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Invisible Impairments: Dilemmas of Concealment and Disclosure

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ABSTRACT   *People with invisible impairments have choices as whether or not to reveal or conceal their impairments in social interaction. They may pass for ''normal'' if they silence impairment and disability experiences. Social conventions support silence. Disclosing impairments may occur in many circumstances, for many reasons and may have many ramifications. People with invisible impairments and the dilemmas they face have received little attention in disability research. This article discusses concealment and disclosure of invisible impairments as ongoing processes with an emphasis on performance, motivation and context.*

Introduction

This article discusses dilemmas facing persons with invisible impairments in interaction with non-disabled others. It aims to problematise (in)visibility of impairment focusing on the context and content of social interaction and the presentation of self. Passing is an important descriptive and analytical concept close to the life experiences of many impaired persons. Passing assumes the concealment or silencing of the impaired self. According to Samuels (2003:233), ''The option of passing provides a certain level of privilege and a profound sense of misrecognition and internal dissonance''. Invisible impairments constitute a ''category crisis'' as they combine able bodied appearance with impairment. Disclosing these impairments against a background of disbelief often entails the difficult task of explaining the unexplainable. Impairment effects are interactions between biological and social factors, bound with socio-cultural labeling practices (Thomas 1999a). Dilemmas of concealment and disclosure are impairment effects.

The term impairment is a general reference to conditions of long term limitations in functional capacities due to illness, injury or from congenital conditions. Invisible impairments are impairments not readily apparent to the untrained eye. Many types of impairment have few or vague visual markers. Diagnostic category may vary widely. Cognitive and neurological impairments, hearing loss, speech impediments, mild learning difficulties, mental illness, asthma, epilepsy and chronic pain are but some examples. The biomedical category may influence the circumstances in which impairment is

(in)visible to others, the self management of (in)visibility and the likely consequences of exposure or "coming out" as an individual with a specific impairment. Mental illness and epilepsy are, for example, more commonly subject to stigmatization than hearing loss or chronic pain. Persons may have both visible and invisible impairments.

There is a fundamental difference between having visible and invisible impairments. Persons with visible impairments are routinely met with preconceived notions others entertain of them by virtue of seeing a sign of impairment. Persons with invisible impairments are not assigned subject positions as disabled people initially. Persons with invisible impairments may on occasion "pass as normal". They are in a position where they may continually reflect upon whether or not, when, how, and to whom they should attempt to conceal or reveal their impairments.

The visual field is said to occupy a highly privileged position in modernity. It is commonly assumed that to see is to know, that vision categorizes objectively and innocently. Post-structuralist disability research recognizing "the violence of the gaze" and the objectification of being seen seeks to problematise the perception of non-disabled actors in constituting the social nature of impairments (Hughes 1999). Hughes' work was conceived in terms of visible impairments, a point he found worthy of clarification only in a brief end note. Given the overriding signification of the visual field, it is all the more notable that so little disability research has focused on invisible impairments. The only impairments generally taken seriously by others are those which are readily visible. This places individuals with invisible impairments in a highly vulnerable position (Matthews & Harrington 2000, Samuels 2003, Stone 2005).

Hahn (1988) makes a distinction between aesthetic and existential anxiety in discussing negative attitudes towards impaired people. Aesthetic anxiety refers to fears engendered by persons whose physical appearance is regarded deviate or unattractive. The ideal in modern consumerism is the slim, youthful, well trained and symmetrical body-perfect. Appearance mirrors order, control and moral value (Hughes 1999). Existential anxiety focuses on autonomy, the threat that the functional impairments interfere with important life activities. Hahn argues that existential anxiety requires some degree of empathy or identification with the position of an impaired person in order to infer and project personal consequences of functional limitations. Invisible impairments do not arouse aesthetic anxiety by definition. Their bearers look just like everybody else. Their "sameness" on the appearance dimension may inhibit existential anxiety.

Disability research on stigmatization in social interaction has tended to focus on responses to highly visible impairment markers – use of wheelchairs or guide dogs, facial scaring, absent limbs, strikingly different physical appearance. A common conclusion is that highly visible impairments become hyper-visible, eclipsing at least for a time all other identities a person may wish to present. An increased appreciation of dilemmas facing bearers of invisible impairments adds to our understanding of impairment effects as a social construction. It adds to understanding of the lived experience of

disability in a large but often overlooked category of people – those with invisible impairments. It has been estimated that as many as 40% of impaired persons have invisible impairments (Matthews & Harrington 2000).

