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JONATHAN COLE\*

## FROM THE OUTSIDE IN; TOWARDS SHARED PERSPECTIVES, A NEUROLOGICAL VIEW<sup>1</sup>

The experience of people with neurological impairments, either of facial visible difference or of spinal cord injury, are given in narrative 'neurophenomenological' form. These show how these conditions can alter peoples whole perception of their selfhood and their social interaction. It is suggested that in order to understand these experiences a heightened and deepened form of empathy is required which can also, by extension, be of use in other exchanges and dialogues.

*Keywords:* narrative biography, empathy, spinal cord injury, facial disfigurement.

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<sup>1</sup> Based on a plenary lecture at Lugano, July 1<sup>st</sup>- 4<sup>th</sup>, 2002.

## 1. Introduction

The experience of those with neurological impairments may seem a curious area for argumentation and dialogical analysis to concern itself with. It is hoped, however, in this paper, to suggest some ways in which such an analysis may be of use. Firstly as a reminder that for a successful resolution of debate or argument a shared experience and shared language is needed, and that for some with such impairments this can be a problem. Secondly that in order to understand there is required a human dimension of communication and comprehension. It is also suggested that in listening to the experience of others, subsequent analysis by “arguing” or “criticizing” may be irrelevant or even amoral.

Within a more clinical or research perspective a case is made for an enriched empathetic approach to understanding the situation of others, since from this arises a deeper understanding of clinical and other needs. Such an approach is of more importance in chronic neurological impairment than within acute medicine and surgery for two reasons. Firstly because, unfortunately, it is rare that such conditions can be cured, and the role of health care professionals is to relieve symptoms and assist with care. Secondly because this care requires an understanding of a situation often beyond one's normal experience, so that an awareness of the subjective experience of living with the illness becomes crucial.

The title, *From the outside in* is not simply because, as a clinical neuroscientist, I am an outsider within the field of communication studies. Some few years ago I was fortunate enough to be involved in a play based on Oliver Sacks', *The Man Who Mistook His Wife For a Hat*. Peter Brook's company tried, for sometime, to re-create this for stage and found it too difficult. Initially they did not know why, and then slowly they began to realise that, normally, acting proceeds from the 'inside out'. By this they meant that an actor will identify in him or herself an emotion and explore - and magnify - this to understand and then portray a character: thus for Othello jealousy, or for Macbeth ambition. But when trying to portray the experience of those with neurological impairments this proved impossible, since their experience was unknown and unimaginable. They had to go to people with the impairment, spend time with them to observe in order to try to impersonate on stage, from the 'outside in.'

Perhaps this was because Brook and his group were actors. Perhaps doctors may have a better understanding of what it might be actually like

to be ill? The evidence is not great. Kay Toombs, a philosopher who has written about her own MS that has led her to live from a wheelchair,

In discussing my illness with doctors it often seemed that we were talking at cross-purposes. It was not simply that doctors had different levels of knowledge, the two groups view illness from profoundly different perspectives: one concerned with the pathophysiology of disease and the other the impact the disease has on the life that is lived... there is a decisive gap between one's experience of an illness and a conventional scientific explanation. (Toombs 1993)

Often there are decisive gaps between people's perceptions of a problem from within and without, and not confined to medicine. It is precisely in those in whom this gap is widest that we need to try to understand, since otherwise they are forever beyond our empathy and help. These gaps between a person's view and how others perceive them can, in fact, affect a person's whole sense of self and being in the world.

In this paper short narratives of those with two neurological problems, facial disfigurement and spinal cord injury, will be considered to make explicit the needs suggested above. Such a narrative approach has a rich literature, from the pioneering accounts of Weir Mitchell in the 19<sup>th</sup> century (Mitchell 1872) through the accounts of Luria, (1987a; 1987b) and of Sacks, (1973; 1985). In the fields to be considered Robert Murphy (1987) and John Hockenberry (1995), and James Partridge, (1990) have written more recent wonderful accounts. Within these the need for an empathetic account of illness to enable a proper understanding is repeatedly made, but usually implicitly. One inclines towards a similar implicit approach with a need to go to patients to learn of their experiences so that then their clinical and other requirements can be addressed. Though this may appear initially to be without a clear conceptual framework I hope it will become evident that this bottom-up approach allows patients' concerns to be addressed. It has also allowed refinements in the concept of impairment and in the focus of rehabilitation.

