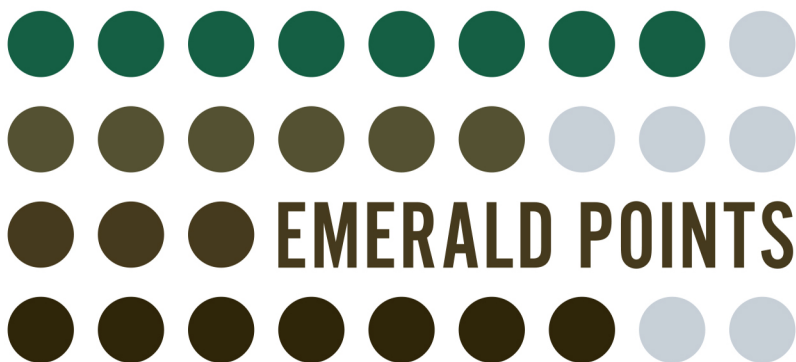


INTELLECTUAL DISABILITY NURSING

An Oral History Project

Bob Gates, Colin Griffiths, Helen L Atherton,
Su McAnelly, Paul Keenan, Sandra Fleming,
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emerald
PUBLISHING

United Kingdom – North America – Japan – India
Malaysia – China

Emerald Publishing Limited
Howard House, Wagon Lane, Bingley BD16 1WA, UK

First edition 2020

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British Library Cataloguing in Publication Data

A catalogue record for this book is available from the British Library

ISBN: 978-1-83982-155-4 (Print)

ISBN: 978-1-83982-152-3 (Online)

ISBN: 978-1-83982-154-7 (Epub)



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standard
ISO 14001:2004.

Certificate Number 1985
ISO 14001



INVESTOR IN PEOPLE

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LIST OF ABBREVIATIONS

ABA – An Bord Altranais

BNS – Bachelor of Nursing Sciences

BSc – Bachelor of Science

C and G – City and Guilds

CCETSW – Central Council for the Education and Training of Social Work

DOH – Department of Health

DOHC – Department of Health and Children

EN (MH) – Enrolled Nurse Mental Handicap

EN (MS) – Enrolled Nurse Mental Subnormality

H. Dip. – Higher Diploma

HE – Higher Education

HEE – Health Education England

HIQA – Health Information and Quality Authority

HSE – Health Service Executive

INMO – Irish Nurses and Midwives Organisation

MA – Master of Arts

NHS – National Health Service

NMBI – Nursing and Midwifery Board of Ireland

NMC – Nursing and Midwifery Council, United Kingdom

NNIDI – Nursing Network in Intellectual Disability Ireland

NVQ – National Vocational Qualification

PGCE – Post Graduate Certificate in Education

PhD – Doctor of Philosophy

RCN, UK – The Royal College of Nursing, United Kingdom
(gained royal patronage in 1939, previously the College of
Nursing)

RFN – Registered Fever Nurse

RGN – Registered General Nurse

RMPA – Royal Medico Psychological Association

RNID – Registered Intellectual Disability Nurse

RNLD – Registered Nurse Learning Disabilities

RNMH – Registered Nurse Mental Handicap

RPN – Registered Paediatric Nurse

UKCC – United Kingdom Central Council for Nursing,
Midwifery and Health Visiting

ABOUT THE AUTHORS

Bob Gates is semi-retired and works part-time at the University of West London. He is Patron to 'Stanley Grange', and 'Razed Roof'. He has an extensive research and publication record, and in July 2018, he was named as one of 70 of the most influential nurses in the history of the NHS.

Colin Griffiths is a retired Assistant Professor, School of Nursing and Midwifery, Trinity College Dublin, and qualified in intellectual disability nursing. He spent half of his career working with people with intellectual disabilities, and the remainder in Higher Education. His research interests focussed on how people with profound and complex intellectual disabilities communicate.

