

## **Physical disability, a Mark of Cain? The impact of disability stigma on access to rehabilitation services**

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### **Introduction**

The World Health Organisation, (WHO), describes disability as a term covering “impairments, activity limitations, and participation restrictions”. In essence, disability is not just a health problem but also a reflection of the interaction between a person’s body, the society they live in and the environmental and social barriers these may create. More than a billion people (15%) worldwide are living with a disability. This number is growing as the aging population and the number of people with chronic health conditions increase.<sup>1</sup> Learning that one has a disability or chronic health condition is a life-changing event in a person’s life. Kleinman<sup>2</sup> said that “the integrity of our bodies is so central to our belief system that it is often assumed that chronic illness is a betrayal of that fundamental trust”.

Rehabilitation medicine is concerned with the diagnosis and treatment of conditions that lead to disability and the active participation of people with disabilities to prevent secondary complications and optimise quality of life.<sup>3</sup> Jennings<sup>4</sup> said " To rehabilitate is to restore the power or capacity for living. Living does not signify merely biological life and function but it takes on a qualitative dimension. It is the restoration of the power of living well, living meaningfully that rehabilitation seeks". With the right kind of rehabilitation, people with disabilities and chronic illnesses should be able to optimise physical and cognitive functioning as well as modify personal and environmental factors to ensure the best outcomes.<sup>5</sup>

There are many barriers to rehabilitation which include factors such as funding, family support and staff availability. Stigma is a barrier to rehabilitation which is not often spoken about.<sup>6</sup> It is described as “the idea of perceived deviance of an individual’s characteristics from what is typical or the norm in a given context”.<sup>7</sup> Stigma affects every facet of life of people with disabilities in a negative way.

In this essay, (having gained her consent), I will use my mother's personal experiences as an example to explore how stigma affects a person's view of their physical disability and how this can become a barrier to accessing rehabilitation services. I will also discuss ways in which the barrier created by stigma can be overcome and what can be done differently.

### **The effects of stigma on people with disabilities**

My mother, who is a psychiatrist, was diagnosed with rheumatoid arthritis at the age of 22 when she was a medical student. Despite treatment, her condition got progressively worse and by the age of 41 she could barely walk due to joint damage and deformity. She started to use crutches and eventually a wheelchair for mobility when she turned 44. The biggest hurdle she had to overcome was accepting that she had a disability and needed aids to mobilise as this meant that she had to accept the label of being 'disabled'. To be disabled was to accept all the negative stereotypes and stigma that went along with it and it took her years to come to terms with this.

Living with a long-term condition or disability often forces a person to adjust to limitations whilst redefining how they see themselves.<sup>8</sup> Individuals face intense emotions relating to accepting their new lifestyle which may be radically different from the one they had lived or envisioned.<sup>9</sup> Unfortunately, adaptation to long-term conditions and disability can be hindered by having to go through this process within a non-supportive and non-inclusive social climate.

Goffman<sup>10</sup> describes two ways in which stigma can be experienced. A person can be discredited or be discreditable. A discredited person is someone who shows visible signs of attributes that can be stigmatised, for example an amputee. In contrast, a person with attributes that can be hidden is discreditable but has not yet been discredited. Having a hidden disability can lead to people concealing their disability as they fear being discredited and stigmatised. This also poses a dilemma for them as, if they choose not to disclose their disabilities, they may miss out on opportunities to receive support from others.

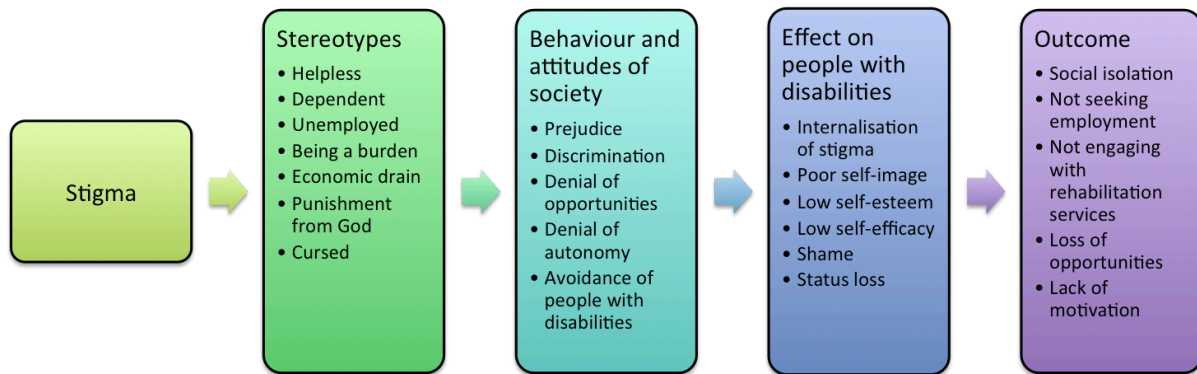


Figure 1 – A flowchart showing the process by which stigma affects people with disabilities.

