“WE ARE RESEARCHERS”: STUDENTS WITH AND WITHOUT INTELLECTUAL DISABILITIES RESEARCH THE UNIVERSITY EXPERIENCE IN A PARTICIPATORY ACTION RESEARCH COURSE

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ABSTRACT
This article describes an undergraduate Participatory Action Research (PAR) course in which students with and without intellectual disabilities collaborated as co-researchers in order to explore various aspects of the university experience. The article describes the university course as well as presents results of the students’ PAR projects. The students’ PAR projects revealed that (a) eating healthy at the university was challenging, expensive, and at times, impossible; (b) although University of Vermont (UVM) is thought by many to be a haven for social justice, misunderstanding of and discrimination against students who identify as transgendered occur on the campus; and (c) students’ home cultures often clash with the mainstream university student culture. Students and PAR course instructors reflect on their experiences.

KEYWORDS: Participatory Action Research, Students with Intellectual Disabilities, Self-determination, Inclusion

1 Preparation of this article was partially supported by a grant from the US Department of Health and Human Services, Administration on Intellectual and Developmental Disabilities awarded to the Center on Disability and Community Inclusion at the University of Vermont. The opinions expressed herein do not necessarily reflect those of the funding agencies and no official endorsement should be inferred.
PAR: PRINCIPLES, DEFINITIONS, AND CHARACTERISTICS

Across academic fields, people with intellectual disabilities are often targeted as the subjects of studies, but are seldom involved as researchers themselves. This article illustrates how students with and without intellectual disabilities engaged in Participatory Action Research (PAR) as part of a course investigating the university experience. Students picked their own PAR projects and the topics covered various aspects of the university experience, including issues of nutrition, diversity, and culture. This article reports on their research projects and emphasizes how their PAR research efforts affected them, their fellow students, and the course instructors.

Participatory Action Research has the potential to include populations who are often underrepresented in communities and more often than not, are disenfranchised. Reason and Bradbury (2001) defined PAR as follows:

[PAR is] a participatory, democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes. It seeks to bring together action and research, theory and practice, in participation with others and pursuit of practical solutions to issues of pressing concerns to people, and more generally the flourishing of individual persons and their communities. (p. 1)

Israel, Schultz, Parker, and Becker (1998) noted that PAR is: (a) participatory, (b) collaborative, (c) a process through which participants can increase control over their own lives, and (d) a way to balance research and action. Gibson (1991) and Minkler (2000) implied that action research is closely connected to empowerment.

A number of parallels exist between PAR and values and concepts of self-determination and inclusion consistent with disability groups. First, both PAR and the values of disability studies reflect “from the ground up” practices growing out of the experiences, perceptions, and beliefs of a disenfranchised group. Second, both PAR and policies of many disability advocacy groups rely upon democratic participatory processes and social learning. Third, they both emphasize the strengths of people and community, including capacity for problem solving. Finally, they are both committed to community priorities rather than top-down or external priorities (Green, George, Frankish, Herbert, Bowie, & O'Neill, 1995).

CONTEXT FOR AN INCLUSIVE PAR UNDERGRADUATE RESEARCH COURSE

In 2011, the Center on Disability and Community Inclusion at the University of Vermont was awarded a 5-year grant from the United States Department of Education, Office of Postsecondary Education, funded under the competition of the Transition Program for Students with Intellectual Disabilities (TPSID). One ongoing goal of the TPSID program is to support the academic inclusion of students with intellectual disabilities at the University of Vermont. Students in the TPSID program are nonmatriculated students between the ages of 19 and 30 who have an intellectual disability. One specific activity of the grant was to develop and teach an undergraduate course on PAR that would be delivered to TPSID students as well as to undergraduates without an intellectual disability. The purpose of the
course was to model academic inclusion and to provide students with intellectual disabilities the opportunity to partner in the research process as opposed to being the subjects or recipients of research.

