

THE JOSHUA STORY: How Personal Experiences Can Inform Professional Work

This narrative describes the way in which experiences with my son, Joshua, who has multiple handicaps, have informed my understanding of the true meaning of social work. Through the process of becoming a recipient of help, I have developed new insights into the helping process and a deeper commitment to reforming our formal networks of care so that they more effectively assist people in finding their own voice within a community of others in the midst of suffering.

by Kathleen H. Powell

Kathleen H. Powell, M.S.W. is Chair, Department of Social Work, Frostburg State University, Frostburg, MD

Frederick Reamer (1987) writes about social work as a "calling" similar to that traditionally linked to the ministry. This principle has been true in my own experience. I wanted to become a social worker before I even knew what social work entailed. I don't quite know how to explain this. It's not that I had any personal experience with a social worker. Perhaps my "calling" came out of growing up in an area with a high poverty rate. Or perhaps, it came out of growing up in the 60'S during a time of great social change. Whatever the reason, for me, social work is a master status — part of my identity, my soul, my life. I can't imagine being anything else.

Despite my close identification with the profession and years of education and practice experience, I don't think I fully understood social work until recently. This narrative is about the lessons I have learned regarding the true meaning of social work and about my teacher, my son, Joshua.

For most of my life, I have led a relatively charmed existence. I have always enjoyed the benefits of a stable family, a comfortable home, a fulfilling career, and a decent income. Be-

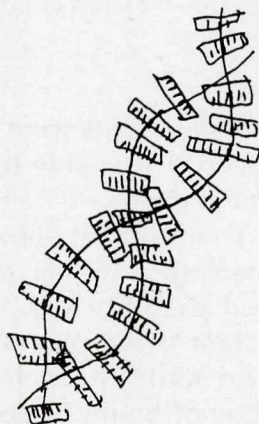
cause these benefits were never threatened, I was able to take them for granted.

Four years ago, however, with the birth of Joshua, my life changed dramatically. Over these last four years, my husband and I have logged hundreds of hours in doctors' waiting rooms, frequented the lobbies of numerous hospitals and clinics, spent many sleepless nights, and cried oceans of tears. The reason is that Joshua is multiply handicapped. At four he is unable to sit up, roll over, crawl, walk, or talk. He does not use his hands partly due to a condition the therapists have called sensory defensiveness in which normal sensations are experienced with displeasure and pain. He has between three and eight seizures a day that are interspersed with "myoclonic jerks," a series of startle responses stimulated by internal "misfirings" in the brain. He is chronically constipated which, I have come to understand, is a common problem associated with severe physical handicaps. Several times each year he is hospitalized with pneumonia due to his tendency to aspirate his own secretions. The worst part of all is that Joshua rarely smiles. He

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is frequently miserable — moaning and crying. When he is happy, he seems to be completely oblivious to his surroundings. Our family album is filled with pictures of Josh sucking his thumb and staring endlessly into space.



The doctors (and we've seen many) have not been able to determine the cause of Josh's problems. I had a normal pregnancy and delivery and family histories on both sides are devoid of problems. About two years ago, two MRI's, four tissue samplings, and countless blood and urine tests, we were told that Josh had a relatively rare genetic disorder known as Batten's Disease in which the body's cells slowly die due to an accumulation of a fatty substance. Being an academic, I immediately went to a genetics text which provided the following information:

Batten's Disease (neuronal ceroid lipofuscinosis: NCL) A group of invariably fatal childhood neurologic nervous system disorders. The first symptoms are deteriorating vision or seizures, progressing to personality and behavior changes, loss of communication skills, increasing spasticity and loss of motor skills, facial grimac-

ing, abnormal body movements, and mental impairment. Affected children eventually become blind, bedridden, and demented. . . . Currently there is no treatment available. Research on animal models is being conducted. . . (Wynbrandt and Ludman, 1991, pp. 37-38)

The news was so horrifying that I skipped the rest and went to the last section of the text that described the type of Batten's Disease the doctors thought Josh had. It read:

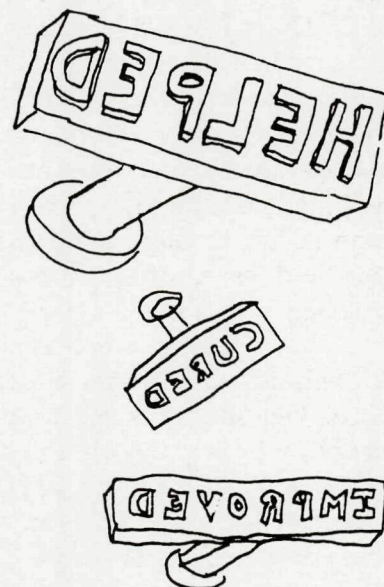
Infantile (Santavuori disease). Age of onset is about eight months and progresses rapidly. Infants fail to thrive, head growth slows, resulting in an abnormally small head (Microcephaly), and they exhibit shock-like muscle contractures (myoclonic jerks). Death usually occurs by age five, though some have survived a few years longer in a vegetative state (Wynbrandt and Ludman, 1991, pp. 37-38).

