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Issues In Disability & Chronic Illness Across the Lifespan

NASW MA Chapter Committee for Social Workers Concerned with Disability and Chronic Illness

Introduction

In 2002, the NASW Committee for Social Workers Concerned with Disability and Chronic Illness reconvened after some years of inactivity. Although a small group, we are a lively and committed extension of NASW that focuses most of its efforts on education and advocacy on behalf of people with disabilities and chronic illness.

In September of 2004, the Committee sponsored a conference entitled "In Our Own Voices: The Challenges of Disability and Illness and Implications for Policy and Practice". This conference was well attended and very favorably received. The predominant message from the evaluation forms indicated that this subject is too often overlooked in our practices and in our own lives as clinicians, and is due further attention.

In response to this call for more training and the need to address issues of disability and chronic illness among our own ranks, the Committee has spent the last year assembling a collection of academic papers for publication in NASW Focus. We are pleased and proud to share these articles with you, some of which are written by our own Committee members, and others which are written by Boston-area social workers and other professionals who are doing important work in the field. We chose to present articles that deal with issues across the lifespan, to encourage our colleagues to consider how issues of disability and illness present themselves for children, adults, elders, social workers themselves, and for individuals from other cultures.

Our first article, "A Response to Chronic Illness and Disability" is written by Dana Snyder-Grant, LICSW. Ms. Snyder-Grant focuses on issues of illness and disability, both from an academic perspective and from a personal point of view. Ms. Snyder-Grant notes that chronic illnesses are becoming more prevalent as baby-boomers grow older and as medical treatments are available that were not in the recent past. The need for people with illness to be listened to is emphasized in this article; social workers are trained to be empathic listeners and are well equipped to respond to the need to be heard which is an all too commonly ignored aspect of helping people to cope. Ms. Snyder-Grant speaks with special sensitivity as she herself lives her life and carries on her practice with a disability of her own. There is seldom any mark of truth which speaks more clearly than personal experience borne with strength and wisdom.

The issue of stigma is presented collaboratively by Carol Curtin, LICSW, Chair of our Committee, and Steven Lappen, past president of MDDA, the Manic Depressive-Depressive Association. They write about the marginalization that stigma brings to sufferers of illness and disability and describe, in the words of Erving Goffman, that stigmatized individuals are regarded as having an "undesired differentness." Mr. Lappen offers a personal vignette about his own experience dealing with this refractory condition (to use his doctor's words) and the shame that it has brought in its wake. He makes a point of the isolation that such a disease brings. It is our work to learn from and appreciate his disclosure.

In his article "When a Social Worker is Ill or Disabled", Richard Aberman, LICSW, focuses on the challenges when a social worker him or herself becomes ill or disabled. No one is ready at the moment of diagnosis for the impact that this brings. Such an occurrence, says Mr. Aberman, has ripple effects: it pulls into sharp relief issues of vulnerability and mortality which people usually manage to keep under control. Serious illness brings with it a shift in one's sense of identity. The therapist now sees her/himself as a patient, someone with a medical condition which to some extent occupies the center of consciousness. It raises, as Ms. Snyder-Grant says, issues of vulnerability and anxiety regarding the future, especially the way in which one will be viewed by others.

Ruth B. Smith, MSW, PhD writes about working with children with disabilities and special health care needs. When working with children, the clinician must work not only with the family system, but also with the systems that impact the family. Dr. Smith outlines the issues faced by families and the ways in which we can assist to insure the child's functioning as well as successful adjustment and adaptation on the part of the entire family.

Following Dr. Smith's article about families, Jerry S. Jacobs, LICSW writes about the issue of fathers raising children with disabilities. Until very recently in our history, "parenting" has referred mainly to mothering, with the role of fathers relegated to the sidelines. Some have even contended that children do not really need fathers at all. Expectedly, then, little research has been done on the impact on fathers of raising a disabled child and their self-perception. Mr. Jacobs shares his experiences in running workshops for fathers in the Boston area, and from these has been able to define some of the differences between the ways in which mothers

and fathers deal with their reactions to parenting children with disabilities. Recognizing the important roles that fathers should and can play, and devising clinical programs that meet their needs can serve to draw fathers into the mainstream where they can work with their wives and other children in dealing with a child in the family who has a disability.

Katherine Fox writes a provocative piece on aging and developmental disability. She points to the issue of increasing longevity of people with developmental disabilities (DD) and the fact that it is a world-wide phenomenon which has caught policy makers and service providers unawares. In light of this number of older adults with DD, more advocates, service providers, families, legislators and others are needed to recognize and adequately address their needs. Ms. Fox describes and advocates Person Centered Planning (PCP) – a strategy for designing inclusive supports and services to older persons with DD, an approach designed to reveal unique capacities of individuals in order to create more desirable futures and to allow them more control over their own lives.

Finally, the meaning that disability has across cultures must be appreciated; one cannot make assumptions about how disability is experienced by all persons, without consideration of the cultural dynamics at play. In her article, *Cultural Considerations of Disability: A Cultural Competency Tool As Applied to a 15-Year Old with Dyslexia*, Zarita Araújo-Lane, LICSW writes about the nexus of a child with a learning disability, her cultural difference from the main society, and the skillful drawing in of her understanding parents in her care and upbringing. Through the story of Carina, a fifteen-year-old student with dyslexia, Ms. Araujo-Lane illustrates how coming from a Portuguese background shed a different light on her disability; Carina's mother saw her difficulty not as something shameful, but as a special gift. Blessed with a cultural outlook that celebrated differences, Carina drew from her background in the Azores, and was able to recognize the treasure from her country of origin that placed a creative and powerful vision in her life.

We are very grateful to our colleagues who have contributed to this written CE course and wish to thank them for sharing their knowledge and wisdom about issues related to disability and illness. We hope you will find this compendium of articles of interest and hope they will inspire you to join our Committee. We meet monthly during the school year (September-June) from 10-11 a.m. on the first Monday of each month at the Eunice Kennedy Shriver Center, 200 Trapelo Road, Waltham, MA. If you wish further information, you may call Rebekah Gewirtz, NASW Staff Liaison at (617) 227-9635 ext. 12 or via email at gewirtz@naswma.org or contact Carol Curtin at (781) 642-0256 or email at carol.curtin@umassmed.edu.

Please consider joining our wonderful Committee!!

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A Response To Chronic Illness and Disability

Dana Snyder-Grant, LICSW

If social workers focused on issues of chronic illness and disability, what problems would this raise in each of us? Chronic illnesses are becoming more common as baby-boomers age and as medical treatments are now available that were not in the past. Even cancer and AIDS are now often experienced as chronic, not terminal. We all need to learn to live with chronic illness and disability, and our vulnerability to them.

I use the words illness and disability interchangeably in this paper, although there are distinctions and similarities between the two. Chronic health conditions often place limitations, e.g. disabilities, on the person with illness. For example, fatigue is a component of many illnesses, and it demands a reevaluation of one's plans and priorities. The impact, whether visible or invisible, may be experienced as disabling. People with disabilities may not have any complicating health factors or, by contrast, their disabilities may indeed pose health risks. But those with illness or disability share a central commonality: they live with a difference, an "other" quality.

The Client's and Clinician's Experience

For our clients to speak of the ailing body is to speak of fear for most, shame for some, challenge for others, and frailty for many. But we don't like to talk about serious illness. It makes us too powerless and scared. People with illness witness how these reactions to illness are pervasive in our culture. Similarly, vulnerability and helplessness are sometimes aroused in clinicians when they are expressed by clients. They may be aroused in you, especially if you are really present with your client. It behooves social workers to stay with these feelings, for if we flee from them, we are running away from the very feelings that so need validation by our clients. We must speak about the feelings that come up in our work, in supervision and with our peers.

Good mental health practitioners are active, empathic listeners. Many people with illness have a need to tell their stories and be heard, without receiving advice. They receive advice in many parts of their lives. Although this is often done out of kindness, it can also leave clients feeling distanced from well-meaning friends and family, and from the outside world. A feeling of disconnection from others develops, just when genuine connection would soothe the soul.

The greatest challenge for people with illness or disability is that there is often no place to speak about their experiences, struggles, pain, and triumphs. It can be taboo in our society--where health, vigor, and independence are so honored--to talk about illness, never mind to find meaning from it.

Arthur Frank, a sociologist and patient who lived through heart failure and cancer by the age of 40, writes about the importance of telling illness stories: "Too many ill persons are deprived of conversation. Too many believe they cannot talk about their illness" (*Frank, p. 4*). He continues, writing that the ill are not responsible

for getting ill or well, only responsible “to witness their own suffering and to express this experience so that the rest of us can learn from it...I only believe that those who express their illness live their lives fully to the end of their illness” (*Frank, pp. 123, 127*).

A Paradigm

The ideas of Arthur Kleinman (1988) and Ken Wilbur (1991) were formative in my development of the following framework by which to view the illness experience. The concepts of disease, illness, and sickness form this paradigm.

Kleinman, a psychiatrist and anthropologist, identifies “disease” and “illness” as two separate entities, defining disease as the medical problem and illness as the human experience. I submit that these disparate views of chronic illness respectively reflect the different orientations of the medical profession, and of the individuals who experience illness symptoms and struggles. The disease model, with its more sterile and factual approach, creates a disconnect for our clients who are searching to be understood and validated. Their illness or “human experience” too often gets lost in the doctor’s office where the physician speaks a technical language and the patient speaks the more human language of questioning and longing.

Culture

The third concept in this paradigm is “sickness.” Psychologist Ken Wilbur identifies sickness as the cultural meaning that we give to illness or disease. Sickness often serves to put people with illness in a box of stigmatization and blame. Many of the issues faced by people with chronic illness and disability are very little about their particular diagnosis or illness and much more about what happens to them socially when they become ill or disabled, when others view them as diminished. The person with illness is blamed and stigmatized for the illness.

Cultural Attitudes

Telling and listening to illness stories breeds connection, voice, and empowerment. The irony is that our culture’s unhelpful attitudes towards illness and disability leave people with illness disconnected.

Our society bestows meaning on illness. Throughout history and presently, we have a lot of explanations, some of which are based on personality, as to why people get sick. This comes from our need to control and make sense out of the nonsensical. In our attempt to control random events, we blame people for their illness. Surely, we all have a responsibility to take care of ourselves as best we can. But bad things still happen.

Plagues and famines used to be viewed as acts of a vengeful God, a punishment. In the nineteenth century, tuberculosis was seen as the process of consumption, a wasting away. People with weak characters, often women, were slowly consumed. There are even people today who still embrace the notion of a “cancer personality” that those who tend to suppress anger and other emotions are at greater risk for developing cancer.

In 1950, psychoanalyst Franz Alexander (1950) wrote that asthma was the result of a child’s unhealthy dependence on the moth-

er. We now know that a host of environmental factors contribute to the development of asthma. And we also know that illness can breed dependence. So which comes first? The illness or the dependence?

Finally, AIDS has also been seen as a punishment and is plagued with prejudice. All of the above is a reflection of what Susan Sontag called “illness as metaphor.” She wrote that in this culture, scary and incurable diseases, like TB and some cancers were seen as obscene and repugnant. They had meaning beyond just being a disease.

Prejudices abound about the meaning of disability in our culture as well. Until just several decades ago, children born with birth defects and/or mental retardation were often institutionalized. Hiding these differences was accepted by our culture that did not embrace or even tolerate disparity in human intelligence and ability. In her memoir, *In the Shadow of Fame*, the daughter of Erik Erikson writes of her parents’ decision in the 1940’s to “banish” her brother at birth and hide him and his Down syndrome from the world (*Boland, 2005*).

