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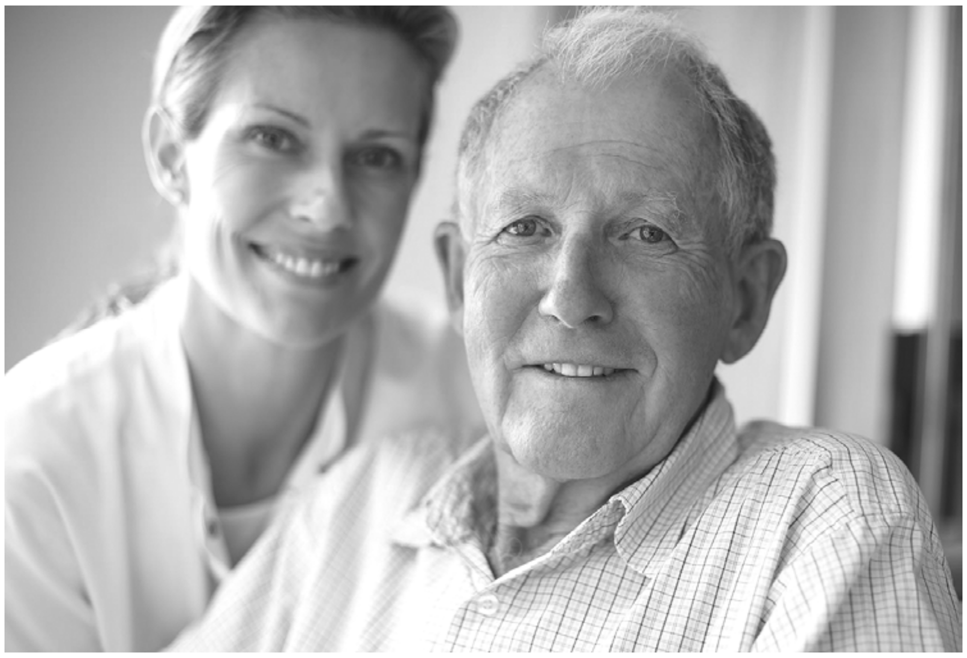
Addressing the Needs of Caregivers

By Michael B. Friedman, LMSW
and Kimberly A. Williams, LMSW
The Center for Policy, Advocacy, and
Education of the MHA of NYC



Our society relies on families to provide care for disabled family members. They provide 80% of such care, and the financial value of their work is close to $400 billion per year. If families did not provide this care, it would add 15 to 20% to the costs of health care in the United States.

I suppose there are people who believe that there is nothing remarkable about this. Aren't families supposed to take care of their own? It's basic morality, a fact of life in every human culture.

Perhaps, but it is also a fact about human cultures that families don't have to bear their burden alone. Extended family, neighbors, members of one's religions, philanthropic organizations, and other non-governmental social institutions often lend a hand.

What about government? In modern, non-communal, economically interdependent societies, government has to fill some of the gaps left by the shift from agrarian, communal societies to industrial and post-industrial societies. And of course, governments do step in. For example, in the U.S. Medicare and especially Medicaid pay for some help in the home, for day services, and for institutions such as nursing homes. In New York State the cost of long-term care in Medicaid alone is about $12 billion. Nationally, it is about $100 billion. The fact is that government does take on some of what would have been family responsibilities just a half-century ago—though it doesn't do much to support families who do not turn to government to take over caregiving.

So those who argue that it is right and natural for families to take care of their own without assistance are just mistaken about the facts of both human cultures generally and of contemporary Western societies. The question is not whether government *should* provide care for people with disabilities and support for their family caregivers, but *how and to what extent*.

This is a complex question because there are so many different forms of family caregiving.

- Parents care for young children and adolescents with disabilities.
- Parents also care for grown-up children with disabilities.
- Grandparents and other relatives take care of—indeed raise grandchildren, nieces, nephews, siblings and cousins because their biological or their adoptive parents cannot.
- Working age adults take care of their parents, grandparents, or siblings.
- Married people and people in long-term committed relationships take care of their spouses and partners.
- Some children (as young as 8) are providing care for siblings, parents, and/or grandparents.

In addition to the differing relationships of family caregivers and their family members, there are different kinds of disabilities that they address. Some are transient; some

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The Challenge of Caregiving: A Personal Story

By Janice Fitzgerald
Executive Director
Parent to Parent of New York State

Parents, spouses and other caregivers of individuals with illnesses and disabilities do not have special gifts. We are very average people who tap into our superhuman strengths that everyone has, but don't always need to draw on.

Twenty five years ago this Fall my life changed forever. My son, John, who was six-months old at the time, became very ill. He was admitted to the medical center in Burlington, Vermont and diagnosed with Infantile Spasms, a rare and violent seizure disorder. We left Burlington on Christmas Eve in 1985 not knowing if he would survive, and if he did live through this period, there was no prognosis of what his future would hold. He did survive, the seizures did stop, but his mental development was delayed.

When John was a youngster, his behaviors were a challenge to be around. Regularly, his outbursts sent me, my husband and our other two sons running for cover. Between 1 and 5, he had an attention span of less than 10 seconds; he required constant and intensive monitoring. We live in a rural wooded area and John would wander off into the woods with no concept of danger. He would wake up during the night, climb out of his crib and wander in our house. He would climb to the top of a playground slide, out of my quick reach and grab a handful of hair from another child's head. It was impossible to leave him unsupervised for a second.

Through all of this, we were also trying to be good parents to our other two sons. For several years we were a house divided – one parent staying home with John, and one parent going to school functions, scouts, parties or picnics.

We never gave up and John did progress. He started to talk when he was 5 and eventually he learned that there were consequences to his behavior and there were privileges to be earned when that behavior was kept in line. He learned to ride a bike and to downhill ski at 8.

When John was young his assaultive behaviors were disruptive. As he got older, we could no longer "wrap him up" or pick him up and get him to his room. Butting the back of his head into my face sent me reeling. When John was 8 1/2, we were finally connected to a physician who was able to prescribe medication that worked for John. Once his behavior was under control, he was able to learn and be more involved in activities. Gradually he learned accountability for his actions. He learned and understood that as he got older, he could be arrested for being violent.

Today, John is a responsible 25 year old citizen who works hard and continues to learn and mature. He is an Eagle Boy Scout and works full time as a dishwasher in a dining hall at a local private college. He has his driving license and drives to work. That was huge. He is a responsible, cautious driver.

Fifteen years ago, I would not have been able to write about all of this. My emotions were so jumbled. It took a long time to come to grips with and accept that one of our children had special needs. There was bitterness and anger about missing many of the things my other children were a part of. There was the guilt of not being able to share an equal amount of time with our other sons. There was

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Being Your Own Caregiver When There Is Nobody Else

By Ira H. Minot, LMSW
Founder and Executive Director
Mental Health News Education, Inc.

This issue of *Mental Health News* examines the topic "Addressing the Needs of Caregivers." The response to our theme was very enthusiastic with many people indicating how happy they were that we were examining this import and timely subject. Throughout the many wonderful articles in this issue we take a look at many of the needs and challenges facing caregivers of people with mental illness and individuals with other challenging illnesses.

There is one subject that was not covered in this issue's articles that came to me when I sat down to write my column. "How can a person with mental illness be their own caregiver when there is nobody else?" As a person who battled to overcome a serious mental illness, I can tell you from my own personal experience that this situation does occur and is not that unusual.

For me and many others, our fall into mental illness came later in life after we had left the care of our parents and entered adulthood. For adults, the onset of mental illness occurs after years pursuing a career, raising a family or following a divorce which then left us fending for ourselves as single adults once more.

In my own case, my battle with depression didn't begin until I was almost forty years old, following a series of personal losses. As the youngest of five children, my parents were already in their late sixties. I was living at the time in Upstate New York. My mother had recently lost a courageous battle with cancer and my father lived in Florida and was rebuilding his own life. My friends, and four brothers and sisters were located in other cities in New York, Massachusetts, and Florida. I was living alone, becoming quite ill, and had no clue as to how to care for my deepening depression. My illness grew in intensity and lasted for over ten years during which time I had to learn to be my own caregiver. The same holds true to this day.

Now, some twenty years later, I am able to tell you how I learned to be my own caregiver when there was nobody else. At times it seemed like an insurmountable task, especially when my illness was interfering with my thinking and smothering me with negativity and hopelessness. I could have used a guidebook or a roadmap to give me some direction, but there was none. That's why I eventually went on to start *Mental Health News*. Here are some helpful hints.

Educate Yourself About Your Illness

You can't begin to be successful as your own caregiver or assist someone who is trying to help you if you don't thoroughly understand your own illness. Working with and developing a trusting relationship with your mental health professional and others on your treatment team is a good place to start. Even though it's hard to work with people you don't really know that well, it is important that you trust in them to help you to the best of their ability. In a good recovery-oriented therapeutic relationship, your psychiatrist and other treatment team members should be willing to tell you about the nature of your illness including: what it is called, what may have triggered its onset, how it will be treated and for how long, and what are the core elements of how to manage it and if possible recover from it. Carry a spiral notebook to write down your questions and everything that you learn along the way.

Ira H. Minot, LMSW

Start With the Essentials

Everyone is different, but there are some essentials that all of us require to survive on our own. First and foremost are the basics such as food, clothing, shelter, healthcare, transportation, and some form of financial support. Many communities have organizations designed to helps people begin their recovery. If you have suffered a serious breakdown, have no means of supporting yourself, and end up in the hospital, you may be fortunate enough to be given some form of follow-up discharge plan. Ideally, this plan will pair you with agencies in your community that can help you with immediate needs such as housing, obtaining financial support such as Medicaid, SSI, SSD and food stamps, and provide you with outpatient mental health and medical care.

Donald Fitch, author of the *Mental Health News* column titled "The Economics of Recovery" has identified nine "Essential Goals for Self-empowerment in the Community for a Full and Balanced Life." They are: (1) meaningful work, (2) a happy home, (3) financial stability, (4) family and friends, (5) spiritual well-being, (6) education and skills training, (7) good mental and physical health, (8) fun and recreation, (9) and accessibly for people with physical limitations.

Build Your Own Recovery Community

You may be your own caregiver, but that doesn't mean you should live in a vacuum or on a desert island. One of the best things you can do for yourself is to surround yourself with the best treatment professionals, advocacy experts, coaches, cheerleaders and friends who believe in you. It will take a community of people around you to get through this difficult time in your life.

Work With Your Treatment Team

In a perfect world we are all being treated by the best mental health, medical, and support team professionals available. However, due to financial reasons, location, and availability, this might not always be possible. Good treatment relies on a supportive team effort and for you to become an educated consumer. You should feel comfortable asking questions about your care. If you are expected to sit still and not have any expectations of how and when your recovery is to take shape, I would be a bit worried. Some of the top people in the field of mental health that I have met are caring professionals who are easy to speak with and encourage you to expect progress in a reasonable amount of time. Many medications can take weeks to become effective, so you often have to be patient and work with your doctor on this. If however, after several months you aren't feeling any better, or if the side-effects of your medications are intolerable, tell your doctor and see if there is another course of treatment available.

Some of the Best Therapy Can Be Found Outside the Therapeutic Setting

One of the other best things you can do for yourself is to keep busy and keep moving forward in your recovery—starting if you can from day one. Depending on your treatment plan, you may only be assigned to going to outpatient psychiatry visits to refill your medication prescription when they run out, and one or two counseling sessions per week. Some consumers are placed in a daily outpatient treatment program which is helpful when you are in need of regularly structured care. Depending on the hours, these types of programs may only occupy your mornings or end in the early afternoon. If you are not employed or are only doing limited volunteer work during the other hours of your week, look for recovery-oriented activities to occupy the remainder of your day. Treat your recovery like it's a full-time, nine-to-five job. The most harmful thing to do is to have hours of idle time, sitting alone in a lonely apartment, ruminating about your problems. Believe me that's not good therapy, and can quickly land you back in the hospital.

Many communities have organizations that provide other mental health and recovery oriented resources for consumers and families. There are vocational programs, nutrition and wellness programs, drop-in centers, and advocacy programs to name few. In addition there are organizations such as the Mental Health Association (MHA) and the National Alliance on Mental Illness (NAMI) which often have recovery oriented programs you can participate in. Some of the best things you can do to advance your recovery can be found in the company of other consumers who are also working on their own recovery. It's important to have friends that are non-judgmental and who can share their experiences with you on what has worked for them in their recovery. Many clubhouses and drop-in centers offer more than just a couch and TV to sit around, and have structured educational, vocational, and socialization programs for you take advantage of. Get a pocket calendar and schedule your week with activities to attend—and don't forget weekends. A good community Public Library can also offer you relaxing time reading a good book or magazine, listening to music, or attending a special class.

Telling Your Story and Helping Others is Therapeutic

I never thought of myself as a spiritual person, but when I finally began to recover from my illness I had somewhat of an epiphany. I began telling people about my illness and how I had the idea to start *Mental Health News* to help others find their way through their own difficult times. Throughout my ordeal I had been filled with shame, fear and stigma about my illness. What I found was that the more I told my story, the more people I met that understood what I had gone through. Even if they were not consumers themselves, they had a brother, sister, parent or friend who had struggled with a mental illness. I found that by simply telling my story to others, I began to feel better about myself. I learned that mental illness is a medical condition that can strike anyone at anytime, and that it wasn't my fault. Since the career I had before I became ill had long since been left in tatters, I had no prospects of finding work. I didn't realize it at the time, but my idea to start the newspaper got me working again, and at something I deeply believed in—helping others. Even though I was not getting paid to do the work each and every day, the joy and energy that it provided to me was payment enough. I called it my "labor of love," and I think it played a major role in my recovery.

Here's a suggestion. Find something that you really like to do or that you are very passionate about. There are people in your community that will help guide you down this path. Some are called vocational counselors and some are called job coaches. Try lots of different things if you are not sure. Work at it a little bit every day and maybe you will find a new direction in your life. Working at something everyday that you enjoy is very therapeutic.

I believe that "pulling yourself up by the bootstraps" (to the best of your ability) is not only possible but is an essential part of the recovery process. Going through this process not only helps our self-esteem, but it helps lessen our fear of being alone and fear that we can not take care of ourselves. As my brother Jeffrey always said, to encourage me to overcome *my* fears, "Left Foot - Right Foot." It was his simple and caring way of saying that everything in life starts with taking that first step. Taking *your* first step can be the beginning of something wonderful.

Good Luck in Your Recovery
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Caring For Lesbian, Gay, Bisexual and Transgender Clients And the Providers Who Serve Them

By Christian Huygen, PhD
Executive Director
Rainbow Heights Club

To paraphrase Tolstoy: happy clients are all alike – but unhappy clients are each unhappy in their own way. However, as the recovery movement gains ground, providers are finding that clients can have a bewilderingly diverse array of ideas about what would make them happy.

These days, clients can, and often do, express recovery goals that include education, work, love, and relationships, in all their rich variety. Care providers are now allies and supports for a vastly broadened horizon of possibilities.

This new widening of the horizons can sometimes make care providers feel unequipped to support the range of goals and objectives that their clients are now asking for help with. What if a mental health consumer asks a care provider for help with finding a same-sex partner to date and settle down with? What if clients ask for supportive resources to explore their gender identities? Care providers want to help, but they may be uncertain about how, exactly, to move forward with these challenges. They may also feel confused when clients ask for help in moving toward recovery goals that either used to be pathologized in the DSM (such as same-sex relationships) or still are (such as the exploration of gender identities that don't conform to the gender the client was assigned on the day they were born).

That's why, several years ago, Rainbow Heights Club developed a training program for mainstream care providers. Care providers don't have to be LGBT (lesbian, gay, bisexual or transgender) to be effective and affirming with LGBT clients. They just need some basic information, and a commitment to do this work. Rainbow Heights Club's cultural competency training program sets out to give care providers the tools they need to be effective with all the clients they serve.

We know (based on data from the annual Community Health Survey conducted by the New York City Department of Health and Mental Hygiene) that between 5% and 10% of New Yorkers have same-sex sexual relationships. These figures don't include LGBT people who are celibate, as many people living with serious and persistent mental illness choose to be. The numbers also don't include people who identify themselves as transgender, or who don't conform to stereotypical experiences or expressions of their gender identity. (Unfortunately, research with this population is still in its early phases, and it's impossible to make accurate estimates of prevalence at this time. However, one-third of Rainbow Heights Club's active client base is transgender or gender non-conforming, which indicates that for many people, affirmation of their gender identity can be an extremely salient part of their mental health recovery process.)

Christian Huygen, PhD

Rainbow Heights Club is a publicly funded psychosocial support and advocacy agency specifically serving lesbian, gay, bisexual and transgender people who are living with serious and persistent mental illness. We are located in downtown Brooklyn, and we provide services to clients living in all five boroughs. We've been providing our services entirely free of charge since we opened in 2002, and we now have over 500 members. Our doors are open six days a week, with evening hours Tuesdays through Fridays. Members help to plan, shop for, prepare and clean up after an evening meal each day. We even offer Sunday brunch.

We know that LGBT people often have a hard time finding affirming and culturally competent mental health services. LGBT people seek mental health treatment more often than our heterosexual counterparts, but we often don't find the support that we need, which frequently results in our leaving treatment prematurely (Garnets, Hancock, et al., 1991: Issues in psychotherapy with lesbians and gay men, American Psychologist, 46:964; Liddle, 1996: Therapist sexual orientation, gender, and counseling practices as they relate to rating on helpfulness by gay and lesbian clients, Journal of Counseling Psychology, 43:394). The same NYC DOHMH community health survey cited above also found that gay and lesbian people experience more poor mental health, more smoking, more drinking, more drug use, and even more domestic violence than our heterosexual counterparts do. In other words, we badly need competent and affirming care. (I say "we" because I'm a member of the LGBT community myself.)

That's why Rainbow Heights Club was formed, seven years ago: to provide a way out of the isolation that multiple layers of stigma can bring.

A study by Lucksted (in Hellman & Drescher, 2004, eds.: Handbook of LGBT Issues in Community Mental Health. Binghamton, New York: Haworth Medical Press), commissioned by the Center for Mental Health Services, summarizes a number of issues and problems cited by LGBT mental health consumers across the country. In mainstream mental health settings, they often feel compelled to hide their sexual orientation or gender identity; conversely, in the LGBT community, they try to hide their mental health status. Care providers often consider any exploration or expression of sexual or gender identity on the part of their clients to be further evidence that the clients are mentally ill. Moreover, especially in inpatient units and day programs, other consumers are frequently derogatory or even threatening toward LGBT clients. These obstacles impede the recovery process and the effectiveness of the treatment and services being provided (for instance, see Rosenberg S, Rosenberg J, Huygen C, Klein E, 2005: No need to hide: Out of the closet and mentally ill. Best Practices in Mental Health, 1:72-85).

Unfortunately, mental health professionals have helped to create this situation. Until 1973, the American Psychiatric Association defined homosexuality as a mental illness, and even today, people who question the gender they were assigned at birth are considered mentally ill. LGBT people with mental illness are acutely aware of their dependency on their care providers; as a result, they hesitate to do anything that might cause providers to withdraw their care and support. Many LGBT people have experienced the loss of friendships, family relationships, and the support of religious communities as a result of disclosing their sexual or gender identity. Unless care providers do something to demonstrate that they want to accept and affirm clients' choices regarding the expression of their sexual or gender identity, clients are likely to assume that their providers would rather not hear about their sexuality, gender identity and relationships. Even in New York City, many LGBT clients state that they have never dared to disclose to their own therapists and psychiatrists the simple fact that they are LGBT. Unfortunately, this makes it impossible for care providers to provide help where it is needed the most.

Rainbow Heights Club was designed to provide a safe place where LGBT people who have been struggling with serious and persistent mental illness in isolation can finally find the safety and support that they need to support their recovery. We offer support groups, activity groups, Internet access, computer tutoring, cooking classes, and most of all, a safe place to build social skills and social support. Members help to design the programming, plan the meals, and come up with events and excursions. Many of them state that Rainbow Heights Club is the first place they have ever felt welcomed and accepted, and the first place where they have felt comfortable telling the complete story of who they are.

Over the past seven years, we've conclusively demonstrated that when LGBT people receive the support and affirmation that they deserve, their ability to care for themselves, and each other, dramatically improves. Over 87% of our members say that they are able to stay out of the hospital and in the community every year, because of the support that they receive at Rainbow Heights Club.

Over the years we've provided training to the staff of over 150 agencies, hospitals, residences, clinics and day treatment programs. The staff at these agencies report that since the trainings, they are experiencing better relationships with their clients, and better treatment outcomes, as a result of improved ability to affirm and effectively work with all of their clients, regardless of their sexual orientation or gender identity.

At Rainbow Heights Club we believe that it is vital to meet the needs of both consumers and providers. Our members receive direct support, and are encouraged to take on roles of leadership and direct participation in the club's activities. We reach out to providers to build referral networks and linkage agreements, but also to share information and education that will build providers' competency and confidence in working in an affirmative way with the full range of their clients, regardless of their sexuality or gender identity. The same values drive our work with both consumers and providers: we believe that if we give people a supportive environment and the respect and safety that they need, they will spontaneously grow past their former limitations. I encourage all care providers who have expertise in working effectively with marginalized or underserved populations to do the same.

Christian Huygen, PhD, is a licensed clinical psychologist, and the Executive Director of Rainbow Heights Club: Caring for lesbian, gay, bisexual and transgender clients – and the providers who serve them (www.rainbowheights.org). He may be reached at christianhuygen@rainbowheights.org.

The Care Manager as Storyteller and Coach: Giving Voice to the Caregiver's Reality and Opening Doors

By Sonia Wagner, LCSW-R
Executive Director, Jewish Family
Service of Orange County, New York

Imagine being so consumed with the work of caregiving that an eviction notice doesn't scare you. This true story reminds us of how dangerous it is for caregivers to feel disempowered and how powerful storytelling can change the lives of caregivers in crisis.

Janice was diagnosed with neck cancer when she was only in her forties and raising two children with her husband. While the cancer went into remission, she developed additional medical problems and ultimately needed a feeding tube.

Her husband, Bob, worked full-time as a salesman, and his job had provided the family's health insurance. However, there were considerable out-of-pocket medical expenses which totaled over $200,000. Afraid to jeopardize Janice's health care, the couple tried to keep up with the bills. Ultimately they sold their home and moved into a mobile home park, but this was not sufficient to keep them afloat.

By the time Bob called Jewish Family Service, he was facing a pending eviction notice. Returning home from work one day, he had found Janice lying on the floor, where she had been for hours, unable to get up by herself. He became increasingly afraid of leaving her alone but could not afford home care, so he gradually reduced his work hours until he was no longer earning any money. Soon the couple fell behind in their lot rent and began receiving shut-off notices from the electric company.

Sadly their financial situation was not unique, nor was the calm attitude with which Bob seemed to approach looming homelessness. Like many caregivers feeling overtaken by life's increasing challenges, he had become numb to crisis almost to the point of inertia.

Sonia Wagner, LCSW-R

Seligman and Maier (Failure to escape traumatic shock. Journal of Experimental Psychology, 74, 1-9. 1967) observed the phenomenon of learned helplessness among dogs who "learn" not to try escaping electric shock when earlier attempts to escape fail. Seligman subsequently theorized that people are similarly prone to passivity and depression when their actions to better themselves seem repeatedly ineffective. It's easy to imagine how confronting a debilitating illness of a loved one and rising health care costs that reach beyond a family's means can leave a caregiver feeling alone, disempowered, and without a voice.

Bob needed to experience success in working with hospitals, utility companies and other systems. His story had to be told – and to be told to the right people in a way that they could hear it.

JFS care manager Stacy Ocko-Lulkin likes to "present the person" by giving her own impressions of the person in need. Whenever possible, she makes her advocacy phone calls while the individual is sitting by her side and she invites them to join the conversation once a warm tone has been established.

"I'm calling you, with Bob sitting right here beside me" she told one hospital administrator, "He has been working so hard to care for his wife who has cancer, is eating through a feeding tube, and homebound. He's come to us for help so that he can pay his bills."

The word "us" is very helpful in such calls. It suggests that the care manager and the administrator are on the same team. In addition, Stacy quickly addressed the financial issue, suggesting that Jewish Family Service will help Bob handle his accumulated debt. Stacy's tone of voice was warm and professional, and she had the credibility of the agency behind her. For all these reasons, she became a person the hospital administrator wanted to talk with.

Having engaged the administrator, she could begin telling Bob's story – and then involve Bob in the discussion. First she explained that Bob had become overwhelmed with the daily responsibilities of feeding, bathing, and keeping company with a loved one, who had become more and more ill over the years. "He was a hard worker who had always paid his bills in the past," she said (helping the administrator to identify with him) "and very much wanted to fulfill his obligations now." Bob strongly reiterated these points.

A critical ingredient in any advocacy call is a vivid description of efforts that the client is making to solve their own problem. Requests for local financial assistance and attempts at saving money should be discussed. In this case, Stacy explained that Bob very much wanted to return to work, a plan that was feasible since Jewish Family Service intended to help him secure daytime homecare.

She subsequently helped him apply for Medicaid and connected him to the Office for the Aging, the Department of Social Services, and a managed care provider that offered a home health aide. Just as importantly, however, she coached Bob on advocating for himself and ultimately helped him find his own voice. As they found more assistance, Bob began to feel that he could help shape his family's future even in the midst of serious medical challenges. This confidence was lifesaving as he ultimately needed to "make a case" to Janice to seek essential medical attention.

Exhausted from dehydration and malnutrition, she was unable to consider her treatment options and was consequently declining all assistance without discussion. With the care manager's support, Bob was able to step into his role as health care proxy and secure necessary treatment for her.

Like so many caregivers, Bob had come to feel powerless. Helping him tell his story, engender the compassion of strangers, and speak up for his family was a priceless gift that continues to touch his life today.

Jewish Family Service of Orange County, New York is a nonprofit social service agency that strengthens families through care management, emergency financial assistance, and supportive counseling. Services are open to the entire community.

Seven Advocacy Tips Regarding Overdue Medical Bills

1) Keep even the smallest bills out of "collections" by promptly calling the billing department and expressing your intention to pay. If your case is in "collections," ask if this is an internal collections effort (i.e. within the hospital) or outside. The hospital has less flexibility when an outside collections agency is involved.

2) Request that bills be resubmitted to the insurance company. Bills are often erroneously rejected when first submitted.

3) Review the medical bills and directly ask your doctor to assist with appealing decisions regarding visits or treatments.

4) Explain to the billing department what has made payment difficult and the steps you are taking to resolve the issue. Make realistic payment commitments – be truthful.

5) Ask about Medicaid and spousal Medicaid.

6) Ask about "loan closets," which lend medical equipment for free.

7) Ask for a bill reduction. Hospitals generally have some flexibility for hardship cases.

Care managers and social workers can help. Reach out to them.

Caring for Caregivers: An Integrative Approach

By Joan Barry
Direct of External Affairs
Wellspring

An often-aired television advertisement for a depression medication asks, “Who does depression hurt?” The answer is “Everyone.” Serious mental health issues bring unique challenges for caregivers of individuals who struggle with major depression, bi-polar disorder and other serious mental health issues.

