



Making it Happen!

Stories of Self-Determination using Consolidated Supports & Services in New York State



A publication of the
Self-Advocacy Association
of New York State, Inc.

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Introduction

In every movement, in every new step we take as a society, we need heroes to lead the way. The following stories are real examples of some of the pioneers of Self-Determination in New York State. They have bravely moved outside of traditional services and developed supports based on their needs and dreams. These individuals are forging ahead, helping to evolve our system to one that provides more individualized, person-controlled services for people with developmental disabilities.

The SANYS Board is proud to present these inspiring stories.

The key elements of self-determination as defined by the Self-Advocacy Association of NYS, Inc., (SANYS) are: Freedom, Control, Authority, Support, a Portable Budget and the contribution of Self-Advocacy.

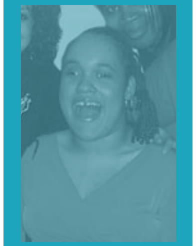
The Office of Mental Retardation and Developmental Disabilities (OMRDD), in partnership with SANYS, developed Consolidated Supports and Services (CSS) as a funding mechanism: a new way to pay for supports and services, (an alternative to the traditional agency model). CSS gives people control over whom they hire and which supports are provided to them. While CSS is not the only way people can be self-determined in New York State, it is one way that people can truly create the life they want.

At present there are 200 opportunities for people to access this service option in New York State. To take advantage of this opportunity you must be receiving, or be eligible to receive, services from OMRDD.

Each person using CSS develops a circle of support, completes a practical person-centered plan, designs a weekly schedule of supports, and creates an individual budget, which includes their personal resources as well as the cost of services being accessed.

If you are interested in finding out if self-determination can work for you, see the contact list on page 38.

For additional copies of this booklet, please call the SA office at 518-382-1454 or visit our website at sanys.org and download a PDF of the booklet.



At last: my own policies!

Veronica Johnson

Before finding out about Self-Determination using Consolidated Supports and Services (CSS), I had been trying to accomplish my dreams through the system that was already in place. However, the policies of so many agencies and organizations acted like roadblocks and setbacks in my path. I was sick and tired of hearing about what I couldn't do, or couldn't get, because of someone else's policies. Again and again, someone else was in control telling me what I should and shouldn't have, and what I did and didn't need. I thought my goals of living on my own, getting my college degree and living a meaningful life would never happen.

My dream of acquiring degrees in psychology and law hit two 'policy brick walls'. First, my home attendant agency wouldn't allow my attendant to accompany me to school to assist with note-taking and personal things that came up during the day. I thought I had solved the problem by having my grandmother accompany me to class, but then the college informed me that family members couldn't come to class unless they worked for me officially as an aide. So, because of the policies of both the agency and the school, I was forced to put off my education and any chance of seeking competitive employment.

Veronica (above) with her mother, grandmother and great-grandmother; (right) with her staff

I had also been seeking to move into my own apartment, but dealing with the policies of the home attendant agency & the local Human Resource Administration office, CASA X, made it impossible to do so. I was told that I should move into a group home, and that was not the life I had envisioned for myself.

Since beginning to plan my future through Self-Determination using CSS, many things have changed. The program has given me the chance to finally realize the dreams and goals I have always envisioned for myself.

To begin with, my Circle of Support has helped me to find my own apartment. Since the agency would still only give me 12-hour home attendant service, in the beginning my grandmother stayed overnight with me a couple of nights a week and I spent the other nights at my mother's house. Eventually, the agency gave me 24-hour service, but they had a hard time finding people to work such long shifts three days at a time.

Also, the home attendants were not allowed to accompany me to school, therapy, doctors appointments or out in the community. This was a real problem because I can't push a manual wheelchair by myself. If my motorized wheelchair breaks down, I'm stuck in the house until my mother or grandmother comes home.

Developing my plan took some time, because we had to figure out how I would be able to receive 24-hour service. My CSS budget wouldn't cover that amount of support plus the other services I required. Fortunately, my Medicaid Service Coordinator at the time, Simone Jelks, hit on the idea of transferring my home attendant service to overnight, and then hiring staff through CSS to work during the day. My approved plan now has 14-hours overnight home attendant service (from an agency that allowed me to choose my own staff through them), and 10-hour CSS staff seven days a week.

Through CSS... I feel like I'm an equal member of society who is respected and treated as a human being

Definitely one of the best part of CSS has been hiring my own staff – which I did by using funds set aside in my CSS budget for advertising. My mother and I placed ads in newspapers and on the Internet and received numerous responses. I made sure that my ad included details about the kind of personality the person needed to have in order to work with me: you can't spend ten hours a day with someone if you can't get along with them! They also had to be willing to travel with me.

Many of the people sounded great over the phone, but failed the interview. The biggest reason for not making it was that when I asked a question, instead of talking to me, they would look at my mother and respond. I felt that that was disrespectful. Others seemed like they just wanted a job and a paycheck and were not concerned with me as a person. In the end though I found great individuals to work with me, both during the day through CSS, and at night through the home attendant agency. Another issue surfaced at my college: I needed tutoring, but because of a college policy I couldn't get the help I needed through the school. So, I decided to go through CSS and hire my own tutor. In my plan, I now have a tutor who I hired & who works within my schedule.

As a person with a disability, it always seems that policies and money come first and somewhere near the bottom of the list are the disabled themselves. With CSS, I come first and the money is there to back me up. I'm using it to establish my own policy of getting what I need to succeed in life.

In the past I felt like a prisoner in my own home: a third-class citizen who is just a dollar-sign in the 'traditional' system that's in place. Now, through CSS, I have finally gained my independence and I'm pursuing my goals. At last I feel like I'm an equal member of society who is respected and treated as a human being. ~

My journey to independence

Carrie Bergeron

Before I got involved in the Self-determinationPilot Program (SD) I was in a Home Waiver program through the Resource Center for Independent Living (RCIL) in Utica, NY. My home waiver staff member worked with me two times a week, doing independent living skills. She assisted me with study and comprehension skills when I was a student at Herkimer County Community College. We also worked on household skills such as grocery shopping, money management, and cooking skills. I was able to be around people in different communities and gained confidence in my social skills.

Carrie (center) with fiance, Sujeet, and Chris, her Self-determination suppRt staff member

Then, I got engaged to a talented musician! My needs changed at that point. I would be moving to a city 55 miles away after our wedding. I decided to become involved in the SD plan to help me through this transition of moving from home soon. Basically, I wanted to be responsible and independent and, along with my Circle of Support, to control my own life. SD assisted me by having the resource money given to me, the consumer, instead of an agency. I am now, along with my Circle, in charge of hiring and firing my own support staff!

Since September I have been working with a support person, who is assisting me in becoming involved in Rome, NY where I will be living. I have been taking voice lessons, working out at the YMCA and volunteering at the Upstate Cerebral Palsy working with toddlers who have special needs. We also work on cooking skills, collecting recipes, safety skills, travel training, navigation/map skills, paperwork for my SD/CSS plan. She also takes me to a fitness center to exercise in Herkimer, NY. All this is helping me to prepare for my future!

