

POLICY STATEMENT: Rights of Persons Served

Adopted by the Board of Directors 05/28/2015

People with disabilities are afforded the same rights as other citizens. Rights include basic protections and citizen guarantees as outlined in the US Constitution, the US Bill of Rights, the Universal Declaration of Human Rights, and local, state and federal laws. It is the policy of Open Options UCP to respect, protect, and promote the rights of people we support, and to advance this commitment through the delivery of services and supports. In all of our interactions with persons served and stakeholders we will strive to promote their interdependence and self-determination. Minimally, promoting people's rights is comprised of respecting individual preference and choices, and providing assistance to people in exercising their rights. Protecting rights includes responding when individual rights are ignored or infringed upon. Exercising rights is a function of personal choice and individuals may decide not to exercise certain rights. Restricting freedoms or rights should be a last resort and only as a matter of protection of individuals, not as a means of enforcing consequences, punishment, or for the purpose of changing behavior.

All rights detailed by state statute and policy, and by the policies of Open Options UCP, shall be communicated to persons served in meaningful ways at the beginning of services and at least annually. Information about rights, including training and education, shall be made available to persons served and employees on a routine basis. Procedures will address the rights to confidentiality, privacy, freedom from abuse and mistreatment, freedom from retaliation, informed consent, access to outside representation, and investigation of alleged infringements on rights.

All persons served, including his/her guardian, family member or advocate, are entitled to informal and formal methods of complaint or grievance. The procedures shall ensure adherence to an appropriate process with levels of review and defined timelines. Certain rights may be subject to limitation only if exercise of a right is inconsistent with a person served's health, safety or general well-being. Procedures shall clearly delineate the approval process, length of limitations, appeal process, and the process of gaining informed consent.

PERSON SERVED RIGHTS

PROCEDURE - All Programs

All Open Options UCP employees and persons served will be educated on and receive information about individual rights. This will occur upon admission or hire and at least annually. Information will be made available in alternative formats as needed. All employees of the organization shall adhere to the following list of rights to ensure that no individuals will be discriminated against when receiving supports and services of the organization.

Each person served shall be entitled to the following rights:

1. To be treated with dignity as a human being; courteously and in a manner befitting and respecting his or her age.
2. To have the same legal rights and responsibilities as any other person unless otherwise limited by law.
3. To have the right to due process review when any limitation to rights is proposed or alleged to have taken place.
4. To give informed consent or refusal, and / or an expression of choice regarding types and manner of service delivery, release of information to others, use of additional or concurrent services, and involvement in research projects.
5. To receive services regardless of gender, race, creed, marital status, national origin, disability or age.
6. To be free from physical, verbal, mental and sexual abuse and neglect; to be free from financial exploitation; to be free from retaliation for reports or grievances.
7. To receive appropriate humane and high quality services and supports as determined by the person's support team, which may include, but not be limited to, the person, parents, guardian or authorized representative, and to give informed consent or refusal regarding the composition of the support team.
8. To receive these services and supports in the most integrated setting appropriate for the person's particular needs.
9. To have access to state rules, policies and procedures pertaining to services and supports; to have access to legal representation; to have access to advocacy support services.
10. To have access to personal records, including information needed to make decisions

in sufficient time to facilitate decision-making.

11. To have personal records maintained confidentially.
12. To personal privacy within one's own home and where receiving services.
13. To have services, supports and personal records explained so that they are easily understood.
14. To a fair and impartial investigation and resolution of alleged infringement of rights.

Employee and Person Served Training

Employees will receive training in individual rights at new-hire orientation and through periodic training thereafter. Persons served will receive information about their rights at the time of admission and rights will be reviewed with them at least annually. Identified training needs (when additional instruction is indicated) should be included in the individual's person centered plan.

Progression of Intervention

Open Options UCP will support individuals without limitations in their actions as often as possible. At times individual's actions are such that there is the potential of harm to themselves or others and intervention is needed. When this is necessary, the support team will thoroughly assess the situation to determine alternatives and first use non-invasive methods. If those are not effective or the situation is too serious to start there, some limitations or restrictions may need to be put in place.

Any time a limitation or restriction is determined necessary by the team, the least restrictive measure for the situation will be attempted. If less invasive procedures are ineffective, as necessary to protect individuals, more intrusive measures will be used. Restrictions are often a short-term measure until other supports can be put in place for the individual.

