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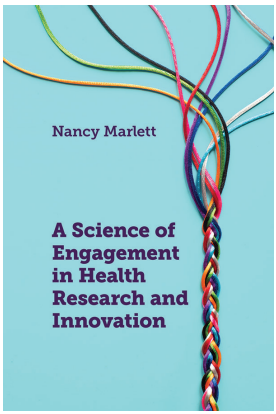

A SCIENCE OF ENGAGEMENT IN HEALTH RESEARCH AND INNOVATION

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A Personal Narrative of Social Innovations in Health: Research Examples of the Changing Roles of Patients

Highlights

- Evolution of the system from behaviour control of patients in psychiatric institutions to patients as peer researchers and social entrepreneurs
- Personal research narrative of innovation within health systems and the ability of systems to resist change
- The promise of community, self-help, new social movements, and social enterprise health options
- The importance of new research roles for persons with lived expertise during innovation and change as part of digital paradigm shifts that will impact patient roles and healthcare options

Personal Experience with Social Innovation

I was born during the Second World War, as countries struggled to recover from the challenges of two World Wars, a pandemic, and a global economic depression by creating large, evidence-based social institutions. By the 1960s, during my university years, these social institutions were already being challenged by the feminist and civil rights movements, and I marched, protested, and became aware that I, too, was discriminated against within systems, because I couldn't read, or focus, or remember faces for any length of time. In graduate school, I easily learned strange computer languages for large and cumbersome computers. I eagerly spent my first paychecks on the first Mac 128K.

From early experience with social innovation within psychiatric institutions in Ontario, I moved to Alberta. I worked as a contract researcher to government departments, community-based health systems, from home programs for severely handicapped babies to long-term care, policy research for guardianship, developing adaptive aids, and Assured Income for the Severely Handicapped (AISH). I was hired to help develop a university institute for innovative vocational and rehabilitation research, and from there I moved to the University of Calgary to develop a disability studies program (Community Rehabilitation and Disability Studies—CRDS) within the Faculty of Education, based on principles of social justice and community inclusion.

Universities, at that time, were adopting a military internet communication platform, and I was eager to develop distance programs for our new undergraduate and graduate degrees. I eagerly jumped at the chance to create distance online options to reduce costs and travel. This was followed closely by a large community grant to create a Canadian internet presence for persons with disabilities. This seemed logical because so many communication devices were developed and used extensively by persons with disabilities.

Within the university, education and other graduate programs in business, environmental design, and social work banded together to support early online curriculum development and delivery. Because of this, we were able to secure early funding to create laddered degree programs with colleges across Canada and a blended Master of Science degree in disability studies.

When CRDS moved from the Faculty of Education to Medicine, I had the chance to use internet resources to support an equity, diversity, and inclusion (EDI) program that supported community experience for medical students. Small teams of students were led by mentors with lived experiences in the six target marginalized populations that were part of the Canadian medical curriculum: homeless, disabled, Indigenous, considered to be mentally ill, and refugees. One-third of the students felt that they were deeply impacted by their experience, one-third were insulted by being taught by people without academic credentials, and the rest seemed to think it was not important that they know about the lives of people not served by the Faculty of Medicine. I retreated rapidly from trying to influence students and humbly set out to study how to open dialogue between people with lived experience (PWLE) and medical professionals through new research models. This motivated a series of studies to create a patient research voice that would break through the glass ceiling that existed for patients in healthcare.

Social Innovation Impact and Paradigm Shifts

Social innovation and social enterprise are recent extensions of the term 'innovation' that had come to be associated with products, services, and processes that were marketable. Definitions of social innovation were developed to identify new ideas that resolve existing social, cultural, economic, and environmental challenges for the benefit of people and the planet. A social innovation is a personal, social, and systems change that alters the perceptions, behaviours, and structures of individuals, groups, and societies. Even more simply, a social innovation is an idea that works to improve the public good (Centre for Social Innovation, n.d., https://socialinnovation.org/about/our-story-and-impact/). A more recent definition, "change in social relations, involving new ways of doing, organizing and/or knowing" (Haxeltine et al., 2016, p. 19), has been adopted within current theory related to narratives of change, and aligns with Conger's (1974, https://doi.org/10.1111/j.1467-9833.1974.tb00448.x) definition of social innovation that was adapted in my PhD thesis to focus on new ideas and organizations that change the way people see themselves and relate to each other. This implies a focus on changing roles, relationships, and structures within existing systems and, as they transition, in response to shifting societal values.

Table 1.1 introduces the general evolution of systems and systemic challenges addressed in the chapter. It identifies how the roles of patients, professionals, and systems become constricted as systems become inflexible and more powerful through government funding, bureaucratization and specialization, professionalization of care, and finally the medicalization of deviance. Current healthcare systems are protected by the close connection between science and the promise of cure that make the system resistant to change.

The figure provides an overview of reactions to the growth of health systems through the negative impacts, emancipatory forces, and anticipated futures. These are summarized through the experiences of patients, professionals, and the healthcare systems. The figure maps the features of health systems and how they influence people with lived experience, professionals, and the systems.

Table 1.1 *Process of Social Change in Health and Healthcare*

Systematization of Health by	*Negative Impacts on*	*Emancipatory Forces such as*	*Anticipated Futures*
Growth in government funding and control Bureaucratization and specialization Professionalization of healthcare interaction Medicalization of deviance used as access to care Systemic discrimination challenges	**People with lived experience** Loss of control and identity; dependence on professionals **Professionals** Loss of connection, effectiveness, depersonalization, meaning **Health systems** Rising costs; increasing expectations; increasing justification of reduced accessibility; systemic discrimination	**People with lived experience** Peer support; advising health teams; decision-making **Professionals** healthcare partnerships; more community engagement of health professionals **Health systems** Increased patient choice and responsibility; partnerships in care and research; technology advancements in individualized solutions	**People with lived experience** Increased engagement in personal health and healthcare with technology **Professionals** Shifting roles to support technological change; working for patients (individualized funding) **Health systems** Increasing prevention; reduced burden of disease for non-communicable and stress-related disease; more focus on the health of communities

Narratives of Social Innovation

I needed a way to tell this story of change, and my experiences acted as case studies of systems, roles, and relationships, forming a foundation for social change and innovation within health-related systems. And these stories became stories of emerging theory.