Discussion

The person with illness or disability confronts this dynamic of how society views the difference. In the words of Ken Wilbur, “...we would much prefer to be saddled with harmful and negative meaning than to have no meaning at all. And so whenever illness strikes, society is on hand with a huge supply of ready-made meanings and judgments through which the individual seeks to understand his or her sickness. And when that society is in fact ignorant of the true cause of an illness, this ignorance usually breeds fear, which in turns breeds negative judgments about the character of the person unlucky enough to come down with the illness. The person is not only ill but sick, and this sickness, defined by society’s judgments, all too often becomes a self-fulfilling and self-reinforcing prophecy: “Why me? Why am I sick? Because you’ve been bad. But how do you know I’ve been bad? Because you’re sick” (*Wilbur, p. 42*).

Society, in search for meaning, ends up blaming the victim. In the case of disability, especially from congenital defects, we shun and blame the family. The unknown and uncontrollable creates fear. Fear of the unknown creates blame. This is our sickness.

The Clinician’s Task (weaving the intrapsychic and the cultural)

Because the person with illness may have been bombarded by meanings of others and society, it is helpful to explore the meanings they have bestowed on their illness. Questions that are helpful to ask clients include:

What meaning have others given your illness? How have you responded? What kind of meaning have you given your illness? How have your family history and perceptions regarding illness influenced your attitudes? And ask your client, “Why do you think you became ill?” Look together at what the answers indicate about the person’s self concept and identity.

These contrasting viewpoints - of disease, illness, and sickness - send contradictory messages to the person with illness, which lead to and/or exacerbate isolation and depression. The degree of control that our clients have over illness may be limited. But they are in charge of their response to the illness - of the judgments they make of themselves, of the nature of relationships they form with medical professionals, family, and friends. They are in charge of their ability to trust their own judgment, to understand their body's signals, and make lifestyle changes which may have a positive effect on their health. Patients must find their selfhood beyond their illness. They've been dealt a lousy hand of cards, but how they play them is under their control, and something you are there to facilitate and witness.

Our task is to validate our clients' experience and by doing so, sustaining and empowering them to look at themselves, how they cope that helps them and how they cope that doesn't help. We are challenged with our clients to deal with chronic illness, because a mutual relationship between helper and helpee goes both ways and fosters resilience in our clients. You must learn how to manage chronic illness, to help clients learn what they can control and what they can't. For example, fatigue as a consequence of many illnesses demands that one evaluate priorities, learn to say no, and pace oneself. All these may be drastic changes for people - don't expect them to happen overnight. Your awareness of their challenge can assist clients to come to terms with illness and renegotiate their lives.

Karen Armstrong, the religious scholar, in her recent memoir, *The Spiral Staircase*, writes about her response to a diagnosis of epilepsy after being misled for many years about her blackouts and auras. Her comments affirm the importance of validation to her response and coping: "I walked down Mortimer Street in a daze. For many people, I am sure, a diagnosis of epilepsy must be unwelcome news, but for me it was an occasion of pure happiness. As I looked at the grimy buildings, the diseased London pigeons flapping untidily round the gables, the littered streets, and the overflowing dustbins, this urban detritus seemed a vision of beauty. For the first time in years, I felt neither broken nor irretrievably flawed. I was not mad, and need not expect to end my days in a locked ward. The world had been given back to me, and perhaps for the first time ever, I felt that I could take charge of my life" (Armstrong, p. 182).

Let's look at our responses to illness and disability. Then we can empower our clients to do the same.

Dana Snyder-Grant, LICSW is a clinical social worker specializing in chronic illness and disability. She received her MSW from Simmons College School of Social Work in 1986. Dana provides individual and group psychotherapy at Eliot Community Human Services in Concord, MA and facilitates groups for the National Multiple Sclerosis Society in Waltham, MA. She is publishing a book of her writings on illness and disability, *Just Like Life, Only More So and Other Stories of Illness*. For more information, see her website: <http://www.snyder-grant.org/dana> or email her at danasg@newview.org.

On Stigma

Carol Curtin, LICSW and Steven Lappen

One cannot write about disability and chronic illness without recognizing that stigma, to a lesser or greater extent, takes a central place in our lives. Stigma is a phenomenon described powerfully by Erving Goffman (1963) by which individuals who possess an "undesired differentness" are perceived negatively by the dominant society, devalued, accorded lower social status, and excluded or avoided. Despite the disability rights movement, deinstitutionalization, inclusionary educational practices, the Americans with Disability Act, and a host of other policies and reforms, the effects of stigma are still felt by persons with disability. Stigma is an issue that we must address in our clinical practice as well as in advocacy and systems change work.

Defining Stigma and Its Consequences

Each society makes judgments about certain differences among people and ignores other differences. Differences that are considered to be socially irrelevant are largely ignored; for example, in our society the size of one's feet is not typically considered to be highly relevant or important. However, differences that are deemed to be important or salient such as IQ, race, sexual orientation, and physique, to name but a few, are identified, labeled, and their importance is learned very early. This labeling is the basis for stereotyping and stigma. People who possess one of the so-labeled characteristics then experience rejection, loss of status, and discrimination. The resulting loss of power is experienced individually (by people themselves) and is expressed structurally within society, as stigmatized persons have restricted access to resources and economic and social capital (Link et al., 1989; Link and Phelan, 2001; Crandall and Coleman 1992). Strong social conventions lead to judgments about certain characteristics of people; some characteristics are viewed negatively, while others are viewed favorably or even celebrated. Unusual or deviant behavior, outward manifestations of illness or disability, and diminished competence are likely to earn especially harsh appraisal. These perceptions are communicated through dominant social values, media influences, and other socially transmitted messages. Goffman recognized in his ground-breaking essay that no particular characteristic is stigmatized per se; it is only when a particular characteristic is devalued by the society that people with that characteristic are objects of discrimination, devaluation, and loss of status. Thus, stigma is a sociological phenomenon; its roots are found in our cultural and shared social values.

Research over the last 40 years has revealed substantial effects of stigma on the self-esteem, social functioning, motivation, and achievement of persons in stigmatized groups, such as those with mental illness, HIV, epilepsy, and others (Crocker and Major, 1989; Crocker and Quinn, 2000; Dovidio, Major, and Crocker, 2000; Gibbons, 1985; Wahl, 1999; Green, 1995; Scambler & Hopkins, 1986; Link et al. 2001). Research on stigma has documented that stigmatized groups are disadvantaged when it comes to a "general profile of life chances" such as income, education, psychological well-being, and health (Link et al., 2001). The social, emotional and behavioral consequences of stigma induce stress, and a growing body of research reveals that persistent stress has deleterious

health and mental health effects (McEwen, 2002). Thus, the stigmatization of persons itself creates a vicious cycle that perpetuates symptomatology and social marginalization.

People devise various ways of coping with the stigma they experience, and these coping strategies can be more or less successful in avoiding the damaging effects of stigma. Some coping mechanisms may successfully protect self esteem, while others have unintentional negative effects (Link et al., 1991; Camp et al., 2002). For example, among adults with mental illness, 39% said they avoid disclosing their illness, and 31% report avoiding social contact because of perceived stigma (Wahl, 1999). Research has shown that the stigma and the fear that others will be critical and rejecting has interfered with seeking and adhering to treatment (Sirey et al., 2001; Meltzer, Bebbington, Brugha, et al., 2003). The experience of stigma has been shown to impinge on the self-esteem of persons who have significant mental illness. Link et al. (2001) showed that the perception of being devalued or discriminated against, and social withdrawal because of this perceived rejection, strongly predicted lower self-esteem among patients with mental illness. Some individuals may internalize the stigmatizing attitudes, resulting in shame and feelings of unworthiness. Others may come to understand that they are objects of unjustified treatment and may seek to cope by identifying with the 'out-group' and engaging in political efforts to combat discrimination.

Below, a personal vignette illustrates how stigma, almost more than the illness itself, has a corrosive effect on a man's sense of self, his self esteem, and his struggle to find a way to cope with the fear of judgment, rejection, and the shame he feels.

A Personal Vignette

Steven Lappen

How many feel a sense of shame about having a mental illness? Imagine having an enlightened therapist who begins the relationship by asking, 1) How do you feel about having a mental illness? and 2) What does it mean to you to have a mental illness?

The responses to these two queries are critical to the successful management of my illness. Shame is probably the most common and toxic side effect of mental illness, and tragically, I maintain, the most ignored. Left untreated it overwhelms the illness to such a degree that discussion of illness management is rendered nearly meaningless.

What are the tried and true treatments for shame as a side effect of mental illness? Do we even have a calculus to measure them?

I was diagnosed with bipolar disorder in 1969 – a time when “bipolar disorder” was not even part of the psychiatric vocabulary. My condition has been described by three psychiatrists as severe, even refractory. One wrote in his summary report that my prognosis was guarded. Yes it was, and to a lesser degree remains so. That it was, and is, is indisputable. Understanding the whys and wherefores of my battleground will not naively remove me from the front lines, but it will better arm me against those with whom I must battle. My mission straight on is to understand how the twin-

headed beast of shame and self-loathing which followed from, accompanies, and fuels my mental illness came to life and became larger than the illness itself.

Those of us who have carried mental illness for many years, and have struggled alone because of our families' apparent indifference and ignorance, have internalized the stigma from families unwilling (or unable) to support us and from a society unwilling to embrace us. And from this condition there is a small step one takes to develop a sense of suffocating shame. There is a regrettable loss of nobility – we lose sight of our nobility when we mistake our illnesses for who we are. A significant part of my recovery is fashioned through my ongoing participation in a peer-led support group. At the beginning of each group we individually check in. It is at this time that we introduce ourselves by first name and discuss our diagnoses and the struggles and successes we encounter in managing our mental illnesses. At these groups it is not uncommon for one to identify oneself as being bipolar or depressed. I cringe at this identification because it represents how individuals' identities are inextricably woven into their illnesses. A person who has prostate cancer or hypertension would never think to identify him/herself as **being** prostate cancer or **being** hypertension. He/she has not confused the part for the whole. **I am not my illness and you are not yours.**

Some years ago I rented a captivating French film entitled *The Eighth Day*. It depicts the story of this young man who has Down syndrome who lives with his mother. They are utterly devoted to each other. When she dies, he is unceremoniously placed in a residential facility as his sister is unwilling to care for him in her home. On this given weekend, all the residents are going home to their families – with one notable exception. Undeterred, he dresses in jacket and tie, packs a bag, walks to the highway and extends his thumb. Soon he is picked up by a harried corporate executive. A wonderful friendship ensues. At one point they stop at a bar with dancing. The protagonist is wearing sunglasses. He invites a woman to dance with him. She consents. She smiles. She laughs. When the music dies, he removes his shades. His partner recoils in horror. At this moment he has been objectified – whatever he was, is, and might have been are sadly removed from his plate of human possibility. So, too, when I feel greatest familiarity with my diagnosis, I lose sight of the nobility of who I am and the possibilities of what I may become.

Although I don't have Down syndrome, I wear shades. And I have worn them for far too long. What compels me to wear them? From whom do I seek refuge? It seems clear to me that if I didn't have this need to hide, there would be no shame. It's really a simple equation:

NO VEIL = NO SHAME. The equation might be simple, the solution is another matter altogether.

It takes courage and resolve to be open about my illness and myself. It takes fortitude to tear away the shades. But at what cost! The very act of unveiling, if done without support, can leave me raw and open to relapse. If I've been in darkness for so long, an imprudent unveiling may only substantiate a negative self-image I've harbored for far too many years. Care must be taken to avoid the imprints of shame and self-loathing. I try to surround myself

with trusted supports before I lose the veil. Regrettably, this process of unveiling is not “once and I’m done.” My sense of shame is too deeply embedded to be loosened by a single unveiling, or a score for that matter. But forge ahead I will.

