Brookville Center for Children's Services

TRANSITION GUIDE

Table of Contents

updated December 2023

QUICK REFERENCES, (see the digital version at brookvillecenter.org for clickable links)

ABLE National Resource Center	http://ablenrc.org
AHRC Entitlements Specialists	516-293-2016 ext. 5319
Karen Lukas	klukas@ahrc.org
AHRC Foundation, Special Needs Trusts	mmcnamara@ahrcfoundation.org
Mary McNamara	516-626-1075 ext. 1133
Care Coordination Organizations (CCO's):	
Advanced Care Alliance	833-692-2269
Care Design NY	518-235-1888
Tri-County Care	844-504-8400
or call OPWDD	631-434-6100
CDPAP – NY Independent Assessor (NYIA)	1-855-222-8350
DSS, to apply for Medicaid	
Nassau	516-227-7474
Suffolk	631-853-8730
LIFSSAC (for helpful information)	https://www.lifssac.com/
	Agencies and Services List
	Family Grant Program List
OPWDD	
Long Island office/Front Door Access	631-434-6000
Long Island office/Eligibility	631-416-3902
Application Transmittal form	Online Transmittal Form
Guide to eligibility resources	Eligibility
Front Door – information sessions	Schedule
HCBS Waiver application	HCBS application
Parent to Parent	http://parenttoparentnys.org
Selective Service website	https://www.sss.gov/
Social Security	1-800-772-1213
SOYAN	soyan.org
Voucher/Family Reimbursement, AHRC	516-293-2111, ext. 5303
Leonard Giarraputo	lgiarraputo@ahrc.org
Voucher/Family Reimbursement, Citizens	516-293-2111, ext. 5610
Loretta Goldson	lgoldson@AHRC.org

Our contact information:

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ext. 3317

Vanessa Martinez-Mautino, School Social Worker
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ext. 3347

Jennifer Fazio Lunn, Transition Program Coordinator, Cissy Birnbaum Building
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ext. 2457

Patti Edwards, Transition Program Coordinator, Silver Building
pedwards@brookvillecenter.org
ext. 3330

SECTION 1

Initial Transition Planning Timeline

Ages 12 – 15

1. Begin planning for the future; meet with school and school district in person.
2. Start scheduling adolescent-type activities, e.g.:
    a) overnight respite
    b) camp
    c) visits with peers
3. Allow children to do as much as possible for themselves, including simple household chores. If appropriate, schedule a series of "in-home responsibilities".
4. Save **all** information/paperwork (especially medical) regarding child's diagnosis, evaluations, medication, etc. You will need it.
5. Contact OPWDD (631-434-6000) to register your child and determine eligibility, as well as to schedule a time to attend a Front Door Access to Services Information Session for Individuals and Families.

Ages 15 – 18

1. Begin to explore probable Adult Day Program outcomes, e.g. Self-Directed Services, Certified Site-Based Day Habilitation, Program Without Walls, Supported Employment.
2. Explore establishing guardianship and possibly setting up a special needs trust.

Ages 18 – 21

1. Apply for SSI and Medicaid. You can make an appointment with Social Security (1-800-772-1213) the month after your child's 18th birthday. You can contact AHRC Entitlements Specialists (516-293-2016 ext. 5319) for additional information or assistance.
2. Apply for care coordination, which you **must** have to access services. Contact one of the three Care Coordination Organizations (CCO's) that serve Long Island. They are:

    Advanced Care Alliance, (833)-692-2269

    Care Design NY, (518) 235-1888

    Tri-County Care, 844-504-8400
3. If interested, you and your Care Coordinator can begin application for a community residence, as well as for services such as community habilitation, residential habilitation, respite, and recreation programs.
4. If you established eligibility for your child before the age of 8, you will need to recertify.
5. ALL 18-year-olds can register to vote. And then they can vote.
6. ALL 18-year-old males must register for selective service, even if significantly disabled (see information from the Selective Service website at **http://www.sss.gov**).
7. **If your child uses an augmentative communication device** such as an iPad, and if it is provided by your school district, ask the district if your child can keep it after graduation. If the answer is no, seriously consider purchasing a device before graduation, so it can be set up in school for use after graduation.

Guardianship: Information from the NY State Courts System

Adapted from: *http://nycourts.gov/courthelp/Guardianship/17A.shtml*

Guardianship of a person who is intellectually or developmentally disabled

In New York State, when a person becomes 18 years old they are assumed to be legally competent to make decision for themselves. This means no other person is allowed to make a personal, medical or financial decision for that individual. If a person is "intellectually disabled or developmentally disabled," has difficulty making decisions for themselves and over 18 years old, you can ask the Surrogate's Court to appoint a guardian for him or her.

In New York State, a guardianship case is handled by the Family Court, Supreme Court or Surrogate's Court depending on the type of guardianship asked for and the ward (usually 17A for our students).

About Article 17-A Guardianship

An Article 17-A Guardianship is available only for individuals who are "intellectually disabled or developmentally disabled." These are the legal terms used in Article 17-A of the Surrogate's Court Procedures Act.

A certification from one physician and one psychologist or two physicians must be filed with the petition certifying that the person has a disability and is not able to manage his or her affairs because of intellectual disability, developmental disability or a traumatic head injury. The Surrogate's Court can appoint a guardian of the person, the property or both.

An Article 17-A Guardianship is very broad and covers most decisions that are usually made by a parent for a child, such as financial and healthcare decisions.

To start your case, contact your attorney, or use the free DIY Forms program at http://nycourts.gov/courthelp/Guardianship/17A.shtml , or you can contact the Surrogate's Court for an Article 17A Guardianship Packet.

There is always a hearing. During the hearing, evidence is presented to the judge showing why the petitioner thinks a person needs a guardian. The judge officially appoints a guardian by issuing "letters of guardianship" that specifically says what the guardian can do.

Supported Decision Making as an Alternative to Guardianship

https://sdmny.org

As a less restrictive alternative, SDM can be used to avoid the necessity for guardianship. Supported decision-making (SDM) is increasingly being recognized as a preferable and less restrictive alternative to guardianship. By providing a person with an intellectual or developmental disability with supports from trusted people in his or her life, he or she is able to make his or her own decisions and retain all his or her legal and civil rights.

SDM can be entirely informal, as is the case for the majority of people with I/DD who live in the community and get decision-making support from family, friends, and care providers on an as-needed basis.

SDM can be more formalized, as when it is the result of a planned facilitation process, such as that used by SDMNY. The person with I/DD (the "Decision-Maker") and trusted persons they have chosen (the "Supporters") reach a Supported Decision-Making Agreement that describes the areas in which the Decision-Maker desires support, the kinds of support they want from each Supporter, and how they want to receive that support.

SDM can be "legalized" when there is a law that recognizes the process and affords legal recognition to SDMAs. Currently eight states and the District of Columbia have passed such laws, and a number of other states are in the process of considering them.

New York's New SDMA law

New York's new SDMA law, technically, Article 82 of the Mental Hygiene Law, was signed by Governor Kathy Hochul on July 26, 2022, the anniversary of the Americans with Disabilities Act (ADA). The new SDMA law:

- recognizes supported decision-making, as a less restrictive alternative that courts should consider before imposing guardianship.
- prevents discrimination against people with I/DD by requiring third parties to accept decisions made by persons with SDMAs that have been entered into through a facilitation process set out in regulations to be drafted by OPWDD within a year of the law's signing. Those regulations are expected to closely mirror SDMNY's facilitation process.
- describes who may be a supporter, the kinds of support they can give, and the limitations on supporters' authority.
- ensures that making an SDMA is voluntary

What the new law does NOT do:

- affect families' and others' ability to petition for guardianship if they so choose
- require anyone to do supported decision-making, including as a requirement for receiving services
- prevent a Decision-Maker from seeking support outside the provisions of their SDMA, including from family members and others who may not be named as Supporters (though only decisions made pursuant to the terms of the SDMA will be legislatively recognized)
- extend legislative recognition to decisions made with SDMAs to groups other than persons with I/DD (older persons with cognitive decline; persons with psychosocial disabilities; persons with traumatic brain injuries [TBIs])

Letter of Intent

A guide to your child

What is a Letter of Intent?

A Letter of Intent (LOI) is a document that conveys "This is what I know about my son/daughter with disabilities and what I want as a parent for his/her care if and when I am unable to take care of him/her." It is a document that comprehensively describes, in a very personalized manner, updated information about likes, dislikes, needs and desires of the beneficiary in as much detail as possible.

That said, an LOI should be what you and your child need or want it to be. All of the following, including the template, are suggestions.

LOI Work Sheet

For each applicable area below, consider your family member's future. List 3-4 options to guide future caregivers in decision making and interaction with your family member. Draw upon what you know about your family member, through observation and through discussion with your family member and others.

Residence: If something should happen to you tomorrow, where do you want your family member to live?

Education: You have a lifelong perspective of your family member's capabilities. Share it!

Work: What does your family member enjoy? Consider their goals, aspirations, limitations...

Health: What has and has not worked with your family member? What should future caregivers know?

Behavior: What consistent approach has worked best in your absence during difficult transition periods in your family member's life?

Social: What activities make life meaningful for your family member?

Religious: Is there a specific church or synagogue or person your family member prefers for fellowship?

Finance: What financial resources are available for the plan?

Mobility: What arrangements are necessary to transport your family member to the above-mentioned activities?

Advocate: Who will look after, fight for and be friends to your family member?

Guardian: List 3-4 options of persons

Trustee(s): Who do you want to manage your family member's supplementary funds? List 3-4 persons your child's age that can act as a successor guardian.

Also list:

- likes and dislikes
- what works: living situations, foods, recreation
- what doesn't work
- social/recreational activities
- food preferences
- clothing preferences
- habits and routines

The LOI…

- ensures that caregivers understand your wishes
- ensures that those who come after you need not waste precious time figuring out the best way to provide the best possible care for your child
- should be a living document; review and revise it annually, perhaps as an end-of-year task, or on your child's birthday
- should be flexible, clear, and personal
- should document what you feel is important for a caregiver to know
- is not a legally binding document
- can be a statement of the kind of life you envision for your child
- can include input from other family members, or whoever you want input from
- may be addressed to whomever you wish
- can be in any form you prefer; e.g. using a sectioned binder can help you to be flexible and thorough
- might be given to:
    - your attorney with other estate planning papers
    - the executor of your will
    - your child's current and/or future guardian(s)
    - your other children
    - whoever you think should have it
- can be given whole or partially (perhaps one person would need only one of the pages)
- can be part of your future planning process for your child, e.g. in completing the LOI, you might see things you need to address

LOI Template

There are many LOI samples and templates available on the internet. Looking at some of them, as well as the suggestions that accompany them, might give you a good idea of what you would like your LOI to be. You

Letter of Intent

Name of individual filling out this form: _____

Relationship to person: _____

Effective Date: _____ Revised copy date: _____

Name: _____ Nickname: _____

Date of birth: _____ Place of birth: _____

Address: _____

Phone number: _____ Gender: _____

Height: _____ Weight: _____ Social Security #: _____

Citizenship: _____ Ancestry: _____

Language spoken: _____ Religion: _____

Mother's name: _____ Mother's maiden name: _____

Father's name: _____ Phone #: _____

Are there siblings? _____ Do they live at home? _____

Siblings: (list address and phone number if not living in your home): _____

_____

_____

Are there any concerns about the siblings? _____

If there is more than one emergency contact, please prioritize.

