Contemporary Themes

Family stigma in congenital physical handicap

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It seems ironic that, for all the discussion last year in the medical press about the disabled, so little was said about stigmatisation, part of the process permitting society to set the disabled apart as a group deserving of their own "Year." Perhaps this should not be surprising since stigma is a concept less familiar to doctors than to anthropologists¹ and sociologists.² It has been applied to groups³ as well as to individuals. While similar to each of these, the stigmatisation of families, also important, has its own unique features. Nowhere can these be better seen than at the birth of a handicapped or otherwise abnormal child, which has profound effects on parents and professionals alike. While it would be naive to suggest that responses to such an event could be reduced to the level of stigma and its management, focusing particularly on this affords useful insight into some of the difficulties faced by families under such circumstances. Stigmatisation also offers an appropriate perspective within which to view certain aspects of the development of handicapped children, notably their perceptions of themselves. Such issues are important in the medical and psychological management of these children and their families.

Stigma

Stigmatisation may be considered the consequence of deviation, negatively valued, from some social norm. Goffman² refers to it as "shameful differentness." Two points deserve emphasis here. Firstly, there is no universal norm; this varies according to the circumstances. Only among the racially prejudiced, for example, is someone of a different skin colour stigmatised. Everyone can identify situations in which they have themselves imposed norms on others and vice versa. It follows that stigma and its management are universal experiences. The differences between the handicapped and others in this respect are ones of degree; the latter have more opportunity to avoid stigmatisation than the former. The second point concerns the imposition of norms; the handicapped are not considered responsible for the stigma imposed on them by others, any more than they should be responsible for their handicaps. Yet, paradoxically, when it comes to managing stigma, the onus is very much on the stigmatised rather than the rest of society.⁴

It is useful to distinguish between stigmatised individuals who are *discredited* because of an immediately apparent stigma and those who are *discreditable* because of a stigma that can be disguised or may not manifest itself.² Examples of the latter include children with epilepsy or some mild congenital heart defects. The problems faced by these two groups will be different to some extent. For simplicity, only the former group, the discredited, will be considered further.

In their interactions with the stigmatised, others expect to be uncomfortable.^{2 5-7} Since successful management of stigma is often judged in terms of the reduction of such discomfort, it can be argued that discomfort, even more than the "shameful differentness" that generates it, should be considered the cardinal feature of stigma in this respect. That this ought to be considered a task primarily for the stigmatised has been rightly criticised.^{8 9} It is also true, however, that a handicapped person, usually having the opportunity to meet more people without handicaps than vice versa, has more scope to develop the necessary skills in managing stigma.¹⁰

Other aspects of stigma are also important for the handicapped. One such is the "spread phenomenon,"¹¹ whereby an individual's stigma is likely to distort perception of his or her other attributes. Thus, for example, it may be difficult for some to remember that someone severely physically handicapped may still have normal intelligence and, equally importantly, the same range of emotions as (able-bodied) others. Allied to this is the "sick role" or "role of helplessness" to which the handicapped and their families are sometimes assigned. Adequate adjustment of families to their handicapped children is viewed by some, including professionals, as an insurmountable obstacle; evidence of stability or adjustment is misinterpreted to justify the need for continuing "help".¹² Similarly, the refusal of unsolicited help from well-meaning strangers is open to misinterpretation, as may be the favoured response to their unwarranted sympathy.

Birth of a handicapped child

Even though this review aims to draw attention specifically to stigma and its management, this must be viewed in the overall context of the multitude of problems facing the family of a child born with a handicap or other abnormality. The psychological problems consequent on such an event, extensively reviewed, have recently been highlighted by Professor Taylor.¹³ The birth of a handicapped child completely disrupts the usual process of adjustment to parenthood¹⁴ and comes at a time when mothers especially have to cope with considerable psychological upheaval and unusual vulnerability.¹⁵⁻¹⁷ Parents are expected to face the needs of their handicapped child while simultaneously mourning the loss of the "ideal" child they wanted.

