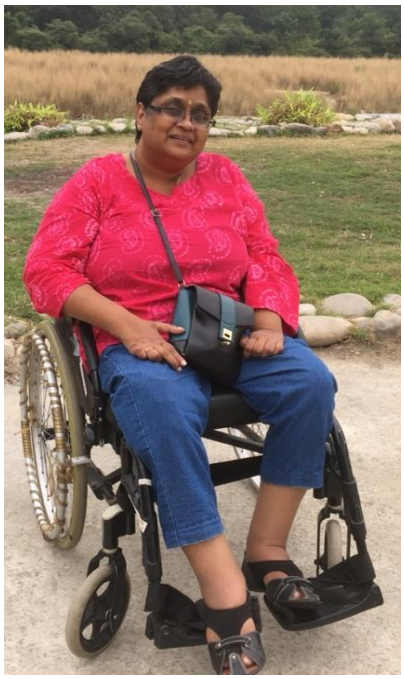

***Dr Shivani Gupta** founded AccessAbility, a cross-disability consultancy working for the inclusion of persons with disability. AccessAbility started as the first professional and the premier accessibility consultancy service in India with its motto "Access = Ability" that metamorphosed into a consultancy working toward inclusion and participation of persons with disabilities rather than only accessibility. Shivani founded AccessAbility after completing her M.Sc. in 'Inclusive Environments — Design and Management' from the University of Reading, UK. She is presently pursuing her PhD at the Maastricht University, Netherlands. Her thesis titled 'Invisible lives – Lives of persons with severe disabilities in rural India' highlights the lack of support services and accessibility in these areas. Shivani has worked on international projects with the Office of the United Nations High Commissioner for Human Rights, Centre for Inclusive Policy, International Disability Alliance (IDA), and CBM International and undertaken accessibility work in several countries, including Egypt, Jordan, Pakistan and Fiji. She has also co-authored publications about improving accessibility in physical environments,*

public procurement, assistive devices, support services, etc. For her achievements in the disability sector and her courage, Shivani has received several national and international acclaim, including the National Role Model Award (2004) by the President of India. She is a person with a spinal cord injury.

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Low-income home in rural India: Challenges for persons with disabilities, especially persons with spinal cord injuries

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Introduction

According to the WHO, each year, there are up to five lac new persons with spinal cord injuries(SCI) globally[1]. According to an international conference on spinal injury, there are fifteen thousand new cases of spinal injury added each year in India[2]. There are multiple functional limitations associated with SCI, including mobility loss, loss in sensation, incontinence, renal problems, pressure sore, blood pressure, chronic pain, depression, to name a few[1]. The mortality rate amongst persons with SCI is 2 to 5 times higher than those without SCI. Yet, SCI is clubbed under the locomotor disabilities category of the 21 types of disability under the Rights of Persons with Disabilities Act, 2016[3] legislation. Thus the system doesn't fully recognise the additional functional limitations they encounter.

Rehabilitation, however, is the key for the better life outcomes of persons with SCI. As a part of rehabilitation, ensuring they return

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[1] Spinal cord injury: Key facts, WHO, 2013. https://www.who.int/news-room/fact-sheets/detail/spinal-cord-injury
[2] Chhabra, H.S & Mittal, R. (n.d.), Spinal cord injuries, Rehabilitation council of India. http://www.rehabcouncil.nic.in/writereaddata/spinal.pdf
[3] The Rights of Persons with Disabilities Act, 2016, Department of Disability Affairs. http://disabilityaffairs.gov.in/content/page/acts.php

to an accessible home is a precondition to enable some persons with spinal cord injuries (SCI) to live independently, requiring a lesser amount of support to undertake activities of daily living. The lack of home accessibility has often resulted in their inability to get out of home and amplifies the amount of support they require from their families.This impacts their autonomy and can result in a lowered self-esteem of the person with SCI due to over-dependence[4]. Yet home accessibility is not an aspect that has been much debated or demanded by the disability movement in India.

