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What Counselors Need to Know About Physical Disability: Lessons Learned

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The response to an injury that results in a physical disability is well noted in the literature to be multidimensional. Many health professionals, including nurses, occupational therapists, and physical therapists, discuss or uncover strong emotional responses that require a referral to a professional counselor. Interdisciplinary cooperation among health care providers at all points in the rehabilitation process, not just during the acute inpatient phase, is imperative if clients with physical disabilities are to be fully understood and assisted toward an optimal, healthy response to a disability. This can only occur when open communication between treating professionals is encouraged and expected. The collaboration of team members enables the client's issues to be addressed from a truly holistic approach, as even the most experienced rehabilitation counselor may benefit from conversations with the treating occupational and physical therapist to gain practical information regarding the physical and functional status of the client in relation to his or her psychological response.

Often that psychological response is conceptualized by service providers in terms of some theory of adjustment learned years ago in graduate course work. Theories of adjustment to disability (Livneh & Antonak, 1997; Kubler-Ross, 1969) have been challenged recently (Parker, Schaller, & Hansmann, 2003; Treishmann, 1988) as being inadequate to explain the complex process of adjustment that occurs when an individual experiences a disabling condition. Further, men and women may approach the same event differently (Nosek & Hughes, 2003). Recently, the term *adjustment* has been criticized as inadequate to capture the essence of what occurs in individuals following a disability, and Smart (2001) has suggested that *response* is a better way to describe the process. It is believed that *response* captures the elements of the progression through recovery, specifically the individual perception and meaning the person with a disability ascribes to events encountered on a daily basis. The individual's response to a disability occurs across all dimensions of the individual's life, not just the psychological, as the term *adjustment*

implies. *Response* more accurately suggests an ongoing process, not an end result.

Livneh and Antonak (1997) proposed the most widely used model of response to disability. They suggested a three-cluster approach that involves eight phases that unfold in a sequential process:

1. early reactions of shock, anxiety, and denial;
2. intermediate reactions of depression, internalized anger, and externalized hostility; and
3. later reactions of acknowledgement and adjustment.

This model expands the reactions to include four additional classes of variables: variables associated with the disability, variables associated with sociodemographic characteristics, variables associated with the individual's personality, and variables associated with the physical and social environment (Livneh, 2001). Livneh and Antonak (1997) recognized and readily admitted that even with the addition of the associated variables, the sequential hierarchical model may be insufficient to fully explain the complex network of responses to disability that individuals face.

This stage model is not without its benefits, though. For years it has offered service providers a tangible framework for conceptualizing client adjustment/response to disability and helped counselors normalize disability reactions for their clients. However, most of the benefits of the stage model assist counselors, not clients. A strict adherence to the stage model can be damaging to the client if the counselor ignores the individual's unique response to a disability. Often that unique response will not fit neatly into a stage model, and the individual may be pathologized because of it. A well-intentioned counselor may unwittingly attempt to force a client to experience a particular stage in an effort to move the client through the stages to the end result of acknowledgement and adjustment.

Researchers have found little empirical evidence to support the stage theory of response/recovery. Triesmann (1988), in a review of the literature on

individuals with spinal cord injuries, concluded that “no data have been presented in any of these articles to demonstrate reliably and validly the existence, sequence, or duration of these stages” (p. 69). Parker, Schaller, and Hansmann (2003) criticized Livneh and Antonak’s (1997) literature review of the stage model as being “based on opinions, informal observations, case studies of doubtful reliability and fidelity, and correlational studies of questionable research validity” (p. 235). Kendall and Buys (1998) suggested that the linear model of the stage theory poorly serves the individual with disabilities. Parker et al. suggested that more complex, nonlinear paradigms such as chaos and catastrophe models of adjustment would better explain the process of psychosocial adjustment to disability. Nosek and Hughes (2003) contended that the rehabilitation process of women and men, as demonstrated by recent medical research in cardiology, urology, immunology, psychology, and gerontology, is categorically different and needs to be systematically addressed in research and practice. Thus, all service providers need to reexamine their knowledge base and recognize that the use of the stage model may need to be revamped.

Experience in working with individuals with disabilities provides the practitioner with as many case study examples of individuals who follow the stage model of recovery as those who don’t. It is increasingly clear that many complex factors, not the least of which includes premorbid personality factors such as resiliency, problem solving, and coping, may be more important than a stage model. It is also clear from experience that the individual with a disability is likely to need the services of counselors at many different points in the recovery process. The interdisciplinary team approach to treatment that is so evident (and successful) in the acute phase of rehabilitation is often absent once the individual has been discharged to outpatient services or home-based therapy. However, it is usually at these points in recovery that the individual with a disability is more in need of the services of a counselor than he or she was during the acute hospitalization. The authors propose that while the phases described in stage models of adjustment may accurately describe the possible range of emotions experienced by an individual with a disability, these emotions do not follow a sequential pattern and are not experienced universally by all people. In fact, many of the phases are experienced not as a result of the disability itself, but as a result of social and environmental factors associated with the disability. Thus, an individual who is able to accept a sudden disabling condition may not experience depression or anger until faced with a complication of the disability.