Combating Stigma – Clinical and Social Justice Interventions

Stigma is a social psychological phenomenon that is rooted in cultural attitudes and stereotypes, held by members of society as well as those who are its victims. As Steven Lappen has so eloquently described in his essay, persons with disability, in this case mental illness, suffer from self-stigma in which they may have internalized the beliefs that the dominant culture holds about their disorder, or feel so marginalized and devalued that they avoid treatment or contact with others for fear that their ‘secret’ may become known and that they will be rejected. As clinicians and advocates, there are some strategies that we may employ to help our clients cope with poisonous effects of stigma and to also address this problem within the larger social context.

Little research has been done on assisting clients with their own feelings of self-stigma, but preliminary work has shown that utilizing cognitive-behavioral approaches to help clients reframe stigma as an expected event in life can be helpful (*Corrigan & Watson, in press*). In other words, help clients understand that they are in a group that is misunderstood and misjudged, and that the problem is “out there” (in society), rather than inside of them. In addition, work to educate clients about the stereotypes that exist about disabling conditions and assist them to identify and break down the myths that they have been socialized to believe. Corrigan & Watson have developed a “Stop Self Stigma” worksheet that clients, with their therapists or in groups, can use to relearn and confront the stigmatizing beliefs that they have internalized. Clients are encouraged to write down the hurtful belief, define the assumption(s) that the belief is based on, challenge this assumption by asking trusted others if they believe in the assumption, collect and list evidence that challenges the assumption, and restate the attitude in a non-harmful manner that counters the original belief. A sample of the self-stigma worksheet can be found at <http://www.bhrm.org/guidelines/stigma.pdf>. Working to enhance our clients’ sense of self-efficacy and sense of empowerment is a primary goal, and helping them understand the extent to which stigma has placed a barrier to accomplishing this goal is key.

There are a number of ways that challenging stigma on a macro-level can also be accomplished, and as social change agents, social workers have a role to play in addressing the negative stereotypes that are often communicated in the media. Protest can be an effective means by which stigma is reduced; letter writing campaigns, phone calls and public denunciation of stigmatizing images in the media have been shown to be effective in removing these images from public view. At the same time, however, protest approaches have also been shown to lead to an increase in some prejudicial attitudes, so this strategy must be undertaken with great care and used with caution (*Corrigan & Watson, in press*).

Education and contact approaches, whereby the public is educated about the facts of disabling conditions and receive accurate information that debunks stereotypes and myths, have been shown to be quite effective in changing negative or prejudicial attitudes.

Educational programs are geared toward identifying inaccurate assumptions and stereotypes and replacing them with factual information. Education programs in which persons with disability themselves provide this information, thus affording the audience an experience of contact with an individual of the ‘out-group’ have also been shown to be effective. Research has shown that when people in the general public have personal experience with disability in their own lives (e.g., mental illness), they are much less likely to hold prejudicial attitudes (*Corrigan & Penn, 1999*). Thus, exposing the public to persons with disability who can speak to these issues of stigma may be particularly helpful. Various organizations have speakers’ bureaus where individuals with disabilities can address public groups in an effort to shed light on myths and stereotypes.

In summary, the powerful effect of stigma on the lives of people with disability cannot be ignored. We must understand how it plays a central role in seeking and adhering to treatment, as well as our clients’ beliefs about themselves. Incorporating ‘anti-stigma’ work into clinical practice is essential; it affirms for our clients the fact that they face stigma which is very real, and provides them with tools to confront the issue of stigma in their own lives. Likewise, joining with our clients as well as our colleagues to address stigma on a macro level by protesting negative images and developing ways for the general public to be educated on the facts and not the fiction of disability, is an essential part of our work.

Carol Curtin, LICSW is the Chair of the Committee for Social Workers Concerned with Disability and Chronic Illness and a clinical social worker with over 20 years of experience in the disabilities field. She is currently on faculty at the UMass Medical School and works at the E.K. Shriver Center in Waltham, MA where she does research, teaching, and consultation. She can be contacted at 781-642-0256 or via email at carol.curtin@umassmed.edu.

Steven Lappen is the past president of the Manic Depressive - Depressive Association of Boston. He is currently serving on its Board of Directors and will soon assume the role of Secretary. He is a member of the State Advisory Council for the Department of Mental Health and is also a published poet.

When a Social Worker Has an Illness or a Disability

Richard Aberman, LICSW

The emergence of significant illness or disability in a social worker presents a host of challenges and possible responses that have the potential for enriching or derailing a therapeutic relationship. Indeed, the need to interrupt or modify the therapist-client working contract due to therapist illness or disability is as meaningful for the therapist as it is for the client. Among the major issues with which the social worker must contend are the following:

- Dealing with the initial reactions to a diagnosis or disabling condition;
- Sorting out the implications for managing one’s practice;
- Organizing a support system for the social worker;
- Dealing with the question of self-disclosure;
- Managing transference & counter-transference phenomena.

Dealing With The Diagnosis

Illnesses manifest in a variety of ways that may be roughly described as a continuum ranging from acute and survivable on one end (e.g., heart attack, stroke), moving through chronic and survivable (e.g., multiple sclerosis) to chronic and/or acute and not survivable on the other end (e.g., terminal cancer). Furthermore, some conditions (e.g., Crohn's disease) may shift from chronic yet in remission to a more acute and active stage, then shift back to remission. Yet at the moment it happens, no one is adequately prepared for the shock of sudden, incapacitating illness or the diagnosis of a frightening disease (*Philip*). Such an event sends ripple effects through one's life and brings into sharp relief issues of vulnerability and mortality which are ordinarily kept at bay by our usual defense mechanisms. The diagnosis of a significant illness that can or does rise to the level of disability may shatter our customary coping strategies and trigger more extraordinary defenses of denial, anger, depression, avoidance or isolation, all of which can make it more difficult for the social worker to focus on the therapeutic tasks confronting themselves or their clients.

Of course it is to be expected that the social worker's initial focus is centered on the implication of such illness or disability for their personal life. These concerns – regarding their relationships to their family and loved ones – are intensely subjective and personal reactions to the process of adjusting to a specific medical condition. It is usually after such concerns that the social worker begins to deal with the implications of their condition for their professional practice.

With a diagnosis, almost immediately, comes a shift in one's sense of identity. The individual now moves into the role of patient, a person with a particular medical condition which, to some degree, occupies their consciousness and serves as one factor for self-definition. There may well be a heightened sense of resolve as the individual mobilizes their internal resources to meet the challenge of a narcissistic injury. Yet, this process is also accompanied by an increased sense of vulnerability and anxiety about the future, including concerns regarding how he or she will be perceived by others, including clients.

It is important for the social worker to recognize that they will experience a form of grief reaction in response to the diagnosis. Typically they will need to move through stages of shock and denial, anger, bargaining, sadness or depression, to reach a point of acceptance from which they can address their own concerns as well as their client's. If the illness or disability is chronic and cyclical in nature, it may involve a recurrent working through of these stages. From the position of acceptance they can move beyond the initial diagnosis and more realistically deal with the implications for their practice.

Implications For Practice Management

The major factors for assessing practice implications for the social worker have to do with the emergence of the illness or disability – whether there is a sudden or gradual onset of the condition – and the anticipated duration of the illness or disability – whether it is likely to be “time-limited” or chronic and recurrent.

Gradual emergence of a disabling condition allows for planning and reflective decision-making regarding the specific needs of

one's caseload. Such planning should include the following:

- Arranging coverage for any anticipated absences;
- Securing releases to share clinical information with colleagues who are providing coverage;
- Dealing with the question of when to inform clients if medical leave is needed;
- Deciding how much information to provide clients;
- Arranging for terminations or the orderly transfer of clients as necessary.

Situations involving sudden incapacitation of the social worker present more difficulty. In the absence of any organized process for addressing the social worker's absence, the task of informing clients may fall to supervisors, colleagues or even family members. Information may be provided to clients with no provision for helping them to process its meaning or to address the client's anxieties and fears. The potential for violations of client confidentiality are increased and the emotional vulnerability of both social worker and client are heightened.

To avoid such undesirable effects of sudden disabling illness, it is recommended that social workers have in place a thorough emergency response plan that provides for the notification of clients and a colleague or group of colleagues who can assume the roles of an “emergency response team” or “practice trustee(s)”, ensuring that clients' minimal needs for coverage or closure are met (*Steiner*). While preparing for what should be done in case of a social worker's illness, disability or death can feel much like an unnecessary and time-consuming chore, it is an ethical responsibility to our clients which should not be dismissed or ignored.

Organizing A Peer Support System

Just as we social workers would encourage a client who is dealing with a disability or significant illness to seek out sources of emotional support, it is extremely important for the disabled or ill social worker to develop and use a peer support system, whether this is through a group or an individual colleague. Inevitably, practice management and clinical issues related to the social worker's condition will arise, and the availability of other colleagues for emotional support or consultation will be invaluable.

Selectively informing colleagues of the social worker's disability or condition serves two significant functions: first, it mobilizes sources of emotional support and decreases the sense of isolation which often accompanies a disability or illness; second, it helps provide an external reality and clinical check regarding the reactions of both social worker and clients. Peer consultation groups can assist the social worker in dealing with transference and counter-transference reactions, help formulate time frames and parameters for informing clients of medically related absences, or provide an objective “sounding board” for a host of clinical decisions which the social worker may need to make. In agency or institutional settings, the social worker's supervisor may serve the same function as well as providing for the administrative support that medical leave situations may require.

Dealing With Self-Disclosure

The question of self-disclosure – whether the social worker should reveal information regarding their illness or disability to the cli-

ent – is a question that generates much discussion. The traditional psychoanalytical model of therapy would hold that any disclosure of personal information by the analyst has a corrupting influence on the transference and may hinder or inhibit the patient's associations and comments. Non-psychoanalytically oriented therapists and social workers express other concerns regarding self-disclosure of illness or disability. Will our clients abandon us? Will our colleagues refer to us? Will disclosure put a burden of concern on the client and transfer the focus of therapy to the therapist?

Yet there are compelling reasons for the social worker to disclose such information, especially if their illness or disability has visible manifestations or is likely to cause episodic disruptions in the treatment. Some of these reasons are:

- Decreasing clinical ambiguity;
- Being respectful of the client;
- Promoting honesty in the therapeutic relationship;
- Decreasing the social worker's denial;
- Recognizing the social worker as a model for dealing with adversity;
- Facilitating treatment planning.

Disclosure can decrease the potential for clinical ambiguity when a client discerns a disruption in the therapist's focus or attention. Such disruptions can occur despite the therapist's best efforts to compartmentalize their own emotional reactions to their illness or disability and may not escape the intense scrutiny of the client. This attentional drift by the therapist may be interpreted by the client as a reaction to their own projected inadequacies or shortcomings, some failure on their part to be a "good enough client". Disclosure on the part of the social worker provides a context for both therapist and client to realistically discuss such lapses so as not to add to the client's sense of shame or confusion.

If one holds to the view that the social worker is an active collaborator in the therapeutic process, as well as an observer of and commentator on it, then disclosure of one's illness or disability is an attempt to be honest and authentic in the treatment relationship. It reduces the element of denial on the part of the social worker and amplifies the role of the social worker as a model for identification as a person who attempts to face and deal with his or her problems and life – not someone without struggles and challenges either internal or external (*Grunebaum*). As one writer has pointed out, "Making one's humanness known and being intensely present are both facilitated by self-disclosure" (*Steinbach*).