Risk

Open Options UCP respects persons served by providing them support in opportunities to make choices, take chances and make mistakes. The world is not inherently safe and secure and there is some degree of risk in all activities. While limiting individuals from engaging in situations of perceived risk may keep them safe, it also limits their ability to learn and

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experience all that life offers. As service providers, there can be a fine line between allowing for risk and inaction, which may be seen as neglect. To assist the support team in making these determinations, a Risk Assessment shall be completed for activities a person served may desire for which there are safety concerns. The risk assessment will address the following:

- What does the person want to do?
- Describe the person's history of decision-making.
- Describe the possible short and long-term consequences if the person engages in the desired activity.
- Describe the possible short and long-term consequences if the person has limitations or restrictions put in place.
- Describe the support and safeguards that could be set in place to protect the person.

From the gathered information, the support team will weigh the benefits and risk, consider possible safeguards and come to a conclusion which may be:

- Accept the person's decision to engage in the activity.
- Add training, support or safeguards and the person continues with activity.
- Activity will be limited in some way.
- Activity will be restricted for the individual.

If the support team decides to limit or restrict the person's activity in any way, the Risk Assessment and team decision will be reviewed by the Human Rights Committee.

Limitations on Rights

Due to a developmental disability and/or psychiatric conditions, some individuals experience greater personal challenges that may negatively impact their well-being or that of others. They may engage in activities or behaviors that are not preferred lifestyle choices, but are detrimental to themselves or others and are often a result of mental health conditions. In these situations, the safety of everyone involved is the main purpose of limiting the behavior. Limiting a behavior may involve:

- Encouraging (using non-physical and/or physical interaction to transition from one place to another)
- Guiding (using non-physical and/or physical interaction to assist someone to transition from one place to another)
- Assisting (having the person hold on to staff and/or staff physically holding on the

person to steady and support him/her while standing or walking to keep him/her from falling or slipping. The person doing the assisting follows the lead of the person being assisted. The person must be released when he/she no longer needs the physical assist).

- Supporting (providing physical assistance to help a person maintain his/her stance and balance, body mechanics, and body positioning).
- Avoiding (eluding, evading or escaping physical contact through the use of body positioning, shifting, stepping, sliding without making physical contact with the person).
- Redirecting or deflecting (while avoiding, using the hand and/or arm to make physical contact without holding on to the person)
- Releasing (removing someone or something from a physical hold; this may involve holding on briefly to the hand and forearm, just above the wrist, of the person).
- Restraining (limiting and redirecting, but not immobilizing, a person who has engaged in a behavior that is harmful to him/herself and/or others).

Unplanned Limitations A short-term limitation of exercise of a right can be established by an employee if they determine that exercise of that right poses an immediate threat to the health and safety of the person served or others. Before any type of restrictive intervention is used, the threat level of the situation must be assessed. Just because a person is threatening harm to him/herself or others does not mean she/he poses an immediate risk. If an individual is engaging in threatening behavior, three questions must be asked:

- 1) Is there a real (believable) threat to harm to self or others?
- 2) Is the person capable of carrying out the threat of harm?
- 3) Is the threat of harm immediate?

If these questions are all answered “yes,” an employee may need to intervene with a physical interaction, defined as the use of a physical presence, skill, maneuver, or technique to either assist or limit a person’s behavior.

After the threat of harm is over, the employee shall call his or her supervisor to discuss the situation and make a decision of the continuance of the limitation. Such limitation shall be documented in the Progress Notes of the case record and an event report shall be written. The support team must confer as soon as possible (ideally the next business day) to formulate a plan for the situation should it occur again and an addendum to the person-centered plan will be written.

Longer-term limitations may be required when it is determined by the support team that exercise of the right is inconsistent with the individual's well-being. Rights and personal freedoms shall not be unduly limited. When necessary to ensure health, safety and welfare, support team recommendations of limitations shall be subjected to careful review through a Human Rights Committee. If approved, such extended limitation shall be identified and documented as to onset and rationale in the Person Centered Plan. If the period of time is not defined, restoration of the right shall be reviewed at least yearly at the annual person centered plan meeting, and continued limitation must be agreed to by the majority of the team. At least annually, the Human Rights Committee must also review the rights restriction to ensure due process is in place.

Restoration

Generally, restrictions on the exercise of rights or freedoms as a means of limiting risk or ensuring safety of individuals is for a defined amount of time. Each restrictive plan that is in place will also have an outline of the means by which a person will regain that right. In rare instances, restoration of particular rights might be contra-indicated. On a monthly basis, the rights restriction and the corresponding data collected shall be reviewed by the Quality Enhancement Coordinator to monitor progress towards meeting the stated criteria for rights restoration. When an individual meets criteria for rights restoration, the Quality Enhancement Coordinator shall submit the documentation to the HRC chairperson so it may be reviewed at the next Human Rights Committee meeting.

Informed Consent

All limitations will be discussed with individuals and guardians and a specific consent form will be developed with signatures from the individual, guardian, Open Options UCP representative and Support Coordinator, to be presented to the Human Rights Committee.