Primary Emergency contact: _____

Emergency contact: home phone # _____

cell # _____

work # _____

Other Emergency contact: _____

Emergency contact: home phone # _____

cell # _____

work # _____

Other Emergency contact: _____

Emergency contact: home phone # _____

cell # _____

work # _____

Guardianship: ___ yes ___no. If yes,

Guardian's name: _____ (contact info on next page)

Stand by guardian's name: _____ (contact info on next page)

If no, do you have future plans to appoint a guardian? _____

Important Contact Information

Guardian: _____

Address: _____

City, State, Zip: _____

Phone: _____

Standby Guardian: _____

Address: _____

City, State, Zip: _____

Phone: _____

Financial Advisor/Conservator:

_____

Address: _____

City, State, Zip: _____

Phone: _____

Vocational Contact: _____

Address: _____

City, State, Zip: _____

Phone: _____

Care Manager: _____

Address: _____

City, State, Zip: _____

Phone: _____

School/Work Contact: _____

Address: _____

City, State, Zip: _____

Phone: _____

Executor/Will:_____

Address: _____

City, State, Zip: _____

Phone: _____

Other: _____

Address: _____

City, State, Zip: _____

Phone: _____

Medical Information

Diagnosis: _____

Health Insurance information:

Medicaid: _____

Medicare: _____ Other: _____

Healthcare proxy? ____ yes ____ no If yes, who? _____

DNR? ____ yes ____ no

Physicians

Name: _____

Address: _____

City, State, Zip: _____

Phone: _____

Specialty: _____

Date of last visit: _____

Frequency of visits: _____

Name: _____

Address: _____

City, State, Zip: _____

Phone: _____

Specialty: _____

Date of last visit: _____

Frequency of visits: _____

Name: _____

Address: _____

City, State, Zip: _____

Phone: _____

Specialty: _____

Date of last visit:_____

Frequency of visits: _____

Name: _____

Address: _____

City, State, Zip: _____

Phone: _____

Specialty: _____

Date of last visit: _____

Frequency of visits: _____

Other healthcare services (nurses, therapists, etc.)

Name: _____

Address: _____

City, State, Zip: _____

Phone: _____

Specialty: _____

Date of last visit: _____

Frequency of visits: _____

Name: _____

Address: _____

City, State, Zip: _____

Phone: _____

Specialty: _____

Date of last visit: _____

Frequency of visits: _____

Name: _____

Address: _____

City, State, Zip: _____

Phone: _____

Specialty: _____

Date of last visit: _____

Frequency of visits: _____

Name: _____

Address: _____

City, State, Zip: _____

Phone: _____

Specialty: _____

Date of last visit: _____

Frequency of visits: _____

Type and cost of medical equipment needed: _____

_____

_____

Pharmacy / Pharmacies used: _____

_____

_____

General Medical History

Immunizations: _____

_____

Allergies: _____

_____

Childhood diseases: _____

_____

Hospitalizations/surgeries: _____

_____

_____

History of seizures? ____ yes ____ no

If yes, how do you recognize a seizure? _____

_____

What is the seizure protocol? _____

_____

Is there special equipment needed, such as a helmet? _____

Are there specific medical concerns? _____

_____

Are there family history medical concerns? _____

_____

Other medical information: _____

_____

Describe any special diet _____

_____

Daily Living

Food and nutrition

Likes: _____

Dislikes: _____

Other factors: _____

Skills (Describe current level and where assistance is needed)

Personal hygiene: _____

_____

Bathroom: _____

_____

Dressing: _____

_____

Meal preparations: _____

_____

Money management: _____

_____

Current community independence skills: _____

_____

What type of household assistance is needed? _____

_____

Clothing sizes: _____

Other information: _____

_____

_____

Other Factors and Considerations

School/Work: (describe current situation and your thoughts for the future) _____

_____

Literacy level: _____ Does he / she vote? _____

Social: (list level of functioning, strengths, weaknesses and preferences) _____

_____

_____

Hobbies: (list all interests including structured and unstructured recreation, exercise, vacation preferences and activities) _____

_____

_____

Friends, aides, helpers, siblings: _____

_____

_____

Likes: _____

_____

_____

Dislikes: _____

_____

_____

Favorite things: (pets, toys, people, activities, hobbies, stores, restaurants) _____

_____

_____

_____

Holidays / Family traditions: _____

_____

_____

_____

_____

How can family/friends/support staff support this? _____

_____

_____

_____

_____

What are your hopes and dreams for your family member? _____

_____

_____

_____

_____

_____

What are (fill in name) _____’s hopes and dreams? _____

_____

_____

_____

_____

_____

_____

_____

Behavior Support

Level of supervision: _____

_____

List known triggers for behavior issues: _____

_____

_____

_____

_____

List fears or phobias: _____

_____

_____

_____

List absolute no-nos: _____

_____

_____

_____

If a behavior occurs, how do you handle it? _____

_____

_____

_____

_____

_____

_____

Financial Arrangements

List your child's monthly income (SSI, SSDI, court settlements, child support, etc.) and any other government benefits: _____

_____

Bank Accounts

Type: _____ Name of Bank: _____

Owner name: _____

Type: _____ Name of Bank: _____

Owner name: _____

Life Insurance Policies

Company: _____ Name of insured: _____

Owner: _____ Death benefits: _____

Type: _____ Policy #: _____

Premium/frequency: _____ Beneficiary: _____

Cash value: _____

Company: _____ Name of insured: _____

Owner: _____ Death benefits: _____

Type: _____ Policy #: _____

Premium/frequency: _____ Beneficiary: _____

Cash value: _____

Is there a trust? _____ If so, what type? _____

Last update: _____

Who is responsible for the trust? _____

Who will handle the financial affairs if the child moves into an agency run home? _____

_____

Potential Inheritances:

Type: _____ Value: _____

From whom: _____ For whom: _____

Type: _____ Value: _____

From whom: _____ For whom: _____

Other Assets:

Type: _____ Value: _____

Owner name: _____

Type: _____ Value: _____

Owner name: _____

Other Financial issues:

Explain: _____

_____

_____

_____

Have you pre planned any funeral or burial arrangements for your child? _____

If you have please explain: _____

_____

_____

_____

If you have not made burial arrangements, what are your preferences? _____

_____

_____

If the primary caregiver is no longer able to act in that capacity, where will the child live?

_____

_____

Who will handle the financial affairs for the child? _____

_____

_____

Has this information been discussed with the people named and are they in agreement? _____

_____

_____

Is there any other information you want to share? _____

_____

_____

_____

_____

_____

Consider attaching current psychological, psychosocial, IEP/ISP, and any additional paperwork that might be helpful.

RECORD KEEPING

Compiled by Parent to Parent of NYS www.parenttoparentnys.org

An important part of raising a child is keeping records of the major events in your child's life. As a parent of a child with special health care needs or a disability, this record keeping goes beyond when your daughter got her first tooth or when your son broke his arm.

Why keep records?

It is important to have medical information in one easily accessible place. Keeping track of your family's medical information can prevent unnecessary stress. If you move or change doctors, you will be able to share your medial history with the new doctor before your "official" records get forwarded.

What should I keep?

Keep all relevant information related to your child, including:

- Dates of immunizations, hospitalizations, illness, surgeries
- Contact info and dates of service for: doctors, specialists, dentists, surgeons, therapists, insurance companies, schools
- Phone conversations logs for: medical professionals, insurance providers
- Medication information
- Insurance information (copy of policy and correspondence)
- Education/School documents (i.e. 504 Plan, notes from nurse, etc.)
- Equipment, supplies and vendor information
- Emergency contact information
- Other information specific to your child

Where to start organizing your records?

Start with today, this month, this year. Don't let the overwhelming thought of organizing prevent you from beginning. Find a method that works for you and use it. The best method is one that you will use regularly.

Some suggestions:

File folders, accordion folders, notebooks, and a specific box or file drawer all work as locations to keep records. Find what works best for your lifestyle. Use a different notebook, folder, drawer or box for each child. Go through your records annually to keep them current and up to date.

What should families keep & how long?

Forever:

- 1st & last psychological
- Guardianship papers
- Passport
- Copy of non-driver ID
- Updated Letter of Intent
- List of trust funds
- List of schools attended
- Any approval letters
- Evidence of life insurance if you have it.
- Health care proxy, if you have it.
- Birth certificate

A year:

- Most recent rights & responsibilities you signed
- Inventory of what your family member owns versus what belongs to the agency (compare to previous year & update)
- Latest Life Plan, any habilitation plan
- Latest Care Coordination agreement

Other:

- Statement of fees & services (liability form) i.e. cable, internet, phone – until they change
- Irrevocable burial trusts – annual statements
- Keep last physical and medical records
- Current medical insurance – update as needed
- Food stamp letter – a year or if it changes
- If there is a lease, you should have a copy of the current one.
- Save a copy of current social security adjustment letter.
- DNR or DNI, when needed
- Quarterly reports of allowance spending, if not rep payee, bank statements if rep payee – up to a year. If not rep payee you may have to request statement from agency – they aren't required to send it to you.

SECTION 2

IMPORTANT ACRONYMS, TERMS, & INFORMATION

OPWDD – New York State's Office for People With Developmental Disabilities (*http://www.opwdd.ny.gov*). They are responsible for:

- coordinating services to New Yorkers with intellectual and developmental disabilities
- certifying and overseeing voluntary agency providers

DDRO – Developmental Disabilities Regional Offices, i.e. OPWDD's local offices. DDROs are responsible for the following activities:

- **eligibility for OPWDD services** (this is done as part of the Front Door process)
- intake
- waiver enrollment (a Federal-State partnership which makes certain types of services available within the home or community)
- local management of Individual and Community Supports (ICS)
- management of resources for crisis intervention
- advocacy
- shared management of OPWDD statewide applications
- service recruitment and development for the Family Care program
- programs, services and supports for aging individuals with developmental disabilities
- Lastly, DDROs act in a supporting role to DD State Operations Offices with regard to eligibility for others areas of statewide services including but not limited to: level of care determinations; clinical delivery and waiver service delivery; Article 16 clinics; quality improvement processes; review of audit reports for trend analysis; emergency preparedness; safety, security and maintenance; and implementation of OPWDD initiatives.

LI DDRO – Long Island's DDRO (Region 5 – Nassau and Suffolk)

- 415A Oser Avenue, Hauppauge, NY 11788
- Main numbers: 631-434-6100, 631- 434-6000
- **Front Door access number: 631- 434-6000** and **631-434-6100**
  - Michelle Reichert 631-416-3851 Michelle.X.Reichert@opwdd.ny.gov
  - Sandra Green 631-416-3905 sandra.lorraine.green@opwdd.ny.gov
  - Farhana Bertolet 631-416-3927 farhana.bertolet@opwdd.ny.gov
- Eligibility Facilitator:
  - Alison Herchenroder 631-416-3917 alison.b.herchenroder@opwdd.ny.gov
  - Shannon Morse 631-416-3955 Shannon.E.Morse@opwdd.ny.gov
- Local Schools Transition Coordinators:
  - Marie Flanagan 631-416-3920 Marie.E.Flanagan@opwdd.ny.gov
  - Lambert Liu 631-416-3915 Lambert.X.Liu@opwdd.ny.gov
- Self-direction liaisons:
  - Lauren Nelson 631-416-3848 Lauren.Nelson@opwdd.ny.gov
- Family Support Services
  - Christina Bozza 631-416-3986 Christina.E.Bozza@opwdd.ny.gov

- Interim Care Coordination
    - Erin Caglioti 631-416-3943 Erin.A.Caglioti@opwdd.ny.gov
- Community Living/Housing: 631-416-3843

DDSOO – Developmental Disabilities State Operations Offices

Long Island: 631-493-1701

- administer and oversee state operations for OPWDD, including the direct delivery of services and supports to people with developmental disabilities by state staff.
- are responsible for the following activities:
    - development and monitoring of OPWDD systems improvement
    - offering specialized supports/services and service delivery in the areas of clinical and food services, waiver services and volunteers/senior companions
    - acting as advocate when responding to stakeholder questions and legislative inquiries
    - oversight of support services (e.g., Medicaid compliance, HIPAA compliance and clinical records review)
    - oversight of the Statewide Technical Assistance Team, which provides pre-survey and focused technical assistance activities to campus-based ICFs and other state-operated community-based residential programs in which quality improvement issues have been identified; and ensures ongoing compliance with federal requirements and that program certification is maintained
    - management of OPWDD electronic billing and recordkeeping systems
    - oversight of the day-to-day administration of State-operated Family Care
    - coordination of fire safety, including development of evacuation plans in state-operated programs, and maintaining relationships with fire departments
    - act in a supporting role to DDROs in the areas of service development, local management of individual and community supports and crisis intervention.

