



NETWORK NEWS

SPRING 2009

PLANNED LIFETIME ASSISTANCE NETWORK OF PENNSYLVANIA

www.planofpa.org

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EXECUTIVE DIRECTOR'S MESSAGE

I met with one of the PLAN case managers last week and was thrilled to hear that a long standing client has started to attend a day program three days a week. The gentleman she spoke of is a man who has little structure in his life and tends to be isolated although he lives in a group setting. The case manager has been working diligently and patiently to help support our client's very slow movement toward this healthy goal. In addition to attending the day program, he's spending more time in the public areas of his home and interacting with the other residents. This is a huge step for our client and a very positive outcome.

Measuring outcomes in the field of mental health can be a difficult process because success for one client may not look the same as for another. Take shoes for example. A great outcome is being successful in having a client wear a pair of new shoes when she has insisted that the old, worn out sneakers with holes and loose soles are just fine to wear in the snow and ice. For another client, using their clothing allowance to purchase three pairs of the exact same boots is not the outcome for which we aim.

Seeing a psychiatrist? A client who refused to see a psychiatrist for many years finally went and after a while, started to take medication. He is dealing with the side effects of his meds by talking to his case manager and coming up with strategies to help with his fatigue and constant thirst. Again, a very positive outcome. The flip side of this is the client who visits doctors on an almost daily basis without letting one know he is seeing another and keeping this behavior secret. This potentially dangerous situation needs to be corrected.

I'm happy to say that PLAN will be embarking on a new project to develop an outcome measurement tool that will be useful in giving us the feedback we need to assess our strengths in service delivery and also pinpoint areas that need to be re-examined for effectiveness. Questions that come to mind include "To what extent has working with PLAN: helped a PLAN FAMILY MEMBER achieve a more satisfying lifestyle, helped a PLAN FAMILY MEMBER gain access to necessary social services, helped reduce your stress about your PLAN FAMILY MEMBER?" As we move forward with this process, I welcome your ideas about how we can better serve our CLIENT FAMILIES. Please call or email me with your thoughts.

OUR MISSION

The mission of Planned Lifetime Assistance Network (PLAN) of Pennsylvania is to provide assistance to families in the development of an individual life plan to assure that care, support and special needs of a relative with mental illness or other lifelong disability are met when families are no longer able to do so.

PLAN STAFF PROFILE:

Johanna Levitt, MSS, LCSW, is a case manager at PLAN who has been offering emotional support and coordination of services to clients since 2002. She went from full to part time in 2007 to start a private practice in individual therapy.

Johanna found the opening at PLAN posted on the job board at The Bryn Mawr School of Social Work and Social Research. Although she was always interested in what motivated peoples' thoughts and behavior, social work and mental health are a second career for her. She was a professional ice-skater and performed in the US and abroad until her mid-thirties and also worked in hotel management. She says that during her life it seemed people gravitated towards being comfortable talking to her about their problems and telling her things they would later admit they normally

wouldn't tell anyone.

Johanna has a BA in psychology from Rutgers and a Master's degree (Master of Social Service) from The Bryn Mawr School of Social Work and Social Research. She worked with families for an agency in Camden NJ, and also worked in agency counseling doing individual and family therapy. She was involved in research using Neurofeedback with children diagnosed with ADHD and case management with children and their families who were dealing with ADHD, and some adults as well.

Johanna likes the feeling of doing good work and helping people who many times may feel marginalized and disappointed with their lives. She says one of the difficult things about her particular job is the sometimes unrealistic expectations and adds that working with people can lead to a boundary issue of when to stop helping others and take

care of her. PLAN's mission is a unique case management service where many times the client or family member involved has no one else to turn to except a PLAN employee.

