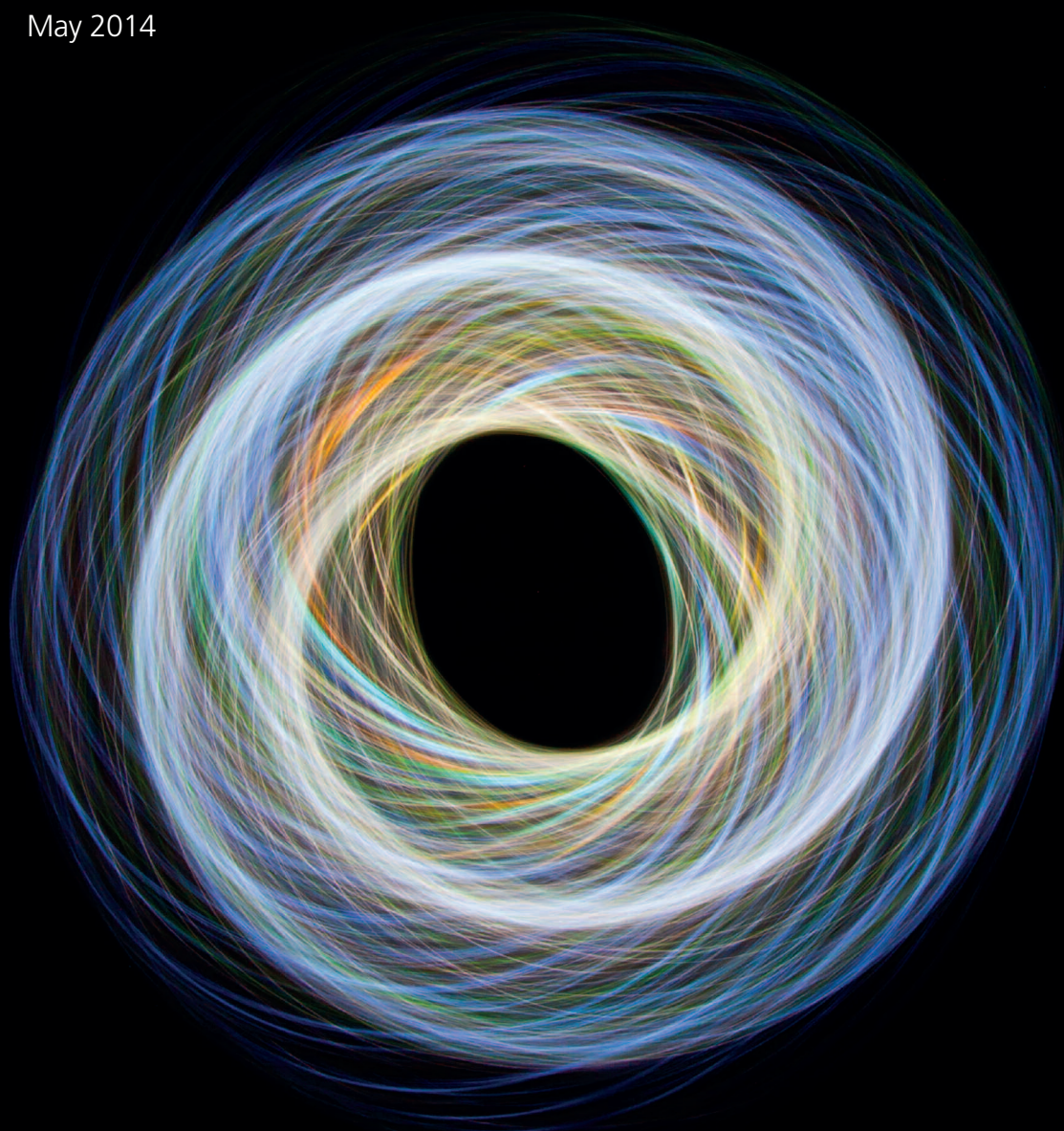# Recognising the importance of physical health in mental health and intellectual disability

Achieving parity of outcomes

May 2014

Editorial Board

Board of Science

This report was prepared under the auspices of the Board of Science of the British Medical Association, whose membership for 2013-14 was as follows:

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> The Board of Science, a standing committee of the BMA, provides an interface between the medical profession, the Government and the public. The Board produces numerous reports containing policies for national action by Government and other organisations, with specific recommendations and areas for action affecting the medical and allied professions.

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- Professor Dame Sue Bailey, President, Royal College of Psychiatrists
- Professor Vivienne Nathanson, Senior Director, BMA
- Professor Graham Thornicroft, Professor of Community Psychiatry, Institute of Psychiatry, King's College London.

Abbreviations

ADHD	attention-deficit hyperactivity disorder
ARM	annual representative meeting
BME	black and minority ethnic
BMI	body mass index
CAMHS	child and adolescent mental health services
CCG	clinical commissioning group
CHD	coronary heart disease
CHRT	crisis home resolution team
CIPOLD	Confidential Inquiry into Premature Deaths of People with Learning Disabilities
CMD	common mental disorder
CMO	Chief Medical Officer
COPD	chronic obstructive pulmonary disorder
CPN	community psychiatric nurse
CPD	continuing professional development
CQC	Care Quality Commission
CQUIN	commissioning for quality and innovation
CVD	cardiovascular disease
DES	direct enhanced service
DFLE	disability-free life expectancy
DH	Department of Health
DHSSPSNI	Department of Health, Social Services and Public Safety, Northern Ireland
DRC	Disability Rights Commission
FASD	fetal alcohol spectrum disorders
FP	foundation programme
GMC	General Medical Council
HLE	healthy life expectancy

HSCIC	Health and Social Care Information Centre
IAPT	Improving Access to Psychological Therapies
ICF	International Classification of Functioning, Disability and Health
JSNA	joint strategic needs assessment
LETB	local education and training board
MCA	Mental Capacity Act 2005
MEC	Medical Ethics Committee
MI	myocardial infarction
MRC	Medical Research Council
MUS	medically unexplained symptoms
NCISH	National Confidential Inquiry into Suicide and Homicide
NHS IQ	NHS Improving Quality
NICE	National Institute for Health and Care Excellence
ONS	Office for National Statistics
PbR	payment by results
PCT	primary care trust
QOF	quality and outcomes framework
RAID	rapid assessment interface and discharge
RCGP	Royal College of General Practitioners
RCN	Royal College of Nursing
RCP	Royal College of Physicians
RCPsych	Royal College of Psychiatrists
SMI	severe mental illness
SUDEP	sudden unexpected death in epilepsy
WHO	World Health Organization

Foreword
Professor Sheila the Baroness Hollins

For too long there has been an acceptance in society, and even in the medical profession, that people with mental health problems and intellectual disability will live shorter lives and will suffer because of unmet health needs. In the vast majority of cases, there is no good reason for this. But the voice of these vulnerable groups often goes unheard, and the status quo remains unchallenged.

It is distressing that in the 21st Century someone with a mental health condition will typically die between 15 and 20 years earlier than someone without, and that people with intellectual disabilities continue to suffer unnecessarily with untreated, or poorly managed, conditions. These vulnerable groups deserve the same rights as everyone else, to live healthier and longer lives. The medical profession has a vital role in helping to achieve this. Not only do we need to set the standard in raising aspirations for these groups and in challenging discrimination, but we also need to make sure our healthcare services deliver the best possible care.

Central to this is addressing the split between mental and physical health. All too often our health services are designed, and our future generations of doctors trained, as if somehow they are happening to different people, as if there is no connection between them. Action is also needed to tackle the stigma and discrimination that people with mental health problems and intellectual disability frequently experience in the provision of healthcare services. On the one hand, this is about improving the attitudes of medical professionals. At the other end of the spectrum, there is a need to tackle organisation-wide issues such as the way services are commissioned separately, and the underfunding of mental healthcare services relative to the scale and impact of mental health conditions.

Taking action on this is not just a matter of equality. It will have benefits across society. I have always believed that if we can get health services right for vulnerable groups, such as people with intellectual disability, then we can get them right for everybody else. Unfortunately we tend to do it the other way round. We try to get it right for people like ourselves first and then are surprised when somehow services do not quite meet the needs of those with more complex needs, or who perhaps need a bit more help navigating their way around the healthcare system.

I have a sense of optimism that we are starting to move in the right direction. In England, the idea of 'parity of esteem', where mental health is valued equally with physical health, is now enshrined in law. This has been complemented by the excellent work undertaken by professional bodies, such as the Royal College of Psychiatrists, as well as numerous charities and support organisations. There are also the right noises coming from health ministers across the UK. What is lacking is a clear range of actions that will help ensure that 'parity of outcomes' across physical health, mental health, and intellectual disability is achieved in practice.

The aim of this report is to start to identify what actions need to be taken to support doctors and the medical profession in changing the status quo. I cannot promise that it has all the answers, but it does set out a range of core actions that need to be collectively implemented, and adequately funded, to ensure that each patient receives 'whole person' care. These focus on the following key areas:
- promoting prevention and early intervention strategies
- delivering 'joined-up' care
- enhancing training and workforce planning
- encouraging a greater research focus on mental-physical multi-morbidity.

My hope is that this report will help lead to change, both in the way healthcare services are delivered to meet the needs of vulnerable groups, and in the attitudes of medical professionals towards intellectual disability and mental health. The key challenge will be to identify the drivers for this change. This will require continued leadership from the medical profession, as we are in the unique position of being able to listen to patients, and champion their rights for better healthcare.

On a personal note, I am so pleased that the Board of Science is publishing this report. I have been keen to raise awareness of the hidden health challenges faced by vulnerable groups ever since I first became involved with the BMA as its President. I am therefore very grateful to the team who have helped produce it, and also to those who have guided its development.

[signature]

Professor Sheila the Baroness Hollins
Chair, BMA Board of Science

Professor Sheila the Baroness Hollins

Professor Sheila the Baroness Hollins is Emeritus Professor of Psychiatry of Disability at St George's University of London, and prior to her retirement was Chair of the Academic Division of Mental Health for 3 years.

She holds an honorary Chair in the Department of Theology and Religion, University of Durham. She was President of the Royal College of Psychiatrists for 3 years from 2005 to 2008, and was appointed an Independent member of the House of Lords in 2010.

After qualifying at St Thomas's she was a GP in South London before training in psychiatry. Until she retired from clinical practice in 2006, she had been a Consultant Psychiatrist in Learning Disability in South West London for 25 years. She has had two secondments to the Department of Health as senior policy advisor in learning disability and autism.

Her clinical and research expertise is in the mental and physical health of people with intellectual and developmental disabilities. She is the chair of Beyond Words, a community interest company, which promotes the use of pictures to communicate about health and wellbeing to people with learning and communication disabilities.

She was President of the BMA from 2012-2013, and appointed as Chair of the BMA Board of Science in June 2013.

Foreword
Norman Lamb MP

There is compelling evidence that people with a mental illness or a learning disability die earlier than the general population. This says something, of course, not only about the services available to support these problems, but also how we, as a society, treat people with a mental illness or a learning disability. This must change.

This is an issue that goes to the heart of parity – the Government's drive to ensure equal priority for mental and physical health in services, testing our ambition to reduce premature avoidable mortality for all people in society.

It's also reflected in the Government's response to the Confidential Inquiry into Premature Deaths of People with Learning Disabilities. We established the Confidential Inquiry in 2010. We funded and supported it for three years. Although the Inquiry's report makes for sobering reading, it gives us a clear indicator of the areas that need to be tackled. Our response makes clear our determination to eradicate substandard practice; and to work in partnership across the health and care system to deliver the improvements that we all want to see.

Our drive for parity and our specific focus on reducing premature mortality, set out in 'Living Well for Longer: National Support for Local Action to reduce premature avoidable mortality' (April 2014), are crucial in addressing the health inequalities which people with mental health problems and learning disabilities face.

But these are just part of a programme of activity from Government and partner organisations designed to deliver system change and a shift in culture and attitudes.

Safe, appropriate, high quality care is a key priority for NHS England. NHS England is under specific duties to tackle health inequalities and advance equality. By 2015, we expect progress to be made on supporting people with multiple long-term physical and mental health conditions and improving their quality of life and preventing people from dying prematurely.

Public Health England will be supporting local action to improve the health and wellbeing of all, with a particular focus on improving the physical health of people with mental illness or learning disabilities – all efforts towards reducing shocking levels of premature mortality.

The NHS Outcomes Framework 2014/15 and the Public Health Outcomes Framework 2013/16 will allow us to measure the quality of services and outcomes for people with mental health problems and learning disabilities.

Taken together, these frameworks set out a spectrum of specific indicators that help us understand how we are doing in preventing people with learning disabilities and mental health problems from dying prematurely. Health improvements for people with learning disabilities and mental health problems will be a crucial element of success across the framework as a whole.

'Transforming Care', our national response to Winterbourne View Hospital, sets out a programme of actions to ensure people with learning disabilities or autism no longer live inappropriately in hospital; and receive optimum care.

People with mental health problems and learning disabilities and their families must remain at the heart of everything we do. Their views, needs and experience should continue to inform national and public policy and service development.

We have a long way to go but change must be effected at scale and pace. There can be no more excuses or procrastination from any part of the system if we are to achieve our collective goal of a society where everyone is valued and has the chance to lead productive and, most importantly, healthy lives.

Norman Lamb MP
Minister of State for Care and Support

Norman Lamb MP

Norman Lamb became Member of Parliament for North Norfolk in 2001. Norman read law at the University of Leicester. He worked for Norwich City Council as a senior assistant solicitor before joining Norfolk solicitors Steele and Co., where he became a partner and head of the firm's specialist Employment Unit.

He was a member of Norwich City Council 1987-91, leading the Liberal Democrats for the last two years of his term. Norman has held various positions in the Liberal Democrat party. He was Lib Dem Deputy Spokesperson for International Development (2001-02), a Treasury spokesman (2002-03), Parliamentary Private Secretary (PPS) to Charles Kennedy (2003-05) and Shadow Trade and Industry Secretary (2005-06).

From March to December 2006, Norman was Chief of Staff for party leader Sir Menzies Campbell. In December 2006 he was appointed Liberal Democrat Shadow Health Secretary. In May 2010 Norman was appointed Assistant Government Whip, as well as Chief Parliamentary and Political Adviser and PPS to the Leader of the Liberal Democrats and Deputy Prime Minister, Nick Clegg.

In February 2012 Norman was appointed Parliamentary Under-Secretary of State for Employment Relations, Consumer and Postal Affairs at the Department of Business, Innovation and Skills. In September of the same year he was appointed Minister of State for Care & Support at the Department of Health. Norman is married with two sons and lives in Norfolk.

Contents

Chapter 1. Introduction

'Third world mortality in a first world country'. This is how one expert in the field of psychiatry describes the disparity in mortality rates experienced by people with mental health problems in high-income countries like the UK.[1] One in three of the 100,000 people who die prematurely each year in England have a mental illness[2]: on average, men with mental health problems die 20 years earlier, and women die 15 years earlier, than the general population.[3,4,5] While this shortened life expectancy reflects higher rates of suicide, as well as accidental and violent fatalities, the majority of deaths in this group arise from preventable causes and could have been avoided by timely medical intervention (see **Chapters 5** and **6**).

It is now well-established that people with mental health problems are at an increased risk of adverse physical health outcomes (see **Chapter 4**). Among patients with a severe mental illness (SMI), such as schizophrenia, an estimated 60 per cent of excess mortality is due to physical illness: a person with an SMI is more likely to have a co-morbid physical health problem, and is more likely to die of that illness within five years, when compared to the general population.[6] Being diagnosed with a long-term physical condition can also have a detrimental impact on a patient's mental health: over four million people in England[7] and 600,000 people in Scotland[8] with a long-term physical illness also suffer from a mental health problem. In the case of depression, a 'bi-directional' relationship is apparent, indicating that depression may be a cause and a consequence of some physical illnesses, including cardiovascular disease, cancer, epilepsy and stroke.[9] Coexisting mental and physical illness is often intertwined with social exclusion and deprivation. Rates of mental health problems have been found to rise as the number of long-term physical conditions increases and as socio-economic deprivation worsens.[10,11]

The statistics are stark, yet physical health problems continue to be under-addressed among people with mental health problems,[12] while the mental health of people with long-term physical conditions is all too often neglected.[6] A similar situation exists for individuals with intellectual disabilities. In 2008, the 'Independent Inquiry into Access to Healthcare for People with Learning Disabilities' reported that people with intellectual disabilities have higher levels of unmet need and received less effective treatment than the general population.[13] More recent findings from the 'Confidential Inquiry into premature deaths of people with learning disabilities' (CIPOLD) – which investigated the deaths of 247 people with an intellectual disability across five primary care trust (PCT) areas in the south west of England between 2010 and 2012 – showed that 29 per cent experienced difficulty or delay in diagnosis, further investigation or specialist referral for an illness.[14] In the worst cases, people with intellectual disabilities continue to suffer unnecessarily with untreated, or poorly managed, conditions.

The persistent excess morbidity and mortality in people with mental health problems, and in people with an intellectual disability, underlines the urgent need to redress the situation and make 'parity of outcomes' across physical health, mental health, and intellectual disability a reality. The aim of this BMA Board of Science report is to understand what needs to be done to realise this goal.

Throughout this report, mental health and intellectual disability are considered side by side. While it is recognised that intellectual disabilities are distinct from mental illness, and can occur without any other mental or physical disorder, this approach mirrors that adopted by a number of organisations, including the Disability Rights Commission (now a part of the Equality and Human Rights Commission) in their report 'Equal Treatment', and the Royal College of Psychiatrists (RCPsych) in their 'Fair Deal Manifesto'.

What action has the BMA already taken?

Mental health problems and intellectual disability can begin at a young age (including from birth in some cases), and their consequences can be felt throughout the individual's life. It is estimated that approximately three quarters of adult mental disorders are extensions of juvenile disorders, and that 50 per cent could be diagnosed before the age of 15.[15] Despite the early onset, diagnosis may take time. Opportunities to protect and promote good mental health must therefore begin before birth and continue thereafter. This 'life course' perspective, where health and wellbeing are integrated on a continuum from pre-conception to old age, is supported by the BMA and underpins the Association's 2013 Board of Science report, 'Growing up in the UK', which examines child health policy across the UK. 'Child and adolescent mental health' was also considered by the BMA Board of Science in 2006 through the publication of a guide for healthcare professionals on the topic. Though

focused primarily on barriers to receiving, and strategies for improving, mental healthcare, the guide also recognised the prevalence of co-morbidity among children under 16 years of age, and the health inequalities experienced by this group. Key findings and relevant recommendations from this report are summarised in **Box 1**.

Box 1: Overview of the key findings and relevant recommendations from *Child and adolescent mental health: a guide for healthcare professionals*

- In 2004, one in ten children and young people (10%) aged 5-16 had a clinically diagnosed mental disorder.
- One in five children diagnosed with a mental health problem had more than one disorder, while children with an emotional disorder were more likely to suffer from poor physical health (23% compared to 5% of children with no disorder).[16,17]

The report stressed that the implementation of child and adolescent mental health services (CAMHS) needs to be properly monitored and that research into the outcomes of the strategies should be conducted. The report also called on the Government to address the shortage of mental healthcare professionals, and emphasised the inadequacy of mental health services for children and young people with intellectual disabilities. The need for mental health promotion, multi-agency working, and strategies to improve mental healthcare was also highlighted.

While some improvements have been made since 2006, including extending the Improving Access to Psychological Therapies (IAPT) Programme to cover children and young people, the overall provision of CAMHS remains an area of concern. A review conducted by Health Inspectorate Wales and the Wales Audit Office in 2013 found that children and young people who access mental health services in Wales continue to be put at risk: despite being expanded, community mental health services are still not available in all parts of Wales. A lack of capacity is resulting in children and young people being placed out of the area in which they live to receive treatment, with some children and young people being inappropriately admitted to adult mental health wards.[18] The distance can inhibit children from seeing their family, and accessing their support networks, which can be important to the patient's recovery.

Similar problems are apparent in England. Despite a pledge made by the DH in 2010 that children and young people would only be treated on adult psychiatric wards in exceptional circumstances, a 2014 investigation by BBC News and the journal Community Care found that 350 under-18s have been admitted so far to adult mental health wards in 2013-14, compared with 242 two years earlier.[19] There is also a paucity of up-to-date data on the prevalence of mental health problems among children and young people. The data collected in 2004 on the mental health of children and young people by the Office for National Statistics (ONS) remains one of the most comprehensive statistical surveys of the mental health of children and young people in Great Britain. Despite being over a decade old, it has not been updated.

Following the publication of 'Child and adolescent mental health', the BMA supported the RCPsych 'Fair Deal' campaign. This was a three year project, running from 2008 to 2011, dedicated to tackling inequality in mental healthcare compared to physical healthcare. In addition to acknowledging the links between physical and mental illness, the 'Fair Deal' campaign outlined how the provision of mental healthcare to people with physical illness, and the quality of physical healthcare provided to people diagnosed with mental health problems, could be strengthened and improved. In their final, 'year three' report, the RCPsych reviewed the effectiveness of the campaign and considered that the profile of mental health issues had risen within the government and public consciousness during this period.[20]

The publication of new mental health strategies by the devolved nations is one example of the rise in importance of mental health issues during the course of the RCPsych's 'Fair Deal' campaign. The Department of Health, Social Services and Public Safety in Northern Ireland (DHSSPSNI) outlined their intentions to establish a more 'holistic' approach to mental health a decade ago in their 2003 mental health strategy and action plan.[21] This was reaffirmed in the DHSSPSNI 2011 'Service

Framework for mental health and wellbeing'.[22] The English[23], Scottish[24] and Welsh[25] mental health strategies, published between 2011 and 2012, also stated their commitment to improving the physical health of people with mental health problems. Some legislative changes have since taken place. In England, Baroness Hollins' amendment to the *Health and Social Care Bill* (now Act) placed the Westminster Government's commitment to 'parity of esteem' – valuing mental health and physical health equally – on a statutory footing (see **Box 2**). Section 1 of the *Health and Social Care Act 2012* requires the Secretary of State to:

'*promote a comprehensive health service designed to secure improvement –*
(a) in the physical and mental health of the people of England, and
(b) in the prevention, diagnosis and treatment of physical and mental illness.'

Box 2: A definition of parity of esteem

Parity of esteem is a term used, but not defined, in the Government's most recent mental health strategy for England, 'No health without mental health'. Building on the RCPsych definition, this report considers parity of esteem to mean *'valuing mental health equally with physical health'*. A parity approach to mental health aims to deliver:
- equal access to effective, safe care
- equal efforts to improve the quality of care
- the allocation of resources on a basis commensurate with need
- equal status within healthcare education and practice
- equally high aspirations for service users
- equal status to the measurement of health outcomes
- holistic, integrated care with mental health considered alongside physical health.

Source: Royal College of Psychiatrists (2013) *Whole-person care: from rhetoric to reality. Achieving parity between mental and physical health. Occasional paper OP88*. London: Royal College of Psychiatrists.

From an international perspective, the World Health Organization (WHO) recognises disability – which it defines as including *'persons with intellectual impairments or mental health conditions'* – as a global public health issue, a human rights issue, and a development priority. In May 2013, the Sixty-sixth World Health Assembly adopted resolution WHA66.9, which endorsed the WHO and World Bank 2011 'World report on disability'. The resolution requests that the Director-General prepare a comprehensive WHO action plan, running from 2014-2021, based on the evidence in the 2011 World report on disability. The 'Better Health for Persons with Disabilities' action plan aims to:
- address barriers and improve access to healthcare services and programmes
- strengthen and extend habilitation and rehabilitation services
- support the collection of appropriate and internationally comparable data on disability, and promote multidisciplinary research on disability.[26]

Three years earlier, in 2010, the WHO launched the 'Better Health, Better Lives' declaration which aims to ensure that all children and young people with intellectual disabilities and autism are fully participating members of society. This was subsequently adopted by all European health ministers in September 2012.[27]

The Sixty-Sixth World Health Assembly also adopted the 'comprehensive mental health action plan 2013-2020', and urged Member States to implement the proposed actions in the plan, as adapted to specific national circumstances. The action plan relies on six cross-cutting principles and approaches (see **Box 3**).

Box 3: Principles of the WHO Comprehensive Mental Health Action Plan, 2013-2020

- **Universal health coverage**: Regardless of age, sex, socio-economic status, race, ethnicity or sexual orientation, and following the principle of equity, persons with mental disorders should be able to access, without the risk of impoverishing themselves, essential health and social services that enable them to achieve recovery and the highest attainable standard of health.
- **Human rights**: Mental health strategies, actions and interventions for treatment, prevention and promotion must be compliant with the Convention on the Rights of Persons with Disabilities and other international and regional human rights instruments.
- **Evidence-based practice**: Mental health strategies and interventions for treatment, prevention and promotion need to be based on scientific evidence and / or best practice, taking cultural considerations into account.
- **Life-course approach**: Policies, plans and services for mental health need to take account of health and social needs at all stages of the life course, including infancy, childhood, adolescence, adulthood and older age.
- **Multisectoral approach**: A comprehensive and coordinated response for mental health requires partnership with multiple public sectors such as health, education, employment, judicial, housing, social and other relevant sectors as well as the private sector, as appropriate to the country situation.
- **Empowerment of persons with mental disorders and psychosocial disabilities**: Persons with mental disorders and psychosocial disabilities should be empowered and involved in mental health advocacy.

Source: Sixty-Sixth World Health Assembly (2013) *Comprehensive mental health action plan 2013–2020, Agenda item 13.3, WHA66.8*.

Why is the BMA publishing this report?

Despite the positive intentions outlined in the mental health strategies of the devolved nations, and in the WHO action plans, mental health in the UK is not universally held in the same regard as physical health, nor does it receive commensurate levels of funding. Excess morbidity and mortality among mental health and intellectual disability patients persists, while stigma and discrimination towards these groups remains apparent. It is also clear that the commitment to address this problem falls short of action taken on physical health conditions. This is epitomised by the 2013 'call to action to reduce avoidable premature mortality' – launched by the Secretary of State for Health, Jeremy Hunt – which noticeably lacked in actions to address the physical health of people with mental illness (see **Chapter 7**).[28]

Caring for patients with physical and mental health problems, and with intellectual disabilities, represents a substantial challenge for doctors and the allied health professions. Management of co-morbidity (or multi-morbidity – see **section 2.3**) has been identified by the WHO as one of the overriding problems facing healthcare systems, with the prevalence of co-morbidities expected to increase in the coming years.[29] Unless they are confronted, the deep-seated disparities in the funding of, and access to, mental healthcare, will make tackling the predicted rise in co-morbidity even more challenging.

What is lacking is clear guidance outlining the types of actions that need to be taken to ensure that parity can be achieved in practice. In April 2012, the RCPsych was asked by the Minister of State for Care Services – in partnership with the Department of Health (DH) and NHS Commissioning Board Authority Medical Directorate – to address this knowledge gap and provide advice to the Ministerial Advisory Group on Mental Health Strategy on how to achieve parity of esteem between mental and physical health. An expert working group was convened and included members of the Royal Colleges, mental health charities, service users, as well as the previous Chair of the BMA's Consultants Committee Psychiatry Subcommittee, Dr Shanu Datta. 'Whole-person care: from rhetoric to reality' was published in March 2013.[30] It features recommendations to achieve parity across 10 areas, including funding, research, treatment, and integrated care.

Recognising the scale of the inequality between mental and physical healthcare, the BMA Board of Science began to pursue its own research into this area in 2012. The Board's aims were as follows:

1.   to demonstrate the urgent need to reduce the excess morbidity and mortality among people with mental health problems and / or intellectual disability;
2.   to make 'parity of outcomes' a reality for these groups by examining what evidence-based interventions are necessary to reduce excess morbidity and mortality.

