

# Learning from the lives and deaths of people with a learning disability (LeDeR) in Gloucestershire

April 2020 – March 2021



## Shorter Easy Read Annual Report



## Part 1 – The report

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We have split this document up into different parts to make it easier to read. Each part is listed below. This is sometimes called a Table of Contents. Each part has its own colour.

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## Part 2 – What these words mean.

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These complex words are highlighted in **bold** in this document.

<b>Advocate</b>	An advocate is a person who offers support to another person to help them to understand what is going on. They can also help to express a person's thoughts and wishes.
<b>Annual Health Check</b>	This is a yearly appointment with your doctor to talk about your health and how to make it better. Annual Health Checks are for adults and young people aged 14 or over with a Learning Disability.
<b>Aspiration Pneumonia</b>	A lung condition caused by choking
<b>Best Interest (Decision)</b>	A best interest decision is made when someone cannot decide what to do for themselves. People who know the person well meet to discuss and make a decision for the person.
<b>Clinical Commissioning Group (CCG)</b>	A Clinical Commissioning Group manages and looks to improve the NHS in a local area.
<b>COVID-19</b>	This is a virus that affects a person's breathing and can also cause other health issues. It has spread around the world since the beginning of 2020.
<b>COVID-19 Virtual Ward</b>	This is a way of looking after people who have, or may have, COVID-19, in their own homes. Patients of the virtual ward are given a device that allows them to check

## Part 2: What these words mean.

	their own pulse and oxygen levels. The readings are sent to the COVID-19 Virtual ward. If this shows someone may be becoming unwell, they are accessed over the telephone.
<b>Do not attempt cardiopulmonary resuscitation (DNACPR)</b>	This is a note on your medical records saying that you do not want doctors to try and restart your heart if it stops.
<b>General Practitioner (GP)</b>	This is a doctor who works in the community. They treat many common illnesses and make referrals to other community health services when people need more help.
<b>Health Inequalities</b>	Health Inequalities are unfair differences seen when someone receives healthcare.
<b>Local LeDeR Steering Group</b>	This is a group of people who help manage, support and check on how the LeDeR programme is working in Gloucestershire.
<b>Mental Capacity Act 2005 (MCA)</b>	This is a law which protects the rights of people who may not be able to make some decisions themselves.
<b>My Health Passport</b>	A health passport lists the things that a nurse or doctor must know about. This includes any medication someone is taking. It also explains things that are important to that person, including what they like and dislike.
<b>Personal Protective Equipment (PPE)</b>	This includes things like masks, aprons and gloves.
<b>Quality Assurance (QA)</b>	This means checking to see if something has been done well, making sure procedures have been followed and identifying what could be done better in the future.

## Part 2: What these words mean.

<b>Reasonable Adjustments</b>	Reasonable Adjustments are changes that are/can be made to help a person with a disability to access a place or a service (for example a doctor's appointment)
<b>ReSPECT Form</b>	ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment. A ReSPECT form explains a person's medical treatment choices and end of life wishes. This helps healthcare workers to make decisions about a person's health when they cannot do so themselves.
<b>ReSTORE2</b>	ReSTORE2 is a tool, used by healthcare workers, to record things like a person's pulse. This can help to show if someone is becoming unwell. It can also help a healthcare worker decide if a person needs different treatment.
<b>Summary Care Record</b>	A Summary Care Record tells hospital staff the key points of a person's medical history and any treatment they have had.
<b>Vaccine Equity Group</b>	This group of people help make sure that everyone in Gloucestershire has the <b>reasonable adjustments</b> they need to have the COVID-19 vaccination.

## Part 3 – Opening Words

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Julie Zatman-Symonds – Chair of the Gloucestershire LeDeR Steering Group and Deputy Director of Nursing

Dr Marion Andrews-Evans – Director of Quality and Nursing



**Julie**

- Gloucestershire has been involved with LeDeR since 2017.
- The issues that cause people with a Learning Disability to die too soon were written in a report by the National LeDeR programme in July 2020. We have done a lot of work to prevent people with a learning disability dying too soon.

