

ADVOCACY PRINCIPLES AND STANDARDS

The mission of the Disability Rights Rhode Island ("DRRI") is to assist Rhode Islanders with differing abilities in their efforts to achieve full inclusion in society and to exercise their civil and human rights through the provision of legal advocacy.

To effectuate its mission statement, DRRI has developed the following principles and standards to guide its advocacy efforts on behalf of people with disabilities. These principles and standards reflect DRRI's commitment to the following values: **choice; autonomy; inclusion; integration; quality and accountability; independence and integrity.**

I. CHOICE

Freedom of expression and choice are fundamental human rights. DRRI protects, expands, and promotes the human and legal rights of people with disabilities. The role of DRRI is not to protect the individual, but to protect the individual's rights, including the individual's right to choose.

- A. Freedom of Choice.** All people have the ability to make and express choices in all aspects of their lives. DRRI affirms the right of freedom of choice by representing the expressed preferences of individuals and presumes the competency of its clients.
- B. Representation.¹** DRRI represents the expressed preferences of the people who become our clients even if a person has a disability, is a minor, or has been adjudicated incompetent. DRRI will not serve as a guardian ad litem, a guardian or in any other protective capacity. Nor will DRRI represent the wishes of a parent or guardian when those wishes are in conflict with the choices of a child/ward. DRRI is not a human service agency, but a law office with a mandate to protect and advocate for the rights of people with disabilities.

DRRI represents clients who have historically been devalued, who are often uninformed of their rights and who face substantial barriers to the enforcement of their rights, particularly enforcement through the courts. DRRI staff have heightened communication and legal advocacy skills to assist clients in confronting prejudice, stigma, and discrimination. Representation skills and efforts are aimed at assisting clients to overcome the passivity, dependence, and isolation that the human service system often engenders.

- C. Communication.** DRRI staff advise and present options to clients to assist them in making informed choices about their lives. DRRI clarifies client preferences in a non-judgmental fashion and ensures that individual preferences are heard and vigorously pursued within the scope of the law.

¹ Pursuant to 42 U.S.C.A. section 14401 et seq., DRRI staff members are prohibited from using federal funds to assert or advocate a legal right to cause, or to assist in causing, the suicide, euthanasia, or mercy killing of any individual.

1. **Alternate modes of communication.** DRRI will ascertain a person's primary mode of communication and will utilize appropriate auxiliary aids and services (e.g., sign language interpreters, writing, communication devices), as well as foreign language interpreters to communicate with individuals.
2. **Clients with limited communication.** DRRI recognizes that some people are unable to communicate their desires through traditional means and acknowledges our limitations in communicating with such persons. Every attempt will be made to ascertain a person's desires by observations of body language, gestures, and/or utterances (such as crying to communicate unhappiness or smiling to communicate pleasure or agreement). When necessary, DRRI will consult with others with knowledge of a person's communication skills (e.g., family members, service providers) in order to facilitate communication. When DRRI is unable to ascertain the person's desires, DRRI will act to preserve the person's autonomy and to maximize the opportunity for the person to be autonomous in as wide a range of settings as possible. DRRI will act to assure that the person's fundamental rights are safeguarded and advanced.

D. Dignity of Risk. DRRI believes that people have a right to control their own bodies, lives and happiness. All people have the right to "dignity of risk," meaning the right to make both "good" and "bad" choices.

Anyone who would interfere with this right may do so only after due process of law. Due process requires thorough and complete showing of legitimate reasons why he or she should be allowed to interfere and a full and meaningful opportunity for the person whose choice is questioned to show why it should be otherwise.

II. INCLUSION

Inclusion means the full participation of all people in the possibilities that society offers with the natural supports necessary to maximize participation. The inclusion of all people in communities is a just and moral obligation, which enriches the community and makes the community more valuable. DRRI uses its efforts and resources to realize this principle: **EACH BELONGS.**

A. Inclusion Description — This means:

- community access, not rehabilitative milieu;
- community supports, not medical or institutional treatment;
- personal choice, not structural dependency;
- friendships, not therapeutic relationships;
- dignity of risk, not organizational liability;
- possibilities, not adaptive and cognitive deficits; and,
- personally valued outcomes, not behavioral objectives.

