

Prevention when working with people with Learning Disabilities

Safeguarding Adult Partnership Event 8 October 2019



Welcome





Aim of today



The focus of this Safeguarding Adult Partnership event is Making Safeguarding Personal,
Prevention and Early Intervention and Risk
Enablement for adults with learning disabilities





Learning Disabilities Mortality Review (LeDeR) Programme





What is LeDeR?

- A national programme looking at the deaths of persons with learning disabilities across the whole of England
- Commissioned by NHS England, coordinated by Bristol University, and delivered locally.
- An individual review of every death of a person aged 4+ is undertaken.
- The findings from these individual reviews are then collated into national and local reports to identify key themes and learning points.
- The third annual LeDeR report was published earlier this year
- A commitment to continue to deliver the LeDeR programme has been included as part of the new NHS 10 year plan



Why does LeDeR matter?

- Persons with a learning disability die 23 years earlier than the wider population if they are male, and 27 years earlier if they are female.
- They are three times more likely to die from something that good care could have potentially avoided
- LeDeR looks at identifying the reasons behind this inequality how improvements in the quality of health and social care for people with learning disabilities can be delivered so we can reduce this 'mortality gap'



How does LeDeR work in practice?

- Death notifications are made to Bristol University. Bristol then allocate each case (based on patient's GP) to the relevant local area for action
- Each area has an identified 'local area contact' (LAC) who arranges for an independent LeDeR review to take place.
- The LeDeR reviewer is expected to talk to family, relevant professionals, and to examine case notes, before completing a written report. Every LeDeR reviewer must have completed training before taking on the role.
- Each LeDeR review uses a standard 60 question template which includes a pen picture of the person who died.
- The completed review, including identified learning and recommendations, is then submitted to Bristol and is shared with the family and relevant others.
- Each completed review is used to inform both the national annual report, and any specific work or learning that needs to be picked up at local level.
- A LeDeR review is NOT an investigation: the focus of each LeDeR review is to identify learning, both in terms of best practice, and the things we might be able to do better going forward.



Involving families in the review process

"It's very strange because after my son died I said 'I wish I could tell somebody that I'm concerned about the fact that people don't get monitored when they've had clots' and then this cropped up and I just couldn't believe it. It was such a good opportunity to talk to somebody, and to try and forward this idea."

Father of a person with LD



Progress in Birmingham to date

- 100 death notifications received in last 2 years
- 77 adult
- 23 children
- 55 adult reviews completed
- 22 adult reviews currently in progress
- 36 reviewers from 11 different organisations
- A local steering group is established
- All completed reviews are being analysed against 10 key themes
- A multi-agency review panel is established and looks at a sample of completed reviews on a bi-monthly basis
- The local annual report is due in December 2019
- A local conference is being held on 21st October 2019



What are people with LD dying of?

The most frequent causes of death as reported to LeDeR:

Pneumonia/Chest infection	30%
Aspiration Pneumonia	25%
Cancer	11%
Heart related	9%
Epilepsy/seizure	6%
Sepsis	6%
Embolism	4%
Other	9%



Key themes we are exploring

- Evidence of routine monitoring of physical health needs
- Recognition of deteriorating physical health
- Timely clinical decision making (i.e no undue delays in treatment)
- Effective pain management
- Effective care co-ordination and inter-agency working
- Holistic approach to care (i.e. consideration of wider wellbeing)
- Advance planning and decision making (effective use of DNAR/RESPECT forms etc)
- Access to End of Life Care
- Effective application of the Mental Capacity Act
- Active family/carer involvement



How you can help.....

You can help the LeDeR programme in three ways:

By raising awareness of the responsibility to report all deaths of a person with a learning disability to the LeDeR programme. LeDeR has a nationwide data sharing agreement under section 251 of the NHS Act 2006. Anyone can make a death notification by phoning 0300 777 4774 or online via the following link:

http://www.bristol.ac.uk/sps/leder/notify-a-death/

Please let families, carers and other professionals know about the importance of making a death notification. Every individual matters and we need learn from every death, not just some of them.



How you can help....

- 2. **By supporting and assisting the work of reviewers**. If you have been involved in the care of a person with a learning disability then an LeDeR reviewer may at some stage want to talk to you. Please, tell them openly what you think! The reviews are a learning process, not an investigation, and the more information you can share the better the quality of the reviews.
- 3. **By becoming a reviewer yourself**. If you are interested, talk to your organisational lead. Reviews generally take between one and two days in total to complete. Reviewers are expected to commit to undertaking at least two reviews each year once they have completed the LeDeR online training package your organisation will therefore need to approve your application to undertake the training package, as there is a time and workload commitment involved.



Next steps

Turning LEARNING into ACTION

What part do you want to play in it?



Further information

http://www.bristol.ac.uk/sps/leder/



Harprit Rai Senior Practitioner

ROLE OF THE TRANSITION TEAM

- The Transitions Team is a city wide service that offers advice, guidance and support to disabled young people, with a range of disabilities/complex health needs who are between the ages of 18 to 25 years.
- The Transition Social Worker will support the Young Person to:
- understand what their ongoing care and support needs might be
- help them to identify and achieve their goals
- Connect the young person to services that are available to support them.