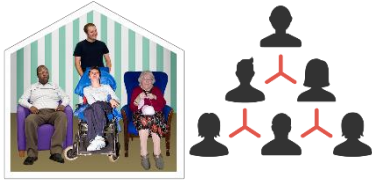


**Marion**

- This report shares what we have found out from our LeDeR reviews, what we can learn from them and how we can make changes to improve services in the future.
- This year we have faced new challenges due to the **COVID-19** pandemic.
- In April and May 2020, 7 people with a Learning Disability died due to **COVID-19**.
- There were less **COVID-19** outbreaks in Learning Disability homes, than in general care homes.



### Part 3: Opening Words.



- Between the 17th of December 2020 and 8th February 2021 there were **COVID-19** outbreaks in 55 disability care settings in Gloucestershire.

- In the first months of 2021, there were a lot of people with a Learning Disability staying in Gloucestershire Hospitals. This was mostly due to **COVID-19**.



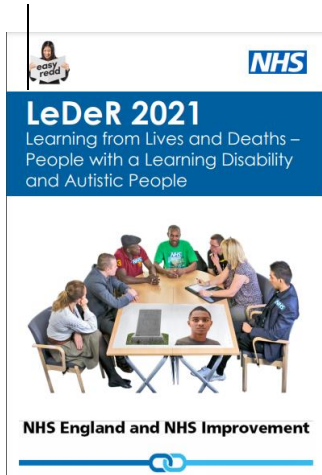
- With the help of the Learning Disability Clinical Programme 91% of people on their doctor's Learning Disability Register have had their first **COVID-19** vaccination.



- LeDeR in Gloucestershire has continued to learn from each review and put that learning into action during the **COVID-19** lockdowns.



- Since 2019, we have been working with Inclusion Gloucestershire. This has been working very well. We planned an event called "*Dying to make a difference*" but had to delay this due to **COVID-19**.



- We will continue to challenge **health inequalities** to Disability dying too soon. The new national LeDeR Policy will help us to do this. To read the National LeDeR policy in Easy Read, follow the link:  
<https://www.england.nhs.uk/wp-content/uploads/2021/03/LeDeR-Policy-2021-Easy-Read.pdf>



### Part 3: Opening Words

#### What our Experts by Experience Said

#### Sammy Roberts, Project Worker at Inclusion Gloucestershire and Expert by Experience member of the LeDeR Quality Assurance (QA) Panel



*'This year our voice as Experts by Experience has played an increasingly valued part of the QA panel. We have been able to represent the voice and stories of people with learning disabilities from around Gloucestershire and make sure their voices are heard. Now we are starting to produce accessible information, which means we are accountable [we answer to] to the people our work affects, people with learning disabilities. Once again, our role as Experts by Experience has been important to share because we are the experts in what our lives are like and how this can affect our health.'*

#### Vicci Livingstone-Thompson, CEO of Inclusion Gloucestershire and Expert by Experience member of the LeDeR Quality Assurance Panel says:



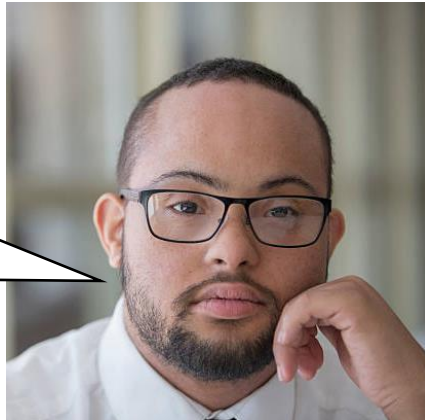
*'This challenging year has really highlighted [shown] the importance of LeDeR, coproduction [working together] and hearing the voices of people with a learning disability and autism. Not only has work on LeDeR continued at pace in Gloucestershire, but we have seen greater levels of co-production, with work starting to disseminate [share] key themes to professionals and the community in an accessible way, and involvement of user-led organisations at a strategic [decision-making] level to inform important discussions and decisions around COVID-19.'*



### Part 3: Opening Words

The views of others at Inclusion Gloucestershire<sup>1</sup> about why LeDeR is so important and how the learning during COVID-19 has improved services.