Invisible impairments are an emerging field in disability research. This article seeks to contribute to this field by a conceptual analysis bringing together diverse strands of disability, narrative and queer sociological literature. Advantages and techniques of concealment will be discussed before turning to advantages and techniques of disclosure. Dilemmas of both will then be considered. Concealment is commonly equated with concepts of passing and covering developed by Goffman (1963). Passing refers to keeping an attribute ascribed stigma from becoming known to others while covering refers to keeping a known attribute as unobtrusive as possible. The discussion draws heavily on Goffman's seminal work while attempting to expand upon its boundaries. Attempts are made to go beyond stigma-attached impairment and beyond causal encounters. Questions are raised about the advantages of passing as a mode of self presentation and emphasis is placed on self disclosure. Unless otherwise stated, the perspective taken in the discussion is that of a person with invisible impairments.

Concealment

In Goffman's classical book on stigma and the management of a spoiled identity (1963:57), people with visible (known) impairments are in association with non-disabled society "discredited" while people with invisible (un-known) impairments are "discreditable". Discreditable persons are passing but are at risk of exposure and devaluation. The primary concern of the discreditable was said to be information management and concealment of the attribute ascribed stigma. Goffman argued (1963:95) that "because of the great rewards of being considered normal, almost all persons in a position to pass will to do so on some occasion by intent." Goffman wrote extensively, if eclectically, on dilemmas facing discreditable persons. Embodied differences and weaknesses visible to the eye were primary examples of stigmatized attributes. Invisible impairments were also assumed to be attached with stigma.

Goffman's concept of passing was situated in a state of pre-knowledge, when impairment is hidden and unknown to others. Once exposed passing is enacted anew only in encounters with new individuals. Passing in this article encompasses both a pre- and a post-knowledge state. This author will argue that knowing and forgetting often go hand in hand. Information is constantly competing for our attention. Social memory may be short when appearances and performances give no indication of impairment, when impairment is unobtrusive. Even in contexts where impairment is known, acknowledged and salient to all parties, time and habit may make impairment normal and in effect "invisible".

Exactly what the great rewards of being considered "normal" are can be debated. Some might argue that the greatest reward of passing is that stigmatizing gazes are directed elsewhere. This implies that passing by intent

is motivated primarily out of fear – fear of devaluation, exclusion or marginalization, of being made to feel shameful for one's body. There is substantial literature pertaining to stigmatization of disabled persons in social interaction (Murphy 1987, Fine & Ash 1988, Morris 1991, Thomas 1999a, Gill 2001, Zitzelsberger 2005). For our present purposes it suffices to assume that some may anticipate stigmatization to follow from exposing impairment and some may experience it. However, as will be discussed here, stigmatization associated with impairment may not be the only consequence under consideration, nor may it be an important consideration for all impaired persons.

Passing by effect or intent allows people with invisible impairments to construct identities undefined by their stigmatized impairment. By avoiding stigmatization people with invisible impairments are afforded ordinary degrees of freedom to be many selves. The absence of stigmatizing responses represents opportunities that might not be otherwise available. This applies particularly to employment opportunities. One study showed that college educated persons with invisible impairments were 14 times more likely to be employed than those with visible impairments (Martz 2003).

Passing protects personal privacy. Ordinary standards of adult integrity are in place shielding one from invasive curiosity of "normals". Literature on social interaction of persons with visible disabilities is replete with examples of invasions of privacy and unreasonable questions posed by non-disabled persons presuming a right to know. Comparatively innocent examples are questions such as "What happened? Does it hurt? Should you still be driving a car?" Persons with invisible impairments may regard information about their impairments as "private information" and its management as integral to "boundary regulation" (Matthews & Harrington 2000). Their choice may be to conceal impairment, thereby avoiding discussion of its effects. People with invisible impairments may also regard passing as concern for others rather concern for self. Concealment may be a means of shielding others from embarrassment and concern, a means of not disrupting the flow of the moment and not attracting undue attention to self.

Passing may be appreciated as moments of forgetfulness when impairment and disability fade into the background. These moments provide a restful "time out" for all. People with recently acquired impairments may seem to be their "old selves". Concealment may be integral dimension of cognitive self therapy which has a positive focus on health, capability and opportunity. By passing as "normal", persons with minor reductions in functional capacities may avoid being reminded of impairments effects. Embodied knowledge of impairment may be repressed.

A "reward" for passing as "normal" may be that an individual with impairments feels most comfortable in this position, most whole, "true" and most knowable to one's self. The case study by Garfinkel (1984) of the ongoing process of doing the social practices of the other has this slant on passing. Persons acquiring impairments in adulthood may fluctuate between pre- and post impairment identities, only gradually integrating impairment into their sense of self (Yoshida 1993). They have substantial pre-impairment

knowledge of the social practices of non-disabled, mainstream society. Being "normal" is what they know best. Shakespeare and Watson (2001) argue that the denial of disability is implicitly based on rejection of the idea of an exclusive "normality" and that it represents a refusal to be categorized.

