

Supporting the Physical Health Needs of People with Learning Disabilities

A handbook for professionals,
support staff and families

Edited by Steve Hardy,
Eddie Chaplin and Peter Woodward



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Published by:

Pavilion Publishing and Media Ltd
Rayford House
School Road
Hove
East Sussex
BN3 5HX
Tel: 01273 434 943
Fax: 01273 227 308
Email: info@pavpub.com

Published 2016

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

ISBN: 978-1-910366-25-7
EPDF ISBN: 978-1-910366-26-4
EPUB ISBN: 978-1-910366-27-1
MOBI ISBN: 978-1-910366-28-8

Pavilion is the leading training and development provider and publisher in the health, social care and allied fields, providing a range of innovative training solutions underpinned by sound research and professional values. We aim to put our customers first, through excellent customer service and value.

Editors: Steve Hardy, Eddie Chaplin and Peter Woodward

Production editor: Ruth Chalmers, Pavilion Publishing and Media Ltd

Cover design: Tony Pitt, Pavilion Publishing and Media Ltd

Page layout and typesetting: Phil Morash, Pavilion Publishing and Media Ltd

Printing: CMP Digital Print Solutions

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About the authors

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Dave currently works as an independent consultant nurse and is also the strategic lead for learning disabilities at Lancashire Care NHS Foundation Trust. Dave has a strong background in developing and delivering services for people with challenging needs, as well as supporting initiatives across the UK which aim to address the health inequalities experienced by people with learning disabilities and to measure the outcomes of effective service delivery.

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Jim is currently a consultant nurse intellectual (learning) disabilities at Great Ormond Street Hospital in London, clinical advisor learning disabilities, NHS Healthy London Partnership and associate professor intellectual (learning) disabilities at Kingston University and St Georges' University of London, as well as clinical advisor learning disabilities, NHS England. He is also the health advisor at the British Institute of Learning Disabilities and the Learning Disability Advisor to the States of Jersey.

From 2008-2013 Jim was consultant nurse learning disabilities at St. George's Hospital in London. Between 2006 and 2009 he was president of the Royal Society of Medicine's council for the Forum on Intellectual Disability. From 2011-2013 Jim was vice chairman of Special Olympics Great Britain. Jim is an expert advisor to the Parliamentary Health Service Ombudsman, an advisor for the Down Syndrome Medical Interest Group and is on the editorial board of www.intellectualldisability.info. Jim is also a specialist clinical advisor to the Care Quality Commission.

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Mark Bradley is the clinical lead for transition, working with Oxleas NHS Foundation Trust across two London boroughs. Mark has previously led on health facilitation, supporting access to primary care, acute hospital and all mainstream NHS services. During this time, he chaired the National Health Facilitation Network. Additionally, Mark has worked with the Valuing People Support Team as project lead for 'promoting equality', supporting the Department

of Health's response to the 2006 Disability Rights Commission report: *Equal Treatment: Closing the Gap*. Mark is a learning disability nurse and has worked in community learning disability services for 16 years.

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Lesley Brown is the professional lead for learning disability speech and language therapy in Oxleas NHS Foundation Trust. She qualified as a speech and language therapist in 1990 and has worked with children and adults with learning disabilities in a wide range of settings. She is an advanced dysphagia practitioner and an advisor on dysphagia for the Royal College of Speech and Language Therapy. She also has extensive experience working with individuals with autistic spectrum disorder and is qualified to use both the DISCO and ADOS. She has a particular interest in the practical application of the Mental Capacity Act and sits on the Oxleas Mental Capacity Act Steering Group.

Phil Boulter

Phil is a consultant nurse at Surrey and Borders Partnership NHS Foundation Trust and an Honorary Lecturer at Kingston University. He has worked in the field of learning disabilities for over 40 years and has been involved in a range of national, regional and local groups advising on learning disabilities. He has a particular interest in physical health issues.

Eddie Chaplin

Dr Eddie Chaplin is a senior lecturer at London South Bank University. He has extensive clinical experience managing and working in a range of local and national mental health services for people with learning disabilities and autism. Eddie is editor for the *Advances in Autism* and *Advances in Mental Health in Intellectual Disabilities* journals, and recently published the first guided self-help manual specifically aimed at people with intellectual disabilities and autism.

