Mencap has called on the UK government to make the NHS safe for people with a learning disability, following the publication of a new report ‘Death by indifference: 74 deaths and counting’, which finds continued institutional discrimination in the NHS.

Five years after Mencap published ‘Death by Indifference’, which reported on the deaths of six people in NHS care, the charity says that, although some positive steps have been taken in the NHS, many health professionals are still failing to provide adequate care to people with a learning disability.

The latest report highlights the deaths of 74 people with a learning disability in NHS care over the last ten years, which Mencap believes are a direct result of institutional discrimination and could have been avoided.

**Hostility**

In an article for the Guardian newspaper on 15 February, Mencap’s chief executive Mark Goldring said: “Prejudice, ignorance and indifference as well as failure to abide by disability discrimination laws still feature too frequently in the treatment of patients with a learning disability. This is illustrated by the case of Alan MacDonald, who died suddenly in Lister hospital, Hertfordshire, in 2009 after being admitted with stomach cramps. From the time MacDonald was admitted, his family felt that they had ‘to beg’ staff to treat him, only to be met with what they described as ‘hostility’. In a society that prides itself on its universal healthcare system, such treatment is incomprehensible.”

The report states that “there are parts of the NHS, as well as other organisations and individuals, that are making a real effort to address the problems of access to equal healthcare for people with a learning disability… but equal healthcare is a legal obligation that should be embedded in the everyday running of the NHS, in every GP practice and in every hospital ward, not an exercise in identifying pockets of good practice.”

The cases that form the basis of ‘74 deaths and counting’ came to light after the 2007 ‘Death By Indifference’ report prompted families to contact Mencap. The charity believes that they are only “a tiny proportion of the actual number of such cases. They do, however, highlight an NHS that continues to fail people with a learning disability, doctors whose practices appear to show no regard to the Equality Act or Mental Capacity Act, and nurses who fail to provide even basic care to people with a learning disability.”

**Clinical inadequacy**

‘74 deaths and counting’ includes the case of Paul Ridd from Baglan, who died in 2009, aged 53. In September 2011 the Public Service Ombudsman for Wales upheld complaints about neglect and poor care that lead to the death of Mr Ridd at Morriston Hospital, Swansea. The Ombudsman pointed to “clinical inadequacy” made by hospital staff after they failed to give due consideration to his learning disability.

Wayne Crocker, Mencap Cymru’s director, said in response to the Ombudsman’s report: “It’s a disgrace that someone can go into a hospital - a place where they should be looked after - and see their chances of survival reduced because they have a learning disability. Whether it’s intentional or not, failing to meet their specific needs counts as institutional discrimination and this tragedy should act as a wake-up call for all health-providers in Wales. Currently, people with a learning disability get sub-standard healthcare compared to those without – it’s as simple as that.”

Mencap state in the report that “steps have been taken since the [UK] government inquiry led by Sir Jonathan Michael reported in 2008. ‘Healthcare for all’ set out ten key recommendations, all of which the [UK] government accepted and set out in [England’s] ‘Valuing People Now’ delivery plan in January 2009.”

**Recommendations**

‘Death By Indifference: 74 deaths and counting’ updates on what progress has been made against each of the ten recommendations, and sets out what Mencap believes has still to be done to stop more people with a learning disability dying unnecessarily.

The report concludes by calling on the UK government to ensure that:
- annual health checks become a permanent part of the GP contract to ensure early detection of health conditions

(Continued on page 4)
Effective partnership working
Partnership working is a common feature, which done well can have huge benefits for all parties involved. This course looks at how to make partnership working successful, with participants covering a range of aspects, including: looking at individuals’ roles within partnerships, being personally more effective and how to develop relationships within partnerships.
Date and Venue: 7 March 2012, Swansea
Cost: £125-£185
Contact: Participation Cymru, tel 02920 431 757, email participationcymru@wcva.org.uk web www.participationcymru.org.uk

Welsh Assembly and Government
Following the referendum in March 2011, the National Assembly has acquired new powers to pass primary legislation and the first Bill will be introduced early in 2012. This new era and the new processes that it introduces will be covered in the course which will also review the Labour administration’s programme for the Government and the legislation that will be introduced in the next 5 years. Attendees will examine in detail the role of both the civil service and parliament in the creation of new policies and law and campaigning strategies will also be studied - looking at who, when and where to engage with, to further their organisation’s agenda.
Date and Venue: 13 March, Cardiff
Cost: £245-£345
Contact: Government Knowledge Training Ltd, tel 0845 647 7000, email info@government-knowledge.com, web http://bit.ly/wUX71X.