- B. Inclusion within DRRI.** Inclusion is realized within the agency by ensuring the participation of persons in decisions about the representation they receive from DRRI. This is exemplified by the inclusion of people with disabilities as members of the staff, Advisory Councils, or members of the Board of Directors, and in meetings and other forums.
- C. Full Inclusion.** DRRI promotes the inclusion of all persons in the community regardless of the severity or complexity of their actual or perceived disability or condition, age, ethnicity, race, sex, sexual orientation, religious or political beliefs.
- D. Entitlements — DRRI believes that all citizens should be entitled to:**
- freedom from threat and harm;
 - a home of their choice which they rent or own;
 - real employment with on-site natural, co-worker supports;
 - education in their neighborhood school, in the regular education system with age appropriate peers and the necessary supports to meet the individual's needs;
 - services that treat people like customers and provide promised outcomes;
 - access to every community benefit and possibility; and,
 - personal control of one's destiny with the natural supports that come from human interdependence.

III. PERSONAL AUTONOMY

People are often perceived as incapable of making choices for themselves. DRRI presumes our clients are competent and believes that a person is capable of expressing his or her choices and guiding advocacy assistance.

DRRI asserts the fundamental right of individuals to be guaranteed meaningful participation in the planning, delivery and evaluation of services. No planning should occur for a person in the human service system without that person's meaningful participation and informed consent.

- A. Attorney-Client Relationship.** In order to promote autonomy, all DRRI advocates strive to maintain attorney-client relationships regardless of a person's real or perceived condition. Clients make the substantive decisions to guide the assistance they receive from DRRI advocates.
- B. Informed Consent.** Decisions about treatment, medication, and living environment are some of the most important decisions in a person's life and should not be made without his/her consent.

Persons should have access to all relevant information regarding the benefits and alternatives for all treatment services in order to make voluntary informed decisions. DRRI advocates shall present information in a manner that can be understood by the client.

Sufficient information should be provided to inform a client about all possible ramifications, both negative and positive, which may result from his or her choice.

- C. Empowerment.** Many individuals are confronted with oppressive situations throughout their lives. DRRI strives to assist persons to develop their self-advocacy skills and to promote their empowerment.

An advocate promotes self-advocacy by providing information and referrals, training and technical assistance. DRRI offers training to individuals and their significant others, as well as consumer groups, so they may become more effective self-advocates.

- D. Changing Direction.** DRRI recognizes that like all people, the people we serve change their minds. In cases where the person changes his or her mind on several occasions and DRRI cannot determine a clear direction, advocates will ensure that the person is provided all necessary information to be able to understand his or her options prior to terminating services.

IV. QUALITY / PROFESSIONALISM / ACCOUNTABILITY

DRRI strives to uphold all relevant and applicable standards, which are consistent with its mission, detail value-based quality indicators for professional advocacy, and further the empowerment of people DRRI serves.

For example, DRRI strives to meet the NDRN adopted "Protection and Advocacy Standards."² These performance standards describe the boundaries of acceptable practice of effective advocacy and provide guidance concerning the quality of DRRI services. The following standards are particularly important to our practice.

- A. Zealous Assistance.** Professionalism for advocates means providing zealous assistance to clients through advocacy that demonstrates loyalty, competency and effectiveness. Zealous assistance is often needed to change the situations and systems by which people are confronted.

Advocates use strategies that will effectively result in the client's expressed choice within the bounds of the law.

- B. Priorities.** DRRI establishes priorities for each program through a planned, public process which determines the primary legal rights protection and advocacy issues to be addressed each year. The statement of priorities and objectives is reviewed annually by the public, staff, PAIMI Advisory Council and approved by the Board of Directors.

1. Priorities within all service area programs of DRRI are consistent with the DRRI mission and strategic plan, and as the law requires, concentrate on core legal and systemic advocacy activities. Priorities focus on:
 - i. Protection of rights of those individuals who are most dependent on government for their health, safety, or welfare, and who are least able to

² See <http://tascnw.com/tasc/images/Documents/Management/Management/PA Standards 10 21 11 final.pdf>. (Last visited 08/05/13)

protect their rights; and,

- ii. Protection of those rights which, if violated, would most critically affect the health, safety, or welfare of the person.

- 2. Priorities may also evolve through legislative mandates, external comments, funding source requirements and/or other requests for services.

C. Resource Commitment. A substantial portion of DRRI resources are committed to individual representation and systemic change activities as delineated by the priority goals and objectives.

Analysis of staff time commitments and budget reviews are conducted periodically to assess adherence to this principle.

D. Professional Growth. Staff demonstrate integrity through their commitment to professional growth and development. DRRI supports staff growth through its orientation and ongoing training efforts, annual workplans, encouragement, teamwork, expertise-sharing, and supervision which is focused on supporting and coaching.

