



Friends of Children with Special Needs

華人特殊兒童之友

FCSN Dream Builders

June 2019

In This Issue:



The Advocate: Janet's Story



**Navigating the Turbulent Years
Van Hai's Story**

Laurie Chu: A Positive Transformation

Drawing on Experience with Autism to Help the Alzheimer's Patient and Caregiver

Sharing by FCSN Youth Volunteers

NBC TV coverage of Friends Coffee and Tea

Parent's Sharing



FCSN Dream Builders

June 2019



FCSN East Bay Headquarters
2300 Peralta Blvd.
Fremont, CA 94536
T : 510.739.6900
F : 510.739.6999

FCSN South Bay Center
1029 S. Bascom Ave.
San Jose, CA 95129
T : 408.725.8000
F : 408.725.8811

www.fcsn1996.org

JUNE 2019 NEWSLETTER

Editors

Wei-Jen Hsia
Johnna M. Laird
Roger Leung
Helen Chou
Cherene Wong

Reporters

Helen Chou
Johnna M. Laird

Art Editor

Helen Chou

Table of Contents

- President's Message CK Lee 3

PARENT SHARING

- The Advocate : Janet's Story Helen Chou 4
- 陪你一起小 — 阿滋海默症的震撼 葉淑芬 6
- Drawing on Experience with Autism to Help the Alzheimer's Patient and Caregiver Sufen Wu 7
- 心之絮 葉淑芬 8
- Tidbits of Thoughts Sufen Wu 9
- Laurie Chu: A Positive Transformation Alice Chu 11
- Navigating the Turbulent Years: Van Hai's Story Helen Chou 12

VOLUNTEER SHARING

- A New Generation of Computer Scientists Jason Yang 15
- Lifelong Skills in Cooking Class Emily You 16
- A New One-on-One LEGO Class Derek Shay 16
- Truly Be Yourself Karen Krause 17
- Turning Passion into Lessons for Life Chloe Chen 18
- 2018 President's Volunteer Service Award (PVSA)FCSN Recipients 19

PAST EVENTS

- FCSN Programs and Testimonials 20
- NBC TV coverage of Friends Coffee and Tea Johnna Laird 21
- 2019 FCSN Activities
 - 2019 Talent Showcase 22
 - Campbell Easter Parade 23
 - FCSN Family Day Trip 23
 - Mother's Day Lego Sale 23
 - Moonlight Coffee and Music Event 24

PRESIDENT'S MESSAGE

*F*or the past eleven months, I have had the honor of being FCSN's co-president. It's been a good opportunity for me to fully understand the FCSN operation. We can divide the FCSN operation into two portions, the family side and the business side. Since most FCSN members are familiar with the family side, I will talk a little more about the business side.

FCSN receives funding from the regional centers, allowing us to hire staff to operate our adult day program, living services, supported employment, and more. FCSN is blessed to have so many dedicated and hardworking staff members. They do an excellent job helping our children lead fruitful and meaningful lives. However, the living cost in the Bay Area is so high, and state funding is limited, so we are constantly looking for more staff. Currently we have almost 20 open positions, so please spread the word that FCSN is hiring. You can check our website, www.fcsn1996.org for more details.

FCSN has been an organization for 23 years, and when I became co-president, I found that we had needs for a technology upgrade, so we worked a lot on those aspects. We have improved and added online registration, a volunteer management system, a member database, a client management system, and more. Our team worked very hard to make these systems run efficiently, and we would love for everyone to use them. We ask that you please switch to the new systems as much as you can. Thank you.

Finally, I'd like to emphasize the importance of participation. Every month we host a coffee social, an afternoon tea social, and a parents' lunch (friendship forever). Even if you aren't able to attend our enrichment programs with your children, please consider joining us at our parents' social events once in a while because FCSN is here to serve every family member, and with your participation our children will have a brighter future.



Coffee social gathering on first Friday of every month at FCSN South Bay Center. More than 11 newcomers attend the April 5th gathering.

CK Lee

FCSN Co-President

The Advocate: Janet's Story

Jasmine was diagnosed with autism and chromosome balanced translocation. Currently 21 years old and attending post-secondary in Santa Clara County School District, Jasmine is non-verbal and uses a device to communicate. Since Janet--Jasmine's mom--retired from her job last year, the two have taken several cruises, traveling to New England, Europe, and Japan with other special needs families. While she currently leads a rewarding and leisurely life, Janet says it took hard work to reach this point. In this interview, Janet tells the story of her experiences overcoming various challenges. – Helen Chou

Challenging the School “Experts:” In Janet’s Words

When Jasmine was 3 years old, she was severely cognitively-impaired and was placed in the early intervention/ Special Day Class preschool program. Citing a lack of Jasmine’s progress after 3 years in the program, the director of special education and the ABA provider from the school district suggested discontinuation of therapies and instead recommended one-on-one care for Jasmine. This did not sit well with me. Jasmine was so young, and for them to make the judgment that she cannot learn so early on in her life was not right. So I decided to investigate myself. I told them to give me 3 months before we made any decision. Taking inspiration from my FCSN member friend, Kaili, I assembled a private team to work with Jasmine. I hired Kaili’s Applied Behavior Analysis (ABA) supervisor and a team of college students to work with Jasmine. After the team worked intensively with Jasmine for 3

months, Jasmine learned to identify colors by successfully sorting them into the correct bins according to instructions. I was able to provide data to prove to the director of special education that Jasmine could indeed learn. Through this opportunity, I not only learned to confidently advocate for Jasmine, but also formed my team which has been instrumental in teaching Jasmine beyond school hours.

School District vs County Program

Even after Jasmine made progress in learning, the public school program still was not suitable for Jasmine’s educational needs. The school district mainly worked with higher functioning kids, but kids like Jasmine whose needs were substantially different were mostly neglected. After I raised my objection and demanded that Jasmine have the right to receive a meaningful education and not just receive daycare, we were offered the Santa Clara County Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) Program. This county program which was better funded and had more resources for kids with higher needs, turned out to be a much better fit for Jasmine. Here Jasmine met an excellent teacher who was very experienced in teaching kids like Jasmine, and with the right teaching method Jasmine was able to make tremendous progress within a short period of time. Another benefit is that both school district and county program-related representatives attend Individualized Education Program (IEP) meetings. Moreover, in our experience the County Office repre-

sentatives are more willing to work with parents’ goals and are more respectful of parents’ opinions.

