

**GOVERNMENT OF THE DISTRICT OF COLUMBIA
DEPARTMENT ON DISABILITY SERVICES**



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Human Rights Definitions

The Abnormal Involuntary Movement (“AIMS”) Scale. The AIMS aids in the early detection of tardive dyskinesia. This simple checklist takes only 10 minutes to complete and uses a five-point rating scale for recording scores for seven body areas: face, lips, jaw, tongue, upper extremities, lower extremities, and trunk. It is used to monitor movement disorders for peoples taking any kind of antipsychotic medication.

Aversive Practice. Unpleasant, painful, uncomfortable or distasteful stimuli used to alter a person’s behavior. The use of aversive interventions is strictly prohibited in all programs funded or operated by the Department on Disability Services (“DDS”), including but not limited to shock therapy, white noise, and bitter tasting foods procedures.

Behavior Support Plan (“BSP”). The BSP defines individually tailored behavior supports designed by a licensed professional or behavior management specialist supervised by a licensed professional to assist a person in ameliorating and/or eliminating the negative impact one or more challenging behaviors have on his or her daily life. The BSP identifies strategies and services necessary to support and encourage the person in his or her decision to reside within the community; decrease the impact of a behavioral event; to assist the person in developing alternative and more effective communication, adaptive and coping mechanisms; and enable the person to achieve positive personal outcomes. The BSP is based on an understanding that there are reasons for challenging behaviors and those in a person's life must work to understand the underlying reasons. Therefore, BSPs must be based on a thorough and thoughtful functional assessment that results in a BSP with steps and methods to help the individual address his/her challenging behaviors.

Capacity. The mental ability to understand the nature and implication of a decision (that there is a choice to be made) and the information (the alternatives) being presented; as well as, the ability to communicate that decision or give informed consent.

Challenging Behaviors. Behaviors that are seriously and consistently disruptive to the physical or social environment, that pose a significant danger to oneself or others, or that interfere with the attainment of learning goals or personal outcomes identified through an ISP process. Such behaviors may result from internal factors, from past learning or from environmental factors.

Chemical Restraint. The application of emergency psychotropic medication to control acute, episodic behavior that restricts movement or function of the person for the protection of the person or others from harm. Also, DDS considers the use of a psychotropic medication without a formal assessment and diagnosis of a corresponding mental health disorder to be a chemical restraint. The use of chemical restraint is strictly prohibited.

Complaint. A complaint is the formal expression by any person of their dissatisfaction or unhappiness with supports and services or treatment provided by or through DDS, their provider agency, or someone employed or volunteering to provide them with supports and services.

Communicative Intent of Behavior: Using a challenging behavior instead of speech for making something happen; to communicate something to another person (e.g. get a favorite item, gain attention, or escape from an undesirable situation).

Communication Replacement: An intervention strategy in which the person is taught a communicative alternative to his/her challenging behavior. In some situations, another behavior already in the person's routine may be used as communicative alternative. In either situation, the communicative alternative serves the same function as the challenging behavior.

Emergency Use of Restrictive Controls. Restrictive controls that are used in an emergency situation to briefly control behaviors that pose a risk of harm to the person or others, or to prevent the serious destruction of property, in a situation when those behaviors were not anticipated and where there is no approved Behavior Support Plan that incorporates the planned use of restraint or other restrictive techniques.

Evidence Based Practice. Evidence-based practice is the conscientious, judicious use of current best evidence in making decisions about care to people with disabilities. This approach is derived from the concept of evidence-based medicine, which began to emerge in 1980 as physicians first performed systematic reviews of the evidence for preventive services as a step in writing clinical practice guidelines. There are six steps in the provision of evidence-based practice: (1) decide what information is needed; (2) formulate one's information needs in the form of a question that a research study could answer; (3) search the published literature to find

the evidence; (4) decide which studies are valid and applicable to the person at hand; (5) apply the findings to the person; and (6) evaluate the outcomes.