Her work is quite varied. A partial description includes talking on the phone and in person with clients; scheduling, arranging transportation and following up on medical appointments; sorting through mail, bills and insurance dilemmas; bringing spending money to clients and purchasing necessary items for the enhancement of their lives. Whatever new or unusual task comes up gets added to the list and as she describes it, "sometimes there are so many things I do for clients that I would do for myself, it just blends into my day". But while she works within a 9-5 framework, Johanna is constantly aware that her clients' lives don't stop within those constraints.

PLAN of PA Receives \$35,750 Grant from The Philadelphia Foundation

PLAN of PA, has received a \$35,750 grant from The Philadelphia Foundation to support its comprehensive services to adults impacted by mental health disabilities and their families in the five county, Philadelphia area. Announcement of the grant was made by R. Andrew Swinney, President of the Foundation, whose Board of Managers approved the grant on 2/2/2009.

The funds will be used for establishing a comprehensive database and to develop an outcome measurement tool.

Having a mechanism to measure the impact of our services will enable us to build on our strengths and make appropriate changes in order to better meet the needs of our clients. In addition, we will be able to improve our ability to track service delivery and manage constituent relationships.

A number of board members and staff were involved in the application process. There were meetings with staff at The Philadelphia Foundation; a capacity assessment was completed in addition to the project description, statement of need, budget and timeline. The development of this grant was a uniquely valuable experience in and of itself.

The Philadelphia Foundation, a public charity, is Southeastern Pennsylvania's leading center for community philanthropic engagement. The mission of The Philadelphia Foundation is as vital now as it was in 1918 when it was first established. Today, with more than \$325 million in charitable assets under management, The Philadelphia Foundation continues to help donors harness their generosity and vision by providing tools, knowledge and financial stewardship directed to maximize the strategic impact of charitable contributions. Grants from more than 750 charitable funds strength-en the effectiveness of non-profits and support programs that are vital to the people of this region.

Manic: A Memoir

By Terri Cheney

William Morrow

The events of Terri Cheney's life are defined by mood, so she does not tell her tale in a timeline. We can attempt to put her story "in order".

She records early childhood mood swings, with an initial suicidal depression at the age of sixteen. The author maintains that it is impossible for a person with her diagnosis to have a normal relationship with food. A bout with depression brought on raging hunger, with the need to eat anything available.

Her depression returned when she was in college and lasted throughout law school. She describes again her problems with food - sometimes overeating, other times imposing

starvation on herself.

The author specialized in entertainment law, and worked for several prominent Los Angeles firms over a period of sixteen years. She was thirty-eight when her beloved father died of cancer. He had said to her, ironically, that her illness was "all in her head". With his death her depression worsened, and after being treated with electroshock therapy, manic episodes began. These are painful to even read about. They sometimes involved days without eating. Due to exaggerated reaction to sensual stimuli and to impaired judgment, they often culminated in casual sex, occasionally of a dangerous nature. She eventually was given a bipolar diagnosis, which was the beginning of her healing and an acceptance of her life and circumstances. Soon after this, she began to

write, which eventually led to this memoir.

Terri Cheney points to the advantages she has received since she began writing her life experiences, and since she devoted herself to the cause of mental illness. She arrived at this openness only after years of hiding her illness. While practicing law, for example, she had sponsored a young musicologist to represent her firm in a Michael Jackson case. When the man admitted to taking lithium, he was not only fired but for months after her law partners made his mental illness the butt of jokes.

The author had warned in her preface that "manic depression is not a safe ride". In an interview after this book was published she affirmed that "there's a light shining on this illness".

PLAN Winter Party

December 18 was a miserably cold and wet day but those who braved the elements were rewarded with a lovely, warm reception at the PLAN

winter party. Between 4:00- 6:00 PM, about 30 people (board, staff, client families and friends of PLAN) joined together to share some stories and get to know each other better. Sweet and savory treats along

with hot chocolate and apple cider added to the festivities. This is quickly becoming a terrific PLAN event and we look forward to more of you joining us next year.

