

# Ethics, Advocacy, and Choice

## Supplemental Resources



## ***Table of Contents***

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This document contains the forms, tables, lists, and websites that were either displayed or referred to in the Ethics, Advocacy, and Choice training. This document also contains additional resources to aide new WSCs in gaining the skills necessary to effectively coordinate the supports and services for individuals on their caseload.

Ethical Standards for Waiver Support Coordinators.....	3
Human values and Not Special Needs Video .....	4
Advocating for Clients and Promoting Self-Advocacy .....	5
Promoting Choice .....	6
Preferred Lifestyle Versus Risk .....	7

# Ethics, Advocacy, and Choice

## ***Ethical Standards for Waiver Support Coordinators***

Waiver support coordinators are in a multifaceted role that includes everything from identifying and connecting clients to services, to supporting clients emotionally and functionally, to advocating for them so that they can live as independently and safely as possible within the community.

### ***Additional Reading:***

Standards related to confidentiality will be covered in detail within the APD required training on the Health Insurance Portability and Accountability Act (HIPAA).

The National Alliance for Direct Support Professionals (NADSP) published Living the Code of Ethics – In Support of People with Disabilities: A Primer. This document can be accessed at:

[workforcetransformation.org/wp-content/uploads/2017/03/Code-of-Ethics-Manual.pdf](http://workforcetransformation.org/wp-content/uploads/2017/03/Code-of-Ethics-Manual.pdf)

## ***Human Values***

Along with ethical and professional values are human values, which are basic to every human being. Although you may be helping your clients address specific needs through supports and services, it is important to know that an individual with a developmental disability values the same things in life as everyone else.

Just like everyone, people with disabilities value:

- Love
- Friendship
- Being respected and treated with dignity
- Accessing information to make choices
- Safe place to live
- Community participation and civic responsibilities
- Freedom from poverty and abuse
- Ability to exercise rights
- Meaningful employment
- Learning opportunities and the ability to grow personally
- Intimate relationships
- Remaining connected with family
- Advocacy and support to pursue life choices

### ***Not “Special Needs” Video:***

Find out more about the values of people with disabilities by hearing it directly from them. The following link will take you to a video that explains that the needs of people with disabilities are not “special” – they are the same as any other human being.

[www.youtube.com/watch?v=kNMJaXuFuWQ](http://www.youtube.com/watch?v=kNMJaXuFuWQ)

## ***Advocating for Clients and Promoting Self-Advocacy***

An important part of the role of a WSC is to work as an advocate for their clients. What is an advocate? An advocate is someone who speaks or acts in the interest of another, particularly those who are most vulnerable. As an advocate, the WSC works to ensure that the individual's voice is heard on matters that are important to them, helps the individual to have their views and wishes genuinely considered regarding their life, and defends and safeguards the individual's civil and human rights, as well as their health and safety needs.

### ***Promoting Self-Advocacy***

An important role of the WSC is to help individuals be self-advocates. Self-advocacy includes speaking up for oneself, making decisions, and exercising one's own rights.

#### ***Additional Resources:***

The APD Resource Directory has information about statewide resources including self-advocacy groups:

<https://resourcedirectory.apd.myflorida.com/resourcedirectory/>

Disability Rights Florida offers a helpful tool to guide individuals to be effective self-advocates:

[http://www.disabilityrightsflorida.org/documents/Disability\\_Rights\\_Florida\\_10-Steps\\_english.pdf](http://www.disabilityrightsflorida.org/documents/Disability_Rights_Florida_10-Steps_english.pdf)

Self-Advocates Becoming Empowered (SABE) is a national board of regional directors from each state in the US. Access their national resources page at:

<https://www.sabeusa.org/resources/links/>

## ***Promoting Choice***

WSCs must ensure that individuals make their own choices as much as possible. This might include decisions about owning or renting a home, decisions related to relationships, activities to engage in, or health and dietary decisions.

WSCs must ensure that individuals have enough information to understand their options and the potential impact of their decisions. This is known as “informed choice.”

### ***Additional Resources:***

The Rutgers Robert Wood Johnson Medical Center publication page includes informative information on supporting individuals with developmental disabilities. The following guide discusses aspects of supporting choice in community life:

<https://rwjms.rutgers.edu/boggscenter/RighttoaCommunityLife.html>

## ***Preferred lifestyle versus risks***

A common issue related to promoting choice is when an individual's preferred lifestyle choices appear at odds with already-identified risks. In these cases, the WSC and the individual's circle of supports must see how they can support the individual to achieve the life they want while still addressing the known risks and needs the individual has.

Steps to keep in mind when supporting clients in making informed choices:

**1. Consider the outcome that the individual desires.**

When everyone understands what is most important to the individual, it becomes easier to guide conversations to the best options that will help the individual reach their goals and minimize any risks along the way.

**2. Identify any barriers to reaching the desired outcome.**

Barriers could be anything from a lack of transportation to current behavioral or medical concerns. Often barriers can be overcome by making changes to the original goal.

**For example,** a client that desires to obtain full time employment has not made progress on this goal due to his severe respiratory needs and frequent pneumonia. This client's WSC asked him if he would like to start by obtaining part-time employment in an environment that would not compromise his respiratory issues and then increase hours as he gains stamina.

**3. Consider necessary supports.**

As will most people, individuals with developmental disabilities can achieve far more when they have the right kind of supports in their life. Discuss with the individual and the support team the supports that would allow the person to make their own choices and avoid serious health and safety risks?

**4. Define alternatives when risks are high.** There may be situations where the individual desires to engage in a life choice that the support team clearly sees as a significant risk to their health and safety. In these situations, the WSC must guide the conversation to determine the actual potential for harm, make sure that the individual understands the risk potential, and offer alternative options that could still address the individual's desired outcomes.

### ***Consider Sherry's scenario:***

Sherry stated that she wants to live in a house by herself without paid staff. She has several medical complications such as seizures, insulin-dependent diabetes, and limited use of her lower extremities. Currently, Sherry requires assistance with bathing, transferring, monitoring blood sugar levels, taking medications, and overall monitoring for safety. Sherry has a part-time job, but this income, along with her benefits, is not enough to live on her own.

Sherry's circle of supports will need to help her identify the barriers to living on her own, which are her medical needs, requiring assistance for daily living tasks, and not making enough money to support her financially. Her circle of supports will then need to brainstorm how the team can help Sherry reach her goal. Are there any assistive technologies to help Sherry take care of her daily needs by herself? Could Sherry learn to monitor her blood sugar on her own with oversight of her doctor or a nurse? Could Sherry get a job that makes more money?

After brainstorming options to help Sherry move toward her goal, the circle of supports can help Sherry say specifically what is most important to her. Is it privacy, the ability to choose her daily routines, or the feeling of accomplishment and maturity by living on her own? Depending on the values, the team can explore with Sherry ways to still achieve those values even if the goal of living on her own is delayed due to safety needs.

## ***Addressing Health and Safety Throughout the Year***

At the first sign of concern, the circle of supports should hold a meeting to address the areas of concern. The main objective of the meeting should be to find the best way to reduce risk by using the strategies described above.

### ***Additional Reading:***

More information on addressing needs, risks, and choice can be found in the *Support Plan Development – Part 2* and *Monitoring Services and Addressing Health and Safety Needs* trainings.