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# A Community Approach: Improving the Health and Wellness of People with Learning Disabilities in Northern Ireland

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# A Community Approach: Improving the Health and Wellness of People with Learning Disabilities in Northern Ireland

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**research article**

## **A Community Approach: Improving the Health and Wellness of People with Learning Disabilities in Northern Ireland**

—Kristen Manning (Editors: Elizabeth Barker and Jennifer Lee)

A role model in my life has been my older sister who has Down syndrome. Through her, I have been exposed to persons with intellectual/learning disabilities, and greatly enjoyed forming relationships with this group of my peers. As I began my undergraduate career as a nursing student, I knew I wanted to continue working with adults with intellectual disabilities. However, I was surprised to learn that the United States currently lacks universal education for nurses in providing care for persons with intellectual disabilities (ID) while other countries, such as Northern Ireland, do provide that training. My desire and knowledge about such educational programs began to fuel the formation of a research project.

Globally, the number of persons with ID has expanded by 25 percent over the past ten years (Parrott, 2008). This has created an unprecedented level of need for health and social care that made me question what these persons think about their health, their access to health care and the nurses who help them. I specifically wanted to hear their voices. I then wanted to hear from the nurses who work with this population and how they perceive their roles. When I learned of the University of New Hampshire's International Research Opportunities Program (IROP) grants for summer research abroad, I teamed up with Associate Professor Joan Hahn of the Department of Nursing, who recruited a professional contact, Professor Owen Barr at the University of Ulster-Magee in Derry, to be my foreign mentor. Together we successfully applied for a grant, and I spent the summer of 2011 in Northern Ireland.



*The author (center) at the Chief Nursing Officer Conference 2011 with foreign research mentor, Dr. Owen Barr, (on her right) and Chief Nursing Officer of Northern Ireland, Martin Bradley (on her left).*

In 2007 the Bamford report indicated that the prevalence of persons with learning disabilities was 9.71 percent in Northern Ireland. The report was an independent review (2002–2007) that examined the law, policy and provisions affecting people with mental health needs or a learning disability. Learning disability is the term of choice in Northern Ireland for what Americans refer to as intellectual or developmental disability, previously known as mental retardation. By definition, learning disability may range from mild to profound, with an array of physical challenges, sensory impairments, and/or behavioral or mental health problems (WHO, 2009). According to the Bamford report, persons with learning disabilities have higher mortality rates, live with greater levels of ill-health, use primary care services less often and are less likely to take up health screening than the general population. And this occurs in a country with universal health care, free to every resident.

## Arrival in Derry and My Research Plan

When I arrived in my ancestral country of Northern Ireland, my new home for nine weeks, I was greeted with welcoming kindness as I simultaneously became aware of the political tension embedded in this country's culture and history. What fascinated me most importantly was the sense of community in the vibrant city of Derry. This was the beginning of a realization of how strong the role of the community can be in improving the health and wellness of the Northern Irish.

My project was a descriptive qualitative study consisting of two phases: phase one involved working with and interviewing persons with learning disabilities, and phase two involved interviewing and shadowing nurses (observing nurses in practice). Prior to beginning my research, Dr. Barr facilitated the opportunity for me to attend the Chief Nursing Officer's Conference, meet the Chief Nursing Officer of Northern Ireland, meet the Northern Ireland Advisor for the Department of Health, Social Services, and Public Safety, and begin to spend time with two groups of persons with learning disabilities.



*The CAN-CAN van, offering valuable employment training for people with learning disabilities.*

The first group was a theater company, located in the community playhouse, whose members were passionate about and active in the performing arts. The second group was a user-led advocacy group that engaged in community service activities that provided both recreation and employment. Both groups' offices were located within walking distance of local shops and businesses. With both of these groups, I spent time developing rapport through their various activities including Zumba, photography classes, bowling, walks on Derry's historic walls, circus training, drumming circles and many more. This allowed me to see how actively persons with learning disabilities participated in their communities, from working to relaxing with friends in a local pub. Once we were acquainted, I then explained my research and asked for volunteers to be part of my research study. In total, I interviewed thirteen adults.

