

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

This Guide is for families who are interested in using Self-Directed Services for their child with developmental disabilities. If you need an introduction to Self-Direction, see “Frequently Asked Questions about Self-Directed Services,” and “Steps to Transition to a Self-Determined Life” at www.nyselfd.org.

There have been significant changes in Self-Directed Services since this guide was written in 2013, many of which resulted from changes in federal Medicaid policies. We’ve done our best to bring you up to date as of November 2016. You will also note we’ve added sections labeled “Our take,” to offer our opinion about the implications of current policies and practices.

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Until recently, most people with Intellectual/Developmental disabilities who finished high school had no other choice but to accept an available slot in a traditional, congregate program, where their chances to explore their interests and be part of their communities were limited.

Currently most people choose Self-Directed Services, which are uniquely designed for, and based on, the individual’s interests, goals and needs. Because of this highly responsive, customized system of supports, people have the chance to develop rich multilayered relationships and spend their time doing activities that absorb them, in addition to working on those “life skills” that we all need. All of us contributing to this guide have seen our children’s lives deepen and mature way beyond our expectations through Self-Direction.

Self-Directed Services require more effort than getting your child on the bus every day (itself not an easy task at times!), but it’s not that difficult. In fact, some people who switch from congregate to self-directed services, talk about how much less stressful it is, because they are to be able to have a say in who works with their child and what they do every day.

When our children started using Self-Directed Services each of us were faced with situations we didn’t have the information or experience 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.

Note: 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. There’s no one right answer for everyone.

Introduction

- For your 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.
- By “**parents**” we mean anyone acting in the parental role.

We’ve tried to keep acronyms and bureaucratic jargon to a minimum, but have included terms that people you speak with may use.

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

We encourage you to sign up for our occasional news blasts: email us at nyselfd@gmail.com.

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.

About Us: New York Self-Determination Coalition (NYSELFD)

New York Self-Determination Coalition is a group of families and a few professionals. We support self-directed services for people with intellectual and developmental disabilities by disseminating information, informally mentoring families, and advocating at the state and local level. We are not affiliated with any government or voluntary agency, and are not paid for the work we do.

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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 ability and 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.

(Developmental Disabilities Act)

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 allowing states to use Medicaid to fund services that support people with disabilities to live in their communities.

The Basics

What is Self-Direction?

In New York State, People with intellectual/developmental disabilities (I/DD) can use funding from the NYS Office for People with Developmental Disabilities (OPWDD) to purchase **Self-Directed Services (SDS)**, instead of enrolling in traditional programs run by state and voluntary agencies.

Self-directed services offer people with developmental disabilities both budget and employer authority. SDS with Budget and Employer Authority are also called **participant-directed services or self-hired services.**

- **Budget authority** provides participants with a flexible budget to purchase the supports and services they need to live in the community
- **Employer authority** allows the individual, with assistance, to schedule, train, and fire staff

Agency Supported Self-Direction Services are an available alternative to SDS with Budget and Employer Authority. With Agency Supported Self-Direction, the person has the authority to hire, train, and schedule staff, but not set salaries-or access other self-directed funding streams. The agency and individual/family sign a memorandum of understanding that describes their respective roles. Community Habilitation, Supported Employment, and Respite can be self-directed in this model.

What services are available when you self-direct in New York State?

OPWDD Waiver Services You Can Self-Direct (either using SDS with Employer and Budget Authority, or Agency Supported SD):

- **Supported Employment:** supports necessary to find and keep a job
- **Respite:** provides relief to the primary caregivers when your child is living at home
- **Live-in Caregiver:** an unrelated care provider lives in the household of the participant and provides necessary support as needed

Community Transition Services: funds that can be used for setting up a household when moving from a certified setting (i.e., group home or Intermediate Care Facility) to a non-certified home.

(Certified housing is owned or leased by the state or a non-profit agency, who also provide staffing. The homes are required to follow all state mandated regulations.)

Our Take: While the regulations were undoubtedly set up to safeguard people, they often result in a lack of flexibility, allowance for individuality, or opportunities for growth.

The Basics

If you use Self Direction with Budget Authority, you will need to use these services:

- **Fiscal Intermediary:** a non-profit agency that provides administrative and payroll support for someone who self-directs.
- **Start-up Brokerage and Support Brokerage Services:** Brokers help the person to develop a Circle of Support, complete a SD budget, and maintain the person's plan, as agreed to in the Brokerage agreement/contract.

If you use SDS with Budget Authority, you can also use your budget to pay for these services:

- **Individual Directed Goods and Services (IDGS):** provides payment for services, equipment or supplies that cannot be covered by other state or federal funding streams, for example consultants, transportation, community classes, health club membership, also:
- **Paid neighbor:** someone who lives near an individual who lives in non-certified housing, and is paid a monthly salary to be available when needed.
- **Self-directed staffing support:** You can hire someone to help with hiring and scheduling staff, and to assist with required paperwork.

Other Than Personal Services (OTPS) are solely NYS funds used to buy goods and services that:

1. Relate to a participant's valued outcome
2. Increase independence and/or the ability to live safely at home (Phone and internet service, staff activity fees, and staff recruitment costs)

Housing subsidy: A monthly sum that can be used to contribute to rental or mortgage payment. The subsidy requires that the participant contribute 30% of their SSI check to rent. Subsidies vary depending on the location of the home, number of roommates, the individual's income, and housing expenses.

Family Support Services: People who self-direct may also use FSS for some services not otherwise funded.

People who self-direct may also access the following services through NYS Medicaid:

(Speak to your MSC)

- **Assistive Technology:** Devices that allow a person to live safely in the community. (for example: augmentative communication devices and vehicle modifications)
- **Environmental modifications:** Physical adaptations to the home, that increase or maintain the individual's ability to live at home with independence.
- **Personal Care Assistance:** Personal care can be accessed through Consumer Directed Personal Assistance Services (formerly CDPAP).

The Basics

Our Take: In some areas of the state, high housing costs make finding housing very difficult – even more so when someone needs accessible housing. For more information on housing, see **The Housing Resource Guide, by Westchester Institute for Human Development:**

www.wihd.org/wp-content/uploads/1970/01/WIHD-Housing-Resource-Guide-UCEDD_revised-020416.pdf

Note: These are brief descriptions. For more information, please see:

- Front Door: Access to Services
<https://opwdd.ny.gov/welcome-front-door/resource-booklet>
- Self-Direction Guidance for Providers
http://www.opwdd.ny.gov/sites/default/files/documents/SD_guidance.pdf
- Individual Goods and Services Definition Chart
http://www.opwdd.ny.gov/sites/default/files/documents/IDGS_chart_04102015.pdf

More about Self-Directed Services (SDS) with Budget and Employer Authority:

As the name says, people using SDS with Budget and Employer Authority control the way the money that supports them is spent. This includes determining the pay rate for staff (within certain limits), the amount of money spent on staffing vs. other goods and services, and other allowed expenses.

NOTE: Having budget authority does NOT mean the individual or COS must do any financial work. The broker does the calculations and writes the budget and the Fiscal Intermediary (see below) does all necessary withholding, and pays staff directly.

These services are delivered under the authority (control) of a 1915(c) Waiver. The Waiver is a contract between New York State and the federal government that describes the services the state will provide in return for funds to support these services. The federal government agency that manages the Waiver is the Center for Medicare and Medicaid Services (CMS).

This year, the Federal government further clarified the meaning of “integrated setting,” by issuing final regulations that define “home and community based” settings. Each state had to submit a Transition Plan, evaluating all their programs from the viewpoint of the nature and quality of the individuals’ experiences. States are now required to modify services that are out of compliance to meet the new standards. Of course, Self-Direction will not need to be changed as it already meets all requirements.

For more information, visit:

Federal: www.hcbsadvocacy.org/learn-about-the-new-rules/

New York State: www.opwdd.ny.gov/opwdd_services_supports/HCBS/hcbs-settings-toolkit

The Basics

What's required to Self-Direct Services?

1. Medicaid Service Coordinator (MSC)

An MSC provides oversight, ensures the person's health and safety, and submits necessary documentation to OPWDD. The MSC is responsible for applying for Waiver services and writing the participant's Individualized Service Plan (ISP).

The Medicaid HCBS Waiver is a contract between New York State and the federal government. It describes the services the state will provide to people with I/DD in return for funds to support these services. You must be "on the Waiver" to use SDS (and most other OPWDD services).

2. Individualized Service Plan

The ISP gives a brief profile of the person, what he/she wants to accomplish, safeguards, and the supports and services they will use to accomplish their goals (also called Valued Outcomes). Writing the ISP is the responsibility of the MSC.

Note: FIDA/IDD is a pilot managed care demonstration program for people eligible for both Medicare and Medicaid. For those using FIDA/IDD, the care coordinator has MSC responsibilities. If you are considering joining, make sure you're able to keep the Broker and FI that you've chosen.

3. Start-Up Broker

A Start-up broker writes and submits the plans for the components of SDS the individual chooses, such as: The Community Habilitation (Com Hab) Plan, Supported Employment Plan (SEMP), or respite, as well as the SDS Budget.

4. Self-Directed Services Budget (SDS)

The budget is based on the individual's support needs. Currently these are measured by the DDP2, which will soon be replaced by the CAS, a more detailed instrument.

5. Fiscal Intermediary (FI)

A non-profit agency whose job is to vet and process staff applications, handle payroll, submit documentation of services to OPWDD, bill Medicaid when necessary, and ensure Medicaid compliance.

6. Circle of Support (COS)

A Circle of Support is made up of people who come together to help the individual accomplish their personal goals and choose which services they want. The COS can meet as needed, but is required to meet quarterly. Two of the meetings can also include the mandated ISP reviews.

For further information, see the NY Self-Determination website, www.nyselfd.org and NYS OPWDD, at <http://www.opwdd.ny.gov/selfdirection>

Getting Started

It's helpful to gather information about Self-Directed Services for some time in advance before making a decision: Speak with your school transition coordinator, a friend whose child is a participant, a support organization like Parent to Parent of NYS, or go to our website, www.nyselfd.org or to OPWDD, www.opwdd.ny.gov/self-direction.

Some people start receiving OPWDD services while they are still in school—either Agency-Based Services or Self-Directed Services. Your child can use SDS to provide supports the school isn't responsible for, for example: A Community habilitation worker can support your child on the weekend to participate in karate class or go to the movies.

If your child has already graduated from high school and is using Waiver services but now wants to Self-Direct, speak to your MSC, who will submit a Request for Service Amendment (on Long Island, called a SAM).

Our take: We encourage you to start using SDS while your child is still in school. Your child will benefit and you will have the chance to become familiar with the process.

Steps to Self-Direction:

We've also created a checklist of these steps in Appendix A, so you can keep track of what needs to be done. Some of the steps are the responsibility of the parent, but many steps need to be done by the people you're working with. Knowing who is responsible for what, can be helpful if the process is delayed.

1. Apply for SSI (Supplemental Security Income)

If your child is approaching 18, you should apply for SSI (Supplemental Security Income), which automatically grants your child Medicaid. Medicaid funds the supports and services supplied through Self-Directed Services. (See www.SSA.gov)

2. Enter the Front Door to request services from OPWDD

Currently, everyone graduating from high school (even if they are already receiving services), must go through the Front Door, the name of the Office for People with Developmental Disability's entry point for new services.

Call them at: 1-866-946-9733.

Getting Started

A. Establish Eligibility for OPWDD Services

OPWDD will determine if your child is eligible by reviewing IQ and Adaptive Behavior testing results, a psychosocial history (these are usually sent directly from the school, as they are part of the student's record), and medical reports. It is recommended that you apply at age 15, but it's never too late! You can ask for a review if eligibility is denied.

B. Learn About Options

You are required to attend a "Front Door" session to learn about various OPWDD services. Your Front Door contact will also speak to you about the services they offer. Many Developmental Disability Regional Offices (DDROs) have special Front Door talks that only discuss Self-Direction—that's where you want to go!

C. Decide on Services

After eligibility is established you will speak with your Front Door Representative again and will be asked about your child's support needs and goals. At that point, if you want the services described in this guide you need to let them know that you're interested in SDS. (Note: You can change your mind about which services you want at any time, although it will cause some paperwork and possibly a delay).

3. Choose your Medicaid Service Coordinator (MSC)

Ask your Front Door contact for a list of names and phone numbers of MSC agencies that have openings for new clients. Have a conversation to make sure you feel comfortable with the person you speak to, but ultimately know that you can't move forward and receive OPWDD services without an MSC. If necessary, you can change your MSC at any time.

- A. MSC completes DDP2 (assessment tool). The MSC will also submit the paperwork to sign you up for the Waiver. (The HCBS Waiver provides funding for most OPWDD services)

Our Take: Occasionally an MSC may be reluctant to help you pursue Self-Direction. They may not think it will work for your child if they're not knowledgeable about the robust and flexible services available to participants. Remember, it's the participant's right to choose SDS. If the MSC isn't prepared to help you, here's what you can do:

- **Speak with MSC supervisor at your agency**
- **Speak with Self-Directed Services liaison at your DDRO**
- **Choose a new MSC, either within the same agency (the MSC supervisor can help you with this), or at another agency.**

Getting Started

4. The MSC forwards your request for Self-Directed Services to your local DDRO where it is reviewed to make sure your child's health and safety needs can be met using Self-Direction.

