



# PLAN of California

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PLAN of California is a 501(c)(3) non-profit corporation, formerly known as Proxy Parents Services Foundation. PLAN was developed and is governed by families of people with mental illness. It exists solely as a voluntary endeavor to educate and assist families who must cope with mental illness.

PLAN administers Special Needs Trusts for people with mental illness. Just like the family would, it coordinates public and private social services and medical care. PLAN safeguards public entitlements for people disabled by mental illness while providing family-like attention to help the person thrive, enjoy and improve his or her quality of life.

[www.planofcalifornia.org](http://www.planofcalifornia.org)

Planned Lifetime Assistance  
Network of California  
17602 Seventeenth St., #102-240  
Tustin, California 92780

*For this, our inaugural issue, and for those who are not already familiar with PLAN of California, I'd like to tell you about PLAN and our mission. Created 14 years ago as a 501(c)(3) non-profit, by family members of disabled loved ones to provide personal support services outside what was and is available in the public system, PLAN's signature Pay-As-You-Go program has expanded to the point that we are a contract provider for such care in seven California counties.*

*PLAN also oversees two Special Needs Trusts, created to protect the government benefits of our beneficiaries so that their inheritances do not have to be spent down before regaining or receiving needs based public benefits such as SSI.*

*With this newsletter, we hope to further our missions of "proxy parenting" and expansion of our Special Needs Trusts' beneficiary base by seeking to both inform the users of our services, reach out to break down the stigma of mental illness, and increasing the woefully inadequate amount of personal support services available to the mentally disabled and their families.*

*Gary M. Chang  
Executive Director*

## What's Going on at PLAN?

Carla Jacobs, PLAN's exceptional executive director for four years has stepped down and is now serving as PLAN's Treasurer. Carla continues to serve on the Board of Directors, Business Committee, and Quality Assurance Committee.

Gary Chang, a PLAN board member and Treasurer for the past four years has been elected as Executive Director and Secretary

for PLAN. Gary continues to serve on the Business Committee and is an attorney. Gary brings continuity and valuable experience with his long history with PLAN.

### Meet a Board Member

John Buck, President and CEO of Turning Point, one of the largest service providers in California, has acted as Personal Support Specialist for PLAN Pay-As-You-Go beneficiaries since the mid 90's.

### How and when did you get into activism?

Since my teenage years I have known and befriended people struggling with mental health issues. In every experience as an adult, I found others affected including military service personnel, fire fighters and college students. I found I had a knack for being with people during their crises.

### Any anecdotes or experiences in the field of Mental Illness that best illustrate or typify your participation?

We all have dreams and goals. My buddy of 12 years, Brian, always wanted to drive a car but his significant psychiatric issues make it an unfulfilled dream. We all have unfulfilled dreams that may be satisfied if altered. Some years ago, I took him out in my old ski boat and I let him drive. He was reluctant and tentative and even frightened the first time out. Over the years I have continued this activity and he's become comfortable. Last summer while speeding across a mountain lake, Brian looked at me, hands on the steering wheel, and asked with a big grin, "Is this what it's like to drive a car?" He was close to his dream and happy about it. So am I.

### Other News

We recently launched the PLAN of California Master Pooled Trust. Ultimately, the pooled trust will give PLAN the financial basis to be a self-sustaining organization. We currently manage/administer eighteen trusts with

assets ranging from under \$10,000 to over \$1 million. Three hundred families have signed up to receive our services now or in the future.

We expanded our Personal Support Services exponentially. Personal Support is provided to PLAN active beneficiaries in seven counties, representing each major population center in California. By year end 2008, we plan on expanding to at least seven more counties.

Our website ([www.planofcalifornia.org](http://www.planofcalifornia.org)) is up and running and will be further expanded.

## A Brief History of PLAN

*By Carla Jacobs*

I remember as a child whenever my mother passed elderly parents with an adult disabled child, she would always say, “They must be so worried about who will care for their child when they are no longer able.” Several years later, it was my mother who had that worry as my only brother had developed schizophrenia. When my mother passed away, PLAN did not exist. She had been his only safety net. My brother received his inheritance directly. To this day, I believe that money prevented Frank from ever receiving adequate care. Until it ran out, it funded his wandering across the United States and into Canada, wherever his delusions drove him. My brother has been missing since the early 90s.

