Safeguarding Adults Board LEICESTERSHIRE & RUTLAND
Safeguarding Children Partnership LEICESTERSHIRE & RUTLAND
Leicester Safeguarding Adults Board WORKING IN PARTNERSHIP TO KEEP ADULTS SAFE
Leicester Safeguarding Children Partnership Board WORKING TOGETHER TO KEEP CHILDREN SAFE

Safeguarding MATTERS

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Welcome

to our special edition of Safeguarding Matters.

This editions focus is on Safeguarding Adults with Learning Disabilities

Safeguarding Adult Reviews locally have identified important learning for multi-agency working and service delivery

We hope that the information in this issue directs reflection on current practice, attitudes, blocks and solutions. to supporting adults with Learning disabilities to be safe and well

Much of the content in this issue is taken from the Safeguarding Adult reviews of Nigel and Anna plus additional information from other reviews and national sources

The work of the Board is a Multi Agency effort but a special thanks goes to Alison Taylor Prowe Designated Professional for Safeguarding Adults LLR Integrated Care Board for her summary of the cases concerned and to colleagues from the LeDeR programme for specialist imput.

Easy Read Resources can be printed

Nigel

Nigel died as a result of Covid-19 when he was 38 years-old. He had a learning disability and autism and required a wheelchair to mobilise.

At the time of his death he was being treated for swallowing problems and as a result he had experienced significant weight loss. At the time of his death his Body Mass Index (BMI) was 9. He had also developed pressure ulcers.

Nigel lived with his parents and attended a Day Centre

Who is Nigel?

This recording was made using the information provided by those who knew him well

I am Nigel Recording

Anna

Anna was 36 years old and had a learning disability and autism.

Anna died of an infection. In the months prior to her death her food and fluid intake had significantly reduced and she became frail due to weight loss. At the time of her death she had a low BMI. Anna was living in residential care and visited by her parents regularly.

The Voice of the Adult is Heard

Reflection Point: *when working with adults with a learning disability how are you assured that you place their voice at the centre of your care plans.*

If you listen you will hear us - Video

The voice of the adults were not heard and as a result the adult's human rights were not upheld. Both adults were unable to verbalise their care needs. Nigel and Anna were non-verbal and as their health deteriorated their communication reduced further. Therefore, they were reliant on those around them to provide them with appropriate assessment and treatment and care. Nigel had a Communication Passport but this was not used by professionals.

Professionals in the community relied on communicating with Nigel's day centre to arrange appointments as his parents did not want professionals in the home. Nigel lived with his parents and when the day centre closed due to Covid and was cared for by his parents at home. His parents then declined professional visits, questioning the competence of staff, other professionals did not request appointments in respect of the parents' preference. This meant Nigel did not get the care and treatment that he required. Inadvertently this led to a focus on the preferences on the parents and not Nigel's best interests. Clinical staff relied on the parents to advise them on his weight and food and fluid intake, which given his BMI at the time of death was likely to have been inaccurate.

Communication Passports

A Communication Passport provides a practical and person-centred approach to passing on key information about people with complex communication difficulties who cannot easily speak for themselves.

A Communication Passport does this by:

- Describing the person's most effective means of communication, so that others can be better communication partners
- Drawing together information from past and present, from many people who know the person, and from different contexts
- Presenting the person positively as an individual, not as a set of 'problems' or disabilities

A communication passport is a way of supporting a person across transitions, drawing together complex information including the person's own views and distilling it into a clear, positive and accessible format.

This helps staff get to know the person. They can then interact/respond consistently to help the person make sense of events and get the best out of what communication abilities they do have.

A communication passport is a vital tool in 'joined–up' inter-agency planning and working. It promotes partnership with families, and is an excellent a way of implementing and recording consultation/participation of the individual.

The communication passport belongs to the person – not to staff or family, though they may help him or her to use it appropriately, and update it. Passports are especially important at times of transition, when new people come into the person's life and information may not be passed on. They are also helpful when new or temporary staff or volunteers meet the person, helping them quickly to acquire key information, or for example, introducing a person to a new service. The process of creating a passport can help in the process of assessing people and their needs, and in identifying gaps in assessment.

What should be included in a communication passport?

It should have photos and pictures so the adult can enjoy reading it, will want to show it, and be involved in adding new things to it. Passports can be made in a wide range of formats; printed or digital (for tablet or PC).

