A Counselling Framework for Understanding Individual Experiences of Socially Constructed Disability

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Abstract

This paper provides a framework for rehabilitation counsellors to respond to persons with disabilities who may seek their assistance to manage the conflicts that characterise their social encounters. This framework covered issues concerning: rehabilitation program philosophy; the socially located definitions of impairment and disability; the reconciliation of paradoxical elements that exist in counselling relationships; understanding individuals' interpretations of their experiences of living with disability; Wendell's (1996) standpoint epistemology (contrasted with the social model of disability) and her questioning of commonly accepted agency/control issues. This framework is advocated by a professional rehabilitation counsellor/psychologist who acknowledges the influence of both traditional and post-modern counselling perspectives; and who favours the co-participation of persons with disabilities in the planning and implementation of rehabilitation programs.

Persons with disabilities are often required to negotiate and resolve tensions between self and socially constructed identities in everyday life. These tensions are likely to be generated via competing individual, social and biomedical perceptions of impairment, disability or handicap (Zola, 1982a,b). In turn, rehabilitation counsellors need to be attuned to how individual clients perceive: their impairments and the extent to which their constructions of disability are confirmed or validated by others; their sense of human agency or mastery in relation to perceived social structural constraints; and their perceptions of social activities and social support networks, which may include counsellors themselves.

The purpose of this paper is to provide a framework that optimises the opportunities for rehabilitation counsellors to respond to persons with disabilities who may seek their
assistance to manage the conflicts that characterise their social encounters. This paper reflects the author's experience as a rehabilitation counsellor and psychologist and covers issues concerning: opposing rehabilitation program philosophies that are encountered by persons with disabilities; the socially located definitions of impairment and disability; the reconciliation of paradoxical elements in counselling; understanding individuals' interpretations of their experiences of living with disability; Wendell's (1996) standpoint epistemology that is contrasted with the social model of disability (Oliver, 1996); Wendell's (1996) re-evaluation of commonly held assumptions regarding agency/control; and opposing rehabilitation program philosophies.

Recent rehabilitation practice has been characterised by opposing models of service delivery and explanations of psychosocial reactions to disability. Persons with impairments or illnesses have encountered, and have had to negotiate with, proponents of different models. Different types of health professionals include, for example, proponents of the medical model whose views of problems of living with disability were individualised and explained as pathology and those who acknowledged that living with impairment and illness involved social judgements that were related to socially constructed standards of health and disability (Annandale, 1998).

The author works within a tertiary rehabilitation agency whose philosophy embraces resource enhancement rather than resource compensation (Greenwood, 1985). This agency is primarily vocational rather than welfare focused with the charter of assisting persons with disabilities to prepare for and obtain open employment and be less dependent upon welfare assistance. Rehabilitation clients are arguably identified as part of a temporary social problem (e.g., being unemployed, welfare dependent) with the expectation that they, rather than the existing social structures, change (Jamrozik & Nocella, 1998). By virtue of their unemployment they may be regarded as "societally devalued people" who by the "use of culturally normative means" (e.g., legislation) are offered the opportunity to strive for "life conditions at least as good as that of the average citizen" (Wolfensberger, 1980, p. 8).

They represent a wide range of social, demographic and medical categories and have experienced a broad range of social experiences that influence the construction or reconstruction of self and social identity. Rehabilitation counsellors should therefore conceptualise disability via the exploration of the meanings behind the language used by persons with disabilities instead of accepting common understandings or generalisations of disability. Disability is "discursively created" (Annandale, 1998, p. 46) and rehabilitation professionals need to appreciate the interpretations that persons with disabilities make concerning the experiences that they share with others (Charmaz, 1990; Kenny, 1998; Wendell, 1996).
Defining impairment and disability

Rehabilitation service providers and policy makers have historically tended to adopt medical definitions when defining disability (Greenwood, 1985; Imrie, 1997). The World Health Organisation's conceptual distinctions between impairment (organic), disability (restriction in performing an activity considered normal for a human being), and handicap (the social consequences of deficient ability) have not usually been adopted in everyday practice. In particular, the terms "disability" and "handicap" have tended "to create the mistaken impression that disability is purely biological and handicap is social, when in fact both are products of biological and social factors" (Wendell, 1996, p. 23). In recent analyses all three terms, impairment, disability and handicap, have been regarded as factors in the social construction of disability (Annandale, 1998; Imrie, 1997; Marks, 1997; Wendell, 1996).