Functional Analysis or Functional Assessment: The assessment seeks to describe the behavior and environmental factors and setting events that may predict the behavior in order to guide the development of effective support plans particularly by guiding the selection of new skills or replacement behaviors that serve the same behavioral function.

Human Rights and Freedoms. Basic rights and freedoms to which all humans are entitled, including but not limited to life, liberty, freedom of thought and expression, privacy, religion, freedom of choice, self-determination and equality before the law.

Human Rights Advisory Committee (“HRAC”). The Department on Disability Services’s HRAC is charged with the responsibility of providing guidance and oversight in all matters pertaining to the human rights of people receiving services as part of the DDS service delivery system. Through its oversight and recommendations, the Committee safeguards and promotes the rights and freedoms of people supported by the Developmental Disabilities Administration by ensuring that all allegations of human rights violations are properly reviewed and resolved.

Informed Consent. The knowing consent voluntarily given by a person (or by the person's substitute decision-maker, if applicable) who can understand and weigh the risks and benefits involved in the particular decision or matter. Whenever the informed consent of the person or his or her substitute decision-maker is required, the following criteria shall apply:

1. The consent of the person or his or her substitute decision-maker shall be in writing and filed in the person's record;
2. The written consent shall be dated and shall expire upon completion of the specific procedure for which it applies; in any event an informed consent shall expire one year after it is signed;
3. No coercion or overbearing inducement shall be utilized to obtain consent;
4. A written record shall be made which:
 - a. details the procedure utilized to obtain the consent;
 - b. identifies the name, position, and affiliation of the person securing the consent; and
 - c. summarizes the information provided to the person from whom consent is secured.
5. The person securing the consent shall:
 - a. explain the intended outcome and nature of, and the procedures involved in, the proposed treatment or activity;
 - b. explain the risks, including side effects, of the proposed treatment or activity, as well as the risks of not proceeding;
 - c. explain the alternatives to the proposed treatment or activity, particularly alternatives offering less risk or other adverse effects;

- d. explain that consent may be withheld or withdrawn at any time, with no punitive action taken against the person;
 - e. present the foregoing information in a manner which can be understood by the person, or his or her substitute decision-maker, if any; and
 - f. offer to answer questions that the person or his or her substitute decision-maker may have regarding the matter for which consent is being sought.
6. The appropriateness of the consent shall be reviewed as part of the annual review of the person's ISP.

Least Restrictive Intervention: Restrictive interventions may be implemented incrementally just sufficient to eliminate the imminent risk of harm or serious property destruction. The least restrictive intervention is considered achieved when less intrusive alterations/interventions would not protect the individual or others from imminent harm or prevent property destruction.

Meaningful Activities: Activities that increase personal satisfaction or enhance positive social interactions across work, academic, recreational, and community settings. Valued outcomes include increases in quality of life as defined by a person's unique preferences and needs and promote positive lifestyle changes that increase social belonging.

Most Integrated Setting. Settings, modes of services and styles of living or working that are as integrated as possible, in settings that are typical and age-appropriate in the community, that interfere the least with the person's independence, and that promote the opportunity to actively engage with other people who live or work in that community.

Non-Restrictive Interventions: Non-restrictive interventions teach, maintain or increase desired behaviors using only positive reinforcement. Non-restrictive interventions include but are not limited to: (1) Environmental enhancements; (2) Role playing; (3) Modeling and imitation; (4) Self-control monitoring/instruction; (5) Prompting; verbal, gestural; (6) Behavioral contracting; (7) Shaping; (8) Differential reinforcement; (9) Chaining: forward, backward;; and (10) Redirection: verbal, gestural..

Behavioral contracting: An agreed upon arrangement where the person is provided with a reward upon meeting a specific behavioral goal

Chaining: An instructional procedure for teaching a new sequence of behaviors in which the person is either taught the last step in the sequence and proceeds to the first step through backward chaining or is taught the first step in the sequence and proceeds to the last step through forward chaining, until all behaviors in the sequence can be performed independently.