Curbing the suicide rate is an important aspect of achieving parity of outcomes, and one which successive governments have tried to address, but without adequately considering the relationship of austerity and joblessness with suicide. Excess mortality, however, mainly results from the under-diagnosis, treatment and prevention of co-morbid physical health problems in mental health and intellectual disability patients. This latter point is now well-documented (**see Chapter 4**). The reduced life expectancy among people with mental illness was argued to represent *'[A]t best a failure to act on evidence; at worse a form of lethal discrimination'* in a 2013 BMJ editorial.[31] The same is true for intellectual disability; Hollins and Tuffrey-Wijne, also writing in the BMJ in 2013, note how *'mainstream health professionals seldom raise concern about failures in the treatment of people with learning disabilities'*, despite studies repeatedly highlighting the premature mortality and unusual patterns of death in this group.[32]

A human rights perspective is therefore essential in responding to the national and international burden of mental disorders. Despite the 'right to health' having become law in 126 countries worldwide – through their ratification of the 'United Nations Convention on the Rights of Persons with Disabilities' – since 2006, human rights violations and discrimination experienced by people with mental health problems and intellectual disability remains widespread. While measurable progress has been made towards treating people with major communicable diseases, such as HIV, Thornicroft highlights how we *'continue to disregard the physical health needs of people with mental illness and act as if they are of less worth than others.'* [31] The BMA Board of Science acknowledges from the outset of this work that establishing parity of esteem, and achieving parity of outcomes, between mental and physical health, are demanding goals, as one Board member reflects:

> *'[…] giving parity to mental health is a massive paradigm shift which will have huge effects for years to come…it is something that most people, and I include myself in this, have not even started to take on board. It is hard to think of a more important change since the closing of the asylums.'*
> Dr Philip Steadman, BMA Board of Science member, and consultant psychiatrist

There is a clear need to move from inaction to action on these issues and a strong commitment to change at policy level is an important place to start. This report sets out the BMA's vision for making 'parity of outcomes' a reality. It has been informed by, builds on, and in some places extends, the analysis undertaken by the RCPsych's expert working group on parity. It also takes account of the 2013 BMA President's seminar on tackling discrimination in the provision of physical healthcare for people with intellectual disabilities and people with mental health problems. A key challenge arising from the seminar was how to improve the identification, treatment and recovery of mental health and intellectual disability patients from physical illness, and erase the discrimination that these two groups encounter. A note of the seminar is provided in **Appendix 1**.

This report starts by highlighting the prevalence of mental health conditions and intellectual disability in the UK, discusses their relationship with physical health, and goes on to examine the barriers that inhibit parity of outcomes from being achieved. **Chapter 7** outlines the areas of action needed to overcome these barriers and make parity of outcomes a reality. It also responds to the RCPsych's call – made in their 2013 report 'Whole person care: from rhetoric to reality' – for the BMA to consider how doctors can adopt a more aspirational approach to the care of people with mental health problems. Areas for action range from rethinking the way in which all doctors are trained in mental health and intellectual disability, to identifying system-level changes.

This report is intended for policy makers with strategic or operational responsibility for the commissioning and provision of health and social care in the UK, as well as for all doctors and other professional associations. It builds upon the BMA's 2006 report on 'Child and adolescent mental health', and focuses primarily on the experience of adults aged 18 and over, though the areas for action are applicable to all ages.

Key message

There is an urgent need to reduce the excess morbidity and mortality among people with mental health problems and / or intellectual disability. To realise this goal, and make 'parity of outcomes' a reality, action is needed to promote prevention and early intervention strategies; enhance training and workforce planning to improve the quality of care these groups receive; deliver more joined-up care, particularly through improving commissioning and delivery processes; and encourage a greater research focus on mental-physical multi-morbidity. Provisions for a national mortality review system should also be implemented across the UK in relation to people with intellectual disabilities, and for people with a mental illness.

Chapter 2. Defining mental health, intellectual disability and physical health

The preamble to the Constitution of the WHO stresses that *'[H]ealth is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.'*[33] This broad, inclusive definition – which recognises the interconnected nature of physical and mental health – is one of the most longstanding, and widely accepted, explanations of what it means to be healthy. Separate frameworks and classifications, have been developed over the years for use in clinical practice and research, particularly in the case of mental health. These are outlined in the following sub-sections.

2.1 Mental health problem

The term 'mental health problem' can be used to describe a wide range of issues, from common experiences of feeling worried and concerned about everyday life, to more severe and enduring psychiatric disorders.[a] A number of frameworks and classifications have been developed to aid the identification of mental health problems including the WHO 'ICD-10 Classification of Mental and Behavioural Disorders'[34] and the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-V).

The terminology used to describe a mental health condition can vary, particularly across different cultures. The following definition is used in the DH 2011 mental health strategy for England, 'No Health Without Mental Health':

> '*Good or positive mental health is more than the absence or management of mental health problems; it is the foundation for wellbeing and effective functioning both for individuals and for their communities.*'[23]

The term severe mental illness (SMI) is often used to describe mental health problems that typically involve psychosis (hallucinations or delusions), such as schizophrenia, and bipolar affective disorder. It is recognised that there is little consistency in how SMI is used in practice and that there is no internationally agreed definition.[35] The National Institute of Mental Health, based in Washington DC, developed a definition in 1987 that categorised individuals as having an SMI if they met three criteria: diagnosis of a non-organic psychosis or personality disorder; duration characterised as involving prolonged illness and long-term treatment (2 years or longer), and dysfunction (based on the 'Global Assessment of Functioning' scale).[35] In this Board of Science report, the term SMI is used throughout while acknowledging the limitations highlighted here.

2.2 Intellectual disability

Intellectual disabilities are distinct from mental illness and can occur without any other mental or physical disorder, though there is a higher prevalence of mental illness in people with intellectual disabilities.[36] A variety of terms are used to describe intellectual disabilities. The Westminster Government adopted the term 'learning disability' in 1991, replacing pejorative terms such as 'mental handicap' or 'mental deficiency'. A 2001 White Paper on learning disability defined it as the presence of:

> '*[A] significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) with a reduced ability to cope independently (impaired social functioning) which started before adulthood, with a lasting effect on development.*'[37]

This definition is broadly consistent with the WHO ICD-10 classification of 'mental retardation' as:

> '*…a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities.*'[b,38]

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a   'Mental health problem' is a term in common use and in this context refers to 'mental illnesses' or 'mental disorders'.

b   The ICD-10, version 2010, continues to use the term 'mental retardation' rather than learning or intellectual disability. The UK Health Departments do not use this term since it is considered outdated and, to many, offensive.

A 'new approach' to intellectual disability was adopted in the WHO's International Classification of Functioning, Disability and Health (ICF).[39] Published in 2001, the ICF aimed to 'mainstream' disability by recognising it as a universal human experience, rather than something that only happens to a minority of people. The ICF is structured around the three broad components: body functions and structure; activities (related to tasks and actions an individual can undertake); and participation (involvement in a life situation). The classification shifts the focus away from examining only the medical or biological cause of disability and towards understanding its impacts. By taking into account the functioning of the whole person, disability is understood as a complex interaction between contextual factors (including social, personal and environmental factors) and the health condition.[40]

Intellectual disability is used throughout this report as interchangeable with learning disability. It is a term that is increasingly used in international dialogue, particularly since 'learning disability' is used in some countries to refer to conditions like dyslexia, where there is no necessary link with an intellectual disability.[41] It should also be acknowledged that people with an intellectual disability are not a homogenous group; they represent a wide spectrum of abilities, clinical presentations, co-morbidities and behaviour.[42]

2.3   Physical health

The burden and impact of disease has traditionally been measured by the general, or condition-specific, mortality rate – the number of deaths in a population per unit of time. Mortality data may also be stratified according to age, class or ethnicity to highlight disparities in health across groups. The infant mortality rate, for example, is a good indicator of the overall health status of a population, and is a major determinant of life expectancy at birth for that population.

Focusing only on mortality does not capture *'the experience of good health and well-being across life'*, nor does it acknowledge variation in the length of time people can expect to live in good health.[43] As life expectancy continues to increase in the UK, it is important to question whether these additional years are being spent in good health or in prolonged poor health and dependency.[44] The DH estimates that there are 15 million people in England living with at least one long-term condition. This is defined by the DH as a long-standing illness, disability or infirmity that cannot be cured but which may be amenable to management through medication and / or therapy.[45] The introductory chapter highlighted that long-term conditions may also be accompanied by co-morbid mental health problems. While there is no agreed-upon definition of co-morbidity, it is traditionally used to indicate the presence of two conditions occurring simultaneously in a patient. Multi-morbidity may be used interchangeably with co-morbidity, though it is increasingly used to denote the occurrence of a combination of more than two illnesses or conditions.

Measures of 'health expectancy' have been developed to address some of the limitations of crude mortality rates and to reflect the burden of long-term conditions. They represent:

> *'…estimates of the average number of years a person would live in a given health state if he/she experienced the specified population's particular age-specific mortality and health status for that time period throughout the rest of his/her life.'*[44]

The ONS publishes two different types of health expectancy estimates:
- healthy life expectancy (HLE) – life spent in very good or good general health
- disability-free life expectancy (DFLE) – life spent free from a limiting persistent illness and disability.

2.4   Premature mortality

There is a lack of consensus among researchers on how premature mortality should be defined and reported. At its simplest, it is the number of deaths under a selected age threshold,[c] reported as a proportion of total deaths. Focusing only on the number of deaths does not take into account the age structure of a population. Data published in the Public Health Outcomes Framework in England are based on standardised rates that make allowances for differences in the age make up of the population and the fact that death rates are higher in older populations.[46] Age-standardised rates are also used in Scotland, Wales and Northern Ireland.

This is further complicated by the use of a number of different terms – sometimes interchangeably – when discussing premature mortality, including avoidable, amenable, and preventable mortality. The ONS has established distinct definitions for these three categories as follows:

Amenable mortality: A death is amenable (treatable) if, in the light of medical knowledge and technology at the time of death, all or most deaths from that cause (subject to age limits if appropriate) could be avoided through good quality healthcare.

Preventable mortality: A death is preventable if, in the light of understanding of the determinants of health at time of death, all or most deaths from that cause (subject to age limits if appropriate) could be avoided by public health interventions in the broadest sense.

Avoidable mortality: Avoidable deaths are all those defined as preventable, amenable or both, where each death is counted only once.[47]

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c ONS methodology defines all deaths among those aged 75 and over as not avoidable: therefore premature mortality data in the UK are shown in relation to all deaths among those aged under 75.

Chapter 3. Prevalence of mental health conditions and intellectual disability in the UK

Mental health problems are the largest single source of disability in the UK. In 2011, they accounted for 22.8 per cent of the 'burden of disease', compared to 15.9 per cent for cancer and 16.2 per cent for cardiovascular disease.[48] While there are limited and patchy data on mental health conditions and intellectual disability, the following provides a more detailed picture of the situation across the UK.[d]

3.1   England

'Valuing people', a report produced by the DH in 2001, estimated that there were approximately 210,000 people (adults and children) with severe intellectual disabilities in England, and about 1.2 million living with a mild or moderate disability. Slightly different figures were produced by the Learning Disabilities Observatory a decade later, based on information collected by government departments on the presence of intellectual disabilities among people using particular services, overall population predictions for England, and the results of epidemiological research. They estimated that there were 905,000 adults (aged 18+) with intellectual disabilities in England in 2011, with 189,000 (21%) known to social services.[49] This equates to a prevalence rate of around 17 persons per 1,000 population, with 3.5 persons per 1,000 population known to services.[37] **Table 1** shows how prevalence estimates vary across age groups and by gender.

Table 1: Estimated number of adults with intellectual disabilities, England 2011

Age group	Known to learning disability services			In the population		
	Men	**Women**	**Adults**	**Men**	**Women**	**Adults**
18-19	5,224	3,186	8,410	22,101	13,672	35,773
20-29	21,649	16,780	38,429	112,025	73,719	185,744
30-39	20,112	15,449	35,561	97,702	66,788	164,490
40-49	26,946	20,256	47,201	105,904	73,893	179,797
50-59	16,324	13,751	30,075	77,873	56,093	133,966
60-69	10,999	8,467	19,465	61,954	45,020	106,974
70-79	4,271	3,109	7,380	34,471	26,862	61,332
80+	1,538	940	2,478	17,478	19,202	36,679
Total	107,063	81,937	189,000	529,507	375,249	904,755

Source: Emerson E, Hatton C, Robertson J et al (2012) *People with learning disabilities in England 2011*. Lancaster: Improving Health and Lives Learning Disabilities Observatory, Lancaster University.

Detailed information on mental health problems in England is provided by the household survey of adult psychiatric morbidity. In 2007, the survey reported that 16.2 per cent of adults met the diagnostic criteria for at least one common mental disorder (CMD) – mental conditions that cause marked emotional distress and interfere with daily function, but do not usually affect insight or cognition. In the same survey, 16.7 per cent of people said that they had thought about committing suicide at some point in their life, 5.6 per cent said that they had attempted suicide, and 4.9 per cent said that they had engaged in self-harm. The overall prevalence of psychotic disorders – which includes schizophrenia and bipolar disorder – in the previous year was 0.4 per cent, or 4 persons per 1,000 population. In men and women the highest prevalence was observed in those aged 35 to 44 years (0.7% and 1.1% respectively).[e,50]

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d   It is important to note that while the most recent data available have been included, in some cases these data are over a decade old. Wherever possible, these data have been supplemented with prevalence estimates from the academic literature and other sources.

e   At the time of writing, the Minister of State for Care and Support, Norman Lamb, had commissioned the next Adult Psychiatric Morbidity Survey, due to run in 2014.

3.2 Northern Ireland

A study of the prevalence of intellectual disability in Northern Ireland was undertaken in 2003. It identified a total of 8,215 persons (adults aged 20+) with moderate, severe and profound intellectual disabilities through data from SOSCARE (Social Services Client Administration and Retrieval Environment), and social security systems. This equates to a prevalence rate of approximately 4.5 persons per 1,000 population. **Table 2** provides a breakdown by age group and severity of disability.[51]

Table 2: The prevalence of intellectual disability in Northern Ireland by age and severity, 2003

Age bands	Moderate	Severe / Profound	Total
0-19	6,432	1,718	8,150
20-34	2,504	1,047	3,551
35-49	1,489	949	2,438
50+	1,473	753	2,226
Totals	**11,898**	**4468**	**16,366**

Source: McConkey R, Spollen M & Jamison J (2003) *Administrative prevalence of learning disability in Northern Ireland. Report to Department of Health, Social Services and Public Safety*. Belfast: Department of Health, Social Services and Public Safety.

The first results from the 2011 Northern Ireland Health and Well-Being Survey found that 19 per cent of the population aged over 16 showed signs of a possible mental health problem such as depression – a prevalence rate of 190 persons per 1,000 population – with women more likely to show signs than men (20% versus 17% respectively).[52] The DHSSPSNI estimate that, in terms of the scale of the problem, prevalence figures for mental health problems in Northern Ireland are 25 per cent higher than in England.[53] Findings from the Northern Ireland Study of Health and Stress – conducted between 2004 and 2008 and based on a face-to-face household survey of 4340 individuals aged 18 and over – found a lifetime prevalence of any mental disorder of 39.1 per cent (391 persons per 1,000 population). The most prevalent disorder category was anxiety disorders (22.6%) followed by mood disorders (14.1%) and impulse control disorders (8.6%).[54]

3.3 Scotland

The annual 'Same as You' review in Scotland surveys the number of adults (aged 18+) with intellectual disabilities who are known to local authorities. In 2011, 32 local authorities provided information on 26,036 adults with intellectual disabilities across Scotland. This represents a 4.9 per cent decrease in the number of adults with intellectual disabilities compared to 2010 figures and is equivalent to a prevalence rate of approximately 6.0 adults per 1,000 population. Geographical variation in prevalence was apparent: while Perth & Kinross recorded a rate of 3.9 adults with intellectual disabilities per 1,000 population, the comparable figure in Dundee was 9.2.[55]

Based on data from 2007, it is estimated that one in five people in Scotland aged over 16 will experience a mental health problem in their lifetime.[56] **Figure 1** provides a more detailed breakdown of the prevalence of mental health problems in Scotland: in 2006, 15 per cent of the population had a possible mental health problem (a prevalence rate of 150 persons per 1,000); 14 per cent had a diagnosed mental health problem (a prevalence rate of 139 persons per 1,000); and 0.4 per cent had been admitted to hospital as a psychiatric inpatient (a prevalence rate of 4 persons per 1,000).[57]

Figure 1: Estimated prevalence of mental health problems in the Scottish adult (16+) general population (4,195,000), 2006

0.4%   17,000

Tier 1
Admitted to hospital as a psychiatric inpatient (year)

No routine data

Tier 2
Accessed specialists community mental health services

14%   629,000

Tier 3
GP or practice nurse identified (diagnosed) a mental health problem (year)

No routine data

Tier 4
Consulted a GP or nurse about mental health symptoms

15%   629,000

Tier 5
General population with a possible mental health problem (in past weeks)

Source: Taulbut M, Parkinson J, Catto S et al (2009) *Scotland's mental health and its context: adults 2009*. Glasgow: NHS Health Scotland. Reproduced with kind permission from Scotland's Mental Health and its context: adults 2009, published by NHS Health Scotland (www.healthscotland.com).

3.4   Wales

As of March 2009, there were 14,100 people registered with intellectual disabilities in Wales, which equates to a prevalence rate of approximately 5 persons per 1,000 population. Of these, 12,300 (87%) were living in community placements (including 49% with family), and 1,800 (13%) were in residential establishments.[58]

The 2011 Welsh Health Survey found that 11 per cent of adults (a prevalence rate of 110 persons per 1,000 population) were currently being treated for a mental illness, with a higher percentage of women (14%) than men (8%) reporting receiving treatment. In households headed by someone who had never worked or was long-term unemployed, 27 per cent of adults reported currently being treated for a mental health problem, compared with 14 per cent in 'routine and manual households', and 7 per cent in 'managerial and professional households'.[f,59]

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f   These categories relate to the National Statistics Socio-economic Classification (NS-SEC) system which measures the employment relations and conditions of occupations, and shows the structure of socio-economic positions in modern societies.

3.5   Great Britain

The 'Longitudinal study of the mental health of adults living in private households in Great Britain', published in 2003, gives more detailed information about the factors associated with the onset of episodes of CMDs. Episode onset was defined in the study as the proportion of people who were not considered to have a CMD when first surveyed, but who were subsequently found to have a CMD at the follow-up interview, 18 months later. The report stresses that the majority of these episodes are likely to be reoccurrences rather than first episodes. The estimated rate of onset of episodes of CMDs was six per cent and did not vary with age to a statistically significant extent: the rate of onset was highest for men in the 25-34 age range (10%) while among women it remained constant from age 16-54 (8%).

There were few statistically significant predictors of episode onset among the social and economic risk factors assessed in the study. The clearest associations were linked to housing tenure and experiencing adverse life events, either before the survey or between the survey and the interview: while 12 per cent of social sector renters, and 11 per cent of private sector renters, had an episode onset, 5 per cent of those who owned or were buying their own homes experienced a CMD. Statistically significant associations were found among men and women when life events occurring between the survey and the follow-up interview were considered. The rate of onset among women who had not experienced any stressful life events between the survey and interview was three per cent, rising to 22 per cent of those who reported three or more such events. The equivalent figures for men were three per cent for those reporting no events, rising to 17 per cent among those reporting three or more. It is worth noting that the authors of the study highlight that the interpretation of their findings remains unclear, and that research is needed to test hypotheses about the social and neurobiological mechanisms that lead to the onset of episodes of CMDs.

Unemployment was also identified as a risk factor among men. Men who were unemployed at the time of the survey were found to be at a high risk of developing a CMD by the time of the follow-up interview, 18 months later. The estimated rate of episode onset for this group was eight per cent. Among those men and women who were defined as long-term sick or disabled at the time of the survey, 16 per cent went on to develop a CMD by the time of the follow-up interview.[60] Local socio-economic circumstances may help to explain why the prevalence rates for mental health problems vary across the four UK nations which, in turn, has important implications for the 'austerity agenda'.

3.6   Gender disparities in mental health and intellectual disability

Much of the data outlined in this chapter highlights that there are gender differences underpinning the prevalence rates of mental health problems and intellectual disability. In the case of mental health, the WHO notes that while gender differences in the prevalence rates of SMIs have not been found, gender differences in the prevalence of CMDs have been repeatedly reported. The reasons for these disparities are unclear: the morbidity associated with mental illness has received '*substantially more attention than the gender specific determinants and mechanisms that promote and protect mental health and foster resilience to stress and adversity.*'[61] It is hypothesised that a combination of social and biological factors are at play. As the WHO explains:

> '[D]ifferences in rates of disorder are only one dimension of the role played by gender in mental health and illness. Beyond rates, gender is related to differences in risk and susceptibility, the timing of onset and course of disorders, diagnosis, treatment and adjustment to mental disorder.'[61]

Gender specific risk factors for CMDs include gender based violence, socio-economic disadvantage, low income and income inequality, low social status, and ongoing responsibility for the care of others.[61] These risk factors disproportionately affect women and are indicative of the strong social gradient in health, including mental health (see **sections 4.2** and **5.2**). Gender differences in help-seeking behaviour are also apparent: women are more likely to seek help from, and disclose mental health problems to, their primary healthcare physician than men, and are 48 per cent more likely than men to use psychotropic medication, even after controlling for demographics, health status, economic status and diagnosis.[62] While the processes involved in help-seeking behaviour are complex and require further research, a trend of delayed help-seeking among men has also been identified for a range of physical conditions.[63]

In the case of intellectual disability, the prevalence rate is higher in men – for both severe and mild intellectual disability – than it is in women. It has been hypothesised that genetics play a role in this gender difference: since men only have one X chromosome, a gene mutation on the X is more likely to have an effect in males than females.[64] A major study published in Nature Genetics in 2009 uncovered nine new genes on the X chromosome which, when disrupted, caused damage to the nervous system. The study involved sequencing 720 out of the approximately 800 known genes on the X chromosome in more than 200 families affected by X-linked intellectual disabilities.[65]

One aspect of prevalence that is not examined in the data outlined in this Chapter is the relationship between ethnicity, mental health problems and intellectual disability. This is considered in further detail in **sections 4.1** and **6.1.1.1**.

Summary
- Mental health problems are the largest single source of disability in the UK, accounting for 22.8 per cent of the 'burden of disease' in 2011.
- There is a lack of up-to-date data on the prevalence of mental health problems and intellectual disability in the UK. Available data suggest that the prevalence of intellectual disability ranges from 3.5 persons per 1,000 to 6 persons per 1,000 across the UK. These figures, however, represent cases that are known to and / or engaging with services and are therefore likely to be an underestimate. Prevalence of mental health problems also ranges from 110 persons per 1,000 population to 190 persons per 1,000 population across the UK.
- There are gender disparities in the prevalence of mental health problems and intellectual disability. CMDs are more common in women than men, while the prevalence rate of intellectual disability is higher in men than in women. The reasons behind these disparities are unclear.

Chapter 4. Understanding the relationship between mental health, intellectual disability, and physical health

This Chapter considers some of the physical health conditions – such as cardiovascular disease and diabetes – that can co-occur with mental health problems and intellectual disability. While the focus on specific conditions stands at odds with the idea of taking a holistic, 'whole person' approach to care that is advocated in this report, it is necessitated by the nature and structure of the research in this area. As stressed from the outset of this report, while some of the excess mortality is related to suicide and accidents, the majority of deaths in these groups arise from preventable causes and could have been avoided by timely medical intervention.

4.1   The relationship between physical health and intellectual disability

People with intellectual disabilities have a shorter life expectancy and increased risk of early death when compared to the general population.[66] In 1998, Hollins and colleagues reported that people with intellectual disabilities are 58 times more likely to die before they reach the age of 50 compared to the general population.[67] Early death was particularly associated with co-morbid cerebral palsy, incontinence, mobility difficulties, and residence in hospital.[67] More recent figures have been produced by the CIPOLD. Its final report, published in 2013, showed that 22 per cent of people with an intellectual disability were under the age of 50 when they died, compared to 10 per cent of the general population. Men with intellectual disabilities died, on average, 13 years sooner than men in the general population, while women died 20 years earlier.[14]

Life expectancy can vary according to the severity of the intellectual disability: while there is evidence that people with mild intellectual disabilities have a life expectancy approaching that of the national average,[68] mortality rates among people with moderate to severe intellectual disabilities are three times greater than in the general population. The same study found that cause-specific mortality rates were more that twice as high in men and more than three times as high in women when compared to the general population.[69] Mortality is also elevated in some minority ethnic communities and in people with Down's Syndrome.[13,66] In the case of Down's Syndrome, this is, in part, because almost 50 per cent of all children with this condition have congenital heart problems, and are at a greater risk than the general population of developing Alzheimer's disease, leukaemia, respiratory disease and cardiovascular disease, though a precise figure is not stated.[70,71]

Prevalence among BME communities is not well documented with most of the existing research concentrating on South Asian families. Mir and colleagues reported in 2001 that the prevalence of intellectual disabilities among South Asians is three times greater than that in majority White communities. Of these families, 19 per cent have more than one member with an intellectual disability.[72] These findings are supported by earlier research conducted by Emerson and colleagues published in 1997. They found that between five and 34 years of age, the prevalence of severe intellectual disabilities is approximately three times higher among the Asian community when compared with the non-Asian community.[73] Possible reasons include the general effects of social and educational deprivation, inequalities in access to maternal healthcare, and higher rates of genetic abnormalities and / or environmental risk factors.[74] Cosanguinity – sharing an ancestor (or, literally, 'sharing blood') – has also been implicated; consanguineous marriages, for example, are a risk factor for bipolar disorders.[75] Despite the heightened prevalence of intellectual disabilities among some BME groups, their health and care needs have not always received sufficient attention (see **section 6.1.1.1** for further discussion).

The prevalence of epilepsy, mental health problems and respiratory disease are also elevated in people with intellectual disabilities. Approximately one third of people with intellectual disabilities have epilepsy – a rate twenty times higher than that found in the general population.[76] The 'National Clinical Audit of epilepsy-related death' reports that *'most premature deaths among people with epilepsy are directly related to the epilepsy itself',* with the majority of deaths linked to seizures. 'Sudden unexpected death in epilepsy', or SUDEP, is identified in the report as the principal cause of seizure-related death in people with chronic epilepsy, though it is not understood what causes it.[77] Respiratory disease, linked to pneumonia, swallowing and feeding problems, remains the leading cause of death;[67,78] it is estimated to be responsible for between 46 to 52 per cent of deaths compared with 15 per cent in the general population.[68] People with Down's Syndrome are particularly at risk of respiratory disease because they have a predisposition to lung abnormalities, a poor immune system, and a tendency to breathe through their mouth. Aspiration or reflux associated with swallowing difficulties also increases their risk of developing respiratory tract infections.[79]

Mental health problems are more common among adults and children with intellectual disabilities. The prevalence of psychiatric disorders among children is estimated to be 36 per cent for those with intellectual disabilities, compared to eight per cent of children without intellectual disabilities.[80,81] Co-morbid conditions are also more common: the RCPsych notes that children with intellectual disabilities are more likely to develop additional developmental disorders, such as autism spectrum disorders and attention-deficit hyperactivity disorder (ADHD), than other children.[82] Diagnostic overshadowing – attributing either the physical or mental health problem to the intellectual disability, and 'normalising' it – can lead to unmet health needs among people with intellectual disabilities; this is discussed in more detail in **Chapter 6**.[83,84]

4.2 The relationship between physical health and mental health

Figure 2 depicts the overlap between long-term physical health conditions and mental health problems in England.

Figure 2: The overlap between long-term conditions and mental health problems, 2012

Long-term conditions: 30 per cent of the population of England (approximately 15.4 million people).

Mental health problems: 20 per cent of England (approximately 10.2 million people).

30 per cent of people with a long-term condition have a mental health problem (approximately 4.6 million people).

46 per cent of people with a mental health problem have a long-term condition (approximately 4.6 million people).

Source: Naylor C, Parsonage M, McDaid D et al (2012) *Long-term conditions and mental health. The cost of co-morbidities*. London: King's Fund, Centre for Mental Health. Reproduced with kind permission from The King's Fund.

