ADVANCING SOCIAL WORK RESEARCH - IMPACT CASE STUDY

MICHELE FOSTER

Title of Case Study:

THE OPERATION AND IMPACTS OF HEALTH AND REHABILITATION POLICY, SYSTEMS, AND SERVICES FOR PEOPLE WHO HAVE CHRONIC AND LIFELONG HEALTH CONDITIONS OR DISABILITY

Researcher and Institution

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Other members of research team
Prof Elizabeth Kendall, Prof Tim Geraghty,
Prof Paul Henman.

1. CONTEXT

Providing effective and accessible services for people with chronic conditions, such as severe spinal cord injury and traumatic brain injury patients, in hospital and community settings, continues as a major challenge. This program of research has focused on policy analysis and the views of patients and front-line service providers. Clinical research is generally favoured and funded in health settings, making it difficult to attract funding for psycho-social research on rehabilitation and related areas.

With a focus on the areas of brain injury and spinal cord injury, this research has three streams: 1) Applied policy and systems research: work on how policy translates into local delivery contexts with emphasis on the financing, governance and administration of policy welfare programs and front-line policy work, and implementation analysis. 2) Rehabilitation and lifetime care for people with complex needs: focuses on the models of financing and management of lifetime care for people with acquired disability through neuro-trauma and progressive conditions. 3) Patient and family experiences living with complex/chronic health conditions and disability: work on the lived experiences of people, self-management and burden of treatment relative to issues such as disability and rehabilitation, complex health problems and palliative care.

2. SUMMARY OF IMPACT

Improved professional understanding of a problem leads to new services. The cumulative impact of the research program is the improved understanding of the patterns of service utilisation for people with acquired brain or spinal cord injury (and related chronic conditions) in the community; their recovery outcomes, and barriers to recovery and support. Prof Foster and her colleagues have identified 'risk clusters' – patients at risk of hardship, poor health outcomes and limited support—and how the service system can better respond to the expressed needs and experiences of these people.

Decisions of health and human service organisations have been informed by research. Health and community service agencies have used the research findings to adopt practices that improve the rehabilitation outcomes in hospital and community-based living for people with acquired brain or spinal cord injury, and related chronic conditions.

Shifts in allocation of public funds. Findings about the mismatch between the location of available rehabilitation services and where clients live, have assisted providers and policy makers to better prioritize the allocation of rehabilitation services.

3. RESEARCH UNDERPINNING IMPACT

Professor Foster has led more than 30 related research projects in the rehabilitation and service system field commencing in 1995 when she was Manager, Acquired Brain Injury Outreach Research Project, Princess Alexandra Hospital, Queensland. The major findings of this program of research that influenced policy and systems change in health and community settings include:

- Identification of patterns of service use for people with severe acquired brain and spinal cord injury, and financial, emotional and systemic barriers to service utilisation;
- Identification of people who are at risk of hardship, poor health outcomes and limited support -and how the service system can better respond to the expressed needs and experiences of these people;
- The benefits of multi-disciplinary services and research in this field of rehabilitation; and
- Financial costs of rehabilitation and service usage and strategies to enhance efficiency and access to services.

The main projects for this program of research were:

- 1. 2012. Financing and Management of Lifetime Care for Adults with Acquired Disability and High Care Needs. Study investigated the experiences and perspectives of disability care of 25 adults with acquired disability, their 22 nominated family members, and 18 service providers. Evidence from this study suggests enacting the principle of reasonable and necessary care and support is problematic, in particular as it relates to personalising the level and scope of services, balancing formal and informal care, and principles of equity. It provides an empirically informed discussion of some of the specific policy implementation challenges concerning the NDIS.
- 2. 2012. Unmet health and rehabilitation needs of people with long-term neurological conditions in Queensland, Australia. This study adds to the limited evidence base on the provision of health and rehabilitation services to people with long-term neurological conditions requiring lifetime care. The findings highlight the enduring challenges of achieving the appropriate mix of disability support and health and rehabilitation services. Importantly, the findings point to the need for a more discernible integrated care pathway to address the complex needs of this population and to overcome inadequacies in the current system.
- **3. 2014.** Person-centred care in a digital hospital: observations and perspectives from a specialist rehabilitation setting. This exploratory mixed-methods study investigated use of electronic medical records (eMRs) in a SCI rehabilitation unit and the implications for person-centred care. Practitioners in this specialised setting were reconciling the emergent challenges of eMR in practice with the advantages of improved accessibility and documentation legibility. eMR increased task complexity and information retrieval, particularly for nurses. Practitioners' persistence and adaptability demonstrated their commitment to person-centred care in the digital environment.
- **4. 2016.** Translating the National Disability Insurance Scheme (NDIS) into practice: Examining choice, collaboration and capacity in the specialist rehabilitation setting. The identification of implementation challenges; mechanisms and processes operationalising choice and collaborative support planning; and emergent resource and capacity issues within the NDIS.
- **5. 2017–2020.** Tracking rehabilitation across complex environments (TRaCE): A longitudinal cohort study This is a mixed methods study to investigate rehabilitation trajectories and experiences of a 12-month cohort of SCI and ABI patients discharged from inpatient rehabilitation to assess social and spatial determinants of service use and wellbeing. The findings are expected to facilitate an understanding of clusters of high and low risk and assist health and rehabilitation practitioners and funders to build capacity and plan necessary and reasonable treatment and support for persons with SCI and ABI. Specifically, policy stakeholders may use the visual maps to plan new health care services and optimally allocate financial resources.
- **6. 2017–2018.** An investigation of social and spatial determinants of resource use trajectories and psychosocial wellbeing for SCI and TBI patients discharged from inpatient rehabilitation. (Gao A, Foster M). Using geographical analysis methods, this pilot study found that within the Brisbane region, the four types of rehabilitation services widely used by individuals with profound or severe disabilities (i.e., occupational therapy, physical therapy, psychology, and speech pathology) were concentrated in inner city suburbs that had a relatively low prevalence of profound or severe disabilities and low potential demand for services. In contrast, rehabilitation services were sparely distributed in suburbs with relatively higher prevalence of profound or severe disabilities and greater potential demand for such services. The findings assisted rehabilitation service providers and policy makers to prioritize rehabilitation service allocations. This project was funded a postdoctoral fellow under the supervision of Prof Foster.

7. 2017–2022 The Hopkins Centre: Research Program on Rehabilitation and Resilience, funded by the Motor Accident Insurance Commission. This funding supports an ongoing research program aimed at improving the well-being of people with severe acquired brain or spinal cord injury through responsive systems of inpatient and community support and rehabilitation.

4. DETAILS OF IMPACT

Approach to impact: Prof Foster stated that: "I always have an impact strategy – all through the program of work." The research team are embedded in health and academic settings, which facilitates continuous application and impact of the research findings. Significant industry-research partnerships have facilitated influence and impact on service delivery. Prof Foster aims to influence by developing strong relationships and networks with health professionals and clinicians across disciplines to support psycho-social rehabilitation research and service models that are centred on the needs of health consumers. In drawing on her social work framework, Prof Foster strives to improve the understanding all clinicians and disciplines have of the patient experience. She noted that: "Clinicians are motivated to do good, but at times they think they know best and they don't ask the patients what they think". Prof Foster states that her research that features the patient experience "...makes them stop and think".

Prof Foster believes that while research generates new ideas and evidence to guide service improvement, decisions about change can be driven by ideology, values and politics, not the evidence. She sees the need for processes and structures to enable better dialogue between researchers, policy makers and government for research to have more impact.

Impact on human service organisations and service delivery: Success in influencing decision–makers was demonstrated in the work on social and spatial determinants of resource use and psychosocial wellbeing for SCI and TBI patients. This showed malalignment of services with the location of services users that persuaded the decision–makers— Motor Accident Insurance Commission—to consider ways to improve service access. The research exposed the challenges of achieving the appropriate mix of disability support and health and rehabilitation services. While direct attribution to the research is not possible, it is likely that it has helped to elevate the focus on integrated care with agencies like Queensland Health and community–based services.

