See What I Mean: Participatory Action Research with College Students with Intellectual Disabilities

Institute for Community Inclusion
University of Massachusetts Boston
See What I Mean: Participatory Action Research with College Students with Intellectual Disabilities

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## Introduction

- Reviewing the plans created and actions taken
- Why is this recommendation important?
- Showing students examples of recommendations
- Working with you to identify common themes
- Reviewing and commenting on the work of co-researchers
- Discussing themes with the facilitator and co-researchers
- Selecting and prioritizing photos
- Captioning and commenting on photos
- Determining if more photos are needed

## Prepare for PAR

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## Document

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- Getting started
- Recording brainstorming sessions
- Selecting digital media tools
- Practicing with digital media tools
- Seeking permission to take photos
- PAR toolkits
- Schedule times to meet

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- Transferring photos
- Organizing student work
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- Captioning and commenting on photos
- Determining if more photos are needed

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- Working with you to identify common themes
- Discussing themes with the facilitator and co-researchers

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- Facilitating an online, real-time discussion
- Having students vote on recommendations

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More and more individuals with intellectual and developmental disabilities (IDD) now have the opportunity to attend college. This is possible not only due to strong advocacy, but also because applications of universal design principles have developed in higher education settings (Behling & Hart, 2008; Silver; Bourke, Strehorn, 1998), there are more grassroots initiatives to adopt supported education models (Mowbray, et al., 2005), and the field of inclusive postsecondary education is advancing non-traditional pathways to enroll and matriculate in college (Grigal, Dwyre, & Davis, 2006; Grigal & Hart, 2010; Hart, Zafft, & Zimbrich, 2001). Given these approaches in creating college access and participation, it is logical that students with IDD have equally accessible, supported and non-traditional methods to evaluate their college experiences.

Traditional evaluation methods are useful for gathering information about students’ college status. For instance, surveys are useful for collecting descriptive information, such as what classes students are taking, if they are taking the classes for audit or credit, what campus resources they are using, and what supports they require to fully participate in college.

Less used but equally important are research methods that gather students’ perceptions of their college experience from the students themselves. One strategy for effectively gathering data from and with students is Participatory Action Research, or PAR.

PAR is an emancipatory and cyclical form of research that promotes collaboration between researchers and participants. Over the last 20 years, there has been an increasing interest by community-based researchers in using PAR to enable people to tell stories that help them to interpret their lives (Ferguson, Ferguson, & Taylor, 1992; Stringer, 2007).

Research facilitators who adopt community-based action research practices put aside traditional research protocols that typically assume researchers will determine questions, employ survey tools, and document what will be the valued outcomes (Minkler & Wallerstein, 2003). Instead, community-based researchers use action research methods that value what individuals want to share about their lives and experiences and, more importantly, value the telling of the story (Ferguson, Ferguson, & Taylor, 1992). It is through these stories that assumptions about individuals or their experiences can be contradicted, shedding light on more authentic perceptions (Taylor, Bogdan, & Lutfiyya, 1995).

In PAR, students with intellectual disabilities are not just research subjects. They are invited to become co-researchers. This leads to richer results and to an increased sense of contribution among students who take part in this work.
Figure 1 shows the seven phases of PAR. This monograph includes a discussion of what happens at each phase. Included are instructions, resources, and examples for researchers who are interested in facilitating research with individuals with IDD. These materials will help you to introduce your own innovative PAR to student researchers.

**Guiding principle for PAR:** This guide will help you to collaborate with students with IDD on research related to their college experience. Through this collaboration, you have the opportunity to establish a strong working partnership with these students. You are not asking them to participate in your study. You are asking them to research college with you, to share the results, to take action, and to reflect on the work together.

**FIGURE 1: PARTICIPATORY ACTION RESEARCH CYCLE**

*This step is for research facilitators*
TIPS FOR RESEARCH FACILITATORS

Research facilitators at Think College have been using PAR with students with IDD to document and gather data on their college experience. We also teach students to use PAR to explore their own questions related to college.

PAR isn’t easy. It takes lots of time—both yours and the students’. It requires you to be patient. But the process of participatory action research can provide you with insights into students’ experiences that you might not gather from other research methods.

Here are some suggestions for research facilitators who are preparing their own PAR work with students with IDD:

• Be as inclusive as possible in your collaboration with students. Talk with them (and staff they know well) to determine the best way for you and the student researcher to communicate and work together.

• Be patient. Remember that students with IDD are rarely, if ever, given the chance to have equal footing in research. If they are missing deadlines, review with them how important it is to share their opinions about college. Additionally, explore different ways to help them follow the research timeline.

• Use more than one strategy to help students participate in all phases of PAR. There are a wide variety of tasks involved in PAR that will likely need some adaptation in order for students to fully engage in each phase of the work. Be prepared to make these adaptations, and also be aware that some adaptations will need to be made on the spot.

• Some student researchers may get support from others to complete PAR tasks. Discuss with the student and support person how important it is that the data collected (photos, video, text) reflects the student researchers’ authentic work.

• Don’t be surprised if the work you do with students sparks deeper conversations. Many times, students open up about their experiences while taking the time to explain why they took the photos they did.

• Prepare to have PAR-related conversations with students outside of scheduled times. Some of the most insightful conversations with student researchers have occurred, not during the PAR meetings, but while driving to the campus together, while taking a break from the research, or while walking on campus.

• Be open to new ideas about how to facilitate PAR. Given the flexibility of PAR and the growing number of technologies available, you are likely to find new ways to implement PAR that will engage students with IDD in college research.

• Be responsible about students’ research. Remember that it is their data. As a research facilitator, unless you specifically asked them if you can use their data, anything they produce is theirs, and it is your responsibility to help them use it as they want to. At the same time, you may find that students need some assistance in determining the best ways for them to share their work with others.

• Consider developing your own research questions while doing PAR with students. As an example, your research may be focused on how the students engage in PAR, or what you are learning about inclusive college experiences as a result of your PAR with students.

• Ask students if you can document the PAR process by taking pictures or videos, or by recording your meetings. Include a consent form in your IRB protocol. These photos and recordings can be very valuable in documenting how the students are engaging in the research and what strategies are most successful.
This guide includes:

(1) Instructions on a seven-step process to facilitate PAR
(2) Examples of research outcomes as a result of PAR with students with IDD
(3) Resources to initiate and sustain PAR with students
(4) References for additional information on PAR and inclusive research methods

This guide will help research facilitators to:

(1) Facilitate participatory action research with college students with IDD
(2) Establish partnerships with students
(3) Offer participants a variety of data collection methods
(4) Evaluate college experiences
(5) Make improvements based on student recommendations
(6) Work with students (the co-researchers) to share information

Facilitating PAR provides opportunities to collaborate with students with IDD who are extending their education to college. Through this work, you will gain access to first-hand accounts of their college experience and its impact on their lives.

A student researcher prepares to share his perceptions of college and independent living on video.
There are a number of tasks that must be done to prepare for a PAR project. Having these preparation tasks done before you begin your work with students will make the process much easier. The tasks include:

1. Logistical planning
2. Preparing an Institutional Review Board research protocol
3. Securing digital media tools
4. Determining how to use digital notepads and apps in your research
5. Preparing informational materials

Logistical planning

**Considering the following can help you prepare to facilitate PAR:**

**Number of students:** Determine how many students you will be able to collaborate with and what kind of time commitment that will entail. Students are likely to be busy balancing work, college, and free time. It is up to you to work around their schedules.

**Expectations:** Prepare a written invitation that specifically outlines what you expect from research collaborators. Since this process takes much more time than other research methods, it is important to be clear how many days, weeks or semesters you expect them to work with you.

**Where PAR takes place:** Plan with students where meetings can take place. Ideally, it's best to meet on campus, but sometimes this is just not possible due to tight college and work schedules. In those cases, consider meeting at a local library, the student's house, or over lunch or coffee at a coffee shop.

**Number of meetings:** Consider how many times you will need to meet with students, whether in person or via video conferencing, social media, or phone. Students with IDD are rarely invited to do activities such as this, and they will need encouragement and support. Plan to meet with students at least every two to three weeks in between phases of the PAR project.
Research support: When working with students with IDD, it is sometimes helpful to have another person in the loop, such as a mentor or educational coach, program director, or teacher. This support person can help you and the student find free time to meet, and choose an appropriate location.

Accessibility and Accommodations: Make your invitation and instructions to student researchers as accessible and universally designed as possible (see Figure 2). Depending on the needs of the student researchers, you may need to request specific accommodations from the college (e.g., sign language interpreters).

**FIGURE 2: PAR INVITATION**

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**An Invitation**

Would you be interested in documenting your college experience? Would you like to use tools such as a digital camera, video camera, or digital recorder to record your experience? If you answered yes, staff from ThinkCollege invite you to join a participatory action research group made up of students participating in college activities.

**WHAT WE ARE LOOKING FOR**

- First hand reports about college
- A commitment to meet with staff 1-2 times a month this semester
- Discussions about what’s going well and what should improve
- A willingness to share your work with other students
- Contributions for the ThinkCollege website that come from students’ work—podcasts, digital stories, or video clips

**HOW YOU WILL BENEFIT**

- Learn about action research
- Have the opportunity to use new technology
- Meet other students like you who are participating in college activities
- Have the opportunity to discuss the benefits of college and brainstorm solutions for things that make college hard

**TO LEARN MORE**

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ThinkCollege is a project of the Institute for Community Inclusion at UMass Boston. It is funded by a cooperative agreement (#90DN0216) from the Administration on Developmental Disabilities (ADD), Administration for Children and Families, Department of Health and Human Services.
**Number of digital media tools needed:** Make data collection accessible for the students you work with. Digital media tools such as digital cameras (to take photos) and pocket video cameras (to film footage) make it simple for students to document or collect data. Consider how many of these tools you will need and decide how students will share the tools.

**Keeping track of digital media tools:** If you are loaning out digital media tools, it will be important to review with students how to take responsibility for the equipment as well as returning it to you at an agreed-upon time. You may find it helpful to number each PAR toolkit (explained further in the “Document” phase) and keep a record of the toolkit loans (see Table 1).

