealed that accessibility as currently understood is limited to a physical/spatial dimension, and a social dimension is missing. While installing ramps, wheelchair accessible lifts and bathrooms, tactile pavements are undoubtedly important interventions, however, the emphasis on this spatial dimension of disability comes at the cost of other equally important dimensions of access—i.e. a social dimension, as explained above. To ensure that access remains consistent and long-term, practices that support the creation of inclusive neighbourhood communities and a sense of social cohesion need to become a policy priority. In other words, the concept of access itself must be expanded to necessarily include a social dimension.

In the RPWD Act, provisions on accessibility are provided across Sections 40-46. These provisions provide for mandatory observance of accessibility norms to physical infrastructure, transport and information and communication technologies ('ICTs'). However, nowhere is the social dimension provided for or imagined as an aspect of access. This betrays a rather narrow

understanding of access as primarily 'physical access' as more attention is paid to the basic hardware of the city, i.e. accessibility of buildings, roads, and transport. Measures to strengthen social well-being and community life and its connection to bettering accessibility for all, but especially for persons with intellectual disabilities is missing. For e.g., in the accessibility check-list provided in the Harmonized Guidelines and Standards for Universal Accessibility in India put together by the Ministry of Housing and Urban Affairs in 2021,⁹⁶ there is no mention of the necessity of social infrastructure to enhance accessibility (such as trained support staff who can assist a person with intellectual disability and their caregivers to navigate busy urban spaces and environments such as airports or railway stations).⁹⁷

b) Need for detailing the scope of community living.

If access is understood broadly, we need to supplement provision of the basic needs of shelter and safety, and examine ways in which the state can invest resources to strengthen a sense of belongingness and support in the form of adequate social infrastructure. This is where developing the right to community living becomes critical. While such a right already exists within the RPWD Act, however, at present, it remains undefined and consequently, more of a dead-letter.

Although a right to community living could have been a crucial link to developing the social dimension of accessibility, a perusal of the RPWD Act, the subordinate legislative framework, guidelines, and schemes from the perspective of persons with intellectual disability reveals that such a right has not truly been developed or implemented. In the absence of clear definition, guidelines or mandates, the idea of community living seems to have been largely conflated with access to residential and assisted living options. This is evident from a study of

schemes like Gharaunda and Samarth under the National Trust Act.

While implementation of such a right may need time, the progressive and step-by-step realisation of measures towards the planning and development of community-based services is crucial, especially to provide alternatives to the institutionalisation and segregation of persons with intellectual disabilities in India. Given how accessibility has become a buzzword within policy circles and social campaigns (Accessible India Campaign), the ignorance of measures to improve community living is a crucial miss. Had community living been connected to accessibility, it could have drawn the necessary attention and resources to the social sustainability of urban life, which remains a neglected pillar of inclusive urbanism. This is particularly detrimental for persons with intellectual disability who are more reliant on social infrastructure and support services to access city life.

c) Need for developing current and specialised schemes and programmes.

While the RPWD Act came into force in 2017, yet many of the schemes relevant for persons with intellectual disability are operational only under the National Trust Act (as mentioned above). Moreover, though the RPWD Act includes attempts to develop capacities of stakeholders through awareness training programmes, courses and other initiatives, the bulk of these initiatives focus on vocational training and employability skills as opposed to building social infrastructure and support services that would enhance social sustainability of urban spaces.

This stress of formal educational and career-based training has been recognised as promoting the categorisation of what is 'competent' and 'incompetent', especially of persons with intellectual and cognitive limitations. This pressure is said to be amplified in urban

rather than rural areas where such expectations are said to be managed within the ambit of the family and social networks.⁹⁸ Thus, while the provisions and specific schemes under the RPWD Act stress more positively on employment and skilling (thus basing the value of persons with intellectual disabilities in terms of how productive they can be) there is a need to also conceptualise and develop schemes and programmes for community based rehabilitation in urban areas, for training and deployment of personnel to provide assistance in most urban areas, and for schemes that promote social cohesion through sports, leisure and other recreation activities.

