

COLORADO CROSS-DISABILITY COALITION

Guiding Principles for Advocacy

Nothing in this document should be taken to affect the freedom that ordinary people have to stand up for others or for themselves in any way they choose.

What is an advocate? An activist?

An advocate for the Colorado Cross-Disability Coalition is someone who freely chooses to enter a relationship with a person with a disability, to understand, respond to and represent the individual's interests as if they were their own. Advocates are unpaid and must be free from conflict of interest. Advocates can also be activists, engaging in direct, vigorous action in support of or opposition to one side of an issue, including but not limited to denial or limitation of medical and health care benefits, and issues regarding the rights of people with disabilities.

All advocates are volunteers; volunteers are not always advocates.

In order to advocate for CCDC client members, the individual must also be a member of CCDC or be willing to join. Advocates must attend training and pass the post-training test or have the agreement of the Executive Director to do this work.

An advocate will always:

- *Operate in an open manner to encourage communication and joint problem solving.*
- *Ensure that people are listened to when decisions affecting their interests are made.*
- *Ensure that decisions are clearly communicated in a timely fashion.*
- *Ensure that people are treated with respect and dignity.*

Standards for Advocacy

CCDC, its staff and volunteer advocates work toward assuring the rights of each person for those things necessary for quality of life: appropriate health and medical care, including services that enable people to live in their own homes and communities; adequate housing, reasonable access to public facilities.

Advocate activities for CCDC clients shall always reflect the dignity and welfare of those we serve and will be influenced by our fundamental commitment to independence, self-reliance and full inclusion for people with disabilities.

An advocate should possess the *willingness and ability to stand alone without the crowd* if need be. Advocacy may require standing apart from various ideas, people, professions, funding sources, agencies, and governments when they are not consistent with CCDC's mission. In advocacy, the person needing an advocate should feel comfortable that the advocate is not in a significant conflict of interest. Someone who is in conflict about their role and the work that needs to be done cannot be an advocate for this organization. Even the appearance of collaboration with the agencies which manage the provision of services will undermine the trust of the client and is likely to result in dismissal as a CCDC advocate.

An Ideal Advocate

An ideal advocate is someone who feels a responsibility toward the community. It is a person who has the personality, knowledge and skills to be able to stand up for someone who has been denied services that are necessary in order to participate fully in life, someone who may not know how or be able to advocate for him or herself.

CCDC advocates never do advocacy out of sympathy or compassion for people with disabilities. They do it because they have the ability, knowledge and commitment to help ensure equal rights for everyone. To do what someone can't or won't or is afraid to do for themselves. They do it because they have a commitment to making a difference and they are willing to fight a government system that often imposes barriers and limitations on individuals who require services in order to be able to live independently.

People with disabilities, their families and friends are in a unique position to act as advocates and activists. People with disabilities may not only have the interest and skills to advocate for others who have disabilities, but also personal experience that enables them to understand the difficulty of dealing with service agencies and the frustration of not receiving the necessary services one requires to live independently. They and their families and friends understand the challenges in locating appropriate assistance and services. They know about 'round-the-clock' care, and financial hardships; they are the ones who know what the important issues are.

Loyalty to the Client

Loyalty to the client is mandatory. His or her interests must be held in highest regard from beginning to end. Advocates must not discuss the client with anyone other than a team member or CCDC staff or betray the client's trust. Loyalty includes being reliable and dependable.

Clients will occasionally challenge our ability to really hear and discern what is desired or needed and what is in the person's best interests. If you take a client and intend to do successful advocacy, you must remain loyal to the client. If you are unable to do so because of issues with the client or conflict of ethics, notify the CCDC Advocacy Coordinator or the Executive Director immediately.

Advocates have a moral and ethical obligation to:

- Treat clients with respect and dignity
- Protect and enforce the rights of clients.
- Act in a lawful manner. Situations may occasionally call for acts of civil disobedience. CCDC's Executive Director will make all decisions that call for group activism and/or civil disobedience.
- Represent clients according to the client's wishes.
- Not proceed in any action on behalf of a client without his/her knowledge and permission.
- Represent their client to the best of their ability, in a timely and responsible manner.
- Inform their client of all options available to them to the best of their knowledge.
- Inform their clients of any potential results of action that the advocate believes may not be what the client wants.
- Present facts accurately and honestly.