Home accessibility is essential not just for persons with disabilities but also for older persons, and both these groups benefit from inclusively designed infrastructure. Still, the focus of the disability sector has remained on the public environment accessibility with the prevalent debate around inclusion in their communities and not at home. However, the older persons movement is more focused on home accessibility, which has created a demand for assisted living centres that have mushroomed around the country.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) addresses home accessibility in article 19 on living independently and being included in the community. According to the convention, home accessibility is vital to enable persons with disabilities to live in a living arrangement of their choice.[5]. India has ratified the CRPD and has taken steps to harmonise its disability legislation, the Rights of Persons with Disabilities Act 2016. The act

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[4]Dimensions of invisibility: insights into the daily realities of persons with disabilities living in rural communities in India, Disability & Society, 2020 DOI: 10.1080/09687599.2020.1788509

[5]General Comment General comment No. 5 (2017) on living independently and being included in the community. Committee on the rights of persons with disabilities

address homes from the perspective of the shared or public areas constructed with the house but does not explicitly address individual dwellings.

Homes, however, are spaces where we spend the maximum amount of time throughout our lives. Therefore, their accessibility has a significant role to play in the quality of life they live. The impact of inaccessible homes is most challenging for persons with disabilities living in low-income housing, whether in the urban slums or rural areas, mainly because houses here are very small congested spaces, with difficult access to sanitation facilities and water.

In this article, first, I provide more details on what accessible homes imply and the situation of these in India for persons with disabilities. Second I share a case study from the Anantapur District of Andhra Pradesh of rural homes and the challenges persons with disabilities, especially those with SCI, face due to the inaccessibility of these homes, finally provide recommendations for the way forward.

Home accessibility in India

Home accessibility implies structuralalignmentof the home infrastructure to include accessibility features such as a step-free entrance, wide doors, lowered height of electrical points, adequate manoeuvring space, a wide enough bathroom to accommodate a wheelchair user, and so on. However, since families may not have a person with disabilities requiring accessibility, the demand for accessibility features may not be included from the beginning of the project. As a result, if accessibility is retrofitted in these homes later in life, as residents grow older, or anyone suffers a temporary

disability, experience pregnancy and have small children, it can be extremely expensive or even impossible to do at times.[6].

In India, personal spaces are not a part of the building bylaws, and individual homes are exempt from complying with accessibility in these bylaws[7]. Therefore, the government has no mechanism to influence the accessibility of personal homes. The government, however, does affect the design of houses built in urban areas or funded by them in rural areas. However, concerning persons with disabilities, their attention is more on the reservation of housing for persons with disabilities[8]. Therefore, there are inadequate efforts to include accessibility in the design of such projects.

Furthermore, the accessibility standards for physical infrastructure in India focuses on public spaces in urban areas and do not address the accessibility of personal spaces such as homes. As a result, there is no appropriate guidance to make homes accessible, particularly in rural areas. On the other hand, some countries have standards and guidelines for making the house more adaptable. Such design considerations make the cost of retrofitting accessibility features later in life is possible without much investment. For instance, in the UK, some councils have adopted the 'lifetime home' guidelines.[9] that provide a few basic infrastructure guidelines for inclusion in the house design from the very beginning. The concept of lifetime homes considers that homes should be adaptable without much extra costs to meet their requirements

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[6] See high cost of retrofitting, page 10 Inclusion imperative: towards disability-inclusive and accessible urban development, CBM & World Enabled.
[7] Model Building By-Laws, 2016, Town and country planning organisation, Ministry of urban planning. http://mohua.gov.in/upload/uploadfiles/files/MBBL.pdf
[8] See details of Delhi Development Authority Housing scheme brochure, 2021 (page 4)
https://eservices.dda.org.in/public/uploads/brochure/YaxFa_1609401011.pdf
[9]Lifetime Hone Standards: 16 point criteria checklist, (2010) Habinteg

through thelifecycle of the resident as young people, middle-aged people, have children, become old with geriatric disabilities etc.

