

# Building the Future Together: Living the Life *YOU* Choose



Las Cruces, New Mexico  
Sept. 27<sup>th</sup>, 2019



# Outcomes

- Receive an update on the CMS Final Rule and the Know Your Rights Campaign
- Learn about person centered thinking, planning and practice and what it means to you
- Understand how providers and advocates work together
- Identify how direct support professionals play a valuable role in supporting advocates
- Hear from advocates about what independence means to them and why it's so important
- Learn about the importance of how getting the right supports can lead to greater independence
- Identify ways you can help monitor results
- Learn how you can be a part of changing the culture

How do you get what you need to live the life you want? PANEL



# How do you get what you need to live the life you want?

- Know your rights
- Gain skills for greater independence
- Get the right supports at the right time and place

# Important Rights Highlighted in CMS Final Rule

- choose where you live
- privacy, respect and dignity
- decorate your room the way you want
- have access to all areas of your home
- have freedom and support to control your schedule



# Important Rights Highlighted in CMS Final Rule

- choose your roommate
- have visitors
- choose your providers and change them if you're not happy with them
- have friendships and romantic relationships
- have food when you want in your home
- be respected and staff should not talk about you as if you were not there
- you (and your guardian) have the right to make decisions about your health

# Participant Validation results

200 waiver recipients (DD and MV) surveys across the state

6 categories of responses

- Choice of Setting
- Community Access and Integration
- Characteristics of the Setting
- Employment
- Staff Interactions and Privacy
- Services and Supports

# Participant Validation Results-what we heard from participants

**Question:** When you want to do something fun (something you enjoy), what do you do to get started?

**Answer:** “I talk to the staff. We do a lot of activities as a group and the girls in the group don’t always like to do what I want to do so we decide as a group to do whatever it is we want to do for the day. I don’t mind.”

**Question:** Are there things you do that are similar to things people who are your age, but do not receive the services you receive do?

**Answer:** “Not always. If there isn’t enough staff members I can’t go where I want to. There have been times where I have missed appointments, meetings or hanging out with friends because there wasn’t enough staff members to take me.”

**Question:** When you want to go somewhere, do you have a way to get there?

**Answer:** “Yes and no. During the day there is no staff available to assist with transportation so I stay home. Staff comes later in the afternoon and can help with transportation then.”



# Participant Validation Results-what we heard from participants

**Question:** Do you enjoy being at this setting?

**Answer:** “Honestly no, I don’t like it. Most of the consumers are younger than me mentally. Or the consumers are a lot older than me. I don’t relate to a lot of people here. I have an attachment disorder where I get attached to people easily. The staff move or leave this agency often and I get crushed when they leave.”

**Question:** Do people give you help when your plan is being made?

**Answer:** “I want to start my own handyman business. ... is helping me get this business up and running but it’s still in process.”

**Question:** Do you need help with things like combing your hair or brushing your teeth?

**Answer:** “I like French braids and my staff will help with that.”

# Participant Validation Results-what we heard from participants

**Question:** Can people you know come and visit you?

**Answer:** “I can have visitors in the home whenever I want. I spend a lot of time with my girlfriend in my home.”

**Question:** Typically, can you come and go from your home when you want to.

**Answer:** “I have to ask permission. That is why I want to have a place of my own. I don’t want to ask permission to do things.”

**Question:** Can you work somewhere if you want to?

**Answer:** “I work at Target and Applebee’s. I work at Target on Monday and Friday 9 am to 12:30 pm and Applebee’s Tuesday, Wednesday and Thursday from 9 am to 11 am.”

# Advocate and Family Themes from the 2018 Town Halls

- **Real** Person-Centered Planning
- **Real** Choices
- Increase **skill-building** for advocates to become more independent with supports
- **Dignity of Risk/Person Centered Planning** and health/safety issues
- Need to **respect** and **listen** to people on the waivers who communicate differently (“non-verbal”)

# Person-centered reality: what we heard

- Provider versus person centered
- Program versus person centered
- Person centered planning is often not really happening

**CHANGE IS NEEDED!**

# How does the system support you to get what you need and live the life you want?

By being person-centered which is the foundation of the CMS final rule and includes:

- Person Centered Thinking
- Person Centered Planning
- Person Centered Practice

# Person centered planning- Panel Discussion

- What does this really mean?
- How do we do this in real life?
- What is the role of the person-centered plan? (ISP/SSP)
- What is the role of the person in services?
- What is the role of the providers and direct support professionals?

Who is an  
advocate?  
What does  
this mean?

PANEL



# Everyone is an advocate

- People in services
- Providers and direct support professionals
- Families and guardians
- Friends
- State staff
- Advocacy organizations
- Unpaid supports

\*Everyone here has a role in working together to create a person centered system.



What are the qualities of a staff person that support being person centered?

- PANEL

# What are the qualities of a staff person that support being person centered?

## **Helpful**

- Staff who listens
- Staff who teach you how to do things
- Staff who let you try new things and make mistakes
- Staff who give you choices and allow you to make decisions
- Staff who allow you to plan your day based on what is meaningful to you

## **Not helpful**

- Staff who does not listen
- Staff who do things for you
- Staff who don't let you fail or make mistakes
- Staff who make decisions for you
- Staff who plan your day for you

# Provider Perspective: Support that makes a difference. **PANEL**

- How do you engage the people you support to be an advocate in their planning?
- In your opinion, what are barriers to people being heard in their meetings?
- If you could tell the team something to improve person centered planning, what would it be?
- Are you supported to be an advocate for the people you support?
- How do you help build independence for the people you support?
- What do you do when you disagree with the person's wishes or think it's a bad decision?

Advocate Perspective: What does independence mean to you and why is it important?

- PANEL



# The right supports lead to greater independence

- Learn what supports are available to you in the waiver
  - Learn what supports are available to you outside of the waiver
  - Identify natural and unpaid supports
  - Rely on community where you can
  - Make sure what you want is in your plan-make your choices known
  - Build you budget to meet your needs, not the needs of others
- \*Not everyone needs 24 hour supports

Strive for independence!

# Treating people like people: How do we do this?

- Changing the culture
- Creating a person-centered system
- Ideas for the future that truly put the person first
- Promoting independence and skills, not dependence on the system
- Getting the word out about innovative solutions and support options
- Working together and supporting each other

# How do we know if it's working?

- How to monitor if things are working?
- Who should monitor?
- What to do if something is not working?

\*If things are not working and we do nothing, nothing changes.

# Get Involved!!

- Speak up, make your choices known and exercise your rights
- Be informed-know where to get reliable, factual information
  - Sign up for NM Allies for Advocacy distribution list
  - Get info on the DDPC/CSA Advocate Leadership Academy
  - Sign up to receive the DDPC newsletter and e-blast
  - Visit the DDSD websites
  - Read the DDSD quarterly newsletter
- Get involved
  - Join the Las Cruces People First chapter- Member to speak
- Get the word out!
- Please complete the evaluation and health survey



# Questions?



# Contact Information

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# Thank You!!!

Las Cruces People First  
NM Heritage and Ranch Museum