In an article updating social innovation, Mason et al. (2015, https://doi.org/10.1093/heapro/dav076) consider how social innovation is manifested as part of health promotion and health equity. This classification has been adapted to describe the stages of the personal narrative.

1. **Service-related social innovations** such as new roles, relationships, new social organizations and institutions, along with an innovative government policy. This, by definition, relates to systems, their rise, and increasing challenges.
2. **Community-based social innovations** that challenge the authority of institutions by creating alternative and inclusive community wellness and support options.
3. **New social movements** or emancipatory networks such as the Black Lives Matter movement, patients international, and the modern hospice movement that were led by those who had recognized and challenged the authority of existing systems.
4. **Innovative forms of social enterprise** that emerged as capitalism became enmeshed in new forms of social innovation. Academic researchers sought ways to turn research advances into commercial products for health and education. With this came the realization that business models could meet social needs. The Ashoka network of university changemakers is an international leader in social entrepreneurship (Ashoka, n.d., https://www.ashoka.org/en-ca). Also included in this is social innovation from a not-for-profit base.
5. **Digital social innovations** in which innovators, users, and communities collaborate to co-create knowledge and solutions for a wide range of social needs at a scale that was unimaginable before the rise of the internet. These digital social innovations have arisen because of the current paradigm shifts in healthcare, health systems and services, and new roles for health professionals and patients.

1. Institutional Service Social Innovations

Healthcare-related institutions for people living with mental illness, developmental disabilities, and wasting diseases began as hospitals and congregate environments that claimed to help patients recover and learn how to exist in society. They soon became long-term institutions based on military, corporate, and industrial systems that grew rapidly, as the goal shifted to removing disruptive or unconventional people from society (D'Antonio, 2011).

By the late 1960s, deinstitutionalization was supported by the promise of cost savings and political pressures to reduce the harms inflicted on patients. New medications were 'on the horizon' to reverse mental illness and enable patients to manage on their own. This did not take into account the devastation of severed family connections, reinforced compliance, and isolation that fostered deviance. These patients became a throwaway generation, living in boarding

houses or on the streets in large cities. Those who had no voice in institutions continued to have no say in the subsequent decisions that impacted their lives.

Token Economies Change Behaviour

The first research narrative captures a moment at the very beginnings of de-institutionalization. The social innovation was operant conditioning using tokens as reinforcements. It fuelled the optimistic belief that even the most difficult of patients could become more acceptable to society. The study took place in a large custodial ward/unit for aggressive and regressed females with an average length of hospitalization of 20 years (Steffy et al., 1969, https://doi.org/10.1177/070674376901400111).

The following is a summary from my research notes.

Very early in the morning, I got on a bus dressed as a young professional and got off at Lakeshore psychiatric hospital. I quickly changed into a 'house dress' and transformed into a quiet, withdrawn patient on a unit for aggressive, regressed mentally ill women. I slipped into my chair as the residents were being showered and dressed to record patient behaviour as a research intern on one of the first token economy projects in Canada. Patients were given coloured poker chips for daily routines and were taught to use the tokens for meals and the small tuck shop. I couldn't resist making small notes on the side of the data sheet that recorded incidents not part of the study, including such as the cluster of nurses worrying about withholding meals when patients didn't earn tokens, the black market in tokens, how dominant patients took tokens as protection money and how I was so easily treated as a patient.

Patients, over time, easily adapted to making their bed, responding to greeting and dressing themselves, in order to pay for their meals and daily treats. Like most token economies, the original behaviour patterns slowly returned when the new expectations were no longer rewarded. However, the power of the research to change behaviour was published and led to other token economies, as the patients were readied to be moved from institutions. The notes and the reflections I made each night on the bus trip home turned out to be my entry into a world of health culture.

This ethnographic view of systems encouraged me to look at research from a patient perspective. They seemed to easily fit into the routine of the ward in order to avoid punishment or removal of privileges. The relationships among patients were covert and based on physical and psychological hierarchies, their relationships with staff a vigilant compliance. These women became my ground zero—people who had no voice, made decisions to obey or refuse to obey based on the level of threat. Operant conditioning worked as long as the reinforcement continued or was transferred into general practice.

My fascination with ward culture was noticed, and I was sent to a psychiatric milieu rehabilitation course at Boston University to learn how to create positive environments within institutional settings. I was able to set up in-house 'research projects' when I returned, to look at ways to prepare patients and staff for deinstitutionalization.

Assessments Change Ward Culture and Roles

My next service innovation was based on the use of the Medfield Rehabilitation Checklist to test a positive, asset-based assessment that would increase the positive culture of a psychiatric ward. The checklist was introduced in a women's ward without any motivators or reinforcements. The Psychotic Reaction Profile (Lorr et al., 1960, https://doi.org/10.1002/1097-4679), a checklist of deviance and psychosis, was introduced to a comparable ward. The staff on each ward assessed the patients once a month and reported on their clients in a staff meeting.

The impact of this simple service innovation was remarkable. Within three months, the staff using the Medfield checklist were more positive and interacted with patients. Further, patients interacted more with each other, they went out of the institution into the community, and family visits increased. On the control ward, staff that used the psychotic reaction profile reported more deviance, but the culture of the ward remained basically the same. One might surmise that the checklist changed the focus, expectations, and role of the staff on the first ward, which provided opportunities to interact positively with their patients. This, in turn, encouraged them to expect more positive activities and more of their patients.

This informal research demonstrated the effectiveness of a positive behaviour checklist that changed the focus of staff attention from deficit and deviance to asset and competence. The role of staff shifted from one of control to encouragement. Patients tried new activities in the community with other patients without staff being present. Positive behaviour checklists reinforce competence as an effective service-based social innovation that changed the way both staff and patients saw themselves and interacted with each other.

Introducing Work Culture in a Psychiatric Hospital

The noticeable change above led to a third innovation, this time to improve the work capacity of patients as part of the politics of deinstitutionalization and community inclusion. I hired a foreman with business experience, and he interviewed and hired patients who were paid according to their work (a form of operant conditioning, based on piece work). Workers were placed in community work sites when they had regained skills and work relationships.

