# Self-Determination in a K Plan World

***Panel Members**:*
***Stephanie Brown-Quinn**, Mentor Oregon Metro Brokerage*
***Cecilia Silcox**, Southern Oregon Regional Brokerage*
***Jessica Kral**, Independence Northwest*
***Michelle Denman**, Creative Supports*
***Laura Noppenberger**, Eastern OR Support Service Brokerage*

*Facilitated by **Katie Rose**, Executive Director of OSSA*

# Self-Determination in a K Plan World

Welcome! Today is meant to be a sharing of practices we've developed to encourage and progress self-direction and determination in the people we work with, using current tools and processes. This segment will include:

- Intro
- Presentation (35 minutes)
- Q&A with Panel (15 minutes)

Please save your questions for the Q&A!

# What is self-determination?

- We understand self-determination to refer to:
  - a **characteristic of a person** that leads them to make choices and decisions based on their own preferences and interests, to monitor and regulate their own actions, and to be goal-oriented and self-directing.
  - both the abilities of the person and **the opportunities presented by the environment** contribute to the degree of self-determination that can be expressed.

# What is self-determination?

The five principles of self-determination:

- freedom
- authority (or control)
- support
- responsibility and
- confirmation

"Self-Determination is a fundamental human right. It means that people have the freedom to decide how they want to live their lives and receive the support they need. It means having control over their resources and taking responsibility for their decisions and actions. Very simply, it means getting a life." - Ellen Cummings Operating Principles of Self-Determination

# Why does self-determination matter?

Self-Determination remains a part of the federal DD Act, and of Oregon's Revised Statutes.

**42 USC 15002(27) – The DD Act (27) Self-determination activities:**

*The term "self-determination activities" means activities that result in individuals with developmental disabilities, with appropriate assistance, having—*

*(A) the ability and opportunity to communicate and make personal decisions;*

*(B) the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individuals receive;*

*(C) the authority to control resources to obtain needed services, supports, and other assistance;*

*(D) opportunities to participate in, and contribute to, their communities; and*

*(E) support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities.*

# Why does self-determination matter?

**ORS 427.007:** *"Individuals with intellectual and other developmental disabilities and society as a whole benefit when the individuals exercise choice and self-determination, living and working in the most integrated community settings appropriate to their needs, with supportive services that are designed and implemented consistent with the choice of the individuals regarding services, providers, goals and activities. Individuals with developmental disabilities, together with their families and advocates, must play a major role in the planning, designing, funding, operation and monitoring of community services. These services should be ultimately focused on the outcomes of independence, integration and productivity."*

# Why does self-determination matter?

Given that Oregon and CMS remain committed to the principles of Self-Determination, we have an imperative from top to bottom to rebuild self-determination and self-direction into the system, and to maintain and expand our level of self-determination and self-direction in the field.

Practice continues to evolve. While this is not meant to be a comprehensive listing of every way to infuse self-determination into your work, it is meant to share our collective experience, and start a conversation statewide.

# Initial Meeting

- Do your homework: reach out to the previous case manager when possible, read the file, note whether or not the person is traditionally verbal and tailor your communication appropriately. Meeting someone and displaying basic knowledge of them shows respect, and that you are committed to person-centered service.

- Know what you want to get out of the meeting, but be prepared to side-line parts of that list in favor of addressing customer needs
  - Prepare ahead of the meeting—know what forms absolutely must be signed at the first meeting, and which could be pushed out if need be
  - Know that the individual or their family may need you to address some misunderstandings, urgent needs, historical bad experiences, or otherwise “clear the decks” before being ready to hear anything you have to say

# Initial Meeting

- Be up-front about what a person can expect from this meeting! Have a conversation about the basic agenda (i.e., "I want to get to know you today, explain the process, and I need to review and have you sign a couple of forms. What do you want us to be sure to talk about today?")

- Whenever possible, take a few minutes to situate yourself and your services into the larger context—explain how they got referred to your services, how you were assigned, and how you will fit into their life. Discuss the basics of self-determination in simple terms, and help them understand that we want to develop their personal abilities to run their own lives to the fullest extent possible. Set the tone for self-determined services.

# Initial Meeting

- For those aging into adulthood at 18: keep in mind that self-direction and self-determination are skills, and people will arrive at different levels of ability.  Be inclusive of the support circle, but clear in your deference to the customer as the ultimate authority on their services.

- Listen and observe carefully for ways that you can foster self-determination as services progress.

# ANA/CNA

- We all know the questions are invasive and can be uncomfortable—acknowledge that up front (with humor!), provide some context for the assessment by explaining its purpose, what it will be used for, and who will have access to the information it contains.

