

Institution: University of Aberdeen
Unit of Assessment: Divinity and Religious Studies
Title of case study: <i>Spirituality and Health and Social Care</i>
<p>1. Summary of the impact</p> <p>The issue of spiritual care is enshrined within both health and social care policy in Scotland. Both sectors often struggle to meet these needs. This impact case study relates to two unique initiatives arising from the research of Swinton that have sought to address this gap in knowledge and practice. The Kairos Forum for People with Intellectual or Cognitive Disabilities has focused on putting academic research into practice for issues relating to spirituality and intellectual disabilities. The Community Chaplaincy Listening Project has taken chaplaincy provision and spiritual care and extended it into the community. Together these initiatives have contributed to better practice in relation to healthcare (especially relating to mental health) and the lives of people with disabilities, for the NHS, churches and social care.</p>
<p>2. Underpinning research</p> <p>In <i>Spirituality and Mental Health Care: Rediscovering a “forgotten” dimension</i> (2001, henceforth <i>SAMHC</i>), John Swinton (Lecturer at the University of Aberdeen since 1997 and Professor in Practical Theology and Pastoral Care since 2005) examined the spiritual experiences of people with enduring mental health issues and the historical, cultural, philosophical and doctrinal reasons why psychiatrists tended to neglect or pathologize the spiritual. Through an exploration of the literature combined with qualitative interviews with people suffering enduring depression, he concluded that spirituality (broadly defined) is a universal human phenomenon with important clinical implications not only for mental health but for human well-being in general. The book is one of the first practical and evidence-based studies of the spiritual aspects of psychiatric practice. It provided insights into ways of intervening therapeutically whether or not one shares the patient's world view. The book was widely hailed by reviewers in medical, social care, theological and psychiatric journals, and has been quoted extensively in journals and books across the disciplines. The research in the book formed the foundation of two further avenues of research Swinton undertook.</p> <p>(A) Learning Disability: Drawing on <i>SAMHC</i>, Swinton's research expanded into the area of the spiritual lives of people with intellectual disabilities. In 1999, he was commissioned by the Mental Health Foundation to explore the extent to which spiritual needs should be considered alongside physical and occupational needs in the lives of people with learning difficulties (published as <i>A Space to Listen: Meeting the spiritual needs of people with learning disabilities</i> (2001)). Through interviews with a series of focus groups (N=60) of people with learning disabilities, their carers and support workers, Swinton uncovered the significance of spirituality for this group of people. He established that people with all levels of learning disabilities have a strong interest in spirituality and that spirituality can function for them both as a mode of language and a form of self expression, affecting how they perceive themselves and their place in the world, and how they cope and respond to crucial events such as bereavement or grief. The research resulted in the development of a model through which agencies could train carers and support workers to recognize and meet spiritual needs. Following the results of this scoping study, Swinton received additional funding for a further piece of extensive research (N=120) which resulted in the report: <i>Why We Are Here</i> (2004). This has been followed by further funded research into community integration (Jerusalem Trust & Porticus Trust) and an AHRC funded project exploring the lives of people with profound and complex learning disabilities. In this project Swinton developed a unique methodology for accessing the spiritual lives of people who are often unable to use words to communicate. Swinton is currently undertaking an AHRC Follow On grant that seeks to transfer the method developed in the AHRC project across to the lives of people with advanced dementia and develop teaching and training materials for families and health and social care workers.</p> <p>(B) Chaplaincy Provision: <i>SAMHC</i> also formed the basis of Swinton's subsequent research in relation to the 2002 Scottish Executive Health Department (SEHD) guidance on spiritual care. This guidance requested that spiritual care policies be developed by the NHS to ensure that responsive and sensitive services are available for patients, relatives and carers. Spiritual care had been seen as something provided by a chaplain or appropriate religious leader, mainly to patients. Up to then, spirituality had been seen as a predominantly religious issue. The new guidance recognized a broader definition of spirituality (centred on meaning-making, values and experience), and posed a challenge for the health and social care sectors in terms of how</p>