SD also includes an element called the Circle of Support. The Circle is a group of people such as family members, friends, and co-workers, who know me well and help with my planning. The Circle is assisting me to become more responsible and independent and pointing out where I will need support when living on my own with my husband.

The Circle meets monthly to discuss my strengths and weaknesses; to think of ways of getting me involved in the Rome community, and helping me with my routines and schedules, my goals and dreams, safety inside and outside of our apartment, and working on strategies and discussing funding options for certain services. In February 2006 my fiancé and I are going to begin to have joint meetings to discuss those services we will need together as we set up our supports and living arrangements in Rome after we are married. We plan to do this through the SD/CSS program also. I am very thankful there is this pilot program which gives flexibility and lets me determine what my wishes and needs are. I was the first infant in Early Intervention in my county in 1976 and am thankful to be a part of this pilot program now!

CSS helps because the money is given directly to me, the consumer, instead of to an agency

The freedom to be spontaneous

Ed Bartz

You can't do that Ed?

How will you manage on your own?

What will happen if you need help?

Do you really think this is a good idea?

What if a fire breaks out?

These are just some of the reactions I faced when I decided to become independent of a traditional residential program.

To help someone who is unfamiliar with that kind of program understand, I'll give some background information. Over the years I have lived in many kinds of situations – many of which would be worth forgetting. However, fortunately, people with disabilities have gained so much dignity and respect that being "put away" in an institution is not even thought of anymore. In any case, most recently I lived in my own apartment and shared support staff with seven other people who needed help.

While that kind of apartment living is a step up from being in a group residence, it still has some drawbacks. The Office of Mental Retardation and Developmental Disabilities (OMRDD) regulates this type of housing. And while the Center for the Disabled does its best to cater to the wants and needs of each individual, with a limited ratio of staff to consumers, this task can be difficult. Depending on the event or activity, I sometimes need help when going out into the community. This requires a lot of planning and the consideration of staff and residents.

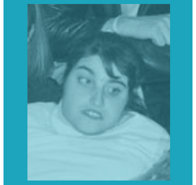
To give a comparison, let's say you plan to attend a concert. You make plans to have somebody help your ailing mother while you're at the concert, but on the day, the person you're relying on can't make it. You call other friends but they have commitments of their own. As a result, you end up not being able to go to the concert. This is what it can be like for a group of disabled folks that rely on assistance. Staff or volunteers get sick or have things going on in their own lives and that impacts you.

Since June 2005, when I began using Consolidated Supports and Services, I have been living a life of true independence. I have complete say in how money is spent to support the services I need, and I have a budget that covers every aspect of my life. I still have to deal with people calling in sick sometimes but my plans can be carried out without interruption.

This means taking on more responsibility, but the freedom to be spontaneous is irreplaceable. Though my patience was really tested while I waited for OMRDD to approve my budget (the process was painstakingly long and tedious and took over two years), it was a relatively short period of time compared to my 43-years of living with a disability. With my Circle of Support behind me I hire people to assist me in living a higher quality of life. My Circle consists of people who have known me for many years. They help me problem-solve and make crucial decisions, and my success is just as important to them as it is to me.

After much persistence and determination, I finally have control of my living environment just like everybody else does and it feels good to have a say in every aspect of my life. I need to be more organized – but I wouldn't give up my new way of life for the world. ~

It feels good to have a say in every aspect of my life



You set your goals and off you go

Alisha Tompkin's story,

told by her mother, Mary

Alisha is a beautiful young woman with a great smile. I could see early on, from the way she reacted to certain situations, that she was full of humor and extremely bright. Those who know her have often remarked that her laugh is infectious. Alisha has a brother and two sisters, and is an aunt. We, her family, have always been strong advocates for her. As a parent I have tried to teach all my children to never give up and to never stop believing in themselves.

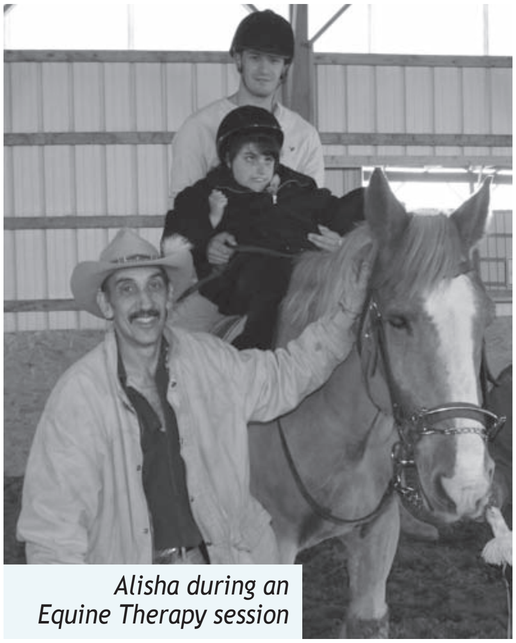
At high school Alisha had a one-on-one aid. My fears grew as the time came to transition from school to a day-habilitation program. One-to-one support was not an option with traditional services in our area. In fact, I knew Alisha would need a continued level of personal assistance and care after leaving school. Alisha had been in an inclusion progam at her school where she interacted with kids with and without disabilities. I didn't want Alisha to lose the community connections she had built-up while she was in school.

Nevertheless, after high school, Alisha began attending a day-habilitation program. We soon realized that there was a lack of communication between Alisha's service provider and us. The program was not offering the type of services she, nor we, were looking for, and it was unsafe at times. I spent a lot of time teaching the program staff how to best support my daughter only to be ignored – as if I had no idea of my daughter's capabilities! We became increasingly frustrated and decided to look for another way to meet her needs.

Through Alisha's Medicaid Service Coordinator, Janet Austin, at the Advocacy Center in Rochester, NY, we found out about Self-Determination using Consolidated Supports and Services (CSS). Janet explained to us that a Home and Community Based Services (HCBS) waiver allows for the freedom and authority to handle your own supports and services. Janet's level of care and dedication helped us take the steps we needed in order to start this process. Soon after, we began developing Alisha's Circle of Support and a Person-Centered Plan. Once her CSS plan was approved by the Office of Mental Retardation and Developmental Disabilities (OMRDD), her Circle Quickly began connecting her to services and supports that would work for her.

One of the highlights of using CSS is that the Circle members are able to budget how the money is used and to juggle resources. For example, we decided how much to spend on transportation and staff supports. We then submitted that for approval. Also, using CSS, Alisha was able to budget two weeks of respite for me during the year. This gave her the support she needed and it gave me the freedom to focus more time on my business. This in turn helped us as a family. There is great peace of mind that comes with using CSS. It's wonderful to know that Alisha has the support necessary to be totally safe.

Alisha and her Circle are responsible for hiring, training and firing staff. With help from her Circle, Alisha interviews and hires staff members (one of whom is her sibling!) who



Alisha during an Equine Therapy session

all go through training with LDA, our Fiscal Intermediary (FI). The FI's role is to pay the bills as described by the approved plan and budget. So, LDA pays the staff and provides all the necessary paperwork, making them only the *employer of record*. The *managing employer* is Alisha and her Circle. LDA is the 'middle-man' between Alisha's budget and the federal government. Alisha and her Circle maintain the authority over her services. Also, we had been dealing with an old, unreliable van. Using CSS, Alisha leased a new van, which she uses to go to and from activities. Aside from reliable transportation she is building credit because the lease and insurance are in her name.