I remember sitting on the floor of the library, hidden in some out-of-the-way stacks, sobbing for what seemed like an eternity.

Over the last year, Josh has not deteriorated as the textbook and the doctors said he would. In addition, subsequent tests and medical consultations have indicated that, in fact, Josh probably does not have Batten's Disease. While we were glad to learn this, we received the news with mixed feelings. We were in limbo once again with no label to assign, no one to blame. We have given up (at least for now) the hope of ever knowing the cause of Josh's problems. In some ways, it doesn't really matter what the cause is. The only thing that matters is the result.

In my quest to discover ways to cope with this situation,

I have consulted many people from many different disciplines, some of them social workers just like me. I have read many books, some of them written by social workers just like me. But, true to the old adage, experience has been the best teacher. My experiences over the last four years have taught me what it feels like to be caught totally off-guard and stripped of normal coping mechanisms. In addition, my personal experiences have given me deeper insights into the helping process; insights that have impacted on my professional work. Probably the most significant lessons in this regard have come about through the process of becoming a recipient of help.



Learning how to ask for and accept help requires a resocialization process. I suspect that this resocialization is difficult for most independent people; however, it is particularly difficult for one who has been socialized (formally and informally) to be a giver of help. Through my experiences, I have

learned how to sit humbly at a church dinner to raise money for Josh's medical expenses. I have learned how to become an advocate when, in meetings with school personnel, it was clear that they felt they alone were the experts in determining Josh's educational plan. I have learned how to be on the other side of the therapy room and describe my rage, my pain, and my never-ending sadness to a mental health professional who concluded that I was depressed and needed to be on medication. I have learned how to smile and say thank you to the neighbor who brought dinner for our family or the friend who offered to babysit our older daughter while we took Josh to the hospital for tests. I have learned how to bare my soul in support group meetings as the other members tried to "solve" my latest problem. In short, I have learned more about helping from these experiences than I have through my education and years of social work practice.

Admitting to one's need for help is a disquieting experience. Our society is not kind to people who are unable to deal effectively with their own problems. While we social workers give lip service permission to those who seek help in whatever forms, the fact of the matter is that we are part of a residual "system" of care that operates on the principle of "less eligibility." We live in a confusing world where reaching out for formal help is viewed either as (a) a sign of weakness, (b) an attempt to secure more than one is legitimately entitled to, or, at best, (c)

a trendy journey to what Harry Specht and Mark Courtney (1994) have termed, "The Church of Individual Repair." Regardless of which label is applied, the bottom line is that the systems within which we work often blame people for their problems. This blaming operates in very subtle ways even in situations where there is a collective compassion at work.

For the most part, people have not held me accountable for my son's disabilities. They recognize that I took appropriate precautions during my pregnancy and delivery, all meant to ensure a healthy child. Generally speaking, most people feel sorry for me. They see our family as people who had the poor misfortune of being the carriers of a genetic malfunction. Despite these compassionate stereotypes, people still hold us accountable to a standard of healing which specifies a time limit on mourning as well as specific coping strategies to deal with losses such as ours. Our being depressed (past the period of initial grief) has not been viewed as socially acceptable; therefore, the suggestion has been to medicate it away. Our being angry with the school system about the fact that our son is without physical therapy services has not been viewed as socially acceptable; therefore, the suggestion has been made that the anger we feel toward the school system is merely the displaced anger we feel about the fact that we have a child with special needs. The fact that we have problems that are likely to get worse rather than better has not been viewed

as socially acceptable; therefore, some have chosen not to relate to us at all, or at least, to relate to us in limited ways. Being deviant is a lonely place in which to find oneself.

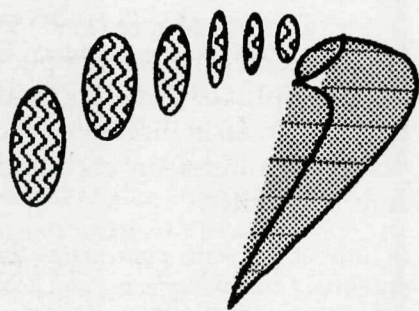
Don't misunderstand me. Not all of the help I have received has been controlling and blaming. Some of the most meaningful kinds of help have been those that have validated my feelings as normal, been patient with my own process of healing, and not attempted to offer pat solutions and quick fixes. Through my own personal experiences, I have learned that social work is not about rescuing people from their pain in an artificial sense. Rather, it's about helping people find ways to learn from their suffering in their own due time. A very wise clinical supervisor of mine once reminded me that sometimes things have to get worse before they get better. As a result of my experiences, I now have a deeper understanding of what she meant.