No Kidding, Me Too

No Kidding, Me Too! (NKM2) is a non-profit group of entertainment industry members who are using their celebrity to combat the stigma of mental illness, or, in their word, "brain dis-ease". It was founded by Joey Pantoliano who was recently diagnosed with depression. He has made his diagnosis public and is

fighting the unfair practices and attitudes that often interfere with seeking treatment for their illness or full participation in work or community. Prior to diagnosis, Joey Pantoliano starred in "Canvas", a film about a family in which the wife and mother is being treated for schizophrenia. When he made his next film and acknowledged taking anti-depressants, he was asked to

sign a waiver accepting fiscal responsibility for any delays if he were to suffer a nervous breakdown during production. Noting that he was also on cholesterol medication, but would not be liable for delays if he were to have a heart attack, he founded "NKM2." For further information or a preview of new projects, visit www.nkm2.org.

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FAMILY TO FAMILY (F2F)

I am Judy Green and am pleased to be asked to write about Family-to-Family (F2F), a signature program of NAMI, the National Alliance on Mental Illness.

Years ago when a member of my own family was diagnosed with a mental illness (brain disorder), I simply knew *F2F* as a program described in a flyer to help educate families about an adult member's mental illness. Today, I am immersed in NAMI and also facilitate the *F2F* program for the NAMI PA, Main Line chapter at least twice a year. I am pleased to write that we also have a program for families who have an ill family member younger than 18 called *Visions for Tomorrow (Visions)*.

F2F is a 12-week curriculum developed for families in 1990 by Joyce Burland, Ph.D. (presently the National Education Director for NAMI) in response to the lack of education and support and ever present stigma she experienced

when navigating the medical system for her sister and daughter, both of whom have schizophrenia.

The program is facilitated by family members all of whom have experienced the traumatic aspects of having a loved one with a mental illness. Regardless of what one's professional training may be, the hat worn when standing before a class is that of "family member" -- a vital component of the program.

In broad sweeping terms, facilitators model and demonstrate peer mastery of basic psycho-social-biomedical knowledge; movement from chaos, trauma and inaction to action; and an acceptance of their changed lives and the importance of self-care -- all of which are empowering.

The course focuses on three main areas: education, support and advocacy. A sampling of class topics include learning about normative stages of our emotional reactions to the trauma of mental illness; what mental illness is and what it

is not; diagnostic criteria and characteristics of major mental illnesses; medical, psychological and social aspects for all involved; co-occurring brain and addictive disorders; brain basics; problem solving skills; medications; understanding the subjective experience of mental illness; how illness interferes with communication; self-care; restoring one's own life; recovery and rehabilitation; stigma; assertiveness and skill training; activism; how to effect change.

No two classes are ever alike; each establishes its own personality and focuses on its needs as learners and care givers. While the demographics vary, the majority of participants tend to be mothers. Initially reluctant to commit to a 12-week program, participants often ask for a part two; and many classes continue to meet as a group.

C L I E N T C O R N E R

Sheryl is a 47 year old woman with schizophrenia. She lives by herself in an apartment in Norristown. Sheryl spends much of her time taking walks and watching television. She is often alone although she maintains regular contact with her parents and siblings.

Sheryl's mother, who heard about PLAN from NAMI, called a year ago when she learned that Sheryl would be receiving a cash settlement

from a large pharmaceutical company. Sheryl developed diabetes as a result of taking a psychotropic medication. She is a recipient of SSI, Medicaid benefits; Section 8 housing and food stamps, all of which would be in jeopardy as a result of these funds.

The value of establishing a special needs trust was explained to Sheryl and her family. After everyone's questions were fully answered and

after an outside attorney reviewed PLAN's document, Sheryl opened a special needs trust. The outcome is that her \$17,000 can be used for supplemental needs such as transportation and cable television. In addition, a PLAN case manager is supporting Sheryl's interest in learning how to use a computer which can be purchased with the trust funds. All of her benefits remain intact.



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