

## **LeDeR Reviews for Autistic Adults**

### **What is LeDeR?**

LeDeR – learning from lives and deaths – people with a learning disability and autistic people - is a local service improvement programme that has been set up to help to improve services for people with a learning disability and autistic people.

### **LeDeR works to:**

- Improve care for people with a learning disability and autistic people
- Reduce health inequalities for people with a learning disability and autistic people
- Prevent people with a learning disability and autistic people from dying too young

### **Notifying LeDeR about a death of someone who has a diagnosis of autism**

LeDeR has accepted notifications of deaths of adults who have a diagnosis of autism since January 2022.

- Anyone can notify the death of a person who has died who was autistic.
- If you want to notify us about the death of someone who has died and they had a diagnosis of autism please go to [www.leder.nhs.uk](http://www.leder.nhs.uk) and fill out the simple form.
- A LeDeR reviewer will carry out the review on behalf of your local integrated care board, the family will be involved in the review and should receive a copy of the review report when it is completed.

The aim of this document is to help explain who can have a LeDeR review and provide information for families, carers and support workers about the LeDeR process.

This document has information about:

- Who can have a LeDeR review?
- Diagnosing autism
- Where a diagnosis might be recorded

The terms autism and autistic are used in this document because many people, their families and carers have told us they prefer to be identified as autistic.

We know that some people don't use these words to describe themselves and respect every individual's choice in this.

## Who can have a LeDeR Review?

### Diagnosis

- For an autistic adult to be eligible for a LeDeR review, they must have had a confirmed diagnosis of autism recorded in their clinical records before their death.
- We are aware of the difficulties in getting a diagnosis and know this is important to consider, but at this time if a person does not have a confirmed diagnosis, they will not be able to have a LeDeR review. LeDeR does **not** include those who self-identify as autistic or anyone who has not received a clinical diagnosis from a qualified health professional.
- They must have been 18 years old or over at the time of their death\*.

### How are people diagnosed?

Diagnosis of autism are classified in two manuals. When someone is diagnosed with autism their diagnosis will come under the classification in either one of these two documents. They are called:

- Diagnostic and Statistical Manual of Mental Disorders (DSM)  
<https://www.psychiatry.org/psychiatrists/practice/dsm>
- International Classification of Mental and Behavioural Disorders (ICD)  
<https://www.who.int/standards/classifications/classification-of-diseases>

These manuals use different classifications of autism and so use different words to describe autism and are reviewed from time to time. The different words they use include:

- Infantile autism
- Pervasive developmental disorders
- Atypical autism
- Asperger's syndrome
- Autism spectrum disorder
- Childhood autism
- Psychoses with origin specific to childhood

Although some of these terms may be outdated because the manuals have been updated, depending on the time and place of diagnosis this may be what is recorded in a persons' medical record and so these are some of the words that LeDeR reviewers look for as proof of a diagnosis. Most of these words are not used when someone is diagnosed now.

### When are people diagnosed?

## Children and young people

- Autism can be diagnosed in childhood. Usually it cannot be diagnosed until a child is older than 3 years of age
- Pre-school children may be assessed for autism after social differences have been observed at home, nursery or when starting school. They may not play with other children in the same way or may behave differently to other children of the same age.
- Older children and teenagers may be diagnosed after first coming to the attention of mental health professionals because of concerns around mood, school refusal or relationship problems with people of the same age group.
- A diagnosis is usually made by a paediatrician, or a child and adolescent psychiatrist.
- There may be other staff who work with a paediatrician or psychiatrist who could be clinical psychologists, speech and language therapists, occupational therapists, and specialist nurses and social workers.
- Sometimes children and young people have multiple difficulties and health conditions that need to be assessed and supported. This means autism may not be diagnosed until later.

## Adults

- A diagnosis in adulthood is commonly called a late diagnosis since autism is present from childhood.
- Individuals may be diagnosed in adulthood due to diagnostic overshadowing; this is where autism is overlooked because they may have other conditions. Some individuals have been able to copy actions of people without autism and this has made formal diagnosis difficult. This is sometimes called masking.
- Sometime this late diagnosis might happen when the person has a learning disability because the learning disability has overshadowed the autism.
- Adult diagnoses are mostly (but not always) made by a specialist autism team of psychiatrists, clinical psychologists, speech, and language therapists, occupational therapists, and specialist nurses.

- Sometimes a diagnosis is made by mental health teams who have experience and skills in identifying autism in individuals with additional mental health conditions, such as psychosis or eating disorders.

### **Where will a diagnosis be recorded?**

- A diagnosis of autism (or past diagnostic term as above) should be recorded in a person's clinical notes and on NHS systems.
- Assessments conducted in the private sector may not be recorded on NHS systems unless the clinician or team has been given consent to send the diagnostic report to the GP, or if the individual or family has shared the information directly.

If the person had a private diagnosis of autism, the Integrated Care System (ICS) would need to make sure that there is a record of the diagnosis in the NHS clinical record before a LeDeR review could be carried out.

**For more information about LeDeR please visit [www.leder.nhs.uk](http://www.leder.nhs.uk)**

\*The deaths of all children are reviewed by the National Child Mortality programme NCMD | The National Child Mortality Database.