This paper then will consider people with two sorts of neurological impairment, one of visible difference in the face (involving blindness, facial immobility and disfigurement) and the second, spinal cord injury, arguably the most devastating neurological loss of all, leading to complete loss of sensation and movement below the neck. Though presenting very different problems to those who live with them, they both allow us to understand ways in which bodily impairments affect our perception of self and others and alter communication between people.

As Merleau-Ponty wrote, 'Our bodies are not simply a means, they are our being in the world'. In discussing the effects of chronic neurological illness this constantly presents itself. But that is not to say that a person with a given condition will respond in a similar manner to anyone else with the same. In order to understand the other's position we need to try to imagine what it might be like to be another, (even though this can be difficult), and to realise that this is dependent not only on a given set of circumstances but also on the individual.

## 2. Un-seeing

John Hull, who lost his sight aged 45 and has never seen his young son, told me of a conversation with his wife,

A year or two ago we had a visitor when Joshua was about three; when the friend had gone Marilyn said, apropro of nothing, "What comes into your mind when I say Joshua?" I said, "Well, Joshua." And she said, "What, what exactly is it." "Well, it's the memory running through my hand, the feeling, kicking, laughing body, of throwing him over my shoulder. Joshua's tummy when I put my hand on it in the bath and the things Joshua and I have done together." "Yes, but what of Joshua himself?" "If you mean what does he look like - nothing." "I can't bear that, I can't bear to hear you say that because I feel that I'm closer to our friend who just left: she and I share the same Joshua." I had to reply that I did not really know what she meant, "Darling, but if we are going to say do we share the same Joshua we might as well say "Do we share the same world? There is a deep and important sense in which we do not. We do not share the same world."

The consequences of losing sight on selfhood and on his very being pre-occupied John for years after the loss. He had known that he would lose his sight and determined to hold onto pictures of his family as a way of keeping contact with them, visual imagery being so important. These photographs he kept in a 'virtual museum' he could visit in his imagination. But slowly these faded and he became most depressed not when he lost sight but when he began to lose visual imagery. He wrote a diary to understand this himself,

To what extent is the loss of the image of the face connected with loss of the image of the self? 'The horror of being faceless, of forgetting one's own appearance, of having no face. The face is the mirror image of the self. (Hull 1992)

Those with certain neurological impairments may have experiences so unlike others that they liken them to living in another world.

### 3. Moebius Syndrome

In this rare developmental, congenital impairment, of which there might be round 400 people with it in the UK, there are several abnormalities. Its core, however, is the absence of cranial nerves 6 and 7, so that those with Moebius lack both abduction of the eyes, making them unable to glance sideways, and any movement of the muscles of facial expression. Such an absence from birth has profound effects on one's view of self.

James, a man in his 50s, is an Anglican priest with Moebius. He had a blessed childhood, apart from the inevitable feeding problems since sucking and then closing the lips during chewing were difficult. At home his facial problems were hardly mentioned. At school, though, the real world intruded and he was teased and bullied. However he was bright and accepted by Cambridge to read theology, following his mother's advice, and then became a parish vicar and, later, married.

In talking with James I had a clear feeling of how his life has been affected by Moebius, even though in talking he never mentioned his face, ascribing any problems he had as a failure of his self, and of him. For instance he has always been distant from others and suggested he was shy, unavailable and uninteresting. Never having experienced feelings on the face he described an almost reduction in intensity of some emotion themselves. Consequently he withdrew from many normal social interactions, living as a priest and gaining an identity from the garments and ritual of his calling.

I have a notion which has stayed with me over much of my life - that it is possible to live in your head, entirely in my head. I think I get trapped in my mind or my head. I sort of think happy or I think sad, not really saying or recognising actually feeling happy or feeling sad. Perhaps I have had a difficulty in recognising that which I'm putting a name to is not a thought at all but it is a feeling, maybe I have to intellectualise mood. I have to say this thought is a happy thought and therefore I am happy.

When he met his wife, he told me,

I think initially was I thinking I was in love with her not feeling it: I was probably thinking it initially. It was some time later when I realised that I really felt in love.