Sarah Clayton

Sarah started working with families whose children were using night time positioning in 1998, and this work was published in *Physiotherapy* in 2000. In 2004 she co-wrote the accredited postural care courses using her skills as a fully qualified teacher. Sarah has worked with national charities such as In Control working to support their partners in policymaking and related family leadership courses since 2004. During 2010 she was shortlisted for an Accolade Award for a partnership project with Skills for Health for Most Effective Practice in Workforce Development.

In 2010 she co-wrote *The Patterns of Body Shape Distortion* with John Goldsmith, published within *Tizard Learning Disability Review*.

In September 2007 Sarah's oldest daughter Abigail was diagnosed with a malignant brain tumour aged just six, and she has undergone extensive treatment. Abi is now 15 and continues to do well with great support at school.

Sarah currently leads a fantastic team at Simple Stuff Works to develop and deliver their nationally accredited courses in postural care alongside their multi award winning equipment range.

Hayley Goleniowska

Hayley's ignorance of Down's syndrome came to the fore when her daughter was born, motivating her to create world-renowned blog Downs Side Up. It challenges fear and stigma and celebrates the narratives of those with the condition.

The award-winning website is part of the greater work Hayley does toward inclusion of those with a learning disability. Her daughter Natty was the first UK model with a disability to feature in a national Back to School campaign as she believes we all need to see ourselves represented in the media.

Publishing a beautiful book for children and support material for new families, writing for various publications, taking part in a BBC documentary, giving countless interviews and working alongside the NHS to ensure medical professionals value everyone's worth equally, Hayley ensures diversity in a gentle, heartfelt way.

Mark Gray

Mark is an independent consultant learning disability nurse specialising in dual sensory loss.

He was formerly the RNIB Multiple Disability Service training research and development officer from 1990 to 2005. He is a visiting tutor in Rehabilitation Studies Visual Impairment at Birmingham City University and runs a health and social care service providing, consultancy, training and personal budget support services. He is widely published and is an editor for several professional journals, a Nursing Times award Judge, and chair of the National Advocacy Charity POhWER.

Renée Francis

Renée Francis has been a registered learning disability nurse since 1997. She is the course director of the BSc (Hons) Learning Disability Nursing at London South Bank University. Her special interests are palliative care of people with intellectual disabilities, participatory research with people with intellectual disabilities and supporting families of people with intellectual disabilities. She is also interested in interprofessional learning and ensuring key messages about the health of people with intellectual disabilities are delivered across the nursing and midwifery curriculum.

Steve Hardy

Steve Hardy qualified as a learning disability nurse in 1994 and has worked in both clinical and educational settings. He is currently a nurse consultant in learning disabilities at Oxleas NHS Foundation Trust. Sharing news, information and developing resources is his keen passion. He is widely published in the mental health needs of people with learning disabilities, capacity and facilitating a platform for people with learning disabilities to be heard.

Jane Hart

Jane Hart has 21 years' experience as a registered learning disability nurse; 15 of which were spent as a nurse manager in residential services supporting people with learning disabilities, their families and carers, which has continued over the past six years in her role as community learning disability nurse with Oxleas NHS Foundation trust. Her professional interests focus on facilitating access to primary health care helping to prevent hospital admissions and supporting people when admitted to hospital by working with wards for better outcomes and safe discharge planning.

Crispin Hebron

Crispin is currently seconded to NHS England where he leads on health inequalities for people with learning disabilities and also works as a consultant nurse in a Mental Health and Learning Disability Foundation Trust in Gloucestershire. He has previously worked in the NHS and third sector in a range of nursing, project and leadership roles. He contributed as an investigator to the confidential inquiry into premature deaths in people with learning disability published in 2013, run by the Norah Fry research centre at Bristol University. He is part of the current National NHS IT review team and has published various articles and book chapters focusing on health issues, inequalities and the delivery of effective services for people with learning disabilities.

Tony Hollands

Tony Hollands, epilepsy nurse specialist, is currently employed in the Adult Learning Disability Epilepsy Service in Bromley, South East London, part of Oxleas NHS Foundation Trust. His background is in learning disability care since 1982. Then in 2003 he completed the MSc in Epileptology at Kings College and focused increasingly on epilepsy care for people with learning disabilities. He then gained experience as an epilepsy nurse in a neurology team at a district general hospital in Kent, before moving into his current post.

