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Western Public Health Casebook 2017

Cases from the Schulich Interfaculty Program in Public Health

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PREFACE

INTRODUCTION

The Master of Public Health Program (MPH) at Western University is a 12 month full-time program that incorporates a 12-week practicum. In addition to didactic courses, the MPH Program curriculum includes innovations such as Brown Bag seminars, Integrative Workshops, field trips and career counselling. The Brown Bag seminars allow the students to hear from, interact and network with practitioners from the field. The faculty of the MPH Program are drawn from across campus, and represent a broad range of disciplines pertinent to public health.

TEACHING CASES

Western's MPH Program relies extensively on the case based/experiential method of learning. The Program aims to deliver 60% of pedagogic material using the case-based approach – a unique feature not found in other MPH Programs worldwide. The case method of learning is not about the traditional lecture-style classroom setting, but is about the student being an active part of the learning experience, which means learning by doing. It introduces complex and often ambiguous real-world scenarios into the classroom, forcing students to think and make decisions sometimes with incomplete and inaccurate data.

The case method is a three stage process that builds on each subsequent step. It starts with individual case preparation, followed by a small group discussion, concluding with a large group discussion (in the classroom) so that the learning objectives are met. To facilitate this process, all students are placed in a learning team of 5-6 members from Day 1 of their journey in the Program. The learning team forms the 'home' of the student for the academic year, and is the basis for peer-support, group and case work.

We view the case method as a vehicle to develop transformational learning, along with the students' leadership skills, teamwork ability, critical thinking capacity, and knowledge of disciplinary perspectives. However, there is a paucity of suitable public health cases to use for this purpose. Case-based pedagogy has been predominantly focused on business cases, which are often not directly suitable for a public health curriculum. In addition, existing health related cases often do not reflect the reality of Canadian and international health systems. Case repositories have few teaching cases that can be used by such programs, creating an opportunity for Western's faculty and practitioner colleagues to develop de novo cases by building on their research and practice experiences.

Along with faculty developed cases, Western has adopted an innovative model of building a catalogue of teaching cases in public health authored by students. As part of the MPH Program's Integrative Learning Experience (capstone course), the overall final deliverable for students is a teaching case and teaching note that is based on their Applied Practice Experience (practicum). Faculty members select the best cases, and work with the students to publish them in the annual ***Western Public Health Casebook***. Our faculty have actively incorporated these student cases in the curriculum, and we often involve the students (now alumni) in co-teaching these cases.

INTEGRATIVE WORKSHOPS

Each year, we schedule full day ***Integrative Workshops***. The objective of these workshops is to pause and reflect on the past six to eight weeks of learning, and to integrate and synthesize interdisciplinary knowledge and practices learned in the various courses till then. The workshops model a real public health issue facing the community, with student teams having to

make decisions under time pressure, often with imperfect information, and present and justify these decisions to experts. Topics are chosen to complement rather than duplicate the materials being used in the courses, and reflect the expanded expertise available on campus beyond the course faculty members, as well as practice experts and community members. This is a team exercise, where students apply the materials and insights from their courses (in addition to the presentations by experts at the workshop) to answer the question(s) posed. Workshop deliverables vary and may include short reports, presentations to a panel of experts, letters to the editor, blog postings or policy briefs.

WESTERN PUBLIC HEALTH CASEBOOK 2017

It is my pleasure to welcome you to this year's ***Western Public Health Casebook***. Herein you will find teaching cases authored by students, faculty members, and community partners, as well as summaries of the Integrative Workshops that were held in 2015/16. Cases are also available for download at <https://www.schulich.uwo.ca/publichealth/cases/>. Our goal is to create a searchable database of freely available public health cases on our website, for use by any program across the world. We welcome feedback and comments on these cases. To do this, please be in touch via the program's email: publichealth@schulich.uwo.ca.

Dr. Amardeep Thind
Director
Schulich Interfaculty Program in Public Health

ACKNOWLEDGEMENTS

Teamwork is the guiding theme for the 2017 **Western Public Health Casebook**. To paraphrase Dr. Amardeep Thind, Director of the Schulich Interfaculty Program in Public Health, public health is a team sport where you are not working alone. We work with people from different persuasions and backgrounds. Teamwork is an important skill for working in this context. Great leaders can work the team's different perspective into strengths.¹ The efforts of a team of students, faculty, staff, community members and public health organizations came together in the production of this Casebook.

We would like to express our gratitude to the following organizations (and the preceptors) who supported the training of our students and the development of the cases in this Casebook: WellFort Community Health Services; Provincial Council for Maternal and Child Health; Gorilla Doctors; Docs4GreatApes; Brescia University College; Public Health Agency of Canada; Centre for Addiction and Mental Health; Irish Red Cross; Irish Prison Service; Camp fyrefly; Pan American Health Organization; Epilepsy Support Centre; Newborn Screening Ontario; London CAREs; St. Joseph's Health Care Centre; London Health Sciences Centre; and South West Community Care Access Centre.

In particular, we thank Dr. Peter Donnelly, President and CEO of Public Health Ontario, and Dr. Robert Kyle, Commissioner & Medical Officer of Health, Durham Region Health Department, for their important insights on teamwork contained herein. This Casebook would not be possible without the tireless, conscientious efforts of Diana Lee, Manager of the MPH Program. We appreciate the significant efforts all of the MPH staff put into producing this Casebook, and the faculty of the MPH Program in honing its content. We warmly thank our student case authors - members of the MPH Class of 2016!

–Ava John-Baptiste and Gerald McKinley

¹ https://www.schulich.uwo.ca/publichealth/future_students/team_based_learning.html

INTRODUCTION TO THE CASEBOOK

Changing the World; One MPH Graduate at a Time

*Peter Donnelly, MD, PhD
President and CEO of Public Health Ontario (PHO)*

I believe a Master of Public Health degree is more than a qualification. It is a passport to change the world. By which I mean that there are very few ways to spend your working life that are as impactful as pursuing a career in public health. Consider the role of a public health leader working with others to effect change in all aspects of people's lives. There are many factors that influence health: income, education, employment, our environment and our biology. Public health issues are created by many interrelated factors and are often system-wide issues involving many different players. The global nature of public health means that issues can cross borders and have an impact at the local, national and international levels. As leaders, we cannot work in isolation if we want to have an impact. Improving population health requires us to work with our partners across sectors to create the conditions that promote health. We need systematic approaches to understand and address the interplay of the many variables that contribute to health. To accomplish this, we need leaders who are able to work with and influence others within and outside of the health system to ensure policies, programs and decisions provide people the opportunities for good health. As such, the ability to make team-based decisions is important for future public health leaders. Public health leaders need to seek to understand issues from different perspectives, garner support from different stakeholders, and create supportive environments to embrace the benefits and challenges of working in teams.

Over the course of my career as a public health executive, I have had the opportunity to work at local, national and international levels. I left Scotland to become the President and CEO of Public Health Ontario (PHO) in 2014, because I believe that in this province, we have the potential to have the best public health system in the world.

PHO is a provincial agency dedicated to protecting and promoting the health of all Ontarians and reducing inequities in health. Our organization plays a critical role in Ontario's health system, by providing expert scientific and technical advice and support to those working in public health, health care, government and related sectors across the province. Our key role is to enable informed decisions and actions that shape policies for a healthier Ontario. To advance our work, we collaborate with our partners and clients across health, education, employment, labour, environment and research sectors and make team decisions to address issues of mutual interest and concern.

One example that comes to mind is PHO's work to prepare for and respond to Zika virus. In 2015, Zika virus emerged as a public health concern in South America. Although it was first identified in Uganda in 1947, this mosquito-borne virus was not considered a serious threat to human health. In 2016, the World Health Organization declared Zika virus a public health emergency of international concern following a cluster of outbreaks in Central and South America that appeared to have a connection with an increase in microcephaly cases and other neurological disorders. As it spread to Mexico, the Caribbean and the United States of America, global attention turned to preventing and minimizing the impact of Zika virus. Recognizing the potential impacts this global virus could have on Ontarians, we established a cross-functional team of PHO experts in emergency preparedness, epidemiology, microbiology,

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entomology, clinical practice, issues management and communications to develop tools and provide support and advice to the Ministry of Health and Long-Term Care, public health units and health care providers. No single individual in Public Health Ontario had all of the expertise to make decisions on the best way to respond to Zika virus. The establishment of a cross-functional team brought together staff across the organization with complimentary knowledge, skills and experience.

Together, the team made decisions to inform the province's overall response. Key aspects of our response to this emerging virus included:

- Monitoring and assessing Zika virus infection in collaboration with the MOHLTC, the Office of the Chief Medical Officer of Health and the Public Health Agency of Canada;
- Evaluating evidence and surveillance to provide scientific and technical support to the Chief Medical Officer of Health;
- Consulting with clinicians on who to test and what tests were available for individual patients;
- Introducing molecular testing for Zika virus in Ontario, in collaboration with the National Microbiology Laboratory; and,
- Co-ordinating specimen testing with the Public Health Agency of Canada's National Microbiology Laboratory.

The convergence of individuals with a wide array of skills, knowledge and experience allowed us to develop products and services to meet the needs of various stakeholders, including physicians, government officials, public health units and the public. Our achievements can be credited to bringing together the right people to better understand the threats posed by Zika virus and develop and implement appropriate advice and tools.

It has been my experience that involving others in the decision-making process not only contributes to developing more effective interventions and approaches to addressing issues, but also solutions that are more likely to be accepted. With the interplay of many factors and players come competing interests and priorities. Stakeholders impacted by decisions want their perspectives to be heard and considered. Team-based decision-making requires openness to the ideas of others. Decisions that only take into consideration one individual's, organization's or sector's perspective are less likely to garner support from others. Team-based decision making also allows those impacted by decisions to come together to develop shared goals, objectives and outcomes. Individuals are also more likely to feel like they were part of the decision-making process and that decisions were made in a transparent way. The process allows public health leaders to gain buy-in for action among those who are impacted. I've often told my staff at PHO that I believe we are stronger as a whole than the sum of our parts. I believe the same is true for our public health system.

One way PHO is supporting team-based decision-making with public health system partners is through our Locally Driven Collaborative Projects (LDCP) initiative. This initiative brings together representatives from public health units, academia and other stakeholders for collective applied research and evaluation projects. The teams explore a topic, intervention or program related to an important public health issue that is relevant across the Ontario public health system. Led by a public health unit, each team typically includes representatives from three to six other stakeholders. Teams for past and current projects have had much success in addressing topics of mutual interest, including:

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- Engaging communities in fall prevention for older adults;
- Identifying best practices for social media planning, implementation and evaluation at health units in Ontario;
- Identifying areas of focus for mental health promotion in children and youth for Ontario public health; and,
- Identifying health equity indicators for Ontario local public health agencies.

One of the strengths of the LDCP initiative is that it allows leaders who are closest to the issue to explore relevant topics together and develop joint decisions. It leverages knowledge, expertise and resources from multiple stakeholders and helps create momentum for teams to work together on an issue of mutual interest. The participation of many partners in the projects has led to the development of tools and programs that are widely accepted and implemented across the province.

I've found that the most effective teams are the ones comprised of a diverse group of individuals – teams that are heterogeneous in their skills, knowledge, experience and perspectives. But diversity alone does not make a team successful. As mentioned previously, teams also need to develop shared goals, objectives and outcomes. To make decisions, teams require supportive environments to collaborate effectively. The focus on creating supportive environments should be on promoting psychological safety and the effective expression of diverse and conflicting perspectives to enable innovation. With diversity comes multiple viewpoints and opinions, which is why it is so important that leaders can manage conflicting perspectives. Teams require supportive environments so that they can embrace challenges.

One of my first initiatives at PHO was to work with the leadership team to identify the types of behaviours we want to see modelled by all of our staff. The norms that we developed complement our organization's six values: credible, innovative, responsive, collaborative, integrity and respect. Together our values and norms help create safe spaces for teams to problem solve and innovate. They also establish a standard that is expected to be modelled by everyone to ensure we all play by the same rules.

At PHO, we have taken our commitment to supporting a psychologically safe work environment even further by requiring all members of the management team to complete workplace mental health training. The training is focused on the development of empathetic and solution-focused leadership skills that promote mental health and optimal performance. It has helped our leaders create a supportive workplace culture and provide staff with the encouragement and confidence to express their views.

As future leaders, you will play a critical role in bringing different parts of the health and other sectors together to make and influence decisions on factors that impact health. You will need to be able to put together information, experiences and people to understand and address issues that impact population health. You will need to garner support from others. And you will need to build supportive environments to nurture a team-based culture. I believe that our best decisions are the ones that result from applying our collective knowledge, skills, experiences and perspectives in a safe and supportive team environment. Working together is what changes the world. This article itself is a demonstration of PHO teamwork. I would like to thank Amrita Maharaj, Mei Ling, Rhonda Pollard and Colleen Geiger for their assistance.

Cultivating Future Public Health Leaders Through Teamwork

*Robert Kyle, MD, MHSc, CCFP, FRCPC, FACPM
Commissioner & Medical Officer of Health, Durham Region Health Department*

On July 2, 2017, I will have been an Ontario medical officer of health for thirty years. For the past 26 ½ years, I have been the Commissioner & Medical Officer of Health for the Regional Municipality of Durham (Region of Durham). During this time, I have seen and experienced many different real world problems but one principle has remained constant throughout...the ability to make team-based decisions is important for public health leaders, past, present and future. In the paragraphs that follow, I will share with you a few stories to illustrate this point. Let me start, however, by telling you a bit about the Durham Region Health Department, the organization I have had the privilege to lead throughout my tenure with the Region. We provide a basket of mainly provincially-prescribed public health and paramedic programs and services to Durham's 670,000 or so residents who live in one of eight local municipalities. Our staff includes medical and dental professionals; public health nurses, inspectors and nutritionists; tobacco enforcement officers; epidemiologists; paramedics; and, administrative staff. These 750 staff are assigned to one of five divisions: Administration, Environmental Health, Oral Health, Paramedic Services, and Public Health Nursing and Nutrition. In addition, there is a seven-person Epidemiology and Evaluation Unit. The Directors of these divisions comprise my leadership team and we make decisions by consensus, as do the many multi-disciplinary teams we have established over the years to address issues, complete tasks and/or share information.

My first story concerns paramedic services. The 1990s were not kind to the broader public sector, including the Health Department. Indeed, flat-lined provincial funding led to attrition and a major downsizing of our staff. In addition, home care programs were removed from board of health oversight, leading to far fewer staff and a narrower focus. That said, towards the end of the 90s, the funding and administration of land ambulance services were "downloaded" to certain cities, counties and regions including the Region of Durham. My boss, the Chief Administrative Officer, handed me this file to manage. At the time, there were six land ambulance services in the Region – one operated by the Ministry of Health, another run by the Ajax & Pickering Hospital, and four privately operated; municipally-based land ambulance services were a rarity. We assembled a multi-disciplinary team to develop and execute a multi-year roadmap to establish a Region-wide land ambulance service. The following tasks were carried out:

- Hiring a consultant to study high-performing land ambulance services, in partnership with the Regions of Halton and York, who provided us with advice and recommendations;
- Consulting key stakeholders, including existing ambulance operators, local hospitals, lower-tier municipalities, and the public about the future state of local land ambulance services;
- Preparing a report, based on the above, with recommendations for Regional Council's approval; and,
- Implementing the recommendations, including hiring the founding Chief/Director.

Cultivating Future Public Health Leaders Through Teamwork

Working together, our team successfully launched the first new municipal land ambulance service, Durham Region EMS, on January 1, 2000. This service, now Region of Durham Paramedic Services, has been such a great success story, and has led to all land ambulance services in Ontario being municipally operated.

My second story is about tobacco control. Early in the 2000s, lower-tier municipalities could pass by-laws restricting or prohibiting smoking in public places and workplaces. However, the no smoking by-laws in the Region of Durham at the time were weak, inconsistent and none prohibited smoking in these places. Fortunately, lower-tier municipalities could upload this power to upper-tier municipalities according to a formula in the *Tobacco Control Act*. A letter from an adolescent requesting smoke-free restaurants in Durham Region created an opportunity for staff to seek approval from Regional Council to ask our lower-tier municipalities to upload this power to the Region and then to consult the public on the proposed by-law. We assembled a new multi-disciplinary team, including a political champion, our Chair of Council's Health & Social Services Committee, to develop and execute a multi-year plan, which included the following tasks:

- Seeking support from all eight lower-tier municipal councils to upload the power to enact a Region-wide smoke-free by-law;
- Once the power was uploaded in conformity with the Act, consulting key stakeholders and the public as to the content of the new by-law, including using an electronic consultation and public hearings in all eight municipalities;
- Drafting the by-law;
- Preparing a report, based on the above, with recommendations for Regional Council's approval; and,
- Implementing the by-law.

Again, working together, our team successfully developed and executed the plan and at the time of its passage in December 2002, the Smoke-Free By-law was the toughest in the Greater Toronto Area and prohibited smoking in all public places, including bars, restaurants, and workplaces, including hospitals and long-term care homes. It even banned smoking at the Great Blue Heron Charity Casino.

The third story focuses on SARS (Severe Acute Respiratory Syndrome), which touched down in east Toronto on February 23, 2003 when Ontario's index case returned to Toronto after being exposed to an infected doctor in Hong Kong. Sadly, she succumbed on March 5. From there, the Toronto-based SARS outbreaks occurred in two waves – March to April and April to June 2003. Four of the six transmission chains originated in a hospital. In total, 44 people in Canada died, approximately 400 became ill, and 25,000 were placed in quarantine. Yet another multi-disciplinary team was assembled to lead our public health response in the Region from March to June, which included the following tasks:

- Creating and staffing a large call centre to respond to SARS-related telephone inquiries;
- Ensuring the isolation and quarantine of contacts of cases;
- Ensuring the provision of infection prevention and control related equipment and supplies to isolated and quarantined contacts in the community; and,
- Disseminating public health information to our community partners, including our community care access centre, first responders, hospitals and long-term care homes.

Cultivating Future Public Health Leaders Through Teamwork

Together, our team rose to the occasion, amid much trial and tribulation, and successfully led an unprecedented public health response to a novel viral pathogen never seen in Ontario either before or since. That said, a critical review of the overall public health response led to many positive changes in Ontario's public health system, through "Operation Health Protection," including the creation of Public Health Ontario, the Provincial Infectious Diseases Advisory Committee, regional infection prevention and control networks and the expansion of the public health workforce. In addition, a similar review at the federal level led to the establishment of the Public Health Agency of Canada and the appointment of Canada's first Chief Public Health Officer.

My fourth story concerns pandemic influenza. In late 2008, global public health officials determined that the type of influenza that was likely to circulate in the northern hemisphere was a pandemic H1N1 strain. It was expected that this strain would be more virulent, strike earlier than in past years and, being H1N1, adversely affect younger populations. Among the public health measures to be put in place were mass immunization and assessment centres to divert "milder" cases from hospital emergency rooms. Once again, a multi-disciplinary team was put in place to lead the following tasks:

- Locating and acquiring/renting sites for mass immunization;
- Storing and distributing the new influenza vaccine to vaccine delivery agents;
- Administering influenza vaccines at mass immunization sites;
- Establishing assessment centres;
- Managing institutional outbreaks of influenza and supporting local hospitals and long-term care homes;
- Implementing the new pandemic information system; and,
- Disseminating information to our community partners and the public.

By the time our response had ended, positive outcomes included the immunization of over 100,000 Durham residents and the dissemination of 10,000 doses of vaccines to local delivery agents.

Unfortunately, on December 16, 2009, towards the tail end of our response, a USB key containing the names, addresses and OHIP numbers of over 83,000 immunization clients was lost. This privacy breach was investigated by the Information and Privacy Commissioner (IPC) who issued a damning report and order, *Personal Health Information Protection Act Order HO-007*, in January 2010. Yet another team was struck to manage the breach, including responding to the order, which was due one month later. Our overall response included:

- Notifying affected clients of the breach (prior to the IPC investigation having been completed);
- Responding to inquiries from the media and the public;
- Removing all non-encrypted mobile media (i.e., CDs, USB keys, etc.);
- Preparing a comprehensive report as part of the IPC's investigation;
- Developing a response to the order and submitting it to the IPC;
- Encrypting all PCs, laptops and purchasing encrypted USB keys;
- Developing and implementing a complete set of privacy and information security policies and procedures;
- Striking a Privacy & Security Committee;
- Hiring a Manager, Health Information, Privacy and Security; and,
- Defending the Region of Durham from a multi-million dollar class-action lawsuit.

Cultivating Future Public Health Leaders Through Teamwork

We emerged from this tragedy much stronger and are now seen as privacy and security leaders within the public health community. As a result, we co-chaired a Ministry of Health and Long-Term Care Information Privacy Working Group, which produced a variety of products for use by the Ministry and public health units as they embarked on their own privacy and security journeys.

My fifth and last story is about solid waste management. The Region is responsible for the disposal of solid waste. For many years, Durham's garbage was transported to Michigan and New York State for burial in landfill sites there. When Michigan closed its borders to the transport of solid waste, the Region had to implement an integrated waste management solution. In addition to diverting waste through recycling, the Region decided to construct a waste incinerator to reduce the volume of its solid waste. It chose this route because building a new local landfill site was simply not an option in the eyes of local residents, owing to Toronto shipping its garbage to the Brock West Landfill Site in Pickering for burial for many years until its closure. The Region of Durham, together with its partner the Region of York, needed to conduct an environment assessment and secure the approval of the Minister of the Environment before proceeding with waste incineration. Another multi-disciplinary team was brought together to steer our participation in this project, which included:

- Conducting a literature review regarding the human health effects, if any, of living near waste incinerators;
- Reviewing a generic human health risk assessment;
- Reviewing an international best practices scan as regards environmental surveillance of waste incinerators;
- Arranging a peer review of the site-specific human health risk assessment;
- Providing public health advice to Regional Council on the environmental assessment and the establishment of a site-specific environmental surveillance program; and,
- Providing public health advice to Regional Council on the modelled dispersion of PM 2.5 emissions from the incinerator.

The Regions of Durham and York accepted all of our advice and as a result, in part, the Minister approved the project with conditions. The waste incinerator, the Durham York Energy Centre, was constructed and after a few bumps along the way, began commercial operations in 2016. What do all these stories have in common? Certainly these real world problems are unique:

- The amalgamation of six land ambulance services to form Durham Region EMS/Region of Durham Paramedic Services.
- The uploading of tobacco control powers and enactment of the Durham Smoke-Free By-law.
- The public health response to SARS caused by a novel respiratory pathogen.
- The public health response to pandemic influenza.
- The management of a serious privacy breach.
- The construction of Ontario's newest waste incinerator in many decades.

Quite simply, the foregoing successful outcomes simply would not have been possible without assembling multi-disciplinary teams who worked together to develop and implement project plans. What are the advantages/benefits of team decision-making and execution? I can think of a few, in no particular order of importance:

Cultivating Future Public Health Leaders Through Teamwork

- Working in teams involves members bringing their complementary assets, knowledge and skills to the table and being equitably responsible for the work at hand.
- Information about the project is shared among the team members, thus benefiting both their disciplines and divisions.
- Team members can offer a variety of options and collectively weigh the pros and cons before coming up with the best solutions, which are usually more accurate, feasible, practical and possibly innovative.
- Team members adopt the shared goals of the project; by taking collective responsibility for their achievement, they are collectively more enthusiastic and more likely to assist one another to achieve the goals.
- By being part of an effective team, members are more likely to share knowledge, skills and responsibilities and take risks, where appropriate, through mutual support and reassurance.
- Teams can often face more complicated and difficult issues than individual members.
- Teams can complete projects more quickly than individual members through, for example, the more effective allocation of human resources.
- As was the case in responding to our privacy breach, new measures can be more effectively implemented throughout an organization through shared understanding and ownership of the issue and the decision and the involvement of all.
- In general, working in teams builds trust and improves morale and motivation.

Upon reflection, taken together, all of the foregoing were evident and in play in the teams that we assembled. However, developing future public health leaders does not start and end with team decision-making and execution. We develop our future leaders by giving them opportunities to participate in leadership events (e.g., active participation in professional associations, serving on/leading internal and external planning tables, etc.) commensurate with their knowledge and skills. These are supported, for example, by/through coaching and mentoring; performance management, with a heavy emphasis on addressing key Regional, public health and professional competencies and by supporting corresponding learning and development plans; supporting evidence informed decision making; staff engagement; and, staff recognition.

In conclusion, to all aspiring public health leaders who happen to read this piece, roll up your sleeves, be part of a team that tackles real world problems, and seize leadership opportunities as they arise...the future is yours!

CASES

CASE 1

Where are the Sex Workers?

Jaspreet Bhullar, RN, BScN, MPH (MPH Class of 2016)
Rebekah Vaughan, BScN (Bloom Coordinator, WellFort Community Health Services)
Gerald McKinley, PhD (Assistant Professor, Western University)

On August 25, 2014, Sarah Briar, an outreach worker for the Bloom Clinic in Brampton, Ontario, sits at a monthly Peel Harm Reduction meeting, hosted by the Peel Harm Reduction Network. Harm reduction is defined as “a range of practical strategies and ideas focused on reducing the harmful consequences associated with drug use and other risky health behaviours” (Ontario Harm Reduction Distribution Program, 2016). This collaborative-based meeting is supported by a collection of various community support services who discuss key issues and build collective efforts towards harm reduction strategies. Sarah is fairly new to the Bloom Clinic and has previous work experience as a health promoter for refugees transitioning into Canada. Sarah’s work experiences have gained her tremendous knowledge on health behaviour risks with newcomers and on challenges associated with resettlement. In addition, her work experience has built effective partnership collaborations and sustainable stakeholder interests for the Bloom Clinic.

Across from Sarah sits Constable Radishwich, of the Peel Regional Police. Constable Radishwich is involved with the Community Support and Safety division of the Police Department. He has been working for the Peel force for 18 years, and has been awarded many medals for his community based achievements. Furthermore, he speaks regularly at public meetings as an advisor for the Mayor of Mississauga and attends the monthly Harm Reduction meetings to support and speak of harm reduction strategies. In addition, he provides suggestions on how the Peel Regional Police can help other community services in reducing the negative impacts affecting community members.

The meeting consists of a brief recap of last month’s minutes and discussions on various community projects and/or concerns. As this meeting was nearing the end, Constable Radishwich informs the attendees of the potential passing of Bill C-36 (*Protection of Communities and Exploited Persons Act*) and how it is targeted at criminalizing the sex buyers. Most of the committee members know about Bill C-36 and are in agreement that this bill will heavily impact sex workers in Canada. As members are leaving the meeting, they chat amongst themselves on the potential implications the bill will have on the sex industry and, specifically, the sex workers.

Since Sarah is new to the Bloom Clinic and the Peel Harm Reduction meetings, she has not heard of Bill C-36 before and feels apprehensive about asking what it is. She listens to the comments by others around her and thinks of her own team’s current challenges of reaching out to sex workers for Hepatitis C and HIV testing and treatment. Sex workers have a high level of stigma attached to their profession, which creates challenges to Hepatitis C and HIV testing and treatment due to fear of judgment. Presently, sex workers are not specified under the Ministry of Health and Long-Term Care’s (MOHLTC) current mandate for the Hepatitis C Team Program Guidelines. The mandate’s goal is to reduce the spread of Hepatitis C and to provide support

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and collaborative care for diagnosis and treatment (MOHLTC, 2013). The current MOHLTC mandate targets certain vulnerable groups who face barriers to accessing health care. The six priority populations, listed below, unfortunately do not capture sex workers.

Sarah leaves the meeting and sits in her car, pondering the implications of Bill C-36 for sex workers. She decides to do a quick search on her smartphone on Bill C-36 to find information on this new legislation. One of the first article links she comes across on Google is titled “Canada’s new prostitution laws: Everything you need to know” from the *Globe and Mail*.



Canada's new prostitution laws: Everything you need to know

JOSH WINGROVE

The Globe and Mail

Published Tuesday, Jul. 15, 2014 10:43AM EDT

Last updated Tuesday, Sep. 09, 2014 12:23PM EDT

The article written by Josh Wingrove (2014) provides a brief synopsis of Bill C-36’s focus, the changes to the *Criminal Code* (1985), and a brief historical timeline that led to the formation of Bill C-36. In addition, the article informs Sarah of the potential violation of the *Canadian Charter of Rights and Freedoms* (1982) in regards to Bill C-36.

Sarah emails the article to the Bloom Clinic team and adds Bill C-36 to the discussion topics of the upcoming team meeting.

BACKGROUND

The Bloom Clinic is a MOHLTC-funded team that facilitates Hepatitis C testing and treatment for the Peel Region (Brampton, Mississauga, and Caledon). In addition, the Bloom Clinic tests for HIV, STIs, and other Hepatitis viruses for care and treatment. This program emerged from a 2009-2014 strategy by the MOHLTC to address Hepatitis C treatment gaps within Ontario (Exhibit 1). Currently, there are 17 Hepatitis C Virus (HCV) teams across Ontario to address the accessibility gaps in screening, care, and treatment. The proposed strategy was based on five components: treatment, prevention, education, support, and research & surveillance (MOHLTC, 2013).

The six priority populations listed below were identified as at-risk peoples due to having barriers “accessing traditional forms of health care” (MOHLTC, 2013):

- Substance users
- People involved with the correctional system
- Homeless people and those with inadequate housing
- Aboriginal Peoples
- Street-involved Youth
- People with tattoos and/or piercings (MOHLTC, 2013)

The specially designed, multidisciplinary Bloom Clinic HCV team consists of a coordinator, outreach worker, nurse, and a psychosocial support worker (MOHLTC, 2013). Additionally, the Bloom Clinic utilizes a peer support worker from the target at risk vulnerable community that provides added support to the team. The peer support worker helps bridge communication and trust between the Bloom Clinic team and the at-risk peoples. The Bloom Clinic’s specialized

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team considers the social determinants of health that surround the individual and the stigmatization associated with testing and treatment in their plan of care. Each team member brings unique skill sets to support the needs of the vulnerable Peel Region community members.

Services offered by the Bloom Clinic include confidential testing and treatment of Hepatitis C and HIV, peer-support workshops, and education on treatment/prevention. In addition, the clinic provides a holistic care approach, referrals to primary care services, and collaborative care with community health care providers (Bramalea Community Health Centre, 2016).

SUPPORTING SEX WORKERS FOR HCV TESTING AND TREATMENT

Sarah Briars' roles and responsibilities outlined by the Hepatitis C Team Program Guidelines are the following:

- Provide education and training for HCV testing, treatment, and prevention.
- Facilitate educational workshops in places easily accessible for the six priority populations.
- Actively outreach in areas where at-risk persons may frequently visit.
- Assist clients with necessary paperwork/documentation (eg. health cards and birth certificates).
- Provide emotional support for clients during medical appointments, if needed.
- Recruit and train peer support workers.
- Report information to the governing agency.
- Design and develop educational materials on HCV and HIV, and distribute this information in various places visited by at-risk persons.

Sarah has been a Bloom Clinic outreach worker for less than a year and has gained valuable experience working with marginalized community members. She works hard to continually reach out to individuals within organizations/places (i.e. shelters, community kitchens, places of worship, and methadone clinics) to attract patients for Hepatitis C and HIV testing and treatment.

The Bloom Clinic's present outreach strategy (Exhibit 2) is based on the following:

- Mapping and exploring community partnerships.
- Responding to and connecting with Peel Region agencies/organizations.
- Identifying target populations who are at risk for HCV and/or HIV.
- Community engagement by identifying barriers to testing and treatment.

However, Sarah wants to expand her outreach beyond the Ministry's current mandate with other vulnerable populations such as sex workers, who are at risk for Hepatitis C and/or HIV infections. Presently, sex workers are not specifically identified in the current MOHLTC mandate; however, some sex workers fit the criteria of an at-risk person under the existing guidelines. Sex workers benefit from a combination of harm reduction strategies and accessibility to health care services for HIV prevention (Lazarus et al., 2012). There is the societal myth that all sex workers are drug users and/or have a history of sexual abuse; thus, this societal myth translates to the assumption that sex workers are captured under the present six specified populations outlined by the MOHLTC (Benoit & Shumka, 2015).

Studies have shown 15% to 30% of individuals who do not seek treatment for Hepatitis C will have their condition progress to cirrhosis of the liver and/or death. It is also challenging for sex workers to obtain health care, as they fear "disrespect from health care providers" (Socias et al., 2015).

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Sex workers are a vulnerable population due to their risk of exposure to infectious diseases and violence; therefore, they are sensitive to negative health outcomes. Sex workers are subjected to the stigma and misperception that the nature of their work is illegal (Lazarus et al., 2012). Hence, sex workers are usually not forthcoming with health care practitioners regarding their occupation due to fear of arrest and/or disclosure of practice to authorities (Deering et al., 2015).

According to Benoit and Shumka (2015), a sex worker is a person who exchanges sexual services for money and/or goods. Sex workers vary in demographics such as age, gender, sexual orientation, ethnicity, religion, education, and income level. In Canada, studies have shown sex workers who are migrants/immigrants tend to be tested less often for infectious diseases due to language barriers when accessing testing and treatment (Lazarus et al., 2012).

Sex workers in the Region of Peel provide sexual services in either indoor markets (e.g. massage parlours) or outdoor markets (e.g. on the streets) (Kaminski, 2016). Approximately 20% of sex workers solicit clients on the street, compared to the other 80%, who work in indoor markets (Canadian Public Health Association, 2014). Therefore, there is difficulty in precise data collection on sex worker demographics in Canada. In addition, complexity in locating sex workers builds challenges for Hepatitis C and/or HIV testing and treatment.

CANADA (ATTORNEY GENERAL) V. BEDFORD

On December 20, 2013, the Supreme Court of Canada presided over the *Canada (AG) v. Bedford* case. The plaintiffs, Terri Jean Bedford, Amy Lebovitch, and Valerie Scott, who were current and/or former sex workers, felt the current laws on prostitution violated the *Canadian Charter of Rights and Freedoms* (1982) and created unsafe work environments for sex workers (Lawrence, 2014). This trial was a landmark case as the Supreme Court of Canada ruled in favour of the plaintiffs, declaring sections 210, 212 (1)(j), and 213 1(c) of the *Criminal Code* (1985) unconstitutional and in violation of section 7 of the *Canadian Charter of Rights and Freedoms* (1982): “everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice” (Alberta Justice and Solicitor General, 2014).

The provisions of the *Criminal Code* (1982) relevant to *Canada (AG) v. Bedford* are:

- (a) s.210, which makes it an offence to keep or be in a bawdy-house;
- (b) s.212(1)(j), which prohibits living on the avails of prostitution¹; and,
- (c) s.213(1)(c), which prohibits communicating in public for the purposes of prostitution. (*Criminal Code*, 1985).

Since the court ruling, which struck down multiple prostitution laws, the courts gave the government one year to implement new legislation. Bill C-36 is a proposed amendment to the *Criminal Code* (1985) resulting from the *Canada (AG) v. Bedford* Supreme Court case. Bill C-36's objectives are based on the following:

- The majority of those who sell their own sexual services are women and girls. Marginalized groups, such as Aboriginal women and girls, are disproportionately represented.
- Entry into prostitution and remaining in it are both influenced by a variety of socio-economic factors, such as poverty, youth, lack of education, child sexual abuse and other forms of child abuse, and drug addiction.

¹ Repealed, 2014, c. 25, s. 13.

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- Prostitution is an extremely dangerous activity that poses a risk of violence and psychological harm to those subjected to it, regardless of the venue or legal framework in which it takes place, both from purchasers of sexual services and from third parties.
- Prostitution reinforces gender inequalities in society at large by normalizing the treatment of primarily women's bodies as commodities to be bought and sold. In this regard, prostitution harms everyone in society by sending the message that sexual acts can be bought by those with money and power. Prostitution allows men, who are the primary purchasers of sexual services, paid access to female bodies, thereby demeaning and degrading the human dignity of all women and girls by entrenching a clearly gendered practice in Canadian society.
- Prostitution also negatively impacts the communities in which it takes place through a number of factors, including: related criminality, such as human trafficking and drug-related crime; exposure of children to the sale of sex as a commodity and the risk of being drawn into a life of exploitation; harassment of residents; noise; impeding traffic; unsanitary acts, including leaving behind dangerous refuse such as used condoms or drug paraphernalia; and, unwelcome solicitation of children by purchasers.
- The purchase of sexual services creates the demand for prostitution, which maintains and furthers pre-existing power imbalances, and ensures that vulnerable persons remain subjected to it.
- Third parties promote and capitalize on this demand by facilitating the prostitution of others for their own gain. Such persons may initially pose as benevolent helpers, providers of assistance and protection to those who "work" for them. But the development of economic interests in the prostitution of others creates an incentive for exploitative conduct in order to maximize profits. Commercial enterprises in which prostitution takes place also raise these concerns and create opportunities for human trafficking for sexual exploitation to flourish. (Government of Canada, 2016).

THE NORDIC MODEL

Bill C-36 is a similar approach to Sweden's 1999 Nordic Model, which criminalizes the purchase of sex. Other countries such as Norway and Iceland have also implemented similar legislation to combat the demand for prostitution. In 2014, the European government advised its member and observer states, which include Canada, to implement the same Nordic-Model approach (Government of Canada, 2016).

Since the inception of the Nordic Model in Sweden, there has been a shift from outdoor prostitution to indoor prostitution. Thus, there are claims that this model has increased the repression of sex workers and built challenges to accessing health care services. Sex workers in Sweden have also faced challenges sustaining housing due to stigmatization (Chu & Glass, 2013).

HIV transmission is a concern among sex workers and using condoms is known as a preventative measure. However, sex workers will not carry condoms in Sweden as law enforcement will link condoms with prostitution (Chu & Glass, 2013).

EXAMPLES OF OUTREACH STRATEGIES IN CANADA

Rezo, Montreal, Quebec (CATIE, 2016a)

- Provides outreach service for male sex workers in hotels, strip clubs, and bars.
- Evening drop-in centre to access health services.

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Orchid, Vancouver, British Columbia (CATIE, 2016b)

- Outreach workers visit primarily massage parlours and develop trust among proprietors by giving cookies (Asian etiquette).
- Rapid HIV and STI (sexual transmitted infection) testing is provided in the massage parlours.

REFLECT ON CONFLICTING INTERESTS

As Sarah sits in the meeting she knows that she needs to propose an action. But what? She considers which outreach strategies she and her team can implement. Should she and her team take a political stand and advocate for improvements to Bill C-36? What could the implications be if they do enter the political arena? How can she influence policy from her position? Is that within her job description? Does the Oakes test² validate her by confirming if Bill C-36 violates the *Canadian Charter of Rights and Freedoms* (1982)?

- 1) What outreach strategies should Sarah Briar and her team implement to reach Sex Workers in the Peel Region for Hepatitis C and/or HIV testing and treatment?
- 2) Does Bill C-36 violate the *Canadian Charter of Rights and Freedoms* (1982)? (e.g. is the Oakes test met?)
- 3) Should the Bloom Clinic team advocate to improve the provisions of Bill C-36? Are there any implications, since they are a Ministry funded team?

CONCLUSION

At the Bloom Clinic meeting, the team discusses Bill C-36. Sarah briefed the team on the Peel Harm Reduction Meeting she attended, and the feedback regarding upcoming pass of Bill C-36. Each team member read the Globe and Mail article and discussed the implications to their care and outreach. The team was in unison over the complex legal implications of Bill C-36, and their limited resources to advocate and build trust within the sex worker community.

² “This two-part legal test, known as the Oakes test, is applied each time a Charter violation is found in order to determine if a law that infringes a Charter right can be justified under s. 1 of the Charter. The Oakes test is outlined as follows:

1. There must a pressing and substantial objective for the law or government action.
2. The means chosen to achieve the objective must be proportional to the burden on the rights of the claimant.
 - i. The objective must be rationally connected to the limit on the Charter right.
 - ii. The limit must minimally impair the Charter right.
 - iii. There should be an overall balance or proportionality between the benefits of the limit and its deleterious effects.” (Ontario Justice Education Network, 2013).

EXHIBIT 1

1 Introduction

The Hepatitis C Secretariat worked with stakeholders across Ontario to conduct a needs assessment, gathering evidence and community input to inform the key recommendations that address the gaps in hepatitis C service delivery.

Community consultations were held in 13 communities across Ontario with stakeholder representation including Aboriginal health and social services, social service agencies, health care providers, correctional facilities and people living with/affected by the hepatitis C virus (HCV).

Subsequent to these meetings, each of the 13 communities were asked to identify a representative to conduct further local consultations with health and social service providers and produce a local community strategy for addressing hepatitis C in their community. The 13 local community strategies were submitted to the Hepatitis C Secretariat and shared with the Ontario Hepatitis C Task Force members. Information acquired through both the local community consultations and the local community strategies were used to inform the Task Force's [A Proposed Strategy to Address Hepatitis C in Ontario: 2009 – 2014](#).

The Task Force's proposed strategy was presented to the Minister of Health and Long-Term Care in September 2009. [A Proposed Strategy to Address Hepatitis C in Ontario: 2009 - 2014](#) focuses on 40 recommendations in 5 priority areas: treatment, prevention, education, support and research & surveillance.

In response, the ministry received cabinet approval in February 2010 to put forward the Ontario Hepatitis C Strategy. The key elements of the Strategy consist of the following:

Enhanced Services and Supports

Creation of 16 "HCV Teams" to ensure a coordinated, comprehensive approach to treatment and support of those living with/at risk of acquiring hepatitis C. The HCV teams consist of HCV outreach workers and community coordinators, additional HCV treatment nurses and access to psychosocial supports.

Education and Outreach

A targeted education and outreach strategy for at risk communities, and a continuing medical education program for physicians and health professionals.

Encourage Prevention

Additional Support for the Ontario Harm Reduction Distribution Program.



Source: MOHLTC, 2013.

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EXHIBIT 2

Bloom Outreach Strategy

Activities	Short-term Outcomes (learning)	Intermediate Outcomes (action)	Long-term Outcomes (change in conditions)
PHASE I			
1 Mapping & Exploring potential Partnerships: Identify allies in the community to partner with	Identifying which community allies can increase our ability to test, screen & treat those living with HCV	Promotes professional networking to identify new testing sites	Increased accessibility for individuals to be tested in community sites and be connected to treatment
	Identifying mutual interests and goals	Engaging in meaningful conversations that lead to collaborative approaches	Strengthens and supports Bloom Clinic goals for testing and treatment access
2 Responding & Connecting: Community engagement with Peel Region partner agencies/organizations	Identifying commonalities that will increase potential partnerships	Collaboration of programs to increase accessibility of HCV support to current and new clients	Strengthens and supports Bloom Clinic goals for testing and treatment access
		Increases more effective referral practices between partner agencies for clients living with HCV	More individuals are connected to supports for HCV and intersecting needs
3 Identify potential target populations	Understanding which target populations are at risk for and are living with HCV	Reaching more community members who want to be tested and access HCV treatment	More individuals are connected to treatment, thus decreasing risk and transmission of HCV/HIV in Peel Region
PHASE II			
1 Community Engagement: Identify intersecting client needs while testing for HCV	Understanding what barriers are impacting individuals seeking testing	Practical, social and emotional needs are met/addressed thus increasing quality of life	Clients accessing additional Bloom Clinic services are aware of testing & treatment support
		Increase understanding of HCV in the community through presentations and workshops, and distribution of program resources	Increased education on transmission methods prompts more individuals to be tested, screened and treated
	Raise awareness on HCV risks and vulnerabilities	Individuals access pre-test/post-test counselling to support adaptive & coping behaviours and strategies	Clients feel more supported and increases adherence to treatment for successful outcomes

Source: WellFort Community Health Services (2016). Bloom clinic strategy. Unpublished internal document.

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INSTRUCTOR GUIDANCE

Where are the Sex Workers?

Jaspreet Bhullar, RN, BScN, MPH (MPH Class of 2016)
Rebekah Vaughan, BScN (Bloom Coordinator, WellFort Community Health Services)
Gerald McKinley, PhD (Assistant Professor, Western University)

BACKGROUND

The Bloom Clinic of the WellFort Community Health Services in Brampton, Ontario is mandated to serve six specific populations for HCV (Hepatitis C Virus) testing. The Bloom Clinic also tests for all Hepatitis viruses, HIV and STIs. The six priority populations listed below were identified as at-risk peoples due to having barriers “accessing traditional forms of health care” (Ministry of Health and Long-Term Care, 2013).

- Substance users
- People involved with the correctional system
- Homeless people and those with inadequate housing
- Aboriginal Peoples
- Street-involved Youth
- People with tattoos and/or piercings

The specially designed, multidisciplinary Bloom Clinic HCV team consists of a coordinator, outreach worker, nurse, and a psychosocial support worker (Ministry of Health and Long-Term Care [MOHLTC], 2013). Currently, the Hepatitis C Team Program Guidelines by the MOHLTC do not include sex workers. However, some sex workers are captured within the six identified specific populations. The mandate's goal is to reduce the spread of HCV by providing accessible support for testing and treatment (MOHLTC, 2013). Statistics show 20% of sex workers work outdoors (e.g. street corners) and the other 80% work indoors (e.g. their own home or client's home, or commercial venues) (Canadian Public Health Association, 2014).

Sarah Briar, the outreach worker for the Bloom Clinic, presently builds partnerships with various organizations, health care providers, and community leaders. Building partnerships is part of the Bloom Clinic Outreach Strategy (Exhibit 1).

Sarah sat at Peel's Harm Reduction meeting and was informed by Constable Radishwich of the potential passing of Bill C-36 legislation. Bill C-36 is intended to criminalize those who purchase sex; this legislation is to resemble the Nordic Model in Sweden. Bill C-36 is the proposed amendment to the *Criminal Code* (1985); however, there is a concern that Bill C-36 will drive more sex workers to work underground and create barriers for health services outreach strategies.

Sarah shares with her team the potential impact of Bill C-36 and how it will affect the outreach strategies for HCV and HIV prevention and treatment. The team is Ministry funded, with limited resources and governance power to improve the provisions of Bill C-36.

Where are the Sex Workers?

OBJECTIVES

1. Learning the implications of legislation (Bill C-36) on accessibility of services for the vulnerable (outreach strategies).
2. Division of Powers (Federal and Provincial) in reference to Bill C-36.
3. Challenge Bill C-36 by applying the Oakes test – *Canadian Charter of Rights and Freedoms*.
4. Challenges working within a Ministry funded program; in regards to exceeding the Hepatitis C team Program Guidelines and objectives.

