safeguarding adults at risk

a cumbria partnership

Judy Benn

September 2016

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JUDY BENN The Critical Last Days

A Significant Incident Learning Process (SILP)

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September 2016

Peoplefirst
Independent Advocacy

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"The concern is that a person with learning difficulties, with 24 hour professional care, died of a treatable complaint..."

HMC Senior Coroner
David Roberts, 2015

Judy on the right, with her twin sister,Liz and brother, David.

Foreword

by Mike Houghton-Evans, Independent Chair of Cumbria Safeguarding Adult Board

I would like to thank People First with Judy's family for undertaking this review on behalf of the Cumbria Safeguarding Adults Board. This is an in depth and excellent account and analysis of the events leading to the death of Judy who, although she was someone with learning disabilities, was an individual in her own right. Whilst the Coroner concluded that no individual or organisational blame was attached to Judy's death, he has noted that she had died of a treatable condition. There is good evidence for a justifiable and current concern that people with learning disabilities with communication difficulties do face a higher risk of having their health and social care needs overlooked.

The Safeguarding Board felt that there was sufficient reason to commission a 'lessons learned review' and that this be through utilising the Significant Incident Learning Process as the most appropriate means of ensuring a transparent focus on the issues and adherence to the principles that underlie the Safeguarding Adults process. That is:

- Keeping the focus on learning not blaming
- Avoiding hindsight bias
- Observing honesty and openness

Another key principle is that there should be commitment from the agencies represented to take forward any action points from learning. This is why the Safeguarding Adults Board (SAB) will continue its involvement in Judy's case. The Board has now received this report and its findings have been fully accepted. A sub-group of the Board will put together to develop an improvement plan and the Board will provide governance over this plan calling agencies to account for improvements they commit to.

Judy's family have contributed to this work and will be invited to be involved throughout the preparation of this plan and with progress, as it is implemented.

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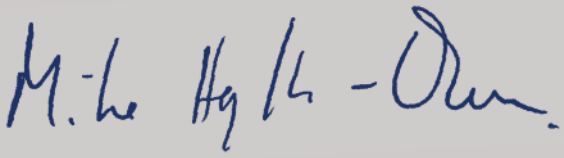


Mike Houghton-Evans

Introduction

This is the report of the Significant Incident Learning Process (SILP) conducted in respect of Judith Benn who died age 54 at Cumberland Infirmary on the 29th April 2014 of a volvulus (a twisted bowel) Judith was a woman with learning difficulties who lived in a supported home environment and received 24 hour care. Judith Benn was known to her family, friends and carers as Judy.

People First Independent Advocacy (PFIA) provides statutory and non-statutory advocacy within Cumbria. David Blacklock, CEO, is a member of the Safeguarding Adult Board and was approached in October 2015 to undertake a SILP in relation to her untimely death.

This report is divided into four sections to follow a chronological view of how the SILP came to take place and the information that needed to be considered in planning and during the event.

Part one starts with a focus on the life of Judy Benn and who she was as a person. This is collated from the memories of staff who worked with Judy, supplemented with information from her brother and twin sister. We wanted Judy to be at the very centre of the work we were doing for the SILP. We follow this by looking very closely at what happened leading up to Judy's death.

Part Two sets Judy's untimely and avoidable death in the context of national research around the premature deaths of people with learning difficulties that was alluded to in the Coroner's report. The focus here is on Judy's death, the post mortem, the Coroner's Inquest and his concern for a SILP to take place. There is a short explanation of the Safeguarding Board procedure for setting up an SILP and what is expected to be achieved by holding an SILP. We also introduce PFIA, our values and how we approached the work.

Part Three of the report details the SILP event and describes the activity that took place on the day; the programme is worked through chronologically. There is a detailed description of the discussion that took place amongst the group around what happened and what could have been done differently to have avoided Judy's death, and to avoid the situation ever occurring again. This resulted in a number of questions being generated that added to the questions from the Coroner's report and asked by Judy's family.

Part Four focuses on the practical application expected by the agencies and organisations involved. The group were asked to consider key points for remedial action taken from the discussions with additional points from PFIA as issues arising. These had clear lines of responsibility and target dates set against the actions. This is displayed as a table followed by a short summation of the process. We have included appendices of key documents and supplementary information.

PFIA, May 2016

PART ONE

Who was Judy Benn?

It is important for us to place Judy at the centre of the work around the Significant Incident Learning Process. This section begins with information about her life and characteristics as remembered by her family and people who worked with her over the years.

Judy Benn was born on the 17th July, 1959. She had a brother, David and a twin sister, Liz. The family lived in Cumbria near Wigton; they had a happy family life. Judy was much loved and was particularly close to her father. Her mum Jean, was a staunch advocate for Judy up until she died. When Judy reached the age of 11, her parents, Jean and Gordon, made an agonising decision for her to go and live at Dovenby Hall, a local institution for people with learning difficulties. Judy lived there for many years, having regular visits from family. She moved out after the institution began its closure programme in 1997.

Judy originally moved into a supported home in the centre of Carlisle and then later moved to the outskirts of town, into a shared home, with two other residents where she received 24 hour care from the care agency United Response (UR). This was the home that Judy lived in until she died at the age of 54.

It was said that Judy had a 'wicked' sense of humour and loved slapstick comedy. She also knew her own mind. On a 'good day' she would be full of smiles and have a sparkle in her eyes. Other days she may not have wanted staff near her or she wouldn't want to go out. She was sensitive to other people's moods and had suffered from depression after the death of her father and later her mother, eighteen months before her own death. She had taken her mother's death 'very badly'.

Critically, Judy did not verbally communicate although she could make her feelings abundantly clear to those around her and those who knew her. She developed her own pattern of communication where rubbing her stomach or pointing to her teeth meant she was in pain; she would clap to say 'no'.

Judy's health was described as 'good' a few weeks before she died. She had been visited by her sister and brother in law and spent the day going out in the car, visiting Silloth, a local seaside town. She had eaten fish and chips and had a great day. Her sister said it was the best she had seen her since the death of their mother.

Medical issues and support needs

Judy has been described in official documents as having 'severe learning difficulties' and also as having 'moderate learning difficulties'. She needed people who knew her to help her communicate effectively. She required 24 hour support and could be vulnerable. It is noted that she had a longstanding issue with constipation which was managed, at times, with high doses of laxatives; Movicol. Judy had also been taking Venlafaxine for her depression since 2012, and in 2013 she had been given Diazepam for three months with a view to it helping her feelings of anxiety when she left the house. Her medications were given in her 'best interests' as she was assessed to lack capacity to consent to medical treatment.

Family day out - Judy was particularly close to her father, Gordon.

Judy's Family

Judy's brother David, a social work manager, lives in Yorkshire and her twin sister Liz, a nurse lecturer, lives in Guernsey. Liz had previously raised concerns about the management of her constipation because of the amount of laxatives taken.

At the time of Judy's death, both her brother and sister had concerns over the treatment and management in the period up to admission to Cumberland Infirmary and questioned if everything was done that could have possibly saved their sister. They were both involved in the coroner's inquest and in the setting up of the SILP.

Key Events and Interventions

There is a wealth of information covering the recorded events leading up to Judy's death, gleaned from organisational records, the chronological report from the Cumbria Safeguarding Adults Board, conversations with the family and the Coroner's report. We have amalgamated and sifted through this information to demonstrate the key facts and events in the lead up to Judy's death. The aim of this section is to provide an overview of *what happened?*

Judy was much loved and had a happy family life.

How did Judy die? Key events and interventions.

In regard of her health and wellbeing, what is known about Judy is that she had difficulties in communicating verbally and that she had been viewed as lacking capacity to consent to medical treatment on the occasions she was administered drugs in her 'best interests'. It was known that she had a lifelong history of bowel problems. Judy's colon in the upper left quadrant was noticed to be distended on a chest x-ray in **September 2013**. Judy had been overweight and had been on a 'healthy eating' plan in the few years prior to her death, going from a size 22 to size 14 in clothing. She had problems with constipation and took laxatives, a cause of concern raised by her sister in **November 2013.** It was also known that Judy was anxious about being physically examined by medical staff and that when she was anxious she did not want to leave the house. In contrast, we know that on her last day out to Silloth with her sister, on **April 20th 2014,** she had appeared to be at the *'best she had seen her in a long time'*.

In the critical few days leading up to her death, Judy's condition changed rapidly. On **Thursday April 24th** Judy had constipation and had been unable to walk or talk. She had 9 sachets of Movicol in the past 24 hours, which had been advised by Cumbria Health on Call (CHoC) the day before. Judy had been 'shouting out in pain'. There was no vomit but she was very agitated and not letting staff near to her. This information was passed to the district nurse to assess her bowels, but staff were concerned Judy may not let anyone examine her. Judy was given two paracetamol.

