Lesson Five: End-Users and Ethics
Center for Sensorimotor Neural Engineering
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LESSON OVERVIEW

Activity Time: 50 minutes.

Lesson Plan Summary:
In this lesson, students will discuss the ethics of neuroengineering. Students will consider and examine the perspectives of various stakeholders and end-users. Students will review the difference between assistive devices and neuroprosthetics. Students will brainstorm ideas for sensory substitution device with end-users and ethics in mind.

STUDENT UNDERSTANDINGS
Big Idea & Enduring Understanding:
- When designing a neuroprosthetic, the needs of the end-user must be considered and addressed.

Essential Question:
- How are the needs/desires of the end-user considered in designing a neuroprosthetic?

Learning Objectives:
Students will know…
- Persons with impaired/missing abilities may have different needs/wants than what is assumed by a person who is able.

Students will be able to…
- Come up with questions to ask an end-user about what their needs and concerns are when designing a neuroprosthesis.

Vocabulary:
- End-user
- **Engineering design:** criteria, constraints

Standards Alignment: This lesson addresses the following middle school Next Generation Science Standards (NGSS).

NGSS Middle School Disciplinary Core Ideas
- **MS-ETS1.A Defining and Delimiting Engineering Problems:** The more precisely a design task's criteria and constraints can be defined, the more likely it is that the designed solution will be successful. Specifications of constraints includes consideration of scientific principles and other relevant knowledge that are likely to limit possible solutions.

NGSS Cross-Cutting Concepts
- **Structure and Function**
- **Cause and Effect**

NGSS Science & Engineering Practices
- **SEP**: Asking Questions and Defining Problems
- **CCC**: Influence of SET on Society and Natural World
- **NoS**: Science is a Human Endeavor
- **NoS**: Science Addresses Questions about the Natural and Material World
  - Science and technology may raise ethical issues for which science, by itself, does not provide answers and solutions.
  - Science knowledge indicates what can happen in natural systems -- not what should happen. The latter involves ethics, values, and human decisions about the use of knowledge.
  - Many decisions are not made using science alone, but rely on social and cultural contexts to resolve issues.

MATERIALS

Material	Description	Quantity
Student Handout 5.1: Stella Young's TED Talk	Students reflect on what "normal" is, write assumptions and questions for end-user	1 copy per student
Student Handout 4.1 from Lesson 4	To review idea of sensory substitution and brainstorm device	

TEACHER PREPARATION

1. Preview TED talk and review questions on handout.

2. If you are able to access it through a public or academic library, read the article "Engineering the Brain: Ethical Issues and the Introduction of Neural Devices" by Klein, Brown, Sample, Truitt, and Goering in the *Hastings Center Report*, November-December 2015.

PROCEDURE

Engage: What Do End-Users Really Want? (10 minutes)
1. Journal or Group Discussion: If someone got in an accident which resulted in paralysis in the lower part of their body (below the waist), what do you think are the functions this person would want restored? How might this person prioritize the functions for which assistive devices or technologies can be developed?
    a. Automatic answer for many students is restoring the ability to walk. However, studies show that restoring basic functions which allow for independence like relieving the bladder, controlling bowels, managing chronic pain and muscle spasticity, and restoring sexual function are most important to people who have experienced a spinal cord injury.

2. Journal or Group Discussion: What do end-users really want? What questions would you ask them? Are there assumptions being made about what end-users want? What do they need? Whose values are we considering? Use the questions on *Student Handout 5.1: Stella Young's TED Talk* to prompt students to think and write.

Explore: Neuroethics (25 minutes)
3. Show Stella Young's TED Talk. Synopsis: "Stella Young is a comedian and journalist who happens to go about her day in a wheelchair — a fact that doesn't, she'd like to make clear, automatically turn her into a noble inspiration to all humanity. In this very funny talk, Young breaks down society's habit of turning disabled people into "inspiration porn." **Maturity Note:** In this video, Stella Young clearly explains the use of the word "porn" as objectifying disabled people for the benefit of nondisabled people. At 7:40 minutes, she uses the word "bullshit."
    a. Stella Young TED Talk:
        https://www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you _very_much?language=en (9:40 minutes)

4. Discuss assumptions one might make about someone with an impaired sense. Come up with questions to interview an end-user. If an end-user is known (for example, a deaf person in the community), send questions for them to respond and share with class.

Evaluate/Apply: Sensory Substitution Devices (10 minutes)
5. Review the differences between assistive devices and neuroprosthetics using *Student Handout 4.1* from Lesson 4.

6. Discuss the concept of sensory substitution and the TED talk.

STUDENT ASSESSMENT

Assessment Opportunities: Student knowledge, skills, and concepts for this lesson will be assessed in a number of ways.
- Assess students on the questions that they might ask an end-user.

Student Metacognition:
- Students reflect on their assumptions of others' needs. Ask students to think about how their thinking has changed before and after this lesson.

