

Learning Disability Nursing Practice:
Origins, perspectives and practice

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Edited by

Mark Jukes



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Introduction

This book claims to be a first in providing a text that encapsulates not only the origins of nursing in the learning disability field but also contemporary perspectives and areas for specialist nursing practice.

Readers may initially be confused when a book which is entitled *Learning Disability Nursing Practice* commences with three chapters given over to the history of a colony and research into mental deficiency nursing. However, for many readers these chapters will present a rich source of what constitutes a little understood era that promoted segregation, a setting apart from society, as opposed to the now more enlightened approach of citizenship and person-centred practice.

For many students of learning disability nursing, whether working in health or social care settings, their professional and historical roots remain largely hidden or are portrayed negatively through reported scandals and inquiries. This book therefore intentionally covers a significant part of the history of this branch of nursing and traces the beginnings of a unique colony for people known to be mentally deficient, in the context of society, and the creation of social policy which advocated a solution to what was called mental deficiency.

The book is divided into four sections: origins, perspectives, practice, and further perspectives.

Section one (origins) describes Great Barr Colony and explores the conceptions of practice of actual attendants and nurses who worked there. It gives readers an in-depth focus on aspects of work and practice not accounted for in the literature to date.

Section two (perspectives) explores social policy perspectives from the past eras of the workhouse, the colony and the hospital, through to the present age of citizenship. Research in learning disability nursing practice is identified through scoping exercises to identify its current status. The section questions the research and practice developments that have come of age and that constitute a challenge within an evidence-based health and social care world.

Section three (practice) identifies a wide range of specialist areas of nursing practice, including community learning disability nursing, epilepsy, forensics, health facilitation, autism, mental health, challenging behaviour, children's services and working with people with profound and multiple learning disabilities.

Section four (further perspectives) addresses areas of contemporary and future concern, namely, educational curricula for nurses and the importance of inter-professional education and practice development.

Section One: Origins

Chapter 1 by Peter Allen opens with an in-depth account of the history of Great Barr Park Colony, later to be known as St. Margarets Hospital. Its aim is to contextualise the era of the colony and hospital in terms of the social policy that influenced such provisions for people who, over time, and through the nomenclature of perjorative labels, were deemed as being mentally defective, subnormal or having a mental handicap.

Mark Jukes follows in *Chapter 2* with research that examines the perceptions of practice of attendants and nurses who were trained and worked at Great Barr Park Colony from 1927 up to the formation of the National Health Service in 1948.

In *Chapter 3* Duncan Mitchell concludes the section with an in-depth account of the difficulties in the relationship between mental deficiency and learning disability nursing. The focus is upon the work of the General Nursing Council and how it grappled with the question of whether work in mental deficiency could be described as nursing.

Section Two: Perspectives

Tony Gilbert, in *Chapter 4*, commences this section with an in-depth appraisal of social policy adopting a theme of ‘The Four Ages of Learning Disability’: the age of the workhouse, the age of the colony, the age of normalisation and the age of citizenship.

Ruth Northway (*Chapter 5*) considers and pursues learning disability research in terms of promoting this essential activity. She generates ideas about how this can be effectively achieved. Recent work is highlighted which places into perspective the current status of research within learning disability nursing practice.

Section Three: Practice

This section commences with *Chapter 6* on the development of community learning disability nursing from its origins to contemporary practice. What is illustrated is an area of work that has been determined and influenced through external events and policies, rather than by internal appraisal and analysis from nurses themselves. Mark Jukes and Simon Jones identify that learning disability nurses have a predominantly health focus, which has the potential impact of promoting change and inclusion for people with learning disabilities and their families.

Susan Brady in *Chapter 7* continues the theme of health in this section on learning disability nursing practices. She provides an in-depth analysis

into her work and research as a strategic health facilitator in Birmingham. Susan's research focuses on the adoption of an electronic health screening template by general practitioners, with the ultimate aim of improving health screening for people with an intellectual disability.