5. Attend OPWDD Self-Directed Services Information Session

The family, Circle of Support, and participant (if possible) attend an OPWDD Self-Directed Services Information Session.

6. Choose start-up broker and Fiscal Intermediary (FI)

- a. Pick a broker from the list the Self-Direction Liaison gives you.
- b. Your Start-up broker tells you which FIs they're affiliated with, so you can sign with one of them to do the initial FI review. (The FI pays the Broker). You can switch to another FI before your plan launches, if necessary.
- c. The Start Up Broker Agreement is processed and reviewed by the FI and DDRO and sent to OPWDD's Central Office (Albany) to approve release of funding for the Broker.
- d. You will receive approval to begin planning.

7. Circle of Support and Person-Centered Planning

Broker helps organize Circle of Support (COS) and helps schedule Person-Centered Planning meeting(s).

8. Broker reviews DDP2 (soon to be the CAS, a new OPWDD assessment tool) with the participant and family, to make sure it accurately reflects their needs.

Our take: During any assessment, be realistic! Describe your child on their worst day, not their best day; don't gloss over truths. When you are asked if your child can perform a task, think not only, "Can he do it?" but will he do it on his own. If the question is, "Does your child shower independently?" answer "No" if in truth you need to remind him to shower daily, make sure there is shampoo available, and help him dry his hair.

There may be parts of the DDP2 that might be disturbing or embarrassing for the participant to hear, particularly in the sections discussing self-care and behavior. In that case, those areas could be discussed privately, at another time. Again, this depends on the individual.

9. With the information gained from Person Centered Planning, the participant, MSC, broker and COS meet to begin to identify the services, supports, and funding sources your child will need to pursue their goals.
10. Broker creates the budget and writes the Com Hab, Respite and SEMP plans if applicable.
11. The participant and COS review the plan, budget and safeguards for accuracy.

Getting Started

12. Broker enters the budget on the online Budget Template and submits it to the FI who must review it before it goes forward. The FI may ask for revisions. (All information is transmitted electronically.)
13. FI forwards the Budget to the Liaison at the DDRO, who reviews it and may ask for revisions.
14. Budget then goes to the Rate Setting unit in OPWDD's central office, where it is again reviewed, and revisions might be requested.
15. Launch - A meeting including the participant, family, broker, MSC and FI. You're on your way!

Getting Started

What does the broker do?

The broker's job is to help you obtain SDS and provide ongoing support. There are two roles for brokers: start-up and support. The start-up broker will generally:

1. Guide person-centered planning
2. Write and submit your Com Hab (also SEMP and respite, if used) plans and budget
3. Negotiate the details of your plan and budget with the local Self-Direction Liaison and FI
4. Shepherd it through until your launch (start of the 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.

The startup broker is funded by OPWDD from NYS money. However, payment for the support broker comes out of your Self-Directed Services Budget. We're including part of the Broker Agreement below because it's important to think about and discuss with the support broker the number of hours needed to maintain the plan. The broker support agreement helps you think about what tasks you want your broker to perform.

Our Take:

Initially, you may be tempted to allocate a minimum number of hours to the broker. However, when you first start using SDS it's helpful to have some extra support. In fact, you might want to check all the boxes on the broker agreement to keep your options open. For example, if this is the first time you're acting as an employer, you might want your broker to interview staff with you.

Also, filling out timesheets can be confusing. Some brokers, to assure compliance, will initially help families by reviewing time sheets and reports, so there's no delay in FI payments to the staff.

Keep in mind that in addition to the time they spend at your COS meeting, or speaking with you on the phone, the broker spends time preparing for the meeting. They also may spend hours after the meeting following through on negotiating with the SDS liaison, speaking with your FI, or filling out forms for you.

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 Self-Directed Services Plans and Budget, and require more time.

Getting Started

Note: The first four tasks are required, and the rest are optional, to be decided between you and the broker.

OPWDD Broker Agreement

Identify the services the Support Broker will provide:

Note: To receive payment, the service must be identified in this agreement. Services provided but not identified in this agreement will not be reimbursed.

Check those that apply. The first four services listed must be delivered.

- ✓ Assist you to develop and maintain a Circle of Support (also known as a planning team) and assist in directing planning meetings.
- ✓ Ensure that planning meetings occur at least four times per year and are face-to-face.
- ✓ Ensure completion of and regular updating of habilitation plans for self-hired Community Habilitation and Supported Employment (SEMP) staff if you choose to have these services.
- ✓ Assist you to develop a comprehensive Self-Directed Budget that is consistent with your Individualized Service Plan (ISP) and to work with you and your circle of support to ensure that all necessary safeguards are included and addressed in your ISP.
- Assist you to develop a comprehensive Person-Centered Plan (i.e. the ISP and related habilitation plans).
- Provide education and training to you and your Circle of Support in implementing the Self-Directed Budget per Medicaid and New York State standards.
- Work with you, the Circle of Support and your MSC to help identify and develop initial connections in the community as identified in the ISP.
- Monitor self-direction expenditures to ensure that spending does not exceed your Self-Directed Budget by assisting you and the Circle of Support to review the expenditure report provided by the Fiscal Intermediary.

Getting Started

- Work with you and your Circle of Support to review and update the Self-Direction Budget as needed, so that it meets your needs and remains current and eligible for Medicaid funding.
- Attend your Individualized Service Plan (ISP) reviews and assist you to review, revisit and update your ISP as requested.
- Assist you to properly document services per Medicaid and New York State regulations and policy. This includes assisting you to review and submit to the Fiscal Intermediary (FI) employee time sheets, the monthly summary note, mileage and expense reimbursement forms, and all other required documentation.
- Assist you to hire and retain appropriate support staff. This includes:
 - Recruiting
 - Interviewing
 - Hiring
 - Scheduling
 - Supervising
 - Assisting you to identify and retain back-up staffing.

OPWDD Support Brokerage Agreement, <http://www.opwdd.ny.gov/node/6200>

Our Take: When the broker works for the FI, it can foster improved communication and coordination. On the other hand, there's also a potential for conflict of interest in that the broker might try to encourage you to purchase their agency's services with your budget, or steer them away from certain options. This isn't a reason to avoid an affiliated broker, just something to keep in mind.

A great way to find a broker is to get a recommendation from the family of someone using Self-Directed Services or your MSC. Just remember, different people respond to different styles. It's a good idea to interview two or three brokers to find someone who's a good fit.

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 SDS 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?

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)

Robust *person-centered planning* is critical to creating a satisfying life, because people who have minimal experience outside of school and the traditional developmental disability system often have no idea about how they want to spend their time. They have not been exposed to a wide variety of opportunities, places, and people and may be unaware of their options. Like many young people, people with disabilities often need to “try on” various employment, volunteer, recreational, and social opportunities for them to have real choice. This may take time – don’t shortchange your child by rushing the process.

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 SDS 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 SDS 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, wear 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.

Person-Center Planning

Person-centered planning IS:

- An open exploration of what is important and meaningful to the person
- A frank discussion of necessary supports and safety issues
- A practical discussion of how their day to day life can reflect their preferences
- 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 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 in a drawer
- A one-time thing
- A new way to decide which day program to choose
- An internet questionnaire

Who participates in the initial person-centered planning meeting?

1. The person (child, teen or adult) whose plan is being developed should be there.

Some teens or young adults can participate for the whole meeting, some may stay for parts and be excused when necessary, some will say hi and walk into another room. It's important to design the location, time, seating even the refreshments of the meeting with the person in mind.

Often, a person cannot clearly speak about their dreams, plans, or fears. That doesn't mean he or she can't use self-directed services. Michael Wehmeyer, (Essential Characteristics of Self-Determined Behavior of Individuals with Mental Retardation, Michael L. Wheeler, Kathy Kelchner and Sandy Richards, American Journal on Mental Retardation, 1996, Vol. 100, No. 6, 632-642) 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.

Person-Centered Planning

2. Parent/Guardian, siblings

The parents/guardians are not required members of the circle. They are typically included, but their inclusion is at the discretion of the self-directed services participant. That being said, the guardian (or parent if the self-directed services participant is a child) may override the circle's decisions.

3. Broker

Having the broker present at the person-centered planning meeting/meetings is not required by OPWDD.

Our Take:

That doesn't make sense to us. The broker needs to participate in PCP to be able to create the Com Hab and SEMP Plans and the budget. They can't do their job if they haven't gotten to know your child. So, make sure to check the box on the broker agreement.

4. Medicaid Service Coordinator-Required to be present

5. Extended family: aunt, uncle, cousin

6. School teacher, teaching assistant, coach, counselor, club leader

For those transitioning from high school much of the team may consist of school staff. However, it is helpful to also invite to the meeting people who know your child from other settings.

7. Close neighbor or friend of the family

8. Behavior consultant or another therapist. Specialists can provide insights and make suggestions for adaptations in different settings

9. Community member who knows your child: clergyman, scout leader, coach, business person

Person-Centered Planning

Who facilitates the meeting?

The start-up broker usually facilitates the meeting, but if you prefer someone else to take the lead, that's fine. You may want to do it yourself, but it may be easier for you to think about what others are saying if you are not running the meeting.

Choose a facilitator who has the following attributes (these are also the qualities of a good start-up broker):

- Team player; works well with others;
- Flexible and open-minded; does not make assumptions
- Person-centered and skilled at keeping the focus of the meeting on the person
- Good listening skills and ability to interpret behavior as communication
- Skilled at checking with the 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)

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 that he wants to be a doctor. The work 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?

Person-Centered Planning

Also, keep in mind: It is common for planned activities not to work out. That's OK, because the individualization and flexibility of Self-Directed Services gives people the freedom to fail at something without their whole schedule coming apart.

For example, if your child receives job coaching through self-hire SEMP, 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, role play interviewing, work with a job developer. Self-Directed Services lets you do all of this without bureaucratic red tape or staffing changes.

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 their box.

2. An open exploration of what is important and meaningful to the person.

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 supports necessary for health and safety.

Depending on the individual and what needs to be discussed, you may want to have part of this conversation when your child is not around. (See page 26 for more information).

4. Developing a plan.

Although most people's initial plan can be written after several meetings, you should not expect to have your child's complete schedule settled the day after you launch (officially begin your Self-Directed Services plan). A full slate of activities can take time to create develop, and try out, and there will likely be empty spaces in the schedule at first. However, you should have a good idea of what needs to be done (and who will do each task) to implement your child's plan.

"Often risk has two sides- like a two-headed coin. On one side is the possibility of loss, injury, or disappointment; but on the other side of the coin, risk can be seen as the possibility for opportunity, success, and personal growth. We can't ignore that the world is full of risks, and we can never avoid ALL risks. Although taking risks provides people the opportunity for personal growth, we have choice in the degree of risk to which we expose ourselves."

OPWDD: Risks and Safeguards

http://www.opwdd.ny.gov/opwdd_services_supports/person_centered_planning/risks-and-safeguards

Person-Centered Planning

Risk

Considering and managing risk is part of parenting; it's what each of us has been doing since our children were born. Every decision requires an understanding of what your child wants, their ability to cope, an assessment of the environment, and the chance of something potentially dangerous occurring. There are no right or wrong answers, just what makes sense for each person in a specific situation.

Safeguards

A primary job of the Medicaid Service Coordinator is to make sure there are adequate supports and services in an individual's plan to keep them healthy and safe. This requires a review of potential risks for the participant. Brokers are required to write the safeguards for the Com Hab plan. (Safeguards are a required part of the ISP for everyone using OPWDD Waiver Services. We'll only touch on a few issues here.)

Some risks are obvious, with clear solutions:

Does Jack know to leave the house immediately if the fire alarm goes off?

Solution: Staff will practice fire drills with Jack.

Mike tends to run off into traffic when crossing the street.

Solution: Staff is required to hold his hand firmly when crossing streets.

Technology can help keep your child safe while hopefully increasing their independence: Speak to your broker, MSC, or SD liaison about options.

- A device that will shut off the stove if it's been on too long
- Panic button in the house
- Prompts on a smart phone to remind him of the day's schedule
- Security camera

Are you concerned your child could have difficult encounters with police or other first responders?

Some families choose to speak with local first responders to make them aware of a specific individual's communication and behavior differences. For example, Project R.E.A.C.H. at the Nassau County Police Department allows you to register anyone in your home who might wander off.

Some risks are subtler:

Linda has been traveled trained, and knows how to get off the bus at her stop—but can a stranger easily talk her into giving away her lunch money or giving out her home address?

Patty goes to college with lots of support in planning her time and organizing her assignments. However, she has great difficulty in interpreting social cues. When a guy shows interest in her, she's flattered, but is not able to process what is happening in the moment. This has resulted in her having sexual interactions she was unprepared for and later regretted.

