

## Unit 2: History of Scientific Research with People and Rules



## Topic 2.1: History of Research with People



### Main Ideas



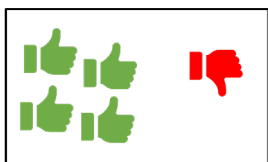
- **Good things can happen** when we do research. The good things that can happen are called **benefits**.
- Research benefits can be for the person in the research study or for other people in the future.



- **Bad things can happen to people in research.** The bad things that can happen are called **harms** or **risks**.
- Examples include hurting someone's body or feeling sad.



- **Research ethics** are about **making sure people are treated well** and that their **rights are respected** when they are in research.



- **Research ethics** are also about making sure **more good things happen than bad things** when we do research.



## Discussion Questions



1. When you **think about research**, what **pictures** or **words** do you think about? What **feelings** do you have?



2. **How** do you think **other people** with developmental disabilities **might feel about research**?



## Discussion Questions

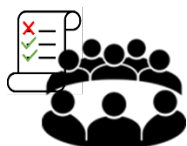


3. How do you think **different experiences with research studies** in the past might **make people feel about** being in **research studies now?**

## Topic 2.2: Rules for Scientific Research with People



### Main Ideas



- **Institutional Review Boards (IRB)** are groups of people who **make sure** researchers **protect people's rights and well-being**.

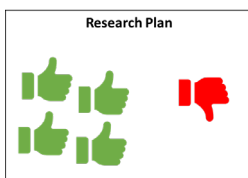
- The **Belmont principles** are the **values** that help us think about **how to treat people** when they are in research. They are:



- **Respect for persons** is about **believing** that **everyone can make decisions** with or without support. Respect for persons also means **taking extra care of people** who have a hard time making decisions.



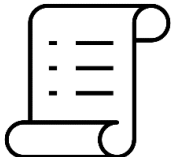
- **Justice** is making sure **all types of people can be in research** and that everyone shares the good and bad things that can happen in research.



- **Beneficence** is about making research have **as many good outcomes** as possible and **keeping people as safe** as possible.

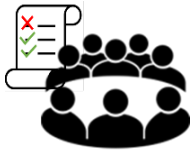


## Discussion Questions



1. **Why** is it **important** to have **rules** for **research** with people?

2. **What** does the **IRB** do?



3. **Why** is what **the IRB** does **important**?



## Putting it into Action: Disability Rights and Research Rules



Talk with your team about how some of the **main values** in **research** and **disability rights** are **similar** and **different**.



You may think of other disability rights—you can talk about those too.

Disability Rights	Research Rules (Belmont Principles)
<ul style="list-style-type: none"> <li>• <b>Assuming people can do things and make choices</b> <ul style="list-style-type: none"> <li>○ This includes making choices that might not always work out or might be risky. This is sometimes called dignity of risk.</li> </ul> </li> <li>• <b>Having the same opportunities as everyone else to do things</b></li> </ul>	<ul style="list-style-type: none"> <li>• <b>Respect for persons</b></li> <li>• <b>Justice</b></li> <li>• <b>Beneficence</b></li> </ul>

## Topic 2.3: Vulnerability



## Main Ideas



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- It is important to be **extra careful with people** who are **vulnerable**. People who are **vulnerable** may **have a hard time making a decision** or need **help understanding and making decisions**. People who are vulnerable **may get hurt** by research more easily than other people.
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## Discussion Questions



1. What **helps** you **understand** and **make decisions**?



2. **How** can you **help someone else** with a developmental disability **understand** a **research** study better?



## Discussion Questions

### 3. How can you help people who have a hard time making



their own **decisions** make a **choice** about being in research?

- How can we help people not feel pressured to make a decision?

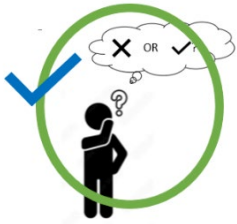


### 4. Can you think of a **reason** we should **not include**

someone in a research study because they are vulnerable?



## Discussion Questions



5. **Why** might we want to **include people** who are **vulnerable** in research studies?

- When we do include people who may be vulnerable, **what can we do to include them safely?**



- **How** can we **make sure** that **the rights** of people who are vulnerable are **respected?**