

# NM KNOW YOUR RIGHTS CAMPAIGN TOWN HALLS February/March 2017



BROUGHT TO YOU BY: THE KNOW YOUR RIGHTS STEERING COMMITTEE  
WENDY CORRY, MS, CHAIRPERSON

# NM Know Your Rights Steering Committee

The KYR Steering Committee was established by the Department of Health, Developmental Disabilities Supports Division and is made up of:

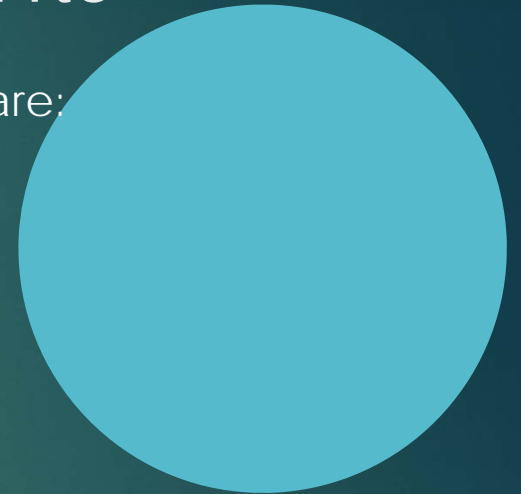
- ▶ Developmental Disabilities Supports Division
- ▶ New Mexico Allies for Advocacy
- ▶ The ARC of New Mexico
- ▶ Case Management Action and Advocacy Council
- ▶ New Mexico Autism Society
- ▶ Developmental Disabilities Planning Council
- ▶ Disability Rights New Mexico
- ▶ Governor's Commission on Disability
- ▶ Human Services Department
- ▶ Parents Reaching Out
- ▶ San Juan Center for Independence
- ▶ Association of Developmental Disabilities Community Providers
- ▶ Family Living Provider Association
- ▶ UNM/Center for Development and Disability



# Why Are We Here: Disability Rights are Civil Rights are Human Rights

Examples of the type of rights people with disabilities have are:

- ▶ Be treated as equals
- ▶ Be treated with respect
- ▶ Choose where they live
- ▶ Make choices about their lives
- ▶ Go to school and choose where they go to school.
- ▶ Work
- ▶ Get married and have children
- ▶ Vote
- ▶ Claim their human rights



# History of Disability Rights

Through the efforts of many people, disability legislation was fueled by the Civil Rights Movement and includes but is not limited to:

- ▶ The Rehabilitation Act (1973)
- ▶ Education for all Handicapped Children Act (1975) replaced by IDEA
- ▶ Individuals with Disabilities Education Act (1990)
- ▶ The Americans with Disabilities Act (1990)
- ▶ Olmstead Act (1999)
- ▶ Developmental Disabilities Assistance and Bill of Rights Act (2000)
- ▶ Centers for Medicare and Medicaid Services (CMS) Home and Community Based Services (HCBS) Settings Final Rule (2014)



NOW IT'S UP TO ALL OF US TO CONTINUE THE  
PROGRESS BY ORGANIZING AND STANDING  
UP FOR DISABILITY RIGHTS, HUMAN RIGHTS,  
CIVIL RIGHTS.

**DISABILITY RIGHTS**  
**ARE CIVIL RIGHTS**

# What is the Know Your Rights Campaign?

The KYR Campaign is a statewide initiative by DDSD in collaboration with the KYR Steering Committee and other stakeholders to:

- Engage stakeholders and communities around the state
- Build and strengthen advocacy with and for people with Intellectual/Developmental Disabilities
- Raise awareness and educate communities across New Mexico that people with disabilities have rights
- Inform you and the public that the CMS HCBS Settings Final Rule is designed to make sure you have the opportunity for integration and access to the community, choice, individual rights, and independence