Our take: Sometimes MSCs are needlessly risk averse, and it can be helpful for brokers and the SD liaison to help think of creative solutions that expand and be more flexible with appropriate supports.

Medication

If your child takes medication, you need to plan for how this will be handled. Can he take pills by himself?

For OPWDD, Self-Medication Administration means that the person knows when to take their medicine, where to find it, and how to take it. Different strategies work for different people. Here are some examples:

Ashley volunteers in the office at an elementary school with the support of community habilitation staff. At lunch, she opens her lunch box; in addition to the meal she prepared in the am, her mom put her pills in a Ziploc bag, and Ashley has learned to take them after she eats.

Jason works part time in a local pizza shop with SEMP support. At 3pm a preset alarm on his smart phone goes off and he takes his meds.

Maria goes regularly to choir practice. While she uses a wheelchair, she knows when it's time to take her medication. She asks her community habilitation staff to put the pill in her mouth and give her some water with a straw.

Bob takes medications in the morning and at night. His mom fills his pillbox once a week and keeps track of when his prescriptions need to be renewed. His smart phone is set to play his favorite song at 8am and 8pm, to remind him to take his pills. He is able to read the days of the week and has learned the difference between AM and PM, so he takes the correct day's dose from the pillbox.

Our take: If you are approved for CDPAS, you can have your SDS support staff sign up with the CDPAS agency. Your staff can then change roles, from SDS staff to CDPAS staff when necessary.

Be aware that the hourly pay for CDPAS is set by the NYS Department of Health, and is usually lower than most people pay SDS staff. In order words, with CDPAS you have employer authority but not budget authority. You can also get personal care services through a traditional home care agency; they supply the PCA, who is their employee.

Medication

Are they unable to self-medicate?

There are several options.

Personal Care Assistance

If a person using SDS requires help with personal needs, medication administration, and other daily tasks they can hire a Personal Care Assistant (PCA). To get these services you need to apply to your local Medicaid office: this is done through your MSC. You can self-hire a PCA through a program called CDPAS (formerly called CDPAP, Consumer Directed Personal Assistance Program/Services).

Like OPWDD SDS, you can hire your own staff, who are paid through an FI, which could be through a different FI than the one you use for Self-Directed Services. Staff hired through CDPAS can be trained by a family member or other member of the COS to give medications.

Note: Payment for PCAs does not come out of your SDS budget, it comes through regular Medicaid, i.e., your Medicaid card, and can expand your child's total hours of services. Also, if an individual needs personal assistance (for example, assistance with toileting) at work, a PCA can work alongside a job coach. This is a rare instance where two people can be paid to support an individual at the same time. A PCA valued outcome for personal care should be included in the plan.

Supporting Medication Administration through SDS

You can also use your SDS budget to support medication administration.

There are two models used in different areas of the state, both use the IDGS indirect consultant line:

1. A participant able to self-administer medication, but who doesn't have family to fill the weekly medication bar, can hire an RN to come fill the box.
2. You can hire someone trained as LPN your community habilitation staff. An LPN may give medications under the supervision of an RN. The RN is paid as an indirect consultant with IDGS to supervise the LPN/Com Hab staff.

On the horizon: OPWDD is planning to create a system in which your FI can obtain authorization to allow medication to be administered by specially trained direct support staff at home or in the community. Your FI or MSC will know when this has begun.

Back Up

Backup Plans

For people that require 24/7 support, is there a backup plan for when staff aren't available? This is a critical issue when people are not living at home, but is also important when everyone in the family works or if a primary caregiver becomes ill or is otherwise unavailable.

Unless the participant lives in a certified setting, family is ALWAYS the (final) back up, except if the Circle of Support has identified an alternate backup plan.

When self-directed services were 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's critical for people who cannot be left alone.

There are two kinds of backup to think about: **planned** and **emergency**.

Planned backup (for vacations/personal time) is easier. Finding **emergency backup** can be one of the chief barriers to using self-directed services. However, many people work, and we're all going to age. We will need to push the system to help us develop sustainable solutions to meet the needs of everyone who wants to self-direct their services.

Using Family Reimbursed Respite (FRR)

With FRR you can pay whoever you wish (except for a family member living in the same house), to be with your child and you can get reimbursed.

Because the respite worker is not an employee of the FI, they don't need to complete an application, be fingerprinted., etc. (However, they need to fill out a W9 tax form for you to be reimbursed.)

A reliable friend or neighbor might be happy to spend some time with your child for the extra cash.

Our take: Family reimbursed respite can also be used to pay someone you want to hire to work with your child regularly, but who hasn't gotten through the FI hiring process yet.

Back Up

Here are some ideas for backup plans. Anyone paid through Self-directed services must go through the FI hiring process (except for Family Reimbursed Respite, see on the right):

- **Does your child have a friend using Self-Directed Services? Will their schedule let their staff person double up for the day?** This works best when you've planned ahead by having your child meet (and share an activity) with the friend and their support staff.
- **Is there a local community center or 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?** Brokers, particularly, may know of staff who are looking for more hours and would be willing to fill in. For this to work, it's important for your child to meet the support person in advance, and for the support person to have some insight into your child's needs.
- **Is there someone who's 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?**
- **A group of families in an area can create an email/text group, where you or the worker can send out a text or email to see if someone can cover.**
- **Can you use technology to provide virtual support?**
 - Alarms that will tell you if the stove is on for too long, and devices to automatically shut it off
 - Cameras that you can monitor from your smart phone
 - Mobile phone or tablet apps that help people to remember things to do, or prompt them through a sequence of tasks
 - Bed movement monitors to detect nighttime seizures
 - Alarms that will tell you if the outside door has been opened

On the Horizon

Every few months there are new technologies available. One company is creating a remote monitoring system. A computer link is set up between the participant and a monitoring station that is continuously staffed. The participant can press a key on their computer to be connected remotely to a live person, for reassurance, advice, or directions on how to deal with something unexpected.

It's great to check the internet yourself, and talk with your MSC and broker when developing the plan to see if any of these new technologies could be useful. Some of these tools can be funded through your SDS services plan; other can be paid for through regular NYS Medicaid.

Back Up

Developing a Plan

Although most people's initial plan can be written after several meetings, you should not expect to have your child's complete schedule settled the day after launch (officially begin your Self-Directed Services plan). A full slate of activities can take time to develop and try out—There will likely be empty spaces in the schedule at first. However, you should have a good idea of what needs to be done (and who will do each task) to structure your child's day.

Keep in mind:

Planned activities may not work out. That is okay, because the individualization and flexibility of Self-Directed Services give people the freedom to fail at something without their whole schedule coming apart. For example, if your child receives job coaching through self-hire SEMP, a lost job is an opportunity to visit places to develop a better idea of where they want to work, practice reading help-wanted ads, update their resume, roleplay interviewing, and work with a job developer. Self-Directed Services allow your child to do all of this without bureaucratic red tape or staffing changes.

Our take:

It can also be helpful to put together a list of tips for supporting your child in different situations, including any safety issues, contact information etc. It's also useful to come up with a list of ideas for when there is no formal activity planned. Especially at the beginning, staff need direction, options and ideas for things to do until a routine gets established. For some suggestions, see section "What do you do all day, anyway?".

(We have noticed that suggestions from staff are often better received by your child than those from you, so consider giving the list to staff in advance.)

What Do You Do All Day, Anyway?

Implementation

It's both thrilling and at times overwhelming to think about what your child will be doing once school ends.

The simple answer is that they'll spend their time doing some of the things that most people do: Brushing teeth, some chores at home, volunteering or work, hanging out with friends, taking a community class, attending their house of worship. Self-Directed Services offer support for all these activities.

However, it's important to understand that the intent of the Home and Community Based Services Waiver (which funds SDS) is to empower and enable people to engage with their larger community. Of course, each person starts from a different place depending on their challenges, personality, and interests.

What is community?

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

On a practical level, we've found that just being out in the community (at the park, at 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, to ushering at a community theater performance, or regularly setting up refreshments after a church or community meeting.

Social Inclusion

For many families, the elephant in the room is "How inclusive should a setting be?" (We're talking about teams, clubs, community classes, etc. here, not being in public places).

Will typical people see my child as a potential friend, someone who shares an interest, a mascot, or just someone to pity? Does my child get so anxious in a setting that they can't enjoy the activity?

Is the pace too quick? Are communication differences accepted?

What Do You Do All Day, Anyway?

Some families feel strongly that they don't want their child to participate in any groups consisting only of people with disabilities, and some people with disabilities feel similarly. Other families feel their child enjoys spending time with people with developmental disabilities who share their interests as well as with people without disabilities. These are individual decisions.

Note: Self-Directed community habilitation can support someone who is participating in a segregated activity, i.e. Special Olympics. However, SDS will not pay fees for a segregated program. (See above for Community Classes.)

Social inclusion means different things for different people:

For someone, with physical challenges, intellectual disability and complex medical needs, being able to join the family at the dinner table at Thanksgiving can be meaningful inclusion. Someone who is physically challenged and intellectually intact and able to do well in a four-year college may find that they can't penetrate the social community of their able-bodied peers. Social inclusion for them is feeling at home in the Student Union, making friends, dating.

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, has found opportunities to follow her passion in many different settings.

Special Olympics (open to people with developmental disabilities only) runs the basketball and swimming programs that she attends weekly.

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

Janet bowls in a regular league at the local bowling alley; her support staff person is a member of 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 and in many places, giving her a more multilayered life.

What Do You Do All Day, Anyway?

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

For people who find it hard to relate to others, there are ways to be apart but together. A sports fan enjoys being in a group of people in a bar watching football. An accommodation for a rock music fan may be getting to a small venue early, and sitting in the front so he doesn't have to look at the crowd.

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

Life is not supposed to be all fun and 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? Never the less, self-directed community habilitation is funded, as the name says to deliver habilitation services. Habilitation's purpose is to help people keep, learn, or improve skills and functioning for daily living.

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.

Michael Smull frames these concepts best:

It's helpful to think about the balance between **Important To** and **Important For**.

What is Important To a person includes those things in life which help us to be satisfied, content, comforted, fulfilled, and happy. It includes:

- People to be with/relationships
- Status and control
- Things to do and places to go
- Rituals or routine
- Rhythm or pace of life
- Things to have

What is Important For a person, includes:

- Physical health and safety, including wellness and prevention
- Emotional health and safety, including support needed
- What others see as important to help the person be a valued member of their community

For everyone, there needs to be a balance of Important To and Important For, and which piece you figure out first, matters. It is critical to learn first about what matters the most to the person, because no one does anything that is Important For them willingly, unless a piece of it is Important To them.

(Person Centered Thinking, SIS, ISPs and Quality of Life, Michael Smull for AAIDD June 2013. Also, see: www.sdaus.com and www.learningcommunity.us for tools to encourage person centered thinking.)

What Do You Do All Day, Anyway?

It may help to ask yourself these questions:

Is the proposed activity something you're sure that they will enjoy once they're involved in it (even if they'll say "no" at first)?

If so, try to figure out what the problem is:

- Is anxiety about the situation stopping them from participating?
- Is the problem transitioning from one activity to the next?
- Do they find a written or pictorial schedule for the day helpful?
- Is there a time of day during which your child is more open to something new?
- Is there an accommodation that the person can use during a stressful situation, for example, wearing headphones for part of the time?
- Can you sell the activity by embedding it into a preferred framework? (For example, we've read about Ron Suskind, who communicates with his son using the voice of a Disney character. Other families make up songs to teach lessons or make required tasks into a "competitive" game.)
- Is there an effective reward?

Or: Is it something they hate to do?

- If so, do they **need** to do it? (Examples: Shower brush teeth, yes; make the bed, fold laundry?)
- At what point in trying to teach/persuade someone to do something does it make sense to give up? One example is learning to make change; at a certain point, it is okay to decide to stop trying to teach a skill that is not going to be learned.

Our Take:

SDS are not intended to support pathology; they are meant to help a person to lead their best life.

For example, Hari, loves Star Wars. He has all the movies on DVD and collects the action figures. When people call him Luke Skywalker he smiles, and when crossed he is apt to threaten his foes with his light saber. When Hari has been doing well, support staff creatively use his passion to include him in the Star Wars enthusiast community. He joined a Star Wars fan club at his local library and is part of an online fan group.

But recently he began to resist coming to the dinner table for meals, rushed through showers, and refused to go to work because every minute away from Star Wars was painful.

This is an example of when a passionate hobby tips over into unhealthy preoccupation. SDS are not intended to support pathology; they are meant to help a person to lead their best life.

It's not productive for staff to use "that's what he feels like doing" as an excuse to not find a way to help him do things that need to be done. Experienced com hab staff will use that passion to motivate someone to do a necessary activity.

(Of course, there are altering levels of wellness, especially for people with dual diagnosis; some days may need to be down days, with a simplified schedule and lowered expectations.

What Do You Do All Day, Anyway?

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 or physically?
- Do they need time built in for transitions between activities?
- Are there particular activities that are stressful for them? Think about spacing these out through the day or week.