Disclosure may be affected by many variables, whether emotional or physical. These variables include the energy available to the social worker at any given time, the degree of disruption to the therapy caused by the disability or illness, how the disability/illness may be subjectively or objectively perceived, the imminence of death, as well as other stressors which may impinge on the therapeutic process. In situations where the disability or illness is terminal, it is imperative that disclosure is made so that clients can grieve and work through the ultimate separation.

Ultimately, the issue of self-disclosure is not about whether a social worker should disclose information regarding their disability or illness or should not disclose such information, but rather when and how much to disclose, and how to use the realities of the situa-

tion to the client's ultimate benefit (*Counselman/Alonso*). There is a delicate balance between revealing too much too soon and thus burdening the client versus being insufficiently open and respectful of the client and the therapeutic process.

Transference and Counter-Transference Issues

Disability or illness of a social worker can bring about transference and counter-transference reactions that are important to recognize and address as they arise. The therapist-client relationship is a mutually created alliance which forms a unique holding environment for the work of therapy. Interpersonal trust is the foundation upon which psychotherapy rests, and any interruption in the therapeutic relationship due to a social worker's disability or illness, whether planned and discussed ahead of time or sudden and emergent, will affect the treatment relationship. It is important that there be an ability to frankly and openly discuss and allow clients to verbalize and explore their reactions to the entire therapy experience, as well as for the social worker to maintain awareness of his or her own reactions.

Aspects of the social worker's disability or illness which can trigger transference reactions include:

- Nature of onset of social worker's disability or illness;
- Absence of the social worker due to disability or illness;
- The perceived vulnerability of the social worker;
- The manifestations of the social worker's disability or illness;
- Particular symptoms of the social worker's disability or illness that evoke idiosyncratic reactions from the client.

The following transference reactions, though not an exhaustive list, are typical of the reactions which clients can experience in the face of their social worker's disability or illness:

- *Denial*: Clients often want to see their therapists as invincible. They may try to deny their social worker's vulnerability as well as their own.
- *Regression*: In the treatment, old issues and fears may reemerge, especially fears of abandonment.
- *Guilt and Shame*: Clients with powerful "internal critics" may feel that they have somehow contributed to or caused the social worker's physical condition.
- *Anger*: Clients may feel disappointed by the social worker's vulnerability and experience anger at the loss of an idealized therapist.
- *Loss and Mourning*: Evoked memories of significant figures from the client's past may trigger grief reactions.
- *Rescuer/Caretaker Wishes and Fantasies*: These can involve a client's feeling that they have to care for or be concerned about the social worker's welfare more than their own.
- *Wishes for Validation*: Clients may experience intensified yearnings for affirmations and acceptance that were never fully met by previous caregivers.

There are several variables that may affect a disabled or ill social worker's counter-transference reactions in the treatment situation. The nature or onset of the disability or illness, whether it is chronic or acute, in remission or active, can affect the social worker's emotional responses and outlook. The desire and need of the social

worker to work is another significant factor, as issues of professional identity and having to assume a role as care receiver (as opposed to caregiver) can affect self-esteem and intensify the need to prove one's competence or intactness. Furthermore, fears and anxieties around money may come into play, leading the social worker to make decisions based more on finances than the reality of their medical condition. This in turn may result in the social worker working while in discomfort or pain, attempting to stay present and attuned to the client even in the face of their own physical distress. The nature of the social network of the social worker and the client may become a factor in counter-transference if there is overlap between their personal and professional networks and information regarding the social worker's condition cannot be readily managed. Finally, the emotional and mental state of the social worker is a significant variable, as they deal with aspects of denial, depression, anger and acceptance of their condition.

The potentially heightened emotional reactivity and vulnerability of the disabled or ill social worker can be manifested by the following counter-transference reactions:

- *Denial*: Just as the client wants to see their social worker as invincible, it is tempting for the social worker to agree with this flattering view and to deny their own vulnerability to physical impairment.
- *Shame and Guilt*: The social worker may have unrealistic negative feelings for *having succumbed to a physical infirmity*.
- *Neediness and Helplessness*: The narcissistic injury inherent in disability or illness may increase one's dependency needs.
- *Envy*: The social worker may feel jealous of the relatively good health of clients or colleagues.
- *Anger and Rage*: As one's physical capacity is diminished, frustration and a sense of loss can trigger intense anger.
- *Feelings of Inadequacy*: Self-doubt and fears of appearing weak or limited may be experienced.
- *Self-Absorption and Diminished Concentration*: Preoccupation with one's physical condition and increased difficulty with compartmentalization may lead to intrusive thoughts that interfere with attention.
- *Wishes for Sympathy*: The social worker may feel that their pain, distress or disability should exempt them from the demands, needs or negative transferences of their clients.
- *Fears of Abandonment*: The social worker may feel intense anxiety regarding the possibility that their clients could end treatment in response to their physical condition.
- *Dread of Death*: Disability or illness is the reminder of our ultimate mortality and may heighten existential anxiety.

Working through such transference and counter-transference phenomena in treatment can offer positive opportunities for the client to correct previously distorted images of the social worker as omnipotent and invulnerable. The social worker can provide a model of courage, equanimity and hope as the client observes him or her coping with the stress of physical limitations or struggles. Treatment may stimulate the client to grapple with prior effects of illness or disability in significant figures from their past, and en-

courage a resolution of conflicts over separation, loss and the inevitability of death. Finally, managing the myriad emotions and reactions that accompany disability or illness may enhance the social worker's sensitivity, their capacity for empathy toward helplessness and regression, and their appreciation of physical and emotional health.

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Children With Disabilities and Special Health Care Needs

Ruth B. Smith, PhD, LICSW

When a clinician works with an adult with a disability or special health care need, the decision to work with other than the individual client is most often clinically and mutually determined. With the possible exception of working with a geriatric patient whose family may be intimately involved, most of clinical social work is with the individual client. However, working with children or adolescents with disabilities and special health care needs brings its own set of challenges. (For the purposes of this article, the word "children" will be meant to be inclusive of "adolescents and young adults").

When working with children, the clinician must work not only with the family system, but also with the systems that impact the family. A more comprehensive treatment plan must be considered if the systems that impact the child can be enlisted as allies to support the child and the family. These systems include schools, state or private agencies providing services, the medical system and other professionals who may be providing a variety of therapies to the child and family.

If the family comes from a different cultural or linguistic background, the family's view of disability and its ability to accept services presents another variable to consider in conducting an assessment and in determining subsequent interventions. Cultural differences may also present a unique set of challenges that must be addressed before appropriate clinical interventions can be determined and implemented.

An ecological perspective (*Bronfenbrenner*), family systems approach (*McGoldrick, Hartman*), developmental stage theory (*Erickson*) and constructivist theories (*Frankline and Nurius; Dean*) are other helpful tools in diagnosing and developing appropriate clinical social work interventions to the child and family.

The diagnosis of a disability may occur pre-natally, at the time of birth, may develop over time or be the result of a traumatic event. Given the modern medical tools and procedures such as amniocentesis and genetic testing, parents may know prior to birth that their child will be born with a disability. An example of such a disability is Down syndrome. Given the advances in our knowledge of children with Down syndrome and medical interventions, many children with this diagnosis can be expected to live a full and rewarding life even with the accompa-

nying diagnosis of mental retardation.

Other disabilities, such as Autism Spectrum Disorders, Attention Deficit Hyperactivity Disorder, Learning Disabilities, sensory disabilities such as Vision or Hearing Impairment, may not be diagnosed until the child is a later stage of development or after schooling has begun. Indeed, some individuals, especially those who function at the higher end of Autism Spectrum Disorders, Attention Deficit Hyperactivity Disorder or learning disabilities, might not even be diagnosed until adulthood. In this event, the child may exhibit other symptomatic difficulties which precipitate a clinical assessment and intervention.

An acquired disability, such as a post traumatic head injury, or the diagnosis of a chronic special health care need such as diabetes or childhood leukemia thrusts many additional challenges and stressors on to both the child and the family.

The presentation of the diagnosis must take into account certain factors such as where the family is in its own life stage development. In making the clinical assessment, certain considerations that might influence the family's response include whether or not the child is the first or one of a number of children, any coping strategies that the family has used in the past to deal with crises, the acceptance and role of the extended family, the availability of services and resources, the parents' educational level, their perceptions, both positive and negative, about the disability or special health care need, as well as their cultural context and religious background.

During the diagnostic stage, the social worker must not only deal with the affective responses of the family, the sense of grief and loss, but also serve in both an advocacy as well as a psycho-educational role. Frequently, the family members receiving the diagnosis and the implications for treatment and prognosis may not hear all of the information when initially presented. In addition, each family member will respond differently, using various defense mechanisms such as denial or avoidance. Initially, such denial or avoidance may serve in the interests of the ego. This is especially true when the disability is the result of a traumatic event such as a traumatic head injury or an accident such as a near drowning or spinal cord injury that results in a disability. Denial in these circumstances may provide the family with some hope that allows them to move forward and to accept treatment interventions. If, however, the denial persists, this may end up being counter productive and may result in an overprotection of the child, hindering emotional developmental growth and progress, within the boundaries of the disability.

The responses of extended family members are important to consider during the assessment period. If a child is born with a developmental disability, an emotional response consisting of feelings of guilt and accompanying blame may ensue. This may be especially true if the child is born with mental retardation or other genetic disorder. If the parents or extended families become involved in attempts to affix blame, this may prevent the family from doing the necessary grief work that will allow them to move forward and begin to consider treatment options and other planning necessary to help the child.

A child's special health care needs may require additional expenditures that are not covered by insurance or entitlement programs. Many families may lose out on professional advancement by the necessity of remaining in a location where services for the child are readily available. These economic issues may also add additional stress and frustration for the family.

Cultural responses are also critical to the initial assessment stage. Various cultures may view disability very differently, one from the other. In some cultures, a child with a disability may be perceived as being punishment for past sins of both living or deceased ancestors, or a sign of the family's shame. In these cultures, the family may be reluctant to accept services from outside providers and may even attempt to hide the child. In other cultures, the child may be perceived as a gift from God and the parents may feel blessed that they have been given extra responsibilities. Responses may also differ within the very same culture depending on the parents' educational and socio-economic levels. Religious beliefs as well as the world view by the cultural group may also influence the response. In some cultures where group affiliation and mutual dependency is viewed as more important than individual independence and success, all of the family members as well as other members of the group may share in the responsibility of caring for the child. Differing views of parenting and parenting styles may also influence the response. The historical political circumstances of immigrant families may also impact and influence the family's response. For example, if families have fled totalitarian regimes, the parents may be very distrustful of government services and may be reluctant to accept such help.

Children's Developmental Stages

During infancy, toddler and pre-school years, the focus for the family and child must be on providing maximum opportunities for development in all areas--physical, cognitive and emotional. The social worker's role may be to help the family review their various options while continuing to address issues of grief and the added stress that results from interacting with various systems including: health care, entitlement programs, on-going diagnostic testing, treatment protocols and schedules from different therapists. If the systems involved in providing services to the child and family are too fragmented and non-collaborative in nature, this puts families under enormous stress. In some families, such as those with a child with autism, there may be more than one child with a disability which adds another stressor to the equation.

As social workers interact with clients in their environment, the worker may also have to assume the role of advocate for the family, intervening with the various systems. At the same time the social worker can serve as a role model to the family, helping its members develop their own skills as advocates for their children. It is critical that the social worker not assume the role of "parent" but work towards empowering the parents by helping them develop the skills and knowledge they will need to provide for their child's needs. In this respect, the social worker and family become partners in providing treatment. This model has been used most effectively in some early intervention programs during the child's early years.

