Department of Health

Premature Deaths of People with Learning Disabilities: Progress Update

September 2014

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Foreword

In July 2013 we responded to the *Confidential Inquiry into premature deaths of people with learning disabilities*, published alongside *"Six Lives": Progress Report on Healthcare for People with Learning Disabilities*. Those investigations had built on the shocking exposure of poor quality and unequal care in Mencap's original report *Death by Indifference*.

We established and funded the Confidential Inquiry from April 2010 to March 2013 to carry out a detailed investigation and share lessons learned. Its message was stark: people with learning disabilities continue to have poorer experience and outcomes compared to people without learning disabilities, including:

- men with learning disabilities died on average 13 years sooner, and women with learning disabilities 20 years sooner, than those without learning disabilities; and
- 22% of people with learning disabilities were under 50 when they died, compared with 9% of people without learning disabilities.

The most common reasons were delays or problems with diagnosis or treatment, and problems with identifying needs and providing appropriate care in response to changing needs. This is unacceptable.

We have made clear our ambition to make the UK among the best nation states in Europe at reducing premature and avoidable deaths. Learning disabilities indicators are in each of the Outcomes Frameworks for the NHS, public health and social care, and are the basis for holding the whole system to account. Each part, including NHS England, Public Health England, and Health Education England have critical roles to play and we will only achieve the transformation needed by working together. National leadership and partnership is in place through the Learning Disability Programme Board.

This progress update summarises action taken or underway against each of the themes identified by the Confidential Inquiry. Examples of local good practice are included as well as national initiatives. These draw on material presented at a DH-sponsored conference to share good practice held in March 2014.

However we now need to step up the pace and make a concerted national effort to see more equal access and outcomes for people with learning disabilities. Three things that all local areas can do are:

- participate fully in the Self-Assessment Framework and act on its results;
- secure the provision of named care co-ordinators; and
- ensure reasonable adjustments are made and audited.

While encouraging progress has been made, as this report sets out, much more still needs to be done to ensure people with learning disabilities have the same rights and access to the same health benefits as the rest of the population. This is a challenge to which we all must rise.

Norman Lamb
Minister for Care and Support

Identifying people with learning disabilities and their need for reasonable adjustments

1.1. Under this theme the Confidential Inquiry report made recommendations for the clear identification of people with learning disabilities in information systems together with recording and sharing of their need for reasonable adjustments, with auditing and sharing of best practice. Under the Equality Act 2010, service providers have a legal duty to make reasonable adjustments to remove any barriers which prevent or make it difficult for people to access and use services because they have a disability.

1.2. To aid identification of people with learning disability, the General Practice register of people with a learning disability from this year onwards is expanded to be an *all age* register, so it will include children and young people with a learning disability. GPs are incentivised to construct this register as part of the Quality and Outcomes Framework (QOF).

1.3. Broader work looking at Equality Evidence, Data and Intelligence is ongoing, with continuing work to identify gaps and to fill them through data linkage and extraction, the inclusion of learning disability questions in general population health surveys, secondary analyses of large-scale general population survey data and systematic reviews in priority areas. The Department of Health is also reviewing if further work needs to be done on information sharing protocols between health and social care. Box 1 describes a local system for linking information on patients with learning disability.

Box 1: *The Sheffield Case Register*

Sheffield's register of people with learning disabilities was set up in 1974, and now provides data linkage with GP lists, an annual practice download to all general practices, and an annual download to Sheffield Teaching Hospitals. This means there is now a large database of information on the care and health of people with learning disabilities in this area. From this they are able to monitor change and identify patterns of problems in the communities, including co-morbidities. Initiatives include linking people with learning disabilities on GP registers with hospital activity data to try to understand how far this population is being underdiagnosed and undertreated for chronic disease and to understand the number and cause of avoidable emergency admissions. The register facilitates planning of services. Recently, they have been working on identifying high users of non-elective (emergency care) and hospital admissions to explore whether there are interventions which would work to avoid this activity, in favour of a more planned response to the person's health needs.

1.4. Nationally, a requirement for providers to undertake an annual audit of reasonable adjustments has been included in the NHS Standard Contract for 2014/15, published on 21 December 2013.

1.5. The Learning Disabilities Observatory (within Public Health England) maintains a national register of examples of reasonable adjustments made by hospital and other health service providers to help ensure that people with learning disabilities can benefit as much from available care as other people.[1] The database was set up on the basis of a national survey undertaken in 2011. A major refresh was undertaken in 2013, and a further refresh will take place in the autumn of 2014.

