

Understanding Your Rights



Facilitator Guide



**Department of
Developmental
Disabilities**

UCCEDD
University of Cincinnati Center for
Excellence in Developmental Disabilities



LifeCourse Nexus
Training and Technical Assistance Center
UMKC Institute for Human Development • UCEDD

Understanding Your Rights Facilitator Guide

Training Description

This training will discuss understanding your rights as you transition from youth health care to adult health care. In adult health care, it is important to understand your rights and protections as you move to different doctors and take charge of your own care. This training goes along with the EZ-Reader *Understanding Your Rights*.

Audience

Young people transitioning into adulthood.

Time

30 minutes

Materials

To facilitate this training, you will need:

- PowerPoint presentation
- Facilitator Guide
- Computer
- Projector (if in person)
- Audio
- EZ-Reader
- Worksheets (see appendix)
- Chart paper
- Sticky notes
- Markers, highlighters, pens and pencils

Learning Objectives

The participant will:

1. Define their rights as they transition into adult health care
2. Identify reasonable accommodations needed for adult health care
3. Recognize the supports needed to make adult health care decisions

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Facilitator Notes

This training is scripted with additional ways you can engage participants. Please review this Facilitator Guide and the notes section of the PowerPoint before you begin the training. This training can be presented by a trainer or co-trainers. There will be opportunities for an additional trainer or a person with lived experience to share their experiences throughout the training.

Vocabulary on the Facilitator Guide:

- **Read Slide**—read word for word from the slide.
- **SAY**—read the script provided (sentences are not on the slide—they are available for extra ways to discuss the slide)
- **ASK**—read the scripted questions (additional ways to engage the participants added if no response)
- Person with lived experience—self-advocate or family member

Key Words

Americans with Disabilities Act (ADA)—a civil rights law that prohibits discrimination against individuals with disabilities in many areas of public life, including jobs, schools, transportation and many public and private places that are open to the general public.

End-of-life care—care given to people who are near the end of life and have stopped treatment to cure or control their disease.


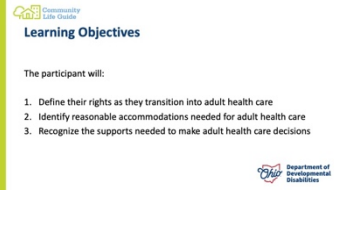

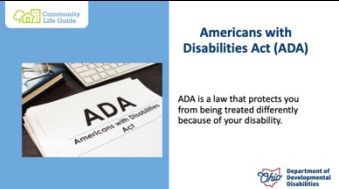
Guardianship—being legally responsible for the care of someone and has the legal right to make decisions.

Informed consent—to have the right to understand before saying yes to treatment.





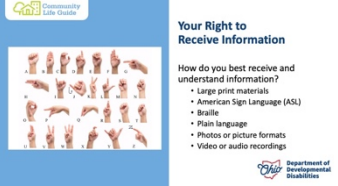
Reasonable accommodations—to make changes to help give appropriate access.

Rights—the freedoms we have that are protected by our laws.


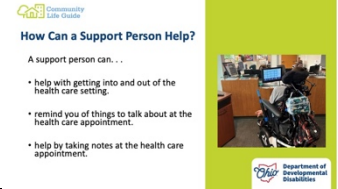


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Discussion Points and Learning Activity	Materials/Slides	Co-trainer or Person with Lived Experience
Section 1 – Introduction 1-2 minutes		
<p>SAY: This training will discuss your legal rights as you transition to adult health care. We will refer to the EZ-Reader <i>Understanding Your Rights</i> throughout the training. A learning activity will be completed in this training. Please ask questions as we go through.</p>		<p>All trainers introduce and tell a little about yourself.</p>
<p>SAY: In the training today, we will talk about: Your rights as a young person transitioning into adult health care. The reasonable accommodations you may need when accessing adult health care. The supports you may need as you make decisions around adult health care. This looks differently for many people.</p>		
Section 2 – Your Rights 3 minutes		
<p>Read Slide</p> <p>SAY: Everyone has the right to quality health care.</p> <p>SAY: Building a trusting relationship with your doctors and other health care workers is your right.</p>		
<p>Read Slide</p>		



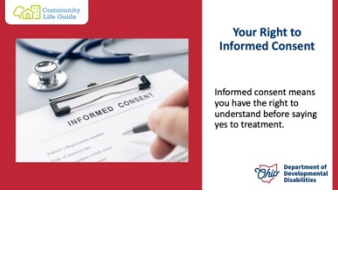
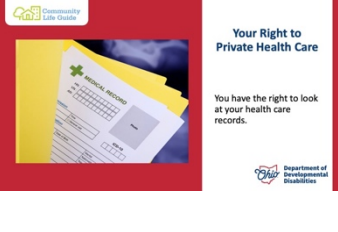

