

Self-Direction does not need to be a solo act

A how-to guide collaboratively produced by members of Statewide Advocacy Network of NY (SWAN), NY Self-Determination Coalition (NYSELFD), Self-Direction NYC, with technical assistance from OPWDD personnel.

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The most up-to-date version of this document will be posted at nyselfd.org. We consider it a work in progress, and welcome your comments and suggestions! You can send them to nyselfd@gmail.com. (Note that we probably won't respond immediately --we are a self-organized coalition of volunteers).

If you have specific concerns about an individual's services, reach out to your local Developmental Disabilities Regional Office (DDRO). The list of self-direction liaisons is on this page:

opwdd.ny.gov/opwdd_services_supports/self-direction/self_direction_liaisons_list

If you have questions, complaints, or suggestions related to Self-Directed Services, contact OPWDD at self.direction.redesign@opwdd.ny.gov. We'd appreciate it if you could cc us at: nyselfd@gmail.com

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Please read this first

Our intended audience is anyone who is helping a New York State resident with an Intellectual and/or Developmental Disabilities to access, maintain or expand Self-Directed Services (SDS). The document assumes you are familiar with the basics. If Self-Direction is new to you, you might want to consult some of the following:

- "In the Driver's Seat".
A general intro to Self-Direction, mixed in with info specific to the Rochester area.
 - Their simplified roadmap tinyurl.com/RoadMapToLaunchSD
 - A gentle introduction to Self-Direction inthedriversseat.org/getting-started
 - Additional resources and sites inthedriversseat.org/stay-connected
- "[Self-Direction in NY: A Practical Guide for Families](#)", one of the resources that you will find at nyselfd.org.
- NY Alliance for Inclusion and Innovation has a page of [Self-Direction FAQs](#)

Who wrote this guide?

Advocates from across NYS self-organized into an ad hoc group, to support and strengthen Self-Direction. The group was led by Brad Pivar of Eastern NY Developmental Disabilities Advocates (ENYDDA), and includes participants from NY Self-Determination Coalition (NY SELFD), Self Direction NYC, DDAWNY Family Committee, and NYC Family Advocacy Information and Resources (NYC FAIR). For the nitty-gritty details of setting up services, we reached out to Fiscal Intermediaries, Brokers, and OPWDD personnel.

We've done our best to make sure that the information below is accurate. For most of these changes you will need to work with your broker, your Fiscal Intermediary (FI) and perhaps personnel from the Regional Office of OPWDD (DDRO). In some cases these professionals will have a complete understanding of choices available through SDS. In other cases, they will need to be educated about what is possible. Don't give up when someone says "you cannot do that." Ask them to show you the ADM or Guidance document they are using. If they can't produce one, show them this document. If necessary, ask to speak with their supervisor. If the supervisor isn't helpful, ask "Who is the administrator in charge of this policy?"

There are still regional differences in how rules are interpreted and applied. If your experience differs from what is described here, we'd like to know. Send your comments to us-- our email appears on the first page of this document.

Self-Directed Services: The Promise and Challenges

The Promise: The New York State Office for People with Developmental Disabilities (OPWDD) offers Self-Directed Services to people with Intellectual and Developmental Disabilities who wish to have more control over their own lives. People who Self-Direct (SDers) get to determine how they spend their time, where they go, and the people who support them. Most SDers also get help from family and friends.

Challenges: Self-Direction as implemented by OPWDD comes with a substantial set of responsibilities. It's like running a small business. There's a budget to manage, people to hire and supervise, paperwork to complete, and varying amounts of crisis management. And like a small business, the supervisor often has to jump in hands-on to solve problems.

The hope and plan for self-directed services was that people would develop natural connections in the community that would lead to an expanded Circle of Support. For most people that hasn't happened, and it feels like there is no one to share the work. Whether it is the parents or the person receiving services, the fact is that many Self-Direction programs are run as a solo act kept going by a Chief Executive Officer who is also chief-cook and bottle-washer.

Many people set up and maintain a program and worry what will happen when they age or have new challenges. Also, many parents set up and maintain a program, but worry about what will happen to their adult child when they are no longer there to manage everyday tasks and important decisions. And while thousands have embraced Self-Direction, many others avoid it because they do not have the time, energy and expertise to be "Self-Direction Program CEO."

But Self-Direction does not need to be a solo act. Below is a list of currently available services that are under-used, that can help. The bulk of this document provides guidance on how to set up these services.

1. Pooled Staff. One Direct Service Professional can serve two or more SDers at the same time. This allows you to get more support hours, by sharing the expense across multiple budgets. The support staff also gets higher pay.
2. Support brokers can take on most of the administrative work, if they agree to.
3. Specialized support brokers can provide expertise on Housing Navigation.
4. Staff Coordinators can arrange schedules and coverage.
5. Paid Neighbors are on-call for emergencies and for backup.
6. Live-In Caregivers can provide backup when the SDer is living in their own home.

