

ABQ People First Meeting  
Listening Session on the DD Waiver Renewal  
October 2, 2019  
9:00 am – 1:00pm  
DDPC

55 Total Participants: 14 self-advocates, 3 family member/guardian, 16 provider staff, 13 advocate agency staff, 9 DOH/DDSD staff

## **I. Rights**

### **Do you know what rights you have – what are they?**

- To be able to be heard by your team – almost everyone said this
- To vote
- You do what you want at your house (have a party)
- To voice your own opinion
- To live where you want to
- To make a mistake
- To join the military
- To achieve goals & dreams – be in movies, plays even when older – never give up on dreams
- To have a career/job
- Happiness is freedom
- I want to make my own decisions
- I don't have a bedtime curfew. I go to bed whenever I want.
- The right to hire and fire your provider
- The right to be in control of my own life

### **Can you stay home from Day Hab or stay home alone if you want to?**

- Many people said yes
- Some people said no because either they have a medical concern or it's inconvenient for staff

### **Is there anything you want to do that you are not allowed to do?**

- Driving due to epilepsy
- I have to check in with my caregiver every hour on the hour and I don't like this, I don't think it's necessary (Response from another self-advocate- "That's ridiculous! That's not even long enough to watch a movie")
- I don't think caregivers need to be part of every decision. It's too much
- Provider tells me I have to go to my room at 9:00 so they can have space in their own house (Family Living provider)
- I don't want a bedtime curfew
- I lost a friend because I was not allowed to invite a certain individual into my house – I left this Supported Living provider and am now in Customized In-Home Support but it's too late for my friend. I went from being crisis client to a leader by going from Supported Living to Customized In-home Support. Now it works really well.
- When I get angry, I like to walk in the neighborhood to cool down, but the staff say I'm eloping. I'm not eloping, I'm cooling down.
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- The team says I can't get therapy because it's too far away, but it's written in my plan and I want to do therapy

**Do you have a key to your house?**

- Almost everyone said yes

**Can you have a snack whenever you want?**

- Almost everyone said yes

**Question from a self-advocate**

- What do I do when my staff won't let me see a movie I want to see?
- Two self-advocates role played this scenario (Did the staff know what the ISP or the Behavior plan actually said, what happens when the staff disagree with a person's choice, staff treat the person like a baby)
- Lots of discussion on how to ask for what we want, how to be respectful and still be firm, importance of negotiating when living with others
- Only one self-advocate had ever read their plan, didn't really know they could do that
- Talked about the right to see and review your service plan whenever you want

**II. Team Process – ISP Process**

**How does your team work for you?**

- If you have 1-1 staff and you don't need it maybe there is a time to change staff
- Arguing to get what you want doesn't work
- Call your team members if you're not getting what you need
- Are things really in your plan – is plan written with you?
- They ask me to leave the room and then they decide
- They do not want to hear me

**Does your team listen to you?**

- Some people said yes, they listen really well, and they really like their team.
- Some people said no. The team doesn't want to hear what they have to say.
- They don't listen to me
- They talk about their lives not mine
- My team didn't listen to me, so I got rid of my agency. The agency was angry at me and I called the Regional Office and they cleaned up the mess. The team dominated my meeting and never listened to what I wanted. Now everything is different with my new team. I run my own meetings and it's the best it's ever been.
- Once I became an advocate my team listened to me
- I am a person-centered person

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**Do you meet with the case manager before your team meeting? Is this helpful?**

- Everyone said yes, either in person or by phone, and it is helpful
- First is just me & my case manager and the next day is the larger mtg

**Do you run your own team meeting? If not, would you like to learn how?**

- Half the people said they run their own meeting.
- Almost everyone else said they would like to learn how to run their own meeting.
- If you have a good case manager, they will help you run your own meeting
- I need help to learn how to run your own meeting
- One of the self-advocates outlined the steps to run your own meeting:
  1. Write the agenda-what you want
  2. Talk about old and new business
  3. Talk about your goals
  4. Write the timeframe for each agenda item
- ABQ People First leaders will train on “How to Run Your Planning Meeting” at the Dec. 4 meeting

**What do you think makes a good team for you?**

- Having the right people at the meeting, invite the people you want to be there.
- I have a good case manager and good people – my team works out perfectly
- Talk about needs, wants, best interest of person
- People you want to be at meeting – makes big difference
- Having an agency that thinks you're an inconvenience is not a good team

