

**ARC of Rockland
25 Hemlock Drive
Congers, New York 10920
(845) 267-2500**

THE RIGHTS OF EACH INDIVIDUAL PROVIDED SERVICE

1. No person shall be deprived of any civil or legal right solely because of a diagnosis of developmental disability.
2. Everyone shall be given respect and dignity 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. There shall be no discrimination for these or any other reasons. Our agency shall not deny care and treatment to, or otherwise discriminate against, persons who are non-English speaking, deaf or hard-of-hearing.
3. The rights set forth in this document 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 needs of certain persons with the most severe handicaps and/or persons whose need for protection, safety, and health care will justify such adaptation. It is the responsibility of ARC of Rockland to ensure that persons' 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. For a person who has had limitations placed on any rights, there will be documentation in the persons' plan of services as to the clinical justification and the specific period of time the limitation is to remain in effect.

4. No person shall be denied:
 - (i) a safe and sanitary environment;
 - (ii) freedom from physical or psychological abuse;
 - (iii) freedom from corporal punishment;
 - (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 14 NYCRR 633.19;

5. Under the auspice of Federal Regulation (CMS-2249 F/2296 F), through provision of Home and Community Based Waiver 1915(c), ARC of Rockland is required to adhere to guidelines related the Person-Centered Planning Process and Settings to ensure protection of individuals' rights. These guidelines include the following:
 - (i) The individual will lead the person-centered planning process where possible. The individual's representative should have a participatory role, as needed and as defined by the individual, unless state law confers decision-making authority to the legal representative.
 - (ii) The person-centered planning process:
 - (a) includes people chosen by the individual
 - (b) provides necessary information and support to ensure that the individual directs the process to the maximum extent possible, and is enabled to make informed choices and decisions.
 - (c) is timely and occurs at times and locations of convenience to the individual.
 - (d) reflects cultural considerations of the individual and is conducted by providing information in plain English and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient.

- (e) includes strategies for solving conflict or disagreement within the process, including clear conflict-of-interest guidelines for all planning participants.
 - (f) Providers of HCBS for the individual, or those who have an interest in or are employed by a provider of HCBS for the individual must not provide case management or develop the person-centered service plan, except when the state demonstrates that the only willing and qualified entity to provide case management and/or develop person-centered service plan in a geographic area also provides HCBS. In these cases, the state must devise conflict of interest protections including separation of entity and provider functions within provider entities, which must be approved by CMS. Individuals must be provided with a clear and accessible alternative dispute resolution process.
 - (g) offers informed choices to the individual regarding services and supports they receive and from whom.
 - (h) includes a method for the individual to request updates to the plan, as needed
 - (i) records the alternative home and community based settings that were considered by the individual.
- (iii) The Person-Centered Service plan must reflect the services and supports that are important for the individual to meet the needs identified through an assessment of functional need, as well as what is important to the individual with regard to preferences for the delivery of such services and supports.

Commensurate with the level of need of the individual, and the scope of services and supports available under the state's 1915(c) HCBS waiver:

- (a) must reflect that the setting in which the individual resides is chosen by the individual. The state must ensure that the setting chosen by the individual is integrated in, and supports full access of individual receiving services Medicaid HCBS to the greater community, including opportunities to seek employment, and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individual not receiving Medicaid HCBS.
- (b) must reflect the individual's strengths and preferences

- (c) must reflect clinical and support needs as identified through as assessment of functional need
 - (d) must include individually identified goals and desired outcomes
 - (e) must reflect the services and supports (paid and unpaid) that will assist the individual to achieve identified goals, and the providers of those services and supports, including natural supports. Natural supports are unpaid supports that are provided voluntarily to the individual in lieu of 1915(c) HCBS waiver services and supports.
 - (f) must reflect risk factors and measures in place to minimize them, including individualized back-up plans and strategies.
 - (g) must be understandable to the individual receiving services and supports, and the individuals important in supporting him or her, at a minimum, consistent with sub-parts 9 and 10 of this document.
 - (h) must identify the individual and/or entity responsible for monitoring of the plan.
 - (i) must be finalized and agreed to, with the informed consent of the individual in writing, and signed by all individuals and providers responsible for its implementation.
 - (j) must be distributed to the individual and other people involved in the plan
 - (k) must include those services, the purpose or control of which the individual elects to self-direct.
 - (l) must prevent the provision of unnecessary or inappropriate services and
- (iv) If any modifications or limitations to an individual's rights are deemed clinically necessary, the person-centered written service plan must include:
- (a) identification of a specific and individual used assessed need.
 - (b) documentation of the positive interventions and supports used prior to any modifications to the person-centered service plan.