There are still significant gaps, and additional services will need to be added to the New York State Self-Direction framework. We're not trying to kid ourselves, or you, that the services discussed here will answer all of the questions that wake parents in a cold sweat at 3 AM. Over the last five years OPWDD has been working to bring SDS to scale, and to move the entire service system to managed care. Now is the time when we should be speaking about the sustainability of SDS after families are gone.

We hope this document will help to both inform and stimulate further conversation.

Feedback

To help work out the supports needed for SDS to be sustainable, we need your help. Your experience in using these options can help to improve and expand them. Set up the services you need currently and will need in the near future, and tell us what worked and what didn't. We will collect your information and use it to advocate for what works and fix what doesn't, as well as identify the gaps that remain. We will also use what you send us to make this document more useful.

- You created a checklist or spreadsheet that might be useful to others? Send it in.
- You wrote a justification statement which sped up approval process? Send it in.

And especially: Please send in to OPWDD reports of problems and difficulties which you have. On the front page of this document you will find contact info for OPWDD and for our coalition.

Examples: How services can fit together

Before we jump into the details, here are a few stories that present a vision of how services can be combined to cover gaps which are typically filled by a parent or a capable individual. We also point out the gaps that remain to be filled, hopefully by changes in current regulations and funding.

Feel free to skip to the next page if you want to get straight to the practical guidance.

“Light Touch” need

Person: Jill is in her late 30s and on the autism spectrum, with an intellectual disability. She is an only child and her last surviving parent died five years ago. Jill prefers to live alone and can handle all of her routine self-care, as well as shopping, cooking and cleaning. She does not pay her own bills nor make her own medical appointments. She can use her cell phone to call for help as needed.

Supports: Jill lives in a studio apartment. A self-hired Job Coach supports her at her part-time job as a re-stocking clerk at a nearby Home Depot. Her **Support Broker** helps her with hiring and scheduling staff. A **Paid Neighbor** comes in for a few hours of Comm Hab work each weekend, to help her empty out the fridge, review incoming mail and help Jill pay her bills.

Remaining Gaps: Jill is doing okay, but her life is stagnant. Neither her Support Broker nor her Care Manager believe they have the time or the authorization to mentor Jill to find new interests and activities. The Circle of Support she began with has evaporated. Her father had set her up with a membership at the gym and art classes at a local community center. Unfortunately the painting instructor moved out of town, and Jill did not hit it off with the replacement. She stopped attending. Similarly, the yoga class schedule changed. Jill’s community involvement has diminished to the part-time job, and walking to a nearby multiplex at 7 PM every Friday to watch a movie.

24/7 needs

Person: Joe is in his early 50s. He has Down syndrome and diabetes. He lives in a three bedroom apartment in a small town. One room-mate is Frank, an old friend who also uses Self-Directed services. The other room-mate is a Live-in Caregiver.

Supports: The **Live-in Caregiver** also performs the **Staffing Support** role. Joe and Frank use **Pooled Staff** for the parts of the day they are together, and also share the cost of the Live-in Caregiver. This lowers their costs and lets them live in a nice apartment. The **Support Broker** takes care of most of the routine paperwork, in cooperation with the **Staffing Support** role. Two **Paid Neighbors**, both within walking distance, serve as backup staff. Joe’s older sister comes in twice daily to check Joe’s insulin levels and give him injections and also serves as backup of last resort,

Remaining Gaps: Joe’s sister doesn’t know who will take care of Joe’s diabetes when she is gone. His budget cannot cover the cost of daily visits from a registered nurse, he has not learned to self-administer, and his staff is not allowed to perform injections. It is possible that he will need to move to a group home when his sister is unable to visit anymore.

Details of the help available

Pooled Staff

Myth: “Staff costs cannot be shared between two participants.”

Background: Most self-directed services are delivered by self-hired Community Habilitation staff who work with a single individual. The service is called Individual Community Habilitation (Individual CommHab). This arrangement provides maximum flexibility. The person receiving services is free to change their plans at any moment. At the other end of the spectrum, you can use a Self-Direction budget to purchase traditional Day Habilitation services. With Agency Run CommHab or DayHab, you do what the group is doing, and go where the group is going. Pooled Staff is somewhere in-between

Fact: Direct Support Professionals (DSPs) can provide services simultaneously to two or three individuals. The DSP gets paid at a higher rate, but the cost is split across multiple budgets and so the hourly cost for each individual is lower. For more details see [Details of Pay Rates for Shared Staff](#) at the end of this document. You can use Pooled Staff for times when maximum flexibility and 1/1 support is not needed, for example during community classes or other group activities. It works especially well for roommates and friends who like to spend time together. However, practical difficulties can arise with shorter classes when the SDer is a person with higher needs-- someone whose health or safety would be at risk if they are left alone.

