

Self-Direction in New York

A Practical Guide for Families

The New York Self-Determination Coalition is an ad hoc group of parents and professionals dedicated to promoting self-determination as an option for persons with developmental disabilities who require support through NYS OPWDD's HCBS Waiver.

Introduction

PLEASE STOP! DO NOT GO ON until you read this brief introduction or sparks will fly and your computer will disintegrate!

Who is this Guide for?

The Guide is primarily for families who have been approved to start the CSS process for their child with developmental disabilities. If all of this is new to you, see “Frequently Asked Questions about CSS,” “Steps to Transition to a Self-Determined Life,” and our films at www.nyseld.org first.

Why did we write it?

When our children started using CSS, each of us were faced with situations we didn’t have the information or skills to deal with. For answers we turned to each other, to compare notes and puzzle out solutions. We’ve compiled this information into the resource we wish we’d had when we began.

Our intention

We’re acutely aware of the individuality and uniqueness of every person and every family, and have tried not to be prescriptive, or underestimate the deep knowledge parents have of their children.

Notes

CSS is usually available starting in the late teenage years. For convenience, we use “child” to mean your son or daughter, regardless of age. When we refer to “your plan” we mean your son or daughter’s plan.

Want to make copies and distribute this guide? Great! Please make sure it’s attributed to New York Self-Determination Coalition, and send an email to tell us what you’re doing.

The information that follows reflects the real life experiences of families of people with disabilities in New York State and is not meant to be exhaustive or official.

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The Basics

What is self-determination?

- Self-determination is a basic human and civil right for all, involving real choice and control.
- People of all ages have the right to rich experiences, learning opportunities, and freely given relationships.
- Individuals with disabilities should run their own lives and control their own money, services, and supports with assistance.
- Self-determination must include economic justice, including a living wage.

Adapted from the National Leadership Summit on Self-Determination

A self-determined individual with developmental disabilities, with support:

- Has the ability and opportunity to make choices and decisions;
- Has the ability and opportunity to exercise control over services, supports, and other assistance;
- Has the authority to control resources and obtain needed services;
- Has the opportunity to participate in and contribute to their communities;
- Has the support, including financial, to advocate, develop leadership skills, become trained as a self-advocate, and participate in coalitions and policy-making.

Adapted from “What is Self-Determination” by National Gateway to Self-Determination

Self-Determination is a Civil Right

In the 1999 Olmstead decision, the US Supreme court ruled that services to persons with disabilities must be provided “in the most integrated setting possible.” The ruling helped move Medicaid funding away from institutions and traditional models by requiring states to fund services in communities. Numerous “Olmstead suits” around the country every year continue to compel states to make it possible for people with all types of disabilities to participate in all aspects of community life

The Basics

What are self-directed services?

Self-directed services offer people with developmental disabilities budget and employer authority. **Budget authority** means that available funds are managed purely for the benefit of the individual; either by themselves or with the help of their family, broker, Medicaid Service Coordinator (MSC) and anyone else they choose. **Employer authority** means that the individual, with assistance, has the power to hire, schedule, train, and fire people who work with them. You may also hear *self-directed services* referred to as *participant-directed services*.

What is CSS (Consolidated Supports and Services)?

CSS is New York State's current self-determination program. It is funded by federal and state Medicaid funds, and administered through New York State Office for Persons with Developmental Disabilities (NYS OPWDD).

CSS requires:

- A Medicaid Service Coordinator (MSC) to provide oversight and ensure the person's health and safety
- A Start-up broker to write and submit the CSS plan
- Fiscal Management Service (FMS) to process staff applications, submit documentation of services to OPWDD, and handle payroll.
- Circle of Support who come together to help a person accomplish their personal goal

For further information, see the NY Self-Determination website, www.nysselfd.org and NYS OPWDD, at www.opwdd.ny.gov

Getting Started

(This is just a brief summary. If you have not yet applied for OPWDD services, see the OPWDD website, www.opwdd.ny.gov and the NY Self-Determination Coalition's "Steps to Transition" at www.nysselfd.org.)

The first step is to apply through the "Front Door," OPWDD's entry point for new services. Before using CSS Your child must be determined "eligible" for OPWDD HCBS Waiver services.

Has your family decided to use CSS?

The first step is to speak to the CSS liaison at your DDRO. The liaison will contact you when you are able to begin the process. Your next step is to choose a start-up **broker**.

Getting Started

Choosing Your Broker

What does a broker do?

The broker's role is to:

- Help the person develop a circle of support
- Facilitate the person-centered planning process
- Help the person develop a complete and appropriate individualized plan and budget for services.
- Provide training and support to help the person gain the skills and competencies he/she needs to:
 - Hire and supervise staff,
 - Document services
 - Complete other specific tasks related to:
 - Get the supports and services he/she wants in order to:
 - Direct his/her own lifestyle, services and supports
 - Establish and maintain relationships with family, friends, and others
 - Live in the home of his/her choice
 - Fully participate in the community

From NYS OPWDD

There are two roles for brokers: start-up and support. The **start-up broker** will generally guide person-centered planning, write and submit your plan, negotiate the details of your plan and budget with the local CSS liaison and shepherd it through until your launch (start of plan). The **support broker** (who may be the same person, it's up to you and the broker to decide)) will continue to support the individual's plan.

How is the broker funded?

The start up broker is funded by OPWDD from NYS money. However, payment for the support broker comes out of the CSS Plan/Budget. It's important to think about and discuss with the support broker the number of hours they should be funded for. This will depend on the level of support needed. For example, if you want them to help you interview direct support staff, they will need more hours than if you want them available for circle meetings only. Another consideration is whether you are planning significant changes to your child's plan over the next year, for example, moving to an apartment. This would require the broker to write and negotiate an amendment to the CSS Plan/Budget, and require more time.

How do you find a broker?

When funding is available for your plan, your CSS liaison will give you a list of brokers in your area. You can also look online at: www.opwdd.ny.gov/opwdd_services_supports/supports_for_independent_and_family_living/consolidated_supports_and_services/broker_listings.

A great way to find a broker is to get a recommendation from the family of someone already using CSS. Just remember, different people respond to different styles. It's a good idea to interview two or three brokers.

Getting Started

Choosing Your Broker

Qualities to look for in a Start-Up Broker

- Someone you feel comfortable speaking to and who understands your priorities.
- Someone knowledgeable. They don't need to know the answer to every question you ask, but should be willing to find the information you need and get back to you in a timely manner.
- Someone willing to help the individual, family, and Circle of Support think about all domains of life: education, work, social opportunities, recreation, and wellness. Maybe people start the person-centered planning process thinking they will only get support for work, but realize that CSS may open many doors for them.

Beware a broker who tries to pressure you into hiring them. Statements like, "I know the system so well, I can get your plan approved sooner," or "My agency has connections and your plan will have more money if you use me," are coercive and misleading.

Suggested questions to ask a prospective broker:

- How many plans have you written?
- How do you guide the process of person-centered planning?
- Can you tell me a problem you solved creatively?
- If I need to contact you, how quickly can I expect you to respond?
- May I have some references from families you have worked with?

Getting Started

Person-Centered Planning

What is the purpose of person-centered planning?

- To assist the person in gaining control over their own life
- To increase opportunities for participation in the community
- To recognize individual desires, interests, and dreams
- Through team effort, develop a plan to turn dreams into reality
- To look at an individual in a different way

Adapted from "Person-Centered Planning," Pacer Center

Person-centered planning is critical to creating a satisfying life. One of the barriers to person-centered planning is people who have minimal experience outside of school and the traditional developmental disability system are often unable to identify how they want to spend their time. They have not been exposed to a wide variety of opportunities and are unaware of their options. It takes time to understand what activities and settings are right for the individual. Like many young people, people with developmental disabilities often need to "try on" various jobs, volunteer positions, recreational activities, and social opportunities for them to have authentic choice.

Here is an example of **authentic choice**: You are ordering ice cream and are asked if you want vanilla or chocolate. You may like vanilla best, so that is what you order. But no one has ever given you a taste of butter pecan, so how would you know it's your favorite? It's not a choice if you (or those close to you) don't have the information and experience to consider all realistic options.

Karen

Karen wants to be on the Olympic ice-skating team but she doesn't know how to ice skate. Her Circle works with Karen to understand what skating at the Olympics means to her. A member of the team who ice skates arranges for her to collect tickets at the rink and take skating lessons.

In her new position, Karen is surrounded by people who love the sport as much as she does. She gets to enjoy watching people twirling in fancy skating outfits. Karen is learning to skate, has a real job, and is becoming part of her local ice skating community.

Sara

Sara wants to be a professional singer. Her family always encouraged her musical interests. When her CSS plan first launched, her circle was able to recruit a graduate student studying voice to serve as direct staff support. That support staffer moved on, and was able to recommend another voice student for the job.

Sara gets to regularly practice her vocal skills and has performed at nursing homes and preschools. She has joined a vocal group with other people using CSS that meets regularly to sing and perform – She's even recorded her own CD.

Mike

Mike loves history and thrives when he gets to share his expertise. His mom spoke to their county legislator who suggested Mike might like to work at the Cradle of Aviation Museum. The museum has a docent-training program where everyone is taught to use the same script.

This position lets Mike share the history he enjoys, where the "official" polo shirt, and be a part of the team. The program is structured so there is always another docent present and Mike's job coach can accompany him.

Getting Started

Person-Centered Planning

Person-Centered Planning IS:

- An open and on-going exploration of what is important and meaningful to the person
- A frank discussion of necessary supports and safety concerns
- A practical discussion of how day-to-day life can reflect an individual's preferences and desires
- A process to be approached with an open mind, creativity, and without arbitrary assumptions

Person-Centered Planning IS NOT:

- A brief meeting between the broker and the parent to fill out a form
- A process in which the end is already known and you're just "going through the motions"
- A paper to file away in a drawer
- A one-time thing
- A new way to decide which day program to enroll in
- An internet Questionnaire

2. **Parent/Guardian.** The parent or guardian is not a required member of the circle. They are typically included, but their inclusion is at the discretion of the CSS participant. That being said, the guardian (or parent is the CSS participant is a child) may override the circle's decisions.
3. **Start-Up Broker (required)**
4. **Medicaid Service Coordinator (required)**
5. **Extended Family (aunt, uncle, or cousin)**
6. **School teachers, teaching assistants, coaches, counselors, club leaders**
For those transitioning from high school, much of the team may consist of school staff. However, it is helpful to also invite people who know your child from other settings to the meeting.
7. **Close Neighbor or family friend**
8. **Behavior consultant or other therapist.** A behavior specialist can be especially helpful in envisioning necessary supports.
9. **A parent who has been through the process with their own child**
10. **Community member who knows your child: clergyman, scout leader, coach, or business person**

Who participates in the initial person-centered planning meeting?