As the concept expanded, other wards started their own workshops and vocational case reviews were started to plan for discharge into employment options. It wasn't long before community and family members joined the meetings and patients were speaking for themselves and the jobs they hoped to find. They had found a voice. However, that voice challenged the culture of psychiatric treatment reviews, and psychiatrists took over the vocational case reviews. The meetings that had been focused on employment were soon incorporated into the regular case conferences. As psychiatric professionals took over, the culture of work returned to a more comfortable culture of occupational therapy.

The success of this innovation was possible because it was, in fact, a social enterprise with the money raised from contracts, providing the incentive pay for the workers and defraying costs to the institution.

2. Community Alternatives as Service-Related Social Innovations

The deinstitutionalization of persons with cognitive delays was a very different story because it was supported by an emancipatory social theory called 'normalization,' which was supported by an active parent movement that led to early and sustainable success. Normalization was perhaps most dramatically articulated by Wolfensberger et al. in *The Principle of Normalization in Human Services* (1972, https://digitalcommons.unmc.edu/wolf_books/1/), alongside feminism and civil rights movements that sought EDI. These early principles are now used to challenge systemic discrimination. This movement led to other emancipatory movements in education, vocational rehabilitation, and community inclusion for seniors and disabled people. Here we focus on the capacity of families and communities to become social innovators of new roles and relationships outside of healthcare systems.

Parent Advocacy for Children Living with Developmental Delays

The parent's movement of the 1960s and '70s created parent support groups, political advocacy, specialized schools, day programs, and workshops. These families created space for their children in society. When those living with cognitive disabilities were discharged during deinstitutionalization, they came to a very different reality. As institutions faded, parent movements grew in power, asserting rights to community inclusion and peer support. The parent's movements had effectively challenged institutionalization and provided alternative community options for families, education, and work. Vecova (2024, https://vecova.ca), then called the Vocational and Rehabilitation Research Institute, at the University of Calgary was one of the 10 centennial projects in Canada that garnered political support in the face of deinstitutionalization. A similar

process was initiated in the United States with the Kennedy Foundation support for university resources to research and support the growing parent movements.

This was a dramatic shift in the roles of developmentally disabled children and adults. They shifted from patient and deficit roles to become children and adults living with their families, with opportunities to learn and contribute to society. The families ignored the roles assigned to their children by medical professionals and created space for social innovation within communities.

Community Capacity Building for Disabled Adults

Because of my experience setting up and researching vocational programs, I was hired as part of the startup team at Vecova to create a culture of capacity from the ground up, through research-informed innovation.

We began by researching asset-based assessments that might raise expectations of staff and trainees to create inclusive vocational, living, and community training and assessments. The assessment process, called the Adaptive Functioning Index (AFI), was created with potential employers, young adults living on their own, trainees of Vecova, and staff. We adopted trainee language to ensure that the assessment was in their voice.

As part of the research and staff training, it was decided to include trainees in completing their own assessments and setting their own goals. When trainees became involved, they were motivated to achieve the goals they set. It was indeed possible to create a culture that challenged the dominant discourse of deficit and incapacity among developmentally handicapped adults. The placement success far exceeded our expectations, and the asset-based culture of capacity and inclusion continues to this day.

As the AFI was sold and used throughout North America, Europe, and Australia, we noticed that staff in traditional programs were reluctant to give up their coveted expert roles as assessors and goal setters. The AFI also came to the attention of funders, who saw it as an ideal way of assessing funding needs, based on the deficit model where the lowest scores received the most funding. In places where this was done, building competence was not profitable and the focus on competence was reduced.

We learned that emancipatory changes in roles and relationships can be profound and lasting when the system is designed to empower those using the service. We also learned that it is difficult to change established staff roles unless they believe that those they work with can and should gain more control over their lives. Funding trumps innovation.

Translating Community-Based Social Innovations to Institutional Systems

Medical Institution for Profoundly Handicapped Children

I was hired in the 1980s to deinstitutionalize a small institution for severely disabled children in Calgary, based on the AFI success at Vecova. We began with a research project to create an assessment for dependent handicapped children to guide staff in creating a family culture with positive expectations for change. This became a social innovation to change attendant roles to parent roles. The family environment within the institution was considered part of the social movement of normalization.

While we were successful in mobilizing and motivating the children and energizing the staff, it collided with a government policy to decentralize government services by building small institutions in small towns to increase rural employment options. Our research, demonstrating that these children could learn and take advantage of a competency-based model, was stopped because it conflicted with their need to believe that severely handicapped children could benefit from being in a small town. However, when the political winds changed, a home-like setting with a family model was created on a portion of land, and the large institution was demolished.

School Curriculum for Profoundly Handicapped Children

The success of the assessment in creating family learning environments with very handicapped children opened the door to the school system, because we showed that these children could learn. I became the chair of a research team developing a novel provincial curriculum for dependent handicapped children that laid out expectations for the new students, classrooms, and teachers based on the previous assessment for dependent handicapped children. This work led me to develop and teach a specialization in special education for profoundly handicapped children through the University of Calgary, to prepare teachers for this new venture. The curriculum was optimistic and hopeful - new teachers expected children to learn and created opportunities for new activities and learning and this, in turn, led to more advanced curriculum goals. This created a belief that all children could learn and changed the views of the education system.

The above experiences, working in partnership with staff, demonstrated that lasting change occurs, and asset-based research can raise expectations and provide opportunities for growth. This is an action-based cycle—as staff expected growth, children (patients) grew and changed, which, in turn, influenced staff to try harder.

We see this when people with Alzheimer's live in community environments, doing their daily chores, interacting with each other, and learning new skills. Community programs are now expected to be inclusive, with adaptations made to enable children, adults, and seniors to be in charge of the choices they make. It is slowly becoming more expected within healthcare settings.

To jump to the future, home healthcare, which developed in the last century to enable seniors with chronic care needs to age in place, is being challenged. Seniors are questioning the introduction of standardized care protocols and digital and telehealth. In order to ensure personalized care, research done by seniors will need to inform new health directions.