CSS is a new program and there were some kinks to work out. We worked closely with Elaine Peckham, our Developmental Disabilities Services Office (DDSO) Self-Determination Liaison, whose care, sincerity and dedication were a real asset. We felt comfortable going to her when issues came up and her follow-though and 'stick-to-it-ness' were remarkable. Also, instead of using a Start-Up Broker, my sister and I worked on Alisha's CSS budget. Janet Austin, Alisha's Medicaid Service Coordinator, was also instrumental in this process.

> *It's a challenge to take on the work that traditional agencies have long offered... but the effort has helped improve Alisha's life in so many ways!*

Now, Alisha's days are filled attending workshops that interest her and allow her to pursue therapeutic and rehabilitative skill-building. One of her activities is Equine Therapy (horseback riding) twice a week. At a recent physical, the doctor noted the positive change in her muscle tone and her increased range of motion, which he attributes to this therapy. Alisha also goes to the Cobblestone Music and Art Center four days a week where she has a part in a production of *Grease*, as one of the pink ladies. This is so great because music and dance have always been a part of her life.

CSS has given us hope again: during preschool Alisha used a limited vocabulary, then as a result of being segregated, lost her ability to speak. Now, slowly, she's starting to use a few words in an attempt to use her speech again. This has reignited the hopes and dreams we have for her independence.

It's a challenge to take on the work that traditional agencies have long offered people with disabilities, but the effort has helped improve Alisha's life in so many ways! We have become great advocates for CSS and make frequent presentations to groups on how Alisha's life has changed for the better. Everyone deserves quality of life: this program goes a long way to making that happen.

We don't waste time looking back at what didn't work – we focus on what lies ahead. Once you've experienced true self-determination, you set your goals and off you go! I know Alisha wouldn't have it any other way. Thank you to all involved for creating CSS, which has enhanced Alisha's quality of life. ~

Directions

Deborah Jean Anderson

I'm 55 years of age, but a kid at heart! I was born in 1949 to wonderful parents who taught me to make my own decisions – right or wrong. Over the years I've had plenty of opportunities to make choices that have affected my life.

For fifteen years, I was involved in a day program and lived in a group home. I was so bored and wasn't provided with ways to keep my mind stimulated. For example, writing has always been the love of my life and I would have given anything to volunteer my services to the editor of the agency's newsletter.

I hated living in this facility and resented living under the rules and regulations of New York State. There was little or no privacy or independence, and the residents were always concerned about voicing our opinions to staff because if we did so our lives would have been made even more unbearable than they already were. Living with nine other residents was challenging: for example, at mealtimes I often had to listen to petty quarrelling between other residents. Another time I was frustrated when the house supervisor made me go to my day program five times a week instead of letting me stay home one day to do homework or read a favorite book. Sometimes, I would have to sit in vain hoping that someone would give me a helping hand with my meal (before I could eat, I needed assistance preparing the food and ensuring the spoon was in the apparatus that I used to feed myself).

I really didn't have a life of my own, yet I was afraid to change my life for the better.

In 1994 I went in to the hospital for neck fusion surgery, and during my recovery I thought about how I wanted to spend the rest of my life. I had many conversations with my Lord about my future. I wanted to be free from all the demands of agencies and yearned to do something worthwhile. I loved the idea of training seasoned and new employees about disability awareness. I wanted to make a difference to trainees and consumers, and be as productive as I could. I needed a lot of physical therapy after my surgery and began to receive residential-habilitation services (commonly known as res-hab) from a not-for-profit agency. However, the staff there did not meet my physical or emotional needs. Again, I felt as if I was required to live by the State's standards and not my own – that rules and regulations were preventing me from becoming the person I felt I was inside.

I began to hunt for a different agency. A friend told me about the Finger Lakes Developmental Disabilities Services Office (DDSO). It was there that my life took on a whole new meaning. For the first time, I began sitting on committees for the DDSO such as the Rights Committee and the Developmental Disabilities Education Network known as DDEN. I remember when an employer came to ask me to sit on this Committee. I was elated: at last 'me as a person' mattered more than my disability; finally people needed me and valued my opinion. I remained on cloud nine for several months after that! Eventually I was hired by Finger Lakes DDSO to do sensitivity training for new hires, just as I'd hoped.

Consolidated Support and Services (CSS) gives individuals the kind of lives they so desperately desire by allocating Medicaid dollars to provide the supports they need to live their ambitions. My goal has always been to write my memoirs and when the Self-Determination Pilot Project came along, I thought that my dream might come true.

My Circle of Support consists of family, friends, and folks who are important to me. They provide the emotional and physical support I need in order to help me realize my goals – like having my book sold around the world.

CSS gives individuals the kind of lives they so desperately desire

At the beginning of the process, I had to submit a Person-Centered Plan to the State. Roughly five weeks after my plan was submitted the State requested a more comprehensive plan, so for the next month my Circle and I met weekly to make the necessary revisions, deletions, and additions. When we submitted the plan a second time, the State wanted us to make even more corrections. Once more, we revised it and returned it.

Several months passed. I felt that nothing we said would be good enough. My faith in CSS began to wane: this was supposed to be the beginning of my new life. Family and friends told me to hang in there and I decided to follow their advice. After all, what did I have to lose?

When my proposal was finally accepted, we celebrated at our next circle meeting – my service coordinator, Carolyn, brought pink ginger ale with bubbles! We met with the Fiscal Intermediary about placing an ad in our local paper for an assistant. I read nearly thirty resumes and eventually hired my current assistant, Patricia, who is super. I'd be lost without her. She proofreads and edits the chapters of my book.

Thanks to this opportunity I'm living my vision, though I never could have accomplished what I have without the support and encouragement of my family and my friends. Without them, my dream wouldn't be a reality – and I love living this dream!

You do it

Patrick Wilcox

Ever since high school my dream was to become a history professor. It was a big dream, but I am now on my way to attaining this life-long goal. I first learned of the Self-Determination Pilot Project from my Service Coordinator at Livingston Wyoming ARC in Mt. Morris, NY. She realized that I needed more help if I were to ever reach my dream of becoming a teacher. A phone call to the Self-Determination Liaison at Finger Lakes Developmental Disabilities Services Office (DDSO) brought about an initial meeting, after which my family and I hired a Start-Up Broker to assist with putting together a Consolidated Supports and Services (CSS) plan.

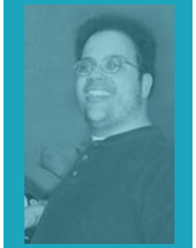
The Start-Up Broker helped set in motion Person-Centered Planning and soon the predominant theme that emerged was the importance of my educational goals. The Start-Up Broker worked with me, my Circle of Support, and my Service Coordinator, to design a CSS plan. There were many revisions, and it took a lot of hard work, but eventually a plan came together and was officially approved.

