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RIGHTS REVIEW COMMITTEE GUIDELINES



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I. RIGHTS AND THE ROLE OF RIGHTS REVIEW COMMITTEE

A. PURPOSE/FOCUS OF ABLED, INC. RIGHTS REVIEW COMMITTEE

Organizations providing intellectual disabilities services in Nebraska must establish a Rights Review Committee as required by law. The Rights Review Committee must review, approve, and monitor restrictive behavior management practices.

The primary purpose and focus of Rights Review Committee is to fulfill an advocacy role unencumbered by conflict of interest to ensure the organization promotes and protects the rights of the people it serves.

ABLED, Inc. has no legal or moral authority over the participants receiving services. However, we have a great deal of responsibility to protect the participants receiving services. This responsibility often places us in the position of limiting or restricting participant rights, as many interventions and procedures intended for protection are in fact restrictive. Having a Rights Review Committee that functions outside of ABLED, Inc.'s authority ensures a level of protection to participants served in the event that rights are limited or restricted.

Rights Review Committee serves as a mechanism to promote and protect participant rights.

The rights review committee must conduct a thorough review, including requesting additional information as needed to make recommendations to the provider as appropriate regarding the following types of situations:

1. Review provider practices, supports, programs, and policies and procedures as they relate to protection of rights and safety.
2. Review the use of restrictive measures and psychotropic medication.
3. Review all situations that utilized emergency safety interventions.
4. Review all reports and investigations of alleged or suspected abuse, neglect, mistreatment, and exploitation.
5. Meets no less than semi-annually.

B. MEMBERSHIP OF RIGHTS REVIEW COMMITTEE

The membership of the Rights Review Committee will include persons with a knowledge of rights issues and a commitment to ABLED, Inc. philosophy. They should understand their duties (including confidentiality) and be willing to challenge current practices.

Rights Review Committee members are recruited from the community. The Committee must have within its membership the expertise to effectively evaluate case referrals.

There is a value in members who have different perspectives.

Committee membership may include but not limited to persons:

1. With rights experience, such as clergy, attorneys or judges.
2. With clinical training, such as pharmacists, psychologists, nurses, or social workers.



3. With a disability.
4. Who are involved family members.
5. Who are members of advocacy organizations.
6. Who are administrators.
7. Who are community members with a particular interest in rights.

The committee members must be persons free from conflict of interest and who will ensure the confidentiality of information related to participants served. The person responsible for approving the participant's program and any staff who provides direct services to the participant cannot participate as decision makers. **At least half of the committee members must be participants, family, or other interested persons who are not provider staff.**

C. ABOUT RIGHTS

A Right is a power or privilege to which one is entitled. There are several types of rights: Rights continue to evolve as advocacy groups, and the state and federal branches of the government, pass laws, establish codes and administrative rules.

People with intellectual disabilities have the same basic statutory, constitutional and human rights as other citizens.

Statutory Rights, also known as civil and legal rights, are established through the legislature.

Constitutional Rights — life, liberty, etc. were established through the Constitution of the United States.

Human Rights were established through the Universal Declaration of Human Rights. Rights granted by an agency or organizations are often referred to as Consumer Rights.

1. Each person determines which rights are most important to them. The exercising of rights is a function of personal choice.
2. People need to be educated about their rights.
3. One of the most important responsibilities ABLED, Inc. has is to assist, guide, and educate participants in the expression and exercise of rights. To carry out this responsibility people need opportunities and support to:
 - a. Make decisions and choices
 - b. Express and set goals
 - c. Increase their personal possessions
 - d. Maintain personal relationships
 - e. Increase involvement in the community Increase privacy

ABLED, Inc. will ensure that:

1. Rights and responsibilities are specified and this specification does not conflict with State



regulations.

2. Each participant supported, parent if a minor, or legal representative is informed of the participant's rights and responsibilities:
 - a. The information must be given at the time of entry to services, annually thereafter, and when significant changes occur.
 - b. The information must be provided in a manner that is easily understood, given verbally and in writing, in the native language of the participant, or through other modes of communication necessary for understanding.
 - c. The provision of supports to participants receiving services in exercising their rights.
3. Rights must not be treated as privileges.
4. Prohibit retaliation against participants' services and supports due to the participant, family members, or legal representatives advocating on behalf of the participant supported. This includes initiating a complaint with outside agencies.