Passing strategies and behaviours

Passing may require different strategies and behaviours in different contexts. Passing may simply require careful planning, clear priorities and realistic choices. It will usually involve self monitoring and self surveillance in a restricted social room. As impairments often involve limitations in stamina, important facilitating factors may involve control over resting and exiting. One passes for just so long. One must know when it is time to withdraw. Helpers may assist in covering over impairment, for example, by offering an arm to steady one's poor balance. Passing may or may not involve lying. It will always involve telling less than the whole story.

Internet exchanges provide maximum invisibility, a disembodied exchange. The focus here is however on face-to-face encounters with non-disabled others. Many aspects of the physical, temporal and social context are involved. Aspects of the physical setting – the lighting, accessibility, acoustics, air quality, etc., may be important for some. Aspects of the activities being performed are likely to be important – the pace, duration, necessary rule comprehension, etc. Passing in a group sitting quietly is less demanding than passing in a group playing a fast moving team sport. The topics of conversation and relationships and interactions between persons present are perhaps most important. Is the conversation lively and referring to mainstream social activities and experiences? How long and intimately acquainted are the persons present? Do impaired persons have someone helping them cover over impairment effects, someone involved in what Edgerton (1967) called "the benevolent conspiracy", or are they all on their own? Concealing impairment effects from strangers is one project; concealing it from one's current or prospective employer, close friends or partner something else again. Concealing impairment as a solo performance is more demanding than it is with the aid of persons privy to one's functional limitations.

The intent here is not to compile a list of all relevant contextual features. What is relevant will vary with the individual, the type and severity of their impairment, "good days and bad days" in the terms of Charmaz (1991), who is present and what they are doing. The point here is rather that given the highly contextual nature of impairment (in)visibility, people with impairments are party to creating invisibility by the contexts they enter and those they avoid. Most people will have some degree of choice in this matter.

A common passing strategy involves concentration of energies on life-worlds the impaired individual gives highest priority. Concentration of effort is then restricted in space and time. Only part of the day is visible to others. Some may choose work and workplace relations as a context where they try their best to ignore impairment and meet ordinary expectations of

productivity. Their particular impairment may have little influence on work capability in a strict sense but most occupations include social interaction in different contexts. If they should fall short of production expectations and/or fall out of job related social interaction they may be able to hide behind a well rehearsed show of busyness. To be busy, to demonstrate busyness is perhaps the most common performance of health and vitality today, the badge of "normality".

Passing in work, family or other contexts may require over-extending one's capacities. Over-extension and the repair work which follows must be hidden. No one can simultaneously perform at more than full capacity in all lifeworlds. Passing by full concentration of energy on one lifeworld is by definition partial. It is likely to yield serious imbalance and increase impairment exposure in lifeworlds of lower priority. Relationships with family and friends are, for example, likely to suffer from efforts at hiding impairment effects at work.

Passing in general requires storytelling. We live in a narrative world where selves are created largely in communication with others. The narrative is an ontological condition of social life. We come to be who we are by being located and locating ourselves in social narratives which are rarely of our own making (Somers 1994). In the selection and telling of tales, talkers are actively constructing their identities and their worlds within prevailing social narratives (Somers 1994, Ochs & Capps 1996, Frank 1997).

The construction of new, interesting stories may be difficult if impairment effects constrict daily life spatially and socially. "No news" and "old news" rarely appeal. Particular impairments, such as hearing loss or reduced cognitive capacity, may impede participation in fast moving conversations. Impaired individuals may have serious difficulties in following and interpreting what others are saying and miss their own entrance cues. A narrative strategy for passing is developing stories about life projects as unaffected by one's impairments as possible. The important point is not what the life project is but that telling about it communicates commitment and orientation towards the future (Giddens 1991). Some persons pass by effect more than by intent. Their social surroundings and/or impairment give them little choice other than remaining silent. A healthy appearance and silence are readily interpreted as shyness. Non-disabled people quickly turn to more interesting conversationalists.

Disclosure

Invisible impairments are often sensed by the non-disabled but are not necessarily understood – that person walks strangely or has poor balance, that one seems to lack energy, seems shy or withdrawn, that one is highly erratic in behaviour. The burden of interpretation is put on the bearer of unclear signs. He or she may feel a need to explain. One may choose to explain about one's impairment(s). One may choose instead common explanations for "faulty" behaviour – no sleep the night before, distracted thoughts, one just stumbled on uneven pavement, etc. Invisible impairments

allow the bearer some discretion in revealing their impairment to others. Bearers may be able to choose the time, place and closeness of relationship (Grue 2001, Heggdal 2003). The ongoing disclosure of impairment to people who already "know" about it, the flip side of Goffman's concept of covering, is largely unexplored territory in disability research. How do people with known but invisible impairments tactfully and effectively remind others of impairment effects?