Being a good communicator

Communication isn't just about talking, it's also listening.

When you're communicating with someone with a learning disability, think about your tone of voice and your body language, as well as the words you use.

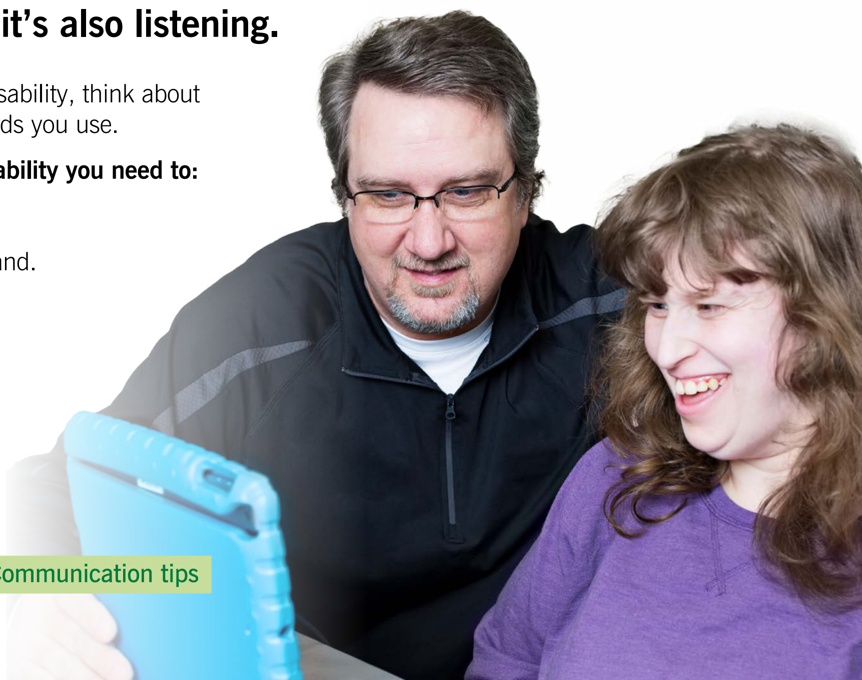
To be a good communicator with people with a learning disability you need to:

- use accessible language
- avoid jargon or long words that might be hard to understand.
- be prepared to use different communication tools
- follow the lead of the person you're communicating with
- go at the pace of the person you're communicating with, check you have understood and be creative.

Below are links to the Local Learning Disability Partnership Boards

Leicestershire Partnership | Leicestershire Partnership Communication tips

Rutland Partnership | Leicester Partnership



Addressing and challenging inappropriate language

***Reflection** - Do you feel confident to address and challenge the use of inappropriate language, including if used by carers and family members*

In a recent case review it was noted that relatives described their adult sister her as 'having the mental age of a three year old'. The review panel discussed how terminology and language can impact on how a person is viewed and they they view themselves.

Language is never neutral, all language has meaning that goes beyond being purely descriptive. It shapes how we see each other, the value we place on different identities, and how we actually behave.

Powerful and pervasive views are often reinforced in the media, books, films, comics, art and language.

Some disabled people internalise negative views of themselves and develop feelings of low self-esteem and underachievement, which reinforce non-disabled people's assessments of their worth.

Language used to describe an adult with learning disabilities or their behaviour can be at times be discriminatory, negative and disempowering. In order to get people to consider their language and change perceptions it is important to challenge what is said.

How To Challenge Discriminatory Language

Top tips for challenging discriminatory language in a kind and constructive way:

Ask questions

A great place to start is by responding to the language with a question, such as "what does that mean?", or "Can you explain that to me?". These kinds of open-ended questions let the other person think about their intentions and explain what they meant by it. Sometimes this can be enough to help someone realise that their words have an impact on others, and that they should think about what they mean before they say something.

Challenge the language, not the person

Remember – everyone makes mistakes and people can change their behaviour over time! If someone has said something unkind, it doesn't mean that they are an unkind person. The aim of challenging it is to encourage them to change their behaviour – try not to focus on what they have done already but instead how they can choose to act differently next time. For example, instead of saying, "You're hurting people's feelings by saying that.", try asking, "How do you think that word might make someone feel?".

Mention how it makes you feel

Sometimes, it might be someone you know or cares for the adult that uses discriminatory language. This can make it even harder to challenge it, because we don't want to upset them or hurt their feelings. However, remember that they care about the person they wouldn't want to hurt them or you – if they have said something that makes you feel uncomfortable, let them know.