Yearly staff evaluations and ongoing supervision help assess professional growth and ensure accountability.

E. Accountability. DRRI uses a number of mechanisms to ensure accountability of its work and its effective use of resources.

Accountability activities include intake meetings, staff meetings, case reviews, client grievance procedures, annual review of priority areas including comments from clients, the public and staff, program monitoring through progress reports, compilation of case statistics, analysis of client outcomes, staff yearly reviews, annual reports by the Advisory Councils, Board of Directors evaluation procedures, and periodic outside evaluation.

V. INDEPENDENCE / INTEGRITY

DRRI is an independent law office program whose administration, operation, and location are separate from service providers and the state. DRRI may receive funds that flow through state or federal agencies that are service providers, but these funds are received under written agreements guaranteeing that the funding source will not directly or indirectly interfere with the management or operation of DRRI.

A. Independence. DRRI is independent from political influences that might seek to redirect the organization's personnel and monetary resources to areas that are not of priority concern for people eligible for services.

To this end, DRRI solicits opinions from people and the general public on priority rights issues to focus its resources and work primarily in these areas. First and foremost, DRRI is accountable to the people we were created to represent. DRRI will be free from arbitrary influences and political ties that are in conflict with the agency's mission or which interfere with its responsibility to represent client concerns.

- B. Conflicts of Interest.** DRRI staff will disclose their affiliations and withdraw from situations where there is a real or potential conflict of interest.

Employees of DRRI will not serve as a voting member of a board of an entity that has an interest contrary or opposed to the interest of a client or class of clients. Nor shall DRRI employees serve as Board members of provider agencies.

- C. Adherence to Rights Protection.** DRRI was created to protect the rights of persons, not to act as a protective service agency. Therefore, DRRI will not act as guardian, conservator, or guardian ad litem of a person eligible for DRRI services.

DRRI will not directly represent a client who seeks assistance in asserting his/her interest against another client or potential client. Every effort will be made to provide appropriate referrals to attorneys and/or technical assistance for individuals who wish to pursue an issue against another client.

- D. Fiduciary Duty.** Members of the DRRI Board of Directors and PAIMI Advisory Council have a special relationship with and responsibility to DRRI. Members are charged with acting in good faith and candor, with due regard for the interests of DRRI, and upholding the trust placed in members.

Members share DRRI's commitment to legal rights protection and advocacy, consistent with the DRRI mission, Board adopted positions, and these Advocacy Principles and Standards.

Members of the Board shall make policy decisions and members of the Advisory Council shall offer advice, but neither shall request or receive confidential client information, nor make decisions on individual or class representation issues.

- E. Duty to the Client.** DRRI establishes a client relationship with people who are eligible for services within given priority areas. Each client will be given the opportunity to understand, deliberate upon, and reach conclusions about matters affecting the client's legal rights.

Even if the client has a parent/guardian, DRRI will treat the person with a disability as the client, particularly with respect to maintaining communication. DRRI will not make contact with parents/guardians if the client chooses not to allow these contacts.

Because in many instances, parents/guardians have the legal authority to retain counsel for their children/wards, DRRI will not represent the desires of a parent/guardian where there is a conflict with the expressed choices of the client.

In those rare circumstances where the client's choice cannot be ascertained and the choice being made for the individual will limit their opportunities and violate their rights, DRRI will take action consistent with section LC. 2 of this policy.

- F. Confidentiality.** DRRI is bound by the law to protect and uphold the confidentiality of all individuals seeking legal representation from DRRI. To promote its ability to investigate allegations of abuse and neglect, DRRI may also protect the anonymity of a source making a complaint to DRRI.

DRRI will protect the confidentiality of any person who makes a report to the office regarding suspected abuse or neglect of a person with a disability.

DRRI will not release records or information about a client without the express verbal or written consent of the client, except as impliedly authorized to carry out representation of a client. DRRI will not report abuse or threats to a third person without the express verbal or written consent of the client.

G. Communication Between Clients and Service Providers. DRRI promotes honesty and openness at all levels of the human service system by encouraging providers to share information with persons they serve. DRRI also encourages clients to approach service providers to request desired changes prior to DRRI intervention.

DRRI may also provide technical assistance to clients so they may learn about their rights and how to advocate on their own behalf. With open communication, clients will gain needed information about options and ensure that their choices are heard and considered.

