

# Arizona Center for Disability Law

Protection and Advocacy System for Arizona

## Your Rights as a Person with Serious Mental Illness

### A Self-Advocacy Guide

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Federal and state law can change at any time. If there is any question about the continued validity of any information in the handbook, contact the Arizona Center for Disability Law or an attorney in your community.

The purpose of this guide is to provide general information to individuals regarding their rights and protections under the law. It is not intended as a substitute for legal advice. You may wish to contact the Arizona Center for Disability Law or consult with a lawyer in your community if you require further information.

This guide is available in alternative formats upon request.

# A Self Advocacy Guide: Your Rights as a Person with Mental Illness

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# **Your Rights as a Person with Serious Mental Illness**

## **Arizona Center for Disability Law**

Some people think that once you're diagnosed with a serious mental illness, you lose many or all of your rights. In fact, some people and agencies tend to treat those diagnosed as though they have no rights. In fact, people with serious mental illness have specific rights that are guaranteed by the laws of Arizona and the United States.

All citizens of the United States and the State of Arizona have certain basic rights of citizenship. In addition, people with certain kinds of disabilities, including psychiatric disabilities, have legal rights designed to protect them from abuse, neglect, and discrimination.

Some people with a serious mental illness will be able to exercise fewer of their basic rights of citizenship because they have been convicted of a crime or they have a legal guardian. Loss of rights does not necessarily follow a diagnosis of mental illness or even court-ordered treatment. Even those people who may not exercise full rights of citizenship are covered by the laws protecting people with serious mental illness.

This booklet and training were designed to help you understand your rights as a person with a serious mental illness in the State of Arizona. You may think of questions as you go through this training, questions specific to your particular experience. We encourage you to ask these questions during the training, or write them down so that you can ask during the time allowed for questions. If you're having a particular problem, chances are good someone else has had the same problem. If you ask about your rights and how they apply to a particular situation, you will also help others learn how to get the help they need.

In Arizona, rights for people with serious mental illness are spelled out in Arizona Revised Statutes § 36-504 through 36-514, and in the Arizona Administrative Code, Title 9, Chapter 21, Section 201 through 211. This booklet will show you the specific statute that defines each right to help you apply them more effectively.

Think about a time when you thought your rights were being violated. What happened? What did you do about it? Were you successful? \_\_\_\_\_

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## Basic Rights of Citizenship

These are some of the basic rights held by citizens:

- ☆ The right to freedom of religion and religious practice. Each person should be able to exercise their own religious practice of preference, without compulsion to practice or change religion. R9-21-201(A)(5)
- ☆ The right to be free from unlawful discrimination by any mental health agency on the basis of race, creed, religion, sex, sexual preference, age, physical or mental handicap, or degree of handicap. R9-21-201(A)(3)
- ☆ The right to equal access to all *existing* publicly available behavioral health and community services provided in Arizona. R9-21-201(A)(4)
- ☆ The right to acquire and dispose of your own money and property. \*\* R9-21-201(A)(1)
- ☆ The right to enter into contracts, to marry or divorce.\*\* R9-21-201(A)(1); R9-21-201(A)(16)
- ☆ The right to have a driver's license or other occupational or professional license.\*\* R9-21-201(A)(1)
- ☆ The right to register to vote and to vote.\*\* Assistance must be provided if you need help. R9-21-201(A)(6)

Can you think of times when these rights have been denied you? \_\_\_\_\_

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### Basic Civil Rights of Persons Receiving Mental Health Services:

- ☆ The right to participate in all phases of treatment, including ISP meetings.
- ☆ The right to consent to or refuse treatment (except in an emergency or by court order).\*\*
- ☆ The right to freedom from unnecessary seclusion and restraint.
- ☆ The right to be free from physical, sexual, or verbal abuse.
- ☆ The right to a written ISP and/or ITDP that sets forth the services you will receive.
- ☆ The right to appeal a court-ordered involuntary commitment and to consult with an attorney and to request a judicial review of court-ordered treatment every 60 days.
- ☆ The right to communicate while in an inpatient or residential facility. This includes the right to reasonable access to a telephone and an opportunity to make and receive calls in privacy. The right to send and receive uncensored and unopened mail is also included, and assistance must be provided if necessary. Telephone use and mail may be limited for good cause. R9-21-201(A)(7)

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\*\* Unless under guardianship

