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Some Reflections from Twenty Years of Psychoanalytic Work with Children and Adults with a Learning Disability

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Traumatic Factors Still Live

Despite the success of advocacy groups, legal progress and improvement in attitudes of health and education service professionals, for many children and adults with severe learning disabilities (mental retardation) around the world their existential quality of life constitutes a trauma. Psychoanalytic thinking can help public debate not only through the insights that come from direct psychoanalytic work with learning disabled clients, but also through applying psychoanalytic ideas to the wider discourse.

Learning disability at this historical moment of time continues to evoke primitive negative societal responses and constructions. From a psychoanalytic point of view, one of the reasons for this recurring inequality is the impact and fear around procreation. A man and a woman, hoping that the best of them will be expressed genetically, cognitively, emotionally, spiritually and physically in a child, experience something that is outside the usual experience. Depending on how much their attachment network supports them, the nature of their surprise impacts on the new baby. The baby therefore internalises the external impact of its learning disability. At the same time as struggling with the impact of it internally, the baby also faces and sees the external response. Additionally, the baby and the baby's family and network has to cope later with the cognitive ramifications and negative economic, political and social constructions around its learning disability.

The birth of babies with learning disabilities is a subject of ethical debate all over the world. Outside of national political genocide, no other group's origins receive so much attention. Abortion is a controversial issue in Western culture. It is an area where religious, ethical, gender and emotional factors inter-relate.

However, outside of the small group whose religious views make any abortion an immoral act, there is a groundswell of support in public opinion for the legal termination of pregnancies caused by either rape or with a disability. Indeed, whilst "ordinary" pregnancy in the UK has a 20 week termination limit, the limit for women with a foetus that is impaired is 40 weeks. Marks (1999), Wolfensberger (1994), Sinason (1994, 1997) and Hubbard (1997) are among those who have pointed out the societal and intrapsychic impact of this.

The deepest and most painful psychoanalytic theme that comes from long-term work is that learning disabled people can experience extreme annihilatory fear because it is hard (or impossible) to separate out the idea of amniocentesis or abortion of unborn learning disabled foetuses from a death wish towards learning disabled children and adults. Whilst it can be traumatic being born a baby in a certain gender, race or class according to the politics and history of a particular geographical area, learning disability carries an Esperanto of unwantedness almost everywhere. Breathing in a societal death-wish is toxic and so is breathing in the infanticidal wishes of the mother whose ethnic and religious and political background forced her into carrying a baby she did not wish for.

There are always complex ethical issues involved in considering any human being. Where there is any disability focused on, whether physical or mental, great care has to be taken. Researchers concerned especially with physical disability have written very critically of the "personal tragedy theory" in which society can disown its part in constructing or creating disability by projecting all responsibility into the individual (Marks, 1999). By examining the individual existential experience of disability I do not wish to fall into that trap. Bury (1996) does not consider that research into the experience of people with disabilities aids their struggle for political empowerment and would therefore see proof of trauma and oppression as part of everyday life that is not in need of further expression. Morris (1993) perceives much research as a "violation" of the experience of disability. Shakespeare (1996) expresses concern over research "which reinforces, rather than challenges," the subordination of disabled people.

As a psychoanalyst I am concerned with psychoanalytic research and treatment as advocacy (Marks 1999) for learning disabled people. It may well be at some unspecified time in the future when society is empowering of its citizens that the unique existential angst of learning disability might be further filtered or eradicated. However, whilst considering the possibility of future change, I can only focus on the present

Internal and External Factors

At the simplest level there are three issues to consider. Something has happened (whether externally or internally) that means an individual cannot do a particular task the way most other people of the same age can. Secondly, there are the consequences of such a fact (emotional, physical, educational) and thirdly there are the ways the external environment mediates or exacerbates these consequences. The individual with his/her disability meets the environment and internalises aspects of it. This creates some of the layers of the individual personality that then meets the outside environment.