It must also be emphasised that inclusion is the collective responsibility of communities at a localised level.⁹⁹ These softer elements of access to communities, and a better quality of life therein can be provided in the form of trained personnel to assist with rehabilitation, therapy and social integration of persons with intellectual disabilities; through efforts at community cohesion and mobilisation in the form of self-help or support groups, which too, are completely missing from the conceptualization of access in local municipal legal and urban planning frameworks.

d) Need for research and data collection on community supports.

While the role of family is important, it cannot be the only pillar of support. Disability scholars recognise how while in India, acceptance and caregiving by family members helps persons with intellectual disabilities function according to their capacities¹⁰⁰ confinement at home, without any social exposure, also leads to further social isolation and neglect for persons with invisible disabilities. Some studies also demonstrate how reliance solely on family and kin, to the exclusion of other networks, can be detrimental given they have limited resources, knowledge and understanding of government legislations, welfare measures and other policies pertaining to disability

benefits.¹⁰¹ It also must be acknowledged that families, especially mothers, experience high levels of stress and caregiving burden which is oftentimes not sustainable.

There is a need to prioritise the provision of alternative informed supports such as through envisioning a coherent community level strategy, and mainstreaming services which cover all types of persons with disabilities who need rehabilitation services, and it should be part of mainstream development in the community.¹⁰² For e.g. There is an absolute paucity of research exploring the strengths and weaknesses of any state-supported housing options.¹⁰³ Some reports even decry such options given reports of prolonged detention, neglect, physical, sexual and verbal abuse from caretakers.¹⁰⁴ Research also indicates that private assisted living facilities are extremely expensive and on average cost Rs. 35,000 per individual per month.¹⁰⁵ Moreover, as gathered through stakeholder consultations and mentioned above, many such homes are also located in far-flung areas which make it difficult to access facilities, services, and recreational activities in a city. Second, while the residential homes itself may be self-sufficient, there is little to no effort to create ties with the larger community beyond the confines of these residential facilities.

There is a need to conduct data-based evaluation of service delivery of such efforts towards community, assisted and residential living options under the RPWD Act and the National Trust Act. There is a complete lack of such monitoring and impact evaluation. Research with respect to services, fund allocation, cost-effectiveness, manpower, training, and technical aid of disabled people should also be strengthened.¹⁰⁶

e) Lack of on-ground measures to dispel stigma and promote awareness.

The social model of disability as reflected in the provisions of the RPWD Act needs to percolate from policy to practice. Persons with intellectual disability face many social problems and improving the quality of life of different grades and various types of intellectual disability is a difficult and challenging task. In many parts of India, intellectual disability is still considered to be the result of divine justice or punishment for sins committed in past lives and persons with intellectual disability continue to be neglected and marginalised. Such persons are often neglected in the community also simply because of inaccessibility to basic services and lack of opportunities like health services, schools, vocational education programs, and jobs. They are viewed as part of a social problem and a liability to society.¹⁰⁷ Lack of data, including on prevalence and intervention effectiveness, further impedes affirmative action.

There is an urgent need for coordinated action by Central and State Governments, including various ministries in the areas of disability, urban planning, social justice and rehabilitation, health and family welfare to implement steps to promote awareness and change in attitudes, including the training and capacity building of policy makers and other on-ground workers on the social and community-based rights of persons with intellectual disabilities. There is also an urgent need for realising local and community level participation and implementation. Reports suggest that for over 70 percent of persons with disability, interventions in furtherance of social inclusion can be done effectively at the community level by persons such as local supervisors/school teachers, and in specific response to the needs of the community.¹⁰⁸

f) Need for reconciling definitions of intellectual disability.

In India, while the RPWD Act uses the term 'intellectual disability', the National Trust Act till date contains and defines the term 'mental retardation'. Though the National Trust Act was conceptualised as a specific legislation providing for protection of specific intellectual disabilities, the current overarching framework under the RPWD Act has brought in a paradigm shift that seeks to change the way that disability is perceived. A first step to address social stigma and prejudice would be to simply bring about a change in the nomenclature (for 'mental retardation') in line with the updated understanding of intellectual disability. This can be done without touching the scope of the National Trust Act in relation to autism and cerebral palsy. As a further step, the differences in the definition and understanding of 'autism' in the two laws must also be noted and reconciled. 'Autism' has its own separate definition in the National Trust Act—"a condition of uneven skill development primarily affecting the communication and social abilities of a person, marked by repetitive and ritualistic behaviour"—which is different from the broader understanding and terminology in the RPWD Act (the term used in the RPWD Act is 'autism spectrum disorder'). Given such differences in understanding and nomenclature, it may also be time to reconcile the reference, scope and understanding of ASD in both the laws.