Location, location, location

There could be a great job or other opportunity that requires significant travel time, and that's okay, but all other things being equal it's best to try to keep it local. Why local?

- People get to know your child when they see them frequently in the community. The more people who know your child, the safer he or she is.
- There are more chances to develop sustainable relationships.
- It helps develop a network of community connections.
- Many people are comforted by feeling more rooted to the place they live.
- 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 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, shopping, etc.?

Remember, you can get reimbursed for staff expenses when they accompany your child, to the movies for example. However, you need to keep receipts.

The system can be as simple as an envelope in the house for receipts and change, or a notebook where expenses are written down.

Out in public while disabled

If your child has a history of yelling, cursing, or other potentially disruptive behavior, you're 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 and larger your child gets. It is very scary when the authority figure you'd normally turn to for help sees your child as a threat.

What Do You Do All Day, Anyway?

It's critical to plan for foreseeable problems so staff can help defuse situations. It's helpful to develop and write down strategies staff can use when they are out with your child. Consider emailing the list to staff so they can access it easily on a smart phone. Here are a few things to consider:

- If your child falls apart in public, is there a breathing technique or a specific phrase that will help them regain composure?
- Give staff a sentence or two to describe your child's disability to an authority figure if necessary.
- Give staff the name and phone number of someone they can call if they need immediate help, such as a parent or another family member.
- Let staff know if they should text you in an emergency or place a phone call so you can speak with your child directly.

A great place to discuss strategies like those above is with your Circle of Support. Veteran staff can model approaches in the field and give advice to others. It is important to remember that such discussion might not be appropriate in front of your child, especially if the content will trigger or upset them.

Remember, with Self-Directed Services, staff are working without a net. The reason we are belaboring these issues is that staff are frequently out in the community alone with your children, unsupervised. The more you can prepare them with strategies, the more comfortable and competent they will be, and ultimately, the safer your child will be.

Supported Employment (SEMP)

The Basics

After finishing high school, the expectation for most people is that they will go to college or to work, and the work will pay minimum wage or more. The same is now true for people with I/DD. OPWDD has recently restructured SEMP to help people become more successful at finding and keeping real jobs. The new approach acknowledges that people often need to try out different jobs in the community to find the right fit, and that more effort needs to be made in individualizing job placements.

OPWDD has labeled the first part of this process **discovery**, and describes it as the opportunity for an individual to participate in vocational community experiences to help determine the individual's skills, abilities, and unique talents and allow the individual to make informed decisions.

(Adapted from OPWDD Day Service Provider Conference Nov 5, 2015)

People can get these experiences in several ways, as discussed below:

The second part of the process of finding and keeping a job is matching the individual to the right job for them, and learning the kind and amount of support they need. That is the role of the **job developer**.

The **job developer** gets to know 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 and would then assist with any accommodations the person needs to do their work.

SEMP is a person-centered employment planning and support service that helps with an individual to obtain, maintain, or advance in self-employment or in competitive, integrated employment in the general workforce, for which the individual is compensated at or above the minimum wage.

[OPWDD's Definition of Supported Employment](#)

Another approach is for a job developer to investigate what a business needs, and create a group of tasks that add up to being a job for someone. This is called a "carved out" job. After a person secures the job, the job developer shows the job coach how to support the person at work.

Some people need ongoing, continuous support of a job coach to be able to function well at work. Other participants benefit from having a job coach stop in once a month to help address any concerns that might have come up for either the person or the employer.

Supported Employment (SEMP)

Some of the tasks a job coach may perform:

- Help the person interact with the manager
- Help the person relate to their coworkers
- If needed, make a checklist of job tasks (maybe kept on a smart phone)
- 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 of their own while working with your child.

Self-Employment

SEMP may include services and supports to assist an individual to achieve self-employment, including home-based self-employment. A service provider may assist an individual in identifying potential business opportunities, developing a business plan, identifying community resources that could assist the individual in operating a business, and providing ongoing supports and assistance, as needed once the business has been created. The service provider is prohibited from staffing the business and purchasing supplies or equipment for the business.

Examples of self-employment:

- Yard work
- Dog walking
- Create a product and sell it

While Still in School

Students with disabilities who have jobs during high school have a clear advantage when looking for work after graduation. It's important to encourage your school district to support your child in a job while still in school. Some people work as part of their school day or (if your child is eligible for an extended year program) during their summer vacation. The earlier you get started, the more work-related experiences your child will have upon graduation.

Self-Employment

Tasha loves to bake. With her community habilitation worker, she has perfected her muffin recipe. Despite many attempts, she has not been successful in any out-of-home work environments.

Her broker is involved with Habitat for Humanity, and thought that Tasha might do well selling muffins at the work site during break time. Now her muffins are in demand at several meeting places around her town.

Supported Employment (SEMP)

Every student who receives special education services is required to have a transition plan as part of their IEP, starting at age 15. Students whose post-high school goal is employment can request work experiences as part of the child's day. For most students, an individualized job placement with one-to-one support is necessary for work in the community.

How to make it happen:

- School service clubs - the school is required to supply support staff if necessary
- Community job during the school day
- In school job, for example: office work, messenger
- Summer jobs - through your child's Extended School Year Program
- Jobs in the afternoon or on the weekend
- Speak to people you know to explore possible volunteer work or employment opportunities in your community

Your child can have a part-time paid job while in high school. The Employment Training Program (ETP) is an OPWDD funded program that your child can access in high school. It offers an opportunity to gain work experience through a paid internship. The school district is responsible for finding the internship and hiring/paying the job coach. OPWDD pays the student's salary through non-Medicaid funds. The great advantage of ETP is that it is completely individualized. Speak to your school's transition coordinator or whoever has that role in your district for more information.

Our Take:

Schools can be reluctant to supply 1:1 support to a student during a work experience and you may have to advocate for your child. Call a CSE meeting to discuss the issue. Invite your school transition coordinator and make the team aware you want to review your child's transition plan.

Another thing to consider is whether to take your child out of a high school class to go to work. While our children are in school, we tend to get caught up in the day-to-day stresses and strains. Have you thought about whether your child will be moving on to post-secondary education or joining the work force after graduation? Consider the benefits of allowing your child to use school time and resources to explore employment opportunities.

Finding the Right Fit

Sophia told her job developer that she wants to be a famous ice skater when she grows up. Her job developer asked her what she loved about ice skating — she answered, "the organ music, the sparkly skirts, and the hot chocolate at the end of a skating session."

After more assessment, Sophia got a part-time job at the skate rental desk at her community skating rink. After work hours, she began skating lessons and ends each lesson with a mug of hot cocoa.

Supported Employment (SEMP)

ACCES-VR

ACCES-VR is a required stop on the road to OPWDD SEMP services after high school. ACCES-VR is an NYS Education Department agency that funds career counseling, job training, time-limited job coaching, and other supports. ACCES-VR will also fund vocational education. Generally, they only offer services to people they believe will be able to eventually function independently (i.e., without paid support) in the workplace. Some people with I/DD can benefit from ACCES-VR services.

Many people with disabilities can work at typical part- or full-time jobs but need continuing support. Finding work for others requires a more creative approach.

After they are contacted, ACCES-VR assesses the student to see if its services are appropriate. ACCES-VR and OPWDD have agreed that if a student has any of the following needs, they can skip ACCES-VR assessment and be directly served through OPWDD SEMP:

- The student can only work for short periods of time
- The student requires a highly intensive set of program, behavioral, transportation, or other supports to work that are unavailable through ACCES-VR
- The student enquires a longer period of program, behavioral, and/or other supports to develop their capacity to work.

Students who meet one or more of these criteria are given a denial letter by ACCES-VR and can go directly to OPWDD SEMP for services.

Self-Directed SEMP through your SDS Budget

If you don't already have a job, OPWDD requires you to go through discovery before you can use your budget to pay a job developer or job coach. As mentioned above, discovery is the process of figuring out the work an individual wants to do and the type of support they need to be successful at the job.

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 though this was a terrible idea, although she was smart enough to keep her opinion to herself. After a visit to the store, Becca agreed to try it out.

Becca has been working at Walgreen's for six years now, earning substantially more than minimum wage. Her hours have slowly increased to five hours a week spread over three days. She comes in to work on a specific task that meets her abilities and loves her job.

JEREMY

Jeremy loves dogs. His neighbor is a teacher with two dogs that need to be walked in the middle of the day. He walks the dogs for about 20 minutes each weekday, accompanied by his staff. He earns \$20 a week. Jeremy gets to be with dogs, 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.

Supported Employment (SEMP)

There are various ways to satisfy the requirement for discovery:

1. **ACCES-VR** – funded through the NYS Department of Education, as discussed above
2. **Employment Training Program (ETP)** – speak with your MSC for more information
3. **Pathway to Employment**
 - a. OPWDD states that Pathway Services focus on:
 - Pre-employment skills
 - Integrated community vocational experience
 - Development of a vocational or career plan
 - Achieving the greatest level of independence possible
 - Self-employment options
 - b. The services are limited to one year or 278 hours total of billable service time. Participants generally use Pathway as part of their day, not as a full-day program. It can be delivered to one person or to a group of up to three people. (Pathway to Employment, MSC Training, September 2014.) Pathway must be purchased as an agency service.
4. **Community Volunteer or High School Internships**

We discussed this option above in detail for students. However, if your child did not have the chance to try out jobs in high school, that's okay! A SDS participant can use community habilitation support to explore volunteer jobs in the community. It's important to note that current regulations do not allow SDS participants to volunteer at a for-profit business.

Our Take: When exploring possible jobs for your child, try to think about all the aspects of the experience. It's not just the task itself that determines whether they will be able to maintain a job or not. Ask yourself:

1. What is the physical environment like?
2. Are the aisles easy to navigate?
3. Is there natural light?
4. What's the ambient noise level?
5. Are their odors or other sensory things that might bother your child?
6. Are there any issues with accessibility?
7. What is the emotional atmosphere like?
8. Do the workers seem welcoming?
9. How many co-workers will your child interact with? How many customers?
10. Is there a good vibe?

Supported Employment (SEMP)

Giving teenagers the chance to volunteer and work in different jobs in their community often gives the most useful information.

Don't underestimate the value of employment for your child. We have seen ongoing benefits of work for our children, even those who work as few as two hours a week.

OPWDD divides SEMP into two categories:

Intensive SEMP services include job development and/or intensive job coaching and may be provided as:

- Intensive 1, which is Intensive SEMP provided to one individual; or
- Intensive 2, which is Intensive SEMP provided to a group of 2-8 individuals
- Extended SEMP services include ongoing job coaching and career development services provided to individuals who may have received up to 365 days of intensive supported employment services and who are currently employed.

Extended SEMP may be provided as:

- Extended 1, which is Extended SEMP provided to one individual; or Final Regulations: SEMP redesign Summary Page 2
- Extended 2, which is extended SEMP provided to a group of 2-8 individuals.
 - The amendments also include provisions for SEMP services and supports to assist an individual to achieve self-employment, including home-based self-employment. Wages earned in self-employment may be below the New York State minimum wage.
 - Intensive and Extended SEMP may be provided as self-directed services to an individual who hires his or her own SEMP support staff.
 - The amendments include qualifications for staff providing SEMP services and a definition of competitive integrated employment to the glossary found in section 635-99.1

OPWDD, summary of final SEMP Regulations, July 2015

Volunteering

For people who are always on the receiving end of services, it can be very satisfying to be the one who is contributing. It also helps others to see value in people with disabilities. Participants in SDS can volunteer for any nonprofit or government entity, but labor laws prevent volunteering at a for profit business.

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

- Your local Yellow Book
- Your Public library
- Your County legislator knows the nonprofits in your area they've gotten funds for!
- www.volunteermatch.org

Ideas for volunteer jobs:

- Community Service Events, like Beach Clean-Ups
- Library
- Park
- House of worship, preschool, offices
- Guide dog foundation
- Nursing homes
- Hospitals, Local government, i.e., filming community closed circuit TV meetings
- Political campaign
- Help with children's sports teams
- Community centers and Ys
- Food bank

Jae

Jae has struggled at finding and keeping volunteer jobs. He often has difficulty staying calm and focused, and his behavior is distracting to others at times. Jae has always enjoyed being in church and likes to keep things neat. Using these interests, his circle created a volunteer opportunity for him; straightening hymnals, sweeping up small messes, and performing other housekeeping tasks. Because there was no fixed time to show up, he could come and go when it was best for him. Jae was successful, and pleased with himself, and his church community was happy for his help.

Circles can play an important role in developing novel volunteer experiences.

Post-High School Education

People using Self-Directed Services may choose to go to college, technical school, or take continuing education or GED courses in the day or evening. Self-Directed Services will pay for support staff.

Many people attending college may not need ongoing daily support, but may need help at transitions. It's a good idea to consult a resource room teacher, guidance counselor, or transition coordinator who knows your child well about the type and amount of support they believe your child will need in college. We have seen that sometimes families underestimate the level of assistance that their children received in high school, especially in the areas of organization and planning.