At the age of 53 he heard of a UK association of those with Moebius and their parents, the Moebius Support Group, and went along.<sup>2</sup> This was the first time he had been given a name for his problem and the first time he realised that he was not alone.

It was also clear, talking with James and others with Moebius, that there were problems with the expression of emotion. It seemed important to express happiness and sadness in the body, and on the face, in order to experience them and learn to control them, both from feedback felt within but also, most importantly, from those round one. For facial expressions are usually an invitation to share, a looping between people. Without that James retreated from such experience and communication of it to a cerebral and isolated existence, thinking rather than feeling.<sup>3</sup>

In his fifties and after leaving parish ministry, but not the church, to explore his selfhood more, James has begun to look at these matters,

If you say where does 'me' now reside, I think I am slowly coming out of my head a bit. I am not sure I can locate where I am but I don't think I am entirely in my head or even my mind. I have an expression of living 'a life of the mind,' but I do accept that the mind is not easily able to communicate its thoughts or even its feelings. I think I was out of touch with my feelings, or even suppressed them.

Not all those with Moebius have had such profound problems with face and a social existence. One woman with the condition took her wedding photos to show friends and several said, 'But you are not smiling.' "But," she said "*I can't smile.*" They had not realised, so good was she in using other channels for communication. In a sense she had transferred her 'face,' her emotion communication embodiment, to gesture and to voice. But on the other hand a boy of 5 with Moebius had asked his father why he could not be happy, linking the facial expression with the emotion.<sup>4</sup>

<sup>2</sup> The Moebius Support Group in the UK meets once a year or so to discuss practical issues with the impairment and for comradeship. There are now other groups, with a large one in the USA and several in Europe.

<sup>3</sup> I gave an address at the US Moebius Group a few years ago describing the problems that adults with the impairment can experience with depression and isolation and profound problems with social relationships with the opposite sex (the first kiss problem). The adults with the condition in the audience were appreciative but the parents of children with Moebius less so. The latter were still at the stage, I thought, of controlling their children's' lives, (as all parents do). How different it is for adults with Moebius, making their way in the world and no longer able to draw on the unconditional love of parents.

<sup>4</sup> If facial expressions are designed to share, and to be socially contagious, so that I smile if you smile etc, then the young boy was not entirely wrong. Without a smile he could

Having considered some of the affects of visible difference on the face on the self and on social interaction the focus will now shift to one of the most severe of neurological impairments, spinal cord injury. In this condition a person may be transformed from being fit to being immobile and without sensation in a moment – an almost unimaginable transformation of body, self and being.

#### 4. A totally different person

Bill was injured 25 years ago and has been unable to move or feel below the neck since. A rather shy surveyor student with little experience of life, he enjoyed rehabilitation in hospital for its sense of community and purpose, and because there was access to the opposite sex. After this he went to university and then, for many years, worked for local government until cut backs and 'efficiency savings' made him redundant. Now he works, but only part time and semi-voluntarily. He lives alone independently with a personal assistant. He has succeeded with his injury from the outside, having worked most of the time since his injury and living independently. But, talking to him, it was clear that he was aware of the effect of his injury on him, and not just in the need for help with aspects of daily living.

Without control you are totally different person. You view the world differently and the world views you differently. People know me as being in a wheelchair, as a wheelchair. I always try to put myself on the other side. If I were looking at me I am sure I would be thinking of that guy in the chair. I can't expect them to think any differently.

I must admit I can't really claim that I have ever been happy or content since I have been in a wheelchair since the frustrations have always been there to take it away.

Bill continued,

Happiness is a positive emotion, short term enjoying a film, an overall feeling. Before I was disabled I was sometimes happy and sometimes not, but since I have been disabled I cannot claim that I have ever been happy. It is too much of a struggle, every day.

not display happiness and so was unable to initiate shared happiness. There are ways, fortunately, to express emotion through other channels, of gesture and voice and it seems important that these should be explored as early as practical in children with Moebius.

I asked if he could forget his injury and be immersed in a book or a film.

I can be immersed in reading, but it is too short term for me to say that this makes me happy. A good book will take me to places that even a film might not. You are right. I tend to have batches of book reading.