On **Saturday April 26th**, Judy was constipated and disorientated with pain. The Movicol did not appear to be helping. The UR staff team were concerned and phoned CHoC. They were told to increase Movicol to 6 sachets a day. There would be a review the following day and the staff were asked to call back if necessary.

On **Sunday April 27th**, UR staff were still concerned that Judy had constipation. She was 'shouting out in pain', was very agitated and would not let staff near to check or change pads[1]. The staff rang CHoC for advice and had a consultation at 12.54 which lasted for 13 minutes. CHoC advised to give Judy Movicol up to 6 in a day at 2 hourly intervals until her bowels opened, then to reduce to twice daily. They were to contact her GP on Monday. UR recorded that 2 district nurses would call to give her an enema. At 15.00, they arrived and attempted to do this, but Judy refused to let them. They felt her stomach which was 'really hard'. They advised to continue with Movicol and give regular paracetamol.

On **Monday 28th April,** staff at UR were concerned that Judy had still not opened her bowels and rang her medical practice. They were informed a doctor would come and visit but had not given a specific time. The doctor visited at 17.30, and queried if Judy had a bowel obstruction; her bowels had not been opened for five days. At 19.50 the service manager contacted the ambulance service as Judy's condition was worsening. An ambulance was booked to take Judy into hospital but UR were informed it could take up to 4 hours as it was not booked as an emergency. They would need to phone 999 if they wanted an emergency ambulance. At 20.10 the service manager phoned 999 to inform Judy's condition had worsened, she was told a paramedic would call back. They said they would try and get an ambulance to the house within 20 minutes. At 20.50 the ambulance arrived at the house. Judy was very anxious and would not allow the paramedics or staff to get near to her to help her into the ambulance. She was becoming more stressed and anxious. It was discussed that she had responded well to diazepam in the past and so it was decided to ask a CHoC doctor to come and administer the sedative and then they would return later to take Judy to hospital. It was agreed it would be best for her to go straight through to a ward and not through A&E.

[1] *Note these notes appear repeated from the 24th but this is how they appear in the SAR chronology from SAB*

At 22.00 the CHoC doctor contacted the house to say someone would call and give Judy the medication she required and then an ambulance would be sent to take her to the hospital. Additional staff were brought on duty at the house so that Judy had someone to support her to the hospital. It was noted that the Cumberland Infirmary was on postcode alert.

A CHoC doctor then went on a home visit to Judy at 00.30. He '*tapped her to wake her up and she seemed mesmerised by him*'. He managed to examine her and found her calm and comfortable in bed. He examined her abdomen which was full and firm but not visibly distended and found her to have no tenderness during a rectal examination; there was a firm to hard stool in her rectum. He felt she was not likely to have an obstruction as she had passed gas; he gave her a micro-enema as that was all he had available in his car to use. He rang the District Nurse to come and give another enema. He said he would not be giving Judy a sedative as she would not be going to Cumberland Infirmary because they had '*closed their door to admissions*'. He said her symptoms did not qualify for admission because it was not an intestinal obstruction. There was a heated discussion between the house staff and the doctor who said '*he could not justify more time spent on constipation*'. He knew the staff were upset so he called his supervisor on the phone and explained the situation; his thinking was confirmed. In evidence to the coroner the supervisor confirmed that the description given at the time did not fit evidence of a classic intestinal obstruction. It was noted by house staff that the doctor had not carried out a vital signs examination on this visit.

At 02.30 on **Tuesday 29th April**, the district nurse arrived to administer an enema. Judy was sleeping so it was agreed she would not be woken up but that the nurse would call back in the morning; the staff were to contact CHoC if there were further problems. At 09.30 the service manager contacted the Learning Disabilities Nurse for advice and support. She advised to phone the GP practice and inform them they needed to put a plan of action into place to admit Judy into hospital. At 10.00 the practice was called and the receptionist said she would call back as Judy's notes were with triage. At 10.30 it was agreed that a prescription for diazepam would be faxed to the pharmacy, staff would collect the medication and once administered, an ambulance would be called. The medication was administered by staff at the home at 12.30.

At 12.45 the home rang the GP practice to say if an ambulance didn't arrive quickly they would need to phone 999. The ambulance arrived whilst the phone call was happening. At 14.00 Judy arrived at the hospital where she was taken to the surgical assessment ward. She did not want to cooperate with staff taking observations. Her oxygen was low so she was given oxygen and fluids. UR staff stayed with her and passed information on to the service manager. After 16.15 Judy was assessed - her blood pressure had dropped and there was notable deterioration. She had a low white blood count and sepsis. It was decided that active intervention was not possible as Judy was too unwell for surgery.

At 16.30 after speaking to doctors and nurses regarding Judy's rapid deterioration, the service manager rang Judy's family to inform them of the situation. At 17.30 the house staff were asked a lot of questions about Judy's history of events over the past few days, which they gave. It was at this point the staff were told that Judy may not survive. One staff member stayed as she had known Judy and her family for over 20 years. Her brother David arrived at the hospital.

Judy died at 20.40 on Tuesday 29th April 2014 at the Cumberland Infirmary.

PART TWO

The premature death of people with learning difficulties – national context

The premature death of people with learning difficulties in Mencap's 'Death by Indifference' (2007) report concerning six deaths of people with learning disabilities in NHS care exposed '*institutional discrimination*' and led to an independent inquiry headed by Sir John Michael. This Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD, 2013) found that 37% of deaths of people with learning disabilities were '*avoidable*'. It also showed that compared with the general population, men with learning disabilities died on average 13 years earlier, while women with learning disabilities died 20 years earlier and yet fewer deaths of people with learning disabilities (38%) are reported to the Coroner compared to the general population (46%). The overarching message of the report was that the '*quality and effectiveness of health and social care given to people with learning disabilities was deficient in a number of ways*'.

The most common reasons for premature deaths identified were delays or problems with diagnosis and treatment and problems with identifying needs and providing appropriate care in response to changing needs.

Regarding factors contributing to premature deaths, CIPOLD pointed out:

- A lack of coordination of care across and between different disease pathways and service providers
- The episodic nature of care provision
- A lack of adherence to and understanding the Mental Capacity Act, 2005, in particular regarding assessments of capacity
- That record keeping was commonly deficient
- That little attention is given to predicting potential problems such as when a person was fearful of contact with medical professionals; amongst other issues (CIPOLD, 5:2013)

Eighteen key recommendations were made to lessen the risk of premature deaths which can be found in Appendix 1.

The cause of death and Post mortem

Judy died on the 29th April 2014 at the age of 54 in the Cumberland Infirmary. The cause of her death was recorded as a volvulus, or twisted bowel which led to perforation of the bowel and peritonitis. Under the law, where a death is not fully explained, the Coroner is advised and arranges for a post mortem examination. The fact that Judy was a woman with learning difficulties and with difficulties in communication were viewed as significant factors in the circumstances leading up to her death. In the light of the conclusion from the post mortem examination, and the circumstances of the death, an inquest was opened.

The inquest into Judy Benn's death

The inquest into the death of Judy Benn was held between the 13th and 16th July 2015, over a year after her death, before Mr David Roberts, HMC Senior Coroner for Cumbria. People involved in the provision of care for Judy were called to the inquest to *establish the facts.* Judy's brother and sister also attended as witnesses and gave their evidence at the start of proceedings.

No individual or organisational blame was attached to Judy's death, but the Coroner noted that she had died of a *treatable condition.* It was suggested that the bowel perforation had probably occurred 6 hours before admission and that if she had been able to get to the hospital between 24 and 48 hours earlier, then it may have been possible to undertake positive surgical intervention, although the timings had to be treated with caution. He acknowledged that the family would always have to live with the worry that there *was at the very least a missed opportunity to provide Judith with care that may have made a difference.*

The coroner went on to exercise his powers under Regulation 28[2], *'where a Senior Coroner has been conducting an investigation into a person's death, anything revealed by the investigation which gives rise to a concern that circumstances creating a risk of other deaths will occur or continue to exist in the future, and in the Coroner's opinion action should be taken to prevent the occurrence or continuation of such circumstances or to eliminate or reduce the risk of death created by such circumstances, the Coroner must report the matter to a person who the Coroner believes may have the power to take such action'*. He went onto address that document collectively to Cumbria County Council, Cumbria Partnership Foundation Trust, United Response and the Out of Hours Service. The point was to create a constructive document based on the *'concern'* which formed the foundation of the SILP day:

The Concern

'The concern is that a person with severe learning difficulties with 24 hour professional care died of a treatable complaint, notwithstanding telephone contact with doctors on three occasions, 2 home visits by district nurses, one by paramedics and 2 personal attendances by different General Practitioners, all within the space of less than three days. The concern is that a person not having such learning difficulties who was able to express herself might have received more timely treatment and could have survived' (HMC Senior Coroner David Roberts, 2015).