Daniel Marsden

Daniel Marsden (Twitter @dmarsden49) is a practice development nurse for people with learning disabilities in East Kent Hospitals NHS Foundation Trust. Having studied at the University of Brighton and Canterbury Christchurch University, Daniel has recently undertaken a participatory action research study relating to My Healthcare Passport, and is currently writing up the results for publication. He also has an article pertaining to EKHUFT 4C Framework for making reasonable adjustments in press. Daniel has spoken internationally on harnessing technology to support the delivery of person centred care for vulnerable adults, which resulted in short listings for Nurse of the Year and the Patient Safety Improvement Nursing Times Award 2013. Daniel regularly lectures at Canterbury Christchurch University and the University of Kent on a variety of subjects, and over the last three years has established a regional community of practice which has successfully generated income.

Daniel recently featured in Health Education England's #inspiringleadersinld campaign and is a founder of @WeLDNurses a two weekly twitter chat for learning disabilities nurses. Daniel is particularly interested in clinical systems leadership and digital facilitation and remains enthusiastic for being a critical companion or offering mentorship to anyone in the clinical leadership programme and the aspiring consultant practitioner programme.

Karina Marshall-Tate

Karina Marshall-Tate is a learning disability nurse who has led and managed national specialist inpatient and community services for people with learning disabilities with additional mental illness or behaviours that challenge. She currently leads an education and training project for healthcare staff who do not usually work in the field with the aim of increasing clinician confidence and capability and improving health outcomes for people with a learning disability.

Karina qualified as an RNLD from the University of Southampton in 2000. She has a BSc in Mental Health Work (University of Greenwich, 2003), using adapted psychosocial interventions for psychosis for people with learning disabilities and she is currently studying for an MSc in Advanced Clinical Practice at King's College London. Karina is a national steering committee member of the Royal College of Nursing Learning Disability Forum.

Marian Marsham

Marian Marsham is clinical lead for health access with Oxleas NHS Foundation Trust. She has 25 years' experience working with adults and children with learning disabilities, across a range of settings and roles. Marian has a passion for promoting excellent practice and cites her professional interest as 'making things better by enabling people to be their best'. In addition to writing about nurse education and accessing healthcare she has published research into the therapeutic role of community learning disability nurses.

Gwen Moulster

Gwen Moulster OBE (MA, Cert Ed, RNLD) is an independent consultant nurse and honorary senior fellow with the Faculty of Health, Social Care & Education, Kingston University and St George's, University of London. She is co-chair of the UK Learning Disability Consultant Nurse Network and a member of the UK steering group for modernising learning disabilities nursing.

Gwen has extensive experience of working closely with people who have learning disabilities, families, advocates and others to improve the quality of health experiences and outcomes. She is part of the team who developed the Health Equalities Framework (HEF), including presenting this with colleagues at conferences across the UK and in Australia and Finland.

Gwen has also been instrumental in the development and implementation of the Moulster & Griffiths model for learning disabilities nursing and pain profiles for people with profound and multiple learning disabilities.

Laurence Taggart

Laurence Taggart is a registered nurse for people with intellectual disability and a research psychologist. He works in the Institute of Nursing & Health Research, Ulster University, where he leads the Centre of Intellectual & Developmental Disabilities. Laurence is the 2013-2016 president of the Royal Society of

Medicine Intellectual Disability Forum and current chair of the Health SIRG of IASSIDD (International Association for the Scientific Study of Intellectual and Developmental Disabilities). Laurence's main interests focus on the health of people with intellectual disabilities.

Maria Truesdale

Dr Maria Truesdale is a lecturer in learning disabilities within the School of Health and Social Care at Edinburgh Napier University, Scotland. Having spent over a decade as a research psychologist in the field of learning disability her interests lie within the health of people with learning disabilities. She is an associate member of the Centre for Intellectual and Developmental Disabilities at Ulster University and is a member of the Health Special Interest Research Group of IASSIDD (International Association for the Scientific Study of Intellectual and Developmental Disabilities).

