

## THE SOCIAL CONSTRUCTION OF STIGMA IN HEALTH CARE SETTINGS

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### *Introduction*

There is a well recognised relationship between stigma, prejudice and discrimination and the notion of those groups and individuals who are stigmatised becoming socially excluded (Social Exclusion Unit, 1998). As such socially excluded groups and individuals are lost to the binding force of communities, this fragments and weakens society as a whole (Social Exclusion Unit, 1999). Furthermore, there is growing concern that many socially excluded individuals turn to illicit drugs, alcohol and crime in response to their plight and this leads to a further weakening of social ties, and in turn to an increase in victimisation (Social Exclusion Unit, 2000). Stigma itself is a damaging and destructive term, which usually carries a negative semantic, and few would openly admit to being stigmatising in their social interactions. However, from the extent of marginalised groups that are noted in our society, it is clear that there must be many individuals and institutions that contribute to discriminatory practices, either consciously or subconsciously. In this chapter, we are concerned with stigma in health care settings,

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particularly in relation to the roles that professionals exercise in the stigmatising process, both in terms of its creation and its perpetuation. As we believe that stigma is fundamentally a social construction, albeit with a recognised practical impact, we will analyse stigma in health care settings from the perspective of social constructionism.

### *Social Constructionism*

Social constructionism is a term that is bandied around academic circles with a frequency that belies its fuller understanding. It is a popular closing retort in intellectual “ping-pong” argumentation to state that “it’s not real, it’s socially constructed” and, if propounded with enough dismissive finesse, this will usually leave other interlocutors flummoxed. However, we ought not to become either too smug regarding this or too disdainful; as Berger & Luckman (1967, p. 13) put it: “the man in the street inhabits a world that is ‘real’ to him, albeit in different degrees, and he ‘knows’, with different degrees of confidence, that this world possesses such and such characteristics. The philosopher, of course, will raise questions about the ultimate status of both this ‘reality’ and this ‘knowledge’”. Berger & Luckman, as sociologists, claim to be on a rung somewhere between the man in the street and the philosopher and we, as nurses, claim to be on a rung somewhere between the lay person and Berger & Luckman. There are a number of elements to be dealt with in our quest to understand the nature of social constructionism and this is our first task.

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### *Reality*

Given that Berger & Luckman have established that both the lay person and the philosopher will have different degrees of understanding as to the status of what constitutes reality, and also that all readers of these words will at least be on the lay rung of understanding, we will briefly outline the perspectives of two philosophers on the nature of reality. René Descartes (1596-1650), often called the father of modern philosophy, was born in the Touraine region of France and, following an education in the scholastic and humanistic traditions, worked mainly in the field of mathematics. Turning to philosophy, Descartes was concerned that what he perceived, in short his reality, could be doubted. He claimed that he had no way of telling that what he perceived was not a dream, an illusion or a hallucination, and might not be reality. He doubted everything and decided to deconstruct the world by hypothesising an all-deceiving evil genius that confused and confounded him at every stage of his thinking. This deconstruction took him back in his thinking until he was at the point at which he could state his "Cogito, ergo sum" proposition (usually translated as "I think, therefore I am"). The deceiving genius pushed him to this first conclusion in rebuilding his concept of the world; that is, if Descartes perceived something, anything at all - a dream, illusion or hallucination - he must therefore exist. From this starting point, he rebuilt his concept of the world up to, and including, the point of being able to prove the existence of God, to his own satisfaction (Descartes, 1637, 1641/1967).

The second philosopher was Plato (427-347 BCE), who was an Athenian Greek aristocrat and devoted follower of

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Socrates. In his central work, the *Republic*, Plato sets out how an ideal society, or an approximation to it, might be justly ruled by philosophers acquiring political power. The most potent image in the *Republic* is the analogy of the cave, now fondly known as Plato's cave, in which he asks the reader to imagine a person born in a cave, fixed to the wall, with no knowledge of the existence of the outside of the cave. Each night, our incumbent sees shadows and flickering lights on the opposite wall and this is his only perception of reality. One night, he is taken down from his fixed position on the wall opposite to the shadows and lights and taken out of the cave to be shown a fire at the cave entrance, with people dancing around it, which was producing the silhouettes on the cave wall. Thus, Plato suggests that the cave dweller now has two realities and, having travelled further afield, with new experiences along the way, he acquires multiple realities. Thus, reality may begin with an internal perception of the self, but also includes a perception of the other, which forms the beginning of social perception (Plato, trans. 1977).

