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## **An Exploration of the Stigma Associated with the use of Assistive Devices**

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This review article explores the use of assistive devices, which have been defined as tools for living, designed to enhance quality of life and facilitate independence in daily living for individuals with disabilities (Petterson et al. 2007). Such devices range from the routine such as hearing aids and glasses, to life sustaining technologies, including dialysis machines and respirators (Brown and Webster 2004). While the benefits of assistive devices in enabling independent functioning have been extensively researched, little attention has been paid to the personal meanings assigned to these devices, by individuals requiring their use in daily life (Petterson et al. 2007). Assistive device usage has been associated with stigmatisation (Parette and Scherer 2004) and so, while such devices may enable, they also appear to be simultaneously wounding (Brown and Webster 2004). Specifically, this review article explores the existence of this stigma and examines the reasons for its association with assistive devices. The concept of stigma, as influenced by social processes, is firstly considered. To follow, a critical synthesis of relevant research is presented, with a predominant focus on the stigmatisation linked to the use of wheelchairs, as representing the archetypal assistive device. The inherent association of assistive devices with the 'sick role', and the social symbolism of these devices, emerge as primary contributors to the experience of stigma surrounding their usage. The implications of this stigmatisation and the applications of these sociological understandings to Occupational Therapy practice are also considered.

## **Introduction**

Assistive devices have been defined as tools for living, designed to enhance quality of life, and facilitate independence in daily living, for individuals with disabilities (Pettersson et al. 2007). Whether electronic, mechanical, manual, or computerised, all such devices are intended to compensate for sensory and functional impairments, aiming to increase, maintain or improve function (Verza et al. 2006). These devices represent external prostheses, extending the body beyond the boundaries of peripheral skin, and commonly include hearing aids, walking sticks and wheelchairs (Brown and Webster 2004). Extensive research conducted in the field of assistive devices has largely focused on the functional benefits and utilisation rates of these devices (Hocking 1999). However, the experiences of individuals with disabilities in using assistive devices has been relatively neglected (Brown and Webster 2004), and only a small body of knowledge exists, concerning the personal meanings assigned to such devices in daily living (Pettersson et al. 2007). The literature available indicates that assistive devices are associated with stigma (Parette and Scherer 2004), defined as “a bodily sign designed to expose something unusual and bad about the moral status of the person” (Goffman 1963, p.1). A contradiction in the use of these devices therefore becomes apparent, in that they are simultaneously enabling and yet wounding, and although they serve to resolve deficiencies, they also highlight the deficiency (Brown and Webster 2004).

While reference has been made to the stigmatisation of assistive devices, little research has examined the reasons for this stigma and the consequences of such. The present review article therefore explores the existence of this stigmatisation and questions its association with the use of assistive devices. To commence this review, a consideration of the concept of stigma, as influenced by social processes, is firstly necessitated. A critical synthesis of relevant research, including that pertaining to the lived experience of those requiring these devices

in their activities of daily living, is then presented. As the literature primarily focuses on wheelchairs as the archetypal assistive device, discussions will be centred on this specific device, yet it is intended that the issues explored may be generalisable to other forms of assistive device. The research reviewed corroborates the stigmatisation linked to the use of assistive devices. It indicates that the inherent association of assistive devices with the “sick role” and the social symbolism of these devices as markers of helplessness, passivity and incapacity, represent primary contributors to the experience of this stigma. The implications of this stigmatisation, in terms of challenging the process of re-embodiment and contributing to the abandonment of assistive devices, are also discussed. Finally, the applications of these sociological understandings to the practice of Occupational Therapy are considered.

### **The Concept of Stigma**

Stigma typically represents a social process, “characterised by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group” (Scambler 2009, p.441). This judgement is based on an enduring feature of identity, such as that associated with a health problem or health-related condition (Scambler 2009). Erving Goffman is recognised as a key figure in the conceptualisation of stigma, presenting the first sociological theory of this construct in his classic publication, *Stigma: the Management of Spoiled Identity* (1963; Scambler 2009). While Goffman’s contributions remain influential, a paper by Scambler (2009) reframes this classical conception of stigma to encompass a more contemporary sociology of health-related stigma, incorporating its embedment in social structures. The traditional ‘personal tragedy’ or ‘deviance’ theory of stigma alludes to the biographical disruption, or disturbance of one’s sense of self and identity, occasioned by impairment. This theory postulates that such impairment is viewed as unwelcome deviance,

incongruent to cultural norms, and requires narrative reconstruction, or a re-adjustment to life (Scambler 2009). Scambler however, holds that, in focusing upon the individual and their impairment, this paradigm neglects the social structural underpinnings involved in the process.