**III. Services**

**Do you get any therapies? If so, does this help you? Do you think you need more therapy or less therapy or is it just right?**

- Therapies are limited in the DD Waiver. We should be able to do nontraditional therapies like acupuncture and massage.
- I used to get massage therapy and it really helped my neck problems; now I can't get it.
- I go swimming and I would like to go more often
- I get group speech therapy but would also like 1-1 speech. It helps me
- Therapies help
- I do dressage and equine therapy and it helps
- My OT quit after I complained. They were not training staff correctly, it was not aligned with my ISP goal. All the OT did was give me movies to watch
- In Farmington. people get speech therapy via skype and the people say it's not productive
- I don't know what therapies are available
- When contractors not fulfilling obligations, we should have the right to seek alternative providers but not many OT's available on the Freedom of Choice list

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- My team wants me to have speech therapy, but I don't think I need it
- Yes, therapy helps me. It got me into karate which I love
- Yes, speech has helped me, it's the right amount
- PT has really helped me, it's the right amount

**Do you get nursing and if so, do you think it helps or that you need it?**

- People said they don't use nursing so no comments on this

**IV. Choices**

**Do you spend your day the way you want to?**

- Yes, I choose the way I spend my day
- I am stuck
- Yes. I volunteer at the Balloon Fiesta for 4 years
- Yes, I will be a greeter at the Balloon Fiesta for the first time, I volunteer at my church, I go to an animal program at my day program, I go to Special Olympics- all things I have chosen
- Yes, I swim, work at Mandy's Farm, walk, ride a bike and go the gym
- Yes, I go kayaking (through an adaptive kayaking program)
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**What do you think of Day Hab programs?**

- I don't think there should be a facility for day hab, I think people should be out in community
- I enjoy being both at my day program and out in community
- I get cabin fever if I'm home too much
- In-home day hab would work best; I am exhausted by Friday and need to rest
- I like Day Hab to see friends
- How can we see friends without Day Hab?
- I changed my Day Hab because I was not treated well
- The DD Waiver needs a variety of options
- Some providers say you have to come to their program a certain number of days a week or you can't come at all. This isn't fair because people like to do a variety of activities. DDSD should tell providers they can't do this; people should be able to decide how often they want to go.
- Need to always ask what the person wants
- Use home for "home base" versus large facility
- We need to get other providers on board for more person-centered planning. This can be a challenge
- Like flexibility to have different providers
- People need to know what choices are available, but we also need to create new choices for what people want

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**Did you choose where you live?**

- Yes. I live by myself with staff in my own house from Monday to Friday. On weekends I live at my parent's house. I interviewed the staff with help; it was hard to pick. I am looking for a roommate that I want but it takes a while.
- Yes

**V. Assistive Technology – Personal Support Technology**

- I use Dragon dictate; I write a lot of stories using the microphone but get frustrated when the microphone doesn't pick up my voice
- There are apps available to learn to ride the bus
- I am trying to get a Medical Alert System because of my health condition
- Yes, I use the powerchair; Big buttons to help me communicate, Alexa to control my radio, TV. I can't reach the buttons when I am in bed so we're working on this.
- People don't know what kinds of technology is available or how to use it.
- I wish DDSD would make more independent apartments available so I could still have supports but me in my own place and be more independent.

**VI. Non-Medical Transportation**

- We need options for people with mobility issues
- Transportation is a big issue
- We need to train staff to use public transportation, sometimes they are scared to use it
- I don't know how to get this or what's available
- I have it on my budget and it really helps
- I have it on my budget but it's not enough money. I use it up too fast and could use more.
- Using the mileage is a challenge for providers because this can't be billed with another service at the same so how is staff to be paid?  
time
- It's good but there are too many limits, not enough money and not enough distance (only 100 miles)
- We need to educate people, so they know what this is
- Uber and Lyft would be great!

**Group Homes**

- I don't like the term group home. It should be "Homes that we live in"
- I don't like living in the group home I want my own apartment

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**VII. Training**

**What training do you think your staff needs that would help you?**

- Staff can use training on how to ride bus, use ride share
- Attitude training
- To listen, be respectful, understand your disabilities
- How to work with people with disabilities
- What the DDW is – different team members living in own silos
- How to understand different medical issues so they can be more understanding
- Treat people like adults
- Money management
- Make it mandatory for self-advocates to be trainers in trainings
- Understand diagnoses better