After this length of time it was difficult for him to consider the time before. Normal for him now was to live from a chair.

I just feel me. Me is the mental side. I am what I think, rather than I am what I do. I release my thoughts into speech or writing or anything else, rather than into any other movement. It is still doing, but less doing. It is more intellectual, but that is one reason why I enjoy cycling, because it is a raw physical release. Before I did not realise how badly I needed it.

Cycling was with a frame cycle and hand pedals, a new hobby, a way of controlling his passage through the world and a way of becoming embodied, of becoming 'in the flesh so to speak'.

Samuel Beckett in his novel, 'Murphy' discusses this,

"How can I care what you DO?"

"I am what I do," said Celia.

"No," said Murphy. "You do what you are, you do a fraction of what you are, you suffer a dreary ooze of your being into doing."

For some of those with spinal cord injury this dreary ooze – of being into doing - is so difficult.

Bill continued,

I do accept that my mind has changed. My total viewpoint and mental processes are different and these cause a major change in personality. Everyone changes as they grow, and age and experience life. But this is more like a landslip; everything changes in one go.

I can say why but not easily how. I feel I have changed because of the physical limitations, because everything has to be planned much more carefully. I think in a totally different way. I have to plan every day, with little spontaneity. But how to define this? Character is what you are. How you behave, how you act, how you think, how you cooperate with others. How you act is physical I accept, but character is mental. But the physical has an effect on everything.

For me each day life is either bearable or unbearable. It has never really got beyond that. There have been very few days which have got above bearable...How did I come to terms with it? I just did. There was nothing one could do. But you weren't going to die so you just got on with it.

Descartes considered what he could take away and still have an identity, and settled on his famous conclusion, 'I think therefore I am.' Alan lives a sort of Cartesian nightmare; thinking without doing.

This way of being, of existing – just - with no alternative, was explored again and again by Samuel Beckett. You may remember that in 'The Unnamable' the narrator, without even a name or pronoun for reasons which are unclear, lives, nearly disembodied, in a jar. The novel ends with a meditation on existence and enduring it without pathos or pity,

You must go on, I can't go on, you must go on, I'll go on.

It is implicit within Beckett that these minimal states of existence, allegories of all of our lives, are endured without heroism - there being no alternative - Bill and many of those with spinal cord injury, go on, there being no alternative.

Bob Murphy, a professor at Columbia, has written a fascinating account of his descent into quadriplegia,

A quadriplegic's body can no longer speak a 'silent language'... the thinking activity can no longer be dissolved into motion, and the mind can no longer be lost in an internal dialogue with physical movement.

The totality of the impact of serious physical impairment on conscious thought... gives disability a far stronger purchase on ones sense of who and what he is than do any social role... which can be manipulated. Each social role can be adjusted to the audience, each role played before a separate audience, allowing us to lead multiple lives. One cannot however shelve a disability or hide it... It is not a role: it is an identity... society will not let him forget it. (Murphy 1987).

The experience of Bill and of Bob Murphy is perhaps not a surprise to you. For those of us without SCI it is like looking over an abyss. But, thankfully, their experience is not common amongst those with SCI, as far as I can discern.

## 5. Impairment and Disability

Mike Oliver was brought up in a working class family in the East End of London. He was bright and passed the 11 plus to go to a grammar school. But this did not suit and he found little in education to interest or detain him. He left school early with a few 'O levels,' found a dead end job he hated, and lived for the weekends in pubs with friends, and for chasing girls.

His accident was on holiday diving into a pool. Paralysed from the neck down, he went off to Stoke Mandeville Hospital. He loved the activity, the rehabilitation and the social life, with friends and women both from the hospital and from outside. But all too soon he was discharged back to his parents' house and he spent the next two years or so living in one room, hating the need to depend on his parents, hating the toilet and bath in his living room.

Then a stroke of luck. A friend from hospital, who was paraplegic, retired from his job in the library at the local remand home and Mike was asked if he would take over the job. Mike suddenly found himself in work. Over the next year or so he did more and more and moved from library work to teaching the inmates, initially simple maths and English but then more complicated subjects he mugged up himself at Night School. The government then introduced higher requirements for the teachers and Mike was asked to get some qualifications. By now he had discovered a fascination with education and particularly with sociology. He enrolled not for qualifications to teach but for a first degree and then moved onto a Ph D. After a succession of university positions he became the UK's only Professor of Disability Studies, at Greenwich University.

