

# **Perceptions of Disability in relation to dwarfism: The problem of access to disabled spaces and facilities**

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## **Abstract**

Dwarfism is not always considered to be a disability by other members of the public (Shakespeare et al., 2010; Thompson et al., 2010). It can be argued that a dwarf's body size is disabling in a built environment created for the average sized person, but that a body size, which differs significantly from the average, is not recognised as a disability in society. This paper seeks to understand how people's perception of disability affects a dwarf's access to disabled spaces and facilities. It can be argued that disability is viewed as homogenous where by non-disabled individuals are unaware of the various impairments that exist, instead having a stereotypical view of disability and therefore effecting who counts as disabled. Overall this paper shows that whilst dwarfs can benefit from using disabled spaces and facilities, people's understanding of disability public affects their access.

**Keywords:** Disability perception, social model, dwarfism, built environment, disabled facilities and spaces.

## **Introduction**

Dwarfism results in a person being no taller than 4ft 10" and having a medical condition (Adelson, 2005). Depending on the type of dwarfism a person's body is either disproportionate or proportionate. Dwarfs whose bodies are disproportionate have a torso of average size but short arms and legs, this is apparent in conditions such as, Achondroplasia. Dwarfs who are proportionate appear only to be small in stature, their arms, legs, trunk and head are in the same proportion as an average size person, only small and they can also have underlying medial conditions.

The correct term to use to refer to someone with dwarfism is often contested and the preferred name for someone with dwarfism ranges from, dwarf, person with restricted growth, person of short stature and little person. In my doctoral research results

showed that majority of participants preferred the term dwarf or did not mind the term. The term dwarf is also the most common term used both medically and socially when referring to someone with dwarfism. The term little person is very popular in the USA, where the term originated, but less so in the UK where the term dwarf is still widely used. In regards to little person, restricted growth and short stature I considered these terms to refer to someone who is just short and not a person who has any of the medical conditions known collectively as dwarfism, including a disproportionate body size.

Dwarfism is not always considered to be a disability by dwarfs and other members of the public (Shakespeare et al., 2010; Thompson et al., 2010). At first glance dwarfs do not appear to be disabled, but in a built environment created for someone of average stature that perception can change. Disability has different meanings to different people and in different circumstances (Rhodes et al., 2008). In this paper I focus on the social interactions between the participants and other members of the public when requiring access to disabled facilities and spaces. Wendell (1989) suggests that how society recognises disability can affect those who they do not perceive as disabled both socially and economically. I want to question whether or not participants are challenged or prevented from accessing disabled facilities and spaces and explore the possible reasons why, including not being recognised as disabled by other members of the public. I therefore aim to show how it necessarily socio-spatial barriers which can cause disabling situations but also attitudes and ideas about what disability is.

### **Disability perceptions**

Despite dwarfism not being an invisible impairment, but on the contrary a very visible bodily difference, Shakespeare et al. (2010) note that other members of the public do not recognise dwarfs as disabled. In their report Shakespeare et al. (2010) argue that the disabling affects of dwarfism, including medical and social aspects, are not always apparent and that the negative aspects of dwarfism are often played down by organisations which represent dwarfs. This differs from usual charity portrayals of disability which play on the impairment and represent it as pitiful and tragic.

Shakespeare et al. (2010) suggest that it is not always clear as to who is disabled and who is not within society. Wendell (1989, 1996) explores disability definitions and how disability is socially produced. In terms of body size Wendell (1996) points out that some bodily differences that do not impair any of their physical functions, such as being unusually large, are disabled by the built environment, but argues that people's understanding of disability can affect whether or not they are recognised as 'disabled'. Disability is often determined by non-disabled people and that in some cases people who encounter disabling barriers are not considered disabled because other members of the public do not recognise their disabling conditions (Wendell, 1989).

Focusing on Epilepsy Rhodes et al. (2008) argue that identity is fluid and is dependent on the various understandings of disability which affect who is recognised as disabled within society. When exploring disability constructs research tends to focus on how people with invisible disabilities, including epilepsy and chronic illness, negotiate access to disabled facilities and spaces due to them not being seen as disabled (Chouinard, 1999; Dyck, 1999; Rhodes et al., 2008; Stone, 2005; Sutherland, 1981). Despite this I aim to show how someone with a visible impairment is still not recognised as someone with a disability. Stone (2005) and Rhodes et al. (2008) explore how having an invisible disability creates problems in terms of not being recognised as a disabled person, especially in relation to reactions from other members of the public as there are no markers of disablement. Problems include being expected to carry out tasks which they are unable to do.