Although parental responses are influenced by culture¹⁸ and are ultimately individual, among those considered common are guilt, denial, and intolerance. This is supported by vivid case descriptions such as that by Lussier.¹⁹ Nevertheless, while the responses themselves may be clear, their interpretation remains controversial. Some see them as inappropriate; Fox,²⁰ for example, is not alone in claiming that parental guilt ought to arouse suspicion of underlying psychopathology.²¹ Again, those who consider such responses as appropriate after birth seldom seem to question the assumption that these need to be worked through to achieve good adjustment. It could be argued, however, that a certain amount of denial, for instance, is a healthy response to such circumstances and need not always be a

suitable focus for attempts at therapeutic intervention. Similarly, chronic sorrow,²² far from being a neurotic symptom, can be recognised as an appropriate but persistent response of some families.

The same issues surround stigma and its implications for handicapped children and their families. While the expectation that parents should endeavour to treat their stigmatised child as they would any others seems quite reasonable, little evidence is currently available either to support or to refute this view. This is particularly important when it is remembered that parents are likely to respect the expectations of those to whom they turn for advice.

Stigmatised parents

The birth of a handicapped child stigmatises its parents, who were probably quite "normal" previously. An abnormality that may seem trivial to them as *adults* (looking at someone else's child) may assume massive proportions for them as *parents*; this may be seen as a particular example of "spread." So profound may be the effects of their child's stigma that parents may come to view themselves in a distorted fashion.²³ If they accept responsibility for their child they have no choice but to be responsible for its stigma also. In all these ways such parents differ appreciably from those who *choose* to associate with the stigmatised, through marriage for example, and thereby adopt what Goffman calls a "courtesy" stigma.²

Such parents face problems whose solutions appear to be outside their own experience and that of their attendants. For example, they must decide when, how, and what to tell family and friends about their child. Should they attempt to disguise the abnormality, or to distract attention from it by emphasising the child's healthy attributes? They might even consider trying to ignore the stigma and attempting to behave as though nothing were wrong. Within the wider context in which they occur, such strategies can be viewed on a practical level as alternative responses to stigma, identical to those used by stigmatised individuals.⁶ Nevertheless, families cannot apply such strategies as readily as can individuals. For one thing, there will possibly be a divergence of views among individual family members regarding the stigma and how it should best be handled. This must contribute to the severe strain such circumstances cause, from which families may never successfully recover.²⁴ Unlike stigmatised individuals also, families ultimately have the difficult option of dissociating themselves from the source of their stigma by having their child adopted or put into an institution.

It is no coincidence that the same issues—of what to tell and when, how to handle the infant, and so on—also concern the professional attendants of the family. They too are vulnerable to the effects of stigma. Their responses should serve as valuable role models for the parents affected, but they often fall far short of this.^{18 25 26} They may even collude with parents to avoid addressing these problems altogether.^{18 26}

The stigmatised child

At birth, the handicapped child has no concept of stigma. The child's understanding of stigma and its personal relevance grows with the maturation of the sense of self and is dependent on the establishment of a social identity. During the first two years of life, progressive development of self-recognition parallels cognitive development²⁷ and allows the child to build up a rudimentary body image or schema,²⁸ into which its handicap is incorporated naturally. Not surprisingly, congenitally handicapped children do not tend to show pronounced distortion of this actual body image.²⁹ More remarkable is the fact that their ideal body images are no different than those of non-handicapped children, as judged by their placing in rank order a series of photographs of children with or without handicaps.³⁰

In general, the ideal self is seen at first predominantly in terms of appearance and physical attributes, but later on more emphasis is placed on personality and relationships.^{31 32}

It seems reasonable that an understanding of what it means to be stigmatised, at least for the physically handicapped, depends on the recognition of a wide discrepancy between actual and ideal body images. In non-handicapped children such a wide discrepancy has been linked to low self-esteem (the evaluative component of self-concept³¹) and is also considered a disruptive influence on personality.³² Others disagree, arguing that increasing discrepancy between actual and ideal self is a healthy sign marking maturity rather than disturbance.³³ Unfortunately, neither of these viewpoints has been adequately tested on handicapped children.

