

Adjustment to Psychiatric Disability

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The rehabilitation literature speaks eloquently of the stages of adjustment to disability for individuals with physical disability, but discussions in the literature about adjustment to psychiatric disability are virtually non-existent. The parallels in the fields of physical and psychiatric disability, and the newly accepted emphasis on rehabilitation of people with psychiatric disabilities, suggest that the psychology of adjustment to disability needs to be broadened to include an application to the field of psychiatric rehabilitation.

Psychiatric rehabilitation, now recognized as a viable, credible intervention for people with severe and long term psychiatric disabilities, focuses on developing the skills and supports which will enable people with psychiatric disabilities to function in the residential, educational, and vocational environments of their choice (Farkas and Anthony, 1989). The most basic tenet of the psychiatric rehabilitation approach is a shift in perspective from pathology and impairment to functional limitations and disability. This view necessitates a shift in treatment models and attitudes toward the client, a shift which is facilitated by applying the stages of adjustment to disability to the process of rehabilitation and recovery of people with psychiatric disabilities.

While there is no universal consensus concerning the nature of the process of adjustment to severe physical disability, the literature suggests several stages (Livneh, 1986a; Shontz, 1978), which might be called Realization, Retreat, Recognition, and Reintegration. The first stage is Realization, when the person first becomes aware of the psychiatric disability (Hughes, 1980; Livneh, 1980, 1986a; Livneh and Evans, 1984; Russell, 1981). The realization that something "mental" is wrong is rarely a sudden experience. It may be after months, or maybe even years, of treatment, that the person begins to ask if the distress is permanent (Chamberlin, 1978).

A person must come to terms for himself with the notion of personal meaning rather than abstract syndromes or disorders. Rehabilitation practitioners may help, as with physical disability, by providing whatever information is available about the nature of the psychiatric disability. Many practitioners find it

awkward to discuss the psychiatric disability itself or may believe they lack sufficient expertise for such a discussion. Others may think it unkind to focus on such potentially painful information, but avoiding these discussions can delay the entire recovery process.

Realization is closely followed by Retreat, a mobilizing of the defenses which help put the realization at a distance (Hughes, 1980; Livneh, 1980, 1986a; Livneh and Evans, 1984; Russell, 1981). Denying the impairment, an example of a retreat into health (Schontz, 1975), is a refusal to acknowledge that the psychiatric disability may be a part of one's life for an indefinite period of time. Denial can be seen in a refusal to attend programs with people with psychiatric disabilities I'm not like them, they're crazy!"), or a refusal to engage in rehabilitation and treatment because of a belief that the disability is only temporary ("In a few months, I will be fine again"). In an apparently contradictory picture, the retreat into illness (Schontz, 1975), the person wholeheartedly accepts the sick role of "mental patient", often expressing feelings of helplessness and a seemingly unjustifiable need to depend on others. The result is that the person may be seen as unmotivated, malingering, lazy, or unsociable, and, in consequence, may be ignored or dismissed by family members and service providers (Falvo, Allen, and Maki, 1984).

The notions of retreat and defense are familiar ones to psychiatry, where they take on a negative connotation. In rehabilitation, retreat in and of itself is not a bad thing. Some denial, some faith and hope, some admission of limitation and reliance on others can help the person in the process of recovery and rehabilitation (Deegan, 1988a). Acceptance of the sick role may be essential for treatment and rehabilitation to occur (Shontz, 1975; Falvo et al, 1982). For people who belong to Schizophrenics Anonymous, the acceptance of the "patient" role is seen as an important first step in the recovery process.

Depression often is seen as a complication of the psychiatric disability (Becker, 1988), or as a second and separate affliction. It seems justifiable, however, that hopelessness and despair can accompany the losses which are a consequence of any disability. For example, the role of the person in the family, in the workplace and the community may be impaired (Becker, 1988). Educational goals and career plans must be changed or abandoned. The person with a psychiatric disability would sensibly grieve such losses, and needs enormous support to face and grapple with these sorrows.

In the study of grief and loss, it is almost a cliché to state that, not only "over-reaction" but "under-reaction" can signal adjustment problems (Lindemann, 1944). Understanding that denial,

adoption of the sick role, and depression are natural parts of the recovery process forces us to consider that not all symptoms are manifestations of a psychiatric disability, but could be healthy manifestations of the recovery process (McCrory, Connelly, Hanson-Mayer, Landolfi, Barone, Blood, and Gilson, 1980; Strauss, Hafez, Lieberman, & Harding, 1985).

The third stage, Recognition, is the point of identifying oneself as a person with a psychiatric disability. This involves restructuring one's self-concept, and often results in mourning, depression, and grief (Ben-Sira, 1983; DeLoach & Greer, 1981; Frankl, 1984; Kubler-Ross, 1969, 1975; Lilliston, 1985; Livneh, 1980, 1986a; Russell, 1981). It is difficult for people with psychiatric disabilities to separate themselves from their disabilities. The same is true for rehabilitation practitioners- finding the person who has the psychiatric disability may be a challenge. A psychiatric disability may be seen as a moral failing or an evil distortion of a normal self. Overcoming this societal stereotype is difficult for everyone.