- ☆ The right to have visitors while in an inpatient or residential facility. The facility may impose guidelines and visiting hours only to protect the privacy of others or to prevent disruption of the normal functioning of the facility. R9-21-201(A)(8)
- ☆ The right to have friends and associates of one's own choosing. Persons receiving services may join with others in associations or groups and they may discuss general program matters with agency staff and directors. People receiving services may publicize and hold meetings with others, inviting friends and others to participate in those meetings. These rights may be limited only if the exercise of these rights creates a serious disruption to the normal functioning of the agency. R9-21-201(A)(9)
- ☆ The right to privacy. No person or agency may take your photograph or your fingerprints without your permission, except that an agency may take a photograph of a client when they are admitted to the agency. The photograph may be used only for that purpose and may not be disclosed except upon a court order. R9-21-201(A)(10); A.R.S. § 36-507
- ☆ The right to wear personal clothing, to keep one's own possessions, and to keep and spend at least a portion of one's money. Agencies may limit these rights if full exercise of the rights creates a risk to the safety of the person or others. Denial of these rights must be fully documented. A.R.S. § 36-507
- ☆ The right to be notified of all client rights, in language that the person can understand. R9-21-201(A)(11)
- ☆ The right to file a grievance if any of these rights are denied. This includes the right to have a grievance considered fairly, in a timely manner, and in impartial procedures. It also includes the right to be free from retaliation for filing a grievance. R9-21-201(A)(12)
- ☆ The right to have access to a human rights advocate to help a person understand, exercise, and protect his or her rights. R9-21-201(A)(13)
- ☆ The right to be represented by an attorney or other designated representative of the person's choice. This includes the right to meet privately with the attorney or representative. R9-21-201(A)(14)
- ☆ The same civil rights as all citizens of the State of Arizona, including the right to live in the community one chooses without any limitations on one's independence, except those that apply to all other citizens. R9-21-201(A)(16)

Can you think of times when these rights have been denied you? \_\_\_\_\_

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## Other Basic Rights

### *Confidentiality*

You have the right to have your medical and mental health records and information kept confidential by your providers, with some exceptions. Records may be disclosed to those persons immediately involved in your care; to persons for whom you have signed a valid release of information document; to legal representatives working on your behalf; and upon a court order. Other information may be released without identifying information for the purpose of gathering statistics and monitoring by Human Rights Committees and other advocacy agencies. (A.R.S. § 36-509)

You have the right to read and copy your own medical and mental health records, *unless* a physician believes that disclosure is not in your best interest. If a physician declines to provide access to your mental health records because it is not in your best interest, the doctor or agency declining your request for access must provide documentation of the reason for withholding records. In addition, the documentation must list the parts of your record that are being withheld. All other portions of your record must be provided to you. R9-21-209(B)

If an agency or doctor refuses to provide your mental health records, you may file a grievance. You can also file a grievance if a doctor or agency discloses your mental health records or information to someone not involved in your treatment without your consent, including to law enforcement.

“Involved in your treatment” has a very narrow meaning. If, for instance, you are receiving services at a local mental health facility (such as a case management site), the people who may have access to your records and information about your treatment include the people who provide *direct* services (doctor, nurse, case manager), their supervisors, quality managers, and people involved with medical records. If you are receiving treatment or services from more than one agency, you must sign a release of information for those two agencies to communicate with one another. This includes vocational rehabilitation, medical doctors, day programs.

Under Arizona law, some basic information may be provided to family members who are actively participating in your care, treatment or supervision. This information is limited to “diagnosis, prognosis, need for hospitalization, anticipated length of stay, discharge plan, medication, medication side effects and short-term and long-term treatment goals” (A.R.S. § 36-509).

Can you think of an example of a violation of the right to confidentiality? \_\_\_\_\_

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***Housing***

It is illegal, under federal and state fair housing laws, to discriminate against people with disabilities in obtaining housing. Under the fair housing laws, a person with a psychiatric disability is someone with a history of treatment or someone who is perceived to have a disability. You cannot be denied housing because you are receiving psychiatric treatment, or because you have received psychiatric treatment in the past.

It is not legal for rental or leasing agents to ask if you or anyone in your household has a serious mental illness, unless the housing is designed specifically for people with serious mental illness and that diagnosis is a qualification for obtaining housing.

People with disabilities may request reasonable accommodation in rules, policies, practices or services. For example, a reasonable accommodation might mean that the rental agent waives the requirement of a previous rental history for someone just leaving a residential or inpatient facility.

Rent or mortgage agreements must be the same for people with disabilities as they are for people without disabilities. Special conditions applying to your disability are illegal. In addition, people with disabilities can be evicted only under the same terms and conditions as other tenants.

If you feel that a housing provider has discriminated against you because of your disability, you may file a complaint of housing discrimination with the Civil Rights Division of the Arizona Attorney General’s Office and/or the U.S. Department of Housing and Urban Development. You may also file a complaint in state or federal court.