Obstacles to keep in mind

- A. **Logistics.** You need to
 - a. Find another SDer who wants to regularly share staff,
 - b. Plan and oversee the transition to and from group service delivery,
 - c. Find a worker who wants the additional responsibility, paperwork, and pay.The last item is perhaps the easiest. The hourly rate for group time is at least 25% higher.
- B. **Holes in one dsp’s schedule.** It is generally not practical to have a short period of shared staff in the middle of the day. You wind up with one staff member who gets a higher pay rate for that time, and another staff member who gets zero pay during that time, but still has to be available to resume work at the end of the shared time-not a good way to inspire staff loyalty.
- C. **Shared Fiscal Intermediary.** The SDers in a shared staff arrangement should be signed up with the same Fiscal Intermediary (FI). OPWDD allows multi-FI arrangements, but in practice they are overly complicated and do not succeed.
- D. **Reimbursement policies.** The FI has information and systems in place that would allow them to help make shared staff arrangements. Unfortunately, there is no mechanism to reimburse the FI for this work. In contrast, your Support Broker can help. See details in [Your Support Broker can cover most administrative work](#)
Sharing staff will require a budget amendment. This part is the job of your support broker

How to set up a Pooled Staff arrangement

1. Find another person using Self-Directed Services who enjoys similar activities, and who uses the same FI (Fiscal Intermediary).
2. Come to an agreement with them on how you will make decisions about shared staff. Recommended: Work together on important decisions such as who to use as staff and what rate to pay them. But have one person make the routine scheduling arrangements. Think about:
 - 2.1. Are there any health or safety issues to consider?
 - 2.2. What happens if one participant is ill, or just doesn't want to get together with their friend that day. This can be a big issue for people with behavioral challenges.
 - 2.3. What happens if the staff person is ill?
3. Consider: Write down the agreement between the SDers-- not as a legal contract, but rather for the sake of clarity and future reference. The agreement can be altered by mutual agreement at any time. Pooled staff works best when everyone understands what they are agreeing to.
4. Determine the times during the week when you would like to use Pooled Staff. Ideally, this will be in large chunks (several hours at a time), or at the beginning or end of the day. Keep in mind the effects of the change on staff's income and schedule.
5. Have a conversation with each desired staff person. Make sure it is clear that:
 - 5.1. you value their expertise, and are certain that they can handle this new way of doing things.
 - 5.2. there will be additional responsibilities when they are working in group-mode.
 - 5.3. there will be extra paperwork, as they switch back and forth between individual and group services.
 - 5.4. the higher group rate will only apply when they are working with two people.
6. Consider: Write down your agreement with the staff person. See #3 above.
7. Optional but recommended. Have a conversation with non-group staff, to explain that they will be getting "down-time" during the group services times.

Your Support Broker can cover most admin work

Myths: “The support broker is allowed to provide only a very small set services.”
“The support broker is only paid for face-to-face meeting time.”

Background: There are a limited number of services which brokers are required to supply:

Assist the individual in developing and maintaining a Circle of Support/Planning Team.

Meet with the individual’s COS/Planning Team at least twice a year.

Assist the individual to develop a comprehensive Self-Directed Budget that is consistent with his/her Life Plan.

Work with the individual and his/her COS/PT to ensure that all necessary safeguards are included and addressed in the Life Plan.

Fact: The support broker is allowed to provide a broad array of optional services:
“The Support Broker ...[becomes] involved with the participant in the day-to-day management of those services.... The extent of the assistance provided is determined by the participant and specified in a written agreement between the participant and Support Broker.”¹

Under the umbrella of these optional Support Broker services, much of the administrative burden can be turned over to a willing Support Broker. The list below is drawn from the document OPWDD created for Support Brokers.² Your Support Broker is allowed to help you with the following, and is allowed to bill you for that work:

- i. Identify and develop initial connections in the community.
- ii. Monitor self-direction expenditures to ensure that spending does not exceed your Self-Directed Budget.
- iii. Assist you to review and submit routine paperwork. This includes employee time sheets, monthly summary note, and mileage & expense reimbursement forms.
- iv. Assist you in all activities required to hire and retain appropriate support staff. This includes assistance needed to recruit, interview, hire, schedule, and supervise.
- v. Help identify and retain back-up staffing.

¹ Page 100 of the authorizing document, the 1915(c) HCBS Waiver, 2019-06-28 version.
https://opwdd.ny.gov/sites/default/files/documents/Approved_Amendment_05_6-28-19.pdf

² Administrative Directive Memo on Support Brokers, 2019-June version, downloaded from:
https://opwdd.ny.gov/opwdd_regulations_guidance/adm_memoranda/ADM-2019-06

Obstacles to keep in mind

- A. **Willingness and Capacity.** Brokers differ in the amount of support they offer, through personal preference or requirements of where they work. It can be difficult to find a broker who will agree to assist with these additional tasks. Talk with your broker about how much support you will need, and then document those needs in your written agreement with the broker. Make sure to remind your broker they will be paid their hourly rate for all the work they do-- not just for their face-to-face meetings. Also, remember that you can change brokers at any time if necessary (not that it is easy to find people).
- B. **Money.** The hours your broker works get charged to your PRA (Personal Resource Account), and some people are reluctant to spend the money that way. Consider your abilities, available time, and other responsibilities. And especially, consider your personal stress. Having more help from a Support Broker might allow you to maintain both your sanity and health.
- C. **Lack of information.** Staff at local OPWDD office and at Fiscal Intermediary might not be aware that you are allowed to get help from a Support Broker for these items, and might refuse to approve an annual budget which has hundreds of hours of Support Broker time. Be sure to include a sufficiently detailed justification in your request as seen in #5 below. And in conversation, gently bring their attention to the [June 2019 Administrative Directive Memo on Support Brokers](#).
- D. **Pending changes.** As of August 2019, the Support Broker is allowed and encouraged to go “into the field” and observe how a person receiving services interacts with their staff and their community supports. However, currently the Support Broker cannot bill for the same time period that staff are billing for. We have brought this to the attention of OPWDD, and they have told us that they will make a correction in the Fall 2019 update to the CommHab Administrative Directive Memo.

