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"The search for the True self in
adolescence - the dilemma of childhood
handicap"

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The search for the 'True Self' in adolescence; the dilemma of childhood handicap.

Mirror, mirror on the wall,

Who is the fairest of them all?

In the early days of my medical practice, or more appropriately, in my 'infancy' as a doctor, I was privileged to come into contact with a group of 'handicapped' babies. My good fortune was that our paths were to cross at frequent intervals during the years so that, as I grew up professionally and developed my ideas and opinions regarding disability, so my young friends grew and provided me with a constant source of inspiration and empathy as they shared their infancy, childhood and adolescence with me.

I will never forget Mandy's birth - It was my first week in paediatrics. I was left alone in charge of the children's ward, special care baby unit and was on call for obstetrics. After a busy friday night and saturday morning I went to get some lunch, I was told there were no imminent deliveries. As I began to eat the telephone rang and a very anxious midwife asked if I could come to the labour suite. Was there a problem?; 'No, no problem, the obstetricians just want you to speak to some parents'. 'OK, in that case if there is no urgency, I will finish my lunch'.

As I entered the labour suite half an hour later I saw a baby in an incubator, I wondered why she was in there and why I had not been told. The baby had her face to me and looked fine, was crying and kicking her legs. As I moved nearer I could see that all was not well with her back; she had spina bifida. I covered the sac with a saline soaked gauze and reprimanded the staff for not having informed me. The obstetrician had left and the midwives were very anxious, baby's father was in the office and kept asking why he could not go into his wife, mother was in another room and kept asking to see the baby. It was left to the most junior member of staff, me, to tell the parents.

We all learn by our mistakes, the midwives were adamant that the father should be spoken to first, on his own and only later the mother. I started to talk to father, would he sit down, no he preferred to stand, - I should have insisted As I gave him the news in the gentlest way I could, all six foot of him came crashing down on top of me in a dead faint.

This disastrous beginning left scars on all four of us. I later realised that I identified with mother being kept 'in the dark' and rather than appreciate the staff's protection by withholding information, I resented it. I also retained the picture of the baby kicking her legs and as over the years I cared for Mandy's completely paralysed legs I could not help feeling a somewhat irrational anger with my surgical colleagues who perhaps did not do enough to preserve her neurological function and with myself for not leaving my lunch and caring for her sooner. Of course intellectually I am quite aware that babies with spina bifida often do move their legs at birth, but emotionally I am in there with mother, both wanting to preserve and mourning the loss of the 'perfect baby'.

Mandy's father never fully recovered from the shock, both parents felt isolated by being told the news separately, and further

isolated when Mandy was whisked away to the neurosurgical unit twenty miles away. Mother eventually dealt with this isolation by immersing herself in the care of her baby when she returned but father felt cut off and excluded from this diad. He later left home on several occasions unable to cope with the idea of a handicapped child. The family stabilised partially five years later when a 'replacement' daughter was born.

The effects of such a traumatic birth can be seen fairly easily in the adults present, but what of the effect on the child? The accepted postnatal picture of mother lovingly nursing her newborn baby, adoring the new daughter or son and being grateful that 'the baby is all right' does not fit for the handicapped child or baby in an incubator.

For all children a reciprocal process or mutual adoration is the healthy way to start life; in the words of Winnicott, "The mother gazes at the baby in her arms and the baby gazes at his mothers face and finds himself therein".

If mother really looks at this child as a unique human being, she will be a true mirror in which the child can find his TRUE SELF but if instead, as often happens, mother reflects her own fears expectations and disappointments upon the child he will not find himself, he will see his mothers predicaments, his FALSE SELF. "The child will remain without a mirror and for the rest of his life would be seeking this mirror in vain." (Alice Miller) He will decide that there a parts of himself which other people do not want and do not like so he hides them from others and from himself. He lives in a world of denial where he can try to be all the things that other people want of him and his real feelings and needs fade out of sight and 'out of pain'.

This building up of a 'False Self' occurs to an extent in all of us, since we do not have perfect childhoods or perfect mothers. Sometimes the 'False Self' may seem to take over completely as perhaps happened to Vincent Van Gogh.

Van Gogh had a brother who died in infancy, his name was Vincent, when the 'replacement' baby was born his mother also called him Vincent and looked upon him not as a unique human being, new baby Van Gogh, but as reborn, can never be as good as the original, Vincent 2. This resulted, I believe, in Vincent really seeing himself as a sufferer, a tormented soul, "One has to suffer for art" was a frequent maxim. He also said, in a very self revealing statement which was actually describing his prostitute companion "I do not consider her bad, she has never experienced goodness so how can she be good?"

Perhaps it was in trying to break away from living the life of his dead brother and in searching for his 'True Self' that he altered his body image by cutting off his ear?

How can a mother provide a true mirror for her child when that child, by virtue of a deformity or handicap can in no way match up to her expectations? The 'False Self' for an 'imperfect' child can assume major proportions creating a life which is forever haunted by the ghost of the idealised child who 'might have been'. Did Winnicott have this in mind when he chose a 'handicapped' teddy bear for the cover of his book "Playing and Reality"?