The course was developed and approved as a pilot class, and the University’s Institutional Review Board (IRB) gave approval for students to conduct research as one of its components. This PAR course was taught during the 14-week semester from January to May 2013. Our expectation was that this pilot class would have a small enrollment; ultimately 10 students enrolled in the course. Three nonmatriculated students were from our TPSID program, and seven students were matriculated UVM undergraduates. Table 1 provides student characteristics. One UVM professor and a professor emeritus taught the course together. Both instructors had experience doing PAR research.

In order to create the course syllabus, lectures, assignments, and readings, the instructors conducted an Internet search using the key words: action research, participatory action research, and university course syllabus. Eight course syllabi, several websites, and other university materials were located as a result of this research. The co-instructors reviewed each syllabus in terms of course content, student assignments, and course process. The course materials and syllabi reviewed did not include any indication that the course was designed to support the inclusion of students with intellectual disabilities. However, each syllabus proved to be a useful resource in designing this particular inclusive PAR class.

We also met with two internationally recognized expert researchers in participatory action research (D. Greenwald, personal communication, November 26, 2012; E.T. Stringer, personal communication, November 26, 2012). As a result of these conversations we gained valuable information for developing the course. Catalogued as EDSP 274, Participatory Action Research was offered through the Continuing Education Department at University of Vermont and secured approval from the College of Education and Social Service. Table 2 provides a list of course topics.

The instructors, who are two of the authors of this article, decided to focus course research projects on the university or college experience since it was a topic or experience common to all the students enrolled in the course. The course was designed so that students would select an aspect of the university experience they wanted to research and then decide on their participants. The instructors acknowledge that the purest form of PAR would have positioned students within various programs on campus and engaged other groups of the University of Vermont students as active participants in the project. However, since a semester lasts only 14 weeks, and our emphasis was on teaching research methods to the group, it was not possible to reach this ideal. Still, students were able to act as “inside” researchers and identify their own particular areas for research. How students chose their focus within the broad topic of “university experience” follows.

The course was offered face to face and synchronously, meeting one night a week from 4 p.m. to 7 p.m. Each class met for 180 minutes, during which the course instructors presented materials via lectures, PowerPoints, and guest speakers, and facilitated small-
group activities or presentations. Each class session also provided time for the research dyads/triads to meet and develop materials, gather or analyze data, or present emerging research findings. During the meeting times of the research groups, the course instructors rotated through the classroom, providing feedback and support.

The first class was designed to generate student involvement in the selection of a more specific research focus. The instructors’ goal was to have students identify what aspect they would like to research within the broader topic of the university experience. In order to complete this goal, the instructors constructed an activity designed to solicit the students’ interests. Each student received three yellow sticky notepads. On each sticky, the student was asked to put a word or a phrase that captured an area he/she would like to research related to the university experience. The yellow sticky notes were then placed on the classroom whiteboard and then collectively grouped and collapsed the content on the sticky notes until there were five potential research topics: (a) nutrition; (b) health and wellness; (c) culture and diversity; (d) finances; and (e) dormitory/residential culture versus home culture. Each student put a star next to the group he/she wanted to research, which led to the formation of student research dyads or triads. Three of the four groups included a student with intellectual disabilities and one or two matriculated students. One group included two matriculated students and one nonmatriculated student. The three groups with students with intellectual disabilities chose to focus on the topics of (a) Health: How healthy is the food at University of Vermont; (b) Culture and diversity: How accepting is the UVM and (c) Culture: How does a student’s home culture differ from the university culture? Their projects and results are described in this article.

Course materials were available to students asynchronously online through the instructional web platform Blackboard. Blackboard instructional content included PowerPoint presentations, an internal discussion board, and Wiki. Course requirements included weekly journals that related to the content as well as their own evolving research projects. Entries included reflections on research questions, methods, engagement with participants, research settings, project data collection and data analysis, and students’ roles as emerging researchers.