Coming out as a disabled person has been discussed in general terms as turning shame into pride, joining the disability movement and sharing a collective cultural and political disability experience (Shakespeare 1996, Swain & Cameron 1999, Reeve 2002). This may be considered coming out as Disabled (with upper case D), a permanent shift in self perception and self presentation. Self disclosure of concern here is more contextually limited and intermittent, more an option or practical necessity in social interaction than an altered mind-set. It is the ongoing coming out of impairment and disability (in lower case). Self disclosure of invisible impairments may be integrated into a general mode of self presentation which includes passing. Self disclosure as discussed here refers to intentional disclosure. Involuntary disclosure through loss control of the body or exposure by others exceeds the scope of this article.

The most studied process of self disclosure is coming out of homosexual orientation. There are similarities in the process of disclosing invisible impairments and disclosing sexual orientation although there are also differences. There is less clarity of the meaning of impairment and disability, less liberation and also less risk of censure in disclosing impairment than disclosing that one is queer. There are a variety of non-verbal and verbal means to signal queer identity that are lacking for those with invisible impairments (Samuels 2003). Ward's and Winstanley's (2005) study of coming out at work points to primary aspects of disclosing sexual orientation as an ongoing process. Every work context has its own logic and its own consequences which are to be weighed. Finding the right time for disclosure is an unreachable ideal. Ward and Winstanley analyse coming out as a performative act. It is in the repetitive nature of action that the practice becomes performative. Samuels (2003) makes the distinction between "coming out" as acknowledgment of self and "coming out to" a person or group in a particular context. Samuels also stresses that coming out (to) is not a static nor singular event.

Disclosure techniques and motives

Applying a performative framework to disclosing invisible impairments, we may ask, how is impairment performed? One means is by lowering or letting go of customary self surveillance. This author makes her spinal cord impairment more visible on occasion by not correcting unevenness in her gait thereby halting more than absolutely necessary. Impairments may also be performed by facial expressions and gestures displaying pain or fatigue. Clothing can be used to hide or reveal impairments as exemplified by Thomas

(1999b). Technical aids such as supportive neck collars or airport wheelchairs may be used. One may participate in activities which carry a high risk of revealing impairment. Impairment may be disclosed in written first person accounts as this author and many others have done (Wendell 1996, Vogt-Svendsen 1998, Lingsom 2004). Most commonly, however, one will have to perform impairment verbally as an ongoing process in the flow of everyday conversations.

Impairment will have to be weaved into a story which gives it credibility and makes impairment effects understandable to others. If one's impairment effects are variable, explaining why one can manage X one day in one context but not on another day or in another context, is especially difficult. The individual may not understand the causes or be able to anticipate variation in his or her condition. Explanations to others falter when even the storyteller is confused. Family, friends and associates may contribute to the confusion by well intentioned gestures of encouragement and support, for example, by repeatedly insisting that of course the person can manage.

The general assumption that impairments are visible produces a distrust of mere spoken claims to disability. Samuels (2003:247) argues that the social narrative is a "convergence of complicated cultural discourses regarding independence, fraud, malingering and entitlement: the form it takes almost always involves a perceived discontinuity between appearance, behaviour and identity". The social narrative forming the backdrop for a story of invisible impairment is thus one of disbelief and suspicion. Persons without a clear medial diagnosis are suspect. Middle aged women with diffuse symptoms are in particular granted little creditability. The general tone in the mass media is critical to the rising numbers of disability pensioners and the number of employed persons on sick leave. People with invisible impairments claiming disability or sick leave benefits raise questions in the minds of observers. Persons claiming respite needs in domestic life may also raise questions in the minds of family. Are functional limitations being used to escape from obligations at home? Social expectations are that persons seen passing in some contexts will be "normal" in all contexts.

Goffman (1963:125) regarded voluntary disclosure as the final, mature, well- adjusted phase in the "moral career" of the stigmatized person. "After laboriously learning to conceal, the individual may go on to unlearn this concealment". For some people, however, disclosure may come first. In cases of traumatic injury for instance, the dramatic story of acquiring impairments may be paramount in early phases of living with impairment effects and concealment learned only slowly in later stages. It may also be argued that concealment and disclosure are commonly learned simultaneously, each informing performance of the other.