It is important to keep in mind that the grief that some parents experience over the loss of the idealized and expected child may

never fully resolve. While most families arrive at a place where the grief subsides and is not acute, it may reappear during various stages of development when certain milestones are celebrated by other families. Rites of passage such as confirmation or bar/bat mitzvah, dating, learning to drive and applying for college may not be realized or realistic for the child with a disability or special health care need. At these times, the suppressed grief may re-emerge for a temporary period of time as the family works through the specific issue.

During the school years, in addition to the above mentioned systems, families now have to learn to work with school systems. While the Individuals with Disability Education Act (IDEA) advanced the integration of children with disabilities into mainstream education, this has not come easily. Frequently, the social worker now must work with the parents' feelings of frustration in working with school systems that may not always work in full cooperation with the family or may not be willing to provide the services that the child requires in order to make "effective progress" as a special needs student. The social worker may now need to function as an advocate for the child and the family as well as advocating along with the family to ensure that the child receives the necessary educational services as required under the law.

As the child ages and moves towards adolescence and adulthood, the family is confronted with a new range of challenges. In many ways, these stages are the most difficult for parents. For most of the child's life, the parents have had to function as the gatekeepers and advocates for services for their child, while addressing their own emotional responses, crises and frustrations that ensue from having a child with a disability or special health care need. The child may be experiencing typical adolescent and young adult demands and may be ready to take on the tasks of these developmental stages--striving to become more independent, making decisions about post secondary schooling or vocational choices and attempting to establish separate and intimate relationships with peers and potential partners. The transition from childhood to adulthood is difficult for most families, but made more complicated when the child has a disability or special health care need. Children at this stage must develop the skills to become self advocates and to be comfortable in their acceptance of self and in interacting with others. Parents must face the challenge of slowly withdrawing from being overly involved and allow the child to become as independent as is reasonably doable, including making decisions about post secondary schooling, employment, separate living accommodations and social relationships. Schools which have been the primary providers of service to the child now move into the background. The transition to adult services is very underdeveloped and families often find themselves without the supports they have had for their child for the last twelve years or more. Inadequate services for adults with disabilities present a new host of challenges for the family and create a new set of frustrations.

Family Life Stages

Like the child, the family is also going through developmental stages. The first challenge in a new marital relationship is sorting out the meaning of what it is to be a couple, rather than two individuals. Establishing the boundaries as a couple is a critical task in the early stages of marriage. Learning how to interact with each others' extended families and friends is a task in addition to learn-

ing how to interact with one another in a different kind of way. Other tasks include learning how to balance work and relationship commitments. For some couples, these tasks are accomplished easily while for others, it takes much more work to establish new boundaries and ways of interacting with each other and with others in their environment. If a child with a disability is born to the couple before their new identification is somewhat established, accomplishing the necessary tasks of the newly established marriage may never be completed. The couple is challenged to learn how to care for themselves as individuals and as a couple in spite of the extra demands of having a child with a disability. The child and the tasks of caring for the child may disrupt the marital connection and marital difficulties may emerge. It is critical for the social worker to address these issues in working with the parents and to help them develop strategies to maintain the integrity of the marital relationship. Meetings with extended family members may become necessary to help the couple find informal social support in caring for the child and themselves.

During child rearing years, the family is busy with the day to day demands made by the need to earn a living, deal with the demands of educational systems and the children's interests in extra curricular activities. In a family with a child with a disability, normal emotional responses including sibling rivalry and demands for individual attention from each of the parents become particularly challenging and add additional burdens to the parents and the marriage. The task involved here is how to give each child the time and attention they need to achieve the required tasks of latency age—educational, physical and emotional growth and the development of social skills. There are many articles about the impact on siblings of children with disabilities and special health care needs. Siblings share their feelings of feeling cheated, yet frequently also feel guilty. They know and understand that the sibling with the disability requires more. Yet, the siblings often feel they do not receive the attention that they need. They also share feelings of compassion and understanding which they feel they have developed because of having a sibling with a disability or special health care need. The challenge for the parents is to attempt to provide adequately for each of their children as well as for themselves.

As the child with the disability enters adolescence and young adulthood, parents may be going through their own mid-life physical and economic changes. The marital couple prepares to launch their children into the world and must now learn or relearn ways of interacting with one another without the demands of children. The demands of aging grandparents may also occur at the same time, adding to increased feelings of stress and responsibility.

In families with children with disabilities or special health care needs, parents may begin to realize that they need to consider the future needs of these children. Issues such as guardianship, the need for special needs trusts and decisions about where their children will live and who will care for them when the parents themselves become ill, too frail or die, begin to emerge. Even while the child without the disability begins to move into independence, parents may delay or postpone thinking about the future of the child with the disability. Often, it may be the social worker who has to raise these issues with the parents. It is critical that the social worker be educated about the resources that will be needed or how to access them for the family. The social worker also needs to help

the family resolve some of the emotional crises of the demands of launching children, planning for the child with the disability and caring for aging parents. There is a need to engage in realistic problem solving involving addressing the reality of time constraints, alleviating stress and developing practical plans for other family members. Couples can be helped to sort out shared responsibilities and to develop a plan for caring for their own emotional needs.

Summary

Having a child with a disability or special health care need can be very challenging. Because social workers are trained to work with the person in environment, social workers have a unique set of skills that can be utilized to help these families. The social worker's understanding of resources, relationships, grief, loss, problem solving, crises resolution and advocacy work are all useful skills in working with families that have children with disabilities and special health care needs. The challenge is to work with such families in partnership, helping them in each stage of growth and development for both the child as well as the rest of the family. Social workers can help such families feel empowered and, in so doing, help them to empower their children.

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Supporting Fathers of Children With Disabilities

Jerry S. Jacobs, LICSW, M.A.

Just twenty five years ago, Michael Lamb, a noted child psychologist described fathers as "the forgotten contributors to child development". In fact, until the 1980's parenting generally implied mothering. Since then, in response to the feminist movement, the fatherhood movement is rapidly growing as more fathers are taking a more visible role in parenting. Fathering is rapidly gaining greater popular press coverage and more research about fathering is being published in professional journals (*Horn and Sylvester, 2002*). In addition, the U.S. government has begun to recognize the value of fathering. In 1994, former Vice President Al Gore at his annual family forum called for a "nationwide father to father movement." He noted,

"we must encourage men to take an active part in caring for their children and we must make available opportunities and the support necessary for them to do so." (Levine and Pitt, 1995).

In this article the word "father" refers to male caregivers or father figures who may or may not be living in the child's household.

"Fathers" refers to men who are cohabiting, divorced, or separated, single, or unwed (*Strug and Wilmore-Schaffer, 1970*). In addition, "fathers" may refer to men who are relatives or other male figures and who have a close relationship with the child.

Fathers, like mothers, of children with disabilities grieve the loss of their parental dream, feel shame, and experience low self-esteem. Fathers compared to mothers also experience higher levels of social isolation around issues related to their child with disabilities and often have fewer personal and social supports in this area outside the workplace (*May, 1992*). Men tend to grieve differently than women, and are raised to "keep the lid on emotions". Men often report feeling that they are not expected to lose control over their emotions, not expected to openly cry, worry, or express overwhelming sadness (*Naseef, 1997*). James May notes that "when a child has a disability... a father has difficulty getting in touch with the feelings swirling inside him. He must reconcile conflicting conceptions of his role as a father and discover means for redefining himself as a man (*May 1992*)."

Little is currently known about the impact on fathers of raising a child with a disability. James S. May and Neil Tift, two practitioners who also are fathers of children with disabilities, have written about their experiences. More research is needed to help fathers and professionals who work with them learn how better to parent children with disabilities. My own thoughts are from personal and professional experiences of running fathers' workshops and groups in community agencies in the Boston area.

Fathers of children with disabilities, compared to mothers, often deal with ongoing diagnoses and treatments differently. Fathers often require more time to accept the diagnoses and tend to be more reticent to accept medications for their children when needed. Fathers may perceive their children's illnesses and diagnoses to be negative reflections on themselves (*May, 1992*). Similarly there is often resistance to participation in counseling and support groups. While fathers often need encouragement from outside individuals to participate in counseling and support groups, once they commit to participation they remain as actively involved as their female counterparts.

While the value of parent support groups is well established in the social work literature, they are a critical intervention that has often been unavailable for fathers of children with disabilities. Research studies have found that father support groups help to improve family communication, improve self esteem, reduce feelings of failure, and reduce stress and depression. In addition father support groups increase acceptance of the child's disability and enhance consistent discipline of the child (*May, 1992*). Fathers' groups are often the one place where a father can discuss his concerns, and find support and validation regarding raising his child (*Meyer, 1994*). There is special value to father led groups because the environment is more conducive to promoting the expression of difficult ideas and important emotions. In this particular environment the leader and veteran members are better able to teach and mentor new members.

As these groups evolve, particular issues and concerns often arise. Initially, fathers often join support groups to learn about managing their children's behavior from other experienced fathers who

have “walked the walk.” For example, fathers new to the group talk about specific behaviors that they are concerned about i.e., poor communication, difficult social interaction, and frequent public tantrums. Veteran dads are quick to offer techniques that have worked for them. After further discussion, however, the group members focus on how best to manage their own feelings of embarrassment about these behaviors.

Yet another area of fathers’ concerns is dealing with a new diagnosis. During a recent group a participant spoke about how difficult it was to accept his daughter’s diagnosis when he first heard it. He spoke of the doctor’s insensitive way of delivering uncomfortable news. Other group members shared that they had similar reactions. After reflecting, members spoke about how it was easier for dads to blame the doctors and the doctor’s bedside manner than to struggle with their troubling feelings of fathering a child with a disability. Group members resolved to move from anger to education. Ways to learn more about new diagnoses were shared as well as strategies for partnering with sympathetic professionals to learn about the newest research and treatment options.

New group participants often discuss the difficult question “why did this happen to me?”

During a meeting prior to Passover and Easter, group members struggled with issues of faith and how they perceived God. A number of group members attend services regularly, and reported being more prayerful during that season than during the rest of the year. One dad tried to identify the right time and place to express his anger at God. A heated discussion followed about the nature of God. Group members had varied opinions about whether God was loving or vengeful. Others resolved that there was no God and that events happened randomly. This topic always provokes an intense discussion regardless of individual members’ religions because faith or belief in a higher force is one way people may deal with overwhelming difficulties. I sought guidance from clergy of different faiths who consistently directed me to Rabbi Harold Kushner’s book, *When Bad Things Happen to Good People*. Individuals in the groups report finding Kushner’s non-judgmental answers profoundly comforting. In this book Kushner discusses God as a positive force rather than a vengeful, punishing parent. Group participants have been profoundly moved by the theological struggles of a rabbi who was also the father of a child with a disability.