Scoring Guide:
- *Teacher Resource 5.1* provides a scoring guide for *Student Handout 5.1.*

EXTENSION ACTIVITIES

Extension Activities:
- If possible, find a person in your community who has an impaired sense or other disability to be a guest speaker (in person, virtually via Skype, or through an email interview). Have students come up with questions to ask this person so they are more informed about the human behind the device they intend to design.

- Watch the movie *FIXED: The Science/Fiction of Human Enhancement* to offer students a broader view of dis/ability and human enhancement.
  - http://www.fixedthemovie.com/

- Finish watching the rest of the David Eagleman TED Talk which focuses on the enhancement of senses.

o https://www.ted.com/talks/david_eagleman_can_we_create_new_senses_for_ humans/discussion?lan

TEACHER BACKGROUND & RESOURCES

Background Information:
An end-user is a person who uses a particular product. It is important for students to not just engineer a solution to a problem, but to learn more about who is using the product and what they might want from that product (and if they want the product at all).

Resources:
- CSNE Website's K-12 Online Resources on Neuroethics and Philosophy, including a series of Case Studies in Neuroethics developed for classroom use, http://csne-erc.org/education-resources-teachers/neuroethics-philosophy
- CSNE's *Neural Engineering and Ethical Implications* curriculum unit for grades 6-12, http://csne-erc.org/education-k-12-lesson-plans/neural-engineering-and-ethical-implications
- Academic articles on neuroethics:
  - Specker Sullivan et al., (2017). Keeping Disability in Mind: A Case Study in "Implantable Brain-Computer Interface Research," *Sci Eng Ethics,* pp. 1-26. This article has a great list of interview questions in the appendix for both engineers and end-users.
  - Klein, Brown, Sample, Truitt, and Goering. (November-December 2015). "Engineering the Brain: Ethical Issues and the Introduction of Neural Devices." *Hastings Center Report*.
  - Gilbert, Goddard, Viana, Carter & Horne. (2017). "I Miss Being Me: Phenomenological Effects of Deep Brain Stimulation." *AJOB Neuroscience, 8*(2), pp. 96-109.

Citations:
Frederic Gilbert, Eliza Goddard, John Noel M. Viaña, Adrian Carter & Malcolm Horne. (2017). "I Miss Being Me: Phenomenological Effects of Deep Brain Stimulation". *AJOB Neuroscience, 8*(2), pp. 96-109.

Laura Specker Sullivan, Eran Klein, Tim Brown, Matthew Sample, Michelle Pham, Paul Tubig, Raney Folland, Anjali Truitt & Sara Goering. (2017). "Keeping Disability in Mind: A Case Study in Implantable Brain–Computer Interface Research." *Science and Engineering Ethics,* pp. 1–26.

Student Handout 5.1: Stella Young's TED Talk

Name:_____ Date:_____

Period:_____

Before watching the video, answer the following questions. Don't worry about right or wrong answers. Be honest and answer to the best of your ability.

1. What does it mean to be *normal*?

2. What role does our society/culture play with regards to persons with disabilities?

3. What are some examples of how persons with disabilities use technology?

4. What do you think the role of technology *should* be regarding persons with disabilities?

5. Do you know anyone with a disability? If so, what type(s) of disability?

After the video:

When considering the person for whom you are designing a sensory substitution device, what assumptions might you be making? What questions would you want to ask that individual or group of individuals?

Assumptions	Questions

Teacher Resource 5.1: Stella Young's TED Talk Answer Key

What does it mean to be *normal*?

Possible answers (there's no right answer here, but try to get students to think about how their version of "normal" is influenced by their upbringing/culture/societal pressure): look and act like everyone else, an average person, however you are born, not missing any part of your body, whatever you're mostly surrounded by

What role does our society/culture play with regards to persons with disabilities?

Possible answers (again, there's no right answer here): making things more accessible to persons with disabilities (braille, sounds at crosswalks, wheelchair ramps, flashing lights with fire alarms); society is not accepting of a lot of persons with disabilities and many look down about persons with disabilities as if they are lacking

What are some examples of how persons with disabilities use technology?

Possible answers: dictation applications, motorized wheelchairs, automated insulin pumps and blood sugar monitors.

What do you think the role of technology *should* be regarding persons with disabilities?

Answers can vary. To consider: with advancing technology, at what point does the technology become a part of the person's identity? For example, does a prosthetic limb a part of the person if it has sensors and can make adjustments without the person's conscious control?

Do you know anyone with a disability? If so, what type(s) of disability?

Answers will vary.

After the video:

When considering the person for whom you are designing a sensory substitution device, what assumptions might you be making? What questions would you want to ask that individual or group of individuals?

Assumptions	Questions
Possible Answers: ● Person wants to restore their impaired or missing function. ● A person will feel depressed if they don't regain what they used to have.	Possible Questions: ● What are the most important aspects you want restored? ● Does it matter what it looks like, or do you want it to just be functional? ● Would you rather learn a new way to deal with your impaired sense or would you rather restore your sense as much as possible?