<table>
<thead>
<tr>
<th>Toolkit</th>
<th>Borrower</th>
<th>Campus</th>
<th>Date loaned</th>
<th>Date returned</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1</td>
<td>Allie</td>
<td>Holyoke Community College</td>
<td>Jan 23</td>
<td>Feb 17</td>
</tr>
<tr>
<td>#2</td>
<td>Meaghan</td>
<td>Holyoke Community College</td>
<td>Jan 23</td>
<td>Feb 10</td>
</tr>
<tr>
<td>#3</td>
<td>Anthony</td>
<td>Holyoke Community College</td>
<td>Jan 23</td>
<td>Feb 17</td>
</tr>
<tr>
<td>#4</td>
<td>Grace</td>
<td>Quinsigamond Community College</td>
<td>Feb 1</td>
<td>Feb 28</td>
</tr>
<tr>
<td>#5</td>
<td>Cassidy</td>
<td>Quinsigamond Community College</td>
<td>Feb 1</td>
<td>March 3</td>
</tr>
<tr>
<td>#6</td>
<td>Arielle</td>
<td>Roxbury Community College</td>
<td>Feb 8</td>
<td>March 10</td>
</tr>
<tr>
<td>#7</td>
<td>Aaron</td>
<td>MassBay Community College</td>
<td>Feb 8</td>
<td>March 16</td>
</tr>
</tbody>
</table>

**Budget:** Keep in mind: (1) the cost of digital tools, (2) the cost of travel to meet with students, (3) any fees to store images on a password-protected website, and (4) compensation for student researchers. All of these potential costs are further explained in this guide. Some researchers include PAR as part of their assessment or evaluation activities, and thus build funding into their project budgets. Other researchers tap into foundation or youth or community research funds.

**Time commitment:** Consider the time it takes to support students with IDD in PAR. Unlike other research methods, PAR extends over time and at a minimum requires the completion of seven research phases. As a PAR facilitator, you’ll need to be prepared for this time commitment. Past projects have generally extended over two semesters, in which data collection and sharing occurs during the first semester, and acting on the research is generally done in the next semester.

**Student compensation:** Consider how you will compensate the students who are committing time and knowledge to this initiative. Financial compensation might be built into grant budgets. It can include hourly pay, stipends, or gift cards. Students may also be compensated in other ways, such as through authorship in publications related to the work or through presentations. Some researchers offer to give students the cameras or pocket video cameras they have been using for the project as compensation for their work. If this is the case, it will be important to budget for this cost.
Preparing an Institutional Review Board research protocol

If your university, college, or school district has an institutional review board (IRB), you will need to submit a research protocol in order to do PAR with students. Federal regulations require that IRBs give special consideration to protecting the welfare of certain individuals, including those with IDD. You will have to be very clear, not only about how you are inviting students with IDD to do research with you, but also about how you are instructing the students to conduct research and ask other people for consent.

Research questions: Consider what aspects of the college experience you want to explore with students in order to propose research questions. While ultimately the student researchers will determine which aspects of college they want to document, it will be necessary to seek institutional approval first before approaching students. The research questions proposed in the IRB application may be fairly open-ended, for example:

(a) How do students with intellectual disabilities describe their college experience?
(b) How do students with intellectual disabilities describe the strengths and weaknesses of their college experience?

You might be preparing research to seek the opinion of students with IDD about new features of the college or newly implemented policies. In that case, you might ask:

(a) How do students perceive the influence of newly trained mentors on their transition to college?
(b) How do students describe their engagement in non-academic campus activities?

Three things make an IRB protocol to facilitate PAR more time-consuming than other IRB protocols.

First, you may need to prepare a number of permission forms to take into account assent and/or consent, and approved release forms should you and the students decide to disseminate the data. Second, if you hope to conduct your own research as part of PAR with students, you may need consent to document the process with digital media yourself. Finally, this type of research may take a little longer than usual to be approved because you are asking students to partner with you to do research, not just to be the subject of the research. The IRB committee may take more time to be sure all necessary consent forms are in order. See the Appendix for examples of consent forms developed for a PAR project with student researchers with IDD.

Make students aware of the protocol you are preparing, and if they are interested, find ways for them to contribute to the process. This might include co-writing the research questions and the rationale for these questions, explaining the methods that will be used to do the research, or drafting and including consent forms that will be used in the field.

Securing digital media tools

Although it is not necessary for students to use digital media tools for data collection, there are a lot of advantages to this format. First, students are often enthusiastic about taking pictures or videotaping their experiences. This enthusiasm can motivate them to collect data. Second, by collecting digital photos and/or video clips, and providing recorded captions, students have a way to share data that is accessible and meaningful for a broader audience. Table 2 describes the pros and cons of several digital tools you might consider offering student researchers.

There are several ways to secure digital media tools for students. For $300 or less, you could purchase some used
digital cameras or pocket video cameras through websites such as Amazon, Overstock, Google Shopping, or eBay. You could also write a small grant to buy refurbished media tools.

Students may have camera or video features on their cell phone, smart phone, or tablet computer. But be aware that the quality of the images taken with those tools may not be as clear as the photographer hoped they would be.

**TABLE 2: SELECTING DIGITAL MEDIA TOOLS**

<table>
<thead>
<tr>
<th>Tool</th>
<th>Pros</th>
<th>Cons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Digital camera</td>
<td>Fairly inexpensive, can be charged on computer, holds many photos and videos. LCD panel allows students to view photo. Student can delete photos.</td>
<td>May not have funds for cameras; may be less convenient for student to carry than camera phone, may be harder to learn how to upload photos.</td>
</tr>
<tr>
<td>Pocket video camera</td>
<td>Fairly inexpensive; can be charged on computer; holds 1+ hour of video. LCD panel allows students to view photo. Student can delete photos.</td>
<td>May not have funds for cameras; may be less convenient for student to carry than camera phone, may be harder to learn how to upload photos.</td>
</tr>
<tr>
<td>Disposable digital camera</td>
<td>Relatively inexpensive way to give all students their own camera. Limited loss if camera is lost.</td>
<td>Some students may have difficulty remembering to advance film, turn on flash. Unable to see photo frame in enlarged window. Student unable to delete photos. Must submit camera for outside photo processing.</td>
</tr>
<tr>
<td>Smart phone</td>
<td>Convenient way to take photos. High quality photos likely. Easy to email to computer and photo sharing sites.</td>
<td>May be difficult for some students to take photos or control framing with camera app.</td>
</tr>
<tr>
<td>Tablet PC/ iPad</td>
<td>Convenient way to take photos. High quality photos likely. Easy to email to computer and photo sharing sites.</td>
<td>May be difficult for some students to take photos or control framing with camera app.</td>
</tr>
<tr>
<td>Cell phone</td>
<td>Convenient way to take photos.</td>
<td>May be difficult for student to review photo. May be cumbersome to email photos. Student may be disappointed with quality of photo.</td>
</tr>
<tr>
<td>Digital recorders</td>
<td>Simple way to record interviews, stories.</td>
<td>Steps may be cumbersome to connect recorder to computer to upload audio file and save to a folder. May involve many steps to edit audio file.</td>
</tr>
<tr>
<td>Audio recording apps</td>
<td>Convenient and simple way to record interviews, stories. Several free apps available. Easy to send file to iTunes account.</td>
<td>May be difficult for some students to use recording app or to edit file.</td>
</tr>
</tbody>
</table>
Determining how to use digital notepads and apps in your research

For research facilitators and student researchers using tablet computers and apps, some preliminary suggestions for their use are included in several sections of this guide, as well as listed in the Resource Section at the back. Clearly this field is exploding. It will be up to the researchers to identify and try out apps that would augment or enhance the PAR phases.

**Relevant apps:** Two apps that may be useful for PAR projects are Dropbox and iCloud. These are both storage apps, and will allow you ready access to student files and instructional materials, no matter where you are working.

Preparing informational materials

There are a number of informational materials that are useful when you are inviting young people to do PAR. Please review the Usability Checklist for PAR Materials in Figure 3 before creating materials for PAR.

**FIGURE 3: USABILITY CHECKLIST FOR PAR MATERIALS USED WITH STUDENT RESEARCHERS WITH IDD**

These recommendations are drawn from self-advocates, accessibility experts, and graphic design specialists. Please see the end of the References list for more information.

**Language**

- Use plain, direct, common words.
- If it’s essential to use a technical term, explain what it means.
- Use short sentences (generally fewer than 15 words).
- Use one-syllable and two-syllable words as much as possible.
- Use respectful language including person-first language.
- Check readability statistics. We recommend Flesch-Kincaid Grade Level 8.0 or less, but make the decision based on your audience.
- Explain acronyms (and avoid them whenever possible).
- Use examples to explain ideas.

**Formatting**

- Make text legible.
- Leave sufficient white space on the page.
- Use bullets or lists whenever possible.
- Make alternative formats available, upon request, such as Braille and large-print versions.
- Include a table of contents.
- Chunk ideas: focus on one idea per paragraph.
- Use meaningful headings.
- Create line lengths that are no longer than 70–80 characters.
- Offer users a choice of “abbreviated version” or “full version” content.
### Print materials
- Use font size 14 or larger.
- Use sans-serif fonts: Veranda, Helvetica, Times New Roman, or Arial.
- Be sure font color contrasts with background (black text with white background is best).
- Format so that leading between paragraphs is between single and one and a half lines.
- Highlight urgent or key information.

### Websites designed to include visitors with IDD
- Allow visitors to self-direct to specific content or a specific page.
- Be consistent with format and how to navigate through the website on every page.
- Do not use menus or other text that appears and disappears when the mouse moves over it.

### Presentation software
- Provide a script to describe images or words in presentations.
- Make alternative formats available such as narrated PowerPoints that can be published as a link to listen to.
- Ensure that printed slides are in at least 14-point font.
- Apply the 6 X 6 rule: no more than 6 words per line, 6 lines per slide.
- Stick to big ideas: limit the number of slides to key points.
- Be deliberate about animation—do not overuse it.
- Include brief audio and video clips when appropriate.
- Use contrasting colors—dark text on a light background is best.
- Highlight and define new vocabulary.

### Images: still, video
- Use images selectively, so that they don’t confuse the reader.
- Consider using photos, which may be more understandable than drawings.
- Provide captions or alternative text for all images.
- Provide text or captions under images, not above images.
- Be sure charts are clearly and simply labeled.
- Use high-quality images in which resolution is correct so that there is no blurring.
- Use captioning, audio description, subtitling, and dubbing as needed.
- If using animation or dynamic displays, include controls that allow the user to adjust speed.

### Checking accessibility
- Have individuals with IDD read through materials to check for accessibility and usability.
Consider creating the following recruitment materials for student researchers:

1. Invitation that describes your PAR project, anticipated outcomes, expected time commitment, and an explanation about how students will be compensated.
2. Graphic that highlights the PAR phases (see Figure 4, next page).
3. Introductory PowerPoint or fact sheet that describes PAR and how other people have used it.
4. Examples of other PAR projects, especially those that were done with students about the same age. There are many examples of PAR and Photovoice projects online.

Before seeking students’ consent, take some time to walk them through the PAR process. Use the invitation to highlight what you hope will come out of the PAR, and use the graphic of the PAR phases to walk through each step. Your introductory PowerPoint should include (a) an explanation of PAR, (b) examples of how others, including those with intellectual disabilities, have used PAR to describe and share personal experiences, and (c) a breakdown of the activities students will complete at each phase of PAR. Show students examples of how other people have done PAR and discuss their reactions.

Here are some links to projects summarized on YouTube:

**DreamGirls Photovoice Project**
(http://bit.ly/16mK1Ok)
In this Photovoice project, young women ages 10-17 participating in the DreamGirls program at the Burlington Housing Authority in North Carolina took pictures to represent challenges and achievements in their lives and communities.