1.6. Projects are categorised for searching by the type of organisation, the clinical area, the type of adjustment and the region. Project materials, such as information leaflets, specimen passports or operational policies can be freely downloaded. At the time of writing 222 pieces of work are described. There is a series of reports relating to reasonable adjustments in specific service areas. These include links to resources and examples of good practice, for example promoting health in social care services.[2] PHE also maintains a web page with a map showing the provision of acute liaison nurses and how to contact them – this is regularly updated.[3] Box 2 contains an example of a local system flagging learning disability and joining up support services.

Box 2: *Risk of Admission Patient Alerts (RAPA) – How this flagging system works for people with a Learning Disability in Derriford Hospital*

Plymouth ICT Shared Service has developed an alerting system that automatically notifies community patient services via NHS mail when one of their patients is admitted to hospital. This software system can also identify any attendance at outpatients or emergency department and sends an immediate alert to the CLDT, GP, and Liaison nurse. Real-time information allows the Learning Disability Liaison (LDL) team to respond and ensure all inpatients with learning disabilities get appropriate reasonable adjustments and support. The result is faster and more efficient information sharing between hospital departments and the LDL team and community staff, which is key to better planning of patient care and shorter hospital stays. Initially used for inpatients only, the system is being expanded towards being alerted to all outpatients appointments made for patients with a Learning Disability. Once an outpatient appointment has been made, the team will be able to make contact to ascertain what support the person needs and refer accordingly.

1.7. Action is also underway in terms of inspections and quality assurance. It was recognised that there is already a system within all NHS Foundation Trusts to provide board approved risk assessments to Monitor about six specific areas of good quality care for people with learning disabilities. On the back of this already established standard Professor Sir Mike Richards has agreed that the following four questions will be trialled in the inspection of acute hospitals:

- Do you have anyone with an LD in hospital at present?
- What reasonable adjustments do you make for people with LD?
- Do you have a specialist nurse for LD?
- Do you audit the care given to patients with LD?

1 www.ihal.org.uk/projects/reasonableadjustments

2 www.ihal.org.uk/gsf.php5?f=312597

3 www.ihal.org.uk/aln

1.8. In addition Professor Steve Field, on behalf of the Care Quality Commission, is exploring the data that can be used for Intelligent Monitoring purposes, in preparation for inspection of primary care providers and how they meet the needs of people with learning disabilities in a primary care setting.

1.9. Many aspects of the adjustment of care for people with learning disabilities are covered in the Joint Health and Social Care Self-Assessment Framework (SAF), a process to assist local areas in reviewing the care they provide against national benchmarks. PHE has been responsible for the administration of this; national collated findings were published in June 2014 and two publicity meetings were held to present and discuss findings with service leaders around the country in March. Part of the strength of the SAF lies in validation of the data returned and it is important that this should include local engagement with self-advocates and family carers.

1.10. Other related work in progress includes:

- an over-arching Information Standards Notice to introduce the collection and recording of data on all protected equality characteristics. This will apply to all health-related data sets. The NHS will collect information on equality including if someone has a disability, although this may not show if someone has a learning disability; and
- version 1 of the re-named Mental Health and Learning Disability Data Set (MHLDDS) went live on 1st September 2014 and will be followed by further versions to be developed and rolled-out.

The particular patterns of ill-health of people with learning disabilities

2.1. The Confidential Inquiry found that people with learning disabilities who had died had a high prevalence of impairments, long-term conditions and treatable conditions, and were significantly more likely to have multiple conditions. It recommended in particular that this should be reflected in the National Institute for Health and Care Excellence's (NICE) guidelines.

2.2. NICE is working on three guidelines which relate to improving the care and support of people with learning disabilities. Although not focussed on premature mortality specifically, they should support the improvement of long-term outcomes for people with learning disabilities. They are:

- Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges.[4] The guideline is due to publish in May 2015. NICE will also be developing a quality standard for this topic, due to publish in September 2015.
- Mental health problems in people with learning disability: management of mental health problems in people with learning disability. The scope for this guideline is currently in preparation. The guideline is due to publish in September 2016. NICE will also be developing a quality standard for this topic, publication date to be confirmed.
- Care and support of older people with learning disabilities. This topic has been referred to NICE and development of a guideline is expected to begin in 2015-16.
- The National Collaborating Centre for Mental Health (which is developing the above guidance on behalf of NICE) will be working with people with learning disabilities to inform the guideline development.