Required participation on the discussion board focused on the weekly course materials and involved discussions about how the students were applying course materials in their data collection and analysis. These discussion board posts allowed students not only to respond to instructor questions, but also to engage with other students online. Students used the Blackboard Wiki to share research materials, including surveys or interview questions and forms, documents obtained through research, and research reflections including emerging data analysis and themes. These online exchanges also provided a source of data for the co-instructors to see how groups were working together, and observe the role of each member and some of their reflections and reactions to the research process. Finally, each of the co-instructors met with each group individually to monitor their efforts. In addition, co-instructors kept notes and reflective logs of their own discussions, which provided a final source of data for this article. Course instructors also took videotapes of student dyad
research meetings as well as student final presentations. All sources of data were used in data analysis.

**Designing, Conducting, Collecting and Analysing the Data**

The student researchers who also coauthored this article identify their research questions in this section. The students describe the methods they used to collect their data, and report results and reflections. Each student used at least two methods to gather data, usually surveys or interviews and gathering and analysis of relevant documents. All students led the data analysis of their own projects and project reports. The student authors were involved in both the data collection and analysis.

Because the course was only 14 weeks, we chose to introduce the students to data collection and analysis at the descriptive level not the interpretive level. For example, the data students collected via surveys were analyzed using descriptive statistics including frequencies and percentages based upon responses to survey items. Interpretive statistics, such as correlations or causations, were not used because the students were not taught those procedures and the data was not sufficient to conduct anything other than descriptive statistics.

Students who conducted more indepth interviews each transcribed and hand-coded their data individually. The transcribed interviews were coded by choosing a word/phrase that represented the content of the interviewee’s response (Bogdan & Biklen, 2007). For example, one interview respondent commented that “offensive conduct can be experienced anywhere on campus, and unfortunately it is.” This was coded as “offended on campus.” A survey comment, “LGBTQ respondents experience a disproportionate amount of unwanted sexual touching” was coded as “sexual touching/assault.”

In student small research groups the group members reviewed each other’s interviews and codes and provided input into the coding. Reliability between the student coders was achieved by calculating the number of agreements and dividing that by the number of agreements plus disagreements to calculate the interrater reliability score. Study groups achieved 90% interrater reliability.

During the data collection and analysis phases of the research students discussed the emerging themes revealed in their data during in class group discussions, small groups and during online discussions. During those discussions students also reflected on their roles as student researchers of the university experience.

**The University Experience:**

**Student Researchers’ Experiences, Findings and Reflections**

This section describes the results of three student research groups who conducted their research during the PAR course. Because each student chose his or her own topic and identified the various data collection methods, there was a high level of student engagement. For example, Alex was very excited about conducting interviews whereas Taylor felt more comfortable handing out surveys. Two students with intellectual
disabilities different research methods that matched their individual abilities and interests. One student self-identified as transgender during the course and was very excited about working on that particular topic during the course. Another student shared that she was “a little shy about asking people questions so I decided to pass out surveys instead.” Regardless of the data collection method chosen, students were diligent about following the IRB and data collection protocols. Each student worked on his/her consent forms, and had them reviewed by both the course instructors and the IRB offices. It was interesting to see that at least one student with an intellectual disability grew very serious about obtaining informed consent. She shared: “I made sure that each person read the consent form and I asked them if they had any questions. I know how important that is because one time someone did research on me and I never signed any consent form. That was wrong.”

The course instructors reflected on the fact that the students with intellectual disabilities seemed, to them, to be more focused on the “rules” of conducting research than the students without disabilities. At times the focus seemed to be almost obsessive to the instructors. For example, one student in the class started to give initials to her mentors as opposed to saying their names even though the mentors were not a part of the research project. The instructors speculated that the overgeneralization of the research rules by students with intellectual disabilities may have occurred because characteristics of students on the autism spectrum disorders include perseveration, overgeneralization of rules, and obsessiveness. Or perhaps the rules were not clear enough to these student researchers.

Students without disabilities voiced their experiences of partnering with the students with intellectual disabilities. One matriculated student shared that “experiences of discrimination by her research partner with intellectual disabilities allowed her to see firsthand what it was like to be a member of an underrepresented group and hence she more fully understood the protection of human subjects and need for confidentiality.”

