



**Down
Syndrome
International**

Down Syndrome International news

be adapted to create a place for him by those who started the system in the first place? The administrators may have good hearts and wish to help individuals with special needs. However, if the system does not allow couples to marry like other members of the community, with the support they need, then shouldn't the system be reevaluated and reformed?

I am very thankful for exceptional laws created by State of New York (USA) for individuals with disabilities. And I am thankful for the people who work hard to make sure they are followed. However, that is their "Day Job". While we parents, who nurture our children day and night at our home realize that those laws STOP working once these consumers are back in their home with their families and wish to be nurtured by their loved ones. We parents are the one who see our children's frustrations when they are at home because the lack of their efficiency to self-advocate. The services need to hear their voices through their parents and families advocating. I believe the one who made these good laws would like them to be followed under any and all circumstances. We parents need to take that initial step to make them aware of its flaws so they can be modified to improve the traditional services.

Sujeet at the 8th World Congress on Down Syndrome, with the President of Singapore and Dr. Balbir Singh



Therefore I decided to try a new, nontraditional state (NYS) funded program called Self Determination (SD). This program involves work-

ing with a trained coordinator who prepares a "Person Centered Plan" (PCP) with the help of parents, a Medical Service Coordinator (MSC) and the "Circle of Friends". The Circle of Friends is a group of people who know both Carrie and Sujeet well and wish to take an active part in planning a safe and secure future for them. They prepare the PCP, the foundational piece for the SD program and subsequent funding. When the PCP is approved by the state, funding by the state it is assigned to the consumer rather than traditionally given to an agency. This facilitates the individual and circle of support to control where and how the money will be spent. They have to hire their own staff to provide services, such as independent living support and transportation. This allows the consumer to have the freedom to live their life the way they choose without depending on the traditional control of the agency. Although, this approach is much more work and time-consuming for the consumer, family and circle of support.

Currently, Sujeet and Carrie are working with OMRDD (Office of Mental Retardation and Developmental Disabilities) and with their SD group. They have already started attending sessions to learn their responsibilities after marriage. Many goals are prepared in these meetings by the SD group. It is hard for Sujeet and Carrie to understand these guidelines, sometimes making them confused and worried. However, they both are constantly discussing the minutes of each meeting on the phone. The Circle of Supports have many responsibilities but the love and determination Sujeet and Carrie show gives us inspiration and reason to fight for whatever is ahead of us. All we need is support from the services, the community and heavenly blessings.

No matter how BLESSED my life has been with Sujeet I could never get rid off my NIGHTMARE thinking "what about Sujeet after me???" Now he has found a partner whom he trusts, I have the chance to get over this nightmare. This is my chance to wean myself from his life and let him

live his life the way he wishes with his life partner.

Travelling around the world with Sujeet was an eye-opener for me. I was so delighted to meet in person so many incredible talented individuals with various disabilities and amazed with their passion to share their voices through their talents. At the same time, I was saddened to see the lack of support they had from the services where they lived but more so by their own parents. It was agonizing to see their own parents afraid to advocate for their children because they thought it was not possible and sometimes because they underestimated their own children. The worst thing parents can do for their children is to underestimate them.

During the last few years, Sujeet has been trying to spread his message around the world through his music and workshops. I sincerely wish that those "Special Moms" around the world hear his message and in their soul make a commitment to follow. The message is "Hiding is not the answer. Taking time to recognize your special children's hidden talents, believing in them and strongly advocating for them is the best way to work with the system. That is the way to break traditional services and pave a new path to make the marriages and any other dreams work for our children with special needs."

Our two angels Sujeet and Carrie, and also the ones you have in your home and heart, seem to have been brought together by God for a special purpose on this earth. They will be always blessed by him to change the world for the better. Although, I think he very much appreciates the help Special Moms provide to their Special Angels.

To know more about Sujeet and Carrie, visit their web sites at

www.sujeet.com and

www.specialtomato.com

See <http://webreprints.djreprints.com/1325950882002.html> for a recent article in The Wall Street Journal about Sujeet and Carrie.

Down Syndrome International news

DSI
Down
Syndrome
International

About Sujeet ...



24 year old Sujeet Desai is an accomplished musician who has Down syndrome. He plays six instruments: Bb and Bass clarinet, Alto Saxophone, Violin, Piano and drums. In June 2001, he graduated from Fayetteville-Manlius High School in NY with honours and in May 2003 he graduated from the Berkshire Hills Music Academy in Massachusetts after two-year residential Post-secondary study in Music and Human services. Emerging from the academy with higher music skills and successful experience of independent living on a college campus, Sujeet continues to do his solo performances and self-advocacy workshops.

Sujeet works in Rome, NY for self-advocacy and disability awareness a part of his job is working as teacher's aid for a music department in an elementary school and in a library helping children with books and also plays music for them as well for a local restaurant and different community places. Sujeet lives in a house with roommates to be on his own and enjoys his independent living.

On April 10, 2005, Sujeet got engaged to "Carrie Bergeron, who is also a self advocate. Currently they both are working on their future plans for their living together after the marriage.

In 1998, when Sujeet started to volunteer to provide entertainment the overwhelming response received from his audience led to his decision to make music his career. Since

March 2000 he has performed in many States, National and International conferences, annual events and is booked in advance till 2006. Sujeet is a recipient of 5 International awards for his achievements. In April 2004 Sujeet received "Honour & Pride" award in April 2004 from World Down syndrome Congress for Most Outstanding Individual with Down syndrome where self advocates from over 35 countries were nominated. Sujeet was honoured with "2004 Christin Puschel Memorial Citizen Award" by The National Down Syndrome Congress in their National conference in Minneapolis on 21 August, 2004, for outstanding achievement as a self advocate. In 2001, he received two awards from the President and Minister of Singapore. In 2000, The Council for Exceptional Children presented him with a "Yes I Can" award.

Besides music, Sujeet has a Black Belt in Tae Kwon Do. He has won gold & silver medals in the World Games '99 Special Olympics in swimming. He has won many medals in Special Olympics in alpine skiing, cross-country running and bowling. He enjoys writing emails to his fans from all over the world who visit his web site. Sujeet opened his web site in 1997 in his computer graphic class, which has been visited by over 67,000 people from around the world with rave reviews.

Sujeet says...

"I was born with DOWN SYNDROME. Therefore, I learn things slowly. I have worked very hard over 10 years to learn what I love to do to overcome limitations of my disability. I would like to be a musician but my MISSION is more than that.

People say that I have been a role model to young children around the world with disabilities, especially those born with Down syndrome either through my web page or music performances and workshops that I do to share my story. I plan to live on my own and continue to provide entertainment as well do workshops as self-advocate. I like to make my presentations especially at conference more than just an entertainment but educational as well as inspirational. So it can be an upbeat on disability issues and continue to bring hopes to individuals with disabilities, their parents, families, educators, doctors and services that work with them so they can have a better life.

My goal is continue to work to make my MISSION POSSIBLE!"



To schedule a concert, purchase his CD and know more about Sujeet's music performances and other achievements, you may visit his web site or contact him by e-mail. You can meet him on his web through his TV interviews as well listen to his music through various links.

e-mail: sdesai@twcny.rr.com

web site: www.sujeet.com.