2.3. NICE has taken account of the need to involve people with learning disabilities when determining membership of its guideline groups and has built this into its process manual on which consultation closed at the end of June 2014.

2.4. Ongoing work within PHE's Learning Disabilities Observatory (described later in this report) will provide documentary evidence of the extent of multi-morbidity in people with learning disabilities.

4 The scope of this guideline is on this link: http://www.nice.org.uk/nicemedia/live/13956/64606/64606.pdf

The fragmentation of the healthcare provided to people with learning disabilities

3.1. The Confidential Inquiry found that care too often took a 'systems' approach rather than looking at the holistic needs of the individual, and recommended measures to counteract this disadvantage for people with learning disabilities or other multiple co-morbidities. These included recommendations for a named healthcare co-ordinator; patient-held records, and standardised health checks leading to health action plans.

3.2. An overarching national initiative to address the fragmentation of care is the Better Care Fund. This provides an opportunity for local services to improve the lives of some of the most vulnerable people in our society. It ensures closer integration between health and social care services to work more closely together in local areas, based on a plan agreed between the NHS and local authorities. Local plans were submitted in April.

3.3. More specifically, the Government's Mandate to NHS England, which sets out the ambitions for the health service, includes an objective 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.

3.4. Published on April 14th, Transforming Primary Care sets out the Department and NHS England's joint vision for safe, proactive, personalised care for those who need it most. From September 2014, over 800,000 people with the most complex needs will experience a step-change in their care, with GPs developing a proactive and personalised programme of care and support tailored to their needs and views – the Proactive Care Programme.

3.5. The Programme will be provided for at least two per cent of adults on GPs' practice list with the most complex needs. The decision about who is identified to receive the Programme is ultimately up to general practitioners' discretion. However, we anticipate that the cohort of people will contain a number of people with learning disabilities.

3.6. Following a review of incentives and sanctions in 2013 NHS England published new CQUIN guidance for 2014 alongside Everyone Counts in December 2013. There are a number of local learning disability CQUINs indicators that commissioners can use from a pick list depending on their local health economy needs, and this includes a CQUIN directed at improving care co-ordination for people with learning disabilities. There also remains scope for commissioners to agree CQUIN incentives or contractual sanctions locally to deliver improved outcomes for people with a learning disability.

3.7. Good health records are an important part of co-ordinated and effective care. The specific needs of people with learning disabilities are being considered as part of the overall work of the Patient Online Programme to provide people with online access to key transactions with their GP practice (appointment booking, repeat prescription ordering)

and to their GP held e-record. The current scope of this is delivery by 2015. This is in the wider context of the development of a fully comprehensive patient held record. The policy framework for this already exists, and NHS England are currently establishing an integrated programme of work to agree a shared vision and implementation plans spanning the next 3 – 5 years. Box 3 describes an example of innovative local practice. NHS England are planning to hold a meeting later this year to look at developing a national standard for a hospital passport. This will be a patient held document that will detail key information to be shared with any contact in the NHS.

Box 3: *A multi-media, interactive, I-Pad based guide to an individual in Humberside*

The parents and key professionals of a man (Matthew) with learning disabilities with profound and complex needs have prepared a multi-media, interactive, iPad based guide to him and his care needs. The work was commissioned by the NHS Trust. The app on the iPad explains their son's needs and has links to various websites as well as detailed accounts of care plans. The app has recorded messages from each of his care team and short videos about a range of his problems and how to deal with them – e.g. videos of his different types of seizures and what to do about them. There are also practical videos on physiotherapy, postural care etc., and a picture gallery of still pictures and videos illustrating various aspects of his life – present and past. In addition, there is an advance care plan and a list of contacts.

Humber NHS Trust is interested in developing similar books for other people with complex needs – a funding bid has been submitted to support this work. A number of other organisations further afield are also considering using the approach to support activities such as person-centred planning and transition planning. There have been around 3,000 hits on the website page describing Matthew's Book and people have been universally positive about the approach.[5]

3.8. In relation to co-ordinated care for children and young people, new arrangements will be introduced from September 2014 for joint assessment, planning and commissioning of health, social care, and education services for children and young people with special educational needs, up to 25 years old. These arrangements are focused around a single Education Health and Care plan which sets out meaningful objectives which will make a difference to the life of the young person, including supporting their transition to adulthood and independent living.