If necessary, a behavior consultant or other staff could be hired (under your SDS budget) to orient the student to their new surroundings, for example:

- Learning their way around the campus
- Rehearsing how to self-disclose to Disability Services, and request any necessary accommodations. (A parent cannot do this for a student if she is over eighteen.) Disability Services can explain the types of accommodations and supports available to students. They can also act as a liaison between your child and her professors, if necessary.
- Setting up a study schedule, especially for completing long term assignments
- Finding the commuter lounge and lockers
- Connecting with the writing center
- Finding which campus café has gluten-free options, or meets other dietary requirements
- Helping the individual organize their time

Creative College Solutions

Mark wanted to learn to speak French, but felt that taking a course for a grade would be too much pressure for him. So, he audited the class for a semester (OPWDD's Self-Directed Services paid for the class), with com hab staff for support.

The next semester, with support of his SDS staff, he took the course for credit (Self-Directed Services can't pay for a credit-bearing course). Whether he completes his associate degree, he is pursuing his interests, expanding his knowledge, and spending time with peers.

Note: 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 Self-Directed Services budget to pay for adult learning courses if they don't result in getting credits towards a degree.

Post-High School Graduation

If your child enjoys school, but doesn't want to or is unable to pursue a degree, think about college in a broader way. Continuing education courses at community college are another option. Both public and private colleges offer continuing education for example cooking or computer skills.

Other opportunities to learn:

- Toastmasters has helped some people to work on their presentation skills in a supportive environment. (www.toastmasters.org)
- Libraries and Community Centers often offer classes in crafts, computer skills, etc.
- Many school districts offer extension courses for community members in cooking, arts and crafts
- First aid courses

Life Skills: Tasks that someone must do for you if you can't do them yourself

For many of our kids, daily activities present countless learning opportunities.

If eating is motivating, different days may focus on recipe searches (library or computer), creating a shopping list, going to the market, or cooking. There's no have to list; 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, counting and weighing, taking a deli counter number and 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 tasks are important to master, but to demonstrate how your child can spend much of their time doing ordinary things, while have it be satisfying, productive, and hopefully, meaningful to them.

Recreation

Recreation is about relaxing and having fun—hanging out with a friend, joining an organized group, or just doing something you like to do on your own.

Community Classes

Community Classes are a good way to meet people who share your interests. Here are some examples:

- Martial arts classes
- Local bowling teams
- Jewelry making class
- Zumba class
- Bird watching group
- Local drama group
- Knitting club
- Fan clubs
- Yoga or Tai Chi

Com hab staff can accompany your child (make sure you clear this in advance), and help support her. For example, a budding artist wants to take a class in drawing at the community center and her com hab worker simplifies the teacher's directions for her to understand. Your SDS budget can pay for integrated community classes.

What if your child has tried regular community classes, but even with support hasn't been able to be successful? For example, the pace may be too quick moving or complex, or extraneous noise may not be tolerated.

If someone want to learn to play a djembe, but group drumming classes are too challenging, you can choose private lessons from a teacher who offers those to anyone. The cost of the lessons can be paid through IDGS.

Recreational Ideas

Meet for snacks, lunch or dinner

Play video games

Take the ferry to Connecticut or Fire Island

Go to the beach

Go out on a day fishing boat

Walk around the waterfront or visit an interesting area

Recreational shopping

Visit an aquarium or planetarium

Picnic in a park

Membership in a local gym

Recreation

You can consider classes offered by OPWDD provider agencies. However, these classes tend to function a lot like traditional day programs. Further, classes run by OPWDD provider agencies for people with I/DD cannot be paid for through your child's SD budget.

A bit more research into a suitable learning environment can prove fruitful; some communities have developed programs that are open to anyone who is looking for a more relaxed atmosphere or slower pace. An arts center in Troy offers classes open to anyone in the community, who because of their attention span, need for breaks, or slower pace, might feel pressured in a regular class.

A karate school in Brooklyn started a class for people who wanted a slower pace and more guided instruction but it's open to anyone. There's a slower pace yoga class for seniors, as part of a school district's continuing education program in Nassau County that also has attracted people with disabilities.

Our take:

If no classes that suit your child's interests are available in your region, help start one! Consider collaborating with a community center, Y, arts center, your school district's continuing education program, or someone with a skill to share. Hand drumming? Cooking? Computer skills?

Sometimes your child may want spend time at activities that are targeted to people with developmental disabilities where there might be more flexibility and less pressure.

Many communities have recreational programs for young adults with disabilities; some are offered by towns, some by local nonprofits. These tend to be either sports and/or social programs. How to find them:

- Call your township, or go to their website and search "recreation guide."
- Special Olympics offers numerous no-cost opportunities for those interested in sports: swimming, basketball, softball, soccer, floor hockey, golf, bowling, swimming and others. Go to the New York Special Olympics website: www.nyso.org. Activities that take place weekly are not listed on the website; you must contact your local office. The contact information is on the website.
- 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 local disability organizations have their own lists –ask your broker, FI, MSC

Friends

When kids are in school they spend most of their day with others of the same age. However, providing social opportunities for people who have finished school and are using Self-Directed Services usually doesn't just happen; it takes planning.

What's a friend?

Because they share experiences, people using Self-Directed Services and the staff who support them may develop a true natural bond. These relationships look a lot like friendships; for many of our children, staff are, in fact, the closest they come to having friends.

We are very grateful that relationships with support staff offer an opportunity to model friendship, but it's 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 directly clearly state that they want friends who aren't paid staff. Others are not. Again, 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.

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 tend 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 child could make a friend; just think about how many people you've had to meet in your life to find a few close friends.

Here are some ways to find friends:

Often, the best way to make a friend is to hang out in places or participate in activities that interest you. Your broker, support staff, MSC, or other professional may know of someone your child may get along with. Would they like to meet for ice cream, go to a park, walk their dogs together, go to a ball game?

Friends

In some areas, families have created interest groups on their own, or with community partners; they set up meetings online. For example: a travel club, a walker's group, (gamers' groups, etc.) The goal of these groups is NOT to reproduce traditional group activities for people with disabilities, but to bring people together to enjoy shared interests and to furnish opportunities for individuals to meet and develop friendships.

Another advantage of these groups is that staff can meet other participants and their staff. These networks can be helpful in connecting people who might get along but would be reluctant to attend a group activity.

An FI on Long Island sends out announcements of community activities weekly, as does Parent to Parent of New York State in some areas.

More about 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 community events, nursing homes, Barbeques and pool parties
- Meet up for an outdoor concert
- Movies

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

Our take:

Remember that it often takes meeting people a few times to know if a friendship could develop. People may need help to facilitate friendships: practicing listening skills, taking turns, sharing, etc. Direct support staff, or a consultant (psychologist, social worker, 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.

Local Bands

Mike is a metal rock aficionado. He enjoys going (with staff support) to local clubs where he listens to the band his boss from the record store plays in. It's usually a small gathering and others from work are there. They're all wearing the band tee shirt and cracking stupid jokes.

Mike knows the words to the songs, and feels surrounded, affirmed, part of the gang. This is the community that's meaningful to him; he's not interested in socializing with people in the usual social venues. Standing on 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 he will carry with him for weeks.

Follow the Money: Budgeting

The broker will write up the Self-Directed Services Budget. Make sure you go over it in detail with her before it is submitted. The financial information can be confusing, so don't hesitate to ask all your questions!

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)**. Self-Directed Services budget costs for an individual's plan may not exceed the PRA. In practice, the amount of money needed to support the participant may be less than the PRA, especially if they are living at home. This is the reason to make sure your plan clearly documents the need for all the supports and services needed to support your child's person-centered plan. **Thoroughly justifying your child's support needs will help to get the level of funding your child requires.**

Our take:

If it seems that your child's PRA is inadequate to support her needs, it can be helpful to look back at the assessment tool to make sure it's an accurate reflection of your child.

Note: Your broker will tell you the allowable range of pay rates in your region of the state.

Questions to ask yourself about the budget

- Do you want to pay certain staff at different rates due to differences in experience, education, or job responsibilities?
- How will you budget for staff vacation/personal/sick time? Make sure to review your FI's policies.

Will you be using consultants (behaviorist, job developer, etc.)? If you are planning to pay for them through SDS, there needs to be money budgeted. Their hourly rate is significantly higher than that of direct support staff. Speak with your broker.

If your child still lives with you, do you want to include respite? Respite is the service that lets you hire staff to support your child when you need (or want!) to be somewhere else. There are several ways to do this, so speak with your broker.

What if you've met with your broker, had all your required meetings, signed all your forms, and the process has stalled?

The first step is to call your broker to make sure the plan has been submitted.

If so, you might want to find out where the plan is in the system. If your broker cannot give you this information, you can call your regional Self-Direction Liaison.

Follow the Money: Budgeting

What if you are dissatisfied with your broker?

Remember, although it's usually better to try to continue the process with the broker you started with, you have the right to change brokers, just as you can change your MSC.

What are the responsibilities of the Fiscal Intermediary Agency (FI) and how do you choose one?

Self-Directed Services plans operate on a co-management model. The individual/family is the managing employer (provides on the ground supervision) and the FI, 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 employee taxes, benefits, insurance, etc. The FI also pays consultants and reimburses you for other expenses covered by your plan. They screen new hires by doing a criminal background check, process their applications, and arrange for fingerprinting by OPWDD.

The FI collects and reviews all paperwork to assure Medicaid compliance. That's why there are very specific rules about documentation ("cross out errors with one line through them, then initial," etc.). They then bill OPWDD to pay for the self-directed services and supports the person has received.

Our take:

Currently FI services offered around the state are not consistent; some FIs, for example, will not support a Live-In caregiver. Make sure your budget is submitted to an FI who supports the services your child needs! If the FI who initially reviews your budget does not support an allowable service that's in your Com Hab plan and budget, you can change FIs.

Also, be aware that FIs offer different benefits to direct support staff, so their fringe rate may differ; and the fringe rate also comes out of your budget. For those who want to understand how the FI calculates budget and benefits to employees, ask your FI about their fringe rate. Keep in mind that a low fringe rate may sound good to you, but it may signify that staff are not getting good benefits, which may influence retention.

Circle of Support

OPWDD seems to be using the words “Circle of Support” very broadly, but there are specific requirements for the Circle of Support in Self-Directed Services.

Your MSC must participate in every Circle meeting, and should be in the room unless it is not possible; in that case, they may join by phone. Your start up broker must attend all meetings, because they are creating the plan. However, the support broker is not a required member of the COS.

Our take:

In our experience, people are most successful when the support broker is an active part of the team, on an ongoing basis.

The circle meets regularly during the planning stages, and is required to meet at least quarterly once the plan has been approved.

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 staff who support the person. As parents, we are sometimes reluctant to ask others, who have their own responsibilities, to join a COS. Sometimes it helps to have the broker or a friend invite someone to join the circle. It’s important for people to know that circles are fluid; people come and go, it’s not a lifetime commitment.

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

If the circle needs expertise in an area, for example someone wants to move, consider inviting a housing specialist to a COS meeting.

Our take: When you’re using a consultant, such as a job developer, it’s helpful to invite them to circle meetings. It’s an opportunity for people who currently support the participant to give valuable information to the developer that will inform the process of discovery; and it’s important for the developer to give an update on his progress so that circle members can reinforce necessary skills.

The circle supports a person by:

- Generating ideas
- Developing strategies
- Creatively solving problems
- Developing community opportunities
- Training staff
- Keeping the focus on the person

Staffing

What's the job of Com Hab staff?

Working as 1:1 support staff for someone with I/DD is a balancing act, between serving as a peer model/friend and being the person responsible for safety, guiding, explaining, encouraging. **The job is not: babysitter, policeman, or bystander.**

1. Support and teach "life skills"

This includes tasks both inside and outside the home, the things that everyone does daily. Keep in mind that some people 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.

2. Facilitate community inclusion

It's relatively simple to be **in** the community, but much harder to be a part **of** the community. For Mike, getting the dog on a leash and out walking in the neighborhood was an accomplishment. But the real payoff came when staff helped him meet other dog owners, speak with them about their dogs, and become part of the dog walker community. (For some strategies look at the section on staff training)

3. Keep the person safe and healthy

4. Advocate

Staff are advocates for the person they support and teach the person to advocate for herself.

Job requirements for direct support staff

1. Playing multiple roles

Supports through Self-Directed Services are 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, and then going to the gym to work out. This flexibility makes the life of someone using Self-Directed Services seamless, and more like everyone else's life, but it may be a challenge for some staff.

Scheduling Staff

Scheduling staff can depend on shared interests as well as a staff person's skills and talents. Two examples:

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

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

Staffing

2. Range of support required

People served by Self-Directed Services have a wide range of abilities and support needs. And 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 be physical, emotional, behavioral, that's the job. Similarly, if someone needs help navigating their college campus, that can be the job too.

3. Need for initiative

Staff are often alone with the person they're 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 people doing this job have good judgment and initiative. They need to be able to read the person, be capable problem-solvers, and have the ability recognize when to ask for help.

