

#### SSAN's Mission

The Statewide Self Advocacy Network (SSAN) promotes leadership and builds bridges that strengthen advocacy among disability communities by focusing on policy change.

"We have a voice! The strength of our voice needs to be heard by all individuals in California. Our job is to make their voice loud as well. As we strengthen those voices they will be empowered to speak up and express what is needed to improve their lives."

~Cheryl Hewitt, SSAN Chair

# **Voices of SSAN**

## Newsletter of the Statewide Self Advocacy Network

### From Cheryl Hewitt, SSAN Chair

Welcome to "Voice of SSAN," a newsletter of the Statewide Self Advocacy Network. This newsletter will help us bridge the gap between those members who don't have day-to-day internet access. It will also show the great things the network is doing in their local areas, hopefully with a lot of pictures.



Hi this is Julie Gaona, from Region 10. The person who inspired me to be an advocate was my mother, Linda Dixon. My whole childhood she always encouraged me to live my life to the fullest regardless of

my disability. Even when I didn't want to do things such as drama or school dances, she'd make me go do these types of things. No matter what, the word 'no' was not in her vocabulary.

She broke down a lot of barriers for me to be independent, such as making sure ramps were built at school and I had assistance during classes, like taking notes and getting my work completed. Later on, when I grew up, I had the confidence she had given me and the knowledge to be an advocate.

I attended college after high school. I was not very successful with that, so God put me on a path to work for an independent living agency. Lucille Walls the old executive director from an independent living center called Community Access gave me a chance to work at the center and I took it. I knew I could accept this challenge because of the confidence and knowledge my mother instilled in me.



### **SSAN Members**

- Jennifer Allen, Region 3
- Michael Arbios, Region 4
- Robert Balderama,
  Region 6
- Desiree Boykin, ARCA
- Rebecca Donabed, Region 8
- David Forderer, SCDD
- Julie Gaona, Region 10
- Cheryl Hewitt, Region 7
- Charles Horne-Nutt, Region 2
- Ted Jackson, CFILC
- Robert Levy, UC Davis MIND Institute
- Joe Meadours, PFCA
- Kyle Minnis, Region 11
- Nicole Patterson, DDS
- Chris Rogel, Region 12
- Kecia Weller, UCLA
  Tarjan Center
- Regina Woodliff, Region 5

### **SSAN Officers**

Cheryl Hewitt, Chair Jennifer Allen, Vice Chair



Hello my Name Is Charles Horne-Nutt. The person that most

inspired me to become a Self Advocate is a gentleman by the name of Steve Connors. I met Steve through my ex-wife about nine years ago. Steve became my Independent Living Skill Instructor through an agency called Do It Leisure.

The things that inspired me the most about Steve is his accomplishments. Steve has worked through Do It Leisure for the last 30 years helping individuals with disabilities and he has also has helped the students as a Special Education Instructor for the last ten years. Steve's most recent accomplishment is that he has done so well helping individuals with disabilities that he has opened his first care home. The accomplishments that Steve has made inspired me. I follow his example as a positive role model for me to be able to grow in a positive and productive way.

The Accomplishment that I have made is that I was Vice President of the People First of the Paradise Chapter. I held that position only for a short time but I learned some valuable things during that time about leadership. After I was Vice President a few years went by. I was married and was in an abusive relationship and Steve helped me cope and learn some valuable tools to be more productive with my life. Steve has helped me accomplish goals that I set out for myself. He has taught me how to live on my own in my own place. During the time as Steve being my ILS Instructor I accomplished getting my driver's license, living on my own, and becoming my own payee. These things are what help me to be my own Self Advocate.

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Self Advocacy is not the same for everyone. I feel that self advocacy is different for everyone. Self advocacy in my opinion is based on goals that individuals set up for themselves. When an individual accomplishes that goal that makes the individual feel good about themselves and they want to accomplish more. An individual might have some struggles during that time but if they stay motivated and on track on accomplishing that goal they will always succeed and become a valuable asset to others in the world.

During the last two years through my road to success I have held positions through Butte College. I was a member of Sigma Alpha Pi, I earned the presidential award through the Honor Society, I also earned the Excellence achievement award. I was Treasurer of the Inter Club Council and also was the Satellite Campus Director through the Associate Students of Butte College.