Here are four examples of 13 year olds with cerebral palsy, severe learning disability, wheelchair-use and two parents. None of them have been abused and none of them live in poverty. I have divided the examples equally between those where external factors have played the largest role (because they also are internalised) and those where internal constitution played the largest role.

External Factors

a) John, aged 13, with cerebral palsy and a wheelchair user lives in a home that hampers his mobility. When his mother or siblings take him out his street exacerbates this experience by having no sloping kerbs that would allow him to negotiate travel on his own. The local shops are not wide enough for a wheelchair to go around. John internalised a fatalistic view that the environment could not help him and then his forays into the outside world corroborate that view.

b) Mary, aged 13, also has cerebral palsy and is a wheelchair user. Her local authority significantly aided her family and provided a bungalow that allowed maximum independence space. Her internalised view was that anything was possible and with her local street providing ramps and her local shop having wheelchair access her external environment corroborates and enhances her sense of confidence and motivation.

Unique individual constitution also plays a part.

c) Steven, aged 13, with cerebral palsy and wheelchair-use lives in a home that hampers his mobility and his local authority have not aided wheelchair users with sloping kerbs. However, Steve was "born a fighter" (says his mother) and remains highly motivated.

d) Dora, aged 13, also with cerebral palsy and wheelchair- use, lives in a home and external environment that have done their best to minimise the impact of her physical disability. However, her unworked through distress at having a learning disability has destroyed any motivation for independence and she remains withdrawn and depressed.

However, for this subject at the moment there is no equal interplay between external and internal. Were we to add on issues of class, poverty, ethnicity, geographical location there might be significant alterations in the weighting. Additionally, were we to look at the actual causes of the initial disability (e.g. whether caused by avoidable forces) the weighting would change again. Traumatic impact on the family also needs to be added to the weighting. Fisman & Wolf

(1991) have found that the pressure on parents with a learning disabled child leads to greater stress in the family and a higher likelihood of a broken marriage than others (Sternlicht & Deutsch, 1972}.

> Emotional weight of learning disability = Enabling or Disabling Pre-Birth (EP or DP) + Enabling or Disabling Home Environment (EH or DH) + Enabling or Disabling Socio/Politico/Educational Environment (ES or DS) + Enabling or Disabling Individual Constitution (EC or DC).

Where there is no organic damage, trauma can be an actual cause of handicap. VIMH (Violence induced mental handicap), malnutrition, drug abuse, alcohol abuse, other substance abuse, poverty, lead toxicity are part of the Traumatic External Stressors in the origins of environmentally determined learning disability

The external stressors that lead to the majority of mild learning disability (Ricks, 1990) include lowest social class, poverty (Rieser and Mason 1990), large number of siblings, paternal unemployment, and maternal deprivation (Rutter 1970) which are clearly documented. Rutter et al. (1970) found maternal absence, paternal unemployment and foster care linked with mild learning disability. He found over half of this group were in large families. The OPCS Study of Disabled Children (1989) found that boarding or alternative provision was needed for 48% of disabled children who were at physical or emotional risk in their home environment. The OHE (1973) found prevalence of learning disability in the children of unskilled urban manual workers was 9 times greater than among non-manual. The Women's Health and Disability (1985) leaflet agrees with this stating, "poverty also causes disability". Buchanan and Oliver (1979) pointed to abuse and neglect as an actual primary cause of primary disability.

The Interim Findings of the National Commission on Children, published in Washington April 28th 1990, estimated that malnutrition affects 500,000 children in the USA directly creating an illiterate underclass. An estimated 100,000 children are homeless. Eleven million children have no direct access to a family doctor. All these external stressors promote mild learning disability.

One child in five in the USA lives below the poverty line and it is considered that the figures for black children are even higher. In 1987 the poverty rate among black children was, among Hispanic children 39% and among whites 15%.