My interview techniques improved through self-reflection and discussions with my mentors, Drs. Barr and Hahn, as my confidence as a researcher built. What proved to be a significant benefit was developing rapport with the research participants in order to create a trusting relationship and get a grasp of their communication strengths and challenges. The more time I spent with each group, the more trust I developed between the participants and myself as the researcher.

## Perspectives from the Persons with Learning Disabilities and from the Nurses

Although I am still analyzing the data, themes are emerging about the adults with learning disabilities' perceptions of nurses and health. A guided questionnaire that I developed included questions such as "What do you think of when you hear the word *nurse*?", "What is important to you about receiving care from the nurse?," and "What is important to you about your own health and how do you think you can improve it?" The participants associated nurses with tasks and care such as blood sticks, needles, blood pressure, temperature, bathing, toileting, tablets and toast. As one individual stated, "[nurses are] the kind people [who] treat sick people." Additional words used to describe the nurse included *good*, *helpful*, and *smart*. Distinct hospital experiences led to more elaborate responses. These individuals wanted nurses to help them with pain, give them toast, and give them advice about how to take care of themselves.

After completing the interviews with persons with learning disabilities, I then turned my attention to the nurses. To understand the perspective of nurses in Northern Ireland who support persons with learning disabilities, it is

important to know the system of nursing education in that country. Like its healthcare system, nursing education is different from that of the United States. Northern Ireland's nursing programs offer specialization in nursing directed toward care of persons with learning disabilities through courses and clinical placements (time that is spent in the nursing field). The Registered Nurse of Learning Disability (RNLD) is a title given to a nurse who has completed this specialty practice. RNLDs can work in many roles, including Community Nurses for People with Learning Disabilities (CNLDs) who practice in communities. Together these nurses have shaped and developed services since the early 1970s within community multi-disciplinary and multi-agency service models for persons with learning disabilities (Royal College of Nursing, 2009). All student nurses in Northern Ireland, regardless of what track of nursing specialty they choose (e.g., adult nursing, mental health, pediatrics), undertake a two-week placement in a setting with a clientele of persons with learning disabilities. In total, eight nurses participated in interviews, some by phone due to the distances involved.



*The author and new friends enjoying afternoon tea in Northern Ireland.*

What I quickly learned is that not all nurses who work in learning disability settings are RNLD. Subsequently, my research sample included eight Registered Nurses who worked in the learning disability field, one without and seven with the specialty nurse education. In addition to conducting interviews, I was able to observe two nurses in adult daycare centers for persons with learning disabilities and one RNLD in the role of health facilitator in the community, as well as tour the learning disability hospital in Derry where several RNLDs worked. Through these experiences I came across the various settings, roles, and certifications of nurses who work with in this specialty. Those settings ranged from daycare centers to local hospitals. Different nursing roles ranged from advisors to the Northern Ireland Department of Health, Social Services, and Public Safety, daycare center nurse managers, health facilitators for the local Trusts, nursing tutors, and residential house managers to respite service coordinators. What follows is what I learned from nurse interview data.

The interviews conducted with persons with learning disabilities in phase one informed my development of a guided questionnaire for the nurses in phase two. During the nurse interviews, I asked about their nursing education and work experience, the factors that affect the nurse-patient relationship, how they viewed the health of persons with learning disabilities, and how nurses could help improve their health.

Four themes stood out for me from the nurse interviews. First, nurses expressed that they find fulfillment in their jobs when they see the persons with learning disabilities receive equity in health care and in society. Nurses are advocates for the individual's health and facilitate access to mainstream healthcare services in local communities. One nurse saw an ongoing role for nurses was to actively promote and invest in the health of persons with learning disabilities to give them better lives:

I think we are doing well at identifying conditions people with learning disabilities have, but we are not doing that well about doing something about it, so I think we need to be more proactive in providing interventions [for] people with certain conditions . . . that will make them live longer or even suffer less from particular conditions that they have . . . [We need to get] at people with learning disabilities and their families early on in their lives to establish healthy lifestyles and to help educate parents and siblings and other key people within health [services] so we try to hopefully start healthy behaviors that aren't disabling and illness promoting.