Thomas Moore (1992) in his book, *Care of the Soul*, applies the principles of Carl Jung and James Hillman in discussing the distinction between care and cure. He writes:

It [care of the soul] appreciates the mystery of human suffering and does not offer the illusion of a problem-free life. It sees every fall into ignorance and confusion as an opportunity to discover that the beast residing at the center of the labyrinth is also an angel (p. 20)... I often think of this paradox as I sit with someone with tears in her eyes, searching for some way to deal with a death, a divorce, or a depression. It is a beast, this thing that stirs in the core of her being, but

it is also the star of her innermost nature. We have to care for this suffering with extreme reverence so that, in our fear and anger at the beast, we do not overlook the star (p. 21).

I think that in my practice as a social worker and in my experience with my son, and others I have been too quick to "slay the beast," that is, to remove the pain. The most meaningful kind of help, however, is that which is offered within the very context of that pain. It does not pretend to offer externally produced answers but rather enables people to discover themselves within their own suffering. Part of this journey, I have come to understand, is exploring our own personal mythology, especially as it relates to that which causes our pain. In my family, we now have an addition to our mythology. We call that addition the Joshua story. If I cannot have control over the cure to Joshua's misery, then at least I can have control over how his (and our) story is told.



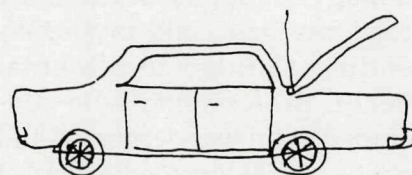
I have found techniques such as storytelling, visualization, journaling, creative writing, art, and music to be enormously helpful in embracing my own "beast" and in telling the Joshua story. I now find myself using these same techniques in my

work with others. Tools such as these seem to help in interpreting the subjective meanings we attach to our experiences. In transcending the objective facts, we enter a world that is surreal, wherein we can begin to see the "angel in the labyrinth." In sharing our stories, our pictures, our poems with others, we begin to build a community of hope and despair. We begin to put aside the awful details of the experience itself in order to gain a new perspective. It has been through telling the Joshua story that I have been able to rediscover a sense of power through the experience of being powerless. The story has helped me to make friends with the "beast" in both Joshua and myself. It has also enabled me to form connections with others in ways that I would not have otherwise.

My experience with Joshua has helped me to understand in an experiential way what I guess I have always known intellectually: It matters how help is given. Alan Keith-Lucas (1972) in his classic text, *Giving and Taking Help*, cautions us not to confuse help with control. He writes, "help is something a person finds. . . Control, on the other hand, is society acting on him(sic)." (p. 9) I now know that much of our "helping" is control rather than help. In formal helping, our clients become objects to be acted upon rather than people in control of their own feelings and decision making processes. As practitioners, we make preconceived judgments about how people are "supposed" to feel under certain circumstances. We pretend to be

the experts and in so doing forget that clients are the experts in their own subjective experiences. I have come to understand that much of our formal helping is not helpful at all. Rather, it is disempowering, stigmatizing, and punitive.

I am reminded of



Dr. Bernie Siegel's (1986) description of the point in his career as an oncological surgeon when, instead of recognizing the personhood of his patients, he had come to view them as though they were broken cars in need of repair. All humanity, both his and theirs, was lost. He hadn't planned for things to develop in this way. They just did.

I think that's the way things happened for me. I was numb to my own humanity and I had become numb to the humanity of others. I had begun to see my clients as objects to be processed on a social service assembly line. I had gotten caught up in the system. I had begun to confuse help with control.

It seems ironic in a profession such as social work, so heavily committed to people, that practitioners and the organizations within which we work can become so inhumane. Although some may laugh at my naiveté, I truly believe that it was my own over-identification with

my profession that blinded me from seeing this process at work in my own practice. The evolution of my experiences with Joshua has enabled me to become more thoughtful about the nature of social work as a humanistic profession. The development of my understanding has been analogous to focusing a camera. At first, my anguish over Joshua obscured my ability to empathize with anyone else. After all, I reasoned, no one could possibly be suffering as much as I was. Everyone else's experiences paled in comparison to my own. It is only recently that the picture through my camera's lens has come into clearer focus.