### *Knowledge*

Knowledge is knowledge of something, and to know is to suggest that this something is understood in relation to other things in the world. All things in the world share a relation with other things and Foucault (1970) referred to this as "the order of things". However, there are different approaches to knowledge, with "scientific" being merely one. The word "science" is derived from the Latin *scientia*, which, in turn, is derived from *sciens*, the present participle of *scire*, which means "to know". Scientific knowledge has credence over other types of knowledge, but only for some people. Some believe that other modes of knowledge are superior to scientific knowledge. These other modes of

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knowledge would include the *authoritarian* mode, which refers to those who are socially or politically defined as being eligible to produce knowledge: "These may be oracles in tribal societies, archbishops in theocratic societies, kings in monarchical societies and individuals occupying scientific roles in technocratic societies" (Nachmias & Nachmias, 1981, p. 5). Other examples of this type of knowledge would include the Pope's undisputed religious knowledge for Catholics and, for Russians, the Soviet Academy of Sciences, which decreed that probability was a non-scientific approach to theory building, in an (abortive) attempt to resolve the conflict between the determinism of dialectical materialism and the theory of probability. In the authoritarian mode, there is a close relationship between the knowledge seeker and the knowledge producer, in which the former requires a high level of confidence in the latter's ability to produce knowledge. Although this type of knowledge can be refuted, it requires a large number of refutations before it is replaced by another type of authority (Nachmias & Nachmias, 1981).

A second type of knowledge is the *mystical* mode, in which people importune knowledge from prophets, divines, gods, mediums and other varied supernatural powers. In one sense, this type of knowledge is similar to the authoritarian mode, but differs as it depends on the manifestation of supernatural indicators, as well as on the psychophysical state of the believer. The production of knowledge in this mode is usually accompanied by rituals and ceremonies, and confidence decreases as the number of disconfirmations increases. The third type of knowledge is the *rationalistic* mode, which involves the belief that all knowledge can be obtained through adherence to forms and rules of logic: "The underlying assumptions of rationalism are that (1) the human mind can apprehend the

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world independently of observable phenomena and (2) that forms of knowledge exist that are prior to our experiences" (Nachmias & Nachmias, 1981, p. 5). So, the answer to the Zen question: "If a tree falls in a forest and there is no one there to hear it, does it make a sound?" is, for the rationalist: "Yes, it does". In short, the rationalist mode is concerned with what must be true in principle and what is logically possible and permissible.

### *Reality of Everyday Life*

Two founding fathers of sociology gave us an early indication of how to proceed in the quest to understand the reality of everyday life. Durkheim informs us that: "The first and most fundamental rule is to consider social facts as things" (1895/1938, p. 14) and Weber argues that: "Both for sociology in the present sense, and for history, the object of cognition is the subjective meaning-complex of action" (1921/1947, p. 101). These two statements first appear to be contradictory, as the former refers to facts and things as objective elements and the latter indicates the subjective interpretation of human behaviour. However, it is a fact that society does have this dual character "in terms of objective facticity *and* subjective meaning that makes its 'reality *sui generis*'" (Berger & Luckman, 1967, p. 30). Thus, in the creation of stigma, the interesting question is: How does the subjective interpretation of the stigmata, i.e. the Jew, the Black, the Catholic, the gypsy or the disabled, become objective facticities, i.e. greedy, lazy, subversive, sub-human or blameworthy, so that they are perceived as inferior? We will begin to address this question with a brief look at three elements: (a) the here and now; (b) the concept of "I"; and (c) the zones of relevance.

In terms of multiple realities, we can note that there is one that is considered to be the paramount reality: that is,

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the reality of everyday life. Being conscious creates an awareness that is at its most focused in everyday life. Everyday life imposes itself on our conscious mind in an imperative manner, as we must deal with it in the here and now. In being awake, we apprehend ourselves as being in a constant now, a moment of consciousness that is ever-changing into the next now, and each future now lines up to pass into our instance of awareness to become the past. Consciousness is always conscious of something: that is, it is directed towards things in everyday life. This consciousness intends towards something from the position of "I" (the first person singular, me). I am conscious of things in the world and am aware that others may be also, from their respective "I" positions, but it is "I" (of me) that apprehends my everyday life, knowing that others do so as well. Finally, it is said that, in my apprehending of the world, I do so in terms of zones of relevance. The closest zone to me is that which I am directly involved in, is easily accessible to me and is open to my influence and manipulation. Further out are other zones that are less accessible to me, that I have little interest in and only partial influence over. The furthest zone of relevance to me is that which is not accessible to me. I have no influence over it and my interest in it is merely potential: that is, I may one day be able to have some manipulation within it. Thus, the reality of everyday life is perceived by me, as well as by others (Schutz, 1970).

### *Social Interaction*

We share the world with others, and we experience these others in different ways. "The most important experience of others takes place in the face-to-face situation, which is the prototypical case of social interaction. All other cases are derivatives of it" (Berger & Luckman, 1967, p. 43). This

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face-to-face situation is shared with each other and, as I apprehend the other, thus he apprehends me. We are in a prime "I and Thou" relation that dominates our experience (Buber, 1922/1937). Although I know more about me, my history and my memory than I do about the other, the face-to-face situation remains dominant. This is because there is a constant interchange of expressivity between us as we interact. I smile, he smiles; I frown, he stops smiling; and so on. All my expressions are oriented towards him and all his to me. It is true that we may misinterpret expressions; nevertheless, it is only here in the face-to-face situation that the other's subjectivity is emphatically "close". Berger & Luckman claim that all other forms of relating to the other are, in varying degrees, "remote". In my interaction with the other, what he is is available to me as I focus on him. However, what "I" am is not quite so available to me, as I must stop and reflect on what "I" am to make it available to me. Thus, what the other is in the face-to-face situation is continuous and pre-reflective.