Ontological and epistemological issues impact upon the socially located definitions of disability. Disability is a complex of socially constructed meanings which involve the perceptions of reality held by individual clients with impairments, the counsellor whose values may shape the counselling process, and by others who are regarded by the client as significant or influential in their lives. For counsellors who embrace traditional counselling methods such as those espoused by Egan (1982), their role is to provide a transitory service that assists the client to (a) appraise and manage social or disability-related demands or problems and (b) move toward constructive behavioural change that (c) he or she has explicitly defined with the counsellor's help. The helper's social influence and client's self-responsibility are not regarded as contradictory terms (Egan, 1982). For other counsellors who have aligned themselves with "post-modern" counselling perspectives (Parry & Doan, 1994; Weingarten, 1998; White, 1991), clients are encouraged: to see themselves in relation to a problem instead of having, or being, a problem; to value multiple points of view; to view self as being defined by a diversity of experiential contexts; and to expand their conceptualisations concerning the link between self and society.

The social construction of disability occurs via a process of interpretation which occurs inter-subjectively and which involves conflict and opposition and which is characterised by dialectical thinking about the interdependence, interpenetration, and unity of opposites (Rowan & Reason, 1981). Three claims are, therefore, made with respect to disability. First, disability cannot be defined and understood without defining and understanding its opposite, that is, being "able". Further, handicap can be better understood in relation to community integration which has been defined as the converse of handicap (Willer, Rosenthal, Kreutzer, Gordon & Rempel, 1993). Second, opposing attributes
of disability and ability can be found within the same individual. Individuals also participate in social exchanges in which contradictory elements co-exist. For example, interpersonal relationships characterised by the continual interplay and exchange of unstable positions of dominance-submission, intimacy-distance (Reason, 1981). Third, living with disability depends on managing satisfactorily the tensions between the self-defined, social and biomedical perceptions of impairment and disability. It is not a question of negating or embracing one particular set of values over another. Instead, opposing values and ideas are best integrated rather than excluded when analysing and understanding disability issues.

This view of disability is underpinned by notions of there being multiple versions of reality, of reality being inter-subjective, and of reality not being akin to a subject-object split (Reason & Rowan, 1981; Rowan, 1981). Thus, it is argued that disability should not be pathologised as an illness or a temporary sick role (contrary to Parsons, 1951), as a personal tragedy, or as any attribute that belongs exclusively to an individual. Nor should disability be viewed as the product solely of factors external to an individual, for example, the operation of the labour market and of social organisations that exclude persons with disabilities (as argued by Oliver, 1996).

Instead, it is more epistemologically correct to adopt a systemic orientation which argues that individuals influence each other and act upon the social systems in which they interact (Rowan & Reason, 1981); and that the meaning of disability derives from shared interactions which is consistent with symbolic interactionist (Charmaz, 1990; Goffman, 1983; Mead, 1971) and "post-modern" narrative therapy perspectives (Parry & Doan, 1994; White, 1991). Individuals can, therefore, be studied in social relationships and be treated as both subject and object. They can be regarded as self and other, that is, as separate persons in dialectical relation to each other. And they can be constructed as an inter-identity that consists of the interlocking, complementary identity of two persons (Reason, 1981).

The reconciliation of paradoxical elements in counselling

It has been argued that social oppression is caused by medical and rehabilitation agencies that identify individual rather than social problems (Imrie, 1997; Jamrozik & Nocella, 1998; Oliver, 1996). An advocate of the social model stated: "Disabled people should not be counselled to cope with disability - this is an oppression practice which needs changing" (Crawshaw, 1994, pp. 3-4). Imrie (1997) was critical of "paternalistic" and "duplicitous" notions of empowerment and of rehabilitation counsellors who conceptualise people with disabilities as "being acted upon, and lacking the capacity to transform their lives without the help of the professional bodies" (p. 266).