CCO – Care Coordination Organization

- the model for coordinating all the services and supports a person with I/DD may need
- you MUST have a care coordination (i.e., a care manager) to access adult services
- three agencies serve Nassau and Suffolk counties: Advance Care Alliance, Care Design NY, and Tri-County Care; contact information for all three is in section 5 of this guide

- **Care Manager**
  - required for your child to enroll in an OPWDD Medicaid Waiver Program (e.g. HCBS)
  - provided through three Care Coordination Organizations (CCO's) that serve Long Island; see Section 5 of this guide for contact information
  - acts as the liaison between your child and service providers

HCBS Waiver – Home and Community Based Services Waiver (waiver services)

- operated by OPWDD, it is a program of supports and services, including:
  - habilitation services
  - respite care
  - care coordination
  - adaptive technologies
- services are provided either by OPWDD's Developmental Disabilities Services Office (DDSO) staff or through voluntary not-for-profit agencies who have been authorized to provide HCBS waiver services by OPWDD or the NYS Department of Health (DOH).
- a person who is eligible and lives in NYS can request to be enrolled in the HCBS waiver by contacting the DDSO or a provider agency that serves the county in which the person lives
  - Long Island: 631-493-1701

Life Plan (replaces the ISP/ Individualized Service Plan)

- Health Home Care Management will continue to provide the service coordination that people currently receive, but will also include coordination of other services, such as health care, wellness, behavioral, and mental health services through a single individualized Life Plan, which will replace the current Individualized Service Plan (ISP); it will still:
  - describe who the person is through strengths, capacities, needs, and desires
  - list supports and services needed by the person to achieve these outcomes
  - identify their goals and helps secure the needed services and supports, including natural supports and community resources, to attain those goals

The "Front Door" Process

What is the Front Door?

"Front Door" is the name of the process OPWDD has developed for families to access services such as respite, community habilitation, and adult day services.

Steps of the Front Door process

1. **Initial contact – Call OPWDD at 631-434-6000 (Spanish - Ana Hernandez 631-416-3909)**
    - Leave a message stating:
        - Parent/guardian's full name
        - Child's name
        - Child's date of birth
        - Phone number
        - Family email
    - Front Door facilitator will return call within 48 hours
        - The assigned Front Door facilitator will establish if the family should work with a Non-Medicaid Service Coordinator or a CCO (Care Coordination Organization).
            - Families of younger children inquiring about Family Support Services, i.e. respite, recreation, and voucher reimbursement will be referred for non-Medicaid service coordination
            - Families who need to apply for Home Based Waiver Services such as self-direction, community habilitation, residential habilitation, adult day services, SEMP, ETP, Pathways to Employment, and residential services will be referred to a CCO (Advance Care Alliance, Care Design NY, or Tri-County Care
                - School referral packets can go directly to a CCO. The family will need to inform the Front Door facilitator that they have already chosen a CCO, and provide the name of the CCO.
            - The Front Door facilitator will assign the individual a TABS number within three days. Keep this, as it is important.
2. **Front Door Information Session** (can be done before the above steps)
    - Parent/guardian must attend an information session
    - Sessions can be found at https://opwdd.ny.gov/get-started/information-sessions
    - What the training covers: "The session will offer participants an understanding of OPWDD's mission and purpose; the process to become eligible for OPWDD supports and services; types of supports and services available including self-directed service options; and where individuals and families can go to get assistance."
    - Once you have done the training, you will not have to do it again, even if you do a service amendment (SAM)
    - When you complete training, you will receive a certificate; KEEP IT.

3. **Determining eligibility for services –**

- Parent/guardian must complete the OPWDD transmittal form - https://opwdd.ny.gov/eligibility. Here is how to fill it out:
    - Section 1 – child's personal information
    - Section 2 –
        - P/A 1 – Parent/guardian information
        - P/A 2 – Brookville Center for Children's Services or referring district, and the social worker assisting with the process
    - Section 3 – Referring agency info – list CCO or non-Medicaid coordination agency
    - Section 4 – check all services that are of interest

- Family and school district provide the required documents for eligibility determination to either the CCO or the non-Medicaid coordination agency

- The CCO or the non-Medicaid coordination agency will upload the eligibility documents into OPWDD's Choices System

4. **Assessment of strengths, needs, and preferences**
    - OPWDD uses the Child and Adolescent Needs and Strengths (CANS) functional needs assessment for people with developmental disabilities ages 17 and younger and their families. It is conducted as an interview with parents and the child and is used to:
        - identify support needs
        - inform decision making and individualized plan development
        - authorize and implement the individual plan

5. **Informed decision making and Individualized Plan development**

   You will work with your child's Care Manager to:
    - determine a program
    - access services

6. **Plan authorization and implementation**
    - Before services can begin, they must be reviewed and authorized by the DDRO
    - Plan implementation will reflect one of the following tracks:
        - **Self-Directed Services** – select a broker (OPWDD provides list) and a financial management services agency (FMS) to develop and manage a plan
        - **Agency Purchased Services** – select an agency to develop and manage services
        - **Combination of Self-Directed and Agency Purchased Services** – select a broker and FMS to help develop and co-manage portions of a self-directed plan; this plan can also include a service(s) that an agency manages

On this page and the next is a helpful Front Door checklist from OPWDD. Print it out and use it to help you navigate the process.

Welcome to the Office for People with Development Disabilities (OPWDD) Front Door!
The New York State OPWDD is responsible for coordinating services for New Yorkers with intellectual and developmental disabilities. The Front Door is a person-centered approach to help individuals learn about and access a variety of services and supports.

The Front Door aims to:

- improve the way people learn about OPWDD services,
- better connect individual needs to appropriate supports and services,
- allow you to direct your own services as much as possible, and
- give people the opportunity to live a richer, fuller life.

Please keep the checklist below and use it to guide you through the steps you will need to complete. Space has been provided for note and contacts. See the back of this page for descriptions about each step. Steps may not necessarily occur in the order that they are listed here.

☑	Key Steps	Notes	Contact person
	Make initial contact with OPWDD		
	Attend a Front Door information session		
	Select a Care Manager		
	Obtain Eligibility determination		
	Complete an Assessment and Review of Needs		

Notes:

Initial Contact
When you call your local OPWDD Regional Office, you will be asked for some basic information. The person you speak with will describe the Front Door, may connect you with a Service Access Agency if needed and available in your area, and will send you relevant information. Front Door staff will also provide you with information about Care Coordination Organizations (CCOs) and their role in helping you access OPWDD services and assisting you with eligibility and other requirements. Please provide the Front Door with your correct contact information (phone numbers, email, address and best times to contact you) and to mention if you need documents and conversations translated into another language.

Eligibility
If you are not already eligible for OPWDD services at the time of ***Initial Contact*** this will be your next step. You will need to gather specific, required documents to be submitted for review. You may need to make arrangements for assessments or evaluations to be done. The information sent to you will contain a checklist of accepted documents. Further guidance can be obtained by contacting the Eligibility Unit at your Regional Office.

Information Session
The required Information Session will tell you about OPWDD, services and supports available, and steps needed to start services. Sessions are scheduled at least monthly and may also be available by phone depending on your area. Upcoming sessions in your area are listed on Information Sessions | Office for People With Developmental Disabilities (ny.gov) or a list can be provided by your OPWDD Regional Office. A family member or advocate can participate on your behalf; that person should be present during your Assessment/Service Review. You can attend the information session at any time during the process and at any location throughout the state, with or without eligibility. Most services and supports cannot start until you have attended.

Care Manager
A care manager is someone who works for a Care Coordination Organization (CCO) who will assist you with applying for eligibility, level of care determination, planning for and accessing services, or obtaining Medicaid. Care managers are required for some supports and services. Your Regional Office will provide you with more information about Care Coordination Organizations and a list of CCOs in your area.

Assessment and Review of Service Needs
An OPWDD Front Door Facilitator will meet with you to assess and discuss your needs and interests and to provide you with information about the types of supports and services that can meet these needs. The Facilitator will review with you your interests, plans for the future, services or supports you already receive, support from your family or community, and areas of unmet needs.

Plan for Services
During the Front Door process, you will be connecting with a CCO and securing a CCO care manager. Your care manager will complete a comprehensive assessment and work with you to develop a plan of supports and services. Your care manager will assist you in submitting required forms for service authorization to OPWDD. Once these services have been authorized your care manager will work with you to select and contact agencies to deliver the supports and services listed in your plan.

About the HCBS Waiver

The Home and Community Based Services (HCBS) waiver allows states to be more flexible with the use of Medicaid funds. Under these special agreements, the federal government sets aside certain Medicaid rules to allow states to use Medicaid funding for services that will support people to live at home with their families or independently in the community instead of in a nursing home or other institutional setting. These services include: respite; residential and day habilitation; community habilitation, plan of care support services; consolidated supports and services; environmental modifications; adaptive devices; and family education and training; prevocational services

The HCBS Waiver is administered through the local OPWDD Developmental Disability Services Offices (DDSO).

Applying for HCBS

To receive the supports and services offered through the HCBS Waiver, you will need to enroll in the program; **your care manager will help you with this**. To request enrollment, you must fill out and submit an Application for Participation .

At the time of enrollment, the applicant must live at home or in a certified Family Care home, community residence or group home.

You will need to provide evidence of:

- A developmental disability
- An appropriate level of need for these services
- Eligibility for Medicaid enrollment
- An appropriate living arrangement
- Other information as necessary

SECTION 3

Supplemental Security Income (SSI)

How to Apply

The month after your child's 18th birthday, call

1-800-772-1213

to schedule an appointment with Social Security.

Bring the following information of your child's to the appointment:

- original birth certificate
- social security card
- medical documentation, including diagnosis of disability
- IEP
- names, addresses, phone numbers of all physicians
- proof of citizenship

See the NLS paper that follows, titled, "SSI Application Process" for more information.

Why it is important to obtain SSI –

- automatic Medicaid
- income to help you care for your child
- additional regulations can prove helpful in the future

NOTES:

- We have heard that it is NOT a good idea at all to try to apply or make an appointment online (but this was a long while ago, so things might have changed).
- It's also better to call Tuesday through Friday, not on Mondays.

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SSI Application Process

When a child or an adult plans to apply for Supplemental Security Income (SSI) benefits, it is important to know what documents the SSI program will need to process the claim. In order to be eligible for SSI, the applicant must establish a severe disability and demonstrate financial need.

To begin the application process, the person must contact the local Social Security Office for either an appointment at Social Security or to set up a telephone interview. The application process for SSI becomes much easier when the SSI program is given as much proof as possible with the application for benefits.