IX. Way Forward: Developing a Right to Community Living

Our assessment of laws and policies from the perspective of persons with intellectual disabilities has revealed that accessibility as currently understood is limited to a physical/spatial dimension, and a social, intangible dimension of accessibility has often been missing from

the larger law and policy discourses on access. To realise this right to community living for persons with intellectual disabilities we identify some ways forward:

a) Develop Law and Policy Frameworks

As mentioned in the issues above, there is a need to determine the scope and contours of the right to community living in the form of tangible legal and policy obligations. To this end, the government must bring out relevant rules, guidelines or policy documents that outline a coordinated, concerted approach, that involves and identifies key stakeholders and allocates enough resources for realising the right to community living.

Accordingly, the legal framework should envision increased adoption of measures providing access to a range of services within the community setting, and involve members of the community in various aspects of community building as well as rehabilitation programmes (e.g. programmes that help in maximising physical and mental abilities of persons with intellectual disability through volunteer work, building hobbies in art and competencies in sports activities, through setting group goals and other such forms of social interaction).

The legal framework should also supplement existing standards for access in the law with measures that help facilitate higher levels of social inclusion in various, identified urban spaces such as restaurants, shopping malls, offices, schools, places of worship, markets, etc. This can be achieved through the deployment of trained personnel to assist persons with disabilities in such spaces; through implementing easily navigable and predictable processes (predictable through identification and repetition of the same spaces—such as in metro rail stations with simple, coloured paths indicating the specific transport line, platform; timely arrival of metro trains, etc.). Building on this, the legal framework should also promote

avenues for more integrated interaction and higher levels of community engagement—by building easily navigable, accessible, and support-staff driven residential environments, schools, restaurants, parks, movie halls, etc.

Finally, given that many of the barriers faced by persons with intellectual disability comprise attitudes and behaviours of the general public, the legal framework should envision measures for sensitisation and awareness building among communities and neighbourhoods. This can be done through local level involvement of disability advocates, school teachers, local leaders and functionaries.

Many of the elements of the above suggestions, and specific additional measures for realising community living are elaborated in the paragraphs below.

b) Move Beyond Residential Homes and Assisted Living Options

Because of the lack of clarity regarding what a right to community living entails, efforts to realise the same seemingly start and end with state-supported residential homes or private assisted living options, such as the Gharaunda scheme under the National Trust Act. These facilities employ a number of trained personnel and caretakers who are able to offer support to persons with intellectual disabilities residing there. While important, they also reveal the lack of imagination when it comes to developing affordable, equitable and inclusive housing and residential options in cities.¹⁰⁹ Such residential homes can easily become a segregated environment if care is not taken to actively facilitate participation of persons with intellectual disability in their local communities. To start with, both government and private stakeholders should be cognisant that such residential homes and assisted living options are not to be provided in a segregated, distant

environment, but are made available within cities and instead of only on the outskirts. As a next step, Central and State Governments should come up with schemes and options for housing that are not only for persons with specific disabilities but integrate the larger community. For e.g. A housing complex with accessible facilities for persons with disabilities that is located within central city limits would help generate a sense of community not just for persons with disabilities, but also promote awareness and understanding amongst families and communities.

c) Prioritise Skill-Development Programmes and Recreational Activities

Mere presence in a city need not translate into participation in community life. To ensure a sense of belonging and identity within local communities, there needs to be a consistent, sustained effort to identify social spaces and opportunities for participation in local environments that facilitate meaningful interaction within one's local neighbourhoods. Social programmes that encourage leisure and recreational activities for persons with intellectual disabilities are as important as vocational training and self-employment initiatives. Recreational activities such as sports for instance, are a key way to promote a sense of social cohesion, participation and belonging within local communities. (See case-study on Special Olympics Bharat in the Annexure). Similar activities which have the potential to develop long-term, sustainable, and regular contact with community members as opposed to one-off measures of engagement, should be given higher priority by the government.¹¹⁰ Thus, social skill development programmes (both for persons with intellectual disability and for the non-disabled persons within their local communities) are the need of the hour.