How to set up a Support Broker to cover the administrative work

1. Find a broker who is willing to take on this additional work effort. You might be able to convince your existing broker to step up. Many brokers are running their service as an independent business. From their perspective, this is getting additional billable hours from an existing relationship.
2. Remind the broker that they are allowed to bill for time they spend when not face-to-face. And inform them that they can have meetings over the phone or via Skype, for all meetings except for the twice-annual Circle Of Support sessions.
3. Update the standard formal agreement with your Support Broker, to include the additional services you are contracting with them to cover.
4. Consider creating an informal “working agreement” about the boundaries, to avoid mis-understandings. What decisions are you delegating, and which are you reserving to yourself? How do you want to be get routine status updates? How do you want to be informed of real emergencies?

5. Have the broker add the expected Support Broker hours to the budget. Provide a written justification, which can be very concise. However, to avoid delays in approval, it should include details of what will typically be done by the Support Broker. For example:

“The Support Broker will spend up to three hours per week assisting with administrative and supervisory work, as described in the Allowable Billable Support Brokerage Services section on page 3 of ADM-2019-06. The Individual and their family will continue to exercise their decision-making power. Approximate weekly effort by Support Broker will be

 - 1 hour assisting with service documentation
 - 1 hour assisting with schedules and supervision of self-hired staff
 - Half-hour reviewing self-directed service expenditures.”
6. If needed, adjust other budget categories down.
7. Your broker will submit the revised budget for approval.

OPWDD central office staff has stated that, as of July 2019, it is rare to see a request for more than one hour per week-- but up to 4 hours per week has been approved when an adequate justification was provided.

Specialists to help with Housing

Myth: “There is no way to get specialized help.”

Fact: The additional allowable services from a Support Broker also permits one to hire a Housing Navigator, who can help you plan for and find non-certified housing.

There is a formal training program for Housing Navigators that was developed by John Maltby while he was at Westchester Institute for Human Development. The program is currently offered through NY Alliance for Inclusion and Innovation.

Housing navigation can be paid through your Support Brokerage budget line. It could also be covered by Community Habilitation, but the top rate for CommHab is currently around \$25/hr, versus \$40 for the Specialized Support Broker.

OTPS (Other Than Personal Services) is another potential source of funding for Housing Navigators. However, that pool of state-dollars-only funding is strictly limited to a total of \$3K per year, and there are many items which can ONLY be funded from that limited pool, such as phone service, and providing meals for staff members.

Obstacles to keep in mind

- A. **Scarcity.** Currently it is difficult to find a Housing Navigator, and even more difficult to find someone who has the expertise and the Support Broker certification as well. Housing Resource Center (<https://nyhrc.org/directory.php>) lists only one person for NYC (“Region 4”). At this time, most trained Housing Navigators work for traditional agencies. To qualify for the Support Broker rate, the Navigator will need to go through the [Support Broker Training](#).
- B. **Cost.** The service will come out of the individual budget (PRA, Personal Resource Account).
- C. **Meetings.** The specialized support broker must arrange two in-person meetings each year with the individual. For the specialist, these meetings do not need to be the Circle of Support sessions, but instead can be scheduled whenever it is mutually convenient.

How to set up a specialized Support Broker

1. Have your broker add this item to the budget, with a justification that refers back to Life Plan:

“As described in the Life Plan, and as part of developing strong initial connections in the community, the specialized broker will provide expert assistance needed to obtain Housing. This activity is authorized by the ‘identify and develop initial connections in the community’ clause on page 3 of ADM-2019-06.”
2. Find an individual with the required expertise, preferably someone who is already certified as a Support Broker.
3. If they are not yet certified as a Support Broker, encourage them to go through the four days of training effort required. This will allow them to get paid by Medicaid for their expertise. The rate is \$40/hr, as of June 2019.
4. Remind them that they are allowed to bill for time they spend when not face-to-face. And inform them that they can have meetings over the phone or via Skype, for all meetings, except for a mandated twice-annual in-person session. Those two-per-year can be the Circle Of Support sessions, or for the specialized broker they can instead schedule separate one-to-one meetings at their convenience. If the engagement with you lasts less than a year, they probably do not even need to have those in-person meetings. But even if it is not required, you probably want a specialist who is available to meet with you in person at the very start and then once every six months.
5. Estimate with the specialized broker how long it will take to achieve the desired goal (hours per week, how many weeks). As a precaution, you might want to double that estimate (the money will remain in your budget if it’s not spent).
6. Sign a formal agreement with the specialized broker.
7. Start using the specialized services, and get a place to live, or a place to work.