Spitz (1945) found that in an orphanage, despite impeccable hygiene, toddlers were more susceptible to illness and had higher mortality rates. The Foundling Home babies start becoming retarded at 3 months on weaning when the "modest human contacts" they had are stopped. He wondered whether a certain level of cognitive intelligence was required as a prerequisite for a psychiatric syndrome, but then realised no child developed a psychiatric condition unless they lost touch with their mother in the 6th-8th month. "In all our cases without exception a gradual decline of the developmental quotient began when the infant was deprived of its love object" (p. 50).

The behaviour of the traumatised abandoned orphanage children was "extraordinarily retarded" (p. 25). He described how children faced with a long period of deprivation "offer pictures reminiscent of brain-damaged individuals, of severely retarded or downright imbecile children" (p. 329).

In other words, the trauma of separation and loss in infancy can "take the form of a retardation...dependent on the severity and duration of the trauma" (p. 35). Spitz calls this infantile depression an anaclitic depression. Our understanding of the traumatic consequences of separation has been underlined by the pioneering research of Bowlby (1979).

Where we come to organic learning disability 300,000 severely learning disabled children and adults live in the UK on average. (Ricks, 1990, p. 518) and over 1 million children and adults have a mild learning disability of which the majority live in deprived circumstances (Rutter). Many have co-existing physical disabilities and, not surprisingly given the burden they carry, there is an increase in emotional disturbance in proportion to the severity of the handicap.

However, it is never too late to internalise a good parental imago. Psychotherapy itself provides an attachment relationship in which a nurturing person is eventually incorporated. As a result of psychotherapy people with learning disabilities can attain their potential and work through the negative constructions they are burdened with. Those who were gifted with loving attachment figures and whose birth was welcomed can move even further in treatment.

Psychoanalytic Treatment and Social Interfaces

Working psychoanalytically with people who have experienced trauma and who do not have adequate access to justice requires taking on empowerment issues. Patients might need letters read to them or indeed written for them. For example, a gay learning disabled man wanted to go on holiday with another young man from his residence. Staff either failed to understand or did not want to understand. Eventually, a letter he dictated achieved his aim.

Where a client does not have access to justice the advocate/therapist needs to help this access. Writing books without words on going to court and disclosing abuse is part of this (Hollins & Sinason, 1994).

Psychoanalytic work with mildly, severely and profoundly learning disabled patients leads to reduction in mental pain and therefore lessens secondary handicap. Secondary handicap (Sinason 1994) is the defensive way a patient might exaggerate a primary disability in order to hide the pain of the real hurt. For example, speech problems, physical mobility problems, language structure, expressions, clothes and demeanour might all be used and transformed into a mask to cover the core self. Reduction in secondary handicap allows working through the pain of the unchosen learning disability, a chance to express anger at the unfairness of genetic lottery and a chance to appreciate attachment, love and good aspects of life. With long-term treatment (Bichard, Sinason & Usiskin 1996) patients with mild, severe and profound learning disability improve in internal and external functioning as measured against a control group.

Conclusion from the Voices of the Subjects

Psychoanalysis may seem like an unlikely ally of the advocacy and empowerment movements, but its whole aim is to free the individual to his or her fullest potential through the attachment relationship and the transference. It is never too late to internalise a good parental imago. As a result of psychotherapy people with learning disabilities can attain their potential and work through the emotional meaning of their predicaments.

Here is a young woman with Down syndrome. She came to therapy smiling all the time and saying "Happy. I'm happy". Her family said they were lucky she had Down syndrome "as Down's people are so friendly". However, after several months in treatment she was able to drop her "false self" appeasing smile and show her real feelings. "My sister is a lawyer and she has got married. They have a lovely house. I wish I lived there. They don't want me there. They want each other. I understand that. My parents get older but I have to stay with them. Why did I get Down's syndrome?" Painful as such expressions are and painful as the feelings they evoke they also represent a willingness to grapple with emotional honesty and unfairness of life. Six months after this she was able to join a youth club for the first time and enjoy new relationships. She had accepted her disability.

Another young woman after several years of group therapy came to her session crying but resolute and made this comment.