Epilepsy and learning disability are almost synonymous by virtue of their co-existence in this population. In *Chapter 8* Fiona Rich and Catherine Doherty present an extensive and comprehensive overview of epilepsy, and also consider the role of the learning disability nurse as a specialist practitioner.

In *Chapter 9* Colin Griffiths and Carmel Doyle explore key areas for assessment and health planning which are essential to apply when relating and working with people who have a profound and multiple learning disability. With an increase of the incidence in learning disability, the involvement of specialist nurses in this area is also bound to be a focus for increased intervention.

Dave Ferguson (*Chapter 10*) explores the dual diagnosis of mental health problems and learning disability. Although contemporary mental health services for people should have its roots in mainstream services, Dave explores the contribution specialist services and the learning disability nurse can provide in educating mainstream providers, family and paid carers.

In *Chapter 11* Tony Osgood provides an overview of one of the most difficult to define and ultimately contentious areas of practice within the field of learning disability nursing – challenging behaviour. Tony provides a rich account of some of the critical issues associated with challenging behaviour that a nurse will encounter in professional practice.

Anne Kingdon follows the theme of specialism in *Chapter 12*, and in this case an emergent area within learning disability nursing practice, that of forensics. The role of the nurse in this area of practice is still in its infancy in terms of community-based provision. The purpose of this chapter is to explore the context and practices of forensic learning disability nursing.

Jill Aylott (*Chapter 13*) provides us with an illuminating account of her work with people who have the diagnosis of an autistic spectrum condition. In particular, Jill shares her research into developing a communication and sensory profile. This is an invaluable resource allowing the learning disability nurse to gain further insight and to develop skills with people who have a different perspective on communication.

Owen Barr has extensive experience as a practitioner and researcher into the needs of children with learning disabilities and the effects their problems have on their families. In particular, in *Chapter 14*, Owen examines how policy and services are planned and the role of professionals in services, with the ultimate goal of promoting equal choice and value.

Section Four: Further perspectives

A new range of demands within health and social care presents new ways of delivering services to clients – which includes nurse education.

In *Chapter 15* Bob Hallawell illuminates some of these challenges specifically within pre-registration nursing curricula in an era of citizenship and person-centred approaches. There have been recent Nursing and Midwifery Council consultations over whether learning disability remains as a discrete field of practice, as do other specialties, or whether it is destined to remain a square peg in a round hole.

Martin Bollard (*Chapter 16*) explores the ubiquitous area of inter-professional education. Collaboration between the professions is not a new concept, but how to provide inter-professional learning is still embryonic for many higher educational establishments. Martin pursues how this may be achieved, highlighting how people with a learning disability can be at the centre of such programmes.

In the final chapter (*Chapter 17*) Caron Thomas and Penny Pritchard outline how practice development for learning disability nurses can sustain and promote their practice. This can be achieved through having a person-centred and carer focus and being involved in research, education and practice-based learning which ensures an evidence-based approach to practice.

This text gives an original and invaluable perspective into the origins and contemporary practices of learning disability nursing. The reader can examine the past and present formulations into what constitutes learning disability nursing practice across the parameters of health and social care.

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I would like to extend my thanks to the attendants and nurses who participated in the research reported in *Chapter 2*, some of whom are no longer with us, who willingly and enthusiastically shared the experiences of their previous lives. Talking with them gave me great insight and I was humbled by the gift they offered.

I would also like to thank all the contributors to this text who are extremely active in promoting person-centred practices in their work with people, families, carers, and students across a broad spectrum of care.

Finally, I would like to thank Margaret for all her patience and support and for being a constant sounding board for my endeavours in promoting quality education and practices with people, families and students within the field of learning disability.

Section One:

Origins

Mental deficiency institutions: Have the obituaries been fair and balanced?

