

INDEPENDENCE ASSOCIATION HCBS Policy: 005

Title: Rights, Privacy, and Dignity Policy

Date: May 16, 2022

Policy:

In addition to adhering to *34-B M.R.S. §5605. Rights and basic protections of a person with an intellectual disability or autism*, Independence Association believes that all people deserve to be treated with dignity and have the right to privacy and respect. Therefore, rights training provided through Maine College of Direct Support must be completed prior to working alone with individuals receiving services. Information regarding individuals must be kept private and confidential. Violations of their rights and basic protections may result in discipline up to and including termination. Any employee or volunteer who has assumed full, intermittent or occasional responsibility for the care or custody of an incapacitated or dependent adult, regardless of whether compensation is received is considered a **mandatory reporter**. All employees, family members, and volunteers associated with Independence Association are considered mandatory reporters. All staff will be trained on this policy at the time of hire. Retraining will promptly occur as needed to ensure policy and procedures are followed correctly and consistently.

Procedure:

1. Independence Association (IA) employees will complete Maine College of Direct Support course *ME Individual Rights and Choice* prior to working alone with individuals receiving services.
2. IA employees will read the rights and protections listed below (as found in 34-B M.R.S.A. §5605, *Rights and Basic Protections of a Person with an Intellectual Disability or Autism*) upon hire and annually thereafter.
3. IA employees will be informed during training of the consequences for violating those rights and basic protections.
4. IA employees must report immediately or, as soon as possible within one (1) business day, all Rights Violations that involve any action or inaction that deprives an individual receiving services of any of the rights or basic protections described in 34-B M.R.S.A. §5605.
5. IA employees will use the guidelines provided in *IA Reportable Events Policy* when reporting a rights violation.

I. RIGHTS AND BASIC PROTECTIONS OF A PERSON WITH AN INTELLECTUAL DISABILITY OR AUTISM

A person with an intellectual disability or autism is entitled to the following rights and basic protections.

1. **Humane treatment.** A person with an intellectual disability or autism is entitled to dignity, privacy and humane treatment.
2. **Practice of religion.** A person with an intellectual disability or autism is entitled to religious freedom and practice without any restriction or forced infringement on that person's right to religious preference and practice.
3. **Communications.** A person with an intellectual disability or autism is entitled to private communications.
 - A. A person with an intellectual disability or autism is entitled to receive, send and mail sealed, unopened correspondence. A person who is a provider may not delay, hold or censor any incoming or outgoing correspondence of any person with an intellectual disability or autism, nor may any such correspondence be opened without the consent of the person or the person's legal guardian.
 - B. A person with an intellectual disability or autism is entitled to reasonable opportunities for telephone and Internet communication.
 - C. A person with an intellectual disability or autism is entitled to an unrestricted right to visitations during reasonable hours unless this right has been restricted pursuant to rules adopted pursuant to section 5604.
4. **Work.** A person with an intellectual disability or autism engaged in work programs that require compliance with state and federal wage and hour laws is entitled to fair compensation for labor in compliance with regulations of the United States Department of Labor.
5. **Vote.** A person with an intellectual disability or autism may not be denied the right to vote.
6. **Personal property.** A person with an intellectual disability or autism is entitled to the possession and use of that person's own clothing, personal effects and money, except when temporary custody of clothing or personal effects by a provider is necessary to protect the person or others from imminent injury or unless this right has been restricted pursuant to rules adopted pursuant to section 5604.
7. **Nutrition.** A person with an intellectual disability or autism is entitled to nutritious food in adequate quantities and meals may not be withheld for disciplinary reasons.
8. **Medical care.** A person with an intellectual disability or autism is entitled to receive prompt and appropriate medical and dental treatment and care for physical and mental ailments and for the prevention of any illness or disability, and medical treatment must be consistent with the accepted standards of medical practice in the community, unless the religion of the person with an intellectual disability or autism so prohibits.
 - A. Medication may be administered only at the written order of a physician.
 - B. Medication may not be used as punishment, for the convenience of staff, as a substitute for a habilitation plan or in unnecessary or excessive quantities.
 - C. Daily notation of medication received by each person with an intellectual disability or autism must be kept in the records of the person with an intellectual disability or autism.

