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Principles: Personal Autonomy

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BACKGROUND

Disability Rights California (DRC) furthers the personal autonomy rights of all people with disabilities. The right to personal autonomy is a basic right of every human being. It includes an individual's right to develop their personality, to express hopes and dreams, and make choices and not be unreasonably limited. It means choosing whether or not to act in a certain way or have certain experiences. A person has a right to determine their own life and make their own decisions, even when those decisions are not ones others would make.

PRINCIPLES

Personal autonomy rights include the right to:

- 1. be independent and make life decisions, including decisions others may believe are not in the person's best interest;
- 2. quality of life;
- 3. give informed consent for treatment;
- 4. refuse treatment unless the person cannot make their own treatment decisions;
- 5. appoint someone to make decisions when the person cannot make their own decisions;

- 6. a guardian ad litem (court-appointed special advocate for minors when their wishes differ from the parents);
- 7. a guardian ad litem when an adult isn't able to make decisions alone;
- 8. be a parent;
- 9. marry;
- 10. be in consensual sexual relationships in alignment with their sexual orientation;
- 11. express their gender identity;
- 12. vote; and
- 13. have information about their rights.

The Right to Personhood, Bodily Integrity and Personal Autonomy

It is not always clear who best represents children with disabilities when protecting against involuntary sterilization, drastic medical interventions, procedures, or experimentations that violate their personhood. Societal support for families has not progressed as quickly as medical procedures. Families, including children, may be isolated and unaware of services to improve their children's lives. Therefore, the following rights cover these topics.

- 1. All people, including children, have the right to maintain personhood and body integrity, be physically safe and self-sufficient and have personal autonomy. They have the right to services and supports they need to grow, develop naturally, and live fully integrated and quality lives in their own homes and communities.
- 2. Children have the right, to the extent they are able, to help make medical, mental health and educational decisions.
- 3. All people, including children, have the right to refuse sterilization, exploitative or abusive medical experimentation, and medical procedures that endanger independence, self-sufficiency, autonomy and personhood.
- 4. Families have a right to education, community support, and awareness about services to improve their children's lives.

Informed Consent and Right to Refuse Treatment, Services and Release of Confidential Records

All people have the right to:

- 1. give informed consent to medication, treatment and services and receive medication support services, should they choose them.
- 2. refuse treatment, including Electro-Convulsive Therapy, unless the person cannot make their own treatment decisions.
- develop Advance Directives for Health Care (ADHC) and appoint a person to make decisions when they can no longer make their own decisions. Conservatees have a right to have ADHCs followed by their conservators.
- 4. review their records and keep their medical and mental health records confidential.

Parenting Rights

- 1. People have the right to be a parent regardless of the type and severity of their disability.
- 2. Parents with disabilities should have all supports and services available under the law to help them parent.

Sexuality, Gender, and Sexual Orientation Rights

People have the right to express their sexuality, gender, and sexual orientation free from discrimination, harassment, interference, and retaliation whether they live in the community or in institutions.

- 1. People have the right to:
 - a. date and marry the person of their choice.
 - engage in consensual sex and sexual activities that do not infringe on other people's rights, and to a private place to express their sexuality.
 - c. needed assistive technology, medical care, or equipment to express their sexuality.
 - d. educational information about sexuality, sexually transmitted infection (STIs), and birth control.
 - e. decide to use or not use prophylaxis or contraceptives, and get the

- preventative tools they choose.
- f. have the right to medical services of their choice related to sexuality, STIs, and reproduction.
- g. affirmation as sexual beings.
- h. refuse sexual relationships without fear or retaliation. A person should never be coerced or forced to have sex.
- i. have information regarding their sexual orientation and gender identity remain confidential.
- 2. People have the gender identity right to:
 - a. identify as a gender other than the one assigned at birth.
 - b. be referred to by their preferred gender pronoun (such as he, she, they) and gender affirming name.
 - c. have access to facilities, treatment, and care that align with and support their gender identity.
 - d. have timely access to gender alignment therapy, health care and services.

Voting Rights

- 1. All people have the right to:
 - a. vote whether they live independently, in group living situations or institutions.
 - b. receive assistance registering to vote when doing business with the Department of Motor Vehicles and at agencies primarily serving people with disabilities.
 - c. vote privately and independently on secure accessible voting systems.
 - d. choose one or two people to provide assistance in the voting booth.
 - e. vote using their own assistive technology while voting in person or while reading and marking a vote-by-mail ballot.
 - f. receive voting information, including the ballot, sample ballot and voter information guide in accessible formats.
 - g. full and equal access at voting locations.
 - h. reasonable modifications in voting policies, practices and

- procedures in order to vote
- i. appropriate accommodations including but not limited to places to sit
- j. be free from interference or coercion, including when registering to vote and casting a ballot.
- 2. People should have nonpartisan information about the voting process, parties, issues and candidates they can understand and in accessible formats.