Staffing Support

Myths: “Self-hired staff are not allowed to provide any assistance with tasks which are not face-to-face with the person receiving services.”

“Staff support can only be provided by someone who has no other paid role in the person’s life.”

Background: In many SD programs today, parents work as unpaid schedulers, and also serve as the Direct Service Professional of last resort when others are not available due to illness or other reasons.

Fact: The Staffing Support role takes over the scheduling effort, and can be filled by an individual who will also work directly with the individual. That way, the Staffing Support person could also serve as the DSP of last resort, if they are willing to do that when no one else can be found. The Staffing Support role provides assistance with

- setting up interviews and other tasks associated with hiring staff
- scheduling self-hired staff
- staffing related paperwork, including checking and filing timesheets and monthly reports

Staffing Support is funded through the IDGS (Individual Directed Good and Services), part of the self-direction budget. The reimbursement rate for Staffing Support is capped at \$20 per hour. The Staffing Support line allows a worker to bill for non-face-to-face time such as interviewing prospects, phoning people to find a fill-in worker, or doing scheduling and other paperwork.

Obstacles to keep in mind

- A. **Out of date information.** Staff at your DDRO and Fiscal Intermediary might not realize that it is now allowed to have one of your Community Habilitation workers also serve as Staffing Support. A quick on-line search will turn up documents from FIs which state-- incorrectly-- that the Staffing Support cannot be CommHab worker.
- B. **Overlap.** Some of the services available from Staffing Support are also available from the Support Broker. Ideally, from the viewpoint of the individual and their family, the Self-Directed Services program would have multiple people involved who are all involved in hiring and scheduling. Unfortunately, Medicaid Services generally disallow duplication of services, and may mis-interpret the support broker and staffing support as duplicative.
You can still have the Support Broker involved in Staffing, just be sure to describe the Support Broker role as “oversight of Staffing Support, and temporary replacement when that role is vacant” or however you wish to arrange it.
- C. **Lack of Backup.** Currently, there is no mechanism for finding a worker to call in with little notice. Perhaps in the future there will be an on-line “marketplace” created by Fiscal Intermediaries, where vetted workers can post their availability for fill-in work.
- D. **Cost.** As usual, having other people do work costs money, which comes out of your PRA (Personal Resource Account-- your budget).

How to set up Staffing Support

1. Figure out which tasks you want done by your staff support person. Ideas are: reviewing timesheets, writing monthly notes, scheduling staff, etc.
2. Estimate how many hours per week of support you will need, and ask your Support Broker to add the line item to your budget. If you want your Support Broker to also be involved in Staffing, then you will want to clearly differentiate the two roles-- the Support Broker can supervise the work of the Staffing Support person, and can also step in as a temporary replacement during vacations or in case of role vacancy.
3. Talk to a staff member who you trust to take on the responsibility. Point out to them that they can bill for time spent on administrative work. Be sure to discuss exactly what you want them to do, including which decisions you want them to make, and how you want them to keep you informed.
4. Consider: Write up an agreement with staff person, for the sake of clarity.
5. Start enjoying the lower stress of doing less paperwork.

Paid neighbor

Myth: “I have to be available all the time.”

Background: In many Self-Direction programs today, a family member is on-call to come in when something goes wrong, or when a worker calls in sick.

Fact: That role can be fulfilled instead by the Paid Neighbor, who is paid a monthly stipend to be on-call. They are paid hourly for CommHab when they are actually called in for work. The maximum monthly stipend is \$800. There is no minimum. If you want, you can set up multiple paid neighbors, and have them coordinate their coverage times.

The paid neighbor should live near the participant. The current regulations say that they can't live more than 30 minutes away. Ideally, you want someone who could get there in a few minutes. The Paid Neighbor can't live with the participant or be a family member.

Obstacles to keep in mind

- A. **Coordination.** You might want to have multiple levels of backup-- two or more paid neighbors so someone is always available. The coordination of their schedules could be one of the responsibilities of the Staffing Support person, or the Support Broker.
- B. **Lack of Backup.** What happens when the paid neighbors head out of town, for example during a summer weekend?
- C. **Cost.** A paid neighbor can take a significant chunk out of the budget.

How to set up a paid neighbor

1. Ask your broker to amend the budget to include the paid neighbor.
2. Find one or more neighbors who are responsible and who are often home in the evening and weekend. School teachers and recent retirees are excellent possibilities. Discuss with them your expectations for their availability. Let them know that the stipend is to reimburse them for the effort required to be on-call, and that they will be paid an agreed-upon CommHab rate for face-to-face time.
3. Get them cleared through your FI as Direct Service Professionals who can provide Community Habilitation services. Our experience has been that about half of the people you approach will drop out without getting clearance. Some will not want to make the effort, others will have some red flag in their history.
4. Consider: Create a written agreement for exactly when they will be available, and how they will coordinate their schedules. Let them know how you want to be informed of any calls for help that they get, and especially be clear on what sort of issues you would like to be informed about immediately.
5. Train the paid neighbor, as you would any CommHab staff, to work with the individual they will support. Although they are mostly “on call”, they should be able to step in at any time of the day.
6. Start enjoying more peace of mind, knowing that the paid neighbor(s) are available to deal with unexpected issues.