While accessible Housing is an issue for all persons with disabilities, it is notably more challenging for persons with disabilities in rural India. Housing in rural Indiais generally low-income housing funded and constructed by local development organisations or more likely built under the Pradhan Mantri GraminAwas Yojana (Prime Minister's Rural Housing Scheme) (PMAY-G). These houses may have different design in different. The PMAY-G scheme guidelines focus on providing a 5% reservation for persons with disabilities.[10]. There isn't adequate attention to accessibility aspects of homes.

The design of houses built under the scheme varies from region to region in differentparts of the country depending upon weather, geographical location, local construction material, etc. The government offers the basic design, and accessibility is not a part of it. Moreover, according to the scheme, the minimum size of the house must be not less than 25 square feet area with a clean cooking area.[11] That is difficult to make accessible, especially for persons with mobility impairments.

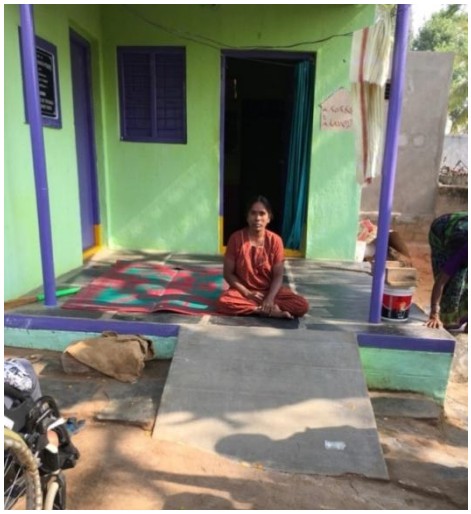
In the next section of this article, we describe the design of the typical low-income home in the Anantapur district of Andhra Pradesh.

Case study: Typical house in Anantapur District and its impact on persons with SCI

[10]Amendments in the framework for implementation of PMAY-G, 2018, Ministry of Rural Development. http://rdd.bih.nic.in/Acts/IAY_G_07_03_18.pdf
[11]Pradhan Mantri Awaas Yojana – Gramin (PMAY-G), Union Ministry of Rural Development.

Houses in Anantapur are primarily funded by the government PMAY-G scheme; however, in addition, a non-governmental developmental organisation working in the area[12]also supports the villagers to build housing.Houses built here have a basic design with one room, kitchen, a veranda in front of the house and a toilet that has a separate entrance.

All houses here have a plinth with a step or two at the entrance. Some persons with disabilities have managed to get a ramp made with the support of the NGO's working in the community. However, those who do not have a ramp (constituting most people) remain confined to their homes, rarely going out. Such persons with disabilities often do not see the benefit of having a wheelchair used only outdoors.



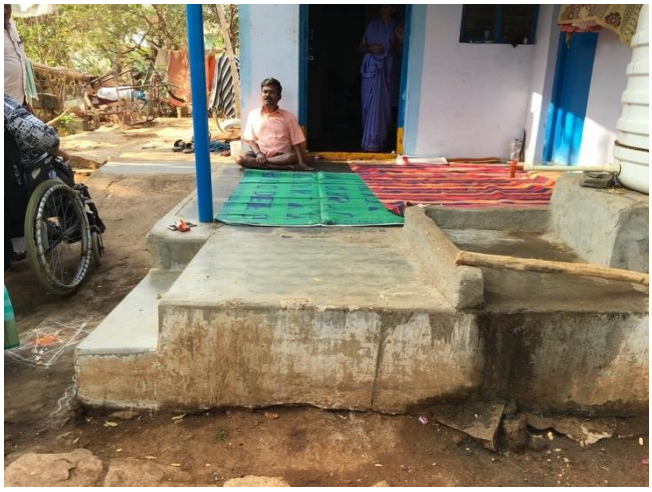
Picture1 All houses are built on a plinth a foot or two high.