I feel very self-fulfilled

Since I am receiving assistance from VESID (which is helping to pay for my college tuition and some of my transportation costs), we decided to use CSS to help with the services and supports that were not being covered by VESID. For example, we decided to use CSS resources to lease a wheelchair-modified van to help me get to my college classes. (This turned out to be a smart decision since my original, rickety old wheel-chair van broke down beyond repair just days before my CSS plan was presented!).

Today I am attending SUNY Brockport and I have the help of staff that assist me with refining my skills at home. I am able to purchase respite care from a respite provider so my family can receive a much-needed break from the demands I make on them.

My Circle members and I would tell you that getting started with CSS is hard work: hard because you have to learn to think for yourself and do things yourself. When describing CSS, the words "you do it" come to mind. But I am doing it, and I feel very self-fulfilled. I love the personal direction and control that CSS and self-determination have given me. I have had the chance to recognize my dreams and go after them. ~



A different set of rules

Peter Franczyk

I really like the Self Determination Pilot Project using Consolidated Supports and Services (CSS). It gives me a chance to have a real say in how I live my life. It took me two years to get my CSS plan off of the ground but all the preparation was worth it. I had help from a real supportive Circle of Support: my mom, my two aunts, my service coordinator and people from the Western New York Developmental Disabilities Services Office (DDSO).

The process involved setting up and getting approval for my CSS grant. It also involved lots of interviews with prospective landlords to find a suitable apartment – it was really important to me that I could have a four-legged friend living with me!

My CSS plan called for living on my own instead of in a congregate care system. People who aren't disabled can choose who to live with. I love to go out in to the community and get to know people, but I was tired of having to live with strangers. It's great that I no longer have to follow an institution's rules and can instead go by the contract I have with my own landlord.

I also set up a contract with an agency so that they hire the staff that I, myself, interview. Now, when I need a new staff person, I'm in charge of selecting them. I have night blindness and I wouldn't be able to go places at night without the help of my staff. They take me out in the evenings and help me out in my apartment as well.

I am now also involved in another program at the Starlight art studios in Buffalo. I go there every weekday and take classes in printing, painting, drawing and so on. When I sell my work, I get to keep half the proceeds, and the other half goes back in to the program to buy art supplies. I make paintings, drawings and some clay pieces.

One of the best things about living on my own is that I got to choose my own very special roommate: my cat Guinevere, also known as Jenny. She's black and white. When I moved into my apartment, she did too!

> *...it was really important for me that I could have a four-legged friend living with me!*

I free - I fly!

Merle Keller's story,

told by his sister, Caroline White

Merle with Support Broker Pathy Levia

Merle and I began exploring the Self-Determination (SD) Pilot Project using Consolidated Supports and Services (CSS) in late 1999 after being referred the program by Stacey Bickett from ARC Otsego. This was spurred in part by my desire to ensure that Merle would be able to continue to live independently and work in the community as he had done all his life – even when there might not be any family members to assist him. Merle was accepted in to the SD/CSS program after an interview with a board of review at the Binghamton Office of Mental Retardation and Developmental Disabilities (OMRDD). The original Pilot Project only accepted 100 people and Merle was one of them.

Thinking that using CSS was but a short step away, I immediately found a realtor to find a home for Merle. In September 2000, a three-family home was purchased, and Merle – with staff hired by Delaware Opportunities – began to live there, along with the other tenants.

In actuality, it took about 5-years for New York State to pass the CSS legislation, and so while waiting we developed an ISP (still part of SD but at that time funded by Medicaid). Once the CSS legislation passed in 2004 we, together with Jay Coloney of Delaware Opportunities, began to form a CSS plan we felt would work for Merle. At this time, Merle and I also met with several people from OMRDD about his plan. Merle told me he was excited and happy, and we embarked on a journey to have the best possible plan written for him.

Merle and I had several meetings with Judy Pease, an acting Start-Up Broker, in person and then by phone, since I live in Florida. Merle and I discussed what kind of life he would like to have and what kind of staff he would need. We also worked with Merle's extensive Circle of Support, consisting of over 30 people all of whom participate at various levels. Most of them met at different times with the Start-Up Broker too.

We considered the various activities that Merle wanted to do, like join the YMCA, attend sports and musical events, volunteer work, church, employment and other things that would promote continued involvement in the community. Merle gave input and I presented other ideas he might want to try and the social activities he had done in the past. Circle members also gave their opinions. All the informal discussions we had had with family and friends over the course of Merle's life, together with the Circle meetings and current research, contributed to the write-up of Merle's plan. We also found a permanent Support Broker in Pathy Levia, as well.

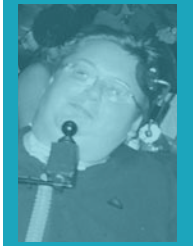
We had some technical meetings with the SD Committee, and after several revisions, finally presented a finished plan. Once the plan was accepted, we learned it would begin in January 2005 and we began to figure out what CSS would pay for. The Fiscal Intermediary (FI) and Pathy worked together to get all the contracts in place and the staff trained so that they could begin working for Merle. Pathy also works with me to ensure that everything is being taken care of – as I consider myself to be Merle's biggest advocate.

> ***Using CSS, Merle has... his own plan rather than an agency's 'one-plan-fits-all'***

The Support Broker is almost like a mini-agency: she takes care of scheduling, community events, volunteer work, and the reimbursement of expenses. She also ensures that the staff is being paid and is receiving the required training, and that Merle's goals are worked on daily. Merle and Pathy sit together every week to talk about what Merle likes and what works for him. They also produce a weekly schedule that best fits his needs and they select staff that he would like to work with. Merle has the freedom to make his own choices and the opportunity to work on different skills.

Merle likes his plan now and so do I. He has staff available to him whenever his schedule requires it, and they assist with his various activities which include art class, OCEC (classes for reading, math and computers), volunteer work, YMCA, sports events and some shows. In the summer, Merle likes to go to baseball games, to walk, and to go to the Farmer's Market downtown to buy fresh produce to help maintain a healthy diet. He also walks in the Pit Run (a charitable fund raiser for the benefit of community programs in Oneonta) and walks for other good causes too. He takes trips to nearby towns like Cooperstown, and enjoys the parks and the mall. Merle has friends in the community who always are willing to lend a hand and take Merle out with them.

I am happy that Merle is receiving the best support and service possible after many difficult times in the past with agencies. Using CSS, Merle has been able to design his own plan rather than conform to an agency's 'one-plan-fits-all' residential program. Merle says he is happy, that he likes his staff, and enjoys his current job as a dishwasher at a restaurant. He is finally living a life that he enjoys and is employing his own staff. Merle's family, friends and Circle of Support are proud and happy of his success. On many occasions Merle can be heard to say "I free, I fly"!



Open to all possibilities

Dennis Pullen

When I was seven years old I was struck by a car. It was an accident that left me quadriplegic and dependent on a ventilator. I felt confined to a life that I hated and I knew there was much more.

Before the Self-Determination Pilot Project, I was living with my parents, sisters, nieces and nephew and spent most of my time in my bedroom. I saw friends just three or four times a year, though we talked on the phone whenever possible. If I was lucky enough to leave the house it was usually only once a week. Sometimes, if the weather permitted, I would be taken out for a walk.

