Learning Disability and Autism Programme

Thursday 9th April 2020

Frequently Asked Questions

Thank you for your questions and comments. We have focussed on questions which summarise a key theme from stakeholders, If you do not think we have answered your question or if we have missed anything please do come back to us at: england.learning.disability@nhs.net

We will provide an update on questions and answers each Friday for the next few weeks.

To support collaborative working across the voluntary and independent sector, health and social care there is a weekly webinar to raise and discuss key issues for people with a learning disability and / or autism with representatives from NHS England and NHS Improvement, the Department of Health and Social Care, Public Health England and voluntary and independent sector organisations taking part.

To receive details about the webinar please contact: england.learning.disability@nhs.net

An online collaborative workspace has been set up: Mental health, learning disability and autism COVID-19 Cell Futures platform. It is not intended for the general public, but is a space for organisational partners, commissioners and key networks to develop and share information and resources.

To join the Mental Health, Learning Disability and Autism COVID-19 Cell Futures Collaboration platform please go to: https://future.nhs.uk/MHLDAcovid19/grouphome

Joint working

We want to collaborate with you and to keep the process as simple as possible.

The learning disability and autism programme coproduction group, which includes advisers with lived experience and our National Clinical Director and quality lead have identified gaps in information and resources currently available. From next week we will be coming out to stakeholders to ask you to work with us to fill these gaps. If you have any ideas or suggestions for how you would like to work together please email jo.skinner1@nhs.net
Issues raised by stakeholders

What will happen if a person with a learning disability or an autistic person becomes ill with COVID-19 and needs to go to hospital?

New guidance due to be published next week (w/c 13 April) will set out what to expect if a person with a learning disability or an autistic person who is an inpatient in a specialist mental health / learning disability hospital becomes ill with COVID-19. This includes guidance on providing treatment and protecting them and others where they are, and also provisions for transferring them to acute hospitals as and when necessary. The guidance will emphasise the necessity of communicating and working closely with families and carers throughout these processes.

Hospital visiting and the acceptance of others providing support, particularly in acute hospital settings, will largely have to depend on the individual hospitals' own requirements and guidelines, which reflect their ability and capacity to protect patients, staff and visitors from infection.

There is guidance for the support of children in paediatric critical care units which addresses visiting and support of families: C0086_Specialty-guide_Paediatric-critical-care-v1-26-March.pdf

Next week we are also aiming to publish guidance on family and carer engagement to support health professionals to work with a person’s family and carers. We are continuing to look at this issue with colleagues across NHS England.

We are grateful to those stakeholders who have been working with us to produce a “grab and go” guide (hospital passport) to support people who are admitted to hospital with COVID-19.

What is the latest information in response to concerns about DNAR (DNACPR)?

Decisions about the best course of action, treatment and care pathway are always made between a patient and their clinicians, and the NHS will always seek to fully protect the rights of people with disabilities. Last week NHS England and Improvement issued a letter about the alleged application of DNAR (DNACPR), it should be read in conjunction with this more recent letter signed by Professor Stephen Powis, National Medical Director and Ruth May, Chief Nursing Officer.

There has been some talk on Twitter about NHS England and NHS Improvement not being willing to release data of deaths by disability including learning disabilities. Is there a reason for this, eg numbers too small? It is felt that this could inform care planning.

We expect notifications to the LeDeR programme to continue with an additional question added to the notification form asking whether the death is related to COVID-19.

It is our intention to monitor the data as it is collected and work with colleagues across the system to build a picture of how COVID-19 is impacting on people with a learning disability, autism or both.

It is our understanding that the role of Designated Medical/Clinical Officer for children has not been identified by NHS England and NHS Improvement as a critical role which has led to some people in these posts being redeployed. Given the centrality of their role to ensuring that those children most at risk continue to receive services this is a real worry. Can you provide any update on this?

We are aware there is growing concern about the re-deployment of the Designated Medical Officers and Clinical Officers and the impact this has for children and young people. We have shared these growing concerns with colleagues in the nursing and medical directorates and aim to provide a further update when available.

**Workforce**


**How is technology supporting people to stay connected during Covid-19?**

NHS England and NHS Improvement is talking to commissioners and healthcare providers in local areas about what additional IT equipment they will need and online access to be able to keep connected to patients virtually during this time. The plan includes equipment being made available to commissioners, clinical experts and experts by experience to allow Care (Education) and Treatment Reviews to happen online.

We have raised the need to think about people with a learning disability and autistic people as NHS digital support is increased over the coming days and weeks to the team that is dealing with digital care. Digital technology has suddenly become such an important tool for keeping in touch with family, friends, supporters and up to date
information. We know that not everyone with a learning disability or family carers have access to the internet or have easy to use digital equipment. We are starting to gather ideas about what needs to happen to ensure as many people as possible can be connected digitally.

User led organisations and advocacy groups have been working exceptionally hard to reach people who are unable to access digital resources and reinforce the importance of this point during the call.

**What steps are NHSE and DHSC taking to make sure the Mental Health Act changes don’t result in more people being sectioned?**

We have been working with the Department of Health and Social Care to ensure that safeguards and checks are built into the guidance for practitioners to use if and when the flexibilities in either the Care Act or Mental Health Act are ‘switched on.’

Guidance can be found [here](#).

**Personal Protective Equipment (PPE)**

Whilst acknowledging the significant improvements in the distribution of PPE, stakeholders have expressed ongoing concerns. These have been shared with those responsible for overseeing this important issue.

Revised national guidance on PPE was published on 07 April and can be found [here](#). It includes PPE recommendations for a wide range of health and social care contexts.

In addition there were some specific clinical enquiries raised on the call which have been shared with the National Clinical Director and we will update in due course.

**Additional information:** Previous week FAQs and 8th April 2020 Webinar Slides are attached to this update.