



Down's Syndrome Association

A Registered Charity No. 1061474

Department for Health and Social Care consultation

Learning disability and autism training for health and care staff

Response from The Down's Syndrome Association

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National Office

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The Down 's Syndrome Association (DSA)

The DSA is a national charity focusing on all aspects of living successfully with Down's syndrome. Established in 1970, we will shortly be celebrating our 50th Anniversary. We have around 20,000 members throughout England, Wales and Northern Ireland. The Association is in contact with over 130 local Down's syndrome support groups and a range of professionals from different agencies. The aim of the organisation is to help people with Down's syndrome lead full and rewarding lives.

The DSA is the lead provider of information, advocacy, support and training to anyone with an interest in Down's syndrome. We are a membership-led organisation, with our membership comprising primarily the family-carers (parents) of children and adults with Down's syndrome and a growing membership of adults with Down's syndrome aged 18+. We are well placed to reflect the needs, attitudes and opinions of people we seek to serve.

About Down's syndrome

Down's syndrome is a genetic condition, caused by the presence of an extra chromosome 21 in the body's cells. Everyone with the condition will have some degree of learning disability. In addition, there are a number of associated medical conditions which affect some, but not all, people with Down's syndrome, meaning the services that they access from the NHS (and social care settings) are of paramount importance to their wellbeing.

The number of people in England and Wales with the condition was estimated at 37,090¹ in 2013.

With appropriate healthcare, many people with Down's syndrome are now living to the age of 60 and beyond.

¹ Wu J, Morris JK The population prevalence of Down's syndrome in England and Wales in 2011 Eur J Hum Genet 2013 Sep; 21(9):1016-9. doi: 10.1038/ejhg.2012.294. Epub 2013

Background to our response

It is of grave concern to us to note the widely recognised health inequalities experienced by individuals with a learning disability. This means that people with Down's syndrome still die at a significantly younger age than the general population and, as the Learning Disabilities Mortality Review (LeDeR) annual reports have already shown, many of these premature deaths could have been avoided. <http://www.bristol.ac.uk/sps/leder>

We would also draw attention to the worrying findings from The Confidential Inquiry into premature deaths of people with learning disabilities <http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf> which demonstrates the significant health inequalities experienced by individuals with a learning disability, a significant proportion of these individuals had Down's syndrome.

The deaths reviewed by LeDeR show that, compared with the general population, the median age of death for someone with a learning disability is 23 years younger for men and 29 years younger for women and often for entirely avoidable reasons. Reviews that have so far been published have shown that mistakes in health and social care provisions have been made. We must learn from these occurrences quickly and translate that learning into effective remedial action, which prevents any repetition.

We are pleased to have the opportunity of commenting on the proposals surrounding the commissioning and delivery of mandatory learning disability training for health and social care professionals. We are generally supportive of this proposal, subject to the recommendations made in this response.

It is imperative that we go on record to state that the proposal to introduce mandatory learning disability training for health and social care staff is a welcome development, but is only one, small, part of the action required to address the unacceptable health inequalities experienced by people with a learning disability.

Other actions also required include:

1. Increasing the powers of the LeDeR programme, so that their recommendations can be enforced by law
2. Strengthening pre-qualification learning disability training for relevant health and social care professionals
3. Where failings in the quality of care are found, especially in the case of avoidable deaths, criminal proceedings should result in the prosecution of the individuals and agencies involved. This must include charges of manslaughter on an individual or corporate basis, where the failings are serious enough to meet the criteria to bring this level of prosecution.

Consultation with the wider community of individuals with Down's syndrome and their family carers

Sadly, recent media coverage of a number of Inquests of individuals with Down's syndrome has highlighted poor standards of care or an avoidable, premature, death. In response to this (and in order to help inform our response to this consultation) we recently invited our wider membership to notify us of any concerns they had relating to the healthcare they had experienced. Within a matter of weeks, we had received more than 30 reports of examples of poor healthcare experienced by people with Down's syndrome (with more reports being received as at the beginning of April). These case studies are currently being written up, but an initial analysis of the reports we received has demonstrated some common themes. These are summarised below (text in italics are direct quotes from family-carers).