This activity level left me feeling trapped and I didn't see a future for myself. My parents, who had done a great job being my main caregivers for 17 years, were getting burned out with the extra stress of having custody of my nieces and nephew. But I was afraid of the unknown – of trying to make changes to my life or moving forward with Consolidated Supports and Services (CSS). This all left me very depressed.

The things I liked about my life were getting out on Fridays, reading books, watching TV and movies, seeing friends and spending time with my nieces and nephew. I also enjoyed volunteering at an elementary school, and when I was younger I worked summers at a youth program and looked forward to that all year.

Things that I didn't like were not being involved in family activities, inconsistent nursing care, and not being able to make my own decisions. I couldn't make my own choices about the food I ate, the money I spent, when I could leave the house, or my daily schedule.

My Medicaid Service Coordinator, Deb Bojarski, began working with me in October 2002, and the following June she introduced me to CSS. I had always dreamed of living my own life, and with my friend, nurse and mentor, Kelly Woolson, I had spoken often of my independence. Still, I just didn't believe that it could be done for someone like me. Deb, and my nurses Kelly, Trina, and Pam, were the only people who said they believed in me and that I could have a productive life.

With their support things began to move rather quickly. First, Deb organized the four of them – plus an occasional friend – into my Circle of Support. My very supportive landlord, Aaron Cass, who was found by ARISE, would be added later. My family was not involved in any of the CSS process.

Then, with my Circle of Support in place, we began developing my Person-Centered Plan, or PCP. We outlined my likes, dislikes, strengths and weaknesses in all aspects of my life. Each Circle member took an active role in helping me achieve some short-term goals. These goals might have seemed pretty simple to most people, but for a person with special needs who had spent most of his life in his bedroom, they would prove to be a real challenge. I had to compress 17 years of development into about twelve months, and learn to address problems and be responsible for all aspects of my life.

Budgeting was, and still is, a difficult part of CSS for me. I had never had to deal with bills, money or learning the value of a dollar. The idea of paying to lease a van, buy gas, get a cell phone and other necessities, seemed out of reach, but my Circle of Support really helped me. To this day I am continuing to learn about daily, weekly, monthly and yearly budgets, but I now manage my own money (including bank accounts), pay my own bills, and have become my own payee on my SSI check.

I spend my days doing what I choose and want to do. Without being involved in the Self-Determination CSS program I would probably just have let life happen to me as I did for the last 16 years. ~

Without being involved in CSS... I would probably have just let life happen to me

Managing my office – managing my life

Mandy Shenkman

When I was a child, my favorite game was ‘playing office’. In our basement playroom, I made a table into a desk. I had a play typewriter, a make-believe telephone and lots of paper and pens. I loved shopping trips to Staples and my best birthday gifts came from that store. My family bought me files, folders, rubber stamps and desk organizers. For Chanukah I always wanted calendars and planners for the new year. When I went to high school, I got a computer and my bedroom became my new office space. I had a real metal file cabinet.

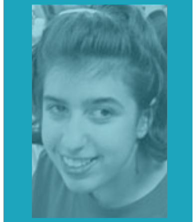
The career goal on my high school Transition Plan was ‘office manager.’ The director of my supported work agency asked me, “How many words a minute can you type?” I said, “One,” and she told me that I would never be able to work in an office. Fortunately, my parents did not accept that and insisted that I be given lots of work experience in different types of offices. After graduating high school, I was hired for a real office job and I have been an office worker since 1996. I am not the office manager, but being part of the Self-Determination (SD) Pilot Project has allowed me to reach the goal of office manager in another way: I manage all the office work needed for my Consolidated Supports and Services (CSS) plan.

I used the money I’d saved in my vacation account to buy a machine that faxes, copies, scans and prints, and with money from my CSS budget, I hired a computer teacher, Rich, who helps me make charts and lists for my hospital volunteer work, as well as for my office job. He is also teaching me how to scan and e-mail the CSS Service Documentation to my Fiscal Intermediary, Alan. Each month, I send Alan the documents he needs. I also keep a log of my expenses, such as the fee for my writing class at a local college. Then I make sure that Alan reimburses me for the correct amount. My grandma and great-aunt were bookkeepers and now I am following in their footsteps.

As my own office manager I sometimes create flyers for my Circle of Support meetings. I also attend SD workshops to learn as much as I can about the work I must do for my CSS budget. I brought my briefcase with me to the SD conference because, for me, it was a business trip.

It’s good to be the boss!

Linda, my service coordinator – the best in the world! – helps me place ads for life coaches. She and I do the interviewing, I do the hiring and scheduling. My life coaches have become important members of my Circle of Support and my Circle members are like office co-workers. I have never had to fire anyone yet, but if I am not happy with one of them I will have to say, “You’re fired!” It’s good to be the boss!



Citizens of our society

Nicole Hastings

I want to tell you about my decision to pursue Self-Determination using Consolidated Supports and Services (CSS).

When I was nine my mother sent me to a camp for young adults and individuals with disabilities. While there I met my best friend and number one fan, Mike Becher (my hero!). He helped me realize that, despite what educators and the world seemed to think about people with disabilities, we can be citizens of our society and make important contributions. With this realization in hand, I exceeded everyone's expectations and completed my education, even though many people said I couldn't.

After graduation I entered a day-hab 'without walls' program and began volunteering with AmeriCorps. I soon realized that the this program was not meeting my needs and goals and went to my Medicaid Service Coordinator to ask for a program that would work for me. She introduced me to CSS.

> *I got my van... and moved into my very own apartment*

During the planning stages, I decided my ultimate goal was to live independently. I wanted supports and services to allow me to lead a productive and independent life. At first, my family and friends felt that living alone wouldn't be feasible – that I didn't yet have the skills necessary to be successful. So my Circle of Support decided I should move in with my grandmother to learn the life skills I would need in order to live on my own. We also realized that I needed a van that was wheelchair-accessible so that I could use a power wheelchair and be more independent.

By January 2005, I was confident I had gained the necessary skills and I started to look for an apartment. I'm proud to say that in March 2005 I got my van, 'the Tweety mobile,' and two days later I moved into my very own apartment. Throughout this whole process my family has provided 'technical' support, and Mike has been my emotional support.

I hope my story will help inspire you to follow your dream. You never know: one day, when you're least expecting it, you're very own number one fan – like Mike is to me – might show up to cheer you on. ~

My schedule works around me

Steve Fleisher

I began my new life in September 2004. That was the month that I left group homes and agency-run day services forever and became part of the Self-Determination Pilot Project.

I lived in three group homes and one two-person apartment It was hard and definitely not for me. There were many rules and restrictions, like frequent fire drills, that I did not like or agree with. I already knew how to get out in case of a fire because I did many fire drills in my lifetime!

In one of the group homes, they always cooked fried food. That can make you really fat! In the other group homes, they had menus that came from the main office of the agency, without asking the guys what they wanted to eat. Guys should have choices in their home. I started Weight Watchers but the staff did not know how to help me. The manager bought me Weight Watcher's frozen dinners, but said it was too hard for the staff to learn about counting points, so my parents helped me bring my own food, and taught me how to write down my points. I called my mom a lot for help! I had to bring "lock bags" for the refrigerator and freezer so that no one took my food or threw it out. It was ridiculous.

