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8 April 2020

Pauline Philip DBE
Director of Urgent and Emergency Care
NHS England and NHS Improvement

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Cc: CEOs, NHS Hospital Trusts

Email:

Dear Dame Pauline,

Meeting the needs of patients who have a learning disability, autism or both

Dimensions is one of the largest not-for-profit social care providers for adults who have a learning disability, autism or both. We support around 3,500 people across England and Wales.

We are preparing for the fact that some people we support will require hospital admission for COVID-19, as well as planning for admission for other reasons that may still occur in the highly pressurised context of this pandemic. I write to you in the spirit of genuine collaboration, to seek to ensure the best possible outcomes for patients who have a learning disability or autism and to ensure that fundamental rights and principles are upheld when it comes to people's care.

People who have a learning disability and/or autism confront many barriers when accessing health services. Research underlines that this can lead to poorer health outcomes and preventable deaths. For this reason, in normal circumstances, we would seek to ensure that someone who knows the person we support well is available to stay with them and support them on admission to hospital.

Recognising that we are in unprecedented times, I am writing to inquire what consideration the hospital is giving to the needs of patients who have a learning disability and/or autism. In particular, I would like to put forward the below points as potential reasonable adjustments that could be made in these difficult times, in line with the Equality Act 2010.

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1. Establishing a known point of contact for all patients who have a learning disability and/or autism – for example, a learning disability liaison nurse.

We are keen to ensure that local support teams are able to make contact with people we support in hospital. If it is not possible for someone who knows them well to visit or stay with them, a communication channel will be vital to provide advice and information about their care and support needs to hospital teams. If no such contact point exists, we hope the hospital will consider establishing some way of working to facilitate communication between hospital practitioners and community support services.

2. Establishing a clear policy and process around using resources such as Hospital Passports, information bands and booklets etc.

We are concerned that, both because of pressured environments and infection control measures, any items sent with a patient to help ensure they receive appropriate support might be set aside or put somewhere that is inaccessible for hospital staff. Hospital Passports and other similar resources often include critical information about someone's communication; how to recognise pain or deterioration in their physical state where they might present a-typically; and information about medication, SALT needs etc. We welcome that a Health Passport has recently been endorsed by NHSE. Ensuring practitioners in the hospital are aware of these resources and how to use them effectively may help to mitigate the impact of patients not having support from people who know them well in hospital.

3. Individual assessment on whether admitting visitors to support individuals would be appropriate.

We recognise the need for policies that prevent people visiting hospital wards and appreciate that in nearly all cases this will be the appropriate course of action. Some people we support will be profoundly disadvantaged if they do not have the support of someone who knows them well whilst in hospital. For these people, we ask that there is an individualised risk assessment carried out and that divergence from the hospital or ward policy will be considered if it might be appropriate and reasonable for someone to stay with a patient who has been admitted to hospital. This applies both to people admitted with suspected or confirmed COVID-19 and those admitted for other reasons.

4. Establishing a policy to allow people access things that will help them to keep them calm and to be able to cope in hospitals. Examples are iPads, 'comfort' items, etc.

In the current circumstances, people are likely to be experienced higher levels of anxiety. Access to comfort items will help to reduce anxiety and this in turn will likely facilitate provision of care and treatment. Such items are normally referred to in Hospital Passports. It is important that infection control policies are not be used as a reason to remove these items when doing so would cause the person distress and lead to their health and care being disadvantaged. A clear policy will help to ensure that health care practitioners understand when it is appropriate to give access to comfort items.

5. Continue to ensure easy read information is available.

Whilst not everyone who has a learning disability and/or autism will use easy read information, it can be hugely beneficial for some. Facilitating communication so that people better understand the care and treatment they are receiving will help to reduce anxiety and involve people in their healthcare decisions. Public Health England easy read advice related to COVID-19 can be found at <https://bit.ly/39NiiMH>

Lastly, please note that clinical guidelines on supporting people with a learning disability or autism for all specialities has been published on the NHSE website which is available [here](#).

As we all do our best to protect life in these difficult circumstances, I hope this communication will prove useful and support healthcare professionals in their roles. We at Dimensions will continue to provide the best support we can to people in this challenging time and to work with health services to seek the best possible outcomes for people we support.

Yours sincerely,



Steve Scown
Chief Executive

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