1. Ambiguous role of family-carers and lack of awareness of the crucial role that relatives have in supporting their loved-one with Down's syndrome. Many relatives feel dismissed and ignored

"Found hospital staff very abrupt/unsympathetic at times".

"GPs at the surgery are also not always approachable - we feel rather "bawled off" at times".

2. Pivotal role of family in coordinating healthcare - concern expressed by family about what will happen to their relative's health when they are no longer around

"I have no doubt that once I am no longer around to provide and co-ordinate all my son's health needs, he will not be able to access the care he needs and will undoubtedly have his life shortened as a result".

3. Diagnostic overshadowing and assumptions about people with Down's syndrome coping with aftercare following surgery, for example

"The doctor left the room to get a form signed. When she came back she said, "It's no good, we don't do it for people like him".

4. Lack of empathy/compassion from healthcare staff for family member with Down's syndrome

"The ward staff hardly saw him at all, even though he had a special wrist band with butterflies that said he needed extra help. He was in a single room and after the op they never came near him. I had stayed with him but they didn't check if we were OK at all. I had to ask for some food for him. Several hours after surgery they brought him a bowl of rice kipsies - even though he was on flat bed-rest post op, so he wasn't able to eat them and they weren't able to offer him anything else-not even a piece of toast".

"Our son was diagnosed with iron overload. He required a number of tests which were done at the hospital. One of the consultants asked if, in view of his other problems, i.e. DS, did we want him to be treated!".

5. Lack of understanding of Down's syndrome, especially an individual's communication needs and support they might require around informed decision making - some evidence to suggest lack of understanding around the Mental Capacity Act.

“My brother has profound difficulty in comprehending and communicating. During a recent hospital stay for a severe gastric episode, including emergency treatment, the communication protocol from hospital staff was poorly managed. Necessarily, my brother was alone in the hospital and during this time had been misinformed of the nature of his ailment. An understanding that he would be unable to comprehend, this misdiagnosis led to unnecessary anxiety for the whole family”

“My son broke his ankle when he was at college. He was about 19/20. We got there as soon as we could. We found he was in a geriatric ward and they were giving him drinks in a Tommy Tippy Beaker!! They had no idea how to deal with him so I stayed by his bedside 24/7 for 4 days. They were giving him morphine, which was making him terribly sick but when I told them to stop I was told he asked for pain relief and when offered Morphine he said yes! They took no notice of me at all as they said he was over 18”

“Initially my son was referred to our local hospital. We saw a consultant who was off-hand and uninterested in my son and the questions I had. I advised him we would need a Best Interest meeting with learning disability team involvement and to take their advice on sedation, before we could proceed. A month later a letter arrived with an appointment for the procedure. I contacted the hospital to advise that certain steps needed to be taken before my son could undergo the procedure, given he does not have capacity. Sometime later, another appointment arrived for the procedure to be done. At that point I asked my GP to refer him to another hospital. This experience really brought it home to me how vulnerable people with learning disabilities are when it comes to health care. My son was OK in the end as he us to advocate for him. If he had been a person without family support, things could have turned our very differently. The first hospital clearly had no framework in place regarding people lacking capacity. In the end my son was extremely distressed and his behaviour needed extremely careful and co-ordinated approaches. He ended up in Intensive Care and I hate to think what may have happened if he had not had the opportunity to be treated at a hospital that does have protocols in place that are followed and has a pro-active Learning Disability Team. We were also followed up after we were home by the "Enhanced Recovery Team" who were there for advice and support for 2 weeks post discharge”.

6. Lack of reasonable adjustments in healthcare

“GPs - pathetic annual health check. Bare minimum. No flexibility i.e. appointments - offered morning ones despite it being recorded we can only access pm”.

