**Learning from Lives and Deaths of people with learning disability and autism (LeDeR)**

**What is LeDeR?**

* LeDeR programme is funded by NHS England and NHS Improvement
* It was established in 2017 to improve healthcare for people living with learning disability and autism.

LeDeR aims to:

* Improve care for people with learning disability and autism people.
* Reduce health inequalities for people with learning disability and autism
* Prevent people with learning disability and autism from early deaths.

**LeDeR Programme locally**

* Locally in Southwest and Southampton ,15 LeDeR Reviews were completed for deaths. This took place between 25/03/2022 – 23/09/2022

**Learning and Positive Practice from these reviews is shared below**

**The learning is for all health and social care professionals and carers involved in a patient’s care**

* Care providers -Primary, Secondary and Community teams should implement positive behavioural support plans and provide autism training to staff
* Patients with LD should have a named GP, which will ensure he/she can build trust with their named GP, break down barriers, is well supported and receives continuity of care
* There is evidence that good care can be provided with a multi-disciplinary team approach
* Regular involvement and consultation with family, and consideration of patient’s best interest and wishes can improve care
* During the pandemic patients did not wish to attend appointments via phone or video link, as this was unfamiliar for them. Therefore, face to face reviews is likely to be more beneficial for patients with learning difficulties and autism
* In the event of any future lockdown, patients with learning difficulties and autism should be classed as ‘vulnerable’ to ensure access to face-to-face consultations when required
* People with learning difficulties and autism are a deprived group which faces health inequalities. This group of patients would highly benefit from annual LD health check as they are at high risk of chronic diseases which can be prevented
* GP practices must provide clear evidence in the person's records of invitation to attend annual LD health checks. These checks must be carried out face to face and not over the phone. The checks should involve the person concerned as much as possible, and not rely on the care staff to complete on behalf of the person
* It is good practice to share ‘Health Check Action Plan’ with patient, carers and family following LD Annual Health Check
* Health and social care professionals should request **reassessment of care needs** as soon as deteriorating health and wellbeing is recognised, to ensure the safety of the person. As their current placement may not be able to meet care needs. Patient’s feelings and wishes must be considered in all decisions.
* **Provision and access** to good primary and secondary care should not be affected by holiday periods
* All health and social care staff must act in accordance with the principles of the Mental Capacity Act (2005) and clearly document **Mental Capacity Assessments** and Best Interest decision making processes, especially if there is refusal to further treatment or admission to secondary care
* People with LD who have **complex pain management** should be referred to specialist pain management services by their healthcare professionals
* **Hospital Passport** is completed in the community by carers for when patients go into hospital. It is to bridge the gap in information regarding how the patient communicates and their usual care needs. This must be updated and easily available
* Primary Care and Secondary Care must ensure regular review of **DNACPR** documentation to support appropriate decision making which should involve the designated Next of kin

**Access to information following death**

* LeDeR reviewers have at times had difficulties in obtaining GP information to aid a timely and thorough case review
* It would be helpful to the reviewers if all primary care staff were familiar with LeDeR, to enable prompt LeDeR reviews to be undertaken.
* **Sharing of positive practice evidenced in one practice-** where there is one admin staff who can deal with LeDeR requests for information.
* It is not always necessary for the reviewer to speak with the patient’s GP in person, unless there have been concerns raised, but it is essential to obtain the GP records for a minimum of 9-12 months period prior to the patient’s death.