NEW YORK STATE | Office for People With Developmental Disabilities

sanys SELF-ADVOCACY ASSOCIATION OF NEW YORK STATE

Rights, Responsibilities & Advocacy

Plain Language

Rights, Responsibilities & Advocacy

As a person with a developmental disability, you have the right to choose your own path and to live your life with as much freedom as possible. Everyone has the same rights protected by the United States and New York State Constitution, but additional rights exist in law and regulation about the services and supports you receive. If you live in a home operated by a provider agency, you have additional rights to protect your privacy and make choices about your living situation.

Sometimes in an emergency, a right may be temporarily limited to protect you or someone else from getting hurt. If a plan of services ever includes a proposal to limit a right for a longer time, you will always have the right to object to that plan and propose alternatives.

Some of your rights include:

- The right to vote.
- The right to participate in the community.
- The right to choose how you live and who you spend your time with.
- The right to lead the Life Plan process to decide what services are right for you.

You also have a right to advocate for yourself and others.

Advocacy is to speak or act in support of someone else.

Self-advocacy is taking control in making decisions in your own life.

Advocating for yourself and others is important for people who want to live as independently as possible. This document provides information about your rights and responsibilities as a person with a developmental disability so you can advocate for yourself and others. It can also be useful to family members, Direct Support Professionals, Care Coordinators, service providers, and others advocating with people with developmental disabilities.

Community

You have the right to:

- Choose where you want to live.[i]
- Protection against eviction and harassment.[ii]
- Join community groups of your choice and partake in community activities.[iii]
- Host social events and have visitors and guests where you live.[iv]
- Meet with friends.[v]
- Share your opinions with elected officials about issues affecting your community.
- Vote (if you are a U.S. citizen, over the age of 18, and meet state requirements).[vi]

Life

You have the right to:

- Choose the types of activities that are important to you, and when you want to participate.[vii]
- Pursue Supported Decision-Making.[viii]
- Challenge a guardianship.[ix]
- Challenge an order of incompetence preventing you from exercising your right to vote.[x]
- Marry (if over the age of 18) or raise a family if you are capable of doing so.[xi]
- Manage your money.[xii]
- Decide what to buy.[xiii]
- Celebrate your culture and identity.[xiv]

- Express the traditions and beliefs of your heritage.[xv]
- Be communicated with in a language you are able to understand.[xvi]
- Participate in religious activities of your choice.[xvii]
- Have relationships.
- Have the opportunity to seek employment.[xviii]
- Have the opportunity to seek education.[xix]
- Live in a safe and clean apartment, house, or room that is arranged the way you like it.[xx]
- Be safe from mental, sexual, and physical abuse and neglect.[xxi]
- Receive respect and dignity no matter your race, religion, national origin, creed, age, sex assigned at birth, gender expression, ethnic background, sexual orientation, perceived sexual orientation, developmental or other disability, or heath condition.

Life Plan[xxii]

You have the right to:

- A Life Plan that includes:
    - Your goals and desired outcomes.
    - Your strengths and preferences.
    - Clinical and support needs.
    - Necessary and appropriate services and supports (identified through an assessment of functional and health related needs).
    - Services you elect to self-direct.
    - An appropriate backup plan.
    - Identifying a person who will monitor the plan.[xxiii]

- A Life Plan written in plain language, primary language, or in a manner that is accessible to you.[xxiv]
- The opportunity to participate in the development and modification of your plan of services, unless constrained by your ability to do so.
- The opportunity to object to any provision within the plan of services and to appeal any decision with which you disagree regarding your objection to provisions of the plan.
- A Life Plan that allows you to engage in meaningful and productive activities which take into account your interests and culture.
- A Life Plan finalized and agreed to with your written informed consent, which is also signed by the provider(s) responsible for implementing the Life Plan.[xxv]
- To participate in a review of your Life Plan at which you, the parties chosen by you, the service provider, and your Care Manager are present.[xxvi]
- Review your Life Plan:
    - At your request or the request of parties you have chosen to be involved;
    - At least two times per year;
    - When your capabilities, capacities, or preferences have changed;
    - When the plan has been determined to be ineffective; and
    - Upon reassessment of your functional need.[xxvii]

