

The International Undergraduate Journal For Service-Learning, Leadership, and Social Change

Volume 9 | Issue 2

Article 4

April 2020

Knitting Service-Learning and Professional Training: Advocating for Dental Care for People with Intellectual Disabilities

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Recommended Citation

Gandhi, Raj (2020) "Knitting Service-Learning and Professional Training: Advocating for Dental Care for People with Intellectual Disabilities," *The International Undergraduate Journal For Service-Learning, Leadership, and Social Change*: Vol. 9: Iss. 2, p. 13-21.

Available at: <https://opus.govst.edu/iujsl/vol9/iss2/4>

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Knitting Service-Learning and Professional Training: Advocating for Dental Care for People with Intellectual Disabilities

Abstract

Service-learning has provided me with the opportunity to regularly engage with adults with disabilities in my community throughout my college education. Service-learning allows students to learn by doing, serving, and reflecting on their work in the community (Witmer and Anderson, 1994, p. 6). Through my involvement in The Boltwood Project, the largest student-led, service-learning organization at my university, I have visited a group home each week since the Fall of 2016. Through this experience, I have discovered striking barriers to accessing adequate dental care among the disability community. This article reports on my Boltwood capstone project advocating for a bill in the Massachusetts Legislature that would dramatically improve the accessibility of dental care for adults with disabilities. In addition, I reflect on the value of service-learning and the strength of its impact on me as a student and future medical professional.

Introduction

It is finally 5:30 pm on a Monday evening – a time that I look forward to each week. I enter the building with a small group of my peers, knocking on each apartment door at the group home to greet the residents. Each of them joins us at our table and we start our usual game of UNO, while our small group of eight engages in different conversations. With a dentist appointment coming up, I vent with my favorite resident about how I hate going to the dentist and how I am dreading my upcoming appointment. The response I got changed my perspective drastically. Joe¹ is a happy, affectionate, 88-year-old man, who has lost nearly all of his teeth. He exclaimed, “I haven’t been to the dentist in over 10 years!” Assuming he was exaggerating, I laughed and waited for him to explain he was joking, as he does have quite the sense of humor. When I finally realized this wasn’t one of Joe’s pranks, I was appalled. He, along with many other people with intellectual disabilities, does not have access to dental care.

Overhearing our conversation, another resident shared that she had also not seen a dentist for a long time, because the last time she tried to see one was quite traumatic. She uses a wheelchair, and when she was trying to get in the van that would take her to the dentist, she fell out of her

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-13-

Journal for Service-Learning, Leadership, and Social Change Spring 2020

¹ A pseudonym to protect confidentiality.

wheelchair and injured herself. These revelations left me both shocked and disappointed. How could it be possible that the residents are not receiving the dental care they certainly need? The harsh reality is that it is estimated that over 100 million Americans do not have dental coverage. While dental care can be considered a challenge for many Americans to access, it is especially inaccessible to people with disabilities – specifically adults.

Even though I dread going to the dentist for an appointment, becoming a dentist has been a dream of mine. I am a pre-dental student in my senior year at the University of Massachusetts, Amherst. Next year I will be attending Boston University Henry M. Goldman School of Dental Medicine to pursue my goal of becoming a dentist. Since my first year of college I have participated in a student-run civic engagement and leadership program, The Boltwood Project, that engages college students to participate in enrichment, recreation, and socialization with adults and children with diverse intellectual or physical abilities. Since last year I have been the student leader (supervisor) for a group that visits an assisted living group home each week to spend time playing games and making crafts with the residents that live there.

The center my group and I visit is home to many different people of varying ages, backgrounds, and abilities. Throughout my time spent with these residents, I have built extremely strong relationships with them. We have engaged in hundreds of conversations over the last four years, during which they have shared their greatest joys, as well as their greatest burdens with me, for which I feel truly privileged and honored.

Background: The Inaccessibility of Dental Care

There are a number of reasons why dental care, and health care in general, is largely inaccessible to people with disabilities. I believe some potential causes are related to societal structures of economic inequality and ableism. But two more immediate barriers stood out to me after researching this dilemma. One reason is the debt accrued by dentists during their time in dental school and the other is the lack of training dentists receive in regard to treating patients with intellectual disability.