3. New Social Movements and Consumer-Led Services

By the 1970s and '80s, the success of Alcoholics Anonymous' twelve-step programs prompted spontaneous self-help groups, where citizen groups informally shared stories and ideas about how to cope with everyday life outside of formal healthcare. These natural relationships heralded the emergence of a collective patient identity, outside of sanctioned health services and facilities. Social support and shared experiences became recognized as important factors of health and well-being. Support groups arose when needed and stopped when the members created more natural friendships. Some self-help groups were encouraged to become agencies, with funding provided by governments and the United Way. Other health-related peer support groups were renamed and reclaimed under the banner of medical psychosocial support (Brown et al., 2004, https://doi.org/10.1111/j.1467-9566.2004.00378.x).

The early self-help groups and disability organizations provided the impetus for consumer advocacy and consumer-led services. Organizations such as Inclusion Canada (https://inclusioncanada.ca), Canadian Association of the Deaf (https://cad-asc.ca), Council of Canadians with Disabilities (http://www.ccdonline.ca/en/), and the international advocacy group Disabled Peoples' International (http://dpi.org/) were early examples of new social movements pioneered by persons with disabilities. Their actions led first to fundraising for community services and research, and eventually to political action and peer support.

During this time, the University of Calgary was initiating an interdisciplinary program (with the Faculties of Education, Social Work, Kinesiology, Nursing, Continuing Education, and Medicine) of research and career development, to prepare professionals to work with persons with disabilities, mental health concerns, and chronic illnesses within community settings and organizations. This program, Community Rehabilitation and Disability Studies, is today located within the Cumming School of Medicine (https://www.ucalgary.

ca/future-students/undergraduate/explore-programs/community-rehabilitation). Faculty members were deeply engaged in new social movements to build the capacity of PWLE and families to advocate for community-based support, full inclusion in society and policy changes. Foundations in emancipatory social science and critical theory changed how we understood the role of PWLE, professions and research in effecting changes in practice and policy. My experience with PWLE and communities convinced me that power is created by groups of people using real-life data and shared meaning to anticipate and activate change. Our work as faculty began with social justice, and we soon adopted the call to challenge and change systems that marginalize through systemic discrimination.

Calgary Association of Independent Living (CAIL)

The Canadian Coalition of the Disabled (CCD) developed the Canadian Association of Independent Living Centres, now called Independent Living Canada (https://www.ilc-vac.ca), who supported disabled citizens to seek and direct their services, and to provide opportunities to help others to become contributing citizens.

The Calgary Association of Independent Living (CAIL) welcomed persons with all disabilities, including those who had been institutionalized for many years. Together, they shared stories and built peer support and independent decision-making about their futures. The director, a graduate of the University of Calgary diploma program, set out to design a consumer-led service that reflected the slogan of the disability rights movement: 'nothing about us without us.' The centre had a strong research foundation and was able to demonstrate the impact of a consumer-led model. The director became an independent service broker that supported members, along with their families and a personal support network, to negotiate an individual service plan that would finance the support services needed to live independently, at any level of disability. The service brokerage model had a strong clinical and research advisory team and produced a number of research projects. Independent service brokerage was a social innovation that was adopted in other countries and is still used today when policy encourages independent living (Marlett, 1988).

CAIL had created a culture of acceptance and service, supported by consumers. The clients identified what they needed and were part of creating the ways to meet their needs. This was my first experience of reversal in roles and relationships. Members who had brokerage contracts were employers of their care providers—they were, in fact, social entrepreneurs. They hired, trained, instructed, and paid their personal staff. Their staff may have been shocked by the reversal but soon came to understand the importance of personal control of care. While individual funding and service brokerage have become accepted

for persons with physical disabilities, the following examples from Marlett and MacLean (1988) depict the impact of these changes in role for those who have multiple cognitive and behavioural disabilities and persons with limited motor and speech:

> LB needed more support than was possible in community services. Through independent service brokerage, he was the first recipient in Alberta of direct payment. With these funds a 'Joshua committee' of parents and friends assisted him to hire and monitor his care providers. He lived in his own apartment with support and was able to attend community activities with support. The difficult behaviours disappeared, and his direct payment decreased and stabilized at a much lower level.
>
> A young mother in the later stages of MS, with only head movement, lived in an auxiliary hospital, but desperately wanted to leave the hospital and live independently. She requested the services of the CAIL service broker, despite the advice of the medical staff. She left after services she required to live independently were costed and funded through service brokerage. An apartment was adapted, and she hired all her staff. She lived many years with natural support, making her own decisions and helping others.

Twenty-eight people were supported using this model, from children to seniors, those in long-term care, institutions, behaviour management programs, and community organizations that could no longer provide service. The brokerage function was later taken over by service providers funded as part of government services.

New roles change the way people see themselves and relate to each other, the very definition of a social innovation. CAIL, run on a shoestring, captured the power of the early feminist and civil rights movements, albeit in a local and restricted manner. It ignited the flame of emancipatory science for me, while challenging my professional view that programs and professionals provided the path to empowerment. Service brokerage philosophy underlies many of the current moves to assured incomes for persons with disabilities that turn clients into social entrepreneurs and purchasers of community services, in stark contrast to the dependence of patients still within the current healthcare system.

The following section presents three major studies related directly to the evolution of peer research and a science of engagement:

- My PhD thesis (Marlett, 1996, https://doi.org/10.21954/ou.ro.0000f617) with seven social innovators of new social movements to test the viability of co-research.
- *Grey Matters* (Marlett & Emes, 2010, https://press.ucalgary.ca/books/9781552382516/), a peer research curriculum with seniors researching resilience with seniors.
- Patient and community engagement research (PaCER): A narrative of twin innovations to teach patients peer research as part of healthcare transformation (ongoing).

The common stages of each of the above research projects are summarized in Table 1.2.