Sexuality

You have the right to:

- Have training and counseling in the area of sexuality.[xxviii]
- Express your gender identity and be recognized by your identified gender.[xxix]
- Express your sexuality alone or with another consenting adult, if it does not infringe on the rights of other people.[xxx]
- Express and communicate your sexual orientation or choose not to share your sexual orientation.[xxxi]
- Receive training and counseling in family planning.[xxxii]
- "SAY NO" and receive protection from unwanted sexual advances (sexual harassment).[xxxiii]
- Feel safe.

Privacy

You have the right to:

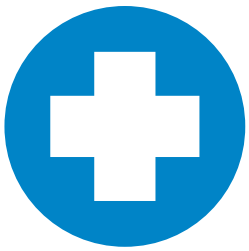
- Keep all your personal information confidential.[xxxiv]
- Keep information contained in your health records confidential.[xxxv]
- Choose who can access your personal information and health records.[xxxvi]
- Keep your clinical records confidential.[xxxvii]

Services

You have the right to:

- Request to change your room, apartment, or agency.[xxxviii]
- Have trained staff work with you.[xxxix]
- File a complaint and express your concerns, to the director of an agency and/or OPWDD without fear of retaliation.[xl]
- Participate in developing your plans, recommend changes in your plans, help define your goals [xli] and what you want to do with your life.
- Select or change your service coordinator/agency.[xlii]
- Receive quality care with respect and dignity.[xliii]
- Report abuse or if your rights are denied for disciplinary (punishment) purposes by staff.[xliv]
- Object to plans of service, proposed relocation or discharge from a program, and reductions or ending of service.[xlv]
- Consent or withhold consent to behavioral support plans (and the right to object to those plans).[xlvi]

Health



You have the right to:

- Know your medications and be informed of their benefits and side effects.[xlvii]
- Consent or withhold consent to medical treatment.[xlviii]
- Refuse psychiatric medications unless a court orders them, even if you have a guardian who makes medical decisions.[xlix]
- Be free from unwarranted restraints.[l]

- Adequate and appropriate health care.[li]
- Receive mental health counseling services.[lii]
- Choose (to the extent possible) your doctor, dentist, hospital, and health care agent.[liii]
- Keep your health status confidential.[liv]
- Receive a second opinion about a diagnosis.[lv]
- Create a health care proxy and decide who can make health care decisions for you if you become unable to.

Additional Rights Specific to Certified Settings

If you live in a home with other people with a developmental disability that is operated by a provider agency, you have the right to make choices and to have privacy. Rights for those living in a group home include:

Community[lvi]

You have the right to:

- A safe and sanitary environment.
- Freedom from physical or psychological abuse.
- Freedom from corporal punishment.
- Freedom from unnecessary use of mechanical restraining devices.
- Freedom from unnecessary or excessive medication.
- Protection from commercial or other exploitation.

Living Space[lvii]

You have the right to:

- A balanced and nutritious diet, in which meals are served at appropriate times and meal composition or timing is not altered for behavioral modification or for the convenience of staff.
- Individually owned clothing which fits properly, is maintained properly, and is appropriate for age, season, and activity, and the right to choose what you wear.
- A reasonable degree of privacy in sleeping, bathing, and toilet areas.
- A reasonable amount of safe, individual, and accessible storage space.
- The opportunity to request an alternative residential setting, such as a new residence or room, and involvement in the decision-making process.
- The opportunity to express (either personally or through a parent, guardian, or correspondent) concerns and suggestions to the chief executive officer of the facility without fear of reprisal.
- An entrance door to your residence which you are able to lock and to which only appropriate parties have access.
- A right to have a key to your bedroom.
- A right to request your own room (not a shared room) unless you have chosen a shared room.
- A right to decline to live with a roommate.
- A choice of roommates if you are sharing a residence/bedroom.
- Freedom to furnish and decorate your residence within the lease/agreement.
- Access to food at any time consistent with similar settings for the broader community.
- Have visitors of your choosing at any time consistent with similar settings for the broader community.