Do you know of an example of a violation of the right to fair housing? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

***Employment***

Several federal laws prohibit employment discrimination based solely on disability, including psychiatric disability. These laws include the Americans with Disabilities Act (ADA), the Rehabilitation Act, and the Civil Rights Act of 1991. These laws define disability in a way that includes people with a history of treatment or those who are perceived to have a disability. Prospective employers may not deny jobs to otherwise qualified candidates because of a history of mental health treatment. Employers may not ask if you have a mental illness or if you have been hospitalized or treated for mental illness, before making a job offer. After a job offer has been made, an employer can require a physical or mental exam, as long as all prospective employees undergo the same exam.

Sometimes you want or need to disclose a disability to a prospective employer. You must disclose the nature of your disability if you plan to request accommodation of any kind. A prospective employer may ask if you know of anything that would keep you from performing the job function. Employers are required to provide reasonable accommodation. “Reasonable”

means the accommodation can't create an undue hardship on the employer. Reasonable accommodation might mean a different work schedule, or allowing a job coach to be with you at work.

In Arizona, vocational rehabilitation services are available to people with a psychiatric disability. You may be eligible if you have a disability that causes significant difficulty with finding employment, and if it's reasonable to expect that services will improve your chances of becoming successfully employed.

Have you seen or experienced violations of the fair employment rights? \_\_\_\_\_

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### ***Access to Public Accommodations***

The ADA requires that public accommodations must be accessible to people with all kinds of disabilities. This includes all public services such as hotels, restaurants, banks, parks, public schools, stores, and libraries. People with disabilities are subject to the same requirements with regard to use of public facilities as are other people. Government services and facilities must be accessible to people with disabilities without discrimination.

## **Right to Support and Treatment**

These rights are documented in the Arizona Administrative Code, Title 9, Chapter 21. The rules apply to people receiving services in the public behavioral health system in the State of Arizona.

- ☆ A client has the right to behavioral health or community services under conditions that support the person's personal liberty to the fullest extent possible, and from a system that is flexible enough to respond to the person's individual needs by changing, increasing or decreasing services as those needs change. R9-21-202(A)(1)(a-b)
- ☆ Services must be provided in a way that preserves the person's human dignity;
- ☆ Services must be provided in a way that respects individuality, ability, need and aspiration without regard to psychiatric condition (providers must treat you like an individual and not like everyone else);
- ☆ Services must be provided in a way that encourages self-determination, freedom of choice, and participation in treatment to the fullest extent possible (your services should promote empowerment and recovery, not dependence);

- ☆ Services must be provided in a way that ensures freedom from discomfort, distress and deprivation that might come from an unresponsive and inhumane environment (service settings and providers should not be inhumane, nor should they ignore your needs);
- ☆ Services must be provided in a way that promotes privacy, including clearly defined private living, sleeping and personal care spaces to the fullest extent possible (this includes your right to confidentiality of records and information);
- ☆ Services must be provided in a way that maximizes integration into the person's community through housing and residential services in residential neighborhoods. Services should rely on generic support services to support ordinary community experiences, using specialized mental health programs located in or near generic community services (as much as possible, services should be provided in your preferred community);
- ☆ Services must be provided in a way that offers humane and adequate support and treatment that is responsive to the person's needs and capable of adjusting to those changing needs (services should be adequate and adaptable to what you need, as your needs change). R9-21-202(A)(c)
- ☆ Services must be provided in a way that provides opportunities to:
  - ☆ Receive services that are adequate, appropriate, consistent with the person's individual needs, and least restrictive of freedom;
  - ☆ Receive treatment and services that are culturally sensitive in structure, process and content;
  - ☆ Receive services on a voluntary basis to the maximum extent possible and entirely if possible;
  - ☆ Live in the person's own home;
  - ☆ Undergo normal experiences, including experiences with an element of risk, unless those experiences create *unreasonable* jeopardy to the safety or well-being of the person or others; and
  - ☆ Engage in activities and styles of living that encourage and maintain integration into the community, consistent with the person's interests. R9-21-202(A)(d)
- ☆ A client has the right to participation in service planning, including participation in the development and revision of one's individual service plan. R9-21-202(A)(2)
- ☆ A client has the right to be provided with a reasonable explanation of all aspects of one's condition and treatment. R9-21-202(A)(3)
- ☆ A client has the right to give informed consent to all behavioral health services. A client also has the right to refuse consent to behavioral health services, except in an emergency or when a person has been ordered by the court to undergo treatment. R9-21-202(A)(4)
- ☆ A client has the right to refuse to participate in experimental treatment unless they give voluntary, written informed consent. A client also has the right to any protections associated with participation in such experimental treatment, and the right to revoke that consent. R9-21-202(A)(5)