These views, however, overlooked the value that some
persons with disabilities have attributed to professional counselling relationships even if these relationships were directed at the effects rather than the causes of social problems (Jamrozik & Nocella, 1998). While these relationships inherently involve the paradox of experts treating them as dependent in the process of achieving independence, it is possible for reciprocal, collaborative and minimally hierarchical relationships to be developed between counsellors and their clients (Tyler, Pargament & Gätz, 1983).

Counsellors, ideally, have strategies in place that optimise their own self-awareness of their beliefs and values that may interfere with their ability to work with particular client issues or cause difficulties in their relationships with clients (Parry & Doan, 1994; Weingarten, 1998; White, 1991; Sanders & Wills, 1999).

Rehabilitation counsellors who see knowledge being derived from everyday concepts and meanings reported by persons with disabilities, may set out to interact with their clients with the aim of understanding their taken-for-granted socially constructed meanings and, in so doing, attempt to minimise the distance or separateness between themselves and their clients. It is not expected that clients' everyday concepts and meanings will simply reflect individual attributes or behaviours. Instead, they are viewed as being embedded in social contexts. The experience of disability, then, is related to other social constructions such as gender, employment status, age, and ethnicity which assists towards achieving analyses of diversity and avoiding false universalisation (Russell, 1999; Wendell, 1996).

It is anticipated that persons with disabilities will differ with respect to their goals and aspirations and that they will not necessarily seek assimilation into mainstream society or embrace dominant cultural norms and values (Oliver, 1996; Wolfensberger, 1980). It is also expected that they may hold different views concerning their experiences of disability. For example, those persons who regard themselves as largely the victims of social oppression and who seek to redefine and reconstruct their social identities (Oliver, 1996) and others who incorporate disability as part of self and social identity and espoused disability pride and self-determination (Gilson, Tusler & Gill, 1997).

These perspectives have polarised debate in the rehabilitation and disability literature rather than highlight multiple or alternative perspectives on disability. This problem reflects the traditional division of impairment and disability in rehabilitation research and practice that has ignored both impairment and disability as factors related to the social construction of disability and that has placed too much emphasis on either individual or social factors (Marks, 1997; Wendell, 1996).

Towards a broader understanding individual experiences of disability

Many rehabilitation counsellors continue to focus upon
how well individuals with disabilities have performed a range of physical and psychosocial activities within the framework of statistical methodologies and biomedical disease models. The unique or personal meaning that individuals ascribe to their psychosocial experiences have been largely ignored. There is still a tendency to under-estimate the validity of the self-reports of persons with particular disabilities, for example, persons with traumatic brain injuries (Crisp, 1993; Nochi, 1997). This problem has been evident in my work as a rehabilitation consultant and psychologist. Psychologists, including myself, in rehabilitation settings have often been aware that "the demands of their practice take them beyond the boundaries of their research base" (Knight & Godfrey, 1996, p. 51). They have recognised the need for the expansion of their clinical or knowledge base to reflect relevant issues for both themselves and their clients (James, 1994; Knight & Godfrey, 1996; McGartland & Polgar, 1994). They have, for example, advocated greater use of direct or qualitative observations that link clinical data to everyday life, that identify behaviours that are socially constructed rather than individualised or pathologised, or that provide a methodological plurality that goes beyond highly specified and standardised test instruments.

James (1994) and McGartland and Polgar (1994) advocated methodological propositions similar to those formulated in interpretivist methodologies (e.g., grounded theory; Charmaz, 1990; Strauss & Corbin, 1990). James argued that different stores of knowledge should complement empirical data. That is, shared beliefs and common practices of professional peers, personal and professional experience should be usefully employed when insufficient empirical data exists. McGartland and Polgar argued that the traditional empirico-mathematical method which "enables the formulation of mechanistic theories which aim to explain causal relationships...under controlled conditions" (p. 21) should be complemented by a culture-understanding or interpretive method whereby the "database is qualitative, revealing the personal meanings and intentions individuals construct in their everyday lives...[and] where the experiences and the development of personal positions of both informants and researchers are traced within the cultural framework" (p. 22).