Helen L. Atherton is a qualified learning disability nurse. She lectures in nursing at the University of Leeds. Her main area of research is the history of people with intellectual disabilities, particularly in relation to eugenic ideas, which was the basis of her PhD. She is a Co-editor of the textbook *Learning Disabilities: Towards Inclusion*.

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Michelle Cleary is a Registered Nurse in intellectual disability nursing. She supports teaching at the Centre of Education, Training and Development in the Muiriosa Foundation, Ireland. She teaches across a number of programmes delivered to staff working with individuals with intellectual disabilities.

Paul Sutton is a Fellow at the University of West London. He is qualified in mental health and intellectual disabilities nursing. He has worked for over 30 years in intellectual disabilities in England and Canada. His research emanating from his PhD includes resettlement and experiences of mental ill health in people with intellectual disabilities.

PREFACE

It is a truism to say that over the last 30 years, intellectual disability nursing has incrementally moved from the narrowly defined roles it occupied within long-term institutional care services to broader roles within a complex landscape of health and social care service provision. Intellectual disability nursing is a specialist part of the wider health care professions occupying a wide portfolio of practice. This specialist part of the wider family of nursing has been supported, endorsed and celebrated by many as unique in its breadth of employment base being located, as it is, among various sectors, and service providers, and is acknowledged in making a valued contribution to the quality of lives of people with intellectual disabilities. The contemporary practice of intellectual disability nursing in England, United Kingdom* has a wide portfolio within services including; community support specialists, liaison posts, hospice care, diversion from custody schemes, epilepsy specialists, secure or forensic health settings, as well as offering a range of specialisms in more generic community nurse roles, and these roles offer support across the age continuum. However, it should be acknowledged that whereas research and policy has supported a clear need for such a range of services in the Republic of Ireland, a diversity of specialist roles has only recently commenced developing as the

*Hereinafter we use England only for this jurisdiction save where the use of United Kingdom is suffixed in another specific context.

necessity for change was identified in key policy documents; such roles in the Republic of Ireland include community liaison posts and clinical nurse specialists.

This unique research monograph is based on empirical research which has used the oral history approach to explore the careers of 31 intellectual disability nurses from England and the Republic of Ireland. It reports on our attempt to understand what had motivated these nurses to work in this field of nursing practice, and to learn lessons that might resonate with current nursing workforce challenges, and in particular in the field of intellectual disability nursing. Data were gathered using semi-structured interviews, and digitally recorded. These recordings comprise an important collection now held by the Royal College of Nursing's United Kingdom nursing history archives.

The origins of what was to become the *Untold Stories Project*, and what was to culminate in this research monograph lay in a bottle of red wine shared in a small village in the Heart of the National Park in the Peak District in the late summer of 2017. Two of the authors, Colin Griffiths and Bob Gates, were reminiscing over their careers, and Colin spoke of his interest in looking back at the careers of a number of nurses in the Republic of Ireland to see if they had experienced the enormity of change that he felt that he had. This was shared by Bob who had a long standing interest in exploring workforce issues in intellectual disability nursing, and he realised Colin's idea would enable him to look at this from a different perspective. The *Untold Stories Project*, as it was to be called, began to organically form as a viable research project, with an aim and research questions seemingly suggesting the oral history method as the most appropriate research methodological approach to address the questions which began to emerge. The project was called the *Untold Stories Project* because so little oral historical research has centred on, or has

been undertaken with intellectual disability nurses; the vast majority of oral history work has focussed on people with intellectual disabilities. At the onset of the project, the College of Nursing, Midwifery and Healthcare, from the University of West London and the School of Nursing and Midwifery, Trinity College Dublin were the two institutions involved in the project. But later on changes to the original personnel involved in the study, along with a need for a more robust research team in England, saw colleagues from the Universities of Leeds and Northumbria join the project.