Peter Allen

*Read not to contradict and confute, nor to believe and take for granted...
but to weigh and consider.*

Francis Bacon

Introduction

The 20th century was the Dark Ages for people with learning disabilities: they were incarcerated in institutions akin to prisons, systematically abused by uncaring nurses and denied basic human rights. Falling foul of parents, being a petty criminal or giving birth to an illegitimate child was sufficient reason to be ‘put away’ for an indefinite period.

If your exposure to the history of this special group of people is largely through the literature generated during and after the 1970s – the ‘scandal decade’ – you may well subscribe to these views. But such a standpoint is distorted and largely inaccurate.

From a close scrutiny of that period and its aftermath emerged a rash of publications intensely critical of institutions for the learning disabled. One such book looked at the life experiences of eight men and nine women who had spent an average of 47 years in an institution, certified under the Mental Deficiency Act of 1913 (Potts and Fido, 1991). Reading the book makes us uncomfortably aware of the injustices and inhumanity that characterised their lives. But just how much of that can we blame on the inherent shortcomings of institutionalised systems of care?

To be outraged is a perfectly understandable response, but we need to keep in mind we are viewing these accounts with modern eyes. The first half of the 20th century was a period of great social upheaval: despair, privation and dehumanisation was commonplace among the ordinary working classes. The most vulnerable sections of this social stratum suffered disproportionately.

Any studies based on edited interviews have well-recognised methodological shortcomings. These vignettes of life in an institution would be immensely more valuable if we were able to compare them with the life experiences of an age-matched control group brought up in the community. Those mental defectives¹ classified as ‘feeble-minded’² under the Mental Deficiency Act and ‘controlled’ by statutory supervision, mostly in their own homes, are obvious candidates. Their education would probably have been through the Special School system; at the age of 16 they would leave and try to procure employment in a harsh world. How did they fare during the years of the Depression and after? Was their quality of life superior to that of their institutionalised peers? How were they affected by ignorance and prejudice? We have not been told.

Although such comparative studies are absent in the literature, the many UK and USA longitudinal and follow-up studies applicable to feeble-minded defectives in open society offer some insights (Tizard, 1958). During the Second World War thousands of UK and USA high-grade defectives living in the community were drafted into the army to perform the more menial tasks. Three of the many studies listed by Tizard examined their performance: a high degree of failure was reported with around half being discharged as unsuitable. Their life experiences in the community were far from positive.

A thorough review of the literature by Cobb (1969) concluded that ‘...as compared with a non-retarded control group, the retarded show a higher incidence of marital, civic and occupational failure, especially in the early stages.’ A more recent analysis arrives at much the same conclusion: ‘...various follow-up studies of such key indicators of adult adjustment as employment, relationships, criminality, and adult mental health do not give cause for optimism’ (O’Brien, 2001). The evidence suggests our missing control group in the community would also have given Potts and Fido (1991) a constellation of depressing life experiences.

Current perceptions of the institutional era are profoundly downbeat, which is saddening. This negativity has been exacerbated by a few miscreants who disgraced the nursing profession around the 1970s. Their actions cast a shadow over ordinary hard-working nurses who considered nursing in an institutional setting as a supremely rewarding experience. Large numbers devoted the whole of their working lives to the care of the learning disabled;

¹The history of learning disability is littered with changes in nomenclature. The terms used in this chapter will be seen to fluctuate according to the time period under discussion. Many of the older terms are now only used pejoratively.

²The term ‘feeble-minded’ was in use from the middle of the 19th century (Brady, 1864; Duncan and Millard, 1866) to distinguish more able mental defectives, largely regarded at the time as lazy or wicked, from idiots and imbeciles.

it was not uncommon for three generations of a family to follow each other into a nursing career. Whatever the inadequacies of the institutional system, it is beyond debate that generations of caring, highly-motivated professionals gave care and succour to the learning disabled equal in measure to anything on offer in this more 'enlightened' age.