D. Periodically, but no less frequently than every 6 months, the drug regimen of each person with an intellectual disability or autism must be reviewed by a physician or other appropriate monitoring body, consistent with appropriate standards of medical practice.

E. All prescriptions must have a termination date.

F. Repealed.

G. Prior to instituting a plan of experimental medical treatment or carrying out any surgical procedure, express and informed consent must be obtained from the person with an intellectual disability or autism, unless the person has been found to be legally incompetent, in which case the person's guardian may consent.

(1) Before making a treatment or surgical decision, the person must be given information, including, but not limited to, the nature and consequences of the procedures, the risks, benefits and purposes of the procedures and the availability of alternate procedures.

(2) The person or, if legally incompetent, that person's guardian may withdraw express and informed consent at any time, with or without cause, before treatment or surgery.

H. Notwithstanding the absence of express and informed consent, emergency medical care or treatment may be provided to any person with an intellectual disability or autism who has been injured or who is suffering from an acute illness, disease or condition if delay in initiation of emergency medical care or treatment would endanger the health of the person.

I. Notwithstanding the absence of express and informed consent, emergency surgical procedures may be provided to any person with an intellectual disability or autism who has been injured or who is suffering from an acute illness, disease or condition if delay in initiation of emergency surgery would substantially endanger the health of the person.

9. **Sterilization.** A person with an intellectual disability or autism may not be sterilized, except in accordance with chapter 7.

10. **Social activity.** A person with an intellectual disability or autism is entitled to opportunities for behavioral and leisure time activities that include social interaction in the community, as set out in section 5610. This right may be waived or restricted only under the rules adopted pursuant to section 5604 or pursuant to a treatment plan approved pursuant to section 5603, subsection 1.

11. **Physical exercise.** A person with an intellectual disability or autism is entitled to opportunities for appropriate physical exercise, including the use of available indoor and outdoor facilities and equipment.

12. **Discipline.** Discipline of persons with intellectual disabilities or autism is governed as follows.

A. Deleted.

B. Corporal punishment or any form of inhumane discipline is not permitted.

C. Seclusion as a form of discipline is not permitted.

D. Deleted.

E. A provider of residential services may establish house rules in a residential unit owned or operated by the provider. A person receiving services who resides in the unit is entitled to participate, as appropriate, in the formulation of the house rules. A house rule must be uniformly applied to all residents of the residential unit where the rules apply. A copy of the house rules must be posted in a residential unit where the rules apply and a copy of the rules must be given to all residents who receive services and, if any resident is under guardianship, to the guardian of the person receiving services.

13. **Behavioral support, modification and management.** Behavior modification and behavior management of and supports for a person with an intellectual disability or autism who is not a patient in a psychiatric unit of an acute hospital or a psychiatric hospital as defined in section 3801, subsection 7-B are governed as follows.

A. A person with an intellectual disability or autism may not be subjected to a behavior modification or behavior management program to eliminate dangerous or maladaptive behavior without first being assessed by a physician to determine if the proposed program is medically contraindicated and that the dangerous or maladaptive behavior could not be better treated medically.

A-1. Support programs may contain both behavior modification and behavior management components.

A-2. The following practices are prohibited as elements of behavior modification or behavior management programs:

- (1) Seclusion;
- (2) Corporal punishment;
- (3) Actions or language intended to humble, dehumanize or degrade the person;
- (4) Restraints that do not conform to rules adopted pursuant to this section;
- (5) Totally enclosed cribs or beds; and
- (6) Painful stimuli.

B. Behavior modification and behavior management programs may be used only to correct behavior more harmful to the person than the program and only:

- (1) On the recommendation of the person's personal planning team;
- (2) For an adult 18 years of age or older, with the approval, following a case-by-case review, of a review team composed of a representative from the department, a representative from the advocacy agency designated pursuant to Title 5, section 19502 and a representative designated by the Maine Developmental Services Oversight and Advisory Board. The advocacy agency representative serves as a nonvoting member of the review team and shall be present to advocate on behalf of the person. The department shall provide sufficient advance notice of all scheduled review team meetings to the advocacy agency and provide the advocacy agency with any plans for which approval is sought along with any supporting documentation; and
- (3) Not included since it pertains to a child under 18 years of age.