**I need to be listened to as the expert in my condition!**



**My life is important!**



**COVID-19 has made health inequalities worse**



**I was relieved to hear that blanket DNACPR's are not being used in Gloucestershire**



**There may be a global pandemic but we must not stop making reasonable adjustments**



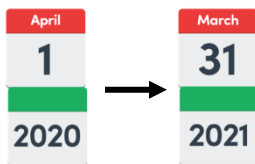
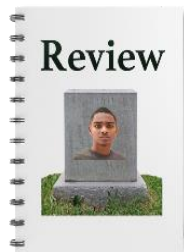
**In the last year, isolation has made some people's health much worse.**



<sup>1</sup> Some of the images are from Stock photos available from [www.gettyimages.co.uk](http://www.gettyimages.co.uk)

## Part 4 – A summary of the report

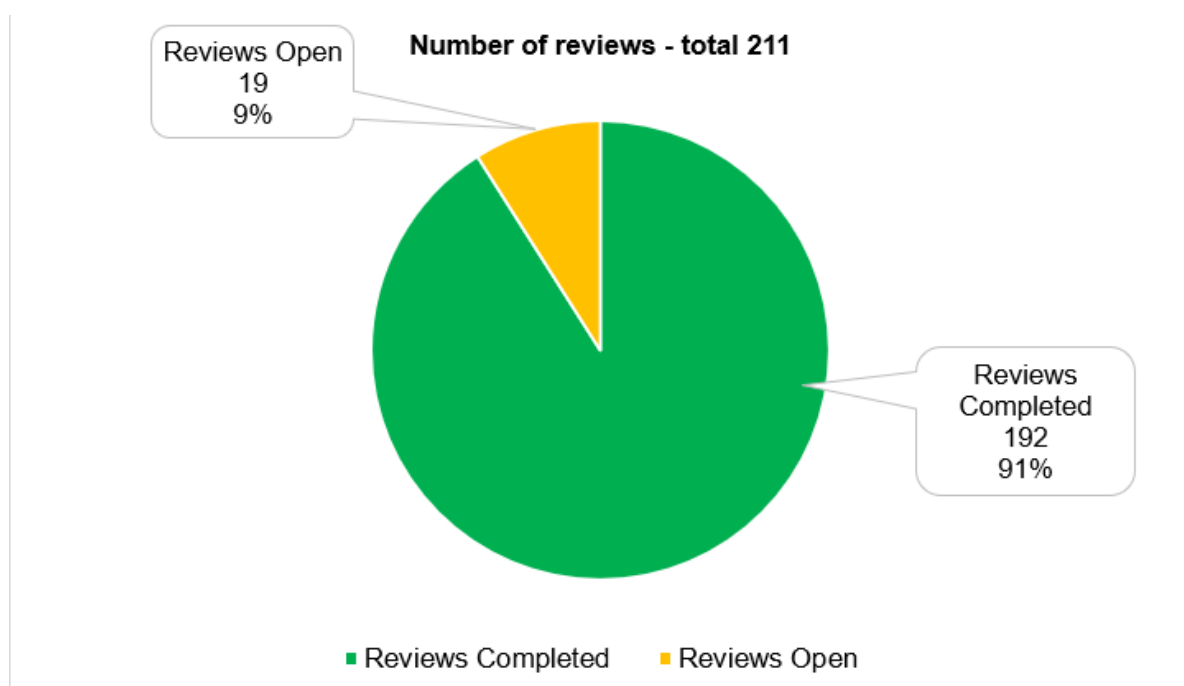
### Background



- This is the third yearly report for the LeDeR programme in Gloucestershire.
- Deaths of people with a Learning Disability over the age of 4 years are reviewed by the LeDeR programme.
- LeDeR reviews help to show if there was anything that could have been avoided and that may have led to the person's death.
- LeDeR reviews also help make services better for people with a Learning Disability.
- This report focuses on the people with a Learning Disability who have died in Gloucestershire between the 1<sup>st</sup> April 2020 – 31<sup>st</sup> March 2021. The report also looks at the number of deaths since the 1<sup>st</sup> January 2017.
- To read previous LeDeR Annual Reports, follow the link:  
<https://www.inclusiongloucestershire.co.uk/engagement/leder/>

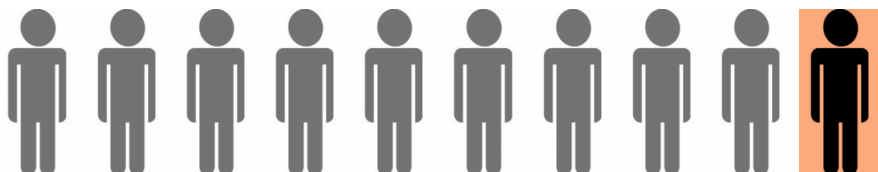
## Part 4: A summary of the report

How many reviews have been carried out up to 31 March 2021?