Application – A completed SSI application must be submitted with all questions answered. It is very important to provide as many disability-related details as possible.

Medical Proof – It is best to submit with the application any medical proof that is currently available. The applicant should provide SSI the full names and correct addresses of all doctors, clinics, therapists, or counselors the person is seeing concerning his or her disability. Letters from doctors and other medical professionals, giving a history of the applicant's condition, symptoms, and treatment can also be very helpful. If the applicant is a child, statements from teachers concerning the impact the disability has on the classroom performance can also be extremely helpful.

Proof of Need – An applicant will need to submit proof of current income, all bank statements, cash surrender value of life insurance policies, and documentation concerning any other income or resources. If the applicant is under 18 years old, the SSI program will need to see proof of parental income and resources. If the applicant is over 18, parental income and resources will not be considered available to the applicant. The SSI program will also need proof of the applicant's living arrangement, since the SSI program bases the payment amount on the individual's living arrangement.

Important things to remember throughout the application process:

- The applicant should always respond to requests for additional information. If the SSI program does not have enough information, the application is likely to be denied.
- The applicant should provide complete and accurate information, to the best of his or her ability.
- If the SSI program schedules a consultative examination with a doctor or other professional, it is very important that the applicant goes to that appointment. An SSI application can be denied solely due to a failure to attend a consultative exam.

Note: This document is produced, printed, and disseminated at U.S taxpayer expense. One hundred percent of the funding for this document is through a Social Security cooperative agreement that funds our Western NY Work Incentives Planning and Assistance (WIPA) Project. Although Social Security reviewed this document for accuracy, it does not constitute an official Social Security communication.

Some FAQ's from the Social Security Administration

https://www.ssa.gov/payee/faqrep.htm

What Type of Bank Account Should I Set Up for the Beneficiary?

A checking account is better in some ways, because you will have cancelled checks or statements that show how you spent the funds. If you decide to use a checking account, consider that some beneficiaries cannot keep balances high enough to avoid service charges. But if you must pay bills through the mail, a checking account might still be cost effective because cashier's checks and money orders have charges associated with them, as well. You should set up an account that minimizes fees and enables you to keep clear records. We encourage using interest-bearing accounts. You must title the bank account so it is clear the money in the account belongs to the beneficiary.

What Is the Proper Use of Benefits?

You should use benefits for current needs (such as food, clothing, shelter, utilities, dental and medical care, and personal comfort items), or for reasonably foreseeable needs. If not needed for these purposes, you must conserve or invest the benefits for the beneficiary. Where the beneficiary has unmet current maintenance needs, saving benefits does not serve a purpose and would not be in his or her best interests.

You must use benefits in the best interests of the beneficiary, according to your best judgment.

Who is Not Required to File a Representative Payee Report?

Due to a recent change in law, we no longer require the following representative payees to complete an annual Representative Payee Report:

- Natural or adoptive parents of a minor child beneficiary who primarily reside in the same household as the child;
- Legal guardians of a minor child beneficiary who primarily reside in the same household as the child;
- Natural or adoptive parents of a disabled adult beneficiary who primarily reside in the same household as the beneficiary; and
- Spouse of a beneficiary.

State mental institutions that participate in our onsite review program also do not have to file an annual Representative Payee Report.

Do I Still Need To Keep Financial Records If I Am Not Required to Annually File the Representative Payee Report?

Yes, you are still required to keep records of how you spent or saved the payments, and make all records available for review if requested by SSA.

Who Do I Contact If I Have Problems or Questions?

You may call us at 1-800-772-1213 between 7 a.m. and 7 p.m. on business days, or contact your local Social Security office between 9 a.m. and 4 p.m. on business days. You can find answers to many questions by visiting our website at www.socialsecurity.gov/payee

MEDICAID

Medicaid Waiver Services cover many services for people with disabilities, including day habilitation, supported employment, self-directed services, and residential services.

APPLICATION PROCESS

You can apply for Medicaid in any one of the following ways:

- Write, phone, or go to your local department of social services.
  - Nassau County DSS: 60 Charles Lindbergh Blvd., Uniondale, New York 11553-3656, (516) 227-7474
  - Suffolk County DSS: 3085 Veterans Memorial Highway, Ronkonkoma, New York 11788-8900, (631) 854-9700 Riverhead (631) 852-3710, Hauppauge (631) 853-8730
  - **NOTE**: don't try contacting any government agency in the 1st few days of the month
- complete appropriate application
- participate in a face-to-face interview (there is a waiting list, but you **MUST** do this; child should be there, or, if not present, give permission)
- document all information on the application (see below)
- disability determination is required

APPLICATION DOCUMENTATION REQUIREMENTS

- income
- resources
- citizenship/alien status
- proof of age – original birth certificate or alien registration card
- social security number (must bring card)
- third party health insurance
- living arrangements

PERTINENT FOR PARENTS

- child support is countable
- you should charge your 18 or over child "rent"
- ask for "long-term care services"
- ALWAYS get a receipt
- http://www.health.ny.gov/health_care/medicaid/

Consumer Directed Personal Assistance Program (CDPAP)

The following information is from *Consumer Directed Personal Assistance Program (CDPAP) (ny.gov)* and *communitycarehhs.com*

Some people who self-direct find that CDPAP is helpful in putting together the services they need and want.

- This Medicaid program provides services to chronically ill or physically disabled individuals, including four distinct communities: *Geriatric, Pediatric, Physically Disabled, Special Needs*
- Recipients have flexibility and freedom in choosing their caregivers/personal assistants, who can include family members.
- The consumer or the person acting on the consumer´s behalf (such as the parent of a disabled or chronically ill child) assumes full responsibility for hiring, training, supervising, and – if need be – terminating the employment of persons providing the services.
- CDPAP & Self-Direction have very similar themes: **empowering the individual with autonomy & independence in directing of the services.**
- CDPAP ***complements*** Self-Direction services such as **Respite & Community Habilitation.**
- CDPAP is an additional resource to families & can allow them to utilize Comm. Hab. Workers to work shifts as a CDPAP PA.
- An individual can have both Waiver services and CDPAP, and is not required to change over to traditional home care.
- To get started,
    - Apply and become approved for Medicaid, if not already done.
    - Call NYIA: (1-855-222-8350) to schedule an assessment to deem if individual is appropriate for community based home care services.
    - Find a Fiscal Intermediary (FI)
        - The FI handles the money that comes from Medicaid, and are the employer of record for any staff hired through CDPAP
        - Find an FI here:
            - Nassau – Find My FI Results | CDPAANYS
            - Suffolk – Find My FI Results | CDPAANYS
        - To be an aware consumer, research each CDPAP FI on Google Business.
- Supporting Our Youth and Adults Network (SOYAN) is an organization of individuals and families who self-direct their services. In addition to being a great resource for all kinds of information about self-direction, there are members who are well-versed in CDPAP matters. Find them at www.SOYAN.org. Get on their mailing list to join their monthly meetings.

AHRC Entitlement Department

AHRC Nassau has Entitlement Coordinators who will speak with you and assist you with the process of determining eligibility.

The entitlement department will also provide professional support to help you begin the process of applying for Federal entitlements which you may be eligible to receive.

Knowledgeable staff are available to answer your questions and concerns regarding:

- Medicaid
- Medicare
- Social Security Disability Insurance (SSDI)
- Supplemental Security Income (SSI)
- Food Stamps

Contacts:

For information regarding entitlements, please contact:

Karen Lukas
516-293-2016, ext. 5319
klukas@ahrc.org

SECTION 4

SPECIAL NEEDS TRUSTS AND ABLE Accounts
An overview

Special needs trusts (also known as supplemental needs trusts) and ABLE accounts allow people with disabilities to save money in their name without jeopardizing their eligibility for public benefits such as SSI and Medicaid.

Below are some differences between SNTs and ABLE accounts. We gathered the information here and here, and there is a really thorough and informative chart comparing ABLE accounts and various types of SNTs here.

- SNTs are meant to pay for "extras", i.e. things that Medicaid does not pay for, e.g. vacations, pets, entertainment, home furnishings, assistive technology and therapies not covered by Medicaid. ABLE accounts are meant to pay for "qualified disability expenses" which includes anything that helps a person with a disability improve their health, independence, or quality of life, e.g., basic costs of living, as well as costs for education, food, employment, transportation, technology, and support services.
- ABLE accounts are easier to set up and manage but have a cap on how much can be added annually; SNTs do not have those limits but can be less accessible and more complicated to manage.
- ABLE accounts require that money left in the account after the beneficiary dies be used to reimburse the state Medicaid agency for services Medicaid paid for after the ABLE account was created, while with a third party SNT that is not required.
- lawsuit settlements & inheritances should go into supplemental needs trusts

There is no need to choose one or the other – an individual can have both types of accounts, and in fact they can complement each other. Some people choose to use an ABLE account for everyday expenses and have an SNT to use for larger purchases that are not covered by their benefits.

On the following pages, you will find more complete information about each type of account, as well as information about AHRC Foundation's Trust Services.

ABLE Accounts

The Achieving a Better Life Experience Act of 2014 (ABLE) allows families to set up 529A ABLE accounts for disability related expenses, similar to college savings accounts. **Assets in ABLE accounts are exempt from the $2,000 cap that voids Medicaid and SSI eligibility.** These accounts allow families to save for housing, education, transportation, medical, and other expenses.

The best resource we have found for information about ABLE Accounts is the ABLE National Resource Center (ANRC), https://www.ablenrc.org/

ABLE Accounts are not limited to the state one lives in, but here is some information for New York, as per ANRC's interactive map, as of December 2023:

Program Name: NY ABLE, 855-569-2253
State Program Manager: Ascensus
Annual Contribution Limit: $17,000
Number Investment Options: 5
Withdrawal Hold Rules: Yes
FDIC Insured: Yes, with some restrictions
State Account Limit: $520,000
ABLE To Work Act Contribution: $13,590
Debit Card Or Prepaid Card: Yes
State Income Tax Deduction: No
Accepts Out Of State Residents: Yes
Medicaid Estate Recovery Status: Under section 529A…, following the death of the account owner…state may file a claim …for the amount of the total medical assistance paid…under the state's Medicaid plan after the account …was opened.

ABLE Accounts: Some Things to Know

adapted from: *http://ablenrc.org/about/what-are-able-accounts* and *realeconomicimpact.org/data/files/other documents/**able** act.ppt (no longer available)*

1. **What is an ABLE account?**
   ABLE Accounts are tax-advantaged savings accounts for individuals with disabilities and their families. The beneficiary of the account is the account owner, and income earned by the accounts will not be taxed. Contributions to the account made by any person (the account beneficiary, family and friends) will be made using post-taxed dollars and will not be tax deductible, although some states may allow for state income tax deductions for contribution made to an ABLE account.

2. **Who is eligible for an ABLE account?**
   The ABLE Act limits eligibility to individuals with significant disabilities with an age of onset of disability before turning 26 years of age. If you meet this age criteria and are also receiving benefits already under SSI and/or SSDI, you are automatically eligible to establish an ABLE account.