The temporal development of self-concept is clearly important, not only when counselling families but also for the recognition of periods of particular vulnerability, the most appropriate times for corrective surgery or fitting prostheses, and so on. Despite this, remarkably little is known of the time course of maturation of either body image or self-concept. There appear to be no adequate longitudinal studies and those that have been attempted fail to agree.^{34 35} Research into handicaps acquired at different ages, which has also produced equivocal results,^{11 36} is in any case of doubtful relevance to congenital handicap.

The stigmatised family

Within any physical constraints imposed by disability itself, the congenitally handicapped child learns about itself by the same means as other children. It discovers the implications of its differentness from others gradually, in pronounced contrast with the parents,³⁷ for whom the stigma is an acquired one viewed from an adult perspective, liable to distortion.³⁸ It is usually from its parents that the handicapped child has the first opportunity to learn about social norms and its own deviation from these. It is not difficult to understand the inclination of parents to protect their child from what they see as a very painful discovery. This is unlikely to serve the child's best interests, however, as the same attitude is not necessarily shared by other adults and certainly not by the child's peers. Needless to say, the success of the child's own adjustment depends heavily on the parents' attitudes.^{11 29}

The child as it grows older and less dependent on its parents will have increasing opportunity to seek its own ways of handling individual difficulties, including adapting to stigma. Success in this allows parents slowly to relinquish what they see as their responsibility and gradually assume the roles of those with a courtesy stigma. The understanding of stigma thus evolves and its meaning changes not only for the family as a whole but also for its individual members.

A useful concept?

Much of the published work on the handicapped and their families has tended to describe and evaluate specific problems rather than to conceptualise them. This approach has led to important issues sometimes being glossed over—for example, a major work on thalidomide children¹⁸ virtually dismisses fathers having found that they tend to play a peripheral part in the crisis after birth. The concept of family stigma, like that of "family disability,"³⁹ serves as a reminder that the consequences of congenital handicap have to be borne by the whole family and are therefore best seen in this context. More particularly, it suggests how a definable range of problems might be expected to change with time and circumstances within an affected family, and thus has a potential contribution to make to the assessment and understanding of the dynamics of such families.

For simplicity, this discussion has concentrated on the families of children visibly stigmatised at birth. Nevertheless, any form of handicap (or indeed impairment or disability⁴⁰)

produces a stigma which, if it arises in childhood, must be dealt with by the family. The approach adopted and its course depend on the nature of the stigma. For example, social development might be delayed or even impaired by mental retardation, altering the possible ways for the family to react. Again, when the handicap is particularly severe, the individual might not be expected to achieve independence from his family, who therefore have greater difficulty reaching the courtesy stigma stage. Parental reactions might be expected to be quite different if the stigma becomes apparent initially some time after birth.

No specific mention has been made of the management of stigma. In principle, this should entail minimising its effects, such as spread and the discomfort it causes. An important preliminary step, however, is its recognition. Because of the universality of stigma, this requires no specialist knowledge or training. The attendants of handicapped children and of their families need to be sensitive to the existence of stigma and particularly to recognise that they, like others and despite their training, are susceptible to its effects. Failure to do so undoubtedly contributes to the often awkward nature of the interactions between stigmatised families and professionals. Through their own responses to a stigmatised infant, professionals have the opportunity of showing how they would present the child to others, a problem that its parents see as immediately relevant. Reassurance here is likely to promote a better relationship between the family and its attendants.

The fundamental problem underlying all this is the extent to which the needs of the handicapped will continue to be distorted by the perceptions of handicap adopted by society. Stigmatisation must therefore eventually be tackled as a problem of society rather than of the stigmatised.

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Correction

Scandinavian and Dutch lessons in childhood road traffic accident prevention

Errors occurred in two of the figures in this article (28 August-4 September, pp 621-6). In fig 8 the key read "% of total due to RTAs": this should have read "% of total due to accidents." Several errors occurred in fig 9 and the corrected version appears below.