DISCUSSION QUESTIONS

1. Apply the Nordic Model (Sweden) to the Canadian context. What are similarities and differences within the two judicial systems and demographics?
2. Discuss the Oakes test – *Canadian Charter of Rights and Freedoms*; is Bill C-36 proposed provisions connected to its purpose?
3. After developing a concept map of the social determinants of health for sex workers, which outreach strategies would you implement?

KEYWORDS

Oakes test; Hepatitis C Virus (HCV); harm reduction; accessibility; social determinants of health; *Criminal Code*; health behaviours; *Canadian Charter of Rights and Freedoms*; advocacy.

CASE 2

Saving the Rural Ontario Maternity Services – Can We Do It?

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Preeti Nigam, BSc, MBA (Senior Program Manager, Provincial Council for Maternal and Child Health)

Shannon L. Sibbald, PhD (Assistant Professor, Western University)

“If you want to go quickly, go alone. If you want to go far, go together.”

– African Proverb

It was a warm summer morning in Toronto, Ontario; Inaya Roy – a promising, young project manager at the Provincial Council for Maternal and Child Health (PCMCH) and already a starlet of the organization – was shifting uncomfortably in her chair. She was intermittently losing her focus trying to read through a report on the recent closure proposal of a birthing unit in Leamington (a small rural town southwest of Toronto). While reading the report, she couldn't help but reminisce on her conversation with an old family friend, Lisa Brown who, like many others, had shared her pregnancy experience with Inaya.

This was the story of Lisa's second baby's birth when she was 25 years old. She had decided to have her delivery at home with a midwife, just like she did three years prior with her first born. Lisa had recalled the first delivery as incredibly peaceful and unobtrusive. The comforting nature of her first delivery and her synergic partnership and established relationship with her midwife had made her choice of home delivery for her second child a no-brainer.

However, Lisa's second birth did not go as smoothly as she had expected. The midwife sensed something was off as soon as Lisa's water broke and observed that her amniotic fluid was thick with meconium, the early stool that an infant usually passes after, not before, they are born. In such a scenario, it is highly likely for the baby to inhale meconium in the mother's womb and struggle to breathe at birth (Grant, 2015). With her midwife's recommendation, Lisa and her husband abandoned the plan to deliver at home, and she was rushed to the nearest obstetrics ward in an ambulance 15 minutes after the complication arose. After half an hour, her second baby, Aaron, emerged – frighteningly silent. The midwife's suspicion came true; Aaron didn't cry out loud until all the meconium was suctioned out of his lungs in the obstetric ward.

Inaya could vividly recall Lisa's shuddering – even three years after the incident – at the thought of not having access to an obstetrics unit so close to her home during her pregnancy complication, as she feared she would have lost her baby son that day. Now three years old, Aaron is completely healthy, giggling, and waving at aunt Inaya from his mother's lap.

Lisa's story is not unique. Inaya has heard countless stories of how lack of access to maternity care plagues the rural and remote areas and adversely affects pregnancy outcomes. Most troubling were the stories about women who live more than four to five hours away from maternity wards and how this affects them both financially and emotionally. Many women must travel a long distance, leave their communities three or four weeks before their due dates, and sometimes have to arrange to stay in hotels close to the hospitals.

Already a rising star at PCMCH, Inaya's unrelenting passion for maternity care had not gone unnoticed by her superiors. They tasked her with a formidable challenge: coming up with an integrative solution for the issues encompassing maternity and prenatal care in Ontario.

BACKGROUND

Ontario, the largest province by population in Canada, is divided into 14 Local Health Integration Networks (LHINs) for better integration and coordination of services and funding health care costs (Born & Sullivan, 2011). However, in this regionalized system, each hospital has its individual board of directors. Currently, there are a total of 96 hospitals in the province providing maternal and newborn services (PCMCH, 2017). According to Ontario's Better Outcomes Registry & Network (BORN, 2015) in 2013-14 a total of 97.1% Ontario births were hospital births and only 2.6% were home births (Exhibit 1).

Maternity Ward Closure at Leamington District Memorial Hospital

Leamington District Memorial Hospital (LDMH) is located in Leamington, Ontario - a rural municipality in the Essex County with a population size of approximately 28,403 (Statistics Canada, 2016). Since 1950, the hospital has been serving the city of Leamington as well as Essex and Chatham-Kent with a catchment area containing a population of 75,000 (LDMH, 2011).

Besides LDMH, the next closest hospital is in the urban city of Windsor, Ontario, and it takes between 40 to 60 minutes (sometimes even longer, depending on weather and traffic) to drive there. When the LDMH board submitted a proposal on October 31, 2014 to close its obstetrical unit in 2015, many community residents and stakeholders expressed concerns regarding the potential risk of having no other birthing centre in Leamington (Erie St. Clair LHIN, 2014). As a result of public protests by the local midwives, midwifery clients, and community residents, on November 27, 2014, the Erie St. Clair LHIN created an expert panel to review, assess, and evaluate the proposal and identify solutions. After assessment and evaluation, the panel recommended a new, sustainable, integrated, community-based, patient- and family-centric birthing service model in their report.

Maternity Services in Rural Ontario

LDMH was not the only maternity ward in Ontario facing closure. In response to external and internal challenges facing Ontario's health system, the province saw the closure of other rural maternity programs, over the last few years (PCMCH, 2015b). More than 40 hospitals, mainly in rural areas, have closed their obstetric wards in the last decade in Canada, and at least ten maternity hospital wards have closed in Ontario in the past ten years (Grant, 2015). Often, the closure of maternity care units in rural hospitals has resulted from the growing trends of centralization of health services towards regional centers (Association of Ontario Midwives [AOM], 2015).

According to the Southwestern Ontario Regional Perinatal Services Project Coordinating Committee report (2003), 12 hospitals in the region have stopped offering obstetrical care and obstetrical units and another 11 hospitals are at risk of closure in the near future (AOM, 2015). Similarly, BORN data shows that another five hospitals in Ontario have closed their obstetrical units since 2011 (AOM, 2015). According to the AOM (2015), different factors contribute to this trend of rural maternity unit closure, including decreasing birth volumes, shortage of different health professionals to provide intra-partum and newborn care, difficulty in recruiting maternal care providers, concerns about the quality of maternal and newborn outcomes in small facilities, occupational stress, perceived medico-legal risk, and budgetary or financial constraints.

Effect of Local Maternity Unit Closure

In Ontario, the number of people living in rural regions is 1.8 million, which is 14.1% of the province's population (Statistics Canada, 2011). Seen through an equity lens, huge disparities and health inequity persist between the urban and rural populations. For example, people living in rural areas have a lower life expectancy at birth, higher all-cause mortality, and worse self-rated health compared to urban populations (AOM, 2015). Additionally, compared to urban women, the rate of severe maternal morbidity is higher in rural women (2.4% versus 1.7%) (Canadian Institute for Health Information, 2013).

Closure of maternity or obstetric units in rural regions has a wide range of effects, from negative health outcomes of mothers and newborns to economic impact on the families of the pregnant women (as they have to pay out of pocket to travel to access maternity care elsewhere). Socioeconomically disadvantaged women face additional challenges such as accessing transportation, getting paid time off work, and finding childcare. Closures can also negatively affect the local businesses and eventually recruitment of young families to the region, as the unavailability of maternity services nearby can increase the chance of absence from work and undue hardships (AOM, 2015). Furthermore, it can cause disruption to the community's sense of belonging - a key health and wellness indicator (Miewald et al., 2001).

According to the Public Health Agency of Canada (2009), 25.6% women had to travel to another city or community to give birth in 2009, and the percentage of these women who travelled more than 100 kilometers to give birth was 2.5%. The separation of pregnant women from their families and communities can cause negative outcomes. The health and economic impacts of the unavailability of local maternity programs is well documented.

Grzybowski, Stoll, & Kornelsen (2011) in their provincial rural study found that distance to service is positively linked to adverse maternal and newborn outcomes. The study showed that women who live more than four hours away from maternity services were at 3.17 times higher risk of experiencing perinatal mortality than women served by local maternity units. Additionally, the study found that women living two to four hours away from maternity services experienced a higher induction rate, and the women living one to two hour(s) away had a six times higher rate of unplanned out-of-hospital delivery or delivery at the side of the road.

“No Robust Evidence Base” for Closing Rural Maternity Units

The co-director of the Centre for Rural Health Research at the University of British Columbia states that there is no 'robust evidence base' for closing small rural facilities. However, there is a concern regarding the quality of maternal and newborn outcomes in small facilities, as there is small delivery volume. Although there are a limited number of studies exploring the link between quality and volume in obstetrics, some Canadian studies showed that there is no relationship between delivery volume and adverse outcomes (Silversides et al., 2013). Klein, Spence, Kaczorowski, Kelly and Grzybowski (2002) found that family physicians' delivery volumes were not associated with adverse or negative maternal or newborn outcomes. Additionally, different studies at national and regional levels show that with or without caesarean section capacity, service models at rural sites are associated with positive outcomes (Grzybowski et al., 2015). In fact, Grzybowski and associates demonstrated the strong need for sustained, small, local maternity services by composite analysis of data from three Canadian provinces.

OVERVIEW OF THE PROVINCIAL COUNCIL FOR MATERNAL AND CHILD HEALTH

In 2008, the transition of the Provincial Council for Children's Health (PCCH) (formed in 2006) to become PCMCH (hosted by The Hospital For Sick Children [SickKids]) began with an expanded mandate recognizing the continuum of care within the maternal, newborn, child, and youth

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health care system in Ontario. Two unique goals of PCMCH are to generate information to support the evolving needs and serve as a resource to the maternal-child health care system in Ontario. The goal is to support system improvement and to influence how services are delivered across all levels of care (PCMCH, 2015a). The organizational structure of PCMCH is shown in the Exhibit 2.

The vision of the organization is “The Best Possible Beginnings for Lifelong Health” and the mission is as follows:

- **Be the provincial forum** in which clinical and administrative leaders in maternal and child health can identify patterns and issues of importance in health and health care delivery for system support and advice.
- **Improve the delivery** of maternal-child health care services by building provincial consensus regarding standards of care, leading practices and priorities for system improvement.
- **Provide leadership and support** to Ontario's maternal and child health care providers, planners and stewards in order to maximize the efficiency and effectiveness of health system performance.
- **Mobilize information and expertise** to optimize care and contribute to a high-performing system, thereby improving the lives of individual mothers and children, providers and stewards of the system (PCMCH, 2015a; PCMCH, 2016a)

‘LOW RISK’ PROJECT OF PCMCH

On November 17th, 2014, the Minister of Health and Long-Term Care met with the AOM. The Minister committed to exploring opportunities to devise a provincial, low-risk maternal/birthing strategy that would develop sustainable models and options for maternity care in smaller communities, support communities that are currently facing difficulties sustaining their local maternity care programs, and support appropriate and safe growth in home and out-of-hospital births (PCMCH, 2015b).

In the ensuing months, ministry staff engaged in discussion with the PCMCH to assess the Council’s interest and capacity to lead the development of the strategy on behalf of the Ministry and provide recommendations to the Ministry. PCMCH leadership reciprocated with earnest interest to undertake this project for the Ministry (PCMCH, 2015b).

The Low Risk Maternal Newborn Strategy project of PCMCH aims “... to design and develop effective low risk maternal and newborn strategy for Ontario (Exhibit 2). Maternal and newborn care lies as a foundational core of healthy continuity of any society – and thus the province of Ontario spends approximately one billion dollars annually to provide and ensure a healthy beginning for mothers, babies and their families” (PCMCH, 2015b).

However, the lack of systemic, province-wide policies and strategies in place engenders equity issues, especially in accessing services like delivery options and timely access to care centers. According to PCMCH, “an effective low risk maternal and newborn strategy will help to ensure that all women have equitable choice of delivery options, and access to the right level of care at the right time, no matter where they live in the province as the majority of pregnancies and births are considered as low risk or ‘normal’” (PCMCH, 2015b, Exhibit 3).

To lead the development of this provincial strategy, PCMCH conducted an environmental scan on the evolving changes in access, quality, technology, etc... of provincial maternity care, as well as quantitative data analysis. They identified potential affected stakeholder groups and convened a group of dedicated professionals to form a Low Risk Maternal Newborn Leadership

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Team and Expert Panel comprised of leaders ranging from midwifery, family medicine and obstetrics to nursing, anaesthesiology, and paediatrics from across Ontario (PCMCH, 2015b).

The identified affected stakeholders are as follows:

- Women and their families who require maternal and newborn services
- Obstetricians
- Midwives
- Primary care providers (e.g. family physicians, nurses) who deliver maternal/obstetrical services
- Other clinicians who deliver maternal services
- Other physicians who support maternal programs (e.g. general surgery; anesthesia)

In developing the framework for a low-risk model of maternal and newborn care, the Leadership Team and Expert Panel defined five unique periods of time, including the pre-pregnancy, antenatal, late third trimester, labour and birth, and postpartum periods and listed specific essential components for each of the five identified time periods.

ENGAGING THE WOMEN OF ONTARIO IN DEVELOPING THE STRATEGY

Engagement of Ontario women is imperative in the development of the strategy. As an ongoing effort, PCMCH conducted a survey in 2015 to examine a diverse set of perspectives of Ontario women from urban, rural, and remote areas. A total of 3,445 women who had given birth in the past five years (2010-2015) participated in the online survey and provided feedback on the draft component developed by PCMCH. The overview of the survey participants is shown in Exhibit 4. The survey also allowed them to share their views on the current system and comment on how it could be improved. The analysis of the survey results suggested strong agreement of the majority with the key components of the strategy (i.e. vision, values, and the essential components of care). Despite certain limitations of the survey (like selection bias), the invaluable feedback would be incorporated into the strategy. PCMCH's final survey report (2016) included the following recurrent key themes from the survey:

1. Health Care Services – Availability, organization, and delivery of certain services needs to be improved.
2. Medicalization of Pregnancy – Pregnancy should be viewed as a normal process.
3. Autonomy & Informed Choice – Women should be provided with the information they need to make the right decisions for themselves. Individual decisions must be respected.
4. Perinatal Support (Educational & Emotional) – Evidence-based information, support and referral should be provided throughout the perinatal period.
5. Interaction with Health Care Providers & the System – Women should be empowered to be equal partners with their care providers during their care (PCMCH, 2016a).

INTER-PROFESSIONAL COLLABORATION – SOLUTION FOR SUSTAINING RURAL MATERNITY SERVICES

During the bi-weekly and monthly meetings, the Leadership Team and Expert Panel of PCMCH, as well as other stakeholders across the province, has indicated the importance of alternative, sustainable models of inter-professional collaboration (IPC) of different maternity care providers and the efficient allocation of human health resources as potential solutions for preventing the closure of rural maternity wards (Exhibit 3). Additionally, the model will ensure access equity and long-term sustainability of rural maternity units. Effective collaboration between general practitioners, midwives, and nurses can potentially ensure the equity in access and quality of care to rural women, given that the rural community services often struggle to sustain a full-time surgical or obstetric specialist due to lack of resources or low patient volume. IPC has also been

identified as the cornerstone of ensuring birth remains close to home by the Society of Rural Physicians of Canada (AOM, 2015).

IS A CULTURE OF COLLABORATION POSSIBLE IN ONTARIO?

One morning, Inaya was reviewing some research articles about IPC, as she would soon start working with the Leadership Team and Expert Panel on a framework for an integrated, sustainable, low-risk model. Looking at the conceptual framework, models, indicators, and components of collaboration, Inaya realized that developing frameworks for a sustainable inter-professional model is theoretically and practically complex, given the diversity of partners, agencies, funders, programs, and health professions across the pregnancy continuum. She found that currently there are different providers and different models of care that exist for delivering maternal and newborn care. In Ontario, obstetricians do 75 to 80 percent of deliveries, and midwives and family physicians share the remainder (Born & Laupacis, 2011). The distribution of low risk and all Ontario births across different care providers is shown in Exhibit 5. Although in some rural settings, different health care providers often have to work inter-professionally, there are several factors that act as barriers for effective collaboration, such as:

- Lack of awareness about the skills and qualifications of other health professionals.
- Fears over liability and risk.
- Lack of funding to support inter-professional work (AOM, 2015).

DEFINING THE FRAMEWORK AND IDENTIFYING THE MOST COMMON BARRIER TO ACHIEVING THE INTER-PROFESSIONAL MODEL

The Low Risk Maternal Newborn Leadership Team and Expert Panel met on May 9th, 2016 to define the framework of an inter-professional model of care that could support the Ontario Ministry of Health and Long-Term Care (MOHLTC) call for proposals. While developing the framework, it became evident that there is a continuum of inter-professional care, and that most low-risk maternal-newborn models today are at the early stages of this continuum. In order to explore different care providers' perspectives, at the PCMCH meeting, Inaya asked the teams to identify one of the main challenges they face working inter-professionally, especially in a low volume rural setting. The Leadership Team and Expert Panel started to discuss the barriers to achieving an inter-professional model of care, which would be further explored with them over the coming weeks.

INEQUALITY IN CURRENT FUNDING MODEL – THE MOST COMMON BARRIER

After the long meeting, when Inaya was reviewing her notes of different care providers' responses, she noticed that almost all of them identified the current funding model as a main barrier for achieving inter-professional models of care. Some of the key themes that emerged from their responses are listed below.

From the Physicians' Perspectives

- There is no difference in remuneration based on patient complexity (i.e. low risk and complex high risk pay is the same).
- Physicians' payments should be considered based on complexity in a fee for service model.
- Physicians' fees for antenatal and for in-patient postpartum and newborn care are low, which creates an incentive to provide intrapartum care and a competition between care providers as to who "catches" the baby. Thus, antenatal and postpartum care remuneration should be reconsidered (right now greatest incentive is for intrapartum care).

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- They should be paid based on complexity of care to give up the 'low-risk' pool to midwives or other providers.

From the Nursing Perspective

- The difference in nursing remuneration in a hospital setting vs. out of hospital (i.e. lower compensation in community) creates disincentive to work in both settings. However, from the patients' perspectives, continuity of nursing care from hospital to community is lost. Patient and nursing satisfaction would be higher if nurses could provide continuous hospital and community care throughout the perinatal phases.

From the Midwives' Perspectives

- Although within their scope, there is no compensation for preconception or pre-pregnancy care.
- There should be equality of payment for different care providers.

From All Perspectives

- Generally, each provider group feels that there is pay inequality – different care provider groups are paid differently for equivalent perinatal care services rendered.
- Case complexity needs to be taken into account in, whatever funding model is used.
- The funding model cannot create incentives/disincentives that would jeopardize women's access to quality of care.
- All providers should be allowed to practice the extent of their scope/skills. There should not be a hierarchy of power in the integrated model.

FINDING A SOLUTION AND HOW TO SATISFY ALL STAKEHOLDERS

After reviewing all these perspectives and her own research notes, Inaya was contemplating the complex problem and how to disentangle the Gordian Knot. Dealing with pregnancy and child birth by itself can be quite daunting and an arduous task for mothers; under no circumstances should a mother have to worry about the availability of skilled help in case of unexpected complications – such help should be available to her immediately and seamlessly. Thus, from a mother's perspective, she should be able to choose the care she wants and a provider who will follow her throughout the process, ensuring best possible clinical outcomes and an overall positive experience. From the perspective of the Ontario Ministry of Health and Long-Term Care, there is an incentive to provide the best care possible in the most cost efficient manner, which is achieved by distinguishing mothers by risk level and availing services accordingly to minimize cost (Born & Laupacis, 2011).

Only a well-integrated model of care can satisfy the wishes of both patients and the health care system. In this model, midwives, obstetricians, nurses, and family physicians all must cooperate and work in collaboration to provide care to patients, each using their special skills when needed. However, the two co-existing and largely independent systems currently in place in Ontario – comprising of midwives and obstetricians – are causing fragmentation and friction between them, resulting in sub-optimal, and likely costly or inefficient, care (Born & Laupacis, 2011).

Inaya pondered whether one integrated model exists that would satisfy all stakeholders in this scenario. In this model, how will provider autonomy be respected? What will be the problem resolution mechanism? How will the decisions be made and who will be held accountable? How will a client's/patient's information (i.e. medical charts) be shared between care providers from different professions? And how can she more effectively engage all the important stakeholder

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groups and incorporate their invaluable input to find solutions? Although seemingly impossible, what gave her hope was the over-arching common end goal: to ensure a safe delivery and the well-being of the mother and a healthy baby.

NEXT STEPS

After a week, using the description of the desired future state of inter-professional models of care, Inaya sent a form by email to the Leadership Team asking them to describe the barriers to achieving this model across the perinatal phases of care (i.e. pre-pregnancy to postpartum care). They would also provide possible solutions to these barriers. This feedback would then be shared with the broader Expert Panel for additional input. In order to obtain the perspectives of different key players of maternity care in Ontario, the findings would then be used to work with relevant partners such as AOM, the Ontario Medical Association, The Ontario College of Family Physicians, The Society of Obstetricians and Gynecologists of Canada – Ontario, the Ontario Nurses' Association, the Joint Provincial Nursing Committee, and the Ontario Hospital Association to develop potential solutions to be shared with the Ministry.

**EXHIBIT 1
Maternity Care in Ontario**

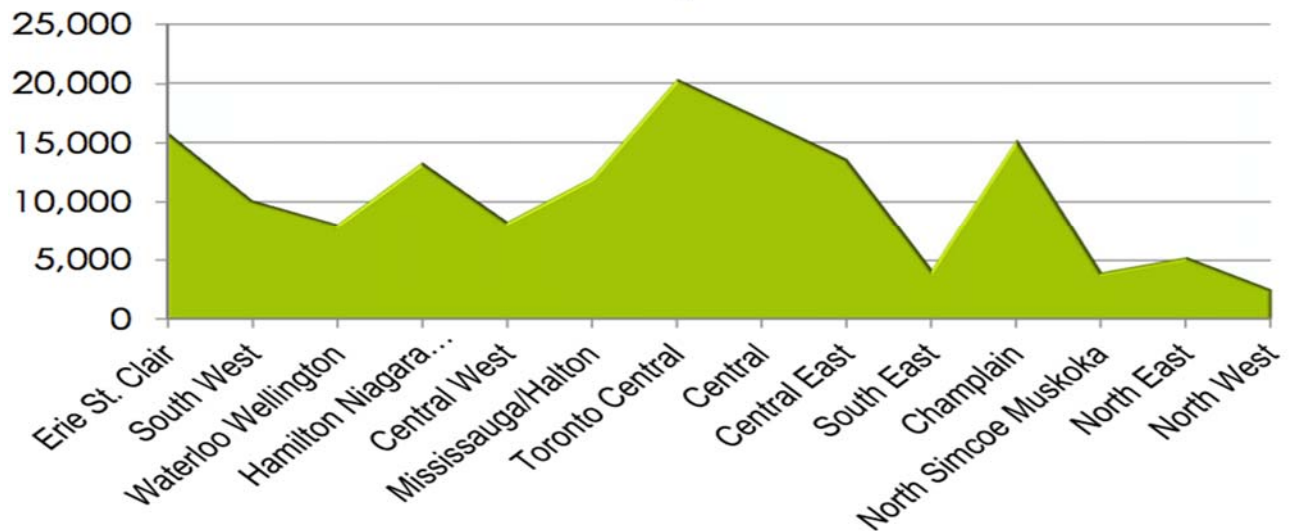
Table: Total Number of Births to Ontario Residents

LOCATION OF BIRTH	2012-2013		2013-2014	
HOME	3563	2.5%	3,705	2.6%
HOSPITAL	137,206	97.0%	135,871	97.1%
BIRTH CENTRE*	N/A		42	0.0%
OTHER†	681	0.5%	336	0.2%
MISSING	11	0.0%	15	0.0%
TOTAL ONTARIO BIRTHS	141,461		139,969	

Source: BORN Ontario, 2015.

Birth in Ontario by the Local Health Integration networks (LHINs)

**Total Births by LIHN 13/14
n=139,594**



Source: BORN Ontario, 2015.

EXHIBIT 2
Organization of the Provincial Council for Maternal and Child Health



Source: PCMCH, 2016b.

The Low Risk Maternal-Newborn Strategy Vision

“Every woman in Ontario will have choice and access to maternal and newborn care that is close to home, from before conception, throughout the pregnancy, and in the first six weeks after birth.”

Source: PCMCH, 2016a.

The Low-Risk Maternal-Newborn Strategy Values

Acceptable & Patient-centered
Health care providers should offer services in a way that is sensitive to an individual's needs and preferences.

Accessible
People should be able to receive the right care at the right time in the right setting by the right health care provider.

Equitable
People should receive the same quality of care regardless of who they are and where they live.

Effective & High Quality
People should receive care that works and that is based on the best available scientific information.

Safe
People should not be harmed by an accident or mistakes when they receive care.

Efficient
The health system should continually look for ways to reduce waste, including waste of supplies, equipment, time, ideas and information.

Source: PCMCH, 2016a.

EXHIBIT 3 Definitions

Low risk pregnancy cohort

Women whose pregnancies fall into Robson criteria 1 to 4, and who do not have any of the health conditions specified below.

- Robson 1 – Nullipara, singleton cephalic, ≥ 37 weeks, spontaneous labour
- Robson 2 – Nullipara, singleton cephalic, ≥ 37 weeks (induced or Caesarean section before labour)
- Robson 3 – Multipara, singleton cephalic, ≥ 37 weeks, spontaneous labour
- Robson 4 – Multipara, singleton cephalic, ≥ 37 weeks (induced or Caesarean section before labour)

Excluding the following health conditions,

Maternal: Diabetes, diabetes complications/ comorbidities, cancer, autoimmune, genetical, cardiovascular, craniofacial, neurodevelopmental, gastrointestinal, gastrouterine, neurology, musculoskeletal, haematological, placental, pulmonary disorders and maternal pregnancy complications.

Fetal: Anomalies or complications.

Source: Best Start, 2016.

Inter-professional collaboration

According to the Canadian Interprofessional Health Collaborative (CHIC), interprofessional collaboration is defined as being “the process of developing and maintaining effective interprofessional working relationships with learners, practitioners, patients/clients/families and communities to enable optimal health outcomes.”

Source: CIHC, 2010.

Inter-professional team models

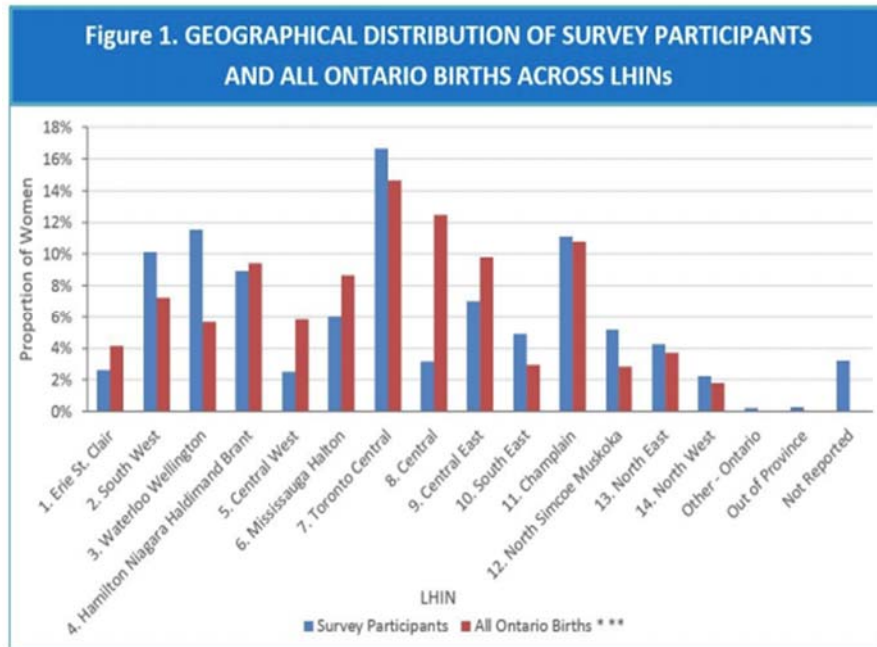
According to Canadian Health Service Research Foundation:

“Interprofessional team models are teams with different health care disciplines working together towards common goals to meet the needs of a patient population. Team members divide the work based on their scope of practice; they share information to support one another’s work and coordinate processes and interventions to provide a number of services and programs. In advanced or mature collaborative teams, the patient and family are included as key members of the team. Examples of interprofessional team models include family health teams, community health centre teams, and integrated health teams. Positive evidence of interprofessional team models is building, particularly for teams working with patients with chronic diseases and/or mental health needs. Interprofessional team models of care vary based on the context, intra-group processes, nature of the tasks, and intensity of collaboration that are engineered in the structure and processes of the teams. The intensity of collaboration ranges from consultative activities to integrative work practices. The effectiveness of teams is dependent on the team members’ knowledge of one another’s roles and scopes of practice; mutual trust and respect amongst the team members; commitment in building relationships; willingness to cooperate and collaborate; and the extent to which the team has organizational supports. Incentives such as appropriate system-level policies/legislation, favourable compensation models, balance in workload, working arrangements (opportunities to communicate, discussion, conducting joint work) and team characteristics (team size, team leadership) influence how team members collaborate to achieve positive outcomes.”

Source: Canadian Health Services Research Foundation, 2012.

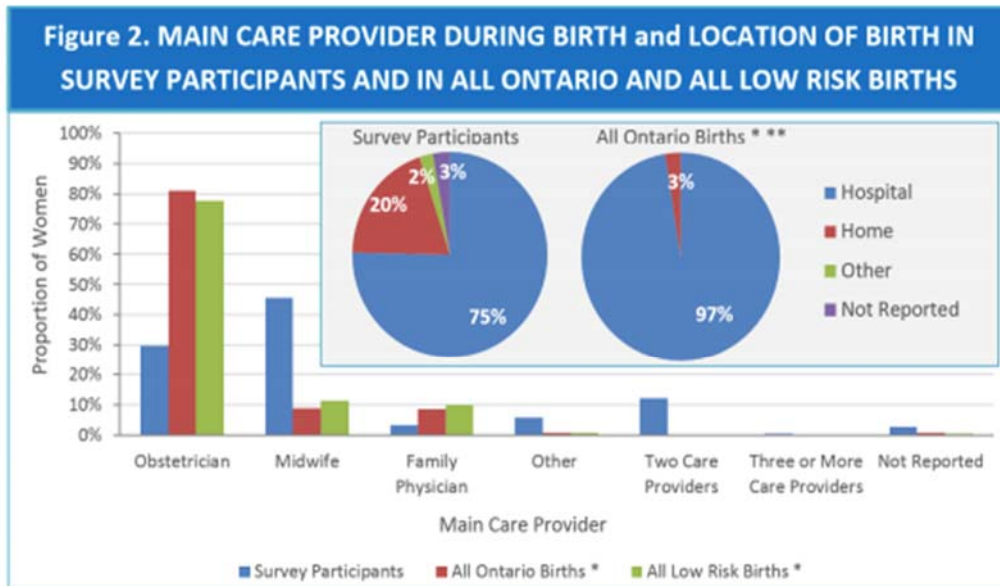
EXHIBIT 4

Overview of the Low Risk Maternal Newborn Strategy Ontario Women Survey



** The distribution of low risk births across Ontario LHINs is comparable to the distribution of all Ontario births

Source: PCMCH, 2016a.



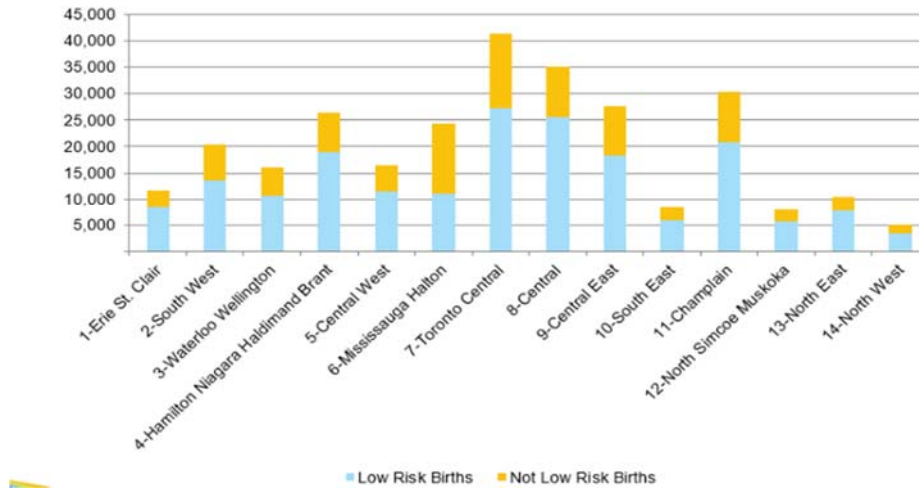
Data Source: BORN Ontario, 2012-2014

** The proportion of hospital vs. home births among low risk women is similar to that in all Ontario women.

Source: PCMCH, 2016a.

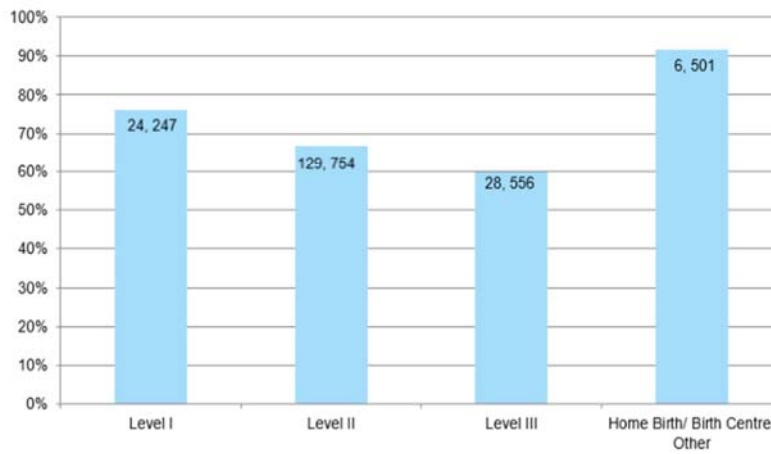
EXHIBIT 5

Number of low risk and not low risk births by LHIN (Ontario, 2012-2014)



Overview of Low Risk & All Ontario Births

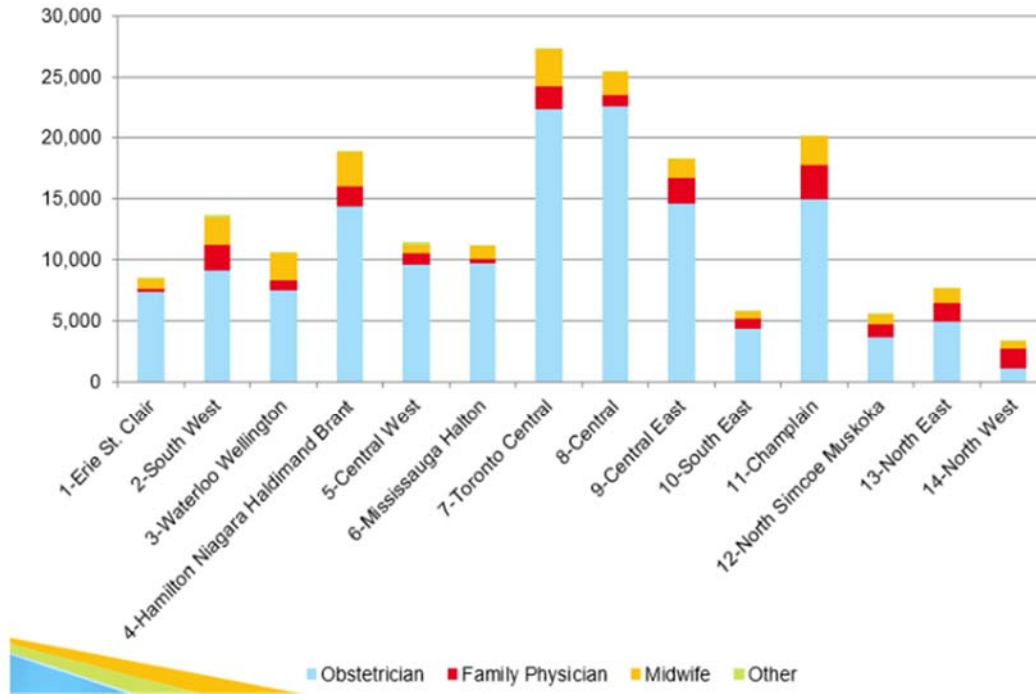
Proportion of all women who are low risk by location of birth (Ontario, 2012-2014)



Source: Best Start, 2016.

EXHIBIT 5 (cont'd)

Distribution of the number of low risk births across delivering healthcare provider specialties by LHIN (Ontario, 2012-2014)



Source: BORN Ontario, 2015.

Number of unattended low risk births across LHINs (Ontario, 2012-2014)

LHIN	Number of Unattended Births
2-South West	18
11-Champlain	13
4-Hamilton Niagara Haldimand Brant	11
1-Erie St. Clair	<6
3-Waterloo Wellington	<6
5-Central West	<6
6-Mississauga Halton	<6
7-Toronto Central	<6
8-Central	<6
9-Central East	<6
10-South East	<6
12-North Simcoe Muskoka	<6
13-North East	<6
14-North West	<6

Source: Best Start, 2016.

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INSTRUCTOR GUIDANCE

Saving the Rural Ontario Maternity Services – Can We Do It?

Sabrina Haque, MBBS, MPH (MPH Class of 2016)

*Preeti Nigam, BSc, MBA (Senior Program Manager, Provincial Council for Maternal and Child Health)
Shannon L. Sibbald, PhD (Assistant Professor, Western University)*

BACKGROUND

Inaya, manager of the 'low-risk' project at Provincial Council for Maternal and Child Health (PCMCH), had to come up with an integrative solution for the issues encompassing maternity care in Ontario. The low-risk project aims "to design and develop effective low risk maternal and newborn strategy for Ontario (2015-2018) to ensure that all women have an equitable choice of delivery options, and access to the right level of care at the right time, no matter where they live in the province". In response to external and internal challenges facing Ontario's hospitals, the province has seen the closure of rural maternity programs over the last few years. The women in communities that are unable to sustain local services must travel to access distant services, and depending on the distance to the nearest referral center, may be away from their homes and communities during the critical pregnancy period and child birth. The separation of pregnant women from their families and communities can cause negative outcomes. The health and economic impacts of the inability to access local maternal programs are well documented. Different stakeholders have indicated the importance of alternative, sustainable models of inter-professional collaboration of midwifery, primary and specialty care, and the efficient allocation of human health resources (PCMCH, 2015). To create the framework of the model, PCMCH formed a leadership team and expert panel consisting of different care providers. Inaya had to identify barriers and potential solutions by engaging different care providers and exploring the challenges from their perspectives. The findings would be used to work with relevant partners, such as associations of different health care professionals, to develop potential solutions for the Ministry.

The goal of the case is to provide readers with the opportunity to apply the concept of collaboration and also explore the barriers to achieving inter-professional collaboration from the key stakeholders' perspectives.

OBJECTIVES

1. Understand the effect of different social determinants on pregnancy outcomes.
2. Understand the importance or role of effective province-wide policies or strategies ensuring equity of maternal and newborn care.
3. Discuss and identify barriers to accessing maternity services in rural settings.
4. Understand the concept and importance of inter-professional collaboration for long-term sustainability of rural maternity services.
5. Identify the key stakeholders and effectively engage with them to determine different barriers to achieving inter-professional care.
6. Explore different maternity care providers' perspectives to find solutions regarding issues related to inter-professional care.

DISCUSSION QUESTIONS

1. What is the main problem or issue discussed in the case?
2. What are some social determinants that can potentially affect pregnancy outcomes?
3. What are some factors or reasons contributing to the problem or closure of maternity services in Ontario?
4. Name some important/key stakeholders in the maternity care sector in Ontario?
5. What is collaboration or inter-professional collaboration? Do you think it is important? Why? Does anyone want to share an experience where you had to work in collaboration with people from different disciplines? How was that? If that was a bad experience, in your opinion, what was the reason behind that?
6. What are the indicators or factors that influence inter-professional collaboration? Which one is the most important for collaboration? Why? In this case scenario, which one is the most important one in your opinion? Why?
7. What are some key challenges or barriers for inter-professional collaboration?
8. Name some funding/remuneration models for care providers in Ontario? What are the strengths and weaknesses of each of the models?
9. What incentives should/could be given to different care providers to ensure effective collaboration and integrated care and to encourage them to work in rural or low volume areas?
10. What are some other challenges that should be taken into consideration while planning and creating a framework for the inter-professional working model?
11. Do you think communication or sharing information between two different care providers would be a challenge in this type of model? If yes, how can this problem be solved?

KEYWORDS

Inter-professional care; collaboration; access; equity; rural health; maternal and newborn health; continuum of care; Ontario policy; funding models; sustainability; maternal services; care providers; Low Risk Strategy.

CASE 3

Providing Continuing Professional Development in a Developing Country – The One Health Initiative

Elyse Burt, BSc, MPH (MPH Class of 2016)

Emily Quinn, BSc (Assistant Investigator)

Rick Quinn, DVM, DVSc, Diplomate ACVO (Founding Director, Docs4GreatApes)

Mike Cranfield, DVM (Co-Director Gorilla Doctors, Chief Veterinarian, The Maryland Zoo)

Shannon L. Sibbald, PhD (Assistant Professor, Western University)

“One Health” is a multidisciplinary initiative to improve the collective health of humans, animals, and the environment. Physicians, health professionals, veterinarians, scientists, researchers, economists, and international organizations are some of the many stakeholders who are working towards the common goal of achieving optimal health of all living things. The initiative is extensive yet, at the same time, rather simple: humans and animals are reliant on our physical environment, and our physical environment is reliant on us – and the health of each counterpart is inextricably linked to the others.

The One Health Initiative requires a holistic understanding of the ecology of our planet and its dynamic relationships (Centers for Disease Control and Prevention [CDC], 2016). It takes into account innumerable factors, such as emerging infectious diseases from the increasing contact between humans and animals; the spread of these diseases due to climate change, globalization, and urbanization; and, the links between deforestation and agriculture with the spread of zoonotic diseases.

This area of study is becoming increasingly popular due to (1) the emergence of many infectious diseases affecting humans, such as Zika and Ebola, and (2) the increasing investment of individuals passionate about the threats to wildlife – particularly those animals that are endangered. The spread of various human-disease strains pose a great danger to these fragile populations, with some infections, such as tuberculosis, having the potential to be the demise of an endangered species (Gorilla Doctors, 2016). By taking a One Health approach, threats to the environment, humans, and wildlife can be analyzed and approached from various perspectives, ensuring that action will not only benefit the subject of interest, but countless other species within its network.

BACKGROUND

At the Gorilla Doctors’ headquarters in Musanze, Rwanda (Exhibit 1), a team is working tirelessly to protect and conserve the endangered mountain gorillas and their natural habitat within the Virunga Massif. The team of veterinarians, trackers, and support staff take on this duty through a variety of channels, including medical interventions, research, disease prevention, community outreach, and anti-poaching initiatives. Although their primary concern is for the health and well-being of the gorilla population, they see first-hand how important a One Health approach is to fulfilling their objectives (Gorilla Doctors, 2016).

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Along the borders of the Volcanoes National Park, there are villages and agriculture within close proximity to where various groups of gorillas live. Although the park is protected and patrolled, the mountainous nature of the gorillas' natural habitat precludes the construction of an effective physical barrier that would prevent the intermingling of domestic animals, wildlife, and the local human population. This increases the exposure level of humans, livestock, and other animals to the gorillas, putting them at risk of contracting various diseases, including many strains of human disease due to the similarity of their genetic make-up (Gorilla Doctors, 2017).

Dr. Mike Cranfield, co-director of Gorilla Doctors, works directly with the wildlife in the park, as well as with the local hospital in Musanze. Noticing the emergence and increase in certain illnesses in the gorilla populations, Dr. Cranfield saw a great need for community initiatives to educate and provide health care to residents living in the area.

The Gorilla Doctors' Employee Health Program ensures all those working directly and indirectly with the gorillas receive routine health screenings, follow-up care, and health education. Gorilla Doctors has also created a rabies vaccination program for dogs and cats, as well as pet care education for their owners, with an aim of decreasing potential spread of the illnesses to other wildlife. Community education initiatives, such as educating on healthy lifestyles, sanitation, and disease prevention, are also extremely important components for the health of the people living around the park. Gorilla Doctors collaborates with local professionals and students working in veterinary science and wildlife conservation, as well as international medical, veterinary, public health, and PhD students who can use their skills and knowledge to contribute to the One Health mission (Gorilla Doctors, 2016).

SUPPORTING CONTINUING PROFESSIONAL DEVELOPMENT IN HEALTH CARE

In 2012, Dr. Cranfield recruited one of his veterinary colleagues, Dr. Rick Quinn, to assist the Gorilla Doctors with training local veterinarians in eye care best practices. Dr. Quinn, a skilled veterinary ophthalmologist from Canada, was happy to travel to Rwanda to help a cause he was personally very passionate about. The experience left a large impression on him, learning a lot about Rwandan culture and meeting many amazing people with a strong will to learn. After spending some time with Dr. Cranfield and learning more about the One Health initiatives, he felt compelled to continue giving his support in any way he could.

Seeing a great potential for further development in health care in the area, as well as being inspired to protect the endangered gorillas, Dr. Quinn returned to Canada and began his own non-profit organization "Docs4GreatApes". He formed this organization with a vision to create "a world community that is passionate about improving the health of Great Ape populations, the communities that surround them, and the ecosystem that we share," fully embracing the One Health initiative (Docs4GreatApes, 2013). Dr. Quinn continued to collaborate closely with Dr. Cranfield and asked what he thought he could do to make a real difference in the area. After speaking with local leaders in Rwanda and doing some of their own research, the pair began to see a great need and desire for professional education in the community health centres.

During the tragic Rwandan genocide in 1994, many of the doctors and health care professionals lost their lives. The country has made tremendous strides in the past two decades, but gaps are being seen in the health sector, where knowledge and experience should have been passed on from older generations (Grundman, 2016). In 2010, several Western University faculty collaborated with the Rwandan Ministry of Health to assess the quality of health care in Rwanda. They interviewed over 1400 local health care professionals across the country to identify the needs of the front-line workers in order to build capacity and enable them to deliver improved health care to the people. One of the significant deficiencies found was the lack of

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opportunities for continuing professional development (CPD), particularly in psychiatry, emergency care, obstetrical emergencies, and ophthalmology. In these areas, a lack of knowledge and experience was leading to insufficient care of patients, causing health problems to go unnoticed or be treated inaccurately. Already dealing with limited resources, misdiagnoses and unnecessary referrals were adding to the burden on the health care system and the few physicians and specialists in the region.