- (c) documentation of less intrusive methods of meeting the need that have been tried by did not work.
 - (d) a clear description of the condition that is directly proportionate to the specific assessed need.
 - (e) a regular collection and review of data to measure the ongoing effectiveness of the modification.
 - (f) established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.
 - (g) the informed consent of the individual
 - (h) as assurance that interventions and supports will cause no harm to the individual.
- (v) The person-centered service plan must be reviewed and revised upon reassessment of functional need as required, at least every 12 months, when the individual's circumstances or needs change significantly, or at the request of the individual.
- (vi) Based on the needs of the individual as indicated in their person-centered service plan, the Home and Community based settings must:
- (a) be integrated in and facilitate the individual's full access to the greater community including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS.
 - (b) be selected by the individual from among setting options including non-disability specific settings and an option for a private unit in a residential setting. The setting options are identified and document in the person-centered service plan and are based on the individual's needs, preferences, and for residential settings, resources available for room and board.
 - (c) ensure an individual's rights of privacy, dignity, and respect, and freedom from coercion and restraint.
 - (d) optimize, but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom they interact.

- (e) facilitate individual choice regarding services and supports, and who provides them.
- (vii) If a residential setting is provider-owned or controlled:
- (a) the unit or dwelling can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services, and the individual has, at minimum, the same responsibilities and protections from eviction that tenants have under the landlord/tenant law of the state, county, city, or other designated entity. For settings in which landlord tenant laws do not apply, the State must ensure that a lease, residency agreement or other form of written agreement will be in place for each HCBS participant, and that the document provides protections that address eviction process and appeals comparable to those provided under the jurisdiction's landlord tenant law.
 - (b) each individual has the right to privacy in their sleeping or living unit.
 - (c) units have entrance doors lockable by the individual, with only appropriate staff having keys to doors.
 - (d) individuals sharing units have a choice roommates in that setting.
 - (e) Individuals have the freedom to furnish and decorate their sleeping or living units within the lease or other agreement.
 - (f) Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time.
 - (g) Individuals are able to have visitors of their choosing at any time.
 - (h) The setting must be physically accessible to the individual.
- (viii) Certain types of facilities are not considered to be Home and Community based. These include:
- (a) Intermediate Care Facilities for individuals with intellectual disabilities.
 - (b) locations that have qualities of an institutional setting, or have an effect of isolating individuals receiving Medicaid

HCBS from the broader community of individuals not receiving Medicaid HCBS will be presumed to be a setting that has qualities of an institution unless deemed otherwise by the Federal or State government.

- (ix) Written individualized plan of services 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 are non-handicapped), and which enables him or her to live as independently as possible. This right also includes:
 - (a) the opportunity to lead the person-centered planning process where possible in the development and modification of an individualized plan of services, unless constrained by a 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 a person's capacity although some risk may be involved, and which takes into account his or her interests;
- (x) services, including assistance and guidance, from staff who are trained to administer services adequately, skillfully, safely, and humanely, with full respect for the person's dignity and personal integrity.
- (xi) appropriate and humane health care and the opportunity, to the extent possible, to have input either personally or through a 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.
- (xii) 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.
- (xiii) observance and participation in the religion of his or her choice, including the right of choice not to participate;
- (xiv) the opportunity to register and vote and the opportunity to participate in activities that educate him or her in civic responsibilities;
- (xv) 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 of who has been diagnosed as having HIV infection, AIDS or HIV-related illness;
- (xvi) 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;
- (xvii) 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;
- (xviii) 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.
- (xix) individually owned clothing which fits properly, is maintained properly, and is appropriate for age, season, and activity; and the opportunity to be involved in the selection of that clothing;
- (xx) adequate, individually owned grooming and personal hygiene supplies;
- (xxi) a reasonable degree of privacy in sleeping, bathing, and toileting areas;
- (xxii) a reasonable amount of safe, individual, accessible storage space for clothing and other personal belongings used on a day-to-day basis.
- (xxiii) the opportunity to request an alternative residential setting whether a new residence or change of room, and involvement in the decisions regarding such changes;
- (xxiv) the opportunity, either personally or through parent(s), guardian(s), or correspondent to express without fear of reprisal grievances, concerns,

and suggestions to the Service or Program Director, the Executive Director of ARC of Rockland, the Commissioner of OPWDD, the Commission on Quality of Care and Advocacy for Persons with Disabilities, the Mental Hygiene Legal Service and the board of visitors; and for people in developmental centers, the ombudsman;

- (xxv) 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
 - (xxvi) the opportunity to make, or have made in his or her behalf, an informed decision regarding cardiopulmonary resuscitation in accordance with the provisions of article 29-B of the Public Health Law, and any other applicable law or regulation;
 - (xxvii) the opportunity, if the person is residing in an OPWDD certified facility, to create a health care proxy in accordance with 14 NYCRR 633.20.
5. Implementation of many of the above rights entails inherent risks to persons. 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 and volunteers shall be advised of the previously listed rights.
7. None of the foregoing rights shall be limited for disciplinary (punishment) purposes, retribution or for the convenience of staff.
8. Pursuant to Section 33.16 of the Mental Hygiene Law, an individual, their guardian or other qualified party 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.

9. 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 when addressing persons who are non-English speaking, deaf or hard-of-hearing. ARC of Rockland has policies and procedures to implement this 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.

