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# Inquiry Journal

Undergraduate Research Journal : Spring 2014

## Research Articles

# Interviewing Adults with Intellectual Disabilities about Oral Health in Brisbane, Australia

—Meghan Maguire (Editor: Sarah Milicia )

Brushing our teeth is as routine as is going to the dentist twice a year. Today so much goes towards preventative care, and yet we still end up with cavities or imperfections that need treatment—even just for vanity. Now, imagine a person with an intellectual disability, a person who may find it hard to remember, concentrate, or make decisions easily or quickly. He or she may need constant reinforcement about the basic tasks of everyday living. Regular teeth brushing and trips to the dentist don't happen, and their oral health suffers.

I am a senior biology major whose interests lie in dentistry. I am a “people person” who wants to make a difference in the oral health field. I heard about the Summer Undergraduate Research Fellowship (SURF) Abroad, which would give me the freedom to follow my interests. Dr. Joan Earle Hahn, of the University of New Hampshire's Department of Nursing, introduced me to the oral health problems experienced by many people with intellectual disabilities. I knew I wanted to help change the methodology of educating them to better suit their needs. I had never worked with people with intellectual disabilities, but I was looking forward to the opportunity.

An Australian study had confirmed oral disease among adults with developmental disabilities to be seven times higher than among age-matched, non-disabled peers in the general public (Scott, 1998). The 2004 Australian Health Ministers Conference noted that in marginalized groups, such as people with disabilities, oral health problems are a concern (DHSV, 2008).

Over the course of two semesters Dr. Hahn and I pulled together a proposal for a SURF Abroad from the Hamel Center for Undergraduate Research for me to go to Brisbane, Australia, in the summer of 2013. There, I would interview people with intellectual disabilities about their perspectives on oral health care. This information, I hoped,



Map of Australia showing Queensland and Brisbane (Courtesy of BrisbaneAustralia.com).



The author with a kangaroo at the Australia Zoo in Beerwah, Queensland.

would help improve methods for teaching about the importance of oral health. Dr. Hahn was acquainted with Dr. Nicholas Lennox, Director of the Queensland Centre for Intellectual and Developmental Disabilities (QCIDD). He connected us with a member of his staff, Dr. Kate van Dooren, who became my foreign mentor. It was a rare opportunity for me to work with an organization that specializes in improving the health of people with intellectual disabilities. And Australia sounded like a very interesting country.

For nine weeks I had the pleasure of residing in a suburban Brisbane neighborhood with Lyn, who welcomed me into her home. This arrangement was made prior to my arrival when I asked about possible living arrangements. Lyn, a coworker of my foreign mentor, offered to let me stay with her. It was the first of many experiences of the warmth that Australians have in welcoming new people into their lives.

## Getting to Work

Understanding all I could about people with intellectual disabilities was a crucial part of being able to do this project. The first step for me was defining what it meant to be a person with intellectual disability. An intellectual disability is a generalized disorder appearing before adulthood, characterized by certain limitations in mental functioning and in skills such as communicating, taking care of him- or herself, and social skills. These limitations will cause a slower development than in a person without disability (NICHCY, 2014). Discrimination and marginalization from the community compound these developmental differences.

The second part of understanding was interaction. Over the course of a month I joined individuals at Healthy Living Seminars, information sessions about different aspects of improving health, run by the University of Queensland Hospital. During this time I got to know people on a personal level as they opened up about their lives. When I believed they would be comfortable talking to me, I inquired if they would be interested in being interviewed for my study. Before beginning an interview, I verbally described the study to the participant and explained the consent form I asked them to sign.

I conducted a qualitative study with an interview guide, or list of basic questions, such as: "What does good oral health mean to you?" and "How many times a day do you brush your teeth?" Based on the responses from the participants, I formulated new questions to discover more details. The basic questions had been approved by the Institutional Review Board for the Protection of Human Subjects in Research at UNH. By the end of my research time, I interviewed nine participants, aged thirty-one to sixty-one years old, consisting of five males and two females with intellectual disabilities as well as two carers, who were professional paid staff. The adults' level of disability was "moderate," meaning they understand daily schedules or future events, make choices about what they would like to do, and develop independence in personal care. However, they will still need lifelong support in daily living and activities (Tracy, 2014). All participants came from the same organization but resided in different group homes. I conducted the interviews with one participant at a time, with one exception when I interviewed two participants together.

I audio-recorded the interviews and then transcribed them, removing identifying information. The transcribed

interviews were read independently by Dr. van Dooren and me. I first looked for words that were repeated across the interviews, such as “fear.” I then looked for common stories or issues that the participants talked about, such as “fear of the dentist.” After Dr. van Dooren and I finished our analyses, we discussed themes, which were the key ideas found throughout interviews that pertained to possible causes for poor oral health and barriers to improving oral health. After much discussion we agreed on three main themes. Dr. Hahn confirmed the themes upon my return to UNH.