VI. COURAGE / RISK TAKING

Pursuit of Ideals

It must be borne in the mind that the tragedy of life does not lie in not reaching your goals, the tragedy lies in having no goal to reach. It is not a calamity to die with dreams unfulfilled. But it is a calamity not to dream. It is not a disaster to be unable to capture your ideal. But it is a disaster to have no ideal to capture. It is not a disgrace to reach for the stars. But it is a disgrace to have no stars to reach for. Not failure, but low aim is the sin. — Benjamin E. Mays

DRRI's goal is to ensure that all persons are equal citizens under the law. It is DRRI's mission to empower persons to act as their own advocates and to support a strong, powerful and cohesive human rights movement for people with disabilities.

It is DRRI's ideal to strive for excellence in all we do for and with persons. It is DRRI's aim to create a new reality:

- Where prejudice and stigma are replaced with pride and status;
- Where discrimination and segregation are replaced by full inclusion;
- Where coercion and repression are replaced by choice and participation;
- Where paper victories and unfulfilled promises are replaced by meaningful changes and positive outcomes; and,
- Where sympathy is replaced by empathy and pity is replaced by care, compassion and concern.

Respect for Dignity

We learn, when we respect the dignity of the people, that they cannot be denied the

elementary right to participate fully in the solution of their own problems. — **Saul Alinsky**

DRRI respects the dignity of persons by representing their choices and making service systems more responsive to individuals. Our goal is to increase the control of persons over their own lives and the services they use by making services responsive to individual preferences.

Risk-Taking / Participatory Decision-Making

We all want a company that our people are proud of and committed to; where all employees have an opportunity to contribute, learn, grow, and advance based on merits, not politics or background. We want our people to feel respected, treated fairly, listened to, and involved. Above all, we want satisfaction from accomplishments and friendships, balanced personal and professional lives, and to have fun in our endeavors. — **Levi Strauss & Co. Aspiration Statement**

DRRI strives to implement the values of choice, participation and inclusion by encouraging risk taking and participatory decision-making. Advocates are encouraged to take risks, to learn new skills, and to benefit from their successes and failures. Our most grave failure would be lacking the courage to take risks.

DRRI promotes teamwork, consensus building, and open dialogue on critical issues. DRRI involves staff in planning their own work activities through setting work goals, making strategic decisions, creatively solving problems, and developing and implementing change. DRRI recognizes our accomplishments, strives to balance personal and professional lives, and to promote a positive and enjoyable work environment.

Leadership

The leadership task is not only to create the vision, but then to find ways to translate it into action. — **Peter Block**

DRRI provides strong leadership within the human service system, the legislature, and other decision-making forums on rights protection and advocacy issues. This often means taking a challenging or controversial position. DRRI strives to help others understand such positions, since differences of opinion promote more productive and inclusive decision-making.

Balance of Power

In my own experience, of all types of human service agencies, residential institutions have been the most resistive to advocacy; among human service professions, social and medicine (including psychiatry) have been the most resistive. — **Wolf Wolfensberger**

Advocacy is necessary to balance opposing and unequal interests. Many times persons are powerless to make even the most fundamental decisions in their lives, not because of their real or perceived conditions, but because of a service system that takes all control of their lives.

What is easier and better for the system is not often the easiest and best situation for an individual. DRRI acts to tip the balance of power in favor of persons, so that they, as equal citizens under the law, may make choices, have control, and request and direct their own

assistance.

Perceptions and Connections

For advocates to maintain an ongoing personal commitment and vigor about our work, we strive to understand what it is like to be termed different/disabled. Such understanding is promoted by ensuring diversity among members of DRRI staff, Advisory Councils and Board of Directors.

We develop and maintain personal relationships with persons to enhance our compassion for and connections with the people and our work. We make decision makers ever mindful of the rights, choices and desires of such persons.

Risk and Courage

Advocacy-like action becomes advocacy when the actor does more than what is done routinely and what would be found routinely acceptable. — Wolf Wolfensberger

Advocacy implies a vigor, a fervor, and a commitment in the form of risk. Advocates know that things can and should be different for persons, and engage in daily courageous acts to see that change becomes a reality.

Advocates promote the individual's right to make independent decisions and to differ on things *that touch the heart of the existing system.*

Whenever advocacy really begins to work it will be persecuted because it will be a threat. Conversely, the phonier an advocacy system is, the more likely it will be praised, legitimized, exalted and funded. — Wolf Wolfensberger

Advocacy may be perceived as a threat even when DRRI's intentions and actions are not threatening. For some, the empowerment of historically devalued persons is disturbing. DRRI strives to stay true to our mission even when it is controversial, hard to understand, and few others agree. **This is our pledge to the people we represent, to our work, and to ourselves.**