

1001-A RIGHTS AND RESPONSIBILITIES OF INDIVIDUALS SUPPORTED BY THE DIVISION OF DEVELOPMENTAL DISABILITIES

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REFERENCES: A.R.S. § 36-551.01, A.R.S. § 41-3801, A.R.S. § 41-1492 et seq., A.R.S. § 41-1959; A.A.C. R9-21-211; A.A.C. R6-6-102; R6-6-104, R6-6-107, R6-6-108, R6-6-804, R6-6-901, R6-6-901-910 et seq., R6-6-1801 et seq., R6-6-1114

PURPOSE

To identify the rights and responsibilities that an individual has by virtue of being enrolled in programs operated or overseen by the Division of Developmental Disabilities (Division or DDD).

DEFINITIONS

1. "Individualized Family Service Plan" or "IFSP" means a written plan for providing early intervention services to an infant or toddler with a disability and the child's family that (a) is based on the evaluation and assessment; (b) includes parental

consent; c) is implemented as soon as possible once parental consent is obtained; and (d) is developed in accordance with IDEA Part C.

2. "Person-Centered Service Plan" or "PCSP" means a written plan developed through an assessment of functional need that reflects the services and supports (paid and unpaid) that are important for and to the member in meeting the identified needs and preferences for the delivery of such services and supports. The PCSP shall also reflect the member's strengths and preferences that meet the member's social, cultural, and linguistic needs, individually identified goals and desired outcomes, and reflect risk factors (including risks to member rights) and measures in place to minimize them, including individualized back-up plans and other strategies as needed.
3. "Planning Document" means a written plan developed through an assessment of functional needs that reflects the services and supports, paid and unpaid, that are important for and important

to the Member in meeting the identified needs and preferences for the delivery of such services and supports.

4. "Support Coordinator" means the same as "Case Manager" under A.R.S. § 36-551.

POLICY

A. MEMBER RIGHTS

1. The Division shall recognize that an individual with a developmental disability has the same rights, benefits, and privileges guaranteed by the constitutions and laws of the United States and the State of Arizona, including the:
 - a. Right to exercise their rights as a citizen;
 - b. Right to participate in social, religious, educational, cultural, and community activities;
 - c. Right to own, rent, or lease property;
 - d. Right to marry and have children;
 - e. Right to be free from involuntary sterilization;

- f. Right to express human sexuality and receive training as appropriate;
 - g. Right to consume alcoholic beverages if 21 years of age or older unless contraindicated by orders of their primary care provider or the court;
 - h. Right to the presumption of legal competency in guardianship proceedings;
 - i. Right to own and have free access to personal property;
 - j. Right to associate with persons of their own choosing;
 - k. Right to manage personal financial affairs and to be taught to do so;
 - l. Right to the least amount of physical assistance necessary to accomplish a task;
2. The Division shall recognize the following additional rights of an individual with a developmental disability receiving supports and services through the Division:

- a. Right to be treated fairly regardless of race, ethnicity, culture, national origin, ancestry, religion, gender identity or expression, age, health, social origin or condition, creed, behavioral condition (intellectual) or physical disability, sexual orientation, genetic information, marital status, medical condition, or ability to pay;
- b. Right to be treated with respect and with due consideration for their dignity and privacy by DDD staff and providers;
- c. Right to a safe, clean, and humane physical environment;
- d. Right to be free from any form of restraint or seclusion used as a means of coercion, discipline, convenience, or retaliation;
- e. Right to protection from physical, verbal, sexual, psychological, or financial abuse, punishment, neglect, or exploitation;
- f. Right to be free from overcorrection or the application of noxious stimuli as a negative consequence of a behavior;

- g. Right to know who their Support Coordinator is and how to request a new Support Coordinator;
- h. Right to an initial Person Centered Service Plan or Individualized Family Services Plan (PCSP or IFSP) planning document prior to receiving supports and services;
- i. Right to participate and share in decision-making once approved and to receive a written PCSP or IFSP based upon relevant assessment results;
- j. Right to participate in the PCSP or IFSP, periodic evaluations, and whenever possible, the opportunity to select among appropriate alternative supports and services;
- k. Right to a periodic review of the PCSP or IFSP planning document;
- l. Right to be supported by the organization to collaborate on decisions with their case manager;

- m. Right to be informed of all case management services available, even if a service is not covered, and to discuss options with their case manager;
- n. Right to be provided choices and to express individual preferences that will be respected and accepted;
- o. Right to be given information in a way they can understand;
- p. Right to have interpreter services or documents translated into their primary language;
- q. Right to be given written notice of their rights in their primary language, in a manner that can be easily understood in the primary mode of communication, if possible;
- r. Right to live in the least restrictive setting. A least restrictive setting refers to an environment in which a member strives to reach their full potential in accordance to the tenets of self-determination;

