‘Human Rights Issues’ for People with Learning Disabilities (PwLDs)

Equity in access to services

The Equality Act of 2010 stipulates that organisations have a legal duty to ensure that all, including those with learning disabilities, have equity in access to services (1, 2). This means that organisations are required to make ‘reasonable adjustments’ to ensure that health inequalities do not result and that people with learning disabilities can achieve the same outcomes as those who have no disability. This means that services delivered by organisations must:

- Have all components to ensure accessibility and effectiveness.
- Meet needs by ensuring that systems are in place to assess individuals and that these assessments are adapted to the needs of these individuals.
- Train their staff to have the knowledge and skills in order to deliver services with these adjustments.

Despite this duty, there is still both systemic and overt discrimination towards people with learning disabilities. They are not afforded the same opportunity to live in good health as the general population and it is increasingly recognised by the World Health Organisation that “disability itself is a human rights issue” (2). This is due to inequalities experienced across the wider determinants of health, subjection to violations of dignity and denial of autonomy for people with learning disabilities (2).

The Learning Disabilities Mortality Review Programme (LEDER) produces annual reports on the deaths that the programme reviews and subsequent ‘Action From Learning’ reports are then compiled by NHS England/Improvement in consultation with partners and stakeholders (3). There were several actions triggered around ‘reasonable adjustments’ as a result of learning from the Covid-19 pandemic, these are as follows:

- The ‘Learning Disability Improvement Standards for NHS Trusts’, which includes guidance with associated quality of care standards was produced by NHS Improvement in 2019 for all NHS hospital trusts (4).
- The ‘Reasonable adjustments flag’ has been built into NHS Spine and there is associated training available around this.
- A ‘Grab and Go’ Guide for when a person with a learning disability is admitted to hospital (or the ‘hospital passport’) (5).
- Demand and capacity guidance for providers and clinical/non-clinical teams (6).
- A visitor letter sent to all specialist inpatient providers to emphasise the importance of reasonable adjustments in relation to family visiting.
- Annual health checks, influenza and Covid-19 vaccine campaigns, including easy-read resources, in order to encourage uptake.
- Reminders sent to system leaders of the need to continue to make reasonable adjustments, highlighting the role of staff with particular experience (e.g. LD nurses), in ensuring understanding and implementation of reasonable adjustments by front-line clinicians.

Mental Capacity Act, 2005

In national reviews in the context of learning disabilities (Confidential Inquiry into Premature Deaths of People with Learning Disabilities, LEDER reviews) (7), they have found a lack of understanding and poor adherence to the Mental Capacity Act (8), which applies to all those aged sixteen and above.

There have been particular areas of concern around:

- Capacity assessments with respect to their absence or that they have been inappropriately carried out.
- Processes of making 'best interests' decisions.
- Processes of decision making, especially what 'serious medical treatment involves'.
- Documentation of assessments and decisions.
- A lack of understanding of roles, responsibilities and competence in discharging the duties placed on professionals under the Act; particularly in relation to the appointment of Independent Mental Capacity Advocates (IMCAs).

People with learning disabilities are encountering delays in diagnosis and treatment of serious medical conditions as a result and key areas for improvement have been identified in LEDER reviews. These areas are around: training around basic principles of the Act; the use of reasonable adjustments in ensuring communication needs are met with maximising an individual's ability to communicate their wishes; use of 'least restrictive' methods when a person does not have capacity (there are calls for the CQC to review the use of restraint, prolonged seclusion and segregation) and correct involvement of family and carers following the principles of 'best interests' decision making.

The actions from learning and subsequent recommendations developed by NHS England and Improvement as a result of the Covid-19 pandemic are as follows (3):

- Development of training courses around the Mental Capacity Act, 'best interests' decisions and IMCAs by LEDER steering groups in some areas of concern.
- NHS England and Improvement are co-producing with experts by experiences some new resources on the Mental Capacity Act for people with learning disabilities.
- They recommend that the low awareness of the Mental Capacity Act widely should be addressed as a matter of urgency by the Department of Health and Social Care.
- They recommend that the standards against which the CQC inspects should explicitly incorporate compliance with the Mental Capacity Act as a core requirement that must be met by all health and social care providers.
- They recommend that the government should work the Royal Colleges and professional regulators to ensure that the Mental Capacity Act is given a higher profile.
- They recommend that local services should strengthen governance around the Mental Capacity Act and provide training and audit of compliance on the ground.

Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) Orders

There has been a particular issue around Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) Orders within the context of the Covid-19 pandemic, however, this issue is not new and had been highlighted in the early Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) report (7) and consistently in LEDER reviews since.

DNACPR orders link directly with the Mental Capacity Act (8). It is a requirement that if a person does not have capacity and 'Part C' is being used as justification on DNACPR orders, that DNACPR must be discussed with family/carers where possible in order to arrive at a decision that is in the best interests of the person concerned. It should be good practice that these individuals are consulted when using 'Part D' too. It is also important to establish whether 'advanced directives' have been made and these should always be adhered to if so.

There have been several issues identified around DNACPR discussions and decisions in reviews by LEDER, these are as follows:

- Premature decisions made not to attempt cardio-pulmonary resuscitation.
- The failure to involve and inform family and carers of decisions made.
- Incomplete documentation, such as unclear recording of the reason behind a DNACPR order being put in place.
- Particularly in the context of the Covid-19 pandemic, recording of 'learning disability' as a justification for a DNACPR and 'blanket use' of DNACPR orders in this context.

There is discrimination running through these issues, with assumptions and judgements being made about a person's quality of life based on their own assumptions.

The most recent updated guidance around these issues was produced in 2016 jointly by the BMA, Resuscitation Council and the Royal College of Nursing (9). As a result of the exacerbation of these issues by the pandemic, there has been much additional guidance produced, an example of which is the joint advice and support co-produced by Learning Disability England and Turning Point. They have produced a 'DNACPR' support pack including a useful checklist for clinicians (10). There will also be training available that is being developed in response to the consultations on proposals for introducing mandatory learning disability and autism training for health and care staff (11). This training is named after Oliver McGowan, whose death shone a light on the importance of addressing these issues (12).

The actions from learning and subsequent recommendations developed by NHS England and Improvement as a result of the Covid-19 pandemic include several joint statements by system leaders and a joint letter from senior leaders of NHS England and Improvement around advanced care planning and the issue of DNACPRs, sent across the system. The British Medical Association, General Medical Council, Care Provider Alliance, CQC, Royal Colleges and the Nursing and Midwifery council have been responsible for these statements (3). In October 2020, the palliative and end of life care team published a document on 'CPR and DNACPR' on NHS England and Improvement's website. In addition, general practitioners have been asked via the Quality Outcomes Framework to review all DNACPRs in order to

judge their appropriateness. The CQC were also asked to review these issues too, an interim report was published in November 2020 and final report in April 2021 (13).

Discussions around DNACPR orders should not be in isolation, they should also link in with broader discussions about future care and treatment. This should be around preferred place of care, whether a hospital admission is in the person's interests or not and then escalation plans once admitted to hospital. These discussions and subsequent decisions can then be reflected in RESPECT forms, so that these decisions are clear for all who meet the person concerned. There have been separate issues too, again exacerbated due to the pandemic with the inappropriate use of 'frailty' indices in order to justify lack of escalation for people with learning disabilities.

Death certification and coroner's referrals

The sequence of events and underlying contributing factors leading to a person's death are recorded by medical professionals on a legal document known as the Medical Certificate of Cause of Death (MCCD). There are also circumstances where a death should be discussed and referred to a coroner before a death can be registered, this is reflected too on the MCCD. A coroner will then determine whether the death needs to be investigated further and may request a post mortem or inquest in order to ascertain the cause of death.