Mental Health Awareness
This course provides an introduction to mental health and distress. The course is intended to improve your understanding and knowledge and aims to reduce stigma and discrimination. It covers: mental health and emotional distress; stigma; depression; suicide; anxiety disorders; self harm; psychotic disorders and recovery.
Date and Venue: 19 March, Cardiff
Cost: £50
Contact: Adele Goodwin, Diverse Cymru, tel 029 2036 8888, email adele@diversecymru.org.uk, web www.diversecymru.org.uk

LDAN Annual Event
This year’s LDAN (Learning Disabilities, Autism and Neurodevelopmental disorders network) conference will be held in Newtown, mid Wales. A programme for the event will be announced soon and be available at www.ldancymru.org.uk/annualevent.php.en.
Date and Venue: 3 May, Newtown
Cost: TBA (usually free of charge)
Contact: Susie Nash, LDAN, tel 01248 388798, email Susie Nash pss056@bangor.ac.uk

LDAN Research Conference
LDAN is the Learning Disabilities, Autism and Neurodevelopmental disorders network. Last summer the Unit for Developmental and Intellectual Disabilities at the University of Glamorgan hosted a conference for people with a learning disability, funded by LDAN, Mencap and Involving People. This was an exciting event and was very well attended. Delegates enjoyed the day and found it useful. This summer, a similar event will be held in Bangor, north Wales. People with a learning disability who may be interested in research will be warmly invited to come with or without a supporter.
Date and Venue: 21 June, Bangor
Cost: Free
Contact: Susie Nash, LDAN, tel 01248 388798, email pss056@bangor.ac.uk

Learning Disability Wales Training

Making Information Easy to Read and Understand - Level 1
16 May, Cardiff
This one day course will help you understand how to make written and printed information more accessible for people with learning disabilities. Attendees will try out ideas for themselves with the new skills and knowledge they will acquire during the day.

Understanding Changes to Benefit System
24 May, Llandudno
A one day course to help you understand how the Welfare Benefits system is changing.

Making Information easy to Read and Understand Level 2
29 May, Cardiff
This course will help you develop your skills in making written and printed information more accessible for people with learning disabilities. You will learn how to apply your skills to more complex documents.

Understanding People with Learning Disabilities
30 May, Newport
A one day course to help you understand the lives and needs of people with learning disabilities.

To book a place or for more information contact: Inacia Rodrigues, Training Administrator, Learning Disability Wales, tel 029 2068 1160, email inacia.rodrigues@learningdisabilitywales.org.uk
Disability Wales launches heritage project to celebrate 40th anniversary

Disability Wales is celebrating its 40th anniversary by launching a new heritage project that will capture the memories of disabled people who were born and have lived in Wales since 1972.

Funded by the Heritage Lottery Fund and titled ‘The story at 40: the lives and times of disabled people in Wales’, the oral film project will involve disabled volunteers in researching and presenting the stories, memories and experiences that have shaped Disability Wales in the four decades since it was established.

In addition to capturing stories on film, the project will feature events and the creation of an archive that will enable both disabled people as a community and the general public to learn about the heritage of disabled people in Wales. The project aims to capture the stories of all disabled people in Wales, including people with a learning disability.

Jennifer Stewart, Head of the Heritage Lottery Fund in Wales said: “Heritage is not all castles, museums and old buildings. Recording memories is an important and popular way of learning about our past and sharing this with present and future generations. This project will create an important record and lasting legacy of the tireless work of Disability Wales in the words of the people who have campaigned to improve the lives of disabled people.”

Rights, equality and independence

Disability Wales was established in 1972 as the ‘Wales Council for the Disabled,’ following Welsh Office recognition that a national coordinating voluntary body was required to liaise with central and local government that could speak on behalf of disabled people. Over the past four decades the organisation has contributed significantly to the development of disability related policy in Wales, pioneered innovative services, established new organisations and initiated campaigns to secure the rights, equality and independence of disabled people.

Congratulating the organisation on its 40th anniversary, Equalities Minister Jane Hutt said: “Disability Wales provides a huge amount of support to disabled individuals across Wales by giving them a voice and helping to ensure that their needs are met. They also make a valuable contribution to the development and delivery of Welsh Government policies and programmes across the piece.”

Andrew Hubbard, Chairman of SAIL (Swansea Association for Independent Living), explained the benefits of being a member of Disability Wales: “SAIL, working with Disability Wales, develops our collective voice and strength as we campaign together to establish our human rights to live where and how we want. The politics of disability and the definition of the Social Model over the last 40 years means we have shared values and strengths to challenge barriers that ‘disable’ us. As a disabled people’s organisation (DPO), the benefit of working together with Disability Wales is we no longer need to hide away as ‘medical problems’ but join together to fight against social isolation and welfare rights discrimination.”