4. Intersection between choice and judgment

Everyone has limitations to their choices: money, family commitments, what's legal and what's not. People using Self-Directed Services have the same constraints.

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

5. Providing direct support through Self-Directed Services

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

Hiring Staff

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, realistically speaking, that you're unlikely to find someone who meets all your criteria. Similarly, we know there isn't a fairy godmother to conjure up the perfect staff for your child. We're just suggesting qualities you might want to think about when hiring. It's your choice.

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

Most important is to trust your gut reaction to the person, and this works both ways. Sometimes you get the sense that someone will click with your child, and that's as important as any skill 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 feelings about someone you're thinking of hiring, pay attention, it's probably important, and more than likely a reason to gather further information before making a final decision.

Staffing

Hiring Direct Support Staff

Choosing your direct support staff is one of the chief benefits of using Self-Directed Services, but hiring isn't always easy. You may have a prospective staff member who looks great on paper and whom you like a lot; but if there's a personality mismatch with your child, it's probably not going to work out.

Things to think about when hiring support staff

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

- Able to think and act independently
- Flexibility
- Organized
- Responsible
- Good communicator
- Share interests with your child
- Personality style
- Sense of humor

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

Consider this: people who have worked in traditional services may be very dedicated to the field. At the same time, people who've worked in agencies have generally not been encouraged to be out of the box thinkers or to facilitate inclusion. However, they may bring skills and experience that are valuable to your child.

Recruitment

Job description:

You want to describe the person who'll be supported, some of the activities they'll be participating in, and the qualities in a worker that you're looking for. Include specific days, hours, and pay. It's useful to be honest about the disability and support needs, but there's 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 (Yankee fan, loves rock music, likes to bake, etc.).

Finding staff

Personal connections:

Think about people your child gets along well with: prior teacher aides or retired teachers, coaches, people in your neighborhood, friends of friends, current or prior respite staff. Ask everyone you know. Ask your Self-Directed Services liaison, MSC, broker, friends of siblings, children of friends. Look around your 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.

Staffing

Our take:

Try to keep your mind open when evaluating job candidates. Some people who apply may be interested in the job due to their background or future job goals; others might be intrigued by working with someone with a shared interest.

Advertising:

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

Talk to your friends and family, give them a copy of your job ad, and ask them to spread the word. Maybe your nephew has a roommate who's eager to do this?

People have varied success with Craigslist or Indeed.com (tips on doing this: require a resume, think twice about putting your phone number in the ad, screen people carefully over the phone first). Pinning up ads on college and university billboards, houses of worship, community centers can be helpful. Also, don't forget about organizations that have electronic community boards.

In some areas of the state, families are organizing meetups of families who need staff and people looking for work.

Hiring

Resumes:

- Not everyone has a resume - it doesn't mean they can't do a great job.
- If the candidate has a resume, does it lead you to believe that they are truly interested in this work?

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

Some of our children respond more positively to having support staff who are young adults themselves. In addition, they can act as cultural informants, helping your child pick out clothes or exposing her to music. Just remember, young adults' lives may be just as in flux as your own child's. Be alert to maturity issues and ability to make a commitment. Young people may need a longer period of mentoring and supervision.

Staffing

Some people who provide direct 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 insight on how they will approach your child.

Boundaries

It may feel wonderful to be able to hire as direct support staff someone who has a close relationship with your child because they're a friend, family member, or neighbor, and this is often a good choice. However, if they unexpectedly leave you in the lurch, or if it's not working out, how will it affect your relationship with them and their family?

Location, location, location

All other factors being equal, it's easier to hire staff that live close to you (or your child, if they're not living with you). Living nearby decreases lateness and absences due to bad weather or traffic problems, and the person may be more easily available for emergency coverage.

References

It's helpful to speak with a current or former employer, and a personal/character reference: Did the employee show up on time, get along with coworkers, take direction from supervisors, get along with customers? If a problem arose, did they have good coping skills?

Speaking to a personal or community reference, such as a teacher, team coach, or neighbor, can give you a more well-rounded picture of the person.

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, bringing different strengths and interests to the job. However, this needs to be individualized; some people are happy with one or two people, others have 4-5.

Emma

Emma, who uses Self-Directed Services, wants to learn to bake muffins and cakes. Her next neighbor Jane, is a great baker, and has known Emma since she was born. Emma and her circle decide to hire Jane to bake with her for 3 hours a week. The circle also suggests that Emma may want to learn to make her own lunches, too.

Nate

Nate earned an MBA, then realized that business wasn't for him; he wanted to be a musician. However, he needed a day job to pay his expenses. He had never thought of supporting a person with disabilities until a friend mentioned Chris, a young man using Self-Directed Services who wanted to learn to play guitar. Although initially anxious about working with someone with a disability, getting to spend time with another music lover and teaching him guitar drew Nate in. He's now one of Chris' favorite support staff.

Staffing

Terms of Employment

Although it may be awkward, it's best to discuss these issues upfront. This helps to avoid later conflicts based on misunderstandings. Be aware that each FI also has an employee handbook with their own policies and procedures.

Clarify expectations

- Will there be a probationary period?
- How often will they need to come to team meetings?
- How often, and in what way, should staff communicate with you? (Text/email/phone calls/in person).
- 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 a problem?

If you can't be available to deal with unexpected issues that come up, they need to have an alternate contact. Remember, with Self-Directed Services, **YOU** are the staff's supervisor. (Some people may be uncomfortable helping your child with "private" things. It's important to be clear before hiring.)

What about giving notice?

It's hard to talk about this before someone has started a job, and no one ever wants to plan for the end of a work relationship, yet we know this is not generally a lifelong job. One way to bring this up is to tell the candidate: "We hope this will be a long-term relationship, but recognize at some point you may move on. 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.

Similarly, staff should give you several weeks' notice if they're going on vacation.

Our take:

Everything we've written above is about the world as we'd like it to be. However sometimes, you're choosing between two less than optimal candidates. Choose based on what's most important: reliability, shared interests, someone who see the person before they see the disability.

Benefits

Health insurance

Speak to your broker or FI about how staff can receive health insurance. Different Financial Management Services (FI's) have different policies concerning coverage. These usually include a minimum number of hours worked.

Staffing

Paid time off (holidays, vacation time, personal time, sick time)

These policies are usually set by each FI. It's helpful to familiarize yourself with them.

Hiring Consultants

Consultants are in a different category than direct support staff, Consultants who work with and train staff, are funded through the IDGS budget line in your plan, and don't receive health care or other benefits. They bill by giving you an invoice to sign and submit to the FI.

There are also consultants who work directly with your child, such as a feeding therapist; those services are considered direct health services and are paid for with your child's Medicaid card or a parent's private insurance.

Recommendations are a great way to find consultants:

Your MSC, broker, SDS 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 through your SDS budget.

Keep in mind that a professional who is perfect for one person may not be a good fit for your child.

Direct Support Staff Training

What skills do staff need?

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 another disability specialist may be useful. (Of course, you can teach these yourself, if you wish).

Want your valued staff to stay longer?

Show people you appreciate the job they are doing with your child. Studies suggest this is a key factor in staff retention.

The easiest way: as we say to our kids, use your words.

Acknowledge that what they do is important and challenging, and praise them for their successes.

Holiday/Birthday gifts: This is very individual, but it's 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 the staff member. For the holidays, many families give staff a cash gift to express their 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

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 creates environments that help decrease interfering behaviors.

Examples:

Paul:

Paul is a night owl; it's stressful for both him and those around him to pry him out of bed before 9am. While Paul 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 SDS, the team decided that 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. However, 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 for the wedding, his mother and behavior consultant came up with a plan to include Mark on this important day:

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

Strategies that have 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 up front to tell them.

Staffing

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 the setting by allaying anxiety
- Focus the person on the interaction
- Model appropriate social interaction for your child: “Hi, how are you?”

(This goes both ways; staff also need to model to the public that your child can speak for himself.)

- Interpret/reframe both sides of the 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”).

Real-life is messy and can be uncomfortable

Direct support staff, like anyone, 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 floss their teeth. It’s important to clarify tasks that are part of the job.

Staff may feel embarrassed waiting while your child counts change at a store painfully slowly (we parents certainly do). It can be helpful to acknowledge this up front, but also explain how important the practice is for your child. Modeling patience for the clerk and the people on the line is also a positive.

What happens when an individual says something hurtful, or lashes out to 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.

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 may be helpful:

1. Create checklists (what must be done before leaving home, what to pack before going to work).
2. Would it be helpful for staff to have a brief go to guide on handling specific situations?
3. Most people have smart phones. You could put important information in an email that can be kept, or use a free app, that everyone can share. This is an efficient way for people to never be without critical medical information.
4. Some people use alarms on their phones to remind them to drink, eat, or take medicine.

Staffing

What's noteworthy about your household?

How strongly do you feel about issues of confidentiality and privacy? This is very variable from family to family. Everyone working with your child is legally required to observe HIPAA (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. Be aware that what you say may travel. If you don't want information to travel outside your home, you need to say so explicitly.

It's good to remind people that what they observe in your home is private, and isn't gossip to be shared with others.

Relationships with Staff

Our take:

Relationships with your child's staff are intimate and complex. They are with your child, they often tell you about their lives, and they come into your house and see when you haven't washed the kitchen floor. Even though they're 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 a key tool in making the relationship work. It's important to tell staff everything they need to know about your child, and to be open to what they would like 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 smart phone, so an easy way to do this is to back up anything important you say in an email or text. For example, if either you or a staff person are requesting a change in hours, make sure anything you've talked about is followed up in writing. Be mindful that staff have their own lives and other commitments.

Finding out about your child's day

Tell your direct support worker what information you want to know about your child's day. Families are different: some want to hear every detail, while others want only the highpoints and problems. Staff may be reluctant to tell you about difficulties that come up because they don't want to "tattle" on your child, or betray a confidence. They also may be uncomfortable admitting that something did not go well, or concerned about bothering you. It may reassure them to hear that you struggle with the same issues they are facing with your child.

Staffing

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 has occurred, you can't help your child get through it.

Similarly, if there was a win, it's great to talk about 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, or questions

It's important to give direct support staff contact information for at least two people. These can include:

- Parents
- More experienced direct support staff
- Behavior consultant (some will respond to calls or texts about problems)
- Anyone that you designate, 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 your exchange or is it better if they're in another room? That's up to you. It's equally helpful to connect by phone, email, or text.

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

Before leaving school, many of our children, when not with family, spend most of their time in the "special" world: special classes, special schools, Special Olympics. In these settings, people around them are aware of their disability, and there's 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 used to our child's reaction to various situations. Their behavior is part of our everyday lives, and we may be unaware of the many accommodations, small and large, that we make to meet their needs. Our responses come naturally to us, but probably won't to others who don't know our child. Don't assume that an individual you hire, whether they have a background in the field or not, knows the best way to support your child.

Support staff need to be educated to foresee and hopefully avoid problematic situations. At the same time, families should remember that the outside world is more unpredictable than school and home, and issues will come up; that's why your child needs support staff.

Staffing

Here's a list of questions to consider:

Health & 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 sex, 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 and cause them to freeze?
- Do they tend to wander off?
- Do they understand they shouldn't go off with a stranger?
- Does the staff 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 himself at times?
- Does staff need to work on hygiene issues?

Your child may need someone to brush his teeth or comb his hair, while trying to teach him to do it by himself. 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 who are peers can help to establish regular shower habits. Again, it all depends on your child.

Medical Information

IMPORTANT: Staff should have the phone number of an emergency contact person. Remember, with SDS you're the supervisor, unless you've made other arrangements.

- Have you told them about a seizure disorder or any medical condition that may affect your child's everyday life?
- Does staff need any specialized information or training? (CPR, seizure protocol, etc.)
- Are staff aware of an allergy to insect bites, food, medication? Do they need to make sure your child carries his Epi-pen?
- 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 and your child that staff arrive on time? Does your child become anxious when someone is late?
- If your child can't 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 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, when they can't order dessert, 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 to prevent or cut short inappropriate behaviors such as: hate speech, public sexual activity, self-injurious behavior, 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 certain situations. A skill they seem to have mastered (like crossing the street safely) can fade away if they're having a bad day due to medical or emotional reasons.

Social issues to consider

Even though we want to keep our kids safe all the time, there's no way to completely avoid risk.

Does your child use the Internet? Are they on Facebook? How will this be monitored to assure their safety?

When your child is out 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.

In school, there are clear guidelines for what's allowable risk and what isn't; when your child is out in the world with support staff, it's up to you to create guidelines. Decisions will be based on your family values and your child's ability to cope with situations. It's helpful to get input from others in your circle, because they have other perspectives. Again, it's not a question of right or wrong, just what makes sense for a specific person at a specific time in their life.

At a party, will there be alcohol or drugs? 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 himself 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.

Touch

How well does your child tolerate touch?

To some it is comforting, to others it is aversive. If your child has sensory problems, staff need to know this. At the same time, if your child walks into the street without being aware of oncoming traffic, staff needs to know how to physically get them out of harm's 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 do a safety assessment.

Training

Who trains the staff?

