Advocacy 101

Participant Handout

NEW MEXICO DEPARTMENT OF
HEALTH

DEVELOPMENTAL DISABILITIES SUPPORTS DIVISION
November 2019
Course Agenda

- Training Outcomes
- What is Advocacy?
  - Key Definitions
  - Qualities of an Effective Advocate
- Rights and Responsibilities
  - What Rights & Responsibilities Do People Have?
  - Supporting People to Learn Rights & Responsibilities
  - Rights Violations
  - Rights Restrictions
  - Client Complaint Procedure
- Supporting Changes and Choices
  - Dealing with Changes
  - Supporting Informed Choice
  - Supporting people to deal with the consequences of choices
  - Informed Consent
- Advocacy Support in Healthcare
  - Key Definitions for Healthcare Support
  - Roles of Healthcare Decision-Makers & Support Teams
  - Who is the HealthCare Decision-Maker?
  - Advocacy Support of Healthcare in Action
  - Communicating Health Information
  - Skills Practice
- Your Role as an Advocate
  - Advocacy Opportunities
  - Encouraging Self-Advocacy
- Review
- Competency
Training Outcomes

Participants will…

- Know how to explain the individual’s right and responsibilities.
- Be able to support individuals to make informed decisions.
- Know how healthcare decisions are made and by whom.
- Advocate for individuals in their homes, at work, in the community, at appointments, in ISP meetings, and in relationships.
- Promote self-advocacy.

People in supports will…

- Learn their rights and responsibilities.
- Make informed decisions.
- Become self-advocates
Key Definitions

Rights

Self-Advocacy

Advocacy

Self-Determination
WHAT ARE QUALITIES OF AN EFFECTIVE ADVOCATE?

WHY CAN IT BE DIFFICULT TO BE AN ADVOCATE?

REASONS WHY WE MUST ADVOCATE!

REMEMBER THAT WE SHOULD BE ADVOCATING ALL OF THE TIME!
Rights and Responsibilities

Individuals with developmental disabilities in New Mexico have…

- The same rights as any other citizen of New Mexico
- Specific rights described in various federal and state laws.

Notes:

Remember that along with rights comes responsibilities. What are some of these responsibilities.

Source: Adapted from the Cutting Edge Consulting Services & NM DOH/LTSD. (2003) "Rights and Responsibilities." Advocacy Strategies for Case Managers and Service Coordinators
# Supporting People to Learn Rights & Responsibilities

<table>
<thead>
<tr>
<th>Factors</th>
<th>Explanations</th>
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</thead>
<tbody>
<tr>
<td>Time of day</td>
<td>When does the person learn best (morning, afternoon or nighttime)?</td>
</tr>
<tr>
<td>Learning environment</td>
<td>Where does the person learn best? What interferes with learning?</td>
</tr>
<tr>
<td>Motivators and perks</td>
<td>What motivates the person to learn (having fun, self-advocacy, etc.)?</td>
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<tr>
<td>Adaptive equipment</td>
<td>What specialized equipment does the person need (eye glasses, large print, communication device, etc.)?</td>
</tr>
<tr>
<td>Processing information</td>
<td>What is the person's processing style (auditory, visual, hands-on, or a combination)? What helps the person comprehend the concepts (short sentences, pointing, etc.)? How much time does the person need to process information?</td>
</tr>
<tr>
<td>Choice-making</td>
<td>How does the person make choices?</td>
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<tr>
<td>Culture</td>
<td>What are the person’s cultural values and beliefs?</td>
</tr>
<tr>
<td>Communication preferences</td>
<td>How does the person prefer to communicate? How does the person express that he/she understands? Review the person’s communication dictionary and familiarize yourself with the person's augmentative communication devices.</td>
</tr>
<tr>
<td>Active listening</td>
<td>Use techniques such as paraphrasing and summarizing. Also, pay attention to verbal and nonverbal cues that may indicate the person’s level of understanding.</td>
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<tr>
<td>Voice tone</td>
<td>Use an equitable tone of voice, not an authoritarian or demeaning one.</td>
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<tr>
<td>Physical presence</td>
<td>Honor the person’s preferences related to personal space, and avoid hovering over the person if he/she is sitting down.</td>
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<tr>
<td>Attitude</td>
<td>Be enthusiastic about helping the person understand rights and responsibilities.</td>
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<tr>
<td>Resource sharing</td>
<td>Provide factual information, rather than opinions.</td>
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<tr>
<td>Active teaching</td>
<td>Adjust teaching methods as necessary and teach at every opportunity.</td>
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<tr>
<td>Responsiveness</td>
<td>Follow-through on plans in a timely manner.</td>
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</table>
Rights Violations

How might someone’s rights be violated?