- Services, assistance, and guidance from staff trained to administer services adequately, safely, skillfully, and humanely with respect for your dignity and personal integrity.
- The right to own and maintain property.

Responsibilities and Involvement

- Take responsibility for knowing your rights established in laws and regulations, which can guide you in taking control and making decisions about your own life.
- Learn how to speak up and bring awareness to the things that are important and of interest to you.
- Identify support systems and use them to pursue what you want in your life and help others to do the same.
- Listen and learn about problem solving mechanisms that can help improve community programs and services for the disabled.
- Value the rights of others by treating them the way you would want to be treated.
- Report suspected abuse of yourself or of someone else.
- Learning and sharing information with others about self-determination.
- Develop and participate in your personalized service plan.
- Be responsible for maintaining and caring for your property and paying your rent or mortgage.
- Take your medication responsibly.
- Take responsibility for your diet.
- Keep your appointments and be on time to the best of your ability.
- Get involved with advocacy organizations and enacting laws for the protection of people with developmental disabilities.

Speaking Up for Your Rights

If something doesn't feel right, you have the right to speak up.

Every person with a developmental disability has the right to be safe, respected, and treated fairly. If you think your rights have not been respected, or something is wrong with the way you are being treated, there are people and programs that can help.

If you live in an OPWDD-Certified Setting and Experience Abuse or Neglect

If you or someone you know is being:

- Hurt or mistreated.
- Left in unsafe situations.
- Spoken to in a harmful or threatening way.
- Not being given care and support.

You can make a report to the New York State Justice Center for the Protection of People With Special Needs. The Justice Center investigates allegations of abuse and neglect in certified settings only.

Certified settings include group homes, supportive apartments, day habilitation and family care.

To report abuse or neglect:

Call the Justice Center's 24/7 Hotline at 1-855-373-2122

Please note: If emergency services (medical assistance, law enforcement, fire department, etc.) are needed, call 9-1-1 immediately. After contacting 9-1-1, then contact the Justice Center to report an incident in a certified setting.

Support for You and Your Family after a report is made:

The Justice Center also has a team called the Individual and Family Support Unit. These advocates can:

- Answer your questions
- Help you understand the process
- Give updates on your case
- Connect you to helpful services

To talk to an advocate, you can:

- Email: supportcoordinator@justicecenter.ny.gov
- Call: 1-800-624-4143

To learn more, visit: www.justicecenter.ny.gov

The Justice Center investigates abuse, neglect and other types of incidents. If your concern is about something else, like a service you are receiving, there are other ways to get help.

If You Disagree With a Service Decision

Sometimes, you may not agree with a decision made about your services, treatment, or care. For example:

- You were told you can't get a service you feel you need
- A staff member wants to make a change to your care plan that you don't agree with
- You feel your voice wasn't considered in the decision

Under 14 NYCRR 633.12, you have the right to object to services. This is called the **Objection to Services Process**.

What is the "Objection to Services Process?"

This is a formal way to say:

"I don't agree with this decision, and I want someone to review it."

You, your advocate, or your family can work with your Care Manager and your treatment provider on beginning the process.

If you do not feel this is necessary or would like to pursue a less formal route, you have other options.

You need help with a problem or concern. You may:

- Not agree with a decision made about your services.
- Feel your voice isn't being heard.
- Be unsure where to turn for help.

That's when the Independent Ombudsman Program can help.

What is an Ombudsman?

An Ombudsman is a helper who listens to your concerns and works with you to solve problems. They are independent, which means they do not work for the people providing your services. They work for you.

The Ombudsman can:

- Help you understand your rights.
- Talk to staff or agencies on your behalf.
- Help you obtain services you need.
- Support you in speaking up.
- Look into concerns and help find solutions.