The direction of the relationship between mental and physical health problems remains unclear. People with SMIs – including schizophrenia, bipolar disorder, and major depressive disorder – have higher morbidity and mortality rates than the general population.[85,86] Analysis of data from the Health and Social Care Information Centre's (HSCIC) Mental Health Minimum Dataset (MHMDS) shows that in 2010-11 the mortality rate was 4,008 per 100,000 (83,390 deaths in total) for mental health services users in England, compared to the general population rate of 1,122 per 100,000.[87] The exact impact of this 'mortality gap' on the life expectancy of SMI patients is unclear; it has been found to reduce life expectancy from anywhere between 13 to 30 years.[88] A review by the South London and Maudsley NHS Trust of people diagnosed with an SMI between 2007 and 2009 reported that life expectancy at birth was reduced by 8 to 14.6 years for men, and 9.8 to 17.5 years for women.[89] Research undertaken in Sweden and Denmark produced slightly different figures: men with mental disorders lived 20 years less, and women 15 years less, than the general population.[4] While suicide is a significant cause of death, it only accounts for a minority of this observed excess mortality.[90,91] De Hert and colleagues reported in 2011 that approximately 60 per cent of excess mortality was due to physical illness.[88,92]

Among patients diagnosed with physical health problems, the prevalence of probable mental health problems – particularly depression – has been found to increase as the number of chronic physical conditions rises.[10,11] The King's Fund reports that people with long-term physical conditions are between two to three times more likely to experience mental health problems than the general population.[7] This trend also has a 'social gradient': people living in deprived areas have a greater number of physical and mental health problems requiring simultaneous management when compared to people living in more affluent areas.[10] This concept underpins much of the findings of the Marmot Review of health inequalities in England.[43] Published in 2010, the Review explains that the lower a person's social position, the worse his or her health will be; this is the social gradient in health. To illustrate the significance of the gradient, the Marmot Review draws attention to differences in life expectancy: after excluding the poorest five per cent and the richest five per cent, it found that, *'the gap in life expectancy between low and high income [in England] is six years, and in disability-free life expectancy 13 years.'*[43] Such inequalities in health cannot be attributed to a person's genetic make-up, or their behaviour (though these factors do matter); rather, the Marmot Review stresses that: '*[S]ocial and economic differences in health status reflect, and are caused by, social and economic inequalities in society.*' The link with the social determinants of health is discussed further in **section 5.2**.

There is strong evidence for a close relationship between mental health problems and cardiovascular disease (CVD), respiratory diseases, stroke, HIV infection, and some cancers (see **Figure 3**).[93,94] Higher rates of co-morbid medical conditions, including diabetes mellitus, viral infections (such as hepatitis), and respiratory tract diseases (such as tuberculosis) have also been identified.[85]

Figure 3: Prevalence of physical health conditions among people with schizophrenia or bipolar disorder in England and Wales, 2005
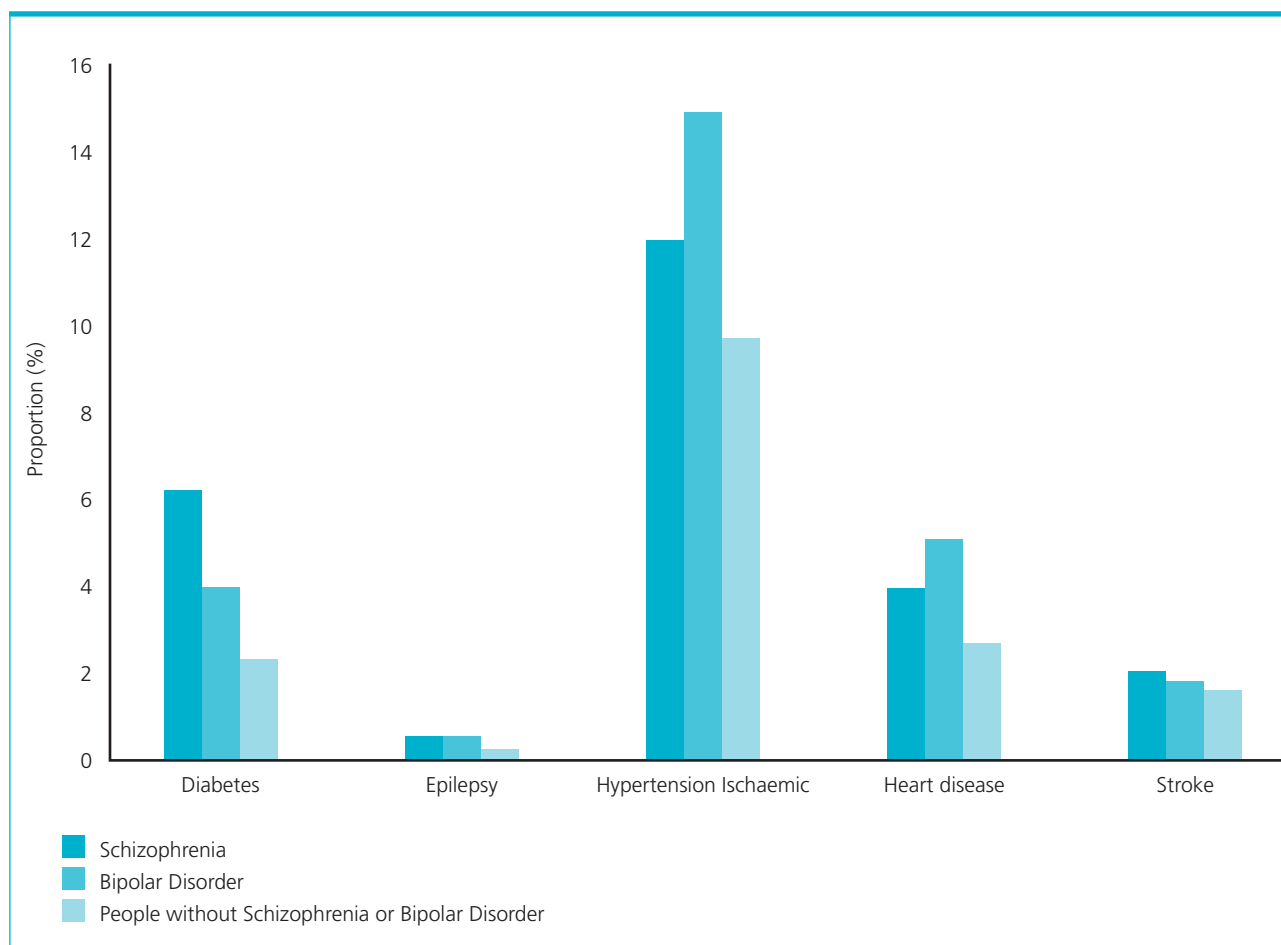
Source: Hippisley-Cox J and Pringle M (2005) *Health inequalities experienced by people with schizophrenia and manic depression: analysis of general practice data in England and Wales*. Nottingham: QResearch, University of Nottingham. Cited in Disability Rights Commission (2006) *Equal treatment: closing the gap. A formal investigation into physical health inequalities experienced by people with learning disabilities and / or mental health problems*. London: Disability Rights Commission.[95] The copyright and all other intellectual property rights are owned by, or licensed to, the Commission for Equality and Human Rights, known as the Equality and Human Rights Commission ('the EHRC').

Clinical data analysis conducted by the Disability Rights Commission (DRC)[g,6] indicated that five year survival rates were lower for patients with mental health problems for a number of key conditions, including stroke, diabetes and respiratory disease. The DRC found that after five years and adjusting for age:

• 22 per cent of people with coronary heart disease (CHD) who have schizophrenia have died, as have 15 per cent of people with bipolar disorder, compared with eight per cent of people with no serious mental health problems

g   In October 2007, the DRC merged with the Commission for Racial Equality (CRE) and the Equal Opportunities Commission (EOC) to form the Equality and Human Rights Commission.

BMA Recognising the importance of physical health in mental health and intellectual disability

- 19 per cent of people with diabetes who have schizophrenia have died, as have 4 per cent of people with bipolar disorder, compared with nine per cent of people with no serious mental health problems
- 28 per cent of people who have had a stroke and have schizophrenia have died, as have 19 per cent of people with bipolar disorder, compared with 12 per cent of people with no serious mental health problems
- 28 per cent of people with chronic obstructive pulmonary disorder (COPD) who have schizophrenia have died, as have 24 per cent of people with bipolar disorder, compared with 15 per cent of people with no serious mental health problems (see **Figure 4**).

Figure 4: Five-year survival rates for people with and without mental health problems in England and Wales, 2006

Source: Hippisley-Cox J, Vinogradova Y, Coupland C et al (2006) *A comparison of survival rates for people with mental health problems and the remaining population with specific conditions*. London: Disability Rights Commission. The copyright and all other intellectual property rights are owned by, or licensed to, the Commission for Equality and Human Rights, known as the Equality and Human Rights Commission ('the EHRC').
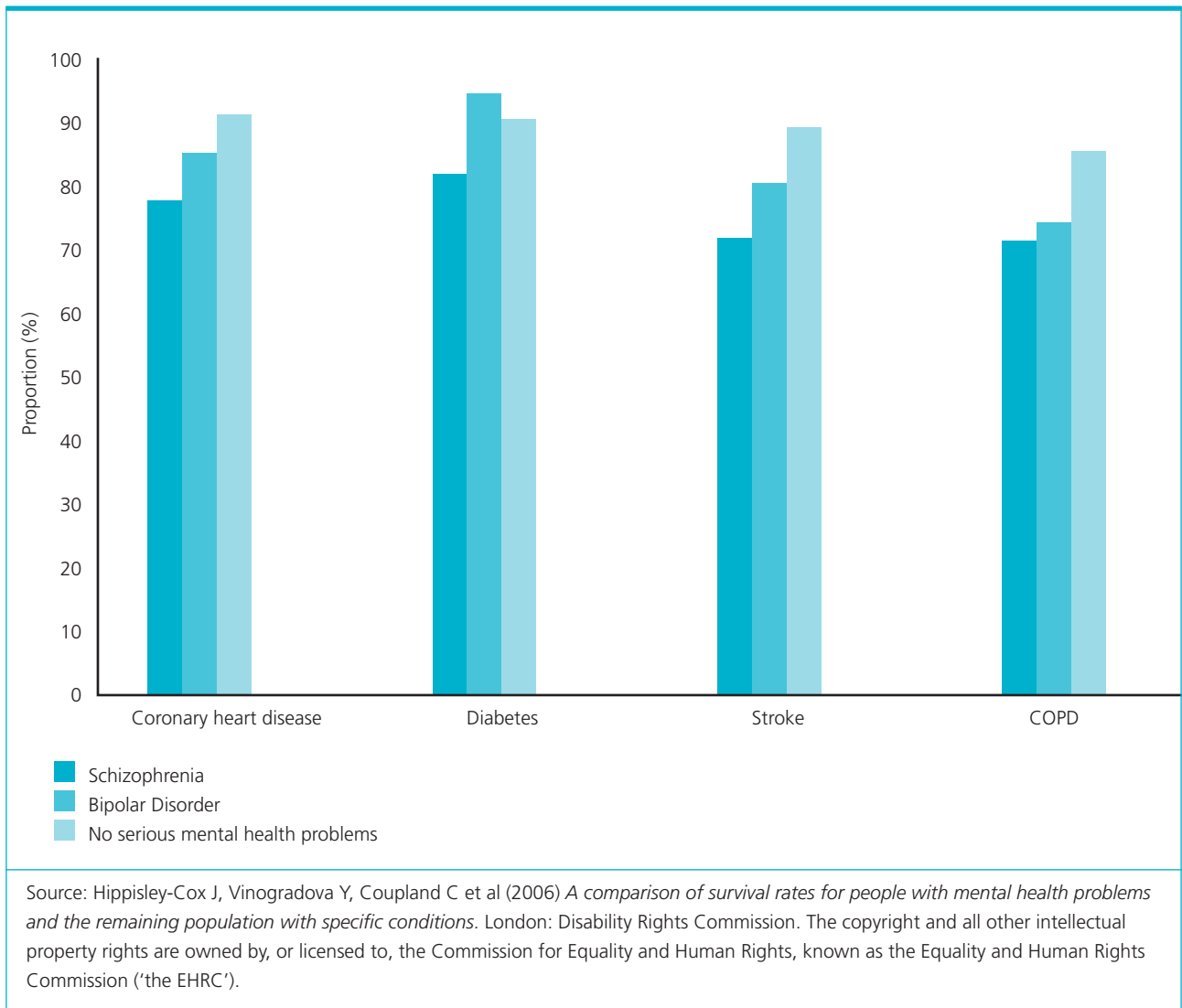
Research published in 2012 highlighted that less severe psychiatric problems are also associated with increased mortality. Russ and colleagues linked the members of the Health Survey for England aged 35 and over, and who were free of CVD and cancer, to National Health Service (NHS) mortality data. They found a dose-response association between psychological distress and mortality from all causes, cardiovascular disease, and external causes. This association was apparent even in those people whose 'psychological distress' existed below the threshold that would lead to a diagnosis of depression or anxiety.[96]

Among patients diagnosed with a long-term physical health condition, much of the evidence of co-occurring mental health problems relates to the onset of depression and anxiety, rather than SMIs. There is a particularly strong, well established, relationship between depression and myocardial infarction (MI). After controlling for disease severity and treatment-related factors, systematic reviews of the prognosis of CHD have found that co-morbid depression is a consistent predictor of adverse outcomes following a non-fatal MI.[97] Such outcomes include more medical co-morbidities, cardiac complications, and a heightened risk of mortality.[94] A 2003 study from the United States estimated that at least 90,000 of the 150,000 deaths that occur in the first year after an initial MI may be related to post-MI depression.[98]

The relationship between diabetes and depression is similarly well established: a meta-analysis of 42 studies found that the presence of diabetes doubles the odds of co-morbid depression and does not differ by sex, type of diabetes, the methods for assessment of depression, or the study design.[99] Patients with neurological disorders, including stroke, Parkinson's disease, Alzheimer's disease and epilepsy[88,100] have also been found to have high rates of depression when compared to the general population, as have patients diagnosed with cancer.[101]

The research outlined in this chapter has focused on the relationship between a physical illness and specific mental health problems. There is also some evidence to suggest that the *number* of conditions is a better predictor of the onset of depression than the presence of any one specific illness.[11] This trend is particularly apparent in patients with 'medically unexplained symptoms' (MUS). Over 40 per cent of outpatients with MUS have an anxiety or a depressive disorder:[102] the more complaints and symptoms reported, the greater the patient's degree of psychological distress.[103]

In addition to the 'mortality gap' discussed previously, a mental health 'treatment gap' also persists. The difference between the number of people needing treatment for mental illness and the number of people receiving treatment is – with the exception of psychosis – universally large. The 'Adult psychiatric morbidity survey' found that, less than a quarter (24%) of people with a CMD in England are in receipt of treatment. The severity of symptoms and the type of disorder were strong predictors of whether treatment was received; the more CMDs people had, the more likely they were to be receiving treatment. Those with phobias were more likely to be participating in talking therapies than those with depression and anxiety (57% versus 15% respectively). The survey did not examine why these differences in treatment occurred, though the authors highlighted that CMDs can go undiagnosed and that individuals often do not seek treatment. It should also be noted that the survey results were published in 2007 when IAPT was only just beginning. Accessing services and treatment are discussed in further detail in **section 6.1.1**.[50]

Summary
- People with intellectual disabilities have a shorter life expectancy and increased risk of early death when compared to the general population: figures published in 2013 by the CIPOLD showed that 22 per cent of people with an intellectual disability were under the age of 50 when they died, compared to 10 per cent of the general population.
- People with SMIs – including schizophrenia, bipolar disorder, and major depressive disorder – have higher morbidity and mortality rates than the general population, reducing their life expectancy from anywhere between 13 to 30 years.
- An estimated 60 per cent of excess mortality among people with mental illness is due to physical ill health.
- People with long-term physical conditions are between two to three times more likely to experience mental health problems than the general population.
- Five year survival rates have been found to be lower for patients with mental health problems for a number of key conditions, including stroke, diabetes and respiratory disease.
- The majority of people with a common mental illness do not receive treatment, though the reasons for this 'treatment gap' are unclear.

Chapter 5. Mechanisms of co-morbidity

The mechanisms underlying the relationship between mental and physical health are complex and are still not fully understood. Evidence suggests that a combination of biological, psychosocial, environmental and behavioural factors are involved.[7] These include unrecognised medical disease, the psychological burden of disease, health behaviours, and poor compliance with, or refusal of, treatment for medical disease.[91] There is also evidence that antipsychotic medication can have a harmful effect on physical health and, in a small number of cases, can lead to sudden death.[6] Biological factors will vary depending on the particular mental and physical health conditions. In the case of CHD and its links to depression, for example, dysregulation of the neuroendocrine system has been implicated.[h,104] Barriers to accessing health services, including failures to make reasonable adjustments, and discrimination, are considered in detail in **Chapter 6**.

5.1 Health behaviours

The most commonly cited reason for the excess mortality and morbidity found in people with physical and mental health conditions is their 'health behaviour', a category which includes alcohol and substance use, smoking, poor diet and a lack of physical activity.[105] The RCPsych reports that the higher rates of physical ill health, and the shortened life expectancy, experienced by people with mental health problems arises *'largely from treatable conditions associated with modifiable risk factors such as smoking, obesity, substance abuse…'.*[106]

5.1.1 Alcohol and substance use

Alcohol and illicit substance use are more common among people with SMIs. In a 2002 Scottish study of 446 people with schizophrenia and 250 controls, more schizophrenia patients reported problem use of drugs in the previous year compared to the control group (7% and 5% respectively), and during their lifetime (20% and 6% respectively).[107] Problem use of alcohol in the previous year stood at 17 per cent among patients with schizophrenia and 10 per cent in the control group.[107] A similar study conducted in Cambridgeshire found that substance use among people presenting to services with first-episode psychosis was twice that of the general population: cannabis use was reported in 51 per cent of patients while 55 per cent of patients had used Class A drugs.[108] Almost half of the sample (43%) met DSM-IV criteria for alcohol abuse or dependence at some point in their life.

The majority of research has focused on co-morbidity in illicit drug users rather than in prescription drug users. There is some research emerging from the United States examining the harmful use of prescription drugs and its association with mental health problems.[i,109] A sample of 324 US Veterans Health Administration patients treated for depression – who committed suicide between 1999 and 2004 – found that patients with chart notations of prescription drug misuse were 6.8 times more likely to die of suicide than those without. Medications frequently misused included pain medications, methylphenidate and benzodiazepines.[110] Research conducted two years later in West Virginia found that almost 50 per cent of people dying from prescription drug overdose in the state in 2006 had a history of mental illness during their lifetime.[111] More recent findings have been drawn from the 2012 National Survey on Drug Use. Data derived from 5,241 US college students who completed the 2012 survey showed that the non-medical use of prescription drugs was 'associated with relatively serious mental illness', as well as a lack of healthcare.[112] Long-term health problems linked to the harmful use of prescription medication will vary depending on the type of drug; high doses of some stimulants can have strong effects on the cardiovascular system and can dangerously raise body temperature and cause irregular heartbeat, or even heart failure or seizures.[113]

It is thought that drinking alcohol and using illicit substances can coexist with, contribute to, or result from, mental health problems. The available clinical, neurobiological and epidemiological evidence is yet to identify a unified explanation as to why there is such a high concordance between substance use and mental health problems.[114] Alcohol and substance use may be a form of self-medication among people with mental health problems.[115] They can also make some mental health problems worse and may contribute to the development of mental ill-health, such as depression. Substance use in people with psychotic disorders is associated with reduced adherence to treatment and poorer health outcomes.[108,116]

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h   A comprehensive overview of biological factors can be found in Benton and colleagues.[100]

i   In the 'ICD-10 Classification of Mental and Behavioural Disorders: Clinical descriptions and diagnostic guidelines', harmful use is defined as a pattern of psychoactive substance use that is causing damage to health.

There is limited information on substance use among people with intellectual disabilities, though it is reported to be significantly lower in this group in comparison to the general population.[13] Prevalence rates of alcohol use are also lower, and while there is research to suggest that some people with intellectual disabilities have a reduced threshold for alcohol-related problems (exhibiting problems from a lower intake of alcohol), the reasons for this are unclear.[117,118] As noted in **Chapter 1**, mental health problems and intellectual disability can begin at an early age (including from birth in some cases), and their consequences can be felt throughout the individual's life. There is research indicating that prenatal factors have long-lasting consequences on later mental health. In 2007, the Board of Science produced a guide for healthcare professionals on Fetal alcohol spectrum disorders (FASD).[119] These are a series of preventable mental and physical birth defects resulting from maternal alcohol consumption during pregnancy: this is the leading known risk factor for intellectual disability that has no identified genetic origin.[120] People with FASD may also be more susceptible to the effects of alcohol. Secondary disabilities – the behavioural, cognitive, and psychiatric results of living with brain damage – include an increased risk of addictive behaviours that can in turn lead to problems with alcohol and potentially continue the cycle of FASD into the next generation.[121]

5.1.2   *Smoking*

While the use of drugs and alcohol in people with mental health problems should not be ignored, there is evidence that they are greatly overshadowed by the use of tobacco. A major report on smoking and mental health, jointly published by the Royal College of Physicians (RCP) and the RCPsych in 2013, found that much of the substantially lower life expectancy of people with mental disorders relates to smoking. In addition to lowering life expectancy by around 10 years, the report highlights how smoking reduces quality of life, exacerbates poverty, increases drug requirements to control symptoms, and adds to the social stigma that this group experiences.[122] In 2006, the overall prevalence of smoking in people with a SMI in England and Wales was 49.6 per cent, compared to 22.3 per cent in the general population.[123] More recent figures are available for England. Drawing on data from the 2010 Health Survey for England, the RCP and RCPsych found that 37 per cent of people with a longstanding mental health issue were also smokers.

Smoking rates can vary depending on the type of mental health problem. An analysis of the 2007 Adult Psychiatric Morbidity Survey highlighted that while 37 per cent of people with depression, and 40 per cent with probable psychosis, were smokers, the likelihood of having mixed anxiety and depression and being a smoker was 29 per cent.[124] People with SMIs also tend to be heavier smokers, defined as smoking over 20 cigarettes a day. A 2003 study conducted in South West Scotland, involving 102 patients diagnosed with schizophrenia, found that 70 per cent were current smokers, of which 54 per cent were heavy smokers. Eleven per cent of the general population of South West Scotland were identified as heavy smokers.[125] It has been suggested that smoking among people with SMIs is a form of self-medication since it has been shown to alleviate some psychiatric symptoms, though the RCP and RCPsych report stresses that the mechanisms underlying associations between mental health problems and smoking are uncertain and in need of further research.[86,105,122]

Exposure to maternal smoking in pregnancy has also been repeatedly observed to be associated with mental health problems, including offspring ADHD and antisocial behaviour. Difficulties in establishing a causal relationship persist, particularly since prenatal risks – such as maternal smoking and stress in pregnancy – tend to also be associated with postnatal risks (eg parent mental health problems, social adversity) for offspring psychiatric disorder. There may also be unmeasured confounders, including maternally transmitted inherited factors.[126]

Despite the high prevalence of smoking among people with mental health problems, and the detrimental impacts it has on their overall health, stop smoking services for this group have not been prioritised. While people with SMIs can find it more difficult to quit, a 2008 review found that this group was as motivated to stop smoking as the rest of the population but were less likely to be offered smoking cessation interventions.[127,128] The RCP and RCPsych report echoes this finding: over the course of a year, they found that half of smokers with mental health problems were advised to quit, while one in ten received prescriptions of medicines such as nicotine replacement therapy (NRT).[122] The charity Rethink Mental Illness has drawn particular attention to the lack of smoking cessation services available in inpatient settings since this can be a good time to offer intensive support if the patient wants to quit.[129] Improving the effectiveness of targeted smoking cessation interventions

in mental health services is the focus of new guidance from the National Institute for Health and Care Excellence (NICE), and is discussed in further detail in **section 7.1**.

A review conducted by Hall and Prochaska, published in 2009, identified a number of reasons why smoking cessation interventions are less likely to be offered to patients with mental health problems. They include the prioritisation of treatment for mental health problems over quitting smoking; beliefs among clinicians that people with mental health problems *'are not able or willing to quit'*, which in turn have *'contributed to a culture in treatment settings that accepts and 'normalises' cigarette smoking'*; and the limited availability of stop smoking services in some hospitals and care settings.[130] Since nicotine intake can impact upon the metabolism of some antipsychotic drugs, smoking cessation (and any relapse) should be accompanied by a swift review of medication doses. It is therefore crucial that primary and secondary care, together with stop smoking services, record smoking status alongside whether someone is using medication for a mental health problem.[122]

Smoking is less common among people with intellectual disabilities when compared to the general population.[13,66,131] The background evidence to the DRC report, 'Equal Treatment', found that 15 per cent of those identified on primary care databases as having intellectual disabilities were current smokers.[123]

5.1.3   *Physical activity and diet*

People with an intellectual disability are at a higher risk of obesity. Research conducted on behalf of the DRC found that the rate of obesity in all those with a recorded body mass index (BMI) was 28.3 per cent in people with an intellectual disability, compared to 19.8 per cent in the general population. It should be noted that when these data were collected in 2006, people with intellectual disabilities were less likely than the general population to receive recorded health checks.[j,123] Robertson and colleagues reported in 2000 that less than 10 per cent of adults from this group ate a balanced diet, while over 80 per cent engaged in physical activity below recommended minimum levels. The more severe the intellectual disability, the greater the risk of inactivity.[132] It is not known what percentage of adults with an intellectual disability also have pre-existing physical impairments that limit their ability to exercise. Among adults with intellectual disability, an increased risk of obesity has been associated with: living in a family setting; a restricted range of opportunities to exercise or eat healthily; lower senior staffing ratios in supported accommodation; and Down's Syndrome.[133] Such findings highlight that the aspirations of carers, including healthcare professionals, are important in encouraging and implementing a good diet and regular exercise whenever possible. Obesity is also more prevalent among people with rare conditions such as Prader-Willi syndrome[k], Cohen syndrome[l] and Bardet-Biedl syndrome[m], and can exacerbate, or lead to, physical conditions including high blood pressure, an increased risk of diabetes, and breathing difficulties.[66]

A review of studies examining physical activity in people with mental health conditions demonstrated that approximately 60 per cent of this group had below average activity levels. The review also noted that little is known about the attitudes and motivation towards physical exercise in this population.[105] A comparison of the dietary habits of the general population of Scotland with patients diagnosed with schizophrenia found that the latter group made poor dietary choices; average consumption of fruit and vegetables was 16 portions per week while the recommended intake corresponds to 35 portions a week (five portions a day).[125] In 2010, the average number of portions consumed by adults per week in Scotland was 22.[134] Similar research conducted in Murcia, Spain showed that patients with schizophrenia had 'detrimental dietary behaviour',

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j   For further discussion see **Section 6.2** on monitoring and assessment.

k   Prader-Willi syndrome is a rare, complex genetic disorder, which is present from birth and continues throughout life. It causes a range of symptoms including a constant desire to eat food, restricted growth, reduced muscle tone, and a lack of secondary sexual development.

l   Cohen syndrome is an inherited disorder that affects many parts of the body and is characterised by developmental delay, intellectual disability, small head size, and weak muscle tone, though the features vary widely among affected individuals.

m   Bardet-Biedl syndrome is a disorder that affects many parts of the body. The signs and symptoms of this condition vary among affected individuals, including among members of the same family. Major signs and symptoms include loss of vision, obesity, presence of extra fingers or toes, and delayed development of motor skills.

displaying a high intake of fast food, snacking between meals, as well as a low consumption of fruit and fish.[135] Concerns have been raised that overweight and obesity may be particularly pronounced in young people with mental health problems. Patients with first-episode psychosis are usually in their teens or early adulthood and, like their peers, are increasingly likely to live a sedentary lifestyle and consume energy-rich, nutrient-poor foods. Bailey and colleagues hypothesise that *'[G]iven the rapid demographic shift in patterns of obesity, the impact on weight gain for young people with psychosis may be disproportionately greater'* and that we may be witnessing the emergence of *'an epidemic within an epidemic'*.[136]

The reasons why people with mental health problems tend to have poorer diets and lower levels of activity are interrelated. Metabolic alterations appear to be connected to the prescribed pharmacological treatment for SMIs: one of the side effects of antipsychotics and antidepressants is an increased appetite and thirst.[137,138] Apathy, reduced levels of energy and motivation, as well as changes in appetite, are also common symptoms of depression and some SMIs. Together these symptoms and side effects can act to increase a patient's propensity to consume nutrient-poor convenience foods, rather than choose a healthier option that takes longer to prepare.[105]

5.2   Reporting health problems and treatment compliance

People with mental health problems are less likely than other patients to report physical symptoms. This can delay help-seeking behaviour and reduce the chance of the illness being detected and diagnosed.[116,139] The reasons behind the delay in seeking help are diverse. Some of the symptoms and consequences of schizophrenia, including social isolation and suspicion, may contribute to the patient not seeking care in the first place, or adhering to any treatment that is prescribed.[12] Anecdotal evidence from BMA members also suggests that the 'Did not attend' (DNA) rate for annual health checks for SMI patients is high. Cognitive impairment can further inhibit the patient's ability to interpret the physical signs of illness.[140] This group may avoid registering with a general practitioner (GP) or find it difficult to make and keep appointments, while the challenging behaviour displayed by some mental health and intellectual disability patients also increases their risk of losing their registration.[146] The DRC found evidence that mental health and intellectual disability patients can face considerable difficulties in refuting allegations that they are demanding or aggressive, which can leave them unfairly denied support.[6] Reporting ill-health appears to be less of a problem among people with intellectual disability: the CIPOLD found that '*the great majority (86%) of the illnesses that led to the deaths of people with learning disabilities were promptly recognised and reported to health professionals'*. Significant difficulties or delay in diagnosis, further investigation or specialist referral, however, were experienced by 29 per cent of the CIPOLD cohort.[14] Barriers to accessing health services faced by people with mental health problems, and by people with intellectual disability, are considered in detail in **Chapter 6**.