Table 1.2 *Evolution of Peer Research Through Three Research Projects*

	New Social Movements (PhD)	***Grey Matters* Seniors' Engagement (CIHR)**	**PaCER Patients as Researchers**
Working Together			
Building trust	Working together as co-researchers	Retired academic mentors	Orientation as preparation
Co-design of research	Classical grounded theory throughout	Full day large group planning in city and rural areas	SET process to identify main concern for research
Negotiating co-production	Give / Get framework	Action teaching with debriefing	Iterative cycles
Data Collection			
Narrative	Integrated narrative methodology	Story template	Use of narrative incidents as data
Individual data	Co-production throughout collection and analysis	Story template from audio tapes	Interview informed story templates
Group data	Not done	Full day focus groups for seniors	Online focus groups

Table 1.2 (*continued*)

	New Social Movements (PhD)	***Grey Matters* Seniors' Engagement (CIHR)**	**PaCER Patients as Researchers**
Theory Building	Root metaphor of innovation for new social movement	Writing group of seniors created general theory of engagement	Grounded theory as explanations of the main concern; some thematic analysis
Dissemination	Within each new social movement; part of conference book	*Grey Matters* as a resource for research with seniors	Academic publications of peer research with research team

Case Studies of Co-research in New Social Movements

My PhD consisted of six case studies of new social movements that changed the way people saw themselves and related to others through new social organizations and movements (Marlett, 1996). Classical grounded theory was chosen as a research methodology because it was suited to the study of innovation.

Gerry Kinsella, a disability rights activist, was the first partner, and the methods we identified were tested and adapted by Dorothy Birtles, who had created a social organization of volunteers, sponsored by the Quakers. The resulting methods were refined and then tested with Cicely Saunders, founder of the modern hospice movement for the dying. These strategies were, in turn, tested with David Brandon, a radical innovator of new roles for citizens living with mental health and developmental disabilities; Henry Enns, who worked at international political levels to challenge systemic discrimination of those with disabilities; and Henry Three Sons, fighting for Indigenous rights for children and families impacted by residential schools.

Gerry Kinsella

Gerry Kinsella, the director of the Greenbank projects (https://www.greenbank.org.uk/about-greenbank/about-us/) in Liverpool, England, saw the need to challenge the systemic discrimination of disabled people as they left school. He created a number of social enterprises, most of them related to new adaptive technologies for work and sports (e.g., competition wheelchairs), and new roles in training and business (e.g., whole food restaurants and businesses). These businesses provided the income to allow Greenbank to challenge medical systems and reinforce emancipatory roles for PWLE. Greenbank College (n.d.,

https://www.greenbankcollege.org.uk) taught employment skills and created employment options and support services that competed with existing professional services.

The new social organizations of Greenbank reinforce a 'give it a go' atmosphere that validates risk-taking, peer mentoring, and personal decision-making. Greenback is considered one of the first social enterprises in the UK. Kinsella bypassed rehabilitation practices to work directly with commercial businesses in creating training modules and hiring disabled graduates. It is a long-term successful social innovation and social enterprise. Peer support, teaching, and mentorship replaced dependent patient roles.

Dorothy Birtles

In later life, Dorothy Birtles became the founder of the British Quaker Prisoner Befriending Scheme. This innovation was a not-for-profit, volunteer-run organization, supported by Quakers International. She studied the brutality of systemic persecution and torture and became the face of non-violence and deep personal connection to prisoners wherever torture was practiced. Quaker letters and cards meant that prisoners felt connected and valued. Social innovation was a deliberate, gentle, and measured challenge to repressive regimes. Within the minefield of international politics and tensions, she found ways to counter the terrorism and systemic violence through oral traditions of sharing stories of everyday life.

The results of these new roles included: prisoners were cherished and connected in spite of their isolation and torture; the Quaker Befrienders used gentle means to advocate and stand up against brutality through sharing their letters with other Quakers and politicians; Dorothy became an activist and changemaker against terrorism from her quiet life and garden shed office. Since then, the Quaker Befriending Scheme has been discontinued. For another example, see Hearman (2016, https://doi.org/10.1080/14672715.2016.1157954).

Dame Cicely Saunders

Dame Cicely Saunders began as a Nightingale nurse, then an almoner or social worker, and finally became a physician and specialist in pain management at the end of her life (Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, n.d., https://www.kcl.ac.uk/cicelysaunders/about-us/cicely-saunders). As an innovative social entrepreneur, Dame Cicely knew that if her vision took money from the health authorities, it would not grow. She vowed not to compete with health systems and independently raised funds for this radical new model of healthcare until it became accepted. The innovative and new forms of caring for the dying were later adopted by health systems.

Patients who had been disregarded because they were dying were encouraged to take up new roles through journalling, preparing their life history for future generations, and to make decisions about their dying. Families, overwhelmed by fear of pain and extreme care needs, had in-home support and the refuge of St. Christopher's Hospice in the final days. Staff who were marginalized in medical institutions gained credibility and value through the science of pain management and the success of hospice.

David Brandon

David Brandon was an impassioned advocate for homeless people and for people with mental health and learning difficulties in the UK. His childhood was brutal, and he lived as a mental health consumer, bringing a unique combination of personal experience and professional expertise to his work and study. David worked the streets, created fledgling consumer-directed services and community development. He was a writer, teacher and academic. He was part of the deinstitutionalization and normalization movement, but from a peer support foundation.

One could say that he deconstructed the power of large service systems that 'bullied defenseless people' in the hope that, if he exposed those in power, they would adopt more humane practices. He saw his role as a changemaker, using personal and volunteer resources as business capital.

He promoted new roles for people that were not defined by their condition, but by their inherent worth. He saw systems and those who ran them as the enemy, but he worked endlessly to bring them to his side. His legacy is great in the north of England, and the memory of his quest for new ways of serving and living together has indeed changed service provision in the UK.

For more information on David Brandon, see Mark Smith's 2006 article (https://infed.org/mobi/david-brandon-homelessness-advocacy-and-mental-health-and-zen-in-the-art-of-helping/).

Henry Enns

Henry was a Canadian human rights activist who was part of the meteoric rise of Disabled Peoples' International (DPI), a grassroots emancipatory movement with strong international political alliances through the World Health Organization (WHO) and national governments. His story captures many emancipatory themes: shared oppressions, coalitions and conflicts within consumer movement, and debates about power. Henry developed rheumatoid arthritis as a teen and spent much time in hospital, where he learned the power of using humour and storytelling against those in power.