The Ombudsman Program is run by Community Service Society of New York (CSSNY) and is independent from OPWDD. They have a helpline that anyone can call and request support from Monday to Friday from 9am to 5pm.

Free and confidential Ombuds helpline: 800-762-9290

Webform: cssny.org/programs/entry/iddo#form

You Can Also:

- Talk to your Care Manager about your options.
- Speak with staff at your provider agency.
- Seek support from a trusted person.

You have the Right to:

- Be treated with dignity and respect.
- Make choices about your life.
- Be safe from harm.
- Get services that support your needs.
- Say “no” or “I disagree.”
- Be included and heard.

If something doesn’t feel right, speak up. You are not alone and your voice matters.

Disability Rights Resources

Disability Rights New York (DRNY)

DRNY is New York State's Protection and Advocacy system. They are independent and help people with disabilities protect their legal and civil rights.

They can:

- Help you file a complaint.
- Represent you in legal matters.
- Advocate for equal access, safety, and inclusion.

To set up an appointment email: intake@drny.org

Phone: (518) 432-7861 Toll Free: (800) 993-8982

Visit their website: drny.org

Email: mail@drny.org

New York State Division of Human Rights

You can also file a complaint if you are being discriminated against in housing, work, education, or public spaces because of your disability.

Phone: (888) 392-3644

Visit their website: dhr.ny.gov

Email: info@dhr.ny.gov

More Rights Resources

The Self-Advocacy Association of New York State, Inc.,

The Self-Advocacy Association of New York State helps self-advocates build the skills to speak up for themselves and others.

Email: sandrews@sanys.org

Address: 500 Balltown Road, Building 12, Schenectady, NY 12304

Phone: (518) 382-1454

Visit their website: sanys.org

Legal and Regulatory Appendix

[i] OPWDD Regulations at 633.4(a)(4)(xxii) and 636-1.4(b)(2)(i)

[ii] OPWDD Regulations at 633.4(a)(4)(xxii) and 636-1.4(b)(2)(i)

[iii] OPWDD Regulations at 14 NYCRR 633.4(a)(4)(viii)

[iv] OPWDD Regulations at 636-1.4(b)(2)(iv) and 633.4(a)(4)(xxiv); Mental Hygiene Law 33.03(a)(9), 33.03(a)(13); Mental Hygiene Law 33.02(a)(9), 33.02(a)(13)

[v] OPWDD Regulations at 636-1.4(b)(2)(iv) and 633.4(a)(4)(xxiv); Mental Hygiene Law 33.03(a)(9), 33.03(a)(13); Mental Hygiene Law 33.02(a)(9), 33.02(a)(13)

[vi] NY Election Law Article 5, NY Mental Hygiene Law 33.01, and OPWDD Regulations at 633.4(a)(4)(xiii)

vii OPWDD Regulations at 636-1.4(b)(2)(iii) and 633.4(a)(4)(viii)(c)

[viii] NY Mental Hygiene Law Article 82

[ix] Surrogate's Court Procedure Act Article 17-a & Mental Hygiene Law Article 81

[x] Surrogate's Court Procedure Act Article 17-a & Mental Hygiene Law Article 81

[xi] NY Domestic Relations Law Chapter 14 and OPWDD Regulations at 633.4(a)(4)(xi)(b)

[xii] OPWDD Regulations at 633.4(a)(4)(xvi)

[xiii] OPWDD Regulations at 633.4(a)(4)(xvi)

[xiv] OPWDD Regulations at 633.4(a)(2) and OPWDD Regulations at 633.4(a)(4)(xxvii)

[xv] OPWDD Regulations at 633.4(a)(2) and OPWDD Regulations at 633.4(a)(4)(xii)

[xvi] OPWDD Regulations at 633.4(a)(8), 633.4(a)(15)

[xvii] OPWDD Regulations at 633.4(a)(4)(xii) and NY Mental Hygiene Law 33.02(a)(4)

[xviii] NY Executive Law 291.1 and NY Mental Hygiene Law 33.01, 33.09

[xix] NY Executive Law 291.2

[xx] OPWDD Regulations at 633.4(a)(4)(i) and 636-1.4(b)(2)(ii)(c)