If your public school program is not suitable for your child, don’t be afraid to raise your concerns and request to observe different programs. There are many options, including County Programs for higher needs kids or kids with behavioral issues, private schools that cater to specific behaviors, even institutions that may address violent behaviors. Having said this, I know there are parents who want to place their kid with higher functioning kids in the hopes that they will become higher functioning themselves. My advice is to not fall for the myth. Challenging your kid at the appro-



appropriate level is good, but placing her in an environment where she doesn't understand what's going on most of the time actually deprives her of the opportunity to learn meaningfully and ultimately is detrimental to her confidence. Every kid is different, and you have to really evaluate what kind of setting, what kind of learning environment, and what kind of teaching style best fits your child.

Data is the Key

When Jasmine turned 18, it seemed that her potty training had regressed. She would not initiate that she needed to pee and would frequently wet her pants. The school nurse requested that Jasmine put on adult diapers. Not one to easily take them at their word, I asked for 60 days of data showing who took her to the bathroom, what time they went, and whether or not she did it. I told them that after 60 days if she still peed in her pants, then I would let her wear diapers. After I requested that they log the data, there were no more accidents. It turned out that she just needed the aides to routinely remind her to use the bathroom.

Best Practices

I have always chosen to work very closely with Jasmine's teachers and therapists and view them as allies with the same goal of helping her learn. I trust the teachers to teach

Jasmine during the long hours she goes to school. In return, the teachers appreciate that I make an effort to update them on her progress, discuss with them her challenges, provide input on IEP goals, and continue to teach her at home. Yet even in healthy collaborative partnerships, there are times when we have differences of opinions, and a lot of these times are during IEP meetings.

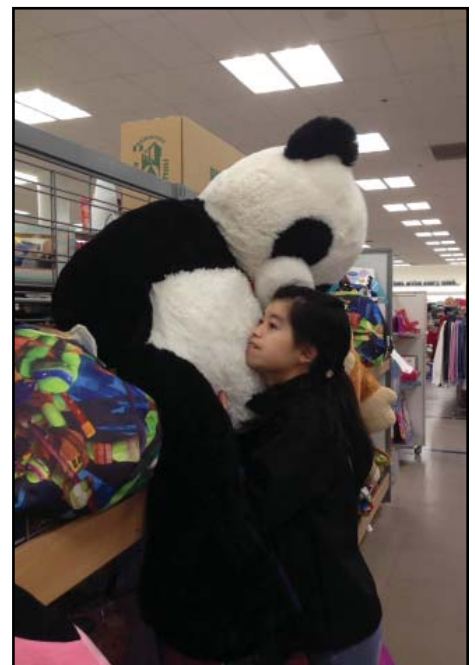
A lot of parents are weary of voicing their concerns during IEP meetings because they don't want to sound too demanding or appear confrontational for fear of reprisal. This fear is unfounded; in fact, teachers are usually glad to know what parents want for their child. As long as you remain calm and respectful of the teachers, most of them will try to work with parents' goals when resources are not an issue. When opinions differ, remember that data is your best friend. You can request data. You can provide data. And if you end up in court, data will be the determining factor.

Make sure that you send a 24-hour notice to voice record all IEP meetings. Having an audio record ensures a more professional tone is set during the meeting and holds the attendees accountable for their words. Knowing that their words may potentially be used as evidence on appeals in court, they are more mindful with their words and de-

meanor, which paves the way to a more productive, efficient, and agreeable meeting. There were a few instances where I did not voice record some meetings, and as a result of the casual and careless choice of words, the tone of the meeting became unpleasant or even accusatory. I look at voice recording the meetings as insurance for having a professional discussion.

Lastly, but most importantly, establish your network of friends. I have benefitted so much from having a group of friends I can bounce off ideas, from discussing IEP goals, potty training strategies, even travel tips. Through sharing experiences, maybe others can offer their experiences that can solve your problem, or maybe you can enlighten somebody else who is struggling with an issue you have experience with. It takes a village to raise a child; it is even more evident when you are raising a child with special needs. It is important to know that you are not alone in your struggles.

- **Request and / or provide data**
- **Audio record every IEP meeting, send 24 hours notice**
- **Establish your support network**



陪你一起小- 阿滋海默症的震撼

葉淑芬

“只是因為在人群中多看了你一眼，就不能忘掉你容顏...”

無關風花雪月，這段歌詞倒表達了我的一點心聲。

只是為了送兩個從墨西哥帶回來的樂器給阿斯海默的病人，我就這樣走入他們的世界。

那在多是中國人的阿斯海默照顧者的聚會中，我第一次和阿斯海默的家人或照顧者見面。聽了他們的敘述，我的心被牽動了！感受了他們的壓力，無助以及不知所終。

對於照顧者，那是一場無望的戰爭！病人腦子變化的原因和治療至今無解，腦，是一身的主宰，一旦神經元被侵襲，腦就會逐漸萎縮死亡，目前在醫學上還找不到有效說醫藥來治療這種...腦的黑死病。

身為特殊孩子的家長，我將心比心的分享照顧者的傷痛和絕望。我們雖然站在人生的不同點（我的孩子發生在在人生的起點，阿斯海默病人多半在生命的中後段，卻也分享了同樣的原因：腦子的病變！

站在照護者的立場，我真誠的感受他們的無奈和絕望。同時也看到在照顧過程中可能改善的地方。

聽照護者的敘述，病人不但忘記人，忘記時間，忘記生活的順序，他們同時也變得極度敏感，易怒，甚至有攻擊行為。因為忘記時間和生活秩序，他們可能晚上醒來就往外面走，阻止他們也許會引起病人發脾氣，甚至動手打人！