Help them understand

Explain why what they're saying might hurt someone's feelings and may affect their self esteem . Try to encourage them to see it from a different perspective than their own – share relevant personal experiences if you feel comfortable to do so. Remember, you might not be able to change everyone's mind, but taking an educational approach to what has happened and explaining why it's harmful might help someone see things differently.

Mencap Resource - Learning Disabilty Explained

Examples Of Ableist Language You May Not Realize You're Using

Assesing Risk when essential care is not provided?

Reflection: *are you familiar with how to escalate concerns regarding deterioration of a persons health and home conditions, including how to make a Safeguarding Alert or case escalation?*

Reflection: *Do you have access to the LLR Safeguarding Adult Thresholds and have you completed Safeguarding Adult Training?*

Reflection: *Do you know how to make a Carers Assessment referral?*

Sometimes families who are providing care to a relative may have established their own ways of managing the care or maybe managing competing priorities or Hidden Harms such as domestic abuse, substance misuse as well as financial problems or mental health problems. Nigel and Anna and others are:

- Family refusing care visits to support continence and hygiene
- Family deciding not to follow the care plans implemented by professionals.
- Family lifting the adult in a manner that is not aligned with safe manual handling techniques.
- Family refusing prescribed equipment or interventions due to their needs or preferences.
- Family requesting services that will not meet the needs of the adult.

It is critical that all professionals working with adults with care and support needs exercise **professional curiosity**. Efforts should be made to establish why a family are opposing the proposed care or treatment. A family carer may not intend harm through their actions and it is essential that professional explore their concerns and resistance and explain the risks. Consider a **Carers Assessment** (City & County & Rutland) for all family carers. Try to establish if there are any safeguarding concerns in the home or if anyone is struggling with their mental health. Professionals may worry that such enquiries will have a negative impact on their relationship with the carer. However, we need to remember that no adult has the legal right to prevent another adult from receiving the care and treatment they require. If the prescribed care cannot be established in a timescale that assures the wellbeing of the adult then a **Safeguarding Alert** is required for the adult **under the category of neglect**.

If there is any concern that an adult is not receiving the care they should be receiving consider whether a Safeguarding Alert is required by applying the Safeguarding Adults Thresholds.

In Anna's case professionals raised safeguarding concerns with a worker in adult social care however they were not explicit that this was a Safeguarding Alert. Inter-agency disagreements regarding safeguarding decisions should follow the LLR Safeguarding escalation process.

Annual Health Checks

Anyone over the age of 14 who is on their GP learning disability register is entitled to an Annual Health Check.

Health checks can ensure that an adult with a learning is supported with their health and wellbeing and problems can be discussed and addressed. In Anna and Nigel's cases they lost significant amounts of weight and became frail as a result. LeDeR (Learning from Lives and Deaths of People with a Learning Disability) have developed the following guidance around consideration of weight concerns which also provides guidance about the expectations around weight management within Annual Health Checks www.bristol.ac.uk/media- library/sites/sps/leder/2103_Nutrition_PDF.pdf

If an adult is not brought to their Annual Health Check please consider your policy video called Was Not Brought

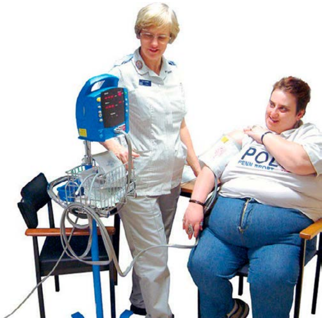
If you are concerned that an adult with a Learning Disability has not had an Annual Health check you can contact the Primary Care Learning Disability Team can be contacted at LPT- PCLN@leicspart.nhs.uk

See Easy Read resources explaining Annual Health Checks

Easy Read Resource

What is an Annual Health Check

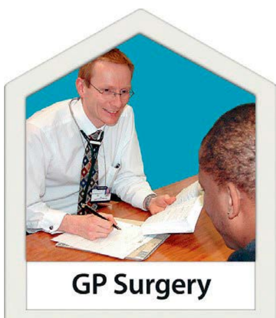
A health check is when the doctor checks if you are healthy.



You don't need to be ill to get a health check. But you can ask your doctor about anything that is hurting or worrying you.

It is a good idea to have a health check 1 time every year.

Health checks normally take between half an hour and 1 hour but you can leave whenever you want.