While the motives for passing are often taken for granted, the motives for self disclosure have received little attention. The following is a tentative and non-hierarchical listing of disclosure motives:

1. *Desire for experience.* The (in)visibility of impairments is, as earlier discussed, often dependent on self surveillance in a restricted social

room. Should an impaired person wish for a different set of experiences and dare to take chances of extending and over-extending bodily limits, then he/she is also taking a calculated risk of disclosing invisible impairments.

2. *Reducing demands.* Illness and impairment are socially legitimate excuses for taking time out, for lower productivity, stamina, etc. Disclosure may be a straightforward attempt to attract concern and offers of assistance and to lessen social pressures.

3. *Altering evaluation standards.* Disclosing impairment and disability may also be rooted in a desire to present the self in the best possible light, not by passing, but by bringing alternative evaluation standards into play. Disclosing impairment invites others to witness how the person manages his/her impairment and disabling social structures and practices when judged according to different standards than usual. It is a request for social recognition and validation given one's capabilities and the social obstacles one faces. In modern society people are increasingly held responsible and hold themselves responsible for how well they manage illness and life difficulties (Kleinman 1988, Giddens 1991, Frank 1997).

4. *Personal integrity and cohesion.* Giving voice to the embodied experience of impairment contributes to a personal sense of continuity and cohesion. It opens up narrative options rooted in both the body and biography. Frank (1997:61) writes that "seriously ill persons have to learn to think differently and that they learn by hearing themselves tell their stories, absorbing others reactions to their stories and experiencing their stories being told". Impairment effects are learned through storytelling.

5. *Value transformation and political activism.* Impairment and disability often lead to new perspectives, new knowledge and a transformation of values (Gill 2001, Shakespeare & Watson 2001). Hahn (1997) contends that it is common to view the world differently after impairment, leading to insights and understandings about major life experiences that differ from those held by non-disabled peers. Disabled people find themselves cast in many unusual situations. Reflecting upon their experiences they may find that some are "interesting" and want to relate them to others. With an increased awareness of the role of social forces in disabling people, some may become more politically active.

6. *Health care and service encounters.* Health care and service encounters are specialized contexts where persons with impairments must present their problems in a credible manner in order to be believed and adequately assisted (Bie, Hooper, Dunn & Croft 2004, Elstad, Grue & Eriksen 2005). The impaired self must be presented to gate keepers and other officials in the formal and informal support systems – health professionals, social security officials, service and benefit providers, etc. Impaired people are required to construct disability when applying for services, benefits and technical aids (Reeve 2002).

Dilemmas of concealment and disclosure

Gill (2001) has argued that the core experience of disabled people in social interactions today is trying to express who they are, not trying to be someone or something else. People with invisible impairments must do more explaining than persons with visible ones. There are limits of language in expressing bodily sensations, especially pain (Bie *et al*. 2004). Invisible impairments involving cognitive functions may have language difficulties at their core – problems finding words and concepts, making comparisons, etc. (Vogt-Svendsen 1998). If one is accustomed to hiding or under-communicating one's impairment, it may be all the more difficult to express it in circumstances when one wishes to disclose difficulties and embodied differences. It takes training to express bodily sensations and to acknowledge impairment effects.

Expectations of "normal" behaviour will be directed at persons with invisible impairments. As impairments are real despite their invisibility, the likelihood is high that the individual will fall short of expectations entertained by others. Stone (2005:295) writes that for persons with invisible impairments "the fear of being misunderstood is ever present ... It is a problem that arises in the context of a society organized around the assumption that when it comes to reading bodies, 'what you see is what you get'". The disbelief of others is thus an important component of impairment effects for impaired persons with able bodied appearance.

In a study of young female survivors of haemorrhagic stroke, Stone (2005) found respondents faced disbelief on two levels. Due to popular conceptions that strokes only affect old people, young women were not believed to have had strokes. Secondly, women with impairments which were for the most part invisible, such as cognitive difficulties, persistent fatigue and/or one-sided weakness, had problems with self presentation as only visible impairments were popularly believed to be serious. The impaired women typically worked to hide their limitations and avoid situations where they knew they would have difficulties.

The responses to self disclosure are likely to vary with time and place, the age, gender and social status constellations of the individuals involved, their past relationships and their expectations of the future, and the degree of stigma attached to the particular impairment. Self disclosure is likely to lead to moments of increased social tension but will often be situated in a context where dialogue creating opportunities for tension reduction is possible. Risks associated with self disclosures may be substantial particularly in relation to employment. In a study of persons with epilepsy and diabetes, Eriksen & Næss (1998) found that informing prospective or current employers can result in failure to secure employment or job loss. Variation was, however, found to be high. Some persons reported stigmatization in work and social life; others did not. Disclosure of epilepsy and diabetes has a practical dimension of increased security in case of acute illness. In general disclosure was regarded with ambivalence and was seen to require careful balancing.