以照顧特殊孩子的生活經驗，我特別覺得自己有能力幫忙。建議如下：

1. 化被動為主動，主動將生活佈置成彩色的日曆！規劃好每天的行程，例如運動購物藝術等等，把日子填滿。
2. 既然記憶正在消失，何妨重新布置房間，重新播放記憶？照片，視屏皆可配合使用。
3. 預防重於治療，預設可能發生的情況而做必要措施。例如，有遊走的可能就要在門上做工夫。瓦斯電器都要重加防護。
4. 善用現代科技。為了增加主動性的對話（中國人好像比較不擅長於‘主動’），可以利用 Echo，Siri，或其他類似的devices，主動發言提醒，例如，「吃藥的時間到了！」「你今天好嗎？」「我愛你啲！」...最好能錄下自己的聲音，設不同的時間發聲，讓房子充滿人氣。
5. 強力推薦這本書：「我想念我自己」（“Still Alice”）讓你看入病人的內心和在患病晚期的思想行為。

本來以為腦雖然精密，一受創卻也可以互相補不足。例如Jill Taylor 寫的真實故事 “My Stroke of insight”（中文譯「奇蹟」）學者，她是哈佛的腦部科學家。有一天

她突然中風而失去整個左半腦的功能，當時連英文字母都不認識了，經過十年的努力，Jill重新回到原來的自己：右腦已經發揮全腦的功能。

今天卻很痛心的發現，阿茲海默的病人沒有這種能力，他們的神經元被侵襲以後只有萎縮死去....

站在照顧者的立場，我聯想到幾部從前看過的電影。

“The Note Book” 是一個美麗的愛情片。而不同於一般的電影情節的是，原來這是一個丈夫對她失智妻子說的故事，（“I read to her every day, she remembers.”）關於他們年輕時的愛情。我最難忘的是，他那罹患愛滋海默的太太總是用充滿感情的聲音，對著她再也不認識的丈夫說：「我喜歡聽你說的故事。」（“this is a good story, I have heard that before”）

另一個電影則是，Brad Pitt 演的 “The Curious Case of Benjamin Button”，Benjamin 出生時是一個滿臉皺紋的老人，隨著年齡的成長，他越來越年輕。這反向的成長造成最後的結局：他變成嬰兒，在太太的懷裏去世... 結果令人唏噓，卻也是預料中- 在接受了這樣的事實以後。

是了！接受事實！就像我們一輩子照護的特殊孩子，只因為我們接受了事實，才能一路向前走。

為人生找一個定位：如果我是照護者，我會用不同的心態，不同的方法：溫柔，冷靜，甚至保持點距離而不致情緒化，重新演繹過去的愛情。

如果不能陪他/她一起老，那就和 Benjamin 的女人一樣，陪著老伴一起變小吧！

Drawing on Experience with Autism to Help the Alzheimer's Patient and Caregiver

by Sufen Wu, FCSN Parent

For the whole weekend, I could not stop thinking of friends that I have met at the Alzheimer center when visiting to bring Magic Harps as presents.

Being new to this field, I felt the worry, the confusion, and even the despair of people at the center. Being a caregiver, I felt their concerns and the concerns of the caregivers touch my heart.

I shared the story of my son, Chiling, being autistic, another type of brain dysfunction who has become an accomplished musician. I had recorded a long audio tape of family members talking and lots of music to call his attention. It worked!

So, this is my thought to help in the caretaking of an Alzheimer patient (especially for a spouse to do in daily life based upon what I have learned

working with autism:

Similar to my making an audio tape in 1992 for my son, create a memory room at home, using all technology. Bring a patient's past in there—photos, videos, posters, favorite music... even if the patient doesn't remember, just tell a story that happens to be the story of the patient's life.

1. Make a daily schedule and follow it as much as possible. Routine in life can be very important. Hopefully the person will fall into the schedule and have some expectation.
2. Set up a strict exercise schedule to maintain physical status and health if possible.

When a spouse fell into this disease (yes, it is an illness!) DO NOT question the patient why he or she forgets again.

It will be very hard to be the caretaker. A family caretaker will likely go through feelings of sadness, denial, and anger, as well as trying very hard to pull the patient back to reality. Caretakers often try to teach the patient who used to be dear to them but now seems far away. Sometimes the attempt makes the patient withdraw more because the patient feels pressured.

Think of it this way: If you see someone has fallen into water and needs to be rescued, you have to keep your mind clear. Tangling with the person who needs rescue will only lead to both of you drowning.

In the movie *The Notebook*, a loving elderly man tells stories from the past to his wife who suffers from Alzheimer's disease. The wife does not remember the story, but she says to her forgotten husband: "I love to listen to your beautiful story!" I still remember her face full of light!

I am reminded, too, of another movie, *The Curious Case of Benjamin Button* starring Brad Pitt, where a very old man grows younger each day until he becomes a baby, dying in his wife's arms.

My point is this: since the medical field has yet to find a cure for this disease, let's make the patient HAPPY and HEALTHY in daily life.

If we cannot grow old together, let's grow young together instead.



心之絮

葉淑芬

一. 從這裡開始- 教材的聯想

沒事喜歡逛逛孩子的教育材料書店，尋找ideas.

偶然看到有”WH” questions 的教材，覺得內容太一般，不過倒可以就此發揮.

所謂的”Wh…”就是”Who”，”What”，”Where”的問題，是給特殊孩子做ABA訓練時其中的一項。

教材裡面有3組卡片，分別是「人名」，「動作」，和「地方」，教學目標是引導孩子按照3個部門造一個完整的句子，（例如：John is walking in the park）這是一個經過分析簡化的學習過程，非常適合特使孩子的語言學習。唯一的問題是還不夠貼身，我們可以利用這個概念，為自己的孩子量身打造另一套教材。

1. 人名：如果是一個小組孩子，用他們的照片代替卡片中陌生的Mary或John.
2. 動作：拍下每個孩子最愛參加的運動或室內活動.
3. 地方：找他們熟悉的地點做場景，如電影院，公園，購物區...