Fortunately, the stigma of mental illness is no longer as pervasive in today’s society. However, feelings of shame, fear, guilt, grief or powerlessness can persist for a parent whose child is ill. A child whose parent struggles with mental health illness may feel shame and guilt, thinking that she caused it. The effects on everyone are enormous - grief and loss emerge as the familiar loved one slips into an altered reality that mental illness can create; frustration comes with the long trial periods to find effective medication, or with the denial of illness and/or non-compliance with treatment; fear of the medication not working and worries about paying the costs of treatment all compound a very stressful situation.

Caregivers for people with mental illness often struggle with balancing devotion to their family member and their own health and well-being. In a survey conducted by Consumer Health Sciences (CHS) and Mental Health America (MHA), data was gathered from 1,328 family caregivers and 879 patients. It revealed that the mental health of many family caregivers bordered dangerously close to clinical depression due to the stressful demands of treating and living with a person suffering from schizophrenia.

As a society, we need to care for and support families so that they can extend compassionate care to each other during moments of vulnerability, crisis and illness, and help them deepen a core of strength and resilience. At Wellspring, caring for caregivers is an integral and vital part of the program as their loved ones struggle towards health. The next section of this article was written by parents of a former Wellspring resident. Their honest story highlights some of the challenges that come with caring for a loved one with mental illness. The pain they faced, and the love and devotion they have for their daughter, shine through.

“Leaving our daughter at Wellspring for residential treatment was daunting; she was only 14 years old. We cried our way home from Bethlehem, Connecticut to Bedford, New York. As parents, we felt bereft and heartbroken, but we trusted that our daughter was safe and in the right program – at least that was our prayer. We found the lack of daily contact with our daughter scary and unsettling. We had no idea that the program would be such a rigorous training for us as well. We were asked to commit to weekly family therapy sessions, during the workday, as well as bi-weekly 3-hour Multi-Family Group therapy sessions on Sundays. We were told that new behaviors developed only over time and, although we were anxious, the process was slow. We had so much to learn. During this process, we were confronted, corrected, and eventually had to bare our souls to the therapists, staff, parents and even the residents. We were raw and vulnerable.

As caregivers, we had to learn new behaviors, communication skills, and boundary settings to better help our daughter. It was all uncharted territory. There were ups and downs and lows that we never imagined. We would look in her eyes and not see the beautiful, energetic, brilliant kid that we thought was our daughter. Would we ever find her again?

At Wellspring, we received badly needed care. We learned that blaming ourselves was unproductive and were told that we did the very best job we could. But, we continued to walk on eggshells with our daughter until we realized that we had to stop engaging in the dance. Until we did, she would remain at Wellspring. We learned to take back control as parents, and very slowly began to experience the changes. We always knew we loved her unconditionally but, as her parents, our job was to create the structure; her responsibility was to choose. That was our family’s breakthrough.

When our daughter was discharged, we had all learned so much but were still unprepared for her re-entry to life as a teenager. There were many breakdowns—and there was no magic bullet. It would be a long and arduous process. Ultimately, we discovered that we needed to create a team of support for her and for ourselves as well. It truly does take a village to raise a child, and we had help to find the right villagers. Today, almost 4 years later, our

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PTSD, Anxiety, and Disordered Attachment

By Richard Beauvais, PhD
Co-Founder & Board President
Wellspring

Post Traumatic Stress Disorder is listed in the DSM IV as an Anxiety Disorder, and rightfully so. But trauma as a source of anxiety is also a frequent component of disordered attachment, except that trauma here is from the cumulative effects of early neglect and abuse, rather than the shock of specific events considered more typical of PTSD. When we examine symptoms of disordered attachment – the lack of trust, hyper-vigilance, an excessive need to control people, heightened reactivity, agitation – all resonate with high anxiety. The neurobiology of cumulative trauma also shows effects similar to those of shock trauma. Memory of early traumatic mother-child interactions remains preverbal or non-verbal, encoded in the brain-body. These trauma-based reactive templates also trigger seemingly unrelated, distorted and disproportionate responses to circumstances and events. Because these physiological, neurological and emotional processes are sensory based and reactive to stress, they tend to operate outside of cognitive, verbal processing. Because they have no words and words cannot reach them, treatment must incorporate other modes of processing than cognitive-verbal approaches or behavior modification alone. This has major implications for the treatment of traumatized children, adolescents and adults.

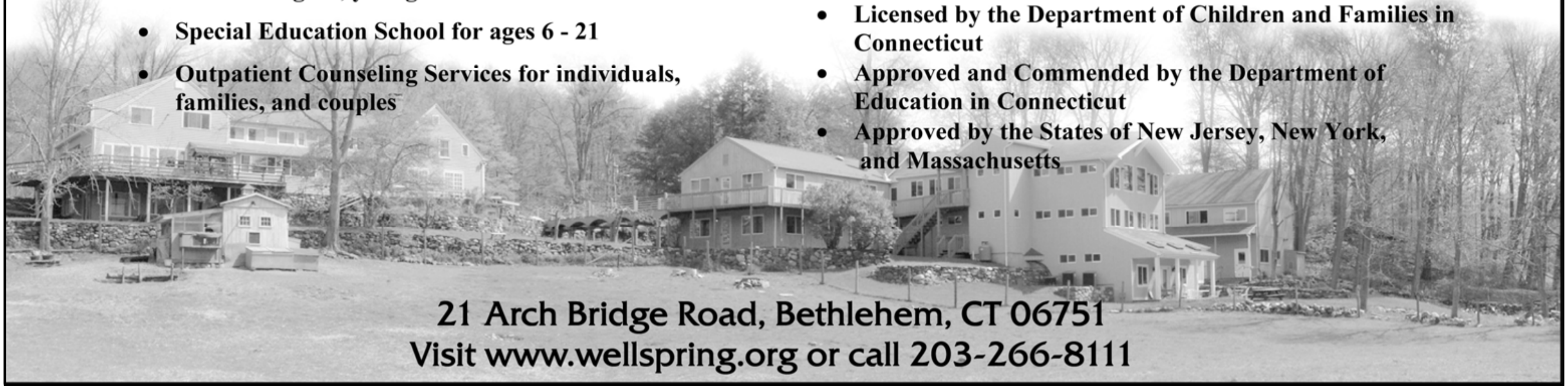
First of all, treatment must be relational to have any hope of success. In his seminal work on the neurobiology of affect development, Allan Schore (1994) shows how the brain is shaped by early relational experience for better and for worse.(1) The question is whether or not it can be re-shaped by relational experience into later life. Siegel (2002), Cozolino (2002) and Farber (2000) all claim that this can happen, because of the continued plasticity of the orbito-frontal cortex, but they insist that it will only happen through qualitatively different relationships that provide closeness, caring and support.(2,3,4) Martin Teicher (2003), on the other hand, would disagree claiming that the brain has become hard-wired by the age of three, so that whatever has been done to the child in terms of brain development cannot be undone.(5) Although the debate at this point remains unresolved, both positions can be true; for if change must come from the quality and consistency of relational care, that care may not be available, regrettably, to most of these children.

Bessel van der Kolk (2002), a recognized authority on trauma, makes an additional point with respect to effective treatment. “Because young children and threatened adults cannot inhibit emotional states that have their origin in physical sensations,” conventional modes of treatment need to be modified to incorporate “bottom-up” rather than “top-down” modes of processing.(6) In contrast to top-down cognitive modes, bottom-up modes are body-based, sensory focused and designed to address the critical role of stress in generating anxiety and trauma-based emotional reactivity. Not only must treatment work through the medium of relationship, it must also effectively manage stress, so that the corrective emotional-relational experiences from therapy and parenting can have their healing effect.

Wellspring, a multi-service mental health agency in rural Connecticut, has combined relational treatment with bottom-up modes of processing in its children’s, adolescent and young adult residential programs. A cornerstone of this approach, particularly with children, is safe, healing and comforting touch. Touch is a powerful medium both for healing and for harm, because it directly contacts the body, the senses and the emotions. As a medium for receptivity and mutual exchange between the physical and psychic fields shared by people, touch is profoundly relational. In the ability of touch to provide comfort, it is also an ideal mode of bottom-up processing, because “touch activates the brain systems involved in the regulation of stress responses.”(Panksepp, 1998) (7)

Because the misuse of touch (e.g., physical and sexual abuse) has harmful effects, risk prevention has tended to dominate the clinical stage at the cost of clinical effectiveness. “No touch” policies have been instituted by many agencies to guard against potential abuse, but more pointedly to guard against the threat of litigation, often without questioning whether more harm may be done to children by perpetuating the destructive effects of early touch deprivation. What Wellspring has done is

see PTSD on page 12



Family Caregivers of Children with Mental Health Needs

By Lauren Agoratus, MA
Parent

I still remember the presenter at a workshop who mentioned that parents of children with challenging behaviors are the second most stressed families of children with special needs. The other is those with severe medical conditions. We're dealing with both as my daughter has autism and is currently on the transplant list for a new kidney, so hopefully I can share what I've learned to help you on your journey as a caregiver of a child with mental health issues.

I had a "light bulb moment" when I realized that not every mom was still diapering and feeding their 5 year old. It was then that I recognized I also had an extra role as a caregiver, which could possibly be lifelong. I remember hearing from National Family Caregivers (NFCA) (www.thefamilycaregiver.org) that caregivers may not have all the choices they had before, or even like all of their choices, but they still had the power to choose. In our case initially it was dialysis vs. transplant, then narrowing down to the different types of dialysis or different ways to do transplant. It was very empowering to recognize that the decisions, although difficult, were ours.

Lauren Agoratus, MA

NFCA basically helps caregivers take care of themselves while caring for another family member. You won't do anyone any good riding on "empty". By taking care of yourself, you can take better care of your child. Also, the number one concern for caregivers is finding respite to take a break. More people enter institutional care due to caregiver burnout, rather than deterioration of their condition. There is a national respite resource found at http://chtop.org/ARCH/National-Respite-Locator.html to assist caregivers in finding help locally.

I also discovered that by finding out as much as I could about my daughter's condition, I didn't feel as helpless. I used the Exceptional Parent resource guide which listed all the national organizations for specific conditions; a free copy of their pocket guide is available by calling (800) E-PARENT.

One-to-one support was the best initial source of emotional strength. I found great support from both Parent-to-Parent (www.p2pusa.org) which matches trained volunteer parents to families of children with the same condition, as does Friends Health Connection at (800) 48-FRIEND. They also have an online community and workshops at www.friendshealthconnection.org.

It wasn't until my daughter was 7 that she was diagnosed as having autism. She was also threatening to kill herself, or us. I found that many of the autism groups do not associate autism spectrum disorder as mental illness, even though it is listed in the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders). The mental health field is also catching up in the area of developmental disabilities, and there is now some crossover of resources for those with a dual diagnosis (mental health/developmental disability).

I found that the Federation of Families for Children's Mental Health was a good source of information and support which can be found at www.ffcmh.org, including state chapters with local resources. Each state also has a Family to Family Health Information Center, which you can find at www.familyvoices.org. Another great resource is the Parent Training and Information Centers found in each state at www.taalliance.org/ptidirectory/index.asp. PTI's can help parents with special education issues as well as advocacy in areas such as inappropriate use of restraints or not signing away parental rights to get treatment.

The best source of support, however, was from the National Alliance on Mental Illness found at www.nami.org. NAMI has parent classes, advocacy, support groups, NAMI Kids (recreational and service outings in the community), and free conference calls including "Ask the Doctor" etc. They can also help families with issues such as minor consent for mental health treatment, and involuntary treatment, as laws vary among states. NAMI's philosophy is that a brain disorder is a brain disorder, period. It doesn't matter if it's childhood schizophrenia, bipolar, autism, ADHD, Tourette's etc. They help parents realize that mental illness is like any other illness, but the organ affected just happens to be the brain, which manifests as behavior. NAMI reduces the stigma associated with mental illness. For example, you wouldn't blame a child for having heart disease. They also use people first language, rather than defining them by their illness.

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Caregivers Plan for the Future With Federation of Organizations' Financial Management Program

By Barbara Faron, LMSW, CPRP
and Suzanne McCarthy
Federation of Organizations

What will happen when I am not around? How can I protect the future of my loved one? These are some of the questions that caregivers ask themselves as they search for reassuring answers. After years of work helping families to prepare for the future of their loved ones, there is one point we cannot emphasize enough: Start now! Learn about available resources and begin to utilize them while you are around to oversee the results so that you can modify your plans accordingly. There is much that can be done to plan for the future and the sooner you begin the better the outcome will be.

Federation of Organizations is a family-based advocacy group, incorporated in 1972, which has grown to a multi-million dollar social welfare agency operating programs in mental health and aging on Long Island and in New York City. Since1992 Federation of Organizations has assisted families to ensure long-term security for their loved ones by providing Financial Management Services and administering trusts that assure continuity of care and responsible use of financial resources.

Barbara Faron, LMSW, CPRP

The program originated to meet the need for Social Security Representative Payee services for individuals who, on the basis of a psychiatric evaluation, were found to be unable to manage their money, often because of problems with substance abuse in addition to serious mental illness. Serving Suffolk County, the program is designed to assure that client funds are spent to maintain basic necessities of life such as food, clothing, and shelter.

The Financial management Program receives Social Security (SSA) and Supplemental Security Income (SSI) payments and all other income on behalf of the client. The financial manager and the client work together to plan monthly expenses and identify spending goals. The program makes payments directly to vendors and distributes the client's personal needs allowance on an agreed-upon schedule. The financial manager assists the client with budgeting, planning, and saving for the future. We report any changes in the client's status to the Social Security Administration and ensure that the individual receives all entitlements. An annual expenditure report for each client is submitted to the Social Security Administration.

During the course of operating the Financial Management Program we learned that sometimes clients find themselves with large one-time payments that can be placed in a trust to preserve the money for long-term use without disrupting eligibility for benefits. In the past, without a trust, people were forced to spend down any windfall or inherited income and/or remain ineligible for benefits until the resources were exhausted.

Using a trust makes a big difference. For example, Patrick (not his real name) received a large retroactive SSI payment in the fall of 2008 which would have made him ineligible for Medicaid. He was referred to Federation and learned that he could create a trust that would enable him to use some of the money to achieve one of his long-term goals: owning a car. Although he had a valid driver's license, he had not driven for some time. He was happy to learn that the Trust could pay for his driving lessons so that he could feel comfortable behind the wheel of a car once again. After careful research with his financial manager Patrick purchased his car in January, 2009.

Often people try their own solutions, leading to major problems. Michael's (name changed) sole surviving parent died without the benefit of advanced planning. An inheritance made Michael ineligible for SSI benefits and Medicaid coverage. Following the advice of a family friend, Michael invested the money in the stock market. By law, the income was reported to the government, and Michael's SSI income was eventually stopped. By that

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Peer-Led Support Helps Parents and Caregivers Cope with Mental Illness

By Wendy Brennan, MS
Executive Director
NAMI New York City Metro

When her teenage daughter was diagnosed with bipolar disorder, Deniece Chi did not know where to turn for help. A native of Belize residing in New York City, she had no experience with or understanding of mental illness. Her relatives dismissed the diagnosis and suggested that a lack of discipline was the true reason for her daughter's behavior. Her provider offered little help beyond a diagnosis and a drug prescription, leaving her to figure out next steps on her own. Deniece was overwhelmed.

Through an Internet search, she eventually connected with the New York City Metro chapter of the National Alliance on Mental Illness, where she accessed a range of free programs designed to support parents and caregivers like her. Perhaps more importantly, she met others who shared her experience and could offer encouragement as she sought the best possible care for her daughter.

Parents and caregivers of family members often share a shortlist of pressing needs. They lack basic information about mental illness. They need help navigating a poorly coordinated mental health system. Their hectic lives, spent balancing work and family, require flexible services to accommodate their schedules.

What parents soon discover is that they also need each other. Peer-led family support reduces feelings of isolation and shame, and gives parents the skills to advocate more effectively for their children. And when they are strengthened with knowledge and know-how, parents and caregivers become part of a grassroots leadership development program that powers the mental health community all around the country.

Parent Matching Program

One of Deniece's first steps was to enroll in the NAMI-NYC Metro Parent Matching Program. This program connects (by telephone) experienced parents of children with mental health issues with parents of children who have been recently diagnosed or who are facing new or urgent challenges. Parent Matching offers parents the opportunity to talk to another parent who has "been there" and who can offer emotional support, coping strategies, the benefit of experience in negotiating the mental health and special education systems, and connection to community resources. This program remains one of NAMI -NYC Metro's most popular offerings.

Family-to-Family Course

Another key step for Deniece was to enroll in a Family-to-Family course, a class for parents and caregivers whose family member has been diagnosed with a major mental illness. These weekly classes are taught by a trained family member and provide information and practical skills in a supportive environment. Course topics include: major mental illnesses and how diagnoses are made; the biology of mental illness; medication updates; developing empathy for your family member's experience; letting go of guilt; self-care and advocacy; and how to communicate more effectively with your family member.

Wendy Brennan, MS

Lunch Hour Conference Calls

Understanding that parents are busy, NAMI-NYC Metro offers a series of lunch hour conference calls in English and Spanish, called "Your Child's Mental Health." This series of presentations by experts in the field provides a live presentation on a mental health topic or resource related to children. Topics have included everything from specific disorders—including ADD/ADHD and bipolar disorder—to overviews of medications, special education, summer camps, and other community resources. After the presentations, parents have the opportunity to ask questions directly of these experts, a level of access that many of them have lacked previously.

Collaborative Workshops

Organizations do well to collaborate on programs, merging their experience and expertise, especially in times like these. In partnership with the Puerto Rican Family Institute, a nonprofit family health and human service agency, NAMI-NYC Metro offers the Responsible Fatherhood Program. This free program offers a series of parenting workshops that

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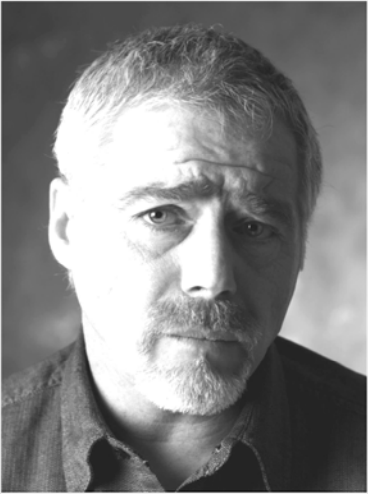

Giving Care to the Caregiver: Visiting Nurse Services in Westchester

By Annie Balzer, RN, BSN
Assistant Clinical Manager
VNSW Mental Health Team

Often, the homecare nurse will encounter that once-in-a lifetime individual who has decided to take on the huge task of being the primary caregiver for an ill family member. Their motivation may vary from person to person. It may be financial, concern for the quality of care, or just wanting to be physically present for their loved one, what ever the reason, they have taken on a most difficult task.

After assuming primary responsibility for the care of their family member, it does not take long for the reality of the situation to hit home. Lack of sleep, frustration, isolation, not to mention exhaustion, conflicting feelings of fear, resentment and anger, not only at the patient, but at other family members, who are now perceived as not contributing enough, can quickly erode the caregiver's ability to provide the kind of care they originally set out to provide.

For the home care nurse this poses a bit of a problem on several levels. At some point many of us are faced with the unpleasant task of saying to the devoted person, that they are in way over their head, and it is time to let someone else step in .The initial reaction may be anger and denial, I have heard people say things like, "nobody else will take care of my mom like I do." The caregiver may also be feeling guilty that they would even consider allowing someone else to take care of Mom, or to compound the internal conflict even further, they may experience relief that someone has noticed how exhausted they are.

Most people feel that admitting they cannot take care of Mom or Dad alone anymore, is equivalent to being uncaring or indifferent towards them . By helping the caregiver understand that Mom can get better care if her caregiver isn't on the verge of collapse may help the caregiver to surrender some of the responsibility to someone else. And then encourage the caregiver to ask other family members for what ever assistance they can provide, no matter how small. For instance, if Mom is in Boston, and the caregiver's other siblings all live in New York, setting up a rotating weekend schedule may help. And creatively reassigning tasks to others can also lighten the load. If Brother Billy lives in California and can't rotate a weekend, maybe he can make sure that the household bills are paid instead.

Eventually, even the most well-coordinated and helpful of family members may have to admit it is time to call in for back up with hired help.

Fortunately, the realm of home care has opened up many possibilities of different levels of accepting help. We no longer have to offer our patients only the two options, full care from family, or off to a nursing home. Many times convincing a family member that it is ok to allow a home health aide to help Mom in the middle of the night is a major hurdle. Offering someone the possibility of an uninterrupted night of sleep can seem like a gift from heaven.

Encouraging the caregiver to get out of the house and do something for them selves can also be helpful. They may be reluctant at first, but if a trusted home health aide or other family member is staying with Mom and she is safe, a gentle but firm push out the door can often give them the strength they need to keep taking care of mom when they come back.

As nurses, we need to show the caregiver that they are no less devoted or loving by accepting help. By giving the caregiver permission to express feelings of frustration safely in an accepting environment can alleviate the feelings of anger and resentment. Putting family members in touch with support groups can also be enormously helpful. By sharing experiences with other people they can accept that many of their feelings are normal, and lessen the feelings of guilt they may be hiding.

Managing stress on a day-to-day basis is also something the nurse can help with. By teaching the caregiver relaxation techniques we can give them a temporary respite when leaving is not a viable option. Deep breathing can be used to create a feeling of calm when confronted with overwhelming situations, playing soothing music in the patients room may not only benefit the care giver, but calm the patient as well.

I am also a big advocate of fresh air and sunshine. If safety and the weather allow, put mom in a wheel chair and take her for a walk around the block. She will enjoy the change of scenery and the caregiver will get a chance to work off some steam, and perhaps gain the opportunity to enjoy Moms' company for a change. Playing cards, doing puzzles or teaching mom some simple video games may not only lower stress levels all around, but may help to improve hand -to -eye coordination , and mental awareness.

If the patient is cognitively impaired or socially inappropriate, a spin around the block in a wheel chair may not be appropriate, but perhaps sitting in the back yard under the shade of a tree, or on a screened in porch may be possible instead. Less mentally demanding activities like manipulating play dough or folding laundry may help to distract the patient for short periods, and lessen the frequency of loud outbursts. If the patient enjoyed a hobby or activity once before, the same activity may be reintroduced, perhaps on a smaller scale.

Hand crafts that do not involve sharp objects can often be enjoyable for both the patient and the caregiver. Going through boxes of old photos together may jog some pleasant memories as well.

Lastly, it is important to give the care giver the all important pat on the back. "Your Mom looks great, I can tell you have done a great job" can mean a great deal to the caregiver who often feels they haven't or cannot do enough.

In addition to nursing care, VNSW provides a full range of rehabilitative therapies, social work and home health aide services. With its dedicated Mental Health Home Care Program, Visiting Nurse Services in Westchester emphasizes treatment of the whole person with the agency's core multidisciplinary approach. For details, visit www.vns.org, call (914) 682-1480 Ext. 648 or e-mail MentalHealth@vns.org.

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take a pro-active approach to the use of touch in treatment that combines in-depth understanding of its integral role in child-development and well-being with ethical and practical guidelines for safe and sound practice. (8)(9)

The use of touch at Wellspring is permission-based, treatment related and trauma-informed. Based on comprehensive assessments, thorough staff training and ongoing supervision, different levels of touch are used that range from supportive hugs to clinically authorized and supervised holdings designed to help fill in developmental gaps. Rightfully used, touch communicates care and affection, while providing comfort, reducing stress and fostering a depth of interpersonal communication that builds trust.

According to Siegel (2002) and Cozolino (2002), emotion is inherently integrative, so that emotionally involving therapies play an important role in the resolution of trauma.(10)(11) Wellspring not only provides an emotionally validating environment in each of its programs, Emotional Expressive Therapy (EET) is also used in group and family therapies as a component of relational treatment and bottom-up processing. EET employs a wide variety of methods, including breath-work, cube work, role-playing, playback theater, and play therapy to facilitate the structured exploration and expression of emotion, along with the processing of its related content.(12) Expressive work always occurs in the context of empathic relational support, and catharsis is only a secondary by-product. Blocked feeling typically becomes freed to flow into relationships, which helps in the effort to restore heart-to-heart familial and relational connections.

At Wellspring, EET has been used extensively and with great effectiveness with adolescents and adults, while play therapy adaptations have been most effective with younger children.

In terms of trauma resolution, emotional expression actually informs cognition, finding words for emotionally driven content, rather than the reverse. In trauma work with both children and adults, it is important to follow the lead and the limits instinctively set by the client in determining the pace and depth of the work. By calibrating emotional expression in manageable doses, the traumatic experiences at the root of it become progressively desensitized rather than re-traumatizing. (Lazarus and Lazarus, 2002) (13) More significant by far than its cathartic effects, EET provides a context for corrective emotional-relational experiences, which stand in sharp contrast to the traumatic past and help to change distorted perceptions of present relational reality.

Instead of encouraging aggression, which some research with children suggests, EET actually serves to diminish it, as evidenced at Wellspring by the steady decrease of restraints with children and the virtual elimination of any restraints with adolescents and adults.(14) While younger children tend to reactively explode, adolescents and adults tend to implode, using self-injury and substance abuse as self-destructive ways to deal with overwhelming feelings. As a coping skill, cutting often serves to numb overwhelming feelings that would otherwise

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Mental Health Treatment in Westchester

The VNSW Mental Health Home Care Program provides:

- **Adjunct service to community mental health programs**
- Structure in the home environment.
- Assistance with home management focusing on inadequate levels of functioning, hygiene issues and compliance with medication regimen.
- Administration of I.M. long-acting psychotropics.
- Liaison with the community treatment team informing them of changes and important symptoms that may indicate decompensation or need for changes in the treatment plan.
- On-going assessment of all health needs relevant to the individual's diagnoses.
- Consultative services for the individual whose primary diagnosis is medical/surgical in nature, however, due to difficulty coping with illness, requires mental health intervention.
- Coordinated home care services for non-compliant individuals and those with complex combined mental health/physical needs that present ongoing problems.

Program Features

- Facilitate psychiatric care from in-patient to home & community
- Prevent in-patient psychiatric hospitalization
- Decrease symptoms & improving functional ability
- Improve knowledge base about medications, illness, coping & staying well
- Improve medication compliance
- Access community services

The Big Picture

Visiting Nurse Services in Westchester (VNSW) believes in a holistic, broad approach to the treatment of mental illness, addressing the "whole person's" life circumstances and environment. VNSW fields nurses with advanced psychiatric training, and in some cases, advanced degrees in related fields. The staff provides home visits for assessment, evaluation and development of a treatment plan with interventions related to mental health issues in conjunction with medical/surgical needs. This program meets the total health care requirements of individuals utilizing a case management approach led by a psychiatric nurse specialist. Adjunct services complementing the mental health component include psychiatric social workers, home health aides, medical/surgical nurses and relevant rehabilitation therapies.

The program serves the elderly, adults, adolescents and children.

To receive further information or make a patient referral, contact:

Lisa Sioufas, LCSW-R, ACSW • Mental Health Program Manager
(914) 682-1480, Extension 648 • e-mail: MentalHealth@vns.org

Visiting Nurse Services in Westchester
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360 Mamaroneck Ave.
White Plains, NY
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NAMI Westchester Family to Family Program Helps Caregivers

By Sharon McCarthy
Family to Family Educator
NAMI Westchester

As a parent of an adult child living with Bipolar Disorder, I am all too aware of the stress that mental illness places on caregivers. I have struggled with the highs and lows and the overwhelming grief and the sense of loss for the life that my child could have had.