As I interact with the other in a face-to-face situation, I apprehend him by means of typificatory schemes. For example, I may apprehend the other as "an American", "a good guy", "a fool", "a drug addict", etc., and all these typifications will influence how my interaction will continue. Similarly, the other is also engaged in typifying me and a sort of ongoing negotiation of typificatory schemes continues throughout. Furthermore, typificatory schemes can be negotiated at a pre-arranged level, as in a bargaining process between buyer and seller. Thus, encounters with others in everyday life are typical in two senses; the other is apprehended as a type and the situation itself may be typical. Typifications of social encounters become progressively more anonymous the further away they are from the face-to-face situation, although they do continue. This means that when I apprehend the other in a



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face-to-face encounter I may, although I also may not, turn my attention to other contemporaries who are not in the face-to-face situation. "Anonymity increases as I go from the former [face-to-face] to the latter [not face-to-face], because the anonymity of the typifications by means of which I apprehend fellowmen in face-to-face situations is constantly 'filled in' by the multiplicity of vivid symptoms referring to a concrete human being" (Berger & Luckman, 1967, p. 47). Although there are obvious differences in my experiences of contemporaries in the world, it is the extent of anonymity or "closeness" that will influence how I typify them. This appears to be a basis for the stigmatisation process, whereby "the Black", "the White", "the Hindu", "the Muslim", "the Catholic", "the Protestant", "the disabled", and so on, become typified. Social reality is thus constructed through a continuous scheme of typifications that become progressively more anonymous the further away they are from the "here and now" of the face-to-face situation. Berger & Luckman (1967, p. 48) sum this up succinctly: "Social structure is the sum total of these typifications and of the recurrent patterns of interaction established by means of them. As such, social structure is an essential element of the reality of everyday life".

### *Language and Knowledge*

Language and knowledge lie at the heart of social constructionism and the central theme to be dealt with concerns human expressivity. Human expression can be objectified, by which means both the producer and the recipient can share a common understanding. This is achieved through products of human activity that are available to all in the shared experience. For example, we can all recognise the bodily indices of the subjective

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experience of anger through facial expressions, posture, shaking fists, etc., and through verbal signs which might include hissing, grunting, screaming, etc. Once outside the face-to-face situation, the physical and verbal signs dissipate. However, the human expression of anger can be transmitted through a sign system. For example, if the angry person leaves an axe buried in my dining-room table or paints a skull and crossbones sign on my front door, they express their feeling of anger to me and to anyone else that may see them. Language itself can be defined as a system of vocal signs and is recognised as the most important sign system of human society (Berger & Luckman, 1967). Language is rooted in the here and now, but can be detached from it when one is shouting across a distance, speaking on the phone or radio, or even when writing (a second degree sign system). In the face-to-face situation, language shares a synchrony with both parties, speaker and listener, as at almost the same instance the speaker speaks and the listener listens to what is being spoken. Furthermore, language is capable of transcending the reality of everyday life and can span discrete spheres of reality. For example, it can interpret the meaning of a dream and explain it linguistically in our wide-awake world.

Language builds up semantic areas or zones of meaning for us that are circumscribed in a linguistic sense, and marks out coordinates of relevance for us. These fields are determined by our geographical and historical experience and, of course, differ for each individual. What is relevant to one person may not be relevant to another. This accumulation of relevant semantic fields constitutes what is known as our social stock of knowledge and includes both what is known and the limitations of that knowledge. The social stock of knowledge differentiates everyday reality through degrees of familiarity, as there

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are areas of life in which many people are extremely knowledgeable and other areas that they know very little about. It is the social stock of knowledge that provides the information for the process of typification that is undertaken routinely in everyday life. One event or situation, including the meeting of a person, is searched for in the social stock of knowledge to establish if it, or they, are typical of a previous experience or encounter, and this provides the basis of the potential response to it or them. Thus, if the social stock of knowledge only contains a negative experience of, say, meeting a sociologist and a situation occurs in which you are introduced to another sociologist, then this is likely to be typified as negative, all other things being equal.

### *Institutionalisation*

All human activity has the potential to become habitualised. This patterning of behaviour is psychologically economical and will both reduce our need to deliberate on choices of action and free up our minds for new innovations. Remember, or imagine, the difficulties of learning to drive a car and attempting to coordinate the brakes, accelerator, clutch, gears, mirrors and steering. Yet very soon the process of driving becomes a habit, and most drivers do not need to concentrate on the intricacies of the driving procedures – though hopefully not to the level of being careless! Notwithstanding the dangerous aspects of this example, we can see that the habitualisation of this action reduces our choices in the way that we drive as, over time, we come to drive the way that we do, and this allows us to think about other things as we drive. Importantly, the meanings attached to this habitualised behaviour are retained and become embedded as routines in our general stock of knowledge. It is not only human

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behaviour, such as driving a car or dressing in the morning, that becomes habitualised, but also social interactions, such as greetings and departures, having tea or coffee with another, or attending a football match as a hooligan. These human actions become valued to both ourselves and the significant others in the social group to which we belong. Habitualisation precedes institutionalisation.