Under-recognition and under-treatment of depression in patients diagnosed with chronic illnesses may also be associated with the patient failing to report, and / or the clinician failing to enquire about, symptoms of mental ill health. Despite numerous campaigns aimed at tackling the stigma surrounding mental illness – such as Time to Change[141] – it remains a subject that some people are uncomfortable with and embarrassed to talk about. 'Treatment stigma'[142] – the stigma and discrimination that individuals believe to be associated with receiving care for a mental health problem – may lead to patients avoiding disclosure of any emotional complaints to their healthcare practitioner and resisting a diagnosis of mental ill-health by attributing their symptoms to physical causes.[143] Not seeking healthcare, or delayed care-seeking, may also be associated with a perceived lack of effectiveness of the treatments on offer, thinking the problem will resolve itself, and / or fear of being hospitalised against one's will.[142]

There is also evidence that the combination of mental and physical health problems can result in the patient becoming less able to self care and actively manage their well-being: poor health can reduce energy, motivation, and confidence levels, and lead to a diminished capacity to seek and comply with treatment.[7] This may be exacerbated by socio-economic deprivation: while there is a limited amount of research on the link between the social determinants of health and mental health, the existing evidence indicates that mental health is closely related to various types of inequality.[144] Research undertaken for the Marmot Review found that the prevalence of psychotic disorders among the lowest quintile of household income was nine times greater than in the highest quintile.[145] Elsewhere there is evidence that people with co-morbid mental and physical health problems are more likely to experience deprivation, including poor housing, poverty, unemployment, and social stigma,

all of which can have a major, adverse effect on a person's quality of life.[92,146] Those who are socially and economically disadvantaged bear a disproportionate burden of mental health problems, as well as their adverse consequences.

Much of the existing research draws on evidence from middle and low-income countries, such as Nigeria and Brazil, often focusing on depression. A review of mental disorders and social determinants for the WHO Equity, Social Determinants, and Public Health Programmes reported that not only were increased rates of depression found in lower socio-economic groups, but that people from these lower socio-economic groups experienced differential exposure to risk factors as well as differential consequences. Exposure to crime, civil unrest, natural disasters, food insecurity, lack of housing, unemployment and under-employment, were overrepresented in poorer communities, creating high levels of inequity in the distribution of exposure to risk factors. The WHO report also points to the ways in which the 'vicious cycle of depression'[n] can increase a person's deprivation through increased costs of treatment and medication, reduced ability to work, and associated loss of earnings – the effects of which are experienced inequitably across socio-economic positions.[147] The Centre for Health Equity at University College London (UCL) is currently working on a report on the social determinants of mental health for the WHO to consider these issues in further detail.

5.3 Psychological burden of chronic disease

Another possible mechanism underpinning the relationship between mental and physical disorders is the psychological burden that chronic and life-threatening physical conditions can have. In some patients, for example, cancer will precipitate a period of depression due to the stress associated with receiving the diagnosis and any subsequent treatment.[9] Difficulties linked to chronic illness – from adverse symptoms, complicated treatment regimes, and necessary lifestyle changes, to the threat of a shortened life expectancy – can also trigger an episode of depression.[116] The more threatening the patient perceives their illness to be, the more likely they are to become depressed.[148]

Summary
- The mechanisms underlying the relationship between mental and physical health are complex and not fully understood: a combination of biological, psychosocial, environmental and behavioural factors are likely to be involved.
- The most commonly cited reason for the excess mortality and morbidity found in people with physical and mental health conditions is their 'health behaviour'. Types of adverse lifestyle behaviours include alcohol and substance use, smoking, poor diet and a lack of physical activity.
- The complex and interrelated nature of physical and mental health problems means that 'health behaviours' should not be examined in isolation: increased morbidity is invariably linked to factors that occur in combination.
- People with mental health problems are less likely than other patients to report physical symptoms, while people with long-term physical conditions may avoid disclosing emotional complaints to their doctor due to the ongoing stigma attached to mental health problems. This can delay help-seeking behaviour and reduce the chance of a co-morbid illness being detected and diagnosed.
- The psychological burden that chronic and life-threatening physical conditions can place on people is another possible mechanism underpinning the relationship between mental and physical disorders.

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n   People who feel depressed tend to have negative thoughts. These can increase the feelings of depression and prevent people from doing things that they would have normally done. This, in turn, can make the person feel lethargic and more critical about themselves, thereby making them feel worse. This is known as getting caught up in the 'vicious cycle of depression'.

Chapter 6. Unmet health needs: barriers to accessing services

Research conducted in Europe and the United States has consistently found that physical illness in people with mental health conditions goes undetected, leaving patients with unmet health needs. This chapter considers the reasons why this trend persists. In the case of CVD, De Hert and colleagues reported that SMI patients have the highest CVD mortality but the least chance of receiving specialised interventions or circulatory medicines.[88] Studies conducted in the United States provide more detailed data. An analysis of a state hospital inpatient population found that 80 of the 100 patients seen in the study had a previously undetected physical illness requiring medical intervention. In 46 per cent of cases, the physical illness was thought to be causative of, or contributory to, their psychiatric symptoms.[149]

A similar study evaluating 529 patients in California's mental health system found that 39 per cent of the participants had an active, important physical disease, but that only half of these diseases had been recognised by the mental health system. In 14 per cent of cases, the patient had a physical condition that was causing or exacerbating their mental health problem.[150] Comparable figures were produced in a survey of 145 long-term users of hospital and day psychiatric facilities in Southwark, London. Based on clinical assessment, 41 per cent of patients were judged to have physical health problems requiring care, 15 per cent of which were not receiving the attention and treatment that was required.[151]

Recognition of mental health problems in patients diagnosed with a physical illness is similarly lacking. A 2007 systematic literature review found that more than half of all cases of depression went unrecognised and untreated by physicians working in a general hospital setting.[143] Even if depression and anxiety are detected, they may be 'normalised' by practitioners as a reasonable response to being physically unwell. This is known as 'diagnostic overshadowing' and is discussed in detail in **section 6.1**.[146]

Unmet health needs are also apparent among people with intellectual disabilities. In 2006, The Welsh Centre for Learning Disabilities found that, after performing health checks on 181 people with intellectual disabilities in south and mid-Wales, 51 per cent had previously unrecognised health needs, while nine per cent had serious new morbidity discovered.[152] Health screening undertaken in the Greater Glasgow area on a group of 50 patients with intellectual disabilities revealed twice as many health needs than were identified in a matched control group of 50 participants receiving only standard treatment.[153] Building on this work, Felce and colleagues examined whether follow-up health checks would identify equally significant newly identified morbidity. Their results, published in 2008, showed that a similar number of newly identified health problems were found at the repeat health check compared to the initial check, even when performed at an average interval of 14 months.[154]

The increased rate of early death in this group, particularly from respiratory disease, led Hollins and colleagues to suggest that people with intellectual disabilities receive less than optimal medical care and that they are in need of better health surveillance and promotion.[67] This point was echoed more recently by the CIPOLD in 2013: premature deaths among people with intellectual disabilities were found to be mostly linked *'to delays or problems with treatment, or because of problems with assessing or investigating the cause of illness'*.[14] While general health checks in asymptomatic patients are not widely recommended,[o] there are clear benefits to providing intellectual disability patients with annual health reviews. It is encouraging to see that these were incentivised through the introduction of a Direct Enhanced Service (DES) in Wales in 2006, with England following in 2009 (see discussion in **section 6.2**).

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o   A 2012 Cochrane Review concluded that '*[G]eneral health checks did not reduce morbidity or mortality* [in adults]*, neither overall nor for cardiovascular or cancer causes, although the number of new diagnoses was increased'*. One trial, for example, found *'a 20% increase in the total number of new diagnoses per participant over six years compared to the control group'.* The authors are careful to point out that nine of the 14 studies analysed for the review were initiated prior to 1980, and that the most recent study began in 1992. It is therefore possible that advances in the treatment of diseases, or of the risk factors identified by screening, may have improved the benefits associated with general health checks over time. Before local authorities took over responsibility for commissioning health checks in England in April 2013, Public Health England (PHE) acknowledges that there was considerable variation in how widely they were offered. PHE, which leads the NHS Health Check programme, launched a ten-point plan in July 2013 to help councils roll them out to 20 per cent of their eligible local population a year – a total of 15 million people by 2018-19.

The reasons underlying these disparities in healthcare are related to a number of factors including: healthcare provision and organisation; the monitoring and screening of people with mental health conditions and intellectual disability; and commissioning of services. Discrimination is another important factor: in 2008, the 'Independent Inquiry into Access to Healthcare for People with Learning Disabilities', and the CIPOLD in 2013, both reported evidence of outright discrimination where access to, and outcomes from, services were concerned.[13] Similar findings of discrimination and stigmatisation, particularly when trying to access health services, have also been reported by people with SMIs.[56,155]

6.1 The organisation and delivery of healthcare

6.1.1 Accessing services and treatment

A patient's options may be constrained by the difficulties associated with accessing treatments for mental health problems. Findings from the adult psychiatric morbidity survey highlight that only a minority of people with mental health problems are in receipt of treatment. Based on data from the 2007 survey, less than a quarter (24%) of people in England with a CMD received treatment for an emotional or mental problem, mostly in the form of medication. The stark difference between the number of people needing treatment for mental illness, and the number of people receiving treatment – the 'treatment gap' – is also apparent on a global scale.[156] Wang and colleagues conducted face-to-face household surveys with 84,850 adult respondents in some low-income or middle-income countries (Colombia, Lebanon, Mexico, Nigeria, China, South Africa, Ukraine), as well as some high-income countries (Belgium, France, Germany, Israel, Italy, Japan, Netherlands, New Zealand, Spain, USA). They found that while up to 30 per cent of the population worldwide is expected to have a mental illness every year, in each country studied, at least two thirds of people who are mentally ill receive no treatment.[157]

Under the NHS Constitution – which applies only in England – mental health services are exempt from the right for patients *'to make choices about their NHS care and to [receive] information to support these choices'*. In December 2012, the Westminster Government stated their intention to amend the NHS Constitution and remove this exemption to free choice.[158] Non-medical consultant-led mental health services (such as art therapy or dietetics) are also exempted from the maximum 18 week waiting time set out in the NHS Constitution, leaving some patients facing long delays to receive treatment. A survey of 1,600 people attempting to access psychological therapies in England – conducted by the mental health charity Mind in 2013 – found that 12 per cent had been waiting over a year to receive treatment, with 54 per cent waiting at least three months.[159] Mind has called on the government to urgently establish access standards in the Improving Access to Psychological Therapies (IAPT) programme so that people will be referred to these services within 28 days. Concerns have also been raised by the Chief Medical Officer (CMO) for England about access standards. The CMO reported in late 2012 that the access rate to psychological therapies for people with anxiety and / or depression disorders was 2.1 per cent, with a fivefold variation apparent between Primary Care Trusts (PCTs) due to the phased roll-out of the IAPT programme.[160]

Recognising that *'access to services for people with mental health problems is more restricted […] than for other services'*, the government directed NHS England, through the 'refreshed' NHS Mandate, to work with the DH to develop new access / waiting time standards, together with *'a range of costed options in order to implement these standards starting from April 2015'*.[161] This commitment was reiterated most recently in 'Closing the Gap: Priorities for essential change in mental health' published by the DH in January 2014.[162] At the time of writing, a limited amount of evidence was emerging indicating that access is gradually improving in advance of formal waiting times being established. According to the HSCIC, for the second quarter of 2013, over 65 per cent of the 241,250 patients in England referred by GPs to therapies covered by the IAPT programme entered treatment[p] within 28 days.[163] A subsequent audit by the RCPsych found that the number receiving 'psychological therapies' within 13 weeks had risen from 85 per cent in 2010-11 to 92 per cent in 2012-13.[164]

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p   The HSCIC define entering treatment as having attended at least one therapeutic session with an IAPT provider. To be defined as a therapeutic session, an appointment must be any appointment type that is not "Follow-up appointment after treatment end", and must have at least one associated therapy type recorded.

Despite these developments in access standards, continuity of treatment remains problematic. Where psychological therapies are commissioned, limits are sometimes imposed on the number of sessions a person can receive on the basis of financial constraints, rather than being determined by an individual's clinical need. Lord Layard and Lord Stone raised this issue during a House of Lords debate in October 2013:

> *'Can noble Lords imagine, for drugs for a physical illness or chemotherapy, being told, "When you've had a maximum of 20 of these injections or radiotherapy sessions, you're on your own, mate"? Why should that be so for treatment for mental illnesses'.*[1]

The RCPsych has argued that more needs to be done to ensure that psychological therapy is continued until people either recover, or receive at least the minimum number of sessions recommended by the NICE guideline for the patient's condition.[164]

The NHS Constitution only applies to England, though non-medical consultant-led mental health services are also exempted from maximum waiting times in NHS Wales. The situation is different in Scotland and Northern Ireland. Under *The Patient Rights (Treatment Time Guarantee) (Scotland) Regulations,* 2012, patients requiring planned or elective treatment should have their treatment started within 12 weeks from the date on which they consent to proceed with the agreed treatment. This guarantee covers mental health services where they are delivered as part of planned and elective care.[165] In Northern Ireland, the 2011-12 Ministerial waiting time target states that at least 50 per cent of patients – including mental health patients – should wait no longer than nine weeks for consultant-led services, and no patient should wait longer than 21 weeks for an outpatient appointment.[166] Northern Ireland also has a 13 week target for access to psychological therapies.[167]

6.1.1.1 Black and minority ethnic groups

Differential access to, and take up of, statutory services by some black and minority ethnic (BME) groups has been a particular focus of concern. Kirkbride and colleagues report that BME individuals have a three-fold increased risk of psychosis (rising to seven-fold in African–Caribbeans),[168] while Bhui and colleagues have identified a two- to three-fold increased risk of suicide.[169] Despite the higher prevalence rates, the DRC notes that people from black groups were more likely than others to bypass primary care and be admitted straight to a psychiatric hospital. Based on this finding, the DRC concluded that the physical health needs of black people with mental health problems were '*likely to be under-addressed in primary care*'.[6]

The situation does not appear to have improved since the DRC first published their report in 2006. A census conducted by the Care Quality Commission (CQC) in 2010 – of 32,799 inpatients, and patients on supervised community treatment – found a higher than average rate of admission, referral from the criminal justice system, and detention under the *Mental Health Act* for Black Caribbean, Black African, and White / Black Mixed groups.[170] Whether this was due to variations in help-seeking behaviour, cultural or language barriers, or other factors, is unclear.[171,172] As Thornicroft highlights, a contradictory situation persists whereby black groups may have '*higher rates of many mental illnesses, lower rates of general referral and treatment, but higher rates of compulsory treatment and forensic service contact.*'[173] Small-scale pilot studies have demonstrated that steps can be taken to improve care for BME groups: one study showed that 'ethnically matched' assertive outreach teams were more acceptable to Black participants (n=83) than standard care provided by community mental health teams, though there was no significant reduction in duration of admission in the group.[174]

'Valuing People Now' – a cross-department three-year strategy for people with intellectual disabilities published by the DH in 2009 – noted how people with intellectual disabilities from BME groups can face 'double discrimination'. This arises through experiencing insufficient and / or inappropriate services, such as those that are culturally insensitive and that make incorrect assumptions about what certain ethnic groups value.[175]

6.1.1.2 Crisis care

Research commissioned by the charity Mind between 2010 and 2011 found evidence of crisis mental health services being closed out-of-hours, of people being told that they were not 'ill enough' to qualify for help, and of crisis home resolution teams (CHRT) being under-staffed. Frustration was also expressed about the threshold at which CHRTs accepted people into their own or hospital care.[176] Patients can find that their best chance of accessing treatment during a crisis is to approach the police, who then have a duty of care to respond. Comments made in 2013 by the Chief Constable of Greater Manchester Police, Sir Peter Fahy, following the publication of statistics on incident rates, show that the force is responding to more emergency calls from people experiencing a mental health crisis than ever before.[177] Statistics published by the HSCIC in June 2013 also show that mental health patients have double the rate of hospital attendances compared to the general population – across accident and emergency (A&E), inpatients and outpatient service – with four in 10 users visiting A&E once in 2011-12, compared to two in 10 of the general population.[178] Recognising that there have long been concerns about the way in which health services, social care services and police forces work together in response to mental health crises, the DH and 21 other organisations signed the 'Mental Health Crisis Care Concordat' in early 2014. The national organisations that are signatories to the Concordat have made a commitment to work together to support local systems to achieve continuous improvements for crisis care for people with mental health issues across England.[179] As one of the signatories to the Concordat, the CQC is reviewing the help, care and support experienced by people in crisis, including differences in approach across the country, with the aim of highlighting good and poor practice. The CQC is due to publish its findings later in 2014.

6.1.1.3 Prisoners with mental health problems or intellectual disabilities

A lack of parity in accessing mental healthcare is particularly apparent in the criminal justice system in the UK. Figures from the survey of 'Psychiatric Morbidity Among Prisoners In England And Wales', last conducted in 1998, found that over 70 per cent of the prison population had two or more mental health disorders. The DH and HM Prison Service have previously stated that *'prisoners should have access to the same range and quality of services appropriate to their needs as are available to the general population through the NHS'*.[180] While there are specialist mental health teams to work with those prisoners who have 'severe and enduring mental illness', primary care for prisoners with common mental health problems has been found to be far more variable.

Lord Bradley's review of people with mental health problems or intellectual disabilities in the criminal justice system, published in 2009, found that there was still *'some way to go'* in prison mental health services achieving equivalence with mental health services in the community. Bradley highlighted the need for processes that facilitated the early identification and assessment of problems, which could then inform how and where the offender was most appropriately treated. To assess the progress made in implementing the recommendations, the Centre for Mental Health has set up an independent Commission to carry out a five-year- review of the Bradley Report. This is due to publish its final report in 2014.

In January 2014, the Care and Support Minister, Norman Lamb, announced £25 million of funding for mental health nurses and other mental health professionals to work with police stations and courts so that people with mental health and substance misuse problems access the right treatment as quickly as possible. Ten areas across England will be piloting the scheme including Merseyside, London and Coventry.

6.1.1.4 Older People and care transitions

Older people are another group experiencing differential access to treatment. Much of the focus in recent years has been on the complex diagnostic challenges associated with dementia and difficulties in accessing interventions without a diagnosis. Psychiatric morbidity in the over 65s, however, is not restricted to this condition. The 'UK Inquiry into Mental Health and Well Being in Later Life' reported that one in four older people living in the community have symptoms of depression that are severe enough to warrant intervention. Only a third discuss it with their GP, with half going on to be diagnosed and treated.[181] Under-recognition and treatment of mental health problems in older people was formally acknowledged by the DH in a 2011 review of the IAPT programme. Analysis of IAPT data collected between 2008 and 2009 indicated that adults over the age of 65 represented an average of 4 per cent of those accessing IAPT services. According to the DH, the expected rate of over-65s in IAPT services, based on the age profile of the population and the community prevalence of depression and anxiety disorders, is 12 per cent.[182]

Access may be further hampered by the compulsory cut off age of 65 years for adult mental health services, after which point patients are seen by mental health services for older people.[q] Negotiating transitions between adult and older adult mental health services, as well as between primary and secondary care, health and social care services, and children's services and adult services, can prove problematic, especially if transitions are not coordinated and information fails to be shared across organisational boundaries.[r] Poorly managed transitions can fracture continuity of care and may lead to the patient becoming 'lost' within the system.[183,184] The administrative prevalence[s] of intellectual disability in the population of England falls from three per cent among children in the education system to 0.6 per cent among adults aged 20 to 29. The Learning Disability Health Observatory reports that it is '*highly implausible that such reductions in prevalence can be accounted for by either reduced life expectancy or sudden improvements in intellectual functioning.*'[49] It appears as though people with intellectual disabilities are falling off the radar during the key transition phase from child to adult services and are not accessing specialised adult social care support. The reasons why care transitions may not run smoothly, as well as ways to improve these transitions, will be examined in a separate report due to be published by the BMA Board of Science in 2014.

6.1.1.5   *Physical and practical barriers to accessing services*

Emerson and Baines, and Tuffrey-Wijne and colleagues, report that additional barriers to accessing services are faced by people with intellectual disabilities and that these are often related to the ways in which services are organised and delivered.[66,185] Such barriers include an overall scarcity of services specifically for this group. A survey conducted by the Royal College of Nursing (RCN) found that 73 per cent of respondents had witnessed cuts in intellectual disabilities services over the past year (see **section 6.3**).[186] Physical and practical barriers to accessing services can range from a lack of ramps and lifts prohibiting easy access into a building, to difficulties making appointments. Busy and noisy surgery waiting rooms (and the absence of a quiet space to wait) can also heighten an intellectual disability patient's anxiety to such a level that they find it difficult to communicate with the doctor once in the consultation room.[6] This can be exacerbated if insufficient time is allocated for the appointment and / or if the person is not supported by someone who knows them well.

These types of barriers could constitute a failure to make 'reasonable adjustments', as defined in the *Equality Act 2010*. Adjustments do not only comprise removing physical barriers to access, they also include '*making whatever alterations are necessary to policies, procedures, staff training and service delivery to ensure that they work equally well for people with learning disabilities.*'[187] Being able to tell someone that something is wrong is the first step towards accessing care. People who have limited or no verbal communication often cannot do this. Those with communication support needs tend to be poorly identified. Tuffrey-Wijne and colleagues found a lack of effective systems to transfer information between primary and secondary care, leaving hospitals unable to identify people with intellectual disabilities, and any support needs they may have, at the point of referral.[185] This can leave patients with intellectual disabilities struggling to negotiate the healthcare system: they may fail to receive information in pictures or another easy to understand format (see, for example, 'Books Beyond Words'[188]). There can also be a tendency for some people with intellectual disabilities to be very agreeable and go along with what the doctor says when, in reality, they do not understand what they are being told or asked.

Developmental delays can also make the transition from children's to adult services particularly difficult to negotiate for people with intellectual disabilities.[13] Links between specialist intellectual disability services and general hospitals, which could help to facilitate this process and provide more tailored care, tend to be poorly developed. Hospital 'flagging' systems to identify people with intellectual disabilities who need reasonable adjustments have been found to be limited by CIPOLD.[14] Further research conducted by Tuffrey-Wijne and Hollins identified a widespread reluctance among staff to flag patients,

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q   In some instances, people who are under mental health services before the age of 65 stay with those services after 65 unless they develop dementia, and only then are they moved into mental health services for older people.

r   With regards to sharing patient information, the BMA's position is that only relevant information should be shared and where there is any doubt, explicit consent should be sought from the patient.

s   The number of people with intellectual disabilities who are known to services.

partly because of the fear that this would 'label' them pejoratively. Staff were also found to lack an understanding of the kinds of adjustments that might be needed to make healthcare more accessible to patients with intellectual disability.

Carers of people with intellectual disabilities can provide essential information and support, particularly when it comes to delivering treatment, helping healthcare practitioners to communicate with the patient and ensuring proper nutrition. Despite knowing the patient well and being well-placed to recognise signs of pain or distress, carers frequently report that their inputs are often rejected or disregarded, especially when attempting to help identify symptoms.[13,185] Some healthcare practitioners, particularly those with limited contact with intellectual disability patients, may make unfounded judgements about how someone with intellectual disabilities will respond to treatment. These judgements may be based upon the practitioner's prejudices about that person's quality of life, their capabilities, and / or value as a citizen, rather than clinical evidence.[82] Ingrained discrimination can result in the individual receiving substandard treatment which may interact in complex and detrimental ways with other social inequalities, placing the patient at an even greater disadvantage. This 'poverty of expectation' by healthcare professions is considered in more detail in **section 6.2** in the context of intellectual disability and mental health patients.[189]

6.1.1.6   Diagnostic overshadowing

Diagnostic overshadowing refers to the symptoms of physical ill health being mistakenly attributed to either a mental health problem or as being inherent to the person's intellectual disability (or vice versa).[66] Carers may also make similar assumptions, or be unaware of the significance of particular symptoms, and fail to recognise that the person needs to be assessed by a doctor. Diagnostic overshadowing may be compounded by the ways in which care and treatment are delivered to people with mental health problems and intellectual disabilities. In the case of the latter, the low priority given to the health and healthcare of people with intellectual disabilities was raised in a 2007 report 'Death by Indifference' published by the charity Mencap.[190] This described the conditions surrounding the deaths of six people with intellectual disabilities while they were in the care of the NHS. Responding to the report, the then Secretary of State for Health in England, Patricia Hewitt, invited Sir Jonathan Michael to head an independent inquiry into access to healthcare for people with intellectual disabilities.[13] 'Valuing People Now', a cross-department three-year strategy for people with intellectual disabilities, accepted all ten recommendations and stated that '*[B]etter health for people with a learning disability is a key priority.*'[175]

In a follow-up report published in 2012, Mencap concluded that the actions needed to address inequalities in healthcare were now well understood. They were not convinced, however, that the changes underway within the NHS would mean that people with an intellectual disability would be a priority.[191] A 2012 survey of 400 doctors, conducted on behalf of the GMC, found that more than one in three doctors reported having personally seen a patient with an intellectual disability receive poorer care or face some form of discrimination.[192] Responding to the results, the GMC's Chief Executive, Niall Dickson, said:

> *'We know that too often patients who have a learning disability receive poorer treatment and that sometimes health professionals fail to see past the patient's disability to identify underlying physical problems.'*[192]

Following the survey, the GMC launched a micro site on intellectual disabilities. It aims to help doctors provide better care for people with intellectual disabilities through interactive learning tools.[193]

While the causes of diagnostic overshadowing in people with mental illness are likely to be complex, Jones and colleagues point out that there has been little attempt to empirically examine how clinicians decision-making regarding physical diagnosis and treatment may be influenced by the presence of a mental illness in their patients.[83] One exception is a small-scale study (n=25) examining emergency department staff (doctors, nurses, nurse practitioners) views and experiences on diagnostic overshadowing relating to people with mental illness. Almost two-thirds of participants acknowledged diagnostic overshadowing to be a common phenomenon, and eight possible contributing factors were identified. These included: problems obtaining a history; problems with examination; clinicians' lack of knowledge about mental illness; environmental problems (lack of privacy and noisiness in emergency departments); labelling and stigma; fear of violence and avoidance; time

pressure (target to see, treat and admit or discharge patients within four hours in emergency departments); and lack of implementation of parallel working with psychiatry.[194]

6.1.2 Coordination of care

There has been a longstanding tendency in the UK to view physical and mental illness as separate and distinct spheres of medicine. This view has manifested itself through the geographic, institutional, and professional division of physical and mental healthcare services in the UK.[t] It has been argued that this organisational structure inhibits the provision of an integrated, coordinated response to the multiple mental and physical health needs of patients, leaving them with unmet health needs.[7] It can also limit accountability for the patient, with responsibility for care being held by 'everyone and no one'; a problem that is exacerbated further by the *'demise of the General Physician […] within a hospital setting'* and increasing subspecialisation.[195] An example of this was highlighted during a Victor Horsley lecture by Professor Linda Gask (Professor of Primary Care Psychiatry) at the BMA's 2012 Annual Representative Meeting (ARM), which noted that the separation between mental and physical healthcare sometimes created uncertainty surrounding who was responsible for following up abnormal blood test results in mental health patients.

Another example of the lack of coordinated care is the patchy provision of liaison psychiatry services – including paediatric liaison services – in hospitals across the UK. Liaison psychiatry teams are designed to assess the relative contribution of physical and psychological factors in a patient's presentation and management (see **section 7.2.3**). Aside from liaison psychiatry, consideration should also be given as to whether the absence of consultant-led psychiatry departments within general hospitals downgrades the importance of the investigation and treatment of mental illness, particularly when it co-occurs with physical illness.

Poor coordination of care is not only experienced by people with mental health problems. The lack of care coordination *'across and between the different disease pathways'* received by people with intellectual disabilities, particularly when compared to a control group with no intellectual disabilities, was highlighted by the CIPOLD.[14] While evidence-based models for single diseases work well for patients with one disease, they can lead to the 'siloing' of care when applied to people with multiple conditions and may ultimately deliver chaotic, fragmented treatment as well as poorer health outcomes.[196] Clinical guidelines tend not to consider co-morbidity, creating the risk that the diagnosis and / or treatment of one disease, delivered as recommended by the disease-specific guidelines, interacts harmfully with the treatment (or natural development) of a co-existing disease.[10,197] To confront these problems, the CIPOLD recommended that NICE guidelines should include information on how to manage people with more than one condition or illness, and that a named healthcare coordinator should be allocated to people with complex or multiple health needs, or two or more long-term conditions.[14]

In the Government's response to the CIPOLD, the DH agreed that NICE clinical guidelines should take multi-morbidity into account where appropriate, with NICE agreeing to *'look at co-opting people with learning disabilities or their carers onto its guideline development groups where the scope suggests this would be useful.'*[198] The DH also agreed with the need for a named healthcare coordinator: NHS England have promised to make *'care coordination a central part of its strategy to help people with more complex healthcare needs benefit from personalised care and know who to turn to for advice in the event of deterioration in their condition.'*

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t   Northern Ireland is a notable exception following the restructuring of the health service in 2009. Under the Health and Social Care (Reform) Act (Northern Ireland), the DHSSPS is responsible for promoting an integrated system of health care designed to secure improvement in the physical and mental health of people in Northern Ireland, and in the prevention, diagnosis and treatment of illness.

6.1.3   *Mental health strategies*

As highlighted in the introductory chapter, the most recent mental health strategies published across the devolved nations have acknowledged that a more coordinated level of care is required. The DH's 2011 mental health strategy for England – 'No health without mental health' – outlined their ambition to establish parity of esteem between services for people with mental and physical health problems.[23] In 2012, the DH worked with a variety of organisations to translate the 'vision' outlined in the strategy into concrete actions. The resulting 'implementation framework' stressed that:

> '[A]chieving our shared vision to put mental health on a par with physical health means ensuring people can access the support and treatment they need, but it also means doing more to tackle stigma and improve attitudes to mental health across the whole of society.' [199]

A key strength of the framework is that it focuses on interventions at all ages, by different public and charitable bodies, working at multiple levels. In addition to reducing stigma and improving physical health, *recovery* from mental health problems – and improving mental health outcomes – are also pinpointed as two key objectives, with £400 million being invested to increase access to NICE-approved psychological therapies. The DH has also committed to extending the IAPT programme to include children, young people and people with an SMI by March 2015, but not yet to include people with intellectual disabilities.[200]

At the time of writing, various changes had been made to GP contracts across the UK. As the consequences of these changes to the GP contracts are uncertain, it is important that their impact is monitored.

Prior to April 2014, the Quality and Outcomes Framework (QOF) provided GPs with incentives to offer regular reviews of the BMI, blood pressure, cholesterol:HDL ratio, alcohol consumption, and blood glucose to those patients with schizophrenia, bipolar disorder, and other forms of psychosis.[201] The BMA and NHS Employers have negotiated changes to the GP contract for England for 2014-2015. As part of these changes, approximately 40 QOF indicators have been withdrawn, including three mental health indictors reviewing BMI, blood glucose and cholesterol:HDL ratio in patients with schizophrenia, bipolar disorder, and other forms of psychosis.

A recommendation that patients with an SMI receive an annual health promotion and prevention review, and advice appropriate to their age, gender and health status, remains in the QOF guidance for England. General practitioners will continue to be monitored on the QOF targets, and there is no expectation that they will, or should, stop providing annual reviews. The withdrawal of the 40 indicators has resulted in the transfer of QOF points into core GP funding to provide greater baseline resources for practices to manage patients according to clinical judgement and need. The changes aim to empower GPs to provide holistic, individualised services to SMI patients, enabling them to tailor treatment to the needs of the patient rather than be bound by rigid targets to do defined activities. The overall level of funding for general practice in England for 2014-15 has not changed.

Changes to the Welsh GP contract for 2014-15, and specifically to QOF, have also taken place. While several mental health indicators have been withdrawn, proposals are underway in Wales to develop a new, 'bundled' indicator to cover mental health and BMI, blood pressure, cholesterol:HDL ratio and blood glucose.[202] A direct enhanced service for the care of people with mental illness is also in place in Wales. It aims to support the development of GPs and their practice teams to understand the needs of patients with severe mental health problems and ensure that routine chronic disease management services are accessible to all patients.[203]

In Scotland, QOF mental health indicators have not been withdrawn under the 2014-15 GP contract. The timeframe across which indicators, such as blood pressure and cholesterol, should be measured in SMI patients has shifted from 12 months to 15 months. The Scottish Government has agreed to return to a 15-month cycle of review (or 27 months for items under two-year review) for the QOF indicators changed in 2013-14. This is to reduce unnecessary bureaucracy and enable the peak time of this activity to move out of the third quarter of the year, allowing GP practices to deal more effectively with acute winter pressures.[204]

In December 2013, mental health outcome measures that can be evaluated were published by the DH. These data are based on pre-existing, publicly available sources of information, though a number of 'placeholder' indicators are included to denote data that will be available in future years.[199] Gaps in the measurement of outcomes and process in mental health treatment and care were previously acknowledged in a 2011 NHS Confederation review, with patient organisations commenting in particular on: *'the concept of recovery and the paucity of relevant information collected in routine practice to help understand whether an episode of care is associated with any improvement'.*[205] In the case of achieving parity between mental and physical health, the implementation framework also has a tendency to focus on improvements to single physical health risk factors, such as smoking and obesity, thereby displaying a limited recognition that increased morbidity is invariably linked to factors that occur in combination.

Similar ambitions to give mental health parity with other health conditions; to ensure that people with mental health conditions are diagnosed and treated; and to encourage a 'recovery and reablement' approach, are outlined in the Northern Ireland Service framework for mental health,[22] and the Scottish,[24] and Welsh mental health strategies.[25] While the Northern Ireland framework sets out key performance indicators, and the Welsh strategy includes outcomes measures, the Scottish mental health strategy is centred on 36 'commitments', some of which lack detail about how they will be operationalised.

6.1.4 Intellectual disability strategies

In England, two White Papers, 'Valuing People' (2001)[37] and 'Valuing People Now' (2009)[175] established a cross-Government strategy for people with intellectual disabilities. These were structured around four guiding principles which apply to individuals and services (see **Box 4**).

Box 4: The four guiding principles set out in 'Valuing People', and 'Valuing People Now', which apply to individuals and services

Rights:
People with learning disabilities and their families have the same human rights as everyone else.

Independent living:
This does not mean living on your own or having to do everything yourself. All disabled people should have greater choices and control over the support they need to go about their daily lives; greater access to housing, education, employment, leisure and transport opportunities and to participation in family and community.

Control:
This is about being involved in and in control of decisions made about your life. This is not usually doing exactly what you want, but is about having information and support to understand the different options and their implications and consequences, so people can make informed decisions about their own lives.

Inclusion:
This means being able to participate in all the aspects of community – to work, learn, get about, meet people, be part of social networks and access goods and services – and to have the support to do so.

Source: HM Government (2009) *Valuing people now: a new three-year strategy for people with learning disabilities*. London: Department of Health.

Learning Disability Partnership Boards were set up to oversee the delivery of this policy, and positive targets were set to improve the health of people with intellectual disabilities: all people with intellectual disability were to be registered with a GP and were to have a health action plan by set dates (see further discussion in **section 6.2** on annual health checks). 'Valuing People Now' acknowledged that the impact of Local Partnership Boards had been variable, while the DRC was concerned that there had been effectively '*no inclusion of the high risks to physical health amongst people with learning disabilities in mainstream targets or health policy*'.[6,175] A model service specification for intellectual disability services is being developed by the National Commissioning Board and the Association of Directors of Adult Social Services (ADASS), in conjunction with the DH and NHS England. At the time of writing, the specification was in the second draft stage and had not yet gone through a consultation process.[187,206] In August 2013, the National Medical Director for NHS England, Professor Sir Bruce Keogh, announced the appointment of 23 National Clinical Directors, including a National Clinical Director for Learning Disability, Dr Dominic Slowie. In addition to working with NHS England to provide clinical leadership and support towards delivering improved health outcomes across the five domains of the NHS Outcomes Framework, Dr Slowie has also been tasked with looking at the feasibility of developing best practice guidelines for the treatment of people with learning disabilities as part of the Government's response to the CIPOLD.[207]

All the devolved nations have encouraged a shift towards providing care in the community while at the same time closing long stay intellectual disability hospitals. Current intellectual disability strategies have identified the resettlement of people with intellectual disability as a success and this trend looks set to continue.[208] The Winterbourne View concordat, for example, published by the DH in late 2012 stresses that:

> '*The NHS Commissioning Board's [now NHS England] objective is to ensure that Clinical Commissioning Groups work with local authorities to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high quality care. The presumption should always be that services are local and that people remain in their communities; we expect to see a substantial reduction in reliance on inpatient care for these groups of people.*'[209]

In Scotland, a new intellectual disability strategy is expected in 2013-14. A review of the 2000 strategy, 'The same as you?', noted that while progress in enhancing the physical health of people with intellectual disability has been made in different parts of Scotland, areas for improvement remained, including the need to promote and ensure consistency.[208] The Welsh Government issued a 'Statement on Policy and Practice for Adults with a Learning Disability' in 2007 in which they acknowledged the ongoing health inequalities faced by this group across Wales.[210] In addition to recommending a programme of regular health checks for individuals with intellectual disabilities, the strategy recognised the importance of making '*specialist arrangements for people with complex health needs in order to ensure that their needs are met effectively and safely*'.[210] While the statement was criticised by the DRC for lacking a robust action plan or rigorous enforcement mechanism,[6] there have been positive changes, including amendments to the GP contract in Wales to give incentives to provide regular health checks for people with intellectual disabilities. To be effective, any identified health problems must be followed up, and a plan of action adhered to.

A strategy to improve the lives of disabled people, covering all types of disability, was launched by the Northern Ireland Office of the First Minister and Deputy First Minister, and opened for consultation, in April 2012. At the time of writing, a finalised strategy had not been published. The 'Bamford Action Plan', however, set out how the '*dignity, social inclusion and assurance of human rights for those with a mental health need or a learning disability*' would be promoted in Northern Ireland.[211] Published in 2009, the Action Plan placed a clear emphasis on ensuring that people with an intellectual disability enjoyed equity of access to healthcare. Notable progress towards realising this goal includes the introduction of 'Directed Enhanced Services' for adults with a severe intellectual disability, which are designed to improve primary healthcare through annual health checks. The NI 'Learning Disability Service Framework' (2012) outlined what people with an intellectual disability can expect in terms of care and support to meet their individual needs. The framework features 34 standards alongside 'key performance indicators' and 'performance levels' against which progress will be measured. Standards 19 through to 25 cover the physical and mental health of this group, and stress that '*all people with a learning disability should be supported to achieve optimum physical and mental health*'.[212]

Summary
- Unmet health needs are apparent among people with mental health problems, long-term physical illnesses, and intellectual disability.
- A scarcity of services, physical barriers to accessing services, and failures to make reasonable adjustments have been identified as organisational barriers inhibiting access to care by people with intellectual disabilities.
- Overt or covert discrimination and diagnostic overshadowing may also lead to inequalities in healthcare for people with mental health problems and intellectual disability.
- England, Scotland and Wales published mental health strategies between 2011 and 2012 that make a commitment to establishing parity of esteem between mental and physical health. Northern Ireland published a 'Service framework for mental health and wellbeing' in 2011. While all the documents feature ambitious and well-intentioned commitments, they lack detail about how they will be operationalised.
- The physical healthcare of people with intellectual disabilities has been considered by all the devolved nations in their 'learning disability' strategies. These strategies are over three years old and some are in the process of being evaluated and reconsidered.

6.2   Monitoring, assessments and service provision

In light of the excess mortality among people with mental health conditions and intellectual disabilities, monitoring and treating modifiable risk factors, such as poor diet, should be part of the routine clinical care received by these groups. The physical healthcare of patients with schizophrenia, for example, is prioritised in NICE clinical guidelines, with emphasis placed on the monitoring of cardiovascular risk factors, such as blood pressure, lipids, and weight (see **Box 5**).[213] The 2012 National Review of Schizophrenia found the monitoring of cardiometabolic risk factors by Mental Health Trusts in England and Health Boards in Wales to be 'extremely poor'.[214] In only 29 per cent of cases were all the cardiovascular risk factors listed in the NICE guidance recorded.[214]

There is evidence to suggest that the limited monitoring of physical healthcare extends beyond patients diagnosed with schizophrenia. A survey of 15,000 users of community mental health services in England, conducted by the CQC, reported that 43 per cent of respondents said that no one in NHS mental health services had asked them about their physical health needs in the last twelve months.[215] A smaller scale analysis of the case notes of 63 patients – who were being cared for by a community mental health and rehabilitation team in Birmingham – found that the monitoring and recording of particular aspects of their physical health were poor: less than 18 per cent of notes referred to the patient's smoking, diet and exercise habits; lipids and blood pressure were mentioned in less than 30 per cent of notes; and only 25 per cent of patients were recorded as having received a blood sugar test.[216]

The expectation is that NICE clinical guidelines will be taken into account when deciding what interventions and treatment may benefit a patient. As clinical guidelines, they are *'not subject to a mandatory requirement regarding funding'*. At the time of writing, the NHS is only required to provide funding for medicines and treatments recommended by NICE through its technologies appraisals.[217,u] Few mental health treatments have undergone a technology appraisal: most NICE mental health guidance is advisory rather than mandatory.

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u   The status of NICE guidance varies across the UK. Further details can be found at:
     http://www.nice.org.uk/aboutnice/whatwedo/niceandthenhs/nice_and_the_nhs.jsp
     In Scotland, the Scottish Medicines Consortium (SMC) is responsible for advising NHS Boards in Scotland about the clinical and cost-effectiveness of all newly licensed medicines, all new formulations of existing medicines and new indications for established products. The Minister for Health and Community Care has publicly stated that *'NHS Scotland should take account of the advice and evidence from the SMC and ensure that recommended medicines are made available to meet clinical need'*. Further information can be found at: https://www.scottishmedicines.org.uk/General/FAQs

As the RCPsych acknowledged, this leads to a lack of parity between physical and mental healthcare:

> *'[…] a greater proportion of mental health treatments than physical health treatments have undergone a clinical guideline assessment process rather than a technology appraisal process. This means that they are in practice less available to service users, as there is not the same legal imperative for mental health service providers to make them available.'*[30]

For many SMI patients, their only contact with health services will be through a mental healthcare team. The evidence outlined in this chapter indicates that this type of contact does not necessarily guarantee good physical care. Despite higher rates of physical ill health, and the shortened life expectancy, experienced by patients with mental health problems, physical health screening and monitoring are not necessarily given priority by mental health professionals. There are important questions about whether they should be expected to be competent in this area:[12,150] while some do not routinely undertake physical health assessments because they believe the patient's physical health is being looked after by a different physician, others report that they do not feel competent to perform this type of examination.[92,218,219] This raises important considerations for the adequacy of medical training, and is discussed further in **section 7.3**. The confidence of mental health clinicians to manage physical health problems may also be compounded by being part of separate organisations from physical health services: this can leave mental health professionals without easy access to routine physical tests and lacking the necessary educational and peer support.

Similar concerns have been reported by GPs about their ability to look after a mental health patient's care.[220] While there is evidence that GPs prioritise the mental health needs of this group over and above their physical health,[221] a number of studies have highlighted GPs concerns about whether they have the necessary skills and knowledge required to treat mental health patients, with time constraints imposed by rigid appointment systems[v] adding further difficulties.[12,92,222]

A GP's lack of confidence about their clinical skills in relation to mental health may have knock-on effects that disadvantage a patient's physical care. Phelan notes that doctors who are uncomfortable with mental health work may resist intensifying their engagement with a patient and avoid asking about physical symptoms or performing a physical examination.[12] This can also lead to disparities in the prescribing of medication for physical health problems. A meta-analysis of differences in prescribing for physical disorders found that individuals with SMIs *'received lower than expected prescriptions'* for essential drugs used to treat high blood pressure, including ACE inhibitors, beta-blockers, and statins. The estimated rate of under-treatment was 10 per cent for those with SMIs.[223]

In addition to GP concerns about their skills, they also face a number of practical, systemic problems when attempting to refer patients to mental health services. The changing NHS landscape has created confusion over what mental health services are available locally as funding arrangements are modified and revised. This problem is not limited to mental health services in England. Board of Science members reported that ongoing over-demand for mental health services has led to the implementation of strict referral criteria regarding who the services will, and will not, accept. Patients must be referred to their catchment area service, and cannot usually be referred to a named clinician. While such criteria are important, they can result in some patients 'falling between the gaps', and being 'bounced' from one service to another without being accepted as a patient because they do not meet the referral criteria. Some referrals may be reviewed by a multidisciplinary team and be 'bounced' before being reviewed by a doctor. Over-demand – often where mental health services are needed most – can also mean that access to services is severely delayed, particularly since non-medical consultant-led services are not subject to waiting time limits in England and Wales. This is sometimes to the extent that GPs regard them as too slow to be helpful.

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v   This may change following the removal of the 'Patient Experience' domain from QOF. This indicator stated that the length of a routine consultation must not be less than 10 minutes. The time GPs have for patient consultations remains constrained due to growing patient demand.

A survey conducted in 2010 by the RCGP of 1,174 of its members found that 65 per cent of respondents could 'rarely access' specialist psychological therapy (eg cognitive behavioural therapy) for an adult patient suffering from depression or anxiety disorders.[224] With psychiatry services over-stretched, GPs have reported that mental health work has been shifted on to GP practices but without sufficient resources – such as community psychiatric nurses (CPNs) – to support them.

In the case of mental health patients, there is some evidence to suggest that the monitoring of their physical health may be associated with the severity of the mental illness. Research conducted on behalf of the DRC in 2006 reported that people with SMIs generally had as many standard tests (relating, for instance, to blood pressure, cholesterol, urine analysis and weight) performed as the general population.[6]

The same was not true for people with an intellectual disability. Despite visiting their GP at a frequency comparable to the general population,[66] people with an intellectual disability who did not previously have an identified physical health problem were *less likely* to receive standard tests.[6] This group were also less likely to receive regular health checks.[66] In 2006, annual health checks for every adult with intellectual disabilities on a local authority register were introduced as a DES in primary care services in Wales, with England following in 2009.[225] Data published in 2011 suggests that the number of annual health checks provided went up by 7 per cent between 2009-10 and 2010-11, from 41 per cent of eligible patients to 48 per cent.[226] The CIPOLD has raised concerns regarding the variability that they found in the content, quality and recording of annual health checks, and recommended that minimum requirements for such checks are introduced.[14]

It should be noted that the DES health check is only offered to those who are known to social services, though some areas also offer annual health checks to everyone on the QOF register.[187] The monitoring and recording of intellectual disability, however, appears to be limited. The RCGP reported in 2012 that QOF registers identify 4.33 people with intellectual disabilities per 1,000 population, whereas the estimated prevalence of people with intellectual disabilities in the population is approximately 20 people per 1,000 population in England.[187] According to Local Medical Committees, those patients with intellectual disabilities living in private sector 'supervised' accommodation are a group that local councils can have no knowledge of, leaving them unable to access supplementary services. Under-recognition of intellectual disability is more common among mild, rather than severe, cases and, as previously reported, is thought to be due to failures of record keeping at transition to adulthood. The identification of anxiety and depressive disorders by GPs can be modest: in 2009, NICE estimated that approximately 30 per cent of people presenting with depressive disorder were diagnosed and offered treatment.[227,228] Accurate identification and monitoring of the prevalence of intellectual disability and mental health problems is essential to inform the commissioning of appropriate services. An up to date register can also help to achieve a better understanding of the patient's health status, as well as enabling their progress to be tracked over time.

6.2.1 *Challenging behaviour and discrimination*
A further difficulty facing doctors when assessing mental health and intellectual disability patients is that their behaviour may challenge and concern service providers. This type of behaviour can result from the fact that the patient finds clinical environments threatening or frightening.[146] Interviews with primary care staff conducted on behalf of the DRC found that fear and mistrust of people with mental health problems and intellectual disability were two additional factors affecting the care given to these groups:

> *'The subtext from the interviews with primary care staff and practitioners was a mix of fear, anxiety and some impatience combined with paternalism and kindness. Even though some of the interviews described the provision of awareness training in both mental health and learning disability, there was still a sense that patients from these groups were like time bombs ready to go off at any moment.'[6]*

The DRC's research findings raise similar issues to those highlighted at the start of **Chapter 6** – namely that discrimination can present a barrier to accessing and / or receiving high-quality healthcare and that training is of paramount importance. An absence of training, for example, can result in doctors failing to recognise the underlying cause of the challenging behaviour, leading to a response which makes the situation worse, and potentially impacting on the safety of the doctor.

Following the publication of the Mencap report, '74 deaths and counting'[191] in early 2012, and the exposure of abuse at the Winterbourne View care home in 2010, the issues of discrimination towards, and abuse of, people with intellectual disabilities have come to the fore. Mencap's report draws attention to the deaths of 74 people with an intellectual disability in NHS care over the last ten years which, they believe, were a direct result of institutional discrimination. The report uncovers errors made by healthcare professionals, including the failure to abide by disability discrimination law, ignoring advice from families, and not meeting basic care needs. Mencap believes that this treatment is underpinned by an assumption, made by some healthcare professionals, that people with an intellectual disability are not worth treating and thus they inevitably have to live with poorer health.

The health and care of people with mental health problems are also limited by the reactions they receive from other people, including healthcare professionals. Physical health summits held by the charity Rethink Mental Illness in 2012, and attended by over 200 participants, highlighted how '*many people felt that their concerns about their physical health were not taken seriously because of their mental illness.*'[128] The importance of health professionals' attitudes towards mental ill health was echoed by the RCPsych: in their 2013 report on parity, negative assumptions about mental health problems were identified as a potential *'cause of poor attention to individuals' physical healthcare needs and low aspirations for their recovery.'*[30]

Discriminatory attitudes among healthcare professionals towards mental health and intellectual disability patients was a key issue raised at the BMA's 2013 President's seminar (see **Appendix 1**). This was found to manifest in miscommunication between healthcare professionals and patients, as well as a failure to make 'reasonable adjustments' as required by the *Equality Act 2010*. The seminar also identified that a poor understanding, and subsequent misuse, of the *Mental Capacity Act 2005* resulted in flawed best interest decisions being taken about the treatment of mental health or intellectual disability patients. It was noted that while a healthcare professional did not mean to harm their patient, a failure to understand how to assess best interests could lead to unfounded judgements about how 'worthwhile' it is to continue treatment, prescribe a particular drug, or carry out a procedure. These judgements may be based upon the practitioner's prejudices about that person's quality of life, their capabilities, and / or value as a citizen, rather than clinical evidence. Proposed solutions focused on improving training to healthcare professionals in identifying and understanding the needs of mental health and intellectual disability patients. Seminar participants also discussed the need to initiate a culture change in the NHS away from ill-informed judgements about mental health and intellectual disability patients towards high quality, holistic, and collaborative care. These areas are discussed in detail in **Chapter 7**.

Elsewhere in the literature, patterns of reduced access to effective and timely healthcare are argued to represent a form of 'structural' or 'systemic' discrimination: actions and policies which are not intended to discriminate *'but whose consequences nevertheless hinder the options of people'* with a mental illness or intellectual disability.[229,230,231] Ways to tackle this 'undercurrent' of low expectations for the physical health of intellectual disability and mental health patients are also considered in detail in **Chapter 7**.

Summary
- The monitoring and assessment of the physical health of patients with mental illness and intellectual disability is inconsistent. The same is true for the mental health of patients with chronic physical health problems.
- Physical health screening and monitoring is not necessarily given priority by mental health professionals. They may believe that another physician is looking after the patient's physical health, or they may feel ill-equipped to perform a physical examination.
- Concerns about whether they have the necessary skills and knowledge required to treat mental health patients have been reported by GPs.
- Annual health checks for people with intellectual disabilities are incentivised via DES. Less than half of those entitled to a check received one in 2010-11 and the quality is questioned.
- The identification of people with an intellectual disability is limited. The RCGP found that QOF registers identify 4.33 people with learning disabilities per 1,000 population, whereas the estimated prevalence is approximately 20 people per 1,000 population in England. The prevalence in school age children is three per cent.
- Mental health and intellectual disability patients can face discrimination that reduces or denies them access to effective, high-quality healthcare.

6.3   Commissioning and funding

The limited screening, assessment and provision of 'joined-up' healthcare for people with mental health problems, and intellectual disability, may be exacerbated by the way in which services for these groups are commissioned and funded. The English mental health strategy integration framework explicitly states that:

> '…clinical commissioning groups (CCGs) are required to demonstrate that they have sufficient planned capacity and capability to commission for improved outcomes in mental health [...] Mental health will be one of eight key commissioning areas that will be used as themes to assess applications for CCG authorisation.'[199]

Achieving 'sufficient planned capacity' requires commissioners to have accurate, accessible information on the physical, mental and intellectual disability needs of the population that the CCG is serving. Information will also need to be collected on the patient's recovery (or otherwise) to help understand whether an episode of care is associated with 'improved outcomes in mental health'.

Local needs are assessed in England through Joint Strategic Need Assessments (JSNAs). There are mixed reports about their effectiveness at identifying people with mental health and intellectual disabilities. Investigations made by the All Party Parliamentary Group (APPG) on Suicide and Self Harm Prevention found that 57 out of 152 (37.5%) upper-tier local authorities (unitary or county council level) in England had identified mental health as a priority by the Health and Wellbeing Board in the JSNA.[232] A similar review was conducted by the Learning Disabilities Observatory in 2012. Of the 141 JSNAs identified, 82 per cent included some mention of intellectual disabilities, though this varied by Government Office region: while 100 per cent of JSNAs in the North East and Yorkshire referred to intellectual disability, only 53 per cent did so in the East Midlands. The majority of these references were to adults with intellectual disabilities, rather than to children or older adults.[233] Variations were also found in the types of information on intellectual disability included in the JSNA. All JSNA's in the North East region contained details of the current prevalence of intellectual disabilities, but less than 30 per cent also featured estimated changes to prevalence in the future.

The CMO for England drew attention to the 'current paucity of data' on mental health in her 2012 report on the state of the public's health,[160,w] while the mandate to NHS England criticised the lack of a *'robust system of measurement in place to quantify the scale of [mental health] problems'*.[161] Similar concerns about the limited amount of relevant information on recovery and improved outcomes gathered during routine practice have been raised by the NHS Confederation's Mental Health Network who identified the need for progress across four areas:

- content – what to measure at national and local level
- process – which data should be analysed and how should it be collected
- utility – the purposes for data analysis
- the burden of measurement – the volume of, and commitment to, data capture by local providers.[205]

The historic underinvestment in mental healthcare also raises questions about whether there can be parity of outcomes in the absence of parity of provision. While there are geographical variations in the annual amount of mental health spend per head of population, the overall level of funding is not proportionate to need. Over 20 per cent of the disease burden in the UK is attributed to mental health problems, yet the funding allocated to mental health services across the UK does not reflect this burden: the RCPsych estimates that nine per cent of the NHS and social services spending in Northern Ireland, 11 per cent in Scotland, 12 per cent in England, and 12 per cent in Wales, is allocated to mental health services.[234]

These figures stand in stark contrast to the costs that mental illness imposes on the NHS. Since approximately one-third of all people with long-term physical health conditions have a co-morbid mental health problem, mental health problems are estimated to raise the costs of physical healthcare by at least 45 per cent. Untreated mental illness is thought to be costing the NHS over £10 billion in physical healthcare costs per annum.[235] The Centre for Mental Health has produced a more conservative estimate: based on their calculations, the extra cost of physical healthcare in general and acute hospitals associated with co-morbid mental health problems is of the order of £6 billion per year.[236] Taking a broader focus, early in 2014, the Organisation for Economic Co-operation and Development reported that a failure to cope adequately with mental health issues was costing the UK 4.5 per cent of gross domestic product each year, caused by productivity losses, higher benefit payments as well as the increased cost to the NHS.[237]

Mental health services tend to be viewed as one of the 'easiest areas to cut' during times of austerity: in 2011, Lord Layard reported to the House of Lords that this practice was *'happening on quite a scale'*.[238] Similar concerns were raised in the House of Commons Health Committee's 'Post legislative scrutiny of the Mental Health Act 2007' report, published in August 2013. The Committee heard evidence that '*commissioners find it easier to cut mainstream mental health services because of the way in which they are commissioned through block contracts*' and that this behaviour was not consistent with achieving parity of esteem.[239] The severity of the situation varies across the devolved nations: the significant reforms taking place in England, and the national differences in organisational structure and health strategies, create a complex healthcare landscape. Total investment in mental health services across England decreased in real terms by one per cent between 2010-11 and 2011-12.[240] Responses to Freedom of Information requests made in 2013 by BBC News and the journal 'Community Care' have provided more detailed information. An overall funding cut of 2.3 per cent in real terms between 2011-12 and 2013-14 was calculated, based on information from 43 out of 51 mental health trusts in England. Data obtained from 36 mental health trusts in England showed that spending on community mental health teams rose from £397.7m in 2011-12 to £412.4m in 2013-14; a decline of 0.03 per cent in real terms compared to 2011-12. In the same period, the average number of referrals being handled by community mental health teams rose by 13.3 per cent.[241]

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w   At the time of writing, the CMO for England was leading a group undertaking a review of public mental health for the 2013 'Annual Report of the Chief Medical Officer'.

In a letter to the Guardian in March 2014, a number of leading mental health organisations raised their concern about the decision by NHS England and Monitor to recommend cutting funding for mental health services by 20 per cent more than that for acute hospitals.[242] This noted that such a decision completely contravened the commitment to parity between mental and physical healthcare. A 2014 discussion paper by the NHS Confederation's Mental Health Network also highlighted the need to match parity of funding on mental and physical healthcare by curbing the cuts in investment in mental health.[243] In the longer term, the paper pointed out that this challenge would be exacerbated by the increasing prevalence of mental health problems in the UK, as well as future funding pressures on the NHS.

The number of beds available has also been subject to cuts. Responses to Freedom of Information requests from 46 mental health trusts in England show that 1,711 mental health beds have been closed since April 2011, including 277 between April and August 2013; a nine per cent reduction in the total number of mental health beds available. [244] Three quarters of the bed closures were in acute adult wards, older people's wards and psychiatric intensive care units. Responding to the figures, the Medical Director of the South London and Maudsley NHS Foundation Trust, Dr Martin Baggaley, said that the current mental health system was in 'crisis': *'it's very pressured, and we spend a lot of our time struggling to find beds, sending people across the country'*. The shortage of beds meant that 50 of Dr Baggaley's patients were in beds outside his Trust, with some patients as far away as Somerset.[244]

At the local level, Norfolk and Suffolk NHS Foundation Trust have set out plans to cut 502 mental healthcare jobs, including almost 50 psychiatrists, by 2016.[245] Dr Shanu Datta, the previous chair of the BMA's Consultants Committee psychiatry subcommittee, raised the issue at RCPsych's Council meeting in February 2013. The President of the RCPsych, Professor Dame Sue Bailey, has now written to the Trust expressing concern that the proposed reduction in senior clinical staffing would result in *'a significant reduction in the quality of services provided and adversely affect patient care'*.[246]

The Welsh Government, in contrast, reported in 2012 that mental health investment had *'increased [over the last 10 years] as a proportion of overall NHS expenditure'*.[247] To support the implementation of *The Mental Health (Wales) Measure 2010*, extra resources (£4 million in 2012-13, and £5 million in future years) were also made available to Health Boards and local authorities. While funding for mental health services in Wales is currently ring-fenced, the Welsh Government acknowledges that due to *'current financial pressures […] mental health services cannot be exempt from a continuing critical review of resource use.'* [247]

The most recent figures for Scotland, published by Audit Scotland in 2009, showed that the amount NHS Boards spent on mental health services rose in cash terms from £641.2million in 2002-03 to £888.7 million in 2007-08; an increase of 38 per cent. Spend on mental health services as a percentage of overall NHS spend, however, fell slightly from 11.1 per cent in 2002-03 to 10.7 per cent in 2007-08.[248] In Northern Ireland, spending on mental health between 2007-08 and 2009-10 increased by around nine per cent in real terms.[249]

One area where a chronic lack of investment in mental health is particularly visible is in the 'mental health estate'. The RCPsych reports that the poor condition of many of the buildings and wards used for mental healthcare *'would never be accepted in settings for physical healthcare'*. Not only does the low quality of some premises highlight the underinvestment in mental healthcare, it arguably *'reflects the lower esteem in which mental health is held'*.[30] The report recommended that a ward's physical environment *'should be considered as part of patient treatment and should be factored into the early designs of wards.'*[30]

In England, the absence of a national Payment by Results (PbR) tariff for mental health was identified by the RCPsych in 2009 as a key reason why mental health services were more vulnerable to funding reductions than other services on NHS budgets.[250,x] Though the DH estimated that implementation of the tariff would begin in April 2013, it has now confirmed

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x   The PbR tariff is the rules-based payment system in England under which commissioners pay healthcare providers for each patient seen or treated, taking into account the complexity of the patient's healthcare needs. It currently covers the majority of acute healthcare in hospitals, with national tariffs for admitted patient care, outpatient attendances, A&E, and some outpatient procedures. This system has not been introduced in Northern Ireland, Scotland or Wales.

that it will not take place during the 2013-14 financial year.[251] The Health Services Journal reported in September 2013 that the mandatory rollout of a national payment by results tariff for mental healthcare providers in 2014-15 had been dropped by Monitor.[252] For parity of esteem to 'be meaningful', the House of Commons Health Committee recommended in August 2013 that the DH should accelerate *'the development of commissioning and payment systems which reflect this objective [achieving parity] and do not make mental health services vulnerable to cuts by local commissioners.'*

The previous Chair of the BMA's Consultant's Committee Psychiatry Subcommittee, Dr Shanu Datta, however, has stressed that there are 'genuine difficulties' associated with implementing meaningful tariffs for long-term mental health problems, like schizophrenia:

> *'With the growing expectations that commissioners should commission complete pathways of integrated care rather than discrete episodes, it is unclear how well mental health tariffs alone can adequately recognise the complexity of treating patients with multiple physical and mental health conditions that fluctuate over time.'*[253]

The PbR tariff system also has the potential to work against the funding of integrated care pathways as the Chair of the BMA's General Practitioners Committee, Dr Chaand Nagpaul, explains:

> *'…PbR results in adversarial commissioning, with polarised incentives of hospitals driven by the motive to income-generate through increasing activity. GPs [are] pulling in the opposite direction of trying to reduce hospital referrals and move services into the community.'*[254]

While never demanding it be scrapped outright, the BMA has repeatedly opposed various elements of PbR.[y] Concern has been expressed by the BMA on the grounds that PbR *'does not reflect the true relative cost of treatment, which is resulting in erroneous funding to providers (and) creates inherent perverse incentives with consequent behaviours that damage patient care.'* Further concerns have been raised that PbR increases spending on administration rather than patient care, and places an unnecessary burden on primary care.[255]

Intellectual disability services are experiencing similar cuts to mental health: a 2012 RCN survey of 500 learning disability nurses showed that 73 per cent of respondents had witnessed cuts in services over the past year.[186] Over half of respondents (56%) reported that they had seen a fall in the range and consistency of services offered, including:
- just over half of nurses surveyed (57.5%) said the area in which they worked offered a patient passport – a document which puts the patient at the centre of their care and informs healthcare staff about an individual's preferences and how best to treat them
- personal care packages or person-centred plans are only being carried out in around three quarters of areas (75.2% and 78% respectively)
- only 59 per cent of nurses said their area provided health education.[186]

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y   Opposition has been voiced at the BMA's Annual Representative Meetings since 2005. At the 2010 meeting, for example, doctors reiterated opposition to PbR on the grounds that it uses patients as 'financial pawns', thereby creating divisions between primary and secondary care.

Chapter 7. Promoting parity of esteem between mental health, intellectual disability, and physical health

Improving the identification, treatment and recovery of patients with co-occurring intellectual disability, mental health problems and chronic illnesses is a key challenge facing the NHS. All too often, patients from these groups are failing to receive the types of interventions that have the potential to reduce the burden of co-morbid disorders and are suffering unnecessarily.[256] There is a clear need to move from inaction to action on these issues. Building on the evidence outlined in this report, this chapter sets out the BMA's vision for making parity of outcomes a reality. It considers the 'areas for action' to promote parity between mental health and physical health, and between intellectual disability and physical health. These have been developed to take account of the changes to the mental healthcare[162], and intellectual disability, landscape. They set out the core actions that need to be collectively implemented – at national, regional and local levels – and adequately funded to ensure that each patient receives 'whole person' care. Wherever possible, it is good practice to pilot and review interventions prior to a major rollout.

This chapter also responds to the RCPsych's call for the BMA to consider how doctors can adopt a more aspirational approach to the care of people with mental health problems through focusing on four key areas: promoting prevention and early intervention strategies; delivering 'joined-up' care; enhancing training and workforce planning; and encouraging a greater focus on research on mental-physical multi-morbidity.

Before discussing these four key areas, consideration has to be given to the overarching need to reduce avoidable premature mortality among people with mental health problems or an intellectual disability. In March 2013, the Secretary of State for Health, Jeremy Hunt, launched 'A call to action to reduce avoidable premature mortality' to address the estimated 103,000 deaths annually in England among the under 75s that are avoidable. While this acknowledged the *'strong association between smoking and mental health disorders'* and the *'shameful inequality in outcomes for people with serious mental illness'*, actions to address the physical health of people with mental illness were noticeably lacking.[28] NHS England have since committed to a number of interventions to reduce premature mortality (see **Box 6**).

Box 6: Commitments from NHS England to reduce premature mortality among people with SMIs

- Using a best practice model which will pick up patients with SMI who have physical health conditions that need assessment and treatment. NHS IQ [NHS Improving Quality] are implementation supports.
- Working closely with experts in medicines management to ensure the effects and side effects of psychotropic medications are routinely monitored and addressed.
- Introducing incentives for physical health checks and treatments to be undertaken in all mental health inpatient settings of all types, in all sectors (a new national CQUIN).
- Developing advice from successful best practice schemes about how to educate staff and patients to achieve smokefree inpatient settings and stop smoking.
- Working with public health and commissioners so targeted smoking schemes for people with mental health issues are commissioned.
- Assessing the evidence about what works in reducing premature mortality and ensuring this information is disseminated across the NHS particularly to CCGs and strategic clinical networks.

Source: NHS England (2014) *NHS England pledge to help patients with serious mental illness* (last accessed on 14.02.13 at: www.england.nhs.uk/2014/01/20/mental-illness/)

Achieving parity of outcomes requires a commitment at the highest level. An important starting point for this is the establishment of a national mortality review process, which is not covered in NHS England's commitments to reduce premature mortality listed in **Box 6**. Mortality reviews are intended to promote a culture of safety through seeking to understand systems issues that are working well and those that need improvement. The aim is not to 'point the finger' and seek individual blame or fault; rather by aggregating and analysing data to identify trends, areas for action can be identified, changes in practice implemented, and the quality of care improved.[257] The case has already been made by the CIPOLD for a permanent 'National Learning Disability Mortality Review Body' to '*take forward the reviews of deaths of people with*

learning disabilities, in order to learn from experience and continue to provide a driver to reduce inequalities in care for this vulnerable population.'[14] In their response to the CIPOLD, the DH agreed that *'better information is needed to enable an accurate assessment of the causes of death of people with learning disabilities'* but that the costs and benefits of establishing a National Learning Disability Mortality Review Body needed to be assessed. NHS England is working with the DH, Public Health England, and other partners to undertake such an assessment.[198]

The establishment of a national mortality review process for intellectual disability would be a welcome development, and should be implemented across the UK. Consideration should also be given to ensuring there is a UK-wide mortality review process that focuses on people with mental illness as another group that experience high morbidity and mortality rates. The 'National Confidential Inquiry into Suicide and Homicide' (NCISH) examines suicide and homicide committed by people who had been in contact with secondary and specialist mental health services in the previous 12 months. It also examines the deaths of psychiatric inpatients which were sudden and unexplained. A mortality review process that focuses on people with mental illness would therefore take a broader focus than the NCISH and include the deaths of people with CMDs.

AREA FOR ACTION

Provisions for a national mortality review system should be implemented across the UK in relation to people with intellectual disabilities, and for people with a mental illness.

7.1 Promoting prevention and early intervention strategies

Across the NHS, there is a well-established tendency to focus on acute services at the expense of ill-health prevention. Mental health is no exception. Based on figures from the 2010-11 National Survey of Investment in Adult Mental Health Services, the Joint Commissioning Panel for Mental Health estimated that spending on the prevention of mental health problems, and the promotion of good public mental health and wellbeing, represented less than 0.001 per cent of the annual NHS mental health budget.[258] This is not sufficient.

Section 5.1 discussed how higher rates of premature morbidity among people with mental health problems arise largely from treatable conditions associated with modifiable risk factors such as smoking, physical inactivity, and illicit substance use. Such factors tend to be the subject of public health intervention programmes. Efforts should be made by commissioners, and those responsible for public health, to integrate a mental health and intellectual disability dimension into physical health promotion. At the individual scale, this could involve ensuring that existing smoking cessation and healthy eating campaigns specifically consider people with mental health problems and intellectual disability, or that targeted interventions on smoking, nutrition and physical exercise are developed for these groups. In November 2013, for example, NICE issued guidance on 'Smoking cessation in secondary care: acute, maternity and mental health services'. This features 16 recommendations including: identify people who smoke and offer help to stop; provide intensive support for people using acute and mental health services; advise on and provide stop smoking pharmacotherapies; and adjust drug dosages for people who have stopped smoking.[259]

Since mental health problems often begin at an early age and continue throughout the life course (see **Chapter 1**), strategies to protect and promote good public mental health should be pursued from the earliest opportunity. 'Growing up in the UK', published by the BMA Board of Science in May 2013, considers a number of early intervention programmes aimed at new mothers and pregnant women. These include home visiting programmes like the Nurse Family Partnership, and Sure Start Children's Centres, that provide help and advice on child and family health, parenting, money, training and employment, including supporting families with a disabled child. Measures introduced at the population level, like Sure Start, hold the potential to reduce health risk behaviours – including the risks to off-spring from smoking and consuming alcohol during pregnancy (see **sections 5.1.1** and **5.1.2**) – and improve mental wellbeing. Unlike actions targeting the individual, they cut across the social gradient, providing benefits for all socio-economic groups.

The BMA, through its Board of Science, has a long history of lobbying the Government to introduce population-level measures aimed at improving public health. Curbing tobacco marketing opportunities, introducing standardised packaging for all tobacco products, and banning the display of tobacco products, for example, can work to prevent people from starting smoking while encouraging existing smokers to quit. The BMA continues to call on the Government to introduce these measures universally, and to make the UK tobacco-free by 2035. With much of the substantially lower life expectancy of people with mental health problems relating to smoking (see **section 5.1.2**), these types of interventions can also act to reduce health inequalities.

Addressing health inequalities is vital: **section 5.2** discussed how people with co-morbid mental and physical health problems are more likely to experience deprivation, including poor housing, poverty, unemployment, and social stigma. Creating good jobs, developing healthy and sustainable homes, and delivering high quality, universal education, are just some of interventions recommended by the Marmot Review team to tackle inequalities and to help ensure that all children and adults enjoy a healthy standard of living.[43] The social stigma and discrimination disproportionally experienced by people with mental health problems and intellectual disability – both of which can present a barrier to accessing and / or receiving high-quality healthcare (see **Chapter 6**) – are also amenable to reduction and prevention. Strategies that improve mental health literacy and raise awareness of mental health problems among the public, like 'Time to Change' (the anti-discrimination programme for England), should be encouraged and appropriately funded.

There are also good examples of projects taking place outside of the UK that aim to combat the stigma and discrimination faced by people with mental health problems, and who are at risk of suffering from poor physical health. The 'Healthy Active Lives' (HeAL) project in Australia, for example, focuses on providing young people experiencing psychosis with the tools they need to maintain good physical health, especially in the areas of nutrition, smoking cessation, and regular physical activity. The project leaders have encouraged governments across Europe to endorse the HeAL international consensus statement and targets.[260]

AREA FOR ACTION

Reducing the prevalence of mental health problems and promoting good public mental health should be a priority for Directors of Public Health across the UK. Public health intervention programmes should specifically consider how people with mental health problems and intellectual disability will be reached. Strategies that improve mental health literacy and raise public awareness should also be encouraged.

7.2   Delivering joined-up care

The geographic, institutional, and professional division of mental health, intellectual disability and physical healthcare was identified in **section 6.1** as inhibiting the delivery of a coordinated response to the multiple needs of patients presenting with co- or multi-morbidities. Addressing this separation requires changes to the way that healthcare is delivered. A growing evidence base indicates that more holistic care that 'joins-up' (or integrates) the physical and mental aspects of healthcare holds the potential to improve outcomes for patients. The BMA is actively exploring the different ways in which healthcare services are structured and delivered throughout the UK and recognises that there are multiple approaches to achieving more joined-up, high quality patient care.[261] Three of these approaches – collaborative care, generalist care, and liaison psychiatry – are discussed in this chapter.

Section 6.2 also acknowledged that there was confusion over the types of mental health services available locally to which a GP, secondary care doctor, or A&E department could refer a patient. An important step in beginning to deliver joined-up care is for doctors to have a good understanding of the types of mental health and intellectual disability services that are already offered. One approach to confront this problem, undertaken by King's Health Partners[z], has been to map current service provision and produce a single overview of what was available, where, and to whom, across the acute trusts. Not only did this help to identify areas of good practice, it also highlighted where gaps in service provision existed, enabling them to plan strategically for the future.[262]

Regardless of the specific model of joined up care adopted, it is clear from the evidence outlined in **section 6.1** that protocols between primary and secondary care, health and social care, and children and adult services need to be put in place to establish 'who is responsible for what and when'. In the case of crisis mental health care, for example, there should be a well-established, understood, and feasible pathway to provide emergency care for someone presenting with suicidal ideation, as is the case with someone presenting with a physical medical condition (eg pneumonia). It should be stressed that the Association considers that the integration of services can and should be delivered without any further major re-organisation of the NHS, legislative change or structural upheaval.

AREA FOR ACTION

The integration of intellectual disability, mental health and physical healthcare should be improved. This should be a priority for all policy makers at a national level, as well as for Directors of Public Health and local commissioning bodies, who must ensure that clear pathways of care, and allocation of responsibility, are established regardless of whether the patient presents with a physical or mental illness.

7.2.1   Collaborative care

A 'collaborative care' model is recommended by NICE for people with '*moderate to severe depression and a chronic physical health problem with associated functional impairment, whose symptoms are not responding to initial interventions.*'[263] It involves a multi-professional team drawn from primary and secondary physical health services, and from specialist mental health services, who work together closely in the delivery of services. A case manager, supervised and supported by a senior mental health professional, liaises with primary care clinicians, specialists, and the patient to plan and coordinate the overall care of the patient. It is the case manager's responsibility to ensure that the patient is not 'lost' in the system, their needs are addressed, and follow-ups are made.[264]

At the centre of collaborative care is a 'shared approach': this means that there should be a mutual understanding between the patient and the multi-professional team of the health problems that require addressing, and a co-produced 'care plan' that documents the treatment to be provided. More collaborative approaches may help to empower the patient by ensuring that they play a central role in their care, making it clear their input matters and is valued. Collaborative care represents an important step towards raising aspirations for these groups. This type of intervention is not new; it is a way of enhancing inter-professional communication, and improving the co-ordination of patient care, through re-organising and combining

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z   King's Health Partners is one of England's five Academic Health Science Centres. It brings together a research led university (King's College London) and three NHS Foundation Trusts (Guy's and St Thomas', King's College Hospital and South London and Maudsley).

existing care processes.[264] **Box 7** outlines a collaborative approach to improve the physical healthcare of people with SMIs currently being piloted in Manchester, an evaluation of which is currently taking place.

Box 7: Improving physical healthcare for people with severe mental illness at Manchester Mental Health and Social Care Trust

The first phase of this pilot project is collaboratively working with six practices from North Manchester CCG and the Trust's North West community mental health team. The project brings together a number of different elements – one being the introduction of a physical health link worker to liaise with GP practices at regular multidisciplinary team meetings. The aim of these meetings is to have joint discussions to plan, manage and improve the physical health management of people with severe mental illness. The project also encourages the use of the Rethink Mental Illness physical health check tool by community mental health teams. To supplement the assessment, a clinical tool is being designed to help community staff make the appropriate physical health management decisions as a result of the information gained from the Rethink assessment tool. This includes the appropriate referral into the community lifestyle services that are available.

Source: Rethink Mental Illness (2012) *Admission and initiation of treatment – physical health* (last accessed on 05.04.13 at: www.rethink.org/how_we_can_help/physical_health/physical_health_resources/admission_and_initia.html)

A 2012 Cochrane Review of collaborative care for depression and anxiety problems presented evidence that it is effective in improving depression outcomes in the short- and medium-term. The review stressed, however, that it is a complex issue and that there was significant variation in the exact nature of the collaborative care interventions in the 79 studies examined.[256] According to NICE, the evidence base regarding the effects of collaborative care on *physical health* outcomes is more limited.[263] While improved depression care is thought to produce physical health benefits, such as improved functioning, Cimpean and Drake found that interventions which focused exclusively on treating the mental health aspect of the co-morbidity did not always translate into improvements in the chronic physical condition.[265] The authors highlighted that a collaborative care model is needed that successfully integrates physical and mental health treatments. Some of the changes to the GP contract in England focus on delivering better care for people with long-term conditions, presenting GPs and commissioners with an opportunity to address co- and multi-morbidity, and to improve integration between physical and mental healthcare.

AREA FOR ACTION

The wider application of the collaborative care model developed by NICE for people with moderate to severe depression and a chronic health problem should be explored by NICE and the UK Health Departments.

7.2.2   Generalism

Delivering a 'whole person' approach to care, where mental health and physical health are integrated, may be inhibited by the *'demise of the General Physician [...] within a hospital setting'* and increasing subspecialisation.[195] A generalist is someone who has a *'sufficient breadth of skills and competencies to handle undifferentiated symptoms safely, and to start initial assessment and treatment.'*[266] Good generalist care is *'pragmatic and iterative, and is based around the symptoms, values, and priorities of the particular person, rather than particular diseases'*.[195]

For patients with multi-morbidities who have one dominant disease, or whose co-morbidities are closely related, a specialist doctor will often be best placed to provide care.[10] Generalist care holds the potential to deliver more holistic, coordinated and cost-effective healthcare for people with multiple conditions, such as co-occurring mental and physical health problems.[266,267] In the UK, primary care is the key provider of generalist care to patients with long-term conditions.[267] It is also estimated that approximately one third of people with a SMI only consult primary (rather than secondary) care for ongoing mental health treatment.

Stakeholders involved in the Royal College of General Practitioners (RCGP) Commission on Medical Generalism suggested that this type of care could be further strengthened by the generalist working closely with a multi-professional team that supports patients' needs in a more integrated way. These stakeholders were of the view that generalism should not simply be a key feature of general practice but that it should extend into other areas including emergency care and mental health.[266] This point was echoed by the BMA General Practitioners Committee (GPC) in their 2013 report 'Developing General Practice today. Providing healthcare solutions for the future'. The GPC has called for more integrated care, closer to home, delivered by a community healthcare team built around the GP practice (see **Box 8**).

Box 8: Providing solutions for the future of general practice care

- Collaborative working across localities with practices either singly or collectively employing or directly managing community nurses who, working together with practice nurses, will provide a seamless and more flexible nursing service for patients in the community.
- Secondary care clinicians and GPs working collaboratively to design and provide care pathways for local health economies, bringing more diagnostics and specialist care out of hospital and into community settings, including hospital-based specialists visiting nursing and residential homes and working alongside GPs in practices when appropriate.
- Patients with long-term and complex needs should be jointly managed through an integrated team in line with a single care plan led by the most appropriate named clinician. This would require a much greater alignment of incentives and funding streams between general practices and hospital and community service providers.
- Specialists given the opportunity to collaborate with and to support primary care, such as in general medicine, elderly care, mental health and paediatrics, acting as a specialist resource across localities to optimise patients' complex health needs and help to prevent unnecessary hospital attendances and admissions.
- A shift to community based care with more doctors and nurses in the NHS working in general practices and community settings or having had experience of working in such settings.
- Joint training and education for GPs and secondary care clinicians.
- Greater collaboration between community pharmacists and practices with a practice-aligned pharmacist undertaking medicines management and other elements of chronic disease management.
- Greater collaboration between practices and social care services, with named social workers or team leaders aligned to every practice and regularly attending multidisciplinary meetings.
- Expand and develop practice premises to allow for delivering increased care in the community, including space for teaching, training and research.

Source: British Medical Association (2013) *Developing general practice today. Providing healthcare solutions for the future*. London: British Medical Association.

Realising these goals is likely to require changes to the training that doctors receive: in their submission to the RCGP's report, the GPC proposed to strengthen generalism by ensuring that *'all doctors have a period of general professional development time after the foundation years'*.[195] The BMA also stressed in their response to the Shape of Training review (see **section 7.3.2**) that there is not a need to introduce a new 'generalist' service delivery post or speciality. Concerns were also raised by the BMA that the term generalist had not been defined in the Shape of Training Review and that different commentators will have varying interpretations of the term. Training and workforce planning are considered in detail in **section 7.2**. Generalism

that consistently takes the mental and physical health needs of patients into account could also be encouraged through a more structured, systematic approach to identification and management, such as annual health checks targeted at mental health and intellectual disability patients, proactively following up with patients who disengage, or screening for mental health problems in patients with long-term conditions.[267]

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AREA FOR ACTION

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To strengthen collaborative care, generalists[aa] located in hospitals and outside of hospitals should act as the responsible clinician, working closely with a multi-professional team to support patients with co- or multi-morbidities in a more integrated way.

7.2.3 Liaison psychiatry

Within the setting of a general or acute hospital, the development of liaison psychiatry services, and paediatric liaison services, may hold the potential to integrate psychiatry and psychology more fully into medical care. Liaison psychiatry services are a relatively recent development: the Faculty of Liaison Psychiatry at the RCPsych was, for example, established in 1997. As well as identifying and addressing the mental health needs of people who have been admitted to hospital with a physical health problem, liaison psychiatrists are equipped to assess the relative contribution of physical and psychological factors in a patient's presentation and management. Paediatric liaison services specifically treat young people with medical conditions who also have psychological difficulties and psychiatric illnesses. The liaison team may include psychologists or nurses with expertise in psychological therapies, though the exact make-up of the service has been found to vary greatly, as highlighted in **Box 9**.

Box 9: The types of variations found in liaison psychiatry services
- The types of patient seen, including groupings by age and health condition
- The hospital settings in which support is provided (eg emergency departments, inpatient wards)
- The nature of the service provided, with a particular distinction between those services which focus mainly on the assessment and short-term management of patients during their time in hospital and those which are primarily treatment-oriented, including the on-going provision of psychological and other interventions after patients have been discharged from hospital
- The balance between clinical work with patients and the education and training of acute hospital staff
- Hours of operation, with some services operating 24/7 but many on restricted hours
- The size, composition and skill mix of liaison psychiatry teams
- Whether liaison psychiatry services are provided by specialist teams physically located within the general hospital or on an out-reach basis by community-based secondary mental health services

Source: Parsonage M, Fossey M & Tutty C (2012) *Liaison psychiatry in the modern NHS*. London: Centre for Mental Health; Mental Health Network, NHS Confederation.

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aa   Generalists are individuals with sufficient breadth of skills and competencies to handle undifferentiated symptoms safely, and to start initial assessments and treatment.

Provision of liaison psychiatry services, and paediatric liaison services, is patchy: the Centre for Mental Health reports that no comprehensive statistics are available on overall levels of activity or expenditure on liaison psychiatry services in general hospitals, while the RCPsych found that only 50 per cent of UK children's hospitals surveyed had dedicated paediatric liaison services.[30,236] A similar absence of data on the effectiveness of liaison psychiatry is also apparent. While the topic has been the subject of numerous studies and reviews, some concerns have been raised about the reliability and validity of the evidence: most studies are descriptive rather than evaluative and are based on small sample sizes.[268] The diverse nature of liaison psychiatry services, as outlined in **Box 9**, also makes it difficult to draw general conclusions. The Centre for Mental Health goes further, noting that much of the evidence comes from studies carried out in the United States that may not be readily transferable to the UK, due to institutional and other contextual differences.[269]

In an attempt to overcome some of these limitations, the Centre for Mental Health published their own research in 2012 on the psychiatric liaison service provided by the Rapid Assessment Interface and Discharge (RAID) team at City Hospital, Birmingham. They concluded that:

> '…the RAID service is good value for money, particularly as the benefits included in the assessment are over and above any improvements in health and quality of life which are the fundamental justification for health spending. Unlike most health care interventions, RAID actually saves money as well as improving the health and well-being of its patients.'[269]

Cost savings come from reduced length of hospital stays and increases in early discharge, as well as reduced re-admissions. Improvements in health outcomes tend to be more modest but generally centre on earlier identification of mental health conditions.

In addition to delivering direct patient care, liaison psychiatry services also provide education, training and support to other members of hospital staff. While the primary aim is to help develop the ability of staff to detect and treat mental health problems, this type of peer-led training can have other benefits. As well as increasing the confidence of non-mental health staff to address psychological distress among their patients, the RCPsych reports that the training delivered by liaison psychiatrists can also foster more positive attitudes towards mental illness.[146] Heightening awareness of the interrelationships between intellectual disability, mental health and physical health, especially among those healthcare professionals that initially screen patients, is vital if parity of outcomes is to be achieved. The increased use of liaison psychiatry across the NHS received strong support from attendees at the BMA President's seminar in June 2013 (see **Appendix 1**). Providing liaison psychiatry in emergency departments may also start to address some of the deficiencies in emergency care for those experiencing a mental health crisis.

Attendees at the seminar acknowledged that liaison services do not necessarily need to be confined to psychiatry, or to a hospital setting. The West London Mental Health Trust has a full time Director of Primary Care to ensure that the physical health needs of patients are being met. The Director has taken on the role of a 'liaison physician'; someone who advises on physical healthcare within a mental health trust.[30,bb] In Lanarkshire, an acute liaison nurse practitioner works with intellectual disability patients prior to admission, during their stay in hospital, and at the discharge planning stage, to help them prepare for their treatment and to assist with any communication or consent issues. Much like liaison psychiatry services, the liaison nurse provides formal and informal training for healthcare staff about the needs of this group, as well as producing accessible information for intellectual disability patients about procedures and screening programmes. St George's hospital, South West London, has gone further: in 2009 they became the first Trust in the UK to appoint an 'acute care nurse consultant for learning disability'. After three years, a range of changes have been introduced, from *making sure visiting hour restrictions are waived for carers, to implementing strict pre-admission protocols, improving routine co-operation between doctors and other staff, and making sure staff comply with the "reasonable adjustments" for vulnerable groups required by legislation.*'[270]

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bb   It is recognised that identifying funding for this type of post may be challenging and should not be adopted to the detriment of mental health services overall.

To deliver more joined up care for people with long-term conditions, the Centre for Mental Health and the RCPsych have identified a need to develop community-based liaison psychiatry: this could involve liaison psychiatrists collaborating more closely with GPs and community nurses, particularly for complex cases. The RCPsych has also worked with the RCGP, the RCN, and Rethink Mental Illness to produce an outline of what an integrated physical health pathway would look like for a patient with mental health problems (see **Figure 5**).

Despite the clear benefits of having such a service, the provision of liaison psychiatry across the country is inconsistent and under resourced. While liaison psychiatry is well thought of in the acute hospital setting, the service is typically commissioned by mental health commissioning groups who may see it as a non-core service – a luxury rather than a necessity despite the economic benefit. There are also practical considerations to be addressed, including how to ensure that primary care organisations are organised in such a way that a liaison psychiatry service can operate effectively. Speaking during a House of Lords debate in October 2013, Lord Hunt stressed that while the RAID service in Birmingham had proven to be successful: *'unless there is a service or a facility to which a patient who has come into A&E and is diagnosed as having mental health problems can be referred, you are still left with the problem about what to do with this patient.'*[1] The lack of a clearly defined, or readily available, pathway for crisis mental health services from A&E was also raised by an A&E consultant during the 2014 All Party Parliamentary Group on Mental Health inquiry into parity of esteem. Focusing on liaison psychiatry in acute hospitals should also not detract from the need to improve access to physical healthcare in mental health settings. Some mental health trusts do not have routine phlebotomy or ECG services available for clinicians to access in outpatient settings. Without these types of basic services, delivering parity of outcomes is made all the more difficult.

AREAS FOR ACTION

- **A liaison psychiatry service, including paediatric liaison services, and intellectual disability liaison services, should be made available in all hospitals.**
- **Mental health trusts should appoint a liaison physician (in psychiatric wards) to support the physical health needs of hospitalised people with mental health problems. Liaison physicians should be appointed to support the physical health needs of hospitalised people with intellectual disabilities (in psychiatric wards).**

Figure 5: An integrated physical health pathway for patients with mental health problems

Integrated Physical Health Pathway

PRIMARY CARE	SECONDARY MENTAL HEALTH SERVICES

Initiation of treatment or admission to impatient setting

Ensure severe mental illness register is up to date.

↓

Share summary record when requested.

Record all relevant information in patients notes.

Request summary record from GP (if not already received).

↓

If starting/changing medication, arrange baseline physical health checks. If admitted to inpatient setting, admitting clinician to arrange within 48 hours.

↓

Check weight every 1 to 2 weeks for 8 weeks. Repeat all checks at 12 weeks. Inform person of results and share with GP.

↓

If adverse results are identified, arrange appropriate intervention or review medication. Share any referral notes with GP.

Discuss all treatment options with the person, providing accessible information on benefits and side effects.

Inpatient only

If patient refuses to be assessed, record in notes and make further attempts to gain consent.

Responsibility for medication monitoring should transfer from secondary to primary care in line with locally agreed time frames. **If this transfer cannot take place, responsibility for monitoring and annual checks must remain with secondary care.**

Annual Health Checks

Invite people for an annual physical check, (including baseline tests and medication review). Informed named carer and care coordinator on invitation.

↓

GP or practice nurse to inform person of results and discuss relevant health promotion information. Share results with named carer and care coordinator.

↓

Arrange any necessary follow up appointments. Share details of these with named carer and care coordinator.

Support person to attend physical health check if necessary.

Record results in patient records.

Baseline Physical Health Checks

- Family history.
- Smoking status, exercise and diet.
- Weight and Body Mass Index.
- Blood Pressure.
- Fasting estimates of plasma glucose (FPG) and/or HbA1c.
- Lipids (total cholesterol, LDL, HDL, triglycerides).
- Consider ECG (if history/family history of CVD, or if taking medication known to cause ECG abnormalities).

This list is taken from Lester et al. (2012) *Positive Cardiometabolic Health Resource: an intervention framework for patients with psychosis on antipsychotic medication.* Royal College of Psychiatrists. London. This is a list of core tests but others might be offered as appropriate, according to local policies.

Care Programme Approach (CPA) Review (Review of Coordinated Care).

Share relevant physical health information when requested.

Record results in notes.

Ahead of CPA review, care coordinator to collate all relevant physical health information, including notes from previous CPA reviews and annual health check results from GP. If an annual health check has not been carried out, care coordinator should organise baseline checks in the appropriate service.

↓

Share CPA outcomes letter and care plan with GP.

On discharge from secondary care, discharge notification/letter should be sent to GP within 1 week, highlighting and ongoing concerns.

Source: Developed by Rethink Mental Illness in collaboraton with the Royal College of General Practioners, Royal College of Nursing and the Royal College of Psychiatrists. Reproduced with kind permission from Rethink Mental Illness.

7.2.4   *Commissioning*

One of the barriers to providing the types of joined-up care outlined in the preceding chapters is the way in which mental health services tend to be commissioned separately from their physical health counterparts, with co-morbid patients failing to be recognised in either process.[7] The planning and commissioning of services for people with intellectual disabilities, mental health problems, and chronic physical conditions must take greater account of the diverse healthcare needs of these groups. To facilitate this, commissioning bodies – such as Clinical Commissioning Groups (CCGs) established under the *Health and Social Care Act 2012* – need to have *'the knowledge and skills to understand how best to provide services for people with mental health problems'* and with an intellectual disability.[271]

Concerns were raised in 2012 by the All Party Parliamentary Group on Mental Health that, following the new arrangements in England, GPs may not possess the expertise and experience to commission mental health services, and that access to good quality care would become a postcode lottery.[272] This unease was echoed by the House of Commons Health Committee in their 'Post legislative scrutiny of the Mental Health Act 2007' report published in 2013.[239] To address these concerns, it is strongly recommended that commissioning bodies should ensure that at least one commissioner is a mental health and / or intellectual disability professional: someone who has a good understanding of the types of care that these groups require, and who can push for improved integration between physical health, mental health and intellectual disability services. As mental health and intellectual disability are pan-speciality issues, commissioners may also benefit from additional training in this area.

In addition to CCGs, local authorities have an important role in implementing the mental health strategies across the devolved nations and improving the mental health of their communities. This has been recognised by a number of NGOs (the Centre for Mental Health, the Mental Health Foundation, Mind, Rethink Mental Illness, and YoungMinds) and the RCPsych who have come together to support the local authority 'Mental Health Challenge'. This aims to encourage upper tier local authorities to take a number of actions – including appointing an elected member as a mental health champion – to promote mental health across the local authority.

Delivering a coordinated response to the needs of patients presenting with multi-morbidities also requires the commissioning of primary healthcare services to be integrated with the commissioning of specialist mental health services.[271] This may necessitate joint working between commissioners, social services, and third sector organisations. The views of patients with mental health problems and intellectual disabilities, as well as their carers, should be sought and used to improve the care that these groups receive.

Knowledge of mental health and intellectual disability must be accompanied by greater access to accurate information on the physical, mental and intellectual disability needs of the population that the commissioning body or Local Authority is serving. This includes data on the prevalence of mental health problems, intellectual disability and chronic illness, so that commissioned services have sufficient capacity to treat the local population. Without this information, it is difficult for commissioners to deliver services that match the requirements and demographics of their area. The commissioning of the 2014 Adult Psychiatric Morbidity Survey is a welcome development and will provide data on the prevalence of treated and untreated psychiatric disorders in England in those aged 16 and over. Similar provisions should be made in Wales, Scotland and Northern Ireland. It is also important that information on prevalence is regularly collected for those under the age of 16: the child and adolescent national psychiatric morbidity survey for Great Britain was last conducted in 2004, and there have not been any similar surveys in the devolved nations.

At a more local level, individual surgeries and hospitals need to make sure that they collect appropriate information about their patients' needs. In the case of a patient with intellectual disabilities, it is difficult for services to prepare properly or make any necessary 'reasonable adjustments' if patients' communication and other special needs are unknown. Some changes are already on the horizon: one of the 'actions' from the Winterbourne View report states that the DH will develop a new *'learning disability minimum data set to be collected through the Information Centre from 2014/15'*.[273] The RCGP, in conjunction with Rethink Mental Illness, has produced a guide about mental illness and disability law in GP practices.[274] The

establishment of the Mental Health Intelligence Network – as outlined in the DH 2014 report 'Closing the Gap' – is a further welcome development. It aims to draw together '*comprehensive information about mental health and wellbeing to provide greater insight into mental health problems, how they vary with age and in different parts of the country, and what the most pressing needs are in each area.*'[162]

It is also necessary to consider whether patient information can be shared between primary and secondary care. Concerns were raised by Board of Science members that delivering a coordinated response to patients presenting with multi-morbidities is made more difficult by an inability to access a patient's records: doctors working in district general hospitals and teaching hospitals can find that they are unable to view a patient's mental health records – either those held by a mental health trust, and / or by the patient's GP. Similarly, there is often no link between psychiatrists working in mental health trusts and GPs that allows records to be viewed or shared by either party.

Across the devolved nations, the way in which the NHS is structured and operates is undergoing significant change. In England, the establishment of NHS England and Public Health England following the assent of the *Health and Social Care Act 2012* presents an opportunity to ensure that these bodies explicitly recognise the importance of placing equal value on mental and physical health when setting their priorities. The mandate from the Government to NHS England states that one of their objectives is to '*put mental health on a par with physical health, and close the gap between people with mental health problems and the population as a whole*', with 'measurable progress' made by March 2015.'[161] Reducing premature death in people with an SMI, enhancing their quality of life, and improving their experience of healthcare also form three of the 27 improvement areas outlined in the NHS Outcomes Framework 2013-14.[275]

The DH's 'No Health without mental health implementation framework' stresses that clear plans need to be drawn up by Public Health England and local public health directors '*to ensure [that] they integrate mental health and wellbeing into all aspects of their work'*.[199] Programmes on smoking cessation or obesity should include a mental health component, as discussed in **section 7.1**. Translating policy into action in this way not only shows a more aspirational approach to mental health and intellectual disability patients, it also is indicative of equal efforts being made to improve the quality of care for these groups.

Data systems also need to be improved to ensure that co- and multi-morbidities are recorded and formally considered as part of Joint Strategic Needs Assessments (JSNA) in England, particularly since JSNAs go on to form the basis of Joint Health and Wellbeing Strategies – the collectively agreed priorities for action. The All Party Parliamentary Group on Mental Health raised concerns in 2012 that, historically, JSNAs have '*not done enough to accurately capture mental health needs'* and that, '*[A]s a consequence of inaccurate data, mental health often loses priority and funding to other health conditions'*.[272] This point is echoed by the CIPOLD: their first recommendation states that '*[T]here is an imperative for the clear and consistent identification of people with learning disabilities, for the provision of key data to be able to determine and monitor the extent of health inequalities at a national level*.'[14]

As 'Any Qualified Provider' is rolled out across mental health services, NHS England must ensure that the data gathered are consistent across all types of providers. Some of this information is collected as part of the QOF, or DES: both have been used to incentivise GPs to provide annual health checks to SMI and intellectual disability patients. NHS England should consider how the Commissioning Outcomes Framework could be used to support commissioning groups to address parity of outcomes in their service specifications. One of the challenges is to link together different registries (eg GP registries of intellectual disability and mental health problems with hospital episode statistics, treatment outcomes, cancer registries and mortality registries).

Health professionals with responsibilities for commissioning and / or public health should ensure that they place equal value on mental and physical health when setting their commissioning priorities and reporting requirements.
- Mental health and wellbeing should be integrated into all aspects of commissioners and public health directors work. A mental health dimension, for example, should be incorporated into physical health promotion (eg smoking cessation programmes).
- Commissioners should have a good understanding of intellectual disability and mental health, and encourage the development of services that deliver integrated care.

Commissioners must have accurate, accessible information on the physical, mental and intellectual disability needs of the population that they are serving.
- Data systems need to be improved to ensure that co- and multi-morbidities are recorded and used by commissioners when setting their service priorities.
- At present, health and care outcomes frameworks have few effective mental health measures thereby giving commissioners too few incentives to invest fairly in mental health.
- The range of reasonable adjustments which need to be made to support people with intellectual disability and people with mental health problems must be estimated, commissioned and resourced.
- It is strongly recommended that commissioning bodies should ensure that at least one commissioner is a mental health and / or intellectual disability professional.
- Provision should be made for adult psychiatric morbidity surveys – including psychiatric morbidity in people with intellectual disability – and child and adolescent psychiatric morbidity surveys, to take place across the devolved nations.

7.2.5   Access and monitoring

Parity of outcomes will not be achieved in the absence of equity of access to appropriate services and treatments. In March 2014, the Cabinet Office published 'Open public services progress report 2014' which made a commitment to give patients the right to choose their mental health provider from April 2014, as is the case for physical healthcare services.[276] While this introduces parity between physical and mental health in the choice of provider, access needs to be considered on multiple fronts. Healthcare providers must ensure that they are compliant with their duties under the *Equality Act 2010*: this includes making 'reasonable adjustments' so that people with mental health problems, intellectual disability and long-term conditions are able to make contact with, and use, mainstream healthcare services.

Examples of good practice include the 'core' reasonable adjustments made for intellectual disability patients at St George's hospital, South West London. These include:
- *no fixed visiting times for family, carers and friends of people with intellectual disabilities.* This general approach permits people to be with the person with an intellectual disability as much as they wish and ensures greater understanding of the person's particular needs. It provides clinicians with vital information and thereby reduces the likelihood of clinical risks
- *food and drink for family and carers* is offered to ensure that they can remain with the person at anytime during the day / night
- *the first or last appointment* of a clinic should always be offered, so people who find it difficult to wait do not have to
- *double appointments* are particularly useful in reducing the risk of diagnostic overshadowing as more time permits greater exploration of often complex issues which in turn should reduce clinical risks and result in more effective treatment
- *a bed and / or chair* is provided for a carer or family member.[277]

Recognising the delay by some healthcare staff to 'flag' patients with a particular condition or vulnerability (see **section 6.1.1.3**), Tuffrey-Wijne and Hollins suggest that *'identifying the need for a specific service adjustment'* (eg needs a carer present, needs extra time for procedures) *'would go some way to avoid the labelling dilemma, as well as some of the difficulties of correctly identifying and flagging the condition'.[278]* This approach would not only benefit intellectual disability patients, it would also help other vulnerable patients, including those with a mental health problem, and / or sensory and physical impairments.

The Equality Act 2010 also includes a clear legislative requirement to tackle the negative attitudes and discrimination that vulnerable groups can face. The Public Sector Equality Duty (Section 149 of the Act) requires public bodies to have due regard to the need to:
a)   *'eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under this Act;*
b)   *advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it;*
c)   *foster good relations between persons who share a relevant protected characteristic and persons who do not share it'.[279]*

Progress towards meeting the Public Sector Equality Duty was made with the introduction of the *Mental Health (Discrimination) Act 2013*. The provisions of this Act extend across the UK and remove the blanket ban that forbids 'mentally disordered persons' that regularly attend for treatment from taking part in jury service. It also amends legislation which states that a person may cease to be a director of a public or private company 'by reason of their mental health', while at the same time removing legislation under which an MP automatically loses their seat if they are sectioned under the *Mental Health Act* for more than six months.

Sections 6.1 and **6.2** highlighted that discrimination on the part of healthcare professionals can take many forms, from making unfounded judgements about how 'worthwhile' it is to administer a treatment, to more structural discrimination, where actions and policies that are not intended to discriminate nevertheless hinder the options of people with a mental health problem or intellectual disability. Meeting the Public Sector Equality duty should go some way towards providing 'equality of options' for people with intellectual disabilities and mental health problems, though legislation alone will not automatically alter ingrained practices or raise aspirations for these groups. A 'quality standard' developed by NICE outlines the level of service that people using NHS mental health services should expect to receive. This includes a quality statement and measure of 'combating stigma'.[280]

Providers' compliance with current legislation and guidelines should be monitored by healthcare regulators and inspectors, such as Monitor and the CQC in England, Healthcare Improvement Scotland, Healthcare Inspectorate Wales and the Regulation and Quality Improvement Authority, Northern Ireland. These bodies should also strengthen their role in scrutinising the standard of general healthcare that people with intellectual disability and mental health problems receive. Monitor's Compliance Framework includes six criteria for meeting the needs of people with an intellectual disability.[281] Mencap have highlighted a number of additional concerns that they believe require attention, including a lack of basic care, poor communication, and delays in diagnosis and treatment.[191]

Developments in the assessment and care of co- and multi-morbidities must be matched by better access to treatments. **Section 6.2** acknowledged that the NHS Constitution confers a right (if clinically appropriate) to drugs and treatments recommended by NICE technology appraisals but not to those recommended by NICE clinical guidelines. As the majority of mental health treatments have not undergone a NICE technology appraisal, mental health patients could experience unequal access to treatments. Parity cannot be achieved unless treatments – such as the IAPT Programme – are universally commissioned so that they are readily available to all patients, regardless of age, ethnicity, or postcode, on a timescale that is comparable to treatment for a physical health condition. The Westminster Government's call for NHS England to work with the DH to develop new access / waiting time standards, together with *'a range of costed options in order to implement these standards starting from April 2015'* is an important step towards establishing parity of outcomes between mental and physical health.[161] This should also represent a positive step towards addressing some of the disparities in mental health treatment and support experienced by some BME communities, as discussed in **section 6.1**.

7.3   Training and workforce planning

Achieving parity of outcomes between mental health, intellectual disability, and physical health is complicated by gaps in training and workforce planning: these are apparent during medical school, the Foundation Programme (FP), and speciality training. A better understanding of mental health and intellectual disability, achieved through training at all stages of a doctor's medical career, holds the potential to raise doctors' aspirations for these groups while at the same time improving access to, and the quality of, care for mental health and intellectual disability patients. The following sections outline areas for action to help ensure that mental health and intellectual disability receive equal status within healthcare education and practice.

7.3.1   *Medical School*

The knowledge, skills and behaviours that medical students learn at UK medical schools are set by the GMC and are laid out in 'Tomorrow's Doctors'.[282] The balance in the degree of professional and patient involvement in care is changing and moving towards a more collaborative, and less paternalistic,[cc] relationship whereby the patient takes an active role in their care.[283] This shift is reflected in 'Tomorrow's Doctors': one of the core duties of a doctor registered with the GMC is that they must *'work in partnership with patients'* to ensure that they deliver person-centred care. As explained in 'Tomorrow's Doctors', this involves:
- listening to patients and responding to their concerns and preferences
- giving patients the information they want or need in away they can understand
- respecting patients' right to reach decisions with you about their treatment and care
- supporting patients in caring for themselves to improve and maintain their health.

Accessible information and good communication skills are crucial if people with mental health problems and intellectual disabilities are to have equitable access to all healthcare services. Students are required to gain skills for working with patients with disabilities, mental health problems, and those who are vulnerable. The curriculum, however, is centred on physical health with psychiatry often taught in a 'block' or module format rather than integrated with other topics. This can lead to the notion that psychiatry is separate from the rest of medicine. There also tends to be a focus on the management of severe and enduring mental health problems which can exacerbate the idea that mental health patients are 'difficult' and untreatable.[146,284] While a focus on SMIs and rotations in psychiatric clinics are important, training should also consider prevention, recovery and rehabilitation, as well as ways to improve the lives of people with mental health problems.

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cc   A paternalistic relationship is characterised by the doctor making decisions on behalf of the patient, thereby acting as the patient's guardian.

More consideration needs to be given to the medical school curriculum and the ways in which students are taught about the relationships between physical and mental health. The RCPsych recommends integrating psychiatry into the curriculum as widely and as early as possible by teaching jointly with basic science and other specialties: *'eg delirium with neuroscience, depression in endocrinology, and child psychiatry with paediatrics'*.[284] This approach, particularly if combined with problem-based learning techniques and community placements, would help students develop their ability to take a holistic stance to diagnosis and treatment. Those who did not go on to choose psychiatry as a speciality would also be in a better position to detect psychiatric problems in patients with physical ill-health.

Some UK medical schools have already taken steps to introduce a holistic approach to patient care early in a medical student's career. Insights provided by the BMA's Medical Students Committee highlighted how students at Hull York Medical School are taught to consider the relationship between physical and mental ill-health in all patients, and especially in those with chronic illnesses or attending oncology. At Manchester Medical School, clinical students are exposed to a full range of mental health conditions early in their fourth year. Students are taught how to how to take a mental health history, as well as the impact of mood disorders on physical health and well-being. These were viewed as important tools that improved the recognition and discussion of mood in patients.

AREA FOR ACTION

Undergraduate and postgraduate medical training should shift from teaching mental health separately in a 'module' format towards integrating mental health and intellectual disability into the core curriculum. The objective is to improve the diagnosis and management of individuals with a combination of psychological and physical problems. This is an area for action for the GMC, Foundation Programme, Deaneries / Local Education and Training Boards, and Royal Colleges.

7.3.2 Foundation Programme

Developing a more holistic approach to care, and understanding the interactions between physical and mental illness, is part of the FP curriculum. Foundation Year 1 (F1) and Foundation Year 2 (F2) doctors are expected to have knowledge of:
- physical problems affecting psychological and social well-being
- physical illness presenting with psychiatric symptoms
- psychiatric illness presenting with physical symptoms
- psychological / social distress manifesting as physical symptoms (somatisation).

The FP curriculum also focuses on the management of patients with acute mental disorders, including self harm.[285] This holistic approach to care should help to challenge diagnostic overshadowing and undermine any assumptions that mental health and intellectual disability patients have to live with poorer physical health.

Experiences of these types of cases may be constrained by the organisational separation of mental and physical health in the NHS, discussed in **section 6.1**, as well as the availability of speciality training posts. The Collins Report identified a 'maldistribution' of speciality posts in the FP and recommended that the dominance of placements in General (Internal) Medicine and Surgery should be reviewed to ensure new doctors have 'broader based beginnings'.[286] Psychiatry was highlighted as a speciality that had a limited number of placements open for Foundation doctors: in 2009 there were 94 F1 and 243 F2 speciality placements, compared to 2,674 F1 posts in medicine and 2,239 F1 posts in surgery.[286] The comparatively small number of psychiatry placements has also meant that some doctors wishing to explore psychiatry as a career option have been unable to complete a FP psychiatry placement before the application deadline for speciality training.

Building on the Collins report, Health Education England published 'Broadening the Foundation Programme' early in 2014. The report states that local education and training boards (LETBs) should ensure that training programmes for F1 and F2 doctors include four-month placements for at least 22.5 per cent of F1 doctors in psychiatry. The report also calls on LETBs to indicate what plans they are putting in place to provide at least 22.5 per cent of F2 doctors with a four-month psychiatry placement from August 2014.[287]

Exposure to psychiatry can be further hampered by the limited amount of protected teaching time afforded to psychiatry and mental health topics. 'Protected time' refers to the release of Foundation Doctors from their clinical responsibilities during which they should not be bleeped, except when a Foundation Doctor is a member of an acute alert team. Data collected from 17 of the 27 hospitals across the Mersey Deanery and North Western Foundation Schools, based on a cohort of F1 doctors entering training in 2010, found that the protected teaching time across the 17 hospitals totalled 2,354 hours. Approximately 43 hours and 15 minutes (1.8% of the time) was dedicated to psychiatry; however, four of the 17 hospitals provided no teaching on mental health topics. The mean total time spent on mental health topics across the 13 hospitals was therefore three hours and 20 minutes. By way of comparison, the study found that 1,009 hours and 50 minutes (42.9% of the time) were spent on medical or surgical topics. Almost a quarter of the sessions on mental health were simply titled 'psychiatry'. While the sessions may have covered the relationship between mental and physical health, such a title suggests that mental health can be taught separately, as a 'block' or a module. The authors of the study also hypothesise that the title *'implies that the whole speciality can be covered in a single sitting [which does] little to improve the image of psychiatry against other medical specialties, where such a broad remit for a teaching session would not be commonplace.'*[288]

To improve the current 'underrepresentation' of psychiatry in the FP, the RCPsych has committed to increasing the number of Foundation Training posts in psychiatry to 7.5 per cent in F1 (by August 2013) and 7.5 per cent in F2 (by August 2014). They have also proposed to increase the number of 'taster' placements (lasting less than five days) so that doctors can experience psychiatry before they apply for speciality training.[284]

This is a welcome development in principle but Board of Science members have highlighted a number of workforce planning issues that need to be overcome, including ensuring that the number and standard of psychiatry placements available are appropriate and meet the educational requirements of trainees. There is also a view, held by some doctors, that they should not be made – and do not want – to undertake a placement in psychiatry. This is indicative of the attitudes towards mental health, and psychiatry in particular, that need to change. It was acknowledged in the 'Broadening the Foundation Programme' report that FP trainees, especially those not intending a career in psychiatry, *'can have relatively negative attitudes towards psychiatry placements'*. After completing the placement, the evidence suggests that they develop much more positive attitudes towards the speciality and have high satisfaction rates.[287]

To deliver a more broadly trained practitioner, both the BMA and the RCPsych also support the development of the 'broad based training programme'.[284] This point was made by the BMA in 2012 in their response to the Shape of Training review, which is looking at potential reforms to the structure of postgraduate medical education and training across the UK. The broad based training programme is designed for doctors who have just completed foundation training and are looking to gain experience in providing integrated care in both primary and secondary care settings prior to choosing their speciality. Broad based training is a two-year structured core training programme providing six-month placements in Core Medical Training, General Practice, Paediatrics and Psychiatry. During each six month placement, trainees also experience elements of the other three specialities so that, for example, when rotating through general practice, the trainee will have experience in managing psychiatric, paediatric and long-term conditions.