There have been concerns around completion of the MCCD and referral to coroners in reviews of deaths by LEDER before the pandemic which have been again exacerbated further as a result of Covid-19. It has been suggested in reviews that 'diagnostic overshadowing' extends into the coronial system and suspected that there are fewer referrals made to the coroner for people with learning disabilities than there should be. In terms of the MCCD, inconsistencies have been found in records of whether a person had learning disabilities; learning disabilities have been incorrectly omitted or recorded as a cause of death in reviews. It has been found that Down's Syndrome and learning disability (or equivalents) are still documented frequently and incorrectly in 'Part 1a' of the MCCD; this is a particular problem for Down's Syndrome as it is in fact one of the most frequent cited 'causes of death' found in reviews (14).

There are several reasons proposed for why these issues have materialised. These are mainly around: lack of training or knowledge (particularly of the deceased by the certifying doctor); inconsistencies in interpreting contributing causes of death; the multiple coding options available for learning disabilities and problems with the availability of medical records (14).

The actions from learning triggered before and as a result of the Covid-19 pandemic developed by NHS England and Improvement, are as follows (3):

- From 2018 and onwards, the 'Medical Examiner system' has been introduced which requires that all MCCDs of those in hospitals have to be confirmed by local Medical Examiners once they are operational in a particular area. It is hoped that this will strengthen safeguards and too ensure that appropriate referrals are made to the coroner.
- The learning disability and autism programme within NHS England and Improvement are also working closely with the National Medical Examiner to inform the work of medical examiners in this context. It is expected that medical examiners will work with doctors in the use of the correct terminology for the MCCD and also support bereaved families.
- The NHS England and Improvement medical director wrote to NHS providers and CCG chief executives to emphasise issues with DNACPR orders and the MCCD during the pandemic.

Useful links for more information

Equity in Access to Services

- Learning Disabilities Mortality Review Programme (LEDER). The Equality Act 2010: Avoiding discrimination and making 'reasonable adjustments' for people with learning disabilities. Available from: https://www.bristol.ac.uk/media-library/sites/sps/leder/2079_EQAct2010_PDF.pdf
- Public Health England. Easy steps to improve support for people with learning disabilities in hospital. Available from: https://webarchive.nationalarchives.gov.uk/20160704150213/http://www.improvinghealthandlives.org.uk/publications/1247/Working_together_2:_Easy_steps_to_improve_support_for_people_with_learning_disabilities_in_hospital
- Learning Disabilities Mortality Review Programme (LEDER). Hospital staff checklist around reasonable adjustments for disabled people in hospital. Available from: https://www.bristol.ac.uk/media-library/sites/sps/leder/2079_EQAct2010_PDF.pdf
- Care Quality Commission. Promoting sexual safety through empowerment. Available from: https://www.cqc.org.uk/publications/major-report/promoting-sexual-safety-through-empowerment
- Easyhealth.org.uk. Easy read health leaflets and films. Available from: https://www.easyhealth.org.uk/pages/4-easy-read-health-leaflets-and-films
- Leeds and York Partnership. Learning disability service, get checked out resources. Available from: https://www.learningdisabilityservice-leeds.nhs.uk/get-checked-out/

Mental Capacity Act

- Learning Disabilities Mortality Review Programme (LEDER). Mental Capacity Act, learning into action bulletin. Available from: https://www.bristol.ac.uk/media-library/sites/sps/leder/MCAMarchNewsletter.pdf
- British Institute of Learning Disabilities. Brief guide to the Mental Capacity Act: implications for people with learning disabilities. Available from: https://www.scie.org.uk/files/mca/directory/bild-mca.pdf?res=true
- Mencap. What is the mental capacity act? Available from: https://www.mencap.org.uk/advice-and-support/mental-capacity-act#:~:text=The%20'Mental%20Capacity%20Act'%20is,need%20to%20make%20those%20decisions

DNACPR

- Learning Disability England/Turning Point. DNACPR Support Pack. Available from: https://www.turning-point.co.uk/DNACPR
- Resuscitation Council UK. Decisions relating to cardiopulmonary resuscitation. Available from: https://www.resus.org.uk/sites/default/files/2020-05/20160123%20Decisions%20Relating%20to%20CPR%20-%202016.pdf
- Learning Disabilities Mortality Review Programme (LEDER). Decisions relating to cardiopulmonary resuscitation and treatment escalation plans. Available from: https://www.bristol.ac.uk/media-library/sites/sps/leder/2099_DNACPR_PDF.pdf

