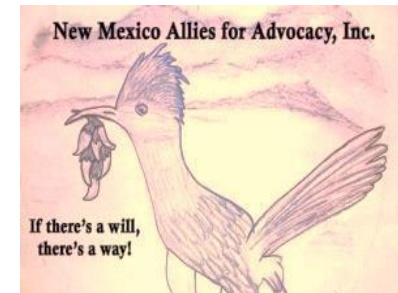


# Advocate Rights and Responsibilities



Alamogordo, New Mexico  
September 20, 2018



# AGENDA

- Jr. ROTC Cadets: Honor Guard- Color Flags/ Pledge of Allegiance
- Welcome and Introductions
- Mayor Richard Boss- Opening Remarks
- Alicia Lucoski- What If
- What Do You See When You Look At Me?
- CMS Final Rule and Know Your Rights Campaign
- Questions and Answers
- Wrap up and Thank-You's

# Panelists

- Henry Bartenbach
- Tony Bradway
- Catelin Boverie
- Wendy Corry
- Roberta Duran
- Daniel Ekman
- Albert Gonzalez
- Mitchell Lucero
- Alicia Lucoski
- Sergio Resendez
- Will Robinson, Jr.
- Jen Rodriguez
- Lindsay Sloan

# Meeting Outcomes

- Promote awareness for people with IDD about their rights and responsibilities
- Support and empower people with disabilities to exercise their rights
- Model advocacy for all people
- Develop advocate-led regional support networks

## *What If...*

Linda Stengle's book, "Laying Community Foundations for your Child with a Disability."

- What if you never got to make a mistake?
- What if your money was always kept in an envelope where you couldn't get it?
- What if you were never given the chance to do well at something?
- What if your only chance to be with people different from you was with your own family?
- What if the job you did was not useful?
- What if you never got to make a decision?
- What if the only risky thing you could do was to act out?
- What if you couldn't go outside because the last time you did, it rained?

What if you took the wrong bus once, and now you can't take another one?

What if you got into trouble and you were sent away and you could never come back because they always remember you are trouble?

What if you worked and got paid 46 cents an hour?

What if you had to wear your winter coat when it rained because it

- was all you had?

What if you had no privacy?

What if you could do part of your grocery shopping, but were not allowed to because you couldn't do all of your shopping alone?

What if you spent three hours each day just waiting?

What if you grew old and never knew adulthood?

***What if you never got a chance?***

# What Do You See When You Look At Me?

- Alicia Lucoski
- Sergio Resendez
- Lindsay Sloan
- Will Robinson, Jr.



## ~ Lindsay ~

- ▶ Love to travel and have been to 9 countries.
- ▶ Lived for 2 months at the Olympic Training Center in Colorado Springs to try out for the USA women's Goalball team (2004 Paralympics)
- ▶ Love to hike and ride horses
- Assisted with Senate Bill 320 –  
Service Animal Legislation
- ▶ Lobbied on Capitol Hill for disability issues with the National Federation of the Blind.
- Passion is working to make a better world for all people.





## ~ Sergio ~

- ▶ Lives in Albuquerque, New Mexico
- ▶ Helped create a “Disability Awareness” curriculum for elementary school aged children
- ▶ Is a Team Leader for the Academy
- ▶ Vice Chair of the New Mexico Developmental Disabilities Planning Council

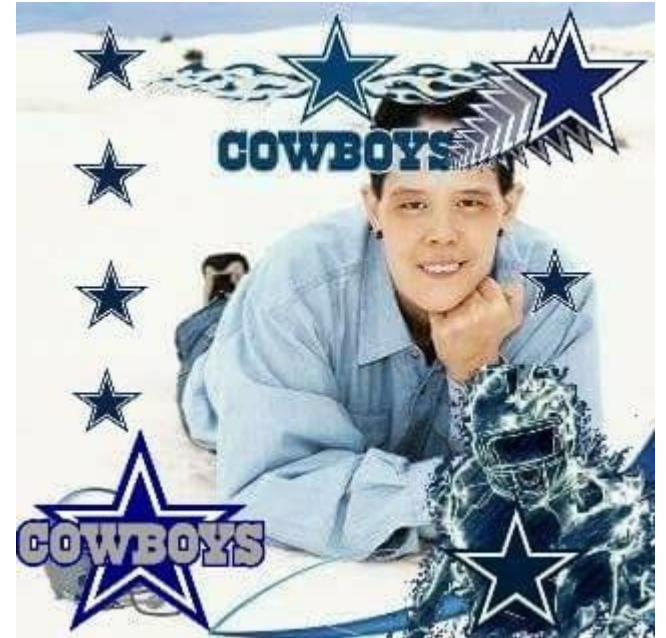


~ *Will* ~

- ▶ Lives in Socorro, New Mexico
- ▶ Is a graduate of the Advocate Leadership Academy
- ▶ Is a Co-Team Leader for the Academy
- ▶ Has experience speaking at legislative hearings about issues facing the disability community.

~ *Alicia* ~

- ▶ Works multiple part time jobs
- ▶ Enjoys participating in Zumba classes
- ▶ Is a two-time Fellow for the Advocate Leadership Academy at DDPC
  
- ▶ Her favorite football team is the Cowboys



# Disability is a Natural Part of Life

- ▶ People are people. We all need to eat, drink, sleep, get dressed, go to school, work, hang out with friends.
- ▶ The “disability club” is the club that anyone can join at any time.
- ▶ Anyone can sustain an injury and be temporarily “disabled” as they recover.
- ▶ All people grow old and have to do things differently as they age.
- ▶ Everyone **DESERVES** respect and the opportunity to try.