3.9. NHS England are also working on the development of personal health budgets for children; exploration of the role of personal health budgets for people with a learning disability and development of accessible information standards, as well as the establishment of an NHS Youth Forum to include the voices of children with learning difficulties.

3.10. The Care Quality Commission have announced that they will, from the Autumn, be inspecting services around their preparedness and plans for children and young people with learning disabilities transitioning into adult services. Box 4 describes an example of the use of 'experts by experience' in CQC inspections.

5 http://designforcare.wordpress.com/projects/supporting-conversations-with-the-ipad/

Box 4: *Health Quality Checkers in Newcastle*

Skills for People Quality Checkers team are people with learning disabilities who have spent the last decade checking how well services support people with learning disabilities; and training others to become Quality Checkers too. They have created 'user led' standards, and carried out Quality Checks on a range of services including independent supported living services, housing, and services for young people. Over the past few years, they have developed 'Health Quality Checkers. Working with Sunderland People First and local health professionals, they created the 'Good Health for All' standards, which they use to find out how well local health services are supporting people with learning disabilities. Health Quality Checkers support local services to make changes and improve practice. They have created a Step by Step guide to help others who wish to become Health Quality Checkers, and have trained several groups in the North East. The team are 'experts by experience' who also work alongside CQC inspectors when they visit services. Now they are working with others to set up a national Association of Quality Checkers.

3.11. It is important that people with learning disabilities have regular health checks which lead to proper health plans. As part of the negotiations on the GP contract for 2014/15, it was agreed to amend the Enhanced Service for the Learning Disabilities Health Check Scheme to extend the age range for these health checks to people from the age of 14. A requirement for Health Action Plans to be part of the annual health check has also been included in the enhanced service which began from 1 April 2014. NHS England was required to offer all GP practices the opportunity to participate in the scheme by 30 April 2014, and is developing a strategy through primary care commissioning, to improve the quality and consistency of annual health checks.

3.12. PHE's Learning Disabilities Observatory monitors the uptake of annual health checks each year. A report on checks in 2012/13 was published last Summer.[6] They are currently obtaining the data for health check coverage in 2013/14 and anticipate reporting on this in the Autumn. Seminars for health service and local authority staff involved in providing or commissioning health checks to report the findings on check coverage are held each year. These are held in different parts of the country to maximise accessibility. Self-advocates and family carers have played a major role in these events.

3.13. This year the seminars included focus group discussions on what staff have found helpful or difficult in their own areas and the solutions they have found. A report was recently published aimed at general practices on practical arrangements that people with learning disabilities have found helpful in improving the uptake and quality of health checks. This includes an annotated listing of useful internet-based resources.[7]

3.14. An updated systematic review has been completed on the research evidence concerning the effectiveness and implementation of health checks. Three factsheets have been produced to outline the main messages from this review.[8]

6 www.ihal.org.uk/gsf.php5?f=17761

7 www.ihal.org.uk/gsf.php5?f=312703

8 www.ihal.org.uk/projects/annualhealthchecks/detail

Deaths amenable to healthcare interventions

4.1. The Confidential Inquiry found that almost two-fifths of people with learning disabilities died from causes amenable to good quality healthcare, many more than was the case for people without learning disabilities. This often stemmed from problems in having illness diagnosed. Associated recommendations under this theme were intended to encourage early investigations and referral where necessary, and better preventative services, in particular taking account of the risk of respiratory illness.

4.2. A review of the evidence on the health and healthcare of people with learning disabilities by PHE's Learning Disabilities Observatory has revealed few systematic reviews in the major causes of death identified by the Confidential Inquiry. The Observatory's work programme for 2014/15 includes systematic reviews concerning epilepsy and dysphagia experienced by people with learning disabilities, including any research on effective service systems and reasonable adjustments. Reports on reasonable adjustments to end of life care services and epilepsy services will be published shortly.

4.3. Public Health England has been active in ensuring that people with learning disabilities have the same access to investigations and treatments as anyone else. It has produced leaflets specifically designed with and for people with learning disabilities, which explain the invitation and screening process for breast cancer, bowel cancer and cervical screening programmes, and guidance for professionals on access to screening, and also on informed consent and best interests decision-making.