- ☆ A client has the right to a humane treatment environment that provides protection from harm, allows appropriate privacy, and ensures freedom from verbal or physical abuse. R9-21-202(A)(6)
- ☆ A client has the right to basic goods and services in a timely manner. In residential or inpatient settings, these goods and services include nutritious and appetizing food at appropriate times; adequate and appropriate clothing that is clean, seasonal and chosen by the person; help with access to medical care, including contraception; opportunities for social contacts in the person's home, school or workplace; opportunities for daily activities, recreation and exercise; and individual storage places for personal possessions. R9-21-202(A)(7)
- ☆ A client has the right to be told of any charges for services, before those services are administered.
- ☆ A client has the right to a continuum of care in a unified and cohesive system of community services that is well integrated, facilitates the movement of people among programs, and ensures continuity of care. R9-21-202(A)(9)
- ☆ A client has the right to a continuum of care that includes, but is not limited to: case management, outreach, housing and residential services, crisis intervention and resolution services, mobile crisis teams, vocational training and opportunities, day treatment, rehabilitation services, peer support, social support, recreation services, advocacy, family support services, outpatient counseling and treatment, transportation, and medication evaluation and maintenance. R9-21-202(A)(10)
- ☆ A client has the right to programs that offer different levels of intensity of services that can meet the individual needs of each person. R9-21-202(A)(11)
- ☆ A client has the right to appropriate mental health treatment, based on each person's individual and unique needs. A client also has a right to those community services from which the person would reasonably benefit. R9-21-202(A)(12)
- ☆ A client has the right to have community services provided in the most normal and least restrictive setting, appropriate to the person's needs. R9-21-202(A)(13)
- ☆ A client has the right to clinical case management services and a case manager. The clinical team is to negotiate and oversee the provision of services and to ensure smooth transitions with providers and among agencies. R9-21-202(A)(14)
- ☆ A client has the right to participate in treatment decisions and in the development and implementation of the person's individualized service plan. A client has the right to participate in choosing the type and location of services, consistent with the Plan. R9-21-202(A)(15)
- ☆ A client has the right to have a written individualized service plan, to file grievances, and to have an advocate or other designated representative help in developing service plans and filing grievances. R9-21-202(A)(16)

Which of these rights did you not know previously? Which of these services is not being provided to you? What would you like to do about it?

Let's take a closer look at some of your rights with regard to treatment and support.

### ***Individualized Service Plan***

Each person has a right to an individualized service plan (ISP), which should be developed in collaboration with the service team and the person being served. The team may include a guardian or family members, an advocate, and any other person who provides services or who is supportive of the person. The ISP should be consistent with the person's choices and preferences and should maximize independence. R9-21-307

A person may reject the ISP if he or she does not feel that it is appropriate or meets needs. The case manager should contact you within seven days of distributing your plan to see if you agree with the plan. You have 30 days from the date of the ISP in which to reject the ISP or any portion of the ISP. If you tell your case manager that you reject your ISP, the case manager is required to provide written notice of your right to immediately appeal the ISP or to meet with the clinical team within seven days. If you choose to reject your ISP, the team is required to work with you to develop a new ISP that is more suitable. You may agree to continue to receive some services during the time that your new ISP is being developed. R9-21-308

A review of your ISP should be conducted at least every six months, or more often if your needs change. The review should be a meeting including you, your case manager, family members or guardian, an advocate if you have one, and any other supporters, plus a representative from every provider who provides services to you. The case manager should arrange the review meeting by inviting all participants at least 10 days prior to the proposed meeting date. The purpose of the review is to be sure that your ISP is always addressed at your current needs, that your needs are met in the most individualized and least restrictive manner, and that services reflect your progress in recovery. R9-21-313

At any time, the person receiving services has a right to request a modification or termination of the ISP. If you think that your service plan is not meeting your needs or it is not being implemented in a way that is useful to you, you can ask your case manager for a review of the ISP. At the review meeting, you can discuss any changes that you would like to your ISP. R9-21-314

How has your experience differed from these rules?