Dental schools are very expensive and continue to increase their tuition. Between 2004 and 2011, dental school tuition and fees increased by 68.6% for public schools and 38.9% for private schools (Formicola, 2017, p. 1008). When dentists graduate from dental school and begin practicing, they can have debt amounting to over \$300,000. The average reported debt for dental school graduates for the Class of 2019 was \$292,169. Students that attended public dental schools faced an average debt of \$261,305, while private school students faced an even larger

debt of \$321,184 (“Educational Debt,” n.d.). This debt is a financial burden that could influence dentists to choose to treat patients that will make them the most money in the shortest amount of time, sacrificing civic responsibility for income. A Michigan survey of dentists found that some dentists cited that lack of reimbursement was a reason that they did not treat patients with disabilities (Byrappagari, 2018, p. 281). A dentist in serious debt due to his or her education may wish to pursue patients who have the resources, i.e. private dental insurance, to be financially rewarding.

Another problem is that dentists do not feel comfortable treating people with disabilities due to insufficient training. The same survey of Michigan dentists found that over 73% of the dentists felt that dental school did not prepare them for treating people with disabilities. Nearly 80% of dentists in this survey agreed that more training should be part of the curriculum of schools to better prepare dentists for treating people with disabilities (Byrappagari, 2018, p. 284). Dental schools are not preparing their future dentists to treat people with disabilities, neglecting a vulnerable and under-served segment of the U.S. population.

A Potential Solution: A Proposed Bill in the Massachusetts Legislature

The state of Massachusetts is poised to join several other states in addressing the issue that I only recently discovered of inaccessible dental care. I learned through my service-learning class, *Boltwood Capstone: (dis)Ability, Ableism, and Social Justice* that there is a proposed bill in the Massachusetts Legislature that could help people with disabilities and other neglected populations get the dental care they need. The House bill, H. 1916 *An Act to Improve Oral Health for all Massachusetts Residents*, along with the Senate bill with the same name, S. 1215, creates the position of a dental health therapist.

The bill creates the position of a dental health therapist who would receive advanced dental training to perform basic dental procedures and provide certain medications to patients (Massachusetts, 2019). A dental health therapist would be a licensed position that requires the supervision and authority of a licensed dentist. In some ways, dental health therapists would be “roughly analogous to nurse practitioners in medicine” (Edelstein, 2011, p. 1831). The obvious benefit from the passage of this bill is simple: Dental care becomes more accessible for more people.

For the group home residents I visit, access to a dental health therapist could be life-changing. The oral health of these residents has an impact on their overall general health, as well, as “stomatologic diseases affect more than the mouth” (Shay and Ship, 1995, p. 1414). Dental health has been connected strongly to cardiovascular health, as studies have suggested adequate

dental care can lead to an increase in artery elasticity (Moneta, 2007, p. 4). A dental health therapist would visit the home to perform dental examinations and additional procedures to improve the oral health of the residents, with regular follow-ups to monitor their health. A population that is routinely neglected would finally have the opportunity to receive appropriate and adequate dental care.

I was surprised to find that the creation of a dental health therapist position has proven to be highly controversial. I learned that the people who oppose the idea of creating a dental health therapist – to my dismay – are actually dentists themselves. Generally, people that oppose the idea of a dental health therapist focus on the possibility of “eroding market share” for dentists (Edelstein, 2011, p. 1831). They also suggest that once the position is established, there is a possibility that dental health therapists may seek additional responsibilities and authority. Another argument against creating dental health therapists is that it would simultaneously create two tiers of dentistry – with dental health therapists acting as a secondary class of care. There is a concern that creating a secondary class of dental care “could endanger the health and safety... of the public” (Edelstein, 2011, p. 1832).

