Balancing Individual Rights and Provider Liability

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The Lewin Group
Our Mission

Improving health care access and outcomes for the people we serve while demonstrating sound stewardship of financial resources
WebEx Quick Reference

- Use chat to answer questions, make comments, share insights
- For technology issues, please chat to “Host”
- For questions, comments or insights please chat to “All Participants”
Today's Goals and Objectives

• Learn what protections for individual rights exist now in current CO statute and regulations.

• Understand how and when providers can restrict someone’s choice or rights.

• Discuss due process.

• Define risk and danger to self and others.

• Explore scenarios related to participant rights, and guardianship within various residential and non-residential settings.
Questions to Consider

• What changes will your organization make in the next month to better align your policies or procedures with Colorado statutes and regulations?

• What changes will your organization make in the next month to balance individual rights and provider liability for your organization? What will this look like for you?
Rule Includes Two Provisions

- **Home and Community Based Service Settings**
  - Increases protections relating to where individuals receive Home and Community Based Services, and
  - Ensures individuals are afforded opportunities to be fully integrated into their community.

- **Person-Centered Planning Process**
  - Increases individual’s input on how services are planned and what is included in the plan of care.
Important Characteristics for all HCBS Settings

- Integration with the Community
- Informed Choice
- Individual Rights
- Individual Autonomy
**Individual Rights and Autonomy**

- The setting ensures an individual’s rights and privacy, dignity and respect, and freedom from coercion and restraint.

- The setting optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment and with whom to interact.
Michele Craig, HCPF

**HCBS-DD AND HCBS-SLS & SUPPORTED EMPLOYMENT COORDINATOR**
Included in Today’s Webinar

- Overview of the IDD system’s rules and the processes used to ensure individuals are safe and healthy and have the same rights as everyone else.

- Review IDD rules that must be adhered to when there is a specific health & safety concern and a restrictive intervention must be implemented within the IDD service system. These processes can be applied to all waiver service recipients.

- These systems are designed to protect the individual receiving services.
Our Ask to You!

- **Listen to understand**: The practices that the DIDD system uses can be used in other waivers along with other populations.

- **Listen to learn**: The processes that exist for individual rights.

- **Listen to inform your processes**: Take the scenarios and adapt/tailor them for your setting!
Individual Rights

Unless a person's rights are modified by court order, a person with an Intellectual and Developmental Disability has the same legal rights and responsibilities guaranteed to all other persons under the federal and state constitutions and federal and state laws.
Individual’s Rights

- Individualized plan or individualized family service plan
- Medical care and treatment
- Humane treatment
- Religious belief, practice, and worship
- Communications and visits
- Fair employment practices
- Vote

25.5-10-219 through 25.5-10-225
Individual Rights

A person receiving services has the same legal rights and responsibilities guaranteed to all other individuals under the federal and state constitutions and federal and state laws including, but not limited to, those contained in section 25.5-10, C.R.S., unless such rights are modified pursuant to state or federal law.

10 CCR 2505-10 8.604.1
Individual Rights

- Agencies must have policies and procedures in place to ensure people have human and statutory rights.

- Information on rights is provided to:
  - All persons receiving services in an individually accessible manner,
  - Parents of minors, guardians and authorized representatives.

- Agencies are to provide on-going support to individuals to exercise their rights.

10 CCR 2505-10 8.604.2
Suspension of Rights

- For protection of the health and safety of the individual and/or community
- Written Notice of suspension of rights required
- HRC review required
- Six month reviews by the individual’s support team required
- Fading plan and supports needed to fade required in the Individualized Plan

10 CCR 2505-10 8.604.3
Notice of Suspension of Rights

- Written notification hand delivered to or sent by first class mail of:
  - The proposed action;
  - The reason or reasons for that action;
  - The effective date of that action;
  - The specific law, regulation, or policy supporting the action;
  - The responsible agency with whom a protest of the action may be filed including the name and address of the director;
  - The Dispute Resolution procedure, including deadlines, in conformity with section 8.605 and procedures on accessing agency records.