A Social Model of Disability

The Down's Syndrome Association, along with other UK learning disability organisations, are strongly in favour of all relevant agencies adopting a *social model* of disability. However, there are some instances where close attention to the specific medical needs of people with Down's syndrome is warranted. Our response to this consultation is one such instance.

We know that individuals with Down's syndrome have a predisposition to higher incidence of some health conditions. All of these conditions require careful assessment, management and monitoring and where any of these provisions are lacking, the outcome for individuals can be significantly detrimental and in some cases, fatal.

It is of paramount importance that all health professionals guard against making assumptions about individuals with Down's syndrome, as we are aware of **diagnostic overshadowing**, where additional health conditions are not acknowledged. Many of these treatable conditions are ignored or simply put down to the fact that 'the person has Down's syndrome'.

We know that individuals with Down's syndrome are more likely to experience medical conditions relating to:

1. Cardiac and respiratory systems
2. Thyroid function
3. Vision
4. Hearing
5. Gastrointestinal system
6. Immune function
7. Growth and cervical spine disorders
8. Early onset dementia

Some of these conditions can be present at birth (or can become apparent in childhood) however, some can develop at any time during an individual's lifetime and ongoing vigilance and regular screening (via primary care led Annual Health Checks) are essential. It is also important to note the limitations of Annual Health Checks and GPs need to be aware of when to refer an individual for further investigation for more specialised assessment. There should be a low threshold for referral, as otherwise potentially significant or life threatening conditions can be missed. This is especially the case for cardiac conditions, which can develop in adults, who have previously not shown any signs of having a heart condition.

We would strongly advocate for early identification of health conditions that are more prevalent in children and adults with Down's syndrome, especially as much can be done to intervene and ameliorate their impact. The Down's Syndrome Medical Interest Group www.dsmig.org.uk provides a summary of the basic medical surveillance essentials for individuals with Down's syndrome <https://www.dsmig.org.uk/information-resources/guidance-for-essential-medical-surveillance/>

We would also highlight recently published research showing the effectiveness of blood tests for babies with Down's syndrome to assess the likelihood of developing leukaemia, which can be significantly more common in babies and children with Down's syndrome <https://www.downs-syndrome.org.uk/news/all-newborn-children-with-downs-syndrome-should-receive-leukaemia-test-under-new-guidelines/?highlight=leukaemia%20>

As one of the outcomes from the LeDeR programme, we welcome the recent development of protocols that focus on:

1. sepsis,
2. aspirational pneumonia,
3. constipation
4. epilepsy

We hope that these will become quickly imbedded in all health and social care settings who need to be aware of this guidance.

Pain

We are aware of recent research which suggests that individuals with Down's syndrome have lower thresholds of experiencing pain and (due to greater challenging in communicating about the site and nature of the pain they are feeling) are less likely to access appropriate pain relief. *Nanda de Knegt (2016), Clinical Neuropsychology Department, VU University, Amsterdam.*

People with Down's syndrome with more complex needs (and / or) a diagnosis of Autistic Spectrum Condition

We are gaining greater understanding of a significant minority of children and adults with Down's syndrome who have more complex needs and / or a diagnosis of autistic spectrum condition. It is perhaps this group of individuals who are at greatest risk of experiencing health inequalities or barriers to accessing the high quality health and social care that they have a right to expect.

Separately, some young adults with Down syndrome have been described as having rapid cognitive deterioration. This regression is characterized by a loss of autonomy and daily skills, reduced speech, and psychomotor activity. Clinical onset can be sudden or progressive, and the evolution is quite variable. The aetiology of regression remains unknown. In some cases, medical conditions (sleep apnoea, Hashimoto's disease, depression) or stressful life events (end of secondary education, death of a close relative or a sibling leaving home and the young adult becoming more aware of the differences in their life chances and that of a typically developing brother or sister) were noticed prior to regression. We hope increased awareness from the medical community regarding regression in young adults with Down's syndrome would improve diagnosis, evaluation, and treatment options. The Down's Syndrome Association has recently launched a new online community support for families affected by this.