從熟悉的人事地開始已經是成功的一半了。一對一教學自不在話下，如果是小組教學，可以考慮做出PPT檔，置入所有的照片，讓孩子們很驕傲的說出以自己為主角的句子：

Jack is watching movie in the theater
(傑克在電影院看電影)

或

Alice is swinging in the park.
(愛麗絲在公園裡盪鞦韆)

至於要讓團體更有參與感，可以把人物情境編入歌裡：例如：

*I am Alice, yes it's me
yi-ya-yi-ya-yo
Alice's swinging in the park
yi-ya-yi-ya-yo
Push me high, push me low
High high low low, high high low low
I am Alice, yes it's me
yi-ya-yi-ya-yo*

利用現成的兒歌音樂，舊瓶裝新酒，也可以變化無窮，其樂融融。

開車時突發的靈感，送給年輕的家長們做參考。

二. 請訓練特殊孩子善用每一個手指頭

一直到現在，我才發現季齡的手指小肌肉還是沒有訓練足夠。

小學一年級，他的字寫得工整有力-真的！一如王羲之，字字比例直透紙背。只因為他是用大肌肉寫字，用整個手掌握筆，常常壓斷筆芯。為了矯正握筆法，我讓他改用細筆蕊的彈性筆，結果字變得歪斜不正，不過緊握手掌的情況好很多。

注意你的孩子是否用拇指，食指和中指握筆？如果不是，到書店買 tripod holder 的筆套。盡量訓練前三指的單獨握力，OT常用的用手指撿銅板，豆子等等都是很好的運動。

你的孩子是否仍用整個手掌拿叉子吃飯？那是因為用三個手指太辛苦，所以用五個手指，而且是掌心

向上的握叉子調羹！

季齡因為學琴，尤其是拉大小提琴，我才發現他的手指需要非常多的訓練甚至矯正。想像你在寫書法，是否需要每一隻指頭的單獨力量？請孩子的OT幫忙訓練指頭的 isolation，才能靈活運用他們，對將來彈琴做事會有很大的助力。

三. 生活的ABA

趁著溫暖的陽光帶三犬（季齡和兩隻小狗）去散步。

對特殊孩子，我無時無刻的在佈置教案。從小開始，ABA絕對不是只在教室發生的事，而是要帶入生活中，例如學了「長短」的概念，在麥當勞吃薯條時隨時拿出兩個薯條讓他辨長短，答對才可以吃。為了去除自閉症的固執性，我們從不走一樣的路線，隨時改變計劃...

那麼，走路要做什麼呢？最近常常訓練季齡打籃球，就拿個籃球一路拍吧！這一小時的散步我們做了什麼呢？

- 拍球撿球一小時
- 牽狗狗（換我拍球）隨時調整路線
- 練唱歌，說話，看風景
- 讀 lost dog 的招貼...

總覺得有些特殊孩子的家長會有些迷思，覺得把孩子送出去給別人教才有用。其實每天開車進進出出，時間都浪費在車子裡了。

相信自己，家長永遠是最好的老師！

Tidbits of Thoughts

By Sufen Wu

1. WHO, WHAT, WHERE – It started with a box game

I found a card game in a nearby educational store, a place that I stop by whenever I have time.

The game is a set of “Who, What, Where” flashcards. This is a great way to teach our kids speech and language skills. Since learning language is tough work for a special needs individual, breaking down a sentence into several elements makes the learning possible.



In this box game, there are three sets of cards, presenting the concept of “Who,” “What,” and “Where;” if you follow the rule, you will be able to put these three categories together to make a sentence like: “Johnny is swimming in the pool.”

The pictures on the card are just somebody doing something in an unfamiliar place. They do not sync with most kids with special needs.

Watching this material, I have an idea.

In a group setting, you create Powerpoint files with the students’ snapshots of themselves, doing different activities in different places. Looking at the familiar pictures, the student will be motivated to say what he or she was doing at the time. The kids get a kick out of seeing themselves in the pictures.

By using familiar pictures to practice, they put together sentences and begin to see how playing this game helps them in their communication and apply it in their daily lives.

To make the game even more fun, use familiar nursery rhymes and adapt the lyrics to fit everyday situations. Here is an adapted rhyme using “Old MacDonalD Had a Farm”

*I am Alice, yes it's me
yi-ya-yi-ya-yo
Alice's swinging in the park
yi-ya-yi-ya-yo
Push me high, push me low
(adding creative motions)
High high low low, high high low low
I am Alice, yes it's me
yi-ya-yi-ya-yo*

Kids love to hear themselves featured in a song, and they will have a blast learning the lyrics and singing the song!

This idea came when I was driving, aa example for our parents with younger children.

2. Everyday OT

When Chiling was in first grade, I was impressed with the neatness of his handwriting. Little did I know, however, that he was inappropriately using his large muscles to carry out fine motor movements. He used his entire hand to hold the pencil. No wonder he frequently broke the pencil lead! To correct this, I switched him to mechanical pencils with fine lead. It took some adjustment, but eventually he started using his fingers to write instead of his whole hand. Even though his handwriting became messier, I could tell that this was the correct way to write and would better serve him over time.

Is your child’s pencil grip correct? Check if she is using her thumb, index finger, and middle finger to support the pencil. If he or she has trouble holding the pencil correctly, the tripod pencil holder can help your child put her fingers in the correct place. Is your child using her entire hand to hold a fork? If so, it is probably because her small muscles in her fingers are not strong enough, so she compensates using her whole hand.

PARENT SHARING

Fine motor skills are very important for carrying out daily living tasks, including dressing, cooking, cleaning, and writing. Occupational Therapy exercises to improve finger isolation can be practiced with musical instruments such as piano and string instruments. This requires a lot of correcting the finger positioning on the instrument, but practice can be very beneficial for fine motor development.



3. Everyday ABA

As a parent of a special needs child, I am constantly looking for teachable moments. I firmly believe that ABA shouldn't be just in classroom settings; instead it should be incorporated into everyday life. At McDonald's the other day, Chiling and I turned eating French fries into a game. I asked Chiling to pick out a French fry that is "long" or "short" to reinforce that concept of length. The fun part is he gets to eat it if he is correct! Another sunny day, we walked our dogs in our neighborhood. I purposely avoided going on same routes to teach Chiling to be flexible. Additionally, we brought along a basketball so that Chiling can practice dribbling as we walked our dogs. When we saw a notice for "Missing Cat," we paused to read and discuss. A simple task of walking the dogs can turn into an opportunity to practice flexibility, dribbling, reading, discussion, singing a few songs, and just conserving about what we see.