1. **The teen or adult whose plan is being developed (required)** Some teens or young adults can participate for the whole meeting, some may stay for parts and be excused when necessary, and some will say, "Hi," and walk into another room. It's important to design the location, time, and seating (even the refreshments) of the meeting with the individual in mind. Often a person cannot clearly speak about their dreams, plans, or fears. That does not mean they cannot use self-directed services like CSS. Michael Wehmeyer describes a self-determined person as being the "causal agent" in their life. In other words, all decisions made about their life are for their benefit.

Adapted from "Essential Characteristics of Self-Determined Behavior of Individuals with Mental Retardation"

Who facilitates the meeting?

The start-up broker usually facilitates the meeting, but if you prefer someone else take the lead, that's fine. Choose a facilitator who has the following attributes:

- Works well with others
- Flexible and open-minded, doesn't make assumptions
- Person-centered and skilled at keep the focus of the meeting on the person
- Skilled listener with the ability to interpret behavior as communication
- Skilled at checking in with person to see if they are being understood
- Consistent and experienced with follow-through

Adapted from PCP Planning Guide, Missouri Department of Health, Feb 2010

Getting Started

Person-Centered Planning

What should you expect from person-centered planning?

1. **For you and your child/adult child to be treated with respect and feel you are being heard.** Many of us, veterans of numerous “team meetings” have felt a great sense of relief at our first person-centered planning session. Suddenly, everyone has the same goal: what’s best for your child. You don’t feel manipulated or that someone is trying to fit your child into a box.
2. **An open exploration of what is important and meaningful to the person,** with a practical discussion of how their day-to-day life can reflect their preferences. People should be comfortable sharing their dreams without fearing they’ll be labeled “unrealistic” and rejected.
3. **A frank discussion of necessary supports and health and safety concerns.** Depending on the individual and the needs to be discussed, you may want to have this part of the conversation when your child is not around. (See page 11 for more information.)
4. **A clear path forward.** Although most initial plans can be written after several meetings, you should not expect to have your child’s complete schedule settled the day after you officially launch your CSS plan. A full slate of activities can take time to think of, develop, and try-out, and there will likely be empty spaces in their schedule at first.

Bear in mind: It is common for planned activities not to work out. That’s ok, because the individualization and flexibility of CSS gives people the freedom to fail at something without their whole schedule coming apart. A lost job is an opportunity to: visit places to develop a better idea of where you might want to work, practice reading help-wanted ads, update your resume, apply for jobs, and work with a job developer. CSS lets you do all of this without the bureaucratic red tape or staffing changes.

What does my child want?

The hardest work of person-centered planning can be to dig down to understand what the individual is trying to express. For example, John, who graduated with an IEP diploma, announces he wants to be a doctor. The mission of the team is to figure out what being a doctor means to John.

Is it helping people feel better? Is it working in a hospital, doctor’s office, or nursing home? Is it to wear a white coat or other uniform? Is it to be able to tell people what to do?

Would his desire be fulfilled by transporting people in a nursing home? Delivering newspapers to patients in a hospital? Working in a lab? Volunteering with a local EMT unit?

Are you your child’s legal guardian?

There’s a philosophical disconnect between guardianship (legal control over all major aspects of your child’s life) and self-determination, but reality is more nuanced; if you aren’t healthy and safe, nothing else works very well. People under guardianship can have choice and authority over their everyday life through self-directed services, but still have supervision and protection. Each family has to resolve these issues for themselves.

There are several types of guardianship; Speak to your MSC or see Center on Accessible Living (www.rcal.org/services/guardianship-and-your-child) to start the conversation.

Getting Started

Person-Centered Planning

Risk

Taking into account and managing risk is part of parenting. Each of us has been doing this since our children were born. Every decision requires an assessment of the environment, of the child's ability to cope, and the chance of something potentially dangerous occurring. There are no right or wrong answers, just what makes sense for each person in a given situation.

Back up

For people that require 24/7 support, is there a back up plan for when staff aren't available? When CSS was first offered in New York State, people who required 24/7 support were excluded. That is no longer the case. It's always important to arrange for back up, but it is critical for people who cannot be left alone.

There are two kinds of back up plans needed: **Planned** and **Emergency**.

Planned back up for vacations or personal time is easier to manage. Finding **emergency back up** can be one of the chief barriers to using CSS. Theoretically, the circle of support should be able to provide back up. Usually, it's the parent (read: Mom), if they are available.. However, many people work and we are all going to age. We need to push the stem to help us develop sustainable solutions to meet the needs of everyone who wants to self-direct their services.

Here are a few ideas. Of course, anyone paid through CSS must go through the FMS hiring process first.

- Does your child have a friend using CSS? Will their schedule let their staff person double up for the day?
- Is there a local community center of Y where your child is well known and could attend an existing program or "help out" during the day?
- Do you, your broker, or other members of your Circle of Support know someone who can be available to fill in when necessary? For this to work, it's important for your child to already know the support person and for the support person to have some insight into your child's support needs.
- Is there someone who has done childcare for you over the years? They may not be an ideal person for regular work, but might be great to fill in.
- Is there a neighbor who gets along well with your child who might like to fill in occasionally?
- Can you use technologies to provide "virtual" support? VueZone is a remote video monitoring system (similar to a nanny cam) that lets you view your home via smartphone app. You can include funding in your CSS budget for technology to keep your child safe.
- Are you concerned your child could get lost or wander off? An example of an emergency resource is Project R.E.A.C.H., a Nassau County Police department program which allows you to register anyone who might wander off and not be able to get home. Call 516-573-5775,

Getting Started

Circle of Support

What is the role of the Circle of Support?

OPWDD seems to be using the words “Circle of Support” broadly, but there are specific requirements for the Circle of Support in CSS.

Your MSC must participate in every circle meeting, and should be in the room unless it is absolutely not possible. The support broker is not a required member of the COS, however they can, and usually are, invited to join.

The Circle meets regularly during the CSS Plan development, and at least quarterly once the plan has been approved.

The Circle of Support helps by:

- Generating ideas
- Developing strategies
- Creatively solving problems
- Developing community opportunities
- Training staff, and most importantly;
- Keeping the focus on the person

Developing your Circle of Support is an ongoing process.

Circles all look different; they vary tremendously in size, composition, and level of involvement, but here’s the dirty secret: despite rhetoric about community support, most circles consist of the family and the staff who support the person.

It can be difficult for families to ask others to join a group to help their child. Sometimes it helps to have the broker or a friend invite someone to join the Circle.

It’s easiest to start a circle of support as part of the transition process, while you child is still in school. A teacher, paraprofessional, guidance counselor, behavior consultant, coach, or club leader can all be a helpful member. You can invite anyone who knows your child and values them as a person.

The initial person-centered planning team usually becomes the circle of support. It’s common for people to come and go; they need to know it’s not a lifetime commitment.

What do you do all day, anyway?

What is Community?

People often talk about “community” as if it’s just the area where you live, but on a deeper level, it’s about belonging: to a bowling team, volunteer fire department, customers who get coffee every morning at a local shop, the PTA, supporters of a local sports team, those who attend morning religious services, or volunteers who work in the community garden.

On a practical level, we’ve found that just being “out in the community” (at a park or the mall) doesn’t foster belonging. There needs to be some type of interaction, or even better, contribution. This can be as simple as being a customer at the pizza place every week, ushering at a community theatre performance, or regularly setting up refreshments after a meeting.

Social Inclusion

In the world of developmental disability, the elephant in the room is social inclusion. Some families feel strongly that they don’t want their child to participate in any “disabled groups, and some people with disabilities feel similarly. Other families feel their child benefits from being with a variety of people. There are individual decisions.

Social inclusion has many meanings. For someone with physical challenges, intellectual disability, and complex medical needs, being able to join the family at the dinner table at Thanksgiving is real inclusion.

For someone with an autism spectrum disorder, it may involve being a member of the audiovisual club at his or her community college.

It’s not all or nothing; it’s what’s best for your child.

Janet loves sports and although she’s not a particularly skillful athlete, she has found opportunities to follow her passion in many different settings. She attends weekly basketball and swimming programs with the Special Olympics.

She is also apart of Rolling Thunder, a running team. Some members walk around the track a few time and some are training for marathons. Runners paired with “coaches” who are volunteers and siblings, and the entire team frequently competes in 5k races. This activity is more integrated.

Janet bowls in a regular league at the local bowling alley with a member of her support staff on her team.

Once or twice a week, she and her staff person go to a neighborhood gym. She loves working out on the machines and is getting to know the people who work there.

By not limiting her involvement to either segregated or integrated programs, she gets to do what she loves with many people in many places, giving her a more multilayered life.

What do you do all day, anyway?

General Considerations

What if all your child wants to do is sit on the couch, watch TV, and play video games?

You may be reluctant to push your child to do things they resist doing; isn't self-determination supposed to be all about choice?

Without the structure of school it is even more important to find ways to engage your child with the world. We know these issues aren't new to parents and each of us has our own strategies. Only you know how far you should go. Having enthusiastic, engaging staff can help a lot.

Ask yourself:

- Is the proposed activity something you are pretty sure that they will enjoy once they are involved in it?
- Is it something they'll enjoy once they get over their initial anxiety?
- Is the problem transitioning from one activity to the next?
- What's really worrying them? Try to figure it out – it may not be what you think.

Consider what supports you can put in place to encourage them to do something they are likely to enjoy

Is there something they really hate to do? If so, do they *really* need to do it? For example, "Yes" to showers, fold laundry? Maybe not so important.

How is a day best structured for your child?

- Are they at their best in the morning or evening?
- How much time are they comfortable spending out in the community?
- Do they need down time during the day to recoup emotionally?
- Do they need time built in for transitions between activities?
- Are there particular activities that are stressful for them? Think about spacing these throughout the day or week.

Location, Location, Location

There could be a great job or other opportunity that

requires significant travel time, and that's ok, but all other things being equal it's best to keep it local. Why?

- People get to know your child when they see them frequently in the community, and the more people who know your child, the safer he or she is.
- Staying local means there are more chances to develop sustainable relationships
- It helps develop a network of community connections.
- Many people are comforted by feeling rooted to the place they live.
- Plus, transportation time and costs are decreased.

What are your arrangements for spending money?

- Does your child have a bank account? Does she know how to use an ATM? Can she remember her password? Do you want the staff to know it? Are there limits on what she can withdraw?
- How will you keep track of money you give your child for the day for activities and shopping? Remember, you can get reimbursed for staff expenses when they accompany your child somewhere that requires admission (like the movies) but you need to keep the receipts.

The system can be as simple as an envelope in the house for receipts and change.

Out in public while disabled

If your child has a history of yelling, cursing, or other potentially disruptive behavior, you are probably aware that people can see these activities as threatening or dangerous, even when you know they are not. Some people in this situation have had unpleasant or even violent interactions with law enforcement officials. This becomes more of a problem the older your child gets. It's scary when the authority figure you'd normally turn to for help sees your child as a threat. It is critical to plan for foreseeable problems.

What do you do all day, anyway?