He caused some concern when, nearly 20 years ago, he wrote an article for The Guardian newspaper about his feelings on his spinal cord injury.

It was the best thing that had even happened to me. For me I think it really was. I was a working class yobbo with a failed education, not very good at relationships in a job that I did not like and I probably would have gone on to drink and smoke too much... I was a promising sportsman but had failed in that too.

Breaking my neck broke that mould and gave me an alternative possibility. It changed the possibility of whom I could become. 40 years later I am a professor of disability studies, I have one marriage behind me and I am happily married again, I have grandchildren and have been all over the world. I have had a good life. I have

no complaints. One thing I do know that if I had not broken my neck I would not be a professor in a university. But equally well I do not want me to be positioned as some sort of hero, who struggled against appalling circumstances. I have just taken opportunities as they occurred.

Michael has combined his professional academic work in the field with work for several groups supporting and advancing the cause of those with spinal injury and, indeed, disabilities of other types.

He dislikes the very idea that his injury was a tragedy and has argued forcefully against the medical tragedy model of disability which accentuates the personal nature of the problem and the loss of function which results. With others in the UK and elsewhere he has argued instead for a re-definition of disability itself, arguing from the personal to the social. This was reflected in a Royal College of Physicians of London document in which, following his advice amongst others, definitions were as follows,

Impairment is the loss or abnormality of a particular faculty of part of the body.

Disability refers to the person's encounter with daily living, the environment and society, not in particular circumstances but encompassing the whole of that experience. (Royal College of Physicians of London 1992)

Michael would go further than this. He considers most disability is due not to a medical model of tragedy, but a social model of oppression. His problems with his own spinal cord injury were not due to sorrow or anger about his situation, but about the fact that he had to live, eat, sleep and toilet in one room and was unable to go anywhere because he was too poor to afford his own car and there was no accessible public transport, and because buildings all had stairs etc. With such a view disability becomes a social state, not a medical condition.

The individual model sees the problem as stemming from the functional limitations or psychological losses assumed to arise from disability, underpinned by their personal tragedy model of disability, suggesting in turn that disability is some terrible chance event occurring at random to unfortunate individuals. Nothing could be further from the truth.

The social model suggests it is not the disability, not individual limitations, which are the cause of the problem but society's failure to provide appropriate services and failure to ensure the needs of disabled people are fully taken into account.

Hence disability is all the things which impose restrictions on disabled people, from individual prejudice to institutional discrimination, to inaccessible buildings to unusable transport systems. (Oliver 1996)

He questions the medicalisation of disability. In this medical sociological model chronic illness is presumed to be causally related to the disadvantages disabled people experience. In the social model there is no causal link: disability is wholly and exclusively social.

This has led to the suggestion that disability has nothing to do with the physical body. For Michael this is true,

Ironically that is precisely what the social model insists, disablement is nothing to do with the body. It is a consequence of social oppression. But the social model does not deny impairment is closely related to the physical body. Impairment is, in fact, nothing less than a description of the physical body.

The social model does not deny that some illnesses have disabling consequences.... Doctors have to treat the impairment and its consequences, but they are no good at disability... The whole medical and rehabilitation enterprise is founded upon an ideology of normality... to restore disabled person to normality. Where that is not possible, the basic aim is not abandoned: the goal is to restore the disabled person to a state that is as near normality as possible. So, surgical intervention and physical rehabilitation, whatever its costs in terms of pain and suffering of disabled individuals... (Oliver 1996).

People with spinal cord injury are asked to try to walk as best they can, when wheelchairs are a perfectly good way of getting round. Further, the medical profession, because of its power and dominance, has spawned a whole range of pseudo-professions in its own image: physiotherapy, occupational therapy, etc., each geared to its own normality.

I asked him, if he made demands for this and that, how I should react if I did not understand him and his needs. In other words I was concerned that, in this argument, empathy would be missing, possibly from both sides.