Disability theory demands a revision of the personal tragedy oriented approach, and in particular, the social model of disability argues that disability is not the consequence of impairment, but of the social restrictions imposed upon those with impairments (Scambler 2009). The framework for understanding health-related stigma offered by Scambler then, centres on his distinction between these concepts of stigma and deviance, which have often been treated as synonymous. He defines stigma as an ontological deficit invoking shame, whilst deviance is referred to as a moral deficit associated with feelings of blame. Scambler posits that cultural norms of shame and blame develop within the context of social structures such as class, command, gender and ethnicity and so, emphasises the importance of social processes in explaining the concept of stigma. This appreciation of health-related stigma, as determined by social processes, may serve to enhance an understanding of the stigmatisation of assistive devices, as stemming from the processes of role attainment and social symbolism.

### **Understanding the Stigmatisation of Assistive Devices**

#### *Assistive Devices and the 'Sick Role' within Medical Care*

An important theme to emerge from the literature, contributing to an understanding of why the stigmatisation of assistive device usage occurs, involves the inherent implication of a “sick role” associated with these devices, especially within medical care services (Sapey et al. 2005). The sick role concept refers to the adoption of a particular status, within the context of an illness, characterised by an exemption from self-care and normal responsibilities

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and an expectation to desire a return to normal functioning and to seek competent professional assistance (Bruce and Yearley 2006). Wheelchair users have typically been treated as patients, reliant on expert opinion, and while recent years have witnessed a shift in such perceptions, the image of wheelchair users as dependent on others persists today, and is particularly dominant in the medical care setting. While in some cases, a dependency may exist between wheelchair and medicine, for many, wheelchair use is necessitated by impairments which are not treatable, and so they may have little contact with medical professions (Sapey et al. 2005).

The socialisation of the rehabilitation profession further contributes to the sick role identity of wheelchair users as, in striving to lead non-walkers to walk again, the rehabilitation industry places a negative value on wheelchair use (Sapey et al. 2005). Not walking is perceived as acceptable when an individual is willing to participate in rehabilitation, however, should an individual choose to not walk, then the power of rehabilitation professionals would be threatened as immobility would fail to constitute a medical condition, and rather represent an element of human diversity (Sapey et al. 2005). While viewing immobility as normal challenges the socialisation of the rehabilitation enterprise, it proves fundamental in contributing to the positive identity of wheelchair users. Furthermore, while many wheelchair users actively participate in everyday living, rehabilitation staff are more likely to focus on their incapacities, as opposed to their strengths. In treating wheelchair users as “sick”, they are expected to assume the patient role, a role typically associated with being cured, yet in this case there is no cure available (Sapey et al. 2005). Thus, the medicalisation of rehabilitation practice may foster an association between assistive devices, such as the wheelchair, and the “sick role”, and appears to play a role in the stigmatisation of such devices. It follows that this implied

negative association may contribute to the establishment of wheelchairs and assistive devices as social symbols of incapacity.