### ***Protection from Abuse, Neglect, Exploitation and Mistreatment***

You are guaranteed the right to be free from abuse, neglect, exploitation and mistreatment by any staff member or other people receiving services at a mental health agency. Mistreatment includes intentional, reckless or negligent action (or failure to act) that creates serious risk of physical or emotional harm. Mistreatment includes (among other things):

1. Abuse, neglect, or exploitation
2. Corporal punishment
3. Unreasonable use of force or threat of force when not necessary to protect you from bodily harm
4. Verbal or mental abuse, by screaming, ridicule, or name-calling
5. Inciting or encouraging you or others to mistreat you
6. Transferring you to another agency, or threats to transfer, as a punishment
7. Restraint or seclusion used for coercion, discipline, convenience, punishment or retaliation
8. Retaliation for reporting violations or filing complaints, grievances or appeals or for requesting an investigation
9. Commercial exploitation

Mistreatment may occur in other ways. You should report anything that you believe to be mistreatment. R9-21-203.

### ***Restraint and Seclusion***

Except under very clearly defined conditions, you have the right to be free from seclusion and restraint. R9-21-204. Agencies may use restraint or seclusion only:

1. To ensure your safety or the safety of others in an emergency
2. *After* they have tried other less restrictive means of helping you control your behavior and found those methods unsuccessful
3. Until the emergency passes and it's clear that you and others are safe
4. In a way that prevents physical injury to you, minimizes your physical discomfort and mental distress, and complies with the agency's policies and procedures
5. Restraint and seclusion *may not* be used for coercion, discipline, staff convenience, punishment or retaliation.

### ***Competency and Consent***

Everyone is presumed to be legally competent to manage one's own affairs and to give consent unless and until a court determines him or her to be incompetent. Court-ordered treatment by itself is not a determination of incompetence. R9-21-206

### ***Informed Consent***

You have a right to have given to you all the information you need to give informed consent to treatment, including all information about known risks or side effects of treatments, including:

- ☆ Psychotropic medication
- ☆ Electroconvulsive therapy, and
- ☆ Telemedicine

You have the right to give informed consent before admission to any medical detox, inpatient facility or residential program operated by a mental health facility.

You have a right to know about alternatives to the proposed treatment or program.

You have the right to revoke consent with no punitive action, and a right to be notified of potential consequences of revoking consent (including commitment). R9-21-206.01

Your right to give or refuse consent is altered if you have a guardian.

### ***Medication***

You have the right to receive information about medication, including information about risks and side effects, how to minimize risks, and any indications that treatment should be stopped. R9-21-207. You can ask about any alternatives.

You have the right to be free from unnecessary or excessive medication.

Medication may not be used for punishment, for staff convenience, or as a substitute for any other appropriate services.

Medication should be given in the least amount medically necessary, taking care as much as possible to minimize side effects.

Medication can be forced *if* it is part of a special treatment plan developed for a person who is undergoing court-ordered treatment.

### ***Court-Ordered Treatment and Evaluation***

In the State of Arizona, a person can be ordered by the court to undergo psychiatric treatment for four causes. R9-21-501. The person must be:

- ☆ A danger to self
- ☆ A danger to others
- ☆ Gravely disabled, or
- ☆ Persistently and acutely disabled

None of these terms is specifically defined in the Code. However, a finding of “persistently and acutely disabled” requires the petitioner to show that the person’s mental illness, if untreated, leaves the person at significant risk for “severe and abnormal mental, emotional, or physical harm that significantly impairs judgment, reason, behavior, or capacity to recognize reality.” In addition, the petitioner must show that the person is unable to submit to voluntary treatment, and that treatment has a likelihood of improving the person’s condition. A finding of “gravely disabled” requires the petitioner to show that the person, as a result of a mental illness, is “likely to come to serious physical harm or serious illness because s/he would be unable to provide for

his/her basic physical needs without hospitalization.” The petitioner must describe how the person’s mental illness impacts the person’s ability to provide for food, clothing, and hygiene, find and maintain shelter, acquire and keep steady employment, respond in an emergency, take care of any medical needs, and manage money. R9-21-504

Before the court orders a person to undergo treatment, for any cause, the person should first be offered voluntary treatment. Petitioners should show that other methods of treatment or engagement have been tried, and they must also show that treatment would be a benefit to the person.

Court-ordered evaluation means a person can be held against their will for up to 72 hours, during which time they undergo an evaluation to determine whether they meet the criteria for involuntary commitment. If the evaluation has not been completed within 72 hours, the person must be released. However, if at the end of 72 hours the facility conducting the evaluation determines that the person does meet criteria for commitment, they can continue to hold the person until a commitment hearing can take place.