D. RESTRICTIONS

A restriction is defined as any externally imposed limitation of rights. Rights should only be restricted to ensure:

- Participant Protection • Protection of Others, and Property • Health and Safety

No one in our society has total freedom to act or live as they choose. Limitations occur as a result of laws, community norms, and involvement with other people. ABLED, Inc. has a responsibility to ensure a level of protection to participants served that may result in the need for an participant's rights to be limited or restricted. When there is a need for a limitation or a restriction, it should be implemented impartially and fairly.

Due process is essential in the event that rights are limited or restricted.

Due process includes consent, review and approval by Rights Review Committee, access to a grievance procedure and, in some cases, legal representation. ABLED, Inc. must apply due process procedures in all situations where rights are limited and/or restricted.

The primary purpose and focus of a Rights Review Committee should be to fulfill an advocacy role unencumbered by conflict of interest to ensure the organization promotes and protects the rights of the people it serves.

Deciding how much protection is too much or too little is not an easy job. Too much supervision/control limits the participant's opportunities to learn and restricts unnecessarily. Too little supervision or support/intervention may put the participant at risk or in danger.

1. Restrictions, when necessary, are not bad.
2. The more mobile and independent people are, the more likely we are to impose unnecessary supports.
3. Restrictions must be individualized.



4. All staff need to constantly evaluate the impact that facility policies and practices have on people's lives and update those policies and practices if they conflict with people's rights.
5. Do not rely on a definitive list to identify restrictions. Consider the "neighbor test" which says if you cannot do it to your neighbor, it is probably restrictive.
6. What is restrictive for one participant may not be restrictive for another.
7. What is the least restrictive for one participant may be too intrusive for another.
8. The participant's opinion about the restriction is important.
9. Re-evaluate often to reinstate rights.
10. There is never just one solution to a rights issue.

E. APPROPRIATE RIGHTS RESTRICTIONS

Appropriate restrictions exist and are a necessary element of the services provided. The use of psychotropic medications, physical restraint, and the denial of food or possessions, are all easily recognized restrictions. But, due to a variety of reasons, participants served are subjected to a variety of less obvious restrictions. Everyone needs to be diligent in assessing the services and supports to determine if restrictions or limitations are imposed.

All ABLED, Inc. staff, subcontractors, and committee members must be mindful and aware of any restrictions or limitations that are imposed. The following are possible indications of a participant's rights being restricted:

- The participant has to ask and get permission to be alone.
- Staff enter a participant's room without permission.
- Staff go through the participant's purse, pockets, drawers, etc.
- The participant does not or is not allowed to make their own decisions.
- The participant is not allowed or has guidelines imposed on things (e.g., smoke, eat junk food, carry money, diet).
- The participant has to ask (or believes they have to ask) for a snack.
- Staff impose an action that could not be imposed on a neighbor.
- Foods the participant prefers are not purchased.
- The participant's body language/communication attempts to remove protective gear aren't supported (e.g., helmets, belts, pads, etc.).
- The participant is not allowed or assisted to answer their phone or doorbell.
- Junk mail is removed from the participant's mail before they see it.
- The participant does not have free access to his/her possessions (e.g., toothpaste, razor, sharps).
- The participant's schedule is not individualized or agreed to (e.g., set time for bed, bath, personal time, visiting, or having friends over).
- The participant asks permission to go anywhere in their own home (e.g., locked doors, cupboards,



refrigerator, gates).

- The power is turned off on any supportive device such as a communication board or electric wheelchair to punish or control the participant.

F. RESTRICTIVE MEASURES

To the fullest extent possible, a participant's rights may not be suspended or restricted. In the event where a restrictive measure is considered:

1. The restrictive measure determined necessary for one participant must not affect other participants who receive services in that setting.
2. The restrictive measure must not be used as punishment, for the convenience of staff, due to shortage of staff, as a substitute for habilitation, or as an element of a positive behavior support plan.
3. The restrictive measure must be the least restrictive and intrusive possible.
4. There must be a goal of reducing and eliminating the restrictive measure.
5. Prior to proposing a restrictive measure, there must be documented evidence that other less restrictive methods have been regularly applied by trained staff and failed.
6. The participant or their legal representative, if applicable, must give consent to the restrictive measure.
7. The restrictive measure must be safe for the participant.
8. The restrictive measure and these considerations must be documented in the ISP.