DPI acted as a social enterprise funded by national and international sources that supported the drive to change national policy and restrictive

government programs. New roles for persons with disabilities were entrenched in the associations he helped create that spoke to the rights to full citizenship, political responsibility, international support for inclusion of persons with disabilities, and the Independent Living Movement (Independent Living Canada, 2024, https://www.ilc-vac.ca/).

Henry Three Sons

Henry was the last case study. He avoided me for three years because he felt he was not an innovator or a changemaker. He was Blackfoot from the Siksika reserve in Alberta and was an integral part of changing child welfare policy, in response to the Sixties Scoop. From the perspective of innovation, he brought the subtlety of working for change within a large, bureaucratic system while remaining fully part of his culture.

The social innovation was the challenge of Indigenous social work practice to prevent children being adopted by white families. He was a bridge between Elder support of traditional child rearing and the white child welfare system. The systemic threat was at crisis level—the future of Indigenous ways was in jeopardy.

Henry challenged the ontology of modern or Western research that considers knowledge to be the result of individual thought and action. I had assumed that changemaking happened when a person challenged systemic problems and found innovative solutions. Henry considered that knowledge was the domain of the collective—the clan and the nation. Change happened when the collective moved in concert to combine Indigenous ways, innovative use of modern technology, and new bridging roles.

The social innovation for me was a wake-up call. I had imposed my assumption of change on all the case studies. I was forced to return to basic assumptions and create a new, contextualized way to understand truth and theory with each of the social innovators. I learned that social innovation needs to live within the traditions of each movement and community.

His legacy is the Henry Three Sons Child and Youth Society. Advances included support for Indigenous parents to raise healthy children in Indigenous ways. His case study provides an example of the strength of Indigenous culture, bridging between dominant and challenging ways of knowing, being, and influencing.

The stories of these founders are found in the resources at the end of the chapter.

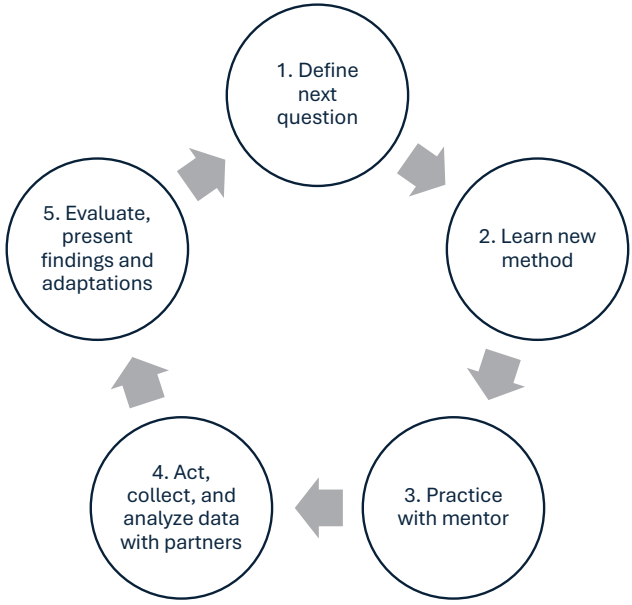
Grey Matters

The second research project was a Catalyst grant from Canadian Institutes of Health Research, to extend the impact of the above co-research thesis of new social movements. We set out to adapt and test the new narrative methods by teaching seniors about peer research. This resulted in a curriculum that included fieldwork, questionnaires, group research, and narrative interviewing that has become a product of peer research methods. The grant consisted of the following stages:

1. A large co-design focus group process with over 100 seniors that identified the model for the research. Retired university researchers supported groups of seniors in researching aspects of resilience as a foundation for testing narrative research methods.
2. Active learning based on participant action research principles. This included a teaching session and practice with the mentor, conducting research with the partner site and sharing results and learnings with the larger group.
3. Each of the methods and the teaching process was hotly debated and modified.
4. A year-long shared writing process used the same action cycle above. Strategies and methods were applied in natural settings as part of the writing process. For example, questionnaires were designed and administered with a seniors' group who wanted to use peer research to design a housing alternative for local seniors.
5. Seniors from the training program joined PhD students studying seniors' resilience to analyze findings from peer research interviews and to support students' research proposals.

Figure 1.1 is the action teaching cycle developed for curriculum development. This has been used in the development of the PaCER courses and in other peer learning situations to operationalize iterative cycles of learning and researching. For full details, refer to page 23 of *Grey Matters* and the Appendix 2 that describes the teaching method in detail.

Figure 1.1 *Participatory Action Research–Informed Inquiry-Based Training*



Note: Adapted with permission (Marlett and Emes, 2010, p. 23).

Seniors are natural researchers—they have learned to watch carefully, take note of powerful people and organizations, and organize for action. The future, in many ways, will be led by today's seniors. They do not want to be placed in institutions, and they have the motivation and capacity to effect change. The power of their research was demonstrated when seniors applied to present their research anonymously and were accepted for the Canadian Conference on Gerontology. All papers were accepted and valued, but the suggestions made by the conference leaders to engage seniors as researchers in future conferences did not materialize.

Shortly after *Grey Matters* was published in 2010, the director of the Kerby Centre was replaced. The Centre of Excellence, that was to be the champion of seniors as peer researchers, was also closed and more traditional programming was initiated. In the months that followed, the lack of a champion to continue this exciting work was the greatest and most sobering learning. Reviews of *Grey Matters* spoke to the potential of peer research, but without a champion to adopt the concept, it became interesting reading and a course resource. Today, there is an active international community of University of the Third Age or

U3A (https://www.u3a.org.uk/), along with the emergence of aging studies programs. With the pending second edition of *Grey Matters*, perhaps this time the Kerby Centre Innovation will move from a resource for students to a new training program for senior peer research.

Twin Innovations in Health Transformation: Strategic Clinical Networks (SCNs) and Patient and Community Engagement Research (PaCER) as Social Enterprises

I was invited, during the early stages of Canada's Strategies for Patient-Oriented Research (SPOR), created by the Canadian Institutes of Health Research (CIHR), to add a patient engagement pillar to Alberta's request for funding. Patients were expected to collaborate in the governance, priority setting, and conduct of research, including summarizing, distributing, sharing, and applying resulting knowledge. This provided an opportunity to assert the potential for patients to take on new roles in health research. This last case study is a narrative about new roles for patients in health transformation that are in keeping with the following publication about researching health together (Shklarov et al., 2017, https://doi.org/10.1111/hex.12591).

