

# **Section E: Rights of Persons Served**

## **POLICY STATEMENT: Rights of Persons Served**

Adopted by the Board of Directors 05/28/2015

Reviewed 02/27/2017

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 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 our interactions with persons served and stakeholders we will strive to promote their autonomy and self-determination. Minimally, promoting people's rights is comprised of respecting individual preference and choices, and supporting people to exercise their rights and responsibilities. Although everyone has the same basic rights, individuals may care more about some rights than others. People determine for themselves which rights matter most to them. Open Options is committed to promoting each person's ability to exercise their rights safely and responsibly. The organization will ensure employees recognize and honor the rights of persons served and will provide education about rights to employees and to persons served on an annual basis and in a manner that matches their unique learning needs. Procedures will address the rights to confidentiality; privacy; freedom from abuse, neglect, exploitation, and mistreatment; freedom from retaliation; access to information and records; informed consent; access to outside representation; adherence to ethics and research guidelines; and investigation of alleged infringements on rights.

Within any society, situations exist where the total freedom to act, do or decide is not possible. Limitations may occur as a result of laws, community or group norms and the needs of other people. Open Options will ensure that each person served is guaranteed the opportunity to be heard and treated fairly in any situation where limitations are imposed. Rights are not to be restricted without due process and a clear plan to restore them. 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 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.

Missouri law gives individuals who receive services from the Division of Developmental Disabilities the following rights:

1. To humane care and treatment
2. To the extent that the facilities, equipment and personnel are available, to medical care and treatment in accordance with the highest standards accepted in medical practice
3. To safe and sanitary housing
4. To not participate in non-therapeutic labor

5. To attend or not attend religious services
6. To receive prompt evaluation and care, treatment, habilitation or rehabilitation about which the individual is informed insofar that person is capable of understanding
7. To be treated with dignity as a human being
8. To not be the subject of experimental research without prior written and informed consent or that of a parent, if the person is a minor, or guardian; except that no involuntary committed person shall be subject to experimental research, except as provided by statute
9. To decide not to participate or to withdraw from any research at any time for any reason
10. To have access to consultation with a private physician at the individual's expense
11. To be evaluated, treated or habilitated in the least restrictive environment
12. To not be subjected to any hazardous treatment or surgical procedure unless the individual's parent, if the person is a minor, or guardian consents; or unless such treatment or surgical procedure is ordered by a court of competent jurisdiction
13. In the case of hazardous treatment or irreversible surgical procedures, to have, upon request, an impartial review prior to implementation, except in case of emergency procedures required for the preservation of life
14. To a nourishing, well-balanced and varied diet
15. To be free from verbal and physical abuse
16. To wear one's own clothes and to keep and use one's personal possessions
17. To keep and be allowed to spend a reasonable sum of one's own money for canteen expenses and small purchases
18. To communicate by sealed mail or otherwise with persons, including agencies inside or outside the facility
19. To receive visitors of one's own choosing at reasonable times
20. To have reasonable access to a telephone booth to make and receive confidential calls
21. To have access to one's own mental and medical records
22. To have opportunities for physical exercise and outdoor recreation
23. To have reasonable, prompt access to current newspapers, magazines and radio and television programming.

The Division of Developmental Disabilities also provides a description of the rights of persons served in people-first language:

- **Due Process**

- When you apply for services, the regional office or habilitation center must give you, your parents, your guardian, or any other person you choose a written copy of your rights. If any changes in your services are made, you will receive a new copy of your rights.
- Regional offices, habilitation centers and provider agencies that have employees who work with you have rules to provide you good help. They have rules to make sure you learn and understand your rights, and that no one takes your rights away before you have a chance to speak for yourself or have someone you choose speak for you. This is called due process.
- You have the same legal rights and responsibilities as any other person unless the court says you do not.
- You have the right to get help. You cannot be denied help because of your race, your religion, your disability or your age. It does not matter if you are a man or woman, married or single.
- Before your rights or services can be limited or taken away, you have the right to be heard or to have someone you choose speak for you. This is called due process.

- Any proposed limitation of rights must be reviewed by DMH Regional Office or State Operated Programs Due Process Committee to ensure that a person's rights are adequately protected.
- **Services and Supports**
  - You have the right to get your services and supports in the most integrated setting and in a way that best meets your needs. To determine those services, these people may be involved: you, your parents, your guardian or any other person of your choice.
  - You have the right to know what the regional office and habilitation center rules are for the services and supports you receive.
  - You have the right to have your services, supports and personal records explained to you so you understand them.
  - You have the right to receive and read your personal records.
  - You have the right to receive and sign a copy of your personal plan.
  - You have the right to have your records kept private.
- **Abuse and Neglect**
  - You have the right not to be abused or neglected. Abuse can be physical, verbal, mental, sexual or financial. Neglect is not getting the things you need to be healthy and safe.
  - If you think you are being abused, neglected, or your rights taken away, you, your parents, your guardian, or any other person you choose can contact your regional office or habilitation center for help. You can also call consumer rights monitor (Constituents Services) in Jefferson City at 1-800-364-9687 for help.
  - People who work for the regional office or habilitation center must report any abuse or neglect that they see or that people report to them.