When people see an individual with a disability, often, due to stigma, all they see is the disability and all other personal attributes are forgotten.<sup>11</sup> Stigma can lead to stereotyping, which is the assignment of negative attributes to traits that are perceived as different.<sup>12</sup> Stereotyping can then lead to discrimination and social avoidance.<sup>13</sup> Disability is associated with a number of stereotypes. As seen in figure 1, these include being seen as ‘helpless’ and a ‘burden’. When people with disabilities are perceived as ‘helpless’, they are seen as an economic drain on society, consuming resources but providing nothing in return.<sup>14</sup> There is also fear that disability is a sign of ill omen which is associated with witchcraft or punishment from God.<sup>15</sup>

People often generalise from one disability to another, which explains why someone might assume an individual in a wheelchair must also be deaf. They shout at the blind or speak to the companion of an individual with a disability rather than converse directly with the person with the disability.<sup>16</sup> This is something that I have experienced on many occasions with my mother who has a physical disability. When I accompany her to appointments, people will often not acknowledge her and will speak to me instead of her. Even when they speak to her, this is done slowly because they assume she would have difficulty understanding them.

These stereotypes and assumptions associated with disability can lead to discrimination. Figure 1 shows that people with disabilities may be denied employment, housing or other opportunities based on these negative views and misconceptions.<sup>17</sup> Factors such as race and gender can also have an impact on discrimination. Hanna and Rogovsky<sup>18</sup> said that being disabled and black or disabled and female can lead to double the amount of discrimination. My mother is disabled, black and female which means that she faces triple the amount of prejudice and discrimination. These negative views of disability can become internalised by people with disabilities and can affect an individual's thoughts and actions and overall impact on their self-esteem and self-efficacy.<sup>19</sup>

### **How stigma can act as a barrier to rehabilitation**

The stigmatisation of disability and chronic illnesses can significantly affect a person's life goals. Sometimes, dealing with the stigma surrounding the condition is more difficult than living with the limitations that may arise due to the disability. Individuals who are stigmatised may not be motivated to seek treatment or services that could help them as they attempt to avoid negative experiences. This leads to lost or delayed opportunities for treatment and rehabilitation that may improve physical health and quality of life.<sup>20</sup> Stigma is such a pervasive problem worldwide that it is considered a public health issue.<sup>20</sup> Individuals can feel stigmatised by devices that signal a loss of function as this is a visible sign that can lead them to being discredited by society. This can act as a barrier to rehabilitation.<sup>21</sup> For example fewer than 25% of adults who needed hearing aids are actually using them, due in part to stigma associated with wearing a hearing aid.<sup>22</sup>

When my mother was using crutches, she experienced disability stigma. However, when she started using a wheelchair, the stigma she experienced became amplified and people reacted to her as though she had suffered a bereavement of some sort or that a calamity had befallen her. Some people were ashamed to be seen with her and on one occasion, at a conference, a woman attempted to pray for her by laying hands on her without her permission. Many assumed that she was unemployed and were shocked to find out that she was working full time as a medical doctor.

People with disabilities can also experience stigma from healthcare professionals. This is because healthcare professionals tend to view disability from the ‘medical model’ (which sees disability as a ‘problem of the person’ caused directly by trauma, disease or congenital disorders), rather than the ‘social model’ (which views disability as a problem created by the social environment rather than the individual). In the medical model, management of these ‘problems’ are focused on a cure or adjustment and behavioural change whereas, with the social model, management is more focused on “the full integration of individuals into society” and therefore is the responsibility of society.<sup>20</sup>

Parsons<sup>23</sup> talks about how in healthcare, it is recognised that “the task of medicine is to treat and the task of the patient is to get well”. Due to this, patients who fail to respond to treatment can be unpopular with healthcare professionals and therefore treated differently. This has been corroborated by a study conducted by Kaplan<sup>24</sup> which showed that rehabilitation counsellors’ attitudes to clients varied with how difficult the counsellor perceived the client to be in terms of rehabilitation. The more difficult the counsellor perceived the client to be, the more negative the attitude of the counsellor was towards the client. This can significantly dissuade people with disabilities from accessing services.