**NEVER GIVE UP ON YOUR DREAMS!!!**

# THE **VALUES** OF INCLUSION


★ EVERYONE IS BORN IN 

★ ALL MEANS ALL

★ EVERYBODY NEEDS TO BE **IN**

★ EVERYBODY NEEDS TO BE **WITH**

★ EVERYONE CAN **COMMUNICATE**

★ EVERYONE CAN **LEARN** 

★ EVERYONE IS **READY**

★ EVERYONE NEEDS **SUPPORT**

★ EVERYONE CAN **CONTRIBUTE**

  
**TOGETHER** WERE **BETTER**

## CMS Final Rule-Promoting rights and responsibilities for people receiving waiver services

1. Person-centeredness
2. Inclusion
3. Access
4. Integration
5. Informed choice
6. Satisfaction with services
7. Achieving desired outcomes







# Know Your Rights Campaign 2017

# Advocate and Family Themes from the 2017 Town Halls

- **Real** Person-Centered Planning
- **Choices**- what if people don't want to "be in the community" all the time? What if they choose to stay home or stay in a day hab setting?
- Increase **skill-building** for advocates to become more independent with supports
- Teach advocate to take **responsibility** as well as **rights**
- **Dignity of risk/Person Centered Planning** and health/safety issues
- Day programming- will there be **options** and **what will this look like?**
- Need to **respect** and **listen** to people on the waivers who communicate differently ("non-verbal")
- **Supported Employment**- how will this change?



# Hear our voices

Written comment from the ABQ Town Hall on Feb. 1, 2017:

- Will they be able have partys sents they took away partys in the group homes and have real candles can they have snakes (snacks) if they want to if they don't need on a diet, can they eat what they want just because someon eles needs to does not mean they should have as well can they get rides to jobs that are not on 9-5 work days and get back home can they have an animal that is not for service they can have a ride for help with him or her can we live where their is no dugs and on a good runing bus rut and not have to be buged for money?"

# Marilyn Martinez- Advocate on the DD Traditional Waiver

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I want to be able to cook when  
I want to and go to church on  
Sunday.

I want to live in my own  
apartment.



Question 1  
What rights  
are  
important  
to you?



# 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
- choose your roommate
- have visitors

# Important Rights highlighted in CMS Final Rule

- 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

# Important Rights highlighted in CMS Final Rule

- Access to competitive employment
- Opportunities to work and be paid fairly
- Control of your money

# Employment

## CMS Final Rule

- Access to competitive employment
- Opportunities to work and be paid fairly
- Control of your money

## Working and Social Security Benefits

- Work Incentives
- DVR Benefits Counselor
- Information on table



## Question 2

# Why Is Work Important for Everyone?

- Why is work important to you?
- What does it mean to you to have a job or career?
- What were some of the barriers you faced to find work?





# Question 3

## What do you need to exercise your rights?

Laurel Deans- Advocate on the Mi Via Waiver

“I have my own apt. I have a job and I have help to budget my money.”



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- Mari Gonzales, an advocate who receives services through the DD Waiver states, “I love having choices because it makes me feel independent”.
  - Shana Heath on the importance of having choices- “It means I have my own independence. I can do things on my own. I can take Sun Van. I have the support of others if I need it, but I can mostly do it on my own”.



# Supports to Exercise Your Rights

- Person Centered Planning is about you and to help you find the support and resources you need to make informed decisions.
- You decide who helps you. This can be:
  - Natural supports (family, friends, the community);
  - Your team;
  - Your Case Manager or Consultant; and
  - Provider or vendor agencies.

Know what to do or who to call if you can't exercise your rights.

Question 4  
What are your  
responsibilities?



**Your Responsibility**

# Responsibility for Choices and Decisions

With rights and choice comes responsibility.

- Know about consequences
- Speak up for yourself and your friends
- Be kind and considerate
- Listen to others
- Compromise and negotiate



# What's Next?

- Educate and raise awareness in communities about advocate rights and responsibilities
- Develop advocate-led regional support networks

# Get Involved!!

- Sign up for NM Allies for Advocacy distribution list
- Get info on the DDPC Leadership Academy
- Sign up to receive the DDPC newsletter and e-blast
- Sign up if interested in creating a Regional Support Network in Las Cruces
- Come to the Attorney Generals Office Disability Conference, Oct. 4 in ABQ
- Please complete the evaluation and health survey

# Questions?





Thank  
You's





We Honor Carolyn  
Elizabeth Samuel

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*Carolyn Elizabeth Samuel*

*March 23, 1941 - October 17, 2017*

*Celebration of Life: Saturday, March 17, 201*

# Contact Info

Developmental Disabilities Planning Council (505) 841-4519

Lindsay Sloan- DDPC Outreach Coordinator

[lindsay.sloan@state.nm.us](mailto:lindsay.sloan@state.nm.us) <http://www.nmddpc.com>

Wendy Corry- DDPC Contractor (505) 238-0047

[wendy@corryconsulting.com](mailto:wendy@corryconsulting.com)

NM Allies for Advocacy, Inc.- [nmallies@gmail.com](mailto:nmallies@gmail.com)

Daniel Ekman- NM Allies for Advocacy Secretary (505) 670-5698



DDSD SW Regional Office- (575) 575-528-5180 or  
866-742-5226 (Toll-Free)

DDSD Deputy Director- Roberta Duran (505) 476-8923

DDSD Community Programs Bureau Chief- Jennifer Rodriguez  
(505) 476-8840

DDSD DD Waiver Manager Christina Hill (505) 476-8836

DDSD Mi Via Waiver Manager- Regina Lewis (505) 841-5519

<https://nmhealth.org/about/ddsd>



**THANK YOU!**