Matriculated and nonmatriculated students shared equally in the data collection and analysis. For example, Beth, Taylor, and Alex each engaged in data collection. Beth conducted interviews, Alex gathered documents, and Taylor passed out surveys. They then met to summarize the data and analyze them together. Each student then individually prepared a final project. For example, Taylor prepared an iMovie that depicted the results of the data collection, the data analysis, and a summary of the three major themes. Beth and Alex each prepared a 10-page research paper. All three students presented their final project in class as a research team.

The aspects of the university experience that were researched by the students who co-authored this manuscript are as follows: (a) nutrition and healthy eating on campus; (b) diversity; and (c) home culture versus university culture. Details related to the three research topics are discussed in the following section. The data presented represent the research teams’ research questions, data collection methods, and findings.
Nutrition and healthy eating on campus. Eating healthy at the university was challenging, expensive, and at times impossible. Beth, Taylor, and Alex chose to research nutrition and health on the university campus focusing on the following research questions: “Do the food services and systems at UVM meet everyone’s needs?” and “Do the prices at the markets on campus influence nutrition choices?” The methods they used to collect the data included interviews and document analysis. They conducted 10 interviews with male and female UVM students during the spring 2013 semester, who were recruited/selected at the university student center. Documents they gathered included university newspapers and materials disseminated by the UVM website, Wellness Center, and food services. Beth, Alex, and Taylor analyzed the data (Bogdan & Biklen, 2007) by searching for key words and themes across both their interviews and documents, developing codes such as: “unhealthy food, healthy food, no money to buy healthy food, and too expensive”.

Beth, one of the student researchers, identified three major themes from the interviews, documents, and observations she gathered:

- **The prices at the food markets are high.** She shared, “This was obvious with 70% confirmation from the surveys and written descriptions in the margins of participants that said ‘prices too high’ and ‘overpriced.’”
- **The prices do influence healthy decisions.** Some respondents wrote “definitely” in the margins of the surveys.
- **Fruit and vegetables are overpriced.** This theme was illustrated by Beth’s sharing one student’s comment in the margins of the survey “Fruit’s expensive, I never get fruit,” and another student saying, “Salads eat up all my points [on my meal card].”

Taylor explained that she “learned more about healthy living as a result of doing this research.” One student researcher in this group shared that the findings were powerful for her as revealed by her reflections on her own reason for choosing this topic:

> I have spent many finals weeks (which is inconvenient when points usually run out) living off a Domino’s pizza I ordered for the week or having a generous friend pay for me with extra points they have, which creates an uncomfortable dynamic. This reality does not seem like a fair trade for paying expensive tuition and meal plans, and trying to better ourselves physically and educationally.

Alex’s interviews and surveys also revealed a campus focus on body image. Her research question was, “Is there enough awareness and help available to students affected by eating disorders?” She conducted 25 surveys and completed 5 interviews with UVM faculty and staff, and also reviewed documents from the student newspaper as well as an Internet search. Alex discovered in a national report that 80.9% of females and 74.7% of males have dieted and/or skipped meals. Also, 19.6% of the national survey participants admitted to having an eating disorder at one point in their lives (Center for Community College Student Engagement, 2009). Alex shared that one of the health and wellness officials she interviewed at UVM indicated that UVM:
provides amazing support for these students both in services they can access on campus, but also in the way we connect with local community providers who we closely collaborate with to create larger teams of support for students. The high quality of our direct service on campus and network of focused case management and coordination of care we provide are above and beyond what most universities provide for eating disorders.

Alex believes students share this viewpoint. One of the students she interviewed stated, “People at UVM are far more laid back and less judgmental about body image than in New York City [where I’m from].” Reflecting on the data she collected, Alex summarized:

From the information found so far, although eating disorders seem almost inevitable given the age group and media vulnerability of college campuses, UVM is actually quite helpful and aware of this issue. The number of organizations that either work at spreading awareness (usually student-run), or that work as help services (that are faculty-run), indicate that both parts of the community are a part of a healthy support system.