When passing has been "successful", responses to self disclosure are likely to be met by expressions of disbelief and counter arguments. The impaired individual may be told, for example, how healthy and fit they look, how they smile, how impossible it is for them to be impaired. For their own wellbeing they must learn to present themselves to others in a way that is psychically comfortable (Stone 2005). It is reasonable to assume that this commonly includes resistance to expectations of looking sick and depressed in order to have their impairments acknowledged.

When passing has only been partially or intermittently successful and the person with invisible impairments has not been meeting expectations of "normal" behaviour, self disclosure may be trading labels. A negative performance label (lazy, incompetent, shy or clumsy) may be traded for a disability label (weak, dependent, a personal tragedy). If disclosure is not deemed creditable, it may also attract other negative moral labels such as being fraudulent or manipulative. Work colleagues are often wary and quick to claim malingering. Impaired persons may be exposed to persistent distrust, even bullying to the point of receiving "anonymous" phone calls at home (Vogt-Svendsen 1998). In reaction to negative responses the impaired person may increasingly focus energies on approaching "normal" productivity and work methods. This is likely to further increase productivity expectations by self and others in a spiralling, unsustainable struggle to ignore functional limitations.

The family is another common context of disbelief. Is the impaired person doing the best they can? Family members see the resting going on backstage that outsiders do not see as well as the successful front stage performances of passing. Although impairment effects are known, they may also be forgotten or repressed in the pressures of daily life and negotiations over the division of household labour. An attribute work and family contexts commonly share is that "poor" performance by the impaired person increases the work loads of others.

Non-disabled persons are often uncertain and anxious as how to approach a person known to be impaired. They are in a dilemma as to whether they should acknowledge their knowledge, particularly when there are no visual markers to hang one's comments on. As shown by Makas (1988) non-disabled persons are often at a loss as to how they should express their "good intentions". Social conventions restraining non-disabled persons from acknowledging impairment result in what may be termed "courtesy passing". In courtesy passing others know of the stigmatizing identity yet act as if "it" were unknown. Even if impairment is introduced into the conversation most do their best to keep the lid on the topic. A common social convention is to treat impairments permanent in nature as if they were conditions which go over or improve, like a bad flu. Another response is to share and "normalize" impairment effects turning them into commonplace experiences (Wendell 1996). Many people are tired when they get home from work or stiff when they get up in the morning. Conventions of sameness contribute to the difficulties invisibly impaired persons face in telling their story of embodied difference.

Disclosure can come too early or too late. Late disclosures may be indicative of little faith in the other. Others have not been entrusted the impaired person's story which implies that they have not been deemed trustworthy enough to deal with the withheld information. Offence may be taken by those who feel that disclosure should have come earlier. Others (family, employers, etc.) may feel that their "right to know" has been transgressed if disclosure is late in coming. The impaired individual may feel that their control over private information is being questioned and contested. Disclosures which come too early are likely to be socially awkward surprises, seemingly out of place or proportion.

Disclosure may come too often or too seldom. Too often and one is likely to be regarded as ego-centred, a chronic complainer and unpleasant company. Perhaps repetitive disclosure is grounded in difficulties of being heard and understood. Perhaps others are not prepared to listen. Impaired people are often regarded and regard themselves as having primary responsibility for reducing social tension in interaction with non-disabled persons, for ensuring everyone a good time (Goffman 1963, Rousso 1988). Concealment is thus often preferred over disclosure. Women with impairments often feel forced to hide pain and other bodily distress in order to not be considered "complainers" by spouses (Charmaz 1987, Fine & Ash 1988, Elstad, Grue & Eriksen 2005). If disclosure occurs seldom, others will have learned to assume "normality". What they see is the impaired individual passing by intent or effect in given contexts. Others will have forgotten about impairment effects and have difficulty understanding and accepting them. They will have come to expect low tension levels in social interaction and conversations which do not touch upon the uncomfortable topic of impairment.

The principle dilemmas associated with concealment and disclosure of invisible impairments are thus related to a complex set of issues concerning creditability, good faith and timing. Passing in general has connotations of leading a double life, of not being entirely honest but also being non-disruptive of mainstream social life. Self disclosure requires explanations. Invisible impairments are suspect, as they challenge the primacy of visual knowledge.

Summary

The intent of this article has been to bring increased attention to dilemmas facing persons with invisible impairments regarding concealment and disclosure of their impairments in social interaction. This article problematises invisibility by reference to its dependence on context and performance and reference to self disclosure. Invisibility is in part an attribute of an impairment, in part a choice of activity and context, in part concealment of the impaired self and in part social conventions of silence, the untrained eye and the disbelief of the others.