- s. Right to equal employment opportunities based on the member's ability to meet qualifications;
- t. Right to fair compensation for labor;
- u. Right to be free from unnecessary and excessive medication. Medication shall not be used as punishment, for the convenience of the staff, as a substitute for a PCSP or IFSP, or in quantities that interfere with the member's PCSP or IFSP;
- v. Right to be accorded privacy when receiving mail, during visits and telephone conversations;
- w. Right to be accorded privacy during personal care, medical treatments, or personal discussions;
- x. Right to confidentiality of information and medical records;
 - i. Have personally identifiable data and medical information kept confidential;
 - ii. Know what entities have access to their information;

- iii. Know procedures used by DDD to ensure their security, privacy and confidentiality.

- z. Right of a school-age member to receive publicly-supported educational services;

- aa. Right of a child to receive appropriate supports and services, subject to available appropriations, which do not require the relinquishment or restriction of parental rights or custody, except as prescribed in A.R.S. § 8-533, which describes the grounds needed to justify the termination of the parent-child relationship;

- bb. Right to withdraw from programs, supports and services, unless the member was assigned to the Department of Child Safety by the juvenile court or placed in a secure facility by the guardian and court;

- cc. Right to file a grievance against the Division.

- dd. Get help understanding the appeal process including how to appeal when a benefit is denied;

- ee. Right to access information about the Division, its staff, its contractors, and staff qualifications.
- ff. Right to refuse interviews related to crimes committed against them;
- gg. Right to consent to or withhold consent from participation in a research project approved by the Division management team or any other research project: right to knowledge regarding the nature of the research, potential effects of a treatment procedure as part of a research project, right to confidentiality, and the right to withdraw from the research project at any time.
- hh. Right to petition the Superior Court for redress when they believe that their rights have been violated, unless other remedies exist under federal or State laws;
- ii. Right to contact the Independent Oversight Committee;

3. The Division shall recognize the following additional rights of an individual with a developmental disability who is eligible for the Arizona Long Term Care System (ALTCS):
 - a. Right to know about providers who speak languages other than English;
 - b. Right to receive services in the community at the same level as others not receiving Medicaid home and community based services;
 - c. Right to select where services are provided based on individual needs, preferences and resources;
 - d. Right to make life choices, including daily activities, physical environment, with whom they interact, and who provides services and supports;
 - e. Right to have personal care needs provided, except for cases of emergency, by a direct care staff of the gender chosen by the responsible person; this choice shall be specified in the Planning Document;

- f. Right to make decisions about their care, including refusing care or getting details about what could happen if they do or do not get care;
- g. Right to get a second opinion from a qualified physical or behavioral health care professional at no cost within their health plan network or outside the network if there is no in-network option;
- h. Right to get information about their treatment options and alternatives in a way that is understandable;
- i. Right to develop a contingency plan with their provider agency to decide what they want to do if a caregiver is late or does not show up for each of their assessed services;
- j. Right to request information about the structure and operation of their health plan, including their contract with the Division of Developmental Disabilities;
- k. Right to know how their health plan pays providers, controls costs, and uses services;

- l. Right to see their health care records at any time and to request they be changed or corrected;
- m. Right to request a copy of their health care records at no cost every year and to receive a response to that request within 30 days of making the request;
- n. Right to receive emergency care at any hospital or other setting without prior approval from their doctor or health plan;
- o. Right to create advance directives that protect their right to refuse unwanted health care or to request wanted care if they are too ill to make decisions;
- p. Right to file a grievance not only with the Division but also with their health plan, the Arizona Long Term Care System (ALTCSS) and Arizona Health Care Cost Containment System (AHCCCS);
- q. Right to get information on beneficiary and plan information;

- r. Right to information regarding the supports and services available through a provider and about related charges, including any fees for supports and services not covered by a third-party payor;
 - s. Right to an administrative review, if in disagreement with a decision made by the Division, by filing a verbal or written request for such with the DDD Office of Compliance and Review, and the right to appeal the decision;
4. The Division shall recognize the following additional rights of an individual with a Serious Mental Illness designation:
- a. Right to receive the right kind of mental health services based on individual need;
 - b. Right to Participate in all areas of mental health treatment, including individual service or treatment plan meetings;
 - c. Right to have a discharge plan before leaving the hospital;
 - d. Right to consent or say Yes or No to treatment (except in an emergency or by court order);

