

PLEASE REMEMBER
NON VERBAL DOES NOT MEAN NON THINKING
NON VERBAL DOES NOT MEAN NON HEARING
NON VERBAL DOES NOT MEAN NON FEELING
NON VERBAL DOES NOT MEAN NON UNDERSTANDING

“Making choices and decisions for ourselves is an important part of who we are. It is fundamental to having control over our own lives and important for securing all other rights: If we are not allowed to make our own decisions, how can we have a voice in anything else that is important to us?” Self-advocates from “Global Report on the Right to Decide”

There is no reference in either the US constitution or the UN Universal Declaration of Human Rights about the right to make a choice or a decision. Perhaps this is because making choices is such a basic part of everyday life that it is taken for granted. But for many people with disabilities, this is not so. People with disabilities have long been over-protected and not allowed to make many of the decisions that impact their lives.

To fully exercise the rest of their rights, people have to be able to make choices: where to live, where to work, how to manage their money, what clothing they want to buy and wear, what to do for fun, what friends to hang out with, what services and supports are desired, how to furnish their home, what daily schedule works best, how they want their future to look like, and so on. People with disabilities are like everyone else – people are defined by the choices they make in life. Without the power to make choices, people appear to be less human, and may be less respected.

Lately there has been a realization of the importance of people to have greater control over their own lives. This is an important element in the HCBS Final Settings Rule which emphasizes person-centeredness and self-determination for people receiving that funding. Legal entities like judges and attorneys, have begun to develop better ways to assess the need for more restrictive decision-making supports, like full guardianship and have begun to encourage consideration of other less intrusive supports, like supported decision making or power of attorney.

People must have education, exposure, and experience to have knowledge they need to make good decisions. Then they have to be empowered to make a decision without being over-protected or unduly pressured. A wide array of options needs to be available, so people can judge the “pros and cons” of each option based on his/her own values, needs, priorities, and desires. Decisions need to be “real” and not token decisions that are meaningless. Supporters must be careful to not judge people’s choices, and support people to make mistakes, if there is no real harm. This allows dignity of risk which promotes learning.

Supporters can help people make good decisions by listening and understanding what is involved in the decision. The person can be supported to make a pros and cons list. If the person does not communicate with words, the list can be pictorial or use objects or symbols. This list should be based on what the supporter knows about the person’s values, priorities, needs and desires. Through discussion with a person, a supporter can

help the person to evaluate each option: how each option would enhance his/her life; the risks and benefits of the each option; what responsibilities go along with each option; what other options need to be explored; and if this truly is the person's choice or someone else is really making the decision.

Even complicated and serious decisions can be facilitated with supported and informed decision making. Sometimes people may need more protection. Other decision-making supports can be considered like a Medical or Financial Power of Attorney or even guardianship. Even when these more controlling supports are in place, the person should remain at the center of both the discussions about options; and the decision they make. "My Choice, My Voice!"

RIGHTS

- Have choices – friends, where to live, work, food, clothing, activities, places to go, home furnishings, routines, money, plans.
- Not have your choices predetermined or limited by others.
- Meaningful and real choices – not insincere, "fake or token."
- Access good information to make informed choices; peer support for non-biased advice.
- Decision making help and supports, if needed and desired.

RESPONSIBILITIES

- Get good information to make the best choices and decisions.
- Consider the pros and cons.
- Get advice and ask for help if needed but voice your opinions.
- Know its ok to make a mistake -learn from your mistakes.
- Take responsibility for your choices.
- Know the rules and the laws.
- Understand and accept the risks
- Embrace the Dignity of Risk – it's OK to fail

SUPPORTS

- Live by the "The Big 'E's'" – Educate, Expose, Experience, Empower.
- Learn about the person's preferences and interests.
- Provide self-advocacy training and peer support.
- Offer a wide array of options.
- Offer non-judgmental support when mistakes are made that do no real harm.
- Assess the decision-making supports – don't over control.
- Support people to experience Dignity of Risk.

Thoughts for Consideration:

- ✓ Spend time observing a morning, afternoon or evening in a residence/day program and look for choice/ decision making as part of the daily fabric – If you didn't see it...
- ✓ People with intellectual disabilities should be encouraged to make decisions and choices that affect their lives, whether major or minor, to the maximum extent that they can do so every single day of their life.
- ✓ Take a poll on what kind of choices are being made daily. How many choices do you make in a day?
- ✓ The ability to make decisions must be determined on an individual basis, and based on the situation and circumstances, without resorting to making assumptions. How does your team avoid making assumptions?
- ✓ Providing choice opportunities to people is important because it helps build cooperative, collaborative relationships – how does your team provide choice opportunities?
- ✓ People feel in charge of their lives when they make choices and it gives their lives meaning. How does your team support choices and decisions even when you disagree?
- ✓ Life is more enjoyable if we choose the things we do – making choices cannot be taken for granted. How many choice do you make a day?
- ✓ Dignity of Risk – What if you never got to make a mistake?
- ✓ How does your team embrace the DSP Code of Ethics?
- ✓ In a few words how does your team live by Educate, Expose, Experience, Empower?