Living area

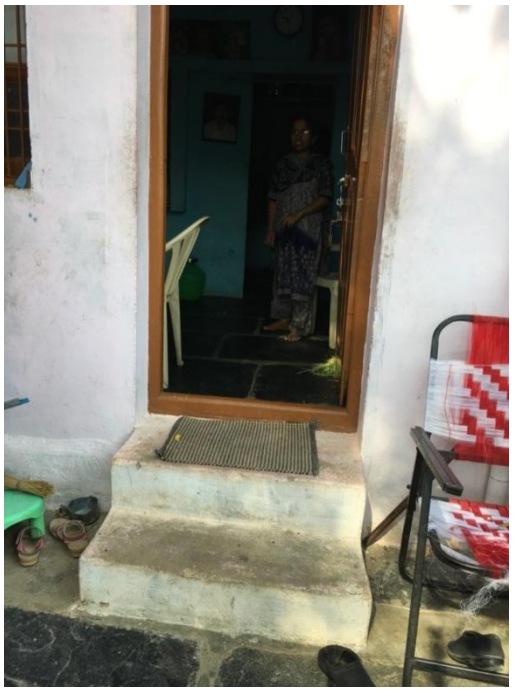
The living area for rural people includes the veranda outside the house and the one-room inside the house.

[12] See Rural Development Trust; Habitat

The veranda is the common area where residents spend their day whenever they are at home, often with visitors. For persons with disabilities, this constitutes a considerable amount of time. They rarely go out of the house, often because of a lack of mobility device or someone to support them to go out or inaccessibility of the public environment.



Picture2 A veranda at the entrance common sitting place

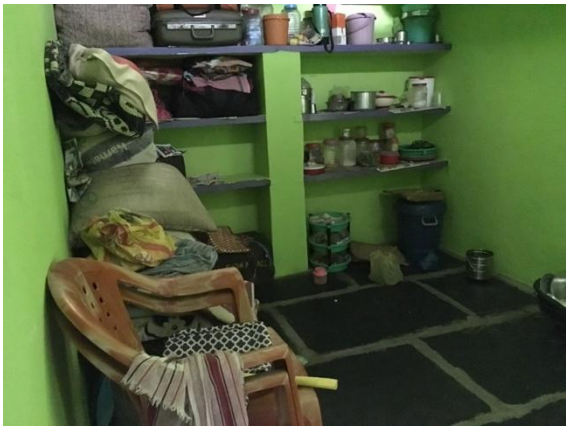


Picture3All doors, especially the entrance door, have a threshold.

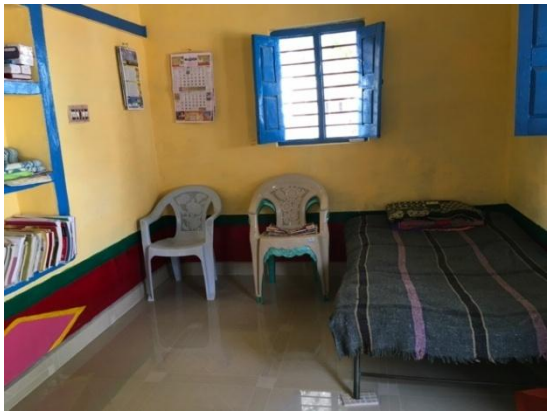
Anantapuris a dry area and home for snakes, lizards and scorpions and other insects and small creatures that can enter the house. Therefore, all doors in the house have thresholds. Thresholds are also a culturally important feature of the house here and are attached to religious beliefs. Often there are religious markings on the threshold. While thresholds seem essential to have, especially at the entrance, these restrict persons with disabilities.

There is usually one room used as the living room by all. The living room typically has slab shelves on one side to storevarious things. Additionally, depending on their requirements, people may keep wardrobes, bed, chairs, trunks, and all other odds and ends in this room. Therefore, how crowded or full the living room is, depends a bit on the size of the family. The living room may be packed with no space to manoeuvre if families are large or have limited things and adequate space to move around if there is only one resident.