Moreover, James (1994) and McGartland and Polgar (1994) deplored the lack of critical self-examination, or non-reflexive methodologies, employed by many clinicians. John (1986, 1990, 1992) argued that Australian psychologists have mistakenly adopted "the scientist" as their role model and in doing so they have concealed their personal characteristics and interests that "seems to emanate from a disembodied impersonal authority" (John, 1990, p. 130). They have also failed to engage in dialogue with social actors and have ignored the impact of their own values. They have utilised "inferential statistics [to] serve a rhetorical purpose in providing epistemic authority in psychology" (John, 1992, p. 144). Similar arguments have been made elsewhere by

It is recommended, therefore: that counsellors focus upon the insider's perspective in which persons with disabilities are regarded as contributors in the rehabilitation process; that, as outsiders, they incorporate the views and values of insiders (Wright, 1983; Zimmerman & Warschausky, 1998); and that they focus upon persons in response to their social environments, ensure close personal interaction with respondents, generate descriptions of social action (or change of self and/or social identity) based upon the personal meanings about particular social contexts, match the counsellor's interpretations with the client's personal meanings, and acknowledge the cultural framework in which they interact (McGartland & Polgar, 1994; Russell, 1999). The emphasis is upon looking at the whole person, his or her experiences, and in understanding individual differences in particular social contexts.

The Australian rehabilitation field has been characterised by constantly evolving clinical and industrial protocols that affect the relationship between persons with disabilities and service providers. In particular, recent changes in services for persons with disabilities have been largely influenced by government policies designed to reduce unemployment (see Jamrozik & Nocella, 1998). However, rehabilitation service providers need to optimise their responsiveness to the needs and problems of, for example, persons with disabilities coping with long-term unemployment or with the transition from unemployment to paid employment. Other issues may concern gender, race, ethnicity, changes of socio-economic status, and individuals' evaluations of the usefulness of rehabilitation and other health/welfare services.

These issues can be best analysed by paying attention to how individuals interpret the conditions in which they live and the processes by which they negotiate with each other the meanings for social action and situations (Charmaz, 1990; Goffman, 1983). It follows then that epistemological questions concerning people with disabilities are best defined by the personal meanings reported by persons with disabilities.

Wendell's standpoint epistemology

A standpoint epistemology that is consistent with the feminist perspective of disability advanced by Wendell (1996) is recommended. Wendell argued that a distinctive group consciousness is not held by persons with disabilities, but that there is a diversity of standpoints held by persons with disabilities that collectively can be distinguished from those held by persons without disabilities.

Wendell's (1996) perspective can be contrasted with the social model of disability (Oliver, 1996). The social model of disability, described by Oliver, views people with disabilities as an oppressed social group, and defines
disability as the failure of institutionalised practices of society to remove disabling barriers and social restrictions. Oliver argued that "the social model is not an attempt to deal with the personal restrictions of impairment but the social barriers of disability" (p. 38). Personal experience is regarded as problematic when people with disabilities internalise social oppression and regard themselves, or their impairment, as the problem. Collective action is advocated to fight oppression, to reject the prescriptions of a "normalising" society and the medical model of health and rehabilitation services.

While Wendell (1996) also viewed the environment as the source of problems and solutions and defined disability as socially constructed, she argued that an exclusive focus on the elimination of social barriers ignores the hard physical realities faced by many people with disabilities. She also argued that seeing people with disabilities as one social group ignores or de-emphasises differences based upon race, ethnicity, class, gender, and age and it falsely universalises the social experience of disability. Like Wright (1983), she cited persons with disabilities who do not "identify with all others who have disabilities or share a single perspective on disability (or anything else)" (Wendell, 1996, p. 70). She claimed, however, that living with disability provides social experiences different from that of persons without disabilities. And that she and others with disabilities "have accumulated a significant body of knowledge...and that that knowledge, which has been ignored and repressed in non-disabled culture, should be further developed and articulated" (Wendell, 1996, p. 73). Wendell (1996) also advocated the categorisation of social experiences of persons with disabilities on the proviso that it unmasks differences that apply to a particular context and that it acknowledges "those who do not identify with it or who disagree with generalizations made about members of the category and their experience" (p. 72).