Paid Work

Many people with disabilities are able to work at typical part-time or full-time jobs. Finding work for others requires a more creative approach. We have seen many benefits of work for our children, even those who work as few as four hours a week.

Students with disabilities who have jobs during high school have a clear advantage when looking for work after graduation. Encourage your school district to support your child in a job while still in school. This also gives you a head start on understanding your child's job preferences and work skills.

For students leaving school, the first step is usually contacting ACCES-VR (Adult Career and Continuing Education Services – Vocational Rehabilitation), a state agency funded through the Department of Education. For more information, see “Steps to Transition to a Self-Determined Life” on www.nyselfd.org.

ACCES-VR fund career counseling, job training, time-limited job coaching and other supports. Generally, they only offer services to people they believe will be able to eventually function independently (i.e., without paid support) in the workplace. CSS participants cannot access job supports through their CSS Plan/Budget until they have exhausted their ACCES-VR supports unless they have an ACCES-VR denial (verbal or written). After the ACCES-VR funded services run out, job coaching can be funded through the CSS plan.

Niche jobs, also called “carved out” jobs, like Becca’s and Jeremy’s (see on right) are often the only way that people with both significant intellectual disabilities and mental illness can find integrated paid work. Having people in your circle who are tightly connected to the community can help find these types of jobs.

If you don’t have a lot of community connections, or know anyone you are comfortable inviting to join your child’s circle, consider inviting a community “expert” to one meeting. This could be anyone in your area who is active in community life: a sports coach, clergyman, businessperson, or member of the town chamber of commerce.

Melanie

Melanie loves to work with young children. She attended community college, and graduated with an associate degree in early childhood education in three years. She now works five days a week as a teaching assistant in a preschool for children on the autism spectrum. The head of school (who knows her since she received services there) participates in her circle of support and provides natural support for her at work.

Becca

Many of Becca’s high school job trials didn’t work out, although they were carefully chosen to suit her interests. At a person-centered planning meeting, someone suggested she might enjoy stocking shelves at Walgreen’s. Her mom thought this was a terrible idea (although she was smart enough to keep her opinions to herself), but Becca, after a visit to the store, agreed to try.

She’s been working there for six years now, at substantially over minimum wage. Her hours have slowly increased—she now works 5 hours a week spread over 3 days, coming in when there is a need for the specific tasks she is able to do.

Jeremy

Jeremy loves dogs. His neighbor is a teacher with 2 dogs, who need to be walked in the middle of the day. He walks the dogs for about 20 minutes each weekday, accompanied by his staff, getting paid \$20 a week. Jeremy gets to be with dogs, get exercise, do something useful, and make money to buy the rock music he loves. And his neighbor doesn’t come home to a mess on her floor every day.

What do you do all day, anyway?

Volunteering

Some volunteer jobs are for community services. Other may have the potential to develop into paid jobs.

Anyone can volunteer for a nonprofit or government entity. However, state and federal laws state that you cannot volunteer for a for-profit business. However, you can intern there. The definition of “intern” has been tightened in the law recently, to protect college students from being exploited.

However, there is tremendous value for people with significant disabilities to develop skills that may be marketable in six months or more. This is an individual decision that’s a great topic to discuss with your Circle of Support.

Find a list of nonprofits that may need volunteers in your area:

- Local Yellow Pages
- Public Library
- County legislator (they know the nonprofits in your area they’ve secured funding for)
- Online
 - www.volunteermatch.org
 - Search “volunteers” and the name of your town or county

Ideas for Volunteer Jobs

- Library
- Parks and outdoor areas
- House of Worship
- Preschools
- Nursing Homes
- Hospitals
- Local Government
- Community Television
- Animal Shelters
- Museums
- Political Campaigns
- Little league sports
- Community Centers
- Food banks
- Environmental cleanup
- Special Olympics
- Charity run or walk
- The possibilities are endless!

What do you do all day, anyway?

Post-High School Education

People using CSS may choose to go to college, technical school, or take continuing or GED courses in the evening. CSS will pay for support staff.

Many people attending college may not need ongoing daily support. However, sometimes families underestimate the level of assistance that their children received in high school in the areas of organization and planning. A teacher, behavior consultant, or other staff could be hired to orient the student to their new surroundings in the following ways:

- Learning their way around campus
- Rehearsing how to “self-disclose” to Disability Services and request any necessary modifications. *To receive accommodations, a child must disclose their disability and ask for help. A parent cannot do this for her if she is over eighteen.*
- Setting up a study schedule
- Find the computer lounge and lockers
- Connect with the writing center
- Finding which campus café fits their dietary needs
- Help the individual get organized and stay organized

ACCES-VR can pay tuition for a vocational school or community college classes that would likely lead to a job (“Yes” to veterinary assistant, “no” to actress). You can also allocate money from the CSS budget to pay for the adult learning courses.

Mario

If your child enjoys school, but does not want to or is unable to pursue a degree, think about college in a broader sense.

Mario wanted to learn French, but he felt that taking a course for a grade would be too much pressure for him. So, he audited the class for a semester, with CSS staff for support. The next semester he took the course for credit and passed.

Whether or nor he completes his associate degree, he is pursuing his interest, expanding his knowledge and spending time with peers.

Continuing education courses at community college are another option. Suffolk Community College offers individual three-hour sessions on cooking.

Opportunities to learn are everywhere:

- Libraries and community centers offer classes on many different subjects, such as crafts, computer skills, etc.
- Many school districts offer extension courses for community members in cooking, arts, and crafts.
- First aid courses.
- Organizations like Toastmasters have helped many people work on the presentation skills in a supportive environment.

What do you do all day, anyway?

Life Skills

Life skills are tasks that someone has to do for you if you cannot do them for yourself.

For many of our kids, daily activities present countless learning opportunities. If eating is motivating, different days may focus on recipe searches, creating a shopping list, going to the market, and cooking. However, for some people, a successful dinner is being able to sit at the table and eat for nourishment.

A more intentional way to teach skills is to break down the activities and develop plans: Cutting out coupons, making (or checking off a pre-made) shopping list, navigating aisles while pushing a cart safely, reading signs and labels, choosing fresh fruit and vegetables, taking a deli counter number and then ordering when the number is called, handling money, packing and unpacking purchases, for example, are all useful skills.

The same approach may be applied to laundry, house-cleaning, money management, trips to the post office, etc. Of course, it's good to choose only a few of these to work on at once, with staff filling in the gaps. Again, it all depends on the individual.

We are not trying to suggest which particular tasks are important to master, but to demonstrate how your child can spend much of their time doing "ordinary" things, while having it be satisfying, productive, and, hopefully, meaningful to them.

What do you do all day, anyway?

Recreation

Recreation can be hanging out with a friend or joining an organized group, or a place you go to yourself or with staff. The group can be a regular community group or one limited to people with disabilities.

Programs for people with disabilities

Many communities have recreational programs for young adults with disabilities; some programs are offered by towns and some by local nonprofits. These are usually either sports or social programs.

How to find them:

- Call your township or go to their website and search “recreation guide”.
- *The Special Olympics* offers numerous no-cost opportunities for those interested in sports: swimming, basketball, softball, soccer, floor hockey, golf, bowling, swimming and others. You can visit the New York State site at www.nyso.org.
- *Rolling Thunder* is a running group on Long Island open to people with disabilities of all ages, and their family and friends. See www.rtsnp.org.
- Get on an email list that informs you of programs and special events for people with disabilities
 - Parent to Parent of NYS (www.parenttoparentnys.org)
 - Many disability organizations have their own lists

Recreation Ideas

Go on a picnic	Play Video Games	Take Day trip
Beach trip	Go out on a day fishing boat	Recreational shopping
Martial Arts classes	Bowling	Jewelry making classes
Zumba classes	Bird watching	Local theatre group
Knitting groups	Fan clubs	Yoga or Tai Chi
Board game nights	Go to the movies	Art projects
Visit aquarium or zoo	Visit a musuem	Membership at local gym

What do you do all day, anyway?

Friends

When kids are in school, they spend most of their day with others of the same age. However, providing social opportunities for people using CSS doesn't just happen: it takes planning.

What is a friend?

Because they share experiences, people using CSS and the staff who support them may develop a true natural bond. Their relationships look a lot like friendships. Many of our children's staff are, in fact, the closest they come to having friends.

We are very grateful that support staff members offer an opportunity to model friendship, but it is good to remember that for the most part, (although not always), it's an artificial construct based on the work connection – a relationship that ends when the person moves on to another job. Real friends are people who stick around.

Some people with developmental disabilities are very sensitive to this distinction and clearly state that they want friends who aren't paid staff. Others are not. This is not to minimize the value of the rich relationships that often develop between staff and the people they work with, but finding real friends is often the hardest part of developing a full life.

One Model of Friendship

Francisco is a heavy metal aficionado. He enjoys going (with staff support), to local clubs where he listens to the band his record store boss plays in. It's usually a small gathering and others from work are there. They are all wearing the band's t-shirt and cracking stupid jokes. Francisco knows the words to the songs and feels surrounded and affirmed as a part of the gang.

This is the community that is meaningful for him. He's not interested in socializing with people in the usual social venues. Standing in line with other metal heads, he notices that his staff person has a tattoo of one of the bands he loves. This experience is a genuine social interaction that will carry him for weeks.

What do you do all day, anyway?

Friends

Finding Friends

Friendship means different things to different people. For some, a friend is a person to confide in. For others, it's someone to play video games with. It's helpful to think about what having a "friend" means to your child.

Some people are reluctant to seek out friends. Their interests to be solitary and they do not seem interested in developing relationships with people their own age. But don't discount the possibility that your kid could make a friend.

Here are some ways to find friends:

- One of the best ways to make friends is to hang out in places and participate in activities that interest your child.
- Your broker, support staff, MSC, or other professional may know of someone your child may get along with. They could meet for ice cream, go to a park, walk their dogs together, or catch a ball game.
- On Long Island, there are a few social groups for people who use CSS, sponsored by community partners such as the PBS Community Foundation and The Long Island Advocacy Center. They have developed loosely organized groups of people who are supported through CSS. Their major goal is NOT to reproduce traditional group activities for people with disabilities, but to furnish opportunities for people to meet and develop friendships.
- Another advantage of these groups is that staff can meet other participants and their staff can act as "matchmakers to find potential friends for people they work with who would be reluctant to attend a group function. Although they meet at times, they act as "virtual" groups, sending out emails, for example, "Anyone want to go to the Aquarium Monday?" People will gather, get the group admission rate, and go off with their friends and support staff to commune with the fish.

Some of the activities these groups do:

- Speed friending (like speed dating, but slower, with a script of suggested questions and making friends as the goal.
- Singing at events
- Barbeques and pool parties
- Outdoor concerts
- Movies
- Walking in the park

An FMS on Long Island has an email list to share information about informal "meet ups" where people can gather, pursue a mutual interest, and maybe find a friend.

