# Final Report - 2017 Equity Enhancement Fund

A final report (3 pages max) must be submitted when you have concluded your project. **Note: The final 25% of the fund is provided on completion of the final report.** Reports must be received by the Equity & Inclusion Office no later than **March 31, 2018.** Send final reports to <u>exec.assist@equity.ubc.ca</u>.

Project Name:	"It's unlike anything I ever imagined": visualizing the lived experience of disability
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Date:	April 28, 2018
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## Summary of work accomplished

### **Objectives and Summary:**

List and describe activities that were part of original application AND those which emerged during the project. List the project objectives and how they were accomplished. If some objectives were not achieved explain why.

The objective of this project was to develop, evaluate and disseminate learning modules (videovignettes and supplemental materials) to support more students in the health professions at UBC to learn from the lived experience of people with a range of disabilities. The focus was on three common problems that people with disabilities in the Health Mentors program discuss with their students: *stereotypes, barriers to access*, and *communication*.

- 1. Six student and community focus groups held in the summer of 2017 identified topics and first products for new learning from patients. Students from a range of health professional programs identified that disabilities, particularly non-physical disabilities, receive little attention in their programs and that they would like to learn more about the *experience* of disability.
- 2. We identified students, faculty, health mentors / patients and community partners with an interest and/or expertise with a range of disabilities. For example, we partnered with the Western Institute for the Deaf and Hard of Hearing to set-up a working group of people who are deaf or hard of hearing to help us develop and pilot a workshop and learning resources for students. This sub-project is being led by medical student Jennifer Ham as the focus of her MEDD 419 FLEX project.
- In December 2017 to January 2018 we surveyed health mentors (patients), representatives from community-based organizations, UBC instructors and students to identify the most important themes associated with the three topics (*stereotypes, barriers to access*, and *communication*).
  15 responded. Themes included common assumptions such as people with disabilities are incapable, limited, have questionable judgement, dependent on others, helpless, dangerous, demanding, and unwell. We found that the major barriers to accessing good health care are not physical but attitudinal. Many communication challenges are a consequence of stereotypes and there is no one-size-fits-all care/communication.



- 4. In January 2018 we organized a Disability Learning Resources planning session attended by 27 health mentors (patients), representatives from community-based organizations, UBC instructors and students. Participants identified ways students might learn about the topics including an online database of existing resources, a human library, video vignettes and workshops. The session resulted in a collection of patient stories for future resource development and a report that was shared with participants.
- 5. We compiled a database of 65+ resources on disability recommended by patients and community organizations. We held a workshop at which students from 5 different health disciplines rated the resources according to their usefulness, along with explanations for their scores.
- 6. We piloted the creation of a digital living library of experienced patient educators who are willing to meet with students and work with faculty to teach students. We started with two experienced patient educator volunteers in order to film two contrasting examples. We held a workshop for 10 additional volunteers to plan out their living library 'books' and expand the collection to include people with disabilities (e.g. cerebral palsy, aphasia).

#### **Project Evaluation:**

What were the major outcomes and impacts of the project? Did you face new challenges or discover new areas of concern to be addressed?

#### Outcomes:

- 1. A database of 65+ existing resources about disability recommended by Health Mentors and community organizations and rated by students.
- 2. Five pilot video vignettes for the human library including the use of assistive communication devices (e.g. a demonstration of a person with Aphasia using an iPad app to communicate).
- 3. A pilot interprofessional workshop for health care students led by people who are deaf or hard of hearing which will be added to the Patient & Community Voices workshop series.
- 4. A collection of illustrative stories about disability for additional resource development.
- 5. Renewed engagement and partnerships with disability organizations including: Richmond Society for Community Living, Multiple Sclerosis Society of Canada, Cerebral Palsy Association, Parkinson Society, Western Institute for the Deaf and Hard of Hearing).

#### Challenges:

Students' schedules are very busy and adding more learning activities into curricula are challenges. Students did not want more stand-alone modules that added to their workload. We are working with UBC Health to find ways to engage faculty to include and refer to resources in coursework.

#### Financial Summary:

List expenses, including those from other sources or in-kind contributions. Allocated funds must be utilized by March 31, 2018. Any unused funds must be returned to the Equity and Inclusion office. Please include information on any surplus or shortfalls.



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EEF: Total \$12,000 Project Coordinator: \$7,253 Winter Work Learn student: \$2,890 Honoraria for students and community members / patients: \$550 Travel: \$128 Forum/Working Group catering: \$1,186

**Other: Total \$10,270** Summer Work Learn: \$6,300 Winter Work Learn subsidy: \$2,400 Website: \$1,570

Project Partners: What partnerships were you able to build in undertaking this work?

Five community organizations were part of this project: Richmond Society for Community Living, Multiple Sclerosis Society, Cerebral Palsy Association, Parkinson Society, and Western Institute for the Deaf and Hard of Hearing.

Faculty from four health professional programs took part: Medicine, Nursing, Occupational Therapy and Physical Therapy.

Students from seven health professional programs participated: Medicine, Midwifery, Kinesiology, Occupational Therapy, Physical Therapy, Social Work, and Speech-Language Pathology.

Jennifer Ham, 1<sup>st</sup> year medical student, is working on this project as part of her MED 419 FLEX course requirements.

Sustainability How will this project be sustained beyond the initial funding period?

The importance of increased and coordinated opportunities for students to learn from the lived experience of patients has been recognized by the UBC Health Council who recently adopted a Patient Engagement Framework and recommendations. As part of these recommendations we are working with UBC Health to develop a website hub to be a one-stop shop for faculty and students to connect with patient educators and learning resources and to support faculty to use them as part of existing curricula.

Feedback: Provide us with feedback you might have on the Equity Enhancement Fund

Equity Enhancement Funds were instrumental in developing resources for students to learn about disability from people with lived experience. We discovered that the way disability is addressed in the curriculum is focused on *biomedical* aspects of disease and students are eager to learn about the *experience* of disability. This funding helped us begin to address important gaps in the curriculum.