Chouinard (1999) explores the importance of recognizing disability, not as a homogenous group, but as a group made up of various impairments which are not always obvious within society. Focusing on some of her own experiences as person with a chronic illness Chouinard explores how people who do not fit assumptions of what disabled bodies should look like affect their use of disabled spaces and create unwanted social interactions. This work provides a spatial analysis of how someone with a chronic illness has difficulties accessing disabled spaces and facilities. Similarly, drawing on narrative accounts with people with physical impairments, Using a psycho-emotional approach to understanding disability identity, Reeve (2006) points out that people who do not match the stereotypical image of a person with a disability, which is often a wheelchair user, can result in their right to use a facility

being disallowed. In a number of cases researchers refer to a wheelchair being a symbol of disability which results in difficulties for other disabled people being recognised as disabled.

Moshe and Powell (2007) explore the International Symbol of Access (ISA) and suggest that it has helped to create a stereotypical representation of disability, which is a person in wheelchair, and this has an affect disabled people, who are not wheelchair users accessing disabled spaces without confrontation. The article helps to show how disability is perceived and the consequences for different disabled people in society. The ISA denotes that access has been provided for disabled people by providing an alternative to an otherwise disabling space. The ISA indicates that only disabled people may legitimately use that facility (Moshe and Powell, 2007). The ISA is also one of the most widely recognised representations of disability, it contains a crude diagram of a person in a wheelchair, and as Morris (1991) points out this stereotypical representation of a disabled person a wheelchair user and does not fully represent disabled people. Morris (1991) and Sutherland (1981) also argue that the ISA creates a false stereotype of disability which affects people with impairments who do not use a wheelchair. Sutherland (1981) focusing on disability stereotypes and definitions states that disability is mainly understood as being unable to walk and thus using a wheelchair. He makes it clear that he believes that disability is automatically linked with being in a wheelchair and this affects public perceptions of disability.



Figure 1 - International Symbol of Access  
(Disability Job Board, 2012)

The symbol represents access for all disabled people yet it is always an image of a wheelchair user which only represents a specific disability. The ISA does not represent an inaccessible environment it represents a personal tragedy view of disability where someone is in need of using a wheelchair, due to a functional limitation. The image only shows a wheelchair, it does not show inaccessibility, only an accessible space for somebody in a wheelchair or why that accessible space is needed. I argue that due to the symbol only representing one disability and a medical model understanding of disability, dwarfism will not always be recognised as a disability and in need of alternative access. A prominent abelist assumption is that you are not 'really' disabled unless the disability is visible, especially through an assistive device (Moshe and Powell, 2007). Dwarfism is visible, but does not necessarily require an assistive device. A wheelchair indicates that somebody cannot walk, crutches or a cane show that somebody has difficulty walking and a white stick indicates that the person is visually impaired. These are all cultural markers of disablement which indicate that the person has some sort of functional limitation and therefore will require the use of disabled facilities and / or spaces. Omansky (2011) suggests that the white cane which is synonymous with blindness is an aid blind people use not only to help them navigate the built environment but also use to show other members of the public that they are blind. The markers do not indicate that there is something wrong with the built environment, but rather that there is something wrong with person who uses the assistive device.

## **Methodology**

The data used in this paper is taken from my PhD research with twenty two dwarfs from across the UK. I used qualitative methods, including semi-structured interviews. The age of participants ranged from 19 to 68 years, with an average age of 31 years. Participants were recruited via organisations for dwarfs based in the UK. These are organisations regularly hold events for dwarfs in various locations across the UK, and were attended by me for the purpose of recruitment. Recruitment also took place via snowballing as participants seemed to keep good relations going with other members of the two organisations. The interviews were either carried out face to face or via telephone and one interview was carried out as a paired interview. Interviews were carried out in a space and time convenient for the participants, most of them being

carried within the participant's homes, which provided a quiet environment which was unlikely to attract the unwanted attention of others. Within each interview, visual methods were incorporated, which included each participant being shown pictures of several different spaces such as a high street and supermarket, as well as maps of where they lived and the surrounding areas. The purpose of incorporating these visual methods was to see where dwarfs may avoid due to spatial or social problems that they may encounter. In all interviews participants mentioned how verbal abuse was a daily occurrence and affected their use of spaces.