But I don't want you to understand me. Why should you want to? To understand my needs, ask me. If you need to understand my needs ask me. I don't want you to try to understand my needs and then meet them because then you might misunderstand my needs. That is what Leonard Cheshire did. He tried to understand dis-

abled people's needs; he understood in his own particular way and stuck 70 000 disabled people effectively in prisons.<sup>5</sup> Thank you. We have that.

For this reason Oliver thinks that disabled people must decide their own destiny and control it since non disabled people will never be able to understand. He distinguishes between a social construction model of change and a social creationist model. The former locates the problems, of hostility to disabled people, within the minds of able-bodied people either individually or collectively; the creational model suggests that the origin of problems lie, instead, in the structures and institutional practices within society. For Mike Oliver the latter model allows the possibility for change from tackling the structures and rules and laws of society.

Michael Oliver is not alone in suggesting his spinal injury was a blessing, others have suggested as much, though others have equally vehemently denied it. Oliver needs a personal assistant to get him up each morning, for bowel care and much else. But, as he says, he has a secretary to type letters and a PA to bath him. For him there is no difference, even though for me this suggests a very different relationship with his body, his embodied self, than for most people.

## 6. Loss of movement... loss of earnings?

Lastly, briefly, a consideration of a man who also has had a spinal cord injury for half his life, but in this case Chris is only 28 now. At 14 he was told to dive into a pool at school and hit his head - he had never dived into a shallow end before. This was in January. He spent the next few months in rehab but insisted on talking his public exam as usual in the summer and then returned to his school in the autumn, moving up a year to be with the same school group he had left. The school timetabled all his class lessons on the ground floor and built some ramps. Chris passed his exams without loss of time or grades and passed his university entrance exams. He went down to University a week early to meet the two personal assistants who were to look after him for the next 3 years - they had no experience and he had to teach them, and the university, about access and impairment as he went along.

At the end of his third year, and in a wheelchair, he went to Venice for 3 months study in history. A less accessible city is difficult to imagine.

<sup>5</sup> Sir Leonard Cheshire was a Word War II hero who went on to found a series of home to look after young disabled people that many with spinal cord injury lived in.

Then he had a further year to qualify in law, having decided on this profession seeing his own case settled in the years after his injury.

He is quite clear that in settling out of court himself he ended up with less money than he otherwise would have had. It was enough for a car, a better wheelchair and a hoist. But he is quite adamant that people waiting for big pay outs after injury may be worse off: they put everything on hold and then no longer go out and struggle with work and access and life in general. People suspend their lives until the money arrives and then frequently find that it is too late, they have adopted a disabled role.

Chris works as a solicitor, mainly with personal injury cases and would like to specialize in SCI. Not only because he knows the law and the procedures, but also so he can turn up to newly injured person, wheel in and show them that there is life after injury.

The irony is that in the UK settlements after SCI and other impairments are determined according to certain criteria. The need for support and a nominal amount for distress are relatively small parts, the largest part is to compensate for loss of earning and potential. Chris had his injury at 14, had taken all his exams on time, gone to University and qualified in law to practice successfully. Despite this most devastating impairment, he had not allowed any disability to intrude on his life and had suffered little or no loss of earnings. In the biographical narrative of his life spinal cord injury had intruded, but not too much.

## 7. Conclusions

I have discussed three people's experience with spinal cord injury, from one devastated to others for whom it was either almost an irrelevance or even a blessing. Their conditions are identical yet their responses to it immeasurably different. Each person demands our attention. For to understand another we need to listen to them and give them sufficient time to relate their experience, their perceptions and their needs. In this condition we cannot generalize, but in contrast to Mike Oliver's suggestion I think we do need to understand and to empathise. Paradoxically it is those whose situations are most difficult for us to understand and imagine that we need most so to empathise. Empathy has been divided into several kinds (Depraz 2001);

1. the passive association of my lived body with another's.
2. the imaginative transposal of myself to the position of another. Note

- not others, but of the experience of a single person.
3. the interpretation or understanding of myself as another person for you.
  4. an ethical responsibility in the face of another.

For the roots of society and of civilization and, for some people, the origins of consciousness and of humanity arise in the relations between people and in the development of the realization that one person has the capacity to think and feel as I do, whether or not they look as I do, move as I do or have shared experiences with me.