## **Appeals and Grievances**

An appeal can be filed when you wish to contest a decision made by an agency. For example, you can request an appeal of: a decision concerning eligibility for services; assessments and evaluations; service and treatment plans and planning decisions; and how decisions are implemented. Usually appeals are made to the agency that made the determination. You should get notification of your right to appeal when you first apply for services, when determinations or decisions are made, during reviews or revisions of your treatment plan or individualized service plan, or when services are suspended or terminated. Appeals can be made for these issues:

1. Decisions regarding eligibility for behavioral health services
2. Sufficiency or appropriateness of assessments or evaluation
3. Long-term view, service goals, objectives, or timelines stated in the ISP
4. Recommended services identified in assessment reports, ISP or ITDP
5. Actual services to be provided as described in a plan
6. Access to or prompt provision of services provided under Title XIX
7. Findings of the clinical team with regard to competency, capacity to make decisions, need for guardianship or protective services, or need for special assistance
8. Denial of a request for a review of a plan, modification or failure to modify a plan, or termination of a service or treatment plan.
9. Application of procedures and timetables for development of ISP or ITDP
10. Implementation of ISP or ITDP
11. Decision to provide service planning, including assessment or case management services, to a client who refuses those services, or a decision not to provide those services to such a client

12. Decisions regarding fee assessments or denial of a request for a waiver of fees
13. Denial of payment for a client; and
14. Failure of the RBHA or the Division to act within the time frames for appeal. R9-21-401(C)

If you disagree with a decision that has been made on your behalf and you have not been notified of your right to an appeal, you may still file an appeal. Ask the provider for information about an appeal, or ask an advocate from the Office of Human Rights.

A client can initiate an appeal, or appeals may be initiated on a person's behalf by a parent or guardian, a designated representative, or a service provider if the client or guardian gives permission to the provider. Appeals should be initiated within 60 days of the decision, plan or action being appealed. Late appeals may be accepted if there is good cause.

The Division of Behavioral Health Services will conduct an investigation in four circumstances:

1. When a client dies
2. When a rights violation is alleged
3. When a condition is alleged that is dangerous, illegal or inhumane
4. When it would be in the public interest to investigate

At the conclusion of an investigation, the investigating office will send a summary of their findings to the person who requested the investigation. If the Office of Behavioral Health Licensing investigates, there is no appeal of their findings. If you request an investigation by the Office of Grievance and Appeals, Division of Behavioral Health Services, you have the right to appeal any findings. The letter explaining findings will tell you how to file an appeal and describe any time limitations.

Requests for investigation must be made to the appropriate entity. If the alleged rights violation occurs in a state-run agency, such as the Arizona State Hospital, the administrator of that facility is responsible for conducting an investigation. If you are claiming a rights violation under Title 9, Chapter 21, you will request an investigation by the Office of Grievance and Appeals.

## **Self-Advocacy**

Often we can get our needs met most quickly by advocating for ourselves. You can learn some skills and techniques that will help you become an effective advocate, both for yourself and for others. This brief guide will take you through some basic steps in self-advocacy.

The four basic steps to self-advocacy are:

1. Defining the problem
2. Developing an action plan

3. Carrying out the action plan
4. Evaluating your effectiveness

### ***Defining the problem***

The first step is to be very clear about the nature of the problem. It is not good enough to know that you are unhappy about something. Be careful that you are not defining your problem as a solution. In other words, if your problem is that the side effects of your medication are unbearable, don't frame the problem as "I want to stop this medication." The actual problem is, "The side effects are unbearable." If you avoid framing the problem as a solution, you leave space for many possible solutions to the problem.

It's helpful if you frame your problem in the language of the laws that describe rights. Study this guide and the applicable laws. Which law or rule covers your problem? Write it down and refer to that.

Next, write down your problem, being very clear and specific. It's helpful if you tackle one problem at a time. It may also be helpful for you to write down some possible solutions, especially the one you want most. Try to be open to alternative solutions other than your favorite one.

### ***Developing an action plan***

Before you do this, be sure you have completed the earlier step and you have a clear definition of the problem and some possible solutions. Now you can make a step-by-step plan to reach your goal, including gathering documentation, targeting people to contact, enlisting support (if necessary or possible), and setting dates for reaching objectives. Break down your plan into individual steps. Keep track of what you've done already.

As part of this step, you can also develop a contingency plan. What if you can't talk to a key person? What if you find out the law has been changed? What if you lose? Decide what parts of your goal are most important and what parts are open to compromise. Know what the minimal acceptable solution is for you. Be as flexible as you can be.

Developing your action plan should take a little time. This is a good investment. The better your preparation, the more likely you will be effective. Preparation time is also a good way to get some emotional clarity. It's never a good idea to engage in self-advocacy while you are angry or fearful. Use your preparation time to get your balance.

