**Learning from Lives and Deaths** People with a Learning Disability and Autistic People (LeDeR)

**A few women sitting at a table

Description automatically generated with medium confidence**

Easy read information for families

and circles of support

**September 2021**

|  |  |
| --- | --- |
|  | **We know this may be a difficult time for you.** |
|  | **We would like to thank you for taking the time to read this leaflet.** |
|  | **You can find out more information about LeDeR on our website –**  [**https://leder.nhs.uk/**](https://leder.nhs.uk/) |
|  | **The LeDeR reviewers will try to find the right way to carry out each LeDeR review.** |
|  | **Each family will be asked their preferred way of taking part in to review.** |

|  |  |
| --- | --- |
|  | **LeDeR is an NHS programme aimed at improving services for people with a learning disability and autistic people.** |
|  | **LeDeR was started in 2017 and funded by NHS England and NHS Improvement.** |
|  | **LeDeR was the first programme in the world to look into deaths of people with a learning disability.** |
|  | **LeDeR works to:** |
|  | * **Improve health and social care for people with a learning disability and autistic people.** |
|  | * **Reduce health inequalities for people with a learning disability and autistic people.** |
|  | * **Stop more people from dying too**   **soon by making care better.** |
|  | **Health inequalities are unfair and**  **preventable differences in health.** |

|  |  |
| --- | --- |
|  | **A LeDeR review looks at things that has happened to the person within health and social care.** |
|  | **We do a LeDeR review to -** |
|  | * **Find out about good things that happened in a person’s care.** |
|  | * **identify where health and care services can be improved.** |
|  | **We share examples of good things that happened across the country.** |

|  |  |
| --- | --- |
|  | **We can learn a lot by involving family members or others who knew the person who died well.** |
|  | **They will often know the most about the person who has died.** |
|  | **They may have thoughts about how services could be improved based upon their own experiences.** |
|  | **Sometimes a family member may not take part in a LeDeR review.** |
|  | **Someone else who knew the person well will then be invited to take part in the LeDeR review.** |
|  | **Reviewers will also talk to other relatives, friends and other key people who knew the person.** |
|  | **The reviewer will ask about -** |
|  | **The person’s life.** |
|  | **Things that happened in the person’s life before they died.** |
|  |  |

|  |  |
| --- | --- |
|  | **Family members or someone who knew the person well can be in involved in the review if they want to.** |
|  | **This is important and helpful to carrying out the review.** |
| **Family of the person who died** | |
|  | **Families often know the most about the care the person who died had.** |
|  | **We can learn a lot by listening to experiences families had of services.** |
|  | **We can then use this information to improve services for other people.** |
|  | **We will tell families when we are doing a review.** |
|  | **We will invite families to tell us information about the person who died.** |
|  | **We will also offer families -** |
|  | * **An chance to comment on the draft review** |
|  | * **A copy of the completed review** |
| **Family involvement** | |
|  | **We understand that all families are different, we will -** |
|  | * **Talk to families to help them decide how much involvement they want in the LeDeR review** |
|  | * **Make sure we explain what LeDeR reviews is** |
|  | * **Explain how families can ask questions or tell us any concerns** |
|  | **We will make sure that families are as comfortable as possible.** |
|  | **if requested we will arrange a further meeting to get the information that is needed.** |

|  |  |
| --- | --- |
|  | **Integrated care systems make sure LeDeR reviews are done.** |
|  | **An integrated care system, or ICS, brings together NHS, council, community and voluntary organisations to support people in their area.** |
|  | **LeDeR reviewers will find out about the health and social care support that was provided to the person that has died.** |
|  | **A LeDeR reviewer will be someone who has a health or social care background.** |
|  | **A LeDeR reviewer will find out about the person’s life.** |
|  | **A LeDeR reviewer will find out things that happened in the person’s life before they died.** |
|  | **Integrated care systems will identify where changes could be made to improve services for other people.** |
|  | **Integrated care systems will make any changes needed.** |
|  | **This will make sure people** **with a learning disability and or autistic people are supported to have longer and healthier lives.** |
|  |  |

|  |  |
| --- | --- |
|  | **Once we have the details of someone’s death, we will start the LeDeR review.** |
|  | **We will aim to complete a LeDeR review in six months.** |
|  | **We know that some family members might not be ready to talk with us straight away.** |
|  | **First, the LeDeR reviewer will do an initial review.**  **This is when the LeDeR reviewer -** |
|  | * **Talks to the family member or someone close to the person who died.** |
|  | * **May talk to some the person lived with or a carer who they were close to** |
|  | * **Talks to** **the person’s doctor (GP).**   **If they can’t talk to the doctor, they will look at the person’s GP records.** |
|  | * **Talks to at least one other person who knew them.** |
|  | **There are two different types of LeDeR review.** |
|  | **Everyone has an initial review and some people also have a focused review.** |
|  | **After the initial review, the reviewer will decide whether a focused review is needed. It will usually happen if -** |
|  | * **The reviewer finds things that need improving or things to learn from.** |
|  | * **If the person was from a Black, Asian, or Minority Ethnic background.** |
|  | * **A family member can ask for a focused review to be carried out.** |
|  | * **The person was an autistic adult** |
|  | **The reviewer will send the completed review to the local governance group.**  **The group will decide on -** |
|  | * **What actions to take.** |
|  | * **Who will take these actions.** |
|  | * **What help they need to reduce health inequalities.** |
|  | * **What help they need to stop people dying too young.** |
|  | **A LeDeR review may not be done in 6 months if other investigations, like a coroner’s inquest, are on-going.** |
|  | **A coroner’s inquest looks into how and why someone died.** |
|  | **A LeDeR review waits until all other investigations have happened first.** |

|  |  |
| --- | --- |
|  | **Everyone with a learning disability aged over four years is eligible for a LeDeR review.** |
|  | **All children who are under the age of 18 have a child death review.** |
|  | **The report from the Child Death Review is then given to LeDeR.** |

|  |  |
| --- | --- |
|  | **Information that can identify a person, such as names, are removed from the LeDeR review.** |
|  | **The LeDeR review is shared with a local governance group.** |
|  | **A local governance group has members from health and social care and experts by experience.** |
|  | **They decide actions to improve services for people with a learning disability and autistic people.** |
| Logo  Description automatically generated with medium confidence | **All reports are looked at each year to provide a summary of all findings of LeDeR reviews.** |
|  | **An annual report is produced each year.** |
|  | **The report will not include any names of the people who died.** |
|  | **The full and easy-read versions of LeDeR’s annual reports –**  **leder.nhs.uk/resources/annual-reports** |
|  | **Our latest Action from Learning report, describing improvements, is available:**  **leder.nhs.uk/resources/action-from-learning-reports** |
| Logo  Description automatically generated | Translated into Easy Read by **Ace Anglia**  For more information please email: **info@aceanglia.com** |