It often takes meeting people a few times to know if a friendship could develop. People may need to help facilitate friendships: practicing listening skills, taking turns, sharing, etc. Direct support staff, or a consultant (psychologist, social worker, or behaviorist) can act as "relationship coaches."

A natural extension of the relationship that develops with staff is for the staff person to invite the person they work with to their home, where they get to socialize with the staff member's family.

Getting the Plan Approved

Budgeting

The broker will write up the CSS Plan/Budget. Make sure you go over it **in detail** with your broker before it is submitted. The financial information can be especially confusing. Don't hesitate to ask all your questions!

Follow the money: Budgeting

When your child's support needs are assessed by OPWDD, the projected maximum cost for those services is calculated. That number is their **Personal Resource Allocation (PRA)**. CSS budget costs for an individual's plan are not to exceed the PRA.

In reality, the amount of money actually allowed for the CSS Plan/Budget may be less than the PRA. The final numbers are worked out in a negotiation between your broker and the DDRO. This is the reason to make sure your plan clearly documents the need for all the supports and services required to maintain your child's person-centered plan. Thoroughly justifying your child's support needs will get the level of funding your child requires.

Be advised, for those who are currently using traditional residential and day services funded by OPWDD, some or all of the funds they are currently using may be reinvested to be used for a CSS plan.

Your broker will tell you the allowable range of pay rates in your area of the state and you need to decide on the salaries for your staff. Some FMS agencies have a pay scale you are required to use. If you disagree with their requirements, look for another FMS.

Things to Consider:

- **Do you want to pay certain staff at different rates due to differences in education?**
- **Will you budget for staff vacation/personal/sick time?**
- **Will your plan cover health insurance?** The Affordable Health Care Act may affect insurance requirements. Speak with your broker about this.
- **Will you be using consultants, such as behaviorists or job developers?** If you are hoping to pay them through the CSS Plan/Budget, there needs to be money allocated to pay them. Their hourly rate is significantly higher than that of direct support staff. Speak with your broker for more information.
- **If your child lives with you, do you want to include respite?** Speak with your broker to learn how this can be done.

Getting the Plan Approved

Submitting the Plan

What happens to the CSS Plan after your broker submits it?

1. The broker submits the plan to the CSS liaison at your local DDRO.
2. After your DDRO signs off on the plan, it is sent to the Central Office in Albany for review and “price development”.
3. When the CSS price is approved, the DDRO sends you an approval letter with the date services may begin.
4. The FMS hosts a “launch” meeting at the local DDRO and you are on your way!

What if the process gets stalled?

The first step is to meet with your broker to find out if the plan is in the system. If your broker cannot give you this information, you can call your regional CSS liaison. If you have further concerns, you can contact Emilie Wright, coordinator of CSS at (518) 473-6393.

What if you are dissatisfied with your broker?

Remember, although it is usually better to try to continue the process with the start-up broker you began with, you have the right to change brokers. You also have the right to change your MSC.

Don't know what to do next? Contact us at nyseld@gmail.com and we will try to help.

What are the responsibilities of the Financial Management Services Agency (FMS)?

CSS plans operate on a “co-management” model. The individual/family is the “**managing employer**” or on the ground supervisor and the FMS, a nonprofit agency, is the “**employer of record**”.

As the “employer of record”, they are legally responsible for paying direct support staff, including dealing with direct support employee taxes, benefits, and insurance.

The FMS also pays consultants and reimburses you for other expenses listed in your plan. They screen new hires by doing a criminal background check, process their applications, and arrange for fingerprinting by OPWDD.

The FMS collects and reviews all paperwork to assure Medicaid/OPWDD to pay for the services supports the person has received.

The FMS must also provide staff training and is supposed to help with other staff issues, if needed.

Remember, you have the right to change your FMS provider if you are unhappy with their services.

See Appendix A for a full list of FMS responsibilities.

Staffing

Direct Support Staff

What is the job of Direct Support Staff?

1. Support and teach “life skills”

This includes tasks both inside and outside the home: the things everyone does on a daily basis. Keep in mind they often our kids learn best by observing the appropriate behavior of others. If your child is learning how to dress for different weather conditions, it is most effective if the staff member is wearing a raincoat or carrying an umbrella just as your child is being prompted to do.

2. Facilitate community inclusion

As discussed above, this means different things to different people. It's all about what is right for the individual.

3. Act as a job coach

A job coach supports a person while they work at a paid or volunteer job. For example, they may:

- Prompt the person to say, “Hi,” to the manager and ask for their assignment
- Help the person complete a task
- Do the task alongside the person
- Facilitate social connections to other workers
- Intervene if the person is having difficulty.

The job coach should understand that although they need to take some direction from the person's supervisor, their job is to support the individual.

4. Keep the person safe and healthy.

5. Advocate

The staff members are advocates for the person they support and also teach the person to advocate for his or herself.

This is just a list of job roles. See the expanded discussions in the sections “What do you do all day, anyway?” and “Staff Training.”

Scheduling Shared Interests

Scheduling staff will depend on shared interests, as well as a staff person's skills and talents.

Jane decided she wants to learn to bake. One of her direct support staff volunteered that she loves baking, and the activity was added to a day she works.

Bryan likes to go to video arcades. He needs single step prompting, but feels embarrassed by his need for support. The staff member chosen for this activity is able to use humor to distract Bryan and relieve his stress.

Staffing

Direct Support Staff

The Nature of Direct Support Work

A direct support worker's job is demanding and requires the staff member to be flexible, open-minded, and creative. There are many factors to take into consideration when considering direct support workers and their qualifications to support your child and their individual situation.

Playing Multiple Roles

Support through CSS is unique in that each staff member is expected to take on more than one role. For example, the same person may act as job coach, community facilitator, and recreation support all in one day. Depending on the individual, staff may help with: getting ready in the morning, volunteer work, meeting someone for lunch, then going to the gym to work out. This flexibility makes the life of someone using CSS seamless, and more like everyone else's life, but it may be challenge for some staff.

Range of Intensity of Support Required

People served by CSS have a wide range of abilities and support needs. The same person may need varying amounts of direction depending on the specific task.

If a person wants to pet the bunny at the nature center, but needs support, whether it is physical, emotional, or behavioral – that's the job. If someone needs help navigating their college campus, that is also a role for support staff to fill.

Need for Initiative

Staff members are often alone with the person they are supporting, either at home or in the community. Especially for people used to working as part of a team, this can be uncomfortable at first. It's important that the people doing the job have good judgment and initiative. They need to be capable problem-solvers and at the same time, be able to recognize when to ask for help.

Intersection Between Choice and Judgment

Everyone has limits to choice in their lives: money, family commitments, what's legal and what's not. People using CSS have the same constraints.

Whenever possible, staff should favor choice. But there is a line between giving someone choice and letting them pursue activities that contribute to negative or unhealthy thoughts or behaviors.

Individualized Supports

Providing direct support through CSS can be difficult for staff because the approach is so individualized. Different families have different expectations and each person is supported with a unique approach. This can be an issue when staff work with several families, as most people are used to having only one employer at a time.

Staffing

Hiring Staff

Hiring Direct Support Staff

Being able to choose your direct support staff is one of the chief benefits of using CSS, but hiring staff isn't always easy. You may have a prospective staff member who looks great on paper that you like a lot, but if there is a personality mismatch with your child, it's probably not going to work out.

Which of these traits are most important to you and your child?

- Able to think and act independently
- Flexible
- Organized
- Responsible
- Good communicator
- Shared interests with your child
- Personality type
- Sense of humor

Should you hire someone with experience in traditional services like day or residential habilitation?

This is something to consider. People who have worked in traditional services may be very dedicated to the field. These same people who have worked in agencies were generally not encouraged to think outside the box or facilitate inclusion. However, they may bring skills and experience that are valuable to your child.

The Right Fit

In some ways, hiring staff is like looking for a prospective mate. You have a list in your mind of what you want, but you know that realistically you are unlikely to find someone who meets all your criteria. Similarly, we know there isn't a fair godmother to conjure up the "perfect" staff members for your child. We are just suggesting qualities to look for when throughout the hiring process.

It may be very tough to find a person who has the qualifications you are looking for, so you may decide to hire someone who seems reliable and gets along with your child. As the old song by Stephen Sills goes, "You gotta love the one you're with". And that may work out just fine!

Most important is to trust your gut reaction to the person. Sometimes you get a sense that someone will click with your child, and that is as important as any skill listed on a resume. The best way to get a sense of this is to watch someone interact with your child.

On the other hand, if you get any negative vibes about someone you are hiring, pay attention: It's important to trust your feelings and definitely a reason to gather further information before making a decision.

Staffing

Hiring Staff

Recruitment

Job Description

You want to describe the person who will be supported, some of the activities they will be participating in, and the qualities in a worker you are looking for. Include days, hours, and compensation. It's useful to be honest about the disability and support needs, but there is a fine line – too much detail might interfere with seeing the “person first”. You can also list some of your child's strengths and interests, such as “Yankees fan,” “loves rock music,” or “likes to bake.”

Finding Staff

Some applicants may wish to support people with developmental disabilities; others may be attracted to working with someone with similar interests. Some of our children respond more positively to having support staff members that are young adults themselves. Remember, their lives may be just as in flux as your own child's. Be alert to maturity issues and ability to make commitments. Young people may need a longer period of mentoring and supervision.

Personal Connections

Think about people your child gets along well with: prior teacher aids or retired teachers, coaches, people in your neighborhood, friends of friends, current or prior respite staff. Ask everyone you know. Many people who would never think about working for an agency would be happy to work for your child, especially if they share a common interest. Ask your CSS liaison, MSC, broker, friends of siblings, and children of friends. Look around your local Y or community center. Is your child taking a college course? Maybe a young person who took the course last year would like to work as your child's tutor.

Advertising

The website www.care.com can be useful and allows you to sort for people who want to work with individuals with disabilities.

People have had varied success with Craigslist. Tips for a successful Craigslist ad include requiring a resume, thinking twice before posting your phone number in the ad, and screening people carefully over the phone before meeting with them.

Pinning up ads on college university boards, houses of worship, and community centers can be helpful too. Don't forget about organizations that have online community boards. Sometimes the most effective strategy for finding staff is to speak to everyone you know!

See sample ad in Appendix B.

Resumes

Not everyone has a resume, but that doesn't mean they can't do a great job. If the candidate has a resume, does it lead you to believe they are truly interested in this work? For example, we have seen several resumes of people with degrees in criminal justice!

Life Experience

People who do direct support have a wide variety of backgrounds. Many may have no prior experience in the field, but could be a great match for your child.

For example, the job attracts many young people still in school, who can bring youthful energy and enthusiasm. On the other hand, because they have other long-term goals, they may only be with your child for a limited time while older candidates tend to be more stable in a position. It's up to you and your child.

Some people who provide support have a family member with a disability. This can be great or not, depending on the circumstances. Hearing a person speak about a sibling with disabilities can give you insight into how they will approach your child.