**VOYCE: Voices of Youth in Chicago Education**
Voices of Youth in Chicago Education (VOYCE) is a citywide youth organizing collaborative that is creating research-based, student-led solutions to the dropout crisis.

**Photovoice: Community Participation After a Spinal Cord Injury**
This Photovoice project is the result of 10 people with spinal cord injury photographing issues of accessibility around Charleston, SC. They planned to use these pictures to educate the public and advocate for change.

**Health in My Hometown: A Youth Photovoice Project**
(http://bit.ly/16ilF86)
Students from 13 communities across the state of Minnesota were armed with cameras and asked to document health disparities in their community.
Laura Lorenz, from Brandeis University, uses a simple sketch to describe the research process she facilitated. (Lorenz, 2010)
At the first meeting with student researchers, cover:

(1) The purpose of the meeting
(2) Getting started
(3) Recording brainstorming sessions
(4) Selecting digital media tools
(5) Practicing with digital media tools
(6) Seeking permission to take photos
(7) PAR toolkits
(8) Scheduling times to meet

The purpose of the meeting

At your first meeting with a student, use a PAR graphic to point out the phase of PAR that you are starting (see Figure 1: PAR cycles). Then, review the purpose of the meeting: to determine what aspects of college the student wants to document, and what tools and strategies the student can use to do this. This is also when the research facilitator will review with the student some rules about doing research.

Here is a suggested way to talk to students about the phases of PAR with the graphic.

**Document:** “As we begin our research together, we will start by discussing what participatory action research is, and look at some examples of PAR projects. We will also go through all the materials and equipment in the PAR toolkit and practice using the tools and asking for permission to take pictures that include people.”

“Finally, we will brainstorm some ideas of things you might want to take pictures of that help other people understand your college experience. Or we can brainstorm other ideas about college that you want to explore.”

“When these tasks are complete, you are ready to take pictures. Let’s plan to meet in two weeks to look at the pictures you have taken.”

**Share:** “Next, we will meet and we will move all your photos from the cameras to a folder on a computer. Then together we will look through your photos or video clips. I will ask you to select some of those to upload on VoiceThread so that the other researchers who are in this project can see your images. You will also be able to see theirs.”

**Discuss:** “Next, you will take some time to look through all the photos and video clips. I will ask you to add some comments to your own examples as well as add comments to the other researchers’ photos and images. I will also ask you if you see some common college experiences that you all share.”
**Recommend:** “In the Recommend phase, I will ask you to think about what your research means and what you think should be done about it. For example, if you and other student researchers decide that there are a lot of positive aspects about college that some people might not be aware of, you might have a recommendation about how that information could be shared. If you discover that there are some common problems that you and other student researchers have experienced at college, you will be asked to make suggestions about what you and others could do to resolve those problems.”

**Act:** “The Act phase is when you and the other researchers will work on your recommended ways to share your information. Maybe you’ll present your work at a conference. Or maybe you’ll write a story together about your work. There are a lot of ways you might act in this phase. The important thing is to remember is that PAR always means doing something with your research. When we get to this phase, I will show you many different ways students have presented their work.”

**Reflect:** “In the final phase of PAR, Reflect, you will be asked to talk about what you thought of your PAR work and also what you think should happen next.”

**Getting started**

There are a number of ways to help students think about what things they would like to document. You may want to ask students to take some time to talk about or write down ideas. Or you may want to interview them about college and then review the transcript with them to see if they can draw some ideas from their own account.

**Storytelling resources**

1. The Center for Digital Storytelling Cookbook ([www.storycenter.org/books/](http://www.storycenter.org/books/)) includes strategies to promote storytelling as well as digital story production. This book is particularly good at walking facilitators through the elements of a good story and how to encourage people to tell their story, using these elements. It is also very good at walking facilitators through the steps of creating a digital story using simple moviemaking software.

2. The Great Questions list from StoryCorps ([http://storycorps.org](http://storycorps.org)) offers readers many examples of short recorded stories. It also provides a list of initial questions that college researchers could customize to talk to other college students with IDD.

One other suggestion is to use a prompt guide such as the “Sample College Prompt Questions” (Figure 6) to spark photo ideas. These questions ask students to think about their college routines, the people they interact with on campus, what they see as strengths and challenges of their college experience, and what recommendations they have about college.

Agree on a first deadline to review the images students collect (usually two to three weeks). Remind them to bring the PAR toolkit to that meeting (see toolkit description on page 26).
FIGURE 6: SAMPLE COLLEGE PROMPT QUESTIONS

Directions: Here are some questions that might help spark some ideas for photos, videos or recordings. You don’t need to answer all of them. They are simply here to give you some ideas to get started!

<table>
<thead>
<tr>
<th>Question</th>
<th>Ideas for a picture, video, audio recording</th>
</tr>
</thead>
<tbody>
<tr>
<td>What are all the places you go to when you are on the college campus?</td>
<td></td>
</tr>
<tr>
<td>What are all the things you do at the college?</td>
<td></td>
</tr>
<tr>
<td>Can you tell me about the people who are involved in your college experience?</td>
<td></td>
</tr>
<tr>
<td>How would you describe your college experience?</td>
<td></td>
</tr>
<tr>
<td>What is going well at college? For example, can you tell me about your college classes?</td>
<td></td>
</tr>
<tr>
<td>What is hard about college?</td>
<td></td>
</tr>
<tr>
<td>What is new that you didn’t know about in high school?</td>
<td></td>
</tr>
<tr>
<td>Do you have any suggestions to make college easier for students?</td>
<td></td>
</tr>
<tr>
<td>What do younger students know about college?</td>
<td></td>
</tr>
<tr>
<td>How do you think college will help you?</td>
<td></td>
</tr>
<tr>
<td>Are there people who wondered whether or not you should try college? Do they feel differently now? Why do they feel that way?</td>
<td></td>
</tr>
<tr>
<td>Do you feel any differently now than you did when you first started college? How do you feel? Why do you feel that way?</td>
<td></td>
</tr>
</tbody>
</table>

Some students may want to develop their own research questions. One student researcher in a program called Inclusive Concurrent Enrollment (ICE) wanted to know more about what other students on campus and faculty thought about college students with IDD being at college.

She formed her own questions, including two for classmates without disabilities:

- What’s it like to have a student from the ICE program in this class? Why?
- Do you think it would be okay for more students with disabilities to come to college?

And two questions for faculty:

- What do you think about having a student from the ICE program in your class? Can you explain your answer?
- Do you think it is easy or hard to teach students with disabilities? Why?

Armed with a pocket video camera, the student collected consent forms from four classmates and two faculty members and recorded her interviews with them.
Recording brainstorming sessions

Often, student researchers prefer talking about their ideas, rather than writing them down. One way to support these students is to use a digital recorder, or a digital app such as Audionote or Audiomemo, to record the conversation. After recording the ideas (e.g., best or worst day at college, best places to talk with friends, best place to study, what other students think about college), the file can be accessed by the student later as a reminder about possible ideas to document. Be sure to use consent forms for audio recordings if you think you might offer this recording option to students.

Another app that is useful for brainstorming sessions is iThoughts, which allows users to record ideas via a graphic organizer. In addition, iThoughts has features to save the organizer in multiple formats and to export the file to email or a virtual storage file.

Note: Often, students ask if they are allowed to use the camera to take other photographs unrelated to PAR. This is up to the research facilitator, but in general, as long as the student understands the PAR documentation tasks, they should also be able to use the camera to take other photos. In fact, sometimes it is these other photos that help students explain how college is influencing their lives.

Selecting digital media tools:

Once students have some ideas about what they want to document, the next step is to discuss options for collecting their data. By using digital cameras or pocket video cameras, students have a way to produce and share data that is accessible and meaningful to themselves, their co-researchers, and others who view their work. Review each option with students: digital cameras to take still pictures or video, pocket video cameras to take video clips, or digital recorders to record conversations with people. Table 2 has a full description of the pros and cons of these digital tools.

For students who carry cell phones (including smart phones) or tablet computers, built-in camera and video features may be the most convenient tools. Work with the student to make sure the quality of the images from those tools is to their satisfaction, and that they will easily transfer to digital storytelling formats.
Practicing with digital media tools

Give students time to practice using the digital media tool they selected. Review all the relevant features. Take time to look at practice pictures and ask students if they like the picture or if they would take it differently next time. Remind students that the photos they take for PAR projects do not need to be perfect. They are meant to serve as just one way to describe experiences to others. The students will also be able to add captions to the photos to further explain their ideas.

Provide students with printed directions that they can refer to when using the media tool (camera, video camera). Sample directions can be found in Figure 7: Taking photos with a regular or smartphone camera.

Seeking permission to take photos

As researchers, students must learn how to ask permission if they want to take a picture of someone or someone’s belongings. At this first meeting with the student researchers, it is important to discuss this aspect of research. Take some time to rehearse asking someone’s permission to take a photo, as well as practicing how to accept a “no” response.

In Figure 8, you will find an example of a customized “Permission to take photo” form student researchers used in a PAR initiative. This form is very important if the student researcher selects that photo in the future to discuss.
with others or to share in any way. The form has also proved to be helpful for explaining the research project to faculty and staff if the student wants to take a picture in a class or elsewhere on campus.

**PAR toolkits**

One way to help student researchers keep track of their data-collection materials is to develop a PAR toolkit. This kit can be as simple as a ziplock bag. In this bag, students can store the following:

1. camera, pocket video camera, or digital recorder
2. printed directions for using the digital media tools and for changing or charging the batteries
3. permission form for taking photos
4. contact information for the research facilitator in case the student needs support
5. flash drive to store all the images taken for the PAR initiative

The PAR Toolkit Checklist can be found in Figure 9.

**Schedule times to meet**

At this first meeting, decide what days you will meet to proceed through the seven student phases of PAR. At a minimum, plan to meet every two to three weeks. This will give students time to follow up on activities for each phase.

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**FIGURE 9: PAR TOOLKIT CHECKLIST**

**PARTICIPATORY ACTION RESEARCH (PAR) WITH DIGITAL MEDIA**

Toolkit Checklist*

- Camera, pocket video camera, or digital recorder
- Printed directions for selected camera or recorder
- Extra batteries or cords to recharge camera or recorder
- Printed direction to change the batteries or recharge
- Permission form for taking photos
- Contact information for the research facilitator in case the student needs assistance
- Flash drive to store all the images taken for the PAR initiative.

* If you choose to use your smartphone or cell phone to take pictures or videotape, please let me know if you need any assistance using these features on your phone.
In the next phase of participatory action research, “Share,” the students move from working on their own to sharing their work with their co-researchers. This involves:

1. Transferring photos
2. Organizing student work
3. Reviewing and explaining photos
4. Selecting and prioritizing photos
5. Choosing a research website
6. Sharing photos
7. Captioning and commenting on photos
8. Determining if more photos are needed

Transferring photos

At your next meeting, bring a laptop or tablet computer (e.g., iPad), or reserve time at one of the college’s computer labs so that you can upload students’ images or audio clips onto the computer and view them together. In this section you will find instructions for students on how to upload and edit their images and video clips (Figure 10).