We know that individuals with a learning disability (and people with Down's syndrome, in particular) have been identified as a priority group of individuals who are more at risk of developing dementia and are more likely to be excluded from mainstream dementia services. Adults with a learning disability have been identified as a seldom heard group by the Dementia Action Alliance (The Down's Syndrome Association is a member of this network). In 2017 the Alliance produced a briefing paper on dementia and learning disability, outlining some of the agreed challenges.

www.dementiaaction.org.uk/joint_work/dementia_and_seldome_heard_groups/people_with_learning_disabilities

We would draw attention to recently developed guidance from Public Health England on reasonable adjustments relating to dementia for people with Learning Disabilities. Making Reasonable Adjustments to Dementia Services for People with Learning Disabilities. September 2013. Learning Disabilities Public Health Observatory.

<https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities>

Examples of Good Practice

We would draw all relevant agencies, especially commissioners, to the innovative work undertaken in the Leicestershire area, which resulted in the development of a Care Pathway for individuals with Down's syndrome from birth to age 25 (so encompassing transition into adulthood). Crucially the pathway also has a focused in mental health as well as physical health and is, as far as we are aware, unique in that respect. It would be extremely beneficial to the population of people with Down's syndrome if this good practice could be replicated nationally. For more information please see :

<http://www.leicspart.nhs.uk/Library/CombinedcarepathwayforDSCBeniteV224052016.pdf>

We would also draw attention to the useful resources produced by an Accident and Emergency Consultant and parent of a child with Down's syndrome, Elizabeth Herrieven, who has produced a poster for use in A & E departments that would alert staff to some of the pertinent issues they need to consider when assessing a child with Down's syndrome in an acute healthcare setting <https://www.downs-syndrome.org.uk/download-package/top-tips-for-triaging-treating-children-with-downs-syndrome/>

An innovative tool, developed by Cardiff and Vale Health Board, '**Show me Where (SMW)**' is a pain communication first-aid tool to enable those with verbal disability to quickly indicate the site of pain or discomfort. It links the carer and the clinician and provides continuity of care for the non-verbal patient where ever they go.

<http://www.showmewherepain.co.uk/>

We know that there has been recent investment made in **Learning Disability Champions** working in acute settings across the NHS. Whilst measures to increase the capacity and skills base of hospital based staff is welcomed, we would highlight that the roll out of these crucial roles has been very piecemeal and varies from one location to another. The role of the Learning Disability Champion is not always understood (even within the setting within which they are based) and their remit is vast, meaning that their ability to influence change is very limited. We would like to see better dissemination of best practice relating to Learning Disability Champions across the NHS and the replication of models where this has been working well.

We are encouraged that there is now a recognition that mandatory learning disability awareness training is needed for all relevant staff and that it should not be seen as the role of a small number of designated specialist staff, however, it is unclear what role existing Learning Disability Champions will have in the implementation of this mandatory training.

Response to specific questions

As requested, we have addressed the specific questions listed in the consultation:

Q1. We have envisaged three main elements to learning disability and autism training: understanding learning disability and autism, legislation and rights,

and making reasonable adjustments: do you agree? Should other elements be included?

We would support these three elements listed above, however, we would suggest the addition of two other elements:

1. An overview of the LeDeR programme, leading to awareness of the health inequalities experienced by people with a learning disability
2. For Tier 3 audiences, some specific information about the co-morbidity of certain conditions more prevalent in people with some types of learning disability, specifically Down's syndrome, so that they know to be vigilant and to guard against diagnostic overshadowing

Q2. Do you agree that awareness of how the Mental Capacity Act impacts on the way in which support is provided needs to be a significant part of training for all staff?