### ***Carrying out the action plan***

This involves following your plan, including any contingency plans. You may want to ask someone to accompany you when speaking to your target person. You may want to take notes with you, or a script, or even handouts. Many people like to practice what they're going to say before meetings. When you're speaking with someone, stay calm and stick to the facts. Stick to your script as much as possible. If you find yourself getting emotional or wanting to argue, ask for a break or end the meeting politely and come back another time. Don't attack people personally; they will become defensive and it will be harder to get what you need. Don't be afraid to look at your notes so you don't get confused. When the meeting is finished, thank the person for their time, whether or not you accomplished your goal.

Take notes of what happens in the meeting, or in a phone conversation. You should write down the names of the people you're speaking with. Ask how to spell their names. Include dates and times. If the person you're speaking with promises to do something, ask when you can expect it to be done and write down the date. If you promise to do something, write that down too along with the date so you don't forget.

If the other people at meetings are taking minutes, be sure you get a copy of the minutes when they are prepared. Compare them to your own notes for accuracy.

### ***Evaluation***

Once you have completed your action plan, look back at your actions and see if you were successful. Did you get what you wanted? Is the solution you got acceptable to you? Is there something else you want? If you're satisfied, review what you did to reach your goal so you know you can do it again if something else comes up. If you're not satisfied, start at the beginning of this process by redefining the problem and preparing a new action plan.

If you didn't get what you wanted on the first try, don't give up! It often takes more than one try. Ask yourself if your request is unreasonable based on what's available, or if you didn't have enough documentation to support your request. Maybe you need to talk to someone higher up in the organization.

Following are some simple forms to help you work through these four basic steps to self-advocacy.

## DEFINE THE PROBLEM

1. What exactly is the problem? \_\_\_\_\_  
\_\_\_\_\_
2. Who is involved? \_\_\_\_\_  
\_\_\_\_\_
3. What happened? \_\_\_\_\_  
\_\_\_\_\_
4. Where did it happen? \_\_\_\_\_
5. When did it happen? \_\_\_\_\_
6. Why did it happen? \_\_\_\_\_  
\_\_\_\_\_
7. How often does this problem occur? \_\_\_\_\_
8. Have I tried to resolve this problem before, what method did I use, and what was the result? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
9. Do other people have this same problem? If yes, who? \_\_\_\_\_  
\_\_\_\_\_
10. Has anybody else I know tried to solve a similar problem? \_\_\_\_\_
11. What has worked in the past? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
12. What hasn't worked in the past? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
13. Does Arizona Administrative Code Title 9, Chapter 21, address my problem? If so, what portions? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## ORGANIZE AND DEVELOP AN ACTION PLAN

Decide the approach you want to use to resolve the problem. Formal resolution methods include:

- A. Filing a formal appeal that leads to attending an Informal Conference to negotiate solutions
- B. Filing a grievance or request for investigation that leads you to describe the problem to an investigator

Choose the solution that fits your problem and break it down into manageable steps to be negotiated. Be prepared to discover solutions that nobody has thought of before. If you can, ask a supporter who is an experienced advocate to help you express your thoughts and prepare your plan. Think through each step and develop your full plan before you start to take action.

1. Who will be attending the meeting? \_\_\_\_\_
2. Who is supportive of your efforts? \_\_\_\_\_
3. Who is not supportive of your efforts? \_\_\_\_\_
4. What are your strong points? \_\_\_\_\_  
\_\_\_\_\_
5. What are your legal rights? \_\_\_\_\_
6. What are the benefits to you and others? \_\_\_\_\_  
\_\_\_\_\_
7. What are the facts in your favor? \_\_\_\_\_  
\_\_\_\_\_
8. What other information is important? \_\_\_\_\_  
\_\_\_\_\_
9. What are your weak points? \_\_\_\_\_
10. Past problems: \_\_\_\_\_
11. What are other possible solutions? \_\_\_\_\_
12. What will be possible claims against your goals? \_\_\_\_\_
13. What is the bottom line minimum that you will agree to? \_\_\_\_\_  
\_\_\_\_\_

## ACTION STAGE

The action stage can be very scary and feels like a big risk. Consider how you respond to this kind of setting. Will you get upset during the meeting? Think about this in advance and see how much emotion will be appropriate. If you have trouble meeting face-to-face, see if you can meet over the telephone. Certainly bring along a supporter, if possible. If you're bringing a supporter, practice with that person and make sure he or she understands the role you want them to play in the meeting. You may ask them to speak for you if you become too emotional.