Prior to implementation of a restrictive measure, ABLED, Inc. will ensure review and approval by the ISP team and rights review committee

G. PSYCHOTROPIC MEDICATION

Psychotropic medications taken by the participant due to diagnosed mental illness (a dual diagnosis of a severe and persistent mental illness in conjunction with an intellectual disability) must:

1. Only be given as prescribed by a physician who has authority in his/her scope of practice to determine the diagnosis. PRN (as needed) psychotropic medications are prohibited.
2. Be reviewed by the ISP team to determine if the benefits outweigh the risks and potential side effects.
3. Be supported by evidence that a less restrictive and more positive technique had been systematically tried and shown to be ineffective.
4. Be reviewed by the Rights Review Committee. There must be an annual review by the prescribing physician and a semi-annual review by the ISP team of all psychotropic medications utilized. There must be clear and convincing evidence that the participant has a person-centered plan demonstrated by data and outcome measures.
5. Not be used as a way to deal with under-staffing; ineffective, inappropriate or other nonfunctional



programs or environments.

6. Also have a support plan established and in place to address if symptoms reappear and the possibility that the use of medication is no longer effective.
7. Be monitored and documented on an ongoing basis by the provider to provide the ISP team and physician sufficient information regarding:
 - a. The effectiveness of and any side effects experienced from the medication
 - b. Frequency and severity of symptoms
 - c. The effectiveness of the positive behavioral supports plan

Psychotropic medications used solely for the purpose of modifying behaviors may only be used if:

1. There is a plan to reduce and eliminate the medication.
2. The drug is used in conjunction with a positive behavioral supports plan.

A positive behavioral supports plan is not required when a participant is prescribed a medication that has the effect of behavior modification, but is prescribed for other reasons, as documented by a physician.

H. EMERGENCY SAFETY INTERVENTION

An emergency safety intervention utilized pursuant to a safety plan is allowed to respond to an emergency safety situation. This is different than physical restraint because it is not used as a behavioral consequence. In instances where the participant must be kept from harm (i.e., running into traffic, leaving a moving car or other serious, unusual life-threatening actions by the participant), ABLED, Inc. must use reasonable and best judgment to intervene to keep the participant from injuring him/herself or others. This may include hands-on guidance to safely protect the participants and others from immediate jeopardy or physical harm.

These situations are not predictable, are unusual, and are usually not reoccurring. In any instances other than these, there must be a positive behavioral supports program in place to work with the participant on alternative displays of behavior that are incompatible with other negative behaviors.

All such incidents must be documented and reviewed by the participant's ISP team and rights review committee to ensure that the emergency safety intervention was appropriate rather than an instance of mechanical or physical restraint.

I. PROHIBITED METHODS

ABLED, Inc. will prohibit the use of mechanical or physical restraints. This includes aversive stimuli, corporal punishment, seclusion, verbal abuse, physical abuse, emotional abuse, denial of basic needs, discipline, or implementation of an intervention of a participant in services by another participant in services, or other means of intervention with the behavior that result in or is likely to result in injury to the participant.



J. EXAMPLES OF INAPPROPRIATE RIGHTS RESTRICTIONS

1. A guardian dictates a restriction. Teams need to determine the appropriateness of ABLED, Inc. imposing any restriction regardless of having consent/direction to do so. The team has a responsibility to evaluate the need for a restriction, and to use the least restrictive alternative. While guardians must consent to restrictions, they do not have authority over ABLED, Inc. or the services provided by ABLED, Inc., nor does consent from a guardian override ABLED, Inc. responsibilities, philosophy, policy and or procedure.
2. A doctor recommends a restriction. Teams must consider the restriction and determine what action is to be taken. The decision to impose a restriction should be based on the risk involved, irreversible impact, intrusiveness, and the participant's ability to make an informed decision. People have the right to get a second opinion.
3. Staff dictate rules for their convenience. Anyone sharing a facility or living with another must abide by some rules or agreed upon routines. However, when a rule is imposed on a participant against their will, it must be considered a restriction. Participants should be involved in the development of the rules and routines in order to learn to live with others, share facilities, respect others, and exercise control over their lives.
4. Staff applies a restriction because they have always done it that way. Teams are to determine the least restrictive level and type of support needed on a participant basis. There should be a rationale for the restriction, and it should be clear that the restriction imposed meets the needs of the participant without being more intrusive than need be.
5. The team proposed a restriction. Despite the best of intentions, a team may not have proposed the most appropriate plan. Rights Review Committee serves as a safety net to ensure that rights are not unjustly or excessively restricted. In order to make such determinations, the Committee must question and evaluate team decisions.