10 CCR 2505-10 8.604
Restrictive Procedure

- Limits an individual’s movement or activity against his or her wishes
- Interferes with an individual’s ability to acquire and/or retain rewarding items or engage in valued life experiences
- May only be used for behavior modification
- Requires Informed Consent
- Requires Human Rights Committee review
- Must be used as part of a behavior support plan

10 CCR 2505-10 8.604 and 8.608.2
Informed Consent

• Agreement which is expressed in writing and is freely given after being provided:

  ➢ A fair explanation of the procedures to be followed, including an identification of those which are experimental

  ➢ A description of the attendant discomforts and risks

  ➢ A description of the benefits to be expected

  ➢ A disclosure of appropriate alternative procedures together with an explanation of the respective benefits, discomforts and risks

10 CCR 2505-10 8.604
Informed Consent

- An offer to answer any inquiries regarding the procedure

- An instruction that the person giving consent is free to withdraw such consent and discontinue participation in the project or activity at any time

- A statement that withholding or withdrawal of consent shall not prejudice future provision of appropriate services and supports to individuals

10 CCR 2505-10 8.604
Mechanical Restraint

• The use of devices intended to restrict the movement or normal functioning of a portion of an individual's body.

• Mechanical Restraint *does not* include the use of protective devices used for the purpose of providing physical support or prevention of accidental injury.

10 CCR 2505-10 8.604
Physical Restraint

• The use of manual methods to restrict the movement or normal functioning of a portion of an individual's body through direct physical contact by others except for the purpose of providing assistance/prompts.

• Assistance/prompts is the use of manual methods to guide or assist with the initiation or completion of and/or support the voluntary movement or functioning of an individual's body through the use of physical contact by others except for the purpose of providing physical restraint.

10 CCR 2505-10 8.604
Physical and Mechanical Restraint

Physical or Mechanical Restraint may only be used:

- When necessary to protect the person from injury to self or others;
- After less restrictive interventions have been exhausted;
- By employees or contractors trained in the use of Physical or Mechanical restraint;
- In an emergency situation, when alternatives have failed.

10 CCR 2505-10 8.608.3
Physical and Mechanical Restraint

- Only used as part of an Emergency or Safety Control Procedure.
- Does not place excess pressure on the chest or back or inhibit/impede ability to breathe.
- Breathing and circulation is monitored during restraint.
- Human Rights Committee Review required.
- Incident Report required for each use.

10 CCR 2505-10 8.608.3
Emergency & Safety Control Procedures

• **Emergency Control Procedure**
  - An unanticipated use of a restrictive procedure or restraint in order to keep the person receiving services and others safe.

• **Safety Control Procedure**
  - A Restrictive Procedure or restraint that is used to control a previously exhibited behavior which is anticipated to occur again and for which the planned method of intervention is developed in order to keep the person and others safe.
Emergency Control Procedures

- Behavior that puts the health and safety of the individual or community at risk.
- Behavior that is infrequent and unpredictable.
- Incident Report required.
- Human Rights Committee review required.

10 CCR 2505-10 8.608.4
Safety Control Procedures

- Behavior that puts the health and safety of the individual or community at risk.
- Behavior is frequent and predictable.
- Requires a written plan.
- Less restrictive interventions are exhausted.
- Incident Report required.
- Human Rights Committee review required.
- If used more than three (3) times in thirty (30) days, support team review required.

10 CCR 2505-10 8.608.4
Psychotropic Medications

• Used only for diagnosed psychiatric disorders.
• Recommended by a psychiatrist after psychiatric evaluation or consultation.
• Documented in the Individual Support Plan.
• Prescribed by a psychiatrist for a time-limited prescription of no more than ninety (90) days.
• Reviewed at least annually by a psychiatrist.
• Is the minimum effective dose possible?
• Side effects are monitored, documented and reported to the psychiatrist.

10 CCR 25050-10 8.609.6
Human Rights Committee

- Each Community Centered Board required to have a HRC
- HRC serves as a third party mechanism to safeguard the rights of persons receiving services
- Reviews:
  - The use of psychotropic medications
  - The use of Restrictive Procedures
  - The use of Suspension Of Rights
  - The use of Safety Control Procedures
  - The use of Emergency Control Procedures
  - Mistreatment, abuse, neglect and exploitation (MANE) investigations

10 CCR 2505-10 8.608.5
Take a Minute to Reflect
Tamara French, Director of Community Programs
Goodwill Industries

PROMISING PRACTICES FROM THE FIELD
Discover Goodwill: An Overview

• Three Facilities
  - Possibilities - EBD Adult Day and IDD Specialized Habilitation
  - Journeys - EBD Adult Day and IDD Specialized Habilitation
  - Voyages - EBD Adult Day and VA approved center

• 2/3 facilities are adopting the Eden concept with person-centered approach
  - With the Eden concept, our environments will go from:
    - Helplessness → Purpose
    - Loneliness → Companionship
    - Boredom → Variety
Organizing a Task Group

• Task group has the following participation:
  - 6 internal staff members to include executive and management team
  - 2 community members