WHAT HAPPENS AT TRANSITION

- All referrals either go through to the front door ACAP or to the Transition Team directly.
- The young person is referred from any of the following:
- Children's Services
- Continuing Care Services
- Children's OT Services
- Children's Asylum / Refugee Team
- Forward Thinking Birmingham (FTB)
- Families
- Care Providers
- Other professionals

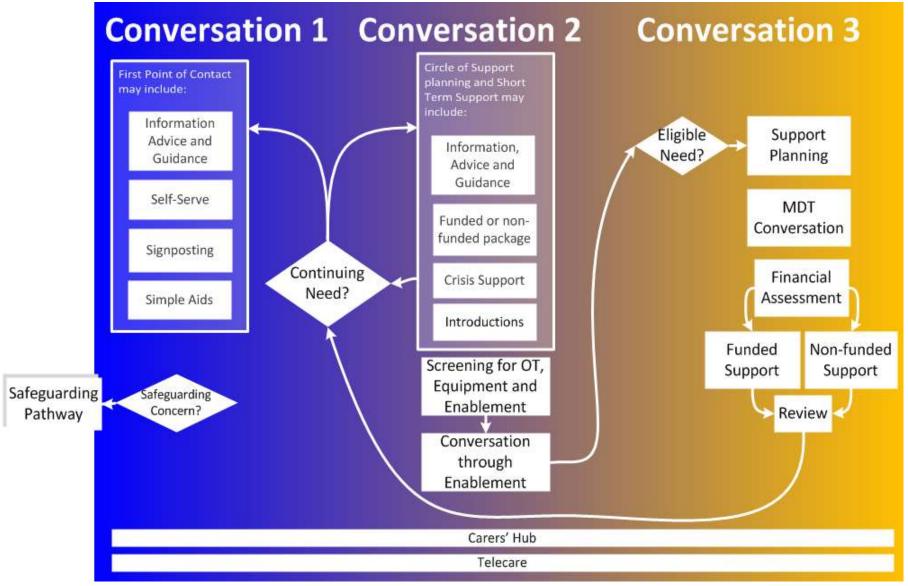
WHAT HAPPENS AT TRANSITION

- Once a referral is received, it will be screened by the duty senior practitioner and a decision will be made about whether the referral is appropriate for the team and a priority level given.
- Referrals from Children Service should be made by the allocated Children's worker within 3 months of the young person's 17th birthday.
- Early referrals support an effective transition, as well as joint work to support the best outcomes for young people.
- A Transitions Worker will be allocated to co-work with a Children's Social worker

WHAT IS THE REALITY OF THE MOVE TO ADULT SERVICE

- Is the young person is disabled, **and** is likely to meet the eligible criteria (Care Act 2014) at 18?
- Ongoing Adult social care needs will be measured against the Care Act 2014 eligibility criteria rather than the Children's Act 1986.
- An adult social worker will be allocated to work alongside the children's social worker who will commence a conversation using the 3 Conversation model (see next slide).
- The social worker will signpost to other services where appropriate to do so and will consider enablement, Continuing Health Care (CHC) and community networks before long term funding is sought.

Three Conversations Model





Enablement Services

- The Transition Social Worker will always consider enablement at conversation 1, 2, & 3 before long term funding.
- The Learning Disability Enablement Service can start working with a young person from 17yrs for a period of up to 6 months.
- Enablement can work with the young person to achieve the following: Meal prep, cleaning, using washing machines, shoppingwriting a list, finance- budgeting, paying bills, understanding money, scheduling- planner for daily tasks, community activities, medication, personal care, maintaining tenancy- finding accommodation, travel trainingroad safety, transport by bus/taxi/train etc

Continuing Healthcare Criteria (CHC)

- At any point of conversation 1, 2 & 3 consideration will be given to whether a CHC assessment is needed.
- The adult social worker will complete a CHC checklist if it is indicated that the young person has a primary health need.
- ▶ The Transition Team have a CHC nurse on the team that can work with a young person from age 17 ½. If the CHC criteria is met, health will take over care management responsibility from age 18.

TEAM STRUCTURE

- 1 Group Manager
- 1 Team Manager
- 3 Senior Practitioners
- 15 Social Workers
- 1 Person Centred Planner
- 1 Transition Nurse
- 1 Specialist LD OT

QUESTIONS





Citizens

How safe do I feel living in Birmingham?





Table Top Exercise

How do we make safeguarding personal for our citizens with learning disabilities?

What do we need to do more or less of?

How can we work together to improve Transitions?







Break & Networking





Safeguarding Adults



Vision, Purpose and Motivation



Effective Engagement

- Children
- Parents



- In Schools
- In Homes
- In the Community



...a conversation with...

- A client?
- A referral?
- A real person...



Thank you for your participation

The next

Safeguarding Adults Partnership Event is:

3 December 2019

VENUE: TBC