After many meetings, interviews, and brainstorming sessions, the VirungaOne initiative was born.

The aim of VirungaOne was to provide CPD to frontline health care workers in remote village health centres in the Virunga Massif, with the goal of creating healthier communities. Founders of the initiative believed that, by working at the grassroots level to educate health care providers, a more sustainable conduit for development and change would be opened. The hope was that health education would result in better health care delivery, creating healthier communities that would also be more willing and better prepared to recognize the value of conservation. Not only would a healthier population decrease the risk of certain disease transmissions between humans and wildlife, it could potentially open doors for opportunity and economic development of the area.

With growing gaps in knowledge, came a critical need for further training, and Dr. Quinn knew he needed to quickly and efficiently set his vision in motion. With eye care being identified as an area of need, Dr. Quinn decided that this would be the most practical area to begin developing the programs as he could utilize his expertise in the subject. With the help of his organization, educators, nurses, and fellow ophthalmologists, educational information was gathered and a learning module began to be developed. The plan was to integrate a primary eye care module, along with the future development of other desired CPD topics, into existing primary health care structures in clinics around the Volcanoes National Park. Dr. Quinn hoped that this education could provide the opportunity to increase responsibilities of health care workers and was optimistic that increasing the capacity in the community clinics would start to close knowledge gaps and provide the people with more comprehensive care.

THE CHALLENGES OF IMPLEMENTATION – HOW IS THIS GOING TO WORK?

With a team in place and CPD module development underway, Dr. Quinn began to realize that critical pieces of information were missing: he didn't know how the training was going to be delivered in rural Rwanda and who exactly would be receiving the training. With no previous experience in program development, especially in an area of limited resources, he didn't know where to begin or what best practices should be followed.

As he began to do some research and look into similar initiatives, Dr. Quinn started to identify different factors and concerns he would need to address to ensure that the VirungaOne initiative would be properly implemented and efficaciously delivered.

The first concern was ensuring that everyone who needed to be involved for the program to be successful was on board. How could his team gain the trust of the local health care workers and the directors of the clinics and hospitals? Dr. Quinn was aware of the difficulties that can arise when foreigners try to do research or development work in a developing country, especially with Rwanda having such a turbulent past. Understandably, walls are often built up due to mistrust and reservation. Local authorities need to ensure that the parties involved are committed and accountable for what they are promising.

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The second concern was how to best design the modules to reach the needs of the health care providers and communities. Dr. Quinn knew he must shift his perspective to a more local context and design the modules at the appropriate educational level for the nurses. He began to see the importance of bringing a local doctor or ophthalmologist on board to identify the most common eye cases in the area and design the educational materials around those topics accordingly. He wanted the material to be applicable and valuable in order to build the capacity to improve the treatment and triaging of patients.

The third concern was the logistics of the implementation phase, which required an understanding of the local infrastructure and resources. How many clinics and health care workers were there in the region? How far were these clinics from one another? What format would be most appropriate and what method of delivery should be used? How reliable was their electricity and would they have internet access? Should the training be voluntary or mandatory for all? Should the nurses receive some sort of compensation or recognition? How can the program be designed sustainably to deliver multiple modules over time with limited resources and international involvement?

These questions were running through Dr. Quinn's mind, and although he had an idea of how he envisioned the program, he wanted to make sure he was making informed and culturally appropriate decisions that would render the initiative a success.

THE ACTION PLAN – SETTING THE STAGE

Dr. Quinn and his colleagues devised an action plan to establish the development and implementation of their CPD training. He decided that the best way to gather the most relevant and appropriate information would be in the field. He learnt that the Rwandan people prefer to meet in person to build a relationship, rather than speaking via telephone or e-mail. Although it would be more time consuming, Dr. Quinn knew that this would be the best way to build trust and obtain buy-in from the clinics.

He also reached out to some local contacts to determine how the clinics were run and who the target population would be for training. He learnt that each health centre employs around ten nurses who are the frontline workers. The clinics are supervised by a "titulaire", or a head nurse, who would be vital to have on board and ensure the training is designed to suit their needs and the needs of their clinic. Dr. Quinn decided that it would be best to visit each clinic and meet with the head nurse to personally introduce himself and the project, as well as gather information that would help shape the development of the project.

By speaking with Dr. Cranfield and his contacts at the Musanze Hospital, Dr. Quinn established that there were fourteen clinics that surround the Volcanoes National Park (Exhibit 2). The clinics belonged to four different districts – Musanze, Burera, Rubavu, and Nyabihu – and were all rather diverse. Some clinics were currently employing as little as seven nurses while others had as many as eighteen; some were within larger towns and villages and others were in rural and remote areas.

With such diversity, distance, and varying levels of development, creating a program to suit the needs of all clinics seemed daunting. Dr. Quinn found himself at a crossroad, not knowing how to move forward with the project until he was able to gain more information. He hoped that through discussion with each titulaire, and collaboration with local physicians and ophthalmologists, his next steps would become clearer.

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THE PRIMARY PROJECT OUTCOMES

Fortunately, Dr. Quinn was right. After getting approval from the Rwandan Ministry of Health and meeting with the directors of the district hospitals to inform them of the VirungaOne initiative, his vision started to come to life. The fourteen clinics were mapped out and interviews were conducted with each of the head nurses. A set of questions and a rating scale were developed to guide the interview process and explore different possibilities for the program, such as location, group size, recognition, and clinic infrastructure and resources (Exhibit 3). The nurses were extremely receptive to the initiative and were able to provide a great deal of constructive feedback. They had a thirst for knowledge that left Dr. Quinn more motivated than ever.

The clinics spanned anywhere from a 30 minute to two hour drive from the Gorilla Doctors' headquarters in Musanze. Despite many differences in infrastructure and location, there was a consensus among most of the clinics on how training would be most practical and effective.

The clinics had little-to-no internet access, as it was often unreliable and very expensive. Electricity also posed an issue for some clinics that did not have back-up generators, as power went out multiple times per week. Dr. Quinn had previously thought that the modules could be downloaded through the internet, but he realized that would no longer be the best option. He also learnt that very few nurses had sufficient computer skills, as it was very rare to have a computer in the home and clinic computers were often only used by the administration. Therefore, having a hard copy of the educational materials for nurses to use and an electronic copy to keep on file in case the hard copy was lost or ruined, was very important to the head nurses.

Initially, Dr. Quinn and his team thought that bringing the training directly to the clinics would be the most convenient and effective way. However, thirteen of the fourteen clinics preferred that the nurses be trained in collaboration with other clinics at a separate venue. The head nurses explained that there would be too many distractions and interruptions for the nurses on site, and that they participated in other types of training where small groups of nurses would gather in Musanze. Creating an open dialogue and involving these leaders in the decision making process shed light on what worked best for the nurses and would give the initiative the community-based support it needed.

Dr. Quinn discovered many other useful findings from these informal interviews: a certificate of recognition should be given to the nurses for completing the training that could be kept on file at each of the district hospitals; training should be mandatory for all nurses as issues often arise with shifting of responsibilities when only two or three nurses are trained on a particular subject; and, training by an external facilitator using a PowerPoint presentation paired with informational booklets for the nurses would be the most effective.

With local ophthalmologists on board to guide content development, support from the Ministry of Health, and new partnerships with each of the clinics, the VirungaOne initiative was in motion. While everything seemed to be running well, the work was really just getting started. Next, Dr. Quinn and his team would need to begin planning for the follow-up and evaluation of the modules. Monitoring the quality and delivery of the training was going to be essential. What would be the best way to evaluate the success and effectiveness of the modules? How would the team be able to collect this information in an efficient and culturally-appropriate way? How would they maintain the much needed support of the various stakeholders?

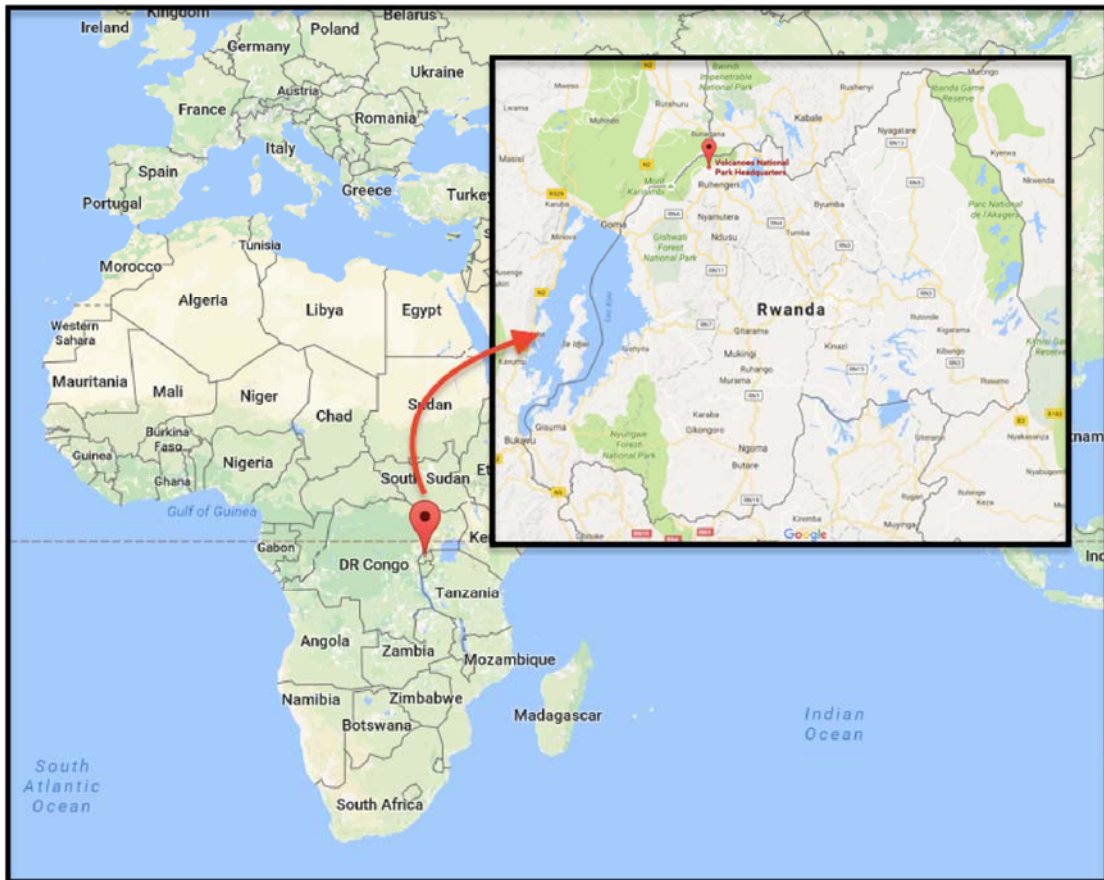
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With optimism and confidence in his team, Dr. Quinn looked forward to resolving these questions and challenges on the horizon and was excited for the future of VirungaOne.

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EXHIBIT 1

Map of Africa Continent: Rwanda and the Volcanoes National Park Headquarters (Majority of Mountain Gorilla Families)

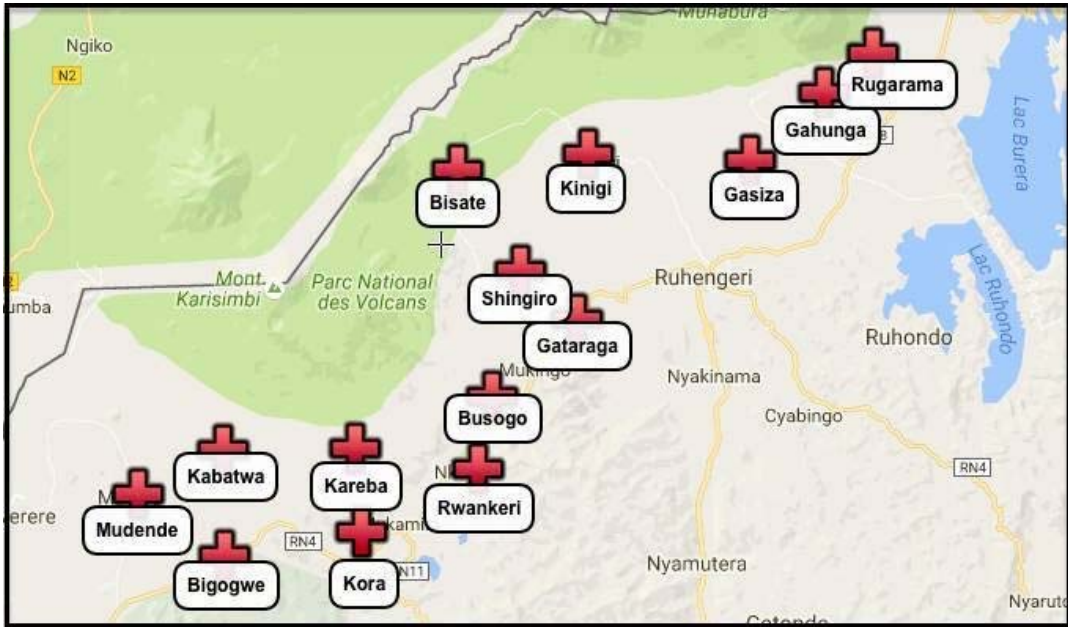


Source: Created by authors.

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EXHIBIT 2

Map of the Fourteen Health Centres and Proximity to the Volcanoes National Park



Source: Created by authors.

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**EXHIBIT 3
Titulaire Interview Form
(Clinic's Infrastructure and CPD Program Preferences)**

<u>General Clinic Information</u>
nurses on staff:
nurses per shift:
Electricity:
Generator:
Computers on site:
Computers at home:
Comfort level using computers:
Would they want user training:
Available internet:
• Unlimited or Pay-per-use:
• Wi-Fi:
Projector on site:
Office space for training:
<u>CPD Training</u>
Format:
• Hardcopy/Print:
• Electronic:
○ Electronic PowerPoint:
○ Electronic document/PDF:
○ Videos:
○ Flash drive or downloadable from internet:
Method of training:
• Taught by facilitator:
○ External facilitator:
○ Train an internal trainer:
• Learn independently (iPad or booklet):
Location of training:
• At the clinic:
• At home:
• At separate venue (school or centre):
Group size:
• Independently:
• Small groups within clinic:
• Entire clinic at once:
• Clinic clusters:
Recognition:
• Certificate:
• Exam passing note:
• Where does recognition go?
Nature:
• Voluntary:
• Mandatory:

Source: Created by authors.

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INSTRUCTOR GUIDANCE

Providing Continuing Professional Development in a Developing Country – The One Health Initiative

Elyse Burt, BSc, MPH (MPH Class of 2016)

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Rick Quinn, DVM, DVSc, Diplomate ACVO (Founding Director, Docs4GreatApes)

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Shannon L. Sibbald, PhD (Assistant Professor, Western University)

BACKGROUND

In Musanze, Rwanda, two NGOs, Gorilla Doctors and Docs4GreatApes, are working on the One Health Initiative to indirectly protect the endangered mountain gorillas. They aim to build capacity and strengthen the public health care of the people who live in close proximity to the gorillas' habitat. By creating healthier human populations, there will be less risk of disease transmission, such as TB or parasites, to the gorillas, and the overall well-being and development of the area will be improved.

An unpublished study by Western University in 2010 identified areas in the public health system in Rwanda that health care professionals felt were lacking necessary knowledge and experience. The goal of the "VirungaOne" initiative is to develop and deliver continuing professional development (CPD) modules to train the nurses who work in the local health centres.

This case focuses on the issues Dr. Rick Quinn, the founding director of Docs4GreatApes, faced in discovering the most culturally appropriate and efficacious way to design and deliver the CPD training in a resource-poor setting. It centers around health promotion through education, while incorporating aspects of social determinants of health, environmental health, community health assessment and program evaluation, and aboriginal health.

OBJECTIVES

1. Explore similarities and differences between a developed and developing country in regards to program development.
2. Use different frameworks and models to analyze and design a CPD training program.
3. Identify key factors in creating a successful initiative for health education.

DISCUSSION QUESTIONS

1. How could Dr. Quinn's team gain the trust of the local nurses and the directors of the clinics and hospitals?
2. How could he ensure that the modules were relevant and appropriate?
3. What types of barriers or facilitators could you see in the implementation phases of the modules?
4. What similarities and differences can you draw between this context and the Canadian context? Particularly in Northern or Indigenous communities?

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5. What do you think is the best way to design the modules and the training sessions for the nurses?
6. How should the programs be monitored and evaluated in a culturally appropriate way?

KEYWORDS

One Health; program development; continuing professional development; education; promotion; capacity building.

CASE 4

Changing School Food Environments: Is Policy Enough?

Sai Chaphekar, MBBS, MPH (MPH Class of 2016)
Paula Dworatzek, RD, PhD (Associate Professor, Brescia University College)
Amanda Terry, PhD (Assistant Professor, Western University)

Dr. Michelle Burt sat down at the table staring at the document in front of her. She took a moment to grasp the details of the school hot lunch sign-up sheet that her eight-year-old daughter had brought home. The sign-up sheet had a list of food options provided by the school, which included pizza, cookies, and other items high in fats, salt, and/or sugars. As Michelle held a PhD in nutritional sciences, and was a nutrition researcher herself, she was aware that these options conflicted with the nutrition standards for foods sold at school. Keeping in mind the increasing prevalence of childhood obesity, she was concerned about the health of school children, including her own child. She knew that Canada did not have a national school-meal program and the existing provisions for school meals were not of an appropriate standard, which was evident in her daughter's school meal sign-up sheet.

To address the nutritional standards of foods provided at schools in Ontario, the Ontario Ministry of Education developed the School Food and Beverage Policy (Exhibit 1). The objective was not only to assist schools in providing a healthier environment for students (Ontario Ministry of Education, 2010) but also to influence manufacturers to supply healthy foods to schools. Being a mother, as well as a dietitian, Dr. Burt was aware of this policy and so it was an easy decision for her to not sign up for the hot lunch program. She wondered if all the other parents were aware of the policy and would make the same choice as she did. As a researcher, what steps could she take to ensure the food choices available in schools were aligned with the policy?

BACKGROUND

Healthy Schools

Lack of consumption of recommended quantities of fruits and vegetables is identified as one of the many factors associated with children's poor health (People for Education, 2013). Healthy nutrition not only helps in preventing chronic disease, but is also essential for growth and development, which is important during the early stages of life (Davison et al., 2012). Schooling plays a major role in children's educational achievements, and their acquisition of knowledge and literacy. In addition, schools have an indirect effect on the development of children's attitudes and behaviours through peer influence and role modelling of teachers (Sylva, 1994). According to the Schools for Health in Europe (SHE) (Schools for Health in Europe, 2013) and Organization for Economic Cooperation and Development (OECD) (OECD, 2010) schools are an ideal place for health promotion. They provide easy access to the target population by enabling community outreach.

School Food and Beverage Policy

The development of the School Food and Beverage Policy is an important step towards creating healthier school environments. This policy emphasizes the importance of the school

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environment in influencing student attitudes, preferences, and behaviours. The policy was announced in January 2010 and took effect on the 1st of September 2011. It is applicable to all foods and beverages sold at schools (Ontario Ministry of Education, 2016).

This policy is part of a broader and bigger goal of developing healthier environments by influencing the attitudes and behaviours of students and parents. This, in turn, can influence food vendors to provide healthier options to sell to schools, such as whole wheat pizza with low-fat cheese, to help improve the diet of school children as well as their overall development (Ontario Ministry of Education, 2016). In order to achieve this goal, nutrition standards were established for food and beverages sold in publicly funded schools. The nutrition standards are divided into two parts: Nutrition Standards for Food and Nutrition Standards for Beverages.

Nutrition Standards for Food

As per Canada's Food Guide, the Ontario Ministry of Education document divides food into four groups: Vegetables and Fruit, Grain Products, Milk and Alternatives, and Meat and Alternatives (Ontario Ministry of Education, 2010). Food items such as pizza, pasta, soup, salads, and sandwiches which contained more than one food group were categorized as Mixed Dishes by the Ministry (Ontario Ministry of Education, 2010). Other items, which were grouped into Miscellaneous items, included condiments, sauces, dips, and oils which could be used in limited amounts, while confectionery such as candy and chocolate were not permitted for sale (Ontario Ministry of Education, 2010).

Nutrition Standards for Beverages

Nutrition standards for beverages were developed separately. As per Canada's Food Guide, the Ontario Ministry of Education suggests satisfying thirst with water, drinking skim, 1%, or 2% milk, and consuming fruits and vegetables more than juice (Ontario Ministry of Education, 2010).

Detailed nutrition standards provided by the Ontario Ministry of Education are shown in Exhibit 1. This is a comprehensive approach towards the food and beverages sold at schools. The implementation of nutrition standards is a priority as they reinforce knowledge, skills, and attitudes towards healthy eating, which, in turn, supports a healthy school environment. To support the policy guidelines, other supplementary resources were provided by the Ontario government to help teachers and parents (Ontario Ministry of Education, 2010). Given all of these resources and information contained in the policies and other documents, Dr. Burt wondered why the policy failed to translate to the meals and snacks that were being provided for sale at schools. Were there any other factors at play besides providing the policy to schools which needed to be considered for its successful implementation?

FIRST STEP

Keeping this in mind, Dr. Burt thought about talking first to the school authorities, since they held decision making power. She requested a meeting with the school principal to discuss the misalignment of the school lunch menu with the policy. Her meeting with Mr. William Rogers, the school principal, did not result in immediate changes to the food provided at school; however, it did give her an overview of the challenges faced by the school administration in successfully implementing the policy.

Dr. Burt knew the enormity of the task ahead of her, so she decided to team up with some of the parents and children she knew from the Home and School Association. She also realized that the teachers and school authorities played an important part in the school's lunch menu and planned to gain an audience with them. To reduce the communication gap between the school

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board, teachers, parents, and students, collaboration was pivotal. Her first tasks were assessing the knowledge of parents and children regarding the policy, and further identifying barriers hindering compliance. To achieve this, Dr. Burt planned to meet some of the parents she was friends with. The first question for the parents was whether they were aware of the policy, and if so, how well did they know it? Later she questioned them regarding the challenges they faced or would face in order to comply with the policy. The responses she got from some of the parents were not unexpected as many of them were unaware of the policy. One of the parents stated that, "I do not know what this policy is about and did not receive any information stating it." Another parent who knew about the policy said, "This policy is for the food provided at school, shouldn't it be the responsibility of the school to make sure that it gets executed?" In the case of the children, the questions were directed at their awareness and understanding of the policy. They were also asked what they would prefer to be served in schools and if healthier options were made available, if they would desire them. One of the girls mentioned that she did not mind healthier options as long as they were sold at a reasonable price and appealed to their taste buds, while another child complained that he wanted to buy an apple, but it was expensive so he bought chips instead.

The primary objective of these meetings was to gauge the general understanding of the policy and the obstacles faced in implementing the policy. The feedback received helped in the preparation of a report to be presented to parents and school administration as well as to vendors selling food and beverages. These discussions provided a deeper understanding of the participants' views on the policy, their experiences, and their insights into the challenges faced. The commonly observed challenges were the lack of communication, limited school resources, lack of responsibility and accountability by stakeholders, and the lack of consideration of students' preferences. Consequently, some of these factors also had a detrimental effect on the school's revenue, which made it more difficult to implement and monitor the policy (Agron, 2010).

RESOURCES

Financial and human resources play an important role in supporting and ensuring the implementation of policies. The meeting with the school clearly identified the lack of funding, which limited the ability of the school authorities in executing the policy. Furthermore, Home and School Associations rely on revenues from the hot lunch programs, which feed back into school resources. This gives the school administrators the difficult task of choosing between nutrition standards and increasing revenues. Further discussions with the administrators revealed the lack of facilities, kitchen staff, and funding to prepare healthy foods.

COMMUNICATION

Communication was one of the key factors for determining the success of the policy. It is a link that binds all the stakeholders (students, parents, teachers, and school authorities) together and facilitates information and knowledge dissemination. Studies have shown that lack of adequate communication between stakeholders is one of the major barriers in implementing effective food policies (MacLellan, 2010). Discussions with parents revealed that a majority of them were unaware of the policy and those who were had no idea of its comprehensive nature due to inactive participation. As a dietitian, Dr. Burt was aware of the policy but did not receive any information about it from the school. She understood very well the state of mind of parents, their questions, and their doubts. Moreover, teaching new policies and nutrition standards to the students was neither a part of the curriculum nor was it discussed at the Home and School Association meetings (Story, 2009).

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In one of her discussions with a teacher, Miss Evans, Dr. Burt understood that the teacher felt that she was neither qualified to categorize food as per the policy nor did she understand the nutritional values mentioned on it. She attributed this to her non-nutritional background and acknowledged that it was not only her, but that most of the teaching staff felt that way. They wanted more training to effectively promote the policy.

On the other hand, when students were asked about their opinion regarding the policy, a majority of them had no recollection of their teacher discussing the policy with them or providing information about it to take home for their parents. If healthier food options were provided, they wanted the prices to be reduced, since the existing healthy food options were too expensive. The inclusion of student preferences should have been considered before implementing the policy. Overall, there should have been open communication to facilitate the operationalization of the policy.

SOCIAL ENVIRONMENT

Social environments, including homes and schools, influence an individual's attitudes and behaviours. Family members and teachers serve as role models by engaging with students in practices that promote health (Christensen, 2003). This can help in decreasing the resistance to policy implementation by bringing about a behavioural change in students. The School Food and Beverage Policy could help in reinforcing knowledge, skills and attitudes towards healthy eating. Such efforts are fundamental in encouraging healthy eating behaviours not only in school environments, but also outside the school.

Dr. Burt realized the importance of the role of social marketing, which influences the decision making of students and school authorities. Food marketing influences purchasing behaviour and subsequent consumption by students (Neumark-Sztainer, 2005). The government also aims to influence the sale of healthier food via the vendors in schools (Ontario Ministry of Education, 2010).

The social ecological model includes five levels of influence on behaviour such as intrapersonal, interpersonal, organizational, community, and public policy (Winch, 2012). By incorporating this model, factors which prove to be a hindrance to the implementation of the policy at each of these levels could be identified. This model helps in understanding the influence of social environments on an individual in terms of behavioural change. Examining these levels with reference to this policy would give a better insight in proposing practical solutions to this issue.

ACCOUNTABILITY

The Ontario government has laid down detailed policy guidelines and has provided schools with additional materials to understand nutritional standards (Ontario Ministry of Education, 2010). However, it fails to specify the roles and responsibilities of individuals to implement the guidelines. Most parents and children were unaware of the policy. Without proper training, parents felt that they were incapable of understanding the information (such as serving size, nutrient content, and food labels) provided. Furthermore, teachers often felt that parents have a greater influence over their children's attitudes and behaviours.

INSTITUTIONAL WILLINGNESS

Availability of resources, communication between individuals and institutions, and the influence of social environments on the attitudes and behaviours of stakeholders could determine institutional willingness to implement the policy effectively (MacLellan, 2010). Dr. Burt realized that her daughter's school lacked the above factors, and therefore were hampered in their ability to implement the policy. Furthermore, she noticed the lack of indicators evaluating the extent of

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a school's readiness in adopting the policy. When organizational willingness is high, institutional members are more receptive to change, and show increased persistence and cooperation to implement changes (Weiner, 2009). Thus, Dr. Burt comprehended the need for these issues to be tackled as high priority in order to make the policy practically functional.

NEXT STEPS

Dr. Burt's next step is to present the results and information to the parents and school administration. She was impressed with the amount of information that came forth in the meetings. This gave her a sense of responsibility to make good use of this information to initiate a change or open up a dialogue for future changes. She requested to present the results at the next teachers' meeting as well as at the next Home and School Association meeting. By doing this, she hoped to resolve the issues mentioned above through the collective efforts of the school administrators, teachers, parents, and students.

Before confronting everyone, there were many criteria to be considered. How would the school overcome the barriers mentioned above without affecting the quality of nutritious food? Did the policy itself require critical analysis of its shortcomings, besides the issues identified above? What indicators would be used to determine the effective implementation of the policy? Dr. Burt hoped that her findings would help resolve the shortcomings in implementing the policy in other schools too, thereby providing a foundation towards a collaborative solution.

EXHIBIT 1

Policy/Program Memorandum No. 150

Date of Issue: October 4, 2010

Effective: Until revoked or modified

Subject: SCHOOL FOOD AND BEVERAGE POLICY

Application: Directors of Education

Supervisory Officers and Secretary-Treasurers of School Authorities

Principals of Elementary Schools

Principals of Secondary Schools

Principals of Provincial and Demonstration Schools

Reference: This memorandum replaces Policy/Program Memorandum No. 150, January 15, 2010.

INTRODUCTION

The Ontario government is committed to making schools healthier places for students in order to establish the conditions needed to realize the potential of all students. A healthy school environment enhances student learning and success, and enhances students' social and emotional well-being. Schools have an important role to play in helping students lead healthier lives, including teaching students the skills to make healthy choices and reinforcing those lessons through school practices.

The purpose of this memorandum is to set out nutrition standards for food and beverages sold in publicly funded elementary and secondary schools in Ontario.

APPLICATION

School boards¹ are required to ensure that all food and beverages sold on school premises for school purposes meet the requirements of this memorandum, including the nutrition standards set out in the Appendix to this memorandum, by September 1, 2011. The nutrition standards apply to all food and beverages sold in all venues (e.g., cafeterias, vending machines, tuck shops), through all programs (e.g., catered lunch programs), and at all events (e.g., bake sales, sports events).

The standards do not apply to food and beverages that are:

- offered in schools to students at no cost;
- brought from home or purchased off school premises and are not for resale in schools;
- available for purchase during field trips off school premises;
- sold in schools for non-school purposes (e.g., sold by an outside organization that is using the gymnasium after school hours for a non-school-related event);
- sold for fundraising activities that occur off school premises;
- sold in staff rooms.

LEGISLATIVE AUTHORITY

Paragraphs 29.3 and 29.4 of subsection 8(1) of the Education Act provide the Minister of Education with the authority to establish a policy with respect to nutrition standards for food and beverages and for any ingredient contained in food and beverages provided on school premises or in connection with a school-related activity, and to require school boards to comply with the policy.

RATIONALE FOR A SCHOOL FOOD AND BEVERAGE POLICY

The school food and beverage policy contributes to improved education and health outcomes for all students. Research shows that "health and education success are intertwined: schools cannot achieve their primary mission of education if students are not healthy"² and that "healthy eating patterns in childhood and adolescence promote optimal childhood health, growth, and intellectual development".³

The school environment profoundly influences students' attitudes, preferences, and behaviours. Research also shows that when nutritionally inadequate food and beverages are available and promoted at school every day, even along with healthier food and beverages, it becomes increasingly difficult for students to have a healthy diet.⁴

The implementation of the school food and beverage policy in Ontario's publicly funded schools will contribute to reducing students' risk of developing serious, chronic diseases, such as heart disease, type 2 diabetes, and certain types of cancer.

The school food and beverage policy constitutes a comprehensive approach to the sale of food and beverages in schools province-wide. The implementation of this policy is another important step in creating healthier schools in Ontario.⁵ It also reinforces the knowledge, skills, and attitudes regarding healthy eating that are developed through the various subjects and disciplines in the Ontario curriculum.

NUTRITION STANDARDS

The nutrition standards embody the principles of healthy eating outlined in Canada's Food Guide, and are intended to ensure that the food and beverages sold in schools contribute to students' healthy growth and development. The nutrition standards for food and beverages are set out within the following two sections:

Nutrition Standards for Food. Food is divided into "Vegetables and Fruit", "Grain Products", "Milk and Alternatives", and "Meat and Alternatives", following Canada's Food Guide. There are also "Mixed Dishes", for products that contain more than one major ingredient (e.g., pizza, pasta, soup, salads, and sandwiches), and "Miscellaneous Items", for items that are to be used in limited amounts (e.g., condiments, sauces, dips, oils, dressings) and for confectionery, which is not permitted for sale (e.g., candy, chocolate).

Nutrition Standards for Beverages. Standards for beverages are provided separately for elementary schools and secondary schools.

The above two sections outline nutrition criteria⁶ that food and beverages must meet in order to be sold in schools. The nutrition criteria are provided in the following categories:

Sell Most (≥ 80%). Products in this category are the healthiest options and generally have higher levels of essential nutrients and lower amounts of fat, sugar, and/or sodium. They must make up *at least 80 per cent* of all food choices⁷ that are available for sale in all venues, through all programs, and at all events. The same requirement applies to beverage choices.⁸

Sell Less (≤ 20%). Products in this category may have slightly higher amounts of fat, sugar, and/or sodium than food and beverages in the "Sell Most" category. They must make up *no more than 20 per cent* of all food choices that are available for sale in all venues, through all programs, and at all events. The same requirement applies to beverage choices.

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Not Permitted for Sale. Products in this category generally contain few or no essential nutrients and/or contain high amounts of fat, sugar, and/or sodium (e.g., deep-fried and other fried foods, confectionery). Food and beverages in this category may not be sold in schools.

Often a type of food or beverage (e.g., bread, meat, cheese) will fit in all three of the above categories, depending on its nutritional value. To determine whether a specific product may be sold in schools, it is necessary to read the information on the food label – particularly the Nutrition Facts table and the ingredient list – and compare this information with the nutrition criteria.

Food should always be prepared in a healthy way – that is, using cooking methods that require little or no added fat or sodium, such as baking, barbecuing, boiling, broiling, grilling, microwaving, poaching, roasting, steaming, or stir-frying.

EXEMPTION FOR SPECIAL-EVENT DAYS

The school principal may designate up to ten days (or fewer, as determined by the school board) during the school year as special-event days on which food and beverages sold in schools would be exempt from the nutrition standards outlined in this memorandum. The school principal must consult with the school council prior to designating a day as a special-event day. School principals are encouraged to consult with their students in making these decisions.

Notwithstanding this exemption, on special-event days, schools are encouraged to sell food and beverages that meet the nutrition standards set out in this memorandum.

ADDITIONAL REQUIREMENTS

The following requirements must also be met:

- School boards must comply with Ontario Regulation 200/08, "Trans Fat Standards", and any other applicable regulations made under the Education Act.
- Principals must take into consideration strategies developed under the school board's policy on anaphylaxis to reduce the risk of exposure to anaphylactic causative agents.
- Food and beverages must be prepared, served, and stored in accordance with Regulation 562, "Food Premises", as amended, made under the Health Protection and Promotion Act.
- School boards must ensure that students have access to drinking water during the school day.
- The diversity of students and staff must be taken into consideration in order to accommodate religious and/or cultural needs.

PRACTICES FOR CONSIDERATION

Boards and schools should take into consideration the following when food or beverages are sold or provided in schools:

- Offer, when available and where possible, food and beverages that are produced in Ontario.
- Be environmentally aware (e.g., reduce food waste, reuse containers, recycle food scraps).
- Avoid offering food or beverages as a reward or an incentive for good behaviour, achievement, or participation.

IMPLEMENTATION AND MONITORING

Any existing school board policies or guidelines related to food and beverages sold in schools must be in accordance with this memorandum. The ministry recognizes that there may be differences in approaches and implementation at the local level. School boards and schools are encouraged to continue to work with students, parents, school staff, community members, public health professionals, and food service providers to ensure that appropriate strategies are in place to implement this memorandum.

School boards are encouraged to consult with their board of health to implement the nutrition standards. Under Ontario Public Health Standards, 2008, boards of health have a mandate to work with school boards and schools on healthy eating in schools.

School boards are responsible for monitoring the implementation of this memorandum.

At the end of the 2010-11 school year, school boards will be required to attest that they will be in full compliance with this memorandum on September 1, 2011.

For more information on support that is available to assist with implementation, see www.ontario.ca/healthyschools.

¹In this memorandum, *school board(s)* and *board(s)* refer to district school boards and school authorities.

²M. M. Storey, M. S. Nanney, and M. B. Schwartz, "Schools and Obesity Prevention: Creating School Environments and Policies to Promote Healthy Eating and Physical Activity", *The Milbank Quarterly*, 87(1), (2009), p. 72.

³Centers for Disease Control and Prevention, *Guidelines for School Health Programs to Promote Lifelong Healthy Eating*, MMWR 1996;45 (No. RR-9), p. 1.

⁴Dietitians of Canada, "School Food and Nutrition Recommendations for Ontario Ministry of Education Regarding Snacks and Beverages Dispensed by Vending Machines", p. 3, published with Ontario Ministry of Education, Policy/Program Memorandum No. 135, "Healthy Foods and Beverages in Elementary School Vending Machines", October 20, 2004.

⁵For further information, see [Foundations for a Healthy School](#).

⁶The nutrition criteria are based on scientific research, on the Canadian Food Inspection Agency's [Guide to Labelling and Advertising](#), on a cross-jurisdiction scan, and on market research on available food and beverage products.

⁷The following are examples of food choices: a bran muffin is one food choice and a banana muffin is another food choice; an apple is one food choice and an orange is another food choice.

⁸The following are examples of beverage choices: plain milk is one beverage choice and chocolate milk is another beverage choice; orange juice is one beverage choice and apple juice is another beverage choice.

Source: Ontario Ministry of Education, 2010.

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INSTRUCTOR GUIDANCE

Changing School Food Environments: Is Policy Enough?

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BACKGROUND

Nutrition is important for overall physical, mental, social, and cognitive well-being. It is especially crucial for children as it is linked to all aspects of their growth and development, which is connected to their health as adults. Children on their own are incapable of deciding what foods are good for their health. Hence, it is important to provide them with the right nutrition and a supportive environment to instill healthy eating habits. These habits will promote a better quality of life that will be perpetuated later on (Children's Heart Centre, 2007). To address the nutritional standards of foods provided at schools in Ontario, the Ontario Ministry of Education developed the School Food and Beverage Policy. The objective was not only to assist schools in providing a healthier environment for students (Ontario Ministry of Education, 2010) but also to influence manufacturers to supply healthy foods to schools. This case revolves around the challenges faced by schools in implementing the School Food and Beverage Policy. These challenges involve the potential barriers faced by the school board, teachers, parents, and the students to abide by the policy.

The goal of the case is to provide an understanding that merely providing a policy is not the only solution to an issue. Factors such as monetary resources, communication, social environments, institutional willingness, and stakeholders' accountability help facilitate a policy's successful implementation. Furthermore, these factors play an important role when continuously monitoring and evaluating a policy. Policy evaluation is critical to understanding the impact of the policy on the community, institutional, and individual levels (Ross C. Brownson, 2009). Moreover, the case also encourages readers to think about the social determinants of health pertinent to healthy eating and access to healthy foods.

OBJECTIVES

1. Understand the barriers to the implementation of the School Food and Beverage Policy.
2. Explore the implications of the policy on the social environment and on individual attitudes and behaviours.
3. Illustrate the application of the social ecological model in the context of the School Food and Beverage Policy.
4. Propose realistic and feasible recommendations to the issues identified in the case.

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DISCUSSION QUESTIONS

1. What are the issues that might cause implementation gaps in the policy besides those mentioned in the case?
2. What are the social determinants of health related to the case? How are they affecting the policy?
3. What steps should be taken to avoid the 'nanny state' argument during the implementation of the policy?
4. Is the policy limiting the freedom of choice of the students?
5. Is educating teachers, parents, and students enough to facilitate the implementation of the policy?

KEYWORDS

Nutrition policy; school; healthy eating; healthy schools.

CASE 5

Investigating Suspected Outbreaks of Rare Infectious Disease Using Surveillance Data: The CJDSS Perspective

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BACKGROUND

Renée Dubois, a public health nurse consultant of fifteen years, sat at her desk at the Public Health Agency of Canada, sipped her tea, and stared out the window. It was a beautiful spring morning in Ottawa, Canada. From the corner of her eye, she noticed a red light flashing on her landline and listened intently to the voicemails left on the Creutzfeldt-Jakob Disease Surveillance System (CJDSS) phone line over the weekend. She listened to the first message, then the second, and then the third. As the train of voicemails ended, her eyes widened. For the first time in a decade, there had been a suspected outbreak of variant Creutzfeldt-Jakob Disease (CJD) in Ontario.

Dr. Lawson, the referring doctor on the last voicemail, sounded calm despite the situation at hand. “If you would please call me back as soon as possible, I would like to speak further about the next steps.” Dr. Lawson is a neurologist at a well-known neurology center in Toronto, and she called regarding a suspicious cluster of possible variant CJD cases in the Greater Toronto Area. A set of five patients were displaying early symptoms of rapidly progressive dementia. Noting that several of these patients were much younger than the typical age demographic prone to sporadic CJD (Exhibit 1), Dr. Lawson immediately contacted the CJDSS to investigate these cases as possible cases of variant CJD.

Upon receiving this information, Renée immediately sent out a department-wide email notifying the other nurses of the situation. She had previous experience with a possible CJD outbreak a decade prior. Luckily, the cases were not variant CJD (as confirmed by autopsy), and were instead misdiagnosed cases of sporadic CJD. From this experience, Renée knew that the consequences of an outbreak of variant CJD had wide ramifications, which required pre-planning, inter-sectoral collaboration, and effective mobilization of resources to quickly diagnose and isolate the source of a possible outbreak.

CREUTZFELDT-JAKOB DISEASE

Creutzfeldt-Jakob Disease (CJD) is a rapidly progressing, fatal, neurodegenerative disease. It is the human form of bovine spongiform encephalopathy (BSE), popularized as “Mad Cow Disease” in the early 2000s. The worldwide incidence of CJD is approximately one to two cases per 1,000,000 persons (NCJDRSU, 2016). In Canada, this translates to 40-50 new cases per year (Exhibit 2). Since 1994, there have been over 800 cases of confirmed CJD in Canada (Exhibit 3), with a majority of cases in Ontario and Quebec (Exhibit 4).

DISEASE SYMPTOMOLOGY AND PROGRESSION

Creutzfeldt-Jakob Disease is characterized by the accumulation of prion proteins in the brain and neural tissue degeneration, which gives the tissue a spongy appearance (PHAC, 2012).

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At onset, patients often experience psychiatric or sensory symptoms, including anxiety, depression, visual hallucinations, and aphasia (WHO, 2012). As the disease rapidly progresses, neurological defects develop within weeks, resulting in involuntary movements, dementia, and ataxia (UCSF, 2016). The average duration of illness, from initial neurological symptoms to death, can vary from four to 40 months (Kovács et al., 2005). At time of death, patients are completely immobile and mute (WHO, 2012).

TYPES OF CJD

There are three types of CJD: sporadic, genetic, and acquired. In ~85% of patients, the disease occurs sporadically, without any known external source of infection. This is referred to as sporadic CJD. In 10% to 15% of patients, CJD develops in familial clusters, passed down through inherited mutations of the prion protein gene PRNP. This type of CJD is referred to as genetic CJD. Lastly, acquired CJD can develop in several ways and is the rarest form of CJD, occurring in approximately 1% of patients. Acquired CJD is an umbrella term used to describe iatrogenic CJD and variant CJD. As the name suggests, iatrogenic CJD is transmitted iatrogenically, induced accidentally via hospital or diagnostic procedures. Iatrogenic CJD is linked with exposure to contaminated hormones, infected dura mater or corneal grafts, and contaminated neurosurgical instruments. However, *variant* CJD (vCJD) develops from the ingestion of BSE-contaminated meats, or blood transfusions from a vCJD-positive donor (WHO, 2012; Budka & Will, 2015). WHO's case definitions of CJD are presented in Exhibit 5.

PRIONS AS INFECTIOUS AGENTS

The prion protein (PrP) in its normal form is present in all humans and animals (WHO, 2011). However, PrP is in an altered, self-propagating form in diseases like CJD and is referred to as a prion or a proteinaceous infectious particle (Prusiner, 1998). When PrP is in its mutated form, it is able to infect non-mutated forms of the protein, resulting in a cascade effect in the brain. Contact with tiny amounts of prion-contaminated material can initiate the disease process in an otherwise healthy individual. Once they appear, abnormal prion proteins aggregate. The aggregation of proteins contributes to widespread neuron loss. However, the exact molecular mechanism of this process is unknown (Clarke et al., 2001).

The altered form of PrP is responsible for a host of diseases including Kuru, Gerstmann–Sträussler–Scheinker syndrome, and fatal familial insomnia (Will, 2003), with the latter two implicated in genetic routes of transmission (Collins et al., 2001).

Certain surgical procedures can transmit prions. These include dura mater grafts, corneal grafts, and any surgery involving neural tissues (PHAC, 2007). Prions can also be spread via exposure to BSE-containing foods. However, there is no evidence that CJD can spread via social contact, sexual contact, mother-to-child, blood transfusion, or through routine health care (PHAC, 2007). CJD tissue infectivity is outlined in Exhibit 6.

A HISTORY OF VARIANT CJD IN CANADA AND WORLDWIDE

The earliest cases of vCJD were identified in 1994 in unexpectedly young individuals in the United Kingdom (Will et al., 1996). Since then, over 200 cases of vCJD have been identified worldwide, with 175 cases in the UK alone and 49 cases in other countries around the world – including two in Canadian residents (WHO, 2012).

After 1996, the United Kingdom implemented strict food safety measures to prevent further contamination in its food supply. Canada followed suit after the first Canadian case of vCJD was identified in 2002 (Jansen et al., 2003).

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Furthermore, scientists discovered that several patients in the UK were infected with vCJD-positive blood via blood transfusion (Belay & Schonberger, 2005; WHO, 2008). This revelation spurred many countries to take preventive measures to regulate their blood supplies and to minimize the risk of vCJD being spread by blood transfusion. This remains true even today, as Canadian Blood Services and Héma-Québec ensure that blood donations are not accepted from individuals who may be silent carriers of CJD – for example, individuals who may have lived a cumulative of three or more months in the United Kingdom between 1980 and 1996, or five or more years in Western Europe from 1980 to 2007 (Héma-Québec, 2014).

Currently, the Government of Canada regulates the Canadian beef industry to minimize the risk of BSE contamination. It has also minimized the risk of infection through surgical procedures (PHAC, 2007) and through blood transfusion (Héma-Québec, 2014). By implementing various infection-control guidelines, as outlined in the Creutzfeldt-Jakob Disease Quick Reference Guide (PHAC, 2007), the risk of BSE infection in Canada is considered to be extremely low.

CREUTZFELDT-JAKOB DISEASE SURVEILLANCE

The Canadian Creutzfeldt-Jakob Disease Surveillance System (CJDSS) was established by Health Canada in 1998 (PHAC, 2003), in response to the widespread outbreak of vCJD in the United Kingdom. It was created as a national surveillance system for Creutzfeldt-Jakob Disease. Currently, the role of the CJDSS is to assist in the investigation and diagnosis of suspected cases of CJD in Canada, provide support to patients and health care providers, and ultimately protect the health of Canadians by reducing the risk of CJD transmission.