Live-In Caregiver

Myth: “If a person needs continuous support, the only choices are living at home with parents, or moving into a group home.”

Fact: The Live-In Caregiver (LIC) can be hired to live in a home owned or rented by the person receiving services in return for providing “companionship and protection.” The LIC gets free room and board. The maximum food subsidy is \$5K per year. The maximum rent subsidy varies by region, from a low of \$1156 per month to a high of \$1600 per month. However, in practice the amount is sometimes much lower, based on an opaque formula.

LIC services are distinct from Community Habilitation. However, the LIC can also act as part of the backup coverage, like a Paid Neighbor. That is, the LIC can be paid as a CommHab worker when needed.

You can also choose to have a LIC serve routinely as a CommHab worker, when the needs of the individual move beyond companionship and cross-over into the need for assistance. This is a fuzzy line, and the boundaries should be defined as clearly as possible in the formal agreement between the LIC and the individual. For example, you can specify that eating a meal together is companionship, but getting cooking lessons falls into Community Habilitation, and can be billed for.

Some Fiscal Intermediaries believe that the best practice is to allow the LIC to routinely serve as a CommHab worker. They see that the alternative is either to have the LIC fill that function without compensation, or to leave a need un-filled until an “authorized” CommHab worker is available to come in. Other FIs believe that the LIC should only serve as CommHab in case of emergency. There were less than a hundred LIC roles funded as of the end of 2015, so there has not been much experience with either approach. You should set up the arrangement which works best for you. **As long as you obey the ADMs, the details of your self-direction program are up to you.**

You should consider using a Housing Navigator to help you with the many moving parts of setting up an LIC and a place to live. You might also find it useful to look at the [NY Alliance Toolkit for Shared Living](#).

Obstacles to keep in mind

- A. **Lack of up to date knowledge.** Staff at your local OPWDD office and Fiscal Intermediary might not be aware that your Live-In Caregiver can also serve as one of your Community Habilitation workers. OPWDD allows this, but leaves it up to the individual FI to set their policy. Based on the principle of maximizing flexibility and continuity, we recommend pushing for allowing the LIC to “switch hats” and routinely act as CommHab.
- B. **Housing costs.** OPWDD guidance says that the payment will cover the “additional costs of room and board...reasonably attributed to the Live-in Caregiver.” In practice, the payment for LIC’s rent is not sufficient to cover those costs in the downstate region. The payment is calculated as if the LIC were another individual with I/DD, getting a maximum subsidy of 70% of the cost of rental, up to a maximum which is based on rents of 20 years ago. Rental subsidies in general are an active area of advocacy. The costs of a certified group home in NYS are much higher than the subsidy.
- C. **Gray areas.** The housing subsidy covers some, but not all, of the LIC’s share. Typically, the family or the person makes up the difference, rather than charging the LIC for the remaining 30% or more of their portion of the housing cost.
- D. **Trust and Oversight.** The LIC will be, in many cases, substituting for the oversight and daily monitoring and mentoring provided by a parent. In other cases and at other times, they will be acting as a room-mate. And if you opt for maximum flexibility, they can switch over to CommHab mode and start charging for their time, at their own discretion. This requires trust in the goodwill and integrity of the LIC.
- E. **Things change.** Consider that your LIC will most likely move out at some point. If that happens, or if they are ill or otherwise unable to work, it may take some time to replace them. What is your plan for that possibility?
- F. **Cost.** As usual, this is money out of your budget. However, the cost of a LIC is generally lower than paying for overnight staff. For an individual that wants to live “alone,” it is usually the only way to cover staffing costs.
- G. **Complexity.** Creating an LIC arrangement requires coordinating a lot of components. See outline below.

How to set up a Live-In Caregiver

Line up:

- a potential caregiver who
 - has passed the background checks.
 - needs housing, but not urgently and will commit to a year, or whatever time you decide.
- A house or apartment which will stay available until the paperwork gets processed.

To reduce the wait time, take care of a lot of the paperwork beforehand. You can have the Life Plan and budget formally approved long before you have lined up a person and a place to live. You might get some push-back, based on an erroneous belief that this is not allowed. The fact is that no money can be paid out until you have a LIC living with the person receiving services-- but the budget items can be approved in advance.

To speed things up even more, you can also request that the FI and DDRO perform an informal review of your documents in advance. They are under no obligation to do this.

If you have the financial flexibility and are willing and able to take the risks, you could have the LIC and the person receiving services start living together while the paperwork is being processed. You cannot get reimbursed for the rent you pay during that waiting period, and it could take months.

