

Prime Care Coordination Rights and Responsibilities of Persons Receiving Services

Prime Care Coordination is providing you and your family with your rights and responsibilities so that you and your family have the information you need to make informed decisions about your services.

The rights set forth in this document are intended to establish the living and/or program environment that protect individuals and contributes to providing an environment in keeping with the community at large, to the extent possible, given the degree of the disabilities of those individuals. Rights that are self-initiated or involve privacy or sexuality issues may need to be adapted to meet the need of certain persons with the most severe disability and/or persons whose need for protection, safety and health care will justify such adaptation. It is the responsibility of the agency/facility or the sponsoring agency to ensure that rights are not arbitrarily denied. Rights limitations must be documented and must be on an individual basis, for a specific period of time, and for clinical purposes only.

If you have any questions or concerns about these rights and responsibilities that your Care Coordinator cannot resolve, either you or your representative can express questions, grievances, concerns and suggestions to the **Quality Assurance/Corporate Compliance Department at Prime Care Coordination, 860 Hard Rd, Webster, NY 14580 - Telephone (877) 387-7293**, and/or other individuals set forth below.

Any such inquiries can be made without fear of reprisal.

New York State regulations (14 NYCRR 633.4) describe your rights and responsibilities as follows:

(a) Principles of compliance.

- (1) No person shall be deprived of any civil or legal right solely because of a diagnosis of developmental disability (see glossary, section 633.99 of 14 NYCRR [hereinafter "glossary"]).
- (2) All persons shall be given the respect and dignity that is extended to others regardless of race; religion; national origin; creed; age; gender; ethnic background; sexual orientation; developmental disability or other handicap; or health condition, such as one tested for or diagnosed as having an HIV infection. In addition, there shall be no discrimination for these or any other reasons.
- (3) The rights set forth in this section are intended to establish the living and/or program environment that protects individuals and contributes to providing an environment in keeping with the community at large, to the extent possible, given the degree of the disabilities of those individuals. Rights that are self-initiated or involve privacy or sexuality issues may need to be adapted to meet the need of certain persons with the most severe disabilities and/or persons whose need for protection, safety and health care will justify such adaptation. It is the responsibility of the agency/facility or the sponsoring agency to ensure that rights are not arbitrarily denied. Rights limitations must be documented and must be on an individual basis, for a specific period of time, and for clinical purposes only. (Note: See section 636-1.4 of 14 NYCRR for documentation requirements specific to the person-centered service plan and section 633.16 of 14 NYCRR for documentation requirements concerning person-centered behavioral intervention.)
- (4) No person shall be denied:
 - (i) a safe and sanitary environment;
 - (ii) freedom from physical or psychological abuse;
 - (iii) freedom from corporal punishment (see glossary);
 - (iv) freedom from unnecessary use of mechanical restraining devices;
 - (v) freedom from unnecessary or excessive medication;
 - (vi) protection from commercial or other exploitation;
 - (vii) confidentiality with regard to all information contained in the person's record, and access to such information, subject to the provisions of article 33 of the Mental Hygiene Law and the commissioner's regulations. In addition, 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 of 14 NYCRR;
 - (viii) a written individualized plan of services (see glossary) which has as its goal the maximization of a person's abilities to cope with his or her environment, fosters social competency (which includes meaningful recreation and community

programs and contact with others who do not have disabilities), and which enables him or her to live as independently as possible. Such right also includes:

- (a) the opportunity to participate in the development and modification of an individualized plan of services, unless constrained by the person's ability to do so;
- (b) the opportunity to object to any provision within an individualized plan of services, and the opportunity to appeal any decision with which the person disagrees, made in relation to his or her objection to the plan; and
- (c) the provision for meaningful and productive activities within the person's capacity although some risk may be involved, and which take into account his or her interests;
- (ix) services, including assistance and guidance, from staff who are trained to administer services adequately, skillfully, safely and humanely, with full respect for the individual's dignity and personal integrity;
- (x) appropriate and humane health care and the opportunity, to the extent possible, to have input either personally or through parent(s), or guardian(s), or correspondent to participate in the choice of physician and dentist; or the opportunity to obtain a second medical opinion;
- (xi) access to clinically sound instructions on the topic of sexuality and family planning services and information about the existence of these services, including access to medication or devices to regulate conception, when clinically indicated. This right includes:
 - (a) freedom to express sexuality as limited by one's consensual ability to do so, provided such expressions do not infringe on the rights of others;
 - (b) the right to make decisions regarding conception and pregnancy pursuant to the mandates of applicable State and Federal law.
 - (c) the right of facilities to reasonably limit the expression of sexuality, including time and location thereof, in accordance with a plan for effective facility management;
- (xii) observance and participation in the religion of his or her choice, through the means of his or her choice, including the right of choice not to participate;
- (xiii) the opportunity to register and vote and the opportunity to participate in activities that educate him or her in civic responsibilities;
- (xiv) freedom from discrimination, abuse or any adverse action based on his or her status as one who is the subject of an HIV-related test or who has been diagnosed as having HIV infection, AIDS or HIV related illness;
- (xv) the receipt of information on or prior to admission, regarding the supplies and services that the facility will provide or for which additional charges will be made, and timely notification of any changes thereafter;
- (xvi) the use of his or her personal money and property, including regular notice of his or her financial status and the provision of assistance in the use of his or her resources, as appropriate; (xvii) a balanced and nutritious diet. This right shall provide that:
 - (a) meals are served at appropriate times and in as normal a manner as possible; and
 - (b) altering the composition or timing of regularly served meals for disciplinary or punishment purposes, for the convenience of staff, or for behavior modification shall be prohibited;
- (xviii) individually owned clothing which fits properly, is maintained properly, and is appropriate forage, season and activity; and the opportunity to be involved in the selection of that clothing;
- (xix) adequate, individually owned, grooming and personal hygiene supplies;
- (xx) a reasonable degree of privacy in sleeping, bathing and toileting areas;
- (xxi) a reasonable amount of safe, individual, accessible storage space for clothing and other personal belongings used on a day-to-day basis;
- (xxii) the opportunity to request an alternative residential setting, whether a new residence or change of room, and involvement in the decisions regarding such changes;
- (xxiii) the opportunity, either personally or through parent(s), guardian(s) or correspondent (see glossary), to express without fear of reprisal grievances, concerns and suggestions to the chief executive officer of the facility; the Commissioner of OPWDD; the Justice Center for the Protection of People with Special Needs (Justice Center) (see glossary); for people in developmental centers, and in the community on conditional release from a developmental center, the Mental Hygiene Legal Service and the board of visitors; and for people in developmental centers, the ombudsman;
- (xxiv) the opportunity to receive visitors at reasonable times; to have privacy when visited, provided such visits avoid infringement on the rights of others, and to communicate freely with anyone within or outside the facility; or
- (xxv) the opportunity to make, or have made on his or her behalf, an informed decision regarding cardiopulmonary resuscitation (see glossary), in accordance with the provisions of article 29-B of the Public Health Law, and any other applicable law or regulation. Each developmental center (see glossary) shall adopt policies/procedures to actualize this right. (xxvi) the opportunity, if the person is residing in an OPWDD operated or certified facility, to create a health care proxy (see glossary) in accordance with 14 NYCRR 633.20.

(5) Implementation of many of the above rights entails inherent risks. To the extent reasonable, foreseeable and appropriate under the circumstances, such risks shall be described to individuals and/or their parents, guardians or correspondents. However,

these individuals assume responsibility for those risks typically associated with participation in normal activities, to the extent the person's abilities permit such participation.

(6) Staff, volunteers, and family care providers shall be advised of the previously listed rights.

(7) None of the foregoing rights shall be limited for the convenience of staff, as a threat, as a means of retribution, for disciplinary purposes or as a substitute for treatment or supervision.

(8) Each person, and his or her parent(s), guardian(s), or correspondent, prior to or upon admission to a facility and subsequent to any changes that occur thereafter, shall be notified of his or her rights at the facility and rules governing conduct, unless the person is a capable adult who objects to such notification to a parent or correspondent. Such information shall be conveyed in the person's and/or the parent's, guardian's, or correspondent's primary language if necessary to facilitate comprehension. There shall be agency/facility or sponsoring agency policies/procedures to implement this process as well as the process whereby individuals can be made aware of and understand, to the extent possible, the rights to which they are entitled, how such rights may be exercised and the obligations incurred upon admission to and participation in the programs offered by the facility. (Note: Also see paragraph [b][4] of this section).

(9) An individual or his or her parent(s), guardian(s) or correspondent may object to the application, adaptation or denial of any of the previously stated rights made on his or her behalf in accordance with section 633.12 of 14 NYCRR.

(10) Pursuant to section 33.16 of the Mental Hygiene Law, and subject to the limitations contained therein, a person (see glossary, subdivision [bw]), or other qualified party (see glossary, subdivision [bs]), may make a written request for access to the person's clinical record.

(i) If the facility denies such access in whole or in part, it shall notify the requestor of his or her right to obtain, without cost, a review of the denial by the OPWDD Clinical Record Access Review Committee.

(ii) The Clinical Record Access Review Committee shall consist of an OPWDD attorney, an OPWDD practitioner, and a representative of the voluntary agency provider community. The chairperson shall be the OPWDD attorney and requests for review of denial of access shall be addressed to the Office of Counsel for OPWDD.

(iii) The Clinical Record Access Review Committee shall conduct its deliberations and reach its determinations in accordance with section 33.16 of the Mental Hygiene Law. If the committee upholds the facility's decision to deny access to the clinical record, in whole or in part, the chairperson shall notify the requestor of his or her right to seek judicial review of the facility's determination pursuant to section 33.16 of the Mental Hygiene Law.