**FIGURE 10: VIDEO TRIMMING INSTRUCTIONS**

| Introduction: |
| "Trimming" allows you to cut out footage at the beginning and end of a video in order to highlight a certain scene or to remove any unwanted video footage. |

| Tips to Remember |
| You can only trim videos; you cannot trim movies. |
| In order to trim a video, you must have the Flip camera plugged into the USB port on your computer, so it must be connected in order to utilize it. |

| How to Start |
| There are a couple ways to begin the trimming process: |
| Step 1: When single or thumbnail pictures of the video are open, click on the Trim button in the bottom right hand corner of the video. The Trim button has a picture of a pair of scissors on it. |

| Step 2: |
| When the Trim window opens, the selected video will appear. Drag the left slider (the "slider" is below the video window and says "start" on it) to the place on the bar where you want the trimmed video to begin. |

| Step 3: |
| Next, drag the right slider (this "slider" is below the video window and says "end" on it) to the place on the bar you want the video to end. |

| Step 4: |
| Click the Save as button, then enter a name for the trimmed video. This creates a new copy of the video. If you wish to save the trimmed video and exit the procedure, click Save, then click Close. |
Organizing student work

File organization is one of the key activities for the research facilitator, and it will make it much easier to assist students through each phase. A folder system will help you keep track of each student’s brainstorming ideas, photos and video clips, and captions or narratives. Start a file on your desktop for each student’s work. Then help students to transfer the file of their work to the flash drive you provided in the PAR toolkit. By doing this, you each have a copy of the files.

Reviewing and explaining photos

Once the photos or video files have been uploaded and filed, remind students that this project is less about the quality of the pictures or audio clips and more about why they are important. Also remind students that, if they choose to, they can use the camera or digital recorder again to re-do a photo or audio clip.

As you review each image or video clip, give the student an opportunity to answer some questions:

~ Who is in this picture?
~ What are they doing?
~ Why did you take this picture?
~ How does this picture help people understand your experiences at college?
~ What should people understand about this picture?
~ Is there something students who haven’t gone to college can learn from this picture?

These questions may prompt captions for the photos that students decide to share with others.

Selecting and prioritizing photos

After the student has had a chance to review all the photos, ask him or her to select five to seven photos that they would like to share with other student researchers. These photos should help others understand what the student thinks about going to college.

Choosing a research website

Once student researchers have selected the photos they want to share, decide how they will access each other’s photos. If they are meeting face to face, you could combine all the photos to develop a slideshow so that students can take turns presenting their photos. However, the students you are working with are likely attending different colleges or have tight schedules, so using a photo-sharing or digital-storytelling site that they can access from their own computers is highly recommended.
USING PHOTO-SHARING WEBSITES IN PAR WORK

There are a number of advantages to using photosharing websites to hold students’ PAR work. For one thing, having one place to review and work with data makes it easy for students to find all their work in one place. Additionally, fellow researchers can access and comment on each other’s work.

An important factor to keep in mind, though, is how you can ensure students’ privacy and security of their work. All the sites identified earlier in this section can be made public or private. Other sites, such as Facebook groups, may not be private or are not as easily set to be private.

When selecting an online format to store students’ work, be sure you have chosen a site that is as secure as locking the work in a file cabinet. There are a number of these sites available, many of them with minimal fees if you want to keep the files private. The following are resources you should check out!

**Voicethread**
www.voicethread.com

**Dropbox**
www.dropbox.com

**Wikispaces**
www.wikispaces.com

**Photobucket**
www.photobucket.com

**Smug Mug**
www.smugmug.com

**Cowbird**
www.cowbird.com

**Flickr**
www.flickr.com

**Picasa**
http://picasa.google.com
Introduction

This tutorial will show you how to register for a Voice Thread account and create your own Voice Thread. This tool allows you to tell a story through images while getting feedback from others.

Learning Objectives

1. Registering for an account
2. Creating a thread
3. Narrating a thread
4. Inviting friends to view

Learning Objective 1

Registering for an account

This learning objective will teach you how to create an account with Voice Thread. Skip this objective if you already have an account or if you are already familiar with registering for online accounts.

Steps

• Type www.voicethread.com into a web browser such as Explorer.
• Select Sign in or Register on the top left corner.
• A window will pop up prompting your email and password. Select Register and enter all information.
• Once you have three green check marks (  ) Select Register.

Learning Objective 2

Creating a thread

This learning objective will show you how to upload digital images and videos as well as how to organize your media in the order you want.

Steps

Step 1

Once you have registered for an account you are ready to login and begin creating a thread. The following steps will show you how to upload an image/video to your thread.

1. Select the Create option in the menu.
2. Select Upload and choose my computer. Locate the file that you would like to use as your first image or video.
3. Once you have located the file you want to use, select open. Repeat these steps until you have uploaded all images and videos you wish to use.

Step 2

You can reorganize your images or videos after uploading. Follow these steps to learn how:

1. Click and drag the image or video that you wish to move.
2. Drag the image to the desired location. Continue reorganize your images/videos until you are satisfied with the order.

*Developed by Lori Mateljan, University of Massachusetts Boston
Learning Objective 3
Narrating a thread

The following steps will show you how to narrate your thread using voice, text or doodle.

Steps

Step 1: Recording a Comment
You can narrate your voice thread by recording what you would like to say through a microphone. Follow these steps to learn how:

1. Choose the photo that you would like to comment on. Select the Comment feature.
2. Your picture will then enlarge and a menu bar will appear below it. Select the Record option and begin to speak.
3. When you are done recording click Stop Recording.
4. Your recording will automatically play back for you. If you are satisfied with your recording, select Save. If you would like to rerecord, select Cancel and record again.

Step 2: Leaving a Text Comment
If you do not have a microphone, you can leave a comment using text. Follow these steps to learn how:

1. After selecting an image and clicking on the comment feature, your picture will enlarge and a menu will appear below.
2. Select the Type feature and a text box will appear. Type out your comment and select the Save option.

Step 3: Doodling
Sometimes it is difficult to point out an aspect of your picture through voice or text. Use the Doodle tool to point out important parts of your picture. Follow these steps to learn how:

1. The Doodle tool can only be used with another form of commenting. Select the type of commenting you would like to use and the Doodle option will appear.
2. Click on the color you would like to use. Left Click and hold your mouse as you drag it over your picture. You've just doodled!

Learning Objective 4
Inviting friends to view

The following steps will show you how to invite your friends to view your thread.

Steps

Step 1: Inviting Friends
Inviting people to view your voice thread will allow you to get some feedback. Follow these steps to invite friends:

1. At the end of your voice thread there will be a slide that gives you the option to share your thread. Select invite your friends.
2. Add new contacts by providing their email address and name. After selecting Add they will appear in your list of contacts.
3. Decide who you would like to invite to view your thread. In this example, the author of the thread decided to invite John and Maria.
4. Click on your contacts names to select them. If they are highlighted in yellow, like in the example, they have been selected.
5. Click Send Invite when you are ready to invite your contacts to view your thread.
You’ll need to make sure that students’ work is secure and private on whatever photo-sharing site you choose. This will serve as your research website, and must be treated as such.

Sharing photos
Once you have chosen a photo-sharing site (see page 23 for examples) to share images and comments, create an account specifically for this research. Then you will have a password-protected link to this website that you can share with the students. Once they have the link, you can then help students to access the site, set up an account, and upload the images they’ve selected to share with other students.

Written step-by-step instructions with related screenshots are helpful for students to follow as they upload their photos (see Figure 11).

Captioning and commenting on photos
When students have finished uploading their photos, show them how to add captions. Some photo-sharing sites, such as VoiceThread, offer several captioning options. These include typing captions in, phoning them in, using the computer’s webcam to record them, or using a computer microphone to record a caption and other comments about the photo. A completed VoiceThread can be seen in Figure 12.

Determining if more photos are needed
Before completing this phase, ask the student if he or she needs the camera again to take any additional photos. Some students find that an important photo does not meet their expectations, or that they now have new ideas after taking a first set of pictures. They should have the opportunity to take the camera one more time to finish their data collection.
In the next phase of participatory action research, “Discuss,” the research facilitator works with students to discuss and identify themes in their collective work. To prepare for this, ask each student to complete the following tasks:

1. Review and comment on the work of co-researchers
2. Work with you to identify common themes
3. Discuss themes with the facilitator and co-researchers

**Review and comment on the work of co-researchers**

At your next meeting, the student should have access to a computer to access the research website to look at the contributions of the co-researchers who also uploaded selected files. As the student is looking through their co-researchers’ photos, video clips, and comments, encourage them to give feedback, using the “comment” buttons. One way to help is to give students some questions to consider when looking at the images. Here are some suggestions:

- Does this image remind you of your college experience? If yes, how? If no, how is your college experience different?
- What do you think people should understand about college from looking at this image?

Students should be encouraged to comment on at least one image from each co-researcher’s work.

**Work with research facilitator to identify common themes**

After all the students have commented on each other’s work, you will assist them with finding collective themes. Ask students to sort the photos into categories, either on the desktop or with printouts you’ve prepared ahead of time. These categories might grow out of a specific topic (e.g., college classes), or out of the number of comments on a specific photo (e.g., multiple pieces of feedback on a discussion about mentors).

Repeat this process with each student so that everyone has a chance to contribute to the themes. When themes have been finalized, find images that represent each theme, title them, and post them on the research website.
Discuss themes

Once the students have agreed on themes, ask each student to post a comment on one or more of the themes. Some students will have no difficulty commenting on themes; others may need some support. Some guiding questions:

- Is this topic important to you? If yes, why is it important?
- Do you think other college students are familiar with this issue? What makes you think so?
- What could be done to improve this?

In Figures 13 and 14, students discuss themes that emerged from their work.

**FIGURE 13**

**VoiceThread: Feeling Different in College**

Meghan: I can meet more people and I have more freedom

Wilson: I feel more mature in college. I don’t fight. I just read Sports Illustrated.

Christine: I think it’s great. Once you get into college you will like it. It’s a lot of fun.

Stephan: I feel different because I am getting an education and meeting new people. College might be hard but you can get through it. It’s like they say, everything can’t be easy but you gotta get through it.

Cassidy: College is hard. There is a lot of homework plus I have a new job at college. It’s more responsible.

Joe: You get to be yourself at college.

Grace: In college I’m around more people than in high school.

Allison: Yes, I feel differently in college. I don’t know what happened.
**VoiceThread: Travel to College**

Stephan: This is my community. Where I grew up. It’s always busy and never changes. Always busy. Always drama. I’m always late for college but I keep saying it’s not my fault. It doesn’t look busy now but try leaving for school about 9:00 and it is so busy.