The small living area is a challenge specifically due to this. First, most persons with spinal cord injury may not crawl like many other persons with locomotor disabilities and can only bottom shuffling or need to be carried. Bottom shuffling may be hazardous for them since they are already at risk of getting pressure sores. Second, have only one small room can compromise the privacy they require to address their bladder and bowel management requirements. Women with SCI are disproportionally impacted due to lack of privacy to manage their incontinence and menstrual needs.

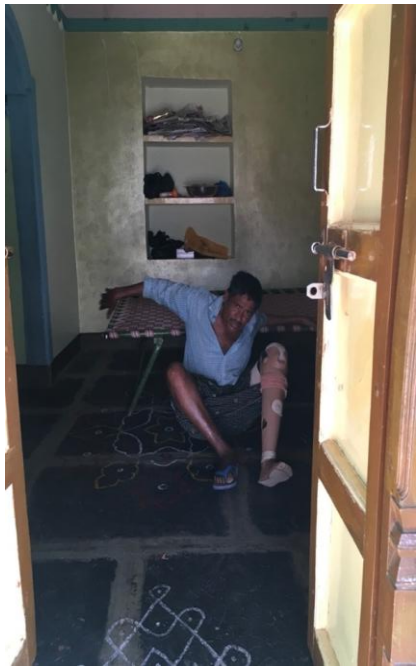


Picture 4 living room of a family of three membersPicture



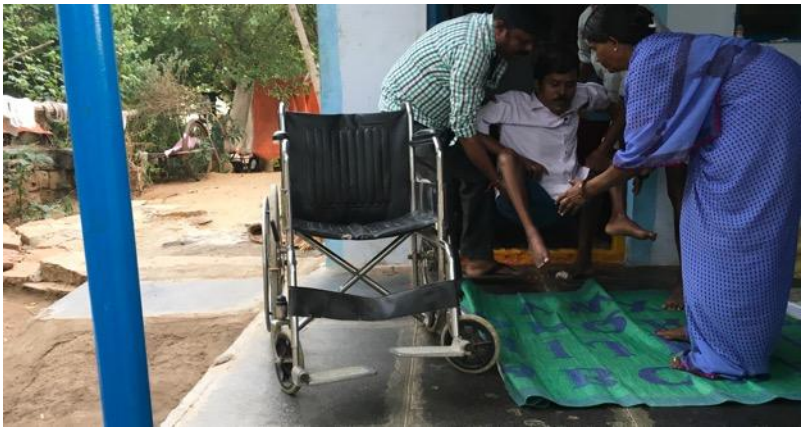
5 Living room of a single resident

In rural areas, it is common practice to undertake all activities like eating, cooking, sleeping on the floor. However, some persons with disabilities use a folding cot to sleep. Since the floor level is the level for activities, disabled persons are usually required to sit on the floor.



Picture 6 Transferring from floor level to the cot is difficult for some and impossible floor others.

There are critical challenges this puts forth specifically for persons with SCI. First, sing persons with SCI are prone to pressure sores, and rehabilitation experts prescribe a cushion to be used on a wheelchair by them. However, in rural areas, such requirements are ignored, and they sit on a concrete or stone floor for long hours, putting them at a higher risk of getting pressure sores. Second, only a handful of persons with SCI may transfer onto a cot or a wheelchair without receiving a significant amount of support.Thus it becomes difficult in the long term for the family as they begin to experience back pain and other health issues. Third, even for the person with disabilities, it is dangerous and makes them not get into the wheelchair as often they may like to not wanting to trouble their family members.



Picture 7 Being physically lifted from floor level to the wheelchair increases health risks for both the person with disabilities and their family.

