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Secondary Handicap & Learning Disability: A Component Analysis

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Abstract

The term 'secondary handicap' is frequently encountered in services for people with disabilities. The term has its origins in Freud's original description of secondary gain (Freud, 1901), and Winnicott's description of the 'false self' (Winnicott, 1965). Since the late 1980s, however, the term has largely been associated with the psychoanalytic writings of Valerie Sinason at the Tavistock Centre in London. This article examines the evidence base for secondary handicap and concludes that although no empirical evidence exists for the concept as a whole, evidence can be found for individual components that make up the phenomenon. It is concluded that sufficient evidence exists to *infer* the existence of secondary handicap. Therapy provided to people with learning disabilities must not, however, proceed in a formulaic or manualised manner as the stripping of individual defence mechanisms may cause more harm than good unless carefully considered.

Introduction

The term 'secondary handicap' is frequently encountered in services for people with disabilities. Despite its apparent popularity, there is no clear agreement on a precise meaning for the term although most authors use the phrase to refer to an additional or further (psychological or environmental) handicap that follows from an initial (usually organic) impairment.

Such usage is in keeping with the distinction made by the World Health Organisation between impairment, disability and handicap as follows:

- Impairment is a physical or neurological disorder which might be present at birth or occur after birth. It may be temporary or permanent.
- Disability is the impact of this impairment on a person's ability to do things which are basic to everyday living – like walking and speaking or looking after oneself.
- Handicap is the disadvantage caused to the person because of the impairment or disability. This limits how far someone can lead a life which is seen as normal for their age or culture. This is often viewed in a negative way by others, leading to the person seen as handicapped being treated differently, and of less value, than others (WHO, 1980).

Prior to 1992 there was little agreement between authors as to exactly what constituted a 'secondary handicap' (Galton, 2002). Thus, Farley et al. (1986) discussed the characteristics of 28 individuals who had a primary learning disability and a secondary handicap described as a 'character, personality, or behavior disorder'. Livingston and McCabe (1990), described young people with head injury as having a 'secondary handicap of low self-esteem'. Byers-Brown (1987) suggested that a communication disorder was a 'secondary handicap associated with a primary motor or cognitive impairment' (p. 187).

In 1992 Valerie Sinason published the book Mental Handicap and the Human Condition: New Approaches from the Tavistock (Sinason, 1992) and since this time the phrase 'secondary handicap' has largely been associated with her conceptualisation of the term. Strongly influenced by the psychoanalytic tradition, Sinason regarded secondary handicap as concerned with how the primary handicap (or disability) is made worse by defensive exaggerations (secondary handicap).

Sinason proposed that as a person with learning disabilities develops they become aware of their differences from others. It was noted that this awareness could be at an intellectual level, an emotional level, or both. People with learning disability must often face the realisation that they may not achieve mainstream societal goals such as learning to drive, living independently, getting married etc. (Sinason, 1992). Therefore, both reactions from others, and an individual's own awareness of differences can lead to a defensive secondary handicap, as a means of coping. She distinguished between three types of secondary handicap which were thought to complicate and exacerbate the difficulties faced by people with learning disability.

Mild Secondary Handicap

The first type of secondary handicap which Sinason (1992) proposed was termed mild secondary handicap. Individuals who experience mild secondary handicap are reported to compliantly exacerbate their original handicap to keep the outer world happy with them. The defensive exaggeration of difficulty also serves to hide from the self the discrepancy between what one is and what one might have been: 'It can be easier to behave like the village idiot and make everyone laugh than to expose the unbearable tiny discrepancy between normal and not normal on the human continuum' (pp. 20-21).

Sinason (1986) had previously written about the 'ubiquitous handicapped smile' accompanied by the 'outward friendliness' of people with learning disability. This smile was seen as another form of mild secondary handicap that was utilised as a defence against a perceived societal death wish which she claimed people with learning disability often accurately perceived. Sinason (1992) suggests that people with learning disability are well aware of society's wish that they had not been born. In successfully concealing their true potential, individuals have perhaps one of few opportunities to feel superior due to the fact that they deceive others with regard to their capabilities. In this sense, secondary handicap could be considered as a shrewdly utilised strategy that may quietly give people comfort in relation to the intelligence that they, or others, may feel they typically lack.