How was people's care?

- 9 out of 10 people's care was rated good enough or better than that.



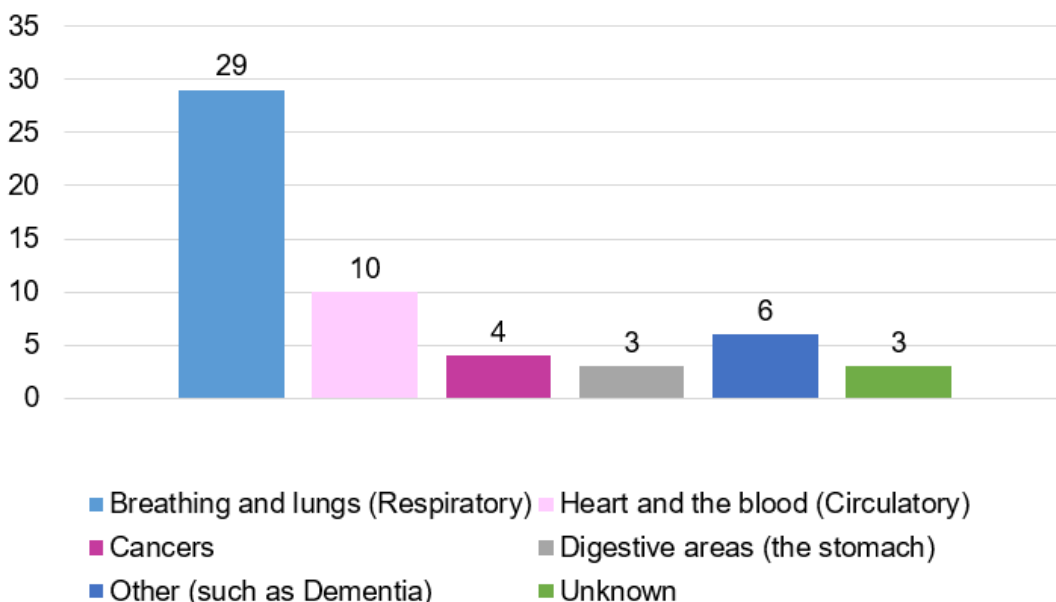
- 46% of the people died in hospital. This is the same as people who do not have a Learning Disability.



## Part 4: A summary of the report

57 people with a Learning Disability died during the year.

**Cause of Death 2020 -21  
Number of People**



- There have been 14 deaths of people with a Learning Disability from **COVID-19**

## End-of-Life Planning

- 57% of the 30 deaths (where this information was written down) had an plan in place which told health professionals what they wanted (sometimes called a ReSPECT form).
- 100% of the people who were expected to die had an end-of-life plan. Last year only 92% of people had one.

## Part 4: A summary of the report



### What we have learnt, what we are doing and what we can improve - where people are living in a supported environment or a care home



- Online training about **Personal Protective Equipment (PPE)** is starting again, for staff in care homes and shared supported living environments.



- The **CCG** keeps in contact with care homes in Gloucestershire by sending a monthly bulletin. A bulletin is like a newsletter.



- The **CCG** is making sure all care staff get the training they need to do their job well.

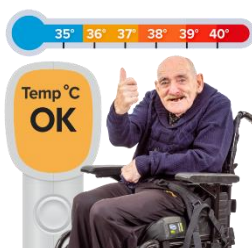
- Inclusion Gloucestershire have an online hub of easy-to-read **Coronavirus (COVID-19)** information, in different formats and languages.

- To look at the information, visit this website:  
<https://www.inclusiongloucestershire.co.uk/covid-19/>



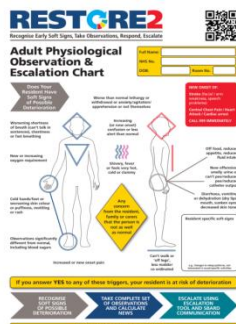
### Using technology to keep well.

- Technology that helps people manage their health needs, without having to visit the doctor, is being used in 11 care homes in Gloucestershire.





## Part 4: A summary of the report



- Care Home staff should have training in how to see when a person is becoming unwell. They should know how to use the **RESTORE2** tool.