d) Develop Social and Human Infrastructure

To develop such skill development programmes and offer individualised support, a cadre of specialised, trained professionals is indispensable. Often the entire burden of fostering community participation falls on the family members or caregivers of persons with intellectual disabilities. However, given that the majority of their time is spent on day-to-day caretaking, it leaves them very little time and resources to pay attention to the ways in which the more subtle, intangible needs of social belonging can be met. Manpower generation by promoting new courses and initiating degree and diploma courses like Physical Medicine and Rehabilitation will address the problem of shortage of manpower in the long run.¹¹¹

Without such specialised support, social and community life has the danger of becoming a bureaucratic tick box exercise of occasional outings in the city. As research has shown, this is not enough. Persons with intellectual disability do better when they have regular interaction in a familiar environment. This gives them the opportunity to participate and feel included in the life of the community. Acknowledging this would mean changing the nature and type of social interactions a person with intellectual disability usually has. For instance, there is a difference between taking a person with intellectual disability for an occasional picnic versus enrolling them in art classes or programmes where they can develop social bonds through regular interaction. Both might be important in their own way, but the latter allows for more meaningful, holistic participation.¹¹²

Additionally, stakeholder consultations rightly point out that there is a need to simply put forward trained manpower to provide routine assistance to persons with disability—similar to how one can avail assistance for any special needs from airport personnel.¹¹³ In this manner, common urban spaces such as malls, movie

theatres, airports, railways stations should be equipped with help centres with designated trained personnel who can provide assistance to anyone facing difficulties in navigating such spaces.

e) Awareness Generation

Finally, to strengthen the social dimension of accessibility through community living, it is important to create a culture of awareness and acceptance of what is otherwise stigmatised as “undesired differentness” from the socially defined “normality”.¹¹⁴ For this, the state must invest in regular sensitisation programs and awareness campaigns that provide an understanding of disability. Such sensitisation campaigns should begin at an early age and not be treated as a one-time activity. Rather, sensitisation is needed at every level and every sector- whether it be schools, colleges, offices, law enforcement organisations, hospitals etc. These sensitisation and awareness building efforts should be tailor made for a variety of stakeholders (social workers, care-workers, families of persons with intellectual disability and non-disabled members living in the community) to mitigate the many attitudinal barriers to social participation and involvement.

Governments, voluntary organisations and DPOs; and professional associations should consider running social marketing campaigns that change attitudes towards persons with intellectual disabilities. Involving the media is vital to the success of these campaigns and for ensuring the dissemination of positive stories about persons with disabilities and their families.¹¹⁵ The involvement of persons with disability in this process is of paramount importance as they can provide a clear insight into their problems and suggest possible solutions.¹¹⁶

Research is also essential for increasing public understanding about disability issues, developing appropriate disability policies and programmes,

and allocating resources efficiently.¹¹⁷ For instance, most programmes catering specifically to those with intellectual/neurodevelopmental disability, focus exclusively on job skilling, vocational training and self-employment opportunities. While these are important, they put the entire onus on persons with intellectual disability to work towards their own inclusion. There are relatively fewer programmes on promoting their well-being, social skill development, community integration and participation in local neighbourhoods and community life.

Such programmes can only be developed when there is specific research to support understanding on the ways to improve the quality of life and well-being of persons with intellectual disabilities; barriers to mainstream and specific services, and what works in overcoming them in different contexts.¹¹⁸

X. Conclusion

Despite social inclusion being a significant contributor of well-being for all people, it remains something that many people with intellectual disability rarely experience in the broader community. In fact, people with intellectual disability continue to experience high rates of social isolation.

This is where developing the right to community living holds promise. Such a right can become the framework within which social inclusion can be realised. It does this by drawing attention to the social dimension of accessibility and offers a pathway to combat invisible, attitudinal barriers to inclusion within local communities and urban environments.

While the overall aim of the working paper series is to help identify gaps and critical points of intervention in the existing legal and policy framework and to recommend

measures that help create truly inclusive cities for all, it is hoped that this working paper has been able to examine and put forward how accessibility must be understood and reimagined from the perspective of those living with intellectual disability and the role that a 'right to community living' can play in this context.