Christy: It never feels good to be late for college. One time I got late for college too, and some times I may get late for school too.

Wilson: You can take the Red line to Downtown Crossing and change for Orange line to Community College.

Stephan: You have to take the bus to go down Ruggles and take the outbound train to Community College. I have a later class this semester so now I’m not late anymore.
In the next phase of PAR, “Recommend,” the research facilitator asks the students to make recommendations based on the themes of their work. To facilitate this PAR phase with student researchers, you will be:

1. Showing students examples of recommendations
2. Brainstorming solutions
3. Facilitating an online, real-time discussion
4. Having students vote on recommendations

**Showing students examples of recommendations**

First, make sure that students understand what recommendations are and how they relate to the issues that come out of PAR work.

One example comes from a Think College PAR study with nine college students with IDD. In this study, students from four colleges made recommendations based on six themes that came out of their PAR work. These included advice to younger students about college preparation, and recommendations to the college about greater access to career-oriented courses. The publication is in the Recommended Resources section.

**Brainstorming solutions**

Ask students to consider how the college experience can be better. Some might have ideas immediately. If they don’t, use these prompts:

**Based on your research:**

- Is there anything you wish you knew more about before you started college? If so, what?
- Is there anything you wish was different at college? If so, what?
- Is there anything you wish you could do at college that you are not able to? If so, what?
- What should college professors know about students with intellectual disabilities going to college?
- What should transition teachers know about students with intellectual disabilities going to college?
- What should parents or families know about students with intellectual disabilities going to college?
- What should mentors or coaches know about students with intellectual disabilities going to college?
- Who should hear about these ideas and recommendations?
- How can we share these ideas and recommendations with those people?
Facilitating an online, real-time discussion

Students may want to have a supported discussion about the themes of their work, and then make recommendations as a group. One convenient way to do this is via a real-time discussion online, either through voice calls over the Internet (such as Skype), a phone conference, or a web conference.

Give students clear instructions about how to access the call-in system and how to get assistance during the call. Many of the same questions listed above could be used to guide the discussion. The pros and cons of using each format are listed in Table 3:

### Table 3: Pros and Cons of Formats for Online, Real-Time Discussions

<table>
<thead>
<tr>
<th>Format</th>
<th>Pros</th>
<th>Cons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Voice calls over Internet (such as Skype)</td>
<td>Free to facilitator and students.</td>
<td>All participants must have computer.</td>
</tr>
<tr>
<td></td>
<td>Clear sound.</td>
<td>Facilitator and students must establish account to make or participate in calls.</td>
</tr>
<tr>
<td></td>
<td>Screen sharing allows use of visuals.</td>
<td>If person has poor reception, calls will drop.</td>
</tr>
<tr>
<td>Phone conference</td>
<td>Easy to set up.</td>
<td>May be necessary for research facilitator to set up phone conference account.</td>
</tr>
<tr>
<td></td>
<td>Most participants have phones.</td>
<td>Requires participants to call conference number and enter account number.</td>
</tr>
<tr>
<td>Web conference</td>
<td>Allows participants to see names of all participants on call.</td>
<td>May require participants to follow two or more steps to access webinar and phone features.</td>
</tr>
<tr>
<td></td>
<td>Facilitator can use PowerPoint and online chalkboards such as the whiteboard to guide discussion.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Facilitator can set up survey so students may vote on recommendations.</td>
<td></td>
</tr>
</tbody>
</table>

Having students vote on recommendations

Students may finalize their recommendations by listing recommendations from all co-researchers and then voting on the top three. This could be done in individual face-to-face meetings or virtually (via a survey on a webinar or through a web survey site). As you assist students to choose the best format make sure their presentations are accessible (see “Usability Checklist for Think College PAR Materials” in the Prepare section).
In the next phase of PAR, “Act,” the research facilitator works with the students to take action on their recommendations. Students may choose to work on recommendations individually or in small groups. In any case, there are several steps you can take to help students act on their recommendations. Stringer suggests this series of questions to prompt the “Act” phase (Stringer, 2007):

1. Why is this recommendation important?
2. What action needs to happen?
3. How will it get done?
4. Who is going to do what?
5. Where will it get done?
6. When will these tasks begin and end?
7. What resources are needed to get these tasks done?

Why is this recommendation important?

Ask students to talk about why each recommendation they have made is important to share with others. Then, use this discussion to move through the rest of the tasks to take action, as outlined in Table 4.

For instance, in one PAR study outlined below, students recommended that educational coaches let students have more independence at college. They also recommended that students accept responsibility for as much as they can before asking for help. When asked why this is important, students responded that, as college students, they are expected to do things on their own.
What action needs to happen?

Next, ask students what they could do to address their recommendation. In the example about the educational coaches, the research facilitator suggested a number of options to take action on this recommendation. She suggested that they could:

1. Try out a new planning tool for students and coaches and then write a story about that tool.
2. Present their recommendations at a meeting with their college advisors.
3. Share their experiences about working with educational coaches with younger peers.

As a group, the students voted to do the first one: try out a new planning tool for students and coaches and then write a story about that experience for other students and coaches.
How will it get done?
Once the students have made some decisions about what they want to do, help them prepare a list of tasks that will need to be done to address their recommendation. How will they do it?

Who is going to do what?
Next, help students organize how they can each take responsibility for tasks getting done. Make sure that all students have a part in the project.

Where will it get done?
If students want to work on tasks while they are on campus, look at their schedules with them. Together, decide when they can work on tasks and what location makes the most sense: on or off campus.

When will these tasks begin and end?
Help students to put together a master schedule and a timeline to decide when tasks should start and when they should be completed. Make sure a copy of this timeline is printed out or emailed to all students.

What resources are needed to get these tasks done?
Help students to list all the resources that will be needed to accomplish these tasks. What will need to be paid for? Will students need help to complete tasks they volunteered to do? What resources can you provide?

Project Summary Examples
On the following pages are examples from four PAR projects facilitated with transition-aged students with disabilities. A brief summary of each of these projects is described below:

Project #1 Summary: See What I Mean? Student Research Tells It Like It Is.
Transition-aged students documented both their aspirations and concerns about their lives after high school. One of their primary concerns was obtaining paid employment. Their action steps included discussing their concerns with the school principal and city mayor and presenting their research at a public reception at city hall.

Project #2 Summary: Seeking a Pledge for Employment
High school students enrolled in an employment support program used participatory action research methods to document their efforts to move from unpaid, entry-level work to paid work that aligns with their career interests. Their action steps included seeking a pledge from the local Chamber of Commerce to assist them with jobs, as well as presenting their research at their school.
**Project #3 Summary: Think, Hear, See, Believe College**

Students from the Massachusetts Inclusive Concurrent Enrollment (ICE) partnerships discussed their perceptions of college using digital cameras and pocket video cameras. They used the digital storytelling site VoiceThread to discuss their research with each other and to plan their action steps. These steps included writing two briefs related to their findings. Several students presented their work at ICE partnership meetings and at state conferences. Some students used the research to advocate for more college funding to state legislators and the MA Department of Higher Education.

**Project #4 Summary: Getting the Word Out About College**

Concurrently enrolled students with intellectual disabilities were invited to participate in research, training and dissemination activities that would help spread the word about college in ways that were meaningful and engaging to young people with intellectual disabilities. With the use of digital media and storytelling methods, students partnered with Think College staff to develop the college database tutorial, make recommendations for an interactive website, develop stories and videos about college, and to publicly advocate for college access and funding.
This project was supported by the Massachusetts Department of Education, which was awarded a three-year, United States Department of Education (USDOE) funded State Improvement Grant (SIG) - Project FOCUS Academy (PFA). The Project FOCUS Academy was designed to develop professional development programs to help students with disabilities build sound career goals and learn skills to ensure successful post-secondary outcomes.
Seeking a Pledge for Employment

Data suggest that only 6% of individuals with IDD ages 16-21 and 17% of individuals with IDD ages 22-30 are working in typical paid jobs.

American Community Survey. (2010)

Students from a high school employment program seek pledge for jobs from local Chamber of Commerce

Pledge

I WILL HELP BROOKLINE HIGH SCHOOL STUDENTS EXPAND THEIR CAREER OPPORTUNITIES BY:

- Hosting informational interviews
- Providing job shadowing opportunities at my workplace
- Participating in practice interviews with students
- Hosting interns
- Identifying potential jobs
- Networking with others in my field
- Speaking to classes about my career

The employment support program of Brookline High School helps students with disabilities obtain and maintain employment in jobs that match their skills and interests.

“I don’t want to still be at this same job when I’m old.”
Sarah, 20

“I know I need a job. What else will I do after high school? I don’t know.”
Ryan, 21

“I volunteer now but I hope with more work experience and training I can get paid.”
Dimitri, 19

Fred, 20

“That’s the funny thing... I can get a job doing food but I want to do something big”
Project #3 Summary
Think, Hear, See, Believe College

“In college professors don’t baby you. You’re responsible for your own work.”
Grace Quiah, 20

“The best part of college is taking classes for my career.”
Cassidy Bauer, 21

“The reading and tests are hard but I will never ever give up.”
Joey Fearbay, 21

Students with intellectual disabilities document their college experience and get the word out to others.

“I like my ed coach, but sometimes she gets under my skin. I want to try doing college work on my own.”

“I feel different. I feel like I’m getting an education.”
Stephan Wright, 20

This PAR project was funded by Think College. Think College is a project of the Institute for Community Inclusion at UMass Boston. It is funded by a cooperative agreement (#90DN0216) from the Administration on Developmental Disabilities (ADD), Administration for Children and Families, Department of Health and Human Services.
Project #4 Summary

Getting the Word Out About College

- Advising Others
- Creating Videos
- Designing Websites
- Doing Research
- Testifying to Legislators
- Presenting Facts
- Writing Articles
- Recording Stories
- Reviewing Materials

This PAR project was funded by Think College. Think College is a project of the Institute for Community Inclusion at UMass Boston. It is funded by a cooperative agreement (#90DN0216) from the Administration on Developmental Disabilities (ADD), Administration for Children and Families, Department of Health and Human Services.
In the final phase of PAR, “Reflect,” the research facilitator takes some time with the students to think about their work. This can be done with students individually, but is more effective if students can meet in person or participate on a conference call. There are four steps that you can take to help students during this last phase of research:

1. **Reviewing the plans created and actions taken**
   Talk to the students about the plans they made and the tasks they undertook. Did they work out? Were the outcomes what they had expected or hoped for?

2. **Assessing the response to PAR**
   Ask students to think about the feedback people had about their PAR work. Did people respond as students wanted them to? If not, why not?

3. **Deciding if plans need to change**
   Check in to see if students are still happy with the plans they made to address their recommendations. If they want to make changes to their plans, help them to decide how to proceed with those changes.