1. There is no single way to get this started, and no one has enough experience yet to make a firm recommendation. There are barely 100 LICs in all of NYS today. You have to get all the following done-- there is no mandated order, but everything must be in place before you start getting reimbursement.
2. Determine what you want, and what you are willing to spend.
 - 2.1. Explore what the LIC could do, and what you want them to do.
 - 2.2. Decide if LIC should also be self-hired staff. (We recommend this).
 - 2.3. Work with Support Broker to determine how much of the budget (PRA) you are willing to devote to cost of LIC.
3. Submit the updated LifePlan and Budget.
 - 3.1. Work with Care Manager, Support Broker and FI to establish need and expectations for the LIC service. Get it added to Life Plan.
 - 3.2. Work with Support Broker to determine the amount of housing subsidy, food and utility expenses to be attributed to the LIC.
 - 3.3. Explore how LIC would fit into the SD budget and what amendments will be needed.
 - 3.4. Work with Support Broker to complete a formal Budget Amendment which includes LIC and housing subsidy.
4. Put the draft agreements together and get them reviewed by the FI. Some FIs will supply you with 'starting drafts' that you can alter to fit your particular needs for services and for hours. Their starting drafts will, presumably, address the requirements of [ADM 2016-03](#).

- 4.1. Develop the agreement with the LIC, addressing all of the twelve requirements detailed in ADM 2016-03, page 4.
- 4.2. Develop the agreement with the FI, addressing all of the seven requirements detailed in ADM 2016-03, page 5.
5. Recruiting.
 - 5.1. Determine the characteristics you are seeking for the person who will be in the LIC role, including expectations on the level of companionship services and contingency plans.
 - 5.2. Advertise, interview, and select the LIC
 - 5.3. Work with the FI to have the LIC complete required background checks and trainings. The easiest way to get this done is to hire the LIC for an Individual CommHab role. In the best case, the background checks can be completed in about ten working days.
6. Find a place.
 - 6.1. Locate the residence, establish a lease or mortgage in a way that allows the housing subsidy to be paid. Ideally, you would tap into the expertise of a Housing Navigator to help you with this. If not, your broker can work with your DDRO SD liaison and your FI.
 - 6.2. Submit the paperwork for the individual LIC to be approved to share the apartment, a process that may take anywhere from one month to five months.
7. In the end, OPWDD requires that three sets of things be in place for you to get reimbursement for the costs of room and board for an LIC:
 - 7.1. Justification in the Life Plan.
 - 7.2. An approved budget agreements:
 - 7.3. Multiple signed agreements:
 - Between the person receiving services and the Fiscal Intermediary,
 - Between the LIC, the person receiving services, and the FI.
 - Between the LIC and the person receiving services, reflecting the details of their agreement.
8. That agreement between the LIC and the person receiving services can be flexibly defined to include whatever you need, as long as it does not stray into territory that is covered by CommHab, Staffing Support or Support Broker. The LIC is fundamentally about fellowship and safety. It is up to you and your LIC to negotiate a mutually agreeable contract, and then stick to it.
9. Once the place to live and the LIC are set up, you will get payments from the FI. No money is sent directly to the LIC. Common practice is to cover 100% of the rent and food expenses for the LIC.
 - 9.1. Rent. You will get payment for the rent subsidy. Depending on the sophistication of the FI, you might get this as direct deposit.
 - 9.2. Food costs. You will need to get receipts from the LIC, and you will need to submit them monthly. Only food items are covered, not other household needs that are commonly purchased at grocery stores, such as paper towels. If you have the flexibility, provide the LIC with the money in advance for each month's food expense.

Resources: If You Want a Deeper Dive

Here are additional materials which you might find handy-- but you should be able to setup additional services without looking at these.

Documents on Setting up Self-Direction

Advocate-authored Guidance for Families

- A comprehensive document, "[Self-Direction in NY: A Practical Guide for Families](#)" can be found at [NYselfd.org](#) (and multiple other places across the web)
- For a gentler introduction to Self-Direction, go to [inthedriversseat.org](#). The web-site of this Rochester-based organization provides general guidance on Self-Direction in NYS, mixed in with information that is specific to Rochester.
- NY Alliance for Inclusion and Innovation has some great information resources. They tend to be more technical, but do make an effort to be read-able. At the very least, you can point your FI and Support Broker here for guidance. Especially good are:
 - [nyalliance.org/articles/SD_FAQ](#)
 - [nyalliance.org/images/downloads/shared_living_tool_kit_report_12_3_17.pdf](#)

Guidance on how to deal with staff

See the Staffing section starting on page 57 of [Self-Direction in NY: A Practical Guide for Families](#) which you can find on the home page of [nyseld.org](#).

For more general guidance, search for info on managing and motivating people. One good resource: Daniel Pink's [Drive: The Surprising Truth About What Motivates Us](#).