The following narrative of social enterprise is based on a collection of writings about PaCER and Alberta's Strategic Clinical Networks (SCNs) written by the founding team: Tracy Wasylak, the administrative director of Alberta's SCNs; Dr. Deborah Marshall, a CIHR research chair and fellow of the O'Brien Institute of Public Health; and me, Nancy Barlett, the originator of the research and training method. This short video was captured from a presentation about the first cohort of students in the PaCER program (Marlett & Penman, 2013, https://www.youtube.com/embed/QX2Z_FeF6UY).

Alberta created a comprehensive and single health system in 2008, and SCNs were formed as engines to drive this transformation. In the SCNs, those who deliver and receive care are equal partners in designing and implementing ways to reduce unwarranted geographic and cultural variation, using evidence and research. The SCN leaders knew that strong patient and community voices were essential when determining priorities and strategies for change, and they were ready to implement radical system changes to make this happen.

When we started, patient advisors were already working on professional and research teams with early indications of increased patient-centred care and research uptake. We soon realized that we were well positioned to develop new roles, relationships, and strategic partnerships because there was the political will to invest in training patients to create research-informed patient advisors.

There are three distinct stories in this narrative of social innovation:

- **Emergence**: This part of the story uses the *Grey Matters* curriculum to teach patients to become members of the SCNs as patient researchers.
- **Survival**: This story shows social enterprise as an alternative way to continue the training after grant funding ceased. It also supported contract peer research partnerships with the SCNs and academic health researchers. Both stories were guided by research and independent evaluation.
- **Coming of age**: The third story captures the collaborative efforts to formalize training within the University of Calgary, create an administrative home, placement options, and contract research with Alberta's Strategies for Patient-Oriented Research (AbSPOR). During this time, I continued to develop the science of engagement in health to support research teams and health systems to sponsor and support peer and community research.

Emergence

This first story captures the development of a training program as part of the Catalyst grant from the Canadian Foundation of Healthcare Improvement (CFHI). We used action-based teaching to test the 'Set, Collect, Reflect' engagement strategy and the curriculum that emerged from *Grey Matters*. The grant funded two full-year internships, and graduates went on to work as patient research advisors with the SCN and national research teams.

It soon became clear that the SCNs, as a receptive social innovation itself, were willing to form a disruptive relationship with patients as colleagues and to use PaCER research to inform and implement change. From previous experience, they knew that putting patients in the centre of a disruptive transformation strategy without support and skills was a risk. PaCER training has helped to minimize these risks through rigorous training in conducting research that engaged patients and communities. These patients became not only advisors and researchers, but also the drivers for changing the culture in the SCNs and research teams. Also unexpected were the leadership roles patients took on and the emergence of their self-identity as change agents.

Survival

Once we had inadvertently created a marketable product that demonstrated the impact of training patients to conduct research using methods co-designed and tested with patients, we were lucky to attract John Lacey, a retired business man, and a support team to help establish a social enterprise within a university environment hoping to use the potential of social enterprise. There were

serious obstacles to operating an enterprise within a university grant structure that had created complex systems that were not able to accommodate the early uptake of innovation or an advisory committee, and a strong partnership with the health system.

PaCER became an early adopter of the language, motivation, and potential of academic social enterprise. In hindsight, had we known about Ashoka, we would have had allies in the uphill struggle of creating a culture of social enterprise within the university.

As our grant funding came to an end, the formal outcomes mapping evaluation and grounded theory research of the key stakeholders indicated that training had been successful in producing peer research capacity within the SCNs. We had created a strong partnership between healthcare, health research, and patient engagement that sparked new ideas, challenges, and opportunities in an environment committed to and able to test new ideas. The lessons we had learned about the viability of the concept now faced the crucible of funding an infrastructure to continue the internship training of emerging peer research teams.

We moved quickly to create a social enterprise to support our training and scale up peer research. We created a business plan and discussed it within the faculty and was assured that, as long as I maintained responsibility for the research, we could experiment to see if the concept was viable. The income sources included training sponsorships and research contracts for peer research services. PaCER became a test case of social entrepreneurship and innovation within our university, as we created new employment, payment, ethics options, and legal, financial, and accounting processes with the university and Alberta Health Services (AHS) infrastructures.

Developing and managing 16 internship teams over seven years along with 24 research projects was taxing without formal infrastructure. We relied on the continued liaison team that founded PaCER, part-time academic and ethics support, and a volunteer management team of PaCER leads. During this time, an advisory board and formal business were established. We earned funds to support research teams and training sponsorships, but not the academic and administrative infrastructure.

As a social enterprise, we learned that researchers were willing to 'buy into' a novel approach of engaging patients in research when they were satisfied that PaCER could manage and oversee the academic integrity and that the cost was reasonable. Direct academic oversight, quality assurance, adherence to legal protocols and ongoing consultation with the university ethics review board ensured that PaCER was seen as a legitimate academic resource. The training and research methods were tested and adapted to ensure lay language and simplified

robust methods. This had added benefits because the results were sound, practical, easily understood and implemented, and were, therefore, publishable.

The main learning from this story was the essential role of the SCNs as the champions of PaCER. Their mandate for evidence-based health change and the ability to implement innovation enabled patient research voices to be included in decisions and future planning. SCNs connected PaCER to other research and quality improvement opportunities, acting as a vehicle to spread innovation and continue support of training.

We moved from the moral imperative of engaging patients to engaging patients as full members of research teams throughout the research cycle. It was becoming more common to be asked to conduct research into troubling and resistant issues that require a deep understanding of how patients make decisions and what matters most to them.

However, we knew the next stage had to be expansion, to respond to demand, both provincially and nationally. A large Indigenous training grant provided the funding to expand. The transition was extremely rapid, and, as with rapid expansion, we lost the capacity to plan, evaluate, and adjust. We needed a predictable product because our contract was high profile and risky. In order to deliver the training by distance around the province, we partnered with the university's Continuing Education unit to create online education and internships.