4. **Celebrating the team’s accomplishments**
   Most importantly, acknowledge with students the work they did to perform this research. They not only reported on experiences or issues, but also took action to discuss and address problems. Whatever the results of their PAR experience, acknowledge the time, effort, and thought that students put into their research.
REFERENCES


References for Usability Checklist:


Recommended Resources for Designing Participatory Action Research


Creswell provides readers with simple, direct instructions for designing research. Very helpful for researchers who are conceptualizing their PAR studies and for preparing IRB protocols.


Haarstad’s Bill of Rights is a helpful tool to use when talking to researchers with intellectual disabilities and when preparing consent forms. It sets the right tone for respecting rights in research.


This guide is helpful when preparing to talk to individuals with IDD about research, and about how they can get involved in research projects.


Jurkowski’s study with PhotoVoice methods highlights how individuals with IDD can participate in PAR, and how the results can be used to discuss participants’ perceptions of health.


Kemmis and McTaggart thoroughly explain the theory and applications of PAR, and discuss ways to engage individuals in PAR.


This book is a great introduction for researchers who are interested in further exploring digital storytelling as a PAR method.


If you are interested in learning how a research facilitator can explore her own research questions while facilitating PAR with student researchers, this study may be helpful.


This brief is an example of how student research can be documented and published for wide audiences who are interested in hearing directly from students.
Research facilitators who are exploring inclusive postsecondary education are likely to identify issues that may not yet be present in the literature. Strauss and Corbin offer a number of grounded theory applications to help researchers make sense of their findings.


This textbook is useful in guiding researchers through every phase of PAR.


Rita Valade presents her work with adults with IDD who lived in group homes. She presents an honest account of what worked well in her effort to complete every phase of PAR with her co-researchers, as well as what was difficult to do.


Walmsley and Johnson, researchers from the United Kingdom, report on their years of experiences including individuals with IDD in all phases of collaborative research, including writing up findings. This book is helpful in understanding what inclusive research is and the commitment it takes to do it responsibly with co-researchers with IDD.


Carolyn Wang developed the PhotoVoice method, using it to encourage people who were often the recipients of services to instead take a lead in identifying personal and community strengths and needs. Her methods have been applied in many different contexts to discuss public health, housing, and community safety. More recently, these methods have been used as a way to draw out the voices and perceptions of individuals with IDD. Understanding the spirit and basic principles of PhotoVoice can be very helpful for inclusive researchers.

**Photo Sharing Resources:** Here are some free online spaces where you can store and share photos with co-researchers:

- **Voicethread** (www.voicethread.com/)
- **Dropbox** (www.dropbox.com/)
- **Wikispaces** (www.wikispaces.com/)
- **Photobucket** (www.photobucket.com)
- **Smug Mug** (www.smugmug.com)
- **Flickr** (www.flickr.com)
- **Picasa** (www.picasa.com)

**Relevant apps:** A few apps might be useful for student researchers who want to develop visual stories or posters that highlight findings for the “Act” phase:

- **Pictello:** Allows users to create stories using their own images and voice to narrate the story.
- **Sonicpics:** Allows users to create a custom slideshow with their own images.
- **Comic Creator:** Allows users to create a full-length comic book with their own images and captions.
- **Frame Magic and My Sketch:** Allow users to re-design their images in sketch formats or for posters.
Project Name: Using Participatory Action Research with Students with Intellectual and Developmental Disabilities to Discuss their College Experience “The National Consortium for Postsecondary Education for Individuals with Intellectual and Developmental Disabilities”

I Rationale:

Transition-age students with severe disabilities rarely have the opportunity to document for themselves their transition from school to postschool activities (Cinomon & Gifsh, 2004; Dowrick & Scouge, 2001; Lehmann, Bassett, & Sands, 1999; Thoma and Wehmeyer, 2004; Thompson, Fulk, & Peircy, 2000). First-hand accounts of the process and specific transition activities would both help families and practitioners learn how they can better assist with the process as well as inform younger peers what the transition experience is like. For those students who are involved in inclusive experiences, it is even more critical that stakeholders understand what is and what is not successful in these experiences.

During the fall of 2010, the Institute for Community Inclusion was awarded a new grant from the Administration on Developmental Disabilities to establish the National Consortium for Postsecondary Education for Individuals with Developmental Disabilities. This Consortium is funded to conduct research, provide training and technical assistance, and disseminate information on promising practices that support individuals with developmental disabilities to increase their independence, productivity and inclusion through access to postsecondary education resulting in improved long-term independent living and employment outcomes.

Research site
Currently, there are approximately six partnerships in Massachusetts between institutes of higher education and high schools funded by the Massachusetts legislature to create access to postsecondary education for students with disabilities. These students must be between the ages of 18-22 years old, be identified as having severe disabilities, are determined to not likely meet the requirements for a high school diploma and are still eligible for special education-specifically transition services. The primary purpose of this access is to promote improved postschool outcomes in the area of employment by pairing work and school experiences that reflect their career interests.

Since this initiative began in January 2007, the students involved in this initiative, referred to as the College Career Connection, participate in a survey every semester to answer questions about their experience (Protocol # 2007.135 Inclusive Concurrent Enrollment Partnerships Programs for Students with Disabilities). In many instances, the students want to expand on their answers or discuss other issues that impact their college experience. This proposed participatory action research initiative provides a way for students who have had at least one semester of college to document first-hand how they are experiencing college and identify recommendations they would make for improvements.

**Information will be gathered on:**

1. How students with intellectual disabilities engage in participatory action research (PAR) that includes the use of digital media tools?
2. How students with intellectual disabilities who have taken at least one college class describe their experiences in inclusive postsecondary activities?
3. How students propose to improve this college experience for themselves and others?
II Methodology

This will be a pilot study of the participatory action research (PAR) method, an emancipatory and cyclical form of research that promotes collaboration between researchers and participants. In doing so, PAR produces authentic data that can be applied to create solutions (Kemmis & McTaggart, 2000; Selener, 1997). Evidence suggests that PAR methods have been successful in promoting the voice of individuals with intellectual disabilities to discuss issues that impact their lives including their health status (Jurkowski, 2008), circles of support and how those supports influence transition outcomes (Stevenson, 2007), transportation concerns (Valade, 2008), social integration (Mactavish, Mahon & Lutfiyya, 2000) and quality of life issues (Ward & Trigler, 2001). In addition, PAR is a flexible process that does not dictate one particular strategy, only that the strategies employed promotes the personal involvement of those affected by the research endeavor (Valade, 2008). For this study, digital media options, which allow participants to produce visual as well as narrative data, will be offered to participants as a way to identify their perceptions of the college experience. These options will include photovoice (Wang & Burris, 1997), digital storytelling (Lambert, 2006) and digital recordings. By using these visual and audio tools, the participants have an opportunity to develop and share data that is universally accessible to them, their peers, their research collaborators and decision makers with whom they determine to discuss their concerns.

Anticipated outcomes: PAR includes taking action and in this study, participants will be asked to consider how their findings about problems or concerns can be addressed through action planning and in turn, how their research can be disseminated. PAR staff and participants will invite the Principal Investigator of the College Career Connection grant to attend a meeting to determine how their findings can be shared with the Project Advisory Committee and to
determine what other opportunities exist where participants could discuss specific issues. In addition, PAR staff will work with project staff to include findings that participants consent to share on ICI’s ThinkCollege website (http://www.thinkcollege.net/). PAR staff will also work to provide ways for participants to disseminate their work more broadly through (1) publications focused on postsecondary education, self-advocacy, or action research, (2) presentations at local, regional and national conferences, and (3) public forums to discuss specific issues related to their college experience.

**Site selection:** As stated in the rationale section, this study will focus on students participating in the College Career Connection grant, which is currently funded through December 2012. As of now, there are six partnerships between institutes of higher education and selected school communities. These partnerships are funded to promote college access to transition age students with intellectual disabilities between the ages of 18-22 who are still eligible for special education services and are not likely to meet the requirements for a high school diploma. The partnerships include Quinsigamond Community College Partnership, MassBay Community College Partnership, Bristol Community College Partnership, Holyoke Community Partnership, UMass Boston/ Bunker Hill Community Partnership and the Mt Wachusett Community College Partnership.

**Participant recruitment strategies:** This pilot study is designed to include one to two representative students from each of the college-school partnerships. To recruit students for the study, the researcher will meet with the postsecondary education liaison to the schools at each partnership to explain the purpose of the study and to request permission to be added to the monthly partnership meeting to distribute a recruitment flyer for researchers (see Appendix A: Recruitment Flyer). At that meeting, the researcher will explain to the college and school
partners the purpose of the research, the criteria for student selection, and the anticipated time commitment. She will also ask for the assistance of the members to identify students who meet criteria and to ask how she could meet them to invite them to the study. (See Appendix B: Sample schedule and timeline). She will provide information about the project that can be distributed to students who fit the criteria for participation, answer any questions they have and then ask if they could seek permission from the students to meet with the researcher if they are interested in the project. When a day and time is identified to speak to the students on campus, the researcher will introduce the project to them, and will show them sample student work using digital media from similar projects. The researcher will ask the teachers and liaisons for each students' preferred communication method and will prepare and present the materials and consent forms in appropriate formats to ensure that students understand what the study will involve and what she is asking them to do (See Appendix D: Sample presentation to students). The researcher will emphasize the students’ voluntary participation. The teachers and liaisons will translate consent forms into all necessary languages as identified.

Data collection procedures:

Using Participatory Action Research Project staff will follow the Kemmis and McTaggart approach to PAR which involves six self-reflective cycles: (1) planning a change, (2) acting and observing the process and consequences of the change, (3) reflecting on these processes and consequences and then (4) replanning, (5) acting and observing and (6) repeating the cycle. In essence, reflection occurs when participants identify a shared concern or problem. Planning involves a discussion and critical examination of the problem. Action is utilizing the plan to achieve the desired outcome or improvement. Observation is where results or results or changes are made (Valade, 2008). In addition, recommendations by Ward and Trigler (2001) and
Valade (2008) that concern doing PAR with participants with intellectual disabilities will be incorporated into the design. These include (1) orienting and teaching the participants about the research process using meaningful formats, (2) clarifying the roles of the participants and project staff, (3) negotiating the time commitment of the study and (4) starting small by working first with a small subset of the participants.