All interviews were recorded with the consent of the participants and later transcribed. The data was then coded to draw out the main themes and sub themes. I used a thematic analysis approach to draw out relevant themes through reading and re-reading each transcript (Fereday and Muir-Cochrane, 2006). I went through each transcript, focusing on one research question at a time, and highlighting relevant information to generate themes which would then help to answer each research question. Thematic analysis is the search for themes that emerge as being important to the research (Fereday and Muir-Cochrane, 2006). For the purpose of confidentiality all participants have been given pseudonyms. Prior to carrying out any fieldwork ethical approval was given by Newcastle University.

### **Questions of who uses Disabled Facilities and Spaces**

From the 1960s onwards it was recognised that people with impairments were disabled by the built environment and that many disabling barriers could be overcome by their removal and the implementation of disability facilities and the creation of disabled spaces. Over half of the participants in the research spoke about how often disabled facilities and spaces were more suitable for them to use as opposed to non-disabled facilities and spaces. This was often because the facility had been lowered in order for a wheelchair user to access. Kruse (2003) points out that spaces and facilities which have been lowered, such as ATMs, although lowered with intention of wheelchair users, can benefit dwarfs through providing them with better access to the built environment. Despite this social attitudes can effect whether dwarfs can access them without confrontation, demonstrating a lack of knowledge upon how the built environment causes disablement.

In most cases separate disabled facilities and spaces, including disabled toilets and disabled parking spaces, are represented by the International Symbol of Access (ISA) (figure 1). The picture of a wheelchair user automatically shows that disabled facilities are for people in wheelchairs, which does not wholly represent disabled people, as Lydia further explains:

*The stick person in a wheelchair only represents between five and eight percent of the total population of disabled people, so the logo is wrong (Lydia, face to face interview).*

Lydia works with people with Cerebral Palsy which may be why she showed a very sophisticated understanding of issues surrounding disability. Although disabilities requiring the use of a wheelchair are more common than dwarfism, less than 10% of disabled people living in the UK use a wheelchair (Sapey et al., 2005). Due to the ISA being represented by a picture of a wheelchair user, both Ivy and Monica state it is why other members of the public fail to consider dwarfs to have a disability.

**Erin:** *Why do you think people wouldn't consider you to be disabled?*

**Ivy:** *Well because they, the disabled symbol is a wheelchair and they always think it is people in a wheelchair (telephone interview).*

*The sign for disability is somebody in a wheelchair. I don't think people know whether to categorise us as disabled (Monica, face to face interview).*

The ISA is a prominent symbol which may influence what believe to be disability. This symbol is placed in most accessible spaces. A very recognisable disabled facility is the disabled toilet which is often found in various spaces within the built environment, but is often segregated from the non-disabled toilets. Most, if not all, of the adaptations have been made to accommodate a wheelchair user. Despite the adaptations being made for a wheelchair user the lowered facilities also make the disabled toilet accessible for participants. Although the disabled toilet may be more suitable for participants, assumptions from other members of the public can lead to an unwanted social interaction. Jade talks about being told off for using was the disabled toilet, despite the toilet being accessible for her:

*I had wheelchair user tell me off once for using a disabled toilet, because I wasn't in a wheelchair. I explained how I couldn't reach the sink, the lock, the dryer or see the mirror. She still didn't think that they were also for us, because that symbol seems to say that it is specifically for them (Jade, face to face interview).*

