

September 5, 2015

Issues from self advocates in the Northeast Region:

Training is needed for service coordinators so they can explain what self direction is and support individuals if they are interested in learning more. It is not the place of the service coordinator to decide whether or not self direction is right for someone.

Everyone should be educated at their ISP about the three different ways to receive services and have a right to know and consider the service options that fit their needs and goals best. Recently self advocates have experienced a lack of support or responses like, "We don't do that in this area; it's too complicated," or "If you do that, you will lose me as your service coordinator!"

Training of service coordinators to get the message out about self direction is needed to be sure this service is a fair option for everyone. Outreach and materials to all people who receive services and/or their guardians regardless of the degree of support is needed in simple language that everyone can understand. Otherwise, self direction is limited to individuals and families who are in the know whereas many others could benefit and have a right to choose this option.

Training for brokers to be sure they understand self direction and the values. This is key to be sure that family or other team members are not overshadowing the voice and wishes of the person who is receiving services. We know of many instances where the wishes of the individual are not adequately represented as opposed to others on the team or in their family. Guidelines for ethical "substitute judgment" would be very helpful to educate team members, families and agencies that it is the person receiving services who should always be the one confirming the type of supports he/she has.

Having the tools to be informed and supported to make decisions about your budget. Both the initial creation of a budget, as well as ongoing changes when necessary is needed.

Use of tools to support the self advocate in creating a job description setting goals and building their support network to achieve their dreams.

Along this same line of thinking, we've seen a few instances where an individual has pushed for self direction and worked with a broker to change services without having a person-centered planning process. A standard and fully inclusive person-centered process would help ensure that needs and goals are captured and that the person is drawing upon all potential natural supports and resources to make their venture into self direction a success.

Hiring and keeping staff is very difficult for many people. Finding staff people to work has been very difficult for some people. More individuals would choose self direction if they had access to more people to support them in the process (be that their service coordinator, brokers, or knowledge of where and how to find people to work with them).