



Office for People With
Developmental Disabilities



Rights, Responsibilities & Advocacy

October 2024



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 harassmentⁱⁱ
- 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 health condition.

Life Plan^{xxii}



You have the right to:

- A Life Plan that includes your
 - goals and desired outcomes;
 - 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; and
 - identifies 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 of 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;
 - 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}

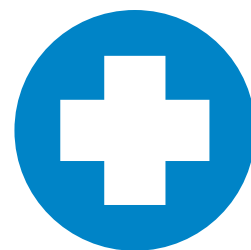
Services



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.^{xi}
- Participate in developing your plans, recommend changes in your plans, help define your goals ^{xii} 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.^{xlvi}
- 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.ⁱ

- 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.

Grievance Process



What to do if your rights have been violated:

1. Communicate your concerns with your Care Manager

Care Managers are required to make certain that each person's health and safety are an integral component of the care planning process.

Staff must inform the provider agency of any reportable incidents.

Provider Agencies are required to report the following incidents involving vulnerable persons to the NYS Justice Center for the Protection of People with Special Needs.

- Reportable incidents include:
 - Physical abuse
 - Sexual Abuse
 - Psychological Abuse
 - Deliberate inappropriate use of restraint
 - Use of aversive conditioning
 - Obstruction of reports of reportable incidents
 - Unlawful use or administration of a controlled substance
 - Neglect

2. Ombuds Program

An ombuds program for OPWDD was signed into law in 2023. The Ombuds program is an independent service that can help you navigate complaints, issues, and/or problems with OPWDD, providers within the OPWDD system, or Care Coordination Organizations (CCOs). OPWDD is contracting with an independent organization to provide these services, which will be available in the near future.

3. **Anyone** – including a person with a developmental disability, self-advocate, parent, advocate, or guardian – can make a report to the Justice Center’s Vulnerable Persons Central Register (VPCR) hotline and is encouraged to make a report when they have knowledge or have reason to believe that a person with special needs has been abused, neglected, or mistreated.

To file a report:

[Reporting an Incident | Justice Center for the Protection of People With Special Needs \(ny.gov\)](#)

For more information visit:

[Justice Center | Justice Center for the Protection of People With Special Needs \(ny.gov\)](#)

Email: supportcoordinator@justicecenter.ny.gov.

Phone: 1-800-624-4143

What to do if you want to challenge a treatment decision:

- **Communicate your concerns to your Care Manager**

If your Care Manager is unable to address your concerns, they will bring the necessary parties together to participate in a dispute resolution process.

- **Dispute Resolution Process**

Dispute resolution happens with the provider agency and your circle of support. Sometimes it may also include staff of OPWDD’s regional office.

- **Due Process**

People receiving services certified or operated by OPWDD, must be afforded the due process required by OPWDD regulations at 14 NYCRR 633.12: Objection to Services Process. These rights apply whenever a provider proposes to:

- modify what services you receive,
- discharge you from your residential facility,
- relocate you to a new residential facility;
- reduce, suspend, or terminate an HCBS waiver service, and/or
- initiate changes to a personalized service plan, including your Life Plan.

You must also always be given the opportunity to object to an existing personalized service plan, even if no changes to it have been proposed.

When an objection is made, the provider and/or the regional office will try to resolve the issue informally. If the objection cannot be resolved informally, you will have the right to request a hearing with a neutral hearing officer. The objecting party may offer information and ask relevant questions of any parties participating in any such hearing. You have the right to request that the objections and appeals process be reviewed with you.

More Rights Resources

[Disability Rights New York • Welcome to DRNY](#)

Email: mail@DRNY.org

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

Phone: (518) 432-7861

Toll Free: (800) 993-8982

[Contact | SANYS](#)

Email: sandrews@sanys.org

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

Phone: (518) 382-1454

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)
- ^{xliv} 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)
- ^{xlvi} OPWDD Regulations at 633.4(a)(4)(v)
- ^{xlvi} OPWDD Regulations at 633.11
- ^{xliv} OPWDD Regulations at 633.16(h)(3)
- ⁱ 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



**Office for People With
Developmental Disabilities**



NYS Office for People
With Developmental Disabilities

www.opwdd.ny.gov

Self-Advocacy Association
of New York State

<https://sanys.org>

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