When interviewing Jade it was apparent that she had clear understanding of how the built environment disables people with impairments, and spoke about a number of her own disabling experiences due to her dwarfism. Jade's need to use the disabled toilet reflects a social model understanding of disability, where a number of facilities in the non-disabled toilet are too high for her to use and thus disable her. Despite the disabled toilet being accessible for Jade, she points out that the wheelchair user did not recognise her needs, only her own, which was supported by the ISA. The ISA symbolizes the woman's disability, not Jade's and thus she failed to realise that the disabled toilet provides access for a range of people whose needs are not always noticeable. Cultural markers of disablement, such as a wheelchair, signifies that the person has a functional limitation and helps to indicate that person is disabled and in need of accessible spaces. The term 'disabled' often refers specifically to wheelchair users, as in the case of such phrases as, 'disabled toilets' (Sutherland, 1981: 1). The ISA is often placed prominently on the entrance door of the toilet, indicating that it is only for disabled people and only they may enter that space. The ISA creates a common problem for disabled people who are not wheelchair users as they are often policed when using a disabled facility (Moshe and Powell, 2007). People's perception of who can legitimately use the disabled toilet overrides the aim of the facility which is to provide alternative access for people who would otherwise be left unable or to struggle using the non-disabled toilets.

Despite various impairments being able to benefit from using disabled facilities and spaces people's perceptions can determine who can use them without question. Naomi mentions being disallowed from a disabled space which could have otherwise alleviated a disabling situation:

*The other problem is when you go to rock gigs is that you go into the disabled platform if you are in a wheelchair, but I am the same height as somebody in a wheelchair, but they won't let me because I am not in a wheelchair (Naomi, face to face interview).*

Naomi spoke in her interview about how she was a fan of Bon Jovi, a popular rock band, and sometimes went to their concerts. Having access to the platform would allow Naomi to receive the same benefits as a wheelchair user, which is to be high enough to be able to see the performers over the crowd. Several participants, including Naomi, mentioned how they did not like being in a crowd as they often had to face somebody's backside and that they could be easily knocked. Kruse (2010) states that dwarfs tend to avoid large crowds as they can be dangerous for them as they can be easily shoved or knocked to the ground due to their height and lower body weight. If Naomi had been granted access to the disabled platform there would have been less chance of her being knocked or shoved, thus increasing her safety, as well as allowing her to see the band. Being disallowed from using a facility due to not being in a wheelchair calls into question what other members of the public perceive disability to be and whether or not they recognise its association with the built environment. Reeve (2006) suggests that people who do not match the stereotypical image of a disabled, which is often a wheelchair user, can result in their right to use a facility being disallowed. Both dwarfs and wheelchairs users require access to the disabled area in order to be able to see over the crowd, but clearly the member of staff only saw the wheelchair users as needing alternative access.

Low level counters are between 750 and 800mm, just less than three feet from the floor (Good Access Guide, 2002). The average height for a standard counter is between 1000 and 1200mm, which is between three feet, three inches and just under four feet (ibid). Heights of the participants ranged from three feet two inches to four foot six inches, although most participants were less than four feet tall. The height of the participants and the height of a standard counter would mean that most of them would barely be able to see over a standard counter and due to their short arm length they would also have difficulty reaching across them, such as in order to pass or sign documents. This demonstrates that for dwarfs the standard counters would either be difficult or impossible to use.

A low counter is a more suitable alternative as it low enough for a dwarf to see over allowing for better communication between them and the member of staff. It will also allow them to be able to use the desk to sign any papers and to transfer any documents to the member of staff. Despite the increased accessibility participants spoke about

how they had been challenged or sent away from the low counter and made to struggle by using one of the higher counters. Ivy talks about how she was challenged when wanting to use the low counter in her local bank, mainly because the member of staff was unaware of Ivy's needs:

*...A year or so back I went into my bank and I went to the low counter and the woman called across and she said, 'we have got no staff there, you'll have to come up to one of the others'. I dealt with the person I had to deal with and he said, 'sorry about that'. I didn't say anything, but when I got home I am known for writing letters more than I am for phoning and talking to people and as well a phone call can be forgotten. I wrote a letter and said that I had got embarrassed because I went to the low counter, and I know I am not in a wheelchair but it is ideal for me, and I was told to go to another one. I got a phone call and an apologetic letter saying that I should have said I want to be served here and they would have got somebody. Once again that would have all caused attention and they saw my need but still told me that there was nobody serving there. They asked me to go in as well and I was told by the manager that they were in the wrong, they were short staffed at the time and now they have all been explained to ...When I have gone in they have said, 'You want to go to the low counter?' and I have said, 'yes, please' and that is it (Ivy, telephone interview).*

Taub et al. (2004) suggests that in order for disabled people to receive disability assistance they must first assert the existence of their disability. Ivy could not just walk in and choose to use a facility most suitable for her, but first had to prove her need for it. Since Ivy explained the situation Ivy is now allowed to use the low counter showing that there was a lack of understanding of Ivy's needs, in the sense that the member of staff at the bank did not recognise how a low counter would be suitable for somebody who is only 3ft 11" tall.