The vast amount of our human experience passes into our subconscious or unconscious minds and only a very small amount is held in our consciousness. If this were not the case, we would soon become “frozen” in inaction. Human experience, as it occurs, soon becomes sedimented in our recollections as memories, and we recognise these as our biography, as well as those of others as their history. Inter-subjective sedimentation occurs when an experience has been objectified in a sign system, predominantly a linguistic one, and only when this occurs can the meaning that it is endowed with be transmitted to others: i.e., the next generation. This becomes the basis of tradition. For example, both the hunting and the anti-hunting lobbies hold their traditions as valuable, with the “experience” of hunting being inter-subjectively sedimented. This is despite the fact that few in either group would actually have the basic experience of hunting for survival in its true sense, or of being hunted themselves. A bond is formed within both groups, based on the sedimented experiences embedded in the traditions of previous generations. These transmitted sedimentations are institutionalised and lead to those with their respective values performing a role in accordance with those beliefs: i.e., the hunters dress up and ride horses, with hounds and horns, and the anti-hunters engage in behaviours that are designed to try to stop them. We would not expect that a member of one of these groups would act in accordance with the beliefs of the other,

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although this may be both wished for and striven for. If these sedimented experiences, values and traditions involve what we may consider to be prejudice and stigma, then we can now appreciate how they become institutionalised within groups in society.

### *Legitimation*

It would be rare for someone to state that they are prejudiced, that their belief system may be false, that their behaviour is discriminatory or that their actions are wrong; however, such insightful revelation would be the most important step on the road to change. Legitimation is the process by which the chances of this self-reflection are curtailed and Berger & Luckman (1967) refer to it as a second-order objectification of meaning. By this, they mean that legitimation produces new meanings, which incorporate the original meanings already formed from the institutionalisation processes. The second-order meanings are integrated into the first-order meanings to form a totality of meaning as an overall symbolic structure. These are referred to as symbolic universes. As Berger & Luckman (1967, p. 113) state: "These are bodies of theoretical tradition that integrate different provinces of meaning and encompass the institutional order in a symbolic totality". This allows us to appreciate symbolic universes such as "the police", "the army" and "the hospital". In taking the term "the police" as an example, we can see that it clearly comprises thousands of individuals who learn and operate the rules of policing. However, we can also appreciate "the police" as a single entity, in the sense of "That is what 'the police' do" or "That's 'the police' for you". "The police" in Britain are often said to be institutionally racist and we should now be in a position to see how this tradition, if it is true, is

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maintained. For this to become legitimated within “the police”, the individual practices must become absorbed as a total overall symbolic universe into that which becomes known as “What ‘the police’ are”. Legitimation governs the here and now and also governs the institution through its collective history. In social constructionist terms, this explains why such negative practices as institutional racism are perpetuated; but it also explains why positive practices are maintained. We will now move on to focus more closely on the second strand of our chapter, and that is a brief outline of some of the major writers on stigma.

### *Stigma*

In its simplest sense, stigma is concerned with some form of mark that carries a disgrace and has negative connotations attached to it. Stigmata may be attached to a circumstance, quality or person, and has its Christian heritage in the marks on Christ’s body following the crucifixion. There have been many writers on stigma, from many disciplines such as philosophy, theology and anthropology, and the five that we are about to outline are those that we consider to be the most relevant to our work on stigma in health care settings.

### *Foucault*

Michel Foucault, the French intellectual, philosopher and historian of ideas, produced a central thesis on the notion of difference in his work *Madness and Civilisation* (1961/1967). Foucault argued that stigma had its etymological roots in religion, not only by referring to the marks of the crucifixion, but more importantly by marking out a difference. He suggested that early Christian society required the identification of difference based on that

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between those in God's favour and those who had fallen out of His good grace. Those that were considered to have fallen from favour were afflicted with a mark to identify them, and this mark, according to Foucault, was leprosy. He developed the thesis that, during the first ten centuries after the birth of Christ, leprosy defined difference through this highly visible mark from God and this allowed all manner of actions to be delivered to those with this condition. Throughout Europe at this period, leprosy was rife and lepers were colonised in lazar houses. Lazar refers to a poor and diseased person and, in particular, a leper. Over centuries, through the forced process of colonisation, leprosy in Europe was eventually eradicated. Foucault argues that this purge left a moral vacuum in society, whereby the difference between "them" (those out of God's favour) and "us" (those in God's favour) could no longer be seen via the mark of leprosy. Such a lack of a visible difference is threatening to society and could lead to all manner of fractures to the social bond. This appears closely related to a type of knowledge mentioned above and forms a reality for those involved.