XI. Annexure: Case Studies

PARIVAAR

PARIVAAR is a confederation of 272 parent organisations that works pan-India to support persons with Intellectual and Developmental Disabilities ('IDDs'). The organisation was formed in 1995, and its members have been networking with Central and State governments and stakeholders in the disability sector to facilitate policies and their implementation for empowering persons with IDD.

Since its inception, PARIVAAR has been playing a key role in advocacy, awareness raising, provision of services, participation in legislative and policymaking, and implementation of relevant policies and programs. They believe in the power of self-advocacy and towards this end, they have formed a Self-Advocates' Forum of India or SAFI that has registered members who are persons with IDD. There are more than 6,000 self-advocates across India who are members of SAFI. They meet regularly in small groups and contribute effectively towards PARIVAAR's work. To make self-advocacy a sustainable movement in India, PARIVAAR planned and formed a team of master trainers to conduct training of trainers in different states of India. This enabled some states to have their own master trainers who could conduct mentor training for parents and community volunteers.

In addition, PARIVAAR conducts programmes to build awareness among parents and stakeholders regarding rights, policies, and schemes for persons with disabilities. It is a vibrant organisation with some recent innovative activities such as a leadership development programme for parent associations, self-advocacy training, and supported decision making for individuals with IDD. It strongly supports all-round inclusion of persons with IDD,

including education, social, employment, and assisted living.

SPECIAL OLYMPICS BHARAT

Special Olympics Bharat is a National Sports Federation that was registered under the Indian Trust Act, 1882 in 2001. Its focus is on training and supporting persons with intellectual disabilities to participate in athletic tournaments and activities at both national and international levels. The organisation aims to promote holistic development and inclusion for persons with intellectual disabilities through sports and community involvement.

As part of this initiative, Special Olympics Bharat trains teachers and creates role models to inspire children and parents. It also works towards greater public understanding and acceptance of persons with intellectual disabilities. The goal is to encourage athletes to transition from Special Olympics to regular sports activities.

To achieve this goal, Special Olympics Bharat runs several community-based programs across all Indian states. One such program is the Unified Sports and Youth Activation programme, which aims to bring together individuals with and without intellectual disabilities to train and compete as teammates in a variety of sports. The program helps athletes improve physical fitness, develop skills, and form bonds on and off the field. It also provides opportunities for socialisation and community interaction outside of Special Olympics. By creating inclusive spaces for those with intellectual disabilities to play alongside non-disabled individuals, the program challenges socio-cultural norms around persons with disabilities and fosters community inclusion.

At the same time, Special Olympics Bharat works with families of those with intellectual disabilities and makes them part of the movement. Through programs such as the Sibling Engagement Program and the Family Support Network or FSN, it reaches out and works with the families of persons with intellectual disabilities to spread awareness. The organisation recognizes that families are the key support structure for athletes with intellectual disabilities and tries to foster a sense of community amongst the families so that they may support each other. Over 75,000 families in India have registered under the FSN program so far.

DISTRICT DISABILITY REHABILITATION CENTRES

The District Disability Rehabilitation Centres ('DDRCs') were established in 1999-2000 to provide comprehensive rehabilitation support to persons with disabilities. Although servicing rural and not urban areas, this is an important community based rehabilitation initiative. Of note is the appointment of a person with disabilities as a grass roots level worker. This person, called 'Viklang bandhu', (friend of persons with disability) works towards reducing social isolation and enhancing participation of individuals with intellectual disability and their families by helping them access government services and initiatives. They improve community awareness and attitudes through initiatives like street plays, rallies, and distribution of educational materials. These grassroot workers act as liaisons between the local community and the Government by helping families access services and social security benefits, educational and employment opportunities. Such initiatives, though operative primarily in rural areas, hold significant promise in closing the gaps in service delivery and implementation of Government schemes and programmes and ought to be tested in urban and semi-urban environments as well. Realising this, Central and State Governments have started funding

more and more such community based rehabilitation programs all over India.

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- nicate, understand relationships and relate to others, and is frequently associated with unusual or stereotypical rituals or behaviours.”
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