In the first chapter, we provide a contextualising introduction which culminates in articulating the aim and objectives of the study. This is followed by a chapter that provides a comprehensive background as to the origins of intellectual disability nursing as a workforce, and in particular its precarious positionality within the family of nursing, along with the health and social care workforce more widely. This chapter explores, and in some considerable detail, the inter-related factors which have directly and indirectly contributed to on-going questions as to the vulnerability, and therefore the potential sustainability of intellectual disability nursing in both England, United Kingdom, and the Republic of Ireland. In Chapter 3, we provide a detailed account of the research method employed, and the two subsequent chapters report on findings and provide a detailed discussion, before moving to the concluding chapter of the monograph that presents a series of conclusions, and observations, as well as acknowledging the inherent limitations and strengths of this study.

We offer a note at the outset on terminology that we have adopted in this text. Generally speaking within the United Kingdom, the term 'learning disability' is a descriptive term used to identify, describe and at times categorise people who have significant developmental delay that results in arrested or incomplete achievement of the 'normal' milestones of

human development. Terms of equivalence used internationally includes: developmental disability, intellectual disability, mental retardation and mental handicap. Notwithstanding this wide array of terminology, and the inappropriateness of some we chose to adopt the term 'intellectual disability' and 'intellectual disability nursing' throughout this book, as we believe they are more universal than that which is used in the United Kingdom, thereby hopefully providing the book with a more universal appeal. Therefore, throughout the text, and from here on in, the term intellectual disability is used; save where certain Acts and/or other technical works require us to use other terms for accuracy.

Finally, we earnestly hope that the many professions and undergraduate students from the wide range of different professional and academic backgrounds that have an interest in historical aspects of the lives of those with intellectual disabilities, and in particular oral history might find this text both interesting and helpful. We also hope that it will be used to promote this specialist field of nursing and recognise the contribution that intellectual disability nurses have made to the lives of people with intellectual disabilities in the past, and the need to sustain this specialist field of nursing practice for the future.

Bob Gates; Colin Griffiths; Helen L. Atherton;
Su McAnelly; Paul Keenan; Sandra Fleming;
Carmel Doyle; Michelle Cleary and Paul Sutton

ACKNOWLEDGEMENTS

There are many people to acknowledge for bringing this project to a successful conclusion: From its original inception by Dr Colin Griffiths, from Trinity College Dublin, through to its publication as a research monograph with Emerald. Firstly, and most importantly, we must acknowledge and thank the participants of this study, 31 intellectual disability nurses, who without their generosity of time, and sharing their oral histories with us this project simply would not have been possible. It was a genuine pleasure and a humbling experience to meet and interview so many talented and inspirational people.

We must also extend our sincere thanks to the Royal College of Nursing, United Kingdom for their invaluable support and expertise in assisting us to archive most of the oral histories of the nurses collected for this study and who are the subject of this monograph. In particular to Teresa Doherty, Joint Head Library and Archive Service, and Royal College of Nursing Professional Lead for History of Nursing, London and Fiona Bourne, Archives Operational Manager, Library & Archives Service, Royal College of Nursing Archives, Edinburgh. We also owe an enormous debt of gratitude to the Irish Nurses and Midwives Organisation, Republic of Ireland for their very generous financial support for the Irish 'arm' of this study. And in particular to Liam Doran, Former General Secretary, of the Irish Nurses and Midwives Organisation, Dublin.

Thanks must be recorded to the many reviewers we have encountered on our journey from the very beginnings of this research project with a research proposal. Also to the invaluable help and insights offered by the ethics committees from the Universities of West London and Trinity College Dublin. And heartfelt thanks are due to those who have reviewed the very many abstracts of our work developed for presentations at numerous national and international conferences; this is sometimes a 'thankless task', but we wished to acknowledge these individuals, and the enormity of importance of peer review. Also to our publishers who have been so supportive in seeing our work through to publication.

Finally, there ought to properly be an acknowledgement of the many voices of yesteryear, those who have prepared reports and written papers, as well to the librarians, historians and archivists who have seen fit to archive and preserve their works. Perhaps if we had listened to at least some of them and followed their wise words, we might have learnt something, and we might not be repeating the same mistakes of the past.