Following this he explained that all those involved in Judy's care should seek to ensure that lessons could be learned so that the risk of death of other people with learning difficulties are reduced. He would also copy the document to Mencap and the Secretary of State for Health because he felt there were wider issues to be learned.

The Action

The action stated was to *'liaise with all those involved in Miss Benn's care to seek to ensure that lessons are learned from these tragic circumstances so that the risks of death of those having learning difficulties are reduced'*.

[2] *This is Paragraph 7 of Schedule 5 of the Coroners and Justice Act (2009) which follows through to Regulation 28 in the Coroners Regulations.*

The national and local position on Safeguarding Adult Reviews.[3]

The Care Act (2014) and accompanying guidance sets out the requirement of Safeguarding Adult Boards (SAB) to conduct Safeguarding Adults Reviews (SAR).

Different Models for SARs

There are a number of different models used for SARs. SCIE has consulted and written about 'available models to choose from', including Root Cause Analysis from high risk sectors (Reason 1999); 'Learning Together' from the children's sector (Fish, Munroe et al, 2009); and Systems Theory and Action Learning (Revans, 1982). SCIE (2015) are clear to point out that there is space for 'alternative ways of thinking about different approaches' that may, through subsequent trial and testing, help to build an effective toolbox of approaches. Therefore SAB's were encouraged to think about considering research and development options.

In sum, the Social Care Institute of Excellence (SCIE, 2015) set out there are no prescriptive methods for conducting a SAR but the heritage of previous approaches is important to take into consideration in ensuring the process is systematic and robust. Some of the key factors PFIA wanted to consider from this were:

- How to keep the focus on learning not blaming
- How to avoid hindsight bias
- Making clear that honesty and openness are desired from top management
- How to gain commitment from agencies represented to operationalise any action points from learning.

The Significant Incident Learning Process (SILP) is an action learning model which is used to conduct a SAR and involves front-line staff and their managers in reviewing cases. The focus of the SILP is on:

1. What happened?
2. Why the people involved acted in the way they did at the time?
3. What could be done differently?

This focus allows for the organisational processes at the time to be scrutinised, reviewed and changed, leading to a number of key actions to be agreed and taken forward for reshaping future practice.

[3] The Care Quality Commission (CQC) has recently described how they will carry out a review of how NHS trusts investigate and learn from deaths of people using their services (April 2016). This followed a request from the Secretary of State for Health which was part of another Government response to a report into the deaths of people with a learning disability or mental health problem in contact with Southern Health NHS Foundation Trust. This followed the tragic drowning of Connor Sparrowhawk, in a bath at the facility he was staying in - a man with learning difficulties and a known history of epilepsy who had been left alone. This case has attracted a lot of national publicity.

The principles underlying the SILP are:

- Proportionality
- Learning from good practice
- The active engagement of practitioners
- Engaging with families
- Systems methodology[4]

As such, the review should be a trusted and safe experience that encourages honesty and transparency in order to share information effectively. The point is to learn from the SILP and apply those lessons to other situations.

The Safeguarding Adults Board must arrange a SAR when an adult in their area dies as a result of abuse or neglect (whether known or suspected) and where there is concern that agencies could have worked more effectively to protect the person.

The Safeguarding Adults Board are required to have early discussions with family members about the situation and agree how they would like to be involved in the process. The SAB will decide what particular type of review should be held in order to promote effective learning and improvement action to prevent future deaths or serious harm occurring again. In the case of the death of Judy Benn, a SILP was viewed as the appropriate option.

There is no one model of SILP that could be deemed as applicable to all cases. The focus has to be on what needs to happen to achieve the understanding and remedial action and provide answers or reassurance to family and friends of adults who have died: the process has to be meaningful.

Once a decision is made to proceed with a SILP, it is delegated to the Safeguarding Adult Review Panel. In Cumbria, this panel, at this time, is chaired by Tony Corcoran. Clear terms of reference are drawn up for the conduct of the review, identifying individuals and agencies who will contribute.

The terms of reference (see Appendix 2) clearly set out what information is required, how it will be obtained and analysed and over what timespan the review should focus. It also addresses which agencies and individuals contribute to the review and how family members and friends are involved, as well as timeframes and issues around confidentiality.

[4] *See Atkins, B. (2014) Cambridgeshire Safeguarding Children Board, Serious Case Review using the Significant Incident Learning Process of the circumstances concerning Child J Final report*

The Involvement of People First Independent Advocacy (PFIA)

Following an initial meeting, PFIA, through David Blacklock, CEO, were asked to facilitate the SILP event and produce an independent report. Dr Rohhss Chapman from Research and Education at PFIA and Louise Townson, an expert through experience, were enlisted to co-facilitate the event.

PFIA agreed to arrange the SILP event for practitioners and professionals who knew and had contact with Judith. The aim of the review was to promote effective learning and improvement to prevent future deaths or serious harm occurring again, as stated by the Coroner in his Regulation 28 Statement.

Values and Methodology

PFIA are an independent advocacy organisation providing assistance and support to some of Cumbria's most vulnerable citizens. The People First vision is where each and every individual is treated equally, fairly, and where their rights, choices, and beliefs are respected.

Although PFIA is a relatively large organisation within the third sector and represents peoples voices from all parts of the community, its methods and practice have grown from the foundation of working alongside people with learning difficulties and applying these principles across the board. Practice within PFIA is person centred, holistic and values driven. PFIA's methodology for the SILP was firmly placed within these values. This required that:

- Judy was at the centre of the of the process
- The process was inclusive of those who were important in her life, particularly her family
- The process would be inclusive of the organisations featuring in her life in a spirit of partnership
- The process would involve an expert through experience in assisting to lead the day
- The process would be underlined with respectful understanding and mutual recognition of all parties involved.

The planning therefore started with Judy at the centre of the process. The team prepared for the event by speaking with family members, reading and discussing all available documentation, creating timelines and developing resources to be used during the event.

About the facilitators

The SILP event was led by three facilitators from PFIA.

Louise Townson has worked in partnership over a number of years, lecturing in universities, undertaking research and presenting at conferences. Louise was asked for her input as an expert by experience. The importance of this was to bring insider knowledge, of what the experience is like for a disabled person receiving services. Louise was commissioned by PFIA.

Dr Rohhss Chapman worked as programme manager and lecturer in Learning Disability Studies at the University of Manchester for over eight years and currently works as head of Research and Education for PFIA. As an independent consultant, Rohhss brought a great deal of experience in training, dealing with evaluations of organisations and investigating complaints. She has a number of peer reviewed publications in relation to working inclusively with people with learning difficulties.

David Blacklock is Chief Executive of PFIA, he has worked with the company for over 15 years. David is a trained psychotherapist and holds positions on many local and national health and care decision making boards, such as the Health and Wellbeing Board and Safeguarding Adult Board in Cumbria. He also holds a position on the Healthwatch England Advisory Group. He has personal experience of having a son with learning difficulties.

Framework of the SILP

The questions that the SAB required to be answered from the process were:

a. What happened

b. Any errors or problematic practice and/or what could have been done differently

c. Why those errors or problematic practice occurred and/or why things were not done differently

d. Which of those explanations are unique to this case and context, and what can be extrapolated for future case and so become findings

e. What remedial action needs to be taken in relation to the findings to help prevent similar harm in future cases

The core questions were shaped into our own processes, utilising graphics and creative techniques employed in PFIA focussed activities.