3. **Which expenses are allowed by ABLE accounts?**
   A "qualified disability expense" means any expense related to the designated beneficiary as a result of living a life with disabilities. These may include:
   - ***Education*** *- including tuition for preschool thru post-secondary education, books, supplies, and educational materials related to such education, tutors, and special education 6 services.*
   - ***Housing -*** *Expenses for a primary residence, including rent, purchase of a primary residence or an interest in a primary residence, mortgage payments, real property taxes, and utility charges.*
   - ***Transportation -*** *Expenses for transportation, including the use of mass transit, the purchase or modification of vehicles, and moving expenses.*
   - ***Employment Support -*** *Expenses related to obtaining and maintaining employment, including job-related training, assistive technology, and personal assistance supports.*
   - ***Health Prevention and Wellness:*** *Expenses for health and wellness, including premiums for health insurance, mental health, medical, vision, and dental expenses, habilitation and rehabilitation*

services, durable medical equipment, therapy, respite care, long term services and supports, nutritional management, communication services and devices, adaptive equipment, assistive technology, and personal assistance.

- ***Other Approved Expenses*** *- Any other expenses which are approved by the Secretary under regulations and consistent with the purposes of this section.*
- ***Assistive Technology and Personal Support*** *- Expenses for assistive technology and personal support with respect to any item described in clauses (i) through (vi).*
- ***Miscellaneous Expenses*** *- Financial management and administrative services; legal fees; expenses for oversight; monitoring; home improvement, and modifications, maintenance and repairs, at primary residence; or funeral and burial expenses.*

4. **Can I have more than one ABLE account?**
   No. The ABLE Act limits the opportunity to one ABLE account per eligible individual.

5. **Do states offer options to invest the savings contributed to an ABLE account?**
   Like state 529 college savings plans, states do offer qualified individuals and families multiple options to establish ABLE accounts with varied investment strategies. Each individual and family will need to project possible future needs and costs over time, and to assess their risk tolerance for possible future investment strategies to grow their savings. Account contributors or designated beneficiaries are limited, by the ABLE Act, to change the way their money is invested in the account up to two times per year.

6. **How is an ABLE account different than a special needs or pooled trust?**
   An ABLE Account will provide more choice and control for the beneficiary and family. Cost of establishing an account will likely be considerably less than either a Special Needs Trust (SNT) or Pooled Income Trust. With an ABLE account, account owners will have the ability to control their funds and, if circumstances change, still have other options available to them. Determining which option is the most appropriate will depend upon individual circumstances. For many families, the ABLE account will be a significant and viable option in addition to, rather than instead of, a Trust program.

ABLE ACCOUNTS COMPARED TO OTHER SAVINGS VEHICLES

a. 529-ABLE Plans vs 529 Education Savings Accounts: *Money that is saved in 529 Education Savings Accounts must be used for education.*

b. 529-ABLE Plans vs. IRAs? *529-ABLE Plan funds can be accessed throughout a beneficiary's lifetime.*

c. 529-ABLE Plans vs. special needs trusts? *Special Needs Trusts are regulated at the state level and need to be reviewed and updated if a family moves to another state. Special needs trusts are taxed at the highest individual tax rate, and they can be expensive to set-up and maintain. Special needs trusts do not have contribution limits, and the allowed expenditures are not as limited as a 529-ABLE Plan. If a special needs trust is set-up as a 3rd party trust, then a Medicaid payback is not required.*

d. 529-ABLE Plans vs. pooled trusts? *Pooled trusts are fully taxable, require set-up and maintenance costs, and are regulated at the state level. A portion of the money left in the account after the beneficiary's death stays in the account for other participants before the Medicaid payback applies. There are no contribution limits and the allowed expenditures are broader than with a 529-ABLE Plan. Set-up and maintenance of pooled trusts are generally done by disability organizations. The set-up fees can be less expensive than special needs trusts and the organizations that maintain them are familiar with how the funds can be used on behalf of the beneficiary. 529-ABLE Plans, like pooled trusts, require a Medicaid payback upon death of the beneficiary.*

Can an individual have a 529-ABLE Plan and a special needs or a pooled trust? *Yes, all are tools for providing disability-related supports and services to individual with a disability. Which ones work best or in combination will depend on individual circumstances.*

Supplemental / Special Needs Trusts

From Wikipedia *http://en.wikipedia.org/wiki/Supplemental_needs_trust*

A **supplemental needs trust** is a US-specific term for a type of **special needs trust** (an internationally recognized term). Supplemental needs trusts are compliant with provisions of US state and federal law and are designed to provide benefits to, and protect the assets of, physically disabled or mentally disabled persons and still allow such persons to be qualified for and receive governmental health care benefits… under the Medicaid welfare program. Supplemental or Special Needs Trusts are frequently used to receive an inheritance or personal injury litigation proceeds on behalf of a disabled person in order to allow the person to qualify for Medicaid benefits.

What Is a Special Needs Trust?

Adapted from Special Needs Answers
http://specialneedsanswers.com/what-is-a-special-needs-trust-13601

A special needs trust is set up to supplement any benefits a person with special needs may receive from government programs, while not compromising access to those benefits. A properly drafted special needs trust will allow the beneficiary to receive government benefits while still receiving funds from the trust. There are three main types of special needs trusts: the first-party trust, the third-party trust, and the pooled trust. All three name the person with special needs as the beneficiary.

- A "first-party" special needs trust holds assets that belong to the person with special needs, such as an inheritance or an accident settlement.
- A "third-party" special needs trust is most often used by parents and other family members to assist a person with special needs. These trusts can hold any kind of asset imaginable belonging to the family member or other individual, including a house, stocks and bonds, and other types of investments.
- A pooled trust holds funds from many different beneficiaries with special needs; essentially, a charity sets up these trusts that allow beneficiaries to pool their resources for investment purposes, while still maintaining separate accounts for each beneficiary's needs.

Note: You will need an attorney who is well-versed in special needs planning to set up a special needs trust. We have recently been hearing of people having trouble with SNT's that were not set up properly.

Trust Services at AHRC Foundation

From: https://ahrcfoundation.org/our-work/services/supplemental-needs-trusts/

Supplemental Needs Pooled Trusts

The AHRC Foundation established its Community Trust Services which allows people with intellectual and/or developmental disabilities to have their own trust fund to provide for their supplemental needs without affecting their eligibility for government benefits. Government benefits can include SSI, Medicaid and other public benefit programs.

A parent, relative or any other person may establish an account within the Trust and designate a person with a developmental disability as the beneficiary. A trust can also be established by beneficiary individually.

AHRC Foundation currently administers two Trusts

Community Trust I is a Third Party Trust. Parents, grandparents and/or any interested person might consider this trust the perfect way to ensure the supplemental needs of a person with a developmental disability are secured. This trust is most often funded through a Will as part of an estate plan where the donor names the Trust as beneficiary of an inheritance, life insurance policy, other cash assets and/or monetary gifts.

A third party supplemental needs trust can be established and funded during a donor's lifetime. The minimum initial contribution to establish a third party trust is $10,000 upon acceptance of the completed sponsor agreement, which further agrees to funding the trust up to $25,000 within 5 years of establishing.

In Trust I, upon the death of the beneficiary, the first $25,000 of the principle remains with the AHRC Foundation. The remaining funds are then distributed according to the wishes of the donor/person who established the trust. In this way, funds are available during the lifetime of the person who is disabled, and can flow to others when no longer needed by the person.

Community Trust II is a First Party Trust. Community Trust II allows people with developmental disabilities who already have their own resources through income, inheritance, lawsuit award or legal settlement to participate and thereby protect their assets while maintaining their eligibility for public benefits. These trust funds can be utilized by the person to enhance their overall quality of life. Upon the death of the person, the funds remain in the pooled trust for the benefit of other trust participants. There is no government payback required.

To discuss AHRC Foundation's supplemental needs trust program, please call Mary McNamara, Foundation Director at 516-626-1075 at extension 1133.

SECTION 5

Care Management

What is a Care Coordination Organization (CCO)?
CCOs are organizations that are staffed by Care Managers with training and experience in the field of developmental disabilities.

What is a Care Manager?
A Care Manager is a person who works with you to create your Life Plan. Your Care Manager helps coordinate your services across systems, including the Office for People With Developmental Disabilities (OPWDD), providing you one place to plan all your service needs. Your Care Manager has the responsibility to make sure you are supported in all the ways that lead to the best outcomes for you.

What is a Life Plan?
The Life Plan reflects your life goals and changing needs. Your Care Manager will work with you to create a plan based on your wants and needs. Your Life Plan will include coordination of your developmental disability related supports and your other services, like medical, dental, and mental health. It is reviewed routinely and updated as needed.

Am I required to participate in Health Home Care Management?
If you do not want to receive the more comprehensive care management that will be provided with Health Home Care Management, you can consider the option of Basic Home and Community Based Services (HCBS) Plan Support. Basic HCBS Plan Support will also be provided by the CCO, but it is a very minimal coordination option, and will not include coordination of health care or mental health services. With Basic HCBS Plan Support, your contact with the person coordinating your services will be limited.

Will I be able to choose my own services and providers?
Yes, you will choose your services and providers. Within the CCO, a team of professionals, including your Care Manager, will work together with you to coordinate your services based on your wants and needs.

How do I enroll with a CCO to receive Care Management?
Contact one of the three organizations listed on the next page of this guide. The CCO will assist you with enrollment.

Who will have access to my plan and how will my personal information be protected?
CCOs are required to have an electronic health record system that links the service providers involved in your care and allows your health information and Life Plan to be accessible to you and your care team. All CCOs must follow strict security protocols to protect your Personal Health Information.

Can I change my mind once I choose a CCO?
If you are not happy with the Care Management being provided by your CCO, you can choose another Care Manager in that CCO and/or change the level of service you receive. You may also choose a different CCO within your region.

What will happen if the CCO decides to change my services or give me fewer services?
The CCO does not authorize services and therefore will not be able to take away or lessen your services, including self-directed services. You, in partnership with your care team, will identify the supports and services you receive based on your wants and needs. OPWDD Regional Offices authorize supports and services.

Contact information for the Care Coordination Organizations that serve Long Island:

Ready for a Care Manager? Here is where you'll find one...

ACA / Advance Care Alliance

833-MYCANY (833-692-2269)
https://acany.org/
1410 Broadway, 2nd Floor
New York, NY 10018

Contact	Email
Michael Fleischmann, Director of Admissions	michael.fleischmann@myacany.org
Dina Forgione, Assistant Director of Admissions	dina.forgione@myacany.org

Care Design

518-235-1888
caredesignny.org
8 Southwoods Boulevard, Suite 110
Albany, NY 12211

Long Island
1 Michael Avenue
Farmingdale, NY 11735

Contact	Phone/Email	
Jocelyn Zeller, LI Regional Director	JZeller@caredesignny.org	516-531-7579, x1424
Simone Chung, LI Intake	schung@caredesignny.org	631-983-6632 x1448

Tri-County Care

https://www.tricountycare.org/
info@tricountycare.org
829 East 15th Street
Brooklyn, NY 11230

Contact	Phone/Email	
Jason Mazzuca, VP of Care Management	j.mazzuca@tricountycare.org	844-504-8400, x 9214
Gamal Byfield, LI Regional Director	g.byfield@tricountycare.org	844-504-8400, x 9575
Mimi Singer, LI Regional Intake Specialist	m.singer@tricountycare.org	844-504-8400, x 9250