**Culture and diversity.** Although the UVM campus is seen as a haven for social justice, misunderstanding of and discrimination against students who are “different” (including transgender students) occur on the campus. Luke and BJ chose to research the history, politics, and opinions of transgender people on campus. Their research question was “How do the UVM policies towards the transgender community compare to the student population’s opinion of the transgender community?” The methods these two students used to collect data were surveys and documents. Over the course of their research they interviewed 20 participants, including male and female students. They also administered 10 surveys to both male and female students. Three themes emerged from the surveys and documents reviewed:

- **We’re comfortable.** The surveys indicated that by and large, the UVM student population was comfortable with the transgender community even if they did not know anyone who was part of that community.

- **UVM has improved.** Luke and BJ analyzed documents for their research study. Historic documents, some as recent as 2002, provide evidence of the harsh abuse previously experienced by the transgender community. Some documents revealed that “a student who lived on campus was targeted by repeated threats by phone, notes slid under the door to his room, within his suite, and even a note taped to the wall next to his window,” all because the student was a member of the Lesbian, Gay, Bi, Transgender, and Queer (LGBTQ) community. Luke and BJ discovered through analyzing the surveys and the documents that “recent policies about the transgender community have made today’s UVM one of the most accepting schools for people who are transgender.”

- **Experiences of transgender students.** BJ and Luke did not receive permission from the IRB to directly interview students who identified as transgender. However, respondents to the survey who had friends who are transgender painted a picture that was not entirely positive. These respondents indicated that the transgender
community still experiences problems and issues of prejudice even if things have improved somewhat, concluding that there is still work to do.

Luke summarized the biggest takeaways from conducting this research as “PAR is heavily focused on the community and you really want to get to know the community before you conduct any research.” BJ shared that he was “surprised to see that the female UVM students were much more accepting than the male students of transgender issues.”

**Home culture versus university culture.** Students’ home cultures often clash with the mainstream university student culture. Cora’s research question was, “Does a UVM student’s home culture have an effect on their overall college experience?” Cora and her research partner focused their efforts on interviewing 10 students, including both male and female. They then transcribed and coded the interviews. Some of the codes included: *Groovy UVM, the Green initiative, my home culture fits with the UVM home culture, my home culture does not fit with UVM, positive college experience, and negative college experience.* This student research group summarized three themes as a result of their interviews:

- UVM claims to be an open and accepting culture, but a disconnect exists between this claim and the experiences of some UVM students. For example, one student who was interviewed shared: “I have felt isolated and picked on in some situations here because I am a strong Christian and that goes against some of other students’ values.”
- UVM is passionate about promoting cultural diversity, but does not have as much diversity as it wants.
- Students whose home cultural values lined up with what they perceived as UVM culture and values had a much more positive experience overall than students whose home cultures did not align. An example of lack of alignment concerned a student who was raised in a military conservative culture, which was in conflict, the student felt, with the overall liberal culture of [the university]. Cora and her co-researcher reflected: “it is important to keep in mind the profound effect that home culture has on the college experience, which is particularly true of the first-year experience.”

**Taking Action and Reflections on the Project**

Students shared the results of their research in several ways. Taylor, one of the non-matriculated students, presented her nutrition project at the 2013 College of Education and Social Services Research Symposium. Other faculty and undergraduate student researchers were present to ask questions and to share feedback with her. Luke and BJ presented their project to a subgroup of the LGBTQ group on campus. Finally, Cora shared results of her culture project with other resident advisors at UVM in an effort to further their understanding of how home culture impacts a student’s experiences within the UVM culture. The students largely initiated these efforts at dissemination of their research results.

There is at least one significant limitation to this project. Because this PAR course was a pilot, individual connections between students and insider groups within UVM were not
made. If students had been placed into particular subgroups within the UVM and if those subgroups had been integral parts of the study from the onset, this would have resulted in a more authentic PAR project. The fact that the students designed, implemented, and carried out the project without specific involvement from other UVM entities made it more difficult for meaningful action to result from any of the PAR projects.