A balanced appraisal of the era of mental deficiency institutions requires you to take a close look at why and how these establishments were set up, how they functioned on a day-to-day basis, and their response to change. You will look in vain in the academic literature for such an overall view. This vacuum may partially be filled by this warts-and-all historical summary, in essence a complete life-cycle, of Great Barr Park Colony (Barr Colony), the fourth largest such establishment for mental defectives in England. Like so many of its ilk, it was in turn spawned and destroyed by the same agent – social pressure.

Barr Colony, known as St Margaret's Hospital after 1948, was established on the old Great Barr Hall Estate, a location in the West Midlands near to what is now Junction 7 of the M6. Walsall and West Bromwich, two large towns central to its evolution, are situated close by. It has the distinction of being the first large mental deficiency colony to be approved by the Board of Control under the Mental Deficiency Act of 1913.

The evolution of mental deficiency colonies

Why was the Mental Deficiency Act of 1913 received with so much enthusiasm? Why were so many mental defectives taken out of society? How was it possible for impoverished Poor Law Unions to acquire landed estates? To answer these and other questions we need to examine the social dynamics then in play.

Overcrowding and intermixing in Poor Law establishments

From Elizabethan times up until the passage of the Poor Law Amendment Act in 1834, provision for the poor was administered at parish level. The system had many critics; assistance was often meted out in a haphazard manner and abuse was rife both by relievers and relieved. The new Act formed parishes into unions with their neighbours, abolished out-relief, and required those in need to surrender their liberty and enter purpose-built residential workhouses. Diet and conditions were standardised nationally by central Government edict and rigidly applied at local level by Poor Law Guardians, elected from the ratepayers. It was envisaged that a Draconian regime would discourage the unemployed able-bodied, those mostly in receipt of relief at that time, from pursuing a life of indolence on the local rates.

By the early part of the 20th century, very much against expectation, some 85% of persons receiving assistance were suffering from physical, mental or 'moral' disability. Poor Law institutions were increasingly becoming choked with the aged and infirm, abandoned and orphaned children, mental defectives, consumptives and other disadvantaged classes.

In 1905, a Royal Commission was appointed to enquire into the workings of the Poor Law system. Many far-reaching proposals were incorporated in their report (Royal Commission on the Poor Laws and Relief of Distress, 1909). In particular, the Royal Commission strongly favoured the removal of all children from workhouses. With the recommendations of the report in mind, Poor Law institutions throughout the land were inspired to seek ways of segregating the various classes according to their individual needs.

So what was the plight of local mental defectives before the Mental Deficiency Act changed the scene irrevocably? Alas, appropriate records for Walsall and West Bromwich Poor Law Unions do not survive in sufficient volume for the question to be answered authoritatively. But there is much to be gleaned from local newspapers – particularly the lengthy reports of weekly meetings of the guardians. Such information was eagerly devoured, after all guardians were spending local money and ratepayers were their severest critics.

This is the picture at the turn of the century. For ordinary working-class families, leading a hand-to-mouth existence, the added burden of a dependent mental defective was financially crippling. Unless able to hold down some kind of lowly employment, and so contribute towards their own upkeep, relatives of these unfortunates must, of necessity, place them in the hands of the Poor Law authorities. Within the workhouse they would perform the most menial domestic tasks or, if their disability was more profound, live out a wretched life in the imbecile wards of the infirmary. As a last resort those who were particularly troublesome would be sent away to the county asylum at Burntwood, certified under the lunacy laws. Guardians were no spendthrifts and they loathed having to pay the high maintenance charges so incurred.

Less costly arrangements were occasionally entered into with fellow unions possessing the necessary expertise and resources to handle special groups. In 1913, to relieve overcrowding, West Bromwich Guardians had 26 imbeciles boarded out with Stourbridge Union, with the facility to send double that number if they so desired (*Midland Chronicle*, 1913).

Defectives in middle-class families fared a little better than their impecunious fellows. For the privileged few the Midland Counties Idiot Asylum had been established at Knowle in the late 1860s. It offered residential care for around 60 patients and was the only asylum of its type in the whole of the five counties making up the central Midlands. Demand