- e. Right to have treatment or medical help in a similar area as others or in the least restrictive area to meet the individual needs;
- f. Right to be free from unnecessary seclusion or restraint;
- g. Right to not be physically, sexually, or verbally abused;
- h. Right to privacy (mail, visits, telephone conversations);
- i. Right to file an appeal or grievance when unhappy with services, something is not working, or feel treated unfairly;
- j. Right to choose a designated representative(s) to assist during service or treatment planning meetings and in filing grievances;
- k. Right to a case manager to work with you to get the services or help needed;
- l. Right to a written behavioral health service or treatment plan that sets forth the services you will receive;
- m. Right to associate with others;

- n. Right to confidentiality of psychiatric records;
 - o. Right to get copies of psychiatric records (unless it would not be in the best interest to have them);
 - p. Right to appeal a court-ordered involuntary commitment and to consult with an attorney and to request judicial review of court-ordered commitment every 60 days; and
 - q. Right to not be discriminated against in employment or housing.
5. The Division shall recognize the following additional rights of individuals living in Community Residential Settings:
- a. Right to be treated with dignity and respect by DDD staff and providers;
 - b. Right to impartial access to treatment or accommodations;
 - c. Right to a safe, humane, and clean physical environment;
 - d. Right to make decisions about their care, including refusing care or getting details about what could happen if they do

or do not get care and communicate directly with those responsible to provide care;

- e. Right to choose their personal care provider;
- f. Right to be informed of their medical condition, of any technical procedures which may be performed, of the identity of the persons who will perform the procedures, attendant risks of treatment and the right to refuse treatment;
- g. Right to be free from unnecessary drugs and physical restraints, except as authorized in writing by a physician for a specified time period and in accordance with the Division rules regarding behavior supports;
- h. Right to a physical examination and prompt medical attention;
- i. Right to refuse to talk with or see someone;
- j. Right to participate in social, religious, and community group activities;

- k. Right to manage their own financial affairs and be taught to do so to the extent of their capabilities;
- l. Right to refuse to perform services for the home, but if they do provide services, right to be compensated at prevailing wages commensurate within state and federal laws and as prescribed by the Industrial Commission;
- m. Right to file an incident report;
- n. Right to file a grievance not only with the Division but also with their health plan, the Arizona Long Term Care System (ALTCSS) and Arizona Health Care Cost Containment System (AHCCCS);
- o. Right to the least amount of physical assistance necessary to accomplish a task;
- p. Right to have care for personal needs provided, except in cases of emergency, by a direct care staff of the gender chosen by the responsible person and to have the choice specified in the PCSP or IFSP planning document;

- q. Right to use available resources to select the home in the community in which they live;
- r. Right to have a written residency agreement in place;
- s. Right to have keys to their home and bedroom doors, or alternatives in place, to support the free entry and exit from their home;
- t. Right to physically access their home and areas within their home;
- u. Right to have choices over whom they live with, and only share a bedroom if they choose to do so;
- v. Right to decide how to furnish and decorate their home;
- w. Right to decide how to use outdoor spaces;
- x. Right to have access to privacy within their homes including privacy with regard to written correspondence, telephone communication, and visitors;

- y. Right to make informed choices about how they spend their time in and outside of their homes;
- z. Right to have access to food and supplies within their home;
- aa. Right to have visitors when they want to;
- bb. Right to own and have free access to personal property.

B. MEMBER RESPONSIBILITIES

1. The Division shall notify all individuals supported by the Division of Developmental Disabilities that they have the responsibility to:
 - a. Be as active a participant as possible in their person-centered service plan (PCSP) meetings;
 - b. Notify their Support Coordinator in advance if they are unable to attend their scheduled person-centered service planning meetings;

- c. Follow the mutually agreed-on person-centered service plan or notify their Support Coordinator if they cannot follow the plan;
 - d. Notify their Support Coordinator and their usual care provider(s) if they disenroll from DDD;
 - e. Provide DDD with accurate and timely information necessary to deliver services;
 - f. Participate in the DDD redetermination process at ages 6 and 18 or at any time deemed appropriate by the Division's Assistant Director.
2. The Division shall notify all individuals supported by the Division of Developmental Disabilities who are also eligible for the Arizona Long Term Care System (ALTCS) that they have the responsibility to:
- a. Participate in the Arizona Long Term Care System (ALTCS) eligibility process, including providing documentation when requested;

- b. Keep scheduled doctors and therapy appointments or cancel them at least 24 hours ahead of time;
- c. Go to your doctor during office hours if possible instead of using urgent care or the emergency room;
- d. Provide accurate and honest information to health care providers;
- e. Notify the Division of changes in private/commercial health insurance coverage, including Medicare or Tricare, or other qualifying life event;
- f. Follow instructions provided by health care providers and ask questions if they do not understand the instructions.