The family has a major role to play in staff training. As the saying goes, you know your child best. You can train staff both by giving them information directly, and by modeling ways you interact with your child.

Our Take: we have occasionally seen that new staff accept training and direction from experienced staff or consultants more easily than from a parent.

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

Veteran support staff

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

Circle of Support meetings

Circle of Support meetings can be a great opportunity to share information and strategies with staff. You might consider arranging for an alternate activity at the end of the regular circle 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.

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 staff at once. When your child has behavioral challenges a behavior consultant expert in positive behavior support can be invaluable.

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.

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 her best.

Training

Conflict Resolution

Sometimes, people don't see things the same way; there can be disagreement between the person being supported and staff, family and staff, or between two staff members, for example:

- Staff may feel they are being asked to do things that are not their job
- A direct support worker is consistently 15 minutes late to work
- You are not getting information you asked for (for example: Your child had a meltdown at work)
- Staff may complain about how they're not being treated as well as another staff on the team

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

Often, conflicts can be resolved. However, if one very bad thing happens (an action that threatens your child's well-being, for example), 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. It is important to check with your FI, they may provide guidance. Here are some issues to consider:

Decide whether you want to let them go in person, or over the phone.

- Would it negatively affect your child to hear the conversation?
- Do you want someone (broker, friend) to help you prepare a script?

If you feel the situation could become extremely contentious or explosive, do it by phone.

We've learned:

Quite like 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

- There may be major problems, but you're worried that you won't find anyone as good to work with your child.
- The worker is unreliable, but you know she's 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.

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 behavior job, do travel training,

It's helpful to ask for references from your broker or other families.

Housing

Housing

85-year old widow dies suddenly; her 50-year old son with developmental disabilities is inconsolable over losing both mother and home.

No one wants their child in this nightmare headline. If your child is living at home, it's 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 reinforced in a positive way over a period of years. And then there are those who insist that they won't ever move, loudly and often. 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's important to start the conversation.

Note: If you're planning to have your child live in your home after you're gone, speak with your MSC and consult a lawyer to make sure that their benefits will be protected.

To be able to pay for housing through a SDS budget, a person needs to have a Residential or Both SDS Plan. Housing costs are paid for by any wages the person earns, SSI, and, often an OPWDD housing subsidy (called an ISS grant). The person is expected to contribute 30% of his/her income (wages and SSI) to housing costs. The housing subsidy may be used toward rent or a mortgage payment, but the person must have tenancy rights, that is, his/her name must be on the lease or mortgage.

Think about: Your Child

- Has your child seen brothers and sisters move out of the house and has that made them eager to leave?
- Does he just want to get out of your house? For some, it seems to be a developmental phase – their words and behavior provide clear evidence they're trying to separate from mom and dad.
- Does your child resist change of any kind and want to live with you forever? Do you also want that? If not, can you point out the advantages to them of having their own place?
- Can they visit someone who lives with support, in an apartment in the community, and get an idea of what that would be like for them?
- Is your child living in a group home or other certified setting but wants to move into an apartment or house in the neighborhood?

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 outside the family home.

Housing

Your Family

Every family is different. Changes in family circumstances, such as illness, job responsibilities, needs of other family members; or when having your child at home becomes overwhelming all 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 SDS, OPWDD will contribute a rental subsidy, which can be used for an apartment, house or co-op.

Our take:

The rental subsidy varies by region of state, and in some high cost housing areas is inadequate, especially given the universal lack of safe affordable housing. There are efforts currently underway to try to address this issue. There are ways in which family resources can be used towards a participant's housing without jeopardizing Social Security and Medicaid benefits. For an introduction, see the housing resources below.

Housing

Living alone

Some people want to live alone in an apartment or house. Those who have minimal support needs may do well with hiring staff to work a few times a week to help with paying bills and maintaining their home.

There are also people with high support needs who live alone; they can receive additional Medicaid services to supplement their care. Speak to your MSC.

Roommates

To make housing expenses 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. In addition, it is often necessary to share staff at times; both roommates must use the same FI. It also makes it easier to pay the rent!

However, it can be difficult to find the right roommate. Ask your broker to get the word out to other brokers to see if any of their clients might be interested, or perhaps your FI might be willing to send out a “roommate wanted” email to participants or brokers. If the future roommates do not already know each other, it’s important to have them meet at least a few times, preferably in different settings, to see how they get along.

Our take:

Remember, roommates often come with families, and their values and expectations may differ.

How important is neatness?

Must TV time be limited?

When you share staff, what are you looking for?

Are there different religious beliefs or practices that would affect daily life?

Do people have different ideas about privacy?

If the apartment isn’t chosen yet, do the families have different ideas on where they want their children to live?

Pets?

We’re all used to presenting our children in the best possible light, but this is the time to be honest. If your child uses profanity or punches the wall when they’re angry or becomes upset when someone moves their hairbrush in the bathroom, it’s critical to mention these issues before people move in together.

Housing

Supports for Community Living

1. Social contract

It can be helpful for roommates, with support from their Circle, to discuss issues that might arise and write an informal “social contract” to establish ground rules for living together. Referring to the rules agreed to in a contract during conflicts makes the issue less about who’s right and who’s wrong. Here are some issues to consider:

- How will chores be divided?
- What’s your definition of clean?
- Will food be shared?
- Can people visit at any time? Can they sleep over?
- Does the roommate have different needs for privacy?
- Will there be quiet hours (no loud music or other noise)?

2. Relationship coach

Do people need help in negotiating the day to day issues that arise when sharing space with others?

Sometimes an outside party can help negotiate issues that come up. Anyone who can effectively facilitate conversation between the roommates can serve in this role. For some people this could be a behavior consultant, for others it could be an experienced staff member.

Our take:

When people live together, relationships may become complex in ways you can’t foresee. Behaviors including bullying and coercion, involving roommates, or staff and a participant can be subtle. People who work with your child be alert to warning signs.

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’s food in the home
- Check for pests (bed bugs, mice, etc.)
- Ensure that no one is preying on the individual
- See if a roommate is taking advantage by having her boyfriend stay over indefinitely

Housing

4. Managing finances

Who writes the checks for rent, cable, etc. and makes sure they are paid on time?

- Family, a trusted friend or relative
- Trusted direct support worker
- Support broker (if you have funded their time in your SDS budget)
- Someone from a community social service agency
- FI agency

Another alternative:

Have funds that will go for housing expenses deposited into a shared account, and arrange for automatic payment of regular bills through the bank.

5. Even if you have funding for housing, your SDS plan may not immediately be fully funded to cover 24/7 support.

Here are some ideas families use:

- You can support your child in their home, or they can come visit you for a day, or part of a day, every week
- Takes turns with roommates' families to stay over
- Chip in to pay for someone privately

Our take:

Clearly, these are not long term solutions, as parents will eventually be out of the picture, and many people do not have other family members able to take on the role of helping someone self-direct. We believe that families need to work with nonprofits and OPWDD to advocate for the development of both the financial resources and administrative policies and supports that allow people continue to live in non-certified settings after their parents are gone.

6. 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.

(For more information: Toolkit for Providing Shared Living in New York. Pub. April 2016 by New York State Association of Community Residential Agencies,

http://www.nysacra.org/docs/Shared_Living_Tool_Kit_Report_new.pdf)

Housing

7. Paid neighbor

A paid neighbor is someone who lives nearby, and can respond if something unexpected comes up and the person needs support. Paid neighbor is paid through IDGS funds.

(For more information: Toolkit for Providing Shared Living in New York. Pub. April 2016 by New York State Association of Community Residential Agencies, http://www.nysacra.org/docs/Shared_Living_Tool_Kit_Report_new.pdf)

8. Home of Your Own (HOYO)

HOYO is open to income-eligible people with I/DD, or their parents who want to buy a first home. It includes many supports throughout the process of buying a home, including financial management assistance, homeownership counseling, and access to a long term low interest mortgage. For more information, speak to your broker or MSC, or go to www.OPWDD.gov.

Housing Resources

The Housing Guide, Westchester Institute for Human Development-The most complete guide to housing for people with I/DD in New York. Find it at http://www.wihd.org/wp-content/uploads/1970/01/WIHD-Housing-Resource-Guide-UCEDD_revised-020416.pdf

Investigate a **Community Development Financial Institution** (CDFI), such as Disability Opportunity Fund Foundation, which can provide financial advice for families wishing to purchase housing, as well as bridge loans. (See: www.thedof.org)

Once You're Up and Running

Documentation of Services

The money for SDS comes from New York State and Federal funds, so careful and complete documentation of how the money is being spent is required. The FI is only a pass through for the money and they can't pay staff or reimburse costs unless the correct documentation is submitted within a 30-day time frame. If those rules aren't followed they are out of compliance and won't be reimbursed by the government.

Timesheets

These are generally submitted every two weeks. Depending on the FI, you may have to mail paper forms or review and submit them online. If you submit paper forms, it is helpful to keep copies if you can, as sometimes forms may be lost or misplaced. In some plans the family makes copies, in some the workers do.

Mileage forms

Mileage forms are generally submitted monthly. It is also helpful to keep copies of these.

Monthly Summary Notes

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

It's easy to forget to do these; try writing it on your schedule.

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

EMERGENCIES

If a primary family caregiver has a medical emergency, it may be possible to get permission from the liaison for additional staff time. Call your broker or liaison as quickly as possible, because services can't be budgeted retroactively.

Life is Change

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

SDS have given our children the infrastructure, flexibility, and motivation to mature and develop new skills. Their growth also challenges us to reevaluate limits we sometimes set for them.

Once You're Up and Running

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

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

Emily likes to stay in her home, and loves colorful flowers. A new community flower garden was starting at one of the local parks. The circle felt that Emily would benefit by being outdoors, and perhaps make some social connections. They thought that she'd 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, Emily 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, Emily's enthusiastic direct support worker felt that Emily 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 Emily about their destination. Landing back at the park, Emily 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 with new experiences and challenges, is a continuing conversation for each family and circle.

Expect the unexpected

Allison loves to swim; she's always the first one in and the last one out of the pool. One day she responded to a staff member's suggestion that they meet friends to swim by saying no. When questioned by her mom she 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 possible 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 that she was anxious about picking out clothes to change into after swimming, because she was worried she might not want to wear what she had picked out. And swimming was out for the day. This was her choice, we understood her concern, and no one pressed her to go, even though we knew she'd enjoy it once she got there. The next day she backed her bag for swimming the following afternoon.

Behavior is communication; there's always a reason.

Once You're Up and Running

Thinking long term-sustainability of self-direction.

We're all aging, and won't be around forever. It's difficult, but essential to think about what structures will be in place to support your child's life when you are no longer able to take care of him.

Here are some considerations:

1. Who will take over the executive part of your role in supporting your child?

(For example: hiring and training direct support staff and consultants, setting wages, addressing problems that arise with staff; deciding on need for medical attention; financial decisions about budget.)

2. Who will take on the hands-on parts of the parent role?

(For example: coverage for people who need 24-7 in both planned (staff vacations) and unplanned (staff illness, car problems, storms) circumstances when no one else can work?)

Potential options now are live-in caregiver and paid neighbor (see above).

3. How to assure the person can age in place in a noncertified setting?

Your COS, including your MSC and broker can help you think through creative solutions.

It is especially helpful to prepare a planning document that captures everything important to and for your child (this is also called a Letter of Intent); from the only style of jeans he will wear and toothpaste he insists on, to strategies to handle meltdowns, to the people who are important to him.

Besides the obvious (medical information, name of doctors, contacts for family members, financial resources, etc.), here are some examples of what you might include-this is FAR from an inclusive list:

- Preferred activities, alone and with others
- People they are close to, contact information, and how often they like to seem
- Clothing requirements-elastic pants? Sneakers only?
- Preferences, dreams, aspirations
- How to interpret behaviors as communication
- Favorite foods
- Strategies for dealing with difficult situations

Once You're Up and Running

A useful resource is an 88-item checklist, written by Mark Russell and Arnold Grant. It's available at: <http://www.bridges4kids.org/letter-of-intent-form.pdf>

We also recently found "Special Needs Vest", an inexpensive online service that provides a structure to store information about your child. It's at www.specialvest.com.

Our take:

We believe it is essential to develop additional options to support people who used self-directed services throughout their lives.

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)

This organization is based in Canada, but has an interesting model of developing Social Networks for people with I/DD (http://institute.plan.ca/wp-content/uploads/downloads/2012/11/reaching-out__29373.pdf)

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!

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, SDS liaison at the NYS OPWDD Region 5 DDRO

Emilie Wright, Coordinator, Retired, Consolidated Supports and Supports, OPWDD

The dedicated staff of the Long Island Advocacy Center and Positive Behavior Support Community Foundation.

Independent Support Services

Advocates Incorporated.