Staffing

Hiring Staff

Different Approaches to Recruitment

Some staff will be attracted to the job because of a shared interest.

Emma is on a CSS plan and wants to learn how to bake muffins and cakes. Her neighbor, Andrea, is a great baker and has known Emma since she was born. Emma and her circle decide to hire Andrea to bake with her 3 hours a week. The circle suggests that Emma may want to learn how to make her own lunches too and Andrea is game to help.

Carlos earned an MBA and later realized that business wasn't for him – He wanted to pursue music. However, he needed a day job to pay his expenses. He had never thought of working with someone with disabilities until a friend mentioned Chris, a young man using CSS who wanted to learn guitar. Although initially anxious about working with someone with a disability, getting to spend time with another music lover and teach him guitar drew Carlos in. Carlos is now one of Chris's favorite support staff.

Boundaries

It may feel wonderful to be able to hire someone who has a close relationship with your child because they are a friend, family member, or neighbor. But don't forget to consider how it will affect your relationship with them and your family if they unexpectedly leave you in the lurch or it is not working out.

Hiring Local

It's easier to hire staff that live close to you or your child, if they are not living with you.

References

You want to speak with a current or former employer and a personal/ character reference.

Possible questions for a former employer:

- Did the employee show up on time?
- Did they get along with coworkers?
- Did they take direction from supervisors?
- Did they get along with customers?
- If a problem arose or something did not go well, did they have good coping skills?

Speaking to a personal or community reference can give you a better picture of the applicant.

Should I hire one person or several?

Many people have found that having a variety of people to support their child has benefits: Providing coverage when someone can't work, exposure to people with different personalities and interests, not losing all your staff if one person leaves, and people who bring different strengths to the job. However, this needs to be individualized. Some people are happy with one or two people and others have four or five

Staffing

Hiring Staff

Terms of Employment

Although it may be awkward, it's best to discuss all these issues upfront. This helps to avoid later conflicts based on misunderstandings.

Clarify Expectations

Will there be a probationary period? How often will they need to come to team meetings, for which they are paid? How often, and in what way, should staff communicate with you? Do you want a detailed report of your child's day, just the highlights, or do you only want to hear if there are problems? Do you want them to call you during the day if they have a question or problem? If you cannot be available to deal with unexpected issues, they need to have an alternate contact – Remember; with CSS you are the staff's supervisor.

What about giving notice? It's hard to talk about this before someone has started a job, and no one wants to plan for the end of a work relationship, but we know this is generally a not a lifelong job. One way to bring this up to a candidate: "We hope this will be a long term relationship, but recognize at some point you may move one. Therefore, we respectfully request at least 4 weeks notice as it takes a long time to recruit and hire someone."

When the issue is framed in a positive way, families have good results.

Some people may be uncomfortable helping your child with "private" things. If your child requires personal care, it is important to be clear about that before hiring.

Benefits

Health Insurance

Speak to your broker or FMS about how staff can receive health insurance. Different Financial Management Services have different policies concerning coverage. These usually include a minimum number of hours worked. (Note: Insurance requirements may change when the Affordable Care Act goes into effect for businesses.)

Our take as parents and staff supervisors is that it is generally good to offer health insurance to staff. Not everyone needs it, but for those who do it can be a deal breaker. It also seems to help with staff retention.

Paid Time Off

Holidays, vacation time, personal time, and sick time are important considerations. Some people feel their budgets are too limited to give staff paid time off. Many disagree and pay staff for holidays and personal/sick/vacation time to establish direct support as a "real job" and increase staff retention. One way to do this is to increase paid time off the longer staff work with your child.

Want your valued staff to stay longer?

Show people you appreciate the job they are doing with your child. This is a key factor in staff retention. The easiest way is to use your words. Acknowledge that what they do is important and challenging and praise them for their successes.

Holiday/Birthday gifts: This is a personal choice, but it is important to acknowledge the contribution made by support staff to your child's life. For birthdays, consider having your child buy a small gift. For holidays, many families give staff a cash gift to express appreciation.

Is there a training they want to attend that will improve their ability to work with your child? If you can, pay for those hours through your plan.

Staffing

Hiring Staff

Hiring Consultants

Consultants are in a different category than direct support staff. They are funded from a separate budget line in your plan, don't receive health care or other benefits, and bill by giving you an invoice to sign and submit to the FMS.

Recommendations are a great way to find consultants: Your MSC, broker, CSS liaison, or other families may be able to suggest someone. Or someone from your school district who knows your child well might agree to continue to work with your child, paid by CSS.

Traditional disability service agencies may also have consultants you can hire. Keep in mind that a professional who is "perfect" for one person may not be a good fit for your child.

If you are hiring a consultant at a cost higher than the "pricing parameters" used for the CSS Plan/Budget, you and your broker will have to write up what you need and get three bids to submit with your child's CSS Plan/Budget when it is submitted for approval.

Staffing

Training Staff

Who trains staff?

The family has a major role to play in staff training. You know your child best. You can train staff both by giving them information directly and by modeling the way you interact with your child. We have occasionally seen new staff accept training and direction from experienced staff or consultants more easily than a parent.

Some individuals choose to train their own staff on how they wish to be supported.

1. Current Support Staff Members

Someone who has successfully worked with your child is often the best person to train new staff. Many of us have new staff members shadow an established staff member and your child for a few days. They can introduce the new staff member to the people your child interacts with and show how to support your child successfully.

2. Circle of Support meetings

COS meetings can be a great opportunity to train staff. Everyone is there, so it can be a good time to share information and successful strategies. You might consider arranging an alternate activity at the end of the regular COS meeting so your child can leave and the rest of the Circle can train on a skill so everyone is supporting a person the same way.

3. Consultants

Consultants can be very helpful in training direct support staff. They can train support staff one-on-one, with or without your child, or can train several of your support team at once. When your child has behavioral challenges, a behavior consultant with expertise in positive behavior support can be invaluable.

Be aware that many behavior consultants work primarily in schools where their job is to help the child function in a relatively rule-heavy and inflexible environment. They may need to be reminded that community life is more accommodating and offers many more opportunities to create a space that lets your child be his or her best.

Staffing

Training Staff

What skills do staff need?

Once you have hired your support staff, it is time to provide them training.

1. How to teach your child something new

Staff may need to be taught techniques that will help your child learn, such as breaking down tasks, starting a task near the end and letting the person finish, partial participation, etc. A teacher, job developer, or other disability specialist may be useful, but of course you can teach these your self if you wish.

2. Behavior Support

Positive behavior support is a set of strategies and practices based on the assumption that all behavior meets a specific need. It then builds on a person's strengths and motivating interests to teach coping skills, and also creates environments to help decrease interfering behaviors.

Strategies that had positive responses from others may not work for your child. Don't assume that because staff has worked with someone with similar needs to your child, that they will necessarily know how your child needs to be supported. You (or a consultant) need to do the work upfront to tell them.

3. Facilitating Inclusion

Often, a major role of direct support staff is to help connect the individual they support to the people they encounter throughout the day.

Here are useful strategies:

- Help the person be comfortable in a setting by allaying anxiety
- Focus the person on the interaction
- Model appropriate social interaction for your child: "Hi, how are you?" Staff also needs to model to the public that your child can speak for his or herself.
- Interpret/ reword both sides of conversation, if necessary
- Encourage the person to interact with verbal or nonverbal cues. ("John wants to order a slice of pizza. John, tell the server which one you'd like.

Staffing

Training Staff

Tips for Day-to-Day Management

We give the people who work with our kids a great deal of information. It's a lot to remember! The following ideas can be helpful:

- Create checklists (what has to be done before leaving home, what to pack before going to work, etc.)
- Create a brief "go-to" guide on handling specific situations
- Most people have smartphones. You can put important information in an e-mail that can be kept, or use a free application like *Evernote*, that everyone can share. This is an efficient way for people to never be without critical medical information.
- Some people use alarms on their phones to remind them when to drink, eat, or take their medications.

Real life is messy and can be uncomfortable.

Direct support staff (as would any of us) would rather do the fun stuff with our kids. Going to the movies or shopping is a lot more interesting than cleaning the bathroom or helping someone to floss their teeth. It's important to clarify tasks that a part of the job.

Staff may feel embarrassed waiting while your child counts change at a store painfully slowly. It can be helpful to acknowledge this upfront, but also explain how important the practice is for your child. Modeling patience for the clerk and the people in line is also a positive example for your child.

What happens when an individual says something hurtful or lashes out at a staff member? You need to have a frank conversation with staff explaining how to support the individual and manage their own feelings at the same time.

What is particular about your household?

How strongly do you feel about issues of confidentiality and privacy? This varies from family to family. Everyone working with your child is legally required to observe HIPPA (Health Insurance Portability and Accountability Act of 1996), which protects the privacy of individually identifiable health information. However, people are people, and staff will talk. If you don't want information to travel outside your home, you need to say so explicitly. It's a good idea to remind people that what they observe in your home is private and is not gossip to be shared with others.

Behavior Support in Action

Victor

Victor is a night owl; it is stressful for both him and those around him to pry him out of bed before 9AM. When Victor was in school he had to catch the bus at 7:30AM.

Every day started with a battle, which put him in a bad mood for hours. Multiple attempts at modifying his "behavior" were unsuccessful.

After he finished school and began using CSS, the team decided it made sense for him to start his day at a time comfortable for him. Now he regularly gets himself up at 9AM to be ready to meet his direct support staff at 10AM, when their day begins.

Mark

Mark's brother is getting married, and the whole family will be in the wedding party. Mark, who has autism spectrum disorder, is extremely sensitive to the way clothes feel on his body and has never worn a suit. To prepare to the wedding, his mother and behavior consultant came up with a plan to include Mark on this important day:

- Elastic was put in the waistband of his pants so he didn't need to wear a belt.
- His mom made a social deal with him that after the ceremony he could change into his own clothes. He chose the clothes to change into and packed them into a special bag he could keep in sight during the ceremony.
- He got to pick which cousin would walk down the aisle with him.

Staffing

Training Staff

Relationships with Staff

Relationships with your child's staff are intimate and complex. They are with your child throughout the day, they often tell you about their lives, and they come into your house when you haven't washed the kitchen floor. Even though they are there to support your child and you depend on them, you're also their supervisor. It's wonderful to have great people involved in your kid's life and you can get close to staff, but it's helpful to be mindful about boundaries.

Communication

Clear communication is key to making any relationship work. It's important to tell staff everything they need to know about your child and be open to what they have to say.

On the most basic level, you want to be clear about schedules, duties, and any changes or special activities. Nowadays almost everyone has a smartphone, so an easy way to do this is to back up anything important you say in email or text. For example, if you or a staff person is requesting a change in hours, make sure anything you've talked about has followed up in writing.

Finding out about your child's day

Tell your direct support worker what information you want to know about your child's day. Some families want to hear every detail while others want only highlights and problems. Staff may be reluctant to tell you about difficulties that may come up, either because they don't want to "tattle" on your child or betray a confidence, or because they are uncomfortable admitting something did not go well or worry about bothering you.