Editor's Note: If you are a parent of a special needs child and you have tips to share, please consider sharing your knowledge in our next newsletter.

Contact Wei-Jen Hsia at:
hsiawj@yahoo.com

Laurie Chu: A Positive Transformation

By Alice Chu, FCSN Parent

My husband, Wilson, and I have attended several FCSN Special Needs Talent Shows and volunteer events in which our daughter, Laurie, has participated.

We have seen a progressive development and evolution in her social and interactive skills.

Through the 46 years my husband and I have raised Laurie, I have never witnessed such an exponential growth in Laurie's confidence and in her desire to interact with others. Since Laurie has been a part of FCSN, she has participated in many FCSN programs. She has been actively involved with the dance group,

the Dream Seekers, and she recently joined the newly-formed Color Guard. She works at TJ Maxx with the help of FCSN's work placement program.

Our family is deeply grateful to FCSN and the entire staff which has helped to develop many of Laurie's basic life skills that are so necessary to function in society.

Laurie is very happy living at FCSN's Fremont facility. She has many friends who include FCSN occupants, students, and staff members. As Laurie's mother, I can honestly say that I have never seen Laurie with so many friends that genuinely care about her. Every time I talk with

Laurie, she is always telling me how much she enjoys being part of the FCSN community.

I will be forever thankful to FCSN for unlocking Laurie's true potential as a member of society and will always consider FCSN as an extended part of my own family.

Thank you to everyone at FCSN for showing kindness and for welcoming Laurie plus our family into the larger FCSN family.

Sincerely,

Alice Chu



Navigating the Turbulent Years

Working at TJ Maxx's stockroom unpacking soft goods, Van Hai knows that he is one of the lucky few who has obtained employment. Indeed, when TJ Maxx offered FCSN this job opportunity, there were 28 applicants applying for only three open positions. Through rounds of interviews with his job coach, Van Hai was one of the three who got the job. For three years now, he has been going to work twice every week, each time for 3 hours. Although his job is part time, Van Hai relishes this independence. With his hard-earned wages, he is able to use his own money to pay for his favorite foods when he goes on outings.

At 31 years old, Van Hai comes across as a friendly and capable, high functioning individual; one would never have guessed that he had such challenging childhood and teenage years. This interview with Van Hai's mother, Jwu Shyan, details the challenges they faced while he was growing up. -Helen Chou

Aligning the Right Allies

Our family is a multi-generational one, consisting of three generations living under one roof. As an immigrant family, we were by no means well-off; both my husband and I had to work. My in-laws were the ones who took care of the children, and Van Hai, the second-born of our three children, was their favorite grandson. They spoiled him during those first couple of years and resisted any form of discipline that we tried to put upon him. Even after the

doctor informed us of his diagnosis, and after the teacher instructed us to impose some basic rules so that he could learn to function in a school setting, they resisted relinquishing control to me.

I got a rude, wakeup call when his speech teacher informed me, "Your child is able to talk, but he prefers not to do so. If he doesn't learn how to use his words to communicate before his teenage years, he will very likely not talk for the rest of his life." I knew that I had to find a way to help him speak, and the first step was to find the right people to help put me in control of the situation. The teachers were able to help me persuade my husband about the severity of the situation. Then I asked my sister-in-law to help me to persuade my in-laws; all I asked was for them to refrain from interfering with my attempts to teach Van Hai. It took a lot of convincing but reluctantly, they agreed and I finally was able to start teaching Van Hai myself.

Battle of Wills

At this point, Van Hai had a lot of bad behaviors. He had no manners and would not respond to verbal instructions. Any attempt to teach him would send him into a meltdown. With a stern warning from the speech pathologist, I persevered, determined to help Van Hai.

One of Van Hai's biggest motivators was food. I remember my first attempt to get him to use his words, Van Hai wanted to drink juice and

went for the fridge. I wanted him to use his words. I asked him, "What do you want?" As expected, he flew into a tantrum. I held him in my arms and sat in front of the clock. Every time he paused to take a breather, I asked him the same question. I knew that he could say it, it was just a matter of whether he was willing to use his words to get what he wanted. After 40 minutes of screaming, he finally said "juice," and I promptly gave it to him. The next time he wanted to eat, I again asked him to use his words which sent him into a rage for 15 minutes until he said "orange." The third time, he whimpered for 3 minutes and said "rice." He was getting the idea that I would not cave until he properly used his words.

With absolute discipline from school and from home in support of each



Van Hai's art work

other, we were able to slowly teach him to use his words instead of throwing tantrums. From then on, we were able to teach him basic manners, and finally be able to attend classes. With a reclaimed sense of calm and order, we decided to add a new family member. We welcomed my youngest daughter Wendy, who is seven years younger than Van Hai.

The Challenging Teenage Years

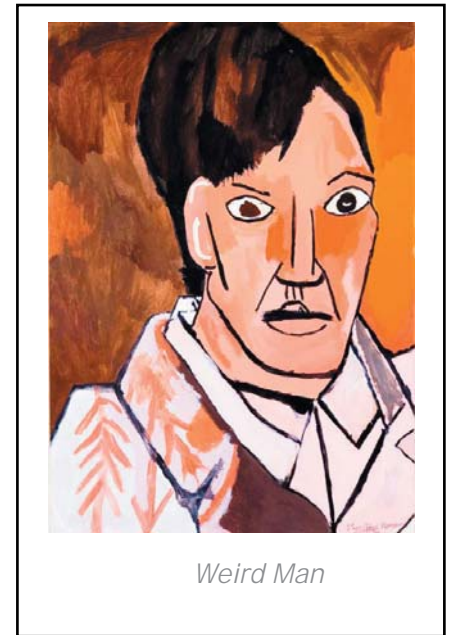
Things abruptly changed when Van Hai reached puberty. I had heard that many special needs children experience drastic physical and emotional changes during this period of time, but I was woefully unprepared for the severity of his changes: in a very short period of time, Van Hai became aggressive and violent. Seemingly without provocation, he would explode and become aggressive and the target of his outrage was unfortunately his smaller and defenseless younger sister, Wendy.