Prof Foster received a personal letter from the Deputy Director–General of the Qld Department of Community Services, which stated her research provided useful insights into some of the key issues impacting on service providers and areas where future research could be pursued to improve policy. In particular, the DDG noted the timing of the research would mean it would play an important role in the national agenda regarding the National Disability Insurance Scheme and its rollout in Qld.

Research exploring why acquired brain injury clients were often not coming back to day therapy, led to the development of a 6 week education program for individuals and families, which aimed to allay their fears and uncover what they wanted from day therapy.

Impact on quality of life for community members: The research program has not specifically evaluated patient or service user well-being. It is notable, however, that the research features and advocates for the engagement of patients, service users, and their families or carers so that their experiences can guide health service models. The analysis of risk clusters has uncovered patients who are more isolated and in hardship, while others can be advantaged. Thus, the research aims to improve client/ patient well-being, but there is no direct evaluation to provide evidence of this.

5. ENGAGEMENT

Prof Foster states that her strength as a social work researcher is within a multi-disciplinary team approach and the networks she has built within health, community and academic settings. This fosters interest in and application of research evidence into policy and practice reform, across settings and disciplines.

She actively engages with health providers, policy makers and funders in her research. She stated that these relationships are essential to the research and that much of her time is spent building these and exchanging information. To achieve 'buy-in' and impact, she commonly uses strategies such as:

- Policy roundtables and workshops—such as sessions with funders, Lifetime Care, the Public Trustee, MAIC and senior departmental officials to ensures that "policy people are on board from word qo"
- · Policy briefs and key message briefs for government and industry
- the 25/3/1 research reporting model that is, a 25-page detailed report,
 3-page summary, and 1 page brief.

Industry appointments, memberships and awards Appointments to reference and advisory groups recognise Prof Foster's expertise in disability research and provide opportunities to use research findings to influence policy and practice.

- 2012 Contributor to World Health Organization's (First) World Report on Disability published in 2011
- 2010 Member National Disability Research and Development Roundtable, Oueensland

Professional development and training

Prof Foster and her colleagues actively engage in professional development and information exchange activities within health care, community and academic settings in Australia and internationally to advance the research program and its findings. For example:

Foster M. Choice and Control: the challenges of application in practice. Invited address. Metro South Health International Day of People with Disability, Translational Research Institute Brisbane, December 2017.

Foster M. Back to the future: what could sub-acute look like in the future. Invited address. Allied health sub-acute referral pathway hosted by Allied Health Professions' Office of Queensland, Park Royal, Brisbane, 30 November, 2017.

Foster M. Personalised rehabilitation in trauma management. Invited address. Princess Alexandra Hospital Symposium, Brisbane. 1 August, 2017.

Foster M. Social Work Research Symposium. Keynote address. Lady Cilento Children's Hospital, Brisbane. 21 March, 2016.

Foster M. Griffith University NDIS Symposium: Children with Disability and Complex Health Needs. Chair. Lady Cilento Children's Hospital, Brisbane. 9 November, 2015.

Foster M. Legal, Economic and Policy Panel: Management of Catastrophic Injury, Panel Chair. CONROD Symposium 2015. Griffith University Southbank Campus, 28 September, 2015.

Strivens E, Foster M. Patient, carer and provider perspectives of older people's care transitions across acute, sub-acute and primary care. Presentation. Research and Quality Symposium 2015: Health systems serving people: partnerships, collaboration, and responsiveness. Cairns Hospital Health Service, 5 August 2015.

Foster M. Building strategic allied health research programs in a context of change. Keynote address. Showcasing Allied Health, Cairns Hospital and Health Service, 19 June, 2013.

Jackson C, Hollingworth S, Foster M, Burridge L. Translating research into practice: a framework for planning and guiding implementation of innovative models of care in local contexts. Workshop, Primary Health Care Conference, Canberra, 18-20 Jul 2012.

Foster M. Utilisation of allied health services by people with chronic disease. Invited address. Department of Health and Ageing, Canberra, 29 November 2012

Foster M. Personalization of lifetime care and support: National disability reform in Australia. Invited address. University of York, UK, 1 June, 2010.