Failing to see how disabled facilities and spaces will help someone, even if obvious, like a low counter, suggests that people do not recognise that it is the built environment which causes disablement, not the actual impairment. Being disallowed or challenged is because according to Monica people are unsure whether or not dwarfism is a disability:

*If you go to a normal counter they never think about going to the low counter and serving you there. Again, I think it is about people not quite*

*knowing whether we are disabled or not (Monica, face to face interview).*

If, as Monica points out people are unsure as to whether or not to class dwarfism as a disability, then participants may be questioned or prevented from using the low counter, as shown, preventing the accessing a more suitable facility. It is not enough that the facility is available in different spaces, but that people recognise that the facility can benefit a number of users who would otherwise struggle. Despite a dwarf's small stature being a visible bodily difference lowered counters are only seen as for wheelchair users, despite dwarfs being able to benefit from a facility which is more ergonomically suitable for their body size. Other members of the public often assume that accessible spaces are solely for wheelchair users, despite the fact that the spaces benefit other disabilities (Moshe and Powell, 2007). A low counter is used by somebody in a wheelchair, not because the person cannot walk, but because being in a wheelchair makes them smaller in height, as they are in a sitting position as opposed to a standing one. Thus, the purpose of the low counter is to serve someone who is shorter and this would include dwarfs.

In some cases where there is only one low counter, but several other regular counters available, it can mean that a person's probability of ending up at the one low counter is unlikely, which Amanda further discusses:

***Erin:*** *What about if there was only one low counter?*

***Amanda:*** *I wouldn't be guaranteed it in the queue and I am not in a wheelchair so I couldn't just go up to it (face to face interview).*

Amanda has to hope that she ends up at the low counter instead of being able to assert her right to use it. It is how Amanda presumes people will react to her using the low counter that denies her using it. Kayleigh on the other hand avoids the chance of having to use a high counter by not queuing up and going directly to the low counter:

***Kayleigh:*** *I had it at the train station because there was only one low counter for wheelchair users so I lined up and that meant I jumped the queue because there was a queue of fifty people for twenty desks but there was only one desk which was low so I had to line up behind the low desk. The woman said, 'I am sorry madam but there is a queue'. I told her that I was only able to use her desk because if I line up with everybody else I*

*actually end up lining up twice as long because all the other desks are inaccessible so I have to let people go past and use them and wait for the low counter to become free. It is the same in the post office as well.*

**Erin:** *Somebody was saying that before that you are not guaranteed that when it is your turn you are going to get the low counter. Do you think it would be different if you were in a wheelchair though?*

**Kayleigh:** *Yes. They would automatically see it as the wheelchair counter as opposed to the disabled counter (face to face interview).*

Kayleigh, who showed a lot of confidence in her interview, challenged the member of staff who did not recognise her need to use the lower counter despite Kayleigh being only 3ft 2” tall and thus too small to use the regular counter. Instead the member of staff accused Kayleigh of queue jumping because as Kayleigh suggests people recognise the counter as a counter for wheelchair users and not for someone such as herself who needs a counter which is lower in order to accommodate for her short stature. This demonstrates that it is acceptable for Kayleigh to wait in line and allow people to go before her, but is unacceptable for Kayleigh to go before them and use the one counter which is suitable for her. Several participants pointed out they did not enjoy being in a queue, including Kayleigh, as they were often given a lack of personal space by other members of the public, and in some cases they were unable to stand up for long periods of time due to mobility difficulties. Being able to go straight to the low counter would therefore also help to alleviate the problems of queuing, as well as allowing them to use a counter ergonomically suitable for their height.