K. LEAST RESTRICTIVE ALTERNATIVE

Least restrictive alternative is defined as the level of intervention determined to be the least intrusive, least disruptive and represents the least departure from normal patterns of living that can be effective in meeting the participant's developmental needs.

ABLED, Inc. Rights Review Committee should ensure that services and supports are as minimally restrictive to a participant's personal liberty as possible. Evaluating whether or not teams have examined options and have chosen based on the least restrictive alternative is an important step in promoting and protecting a participant's rights.

There are numerous interventions that a team can choose from when a participant's behavior is such that the team must intervene. In order for a Rights Review Committee member to make a determination as to whether or not a proposed intervention is the least restrictive alternative, the following questions should be asked to determine if the restriction is the least restrictive alternative:

1. What right is being infringed upon?
2. What less intrusive/restrictive options have been tried?



3. Does it appear the team has discussed/exhausted less restrictive options?
4. Does the level and method of restriction seem appropriate?

Committee members should feel free to ask questions and feel comfortable withholding their approval if the proposed restriction does not appear to be appropriate.

II. THE REVIEW PROCESS

A. ISP TEAM IDENTIFIES RESTRICTION

Implementation of any rights restriction enforced by ABLED, Inc. must be identified as such and the participant served must be accorded due process. Prior to Rights Review Committee review, the Individual Support Plan (ISP) team discusses alternatives and decides on a restriction.

B. FOLLOW THE RESTRICTION

1. The ISP Team may establish a Behavior Tracker to identify the frequency of those behaviors that the restriction is intended to eliminate.
2. The ISP Team may establish a positive teaching program with data collection to assist the participant in learning skills that will help to eventually lessen or eliminate the restriction.

C. RESTRICTION REVIEW

All information brought to the Rights Review is considered confidential. The Committee reviews the participant's history and pertinent issues. Additionally, Rights Review Committee looks for assurance that the ABLED knows the participant and any restrictions are proper. They analyze programmatic issues.

1. The Committee will have a subcommittee review medications, diagnoses and behaviors to be tracked. The ABLED RN will lead the subcommittee for med reviews. The subcommittee will meet prior to the full committee meeting.
2. The Committee will discuss participants' medical appointments/diagnoses, any relevant history, behaviors, restrictions, and changes since last review.
3. Analyzed discrepancies between staff saying the participant is doing well when the data says otherwise or vice versa.
4. The discussion and documentation will be clear, concise, and honest without speculation.
5. Any unclear medical terms must be explained.
6. The Committee must know what is being tracked. Behavior language must be specific.
 - a. "Appropriate/inappropriate behavior" is a poor use of words, the committee needs specific descriptions of the behaviors
 - b. "Follows request" is too vague unless the program design specifies the actual request and ties it to the specific situations



D. ABUSE AND NEGLECT

All reports of abuse and neglect, including staff to participants supported and between participants supported, will be investigated and reviewed. All ABLED staff will report 12 suspected abuse and neglect to APS/CPS. The ABLED Investigator will prepare an Investigation Report for DHHS. The Investigation Report that includes:

- The allegation
- Who was interviewed
- Responses
- Conclusion

The report will be submitted to the Rights Review Committee at the next meeting. The Committee's decision regarding the report will be conveyed to:

1. The participant allegedly abused.
2. Parent/Guardian, if applicable.
3. DHHS Service Coordination.
4. ABLED, Inc. Directors.

Notification will occur no later than five days after the meeting.

ABLED, Inc. will follow the requirements/requests/guidelines of any external investigating agency so as not to jeopardize their investigation.

E. THE CASE DECISION

The Rights Review Committee review form will provide the written documentation of the Committee's review and decision. The Committee can approve, give provisional approval and request more information, or not approve and return the restriction to the ISP Team for reconsideration.