We have found that this can be a significant problem. It may reassure them to hear that you struggle with the same issues they are facing with your child.

It's also important to explain to staff that long after they've gone home, your child may obsess about an incident or conversation that occurred during the day. This may then come out in their behavior or ability to move on in their day, and if you don't know what happened, you can't help your child through it.

Similarly, if there was a win, it's great to talk about it and build on those successes.

We recommend you keep reminding them that no question is too silly to be asked and that you don't expect them to know everything.

Emergencies, Problems, and Questions

For emergencies, it's important to give direct support staff contact information for at least two people. These can include parents, more experienced direct support staff, a behavior consultant that will respond to texts or calls about issues, or anyone you designate, such as a trusted friend or neighbor.

For day-to-day issues

If your child is living at home and you are there when they return, the easiest way to communicate is a brief chat. Will it upset your child to hear the exchange? Is it better if they are in another room? That is up to you. It can be equally helpful to connect by phone, e-mail, or text messaging.

Staffing

Training Staff

What does your child's direct support staff need to know?

Before leaving school, many of our children spend most of their time outside the home in the "special" world: special classes, special schools, Special Olympics. In these settings, the people around them are aware of their disability and there is always backup if something unexpected happens. That is not the case when people are out in the community with one other person.

As families, we become accustomed to our child's reactions to various situations. Their behavior is part of our everyday lives and we may be unaware of the many accommodations, small and large, we make to meet their needs. Our responses come naturally to us, but probably will not to other who don't know our child. This is why it is important not to assume that someone you hire, whether they have a background in the field or not, knows the best way to support your child.

Support staff needs to be educated to foresee and hopefully avoid problematic situations. Families should also remember that the outside world is more unpredictable than school and home – issues will come up. That is why your child needs support staff. **The following is a list of important questions you should consider explaining to support staff:**

Health and Safety

- Does your child need prompts to use the bathroom?
- What level of support does your child need in a public bathroom? Are they able to fasten the lock on the stall reliably? Must their staff member be the same gender, so they can accompany them?
- Can they cross the street or walk in a parking lot safely? Will seeing a dog, for example, frighten them or cause them to freeze? Do they have a tendency to wander off?
- Do they understand they shouldn't go off with a stranger?
- Does the staff member need a key to your house, or can your child reliably carry one?
- In the kitchen: Are they able to use a stove or oven safely? Are they safe around knives?
- Does your child harm his or herself at times?
- Does your child use the internet? Are they on Facebook? How will this be monitored to assure their safety?
- Do staff members need to work on hygiene issues? Your child may need someone to brush his or her teeth or comb his or her hair while trying to teach them to do it on their own. Sometimes more subtle support is effective. For example, Staff could reinforce the importance of showers by purposefully commenting when someone's hair looks clean and shiny. Some of us have found that remarks like, "You smell stinky today," by staff members who are peers can help establish regular shower habits. Again, it all depends on your child.

Staffing

Training Staff

Medical Information

It is crucial that staff have the number of an emergency contact person. Remember, with CSS you are the supervisor unless you have made other arrangements.

- Have you told staff about a seizure disorder or any medical condition that may affect your child's everyday life?
- Does staff need any specialized information or training, like CPR or seizure protocol?
- Are staff members aware of allergies, such as insect bites, food, or medication?
- Do they need your child's medication list? A letter giving doctors permission to treat? A copy of your child's insurance card?

Interacting with the World

- How important is structure to your child? How do they manage transitions? How should that affect each day's plans? Would your child benefit from a written/ graphic/ iPad-based schedule?
- How important is it to you that your child and staff members arrive on time? Does your child become anxious when someone is late? If your child cannot be left alone, does someone need to be there on time so you can get to work? Even if they can be alone, does information need to be passed on to staff?
- If your child is with two different support staff members during the day, does information need to be transmitted between them?
- Does your child have behavior issues? Are there specific settings, circumstances or people to avoid? What strategies are effective when challenges arise?
- Does your child have meltdowns in certain situations, for example, stopping a preferred activity, not ordering dessert, or if it starts to rain?
- When confronted with certain situations, does your child yell or act aggressively?
- Does your staff need to know how to intervene, prevent, or curtail inappropriate behaviors such as hate speech, public sexual activity, self-harming behavior, or destruction of property?

Some people are quite consistent day-to-day. Others show widely varying levels of coping ability and judgment at different times or in particular situations. A skill they seemed to have mastered (like crossing the street safely) can fade away if they are having a bad day due to medical or emotional reasons.

Staffing

Training Staff

Social Issues

When your child is in the community, they will be in groups of people you don't know, and whose behavior you can't predict. And you won't be there. Even though we want to keep our kids safe all the time, there is no way to completely avoid risk. In school there are clear guidelines for what is allowable risk and what isn't. When your child is out in the world with support staff, it is up to you to create guidelines. Decisions will be based on your family values and your child's ability to cope with situations. It is helpful to get input from your circle because they have outside perspectives to offer. Again, it is not a question of right or wrong, just what makes sense for a specific person at a particular time in their life.

- At a party, will there be alcohol or drug? May your adult child drink alcohol?
- What about having a staff person go to a bar with them to act as a "wingman"?
- Does someone always need to keep them in sight? What level of risk are you comfortable with?

Inclusion in the community is almost always a positive thing, but there is a potential dark side. Wishing to be socially accepted, your child may put him or herself at risk by trying to please a typically developing peer. This may involve giving money away, holding an illegal substance, or being led into an unwanted sexual situation.

Sensory Issues

- How well does your child tolerate touch? To some, it is comforting. Others are averse to touch. If your child has sensory problems, staff members need to know about it. At the same time, if your child walks into the street without being aware of oncoming traffic, staff members need to know how to physically get them out of harms way.
- Is your child a hugger? Some people need clear limits set for physical demonstrations of affection. Are there different rules for different people in your child's life?
- How about accepting affection? May a child accept a hug or kiss from a staff member? Friend? Acquaintance? If they have a boyfriend or girlfriend, have you been clear with staff about their relationship?

If you don't know the answer to some of these questions, a consultant or team member can help you do a safety assessment.

Staffing

Training Staff

Conflict Resolution

Eventually, conflict will arise. People don't always see things the same way. There can be a disagreement between the person being supported and staff, family and staff, or between staff members. For example:

- Staff may feel they are being asked to do things outside their job description.
- A direct support worker is consistently 15 minutes late to work.
- You are not getting information you asked for, such as a meltdown at work.
- Staff may complain they are not being treated as well as other staff on the team.

It is easiest to handle conflicts as they arise, so that no one builds up feelings of resentment. If that is not successful, you might ask your broker, MSC, or FMS to help facilitate a conversation.

Often, conflicts can be resolved. However, if one really bad thing happens (such as an action that threatens your child's well being) or a chronic problem persists (lateness, inability to take direction) despite multiple conversations, it may be time for the relationship to end.

It's never easy to fire someone, especially when they work closely with you and your child. Here are some issues to consider:

- Decide whether you want to let the staff member go in person or over the phone. Would it negatively affect your child to hear the conversation? Do you want someone, like a friend or your broker, to help you prepare a "script"? Practice helps.
- If you feel the situation could become extremely contentious or explosive, do it by phone.
- Similar to "Stockholm Syndrome" in which captives, over time, tend to bond with their captors, many of us have held on to staff for far too long. *Symptoms of Staff-induced Stockholm Syndrome include:*
 - You are worried you won't find anyone as good to work with your child, even if there are major problems.
 - The worker is unreliable, but you know she is going through a difficult time, and feel bad for her.
 - When you complain about the person, others advise you to fire them, but you feel you can't.

Staffing

Consultants

A consultant is often brought in at a transition point or to address a specific issue: develop a job, come up with strategies to manage challenging behaviors, or do travel training.

Job Developer

The job developer gets to the person to understand the type of work they want to do and the level of support they need. They may find a typical job the person could fill, but would then assist with any accommodations the person needs to do their work.

Another function of job developers is to investigate what a business needs and create a group of tasks that ass up to being a job for someone. This is called a “carved out” job. After a person secures a job, the job developer shows the direct support worker (who is acting as job coach) how to support the person at work. They may teach the coach to:

- Help the person interact with the manager
- Help the person relate to their coworkers
- If needed, make a checklist of job tasks
- Manage transitions at work
- Make sure someone in the workplace has your contact information in case the direct support worker has a crisis, sudden illness, or family emergency while working with your child.

Community Developer

This is a function more often than a title and may be done by a job coach, a behaviorist, or a direct support worker. A community developer looks for ways to involve the person in the community; whether it’s a comic book club at the library or a yoga class. He or she starts by understanding the individual’s interests and looks for opportunities to connect the person to like-minded people.

Special Education Teacher

A special education teacher can help a student transition from high school and also train direct support staff.

Kevin

Kevin completed school and transitioned into a CSS plan. Using CSS funds, his mom hired a special education teacher (Kelly) who had worked with him previously to help him keep the connections he had already established. Kelly took Kevin’s support worker to places Kevin had become comfortable – the shop where he regularly gets his glasses tightened and the ice cream shop where they guy behind the counter is friendly. She showed the staff how to help Kevin with money and to prompt him to speak loudly at the pizza place so his order is heard. Even more importantly, she showed them that it is okay to let Kevin count out the money on his own, even if it takes a long time and they feel embarrassed. Kelly also helped Kevin and his support worker develop a daily routine and checklists they could use together. **See Appendix for examples.**

Behavior Consultant

A behavior consultant may be a psychologist, a board certified behavior analyst (BCBA), or anyone with extensive experience in supporting people with challenging behaviors who meets the criteria established by the NYS Education Department. It’s helpful to ask for references from other families when seeking out a behavior consultant.

Housing

EIGHTY-FIVE YEAR OLD WIDOW DIES SUDDENLY; HER FIFTY-YEAR OLD SON WITH DEVELOPMENTAL DISABILITIES IS INCONSOLABLE OVER LOSING BOTH MOTHER AND HOME

No one wants his or her child in this nightmare headline. If your child is living at home, it is important to think about their long-term living arrangements. Some of our children with disabilities are eager to leave home while others need to be introduced to the idea and have it positively reinforced over a period of years. The decision to move out depends on many factors: your child, your family, funding, and finding a place to live, among others. You certainly don't need to know all the answers, but it is important to start the conversation.

To be able to pay for housing through CSS, a person needs to have a "Residential" or "Both" CSS Plan/Budget. (The person may also need "Other than Residential" or OTR funding to pay for staffing during the day.) Any wages the person earns, Social Security Income, and often, a New York State housing subsidy pay for housing costs. The person is expected to contribute 30% or his/her income to housing costs. The housing subsidy may be used toward rent or a mortgage payment, but the person's must have tenancy rights, which means his or her name must be on the lease or mortgage. Some of the new initiatives families are developing require a financial contribution.