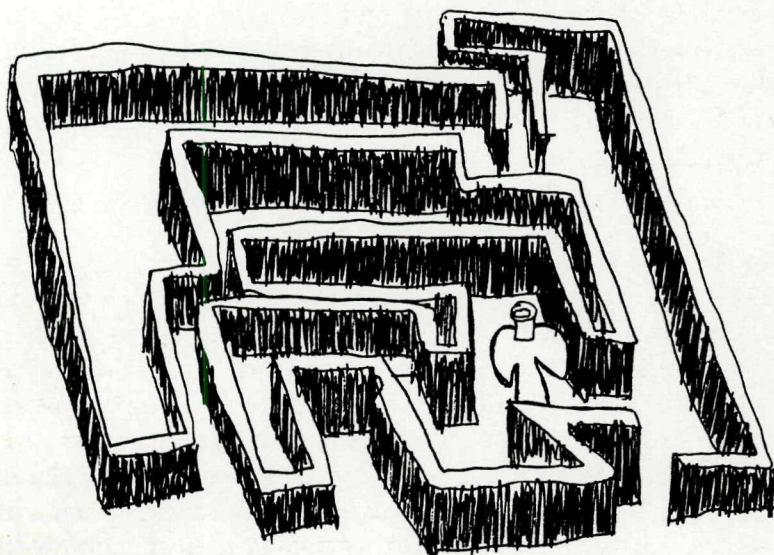
I now know that comparing the details of one person's experiences to another's is meaningless. Your own problems seem worse than other's simply because they are *your* problems. I am troubled, however, about the way in which we invariably

get trapped in this arbitrary and meaningless comparison. Much of the research that provides our knowledge base in social work attempts to do this by applying positivistic methods that overlook the contextual meaning attached to human events. The treatment modalities we use often pre-suppose that certain techniques are the only viable methods to use in working with people who share common characteristics. The organizations within which we work attempt to categorize people in various ways because of their funding and/or regulatory requirements.

If you had confronted me several years ago about the nature of my own practice, I would have denied owning most of the problems I have just described. Not me, the woman who always tried to practice from an empowerment model. Not me, the woman who always tried to give people choices. Not me, the woman who attempted to be

eclectic and utilize whatever techniques (micro and macro) might work in a given situation. Not me, the woman who tried to take my cues from my clients and bow to their infinite wisdom. Not me, the woman who chose to work in small, community-based agencies that seemed closer to the clients served. I now know, however, that a kind of numbness was exactly what had beset me. As in Bernie Siegel's case, it happened before my very eyes despite my best intentions. My commitments to others, it seems, were merely words and token actions. I had no experiential understanding of what it meant to be vulnerable and in need of help.

In my work, I am now better able to understand that, despite all my years of education and experience, I am not the expert — the client is. In my pre-Joshua period, I didn't know what it was to look death in the eye and mentally plan my own child's funeral realizing full well that, in the end, if I called 911, the rescue personnel would be legally obligated to resuscitate him against my wishes. I didn't know what it was to face the possibility that, if I lost my job, my family would be unable to secure health insurance for all our members because my son would be labeled a "bad risk." I didn't know what it was to complete a 10 page application for financial assistance complete with all the accompanying documentation only to be denied due to the fact that my family wasn't considered "destitute." I didn't know what it was to make five telephone calls to social service



agencies only to find out that my son was ineligible or, at best, would be put on a waiting list for services because his needs were not considered to be critical at this point in time. Although I had gone through similar motions with clients, up to that point, my work had been a purely academic exercise.

My experience with Josh has transformed me in some very profound ways. I have come to the conclusion that one cannot be a truly effective social worker unless one has experienced a major problem in one's life for which one had to seek help. I would almost advocate that we make this a prerequisite for admission to social work education. What is a major problem? Well, who knows? We must leave the definition to people themselves. All I know is that, before Joshua, I was not fully able to understand my clients' experiences in becoming a recipient of help. I wasn't able to empathize with them fully because I had come to see social work as an act performed on behalf of other people rather than as an interactional process that required some give and take on the part of both parties.

I look at things differently now. I have a greater appreciation for the precarious nature of life — the delicate balance in which we live out our existence. I understand that we are all one step away from potential catastrophe. But, I also understand that even in very dark places, there is light. I now know that, as people, we have untapped capacities — strengths that we didn't even know we

had. I also know that our communities have a wealth of resources both formal and informal that can work if we only hold them accountable.

I seem to have more questions now about my practice than I have answers. Perhaps it's progress that I am at least able to raise the questions. I do know that I have a greater appreciation for the need to recognize clients as experts and a belief that, as practitioners, we should avoid imposing our own professional hegemony. I also have a deeper commitment to reforming our system of care so that it recognizes clients as people first and affords them with opportunities to accept help on their own terms rather than ours. I now know that my clients and I have something in common. We both make mistakes. We both struggle to find answers. We are both afraid. In short, we are both fully human. □

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