We fully endorse the inclusion of awareness of the Mental Capacity Act in this training. Our members' responses to our request for examples of difficulties they have encountered in accessing healthcare frequently identified that poor understanding of the MCA amongst health staff have contributed to failings. We would draw attention to the recent inquest of Jacqueline Maguire (a woman with Down's syndrome), where lack of understanding of the MCA by paramedics was identified as a contributory cause of her premature death <https://www.downs-syndrome.org.uk/news/statement-on-decision-by-high-court-to-permit-judicial-review-into-decisions-made-by-coroner-at-the-inquest-into-the-death-of-jacqueline-maguire/>

Q3. Are there additional elements which need to be covered by training on awareness of autism and the needs of autistic people?

Yes, as we have said above:

1. An overview of the LeDeR programme leading to awareness of the health inequalities experienced by people with a learning disability.
2. For Tier 3 audiences, some specific information about the co-morbidity of certain conditions more prevalent in people with some types of learning disability, specifically Down's syndrome, so that they know to be vigilant and to guard against diagnostic overshadowing.

Q4. Do you agree that the different levels of training should reflect the Learning Disability Core Skills Education and Training Framework (and in due course, the Autism Framework)?

Yes, we feel there are advantages for these to be streamlined and to cross-reference each other. The success of this, will of course, depend on how imbedded the Learning Disability Core Skills Education and Training Framework has become within relevant services.

Q5. We propose that individual employers should assess which level of training staff need and ensure that they get it. Do you agree?

We feel this is a serious weakness in the proposal. Self-identification and delegating the responsibility to ensure relevant staff access the training will lead to some professionals

who require the training missing out, or receiving only the most basic level of training. It is highly likely that employers (who feel pressures of time or cost or who do not see the intrinsic value of this training) will only opt for the most basic level of training. The targeting of the training and monitoring of its roll-out and impact should be a central function, overseen by the Department of Health and Social Care and linked to Health Professionals registration, to guarantee appropriate uptake.

Q6. What support might employers need in determining the appropriate level of training for a member of staff - e.g. a more detailed tool for assessment?

We would advocate for these decisions to be far more prescriptive and that criteria for determining the appropriate level of training being robust and set nationally, with little scope for interpretation. If decisions are to be delegated to employers, tight and detailed criteria via a detailed assessment tool must be provided and appropriate quality assurance / monitoring of local implementation must be facilitated.

Q7. We do not propose that all staff should have face to face training; just those with roles which mean they will be in regular contact with people with a learning disability or autistic people in Tiers 2 and 3. Do you agree?

We have some significant concerns that, potentially, a large group of relevant staff would not be subject to face-to-face training. Whilst acknowledging the resource implications, we cannot over-stress the importance of staff interacting with individuals with a learning disability and 'learning by experience'. If Tier 1 training is to be provided via an online e-learning route, these resources must include sufficient film-clips of people with a learning disability and co-facilitated with their involvement, as much as possible. The lived-experience of people with a learning disability should not be omitted from this tier of training.

We would also state reservations that e-learning can become a tick-box exercise, where large groups of staff are encouraged to demonstrate that they have accessed the training, without safeguards in place that they have given the training an appropriate level of attention. We would therefore suggest that any e-learning package contains an online assessment component, which is structured in way that will ensure people accessing the training have processed and understood the information they have been presented with.

Q8. Should there be a standard form of documentation, to act as a training passport, portable between employers, indicating when and where training was undertaken, and documenting the specific skills developed?

Yes, we fully support this notion. Evidence that an individual professional has accessed the training should be transparent and portable. Health professionals naturally move from role to role and from one geographical location to another. It is imperative that documentation and passports (which evidence access to the training) are portable.

Q9. We propose that a common curriculum for the content of training in learning disability and autism for health and social care staff should be developed which could inform implementation of professional standards. Do you agree?

Yes, we fully support this notion. The content of the training should be consistent and must not differ depending on where in the UK the training was provided. It is also vital that completion of the training is directly linked to professional standards. The training must be mandatory and evidence that the training has been completed should be linked directly to a professional's ability to continue their practice.