For Foucault, the creation of difference through a visible sign was central to the idea of creating a "them" and an "us", which makes "us" feel safe. The lack of a "them" is threatening, as those out of God's favour cannot be identified amongst "us". This leads to social paranoia, as seen in witch-hunts, and accusations abound, damaging social ties. Foucault argued that, following the purge of leprosy, the social vacuum that was created was filled by madness. The lazar houses across Europe were filled by the mentally ill. Whereas, prior to this, madness was a community affair, popularly seen in terms of the "village idiot", the mentally ill now began to be excluded from society as the new "them". They were forced into colonies, which later became institutions, and in effect forced on to a

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“journey”. Foucault made good use of this notion of “journey” and employed Hieronymus Bosch’s famous painting of the “Ship of Fools” (ca. 1494) as a symbol representing the idea of the mentally ill of that time being put on to ships to sail the canals of Europe. The ships were constantly in motion, moving “the problem” on to the next village or town in a perpetual movement. For Foucault, once they embarked on their “journey”, there was no point of disembarkation and we can see much of modern psychiatry in these terms. For many patients with mental health problems, once they engage with modern psychiatric services, they are forced on a journey of “cure”, from which they may never disembark.

### *Becker*

Putting to one side simplistic notions of deviance, essentially based on the statistical definition of that which deviates from a norm or average, Howard Becker (1963) incorporated certain social elements into the concept. Becker’s work on deviance is closely allied to stigma, as he also shelved the notion of the pathology of deviance as correlating to “diseased” as opposed to “healthy”. He also disliked the sociological model of deviance, which predominantly saw some elements of society as promoting stability (“functional”), whilst others promoted instability (“dysfunctional”). He believed that society comprised many groups and sub-groups of people, each having their own sets of rules and sanctions for any transgressions. Individuals could belong to many different groups and could function within them, even though they might well be at odds with their values. For example, a person could belong to a respectable organisation and could also belong to a group of football hooligans. Members of any group who transgress the rules of that group are not a



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homogenous set, but merely deviant within the rule structure of the group to which they belong. Thus, the members of the group identify what it is that will be stigmatised. For the gang of football hooligans, it may be that to show compassion for an injured victim is a deviation from the norm of the group and that this will therefore be stigmatised accordingly. This, again, is the reality of everyday life.

Becker defined deviance in terms of how it was constructed by the social groups that formed the rules whose infraction constituted what they considered to be deviant. Becker puts it this way: "From this point of view, deviance is *not* a quality of the act that a person commits, but rather a consequence of the application by others of rules and sanctions to an 'offender'. The deviant is one to whom that label has successfully been applied; deviant behaviour is behaviour that people so label" (1963, p. 9). Becker's work located deviance at a social level and claimed that various media communications were part of this social character. Once so labelled, deviant groups also developed certain mechanisms of a social character to reinforce and maintain their status. These included such concepts as common fate, rationalising their position, self-justifying strategies, and a history on which to pin their experiences. Although Becker used the deviant behaviour of using marijuana as an example of deviancy, we can substitute any of the socially recognised stigmatising conditions in our society; for example, HIV/AIDS.

### *Goffman*

Ervin Goffman, in his seminal book *Stigma: Notes on the Management of Spoiled Identity* (1963), defined stigma in terms of our personal knowledge of the person before us. He stated that: "While the stranger is present before us,

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evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind – in the extreme a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted one. Such an attribute is a stigma” (p. 12). He outlined three different types of stigma: first, abominations of the body, such as various physical deformities; second, blemishes of individual character, which may be perceived as including weakness of will, being domineering, having unnatural passions, treacherousness, holding rigid beliefs and dishonesty; and third, the tribal stigmas of race, nation and religion. Although Goffman’s text remains central to any work on stigma, he has been criticised as presenting too narrow a version. For example, Page (1984) argues that “physical deformities” is too restrictive in terms of suggesting deprivation pertaining to congenital abnormalities or malformations of human structures. Similarly, “blemishes of individual character” suggests a behavioural manifestation and Page argues that the term “conduct” more suitably fits this dimension of stigma.

Notwithstanding these criticisms, Goffman’s understanding of stigma locates it from the viewpoint of society and shows how the individual can emerge socially as different. His concern with appreciating how and why some members of society choose to stigmatise a particular social group is important, as it also focuses on the perceptions of the stigmatised themselves. Thus, he identifies a relationship between those that stigmatise and those that are stigmatised. The tension that is created within this relationship is easily noted when a physically deformed person walks down the street; either he is stared at as a spectacle or eyes are quickly averted. Both responses lock both individuals into a self-reinforcing

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process of stigmatisation. There are a large number of vignettes in Goffman's text that are based on the personal experiences of stigmatised individuals and it is suggested that it is these personal accounts that ground the book in the life world of the marginalised "Other". He clearly sees stigma in terms of a two-way process, in which the stigmatising and the stigmatised are trapped in a value-laden course of interaction. It is interesting to note that, when the stranger (to be stigmatised) becomes known to us on a personal level, Goffman suggests that they largely become de-stigmatised. This resonates with our experiences in modern day society of racial and religious tensions between many groups of people who are not known to each other on a personal level. It also resonates with the grouping of people together, such as "the disabled"; our perceptions of them when we know the person as an individual alters, and this is closely associated with the notion of typification outlined above.