Impact case study (REF3b)

such spiritual care should be administered and how such support should be focused. As a result, chaplains were pushed to the centre of healthcare in Scotland. In order to understand better the service they provide, the Scottish Executive funded **Swinton** and a team of researchers from the University of Aberdeen (2003-2005) to describe and conceptualize the present situation, with a view to providing guidance on ongoing developments, in the area of spiritual care and chaplaincy in NHS Scotland. **Swinton's** team interviewed all 44 full-time Health-Care Chaplains working in Scotland twice over a period of 18 months. The final report, published as *What Do Chaplains Do?* (2005), detailed the key configuration of listening, presence, counselling and accessibility that form their duties within a secular NHS and outlined the challenges raised by their shifting role.

3. References to the research

- **Main Research Source Document:** John Swinton, *Spirituality in Mental Health Care: Rediscovering a "forgotten" dimension* (London: Jessica Kingsley Publishers, 2001).
- **Reports arising from Main Research Source Document:** A number of reports were commissioned in response to the research findings of the main research source document: [1] John Swinton, *A Space to Listen: Meeting the spiritual needs of people with learning disabilities* (2002) London, Mental Health Foundation ISBN 1903645255; [2] John Swinton, *Why Are We Here: Understanding the spiritual needs of people with learning disabilities* (2004) London, Mental Health Foundation ISBN 1903645530; [3] John Swinton, *What Do Chaplains Do?: A report on a two year investigation into the nature of chaplaincy in the NHS Scotland* (2005) Edinburgh, Scottish Executive ISBN 0954990102; [4] John Swinton, Cristina Gangemi, Matteo Tobanelli, Giada Vincenzi, *Enabling Communities to meet People with Learning Disabilities and respond effectively to their expressed Spiritual and Religious Needs: A Participatory Action Research Approach* (March 2013, Kairos Forum:<http://thekairosforum.com/>)
- **Grants:** [1] Mental Health Foundation; Spirituality and People with Learning Disabilities; 2001-03; RGB1510; £70,320; [2] Scottish Executive Health Department; Meeting the Spiritual Needs of Patients in the NHS in Scotland - the Implications for the Role of the Hospital Chaplain; 2002-03; RGC1121; £89,175; [3] Scottish Executive; Developing Health Care Chaplaincy; 2007-08; RGC1700; £10,000; [4] NHS Education for Scotland; Developing Health Care Chaplaincy; 2007-08; RGC17001; £10,000 (linked with RGC1700); [5] AHRC; Understanding the Spiritual Lives of People with Profound and Complex Learning Disabilities; 2008-10; RGA1199; AH/F011482; £163,754; [6] The Jerusalem Trust; Enabling Communities to meet the Religious and Spiritual Needs as expressed by People with Learning Disabilities: A Participatory Action Research Approach; 2008-10; RGB3088; £25,000; [7] The Waterside Trust; Enabling Communities to meet the Religious and Spiritual Needs as expressed by People with Learning Disabilities: A Participatory Action Research Approach; 2008-10; RGB3089; £50,000 (linked with RGB3088).

4. Details of the impact

The publication of the book *SAMHC* led to two distinct streams of impact. The first relates to the impact of the ethos and approach of the research through The Kairos Forum for People with Intellectual or Cognitive Disabilities; the second through chaplaincy provision in GP practices.

A. Learning Disability Impact: The Kairos Forum Impact from *SAMHC* in relation to intellectual disability has come about primarily through the formation and work of The Kairos Forum for People with Intellectual or Cognitive Disabilities. The route to impact from this underpinning research came through the commissioned reports outlined above (section 2). **Swinton** and his team were commissioned to carry out research and develop training and teaching materials for a number of organizations including the Mental Health Foundation, the Scottish Executive, the NHS and the Catholic Bishops' Conference of England and Wales. The commissioned reports informed the work of religious communities, health and social care providers, and families. The very commissioning of the reports identified a clear need in society for consultancy, policy formation and advice for churches, para-church organizations and the government in relation to specialist provision for the spiritual lives of people with disabilities. These reports had wide distribution, and became central to the research and education stream that the Foundation for People with Learning Disabilities (which is part of The Mental Health Foundation) developed in relation to spirituality and religion from 2004 onwards. From the reports and the research, a number of teaching materials were produced for churches, schools, social care facilities and families, aimed at enabling the meeting of spiritual needs. These were made available free online and widely utilized (419 page views & 601 downloads). Combined with a series of teaching sessions carried out by **Swinton**,