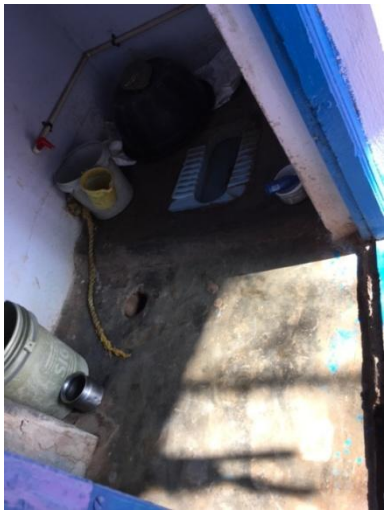
Kitchen and bathroom

I club these two aspects in thiscase study as both of these require access to water. Unfortunately, rural areas most often lack access to a plumbing water supply. Therefore, water is gathered from the common water supply areas such as a hand pump, well, a water tank etc., in the village and stored in the bathroom and the kitchen for use, making it challenging for persons with disabilities on many

fronts. First, reaching the common water point can be difficult due to untarred pathways; second, the water point may not be accessible. Finally, carrying water back home from the water point may not be possible without some assistive device. Therefore, due to not having access to piped water, persons with disabilities become more dependent on their family members.

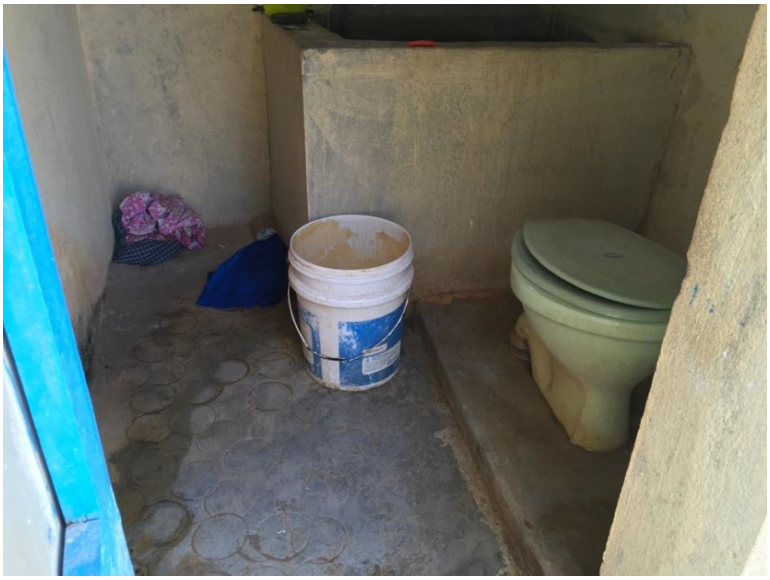
For persons with SCI, lack of access to adequate water results in added challenges for them and their families because of the incontinence they experience. For example, in addition to accessing water for toileting and bathing, there may be added water requirement to wash clothes and self more regularly. Moreover, clean intermittent catheterisation that they may be practising for bladder management requires access to clean water to perform.

In addition to access to water, there are other barriers they face, especially while using the bathroom. Toilet in the houses are located away from the main home and has a separate entrance. The toilet entrance is not too wide and has a threshold. The bathroom area is small without much manoeuvring space. The toilet is most likely Indian style that requires squatting on the ground.



Picture 8 Toilets are usually Indian style and relatively small in size. This family has, however, put a water tank with piped water connection.

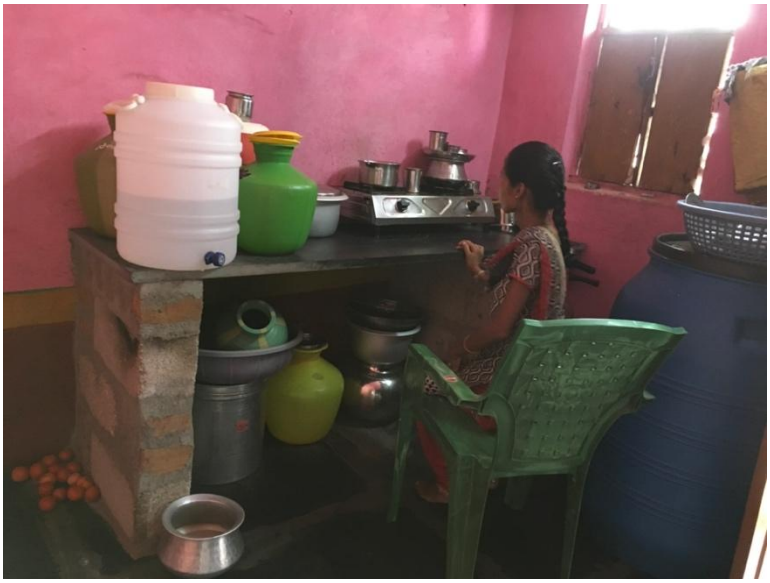
However, persons with disabilities and their familiesrecognise the importance of an accessible toilet. As a result, some people have changed to western-style commode to improve accessibility, often from their funds.