4.4. PHE has also developed an Equalities in Screening Project bringing together best practice examples which include guidance on improving access. Working with people with a range of disabilities, this aims to help local screening services remove the barriers to screening and to reduce health inequalities. There is guidance currently in production about improving access to bowel cancer screening for people with disabilities including learning disabilities.

4.5. The Self-Assessment Framework provides for the first time collated reports from local health service commissioners about the coverage they are achieving in cancer screening for people with learning disabilities as compared to others in the population. Box 5 describes a local example of tackling low uptake.

Box 5: *Cancer screening in Derbyshire*

Hardwick CCG and the NHS Foundation Trust have been trying to address the low take up of cancer screening by people with learning disabilities in their area. Led by the Public Health department, they have been working with GP practices to conduct a baseline audit, identify people with learning disabilities who are eligible for the screening programmes, and develop pathways to make reasonable adjustments as required. They have developed a pack which has easy read letters and three pathways and are flagging the reasonable adjustments and the support which should be considered for an individual including preparatory work prior to screening. All strategic health facilitators are linked with GP practices. A follow up audit in March 2014, concluded that there was a statistically significant increase in the use and recording of mental capacity and best interest assessments across all 3 screening programmes in a range of GP practices, suggesting that GP practices have engaged with this work. There was no significant increase in screening coverage in people with learning disabilities, although this may in part reflect that full change will not be apparent until a full call and recall cycle is completed. It has been recommended that this work will be rolled out to the other CCGs within Derby and Derbyshire.

4.6. The Mandate to NHS England reinforces the expectation that they will work with CCGs and local authorities to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high quality care. Together with NHS England, CQC and the Royal Colleges, the Department will undertake a review of the role of Community Learning Disability Teams, looking at the balance between supporting people to access mainstream services, training and education of mainstream services, and providing specialist health and social care services.

4.7. NHS Local Area Teams will ensure that arrangements are in place to actively reduce health inequalities; plans include provision of vaccinations for adults and children that do not readily engage with the health system in high risk settings such as care homes and special schools. As part of the rollout of childhood flu immunisation for 2014/15, London Area Team is focussing specifically on special schools.

4.8. Changes have gone into the national flu immunisation plan this year to be more specific about targeting people with learning disability for immunisation as they are more vulnerable to respiratory related disease. This year's annual flu immunisation letter asks GP practices to prioritise vaccine uptake in people with learning disabilities. The plan is also clear that carers are eligible for flu immunisation.

4.9. In relation to the important area of dental commissioning, the National Dental Commissioning Group has identified a working group to look at addressing dental needs in vulnerable patients including people with learning disabilities. A task group on dentistry for vulnerable people has been established and has met several times with a wide variety of stakeholders and supplied progress reports to the National Dental Commissioning Group.

4.10. More broadly, changes to GP services being implemented in 2014/15 include introduction of a new enhanced service (as well as the improved enhanced services for learning disability annual health checks) which has been designed to help reduce avoidable

unplanned admissions by improving and delivering more proactive and tailored services for vulnerable patients and those with complex physical or mental health. The service aims to secure the following for the top 2% of patients who are at high risk of hospital admission or re-admission, overseen by a named, accountable GP:

- increased practice availability via timely telephone access;
- proactive case management of these patients;
- review and improve the hospital discharge process for these patients and coordinate delivery of care; and
- undertake internal practice reviews of emergency admissions and A&E attendances.

Adherence to legislation and guidelines

5.1. The Confidential Inquiry emphasised that the Mental Capacity Act (MCA) has the potential to improve health outcomes for people with learning disabilities when it is implemented effectively. Individuals who may lack the capacity to make certain decisions can be empowered and protected by capacity assessments, best interests decision-making, and the involvement of Independent Mental Capacity Advocates (IMCAs). However, recommendations highlighted the need for better awareness and more consistent implementation of the Act; to address these concerns, it made several recommendations linked to improved training and advice.

5.2. Since July 2013, the Government and system partners have worked to meet the recommendations. For example:

- the Department of Health has established the Mental Capacity Act Steering Group, which brings together the main health and social care partner organisations which are responsible for the implementation of the Act. NHS England is a core member. The group released a joint statement of ambition in March 2014;
- the British Medical Association (BMA) has continued to develop its online MCA training tools; and
- the Royal College of General Practitioners (RCGP) has worked to embed the MCA into the GP curriculum and raise awareness of educational resources on the MCA for GPs.