A second theme that was expressed repeatedly was that current services, while they have come a long way from institutionalization in the past, still have some improving to do. Barriers to services include limited physical access to buildings as well as overcomplicated automated phone systems that do not allow the persons with



learning disabilities to be autonomous in access to health care. Notably, a client who uses a wheelchair is not able to attend local programs that he would otherwise be able to attend, due to his physical impairment. A third theme was that the nurse played a central role as a member of the healthcare team. Nurses spoke to the necessity of collaboration and seeking advice from members of the healthcare team to seek expertise when they did not have it in order to achieve advances for the individual with learning disabilities. Fourth, each of the nurses I interviewed expressed enthusiasm and a thirst for additional training to increase their skills in providing care. This last response supported my feeling that the nurses themselves are interested in receiving additional formal educational training in order to provide clients with learning disabilities better care.

## The Road Ahead

While this research study is ongoing, I have already learned a great deal from my experience in Northern Ireland. The interviews completed with both persons with learning disabilities and registered nurses, the majority of whom had education in the nursing specialty as RNLDs, provided rich data that illustrated that while persons with learning disabilities see the nurses as benevolent and that nurses report satisfaction in their role as advocates for health equity, barriers yet remain and further education for nurses would be welcomed. Since the health disparities of persons with learning disabilities are recognized, I believe that it is time for everyone in the life of these people to be actively involved in order to promote a healthy lifestyle in all aspects of the person with learning disabilities' life during day-to-day activities. This highlights the interdependence between persons with learning disabilities, their families, nurses and the local communities.

From my interviews, I found that the majority of persons with learning disabilities live with family caregivers, implying that family caregivers may play a key role in their health. The interview findings suggest that individuals with learning disabilities may play a minor role or were lacking in information about improving their health. Interestingly, in interviews, participants became silent and did not know how to answer the question about how they would like to improve their health. Overall, persons with learning disabilities are positive about the role of nurses. However, they have little focus on the medical-based nursing interventions or skills of nurses; rather, they perceive nursing care as being treated with kindness. For example, one participant remarked that she remembered the nurse for bringing toast to the bedside. Perhaps, if discussion of health promotion was more inclusive of persons with learning disabilities, then it would lead them to be more invested, involved, and take greater part in their health care.



*A General Practitioner's office located in the Glens of Antrim. Nurse facilitators visit all local GP practices to help decrease barriers for persons with learning disabilities in local communities.*

Northern Ireland is an exemplary country working to tackle the health needs of persons with learning disabilities in nursing through its implementation of the learning disability health facilitator and nursing student clinical placements. A health facilitator is a key individual (registered nurse, and often a RNLD) who works with the Trusts (synonymous with "states" in the U.S.) to create leadership that is linked with general physician (GP) practices to ensure that all individuals with learning disabilities are getting their health needs met with annual health checks. Through my shadow observation experiences, I observed, first, how this specific nurse is the key to the creation of community partnerships. Second, the Nursing and Midwifery Council of the United Kingdom is doing its part to make sure that all branches of nursing—adult, child, and mental health—will have a more expansive theoretical and practical experience of working with learning disabilities through the theoretical instruction and related practice learning

placement in a setting with persons with learning disabilities. Hopefully, increasing exposure will lead to increased acceptance and a realization of the importance of the role of multiple players—persons with learning disabilities, families, nurses, and their communities.

The community that shows respect for persons with learning disabilities, the community that invests in community-participatory programs for persons with learning disabilities, and the community that works in a team approach with its healthcare services can help individuals with learning disabilities lead healthier lifestyles. This allows all to find success according to their individual abilities and to contribute to society.