### *Assistive Devices as Social Symbols of Incapacity*

The social symbolism of assistive devices as markers of incapacity represents an additional, and potentially consequential, theme apparent in the literature (Papadimitriou 2008). A social symbol refers to any gesture, artefact, or sign which serves to denote something as a concept. Such symbols are public and express shared emotions, information or feeling, and may therefore function for social cohesion or conversely social dysfunction, in representing social conflicts (Abercrombie et al. 2000). A fundamental premise of stigma is that internal worth can be inferred on the basis of an external sign or characteristic (Papadimitriou 2008). Visible assistive devices may serve to signal membership of a minority group, “the disabled”, and are associated with images of helplessness and passivity (Hocking 1999). In exploring the lived experience of individuals using assistive devices post stroke, Petterson et al. (2007) found that half of the study’s 22 participants reported a changed relation to society caused by feelings of stigmatisation. A feeling of exposure was experienced in the initial stages of using mobility devices out of doors, which was linked to the symbolism inherent in the equipment, as indicative of disability. Similarly, a study conducted among individuals with spinal cord injuries learning to use a wheelchair and incorporate into their way of living, found informants to experience discrimination on the sole basis that they were wheelchair users (Papadimitriou 2008). The wheelchair, an external sign, can invoke ableist assumptions that the person using the chair possesses particular attributes, such as dependency and uselessness, consequently devaluing the wheelchair user and condemning them to an inferior status, as emphasised by one informant’s quote, “the chair defines who you are, and who you are is not valued” (Papadimitriou 2008, p.699).

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Associating the wheelchair with disability is so commonplace, that the universal symbol of handicap depicts a person sitting in a wheelchair, in spite of the fact that only a minority of disabled individuals are wheelchair users (Sapey et al. 2005). Inherent in this association is the assumption that the person is ‘in’ the chair, as opposed to a ‘user’ of the chair and while the term “wheelchair user”, portrays the individual as active, “wheelchair bound” implies passivity, incapacity and dependence (Papadimitriou 2008). Much like racial and ethnic minority groups that experience discrimination, wheelchair users are stigmatised, not on the grounds that they demonstrate inappropriate or socially unacceptable behaviour, but rather they are treated as inferior based on visible, external attributes. Thus, the stigmatisation of wheelchair users is distinct from the experience of deviance, as outlined by Scambler (2009), as individuals are not required to act in deviant ways in order to be labelled as incompetent or different, and their negative stereotyping is simply related to their use of a wheelchair (Papadimitriou 2008). Stated by one participant in the Papadimitriou (2008) study, “if people see the chair first, and the person second, then all you see is disability”. The wheelchair and other assistive devices appear to represent a symbol of incapacity and may become the defining characteristic of an individual’s status. These devices therefore, act as both the symbol and the object of stigmatisation (Papadimitriou 2008, p.698).

### **Implications of the Stigmatisation of Assistive Devices**

#### *Stigmatisation as a Challenge to Re-embodiment*

In addressing the implications of the stigma associated with using assistive devices for the lived experience of an individual, a common finding appears to be that this stigmatisation may act to hinder the process of re-embodiment for individuals who have acquired a disability (Papadimitriou 2008). The re-embodiment process refers to the reconstruction of the mode by which one practically engages with, and understands, their world (Abercrombie et al.



2000). Following disability, this process may involve learning to adapt to the use of assistive devices and incorporating them as part of one's embodied experience (Papadimitriou 2008). These material objects must be integrated into the body schema (Papadimitriou 2008), the representation of spatial relations among the body parts (Jacobs and Jacobs 2004). Papadimitriou (2008) describes the course of re-embodiment for individuals becoming wheelchair users post spinal cord injury, as a transformation of one's being in the world, from disabled to newly abled, moving away from inability and dependence to focus on what one can do, and can re-learn to do. Indeed, some individuals may be successful in the incorporation of assistive devices to become a part of their own body (Pettersson *et al* 2007). However, the endeavours of wheelchair users to achieve re-embodiment can be hindered by ableist assumptions of their inferiority, placing wheelchair users in state of feeling both abled and disabled (Papadimitriou 2008). In re-establishing one's identity, an individual with a disability may engage in two interrelated processes; at times dealing with a disabled identity, for example when seeking or receiving assistance, and at other times, adopting a non-disabled identity, wishing to be seen and treated as such (Hocking 1999). The presence of assistive devices in an individual's personal environment may reinforce one's perception of oneself as assuming a "sick role", and these objects may be negatively incorporated into one's self image (Hocking 1999). The successful reformation of identity following disability may therefore be threatened by the negative social symbolism and consequent stigmatisation associated with the use of assistive devices.