Picture 9 Some persons with disabilities have retrofitted western water closets.A water storage tank is constructed behind the water closet.

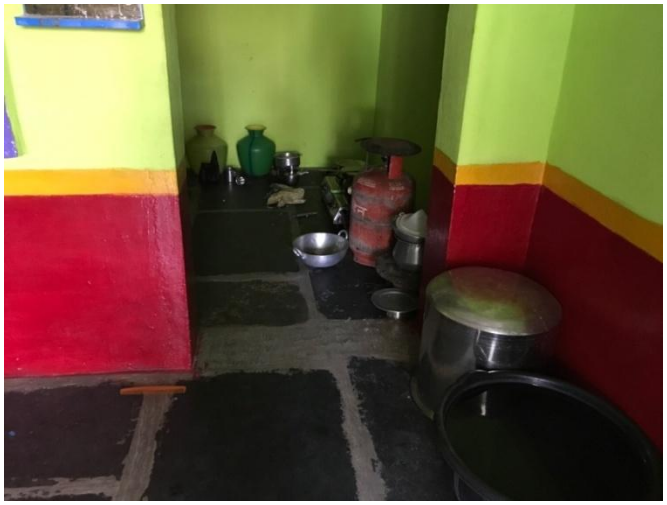
Many families continue with open defecation that again puts the persons with disabilities at a disadvantage and increases the support they require. For persons with SCI, open defecation poses several challenges. First, the route to getting to the fields on the wheelchair is inaccessible. Second, their inability to squat on the floor may make it difficult for them and add the support they require from their family members.

Cooking is an activity undertaken only by women. Therefore, the accessibility of the kitchen is essential for women with disabilities. Kitchens are usually constructed for cooking by a standing person. In such instances, the reach of the person with disabilities may be difficult. Some women with disabilities can manage to work in the kitchen sitting on a chair.



Picture 10 Some women with disabilities sit on a regular plastic chair and work in the kitchen

Cooking at ground level is also a common practice in rural areas. Women with disabilities who can crawl find such an arrangement suitable. However, alternate solutions, including floor level mobility devices, may be required for women with SCI.



Picture 11 Cooking at ground level is common for women with disabilities who can crawl.

To summarise, low-income homes in rural India are not suitable for persons with disabilities especially, those with SCI who face additional challenges due to the home design. The built-up area of such a home is 25 square feet according to the PMAY-G scheme, which is too tiny for designing an accessible home. Moreover, it denies them the right to privacy for persons with SCI, making it extremely difficult for them to function and remain healthy.

The geographical location and the regional customs of people play an essential role in how homes are designed. However, altering design based on such perceptions may be difficult. For instance, all activities in rural areas are generally undertaken at the floor level, making it difficult for the families and for persons with disabilities who bottom shuffle or need to be lifted to move.In the case of persons with SCI, it increases the risk of their getting pressure sores. Moreover, transferring to a wheelchair or a cot from floor level is also more challenging for them, requiring additional support from their families.