14. **Physical restraints.**

14-A. **Restraints.** A person with an intellectual disability or autism is entitled to be free from restraint unless:

- A. The restraint is a short-term step to protect the person from imminent injury to that person or others; or
- B. The restraint has been approved as a behavior management program in accordance with this section.

A restraint may not be used as punishment, for the convenience of the staff or as a substitute for habilitative services. A restraint may impose only the least possible restriction consistent with its purpose and must be removed as soon as the threat of imminent injury ends. A restraint may not cause physical injury to the person receiving services and must be designed to allow the greatest possible comfort and safety.

Daily records of the use of restraints identified in paragraph A must be kept, which may be accomplished by meeting reportable event requirements.

Daily records of the use of restraints identified in paragraph B must be kept, and a summary of the daily records pertaining to the person must be made available for review by the person's planning team, as defined in section 5461, subsection 8-C, on a schedule determined by the team. The review by the personal planning team may occur no less frequently than quarterly. The summary of the daily records must state the type of restraint used, the duration of the use and the reasons for the use. A monthly summary of all daily records pertaining to all persons must be relayed to the advocacy agency designated pursuant to Title 5, section 19502.

14-B. Repealed.

14-C. Repealed.

14-D. Not included since it pertains to individuals under 16 years of age.

15. **Records.** All records of persons receiving services must remain confidential as provided in section 1207.

- A. The person with an intellectual disability or autism or, if the person is incompetent, a parent or guardian is entitled to have access to the records upon request.
- B. The commissioner is entitled to have access to the records of a provider if necessary to carry out the statutory functions of the commissioner's office.

16. **Therapeutic devices or interventions.** Therapeutic devices or interventions must be prescriptively designed by a qualified professional and applied with concern for principles of good body alignment and circulation and allowance for change of position. The department may adopt rules concerning the use of therapeutic devices or interventions. Rules adopted pursuant to this subsection are routine technical

17. **Safety devices and practices.** A safety device or practice must be prescribed by a physician. A safety device must be designed and applied with concern for principles of good body alignment and circulation and allowance for change of position. The department may adopt rules concerning the use and

approval of safety devices or practices. Rules adopted pursuant to this subsection are routine technical rules as defined in Title 5, chapter 375, subchapter 2-A.

II. PRIVACY, DIGNITY, RESPECT

Main Entry of Community Support Programs, Residence, Bedrooms, Living Space

1. Unless otherwise indicated in an individual's PCP through a HCBS rights modification addendum, all individuals may enter and leave their home or any IA owned/operated facility independently without prior approval.
2. Unless otherwise indicated in an individual's PCP through a HCBS rights modification addendum, all individuals will receive a key to the main entry door of their residence and the door of their bedroom if they live with others who are not family members. This provides the ability to independently lock or unlock their living space and bedroom door as they choose.
3. Unless two individuals mutually desire to share a bedroom, it is the policy of IA that each resident supported in a residential setting will have their own bedroom which will be capable of locking and hosting an invited guest.
4. All bedrooms will have access to a chair to host a planned or unplanned guest in private.
5. All group homes operated by IA will have a programmable key box outside of each home. Residents will be trained on how to use this box in the event they lose their key.
6. All individuals who need assistance to effectively use their key will be supported through skills training and/or individualized support which will be detailed in the individual's service plan.
7. They will also be supported to determine the best place to store their personal key to prevent loss.
8. Residents have a right to prevent others from entering their private space uninvited and have a secure place to store personal belongings in their home.
9. Unless contraindicated in their PCP through a HCBS rights modification addendum, bedroom door locks (that lock from inside and outside) will be installed in all residences, as needed.
10. Locks on bathroom doors will only lock and unlock from inside the bathroom.
11. Every reasonable effort will be made to ensure everyone served is able to independently enter/exit their own residence and is granted effective security and privacy in their bedroom as well as privacy in the household bathroom.
12. All individuals have a right to choose private dining at the setting or in the privacy of their own room without needing permission if so desired and may receive assistance if needed.
13. In Shared Living settings, Home Providers will have a master key to the living space and/or bedroom; this will be documented and justified in the individual's person-centered plan and reviewed on at least an annual basis for ongoing appropriateness and informed consent.
14. In Group Home Living settings, the program manager, team leader or CRMA on duty will have a master key maintained on their person along with the medication keys. Master keys will be to the living space and/or bedrooms; this will be documented and justified in the individual's person-centered plan and reviewed on at least an annual basis for ongoing appropriateness and informed consent.
15. Home Providers and staff members will only enter the locked living space under circumstances agreed upon by the individual.