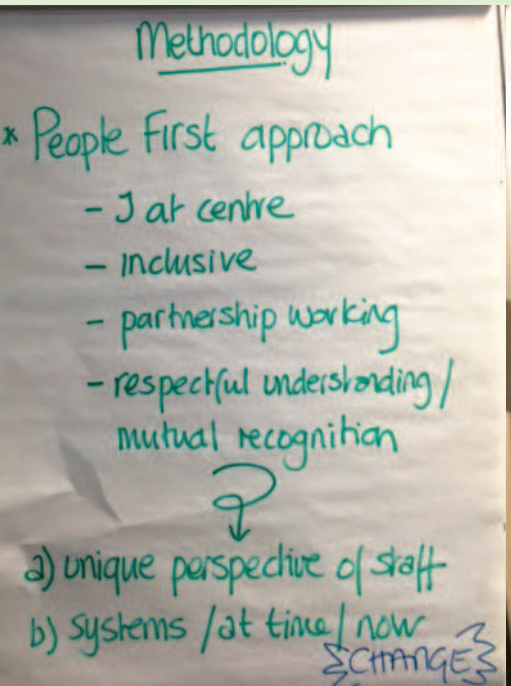
Invitations to the SILP

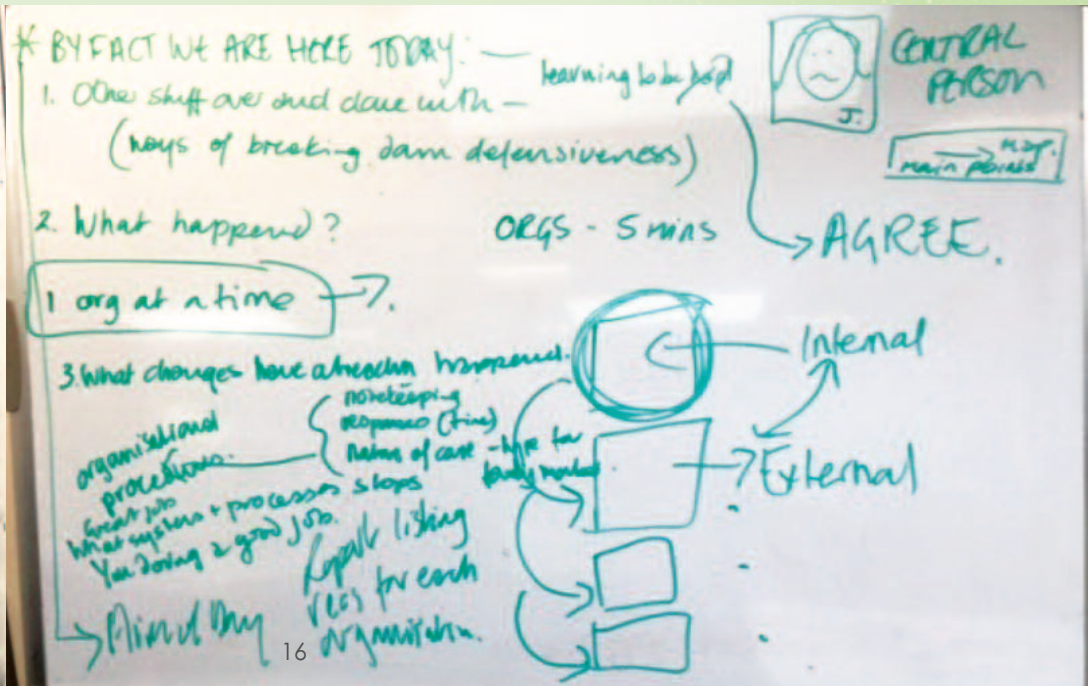
Invitations to the SILP went out to all the organisations involved in Judy's care at the time. We asked for people who had worked directly with Judy in providing care or who came into contact with her during her last few days, such as Cumbria Health on Call (CHoC) and the ambulance service/ hospital services. We also asked for a senior representative from each organisation or agency who was empowered to shape policy and therefore commit to the action points that would be raised at the end of the session.

The invitation made clear the process of the day alongside PFIA values and methodology, highlighting the no-blame culture of the event and the need for active involvement and spirit of openness.

It was difficult to get commitments for the event, which was not finalised until the last week. In the event the Ambulance Service and North Cumbria University Hospitals Trust were unable to attend. Additionally some key staff had moved on in the intervening two years.

Below and on following pages; flip charts and discussion points relating to the incident.





People who attended:

Sue McCarthy	*Learning Disability Nurse*	CPFT (LD Team)
Maria Glaister	*Service Manager*	United Response
Janet Cameron	*Support Worker*	United Response
Davina Collins	*Lead Nurse Practitioner*	CHoC
Julie Hedley	*Community Nurse*	Cumbria Partnership Trust
Matthew Devlin	*Social Work Team Manager*	Health & Care Services
Adrienne Halliwell	*Senior Manager*	Adult Social Care
Tony Corcoran	*Governor*	HMPS Haverigg
Simon Parker	*Deputy Designated Nurse - Safeguarding*	Cumbria CCG
Venetia Young	*GP Safeguarding Lead*	Cumbria CCG
Nick Waterfield	*County Manager*	Cumbria Adult Social Care
Sally Roberts	*GP*	St Pauls Medical Centre

Preparations for the event[5]

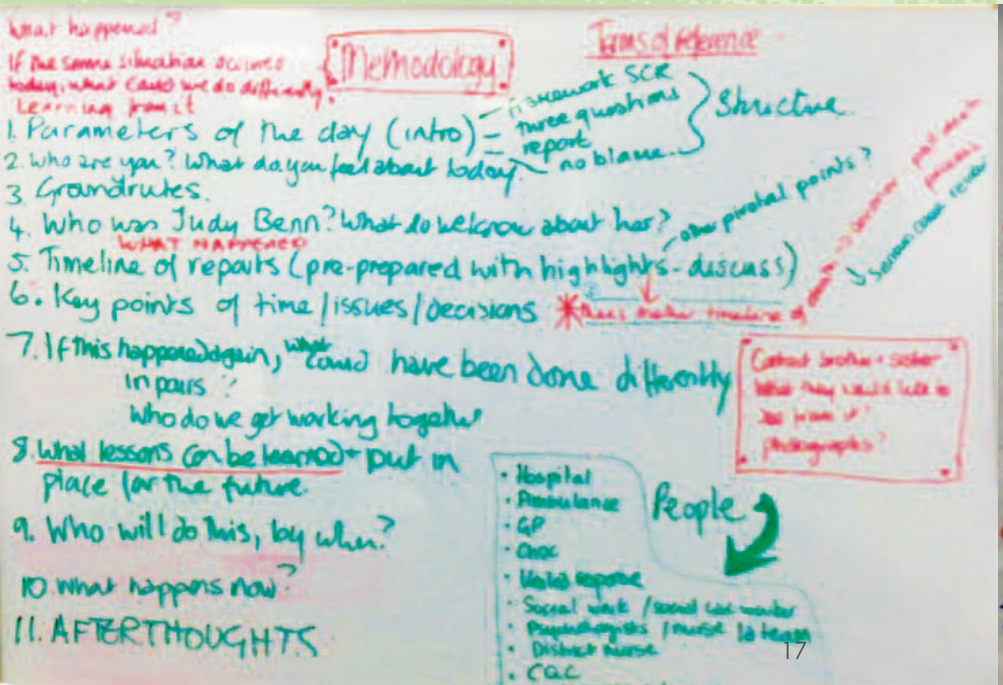
Keeping Judy at the centre of the process demanded that we look at her life in detail at the very beginning of the event, so we placed her photographs around the room and projected them onto the wall.

Judy's photograph was placed at the centre of a large sheet of paper to facilitate the personal profile at the start of the session, *'Who was Judy Benn?'* A timeline was prepared along the back wall of the room listing some key events in the days, weeks and months leading up to Judy's death. There was space left on the timeline to include much more detailed comments from the group on the day.

We prepared a question sheet to structure the discussion about *'what could have happened instead?'* Action lists for commitments from the different organisations were prepared.

The room was arranged as a large circle of desks so that everyone present had eye contact. Refreshments were placed around the room and participants were welcomed and offered a drink as they arrived. A note taker was present for the whole event.

[5] *See Appendix 3 for the finalised programme for the event*



PART THREE

The SILP Event

Introduction

David introduced the team with a brief description of the SILP. After introductions from those present, reference was made to the 'concern' set out under regulation 28 by the Senior Coroner that it was possible that Judy could have survived. Rohhss referred to the national context of premature deaths of people with learning difficulties as a foundation to the event. The methodology was explained with time for questions.

Ground rules

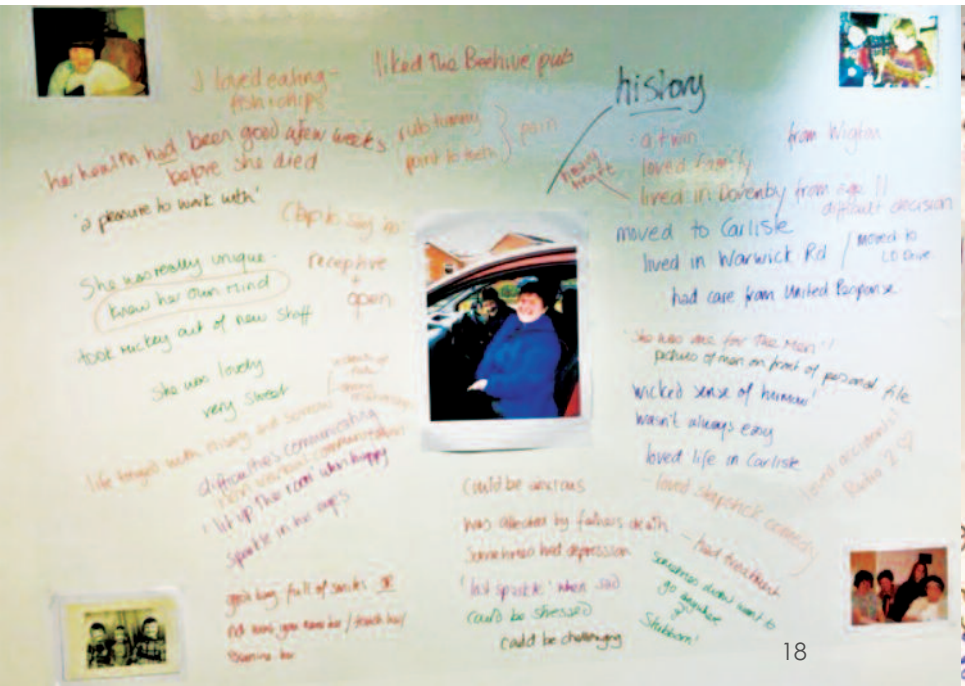
The group were asked to think about the ground rules they would like to inform the day.

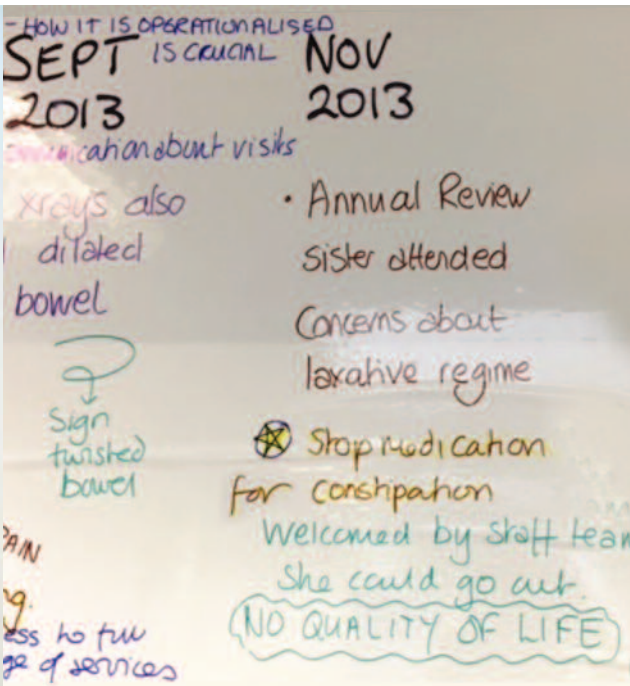
1. Adopt a 'no blame' approach
2. Honesty and openness
3. Listening and clarifying
4. Mobile phones off
5. Respect each other
6. Giving space
7. Breaks

These were left on the wall for the duration of the event but it was not required to come back to them.

Participants were asked what they thought the outcome of the process should be. It was agreed the event was to be a learning exercise to help avoid such a happening occurring again in the future. The group verbally committed to openness for the process to have full benefit.

Confidentiality was a high priority and discussed within the group. Regarding data protection, all precautions were taken to ensure that documents and correspondence had protected Judy and staff identity, but following the event Judy's family are keen for her to be named.





Who was Judy Benn?

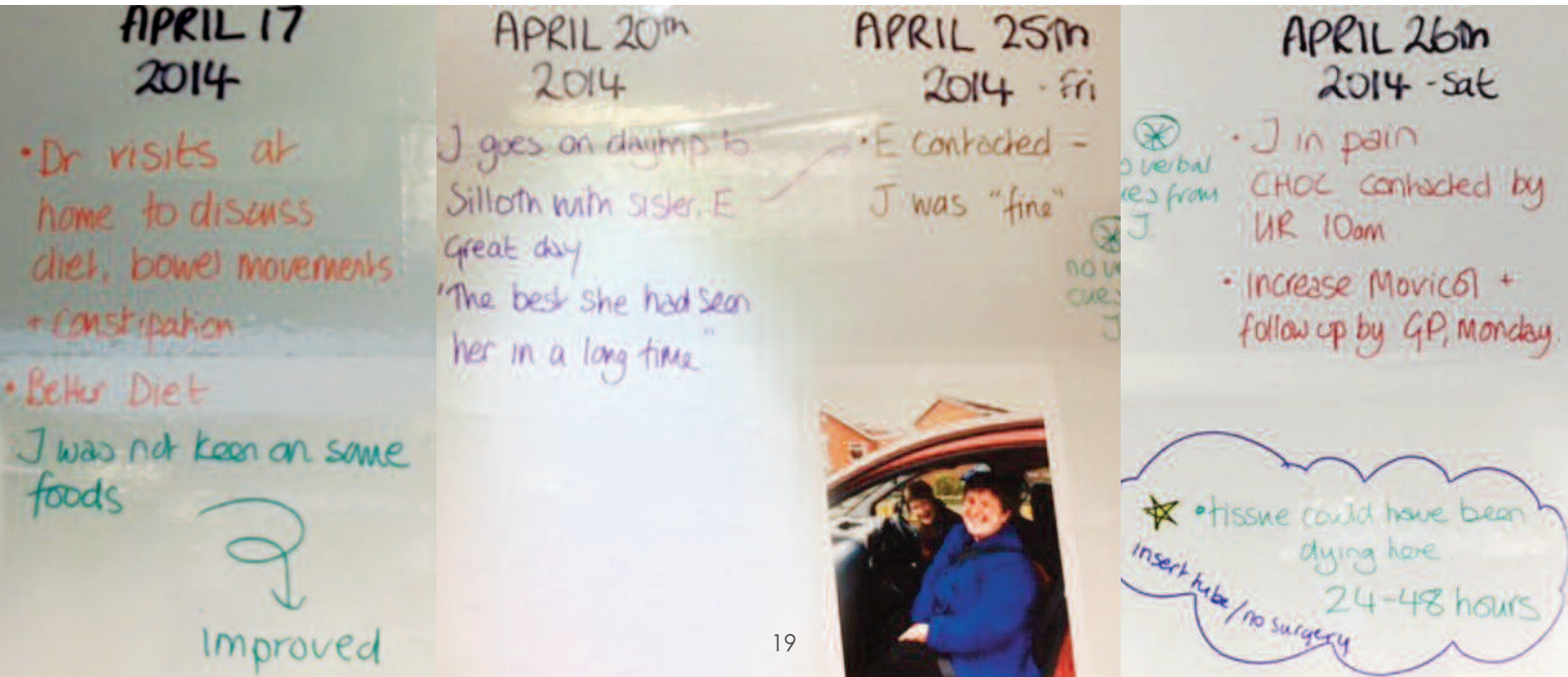
Louise led the profile session, facilitating the views of those present, as to how they remembered Judy and what her character was like (see page 6 and 7). This also enabled people who had not met Judy to gain a view of her personality before proceeding.

When she had been younger and living at Dovenby Hall, Judy had returned home every weekend. Her sister had recalled how she had been very loving and helpful with her own children; the sibling descriptions were added to the list.

One of the group who had known Judy over the years was particularly helpful in allowing the whole group to gain an in depth picture of her personality and different characteristics. She loved comedy, rolling about laughing at hilarious jokes. She was described as having a *'wicked'* sense of humour. She was described as *'lovely and very sweet'* and could light up the room with her smile; she was *'a pleasure to work with'*. Judy loved her food; she loved Radio 2 and would clap along to the music. She liked staff to take a positive approach with her, disliking *'meek'* support and would *'take the mickey'* out of new staff. She liked going to her local pub.

Some of the more difficult issues for Judy were also mentioned. She had suffered from depression, particularly after the death of her father who she was very close to, it was said that she had the best connection of all to him. She could be anxious; she *'lost her sparkle'* when she was sad and *'could be challenging'*. She was also badly affected by her mother's ill health and death in 2013. The words *'misery'* and *'sorrow'* were used to describe Judy's more difficult times. She could be stubborn and would refuse to do things she did not want to do, like go out of the house, or be examined by a doctor. There was also a lot of discussion about her ways of communicating. She did not communicate verbally but would point to things, clap to say no, put her hand into a fist to show she was not happy, point to her teeth or rub her stomach to show she was in pain.