Q10. What support are employers of health and social-care staff likely to need to ensure their staff can have mandatory learning disability and autism training?

We are aware that, in the current climate of austerity, one of the budgets that is most prone to pressure is an organisation's training budget. It is vital, therefore, that employers of health and social care staff are given additional resources to implement the training. Even if the training is funded directly by The Department of Health and Social Care, it does not come without a cost to employers, since the greatest cost is related to releasing staff from their duties in order to attend the training. This must be included in the costing of the roll out of this proposal and appropriate mechanisms put in place to ensure this funding filters down to employers at a local level.

There will be a significant number of professionals needing to access this training and in the initial stages there will need to be very wide availability of training sessions at a local level – especially if we are to be sure that access is facilitated in **all** locations of the UK. Employers should not be put in a position where staff would need to travel significant distances in order to access a training opportunity.

There would need to be a comprehensive public information programme to ensure that all relevant employers and their staff are aware of the training and how to access it.

Q11. What best practice are you aware of in delivering training on learning disability or autism?

The Down's Syndrome Association has a long established history of delivering face-to-face training to health and social care professionals. This has included a well-received training course on supporting adults. For more detailed information on our training services, please see <https://www.downs-syndrome.org.uk/for-professionals/health-medical/>

For the last 5 years, we have been working closely with Public Health England in delivering face-to-face training sessions for health professionals working on the Fetal Anomaly Ante-natal Screening Programme (FASP). This has include family-carers sharing their lived-experience and the commissioning of filmed case studies of adults with Down's syndrome, sharing their lived-experience <https://phescreening.blog.gov.uk/2018/09/19/nipt-implementation-how-professionals-felt-about-our-face-to-face-training-and-development-events/> gives more information.

For the last decade the Down's Syndrome Association has developed face-to-face training sessions for midwives and other health and social care professionals involved in supporting new and prospective parents. This training is co-produced by individuals with Down's syndrome and includes them and parents of children with Down's syndrome who present at the events as co-trainers. We have now trained more than 6,000 health professionals under this scheme and the training course has received accreditation by The Royal College of Midwives <https://www.downs-syndrome.org.uk/?s=tell+it+right>

The Down's Syndrome Association received Big Lottery funding some years ago to develop a co-produced health training programme in Northern Ireland called Our Shout. This involved adults with Down's syndrome developing a training programme and delivering this for health professionals across Northern Ireland.

Q12. Who should be responsible for ensuring the promotion of best practice in how to support people with a learning disability or autistic people (e.g. through guidance or training for trainers)?

We feel in order to maintain consistently and to give this scheme the kudos it deserves, the responsibility should lie with The Department for Health and Social Care, working with relevant partners (including those drawn from The Third Sector), as appropriate.

Q13. How quickly after taking up a post should new members of staff who have not previously received training have to complete training?

Mistakes made in the provision of care and support to someone with a learning disability can have catastrophic consequences. This is an issue of patient safety. The propensity for a newly appointed, inexperienced, member of a team to make a mistake is greater still and we would therefore advocate for this training to be an essential part of all health and social care staff's induction training, ideally completed before they are placed in a setting where they come into contact with anyone with a learning disability. Understanding the practicalities of providing this training before someone is able to take up their responsibilities, we would say a window of around 1 month to 6 weeks after appointment should be a maximum period allowable.

Q14. What are the barriers to involving people with a learning disability or autistic people in delivering training as proposed?