Appendix A: Check List to Track the Progress towards Self Direction

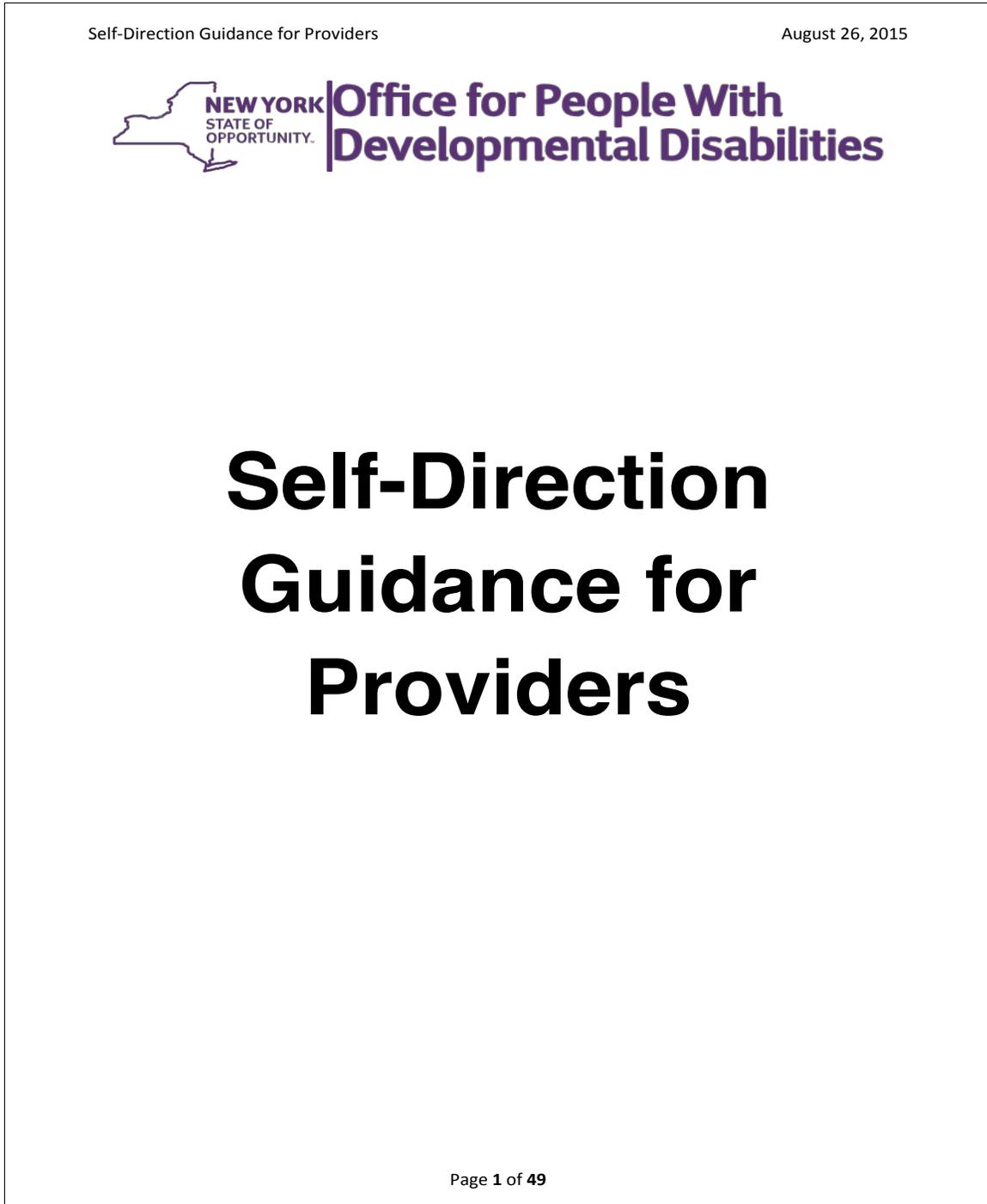
- For those who want to peak behind the curtain to follow every step it takes for starting SD, we've included this expanded list.
- Family applies for SSI (which will give you Medicaid coverage)
- Participant/Family Enter Office for People with Developmental Disabilities' Front Door
 - A. Obtain eligibility
 - Attend Front Door Information Session, learn about options, and choose Self-Directed Services (SDS)
- Family chooses Medicaid Service Coordinator (MSC) from list given to you by Front Door Staff
 - MSC completes DDP2 (assessment tool) and writes the ISP
 - MSC submits application for the Waiver
- MSC makes a referral for Self-Directed Services to the Front Door contact at the Developmental Disabilities Regional Office (DDRO)
- Front Door staff and the local SD Liaison meet to assure that the individual's health and safety needs can be met through SD
- The Self-Direction liaison calls the MSC to get additional information if necessary
- An info session on Self-Direction is scheduled and attended by the person (if possible), parents, and MSC
- Choose Start up Broker and Fiscal Intermediary (FI)
 - Pick broker from the list the Self-Direction Liaison gives you, and sign broker agreement
 - Broker tells you which FIs they're affiliated with so you can sign with one of them to do the initial budget review. (You need to do this so the Broker can be paid). You can switch to another FI before launch of your plan, if necessary)
- The Startup broker agreement is processed and approved by the FI then the DDRO office and sent to Central office for funding approval. This releases funding so the Broker can begin to work with you.
- The participant is sent the approved broker agreement, template and authorization letter for Broker and Fiscal Intermediary services.
- Broker helps organize Circle of Support (COS) and facilitates Person-Centered Planning meeting(s)
- Plan development starts with the person, their broker, MSC and their Circle of Support to include the budget, Com Hab, SEMP plan and safeguards
- Broker reviews DDP2 with family to make sure it accurately reflects their child's needs
- Broker and COS identify the services, supports and funding sources the participant will need to pursue their goals, with the information gained from Person Centered Planning.

- **Broker creates the budget and writes the Com Hab Plan, SEMP Plan, and Respite plan**
- **Participant and COS review the budget, Com Hab Plan, SEMP Plan, Respite and safeguards for accuracy**
- **Broker enters the budget on the Template and submits it to the FI who must review it before it goes forward. (All information is transmitted electronically)**
- **FI forwards the Budget to the Liaison at DDRO, who reviews it and might ask for revisions**
- **Budget then goes to “Rate Setting” in OPWDD’s Central Office, where it is again reviewed, and revisions might be requested**
- **Launch! Broker finalizes the Com Hab Plan, SEMP Plan, Respite, and MSC submits ISP addendum which includes the plan(s).**

Note: The person can start using their self-directed budget based on the date in the authorization letter, which is always on the 1st of a month.

Appendix B

Click [here](#) to view the document.



Appendix C: Glossary

Budget Authority – One of two “authority” choices in Self-Direction (see the other, Employer Authority, below) in which the person/family has the authority to make budget decisions, including hourly staff pay, in addition to hiring, firing and supervising staff.

Coordinated assessment system (CAS)- OPWDD’S new assessment tool, replacing the DDP2

Circle of Support – The “Circle of Support” consists of the person, the Support Broker and the MSC; the person chooses to invite other family, friends and professionals who are committed to helping him/her live a self-directed life.

Center for Medicare and Medicaid Services - CMS is the part of the federal government that funds healthcare.

Community Habilitation (Com hab) - Com hab is a service that supports people to live in the home of their choice, and spend their time doing things that interest them, with people of their choosing. Supports include: teaching /assisting with daily living skills, facilitating community inclusion and relationship building, and training and support for community activities.

Developmental Disabilities Profile (DDP-2) – A needs-assessment tool; Scores from this assessment are used in developing the Personal Resource Allocation (PRA) for the Self-Direction budget.

Developmental Disabilities Regional Office (DDRO) – OPWDD’s local offices which oversee and coordinate delivery of Medicaid Waiver services.

Effective Date – A calendar date on which the Self-Direction budget can begin paying for goods and services.

Employer Authority – One of the two “authority” choices in Self-Direction (see the other, Budget Authority, above) in which the person/family makes staffing decisions only. The hourly pay- and fringe-rates are set by the provider agency contracted by the person/family to provide staffing.

Fiscal Intermediary (FI) – A not-for-profit agency that serves as “employer of record” for Self-Direction plans with Budget Authority; In that role, the FI conducts background checks, collects service-related documentation, pays for or reimburses for budget-approved goods and services, and provides payroll/benefit services.

Habilitation Plan – Not to be confused with the ISP, habilitation plans provide self-hired staff with valued outcomes identified by the person in their plan, and the supports and safeguards staff are expected to provide to help achieve those outcomes.

Home and Community Based Services (HCBS). See Medicaid Waiver below.

Individual Directed Good and Services (IDGS)-Services, equipment or supplies not otherwise available through OPWDD’s HCBS Waiver or through regular Medicaid that address an identified need in a person’s ISP.

Individualized Service Plan (ISP) – A document prepared by the MSC and based on information gathered from the person during Person-Centered Planning; the ISP provides a detailed profile of the person, and identifies natural and

community supports, Medicaid State Plan and/or Medicaid Waiver supports, and safeguards necessary to help the person achieve their dreams.

Medicaid Service Coordinator (MSC) – A professional, selected by the person and/or family from an approved list, who helps the person access supports and services.

Medicaid Waiver – An authority granted to states by the federal government to develop delivery or payment methods for Medicaid supports, such as Self-Direction, that are a departure from those approved in the Medicaid State Plan.

Person-Centered Planning – A process that aims to understand the person’s vision for a meaningful life, considering his/her strengths and abilities, needs, and planning for outcomes consistent with that vision; This process takes place through a series of conversations between the person, family (as needed), the MSC, and/or Support Broker.

Personal Resource Allocation (PRA) – The maximum amount of money, based on the needs-assessment, which can be budgeted to pay for the person’s supports and services.

Self-Direction Budget – A detailed budget developed by the Support Broker using an OPWDD-provided Excel template with an itemized amount of money to be allocated for supports and services included in a person’s ISP.

Self-Direction Information Session – A training session, conducted by the Self-Direction Liaison at the local DDRO, for people/families seeking to self-direct their services and supports.

Self-Direction Liaison – A DDRO staff-member who provides training on OPWDD’s Self-Direction option to people/families, Support Brokers and Fiscal Intermediaries; Liaisons also review and approve Self-Direction budgets.

Self-Hire Self Direction. Same as Self-Direction with Budget and Employer Authority

Start-Up Budget – A preliminary budget developed by the Support Broker and sent to the Self-Direction Liaison for approval. Once approved, the process of developing the comprehensive Self-Direction Budget can begin.

Support Broker – A professional who educates the person/family on Self-Directed service options, and assists the person in developing a Self-Direction budget, writing Habilitation Plans and facilitating Circle of Support meetings.

Appendix D

Community Habilitation Service Comparison		
	Agency Supported Self-Directed Community Hab.	Self-Hired Community Hab. (Purchased through Self-Direction Budget)
	Person has <u>employer authority</u> (choice of staff, staff schedule and daily activities)	Person <u>has employer authority</u> (choice of staff, staff schedule and daily activities) AND budget authority (choice of Mentor pay rate, items included in SD Budget)
Number of Community Hab. hours	Typical number of CH hours approved: 6-12 hours/week - Person in school 30-40 hours/week - Adult who has transitioned out of high school 30 hours/week – Adult living in a Certified Setting (ex. IRA) Hours can be used flexibly throughout the calendar year (hours are “reset” each January).	Number of CH hours is chosen by person and Circle of Support, working with Broker to fit within Self-Direction (SD) Budget Personal Resource Account (PRA). Self-Hired hours are less expensive than Agency Supported hours, so typically more Self-Hired hours can be afforded in an SD Budget. Hours can be used flexibly throughout the SD plan budget year (hours are “reset” each plan year).
Staff pay rate	Agency chooses the pay rate. Agency may determine pay rate based on level of support needed, or may determine pay rate based on staff experience.	Person/Circle of Support choose their own pay rate, working with Broker to fit within SD budget.
Paperwork and managing Budget	Agency is responsible for monitoring number of hours used and is responsible for all paperwork. Person/Circle of Support do not need to review or sign Mentor paperwork (Timesheet/Daily Service Note).	Person and Circle of Support take responsibility for monitoring SD Budget (ex. Number of hours and mileage used, money available in budget). Broker and FI assist with monitoring and managing SD Budget. Person/Circle of Support take responsibility for reviewing and signing off as supervisor on Mentor’s paperwork (Timesheet/Daily Service Note). FI assists with making sure paperwork is compliant.
Required Meetings	2 meetings/year (Annual and Semi-Annual ISP meetings) Interviews scheduled as needed to hire staff	4 meetings/year (Annual and Semi-Annual ISP meetings and 2 Planning Team Meetings) Interviews scheduled as needed to hire staff
Respite	\$1,200/year max Family reimbursed respite may be funded through Family Support Services	\$3,000/year max Family reimbursed respite may be funded within SD Budget
Housing Subsidy	70% of rent may be funded through Individual Supports and Services (ISS)	70% of rent may be funded through Housing Subsidy within SD Budget
Classes, memberships	May be funded through Family Support Services (\$1,200/year max)	May be funded through Individual Directed Goods and Services (IDGS) within SD Budget
Other funded items	N/A	Cell phone, Subsidies and Staff activity fees may be funded through Other Than Personal Services (IDGS) within SD Budget

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