I did not have freedom to come and go to the activities of my choice.. I did not like doing activities with some of the guys because they sometimes got out of control and it embarrassed me. Sometimes I got nervous, and so I refused to go to the outings the house planned.. Then no one could go, and they got angry at me.

When there were things I wanted to do, other guys always had to come with me. I couldn't play on my baseball team unless someone was able to take me, there was a car available, and other guys were willing to come along for a ride. I worried about it all week. Finally, my parents took me to my practices and games. When I went to my personal appointments, I had to lock the passenger car doors, or one of the other guys would get into the car..

When there was not enough staff, you were stuck in the house. In one of the group homes, two of the guys needed one-on-one support,, leaving one staff for the remaining four guys. Once, all day long they promised to take me to 7-11, but they kept needing to help the other guys. Finally I said, this is ridiculous and went by myself. Next thing I knew, they had called the cops because I was out alone. I just wanted to buy a newspaper and soda!

Sometimes some guys would get out of control, and damage the walls, scream or yell. Sometimes I yelled back at them, but it only made things worse. I know they couldn't help it, but it drove me nuts.

My day services were called "Opportunities Without Walls". It was just me, with one worker, and we were supposed to do stuff in the community. That was the good part. Here is the bad part...it was only from 10am to 3pm. That made it very hard to get anything done.. I love to travel into Manhattan by train, but by the time I would get there, I would have to turn right around. I wanted a job, but nobody hires someone for just those hours.

Group homes and agency programs might work for some people, but I was determined to live on my own and have my own life. Then my parents heard about Self-determination using Consolidated Supports and Services (CSS). At that time, there were no Start-up Brokers. Now you can pay someone to help you get started. But I was very lucky because I had a great Circle of Support who helped me get everything going.

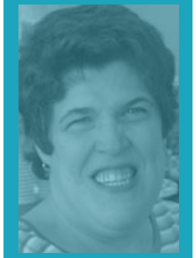
CSS really works for me. I live alone in my own apartment and, with the help of my parents, hire... staff to assist me

There are many reasons CSS works for me. I live alone in my own apartment, with support staff always there to help me. I hire and supervise my own staff, with the help of my parents. . In a group home, my activities had to work around the staff's schedule, but with CSS, the staff's schedule works around my activities. I can go on my personal appointments alone, make my own schedule, organize how to get to my baseball games, get my own job and work the hours I want to work. I can go to Manhattan --or anywhere else --whenever I want without having to get permission from an agency. Last Labor Day, I got to do something I always wanted to do: I volunteered and answered phones at the Labor Day Telethon. I can choose to do activities with other people who have disabilities, or people without disabilities.

I am now part of the New York State Self-Determination Speakers Bureau, where I speak to agencies, classrooms and colleges about self-determination. This is a paid position, and I don't have set hours, which is great.

I am really interested in law enforcement. I really wish I could be an undercover cop in the street crime unit in a law enforcement agency. Maybe some day I could get involved in something like that. I would also like to increase my time spent advocating for people with disabilities, and advance my career doing that. With CSS, it is possible.

Now I have a real life!



Make a change

Kim Henchen

Have you ever done something for a long time and then realized that you wanted to make a change? Did this change happen overnight or did it take a while? I was in a situation like that and I'm really happy that I made the change in my life that I'd hoped to.

I attended the CP Rochester Center for 18 years. I learned a lot of great things and really enjoyed working with the staff there. While I was at the Center, I worked as a member of AmeriCorps and discovered that public speaking was the thing I really like to do. When my term with AmeriCorps was up, day habilitation supported me in volunteering for AmeriCorps two days a week. (Actually, I wish that I could have volunteered everyday!)

During this period, I learned about the Self-Determination Pilot Project and three years ago I started working on my own Consolidated Supports and Services (CSS) plan. It costs Medicaid so much money to allow me to attend a program like the CP Center. Instead, CSS means being able to work with Medicaid on how I want that money to be used: on how to spend my time and what services I want to receive.

With the help and support of my Service Coordinator, some friends and my mother, we came up with a plan for me to get my own van and a personal assistant. This was a long process, but on January 20, 2005, we found out that my plan was approved.

I got the van first. I had to go through the steps of signing the lease and getting the insurance. My van has a ramp that allows me to get in and out, and I sit right up next to the driver. Having my own vehicle makes me feel as free as a butterfly because I can go everywhere in my electric wheelchair and be totally independent.

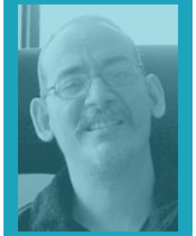
The next step was to find a personal assistant. LDA Learning and Lifetime Services is the Fiscal Intermediary (FI) for this project: this means that they help me pay my bills and manage my money. The head of human resources there assisted me in putting an ad in the paper for a personal assistant. At the same time, I sent an email to my family and friends telling them about my great CSS news and one of my friends, Marie, wrote back to say that she was interested in the personal assistant job. She used to work with me at the CP Rochester Center and was familiar with the type of help I needed. I set up an interview with her and was pleased with the results – so I hired her.

Marie comes everyday: she helps me with my volunteer work, accompanies me to the Self-Advocacy office, and makes sure I get to all of my presentations. I have been busy doing children's presentations and some staff trainings at the Developmental Disabilities Service Office (DDSO). Marie and I work really well together and I am very happy.

I also have money for a residential habiltator and respite staff and am in the process of hiring someone for both positions. The respite staff will stay with me when my mother wants to go out occasionally.

I miss everyone at the Center but I get to see them on the days that I have therapy. Having my own transportation, and having Marie as my assistant, makes me feel so independent. I love the things that I am doing now. Making changes can be scary and can take time – but I found out that the CSS process is worth everything!

Having my own vehicle makes me feel as free as a butterfly



Freedom to be myself

Scott Wing

After I got out of school I spent a year at home before attending a series of day-habs. At the first day-hab, we did some things in the community, but I wasn't happy there. When they tried to make me ride with a transportation service that was unsafe and dirty, I left.

The next place was part of a nursing home where most of the residents were older people. We did not go out in to the community. We watched movies that the staff picked out for us. Eventually I found a way to spend the majority of my day with the nursing home residents who had no visitors. When the administration discovered that I was checking out other day-habs in the area I was asked to leave.

At the third day-hab, we spent a lot of time walking the malls and once in a while we went bowling. However, I became good friends with the director of the facility and he knew I wasn't happy in that setting. When the Self-Determination Pilot Program using Consolidated Supports and Services (CSS) first came along he did the paperwork and submitted my name. He didn't say anything to me about it because he didn't want me to be disappointed if I wasn't picked.

Shortly after submitting my name, the director was offered a job with a different organization and asked me if I wanted to come along and attend that day-hab instead. I did. However, just before we left I found out that I had been selected for CSS.