16. Replacement keys, as needed, will be paid for by the individual.
17. Continued loss of keys will be addressed with skill acquisition goals.

Choosing Housemates

1. At the initial intake and at least annually thereafter, IA will include the opportunity for an individual to choose a setting operated by IA that offers a private bedroom if the individual's financial resources make it possible for the individual to afford the cost of having a private bedroom.
2. At the initial intake and at least annually thereafter IA will revisit the opportunity for the individual to share a bedroom with someone else:
 - a. Where there is mutual agreement between the parties that they wish to share a bedroom,
 - b. Where both individuals are willing to enter into a legally enforceable lease or residency agreement with the provider,
 - c. Where both individuals can afford the cost of room and board associated with the shared bedroom arrangement.
3. IA will not prohibit sharing based on each individual's:
 - a. funding source for supports (including whether both have paid supports).
 - b. age, gender,
 - c. nature of relationship between the two individuals that wish to share or any other factors that would be considered discriminatory and unfairly restricting individuals' choices.
4. As noted in the Residential Services Agreement, the opportunity to choose housemates will be facilitated by the manager through a series of "meet and greet" introductions, opportunities for the candidate to socialize with the existing residents, and opportunities to have a "sleepover" to allow individuals to self-assess compatibility and reach mutual decisions about the choice to live together.

Knocking and Receiving Permission to Enter

1. Staff and other members of the household, if applicable, will not enter an individual's bedroom and/or living space without first knocking on the door and obtaining permission from the individual to enter. This includes entering the unit and entering an individual's private space within the unit (e.g., bedroom and bathroom).
2. If the individual is not able to hear a knock or express permission, adaptations to ensure privacy will be recommended.
3. Every reasonable effort will be made to ensure the individual has privacy, is aware when others are present and is able to give permission for others to enter their living space and/or bedroom.

Confidentiality

1. IA employees will keep each individual's information private and confidential by not posting in any public space, office or bedroom:
 - a. Schedules for any therapeutic services such as PT, OT or speech.
 - b. Medication administration schedules.

- c. Dietary restrictions or needs schedules.
 - d. Dental/medical schedules.
 - e. Positive Support Plans/Behavior Management Plans/Safety Plans.
2. To the maximum extent possible, staff will ensure the privacy of all persons served, inside and outside of the program when assisting them with Activities of Daily Living (ADL).
 3. Staff to staff communication that concerns an individual receiving services are never conducted in the presence of anyone other than staff and the person being discussed.
 4. When discussing the concerns of an individual receiving services with another staff member, in the presence of the person being discussed, staff will fully acknowledge the presence of the person being discussed and attempt to engage them in the discussion.

Communication

1. All group home and shared living residents will have access to a minimum of one telephone.
2. All group home and shared living residents will be afforded the space for the private use of a telephone. For most residents this will be in their respective bedrooms.
3. Residents will be informed of the phone's availability and will receive assistance to make outgoing calls upon request. Residents do not need permission to use the telephone unless contraindicated in their respective PCP through a HCBS rights modification addendum, an approved Positive Support Plan or Behavior Management Plan
4. Staff will always engage person's served using respectful communication and maintain respectful interactions inside and outside of the programs.
5. All individuals served will be asked as to how they prefer to be addressed and engaged by staff, and this will be included in the "All About Me" books. Staff will reference these books so they may understand preferences and consistently communicate with individuals in ways that reflect those preferences.
6. Individuals are encouraged to use their personal communication devices both inside and outside of the setting. This includes access to the internet for cell phones, computers, tablets, and other devices. Each individual's service implementation plan will document if an individual has one or more personal communication devices and will describe the supports from setting staff that the person may need to ensure they have consistent access and an ability to effectively utilize their communication device(s).