Differential reinforcement: A procedure in which behavioral responses that meet a specified criterion receive positive reinforcement while behavioral responses that do not meet the specified criterion do not receive positive reinforcement.

Environmental enhancements: A procedure that alters the physical environment, staffing, setting, use of assistive technology, available choices, or task demands to make it more likely that a desirable behavior will occur.

Imitation: A new skill or desired behavior is emitted by a person immediately after the person has observed a demonstration of the new skill or behavior

Modeling: Procedure for teaching new skills in which the person observes a demonstration of the desired behavior or skill

Prompting: Instructional procedure that provides help or assistance with performing a desired behavior. Prompting may consist of verbal reminders to perform a task, gestural reminders to perform the desired behavior or modeling the desired behavior.

Redirection: Verbal or gestural intervention procedure that is used to shift a person away from an inappropriate behavior and toward a more appropriate or desirable behavior.

Role playing: Procedure in which a person receives feedback while practicing social skills, problem-solving skills, or other skills in a contrived interpersonal situation.

Self control monitoring: Teaching a person to observe, record, and evaluate his/her behavior.

Shaping: Instructional procedure for teaching a desired behavior that involves positively reinforcing gradual changes in a behavioral response until the desired response is performed correctly.

Office of Rights and Advocacy (ORA): The Office of Rights and Advocacy, in the Quality Management Division, maintains overall responsibility for the coordination of all of DDS's advocacy activities and rights promotion and protection activities.

Other Responsible Parties. As used in these policies and procedures, this phrase is meant to encompass the substitute decision-maker, attorney and advocate of a person receiving DDS- funded or arranged service as well as other people and entities that have a legal responsibility to monitor providers.

Permanent Limited Guardian for Healthcare Decisions. An individual who is appointed by a court order to make medical decisions based on substituted judgment as a guardian for someone else pursuant to D.C. Official Code§ 21-2047. The individual named as the permanent limited guardian may include but is not limited to the person's parents, siblings, next of kin, court-appointed advocate, court-appointed Probate attorney, or others.

Positive Behavior Supports (PBS): Positive Behavior Support (PBS) is an evidence-based, person-centered approach to preventing challenging behavior that is based on a functional assessment of the behavior and the circumstances under which it occurs. PBS strengthens existing skills and teaches new behaviors that serve the same function as the challenging behavior, making the challenging behavior unnecessary. Through positive reinforcement strategies and modifications to the environment, PBS facilitates behavioral changes that promote independence and community integration.

Positive Reinforcement: applying a stimulus to increase the frequency of desired behaviors without depriving a person of his or her rights or imposing other prohibitions outlined in the DDS human rights policy.

Proactive Strategies: Proactive strategies include:

Environmental modifications or attempts to identify and change those features of the person's physical, interpersonal, or service environment, such as daily programming used to support the person's choices and teach practical skills, that might contribute to target behavior.

Positive Programming strategies for teaching new replacement skills and new competencies that provide a more effective/appropriate way of achieving the same function as the target behaviors. New skills are taught through direct instruction shaping, prompting, chaining, role play, or modeling/imitation.

Focused Support strategies that use differential reinforcement strategies to increase the use of alternative behaviors the person currently has in his or her repertoire.

PRN. "As needed" (*pro re nata*). PRN refers to a standing order for a medication or procedure, specifying the circumstances for which they would be used. The prescription and or administration of psychotropic medication to a person receiving DDA services on a PRN basis is strictly prohibited.

Provider. A private or public entity contracted with the District of Columbia Government who provides services and/or supports to people receiving services as part of the Department on Disability Services service delivery system.

Provider Human Rights Committee. A Committee established by a provider agency to review allegations of rights violations, serious reportable incident investigations, behavioral plans, etc., for receiving services to ensure that the human rights of people in their care are protected.

Psychotropic Medications. Medication prescribed specifically to stabilize or improve mood, mental status, or behavior. Common psychotropic medication include neuroleptics or anti-

psychotic (including major tranquilizers); anxiolytics (including minor tranquilizers, sedatives and hypnotics); stimulants, mood stabilizers; and anti-depressants. Anticonvulsants and other classes of drugs are included in this category when they are prescribed for behavioral purposes.