Human Rights Committee

In keeping with continuous efforts to ensure the rights and dignity of persons served, a Human Rights Committee is established.

In addition to the information stated, the Human Rights Committee of Open Options UCP is subject to all guidelines and protocols indicated in the Division of Developmental Disabilities

directive dated 02/01/2013 titled “Human Rights Committee.” This directive as well as updates can be found by accessing: dmh.mo.gov/docs/dd/directives

Committee Structure – the Human Rights Committee will consist of members who are not employees of Open Options UCP or membership as specified by state regulations. Committee members will be appointed by the Human Rights Committee Chairperson, or designee, and be asked to serve at least a one-year term. Minutes shall be kept of all Human Rights Committee meetings. Open Options UCP will assure that each committee member is given training in the duties and responsibilities of the committee, Open Options UCP’s mission and values, applicable regulations, policies (e.g. behavior support, rights, abuse/neglect, confidentiality, PWS-specific supports, etc.) and procedures.

Duties of members shall include:

- To attend meetings regularly
- To participate in discussions and decision making
- To keep confidential all business discussed
- To fulfill duties as described under Committee Functions

Committee Functions – The committee will review, approve, and monitor all policies, procedures, programs, or practices that may adversely affect the rights and dignity of any person supported by Open Options UCP. Specific committee functions include:

- 1) Review prior to implementation, approve, and monitor behavior support and other programs and interventions that include restrictions of any kind (i.e. physical restraint, psychoactive medications, consequences, etc.) to ensure that:
 - a. Appropriate less restrictive methods have proven ineffective (must be documented as tried and failed)
 - b. Routine monitoring and evaluation of the program/intervention is occurring
- 2) Ensure that all programs, restrictions, and interventions are implemented only with the written informed consent of the individual, parents (if the individual is a minor), or guardian (if the individual has been adjudicated incompetent and appointed a guardian).
- 3) Review the frequency and reasons for the use of emergency restraints.
- 4) Review all individual rights restrictions to ensure:
 - a. The reason for the restriction is clear
 - b. It is time-limited
 - c. Signed, informed consent has been obtained
 - d. There is a plan for rights restoration
- 5) Review investigation reports of alleged incidents of mistreatment, abuse, neglect, or exploitation to ensure that appropriate actions have been taken by Open Options UCP. At least one time per year, examine accumulated data on incidents and examine for trends.

6) Assure Open Options UCP engages in proactive activities that promote and protect people's rights.

Member Requirements

Individuals wishing to serve as a Human Rights committee member must complete the following trainings:

- Abuse and Neglect Module (includes annual recertification)
- Individual Rights Module
- Confidentiality and HIPAA Module
- Meaningful Life, Quality Outcomes Module
- Prader-Willi Syndrome Module
- Positive Behavior Support Module (includes annual recertification)
- Procedure for Referral to DMH Office of Constituent Services

The Committee Chairperson is expected to also acquire and provide training as needed to committee members.

Meeting Frequency and Notifications

The Human Rights Committee Chairperson is responsible for scheduling committee meetings no less than monthly. The chairperson will notify the respective Support Coordinators as well as the designated Kansas City Regional Center personnel of scheduled committee meetings. The respective Support Coordinators are then responsible for notifying any other parties.

Meeting Structure

The membership of the committee is a minimum of five members with at least one of those being an individual who is not in a business relationship with Open Options UCP. A quorum is established by a minimum of five attendees including one attendee not in a business relationship with Open Options UCP. In addition to standing members, other attendees may be asked to attend the meeting at the request of the guardian or person served. These persons may include Support Coordinators, other family members, an external advocate, and ideally a self-advocate. Kansas City Regional Office personnel may also attend committee meetings to provide feedback and input as well as to ensure the committee's fidelity to Division of DD Directives.

Meeting Agenda

Human Rights Committee meetings will have a standard agenda that will include the following items:

- 1) Old Business: Review of any outstanding items or plans of action requested from previous meetings. This may include the status of overdue reviews or individuals who have met criteria for reducing or eliminating a restriction prior to their scheduled HRC review date.
- 2) Rights Restrictions Review: Review of submission forms for behavior support and/or other programs and interventions that include restrictions of any kind (i.e. physical restraint, psychoactive medications, consequences, etc.). This review is conducted to ensure all required information is obtained. For any potential rights restrictions, this information must provide adequate documentation addressing the following:
 - a. What is the specific restriction being submitted for review? [Clearly define the behavior for which the rights restriction is being proposed, including the frequency and severity. Clearly define and delineate the proposed intrusive method/restriction to be put in place, including when and where the restriction is to be present – i.e. what are the conditions under which it is implemented?]
 - b. What is the reason for this restriction? [Provide support documentation for the need for this restriction. Does the severity of the behavior put the individual or others at risk? Does the severity of the behavior outweigh the risk of the proposed intrusive intervention? What are the possible short term and long term consequences if this restriction was not put in place? What is the expected outcome from placing the restriction in place?]
 - c. Is the proposed rights restriction the least restrictive alternative? [Provide documentation of less intrusive methods that have been used and shown to be ineffective.]
 - d. What is the training component that teaches the person the skills they will need so the restriction will no longer be needed? [What are the strategies to address the behavior(s) related to the risk and proposed restriction?]