*Jones, Farina, Hastorf, Markus, Miller, & Scott*

Edward Jones and his co-workers produced a text, from a social psychology perspective, entitled *Social Stigma: The Psychology of Marked Relationships* (1984). Using different language to Goffman, they stated that: "We intend to focus in this book on a particular category of social relationships – those in which one participant has a condition that is at least potentially discrediting. We shall be concerned with the cognitive and affective underpinnings of such relationships and with the behavioural problems they entail. We shall also be concerned with the course and development of such relationships over time" (p. 6). This focused the work on the relationship between societal values and the perceptions of the marginalised individual as a devalued person. Therefore, it is concerned with the

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feeling of stigma as perceived by vulnerable individuals, which in this context deals with personal responses, such as fear, anger, worthlessness, depression, etc. The emotional impact of these engendered feelings, whether or not explicitly evoked by societal responses to the stigmata, is implicitly felt as a corollary of those social expectations. The result of this, according to Jones et al., is the development of a mental strategy to deal with the social implications of the stigma. These were termed the “six dimensions”.

These dimensions were, first, *concealability*, which refers to the extent to which the stigmata can be hidden and deals with the questions of to what extent its visibility is controllable or the wish to control it desirable. Clearly, a facial disfigurement is difficult to hide unless the person becomes socially isolated, and an unwanted pregnancy can only be hidden until the growing abdomen reveals its presence. The second dimension is *course*, which is concerned with the pattern of change in relation to social expectations of the stigmatised condition and examines what the anticipated social consequences of the outcome are. For example, with a terminal illness, there are a set of social relations that surround the person as they move towards their death which will affect conversations, particularly regarding the future. Third, *disruptiveness*, which refers to the extent to which the condition blocks or hampers either the social interaction of the stigmatised person or their communication with the social network: stigmatised conditions do affect the social network to one degree or another, and will govern what that person does and who they do it with. The fourth dimension refers to *aesthetic qualities*, which involves the signs and symbols of the condition that make the possessor repellent, ugly or upsetting. Burns, amputations, facial disfigurements, etc., may evoke a negative reaction in the perceiver, whilst

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more hidden conditions do not, and this creates an emotional reaction. Fifth is *origin*, which refers to the aetiology of the circumstances that led to the stigmatised condition in relation to the accounting of blame and involves identifying who holds responsibility for it. If the responsibility for a condition can be located as the person themselves, then they are more likely to be stigmatised for it. The final dimension is *peril*, which refers to the extent to which the condition poses any social danger and, if so, how imminent or serious it is. For example, a person with HIV/AIDS may be stigmatised as posing a social danger, as the perception is one of contagion. Again, we can see in the work of Jones et al. that stigma is centrally a social construction, through these six dimensions.

### *Scambler*

Graham Scambler, writing in the UK, has made, and continues to make, a significant contribution to our understanding of stigma. The personal anxieties concerning stigmatised people's attempts to cope with their conspicuous positions in society is enlightened by his identification of *enacted* and *felt* stigma. Focusing his work on epilepsy, Scambler claims that enacted stigma produces very profound and damaging experiences when the person with epilepsy recalls being discriminated against. Enacted stigma refers to the stigmatised person being identified as such and then living the experience of stigmatisation. They are, in effect, "outed" and then live according to the expectations that society has of them. Scambler argues that the powerful force of the label "epileptic" creates a pattern of expectations, which the person then lives by. Felt stigma, on the other hand, refers to the shame that the person feels towards being associated with the diagnosis "epileptic". Furthermore, there is a fear of being

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discriminated against simply on the grounds of this label and Scambler goes on to state that “the sense of felt stigma is so strong that people with epilepsy typically do their utmost to maintain secrecy about their symptoms and the diagnostic label: they disclose only when it strikes them as prudent or necessary” (1997, p. 176). We can see that keeping the label hidden would reduce the likelihood of encountering enacted stigma, but we can also see that felt stigma would be more disruptive to the lives of the stigmatised.

Scambler has examined a number of medical conditions that create stigmatisation, and these include rectal cancer, HIV/AIDS, psoriasis and severe burns. Analysing these conditions in the framework of health and illness, he shows how these “stigmatising conditions can be defined as conditions that set their possessors apart from ‘normal’ people, that mark them as socially unacceptable or inferior beings” (1997, p. 187). Illness involves deviance and stigma on two levels. Firstly, by the individual deviating from the social norm and being labelled as “sick”; and secondly, by having a condition that is socially uncomfortable to the remainder of society. These conditions, and there are many more, inevitably require contact with the medical professionals who are attempting to provide a quality care service, and the encounter with these health professionals is crucial in the stigmatising process. We will now look at a number of examples of this in health care settings.

### *Health Care Settings*

Health care settings are communities with characteristics that in some fundamental and profound way set them apart from the rest of society. They are places where vulnerable, injured, damaged and hurt members of society

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intersect with professional people, whose purpose is to aid, assist and care for them. These settings can embrace any social situation in which those who have a health care need are administered some form of medical attention, in its all-inclusive sense. Outside the home, these can range from a General Practitioner's surgery to a field hospital in a war zone. All of those people who need this medical attention present some vulnerable attribute, which has tarnished their image of themselves in some way. The vulnerability of patients in health care settings, because of their "difference", all too frequently leads to their being subject to and experiencing stigmatisation both from the wider society and from the health care professionals.