Following the World Health Organization's (WHO) model for comprehensive surveillance of human prion diseases, the CJDSS offers support to collaborating health care professionals. This is completed via initial consultation, referral for laboratory testing, provision of logistic support, education, and awareness. With informed consent from patients, a detailed medical chart review and family interviews are also completed. The resultant diagnostic and epidemiological information gathered by the CJDSS is assembled in a comprehensive online database and is used to support further epidemiological analysis and public health decision-making (PHAC, 2016).

HOW IS CJD DIAGNOSED?

Currently, there is no single definitive diagnostic test for CJD. However, if a patient is exhibiting symptoms of CJD, there are several recommended laboratory tests that can be completed to rule out more common causes of dementia or neurological symptoms, including encephalitis or chronic meningitis (NINDS, 2003). Recommended laboratory testing for CJD is outlined in Exhibit 7.

PUBLIC HEALTH CHALLENGES OF PRION DISEASES

Prion diseases like CJD pose a unique combination of challenges to public health. These include their long incubation periods (upwards of a decade), a lack of host immunity, a strong resistance to decontamination (for example, in neurosurgical instruments), limited diagnostic testing, and potential for zoonotic and health care-based transmission (Coulthart et al., 2015).

Because the early symptoms of CJD are often non-specific, and the disease itself is quite rare, it can be very difficult for physicians to diagnose. The disease also progresses quickly, and it can be difficult for physicians to support families through the quick deterioration of their loved one. Thus, it is important for public health to be aware of CJD and its risks and to be able to mobilize resources to isolate and quarantine the source of a possible outbreak situation.

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BACK TO RENÉE – THE CASES AT HAND

After conducting an initial intake questionnaire with physicians and health care providers, Renée amalgamated essential information regarding the five cases of suspected CJD, taking care to note that all cases occurred within 50 km of Toronto. She recorded the patients' dates of birth, dates of onset, symptoms, and test results. She also noted rapidity of symptom progression.

Some initial test results are recorded in Exhibit 8. However, due to the varied availability of equipment and quality of care experienced by Ontarians, not all recommended diagnostic tests were completed prior to patient death (as in Case #3), while some results are still pending (Case #4 and #5).

MASS MEDIA GETS THE SCOOP

Two weeks after Renée received the first voicemail from Dr. Lawson, Renée received word from Dr. Lawson that the first patient of the five patients passed away. Mr. C. (Case #2) was a young, prolific athlete, who was set to compete in the upcoming Olympics in Brazil. His rapidly declining health was covered extensively in the public eye, with frequent posts to social media outlining his deteriorating physical state.

Local reporters had begun flooding the neurology clinics and hospitals frequented by Mr. C., demanding answers. Several news outlets also released articles sensationalizing the potential return of "Mad Cow Disease," and imploring the federal government to intervene in the investigation. Lobbyists began to spread sensationalized articles demanding a beef ban, and Health Canada was being pressured to release a statement.

DEVELOPING AN INVESTIGATIVE STRATEGY: RENÉE'S DECISION

Renée tasked two nurses to compile the medical records and clinical information for each case. Knowing the causes and methods of transmission of CJD, Renée struggled to come up with the root cause of this outbreak. Without access to each patient's medical history, she was struggling to weave a connecting thread between the individual cases.

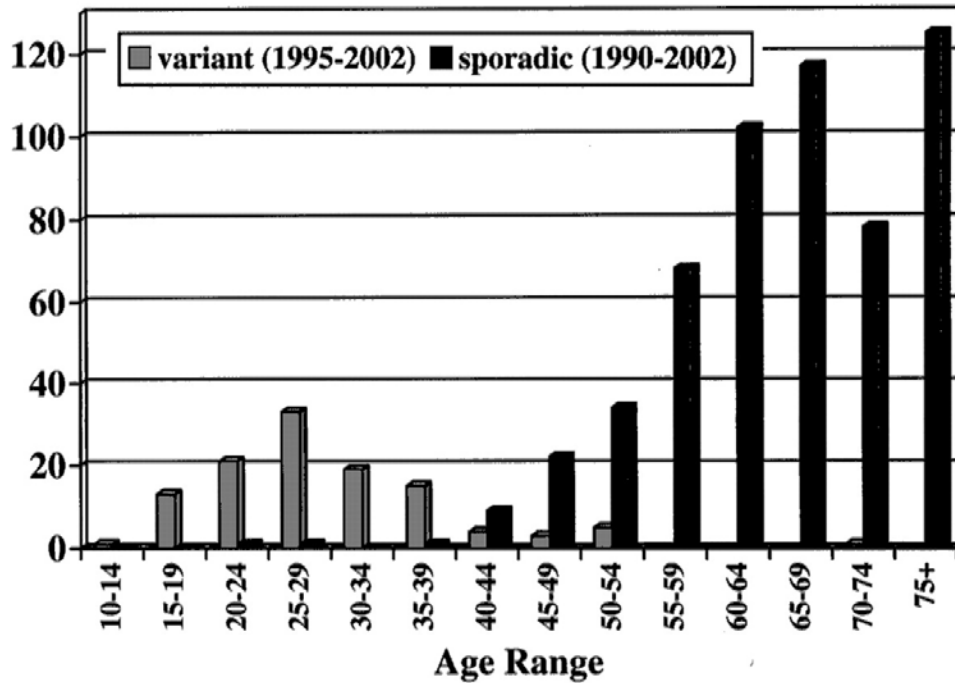
Renée needed to figure out the best course of action to lead the team of nurses to the correct diagnosis. From her previous experiences working in a neurology clinic for 10 years, she was very familiar with CJD diagnostic tests and how to interpret them. What were the best diagnostic tests for her to pursue? What were some potential root causes she could suggest the team to concentrate on to direct their investigation? Were these cases connected? If so, what should she do next?

A confident speaker, Renée often presented about CJD at universities and conferences across Canada. From her experiences as a keynote speaker, Renée knew that referring to CJD as "Mad Cow Disease" would merely fan the flames of public hysteria. Reducing the sensationalized stories in the media was her first goal.

In the case of Mr. C., what essential information should Renée recommend that the hospitals and neurology clinics share to the media? What should Renée's main message be? Who should Renée collaborate with to get her message out to the public? What cautionary information should the public campaign include?

Investigating Suspected Outbreaks of Rare Infectious Disease Using Surveillance Data: The CJDSS Perspective

EXHIBIT 1
Distribution of Variant and Sporadic CJD Cases in the UK, by Age



Source: Will, 2003. Reproduced with permission from Robert G. Will. Acquired Prion Disease: Iatrogenic CJD, Variant CJD, Kuru. British Medical Bulletin (2003) 66 (1): 255-265. Published by Oxford University Press online at: <https://academic.oup.com/bmb/article/66/1/255/284826/Acquired-prion-disease-iatrogenic-CJD-variant-CJD?searchresult=1> For permissions please email: journals.permissions@oup.com.

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**EXHIBIT 2
Incidences of CJD in Canada: 1999-2016
As of June 30, 2016**

Year of Death	Total CJD Cases	Population of Canada	Incidence Rate
1999	32	30,492,106	1.05
2000	35	30,783,969	1.14
2001	30	31,130,030	0.96
2002	36	31,450,443	1.14
2003	29	31,734,851	0.91
2004	44	32,037,434	1.37
2005	44	32,352,233	1.36
2006	44	32,678,986	1.35
2007	39	33,001,076	1.18
2008	49	33,371,810	1.47
2009	53	33,756,714	1.57
2010	38	34,131,451	1.11
2011	51	34,472,304	1.48
2012	63	34,880,248	1.81
2013	51	35,289,003	1.45
2014	55	35,675,834	1.54
2015	51	35,702,707	1.43
2016	11	35,985,751	0.61

Cases with definite & probable diagnosis to date.
[2015 Population Source](#)

Source: PHAC, 2016.

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**EXHIBIT 3
CJD Deaths Reported by the CJD Surveillance System (1994-2016)
As of June 30, 2016**

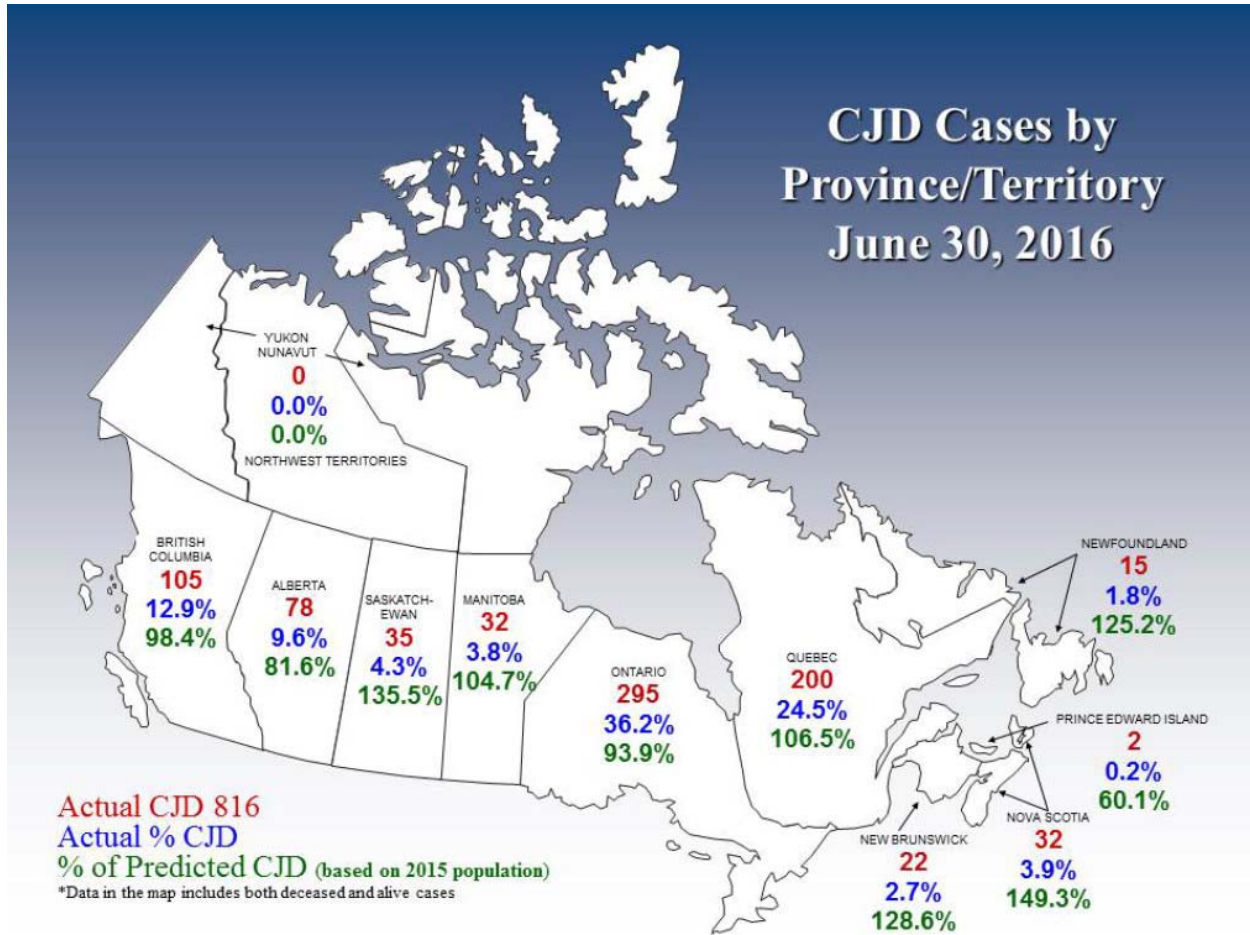
Deaths of Definite and Probable CJD							
Year	Sporadic	Iatrogenic	Familial	GSS	FFI	vCJD	Total
1994	2	0	0	1	0	0	3
1995	3	0	0	0	0	0	3
1996	13	0	0	0	0	0	13
1997	16	0	1	1	0	0	18
1998	22	1	0	1	0	0	24
1999	27	2	2	1	0	0	32
2000	32	0	0	3	0	0	35
2001	27	0	2	1	0	0	30
2002	31	0	2	2	0	1	36
2003	27	1	1	0	0	0	29
2004	42	0	1	1	0	0	44
2005	42	0	1	1	0	0	44
2006	39	0	1	3	1	0	44
2007	35	0	0	4	0	0	39
2008	48	0	1	0	0	0	49
2009	48	0	3	2	0	0	53
2010	35	0	3	0	0	0	38
2011	46	0	3	1	0	1	51
2012	62	0	1	0	0	0	63
2013	50	0	0	0	1	0	51
2014	50	0	4	0	1	0	55
2015	44	0	4	1	2	0	51
2016	10	0	1	0	0	0	11
Total	751	4	31	23	5	2	816

Cases with definite & probable diagnosis to date.

Source: PHAC, 2016.

**Investigating Suspected Outbreaks of Rare Infectious Disease
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**EXHIBIT 4
Map of CJD Cases in Canada
As of June 30, 2016**



Source: PHAC, 2016.

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EXHIBIT 5 Case Definitions of CJD

At time of death, all possible CJD cases in Canada are classified according to the WHO diagnostic criteria for CJD:

Definite CJD

- Requires neuropathologic examination
- Confirmed by cranial autopsy

Probable CJD

- Case is lacking neuropathologic examination
- Based on combination of non-neuropathologic criteria:
 - Clinical profile (ataxia, rapid progressive dementia, etc.)
 - Results of cerebrospinal fluid (CSF) protein immunoassays
 - EEG
 - MRI
 - Genetic analysis
 - Brain/tonsil biopsy

Possible CJD

- Information is even more limited.

Source: WHO, 2008.

**Investigating Suspected Outbreaks of Rare Infectious Disease
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**EXHIBIT 6
CJD Tissue Infectivity**

High Infectivity	Low Infectivity
<ul style="list-style-type: none"> - Brain - Cerebrospinal fluid - Dura mater - Pituitary gland - Posterior eye - Spinal cord and ganglia - Trigeminal ganglia 	<ul style="list-style-type: none"> - Cornea - Kidney - Liver - Lung - Lymph nodes - Placenta - Spleen
No Detected Infectivity	
<ul style="list-style-type: none"> - Adipose tissue - Adrenal gland - Appendix - Blood (including cord blood) - Blood vessels - Bone marrow - Breast milk - Dental pulp - Epididymis - Esophagus - Feces - Gingival tissue - Heart - Ileum - Jejunum - Large intestine - Nasal mucosa - Nasal mucous - Ovary 	<ul style="list-style-type: none"> - Pancreas - Pericardium - Peripheral nerves - Placental fluids - Prostate - Saliva - Semen - Seminal vesicle - Skeletal muscle - Skin - Sweat - Tears - Testis - Thymus - Thyroid gland - Tongue - Tonsil - Trachea - Urine

Source: PHAC, 2007.

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EXHIBIT 7 Recommended Laboratory Testing for CJD

Upon initial intake of a patient, it is recommended that the following tests be conducted in order to confirm or rule-out the possibility of CJD:

1. CEREBROSPINAL FLUID (CSF) TESTING

In all cases of CJD, CSF testing is highly recommended. CSF is collected via lumbar puncture and is tested for levels of various proteins. Some protein tests that are conducted using CSF include 14-3-3, S100B, and tau protein tests (Coulthart et al., 2011). Elevated levels of these proteins have been reported to support a CJD diagnosis. However, each test has varying levels of sensitivity and specificity, and the threshold limits of each protein can differ from patient to patient. Currently, CSF tau shows the best overall diagnostic accuracy, compared to 14-3-3 or S100B protein markers (Coulthart et al., 2011).

2. COMPUTERIZED TOMOGRAPHY (CT) SCANS

Computerized tomography (CT) scans of the brain can sometimes rule out the possibility that exhibited symptoms may have resulted from another neurological issue including strokes or tumours in the brain (WHO, 2008).

3. ELECTROENCEPHALOGRAPHY (EEG)

Electroencephalography (EEG) measures waves of electrical activity in the brain. This test can be valuable as certain sharp wave complexes are characteristic in sporadic CJD. However, EEG is not useful in the diagnosis of vCJD (WHO, 2008).

4. MAGNETIC RESONANCE IMAGING (MRI)

Magnetic resonance imaging (MRI) brain scans also can reveal characteristic patterns of brain degeneration that can help diagnose CJD (WHO, 2008).

5. GENETIC TESTING

Blood samples can be used to prepare DNA for genetic analysis. Specific mutations in the PRNP gene, including P102L, E200K and D178, are CJD-causing variations. However, some variations are silent, and do not cause disease – for example, M129V (Swietnicki et al., 1998).

6. TONSIL BIOPSY

Prion proteins can often be found in tonsil tissues in CJD-positive patients. However, this test is not useful in diagnosing sporadic or genetic CJD (WHO, 2008).

7. BRAIN AUTOPSY

While the results of the aforementioned six diagnostic tests may lead to a strong diagnosis of CJD, the only definite method of knowing whether the patient has CJD is through brain autopsy at time of death. However, autopsy is a lengthy process, requiring several months to complete. Some characteristic changes in a CJD-positive brain include:

- Spongiform change
- Loss of neurons
- High astrocyte density
- Presence of abnormal prion proteins

**Investigating Suspected Outbreaks of Rare Infectious Disease
Using Surveillance Data: The CJDSS Perspective**

**EXHIBIT 8
Case Characteristics and Test Results**

Case #	Age at Onset	CSF Results	EEG	MRI	Status
1	42	Positive	Negative	Negative	Alive
2	25	Positive	Negative	Positive	Dead
3	33	Pending	Unknown	Unknown	Dead
4	44	Positive	Negative	Pending	Dead
5	36	Pending	Negative	Pending	Alive

Source: Created by author.

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INSTRUCTOR GUIDANCE

Investigating Suspected Outbreaks of Rare Infectious Disease Using Surveillance Data: The CJDSS Perspective

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Michel Deilgat, BA, MD (Medical Advisor, Public Health Agency of Canada)
Mark Speechley, PhD (Professor, Western University)

BACKGROUND

A suspected cluster of variant Creutzfeldt-Jakob Disease (CJD) cases (a fatal neurodegenerative disease) has been identified in Toronto. Renée Dubois, a public health nurse, must utilize epidemiological data to recognize the outbreak, and mobilize resources to support patients and health care providers. The assembled epidemiological information gathered by the CJD surveillance system must be used to further support data analysis, public health decision-making, and public messaging. This case may be used to supplement lectures covering relevant public health events or epidemic analysis.

OBJECTIVES

1. Understand the importance of case reporting and laboratory data for surveillance of infectious diseases and outbreak detection.
2. Identify limitations of diagnostic tests and laboratory data, as well as the importance of ethical guidelines and informed consent in patient sampling.
3. Devise an emergency preparedness management strategy in the event of a communicable disease outbreak.
4. Interpret epidemiological data to understand the spread, origin, and effects of communicable disease.
5. Interpret laboratory data in context of epidemiological data in order to make recommendations for timely public health action.

DISCUSSION QUESTIONS

1. What is an outbreak?
 - a. What are some modern examples of outbreaks?
2. How can you recognize an outbreak?
3. What sources of information would you consult to confirm that it is an outbreak?
 - a. How would you access this information?
 - b. What are the limitations of diagnostic tests and laboratory data?
4. What information is most relevant for public health decision-making?
5. What is the role of media in outbreak investigation and communication?
 - a. How do you ensure confidentiality in a high profile outbreak?
 - b. What is the public message you would communicate, and what would that look like?
 - Relate this to current public health events.

KEYWORDS

Epidemiology; Creutzfeldt-Jakob Disease (CJD); outbreak management; surveillance data; PHAC.

CASE 6

“I know there is hope, even in a world of loss”: A Local Community-Based Intervention to Address Mental Health Challenges Among First Nations Men and Boys

Jasmine Fournier, BHSc, MPH (MPH Class of 2016)

Julie George, PhD (Independent Scientist, Centre for Addiction and Mental Health)

Samantha Wells, PhD (Scientist, Centre for Addiction and Mental Health)

Lloy Wylie, PhD (Assistant Professor, Western University)

Moving back and forth between multiple treatment centres across Ontario and his home community, River Rock First Nation (RRFN)¹, Kieran has lost invaluable time that could have been spent with his four-year-old daughter, Sara. When Kieran is home, not away at a treatment centre, he works full-time as a carpenter during the spring and summer months. He has been steadily working his way up the company ladder since he started carpentry in high school and was well on his way to becoming a crew leader until he started misusing pain medication that was prescribed to cope with an injury he sustained at work. Once his injury had healed, Kieran tried to quit using the prescription medication; however, he found the withdrawal symptoms too overpowering. When his prescription eventually ran out, he had to buy his drugs on the street to ward off unbearable withdrawal symptoms. Kieran’s addiction to pain medication was further compounded by other self-destructive behaviours, such as marijuana and alcohol use, which he used to deal with his deep-seated trauma from ongoing family disputes and his recent separation from his wife. When he visited the doctor seeking help for his addiction, Kieran was also diagnosed with anxiety and depression. Despite his efforts to get help, the health care providers told him to “tough it out”. Kieran’s self-medication with pain pills, marijuana, and alcohol sent him into an uncontrollable downward spiral. Fearing he might lose his job and precious time with his daughter if he did not regain control of his life, Kieran’s anxiety worsened as his addiction became all consuming.

The people who Kieran went to for help outside his community tried to give him advice; however, they had no understanding of his background or culture. He remembered the Elders from his community telling him that to assess a person’s health and well-being, the physical, mental, emotional, and spiritual aspects of health must be understood. However, when Kieran tried to explain these needs outside his community, there was no one to talk to who would listen to him or try to understand where he was coming from. Most treatment centres did not address the underlying issues he faced. Kieran knew that he wasn’t the only one facing these issues. He had seen other people from his community, especially young men, go down this path. Dreading he might miss yet another one of Sara’s birthdays, Kieran began to wonder why there were no mental health services for boys and men in his own community that were rooted in his own culture. Something had to be done. But what could be done and who could help make this happen?

¹The name of the community is fictional.

“I know there is hope, even in a world of loss”: A Local Community-Based Intervention to Address Mental Health Challenges Among First Nations Men and Boys

BACKGROUND

Mental health is a major public health concern in Canada. Approximately one in five Canadians will be directly affected by a mental illness over their lifetime, while the remaining four in five will have a family member, friend, or co-worker who has personally experienced mental illness (CMHA, 2016). According to the Centre for Addiction and Mental Health (CAMH), “mental illness is a leading cause of disability in Canada” (CAMH, 2012). Mental health concerns affect a person’s ability to perform daily activities, resulting in employment instability, disrupted sleep patterns, and impaired cognitive functioning (CAMH, 2012). Results from the 2012 Canadian Community Health Survey – Mental Health (CCHS – MH) indicated that 7.8% of all Canadians surveyed rated their mental health as fair or poor (Statistics Canada, 2013). Negatively perceived mental health is linked to poor health outcomes and comorbidities, such as depression, suicide, stroke, and diabetes (Olfiffe & Phillips, 2008). Most troubling is the link between mental illness and suicide. Suicide is a leading cause of death, especially among young people across all ethnicities (CMHA, 2016). Given that every Canadian is either directly or indirectly affected by mental illness and poor mental health is one of the leading causes of death in youth, improving mental health services is a major priority that could have an important positive impact on the entire country.

Although mental health and mental illness are defined, expressed, and experienced in different ways by different subpopulations, Indigenous populations² have been disproportionately affected by mental health challenges. It is well recognized that these challenges largely stem from the effects of colonization, everyday racism, and structural violence (Allan & Smylie, 2015). Survey data collected from two First Nations communities in Southwestern Ontario revealed that, of the men surveyed, 80% were treated unfairly at restaurants, 86% were treated unfairly by police or other law enforcement personnel, 65% were treated unfairly by doctors or other health care providers, and 65% were treated unfairly in the workplace (George, 2013-2016). These everyday encounters are major mental health stressors for Indigenous People. With an improved understanding of these issues, it may be possible to start breaking down barriers to optimal health for Indigenous Peoples and those involved in the struggle for equity.

Statistics and other information from large surveys, such as the CCHS – MH, are useful when trying to understand major patterns in health problems across the country. For example, one study found that death due to suicide is five to six times more likely among First Nations youth than among non-First Nations youth (Health Canada, 2013). However, these statistics identify general patterns and do not highlight the uniqueness of each community’s situation. While overall rates of suicide may be disproportionately high for Indigenous populations, Hallett, Chandler, & Lalonde (2007) found that First Nations communities in British Columbia have reduced their rate of suicide to below the national average by focusing on cultural continuity, such as language retention. Thus, on the surface it would appear that suicide and suicide prevention should be a focus in every Indigenous community. However, this broad generalization pathologizes communities and does not consider the uniqueness of each community.

Gender differences with regards to mental health must also be considered. For example, Olfiffe & Phillips (2008) have asserted that men’s and women’s expression of depression is different. To further complicate matters, the current diagnostic criteria to detect depression are based on

² When possible, it is imperative to use the specific name of the group or community that researchers are working with. When one specific community cannot be identified, the term “Indigenous” will be used throughout this case to encompass all First Nations, Inuit, and Métis peoples. Although the all-encompassing term “Indigenous” will be used, it should be reinforced that every individual, family, and community has their unique cultural experiences, strengths, and challenges.

“I know there is hope, even in a world of loss”: A Local Community-Based Intervention to Address Mental Health Challenges Among First Nations Men and Boys

women’s rather than men’s symptoms of depression, resulting in underreporting and misdiagnosis in male patients. They further explain that the social construction of the ideal male persona is a major barrier to seeking and accessing the mental health services that boys and men may need (Oliffe & Phillips, 2008). Many organizations, both nationally and internationally, have specialized programs addressing women’s health. This may be due to consistent evidence that women have higher rates of mood disorders than men, while men have higher rates of substance use disorders than women (Pearson, Janz, & Ali, 2013). These findings suggest that a female focus on mental health and a male focus on substance use may be justifiable. However, mental health and substance use challenges often go hand-in-hand. For example, close to one in five people within the mental health system have a concurrent substance use disorder (Rush & Koegl, 2008). Overall, from an equity standpoint, it is important for males to have improved access to mental health services.

It is also important to note that the use of opioids is a major public health concern not only globally, but in Canada as well. In 2012, it was estimated that nearly 200,000 Canadians were addicted to opioid based painkillers (Webster, 2012), with Canadians ranked among the highest opioid consumers in the world (United Nations Office on Drugs and Crime, 2014). Canada’s dependence on opioid based painkillers can be attributed to the over prescription of these addictive medications (Webster, 2012). Clearly, professionals in the health care field, pharmaceutical companies, and the general public need to work together to tackle this ever growing concern.

MEET YOU AT THE USUAL SPOT – HOW THE IDEA GERMINATED

While watching the water crash on the rocks at the bottom of River Rock falls, Kieran and his childhood friend, Jake, got to talking. The two often met by the water to de-stress and clear their minds. After a long moment of silence, Kieran confided in Jake, “You know what? I wish we had a place to go for help that is right here in River Rock and follows the teachings of our Elders.”

Confused by what he meant, Jake replied, “What are you talking about, man?”

Kieran replied, “Our brothers, sons, and fathers – we have suffered a lot and some of us need help, but we need help that understands our people. We need a place to go where our well-being follows the medicine wheel, including physical, mental, emotional, and spiritual well-being, following the history of our peoples.”

At first, Jake silently nodded his head in agreement and eventually spoke, “Have you heard that Jade is back in town?”

“No. What is she up to? I thought she got her PhD or something,” replied Kieran.

“She’s the new person at the community health centre. Jade did her PhD on mental health. Guess the city wasn’t for her and she came back.”

The friends united in deep belly laughter.

The next day Kieran and Jake went to the health centre to meet with Jade and tell her about their riverside conversation. Jade agreed that a mental health program designed specifically for men and boys was greatly needed. The trio decided to become a mental health taskforce team, but they knew they needed outside supports. After contemplating the different avenues this new project could take, Jade decided that the Centre for Addiction and Mental Health (CAMH) would be a great organization to partner with. She had heard about a research project at CAMH that

“I know there is hope, even in a world of loss”: A Local Community-Based Intervention to Address Mental Health Challenges Among First Nations Men and Boys

had identified men’s mental health as an important issue. Working together would be of mutual benefit for both the community of RRFN and CAMH.

CENTRE FOR ADDICTION AND MENTAL HEALTH (CAMH)

CAMH is a large teaching hospital and a leading research centre in addiction and mental health that collaborates with other research centres worldwide (CAMH, 2016). Recent CAMH initiatives include research on cannabis, alcohol, and prescription opioids, as well as mobile applications designed to improve access to mental health resources. CAMH is also strengthening its partnerships with First Nations, Inuit, and Métis peoples to provide culturally appropriate clinical support. CAMH recently opened a sweat lodge on traditional ceremony grounds at the CAMH Toronto location. CAMH also supports research and knowledge exchange to improve Indigenous mental health. More specifically, the research project that Jade had heard about aimed to improve the understanding, prevention, and treatment of co-occurring mental health, substance abuse/addiction, and violence challenges in diverse communities across Ontario. Among the communities involved in this project were two First Nations. In this research, Jade found out that “more than 20% of male study participants in [one community] reported that they needed help for their emotions or mental health but did not receive it” (George, 2013-2016, p. 5).

Drawing on what she had learned throughout her schooling and the research done by CAMH, Jade knew that the best way to ensure that this project would be successful was to involve the community every step of the way. They needed to start a mental health program for boys and men, uniquely led by men in the community, backed by research and the lived experiences of the participants, their families, and community members. Kieran, Jake, and Jade decided to organize a community barbeque on the following Friday to engage with community members and to hear what they had to say about the idea of a mental health program for boys and men.

While waiting for the event, Jade decided to review scientific papers and unpublished reports to find any available information on Indigenous mental health programs. To her dismay, she found very little information about Indigenous-specific mental health programs and even fewer on male-specific programs. After discussing her scan of the literature with Kieran and Jake, the trio decided that they should look at local research data to identify community needs and strengths, as well as opportunities for improvements. This information would be used to make their program meaningful and appropriate to the community, and therefore the best it could possibly be.

RIVER ROCK FIRST NATION (RRFN)

In order to provide the best programs for the community, it is imperative to understand the needs of the specific community at hand. Located on the southern shore of the St. Lawrence River, RRFN has approximately 1,000 people living on reserve. RRFN houses a health centre that provides services to all of the surrounding communities. At the centre, clients can access primary care doctors, nurses, dentists, mental health and addictions services, educational programs for all ages, and medical transportation for hospital visits. Along with the health centre, there is a grocery store, gas station, a few small family businesses, and an elementary school on the reserve.

Through determination, perseverance, and the support of community members, Kieran was able to complete his high school diploma and continue his job with the construction company. Jade was also given a great deal of support and completed her PhD. However, Jake only got to grade 10 before quitting high school. While there has been a narrowing in the gap, educational attainment of working age (i.e. ages 25 to 64) Indigenous Peoples remains lower compared with

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non-Indigenous people, with many Indigenous Peoples still not receiving a high-school diploma (Gordon & White, 2014). This lower incidence of high school completion can be partially attributed to the fact that many people have to commute long distances to receive secondary schooling. For the people of River Rock, the closest high school is a 45-minute drive outside of the community. Communities of a similar size with a high school on the reserve tend to fare better in educational attainment (Aboriginal Affairs and Northern Development Canada, 2014). With lower levels of education, it can be more challenging to attain steady employment, which could lead to higher rates of food insecurity and absolute poverty.

Although Kieran, Jake, and Jade knew a great deal about their community, they didn't know about the specific needs of boys and men or the strengths they draw on to heal that could be used to develop a mental health program. The trio decided that research was needed to better understand the experiences of boys and men in RRFN, how they face mental health issues, where they go for help, whether their experiences are positive or negative, and to learn how positive change can be made in the community.

While they knew that research was needed, they were worried that research alone might not provide the answers they were looking for. Through their community barbeque they learned that people in other communities were unhappy with how research was conducted in their communities and how it was used. The people they spoke with felt like the researchers were only in the community for a self-serving purpose that did not benefit those who participated. Considering this, the trio decided to find out more about how to do research in a community like theirs to ensure a mutually beneficial relationship between researchers and the community.

GUIDING ETHICAL RESEARCH PRINCIPLES

Historically, research has been done on or to Indigenous Peoples and the resulting data was taken away from the community, sometimes never to be returned, with little to no benefit to the individuals or communities that participated in the project (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2014). The research participants were treated as passive observers as opposed to active participants in research. The knowledge of the Indigenous Peoples was devalued and largely ignored. Without consulting the individuals, groups, or communities involved in the research, there was little consideration of their unique worldviews. This misrepresentation has led to Indigenous mistrust in, and unwillingness to work with, researchers.

This negative research legacy has led to the development of multiple ethical guideline documents for working with Indigenous Peoples in Canada. Four of the main overarching documents include: 1) The Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, Second Edition (First Nations, Metis, and Inuit focused); 2) Ownership, Control, Access, and Possession (OCAP) Principles (First Nations focused); 3) Principles of Ethical Métis Research (Métis focused); and, 4) Inuit Perspectives on Research Ethics (Inuit focused). It is important to also consider any guidelines that an individual community may have, such as Manitoulin Island's Guidelines for Ethical Aboriginal Research.

The Tri-Council Policy Statement has the three main principles of respect for persons, concern for welfare, and justice (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2014). The OCAP Principles assert that information is owned collectively by the participants and researchers. Indigenous Peoples control all aspects of research and information management that pertains to them. They must have access to the data and it is the

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community that possesses the rights to the data (First Nations Centre, 2007). The Principles of Ethical Métis Research has six principles including reciprocity, respect, safe inclusive environments, diversity, relevance, and Métis worldview (National Aboriginal Health Organization, 2010). Inuit Perspectives on Research Ethics focus on a population specific approach, relationship building, cultural competency training, privacy, and consent (Nickels & Knotsch, 2011). Any community specific documents, such as the *Guidelines for Ethical Aboriginal Research in the Manitoulin Area*, must be considered on top of the Tri-Council Policy Statement and OCAP principles. The criteria for this document are similar to the above overarching documents; however, its main focus is respect (Noojmowin Teg Health Centre, 2003).

DECIDING ON THE RIGHT APPROACH

As there are currently no specific guiding documents for research with RRFN, the Tri-Council Policy Statement guidelines and the OCAP Principles must be followed to properly conduct research with this community. Kieran, Jake, and Jade were now faced with deciding what type of research would best address these ethical principles. Jade had heard about Participatory Action Research (PAR) but the trio felt they needed to know more about how to conduct this type of research properly. They contacted a CAMH researcher who had previously used PAR in a different First Nation community with great success.

Participatory Action Research (PAR)

PAR is a research methodology that sees participants as active and intelligent individuals of a community, or a subset of a community, who are working collaboratively with relevant stakeholders in every aspect of the research project to tackle challenges that are identified as important in the local context. This approach was introduced in the 1940s by Kurt Lewin as a way to promote social justice and change in marginalized populations (Castleden, Garvin, & HUU-ay-aht First Nation, 2008). PAR is appropriate in Indigenous communities as it starts to break down divisions of power, sees participants and researchers as equals, and allows open communication for ethical research practices, such as the OCAP Principles. PAR has been found to create a sense of ownership, build capacity and trust, and acknowledge the incorporation of Indigenous worldviews (Castleden et al., 2008). Ultimately, these qualities create community buy-in, which may foster a continuation of the research project after the main researchers or funding are gone. There are many different approaches to PAR, including photovoice, body mapping, music therapy, art therapy, and peer led support groups.

Photovoice

Photovoice is a PAR approach in which participants take photographs that elicit emotions backed by a narrative to accompany the photograph. In some projects, the researchers and participants come up with a particular theme, such as environmental problems or mental health challenges. The participants and researchers then engage in a meaningful and action-oriented discussion about the photographic images. These discussions can then be used to influence policy makers and key stakeholders (Castleden et al., 2008). This approach appears to be appropriate for Indigenous communities as it gives people the platform to talk openly about a difficult topic in a constructive environment and it is in line with the Indigenous value of storytelling (See Exhibits 1 & 2 for examples from the Photovoice project).

HOW IT ALL CAME TOGETHER

After careful consideration, Kieran, Jake, and Jade decided that the best approach to conducting research in their community was to use Participatory Action Research through Photovoice. The next challenge was to secure funding for their project. The trio searched for potential grant opportunities to support their community-led intervention to develop a boys' and

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men’s mental health program that incorporates physical, mental, emotional, and spiritual aspects of health. After months of applying to different grant programs, they finally received funds from a worldwide investor in men’s mental health for a three-year period to develop a boys’ and men’s mental health program. The objectives of the program were to: 1) raise awareness and knowledge of First Nations boys’ and men’s mental health; 2) reduce stigma; and, 3) support prevention, early recognition, and recovery (George, 2013-2016). The team planned to achieve these objectives using a consumer-driven and holistic approach that builds on existing community strengths.

As part of the project, the team decided to develop user-friendly knowledge translation toolkits that are evidence-based, culturally-safe, and gender-specific to address boys’ and men’s mental health and can be adapted and used by other Indigenous communities across Canada. As part of their knowledge translation strategy, they planned to develop a widely accessible website with a discussion board and interactive videos.

First, however, the trio needed to recruit a group of men who would participate in the Photovoice project. Following PAR principles, they decided to have a few information sessions where they could consult with the community on the most appropriate method to recruit participants and inform the community about the project. At the sessions, Jade prepared a short presentation that informed the viewers about PAR and Photovoice, followed by a question and answer period. By the end of the information sessions, they had secured the participation of six willing boys and men of varying ages, who all faced unique mental health and substance use challenges. During their first meeting as a group, they decided to take photos that explored the underlying causes of these challenges for each participant.

After a period of six months, the men and boys had taken upwards of 100 photographs each. When Jade asked her contact at CAMH if this was an average amount, her contact informed Jade that many of the women’s groups she had led only produced approximately a quarter of that number. Thrilled by the results, Jade began to conduct follow up interviews where the participants talked about their photos and what they meant to them. Throughout the process, the health centre offered debriefing, counselling, and education for the participants and their families.

After the overwhelming success of the Photovoice project and realizing that they were becoming positive role models in the community with the potential to influence change, the participants decided they needed to offer further supports for the boys and men in their community. Witnessing young boys struggling with the justice system, the boys’ and men’s group decided to create a comprehensive mentorship program for male youth. As part of the mentoring program, the boys’ and men’s group organized an art program, workshops on traditional practices facilitated by respected community Elders, and a recovery drum circle. These programs were made available to boys and men throughout the year to ensure ongoing supports.

KIERAN’S CONTINUED MENTAL HEALTH JOURNEY

Prior to his riverside conversation with Jake, Kieran was facing multiple mental health challenges. He was misusing pain medication that was originally prescribed to him, partying with marijuana and alcohol, and had been diagnosed with anxiety and depression. After confiding in Jake and creating the mental health taskforce team with Jade, Kieran started to develop a stronger social support network. Hearing the inspirational stories from the other men and boys in the group, Kieran’s thought patterns became more positive and open-minded. As a result, his depression lessened, although his anxiety remained the same. The health team started him on a low dose of suboxone to help curb his pain medication addiction. Although life is currently

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looking better for Kieran, he must continue his self-care journey, and remember his support system when he starts to feel like starting up old habits.

WHAT NEXT?

As the end of the three-year funding window creeps closer and closer, the community must come up with a way to sustain their largely successful program for boys and men. What is the best way to sustain the program in their community? What could be some barriers to continuing the programming? What other community initiatives might be needed in River Rock and other First Nations? What is the next move for the boys' and men's group? What about Kieran, Jake, and Jade?

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EXHIBIT 1



“I have been telling my family since I was little that I want to be a Warrior and to learn about and practice cultural ways. They get angry when I talk about it and tell me that Christianity is the only way to live. I believe that everyone should be free to choose their spiritual path, but I am afraid I will lose connection with my family if I choose traditional ways”.

– Photovoice Participant, 2016

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EXHIBIT 2



“This reminds me of my healing journey. The stem of the feather is my life and each little hair represents all the paths I need to go down to heal”.

– Photovoice Participant, 2016

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INSTRUCTOR GUIDANCE

“I know there is hope, even in a world of loss”: A Local Community-Based Intervention to Address Mental Health Challenges Among First Nations Men and Boys

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Samantha Wells, PhD (Scientist, Centre for Addiction and Mental Health)
Lloy Wylie, PhD (Assistant Professor, Western University)

BACKGROUND

Kieran, a young man from River Rock First Nation (RRFN), is frustrated that there are no evidence-based, culturally-safe, and male-specific mental health resources available at any of the treatment centres he has attended. Kieran and his friend Jake partner with Jade, a recent PhD graduate, to initiate a boys' and men's mental health program in the community. Using the information Jade gathered for her PhD as a foundation, as well as drawing on applied research at the Centre for Addiction and Mental Health (CAMH), the team uses a participatory action research approach, including photovoice, to address mental health challenges of boys and men in RRFN.

The goal of this case is to provide a platform for the reader to think critically about how mental health concerns can be addressed in Indigenous communities and have meaningful impact using the resources available to the community. This case will also allow students to explore methods that can be employed to build community capacity to develop evidence-based and culturally appropriate programming within a resource-scarce environment. After reading the case, students will start low on the Bloom's cognitive taxonomy pyramid; through class discussions and instructor guidance the learners will advance to a higher cognitive domain.

OBJECTIVES

1. Identify and differentiate between the proximal, intermediate, and distal social cultural determinants of health (SCDOH) that affect the mental health of Indigenous Peoples in Canada and specifically in the fictional community of RRFN.
2. Explain mandatory ethical research principles used when conducting research with Indigenous Peoples.
3. Discuss the importance of community involvement in research projects.
4. Critically analyze potential intervention strategies to mitigate mental health disparities using the resources available to the community.

DISCUSSION QUESTIONS

1. Why is it important to consider the SCDOH of the community you are working with?
2. What are the potential risks of participatory action research? How can these risks be mitigated?
3. Do you think this program would work in other Indigenous communities? Why or why not? How can the transition to other communities be made easier?

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4. How would you implement a mental health program with little to no funding?
5. How would you ensure that this program continues when the funding stops?

KEYWORDS

First Nation; Indigenous; participatory action research; mental health; addiction; male.

CASE 7

Transitioning from Prison to Community

Alison Green, BSc (Hons), MPH (MPH Class of 2016)
Graham Betts-Symonds, BA (Hons), DA (Hons), Pg.Dip, RGN, RCNT
(Programme Director, Community-Based Health & First Aid in Prisons, Irish Red Cross)
Amardeep Thind, MD, PhD (Professor, Western University)

“My name is Joe and I’ve been working as an inmate Irish Red Cross volunteer, helping other prisoners with improving hygiene and delivering healthy messages. In the past, I was always a taker – doing drugs, stealing cars, and not thinking about my family – me winding up in prison. Now, when I tell my family what I’m doing, they’re really proud of me, especially my mother. I’m surprised at myself giving back; it makes me feel good about myself.”

This is a reflection of an Irish Red Cross (IRC) inmate volunteer talking at his graduation where his mother and family proudly shared his day.

Carrie McGowan, the IRC, Community-Based Health & First Aid (CBHFA) Prison Programme Manager, applauded as she and everyone else in the room congratulated the latest group of IRC inmate volunteers to graduate from the CBHFA Prison Programme at Wheatfield Prison. “Working with you lads these past six months has been fantastic, and your work as volunteers has had a tremendous impact on the prison community. Fair play to you!” exclaimed Carrie.

The CBHFA Prison Programme trains prisoners as special status IRC volunteers in an effort to promote the health and safety of the prison community through peer-to-peer health education and the implementation of health promotion projects on the prison wings. The Programme operates through a partnership between the IRC, Irish Prison Service (IPS), and Education and Training Boards Ireland (ETBI). As of 2014, approximately 700 prisoners had been trained as volunteers since the Programme’s inception in 2009. Through the Programme, many of the volunteers have demonstrated immense personal development, internalized a more constructive identity, and gained knowledge and skills in the areas of health awareness and personal and community well-being. Due to IRC policies, many inmates only keep their IRC volunteer status whilst in prison and therefore, their skills and knowledge are not harnessed upon their release. They are unable to continue exercising their pro-social identity by way of their roles as IRC volunteers.

Ryan, another inmate IRC volunteer, commented on his experience with the Programme and how it has impacted him:

“They got me started with First Aid training and I loved it. I couldn’t believe that I could deal with these things. I never believed in myself. That is how it all started and I haven’t looked back. It’s especially satisfying to help other inmates overcome the kind of addictions I was once facing. I feel that I am giving the lads some hope. When I came in, I was dependent on drugs and alcohol so I know how it feels. This was the help I needed...I would like to continue with the IRC on the outside if

Transitioning from Prison to Community

possible. This was the help I really needed. I don't want to go back to the old Ryan, the old lifestyle. That will never happen."

Since receiving feedback like Ryan's, the CBHFA Prison Programme team has started working on phase II of the Programme. With phase I of the Programme being the CBHFA Prison Programme that was and is currently in place within the prisons, phase II was being designed to take the Programme in a new direction, from prison to community. The Programme team recognized that the process of reintegrating prisoners into society was filled with many challenges. The thinking that drove phase II development emerged from wondering whether a continuation of the Programme could aid in this transition by providing opportunities for ex-offenders to achieve "active citizenship" by enabling them to take responsibility and initiative in their local community. They could then continue to exercise the positive identity they developed through the Programme while in prison. The team knew that such a Programme came with certain risks and challenges but believed that the potential benefits for both the community and the ex-offenders outweighed said risks.

BACKGROUND

The Irish Prison Service (IPS)

The IPS is one of the CBHFA Prison Programme's primary partners, and it operates as an executive agency within Ireland's Department of Justice and Equality (Irish Prison Service, 2012). Each of the 14 prisons that comprise the IPS possess a similar staff structure with each having a Governor, Assistant Governors, Chief Officers, and Assistant Chief Officers to oversee operations as well as other prison staff. Despite these structural similarities, Ireland's prisons are unique with respect to their level of security, demographic makeup, and particular needs and challenges.

The mission and vision of the IPS is to provide safe and secure custody, dignity of care, and rehabilitation to prisoners in an effort to create safer communities. The IPS strives to achieve excellence in prisoner care and rehabilitation by working closely with several agencies in order to provide opportunities for offenders to access services to improve their lives. Services provided by the IPS include education, a library, work training, mental health services, probation, and health care services (Irish Prison Service, 2012).