1.) 2.) 3.)

Things to consider if a rights violation occurs:

- What was the reason for the rights violations?
- Has the interdisciplinary team (IDT) discussed the matter?
- Should the IDT consider a rights restriction?
- What does the person in supports have to say about the situation?
- Should the Client Complaint Procedure be initiated?
- Does the rights violation involve suspect abuse, neglect, or exploitation?
  
  o If so, you must follow incident reporting procedures, which involves reporting to Division of Health Improvement's hotline immediately.

Notes:
Rights Restrictions

Identify specific situations when it might appropriate to restrict someone's rights:

What should teams discuss when considering restriction of rights?

☑ What right would be restricted?
☑ Is it possible to restrict only part of the person’s right?
☑ What is the justification for the restriction?
☑ What less restrictive measures have already been attempted?
☑ What training and supports does the person need?
☑
☑
☑

What should teams do if someone’s rights have been restricted?

☑ Determine if the person would be a danger to himself/herself or others if the rights restriction was lifted.
☑ Discuss the methods used to implement the restriction. The restriction may be justified, but its actual implementation may violate other rights.
☑ Identify steps that are being taken to help restore the right to this person.
☑ Provide training and/or support to help the person restore his/her rights.
☑ Ensure that a Human Rights Committee has reviewed the restriction at least quarterly or at the time listed in the HRC Review Schedule.
☑ Discuss the restriction of rights on a regular basis.
☑
☑
☑

Remember: Human Rights Committee needs to review and approve all rights restrictions before implementation!

☑ All rights restrictions are reviewed and approved periodically, quarterly for most restrictions. Please see DDW 2018 Standards Chapter 3.3.2 for the full HRC Review Schedule.

Advocacy 101
New Mexico Department of Health Developmental Disabilities Supports Division
Handout Packet – November 2019
Client Complaint Procedure

- This procedure is available to individuals with developmental disabilities receiving services with providers that receive funding through the State of New Mexico.

- Complaints that will be reviewed are Rights Violations committed by a service provider, its employees, and/or those under contract with the provider.

- The person, Legal guardian, Employees of the service provider, or a representative chosen by the person (Advocate) may file the complaint.

<table>
<thead>
<tr>
<th>Service Provider Agency Review</th>
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<tbody>
<tr>
<td>A formal complaint may be filed according to the <em>provider’s grievance procedure</em> within 180 days of the event. The person who files the complaint will receive a written response from the service provider within 15 days of the complaint.</td>
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<tr>
<th>DDSD Regional Office</th>
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<tr>
<td>The office will review and determine the type of investigation (if any) that will be conducted. The office will issue written reports of its findings to the Bureau Chief of the Regional Office.</td>
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<thead>
<tr>
<th>Regional Bureau Chief Review</th>
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<tr>
<td>The Regional Bureau Chief will review the Regional Office’s report and issue a written decision. The Regional Bureau Chief’s decision is final unless the person who filed the complaint requests an administrative hearing.</td>
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<tr>
<th>Administrative Appeal Process</th>
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<tr>
<td>A hearing will be held to review the Bureau Chief’s written decision. An Administrative Hearing Officer will issue a recommendation to the Secretary of the Department of Health. The Secretary’s decision is final.</td>
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</tbody>
</table>
# Dealing with Change

In general, how do you respond to changes in your life?

Think about other people you know; how do they respond to changes?

What are some important factors to consider when a person you support has experienced (or may experience) a change in a home, job, or relationship?

<table>
<thead>
<tr>
<th>Health (physical, mental, and emotional):</th>
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<table>
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<th>Values and beliefs:</th>
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<table>
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<tr>
<th>Environment:</th>
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<table>
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<tr>
<th>Support System:</th>
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<table>
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<tr>
<th>Other:</th>
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What can we do to support individuals who may experience or have experienced a change?

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Supporting Informed Choice

Informed choice occurs when a person considers options, consequences, their own rights, the rights of others, and responsibilities in making decisions.

Making Informed Decisions:

1. Recognize need to decide
2. Identify options
3. Consider possible outcomes
4. Evaluate possible outcomes
5. Make a decision

Strategies to Support Informed Decision-Making
Supporting People to Deal with the Consequences of their Choices

How can you support someone as they deal with the consequences of their choices?