Foster M. International Classification of Functioning and Health (ICF) and Application to Rehabilitation. Keynote Address. Princess Alexandra Hospital Clinical 2-Day Symposium, 11th – 12th August 2005.

Conferences also provide an avenue to disseminate findings to professionals and industry leaders:

Burridge, L., Foster, M., Donald, M., Zhang, J., Russell, A., Jackson, C. Making sense of change: patients' views of diabetes and GP-led integrated diabetes care. Presentation. Australian Disease Management Association 10th Annual National Conference, Melbourne, 11-12 Sep 2014.

Foster M. The role of allied health in management of complex conditions in primary care settings. Keynote address. Australian Governance and Quality Conference, the Australian Centre for Healthcare Governance in Melbourne, 19/20 May 2011.

Foster M. Qualitative research in health services research. Invited Plenary. 7th Health Services and Policy Research Conference of the Health Services Research Association of Australia and New Zealand (HSRAANZ), Adelaide 5–7th December 2011.

Foster, M., Mitchell, G. Lost in Translation? Enacting the goal of consumerism in primary care. British Sociological Association (BSA). Presentation. Medical Sociological Association 41st Annual Conference, Manchester 3–5 September, 2009

Foster, M., Haines., T. Mitchell G. Earl, P. Eliciting consumer preference for health care. Presentation Social Policy Association Conference, Edinburgh, UK, 29 June – 1 July, 2009.

Foster, M. Post-hospital care following traumatic brain injury: Understanding inequities in access. Presentation. Third Health Services and Policy Research Conference, 16–19 November 2003, Melbourne.

Reports for industry

Industry reports increase access to research for policy makers, practitioners, and community members.

Strivens, E., Harvey, D., Foster, M., Quigley, R., & Wilson, M. (2015). *Analysing sub-acute and primary health care interfaces – research in the elderly. ASPIRE study.* Canberra: Australian Primary Health Care Research Institute (APHCRI).

Foster, M., Haynes, M., O'Flaherty, M., Mitchell, G., Skinner, E., & Haines, T. (2012). *Utilisation of allied health services by people with chronic disease: differences across health insurance coverage and policy change.* Canberra: Australian Primary Health Care Research Institute (APHCRI).

Mitchell, G., Senior, H., Foster, M., Williams, I., Chaffey, J., Chamber, R., Henwood, T. & Freeman, C. (2012). *The role of allied health in management of complex conditions in a comprehensive primary care setting*. Canberra: APHCRI.

Balcazar, F., Blanchet, K., Cieza, A., Esteban, E., Foster, M., et al. (2011). General Health Care. In W. H. Organization (Ed.), *World Report on Disability* (pp. 57-92). Geneva: WHO.

Harris, J., Foster, M., Jackson, K., & Morgan, H. (2005). *Outcomes for disabled service users: Department of Health Final Report*. Social Policy Research Unit, University of York/Department of Health.

Significant industry partnerships

Prof Foster has a rolling program of research funded by long-term partners—MAIC, health agencies and Australian Primary Health Care Research Institute (APHCRI) and with multi-disciplinary clinical and service partners.

6. RESEARCH INCOME

Prof Foster and colleagues have attracted \$4.5m funding through competitive grants including: NHMRC CRE; ARC Discovery; ARC Linkage; Australian Primary Health Care Research Institute (APHRCI), funding via contract research, and \$5.3million in research capacity building grants through the Motor Accident Insurance Commission. The 7 projects listed have a monetary value in excess of \$6 m.

Category 1 (international and national competitive)

 Foster, M., Henman, P., Fleming, J. & Tilse, C. Financing and Management of Lifetime Care for Adults with Acquired Disability and High Care Needs, 2012. ARC Linkage Grant with industry partners MAIC and the Public Trustee, \$278,031. Includes sub-study: Foster, M., Allen, S., & Fleming, J. Unmet health and rehabilitation needs of people with long-term neurological conditions in Queensland.