Students who meet the criteria and who consent to participate in the study will be invited to participate in a PAR process, which will conclude after the students present their data. The researcher will both facilitate the process with the students and collect research data (See Figure I: Data Collection Methods and Data Sources). Involvement in the study will include:

- Meeting with PAR facilitator 1-2 times a month from December 2011- June 2012
- An introduction to digital media for storytelling and participatory action research.
- Instruction on using digital media and securing permission from photo subjects to take his or her picture.
- Participating in an interview to discuss postsecondary plans.
- Discussing photographs and audio recordings and determining what they represent.
- Learning how to reflect on similarities between work and how to draw conclusions from that
- Choosing pictures based on common group themes.
- Determining how to present the results and identifying individuals who should hear them
- Hosting a presentation and follow-up discussion of the presentation.
- Evaluating PAR process and determining next steps

**Data Collection**

For this study, the researcher proposes to use five data collection strategies to explore PAR with students with intellectual disabilities: observation, interviews, group meeting, a
journal, and document analysis (See Figure 1: Data Collection Methods and Data Sources). As the PAR facilitator, the researcher proposes to collect data several times throughout the process and will arrange to meet with participants from each partnership 1-2 times a month. One visit will be arranged when she is already there for the monthly partnership meeting at the college. The other meeting will be arranged at the students’ convenience. Data will be collected through student interviews (See B: Sample interview and meeting agenda), photographs, audio files, narratives, and from group discussions. Since the researcher will be dually facilitating the meetings with students and taking data at several sessions, she will use journaling to document six sessions. She will also schedule times during and after the process to collect data on the process. This will include scheduled observations of targeted sessions (See Appendix C: Sample observation protocol) and meetings with all the participants at the end of the process (See Appendix B: Sample interview and meeting agendas). All notes will be kept on file with password protection with the other research materials.

Figure 1: Data Collection Methods and Sources

<table>
<thead>
<tr>
<th>Session</th>
<th>Purpose</th>
<th>Data collection method/data source</th>
</tr>
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<tbody>
<tr>
<td>#1</td>
<td>Introduction PAR, review of consent form,</td>
<td></td>
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<tr>
<td></td>
<td>photography ethics.</td>
<td></td>
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<tr>
<td>#2</td>
<td>Students learn to use digital tools. Practice</td>
<td>Observation #1 (notes include</td>
</tr>
<tr>
<td></td>
<td>using tool of choice</td>
<td>modifications).</td>
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<tr>
<td>#3</td>
<td>(a) Discussion. Introduce overall issue:</td>
<td>Tape record session (Transcript</td>
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<tr>
<td></td>
<td>college experience</td>
<td>of group discussion).</td>
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<tr>
<td></td>
<td>(b) Individual interviews w/ students to plan college documentation</td>
<td>Interview students individually (Transcript of individual interviews).</td>
</tr>
</tbody>
</table>
| #4 | (a) Instruction on downloading pictures, audio files  
(b) Plan next week or two of documentation | Observation #2 (notes include modifications). |
| #5 | (4) Review new documentation  
(5) Students select from photos, files to share with other participants | Observation #3 (notes include responses and modifications). |
| #6 | (a) Students begin to narrate photos.  
(b) Students present 2-3 photos to group | Observation #4 (notes include responses and modifications, discussion w/peers.). Data: Photos and narratives |
| #7 | (a) Students identify common themes from their photos.  
(b) Students choose pictures from their files to contribute to themes. | Record group discussion. (Transcript from group discussion). |
<p>| #8 | Students complete work on narration. Students discuss how | Record discussion (Transcription of discussion). |</p>
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<tbody>
<tr>
<td>#9</td>
<td>Students split up work to organize presentation(s).</td>
<td></td>
</tr>
<tr>
<td>#10</td>
<td>Students organize photos for presentation format.</td>
<td>Final photos and narratives</td>
</tr>
<tr>
<td>#11</td>
<td>Mock presentation</td>
<td>Observation #5 (notes include accommodations and modifications).</td>
</tr>
<tr>
<td>#12</td>
<td>Presentation to decision makers as determined by participants</td>
<td>Observation #6 (notes and photographs of presentation).</td>
</tr>
<tr>
<td>#13</td>
<td>Follow-up meeting with students: How does process assist you in communicating college experiences to others and what should happen next?</td>
<td>Meeting (transcript of meeting)</td>
</tr>
</tbody>
</table>

**Students’ own data collection tools:** After reviewing an overview of each media process, student participants will have the option to select from one of four options to reflect and document their college experience. These processes include (1) photovoice, in which participants are asked to take pictures of, select, discuss and narrate images that describe a perception, strength or concern they have about a particular issue (Wang & Burris, 1997); (2) digital story, in which participants sequence photographs and/or artifacts and record a story that describes events
in a person’s life (Lambert, 2006), (3) voice thread, in which participants upload images onto a website and encourage others to view and respond to the image and narrative, or (4) create a podcast in which a participant will record a story about an issue or concern. In each case, participant will be asked to focus on issues related to their college experience. As part of the PAR study, the facilitator will instruct the students in photography and audio recording ethics and will provide the students with multiple opportunities for the students to role-play scenes where they must seek permission from a possible photo subject. In addition, the facilitator will model the practice by seeking consent from the students to take their picture for the project. The procedure will emphasize (a) always taking photo release forms with you when you plan to take pictures, (b) explaining the purpose of the photograph to the photo subject, (c) fully explaining where the photograph might be used, (d) assuring the subject that they may change their mind at any time and (e) explaining how the subject can contact the photographer or project facilitator.

**Overview of data analysis:** Ward and Triglar (2001) identify data analysis and interpretation as the most challenging cycle to implement with individuals with intellectual disabilities. Time commitments and the challenge to extrapolate data beyond their own experience to a representative group were identified as the key issues. To address this, project staff will identify strategies to streamline the process where possible and also prepare a tutorial with concrete examples to move from using their own examples to examining many different examples from the cohort to draw conclusions and make recommendations. A modified qualitative data analysis process will be used with the participants so that at each stage participants will have concrete ways to review each other’s stories, complete charts to track themes, determine similarities, and identify common problems. Steps in the data analysis phase will include gathering the data (student stories, research journal notes from individual and group meetings, reflections),
cataloging the data, applying codes to the data, chunking the codes, identifying patterns and reviewing the research question to interpret the patterns (LeCompte & Schensul, 1999).

III HIPPA Compliance Information:
N/A

IV Participant data

Sample Selection

The researcher proposes to work with 1-2 students from each of the college/school partnerships for a maximum of 12 participants. She will use purposeful sampling to identify students with intellectual disabilities who meet the criteria of being involved in the College Career Connection project, have completed one college course through the initiative, are willing to document their experiences with digital media, are willing and available to commit to working with the facilitator 1-2 times a month over the span of seven months, and will consider sharing their work with others. Since the majority of participants in the project average just one course, the pool of applicants is likely to be small. All eligible applicants will be considered for participation.

Inclusion criteria: As stated above, students with intellectual disabilities who meet the criteria of being involved in the College Career Connection project, have completed one college course through the initiative, are willing to document their experiences with digital media, are willing and available to commit to working with the facilitator 1-2 times a month over the span of seven months, and will consider sharing their work with others will be considered for participation in the PAR study. There is no skill criteria for students to participate in the research activities since the researcher is exploring how digital media can be used to make the PAR process accessible to all students including those with intellectual disabilities who may have
limited or no verbal, reading and writing skills. For those students with no verbal skills, the researcher will use the students’ preferred augmentative communication system.

**Exclusion criteria:** Students enrolled in the College Career Connection project who do not meet one of the criteria will be excluded from consideration. The primary issue will be identifying students who have at least one semester’s college experience who can reflect on the whole college experience.

**V Procedures for vulnerable populations.**

In addition to providing students with multiple formats to introduce the project, the researcher will also advise the students, whether or not they are their own guardians, to review the project materials and consent forms with someone they know and trust before signing the consent or assent forms. She will immediately follow-up the meeting with individual private conversations with each student to confirm their understanding of the project, including the meetings, documentary activities, discussion groups, and the public presentation (whatever form that takes). The researcher will review the potential risks, discomforts and benefits the students may experience and the steps she has built into the project to minimize risks and discomforts. The researcher will describe measures that will be taken to ensure confidentiality and their right to withdraw from the project at any time. She will answer any questions about the project and explain the time commitment students will need to make to participate in every phase of the project. Finally, for those students who express an interest in consenting to the study, the researcher will also prepare a package of materials for the participants' parents and guardians to review as well as consent forms for those students who are not their own guardians. She will include her contact information and a prepaid stamped envelope to send back the signed consent form.
Throughout the project, the researcher will use presentation formats that best match students' receptive and expressive communication skills, as determined in consultation with teachers and family members.

**VI Description of risks and benefits.**

It is understood that there are some risks and minimal discomforts that participants might experience. It is possible that students might feel they are disclosing a disability by participating in the study. Any foreseen discomfort, such as participants’ uneasiness in sharing photographs or narratives with other project participants, teachers, staff or project facilitators in class or through a presentation of their work will be acknowledged and every attempt will be made to assure students of their right to exclude any photograph or narrative from the project, at any time and for any reason. Consent forms will be used extensively during the process. Permission will be sought from participants to (a) participate in the study, (b) allow facilitator to record six sessions, (c) record individual student interviews, (d) use identified photos, audio files and/or narratives for presentation to decision makers, (e) participate and allow facilitator to tape record a follow-up meeting at end of study. Participants will also be taught to seek permission from photograph subjects to (a) take picture of subject or subject's personal possessions and (b) to obtain permission from anyone who is in a picture that a student plans to include in a presentation.

Participants will also be informed of the anticipated benefits of the study as widely as possible. One primary benefit of exploring this process for students is the possibility of identifying a method that be prove useful and beneficial to other students to describe to decision makers what strengths or problems they see in postsecondary activities they are involved in at the time, specifically postsecondary education.
VII Informed consent.

The aim of this study is to secure participants’ voluntary involvement. This will be achieved through informed consent, a description of harms and benefits and a statement of confidentiality procedures. The researcher intends to use every means possible to protect participants’ privacy and at the same time encourage their self-determination and self-advocacy in a way that is comfortable for them. She will submit the study protocol, including all instruments, procedures, informed consent documents, recruitment materials, and instructions to the University of Massachusetts Boston Institutional Review Board for Humans Subject Review. She will begin to recruit participants when she receives protocol approval.

This PAR study involves photographs, dictation or narration and participants with intellectual disabilities who, in some but not all cases are not their own guardian. In addition, the study involves a presentation of the participants’ perceptions and feedback. Therefore, multiple consent and assent forms are necessary to ensure that both participants and guardians consent to the study, that participants and guardians consent to participants being observed during the PAR sessions, that participants and guardians consent to participants being recorded during meetings and as a modification to writing narrative if necessary, and that the subjects of any photographs consent to photographs being used for the study (See Figure 2: Consent forms for study).

Figure 2: Consent and assent forms for study

<table>
<thead>
<tr>
<th>Forms</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Student recruitment flyer</td>
<td>Invite students to hear more about PAR</td>
</tr>
<tr>
<td>Student form to participate in project</td>
<td>Form with images seeking student assent/consent to participate in study.</td>
</tr>
<tr>
<td>Student form to allow researcher to</td>
<td>Participant form with images seeking student</td>
</tr>
</tbody>
</table>
Each student or guardian will be asked to complete an informed consent form after they have received a full explanation of the study, their rights, and ability to withdraw from the study at any time (See Appendix E: Sample forms). Students with guardians will also be asked to give their assent to participation in the process. Guardians will receive a full explanation of the study, their rights and the rights of students, and ability to withdraw participation at any time. The researcher will provide the name and number of the researcher to the participants or their parents or guardians and explain that they may call at any time for further clarification of the study. All participants will receive their own copy of the informed consent form with all the necessary signatures.