these resources impacted health and social care professionals, and ensured that a broad range of service providers have access to the findings and the educational materials. All the reports and research projects took the model and understanding of spirituality laid out in *SAMHC* as central, since very few, if any, empirically based resources had been available prior to these projects.

The effect of these projects clearly identified the need for finding creative ways of operationalizing the research findings in *SAMHC* and effectively communicating it to people 'on the ground', in forms that facilitate understanding, education and effective training, so as to enable families, churches and social services to notice and respond to an area of human experience that frequently went unnoticed, was often not taken seriously, and for which there were limited resources to inform practice. This insight (arising from the above projects that flowed from the findings of *SAMHC*) led directly to the formation of the primary impact entity: the creation of The Kairos Forum for People with Intellectual or Cognitive Disabilities. The Forum has been in existence since April 2012, and uses the underpinning research to provide specialist services and resources designed to support the spiritual lives of people with disabilities (<http://thekairosforum.com/>). Reports and teaching materials from the research projects are now available online and the research from *SAMHC* is currently being delivered to a broad range of health, social care and religious communities via the Kairos Forum, to improve provision for the spiritual needs of those with intellectual and cognitive disabilities (see, for example, <http://thekairosforum.com/content/everybody-has-story>). The Forum is the first and only university based, empirically supported specialist provider of resources, training, continuing professional development, consultancy, and expert policy advice in relation to the spiritual lives of those with disabilities. It facilitates the crafting and empowerment of 'Communities of Belonging', within both religious and secular settings, and does this by providing specialist services which enable and empower people with disabilities to experience dignity, respect, care, access and authentic participation within well formed and empathic communities. It provides: (1) a forum for inter-professional networking; (2) the identification of need, development and introduction of new and effective resources for spiritual care, religious practice, support and accompaniment for people with cognitive or intellectual disabilities; (3) a consultancy service designed to enable the implementation of person-centred modes of spiritual care, support and accompaniment for people with mild and severe disabilities; and (4) the development and production of educational programmes for lay and professional people and for people with disabilities. The following are examples of its impact thus far:

- *Many Yet One*: Curriculum directory for the catechesis of people with intellectual disability preparing for the sacrament of first Eucharist and reconciliation. This is a curriculum guidance document and will be published by the Bishops' Conference Department of Education in 2013. It specifically names **Swinton's** work as its underlying theological basis.
- Kairos was the advisor and provider of training to the *More Than Gold Olympic* organization which offered pastoral support for the Olympic and Paralympic games in 2012, for whom Kairos was the official press spokesperson and writer of a nationwide training programme for the Christian laity. Kairos also contributed to the development of the Transport for London Olympic preparation consultation paper, providing two direct recommendations relating to the training of staff in effective communication and presenting information in symbols.
- At the request of Archbishop Vincent Nichols, Kairos is now represented on the executive board of the John Paul II Foundation for Sport (JPIIFS), offering advice on issues relating to disability for the Roman Catholic Church. This means that, following on its work on the 2012 Paralympics, Kairos now has a direct impact on the Catholic Church's strategy on theology and sport and is providing support for the preparations and training for the next Paralympics in Rio 2016.
- At the request of Maria Miller (UK Minister for Disability 2011), Kairos was invited to Westminster to discuss its vision for the provision of services. As a result of this, Kairos gave a formal response to a UK government consultation paper named 'Fulfilling Potential': odi.dwp.gov.uk/docs/fulfilling-potential/discussion-so-far-rich-text.rtf
- The Forum has been employed (2012-2013 renewable contract) by the Catholic Bishops' Conference of England and Wales as the adviser for all policy making and Bishops' Conference disability initiatives.
- The Forum has been employed to provide consultancy and training for agencies, clergy, catechists and parents in the Roman Catholic Diocese of Leeds.
- The Forum developed a programme of training on spirituality for management and staff working

for Adelaide Care, a private healthcare provider.