- Keep their client informed of the progress made in an advocacy effort.
- Keep information received from their client or about their client in the strictest of confidence. CCDC may share successes of advocacy and activism; staff will determine appropriateness and timeliness of such information.
- Continue their efforts until a resolution is reached.
- Be informed and knowledgeable of changes in the laws or policies that affect their clients.
- Know what the client's rights are and how to get them.

Advocates must not:

- Take over a client's life or problem and make decisions for them. An authorized representative will speak for a client, based on the client's wishes and needs. A guardian makes decisions. If a guardian is involved with the client, that individual must be in agreement with any proposed action in the client's behalf.
- Censor or suppress the client's efforts toward self help.
- Reinforce or encourage feelings of helplessness and dependence.
- Keep clients or guardians uninformed of the client's rights so the advocate must do everything.
- Discourage the client or their families from becoming advocates and/or activists.
- Make excuses for unavailable/inadequate services required by the individual.
- Persuade families or individuals to accept "MAKE DO" services and programs. Not *ever*.
- Drop a complaint with an agency after the initial contact has been made, unless the problem has been satisfactorily resolved.
- File a lawsuit or encourage the client to file a lawsuit as the FIRST approach to the problem. CCDC's Executive Director and legal program staff will determine the appropriateness for legal action, based on the merits of the issue and discussion with the client.

Advocating Assertively

"Effective advocates are assertive advocates. Assertiveness can be defined as the direct, honest, comfortable and appropriate expression of feelings, opinions and beliefs through which one stands up for his/her own rights - without violating the rights of others". (Alberti & Emmons, 1970) For purposes of advocacy for CCDC clients, the volunteer advocate will stand up for the rights of the client.

Assertiveness is

- Expressing needs clearly and directly;
- Expressing your ideas or describing the client's needs with out feeling guilty or intimidated.
- Sticking up for what you believe in;
- Treating professionals and others involved in the issue with respect. Causing a scene or behaving in a negative manner in an office or agency will get you and your client nowhere.
- Exhibiting self confidence when communicating

- Self reliance and independence
- Persisting until you get what your client needs.

Assertiveness is NOT

- Beating around the bush before stating what you want;
- Feeling too guilty or afraid to express your needs;
- Agreeing with others when you would rather not;
- Leaving everything to others because "they know best";
- Apologizing when asking for what is rightfully yours (or your client's in advocacy);
- Relinquishing your right to advocate;
- Reliance and dependence on others or giving in to defeat;
- Giving up when you run into the "red tape" bureaucracy;
- Making assumptions before you obtain all the facts.

Principles of Advocacy

- ❑ Always respect the dignity, privacy and self-determination of clients.
- ❑ Make an effort to treat staff and employees in agencies, physician and provider offices or other entities honestly and with respect.
- ❑ Honestly and accurately represent yourself regarding your qualifications, authority and responsibilities.
- ❑ Work actively to assure that the services to which clients are entitled are not compromised. Begin immediately to work on the client's issue after you are contacted. Do not procrastinate.
- ❑ Develop a partnership with the client, and involve him/her directly in advocacy activities if they desire.
- ❑ Assure that clients are fully informed about advocacy activities undertaken, and about information which is gathered in the course of advocacy.
- ❑ Be responsive to a client's complaints concerning your activities involving advocacy efforts in their behalf.
- ❑ Identify and avoid conflicts of interest which may compromise your ability to represent the rights of your client.
- ❑ Never proceed on behalf of a client without consent and agreement of the client.
- ❑ Never take action inconsistent with the client's expressed wishes.
- ❑ Keep sensitive medical or personal information received from your client(s) confidential. CCDC staff will decide what can be shared publicly or with government agencies.
- ❑ Present facts accurately and honestly.
- ❑ Understand applicable laws and published state agency regulations and procedures for enforcing such laws and regulations.
- ❑ Never stop learning and gaining knowledge.
- ❑ When the application of more than one principle results in an ethical conflict, advocates have a duty to use their best judgment in the context of the entire ethical code to resolve the conflict.