Opportunist Secondary Handicap

Sinason (1992) considered opportunist handicap to be a more serious kind of secondary handicap that took the form of 'severe personality mal-development'. This type of secondary handicap could again be an exaggeration of the primary handicap, but in this instance the individual seeks to defend against 'dangerous impulses, such as sexual or violent feelings' (Stokes & Sinason, 1992). In addition to the difficulties an individual faces due to their primary disabilities, they may feel intense anger in relation to their life experience. This anger is linked to the primary handicap, but is a separate internal experience which, according to

Sinason (1992) if not dealt with, could 'find a home in an opportunist handicap'. It is the expression of these feelings through violence or angry outbursts which Sinason seems to deem as being most problematic. While mild secondary handicap traditionally appears to deal with an individual concealing their abilities in order to obtain a sense of control, opportunist handicap is a struggle to gain control through the extreme expression of a wide variety of emotional experiences. Such efforts to gain control lead to behaviours that others may label as 'challenging' or 'maladaptive'. Inherent in this description is the irony that behaviours can be termed 'maladaptive' due to the fact that they are not accepted or deemed the 'norm' in society, despite the fact that they may be highly adaptive for the individuals who utilise them to defend themselves or in an effort to communicate.

Secondary Handicap as a Defence Against Trauma

The third type of secondary handicap that Sinason (1992) outlines is that which is a defence against a person's traumatic life experiences. People with learning disabilities are reported to seek protection against the memories of the traumas they have faced. These traumatic memories within this population can be in relation to the trauma of the original organic handicap, or due to trauma resulting from sexual or physical abuse. It should be noted in this regard that over the past two decades, Sinason has been particularly instrumental in raising awareness of the vulnerability of people with learning disabilities to abuse (Galton, 2002).

The psychoanalytic interpretation of secondary handicap as described by Sinason is not new and owes much to Freud's original description of secondary gain (Freud, 1901), Winnicott's description of the 'false self' (Winnicott, 1965), and Symington's (1981) suggestion that a learning disabled person might exaggerate his or her disability as a defense against the pain of the original handicap.

Nonetheless, with the publication of Mental Handicap and the Human Condition (Sinason, 1992), Sinason presented the most detailed and clearly articulated account of the phenomenon and this source has clearly been the most influential in terms of theoretical analysis and service provision (Galton, 2002).

The type of therapy that Sinason proposes, is firmly nested within the psychoanalytic psychotherapeutic tradition. It is summarised by Galton (2002 pp. 586-587) as follows:

> 'The therapist must acknowledge to the patient that there is a better functioning self underneath his or her twisted movements and guttural sounds. The therapist needs to acknowledge the angry, hurt, and painful feelings that lie behind the handicapped smile. There follows an opportunity to treat the more pathological kind of secondary handicap represented by the disturbed, envious, and destructive aspects of the personality. The therapist becomes an auxiliary brain, helping thinking and filling in missing words or sentences, being careful not to continue this when the patient is capable of managing without it (Hollins, Sinason & Thompson, 1994). This is likely to be a period of crying, rage, grief, and depression as the patient mourns their lost healthy self, their limitations, their dependency and their terrible feeling of

> aloneness (Sinason, 1995). The trauma can be remembered, acknowledged and healed, in a safe setting with the therapist as protector' (Sinason, 1986).

The Search for Evidence

In keeping with much psycho-analytic writing, Sinason's account of secondary handicap is presented in descriptive narrative form. While this undoubtedly finds a receptive ear with a psychoanalytically orientated audience, the wider professional community requires more than a descriptive anecdotal account of concepts, however intuitively appealing or articulately presented.

The present authors, therefore, attempted to find evidence to support the construct of secondary handicap in the wider literature on learning disability.

Method

The following terms were input into three search engines, Web of Knowledge, PsycINFO and CINAHL, which scoured a multitude of databases for the words in question:

- Secondary handicap and learning disability
- Secondary handicap and mental retardation
- Secondary handicap and mental handicap
- Secondary handicap and intellectual disability

Despite such extensive searches, there did not appear to be any large-scale quantitative evidence in support of the existence of secondary handicap in learning disabilities. Rather the relevant literature consisted of a number of theoretical articles expanding on the description of the phenomena, often accompanied by anecdotal accounts and case details from authors engaged in psychoanalytic therapy with people with learning disabilities (e.g. Banks, 2006; Beail, 2003; Gaedt, 1995; 2001, Frankish, 1992; Galton, 2002; Sinason, 1986;1992). Once again however, although compellingly written, such accounts contained the views of the authors on the existence of the phenomenon, rather than any form of verifiable independent evidence pertaining to the existence of secondary handicap.