The character of Judy became very clear through the contributions made, bringing her personality to life to offer a real in depth understanding. The presence of the photographs were also very helpful in relaying this. The paperwork was left on the wall to refer back to throughout the process.



Timeline

2013

Sept Chest X rays also showed dilated loop of bowel.

Nov Annual review, sister attended, concerns about laxative regime.
Stopped medication for constipation.
Staff welcomed this as Judy could go out.

2014

April 17th Dr A visits at home to discuss diet, bowel movements and constipation.
Better diet.

April 20th Judy goes on daytrip to Silloth with her sister. They have a great day.
The *'best she has seen her'* in a long time.

Fri April 25th Sister contacted the house. Judy was *'fine'*.

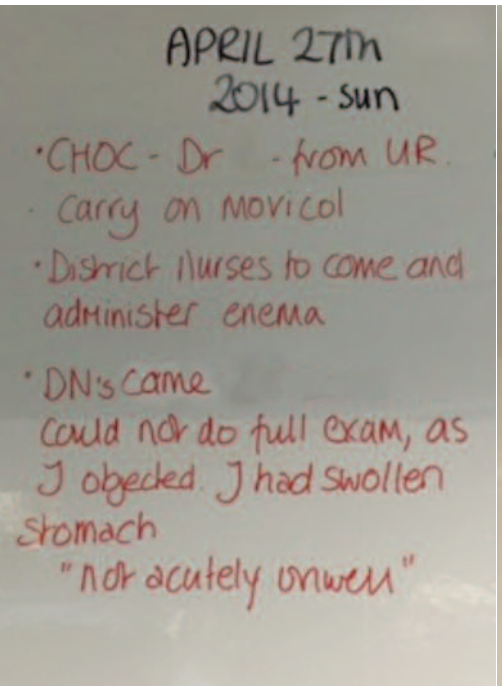
Sat April 26th Judy was in pain. CHoC were contacted by UR. Increase Movicol and follow up with GP on Monday. Judy had an unsettled night.

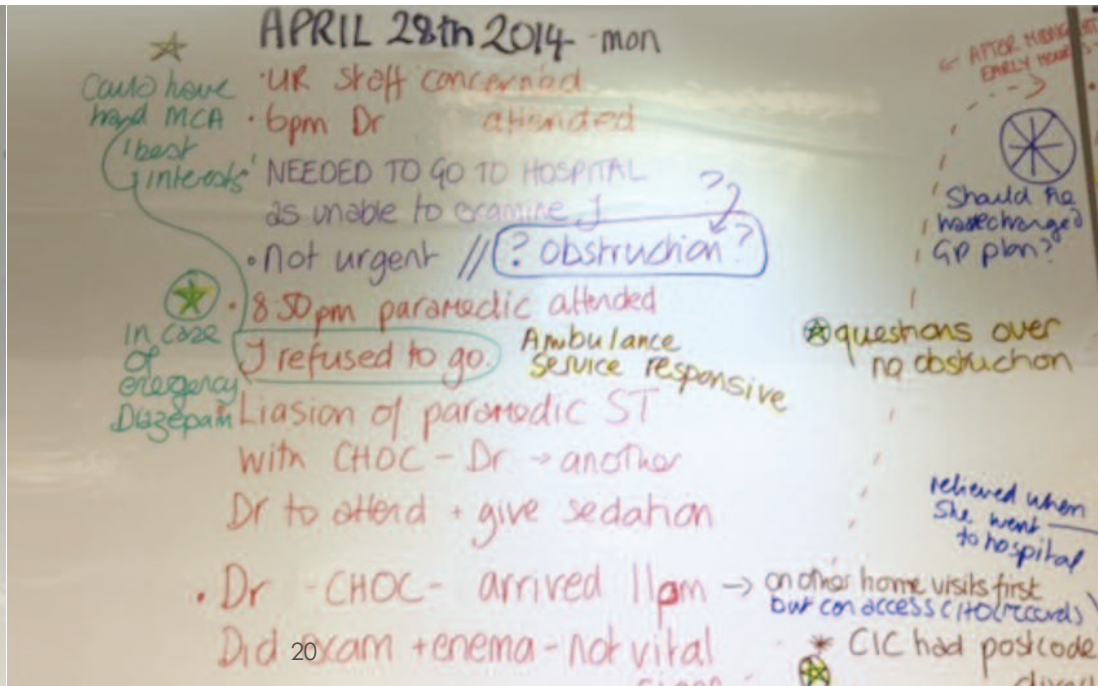
Sun April 27th CHoC Dr B - called by UR - said carry on Movicol.
District nurses to come and administer enema.
District nurses C and D come, could not do full exam as Judy objected
Judy had a swollen stomach.
'not acutely unwell'.
(At this point Judy had not opened bowel for 6 days)

Mon April 28th UR staff concerned. 18.00, Dr E attended, said needed to go to hospital as unable to examine Judy.
Query- obstruction?

20.15 Paramedic attends – Judy refuses to go to hospital
Liaison of paramedic with CHoC to Dr F – another doctor to attend and give sedation.

23.00 Dr F of CHoC arrived. Did exam and partial enema but not vital signs.
(At this point Judy in continuing discomfort).





Tue April 29th *Early hours of morning* - Dr F said 'no intestinal obstruction - no criteria for transfer'
Discussion with UR staff.
Said district nurse should attend to administer suppository.
Dr F spoke to senior, Dr G.

02.30 District Nurse H attended.
Judy asleep – agreement not to disturb

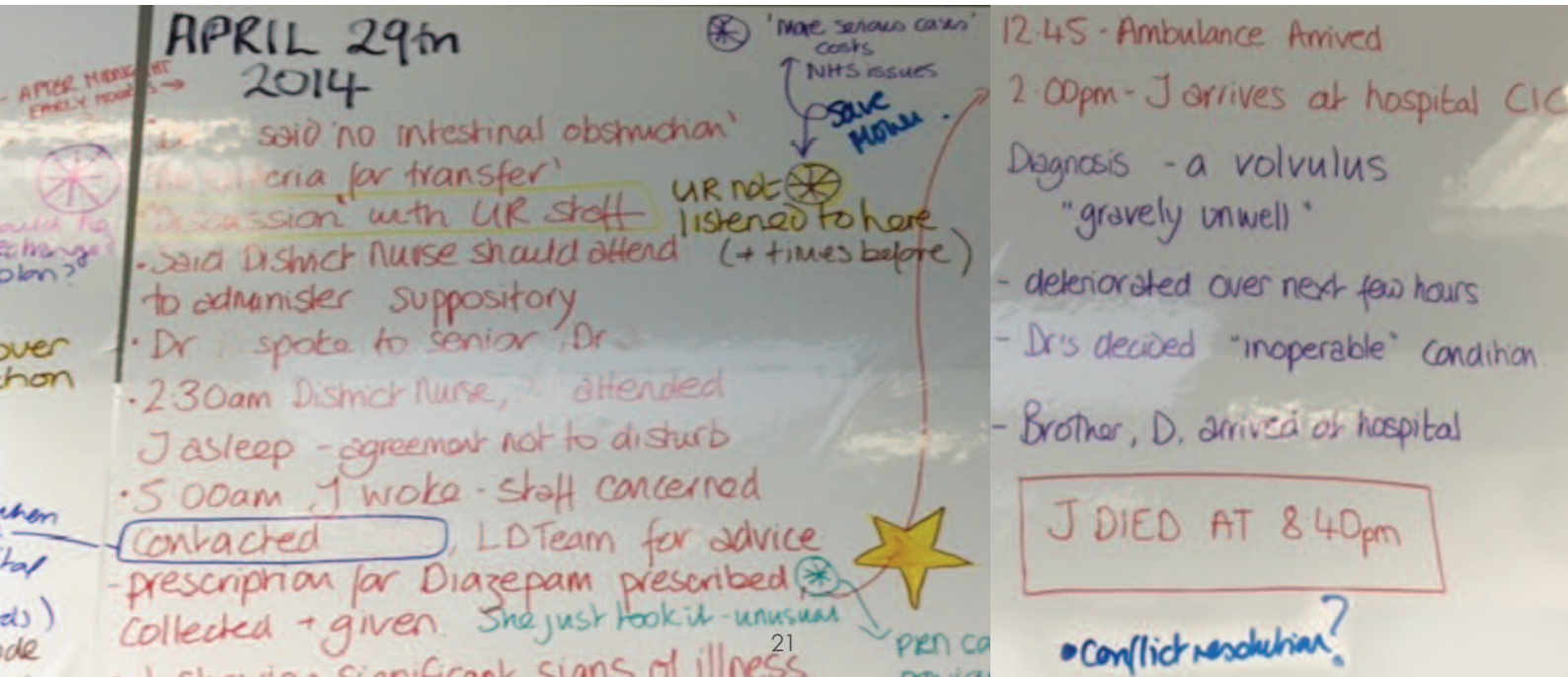
05.00 Judy awoke – staff concerned and contacted J of LD team for advice.
Prescription for Diazepam prescribed, collected and given.
Judy was showing significant signs of illness.