Fathers may want to participate more in their children’s educational, medical, and human services meetings, however lack of comfort and experience may make increased participation difficult. Support groups for fathers provide encouragement, knowledge, and training. One important topic includes teaching strategies for advocating for optimal special education services including learning about Federal and State special education laws, legal rights, procedures, and how fathers could best conduct themselves in special education meetings. Another topic is interfacing with medical and human service systems including ways to get clarity in diagnoses and treatments. Parent participation in both of these areas often creates conflicting emotions. For example, during a recent group, fathers spoke about feeling confused and overwhelmed during crucial meetings with professionals. Individuals identified various roles that should be played in the meeting. One felt his role was to support his spouse. Another group member saw his role as

being an advocate for his child. Yet another suggestion made was that dads should serve as educators, to teach professionals more about the unique needs of their child. All dads tried to stay positive but struggled with anger and sadness as to how different these meetings were in comparison to the meetings that they attended for their typically developing children. They longed for easier meetings rather than meetings where they had to become so vigilant. During these groups we have talked about strategies for managing conflicting emotions. Many group members hired special education advocates so that they could simply be caring parents at the meetings. In addition, often providers are also not accustomed to the presence of fathers at appointments and intervention meetings. More work is needed to create a more welcoming atmosphere for fathers. Neil Tift has prepared an excellent guide called, “The ABC’s of Creating a Father Friendly Program”. The guide lists twenty six easy steps to help medical professionals, schools and human service agencies become more father-friendly. This includes having posters in the office that depict fathers as well as mothers, disseminating reading materials that are geared for fathers as well as mothers, and training staff on how to best serve dads as well as moms.

In summary, fathers often feel isolated without a natural network of support for issues related to their children with disabilities. Father-led support groups have been shown to be beneficial interventions. This article identified the importance of these support groups and key issues that have been raised by participants. These groups provide information and support and help to restore hope. As fathers benefit from support groups they will become more actively involved in medical visits, and school and human service meetings. While fathers are becoming more involved in their children’s medical, educational, and human services meetings, social workers and other professionals should evaluate current service delivery and adopt strategies to make their meetings and programs more father-friendly.

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Aging and Developmental Disability

Katherine E. Fox, MHA

“Growing old with lifelong developmental disabilities is, at once, a recently acquired privilege for many individuals, an unexpected event for families who have raised them, and a challenge for policy makers who guide, and practitioners who deliver, the various support services these individuals need to remain in their communities” (*Ansello & Janicki, 2000*).

Introduction

Adults with developmental disabilities represent a group of individuals with a broad range of interests, capabilities, physical conditions, and special health needs. Like the general population, people with developmental disabilities (DD) are also experiencing greater longevity.

The term “developmental disability” means a severe, chronic disability of an individual that: (1) is attributable to mental or physical impairment or combination of mental and physical impairments; (2) is manifested before the individual attains the age of 22; (3) is likely to continue indefinitely; (4) results in substantial functional limitations in the following areas of major life activity: self-care, receptive and expressive language, and economic self-sufficiency; and (5) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized support, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated (AUCD).

The aging of adults with DD is a recent, world-wide phenomenon that has caught policy makers and service providers unprepared (Ansello, 2004). The test facing disability service providers in the future is to obtain the necessary resources to allocate to services specifically geared to older adults in order to respond to an aging population. The challenge to those who are concerned about this population is to define constructive public policies and offer a wide array of options and supports that can accommodate their needs (Janicki and Ansello, 2000).

The increasing number of older adults with DD requires that advocates, service providers, families, legislators, and others seek opportunities for recognizing and addressing their needs. Individuals with DD have benefited from advances such as better health monitoring and primary care, more aggressive medical interventions, and efforts to improve quality of life.

Demographics

In the year 2000, there were an estimated 641,161 adults with developmental disabilities (DD) age 60 and older in the United States. It is projected that this group will nearly double in size to 1.2 million by 2030 when the last of the baby boom generation reaches age 60 (Factor, 2005). Currently about 75% of all older adults with DD are in the 40 - 60 age group. Life expectancy has increased to age 66, representing an increase of 247% between 1930 and 1966 (Janicki, Dalton, Henderson & Davidson, 1999). By 2020, 7 million persons in the US will be over the age of 85; this number will double by 2040. “Rule of thumb” estimates are that for every 1000 older adults, age 60 and over, there are 4 to 5 adults with an intellectual or developmental disability. It is further estimated that there are approximately 9,000 adults with DD affected by dementia in the United States (Janicki, et al., 1998).

Sixty percent (60%) of adults with DD live with their family of origin and, a quarter of the time, their caregivers are age 60 or older. By 2035, the number of two-generation elderly families living together where parents are 80 years of age or older and caring for a family member with DD will increase. Such in-home supports are provided by family caregivers who will be aging beyond their capacity to continue care over the next 10 to 20 years. Families will

remain living together as long as possible, even though pressing health care needs will make caregiving more challenging (Factor, 2005). Increasingly scarce Medicaid resources, the demographics of the developmental disabilities and elderly populations, and the shrinking direct service workforce converge to create a pressing need for thoughtful planning and collaboration that moves away from business as usual (Nerney, 2003).

Aging and Disability Service Systems

“Categorical responses to need have produced structures and programs that preclude proper response to human need” (Cohen, 2004).

In order to address the issues associated with a growing number of older individuals with DD, it is essential to have some understanding of the history and current issues that are characteristic of both the disability and the aging systems. Recognizing the relationships between older individuals and people with disabilities is a recent area of interest for both scholars and practitioners (Cohen, 2004).

Many of the aging related concerns of individuals with developmental disabilities are the same as those of elder in general: maintaining good health, remaining at home and in the community, having a meaningful retirement that sustains lifelong contributions, and having access to environmental modifications and assistive devices that facilitate aging in place. As with society in general, people with DD are aging, and facing many of the same choices regarding healthcare, retirement, and living options that are faced by the general elder population. In the United States, we distinguish aging and disability as separate entities. When federal initiatives to develop services began, older adults and people with disabilities were tracked along separate political agendas. Many of the disability-related policies in recent years (e.g., the American with Disabilities Act (ADA) and the Individuals with Disabilities Education Act [IDEA]) have been focused on civil rights. This civil rights focus has not appeared as the foundation for aging policy until very recently (Putnam, 2004).

For many years, advocates have been demanding equal access, as well as equal rights, for people with disabilities. Emphasis has been on creating the same choices and opportunities that are afforded other people in our communities. These opportunities and best service practices need to be afforded to people with disabilities at all ages, throughout the lifespan (Blaney, 1994).

Elder populations compete with each other for resources and attention. Concern with the health issues affecting older persons with lifelong disabilities is relatively recent. Research and advocacy efforts are relatively small compared to similar efforts for elders or people with disabilities more generally. Small numbers combined with a short history of both research and service provision means that resources for elders with lifelong disabilities must compete with better established and defended requests (McCallion & McCarron, 2004). These common concerns underscore the importance of aging and developmental disability collaboration at the national, state, and local levels.

At the same time, most, if not all intersystem collaborations face numerous challenges initiating and sustaining alliances. Systematic

collaboration between aging and disability service organizations must confront obstacles ranging from fundamental differences in beliefs regarding disability to a long history of very separate service delivery systems, an aging system based on a medical model and a disability system based on rights and choice (Cohen, 2004).

The Impact of Aging and Disability Stereotyping

For decades, there has been controversy over whether to create a separate senior services track for people with developmental disabilities or to collaborate with the aging services network. These concerns arise from the devaluation of elders in our society and the inherent problems associated with enrolling people with DD in service structures designed for a devalued population (Blaney, 1994). When chronological age becomes the major criterion for describing one's peer group, the needs of the "elderly" are presumed to be predicted by their oldness.

When disability becomes the predominant definition of a person, the potential for true acceptance and recognition of individual capacity is diminished, if not lost altogether. Taken together, the combined stereotyping and discrimination of both groups places older adults with developmental disabilities in a new and devalued categorical group. When we group people by "old" as a principle specialization of services, we are likely to create programs based on the false assumption that older adults all share common interests, desires, and abilities. This assumption guarantees that the essential individuality and uniqueness of each older person is lost and is replaced by the stereotypes and prejudice we call ageism (Blaney, 1994).

Judy Heumann, co-founder of the World Institute on Disability, offers the following perspective on segregating services to older individuals:

"It has taken an enormous amount of time, energy, and emotional turmoil for me to recognize that a segregated system is wrong for younger disabled individuals. My experience convinces me that a segregated system is also wrong for the elderly. I know how hard most disabled people have had to struggle to learn how to respect ourselves as equal human beings. I also know that elderly people see disability as an indication that they are also at death's door. I fervently believe that the issue of segregation of service delivery for the elderly must be understood and resolved before the elderly find themselves disabled and set aside from those they previously considered their peers – namely, non-disabled people, young and old. We must stop erecting buildings and developing programs that further divide and segregate the elderly and disabled from others (Heumann, 1986)."

Although there are increasingly more examples of highly effective and personal support models for older adults with developmental disabilities, patterns of role exclusion, age segregation, and narrowing choices prevail. It is striking to realize that many of the same individuals whose freedom and opportunities for community we fought so relentlessly during the height of de-institutionalization are the very same people at risk of further segregation and decreased self-determination due to age (Blaney, 1994).

Many older individuals with developmental disabilities do not currently have individualized services designed to meet their needs as they get older. For those individuals still living with their families, often information and resources that might help assist their family member are not well understood. Many community-based services for senior citizens are not prepared to meet the special needs of older adults with disabilities. And many disability-based organizations do not recognize the problems of older adults with disabilities and are not prepared to address their needs (AAMR/The Arc, 2002).

Person-Centered Planning

Older people with DD are entitled to community support, including help from those agencies that serve the needs of all senior citizens. This group of individuals wants to enjoy their older years in the same manner as other people their age. For many, this will require greater levels of support. As they age, it is important that they remain respected members of the community. People with DD who are older should be afforded the same rights, dignity, respect, and opportunities as other older people in their communities, have access to housing, health care, social services, transportation, and other services available to all older Americans in their communities and should be free from the fear of inappropriate institutionalization due to age-associated decline (AAMR/The Arc, 2002). Person-centered planning (PCP) is one strategy for designing such inclusive supports and services to older individuals with DD.

PCP is a generic term encompassing a variety of techniques and approaches designed to reveal the unique capacities of individuals to create more desirable futures and have more control over their own lives. This approach is consumer directed and can be used to assist elders with DD, their families and caregivers in developing plans and achieving goals that maximize the utilization of natural supports and personal networks and facilitate the continuation of home and community life that most individuals desire. PCP practices contradict aging stereotypes and distinguish between planning for a person and planning for "the elderly". When individuals with DD want to continue their social, spiritual, educational, or recreational engagements, PCP can assist in designing the essential supports needed to accomplish these goals (Mount, 1994).

PCP brings the individual with DD and the friends, family, neighbors, and service providers he/she desires together. Meetings are led by a facilitator who uses one of the person centered planning tools (O'Brien and Lovett, 1992). The group agrees to specific roles and tasks related to creatively using resources and supports to implement the elements of the person centered plan. Examples of such elements might include desires relative to one's home, vocation, health supports, adaptive equipment, community membership, education, social relationships, travel, spiritual practice, end-of life care, and family. This group acts as a source of support and meets as needed over time to respond to changing needs as illustrated by the following story.

Mary is a 78 year old woman who has lived to get up early to start her day at work. She fully appreciates the importance of having someplace meaningful to go, having spent decades in an institution for people with mental retardation where she spent many years do-

ing very little. Even after being diagnosed with cancer and becoming ill very quickly, Mary had no desire to retire. Mary, her friends, and support workers utilized the principles and practices of person centered planning to think about the supports needed to keep her involved in the routines, rituals, and relationships that she said made life worth living. As a result, supports were designed that make it possible for Mary to work from home when she wasn't feeling well, to have neighbors and friends to her home several times a week for a meal or a visit, to be accompanied to her medical appointments by someone who had known her for many years, to learn how to use email to send notes and photographs to her co-workers, and to make plans to celebrate her next birthday with her sister in California.