1. **Write down the date and time of your meeting.** Be sure you have transportation, you know how to get there and where to park, and you allow enough time to arrive on time.
2. **Keep it simple.** Start your presentation with the most important facts. Say only the most important things about the problem and what you want. Keep it short. Say what you have to say and stop. Do not keep repeating the same thing over and over again. Avoid bringing in other unrelated topics or problems.
3. **Be willing to listen.** Your adversary may want to negotiate. They have listened politely to you, so you should be as courteous. If they have concerns or questions, answer them as completely as you can. Try to think of reasons why your solution is the best possible one.
4. **Make agreements.** State what you are willing to do. State your understanding of what others have agreed to do. Write down these agreements. Also write time lines for resolution.
5. **Document your efforts.** Keep a record of all phone calls and meetings. Write down all agreements. Get a copy of the meeting minutes. Compare the copy with your own notes. After a meeting, you may want to write a letter to the other people involved, including what you understood happened in the meeting and what you expect to happen next.

## EVALUATION

1. Did I get what I wanted and/or needed? \_\_\_\_\_
2. What went right? \_\_\_\_\_
3. Why? \_\_\_\_\_
4. What did I learn? \_\_\_\_\_
5. Can I use the same method again? \_\_\_\_\_
6. How do I feel about myself? \_\_\_\_\_
7. Are my needs met? \_\_\_\_\_
8. What went wrong? \_\_\_\_\_
9. Why? \_\_\_\_\_
10. What can I change? \_\_\_\_\_
11. How do I feel? \_\_\_\_\_

## Basic Advocacy Skills

### Remember these steps:

- ☆ Be prepared. Get as much information as possible.
- ☆ Talk to people on both sides. Everyone involved “owns” part of the problem.
- ☆ Be patient and polite, even if they aren’t. Remember that you may have to work with these people again.
- ☆ Take notes. Write down what they said and what you said. Especially write down what each of you said they would do.
- ☆ Keep your word. If you said you would do something, be sure to do it on time.
- ☆ Hold others accountable. If they said they would do something, follow up to be sure it’s done in the right way, on time.
- ☆ Remember that you deserve it. If you advocate for something based on your rights under the law, there’s no question about worthiness. They are here to serve you, not the other way around.
- ☆ Be flexible. There may be a way to resolve your problem that’s not exactly what you had in mind, but will work anyway.
- ☆ If you begin to feel angry, politely ask for a break, or reschedule for another time.
- ☆ Take a friend, supporter or other advocate whenever possible

### Try to avoid these bad habits:

- ☆ Don’t make it personal. Be hard on issues, not on people.
- ☆ Don’t tell lies, even “white lies” or “partial truths.” Once you damage your credibility, it’s hard to win it back.
- ☆ Don’t exaggerate, for the same reason you won’t tell lies.
- ☆ Don’t try to advocate with partial information. You’re likely to embarrass yourself and damage your case.
- ☆ Don’t raise your voice, make threats, call names, or engage in other unproductive behavior. It won’t help you win, and may get the wrong kind of attention.
- ☆ Don’t take “no” for an answer unless you’re absolutely sure you’ve tried all avenues and all possibilities.

## Advocacy Resources

There are many resources to help you with advocacy. Start with the advocacy agency closest to your problem. If you cannot get the help you need there, move up to the next agency.

Each RBHA has a customer service line. If you can't get help from your case manager or their supervisor at your service site, try the customer service line.

Each RBHA also has at least one Human Rights Committee. The Human Rights Committees are volunteer groups that have a legal mandate to monitor incident reports, seclusion and restraint, and rights violations. To learn more about these committees or to participate in one in your area, you can contact the RBHA in your area or call Jason Smith at the Division of Behavioral Health Services.

The Division of Behavioral Health Services operates an Office of Human Rights that employs advocates. You can reach an advocate at DBHS by calling (800) 421-2124.

The Arizona Center for Disability Law is the federally mandated protection and advocacy system for people with disabilities in the State of Arizona. You can get help and/or referrals if you are having problems getting services or are being discriminated against *because of your disability*. The Center has an office in Phoenix and one in Tucson. You can reach the Phoenix office at:

(602) 274-6287

(800) 927-2260

and the Tucson office at:

(520) 327-9547

(800) 922-1447

The Center also has a website at [www.acdl.com](http://www.acdl.com).

*NOTE: The information in this document is taken from the Arizona Administrative Code, the Arizona Revised Statutes, and publications of the Arizona Department of Health Services. Always check the current laws instead of relying solely on information from other sources, including this one.*

*AZ Administrative Code:* [www.azsos.gov/Rules\\_and\\_Regulations.htm](http://www.azsos.gov/Rules_and_Regulations.htm)

*AZ Revised Statutes:* [www.azleg.state.az.us/ArizonaRevisedStatutes.asp](http://www.azleg.state.az.us/ArizonaRevisedStatutes.asp)

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