Based on our thematic analysis of the interview data, we found that the participants with intellectual disabilities were educated about oral health. The carers were providing them with the tools to take care of their teeth, such as brushes and toothpaste, and information about how and why to use them. Most of the adults interviewed could tell me what they were supposed to do, yet not many followed through. With all the tools and information available, why do these adults still rank the lowest in good oral health? The themes that we derived from the data suggested three causes: a lack of understanding of how to use the information provided them, the difficult job of their carers in balancing their independence with support, and fear of and/or misconceptions about the dentist.



A view of the coastal city of Brisbane.

## The Themes

The first theme is that among the participants there is a lack of connection between knowing the facts and being supported to apply them for their oral health. The participants understood that oral infection and disease are results of not brushing teeth and no regular checkups. However, this understanding is rarely applied. A participant who illustrates this theme told me that in order to keep your teeth healthy, you need to “brush, get a checkup and no sugary stuff” — all correct information. When I asked how many times a day she brushes, or the last time she has gone to the dentist, she replied that she does not brush and has not gone to the dentist in sixteen years. The reason for not caring for her teeth seemed logical: she told me that she does not brush because a tooth was falling out, and she was afraid brushing would cause it to come out completely. When asked why she has not gone to the dentist, she told me that “he’s a butcher,” an opinion resulting from the bad experiences she had had. In addition to fearing the dentist (the third theme), she had not been supported in connecting what she had learned about oral health with actual care of her teeth.

The second theme is that carers struggle with helping adults with intellectual disabilities to achieve independence while at the same time providing sufficient support. Independence is something that adults with mild and moderate intellectual disabilities need to develop as much as possible. Therefore, being charged to promote independence, carers are taught that basic skills are to be encouraged. A carer explained that they are there to educate the adults with intellectual disabilities about the importance of daily teeth cleaning while at the same time making sure they are doing it. The head carer of one of the group homes stated that the adults are, “to do it for themselves, and that goes across the board with everything.” Analysis of my interview responses suggests that this standard may not be appropriate for all of the people assisted by the carers.

Most participants I interviewed felt they were neglected in terms of getting help with cleaning their teeth and that

they should be getting more help. One participant spoke openly about the subject: "Every person needs to have a more active role. The problem is that no one cares, right? They will say to you, 'Well, you are the individual, right? You do it!' No carers would help me out." He expressed that he feels independent all of the time with or without the extra help the carers provide. He does brush his teeth on his own, but he recognized that not all his peers are as capable as he is, and felt the carer should do more.

The third theme is that many of the adults interviewed had misconceptions about and/or fear of the dentist. A common misconception is that one goes to the dentist only when teeth cause trouble and pain, and many participants reported not seeing the dentist in several years. One cause for not seeing the dentist can come from the expense of dental visits. Some adults with intellectual disabilities experience low socio-economic standing; therefore, they may never have seen a dentist for routine care. Another misconception was expressed by a participant, who said that you "go to the dentist less, because that means you are taking good care of your teeth." This is a logical argument for someone who does not see the significance of a dentist for preventative treatment and believes that brushing alone can prevent all oral health diseases.

When participants have gone to the dentist because of teeth problems, they have often experienced pain. This naturally makes them fear dentists and avoid going to them even for routine checkups. Two participants, a male and female between the ages of fifty and sixty, recalled when they had most or all of their teeth removed in one sitting with only Novocain. The female participant recollected the event in great detail:

I had them all ripped out when I was ten because I had pyrea in the gums...They ended up having me sit for two hours...they ended up sticking two needles in the top there and two in the bottom here and then they pulled all front [teeth] out. . . .You go through it and see what the hell it was like. Honest.

It was quite clear that what needs to be better conveyed is the concept of preventative care: routine dental visits and teeth brushing are part of maintaining good oral health.

## **The Future**

These three themes derived from the interviews make a strong case that preventative care needs to be reinforced. The findings I gathered suggest that participants are continually taught the facts and yet still experience barriers to implementing that knowledge in their lives. Carers are taught to give independence to the adults with intellectual disabilities, but fostering independence can run the risk of neglect. Due to bad or even traumatic experiences the participants have had, the dentist's office is avoided instead of being viewed as a place for preventative treatments. Oral health education for people with intellectual disabilities needs to be presented in a new form to have a more effective and longer lasting impact.