I started to put my Circle of Support together. It's a small but powerful group which consists of my mother, my service coordinator, some friends and my personal assistant. We had numerous meetings, including many with the people from Central New York Developmental Disabilities Services Office (CNYDDSO). With the help of TLC (a medical transportation service) we did a lot of research into transportation costs. It became clear that it would be less expensive to actually buy a van than to lease one or rely on a service. So, with the help of my Circle I was able to actually purchase a van of my own. I also hired a personal assistant who helps me throughout the day: he drives me everywhere I need to go (for example, I go for therapy (OT, PT, and Aquatic) three times a week); fixes my lunch; takes notes at meetings and helps me get ready for Aquatic therapy sessions.

After joining CSS, I became an AmeriCorps member for two years. After that, I worked for two years at the CNYDDSO as an Advocacy Specialist. Since leaving there I have stayed very busy in the community. I do new-hire trainings at the CNYDDSO and I am involved in numerous volunteer activities for Enable. For example, I worked on their capital campaign and put together a PowerPoint presentation for them to use for their new-hire orientations. I am on their community development committee, and have also visited various doctors' offices to deliver information about Enable and the services they provide.

In addition to all that, I serve on advocacy committees at Enable and the CNYDDSO, and am on a public transportation committee that advocates for people with disabilities. I am a past board member for the Human Policy Center and I also advocate for people who have no one else to advocate for them. I volunteer at Upstate Medical University Hospital, too.

In May 2005, I was invited to go to Albany to receive an award from Senator DeFrancisco for my advocacy work.

With my new-found freedom I am much more independent. I no longer have to go to a day-hab facility. In fact, through the New York State "Home of Your Own" program I have been able to buy my own house.

Without CSS, I would still be a very unhappy person attending day-hab. CSS has given me the freedom to be myself, to do the things that I enjoy, and to give back to my community.

CSS has given me the freedom to be myself, to do the things that I enjoy, and to give back to the community

Turning points & challenges

Cathy Van Laar

Cathy and support staff

I was born with soft bone disease and I use a motorized wheelchair to get around. I have four siblings, one brother and three sisters, and I am the only one with a disability. I was born in 1963 and growing up, I did not have an opportunity to go to public school. The only education I received was from a tutor for one hour a day – obviously not a very good education. Finally, a social worker researched and found the Long Acres School for the disabled and I was accepted there at the age of 16.

This was the turning point in my life: I had friends, I met people for the first time who were disabled like me, I traveled on a school bus, I dated, and I was part of the real world. After a few years, I mainstreamed into the public school system and I graduated when I was 21 years old. I then went to a sheltered workshop, and, after that, a day habilitation program where I learned to be more independent. I became a volunteer at the Long Island State Veterans Home and I joined AmeriCorps. This was the starting point for my career path. I was educating the community about disabled individuals.

Most importantly, I'm becoming more confident and independent

As a public speaker with AmeriCorps for two years, I had an opportunity to bring awareness about disabled individuals to the public. This was a very positive experience for me. After the program ended, I felt very strongly about continuing: I feel people need to know we are just like everyone else.

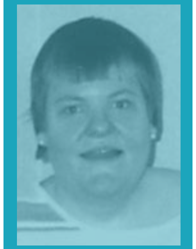
In my pursuit to be a speaker, I contacted Marisol Getchius, an advocate from a Suffolk County agency. We discussed my goals in life and she gave me an application to become part of the Self-Determination Pilot Project using Consolidated Supports and Services (CSS). Here I am five years later well on my way to fulfilling my dream.

Getting started in CSS required me and my Service Coordinator, Joe Boardman, to write up a plan for the future and what I hoped to achieve in life. After we researched grants and how to set up a small business, I was more determined than ever to succeed. Integral to this process was the involvement of VESID, the Developmental Disabilities Services Office (DDSO), and Professor Edward Fritz, the Director of the Small Business Development Center at Stony Brook. I formed my Circle of Support made up of people whom I chose to assist me in achieving my goals, and we worked together to set up a budget, and to determine staffing needs, job descriptions and salaries. We meet every two months to review progress, research and brainstorm new business ideas, and to make adjustments as needed.

I interviewed and hired my own staff, (a personal aide, Service Broker, and Employment Support person) and, with help of the DDSO, an agency was hired to be my Fiscal Intermediary to handle finances and business expenses.

I'm thankful each day that I'm involved with CSS. My learning is on-going and, most importantly, I'm becoming more confident and independent. I accept any challenge that comes my way. I encourage others to follow the same path I have chosen and to always work toward fulfilling their dreams.

Cathy Van Laar passed away in 2005. She was passionately committed to the idea of Self-Determination and her story is published here to honor her memory.



One exciting mountaintop high!

Jenn Seybert

My first and foremost love is being able to reach out to help others, and the door that allows me to do that opened on July 18, 1995. That was when I was evaluated for Facilitated Communication and my silence was broken forever. From that day forward, I have been able to demonstrate my capabilities and intelligence.

The ability to type on my computer and have my thoughts read for all to hear; to have my Person-Centered Planner clarify those thoughts using colored markers on paper; to sit with my Circle of Support and share dreams that have been a part of me for so very long; to have my Circle brainstorm on how to make my dreams a reality – that is one exciting, mountaintop high!

My life was not always this promising. I grew up in Pennsylvania and spent my school years in self-contained classrooms for the retarded. We were taken out for specials such as art, adaptive physical education and music – and on good days we joined the rest of the school for programs in the gym. The best time of the day was taking the lunch count to the cafeteria and notes to the office. I was never included in an academic setting and what I learned I gleaned from home and TV.

After I aged-out of the school system, I spent three days a week in a sheltered workshop where I put paint sets together and wires in a bag. The other two days were spent in a day program that taught me life skills: I learned to make a bed – over and over and over again; I identified a penny, nickel, dime, and quarter, month in and month out; I matched colored teddy bears to colored cards and I colored pictures torn out of a coloring book; I can make toast with my eyes closed. Need I go on? The program aides were very kind and caring: it was the program that was the problem.

All this time I knew I could communicate but had no way to express it. I kept watching other people and seeing how productive they could be in society once given the chance, and my frustration raged within me.

Then July 18, 1995 came. I was now free! It took a year of getting used to being able to share my thoughts. It also took a while for me to trust. However, at some point, my mentor who was helping me develop my typing skills, felt I was ready for help on another level – that is was time to choose an agency to help me plan my future.

I actually had a Circle of Support and a Self-Determination piece in place, long before Pennsylvania provided funding. Rosa McAllister's agency, Networks for Training and Development, supported me in Pennsylvania since my county MH/MR (the PA equivalent of OMRDD in NYS), did not have the experience or the knowledge that Networks had. Besides reaching out to others through keynote addresses, I gave trainings and workshops for the Pennsylvania state-wide Office of Mental Retardation and Developmental Disabilities (OMRDD). Topics included Autism, Facilitated Communication, Self-Advocacy and Self-Determination.

Because I never got to experience any academics in my high school years, I wanted to go to college. I love learning and am hungry for knowledge. My Circle met many times as we figured out how to make this happen. I chose Penn State and became a matriculated student there after building my courses semester by semester. By the time my father accepted a new position in central New York, I had earned 33 credits and transferred them to LeMoyne College.