After Butte College I wanted to do more so I asked my Far Northern worker if there was anything that I could do to help others with my achievements that I have made. What is weird but cool at the same time is that she received an email about SSAN through the State Council and this where I learned about this position. I also became part of the Area Board 2 as an appointee from the Governor. I know that God has a lot more training and lessons for me to learn and that I am not done going through all my trials and tribulations. I am going to do my best at what ever God throws my way to learn and I know that God will never give you more than you can chew.

Thanks for taking the time to hear what makes me a positive and productive advocate.



# SSAN Partner Agencies

- Association of Regional Center Agencies
- California Foundation of Independent Living Centers
- Department of Developmental Services
- Disability Rights California
- People First of California
- State Council on Developmental Disabilities
- University Center for Excellence in Developmental Disabilities (UCEDD) UC Davis MIND Institute
- UCEDD UCLA Tarjan Center
- UCEDD USC

Desiree L Boykin: I learned about the South Central Los Angeles Regional Center (SCLARC) in 1998 and how it helps the developmentally



disabled community. I quickly became a part of the Self Advocacy group and went to my first People First of California and Supported Life Conference in 1998. I was able to receive more information about the Self Advocacy movement. I became President of the Self Advocacy group at SCLARC in 1999 -2003 and I was able to be a part of the Board of Directors in 2000. I served on the board three different times 2000-2003, 2006-2008, 2008-2011. I was the President of SCLARC's CAC from 2008 to 20011. I went to many self advocacy conferences to learn about different topics: the Lanterman Act, Relationships, how to take care of your health. I hold a B.A degree in Human Services from California State University Dominguez Hills (CSUDH). I've volunteered at Cedars Sinai Medical Center for three years. Then started part time as the Consumer Advocate in December 2011 and was able to move into fulltime position the following year. The person who inspired me to be a self advocate is my late maternal grandma Eloise R. Kirksey.



Cheryl Hewitt . My story about who inspired me to become a self-advocate: Actually there are two people, the first is Cathy McAdam. She was my field supervisor for my masters program during my last year of graduate school. The school initially gave me the hospital placement that was too far away from home and would cost too much for a taxi cab so I asked for a placement near to my home. The school made arrangements with the

Rehabilitation Institute for me to do an internship there and assigned Cathy as my field supervisor. The one thing unique about Cathy was she was totally blind. I would hold onto her guide dog and she would push me down the hall. Cathy was a real tough supervisor. She would make me do things over several times until she said I got it right. One time she even sent me home for not being dressed appropriately. She kept scrutinizing my paperwork until she said I got it right. One time I sat down and asked her, "Why are you being so picky?" She stated I'm being picky because I have been where you are, you have a severe disability and people are going to scrutinize you and expect you to do 110 % while they do 90 % and get away with it. I finally got what she was trying to teach me, even showing up for work during snow storms. One time during a bad snow storm only me Cathy and I showed up for work. The doctors asked us why we showed up and not any of the able bodied staff showed up. We stated we couldn't answer that question. Because of that experience I've been able to hold down employment for over 20 years. Everything Cathy taught me was valuable. She taught me to always remember where I came from and to help others achieve the same things that I have.

The next person is Christine Smick. I met Christine when I was on the Board of CIL in Detroit. She was a little person. I was always amazed at her because she was married to a man who had cerebral palsy and they successfully adopted a daughter with severe disabilities. Her attitude in life was, 'I deserve everything an abled bodied person deserves and I'm going to get it no matter what I have to do.' She was polite in her tactics but she still got what she needed. And was always sticking up for other disabled groups and teaching them how to be an advocate by pushing the

boundaries but not breaking through them. Christine taught me that I could be vocal with my concerns and to be honest and upfront with what I thought was going on. That is one thing I will always thank Christine for. These two people are no longer here but both have left a lasting impact in my life.

# Resources

#### Here are some health care resources from SSAN:



# The Road to Wellness: Accessing Medical Services and Navigating the Managed Care System

http://www.dds.ca.gov/Wellness/docs/medicaldirectorybklt.pdf How to get Medi-cal, what Medi-cal covers, what to do if you have a problem.



### Far Northern Regional Center's Live Well

www.fnrclivewell.com Internet Safety, Bed Bugs, Preventing Heat Illness, & more.



### **Guide to Healthy Living**

http://www.dds.ca.gov/ConsumerCorner/docs/GuideHealthyLiving\_English.pdf