Factors to Consider

Child

- Has your child seen siblings move out of the house and has that made them eager to leave?
- Does he/she want to be on his/her own? For some it can be a developmental phase..
- Does your child resist change of any kind and want to live with you forever?
- Is your child living in a group home or other certified setting and want to move into an integrated apartment complex or neighborhood house?

As parents, we may have a list of skills we believe our child needs to master to be "ready" to live away from family. It's often more productive to think about developing the supports necessary for your child to live successfully on their own.

Family

Every family is different. Changes in family circumstances (illness, job responsibilities, needs or other family members) or when 24/7 care is overwhelming for the family may be reasons to think about looking for a new home for your child.

Availability of Money

People are expected to contribute money for rentals out of their SSI payments and paychecks, if they have a job. Currently for people using CSS, OPWDD will contribute a rental subsidy, which can be used for an apartment, house, or co-op.

Availability of Housing

The price of housing varies widely around the state, making both renting and buying difficult in high-priced areas.

Housing

Housing Options

There are many options for housing. This is by no means a complete guide. *See Appendix E for a list of housing initiatives.*

Living Alone

Some people live independently in an apartment or house. They may meet with their support staff a few times a week for help with paying bills and maintaining their home.

Roommates

To make housing more affordable, many people choose to live with a roommate or two when they move out of their family home. This provides mutual support and decreases social isolation.

Live-In Caregiver

In this model, a caregiver lives in the apartment with your child and provides companionship in return for free rent and a stipend. The live-in caregiver may be paid to provide some staff supports if the situation requires. Like all options, there are pros and cons.

Family Care

Family Care is an OPWDD program this is, essentially, Adult Foster Care.

Home of Your Own

Home of Your Own offers housing counseling and access to low-interest fixed mortgages. For more information, visit:

http://www.opwdd.ny.gov/opwdd_community_connections/housing_initiative/home_of_your_own_hoya

Families, OPWDD, and some community coalitions are exploring new and creative avenues of financing home buying and developing affordable rentals. In some of these models, a family or individual's special needs trust must contribute money to participate.

Strategies to Support Community Living

1. Social Contract

It can be helpful for roommates to discuss issues that might arise and write an informal "social contract" to establish ground rules for living together. The contract should cover how chores will be divided, how food is shared, guest policies, privacy, and "quiet hours."

2. Relationship Coach

Do people need help in negotiating the day-to-day issues that arise when sharing space with someone else? Sometimes an outside party can help negotiate issues that come up. Anyone who can effectively facilitate conversations between roommates can serve in this role.

3. Medicaid Service Coordination

MSC visits are mandated quarterly, but they can visit more frequently to check on health and safety issues. They can make sure there is food in the home, check for pests, ensure no one is preying on the individual, and see if a roommate is taking advantage by having her boyfriend stay over indefinitely.

4. Managing Finances

Who writes the checks for rent and utilities and makes sure they get paid on time? It can be family, a trusted friend or relative, a direct support worker, a support broker (if you have funded their time in your CSS budget), someone from a community social service agency or an FMS agency. Another alternative is to arrange for funds that go toward housing expenses deposited into a shared account and to set up automatic payment of regular bills through the bank.

5. Back Up Plans

Even if you have funding for housing, your CSS Plan may not immediately be fully funded to cover 24/7 supports. Some families strategize in the short-term by having their child come home one day a week, taking turns with other families to stay over, or chip in to pay for someone privately.

Once You're Up and Running

Documenting Services

The money for CSS comes from New York State and Federal funds, so careful and complete documentation of how the money is being spent is required.

Timesheets

There are generally submitted every two weeks. Depending on the FMS, you may have to mail paper forms or review and submit them online.

Mileage Forms

Mileage forms are generally submitted monthly.

Monthly Summary Notes

These are required to be submitted by the 10th of the next month.

It's easy to forget to do these, so it's important to place a reminder in your schedule.

The CSS participant or as a designee specified in the CSS Plan/Budget is required to review and sign these forms each month. It's important to remember that only the person(s) specified in the CSS Plan/Budget can sign the forms on behalf of your child.

Emergencies

If the primary family caregivers have a medical emergency, it may be possible to get money added to your child's budget for additional staff time. Call your broker or liaison as quickly as possible because services cannot be budgeted retroactively.

Once You're Up and Running

Life is Change

Person-centered planning should really be called person-centered living. People with developmental disabilities develop new interests, leave jobs, move, make new friends, split from old ones, and develop new medical and psychiatric problems just like everyone else.

Megan

Megan loves to food shop, has a shopping routine, and is becoming more and more familiar with the store. Megan says she wants to shop for herself. Her mother is a bit nervous but feels it is okay for her direct support worker to be an aisle away and check on her every 5 minutes.

With the opportunities given them using CSS, we have seen our children mature and develop new skills. Their growth also challenges us to reevaluate the limits we set for them. Sometimes the child leads the way .

Allison

Allison loves to swim. She always the first one in and last one out of the pool. One day a staff member suggested that they meet friends to swim and Allison said no. When questioned by her mom, Allison started sobbing and was too upset to leave the house. When asked what the problem was, she said she hated changing into her bathing suit after work. This brought up a lot of issues: Did something happen while she was changing in the ladies room in the store where she works? Did someone say something upsetting or touch her? Was the ladies room difficult to change in?

It turned out Allison was anxious about picking out clothes to change into after swimming because she was worried she might not want to wear what she picked out. So swimming was out for the day. This was her choice, she's voiced her concern, and no one pressured her to go, even though we knew she would enjoy herself once she got there. The next day she packed her bag for swimming the following afternoon.

There is always a reason.

Sometimes it seems right to push your child out of their comfort zone, but at what point is it coercive?

Fatima

Fatima likes to stay in her home and has a passion for colorful flowers. A new community flower garden was starting at a local park. The Circle felt that Fatima would benefit by being outdoors and perhaps make social connections. They thought she would be engaged by the idea of planting flowers and watching them grow.

The first day she didn't want to get out of the car. Her support worker asked the garden director to speak to her, and he convinced her to walk the flowerbeds. On subsequent days he offered her the chance to choose the group she would work with and which flowers to plant. Even with gardening gloves (chosen by her) and a sunhat for shade, Fatima was not happy. Despite a half dozen attempts with modifications, after a few weeks it was clear to all that this wasn't a good fit.

Three weeks later, Fatima's enthusiastic direct support worker felt that Fatima "should" enjoy flower gardening, and besides, the worker enjoyed gardening and being with and other gardeners at the park. They got into the car, but she misled Fatima about their destination. Landing back at the park, Fatima had a meltdown, and consequently never trusted the staff member again. There's a fine line between encouragement and coercion.

The balance between keeping your child safe and helping them move forward is a continuing conversation for each family. Your circle of support can help figure this out.

Once You're Up and Running

Thinking Long Term

We are all aging and won't be around forever. It is difficult but essential to think about what your child's life will be when you are no longer able to take care of him or her. We believe there is a dire need for a structure to support self-determination. We are not quite sure what it would look like, but it will need to continue to oversee each person's plan to keep the focus on the individual.

There are some national organizations that offer resources to help support your child when you cannot. These listings are for information only and are not meant as endorsements.

Planned Lifetime Advocacy Network

www.plan.ca

Helping to plan for your child's future while you're still alive.

Life Services for the Handicapped

www.disabledandalone.org

A non-profit agency that lists as its goals, to help families plan for the time when they will no longer be here and provide direct services to people with disabilities whose families have left assets for their care.

Thank you!

A heartfelt thanks to those who have taught us so much,

Beth Mount, Tom Nerney, John O'Brien, and Mike Wehmeyer for their vision.

Michelle Guiliano, CSS liaison at the NYS OPWDD Region 5 DDRO, and Emilie Wright, Coordinator, Consolidated Supports and Services, OPWDD for their can-do spirit and making it happen.

The dedicated staff of the Long Island Advocacy Center and Positive Behavior Support Community Foundation for showing what is possible for our children.

Appendix A

Financial Management Service (FMS) Core Tasks and Functions

The Financial Management Service (FMS) agency provides a variety of services that support the individual whose services are funded through an individualized budget. The FMS agency is the employer of record for self-hired staff and is the provider of record to the individual who hires and manages his/her staff and/or supports. Authorized services funded through the FMS (FEA) Payment on the Consolidated Supports and Services (CSS) price sheet are listed below. Authorized services in **categories 1-4** apply to **all individuals** whose services and supports are funded through an individualized budget; authorized services in **category 5** apply **only to individuals who are self-directing staff**.

A. Included in FMS Monthly Fee - General Tasks & Functions

1. Billing and payment of approved goods and services on behalf of participants
 - a) Receive, verify and process requests for payment for all goods and services shown in the approved budget (including Mileage Reimbursement Form, Monthly Summary Note, Invoice/Service Record for Contracted/Vendor Services)
 - b) Promptly notify participant or designee of any requests for payment for services that have not been identified in the participant's approved service plan and budget
 - c) Confirm credentialing of contractors/vendors
 - d) Adhere to monthly billing rules/billing standards for services as defined by NYS OPWDD
 - e) Submit timely billing (hourly & monthly), as appropriate, to Medicaid (eMedNY) and/or OPWDD for reimbursement of service costs
2. Fiscal accounting and reporting
 - a) Establish and maintain a separate account for each participant
 - b) Track disbursements and balances of participant funds
 - c) Send monthly expenditure and balance reports to the participant and DDSO promptly
 - d) Report inconsistencies in approved service plan and budget to state authorities
3. Ensure Medicaid and corporate compliance
 - a) Review all service documentation that supports billing to eMedNY and OPWDD for accuracy, completeness, and compliance with applicable requirements, including ensuring that the habilitation plan is reviewed at least once every six months, and whenever there is a significant change in the service. One of the two reviews each year occurs at the annual Individualized Service Plan (ISP) review.
 - b) Maintain current copies of the ISP and self-directed service plans and budgets, and hold for a period of 6 years from the date the care, services or supplies were furnished or billed, whichever is later
 - c) Maintain all components of the individual service record and documents supporting billing for a period of 6 years from the date the care, services or supplies were furnished or billed, whichever is later
 - d) Provide expenditure reports and service documentation to state authorities as requested
 - e) Participate in quality and fiscal compliance audits
4. General administrative supports, including but not limited to:
 - a) Conduct necessary meetings once plan/budget is approved, e.g., launch meeting and required annual and semi-annual CSS Plan reviews
 - b) Participate in annual and/or semi-annual ISP meetings to discuss issues related to self-directed staffing and/or supports and budget expenditures as needed or as requested
 - c) Participate in Circle of Support (COS) meetings as a budget resource as needed or as requested
 - d) Assist individual with budget management
 - e) Incident Management - reporting/investigating as required
 - f) Ensure that the DDP-2 is updated as needed, at least every two (2) years
 - g) Conduct Medicaid fraud investigations as necessary
 - h) Maintain communication with OPWDD regarding participant and services
 - i) Travel time when necessary to address above listed responsibilities
 - j) Other expenses associated with agency administrative overhead