> Boys on my estate hurt me. They threw stones at me and shouted "Spastic! Spastic!" I said to them "You are right. I am a spastic and you are lucky boys because you are not. But you are rude boys and I am not rude". She did not defend herself with a pseudo-political correctness of saying "I am not a spastic. I am a person with a mild learning disability".

She knew that whatever they called her represented "the other", the disowned unwanted aspects of the deprived boys that were externalised and projected onto her. She knew her difference frightened them. However, their behaviour was rude. She had worked through the meaning of her disability and was not imprisoned by it.

A man of 28 comments "Before I had therapy I did not think I had a brain. I thought my voice was funny so I did not speak. Now I can talk to people. I have a learning disability so I can't read. But I still have a brain and now I know it".

A boy of 12 comments: "Brain not work. Other people bodies not work. Other people mad. Other people in war. People on TV starving. My brain. It's OK."

References

Bichard, S., Sinason, V. & Usiskin, J. (1996) *Measuring Change in mentally Retarded Clients in Long Term Psychoanalytic Psychotherapy*, The National Association for Dual Diagnosis, USA.

Bowlby, J. (1979) 'On knowing what you are supposed not to know and feeling what you are not supposed to feel'. *Canadian Journal of Psychiatry*, 24, pp. 403-408.

Buchanan, A. & Oliver, J.E. (1979) 'Abuse and neglect as a cause of mental retardation'. *Child Abuse and Neglect*, 3, pp. 467-475.

Bury, M. (1996) 'Defining and Researching Disability: Issues at Stake', in C.Barnes and G. Mercer (eds) *Exploring the Divide: Illness and Disability*, Leeds: Leeds University Press.

Fisman, S. & Wolf, L. (1991) 'The handicapped child: psychological effects of parental, marital and sibling relationships'. *Psychiatric Clinic of North America*, 14 (1) pp. 199-217.

Hollins, S. & Sinason, V. (1994) *Going to Court*. Voice UK Ltd for St George's Mental Health Library.

Hubbard, R. (1997) 'Abortion and Disability: Who Should and Should Not Inhabit The World', in L.Davis (ed) *The Disability Studies Reader*, London: Routledge.

Marks, D. (1999) *Disability Controversial Debates and Psychosocial Perspectives*, London and New York: Routledge.

Morris, J. (1993) *Independent Lives: Community Care and Disabled People*, London, The Macmillan Press.

Office of Health Economics (1973) *Mental Handicap*. OHE Pamphlet 47. White Crescent Press.

OPCS Study of Disabled Children (1989) *Disabled Children: Services, Transport and Education*. Report 6 HMSO.

Ricks, D. (1990) 'Mental handicap'. In H. Wolff et al. (eds) *U.C.H.Textbook of Psychiatry*. London, Duckworth.

Rieser, R. and Mason, M. (1990) *Disability Equality in the Classroom: a human rights issue*. Inner London Education Authority, London.

Rutter, M., Tizard, J. & Whitmore, K. (1970) *Education, Health and Behaviour*. London: Longman.

Shakespeare, T. (1994) 'Cultural Representation of Disabled People: Dustbins for Disavowal', *Disability and Society*, Vol. 9 (3).

Sinason, V. (ed.) (1994) *Treating Survivors of Satanist Abuse*. London; Routledge.

Sinason, V. (1997) 'The learning disabled offender'. In *A Practical Guide to Forensic Psychotherapy*, ed. E. Welldon & C. Van Velsen. London: Jessica Kingsley, pp. 56-62.

Spitz, R.A. (1945) Hospitalism: an inquiry into the genesis of psychiatric conditions in early childhood. pp.1-28. (Reprinted from Psychoanalytic study of the Child Vol.1.) In R. Emde, ed. *Dialogues from Infancy*. New York: International Universities Press, 1983.

Sternlicht, M. and Deutsch, M. (1972) *Personality and Social Behaviour in the Mentally Retarded*. Lexington, Mass: Lexington Books.

Wolfensberger (1987) *The New Genocide of Handicapped and Afflicted People*. Syracuse: Syracuse University Division of Special Education and Rehabilitation