When I was first pulled into this rocky road of mental illness I was at a total loss about what to do, where to get help and how to cope. It was not until I became involved with NAMI Westchester that I found direction. Through their encouragement, I pursued getting a re-evaluation of her diagnosis. This new evaluation resulted in a correct diagnosis and set us on the road to hope. I took the NAMI Family to Family Education Program. This valuable 12-week program has helped me to cope as a caregiver and parent. I became a Family to Family educator so I could help others benefit from the impact that this program can make in their lives.

During the class I learned about medication, the biological effects of mental illness, problem solving, communication skills and so much more that enables me to have a healthier relationship with my child while coping with my own emotional state. This program empowered me so that I could advocate and assure that the best care was given. As a result, I was able to find a psychiatrist who truly understands the needs of his patients, and supports them in pursuing a quality of life that will allow them to reach their potential. I also used my new-found knowledge to seek a therapist who would also support my daughter as she works to achieve her goals. I learned that we have a right to be informed and educated regarding treatments, and that successful recovery occurs when the treatment teams and families work together in the best interest of the individual.

Sharon McCarthy

In addition, through this educational program I was able to finally give myself permission to take care of myself. As a caregiver and one of my daughter's primary support persons, doing things for myself had to be considered a priority so I could sustain a balance in my life. With that in mind, I make sure that I find time throughout my week to do some of the things I enjoy. I also realize the importance of maintaining relationships with other members of the family, because mental illness affects everyone in a family in many unique ways, and the stress can pull families apart. Planning family gatherings that do not revolve around the individual's illness is so important in preserving these relationships. Allowing everyone in the family the ability to take a "time out" when needed is not only healthy but a necessity.

One of the greatest gifts that came from my Family to Family class is my monthly dinner support group. During the 12 week course, strong bonds can develop as people meet. It is a relief to be with others who have felt similar isolation, grief and worries. When our 12-week class was coming to a close, the class realized that we wanted to keep our "bond" going. We have been able to help each other through difficult times with words of encouragement and, most importantly, emotional support. We are able to find laughter as well as rejoice in the smallest of successes for our family members with mental illness. It has certainly helped alleviate the isolation that as caregivers we often feel. During times when my child has had to be hospitalized these individuals kept my strength up through their supportive emails, cards and phone calls (not to mention the many meals they provided).

It is difficult for families and friends to understand the impact mental illness has on the daily lives of those living with it. Days are spent maintaining the emotional and financial foundation that your ill loved one needs to forge ahead towards recovery. It is hard for others to accept that your support may be the one "piece of thread" keeping them going in their struggle. Once stability is achieved you still need to be on alert for the potential "shoe drop" when you are once again in the midst of a crisis.

We all have dreams, expectations and goals for our children while they are growing up. Through Family to Family I learned to let go of these dreams, expectations and goals, and that grieving this loss is normal and healthy. I have come to realize that what is truly important is for our loved ones to find their own happiness and for us to accept whatever that path may be.

Family to Family has shown me that we need to hold on to the hope for recovery and that we are not alone in our struggle. As a Family to Family Educator, I am not only able to help other family members but with each class I find renewed strength and hope. My Family to Family support group gives me, as a caregiver and parent, a place to unload my grief, shed my tears, find laughter and share my joy when small milestones are achieved.

Don't Let Caregiving Make You Sick

By Valerie Rissman, LMSW
and Jane Slevin, LMFT
Westchester Jewish Community Services

With more than 44 million family caregivers in the United States, chances are you or someone you know is taking care of a loved one. This can be an extremely rewarding experience as it allows caregivers the opportunity to demonstrate their love for someone dear. Yet, caregiving also can be quite demanding; making it easy and common for caregivers to feel overwhelmed, compromising their emotional and physical health. Additionally, some caregivers may be part of the "sandwich generation," which demands that they juggle work and children in addition to their caregiving responsibilities.

Caregiving can take an emotional as well as physical toll. Tasks such as lifting or maneuvering assistive equipment can cause back and shoulder injuries. Worry associated with the responsibility can bring about depression. Often caregivers' health is compromised because they neglect their own care and don't take the time to nurse themselves back from colds or steadfastly monitor their own chronic conditions such as diabetes or high blood pressure.

Additionally, caregivers may feel burdened, which can put a strain on their immune systems jeopardizing their health. If a caregiver's health suffers, so too may the health of the loved one. Therefore it is crucial for caregivers to take care of themselves. Being able to recognize the signs of "caregiver stress," such as sleeplessness, irritability, poor concentration, change in appetite and social withdrawal is very important.

Caregivers can try to relieve some of this stress by participating in support groups, maintaining a regular exercise program and accepting the reality that they can't do or control everything — illness and disease take their own course. Putting aside time for yourself, ensuring enough sleep, taking breaks, accepting help and/or talking to a friend or professional for emotional, legal and/or financial advice can go a long way toward alleviating "caregiver burnout." Remember that the point of caregiving is to help a loved one. Putting your own health in jeopardy leaves your loved one at risk. While caregivers can often feel guilty about taking time for themselves, it is necessary under these circumstances.

The burdens of caregiving can often be eased by outside organizations and services. There are many federal, state, county as well as local resources and supports available to caregivers. The trick is knowing where to turn. Services such as respite programs and home health aides are available through many local organizations. Check your local listings as services may vary by community.

Other Resources Include

- Medicare Rights Association
- Social Security Administration
- Food Stamps
- Low-Income Energy Assistance Programs (HEAP)
- Elderly Pharmaceutical Insurance Coverage (EPIC)
- Para Transit
- Meals-On-Wheels
- Adult Day Centers
- Caregiver Support Groups
- Disease-Specific Support Groups (Gilda's Club, American Cancer Society, Alzheimer's Association, Cancer Support Team)
- Geriatric Care Management, Geriatricians, Geriatric Psychiatrists
- Expanded In-Home Services for the Elderly (EISEP)
- Local Office for the Aging

Additional information can be found at www.caregiver.com, www.cms.hhs.gov, www.careguide.com, www.benfitscheckup.org www.aarp.org, and www.careguide.com.

Caregivers should not hesitate to contact these organizations; their purpose is to assist you. Fortunately, as more and more people take on the role of caregiver, additional services and resources are available to aid in this tremendously rewarding and challenging job. While caregiving is challenging for a variety of reasons, it also can be fulfilling and gratifying. Try to take the time to appreciate the rewards it brings. Embrace the opportunity to deepen or renew your relationship with your loved one.

Valerie Rissman, LMSW is Coordinator of Project Time-Out and Jane Slevin, LMFT is Coordinator of the Family Caregiver Network at Westchester Jewish Community Services.

Clinicians and Suicide Loss

**By Nina J. Gutin, PhD
and Vanessa McGann, PhD, Co-Chairs,
American Association of Suicidology
Clinician-Survivor Task Force**

For mental health professionals, the loss of a client to suicide is surprisingly common, if not an unfortunate occupational hazard. Studies show that one in five psychologists and counselors (Bersoff, 1999; McIntosh, 2000, McAdams and Foster, 2000) and one in two psychiatrists (Ruskin, 2004; Chemtob, Hamada, Bauer, Kinney, & Torigoe, 1988) lose a patient to suicide in the course of their careers. Despite this, many mental health professionals continue to view suicide loss as an aberration. Consequently, there is often a lack of understanding and preparedness for such an event when it does occur.

Despite the many published guidelines, suggestions and postvention protocols available to help clinicians and mental health settings navigate the often-complicated sequelae to such a loss (see below for bibliography info), these resources have not been integrated into clinical training and tend to be poorly disseminated. Thus, clinicians are often left to cope with the consequences of this difficult loss on their own and under less than optimal conditions.

Nina J. Gutin, PhD

Vanessa L. McGann, PhD

Grief After Suicide Loss

In many ways, the responses of clinicians after the suicide of a client are similar to the responses/reactions of survivors after the loss of a loved one to suicide, generally considered to be a "traumatic" loss. Reactions typically include initial shock, denial and numbness, intense sadness, anxiety, anger and intense distress. Survivors are also likely to experience PTSD symptoms such as intrusive thoughts, experiences of detachment, and dissociation. In addition, suicide loss is often accompanied by intense confusion and existential questioning, reflecting a blow to one's core beliefs and assumptive world. Survivors also commonly experience guilt and shame, and this may be socially reinforced by the gene3ral stigma around suicide as well as the actual blaming and avoidance responses of others (Brown, 1987; Cvinar, 2005; Goffman, 1963).

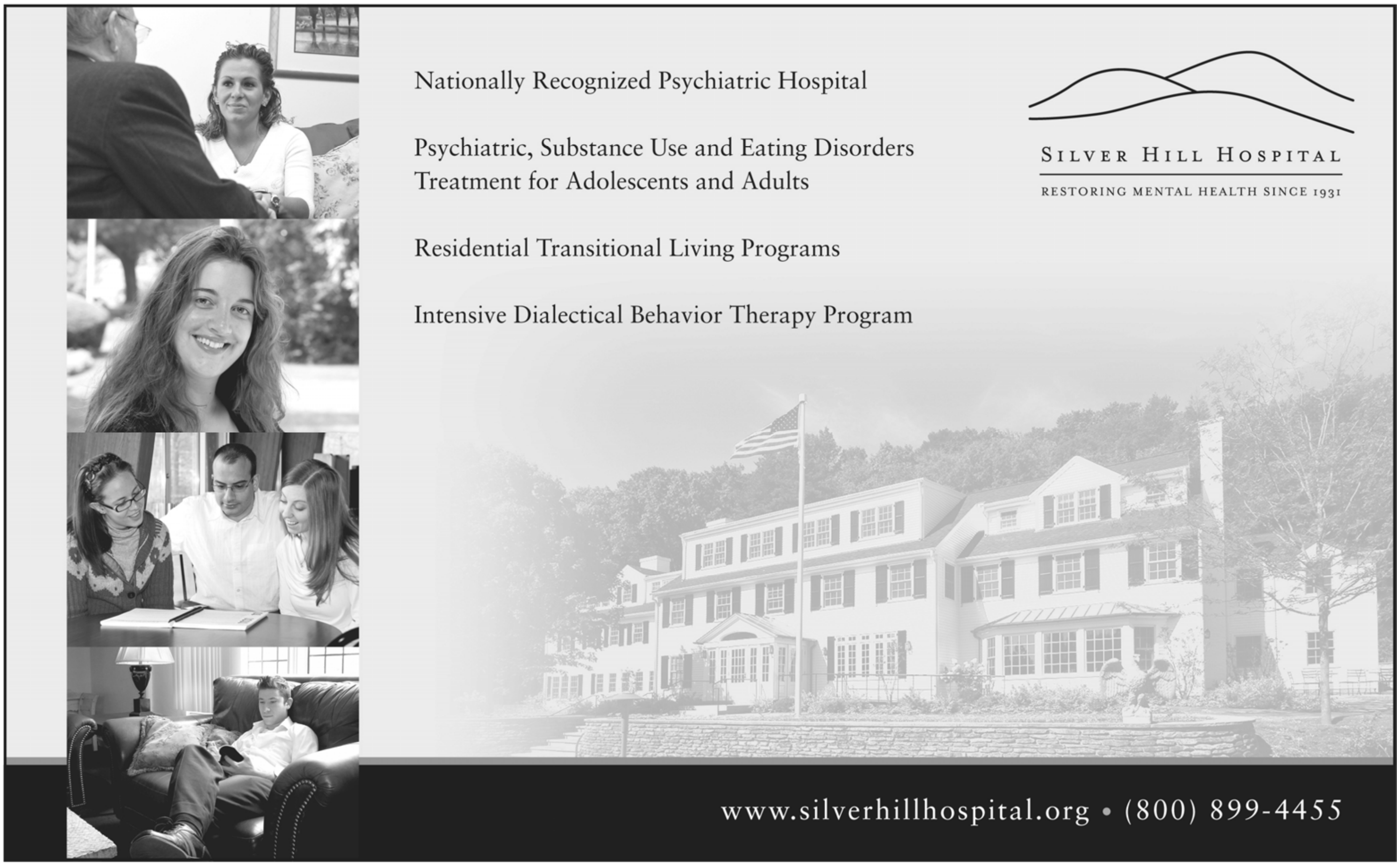
Professional Issues

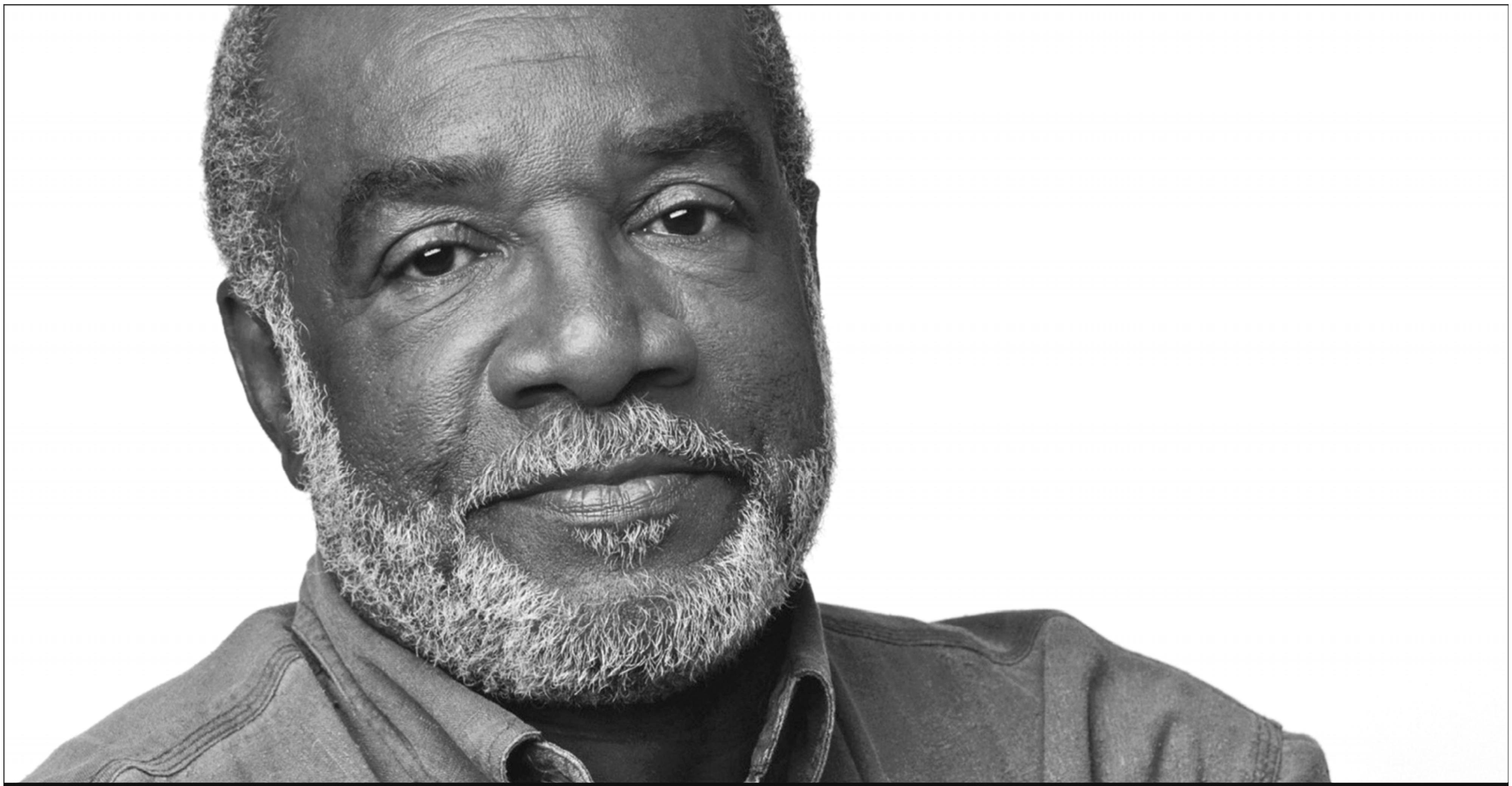
Suicide loss affects clinicians on both personal and professional levels. In addition to the personal grief reaction entailed in losing a client, this loss is likely to impact clinicians' professional identities, their relationships with colleagues, and their clinical work.

Assumptions around one's clinical competence are often challenged, if not shattered, when a client takes their own life. A clinician's sense of professional responsibility, the self-blame that may accompany this, the fear of and actual blame of colleagues and family members, as well as the real or imagined threat of litigation, may all greatly exacerbate this distress. Additional components of the grief reaction for clinicians may include "guilt, loss of self-esteem, self-doubts about one's skills and clinical competence, fear of being blamed for the suicide and fear of relative's reactions" (Farberow, 2005).

Hendin, Lipschitz, Maltsberger, Haas, and Wynecoop (2000) found that therapists described losing a client as "the most profoundly disturbing event of their

see Suicide Loss on page 36





THE MENTAL HEALTH LAWYER

Addressing the Needs of Caregivers

By Carolyn R. Wolf, Douglas K. Stern, and Eric Broutman, Esqs.
Abrams, Fensterman, Fensterman, Eisman, Greenberg, Formato & Einiger, LLP

Carolyn R. Wolf, Esq.

All too often, the severely mentally ill do not have family or friends involved in their care to act as a vital support system when they become symptomatic. For those people who are lucky enough to have supportive family and friends, those support people are often, and validly so, frustrated with their inability to obtain information or make critical decisions when they know their loved one is psychiatrically decompensating. As an attorney representing psychiatric facilities, families and individuals, I have had countless conversations with family members expressing their aggravation over the fact that hospital staff or mental health professionals are legally barred from speaking with them about a patient. On the other hand, patient confidentiality, and the confidentiality of all medical information, is the right of every patient, whether they are being treated for a medical or psychiatric condition. Hence, a delicate balancing act takes place weighing the patient's right to confidentiality with the family's desire and need to obtain information so they can help in the healing process.

This article will examine the present state of the law as it relates to the confidentiality of patient information. It will also discuss ways in which supportive family and friends can act in advance to better facilitate the flow of information. Lastly, the article will take a critical look at the law, suggesting potential compromise and change that can achieve the dual goal of maintaining patient confidentiality as well as the need to include family and friends in the process.

In 1996 Congress passed the Heath Insurance Portability and Accountability Act, better known by its acronym, HIPAA. While the law accomplishes other tasks, for our purposes HIPAA created a federally protected right in the confidentiality of medical records. After the law's passage, the unauthorized release of general medical records became a federal offense. Hence, pursuant to HIPAA hospitals and mental health professionals are barred from sharing any medical information with family or friends unless the patient has specifically provided consent for the release of these records.

Well before HIPAA was enacted, any facility providing mental health services in New York State was controlled by the confidentiality requirements of the Mental Hygiene Law. The Mental Hygiene Law not only prevents hospitals from providing medical information to others, including family, it also prevents hospitals from disclosing whether or not a particular individual is even a patient in their facility.

In addition, New York law provides for discretion to clinical providers when it comes to the release of psychiatric records to a patient or family. An inpatient treating psychiatrist can deny a patient access to their own records if in the treating psychiatrist's opinion providing these records would be harmful to the patient's continued treatment. Moreover, a treating psychiatrist is given the same discretion with respect to providing treatment records to family, friends, or any other individual the patient wishes to provide his or her medical records to, if in the view of the treating psychiatrist it would not be in the best interest of the patient. The law allows for an elaborate appeal procedure to the Office of Mental Health ("OMH") if the patient or the family member believes they were wrongly denied access to records.

With a Health Care Proxy and Power of Attorney for health care decision making, a mentally ill individual can provide advance authorization to allow access to his or her medical records. However, these advance directives will only remain valid with respect to the release of records if the mentally ill individual does not explicitly deny access to their records. In other words, these directives are void if the patient prohibits access. The only way to nullify a patient's refusal to allow access to records is if the individual is judicially found to be incapacitated and a guardian is appointed. A guardian generally is empowered to access the patient's records.

Despite some limitations of advance directives it is an easy and minimally restrictive process that will allow access to records in most circumstances. Additionally, it requires only that the mentally ill individual execute a form, and unlike the guardianship process, it does not require a legal proceeding and a judicial determination of incapacity.

It should always be known that while a hospital or practitioner may not be able to provide information to family, nothing prevents a treatment provider from listening to information that family and friends may have.

In terms of decision making, neither a Health Care Proxy, nor a Guardianship, will allow a surrogate decision maker the right to make psychiatric treatment decisions for a mentally ill person. The Courts have been quite clear that only a court, conducting a hearing on the specific facts, can make that decision.

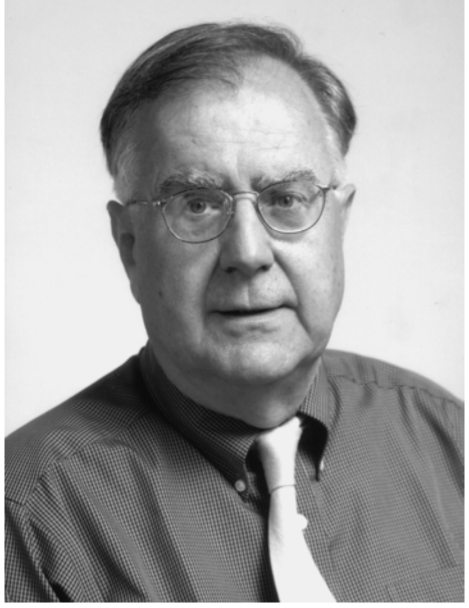
One recent change to the Mental Hygiene Law requires all mental health and developmental disability treatment facilities to notify family in cases of incidents of abuse or injury. The law is commonly known as "Jonathan's Law." It is titled after Jonathon Carey, a profoundly developmentally disabled boy, who died when put into restraints while at a state facility. Jonathan's parents, suspicious of their son's maltreatment, attempted to obtain records of his care and were repeatedly denied. While the Law was mainly aimed at notifying parents of disabled children of incidents of abuse, the law is equally applicable to psychiatric facilitates providing care to mentally ill adults. Jonathan's Law requires psychiatric facilities to notify the parents, spouse or adult child of a patient if they are injured.

Conclusion

The law in the area of confidentiality attempts to balance very strong competing interests of family access and confidentiality. Due to the effects mental illness has on one's capacity, allowing additional access to family and friends would often be of great benefit. This can be accomplished by allowing a Health Care Proxy, or other advance directive, to remain valid, at least with respect to access of records, even during periods where the patient explicitly denies access. Additionally, since guardians are allowed the authority to make the most serious of medical decisions, including surgery, they likewise should be allowed to make psychiatric decisions in certain circumstances. These changes, while still respecting patient confidentiality, will allow truly committed family members needed access.

— The Economics of Recovery — Threading the Needle

By Donald M. Fitch, MS
Executive Director
Center for Career Freedom



Donald M. Fitch, MS

The Government Guy was summing up his four hour PowerPoint presentation on how easy it was for people with disabilities to get a job; “You just need to take advantage of the many work incentives like Ticket-to-Work, PASS Plan, Medicaid Buy-In, IRWEs, Subsidies, Tax Credits, etc., don’t worry – just fill out the applications.”

The audience of mostly Consumers looked confused; “But won’t SSI deduct half my salary over $85/mo?” (yes). Won’t HUD add thirty percent of my salary to my rent?” (yes). “Won’t I lose my food stamps?” (probably). “Of the six million people on SSI, how many have gone back to work?” (one half of one percent). The questions went on --- “Aren’t we still in a recession; with an almost ten percent unemployment rate?” (yes). “Then, how is a person on disability who can’t afford to lose their benefits, has few skills, a spotty resume and only enough stamina to work 1-2 days/week going to find a job?”

The good news is that even with these issues, Recipients of SSDI/Medicare (about half of the twelve million persons on disability in the U.S.) are able to return to work because SSDI Recipients worked at least ten years and paid their Social Security. This accomplishment allows them to go back to work and earn up to nine-hundred eighty dollars a month and, still receive their disability checks. They are able to work their way off their benefits.

The bad news is that, SSI/Medicaid Recipients are not able to earn more than eighty-five dollars per month without severe penalties. I asked an SSA Deputy Commissioner; “Why the disparity and could there ever be parity between SSI & SSID?” He told me SSA could not afford a parity policy because SSI Recipients paid so little into Social Security. They couldn’t afford to level the playing field. In order to achieve SSI-SDI parity, the laws would have to change and billions of dollars found elsewhere. I don’t believe this will happen in my lifetime.

So, what is the solution for the almost three hundred thousand persons on SSI in New York State? (About one-third have been diagnosed with “mental disabilities”). The question is; “Are there legal ways to get around the income penalties of SSA, HUD and FDA that could provide significant improvement in the lives of SSI Recipients?”

To compound this problem, SSA can deduct the market value of any unearned income e.g. in-kind support such as room & board, clothing, gifts, etc. that SSI Recipients receive from family and friends. While some work-related expenses may be excluded and some earned income set aside through the PASS Plan, it is limited, negotiable and temporary (SSA.GOV).

The IRS, however, is clear when it comes to reimbursement of work-training expenses; the IRS doesn’t count it as income (IRS publication 525).

Once we were able to navigate a path through the economics of recovery regulatory forest, we could address the issue of how to meet the employer’s work skill requirements. If our Microsoft Office Certified interns were to be successful, they would have to perform the job tasks correctly and on time as defined by their employer, not their instructor. The transition from being person-centered to employer-centered would require skill, self-discipline and maturity.

A recent study of Corporate Human Resource Departments conducted by the Business Council of Fairfield, Connecticut found “Lack of Skills” to be the major barrier to hiring persons with disabilities. Acquiring competitive keyboard and Microsoft Office skills solves this problem. All too often, we have seen non-profits attempting to “guilt” corporations into hiring persons with disabilities. Many NFP’s fail to understand that the corporations’ mandate is to earn a profit. It is not a charity. Hiring employees is a business decision based on matching skills with needs.

Once we addressed the Governments’ and Employers’ requirements, we were free to enjoy listening to our student’s dreams for self-empowerment in the community, for a full and balanced life.

Over the years, our students had helped us visualize what their goal of Self -Empowerment looked like. To them, “recovery” wasn’t an abstract academic term to be tossed around in meetings – it was comprised of specific components whose achievement could be quantified. Once articulated, trade-offs, compromises and choices could be made, plans and supports defined.

In developing our Cross-Disability Employment Program, (CDEP) the challenge was to choose students’ goals that were within the Government’s regulatory pallet of training and work-related expenses; stipends, transportation, meals, work clothing, time management; an alarm clock and wristwatch, computer and programs, driving lessons/license, a car, community college courses, etc. In the focus groups, when a number of women told us they could be healthier if they belonged to a gym - we negotiated a $250 full membership at the local “Y”, a $500 savings!

When functional, the program will offer weekly work adjustment counseling sessions which include stress, money and weight management and smoking cessation.