In 1986, the same year my mother had died, Tony Hoffman, one of the founders of the California Alliance for the Mentally Ill (now NAMI-CA) organized a workshop at that organization’s Spring Conference, on the topic of “Legal Estate and Financial Planning for Parents of the Mentally Disabled”. Soon thereafter he and then president of San Mateo AMI (now NAMI San Mateo), Terry Walker, co-sponsored a workshop in Oakland entitled, “Providing for Our Loved Ones After We’re Gone.”

In 1990, other CAMI leaders, Don Richardson, an educator, and Joe Ehrenreich, an economist and professor at University of Southern California, met with Richard Van Horn of the Los Angeles

Mental Health Association to explore their organization’s mutual interests in future care planning. Under this leadership, in 1990, the California Alliance for the Mentally Ill (now known as NAMI-CA) and the Mental Health Association in Los Angeles, formed Proxy Parent Service (now known as PLAN of California), as a separate 501(c)(3) non-profit. An answer to my mother’s question had been given: PLAN of California would be there to care for sons and daughters with mental illness after their parents had passed away.

Families remain geographically scattered and sometimes ill-equipped to help. People with mental illness are poorly served by the current governmental system of services that has no one agency at any level totally responsible for coordination of funding, treatment, and care. Since the mid-1950s funding has become increasingly fragmented as state mental hospitals have been depopulated, community services have been developed, and federal entitlement programs such as Medicaid, Medicare, and Supplemental Security Income (SSI) have been introduced. Regardless of whether an individual with mental illness receives SSI and or Medi-cal, families remain the largest care givers. To bridge the systemic gap in care once families have passed away, PLAN of California serves two functions.

We are trust protectors and we are proxy parents. Families who set up PLAN of California Special Needs Trusts not only can protect their relative’s ability to qualify for “needs based government entitlements such as SSI and Medi-cal, they are assured that a sophisticated substitute judgment is in place to assure their relative’s ability to receive benefit from the financial inheritance they are able to leave them.

We are proxy parents. No one’s son, daughter, brother, sister should be lost like my brother was, simply another statistic on some city’s skid row. As a sister, I was not able to stop the money that fueled his flight into the bankruptcy of his delusions. But, PLAN’s educated, experienced Personal Support Specialists have resources and experience I did not have then.

In 2003, PLAN Board Members Ann Eldridge and Murray Olderman approached me to act as Director of PLAN of California after the retirement of John Siegel. It has been my honor to volunteer with this exemplary group of people. I am now retiring as Executive Director and will continue to serve on the PLAN Board of Directors. Our past has been stellar. Our future is strong and vibrant. PLAN is like my family. Please feel free to call us whenever we can help your own.

\*\*\*

## PLAN of California Establishes Pooled Trust

For over ten years, PLAN of California has acted as a trust protector for “stand alone” Family-Generated Special Needs Trusts. A financial institution serves as actual financial trustee with PLAN of California directing that institution as to proper expenditures from the trusts that will be most appropriate for the mentally ill beneficiary as well as providing personal support services to the individual to improve their quality of life.

In 2007, PLAN established the PLAN of California Master Pooled Trust. Open to any disability type, this trust has no asset limitation and can accept both first party (self-settled) and third party (family generated) trusts. A first party trust is one that can be funded with the individual’s own assets while protecting their eligibility for means-tested government benefits such as SSI or Medi-cal. Example: Robert, who is disabled and receiving SSI and Medi-cal, receives a settlement of \$25,000 from a car accident. Normally he would have to immediately “spend” down this money to maintain his eligibility for government benefits. Instead, Robert can place the funds into the PLAN of California Master Pooled Special Needs Trust and keep his government benefits. A separate subaccount within the trust is set up specifically for Robert and the funds within it are used to supplement his needs for quality health care, education, purchases and recreation. PLAN of California is the non-profit trustee and



through its staff, Board of Directors, and Committee Members, provide day-to-day review and supervision of the Trust’s Investments and its Administrative Managers. Additionally, by separate contract, PLAN of California can provide Personal Support Services to a beneficiary of the Trust. For more information, please call PLAN Executive Director Gary Chang at 714.997.3310.