SECTION 6

52-53 **Self-Directed Services**

- OPWDD's brief guide to self-directed services
- Explanation of terms

A How-To Guide to Starting Self-Directed Services

Person-Centered Planning	Your Care Manager will have conversations with you about what you want to achieve in life. Based on those conversations, your CM will tell you about the service options available to help you meet your life goals and develop a Life Plan. This process is called Person-Centered Planning and is at the heart and soul of Self-Direction. Your Life Plan should be comprehensive and reflect your goals.
Understand Self-Direction	From the options presented by your Care Manager, you can choose to Self-Direct your services. If you choose to self-direct, you will need to attend a Self-Direction Information Session at your local Developmental Disabilities Regional Office (DDRO). If you are already Medicaid Waiver-eligible, your Care Manager will submit a request for self-directed services through the Front Door. If you are not Medicaid Waiver-eligible yet, you will need to complete a Waiver application and apply to be enrolled in the Waiver, with help from your Care Manager.
Determine your Self-Direction Budget Amount	When you choose to Self-Direct, your needs will be assessed using the Developmental Disabilities Profile (DDP-2). It can be done by your Care Manager or an OPWDD Front Door staff. This assessment is also used to determine your maximum budget amount, also known as the Personal Resource Allocation (PRA). Your Care Manager will have conversations with you about what you want to achieve in life. Based on those conversations, your Care Manager will tell you about the service options available to help you meet your life goals and develop a Life Plan. This process is called Person-Centered Planning and is at the heart and soul of Self-Direction. Your Life Plan should be comprehensive and reflect your goals.
Hire a Support Broker and Fiscal Intermediary	If you want to manage your budget with Budget Authority, your DDRO Self-Direction Liaison will give you a list of Support Brokers. You can interview Brokers from this list. Once you hire a Broker, you sign a contract with that Broker that outlines his/her duties and how he/she will support you. You and your Broker will request a Start-up Budget through OPWDD. When your start-up is approved, the Liaison will send you an Approval Letter. You can now start developing a complete Self-Direction budget. You should also interview and select a Fiscal Intermediary (FI) from a provided list and ask people who support you to make decisions to be part of your Circle of Support.
Develop your Self-Direction Budget and Plan(s) Person-Centered Planning	You will work with your Support Broker to develop a complete Self-Direction Budget that includes the supports and services you identified during Person-Centered Planning. Your Broker will also develop Habilitation Plans for any self-directed services that you choose to hire your own staff for. During this time, you should start looking for potential staff. When you find staff you like, you can begin the hiring process through the Fiscal Intermediary (FI).
Submit Your Budget for Approval	Once your budget is complete, your Broker will submit it to the Self-Direction Liaison for approval. Once it's approved, you, your family or designee, your Care Manager, Fiscal Intermediary and Broker will receive a letter from the Liaison that lists an effective date. This date is when your budget begins and falls on the first of a month.
Hold Your Launch Meeting	Once your budget is approved, you'll have a launch meeting to review your budget, self-directed services and plans. Your FI, Support Broker, Care Manager, and other team members will all be invited. **CELEBRATE!**

https://opwdd.ny.gov/system/files/documents/2020/02/family-friendly-guide-to-sd-1.27.pdf

Prepared by Lower Hudson Families for Self-Direction and OPWDD

Self-Direction (formerly known as CSS or Consolidated Supports and Services)

- offers the opportunity to design services based on an individual's desires an needs
- funded through Home and Community Based Services Waiver (HCBS)
- is a Medicaid funded program

- **Circle of Support**
  - a voluntary group of people who commit to assisting an individual
  - helps clarify goals, determine valued outcomes, and assist with exploring different ways that the person might reach the desired goals
  - the MSC functions as part of the Circle and is the communication link to the local DDRO and OPWDD

- **FI** – Fiscal Intermediary
  - is the employer of record for a person's direct support staff
  - acts as the individual's fiscal and business agent – i.e. they pay the bills; all money goes through the FI
  - is a necessary element of a self-directed program
  - each DDRO has identified an FI for their region of the state

- **Support Broker** – also simply called a broker
  - an independent professional who may be hired by to provide advice, information, and technical assistance for a self-directed program
  - negotiates for the services to be provided
  - can facilitate and develop a Person Centered Plan
  - your DDRO self-direction liaison will give you a list of brokers to help you find one

From Parent to Parent of NYS

SECTION 7

55-56 Finding Services

Links to current lists, from LIFSSAC:

- Agencies & Types of Services Provided
  - Children's Services
  - Clinic Services
  - Community Habilitation (CH)
  - Crisis Services
  - Early Intervention
  - Employment Services
  - Fiscal Intermediary (FI)
  - Family Support Services
  - Pre-Vocational (Prevoc)
  - Residential Services
  - Supported Employment (SEMP)
  - Day Habilitation (DH)
  - Respite
  - …and more
- Family Support Services Grant Programs
  - After school respite programs
  - School vacation respite
  - Crisis intervention
  - Family counseling, training and advocacy
  - Parent training for parents with D.D.
  - In-home respite
  - Overnight freestanding respite
  - Weekend and recreation respite
  - Sibling support
  - Town recreation
  - Voucher reimbursement
  - Non-Medicaid service coordination

The role of the Long Island Family Support Services Advisory Council (LIFSSAC) is to provide a strong voice for individuals and families on the local level, working with and through the DDRO to plan, develop and monitor Family Support Services in that area. LIFSSAC maintains a website containing useful information for families, including comprehensive lists that will assist you in looking for services for your child, both when they are in school, and when they transition to adulthood.

Their Agencies & Types of Services Provided in the Long Island Region list is a good place to begin looking for all types of services, including adult day programs. There you will find many pages of agencies, listed alphabetically.

Unless you are looking for a particular agency, you'll want to start with the third column, which tells which counties an agency serves, e.g.

AGENCY	SERVICES PROVIDED	COUNTIES SERVED
AHRC Nassau 189 Wheatley Road Brookville, NY 11545 Phone: (516) 626-1000 Ext. 1101 Stanfort J. Perry www.ahrc.org	Clinic Services Community Habilitation (CH) Fiscal Intermediary (FI) Family Support Services Pre-Vocational (Prevoc) Residential Services Supported Employment (SEMP) Day Habilitation (DH) Respite	Nassau

…and then look to see if they provide the service you are looking for…

AGENCY	SERVICES PROVIDED	COUNTIES SERVED
AHRC Nassau 189 Wheatley Road Brookville, NY 11545 Phone: (516) 626-1000 Ext. 1101 Stanfort J. Perry www.ahrc.org	Clinic Services Community Habilitation (CH) Fiscal Intermediary (FI) Family Support Services Pre-Vocational (Prevoc) Residential Services Supported Employment (SEMP) Day Habilitation (DH) Respite	Nassau

Click above or here to find the list.

(in the paper version of this guide, look for the list in the back of the book)

LIFSSAC's Family Support Services Grant Programs list is a guide to services for families that have not yet accessed Medicaid. It includes program and contact information for:

- After school respite programs
- School vacation respite
- Crisis intervention
- Family counseling, training and advocacy
- Parent training for parents with D.D.
- In-home respite
- Overnight freestanding respite
- Weekend and recreation respite
- Sibling support
- Town recreation
- Voucher reimbursement
- Non-Medicaid service coordination

It is set up by program type, in the order listed above, and then within each section alphabetically by agency. The following example is from the School Vacation Respite section:

AGENCY	LOCATION	HOURS	POPULATION SERVED	FEE	COMMENTS	CONTACT PERSON
Brookville Center for Children's Services	189 Wheatley Rd. Brookville	Christmas/winter break, Easter/Passover break, & 1 week in August 10am-3pm	Ages: 5-21 years Developmentally Disabled children	$200 per session	Nassau & Suffolk Counties Respite during school holidays Wheelchair Accessible Does not accept individuals enrolled in self direction	Denise Gaughan 516-626-1075 x 3364 dgaughan@brookvillecenter.org

Click above or here to access this list.

(in the paper version of this guide, look for the list in the back of the book)

SECTION 8

Information about BCCS's affiliate agencies

from www.ahrc.org

from ahrc.org

WHO WE ARE:

AHRC Nassau empowers people to live fulfilling lives together with family, friends, and community.

A family-led organization and a Chapter of The Arc New York, AHRC Nassau has continually grown to meet the evolving needs of people with intellectual and developmental disabilities, and their families.

AHRC Nassau provides person-centered supports to over 2,200 people throughout Nassau County. Our organization partners with a family of organizations including Brookville Center for Children's Services, Citizens Options Unlimited and Advantage Care Health Centers, so that together, we can provide a true continuum of services and supports across a person's lifetime.

AHRC Nassau has been designated a COMPASS agency by New York State Office of People with Developmental Disabilities (OPWDD). As a COMPASS agency, we are recognized for our commitment to engaging all stakeholders in working together in a person-centered environment with the goal of promoting and achieving valued outcomes for the people we support. Of the more than 750 provider agencies in New York State, only four (4) are currently designated as a COMPASS agency.

In 2018, CQL, The Council on Quality and Leadership recognized AHRC Nassau with Person-Centered Excellence Accreditation *With Distinction*, its highest designation. CQL promotes excellence in person-centered services and supports that lead to an increased quality of life for people receiving supports and services. There are less than 30 organizations world-wide who have achieved this accreditation which is reflective of our unparalleled commitment to the people supported by our services, our staff, families and the community in which we all live.

AHRC Nassau, and partnering organization Citizens Options Unlimited, are the only two agencies in New York State to achieve both COMPASS designation and CQL's Person-Centered Excellence Accreditation With Distinction.

To explore any of the following options, contact AHRC's Central Enrollment office at: (516) 644-4800 or email through https://www.ahrc.org/contact/

ADULT DAY SERVICES

PERSON-CENTERED DAY HABILITATION SERVICES

AHRC Nassau provides OPWDD-approved Day Habilitation Services for adults with IDD in over 21 locations across Nassau County, Long Island. We offer both traditional, site-based day habilitation services in a community-based setting, as well as Program Without Walls (PWW) options. PWW provides an additional opportunity for men and women to learn new skills, build relationships and develop self-esteem through volunteerism outside of the traditional setting.

All day habilitation services are designed to support each person in discovering their personal interests, while improving their communication and socialization skills. The services are designed to include a special focus on opportunities for building successful and meaningful interactions with other members of our community.

Unique to AHRC Nassau is the opportunity for men and women, regardless of site location, to participate in the inclusive, hands-on activities of animal care, planting, gardening, painting and wellness all in this beautiful, north shore location. Whether a person is enrolled in Person Without Walls (PWW) supports, or through a site-based opportunity, men and women throughout AHRC Nassau's day services can enjoy the Wheatley Farms & Arts experience.

As a person-centered program, personal interests and goals drive the program planning process, while dedicated staff members provide health, safety and wellness supports.

A person can expect the following outcomes from AHRC Nassau Day Habilitation Services:

- Greater self-expression and communication through art, music, photography, clubs and horticultural activities.
- Participation throughout the community through valued volunteerism opportunities.
- Development of independent living, communication and socialization skills.

For more information, please contact AHRC's Central Enrollment office at: (516) 644-4800 or email through https://www.ahrc.org/contact/

PRE-VOCATIONAL SERVICES
Provide the Skills Needed to Go to Work

Pre-vocational services are designed to discover employment interests, assess job readiness and create a support program that has gainful employment as its ultimate goal. Pre-vocational services also includes the employment training program (ETP), a paid internship leading to employment.

EMPLOYMENT TRAINING PROGRAM (ETP)
An Intensive Internship Program Launching Men and Women into the World Of Work

The employment training program (ETP) includes full employment discovery, targeted job development, employment readiness classes, coaching, and support in transitioning from the internship into supported employment (SEMP). ETP acts as an entry point for people who can benefit from an intensive discovery phase to determine a desired job and placement or who need to build their employment history. All work during the internship is paid at minimum wage.