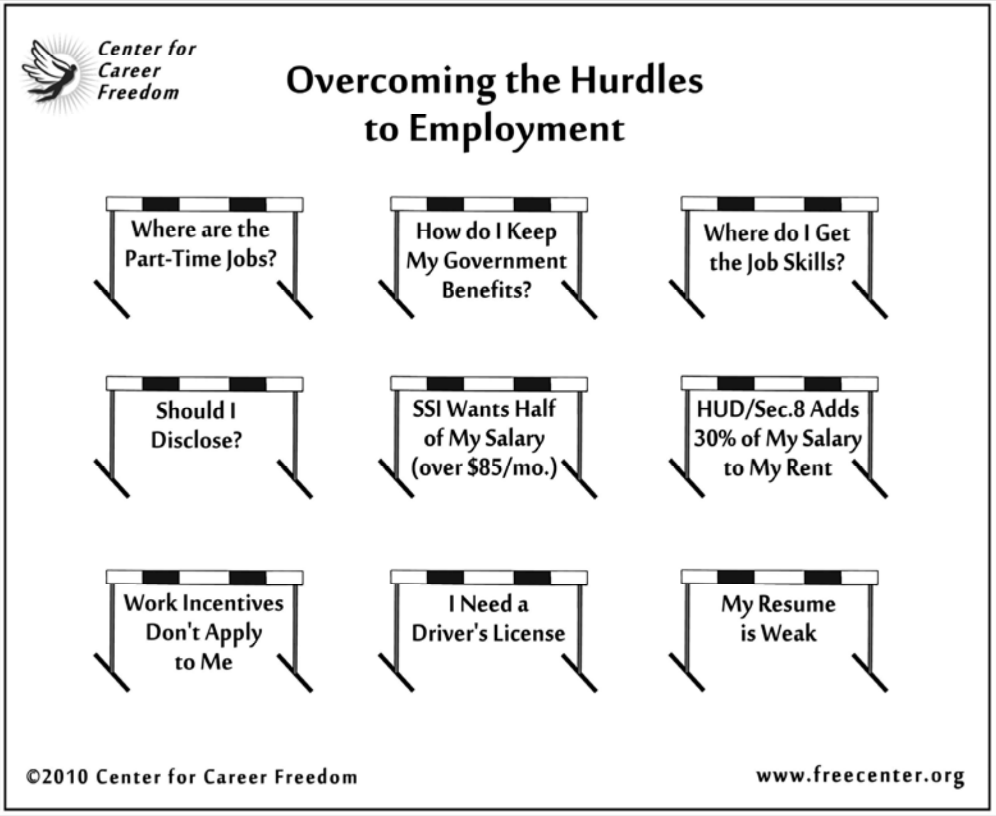
The Center’s unique status as a NYS ED licensed Business School, Microsoft Certified Office Specialist Training Center, an Employment Network (EN) for SSAs’ Ticket-to-Work Program, a 501 (c) (3), and one-hundred percent consumer- run agency, enables us to qualify for funding from a variety of sources.

With guidance from our Corporate Advisory Board, our own Board and Westchester’s’ Department of Community Mental Health, we plan to launch the CDEP Program this fall.

The Center is now accepting applications for this model Employment Program Pilot. Currently, there are fifteen slots available. Applicants must be residents of Westchester County, persons with a mental and/or physical disability (SSS/DI) who type at least 25wpm, 95% accuracy, are Microsoft Word Certified and able to work at least one-two days per week. Background checks are required.

The two hour CDEP Intake Interview includes a Typing Test (Mavis Beacon), a Microsoft Office Word Test, a simulated Office Document Test and personal interview.

Persons interested in this program or our Certified Microsoft Office Training (Word, PowerPoint, Excel, Access and Outlook) should call Joanne at914-288-9763.



— The NYSPA Report —

Mental Health and Addiction Parity: Law and Regulations

By Jennifer Tassler, JD
Deputy Director for Regulatory Affairs
American Psychiatric Association

On October 3, 2008, President George W. Bush signed into law H.R. 1424, which was known as the Emergency Economic Stabilization Act of 2008. The law was more commonly referred to by the system it created, the Troubled Asset Relief Program or TARP, which was used to stabilize the economy during the financial market collapse. However, what may have gone unnoticed to most of the public was H.R. 1424's original title and purpose, which was "The Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA)." The passage of MHPAEA in 2008 was the culmination of over a decade's worth of effort by mental health professional associations, consumer groups and other advocates to finally ensure that there would be comprehensive parity for mental health and substance use disorder treatment.

While there had been prior mental health parity legislation passed in 1996, the new parity law was much broader in scope and coverage than the earlier law. MHPAEA requires that any group health plan that covers more than 50 employees and offers mental health and/or substance use disorders coverage must provide that coverage with no greater financial requirements (i.e., co-pays, deductibles, annual or lifetime dollar limits) or treatment limitations (i.e., number of visits) than the predominant requirements that it applies to substantially all medical/surgical benefits. Previous federal legislation in 1996 provided limited parity on lifetime and annual dollar limits and did not extend to substance use disorders. The law is estimated to provide parity of coverage for 113 million people, including 82 million enrolled in self-insured plans. MHPAEA became effective for plan years beginning on or after October 3, 2009, meaning that for calendar year plans, the law took effect January 1, 2010.

While enactment of MHPAEA was a big step forward, the law does have some ambiguities left to be clarified. In order to better define certain legislative terms and provide more guidance, the law directed the three federal agencies in charge of implementation – Departments of Health and Human Services (HHS), Labor (DoL) and the Treasury – to issue regulations one year after enactment. Unfortunately, it took a little longer than expected, but on January 29, 2010, the Departments issued an Interim Final Rule (IFR) implementing MHPAEA. The IFR was developed with formal input from advocacy groups, physician and provider organizations, insurers and employers all of whom submitted extensive comments.

The IFR provides further details about how the law should be implemented and what insurers and employers must do to comply with the law. According to the rule, if a plan covers a mental health/substance use disorder, it must provide benefits in each classification for which any medical or surgical benefits are offered. The six benefit classifications defined in the rule are: inpatient, in-network; outpatient, in-network; emergency care; inpatient, out-of-network; outpatient, out-of-network; and prescription drugs. Further, the plan must determine what the predominant limitation is on the medical/surgical benefit and then set a comparable limit on the mental health benefit. For the purposes of determining the predominant limitations, the IFR states that plans must compare limitations *within* a given benefit classification and *may not* compare mental health/substance use disorders to specialist limitations, which typically have higher copays and other out-of-pocket costs for consumers.

Jennifer Tassler, JD

MHPAEA required parity in both financial requirements and treatment limitations. Some of the most common financial requirements include copayments, coinsurance, and out-of-pocket maximums, which plans must be at parity with comparable limits on the medical/surgical benefit. The regulations clarified that plans must maintain a single combined deductible for MH/SUD and medical/surgical benefits. Plans are not permitted to have separate deductibles for treatment related to mental health or substance use disorders and medical or surgical benefits, even if they are equal.

With respect to treatment limitations, the regulations state that there is a distinction between quantitative and non-quantitative limitations, but that both are covered by the law. Quantitative limitations are limitation which can be expressed numerically, such as an annual 20 outpatient visit limit. In addition to the requirements for out-of-pocket costs and benefit limits, the rules require parity in the areas of prior authorization and utilization review. According to Departments issuing the rule, "these practices must be based on the same level of scientific evidence used by the insurer for medical and surgical benefits."

Non-quantitative limitations are those which cannot be expressed numerically, but which otherwise limits the scope and duration of benefits for treatment. Examples of these limitations include: certain medical management standards; formulary design for prescription medication; standards for provider participation in network, including reimbursement rates; methods for determining usual, customary and reasonable (UCR) rates; fail-first or step-therapy protocols; or exclusions based on failure to complete a course of treatment. The Departments also stated that they are seeking more input from the public on how these non-quantitative treatment limitations are currently used and what the limits are on the medical/surgical side.

While the IFR covered a number of topics from the law which needed clarification, there were still areas left open. For example, the Departments stated that they are seeking comments on the "scope of services" which should be covered under the law. There have also been questions raised about how the law and the rules apply to Medicaid managed plans. The Departments have stated that MHPAEA covers these plans, but that the IFR does not. Advocacy groups are currently looking for more guidance in this area and hope to have official word soon. Finally, there are concerns about enforcement, since cases arising out of violations of the rules will be extremely fact intensive and will require a great deal of effort from the Departments overseeing implementation.

Overall, MHPAEA was a watershed achievement for patients with mental illness and those that care for them, but it was not the end of the advancements in the field. With the recent healthcare reform legislation, mental health parity was an important part of the debate. The Patient Protection and Affordable Care Act and accompanying reconciliation bill included provisions that specifically preserved the advances of MHPAEA. The legislation also required that mental health and substance use disorder coverage be included as a part of the minimum benefit package in any insurance plan offered in the state exchanges and that those benefits be at parity with medical/surgical coverage. This shows that parity for mental health and substance use disorder coverage will continue to be a part of health care improvements and, while there is still work to be done, this ensures mental health is a part of the conversation to come.

Who Cares for the Caregiver? Responding to the Needs of Grandparents Raising Grandchildren

**By Deborah Langosch, PhD, LCSW,
Director, Kinship Care Program,
Center for Trauma Program
Innovation, Jewish Board of Family
& Children's Services (JBFCS)**

When parents are unable to raise their children, relatives are often called upon to become primary caregivers. In the U.S. approximately 2.5 million kin caregivers have assumed this role -- often unexpectedly, due to parental substance abuse, mental illness, violence, domestic violence, abuse and neglect, incarceration, physical illness, death, divorce, deportation and most recently, military deployment (US Census, 2003). These exposures can profoundly affect all members of the family -- the children, the biological parents and the kin caregiver.

Research has shown that children living in the care of their relatives function better than those placed in traditional foster care (Rubin et al, 2008). To counter the impact of disruptive separations, kin caregivers (most frequently grandparents) take on this tremendous responsibility to help their relative children maintain a sense of family identity and to provide continuity. There is growing evidence, however, that kin caregivers make tremendous sacrifices for themselves. Much can be done to support these caregivers in this time-disordered role. A number of factors need to be considered, including how practitioners can best respond to the concrete and emotional needs of kin caregivers and how self-care can be emphasized and practiced.

Caregiving causes grandparents and other relatives to alter their lives in later adult developmental stages as they give up ambitions and goals for their future and shift identity to become parents again. They are a generation older, and at times have less stamina, more health problems and greater risk for depression, anxiety and isolation in this role. Many are struggling with complex losses and traumatic events without the necessary resources to cope.

Although the life transition of kin caregiving is filled with challenges and obstacles, a number of interventions can provide support, psycho-education and validation for the caregivers. When practitioners increase awareness of the challenges and obstacles kin caregivers face, they can develop effective interventions to sustain the caregivers. A thorough assessment is a critical first step that looks at the prevalence of trauma and loss, the functioning and coping capacity of the family, and adaptive and maladaptive responses. Concrete and psychosocial services to address the family's needs should be identified and provided to the caregiver along with psycho-education regarding the benefits of assistance. Practitioners may need to guide the caregiver through the application process for concrete services, since each system -- e.g. mental health, special education and medical insurance -- has specific and often unrelated admission criteria which can quickly become overwhelming.

Practitioners should give careful consideration to the meaning of psychological referrals within the cultural context of the family. For example, in some cultures receiving psychotherapy can carry a stigma or feel threatening. Part of the practitioner's role is to clarify misconceptions about treatment, describe how it works and *alleviate* any concerns. Families may also be unaware that Medicaid usually covers the entire cost of therapy and Medicare covers 50%. Practitioners may need to expand a family's awareness of the broad range of mental health services currently available, such as specific trauma-focused treatments, AA, psycho-educational approaches, health promotion, school-based interventions, expressive art therapies, mediation services and family focused approaches that consider systems of care.

see Grandparents on page 41

Me First? A Personal Account of Self Care

**By Christina A. Grosso, LCAT, ATR-BC,
BCETS, Director of Training
Center for Trauma Program Innovation,
Jewish Board of Family and Children's
Services (JBFCS)**

When flight attendants give their safety talk at the beginning of each flight- where everyone listens to their iPod or begins to read a magazine- they state: "If there is a loss of cabin pressure, oxygen masks will fall from above. If you are traveling with a child or someone who needs your assistance place the mask over yourself first before assisting others." What…really? This seemed counterintuitive. I have always been a helper. If someone is in danger, how do I not help them?

I began my work as a therapist over ten years ago and nothing prepared me for the impact of this work. I learned theory, practice, and various modalities of treatment to work with clients carrying many diagnoses. But no theorist or faculty ever taught me what it would *feel* like to be a therapist…nonetheless a trauma therapist. No one readied me for the emotions I would feel when a child shared their traumas or their disappointment when they couldn't go home. No one taught me how to manage an overflowing caseload and unrealistic paperwork demands. I worked in a long term residential program, where children with severe psychopathology and complex trauma resided often without family connections due to abandonment or termination of rights. Progress was slow, at best. We all felt overwhelmed and ineffective.

After only two years in the field, I was feeling helpless and hopeless. I wondered why I didn't follow my parents' advice and become an accountant. Problems that *could* be solved and where there was always a *right* answer. This became my imaginary job, the one you fantasize about when you are feeling overwhelmed.

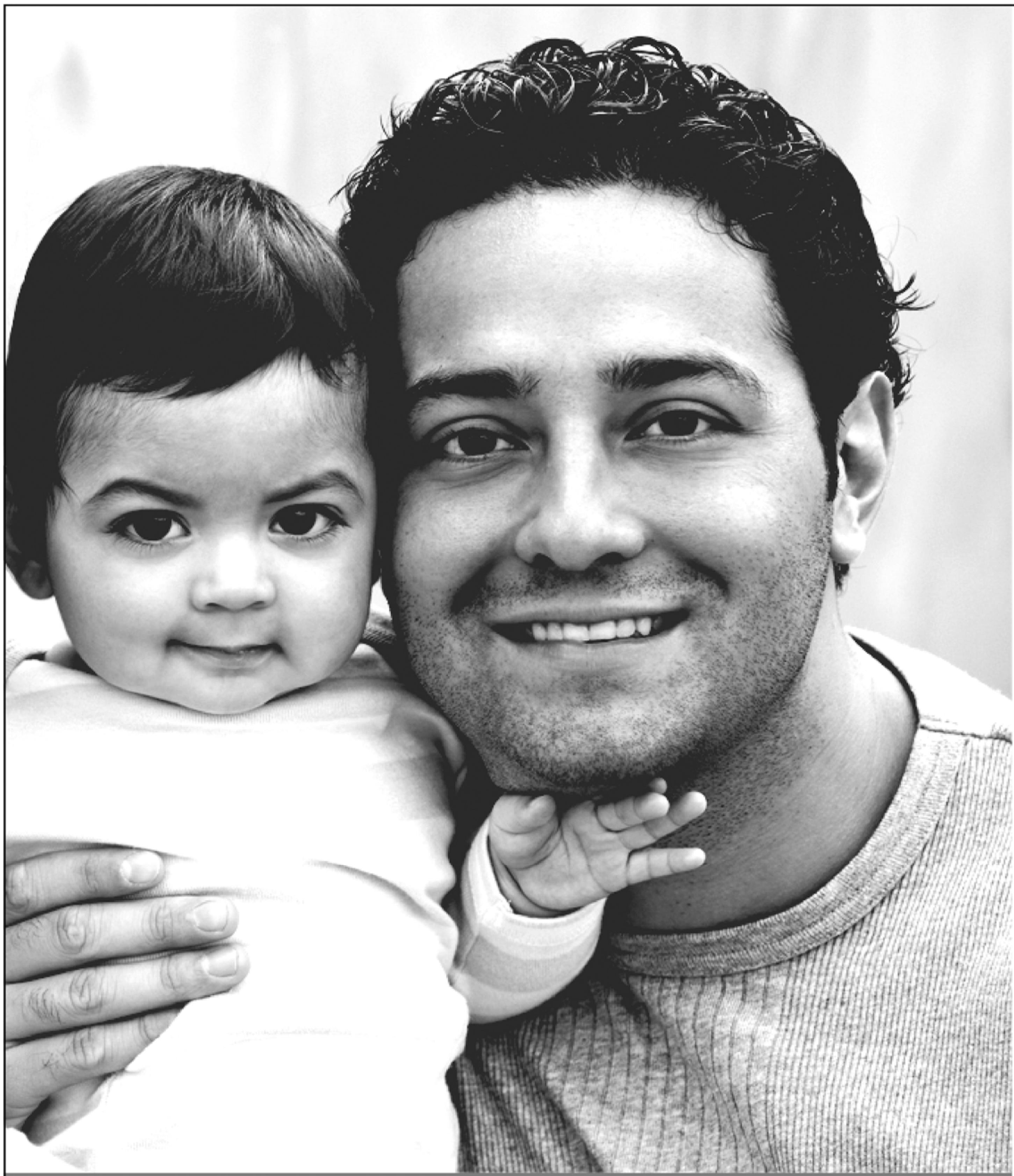
These feelings of hopelessness and helplessness didn't go away. I started feeling anxious, had difficulty sleeping and it became more and more difficult to get out of bed for work. As a therapist, I recognized something was wrong and I needed to go back to therapy. As a therapist, I delayed this for as long as possible. My symptoms became unavoidable. Where were they coming from? Why did they look like post traumatic stress symptoms? I never imagined it could be the work.

With further examination I realized that I was always helping others and not helping myself. Most of my clients were trauma survivors. I worked long days and brought work home. I spent a great deal of my free time reading and engaged in lectures at my post-grad trauma program... then my therapist talked to me about vicarious trauma. Could this be? My work impact was beyond normal empathy or even compassion fatigue. So, what to do…first, recognize that I have a problem—check. Second, make strides to address the problem—not so easy. I was asked to examine five areas of self care and see how I measured up.

Exercise. I walked up the stairs to my office. *Take Breaks.* Rarely, to use the restroom, nonetheless take lunch. *Mindfulness.* I ate my lunch- or should I say inhaled my lunch- at my desk while checking email and phone messages. *Leave Work at Work.* I read articles on emerging trauma treatment and thought about how I could apply it to my cases. *Have Fun.* Hmm… does going to a lecture on "Facilitating Trauma Narratives" count?

There was a lot of literature out there on self care offering a great deal of advice and it all seemed ideal and undoable. I didn't need my "treatment plan" leaving me feeling overwhelmed and ineffective too. My work demands were not going to change; I didn't have time for daily lunch hours and long trips to the gym. I couldn't afford weekly massages and extravagant vacations. I needed to do something everyday in small blocks of time. So, I kept it short and simple. Everyone has five minutes. Instead of becoming discouraged and not doing anything, I chose to do something with the time I had. *Exercise*. I began using those five minutes to get up from my desk to walk, stretch, get outside and breathe the fresh air. Even on rainy days, I would walk up and down a few flights of stairs. Exercise increases endorphins… and guess what, I began to feel better, I had more energy and my mood improved. *Take Breaks.* I drank lots of water and took as many restroom breaks as needed—simple AND effective. I brought in pictures of my favorite place and found a moment of escape between clients for relaxation and grounding as I looked at soothing images. *Mindfulness*. I became mindful about eating—even if it was at my desk and even when I only had 15 minutes. I limited distractions and didn't multitask. I focused my senses on what I was eating- what it tasted like, smelled like, felt like in my mouth? *Leave Work at Work.* Creating this boundary was very difficult but I began using my commute home to unwind. When I got home I spent more quality time with family and friends and began reading fiction as a contrast to my work life. *Have Fun*. In addition to laughing more, I began studying karate—which became my perfect blend of meditation and catharsis—nothing like kicking and punching a heavy bag to release frustration!

see Self Care on page 41



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Staff Wellness and Self-Care: One Agency's Model

By Benjamin R. Sher, MA, LMSW
Director of Training & Staff Development
Institute for Community Living


Benjamin R. Sher, MA, LMSW

A rather unsettling fact about American society is that within it there exists a high rate of violence and abuse. According to Kessler et al (1995), 60.7% of men and 51.2% of women will experience at least one traumatic event in their lifetime. Given this fact, Kessler et al also state that of this group, the rate of those who will develop symptoms of Post-Traumatic Stress Disorder (PTSD) is high. Therefore, it is very likely (statistically) that many staff in agencies serving people with mental illness will have experienced some sort of trauma themselves. Couple this with the fact that the populations of people served experience trauma in ranges of 60% to 100%, there is a strong possibility of challenges in staff managing their own wellness and self-care. This article addresses one agency's model for helping staff to work in this demanding environment.

The Institute for Community Living, Inc. (ICL) is a behavioral healthcare network serving over 8,000 people with mental illness and developmental disabilities per year. Offering programs in Brooklyn, Manhattan, Queens, The Bronx, and Willow Grove, Pennsylvania, ICL is a comprehensive care consortium that offers housing, rehabilitative and habilitative services, outreach, assertive community treatment, healthcare, outpatient, day treatment, vocational, case management and linkages services to individuals and families experiencing, or who are at risk for, mental health or development disability concerns. ICL now operates over 100 programs in congregate settings, shelters, schools, apartments, clinics, and the community.

ICL primarily receives funding from public entities, such as The New York State Office of Mental Health and The New York State Office of Mental Retardation and Developmental Disabilities. Funding sources such as these expect that ICL will accept and serve populations who are underserved or not present in private settings. Therefore, ICL works with young adults, individuals who have had contact with the criminal justice system, long-term shelter inhabitants, dually (e.g. MICA or MR/MI) or triply diagnosed (homeless, mental illness and chronic medical conditions) individuals, institutionalized consumers, and many individuals who have fallen out of traditional systems of care. Therefore, it is quite common that the average person served at ICL will have a homeless history, have used substances at some point in his or her lifetime, may have poor impulse control problems, have had contact with the criminal justice system, be at risk for a serious medical condition (or already be living with one) and have experienced a "revolving door" of treatment rather than consistency.

All these factors contribute to our client's vulnerability to stress and its management. Persons served at ICL have a high need for intervention, natural supports such as family, and friends are not available, and as a whole they are at an economic disadvantage. These precipitating factors often lead persons served to express frustration towards staff that, due to their disempowerment, they cannot express easily towards the real source of their stress or anxiety. This naturally takes a toll on staff, and makes them vulnerable to secondary traumatic stress (STS), compassion fatigue (CF) and even burnout.

According to Pulido (2006), STS is a normal response for direct support professionals who are exposed to painful traumatic material as listed above. STS is different from basic trauma, in that the actual trauma is experienced by one person (the client), and it affects the helper in some other way. In secondary trauma, the worker exposed to the traumatic "stories" of the client develops reactions (signs and symptoms of trauma exposure) that mimic the reactions experienced by the person served. STS can change the way the worker thinks and feels about her or himself. Some of the signs and symptoms of STS can include increased vigilance, nervousness, intrusive dreams, and depersonalization (feeling like one's life is not real) — all of which can impact a staff worker behaviorally, physically, psychologically, cognitively, spiritually, and socially. A common STS anecdote is that a worker who listens to stories of rape and violence begins to feel very edgy and worried when they are walking down an empty or darkened street. An important point to reiterate about STS is that it is a normal reaction to the exposure of working with traumatized persons; however, it is also a warning sign that the professional should seek support through personal therapy or counseling.

Similar to secondary traumatic stress is Compassion Fatigue (CF). According to Hudnall Stamm (2009), CF is also about work-related, secondary exposure to traumatic or extremely stressful events. Workers in the field of mental health often hear stories about the traumatic events that have occurred to other people, commonly called Vicarious Traumatization. Like STS, CF may include being afraid, having difficulty sleeping, having images of the upsetting event pop into one's mind or avoiding things that remind the worker of the event. CF, like STS, is another warning sign that the worker must seek support. The risk in both symptoms is burn-out.

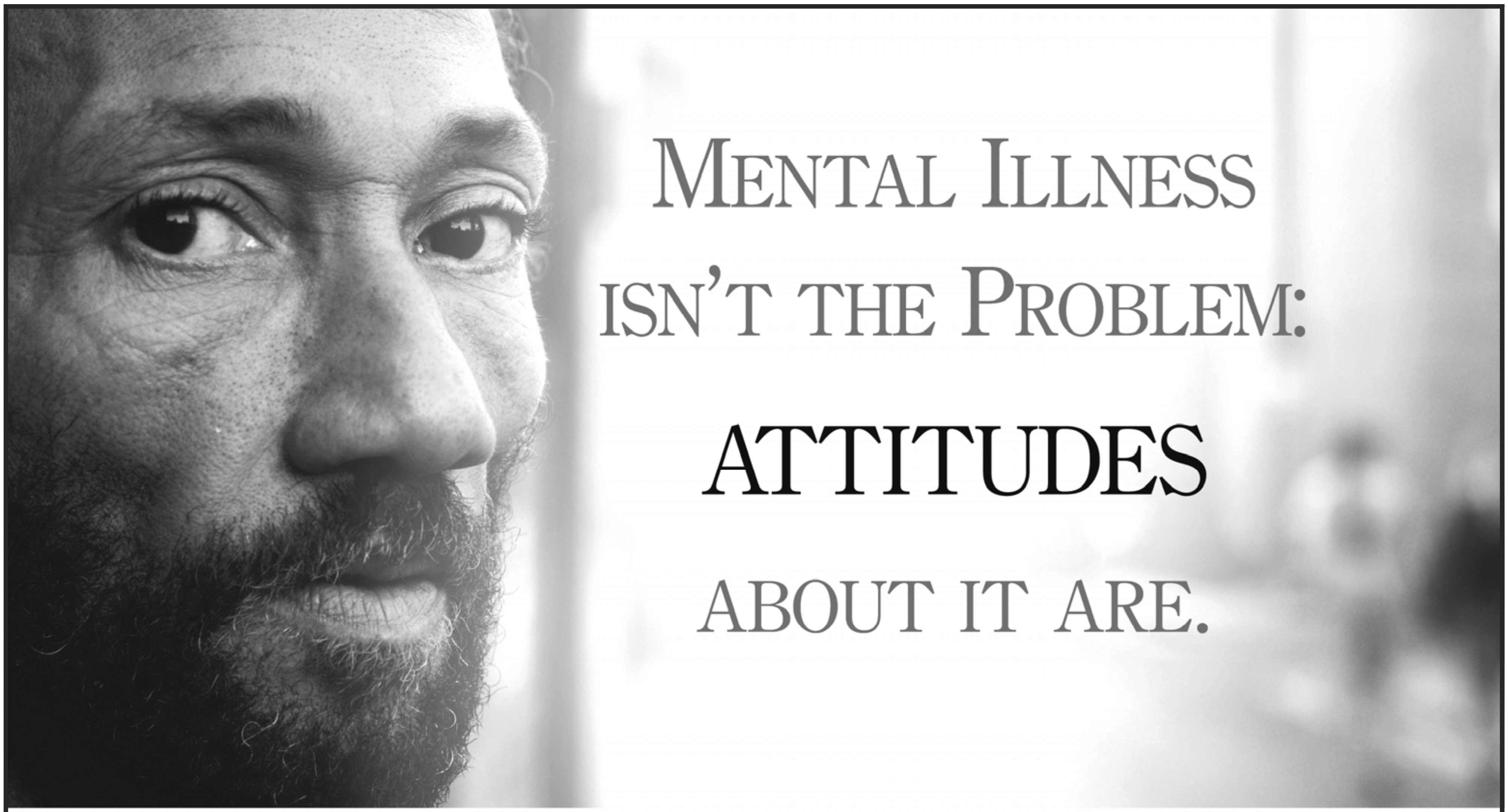
Burn-out is one of the elements of compassion fatigue, according to Hudnall Stamm (2009). It is associated with feelings of hopelessness and difficulties in dealing with work or doing one's job effectively. These negative feelings usually have a gradual onset. They can reflect the feeling that one's efforts make no difference, or they can be associated with a high workload or a non-supportive work environment. Signs and symptoms of burn-out include anger about coming to work, avoiding work altogether, physical ailments, frustration, increased anger, low morale, anxiety and stomach upset. If untreated, STS and CF can lead to burn-out which in turn can truly affect the worker to the point of needing to take a leave of absence or quitting his or her job.