B. Included in FMS Monthly Fee - Self-Hired Staff-Related Tasks & Functions

5. As the "Employer of Record" & co-manager of self-directed staff
 - a) Provide training to the individual on his/her employer responsibilities by:
 - 1) Providing **participant** with orientation and support in areas of staff hiring (including assistance with job descriptions), staff management, performance evaluations, staff conflict resolution
 - 2) Reviewing Department of Labor information and agency employment policies with participant
 - 3) Addressing relevant co-management practices which relate to agency vs. participant responsibilities
 - 4) Discussing use of overtime with participant, i.e., budget consequences & other implications
 - 5) Discussing with participant effect of hospitalization on Medicaid funding & individual budget
 - 6) Teaching participant importance of proper documentation of staff work hours, expenditures, and provision of services & how to review Employee Time Sheet/Daily Service Record, Mileage Reimbursement Form, Monthly Summary Note, Invoice/Service Record for Contracted/Vendor Services and any other claims for payment to ensure that documentation is complete and accurate
 - b) Help individual manage staff by:
 - 1) Providing and supporting hiring and discharge practices for self-directed staff
 - 2) Verifying staff citizenship status
 - 3) Completing required background checks: CBC, DMV, Central Registry, etc.
 - 4) Providing enrollment/employment package for all new self-directed staff that includes one copy of all necessary forms
 - 5) Providing all OPWDD approved basic agency mandatory trainings for all self-directed staff (i.e., incident reporting)
 - 6) Providing other trainings for self-directed staff as agreed upon with individual
 - 7) Scheduling back up staffing, if agreed upon with individual
 - 8) Maintaining staff background records
 - c) Complete payroll functions, including:
 - 1) Collecting, verifying and processing time sheets/service records (Employee Time Sheet/Daily Service Record, Invoice/Service Record for Contracted/Vendor Services)
 - 2) Processing payroll; withholdings; federal, state, and local taxes; making tax payments to appropriate tax authorities (such as FICA, Workers Comp, unemployment, etc.)
 - 3) Identifying and managing individual staff benefit and fringe packages as defined in the participant's approved service plan
 - 4) Ensuring timely staff payments
 - 5) Managing staff accruals

Appendix B

Sample Ad: Recruiting for Direct Support Worker

Educational Assistant and Direct Support Provider

(Glen Cove-Oyster Bay Area)

Direct, part-time support staff needed for young woman with autism. Must be female, college educated, patient, compassionate, reliable, and have a good sense of humor. You will be working with her on an organic farm and at a university setting, where you will be accompanying her in class and helping her with her studies. We are looking for someone 2-3 days/week. Hours are flexible- usually around 10AM until 4 PM or so. This job involves a fair amount of driving, you need to have your own car and live within 45 minutes of our home. Please send resume.

Appendix C

Job Development Tools

APEC Checklist

- Greet staff at front desk.
- Sign in
- Put away belongings
- Get name tag
- Wash hands
- Check water bottles/food and fill when necessary
- Exercise turtles or brush guinea pigs
- Wash hands
- Return name tag
- Gather belongings
- Sign out
- Say goodbye to staff at front desk.

Appendix C

Sample Note for Job Coach

Hi-

Just a few things to remember from the meeting with Dyan at APEC yesterday...

Sam's hours at APEC are 12:30-2:00. He should arrive at APEC **at least** five minutes prior to his start time. This will give him time to walk through the parking lot (which is not paved, so it may take him a little more time to navigate). It is essential that he arrives on time every day he works. While you are responsible for transporting him to work, you are also responsible for modeling for him appropriate work behaviors, which includes arriving on time and working until a shift ends.

Establish a routine from day one. He should enter the building and greet the staff member at the desk (on his first visit and when there are different staff members at the front desk, he needs to introduce himself and learn the staff member's name, so he may use it to greet them in the future when he arrives at work).

On his first visit, he should be shown where the sign in binder is located and how to locate his sign in sheet. He will need to fill out the top of his sign in sheet. You can let him know that he can tell you the information and you will write that information on the sheet for him. I would like to see actually sign in when he arrives/leaves work each day. He can write in the date and time he arrives/leaves. He should also complete the sections on amount of hours. You can help him figure out what to write in that box, and it should become automatic for him. You will need to assist him in recalculating should his hours change or he does not work the same amount of time. Remind him he can use more than one line to write on, as the sheet is only for him to sign in on. Please let us know if this task seems frustrating or difficult for Sam.

During the first few visits, he should ask for Dyan until a routine is established. Once Dyan feels comfortable that Sam does not need to report to her when he arrives, he can just walk to the back desk, sign in and begin work.

After signing in, Sam should place his belongings in one of the spaces Dyan designated, either in the classroom or in the kitchen area. Keep in mind, in the kitchen he may not be able to reach the spot to hang his coat. I would show him the two options when you arrive the first visit and ask him which he prefers. That will be the space every time. It is important that this location remain consistent and part of the routine so that Sam can become independent in remembering to get his belongings when he leaves.

After putting away his belongings, he should walk into the kitchen area, retrieve his name tag from the wall and wear it. It can be his choice if he wears it on his shirt collar, bottom of shirt or pants pocket. I suggest having him try the spot he prefers and see if it gets in the way when he works. If it appears to be difficult for him to attach the name tag, please let us know and we can figure out an alternative.

Sam needs to wash his hands before he begins work.

Tasks will include:

1- Checking water bottles/food and filling as needed. You will need to set up a routine the first day for checking the water bottles and food. I would follow the same routine everytime so it becomes automatic. Given that removing the water bottles seems complicated, you will need to remove them/replace them for Sam in the beginning and once you figure out the best/easiest way to remove them, then teach Sam those skills. Keep in mind, that he will need to use both hands to do this and it may be difficult for him to do independently. You should teach him in a chain, meaning you will do all of the steps to start and then have him do one step. As he becomes proficient in that step, have him do two steps, increasing until he is able to complete the task independently. As was discussed, he will only be working with the guinea pigs and rabbits at this time. In the future, you can add the doves, but I would hold off on that for now.

You will need to work with Sam on opening/closing the water bottles. See if he can unscrew/screw them first. You may need to loosen/tighten them, but he will be able to do this task.

When teaching Sam to scoop up the feed, remind him only to fill it up half way. If it is difficult for him to carry the food without spilling, please ask Dyan for a container for him to place the scoop in. As the scoop is deep, I feel he can carry it without spilling.

Appendix C

Sample Note for Job Coach (continued)

2- Box turtles- Please make sure when working with the turtles, Sam pays attention to which turtle he is working with as it must go back into the correct cage (or they will fight each other). As of now, you will take out the turtle and carry it to the back. Dyan will be working with Sam on picking up and holding the turtles until she feels comfortable he can hold on without becoming startled or lose his grip. Remember, the turtles will wiggle when picked up so we need to make sure Sam can hold on when this happens. When practicing, Sam should be sitting on the ground. As he becomes proficient, he should move to standing and then walking short distances before being asked to carry it across the room. Please make sure Dyan gives the ok prior to Sam picking up/walking with a turtle.

When outside, Sam is responsible for making sure the turtle does not eat anything inappropriate (which sounded like anything we wouldn't eat, plastic, etc.) In the beginning, he will need to point out to you when a turtle needs to be moved. Once he gets proficient in picking up a turtle, he can pick it and move it. Again, please have Dyan give the ok before allowing Sam to do the task. Should Sam resist or feel he is ready, remind him that he must follow the instructions from his boss. Some things are not choices and this is one of them.

3- Brushing guinea pigs- Sam can alternate this activity with the box turtles each week. He may have time to brush the guinea pigs and exercise a couple of turtles. He will brush them while in the cage. Please have Dyan show him how to brush them and have her evaluate Sam's pressure with the guinea pigs prior to allowing him to do it independently. It is important to remember, that while we know Sam loves animals and would never harm them, he sometimes is unaware of the amount of pressure he is using and this needs to be monitored. He needs to return the brush to the drawer when he is finished with it. Please ask Dyan about cleaning the brush.

4- Wash hands- At the end of Sam's shift, please have him wash his hands and return his name tag to the wall. He can retrieve his belongings and sign out. He should say goodbye to the staff member working at the desk.

If Sam gets distracted at work by looking at the animals, he may take five minutes at the end of his shift (after his checklist is completed) to look at the animals. He must adhere to the rules of which animals he may and may not touch.

The goal is for Sam to be as independent as possible. Your role is to support his independence, while supervising and prompting him as needed. Sam should be responsible for remembering the routine (with the help of a checklist) and you should be prompting him to check it, not telling him what to do.

It is important that you are constantly evaluating Sam's performance and correcting it as necessary. He will not know he is doing something wrong, unless you point it out to him. You should be attentive to what he is doing and prompt him as necessary to avoid frustration which may lead to task avoidance.

Sam should remain professional at work. He may make "small talk" if he has time, however, should not be sharing personal or home information with his work colleagues. He may talk about things he enjoys, such as music, movies and animals, but should never be allowed to discuss politics, religion, and other beliefs he may have. This is not the appropriate venue to do this.

Do not allow Sam to engage in inappropriate comments about his boss or anyone at work. If he becomes upset or frustrated by a task, he should not be encouraged to discuss this in the workplace. Remind him that at work, he has to follow the instructions of his boss and that some things are not up for discussion. Do not allow him to vent or engage in a conversation about why his point of view is correct, he needs to learn in some situations things are not open for discussion or change.

As always, please contact me with any questions. It is essential that Sam's Mom be kept abreast of any difficulties that may arise at work. As I explained to Dyan yesterday, we would like to know of any problems/difficulties as soon as they occur so we may address them as soon as possible.

Thanks

Appendix D

Sample Script for Calling Manager at Job

Barnes and Noble-

"Hello, this is Jon Greene, I work at the store, may I speak to the manager in the music department."

Wait for the manager.

When the manager says hello say:

"Hello, this is Jon Greene. I will not be at work today as I am sick. I will see you on Monday. Thank you."

Appendix E

Housing Initiatives

Here's a listing of housing initiatives. (We're not endorsing any of these, so do your research)

Disability Opportunity Fund

www.thedof.org

Finances creative, highly scalable solutions for people with disabilities and their families.

Networking Neighbors-Building sustainable communities

Robyn@NetworkingNeighbors.org

Developing customized, integrated housing, opportunities for work and recreation activities in downtown areas on Long Island.

SustainAbility Services Inc. and SustainAbility Farm Project

Wendy Kaplan

516-674-9069

wgkaplan@aol.com

www.sustainabilityservicesinc.org

Supports individuals who have autism and other developmental disabilities to fulfill their vocational, recreational, and residential needs and aspirations.

Friends of L'Arche Long Island

vcover@optonline.net

www.friendsoflarcheli.org

A Group dedicated to developing a L'Arche Community on Long Island. L'Arche communities are family-like places where people with disabilities live in community with assistants.