• With the task force, we have accomplished the following tasks:
  - Meet monthly, every other month with the community members
  - Created plan to implement the Eden Concept for Journeys and Voyages
  - Created plan for person centered training for all staff and implementation process
  - Evaluated provider liability
Organizational Task Group focused on Provider Liability

• Catalyst was the Final HCBS Settings Rule

  ➢ **Task Group Goal:** Find a balance between provider liability and client risk analysis for community integration

  ➢ **Standing Agenda Items:** Create a risk assessment for independent community integration

  ➢ 9 different categories on the risk assessment:
    - Eating, community risks, environmental, financial independence, medical, safety, supervision, abuse, and high risk sexual behavior

  This risk assessment will be approved by both community partners, prior to full implementation, to ensure we are in full compliance with the state and our CCB partner.
Next Steps

- Complete and finalize the internal risk assessment
- Train all staff on Person Centered Planning
- Get two staff certified to implement the Eden environment
- Roll out new assessment and Person Centered Planning
- Review internal policies and change as necessary
- Create staff goals around new implementation for 2017
Take a Minute to Reflect
Choice vs. Risk: A delicate balance

Sarita Reddy
Greeley Center for Independence
Organizational Statements

**Vision:** People with disabilities leading connected, interdependent lives

**Mission:** GCI serves people with disabilities by providing services tailored to meet individual needs
LONG TERM SERVICES - These are supports that enable people with disabilities to participate in community life

1. Affordable, accessible housing (47 apartments)
2. Long Term Home Health services (22 people with a variety of disabilities)
3. Supportive Living Program (18 adults with brain injury - 24/7 support)

INTERMITTENT SERVICES - GCI serves the larger community of Greeley/Weld County by providing these services to the general public. All the services in this category may be utilized by GCI residents if they desire them.

- Day Program - 30 participants
- Hope Therapy Center - Physical/Occupational Therapy
- Hope Pool and Wellness Gym - Warm water pool and gym
Supportive Living Program

- 18 adults who qualify for the HCBS-Brain Injury waiver
- A few have strong family connections
- Each person has their own studio apartment
- Common dining and recreational areas
- 24/7 staff support funded through Medicaid waivers
- In the process of being licensed as an Assisted Living Residence (ALR)
People we support have taught us that:

- People with disabilities have the same dreams/wishes/desires as people without

Therefore, in doing our work we:
Start with the golden rule... and then tweak it

- Begin with... “What would I want in this situation?”
- Move to... “What does this person want in this situation?”
People we support have taught us that:

- Disability creates barriers for the people we serve

Therefore, in doing our work we:

- See our job as removing barriers that disability creates
- When we do it well, we (staff, the agency) are invisible
People we support have taught us that:

- Loneliness and lack of control are two of the main challenges people receiving services face

Therefore, in doing our work we:

- Create a culture of constant conversation... with people served, with those who know and care about them, with each other... so our decisions are always informed by the person’s wishes

- See ourselves as a bridging organization... we actively seek opportunities for connections with others (unpaid) and with community resources
People we support have taught us that:

- The structure of the service system is often at odds with the supports people with disabilities say they want and need

Therefore, in doing our work we:

- Continually redefine what support should look like for each person
- Work to build a network of advocates for the person
- Call upon people at all levels of the system to help us to think through tough decisions
- MAKE AN INFORMED CHOICE TO ASSUME RISK
We believe strongly in supporting people we serve to exercise their rights.

We recognize that this includes the right to make bad choices.

We are painfully aware that, fair or unfair, we may be held liable for the consequences of such bad choices.

It’s a constant balancing act.
Balancing Act: Some Examples

Individual Choice

Health Safety
Impact on Others
Costs/Resources
Bill’s Story - What We Know

- Bill is in his 50’s; had an accident when he was 18 which caused his brain injury
- He was in several places including a nursing home before he came to us
- His mother and sister are co-guardians and close to him; no other supports
- He is not always able to describe specifics of a situation; his reality does not align with others’; sees a psychiatrist; has a history of significant substance abuse
Bill wants **FREEDOM** and **MORE MONEY**; he sees us as a barrier to attaining these goals

In the past year Bill has been going out to drink; he knows we do not allow alcohol on our premises and respects that

**Our Challenge**: It is dangerous for Bill to drink and take the meds he takes at bedtime
It is important for Bill to be in a safe place, and not have alcohol and meds interact.

It is important to Bill to drink, to come and go as he pleases, to feel in control.
What we are Trying

- We are talking to Bill a lot; reassuring him that he can come and go; asking him to simply let us know when he leaves.