I began desperately searching for doctors to address his situation. It

turned out that Van Hai was intolerant of 36 environmental and food allergens, which sent his body into a state of extreme discomfort, causing him to snap and have violent outbursts. We immediately put him on an elimination diet, and he started receiving a regimen of oral medication as well as IgG and IgE shots to control his symptoms. We began to see results as his violent outbursts subsided. The treatment was very costly, and I was even more concerned with the frequency of the shots leaving long term negative side effects in his system. I continued to search for solutions until I came upon Brain Enhancement Program (BEP). After completing his 3-month therapy course, his systems were regulated and he needed no further treatments.

A Blessing in Disguise

During this period of time, Van Hai's life was so disrupted that he regressed in many areas. At school, he was failing in all 6 classes, which led to him being labelled "6 F" by



Van Hai's art work

bullies at school. Although I spoke to the teachers and administrators several times about the bullying, requesting that they either reprimand the bullies or transfer Van Hai to another school, they dismissed the severity of the situation and refused to do anything about it. Van Hai began to dread going to school, and the stress of being bullied eventually pushed Van Hai to the limit and caused him to hit the bully. We didn't know it at the time, but this was actually a blessing in disguise. Because of this incidence, our Regional Center Case Manager stepped in and helped us take our case directly to Sacramento for a ruling in our favor. After trying to change schools for so long, we were granted our request and in less than 2 weeks, Van Hai was transferred to Leland High, which turned out to be a much more supportive environment.



Van Hai's art work



Van Hai's art work

PARENT SHARING

Looking Back

Life is full of challenges, especially for us parents of special needs kids. It certainly felt overwhelming and lonely when I was going through the numerous, challenging situations. Now looking back, I am glad that I reached out, and through my network I was able to find allies to help me deal with the challenges, and friends who led me to solutions.

When you open up about your child's problems, you might come across somebody who has already been down that path and be able to offer you some suggestions. Most

importantly, by opening up yourself, you will come to see that you are not alone. We Asians want to “save face” and hide the unsavory facets of our lives. But for the sake of our children, “saving face” is not worth a penny! Only when you share your story will you be able to discuss the problems you face, share your burden, and find solutions that might change your child's life. You might also offer other families insight into a situation you've been through before. It is so important to have a supportive community like FCSN that can allow our families to grow up together.



Van Hai working at TJ Maxx

FCSN currently has two types of employment programs available for clients, both of which follow Regional Center's Person-Centered Planning guidelines. Clients in the Adult Day Program (ADP) participate in pre-vocational training and volunteering opportunities to learn job skills. Once employed, a shared job coach is assigned to shadow the clients whenever they go to work, providing the support and direction they need to perform the job successfully. However, it is very challenging to find an employer willing to hire four clients (to maintain instructor-client ratio) On the other hand, Supported Employment Program (SEP) benefits clients who can work more independently. Through SEP, clients receive career planning, job training, resume development, interview and soft-skills building, job search and placement. Once hired, a job coach will provide intensive job training to maximize job independence. Within six months, job coaching services will reduce to 20%, while providing ongoing support through advocacy, intervention and support.

South Bay Program Director, Vivian Chung describes her clients' motivation for working: “Our clients really want to live like people without special needs. Even more important than the money, they really treasure the pay stub they receive in an envelope. This is the token that signifies that they have a job and they get paid, and they can be just like anyone else and be productive members of their communities.”

VOLUNTEER

A New Generation of Computer Scientists

by Jason Yang

FCSN Youth Volunteer

For an hour on Saturday afternoons for the last four years, a group of FCSN youth volunteers have taught a variety of classes to satisfy student and parent needs. Some basic courses that we offer include Scratch and Animation along with more difficult classes like Java and JavaScript. Since no experience is necessary to join our beginner classes, many students are eager to participate. We try to make learning as much fun as possible by working closely with students, offering raffle prizes, throwing parties, and awarding certificates upon class completion.

Since the beginning, classes have expanded, quadrupling the number of students we attract. In spring 2019 we had more than 20 students among all classes, with a student-to-teacher ratio of 2:1. All of our teachers are properly trained and have sufficient knowledge in the subject to answer any student question or guide their actions. Our program attracts so many students due to the hardworking teaching staff that takes a lot of time to plan the curriculum. Every week, the teachers and I have a meeting to prepare for our classes. We create slides and example code to teach basic concepts, write homework questions

and answers, send class reminders and recap emails, and plan for the year-end parties.

I immensely enjoy volunteering with FCSN and working with the students. It has been so fulfilling to witness our students' progress. The computer programming classes have not only equipped them with the tools to create apps and websites, but they have also helped them develop their analytical, logical thinking, and even social skills. Moreover, these courses have given my fellow volunteer teachers and me an opportunity to spread awareness of autism to the public to develop more student leaders in our community.



VOLUNTEER

Lifelong Skills in Cooking Class

By Emily You
FCSN Youth Volunteer

I began teaching cooking classes after school this past fall at Friends of Children with Special Needs, and teaching these students has truly motivated my desire to contribute more to my community. Initially, I had reached out to FCSN because I was seeking to complete a Girl Scout Gold Award Project through participation with FCSN. After meeting with a few coordinators at FCSN regarding the types of classes and events they hold, I immediately knew this was the place to not only contribute for my Girl Scout Gold Award Project, but also to familiarize FCSN students with important, useful life skills for the future, such as cooking. I held a true passion for helping those in need and mentoring individuals; FCSN was the perfect place to start.