Health checks happen at the doctors.

Your doctor should do some of your health check. A nurse might do some as well.

You can ask someone to come to your health check with you if you want.

At a health check the doctor or nurse will check things like

- how much you weigh

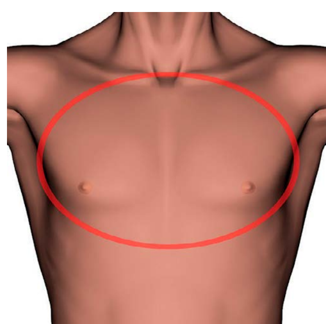
- your eyes

- any medicine you take

- if you are feeling happy or sad

- what food you eat.

There is a list of everything they should check at the end of this leaflet.



The doctor or nurse might ask you to take some of your clothes off so they can check things like

- your chest

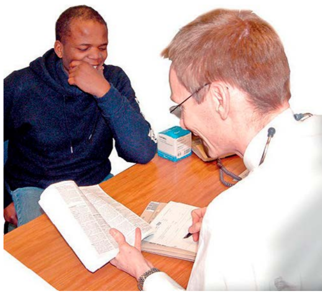
- your tummy.

Your doctor might want to check your wee.

You can bring this with you in a bottle. Or your doctor can give you a bottle to wee in when you come to the doctors.

You don't have to do this if you don't want to.

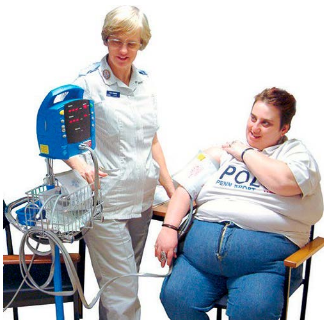
You can say no to any part of the health check if you are unhappy.



After your health check the doctor or nurse will say if you need to go and see any other people that can help you.

Easy Read Resource

How to get a Health Check



Lots of people with a learning disability can get a health check.

You can speak to your doctor to find out if you can get a health check.

Some doctors don't do health checks.

If your doctor does not do health checks, you may still be able to have a health check somewhere else.

Ask your doctor to tell you about another doctor that will give you a health check.

If you can have a health check you don't need to pay for it.

You can ask someone to help you get a health check if you want.

- You can ask someone like
- your carer
- someone in your family

Everything that should be checked in your health check

You can use this list to make sure your doctor or nurse checks everything you want them to.

If you don't want your doctor or nurse to check some of these things just tell them.

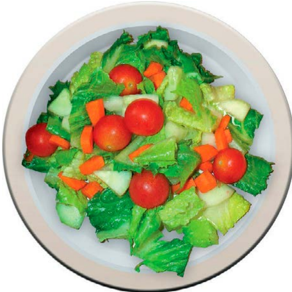
Has your doctor or nurse checked

- how much you weigh

☐ Yes ☐ No

- how tall you are

☐ Yes ☐ No



- what food you eat

☐ Yes ☐ No

- what exercise you do

☐ Yes ☐ No

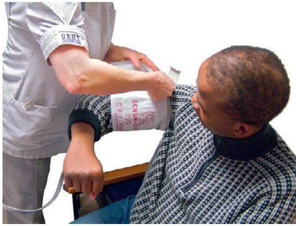
- if you smoke

☐ Yes ☐ No

• if you drink **alcohol**

Alcohol means drinks like beer and wine

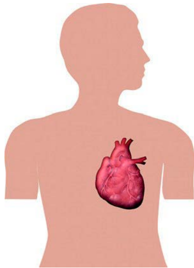
☐ Yes ☐ No



• your **blood pressure**

Blood pressure means how fast your blood moves around your body. If blood moves around your body too fast it could make you unhealthy.

☐ Yes ☐ No



• your heart

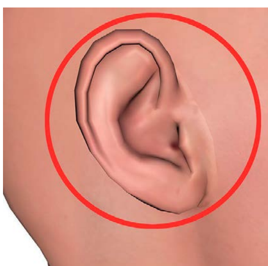
☐ Yes ☐ No

• how you breathe

☐ Yes ☐ No

• your eyes

☐ Yes ☐ No



• your ears

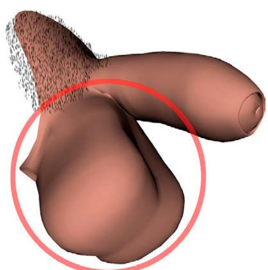
☐ Yes ☐ No

- what medicine you take

☐ Yes ☐ No

- your wee

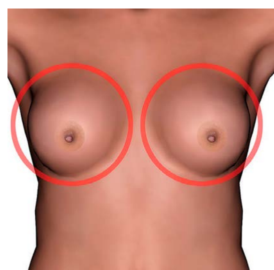
☐ Yes ☐ No



any other tests you have had

For example you might have had your balls checked if you are a man.