Later life PCP incorporates a perspective of increasing control of one's life and increasing decision through providing information, skills training, and opportunities to make informed choices. This approach rests on the belief that both growth and change are possible throughout the life cycle and that successful adaptation to many of the developmental tasks of older adulthood can be assisted through thoughtful planning (Sterns et al.).

Conclusion

The challenge to those who are concerned about this population is to define constructive public policies and offer a wide array of options and supports that can accommodate individual needs (Janicki, 1994).

The history of aging and disability has segregated people by ages, even though many similar concerns and perspectives exist. Our ability to collaborate in ways that create responsive policies and services for this broader heterogeneous population will require much hard work, outreach, understanding and knowledge development. Such efforts can broaden our own understanding of the human experience of aging, with or without a lifelong disability (Putnam, 2004).

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Cultural Considerations of Disability: A Cultural Competency Tool as Applied to a 15-Year Old With Dyslexia

Zarita Araújo-Lane, LICSW; edited by Vonessa Phillips

Human beings share an interwoven fabric comprised of many threads. Among these are honor, respect, generosity and trust. But for many reasons -- socioeconomic status, ethnicity, age, gender, disabilities--we may not always feel honorable, important or empowered to share our feelings--both negative and positive--about

who we are.

Carina, a 15-year-old high school Honors Student, has written courageously over the years about being dyslexic. This article will examine some of Carina's writings and identify the main threads that run through her accounts of her struggle with dyslexia. Then, the author will introduce a cultural competency model, The Four Character Values, as an assessment and intervention tool.

When we discuss "threads" in this article, we are referring to core values. When interwoven, our many threads create "layers" of culture. All of us, as individuals, carry many layers of culture. There are layers of the "inner circle", which include our age, race, culture, ethnicity, religion, socioeconomic background, language, disabilities, and immigration status. The layers of our "outer circle" relate to how we feel we are perceived by institutions and individuals. The outer circle is influenced by expectations and normative functioning based on the values of a majority group.

"My mother and I stand in the middle of the pool. We are surrounded in an island of light and the only thing in my world is her. I am like a monkey clinging to her body, she holds me above the water; above all shame and fear. We stand together completely alone, a mixture of chlorine with a hint of safety hanging in the air like a blanket. My cheek which is resting against her throat sends the vibration of her voice down my neck.

"The family friend that she is talking to nods his head in understanding, his white face made almost iridescent by the pool's light. My mother is telling him about the latest subject in my life. Something that makes me feel special. Something that makes me feel like I could fly.

"Later that night, in the same pool my mother goes over what she had told me months ago. "Carina," she says, "you know that you are different. You are special; you have something that makes you shine like no one else.

"That night the sky had been so black, it was like someone used magic marker to color out the stars. The only light I had was my mother.

"Sometimes when people are dyslexic it takes them a longer time to learn things, because you see the world differently from most. Sometimes seeing the world in a different way is going to be difficult for you, but it's going to be something that makes you special. Something that makes you, you.

"My mother was telling me that I was dyslexic. She was telling me that I was born different, that life was going to be harder for me, because my brain and my eyes don't always agree on what direction a letter is pointing. But on that night in Florida, my mother tells me that I am not stupid or lacking what I should have, but that I am special. I am something amazing, different and unique, because of my "disability."

"The way that my mother handled telling me about my

dyslexia changed my life. Growing up, I was aware that I had a learning disability, but to me I never viewed it as if I was lacking something that I should have had. My mother made me feel like I had a magic power. She taught me that even though I was going to struggle with dyslexia for the rest of my life, it was going to be something that ultimately gave me strength and insight that others could not achieve. I am forever grateful for that.

Two main threads in Carina's stories are those of loneliness and shame:

"We are surrounded in an island of light and the only thing in my world is her. I am like a monkey clinging to her body, she holds me above the water, above all shame and fear".

But at the same time, Carina carries a sense of inner strength:

"But on that night in Florida, my mother tells me that I am not stupid or lacking what I should have, but that I am special. I am something amazing, different and unique, because of my "disability."

Carina's sense of inner strength may have been fortified by the core values of her family culture. Her parents, both human service providers, adopted a family policy of "no secrets". They felt that they owed it to their children to be open about Carina's dyslexia, and they continuously reassured her that although she at times feel "alone", she has family and friends who know about her disability and support her:

"The way that my mother handled telling me about my dyslexia changed my life. Growing up, I was aware that I had a learning disability, but to me I never viewed it as if I was lacking something that I should have had. My mother made me feel like I had a magic power. She taught me that even though I was going to struggle with dyslexia for the rest of my life, it was going to be something that ultimately gave me strength and insight that others could not achieve. I am forever grateful for that."

Anne Fadiman, in her book, *The Spirit Catches You and You Fall Down*, relates a conflict between the California health care system and a Hmong family. The family perceived their daughter's seizure disorder as the result of a divine force that made her a very special person. On the other hand, medical providers describe the disorder as a horrible illness needing treatment. Two very different takes on a disorder: is it a "blessing from God" or a "curse"?

A similar conflict occurred between Carina's parents and kindergarten principal in regard to her dyslexia. At first, Carina's parents felt a certain shame. They wondered if they had done something wrong (who passed the "bad" genes to her?). But they knew that their daughter was a very special little girl.

By the age of five, Carina would come home and tell her parents that her teachers were not showing how they really felt about her. On many occasions, she told her parents that the teachers confused her, because "they say nice words but their mouths are not smiling." Carina's parents were amazed at her ability to read facial expressions and capture the feeling of a moment.

While in pre-school, Carina would have trouble with the letters of the alphabet when expected to follow a sequence with other children. When her turn came, she would blurt out a random letter, and her teachers would say, "Carina, you're trying to trick me!" Little did the teachers realize that Carina was beginning to experience her learning disability.

A year later, when she entered kindergarten, she was extremely anxious and under pressure to perform. She loved to listen to stories and to look at the pictures, but she could not correctly read most of the words. There was a pattern to her reading that her parents noticed: she inverted words and she mixed the letters "b" and "p". She also had a hard time with words that were not representative of objects.

Carina was bright, sensitive and extremely caring towards others, but she was lonely and felt terrible about her learning progress. Most schools will tell parents to wait until first or second grade for testing for dyslexia, but Carina's parents requested an immediate evaluation.

Carina had all the symptoms of a child who was dyslexic. But the school was reluctant to call her dyslexic and in fact the principal tried to convince her parents that it would be better if Carina and her classmates were not aware of her disability. He believed that this would cause her unnecessary distress. Her parents disagreed with his recommendation and decided to validate her "anxiety" by telling her the truth.

When Carina seemed extremely nervous about going to school, her parents listened to her feelings and helped her express herself by narrowing them down until she was able to identify the one that was the most worrisome. One summer night before starting first grade, she expressed great anxiety about going back to school and how she was going to handle the fact that she still could not read. Her parents walked her through these feelings and she cried. She was scared of how she would be perceived by teachers and fellow students. Her mother asked her how she perceived herself and suggested that she give a speech to the class about her dyslexia. Carina asked her older sister to type the following speech as she recited it:

"It all began when I was a little baby. When I saw my mother's elbow, a picture of my mother's head would come to my head. Or, if I saw a kitten curled up in a ball-regular people would see a ball, but I would see a kitten. Some people who have dyslexia are very famous. In fact, they include: Whoopi Goldberg, Albert Einstein, Jay Leno and even Walt Disney. Albert Einstein had it the worst.

"The reason why it is so hard for me to learn how to read is because when my brain sees a letter, it sees lots and lots of letters; upside down, sideways and even apart. Dyslexia is a condition that different brains have. It doesn't really matter if it runs in your family, it just happens.

"The best way that dyslexics can learn how to read is probably memorizing the words and recognizing them by memory. The dyslexic's brain works like anyone else's brain, it's just harder for them to learn how to read."

Thus, Carina set the tone for the new school year--she was not hiding something that would be a part of her life from now on. She was free to learn! Carina and her family had added another layer to their fabrics: the culture of living with dyslexia. At home, to help Carina cope with the dyslexia that would so heavily impact her life, her parents used storytelling to share personal experiences of feeling different or of feeling a sense of loss. Their stories were genuine and were a great way for the family members to connect with each other's inner and outer circles. Two years ago Carina wrote about one of these stories:

"My mother grew up in the Azores, a group of nine islands in the North Atlantic that are part of Portugal. When she was my age eleven, the Portuguese were having a civil war with the African colonies. The colonies wanted to become their own country. At night my mother would dream of losing her family "What will happen to me if they die or get hurt?" Every day she thanked God that she didn't have any brothers, so they would not take place in the bloodshed. The very thought of war filled her with sorrow and pain. It hurt her to think how many lives were being lost.

"With these feelings, you could just imagine how she felt when one sunny morning, she woke up to find the American Navy infested on the beach of her childhood, where many summer days were spent laying on her back letting the sun's warmth engulf her. Men in camouflage crawled in the sand with guns in their muscular hands, while amphibious boats painted in menacing green, parked on the sloping ground, looking awkward, as if wondering why they would be needed in such a beautiful place. The Americans were fighting in the Vietnam War. My mother knew this because she had read many articles about how they had burned villages, and killed many people.

"At that dreadful moment my mother thought the worse, that the mighty army that wore red, white and blue, had come to crush and destroy what and who she loved most. Luckily the American men had only come to her island for a drill. She recalled how at the end of their practice they threw out green army blankets and chocolates in the sand, instead of giving the children the treats from their hands, as if in some way the soldiers were greater than her friends and family. Also, the Americans were cocky and arrogant. "How dare they come to our shores and act as if we were below them!" From then on, during my mother's childhood America was not her favorite country!

"As she grew older she began to see that not all of the Americans were like the soldiers that she saw on the beach. "I think what happened" said my mother, now forty-four, "was that when I was younger I only saw one side of things, but as I got older I began to realize that there are always two sides of a conflict and that you have to see both of them."

In consideration of the many layers of Carina's cultural fabric, we recall a cultural competency model created years ago by the author of this article. This model, The Four Character Values, is a valuable tool for application as a clinician, a parent, a professional, and in everyday interactions with others.

The Four Character Values is based on the premise that all human beings have an inner "tree", with roots (honor), branches (respect), leaves (generosity) and a canopy of trust.

How we grow our trees and how we expose our roots will differ from individual to individual (inner circle) or from country to country (outer circle). But we all know that a tree with damaged or missing roots will die.

Honor is a sense of worth or dignity that is defined in a person's traditions, rituals, beliefs or history. In general they are buried, at a subconscious level. A person acts a certain way based on a value that has been passed on from generation to generation. A person or a family may also grow a value into a root so to balance other values (generally ethnic values) that didn't work well for them.

New roots can be added to the tree as an individual is able to integrate new ideas from the inner and outer circles. In Carina's story, we see the family tradition of "no secrets" and open communication. These values were passed on by her parents through positive reinforcement and storytelling as an attempt to add new beliefs to their original roots. This new tradition was in some ways contrary to her mother's upbringing, in which secrets were acceptable whenever they protected a child or a family from forces of the outside circle. Apparently, the principal of Carina's school shared a similar view on secrets.

Another root was being Portuguese, and her mother's account of not picking up the candy thrown on the ground by American soldiers conveyed a sense of honor. Carina's religious values were instilled by her parents and her Reform Jewish background, through rituals such as preparation for her Bat mitzvah. Another of Carina's "roots" or values, is the understanding that as a dyslexic person, she would better manage three dimensional objects and facial expressions than letters and numbers.