- e. What is the plan for the collection of targeted behavior data to monitor the effectiveness of the proposed restriction/medication? [Clearly define all data collection systems to be used, and who will be monitoring them.]
- f. What plan is in place to remove this restriction in the future? [What is the criterion for reducing/eliminating the restriction?]
- g. How will staff and the support team be trained on the restriction(s) and safety/protection from harm?

For proposed psychotropic medications, this information must provide adequate documentation addressing the following:

- h. What is the specific reason for the medication? [Clearly define the behavior and diagnosis which the medication is targeting, including the frequency and severity].
- i. What is the expected outcome or intended benefits for the individual taking this medication?
- j. Is the proposed rights restriction the least restrictive alternative? [Provide documentation of less intrusive methods/medications or alternatives that have been used and shown to be ineffective. Is the medication at its lowest effective dose? What is the recommended dosage range?]
- k. What is the training component that teaches the person the skills they will need so the medication will no longer be needed? [What are the strategies to address the behavior(s) related to the risk and proposed restriction?]
- l. What is the plan for the collection of targeted behavior data to monitor the effectiveness of the proposed restriction/medication? [Clearly define all data collection systems to be used, what behavior(s) will be documented, and who will be monitoring them.]

- m. What plan is in place to remove this restriction in the future? [What is the criterion for reducing/eliminating the medication?]
 - n. What are potential side effects to this medication?
 - o. What are potential drug reactions when combining this medication with prescription and nonprescription medications, including alcohol, tobacco, caffeine, illicit drugs, and alternative medications?
- 3) Emergency Restraints: Review of the frequency and reasons for the use of emergency restraints. This review is conducted to ensure any use of emergency restraints or unplanned restrictive interventions were warranted and implemented based on the targeted behavior posing an imminent and immediate health and safety risk to the person served or others. The team may also wish to discuss whether this intervention is potentially ongoing and thus a plan must be formalized and submitted to the committee for review prior to implementation.
- 4) Event Report Data: Review of event report data, including the Event Report Analysis and Follow-up data for the previous month, as well as the Event Report Tracking by location. This review is completed to ensure events that involve potential rights restriction are managed in an appropriate manner, per the supports indicated in the respective individual's support plan, and in accordance with the best practices indicated in the Positive Behavior Support curriculum and Mandt system. Specific feedback or concerns regarding events are to be communicated in writing by the Human Rights Committee Chairperson to the appropriate Program Director. In some cases, a plan of action may be requested documented the completion of any requested follow-up.
- 5) ANE Data: Review of investigation reports of alleged incidents of mistreatment, abuse, neglect, or exploitation. This review is conducted to ensure that appropriate actions have been taken by Open Options UCP, including but not limited to the following checklist items:
- a. Alleged perpetrator was placed on leave
 - b. Alleged victim was given appropriate medical attention

- c. Alleged victim was protected from further harm
- d. Was the inquiry/investigation initiated within 24 hours?
- e. Event report completed?
- f. Appropriate agencies notified of incident and that inquiry is being conducted?
- g. If alleged sexual abuse, abuse or neglect resulting in physical injury, or misuse of property or funds, or the absence or theft of a controlled substance is suspected, was law enforcement notified?
- h. If injuries were alleged, were they observed by the investigator(s) and photographed?
- i. Was the reporter interviewed?
- j. Was the alleged victim interviewed?
- k. Were all possible witnesses interviewed (including persons served)?
- l. Was the alleged perpetrator interviewed?
- m. Were written statements obtained after interviews?
- n. Was all relevant documentation reviewed (work schedules, staff schedules, event reports, progress notes, etc.)?
- o. Is the summary fair, objective, and clear?
- p. Was the incident inquiry/investigation completed within 5 business days of the alleged incident?
- q. If not completed within 5 business days, was a status report given to the President/CEO with a revised target date of completion?
- r. Are the findings and conclusions provided?
- s. Are recommendations made?
- t. Are the recommendations and responses completed and documented?
- u. Were the appropriate parties notified of the inquiry/investigation outcome and follow-up?