The turmoil associated with suppression of the child's 'True Self' will occur in infancy so that, by school age, as the stage of 'latency' is reached, many handicapped children knuckle down to working very hard at complying with their carers wishes to become 'more perfect'. Mandy spent hours each day learning to walk with sticks, calipers and assorted aids while we all praised each grotesque step and did everything in our power to stop her being wheelchair bound, even though it must have been obvious to an outsider that this

was all she could ever be.

Sharon, disabled by Thalidomide, practised religiously with her clumsy artificial arm which fitted over her phocomelic upper limb. She looked quite 'normal' wearing it and we all felt proud that we were 'doing something' and that somehow assuaged our guilt about the handicap. When left alone she would whip it off and perform forbidden feats of dexterity with her little stump and with her toes.

During this time the family and carers provide a protective capsule within which the child can hold on to a sense of normality. Margaret Donaldson describes the need of children to 'feel effective, competent and independent' At first they may see themselves as loved and wanted but gradually they see that their needs are not being met, that they are not competent or independent, acquisition of a sense of difference also brings vulnerability.

Adolescence is a period when ideas of 'self' resurface, the teenager is preoccupied with body image, with who he is and with his place in the world. He seeks a new independence and is able to confront and reject others views of himself and find his own values. Thus adolescence can be a golden opportunity for intervention, for allowing mistakes to be rectified. Adolescence gives the 'caring' professionals a second chance to get it right this time and to help the teenager to find his True self rather than reinforce the 'False Self' which made us feel more comfortable, less guilty and less threatened in early years.

Thus I ordered an electric wheelchair for Mandy and helped her decorate it with her favourite rock idols, she joined the local PhAB club (Physically handicapped and able bodied) and learned to disco dance in her wheelchair, something she could never do on her sticks and frames!

The anthropologist Arnold Van Gennep in describing 'Rites of Passage' in adolescence states "The novice is considered dead (separation from childhood past), is resurrected and taught how to live differently than as a child (transition) and undergoes a change symbolising identification and acceptance as an adult (reintegration). In order to develop a sense of True self, the handicapped teenager must 'lay the ghost', the 'False Self' must be considered dead, the loss of perfect child must be acknowledged and mourned. Only then can the true nature of the individual 'warts and all' be accepted and identified with.

This cannot be put better than by Alice Miller in "The Drama of being a Child" - 'The child has a primary need to be regarded and respected as the person he really is at any given time ...' "What would have happened if I had appeared before you bad, ugly, angry, jealous, lazy, dirty, smelly? Where would your love have been then?" We can continue ... deformed, incontinent, paralysed, crippled? "Was it not really me whom you loved but only who I pretended to be?"

All 'handicap' will affect the teenager's self image but perhaps those conditions which render the adolescent as overtly 'different' interfere most profoundly with the sensitive area of body image. A boy with retarded growth and short stature or with absent limbs, like David, a Thalidomide victim with no legs has tangible, visible evidence of his disability, while a teenager with cystic fibrosis may be more disabled while this fact may not be outwardly visible to the world. Both have their problems; body image may be expected to be most disturbed in the former, but the sense of denial of handicap can be worse in the latter.

Denial, justification of handicap and compensation are all strategies used to avoid acceptance and reality. All bring more pain and reinforce the spectre of the 'False Self'. We have all met the

mother of the brightest Downs girl in the world, the fastest one legged swimmer, the CF girl who had the finest wedding. Thalidomide victims I have known have parachute jumped with no arms and legs, written novels and TV plays, and performed feats of endurance and skill - all very admirable but often more than tinged with overcompensation and a sort of perverse one upmanship.

Even the 'famous' are not immune to such pressures. Adler proposed that a sense of inferiority could prove to be an asset. He suffered as a child from severe rickets and acknowledged his sense of inferiority as a adult, he had a poor body image and was very short. This engendered in him a sense of aggressive competitiveness and his main arguments with Freud were centered around Freud's focus on the 'pleasure principle' when Adler gave importance to the 'power principle'.

I see as more of a 'Healthy' adjustment the way in which David coped with adolescence and emerged as a well adjusted man. I asked David to come and speak to an audience of doctors and professionals at a conference on disablement, he was then 20. He had discarded the over short artificial legs which he had been supplied with and which maintained the image of the childlike handicapped person needing to be cared for and insisted on taller ones which suited his trunk length, he thus literally 'grew up'. David however maintained a realistic outlook, not disguising his disability but sharing with us the times when he 'fell off his legs' and how when this happened he asked for help to get back on them.

Accepting that handicapped teenagers do 'grow up' is often difficult. We can collude in keeping them as children, this is easier to cope with, children need caring for and are under control. Adults can say when they want help and reject caring and be independant.

Boys are sexual, children are not. Handicapped adolescents are not expected to be sexual. Mandy started her periods at ten, a fact which her family found very hard to take. Clare's parents were so convinced that she was cocooned in an asexual world that they could not believe that at fifteen she was picking up men in the street, thinking that this was the way to behave.

The world is a tough place whether we are handicapped or able bodied, the important thing is to keep a grasp on reality and accept ourselves for what we are, with our feelings, fears, abilities and disabilities, only then can we accept others and help our adolescent friends to accept themselves.

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