The Irish Red Cross (IRC)

The IRC is a member of the International Federation of Red Cross & Red Crescent Societies (IFRC), which is the world's largest global network of voluntary humanitarian action. It is made up of approximately 190 Red Cross and Red Crescent societies in nearly every country in the world. The IRC was formally established in 1939 and has since been providing humanitarian support and community services to the most vulnerable, both locally and abroad (Irish Red Cross, 2016a).

The IRC's work in Ireland is both extensive and diverse. Their programs and services range from ambulance and rescue services, to programs to assist in reconnecting families who have lost contact with each other, and to promoting the awareness of International Humanitarian Law (Irish Red Cross, 2016a). Included amongst this list of programs is the award-winning CBHFA Prison Programme, which is one of the IRC's most innovative community health programs.

The CBHFA Prison Programme was modeled after the CBHFA in action approach, which is an IFRC approach to health education and First Aid. It was designed for use in communities around the world through each country's respective national Red Cross/Red Crescent Society (Irish Red Cross, 2016b).

Transitioning from Prison to Community

The CBHFA approach involves training and mobilizing volunteers from the community to carry out relevant health and safety activities. It is based upon the belief that volunteers from the community understand the community and its needs best and thus know the best ways to address them.

Ireland is the first country in the world to introduce the CBHFA Prison Programme in a prison context, using groups of special status IRC inmate volunteers. The innovative nature of the Programme applied to prison health has captured the attention of many international organizations in the field of prison health and criminal justice.

Carrie McGowan, IRC CBHFA Prison Programme Manager

Carrie studied Psychology at the National University of Ireland from 2006-2009, which she subsequently followed with a two-year Master's degree in Counseling & Psychotherapy at the Irish College of Humanities & Applied Sciences.

Prior to becoming the manager of the CBHFA Prison Programme in March of 2015, Carrie had worked as a psychotherapist in Wheatfield Prison for four years. While working there, Carrie had been very aware of the CBHFA Prison Programme, as several of her clients had become IRC volunteers, and she had noticed first-hand the positive impact the Programme was having on them.

Carrie became involved with the Programme by first providing support to some of the project work the volunteers were doing surrounding overdose prevention and the development of an overdose prevention module.

As Carrie witnessed the power of peer-to-peer education within the prison, her interest and involvement with the Programme grew. She eagerly pursued becoming a part of the CBHFA Prison Programme management team, especially because the Programme was moving to focusing on the transition from prison to community. From her work as a psychotherapist, she had heard first-hand the battles prisoners faced upon leaving prison and returning to the community. She believed that this Programme, which was changing the lives of people in prison, could continue to do so outside of the prison walls.

Graham Betts-Symonds, Programme Director, IPS CBHFA Prison Programme

Graham Betts-Symonds was trained as a registered nurse, teacher, researcher, and manager with experience in community and preventive health, disaster management, emergency care, trauma, and orthopedics. His doctoral research was in the field of change management, experimenting with chaos and complexity theory applied to management learning, which underpinned much of his work in both disaster management and community health.

Graham was previously Director of Combat Medicine for the Middle Eastern Armed Forces after the Gulf War before being appointed as the Emergency Medical Technology Director at Northeastern University – Middle East campus. He later worked with the IFRC as a Regional Disaster Management Delegate for the Middle East based in Jordan with the British Red Cross. Subsequently, Graham became Senior Officer in Disaster Preparedness and Risk Reduction for the Middle East, North Africa, and Asia-Pacific based at the IFRC in Geneva.

Graham has experience in developing and implementing community based programs in Asia, including China and the Pacific Islands.

During the Gulf War, he oversaw the medical management of prisoners of war in specific wards of military hospitals. Graham was responsible for training all medical staff on war-casualty

Transitioning from Prison to Community

management, including Chemical and Biological Warfare casualties. The high risk of chemical attacks overlaid on traditional war casualties created a complex preparedness and response training need as well as significant ethical perspectives never envisaged before (Betts-Symonds, 1994).

As a consultant to the IFRC, Graham designed the methodological approach of CBHFA in Action for the Health Department in Geneva published in 2009 for global use. This built on his previous systems and cybernetic approach to community vulnerability and capacity assessment developed for global use in risk reduction and disaster preparedness.

In 2008, Graham moved to the Irish Prison Service in Dublin, and became responsible for prison health in two major prisons with a remit to implement change management within the health system to create a culture of proactive, preventive health. A collaborative approach was used developing partnerships with the IRC and the ETB and as an example of the Whole Prison Approach to health (World Health Organization, 2007).

The development and implementation of CBHFA in prisons was the change management strategy employed based upon the *learning and action* experience in earlier combat medicine and International Red Cross settings in community health, disaster preparedness, and risk reduction.

THE COMMUNITY-BASED HEALTH AND FIRST AID (CBHFA) PRISON PROGRAMME (Phase I)

The CBHFA Prison Programme was born out of a noticed gap in prison health care delivery with respect to the nine IPS Health Care Standards following an audit in 2008 (Exhibit 1). The fifth standard encompasses all elements of prisoner/patient health awareness and education relating to disease prevention and the maintenance of healthy lifestyles and well-being. The audit of this standard scored poorly — from a prison community-based perspective — because the dissemination of health information was not being undertaken within the community as a result of resource constraints, making nurses only available to provide health advice/information on a one-to-one basis (Betts-Symonds, 2016). As a result, the CBHFA Prison Programme, a peer-led, community, public health program, was developed through the adaptation of the IFRC's CBHFA in action approach and was piloted at Wheatfield Prison in 2009.

As previously highlighted, the CBHFA Prison Programme operates through a partnership between the IRC, IPS, and ETBI. It involves inmates becoming special status IRC volunteers in order to serve as peer health educators and build community capacity relating to public health and First Aid (Betts-Symonds, 2016). The Programme modules (Exhibit 2) are delivered weekly over a six-month period by ETBI teachers in the school unit of the prisons and by allocated nurses/health care professionals who are employed within the prison health care system. This makes the Programme extremely cost effective.

The Programme design is based upon the principle of “learning by doing,” whereby the volunteers apply what is learned in the classroom on the prison wings as they progress through the Programme modules. Throughout the Programme, inmate volunteers assess the needs of their community, learn specific skills based on relevant health topics, and subsequently plan and implement various health promotion projects on the prison wings.

A CBHFA Prison Programme management structure is implemented in each prison. The effective functioning of this structure is crucial to the success of the Programme, as buy-in from governors and prison staff is necessary in order to grant volunteers access to the prison wings

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(Betts-Symonds, 2016). This structure is put in place and attached to each CBHFA Prison Programme in every prison:

- Governor
- Chief Officer
- Assistant Chief Officer
- Prison Officers
- Teacher
- Nurse
- Representatives of the Volunteer Group

This structure also represents the membership of the Community Health Action Committee (CHAC) in each prison, which meets monthly to monitor and drive health projects being planned or implemented by the CBHFA inmate volunteers.

The CBHFA Prison Programme has ensured sustainability by training qualified IRC volunteer inmates as facilitators for CBHFA. These facilitators take on the role of teaching selected CBHFA modules to new volunteers as well as supervising and assisting new volunteers with their project work. Inmate facilitators have had tremendous success in their delivery of both the Overdose Prevention and Culture of Non-Violence and Peace Modules. The Culture of Non-Violence and Peace Module has also been developed into its own workshop, which is delivered by IRC inmate facilitators to the general inmate population on a monthly basis in an effort to help prevent, reduce, and mitigate incidences of violence in the prison community.

THE IMPACT OF THE CBHFA PRISON PROGRAMME

The CBHFA Prison Programme was first piloted at Wheatfield Prison in June 2009 and, following several successful evaluations, was extended to all of Ireland's 14 prisons in 2014. Results from the 2009-2014 evaluation period have shown the profound positive impact the CBHFA Prison Programme has had on prison health and the prison community. The success of many of the projects and campaigns implemented by the IRC volunteers is thought to be a result of the power of peer-to-peer education, which has been shown to be effective at accessing hard-to-reach populations (Clements & Buczkiewicz, 1993).

The positive impact of the CBHFA Prison Programme can be seen through the various health promotion projects undertaken by the IRC volunteers, with a list of the various different projects shown in Exhibit 3. An example of positive impact can be seen in the HIV Mass Rapid Testing & Reduction of Stigma campaign linked to St. James's Hospital's HIV Clinic. This campaign was implemented in three prisons in the Dublin area after discovering that less than 10% of the prison populations knew their HIV status (Betts-Symonds, 2012; 2016).

Inmate volunteers advocated for testing and encouraged discussions about HIV and AIDS amongst inmates, resulting in 55-75% of all inmates from the three prisons presenting for voluntary testing. Many prisoners indicated their participation in the voluntary testing was a result of the advocacy efforts of their peers, rather than doctors and nurses, providing support for the power of peer-to-peer education (Betts-Symonds, 2016).

Ryan first became aware of the IRC volunteers' work during the HIV Testing campaign and commented on how it influenced him to promote his own health:

"My father died when I was ten, and my mother died when I was only fifteen. After my mother died, I turned to alcohol and drugs. When I came into prison, my life was upside down. I thought I might have had AIDS."

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An inmate IRC volunteer befriended me, and they encouraged me to get tested for HIV in the mass voluntary HIV testing campaign organized by Healthcare staff and Red Cross volunteers.

It came back negative. It was a huge weight off my shoulders. It was a second chance.”

The Weapons Amnesty Project is another example of a successful project that was undertaken by the inmate IRC volunteers. This project was linked to the Programme’s Violence Prevention and Reduction module and was planned after inmate IRC volunteers identified violence using cutting weapons as a serious problem in the prison community. The volunteers and prison management decided to work together to address this problem by planning a week-long weapons amnesty (Betts-Symonds, 2016). The IRC inmate volunteers advocated for prisoners to make the prison community a safer place by giving up cutting weapons; prisoners were assured this would not lead to any sanctions against them. The initiative was a huge success, with the percentage of all attacks on prisoners with a cutting weapon dropping from 97% to less than 6% in the months after the amnesty (Betts-Symonds, 2016).

In addition to the impact the CBHFA Prison Programme has had on prison health and safety, the Programme has also fostered significant personal development and empowerment among the inmate IRC volunteers. The benefits of the Programme to the volunteers include improved self-esteem, self-respect, and confidence, and this can be seen in the examples of the guided-reflective exercise undertaken with IRC inmate volunteers during an evaluation of the Programme (Exhibit 4) (Betts-Symonds, 2016).

The significant personal development the Programme has fostered amongst the volunteers was a strong contributor to fueling the team’s belief in the value of a continuation of the Programme that focuses on prison to community. Phase II would allow ex-prisoner volunteers to continue exercising their pro-social identity and living by the humanitarian principles of the IRC.

THE PROBATION SERVICE

In late 2014, the CBHFA in Prisons team brainstormed potential strategies and additional partners for the development of phase II of the Programme. They thought of The Probation Service as an ideal partner, who would be useful to turn to for supporting the intended direction of phase II.

The Probation Service is another agency in the Department of Justice and Equality, which works closely with the IPS as well as with a number of other agencies and community organizations. By definition, to be “on probation” means to be given an opportunity to prove oneself after committing an offence, and the concept emerged over a hundred years ago as a humane approach to helping offenders to change (The Probation Service, 2015).

The Probation Service aims to reduce levels of crime and increase public safety by working with offenders to help change their behaviour through a variety of professional services and supports. Among such services include probation supervision, community service, anti-offending behaviour programs, and specialist support services (The Probation Service, 2015).

According to both The Probation Service and the IPS, the national prison population in Ireland reduced to approximately 3,500 in 2014 from 4,500 in 2009. This reduction in the prison population was thought to be due to a change in the correctional approach, which included a greater use of Community Service Orders and the introduction of a Community Return Scheme (Betts-Symonds, 2016).

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Community Service Orders are an alternative to a prison sentence, which gives convicted offenders the opportunity to instead perform unpaid work for the community. The objective of Community Service is for offenders to pay back the community for the damage caused by their offense (The Probation Service, 2015).

The Community Return Programme, on the other hand, is an incentivized scheme, which provides for earned temporary release in return for supervised Community Service (The Probation Service, 2015). Prisoners are eligible for this scheme if they are serving sentences of one to eight years, with over half of their sentence served, and are assessed by officers of The Probation Service as suitable.

In the early planning stages of phase II, the CBHFA team negotiated with The Probation Service for the possibility of a partnership between The Probation Service and the CBHFA Prison Programme. This was aimed at a possible continuation of the Prison Programme and its volunteerism working in association with one or both of the Community Service Order and Community Return Schemes.

RECIDIVISM IN IRELAND

In 2013, the IPS, in collaboration with the Central Statistics Office, conducted a study of recidivism among all prisoners released by the IPS on completion of a sentence in 2007; the study was based on reoffending data up to the end of 2010. The study demonstrated a national recidivism rate of 62.3% within three years and over 80% of those who reoffended did so within 12 months of release. The high rate of recidivism found in this study demonstrated the need for a greater emphasis on a structured multi-agency approach to preparing prisoners for their release and reintegration into the community (Irish Prison Service, 2013).

This study was the first of its kind in Ireland and was thought to provide the support needed for the development of phase II of the CBHFA Programme, aimed at improving prisoner reentry, reducing recidivism rates, and improving community health. Whilst it is too soon to draw firm conclusions, it is encouraging to see that, between 2009 and 2014, 700 inmates were trained as CBHFA volunteers and of the 350 that were released, 75% remained out of prison in 2015.

PRISONER REENTRY

The successful reintegration of prisoners back into society is a critical process due to the personal and emotional costs to former offenders as well as the maintenance of public safety, community vitality, and controlling the costly expansion of criminal justice systems (O'Donnell, Baumer, & Hughes, 2008). However, this process carries significant challenges and there are several factors that likely have a role in shaping the high rates of recidivism that accompany unsuccessful reintegration.

Risk factors predictive of offender recidivism have often been categorized as either static or dynamic (Andrews & Bonta, 1994). Static risk factors are aspects of the offender's past that are predictive of recidivism but cannot be changed, such as young age and previous convictions (Gendreau, Little, & Goggin, 1996). Dynamic risk factors, also known as criminogenic needs, are changeable and thus, are often targeted in rehabilitation programs. Examples of dynamic risk factors include antisocial cognitions, antisocial companions, antisocial values, and antisocial behaviours (Andrews & Bonta, 1994).

Some argue that the reentry process is often difficult as a result of the damaging effects of incarceration on prisoners' social functioning, ultimately contributing to his or her return to offending following release (Irish Penal Reform Trust, 2016). To exacerbate the challenges associated with the damage that may be done to social functioning, many prisoners also leave

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prison with little money, resources, or social capital; and as a result of their criminal record, are unable to find employment or housing (Makarios, Steiner, & Travis, 2010). Petersilia (2003) argues that due to these deficits, the successful reentry of many prisoners is both difficult and unlikely.

Additional theoretical explanations for why prisoners recidivate also include (a) insufficient positive attachment to social groups, institutions, and supports and, (b) the way certain communities burden residents with stigma, social constraints, territorial confinement, and institutional boundaries that foster recidivism through denied opportunities and hyperscrutiny (Bowman & Travis, 2012).

Numerous societal features also likely play a prominent role in fostering desistance, such as the availability of programming aimed at enhancing the likelihood of successful reintegration — both in prison as well as upon release (O'Donnell et al., 2008). Braithwaite's (1989) theory proposes that certain societal features, most notably strong social interdependencies and high levels of collective participation and social capital, should yield both lower overall crime rates and lower recidivism rates. One of the ideas behind this theory is that such societal conditions make it less likely for offenders to be categorically stigmatized as "offenders" and more likely to be socially supported as contributing members of society upon release (O'Donnell et al., 2008).

The challenges that accompany the reentry process extend beyond recidivism, with prisoner reentry also being associated with adverse health and well-being outcomes, substance abuse challenges, and an increased chance of death (Bowman & Travis, 2012). According to data in Ireland, a significant number of accidental drug overdoses occur in ex-prisoners who do not take into account their loss of drug tolerance upon leaving prison, posing a serious public health challenge in this vulnerable population (Betts-Symonds, 2016).

IRISH CONTEXT: ISSUES & CHALLENGES

When considering the development and implementation of phase II, it was important for the team to understand the characteristics of the Irish prison population and the difficulties faced on an individual level by those who come into contact with Ireland's criminal justice system.

Firstly, the rates of mental illness among the Irish prison population are significantly higher than the general Irish population. Often prisoners with mental illnesses also have problems with drugs and alcohol, with illicit drug use and smuggling having long been a recognized problem within the Irish prison system (Martynowicz & Quigley, 2010). Furthermore, homelessness has also been recognized as a barrier to integration among the Irish prison population. The issue of homelessness and its connection to crime is important because prisoners released without a place to live are more likely to reoffend (Social Exclusion Unit, 2002). According to a study by Seymour and Costello (2005), one in four prisoners in Dublin had been homeless upon committal, and over half of prisoners had experienced homelessness at some stage in their lives.

Ex-prisoners also encounter many barriers in accessing and maintaining employment. Obstacles that impede on ex-prisoners' access to employment include low self-esteem, lack of educational qualifications and training, insecure housing, lack of recent job experience, difficulty in setting up a bank account, and discrimination in trying to get a job (IPRT, 2016). In addition to such barriers, having a criminal record has been recognized as an obstacle to securing employment. Employment is important, as unemployed ex-prisoners are twice as likely to reoffend in comparison to those in full- or part-time jobs (Irish Law Reform Commission, 2007).

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Recently, Spent Convictions legislation, a criminal policy in Ireland that was signed into law in February 2016, was developed to help address the difficulties ex-offenders face with disclosing criminal convictions for employment purposes. Under the *Criminal Justice (Spent Convictions and Certain Disclosures) Act 2016*, a range of minor offences will become “spent” after seven years, meaning adults convicted of an offence covered by the Act would not have to disclose the conviction after seven years except in certain circumstances. Despite good intentions, the positive impact of this legislation may be limited due to restrictions on the types of convictions covered, as well as the requirement that the length of the term of imprisonment be 12 months or less.

In addition to individual-level challenges faced by prisoners, several systemic issues exist in the Irish criminal justice system, which pose a threat to successful prisoner reintegration. Among this list of challenges there exists a large rural versus urban divide with regards to the provision of services in the community, with the majority being concentrated in cities and larger towns. In addition, there seems to be a prioritization of resources by level of risk of committing serious crimes and therefore, risk to the community. This results in limited resources being made available to offenders who pose little or no risk of committing serious crimes, but who could still benefit from increased support. Lastly, even when services are available both in prison and in the community, such information is not always provided on committal to prison, during the sentence, or in preparation for release (Martynowicz & Quigley, 2010).

THE WOUNDED HEALER IN PRISONER REENTRY PROGRAMS

The CBHFA Prison Programme team began to consider ways in which inmate IRC volunteers may be purposefully used in the community after their release. As they brainstormed, they turned to the criminal justice literature to review theories and principles used in various prisoner reentry programs that could help in the development of a suitable program for phase II.

They found that recently, researchers have begun to recognize a coping strategy among formerly incarcerated individuals involved in becoming a “professional ex-” (Brown, 1991, p.219) or a “wounded healer.” Such concepts involve former prisoners taking on helper roles in programming surrounding the rehabilitation and reintegration of other offenders (LeBel, Ritchie, & Maruna, 2015). These strengths-based practices, which make use of individuals’ skills and personal strengths, treat offenders as community assets to be used rather than as liabilities to be supervised (Travis, 2000). Maruna and LeBel (2009) argue that becoming a wounded healer functions as a form of stigma management or reverse labeling, allowing such stigmatized individuals to overcome their labels and reconcile with society for their criminal past.

This concept is further supported by research on narratives of desistance that have found that a characteristic that distinguishes between successful and unsuccessful reformed ex-prisoners is engagement in “generative” activities, which are activities designed to give something back to individuals in his or her community (Halsey, 2008; Marsh, 2011; Maruna, 2001; Vaughan, 2007).

In addition to the benefits incurred by the wounded healers themselves, it has been found that many prisoners and former prisoners wish to receive mentoring from formerly incarcerated persons who have successfully reintegrated into society (LeBel et al., 2015).

The characteristics and roles of the wounded healer in the desistance process is also consistent with several of the major risk/need factors (Exhibit 5) in the Risk-Need-Responsivity (RNR) model including reduced antisocial cognitions, fewer antisocial associates, and a supportive work situation (LeBel et al., 2015). The RNR model is one of the most influential models for the assessment and treatment of offenders and identifies several criminogenic risks and need factors that have the greatest impact on recidivism. It can also be used to direct the focus of

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treatment programs. Evidence has shown that rehabilitation programs can produce significant reductions in recidivism when such programs are in adherence with the RNR model (Andrews & Bonta, 2010).

Research examining the potential benefits of this sort of employment in the desistance process of formerly incarcerated individuals in prisoner reintegration programs has shown promising results. Studies found ex-offender staff members engaged in this sort of employment perceive laws to be less unjust than clients and have lower scores on both the criminal attitude scale and the forecast of arrest for themselves (LeBel et al., 2015).

Such findings support the use of strengths-based activities, such as becoming a professional ex- or wounded healer, and suggests that former prisoners can form positive, prosocial relationships with their peers and can be positive role models to others. Involvement in such work may improve a former prisoner's life satisfaction and self-esteem by giving his or her life purpose, meaning, and significance (LeBel et al., 2015).

REFLECTIONS

As the CBHFA team members sat at their desks reflecting on the Wheatfield graduation ceremony, they thought about the conversation earlier that day with the latest Wheatfield IRC inmate graduates, where they had expressed their desire to continue volunteering with the IRC upon their release:

"We need to expand beyond the prison to back in the community. We've gained a lot of skills and become more confident and we would like to use that in some way to help with IRC after release."

They knew that once released from prison, if inmate volunteers wished to continue volunteering with the IRC, they had to apply as a member of the general public. This process involves police vetting, and the resulting decision depends on the nature of their criminal offence, which results in many of the inmates not being accepted as IRC volunteers outside of the prison. This policy was in place in order to protect the safety of the public, but the team wondered whether there was an opportunity for exceptions to be made in order to develop phase II of the CBHFA Prison Programme.

The Programme team met and discussed the notion of applying the wounded healer approach in the development of phase II. The team also saw that the CBHFA Prison Programme contained several modules that addressed health issues that were prominent in the prison as well as among the population of recently released offenders, such as violence and substance abuse.

The team had many decisions to make and questions to consider. Could the delivery of selected Programme modules address certain public health challenges faced by such vulnerable populations? Should phase II of the Programme extend beyond CBHFA modules and also encompass other forms of support that may assist in desistance and reintegration? Who would the Programme be targeting and could there be an opportunity to partner with The Probation Service's Community Service Order and/or Community Return Scheme? Were there other organizations and agencies that the team should look to for support in developing the Programme further and that could serve as Programme partners?

Carrie and the team knew that the time to act was now. A political window was in place as a result of this newly enacted piece of legislation, highlighting the importance of employment in reintegration as well as the relatively recent recidivism study showing high rates of recidivism in

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Ireland. Furthermore, there was commitment from the IPS & The Probation Service to address reoffending and reintegration challenges along with an ample amount of evidence showing the high costs and usage of national resources associated with incarceration.

CONCLUSION

Carrie and the team were left to determine what theories and research findings to use in order to design phase II. Subsequently, they would need to decide what public health issues to target in this phase of the Programme, as well as how exactly it would be implemented and delivered. The team also needed to discuss what risks, if any, a program involving the use of ex-offenders to promote community health would pose, to both the community and partner organizations. Should the Programme be limited to offenders convicted of certain types of crimes? What impact would placing such restrictions have?

The Programme team was left to use all their individual, unique skills and experience to determine how to implement a program that would make use of the IRC inmate volunteers' skills upon their release. With the number of CBHFA Prison Programme graduates increasing, a window of opportunity and a need for phase II of the Programme, the team knew they had to act quickly in developing recommendations for the Programme's implementation.

EXHIBIT 1

Irish Prison Service Health Care Standards

Standard 1: Health Assessment on Initial Reception into Prison from the Community

1. All prisoners on reception will undergo a clinical assessment.
2. Initial Committal assessment will be carried out on the day of reception in the reception area or other appropriate clinical area. It is desirable that this initial committal assessment be undertaken by a qualified nurse in view of the various health care issues which may arise. In those prisons where nursing staff are not consistently available this function can be undertaken by medical orderlies.
3. Within 24 hours of reception a doctor will undertake a clinical assessment of the prisoner's physical and mental health.
4. Suitable interview and examination rooms which are properly equipped and maintained will be provided within the reception area and/or other suitable area within the prison.

Standard 2: Primary Care

1. Primary Care Services will be provided to a standard equivalent to that available in the general community (GMS standard).
2. Suitable, properly equipped accommodation and facilities for the delivery of primary care will be provided.
3. Access to specialist services appropriate to the health care needs of prisoners will be provided within the prison.
4. Efficient arrangements for referral to external outpatient facilities will be in place.

Standard 3: Mental Health Services

1. To provide an integrated service that meets the needs of prisoners suffering from mental disorder. Services should include appropriate implementation of, a) policy on preventing self-injury among prisoners and, b) relevant mental health legislation.

Standard 4: Transfer, Release and Throughcare

1. To ensure that the health care needs of prisoners are considered and taken into account before transfer to another prison and that these needs are provided for during transfer and on reception at the receiving prison.
2. To ensure that all prisoners with ongoing health care needs are assessed by a Doctor or Health care professional prior to planned release (and appropriate arrangements made for follow up).

Standard 5: Clinical and Related Services for Promoting Health

1. To provide services to prisoners which may prevent illness and promote health.
2. To provide prisoners with the information and opportunity to enable them to make reasoned choices regarding the adoption of a healthy lifestyle.

Standard 6: Communicable Diseases

1. To provide prisoners with appropriate screening facilities based on current public health advice.
2. To provide appropriate diagnostic and treatment facilities to prisoners considered at risk.
3. To provide throughcare and arrange appropriate aftercare where required.

Standard 7: The Use of Medicines

1. To provide pharmaceutical services to prisoners that are efficient, cost effective, meet legal and professional requirements, and reflect good professional practice.
2. To provide a safe and effective system for enabling prisoners to hold prescribed medicines in their possession for self-administration.
3. To provide a system of management for controlled drugs which complies with the relevant legislation and regulations.

Standard 8: Dental Services

1. To provide dental treatment to prisoners of an equivalent standard to that normally available to citizens in the general community covered by the GMS Dental Treatment Services Scheme – DTSS.

Standard 9: Drug Treatment Services

1. To provide clinical services for the assessment, treatment, and care of substance misusers comparable to those available in the community, and which are appropriate to the prison setting.

Source: Irish Prison Service, 2009.

EXHIBIT 2

Community Based Health & First Aid Programme: Summary of Modules & Topics

Seven modules, some compulsory, others optional depending on the health needs identified.

- **Module 1, 4 topics.**
 - The International Red Cross Red Crescent's history and organizational structure, Emblems, Seven Fundamental Principles, National Red Cross Society, Community Based Health & First Aid (CBHFA) in action volunteer.
- **Module 2, 4 topics.**
 - Communication and building relationships, volunteers identify groups and meet with potential partners for the CBHFA programme, implement an awareness-raising meeting to inform the community, promote CBHFA in action activities.
- **Module 3, 8 topics.**
 - Assessment of the community by volunteers through direct observation and community mapping, identify and prioritize health, first aid, and safety issues, develop a CBHFA action plan, learn specific skills and knowledge based on needs identified during the assessment, report on activities in the community.
- **Module 4, 20 topics.**
 - Accredited First Aid Course. Volunteers learn how to assess, plan, implement, and evaluate first aid for various injuries and illnesses and practice communicating injury prevention messages with members of their community.
- **Module 5, 2 topics.**
 - Major emergencies and how that may affect the community, preventing and responding to epidemics.
- **Module 6, 16 topics.**
 - Disease prevention and health promotion including Nutrition, Immunization, and Vaccination Campaigns, Safe water, Hygiene and Sanitation, Diarrhoea and Dehydration, Acute Respiratory Infections, HIV and Sexually Transmitted Infections, Reducing Stigma and Discrimination, Tuberculosis, Influenza. Volunteers support the community to adopt healthy behaviours.
- **Module 7, 8 topics.**
 - Focuses on providing community education and assistance; for example, volunteers learn about Overdose Prevention highlighting the dangers of taking drugs.
- **Additional Module**
 - Non-communicable diseases such as cardiovascular & chronic lung disease, cancer and diabetes.

Additional topics relevant to the prison context such as Mental Health Awareness and a Culture of Non-Violence & Peace are also included.

The projects that are undertaken by the Irish Red Cross Volunteer Inmates either emerge from the Community Assessment in Module 3 or as a result of a Health Emergency that arises, or linked in with national health educational campaigns.

Source: Irish Red Cross, 2016c.

EXHIBIT 3

Example of Projects Promoted by IRC Volunteer Inmates in Different Prisons

- Personal, in-cell, and prison hygiene awareness. IRC volunteer inmates provide instructions on good hand washing techniques and in many prisons a colour coded bucket & mop system has been introduced, thus contributing to cleanliness and the prevention and control of disease.
- Contribute to TB awareness in all prisons and in Mountjoy encouraged mass chest X-ray screening with just over 400 prisoners screened.
- Increase local awareness about seasonal flu, the winter vomiting bug, and hepatitis vaccinations.
- Volunteer led projects on nutrition, fitness, cholesterol, blood pressure checking, and dental hygiene.
- HIV & AIDS awareness and anti-stigma campaigns with voluntary HIV Mass Rapid Testing in Wheatfield, Cloverhill, and Mountjoy Prisons.
- In some prisons volunteers actively conduct practical demonstrations in CPR and basic first aid around the prisons.
- Violence reduction through a Weapons Amnesty Project at Wheatfield – assisting management with an advocacy role through the volunteers linked to the 7 Fundamental Principles to remove cutting weapons from the prison. The results have shown a 95% reduction in cuttings with a weapon and 50% reduction in assaults.
- Volunteers designed a peer led violence prevention course linked to CBHFA that takes place on a monthly basis in a number of prisons.
- 'Safe Zone' in Castlerea where the school is a safe area and inmates have signed a form agreeing not to bully, intimidate, or assault any person while attending the school.
- Overdose Prevention Programme by trained volunteer facilitators in partnership with Merchant's Quay Ireland prison based counselling team.
- 'Packing Project' in two prisons around the practice of packing the rectum with large quantities of drugs. There is not only the danger of over dosage but the long term damage that can occur.
- Volunteers facilitate Smoking Cessation Courses with good success rates.
- Carried out the Irish Heart Foundation's F.A.S.T. Stroke Awareness Campaign & raised awareness about heart disease.
- Mental health & well-being awareness in prisons about key issues including the risks of self-harm, and suicide prevention.
- Advocacy work in setting up unit based nursing, primary care systems improvements such as the allocated days for GP appointments and the medications "in-possession" system.
- Paracetamol reduction project and awareness around the safe use of antibiotics.
- Volunteers at Wheatfield have instigated a prisoner support network particularly aimed at 'lifers'.
- Information leaflets & support to new prisoners, Red Cross Buddy project in Portlaoise.
- Parties for senior citizens to mark International Day for the Elderly in Mountjoy and Christmas party for the elderly at Shelton Abbey.
- Intercultural Day promoted by volunteers with the help of staff in Castlerea.
- Benzodiazepine Awareness Campaign.
- 'How to Say No to Bullying' project in Cork prison.
- Sun Safe Campaign in association with the Irish Cancer Society.
- Caring for elderly prisoners in Arbour Hill, i.e. providing Meals on Wheels, cell cleaning, and social activities.

Source: Irish Red Cross, 2016c.

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EXHIBIT 4

Examples of the Guided Reflective Exercise Undertaken with IRC Volunteer Inmates

Think of a time in prison before you became a Red Cross Volunteer What can I see, hear and feel about myself?	Level	Think of a time since you have been working as a Red Cross volunteer in the prison What can I see, hear and feel about myself?
I see a lot of inmates doing Red Cross and they introduce me as well	Goals What are my goals?	I'm proud of myself of being a volunteer of Irish Red Cross and want to continue after prison.
I'm always down, thinking of can I make it in prison?	Identity Who am I?	I have really changed from who I am when I first came to prison.
All my belief is in doing my time and learn something while I'm in prisons	Beliefs and Values What do I believe in and what is important to me?	To make myself available whenever I'm needed for volunteering.
I'm not very bold to express myself to any inmate before	Capabilities What am I able to do?	I'm bold to do some volunteer work, like going to landing telling inmates about the Red Cross.
My behavior was very bad before	Behaviours What am I doing?	My behavior is totally changed at the moment.
I feel not safe when I came into prison	Environment What is this place like?	I feel really safe now with the work of Irish Red Cross

Before		After
No goals	Goals What are my goals?	Since starting Red Cross my goal was to complete the course and pass on my experience to other prisoners.
Before starting – didn't know who I was. I was very shy especially talking in front of a group.	Identity Who am I?	Since starting I'm able to speak in front of a large group and not shy anymore.
I didn't believe in getting educated in prison	Beliefs and Values What do I believe in and what is important to me?	Now I believe it's important to learn and get educated whilst in prison because of the Red Cross
I wasn't capable of doing anything	Capabilities What am I able to do?	I'm capable of doing things for myself such as going to school, working and communicating with other people.
Unsure of the unknown	Behaviours What am I doing?	I find myself taking time out to talk and listen to other people
I was on a basic landing.	Environment What is this place like?	I'm on enhanced and the environment is much better

Source: Irish Red Cross, 2016c.

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EXHIBIT 5

The Risk-Need-Responsivity Model – Seven Major Risk/Need Factors Along with Some Minor Risk/Need Factors

Major risk/need factor	Indicators	Intervention goals
Antisocial personality pattern	Impulsive, adventurous pleasure seeking, restlessly aggressive and irritable	Build self-management skills, teach anger management
Procriminal attitudes	Rationalizations for crime, negative attitudes towards the law	Counter rationalizations with prosocial attitudes; build up a prosocial identity
Social supports for crime	Criminal friends, isolation from prosocial others	Replace procriminal friends and associates with prosocial friends and associates
Substance abuse	Abuse of alcohol and/or drugs	Reduce substance abuse, enhance alternatives to substance use
Family/marital relationships	Inappropriate parental monitoring and disciplining, poor family relationships	Teaching parenting skills, enhance warmth and caring
School/work	Poor performance, low levels of satisfactions	Enhance work/study skills, nurture interpersonal relationships within the context of work and school
Prosocial recreational activities	Lack of involvement in prosocial recreational/leisure activities	Encourage participation in prosocial recreational activities, teach prosocial hobbies and sports
Non-criminogenic, minor needs	Indicators	
Self-esteem	Poor feelings of self-esteem, self-worth	
Vague feelings or personal distress	Anxious, feeling blue	
Major mental disorder	Schizophrenia, manic-depression	
Physical health	Physical deformity, nutrient deficiency	

Source: Bonta & Andrews (2007). Reproduced with permission of the Minister of Public Safety and Emergency Preparedness Canada, 2017.

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INSTRUCTOR GUIDANCE

Transitioning From Prison to Community

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Amardeep Thind, MD, PhD (Professor, Western University)

BACKGROUND

The Irish Red Cross (IRC) Community Based Health and First Aid (CBHFA) Prison Program was piloted at Wheatfield Prison in 2009 and, following several successful evaluations, was implemented across all of Ireland's 14 prisons in 2014. The CBHFA Prison Program trains inmates as special status IRC volunteers through weekly CBHFA training sessions, which take place over six months. After completing the community assessment module within the CBHFA program, volunteers, with the support of prison staff, implement projects and engage in peer-to-peer health education in an effort to promote the health of the prison community. In addition to having a positive impact on prison health, many volunteers have internalized a more constructive and positive identity and have developed greater self-esteem, self-respect, and confidence. Unfortunately, as a result of policies surrounding the IRC volunteering process, many inmates only keep their volunteer status whilst in prison and therefore their skills and knowledge are not harnessed upon their release.

With high rates of recidivism and a reentry process filled with challenges, the CBHFA management team wanted to develop the program to allow for its continuation in the community. A continuation of the program could help released offenders maintain their association with the IRC and thus their associated positive identity, as well as help address various health challenges associated with transitioning from prison to community. The CBHFA team debated whether to use the "wounded healer" approach for the program design, which involves ex-offenders taking on helper roles in programming surrounding the rehabilitation and reintegration of other offenders. After determining the general design of the program, the CBHFA team would need to develop recommendations regarding the program's content and its method of implementation and delivery.

OBJECTIVES

1. Identify the social determinants of health, relevant to offenders and ex-offenders, and determine what societal conditions are thought to be conducive of successful reintegration using a social determinants of health lens.
2. Identify the interactions that exist between various social determinants of health and the potential impact such interactions have on individuals and communities.
3. Use a social determinants of health model to assess the protective and risk factors that exist for given public health interventions and propose ways to mitigate risks and harness strengths.
4. Formulate relationships between public health interventions and the social determinants of health in terms of the three levels of interaction: micro, meso, and macro.
5. Assess programs using a health-equity lens and generate implementation recommendations as well as predict potential challenges.

Transitioning from Prison to Community

DISCUSSION QUESTIONS

1. How do social and cultural factors shape patterns of recidivism and the reentry process?
2. What societal conditions are thought to be conducive of successful reintegration?
3. How should the program move forward in its implementation in order to address the outlined issues – consider partners, program design, etc.? What are the benefits and risks?
4. Which CBHFA modules (as well as non-CBHFA, module-based content) would be relevant for use in the prison-to-community program in terms of addressing identified challenges?

KEYWORDS

Social determinants of health; strength-based programming; peer-to-peer education; health promotion.

CASE 8

Camp fYrefly

Nina Malek, BSc, MPH (MPH Class of 2016)
Spencer J. Harrison, PhD (Director, Camp fYrefly)
Ava John-Baptiste, PhD (Assistant Professor, Western University)

BACKGROUND

As Dr. Spencer J. Harrison sat in his office, he became increasingly excited about the upcoming summer. After donating his time as the artist in residence to Camp fYrefly in Saskatchewan, he was chosen to act as the director for the camp in Ontario. Camp fYrefly is a leadership retreat for sexual and gender minority (SGM) youths and their allies. Allies of SGM youth include individuals who support gender equality, equal civil rights, the LGBTQ (lesbian, gay, bisexual, transgender, queer/questioning) social movement, and challenge homo-, bi-, and trans-phobias. Since its founding in 2004, Camp fYrefly has expanded to serve three cities, with 2017 planned as the first year the camp would be hosted in Ontario. Planning for Camp fYrefly's inaugural summer in Ontario and future expansion was proving to be a big task, and Dr. Harrison wanted to ensure the success and positive impact of Camp fYrefly for years to come.

An artist and activist, Dr. Harrison was extremely passionate about Camp fYrefly's programming. Although it is a leadership retreat, Camp fYrefly uses arts-based delivery in workshops throughout the camp experience. As a visual artist, Dr. Harrison enjoyed using his arts background in creating workshops for the youth of Camp fYrefly. Familiar with the social exclusion faced by many SGM youth, Dr. Harrison was enthusiastic about the camp's ability to build resilience and leadership capabilities in these groups. Following camp, youth could move forward to create positive social changes and advocate for the rights of LGBTQ individuals within their own communities.

Looking to expand Camp fYrefly's positive impact, Dr. Harrison hoped to incorporate programs to address some of the health disparities faced by SGM youth within pre-existing camp programming. He envisioned a holistic approach to health that would address the syndemic nature of negative health conditions more prevalent in SGM youth than in their heterosexual peers. To assist in the development of a holistic health plan, Dr. Harrison recruited a health promotion specialist.

THE HEALTH OF SEXUAL MINORITY AND GENDER VARIANT YOUTH

Sexual minorities and gender-variant individuals face a number of health disparities, many of which are linked to conditions experienced during early development. Some of the prominent disparities are linked to unsafe sexual behaviours, such as an increased prevalence of sexually transmitted infections as a result of unprotected sex. However, many health disparities are not related exclusively to sexual behaviour – they are a response to the stigma and discrimination experienced as youth (Mayer, Garofalo, & Makadon, 2014). Many of the causes of psychological distress and later-risk-taking behaviours stem from childhood and youth experiences, including abuse by family or peers, societal stigma, and discrimination.

Due to a changing social context, many youth are recognizing their sexual identities earlier in their life than previous generations (Drasin et al., 2008). Greater visibility, increased

acceptance, and increased accessibility to LGBTQ subculture makes it possible for SGM youth to self-identify at younger ages, meaning that they may confront bias, stigma, and other social challenges when they are less mature and thus ill-equipped to do so. In addition, youth may have fewer social supports than older adolescents and young adults. Internalization of social challenges appears to play a role in creating many of the health disparities faced by sexual and gender minority youth when compared to their heterosexual counterparts. Some of these health disparities include increased rates of sexually transmitted infections, substance abuse, abnormal weight, cancer-related-risk behaviours (such as smoking), and other risk-taking behaviours (such as reduced seatbelt use) (Mayer et al., 2014). Many of the root causes of these disparities relate to familial and societal rejection, which create a cycle of alienation, depression, reduced self-efficacy, and an impaired ability to adjust in the process of maturation.

In addition to familial and societal factors, many health care professionals are ill-equipped to treat SGM youth, making it more difficult for them to access competent care despite their desire to do so.

CAMP FYREFLY

Organizational History

Camp fYrefly is a national leadership retreat for SGM youth and their allies. It began in 2004 at the University of Alberta, where Dr. Andre Grace and Dr. Kristopher Wells designed a university-community educational outreach project targeting the needs of SGM youth. Since 2004, Camp fYrefly has evolved into a four-day summer leadership retreat for these youth and their allies. The main focus of Camp fYrefly is building leadership potential and personal resiliency in participants so they can act as agents for social change in their families, schools, and communities (Camp fYrefly, n.d.). There are currently camps held in Alberta and Saskatchewan. Camp fYrefly is expanding to include an Ontario location in 2017.

Program Delivery Model

Camp fYrefly programming consists of two major components. The camp itself (as previously described) is the primary Camp fYrefly program geared towards building resiliency and leadership capacity in SGM youth. The second component of Camp fYrefly is the *fYrefly in Schools* program. The *fYrefly in Schools* program was developed to help reduce discrimination against SGM youth within schools (Camp fYrefly, n.d.). The initiative is meant to increase awareness of the impacts of homophobia and transphobia and teach students how to be effective allies for diversity, equity, and human rights. Previous Camp fYrefly attendees compose a student panel, which travels between schools to discuss these issues. The *fYrefly in Schools* program is currently only offered in Edmonton and Calgary.

Applying to Attend Camp

Future campers complete a short application package. The application package includes a variety of questions to gauge each applicant's interest in and need for attending the camp. Application packages are reviewed by a committee, and up to sixty successful applicants are selected from the application pool to attend each camp location.

Camp fYrefly covers all camper expenses, including travel, food, and accommodations. The only cost to campers is a \$25.00 enrollment fee to ensure attendance during the camp. Underage campers must also submit a permission form signed by their parents or legal guardians. Permission forms present Camp fYrefly as a leadership retreat to maintain privacy for youth who have not come out or for youth with unsupportive parents.

A Day at Camp fYrefly

A typical day at Camp fYrefly begins at 7:00 am (Exhibit 1). Campers have the option of waking up to participate in a morning activity or to sleep in and attend breakfast at 8:00 am. Throughout the day, campers participate in a variety of workshops and activities, many that are designed to foster the formation of relationships between campers, build resiliency, and address issues relevant to SGM youth. Camp programming includes opportunities for campers to reflect on their experiences individually and for larger group discussions that may range in size from eight campers to the entire camp population (approximately 60 people). Formal workshops typically revolve around topics pertinent to SGM youth, such as safe sex, and occur in smaller groups. Past workshops include *Non-Binary Gender and You*, and *Celebrating Our Gay Identities* as described in Exhibit 2 (Camp fYrefly, 2015).

Camp fYrefly relies heavily on volunteers for day-to-day programming. Each camp location is planned and run by a camp coordinator. When funding permits, a camp assistant is appointed to support the coordinator through many aspects of camp planning (iSMSS, 2015). Youth leaders are often former campers who have returned to Camp fYrefly in a leadership capacity. Youth leaders are responsible for guiding their assigned groups of campers through the fYrefly experience. Adult volunteers support youth leaders in mentoring campers. In addition to youth and adult volunteers, there are both medical and counselling teams on staff. Members of these teams include nurses, doctors, and social workers. Each Camp fYrefly location also has both an artist and Indigenous elder in residence. The artist in residence is responsible for leading arts-based programming. The elder in residence is responsible for mentoring indigenous SGM youth and building camper knowledge of sexual and gender diversity in indigenous communities.

Partner Organizations

University of Alberta

Camp fYrefly was founded by Dr. Andre P. Grace and Dr. Kristopher Wells – researchers and educators within the Faculty of Education at the University of Alberta. Camp fYrefly is the only national gender and sexual minority youth leadership camp affiliated with a major research university – the University of Alberta. Affiliation with the university ensures that the camp uses programming informed by evidence-based youth health and safety trends (Camp fYrefly, n.d.).

Institute for Sexual Minority Studies and Services

Within the University of Alberta, Camp fYrefly is also affiliated with the Institute for Sexual Minority Studies and Services (iSMSS). Dr. Grace is also the director of research at the iSMSS. His colleague and former student, Dr. Wells, also works with the iSMSS as the Faculty Director. The iSMSS leads research that affects policy development, intervention, education, and community outreach for sexual and gender minorities. Research at the iSMSS is not only targeted towards youth; it also guides professional development for a variety of disciplines, including teachers, social workers, physicians, and psychologists, enabling them to provide better support, resources, and advocacy for social justice. In addition to working on campus and within the surrounding communities, the iSMSS impacts national policies and services through its work with various agencies and organizations, including the Office of Canada's Chief Public Health Officer, the Canadian Teachers' Federation, and the Public Health Agency of Canada (iSMSS, n.d.).

Geographic Area

Camp fYrefly was founded in Edmonton, and the camp continues to run there every summer. Since the first fYrefly program, an annual camp was opened in Saskatchewan (rotating between Regina and Saskatoon), and shortly after, a third annual camp was opened in Calgary. Plans are currently underway to open a fourth camp at the Trent University campus in Peterborough, Ontario.

Although only four camp locations exist, youth apply from all over the country to attend. Space at camps is limited. Despite national applications, the majority of youth that attend come from surrounding communities.