It should be remembered that the impact and force of stigmas change over time. Our prejudicial views alter according to our social norms, which are rooted in the particular period of history in which we are living. For example, in the 1980s the gay community suffered an onslaught of the stigmatisation process. Of course, the gay community has always felt excluded and alienated to varying degrees, but the HIV/AIDS epidemic brought a resurgence of stigma from the wider society. Stigma, of whatever origin, is rooted in fear and this fear all too frequently stems from an ignorance of the "affliction". As society's knowledge base of HIV/AIDS has developed, and as it is no longer a disease that exclusively targets homosexuals, society's moral panic has somewhat fallen. We are, in theory at least, a society which is becoming more integrated, and as those people with potential and anticipated stigmatising conditions, as described by Scambler (1997), increasingly live and work in mainstream society, their experiences of being stigmatised should fall (Goffman, 1963; Whitehead, 2001). We will now discuss three areas of stigmatisation in health care settings and, despite their unique characteristics, they illustrate a

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number of fundamental properties that are common to all stigmas.

### *The Stigma of Congenital Abnormalities*

Farrell & Corrin (2001) outline the case of stigma and congenital abnormalities. They begin their chapter with the historical impact of stigma in relation to congenital abnormalities and show how this has changed over time. For example, in early Greek times congenital abnormalities were seen as a sign of divine retributive intervention for sins committed in a previous life, and in early Roman civilisation there is some evidence that statutes existed which instructed the head of the family to kill their child if it was born with a deformity. Furthermore, in medieval and Tudor times, babies born with congenital abnormalities were seen as *changelings*: that is, the devil's substitutes for human children. We are also told that Martin Luther, the Protestant reformer, considered the disabled child to be the devil incarnate and recommended terminating the baby's life.

The authors go on to discuss the great expectations that surround the impending birth of a child, with the many social interactions that accompany it and create an air of anticipation at this time. The shattering of these expectations is profound if the baby is born with a congenital abnormality, and the reactions of professionals, then of parents, and then of the social network, reinforce negative perceptions of the deformity. At the point of birth, the two main questions that parents ask are (a) "Is it a boy or a girl?" and (b) "Is it alright?" Professionals, doctors and midwives who are unable to respond positively to the latter question are faced with the dilemma of how to answer and the inevitable hesitancy and avoidance begin the process of stigmatisation. Parents lose their prime



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expectation of a “healthy baby” and give way to a perception of weakness, vulnerability and pity. Their self-image as “good parents” is challenged and leads to intense psychological trauma. Parental feelings range from ambivalence to revulsion in the aftermath of this. The social network is altered, as some family members and social friends become hesitant at approaching a family with a child with an abnormality, as they do not know what to say or do. Many parents of a child born with such a deformity may seek the company of others in a similar situation, often in the form of support groups. In any event, the social network is altered, and there are many reports of awkward encounters in social settings when a baby with congenital abnormalities is thrust upon an unsuspecting stranger.

Although modern-day surgery can correct or lessen the impact of such congenital abnormalities, it is often unhelpful to the parents to dismiss the deformity with unrealistic positive comments regarding the future. Although these are designed to help, they rarely do. Farrell & Corrin (2001) argue that stigma can be lessened by reflection, recognising the individuality of the child and the family, focusing on the personal attributes of the child, engaging in active listening and forming a therapeutic relations framework. Society sees the child with congenital abnormalities as a stranger, both in terms of being unknown and also deviating from the norm, and constructs a response to this, which is largely negative. Only by getting to “know” the child and its relation to the disability, and in turn its relation to society, can the stigma be overcome.

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### *Teenage Pregnancy, Stigma and Differential Provision of Health Care*

According to Jacono & Jacono (2001), teenage pregnancy is a major concern in most industrialised countries and, although it has long been considered “shameful” in Western society, its current “epidemic” is seen to have its roots in the “sexual revolution of the sixties”. The concern alluded to here involves social, moral and financial issues. The rates of teenage pregnancy are on the increase, with half a million reported each year in the USA and 20 per 1000 teenage women giving birth in Britain (Jacono & Jacono, 2001). The social concerns surround the breakdown in social networks, as these teenagers lose an element of “freedom”, and the high rates of divorce, leading to an increase in single parents becoming socially isolated. The moral issue has its roots deep in religious traditions, the family and the sanctity of sex within marriage; those seen to have “succumbed” being deemed to have fallen from God’s grace. The financial issues largely involve the fact that approximately half of all teenage pregnant women go on welfare in the USA and 90% receive income support in Britain (Jacono & Jacono, 2001). There are, of course, other issues that are important for teenage pregnancies and these include higher death rates, lower birth weights and higher rates of psycho-physiological dysfunctions in the children of teenage mothers.