[xxi] OPWDD Regulations at 633.4(a)(4)(ii) and 624.3; NY Penal Law Articles 130, 230, 255, and 263

[xxii] CCO Policy Manual | Office for People With Developmental Disabilities (ny.gov); OPWDD Regulations at 636-1.3(a-f)

[xxiii] OPWDD Regulations at 636-1.3(b)(1-9); OPWDD Regulations at 636-1.3(c)

[xxiv] OPWDD Regulations at 636-1.3(b)(1-9); OPWDD Regulations at 636-1.3(c)

[xxv] OPWDD Regulations at 636-1.3(d)

[xxvi] OPWDD Regulations at 636-1.3(f)

xxvii OPWDD Regulations at 636-1.3(f)(1-5)

[xxviii] OPWDD Regulations at 633.4(a)(4)(xi) and ADM-2023-03; OPWDD Regulations at 633.4(a)(2) and 633.4(a)(4)(xxvii)

[xxix] 633.4(a)(4)(xxvii)

[xxx] OPWDD Regulations at 633.4(a)(4)(xi)(a)

[xxxi] (633.4(a)(2)

[xxxii] OPWDD Regulations at 633.4(a)(4)(xi)

[xxxiii] NY Executive Law Article 15

[xxxiv] OPWDD Regulations at 633.4(a)(4)(vii) and NY Mental Hygiene Law 33.13

[xxxv] OPWDD Regulations at 633.4(a)(4)(vii). Confidentiality regarding all information contained in a person's record and access to such information is subject to the provisions of article 33 of the Mental Hygiene Law and any other OPWDD regulations. Confidentiality with regard to HIV-related information shall be maintained in accordance with article 27-F of the Public Health Law, 10 NYCRR Part 63, and the provisions of section 633.19

[xxxvi] Ibid.

[xxxvii] Ibid.

[xxxviii] OPWDD Regulations 636-1.2 and 633.4(a)(4)(xxii) See also: Due Process | Office for People With Developmental Disabilities (ny.gov)

[xxxix] OPWDD Regulations at 633.4(a)(4)(ix)

[xl] OPWDD Regulations at 633.4(a)(4)(xxiii) and 633.4(a)(12)

[xli] OPWDD Regulations at 633.4(a)(4)(viii) and 636-1.2; Mental Hygiene Law 33.02(a)(11)

[xlii] OPWDD Regulations at 635-11.8 or 635-11.9

[xliii] OPWDD Regulations at 633.4(a)(2) and Mental Hygiene Law 33.02(a)

[xliv] OPWDD Regulations at 633.4(a)(4)(xxiii), 624.3, and 633.16(j)(2)

[xlv] OPWDD Regulations at 633.12, 633.4(a)(4)(viii) and Mental Hygiene Law 33.02(a)(12)

[xlvi] OPWDD Regulations at 633.16 and Mental Hygiene Law 33.02(a)(12)

[xlvii] OPWDD Regulations at 633.4(a)(4)(v)

[xlviii] OPWDD Regulations at 633.11

[xlix] OPWDD Regulations at 633.16(h)(3)

[l] OPWDD Regulations at 633.4(a)(4)(iv)

[li] OPWDD Regulations at 633.4(a)(4)(x)

[lii] OPWDD Regulations at 633.4(a)(4)(xi) and 633.4(a)(4)(x)

[liii] OPWDD Regulations at 633.4(a)(4)(x) and 633.4(a)(4)(xxvi)

liv NY Mental Hygiene Law 33.13

[lv] OPWDD Regulations at 633.4(a)(4)(x)

[lvi] Section 633.4 – Rights and responsibilities of persons receiving services

[lvii] Section 633.4 – Rights and responsibilities of persons receiving services; Section 636.1.4 - Documentation of rights modifications in HCBS Medicaid Waiver services in settings certified by OPWDD

Notes

Notes

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Self-Advocacy Association
of New York State

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