With 15 students in the class each week, I have familiarized myself with many faces and can call students by name to increase engagement. Over the past five months, the class has made dishes from chicken noodle soup to simple, healthy lunch items

like salads and sandwich wraps. Students learn to engage in conversation with their peers, learn to cook a new dish they may be able to cook for themselves in the future, and exhibit good etiquette/manners when sharing the completed meal. Even though students may be unable to perform certain tasks such as cutting vegetables and washing dishes on their own, they are learning the steps both to simple recipes, but also manners which they need throughout their lives. I have realized that although the students may lack other skills or are too timid to speak up, many know the answer and have

already improved in their ability to convey their thoughts. Seeing the students improving gradually motivates me to volunteer at FCSN in hopes of helping these students gain important life skills.

Through every class and each new recipe, I have learned to also become more comfortable speaking publicly in a room with volunteers and students eager to learn. Most of all, teaching cooking classes at FCSN has taught me to be a more worldly individual, one who is inspired by others to give back to the community whether it be large or small.



A New One-on-One LEGO Class

By Derek Shay
FCSN Youth Volunteer

My friend introduced me to FCSN, and I began volunteering in a one-on-one art class. In that class, I worked with students on coloring inside the lines and drawing pictures; however, after a few lessons, I discovered that the students had the potential for a

more creative and hands-on learning experience. I got permission to try something new, and I eventually started a one-on-one LEGO class, influenced by my passion for LEGOs when I was young. I was anxious, not knowing if my students would be interested in building LEGOs or whether they would find it boring, but I ventured on.

I bought three simple LEGO sets for my initial three students so that I could test the waters. After a few weeks, I realized that these students all had different skill levels and interests, so I made an individualized curriculum to address each student's needs. I then bought more LEGO sets with varying ranges of difficulty matched to each student's capabilities.

Truly Be Yourself



By Karen Krause
Special Melodies Choir
Lead Instructor

When I started working with FCSN in the seventh grade, I never could have anticipated the wonderful experiences that awaited me. Being a teacher in this community has helped me understand the difficulties that our students deal with, making it possible for me to support them in every way that I can. Through our singing and dancing classes, I hope that I am able to contribute by giving students opportunities to pursue their hobbies and interests that otherwise may not be available to them.

One of my favorite memories while volunteering at FCSN happened

during one of the vocal classes that I led. After we finished practicing the lyrics with some time to spare, I decided to have everyone create their own individual dance for the song. All of our students and teachers stood up, and as we sang together, we each performed our own unique (and weird) choreographies. In that moment, I remember looking around, delighted to see the students express their creativity with ear-to-ear smiles across their faces. After that one class, I realized how encouraging one environment can be if we enable students to passionately express themselves in their own ways. Now when I lead classes, I hope every time to inspire and encourage our students to truly be themselves and to never be afraid

of what it means to be unique and different.

Here at FCSN, I volunteer to teach students songs that they can sing and dance to. However, FCSN is more than just a volunteer program to me as I'm sure many of the other teachers and mentors can attest to as well. The skills that I've learned, the responsibilities that I've managed, and the friends that I've made are immeasurable. I know that in the future, regardless of where I am or what I am doing, I will always cherish and be grateful for the memories that I have made while at FCSN.



During class, I take notes on what each of my students accomplishes, keeping track of their progress: hand-eye coordination, visualization, concentration, and the ability to follow instructions. Through the progression of lessons, my students' cognitive and motor abilities improved faster than I expected. With every session, I see each of my student's advancement in building LEGOs. It means so much

to me every time I see their eyes light up or their faces turn into smiles when they put a piece in the right place.

Currently, my one-on-one LEGO program has more and more students joining, posing a great challenge for me to accommodate all the interest. The experience has proven to be rewarding for both the students and me.



Turning Passion into Lessons for Life

By Chloe Chen
Special Melodies Choir
Lead Instructor

When I first joined Special Melodies, a vocal choir of Friends of Children with Special Needs, I never imagined that our little group of eight students and four teachers would grow to become a family of more than 20 students and 27 teachers.

During the humble beginnings of this program, each teacher took turns to lead the vocal and dance sections of class. At first, I never thought much of the weekly one-hour classes. As I helped find new candidates to teach, our choir started to grow, and we developed new teacher roles and split classes into five separate classrooms with two, time blocks. As both a lead teacher and teacher mentor, I was responsible for managing the

overall flow and pace of the class and also guiding other lead teachers in organizing their classes.

Through experience and time, we teachers have learned key skills such as to speak cheerfully and loudly to get the most of our students. To deal with individual needs and to prevent anger or frustration, we work to interact with our students one-on-one. Our behavior and engagement are huge characteristics of our jobs as teachers. When creating movement for the dance portion of class, I tackle the challenge of creating choreography that is simple enough for students to follow along but entertaining for audience members.

As my fourth year of teaching starts, Special Melodies has become a special part of my heart. Students have opened my eyes to see their world

that is so pure and to understand the way students show compassion. I have become more aware of the community of children with diverse mental and physical capabilities and their families.

It is an honor to spread and share my passion for the performing arts to kids who are not as privileged as those that are in my school community. I feel that the title “teacher” does not really fit and serve these children since I have learned so much from them. I now appreciate how lucky I am to explore life through my students’ perspectives. Through my experience and memorable friendships with these children, I have discovered the importance of being grateful for every opportunity I receive and to see the broader picture in every moment.





The President's Volunteer Service Award (PVSA) 2018 FCSN Recipients

The President's Volunteer Service Award (PVSA) is the premier volunteer awards program, encouraging citizens to live a life of service through presidential gratitude and national recognition.

We encourage you to take a look around, be inspired and take positive action that changes the world

- ❖ Andrew Chiang (Bronze Award, Young Adults Group)
- ❖ Albert Ding (Bronze Award, Teens Group)
- ❖ Joy Kuo (Bronze Award, Young Adults Group)
- ❖ Andrew Lam (Bronze Award, Young Adults Group)
- ❖ Angus Lam (Bronze Award, Young Adults Group)
- ❖ Allison Liu (Bronze Award, Young Adults Group)
- ❖ Serena Meng (Gold Award, Teens Group)
- ❖ Edbert Wang (Bronze Award, Young Adults Group)
- ❖ Matthew Wu (Silver Award, Young Adults Group)
- ❖ Christopher Yi (Bronze Award, Young Adults Group)

Hours by Award	Bronze	Silver	Gold
Kids (5-10)	26 – 49	50 – 74	75 +
Teens (11–15)	50 – 74	75 – 99	100 +
Young Adults (16-25)	100 – 174	175 – 249	250 +

PROGRAMS

AFTERSCHOOL PROGRAM TESTIMONIALS

My son has been part of their after school program for the past two years, learning, growing, and making new friends in a safe, nurturing, and enriching space. FCSN also helps my son and his friends with job training, adult day programs, independent living, and community involvement. They also help their families with support groups, educational seminars, and fostering a sense of community.