**Authors’ Reflections**

The content of the university PAR course, and the research that was engaged in, had a transformational experience on the students. One author with an intellectual disability shared: “I never imagined that I could take a university course and be a researcher, I was so proud of myself. I learned a lot. We are all researchers!” Another author, a matriculated student enrolled in the elementary education program, shared that he “worked as an equal partner” alongside his peer who had an intellectual disability and gained insights into how discrimination of the disenfranchised still exists on campus.

Two authors for this article were also co-instructors of the PAR course. As co-instructors, they found it incredibly powerful to support students’ self-determination and inclusion throughout the course:

> There are research courses on this campus but none where students with intellectual disabilities are members. There are also few courses where undergraduate students learn the theory of research while simultaneously conducting their own research. This PAR course pushed the boundaries of undergraduate research and revealed to the co-instructors that though there were moments of confusion and messiness, there was also a growing sense of self-confidence and self-determination in all the students, particularly the students with intellectual disabilities. As instructors, “we sometimes led, sometimes guided, and sometimes stayed out of the way, as students pursued their roles as researchers”.

Brydon-Miller, Greenwood, and Maguire (2001) posited in the introduction to the *Journal of Action Research* that there is work to be done to articulate inclusive theoretical foundations that reflect indigenous knowledge systems. The co-instructors believe that our experience teaching PAR to students with and without intellectual disabilities is an example of inclusion, self-advocacy, and self-determination.

**CONCLUSION**

There is much untapped potential for a greater involvement of undergraduate researchers, including researchers who have an intellectual disability in improving higher education through participatory action research. PAR offers a promising approach for realizing this potential. For example, universities could open their doors to students with intellectual disabilities. The inclusion of students with intellectual disabilities in the PAR course proved to enhance the overall learning of all students. Undergraduate students, once introduced to PAR, could use action research within student organizations to improve the overall university experience for all students.
REFERENCES


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Appendix 1: Demographic Characteristics of Students

<table>
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<th>Student</th>
<th>Student status</th>
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### Appendix 2: Course Weekly Topics

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<tr>
<td>Week 1</td>
<td>Introduction and Course Expectation &amp; Introduction to PAR</td>
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<tr>
<td>Week 2</td>
<td>Community Engagement and PAR</td>
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<tr>
<td>Week 3</td>
<td>Identifying Research Questions and the PAR Process</td>
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<td>Week 4</td>
<td>Ethics and Vulnerable Populations</td>
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<td>Week 5</td>
<td>Informed Consent and the Institutional Review Board Process</td>
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<td>Week 6</td>
<td>Students Work on the IRB Proposals</td>
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<td>Week 7</td>
<td>Making Research Accessible</td>
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<td>Week 8</td>
<td>Data Collection</td>
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<td>Week 9</td>
<td>Power Balance in Research: Maximizing power and participation among the disenfranchised</td>
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<td>Week 10</td>
<td>Establishing and Maintaining Rapport</td>
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<td>Analyzing Data</td>
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<td>Week 11</td>
<td>Conducting Research Across Cultures</td>
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<td>Week 12</td>
<td>How PAR Principles Can Modify Research (Action Research)</td>
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<td>Week 13</td>
<td>Moving Into Action: Using Research to Make a Change: Research to Advocacy</td>
</tr>
<tr>
<td>Week 14</td>
<td>Student Projects &amp; Discussions</td>
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### Appendix 3: Student Researchers’ Topics

<table>
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<tr>
<th>Student Researchers</th>
<th>Research Topic</th>
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<tr>
<td>BJ &amp; LL</td>
<td>Culture and Diversity: How Accepting is UVM?</td>
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<td>TT, BS, AK</td>
<td>Health: How Healthy Is the Food at UVM?</td>
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<td>CS &amp; WS</td>
<td>Home Culture Versus the UVM Culture</td>
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<tr>
<td>TD &amp; BS</td>
<td>Disability: What Are Students’ Experiences</td>
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**Biographical note:**

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Alex M. Karambelas, Luke Lampugnale, Bernard J. Parrott, Cora E. Sagar and Taylor V. Terry were all UVM students and enrolled in the UVM PAR course. They have all since graduated from UVM and are working in various jobs in the area.

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