**Assent forms** For students who are not their own legal guardian, the researcher will seek assent from the students to participate in the study after receiving consent from the student's parent or guardian. If the parent does not give consent, the researcher will offer to meet with them again to re-consider participation during the next semester, given IRB approval to continue.

**VIII Confidentiality:** The researcher will inform participants that safeguards will be established to keep data (photographs, audio files, narratives, etc) confidential unless they explicitly give
consent to share their work. All photographs, audio files and recorded narratives will be coded so that speakers and responses are identified only by codes. Only the researcher will have access to the code list and the data collected unless the student gives explicit consent to share photographs and narratives. She will keep all files, transcriptions, journals and code lists in a locked file cabinet and will destroy these materials after the project is completed. Digital images and electronic data filed on the computer will be kept on flash drive and stored in the locked cabinet. Participants will be informed that none of the photographs, audio files or narratives from the project will in any way affect or be connected to their grades, relationship with their teachers or with the college community. Each student will keep a copy of their pictures, files and notes in a binder or flash drive (their choice) and the researcher, with assistance from either teachers, college staff or family members, will assist them to identify a place where they will be secure when they are not using them.

IX Consent Documents and Interviews/Measures

See Appendices

References
You have been asked to be part of a participatory action research study called “Think, Hear, See, Believe College”. The study is designed so that you and other students who are enrolled in the Inclusive Concurrent Enrollment project have an opportunity to document and discuss your college experience. Anyone who agrees to take part in a research study has special rights. **You have the right to be told:**

<table>
<thead>
<tr>
<th>1. What the study is trying to find out.</th>
</tr>
</thead>
<tbody>
<tr>
<td>In this study, we will look at questions like these:</td>
</tr>
<tr>
<td>• What you think about college?</td>
</tr>
<tr>
<td>• What is going well and what has been hard?</td>
</tr>
<tr>
<td>• Do you have suggestions to make it easier?</td>
</tr>
<tr>
<td>• What should younger students know about college?</td>
</tr>
<tr>
<td>• How do you think college will help you?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. What will happen in the study? What will you be asked to do?</th>
</tr>
</thead>
<tbody>
<tr>
<td>In this study, you will be asked to participate in one or more activities listed below:</td>
</tr>
<tr>
<td>• Talk about college</td>
</tr>
<tr>
<td>• Use a camera</td>
</tr>
<tr>
<td>• Record a podcast</td>
</tr>
<tr>
<td>• Create a digital story</td>
</tr>
<tr>
<td>• Make recommendations</td>
</tr>
<tr>
<td>• Present your work</td>
</tr>
<tr>
<td>• Talk to other students</td>
</tr>
<tr>
<td>• Meet with co-researchers</td>
</tr>
<tr>
<td>• Learn about research</td>
</tr>
<tr>
<td>• Help develop website</td>
</tr>
</tbody>
</table>
3. **What exactly you will be asked to do and for how long.**

   In this study you will be asked to
   - Meet with Maria 1-2 times a month for one hour at your convenience
   - Participate in the study for the entire school year
   - Use a digital tool to document your college experience
   - Share your work with other participants
   - Learn to draw conclusions from all the participants’ work (up to 10 people)
   - Make recommendations
   - Use the work to create student website

   Then you decide YES OR NO if you want to participate.

4. **If you might be taking a risk and what that risk could be?**

   In this study, the risks might include:
   - Other people learning you have a disability
   - Getting upset or feeling embarrassed when you talk about college
   - Losing privacy when other people know your name or see your work

   Every opportunity will be taken to ask you if you want to withdraw from the study or to direct Maria to discard your work

   Then you decide YES OR NO if you want to participate.

5. **What good things could happen to you? Will your life be better?**

   In this study, benefits include:
   - Helping other people learn from your experiences
   - Learning and using new digital technology
<table>
<thead>
<tr>
<th>Learning to do research</th>
<th>Help others find out what works best for people with disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helping to create a website about going to college</td>
<td>Presenting your work to advisory groups and conferences if you choose</td>
</tr>
</tbody>
</table>

Then you decide YES OR NO if you want to participate.

<table>
<thead>
<tr>
<th>6. What other choices you could try instead? How those choices might be better or worse than being in the study.</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the case of this study:</td>
</tr>
<tr>
<td>Decline and not risk being in the study</td>
</tr>
<tr>
<td>Try another method that has been used instead like a survey</td>
</tr>
<tr>
<td>Wait and be in another study later</td>
</tr>
</tbody>
</table>

No matter what you decide, it will not affect your participation in the Inclusive Concurrent Enrollment project in ANY way.

Then you decide YES OR NO if you want to participate.

<table>
<thead>
<tr>
<th>7. You can ask any questions about the study. You can ask questions before you start and at any time during the study.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Examples of some questions other people have asked:</td>
</tr>
<tr>
<td>How long will this take?</td>
</tr>
<tr>
<td>Can I stop, if I change my mind?</td>
</tr>
<tr>
<td>Do I have to do this?</td>
</tr>
<tr>
<td>Why are you doing this study?</td>
</tr>
<tr>
<td>What else might work?</td>
</tr>
<tr>
<td>How can I find out the results?</td>
</tr>
<tr>
<td>How will you keep my information private?</td>
</tr>
<tr>
<td>Who can I contact with questions?</td>
</tr>
<tr>
<td>Will I be paid?</td>
</tr>
</tbody>
</table>
Then you decide YES OR NO if you want to participate.

8. Who do I talk to if I have questions?

Maria will answer any of your questions when she meets with you or though phone calls or emails.

You can reach contact her these ways:

Maria Paiewonsky  
Institute for Community Inclusion  
UMass Boston  

**Work phone:** 617-287-7697  
**Cell phone:** 617-233-8743  
**Email:** maria.paiwonsky@umb.edu

Then you decide YES OR NO if you want to participate.

11. What if I want to talk to someone else about this study:

If you have any questions or concerns about your rights as a research participant, please contact the University of Massachusetts Boston Institutional Review Board, who make sure research is done correctly and appropriately by anyone who works at the university. They may be reached at IRB, Quinn Administration Building 2-080, University of Massachusetts Boston, 100 Morrissey Blvd., Boston, MA 02125-3393. You can also call them at (617) 287-5374 or email them at human.subjects@umb.edu

Then you decide YES OR NO if you want to participate.

9. You can say NO. You can refuse to participate at all. You can say “no” right away or after the study has started. If you say no, you must still be offered all the services available to anyone else.
Examples: Ways that other people have said no.

- I don’t want to keep going.
- I guess not.
- I would rather not.
- I don’t think so.
- This won’t work for me.

You have a right to decide YES OR NO.

To make sure you have a plan in case you want to stop participating, I will record the name and contact information of the person you would like to tell if you decide you don’t want to participate in this project anymore. We will tell that person that you would like to trust that person to let me know you are going to stop. I will give both of you one of my business cards with my contact information.

Name: ___________________________________

Best way to contact them: ___ At transition activities
___ By phone
___ By email

Contact information:

If you decide to take part in the study you have other rights. Telling someone yes is not enough. Researchers must get your written consent to show that they have helped you exercise your rights. After you say yes, you have a right to:

11. Get a signed and dated copy of all consent forms.

Examples:

- Ask for a copy of any forms you sign.
- If a form is not provided, ask if you will get a copy in the mail.

You have a right to get copies of the forms.
12. To be told if your name, address or comments will be shared with someone who is not involved in the study.

Examples: People who should not see your data without your consent include:

- Someone from a newspaper or TV station
- People who happen to live in your community
- People who read about the study later in a book or article
- People who go to school with you or work with you
- People at another school or university who are not involved in the study

You have a right to privacy.

How we keep information private:

- All your photos, stories and interviews are private unless you agree to share them with the other participants.
- All the documents will be kept in a secure file online that is password protected by everyone except Maria Paiewonsky
- Maria will review exactly which materials you would like to share with other participants and which ones you would like to publicly share with others and will have you review separate consent forms for those decisions

13. Take your time to think things over and decide if you want to participate. Don’t be pressured by other people to say yes.

Examples: Some things that people do to take their time.

- Read everything over twice
- Take materials home and think about it
- Ask a friend or family member you trust to help you think it over
- Wait a few days before saying yes or no
- Make a list of questions before deciding

You have a right to make decisions without pressure.
Examples: Things people say to pressure others into saying yes. People who are doing a good job will not say these things.

- There’s not much time. I need you to decide right away.
- If you want a gift or prize you’d better say yes.
- Everyone else has said yes. You should too.
- If you say no, it will be awkward.

Don’t let others talk you into doing something. Decide yourself.

I have reviewed this form. I understand my right to be informed and make decisions as part of a research project.

________________________________________  __________
Signature of participant                    Date

________________________________________  __________
Signature of researcher                      Date
Audiotaping, observations, interview and meeting consent form for
Think, Hear, See, Believe College: Students using Participatory Action Research to
evaluate their postsecondary education experience.

Student Form

University of Massachusetts Boston
Institute for Community Inclusion
100 Morrissey Boulevard
Boston, MA 02125-3393

Directions: The Participatory Action Research (PAR) facilitator will read this form to you and
you may sign it if you agree to everything in the form. However, you may also read it through
with someone you trust to make sure you understand everything. Please return it to your teacher
as soon as possible.

You understand that this study involves audio taping observations, PAR sessions, interviews and
a final meeting at the end of the project. Neither your name nor any other identifying information
will be associated with either audiotapes or transcripts. Only the researcher, Maria Paiewonsky,
will be able to listen to the tapes.

You understand that the recording will be transcribed by the researcher and erased once the
transcriptions are checked for accuracy. Transcripts of your interview may be reproduced in
whole or in part for use in presentations or written products that result from this study. Neither
your name nor any other identifying information (such as your voice or picture) will be used in
presentations or in written products without explicit written consent.

You further understand that immediately following the interview you will be given the
opportunity to have the tape erased if you wish to withdraw your consent to participate in the
study.
By signing this form you are consenting to:

<table>
<thead>
<tr>
<th>Having your interview recorded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allowing some sessions to be audio recorded</td>
</tr>
<tr>
<td>The facilitator taking notes;</td>
</tr>
<tr>
<td>Participating in a final meeting</td>
</tr>
<tr>
<td>Having the transcripts transcribed</td>
</tr>
<tr>
<td>Allowing results of the process to be written up for a study</td>
</tr>
</tbody>
</table>
By checking the box in front of each item, you are consenting to participate in that procedure. You understand that you may withdraw your consent at any time, for any reason.

The above permissions are in effect until the following date: December 20XX.

Student researcher: __________________________________________________________

Research facilitator: _________________________________________________________

Date: _____________________________________________________________________