In addition to educating and enabling individuals to exercise their rights, Open Options is also committed to ensuring its settings meet the characteristics of Medicaid Home and Community-based Services. Please refer to Section J, Support Services for Persons with Prader-Willi Syndrome policy for further information on specific programming. The characteristics of the Medicaid Home and Community-based services include:

1. The setting is selected by the individual.
  - Individuals will be given a choice of available options regarding where to live/receive services.
  - Individuals will be given opportunities to visit other settings.
  - The settings will reflect the individual's needs and preferences.
  - The Director of Community Living will ensure this occurs when people move into the program or move to different locations while in the program.
2. The individual participates in unscheduled and scheduled community activities in the same manner as individuals not receiving Medicaid HCBS services.
3. The individual is employed or active in the community outside of the setting.
4. The individual has his/her own bedroom or shares a room with a roommate of choice.
  - The individual is periodically reminded that s/he can request a roommate change if they chose.
5. The individual chooses and controls a schedule that meets his/her wishes in accordance with a person-centered plan.
  - The individual has access to leisure activities that interest him/her and s/he can schedule such activities at his/her convenience.
  - Individuals have access to his/her funds.
  - Individuals are not required to sign over his/her paychecks to Open Options.
7. The individual chooses when and what to eat.

8. The individual chooses with whom to eat or to eat alone.
9. Individual choices are incorporated into the services and supports received.
  - The Division Directors will ensure individuals are asked about needs and preferences to insure they are incorporated into supports received.
10. The individual chooses from whom they receive services and supports.
11. The individual has access to make private telephone calls/text/email at the individual's preference and convenience.
12. Individuals are free from coercion.
13. The individual, or a person chosen by the individual, has an active role in the development and update of the individual's person-centered plan.
14. The setting does not isolate individuals from individuals not receiving Medicaid HCBS in the broader community.
15. State laws, regulations, licensing requirements, or facility protocols or practices do not limit individuals' choices.
16. The setting is an environment that supports individual comfort, independence and preferences.
17. The individual has unrestricted access in the setting.
18. The physical environment meets the needs of those individuals who require supports.
19. Individuals have full access to the community.
20. The individual's right to dignity and privacy is respected.
21. Individuals who need assistance to dress are dressed in their own clothes appropriate to the time of day and individual preferences.
22. Employees communicate with individuals in a dignified manner.

The Director of Community Living and the Division Directors are responsible for ensuring people supported are reminded of these items on at least an annual basis. Employees will be trained at the time of hire on these important requirements.

There are additional characteristics expected to be in provider owned or controlled homes through the Medicaid Home and Community Based waiver. Open Options is committed to ensuring its settings meet these characteristics. These include:

1. Modifications of the setting requirements for an individual are supported by an assessed need and justified in the person-centered plan.
2. Individuals have privacy in their sleeping space and toileting facility.
  - Employees will knock and receive permission prior to entering a bedroom or bathroom.
  - Individuals can close and lock the bedroom doors if they chose.
  - Individuals can close and lock the bathroom door if they chose.
3. The individual has privacy in his/her living space.
4. The individuals have comfortable places for private visits with family and friends.
5. Individuals furnish and decorate their sleeping and/or living units in the way that suits them.
6. There is a legally enforceable agreement for the unit or dwelling where the individual resides.
7. Individuals are protected from eviction and afforded appeal rights in the same manner as all persons in the State who are not receiving Medicaid HCBS.

## **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 Support Plan.

## **Progression of Intervention**

Open Options 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 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 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 Kansas City Regional Center's Due Process 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 an employee and/or an employee physically holding on to 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 and Emergency Rights Restriction Approval 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, defines 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 immediately 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 individual record in Therap and a general event report shall be written. The support team must confer as soon as possible (ideally the next business day) to formulate a plan for safety. A plan for safety cannot be implemented without prior authorization of a Division Director or member of Executive Team; additionally, an addendum to the person-centered plan will be written and approved by the Kansas City Regional Office Due Process Committee.