Component Analysis

It could be argued that it is impossible to find empirical evidence for a concept that is reputed to be located in the unconscious mind of people with learning disability, and that therefore our quest for independent evidence was foolhardy. There is some merit in this suggestion. However, another possible avenue of investigation would be to search for evidence surrounding the *components* of a phenomenon. We reasoned as follows: Even if it would not be possible to find evidence for secondary handicap *per se*, assumptions about the existence of the phenomenon require the presence of a number of sub-components and evidence might be available to support the existence of these components. We therefore carefully examined the literature cited above and found that claims for the existence of secondary handicap were dependent on the presence of the following components:

- A denial of difficulty and a rejection of the label of learning disability while at the same time:

- A feeling of being excluded
- A mourning the 'normal' self that was lost
- A perception of being bullied, excluded and being treated like a child
- A sense of low self efficacy
- A minimising of existing skill when confronted with someone who is perceived to be brighter

To some extent evidence for all of these sub-components can be found in the literature.

In terms of objective data, there is clear evidence that people with learning disabilities experience disadvantage, exclusion and marginalisation. For example, existing data suggest that both children and adults with a learning disability are at an increased risk of being bullied (Norwich & Kelly, 2004; O'Moore & Hillery, 1989; Thompson, Whitney and Smith, 1994). Bullying towards individuals with learning disability may also persist over long periods of time (Sheard, Clegg, Standen & Cromby, 2001). These findings in relation to bullying are consistent with research in other areas of victimisation of people with learning disabilities, such as physical and sexual abuse (Petersilia, 2001; Sobsey, Randall & Parrila, 1997; White, Holland, Marsland & Oakes, 2003), and also data on exposure to life events including physical attacks by others (Owen et al., 2004).

In terms of more general life experiences, these too are more negative in comparison to the general population. People with learning disabilities have fewer employment opportunities (Department of Health, 2001), have less satisfying social relationships (Chappell, 1994), fewer opportunities for leisure (Wertheimer, 1983) and are less likely to get married (Koller Richardson & Katz, 1988). It is also clear that people with learning disabilities are themselves acutely aware of their disadvantaged status compared with the non-disabled population.

For example, Davies and Jenkins (1997), in interviewing people with learning disabilities, discovered that participants were intensely aware of the differences between them and their non-learning disabled siblings. And yet denial of the existence of learning disability is also common and was reported by Szivos and Griffiths (1990) as being a primary obstacle to the development of a positive group identity in group therapeutic work. Members of this group recalled the insensitive and abrupt way in which the news of their disability was conveyed to them and the resultant shock, anger, and distress they felt (Szivos & Griffiths, 1990).

Similarly, Manners and Carruthers (2006) presented a case example of the difficulties experienced by a person with learning disabilities. This was co-written by the individual with learning disabilities. An experience of mourning the loss of a 'normal life' was reported and the individual related her feeling of being different to others as she felt it was difficult for her to achieve 'normal things'. Furthermore, she reported negative treatment from others, both those working in services and individuals within the community. Examples of such treatment included being treated like a child, being 'picked on', and being unfairly criticised (Manners & Carruthers, 2006).

In terms of self-efficacy, there is an extensive literature extending back over three decades, showing that people with learning disabilities have low expectations of personal success (e.g. Zigler & Hoddap, 1986). Many studies attest to the fact

that perceived beliefs regarding abilities are more influential than actual abilities (e.g. Bergeron & Floyd, 2006; Nota et al., 2007).

Perhaps one of the clearest examples of a deliberate minimisation of existing skill is shown in an experiment described by Miller et al. (1991). In this experiment, children with learning disabilities engaged in a telephone conversation with peers. In one condition they were told that the person on the other end of the telephone attended a regular education class. In the other condition they were told that the person on the other end attended a special education class. Consistent with the descriptions of secondary handicap outlined by Sinason (1992), the children performed more poorly and displayed more stigmatising behaviours when they believed they were talking to a peer in regular education. Non-learning disabled students did not show this tendency under similar conditions.

Clearly, finding evidence for the components of a phenomenon does not necessarily constitute empirical support for the existence of that phenomenon. On the other hand a failure to find support for individual components would pose a major threat to the theoretical basis of secondary handicap as a construct.

It appears that there is sufficient evidence to support many of the assumptions that underlie Sinason's (1986; 1992) conceptualisation of secondary handicap. Individuals with learning disability do appear to be aware of the exclusion, marginalisation and disadvantages that they face when compared to their non-disabled peers. Awareness of the negative connotations of the learning disability status, denial of the label, and a perceived sense of mourning for the self that might have been can also be found. Evidence also exists to support both the assumption of lowered self efficacy and for a deliberate minimisation of existing skills when interacting with non-disabled peers.