It is also a common experience that the individual cycles through the emotions many times during the recovery process, as their condition improves or worsens. Regardless, an interdisciplinary team approach is necessary at all phases of recovery, since response/adjustment depends heavily on the complex and changing biological, social, financial, environmental, spiritual, and psychological needs of the individual; and the client’s readiness to disclose important information related to his or her response/adjustment to different service providers occurs when particular issues are most salient.

Take the example of a professional woman who was born with cerebral palsy. Growing up in a home where her disability was accepted as normal, she was pushed to achieve in both the physical and cognitive arenas. As an intelligent, professional woman, she understood the progression of her disease well and fully comprehended the concept of energy conservation. She experienced anger over the fact that she would eventually require the use of a power wheel chair for mobility because her own physically powered mode of mobility (loftstrand or forearm crutches) was slowly eroding the structure of her shoulders and causing premature arthritis. Physically, her body was ready to accept a power wheel chair long before she would emotionally concede the symbolic loss of independence that the wheel chair represented to her. The linear model of adjustment theory simply did not apply in this case, and service providers had to work with the symbolic loss issues involved. This client will continue to cycle through the emotions of denial, anger, and depression each time she faces adapting to a more restrictive form of assistive device for mobility because of her advancing age and the progression of her disease.

Another woman, years after the automobile accident that left her with quadriplegia, reexperienced anger when faced with medical interventions that did not suit her small physical frame. This petite female client who sustained a spinal cord injury found that the Bacfen pump, surgically placed in her abdomen to control spasticity, was huge in comparison to her body size, and visible even when her clothing was loose and draping. The manufacturer of the device readily admitted that the unit was designed to fit a 5’10” male weighing approximately 170 lbs., the typical SCI population who required this intervention. The client felt anger, injustice, and discrimination when faced with factors beyond her control. Self-esteem and body image issues were suddenly additional concerns that surfaced because a medically necessary device was poorly designed, yet necessary for her independence in other areas of life such as walking, self-care, home management tasks, and driving. Again, this client’s

progression to recovery did not follow a linear stage model but required that service providers meet and treat her where she was on her emotional journey.

Another young female client was seen after an all-terrain vehicle accident rendered her completely dependent for several weeks. She was seen by an occupational therapist in a hand clinic for a degloving injury that left unsightly cosmetic scarring. Emotionally, the client was unable to actively participate in her recovery process because she was unable to look at the scar, and thus unable to perform her own scar massage. Only through open collaboration with the rehabilitation counselor and the occupational therapist was the client able to cope with the emotional reactions to the disability and progress to the point of being an active participant in her treatment.

Lessons learned from interdisciplinary collaboration in the treatment of clients with physical disability:

1. Adjustment/reactions to disability are complex and change throughout the recovery process.
2. Interdisciplinary teams of service providers need to be involved at all points in the rehabilitation process to maximize treatment options for the individual with a disability.
3. Often it is not the disability itself that causes negative or problematic reactions in the individual, but the complex interactions of social (both familial and societal), physical, financial, litigable, environmental, and ergonomic variables that create seemingly insurmountable barriers for the individual with a disability.
4. Individuals with disabilities in need of services will often share emotional reactions, needs, or struggles with any service provider who is available and trusted at the moment the need becomes most salient to the individual. Thus it is essential that every service provider be attuned to these expressions of need and make appropriate referrals.
5. A true client-centered approach allows the individual with a disability to participate in the response process by encouraging the client to actively play a role in his or her own recovery, and to make own choices regarding a care direction, equipment and devices to aide independence, and daily routine scheduling. Collaboration among the rehabilitation counselor, occupational therapist/other health professionals, and

client must occur for the client-centered approach to be most successful or maximized.

6. The wishes of the client, however unrealistic they may seem to the service provider, must be valued and respected by all treating professionals. Service providers must utilize a nonjudgmental and caring approach with clients and recognize that response to disability is similar to a journey that the client must make on his or her own with the support and guidance of the medical, psychosocial team. Each journey is different and may change from day to day.

In conclusion, it has become apparent that each person with a physical disability fluctuates greatly in his or her ability to cope with the effects of a disability and with integrating a healthy response that leads to improved quality of life. A healthy, life-giving, positive response to physical impairment is most likely to result when all service providers include the client in communicating openly and collaborating on treatment goals. This alliance is able to incorporate the client's wishes and demands through the lifetime process of the healing journey.

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