SUPPORTED EMPLOYMENT
Offers the Opportunity to Obtain and Maintain Competitive Employment

Supported Employment (SEMP) provides job development, placement services and ongoing support to maintain employment. SEMP services are available to men and women over the age of 18 enrolled in OPWDD'S Home and Community Based Waiver Services or enrolled through Adult Career and Continuing Education Services Vocational Rehabilitation (ACCESS-VR)

COMMUNITY HABILITATION

Community Habilitation is a service provided to a person with a developmental disability in their own home or community setting. The person, working together with their family and Care Manager, will create a support plan that best meets the needs of the person and family. This plan can create supports which promote personal independence, are focused on desired skill acquisition, and/or engage in a wide range of community activities. Hours are flexible. Eligibility: The person must be over the age of 18 and approved for OPWDD services.

RESIDENTIAL SERVICES

AHRC Nassau operates the largest residential program on Long Island. With over 100 supervised and supportive settings, each home reflects the interests of its residents. Direct Support Professionals work with each person supported toward reaching their goals and desired outcomes. Registered Nurses and licensed dietitians provide ongoing care planning and support to ensure that each person maintains their best possible health. Behavioral health services and positive behavioral supports are provided by Behavior Intervention Specialists (BIS).

To be eligible for residential services, the person must meet OPWDD eligibility and be approved by OPWDD for placement.

FAMILY SUPPORTS

The dynamic partnership between the person with developmental disabilities, their family and friends, and our professional supports distinguish AHRC Nassau from other service providers. Services to families are provided to strengthen families' capacities to support family members with intellectual and developmental disabilities and to build their own supportive network. We offer individualized resources and opportunities, with key services including family respite services, sibling supports, family reimbursement program and guardianship resources.

SIBLING SUPPORT GROUP

The Sibling Group is for adult brothers and sisters who have a sibling receiving services through AHRC Nassau. Meetings often present a topic of interest, serve to support one another and offer guidance based on real-life experience. A staff member is available to offer support and discuss current life challenges/concerns. Come join us! Siblings meet four times a year.

For meeting information, please contact Colleen Tapia at ctapia@ahrc.org

FAMILY RESPITE

For people with developmental disabilities who live at home with their families, AHRC Nassau provides overnight, out-of home residential respite to support families.

Residential respite provides short-term care on a planned basis to families caring for an adult (18 years and older) who is OPWDD eligible. Respite services include the support of professionally trained and certified staff members along with nursing oversight.

For more information, contact AHRC's Central Enrollment office at: (516) 644-4800 or email through https://www.ahrc.org/contact/

GUARDIANSHIP RESOURCES

At the age of 18, every person, regardless of any developmental disability, is legally considered to be emancipated and are recognized as an adult capable of acting in his/her self-interest. Under current NYS law, guardianship is appropriate for a person with an intellectual or developmental disability for whom it has been determined by two qualified professionals to be legally incapable of managing his/her own affairs, specifically concerning daily living, healthcare, residential, and/or financial decision-making.

Parents of a child who meets the above criteria can consider establishing legal guardianship when their child reaches 18. Assistance with obtaining guardianship for a family member with a developmental disability is available, as is assistance with future care planning.

In cases of last resort, The Arc New York has the authority to act as guardian for an adult with an intellectual and developmental disability living in Nassau County. Serving as a corporate guardian, The Arc New York may be available to serve as primary, standby, or alternate standby guardian. In order to have The Arc New York serve as guardian, you must apply and be approved by both AHRC Nassau and The Arc New York.

To learn more, contact Eileen Stewart-Rooney, Guardianship Coordinator by phone at 516-546-7700 ext. 4205 or by email at erooney2@ahrc.org

FAMILY REIMBURSEMENT PROGRAM

Many families who have a family member with a developmental disability living at home have special expenses that the typical family does not have. OPWDD's family reimbursement program, which is administered by agencies including AHRC, helps with these expenditures. The program reimburses expenses up to $3000 per year that are related to the disability and are not covered by other sources. The program has eligibility and application criteria that are determined by OPWDD and a review committee. The program prioritizes health and safety issues and quality of life. Find a list of allowable and non-allowable expenses here.

To be eligible for reimbursement, the person must qualify for OPWDD services, the expenses must directly benefit the person with a developmental disability, and the expenses must not be able to be covered by any other means.

To learn more, contact Leonard Giarraputo at 516-644-4800 ext. 5303 or lgiarraputo@ahrc.org

VIRTUAL SUPPORTS – THE BEAT!

Connecting Our Community Online

AHRC Nassau's Online Learning and Resource Center featuring a variety of unique learning opportunities and resources for the people we support, their families and the greater community.

Explore and discover free classes, tools, videos, resources and more to connect with your peers, grow your skills and find support when you need it.

Click here for a calendar of upcoming classes.

from https://www.citizens-inc.org/

Citizens Options Unlimited (Citizens) Citizens believes that when people come together and work as a team, great things happen. Citizens works closely with personal outcome trainers to assist people with I/DD in defining their personal goals and dreams, while developing a life plan that includes natural supports, community supports, and choice of service provision options.

Mission: Citizens supports people to live the lives they choose.
Vision: A world where all people are valued.
Values: At Citizens, we believe that:

- Everyone should be treated with dignity and respect
- Supports are best provided around people's needs, desires and choices
- A dedicated, compassionate and well-trained team provides exceptional supports
- Open and honest communication builds trust
- There is strength in diversity and inclusion
- Sound business practices, financial stability and innovation promote success
- Relationships with people and their families are vital to our success

Recognized as a leading agency in the field, our programs, include:

- Self-Directed Services, including Fiscal Intermediary, ISS
- Family Support Services
  Camp Loyaltown, Family Reimbursement; Community-based Respite
- Residential Respite Services
- Residential Supports and Services
- Citizens also works hand in hand with Advantage Care Health Centers to provide coordinated medical, psychiatric and dental care.

Citizens' dedication to excellence has been recognized by the Office for People with Developmental Disabilities (OPWDD) through its awarding of the Compass agency status; one of only four agencies in New York State with this designation. As a Compass agency, Citizens ensures that all services are person directed, meaning the person receiving Citizens' services has a voice in decisions, policies and procedures, as well as overall quality management and improvement initiatives.

Citizens is also accredited with Person-Centered Excellence *with Distinction* by the Council on Quality and Leadership (CQL). There are only two agencies in all of New York State with both Compass designation and Person-Centered Excellence *With Distinction.*

SELF-DIRECTION

Citizens provides Self-Direction Services, including Fiscal Intermediary (FI) and Broker Services. Self-Direction allows people to develop a self-directed plan which supports choice as to where to live, day activities, friends and relationships, and how to participate in the greater community. Self-Direction allows people the opportunity to hire their own support staff. FI and Broker Services are necessary to pursue Self-Direction.

To learn more, contact Michele LaSpina, Assistant Director
Fiscal Intermediary, ISS and Self-Directed Services
115 East Bethpage Road, Plainview NY 11803, 516-293-1111 ext. 5116 | 516-725-2421 cell
mlaspina@citizens-inc.org

FAMILY SUPPORT SERVICES

CAMP LOYALTOWN

Camp Loyaltown is located in the Catskill Mountains, 2 and 1/2 hours north of New York City and 3 hours north of Nassau County's western border. Each year, more than 650 campers enjoy the wonders of the outdoors in a safe and fun environment. We are accredited by the American Campers Association (ACA). Campers and staff live in modernized, rustic-style cabins which house anywhere from 4 to 12 campers and staff members. Each cabin has its own showers and restroom facilities.

Camp Loyaltown has fully renovated recreation facilities including:

- fully accessible, 9 hole miniature golf course
- heated, swimming/activity pool
- adaptive playgrounds, ball fields and indoor/outdoor basketball courts
- a performing arts stage

Camp Loyaltown provides a 4:1 camper to counselor ratio and provides 1:1 care when needed. Counselors are energetic, enthusiastic, patient and loving and are thoroughly trained at Camp Loyaltown before the first campers arrive. Our on-site, state-of-the-art health center is equipped to handle each camper's medical needs and is staffed by RNs with years of experience caring for individuals with developmental disabilities. Additionally, Camp Loyaltown has access to a doctor in the local community.

Learn more at https://www.citizens-inc.org/camployaltown/ or by contacting camp@citizens-inc.org or 518-263–4242 (summer) or 516-626-1075 Ext. 1452 (winter)

Camp Loyaltown's weekend respite program is scheduled to resume in the Winter of 2023. If you would like to know more about this, please email camp@citizens-inc.org or contact: 1 516 293 2016 ext 5165

Family Reimbursement

Many families who have a family member with a developmental disability living at home have special expenses that the typical family does not have. OPWDD's family reimbursement program, which is administered by agencies including Citizens, helps with these expenditures. The program reimburses expenses up to $3000 per year that are related to the disability and are not covered by other sources. The program has eligibility and application criteria that are determined by OPWDD and a review committee. The program prioritizes health and safety issues and quality of life. Find a list of allowable and non-allowable expenses here.

To be eligible for reimbursement, the person must qualify for OPWDD services, the expenses must directly benefit the person with a developmental disability, and the expenses must not be able to be covered by any other means.

For information, contact Loretta Goldson 516-293-1111 ext.5610 lgoldson@ahrc.org

Community-Based Respite

Citizens offers respite programs during the week and on weekends for those who are 18 years or older. This includes quality care in a fun and engaging environment, and various activities from Arts & Crafts, to Music and Games to name a few.

For more information, see https://www.citizens-inc.org/respiteconnections/

Residential Respite

Citizens' respite program provides respite services in a location that is part of the residential program. It can be provided, during the day, evenings or overnight. Respite is an "indirect" service that provides relief to individuals who are responsible for the primary care and support of an individual with a developmental disability. When a family member, Family Care provider or live-in/house-parent staff person has to deal with such things as illness, emergency, and caregiver or staff vacation, respite services can ensure that their loved one's needs are met.

The person's Care Coordinator/Manager will complete paperwork and submit to the DDRO. The DDRO shall authorize units of Respite based upon a needs-based assessment of the individual. Authorized Respite units may be used for any of the following categories of Respite: Site-Based, Recreational, In-Home, and Camp Respite. It is the responsibility of the provider to ensure that the appropriate category of Respite is billed for the Respite service delivered.

For more information contact Maria Carmela Melendez at 516-293-2016 Ext. 5615

RECREATION

Citizens' recreation is a great way to meet new people. Whether it's going to the bowling alley, dances, special themed events, movie review club, writing club, yoga, or even our 7-day-a-week Virtual Program.

For more information about eligibility and applying, see https://www.citizens-inc.org/rec/

RESIDENTIAL SUPPORTS

Citizens has a wide range of residential supports throughout Nassau and Suffolk County. Each person receives individualized supports based on needs identified in a person centered planning process. Staff are trained on each person's level of support, and provides assistance with all activities of daily living and community engagement.

ICFS

An Intermediate Care Facility (ICF) is a community based home that provides clinical and supportive care to people with ID/DD. People living in an ICF typically require long term care, and have a higher level of need related to medical or behavioral complexities. Clinical supports are provided on-site through an interdisciplinary team process. An ICF is regulated by the NYS Department of Health through an annual auditing process by the Office of People with Developmental Disabilities (OPWDD).

IRAS

An Individualized Residential Alternative (IRA) is a community based home that provides individualized supports based on needs identified in a person centered planning process. People are supported to be independent at their level of ability, and to live the life that they chose. An interdisciplinary team process helps determine priority needs; although there is oversight by a Registered Nurse and Behaviorist, all clinical needs are addressed through services within the community.