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<p>SAY: ADA says reasonable accommodations must be available when going to the doctor.</p> <p>Read Slide</p>		
<p>SAY: Always let your doctor’s office know if you need additional physical accommodations. Most business are ADA compliant. Meaning, they have ramps, doors that automatically open, etc.</p> <p>SAY: You may need more and communicating the accommodations you need will help you feel supported.</p>		
<p>Read Slide</p> <p>SAY: Be clear about how you best communicate and understand information.</p>		
<p>Read Slide</p>		
<p>Read Slide</p> <p>Facilitator Notes: <i>Ask participants what reasonable accommodations they need (if they are willing to share).</i></p>		<p>Share reasonable accommodation examples to get the conversation going.</p>

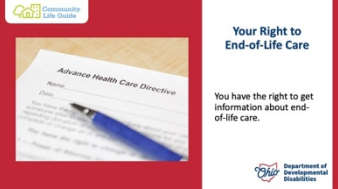



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Section 3 – Support Person 1-2 minutes		
<p>Read Slide</p> <p>SAY: You can tell the person exactly how to help at your doctor visit.</p>		
<p>Read Slide</p>		
<p>Read Slide</p>		<p>Share if you have a support person and how they support you.</p>
Section 4 – Rights with Health Care 5 minutes		
<p>SAY: The doctor must listen to you and ask questions if they do not understand.</p> <p>SAY: The doctor should respect your thoughts and beliefs.</p> <p>SAY: The doctor and other staff must respect your privacy.</p>		

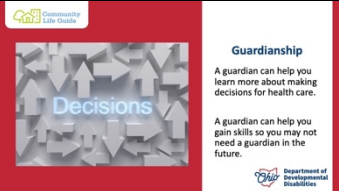
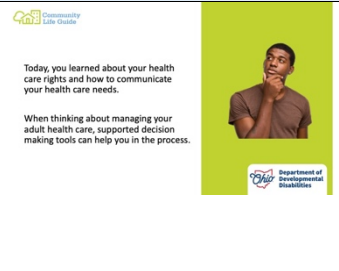
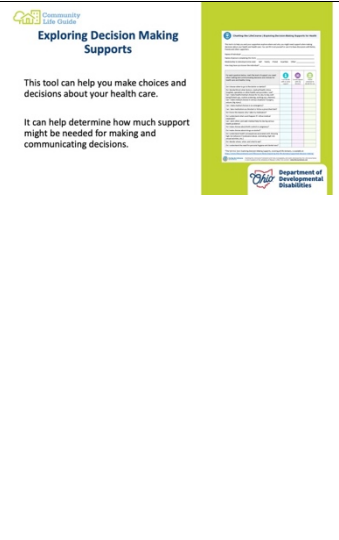
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<p>Read Slide</p> <p>SAY: The doctor must respect your personal privacy during exams, treatments or personal care.</p>		
<p>Read Slide</p> <p>SAY: It is your right to say no to health care treatment even if it might save your life.</p>		
<p>Read Slide</p> <p>SAY: Ask as many questions as you need about your health care until you understand.</p> <p>SAY: It is your job to tell the doctor if you do not understand.</p>		
<p>Read Slide</p> <p>SAY: Only your care team and those you give permission may look at your health care records.</p> <p>SAY: You can choose others to look at your health care records.</p>		
<p>Read Slide</p> <p>SAY: You must be given a copy of your health care records if you ask.</p> <p>SAY: You could be charged a fee for making copies.</p>		









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<p>Read Slide</p> <p>SAY: You have the right for your end-of-life choices to be respected.</p> <p>SAY: You have the right to receive hospice care for comfort at the end of your life.</p>	 <p>Your Right to End-of-Life Care</p> <p>You have the right to get information about end-of-life care.</p>	
<p>SAY: You have the right to be safe from discipline and mistreatment during health care.</p> <p>Read Slide</p>	 <p>Your Right to Be Safe in Health Care Setting</p> <p>You have the right to be safe from any form of abuse during health care.</p>	
<p>SAY: You have the right to be safe from any form of abuse during health care.</p> <p>Read Slide</p>	 <p>Your Right to Be Safe in Health Care Setting</p> <p>Discipline and mistreatment during health care can be a form of:</p> <ul style="list-style-type: none"> • Restraint • Seclusion • Harassment • Physical Punishment 	
<p>Section 5 – Guardianship 2-3 minutes</p>		
<p>Read Slide</p> <p>SAY: You may not be the final decision maker if you have a guardian.</p> <p>SAY: Being safe and asking for reasonable accommodations are your rights even if you have a guardian.</p>	 <p>Guardianship</p> <p>Guardianship means someone has the legal right to make decisions for you.</p>	