At least one time per year, the committee will examine accumulated data on incidents and examine for trends. Any noted concerns or issues are to be communicated in writing to the President/CEO or Senior Vice President/CFO within 3 business days of the committee meeting.

Meeting Minutes

The chairperson or designee is responsible for maintaining meeting minutes that accurately reflect the members present, names of additional meeting participants, a record of decisions

and recommendations that readily identifies the issues reviewed, the decisions reached, and the follow-up that is necessary. Following each meeting, the HRC chairperson will send meeting minutes to the designated Kansas City Regional Center personnel for their review. Meeting minutes are kept in a locked, confidential location at the Open Options UCP administrative office and maintained by the committee chairperson.

Referral

A written/verbal request can be submitted by the person served, family member, guardian, committees, interdisciplinary teams where possible limitations or restrictions are being proposed or implemented. Requests can also be submitted to the Kansas City Regional Center Human Rights Committee. To initiate a review by Open Options UCP's Human Rights Committee, the Quality Enhancement Coordinator and/or Support Coordinator will submit the appropriate paperwork to the Committee Chairperson, which may include the following:

- HRC Submission Form - Psychotropic Medication
- HRC Submission Form – Rights Restriction
- Medication Administration Assessment
- Money Management Assessment

It is important to note that prior to submission to the Human Rights Committee, the rights restriction (s) must be reviewed by the person's support team and agreed upon (as documented on the informed consent section of the Submission form). Unless an emergency approval is sought, reviews and referrals are reviewed on a scheduled basis. This schedule has all assessments used in the person centered planning process completed three months prior to the individual's implementation date. Any rights restrictions are reviewed by the Human Rights Committee two months prior to the individual's implementation date. Referrals to the Human Rights Committee will be reviewed and completed within 30 working days from the submission of the referral. If the review is not completed within this timeline, the chairperson will document the reason in writing, including a potential justification for why the review timeline has been extended. When requested documents have not been received to meet timeline, the HRC chairperson will contact the person responsible and/or his or her supervisor to establish a new due date.

The Human Rights Committee Chairperson may assign specific committee members to review prior to the meeting specific submission forms or data for this committee member to then present to the committee. This review prior to the meeting is done to ensure adequate time for a thorough review by at least one third-party prior to the discussion that occurs within the Human Rights Committee monthly meeting.

Approval

The committee shall discuss the proposed restriction using provided guidelines and will vote on the use of the restrictive intervention. The committee may vote to approve or not approve the plan. They may also request more information, suggest alternatives to the proposal or approve the proposal with some revision. The committee will then decide how often the restriction shall be reviewed, which shall not exceed one year. A majority vote rules. In the case of a tie, the votes of the majority non-Open Options UCP employees will prevail. Documentation of the review and approval will be sent to the Support Coordinator, guardian, and a hard copy filed in the individual's Case Record book.

Emergency Approval

In an emergency where there is imminent danger or potential harm to an individual or other persons, qualified staff may limit or restrict rights to prevent harm to the individual or others. Examples of situations warranting potential limitation or restriction of rights would include:

- An individual is engaging in a behavior that poses an imminent and immediate threat to harm to him/herself
- An individual is engaging in a behavior that poses an imminent and immediate threat to harm to others

(Limitation/restriction of individual rights must follow the process of reporting as outlined in 9 CSR 105.206 (community services). This must be reported to supervisory personnel as soon as is practical following the event. Any continuation (two or more times) of the restriction must be reviewed. When the Human Rights Committee cannot meet before approval is needed, the Quality Enhancement Coordinator or designee will ensure individual/guardian approval, ensure the Support Coordinator is in agreement and contact at least two Committee members for conditional written approval. Once obtained, the restrictive procedure can be established until the next scheduled Committee meeting, where it will be resubmitted for full review.

Appeal

A person served, family member, guardian, or other support team member may appeal any limitation imposed through the grievance process. Family members, guardians, or other support team members may initiate a formal appeal by contacting the Human Rights Committee chairperson either through email or phone or may also choose to initiate the grievance by contacting the QE Team or Human Rights Committee personnel at the Kansas City Regional Office. Any staff member receiving a grievance from a person served involving a limitation on rights must provide prompt support or assistance in initiating the grievance procedure. For specific information on the grievance procedure, refer to Open Options UCP Policy and Procedure Manual Section E. Rights of Persons Served/Persons Served Grievances.

If an individual so chooses, an appeal can also be initiated by contacting the Kansas City Regional Center Quality Enhancement department or the Kansas City Regional Center Human Rights Committee.