(11) An agency/residential facility, and the sponsoring agency of a family care home, shall:

(i) help ensure that each adult person who formulates a health care proxy while residing at the facility does so voluntarily and without duress; and

(ii) if provided with a person's duly executed health care proxy, ensure that the health care proxy or a copy thereof, becomes part of the medical portion of that person's clinical record; and

(iii) if, for any reason, is of the opinion or has brought to its attention, that there is reason to believe that a person did not understand the nature and consequences of a health care proxy and/or did not execute a health care proxy willingly and free from duress, bring this to the attention of MHLS; or take action as set forth in section 633.20(a) (21) and (22) of 14 NYCRR.

(12) There shall be a means to advise individuals and/or and their parents, guardians or correspondents, on admission and as changes occur, of the availability of the following parties to receive complaints and concerns, with current addresses and telephone numbers:

(i) The director of the DDRO.

(ii) The commissioner of OPWDD.

(iii) The Justice Center for the Protection of People with Special Needs (see glossary).

(iv) The Mental Hygiene Legal Service (see glossary), for developmental center residents and persons in the community on conditional release from developmental centers only.

(v) The board of visitors, for developmental center residents and persons in the community on conditional release from developmental centers only.

(vi) The commissioner or the Justice Center may be contacted at the following locations:

(a) Commissioner

Office for People With Developmental Disabilities

44 Holland Avenue Albany, NY 12229

(518) 473-1997

(b) Justice Center for the Protection of People with Special Needs
161 Delaware Avenue
Delmar, NY 12054
(518) 549-0200

(13) For those persons admitted to a facility prior to the implementation date of 14 NYCRR Part 633, the facility shall ensure that such required information is shared with the person and/or, parents, guardians or correspondents within a reasonable time frame, if the facility has not already done so.

(14) In developmental centers, a statement summarizing the rights, duties, and requirements regarding cardiopulmonary resuscitation is to be posted in a public place.

(15) Meeting the communication needs of non-English speaking persons seeking or receiving services.

(i) Section 13.09(e) of the Mental Hygiene Law requires the commissioner to promulgate regulations to address the communications needs of non-English speaking individuals seeking or receiving services in facilities operated, certified or funded by the Office for People With Developmental Disabilities. For the purposes of this paragraph, non-English speaking refers to persons who do not speak English well enough to be reasonably understood, persons who are deaf or hard-of-hearing, and persons without speech capacity who use alternative means of communication.

(a) No facility shall deny care and treatment to, or otherwise discriminate against, persons who are non-English speaking.

(b) Each facility shall facilitate access to services by persons who are non-English speaking when such persons seek, or are referred for services, and when such persons are in actual receipt of services.

(c) In addressing the communication needs of persons who are non-English speaking, each facility shall take reasonable steps to ensure that:

(1) the overall quality and level of services are equal to that made available to all other persons or referrals;

(2) necessary steps are taken to provide information in appropriate languages; (3) interpreters are provided in a timely manner when necessary for effective communication; and

(4) parties serving as interpreters are sufficiently competent to ensure effective communication. Such interpreters may include, but are not limited to, facility staff, community volunteers or contractors. In no event shall service recipients or their families be charged for the use of interpreter services.

(d) The clinical record for persons who are non-English speaking, shall identify any significant related effect on such persons' functioning and treatment, and identify associated recommendations for treatment including any reasonable accommodations. (e) The non-English speaking person's adult family member, significant other, correspondent, or advocate may serve as an interpreter for the person if he/she and his/her family member, significant other, correspondent or advocate agree to the arrangement, the arrangement is deemed clinically appropriate, and the parties have been informed of the option of using an alternative interpreter identified by the provider. Providers shall not condition service delivery on the use of family members or significant others as interpreters.

(ii) Effective communication with non-English speaking persons shall be provided in accordance with Title VI of the Civil Rights Act of 1964 (42 USC 2000d). Said law is published by the West Publishing Company, St. Paul, Minnesota and is available for review at:

(a) the Department of State, Office of Information Services, 41 State Street, Albany, NY 12231; and

(b) the Office for People With Developmental Disabilities, Office of Counsel, 44 Holland Avenue, Albany, NY 12229.

(iii) Effective communication with persons who are deaf or hard-of-hearing shall be provided in accordance with the Americans with Disabilities Act of 1990 (Public Law 101-336). Said law is published by the West Publishing Company, St. Paul, Minnesota and is available for review at:

(a) the Department of State, Office of Information Services, 41 State Street, Albany, NY 12231; and

(b) the Office for People With Developmental Disabilities, Office of Counsel, 44 Holland Avenue, Albany, NY 12229.

Any variation between this notice and 14 NYCRR 633.4 shall be controlled by the regulation. If you are a resident of an Intermediate Care Facility (ICF) as defined under federal regulation you are entitled to additional rights pursuant to applicable federal regulations such as 42 CFR Part 483.10.