☐ Yes ☐ No



For example you might need your breasts checked if you are a woman.

☐ Yes ☐ No

a check of any other illnesses or problems you have

For example you might have epilepsy.

☐ Yes ☐ No

a blood test if you need one?

☐ Yes ☐ No

Diagnostic Overshadowing

We know from research that adults with a learning disability are at risk of diagnostic overshadowing.

"This occurs when the symptoms of physical ill health are incorrectly either attributed to a mental health/ behavioural problem or considered inherent to the person's learning disability or autism diagnosis"
(NHS England, 2021).

In the context of learning disabilities this means that 'symptoms of physical ill health are mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person's learning disabilities' (Emerson and Baines, 2010).

What are the implications of diagnostic overshadowing?

Diagnostic overshadowing, leads to compromised patient care and likely contributes to increased mortality experienced by individuals with mental illness. Prior to their deaths Anna and Nigel were unable to eat and drink adequately.

Sometimes adults with a learning disability and autism can experience difficulties eating and drinking. It is critical that the cause of this is assessed and an appropriate treatment plan is put in place. You can access the LPT Learning Disability Nursing Team: through the LD Access service LDACCESSTEAM (LEICESTERSHIRE PARTNERSHIP NHS TRUST) lpt.ldaccess@nhs.net or via Referrals - Leicestershire Partnership NHS Trust (leicspart.nhs.uk)

Any differences of opinion between professionals should be managed through respectful challenge. If differences cannot be resolved between professionals then the internal organisational escalation processes should be used. If interagency disagreements cannot be resolved between professionals then concerns should be escalated between organisations using local escalation processes.

If there is any concern that an adult is not receiving the care they should be receiving consider whether a Safeguarding Alert is required by applying the Safeguarding Adults Thresholds. In Anna's case professionals raised safeguarding concerns with a worker in adult social care however they were not explicit that this was a Safeguarding Alert. Inter-agency disagreements regarding safeguarding decisions should follow the LLR Safeguarding escalation process

Mental Capacity

Reflection: are you confident in applying the MCA and have you completed MCA Training?

The Mental Capacity Act (MCA) is a tool for empowering adults who are unable to make decisions for themselves

The MCA is essential in placing the adult at the centre of your care, appropriately used the MCA ensures that the adult's human rights are upheld. Professionals did not attempt to gain Nigel's consent to treatment. Nigel's family were treated as the decision makers. In Anna's case professionals did not consistently communicate with a shared understanding of the MCA. Some professionals acted in Anna's Best Interests as defined by the MCA, however others did not which contributed to unresolved disagreement between professionals. If an adult is assessed as lacking capacity to make decisions around care and treatment then decisions should be made in their Best Interests (as defined by the MCA). In Anna's case not all professionals considered her Best Interests using the MCA.

Relevant MCA assessments and Best Interest decisions should be documented in their records and reflected in care plans. It is important that family providing care for an adult understand their roles and responsibilities under the MCA. Professionals and family should apply the five principles of the MCA in their provision of care and treatment. These obligations should be explained to families and education should be provided to the family. If after explanation and education professionals or family members are not acting in the adult's Best Interests (then this is a safeguarding concern under the category of neglect and Safeguarding Adult Alert should be made.

For more information What the Law says - My Adult still my Child

Mencap – Mental Capacity Act Resource Pack for Parents and Carers

See Easy Read Resource to explain the issue of consent and Best Interests

Easy Read Resource

Consent and capacity

Helping you make important choices

Consent is being asked if you agree to something.

This means saying **yes** or **no**.

Sometimes we have to make very big choices like:

- Do I want to live in this house?
- Should I have an operation at hospital?

Capacity is whether you understand the choice you need to make.

The law says that everyone over 16 years old can make their own choices unless we find out they can't.

We must work hard to help people understand their choices before we say they don't understand.

Helping you to make big choices.