Investigation of Alleged Infringement of Rights

Any employee observing or receiving a report regarding the violation of a person served's rights that has not been through due process, shall report the situation immediately to the supervisor of the location (or directly to the Program Director if the supervisor is not the appropriate person to receive the report.) An Event Report shall be completed by the employee. The supervisor shall conduct preliminary fact-finding and report the situation to the Program Director. For situations involving a disagreement between two (or more) persons served, the supervisor or designated staff may mediate the disagreement, referring the involved persons served to the grievance procedure if resolution cannot be achieved.

In situations in which it is observed or suspected that an employee (or any member of the organization's workforce) has violated the rights of a person served, the Director of Community Living and/or Division Director shall designate corrective action to be taken. Corrective action may include, but is not limited to, counseling/retraining the involved employee, disciplinary action, suspension and/or termination.

Any employee who engages in repetitive or deliberate violation of a person served's rights, or who fails to promptly report a violation of rights, shall be subject to disciplinary action, including immediate termination.

There shall be no reprisal or retaliation against any employee or person served who makes a report in good faith regarding an alleged infringement of consumer rights. Any employee who threatens or takes action of retaliation against any employee or person served shall be subject to disciplinary action, up to and including termination.

PROCEDURE: Specific Ongoing Limitations for Persons with a Diagnosis of Prader-Willi Syndrome

In keeping with specific program goals and needs of persons served with Prader-Willi Syndrome, limitations on certain rights of all person served in this program may be imposed for the protection of all persons served. Persons served and their families shall be informed of these limitations at the time of admission. Refer to Section J. of this Policy and Procedure Manual.

POLICY STATEMENT: Stakeholder Input

Adopted by the Board of Directors 05/28/2015

It is the policy of Open Options UCP to obtain input on an ongoing basis from persons served, family members of persons served, employees, and other stakeholders. Open Options UCP considers the input and involvement of those persons served, and of stakeholders representing the interests of the person served, necessary to determine if the organization is fulfilling its mission or to determine if improvement, revision, or changes to the programs should be initiated. This input may be gathered through, but not be limited to the following mechanisms:

- a) representation on the Board of Directors by persons served and/or representatives, and representation on various committee and task forces assembled,
- b) periodic surveys of persons served and other stakeholders,
- c) person served involvement in the development of individual programs,
- d) solicitation of stakeholder input for program evaluation and planning,
- e) suggestions from persons served meetings, staff meetings, and other stakeholder forums, and
- f) persons served grievances, and/or summaries thereof.

Stakeholder input shall be utilized in ongoing processes for quality improvement, including but not limited to:

- a) strategic planning,
- b) development and revision of person centered plans, and
- c) ongoing evaluation and management of service delivery such as financial planning, resource planning, and performance improvement activities.

PERSON SERVED AND STAKEHOLDER INPUT

PROCEDURE - All Programs

In order to promote the self-determination of persons served, and to monitor and improve programs by gathering input from those served in an ongoing manner, the organization will utilize the following methods to involve those served and to recognize the importance of their input:

- Periodic persons served questionnaires regarding specific programs or services of the organization shall be conducted and shall be regarded as confidential, including “satisfaction surveys” reported in the Program Evaluation system.
- Formal and informal input from individual persons served, parents and/or guardians will be solicited regarding the program and services received from the organization.
- Results of post-discharge follow-up will be reviewed by designated employees on an annual basis.
- Persons served or their representatives may be recommended for participation on the organization’s standing committees or ad-hoc committees. Persons served who request involvement shall be referred to the appropriate volunteer or employee for consideration, as well as ~~staff~~ employee recommendations for involvement.
- Persons served or their representatives shall be solicited to serve on the Board of Directors. Requests and/or recommendations shall be referred to the Executive or Leadership Development Committee.
- Procedures for responding to person served grievances shall be handled without prejudice.
- Persons served input for individualized planning shall be gathered prior to the planning meeting and during the meeting. Employees shall make efforts to ensure the participation of parents, relatives, and advocates in the planning process. The Support Coordinator or designated plan writer shall ensure input is incorporated into the total plan, including specific outcomes and action plans. The plan will be reviewed with the person served at least four times per year and his/her input shall be recorded.
- The persons served’s right to be involved in his/her care, treatment, and habilitation shall be communicated at the time of admission and employee violation of this right shall be sanctioned as described in Personnel Policies.

- Persons served meetings shall be convened at least twice per year. Employees in attendance shall solicit feedback, ideas, grievances and solutions. Records of each meeting shall be recorded and retained on file, and utilized in organizational planning efforts. Pertinent issues shall be communicated to the appropriate Division Director.
- Requests by stakeholders for services shall be encouraged. Stakeholders may submit verbally or in writing their ideas for programs, services, events, and organizational expansion. Suggestions will be reviewed by the appropriate party with verbal or written response given to the person making the suggestion.

