

Nursing and Midwifery Council response to the Department of Health & Social Care's consultation on proposals to introduce mandatory learning disability and autism training for health and care staff

Background

- 1 We are the independent regulator for nurses, midwives and nursing associates. We hold a register of the 690,000 nurses, midwives and nursing associates who can practise in the UK.
- 2 Better and safer care for people is at the heart of what we do, supporting the professionals on our register to deliver the highest standards of care.
- 3 We make sure nurses, midwives and nursing associates have the skills they need to care for people safely, with integrity, expertise, respect and compassion, from the moment they step into their first job.
- 4 Learning does not stop the day nurses, midwives and nursing associates qualify. To promote safety and public trust, we require professionals to demonstrate throughout their career that they are committed to learning and developing to keep their skills up to date and improve as practitioners.
- 5 We want to encourage openness and learning among health and care professions to improve care and keep the public safe. On the occasions when something goes wrong and people are at risk, we can step in to investigate and take action, giving people affected, patients and families a voice as we do so.
- 6 As the largest professional regulator in the UK we are absolutely committed to supporting improvements in practice in equality, diversity and inclusion across the health and care sector.

A catalyst for change

- 7 We welcome the opportunity to respond to this consultation on proposals to introduce mandatory learning disability and autism training for health and care professionals. We wholeheartedly support proposals which will improve the safety and the experience of health and care of people with learning disabilities and autism. We recognise that training is only one element of the response needed to make improvements but it is an important one.
- 8 Regulation in health and social care is about people's lives – people like Oliver McGowan. It is our responsibility to listen to his mother, Paula McGowan, when she says a lack of understanding of learning disabilities and autism cost Oliver his life. Everyone has a right to safe and effective care, and we must use our influence to call for change where people's needs aren't being met and lives are at risk.

- 9 We have heard the heart-breaking stories of people using services, families and advocates which demonstrate there is a fatal gap in knowledge when it comes to the needs of people with learning disabilities and autism. We are saddened and shocked by stories of tragic and often wholly preventable deaths, as the recent inquest into Giuseppe (Joe) Ulleri's death has highlighted.
- 10 Joe's family said that his experiences must be 'a catalyst for change' – and we agree that the experiences of people with learning disabilities and autism accessing health and care services must improve. The data,¹ which tells us that women with learning disabilities on average die 18 years earlier, and men 14 years earlier, than people without learning disabilities, demonstrates the urgency with which everyone involved must act.

Training which addresses and reduces the real risks

- 11 We agree with the statement in the NHS Long Term Plan that healthcare professionals have a crucial role to play in helping people with a learning disability, autism or both to lead longer, happier and healthier lives.
- 12 In order for that to happen, professionals should be trained on how to respond to people's needs and preferences. The impact of listening effectively and making appropriate adjustments can be life-saving, and we are encouraged to see proposals that the training will cover communication skills, empowering people using services to make decisions, and how to create an inclusive and supportive environment.
- 13 It is key that the training includes information on equality legislation, including the duty to provide reasonable adjustments. We feel it is important that the legal framework is outlined for avoidance of doubt about the responsibilities both employers and the people on our register have, including removing barriers for people accessing services.
- 14 We recommend the training addresses and seeks to reduce the real risks associated with diagnostic overshadowing, which occurs when professionals without adequate knowledge about learning disabilities and/or autism see the disability before the person, assuming someone's behaviour or symptoms are a part of their disability rather than an underlying health condition.
- 15 We believe the training should reflect the diversity of people using health and care services by recognising intersectional identities. Someone's disability is only one part of who they are, and someone's gender, age, ethnicity, faith and other protected characteristics should be reflected in the person-centred care they receive.
- 16 In particular, we agree that relevant health and care professionals should receive training which highlights the importance of avoiding assumptions based on first impressions, and recognises that the right attitudes and behaviours are key to influencing a positive culture of care.

¹ <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2017-to-2018>

Delivering impactful training which gives people a voice

- 17 While we agree that decisions about a person's training needs should be based on an assessment of their role, we also echo the Department's comments that, equipped with the right skills and training, all health and care professionals can make a difference to the health and wellbeing outcomes of people with learning disabilities and autism.
- 18 We recommend steps are taken to ensure co-production and co-delivery with people who have learning disabilities and/or autism is at the heart of the training. Recently we invited people with learning disabilities to tell us about their healthcare experiences. We heard how people miss opportunities to understand and hear them because 'everyone is always rushing around'. As we experienced during the event, meaningful learning starts with people and their stories, and this should be reflected in the training proposals.
- 19 The training needs to be suitable for the variety of settings within which people on our register work – including care homes, schools and prisons in addition to hospitals and GP surgeries. We note that the proposals relate to England only, and as a four country regulator we would welcome a consistent approach across all four countries.
- 20 We would like to see information about whether health and care professionals will be afforded protected time in order to fully engage with the training. We would also like to see plans for ongoing learning, with regular training opportunities rather than an isolated session.
- 21 It's crucial that effective evaluation of the training takes place. The impact of the training must be monitored, and its effectiveness must be measured not by completion rates, but instead by the lived experiences of people with learning disabilities and/or autism.