10. ARC of Rockland shall meet the communication needs of non-English speaking persons seeking or receiving services. 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 communication.
 - a) The agency shall not deny care and treatment to, or otherwise discriminate against, persons who are non-English speaking.
 - b) The agency 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, deaf or hard-of-hearing, ARC of Rockland will take reasonable steps to ensure that:
 - (i) the overall quality and level of services are equal to that made available to all other persons or referrals;
 - (ii) necessary steps are taken to provide information in appropriate languages;
 - (iii) interpreters are provided in a timely manner when necessary for effective communication;
 - (iv) 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.

The clinical record for persons who are non-English speaking, shall identify any significant related effect or such persons' functioning and treatment, and identify associated recommendations for treatment including any reasonable accommodations.

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.

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).

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).

11. Individuals provided case management by ARC of Rockland have a right to choose their service coordinator. They have a right to elect to terminate the services of the service coordinator at any time. ARC of Rockland encourages individuals, their family members or guardians to speak with a supervisor if any such concerns have been generated. If an individual wishes to have service coordination rendered through another provider, then ARC of Rockland offers assistance in the matter.
12. An individual or his or her parent(s) or correspondent(s) may object to the application, adaptation or denial of any of the previously stated rights made on his or her behalf in accordance with the agency rights grievance procedure.
13. ARC of Rockland will:
 - (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 The Mental Hygiene Legal Service; or take action as set forth in 14 NYCRR 633.20(a)(21) and (22).

14. Parents, guardians or correspondents are advised 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 Executive Director of ARC of Rockland
- (ii) The Director of Hudson Valley DDSO
- (iii) The Commissioner of OPWDD
- (iv) The Commission on Quality of Care and Advocacy for Persons with Disabilities
- (v) The Mental Hygiene Legal Service

These individuals may be contacted at the following locations:

Executive Director
ARC of Rockland
25 Hemlock Drive
Congers, NY 10920
(845) 267-2500

Director
Hudson Valley Developmental Disabilities Service Office
P.O. Box 470
Thiells, NY 10984
(845) 947-1000

Commissioner Office of Mental Retardation and
Developmental Disabilities
44 Holland Avenue
Albany, NY 12229
(518) 473-1997

Commission on Quality of Care
And Advocacy for Persons with Disabilities
410 State Street
Schenectady, NY 12306-2379
(518) 488-12281

Mental Hygiene Legal Service
140 Old Orangeburg Road
Building One
2nd Floor
Orangeburg, NY 10962
(845) 359-0606

You will be notified in writing of any amendments or changes occurring regarding a person's rights and responsibilities or of any changes in whom to notify with concerns.

GRIEVANCE PROCEDURE

Adult persons, parents, guardians or correspondents or the Mental Hygiene Legal Services may object to and appeal any part of a plan of services, proposed changes, other care and treatment issues with which they disagree, plans for placement or a proposal to discharge. This being the case, ARC of Rockland has instituted the following grievance procedure which has been listed in the order that the process should be followed:

STEP 1: An initial objection to a treatment issue should be brought to the attention of the ARC of Rockland staff member responsible for treatment planning for the individual in question. The most appropriate time to voice a concern is prior to or during a treatment plan meeting. The matter will be immediately addressed. If the problem is still not resolved, then contact should be made to the Service or Program Director to address the issue further.

STEP 2: If resolution cannot be reached on an informal basis, the objecting party is given the opportunity to submit a formal written objection to the Executive Director of ARC of Rockland. A meeting shall be scheduled with the Executive Director to address the objection. The Executive Director may choose to involve other members of ARC of Rockland in the discussion. Written confirmation of resolution or the inability to reach a resolution shall be sent to the objecting party by the Executive Director.

Step 3: If a resolution cannot be reached, the objecting party is given the opportunity to submit a formal written objection requesting a hearing to the Hudson Valley DDSO director. Within five days of receipt of a formal written objection, a hearing, to take place before a hearing officer, shall be scheduled, with no less than ten (10) days notice to the involved parties. A written decision by the hearing officer shall be sent to the involved parties within fourteen (14) days of that hearing.

Step 4: If any party to the proceeding is not satisfied with the decision, it may be appealed within ten days to the commissioner of OPWDD who will issue a final written decision to all parties within fourteen days of receipt of the appeal. The commissioner of OPWDD may, at his or her discretion, send the matter back to the hearing officer for further review.

Step 5: The commissioner of OPWDD's decision is the final administrative remedy available and may be appealed in accordance with the provisions of Article 78 of the Civil Practice Laws and Rules.

No person shall be denied the opportunity to participate (including the use of interpreters for non-English speaking persons) in any hearings related to the objection of any plan or part thereof or proposed changes thereto, other care and treatment, plans for placement, or a proposal initiated by the agency/facility to discharge.

GRIEVANCE PROCEDURE

continued...

During the period that an objection is undergoing administrative review, a person shall participate in programming mutually agreeable to the objecting party, the service provider, the person and his or her parent, guardian or correspondent. Every effort feasible shall be made to maintain the person in at least his or her current level of programming. However, to protect a person's health, safety, or welfare or the health, safety, or welfare of others, nothing herein shall preclude a change in programming for, or the relocation or discharge of a person. While an objection to placement or discharge is undergoing administrative review, relocation or discharge shall only take place with the commissioner's approval.