ICL recognizes that in working with a traumatized population, the risk for employee STS, CF and even burn-out is high. This is why the agency has embraced a model of staff wellness and self-care. A core element of this model is a training module offered to all direct support professionals during their first six months of hire. Staff attends a 1.5 hour course that focuses on descriptions of STS, CF and burn-out, and walks staff through stress management techniques that include deep breathing, muscle relaxation and guided imagery. Staff is taught to use these techniques on a daily basis, and the importance of self-care is emphasized. The concept behind self-care is that as care-givers, mental health professionals are often better at caring for others than for themselves. Therefore, each attendee of this training makes a commitment to do a self-care activity for themselves every day beginning with the training date and forward. This can include anything from a daily walk, deep breathing, exercise, getting one's nails done, a massage, watching a comedy, or reading something funny, to getting enough sleep and having a proper diet. The course instructor follows up with the trainees a few weeks later to check on how the self-care is going, whether they are keeping up with it, what obstacles are getting in the way of completing self-care and what the instructor and others in the person's life can do to help maintain self-care.

The training ends with an assessment scale entitled the Professional Quality of Life Scale (ProQOL), developed by Hudnall Stamm (2009). The scale helps trainees measure their compassion satisfaction (e.g. the pleasure they derive in being able to do their work well), their level of burn-out and their compassion fatigue. Respondents are told the scale is meant to reflect how the person feels in the *last thirty days*. They are also told that the scale is but one piece of assessing these areas and that the respondent should not take the answers as "gospel." They should, however, be mindful of scores that evidence burn-out and compassion fatigue and should, as a consequence, seek support (e.g. The Employee Assistance Program, supervisory or collegial support, and/or other means). Respondents are also encouraged to use this tool again at a later date to assess if their scores have changed.

"Staff Wellness and Self-Care" training has been in effect at ICL for eight years. It consistently receives marks of "excellent" to "good" on training evaluations, and qualitative data reports that staff members feel it really helps them to understand they are not alone and that they can experience STS and still do their jobs. Respondents report that they use the stress management techniques long after the training has been completed.

The realities of working in the mental health field are that the direct professional's job is demanding and stressful. Clients are traumatized, and it is statistically likely that staff has been too. It is essential in caring for the caregivers that more classes like "Staff Wellness and Self-Care" are offered to personnel who are employed in mental health programs. Such classes are a solid cure for burn-out, and they help educate workers on their own vulnerabilities. As it is often said, if the mental health worker does not care for themselves, how can they care for others?


MENTAL ILLNESS
ISN'T THE PROBLEM:
ATTITUDES
ABOUT IT ARE.

Life is a Journey: Helping Caregivers Understand the Challenges of End-of-Life Decision Making for Those with Mental Retardation

By Judith Pollack, LCSW, Clinical Coordinator, and Lori Hardoon, LCSW, Director, F·E·G·S, Partners in Dignity

Birth is a beginning and death a destination. Those of us who are considered to have capacity to make decisions for ourselves are nevertheless often unprepared as we face the end-of-life. We live in a death denying culture, which frequently prevents many of us from considering our options when we are mentally, emotionally and physically able. Those who are developmentally disabled and mentally retarded usually have to depend on caregivers to facilitate end-of-life choices and/or make those decisions for them, depending on their capacity. This article addresses the many complexities and barriers to sensitive end-of-life care and decision making for those whose developmental disability is mental retardation, specifically those with cognitive impairment.

By definition, a developmental disability must originate before the age of 22. This may include mental retardation, some forms of cerebral palsy, Autism Spectrum Disorder and neurological impairments. People with developmental disabilities may have trouble learning as quickly as others and/or expressing themselves clearly. Many have more than one disability.

More than 280,000 people in New York State are thought to have developmental disabilities. That number is rising because individuals are living longer due to medical advances, better medical care, and increasing numbers of community-based residential and other services, which improve quality of life. Medical advances also result in people living over extended periods of time even with serious, chronic and terminal illnesses. Caregivers face many challenges because there may be varying levels of cognitive impairment that affect the need for others to make health care decisions on behalf of the individual.

The combination of an individual's will to live, the medical profession's mission and mantra to save lives at all costs, and our cultural difficulty with facing death, often result in inertia. In the case of those with developmental disabilities, the issues become even more challenged. Both personal and professional caregivers are burdened by the difficulties of making decisions for those in their care. These highly charged decisions are commonly wrought with ignorance and disagreement around an individual's ability to understand and participate in their own decision making. Caregivers are also very commonly challenged with their desire to protect those in their care, especially when they are unsure about what is best for them.

In the absence of advance directives (Health Care Proxies and Living Wills), all of us can be subject to medical interventions that serve to prolong death rather then prolong life. Cardiopulmonary resuscitation (CPR) performed on a frail person who is already declining from a terminal illness, can do and often does more harm than good. Once the heart starts to beat again, the person who is resuscitated is sometimes left in even worse medical, psychological and/or spiritual condition. Making decisions about how we want to be cared for when we are critically ill is ideally done when we are emotionally, physically and intellectually capable. When we are not conscious, competent or deemed to have capacity to decide, as is often the case with individuals with developmental disabilities , then we must rely on others, primarily a Health Care Agent, to make these decisions for us.

There is a trend toward increased awareness about, acceptance of and accessibility to end-of-life care for the non-developmentally disabled population, including palliative and hospice care. Palliative care is an interdisciplinary therapeutic model, which is targeted to the care of patients with all types of chronic progressive illnesses and is focused on helping patients and their families maintain a satisfactory quality of life, manage the burden of illness, and reduce the sources of suffering throughout the course of the disease. Contrary to popular belief, palliative care can be delivered along with aggressive and curative treatment. Hospice services are generally delivered in an individual's home at the point that curative, aggressive care is determined to be ineffective or the individual declines further treatment. The goal of hospice care is to provide comfort and support, alleviate physical, emotional and spiritual distress, during the process leading up to death and during the time of active dying.

While palliative and hospice care can serve individuals living in group homes of all categories, sadly, individuals with developmental disabilities rarely receive palliative care through hospice. One hospice program reported that of 1200 people served in the past year, only four were developmental disabilities. One clinician, who worked in this hospice for 30 years, could not remember even one person who was developmental disabilities. Most individuals with this diagnosis die in hospitals and, at best, might spend their last days in a nursing home where they may or may not receive hospice services.

As we examine the challenges faced by caregivers of those with mental retardation at the end-of-life, let us consider Jose (name has been changed to protect client's confidentiality).

Jose is a 27-year-old male, diagnosed with a mild to moderate developmental disability, with a full scale IQ of 51. He lives in a community residence with other developmental disabled adults with varying levels of functionality. There are staff present 24/7.

Jose has relatively strong verbal skills, can follow multistep instructions and make simple decisions, but he also requires staff direction. He cannot tell time. His reading and writing abilities are limited to writing his name and recognizing some road and community signs. He is independent in activities of daily living but requires reminders from staff. He is unable to travel or make purchases on his own. He has good social awareness, knows the names of people regularly encountered and relevant information about them. He is able to label emotions and distinguish between basic emotions.

Jose lived with his family until three years ago and was then moved into his current group home. His family has had moderate, but inconsistent involvement in Jose's daily life. Due to other family stressors, they do not often visit at the residence and have been unable to arrange for visits home. They occasionally attend treatment-planning meetings, but this participation has also been inconsistent. Because he is an adult, Jose's parents are no longer his legal guardians, although they could apply for that status, if they so chose.

Jose was diagnosed in April 2008 with a cancerous tumor of the bile duct(s). His symptoms of abdominal pain, anemia, yellowing of skin (jaundice), chills, fever, itching, weight loss, bloating, nausea and loss of appetite, occurred suddenly. It was necessary to perform surgery and subsequently he received chemotherapy. Despite treatment of chemotherapy and radiation, the cancer spread to his liver and he became even sicker and has a poor prognosis. He had a very poor reaction to the chemotherapy.

Jose has never been educated about death and dying and has not participated in any rituals, including funerals. When someone has died in his life their absence has been either ignored or explained away. While he is aware that he is very ill, he has not been asked what he wants or what he thinks. Despite the progression of his illness, there are no advance directives in place and Jose does not have an appointed health care agent. Jose has recently expressed a desire to stop treatment, because he has experienced significant discomfort, negative side-effects and he has said on numerous occasions that he is afraid. Despite these facts, Jose's family members and his professional caregivers have generally avoided talking with him about his condition and prognosis, but have persistently encouraged Jose to continue with the chemotherapy and other aggressive care. Furthermore, the issue of who is in a position to make decisions about Jose's care is unclear.

Jose's case is not exceptional. There are many myths about this population with regard to their understanding about end of life and their capacity to participate in decisions that affect their life…and death. Many caregivers struggle with how much to explain and worry that the information, especially when the prognosis is grim, will be too upsetting to the individual.

Among the myths, it is commonly believed that those with mental retardation:

- Cannot comprehend the finality of death;
- Are incapable of making end-of-life decisions;
- Do not fully experience grief and just forget that their loved ones are gone;
- Will be traumatized from participating in end of life rituals (funerals, etc);
- Can't form or sustain attachments;
- Don't experience pain in the same ways that those without disabilities experience it.

In addition to the myths that impede the involvement of an individual with mental retardation in their own health care decisions, other barriers that come into play include:

- Caregivers commonly wanting to protect their loved one from having to make these kinds of decisions;
- Caregivers often have conflicting views about the individual's capacity to make his/her own decisions, including the ability to decide on a health care agent;
- Caregivers – and society -- often lack knowledge about the Health Care Decisions Act for People with Mental Retardation, which provides guidance about the appointment of a surrogate decision maker when a health care agent has not been assigned;
- Confusion among two terms– *competency* and *capacity*, which are commonly

see End of Life on page 42

F·E·G·S Caregivers: On and Off the Job

By Ellen Stoller, Assistant Vice President, Professional Development and Consumer Affairs, Behavioral Health and Behavioral Health Residential Service, F·E·G·S Health and Human Services System

People working in the Mental Health field, who also have a family member that has a mental illness, may give a richer perspective on recovery in both parts of their lives. Laura Williams, F·E·G·S Regional Director of SRO's and Jerry Ramos, F·E·G·S Assistant Vice President of Community Residences and Homeless Services have been colleagues and friends since the late 1990's. They have a lot in common, both started their careers in residential services at F·E·G·S at the same time, they live in the same community and they are both caregivers for siblings who have a mental illness. It isn't easy to be a caregiver, nor is it easy to manage the large network of F·E·G·S Behavioral Health Residential Services, both are a 24 hour a day 7 day a week responsibilities.

Laura and Jerry have become a support system for each other, they intuitively understand each other's needs at the job, the needs of their families and the needs they both share as caregivers; on and off the job.

Cultural Belief in Recovery

Both Jerry and Laura's families share in some cultural beliefs around their siblings, Andy and Margo's mental illness. It's sometimes easier for families to believe that unnatural forces or an evil misfortune befell a child as explanation of why things went wrong in the family. As mental health professionals, both Laura and Jerry see their siblings' illness differently from their family's beliefs. They can explain what behaviors, diagnosis, and functioning mean. They can be confident that recovery is a real goal for their respective siblings. In understanding the mental illness they're also helping to broaden perspectives and enlighten other family members.

Laura's Sister, Margo

Laura's sister Margo got sick when she was 16 years old, right after their mother died. They grew up in a large family, there are eight siblings, and at various times since their father died Laura's other siblings have taken turns housing and caring for Margo. But Margo moved to New York five years ago and after an unsuccessful move to an adult home, came to live with Laura.

By day Laura sees to the staff and consumer needs in F·E·G·S's SROs, by night she sees to the needs of Margo. Although Margo is getting more independent she still needs help picking out her clothes for the next day and in the morning needs help getting ready to go to her program. Plus, now at age 51 she has health problems that Laura has to coordinate care for. As Laura says, "I live it, I breath it. When I see our consumers I see my sister. I don't burn out because I can relate to them and their families." Although the caregiver role comes with a 24 hour 7 day a week responsibility, Laura's active involvement with her own 8 children and 13 grandchildren keep her moving in many arenas and Margo is part of that world too. Recently Laura went on a vacation that Margo accompanied her on. They go to church together, talk about family and dance to Motown music. Although a goal for Margo is to move into a housing situation were she can be somewhat more independent and develop interests and friends separate from Laura, they are a dynamic duo. Hard as it is to be a caregiver Laura was born to the part. She remembers herself as the family caregiver long before she ever dreamed of being a social worker. After their mother died Laura held the family together, often putting her own needs last. It took her 20 years of stopping and starting to complete her undergraduate degree. Her social work degree came soon after.

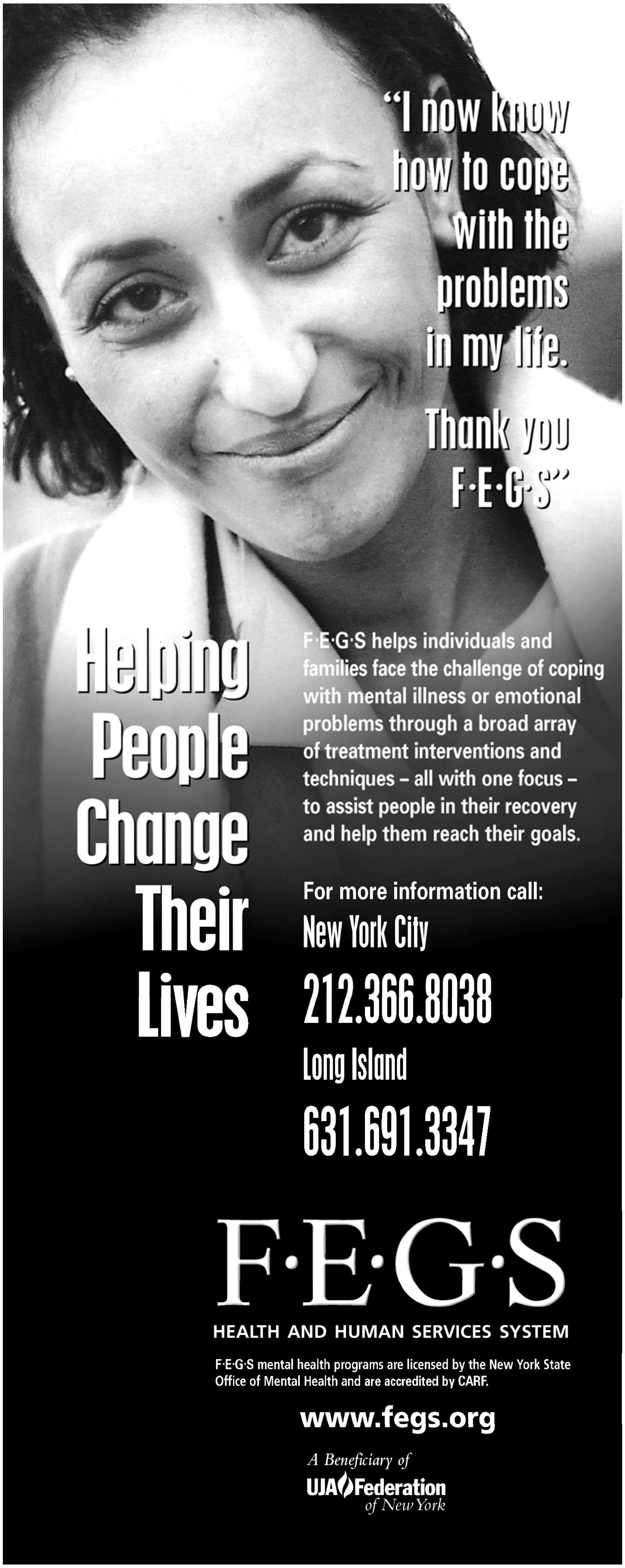
Jerry's Brother, Andy

Jerry Ramos and his brother Andy were born and raised in Puerto Rico, where their parents still live. When Jerry was 20 he came to the US and 18 year old Andy soon followed. Andy, who suffered a fall and a serious concussion when he was 8 years old, began acting out when he was 12, first with school truancy.

Other trouble followed, including drug use. For the last 27 years Andy has bounced in and out of drug treatment programs, living with Jerry, then moving to Puerto Rico for three or four months at a time and then back to New York. Through all of this Jerry managed to work his way up from his first job as a dishwasher in the cafeteria of a hospital to completing two masters' degrees; Masters of Public Administration and a Masters of Social Work.

For years Jerry felt that treating his brother's substance use alone was a mistake. He knew that Andy had a serious mental illness too. One year ago Andy disappeared in Puerto Rico, everyone was sure he was dead. When he reappeared Jerry brought him to New York. This time Andy was ready to try an integrated treatment program and start working on his mental health issues. For the first time in his life he started following through with the steps to get housing. Although Jerry says that Andy often doesn't listen to him because he is his older brother, clearly, without Jerry's commitment, dedication and knowledge of the field, Andy might easily have gotten frustrated and given up on getting housing. They both persevered and Andy now lives in a supported housing program. As Jerry says, "No one can tell me about hope, stability, and all that. I lived it; I still live it every day. Everyday for many years I held out hope for my brother, it took awhile, but it paid off."

see FEGS Caregivers on page 40



Parenting the Second Time Around

By Diane Henry, LCSW-R
Director Community Based Services
Putnam Family And
Community Services, Inc.

Imagine you are at work and the telephone rings. It is the Department of Social Services. You hear the worker on the other end of the telephone say, "Please come to the courthouse immediately. Your grandchild is being removed from the care of her parent and may be in jeopardy of being placed in foster care."

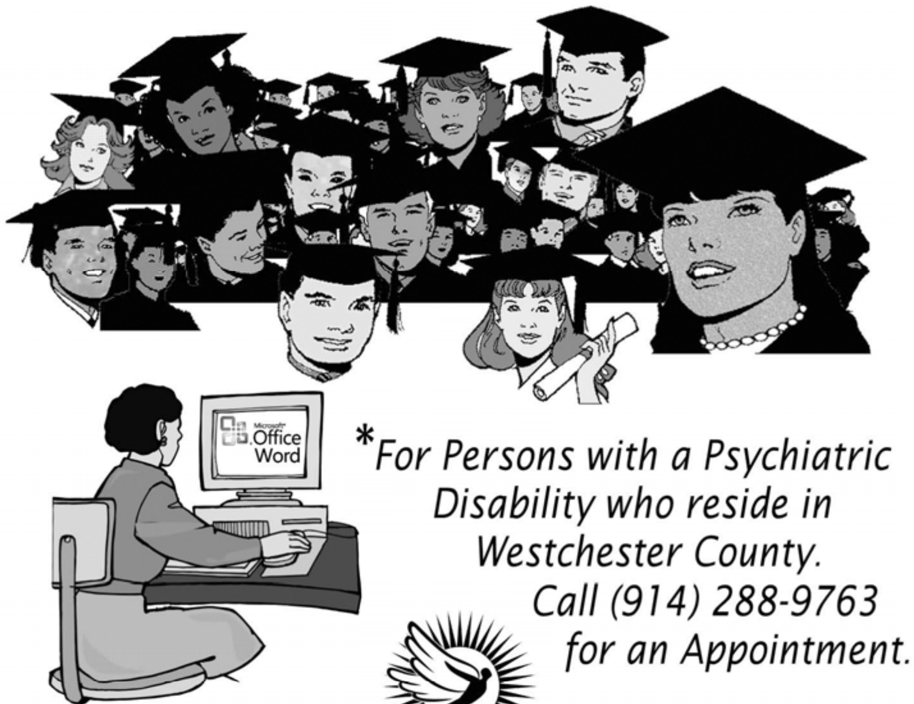
This is the scenario that many of the participants in our Relatives as Parent Program support group describe as being their first experience with the Department of Social Services system of care for children. Relatives as Parent Program or "RAPP," is a support group run by Putnam Family And Community Services, Inc. The group meets the third Monday of every month from 6:30 -8:00PM. Child caregivers can be grandparents, aunts, uncles, or adult siblings of children, who come together and discuss their special issues as Rapp families. They receive information, and support in order to refuel for the task of caring for children who have unexpectedly joined them in their homes. RAPP staff offer assistance with parenting and coping skills, advocacy and support. The Relatives as Parents Program (RAPP) was initiated in 1996 by The Brookdale Foundation in New York City. It is designed to encourage and promote the creation or expansion of services for grandparents and other relatives who have taken on the responsibility of surrogate parenting due to the absence of the parents.

Diane Henry, LCSW-R

There are many ways that RAPP families come together. One working single grandfather we'll call John who is in our support group, went to court one day and came home with four small grandchildren under the age of eight. He immediately needed to equip his home with beds and all the necessary items to care for these children. John also needed to figure out how he was going to get these children the special services they needed while working a full time job. Suddenly, he was cooking, cleaning, doing laundry, and helping the children with their homework. John is not alone in his quest to handle these weighty responsibilities. Relatives that take on the role as parents, face tremendous challenges as they now have the full responsibility of these children. They need help enrolling the children in school, accessing health insurance as well as medical and behavioral healthcare, and securing legal assistance. They need to make appropriate decisions regarding guardianship and kinship-foster care that is available to families through Temporary Assistance for Needy Families (TANF). RAPP caregivers can become confused by the sometimes complicated legal system for children and may make uninformed decisions not knowing the ramifications that those decisions will have on the children. RAPP staff and the support group offer first hand experience about negotiating the systems that caregivers must deal with. In group, RAPP families can hear how other caregivers are addressing tough issues and how they are safeguarding the children and themselves.

Like John, RAPP families are usually at a stage in life where they were slowing down maybe working part-time and looking forward to retirement. They never envisioned themselves being suddenly thrust onto the express track of parenthood again. Additionally, children in RAPP need to heal and recover in therapy from the sometimes traumatic experiences of their young lives. They often need to sort out the situations that they have been exposed to in their original parental home. These situations can include domestic violence, parental alcohol and drug addiction, and unstable parenting. Some have been neglected or physically abused without the ability to understand that it is not their fault. They have internalized feelings of low self esteem, low frustration tolerance, poor communication skills and few coping skills. RAPP staff can assist the group members with updating their parenting skills to deal with these children and their special needs. Often, the parenting style they used the first time around for their own children do not meet the needs of their grandchildren. Families receive help in order to learn about and

see Parenting on page 40



Caring for The Caregiver : Becoming Fearless During Illness and Loss

By Brenda Shoshanna, PhD

When illness comes the entire family network starts hurting. Everyone in it becomes sensitized and in need of greater attention and care. Rivalries may begin to develop with family members jockeying for control. A great deal of fear and anxiety can get stirred up. Sometimes an individual becomes intrusive and demanding. At other times unconscious feelings towards the sick family member may get stirred up and be expressed.

Faced with the loss of her sister, Annette clear said, “My sister is very ill. It's not just her. It's me, too. I'm also facing all the fear and pain she is going through. Please realize, I need help too. I'm very frightened. Now I have to be extra strong, giving and understanding, no matter what she says. I was never so understanding before. I'm trying my best, but there's nobody here being understanding of me.”

Often there is an implicit demand by the patient that others come through for them. The expectation is that now a family member will love, support and give to the patient in ways they were never able to before.

This in itself can create a lot of difficulty and be hard to bear, creating guilt. It is very important to bring this dynamic to light. Once it is looked at and discussed, a great deal of pressure may subside for all.

Brenda Shoshanna, PhD

Undoing Guilt

Anything that helps dissolve the pressure of guilt is crucial at this time. Guilt is both powerful and lethal during a time of illness and loss. Guilt itself can be considered to be a form of serious illness that constantly erodes the quality of our lives. Unfortunately, during a time of illness much of the interaction between patients, family members and care givers may be infused with guilt. Some feel guilty that they are healthy, while this family member is ill. Others may blame themselves for patient's illness, feeling that they did not love them enough or give fully to them in the past.

The guilt is not one-sided. Patients may feel extremely guilty too. They may be feeling helpless, worthless and unable to contribute anything now. Some feel like a drain on others and express a wish to be dead rather than feel this way.

All interaction that arises from guilt inevitably goes the wrong way. It never produces the kind of satisfaction and comfort all are in real need of. In order to care for the caregivers and remove the pressures of anxiety and fear the first step is to help dissolve guilt.

When patients, family members and care givers can learn to become aware of, accept and express their feelings a great deal of good can be done. Individuals no longer feel so alone, patients do not feel so abandoned. By expressing feelings, hopes and expectations with kindness and receiving feedback, everyone can realize that their feelings may not point to the truth. It can be very shocking and healing to bring feelings to the open and get in touch with the reality of what is going on.

Here is a wonderful process for a family (friend, partner or caregiver to use to help dealing with guilt:

- What have you not yet done for the patient that you feel you really should do?
- Write it down. Make a list.
- Now, write down what you think the patient would like you to do.
- What would you really like to do?
- Notice the differences and similarities between the three lists.
- Now, go on. What has the patient not yet done for you that you still want him to do?
- Write it down. Make a list.
- Can you ask the patient for what you want?
- Can you check with the patient about what their needs are?
- Can you do for the patient what has to be done?
- What is getting in the way? Are you at least willing to try?
- Also, make a list of all the things you have done for the patient.
- Write down all the things the patient has done for you.

Sit down with the patient and discuss

see Becoming Fearless on page 36

Where Do I Fit In? Elderly Caregivers of Children

By Rosa Serrano-Delgado LMSW
and Gail K. Golden, LCSW, EdD
VCS Inc.

Growing numbers of grandparents and (other relatives) are raising family member's children. Historically, in some communities, it was not unusual for children to live with grandparents for all or parts of their childhoods. More recently, the arrival of drugs, consequent incarcerations, and illnesses, including AIDS, has resulted in larger numbers of families from more varied communities raising relative's children. Thus, these current kinship placements often have roots in serious family trauma. The consequent adjustments required of aging caregivers are many, as are the challenges to their emotional well being.

Rosa Serrano-Delgado & Gail Golden

Aging in itself can present challenges: e.g. less income, health issues and losses. Grandparents raising grandchildren have these issues to deal with and simultaneously have to once more adjust to the needs of growing children. Grandparents' long awaited chances to slow down give way to youthful needs and energies. (It should surely be noted that most grandparents find their lives deeply enriched by the children in their care. Nonetheless, the necessary adjustments can be very stressful for elderly caregivers.)

Socially and psychologically, grandparents raising grandchildren may suffer from an unnamed, unidentified, identity crisis. Where do they fit in? Where do they belong?