Respect is the acknowledgement of a person's roots. Respect can be broken because one does not always know another person's roots or values. The good thing is that respect can be repaired as long as the offender does not justify his or her actions or impose personal values on others. Respect can be manifested by listening to a person, and accepting their information as valid, even if you don't agree with it. In Carina's story, her parents showed respect by listening to her stories about school and to her anxieties and fears. Rather than allow Carina time to describe the teachers' faces, other parents might have just said, "I just don't see it, honey. I'm sure your teachers like you a lot!" Carina's parents, by respecting her values, helped her to find solutions to the challenges of dyslexia.

Generosity is the willingness to do something out of the ordinary that creates a sense of common ground. Storytelling itself is a form of generosity, and when parents or therapists take time to genuinely echo their children or patient's fears in story form, the result is often a growing dynamic of trust, or as Carina put it, "a hint of safety hanging in the air like a blanket".

As a therapist or a parent, it may not always be easy to show respect through the acknowledgement of a patient or family member's roots, especially if they are different from your own, or if the person in question doesn't fit your preconceived notion of what is normal or acceptable for the group of which you perceive the person to be a part. For example, as you were reading the introduction to this article, you may have found it difficult to identify with Carina as an Honors student, especially if your experience with

dyslexic individuals has been limited to those whose cognitive and emotional levels have not reached those of Carina at this stage in her life. Or you may have found it difficult to reconcile Carina's Jewish religion with her Portuguese ethnicity.

Two strategies that may help you to a more "culturally competent" path are to identify and understand your own cultural triggers and to find common ground with your patients or coworkers, which is a form of generosity. Cultural triggers are any action that hurts your roots as an individual. These triggers are shaped by your own layers of culture, which as considered above, reach far beyond language and ethnicity into your cumulative life experience. Your cultural triggers are like "hot potatoes." When you know what makes you tick, you can then learn to better manage your reactions to certain situations and to pass those "hot potatoes" along so that no one gets "burned".

A way to establish common ground with your patients or colleagues and thus exercise professional generosity is to approach matters by first echoing the thinking of the person in question. Phrases like, "It seems to me that..."; "Is it true that...?"; "Can you tell me more about...?" and "Am I hearing you correctly when...?", all serve to open a culturally sensitive dialogue around delicate issues.

A culturally sensitive approach to the assessment and treatment of learning disabilities worked for Carina. Her parents were able to work at home and within themselves to integrate Carina's inner and outer circles and did not seek therapy. With many of the Portuguese families that I have treated, one of the first issues to be addressed was how they were going to handle their outer circles. The first challenge was to work around the stigma of seeking help from an outsider. We see this value less and less as a family's socioeconomic situation changes.

In conclusion, find common ground with the individuals or families you treat. If you begin to feel "turned off" by a root of value of a patient or coworker, take a deep breath and a moment to reflect on your inner and outer circles. See what your reaction to that person reveals about the inner you.

Do not start relationships based on differences, but rather find something in common with the individuals you work with, and connect around that commonality. Recently, Carina went to the school nurse, who started the interaction with the comment that Carina's last name is the same as her daughter's maid -- perhaps not the best introduction!

Likewise, when your patient or coworker is noticeably different, (for example, if they have a foreign accent), asking, "You have an accent--where are you from?" is not the best way to connect with the person. This can be a very personal question, and you may have to work to earn a person's trust before they share this information with you. An alternative conversation opener with a patient might be, "Can you tell me how you feel about being here?" If the conversation leads to the pressures of the outside circle, perhaps a stigma about seeking behavioral health services, you might tell a story that acknowledges the issue and provides open-ended tools for coping.

I find storytelling a great way to learn about a patient's tree. As you are listening to the patient, draw a tree and begin to write on different parts of the tree, the values and behaviors expressed by

the patient. Or you can write the values down on a piece of paper and ask the patient to place them with you on the right parts of the tree. You can also draw inner and outer circles and have the patient place values in either or both categories.

There were times when I first met with patients outside the clinic so that the community would not see them enter the clinic. With any other subject, we therapists are so good at meeting a patient "where they are", but when it comes to the physical location of treatment sessions, we generally expect them to meet us where we are! But if the location of a session will make the difference as to whether a patient comes for treatment or not, then why not be flexible?

This story is a personal story. As I was going to write about my clinical work, I came across some of my daughter Carina's writings, and I decided to share her story instead. We, as Carina's parents, joined later by her teachers, helped her to express, understand and manage the challenges of dyslexia. And Carina is thriving as a student, a writer and a captivating young person!

Then, just like that, I had it. It was a poem about bears, honey, and rainbows, something that any satisfied six year old would have thought up, but I scribbled it down on piece of paper and showed it to my mother. "Carina," she exclaimed after reading it, "that's beautiful, you're a writer!".

And just like that I was. My mother showed my masterpiece to my father who praised it, his voice glowing, then she showed it to my first grade teacher, who typed it up for me on a piece of paper decorated with rainbows. I can still remember thinking that my rainbow-decorated poem was the prettiest thing I had ever seen. To this day I love to write, and know that no matter what I end up doing, my skill of writing will be with me.

Sometime I wonder if I love writing because I was destined to love it, or because my mother told me I was good at it. I wonder if she had reacted differently about that poem, if she had laughed at it, or gone back to reading her newspaper after viewing it, if I would have still found my passion in words. Thanks to the reaction I received when I first showed my writing to my mother, I have had the confidence and the drive to expand my writing ability. No matter whether I'm writing an essay for history, short story for English, or a regular homework for science, I find joy in putting my thoughts in words. That is the unique gift my mother has given me. She has shown me something that makes me happy, something that will be a tool for me no matter what I choose to do in my life.

***Zarita Araujo-Lane**, LICSW is the president of Cross Cultural Communication Systems, Inc. in Woburn, MA. She has over 20 years experience working with cross-cultural populations in medical and mental health organizations. Zarita is a native of Portugal and speaks Portuguese and French. She has published articles in Cross Cultural Management including a chapter written in 1996 and 2005 on "Portuguese Families" for the book, *Ethnicity and Family Therapy* by Monica McGoldrick. She is also an interpreter and translator for the Portuguese language and has co-authored several articles on medical interpretation for different publications by the American Translations Association and for the Cross Cultural Communicator at her own agency. Contact: zaraujo_lane@cccsorg.com*

Issues In Disability & Chronic Illness Across The Lifespan

Post-Test Questions & Answer Key

1. In Snyder-Grant's paradigm of "disease, illness, and sickness" the concept of "sickness" relates to:
 - a) The cultural meaning we give to disease and illness
 - b) Familial responses to illness and disability
 - c) The medical aspects of disease
 - d) All of the above
2. Susan Sontag's notion of "illness as metaphor" conveys that:
 - a) Serious illness is a result of a child's unhealthy dependence on the mother
 - b) Cancer can be typical of people who suppress emotions
 - c) Serious illness is seen as a obscene and repugnant
 - d) None of the above
3. Questions that are helpful to ask a client with an illness are:
 - a) Have your religious views/beliefs or lack of them contributed to your illness?
 - b) What meaning have you given to your illness?
 - c) Why do you think you became ill?
 - d) All of the above
 - e) B and C
4. The stigmatization of people with disabilities creates a vicious cycle that can perpetuate:
 - a) Social isolation
 - b) Symptomatology
 - c) A disadvantaged "general profile of life chances"
 - d) A strong bond with other stigmatized individuals
 - e) A, B, and C
5. "Anti-stigma" work in clinical social work practice can include:
 - a) Cognitive-behavioral approaches to help clients reframe stigma.
 - b) Assisting individuals to adhere to medication regimens.
 - c) Advocacy campaigns including letter writing and phone calls.
 - d) Education programs in which people with disabilities themselves provide information.
 - e) A, C, and D
6. When a social worker becomes ill or disabled, planning for one's caseload should include the following:
 - a) Dealing with the question of when to inform clients about one's medical leave.
 - b) Arranging coverage for anticipated absences.
 - c) Deciding how much information to provide clients.
 - d) Securing releases to share information with colleagues.
 - e) B and D
 - f) All of the above
7. Aberman believes that positive outcomes of working with a therapist who becomes ill or disabled may include:
 - a) Providing a model of courage and hope in coping with adversity
 - b) The opportunity to confront separation, loss, and death
 - c) Increased motivation to change
 - d) Grappling with the prior effects of illness in significant others
 - e) All of the above
 - f) A, B and D
8. "Attentional Drift" by a therapist refers to:
 - a) Therapists' short attention spans
 - b) A therapist with ADHD
 - c) A disruption in the therapeutic process due to the therapist's emotional reaction to their own illness or disability
 - d) Memory lapses by the therapist
9. _____ is one strategy for designing inclusive supports and services to older persons with developmental disabilities.
 - a) Planning for the elderly
 - b) Person Centered Planning
 - c) Nursing home diversion
10. The father of a child with a disability may:
 - a) Often repress emotions
 - b) Experience difficulty understanding his feelings about the child
 - c) Feel shame and low self-esteem related to the child with a disability
 - d) All of the above
11. Fathers differ from mothers in their response to a child's illness or disability in the following ways:
 - a) Require more time to accept the diagnosis
 - b) Perceive their child's illness/disability to be a negative reflection on themselves.
 - c) More quickly accept need for counseling and support groups.
 - d) A and B
 - e) A, B, and C
12. Tools that may be helpful in diagnosing and developing clinical social work interventions to the child and family include the following:
 - a) A family systems approach
 - b) An ecological perspective
 - c) Developmental stage theories
 - d) Constructivist theories
 - e) All of the above
13. Challenges for parents of adolescent and adult children with disabilities are:
 - a) Mitigated by a growing child's independence.
 - b) Made simpler by greater social services available for adults with disabilities.
 - c) Made more difficult by the withdrawal of the school as a primary source of support for children and adolescents.
 - d) Similar in scope to those raising children without a disability.
14. When describing layers of culture, the "Outer Circle" refers to:
 - a) Race
 - b) Expectations and normative functioning based on majority group values.
 - c) Disability status
 - d) Core family values
 - e) A, B, and C
15. The Four Character Values is:
 - a) A cultural competency model
 - b) Honor, Respect, Trust and Generosity-four values based on our inner "tree".
 - c) A useful tool that can be applied by professionals/parents in their daily interactions.
 - d) All of the above.

Focus CE Course Evaluation - July 2006

Issues In Disability & Chronic Illness Across The Lifespan

Please indicate whether the following learning objectives were achieved:

1. Apply the concept of culture, stigma and meaning to the experience of illness/disability.

Achieved in full 5 4 3 2 1 *Not Achieved*

2. Understand the social/emotional impact on clients and on social workers as they deal with their own illness/disability.

Achieved in full 5 4 3 2 1 *Not Achieved*

2. Understand the impact of illness/disability on various groups, including children, older people with developmental disabilities, and fathers of children with disabilities.

Achieved in full 5 4 3 2 1 *Not Achieved*

Please evaluate the course content:

4. This course expanded my knowledge and understanding of the topic.

Achieved in full 5 4 3 2 1 *Not Achieved*

5. The course material was clear and effective in its presentation.

Achieved in full 5 4 3 2 1 *Not Achieved*

6. This course was relevant to my professional work/interests.

Achieved in full 5 4 3 2 1 *Not Achieved*

7. As a result of this course, I learned new skills, interventions or concepts.

Achieved in full 5 4 3 2 1 *Not Achieved*

8. The resources/references were comprehensive and useful.

Achieved in full 5 4 3 2 1 *Not Achieved*

9. This course addressed issues of diversity and/or the social justice implications of the topic.

Achieved in full 5 4 3 2 1 *Not Achieved*

10. Please provide comments on current course and suggestions for future courses.

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