The lack of piped water in rural homes significantly increases the amount of support that persons with disabilities require from their family. Thus, discriminately impacts persons with SCI for whom access to water is critical for managing their incontinence. Furthermore, lack of access to water also reduces the chances of persons with disabilities contributing to family activities such as washing clothes or utensils. However, few families with a disabled family member have made adaptations, especially in the toilet, attaching a pipe to their water tank or building a water storage space in the bathroom.

Finally, open defecation is still prevalent in rural areas. While it is difficult for all persons with disabilities, it is notably more difficult

for persons with SCI who may find it difficult to reach the fields and squat.

Way Forward

About seventy per cent of persons with disabilities in India live in rural parts of the country.Living in rural India is marked by a shortage of basic services and facilities and a lack of livelihood opportunities in general for all. Persons with disabilities are disproportionately impacted by this, mainly because not only do they encounter the general scarcity of options, but additionally, they are entirely dependent on their families due to lack of accessibility and other support services. Therefore, the challenges for persons with SCI are multiplied, as discussed in the case study.

Lack of accessible homes for persons with SCI infringes on several human rights. First, it denies them to right to have an accessible home as is mandated by the CRPD. Second, their right to privacy is compromised since they do not have privacy to manage their bladder and bowel without disturbing the family. Third, their right to mobility within their homes is denied that forces them to sit long hours on the hard floor, bottom shuffle for mobility, putting them at a higher risk of getting pressure sores, thus impacting their right to life and good health itself.

Moreover, all persons with disabilities in rural areas depend on their families to support them because of the inaccessibility of homes, making it difficult to do activities themselves. However, for persons with SCI, the inaccessible homes make them more dependent on their families, which increases the stress of their family caregiving.

Therefore, it is crucial and urgent to relook at the low-income housing system of our country. Furthermore, as the rural areas in

the country proceed towards prosperity, there is a need to address disability-specific issues such as the accessibility of homes simultaneously.

The minimum house size of 25 square feet under the PMAY-G is indeed too small to design a house that is accessible. Therefore, not taking into consideration the requirements of persons with disabilities. Therefore, there is a need to address this first point of inaccessibility and increase the minimum space allocation per houseto allow in-home accessibility for all persons with disabilities, specifically considering the needs o persons with SCI.

Simultaneously, however, it is vital to consider functioning from the floor level, which is a common socio-cultural practice in rural areas. Thus, making a wheelchair an unsuitable device for use within the home.Therefore, the suitability of a wheelchair as a mobility device for indoor mobility of persons with disabilities, especially for persons with SCI in rural areas, maybe reevaluated.Gupta, Meershoek and Witte, (2019)[13]identifying this issue suggest a need for further research in suitable indoor mobility devices for low-income homes in rural areas.

Furthermore, home accessibility as a topic needs further deliberations within the disability movement to create an actual demand. The government is obliged to draft legislative policies around it.

Some crucial aspects that need to be addressed are:

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[13]Barriers to using mobility devices in rural homes in low resource settings: development of a practical assessment tool for local fieldworkers. Edited by Layton, N. & Borg, J. Global Perspectives on Assistive Technology – Proceedings of the GReAT consultation 2019. WHO Headquarters: Geneva, Switzerland. 23-24 August 2019, (Pg. 270-284)

- ***Providing accessibility of individual homes as a criterion to be included in all policies and schemes related to housing to be adopted.***
- ***Research and development of standards for accessible homes for low-income and middle and upper-income housing are universally applicable across the country.Such criteria may like Lifetime Homes, make housing more adaptable to become accessible when required during the lifecycle.***
- ***Awareness-raising of persons with disabilities, their families, and the community at large about the benefits and needs of universally designed homes that can account for the life cycle changes residents experience. Simple leaflets with ideas and other information may be developed and disseminated.***
- ***Capacity building of professional such as architects, interior designers, occupational therapists etc., in designing accessible homes.***
- ***Research and development for assistive devices for independent living specifically from the point of view of persons with SCI.***
- ***Creation of a government scheme that provides financial support and technical advice to persons with disabilities, making it possible for them to modify their homesto meet their requirements.***