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<p>Read Slide</p> <p>SAY: A guardian should honor and respect your choices or preferences when possible.</p>		
<p>Section 6 – Learning Activity 10-15 minutes</p>		
<p>Read Slide</p> <p>SAY: Supported decision making is about helping people make their own decision by using a variety of supports. Supported Decision Making Tools can help a person understand their choices, ask questions and communicate their decisions to others.</p>		
<p>SAY: This Supported Decision Making Tool focuses on the Healthy Living Life Domain. For each question, decide the level of support you need when making and communicating decision and choices about your health care.</p> <p>SAY: You have 3 choices, "I can decide with no extra support. I need support with my decision. I need someone to decide for me."</p> <p>Facilitator Notes</p> <p><i>The participants can review this and take it with them to complete on their own. You can split into groups to have conversations about the tool or talk through as a whole group. It may be helpful to read through the questions and have the participants think about where they fall.</i></p>		

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<p>SAY: These resources were used to create this training. It is important to understand how to transition to adult health care. Understanding your rights when talking with doctors about your health care. This training goes along with the EZ-Reader <i>Understanding Your Rights</i>. Thank you for joining us.</p>	 <p>Resources</p> <p>Charting the LifeCourse: Supported Decision Making www.life-course-toolkit.com/life-course-library/exploring-the-life-domain/supported-decision-making/</p> <p>Cincinnati Children's Hospital Patient Rights www.cincinnatichildrens.org/patients/visit/visiting-guidelines/rights</p> <p>Your Rights Under HIPAA www.hhs.gov/ohrp/for-individuals/evidence-materials-for-consumers/index.html</p> <p>Frequently Asked Questions About Durable Powers of Attorney for Health Care www.lawhelp.org/66/resource/frequently-asked-questions-about-durable-power</p> <p>Advance Directives www.carinfo.org/planning/advance-directives/</p> 	
	 <p>Resources</p> <p>Power of Attorney www.carinfo.org/planning/advance-directives/power-of-attorney-and-advance-directives/</p> <p>HHS OCR - HIPAA Rights www.ocr.hhs.gov/privacy/faq/faq-516</p> <p>HHS OCR - Communicating with Family, Friends, and Others Involved in Your Care www.ocr.hhs.gov/privacy/faq/faq-516</p> <p>Abuse Awareness and Prevention www.life-course-toolkit.com/life-course-library/exploring-the-life-domain/abuse-awareness-and-prevention/</p> <p>HIPAA, PHI (Protected Health Information): Definition of PHI and List of 18 Identifiers www.ocr.hhs.gov/privacy/faq/faq-516.html</p> 	
	 <p>A Project of:</p>  <p>Developed By:</p>  	

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Healthy Living | Exploring Decision Making Supports for Health




This tool is to help you and your supporters explore where and why you might need support when making decisions about your health and health care. You can fill it out yourself or use it to have discussion with family, friends and other supporters.

Name of Individual: _____

Name of person completing this form: _____

Relationship to individual (circle one): Self Family Friend Guardian Other: _____

How long have you known the individual? _____

For each question below, mark the level of support you need when making and communicating decisions and choices for health care and healthy living.	 I can decide with no extra support	 I need support with my decision	 I need someone to decide for me
Do I choose when to go to the doctor or dentist?			
Do I decide/direct what doctors, medical/health clinics, hospitals, specialists or other health care providers I use?			
Can I make health/medical choices for my day-to-day well-being (check-ups, routine screening, working out, vitamins)?			
Can I make medical choices in serious situations? (surgery, big injury)			
Can I make medical choices in an emergency?			
Can I take medications as directed or follow a prescribed diet?			
Do I know the reasons why I take my medication?			
Do I understand the consequences if I refuse medical treatment?			
Can I alert others and seek medical help for serious health problems?			
Do I make choices about birth control or pregnancy?			
Do I make choices about drugs or alcohol?			
Do I understand health consequences associated with choosing high risk behaviors? (substance abuse, overeating, high-risk sexual activities, etc.)			
Do I decide where, when, and what to eat?			
Do I understand the need for personal hygiene and dental care?			

*The full CTLC Tool: Exploring Decision-Making Supports, covering all life domains, is available at: www.lifecoursetools.com/lifecourse-library/exploring-the-life-domains/supported-decision-making/



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