- We are trying to keep him engaged so he’s not constantly thinking about leaving.

- We have his permission to set up a time for a meeting.

- He wants his mother, his sister and a therapist he has known for a while at the meeting.

- We are working on getting him a cell phone.
Other Ideas

- We have spoken to the RCCO case manager and have been told there is nothing she can do.

- We would like to see if there is a way to support Bill in his own home... we will need help from the State to even explore this option.
The Bottom Line...

We will keep talking and engaging others in the conversation as long as Bill will let us!
Take a Minute to Reflect
Nancy Bowden

PROMISING PRACTICES FROM THE FIELD
The Arc Aurora

- Private not-for-profit 501 (c) (3) organization dedicated to supporting and advocating for people with Intellectual and Developmental Disabilities and their families.

- Advocacy is acting with or on behalf of an individual or class in the least intrusive manner to resolve an issue or to obtain a needed support or service. It is essential in maintaining, improving and sustaining the quality of life for people with Intellectual and Developmental Disabilities.

- Visit us at www.thearcofaurora.org or find us on Facebook and Twitter!
Case Study: Billy 22 years old

- Young man who would be considered “high functioning” and diagnosed with Cerebral Palsy as a child.
- He utilizes a wheelchair for mobility and has a limited ability to transfer independently.
- He refuses typical day programming and just wants to hang out with the “normal kids.”
- History of being “hard to place”... multiple, reported conflicts with Host Home and Foster Care providers.
- Wants to live independently in an apartment setting with “push-in” supports.
- Contacted The Arc of Aurora because he didn’t feel heard and no one would honor his wishes.
Perceived Systemic Barriers to Achieving Billy’s Goal

- Billy’s “Hard to Place” history and reputation had led to rights suspensions to avoid ongoing conflicts with Host Home Providers
- Mother, while not his guardian was very involved - had MANY concerns, fears, and reservations
- Long time Case Manager thought living semi-independently would be impossible
- Residential Service Provider had concerns regarding his Health & Safety and what the “state” will say.
- Major fears around Billy’s physical ability to live independently:
  - “What if he needs to use the bathroom at night?”
  - “What if this doesn’t work?”
  - “What if there is a fire?”
Eliminating Environmental Barriers

- Worked to create an accessible apartment setting.
- Brought in OT to identify workable solutions for when staff wasn’t immediately available.
- Leased apartment through Service Provider to maintain ability for situation NOT to work and for Service Provider to maintain setting.
Eliminating the Systemic Barriers

- Worked with Providers to discuss with HRC the elimination of any unnecessary restrictive procedures/rights suspensions which would impede his ability to live semi-independently.

- Built standing monthly IDT meetings with 5 “must haves” from each meeting: Billy was safe, healthy, happy, making progress towards his SP goals, and desired to stay in the current setting.

- Agreement with Service Provider that any issues that arose regarding “Health & Safety” would be addressed with Billy and the team’s support within one month.

- Documented through Service Plan and IDT notes Billy’s Person Centered Goal and the ways the team was helping him meet his goals AND protect his Health & Safety.

- Built Self-Report documentation system for Billy to use alongside Staff daily documentation log.
Eliminating the Attitudinal Barriers

• Hardest work was convincing the care planning team that Billy **HAD THE RIGHT** to:
  - Fail, make mistakes, experience natural consequences;
  - Live semi-independently;
  - Develop and experience a Person Centered Plan that was meaningful to him!
Guess what?

• Billy decided after 7 months there were too many rules at the apartment complex that he wasn’t willing to abide by.

• He wanted good people around, more often.

• He said living semi-independently was “too hard.”
Some would say it didn’t “work”... BUT:

- Billy has lived with his current Host Home Provider for 5 years, with no restrictive procedures/rights suspensions in place.
- He is no longer considered a “problem” in the System.
- He works independently at a local grocery store and has “normal” friends that he hangs out with on the weekends.
BILLY IS HAPPY, HEALTHY, AND SAFE!!!!

IT WORKED!
Take a Minute to Reflect
Upcoming Trainings!

May 18, 2016 at 1pm MT:
Residency Agreements and the HCBS Settings Final Rule
Where can I go for more information on the Final Rule?

- A summary of the regulatory requirements of fully compliant HCBS settings and those settings that are excluded.
- Additional technical guidance on regulatory language regarding settings that isolate.
- Exploratory questions that may assist states in the assessment of:
  - Residential Settings
  - Non-Residential Settings
- Questions and Answers Regarding Home and Community-Based Settings
- Medicaid Home and Community Based Services Website
Contact Information

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