In cultures which emphasize the visual as knowledge and associate appearance with order and morality, the (in)visibility of impairments may have substantial consequences for their bearers. Invisible impairments may

open opportunities for passing "as normal" in social interactions. Passing as "normal", however, carries with it conventional expectations as to behaviour and stamina, expectations persons with impairments may be unable to meet because of their impairment(s).

The performance of concealment has been discussed with emphasis on choice of context, concentration of effort and the construction of "happy stories". The concept of courtesy passing is suggested for social conventions supporting silence. Passing may have restricting personal consequences for impaired persons. Concealment requires self censorship and self surveillance in a restricted social room. To pass as "normal" impaired persons must silence their body-self and their impairment experiences. Their distinctiveness as storytellers in a narrative world is thus diminished. It takes training to focus on and express bodily sensations, to acknowledge limitations and to recognize discrimination. Passing as a mode of self presentation deprives one of the training.

Passing as a mode of self presentation also has social consequences. If persons with invisible impairments devote their energies and aspirations towards passing as "normal" and concealing their impairments, they strengthen for themselves and others the already strong cultural aversions to pain, vulnerability and difference. By holding their impairments hidden they enhance narrow conceptions of normality and contribute nothing to dismantling social and structural barriers to participation, belonging and wellbeing of all people.

This article suggests that both concealment and disclosure are ongoing processes. In alternating between non-disabled and disabled worlds persons with invisible impairments are constructing multiple and somewhat conflicting identities which challenge conventional categories. The social construct of impairment is expanded; its boundaries made more diffuse.

As discussed here, disclosure is not always easy or straightforward. Some people pass by effect rather than intent because of their difficulties in explaining functional limitations. Dilemmas related to concealment and disclosure involve a complex set of issues regarding honesty, good faith, timing and credibility. The social narrative under which they tell their stories is one of disbelief and suspicion of malingering. People with invisible impairments have a lot of explaining to do if others are to understand impairment effects. These difficulties are themselves impairment effects. Dilemmas regarding the "right" timing and frequency of disclosure and its effective performance are problematic, independent of stigma attached to impairment effects. They are problematic as living with impairment effects is problematic for self and for others.

Invisible impairments are a growing field of interest in disability research but are still at the margins, an unexplainable, incongruent category. Loops of expectations, performance and responses call for studies of social interaction in different contexts giving voice to both disabled and non-disabled persons. Both small and large scale empirical studies are needed to increase our understanding of the variation in social practice and the influence of social

policy and structure. Appreciation of the dilemmas faced by persons with invisible impairments may in and of itself help reduce impairment effects.

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References

Bie, N. O., Hooper, H., Dunn, K. & Croft, P. (2004) Establishing self and meaning in low back pain narratives, *The Sociological Review*, 52, pp. 532–549.

Charmaz, K. (1987) Struggling for a Self: Identity Levels of the Chronically Ill, *Research in the Sociology of Health Care*, 6, pp. 283–321.

Charmaz, K. (1991) *Good Days and Bad Days. The Self in Chronic Illness and Time* (New Brunswick: Rutgers University Press).

Edgerton, R. (1967) *The Cloak of Competence. Stigma in the Lives of the Mentally Retarded* (Berkeley: University of California Press).

Elstad, J. I., Grue, L. & Eriksen. J. (2005) *Smerte og livsmot. En analyse av 74 fortellinger om livet med revmatisme* (Pain and Courage. An analysis of 74 stories of life and rheumatism, not available in English). NOVA rapport 4/05. (Oslo: Norwegian Social Research).

Eriksen, J. & Næss, S. (1998) *Epilepsi og diabetes. Livskvalitet, stigmatisering og mestring* (Epilepsy and diabetes. Life quality, stigmatization and coping, not available in English). NOVA rapport 16/98. (Oslo: Norwegian Social Research).

Fine, M. & Ash, A. (Eds) (1988) *Woman with Disabilities. Essays in psychology, culture and politics.* (Philadelphia: Temple University Press).

Frank, A. (1997) *The Wounded Storyteller. Body, Illness and Ethics* (Chicago: University of Chicago Press).

Garfinkel, H. (1984) *The Study of Ethnomethodology* (Cambridge: Polity Press).

Giddens, A. (1991) *Modernity and Self-Identity. Self and Society in the Late Modern Age* (Cambridge: Polity Press).

Gill, C. (2001) The Social Experience of Disability, in: G. Albrecht, K. Seelman & M. Bury (Eds), *Handbook of Disability Studies* (London: Sage Publications).

Goffman, E. (1963) *Stigma. Notes on the Management of Spoiled Identity* (New York: Penguin Books).