## End of Life



- Some people with Learning Disabilities are dying without a **ReSPECT form** being filled in.
- We have started a group bringing together organisations and individuals from across the care system in Gloucestershire, to look at how we can have better conversations about **ReSPECT forms**, with people who have a range of health needs.



- This will help make sure we have a 'person centred' approach to care planning.

## Using the law

- Sometimes an **advocate** must be provided to help a person make a decision or help explain their choices. Better outcomes have been seen when the **Mental Capacity Act** has been used to support decision making, using an **advocate**.





## Part 4: A summary of the report

### The COVID-19 Vaccination

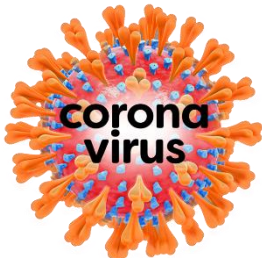


- The person giving the vaccine must work out if the person is able to make the decision for themselves. This is called consent.
- If a person cannot make the decision for themselves and no one has been asked to make decisions for them, a **best interest's decision** must be made.



- To see a video, made by the NHS, which talks about the **COVID-19** vaccine, follow the link:  
[https://www.youtube.com/watch?app=desktop&v=M3Wh23PDnfE&feature=emb\\_logo&fbclid=IwAR1LdOsbdE7hBTYtVvJk7x2DOTEoEM6\\_b3sc3RY0KmW6w9n0MXoQplhKVOW](https://www.youtube.com/watch?app=desktop&v=M3Wh23PDnfE&feature=emb_logo&fbclid=IwAR1LdOsbdE7hBTYtVvJk7x2DOTEoEM6_b3sc3RY0KmW6w9n0MXoQplhKVOW)
- The **Vaccine Equity Group** checks that people are getting the **reasonable adjustments** they need.

### Hospitals



- Referrals can be made by the disabilities commissioning team to the **COVID-19 Virtual Ward**.
- This means that more people with a Learning Disability can be cared for where they normally live.

## Part 4: A summary of the report

We are continuing to explain the benefits of having a **My Health Passport** that people can fill in themselves when they are well.

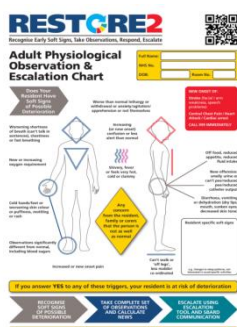
- This form can be used to tell doctors and nurses about someone with a learning disability.
- A note of a person's **reasonable adjustments** should be put on their **Summary Care Record** with additional information. Ask your GP if your reasonable adjustments are recorded in this way.
- A guide has been written to help staff support people with a Learning Disability during **COVID-19**.



## Part 5 – Conclusions and What is Recommended

### What we still have to do (further actions)

#### Physical Health (including **COVID-19**)



- We need to look at how well technology (telehealth) has helped people manage their care needs without having to visit the doctor.
- We want more people to use the **RESTORE2** tool and for it to help to show is someone is becoming unwell. We will do this by involving people with Learning Disabilities, their families and other organisations. We would like this tool to be used in different care settings.
- We want to let more people know about the Mouthcare Matters (<https://mouthcarematters.hee.nhs.uk/>) and the 'dying for a poo' campaign (<http://www.bris.ac.uk/media-library/sites/sps/leder/January%20Constipation%20easy-read%20newsletter.pdf>).



- We want to work with the Frailty Clinical Programme to make sure frailty is not just seen as someone who is an older person.

### Annual Health Checks and Health Action Plans



- We would like to make sure doctors use accessible Health Check Action Plans.

## Part 5: Conclusions and what is recommended

- We will carry on reviewing the resources used by healthcare workers to help explain more about an **Annual Health Check**.



- We want more children with a Learning Disability to go on their doctor's Learning Disability Register.
- We want to agree how a person with a Learning Disability is diagnosed and is added to the Doctors Learning Disability Register.

## End of Life and Planning for Care in the Future



- We have put together a group to work on end of life and planning for care in the future.
- We want them to:
- Work on making the ReSPECT process a conversation about future care planning and not just the filling in of a form.



- Make better information that is easy to understand, to help when talking about care planning for the future.
- Tell more people about the ReSPECT process and give training to more staff about it.

## Part 5: Conclusions and what is recommended

### Closing gaps in Training



- The **CCG** will carry on giving staff the training they need to do their job well. Training is being focused on Learning Disabilities and the importance of communication.