~ Monica Arce (parent)

My daughter loves the FCSN after school program; she is all smiles each day when I pick her up. The teachers make her feel special and loved, teach her important daily living skills, and make sure she has lots of fun!

~ Carrie Cassidy, parent & educator

FCSN's after school program provides a loving, fun, and safe environment for my boys. The boys

continuously learn through their enrichment programs and also enjoy the social life there.

~ Pei Wang, parent & advocate

We are glad our daughter has been in this structured and diverse environment for the past 3 years. The staff, caregivers, and volunteers are always offering love, patience and discipline.

~ Winnie Ho, parent

Enrichment Programs : East Bay

Blue Devils Special Needs Color Guard	Wednesdays 7PM-8PM	Kelly Ko
Special Shine Chinese, Art, Zumba	Saturdays 9AM-12PM	Sally Wu
Special Shine Choir	Saturdays 1PM-2PM	Sally Wu
Ping Pong	Saturdays 10AM-12PM	Terence Chan
Young Children Social Playgroups and Integrated Playgroups	Fridays 3:30PM-4:30PM	Moon Chia
Private 1:1 Piano, Violin	Varies	Stephanie Yu
WeDo2 Lego Class (1 hour classes)	Sundays 2PM-5:30PM	Maggie Huang
East Bay Young Kids Music Class	Varies	CK Lee
Badminton Class	Varies	Sally Wu

Enrichment Programs : South Bay

Group Lego Robotics, Art, Dance	Sundays 2PM-5PM	James (lego) Joann (art), Yingmei (dance)
Art	Saturdays 2PM-4PM	Jacqueline Yu
Felt	Saturdays 2PM-4PM	Jacqueline Yu
Dance Fitness Class	Sundays 1:30PM-2:30PM	Ting Chien
Life Empowerment Program	Tuesdays 3PM-6PM	Roxana Chiu
Work Empowerment Program	Every other Saturday 4:30-6PM	Sherry Meng
Mental Math Class	Every other Sunday 10:45AM-11:45AM	Sue Lin
Private 1:1 Violin, Art, Tutoring, Math, Chinese, Singing/Dance	Varies	Chingyu Wu
QuickBooks Program	Saturdays 4:30PM-6PM	Sherry Meng

PAST EVENTS

NBC TV coverage of Friends Coffee and Tea



By Johnna Laird

Friends Coffee & Tea made the nightly television news in January when NBC Bay Area featured FCSN's coffee shop during a three-minute segment on KRON-TV Channel 4.

Executive Business Director Sylvia

Yeh was interviewed along with Friends Coffee & Tea Manager Roxana Chiu in the segment that described FCSN as a unique organization providing assistance and support.

Several FCSN clients who work at Friends Coffee & Tea, an employment training center, appeared in the segment—measuring coffee, filling up coffee filters, working at the register taking orders, emptying trash and wiping down counters.

Sylvia used her own screen time during the segment to educate about Friends of Children with Special Needs and its efforts to get

clients into the community through work and volunteer efforts, counteracting the stigma that Chinese families often feel about having children with disabilities.

“We want people to come to enjoy the delicious and unique house coffees and lattes they can't get other places. We have an array of gift items. We want people to come with their friends, not only for support, but to enjoy themselves,” Roxana told viewers in the segment.

Last summer *The San Jose Mercury News* featured Friends Coffee & Tea on its front page.



2019 TALENT SHOWCASE





FCSN partnered with the City of Campbell at the Bunnies and Bonnets Easter Parade in Downtown Campbell on Saturday, April 20. FCSN musicians performed "Twist and Shout." FCSN children, young adults, and family members joined a flash mob dance at the parade's end.

Congratulations to the 5 FCSN moms for receiving the Annual Mothers of the Loving Heart Award hosted by the Chinese Women Association. The 5 Mothers are: Joann Deng, Mary Tang, Shirley Yu, Candy Chen-Hu, and Dongmei Zhang



◀▲ Photos from FCSN family day trip on June 7, 2019.



◀▼ On April 27th and May 4th, members of the LEGO Job Training Program held a Mother's Day promotion sale of Lego products outside a Safeway supermarket. They sold 35 candy dispensers and 14 napkin holders, for a total revenue of \$1797!

Launched in the summer of 2017, this program is dedicated to providing training and environment for FCSN young adults to work independently. This program currently has 13 members from both South Bay and East Bay and meets once a week at South Bay.

Lego sale group photo (from L to R): Ansley, Charlie, Emily, Andrew, Brian, Justin, Julian, Jeffrey, Samuel, Connie, Eric and Michael.





“To Dream the Impossible Dream”

Mission Statement

FCSN’s mission is to help individuals with special needs and their families to find love, hope, respect, and support through integrated community involvement.

Families and Friends enjoyed a Moon-Light Coffee and Music event following FCSN’s South Bay Family Gathering dinner May 4th. The multipurpose room transformed into a café with candle lights, flowers, and a musical performance.

Roxana prepares café servers, our special love ones, to greet customers, take orders, and serving

FCSN workers serves the crowd, serving drinks and desserts.



Customers enjoyed music and singing performance by ChiLing, Tsai-Wei, Jennifer, and Jason South Bay Center

Shuling led everyone for a dance exercise at the end

Friends of Children with Special Needs

Headquarters: 2300 Peralta Blvd., Fremont, CA 94536 T: 510-739-6900 F: 510-739-6999

South Bay Center: 1029 S. Bascom Ave., San Jose, CA 95129 T: 408-725-8000 F: 408-725-8811

www.fcsn1996.org Email: administration@fcsn1996.org