My research supports the importance of including content about providing care for persons with learning disabilities throughout all levels of nursing education. If this is done, I think more nurses will realize that persons with learning disabilities are valuable members of our society who, if we invest in their health, will be able to contribute to our world in meaningful ways and thus enrich each other's lives. Additionally, the nursing workforce will be able to provide exemplary care for this expanding population. If nurses can listen to the voices of about providing care for persons with learning disabilities, we will hear what is important to them about their health and be able to invest in a better future.

This entire journey has broadened my perspective of learning disability nursing to a global level. Thanks to this project I aspire to be a nurse who specializes in providing care for persons with disabilities. I want to educate other nurses about how health care for these individuals can be improved. I want to provide the support individuals with intellectual and learning disabilities may need when they find themselves in need of health care, especially in emergency medical situations. I am determined to decrease the barriers that prohibit individuals from being autonomous in their own health.

This project has contributed to these goals by exposing how nurses in the country of Northern Ireland have shaped the field of nursing care for individuals with learning disabilities and has allowed me to hear from adults with learning disabilities themselves. Throughout life, I want to continue to serve as a role model in treating all individuals with compassion and respect and will always remember what I learned this past summer, in the country that I now love so well.

*This journey of a lifetime would not have been possible without several people: Dr. Joan Earle Hahn— thank you for sharing, every step of the way, your nursing expertise and guidance; thank you, Dr. Owen Barr, for welcoming me to Northern Ireland and for your continuing support. To Dr. Georgeann Murphy of the Hamel Center for Undergraduate Research, my IROP donors, and my friends and family—thanks for all of your words of support and encouragement!*

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### **Author Bio**

**Kristen Manning**, from Hanover, Massachusetts, is passionate about the new prospects in the field of nursing. Her project, supported by an International Research Opportunities Program grant, allowed her not only to travel to the country of her family's origin, Northern Ireland, but also to discover new ideas and treatments for learning disabilities, a field that is personally and professionally of interest to her. Though at times her research was challenging, Manning believes that this opportunity has enabled her to find her calling in the nursing field. "I am determined to decrease the barriers that prohibit persons with intellectual disabilities from being autonomous in their own health care," she says and has directed her professional education toward the improvement of health care for this population. An Honors in Major student, Manning will graduate with a Bachelor of Science in Nursing in May 2012. She plans on pursuing a Masters in Nursing after graduation.

### **Mentor Bio**

**Dr. Joan Earle Hahn** APRN, GCNS-BC, GNP-BC, CDDN joined the Department of Nursing at the University of New Hampshire as associate professor in fall 2008. Dr. Hahn's research expertise is in nursing interventions and curriculum development for nurses and other health care professionals about promoting health and well being of persons with disabilities to reduce health disparities and promote full participation in life activities. Her research interests and skills were a perfect match to Kristen Manning's interest in conducting research in Ireland on health issues of adults with learning disabilities and the nurse's role in promoting health among adults living in the community. These mutual interests have led Dr. Hahn and Kristen along with her foreign mentor, Dr. Owen Barr, to produce a co-authored paper that will be presented at the International Association for the Scientific Study of Intellectual Disabilities in July 2012. Dr. Hahn feels that Kristen "gained improved communication and research dissemination skills from the experience of writing for Inquiry."

Kristen's foreign mentor, **Dr. Owen Barr**, is professor and Head of School of Nursing at the University of Ulster. Both his teaching and research interests lie in community nursing and access to general health care for people with intellectual disabilities. Drs. Barr and Hahn had met through professional networks and made a perfect team to help Kristen refine her research project and complete the ethical approval process. In Northern Ireland, Dr. Barr provided access to participants for Kristen and met with her regularly, when they often held Skype conferences with Dr. Hahn. This was a first mentoring experience for Dr. Barr and, he says, "It was great. I learned so much about her course and experience of nurse education."