If they are raising their grandchildren, something is not "in place" with their adult child. If the kinship placement is a result of their adult child's drug abuse, neglect, child abuse, incarceration, or mental illness, then that relationship is often conflicted. The elderly person may feel anger, disappointment or grief with regard to their own child, yet may still want to help them. They also know the grandchildren are at risk if they return to their parent. Feelings of having 'failed' with their own children can create additional anxieties about how to raise grandchildren.

The adult child may resent their parent for having custody of the grandchildren. This puts a strain on the grandparent's role and confuses the relationship to their adult child. Adult children who are struggling with their own problems can interfere with the grandparent's child-rearing efforts. Visitation between children and parents can be difficult and painful. The parent's absence or erratic presence upsets children. Conflicting loyalties are painful, as elderly caregivers feel torn between the needs of their own children and the needs of their grandchildren. This also creates role conflict.

Moreover, grandparents may not 'fit' well with their grandchildren. Grandchildren are sometimes upset that they are not with their parents and blame the grandparent. Children's perceptions that grandparents are keeping them away from parents can help preserve the child's ideal of the good parent, while fueling anger at grandparents.

Children are sometimes embarrassed that their caregiver is so much older than their peer's parents. They are impatient with the grandparents 'old fashioned' views, and their distance from current youth culture. For the elderly caregiver, the longed for role of the grandparent who can enjoy children during relaxed visits is a lost dream.

Socially, the grandparent often feels that they don't fit in with the cohort of parents in school because of the age differences. When attending school functions, they of course find much younger parents who have friendship circles that do not include them. They may not relate to each other comfortably.

Finally, elderly caregivers often do not fit in with their own peers because now they have added responsibilities connected to the children, which their peers do not share. While friends are getting together, going to senior centers, planning trips or signing up for classes, they are

see Fit In on page 40

The Americans with Disabilities Act Amendments Act

By Carolyn R. Wolf, Douglas K. Stern,
and Eric Broutman, Esqs.
Abrams, Fensterman, Fensterman, Eisman,
Greenberg, Formato & Einiger, LLP

The Americans with Disabilities Act (ADA) was signed into law by the first President Bush in 1990. The bill, championed by Senator Bob Dole, who himself suffers from a physical disability, was enacted with the intention of eliminating discrimination against the disabled, whether it be a physical or mental disability. In addition to eliminating outright disability discrimination, the law allows disabled persons to request a reasonable accommodation from, amongst others, employers. Such accommodations allow the disabled individual to function normally, and creates an even playing field in the work arena and society in general.

As disabled people brought claims under the ADA, and lawsuits were argued in the courts, Appellate Courts and even the Supreme Court began interpreting the language in the ADA in a more restrictive manner, thereby limiting the statutes protections to a smaller and smaller group of people. Many saw this limiting interpretation at odds with the bills "wide-net" origins. Of particular note, was the way in which Court's were restricting the definition of the term "disability", a definition one must meet in order to claim the protections of the statute.

Douglas K. Stern, Esq.

Eric Broutman, Esq.

For those suffering from a mental illness, and in particular anxiety disorders, the limiting nature of the Supreme Court's rulings made it harder and harder to claim that one was disabled. If the person was not disabled under the ADA that person was therefore not entitled to the Act's protections.

Thankfully, in 2008, George W. Bush signed into law the Americans with Disabilities Act Amendments Act (ADAAA). This law, in large part reversed much of the Courts' prior rulings in an attempt to return the statute to its original intention of protecting all those who suffer from a disability.

This article will discuss the original ADA and how the Court's interpretations have resulted in limited coverage, specifically for those suffering from an anxiety disorder. Moreover, the article will discuss for each previously limiting area, how these difficulties were remedied under the ADAAA.

The Original ADA and How The ADAAA Changes the Law

First and foremost, as mentioned previously, for one to be covered under the ADA they must have a "disability" as that term is defined under the ADA. If one is not "disabled" under the ADA they can legally be discriminated against as a result of their physical or mental ailment whether that discrimination is in employment, their physical surroundings, or treatment by the government. Under the ADA disabled is defined as "a physical or mental impairment that substantially limits a major life activity." While major life activities are ultimately defined by the Courts, the Equal Employment Opportunity Commission ("EEOC"), the agency charged by Congress to issue regulations with regard to the ADA, has included certain activities, such as hearing, seeing, walking, etc. as major life activities. While the EEOC list is non-exclusive Courts have regularly looked to it in defining the term "major life activity"

There are four significant areas where Courts have interpreted the terms disability and major life activity, which negatively affected many individuals who suffer from a mental illness, and in specific, those who suffer from anxiety disorders. These rulings worked to limit, if not outright prevent, those suffering from anxiety disorders from seeking protection under the ADA in Court.

First, there is the issue of taking corrective measures, such as taking medication, to alleviate the symptoms of an ailment. Under the old ADA, the Supreme Court ruled that in circumstances where one suffers from a disease, even a debilitating disease, if that person took medication which alleviated the symptoms of that disease they would not be covered under the ADA. This is true even if without the medication the symptoms of the illness would surely leave the person disabled. This view seems to be somewhat myopic,

see ADAAA on page 40

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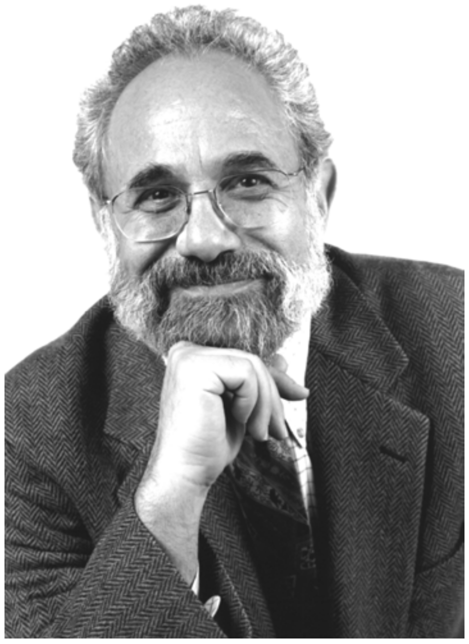
Addressing the Needs from page 1



Michael B. Friedman, LMSW

Kimberly A. Williams, LMSW

are recurrent; some are permanent. Some are physical; some are mental. Many are co-occurring.

Each form of family caregiving has its own dynamics. Indeed, each case has its own dynamics. But there are some common dimensions of caregiving.

(1) Family caregiving is hard—very hard—and very stressful. It is hard to juggle the additional demands of a life to which caregiving has been added as a responsibility. The average family caregiver of an older adult, for example, spends about 20 hours per week providing care—the equivalent of an additional half-time job. It is hard economically; except for those who are so rich that expenses averaging $5-6000 for older adults, and that can run to tens of thousands of dollars, per year are pocket change. And it is hard emotionally. That a family member is disabled is often a source of great sadness. How to take care of a person with disabilities is often a source of conflict within a family. Many family members experience guilt—about not doing enough for their disabled family members or about neglecting family members who are not disabled. The stress leaves caregivers at high risk of major depressive and anxiety disorders and of physical illness. Burnout is commonplace.

(2) It is also commonplace that—as Rodney Dangerfield would put it—family caregivers "get no respect." Physicians and other treatment providers often will assume that family members (especially women) will be caregivers no matter what it takes. When they are smart and humane, physicians may assign someone, such as a social worker, to help the person assumed to be a caregiver to work out what has to be done. But most of the people I know who are or have been family caregivers report experiences remarkably similar to my own. Not only did I get no help; it fell to me to help the professionals, who deal with these situations everyday, to think through what has to be done to manage.

Fundamental to the failure to provide support for family caregivers is the fact that very few professionals regard family caregivers as equal members of the treatment team. The pros figure everything out; we caregivers get our instructions.

(3) Most family caregivers find it difficult to get all the services their family members need or that they themselves need. There are three major reasons for this. First, there is a dreadful shortage of services, especially good services. Second, many, maybe most, people don't know what services would be helpful or how to get access to them when they do exist. Third, people often need help at moments of crisis; and, with the exception of ambulances and emergency rooms, there are not many services that are available at the time of crisis.

While there are many more dimensions of the difficulties of family caregiving, these three alone have major implications for public policy, implications that are slowly being drawn and translated into helpful services and supports. Here are a few of them:

(1) Government should fund family support. This should be a component of all governmental initiatives related to serving people with disabilities—home and community-based waiver programs, community physical and mental health centers, long-term care reform, etc. Respite is among the most requested forms of family support. Some family caregivers benefit from support groups, though many are just too busy to get to them. Other state-of-the-art approaches include family psycho-education, education about mental illness, training in problem-solving skills and in behavior management strategies, as well as highly individualized services that combine responsiveness to crisis, flexible delivery of individual counseling for caregivers, and family counseling designed to end recriminations and get family members on the same page.

In addition to services family caregivers often need economic support. Tax credit approaches are most frequently proposed.

(2) Increased Access to Services: There need to be more community-based services for people with disabilities and for their family caregivers. And it is particularly important that these services be more accessible. That means that they have to be available at hours when family caregivers can be free, that they have to be available in home and community settings, that they need to be available in the languages of minority populations—who are in fact more likely to provide caregiving at home than is the general population. Also critical are well-publicized sources of information, individualized needs assessments, and assistance to help steer people to the right place at the right time and to be sure they get the services they need.

(3) Recognition of the Importance of Mental Health: Although disabilities are often primarily physical, for many people the primary disability is rooted in a mental condition such as schizophrenia, dementia, profound affective disorders, and/or severe anxiety disorders. For them the availability of good treatment for their mental condition is clearly critical. In addition, as is too frequently forgotten, people with physical disabilities often experience emotional problems or co-occurring serious mental or substance use disorders as well as physical disabilities. Failure to identify and respond appropriately to their mental health and/or substance use disorders can exacerbate their physical disabilities and increases their risk of premature mortality.

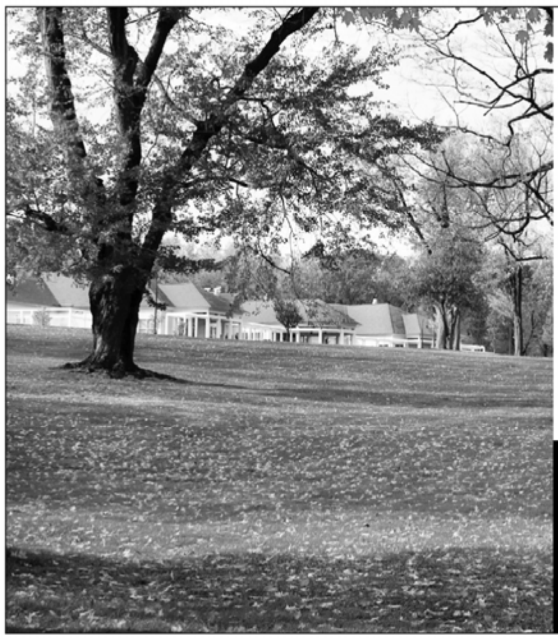
In addition, as I have noted already, family caregivers are at high risk of mental and physical disorders. They burn out and, as a result, disabled family members are at higher risk of placement in institutions. Addressing the mental health needs of family caregivers benefits them, the family members they care for, and a society trying to hold down the use of institutions.

(4) Dissemination of Best Practices: In my experience most people, when they think about it, understand how difficult caregiving is for the family members who take it on. But it seems to me that they rarely think about it and that service providers from physicians to nurses, from social workers to home health aides, from case managers to protective services workers and more, do not know much about how to provide support for family caregivers. Public policy should include a determination to spread understanding and build competence.

Public policy initiatives in the four areas noted above would go far to give the kind of support that family caregivers need and deserve. As I said at the beginning, our society relies heavily on family caregivers and owes them a debt of gratitude. Isn't it time we begin to pay that debt?

Michael B. Friedman will retire as The Director of the Center for Policy, Advocacy, and Education of The Mental Health Association and as Chair of The Geriatric Mental Health Alliance of New York at the end of June 2010. Kimberly Williams will succeed Mr. Friedman as the Director of the Center effective July 1, 2010. She will also continue to serve as Director of the Alliance. The opinions in this essay are their own and do not necessarily reflect the opinions of MHA or the Alliance. They can be reached at mbfriedman@aol.com.

You can visit the webpage of The Geriatric Mental Health Alliance at www.mhaofnyc.com/gmhany



An Update on the RAISE Schizophrenia Research Project
An Interview with Jeffrey A. Lieberman, MD

By Ira H. Minot, LMSW
Executive Director
Mental Health News Education, Inc.

Over the past several issues, *Mental Health News* has been following the progress of the RAISE project, an NIMH sponsored research study that is examining the role and potential that early and specific interventions can play in the recovery of people that have just been recently diagnosed with schizophrenia. In the interview that follows, Dr. Jeffrey A. Lieberman, MD, one of the principal investigators of the project, gives us an update on his team's part of the project and gives us some new and important information about how the findings from the RAISE project have the potential to change the way mental healthcare is provided and can radically improve the lives of people who are at risk to develop schizophrenia.

Jeffrey A. Lieberman, MD

Q: In our continuing effort to cover the progress of this important study, can you help us to better understand its rather complex nature.

A: RAISE (Recovery After an Initial Schizophrenia Episode) is the acronym that names the project which the National Institute of Mental Health (NIMH) is orchestrating to develop and test an intervention that will foster recovery and prevent disability in patients in their first episode of schizophrenia. The RAISE project consists of two studies. Our study is being led by myself at Columbia University and Lisa Dixon at the University of Maryland, along with our colleagues at those institutions and several others across the country. The second study is being led by Dr. John Kane, MD at The Zucker Hillside Hospital on Long Island. Both studies make up two distinct investigations within the entire RAISE project.

The Columbia and Maryland study is based on a very specific type of public mental health model. For us to be chosen to carry out this project, NIMH asked us to come up with an intervention plan based on what we know from research on the natural history and clinical course of schizophrenia and what we have learned from intervention studies that have focused on patients in the early stage of the illness, and then to demonstrate that this optimized intervention could prevent disability and foster recovery in schizophrenia when implemented soon after patients experience an initial schizophrenia episode. To make the results of the study generalizable to the world of mental health care, they wanted us to do this in a way that is ecologically valid – meaning that it must be done in real world and representative clinical settings. In addition NIMH has also stipulated that the interventions in the studies must be able to be implemented within the context of existing reimbursement systems. This was certainly a challenging task but means that if the study is successful in proving the hypothesis, this early intervention model can then be rolled-out and implemented in clinical practice, almost immediately. In other words NIMH is looking to fast-track the results of this research into clinical practice rather than wait the usual 8 to 10 years for their translation to practice that is usually required.

To implement these rigorous standards, we have chosen to devise and test our intervention in partnership with two state mental health agencies – The New York State Office of Mental Health (NYSOMH) and the Maryland State Office of Mental Health (DHMH). Consequently, members of the leadership of these agencies including Mike Hogan, PhD, Lloyd Sederer, MD, John Allen and Joe Swinford in NY and Brian Hepburn, MD, and Gayle Jordan Randolph MD in Maryland are working with us on this study.

The commissioners of both state offices of mental health felt that we have a unique opportunity to change the way mental health services are delivered and the way in which future generations of people with schizophrenia are treated in the United States. Both offices of mental health would then agree to provide support for the services at clinical sites that they either license or directly support.

Q: Can you clarify the distinctions between your part of the RAISE project and Dr. Kane's part of the study?

A: The Kane team is using a network of approximately 30 clinical sites in different locations across the nation, as opposed to our approach of working with two state mental health systems and using the sites that we identify with them within their state-wide systems. There are also differences in the interventions that John's team and our team are using, such as in the specific choice of one type of psychosocial treatment or another – or one type of pharmacologic approach versus another. Beyond that, the promise that we will each using different approaches take what

see RAISE on page 34

Portraits of The Self

By Thomas Good
Photojournalist

I've always identified with the subterranean souls, the underdogs, the ones that needed a helping hand and got kicked in the teeth for it. And so, as a young firebrand, I went into health care, working with people with mental illness.

Twenty-five years ago I was the young supervisor of a locked psychiatric unit. It was locked because the patients didn't respond well to medication and couldn't function without a lot of staff assistance. Like all health care workers who deal with the disenfranchised, I learned to love these folks who wanted only two things: to live on their own and to have a job. Nothing grandiose about these desires. But of course, many of my patients would never realize their dreams. What most people take for granted. So, many of them had a short term goal — to be accepted as human. Sadly, this dream also proved elusive.

One man, very tall, very ill — a Jewish man we'll call Daniel — lived on my unit. For the most part, his symptoms didn't respond to medication. But he was harmless, a gentle giant. I liked Daniel although I didn't know him well. I saw him everyday and he impressed me. Despite his suffering — he heard voices that berated him — he found joy in simple things.

One day a small man, very gray and frail looking, came to the unit. It was a stark contrast, father and son. The large Daniel and the small dad. They sat together sharing some candies and chuckling occasionally over a small joke. It's an indelible image for me.

It was a warm day, the day Daniel's father came. And so, midway through the visit he removed his sport coat and he rolled up his sleeves. I walked by the table where father and son were conversing and as I passed I noticed the numbers. I had never seen Holocaust numbers tattooed on an arm before and it was startling. Particularly as I am German American. I still grit my teeth whenever I think of it.

After the visit I could only marvel at the father's ability to laugh. Surviving the Holocaust only to see his son stricken with schizophrenia. I have no words to describe the combination of emotions this image elicits — 25 years later.

Another man with mental illness I knew named Joseph, responded better to his medication than most of the patients who lived on my unit. Joseph eventually graduated from a halfway house and lived in an apartment with other patients in recovery. Joseph lived simply with his one "possession" – a dog. The dog was a friendly little beast named Herman. A neighborhood girl, a grade-school-age youngster, often smiled at the dog when Herman's owner took him for a walk. One day the girl asked if she could pet the dog. Joseph was anxious about interacting with people he didn't know but he said OK. Later that night, the girl's angry father showed up at Joseph's home — armed with a baseball bat and accompanied by some like-minded individuals. They beat Joseph so severely that they fractured his skull. Several surgeries and a steel plate later the fracture was all but mended. And so, leaving Herman behind, Joseph got on a train and headed upstate. Somewhere north of the city he got off the train and walked into the woods. He sat down and waited to die from exposure. He was too frightened to continue living. The police called to let us know that he had been found dead. I don't know whatever happened to Herman.

Thomas Good

When I hear people talk about how they don't want people with mental illness to live in their neighborhoods I think to myself that I have never met a person with mental illness who would use a baseball bat to crush another person's skull.

If I could find a way to convey this to the intolerant, to speak out for the least among us, I would do so. I would be shouted down, perhaps threatened. But the truth would out.

Thomas Good is Editor of Next Left Notes (www.nextleftnotes.net and video.nextleftnotes.net). He is a member of the National Writers Union - UAW Local 1981, International Federation of Journalists.

Mental Health News Education, Inc. Welcomes New Board Members

Staff Writer
Mental Health News

The Board of Directors of Mental Health News Education, Inc. (MHNE) is pleased to announce the election of two outstanding community leaders to its Board. MHNE is the nonprofit organization that publishes *Mental Health News* and *Autism Spectrum News*. The new board members are Theresa Pirraglia, a leader of the Westchester County, New York autism community, and Alan Eskenazi a member of the management team at Saint Vincent's Hospital Westchester. In announcing the new appointees Peter D. Beitchman, DSW, Chairman of the MHNE Board stated, "We are extremely delighted and excited to welcome Theresa Pirraglia and Alan Eskenazi to our Board. Theresa has a wealth of knowledge and experience about autism spectrum disorders and the needs of the autism community, and Alan is very knowledgeable about the mental healthcare delivery system and its impact on people with mental illness and their families in the mental health community."

Theresa Pirraglia

Alan Eskenazi, MA, CPHQ

Theresa Pirraglia

Mrs. Pirraglia, a member of the Editorial Board of Autism Spectrum News, is a Co-founder and Board member of the Foundation for Educating Children with Autism, (FECA). In 1996 she also co-founded the Devereux Millwood Learning Center, (DMLC) located in Millwood, New York. DMLC is a day school for students with autism ages 5-21 that utilizes the principles of applied behavior analysis in all its methods of instruction. In 2009 she designed and founded the Devereux Millwood Enhanced Supported Employment - Day Habilitation Program for Adults.

Theresa earned her Bachelor's Degree in Communications at Fordham University. She is a former member of the Board of The Putnam Associated Resource Centers, (PARC), a chapter of the ARC, a former member of the New York State Autism Network, and currently serves as a member of the Westchester County Autism Advisory Committee. In 2007 Theresa received the "Martha Fitzpatrick Citizen Advocate Award" from The New York State Rehabilitation Association, Inc., (NYSRA), and in 2008 she received a "Lifetime Achievement Award," from The Foundation for Educating Children with Autism, (FECA).

Alan Eskenazi, MA, CPHQ

Mr. Eskenazi is the Vice President of Quality and Regulatory Affairs for Behavioral Health Services at Saint Vincent Catholic Medical Centers. He earned his Bachelor's Degree in Psychology at Brooklyn College of the City University of New York, and his Masters Degree in Counseling Psychology at New York University. He is a New York State Credentialed Alcoholism and Substance Abuse

see Board Members on page 38

Anti-Racism Movement Growing in Mental Health Sector
Theme to be Addressed in Upcoming Winter Issue of Mental Health News

Staff Writer
Mental Health News

Paul Levine, Executive Vice President and CEO and Mary Pender Greene, Assistant Executive Director of The Jewish Board of Family and Children's Services (JBFCS) have been leaders in what can only be described as a growing Anti-Racism movement within the local nonprofit community.

JBFCS has fully committed itself to rooting out the structural and systemic racism which is endemic in our society and even infects well intentioned, highly functioning mental health and social service organizations. While it has played a leading role in this effort, JBFCS is not alone. Over the past few years, more than 3,000 members of the local nonprofit human service provider community, including CEOs and senior executives at many agencies, faculty and deans of the schools of social work have attended Undoing Racism™ workshops and other presentations by the People's Institute for Survival and Beyond (PISAB).

Many leading organizational and professional associations have now established strategic partnerships with (PISAB) to further this effort. These include the Human Services Council of New York City (HSC), Council of Family and Child Caring Agencies (COFCCA), Black Agency Executives (BAE), The Black Equity Alliance (BEA), the National Association of Social Workers – NYC (NASW), a number of the metropolitan schools of social work, and the Anti-Racist Alliance (ARA). Through the collective efforts of these organizations, human services staff, social work educators, and practitioners now lead a movement committed to transforming service delivery and undoing structural racism in the field of mental health and social services. During the Spring/Summer 2010 both COFCCA and the HSC are scheduled to sponsor Undoing Racism™ presentations for board members and executives of some of New York City's leading human service agencies.

Paul Levine

Mary Pender Greene

With regard to the need to address issues of racism within the mental health sector, Paul Levine, states: "First, I would hope everyone would set aside the notion that we are all experts on issues of race in organizations because we have worked with a diverse staff for however long. My experience is that the more sensitive and complex any subject the more we have to be willing to expose ourselves to new perspectives on it. There is no subject that is more complex than race. I am well aware that there are always significant demands on overwhelmed executives. We frequently butt up against deadlines, budget crises, and this year it will be the effects of the new RFP results, clinic restructuring or the social work licensing issue. I can predict right now that a good percentage of executives will want to postpone participating because of these and other competing issues. I also am willing to take a risk and say that it will always be difficult to get people to attend because of the subject of race. The struggles with race are so ingrained in us that we treat it as a "given" that is always with us and that permits us to ignore how powerful it is — sometimes on a level that is not conscious. The best evidence I can give for this is my own personal experience of how hard it is to keep engaging this issue."

Mr. Levine believes that the Undoing Racism™ workshops and other presentations will "open up more avenues for organizations to address race in ways which will improve morale and make us feel even more proud of the work that each of our organizations does."

According to Mary Pender Greene, "Understanding the impact of race and racism are essential guiding principles for mental health and social service agencies. Racism greatly burden and impact the lives of all people of color, which includes both our clients and staff. One cannot claim clinical excellence without the

see Anti-Racism on page 40

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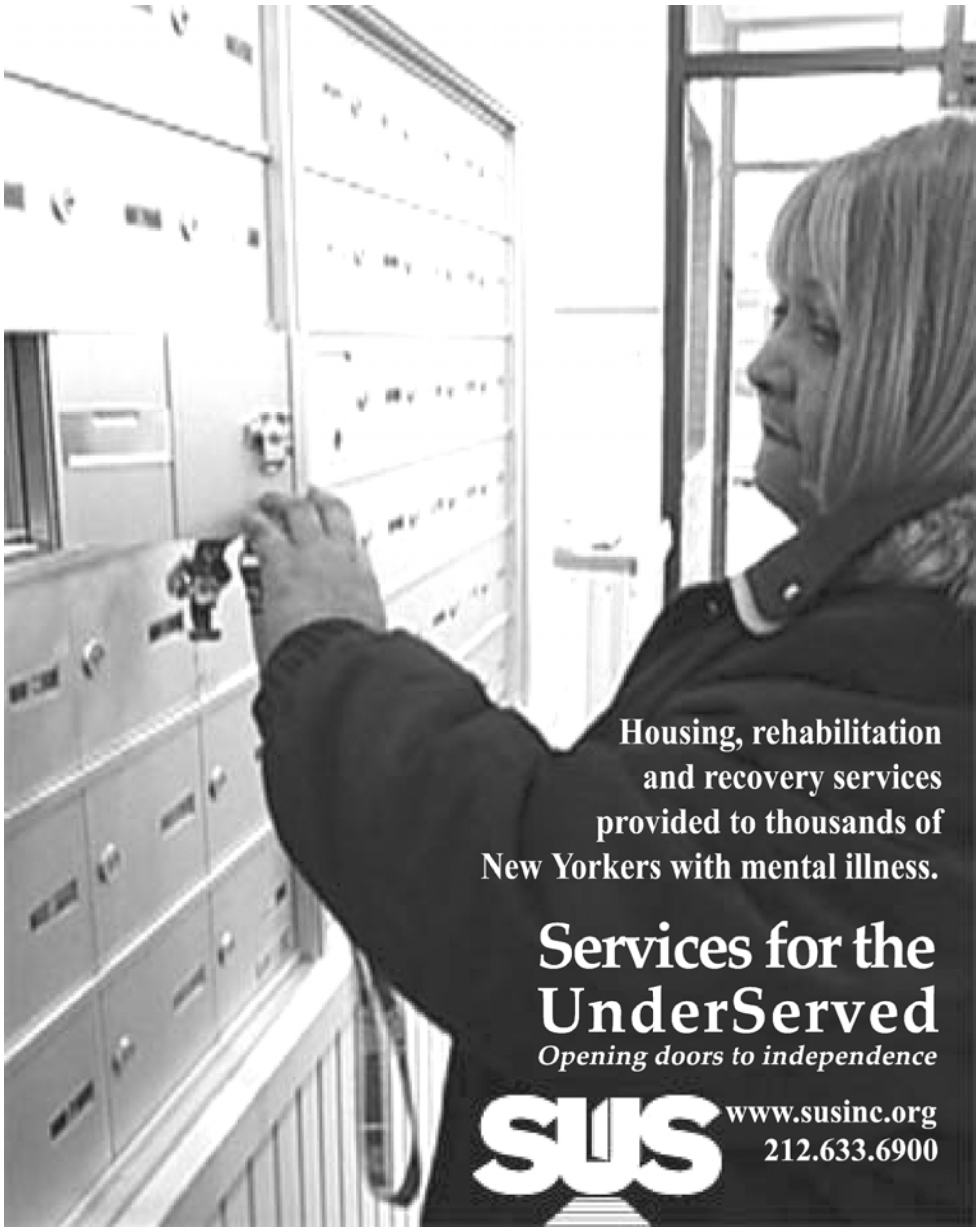

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we have learned from the past 20 years of research in early stage schizophrenia and see if we can apply at the clinical service level in community based sites.