Contact Information:

Jerry Powers: 516-293-2016 ext. 5329
Marta Garavito (Plainview ICF): 516-367-2740 ext. 8346
Mary Gilleran (Shoreham ICF) 631-744-7158 ext. 6200

https://advantagecaredtc.org/

Advantage Care Health Center and the Fay J. Lindner Center for autism and developmental disabilities are Long Island's premier Federally Qualified Health Centers. Together we provide quality medical, dental and mental/behavioral health services to all members of the community.

Advantage Care Health Center:

Advantage Care Health Center offers primary and preventive care to all members of the community.

Advantage Care's team of compassionate and caring medical professionals have the training and experience necessary to deliver high quality health care services to all patients including those with special needs. The Advantage Care team is committed to forming a relationship with you to help meet your health and wellness goals.

Services:

PRIMARY MEDICAL CARE FOR ADULTS

- Comprehensive interview and evaluation of medical history
- Examination and treatment of acute and chronic medical conditions
- Review of laboratory data, including genetic testing
- Immunizations
- EKG
- Coordination of care with other physicians and/or service providers concerning medical status of patient
- Hospitalist to admit and track an individual during a hospitalization

PRIMARY MEDICAL CARE FOR CHILDREN

- Comprehensive interview and evaluation of medical history
- Examination and treatment of acute and chronic medical conditions
- Well visits, school and camp physicals
- Physician on call and in close communication with nursing staff
- Review of laboratory data, including genetic testing
- Venipuncture
- Immunizations
- EKG
- Coordination of care with other physicians

- Communication with nursing staff, schools psychologists, speech therapists and occupational therapists

PREVENTIVE CARE SERVICES

- Cancer screening
- Well-child service
- Screenings for elevated blood levels
- Communicable diseases screening and treatment
- Pediatric eye and ear screenings

PODIATRY CARE SERVICES (Medically necessary podiatry services only.)

- Initial podiatric assessment of patients
- Biomechanical foot orthotics
- Preventive diabetic foot care – LOPS testing
- Evaluation and management of ulcers or infections
- Treatment of fungal infection, nail removal
- Evaluation and treatment of foot and/or ankle pain
- Treatment of neuroma, bunion and hammer toe

DENTAL CARE FOR CHILDREN AND ADULTS

- Initial dental assessment
- Bi-annual examinations
- Dental hygiene services (cleanings, x-rays)
- Fluoride treatment
- Sealants
- Cosmetic procedures
- Restorative dental services (fillings)
- Prosthodontic services (crowns)
- Endodontic services (root canal treatment)
- Periodontal services (treatment of gums)
- Ambulatory/same day surgery services
- Patient and family dental care training
- Dental desensitization

MENTAL AND BEHAVIORAL HEALTH SERVICES

- Comprehensive and individualized evaluations and treatment recommendations.
- Diagnosis and treatment of psychiatric illness
- Identification of psychiatric disorders, evaluation of psychiatric disorders, and pharmacologic medication management
- Monitor efficacy of medication, dosage, toxicity and adverse reactions
- Monitor autonomic involuntary movement disorders (AIMS testing)

- Monitor extrapyramidal symptoms
- Educate patients, families and caregivers about the risks and benefits of medication
- Consultations and ongoing psycho-pharmacological visits are available.

PSYCHOLOGY SERVICES

- Psychotherapy
- Cognitive behavioral therapy (CBT) – individual and group sessions
- Social skills interventions – individual and group sessions
- Parent training
- Family therapy
- Parent and sibling support groups
- Family support and education

FAY J. Lindner Center

The Fay J. Lindner Center offers a wide range of services that are designed to support individuals and their families, specializing in autism spectrum disorders (ASDs). Clinicians develop individualized treatment recommendations addressing social, emotional, communication, cognitive, adaptive, affective and behavioral lines of development.

Services include:

- Psychiatric evaluations
- Pharmacologic medication management
- Psychological consults
- Psychological evaluations
- Neuropsychological evaluation
- Psychotherapy (individual, family, group)
- Individual/parent/family training
- Workshop series such as positive behavior supports and working with your school/community
- School consultation program

Phone: 516-686-4440

Brookville location

189 Wheatley Road
Brookville, NY 11545

Freeport location

230 Hanse Avenue
Freeport, NY 11520

APPENDIX A

71-74 **OPWDD's Family Reimbursement Program**

Family Reimbursement

Many families who have a family member with a developmental disability living at home have special expenses that the typical family does not have. OPWDD's Family Reimbursement Program, also known as Voucher Reimbursement, is intended to enhance a family's ability to provide in-home care to their family member and might help with these expenditures if they are not covered through other means.

The program reimburses expenses up to $3000 per year that are related to the disability and are not covered by other sources. The program has eligibility and application criteria that are determined by OPWDD and a review committee.

Family Reimbursement is administered by various FSS providers, including AHRC and Citizens. Other agencies that are FSS providers can be found on LIFSSAC's Family Support Services Grant Programs list (click the link or see page 60 of this guide).

To be eligible for reimbursement, the person must qualify for OPWDD services, the expenses must directly benefit the person with a developmental disability, and the expenses must not be able to be covered by any other means. The program prioritizes health and safety issues and quality of life. Find a list of allowable and non-allowable expenses on the next three pages, or by clicking here.

NEW YORK STATE OF OPPORTUNITY. Office for People With Developmental Disabilities

Family Support Services Family Reimbursement
Allowable and Non-Allowable Items
Updated 4/3/23

Allowable Items:

- Recreation Activity/Program/Equipment
  - Integrated, community-based activity fees/supplies
  - Instrumental and music lessons/fees (e.g., guitar lessons, piano lessons)
  - Braille bingo cards, playing cards and dominoes
  - Cooking classes (not resulting in certification)
  - Theatre classes/workshops
  - Museum membership
  - Art classes
  - Crafts
  - Gym membership
  - Fitness classes
  - Swim lessons
  - Sports lessons/fees (e.g., Soccer, Baseball, Golf, Bowling, Cheerleading)
- Recreation Activity/Program/Equipment, continued
  - Martial Arts lessons (e.g. Karate, Tae kwon do)
  - Dance/ballet lessons
  - Equine therapy/Hippo therapy/Horseback riding
- Sensory Items
  - Balance chair
  - Bean bag chair
  - Indoor swing
  - Mini trampoline (single user)
  - Climber
  - Fidget items/sensory toys
  - Shower head
  - Positioning cushion/wedge
  - Floor mats
  - Therapy tunnel
- Items/Services that are not covered or available through other means and are reviewed and approved by the committee
- Respite
- Camp (see section G of the ADM)
- Electronic devices (see section J of the ADM)
- Supplements approved by a clinician and outlined in the individual's treatment plan
- Legal fees related to guardianship and special needs trusts
- Clothing as a necessity or if there are specific needs related to the intellectual/ developmental disability (I/DD) (e.g., excessive chewing, destruction due to behavior or urination) as clinically indicated (i.e., included in the Life Plan or with other appropriate documentation requested by the DDRO); and
- Other items as deemed appropriate and reimbursable by the DDRO

Non-Allowable Items:

Healthcare/Personal care:

- Items covered by Medicaid or healthcare insurer, including incontinence items & prescription medications/medical supplies
- Diapers
- Bed protector
- Wipes
- Bibs
- Experimental treatments/therapies
- Dental activities
- Toothbrush
- Prescription eyeglasses
- Dermatology services
- Sedation
- Enemas
- Oral swabs, syringes
- Portable tub
- CBD or marijuana products
- Nutrisystem – weight loss program
- Personal training
- Life coach
- Exercise equipment (e.g.: elliptical machine, treadmill, free weights)

Household Expenses:

- Appliances, large and small (e.g., washing machine, dryer, blender)
- Furniture
- Mattress
- Home repairs*
- Rent/rental deposit*
- Maintenance items*
- Air conditioner
- Snowplow/snowplow services
- Video monitoring system
- Pool cover
- Water fountain
- Bento box, water bottle

Travel/Transportation:

- Vehicles (e.g., cars, motorcycles)
- Car repairs
- Battery (for side-by-side bike)
- Car fuel
- Car seat
- Hotel/lodging, mileage and travel costs
- Conference expenses
- Bicycles/Tricycles/Scooters
- Taxi service/Uber or Lyft rides
- Stroller

Fiscal Expenses:

- Real property (e.g., home or apartment related costs)*
- Finance charges
- Tax bills
- Sales tax
- Shipping fees
- Co-pays
- Fines
- Funeral expenses

Duplicative Expenses/Otherwise Covered:

- *Upgrades* to items/services covered by HCBS Waiver or other sources, including self- direction budgets (e.g., upgrading fencing materials, additional funding for a higher cost camp)
- Items/services related to/required for [Waiver based] day program participation/enrollment
- Items covered by other state paid benefits (e.g., free cell phone programs)
- Items covered by self-direction budget, *if* someone is self-directing services
- Equipment repair/replacement

Non-Allowable Items, Continued:

Educational Based Services/Goods:

- College courses/Certification programs
- Homeschool books
- Tutoring
- After-school programs
- Academic testing/retesting
- Items and services that an individual is eligible for in the context of their educational services (e.g., occupational therapy, physical therapy)
- ABC Mouse learning program/app

Miscellaneous Items/Services:

- Regular and ongoing subscription plans
- Cell phone purchase and cellular plans
- Data plans for iPad
- Headphones
- GPS Trackers/devices; video or audio monitoring devices
- Luxury items (e.g., swimming pools, hot tubs)
- Concert tickets
- Ski lessons/equipment rentals/lift pass
- Other items deemed not appropriate for reimbursement by the DDRO

***See section I (3) of the ADM for Allowable One-Time Reimbursements of these items/services**

APPENDIX B

76 **Registering for the Draft**

REGISTERING FOR THE DRAFT

http://www.sss.gov

The following is from the U.S. Selective Service website:

WHO MUST REGISTER

Almost all male U.S. citizens, and male immigrants, who are 18 through 25, are required to register with Selective Service. It's important to know that even though he is registered, a man will not automatically be inducted into the military. In a crisis requiring a draft, men would be called in sequence determined by random lottery number and year of birth. Then, they would be examined for mental, physical and moral fitness by the military before being deferred or exempted from military service or inducted into the Armed Forces.

DISABLED MEN

Disabled men who live at home must register with Selective Service. A friend or relative may help a disabled man fill out the registration form if he can't do it himself.

Men with disabilities that would disqualify them from military service still must register with Selective Service. Selective Service does not presently have authority to classify men, so even men with obvious handicaps must register now, and if needed, classifications would be determined later.

How to Register

The easiest and fastest way for a man, from age 18 through age 25, to register is to register online.

NOTE: Anyone, U.S. citizen or immigrant, who attempts to register from our website with a social security number that is not first in our system will find they are not able to complete their registration online. These men can still register by filling out a registration form and mailing it to the Selective Service System. The registration form asks for the young man's full name, address, date of birth, gender, and social security number (if he has one). On the form that is mailed to Selective Service, the man's signature is also required.

Online

Young men with a valid social security number may register with Selective Service at https://www.sss.gov/Registration/Register-Now/Registration-Form

At The Post Office

Selective Service mail-back registration forms are available at any U.S. Post Office. A man can fill it out (leaving the space for his social security number blank, if he has not yet obtained one *****), sign and date, affix postage, and mail to Selective Service without the involvement of the postal clerk. Men living overseas may register at any U.S. Embassy or consular office. ***** *Remember* to provide your social security number to the Selective Service as soon as you obtain one.

Reminder Mail-Back Card

A young man may also register by filling out a reminder mail-back card received in the mail. Selective Service sends this card to many men around the time they turn 18 years old. A man can fill out the card at home and mail it directly to Selective Service.