- Ask the person to share their thoughts and feelings
- Be positive and encouraging
- Help the person focus on what they have learned
- Ask the person to think about what they will do next time
# Informed Consent

**INFORMED CONSENT:** To give or deny permission or approval based upon reasonable knowledge and understanding of available options and possible outcomes

## THREE KEY AREAS OF INFORMED CONSENT:

<table>
<thead>
<tr>
<th><strong>Capacity:</strong></th>
<th>Involves the ____________ of how and to what ____________ the person understands, ____________, and communicates.</th>
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<tbody>
<tr>
<td><strong>Information:</strong></td>
<td>Involves providing enough ____________ (options and possible outcomes) to the ____________ in a way that the person will ____________.</td>
</tr>
<tr>
<td><strong>Voluntariness:</strong></td>
<td>Involves the person making a ____________ without being forced or ____________.</td>
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Key Definitions for Healthcare Support

The New Mexico Uniform Health Care Decisions Act is the primary statute that governs healthcare decisions in New Mexico. The purpose of this statute is for individuals to give as much input as possible into their own specific medical decisions. It covers a broad range of different types of healthcare decisions. It can be found at the following link: https://hscethics.unm.edu/common/pdf/uniform-healthcare-decisions-act.pdf

What is a DNR (Do Not Resuscitate)? What is the physician's role in a Do Not Resuscitate Order?

A Healthcare Decision is a decision made by an individual or the individual's agent, guardian (note: if judicially appointed to have authority to make a healthcare decision for an individual) or surrogate, regarding the individual's healthcare, including: 1) selection and discharge of healthcare providers and institutions; 2) approval or disapproval of diagnostic tests, surgical procedures, programs of medication and orders not to resuscitate; and 3) directions to provide, withhold or withdraw artificial nutrition and hydration and all other forms of healthcare (NM Uniform Health Care Decisions Act).

Who can make a healthcare decision? Can Direct Support Professionals (DSP) make a healthcare decision?

Advanced (Medical) Directives are legal documents that allow one to give directions for their own medical care. This could be a living will or a durable power of attorney for healthcare. An Advanced Directive is a written or oral statement in which a person expresses his or her wishes regarding medical care should he or she loses the ability to make such decisions.

Who can make an Advanced Directive?
### Roles of Healthcare Decision-Makers & Support Teams

#### Possible Healthcare Decision-Makers

<table>
<thead>
<tr>
<th><strong>Individual</strong></th>
<th><strong>Guardian or Surrogate with authority over health care decisions</strong></th>
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</thead>
<tbody>
<tr>
<td>- If the person has capacity: makes health care and advanced directives decisions.</td>
<td>- Learns about diagnosis and treatments options</td>
</tr>
<tr>
<td>- If the person lacks capacity: expresses preferences</td>
<td>- Determines the person in supports preferences</td>
</tr>
<tr>
<td>- Learns about any conditions/treatments</td>
<td>- Collects input from the team – as appropriate</td>
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<tr>
<td></td>
<td>- Informs the team of decision</td>
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#### Supporting Team Members:

*The information given below is based on the teaming model required by the DD Waiver; application may vary across other disability waivers/programs. With individuals with brain injury, a triage approach is used with consumer/family, case manager, life skills and/or crisis interim services. With the D&E waiver, the process is individually decided. The Medically Fragile waiver uses a team approach. Note: The term “decision-maker” can mean the individual and/or someone else, depending on the situation and the capacity of the individual.*

<table>
<thead>
<tr>
<th><strong>Physician</strong></th>
<th><strong>Case Manager</strong></th>
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<tbody>
<tr>
<td>- Assists in determining capacity of individual with a second health care professional</td>
<td>- Educates the decision-maker about the Uniform Health Care Decisions Act and encourages forethought</td>
</tr>
<tr>
<td>- Educates the individual to ensure informed consent</td>
<td>- Helps the decision-maker access supports for decision making</td>
</tr>
<tr>
<td>- Coordinates with the IDT</td>
<td>- Assures all team members are informed of decisions and know how to implement them</td>
</tr>
<tr>
<td>- Gives professional advice</td>
<td>- Assures appropriate documentation of the decision is in place</td>
</tr>
<tr>
<td>- Implements decisions</td>
<td>- Educates the decision-maker about the right to change a decision and/or challenges a determination of lack of capacity</td>
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<table>
<thead>
<tr>
<th><strong>Family Members without Health Care Decision Authority</strong></th>
<th><strong>All IDT Members (including Support Staff &amp; Therapist)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Assists in determining the individual's preferences</td>
<td>Note: may request transfer if cannot support decision</td>
</tr>
<tr>
<td>- Provides input and support to the decision-maker</td>
<td>- Assist in determining the individual's preferences</td>
</tr>
<tr>
<td></td>
<td>- Provides input and support to the decision-maker</td>
</tr>
<tr>
<td></td>
<td>- Learns about diagnosis and treatment chosen</td>
</tr>
<tr>
<td></td>
<td>- Informs relevant persons of decision (such as Emergency Room)</td>
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</tbody>
</table>

#### Agency Nurse

*In addition to items under All IDT Members:*

- Helps decision-maker interpret medical information
- Educates team on protocol for implementing decision
Who is the Decision Maker for Health Care Decisions for Adults (over 18) with Intellectual & Developmental Disabilities?