Stigmatisation occurs through a process of victimisation, as the teenager is considered to be morally “weak-willed” in not resisting the drives and urges of male advances and her own passions. She is considered to be inferior in not being able to wait until marriage and ignorant in not taking precautions. She is regarded as being responsible for her condition and is viewed as

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having to be fully accountable for her future. Whitehead (2001) argues that this leads to a form of “social death”. Teenage pregnant women are perceived as having “loose morals” and of being “over-sexed” and they can be seen as a mark of shame for family and friends. Parental reactions may include anger, deep feelings of disgrace and betrayal, and may even lead to the abandonment of the daughter, who can become ostracised and isolated, especially if the father of the pregnant teenager is no longer in the relationship. As Jacono & Jacono (2001, p. 229) point out: “Since there appear to be no social, religious, economic or cultural boundaries that it does not cross, it generates a great deal of fear in those who perceive themselves (or their loved ones) to be at risk for becoming part of this group”. Thus, the social construction of the stigma of teenage pregnancy is processed through the mediums of religion, family, parents and culture.

### *Breastfeeding*

One does not automatically associate breastfeeding with stigma in the way that one would congenital abnormality or HIV/AIDS; however, Smale (2001) offers a sophisticated account of how this occurs in our society. There are cultural differences in breastfeeding in public, with Africa, Asia and Scandinavia largely accepting this practice, whilst in Britain it is largely unacceptable. In fact, Smale (2001) argues that breastfeeding in public in Britain appears to be less tolerated the further one travels from London, and she explains the process by which this natural practice becomes stigmatised. She focuses on two of the dimensions of Jones et al (1984), “origin” and “peril”, to show how this occurs. The visible signs of the stigmata are the damp stains from the nipples and the possibility of the related smell; millions of pads are sold each year to manage this.

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The possibility of let-down as the baby ceases suckling, with arching streams of milk squirting from the breasts, is a visible and embarrassing sign. Noises, such as the gulping of milk by a hungry baby, betray the passage of body fluids, and even silent, or discreet, breastfeeding may provoke reactions in others. Smale (2001) sees the dimension of peril and breastfeeding, not as a direct threat to others, but as a challenge to the social order. The production of bare breasts in our society is culturally disallowed, unless in certain defined areas such as when sunbathing on the beach, and the management of transfer from invisible breasts to a bare breast being suckled is particularly difficult for women with twins or with large breasts.

Smale (2001) gives us numerous accounts of women being asked not to feed their babies in public, being requested to go to the toilet to feed, being told it is “rude”, revolting or disgusting, and that the expulsion of all body fluids from orifices should be done in private. Smale argues that, although most of us like to eat out and do not mind being in the presence of others eating out, this does not always extend to babies breastfeeding. She also highlights how language and silence are employed in the social construction of the stigma of breastfeeding. “Journalists have compared public breastfeeding to the siting of urinals in bars or vomitaria in restaurants, and to self-medication (“shooting up”) by diabetics .... These powerful parallels reveal powerful meanings, just as the action of an irate shopkeeper – throwing dirty water over a mother and baby as they breastfed outside his shop – recalls that of someone separating copulating dogs” (p. 239). In this very powerful chapter, Smale reveals how this natural and benign activity can become stigmatised through the social construction of the breast as belonging

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to the domain of sex; thus, it should be kept hidden from public view.

### *Conclusions*

We have been concerned throughout our work on stigma and social exclusion with how professional health care staff contribute towards the stigmatisation process and then perpetuate it in their practice. This is not to say that we believe that this process is often undertaken malevolently or deliberately, although occasionally this might well be so, but that it occurs unknowingly or inevitably. In this chapter, we have attempted to identify some of the major components of social constructionism, followed by a brief outline of the work of some of the major workers on stigma, and then highlighted three areas in which health care staff may contribute towards the stigmatisation of others. By employing these three areas, social constructionism, stigma and health care settings, we hope that we have gone some small way to revealing the complexity of a cultural mosaic that is constructed of many elements. The first involves the fact that we are first and foremost socialised individuals in the society to which we belong, long *before* we become professionalised members of our chosen discipline. Our professional values and ethics may well be at odds with our personal ones and create a tension and, although we may like to think that we can bracket off our personal views in order to operate with our professional ones, sometimes this fails. Furthermore, this situation is further compounded when we add to the analysis of the social dimension cultural values, which again may conflict with our personal and professional standards.

In conclusion, there are a number of measures that ought to be undertaken by all involved in the

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stigmatisation process, and not just health care professionals. The first, we would argue, is to reveal to ourselves our role in the process of stigmatisation and not to deny it. This requires a self-reflective approach to our thoughts and actions, and it can be a painful endeavour. However, it is fundamental to the change process. The second is to see people beyond a mere label and to “know” them as individuals. Empathy is required for us to be able to identify with them. Thirdly, we need to check our thoughts against our actions, to see if there is a contradiction between them and to establish if we are thinking and doing different things. Finally, for now, we should educate and train our professionals to identify areas in practice that are creating and maintaining stigma and to provide them with the skills and expertise to change this. Stigma, discrimination and prejudice have no place in a civilised society, and certainly no place in our health care services.

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