The reciprocal influence between individuals and their social environment has been integral to several person-environment perspectives in the rehabilitation psychology (Wright, 1983; Zimmerman & Warschausky, 1998) and sociology literature (Annandale, 1998; Antonovsky, 1987; Wendell, 1996). Taking a systems (or person-organism-environment interaction) approach is considered more useful than the traditional medical model that over-emphasises psychological, intrapersonal factors and ignores social and environmental factors. Conversely, an over-emphasis upon environmental factors that defined social problems in terms of prejudiced attitudes of individuals or the institutionalised practices of society (Oliver, 1996) may, as argued by Imrie (1997), "identify the 'socialization of disability' as reducible to the material conditions of society" (p. 268) and ignore the reality that impairment per se requires a difference in the way society responds to persons with disabilities. Even if social oppression were eradicated, the physicality of the body
would not be removed (Annandale, 1998; Imrie, 1997; Wendell, 1996). A similar argument applies to persons with cognitive impairments: loss of self or social identity may occur due to, for example, loss of memory as well as labels imposed by others (Crisp, 1993; Nochi, 1997).

Wendell's re-evaluation of agency/control

Wendell (1996) argued that the concepts of "autonomy" and "independence" create problems for people with disabilities that should be avoided since nobody, non-disabled or disabled, is fully autonomous. She preferred to use the term "interdependence" with others, since it is less likely to devalue those persons who can not live without the assistance of others.

Yet, human agency is a guiding value for both counsellors (Egan, 1982) and the community at large (Annandale, 1998). Wendell (1996) attacked the psychologising of illness and disability that promotes the belief "that recovery from illness or disability can be accomplished with the right attitude" which "has the implication that everyone who did not recover had the wrong attitude" (p. 102). Wendell did not dispute the notion that the mind effects the body. Instead, she railed against culturally embedded views that "discount the body as a cause of events" (p. 103) and that results in "the guilt and stigma we inflict on those whose bodies are out of control" (p. 105).

Having the "right attitude" is arguably synonymous with having ability not disability, with human agency and control, and with productive problem-solving coping strategies. In terms of the interaction between individuals and their social systems, it is usually stated or implied that individuals who report higher levels of control also report higher levels of engagement in social systems. Wendell (1996), however, argued that disability is the product of both biological and social factors and that an individual's perception of control, or lack thereof, may be based upon an awareness of biological and environmental restrictions.

An individual's response to his or her experience of biological and/or social restrictions may entail physical and psychological (e.g., emotional) problems. The social model rejected analyses of personal or psychological problems (Oliver, 1996). Other sociological writers (Antonovsky, 1987; Thoits, 1995) addressed the psychosocial problems related to social stressors and sought to normalise the process by describing how individuals can learn to negotiate with others to formulate their own ways of adaptation.

Recent research (de Ridder, Depla, Severens and Malsch, 1997; Folkman, 1997) suggested that beliefs on coping with illness and/or stress elicited both positive and negative meanings (that is, seeing illness/disability as a challenge or as an enemy) and involved a balanced attitude which allowed for active as well as passive coping strategies. That is, there are several ways of coping that enable an individual to preserve autonomy, to accept the fact of illness, to mobilise
social support and control, or to express denial, resignation and dependency. In the study by de Ridder et al., respondents employed many of these coping strategies. They preferred active, approach-like (as opposed to passive, negative) ways of coping with illness and they wanted a health care system that was co-operative and consultative: "patients seem to be willing to accept their illness and...to acknowledge dependence on physicians, on the condition they do not lose autonomy and self-respect" (p. 558).

Conclusion

This paper provided a framework for rehabilitation counselling and therapy programs to respond to persons with disabilities who may seek their assistance to manage the conflicts that characterise their social encounters. This framework covered issues concerning: rehabilitation program philosophy; ontological and epistemological issues that impact upon the socially located definitions of impairment and disability; the reconciliation of paradoxical elements that exist within the relationship between counsellors and persons with disabilities; ways of broadening counsellors' and researchers' understanding of individual experiences, as opposed to biomedical perceptions, of disability.

Based upon my own experience as a rehabilitation counsellor and psychologist in Australia, it is recommended that counsellors adopt a systems approach and place less emphasis upon intrapersonal or clinical analyses than on psychosocial frameworks and encourage the co-participation of persons with disabilities in the planning and implementation of rehabilitation programs. The author favours Wendell's (1996) standpoint epistemology as a way of understanding disability issues.

References


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