A response to this argument is that, there are many areas in the United States that have a shortage of licensed dentists (Friedman and Kavita, 2017, p. 1005). Creating the position of a dental therapist would help solve that problem. This is a view that was articulated by the Federal Trade Commission, in a letter written to an Ohio senator stating that creating the position of a dental health therapist could “increase the supply of basic services and improve the overall quality and convenience of care” (Koslov, Jin, and Feinsein, 2017, p. 5). As someone who will be practicing dentistry in the future and someone that has seen first-hand the barriers that people with disabilities face to receiving dental care, I believe the creation of dental health therapists will serve as part of the solution to making dental care more accessible. I do not believe dental health therapists will create two tiers of dentistry, I believe they will help serve neglected populations that dentists are currently unable to serve. Currently in the United States, there is a shortage of dentists which has created Health Professional Shortage Areas (HPSAs) across the country (Vujicic, 2015, p. 347). There are 57 million Americans across 6,813 HPSAs that face inaccessible dental care due to the lack of dentists in their area. It would take over 10,000 dentists to eliminate the dental HPSAs in America (“Health Professional Shortage Areas”, n.d.). The analysis conducted by the United States Health Resources and Service Administration predicts that every state in America will face a shortage of dentists by the year 2025 (Vujicic, 2015, p. 347). The need for more practitioners is stronger than ever before, and dental health therapists will help serve the Americans, including patients with disabilities, that are unable to be served now.

Despite some opposition from dentists against the proposed Massachusetts bills, the Massachusetts Dental Society is now in favor of passing this bill into legislation. The Massachusetts Dental Society represents around 80% of the dentists in the state, declaring itself the “leading authority on oral health care” in Massachusetts. The organization recognizes that providing dental care for underrepresented communities and breaking barriers to dental care should be top priorities for the state. They have clearly supported the idea of the dental therapist, stating “Massachusetts is best served by requiring dental therapists to work in partnership with licensed dentists” (Massachusetts Dental Society, 2019, p. 2).

A Service-Learning Capstone Project

As a part of my service-learning coursework in college, I took the course *SRVCLRNG 496, Boltwood Capstone: (dis)Ability, Ableism & Social Justice* in Spring 2019. For this class, I had the opportunity to complete a capstone project advocating and raising awareness for the bill *An Act to Improve Oral Health for All Massachusetts Residents*. To raise awareness for this bill, I created an on-line petition and also spoke at a public forum regarding disability in the Pioneer Valley.

The petition I created included a summary of the issues related to the bill I was advocating for, as well as how the bill would help solve the problem of people with disabilities not seeing a dentist often enough. I included the testimonies of the residents from the assisted living center I visit as anecdotal evidence of this problem, which I believe resonated with many people who read my petition. This petition gathered over 200 signatures, which helped me demonstrate to legislators why this bill needed to be passed.

On April 26th, 2018, I spoke at a public forum titled *Disability in the Pioneer Valley*. I attended this forum with the intention of speaking about my capstone project and hoping to gather more insight on how to solve the issue, as I knew the people attending the forum would all be passionate and knowledgeable about issues facing people with disabilities. After explaining my project, the inspiration behind it, and my research, the people in attendance at the forum were eager to engage in further conversation about this critical issue. They were all appreciative of my project and thanked me for my work, which was very humbling. Some of the attendees of the forum informed me of dentists in the area who are very comfortable working with patients with disabilities, while others shared their unpleasant experiences with dentists. It was amazing to see the passion surrounding the issue.

This forum took on a new level of importance when State Senator Jo Comerford arrived towards the end of my presentation. Senator Comerford is the representative in the Massachusetts State

-17-

Journal for Service-Learning, Leadership, and Social Change Spring 2020

House for the people of Hampshire, Franklin, and Worcester counties in Massachusetts. Involving a legislator who could make a direct impact on the fate of the bill I was advocating for presented more opportunities than I had initially imagined. Throughout my capstone project, I had great difficulty getting in contact with legislators regarding my bill, which was a huge problem. Speaking with Senator Comerford was extremely productive and encouraging for everyone at the forum.

Senator Comerford found the forum productive, and was interested in my project; so much so that she suggested my research should be submitted as testimony in support of the bill at the Joint Hearing of Public Health Committee on May 7th, 2019. The result was that the committee agreed to push the bill to the next step – which was to send it to the next Joint Hearing of the Financing Committee.