Death certification and coroners

- Learning Disabilities Mortality Review Programme (LEDER). Medical certificates of cause of death (MCCD). Available from: http://www.bristol.ac.uk/media-library/sites/sps/leder/2104_CauseOfDeath_PDF.pdf
- Inclusion North. Stop people dying too young (the LEDER programme). Available from: https://inclusionnorth.org/our_work/stop-people-dying-too-young-the-leder-

programme/#:~:text=This%20is%20known%20as%20the,Disability%20Dying%20Too%20Young%20Group.
- Dimensions. Dying to Matter: a guide for families following the death of someone with a learning disability. Available from: https://dimensions-uk.org

References:

(1) Legislation.gov.uk. Equality Act 2010. [Internet]. 2010. [cited 2021 May 3]. Available from: https://www.legislation.gov.uk/ukpga/2010/15/contents
(2) Emerson et al. Health status and health risks of the 'hidden majority' of adults with intellectual disability. [Internet]. 2011. [cited 2021 May 3]. Available from: https://pubmed.ncbi.nlm.nih.gov/21639742/
(3) NHS England and Improvement. LEDER: action from learning: deaths of people with a learning disability from COVID-19. [Internet]. 2020. [cited 2021 May 3]. Available from: https://www.england.nhs.uk/wp-content/uploads/2020/11/C0843-Covid-LeDeR-report-131120.pdf
(4) NHS Improvement. The learning disability improvement standards for NHS trusts. [Internet]. 2018. [cited 2021 May 3]. Available from: https://www.england.nhs.uk/wp-content/uploads/2020/08/v1.17_Improvement_Standards_added_note.pdf
5) NHS England. Covid-19 Grab and Go guide. [Internet]. 2020. [cited 2021 May 3]. Available from: https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0381-nhs-covid-19-grab-and-go-lda-form.pdf
6) NHS England and Improvement. Managing capacity and demand within inpatient and community mental health, learning disabilities and autism services for all ages. [Internet]. 2020. [cited 2021 May 3]. Available from: https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/Managing-demand-and-capacity-across-MH-LDA-services_25-March-final.pdf
7) Heslop et al. Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). [Internet]. 2013. [cited 2021 May 3]. Available from: http://www.bristol.ac.uk/cipold/reports/
8) Legislation.gov.uk. Mental Capacity Act 2005. [Internet]. 2005. [cited 2021 May 3]. Available from: https://www.legislation.gov.uk/ukpga/2005/9/contents
9) Resuscitation Council UK. Decisions relating to cardiopulmonary resuscitation. [Internet]. 2016. [cited 2021 May 3]. Available from: https://www.resus.org.uk/sites/default/files/2020-05/20160123%20Decisions%20Relating%20to%20CPR%20-%202016.pdf
10) Turning Point. DNACPR Support Pack. [Internet]. 2020. [cited 2021 May 3]. Available from: https://www.turning-point.co.uk/DNACPR#:~:text=Turning%20Point%20and%20Learning%20Disability,a%20carer%20or%20family%20member.
11) Health Education England. The Oliver McGowan mandatory training in learning disability and autism. [Internet]. 2020. [cited 2021 May 3] Available from: https://www.hee.nhs.uk/our-work/learning-disability/oliver-mcgowan-mandatory-training-learning-disability-autism
12) Olivermcgowan.org. Oliver's campaign. [Internet]. 2020. [cited 2021 May 3]. Available from: https://www.olivermcgowan.org/
13) Care Quality Commission. Protect, respect, connect – decisions about living and dying well during COVID-19. [Internet]. 2021. [cited 2021 May 3]. Available from: https://www.cqc.org.uk/publications/themed-work/protect-respect-connect-decisions-about-living-dying-well-during-covid-19
14) LEDER. LEDER Annual Report. [Internet]. 2019. [cited 2021 March 3]. Available from: http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf