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 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, 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

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