5.3. The conclusions of the Confidential Inquiry were echoed in the findings of a House of Lords Select Committee's post-legislative scrutiny report on the Mental Capacity Act, published in March 2014. The Government's response in June 2014, *Valuing every voice, respecting every right: Making the case for the Mental Capacity Act*, set out a system wide programme of action to tackle low levels of awareness among professionals and drive progress in implementation. Relevant commitments include:

- the Social Care Institute for Excellence (SCIE) has been asked to conduct a review of MCA guidance to identify 'gold standard' materials for the health and care sector by the end of 2014. These materials can then be jointly endorsed by national system partners and their existence advertised. They will be easily available online;
- Health Education England is conducting a review of its training programmes to determine their compliance with the principles of the MCA;
- NHS England has agreed to explore best practice in the use of commissioning as a tool for encouraging implementation of the MCA;

- the Department of Health will work with system partners and through the MCA Steering Group to develop a credit-card sized statement of rights under the MCA for both professionals and the public; and
- the Government will hold a national MCA event in 2015 both to raise awareness of the Act and to listen to professionals and the public about how the system as a whole can have greater impact.

5.4. Although it is challenging to achieve consistent 'culture change' in the treatment of people who may lack capacity, this programme of work will seek to ensure that professionals are aware of their duties under the MCA and are equipped to act accordingly.

5.5. It is important that Mental Capacity Act advice should be available whenever it is needed. Most hospitals and local authorities have a Mental Capacity Lead person, whose job it is to carry out training needs analyses, commission or offer training, and to help with difficult situations. There should be staff trained in the MCA available 24 hours a day, and there should be specialist advice available in all care settings.

5.6. In addition the Department is commissioning a review of guidance materials on the Mental Capacity Act. This review will ask stakeholders to submit any tools and guidance for review by an independent panel prior to being made available through an online portal.

5.7. Health Education England (HEE) is committed to improving the education and training of the NHS workforce by working with the Department of Health, providers, clinical leaders, Royal Colleges and other partners. HEE has signed the Winterbourne View Concordat, and will also ensure the findings of the Confidential Inquiry are acted upon as it progresses work on educating and training staff that are treating and caring for people with learning disabilities, autism and challenging behaviour. In particular:

- to develop e-learning resources for those working with children, young people and adults across the full spectrum of disabilities, including those with a learning disability, special educational needs or complex health needs. This will include opportunities for training in how to support individuals in line with the provisions of the MCA;
- in response to the House of Lords report, HEE is reviewing its education and training programmes to determine their compliance with the principles of the MCA. HEE will also consider the benefit of including MCA compliance as a feature of our standard contract with education providers; and
- in its efforts to improve dementia awareness in the health and social care workforce, HEE will continue to work to give greater prominence to the MCA across its education and training programmes.

5.8. HEE is also working with the Department of Health to develop new training that ensures that staff do not need to use 'face down techniques' in restraining people who use services. This new training will also equip staff with the necessary skills to ensure that the use of seclusion and segregation is eradicated in practice other than for people detained under the Mental Health Act 1983 and used only in accordance with all relevant legal safeguards and guidance provided in the Mental Health Act Code of Practice.

5.9. HEE will ensure that 50% of trainees completing foundation level training enter GP training programmes by 2016. As part of the 2013/14 Mandate commitment to ensure GP training produces practitioners with the required competencies to practice in the new NHS, HEE will be working with others to ensure that the additional year of training could offer an opportunity to enhance GPs' awareness of and expertise in mental health conditions, learning disabilities and autism and paediatric care.

5.10. The Department of Health has been a respondent in legal proceedings related to Do not attempt cardiopulmonary resuscitation (DNACPR) guidelines[9]. Judgment in the case was handed down on 17 June 2014[10] . In the context of the judgment, the Department will discuss recommendation 13 with the professional bodies responsible for CPR guidance.

5.11. As explained in the government response to the Confidential Inquiry, the Department's policy looks to Trusts to put in place their own local policies and we have commended the Joint Statement, *Decisions relating to cardiopulmonary resuscitation*, as a basis for local policies. The lawfulness of the Department's approach was challenged in the legal proceedings. The Court of Appeal found that the approach was lawful. The Court was also not persuaded that shortcomings in clinical practice in this area were associated with the absence of a national policy. Therefore, while the Department is not convinced that it should introduce national guidelines, more can usefully be done to standardise aspects of the process. In its future discussions with professional and other bodies the Department will explore what can be achieved.