Rights 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

Due Process Committee at the Kansas City Regional Center. If approved, such extended limitation shall be identified and documented as to onset and rationale in the Person-Centered Plan. Restoration of the right shall be reviewed at a minimum of yearly at the annual Individual Support Plan meeting, and continued limitation must be agreed to by the majority of the team. At least annually, the Due Process 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. Rights restriction and the corresponding data collected shall be reviewed as outlined in the Individual Support Plan to monitor progress towards meeting the stated criteria for rights restoration. When an individual meets criterion for rights restoration, the Division Director shall submit the documentation to the appropriate Due Process Committee Representative so it may be reviewed at the next Due Process 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 representative and Support Coordinator, to be presented to the Due Process Committee.

### **Human Rights Committee**

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

**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. Specific committee functions include:

- 1) Review any reported use of emergency rights restrictions.
- 2) Review all individual rights restrictions to ensure:
  - a. they have been submitted in a timely fashion to KCRO's Due Process Committee (before being submitted, signed informed consent was obtained)
  - b. rights restrictions have timelines for restoration
- 3) At least one time per year, examine accumulated data on incidents and examine for trends.
- 4) Assure Open Options engages in proactive activities that promote and protect people's rights.

### **Meeting Frequency and Structure**

- 1) Meetings will be Chaired by the Director of Training and Compliance
- 2) Committee members will be comprised of the President/CEO, Director of Community Living, Division Directors, Health Services Manager and Director of Quality Enhancement. A meeting should include at least three members.

3) The Committee will meet on a quarterly basis, or more often as needed.

### **Investigation of Alleged Infringement of Rights**

Any employee observing or receiving a report regarding the violation of a person served's rights, 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 General Event Report shall be completed by the employee. Rights violation investigation process will be the same as Abuse and Neglect investigation process, for more information see Section A4. For situations involving a disagreement between two (or more) persons served, the supervisor or designated employee 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 rights infringement. 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 02/27/2017

Actively involving persons served and stakeholders in the planning and service processes is critical to achieving organizational and individual-specific outcomes. It is the policy of Open Options to obtain input on an ongoing basis from persons served, family members of persons served, employees, and other stakeholders. Open Options 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. Gathering input is an ongoing process. 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, employee 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, development and revision of Individual Support Plans, and 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.
- Formal and informal input from individual persons served, parents and/or guardians will be solicited regarding the program and services received from the organization.
- All efforts should be made to complete post-discharge follow-up with discharged persons served and the relevant support team member(s) at discharge, with follow up by Director of Community Living as needed. Results of the discharge summaries will be reviewed by the administrative team to be included in the Performance Management and Improvement System.
- 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 or who are recommended for involvement shall be referred to the appropriate person for consideration.
- Procedures for responding to person served grievances shall be established to ensure that the concerns of persons served are appropriately identified and addressed. See section below.
- 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 is responsible for ensuring input is incorporated into the support plan, and the designated Open Options employee will assist with the development implementation strategies for outcomes. The organization shall periodically review goals and outcomes and make any recommendations for revision in a timely manner.

- Open Options will establish policies and procedures to ensure the protection of the rights of persons served.
- Persons served meetings shall be convened as needed or requested for soliciting feedback, ideas, and solutions. Feedback and input from persons served shall be documented and utilized in organizational planning efforts. Pertinent issues shall be communicated to the appropriate program director.
- Feedback from stakeholders shall be encouraged and reviewed by the appropriate party with verbal or written response given to the person making the suggestion.

## **PERSON SERVED GRIEVANCES**

### **PROCEDURE - All Programs**

For this procedure, a Person Served Grievance is defined as a specific formal notice of person served dissatisfaction.

A grievance may be submitted by a person served or another person acting upon their behalf. Formal submission of a written or electronic grievance initiates the formal grievance process. Complaints or informal complaints should be discussed with appropriate members of the support team. If this discussion does not resolve the situation, a formal written grievance may be submitted. For reported issues that meet criteria per policy for an investigation, that policy/procedure shall supersede the Person Served Grievances Policy. Individuals who wish to appeal a decision made by the organization may request a review of the decision.

1. 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.
2. A meeting or discussion will be scheduled promptly to review and resolve the grievance.
3. 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.
4. 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 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 of their choice. 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 on confidential file. 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 02/27/2017

It is the policy of Open Options 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 Policy on Advocacy, the employees assist persons served 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 any Open Options employee 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 Individual Support Plan. Concerns regarding service decisions may be addressed through the grievance procedure.

## **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 employees 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 for research projects, the President/CEO may give approval for Open Options'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' participation may include sharing the project with eligible participants so that they may elect to participate, and supporting their participation through employee assistance and transportation. Open Options may also participate by sharing aggregated data without identification of persons served. 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.