Sue Turner

Sue Turner trained as a nurse for people with learning disabilities in Bristol, and has worked within and managed a variety of services for people with learning disabilities. Sue was the Valuing People Lead in the South West Region for four and a half years. When she joined the National Development Team for Inclusion (NDTi) she led on the Improving Health and Lives (IHaL) Learning Disabilities Health Observatory project for three years. She now leads on learning disabilities for the NDTi, and is a co-director of IHaL.

Sally Wilson

Sally is an experienced RNLD working in an acute hospital as matron for older adults and safeguarding lead. Prior to taking this post she worked in an acute liaison role for five years. Her previous experience includes residential and nursing homes, managing respite, assessment and treatment unit and she has worked with all age groups from children to older adults.

Twenty years after first working with people with learning disabilities Sally is still passionate about all things to do with learning disability care.

She is a founder member of Team @WeLDNurses, which runs a fortnightly twitter chat for LD professionals, and there are other platforms including use of a Facebook page to support the sharing and dissemination of innovation and best practice examples within the field of LD nursing. Through this work, undertaken

as a volunteer, Sally remains committed to improving networking opportunities and the use of social media for people in LD care. Sally is currently studying for her Masters in advanced nursing studies.

Peter Woodward

Peter Woodward is a senior lecturer in learning disabilities at the University of Greenwich. His background is in challenging behaviour, mental health and forensic behaviours as well as the physical health of people with learning disabilities.

Introduction

People with learning disabilities are more likely to suffer from poor physical and mental health compared with the general population. They are likely to face health inequalities and live shorter lives. They are also two and a half times more likely to have multiple health needs than other people. The reasons for this are complex. People with learning disabilities are more likely to be affected by genetic conditions and syndromes, as well as neurological conditions such as epilepsy and developmental disorders such as autism. In addition to physical illness, people with learning disabilities have higher rates of physical disabilities (particularly those with severe and profound learning disabilities). As a result, they may need additional support for a variety of physical and psychological impairments including poor mobility or restricted movement, or sensory impairments such as poor hearing or sight. A number of people may also have physical health issues that have arisen due to lifestyle choices or having a routine imposed upon them. An example would be obesity, which increases the risk of conditions such as heart disease and diabetes.

Social disadvantage experienced by people with learning disabilities compared with the general population may also contribute to increased rates of physical and mental ill health. This can include increased levels of hardship, deprivation and abuse from others (for example hate crime, physical and sexual abuse and neglect). People with learning disabilities are also less likely to engage outside of familiar circles. This may affect quality of life because integration and inclusion are then limited and opportunities often missed. A lack of support may mean that people are unaware of and therefore less likely to access health services.

Reasonable adjustments are often required to improve access to services and the patient experience. This is necessary if we are to achieve equality in healthcare. Often clinicians, by their own admission, lack awareness of how illness may present in people with learning disabilities. They may also lack the skills necessary to capture the person's experience and health concerns accurately. This is required to build a picture of their health needs and any health risks they may be vulnerable to. A lack of awareness of the health needs of people with learning disabilities on the part of healthcare workers will often lead to a negative experience of healthcare. Often people with learning disabilities will have difficulty reporting their health needs or describing their experiences. They may also get frustrated in trying to express and articulate their feelings. This makes assessment more difficult for healthcare workers to complete, and often

symptoms may be missed. This can be worsened if the person is non-verbal or if symptoms are expressed through changes in behaviour e.g. a person might injure themselves if they are in pain. The difficulty in accessing healthcare extends to health prevention and health education programmes, as well regular general health checks, which are also seen at lower rates than the general population. However, there is evidence that in areas where reasonable adjustments are made, people with learning disabilities may access services (such as screening) at higher rates than the general population. Collaboration and co-ordination between health agencies for people with learning disabilities is generally poor, although this situation can vary greatly within different health trusts.

Our aim is to simplify what can be a complex area in order to improve understanding of how to meet an individual's physical health needs. This book provides a practical guide to a range of physical illnesses and health needs and how to support people with these conditions. Physical ill health can have a negative effect on general well-being and may lead to poor mental health. The book also covers mental health and mental well-being, as often people can miss the psychological issues that may arise in tandem with physical ill-health and may be missed.

We hope you enjoy this book, which explores these issues from a number of perspectives, including the point of view of people with learning disabilities and their carers, who bear the brunt of these inequalities.

Eddie Chaplin, Steve Hardy and Peter Woodward