Our standards

- 22 We are currently midway through a programme of work to reform nursing and midwifery education, including a wholesale review of our education standards. We have produced new Standards of proficiency for registered nurses² and Standards of proficiency for Nursing Associates,³ and we are consulting on the Standards of proficiency for midwives. These are standards that people have to meet to access our register. Our aspirations in terms of the skills and knowledge that we believe nurses need in order to care for people with learning disabilities and autism are very much aligned with your own. We are pleased that many of the elements of the training you propose in your consultation have already been incorporated into our new nursing standards. This will mean that in future, nurses at the point of registration will be better equipped to deliver care for people with learning disabilities and autism than they did before.

² <https://www.nmc.org.uk/globalassets/sitedocuments/education-standards/future-nurse-proficiencies.pdf>

³ <https://www.nmc.org.uk/globalassets/sitedocuments/education-standards/nursing-associates-proficiency-standards.pdf>

- 23 The new nursing standards apply across all four fields of nursing practice (adult, children, learning disabilities, mental health) and all care settings. This is to enable registered nurses to meet the person-centred, holistic care needs of the people they encounter in their practice who may be at any stage of life and who may have a range of mental, physical, cognitive or behavioural health challenges.
- 24 Our new Standards of proficiency promote a professional culture that values equality, diversity and inclusion. At the core of our standards is the principle that good care is person-centred and sensitive. Mirroring commitments set out in your training proposals, our standards also emphasise the need for partnership working and effective communication.
- 25 The standards require educators to involve people from diverse groups in the design and evaluation of education programmes and commit to compliance with equalities and human rights legislation. In our consultation on education standards last May, 81 percent of respondents agreed that the framework would support equality and diversity within nursing and midwifery education.
- 26 Standard 1 focuses on being an accountable professional, and requires nurses to 'demonstrate the skills and abilities required to support people at all stages of life who are emotionally or physically vulnerable' (Standard 1.12).
- 27 Standard 1.14 states nurses must 'provide and promote non-discriminatory, person-centred and sensitive care at all times, reflecting on people's values and beliefs, diverse backgrounds, cultural characteristics, language requirements, needs and preferences, taking account of any need for adjustments'.
- 28 Standard 2, on promoting health and preventing ill health, requires nurses to work in partnership with people to develop person-centred care plans that take into account their circumstances, characteristics and preferences. For example, they must 'provide information in accessible ways to help people understand and make decisions about their health, life choices, illness and care' (Standard 2.10).
- 29 Our standards also ask nurses to, 'understand and recognise the need to respond to the challenges of providing safe, effective and person-centred nursing care for people who have co-morbidities and complex care needs' (Standard 7.5) and, 'demonstrate an understanding of the complexities of providing mental, cognitive, behavioural and physical care services across a wide range of integrated care settings' (Standard 7.6).
- 30 Skills Annexe A specifies the communication and relationship management skills that registered nurses must demonstrate. Registered nurses must be able to communicate and manage relationships with people of all ages, with a range of mental, physical, cognitive and behavioural health. We emphasise that these skills are needed to ensure individuals, their families and carers are actively involved in and understand care decisions.
- 31 Where people have special communication needs, a disability, or other long-term health conditions, we are clear that reasonable adjustments should be made in order

to communicate, provide and share information in a manner that promotes optimum understanding and engagement and facilitates equal access to high quality care.

- 32 Nurses, midwives and nursing associates are also subject to the standards set out in the Code. Consistent with the principles set out in your training proposals, the Code states that nurses, midwives and nursing associates must listen and respond to people's preferences and concerns, working in partnership with people (2.1), recognise and respect the contribution that people can make to their own health and wellbeing (2.2), and help people to access relevant health and social care, information and support when they need it (3.3).
- 33 In order to remain on our professional register people are required to revalidate every three years and undertake 35 hours of continuing professional development (CPD). Training in learning disabilities and autism would provide valuable professional development for nurses, midwives and nursing associates.

Conclusion

- 34 Thank you for the opportunity to respond to this consultation and share how our regulatory functions, including the standards we set, are designed to facilitate an inclusive and safe health and care context in which everyone can receive compassionate and effective care from nurses, midwives and nursing associates.
- 35 We hope this response makes it clear that we fully support proposals designed to reduce unnecessary suffering and avoidable deaths, and that we feel action must be taken to improve the understanding of the needs of people with learning disabilities and autism in order to give people, like Oliver and Joe and so many others, the voice, dignity and care they deserve. We believe that a stronger focus on these aspects in the pre-registration education and training of all regulated professionals will deliver a change in culture and approach, which must be reinforced by healthcare organisations implementing appropriate systems, processes and ongoing training.