### **The Abandonment of Assistive Devices**

This review revealed a further implication, stemming from the stigma surrounding the use of assistive devices, pertaining to the disuse or abandonment of these devices. Recent international research, suggests that a high proportion of assistive devices are not used, misused, or never used

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(Hocking 1999). According to Hocking (1999), the disuse of these devices has been assumed to be the fault of the abandoner, and attributed to factors associated with the device such as ineffectiveness, unreliability and operational difficulty. However, the stigma surrounding the use of assistive devices in Western society represents a psychosocial factor, which may significantly contribute to their abandonment. This stigma may invoke concerns relating to one's physical appearance when using assistive devices, the social acceptability of these devices and their attraction of unwanted attention (Hocking 1999). Based on a review of the literature by Hocking (1999), on the abandonment of assistive devices, it emerged that individuals with a short term need for equipment, following a hip replacement for example, report higher usage of the devices while, the rejection of obvious assistive devices appears to be more common among people with slowly progressing disabilities. This implies that the abandonment of assistive devices may vary depending on the degree to which an individual has adapted to an acquired impairment (Hocking 1999). It could be inferred that this is the consequence of the stigmatisation of assistive devices, whereby their short term use may be favoured over long term use, which could potentially have a more detrimental impact upon one's master status.

### **Applications to Occupational Therapy Practice**

In summary, the literature reviewed demonstrated that the stigmatisation of assistive devices stems from their social symbolism as markers of disability, incapacity and dependency. Such stigmatisation acts a significant barrier to the successful re-embodiment and establishment of identity following disablement, and may lead to the disuse, or abandonment, of these devices. As the prescription of assistive devices represents an integral component of Occupational Therapy (Hocking 1999), I feel that the sociological insights arising from this review would prove highly pertinent to the field, and will now

reflect upon the practical implications of these issues, relevant to the philosophy and practice of Occupational Therapy. Current Occupational Therapy practice in the prescription of assistive devices centres on the provision of training to ensure optimal functioning, and in accordance with the client-centred philosophy of Occupational Therapy, care is taken to consider the response of an individual to a particular device. Such considerations however, are generally restricted to issues of aesthetics and usability (Hocking 1999). Petterson et al. (2007) assert that in order to enhance the participation and quality of life of individuals with disabilities, it is essential to understand their lived experience in relation to the use of assistive devices. It follows then, that this review may offer insights, valuable in proposing a truly client-centred approach to the Occupational Therapy prescription of these devices.

In my opinion, this practice would benefit from adopting an approach based on the social model of disability, to enhance awareness of the social meanings associated with assistive devices. Individuals with disabilities must negotiate such meanings in the process of accepting their need to use these devices and in the establishment of their self identity (Hocking 1999). To combat the negative stereotyping associated with the use of assistive devices, I suggest that Occupational Therapists, as advocates for the societal acceptance and inclusion of individuals with disabilities, utilise community-centred interventions to inform and educate the public, in an effort to alter current dominant perceptions of these devices. As envisaged by Sapey et al. (2005), wheelchairs need not be seen as symbolising weakness, illness or failure, but rather simply as a means of mobility utilised by individuals with disabilities in a wide range of roles. As clients' emotional responses to using assistive devices are thought to be as important as the occupational opportunities enabled by the devices, to determining their successful usage (Hocking 1999), I feel it is also essential to tackle this stigma at an individual level, and that clients must be empowered to

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avoid the internalisation of shame, invoked by the stigma of using such devices. Also, clients could be directly involved in all aspects of the prescription process, and afforded with the opportunity to choose devices on the basis of personal preferences. This may facilitate the prescription of a device designed for the individual, rather than for their impairment and may provide the client with a means of self expression, for example in selecting devices possessing particular aesthetic qualities such as a specific colour. Such involvement may aid the process of re-embodiment, and prevent the abandonment of devices. Much further research, exploring the stigmatisation of the wide variety of assistive devices, is necessitated, as the present review has identified the very limited range of research available in the area, which has primarily focused on wheelchair use. Of note, the studies cited were conducted in Western societies, rendering the applicability of findings cross culturally questionable. Future studies could potentially examine the concept of stigma, and its association with assistive devices, across cultures.

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