OPWDD's Guidance for Providers

Self-Direction Guidance for Providers, 2018-March-08 version, downloaded from: [opwdd.ny.gov/opwdd_services_supports/self-direction/self-direction-guidance](#)

Employment services

Lengthy (205 pages) and technical guidance on Supported Employment services (SEMP), 2018-June version: [humanservicesed.org/filehandler.ashx?x=9023](#)

EmployAbility handbook for employers:

[opwdd.ny.gov/sites/default/files/documents/EmployAbility_Layout_21317_0.pdf](#)

Not particularly useful OPWDD website about Employment:

Technical Government Documents

The Waiver

The authorizing document for New York State's Medicaid-funded program for people with Developmental Disabilities is the 1915(c) HCBS Waiver. It is a very lengthy document filled with lots of indecipherable language. And, the allowable scope for the Support Broker is described fairly clearly on page 100 of the 2019-06-28 version.

opwdd.ny.gov/sites/default/files/documents/Approved_Amendment_05_6-28-19.pdf

Administrative Directive Memos

Many of the details of OPWDD policies are described in an ADM, which is the abbreviation for an Administrative Directive Memo. Here's the current site which lists all of them and provides links to download all of them:

opwdd.ny.gov/opwdd_regulations_guidance/adm_memoranda

NYS periodically re-organizes its web-sites, and does not always preserve the old links. If you find that the ADMs have moved, please let us know. And, try searching for the ADM code, such as: ADM-2016-03

The ADMs of most interest for Self-Directors are:

- Support Broker
 - opwdd.ny.gov/opwdd_regulations_guidance/adm_memoranda/ADM-2019-06
 - opwdd.ny.gov/sites/default/files/documents/ADM_Support_Broker_Authorization_Standards_2019-05.pdf
 - As of July 2019, due to the on-going OPWDD web-site re-work, the link described multiple times inside that document is a dead link
 - opwdd.ny.gov/providers_staff/self-direction-support-brokers
 - OPWDD is trying to get an automatic redirect put into place. In the meantime, use this link
 - opwdd.ny.gov/opwdd_services_supports/self-direction/self-direction-support-brokers
- Live-in Caregiver
 - opwdd.ny.gov/opwdd_regulations_guidance/adm_memoranda/documents/ADM-2016-03

Details of Pay Rates for Shared Staff

The chart below shows an example of the maximum hourly rate, including all fringe benefits, that SDS can budget. This example is for Region 1, for rates set in April 2018. In all three regions, the group rates are set so that the maximum rate is 25% higher when serving two, 50% higher when serving three, and 75% higher when serving 4. This is shown in chart on the line labeled “Total reimbursement as % of one-on-one” And since the cost is split among multiple budgets, each individual budget pays less. This is shown on the line labeled “Budget cost as % of one-on-one”.

HOURLY COMMUNITY HABILITATION				
REIMBURSEMENT PER OPWDD in Region 1				
Measure	One-on-one	Serving group of 2	Serving group of 3	Serving group of 4
Max per budget	\$41.07	\$25.67	\$20.54	\$17.97
Budget cost, as % of one-on-one	100%	63%	50%	44%
Total reimbursement	\$41.07	\$51.34	\$61.62	\$71.88
Total reimbursement as % of one-on-one	100%	125%	150%	175%

The current rates set by NYS appear on this page:

health.ny.gov/health_care/medicaid/rates/mental_hygiene/index.htm

HOURLY COMMUNITY HABILITATION				
Reimbursement Per OPWDD				
REGION	Individual Serving 1	Group Serving 2	Group Serving 3	Group Serving 4
1	\$41.07	\$25.67	\$20.54	\$17.97
2	\$42.59	\$26.62	\$21.29	\$18.63
3	\$41.61	\$26.01	\$20.81	\$18.21

As of August 2019, the most recent change in rates was April 2018. Here’s a direct link to the group rates:

health.ny.gov/health_care/medicaid/rates/mental_hygiene/2018-04-01_comm_hab.htm

Support Broker Training

A Housing Navigator can be added to your plan and get the Support Broker rate of pay, after they go through the Support Broker training program. OPWDD is working on making most of that training available on-line and on-demand. Their aim is to reduce the in-person training to a single day.

Today, however, you must attend four days of training, at one of the DDROs (Developmental Disability Regional Offices). In theory, each DDRO is supposed to offer the complete training each quarter. The full set of courses, as described in ADM 2019-05:

1. Self-Advocacy/Self-Determination – ½ day.
2. Introduction and Advanced Person-Centered Planning – 1 day.
3. Broker Training Institute- 2 days.
4. Developing a Self-Direction Budget - ½ day.

For more details, see

opwdd.ny.gov/sites/default/files/documents/ADM_Support_Broker_Authorization_Standards_2019-05.pdf.

In practice, unfortunately, the scheduled classes are typically posted on the Statewide Learning Management System only a week or two in advance, when the DDRO is 100% certain that they have lined up all the instructors and other resources. Few people have the flexibility to alter their schedules with only one-week notice. So your best bets are:

- Register on NYS Learn, and then check on a weekly basis for official notification of the course(s) you need to complete your certification. nyslearn.ny.gov
- Make friends with your county's SD coordinator, so that they will tell you when training is getting tentatively scheduled-- which is often months in advance. Some DDROs have email newsletters which will give early notification. opwdd.ny.gov/coordinator/coordinator-listing/self-direction
- If you have the flexibility to travel to other DDROs, reach out to them as well. The Long Island offices (Region 5) have the most experience with Self-Direction, and historically have run great courses that go well beyond the basics.