Authoritative voice of disabled people

Jim Crowe, Director of Learning Disability Wales, congratulated Disability Wales on four decades of tireless work: “Disability Wales have developed an unrivalled reputation as an authoritative voice of disabled people that has earned the trust of Government Ministers, Assembly Members and statutory agencies. Moreover they recognise the importance of working in partnership with other disability organisations and Learning Disability Wales has valued this commitment.”

To share your own story with ‘The story at 40: the lives and times of disabled people in Wales’ or for more information on the project, contact Miranda French, Policy & Public Affairs Manager at Disability Wales, phone 02920 887325 or email Miranda.French@disabilitywales.org

Access to Work research

The Wales Disability Reference Group (Learning Disability Wales, Mind Cymru, Wales Council for the Blind and Wales Council of Deaf People) is Interested in hearing about the way in which Access to Work applicants are being assessed given recent changes in the way Assessors have been contracted. This includes fewer impairment related specialists and none which operate in Wales.

Anecdotal evidence suggests that applicants are being asked ‘what support/equipment they want’ which is fine if they are clued up on latest developments in technology and whether it will suit their particular needs, but not everyone is of course. Also, as the assessors have no knowledge of Wales it seems they are not being put in touch with agencies here that could offer support. Your experiences of Access to Work are welcome. Email: info@disabilitywales.org
all health professionals act within the law and get training around their obligations under the Equality Act and Mental Capacity Act so they can put this into practice when treating patients with a learning disability

regulatory bodies such as the Care Quality Commission, General Medical Council and Nursing and Midwifery Council conduct rigorous investigations and deliver appropriate sanctions where health professionals clearly failed in their obligations to patients with a learning disability

the NHS complaints process is overhauled: it is not fit for purpose, it is time consuming and defensive, and it does not enable the NHS to learn important lessons quickly enough to prevent further deaths

acute learning disability liaison nurses are employed by every acute service, and are linked to senior leadership, who have a strategic role in supporting ward staff to make reasonable adjustments

a standard hospital passport is made available to all people with a learning disability

all hospitals sign up to Mencap’s ‘Getting it Right’ charter and put in place the good practice that we know saves lives.

Jim Crowe, Director of Learning Disability Wales said: “There can be no excuse for individuals with a learning disability being failed and neglected so fatally by our NHS. It is hard to read these reports without responding emotionally. It is unfathomable that the caring professions can allow this ill-treatment to occur.

“We would encourage all authorities in Wales to sign-up to Mencap’s ‘Getting it Right’ charter, which spells out the nine key activities that all healthcare professionals should do to ensure that there is equal access to health. So far, only six hospitals and authorities in Wales have signed the charter.”

‘74 Deaths’ can be read at read at www.mencap.org.uk/news/article/74-deaths-and-counting. An Easy Read version is also available. Information on the ‘Getting it Right’ charter can be found at www.mencap.org.uk/campaigns/take-action/getting-it-right

The new duty is intended to assist the person caring for the disabled child to continue to care, building on duties under the Children Act 1989 and the Carers and Disabled Children Act 2000 regarding disabled children and informal carers.

Deadline for responses is 28 March 2012.

The consultation and an Easy Read version can be downloaded at http://bit.ly/2bDIBo. For more information contact Robert Hobbs, Children’s Social Services Directorate, phone 029 2082 3307, email VulnerableChildrenMa@Wales.gsi.gov.uk.

Further consultation by DWP on Personal Independence Payment (PIP)

This consultation is intended to seek views on the second draft of the assessment criteria for Personal Independence Payment and in particular on the changes that have been made since the first draft, the proposed descriptor weightings and entitlement thresholds and the draft regulations.

During the initial consultation last summer, many disability organisations said that without the inclusion of descriptor weightings and entitlement thresholds for the rates and components of PIP, it was difficult to understand the impact of the criteria and therefore to comment fully on the UK Government’s proposals. This further consultation should provide the necessary material to make that judgement, and we would encourge organisations in Wales to respond with any concerns.

Deadline for responses is 16 April 2012.

The consultation and an Easy Read version can be downloaded at http://bit.ly/AgfytU. For more information contact PIP Assessment Development Team, email pip.assessment@dwp.gsi.gov.uk

More than just words - Strategic Framework for Welsh Language Services in Health, Social Services and Social Care

This consultation sets out what the Welsh Government aims to do to provide a service that will satisfy the needs of Welsh speakers and their families or carers, so they are able to receive services in their own language throughout the care process.

Deadline for responses is 30 April 2012.

The consultation can be downloaded at http://bit.ly/A55S5Eo. For more information contact Martyn Gray, Welsh Language Policy Unit, phone 029 2082 3756, email mwynageiriau@cymru.gsi.gov.uk.