When a person recognizes that the disability is real, that bargaining and denial will not bring about any change, the person may become depressed, even though s/he has been making progress. The result is a "rehabilitation crisis" (McCrory, et al, 1980), in which the person acknowledges an actual or perceived loss of control (Lilliston, 1985). For people with psychiatric disabilities, feelings of loss of control are often a realistic appraisal of the stigma of the illness (Mansouri and Dowell, 1989) and the nature of treatment in traditional mental health systems (Chamberlin, 1978). While the period of rehabilitation crisis may appear as regression, it may mean that growth is taking place. Rehabilitation practitioners may need to reexamine their "failures" (McCrory, et al, 1980; Roth, 1970) to identify and address these recovery issues.

It is at the stage of Recognition that professionals are most challenged. Helpers have a tendency to tell a person to look at the bright side of things, following a natural inclination to list a person's assets and "blessings." However well intentioned, this approach disregards the person's deep feelings of true sadness. A companion in grief is often welcome (Livneh, 1986b). For practitioners to offer such companionship, they need to examine their own reactions to loss and sadness, as these reactions will be apparent to the grieving person (Deegan, 1988b; Kubler-Ross, 1969).

Offered in combination with genuine understanding and acceptance of a person's misery, hopeful stories and uplifting phrases can do much to facilitate developing a balanced perspective (Cohen, Nemec, Farkas, & Forbess, 1989; Mayer & Andrews, 1981). Some people with psychiatric disabilities have succeeded against all odds, and their stories are now available (Hatfield, 1989; Unzicker, 1989). However, stories about successes must be told with care, as they can create a sense of failure in people with less than heroic achievements (Zola, 1982).

The point of Recognition may also prompt anger - as justifiable as sadness, considering the many injustices experienced by a person with a psychiatric disability. The anger may surface in a non-productive hostility towards caregivers or other available targets. In the person with a psychiatric disability, rational anger may misinterpreted as homicidal rage-thanks, in part to

our constant bombardment by media images of the mentally ill murderer. Concerted efforts to explore and understand the basis for the anger may become the foundation for a trusting counseling relationship. Some anger might be channelled effectively into advocacy efforts, making use of self help and advocacy groups for those with psychiatric disabilities (Chamberlin, 1984; Chamberlin, Rogers, and Sneed, 1989; Unzicker, 1989).

The fourth and final stage in the recovery process is Reintegration, the point of true acceptance (Livneh, 1986a), which follows successful coping with the stresses and demands of the disability (Ben-Sira, 1983). It differs from both Realization and Recognition in that the person experiences a major value change, an enlightening discovery of who one can be and what one can do. The psychiatric disability is seen now in terms of being inconvenient and/or challenging, but not discrediting or overwhelming (Ben-Sira, 1983; Deegan, 1988b; Mayer & Andrews, 1981; Russell, 1981). For some, Reintegration brings a delight in oneself, an appreciation for the benefits of a disability. A person with schizophrenia may describe an experience of moments which are "special," when colors appear brighter, when one's attention is drawn to shadows, textures in a bold, rich way (McGrath, 1984). A person with manic depressive illness may come to count on manic periods to accomplish things, such as periodic housecleaning. The rehabilitation practitioner may need to help a client negotiate treatments and services to balance the advantages and disadvantages of the disability, making choices which best serve the individual's unique needs and interests.

In order to assist the client on the path of recovery, a helper reflects and clarifies the client's feelings (Lilliston, 1985; Livneh, 1986b). Practitioners may hesitate to respond to the feelings of the person with a psychiatric disability for fear of agreeing with "delusions." No matter how unrealistic or unreasonable the counselor may think the client's statements, there is no denying the validity of his or her feelings. It is the feelings which the counselor must recognize and understand. By truly understanding the client's point of view, the counselor will be able to develop meaningful rehabilitation plans and interventions. By grasping the client's perspective, the practitioner can begin to identify the client's unique functional deficits which are a consequence of the psychiatric impairment. Such a personal view of disability permits the client and practitioner to design an equally personal approach to rehabilitation.

Recovery is an ongoing journey, the stages of the trip are simply markers. Each recovery journey is unique (Russell, 1981), a journey which belongs to the person in recovery, not the helper. For many, the recovery process presents continuing challenges; and exacerbations and remissions prompt memories, fears, and a recycling of earlier stages of recovery. Helpers who wish to accompany a recovering person on this road may find such markers offer new hopes and comfort, a sense of familiarity with the territory. Such familiarity can make the counselor a better companion or navigator, and a more effective support at the most difficult times.