EXPANDING CAMP FYREFLY

The task of expanding Camp fYrefly to include a fourth location in Ontario was a challenge. Although all resources from previous camps could be used as a guide in creating a program for Ontario, each camp differed based on its geographic location and available resources. Camp locations are also heavily influenced by their surrounding communities. Dr. Harrison had the tasks of selecting a location, raising funds, planning workshops and programming, and selecting volunteers to ensure that Camp fYrefly would be a success in Ontario.

Continued Advocacy

In addition to his work for Camp fYrefly, Dr. Harrison continues to be an activist for LGBTQ rights. Outside of Camp fYrefly, Dr. Harrison is the artist in residence at a middle school in Toronto, an educator at OCAD University, and equity advisor to the chief of *Toronto Fire Services*. In all roles, he is an expert in creating safe and inclusive environments for SGM individuals and their allies. Part of his role as an activist is to raise awareness of LGBTQ issues within a more public context. He regularly speaks at events such as Chamber of Commerce meetings in small towns, where he shares his own story and demonstrates the need for creating inclusive cultures within smaller communities. Since being appointed as the Ontario camp fYrefly director, Dr. Harrison also uses these advocacy events and speaking engagements as an opportunity to network and create relationships with possible future donors to Camp fYrefly. He hopes that raising awareness and suggesting avenues for change will help to create supportive environments for SGM individuals in the future.

Holistic Health at Camp

Planning to continue the leadership legacy of previous camps, Dr. Harrison hopes to integrate health promotion initiatives within Camp fYrefly's programming. Although camp manuals provide each location with the basic information necessary to open a new Camp fYrefly location, each camp is customized based on the director, surrounding communities, artist in residence, available resources, and geographic location. Although he had little formal experience in health care, Dr. Harrison felt that existing camp programs emphasized the importance of holistic health and wellness. To expand on this and address some of the health disparities faced by SGM individuals in a more formal manner, Dr. Harrison decided to create health promotion programs for the camp. He hoped that the Ontario camp would set an example of effective health promotion for other Camp fYrefly locations.

Finding a Specialist in Health Promotion

Dr. Harrison decided to consult with Dr. Grace before planning his health promotion activities. Dr. Grace recommended that he contact a recent graduate from the School of Public Health at the University of Alberta named Dr. Warren Jared. Dr. Grace supervised Dr. Jared's PhD research. Although Dr. Jared had never worked with Camp fYrefly, he did have experience working with SGM youth. Dr. Jared had worked closely with Dr. Grace to develop health promotion programs for youth living on the streets of Edmonton in hopes of promoting safe sexual practices and reducing the incidence of HIV. Well aware of the many challenges faced by SGM youth, Dr. Jared was excited to work with Dr. Harrison and continue to make a difference in this community.

Creating Health Promotion Programs

Although Dr. Harrison was excited at the prospect of promoting health within the camp environment, he knew it may prove to be a difficult task to do so in a meaningful way. There are

Camp fYrefly

many health disparities faced by SGM youth and a historically difficult relationship between SGM individuals and medical professionals. After meeting with Dr. Jared, Dr. Harrison identified three main challenges existing within the Camp fYrefly environment. The first challenge was the short duration of camp (four days in total). According to Dr. Jared's consult, it may be difficult to make an impact in such a limited amount of time. The second major challenge was the pre-existing leadership and resiliency building mission. Camp days were already full of leadership and resiliency building workshops, making it difficult to integrate new health-related programming. Finally, Camp fYrefly relied on the generosity of donors to open each summer. To ensure sustainability, camp workshops and activities had to adhere to strict budgets. Dr. Harrison wasn't sure what may be possible within the Camp fYrefly context; however, he and Dr. Jared agreed that even small strides towards improving the health of SGM youth would be valuable. With consideration for the camp's leadership capacity and resiliency building, he decided to work with Dr. Jared to plan health promotion initiatives that could be integrated into existing camp programming for Camp fYrefly's inaugural summer in Ontario.

Camp fYrefly

EXHIBIT 1



Time	Thursday – July 23 rd , 2015		Friday – July 24 th , 2015			Saturday – July 25 th , 2015			Sunday – July 26 th , 2015		
7:00am			Optional morning activity			Optional morning activity			Optional morning activity		
7:30am											
8:00am	Staff arrive		Breakfast	Stage team initial meeting		Breakfast	Staff meeting		Breakfast	Staff meeting	
8:30am	Campers arrive and check in		Healthy Bodies/Healthy Relationships			Identity Workshops			Pack and clean room		
9:00am											
9:30am											
10:00am	Introductions and guidelines					Pod time			Choice Workshop Block 4		
10:30am						Human library					
11:00am	Artist in Residence		Pod time – question box						Pod time – letters to self and pod photos, then finish packing		
11:30am									YL meeting		
12:00pm	Lunch		Lunch – Rainbow pods			Lunch			Lunch		
12:30pm											
1:00pm	Choice Workshop Block 1		Question box			Old Stories project	AV meeting	Self-care time		Pod time – surveys, closing with pod	
1:30pm			Pod time					Choice Workshop Block 3		Camp photos	
2:00pm			Pod time				Journey & Dog Therapy				Closing Resources map
2:30pm	Pod time					Pod time		Goodbyes			
3:00pm						Nap			Self-care time		
3:30pm	Graffiti wall	Sweat Lodge building				Showcase prep		Pick-up			
4:00pm						Stage Team meets					
4:30pm											
5:00pm	Old Stories meeting	Self-care time	Showcase prep			Stage Team meets					
5:30pm											
6:00pm	AV Meeting	Supper	Old Stories project	AV Meeting	Supper	Stage team setup	Supper				
6:30pm	Choice Workshop Block 2 (Old Stories project meets)		Showcase prep			Showcase					
7:00pm			Self-care and get ready for swim								
7:30pm			Drive to swim								
8:00pm	Pod time		Swim			Showcase intermission and snack					
8:30pm	Camp fYre					Showcase including Stories finale					
9:00pm	Chill Night – spa, movie, fire, games, sweat		Change from swim			Dance or Fire					
9:30pm			Drive to camp								
10:00pm											
10:30pm	YL meeting	Snack	YL meeting	Snack							
		Get ready for bed	YL meeting	Get ready for bed							
11:00pm						YL Meeting					

Source: iSMSS, 2015.

EXHIBIT 2

Identity Workshops
Saturday, July 25th 9:00 am – 10:30 am

Non-Binary Gender and You with James Harley

This workshop will explore what it means to identify as non-binary, as well as exploring the intersections between (a)gender, (a)sexuality, and expression. All this will be done to the backdrop of building safe and inclusive communities, in particular for non-binary folks. Games and art will be included. Come and explore non-binary gender identity, and learn how to build safer communities!

Actually It's Sir – Navigating Trans Masculine Experiences and Identities with Daniel Tallack

This workshop will empower youth on the trans* masculine spectrum to be advocates for themselves and their medical care. It will show them how to deal with roadblocks along their path to success, and lead them to realize that they are capable of living healthy and productive lives. It will also cover more specific information pertinent to trans masculine identities, such as medical transition (options etc.) as well as document and gender marker changes. As this is a workshop aimed specifically at persons with trans masculine identities, it can be viewed as a safe space for youth to ask questions or discuss what they may not feel comfortable talking about in a mixed group setting.

Ace-ing It: A Primer into Asexuality with Lihn L., Alia S., Richard R.
Asexual, Aromantic, Demisexual, Grey – A.

These are a few of the labels and ways folks can identify within the Asexual spectrum. For those who already identify, are questioning, or curious, this session is for you! Presenters with Alia Schamehorn & Richard Roach, creators/founders of ACE Edmonton.

Celebrating our Gay Identities by Philip Hau

This workshop focuses on the complex identities of gay males. Everyone is a multicultural being. However, media has sensationalized, and potentially stereotyped, what a gay person looks like/behaves. This workshop highlights and breaks down this stereotypical portrayal of gay men. We are a composite of our sexual identity, gender identity, religion, age, ethnicity, socio-economic status, ability, etc. This workshop highlights that yes, we are gay, and at the same time we are more than that. Being gay is just one part of our identities.

Source: iSMSS, 2015.

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INSTRUCTOR GUIDANCE

Camp fYrefly

Nina Malek, BSc, MPH (MPH Class of 2016)
Spencer J. Harrison, PhD (Director, Camp fYrefly)
Ava John-Baptiste, PhD (Assistant Professor, Western University)

BACKGROUND

Since its founding in 2004, Camp fYrefly has become Canada's only national leadership retreat for sexual and gender minority (SGM) youth. The camp has expanded to include two successful locations in Alberta (Edmonton and Calgary), and one in Saskatchewan (either Regina or Saskatoon, alternating annually). The main focus of Camp fYrefly is building leadership capacity and personal resiliency in campers. 2017 is the planned inaugural summer for Camp fYrefly to expand to Peterborough in Ontario. In addition to maintaining Camp fYrefly's original mission of building resilience and leadership capacity, the Ontario camp director hopes to integrate a holistic approach to health within camp programming.

OBJECTIVES

1. Define the challenges faced in implementing a health promotion plan.
2. Apply theories associated with health promotion to create plans for Camp fYrefly.
3. Create SMART goals.
4. Critically appraise health-promotion plans.
5. Apply the PRECEDE-PROCEED model.
6. Understand factors to consider when working with minority/vulnerable populations.
7. Understand factors to consider when working with youth.

DISCUSSION QUESTIONS

1. Should "holistic health" be a priority within Camp fYrefly programming, and why?
2. Is it possible to create effective health promotion programs when direct contact with the target audience is limited to four days?
3. Can plans for health promotion be extended to create healthier environments within the community? If so, how might that occur? What are possible outcomes?
4. How might resources be prioritized in creating health promotion plans?
5. How can the success of health promotion plans be evaluated within the context of Camp fYrefly? What are some of the challenges associated with doing so?
6. How are health promotion plans shaped by their target audience (in this case, SGM youth)?
7. List challenges associated with creating health promotion plans for use in the Camp fYrefly environment.

KEYWORDS

Health promotion; youth; holistic health; holism; sexual minority; gender variant; LGBTQ; SGM.

CASE 9

From Theory to Action: Implementing an Internationally Developed Mental Health and Substance Abuse Program in Indigenous Communities in the Americas¹

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(Unit Chief, Mental Health and Substance Use, PAHO/World Health Organization)

Gerald McKinley, PhD (Assistant Professor, Western University)

BACKGROUND

On June 4, 2016 Juan Santos, leader of the Indigenous Mitzu² tribe, was awoken in the night by an alarming call. Juan was known as a respected member of the community. He left his rural community at the age of 14 to complete his high school studies in the country's capital on the tropical island of Basseterre, off the coast of Central America. His success throughout high school earned him the prestigious Island Scholar award to pursue a university education in sociology. It was this experience that exposed him to diverse groups of people, social conditions, and global issues. Juan returned to his community upon graduation where he now works diligently with his community in developing collaborative efforts to enhance the quality of life of rural peoples.

Juan was astonished to find out that two young girls, ages 14 and 17, had committed suicide by hanging themselves in a remote wooded area, five miles from their community. Initial circumstances regarding the root cause of their deaths was unknown; however, a suicide note dated February 12, 2016, authored by the girls, was found nestled away in a diary. It came to Juan's attention that several suicide risk factors were prominent, outlining the young women's challenges living in an isolated community.

With his attention fixated on the risk factors for suicide coupled with the social injustices faced by the indigenous people of the Mitzu tribe, Juan decided to declare a state of emergency for his community due to the growing suicide trend. The proclamation came after four Mitzu youth

¹ *The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of the Secretariat of the Pan American Health Organization concerning the status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries.*

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² *The name of the community is fictional.*

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aged 7, 12, 14, and 16 committed suicide in the community within the span of six months, prior to this newest incident. Juan decided to take measures beyond his local government and plead for international support for the development and implementation of a suicide prevention strategy for his community. Juan made an urgent appeal to the United Nations Permanent Forum on Indigenous Issues (UNPFII) and requested technical support from the Pan American Health Organization (PAHO).

EPIDEMIOLOGY OF SUICIDE AND SUBSTANCE ABUSE IN THE AMERICAS

Alarming statistics show that indigenous peoples across the globe face a higher risk of suicide than their non-indigenous counterparts. Suicide rates in indigenous communities have been reported to be four times greater than in non-indigenous communities on average across the region (PAHO & the Economic Commission for Latin America and the Caribbean (ECLAC), 2011). For instance, First Nations communities in Canada experience suicide rates of 126 males and 35 females per 100,000 people, as stated by the Centre for Suicide Prevention, a nonprofit organization in Calgary, Alberta (Centre for Suicide Prevention, 2013). This figure is substantially higher than average within the Canadian general population, which is reported as 24 males and 5 females per 100,000 people (Centre for Suicide Prevention, 2013). In the United States, Native Indians have displayed similar trends with youth suicide rates of 19.5 per 100,000 people between the ages of 15 to 43; a rate 1.5 times greater than the national USA average (Centers for Disease Control and Prevention, 2015). South American countries such as Chile, Brazil, Argentina, Nicaragua, Paraguay, and Venezuela have a greater proportion of indigenous youth committing suicide than the non-indigenous populations. Across the region, a higher proportion of males have been reported to successfully complete the act, while women display a greater number of unsuccessful attempts (PAHO and ECLAC, 2011).

The link between mental health conditions and suicide is related to the influence of risk factors, such as substance abuse. It becomes essential to highlight the relationship between risks and suicide present in indigenous peoples, as preventative frameworks are contingent on a holistic understanding of the many factors leading to disparity and social suffering present within these communities. Within the Americas, indigenous populations display a disproportionate rate of substance abuse as compared to non-indigenous peoples. Alcoholism prevails as a leading contributor to comorbidity and serves as a precursor for unintentional death through life threatening behaviour and accidents. In Native Indian populations in the United States, admission to the hospital for alcohol-related diagnoses are three times higher than the national average (Walker, Walker and Kivlahan, 1988). Similarly, it is reported that 43.7 per 100,000 deaths in the Canadian aboriginal population are attributed to alcohol use in comparison to 23.6 per 100,000 in the general population (Chansonneuve, 2007). Furthermore, there is a higher prevalence of binge alcohol drinking among Inuit and Native Indian mothers in comparison to their non-aboriginal counterparts in the Northwest Territories (MacMillan, MacMillan, Offord, & Dingle, 1996). Indigenous peoples of South American countries echo these trends as in the case of Venezuela, where significant rates of alcohol in mountainous villages have promoted physical and social complications for up to 46% of the indigenous population (Arévalo, et al., 2013).

EXPRESSIONS FROM THE LETTER: THE ORIGINS OF SOCIAL DISPARITIES

This town is a forgotten place, with no hope, no support and nothing for us to look forward to. I share a room with my grandmother and my two cousins, the men are always fighting after getting drunk, and we cannot take the stress anymore.

– Deceased girls, May 3rd 2016

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Indigenous adolescents and youth represent approximately 50% of the total adolescent and youth population in the Americas (PAHO and ECLAC, 2011). Between 67% to 90% of indigenous youth reside in impoverished rural areas with severe illiteracy, high rates of mortality due to injury, and lack of health care support for such injuries, which have often been cited as a result of the rural nature of indigenous communities. As such, financial disparities within such communities are augmented due to the lack of accessibility (PAHO and ECLAC, 2011). These barriers present unique challenges for such underserved populations despite often living in robust developed nations. Indigenous peoples are often described as living in 4th world conditions, which denote minorities living within the boundaries and bureaucratic administration of first and second world countries. These indigenous people have lost the power to direct the course of their livelihoods because of the poor upholding of basic rights (Graburn, 1976). The lack of basic rights often contributes to social and cultural inequities that lead to systematic barriers to progress in society.

The relationship between public health and social disparity is of growing concern for the international community. Despite the rich cultural make-up of indigenous peoples in the Americas, health disparities and trends are often parallel across the region. The United Nations Declaration on the Rights of Indigenous Peoples recognizes this pattern as the result of human rights violations. The neglect towards the understanding of self-determination, land/treaties, and cultural expression, to name a few, with the lack of fulfillment in upholding such rights across the Americas, has been correlated with poor mental states, disability from injury, and reduced life quality (The Inter-Agency Support Group on Indigenous Peoples' Issues, 2014).

PROXIMAL INEQUITIES

Social injustices and neglect of proximal determinants of health serve as fundamental precursors for the deterioration in physical, emotional, mental, and/or spiritual well-being (Wein, Reading, 2009). Proximal determinants of health include, but are not limited to, housing, health behaviours, education level, employment, and physical environments.

Housing

It was identified from the young girls' letter that their community had been subject to overcrowding due to a lack of infrastructure for housing. This is echoed through their expression of living in a "forgotten place." These young girls resided in a one-bedroom house that accommodated six people from as young as two years of age to 76 years of age. Their story is felt across many nations within the Americas. Overcrowding has been linked to the onset of elevated stress levels, learning difficulties, and behavioural challenges in youth. Substance abuse and other social problems have been reported as a result of the inability to indulge in personal space and relaxed living in such conditions. The influence of poor housing serves as a driving factor for emotional stress and trauma (National Collaborating Centre for Aboriginal Health, Wein and Reading, 2009). The World Bank's poverty assessment for Ecuador found that households comprised of indigenous peoples often lacked fundamental housing services, which include access to clean water, sewage, and basic electricity (Incayawar, 2007). The lack of development in indigenous communities, coupled with the effects of poverty and animosity between the indigenous and their non-indigenous suppressors, has fostered sentiments of social exclusion within communities. Alternative coping mechanisms and feelings of hopelessness are augmented, as the connection between the voices of governments and communities are often mismatched. For example, within Latin America, 88% to 95% of the indigenous communities live in exclusion because of discrimination and structural policies (Incayawar, 2007). This determining factor may lead to feelings of hopelessness and despair, which have profound effects on youth during adolescence.

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Health Behaviours

One of the most well studied health behaviours in indigenous peoples is the misuse of alcohol. This often leads to self-harm, excessive intoxication, and the initiation of drinking in youth. Misuse of alcohol may often become embedded in the cultural framework of indigenous communities. For instance, the Carib indigenous population in Venezuela partake in corn liquor drinking ceremonies, which promote excessive intoxication. These ceremonies have been associated with settling of grudges, facilitation of fighting, and often abuse of women through intoxication (Seale, Shellenberger, Rodriguez, Seale, & Alvarado, 2002). The psychological and mental impacts associated with the repercussions of drinking facilitate mental turmoil and intergenerational stressors that maintain substance abuse as an outlet.

Employment, Education, and Negative Health Outcomes

Socioeconomic factors have been cited as key determinants of health. These determinants are often augmented due to the rural and isolated nature of indigenous communities. As such, an exacerbation of health care challenges may generate negative health outcomes.

We can't afford to go to school. Our parents never went, and the nearest high school is in the capital, 3 hours from home.

– Deceased girls, May 15th 2016

The lack of access to financial and physical resources enables the development of poor nutritional behaviours and the onset of diseases such as diabetes and cardiovascular disease (National Collaborating Centre for Aboriginal Health, Wein and Reading, 2009). The most significant contributors to poor mental health and substance abuse are the circumstances of poverty. Low income and educational attainment has been linked to anxiety and low self-esteem. This increases physiological stress, which often results in frustration, violence, poor parenting, social exclusion, suicide, and substance abuse (National Collaborating Centre for Aboriginal Health, Wein and Reading, 2009).

DISTAL INEQUITIES

Historical Impacts of Colonialism

Colonialism has resulted in a disconnect between indigenous peoples and their traditional land. The United Nations Office of the High Commissioner for Human Rights has identified the cultural, mental, and physical connection necessary for the mental well-being of indigenous peoples in honouring their right to traditional lands and treaties. The land represents more than possessions and production; it serves as a means of spirituality, economic sustainability, cultural continuity, and traditional knowledge passed down through generations (United Nations, 2013). The weaning of traditional peoples from their land has grave implications on traditional food choices and the ability to make autonomous decisions in supporting physical needs. For example, hunting restrictions, climate change, and access to nutritious food in remote areas result in uncertainty of both the quality and quantity of resources on their land, affect Indigenous Peoples' physical health, and augments stress (Norton-Smith et al., 2016). The ramifications of such inequity are felt through the loss of self-determinism, which encompasses the ability to govern lands and resources within the territories of indigenous peoples (Norton-Smith et al., 2016). The deceased 14-year-old girls state:

Without us here, our community will be forced to come together, to celebrate, to remind themselves of who the Mitzu are. We have no purpose, but maybe us dying will give them one.

– Deceased girls, May 25th 2016

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The use of suicide as an expression of hopelessness has been tied to feelings of culture discontinuity, which is the lack of identification with one's historical heritage due to the impacts of forced migration and colonialism. Death in some indigenous communities thus serves to strengthen community bonds; it allows for the expression of community ideals and cultural traditions. For example, grave digging ceremonies, coffin making, and body washing traditions reaffirm community connectedness and promote the embracing of social roles and individual meaning in society (Wexler & Gone, 2012).

ROLE OF THE PAN AMERICAN HEALTH ORGANIZATION AND THE UNITED NATIONS

PAHO is the regional office of the World Health Organization (WHO) for the Americas, and serves as the specialized health agency for the United Nations (PAHO, 2017). PAHO's headquarters is located in Washington D.C.; however, the organization includes 27 country offices and three specialized centers in the region (PAHO, 2017). Through the guidance of its 48 member countries and territories, PAHO engages in collaborative efforts between governments, specific country agencies, and local organizations to fight communicable and non-communicable diseases and their causes, to strengthen health systems, and to respond to emergencies and disasters (PAHO, 2017). In collaboration with various ministries of health, government organizations, civil societies, universities, social security agencies, community partners, and governing bodies, PAHO seeks to promote evidence-based decision making in informing sustainable development and health promotion strategies. The organization promotes the inclusion of health in public policies and calls upon collaboration between multiple sectors to improve the quality of life of people in the Americas (PAHO, 2017).

THE ROLE OF THE UNITED NATIONS PERMANENT FORUM ON INDIGENOUS ISSUES

UNPFII serves as an advisory body to the economic and social council of the United Nations (United Nations Economic and Social Council, n.d). In line with the UNPFII mandate, the forum will:

1. Provide recommendation, advice, and points of concentration from various organizations and leaders to the council, programs, funds, and other United Nations agencies through the economic and social council; and,
2. Generate awareness and interdisciplinary collaboration for the development of activities for indigenous issues.

The UNPFII also assists in knowledge translation of pertinent indigenous issues from annual permanent forum sessions (United Nations, 2016). The UNPFII seeks to establish methods of implementing the initiatives of the UN Declaration on the Rights of Indigenous Peoples (UNDRIP), which addresses pertinent conflicts, peace, and resolution strategies. The UNPFII has specifically called on WHO/PAHO to develop a program targeted towards youth suicide rates, substance abuse, and self-harm in international indigenous populations with particular focus on countries within the Americas (United Nations, 2016).

PAHO'S SUGGESTED INTERVENTION FOR REMEDIATING MENTAL HEALTH, SUICIDE, AND SUBSTANCE ABUSE

PAHO, in conjunction with the UNPFII, has identified mental health and suicide as issues of concern among indigenous peoples. WHO recognizes the link between the lack of health care opportunities within low to middle income countries in tackling the mental, neurological, and substance use disorders as contributors to suicide rates (WHO, 2010). To address suicide prevention among indigenous peoples, PAHO proposes to adapt an existing tool, the Mental Health Global Action Program Intervention Guide (mhGAP IG), to the needs of the indigenous community. This mhGAP was designed upon recognition that 80% of individuals residing in

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lower to middle income countries who suffer from mental, neurological, or substance abuse challenges do not receive any care for their conditions. Current interventions within certain countries in the Americas often lack evidence-based rationale or success in implementation to combat mental health and substance abuse challenges (WHO, 2010). The mhGAP thus seeks to remediate these disparities through enhancing the accessibility of evidence-based interventions in non-specialized health care settings.

How the mhGAP IG Works

The mhGAP IG serves as a set of targeted criteria for health care management to guide the assessment and delivery of care for priority conditions by health professionals and care takers in non-specialized settings. This tool is a flexible guide that focuses on specific priority conditions and may be adapted internationally in accordance with those who use it. The specific priority conditions are: depression, psychosis, bipolar disorders, epilepsy, developmental and behavioural disorders in children and adolescents, dementia, alcohol use disorders, drug use disorders, and self-harm/suicide (WHO, 2010). The mhGAP IG outlines focused methods for initially triaging and identifying those who display signs of the above conditions. As displayed in Exhibit 1, the tool follows a sequential set of steps for managing current conditions of elevating the rigor of care for suspected priority conditions. The selection of priority conditions was brought forth from evidence displaying large health disparities in mortality, disability, exacerbated costs, and inadequacies in meeting fundamental human rights (WHO, 2010). The tool has been crafted from extensive systematic reviews and inputs from the World Health Organization Guideline Development Group, which is comprised of international experts and individual topic-specific experts. The WHO and topic experts can access relevant recommendations and strategies outlined in the toolkit for a specific demographic (WHO, 2010). Through a guided set of assessment questions, critical identifiers promote either the use of preventive management strategies, physiological therapies, or specific treatments through interventions (Exhibit 2). In response to Juan's plea, PAHO agreed to provide technical support in piloting this Program in his community and focus on suicide and self-harm modules (Exhibit 2).

CULTURALLY SENSITIVE APPROACHES TO IMPLEMENTATION

Juan urgently focused his efforts on collaborating with PAHO in implementing the suggested interventions by UNPFII. One month after the girls' deaths, he was able to foster financial and advisory support from his local ministry of health to apply the self-harm and suicide mhGAP IG modules for his community. He was able to advance this initiative through securing limited funding from the ministry to set up basic infrastructure such as assessment stations equipped with medical supplies and preventative substance abuse information such as pamphlets, books, and access to electronic resources. He implemented technology for communication with the nearest hospital, located three hours away from the community. This was a groundbreaking achievement in both establishing community capacity and improving Basseterre's health system outreach. The mhGAP IG tool provides a skeleton of how to approach and triage health care needs within each respective community. The Guide ensures that a referral system is established for the continued care of cases by specialists when the concern is beyond the expertise and scope of non-specialized health care workers or community health care providers.

Juan came to the realization that the mhGAP was too broad in its applicability. The tool was not designed in recognition of the distinct challenges faced by indigenous populations. Juan thus recognized that cultural adaptations specific to his community would be necessary. This task would be contingent on adjustments in: (1) the thorough translation of the mhGAP tool to the local Mitzu language; (2) the expected challenges of program implementation through the

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capacity of the local health care systems to support the Program's directives; (3) addressing sociocultural influences, such as the embedding of alcohol into the daily cultural framework of the Mitzu community; and (4) the identification of key stakeholders (World Health Organization, 2010).

On August 1, 2016, Juan eagerly greeted PAHO's technical support team as they arrived on the island to initiate the implementation of the mhGAP IG. PAHO's support serves a critical role in helping to facilitate the conversation in identifying necessary human resources, task assignments, financing, information dissemination, and methods of monitoring and evaluating the Program's effectiveness (WHO, 2010). Juan's first step was to mobilize the little funding provided from the ministry to assist with enlisting translation services, which were essential in interpreting and contextualizing the mhGAP tool for the specific social, educational, and linguistic conditions of the Mitzu community. Upon completion of this task, Juan then set forth to secure community involvement from other leaders he thought would be an asset to the mhGAP implementation.

Non-specialized health care providers and community health workers serve as integral components in the implementation, sustainability, access, financing, and quality of care provided (WHO, 2010). Their roles may vary across the region but encompass trusted community members, leaders, and officiates. With the technical support of PAHO, Juan urgently gathered a list of trusted community members to form his action plan working group. With recognition of important community and health care stakeholders for implementation, he first called the local spiritual leader, Ronaldo Phillips, for his consideration. Phillips is a familiar confidant and ally to the community under periods of distress and plays a critical role in the social atmosphere. He has also been chosen to serve as a mental health gatekeeper for youth through his close connection to the community. Next, Juan contacted the community liaison who is familiar with community concerns and is responsible for voicing the community's collective opinions at the Basseterre national level. Her expertise derives from being a resident throughout her life and being familiar with common community challenges. Her role was assigned to allow for holistic and empathetic support of youth. Holistic practices aim to enrich social, psychological, mental, and physical aspects of youth development and success. She would also serve as a profound example of an individual who has used protective factors within the community itself to develop resilience and success as a Mitzu woman.

Ms. Renée, a retired traditional indigenous healer, volunteered to act as the non-specialized health care provider. She hosts weekly ceremonies tailored to reducing social suffering through the development of positive social framing and community bonding through spiritual song, dances, and blessing ceremonies. Juan also incorporated the visiting community physician, who agreed to make biweekly health assessments upon Juan's emergency declaration and maintain frequent communication between the community and larger health care facilities, in the event that serious concerns arise and active medical attention is required for community members. To fulfill the General Principles of Care (GPOC), as seen in Exhibit 3, and acknowledge the key considerations for interactions with those in need, Juan ensured that all members of his working group conducted guided mhGAP training sessions as offered through the technical support from PAHO.

Juan's next challenge, with the adaptation of the Program, was developing methods of remediating alcohol consumption in the community. Alcohol serves as an integral component of daily socialization and carries a positive connotation. With this recognition, Juan decided to use this opportunity to both educate community members of the harmful effects of alcohol and

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conduct suicide and self-harm assessments. Through the utilization of the General Principles of Care, he ensured that communication of possible dangers and risks were highlighted during drinking festivities, in addition to providing and fostering a positive, non-judgmental, and non-stigmatizing interaction between himself, as a community leader, and those engaging in alcohol consumption or contemplating suicide/self-harm (WHO, 2010). He used this opportunity to employ step one and two of the self-harm and suicide assessment and management guide with help from Ronaldo Phillips (Exhibit 3). They were able to assess key risk factors, such as emotional distress, and identify those who displayed feelings of hopelessness or expressed violent behaviours in association with alcohol consumption. Individuals who met the criteria in Exhibit 3 were removed from the situation and placed in contact with Ms. Renee who initiated traditional healing practices for social pain.

The inability for the Ministry of Health to fully fund the Program resulted in minor setbacks to Juan's outreach capacity. He was unable to develop secure and supportive environments through the implementation of healing tents for distressed youth as suggested by the GPOC. Juan was able to mobilize support from the community to use homes volunteered as a place where youth could decompress and indulge in spiritual connectivity through Ronaldo Phillips' and Ms. Renée's guidance. Here, youth were able to indulge in traditional meals and culturally appropriate medicinal healing techniques, which placed them back in touch with their culture and mended broken bonds between the generations. This simple, yet effective adaptation to the Program, strengthened community capacity and allowed for direct lines of communication between at-risk youth. The mhGAP also emphasized step six of the GPOC attention to overall well-being through applying holistic approaches to health care with assistance from the mhGAP action-plan team.

JUAN'S NEXT STEP

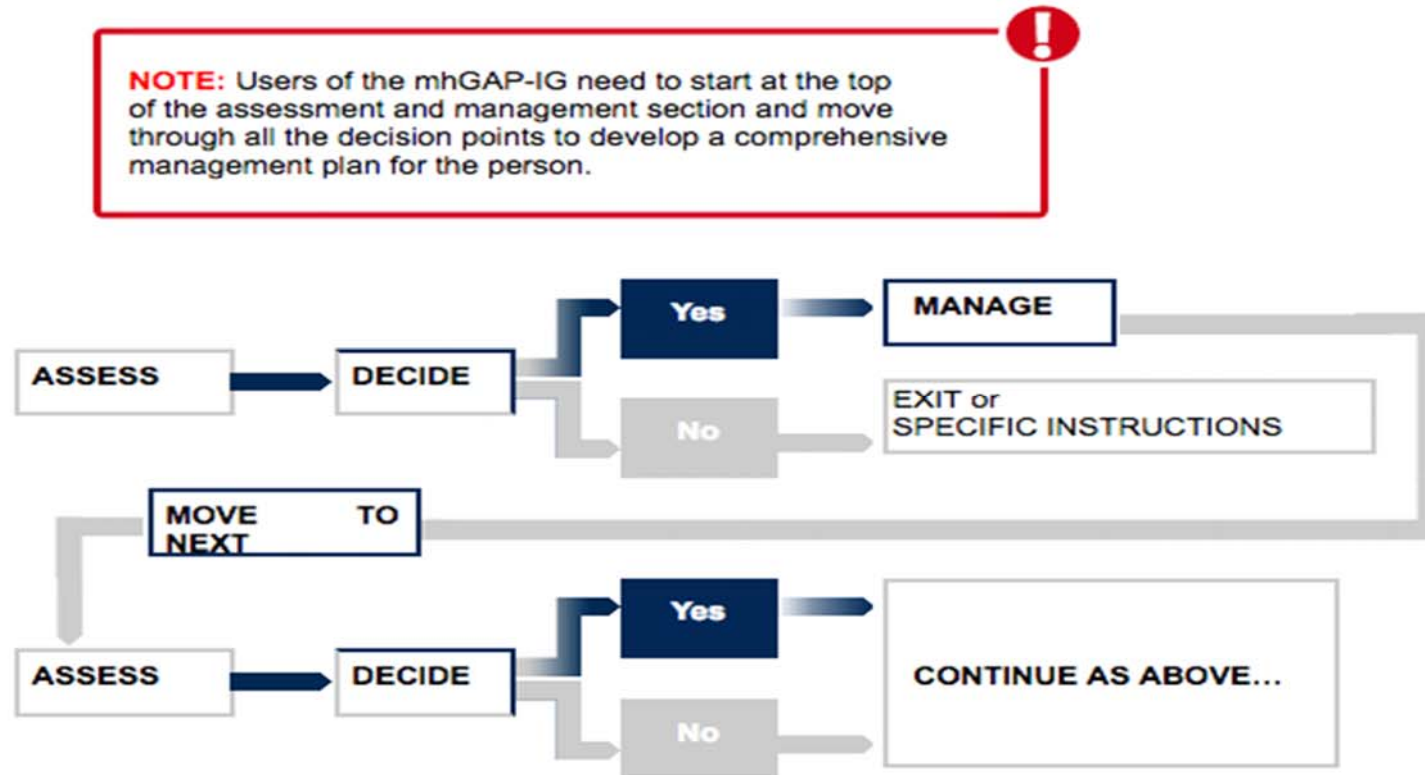
Juan understood that his biggest barrier to implementing this Program was addressing the necessary cultural considerations that are reflective of community values. With the urgency of the situation, Juan specifically adapted pieces of the Program with the technical support of PAHO. However, he was unsure if he had considered all culturally relevant aspects of his community for the successful deployment of this intervention, as the tool had not been designed to target the unique challenges of indigenous populations. He hoped that financial investment and a better understanding of the disconnection often felt between one's reality and one's social/spiritual well-being would be improved to enhance the effectiveness of the Program. This bond would rely heavily on governmental and agency support to develop better social conditions for indigenous peoples, particularly enhancing proximal factors. Juan wondered what the implications of only deploying a suicide and self-harm program would have on substance abuse and other mental conditions. Due to the immediacy of the problem in his community, he hoped the mhGAP would quickly mobilize efforts to remediate the situation. He intended to manage suicide and self-harm diligently, while other contributing deficiencies in social determinants of health would be mitigated to remediate suicidal ideation, self-harm, substance abuse, and the onset of other mental conditions thus fostering resilient youth. He believed that the on-going involvement from the community and the community leaders would be necessary in managing the intervention in the long term. However, the following concerns remain:

- What methods of managing concurrent issues with limited resources would be effective for the Mitzu community?
- How would Juan foster community input and collaboration in developing social supports beyond the emergency declaration?
- What methods would he use to assess the Program's effectiveness and conduct process evaluations?

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EXHIBIT 1

Principle framework for the management of priority conditions and intervention implementation



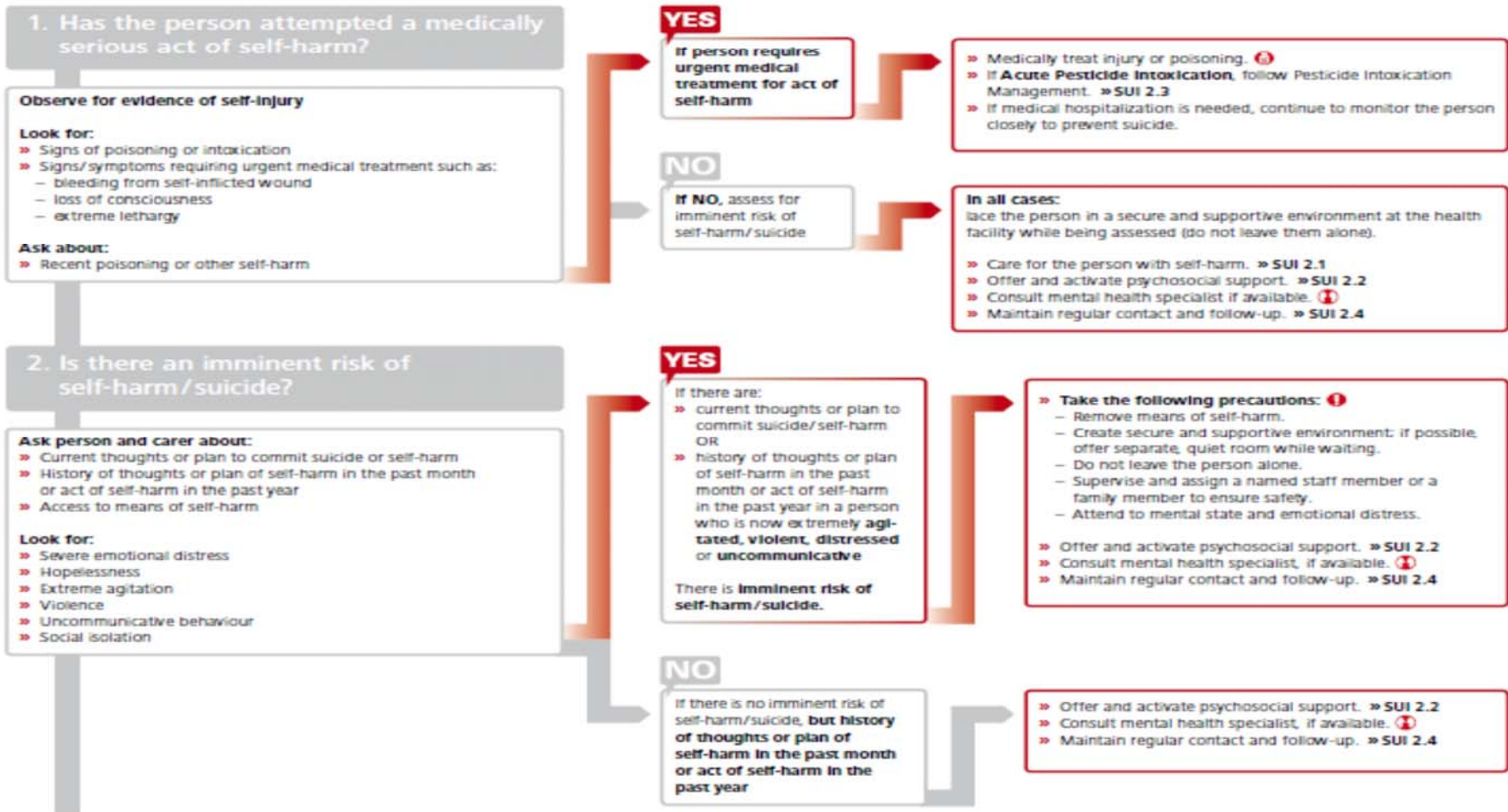
Source: World Health Organization, 2010.

EXHIBIT 2
Suicide Self-Harm Intervention Guide

Self-harm / Suicide

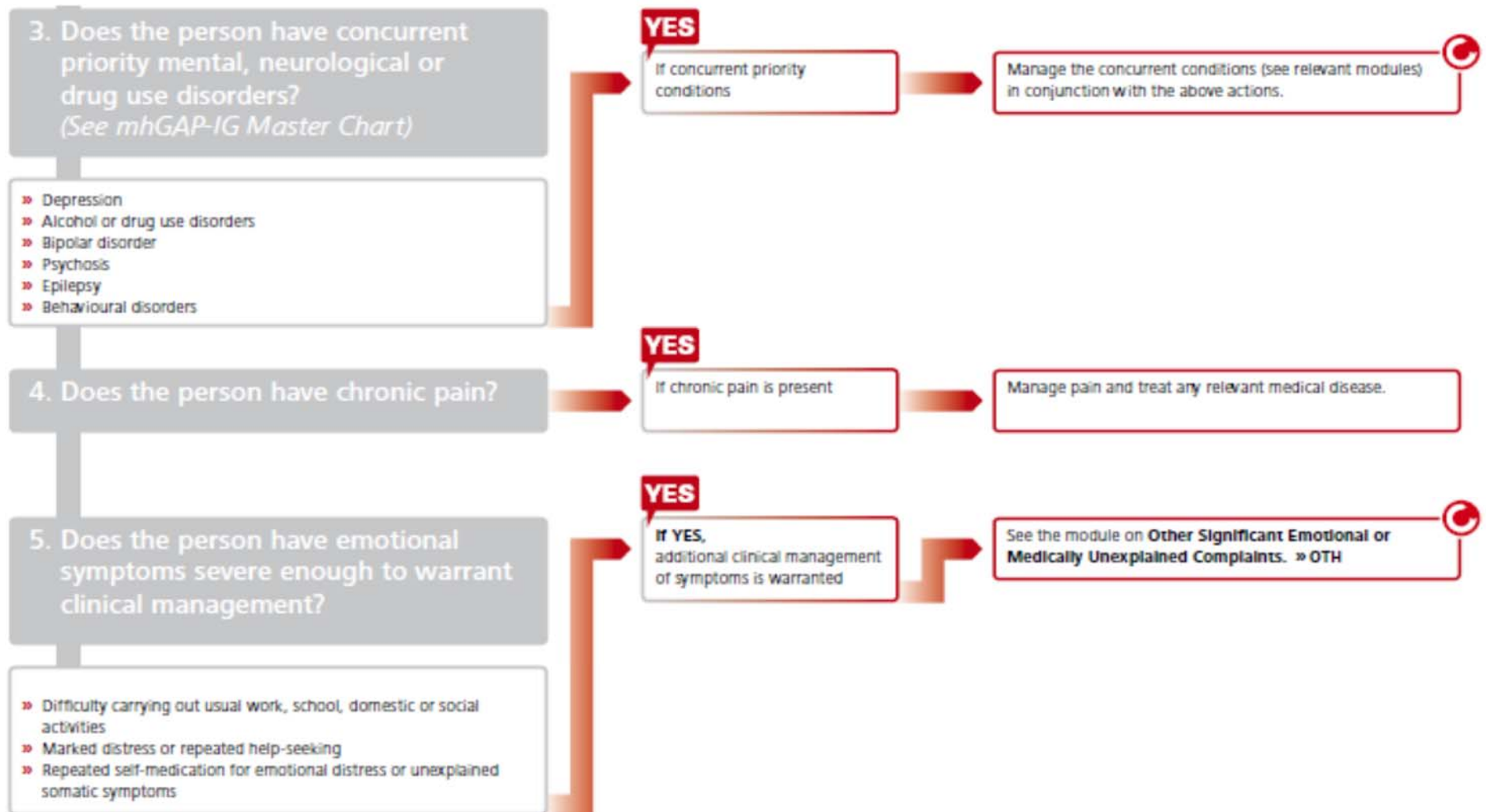
SUI 1

Assessment and Management Guide



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EXHIBIT 2 (cont'd)



Source: World Health Organization, 2010.

EXHIBIT 3 General Principles of Care for Program Implementation

General Principles of Care



1. Communication with people seeking care and their carers

- » Ensure that communication is clear, empathic, and sensitive to age, gender, culture and language differences.
- » Be friendly, respectful and non-judgmental at all times.
- » Use simple and clear language.
- » Respond to the disclosure of private and distressing information (e.g. regarding sexual assault or self-harm) with sensitivity.
- » Provide information to the person on their health status in terms that they can understand.
- » Ask the person for their own understanding of the condition.

2. Assessment

- » Take a medical history, history of the presenting complaint(s), past history and family history, as relevant.
- » Perform a general physical assessment.
- » Assess, manage or refer, as appropriate, for any concurrent medical conditions.
- » Assess for psychosocial problems, noting the past and ongoing social and relationship issues, living and financial circumstances, and any other ongoing stressful life events.

3. Treatment and monitoring

- » Determine the importance of the treatment to the person as well as their readiness to participate in their care.
- » Determine the goals for treatment for the affected person and create a management plan that respects their preferences for care (also those of their carer, if appropriate).
- » Devise a plan for treatment continuation and follow-up, in consultation with the person.
- » Inform the person of the expected duration of treatment, potential side-effects of the intervention, any alternative treatment options, the importance of adherence to the treatment plan, and of the likely prognosis.
- » Address the person's questions and concerns about treatment, and communicate realistic hope for better functioning and recovery.
- » Continually monitor for treatment effects and outcomes, drug interactions (including with alcohol, over-the-counter medication and complementary/traditional medicines), and adverse effects from treatment, and adjust accordingly.
- » Facilitate referral to specialists, where available and as required.
- » Make efforts to link the person to community support.
- » At follow-up, reassess the person's expectations of treatment, clinical status, understanding of treatment and adherence to the treatment and correct any misconceptions.

- » Encourage self-monitoring of symptoms and explain when to seek care immediately.
- » Document key aspects of interactions with the person and the family in the case notes.
- » Use family and community resources to contact people who have not returned for regular follow-up.
- » Request more frequent follow-up visits for pregnant women or women who are planning a pregnancy.
- » Assess potential risks of medications on the fetus or baby when providing care to a pregnant or breastfeeding woman.
- » Make sure that the babies of women on medications who are breastfeeding are monitored for adverse effects or withdrawal and have comprehensive examinations if required.
- » Request more frequent follow-up visits for older people with priority conditions, and associated autonomy loss or in situation of social isolation.
- » Ensure that people are treated in a holistic manner, meeting the mental health needs of people with physical disorders, as well as the physical health needs of people with mental disorders.

4. Mobilizing and providing social support

- » Be sensitive to social challenges that the person may face, and note how these may influence the physical and mental health and well-being.

General Principles of Care



- » Where appropriate, involve the carer or family member in the person's care.
- » Encourage involvement in self-help and family support groups, where available.
- » Identify and mobilize possible sources of social and community support in the local area, including educational, housing and vocational supports.
- » For children and adolescents, coordinate with schools to mobilize educational and social support, where possible.
- » Pay special attention to confidentiality, as well as the right of the person to privacy.
- » With the consent of the person, keep carers informed about the person's health status, including issues related to assessment, treatment, follow-up, and any potential side-effects.
- » Prevent stigma, marginalization and discrimination, and promote the social inclusion of people with mental, neurological and substance use disorders by fostering strong links with the employment, education, social (including housing) and other relevant sectors.