PERSONS SERVED MEETINGS

PROCEDURE - All Programs

Meetings should be planned in advance with proper notice given to persons served. Meetings shall be held at times and locations convenient to the majority of persons served involved. Locations should be accessible with consideration given to architectural accessibility and transportation needs of persons served. Whenever possible, additional accommodations or alternative presentation formats will be made available upon request.

Notes shall be kept of all persons served meetings and pertinent feedback shall be provided to management.

PROCEDURE - Community Living programs

In locations serving three or more persons, it is recommended that residents of the home participate in regular meetings of the household. Such meetings may be held formally or informally and provide an opportunity for persons served to engage in self-determination and self-advocacy.

Whenever possible, decisions and commitments should be kept in written notes. Pertinent feedback should be provided to management in a timely manner.

PERSON SERVED GRIEVANCES

PROCEDURE - All Programs

Any person served, legal guardian, relative, or advocate of a person served who has a complaint, grievance, or concern regarding treatment, living conditions, employee interaction,

other persons served, and/or perceived violation of rights may pursue a formal resolution of the complaint. Individuals who wish to appeal a decision made by the organization may request a review of the decision.

1. An informal discussion about the grievance, concern, or decision will occur with the appropriate members of the support team. If this discussion does not resolve the situation, the following steps will be followed.

2. Request a private meeting or discussion with a member of the respective program management. This request may be given verbally or in writing. Grievance forms may be used, but use of the specific form is not required to initiate the grievance process.

3. A meeting or discussion will be scheduled promptly to review and resolve the grievance.

4. If resolution or satisfaction is not reached as a result of the initial meeting/discussion, the Director of Quality Enhancement may request to meet with the person served, employee, and/or others involved. The Director of Quality Enhancement or designee shall prepare a brief written summary of the grievance (if not yet written) and make a copy available to involved parties within five working days. Within ten days of receipt of the grievance, the Director of Quality Enhancement shall render a written resolution. The resolution does not have to contain an assignment of blame, but at least should outline instructions to involved parties as to how to avoid similar concerns in the future.

5. If the resolution is not to the persons served's satisfaction, he/she may request that the grievance be reviewed by an ad-hoc committee. The request for committee review must be made within ten working days after receipt of the written resolution. The ad-hoc committee shall be appointed by the Director of Community Living and shall consist of a non-involved person served and employee from another Open Options UCP program/location, and a non-involved administrative employee. The committee will meet with the aggrieved person served within ten working days of receiving the request, and will present a written judgment within five working days of the meeting. The person served has the right to be accompanied in the meeting by an advocate, including a Support Coordinator, employee of Missouri Protection and Advocacy, or friend / family member. This right shall be communicated to the person served when the ad-hoc committee is requested, and contact information for outside resources will be provided along with whatever assistance is needed to make the contact. The committee's judgment is final.

All documentation involving grievances and resolutions shall be kept in a confidential file in the Administrative Office. The file will be reviewed annually, deleting names of specific individuals involved, for analysis of trends.

The act of filing a grievance or appeal shall not result in any form of retaliation or barriers to services.

It is the responsibility of all employees to be aware of the grievance procedure and to refer any persons served to this procedure when resolution or satisfaction cannot be reached on an informal basis. Employees are expected to assist the person served in utilizing these procedures and/or to refer the persons served to an available advocate if one is needed. Disciplinary action up to and including termination shall be instituted against any employee who discourages or prevents a person served from filing a grievance, who fails to inform a person served of the procedures when a grievance filing may be appropriate, or who engages in any form of retaliation in response to a grievance or appeal.

Information regarding the grievance procedure will be provided in an understandable format to persons served at the time of admission and will be reviewed annually. Employees will receive training regarding the grievance procedure at orientation and periodic training thereafter.

POLICY STATEMENT: Advocacy
Adopted by the Board of Directors 05/28/2015

It is the policy of Open Options UCP that advocacy services will be offered to or accessed for the persons served by the organization.

Advocacy in this context is speaking and/or acting on behalf of a person or family to ensure that legal and human rights are met. This includes the rights to education, property, community service, employment, social involvement and other necessities of life, medical and therapeutic care, as well as all the rights listed in our "Rights of Persons Served" policy and procedure.

Advocacy services may be delivered in the following manner:

1. Individual or case advocacy_- ensuring the persons served of their rights to appropriate services including access to information pertinent to informed choice and decision making.
2. Systems or class advocacy - seeking to change a policy or practice which affects those persons served by the organization.
3. Self advocacy – supporting, advising, and encouraging so as to enable the person to advocate on his/her behalf.
4. Legislative advocacy - as permitted by law - seeking legislative enactments which would enhance the rights and opportunities for persons served by the organization.

Individuals may also access or be referred to legal entities for appropriate representation as appropriate to circumstances.