### **How can we overcome this barrier to rehabilitation?**

People with disabilities report requesting more healthcare than those without disabilities and yet they have some of the highest unmet needs.<sup>1</sup> As discussed above, stigma has a big part to play in this. Thus, it is imperative that we overcome the negative effects of stigma and remove the barrier it creates in accessing rehabilitation services.

Healthcare professionals need to be aware of the stigma they may be consciously or unconsciously putting on their patients. Attitudes of healthcare professionals can be changed by the integration of “expert” or “experienced” patients into faculty or rehabilitation training courses. These patients, (such as my mother who due to chronic illness has been to multiple clinics and hospital appointments and has an understanding of the patient experience in ways that healthcare professionals cannot), have a perception that is critical to the delivery of patient care and can positively impact on procedures, policies and patient advocacy.<sup>25</sup>

Even if the stigma from healthcare professionals is addressed, there is still the issue of public stigma. I once attended a dental clinic for a procedure which required sedation and was told that an adult had to accompany me home after the procedure so I went with my mother. Upon our arrival, the Practice Manager assumed my mother was the patient and when we informed her that I was the patient, she asked who was going to accompany me home after the procedure. I told her that my mother would be. She looked at her and said *“she can’t accompany you home because she is in a wheelchair. We are going to have to ask you to cancel the appointment and rebook it for a time when you can come back with someone who is not disabled to accompany you home”*.

We were shocked and baffled by her response. My mother uses a motorised wheelchair and drives. The car park was adjacent to the clinic and one of the nurses was going to accompany me to the car after my procedure. We could not understand why she had responded in this way and asked her to justify her comments by showing us their policy regarding this. She was unable to but kept arguing with us. Eventually, we insisted on speaking to the dentist carrying out the procedure who apologised profusely for her behaviour and said that my mother could accompany me home after. This is a clear example of how stigma and assumptions can lead to prejudice and discrimination.

How do we address the issue of public stigma which involves so many people? People’s perceptions of disability can be changed through the media which plays a role in propagating misconceptions of disability and the perception of people who have disabilities, especially in groups of people who have minimal information and interaction with people with disabilities.<sup>26</sup> One way this happens is through the language that the media uses around disability. For instance, the media often uses terminology that reinforces the ‘sick role’ by using phrases such as “suffering from” or “afflicted with”. This gives power to the condition and paints the individual with the disability as a helpless passive victim.<sup>27</sup>

Using my mother as an example, stating that “she has rheumatoid arthritis” rather than “she is suffering from rheumatoid arthritis”, just as accurately reports the facts and doesn’t impose

any extra meaning. Words that empower people with disabilities will result in positive change, not just for the general public but for people with disabilities too as frequently, the negative terminology is internalised and can affect a person's self-image.<sup>27</sup> There is also a need for the media to follow the social model of disability and diversify by integrating people with disabilities into every day media. In a study conducted by Farnall and Smith<sup>28</sup> it was concluded that exposure to positive portrayals of people with disabilities, especially in films was associated with more positive opinions towards disability. This has already started with the appearance of Lauren Steadman, (a paratriathlete), on 'Strictly Come Dancing' and shows like 'The Last Leg' which was created to cover events in the Paralympics in which two of the presenters use prosthetics. If we continue to 'normalise' disability in this way in the media, we will be well on our way to reducing disability stigma.

## **Conclusion**

Stigma can have a detrimental effect on the lives of people with disabilities especially when it becomes a barrier to accessing healthcare and rehabilitation services. In a group where secondary complications and co-morbidities are common, it is extremely important to remove any barriers to healthcare.<sup>1</sup> In order to address the problem, it needs to be recognised and addressed by all parties involved. The media has a significant role to play in changing attitudes and perceptions towards disabilities. People with disabilities need to be seen as functional members of the society who can contribute positively and make a lasting impact. The late Professor Stephen Hawking, a theoretical physicist, is an example of a person who despite his disability made great strides in his field.

Finally, more focus needs to be put on what people with disabilities can do rather than what they cannot do. My mother may not be able to walk but she is able to work full time as a medical doctor, treating patients and improving the quality of their lives thereby contributing positively to society. Rehabilitation medicine also has a role to play as it is a speciality where people with disabilities are the majority of the patients and the biopsychosocial model is essential. It should be at the forefront of diminishing the impact of stigma.

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