The Shape of Training Review reported in October 2013 and made a wide range of recommendations, including overhauling the training programme structure so that doctors develop more generic capabilities. After the FP, the review proposed that doctors will enter broad based specialty training. Specialties or areas of practice will be grouped together and these groupings will be characterised by patient care themes (such as women's health, child health and mental health), and will be *'defined by the dynamic and interconnected relationships between the specialties'*.[289] The BMA does not believe that the postgraduate training structure needs to be overhauled in this way to achieve the aims sought by the Shape of Training Review.

AREA FOR ACTION

There should be adequate workforce planning to ensure that every F1 and F2 doctor has a placement in psychiatry. These placements must meet the educational standards and requirements of trainees.

7.3.3   Speciality training

In its recruitment strategy, 2011-16, the RCPsych reported in 2012 that the recruitment and retention of medical graduates into specialty training in psychiatry is too low. At the end of the second recruitment round in August 2011, 17 per cent of the 478 core training year one (CT1) vacancies in psychiatry had not been filled in England and Wales.[284] A number of factors have been identified by the RCPsych as contributing to the shortage of applications:

- the stigma attached to psychiatry as a speciality
- patients are seen as 'difficult' and untreatable
- psychiatry is seen as 'unscientific' and its treatments as non evidence based when compared to other specialities
- psychiatry is perceived as being remote from the rest of medicine
- limited experience of, and exposure to, psychiatry (as discussed in **sections 7.3.1** and **7.3.2**).[284]

Achieving parity of outcomes requires all doctors to have a better understanding of the relationship between physical and mental health. While speciality training must focus on skilling the doctor in the speciality at hand, it should not lose sight of the need to treat the 'whole' patient, and to recognise physical and mental co-morbidities. Recruiting and training more psychiatrists is an important step towards realising this goal but it will not, on its own, solve the problem.

The RCGP and RCPsych have made a number of recommendations to improve psychiatrists and GPs management of patients with physical and psychological problems. For those doctors who specialise in psychiatry, the RCGP and RCPsych suggest that they should receive teaching on common physical health problems experienced by people with mental health problems. The same report encourages psychiatry trainees to use *'special interest sessions to gain experience of primary care to improve their understanding of the management of mental health problems in primary care.'*[290] The RCGP and RCPsych also propose that GP registrars consider spending a period of time during their training attached to a liaison psychiatry firm so that they can gain experience of supporting patients with complex physical and mental health needs.[290] There is evidence that this type of training does exist in some areas for physical healthcare teams who want to improve their core mental health skills. The IMPARTS initiative, running across Guy's, St Thomas's and King's College Hospitals, London, aims to equip clinicians working in a general hospital setting with key clinical skills in the assessment and treatment of common mental health problems.[291]

7.3.4   Intellectual disability training

Training provided to medical students and to postgraduate clinical trainees on intellectual disabilities is inconsistent and sporadic. While it is a recognised theme in the undergraduate medical curriculum, the way in which it is taught and incorporated into medical courses varies widely across UK medical schools.[292] There are examples of good practice, such as the teaching programme at St George's University of London, which was one of the first to provide a comprehensive intellectual disability component in the medical school curriculum. As part of the course, students have an opportunity to meet people with intellectual disabilities and to think about issues that affect their care and treatment, such as institutional discrimination, communication, and diagnostic overshadowing. During their GP attachment, all students have a specialist intellectual disability attachment where they meet a patient and their carer in the community to conduct a health check.[293] St George's also employs people with intellectual disabilities to work as trainers with medical students, medical staff, and researchers. The trainers work in numerous different ways, including:

- helping others to think about the issues that affect people with intellectual disabilities in their lives
- making information easier to understand
- giving advice on how to listen to people with intellectual disabilities
- giving advice on how to include people with intellectual disabilities.[294]

Speciality placements in intellectual disability are very limited: in 2009 less than one per cent of F1 and F2 doctors had any experience of intellectual disability psychiatry.[286] Limited personal contact with this group, combined with poor understanding of the health problems presented by people with intellectual disabilities due to a lack of training, can:

> 'reinforce negative attitudes and values towards people with learning disabilities and their carers and contribute significantly to a failure to deliver equal treatment'.[13]

Training in intellectual disability, which explicitly tackles 'diagnostic overshadowing' and unequal treatment, should be integrated at undergraduate, postgraduate, and continuing professional development (CPD) levels. Such training should, wherever possible, involve people with intellectual disabilities and their carers. It is encouraging that the RCGP Curriculum 2010 already contains a dedicated section on the care of people with an intellectual disability and, as noted in **section 6.1.1.6**, the GMC has produced teaching materials around these issues.[295] Other specialities should begin to incorporate an understanding of the relationship between intellectual disability, and mental health problems, in their training, examinations and assessments.

Doctors not only need to be aware of the co- and multi-morbidities that affect people with an intellectual disability, they must also be equipped to communicate effectively with them, as well as liaise with their family, carers and various teams of healthcare professionals. As the BMA's 2007 report 'Disability equality within healthcare' highlights, medical competence includes treating all patients with respect, not making assumptions about how someone wants to be treated, and being able and willing to ask questions when necessary. Increased understanding among healthcare professionals about the diverse needs of the population is vital in order to maintain high standards of healthcare.[292] Better understanding and training also helps to challenge some of the negative and prejudiced attitudes towards people with intellectual disability and mental health problems, highlighted in **sections 6.1** and **6.2**.

7.3.5 Continuing professional development and peer-to-peer training

The GMCs 'Good Medical Practice' requires doctors who have completed their undergraduate medical education and postgraduate training to keep their knowledge and skills up to date *'by regularly taking part in activities that maintain and further develop your competence and performance'*.[296] According to the GMC's guidance, CPD can involve formal and informal learning activities. When reflecting on their practice, doctors should consider if they would benefit from learning more about the interactions between physical and mental health.

AREA FOR ACTION

All healthcare professionals should undertake mental health, and intellectual disability, awareness training as part of their continuing professional development.

During discussions at the BMA President's seminar (see **section 6.2.1** and **Appendix 1**) it was noted how a poor understanding, and subsequent misuse, of the *Mental Capacity Act 2005* (MCA) resulted in flawed best interest decisions being taken about the treatment of mental health or intellectual disability patients. This point has been examined in detail by the House of Lords Mental Capacity Act 2005 Select Committee. The MCA extends only to England and Wales: similar legislation was passed in Scotland in the form of the *Adults with Incapacity (Scotland) Act 2000*. At the time of writing, there is no equivalent law in Northern Ireland on mental capacity, though the Northern Ireland Assembly is working towards statutory provisions.

Mental capacity is an area where doctors and other health professionals could benefit from further training: the CIPOLD recommended that MCA advice should be available 24 hours a day and that all health and social care staff should have training and regular updates on the Act.[14] In 2014, the House of Lords Select Committee on the MCA published a report on whether the Act was working as intended. This noted that the MCA needs a higher profile among professionals in order to be properly understood and effectively implemented. It recommended that the Government work with professional regulators and the medical Royal Colleges to ensure that the Act is given a higher profile. In particular, the report called on the GMC to '*ensure that there is leadership in psychiatry within all medical schools in order to give a higher profile to mental health*', to '*place proper emphasis on the Mental Capacity Act in its publication "Good Medical Practice"*', and to '*enhance training on the Mental Capacity Act in all post-graduate education, especially for GPs*'.[297]

The need to improve doctors' understanding of the MCA is supported by the BMA. In 2008, the BMA Medical Ethics Committee (MEC) produced a Mental Capacity Act toolkit that covers issues such as how to assess capacity, the basic principles of the Act, advance refusals of treatment, research, and Lasting Powers of Attorney (LPAs). This was followed in 2009 by guidance on ethical and medico-legal issues in Scotland in relation to the medical treatment for adults with incapacity.[298] The MEC is also in the process of producing a single sheet 'flowchart', in a number of formats, as a quick reference aid for doctors and other health professionals.

Section 7.2.3 noted that liaison psychiatrists are in a good position to deliver extra training to doctors in hospitals to assist them in detecting and treating mental ill health in their patients. They can also play a critical role in raising awareness of the need for parity, and for doctors to be alert to the potential for mental health problems to occur in patients with long-term conditions, and vice versa. Similar opportunities for teaching and raising awareness exist in primary care. The DRC makes the case for delivering training *'to the whole primary care team so that everyone from receptionists, to practice managers and GPs engage in improving'* equality of access and treatment for people with mental health problems and intellectual disability.[6] Part of a doctor's training (or CPD) should also include working with liaison intellectual disability nurses so that they can learn about the needs of this group of patients, as well as how to minimise any distress associated with seeing a GP, or being admitted to hospital. At the same time, it is important to reflect on what aspects of clinical practice may be stigmatising, and to consider if an alternative approach is possible: rather than focusing solely on a patient's illness, doctors could adopt a more aspirational attitude and instead think about what the patient can do and achieve.

From a broader perspective, developing 'mental health literacy' in the workplace holds the potential to improve first responses when people become unwell. As one of the largest workforces in the UK, the NHS is well placed to lead the way by offering supervisors and managers mental health training, reviewing policies, and positively encouraging people with mental health problems to work for the NHS. This latter point is particularly important since very few people with mental health problems access evidence-based employment support: the CQC's 2012 community mental health survey found that 43 per cent of people who wanted help from NHS mental health services to find or remain in employment did not get the support that they needed.[299]

AREAS FOR ACTION

- **Within primary and secondary care, doctors should have the opportunity to work with, and learn from, liaison psychiatrists, to improve detection and treatment of mental ill health in their patients.**
- **Mental health literacy in the workplace needs to be improved, and more support should be made available to people with mental health problems who are seeking employment, including within the NHS.**
- **Doctors should receive specific training in how to communicate with people with intellectual disability and how to make reasonable adjustments to enable them to benefit fully from health services.**

7.4   Research

Reversing the 'siloing' of care identified in **section 6.1** not only requires different ways of caring for patients, it also needs to be supported by shifts in the design and funding of research. A 2010 'Review of Mental Health Research' by the Medical Research Council (MRC) acknowledged a disparity between the disease burden (determined by disability-adjusted life years) and the scale of research, with funding for mental health research lagging significantly behind other disorder-based research.[300] Establishing causal relationships between physical illness and poor mental health was also identified in the same MRC review as presenting a 'distinct opportunity' to help prevent mental ill health.[300] Researchers from The Mental Health Foundation, and the Institute of Psychiatry at King's College London, also hypothesise that this type of research could *'yield generalised health gains as well as large cost savings.'*[301] While there has been a rise in the number of co-morbidity studies investigating the association between a single physical condition and a single mental health condition, Mercer and colleagues note that research involving patients with multi-morbidities remains rare.[267] This is despite the fact that multi-morbidity is becoming the norm rather than the exception.[10]

The 2001 DH report, 'Valuing People', noted that a considerable amount of research activity on intellectual disability was taking place in the NHS: over 130 separate research projects were listed on the National Research Register (NRR) as having been completed by 2001, while approximately £3 million was being spent on 50 ongoing studies. Developing new ways of caring for people with intellectual disabilities was given further momentum by a £2 million DH research programme. Known as the 'Learning Disability Research Initiative' (LDRI), the programme ran from 2002 until 2007 and examined (among other things):

• social inclusion, including access to good healthcare, and the factors which create disability barriers in people's lives
• organisation development to show how staff performance in learning disability services can be supported to achieve better services.

The 'Learning Disabilities Observatory' was set up as a three year programme running from April 2010-13. Its establishment was prompted by a recommendation, made by Sir Jonathan Michael in his 2008 'Inquiry into Access to Healthcare for People with Learning Disabilities', to raise awareness in the NHS of the risk of premature avoidable death, and to promote sustainable good practice in local assessment, management. The Observatory is a collaboration between the NHS North East Public Health Observatory, the Centre for Disability Research at the University of Lancaster, and the National Development Team for Inclusion. It has published almost fifty reports examining different aspects of the health and wellbeing of people with intellectual disabilities. Many of these reports also have an 'easy read' version. By gathering information from across England, the Observatory aims to help health providers to understand better the needs of people with intellectual disabilities. From 1 April 2013, the Learning Disabilities Observatory became part of Public Health England.

AREA FOR ACTION

To advance our understanding of the relationships between intellectual disability, mental health and physical health, the disparity between the scale of research on multi-morbidities and the burden of multi-morbid disease needs to be addressed.

8. Conclusion

People with mental health problems and intellectual disability have a shorter life expectancy and increased risk of early death when compared to the general population. The evidence outlined in this report makes it clear that excess morbidity and premature mortality predominantly result from the under-diagnosis, treatment and prevention of co-morbid physical health problems in mental health and intellectual disability patients. In the worst cases, people from these vulnerable groups are receiving less than optimal medical care and are suffering unnecessarily with unmet health needs.

The wealth of evidence on excess morbidity and mortality has not been consistently acted upon, scant attention has been paid to individuals' physical healthcare needs, and an undercurrent of low expectations for the physical health of intellectual disability and mental health patients has persisted. Delivering 'whole person care' has been further hampered by the geographic, institutional, and professional division of mental health, intellectual disability and physical healthcare that remains apparent across the healthcare system. Recent years have seen cuts to mental health budgets, the commissioning of mental health and intellectual disability services separately from their physical health counterparts, an absence of integrated care, and gaps in healthcare training and workforce planning. These factors inhibit the delivery of a coordinated response to the multiple needs of patients presenting with co-morbidities.

This report outlines what needs to be done to make 'parity of outcomes' across physical health, mental health, and intellectual disability a reality. Shifting organisational structures and mindsets requires a coordinated and concerted effort, from strong government leadership at the highest level, all the way through to doctors and healthcare professionals working in their local communities. The following areas for action set out the steps that need to be taken across the healthcare system to curb the excess morbidity and premature mortality among mental health and intellectual disability patients.

Mortality review
- Provisions for a national mortality review system should be implemented across the UK in relation to people with intellectual disabilities, and for people with a mental illness.

Promoting prevention and early intervention strategies
- Reducing the prevalence of mental health problems and promoting good public mental health should be a priority for Directors of Public Health across the UK. Public health intervention programmes should specifically consider how people with mental health problems and intellectual disability will be reached. Strategies that improve mental health literacy and raise public awareness should also be encouraged.

Delivering joined-up care
- The integration of intellectual disability, mental health and physical healthcare should be improved. This should be a priority for all policy makers at a national level, as well as for Directors of Public Health and local commissioning bodies who must ensure that clear pathways of care, and allocation of responsibility, are established regardless of whether the patient presents with a physical or mental illness.

- The wider application of the collaborative care model developed by NICE for people with moderate to severe depression and a chronic health problem should be explored by NICE and the UK Health Departments.

- To strengthen collaborative care, generalists[dd] located in hospitals and outside of hospitals should act as the responsible clinician, working closely with a multi-professional team to support patients with co- or multi-morbidities in a more integrated way.

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dd   Generalists are individuals with sufficient breadth of skills and competencies to handle undifferentiated symptoms safely, and to start initial assessments and treatment.

- A liaison psychiatry service, including paediatric liaison services, and intellectual disability liaison services, should be made available in all hospitals.

- Mental health trusts should appoint a liaison physician (in psychiatric wards) to support the physical health needs of hospitalised people with mental health problems. Liaison physicians should be appointed to support the physical health needs of hospitalised people with intellectual disabilities (in psychiatric wards).

- Health professionals with responsibilities for commissioning and / or public health should ensure that they place equal value on mental and physical health when setting their commissioning priorities and reporting requirements.
  - Mental health and wellbeing should be integrated into all aspects of commissioners and public health directors work. A mental health dimension, for example, should be incorporated into physical health promotion (eg smoking cessation programmes).
  - Commissioners should have a good understanding of intellectual disability and mental health, and encourage the development of services that deliver integrated care.

- Commissioners must have accurate, accessible information on the physical, mental and intellectual disability needs of the population that they are serving.
  - Data systems need to be improved to ensure that co- and multi-morbidities are recorded and used by commissioners when setting their service priorities.
  - At present, health and care outcomes frameworks have few effective mental health measures thereby giving commissioners too few incentives to invest fairly in mental health.
  - The range of reasonable adjustments which need to be made to support people with intellectual disability and people with mental health problems must be estimated, commissioned and resourced.
  - It is strongly recommended that commissioning bodies should ensure that at least one commissioner is a mental health and / or intellectual disability professional.
  - Provision should be made for adult psychiatric morbidity surveys – including psychiatric morbidity in people with intellectual disability – and child and adolescent psychiatric morbidity surveys, to take place across the devolved nations.

- Equality of access to mental health and intellectual disability services must be made a reality.
  - Healthcare providers must ensure that they are compliant with their duties under the *Equality Act 2010*.
  - Negative attitudes and discrimination must be tackled across the medical profession and 'equality of options' promoted for people with intellectual disabilities and mental health problems by the UK Health Departments.
  - Providers' compliance with legislation and guidelines should be monitored by healthcare regulators and inspectors, such as Monitor and Healthcare Improvement Scotland.
  - Developments in the assessment and care of co- and multi-morbidities must be matched by equal access to treatments.

Training and workforce planning
- Undergraduate and postgraduate medical training should shift from teaching mental health separately in a 'module' format towards integrating mental health and intellectual disability into the core curriculum. The objective is to improve the diagnosis and management of individuals with a combination of psychological and physical problems. This is an area for action for the GMC, Foundation Programme, Deaneries / Local Education and Training Boards, and Royal Colleges.

- There should be adequate workforce planning to ensure that every F1 and F2 doctor has a placement in psychiatry. These placements must meet the educational standards and requirements of trainees.

- As part of their speciality training, psychiatrists should be offered teaching on common physical health problems experienced by people with intellectual disabilities and mental health problems. General practitioners in training should spend an attachment in psychiatry, liaison psychiatry, or intellectual disability. This is an area for action for the Royal College of Psychiatrists and the Royal College of General Practitioners.

- Training in intellectual disability that explicitly tackles 'diagnostic overshadowing' and unequal treatment should be integrated at undergraduate, postgraduate and continuing professional development levels. All doctors should understand the requirements of the *Mental Capacity Act 2005* and the *Equality Act 2010*. This is an area for action for the GMC, Deaneries / Local Education and Training Boards, NHS Education for Scotland, and the Northern Ireland Medical and Dental Training Agency.

- All healthcare professionals should undertake mental health, and intellectual disability, awareness training as part of their continuing professional development.

- Within primary and secondary care, doctors should have the opportunity to work with, and learn from, liaison psychiatrists, to improve detection and treatment of mental ill health in their patients.

- Mental health literacy in the workplace needs to be improved, and more support should be made available to people with mental health problems who are seeking employment, including within the NHS.

- Doctors should receive specific training in how to communicate with people with intellectual disability and how to make reasonable adjustments to enable them to benefit fully from health services.

Research
- To advance our understanding of the relationships between intellectual disability, mental health and physical health, the disparity between the scale of research on multi-morbidities and the burden of multi-morbid disease needs to be addressed.

Appendix 1

BMA President's Seminar Series
Attlee Room, House of Lords, 11 June 2013

Tackling discrimination in the provision of physical healthcare for people with learning disabilities and mental health problems

Speakers

Chaired by **Professor Sheila the Baroness Hollins of Wimbledon and Grenoside**, and President of the British Medical Association

Mr Norman Lamb MP	Minister of State for Care and Support
Dr Paul Gill	Chair of the Faculty of Liaison Psychiatry, Royal College of Psychiatrists
Dr Irene Tuffrey-Wijne	Senior Research Fellow, St George's University of London and Kingston University

In attendance

Dr Ruth Allen	Transitional Faculty Chair, Mental Health Faculty, The College of Social Work
Dr David Branford	Chief Pharmacist, Derbyshire Healthcare NHS Foundation NHS Trust
Dr Tony Calland	Chair of Ethics Committee, BMA
Mr John Crook	Post Winterbourne View Implementation, Independent Living, Social Care, Local Government and Care Partnerships
Ms Beverley Dawkins	National Policy Manager, Mencap
Dr Tony Delamothe	Deputy Editor, BMJ
Professor Peter Fleming	Professor of Infant Health & Developmental Physiology, University of Bristol
Dr Gyles Glover	Co-Director, Learning Disabilities Team, Public Health England
Dr Pauline Heslop	Manager, Confidential Inquiry into premature deaths of people with learning disabilities, University of Bristol
The Lord Hunt of Wirral	
Dr Josie Jenkinson	Clinical Lecturer/ST5, Old Age Psychiatry, Kings' College London
Baroness Jolly	
Ms Ingrid King	Executive Director, Association for Child and Adolescent Mental Health
Professor Vivienne Nathanson	Director of Professional Activities, BMA
Ms Ann Norman	Learning Disability & Prison Nursing Adviser, RCN
Mr Robert Okunnu	Head of Public Affairs, BMA
Mr Zawar Patel	Department of Health
Lord Rix	
Ms Elizabeth Rough	Senior Policy Executive, Science and Education, BMA
Mr George Roycroft	Deputy Head of Science and Education, BMA
Dr David Shiers	Member of the Management Board, National Collaborating Centre for Mental Health and retired GP
Mr Greg Smith	Policy Analyst, The Royal College of Psychiatrists
Mr Andrew Stunell MP	
Sir Richard Thompson	President, The Royal College of Physicians
Professor Tamar Thompson	
Professor Graham Thornicroft	Head of Health Service and Population Research Department, Institute of Psychiatry, King's College London
Ms Lucy Thorpe	Head of Policy Unit, The Royal College of Psychiatrists
Mr Michael West	Section Head of Mental Health Policy, Department of Health
Ms Anita Wilkinson	Senior Writer, News / Communications Directorate, BMA

Introduction

The aim of the seminar was to discuss how to tackle discrimination in the provision of physical healthcare for people with intellectual disabilities[ee] and mental health problems. A key challenge is how to improve the identification, treatment and recovery of mental health and intellectual disability patients from physical illness, and erase the discrimination that these two groups encounter. This note explores a number of the themes that emerged during the seminar, including the inequalities faced by these groups, and the barriers to accessing and delivering good physical healthcare to mental health and intellectual disability patients. It concludes by outlining some of the policy changes and practical solutions discussed during the seminar which could deliver more effective, and less discriminatory, physical healthcare for these vulnerable groups.

The scale of the problem

People with intellectual disabilities and mental health problems have a shorter life expectancy and increased risk of early death when compared to the general population. In the worst cases, patients are suffering unnecessarily with untreated, or poorly managed, conditions. Data from the 2013 'Confidential Inquiry into the Premature Deaths of People with Learning Disabilities' found that 22 per cent of people with an intellectual disability were under the age of 50 when they died, compared to 10 per cent of the general population. Premature deaths in this group were mostly linked to delays or problems with investigating, diagnosing, and treating the cause of illness and in providing appropriate care. A similar situation exists for individuals with serious mental health problems. A 2012 meta-analysis estimated that a patient with a severe mental illness has an excess mortality that is two to three times higher than the general population, reducing their life expectancy by 13-30 years. While suicide is an important cause of death in this group, the same analysis estimated that 60 per cent of this excess mortality is due to physical illness.

Barriers to the provision of non-discriminatory healthcare

While much of the increased morbidity and mortality among intellectual disability and mental health patients is linked to modifiable risk factors, a lack of parity in the access to, and provision of, physical healthcare plays a significant role. Three key areas were identified as causes of this disparity.

1. Knowledge and attitudes of healthcare professionals

Discriminatory attitudes towards mental health and learning disability patients persist across the health sector. A lack of training at all levels contributes to the poor recognition and understanding of the health needs of these groups. This can lead to a miscommunication between healthcare professionals and patients, as well as a failure to make 'reasonable adjustments' as required by the *Equality Act 2010*. Feelings of fear, mistrust and impatience among healthcare professionals, stemming from societal prejudices and limited experiential training, may further hamper the provision of good quality care. These patterns can be self-perpetuating; when the specialist care needs of intellectual disability and mental health patients are not recognised, it can be hard to persuade healthcare managers of the benefits of enabling their staff to undertake extra training to support these patients more effectively. Healthcare professionals may be unaware that they are discriminating and acting in ways that have detrimental consequences.

Limited knowledge of mental health and intellectual disability can result in physical health conditions being missed in these patients – sometimes with fatal consequences – through the process of 'diagnostic overshadowing'. Symptoms of physical ill health may be mistakenly attributed to either a mental health problem, or as being inherent to the person's intellectual disability (or vice versa). A poor understanding of the *Mental Capacity Act 2005* compounds flawed best interest decisions being taken about the treatment of mental health or intellectual disability patients. While a healthcare professional does not mean to harm their patient, a failure to understand how to assess best interests can lead to unfounded judgements about how 'worthwhile' it is to continue treatment,

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ee   The term intellectual disability is used in this note as interchangeable with learning disability.

prescribe a particular drug, or carry out a procedure. These judgements may be based upon the practitioner's prejudices about that person's quality of life, their capabilities, or value as a citizen, rather than clinical evidence. More broadly, mental health and intellectual disability are not sufficiently recognised as an avoidable co-morbid cause of premature mortality in the same way physical conditions are.

2.   Funding and commissioning

At a time when austerity measures are leading to cuts, there is evidence that services for vulnerable groups are some of the first to lose funding. Staff levels in mental health settings already tend to be lower than those in physical healthcare, while data published by the Care Quality Commission in 2013 identified eight mental health trusts with unsafe staffing levels. A reduction in funding compounds this problem. Liaison psychiatrists work in hospital settings and are equipped to support physicians and surgeons assess whether there are any psychological factors in a patient's presentation, and thus to help ensure that any physical symptoms are not overlooked or overshadowed. In addition to delivering patient care, liaison psychiatry services also provide education, training and support to other members of hospital staff. Despite the clear benefits of having such a service, the provision of liaison psychiatry services across the country is patchy and under resourced. While liaison psychiatry is well thought of in the acute hospital, they are commissioned by mental health commissioning groups who may see it as a non-core service – a luxury rather than a necessity.

Similar problems exist for intellectual disability – there are only 30 learning disability liaison nurses across the UK, and only one acute care nurse consultant for learning disability, based at St George's Hospital in London. In addition to improving routine co-operation between doctors and other staff, and making sure staff comply with the 'reasonable adjustments' for vulnerable groups, learning disability liaison nurses also deliver regular training to healthcare professionals. This helps to reduce discrimination by fostering understanding and more positive attitudes, and improving the level of appropriate care received by intellectual disability patients. Funding pressures mean that these roles are being eroded and lost, and as a growing number of learning disability liaison nurses reach retirement, their positions are not being filled. This is despite repeated recommendations from national inquiries that these posts are effective.

The provision of services for intellectual disability and mental health patients is adversely affected by payment by results (PbR) tariffs which focus too much on throughput rather than holistic care. There is also insufficient consideration of intellectual disability and mental health issues in the development of NICE clinical guidelines.

3.   Poor quality data

A substantial barrier to effective commissioning is the lack of good quality data on the prevalence of mental health and intellectual disability. Without measuring the problem, there is a limited sense of its scale, or whether an episode of treatment is associated with an improved outcome. Data on mental health and intellectual disability is wholly inadequate.

What policy changes and practical solutions are required?

Collecting and sharing data – effective cross-agency working, commissioning accessible services, and gauging the effectiveness of treatment will require robust systems to collect, record and share data for patients. One of the challenges is to link together different registries (eg GP registries of intellectual disability and mental health problems with hospital episode statistics, treatment outcomes, cancer registries and mortality registries). Bringing about this change will require Government intervention.

Training – all staff should be able to identify and understand the needs of intellectual disability and mental health patients. This should be integrated into all levels of training and assessment, and opportunities for experiential training should be made available. Working alongside experts, such as liaison psychiatry teams and learning disability liaison nurses, should also be encouraged as a way to improve understanding, attitudes, and care. Training should also focus on the Mental Capacity Act 2005, and the BMA's Ethics Committee is committed to producing a simple, easy-to-understand guide to support this goal.

Cultural and behavioural change – there needs to be a culture change in the NHS away from unfounded ill-informed judgements about mental health and intellectual disability patients towards high quality, holistic, and collaborative care.

Access standards – mental health and intellectual disability patients should be subject to the same access standards as physical health patients, including maximum waiting times and improved 24 hour crisis care.

Commissioning – mental health and intellectual disability services – including liaison psychiatry services and learning disability liaison nurses – should be seen by commissioners as necessities rather than luxuries. As local authorities take on an increasingly important role in commissioning, emphasis should be placed on lobbying the Local Government Association to promote these aspects to their members.

Reducing premature mortality – there is a clear need for a national mortality review process that considers mental health and intellectual disability as two groups that experience high morbidity and mortality rates. A strong case should also be made to Ministers that improving the physical healthcare of intellectual disability and mental health patients will lead to significant gains in the drive to reduce avoidable premature mortality.

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