On October 22, 2019, I went to the Massachusetts State House with a small group of University of Massachusetts service-learning students for our annual “Statehouse Visit”. This day is devoted to learning more about how legislative policy is enacted. I met Senator Comerford again, for the first time since the public forum we attended. She remembered me, my project, and the public forum almost immediately. In a subsequent email with Senator Comerford, she said of my project:

There are few things more powerful than an individual, passionately motivated to address an inequity. Such is the power and associated impact of Raju Gandhi and his drive to improve the oral health of Commonwealth residents. Raju's advocacy is motivated by his own relationships with those who have been without adequate dental care. The focus of his work has been to help propel a smart piece of legislation surrounding dental therapists. I attended Raju's public forum in Amherst before being sworn into office and left tremendously inspired. Once in the Senate I was appointed Senate Chair of the Joint Committee on Public Health---delighted that I had the dental therapist bill in my committee. Raju's efforts jump-started my due diligence and focus in on this legislation amid a sea of hundreds of other bills. And Commonwealth residents will be healthier because of it. (J. Comerford, personal communication, December 10th, 2019):

These words showed me how important my project was, and the importance of service-learning as a whole.

Reflecting on the Project

This project was a huge opportunity for my personal growth and development as a productive civic activist. The first lesson I learned was that advocacy, especially when it involves

the legislative process, can move very slowly and requires a lot of patience. I started this project with the idea that H. 1916 *An Act to Improve Oral Health for All Massachusetts Residents* could be passed within one semester. Reflecting on this project a year and a half later, it has still not passed. However, it is moving along in the right direction and gaining attention and momentum as it does so. In the early stages of my project, it did not feel like I was making much of a change. However, by spreading awareness slowly and by persistently contacting legislators, I was eventually able to see the impact of my efforts.

Even more so, through my work, I saw how strong the power of service-learning is. Service-learning involves compassion, empathy, and understanding. Through my service-learning classes, I was introduced to new ideas, situations and people that I would otherwise have never experienced. The service-learning work I have done throughout college has taught me more than anything I have learned in the traditional classroom or from a textbook. Interacting with people of all abilities and backgrounds each week for the past three and a half years, hearing about their daily problems, as well as their happiest moments, has broadened my perspective of society and has shaped me into a more critically aware and compassionate person. The knowledge I have attained through service-learning will resonate with me for the rest of my life and will impact the way I practice dentistry in the future. After seeing first-hand how neglecting a population of people looks and feels, I will actively seek to serve patients from historically under-served groups.

Although service-learning has been arguably the most important part of my college education, it is not and has never been a requirement for any student at my university. Students are not required to do service-learning; they have to seek it out and get involved themselves. While this may be a reason why service-learning has been such a positive experience at my school, I feel that it should be required for all college students to complete at least one semester of service-learning in order to graduate. Regardless of a student's future career, service-learning can teach them valuable, lifelong skills that will make them more aware and responsible citizens.

Future Directions

After pursuing a Bachelor of Science degree in biology and being a part of The Boltwood Project for each year of college, I have found a passion for dentistry. This is a profession that will allow me to use my education in science to treat patients that need dental care. It is also a profession that will allow me to be part of the solution in making dental care more accessible to underserved populations. For now, I can urge legislators to make decisions that will make dental

care more accessible. However, when I am a practicing dentist, I will have the ability, and desire, to go out into communities independently and treat neglected populations on my own time. While I am aware that I will only be able to impact so many communities myself, I hope to continue spreading awareness about the inaccessibility of dental care and advocating for more accessibility as I become a dental student next year and eventually a dentist in the near future.

Next year I will be joining the Class of 2024 to pursue my Doctor of Medicine in Dentistry degree at Boston University Henry M. Goldman School of Dental Medicine. At this school, I will have a variety of opportunities to continue my community outreach. One of the opportunities that will be available is to collaborate with Work Inc., a program specifically designed for people with disabilities. The goal of Work Inc is to provide dental health and hygienic recommendations to the adults in the program, as well as their caregivers (“GSDM’s Community-Based Programs”, n.d.). I know that the service-learning work I have done in college has better prepared me for a variety of patients that I will treat in the future. Without my involvement in the Boltwood Project, I would not have been as prepared to serve community members of all backgrounds. A service-learning program inspired this project, and as Senator Comerford said, “*Commonwealth residents will be healthier because of it.*”

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