Q: In your many years of work to improve the lives of people with schizophrenia, has there ever been such a monumental and promising approach to changing the models that are currently being used to help people with schizophrenia?

A: When I began training in the late 1970's there was a type of therapeutic nihilism that pervaded clinical approaches to schizophrenia – meaning that you could suppress psychotic symptoms but you couldn't really do that much to rehabilitate or restore people's lives to what they were before their illness. It was generally thought that people with schizophrenia were doomed from the womb with an inexorably progressive disorder, a dogma that had its roots in Kraepelin's original formulation of schizophrenia from the late 1900's and amplified by genetic theories. However, the research that was conducted in the 1980's, 1990's and into the 21st Century suggests that if you intervene early and optimally, you can prevent the disability from occurring. This strategy has found its most zealous expression in the form of the early detection intervention prodromal approach to psychotic disorders which has caught on and is being pursued around the world in many countries. However the problem with that approach in terms its readiness for prime time, is that we do not have a specific and reliable means of identifying patients without identifying a significant proportion of so-called false positives – people who may have the so-called prodromal criteria, but never go on to develop a syndromal psychotic disorder. We know that when most people develop syndromal schizophrenia they do not necessarily seek or receive treatment right away. The mean duration of symptoms before a first treatment is generally about a year. We have learned that the sooner we treat them the better. We also know that the fewer relapses that they have after recovery from the first episode, the better their chances for maintaining their recovery and preventing what research now understands as an actual deterioration in the synaptic pathways of the brain. Right now, our ability to test optimal interventions after people do meet syndromal criteria is ready for prime time – and that's basically what the RAISE study is all about.

Q: So what you're saying is that without early intervention, continued episodes of schizophrenia actually destroy synapses in the brain – and a person's inability to recover at that point is not because they have been so terribly traumatized psychologically after such scary and upsetting events?

A: It's a matter of brain chemistry and neural circuitry. We know that a chemical disturbance in the brain with the neurotransmitters dopamine and glutamate initially gives rise to psychosis. When it is not stabilized or suppressed in time and is allowed to go on too long then that creates a toxicity which disrupts the integrity of the cell membranes and produces a structural pathology whereby patients lose synapses. The same thing occurs if they have recurrent episodes in the form of psychotic relapses. If this happens repeatedly, this causes the same type of progression from neurochemical pathology to structural pathology. When they get to the point of structural pathology that's where the medications we have can't necessarily restore those synaptic connections. To combat this deterioration, we will need to have newer medications with potentially neurotrophic effects and/or with the potential to stimulate neurogenesis, and to potentially exert neuroprotective effects. Our current antipsychotic drugs, although they are good at suppressing the overactive chemical stimulation are not able to produce these neurotrophic and neurogenesis type effects.

The demoralization and discouragement that you referred to in your question can frequently lead to people committing suicide. That generally occurs because people can't get back to where they were. While they still have some awareness of that they become really dispirited and demoralized by it.

Q: Does this new knowledge of synaptic deterioration also apply to other illnesses such as depression or bipolar disorders?

A: It seems to a lesser degree in bipolar disorder where people have multiple episodes or sustained periods of manic psychosis. They do experience some degree of deteriorative progression but not nearly to the extent that people with schizophrenia do. In terms of depression, there has also been some new research which has explored the possibility of some form of neurotoxicity that occurs – particularly in the medial-temporal lobe in the hippocampus. It is believed that this neurotoxicity may be caused by too high of a level of circulating cortisol that we believe is brought on when people experience high levels of stress. This has not yet been fully verified.

With schizophrenia however, we have upwards of twenty studies that have shown the loss of brain gray matter which we believe reflects synaptic deterioration. MRI studies have shown that there is an actual loss of gray matter in the brain in the frontal and temporal lobes and to a lesser extent to the parietal lobe – which can amount to a loss of from 1-3 percent of brain tissue per year in the initial stages of schizophrenia. This is related to how many episodes a patient has had and how well they have responded to treatment. It is believed that this is a biological marker of this progressive process and this clinical deterioration.

This is why the RAISE project is so important. We know that people are most responsive to treatment at the beginning of their illness and that they are most susceptible at that point to the progression of the illness and its deteriorating effects if the illness is not stopped in the first episode. Therefore, the best time to stop schizophrenia in its tracks is to get people at the beginning of their illness and make sure we treat them as effectively as possible, keep them engaged in treatment, and help them to remain stable throughout the remission processes.

What I think has become almost uniformly observed and understood in patients is that when people get sick for the

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The Disability Studies Program At CUNY School of Professional Studies

By Mariette J. Bates, PhD
Academic Director, Disability Studies Programs, Distinguished Lecturer
CUNY School of Professional Studies

Mariette J. Bates, PhD

In 1975, when I began working for Max Schneier and Mort Posner at the Federation of Parents Organizations for the New York State Mental Institutions, there were no courses to teach me what I needed to know about disability, deinstitutionalization, or advocacy for service recipients and their families. The idea of community based programs was a new and compelling one. Many agencies and programs were being created for the first time to serve those moving from institutions or who were living at home. New to the field, I read everything in our office, and I learned about mental health advocacy from those publications and from my daily work with Max and Mort. In 1977, now working for One to One, the foundation started by Geraldo Rivera after his exposé of Willowbrook State School, I created the first national library on community care for people moving from institutions to the community.

Over 30 years later, we have agencies and services that our earlier selves could have only dreamed about. However, the need is still there to help workers at every level to understand their important place in our nation's history, to explore the phenomenon of disability and its relationship to public policy, law, the humanities, science and social science, and to reflect on how disability intersects with contemporary culture. That's why I'm thrilled to be heading CUNY's School of Professional Studies' Disability Studies Program.

It was just 18 months ago, in January of 2009 that the first group of students enrolled in the Master of Arts in Disability Studies program. Our program is designed to prepare a new generation of service providers, advocates, researchers and policy makers to become more insightful and skilled professionals. Students gain new perspectives on their work, new confidence in their abilities, and new commitment to working on behalf of people with disabilities. Nationwide, there has been a surge of interest in Disability Studies in the last several years, with more programs being created at universities each year at the undergraduate and graduate level.

In addition to the M.A. program, we offer an Advanced Graduate Certificate and undergraduate course work in Disability Studies. The Advanced Certificate is a good choice for students who want to learn more about disability but are unsure about whether they want to pursue a Master's Degree. Both the certificate and degree programs were developed in partnership with the John F. Kennedy Institute for Worker Education; the degree program grew out of the increased interest and demand for graduate level courses beyond those offered in the certificate program. We celebrated the first Masters graduates in early June, 2010.

Our students bring a variety of experience with them: some of them work in agencies providing services, some work on policy and administration, and others are interested because of a personal connection. Students who have worked in the field of mental health or intellectual disabilities for decades are just now learning the history of the field for the first time, as well as being challenged to think critically about disability and society, and they are energized and excited about the coursework. "In each of the four classes I've taken, I've seen more enthusiasm than I have ever witnessed by fellow classmates," says student Caryn Giananti. "The program has been nothing short of excellent. It's a privilege to learn from professors who are part of the leading generation to examine U. S. life through this lens." About ten percent of our students have disabilities, and we also have several faculty members with disabilities. Their experience and perspectives enrich class discussions and inform the course reading.

The current fiscal climate only serves to underscore the need for creativity and advanced skills in the workforce making the Disability Studies programs especially relevant. Students have the opportunity to step back, learn and reflect, and then re-engage with renewed energy and expertise.

Applications for the fall 2010 certificate courses will be accepted through May 15, 2010, while applications for the Masters degree (Spring 2011 cohort) have a deadline of December 1, 2010. For more information on the Disability Studies programs at the CUNY School of Professional Studies, visit www.sps.cuny.edu/madisability or call 212-652-2869.

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professional careers", noting that one-third of these therapists experienced severe distress that lasted at least one year beyond the initial loss. Many considered leaving the profession after this experience.

Many factors can affect the duration and intensity of a clinician's response to this loss, such as treatment context, supervisory and colleague support, legal issues and personal history. Legal prohibitions around confidentiality, and the subsequent lack of access to grief rituals make the normative processing of grief difficult, if not impossible. In addition, many clinicians experience reactions from colleagues, staff and supervisors which are quite unsupportive. Quinnett (2008) reports that many clinicians reported a pattern of isolation and interpersonal discomfort with their colleagues, who implicitly or explicitly expressed judgment about their competence. Such reactions may lead to a well-founded ambivalence about disclosure, and consequent resistance to seeking out optimal supervision/consultation or even personal therapy that could help clinicians gain clarity or support. Many professionals have described feeling completely abandoned by their colleagues and by their own hopes and expectations for support, after the distressing experience of losing a client to suicide.

Effects on Clinical Work

In general, the suicide loss of a client commonly leads therapists to question their clinical abilities, and to experience a sharp loss of confidence in their work. The common responses to a suicide loss (including numbness, sadness, anxiety and generalized distress) are likely to result in at least some temporary disruption of a clinician's optimal functioning. PTSD symptoms may impair clinical response and therapeutic judgment, and since such symptoms and states may be triggered by exposure to other potentially suicidal clients, they are more likely to impact clinical functioning when working with suicidal individuals. Hendin et al. (2000) noted that even the most experienced therapists expressed difficulty in trusting their own clinical judgment, or accurately assessing risk after a suicide loss, often tending towards hypervigilance in relation to potential suicidality or, conversely, the minimization or denial of suicide potential.

Positive Changes/Posttraumatic Growth

Traumatic experiences can paradoxically present a multitude of opportunities for new growth. Fuentes and Cruz (2009) found that post-traumatic growth was fostered by perceived social support, the willingness to discuss distressing issues with supportive others, and openness to change.

Despite their initial distress, many clinicians are able to identify retrospective benefits to their experience. These include becoming better educated about suicide and the likelihood of its occurrence, and an increased sensitivity towards suicidal clients and those bereaved by its loss. In addition, clinicians report more realistic appraisals and expectations in relation to their clinical competence, and more awareness around their own therapeutic limitations. They also become more aware of the issues involved in the aftermath of a client suicide, including perceived gaps in the clinical and institutional systems that could optimally offer support to both families and clinicians.

In addition to the changes related to knowledge and clinical skills, many clinicians also note deeper personal changes subsequent to their client's suicide. Many clinicians feel that once they are more resolved with their own grief process, have expressed the desire to support others with similar experiences.

Clinician-Survivors Task Force

The Clinician-Survivors Task Force of the American Association of Suicidology provides consultation, education, support and resources to clinicians who have experienced the suicide loss of patients, family members, clinical colleagues or therapists. We recognize that all of these losses carry implications within personal, clinical and professional domains. The Task Force provides a listserve and a website, on which there are opportunities for clinicians to share experiences about suicide loss, a bibliography of relevant publications, and postvention protocols. In addition, the chairs of this task force conduct Clinician-Survivor support activities at annual AAS conferences, and in their respective geographic areas. Future goals for the task force include empowering current clinician survivors to advocate for the support of future clinician-survivors, to disseminate the information that is currently available on the sequelae of clinician suicide loss, and to increase the research that is conducted on this topic. To access the CSTF website, visit the AAS website (www.suicidology.org) and scroll down to the "I am" section of the home page or go to the "Survivor" page and click on the "Clinician-Survivor" link. To request to join the listserve, please contact Dr. Vanessa McGann at vlmcgann@aol.com.

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your list. Accounts get settled amidst laughter and tears. This process can also be done by a patient who is experiencing guilt with a given family member. The most helpful part, of course, is opening all of this up for discussion with one another. Tremendous relief and renewal are available here.

Relinquishing Blame

Another important of relieving anxiety and fear is helping family members (especially children) to see that their feelings did not injure their family member. Another person's illness is never created by them. It may greatly help to say that no one is to blame for what is going on. It is surprising how much this may calm everyone down. Just by acknowledging and accepting the truth of the matter, a lot of self blame and guilt can often be dissipated.

Casting blame (on others and oneself) happens so often that it merits real examination. The deep sense of not having done

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enough, not having been able to save a loved one, leads many widows to die within a year of their husband's death. They may not feel they deserve to live happily once their beloved is gone.

In the case of a child dying in the family, spouses usually blame each other. All the times they did not love enough now appear in front of their eyes to be reckoned with. Blame cries out to be looked at and understood as a perfect example of misplaced sense of responsibility.

Families and care givers need to realize that they are not in control of the patient's life, illness or recovery. No matter how much they care for the patient, ultimately each person has their own destiny and life course and must answer for themselves.

Manipulation and Control

There is no one as powerful as a sick person. The weaker and sicker they are, the more they can create feelings of guilt and obligation in those around. What a tremendous trap this can be. Certain patients use their illness to get what they want. Their illness becomes a sudden opportunity to make all kinds of claims upon others, claims they may have had no right to make before. This kind of domination can be so overpowering that family members and care givers need protection from it.

A person may have been needy and hungry for a very long time. Now all of a sudden their illness gives them the right to let it all loose. It is easy to be overwhelmed by the demands of this needy person.

Another person may be deriving so many benefits and pleasures out of being ill that they can become unconsciously determined not to get well again. Why should they? What's in it for them?

Some patients become sick in order to "get back", to make someone else in the family pay. They may be saying implicitly, "Now you have to take care of me, whether you like it or not. You didn't love me enough before. You just have to love me now."

The price they pay for this kind of love is sickness and pain. Some pay it willingly. Unconsciously they are pleading, "I'll stay helpless and weak if only you'll give me your love."

Not too many family members are strong enough to remain unmoved by this kind of tyranny. Most feel trapped and begin to comply. They are not trapped by the patient really, but by their own feelings of guilt and fear.

In this case, complying with the demands of the patient can only make matters worse. When we give out of compulsion, the needs of the person to whom we are giving only intensify, and may seem insatiable to all.

As the person's insatiability grows, our own sense of inadequacy deepens. Nothing we give will ever be enough. The more we give in this manner, the unhappier we all become.

Extricating Ourselves From Binds

In order to extricate ourselves from binds it is necessary to understand that if we are giving at our own expense, if we are suffering as a result of what we are giving, or if the person we are giving to is suffering, this is not true giving at all. Eventually it will backfire.

If we are giving (or being given to) out of fear, sadness, obligation, desperation, then that is exactly what the gift contains—fear, sadness, obligation, and desperation.

All we have to give to someone is our own state of being. It is always only ourselves that we are giving. If we come to one's bedside grim, exhausted and filled with a sense of obligation, then that is what we are giving. However, this resentment will not be present when you can say "no" comfortably, when you can find your own inner rhythm, take the time needed to nourish yourself, find your own balance and determine what you can comfortably give.

Once this is done, give what you can gladly. You will feel wonderful. If the person wants more, you will be able to refuse them clear-mindedly. And what you give will be whole-hearted, beneficial for you and others as well. When you learn to give in that manner, an emotional healing takes place, both for you and those you interact with. Then guilt and fear have no place to hold on.

This article is based upon Brenda Shoshanna's new book Fearless: (The 7 Principles of Peace of Mind), Barnes & Noble, Sterling Press. www.becomefearless.org. Dr Shoshanna's work is dedicated to assisting you in dissolving your fears so you can reclaim your original, strength, wisdom and resilience. She shows you how to transform fear into courage so that you can live life to the brim. Workshops available. Contact: topspeaker@yahoo.com

If you are experiencing a difficult time

in your life, always remember that you are not alone.

There is a caring and helpful mental health community

nearby that can help you get through this difficulty.

Don't feel embarrassed or afraid to ask for help,

it is not a sign of weakness.

Best wishes from Mental Health News.

Financial from page 10

time he owed an SSI overpayment of approximately $20,000. Fortunately, Michael learned of Federation's Community Trust B which allows disabled individuals to fund a trust account on their own behalf. After repaying his overpayment to SSI and funding the Trust with the balance of his inheritance, Michael re-applied for SSI benefits and was approved. In the last 5 years, Michael been able to use funds in the Trust to purchase a car, pay for auto insurance, purchase furniture for his apartment as well as pay for medical expenses not-covered by Medicaid. He remains eligible for SSI and Medicaid and resides in a Section 8 apartment. As Michael says, "I don't really live any differently, but I feel better knowing the money is available."

The establishment of a special needs trust is a serious legal matter that requires the assistance of an attorney with expertise in this area. There are several different options and rules change. Decisions are made on the basis of individual need. There is nothing that can replace the peace of mind that caregivers achieve when they know that the future of their loved one has been protected properly. Federation has become expert in administering trusts that ensure the long-term financial future of individuals with serous disabilities.

For more information, e-mail Suzanne McCarthy, Manager, Financial Management Program at: SMcCarthy@fedoforg.org. Barbara Faron, LMSW, CPRP, is Chief Executive Officer of Federation of Organizations.

Mental Health from page 9

For example you wouldn't say someone is cancer but that they have cancer. As some children with mental illness require medication, NAMI reduces the stigma with the analogy that mental illnesses are biologically based brain disorders, and you wouldn't deny someone with diabetes insulin to balance out their body chemistry, so mental illness is no different. Getting past the inappropriate shame and blame allows parents to take better care of themselves as well as their children with special mental health needs.

Lastly, for a comprehensive national listing of children's mental health resources, (including websites, articles, databases) for both parents and professionals, there is the Maternal & Child Health Knowledge Path found at www.mchlibrary.info/KnowledgePaths/kp_Mental_Conditions.html. There is also a preventive/wellness path at www.mchlibrary.info/KnowledgePaths/kp_Mental_Healthy.html.

Lauren Agoratus is the parent of a child with autism/kidney disease. She is the NJ Coordinator of Family Voices, the national network that advocates on behalf of children with special healthcare needs. Families can find free help in their state at www.familyvoices.org/states.php. She is also volunteer NJ Caregiver Community Action Network representative for National Family Caregivers Association found at www.thefamilycaregiver.org.

Board Members from page 32

Counselor (CASAC) since 1991, and a Certified Professional in Healthcare Quality (CPHQ). Prior to his current position at Saint Vincent's, where he has served for over nine years, Alan was a Program Administrator for the Alcohol and Substance Abuse Unit at the Westchester County Department of Community Mental Health for six years. Previous positions included Clinical Coordinator at the Realization Center Chemical Dependency Treatment Center in New York City, Senior Chemical Dependency Counselor at Phelps Memorial Hospital in Tarrytown, NY, Instructor for undergraduate psychology and social work students at St. John's University in Queens, a Psychotherapist at National Neighborhood Counseling Centers in Brooklyn, NY, and a Substance Abuse Counselor at Gramercy Park Medical Group in New York City.

Alan is a member of the American College of Healthcare Executives; the National Association for Healthcare Quality; the New York Association for Healthcare Quality; and is a Board member of the Westchester Chapter of the American Foundation for Suicide Prevention. In 2008, he was instrumental in developing an effective falls prevention program at St. Vincent's Westchester which earned the hospital a Maryland Indicator Project Quality Award. Similarly, in 2004, he coordinated a highly effective restraint reduction initiative for which the Healthcare Association of New York State (HANYS) awarded the hospital the Pinnacle Award for Quality Improvement, the highest honor bestowed by HANYS and St. Vincent's Westchester was the first behavioral health facility to win the award. Alan has had the honor of presenting numerous speaking events throughout the country and has published and/or contributed to many articles relative to falls prevention, minimizing readmissions, restraint reduction, and treatment planning performance improvement initiatives. His overall mission and passion is to help develop simple, replicable, yet effective processes and procedures that yield the highest possible quality of care and patient care experience for consumers of behavioral health care services.

MHNE Founder and Executive Director, Ira H. Minot, LMSW, stated, "I am truly grateful that Theresa and Alan have agreed to serve on our Board, and know that our mental health and autism community education mission will be greatly served by their participation."

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first time with a psychotic illness – whether its schizophrenia or schizoaffective disorder or even affective psychosis, even if they respond to treatment and have recovered – is that they don't have a lot of awareness of what they just went through. They understand that something happened to them and they may have been sick, but they don't know what schizophrenia means and they don't know that is likely to be a recurring and life-long illness. In addition, they don't particularly like having to take medications – especially if they cause side-effects. Patients often say "OK, I will take this medication until everything is gone, and then I am going to get back to my life and leave this episode behind me." This generally occurs because patients don't like their medications' side-effects or they believe that they simply no longer have to take them. They lack the awareness that they are on a precipice and flirting with sliding down the slippery slope of deterioration. The next thing you know, they have had a relapse and even if they are treated, they may not get better, and if they do get better, they are still prone to making the same mistake.

What the RAISE project is gearing up to do is to basically say, "Let's take everything that we believe or has been shown to work and let's provide this to people in a team-based approach." Using this approach we want to ensure that they have a smooth course to remission and recovery, keep them there and enable them to re-engage in life and to get re-involved in what they were doing before they became ill – be it school, work, and social activities. We want to prevent people from running away from the psychiatrist and mental health professionals but to stay engaged with them. The hope is that if we do that, people will have a higher rate of recovery, they'll remain stable and in remission for longer periods of time, and there will be fewer people who will need to ultimately go onto government supports such as Medicaid and Social Security Disability (SSD). So in addition to the human suffering and productivity dimension to the outcome, there is also an economic cost-effectiveness to the outcomes that the RAISE study hopes to confirm.

Q: All of this knowledge and hope for the project begs the notion that there really needs to be a nation-wide public health campaign to educate people more about schizophrenia and staying in treatment – which because it is such a devastating illness – still remains in the shadows in terms of people's fears and understanding.

A: Exactly. The first limiting factor is to have a provider network that can actually deliver the kind of care we believe the project will confirm is required. Next, we will need mental health professionals with training in supportive employment, supportive education, case management, cognitive remediation, psychoeducation, peer counseling, psychopharmacology – and to have this expertise available in clinical settings where patients are being seen and treated. Then there needs to be reimbursement for those services. The only way that's going to be able to happen is if there is evidence that can be taken to mental health care policy administrators and reimbursement agencies – to say that this works not just in terms of our clinical outcome measures but in terms of very hard cost-outcome measurers.

Q: Are you worried that the current socio-economic and political atmosphere we have been under will loom as a cloud over the RAISE project and the recommendations that it will eventually propose be implemented at the national, state and community level?

A: It's like a best of times, worst of times type of situation. I think on one hand we have an economic situation which is extremely ominous and without clear prospects of getting better in the near future. We also have a health care financing system which has been chronically dysfunctional, and a mental healthcare delivery system which has been fragmented and woefully inefficient. On top of that we now have healthcare reform which threatens to shake things up in a way that we have no idea if it will make things better or worse, and if so, how? You couldn't pick a more unfavorable or inhospitable situation to try to do something new and innovative. On the other hand, when it comes to psychiatric medicine and mental healthcare, I think the situation is extremely optimistic and very good. Our field is more vibrant than it has ever been in terms of the intellectual dimensions of it, many interested young people are coming into the fields of mental health care and neuroscience research, the science of understanding the brain and how disturbances in the brain that give rise to mental illness has never been stronger. All of these factors are stronger than they have ever been before. Even on the stigma side, there has been progress, and this seems to be getting better all the time. The promise of the RAISE project is that if we are successful in proving our early intervention hypothesis, present this intervention model of service delivery, and get this to be taken seriously on a national level, this can have a huge impact on the lives of future generations of people who develop schizophrenia and economic benefits to the mental healthcare field and our country.

Q: Where are we now in terms of the calendar of the project?

A: It's not quite a year underway. It will presumably be a 5-year project. We are now finalizing the protocol and selecting the sites and training the people at these sites. We hope to be set to go before the end of this calendar year.

Q: How many people are involved on your study's team?

A: We've got a pretty big multidisciplinary team of over fifty people from a variety of universities and the two state mental health agencies. They include people who are psychiatrists, psychologists, social workers, anthropologists, a number of peer counselors and also people who are selected from different advocacy groups.

Q: Are some of these staff shared between your group and Dr. Kane's group?

A: No, they are completely independent

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A Personal Story from page 1

exhaustion, lots of exhaustion. There were times when we did not have childcare; the doors of day care providers' homes don't open so easily for children with behavior challenges. When there was no childcare, I could not maintain a job, and therefore we went into debt.

We experienced long periods without a break in the care giving.

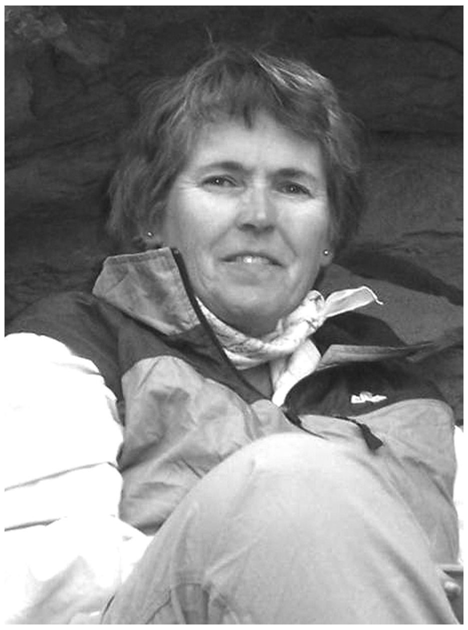
There were times that I wanted to give up and walk out of my house and never look back. I didn't walk out, I couldn't. When I think of those times now, I know they are the times that my inner strength had another growth spurt.

We had things to adjust to through the years. The acceptance of that first illness, and then the acceptance of the ongoing extra care that lasted beyond the terrible two's of a baby. Acceptance has come to us, but it took time and a lot of compromise and working together.

Caregiver burnout can happen at any age. It is often seen when a spouse becomes ill, when caring for an elderly spouse or parent, or, as in our case, when we faced exceptional parenting challenges of a young child.

Take a few seconds to think about what it would be like for you if suddenly you were so physically ill or injured that you could not take care of yourself. Think about the people you know. Who are your friends, your relatives, your spouse and your children? Think very seriously about who you would want to have taking care of you? Who is it that you would want to depend on? Think about the qualities of the person you would need to depend on.

Next, think about the possibility that the person caring for you has moved into your house with you. They've given up their job and their friends. They do this out of LOVE, the ultimate love of another person.



Janice Fitzgerald

Now, let's say your illness or recovery time takes 10 times longer than anyone predicted. Or, you learn that you are never going to fully recover. And for the entire time, the same kind, compassionate person has been your caregiver. Doing your laundry, helping you bathe, cooking your meals, and taking you to doctor appointments, helping you go to the bathroom.

Two years have passed and this wonderful person has not had a vacation. In fact, they haven't even been away from you for a day in two years. They have not met up with their own friends for even a few minutes because they worry that you will not be ok. They worry that no one else can understand what you need. This may sound wonderful to have someone so totally committed to you, but guess what? It can't go on forever. Burnout inevitably comes along. It will manifest itself as depression, constant fatigue, or a declining interest in pursuing any outside activities. It might be withdrawal from social contacts, or maybe an increase in the use of stimulants or alcohol. Those are some of the symptoms.