## National Disability Rights Network Comments on CMS Final Rule: Curt Decker, Exec. Dir. of NDRN

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“This final rule is important to let states, providers, families, and individuals with disabilities know that the services paid for by Medicaid home and community based waiver funds will be in integrated settings, not some place that is called integrated, but is actually segregated from the public”

## The final rules require that all HCBS settings (residential and non-residential) must:

- ▶ Be integrated in and facilitate full access to the greater community
- ▶ Maximize independence in making life choices
- ▶ Be chosen by the individual (in consultation with the guardian if applicable) from among residential and day options, including non-disability specific settings
- ▶ Ensure the right to privacy, dignity, respect and freedom from coercion and restraint
- ▶ Provide an opportunity to seek competitive employment
- ▶ Provide individuals an option to choose a private unit in a residential setting and
- ▶ Facilitate choice of services and who provides them



# How is the Know Your Rights Campaign linked to the CMS Final Rule?

The Know Your Rights Campaign AND the CMS Final Rule: HCBS Settings Requirements provide individuals (in consultation with their guardian if applicable) opportunities for:

- Integration and access to the community
- Choice
- Individual rights
- Independence

Source: Getting the Community Life You Want (A Guide to Home and Community Based Services Advocacy)  
The Boggs Center on Developmental Disabilities  
New Jersey's University for Excellence in Developmental Disabilities Education, Research, and Service  
Rutgers Robert Wood Johnson Medical School

# 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 dug and on a good runing bus rut and not have to be bugged for money?”

# Integration and Access to the Community

Integration and access to the community means that you have chances to:

- ▶ Find competitive employment working alongside with people without disabilities
- ▶ Participate in local activities
- ▶ Control your own budget
- ▶ Access services in the community just like people without disabilities

Source: Getting the Community Life You Want (A Guide to Home and Community Based Services Advocacy)

The Boggs Center on Developmental Disabilities

New Jersey's University for Excellence in Developmental Disabilities Education, Research, and Service

Rutgers Robert Wood Johnson Medical School

# Choice

- ▶ Choice means that you can select the services and supports that you need
- ▶ Choice means that you can select who provides services and supports and where you receive them
- ▶ You should have the option to live and receive services in places that are for people with and without disabilities.
- ▶ A choice of housemates
- ▶ A choice of how to decorate your room or living unit

Source: Getting the Community Life You Want (A Guide to Home and Community Based Services Advocacy)  
The Boggs Center on Developmental Disabilities  
New Jersey's University for Excellence in Developmental Disabilities Education, Research, and Service  
Rutgers Robert Wood Johnson Medical School



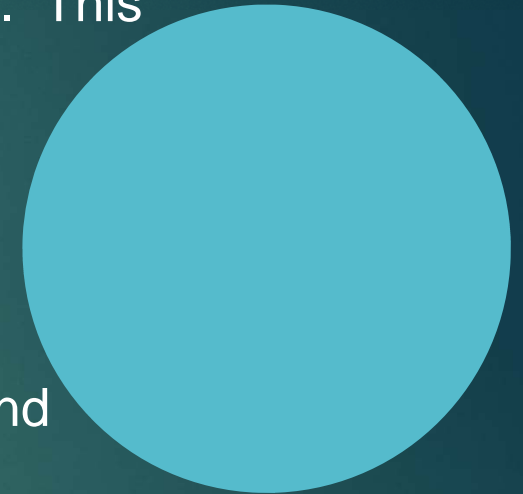
# Individual Rights and Independence

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Individual Rights and independence means that you are in charge of making decisions about your life and what you want to do. This includes:

- ▶ Privacy
- ▶ Dignity and respect
- ▶ Freedom from coercion and restraint
- ▶ Have freedom and support to control their schedules and activities and have access to food at any time
- ▶ Have visitors at any time
- ▶ A setting that is physically accessible to the individual

Source: [Getting the Community Life You Want \(A Guide to Home and Community Based Services Advocacy\)](#)  
The Boggs Center on Developmental Disabilities  
New Jersey's University for Excellence in Developmental Disabilities Education, Research, and Service  
Rutgers Robert Wood Johnson Medical School