- Use methods like the ANA Field Notes tool to gather information without getting bogged down in the minutiae of scoring.

# ANA/CNA

- Take the hint: if discussing certain sections in person with you is clearly tortuous for a person, offer to collect the info a different way (from someone else, in writing, via email, etc.).

- The initial ANA assessment is a great place to get a baseline read on a person's level of self-determination and ability to self-direct—take note: who provides the information, how much of this person's life is in his/her control, what is the body language telling you, etc.

# ANA/CNA

- Make the experience more positive by reflecting back the skills and accomplishments that are observed or reported during the assessment. (i.e., “I just heard you say that you do your own laundry once each week. That is such a big deal when it comes to living on your own!  I’m impressed that you take that on. I wonder what else you could do with a little coaching.” “You just reminded your mom of your neurologist’s name—what a great memory! Memory is important for a lot of skill-building, you have a great start on your goals.”)

# Risk Identification Tool

- This is a new tool, best practice is still evolving. Be flexible in your approach and know your audience. For some, it may be appropriate to send the form on ahead for the customer and their support circle to review and attest to by filling in their information ahead of the meeting. Gather as much information as possible from the written records available to you.

- Provide the context needed for everyone involved to understand this tool: it is invasive, much of it may not apply to the individual, but it's important to be clear about what is needed to safely support each person in order to facilitate appropriate supports. Honest conversation now will avoid conflict in the future. "If all of your natural supports were to go away tomorrow, what would you need to be safe?"

# Risk Identification Tool

- Though it is not preferable, a full review of the form in interview style can often be necessary with new customers to make sure that all information is gathered and understood as accurately as possible. When possible, it may be good to combine the ANA assessment and RIT review in order to conserve time. If you're doing that for the benefit of the person and their family, let them know!

# Risk Identification Tool

- When controversial information is reported, prepare in advance to review this information with the individual. (for example: parent is reported as a risk for financial exploitation, customer in services is reported as a risk to sexually harass employees, etc.) Fill out the section noting that the individual does not agree with the specific information contained, and be clear about the person's objections. Review this with him or her to acknowledge the objections, and reaffirm that it does need to be on the form. Review your language to be sure that your account is free of judgment, and as neutral as possible. If the subject is extremely sensitive, or you have strong feelings, ask for a review from a supervisor.

# ISP

- Set the right tone by contacting the customer directly, if possible, about the meeting itself. Find out who he or she wants on the invite list, and where he or she would prefer to hold the meeting. Reinforce the person's ownership of this process.

- The ISP process is a balancing act between honoring a customer's wishes, and facilitating the work that the case manager and providers must do. Resist the urge to make this meeting "one-stop shopping." A meeting that goes into detail on topics of a medical, relationship, employment, and home-life nature might be easiest for you, but they may not be acceptable to the person at the center of the meeting. (Would you want your doctor, supervisor, and romantic partner in a room sharing information with each other? Probably not.)

# ISP

- If some interested parties are not invited to the meeting itself, send out an email ahead of time to let them know it is occurring, and request updated information from them about the person's support needs.

- As with the initial meeting, come with your agenda planned, but be prepared to adjust based on whatever might be going on in the life of your customer. Be up front about what you need to do, and ask what the person might want to get from the meeting.

# ISP

- Is the customer looking for a new physician, or working toward employment? Encourage them to use the one-page profile as a tool to educate others, and complete the profile with that purpose in mind.

- After the meeting, send out another email to interested party with a quick summary of salient points and follow-up items, so that everyone feels engaged and knows what to expect.

# On-Going Services

- Establish contact expectations with the individual. Let them know why and when they will be contacted by a case manager, and find out the frequency and mode of contact that works best for them. (see example handout from UCP)

- Close the loop on the initial meeting—know where this person is at with the skills of self-determination, and keep in mind ways you can reinforce and build on those skills in the coming service years.

# On-Going Services

- For people with paid caregivers who are not as able to self-report, plan to have regular face-to-face contact to spot issues.

- For those with identified Employers of Record, Designated Representatives, and legal guardians,  the person receiving services can and should still be as involved as possible in the decision-making and service direction.

# On-Going Services

- Choice of service provider is a core component of self-directed services—remind the individual that this is not a permanent relationship. People in services have the right and the responsibility to speak up when something is not right, or isn't meeting their needs. We are all required to be good stewards of public funds by fully engaging in their use.

# Q&A

What questions do you have for the panel?

# Thank you for joining us today!

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