9 http://www.judiciary.gov.uk/judgments/the-queen-on-the-application-of-david-tracey-personally-and-on-behalf-of-the-estate-of-janet-tracey-deceased-v-cambridge-university-hospitals-nhs-foundation-trust-and-others/

10 http://www.judiciary.gov.uk/court/court-of-appeal/

The imperative to forward plan

6.1. The Confidential Inquiry found that much more attention needed to be given to predicting potential problems, recognising changing needs and adjusting the provision of care as needs changed, with services being more proactive in forward planning.

6.2. NHS England is committed to introducing consultative and participative care planning as part of the care of people with long-term conditions, including those with learning disabilities. It is working with partners to support the delivery of the Mandate commitment for everyone with a long-term condition to be offered a care plan including:

- introducing the new Unplanned Admissions Enhanced Service;
- supporting the Coalition for Collaborative Care – a group of individuals and organisations across the health, social care and voluntary sectors who, through care and support planning, want to make person-centred, coordinated care a reality for people living with long-term conditions; and
- working with partners to co-produce practical guidance on care planning for commissioners and practitioners by March 2015.

6.3. NHS England is a key partner with Year of Care Partnerships, National Voices, Nesta and the Royal College of General Practitioners to help guide the cultural and organisational shift needed to introduce collaborative care planning into routine care planning, using the 'House of Care' model. Box 6 describes a local example of efforts to overcome some of the difficulties that would otherwise be faced in planning ahead and taking up healthcare opportunities.

Box 6: *'Big Health' day, Peterborough City Council*

Feedback from a survey of GP practice nurses identified that nurses found it difficult to explain some aspects of health interventions to people with learning disabilities. A 'Big Health' day was held to act as a desensitisation exercise for people reluctant or frightened to attend their GP surgery for a health check. The day included a number of sporting and other activities, the provision of lifestyle advice, and blood pressure measurements on people with learning disabilities. They found that these events empowered and informed families and professionals and helped people to understand what could be done on a regular basis. Another successful Happy Days event took place on Friday 20th June 2014, where health, sports and personalisation were integrated. The event enabled individuals to take part and compete in taster sports activities, talk to health and social care professionals, and purchase items from micro enterprises that employ adults with disabilities. The event was opened by a service user and fully supported by individuals with disabilities. The Happy Days facilitators will also be collaborating with the 'Feel The Force' event in October, the only film and tv convention in the world specifically for people with disabilities.

6.4. NHS England also continues partnership with the Action for Long Term Conditions group, working to enable the culture change needed and incentivise care planning for all patients. It is establishing a hub to support a national offer of support for care planning. There is a particular requirement for care planning for people with learning disability to take into account likely future events (e.g. deterioration in health, hospitalisation) rather than catering for the 'here and now' only; such forward looking is likely to be central to the Principles for Care and Support Planning which National Voices are working on.

End-of-life care

7.1. The Confidential Inquiry found that people with learning disabilities were less likely to have access to specialist palliative care services and pain relief, and identified concerns about how decisions to move people with learning disabilities out of active care programmes were being made. It also referenced a number of initiatives and examples of good practice underway including the NHS National End of Life Care Programme and its publication of *The Route to success in end of life care – achieving quality for people with learning disabilities and Preferred Priority for Care*.

7.2. The Government's response was clear that people with learning disabilities are entitled to good end of life care and decisions about moving people out of active care programmes need to be informed by the Mental Capacity Act. We will make sure this happens through the response to recommendations about improving MCA training and prioritising health and care planning as set out in earlier sections of this report.

7.3. One example of good practice is 'Deciding right' – a nationally adopted tool for enabling clinicians to make decisions with patients and carers about end of life care. It is adapted for use with people with a learning disability and takes into account capacity and best interest decisions.

7.4. In addition guidelines on reasonable adjustments to end of life services for people with learning disabilities have been published by PHE. This includes examples of good practice.