# Guardians and the Know Your Rights Campaign

- ▶ CMS recognizes that plenary guardians get to make final decisions on certain things.
- ▶ However, CMS requires that states meet the person centered planning requirements of the rule which generally require that the process be driven by the individual themselves.
- ▶ CMS expects guardians to follow a “substituted judgment” decision-making process that requires that the guardian talk with the individual and attempt to assess what the individual’s own wishes and preferences would be.
- ▶ A Protected Person for whom a guardian has been appointed retains all legal and civil rights except those that have been expressly limited by court order.

# How will the State Comply with the CMS Final Rule?

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- ▶ All settings, residential and non-residential must meet the settings requirements previously outlined
- ▶ Providers conducted a Provider Self-Assessment
- ▶ The University of New Mexico, Center for Developmental Disabilities (UNM/CDD) will help the State by conducting a survey of providers and participants
- ▶ The State has to comply by March 2019

# Participant Survey

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- ▶ UNM/CDD may contact you or your guardian to ask you to share your thoughts to help the state learn more about what people with developmental disabilities want from the HCB services they receive.
- ▶ This is your chance to tell the state if you think services and supports you receive provide the opportunity for integration and community access, choice, individual rights and independence.
- ▶ Example of questions UNM/CDD will ask include:
  1. Did you get to choose who gives you services (get to choose the provider)?
  2. Can people you know come and visit you?
  3. Do you do things like go shopping or see your family or friends, when you want?



# WHAT'S NEXT

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We Want To Hear From You! How can you be Involved?

- ▶ Participate in the Waiver Participant Survey if selected
- ▶ Participate in town halls
- ▶ Talk to your family, community and legislators about your rights
- ▶ Be prepared to comment on plans multiple times during the transition period.
- ▶ Public input opportunities in the transition process include waiver amendments; changes to state rules, policies, and procedures related to the HCBS programs; and changes to state statutes or code.
- ▶ It is crucial that advocates and family members weigh in to support states' efforts to comply
- ▶ Keep up with what's going on:  
[www.ACTnewmexico.org](http://www.ACTnewmexico.org)  
[www.HCBSadvocacy.org](http://www.HCBSadvocacy.org)

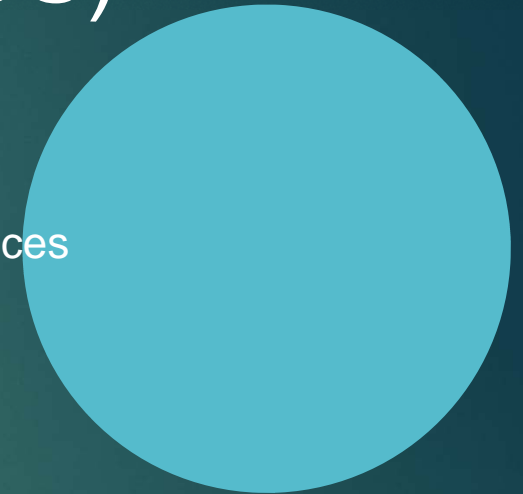
# ORGANIZE AND SPEAK UP FOR RIGHTS (IT'S UP TO ALL OF US)

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Let your voices be heard:

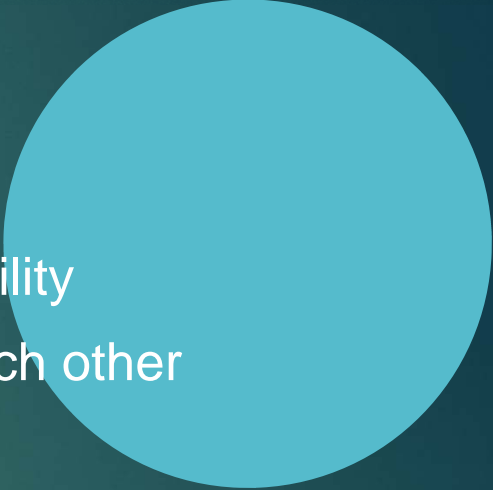
## NO MORE

- ▶ Only being offered disability-specific supports and services
  - ▶ Being grouped on agency-controlled outings
    - ▶ Living with people you don't want to
      - ▶ Sheltered workshops
  - ▶ Being denied employment due to disabilities
  - ▶ Being denied relationships or adult activities
    - ▶ Being treated like a child
    - ▶ Being denied access to healthcare
- ▶ Being labeled as a disability instead of a person



# WE WANT MORE:

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- ▶ Awareness
    - ▶ People having a voice and being heard
    - ▶ People being seen as people and not a disability
  - ▶ People talking, working, and playing alongside each other
    - ▶ Healthier people
    - ▶ Having more happiness and fulfillment in life
  - ▶ People being more self-sufficient and less dependent on systems and paid staff
- 

# “Nothing About Us Without Us”

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- Get involved
- Educate yourself and your family
- Educate your community
- Share your experiences and feedback
- Help ensure NM efforts lead to positive systems change
- Be an advocate for choice and full inclusion





# State-Wide Town Halls 2017

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- ▶ Albuquerque: February 1st
- ▶ Santa Fe: February 9th
- ▶ Las Cruces: February 16<sup>th</sup>
- ▶ Taos: February 28th
- ▶ Roswell: March 7<sup>th</sup>
- ▶ Gallup: March 14th
- ▶ Farmington: March 29<sup>th</sup>
- ▶ Silver City: April 3<sup>rd</sup>

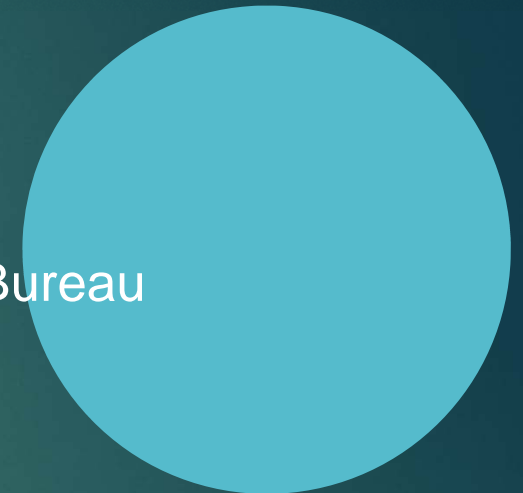


# Adapted from the Developmental Disabilities Supports Division: Know Your Rights Campaign

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# Resources

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1. HCBS Settings Rules: How to Advocate for Truly Integrated Community Settings (Unabridged)- HCBS Advocacy Coalition. <http://hcsadvocacy.org/national-resources/>
2. The Medicaid Home and Community Based Services Settings Rules: What You Should Know!- HCBS Advocacy Coalition. <http://hcsadvocacy.org/national-resources/>
3. The Home and Community-Based Settings Rule: What Does it Mean for You?, <http://hcsadvocacy.org/national-resources/>
4. Questions and Answers - 1915(i) State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, Setting Requirements for Community First Choice, and 1915(c) Home and Community-Based Services Waivers - CMS 2249-F and 2296-F
5. HCBS FINAL REGULATIONS 42 CFR Part 441: QUESTIONS AND ANSWERS REGARDING HOME AND COMMUNITY-BASED SETTINGS <https://www.medicaid.gov/Medicaid-CHIP-Programs/Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html>
6. Change Your Life With Human Rights (Harvard Project on Disability), <https://worlddownsyndromeday.org/>
7. Getting the Community Life You Want (A Guide to Home and Community Based Services Advocacy) The Boggs Center on Developmental Disabilities, New Jersey's University for Excellence in Developmental Disabilities Education, Research, and Service and Rutgers Robert Wood Johnson Medical School

# THANK YOU

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