Oregon DD Coalition

Advancing Opportunities

To: Sen. Gelser, Chair, Senate Human Services Committee and Committee Members

From: Ross Ryan, Vice Chair, Oregon Developmental Disabilities Coalition

RE: Opposition to SB 20 changing the definition of self-determination and focusing on “placements” rather than people

Chair Gelser and Members of the Committee:

The Oregon Developmental Disabilities Coalition (DD Coalition) is made of parents, self-advocates, providers and DD advocates. The DD Coalition meets every month to discuss urgent issues and things that are impacting the DD Community. We work together to fix these things.

The DD Coalition’s vision is to have people with intellectual or developmental disabilities and their parents in the community together and working together to making things better for everyone.

According to the Office of Developmental Disability Services (ODDS), the intent of SB 20 is to create change that can improve the DD case management system. The DD Coalition agrees that case management change is necessary to allow people to use their services efficiently as they live their lives.

Even though we like the intent of SB 20, we cannot support it as currently written because it changes the definition of self-determination to focus on “placements,” where we live and what services we are accessing. It doesn’t focus on people.

To me, self-determination is about being able to decide what you want to do, being the guide of your life and being part of your community. With self-determination, self-advocates are in charge of their services and speak up for themselves. Without this, things would be handed to us without our input.

Self-determination supports people to be successful. When someone decides what they want to do, they are more successful because they buy in to what happens. People need to be in charge of their services because they know what they want out of services. It is not fair to let someone else control service because services support the self-advocates' lives. We are in charge of our lives – so we need to be in charge of our services. Only we know what we want and need. We have a right to be supported to speak up and get it. Self-determination does that.

Recently, the Oregon Council on Developmental Disabilities held focus groups around the state. They talked to 63 self-advocates about what they want out of their services. The report is attached.

The self-advocates wanted to be in the community and have control over their lives, set goals based on what they want and have a service plan that is based on their needs and goals. The most important thing to them was to have services and control their own lives. They are calling for self-determination. Oregon should update the definition of self-determination to reflect this.

The DD Coalition recommends that the issues with SB 20 be resolved through a workgroup process with strong membership from the DD community, including self-advocates and family members. Through the workgroup, we hope to find solutions so we can all work together.

# Experiences of Self-Determination in Service Planning
## January 21, 2019

Self-determination means “being the boss” of one’s own life. A person with intellectual or developmental disabilities (self-advocate) is the boss of their own life – or practices self-determined behaviors (with or without assistance) – when they:

- Make their own choices and decisions;
- Exercise control over their own services, supports and other assistance;
- Control or have a say over how resources are used to obtain needed services and supports;
- Contribute to their communities in the ways they choose; and
- Speak up or advocate for one’s self and others, including participating in policy making and legislative processes.

Facilitators from the Oregon Council on Developmental Disabilities and the Oregon Self-Advocacy Coalition met with 63 self-advocates from eight communities around Oregon during fall 2018. We asked five questions related to the developmental disability service planning process. Our findings demonstrate how self-advocates experience self-determination related to service planning. Below is a high-level summary of major self-determination themes in order of importance.

### 1. What is a good life?

Relationships with friends, family and romantic partners and being able to spend time with them

Health, being active, exercising, doing things that make you feel happy and having access to quality healthcare

Being in the community like going to church, volunteering and doing other activities

Having a paid job, going to work, working hard, having money to pay bills, “having enough money to not be afraid”

Choosing where to live and choosing whether to live alone or with a partner; choosing roommates

### 2. How can your plan help you to have a good life?

Flexibility and getting help when I need it

My plan is based on my needs and goals and includes supports at home, work and in the community; supports to get to know my community

My plan includes plans for the future, like having a back-up plan for supports or an end of life plan

Being able to communicate with my SC/PA to problem solve or ask for help when I need it

Setting our own goals, like choosing where to live, who I live with, where I work, going to school, being involved in advocacy and being able to change our goals

Choosing providers and supports to reach our goals and dreams

Contributing to our communities by volunteering, developing relationships, working on projects, meeting new people, and doing things we like

Being in control of my plan by making my own decisions, getting help to make decisions and having a copy of my plan
Supports to be independent and learn new skills based on my interests and goals
Supports to maintain or create relationships and prevent people from being isolated
Being listened to and treated with respect
Having a good relationship and good communication with my SC/PA

**3. What helps you be in control of your plan?**
Being in charge of my plan and planning meetings like running my meetings, being heard, choosing where to meet and who to invite, saying what I want and don't want, choosing my SC/PA and changing my SC/PA, when needed
Making my own decisions and setting my own goals by advocating for myself, "what I want; not what *they* want," getting a job, going to school, choosing where and with whom to live; keeping track of progress on goals and changing my goals when needed
Getting the supports I need including planning for my meetings, learning new things, being able to talk to my SC/PA, problem solving, and having both paid and unpaid supports
Being informed about how to prepare for planning meetings, what to expect and who I can invite, what resources or supports are available, how to file a grievance, who to call when things change; making informed decisions
Being listened to and treated with respect; not being told what to do, "getting on the same page" before the meeting
Relationships with family, friends and romantic partners

**4. What gets in the way of you being in control of your plan?**
Not getting enough support like not being able to find or keep providers, not enough mental health supports available, not getting support to understand, others not "thinking outside the box" for solutions, when supporters don't follow through, when people don't help
Not having control like people telling me what to do or placing restrictions on me, when people don't give me a chance, when others talk for me
Being afraid to ask for what I want or feeling pressure to agree or say what others want to hear
Not being treated with respect like when people don't take me seriously or value what I have to say; when people don't listen; discrimination
Not having enough information about my rights or how to speak up for myself; not enough information about the ONA and the planning process, my plan, what my options are or what supports, or resources are available
Problems with transportation like lack of transportation when we need it, not knowing how to use the bus, provider mileage not being paid for and transportation that makes me late to work

**5. Overall, what is most important to you?**
Being in charge of my plan – it's all about the person and includes what they want, having a copy of my plan, being happy with my plan, the plan suits the person; "we want our plan to be about who we are and what we want and need"
Speaking up for ourselves, saying what we want and don't want, having a voice; "it's my plan not my case manager's plan,"

Getting the supports we want and need to live the lives we want, like support to understand the ISP process and be in charge or our plans, support to be healthy and active, support to learn new things, make decisions, reach our goals, and live the lives we want
Being listened to and treated with respect
Being informed about the ISP process and our options, like understanding the planning process and what it means to me, getting documents in user-friendly language, getting documents a month before the meeting, being able to ask questions and getting help to understand
Reaching our goals by choosing our own goals, getting support to reach our goals, and support to be independent, have healthy relationships, find or keep a job, be active in the community and live a happy life.