Category 3 (Other industry)

- Kendall, E., Foster, M., Geraghty, T. & Zeeman, H. The Hopkins Centre: Research Program on Rehabilitation and Resilience, 2017–2022. Motor Accident Insurance Commission \$5.3million.
- 2. Foster, M., Parekh, S., Legg, M., Kendall, E., Geraghty, T., Fleming, J., Jones,

- R., & Nielsen, M. Tracking rehabilitation across complex environments (TRaCE): A longitudinal cohort study, 2017–2020. Division of Rehabilitation Metro South Health part funder for RA and post–doctoral fellow. Division of Rehabilitation and Motor Accident Insurance Commission. Percentage of \$5.3 m grant above.
- Kuipers, K., Houston, V., Nolan, M., Seymour, J., & Foster, M. 2016.
 Translating the National Disability Insurance Scheme (NDIS) into practice:
 examining choice, collaboration and capacity in the specialist rehabilitation
 setting. Hopkins Centre Seed Grant, \$25,000.
- 4. Gao, A. & Foster, M. An investigation of social and spatial determinants of resource use trajectories and psychosocial wellbeing for spinal cord injury and traumatic brain injury patients discharged from inpatient rehabilitation, 2017–2018. Division of Rehabilitation, Princess Alexandra Hospital, Metro South Health \$166,000.
- Burridge, L., Foster, M., Jones, R., Geraghty, T., & Atresh, S. Person-centred care in a digital hospital: observations and perspectives from a specialist rehabilitation setting, 2014. Division of Rehabilitation Metro South Health unfunded, in-kind support for research assistance.

7. RESEARCH OUTPUTS

There are over 82 publications including books, book chapters, refereed articles, abstracts and research reports and manuscripts under review related this research. Selected publications are:

- 1.Gao A, Foster M, Liu Y. (2018). Disability concentration and access to rehabilitation: A pilot spatial assessment of applying geographic information system analysis. *Disability & Rehabilitation*. doi.org/10.1080/09638288.201 8.1468931
- 2. Burridge L, Foster M, Jones R, Geraghty T, Atresh S. (2017). Person-centred care in a digital hospital: observations and perspectives from a specialist rehabilitation setting. *Australian Health Review*. doi.org/10.1071/AH17156.
- 3. Harvey D, Foster M, Quigley R, Strivens E. (2018). Care transition types across acute, sub-acute and primary care: case studies of older people with complex conditions and their carers. *Journal of Integrated Care*. doi. org/10.1108/JICA-12-2017-0047.
- 4. Burridge, L., Foster, M., Donald, M., Zhang, J., Russell, A., & Jackson, C. (2017). A qualitative follow-up study of diabetes patients' appraisal of an integrated diabetes service in primary care. *Health & Social Care in the Community*, 25(3), 1031–1040.
- 5. McIntyre, D., Fleming, J., Foster, M., & Tweedy, S. (2017). Experiences of adults with high care needs and their family members with housing and support pathways in Australia. *Disability and Rehabilitation*, 39 (18), 1829–1839.
- 6. Anderson, K., Foster, M., Freeman, C., & Scott, I. (2016). Planning, implementing and evaluating a multi-faceted intervention to reduce inappropriate polypharmacy in primary care co-creation opportunities in a pilot study. *Medical Journal of Australia*, 204(7), \$41–\$43.
- 7. Foster, M., Henman, P., Tilse, C., Fleming, J., Allen, S. & Harrington. R. (2016). 'Reasonable and necessary' care: the challenge of operationalising the NDIS policy principle in allocating disability care in Australia. *Australian Journal of Social Issues*, *51*(1), 27-46.
- 8. Harrington, R., Foster, M., & Fleming, J. (2015). Experiences of pathways, outcomes and choice after severe traumatic brain injury under no-fault versus fault-based motor accident insurance. *Brain Injury*, 29 (13-14), 1561-1571.
- 9. Taylor, S., Foster, M., & Fleming, J. (eds.) (2008) *Health Care Practice in Australia: Policy, Context and Innovations*. Oxford University Press.
- 10. Balcazar, F., Blanchet, K., Cieza, A., Esteban, E., Foster, M., et al. (2011). General Health Care. In W. H. Organization (Ed.), *World Report on Disability* (pp. 57–92). Geneva: WHO.