# PAY-AS-YOU-GO

By Bruce Lewitt

PLAN of California offers a Pay-As-You-Go program for families seeking the services of PLAN Personal Support Specialists in the “here-and-now” prior to the family’s passing. These Personal Support Specialists provide extra support and care, advocacy and friendship unavailable within the public mental health system. Pay-As-You-Go is funded by the family with a six-month

deposit, the amount of which is determined by a budget and service plan developed through a Needs and Resource Assessment with the family.

Whether providing assistance getting to and from doctor’s appointments, obtaining housing, providing recreational activities or a myriad of other services, PLAN Personal Support Specialists commit to the same long-term relationships with beneficiaries of PLAN Special Needs Trusts. Only families that have demonstrated a commitment to that long-term relationship are eligible to participate in the Pay-As-You-Go program. Enrollment in PLAN of California is a necessary demonstration of that commitment.

## *Personal Interview with Bruce Lewitt*

Bruce Lewitt has been promoted to Director of Social Services for PLAN of California and has acted as a Personal Support Specialist for active PLAN beneficiaries (as well as Pay-As-You-Go) since the mid 90s. Bruce has over 15 years experience managing mental health programs and advising seriously mentally ill clients and their families.

### *How and when did you get into activism for Mental Illness?*

While researching a documentary on the mentally ill homeless in Santa Monica, I met the Executive Director of a leading local mental health center. I realized I knew nothing about Mental Illness and she invited me to volunteer at the agency, listen to clients and learn about mental illness from working with them. Once a volunteer, I knew working with people with mental illness would be my life-long career.

### *Any anecdotes or experiences in the field of Mental Illness that best illustrate or typify your participation?*

One day at the center, a bald-headed woman in a blue-net bikini ran in through the front entrance. She immediately dropped to her knees and began chanting, “Nam Myo Ho Renge Kyo”. I politely informed her that the Buddhist temple was around the corner and she was in a center for adults with mental illness. “No Problem”, she answered without missing a beat, “I’m bipolar.” When I started to give her some information about the Center, she quickly changed her previous assessment and declared that, in fact, she merely had P.M.S. She then suddenly ran for the exit, rubbing up against some of the members as she went by. She admonished a group watching T.V. to “Be true to yourself.” A television watcher in the room shouted that she was blocking his view of the screen. The bald headed woman in the bikini turned and ran out the door. I shouted out asking her if she needed any sunscreen but she was gone already. I’ll never know if she was showing symptoms of bipolar disorder or only acting peculiar; I just didn’t want her to get sunburned. The incident foreshadowed an important aspect of my work on behalf of PLAN beneficiaries – I was like a caring family member who hated to see her go without a little something that she might have needed.

## *Confessions of a PLAN Personal Support Specialist* By Jim Whitted

As a **PLAN Personal Support Specialist** I assist clients to achieve and maintain the quality of life standards no longer provided by their families. In effect, I am a “**proxy parent**”. Frequently, my clients are housed in board-and-cares or locked skilled nursing homes with little in the way of social activities, poor day care programs, no interaction with the outside world. So my most important function is to provide on-going social contact and friendship.

I visit my clients once a week (or more if the trust provides for it) and we go on “outings”: lunch, a movie, shopping or just a walk. And a call on a non-visit day can make a big difference to someone who has very little to look forward to. I can take them to dental or other appointments. If I feel my clients are having problems that the system should be taking better care of, I try to negotiate and help to solve them.

As a PLAN Personal Support Specialist, I know I can’t take place of loving family members. But if family is gone or incapacitated, I really must believe I do a lot better than overworked public employees or impersonal trust administrators who don’t understand mental illness.

And (just between you and me), I do one thing more. I often find the other residents in the facility to be hungry for social contacts. I feel sorry that they don’t have someone to visit them, so I may spend a little time “off the clock” just visiting with some very lonely and forgotten people.



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