12.45 Ambulance arrived.

14.00 Judy arrived at hospital
Diagnosis of a volvulus, '*gravely unwell*'.
Deteriorated over next few hours.
Doctors decided 'inoperable' condition.
Brother, David, arrived at hospital

20.40 Judy Died.

Judy enjoying some time with Chris



Discussion of what happened and what could have been done differently

In the discussion that followed, further points were added onto the timeline, as demonstrated by the photographs above.

The SILP was to focus in on the year leading up to Judy's death. It was noted that Judy had a long history of bowel problems and had been on a diet where she had lost a lot of weight- going from a dress size 22 to a 14. UR had worked with the dietician to provide healthy foods and menus in the home. However there were questions about the extent of her bowel problems with the amount of laxatives given. It was asked if continence nurses had been involved and how far they had access to a full range of services.

The issue of pain was discussed in some depth. There was a concern that no one had actually assessed Judy's level of pain during this episode. CHoC asked if there was a DisDAT in place[6]. A Mental Capacity Assessment (MCA) had been formally undertaken at some stage but the question was how exactly that was operationalised in specific circumstances. Overall, it was the staff at UR who knew Judy best and they were the people who needed to be empowered in this situation.

It was also noted that a dilated loop of the bowel had been seen, in passing, on a chest x-ray taken in **September 2013.** It was discussed if this could not have been followed up given Judy's medical history.

Overall, it was hard to understand if Judy could have been saved in the last hours as her twisted bowel led to subsequent tissue death which could have been happening since the 26th April. If she had been seen at this time she could have had a tube inserted which would have negated the need of an operation. This underlies the Coroner's comments about a death that could have been avoided. Earlier interventions and practices may have helped.

Regarding the events of the **28th April,** there were questions over the diagnosis of 'no obstruction' regarding Judy's bowel. However, the group were aware of hindsight bias and agreed that all of the staff involved did their best under what was presented to them in the context of the time, because the symptoms and Judy's presentation did change and was described as 'sporadic' throughout the last few days of her life.

Judy's refusal to get into the ambulance was discussed in the perspective of the possibility of a Mental Capacity Assessment. If this had happened and been in place, would this have helped to get Judy to the hospital earlier in her best interests? In the following discussion it was apparent that the surgeon had thought she would have needed to be in the hospital at least 24-48 hours earlier than she eventually arrived in order to have had a viable chance of getting surgery. However, 24 – 48 hours earlier there had been no verbal cues from Judy and she was not thought to be 'acutely unwell'.

Additionally, it was known that Judy had a fear of being examined and if stressed would refuse to leave the house. There was no PRN medication in the house in order to sedate Judy to be examined and get into the ambulance when the paramedic had initially arrived. Diazepam had been useful to Judy in the past in this respect, and could have previously been accessed, but the prescription had stopped so more had to be ordered from outside, taking more time.

[6] *DisDAT (Regnard et al 2003; 2007) is a Disability Distress Assessment Tool to help observe and identify distress in people who have limited communication because of cognitive impairment or physical illness.*

In regard of **April 29th**, the UR staff felt that they had not been listened to. There had been a heated discussion at the house with the CHoC doctor, who had phoned his senior for affirmation of his plans, which was given. UR could not understand why the current GP had overturned the plan made by the GP who had attended the previous day. A comment had been made by the second GP about 'more serious cases' and the cost to the NHS, which was felt should not have come into the discussion. It was noted that Cumberland Infirmary had a postcode divert in place on the night of the **29th April** and that Judy would have possibly had to travel to the other side of Cumbria. It was felt this may have added more stress to the GP's decision about Judy getting to the hospital.

When Judy was finally taken to hospital the UR staff had felt a sense of relief that something would now happen to help Judy. UR added that they had taken Judy's Health Action Plan and communication passport along to the hospital and someone had been with Judy all the time until her brother arrived.

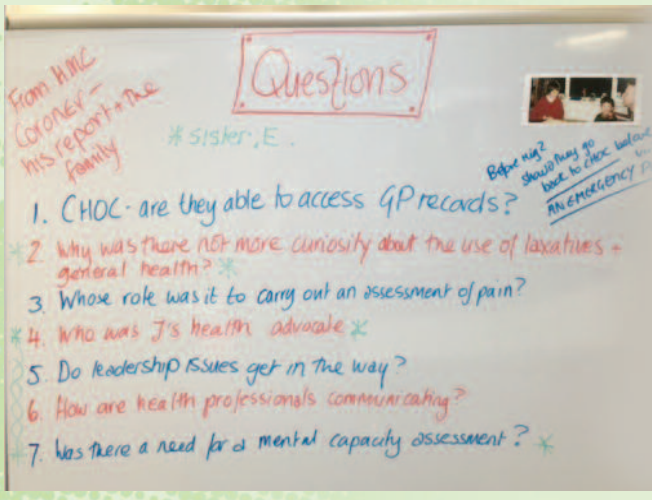
Some of the questions raised through this discussion were incorporated in the dialogue of the following section. These initial questions raised included:

- Is there real continuity of care at weekends covered by health services?
- Would access to 24 hour Learning Disability Services help?
- Should a GP be able to change the plan that a previous GP has made?
- Should there be a flagging system for the number of contacts made- where it rises above a certain level?
- Does CHoC have a register of patients with learning difficulties?
- Should there be a named nurse safeguarding patients with learning difficulties and ensuring reasonable adjustments?

Additional questions from the Coroner's Report and siblings

After the discussion above and a break, PFIA presented the group with the questions that had been asked within the Coroner's report and by the family.

1. Are Choc able to access GP records?
2. Why was there not more curiosity about the use of laxatives and general health?
3. Whose role was it to carry out an assessment of pain?
4. Who was Judy's health advocate?
5. Do leadership issues get in the way?
6. How are health professionals communicating?
7. Was there a need for a Mental Capacity Act (MCA) Assessment?



The group were asked to split into smaller groups to debate each of these elements and include the issues raised earlier by the group discussion of the timeline. The small groups were then given a number of specific topics (collated from the questions) to discuss and importantly to think about remedial actions that could be put in place.

PART FOUR

Key remedial action plans

An aim of the SILP was to come up with some solutions to the problems that had led to Judy's *'avoidable death'*, in order that this sort of occurrence would never happen again in Cumbria and that lessons could be learned further afield. This matched a heartfelt wish from Judy's family that some good could come from such a tragic event. For this to happen, organisations and agencies have to be ready and willing to make changes and work across and between their organisations. Identifying the issues, in some respects, was a much easier part of the process. The Coroner's inquest had taken place and the organisations had already undertaken their own internal reviews. This was a further opportunity to focus on what had happened. However the SILP is an inter-organisational process and presents a greater level of complexity.

PFIA put a number of tables onto the wall listing the key actions the groups had discussed and then facilitated the group to:

1. Share their thoughts in deciding exactly what the action was,
2. Discuss who may be responsible for overseeing the action, and
3. State when the action would be done by.

The point of this exercise was to locate which person/people or organisation/s held responsibility for the action to keep the process dynamic. The list of key actions and responsibilities are currently overseen by Cumbria SAB. Some actions are linked into CIPOLD as stated and need to be operationalised.