However, with the politics of working with a large, new population of students throughout the province and a lack of internet capacity, the rubric 'go slow and adapt' was swept away by a rapid change in materials, staffing, demand, and basic processes. In the end, it was successful because of the intense commitment of the staff, board, liaison committee, and particularly the Indigenous graduates.

Unfortunately, when the funding ceased, there was no way to fill in for the infrastructure, and new models were needed to go forward. A partnership among the university, Alberta SCNs, AbSPOR patient engagement unit, and University of Calgary Continuing Education has committed to creating ongoing structures to ensure PaCER sustainability.

Social Enterprise

At this point, we introduce the broader influence of social enterprise, where businesses create social mandates and funding partnerships, charities, or not-for-profit services operating a related business. Some examples include:

- Responsible corporate partnerships to support social needs that have become a feature of corporate culture and marketing addressing mental health, animal welfare, children's help lines, etc.

- Micro-financing of small business in low-income countries and marginalized and Indigenous communities and nations.
- Charities and not-for-profit associations that encourage income generation to support services, such as Goodwill.
- Self-employment for persons with lived experience of disability, retirees, low-income citizens, and veterans as outlined in government policies (Blackburn & Smallbone, 2015).
- Entrepreneurial models where people with disabilities hire and manage their own service provision budgets.

Ashoka changemaker networks combine community innovation and social enterprise—programs devoted to building community-based business opportunities and not-for-profit services and programs. Ashoka (https://www.ashoka.org/en-ca) has become an international network of universities, enterprise fellows and citizen changemakers, leveraging research, experience design support, start-up funding and academic support of Ashoka institutions and student programs. This partnership of academic research and social enterprise has led to a major reconsideration of the innovation at the university level.

In keeping with the social enterprise theme, this manuscript has been crafted to encourage social enterprise in health research and innovation through providing the science, the theory, and the methods to encourage researchers, research teams, social innovators, and social entrepreneurs to promote research done by, with and for patients and communities. To complete this section, we refer to Greenhalgh et al.'s policy paper (2016, https://doi.org/10.1111/1468-0009.12197) on achieving research impact through co-creation in community-based health services and the principles for success. This literature review and case study included many of the topics in this manuscript, from democratic, community-focused, and participatory options, along with innovation topics, including design thinking.

4. Digitizing Health

We begin with a bit of history about innovation, which has always been a part of human life as the major driver of change. The first industrial revolution of mechanization, starting at the end of the 18th century, replaced agriculture as the focus of society. The second industrial revolution was made possible because of new energy sources of electricity, oil, and gas to run automobiles and planes. With this, business soon became the focus of invention and innovation. By the third industrial revolution, computers, electronics, biotechnology, and telecommunications introduced an information age, enabling advances in space exploration and advanced automation (robotics).

The fourth industrial revolution builds on the third but has made quantum leaps because it is defined by the combining of physical, digital, and biological technologies. It unleashes major options for healthcare, such as combining the neural networks with robotic limbs, the internet of things that combine appliance and machine sensors with implanted sensors monitoring a wide range of functions, and implants that track health indicators, which are informing homecare telehealth.

The issues related to data ownership have never been more critical than during the current rush to new technology and decision tools. Teams and companies, from large systems to small community agencies, purchase data sets without understanding the potential biases and dangers and without any way to test the technologies. Apps and data are sold and reused without accountability or oversight. As with most technology, the end users—the patients and the frontline staff—must be ready to question and evaluate. To date, the consumers have been able to make decisions, but as technology is worn or implanted, these decisions become more difficult.

There are many specialists involved in new technology development, particularly algorithm teams using artificial intelligence informed by machine learning. These early teams could avoid many of the high-risk pitfalls inherent in data sets if they were able to use peer research to provide real-life, diversified data that overcomes the sources of systemic discrimination. While this will be costly in the beginning, refitting or decommissioning technology is also costly. If we employ a science of engagement to guide technology and decision-making tools that can be adapted and customized as needed, the eventual goal of having informed and motivated patients while reducing systemic discrimination will be achieved.

The Telegraph newspaper ran an article in 2016 that captures the essence of the emerging digital culture shift that is occurring from a patient perspective (Philips, 2016, https://www.telegraph.co.uk/wellbeing/future-health/fixing-the-holes-in-healthcare/). It represents the first level of transfer of healthcare to patients and community options.

If we include patients trained to engage populations in creating real-life data, the shift to personal control and community options will accelerate. Patients, seniors, and those with disabilities and chronic illness already have the expertise in health systems to become advisors and partners in a new technology future for health and healthcare.

Emancipatory patient movements are percolating, and patients are discovering the power of personal and patient-led research (Williamson, 2008, https://doi.org/10.1111/j.1369-7625.2007.00475.x). Established researchers may still balk at token patient engagement criteria for grant approval, and funders

may still be reluctant to move beyond minimum payment for patient advisors or partners. However, there are examples in citizen science, peer research, and patient-led research where patients are trained (Independent Cancer Patients' Voice, n.d., https://www.independentcancerpatientsvoice.org.uk/voice-science-for-patient-advocates/) or are developing training themselves to research problems on the margins, challenge formal research practices that are discriminatory, and search for research allies to support these new options.

Summary

The journey began with institutional and community innovations and ended in an era being changed by technology. The following are some of the questions you might discuss. Try to use personal experience or a project you are familiar with. Keep in mind the changes in patient and professional roles.

Questions for Discussion

1. How have systems found ways to 'manage' change? Have you seen examples of the waiting game, absorbing new language into existing practice?
2. What are some of the features of successful community-run services? How have pilot or Catalyst projects influenced or threatened new ideas? What is the role of social media in community project success?
3. How can peer research open space for social change, peer support, and community entrepreneurship? What is needed to make space for patient and community expertise?
4. What are the challenges to including technologies in social change and cost effectiveness?
5. How might emancipatory patient movements be supported by peer research and new technologies?
6. How might an experience you have had been different if there was a role for peer input or if the technologies emerging today had been available?

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