And along with those symptoms the quality of care will diminish. Impatience, anger and abuse can happen in extreme cases.

Caregivers won't see or admit these symptoms in themselves. If you are a caregiver, think long and hard about what other people are telling you. Think about the possibility of burnout. If enough people start saying the same thing to you, it's probably true. "Take a break, get out of the house…" Two difficult things to do are to admit that you do need a break and to reach out for the help.

For your own mental health, develop a network of friends and colleagues and attend a support group. I found it very difficult to reach out. I used to think it was a weakness to not be able to handle all that I was dealing with. A caregiver support group has benefits. Even a group that does not match the diagnosis or care you are giving will be a help. Talking to other people who understand what you are experiencing can be a tremendous relief. They can also assist you in tapping into resources that you didn't know were around… a good doctor, a source of respite help.

Somehow, some way, get a break – respite is what we call it. Guilt free time out is essential. We do not have to be all things to all people. We may be essential and irreplaceable to the person we love and care for so dearly, but…. they will survive some time without our help. It is ok to let someone else give his or her best care so that we can take some time for ourselves.

We need time to regroup, to rest, to come back somewhat refreshed. We cannot continue with superhuman powers forever. It is important to understand that it is ok to take a break. It is necessary to get a break in order to keep yourself physically and emotionally healthy.

If we become sick or have a medical emergency, who will provide the care we've been giving? Who will take our place? Ask any caregiver who has been at it for any length of time and they will tell you that their own health has suffered when the focus was on another person and they neglected to take care of themselves.

Remember that guilt is a self-made emotion. We do it to ourselves. We internalize our actions and reactions. Guilt is wasted energy and it is energy that we desperately need to conserve.

It would be nice if there was some magical way to avoid illness, to avoid dementia, to avoid disabilities, but that's not going to happen, and denial isn't going to work for very long when faced with a challenging situation.

To all of the parents who are caregivers, we commend you for your dedication and hard work.

Visit Parent to Parent of New York State at www.parenttoparentnys.org.

Some other helpful websites include www.nfcacares.org, www.aoa.gov, and www.caregiving.org.

RAISE from page 38

with no overlap in staff. The only overlap is in terms of the NIMH staff that is working with our two studies.

Q: What final thoughts would you like to give our readers about the RAISE project?

A: Research is something that oftentimes moves forward very slowly, often times at a rate in which the progress being made seems almost imperceptible. Then, suddenly at some point, you get a chance to put it all together and make a great leap forward. I believe that RAISE is one of those opportunities. The NIMH saw this and have really seized the opportunity to take something from the research level and in one fell swoop translate it into clinical practice. With the results of the RAISE project we will have the potential to effect a change in the way mental healthcare is provided and alter the prognosis and prospects of future generations of people who are at risk to develop schizophrenia.

About Dr. Jeffrey A. Lieberman, MD

Jeffrey A. Lieberman, MD, is a physician and scientist who has spent his career of over 25 years caring for patients and studying the nature and treatment of mental illness. Dr. Lieberman is currently is the Lawrence E. Kolb Professor and Chairman of Psychiatry at the Columbia University College of Physicians and Surgeons and Director of the New York State Psychiatric Institute. He also holds the Lieber Chair and Directs the Lieber Center for Schizophrenia Research in the Department of Psychiatry at Columbia and serves as the Psychiatrist in Chief of New York Presbyterian Hospital- Columbia University Medical Center. Dr. Lieberman received his medical degree from the George Washington School of Medicine in 1975. Following his postgraduate training in psychiatry at St. Vincent's Hospital and Medical Center of New York Medical College, he was on the faculties of the Mount Sinai School of Medicine and Albert Einstein College of Medicine, and served as Director of Research at the Hillside Hospital of Long Island Jewish Medical Center. Prior to moving to Columbia University he was Vice Chairman for Research and Scientific Affairs in the Department of Psychiatry and Director of the Mental Health and Neuroscience Clinical Research Center at the University of North Carolina at Chapel Hill School of Medicine.

Dr. Lieberman's research has focused on the neurobiology, pharmacology and treatment of schizophrenia and related psychotic disorders. In this context, his work has advanced our understanding of the natural history and pathophysiology of schizophrenia and the pharmacology and clinical effectiveness of antipsychotic drugs. In terms of the latter, he served as Principal Investigator of the Clinical Antipsychotic Trials of Intervention Effectiveness Research Program (CATIE), sponsored by the NIMH. His research has been supported by grants from the National Institutes of Health and the NARSAD, Stanley, and Mental Illness Foundations. His work has been reported in more than 400 articles in the scientific literature and he has edited or co-edited eight books, including the textbook *Psychiatry*, currently in its second edition; *Textbook of Schizophrenia*, *Comprehensive Care of Schizophrenia*; *Psychiatric Drugs*; and *Ethics in Psychiatric Research: A Resource Manual on Human Subjects Protection.* He also serves, or has served, as Associate Editor of the *American Journal of Psychiatry*, *Biological Psychiatry*, *Neuropsychopharmacology*, *Acta Psychiatrica Scandinavica*, *Schizophrenia Research*, *Neuroimage*, *International Journal of Neuropsychopharmacology*, and the *Schizophrenia Bulletin.*

Dr. Lieberman is a member of the National Academy of Sciences Institute of Medicine and recipient of the Lieber Prize for Schizophrenia Research from NARSAD, the Adolph Meyer Award from the American Psychiatric Association, the Stanley R. Dean Award for Schizophrenia Research from the American College of Psychiatry, the APA Research Award, the APA Kempf Award for Research in Psychobiology, the APA Gralnick Award for Schizophrenia Research, the Ziskind-Somerfeld Award of the Society of Biological Psychiatry, the Ernest Strecker Award of the University of Pennsylvania, the Lilly Neuroscience Award from the Collegium Internationale Neuro-Psychopharmacologicum for Clinical Research and the Exemplary Psychiatrist Award from the National Alliance of the Mentally Ill. He is or has been a member of the advisory committee for Neuropharmacologic and Psychopharmacologic Drugs of the Food and Drug Administration, the Planning Board for the Surgeon General's Report on Mental Health, the Committee on Research on Psychiatric Treatments of the American Psychiatric Association (APA), the APA Work Group for the Development of Schizophrenia Treatment Guidelines, the National Advisory Mental Health Council of the National Institute of Mental Health and currently chairs the APA Council of Research and Quality Assessment.

He resides with his wife and two sons in New York City.

About the NIMH RAISE Project

The NIMH RAISE Project is being conducted by two independent research teams—the Feinstein Institute for Medical Research in Manhasset, NY, and the Research Foundation for Mental Hygiene at Columbia University in New York, NY. The Connection Program of the Research Foundation for Mental Hygiene at Columbia University has been funded in whole or in part with Federal funds from the American Recovery and Reinvestment Act of 2009 and the National Institute of Mental Health, National Institutes of Health, Department of Health and Human Services, under Contract No. HHSN-271-2009-00020C. For more information about the overall NIMH RAISE Project, contact the NIMH Press Office and the NIMH RAISE Project Communications Team: Colleen Labbe, Jean Baum, or Christine Ulbricht (301) 435-8687, (301) 443-1018, (301) 443-3366

ADAAA from page 28

as no medication perfectly alleviates all symptoms of an illness indefinitely.

It is not difficult to imagine how such a ruling would impact those with an anxiety disorder. Many people with anxiety disorders are capable of keeping their symptoms at bay with regular medication. This, however, does not mean that the illness leaves no traces in the person's life. There are doctor's visits that must be met, medication often has deleterious side -effects, and even with the assistance of medication there are occasional flare-ups that require more extensive treatment and even hospitalization. There is all of this, not to mention the general stigma associated with anxiety disorders. If it becomes known that an employee suffers from an anxiety disorder an employer may not promote that person under the misguided idea that added stress will exacerbate their symptoms.

Simply put, under the old ADA someone who suffered from an anxiety disorder that treated their illness with medication would not be protected under the Act. For example, this would bar the employee from requesting a reasonable accommodation, e.g. starting work later in the day in order to take into account the frequent medication side-effect of early morning drowsiness. In all, the Supreme Court's previous holdings in this area unreasonably limited coverage to those that greatly needed it.

Now, under the ADAAA the fact that someone may be lucky enough to mitigate the effects of their illness through medication is not held against them. Hence, all that matters is that with or without corrective measures, i.e. medication, the person suffers a substantial limitation of a major life activity as a result of a mental or physical impairment.

Second, the Supreme Court ruled that only those who suffer from chronic and persistent symptoms of their ailment, which continuously limited them in major life activities, were disabled. Hence, those illnesses, like anxiety disorders, that have episodic flare-ups, despite how debilitating, were not covered under the ADA. The ADAAA overturned the court in this regard. Now, even if the impairment is in remission, as long as during a period of exacerbation it would cause a substantial limiting of a major life activity the person is covered under the ADA.

Third, under the previous ADA for one to be disabled a major life activity must have been substantially limited. Under the regulations enunciated by the EEOC, this meant that a major life activity must have been completely impaired and the individual unable to function. Hence, if the major life activity in question was, for example, being able to interact socially, the person must have been a complete shut in, without the ability to interact whatsoever. One can think of it on a scale from 1-10. Under the previous ADA regulations the person must have been a 10 on the substantially limits scale to be qualified as disabled.

Now, under the new ADAAA, while the language of substantially limiting remains the same, Congress has instructed the EEOC to soften their regulations. Applying that same numerical scale, a 5 would now suffice to be substantially limited. This is all in keeping with Congress' original intent in enacting the ADA of casting a wide net and essentially eliminating discrimination against those with a disability.

Lastly, under the old ADA many Courts had decided that thinking and concentrating were not considered major life activities. Clearly, these are the most important areas of one's life that are affected by anxiety disorders. Often times these were the only two detrimentally affected areas that someone with an anxiety disorder could point to as support that they were disabled. Now, under the ADAAA the law specifically mentions these two life activities as things to be considered when a Court makes a determination as to whether someone has a substantial impairment of a major life activity.

Conclusion

For many years people had complained that the spirit of the ADA was violated by these limiting Court precedents; that the Courts had impermissibly limited coverage in a way that Congress never intended. Now, the ADAAA has fixed many of these problems returning the law to its original intention; to cast as wide a net as possible in order to limit discrimination against those that suffer from physical and mental impairments. Quite possibly this is of most benefit to sufferers of anxiety disorder because seemingly ever limiting area of Court interpretation adversely affected them.

FEGS Caregivers on page 25

Applying Lessons
Across Work and Family

For years neither Laura nor Jerry told many people they worked with about their siblings. They used each other as a two person support group and shared with a few other trusted work friends. But recently, they have both begun to use their own experiences as family members in training their staff at F·E·G·S. Laura and Jerry have both found the powerful impact their stories have on staff. They don't' just talk the talk, they have walked the walk.

Laura and Jerry are not the only members of the F·E·G·S workforce who are caregivers. They are just the two who are ready to share their stories now. Laura and Jerry take care of themselves by talking about their struggles, asking for help and engaging in joyful activities and spiritual practices.

Their personal experiences inform and enrich their professional practices. Their professional experience has benefited both Margo and Andy.

For more information on the F·E·G·S Health and Human Services System network of services call 212-366-8038.

Anti-Racism from page 32

ability to recognize, analyze and discuss racism as it relates to supervision, clinical treatment, client outcome as well as staff relations, recruitment and retention. Cross racial dialogue is key to addressing structural racism, therefore as mental health providers we must develop a common language and become willing to examine our practice, policies and procedures. Additionally, the effort must be lead and endorsed by top leadership, encouraged in management/supervision, and embedded in clinical treatment."

Dr. Peter Beitchman, Chairman of the Board of Mental Health News Education, Inc. stated: "Mr. Levine's and Ms. Pender Greene's article initiates a compelling challenge to our mental health community. No issue has a greater impact on our clients, staff and organizational life than racism. We will continue to publish relevant articles and will devote the Winter issue of *Mental Health News* to a full exploration of the issues. In the meantime, to promote understanding and a meaningful dialogue on race and racism we highly recommend the indispensible training offered by The People's Institute for Survival and Beyond."

For information on trainings in the New York City metropolitan area go to www.antiracistalliance.com or call Sandy Bernabei at 212-957-5305.

Fit In from page 28

helping with homework, attending sick children or carpooling. These intergenerational conflicts can create feelings of isolation and identity confusion for elderly caregivers of children.

It is vital for grandparents raising children to make connections with others in the same situation. Having these connections normalizes their experiences and affords them an opportunity to be heard and understood by others. Support groups become a life line for elderly caregivers of children. In these groups they are able to express concerns and feelings in an honest way without the fear of being judged or misunderstood. Their experience is validated by sharing with peers. This is the one place where they fit very well and feel comfortable. The contact with other relative caregivers helps them consolidate their atypical identities and gain clarity about their varied roles and relationships. At VCS Inc. in New City, NY we provide a wide range of support services for elderly caregivers of children, including several monthly support groups. These groups significantly enhance the emotional well being of grandparents who find themselves in unanticipated parenting roles as they age.

Rosa Serrano-Delgado LMSW, is Program Director of the Relatives as Parents Program, and Gail K. Golden, LCSW, Ed.D, is Clinical Director, at VCS Inc.

Caring from page 8

daughter is in her sophomore year of college. We continue to slide back as she does, but we all know that her demonstration of responsibility for her behavior is the key to her success."

Today, their daughter is engaged in an internship at Boston Children's Hospital and is moving toward independence, accountability and acceptance. "We feel that we were provided an invaluable training and have grown along with our daughter. Had it not been for Wellspring – we don't know where the road would have taken her or, for that matter, us."

While the experience described above is unique, some elements are shared with other caregivers. The Multi-Family Group mentioned above is a group of family units, 12 to 18 at a meeting, made up of the resident child, her parent(s), and other family members, i.e. siblings, grandparents. These meetings provide the opportunity for direct eye-to-eye contact between the caregiver and child for affirmation or needed confrontation, and a forum in which to be heard, to respond, and to be supported. In addition, the Parent Support Group helps to orient parents to Wellspring, where veteran parents of previous and current residents train, support and offer their experiences.

The goal of Wellspring is to help and heal the whole family in order to return our residents to a healthy home environment. Towards this goal, we provide caregivers with support and understanding to grieve, opportunities to learn and grow, and skills that will sustain them following discharge.

Parenting from page 26

utilize other resources available not only at Putnam Family And Community Services, but in the community.

The RAPP group allows caregivers the opportunity to comfortably meet, while their "children" are involved in on-site structured therapeutic activities. The children are able to socially interact with kids who are in similar family situations. They can ask questions of each other without feeling stigmatized or judged. The children learn and practice social skills, along with asking for help. They work as a group and make decisions together. The skills that they learn in group compliment what the caregivers are learning so that the family can live in harmony. When you speak to caregiver families, they express a strong desire to keep the children healthy mentally and physically. The RAPP group allows them to know that they are not alone. With the help of the group leader and each other, they gain information and educate themselves about resources available. RAPP gives them a small respite from regular childcare responsibilities as well as helping them cope with daily issues that they are facing in their new role. Families are all unique, but all families need to experience laughter, joy, positive regard and places to feel safe. RAPP provides one of those places.

For more information on RAPP, contact Diane Henry, LCSW-R at (845) 225-2700 ext. 138

PTSD from page 12

find no outward expression. Combined with individual and family therapy, EET is an effective way to address self injury, substance abuse, and eating disorders, where feelings can be released and explored, rather than suppressed and displaced into symptomatic substitutes. Once emotions have found expression, the content may eventually be brought into the relationships that gave rise to it.

The development of practical coping skills for emotional self-regulation is a necessary complement to emotional expression. Some of these skills are simple; others are more complex. Breath-work, focused relaxation, time-ins rather than time-outs, yoga for adolescents and adults are some of the sensory related skill-sets taught and used at Wellspring. Assessments of hyper-sensitivity and hypo-sensitivity to touch are part of the Touch Training Manual's assessment package that help to differentiate sensory integration and sensory modulation problems from difficulties with attachment. Training in EMDR, as another mode of therapy with bottom-up processing, has been initiated with some staff to enhance the overall therapeutic repertoire.

However, it is the natural environment of Wellspring that is the primary sensory related asset that is fundamental to reducing stress and trauma-based reactivity. Wellspring is located in a rural setting surrounded by fields, gardens and forests that are quite appealing. The country quiet combined with animal care, horticulture and adventure programming offer sensory based body-experiential modes of therapy in each of the residential programs, as well as in the elementary and secondary day schools. Relationship to the natural world, which research has shown to be stress reducing, is fostered through these programs. They also help to offset the growing cultural problem of "nature deficit disorder" that Richard Louv has talked about in his startling book, The Last Child in the Woods.(15) Relationship to the natural world of to soil, plants and animals – to manual work, as well as walking in the woods – reduces stress and is ultimately healing apart from any formal clinical interventions. When these relational and bottom-up modes of processing are also woven into the fabric of a multi-modal residential treatment program, and are anchored by individual, family and milieu therapy, they add the necessary means and power to address traumatic residues from the past.

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Peer-Led from page 10

enable fathers of all kinds—married, single or unmarried fathers, cohabitating fathers, young or teenage fathers and new fathers—to improve their relationships and reconnect with their children. The workshops focus on parenting skills, how to be more involved in a child's life, anger management and conflict resolution.

NAMI Basics

NAMI Basics is a new education program for parents and other caregivers of children and adolescents living with mental illness. It is taught by trained teachers who are also the parents or other caregivers of children and adolescents with behavioral issues, undiagnosed emotional issues, ADD/ADHD, or other diagnoses such as major depression, bipolar disorder, oppositional defiant disorder, and anxiety disorders.

This is a free six-week course, with each class lasting 2.5 hours. All instruction materials are free to participants. The course explores a range of topics important to parents and caregivers: the trauma of mental illness for the child and family; the biology of mental illness; getting an accurate diagnosis; the latest research on the biological basis of mental illness and advances in treatment; an overview of treatment options; the impact of a child's mental illness on the rest of the family; an overview of the systems involved in caring for children and teens and how to advocate within those systems; and the importance of record-keeping.

Saturday Support Group

On two Saturdays each month, a group of parents of children and adolescents with a behavioral or psychiatric disorder can be found in the NAMI-NYC Metro conference room, sharing stories about the impact of mental illness on their families. This peer-run self-help group offers support and practical information in a welcoming environment. Participants share their experiences and learn coping strategies from fellow parents, in a recurring meeting facilitated by parents of children with mental health needs.

Deniece got help, for her daughter and for herself. (In fact, she was so empowered by her experience that she became a volunteer and, ultimately, a full-time staffer at NAMI-NYC Metro). The trauma and sense of helplessness that arise from a diagnosis of mental illness can be transformed by the support that only another parent and caregiver can offer. We see it happen here every day. For more information, call our Helpline at 212-684-3264.

Self Care from page 20

Everyday in our work as therapists we expend energy—through the normal act of empathy we experience compassion fatigue. How do we recharge? How do we balance energy expenditure and replenishment? Self Care. It looks different for each of us but we all need to do something everyday to achieve this balance. Today, I am very diligent about personal self care and teach caregivers how they can ameliorate the impact of vicarious trauma. The best treatment is prevention. If we know how to take care of ourselves, we don't need to experience what myself and many others have. So turn off your iPod, put down that magazine and listen to the flight attendant… "You need to take care of yourself before assisting others." I can honestly say… I don't want to be an accountant anymore.

Christina Grosso is the Director of Training at the Center for Trauma Program Innovation at the Jewish Board of Family and Children's Services. She has worked as a clinician, supervisor, and master trainer specializing in the treatment of trauma and complex trauma in children and adolescents. Ms. Grosso has extensive experience in the practice, implementation and training of trauma based assessment and evidence based and evidence informed practices. Ms. Grosso maintains a private practice in New York City and is an Adjunct Faculty in the Graduate Art Therapy Department at New York University.

Grandparents from page 20

Rather than focusing on pathology, practitioners should utilize a strength model that highlights a family's resilience and healthy coping skills. Spirituality is often a sustaining force in kin caregiving families. Caregivers frequently describe how their prayers and beliefs help in overcoming difficulties and challenges. (Musil et al, 2000, Langosch, 2005). To decrease isolation, caregivers can be helped to expand their support networks and join a kin caregiver support group. There are more than 500 grandparent support groups across the US (AARP, 2003). The group experience provides a safe place for caregivers to share their range of feelings with others in a similar situation. Grandparents often are very knowledgeable about resources and programs for their families and the group becomes a forum to exchange this information.

Helping caregivers expand their social networks also can ease the burden of caregiving. Comprehensive and wrap-around services that address the emotional, financial, educational, legal and entitlement needs of kinship families are essential. One such program, the Kinship Care Program at the Jewish Board of Family and Children's Services, offers support groups for caregivers and their relative children, individual and family counseling, case management, advocacy information, referral and psycho-educational forums.

Often caregivers are so focused on their grandchildren's needs that they take little time for themselves. It is important to help them consider their own self-care and help them develop stress reduction techniques and skills as a means of refueling.

Kin caregivers take up the societal slack of raising and nurturing their relative children when parents are unable to do so. These caregivers give so much and receive so little in terms of needed support and services. Practitioners need to respond comprehensively to these families' needs, identify and validate their strengths and work toward successful outcomes. Services and strategies should strive to build resilience, and sustain and empower these kin in their caregiver role.

The Kinship Care Program at JBFCS provides comprehensive and free services to relative caregiving families in Brooklyn. These services include weekly support groups for kin caregivers and their relative children, case management, advocacy, information, referral, counseling, parent education, and informational forums. For further information, please contact: Dr. Deborah Langosch, LCSW at 212-632-4760 or dlangosch@jbfcs.org or John Watkins, MA at 718-676-4251 or jwatkins@jbfcs.org.

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End of Life from page 24

used interchangeably in viewing whether or not a person with mental retardation has the ability to make his/her own health care decisions. Competency is a general term related to a person's overall ability to understand. IQ can be taken into account when looking at competency; Capacity on the other hand, is more subjective and relates to one's perceived ability to understand a specific issue or question. Capacity is not a legally rendered decision. According to OMRDD regulations, capacity for making a medical decision must be determined by the physician treating the illness but corroborated by either another physician or licensed psychologist with experience, specified by the Office of Mental Retardation and Developmental Disabilities (OMRDD), in working with and treating individuals with developmental disabilities.

Further complicating the process are the myriad legal and legislative policies and regulations which are/can be:

- Confusing and contradictory;
- Manipulated and differently interpreted by the multiple stakeholders with different agendas. Stakeholders include the public regulatory agencies such as the OMRDD, families, medical providers, mental health providers, legal services providers, advocacy groups, residential and other program providers.

Appointment of a Health Care Agent by executing a Health Care Proxy is not generally considered to be a complex decision. A person simply has to understand that he or she is giving another person (the health care agent) the authority to make medical care decisions on his or her behalf if and when he or she is not capable of making these decisions. If an individual were determined not to have capacity for a specific health care decision then the health care agent would be able to step in.

Most agencies serving people with developmental disabilities have not yet established policies and procedures to guide their practices in helping their clients execute a health care proxy and appoint a health care agent. Many are not yet aware of the option and guidelines established by the Office of Mental Retardation and Developmental Disabilities.

In Jose's case, the various stakeholders, including his family and professional caregivers are persistently advocating for continued aggressive treatment. In the absence of a determination regarding capacity it isn't clear who in fact can make these decisions, adding stress and confusion to an already highly emotionally charged situation. Given the description of Jose's skills and strengths, it likely that he would be assessed as capable of appointing a health care agent. He would require an additional assessment of capacity regarding his ability to make health care decisions related to future treatment including discontinuing aggressive and/or potentially curative treatment. Again, based on the description of Jose, it is quite possible that he would be determined to have the capacity to make medical decisions regarding his treatment. If however, it was determined that he did not have capacity for a specific decision and/or his cognitive abilities become further impaired by his illness to the extent that he is unable to make decisions, either his Health Care Agent or a surrogate would be appointed.

The Health Care Agent is the first in the chain of surrogate decision makers. If there is no health care agent appointed and the person is determined not to have capacity for a specific decision, surrogate decision makers can then decide. They must base their decisions on their knowledge and understanding of the individual's preferences, values and beliefs, and in the absence of this knowledge based on the individual's best interest. Best interest is guided by several factors including: dignity and uniqueness of the person; preservation/restoration of health; relief of suffering. The Health Care Decisions Act for Persons with Mental Retardation (HCDAPMR) is a relatively new law that became effective in March, 2003. It has been amended several times and now provides for the following chain of surrogate decision makers:

a. Health Care Agent

b. Legal Guardian

c. Actively involved spouse or domestic partner

d. Actively involved child over 18 years of age

e. Actively involved parent

f. Actively involved sibling over 18 years of age

g. Close friend (an affidavit is required and the person cannot work in the same residence that the person resides).

h. Consumer Advisory Board for Willowbrook Class Members

i. Surrogate decision-making committee (SDMC) or court.

In this complex world of decision making which requires frequent assessments and reassessments, personal and professional caregivers can be confused and conflicted. They may be faced with making decisions that are very difficult or need to accept the autonomy and dignity of their loved one even in the face of decisions that they disagree with. They may also be faced, as in the case of the "friend" who may be a professional caregiver, with the fear of liability. Armed with information, education and a deep respect for the ailing individual, the role of the caregiver becomes clearer, the stress reduced and energy is freed to be a supportive, respectful, loving and healing presence.

In summary, end of life care decisions are intensely difficult under the best circumstances -- i.e., when they are made in advance, directly by the individual who is ill, but at a point where they have the cognitive, emotional, physical and intellectual ability to make sound decisions. When caregivers are in this role, particularly on behalf of loved one with a disability such as mental retardation, the decisions are not only incredibly stressful and challenging, but require many additional steps and considerations. Having a trusted professional who fully understands the issues – emotional, legal, ethical and civil rights-related – can be tremendously helpful and reduce the overwhelming nature of these decisions.

Founded in 1934, F·E·G·S Health and Human Services System is one of the largest, most diverse not-for-profit health and human services providers in the region, offering a comprehensive and integrated network of programs for people with disabilities as well as many other populations. Among its many service areas are a full spectrum of care for those with developmental disabilities. F·E·G·S also operates Partners In Dignity, the Regional Care Center in the UJA-Federation Jewish Healing and Hospice Alliance. This program has assisted thousands of individuals coping with life-limiting, chronic and terminal illness and end of life. Caring professionals guide families through the complex maze of medical care, providing them with information, linkages and advocacy for appropriate care; individual and group counseling; spiritual care; community education and professional training; and volunteer services and opportunities. The Partners in Dignity team have expertise in working with families and training professionals who work with those with developmental disabilities, educating them about end of life issues and concerns for this population. They are trusted resources and guides.

For more information about FEGS Partners in Dignity Program, contact (516) 496-7550. For more information about FEGS Services, call (212) 366-8400 or visit us at www.fegs.org.

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Deadline: August 1, 2010

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On People and Mental Health Services"
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Ad Sizes - In Inches

	Width	Height
Full Page (1)	**10.4**	**12.8**
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Business Card (not shown)	**5.0**	**1.5**

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