As suggested above, for Merleau-Ponty, bodies are not simply a means; they are our being in the world. In this we must be aware that the means of expression depends on the nature of our world as well as on our selves and of our bodies. Mike Oliver et al are pleading for us to be aware that various worlds exclude them, just as other worlds have excluded and reduced the possibilities for expression of stigmatised groups through history.

A question, which must be posed, is why do some people do so well with their facial difference or spinal cord injury and some not? Three sages agree on this if little else: We are social beings.

Though man is a unique individual – and it is his particularity which makes him an individual social being – he is equally the whole, subjective existence, as thought and experienced. He exists in reality, as the representation and real mind of social existence.

Marx quoted in Oliver, (1996).

An individual's concept of his or her self is a reflection or, more accurately, a refraction, (as in a fun house mirror); of the way she or she is treated by others.

George Herbert Mead, quoted in Murphy, (1987).

Merleau-Ponty wrote of the body as being the subject for its owner but also the object for others. But I would like to suggest, this dichotomy is a simplification. Faces do not simply express, they do not simply display; they require a response and a looping of emotional experience between people, a facial conversation, a sharing. Wittgenstein wrote,

Would (a) fixed smile really be a smile? And why not? - I might not be able to react as I do to a smile. Maybe it would not make me smile myself. (Wittgenstein 1980)

Faces invite others to enter into your experiences and feelings. But more, we have developed to be so social that, in turn, our perception of our self-esteem depends on others response to us. The face does not simply express emotion, the responses of others to our facial competence determines our perception of our own success socially, our own sense of self-esteem and indeed selfhood. Merleau-Ponty described it thus,

I exist in the facial expression of the other, as he does in mine. (Merleau-Ponty 1964).

Those with better social skills do well. For those with great social skills the differences tend to fade away and the impairment is less to the foreground in social interaction.

I realize that I may have strayed from arguments and discord, but in discussing disability I hope I have made a case for empathy and for a deep and imaginative understanding of others' experiences, and for the need to close that decisive gap Toombs described. At the roots of discord are often misunderstandings. These are seen in the relations between able-bodied people and those with impairments of various kinds, as well in political debate. The worlds of those with such impairments can be radically different from our own and require different sorts of dialogue and argumentation to address. Maybe, if we can reach and empathise with those who live with neurological impairments, we might tolerate others' different views a little more too.

All these suggestions are applicable to many levels of debate and of society. Within a clinical context, however, such an understanding of the experiences of those with neurological impairments, as discussed, has far-reaching consequences. The worlds that people with such conditions live in are so different to those of the able bodied health care workers that such empathetic approaches should be more widespread and embedded in clinical education. From such an approach the needs of those with chronic conditions may then be met more appropriately. Once the differences between the clinical 'body focused' problems and the consequent socially induced disabilities are made explicit then the shortcomings of society can be debated better. From such a debate and from a reduction, one hopes, in stigma towards the impaired, their differences may be celebrated, or perhaps - even better - ignored. Then the disabled and impaired may be supported and enabled to contribute in various ways to a more humane, diverse and inclusive society.

The finding that social skills may be so important in living successfully with various neurological impairments is known within the field but probably not widely outside. It has the consequence that if such skills can be acquired and taught then this should indeed be done. The UK based charity concerned with facial disfigurement (their term), *Changing Faces*, is aware and gives courses teaching those with facial difference to manage those normal people they meet and to act in ways which allows and enables the development of confidence in personal relationships. Within the UK such psychosocial support is now mandatory in units treating and supporting those with cleft lip and palate. For in those who are born with a condition this self confidence and social skills may never have been acquired; At least for some with spinal cord injury they may have been. As yet I am not aware of more formal teaching of social skills in spinal cord treatment centres in the UK.

From such an empathetic approach to those with severe difference flow many consequences for medical care, rehabilitation and for society in general. *Changing Faces* is well aware of the need to support its clients, but also gives educational courses for health care professionals and teachers and, lastly, lobbies politicians, advertisers and media controllers. From such individual's experiences arise the injunction to engage with and seek to change the views and actions of a wide variety of workers and groups. From this it follows, to echo the philosopher Levinas (1993), that the process of understanding others from their own perspective is not only a method within communication studies, and medicine, but also has profound ethical implications for us all.

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