Judy enjoying the company of Chris and her brother Dave

	KEY ACTION
1	Medical Record access must be improved in order that known complications, history and reasonable adjustments can be known and made.
2	People with learning difficulties and specific support needs should be identified on all clinical record keeping systems. A flagging system should help health care workers who may never have met the individual to understand specific needs and reasonable adjustments that may be required. (CIPOLD R1)
3	A register of people with learning difficulties should be available to OH and CHoC. Mig 2 may help with this (check in car).
4	Health and care services should audit reasonable adjustments for individuals and systemically. Best practice should be shared across organisations.
5	A named healthcare co-ordinator should be allocated to people with complex or multiple health needs, or two or more long term conditions.
6	Mental Capacity Act Training should be provided to GP's to help them understand their obligations as around 'serious medical treatment'.
7	Mental Capacity Act training should be mandatory for healthcare staff. (CIPOLD R12)
8	Advice on Mental Capacity Act should be available out of hours. Assurance to be sought from each organisation that they have information available as to where to seek advice on MCA. (CIPOLD R10)
9	People with learning disabilities should hold their own Personal Health Record. Passports and HAP's are already in place but medical professionals need to understand the importance and know to ask for them. Include in CHoC training. (CIPOLD R5)
10	Pain assessment protocols should be put in place, detailing pain assessment tools that can be used. This is everyone's business.
11	Support staff should know that they can request support from learning disability nursing team when an individual is coming up against barriers to access health care services.
12	Where challenge of individual engaging with emergency services– an emergency contingency should be put in place. For example, anti-anxiety medication to assist access to treatment. There must be an emergency healthcare plan (EHCP) (CIPOLD R7 and R14)
13	Carers often know a great deal about the individual – they must be empowered to advocate assertively.
14	Health professionals should know to listen closely to carers especially when the individual does not verbally communicate; GP training.

Table continues on page 26

	KEY ACTION
15	Annual safeguarding onto GP training.
16	Key findings of SILP report should be shared at Annual GP training sessions.
17	The 'postcode alert' should be better understood by those working within the system
18	Local data should be collected on mortality rates. National comparison and analysis should be included in the JSNA. (CIPOLD R16)

Judy with her mum Jean, sister and niece, Sarah.

Reflections from PFIA

The work on remedial actions fell onto specific groups of people and we wondered if the actions could have been further spread in terms of responsibilities; this is an issue for the Safeguarding Board as they follow up on actions. As facilitators of the event, and having talked to the family and read in depth into the proceedings around Judy's death, we felt we were in a position to add further around what could be learned and needed to be actioned. This list requires discussion as to who is best placed to carry out the recommendations from CIPOLD that need to be operationalised in the county, marked tbc. Some actions had already been implemented from the internal reviews that took place. For example, it was known from the chronological report to the SAB that record keeping needed to be improved, kept up to date contemporaneously and have more details added in.

Discussion around the recommendations related to Judy's death including links from SILP to CIPOLD

The full recommendations of CIPOLD can be found under appendix one.

CIPOLD R1 recommended that there should be clear identification of people within a central registration system and in all healthcare record systems. Although this has happened it was unclear that the CHoC doctors had all information made available to them that they would require through their systems on call.

The idea to have patient held health records (CIPOLD R5) would have helped. An alert to flag risk after a number of contacts had been made would also address the lack of continuity of care issue.

CIPOLD R7, states that '*people with learning disabilities [are] to have access to the same investigations and treatments as anyone else, but acknowledging and accommodating that they may need to be delivered differently to achieve the same outcome*'. Judy's refusal to be examined and to go into the ambulance highlighted questions around the powers of implementation of the Mental Capacity Act. There could have been contingency plans set up for such an occurrence.

CIPOLD R10, states that Mental Capacity Act advice should be easily available 24 hours and day and CIPOLD R12, that training and regular updates in this area must be available for all staff.

Further, CIPOLD R14, notes that advanced health and care planning should be prioritised and commissioning needs to take this into account and be responsive to change. Judy needed to be in a position where she could be examined or get to hospital if it was needed urgently, taking her fear of strangers and leaving the house into account. This may have required that PRN medication was kept in the house and her route into acute care made easier because of her learning disability under 'reasonable adjustments'. It was also pointed out by a member of the group that the hospital 'divert' had not been properly understood and that Judy probably could have been received into care at Cumberland Infirmary. However, as set out in the key actions above, this is a training issue.

CIPOLD R16, clearly states that there should be clearly standardised mortality data collected about people with learning disabilities.

Summary

PFIA were very concerned that Judy had been in a great deal of pain over the last week of her life and had only been given paracetamol to deal with it. The group had talked about introducing a DisDAT assessment which may help in the long run, but Judy's communication issues and her learning disability should have flagged very early on that she was a person who would require effective pain relief as soon as possible and an easier and quicker route into acute care when there are so many barriers to her health and wellbeing.

Raised by SILP, but not included in the CIPOLD recommendations are that key workers who know the person really well need to be listened to by professionals providing medical care, specifically where communication is an issue and the staff understand the person's communication. The group talked about assertiveness training, which may help, but it is also contingent on the medical professional being open to listening. These important relationships may need more emphasis in acute situations.

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Abbreviations

CCG	Clinical Commissioning Group
CEO	Chief Executive Officer
CHoC	Cumbria Health on Call (out of hours service)
CIPOLD	Confidential Inquiry into Premature Deaths of People with Learning Disabilities
CPFT	Cumbria Partnership Foundation Trust
DISDAT	Disability Distress Assessment Tool
EHCP	Emergency Health Care Plan
GP	General Practitioner
HAP	Health Action Plan
HMPS	Her Majesty's Prison Service
MCA	Mental Capacity Act
PFIA	People First Independent Advocacy
SAB	Safeguarding Adult Board
SAR	Safeguarding Adult Review
SCIE	Social Care Institute of Excellence
SILP	Significant Incident Learning Process
UR	United Response, Care Provider

Appendices

1. **18 key recommendations of CIPLOD (2013).**
2. **Terms of Reference**
3. **Programme of the day – PDF**

Appendix one

The key recommendations from the CIPOLD (2014) review of deaths

1. Clear identification of people with central registration system and in all healthcare record systems.
2. Reasonable Adjustments required by, and provided to, individuals, to be audited annually and examples of best practice to be shared across agencies and organisations.
3. NICE 5 Guidelines to take into account multi-morbidity.
4. A named healthcare coordinator to be allocated to people with complex or multiple health needs, or two or more long-term conditions.
5. Patient-held health records to be introduced and given to all patients with learning disabilities who have multiple health conditions.
6. Standardisation of Annual Health Checks and a clear pathway between Annual Health checks and Health Action Plans.
7. People with learning disabilities to have access to the same investigations and treatments as anyone else, but acknowledging and accommodating that they may need to be delivered differently to achieve the same outcome.
8. Barriers in individuals' access to healthcare to be addressed by proactive referral to specialist learning disability services.
9. Adults with learning disabilities to be considered a high-risk group for deaths from respiratory problems.
10. Mental Capacity Act advice to be easily available 24 hours a day.
11. The definition of Serious Medical Treatment and what this means in practice to be clarified.
12. Mental Capacity Act training and regular updates to be mandatory for staff involved in the delivery of health or social care.
13. Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Guidelines standardised across England.
14. Advanced health and care planning to be prioritised. Commissioning processes to take this into account, and to be flexible and responsive to change.
15. All decisions that a person with learning disabilities is to receive palliative care only to be supported by the framework of the Mental Capacity Act and the person referred to a specialist palliative care team.
16. Improved systems to be put in place nationally for the collection of standardised mortality data about people with learning disabilities.
17. Systems to be put in place to ensure that local learning disability mortality data is analysed and published on population profiles and Joint Strategic Needs Assessments.
18. A National Learning Disability Mortality Review Body to be established.

Appendix two

Terms of Reference

Terms of Reference for Case Review in respect of Adult A

1. Adult's details - See attached combined Chronology

Review Group Members	Agency: Health and Care Services, CCC GP CHOC (Cumbria Health on Call) Rapid Response United Response, Provider N. Cumbria Acute NHS Trust North West Ambulance Service
Time period to be reviewed	12 months leading up to A's death on 29.4.15
Key issues identified	The purpose of this review is not to hold any individual or organization to account. The focus is on learning by focusing on: • What happened • Any errors or problematic practice and/or what could have been done differently • Why those errors or problematic practice occurred and/or why things were not done differently • Which of those explanations are unique to this case and context, and what can extrapolated for future cases and so become findings • What remedial action needs to be taken in relation to the findings to help prevent similar harm in future cases
Methodology for undertaking review	
Ethnicity, Religion, Diversity / \Equality Considerations	
Date case review agreed	7th October 2015
Completion due date	Within 6 months of the date above

Appendix three

Significant Incident Learning Process Event (SILP)

28th April 2016

Programme

1.00pm	**Coffee**
1.15pm	**Welcome & Introductions**
	Why we are here - Context
1.30pm	**Who was Judy Benn?**
	Family input and questions
2.00pm	**Timeline of Events and Key Facts**
2.30pm	**Coffee**
2.45pm	**Questions from Coroner, Family and Documentation review**
4.00pm	**Identifying actions and agreements**
4.45pm	**Closing Remarks**

Notes

JUDY BENN The Critical Last Days
A Significant Incident Learning Process (SILP)

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