Therapeutic Implications

A significant literature already exists relating to the application of psychotherapeutic interventions for people with learning disabilities with many accounts of the perceived benefits of such therapy (e.g. Banks, 2006; Frankish, 1992; Gaedt, 1995; Sinason, 1992; Stokes, & Sinason, 1992). As such therapeutic interventions become more widespread, however, there is a need to be cautious about the application of some of the ideas in a generalised or standardised manner.

The concept of secondary handicap implies a defence against unbearable suffering and a deliberate blocking or skewing of objective aspects of the world. Very skilled assessment is required to determine if it is in a person's best interests to strip them of their psychological defences. A key question involves replacement: if a therapist removes a defence, what is there to put in place to replace it?

It may be that the protective strategies utilised by a person are removed through interventions led by the therapist's idea of what *they* believe is the 'best' type of existence and outcome for their client. This may in fact be akin to stripping a person of their armour without addressing the war in which they are fighting.

Fundamentally, professionals must proceed with caution and think carefully before acting on their judgements of what would be an appropriate way of being for their client. Instead, professionals should listen to and observe the desires

and needs of each individual and support them through the process of *their* therapy. What a therapist perceives as a maladaptive strategy cannot be deemed such if the individual who utilises it feels that they benefit from its adoption, if they do not wish to change it, and if it does not lead to harm.

In therapies across all populations, therapists hope that the interventions they utilise will alleviate psychological distress. Therapeutic work with people with learning disabilities is at times complicated by the fact that therapy seeks to promote resilience in an individual, to facilitate their ability to be themselves, to recognise that self as different, but of equal worth to others while they exist in an environment which is largely beyond the control of both client and therapist and which frequently contests the very concepts proposed within therapy. It is understandable that individuals may feel the need to protect themselves in such an environment. If secondary handicap is thought to be a defensive strategy adopted by some, then its removal should be a slow, tentative and very carefully considered step and not something that should ever be considered in a manualised or formulaic manner.

References

Banks, R. 2006. Psychotherapeutic Interventions for People with Learning Disabilities. Psychiatry, 5: 363-367.

Beail, N. 2003. What Works for People with Mental Retardation? Critical Commentary on Cognitive-Behavioral and Psychodynamic Psychotherapy Research. Mental Retardation, 41: 468–472.

Bergeron, R. & Floyd, R. G. 2006. Broad Cognitive Abilities of Children with Mental Retardation: An Analysis of Group and Individual Profiles. American Journal on Mental Retardation, 111: 417-43.

Byers-Brown, B. 1987. Services for Speech and Communication Disorders. In H. M. Wallace, R. F. Biehl, A. C. Oglesby, & L. T. Taft. Handicapped children and youth: A comprehensive community and clinical approach.. New York, NY, US: Human Sciences Press 187-194.

Chappell, A. L. 1994. A Question of Friendship: Community Care and the Relationships of People with Learning Difficulties. Disability and Society 11: 419-433.

Davies, C. & Jenkins, R. 1997. She Has Different Fits to Me: How people with Learning Disabilities See Themselves. Disability and Society, 12: 95-109.

Department of Health 2001. Valuing People. A New Strategy for Learning Disability for the 21st Century. Department of Health: London.

Farley, R C.; Means, R L.; Akridge, R L. & Rice, B. D. 1986. Psychoeducational Training with High-Risk Rehabilitation Clients in a Field Office Setting: A pilot study. Journal of Applied Rehabilitation Counseling. 17: 25-28.

Frankish, P. 1992. A Psychodynamic Approach to Emotional Difficulties Within a Social Framework. Journal of Intellectual Disability Research, 36: 559-563.

Freud, S. 1901. The Psychopathology of Everyday Life, in the Standard Edition of the Complete Psychological Works of Sigmund Freud. Vol. VI, London: Hogarth Press, 1960.

Gaedt, C. 1995. Psychotherapeutic Approaches in the Treatment of Mental Illness and Behavioural Disorders in Mentally Retarded People: The Significance of a Psychoanalytic Perspective. Journal of Intellectual Disabilities Research, 30: 233-239.

Gaedt, C. 2001. Psychodynamically Oriented Psychotherapy in Mentally Retarded Children. In: Dosen A. and Day K. Eds. Treating Mental Illness and Behaviour Disorders in children and Adults with Mental Retardation. American Psychiatric Press, 401-4.