Grue, L. (2001) *Motstand og mestring. Om funksjonshemming og livsvilkår* (*Resistance and Coping. On Disability and Life Conditions*, not available in English). NOVA rapport 1/01. (Oslo: Norwegian Social Research).

Hahn, H. (1988) The Politics of Physical Differences. Disability and Discrimination, *Journal of Social Issues*, 44, pp. 39–47.

Hahn, H. (1997) An Agenda for Citizens with Disabilities. Pursing Identity and Empowerment, *Journal of Vocational Rehabilitation*, 9, pp. 31–37.

Heggdal, K. (2003) *Kroppskunnskaping. En grunnleggende prosess for mestring av kronisk sykdom* (*Developing Embodied Knowledge. A critical process for coping with chronic illness*, not available in English). (Bergen: University of Bergen).

Hughes, B. (1999) The Constitution of Impairment: modernity and the aesthetic of oppression, *Disability & Society*, 14, pp. 155–172.

Kleinman, A. (1988) *IIlness Narratives. Suffering, Healing & the Human Condition* (New York: Basic Books).

Lingsom, S. (2004) *Detour Ahead. A Personal Account of the Long Road Home* (Glen Margaret: Glen Margaret Publishing).

Makas, E. (1988) Positive Attitudes Towards Disabled People: Disabled and Non-disabled Persons' Perspectives, *Journal of Social Issues*, 44, pp. 49–61.

Martz, E. (2003) Invisibility of disability and work experience as predictors of employment among community college students with disabilities, *Journal of Vocational Rehabilitation*, 18, pp. 153–161.

Matthews, C. & Harrington, N. (2000) Invisible Disability, in: D. Braithwaite & T. Thompson (Eds), *Handbook of Communication and People with Disabilities. Research and Application* (Mahwah: Lawrence Erlbaum Associates, Publishers).

Morris, J. (1991) *Pride Against Prejudice. Transforming Attitudes to Disability* (London: The Women's Press).

Murphy, R. (1987) *The Body Silent* (New York: Henry Holt and Co).

Ochs, E. & Capps, L. (1996) Narrating the Self, *Annual Review of Anthropology*, 2, pp. 19–43.

Reeve, D. (2002) Psycho-emotional Dimensions of Disability and their Influence on Identity Construction, *Disability & Society*, 17, pp. 493–508.

Rousso, H. (1988) Friendship and Fairness. How disability affects friendship between women, in: M. Fine & A. Ash (Eds), *Women with Disabilities. Essays in psychology, culture and politics* (Philadelphia: Temple University Press).

Samuels, E. (2003) My Body, My Closet. Invisible Disability and the Limits of the Coming-out Discourse, *GLQ: a journal of lesbian and gay studies*, 9, pp. 233–255.

Shakespeare, T. (1996) Disability, Identity, Difference, in: C. Barnes & G. Mercer (Eds), *Exploring the Divide: illness and disability* (Leeds: Disability Press).

Shakespeare, T. & Watson, N. (2001) Making the Difference: Disability, Politics and Recognition, in: G. Albrecht, K. Seelman & M. Bury (Eds), *Handbook of Disability Studies* (London: Sage Publications).

Somers, M. (1994) The narrative construction of identity. A relational and network approach, *Theory and Society*, 23, pp. 605–649.

Stone, S. (2005) Reactions to invisible disability The experiences of young women survivors of hemorrhagic stoke, *Disability and Rehabilitation*, 27, pp. 293–304.

Swain, J. & Cameron, C. (1999) Unless otherwise stated: discourses of labeling and identity in coming out, in: M. Corker & S. French (Eds), *Disability Discourse* (Buckingham: Open University Press).

Thomas, C. (1999a) *Female Forms. Experiencing and understanding disability* (Buckingham: Open University Press).

Thomas, C. (1999b) Narrative identity and the disabled self, in: M. Corker & S. French (Eds), *Disability Discourse* (Buckingham: Open University Press).

Vogt-Svendsen, M. (1998) *Fremover etter hodeskade – med hodet til hjelp.* (*Forward after head injury – with help from the head*, not available in English). (Oslo, Unipub Akademika).

Ward, J. & Winstanley, D. (2005) Coming out at work: Performativity and the recognition and renegotiation of identity, *The Sociological Review*, 53, pp. 447–475.

Wendell, S. (1996) *The Rejected Body. Feminist Philosophical Reflections on Disability* (New York: Routledge).

Yoshida, K. (1993) Reshaping the self: a pendular reconstruction of self and identity among adults with traumatic spinal cord injury, *Sociology of Health and Illness*, 15, pp. 217–245.

Zitzelsberger, H. (2005) (In)visibility: accounts of embodiment of women with physical disabilities and differences, *Disability & Society*, 20, pp. 389–404.