Representative. A person chosen by the person in order to assist them in communicating their issues and representing their interests. This could be a self-advocate, family member, friend, significant other, substitute decision-maker, or attorney.

Restraints. Actions that limit a person's voluntary movement for the purpose of keeping that person from doing serious harm to him/herself or others. Restraints are permitted only in extraordinary circumstances, where personal safety is at risk and positive behavior supports have not yet succeeded. Approval for any restraint must follow the review and approval guidelines set forth in the, human rights and restrictive control review policies and procedures. All restraints are restrictive procedures. Restraints can be physical, mechanical, and chemical.

1. *Chemical restraint* means a prescribed medication for the purpose of modifying, diminishing, controlling, or altering a specific behavior. *PRN use of psychotropic medication is considered chemical restraint and is prohibited.* Chemical restraint does not include the following:
 - a. Medication prescribed for the treatment of a diagnosed disorder as found in the current version of the American psychiatric association's "Diagnostic and Statistical Manual" (DSM); or
 - b. Medication prescribed for treatment of a seizure disorder.
2. *Emerging methods and technology* means new methods of restraint or seclusion that create possible health and safety risks for the person, including methods or technology that were not developed prior to the effective date of this policy;
3. *Mechanical restraint* means a device that restricts a person's movement or function applied for purposes of behavior support, including a device used in any vehicle, except a seat belt of a type found in an ordinary passenger vehicle or an age-appropriate child safety seat; and
4. *Physical restraint* means a hands-on method that is used to control an identified behavior by restricting the movement or function of the person's head, neck, torso, one or more limbs or entire body.

Restrictive Control or Restrictive Intervention: Restrictive interventions include, but are not limited to any device, procedure, protocol or action that restricts, limits or otherwise negatively

impacts a person's freedom of movement, control over his or her own body; or access to anything that would typically be available to people in the community, including privacy.

Restrictive Control Review Committee (RCRC). The RCRC reviews designated Behavior Support Plans that contain restrictive components to ensure that restrictive interventions are used only as a last resort, when active treatment strategies have been considered/ attempted and would not protect the person or others from harm.

Seclusion. Seclusion means any involuntary confinement of a person alone in a room or an area from which the person is either physically prevented from leaving or from which the person is led to believe he or she cannot leave at will.

Side Effects. Secondary effects of a drug, which are usually undesirable and are different from the therapeutic effect.

Substitute Healthcare Decision-Maker. Any individual authorized (by statute or by common law) to make decisions on behalf of another person to give or refuse consent to medical treatment options recommended by the person's physician. The decision whether or not to give consent shall be based on the known wishes of the person, but if the wishes of the person are unknown and cannot be determined, then the decision should be based on a good faith belief as to the best interests of the person.

Substituted Judgment. Making a decision that conforms as closely as possible with the decisions that the person would have made, based upon knowledge of the beliefs, values, and preferences of the person, as defined in D.C. Official Code § 21-2011(25A).

Tardive Dyskinesia (TD). One of the muscular side effects of anti-psychotic drugs, especially the older generation medications like haloperidol. TD does not occur until after many months or years of taking antipsychotic drugs, unlike akathisia (restlessness), dystonia (sudden and painful muscle stiffness) and Parkinsonism (tremors and slowing down of all body muscles), which can occur within hours to days of taking an antipsychotic drug. TD is primarily characterized by random movements in the tongue, lips or jaw as well as facial grimacing, movements of arms, legs, fingers and toes, or even swaying movements of the trunk or hips.

Temporary Emergency Guardian for Healthcare Decisions. An individual who is appointed by court order to make medical decisions based on substituted judgment as a guardian for someone else, whose authority is for a specified period of time, and who usually is appointed in an emergency care or urgent care situation pursuant to D.C. Official Code § 21-2046.