- The Forum is currently developing a training programme for the Catholic Social Action Network. Impact has taken place therefore in relation to: policy formation; the form and content of associations between people and groups within the church in relation to those with intellectual disabilities; cultural values and social assumptions locally, nationally and internationally in relation to the spiritual lives of those with disabilities and new forms of religious expression; and the content of the education of people, extending significantly beyond the submitting HEI.

B. Chaplaincy Impact: Community Chaplaincy Listening The avenue to the impact of SAMHC on healthcare and chaplaincy in the current census period began prior to this period with a series of invitations to **Swinton** to speak about the research in SAMHC at various health and social care conferences across Scotland and England, culminating in Aberdeen University hosting an international conference titled *Spirituality in Healthcare Practices: Integrating a Forgotten Dimension* (funded by the British academy: £1,600). This in turn led to the Scottish Executive to commission a series of reports (see section 2 above), including specific policy advisory documents arising from the research in SAMHC: *Spirited Scotland. An initiative to raise chaplains and health care professionals' consciousness to the importance of spirituality*. (Scottish Executive: £41,000; 1/4/03); *Religion and suicide in the highlands: An exploratory study of the spiritual landscape of suicide in the highlands*. (NHS Highland, £11,228; 1/6/04); *Developing NHS healthcare chaplaincy research*. (Scottish Executive £10,000; 1/4/07).

These reports provided a route to impact as they burgeoned into an ongoing working partnership between **Swinton** and the NHS. This culminated in 2010 when, as a direct result of work on the role of chaplaincy in healthcare, **Swinton's** research formed the basis of the new NHS Education for Scotland initiative — Community Chaplaincy Listening (CCL). Initially, this project placed chaplaincy 'spiritual listeners' in twelve GP practices across Scotland. These listeners respond to patients who visit their GPs with vague issues and existential/spiritual questions which the GP does not have either time or expertise to deal with. The feedback and assessment via PROMS (Patient Related Outcome Measures) indicates that the act of listening is deeply therapeutic and healing. Initial feedback came from 250 patients, six GP practice focus groups and thirteen chaplains; it reported very positively overall. All said they would like to see CCL as part of the continuing NHS service provision. As a result, in 2012, the Scottish Government asked **Swinton** to manage an extension of CCL across Scotland. This next stage involves a minimum of 32 pilot sites with more than 600 patients benefiting in the first year. 29 chaplains have been recruited and 30 CCL volunteers have been trained for this next stage, as chaplaincy provision in GP practices spreads across Scotland directly as a result of **Swinton's** research; the project is ongoing.

Impact has taken place, therefore, in relation to policy formation, and the development and delivery of public services to support the health and welfare of people in society.

5. Sources to corroborate the impact

As well as the reports listed above, the following individuals and websites can be consulted to corroborate the impact described:

1. The Director for Healthcare Chaplaincy and Spiritual Care, NHS Education for Scotland will corroborate community chaplaincy listening impact.
2. The Former Head of the Spirituality and Intellectual Disabilities Program at the Foundation for People with Learning Disabilities will corroborate work related to 'A Space to Listen' and 'Why Are We Here'.
3. The Kairos Forum Website (<http://thekairosforum.com/>) corroborates the work and impact of the Forum.
4. The Emeritus Professor of Psychiatry at University of Leeds and Past President of the Royal College of Psychiatrists will verify the impact of issues relating to Psychology.
5. The Archbishop of Southwark and the Assistant General Secretary at the Catholic Bishops' Conference of England and Wales will verify impact in relation to the Catholic Church.
6. The Foundation for People with Learning Disabilities catalogue of spirituality research corroborates work relating to the reports produced.
7. The United Church Observer article promoting Swinton's work in this area, with comments emphasizing impact on readership.