Galton, G. 2002. New Horizons in Disability Psychotherapy: The Contributions of Valerie Sinason. Free Association 9: 582-610.

Hollins, S., Sinason, V. & Thompson, S. 1994. 'Individual, Group and Family Psychotherapy', in N. Bouras (ed.) Mental Health in Mental Retardation: Recent Advances and Practices. Cambridge: Cambridge University Press 233-243.

Koller, H., Richardson, S. A. & Katz, M. 1988. Marriage in a Young Mental Retardation Population. Journal of Mental Deficiency Research 32: 93-102.

Livingston, M.G., & McCabe, R. J. 1990. Psychosocial Consequences of Head Injury in Children and Adolescents: Implications for Rehabilitation. Pediatrician 17: 255-261.

Manners, P. J. & Carruthers, E. 2006. Living with Learning Difficulties: Emma's Story. British Journal of Learning Disabilities 34: 206-210.

Miller, C. T., Clark, R. T., Malcarne, V. L., Lobato, D., Fitzgerald, M. & Brand, P. 1991. Expectations and Social Interactions of Children With and Without Mental retardation. The Journal of Special Education, 24: 454-472.

Norwich, B. & Kelly, N. 2004. Pupils' Views on Inclusion: Moderate Learning Difficulties and Bullying in Mainstream and Special Schools. British Educational Research Journal 30: 43 – 65.

Nota, L., Ferrari, L., Soresi, S. & Wehmeyer, M. 2007. Self-Determination, Social Abilities and the Quality of Life of People with Intellectual Disability. Journal of Intellectual Disability Research 51: 850-865.

O'Moore, A. Mona., & Hillery, B. 1989. Bullying in Dublin Schools. Irish Journal of Psychology 10: 426-441.

Owen, D. M., Hastings, R. P.; Noone, S. J., Chinn, J., Harman, K., Roberts, J. & Taylor, K. 2004. Life Events as Correlates of Problem Behaviour and Mental Health in a Residential Population of Adults with Developmental Disabilities. Research in Developmental Disabilities 25: 309-320.

Petersilia, J. R. 2001. Crime Victims with Developmental Disabilities: A Review Essay. Criminal Justice and Behaviour 28: 655-694.

Sheard, C., Clegg, J., Standen, P. & Cromby, J. 2001. Bullying and People with Severe Intellectual Disability. Journal of Intellectual Disability Research 45: 407-415.

Sinason, V. 1986. Secondary mental handicap and its relationship to trauma. Psychoanalytic Psychotherapy 2: 131-154.

Sinason, V. 1995. 'Individual Psychoanalytical Psychotherapy with Severely and Profoundly Handicapped Patients', in J. Ellwood (ed.) Psychosis: Understanding and Treatment, London: Jessica Kingsley Publishers 53-161.

Sinason, V. 1992. Mental Handicap and the Human Condition: New Approaches from the Tavistock. London: Free Association Books.

Sobsey, D. Randall, W. & Parrila, R. K. 1997. Gender Differences in Abused Children With and Without Disabilities. Child Abuse and Neglect 21: 707-720.

Stokes, J. & Sinason, V. 1992. Secondary Mental Handicap as a Defence. In A. Waitman & S. Conboy-Hill (eds). Psychotherapy and Mental Handicap. London: Sage 46-58.

Szivos, S. & Griffiths, E. 1990. Group Processes Involved in Coming to Terms with a Mentally Retarded Identity. Mental Retardation 28: 333-341.

Symington, N. 1981. The Psychotherapy of a Subnormal Patient, British Journal of Medical Psychology 54: 187-199.

Thompson, D, Whitney, I., & Smith, P. K. 1994. Bullying of Children with Special Needs in Mainstream Schools. Support for Learning 9: 103-10.

Wertheimer, A. (1983). Leisure. London: Values into Action.

White, C., Holland, E., Marsland, D., & Oakes, P. 2003. The Identification of Environments and Cultures that Promote the Abuse of People with Intellectual Disabilities: A review of the literature. Journal of Applied Research in Intellectual Disabilities16: 1-9.

Winnicott, D. W. 1965. The Maturational Processes and the Facilitating Environment: Studies in the Theory of Emotional Development, London: Hogarth Press and The Institute of Psycho-Analysis, 1965 140-152.

World Health Organisation 1980. International Classification of Impairments, Disabilities and Handicaps: A Manual of Classification Relating to the Consequences of Disease Geneva.

Zigler, E. & Hoddap, R. M. 1986. Understanding Mental Retardation. Cambridge: Cambridge University Press.