- We will carry on telling more staff about the importance of communication and give them training in how to communicate with people who have a Learning Disability.



- Training about infection control will start again for those who support people in a paid role.



- We will tell more people about the STOMP campaign via the **CCG** Medicine Matters bulletin. STOMP stands for stopping the over medication of people with a Learning Disability, Autism or both.

### Hospital care, focusing on reasonable adjustments and communication.



- The Gloucestershire Hospitals Trust Steering Group have a plan to improve things, including:
- How a Learning Disability Liaison Nurse is contacted

## Part 5: Conclusions and what is recommended



- How the hospital computer system can tell staff a person has a Learning Disability. This is sometimes called a “flag”



- Creating daily reports on the health of people with a Learning Disability when they are in hospital.
- Making an online computer system of resources to help staff support people in hospital with a Learning Disability.



- The Gloucestershire Hospitals Trust's plan includes things to make the people in hospital, their families and staff looking after them feel better about their time in the hospital.



- People with a Learning Disability will be supported to fill in a '**My Health Passport**' before going into hospital, as these help health workers know about any reasonable adjustments needed



- We will work with people across hospital departments to improve how a person's swallowing is checked and give advice about how food should be prepared. This will help to reduce the number of people choking and getting chest infections.



## Part 5: Conclusions and what is recommended

### Mouth Care Matters



**Questions**

1. What do you think about it?

☐ Good

☐ Bad

☒ Not sure

**ReSPECT** Making a Recommendation Summary Plan

**What should happen for you in an emergency?**

**What is it?**  
The ReSPECT plan provides personalised recommendations for your care in an emergency situation. It is a plan that you and your family or carers can use to help you decide what you want to happen if you need to go to hospital or need to be treated in an emergency.

**Who is it for?**  
The plan is for people with long-term health conditions who may need to go to hospital or need to be treated in an emergency. It is a plan that you and your family or carers can use to help you decide what you want to happen if you need to go to hospital or need to be treated in an emergency.

**How does it work?**  
The plan is a document that you and your family or carers can use to help you decide what you want to happen if you need to go to hospital or need to be treated in an emergency. It is a plan that you and your family or carers can use to help you decide what you want to happen if you need to go to hospital or need to be treated in an emergency.

**What does it cover?**  
The plan covers the following areas: 1. What you want to happen if you need to go to hospital or need to be treated in an emergency. 2. What you want to happen if you need to be treated in an emergency. 3. What you want to happen if you need to go to hospital or need to be treated in an emergency.

**Why is this available?**  
The plan is available to help you and your family or carers decide what you want to happen if you need to go to hospital or need to be treated in an emergency. It is a plan that you and your family or carers can use to help you decide what you want to happen if you need to go to hospital or need to be treated in an emergency.

**What else can I do?**  
You can also use the plan to help you decide what you want to happen if you need to go to hospital or need to be treated in an emergency. It is a plan that you and your family or carers can use to help you decide what you want to happen if you need to go to hospital or need to be treated in an emergency.

- We want to work together with the Mouthcare Matters campaign as it has been shown poor mouth health contributes to people who choke catching **Aspiration Pneumonia**
- For staff, we will encourage them to do training about Learning Disabilities by attending the Oliver McGowan Mandatory Training tier 1 and tier 2 training - <https://www.ghc.nhs.uk/oliver-mcgowan-mandatory-training/>
- We want to always ask if anyone is appointed to help support a person in making decisions about their health
- We want to always ask if they have talked about the **ReSPECT** process and planning for care, before the person came into hospital.

## Part 5: Conclusions and what is recommended

### Conclusion and Action from Learning – please also see Figure 1 on Page 23.



- All of the things that are recommended from the LeDeR reviews will be looked at by the **Quality Assurance** panel and put into a local action plan.



- **The Local LeDeR Steering Group** will check that we are doing what we need to, to make the plan happen.



- Gloucestershire will keep listening and learning from the LeDeR reviews, people with Learning Disabilities and their families to make our health and social care support better.

- The Gloucestershire Learning Disabilities and Autism Clinical Programme will carry on challenging health inequalities. This will improve healthcare, to help stop people with Learning Disabilities dying too soon.



- The new national LeDeR policy will help us make LeDeR in Gloucestershire even better than it is now as LeDeR will soon also include people with Autism.

**Part 5: Conclusions and what is recommended**

Figure 1 – Action from Learning