References

- Anthony, W. A. (1982). Explaining "psychiatric rehabilitation" by an analogy to "physical rehabilitation." *Psychosocial Rehabilitation Journal*, 5(1), 61-65.
- Becker, R. E. (1988). Depression in schizophrenia. *Hospital and Community Psychiatry*, 39(12), 1269-1275.
- Ben-Sira, Z. (1983). Loss, stress and readjustment: the structure of coping with bereavement and disability. *Social Science and Medicine*, 17(21), 1619-1632.
- Chamberlin, J. (1978). *On Our Own: Patient-controlled alternatives to the mental health system*. New York: McGraw Hill Book Company.
- Chamberlin, J. (1984). Speaking for ourselves: An overview of the ex-psychiatric inmates' movement. *Psycho-social Rehabilitation Journal*, 8(2), 56-63.
- Chamberlin, J., Rogers, J. A., & Sneed, C. S. (1989). Consumers, Families and Community Support Systems. *Psychosocial Rehabilitation Journal*, 12(3), 91-106.
- Cohen, M., Nemeck, P., Farkas, M., & Forbess, R. (1989). *Psychiatric Rehabilitation Training Technology: Case management*. Boston, MA: Center for Psychiatric Rehabilitation.
- Deegan, P. E. (1988a) Recovery: The lived experience of rehabilitation. *Psychosocial Rehabilitation Journal*, 9(4), 11-19.
- Deegan, P. E. (1988b) *Recovery, Rehabilitation, and the Conspiracy of Hope: A Keynote Address*. Paper presented at the third annual statewide conference of the Massachusetts Department of Mental Health, the Massachusetts Rehabilitation Commission and the Friends of the Psychiatrically Disabled, North Andover, MA.
- DeLoach, C. & Greer, B.G. (1981). *Adjustment to Severe Disability: A Metamorphosis*. New York: McGraw-Hill Book Company.
- Falvo, D.R., Allen, H. & Maki, D.R. (1982). Psychosocial aspects of invisible disability. *Rehabilitation Literature*, 43(1-2), 2-6.
- Farkas, M. & Anthony, W. A. (1989). An overview of psychiatric rehabilitation: The approach and its programs. In Farkas, M. and Anthony, W. A. *Psychiatric Rehabilitation: Putting Concepts into Practice*. Baltimore: Johns Hopkins University Press.
- Frankl, V. (1984) *Man's Search for Meaning*. New York: Washington Square Press.
- Hatfield, A. (1989) Patients' accounts of stress and coping in schizophrenia. *Hospital and Community Psychiatry*, 40(11), 1141-1144.
- Hughes, F. (1980). Reaction to loss: Coping with disability and death. *Rehabilitation Counseling Bulletin*, 23, 251-257.
- Kubler-Ross, E. (1975). *Death: The Final Stage of Growth*. New York: Simon and Schuster.
- Lilliston, B. A. (1985). Psychosocial responses to traumatic physical disability. *Social Work in Health Care*, 10(4), 1-13.
- Lindemann, E. (1944). Symptomatology and management of acute grief. *American Journal of Psychiatry*, 101(2), 141-148.
- Livneh, H. (1980). The process of adjustment to disability: Feelings, behaviors, and counseling strategies. *Psychosocial Rehabilitation Journal*, 4(2), 25-35.
- Livneh, H. (1986a). A unified approach to existing models of adaptation to disability: Part I - A model adaptation. *Journal of Applied Rehabilitation Counseling*, 17(1), 5-16.
- Livneh, H. (1986b). A unified approach to existing models of adaptation to disability: Part II - Intervention strategies. *Journal of Applied Rehabilitation Counseling*, 17(2), 6-10.
- Livneh, H. & Evans, J. (1984). Adjusting to disability: Behavioral correlates and intervention strategies. *Personnel and Guidance Journal*, 13(1), 363-365.
- Mansouri, L. & Dowell, D.A. (1989). Perceptions of stigma among the long-term mentally ill. *Psychosocial Rehabilitation Journal*, 13(1), 79-91.
- Mayer, T. & Andrews, H.B. (1981). Changes in self concept following a spinal cord injury. *Journal of Applied Rehabilitation Counseling*, 12(3), 135-137.
- McCrorry, D. J., Connelly, P. S., Hanson-Mayer, J. P., Landolfi, J. M. S., Barone, F. C., Blood, A. H., & Gilson, A. B. (1980). The rehabilitation crisis: The impact of growth. *Journal of Applied Rehabilitation Counseling*, 11, 136-139.
- McGrath, M. (1984). First person account. *Schizophrenia Bulletin*, 10(4), 638-640.
- Roth, S. (1970). The seemingly ubiquitous depression following acute schizophrenic episodes, a neglected area of clinical discussion. *American Journal of Psychiatry*, 127(1), 91-97.
- Russell, R. A. (1981). Concepts of adjustment to disability: An overview. *Rehabilitation Literature*, 42(11-12), 330-338.
- Shontz, F. (1975). *The psychological aspects of illness*. New York: Macmillan.
- Shontz, F. (1978). Psychological adjustment to physical disability: trends in theories. *Archives of Physical Medicine and Rehabilitation*, 59, 251-254.
- Strauss, J. S., Hafez, H., Lieberman, P. & Harding, C. M. (1985). The course of psychiatric disorder, III: Longitudinal principles. *American Journal of Psychiatry*, 142(3), 289-296.
- Unzicker, R. (1989). On my own: A personal journey through madness and re-emergence. *Psychosocial Rehabilitation Journal*, 13(1), 71-78.
- Zola, I. K. (1982) *Ordinary lives: Voices of disability and disease*. Cambridge, MA: Applewood Books.

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