5. Protection of human rights

- » Pay special attention to national legislation and international human rights standards (Box 1).
- » Promote autonomy and independent living in the community and discourage institutionalization.
- » Provide care in a way that respects the dignity of the person, that is culturally sensitive and appropriate, and that is free from discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status.
- » Ensure that the person understands the proposed treatment and provides free and informed consent to treatment.
- » Involve children and adolescents in treatment decisions in a manner consistent with their evolving capacities, and give them the opportunity to discuss their concerns in private.

6. Attention to overall well-being

- » Provide advice about physical activity and healthy body weight maintenance.
- » Educate people about harmful alcohol use.
- » Encourage cessation of tobacco and substance use.
- » Provide education about other risky behaviour (e.g. unprotected sex).
- » Conduct regular physical health checks.
- » Prepare people for developmental life changes, such as puberty and menopause, and provide the necessary support.
- » Discuss plans for pregnancy and contraception methods with women of childbearing age.

BOX 1

Key international human rights standards

Convention against torture and other cruel, inhuman or degrading treatment or punishment. United Nations General Assembly Resolution 39/46, annex, 39 UN GAOR Supp. (No. 51) at 197, UN Doc. A/39/51 (1984). Entered into force 26 June 1987.
<http://www2.ohchr.org/english/law/cat.htm>

Convention on the elimination of all forms of discrimination against women (1979). Adopted by United Nations General Assembly Resolution 34/180 of 18 December 1979.
<http://www.un.org/womenwatch/daw/cedaw/cedaw.htm>

Convention on the rights of persons with disabilities and optional protocol. Adopted by the United Nations General Assembly on 13 December 2006.
<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

Convention on the rights of the child (1989). Adopted by United Nations General Assembly Resolution 44/25 of 20 November 1989. <http://www2.ohchr.org/english/law/crc.htm>

International covenant on civil and political rights (1966). Adopted by UN General Assembly Resolution 2200A (XXI) of 16 December 1966.
<http://www2.ohchr.org/english/law/ccpr.htm>

International covenant on economic, social and cultural rights (1966). Adopted by UN General Assembly Resolution 2200A (XXI) of 16 December 1966.
<http://www2.ohchr.org/english/law/cescr.htm>

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INSTRUCTOR GUIDANCE

From Theory to Action: Implementing an Internationally Developed Mental Health and Substance Abuse Program in Indigenous Communities in The Americas¹

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BACKGROUND

Intergenerational trauma compounded throughout centuries by the effects of colonialism have left indigenous peoples within the Americas in grave despair. Indigenous communities are subject to a variety of human rights violations and social neglect, which contribute to reduced physical and mental health. The United Nations Permanent Forum on Indigenous Issues has identified these insufficiencies in acknowledging higher rates of poor mental health, substance abuse, and elevated rates of suicide, when compared to non-indigenous peoples. The World Health Organization has developed the Mental Health Gap Action Program Intervention Guide (mhGAP IG) to assess, monitor, and manage, neurological, and mental health conditions, including suicide, in non-specialized health contexts. This case provides an example of how one fictitious indigenous community located off the coast of Central America is seeking to use the mhGAP IG due to the recent suicide clusters within a six month period. The case seeks to highlight how international agencies collaborate in developing interventions for the populations they serve, specifically, between the Pan American Health Organization and the Americas. The protagonist, Juan Santos, is left to question how he will implement the mhGAP in his community with limited resources to encompass cultural considerations and appropriate community engagement to lower suicide rates, mental health, and substance abuse.

¹ *The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of the Secretariat of the Pan American Health Organization concerning the status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries.*

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OBJECTIVES

1. To understand the implications of shortcomings in various social and cultural determinants of health and the onset of and influence on mental health, substance abuse conditions, and suicide.
2. Evaluate the risks and/or benefits of interventions in indigenous communities, with particular attention to cultural continuity, patient-centered care, and outcome assessment tools.
3. Develop an understanding of community collaboration and participatory relationships between public health agencies and indigenous communities.

DISCUSSION QUESTIONS

1. How can public health agencies improve suicide-reporting-data collection for under-reported and suspected cases?
2. Which key elements of implementation science must be adapted for the uptake of interventions in culturally diverse communities?
3. What methods must be employed to assess the Program's effectiveness and relevance?

KEYWORDS

Indigenous peoples; youth; suicide; mental health; PAHO; mhGAP; substance abuse; alcohol; self-harm; cultural continuity; cultural sensitivity.

CASE 10

Moving Towards an Inclusive Society: Implementing Epilepsy Awareness Education in the Ontario Elementary School Health Curriculum

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BACKGROUND

Epilepsy is one of the world's oldest and most recognized medical conditions, with archives dating back to 4000 BC (WHO, n.d.). The World Health Organization (n.d.) describes epilepsy as a "chronic, non-communicable disorder of the brain that affects people of all ages." It is "characterized by recurrent seizures, which are brief episodes of involuntary movement that may involve part of the body (partial) or the entire body (generalized) and is sometimes accompanied by loss of consciousness and of control of bowel and bladder function" (IOM, 2012). Epilepsy affects about 70 million individuals globally. It is a "major public health problem, not only because of its health implications but also for its social, cultural, psychological, and economic effects" (Murthy, Govindappa, & Sinha, 2016).

Martha Stein, a strategic planner at the Epilepsy Support Centre in London, Ontario, was sitting in her office chatting with the Executive Director, Morrison Longos. Martha was concerned about the increasing number of youth living with epilepsy in the London area. She explained to Morrison that her clients missed many opportunities in their lives, such as receiving better health care or pursuing higher education. For instance, adults with epilepsy face difficulties in accessing services such as dental care, optical prescriptions, and renewing driver's licenses, while school-aged children with epilepsy face problems such as difficulties in learning, absenteeism due to fatigue from seizures, and social exclusion. Six out of ten parents reported that their children with epilepsy experienced challenges with learning in school, behaviour, or memory (Clinic to Community, 2017). Martha, who had more than 10 years of experience working with youth with epilepsy, found that they struggle with social stigma and feel 'different' at a time when fitting in is of the utmost importance. These difficulties, if unsupported, affect their overall well-being and success in life. Martha previously spoke with the Thames Valley District School Board and the London District Catholic School Board to understand whether there was any health promotion curriculum on epilepsy awareness for teachers and students. She was surprised that there wasn't a health promotion program for epilepsy, despite the significant number of children diagnosed with this common disorder. Martha decided to propose an initiative to Morrison to create a pilot, school-based health promotion program for epilepsy awareness. This pilot program would be designed to help bridge knowledge gaps about epilepsy in school, promote empathy among elementary school students, and create a safe environment for children with epilepsy to learn, play, and grow.

Being the head of the Strategic Planning department at the Epilepsy Support Centre, Martha saw the need to develop, advocate for, and promote an evidence-based educational program.

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Morrison was fully supportive of Martha's idea and suggested that Martha consider creating this program in alignment with the Ontario elementary curriculum. This would encourage schools and school boards to be involved in the program. This initiative would also teach school teachers how to incorporate the program into their curriculum. The pilot program would not only raise awareness amongst students, but it would also improve teachers' understanding about epilepsy.

THE EPILEPSY SUPPORT CENTRE HISTORY

The Epilepsy Support Centre is one of the many support centres that provide community support services for people with epilepsy. It was first established in 1977 as Epilepsy Ontario's Midwest Chapter on London's Dundas Street as a not-for-profit and non-governmental organization (Epilepsy Support Centre, 2015a). The original founders of the Chapter were a group of parents who had children diagnosed with epilepsy. Their mission was to enhance the lives of people who are affected by epilepsy and seizure disorders by providing a network of services that educate, support, and build community awareness. In view of the rising number of people with epilepsy, the group was renamed in 1983 as Epilepsy London and Area and began serving London-Middlesex, Elgin, and Oxford counties. Despite the change in the Centre's name, the mission remained the same. In 2001, the organization expanded its service area to include Sarnia-Lambton, Chatham-Kent, and Windsor-Essex. Since then, the organization has been renamed once more, and is now known as the Epilepsy Support Centre, reflecting the organization's greater geographic coverage of services (Epilepsy Support Centre, 2015b). Subsequently, the Centre took a leadership role in serving the Southwestern Ontario region by providing and promoting public education programs, creating community activities for people living with epilepsy, and developing support programs such as Clinic to Community (C2C), which helps individuals transition from acute to community care. Over the years, the Centre saw a four-fold increase in the number of clients from 379 in 2013 to 1846 in 2016 (Epilepsy Support Centre, 2013 & 2016). As the number of clients who seek support is increasing, the Centre has also noticed an increase in school requests to present about epilepsy and epilepsy management, from 109 presentations in 2014 to 150 presentations in 2016 (Epilepsy Support Centre, 2014 & 2016).

CURRENT PROBLEMS FACED BY CHILDREN AND ADOLESCENTS WITH EPILEPSY

As Martha was planning for her program proposal, she continued to visit her clients and follow up with their social issues. Her young clients often raised the same issues regarding both school and home. According to the Centre's statistics, 81 of 109 parents with children aged four to 12 years identified that there was a lack of support from the school (Clinic to Community, 2017). Martha found, based on her research and observations, that children and adolescents living with epilepsy face difficulties adjusting in four major domains (Elliot, Lach, & Smith, 2005):

Physical Domain

Many school-aged children and adolescents living with epilepsy often report fatigue as a major complaint. Fatigue often sets in immediately after a seizure. In addition, fatigue makes thinking and learning at school difficult for children and adolescents with epilepsy. Post-seizure sleep could be extensive and last for the entire day. Because of this fatigue, children's and adolescents' ability to be physically and mentally present in class, or to participate in their favourite activities, is limited (Elliot et al., 2005). This could lead to fellow peers not inviting them to participate in community activities, which could result in gradual social exclusion. As a result, children and adolescents with epilepsy often choose to stay at home, leading to a reduction in their physical activities.

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Emotional and Behavioural Domains

Children and adolescents living with epilepsy often experience a wide variety of mood swings. They can switch from intense emotional distress after a seizure to feeling happy when they “forget” about their seizures. However, because of the unpredictability of seizures, they often feel worried, fearful, frustrated, embarrassed, and depressed (Elliot et al., 2005). The feeling of frustration stems not just from the unpredictability of seizures but also from over-protection and supervision from their parents. Parents, for fear of their child’s seizures, restrict their child’s activity choices. This reduces the child’s autonomy in decision making, which can lead to frustration and anger. As such, most children and youth remain indoors and gradually “enclose” themselves by not interacting with family members or friends.

Social Domain

Children and adolescents living with epilepsy experience internal (i.e. lack of self-esteem or confidence) and external (i.e. social exclusion by peers and excessive parental monitoring) constraints. These individuals are afraid to have friends because they assume that if they were to disclose their condition, peers would shun them. As a result, most choose to have only one close friend who knows about their condition and can help them in school (Elliot et al., 2005). Moreover, children with epilepsy may experience bullying that further hinders their ability to make friends (Jacoby & Austin, 2007). Due to these exposures that alter their perception of what “friendship” is, many children and adolescents with epilepsy choose to isolate themselves to avoid being treated differently.

Cognitive/Academic Domain

Seizures take a toll on a child’s mental and physical abilities, resulting in an inability to focus on or remember what they were taught in school. Overtime, this impacts their ability to integrate and synthesize their learning. When peers and teachers are unaware of a seizure condition, they often assume that children and adolescents with epilepsy are simply lazy or daydreaming, hence the poor academic performance (Elliot et al., 2005). The fear of asking teachers to repeat information causes these children to miss out on important information at school. Due to the lack of a supportive environment, these children and adolescents might quit school altogether.

The problems faced by children and adolescents with epilepsy lead to barriers in normal child development and growth. They experience social exclusion and isolation, which can interfere with their ability to adapt in different social environments. At times, these individuals perceive a “seizure as a barrier to normalcy” (Elliot et al., 2005). This could be further seen in students attending different programs such as special education classes, where such programs serve to further divide people’s perceptions of what is normal and what is not normal.

EPILEPSY IN THE CANADIAN CONTEXT

According to a registered Canadian charity, Epilepsy Canada (2016), approximately one in 100 Canadians are diagnosed with epilepsy. This is a pressing public health issue because an average of 42 Canadians learn that they have epilepsy each day (i.e. 15,500 Canadians per year). In this population, 44% are diagnosed before the age of five, 55% before the age of 10, 75% before age 18, and 1.3% over the age of 40. It has been observed that about 60% of new patients are young children and senior citizens (Centers for Disease Control and Prevention, 2016). The Canadian League Against Epilepsy (CLAE) reported that at any given time, the total number of Canadians living with epilepsy is 300,000. In this population, 70% can control their seizures with medications and lead a normal life. However, the remaining 30% often have other social and learning problems (CLAE, n.d.).

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Even though the total number of Canadians living with epilepsy is high, this condition is still poorly understood in Canada (CLAE, n.d.). This lack of knowledge about epilepsy has resulted in misconceptions and stigma. In light of these misconceptions, epilepsy is perceived as a “less important” condition compared to other public health issues, such as cancer and HIV. Funding availability for epilepsy awareness and education is also less than for other public health issues. Currently, only the Ontario Trillium Foundation and the Ontario Brain Institute have been funding epilepsy awareness campaigns consistently over the years.

Martha knew that in order to dispel these myths and misconceptions of the general public towards epilepsy, epilepsy funding, political support for epilepsy, and the right window of opportunity would be necessary to help create greater awareness in society. The Ontario Ministry of Education was in the process of making changes to the Ontario Health and Physical Education Curriculum. Martha saw this as an opportunity to integrate epilepsy awareness educational programs as part of this new curriculum. She began to research the new Ontario Ministry of Education Grade 1-8: Health and Physical Education Curriculum (2015) to identify where best to incorporate epilepsy awareness programming.

EPILEPSY & STIGMA (A PUBLIC HEALTH PERSPECTIVE)

Szaflarski (2014) reported that adults with epilepsy report worse mental health, cognitive impairment, limitations in social participation, and experience health and social disparities (i.e. worse health-related quality of life and low socioeconomic status). These negative outcomes experienced by individuals with epilepsy are attributed to stigma. Stigma is how society perceives or labels an individual or group to be different based on their abilities, which can create stereotypes, disapproval, and discrimination (Goffman, 1986). Stigma can severely impact an individual’s ability to live a normal, healthy, and productive life. In addition, individuals who have seizures can make poorer choices in life when they lack social support. This can potentially cause their seizures to worsen or relapse.

Due to the social inequalities and disparities faced by individuals with epilepsy, there has been a call for increased public health surveillance, health care system interventions, and community programs. Studies have shown that public health initiatives and programs have helped individuals and organizations to understand, manage, and prevent non-communicable chronic diseases, such as hypertension, asthma, diabetes, and epilepsy. Therefore, support organizations in Canada, such as Epilepsy Canada, Epilepsy Ontario, and the Epilepsy Support Centre, have provided social support to people living with epilepsy and research institutes, such as the Ontario Brain Institute, are committed to understanding epilepsy through research.

In spite of having epilepsy support services and programs, social stigma and misconceptions of epilepsy are still prevalent in schools (Keusch, Wilentz, & Kleinman, 2006). To deal with the repercussions of stigma faced by school-aged children, Martha had to understand what appropriate resources and personpower she should engage with. This would help her understand the interactions of social determinants of health and demonstrate the need to develop a sustainable, well-researched, and well-designed school curriculum.

WHAT’S NEXT?

Martha considered developing the proposed program using a health promotion model. She knew that using the six-step planning model developed by Public Health Ontario (2015) would provide systematic guidance on how to plan, manage, and effectively use available resources to design a school-based curriculum.

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School-based Educational Program

Martha knew that societal stigma about epilepsy was highly prevalent, and it would not dissipate without educational programs. Studies have proven that interventional education programs in elementary schools have long-lasting positive impacts on children's behaviours. For instance, healthy eating and exercise programs have been shown to create positive impacts on behavioural change from a young age (Racey et al., 2016). The frequent inclusion of such healthy living programs in the curriculum has allowed children and adolescents to "adopt healthy routines and disseminate accurate healthy living information to family and friends" (Gorga et al., 2016).

Although Martha had no up-to-date statistics that measured students' knowledge, attitudes, and perceptions towards epilepsy, her intensive research found that promoting epilepsy education, awareness, and empathy to children between ages nine and 11 is highly effective. Providing accurate information to children about epilepsy at an early age could decrease stigma and secrecy and promote positive attitudes towards epilepsy (Murthy et al., 2016).

To ensure that all relevant stakeholders were engaged in the decision-making surrounding this school-based health education program, Martha began to consider:

1. What information is required in order to plan an educational program or health promotion campaign?
2. What information is currently available? (e.g. from the Epilepsy Support Centre's database, literature reviews, Statistics Canada)
3. How should she go about doing this? What other information that is not already available is needed?
4. Who can Martha talk to? What else can Martha ask?
5. Who will her stakeholders be?
6. How would Martha determine which needs are relevant in delivering the program?
7. What incentives should she consider to ensure stakeholder buy-in?
8. How would she conduct a situational assessment and gather data?
9. How would she go about developing her six-step health promotion planning model?

She had many questions about the process of developing this health promotion program and was eager to actualize this pilot program with the goal of creating awareness about epilepsy.

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INSTRUCTOR GUIDANCE

Moving Towards an Inclusive Society: Implementing Epilepsy Awareness Education in the Ontario Elementary School Health Curriculum

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BACKGROUND

This case revolves around the stigma experienced by individuals living with epilepsy. It discusses how Martha, a strategic planner at the Epilepsy Support Centre in London, Ontario, identified the negative health and social implications that confront individuals living with epilepsy. It then sets the stage in terms of problems faced by children and adolescents with epilepsy who are living in London, Ontario, and in terms of public health issues, school boards and government, and future directions. As this is a new initiative that is designed to be introduced into the school curriculum, it is crucial to have appropriate and influential stakeholders on board to actualize this epilepsy awareness program.

OBJECTIVES

1. Become aware of how the different social determinants of health impact people living with epilepsy.
2. Apply the knowledge of how to complete a community needs assessment.
3. Analyze how different stakeholders play a role in creating the provincial-curriculum health promotion program.
4. Determine stakeholder values and effectively engage them.
5. Motivate fellow stakeholders and adapt to challenges.
6. Evaluate recommendations and outcomes.

DISCUSSION QUESTIONS

1. What are the dilemmas currently being faced by Martha and Morrison of the Epilepsy Support Centre?
2. Is it enough to just educate elementary school students about epilepsy? Why or why not?
3. Why do you think the Epilepsy Support Centre decided to introduce a health promotion program into the elementary school curriculum? Was this choice appropriate?
4. What elements make a health promotion program successful? How much does scientific knowledge matter in such a health promotion program?
5. Both Martha and Morrison agree that an elementary-school-based program would help increase awareness about epilepsy to younger populations. If you were Martha, how would you convince the Ontario Ministry of Education that this health promotion program is necessary?
6. What steps could Martha and Morrison take to determine the attitudes, knowledge, and perception of students in elementary schools?

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7. Who are the potential key stakeholders in this case? Would there be different levels of interests or values among stakeholders? Why?
8. What are the possible challenges that Martha and Morrison might encounter with implementing this health promotion program?
9. How would you effectively evaluate the recommendations made by Martha?
10. What would be the outcome of a needs assessment that was not properly planned?

KEYWORDS

Epilepsy; health education; health promotion; stigma; best-practice.

CASE 11

United Hearts: Fostering Interdisciplinary Collaboration for the Detection of Critical Heart Defects in Newborns

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INTRODUCTION

Janet prepared for a teleconference with her colleagues from Newborn Screening Ontario (NSO). She sat in her home office in Calgary while her team would be calling in from NSO's location in Ottawa. With the expected birth of her own child just one week away, Janet knew that her last few days of work would be fundamental in the implementation of a novel newborn screening program in Ontario.

As a genetic counsellor with NSO since 2010, Janet was knowledgeable about the 29 rare diseases screened for in newborns. She had witnessed firsthand how early diagnosis and treatment for those diseases through newborn screening could prevent the health complications and even the death of infants. The 29 diseases were screened for using blood-spot testing, and NSO's coordination of newborn screening across Ontario ensured the highest quality newborn screening and care for serious diseases available to every newborn.

The experience and success of NSO with blood-spot testing is notable. Now Janet wondered how NSO should plan for the implementation of a point-of-care test, a new frontier for NSO. This new screening test, called Pulse Oximetry Screening (POS), would aim to identify critical congenital heart defects (CCHDs) in newborns within the first days of life. CCHDs are a serious public health issue that can result in tragic consequences when not detected in the newborn period and treated within the first year of life. Affected infants often look healthy at birth and must be identified before the onset of symptoms in order for treatment to be most effective.

POS will be done in combination with the other two procedures used for CCHD detection: pre-natal ultrasound during pregnancy and post-natal physical examination. Up to 25% of CCHDs in infants are not detected prior to discharge when only pre-natal ultrasound and post-natal physical examination are done (Mouledoux & Walsh, 2013). CCHD screening by POS will therefore aim to identify and treat infants with a CCHD that otherwise would have been missed before being sent home. A missed or late diagnosis can lead to health complications or death for the infant.

POS is a simple and specific screening test that can reliably identify affected infants by detecting low blood-oxygen levels. A newborn with low blood-oxygen levels may have a CCHD, and thus require immediate medical assessment to determine the cause of low oxygenation. Screening every infant in Ontario for CCHDs will aim to diagnose and treat affected infants early in order to ensure the best health outcomes for the newborn.

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Janet discerned that realizing the goals of this program would involve the combined efforts of health care providers across the province. With CCHD screening involving a point-of-care test, there would need to be protocols in place in order to ensure immediate follow-up of a screen-positive infant by a medical practitioner. With a wide variation in available care providers and services at birthing sites across Ontario, how could implementation rely on a single protocol? The care team members that could become involved in the care of a screen-positive infant include midwives, nurses, primary-care physicians, specialists (pediatrics, pediatric cardiology, neonatology), and transfer teams. Continuity of care between care providers is essential in both the treatment of the infant and in relaying the necessary information about an infant's screening results, diagnosis, and subsequent treatment to NSO.

Janet held the belief that interdisciplinary collaboration amongst care providers should be the approach employed to ensure continuity of care in the CCHD screening program. This, in turn, would lead to the best health outcomes for Ontario newborns and the effectiveness of the program.

How could NSO foster interdisciplinary collaboration across the various contexts of Ontario birth sites? How could implementation research allow for the NSO team to plan for context-specific challenges that could arise at certain birth centres? Could this planning mitigate those challenges through interdisciplinary collaboration?

NEWBORN SCREENING ONTARIO

Newborn Screening Ontario's Vision: The best possible health through screening.

NSO coordinates the provincial newborn screening program in Ontario. The multidisciplinary team at NSO is comprised of laboratory, clinical, and administrative staff, who collaborate to ensure that every infant born in Ontario receives the highest quality screening and care for serious diseases (NSO, 2013). The panel of 29 diseases currently screened for by NSO includes metabolic and endocrine diseases, sickle cell disease, cystic fibrosis, and severe combined immune deficiency. Approximately 200 rare disease cases are identified each year. The incidence of all rare diseases is approximately one per 800 infants (NSO, 2013, p. 3). It is critical that every newborn is screened for rare diseases because clinical signs of disease are often not present at birth and most affected infants have no family history of disease. NSO's work saves lives. Families across Ontario have been positively impacted by NSO's comprehensive newborn screening program.

The primary goal of newborn screening is the early identification of affected infants in order to prevent serious health problems. Early diagnosis and treatment can improve the health outcomes for an infant found to have a rare disease and potentially save the infant's life. In contrast, a missed or late diagnosis and treatment may result in mental retardation, serious health problems, or even death of the affected infant (NSO, 2013, p. 3).

The NSO staff coordinates the various components of the provincial newborn screening program. NSO is responsible for testing for the 29 diseases, record keeping, quality assurance of testing, and communication directly with submitters about unsatisfactory or missed samples. When an infant is determined to be screen positive for a disease, NSO's role is in referring the infant to a regional treatment centre and obtaining follow-up information. Follow-up information is retrieved from the health care providers involved in the infant's care and includes information about the treatment that the infant received. Education about newborn screening is a central component of NSO's work in order to educate parents, health care providers, and the general

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public across Ontario about the program. Ontario is a leader in newborn screening and NSO offers one of the most comprehensive newborn screening programs in Canada.

ORGANIZATIONAL GOVERNANCE

Ontario's newborn screening program was moved from Public Health Ontario (PHO) to NSO in 2006 (NSO, 2013, p. 4). PHO's action in Ontario is to protect and promote the health of all Ontarians and to reduce health inequities (PHO, 2016). The transfer of the newborn screening program to NSO allowed for the rapid expansion of the screening panel and dedicated focus to the program. NSO operates out of the Children's Hospital of Eastern Ontario (CHEO) in Ottawa and has coordinated the modernization of Ontario's newborn screening system. This modernization involved NSO's ability to screen for an increasing number of diseases, growing from two diseases in 2006 to 29 diseases by 2013.

NSO is under the stewardship of the Government of Ontario and reports to the CHEO board regarding operations and accountability. The Newborn Screening Advisory Council (NSO-AC) is an independent advisory group of health and other professionals with expertise in newborn and childhood screening. The NSO-AC advises both NSO and the Ministry of Health and Long-Term Care (MOHLTC) on newborn screening policies and programming. If a disease were to be nominated for addition to Ontario's newborn screening panel, then the nomination would first go to the NSO-AC for review. Based on their review, the NSO-AC can recommend screening for the disease, not screening for the disease, or request additional information before a decision is made. If screening for the disease is recommended, then a formal report is submitted to the MOHLTC. The MOHLTC is then responsible for deciding whether to approve and commit funding to screening for that particular disease.

As a member of the NSO-AC, Janet has enjoyed learning about the processes of a proposal moving through the government and about new potential targets of screening. There are many upstream and downstream factors that need to be considered when planning for the implementation of any program.

Janet recalled the process of submitting the report to the MOHLTC for CCHD screening, and the excitement surrounding approval just months ago. Janet worked alongside Jennifer, the NSO Operations Director, who was a major player in moving CCHD screening forward and obtaining MOHLTC approval. As the Operations Director, Jennifer is responsible for the daily operations of Ontario's newborn screening program, risk and resource management, program evaluation, and any special projects or quality improvement initiatives within NSO. Janet knew that this upcoming teleconference would involve many laughs shared between herself and Jennifer, which would ease the sense of urgency that Janet was feeling towards planning for CCHD screening implementation before her upcoming due date.

CURRENT SCREENING PRACTICES

The current newborn screening program involves blood-spot screening for 29 diseases. Nurses or midwives take a small sample of blood from the infant's heel, ideally between 24 to 72 hours after birth, and the blood is placed on a blood-spot collection card. The card is couriered to NSO, where the sample is then tested for the 29 rare diseases (NSO, 2013, p. 6). If an infant's results are negative, then he or she is at low risk of having the diseases, and the report is mailed to the hospital or health care provider who submitted the infant's sample.

A positive result does not mean that the infant has a definitive diagnosis. An infant who has a positive result has an increased risk of having the indicated disease and further diagnostic

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evaluation is required. An NSO physician refers the screen-positive infant to physicians at a regional treatment centre for follow-up diagnostic testing. The NSO physician receives follow-up information from the treatment centre about the diagnosis and corresponding treatment that the infant received. The follow-up information allows NSO to ensure that screen positive infants receive appropriate and timely care. The samples for all newborns are stored in a secure facility as part of the infant's medical record (NSO, 2013, p. 7).

A NOVEL TEST

The Government of Ontario approved the addition of CCHD to the newborn screening panel in March of 2016. CCHD screening will involve the first point-of-care test coordinated by NSO, making its implementation an unfamiliar territory for Janet and her team at NSO. The point-of-care test is called POS, which is a simple and non-invasive procedure that will be performed on each infant.

For this test, the probe of the pulse oximeter device will be placed on the right hand and then either the right or left foot of the infant and secured with a wrap. The device uses light transmission to measure the proportion of oxygenated hemoglobin in the blood and reports this level as the SpO₂ functional oxygen saturation of the newborn's blood. The measurements are taken in the right hand and in the right or left foot in order to get a pre-ductal and a post-ductal measurement, respectively. After birth, a newborn's circulation transitions from fetal to neonatal circulation, which involves the closing of the ductus arteriosus blood vessel in the heart. The ductus is open while the baby is in utero in order for the blood to bypass the lungs but then needs to close after birth when the infant depends on its own lungs for oxygenation. Measuring both pre-ductal and post-ductal saturations is important in detecting CCHDs, particularly those that are duct-dependent and show large differences between the pre-ductal and post-ductal measurements that will alert to a positive screen.

The POS test takes a few minutes and will be executed by nurses and midwives, also known as submitters, across Ontario. While POS will be familiar to the majority of submitters, implementation will involve training in result interpretation, parent screening education, and newborn-specific POS processes. For example, the algorithm and screening protocol guidelines (Exhibit 1) proposed by Kemper and colleagues (2011) for newborn CCHD screening outline how POS results should be interpreted to determine if an infant is a positive screen, negative screen, or requires a repeat screen in one hour. The actions to be taken for either a positive screen or for a negative screen are listed (Exhibit 1), as well as how the actions would most likely be divided among different health care providers (Exhibit 2) in an interdisciplinary-collaborative model.

As it is a point-of-care test, the results will be available immediately, and thus a positive infant would require immediate medical assessment. Therefore, the submitter performing the POS would need to initiate next steps to ensure that the infant is assessed by the most responsible medical practitioner in a timely manner. How would interdisciplinary collaboration among different care providers ensure continuity of care for the newborn? What if the infant needed to be referred to a pediatric cardiologist and the nearest hospital with this service was 200 km away? How would this impact communication? Janet considered the impact of contextual factors on implementation and continuity of care for positive infants requiring urgent care. How can protocols be established among interdisciplinary-collaborative teams in order to ensure timely and continuous care for screen positive infants? Janet quickly jotted down these thoughts in preparation for the meeting.

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CRITICAL CONGENITAL HEART DISEASE

Congenital heart defects occur when a baby's heart or major blood vessels have not formed properly during development. These defects occur in about nine per 1000 live births and are the malformations responsible for the largest proportion of infant deaths (approximately 40%). Approximately 25% of congenital heart defects are "critical," requiring surgery or catheter intervention within the first year of life. Therefore, early diagnosis and treatment are vital in protecting an affected newborn's health and ensuring the best health outcomes.

Current practices for diagnosis of CCHDs include prenatal ultrasound and postnatal physical examination. However, up to 25% of cases are missed prior to discharge by using only these methods and the affected newborns appear to be healthy (Mouledoux & Walsh, 2013). CCHD screening by POS of all newborns aims to identify affected babies that would otherwise not be detected, so that treatment can begin immediately and negative outcomes avoided (Thangaratinam, Brown, Zamora, Khan, & Ewer, 2012).

Janet recognized the role of NSO in educating parents and guardians about CCHDs and the screening program. While NSO would provide the educational materials (pamphlets, posters, online information), the frontline health care providers would have prominent roles in the education component. Considering interdisciplinary collaboration when developing the educational components would allow for a continuous and uniform message for parents and guardians. This could enhance parent/guardian satisfaction with the CCHD screening program, compliance with screening, and trust in the provincial newborn screening program.

THE CHALLENGE OF CONTEXT

Janet's plan to conquer continuity of care in CCHD screening through interdisciplinary collaboration would need to address the challenge of differing birth site contexts across Ontario. NSO could provide a standardized protocol for screening, results interpretation, and subsequent actions in the cases of screen negatives and screen positives. However, Janet recognized the need to take context-specific factors into consideration throughout planning.

Accessibility to certain resources, such as heart echocardiography and health care providers, will differ based on the birth site. For example, an infant is born in a Northern Aboriginal community with no road access and the submitter is an Aboriginal midwife. The midwife would have the responsibility of coordinating air transport of a screen-positive infant to the nearest hospital with the appropriate resources and health care providers. Once transferred, the new site would then determine the cause of low oxygenation for the infant (e.g. pediatric cardiology, heart echocardiography, pediatrics, etc.) and provide the appropriate treatment. Continuity of care for a screen-positive infant will depend on the context-specific protocol that the health care providers have put in place. A lack of interdisciplinary collaboration and communication could result in delays in diagnosis and treatment for an infant in need of urgent care. These delays could lead to detrimental results, such as death of the affected infant.

The contexts that immediately came to Janet's mind were isolated northern communities, community hospitals with no echocardiography equipment, home births, and tertiary care hospitals (Exhibit 3). All of these contexts would require drastically different processes and so implementation research into developing context-specific protocols would be essential prior to the start of implementation. In order to encourage interdisciplinary collaboration in a specific context, Janet believed that NSO would need to engage the health care providers who would be directly involved in the care of newborns being screened to develop the protocols. Janet wondered how care providers, who likely would be facing time constraints and competing demands already, would view the program that would be detecting rare conditions. How would individuals in a birth centre react if they initially complied with the POS protocol, but did not

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experience a confirmed CCHD diagnosis over a long period of time? Would the rarity of screen positive tests reduce compliance? How could NSO play a role in maintaining enthusiasm for the CCHD screening program and in fostering the interdisciplinary collaboration and continuity of care?

THE CARE TEAM: INTERDISCIPLINARY COLLABORATION

“Interdisciplinary implies a deeper degree of collaboration among team members. It implies an integration of the knowledge and expertise of several disciplines to develop solutions to complex problems in a flexible and open-minded way”.

– Nolte & Tremblay, 2005

The urgent care for an infant with a positive result and potential CCHD would involve health care providers from different disciplines, each of whom would have their respective responsibilities (Exhibit 2). The initial submitter would execute the POS. If an infant screens positive, the next steps the submitter would take would be impacted by the particular context. If a midwife is performing the test in a client’s home and the screen was positive, then the next steps would require communication with a hospital in order to facilitate transfer of the infant to the hospital. If the birth and screening took place in a tertiary-care hospital, then the submitter would likely inform the primary-care physician of the results. The physician would then begin a medical assessment of the infant to determine the cause of low oxygen levels and would consult with neonatology and/or pediatrics, if available. If a CCHD could not be eliminated as a potential cause, a pediatric cardiologist would be consulted. The cardiologist may have a sonographer perform a heart echocardiogram to aid in CCHD diagnosis.

Janet created a list of the health care providers who could become involved in a positive screen case, and thus would need to be involved in the program implementation planning. She also jotted down responsibilities that may apply to each provider (Exhibit 2). Recognizing that each type of provider may not be available in each context, Janet knew that there would need to be context-specific protocols developed for each particular birth site and for homebirths. Additionally, a few hospitals in Ontario had already implemented CCHD POS; how would NSO work with those institutions? Would the health care providers at those institutions be reluctant to change their existing protocols?

Just before the teleconference call from Ottawa came through, Janet recalled the conference she went to on *Enhancing Interdisciplinary Collaboration in Primary Health Care in Canada* (Nolte & Tremblay, 2005). Evidence supported that interdisciplinary collaboration among health care providers shifts the focus to a more patient-centred care model, in which patients have greater levels of knowledge about their care and thus increased satisfaction (Nolte & Tremblay, 2005). Collaborative work among health care providers also leads to increased access for patients to a range of services and closes gaps in service (Alberta Health and Wellness, 2000; Kaini, 2015).

In the context of care for children with complex health care needs, evidence shows that interdisciplinary collaboration has resulted in parents/caregivers feeling well-informed, confident in their care providers, and satisfied with the care their child was received through the collaborative approach (Nolte & Tremblay, 2005; Zwarenstein, Goldman, & Reeves, 2009). Janet believed that interdisciplinary collaboration was the key to effective implementation of CCHD screening; however, how would NSO’s planning encourage collaboration amongst teams in Ontario? In addition, interdisciplinary teams in health care are dynamic and adapt to a particular patient’s care needs. Therefore, it would be challenging to create context-specific protocols for a dynamic care team in which its members could be at different institutions, but this

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also points to the importance of ensuring continuity of care. Janet created a list of relevant facilitators and barriers (Exhibit 4) to interdisciplinary collaboration that could be addressed when planning for CCHD screening implementation. NSO would need to have an awareness of these factors and address them in planning.

IMPLEMENTATION RESEARCH

“Successful implementation research begins and ends with successful collaboration.”

– Implementation Research in Health, 2013

Implementation research involves critical analysis of factors that may impact the effectiveness of implementation of an intervention. The intervention in this case is the CCHD screening program. Analysis of the multiple factors and domains that can have an impact on the program aids in determining the best way to implement an intervention in a health care system, and how to plan for program implementation, evaluation, and modification (WHO, 2014, p. 2). The interacting domains (Exhibit 5) to consider in implementation research are the outer settings (social, geographical, etc.), inner settings (organizational culture, structure, etc.), processes for implementation, and individuals involved in implementation (WHO, 2014, p. 5). The outer setting relates directly to planning for context-specific protocols at a particular birth centre. A centre that is geographically isolated needs to plan for infant transfer in the case of a positive result, for example. The inner setting would be interconnected with interdisciplinary collaboration, as Janet knew that power relations, organizational culture, and relationships would directly impact that component of implementation. In the case of NSO’s planning for CCHD screening implementation, implementation research should be initiated prior to the program starting. Janet decided these steps need to be taken now, and she needed to determine which stakeholders to involve at these stages.

Implementation research also helps to plan for and anticipate intervention problems and see how understanding context helps to deliver interventions effectively in diverse settings (WHO, 2014, p. 6). There are many different contexts to be considered in an Ontario-wide CCHD screening, and so context-specific research is an important step in implementation planning. There is no provincial/territorial program already established in Canada for CCHD screening, and so extrapolating results from the programs in other countries will also require additional research into the Canadian context.

Challenges in implementation can arise due to a range of real-world contextual factors, and so implementation research can be employed in context-specific and evidence-informed decision making. A tool found to be efficacious in health care may not actually prove to be effective if contextual factors are not accounted for. Implementation research helps to translate efficacious tools into effective interventions in real-world settings (Exhibit 6) (WHO, 2014, p. 17). In regards to CCHD screening, POS has been found to be an efficacious tool for identifying infants with CCHD (Kemper et al., 2011). However, this does not ensure that the screening program will be effective in Ontario. Accessibility needs to be considered, so that implementation of the program accounts for barriers to access that may be present. The intervention must be accessible to the target group. After accessibility is addressed, provider compliance is also a necessary step towards ensuring effectiveness of the screening program. Health care providers must comply with the relevant processes and policies of screening. Patient compliance to CCHD screening follows provider compliance. NSO’s strong background in education of parents and caregivers regarding newborn screening will be beneficial in educating on CCHD screening. It was also noted that interdisciplinary collaboration can improve patient’s/client’s knowledge about health services and increase their satisfaction with collaborative care teams, which in turn would likely

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increase adherence (Nolte & Tremblay, 2005). The listed components compose the proposed pathway to intervention effectiveness (Exhibit 6) (WHO, 2014, p. 17).

Implementation planning includes evaluation of the intervention, in which implementation outcome variables (Peters, Tran, & Adam, 2013; Proctor et al., 2011) should be considered. These variables include acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, coverage, and sustainability (Peters, Tran, & Adam, 2013; Proctor et al., 2011). Outcome variables act as the indicators of a program's effectiveness. Janet considered adoption in particular, as the uptake of CCHD screening among health care providers would be crucial for the program to be effective. With screening for CCHD being a point-of-care test, the program relied on submitter compliance to screen every infant born in Ontario. In terms of the interdisciplinary team, adoption would be required among other health care providers in regards to the follow-up protocols for a positive infant. If a submitter correctly identifies a positive infant, but a physician is unwilling to follow up with an immediate examination, then the intervention cannot proceed.

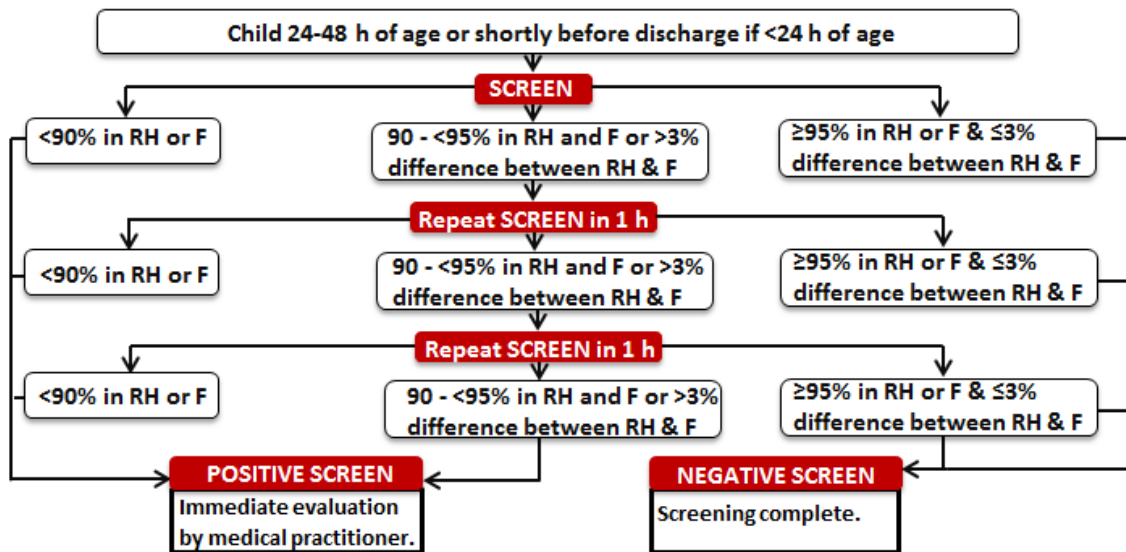
Equity in screening all newborns would also rely on the adoption by health care providers in order to ensure complete coverage, which is another outcome variable. Feasibility would be associated with context-specific facilitators and challenges. Feasibility to screen each newborn and have immediate assessment of positive-screen infants would be very different in a remote nursing station with no physician, in comparison to a tertiary care hospital with access to multiple specialists.

CONCLUSION

Janet hears the incoming call. She would advocate to the team about the importance of continuity of care and interdisciplinary collaboration, but it was yet to be determined how NSO would foster and encourage both among care teams across Ontario. Would health care providers comply to screening protocols? Would NSO be able to ensure entire coverage, so that all newborns would have equal access to CCHD screening? It was clear to Janet that implementation research would be the approach necessary to address the diverse contexts of birth sites across Ontario, but who would lead that initiative once she was on maternity leave? What stakeholders should be involved early on in implementation planning? Janet picked up the phone.

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EXHIBIT 1 Protocol for Critical Congenital Heart Disease Screening in Ontario



Source: Kemper et al., 2011. Reproduced with permission from *Pediatrics*, 128, e1259 Copyright © 2011 by the AAP.

General CCHD Screening Protocol

- Screening of all newborns between 24-48 hours after birth or shortly before leaving the birth centre if discharge is within 24 hours of birth.
- Submitters must inform and educate parents/guardians about CCHD screening; parents have the liberty to decline screening and this action must be documented on the newborn screening card.
- The pulse oximetry readings are taken in the right hand (pre-ductal) and either foot (post-ductal).
- The pulse oximeter used for screening should be FDA approved for use in newborns, measure functional oxygen saturation, and be both motion-tolerant and validated in low perfusion conditions.
- The algorithm (Kemper et al., 2011) is used by submitters to determine if screen positive or negative, but it should not replace clinical judgment.
- Each birth centre has a context-specific protocol for both screen negative and screen positive infants; communication structure in place between care providers that would potentially become involved in the care of a screen positive infant. These providers may be at the same institution or at different institutions, which would require infant transfer.
- An infant's pulse oximetry results are recorded on his/her respective newborn screening card and submitted to NSO.
- A symptomatic baby requires clinical assessment, even if screen negative.

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EXHIBIT 1 (cont'd)

Positive Screen Actions
<ol style="list-style-type: none">1. Submitter documents the pulse oximetry results on the newborn screening card that is sent to NSO.2. The submitter notifies the parents/guardians of the results and the subsequent actions.3. Submitter notifies responsible medical practitioner immediately.4. Immediate medical assessment by the responsible medical practitioner is conducted.5. Evaluation of infant for both cardiac and non-cardiac pathology.<ol style="list-style-type: none">a. Non-cardiac causes of low oxygen saturation include persistent pulmonary hypertension, pneumonia, infection, etc.b. This step may involve consultation with pediatrics and/or neonatology.6. If a cardiac-cause cannot be excluded, then refer the infant to pediatric cardiology and obtain a diagnostic echocardiogram. The individual performing the echocardiography should be trained in interpreting infant echocardiograms.7. If any of the services in the protocol are not accessible at the given birth centre, the infant may be transferred to another institution or telemedicine may be contacted.8. Receipt of pulse oximetry results on the newborn screening card by NSO and data input of results.9. NSO collects follow-up information via the Diagnostic Evaluation Report Form (DERF) sent to submitters and involved medical practitioners in the newborn's care (e.g. pediatric cardiologist, family physician, etc.)
Negative Screen Actions
<ol style="list-style-type: none">1. Submitter documents the pulse oximetry results on the newborn screening card that is sent to NSO.2. The submitter notifies the parents/guardians of the results and informs them that a negative screen does not exclude the possibility of all cardiac defects.<ol style="list-style-type: none">a. If the infant presents with any of the following symptoms, the parents/guardians should seek medical attention for their infant immediately: poor weight gain, sweating around the head especially during feeding, rapid or troubled breathing, tires easily during feedings, pale/bluish skin tone, puffy face and/or feet.3. Receipt of pulse oximetry results on the newborn screening card by NSO and data input of results.4. If a screen negative infant was later found to have a CCHD, this should be reported to NSO in order to document and follow-up with false-negative cases.

Source: Adapted from Kemper et al., 2011.