7.5. In June 2014 the Leadership Alliance for the Care of Dying People published *"One Chance to Get it Right"* setting out the approach to caring for dying people that health and care organisations and staff caring for dying people in England should adopt in future, irrespective of the place in which someone is dying based on 5 priorities.[11] As part of implementing the priorities, CQC has started thematic activity focusing on end of life care

[11] These are that, when it is thought that a person may die within the next few days or hours:

- this possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly;
- sensitive communication takes place between staff and the dying person, and those identified as important to them;
- the dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants;
- the needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible; and
- an individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations

across settings and will publish a national report presenting its findings by March 2015. The thematic work will look at the experience of priority groups including people with learning disabilities.

Reviewing deaths of people with learning disabilities in the future

8.1. In light of the issues raised in the course of the time-limited Confidential Inquiry research, a number of recommendations were made for the purpose of ongoing surveillance and review of the deaths of people with learning disabilities, including establishing a national learning disability mortality review function.

8.2. PHE's Learning Disabilities Observatory is working with colleagues in the Department of Health and the Health and Social Care Information Centre to achieve comprehensive monitoring of mortality in people with learning disabilities. Additional linkage to hospital admission, out-patient and accident and emergency data will permit publication of detailed information about patterns of service use, treatment, and outcomes for people with learning disabilities. This is of particular relevance in developing and monitoring preventive strategies for premature death. By identifying how many 'near miss' health events such as epileptic seizures or diabetic crises requiring hospital based treatment or acute admissions for abdominal crises caused by severe constipation relate to people with learning disabilities, it will be possible for local services to set and monitor local goals and strategies. It will also provide high quality detail about local coverage of cancer screening programmes for people with learning disabilities.

8.3. Work is under way with NHS England, the Health and Social Care Information Centre and Public Health England to provide standardised mortality data for people with learning disabilities to underpin the NHS Outcomes Framework and the mortality review function. In taking that work forward, we must also take account of wider cross-system discussions about the collection and sharing of patient data in compliance with data protection and confidentiality principles, which will inevitably have implications for this work. We are working closely with partners and will act to secure the prioritisation of this work through all appropriate mechanisms.

8.4. NHS England's Business Plan: *Putting Patients First* commits to establishing a learning disability mortality review function by March 2015. However, following recent advice from an expert group established to advise NHS England on the process of establishing a proposed review function, it has become clear that more detailed scoping work is required to define the detail of how a mortality review function would work, before a review can be procured. NHS England will commission the Health & Quality Improvement Partnership (HQIP) to undertake the specification development exercise. Undertaking this work will enable a wide range of partners, including self-advocacy groups to feed in their views about how the review should function and it is likely to result in a better outcome from the review, but does mean that the March 2015 date is no longer achievable. It is expected to have a preferred provider in place for a review function by end of Summer 2015. NHS England remain fully committed to establishing a learning disability mortality review as quickly as possible and believe that taking

extra time at an early stage to fully define the desired output from a review will pay dividends over the long-term.

8.5. NHS England has established a project group to oversee the development and procurement of the mortality review and consider risks to delivery. The group includes representation from Mencap, PHE and the Department of Health. The group met for the first time on 5 June and approved the proposed approach which is to outsource work to develop a detailed specification for the review to Healthcare Quality Improvement Partnership (HQIP). The specification, once developed, will form the basis for procurement of a mortality review. Work is also underway to set out the possible relationship between a national mortality review function and the proposals for a case note review of all deaths in hospitals.

8.6. A question on capacity to analyse local mortality data was included in the Self-Assessment Framework. Responses showed that 51% of partnership boards were able to provide data which permitted calculation of a local standardised mortality ratio for people with learning disabilities.

8.7. NHS England is also reviewing the role of Quality Surveillance Groups which bring together system partners and could potentially play a role in monitoring local trends in mortality.

Summary

9.1. This update, produced one year on from publication of the Government's response to the Confidential Inquiry, reports on progress in taking action to address the themes identified and recommendations made.

9.2. Encouraging progress has been made in several respects and examples of good practice have been identified. However we now need to step up the pace and make a concerted national effort to see more equitable access and outcomes for people with learning disabilities.

9.3. Collaboration nationally and locally on this challenging issue will give us the best chance of delivering equitable health outcomes across our nation. Effective partnerships will be needed so action is comprehensive and suitably scaled, relevant to local communities and takes account of differences across groups and areas experiencing health inequalities.

9.4. We will continue to review progress with the Learning Disability Programme Board with regular status reports which, as with all papers to the Board, will be made available online.

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