All barriers can be overcome with appropriate planning and support. In developing the programme, commissioners should be aware of the following potential barriers:

1. Perceived lack of expertise amongst services hosting the individuals. Planners should seek advice and support readily available from organisations like The Down's Syndrome Association (see our answer to Q15 below).
2. The majority of individuals with a learning disability might like to be involved on a part-time basis, factor this into how you might recruit sufficient co-trainers.
3. Individuals with a learning disability will need information to be provided to them in an accessible format, lots of advice is available on this.
4. Individuals with a learning disability are likely to have a specific learning profile and speech, language and communication profile. Specialist advice needs to be sought to make reasonable adjustments in order to differentiate resources to meet these learning needs.
5. Individuals with a learning disability maybe more limited in their ability to travel and so should be recruited very much on a regional / local level.
6. Individuals with a learning disability should receive comparable payment for their input to this scheme (see our answer to Q17). Many individuals with a learning disability are fearful of taking up paid employment because of the impact this might have on their welfare benefit payments. Appropriate consideration needs to be given to ensure that anyone taking part is not financially disadvantaged.

Q15. What support or advice might be needed for people on how to best involve people with a learning disability or autistic people in developing training?

There are well developed protocols for involving people with a learning disability in projects. Involvement must be meaningful and not a token gesture. Individuals with a learning disability should be valued colleagues and given appropriate status within the process. There is a wealth of experience across the Third Sector and we at The Down's Syndrome Association would be very keen to share our expertise, especially around facilitating health based training programmes which have this element of co-production.

For almost the last decade, The Down's Syndrome Association has facilitated a very successful employment project called WorkFit. We now have significant experience of advising employers on how best to support individuals with a learning disability in the workplace. For more information, please see www.dsworkfit.org

Q16. What support might be needed for people with a learning disability or autistic people to ensure they have the right skills to participate in training?

Individuals with a learning disability are likely to have a specific learning profile and speech, language and communication profile. Specialist advice needs to be sought to make reasonable adjustments in order to differentiate resources to meet these learning needs.

Accessible resources to support their involvement.

Transport and travel training in order to attend training sessions in their locality.

Some individuals may benefit from the provision of a workplace buddy or co-trainer, directly linked to working with them. It would be helpful if this individual was consistent and it is obvious that this key person should have accessed appropriate training in order to have the skills to support someone with a learning disability.

Q17. How should people with a learning disability or autistic people be remunerated for participation in training to health and social care staff?

In order for this scheme to demonstrate the principles of equality, it is vital that co-workers with a learning disability are paid at a comparative rate to their non-disabled colleagues.

Q18. Do you agree with our proposal to use the Regulated Activities regulations to place further requirements on service providers who carry on regulated activities within the meaning of the Health and Social Care Act 2008 with a view to ensuring that all staff whose role may involve interaction with people who have learning disabilities or autistic people have received appropriate training in learning disability and autism?

Yes, we fully support this notion. If this training is to be mandatory, it is essential that it is directly linked to an individual's registration to practice, otherwise uptake risks being piecemeal.

Q19. Do you agree that we could use the NHS Standard Contract to place requirements on providers to ensure unregulated staff have received appropriate training in learning disability and autism?

Broadly, yes, although we have limited experience and knowledge of NHS Standard Contracts to comment more fully.

Q20. What do you think we should do to ensure that self-employed staff / lone practitioners/ partners undertake training to an appropriate level?

We feel that it is vital self-employed and lone practitioners are included within this scheme, this group of professional are perhaps the most vulnerable to making mistakes or lacking knowledge, as they do not necessarily have a team of colleagues in place to routinely seek advice or check their knowledge with. We have limited experience to share in how this could be facilitated, perhaps linking the requirement to evidence having accessed this training (via a training passport, as previously mentioned in Q8) to the HCPC register?

Q21. We envisage that CQC and Ofsted inspections can provide a robust means of ensuring mandatory learning disability and autism training is happening? Do you agree?

We broadly agree with this proposal. We have some reservations:

1. There is a significant resource implication to this assumption. CQC are over-stretched currently and it would be wholly inappropriate to expect them to take on this additional function without increased resources and personnel.
2. The length of time that inspections will take to establish, across the board, that all relevant settings have staff who have accessed the training and the length of time between inspections, meaning that settings compliance may diminish significantly between inspections.
3. What sanctions will be taken against those settings who have not complied with the requirement to have suitably trained staff?