## **Discussion**

The experiences of the participants indicate that other members of the public fail to recognise the disabling consequences of the built environment for them, affecting their use to disabled spaces and facilities. Wendell claims that how other members of the public define disability and who they recognise as disabled has both economic and social consequences for those who they do or do not recognise as disabled. One of the main factors which create disablement for dwarfs is their height as they live in a world created for the average sized person. In the same way a wheelchair user lives in a world created on the premise that everyone can walk, dwarfs live in a world where it is assumed that all adults are of average stature. It is not enough to provide disabled

facilities and spaces, but ensuring that anyone who needs to use a disabled facility or space is given the right to.

There are assumptions of what disabled bodies are which affect people who not fit these assumptions, but who are none the less disabled, access disabled facilities and spaces (Chouinard, 1999). In most cases participants felt that if they were a wheelchair user they would not have had any difficulty in accessing disabled facilities or spaces. Within society it is common to think of disabled people to have walking difficulties or to be in a wheelchair (Imrie, 1996). It may not be that people understand a wheelchair users needs, but that segregated spaces and facilities are for the sole benefit of wheelchair users and dwarfs who use these facilities legitimately, are seen by other members of the public as fraudsters trying to reap the benefits that some disabled facilities bring, such as no queuing. 'One stereotype is that you're either in a wheelchair and helpless or on your own two feet and capable' (Sutherland 1981: 1). Dwarfs and wheelchair users share a common experience which is that both of them require access to lower facilities due to an otherwise unaccommodating built environment. It needs to be realised that people who require the use of disabled facilities and spaces do not necessarily use a wheelchair, but none the less require alternative access. A wheelchair user is likely to be classified as a disabled person because he or she is in a wheelchair, rather than being in a wheelchair because he or she has a disability (Sutherland, 1981).

Spaces being unsuitable due to a person's bodily difference would of course correspond to the social model of disability which places the cause of disablement within society and the built environment. Instead it can be argued that body size is not considered a disability because it is not a functional limitation on the body which is often apparent with the addition of a cultural marker of impairment, such as a wheelchair. Disability is usually understood as a result of a person's physical impairment and not the built environment (Imrie, 1996). Other members of the public may be unaware of how being below average height causes disablement, basing disability upon a personal tragedy model which places disability upon the person, not the built environment. Societies often understand disability as a personal tragedy and regard disability and solely comprising of functional limitations (Chan and Gillick, 2009; Tierney, 2001).

In no situation were participants questioned upon using everyday facilities, such as a low ATMs or drop kerbs, which everyone uses, but what were originally implemented to provide access for wheelchair users. Participants were often challenged when wanting to use facilities or spaces which were segregated, from their non-disabled counterparts, or represented by the ISA. The ISA reinforces a common cultural misconception that disabled people are wheelchair users (Moshe and Powell, 2007). In one particular incident the ISA was used to argue that a participant could not use a disabled facility, despite the facility providing better access.

Recognising that dwarfism is a disability can help to give dwarfs better access to spaces and facilities more suitable for their body size. Most participants shared the experience of feeling that had to explain to others and their need to use disabled facilities, even when obvious as in the case of the need to use low counters. Not fitting the disabled stereotype can result in unwanted attention, including being questioned when trying to access disabled spaces (Chouinard, 1999). Participants that contested their right to use disabled facilities often showed an understanding of disability in relation to the social model of disability. Although they had to argue for their right to use a disabled facility in the end they were often able to, giving them better access to the built environment.

## **Conclusion**

In this paper I have attempted to show how disability perceptions affect a dwarf's access to disabled spaces and facilities. This paper has shown that despite the usefulness of disabled spaces and facilities for dwarfs, their access to these spaces are often challenged by other members of the public. This can lead to disabling situations and unwanted confrontation with other members of the public. The access to disabled facilities and spaces should be hassle free, but this can only come about when it is recognised that people with impairments who are non-wheelchair users require alternative access to spaces and facilities. An inclusive society can only come about if everyone, regardless of the impairment is given access to the built environment and this includes access to alternative spaces and facilities when needed.

Whilst the ISA denotes access for all disabled people, it is problematic for non-wheelchair users as it only represents a specific impairment which does not show access for all. Impairments need to be recognised as not necessarily visible or in need of an assistive device, but as something which varies and is not always readily visible. In relation to dwarfism, recognising certain body sizes as an impairment would lead to better access to spaces and facilities which are more ergonomically suitable. A better understanding of the social model of disability and how the built environment contributes to disablement for people with impairments would provide better access for disabled people.

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