Procedures and guidelines will be established as necessary and followed by employees of the organization.

ADVOCACY

PROCEDURE - All Programs

In accordance with Open Options UCP Policy on Advocacy, the employees assist consumers by acting in an informational and guidance capacity, through information sharing, personal guidance, and encouragement to speak for themselves.

Self-advocacy is recommended when appropriate, and persons served shall receive regular and ongoing training in individual rights and decision-making skills. Employees shall support and encourage persons served in expressing their desires and exercising their rights on an ongoing and informal basis as needed. On a regular basis, persons served may benefit from our direct advocacy – as in speaking and/or acting on behalf of a person or family to ensure that legal and human rights are met. This is offered when self-advocacy is not used or is not successful.

In addition, persons served shall have access to external advocacy services such as People First and state “Protection and Advocacy” agencies. When formal external advocacy intervention is needed, the following procedures shall be utilized:

- a. Inform the Director of Community Living and/or President/CEO of the need and plans for formal advocacy.
- b. Confirm that other appropriate resources have been contacted and invited to participate in

the discussion, for example Protection and Advocacy, Legal Aid, and/or other community resources in the specific area in which advocacy is warranted.

c. Verify all information provided by the person served, if possible.

d. When meeting with all parties involved, including the person served, provide applicable information regarding options that are available, and verify that legal advice is not being given. Ensure that the person served has access and/or referral to legal entities for appropriate representation.

e. Provide appropriate referral information to the persons served, family, and involved organization(s).

f. Document advocacy efforts in the person served record.

g. If additional action/follow-up is needed, ensure that the Director of Community Living and/or President/CEO are informed.

When exercising advocacy responsibilities, always use caution and avoid confrontation. Never make threats of any kind. Advocacy work must always be conducted in a professional manner. The actions of each staff member on behalf of persons served may reflect on the organization and on all persons with disabilities.

OBTAINING INFORMED CONSENT

PROCEDURE - All Programs

Informed consent shall be obtained as required by law and by these procedures. Informed consent shall be based on all relevant facts about a treatment or activity and shall be voluntary. The formality of the consent process shall increase concurrently with the level of risk, intrusiveness, and irreversibility of the treatment. If the individual does not have the intellectual or legal capacity to give consent, such consent will be obtained from the legal guardian. Persons served may have an outside advocate assist with making decisions involving informed consent.

As required by Missouri State law and the policies and procedures of this organization, signed, written informed consent shall be obtained for placement and/or service delivery, for irreversible surgical procedures, including abortion, for HIV/AIDS testing, for behavior management strategies involving the use of restrictive procedures (including psychotropic medications), for the release of records and person served information to outside parties, for limitations/restrictions in the use of personal monies, and for participation in experimental treatments or involvement in research projects.

Copies of consents shall be filed in the Persons Served Record.

In addition, persons served have the right to refuse certain treatments or services, and to make informed decisions regarding services received and composition of their support team. Such decisions shall be included in the person centered plan. Conflicts regarding service decisions may be referred to the organization's Human Rights Committee.

PRIVACY

PROCEDURE – All Programs

All persons served have a right to privacy within their own home and space and with regard to their personal information.

Any private information discussed with a person served must be discussed in as private and respectful manner as is reasonably possible. This includes health related discussions or observations, discussions regarding progress or behavior, and other personal topics.

Person served's personal space shall be regarded as private. Employees, visitors, relatives, and any outside person should seek appropriate entrance from the person served prior to entering his/her home, apartment, or personal space.

- All persons shall knock on the apartment / bedroom door, announce themselves, and wait for the-person served to answer the door or give verbal permission to enter.
- Advance verbal permission by a person served is considered valid for the organization's staff to make an apartment or bedroom available to be seen by visitors, tours, new persons served, or other interested parties.
- Permission to enter may be waived to address significant health and safety issues of an immediate nature.
- The person served must give permission and be present if mail is to be monitored/opened by persons other than themselves.

See also Confidentiality of Person Served Records

See also Health Maintenance – Conditions Common to Prader-Willi Syndrome

RESEARCH PROTECTION

PROCEDURE - All Programs

In the event that outside entities request the assistance of Open Options UCP for research projects, the President/CEO may give approval for Open Options UCP's participation in research projects only when:

- those conducting the research submit a written explanation of the project,
- written informed consent is obtained from the person served /parent/guardian,
- the research proposal meets standard research and ethics guidelines.

Open Options UCP's participation may include sharing the project with eligible participants so that they may elect to participate, and supporting their participation through staff assistance and transportation. Open Options UCP may also participate by sharing aggregated data without identification of persons service. Direct participation shall never be required for any person receiving services.

A copy of the research proposal will be kept on file in the Administrative office.