Personal Autonomy Principles

Amended 6/16/2007, Amended 9/20/2014

Disability Rights California (DRC) is committed to furthering the personal autonomy rights of all people with disabilities. Personal autonomy rights include the following: right to self-direction and self-determination; right to give informed consent for treatment; right to refuse treatment unless there is a finding of incompetency; right to appoint an agent to make decisions when the individual cannot make their own decisions; right to a guardian ad litem (court-appointed special advocate for minors when wishes of the child may differ from the parents); right to have minimum standards for conservators; right to parent; right to marry and engage in consensual sexual relationships; right to vote; and right to information about their rights.

In the case of children with disabilities, it is not always clear who best represents the child in protecting against involuntary sterilization, drastic medical interventions, procedures, or experimentations that violate the notion of personhood. In addition, societal support for families has not progressed at the same pace as medical procedures. Families may be isolated and unaware of services to improve the lives of their children.

The Right to Personhood, Bodily Integrity and Personal Autonomy of Persons with Disabilities

1. All people, including children, have the right to maintain personhood, bodily integrity, and personal autonomy. They also have the right to the services and supports they need to grow, develop naturally, and to live fully-integrated lives of quality in their own homes and communities.

2. Children have the right, to the extent feasible, to participate in medical decisions that affect their lives.

3. All people, including children, have the right to refuse sterilization, exploitative medical experimentation, and medical procedures that violate their autonomy and personhood.

4. Families have the right to education, community support, and increased awareness about services to improve the lives of their children.
Informed Consent and Right to Refuse Treatment, Services and Release of Confidential Records

1. All people have the right to:
   a. Give informed consent to medication, treatment and services and to receive medication support services, should they chose it.
   b. Refuse treatment, including Electro-Convulsive Therapy (ECT).
   c. Develop Advance Directives for Health Care (ADHC) and appoint an agent to make decisions for them when they are no longer able to make their own decisions. Conservatees have a right to have ADHCs followed by their conservators.
   d. Keep their medical and mental health records confidential and review their own records.

Conservatorships of People with Disabilities

1. All conservatees have the right to expect their conservator to act in concert with their wishes and needs and to dismiss a conservator acting in a way that goes against the conservatee’s wishes and needs. Conservatees have the right to dismiss a conservator without a reason.

2. All people should have the right to a limited, as opposed to a general conservatorship, unless they fall within the criteria for involuntary treatment.

Parenting Rights of People with Disabilities

1. All people have the right to be a parent regardless of the nature and severity of their disability.

2. Parents with disabilities should have all supports and services available under the law to help them parent.

Sexuality Rights of People with Disabilities

1. People should be free from discrimination, harassment, interference, and retaliation when exercising their rights to sexuality and their right to refuse to engage in sexual activities.

2. All people have the following sexuality rights whether they live in the community or in institutional settings to:
a. Marry the person of their choice.
b. Engage in consensual sex, to engage in activities of sexual expression that do not infringe on the rights of others, and to a private place to express their sexuality.
c. Educational information about sexuality and contraceptives.
d. Needed assistive technology, medical care, or equipment to express their sexuality.
e. Decide whether or not to use contraceptives and get contraceptives of their choice.
f. Affirmation as sexual beings.
g. Refuse a sexual relationship with another. A person should never be coerced to have sex.

Voting Rights of People with Disabilities

1. All people have the right to:
   a. Vote whether they live independently, in group living arrangements or in institutions.
   b. Accessible voting systems, assistive technology and alternative formats when exercising their right to vote.
   c. Vote independently and privately on secure accessible voting systems.
   d. Full and equal access at polling places.
   e. Reasonable modifications in voting policies, practices and procedures in order to exercise their right to vote.
   f. Be free from interference or coercion when exercising their right to vote, including registering to vote and casting their vote.

2. People should have access to nonpartisan information about the voting process, parties, issues and candidates that they can understand and in alternative formats.