The implications are many. The responsibility falls on families and carers to constantly engage people with intellectual disabilities in brushing their teeth and monitor how they do it, giving assistance and guidance as needed. The idea that good oral health is part of overall health must be reinforced. If this can happen, then people with intellectual disabilities will understand the purpose and application of good oral health habits and will be more likely to go to the dentist for regular checkups.

## **Australian Views**

The SURF Abroad experience was something I never expected to be a part of; it seemed out of my reach. That was



not the case. All it took was passion for an idea and hard work. I had an in-depth experience of the research process, which few university students are able to have.



The author (third from left) with friends and Dr. Kate van Dooren (on her left) at a Brisbane Broncos Rugby Game.

When I traveled to Australia I was expecting cowboys, horses, and desert sand. I walked off the plane into a city built around the Australian World Exposition of 1988, a city with unique architecture and a plethora of diverse people. I sat at a café taking photos of the city and watching the young schoolgirls, who looked like the girls in the childhood story Madeleine. Driving outside of the city, I saw vast landscapes of all different types including farmlands, savannahs, and rainforests. Each town along the main highway architecturally represented the time period it was built in.

I lived in another country and gained lifelong friends who gave me a new perspective on life. Each of them was driven to explore the world and follow their interests; it was a culture that promoted this type of lifestyle. Everyone was very open about what they were thinking. Perhaps it was the accent that made everything they said sound to me more sincere and sweet.

I feared failure but faced that fear, and I was rewarded with confidence, experience, and so much knowledge. This research has confirmed my passion for pursuing dentistry and for conducting research to help people with intellectual disabilities with their oral health—and to not fear me if I am their dentist.

This incredible experience would not have been possible without several people: first and foremost, Dr. Joan Earle Hahn, who helped provide me with an invaluable experience and guidance throughout this entire journey. She inspired me to learn about people with intellectual disabilities and gave me a lifelong goal to help make their lives better. Secondly, I would like to thank my friend and mentor, Dr. Kate van Dooren, from the Queensland Centre for Intellectual and Developmental Disabilities, for providing me with the support for and adventure of working on this project. To Dr. Georgeann Murphy of the Hamel Center for Undergraduate Research, my SURF donors (Mr. Dana Hamel and the J. Raymond Hepler Endowed Fund), and my friends and family—thank you for the much needed support and belief in the importance of this project.

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## Author and Mentor Bios

**Meghan Maguire** of Nashua, New Hampshire, is a senior biology major interested in dentistry as well as in the conservation of plants and animals. Her interest in oral health, her learning about people with intellectual disabilities, and her desire to experience a foreign culture came together in her summer research in Brisbane, Australia. She hopes the results of her project will help improve oral health education for this marginalized population. Meghan was supported in her grant application and research by Dr. Gene Harkless, her mentor Dr. Joan Hahn, and her foreign mentor Dr. Kate van Dooren. After graduation in May with a bachelor of science in biology, she looks forward to dental school or work in biological conservation.

Dr. **Joan Earle Hahn** APRN, GCNS-BC, GNP-BC, CDDN is associate professor in the Department of Nursing at the University of New Hampshire. Over the past twenty years, Dr. Hahn's nursing and interdisciplinary research specializes in interventions to promote health and well being of people aging with disabilities to reduce health disparities and promote wellness and full participation in life activities. Dr. Hahn made Meghan Maguire's interest in conducting international research on oral health possible by linking her with a team of researchers who were doing similar research at the Queensland Centre for Intellectual and Developmental Disabilities in South Brisbane, Australia. Meghan's interest in what people with disabilities think about care of their teeth was a perfect match. "Meghan had a rich opportunity to see first-hand how research is conducted and how oral health is a huge health disparity," said Dr. Hahn, "all the while getting to work with people with disabilities who provide the best education possible." Dr. Hahn said that Meghan "had the qualities of a natural researcher from the beginning of design to completion of the study with dissemination like a pro."

Meghan's foreign mentor was Dr. **Kate van Dooren**, lecturer and primary qualitative researcher at the Queensland Centre for Intellectual and Developmental Disability, part of the University of Queensland's School of Medicine in Brisbane. This was her first experience as mentor to an undergraduate researcher. It was, she said, "an amazing experience" during which "Meghan, Joan and I worked together as a cohesive team" to design and develop the project. Dr. van Dooren assisted Meghan in carrying out her research and found her "an extremely competent and autonomous researcher." Together they conducted a thematic analysis of Meghan's data and are preparing an article to submit to a peer-reviewed journal. Their collaboration will continue beyond this project. "As a team," Dr. van Dooren said, "we have learnt a great deal about the health of a vulnerable and often overlooked population group."

Dr. Hahn mentored Inquiry author Kristen Manning (2012).

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