There are many things the law says people must do to help you understand the choice.

- Spend time with you explaining things.

- Get help from someone who knows you well and can help you communicate.

- Use things like Easy Read Factsheets, photos, and pictures, to help you understand.

Having an Eye Test

You need to have your eyes checked

- Help you visit places like a hospital or an opticians so you better understand what you may be agreeing to.

To give consent you need to be able to:

- Understand the information about the choice.
- Remember the information long enough to make a choice.
- Think about what is best for you.
- Communicate your choice.

What if you cannot understand the choice?

If you really cannot understand your choice other people will need to make the choice for you.

If you are aged 16 or over a family member, social worker, advocate, or care worker cannot usually give consent for you.

They can only give consent for you if the law says they can. They need to have been appointed as a Deputy, or have Lasting Power of Attorney.

If you are not able to consent to one big choice people are not allowed to say you cannot consent to other big choices without trying to help you understand them.

Thinking about your 'Best Interests'.

It is important that you have all the help you need to stay healthy and well. This can include things like:

- Having your eyes tested.

- Having an eye operation if you have cataracts.

People may agree that having an eye test or an operation is the best thing for your health. People cannot decide for you in your 'best interest' just because they do not agree with your choice.

A 'Best Interest' meeting.

If you cannot make an important choice yourself there should be a 'Best Interest' meeting.

At the meeting people talk about what is best for you.

People like your family and advocate should be invited to your best interest meeting.

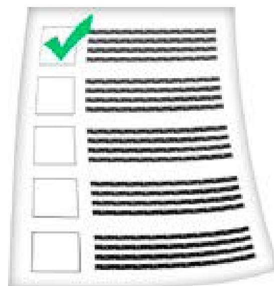
If you don't have a relative

or your own advocate an Independent Mental Capacity Advocate (IMCA) can be found.

An IMCA can help if your choice is about serious medical treatment or changing where you live.

People at the meeting will need to talk about:

- If it is best that you have the treatment.
- The best way to do the treatment so you do not get very upset.
- Helping you get better after the treatment.



My Role

Job title	Primary Care Liaison Nurse (PCLN)	NHS Leicestershire Partnership NHS Trust
Organisation	Leicestershire Partnership Trust (LPT)	

Tell us about your team:

The PCLN team are a hosted service within LPT and consists of three full time posts; City, East and West covering Leicester,Leicestershire and Rutland

The main role and function is to support primary care services to reduce the unacceptable inequalities faced by people with Learning Disabilities (LD) when accessing non specialist LD health services.

The PCLN team are a resource for primary care and mostly provide 'arm's length' guidance, advice and support to primary care staff to enable them to deliver a better service to people with a learning disability.

- Supporting the implementation of the LD annual health check. This involves providing essential training and support directly to practice staff and developing new strategies for engagement with the Integrated Care Bioard (ICB).

- Supporting equitable access to the cancer and non-cancer screening services by providing education, training, advice and guidance to screening services and working strategically with Public Health Commissioners.

- Supporting the implementation of Stopping The Over-Medication of children and young. People with a learning disability, autism or both (STOMP) and. Supporting Treatment and Appropriate Medication in. Paediatrics (STAMP) into primary care, providing training to primary care staff to include pharmacists. Along with providing awareness session to providers and engagement/ collaboration with other services as appropriate.

Tell us about a typical day:

Days vary and are a response to primary care needs engaging in the role and functions as above.

The team very much enjoys working within GP practice, working collaboratively with wider members of a Multi-Disciplinary Team (MDT), screening services, patient user groups.
The Team also have the opportunity to support patients with annual health checks considering reasonable adjustments with access.

Currently the team is running a pilot supporting the delivery of the annual health check to people who for whatever reasons have not engaged with their practice for two years or more or may find the environment, or the process of engagement with health interventions difficult and may present with behaviours of concerns. The pilot works with the patients, families, carers, and primary care.

What is your safeguarding best practice top tip?

Using professional curiosity and always being mindful that the Mental Capacity Act is implemented as appropriate.

Contact Details Contact info
0116 225 6000
lpt.pcln@nhs.net

Contact us

Leicestershire and Rutland Safeguarding Children Partnership and Safeguarding Adults Board

The Safeguarding Partnerships Business Office, Room 100, County Hall, Glenfield, Leicestershire, LE3 8RF. Telephone: 0116 305 7130 Email: lrspbo@leics.gov.uk