I was the first in PA to access Self-Determination funding, and when we moved to central New York I had to begin the process again and locate those who were working in that project. New York was just beginning with the concept of Self-Determination using Consolidated Supports and Services (CSS). I was the first applicant and it took 18-months for me to receive funding. I also needed to form another Circle but did not yet know many people in the area. My new Circle is still evolving as it changes with people moving in and out of my life.

It's great to watch folks with disabilities discover they have choices... they can decide what they want their lives to look like

My CSS dollars go towards hiring Bridge-Builders to link me to the different communities we visit, such as museums, theater-arts, or other community events. I use the YMCA for therapeutic swimming. I also have a Start-up Broker who is helpful and creative, thorough and hardworking.

On May 21, 2006, I will graduate from LeMoyne College with a BA in Psychology and I am a member of the National Honor Society for Psychology majors, (Psi Chi). Soon I will need my Circle of Support more than ever to help with decisions I need to make about my future: furthering my education by going onto graduate school, taking a paid internship, or looking for employment in the area of counseling. My life is wide open. With my Circle around me I will have guidance to sort through my options, and help with hiring the support staff I'll need.

Folks with disabilities are sometimes seen as society's throw-a-ways. It's great to watch folks with disabilities discover they have choices; that by using their voices they can decide what they want their lives to look like. It's exciting to observe and wonderful to experience personally. Self-determination using CSS is a blessing.

Give people a chance

Joey Perez

My interest in the Self-Determination Pilot Project began when I was past-president of the Self-Advocacy Association of New York State, and attended a training session. At that time I lived in a group home where I had little choice and was not growing as a person. The only way for me to go out to a movie was if it was a group decision. I was attending a day-hab and I didn't like it. I answered phones and worked in a store, and also got different therapies.

Consolidated Supports and Services (CSS) sounded like a good idea for me because I wanted the chance to direct my services myself, the way I wanted them. First, I put together my Circle of Support consisting of friends and staff. I also hired a Start-Up Broker to assist my Circle with turning my ideas into a plan. From there we developed a staffing schedule and started to recruit my staff – one person to work with me during the day and another as a backup. By advertising under 'business' (instead of under 'human services') I managed to hire someone with the skills necessary to help me develop my own consulting business.

Now, I bring issues and problems to my Circle members and they offer advice and suggest different options. Ultimately, I decide on what to do. I direct my therapy schedule, and I visit a local gym as part of my CSS budget and plan. If I can't make my appointment, I call and reschedule - it's up to me to deal with it.

> ***We need to be teaching other people that we can manage our lives and be part of society***

They didn't think I was going to use CSS but I really shocked them! With CSS I have the support I need to work on my presentation skills and develop my business as a disability awareness educator for companies.

You have to give people a chance to work on their goals. We need to be teaching other people that we can manage our lives and are part of society – even if we need support to do what we want. All my peers need a chance to figure out a plan and try this. We'll show all the agencies we can do it! I hope all the agencies get on board with Self-Determination using CSS.

Move on to a better life

Larry Sutliff

I have been in a wheelchair for 43-years and I've lived in group-homes for a long time. I spent fourteen years in Rome and often felt like nobody wanted to take care of me. From there I went to the O.D. Heck Center where I felt very comfortable. The people who took care of me, and the programs I attended, were good. While there, I was a student at Maywood High School in Schenectady. After that, I went to a group-home in Cairo and attended Hudson High School from 1980-82. I enjoyed those years. That was followed by 18 years at Van Rensselaer Boulevard, yet another group home.

For the most part, at the group homes, there were lots of personality clashes and the staff was no better than OK. Due to company policy or institutional rules you couldn't say or do anything. You had to abide by what they told you to do – they even told you what time to go to bed! I couldn't deal with that anymore.

I have total choice over what I do...
It's nothing like how I used to live

Now, as part of using Consolidated Supports and Services (CSS), I live in my own apartment with my roommate, and that's a good thing! I have total choice over what I do. I cook when I can: the stovetops are really high, but I can work around that. I love cooking! I love my staff, and the people in my Circle of Support really care about me and support me in my day-to-day decisions.

It's nothing like how I used to live. Self-advocacy helped me speak up for myself and move on to a better life. People did not think I could do what I do now. With the help of CSS I proved them wrong! Yeah, I sure did! ~

A picture of who I am

Clint Perrin

I was born with a developmental disability - the result of a car accident my mother had while pregnant. I grew up in Brewster, NY, attended public schools, went to an ARC workshop and had a job in a supermarket. I lived with my parents, then in a supported apartment, and then in my own apartment.

I've been involved in Self-Advocacy (SA) since 1993, through the Office of Mental Retardation and Developmental Disabilities (OMRDD) and through the Self-Advocacy Association of NYS (SANYS). I was SANYS board president, an SA/AmeriCorps member, and eventually I moved to Schenectady to work for SANYS.

I learned about Self-Determination in 1997 when I was SANYS president. Some colleagues attended a national conference on SD and we then wrote up a proposal for SD in NYS. We presented our ideas to Commissioner Maul and he said 'let's do it'.

In 2004, working at SANYS, I helped develop the New Options Institute, a training program for Start-Up Brokers. During the training, we developed a Person-Centered Plan for my life. It was a dynamic process: I really liked that by reading it you could get a picture of who I am.

I knew CSS could provide for my needs

I thought it would be hard for an agency to provide flexible enough supports to cope with my Plan. I decided to use Consolidated Supports and Services (CSS) because I knew it could provide for my needs. In Schenectady I had a new Service Coordinator who didn't know me well, so I found a Start-Up Broker to help complete the CSS application and organize a budget and weekly schedule. She really helped move the process along. Through CSS I hired someone to help with managing my finances, maintaining my apartment and building connections in the community.

To get support at work I had to re-connect in Schenectady with Vocational and Educational Supports for Individuals with Developmental Disabilities (VESID) which provides funding for employment supports. This was long process and postponed my CSS approval, but in the end it turned out well because VESID funds a job coach as part of my CSS plan. I also formed my Circle of Support which is different from traditional agencies because it consists of people who have known you your entire life. There are both family and friends from Brewster, and friends and co-workers from Albany, in my Circle.

My hope for the future is that I am able to continue my work with policy and advocacy issues, and maybe own my own home with my partner. ~

Some words of gratitude

Thanks so much to the people who have told their stories in this booklet. We believe they will inspire many others to speak up for themselves and create the life they want through self-determination and other individual supports.

Thanks also to the wonderful staff, volunteers and supporters of SA who have worked with great dedication to help develop self-determination as an option in New York State.

In addition, much appreciation goes to our partners at OMRDD. A number of years ago we spoke to Commissioner Maul and asked him to help us create opportunities for people to take charge of their lives. These stories are examples of some people who are doing just that. We are proud of the work we have done with the staff of OMRDD, creating this self-directed option of support. We are committed to continuing our work by improving the process and spreading the news throughout NY about the opportunities for self-determination.

Finally, we want to express our gratitude to the Developmental Disabilities Planning Council (DDPC) for providing the funding for our work on self-determination, which includes the printing of this book. In addition to funding support, DDPC members and their great staff have provided much assistance and encouragement throughout the process of creating opportunities for self-determination.

The Board of the Self-Advocacy Association
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