Does the person have a legal guardian?

Yes

Is the guardian a plenary (full) or limited guardian?

Plenary (Full)

The guardian has authority over health care decisions

Limited

Check the court order to see if the guardian was specifically given authority for health decisions.

Does the person have capacity to make their own decisions?

Yes

Evaluate for capacity with a physician plus a professional experienced in functional assessment of people with I/DD.

No

Unsure

If it is determine the person lacks capacity

No

Determine if the person has previously appointed a surrogate health decision maker via advanced directives or power of attorney

Yes

Appointed individual is decision maker

Appoint surrogate according to UHDA, in order as available:

Spouse, Individual in long term relationship with patient, adult children, parent, adult sibling, grandparents, adult who has exhibited special care for the patient and knows their values, can consider pursing guardianship.
Advocacy Support of Healthcare in Action

Some key points to remember:

- When there are changes to a person’s behavior, the team may need to look at doing a holistic assessment (looking at all areas of a person’s life). The first thing teams should assess for is pain and any other health issues.

- People in supports have the same rights as all New Mexico citizens. As such, people can choose their medical treatment. It is important for teams to ensure people make an informed decision and give informed consent by ensuring people have information explained in the way they understand, support them to get a second or third opinion when desired, and are not being coerced or manipulated into a decision.

- Some people may have others who support them in healthcare decisions, including surrogate health care decision makers. It is important for teams to be aware of the person's ability to give informed consent and others who may be involved in healthcare decisions.

- Regardless of who has legal responsibility for healthcare decisions, the person in supports has the right to be informed of their health status, options, and be provided the opportunity to express their preferences.

- A person with capacity can make an advanced directive which will express the type of treatment or who they want to make those decisions in certain events when they might have lost capacity.

- It is recommended that the case manager initiate the discussion of advanced medical directives with the person supported at the time of their annual assessment. It is recommended that this discussion be held without the team present (this is a sensitive topic for some people).

- It is important that the team be informed whether there are advanced medical directives in place or not. The directives need to be described in the Healthcare Coordination section of the ISP.
Communicating Health Information

✓ Who schedules a doctor appointment?
✓ When and how do you communicate with the Agency Nurse?
✓ When and how do you document medical or health information?
✓ How does this information get to the other team members?
✓ Who updates medical documents (e.g., health passport, face sheet, MAR, MAAT)?
✓ How do prescriptions get filled?
✓ Who makes the follow-up appointments?

What are some ways to ensure this occurs?

• Use the Health Passport Packet
• Let people know if information is in the file is not correct
• Know the plans and what is typical for the individual
• Provide clear documentation
• 
• 
•
# Advocacy Opportunities

![Image](image.png)

<table>
<thead>
<tr>
<th>Ways to Advocate for a Person's Rights</th>
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<tbody>
<tr>
<td>at Home:</td>
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<tr>
<td>at Work:</td>
</tr>
<tr>
<td>at Medical Appointments:</td>
</tr>
<tr>
<td>in the Community:</td>
</tr>
<tr>
<td>In an ISP Meeting:</td>
</tr>
<tr>
<td>In a Relationship:</td>
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</tbody>
</table>
Encouraging Self-Advocacy

Circle the ones you will make an effort to do:

☆ Treat the person as an equal.

☆ Provide supports that assist the person with learning their rights.

☆ Provide the person with enough time to express their opinions.

☆ Encourage the person to facilitate their own IDT meetings.

☆ Include the person in all aspects of their day.

☆ Help the person learn to make informed decisions.

☆ Encourage the person to become involved in self-advocacy groups.

☆ Meet with the person prior to their meeting and help the person prepare.

☆ Encourage other team members to direct all comments and questions to the person supported. This may encourage the person to speak for themselves.
Concept Review

What are some examples of right violations?

What is the first thing that should be done when a person’s behavior changes?
Why?

List several ways you can help maintain an individual’s privacy.

How can you support individuals at medical appointments?

How can you share info from medical appointments with the team?

What factors should be considered when explaining rights and responsibilities?

Who can make healthcare decisions?

What is “Informed Consent”?