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EXHIBIT 2

Responsibilities of the Health Care Providers in CCHD Screening

Provider	Responsibilities
Submitter (nurse, midwife)	<ul style="list-style-type: none"> • Complete training for newborn pulse oximetry screening. • Educate parents regarding newborn screening for CCHDs. • Perform pulse oximetry on newborn. • Record screening results on newborn screening card and submit to NSO • Ensure parents are informed of results. • If infant is screen positive, immediately initiate context-specific protocol (e.g. inform medical practitioner who will perform assessment; if after homebirth, call hospital to inform need for infant transfer to hospital). • As the submitter, fulfill necessary follow-up requirements with NSO after infant screens positive (e.g. complete Diagnostic Evaluation Report Form). • Communicate with other members of the care team.
Examining medical practitioner	<ul style="list-style-type: none"> • Receives screen result from the submitter (nurse, midwife). • May need to arrange for transfer of the infant to another unit or hospital if required services not available in own facilities. • Consult with specialists, such as those from neonatology or pediatrics. • Keep parents informed. • Communicate with other members of the care team.
Specialists (neonatology, pediatrics)	<ul style="list-style-type: none"> • Provide expertise to the examining medical practitioner on the cause of low blood oxygen levels in newborn. • Consider both non-cardiac pathology and cardiac pathology that may be associated with a positive screen result (e.g. infection, persistent pulmonary hypertension), and assess for potential CCHD. • May need to arrange for transfer of the infant to another unit or hospital if required services are not available in own birth centre, such as pediatric cardiology or heart echocardiography. • Keep parents informed. • Communicate with other members of the care team.
Pediatric cardiologist	<ul style="list-style-type: none"> • If a CCHD has not been ruled out, then the pediatric cardiologist will assess for CCHDs. • Arrange for next steps, such as a heart echocardiogram and a chest x-ray. • Diagnose infant with CCHD if applicable and arrange for next steps in treatment. • Keep parents informed. • Communicate with other members of the care team.
Sonographer	<ul style="list-style-type: none"> • Perform heart echocardiogram on newborn suspected to have a CCHD. • Communicate with other members of the care team.
Newborn Screening Ontario	<ul style="list-style-type: none"> • Follow-up with submitters on positive screen results and ensure care of affected infants has been implemented. • Collect follow-up information from health care team on screen positive infant through a Diagnostic Evaluation Report Form. • Collection of pulse oximetry results of all newborns in Ontario and submit into database. • Communication with submitters and their teams regarding program implementation, improvements, and sustainability. • Educate parents, health care providers, and the general public in Ontario about newborn screening for CCHD.

Source: Created by author.

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**EXHIBIT 3
Context-Specific Examples for CCHD Screening**

Context	Available Resources	Suggested reading (if applicable)
1. Indigenous infant born in Northern community at nursing station; no road access.	<ul style="list-style-type: none"> • Midwife (performed birth & pulse oximetry) • Nursing station with two on-staff nurses; 24/7 availability • Traditional healers & community elders • Emergency transport 	Minore, B., & Boone, M. (2002). Realizing potential: improving interdisciplinary professional/paraprofessional health care teams in Canada's northern aboriginal communities through education. <i>Journal of Interdisciplinary Care</i> , 16(2), 139-147.
2. Infant born at Mount Sinai Hospital, Toronto.	<ul style="list-style-type: none"> • Midwife (performed birth & pulse oximetry) • Primary care physician, or obstetrician associated with case • Specialists (neonatology, pediatrics, pediatric cardiology) • Sonographer specialized in pediatric heart echocardiograms 	Posthumus, A. G., Scholmerich, V. L., Waelput, A. J., Vos, A. A., De Jong-Potjer, L. C., Bakker, R., Bonsel, G. J., Groenewegen, P., Steegers, E. A., & Denktas, S. (2013). Bridging between professionals in perinatal care: towards shared care in the Netherlands. <i>Maternal and Child Health Journal</i> , 17(10), 1981-1989.
3. Home birth in Ottawa.	<ul style="list-style-type: none"> • Midwife (performed birth & pulse oximetry) • Ottawa hospitals (e.g. Children's Hospital of Eastern Ontario, with specialty care in neonatology, pediatric cardiology, & pediatrics; available heart echocardiography) 	Narayan, I. C., Blom, N. A., Verhart, M. S., Smit, M., Posthumus, F., van den Broek, A. J., Havers, H., Haak, M. C., & te Pas, A. B. (2015). Adapted protocol for pulse oximetry screening for congenital heart defects in a country with homebirths. <i>European Journal of Pediatrics</i> , 174(1), 129-132.
4. Infant born in community hospital.	<ul style="list-style-type: none"> • Nurse as submitter • Primary care physician (performed birth) • Cardiologist on call at community hospital • Tertiary care hospital 200 km away, with pediatric cardiology and heart echocardiogram services 	Psaila, K., Schmied, V., Fowler, C., & Kruske, S. (2015). Interdisciplinary collaboration of transition of care: perspective of child and family health nurses and midwives. <i>Journal of Clinical Nursing</i> , 24, 160-172.

Source: Created by author.

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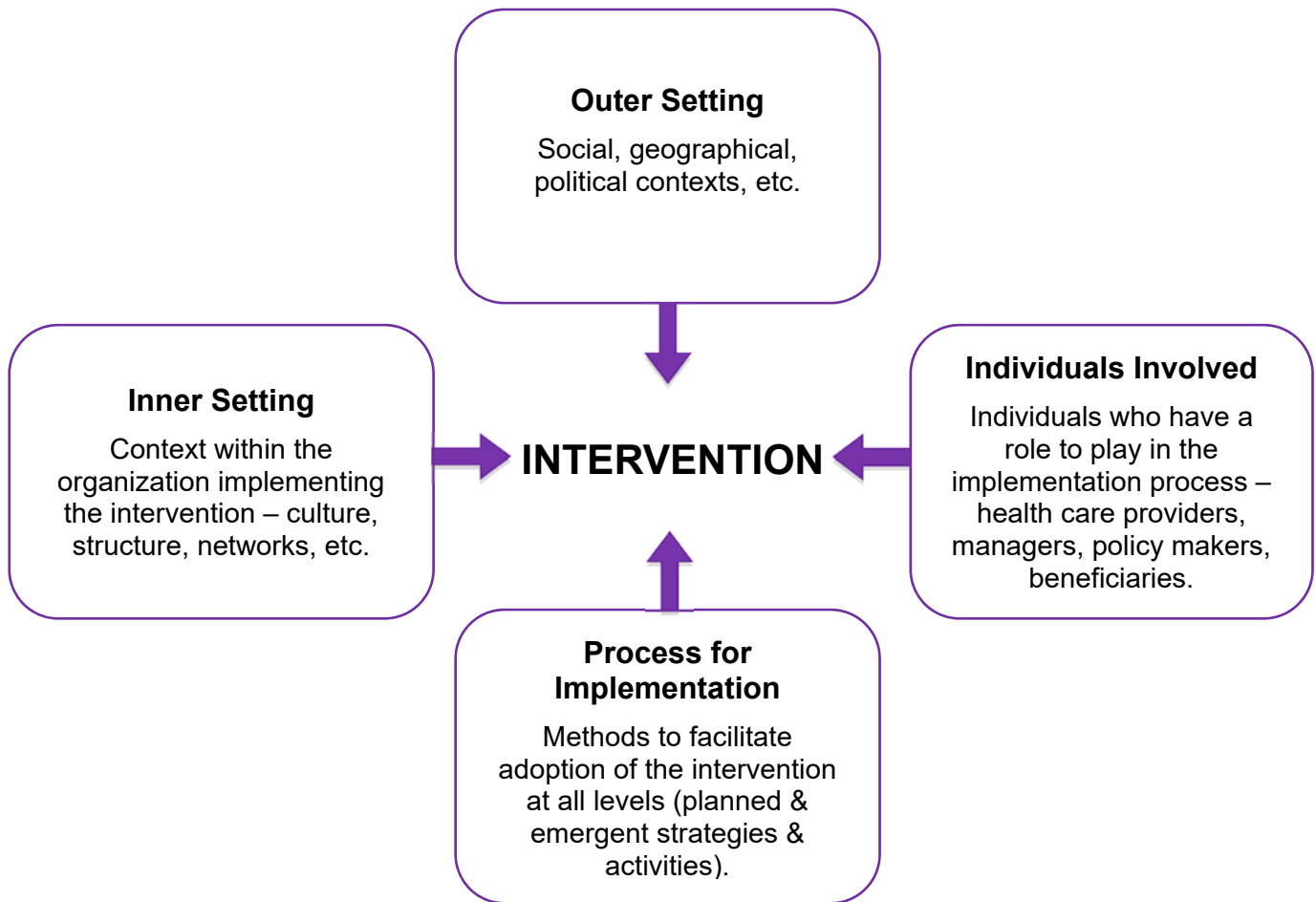
**EXHIBIT 4
Facilitators and Barriers to Interdisciplinary Collaboration**

Facilitators	Barriers
<ul style="list-style-type: none"> • Good leadership at all levels • Shared vision, values, and belief in the value of collaboration and coordinated approach to care • Trust and mutual support • Shared decision-making • Patient and user focused • Effective internal communication • Open and participative style • Strong external partnerships • Routine feedback on performance • Education and professional development • Clear understanding of & respect for team members' roles and responsibilities • Accountability amongst providers • Adequate resources available & accessible 	<ul style="list-style-type: none"> • Need for long-term commitment by all levels within an organization • The need to redefine roles and understand resistance to change • Tension, competition, and role confusion • The need to build clients' awareness and understanding of interdisciplinary approaches • The need for a common understanding of organizational structures and processes • Inadequate resources to support the team • The need to commit to ongoing evaluation and adjustment of the team approach • Difficult to identify best practices because of variation and measured outcome variables in interdisciplinary projects

Source: Nolte & Tremblay, 2005.

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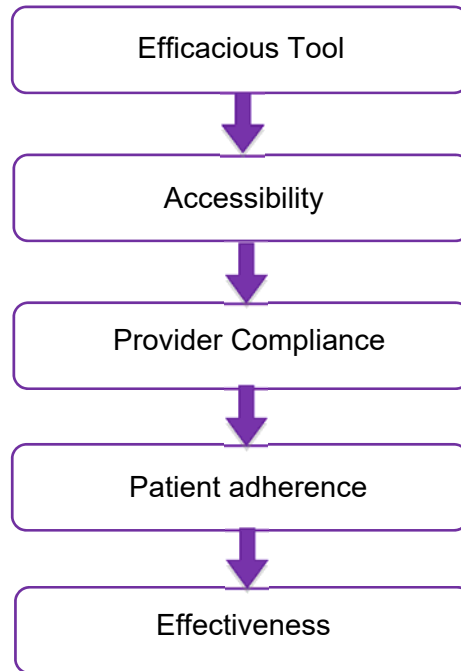
EXHIBIT 5 The Interacting Domains in Implementation Research



Source: WHO, 2014.

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EXHIBIT 6 Influence of Health System Factors on Intervention Effectiveness and Impact



From source: “In order for a proven and efficacious tool to be effective, it must be accessible to the target group, health care providers must comply with the relevant policies, and patients must adhere to the information on use of the tool. However, there are several challenges including inequities that affect the ability of various stakeholders to use the tool as expected eventually rendering the tool ineffective.”

Source: WHO, 2014.

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INSTRUCTOR GUIDANCE

United Hearts: Fostering Interdisciplinary Collaboration for the Detection of Critical Heart Defects in Newborns

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Jennifer Milburn, BSc, MHA (Operations Director, Newborn Screening Ontario)
Ava John-Baptiste, PhD (Assistant Professor, Western University)

BACKGROUND

Newborn Screening Ontario (NSO) prepares to implement screening for critical congenital heart defects (CCHDs) in all newborns born in Ontario. Janet Marcadier, a genetic counsellor at NSO, recognizes the particular challenges of implementing a point-of-care newborn screening test that will be performed by submitters (nurses, midwives) across the province. The other 29 conditions screened for by NSO do not involve a point-of-care test but rather testing is done in the NSO laboratory. While standardization for a provincial program is important, there are many contextual factors that will impact CCHD screening implementation at each specific birth site. Interdisciplinary collaboration among health care providers will be essential in implementation. How could NSO foster interdisciplinary collaboration through implementation planning? NSO needs to consider how primary care teams are often dynamic and include different health care providers depending on the needs of the patient. Would interdisciplinary collaboration help to ensure screening compliance among submitters? By applying concepts of implementation research, context-specific protocols can be developed for interdisciplinary teams at different birth sites in Ontario.

OBJECTIVES

1. Develop a context-specific implementation plan for CCHD newborn screening.
2. Identify contextual factors that can impact interdisciplinary collaboration.
3. Apply implementation research strategies to inform implementation planning for evidence-based CCHD screening and fostering interdisciplinary collaboration.
4. Understand the usability of the interdisciplinary collaboration framework when planning, implementing, and evaluating a newborn screening program in Ontario.
5. Discuss roles and responsibilities of health care providers in the interdisciplinary model for CCHD screening.

DISCUSSION QUESTIONS

1. How did your team define “interdisciplinary collaboration”?
 - a. Was it difficult to come to a consensus?
2. Do you think interdisciplinary collaboration has a role in the future of public health?
 - a. If yes, do you think training of health care providers should be changed and what changes should be made?
3. How did your team incorporate implementation research into planning?
4. What were the three implementation outcome variables that your team identified to be most important in implementation? Provide details about one of the three implementation outcome variables.
5. Should provincial newborn screening plans be designed for many different contexts or should NSO take a standardized approach to implement CCHD screening?

United Hearts: Fostering Interdisciplinary Collaboration for the Detection of Critical Heart Defects in Newborns

6. From your team's particular context, is provincial newborn screening for CCHD an equitable health intervention?

KEYWORDS

Newborn health; screening; interdisciplinary; collaboration; implementation research.

FACULTY CASES

CASE 12

Policy Meets Practice – People Who Inject Drugs (PWID)

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Jacob J. Shelley, LLM, SJD (c) (Assistant Professor, Western University)

INTRODUCTION

Dr. Silverman was heading into a family meeting, and he knew that he was going to be faced with a very difficult situation. The patient in question, known as Mr. W, was extremely ill, had very few resources, no support system, and struggled with drug addiction. The patient had been admitted to the hospital several days earlier because of an infection in his heart, specifically infective endocarditis (IE). The infection, resulting from the patient's drug use, required the administration of intravenous (IV) antibiotics. The patient was deemed ready to be discharged, and hospital management was pushing for immediate discharge. In order for a smooth transition out of the hospital, services were required to allow the patient to receive antibiotics at home. Dr. Silverman knew that the patient had difficulties securing housing and, immediately prior to his hospital admission, Mr. W had been in and out of homelessness. He invited Julian Morrison, the Managing Director at London CARES, to come to a meeting to discuss Mr. W's housing options. Dr. Silverman was also aware that Mr. W was at the beginning of what could be weeks and months of required care and that a secure home environment was essential. In anticipation of the meeting with the patient, Dr. Silverman had been in close consultation with Dr. Newman, a health researcher studying injection drug users and their related health complications. They previously had the opportunity to discuss different aspects of Mr. W's case, and he hoped that Dr. Newman's insight would help them decide on a suitable course of action today.

Dr. Silverman hoped there would be a better option; one that the health system had not yet considered.

BACKGROUND

Drug-related health complications were particularly pressing and challenging issues for the City of London; estimates indicated that there was a high prevalence of addiction to narcotics among residents in the city, when compared to other jurisdictions (Middlesex-London Health Unit, 2014). Intravenous drug use was on the rise, with narcotics being the most commonly injected drugs, and a higher proportion of injection drug users in London report sharing injection equipment in comparison to national levels (Middlesex-London Health Unit, 2012). In addition to blood-borne viral infections, such as HIV and Hepatitis C and B, injection drug users can also contract bacteria, which can result in infective endocarditis (IE). Left untreated, IE can result in life-threatening complications. Individuals with IE are typically treated with antibiotics administered through IV. Patients receiving IV antibiotics do not typically need to stay in the hospital and are often sent home.

In many jurisdictions, patients with IE are treated through home care; in London, the South West Community Care Access Centre (CCAC) is responsible for delivering home care. As part of the Ministry of Health and Long-Term Care's mandate, the CCAC is to provide equitable and consistent care. While many plans are focused on the needs of the health care provider, the CCAC has made a shift towards making plans more patient and family centered. Accordingly,

the CCAC serves vulnerable homeless population groups differently. The CCAC typically operates through referral requests to help patients receive care in the home. Unfortunately, there is often no mechanism to locate homeless individuals, since referrals from hospitals only include a name, sometimes a health card, but often lack any other contact information. In addressing this problem, the CCAC strives to collaborate with service providers to treat these populations wherever they live, regardless of whether or not they are homeless. Since these patients are medically and socially complex, they require an alternate level of care and need attention when they are unable to be served in hospitals. Together, physicians, the CCAC, and the rest of a patient's care team work to create a care plan that is in the patient's best interest.

When a patient has IE and requires antibiotics through IV, the standard treatment options often considered are:

1. a patient is sent home with a peripherally inserted central catheter (a 'PICC'-line) and administers the antibiotic with the assistance of a CCAC nurse;
2. a patient is hospitalized and receives care and IV antibiotics in the hospital; or,
3. a patient receives no treatment.

Mr. W's care team was perplexed by their options. When given a PICC-line in the first scenario, patients who are known to be intravenous drug users are essentially given a new method for injecting drugs – "a highway for illicit drugs". In addition to the risk a patient may face from injecting drugs through the PICC line, there is danger of developing another infection if the needles used are contaminated (Glauser, Petch & Tierney, 2016). The second standard treatment option intends to avoid these risks. In this scenario, a patient would be hospitalized for four to six weeks at a significant cost to the health care system. In this scenario, the patient and their health care providers often become frustrated. Patients can become disruptive, abusive, noncompliant, and often will choose to leave the hospital against medical advice. Providers are often equally frustrated by patient behaviour and by the reality that a hospital bed is required. In the third standard treatment option, a patient is sent home without proper treatment, and will become sicker and often die.

City of London

London is home to an increasing population of over 365,000 residents. London is the largest city in Southwestern Ontario with land areas of 2,656 square kilometers, which can be divided into Central, North East, North West, South East and South West London (Statistics Canada, 2011). There are numerous social determinants of health associated with drug use, including income, age, sex, education, unemployment, and housing.

In 2011, London's population was 48% male and 52% female. Children ages 0-14 years old comprised 16%, ages 15-25 years old constituted 15%, the working age (25-64 years old) composed 54% of the population, and lastly, seniors ages 65+ constituted 15% of London's population.

London's unemployment rate was at 9%, and the city's top three employment industries were Health Care and Social Assistance (13.8%), Retail Trade (11.7%), and Manufacturing (10.5%) (City of London, 2011a). In 2011, 25% of London residents aged 25 and older had attained a high school diploma or equivalent, which was on par with the 24% of Ontarians who did as well. Sixty-six percent of both the London and the Ontario populations received a post-secondary certificate, diploma, or degree; the most common areas of post-secondary study reported were business, management, and public administration (City of London, 2011b).

Low-income rates in London are higher than rates in Ontario and Canada. In 2006, 11.8% of residents had incomes below the Low-Income Cut Off (LICO), and 14.6% of children and youth lived with families whose income fell below the LICO level. On average, 89% of the 360 emergency shelter beds were used each night in 2009 in London. In 2006, 14% of households were in core housing need, which is defined as households that are unable to afford shelter that meets adequacy, suitability, and affordability norms (City of London, 2011c).

London Health Sciences Centre

The London Health Sciences Centre (LHSC) consists of six multi-site health facilities in London, Ontario. In 2011/2012, there were 153,784 emergency visits, 972 hospital beds, and 14,139 employees providing health care service to the 47,903 patients who were admitted for an average stay of 7.1 days among the sites (London Health Sciences Centre, 2012).

The community strategy at LHSC is based on four aspects: (i) harm reduction, (ii) prescription, (iii) enforcement, and (iv) prevention. Harm reduction strategies related to drug use include physicians informing their patients about the risks and harms of sharing needles, as well as other equipment involved in drug use, such as spoons, cookers or washes.

Supports in the Community: London CARES

London CARES has a mandate to end homelessness in London. In 2011, London CARES shifted from supporting people trying to survive on the streets to a Housing-First approach. The new aim was to assist people experiencing chronic homelessness, the effects of poverty, and persistent concurrent disorders in obtaining immediate access to permanent housing of their choice. London CARES continues to offer 24/7 street outreach support to connect with individuals experiencing homelessness, who may not be accessing other existing services in a meaningful way. By setting someone up with a home base from which to address complex health issues, London CARES hopes to break the cycle of homelessness and support individuals in their home which can lead to improved health outcomes.

The London Homeless Coalition

The London Homeless Coalition Memorial Committee monitors how many lives are lost to homelessness, which is a very complex problem. In recent years, there has been an increase in the number of deaths as a result of infective endocarditis, especially in youth.

IV Drug Use Overview: Iatrogenesis

The history of injectable drug use and the prevalence of addiction to narcotics can be linked to the abundance of physicians overprescribing narcotics for pain management during the 1990s and early 2000s. This began with large pharmaceutical corporations who delivered false claims, such as “as long as you’re in pain, you can’t get addicted” and “there is no ceiling on opioids”. As a result of this messaging and relying on the representations from large pharmaceutical companies that there were no adverse effects or potential for addiction, many physicians overprescribed narcotics with dangerous consequence to their patients (Van Zee, 2009). This worsened due to the inability of physicians to manage patients’ behaviours and their lack of knowledge about drug use (Silversides, 2009). An additional complexity is that patients believed that if they used up prescribed dosages of drugs, the smart choice was to obtain alternative drugs off the street, because it avoided waiting for new prescriptions and losing tolerance.

The three most common drugs injected intravenously have been identified as opioids (such as oxycodone, morphine, and codeine), crystal meth, and Ritalin. Opioids and Ritalin are both iatrogenic drugs that the health care system is responsible for providing to the public (National Institute on Drug Abuse, 2016). This meant that the health care system has shared a role in the

current overdose situation, as doctors have overprescribed opioids and Ritalin for pain management.

People Who Inject Drugs (PWID)

The rate of people who inject drugs (PWID) is steadily increasing. There are numerous reasons why people choose to inject drugs as opposed to administering substances through less invasive methods, such as swallowing, snorting, or smoking. These reasons may be related to sociocultural factors or simply related to drug types. The shift in drug consumption methods can be attributed to several factors, including drug dependence, and the belief that injecting drugs provides a more rapid and effective method to obtain desired drug effects (Haber, Day, & Farrell, 2015). Witnessing other individuals injecting drugs and having family or friends who inject drugs are also cited as reasons for choosing injection as the preferred mode of delivery (Haber, Day, & Farrell, 2015).

Currently, the increase in prevalence of PWID has resulted in an overall increase in drug overdoses. As a result, many physicians are placed in a difficult position. Physicians may decide to stop providing analgesic treatment, however, this may result in patients succumbing to an even worse situation. Faced with withdrawal, patients may become involved in “street” activities, crime, and go on to use alternative drugs that are more inexpensive, dangerous, and illegal (Fields, 2011). In contrast, if physicians continue prescribing narcotics after an overdose, they may face risk of litigation from families and affiliated colleges.

IV Drug Use in the City of London

In 2012, a survey of PWID funded by the Public Health Agency of Canada (PHAC) was conducted in Middlesex-London. Of the 204 respondents, 73% were male and 27% were female, with an average age of 36 years old. Fifty-three percent of respondents had less than high school education and 44% of respondents had a monthly income of less than \$1000. Fifty-seven percent of respondents had an unstable housing situation and 20% had been incarcerated in the previous six months (Middlesex-London Health Unit, 2012).

The survey also found that in London, 47% of respondents injected alone, males were more likely than females to inject alone, and women were more likely to inject with a regular sex partner. Prescription drugs were the principal drugs used for injection, specifically OxyContin (a type of opioid), which was used by 70% of respondents, and Ritalin, which was used by 60% of respondents (crystal meth was used by 68% of respondents). In terms of injection and risk behaviors, 27% of PWID lent needles to others, and 20% had borrowed needles in the previous six months (Middlesex-London Health Unit, 2012).

Endocarditis

While the potential to overdose poses an evident danger to the lives of PWID, infections are a major cause of death for drug users and are the most severe complication associated with IV drug use. Specifically, bacterial infections are frequently the result of improper preparation and use of prescribed medication. Medication prescribed in tablet form is to be ingested orally to allow stomach acids to kill any bacteria present. When these drugs are taken intravenously, there is a risk of contaminating the drug (e.g., equipment used to heat and prepare the drug is not sterile, or skin is not sterilized before injection). After bacteria enters the body, infection can develop in various organs, including the lungs, bones, joints, brain, spinal cord, and heart.

When the heart is affected, IE can result. Endocarditis is defined as the infection and inflammation of the inner lining of the endocardium of the heart. Right-sided endocarditis is

extremely common in IV drug users, as non-sterile injections into the venous system usually affect the tricuspid valve (Moss & Munt, 2003).

Common complaints of IV drug users with IE are dyspnea, coughing, and chest pain; as well, IV drug users are more likely to develop pneumonia or septic pulmonary emboli (Moss & Munt, 2003).

IE is typically diagnosed using chest x-rays, blood cultures, electrocardiogram, or echocardiographic techniques. The Duke diagnostic criteria are usually used to identify IE as they combine clinical, microbiologic, pathologic, and echocardiographic characteristics. A definitive clinical diagnosis of IE is met if the patient exhibits either two major criteria, one major criterion and three minor criteria, or five minor criteria (Moss & Munt, 2003). (See Exhibit 1 for more information on IE and a list of criteria.)

Generally, treatment for IE includes a high-dose of IV antibiotics that are prescribed for two to eight weeks, dependent on the bacteria and its susceptibility (Huckell, n.d.). Treatment for IV drug users is often more complicated due to the likelihood they will check out of the hospital before treatment is complete or abuse IV access lines. Therefore, a short IV treatment course or oral therapy is usually recommended. In more severe cases, surgery that may include valve replacement or repair may be recommended.

Prognosis for IE mainly depends on whether or not complications develop. However, if left untreated, IE is fatal. Mortality increases with age, as well for those who have an infection with a resistant organism or who delay pursuing treatment (Huckell, n.d.).

Having shared and exchanged their respective knowledge about the situation, the care team needed to reexamine the treatment options for Mr. W.

MEETING OF THE CARE TEAM

Dr. Michael Silverman – PWID Management

Dr. Michael Silverman, Chief of Infectious Diseases at London Health Sciences Centre and St. Joseph's Health Care London.

Dr. Liam Newman

Dr. Liam Newman is an attending physician at London Health Sciences Centre and St. Joseph's Health Care London.

Dr. Sharon Koivu

Dr. Sharon Koivu has been a physician of over 30 years and is the Site Chief for London Health Sciences Centre.

Donna Ladouceur – Community Care Access Centre

Donna Ladouceur is the Vice President of Patient Care at the Southwest CCAC.

Julian Morrison – London CAREs

Julian Morrison is the Managing Director for London CAREs, which is a community-based housing-first service that strives to improve the housing and health situations of homeless individuals.

CARE OPTIONS

Option One: Care in the Home

“So in Option One, endocarditis is primarily treated in an out-patient setting, where a nurse can visit the patient once a day to administer antibiotics through a PICC line?” Julian asked.

“Right,” Dr. Silverman confirmed. “It’s also recommended that nurses themselves subcutaneously inject the opioid rather than having the patient do it themselves, as there is a risk that the patient will sell their prescribed opioids or overuse the drugs themselves.”

Dr. Newman asked why the hospital could not just give the patient an oral medication. Dr. Silverman explained that opioid medication is generally not prescribed in these situations to avoid the risk of the patients selling the medication when they leave the hospital.

Having established that antibiotics administered through IV was the most likely and most appropriate course of action, Dr. Silverman noted this approach was also the most difficult: “There are many confounding complications arising from treatment associated with the use of PICCs,” he explained. “Often times, the PICCs will be a source of secondary infection. Meanwhile, nurses don’t like maintaining the PICCs when they know the patients are using it for their own illegal drug use.”

Julian remarked that, “Also, patients may not have a suitable housing condition, while community shelters tend to avoid accommodating people who inject drugs.”

Dr. Silverman chimed in, noting: “This, in effect, creates a population of homeless drug-addicted patients with PICC lines.”

“Isn’t this the role for community-care associations?” asked Julian.

Community Care Access Centres

CCACs have transformed health care. They facilitate more than three million home visits a year to patients that would otherwise be in a hospital’s Intensive Care Unit. The majority of the patients that CCACs serve can be considered very complex. CCACs do not provide direct care, but services are provided 24/7 by contracted service providers and health professionals. The CCAC’s care coordinators do, however, direct 17 nurse practitioners. Overall 15,000 referrals are derived from the LHSC for home care, of which, 100 are for IV therapy in the home and 10-12 are patients with IV drug use.

Two legislative acts govern the functioning of the CCAC including the *Ministry of Health and Long-Term Care Act* and the *Community Care Access Corporations Act, 2001*. The acts mandate that patients have a health card; however, the CCAC will often provide care to individuals without one, using charitable donations. The CCAC is obligated to provide a safe environment for care, although this is often controversial.

“The community organizations do great work,” Dr. Silverman noted. However, he explained that there are various goals that need to be accomplished in order for the CCAC and others to best serve these vulnerable populations. He continued, “It is important that a care coordinator is involved and connected with these patients early on during their care while registered nurses and personal support workers need to be involved and educated about how to work with such populations. Unfortunately, there are difficulties that must be addressed as well, including tight financial budgets, withdrawing care providers, and nurse safety without police resources available.”

“Safety of nurses? Police?” Julian asked, with a puzzled look.

Seeing the look of confusion on Julian’s face, Dr. Newman explained that, there were concerns that requiring nurses to administer IV drugs to known drug users in the drug user’s home might put the nurse in a risky situation. “Some have even suggested that police should escort the nurses – especially given that other drug users, not necessarily the patient, might pose a risk. There simply are not sufficient resources for this, however,” Dr. Newman continued.

“On the plus side,” Dr. Newman added thoughtfully, “there are various actions which can be taken to improve the management of injection complications. First and foremost, the use of safe injection sites can be promoted as a place to access sanitary water, equipment, antibiotics, and nurses. As well, responsibility and liability needs to be clarified for the health care providers and community care providers – and even manufacturers of narcotics – to ensure that patients are using equipment and medication properly and safely. Additionally, a model can be implemented in which a police officer is present in such scenarios to promote the safety of the patient and the health care professional. Finally, legislation and policy can potentially be established to protect physicians and hospitals from lawsuits when patients misuse narcotics.”

Dr. Silverman also pointed out that he had recently heard a talk from the Vice President of Patient Care at the Southwest CCAC. “They are aware of the problems, and they are committed to helping address them. However, there is the challenge that the patient in question has no fixed address,” Dr. Silverman reminded the group. “Even if home care was appropriate for this patient, there is no home to speak of.”

“Let’s discuss another treatment option then,” Dr. Newman decided, “we can always come back to this idea later.”

Dr. Silverman nodded.

Option Two: Treatment in Hospital

“Can’t the patient just be admitted to the hospital?” Julian inquired.

Dr. Newman recounted to Julian the conversation the care team had been having about the challenges with hospital admittances.

“It’s just not that simple,” he concluded.

“The good news,” Dr. Silverman observed, “is that LHSC is aware of the problem and has really adopted a harm reduction focus.”

Dr. Silverman pointed out that treatment in a hospital was possible, but not ideal: “As you can understand, this is also a challenging option for hospitals too. There’s often pressure to discharge patients quickly, as a result of bed shortages and financial penalties for an excessively long length of stay. Hospitals are also especially tasked by drug addicts suffering from endocarditis.” He continued to explain that IE accounted for approximately 2000 days of hospital stays, with 12% mortality in hospital and 14% mortality after discharge. “Meanwhile,” he continued, “there remains a low patient follow-up rate with physicians who prescribed antibiotics to persons known to inject drugs – less than 20%, if you can believe it!”

Option Three: No Treatment

The last option is to provide no treatment for PWID suffering from IE given the challenges.

“What happens if a patient doesn’t get treatment?” asked Julian.

Dr. Silverman shuffled in his seat, and pushed his glasses up his nose. “A 100% mortality rate,” he quietly responded.

NEXT STEPS – ACTION PLAN

How should the care team proceed with treatment for the endocarditis patient? Taking into account all of the pros and cons, should they proceed with treatment in the hospital, at home, or no treatment at all? What about other options not considered? Are there options that address more than just the infection and consider the addiction problem and the psychological problems that may be accompanying or underlying the addiction?

**EXHIBIT 1
Symptoms of IE**

Symptoms of IE include fever, rigors, night sweats, anorexia, weight loss, and arthralgia. In terms of cardiac signs, the manifestations of a new heart murmur or alteration in an existing murmur are both indicators of IE. Skin lesions associated with IE may include petechiae, splinter hemorrhages, Osler’s nodes, and Janeway lesions, as well as Roth spots (retinal hemorrhages) (Ashley & Niebauer, 2004). Neurological symptoms include embolic stroke with focal neurological deficits, as well as intracerebral hemorrhage and multiple micro abscesses (Brusch, 2015).

Major blood culture criteria for IE	<ul style="list-style-type: none"> • Two blood cultures positive for organisms typically found in patients with IE; • Blood cultures persistently positive for one of these organisms from cultures drawn more than 12 hours apart; • Three or more separate blood cultures drawn at least one hour apart.
Major echocardiographic criteria for IE	<ul style="list-style-type: none"> • Echocardiogram positive for IE is documented by an oscillating intracardiac mass on a valve or on supporting structures, in the path of regurgitant jets, or on implanted material in the absence of an alternative anatomic explanation; • Myocardial abscess; • Development of partial dehiscence of a prosthetic valve; • New-onset valvular regurgitation.
Minor criteria for IE	<ul style="list-style-type: none"> • Predisposing heart condition or intravenous drug use; • Fever of 38°C (100.4°F) or higher; • Vascular phenomenon, including major arterial emboli, septic pulmonary infarcts, mycotic aneurysm, intracranial hemorrhage, conjunctival hemorrhage, or Janeway lesions; • Immunologic phenomena, such as glomerulonephritis, Osler nodes, Roth spots, and rheumatoid factor; • Positive blood culture results not meeting major criteria or serologic evidence of active infection with an organism consistent with IE; • Echocardiogram results consistent with IE but not meeting major echocardiographic criteria.

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LEGISLATION

Community Care Access Corporations Act, 2001, SO 2001, c 33.

Ministry of Health and Long-Term Care Act, RSO 1990, c M.26.

INSTRUCTOR GUIDANCE

Policy Meets Practice – People Who Inject Drugs (PWID)

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BACKGROUND

Dr. Silverman is the Chief of Infectious Diseases at London Health Sciences Centre (LHSC) and St. Joseph's Health Care in London, Ontario. He is concerned about the increasing prevalence of people who inject drugs (PWID) in London, and the risk to PWID of bacterial infections due to contamination (e.g., improperly or unsterilized injection equipment, skin not being sterilized before injection). Of primary concern is the risk of infective endocarditis (IE), an infection in a patient's heart. Treatment for IE entails antibiotics administered through the intravenous (IV) route. IE is generally treated through home care; in London, the South West Community Care Access Centre (CCAC) is responsible for delivering home care. To treat IE at home, a patient would need a peripherally inserted central catheter (a PICC-line) and assistance from a CCAC nurse to administer the antibiotics. This option, however, is not viable for some patients, including those who fall under the category of PWID or who may not have a fixed address. In the case of PWID, the PICC-line, in effect, becomes a "highway" for injecting other drugs; in instances where a patient may not have secure housing or be homeless, the CCAC nurse may not be able to track down the individual. When a patient in one of these situations is being treated for IE, it puts the care team in a difficult position. The alternatives to home care are hospital admittance or no treatment at all, neither of which are ideal solutions. Dr. Silverman is currently in this position, as he must decide on a treatment plan for Mr. W., a patient who has IE, has struggled with drug addiction (the likely cause of his IE), and who does not have stable housing. In making his decision, Dr. Silverman has included on Mr. W.'s care team two other physicians from LHSC, a representative from the CCAC, and the managing director of London CAREs, a community-based housing-first organization. The care team must determine the best treatment plan for Mr. W.

OBJECTIVES

1. Identify the role of key stakeholders in health care decision-making.
2. Discuss and identify barriers for vulnerable populations (e.g., PWID, homeless individuals) to accessing health services.
3. Understand the concept and importance of inter-professional collaboration for health care delivery.
4. Identify the key stakeholders and effectively engage with them to determine different barriers to delivering home care to vulnerable populations
5. Discuss and identify how competing priorities (e.g., safety of nurses, efficacy of treatment, financial impact) influence health care treatment decisions.
6. Understand the role of community organizations in the prevention, treatment, and management of health care issues.

DISCUSSION QUESTIONS

1. What is the main problem or issue discussed in the case?
2. What role do family meetings have in health care delivery?

Policy Meets Practice – People Who Inject Drugs (PWID)

3. Who is on the care team and what are their roles? Are there any notable absences on the care team? Who else should be on it?
4. What are some factors or reasons that make treating PWID for IE especially difficult?
5. What is the role of collaboration or inter-professional collaboration in health care delivery? Do you think it is important? Why?
6. Who is responsible for ensuring a positive outcome for patients receiving home care?
7. What are some key challenges or barriers to incorporating community organizations in treatment decisions?
8. What are some of the factors that might be contributing to the increasing problem of drug addiction, and specifically the injection of drugs, in London? Who should be involved in helping to identify solutions?
9. What are the legal and ethical obligations of the care team? What about the CCAC nurse? The community organization?
10. How important is it to consider the financial impact of different treatment options?

KEYWORDS

People who inject drugs; endocarditis; homelessness; home care; treatment; health care delivery.

INTEGRATIVE WORKSHOPS

INTEGRATIVE WORKSHOPS

As described in the Preface to this casebook, the MPH Program holds integrative workshops three times a year for its students. These day-long workshops present students with an opportunity to bring the knowledge they have gained in the Program to bear on a topical issue in public health. The following section provides an outline of each workshop held during 2015/16, with a view to sharing examples for others interested in this type of approach to teaching.

INTEGRATIVE WORKSHOP #1 MIGRANT WORKERS' HEALTH FALL 2015

Speakers

Michelle Tew, RN BScN DOHS COHN(C), *Occupational Health Nurse*
Occupational Health Clinics for Ontario Workers

Eduardo Huesca MSc, *Coordinator, Migrant Farm Worker Program*
Occupational Health Clinics for Ontario Workers

Laura Comiskey, *Training & Language Services Coordinator*
Across Languages, Translation and Interpretation Service

Derry McKeever, *Migrant Worker Advocate*
Former Seasonal Worker

Scenario

Your learning team will assume the role of a consultancy that is applying for a contract to develop a research program into migrant workers' health with the Devonshire-on-Tyme county government. Organizations that serve the migrant workers consistently identify the need for engaging the community in migrant workers' health. The majority of county residents are not attuned to migrant workers' needs and view these individuals with mistrust and sometimes disdain. The resulting stigma only serves to enhance the difficulties faced by this population in accessing the health care services to which they are legally entitled.

Task 1:

Create a concept map depicting the stigma associated with migrant health workers and how this impacts their overall health. Identify research priorities on the health of migrant workers.

Your learning team will be addressing a town hall meeting. Your task is to present the following to those assembled:

- a) A concept map. (2 minutes)
- b) Your top three ranked research priorities to improve the health of migrant workers. (3 minutes)

Please upload a picture of your concept map and a document of your top three ranked priorities to Assignments in the MPH 9015Y OWL site by 11 a.m.

There will be 5 minutes of questions and feedback following each presentation.

Integrative Workshops

Task 2:

Your learning team will be partnering with county representatives and researchers at Western University. Through this initiative the organization Occupational Health Clinics for Ontario Workers (OHCOW) will award up to \$150,000 for a successful proposal. Your task is to propose a study using qualitative, quantitative or mixed methodology. You may propose primary data collection or a secondary analysis based on existing datasets. We ask that you present the following components:

- a) Goals and Objectives (1 minute)
- b) Methods (3 minutes)
- c) Significance – why should this project be funded? (1 minute)

The following criteria that will be considered by the reviewers:

Are the objectives linked to the methods?
 Is community engagement addressed?
 Is the proposal feasible?

There will be 5 minutes of questions and feedback following each presentation. Please note that all time limits will be strictly enforced.

Schedule

8:00-8:30	Arrival – tea and coffee	
8:30-8:55	Guest Speaker: Michelle Tew, RN BScN DOHS COHN(C)	Classroom
8:55-9:20	Guest Speaker: Eduardo Huesca, MSc	
9:20-9:45	Guest Speaker: Laura Comiskey	
9:45-10:10	Guest Speaker: Derry McKeever	
10:10-10:25	Break	
10:25-11:00	Instructions and prepare Deliverable 1	LT Rooms
11:00-12:20	8 10-minute presentations and feedback	Classroom
12:20-12:30	Instructions for Deliverable 2	LT Rooms
12:30-1:15	Lunch	
1:15-2:55	Prepare Deliverable 2	LT Rooms
2:55-3:10	Break	
3:10-4:30	8 10-minute presentations and feedback	Classroom

INTEGRATIVE WORKSHOP #2 POLICY MEETS PRACTICE: IV DRUG USERS WINTER 2016

Speakers

Mr. Brandon Agnew, *Managing Director*
London CARES

Ms. Sherine Fahmy, MPH, *Health Policy Analyst*
College of Family Physicians of Canada

Dr. Sharon Koivu, MD, MCFP, *Site Chief*
London Health Sciences Centre (University Hospital)

Ms. Donna Ladouceur, *Vice President, Patient Care*
South West Community Care Access Centre

Dr. Michael Silverman, MD, FRCP, FACP, AAHIVMed,

- *Chair of Infectious Diseases*, Schulich School of Medicine & Dentistry, Western University
- *Chief of Infectious Diseases*, London Health Sciences Centre & St. Joseph's Health Care, London

Background

The City of London has a serious drug problem with high rates of addiction. Intravenous drug use in particular is on the rise. Narcotics are the most commonly injected drugs, and a higher proportion of injection drug users in London report sharing injection equipment in comparison to national levels.¹ In addition to blood-borne viral infections such as HIV and Hepatitis C and B, injection drug users can also contract bacteria which can result in infective endocarditis (IE). Left untreated, IE can result in life-threatening complications. Individuals with IE are typically hospitalized where the treatment for endocarditis is antibiotics administered intravenously (IV). Patients receiving IV antibiotics do not typically need to stay in hospital, and are often sent home.

In many jurisdictions, patients with endocarditis are treated through home care. In London, the South West Community Care Access Centre (CCAC) is responsible for delivering home care. The CCAC receives referral requests to help these patients. Together, physicians, the CCAC and the rest of the care team figure out the best course of action:

1. A patient is sent home with a peripherally inserted central catheter (a 'PICC'-line) and administers the antibiotic with the assistance of a nurse.
2. A patient is hospitalized and receives care in the hospital.
3. A patient receives no treatment.

When given a PICC-line in the first scenario, the patient (who is a known intravenous drug user) now has a new method for injecting drugs. This behaviour can be dangerous in the home care setting of the first scenario. In the second scenario, a patient will be hospitalized for 4-6 weeks, at a significant cost to the health care system. Additionally, it is often the case that both the

¹ Middlesex-London Health Unit, *A Profile of the People Who Inject Drugs in London, Ontario (November 2013)*: https://www.google.ca/?gws_rd=ssl#q=A+Profile+of+the+People+Who+Inject+Drugs+in+London%2C+Ontario+

Integrative Workshops

patient and his/her health care providers become frustrated with this scenario; patients can become disruptive, abusive, and noncompliant and often will choose to leave the hospital against medical advice or “AMA”. In the third scenario, the patient is sent home; however without proper treatment, many patients will die.

Purpose

The purpose of this workshop is to introduce you to the concepts of policy development, analysis, and implementation. You will be using the skills and knowledge you have gained in the MPH Program to analyze a situation that involves the care of injection drug users in London, Ontario. The following objectives will be met:

1. Apply knowledge gained from MPH coursework in analyzing health care issues (for example, effectiveness and cost-effectiveness of models of delivering home care for different patient populations), particularly from a policy perspective.
2. Develop skills in producing plans to influence policy.
3. Gain an understanding of multiple stakeholder perspectives, roles, and responses with regard to health care dilemmas.

Preparations

In your learning teams prepare three questions that you would like to pose to our speakers regarding the integrative workshop topic. Submit these questions by 5:00pm February 17th to Assignments in the MPH 9015Y Transforming Public Health OWL site.

Required Readings:

- Policy Brief – “A How to Guide”
http://www.idrc.ca/EN/Resources/ResearchDBs/Tools_and_Training/Documents/how-to-write-a-policy-brief.pdf
- “Bringing Care Home: Report of the Expert Group on Home and Community Care”
March 2015. (read Executive Summary only)
http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf

Optional Readings:

- Canadian Healthcare Association. 2009. “Home Care in Canada: From the Margins to the Mainstream”. Ottawa (read Executive Summary and List of Challenges only)

Tasks

Presentations will be made by guest speakers from 8:45 to 11:00am and from 12:00-12:15, which will assist you with your tasks for the rest of the workshop. Each learning team will be assigned to join one other learning team. Thus, there will be a total of 4 teams formed for the integrative workshop day. Each assigned team will take on the role of one of four groups/organizations.

During the second break, teams should meet to determine which questions they would like to pose to the panel. These questions can be the same as the questions submitted previously, or they can be new. Each team will be able to ask **one** question per round. If time allows, we will have two rounds of questions. Teams should prepare their top three questions in case another group poses a similar question.

During the break-out session (12:45-3:00) teams will work toward two deliverables: 1) a plan of action; and, 2) a presentation on the plan. Teams should consider the planning models

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presented in the MPH courses and come up with a comprehensive plan which should include the actions you would take as your assigned group/organization to influence policy.

Presentations should be no more than 5 slides; the final slide should be a representation of the whole planning process (this can be a list, a diagram or whatever is most appropriate for the plan). It is not expected that every assigned member will present.

Schedule

8:30-8:45	Introductions & Overview of the Workshop Day	Classroom
8:45-9:15	Guest Speaker: Brandon Agnew	
9:15-9:45	Guest Speaker: Michael Silverman	
9:45-10:00	Break	
10:00-10:30	Guest Speaker: Sharon Koivu	Classroom
10:30-11:00	Guest Speaker: Donna Ladouceur	
11:00-11:15	Break - Assigned Teams to Prepare Questions for Speakers	
11:15-11:55	Panel of Speakers - Assigned Teams to Ask Questions	Classroom
11:55-12:00	Overview of Assigned Team Tasks/Deliverables	
12:00-12:15	Guest Speaker: Sherine Fahmy – Report Back, Policy Observations	
12:15-12:45	Lunch	
12:45-3:00	Break-out Session: Teams to Discuss and Prepare Plan of Action and Presentations Team 1 - Board Room Team 2 - Classroom Team 3 - Foundation Lounge Team 4 - Student Lounge	Varies
3:00-3:40	Assigned Team Presentations (10 min each including time for questions)	Classroom
3:40-4:00	Guest Expert and Faculty Feedback	
4:00-4:10	Conclusion & Close of Workshop	