Q22. How might people with a learning disability or autistic people be involved in assessing or monitoring mandatory learning disability and autism training?

1. Individuals with a learning disability should be equal partners at all levels of implementation.
2. The project management board should include individuals with a learning disability.
3. All training sessions should be evaluated in some way and the questions relating to this evaluation should be shaped by individuals with a learning disability.
4. Quality Assurance visits should be incorporated into the training delivery (where sessions are observed in order to ascertain they are meeting the required standard). People with a learning disability should be included in any team overseeing quality assurance measures.
5. People with a learning disability should be included in the panel making decisions about recruitment of personnel involved in training delivery and the awarding of any contracts to providers.
6. People with a learning disability could be recruited as 'anonymous service users' who put settings to the test and report back any concerns they have about the quality of support they receive.

Q23. What do you think are the likely costs of implementing mandatory training for health and care staff in learning disability and autism?

We would state that the daily cost of £300 per trainer for ad hoc training is on the low side. The Down's Syndrome Association has been levying a fee which is higher than this (£500 per day) for many years and this has been at this level for around the last 10 years. If trainers were employed on a part-time basis (contracted hours) rather than purely ad-hoc, free-lance trainers, the daily fee costs might be somewhat lower, but £300 per day seems out of step with current charges.

Q24. What evidence is available on the economic benefits of mandatory training?

This training should rightly be a Human Rights issue and not reduced to an economic argument. The training has been proposed as a result of findings from the LeDeR programme, which has evidence widespread health inequalities and avoidable deaths of individuals with a learning disability. The costs of such failings are unquantifiable.

It is, however, perhaps relevant to offset the costs of implementing this programme of training against the significant costs of: i) investigating deaths which might have been avoidable, ii) locally based NHS and Social Care complaints procedures, iii) Inquests and iv) any compensation paid to families who have experienced a failing in the care they were provided.

Q25. What evidence can you provide on the current provision of learning disability and autism training around the country?

The Down's Syndrome Association has a long established history of delivering face-to-face training to health and social care professionals. This has included a well-received training course on supporting adults. For more detailed information on our training services, please see <https://www.downs-syndrome.org.uk/for-professionals/health-medical/>

For the last 5 years, we have been working closely with Public Health England in delivering face-to-face training sessions for health professionals working on the Fetal Anomaly Ante-natal Screening Programme (FASP). This has included family-carers sharing their lived-experience and the commissioning of filmed case studies of adults with Down's syndrome, sharing their lived-experience <https://phescreening.blog.gov.uk/2018/09/19/nipt-implementation-how-professionals-felt-about-our-face-to-face-training-and-development-events/> gives more information.

For the last decade the Down's Syndrome Association has developed face-to-face training sessions for midwives and other health and social care professionals involved in supporting new and prospective parents. This training is co-produced by individuals with Down's syndrome and includes them and parents of children with Down's syndrome who present at the events as co-trainers. We have now trained more than 6,000 health professionals under this scheme and the training course has received accreditation by The Royal College of Midwives.

The Down's Syndrome Association received Big Lottery funding some years ago to develop a co-produced health training programme in Northern Ireland called Our Shout. This involved adults with Down's syndrome developing a training programme and delivering this for health professionals across Northern Ireland.

In Wales, The Down's Syndrome Association is invited in each year to deliver a series of lectures to undergraduate medics at The University Hospital of Wales (Cardiff). This training involves adults with Down's syndrome sharing their personal, lived-experience. This type of training is replicated for other health related undergraduate courses at The University of South Wales, Bangor, Swansea and Cardiff Metropolitan Universities.

We would like to register our interest as an organisation which is keen to be involved in the implementation of this proposal. We can demonstrate our capability, the support of our membership of individuals with Down's syndrome and their family-carers and a proven track-record in the delivery of training to health and social-care professionals.