

General Hospital Care for People with Learning Disabilities

Report of a Seminar for Health Board Chief Executives

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scottish
consortium
for learning
disability

Building respect in the
Scottish community



SCOTTISH EXECUTIVE

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Easy Read Summary

Lots of important people from the Health Service met people who care for people with learning difficulties – carers and workers. This report says what they talked about.

Bette Mauchland spoke about how her brother was treated. No one should be treated in hospital the way that Jimmy Mauchland was before he died. People with learning disability have feelings, even if they can't always say what they feel. Everyone should listen to them and to their carers. All health services must act to make care better and they should employ Learning Disability Liaison nurses.

Anne Duffin says that people with learning disability are individuals and should be treated as individuals. She trains nurses to tell them that the health of people with learning disability is important.

Anne Brown's daughter, Fiona, has complex health needs and her family have to do many things to keep her well. When Fiona goes into hospital Anne is expected to go too and look after her! Anne wants to see health workers sharing information, talking to each other and listening to people. She says that if the health service gets it right for people with very complex needs, it will get it right for everyone.

Lisa Curtice from the Scottish Consortium for Learning Disability says that all Chief Executives should find out who in their Board is making sure that the guide, "It's Our Health Service", is being used. There is lots of help available on how to meet the health needs of people with learning disability and to meet the QIS (NHS Quality Improvement Scotland) quality standards. The Consortium can give you many ideas about this.

Linda Allan and Michael Brown said that people with learning disabilities have poorer health than other people and that they may be more at risk of things going wrong when they are in hospital. Good care, health screening, liaison nurses and looking at why people die will all help to make things better.

Good practice examples:

- NHS Lothian have an acute hospital liaison service which gives advice to doctors and nurses, makes information easier to understand, trains nurses and makes sure that people with learning disability are involved.

- Fife Primary Care Trust is developing training for nurses and doctors so that they will understand people with learning disability and their needs better.
- NHS Grampian is involving carers as trainers and in meetings with consultations. Grampian is also doing work to make sure the people who fall get a good service.
- NHS Ayrshire and Arran is developing an electronic patient record to improve access to information.

EXPERIENCE

JIMMY'S STORY by Betty Mauchland

“Hello, my name is Betty Mauchland and I want to tell you a story about my brother Jimmy and the last two years of his life.

It's been a painful and difficult exercise trying to pull this complex story together to make it easy to follow at the same time remembering that the focus of the story is Jimmy.



In 15 minutes I can only give a condensed version of events, I've had to leave out a lot of the detail and that's been difficult for me to do. And although my memories are clear, I have used the statement, which I gave to the police shortly after Jimmy's death, to ensure that this account is accurate.

Please also bear with me as we journey through this story I'm speaking about someone so dear to me, so much part of my life, who is no longer here and I'm sharing this with a group of strangers – so you'll excuse me if I my voice breaks a bit along the way.

This is a photograph of Jimmy – I remember taking it – we were on a hillside in Lourdes in France – Jimmy's favourite place – he was a regular visitor there and he loved it. It was a warm day, and Jimmy was drinking a can of coke – soon he was surrounded by wasps – but he had a favourite saying when confronted with anything creepy-crawly – he said quite loudly “bugger-off” – and flapped his arms around – sending the wasps flying to me – we had a great laugh!! He then remembered where he was, but didn't think that Our Lady would mind this wee slip up. This was a good time for Jimmy.

I wanted to tell you that story to illustrate the humour and “normality” which was Jimmy. He did what most of us would do in a similar situation.

To explain something of the character of Jimmy I would say that he enjoyed the company of people, liked dancing and socialising. Enjoyed singing and usually made up his own words, liked shopping – but when he went shopping with me he usually forgot to bring his money – saying ‘I'll pay you back’. This was a joke between us - he was a very generous and caring man and aware of other people's problems. He lived at home most of his life, until the last few years when he lived in a community house. He had lived most of his life

drug-free (**I have to emphasise this - his health was good and the only medication he took was the occasional paracetamol for a cold/headache**).

Jimmy had a compulsive behaviour disorder – sometimes with funny outcomes. He had an attraction (if that's the right word) for wheels – mostly wheelbarrows. He would “gather” them together and on one occasion he set up a yard on a spare piece of ground, with all the wheelbarrows in rows. The local people thought he was a builder, but the builders of Dundee must have wondered what hit them – because all their wheelbarrows disappeared. It was a hard job trying to re-locate the wheelbarrows to their rightful owner.

There was of course a serious side to the compulsive behaviour, which eventually left him very distressed and ultimately depressed as he tried to fight the compulsions.

I want to say at this point that I spent my life being involved with Jimmy's care, and I wanted this to continue during his stay in hospital

As a result of this depression Jimmy was admitted to a hospital for people with learning disabilities called Strathmartine early in December 1998. It was a forbidding old Victorian institution on the outskirts of Dundee where many people with learning disabilities had lived for most of their lives. The patients were accommodated in dormitories in bleak surroundings and the general tone of the living room (which had been a big ward) and long, lonely corridors was one of neglect and deprivation. He was there for 18 months and his condition grew worse. Treatment consisted of drug therapy, and these drugs had a punishing effect on his health both physically, and psychologically until his condition declined so markedly that he was sectioned under the Mental Health Act and transferred to Liff hospital. This was a mental health hospital where he would begin to receive ECT treatment.

He had 4 treatments, but on 5th December 1999 he fell in a corridor in Liff hospital. After the fall there were changes in his condition, which resulted in a decision to transfer Jimmy to Ninewells Medical Hospital - this was on 6th December. From this first admission to Ninewells, there were many different diagnoses and he was actually discharged and returned back to Liff hospital on 3 separate occasions.

The diagnoses included heart attack, stroke, Guillain Barre syndrome, cancer, unspecified infection – they operated on his hand but found no infection.

Despite my best efforts to inform doctors through my observations and knowledge of my brother, the issues I raised including the fall and nutrition, were not addressed and Jimmy's condition continued to deteriorate.

The final and accurate diagnosis did not come until the 26th December – spinal cord injury at level C4 – 3 weeks after the fall – 3 weeks in which Jimmy underwent a regime diametrically opposed to the correct treatment of such an injury. His condition deteriorated.

On 9th January 2000 Jimmy died.

My experiences from a carer's perspective, in a bit more detail:

Strathmartine:

- Jimmy was a patient there for 18 months and his condition both physically and mentally deteriorated.
- I was never shown a care plan, despite asking on many occasions to see one.
- any case conferences that took place were as a result of my inquiry.
- it was usually me who noticed the side effects of the drugs and pointed them out to the nurses.
- I continually reminded them about his weight and asked that he be weighed regularly.
- no one was taking the initiative – I had to highlight an issue before there was any action.
- I continually had to be 'on the ball' because I knew that they weren't.
- his treatment consisted of drug therapy – there was no cognitive therapy.
- I was a regular visitor – most days/evenings and yet it was rare to see a nurse interacting with the patients. They always appeared to be sitting around a table drinking tea.
- the clinical psychologist who knew Jimmy and worked with him in the therapies department (as an outpatient) was not allowed to retain her interest – and so there was a loss of continuity. This was the consultants' rule. I believe this still applies.

- I lacked confidence in the nurses' ability to care for Jimmy or properly manage his treatment.
- I had this same lack of confidence with the consultant psychiatrist whose remedy was purely drugs and infrequent visits.
- there was also a lack of awareness by some of the staff that their behaviour had an impact on the patients they cared for. I can give you an example:
 - my friend and I attended a meeting in the ward and when we arrived around 9.30 a.m. we were shown into the day room, where patients were having their hair dried, cutting their toe nails, etc, and here we were (my friend was a stranger to them) coming into their "home" – their "living room" with no thought of how they would feel – no question of them giving their permission – it was just accepted.
 - another occasion when I was visiting Jimmy in the ward the television was on – a group of patients were watching a programme when a member of staff walked over to the TV set and switched the channel – without a word to the patients – he sat back and watched the football!!

Disrespect and thoughtlessness come to mind – how do you separate the two? Each has the same impact on the patient, and although they may never say anything – believe that they can feel it.

- I'm aware that I'm painting a bleak picture here – and I don't want to give the impression that every nurse was a bad nurse. Many had worked in this impoverished environment for years and I suppose that had an effect on their morale. But many just didn't give a lot of thought to how they carried out their duties, and it would be unheard of to change routines, or introduce new ideas – much easier to keep with the status quo.

Liff:

- there was a care plan with clear goals and recorded outcomes.
- the nursing staff wanted to get to know Jimmy quickly – they asked lots of questions about his likes and dislikes. They communicated with me, which was a new experience. They were showing me that they were involved in his care and his recovery process and not just 'minders'.
- they were firm, but respectful to him. I had confidence that they knew what they were doing.

- it was on Sunday 5th December when Jimmy was found lying in a corridor in Liff hospital – his arms by his side, his chin resting on a deep skirting board – he was unconscious and unresponsive to pain (this was written in the nursing report). But the nurses moved him back to his bed, cleaned him up and then called for a doctor. Although the nurses were mental health qualified, many would have had little knowledge of general nursing, but ask yourself this question – if you see someone in the street, who has fallen, is unconscious, unresponsive to pain, what’s your first reaction – is it to move the person? Well the answer is no – you dial 999 and ask for an ambulance, which is what they should have done. This may have changed the outcome for Jimmy, but I’ll never know.

Ninewells:

- I have mentioned the variety of diagnoses following Jimmy’s admission to Ninewells. Consistently throughout the doctors weren’t listening to Jimmy and me.
- I could see that Jimmy wasn’t moving, I was helping with his care, I could see that he was very floppy – I watched him being lifted on a hoist – there was no power in his body – he was completely limp.
- a neurologist wrote in her notes ‘he wouldn’t move’ – but he couldn’t move.
- he was doubly incontinent – had sustained a fall, - was floppy – jerky legs – flaccid tone was described in his medical notes - here was a picture building up – yet no one was looking at it.
- I was telling the doctors about the fall – but then I didn’t have a **white** coat. And to quote a friend “It’s the white coat syndrome and I don’t have one”. So they weren’t listening to me. To further compound this situation, the referral letter from the doctor at Liff didn’t mention the fall.
- all the while Jimmy’s nutritional status was not being addressed, despite my pleas – I was bringing in high calorie drinks and other foods and I was feeding him. There was no dietician involved at Ninewells until very late on, and it was my second request. The dietician ordered special milk, but it was only on his tray twice. **ONE OF THE MAIN CAUSES OF JIMMY’S DEATH WAS MALNUTRITION.**
- he was in a side room, the door was nearly always closed and the blind on the window pulled down.
- the room was dirty with bits of plastic from the medication lying on the floor. I watched as the nurses just dropped them there. The rubbish bag

was often overflowing. The urine bag was also in the habit of leaking, as did the PEG feed. Was it surprising then that he contracted MRSA?

- there was no call buzzer in his room – so I had to go out into the corridor to search for a nurse each time Jimmy needed attention.
- there was no TV in his room, so I brought his own one in, but someone took the aerial– my cousin rigged up another one and put his name on it.
- I was with him every day, and there were times when I arrived to find his room cold – the window open, he only had a sheet over him and although he had t-shirts and pyjamas in his locker, the nurses didn't use them, until I asked that he should be kept warm and covered up. I remember a senior nurse saying that the only way to get air the room was to open the window – this was January.
- throughout all this time my cousin and I were the only constants in Jimmy's life. He was seeing a sea of faces every day. He was frightened, sad and he couldn't move – what a terrifying experience this must have been for him.
- I was aware that I was being labelled “the sister from hell”. Why? Because I asked questions – they in turn adopted the attitude that they knew best and didn't listen.
- physiotherapy was not given the weekend he died and it was recorded in his medical notes “because he is taking no part in his treatment”.
- it was not uncommon for doctors or nurses to come into the room and totally ignore Jimmy – they did their job then left – sometimes without even looking at him.
- respect and dignity weren't always employed. Two nurses were changing Jimmy's sheets and they pulled him so hard up the bed that he cracked his head on the iron headrest. He screamed – they apologised – looked at each other and smiled.
- the mobile radiography team who left him barely covered, lying flat on his bed, naked under a sheet.
- after the spinal injury was diagnosed there was no change to his care – he was still in the same general ward (side room) – had the same level of nursing care. If it were you or I we would expect to be moved to a neurology department where more specialised nurses were available.

- his mental state was unchanged – he still had his demons, frightening the hell out of him. His head was the only part of his body he could move. I remember a conversation we had during one of his good days. It was such a heart-rending experience, that I came home and wrote it all down. He said, “am I in hospital, what hospital?”, - he looked at his hand and asked what happened to it – then asked if he would get another operation on his other hand to make them move! He repeatedly said he couldn’t move. He then said, “I miss mum – I think she’s watching over me – I don’t know if I will see her again, but I think I will, I hope I will.” We sang Christmas carols and he knew all the words. He was very happy and smiled a lot – we spoke about Christmas and he said that he didn’t have a present for me. I said to him the best present I could have was for him to get better. We spoke about how important it was to eat and drink and to build up his strength. He said he didn’t want to die. He also said, “they’re not going to make a vegetable out of me” – these were his words.

That conversation is a treasured memory.

Ideas for Change

In a statement issued in 2003, the Minister for Health said that all Health Authorities across Scotland should have regard to and implement the recommendations made by the Sheriff following the FAI into Jimmy’s death.

Two words which are at the heart of the matter are **COMMITMENT AND COMPLIANCE**. Compliance is the easy part, commitment is much harder.

Tayside Health Trust have appointed a Learning Disability Liaison Nurse and have formulated guidelines for treating people who have a learning disability, thus indicating a compliance with the Sheriff’s recommendations.

Following a recent fact finding visit to Ninewells and Perth Royal Infirmary I learned that nurses were unaware of the appointment of the Learning Disability Liaison Nurse or the guidelines for treating people with learning disabilities. This is a clear indication that the policies are not filtering down to staff. I therefore felt that little had changed since Jimmy’s death and I saw no evidence of any improvement at ward level.

The real challenge is to ensure that words are converted into actions and policies are converted into hospital wide practices, which have a real and lasting effect on the quality of service for people with learning disabilities.

Last week I attended the funeral of a lady who had died in Perth Royal Infirmary. She had a learning disability and had been ill for several months.

Nurses in Perth Royal Infirmary failed to advise the family of the existence of a Learning Disability Liaison Nurse. Fortunately the patient's sister spotted a notice displayed at the nursing station advising of a Learning Disability Liaison Nurse with contact details. Contact was made and Lynda Murdach the Learning Disability Liaison Nurse became involved in the lady's care. I know that the family were very grateful for Lynda's assistance because the lady's brother-in-law mentioned her specifically and gave thanks to her at the funeral service.

I took some comfort that both the patient and her family were helped in some small way by Jimmy's experience and the recommendations of the FAI. But that family could have had a very different journey without Lynda's help. **But it proved that when it works it really makes a difference.**

I am glad to have had the opportunity to speak to you today, I've waited a long time to say that you are the people who can affect change – you are the people who can make the difference and direct staff so that they look beyond the learning disability and see the person, they use the family as a valuable resource – not a nuisance, and remember that lack of ability to convey feelings doesn't mean that the patient doesn't have them. And I hope the next time you make a decision about the services for people with learning disabilities, you recall the story of Jimmy.”

Betty Mauchland, assisted by ENABLE Scotland, pressed for an inquiry into Jimmy's death. Eventually a Fatal Accident Inquiry was ordered which reported on 7 March 2003.

In a wide ranging report Sheriff Dunbar made recommendations for how health services could improve. These were followed up by the then Minister for Health, Malcolm Chisholm and from this, health boards were set targets to:

- produce a timetabled action plan to implement the recommendations of the Fatal Accident Inquiry.
- produce a timetabled action plan to implement the recommendations from “Promoting Health, Supporting Inclusion”.
- conduct health needs profiling in collaboration with community child health, learning disability teams and primary care.

- develop a learning disability nurse liaison service.
- develop clinical leaders in learning disability, including nurse consultants.
- introduce protocols for early identification of people with learning disabilities on admission to hospital.
- give patients in general hospitals access to advocacy services.
- introduce nutrition assessment within 24 hours of admission to hospital.
- introduce training in learning disability for staff in general hospitals.
- introduce a policy of treating people with learning disabilities in open wards rather than side rooms wherever possible.
- introduce protocols for dealing with awkward falls within general hospitals.

These recommendations were followed up firstly by ENABLE Scotland and subsequently by the Scottish Executive Health Department.

From a wish to ensure that good practice in implementing these changes was shared throughout Scotland, the SCLD and ENABLE Scotland Health Working Group supported the Scottish Executive to organise this seminar on which this report is based.

You can read Sheriff Dunbar's recommendations at http://www.scotcourts.gov.uk/opinions/cb12_02.html

In addition to the presentation from Betty Mauchland, Anna Duffin presented her experiences as a user of health services and Anne Brown as a carer.

Our Health Matters Too!

Anna Duffin, SCLD



“Good afternoon ladies and gentlemen. Thank you for inviting me here today to talk to you. My name is Anna Duffin. I’m a trainer with the Scottish Consortium for Learning Disability and Key Housing. I’ve been involved in writing courses and delivering training all over Scotland.

In the past people with learning disabilities were often shut away. A lot of people weren’t allowed to do the things that they wanted to do. Like having their own home, falling in love, going to the pub or making decisions. Just ordinary, everyday things that you probably take for granted.

But things have changed. They’re not perfect but they have changed. One thing that has helped these changes happen is “The same as you?” “The same as you?” was the first review of services for people with learning disabilities in a very long time. People with learning disabilities and family carers were involved in writing the review.

“The same as you?” says:

- people with learning disabilities are individuals
- we should be respected
- we should have support to speak for ourselves
- we should have choices
- we shouldn’t be picked on.

Another policy “Promoting Health, Supporting Inclusion” has helped. Within this was a recommendation, as you probably know, that every first year nurse and midwife should be trained by people with learning disabilities and family carers.

I’ve been involved in nurse education for 4 years now. I do a talk to all the students together, 2 weeks before the tutorials start. There were 450 students this year! I tell them about “The same as you?”, “Promoting Health, Supporting Inclusion” and I also talk from my own heart, mind and past experiences.

I led two tutorials this year, where the students could ask me questions about my life and experiences of doctors and nurses.

When I was 10 years old, I was taking 30 tablets a day for epilepsy. I was told that I would not live to see my 16th birthday. I am now approaching my 44th birthday and my medication is down to 12 tablets a day. I have not suffered an epileptic seizure for 9 years. When I was told of my life expectancy, I was living in a children's home and I was told by doctors in my general hospital.

When I was on 30 tablets it was before all modern medication came into force. My support team can tell you what seizures I was having.

The only problem I have encountered with the NHS is when my epilepsy was questioned by a student doctor. I felt the doctor thought I was faking my condition. However, a senior doctor put the student straight and reassured me and told me not to worry. I felt that if the student had checked my medical history, this need not have happened.

I was having an EEG at the time and she didn't even ask my medical history. My file was as thick as the Guinness Book of Records! She discharged me but I only got as far as casualty and then I had a seizure. The consultant gave her a row!

That should have never happened at all – its terrible. That time when I was taken back into casualty, it happened in front of an ambulance. Casualty phoned the Neurology Department and the consultant came in and saw me and ended up getting the police involved and she was sacked on the spot.

These days people with learning disabilities are living longer. In the future there will be more people with learning disabilities with very complex health needs. People with learning disabilities have more health needs than other people. For example, one person in four has epilepsy.

We don't want big fancy things. But when you are with us take us seriously as men and women. Explain what will be happening and check out that we understand. Talk to us directly not to the person we are with. Please be careful not to use big jargon words that we might not understand. Our health matters too!"

The story Anna tells is included in the “Getting it Right Together” learning materials for first year nursing students published by NHS Education for Scotland.

http://www.nhshealthquality.org/nhsqis/files/GIRT_Narratives.pdf

“The same as you?” review of services for people with learning disabilities was published by the Scottish Executive in May 2000. It says that people with learning disabilities should have the same opportunities as everyone else to live a full life

<http://www.scotland.gov.uk/Topics/Health/care/VAUnit/Thesameasyou>

“Promoting Health, Supporting Inclusion” (NHS Scotland 2002) explains how nurses and midwives can support the health of people with learning disabilities. Implementation of its recommendations for nurse education have been taken forward by NHS Education for Scotland.

<http://www.scotland.gov.uk/library5/health/phsi.pdf>

A Carer's Perspective

Anne Brown, PAMIS

“Good afternoon, my name is Anne Brown. I live in Dalgety Bay in Fife and I'm a parent/carer to my lovely daughter Fiona. I am a member of *PAMIS*.”



Fiona is 31 years old and has profound and multiple disabilities and complex medical needs. She has a great personality, a smile that lights up the darkest day, and a zest for life that would put all of us in this room to shame!

She has to cope with the fact that she suffers from cerebral palsy, epilepsy, asthma, recurrent chest infections requiring intense management and oxygen therapy, kyphoscoliosis, is gastrostomy fed and requires 24hr care. She has no balance and needs to wear a body brace and neck collar to allow her to sit up in her specially adapted wheelchair.

Good healthcare and management of her disabilities and health needs is essential to Fiona and is part of the reason she is alive today.

We have an array of machines and equipment at home to cope with Fiona's condition – nebuliser, suction machine, gastrostomy feeding equipment, oxygen, profiling bed, sleeping system, hoists, special chairs, not forgetting the small but essential items which a lot of carers have quite a job to obtain, such as syringes, gloves, tubes, swabs, wipes – the list goes on! And none of this is helped by the fact that my local health authority fails to use consistent guidelines for the issue of supplies to carers across its own area – a recurring and very frustrating problem!

Fiona has a complex range of drugs each day. We use a timetable for their delivery - to make sure that they are all given, and at the right time. This is so critical that we use a wall chart to keep control over it.

As well as this, every day she requires postural drainage and chest percussion as well as physiotherapy to her limbs.

On a good day, when Fiona's health is at its optimum, we can fit in some of the things she likes to do - such as shopping, out for nice walks, visiting her favourite coffee shop, going to her church group, wheelchair curling in the winter, or riding on specially adapted bikes in the summer.

However, on a bad day, when Fiona's health is at a low point, the picture is a very different one. She requires constant and vigilant care. She could choke at any time but is more susceptible to this when ill. She also has increased medicines, more physiotherapy, oxygen, increased nebulisation etc.

Fiona's bedroom then resembles a hospital scene, but I would prefer to manage Fiona at home, rather than have her admitted to hospital – her GP and hospital consultant are well aware of this and fully agree with my view. But I am not stupid about the situation and I know when Fiona does require to be admitted to hospital.

One of the reasons why I would rather cope at home is that when Fiona is admitted to hospital, then so am I! I have to stay with her 24hrs to make sure that she is safeguarded and properly treated – Fiona can't speak for herself! I can't leave her alone in hospital. My husband and I work shifts to care for her but I am the main carer, and my husband will take over to allow me to have something to eat, to freshen up, to visit the toilet – and generally to have a bit of a break and even a sleep!

You may well think that this is an exaggeration, but the last time Fiona was in hospital I did wonder why no one seemed to offer even to help me in her care – till we discovered someone had written on Fiona's notes - "Mum staying, doing 24hr care - no nursing care required"! The resources, training, expertise and equipment are not in place to allow me to safely hand over my daughter's care to the hospital and I can't emphasise the safety aspect enough, but some help when I am there would at least be appreciated!

I understand that liaison nurses are working in some hospitals to link up with staff prior to planned admissions. I am here today representing other parent/carers of young people with profound and multiple disabilities and, as recently as last Friday, one mum said that when she had asked on the ward about the liaison nurse, no one knew who she was talking about! Why are staff unaware about liaison nurses?

That brings me nicely round to lack of communication. Lack of communication - not only between medical disciplines but also with parents and carers.

I know that I am regarded sometimes as a necessary evil on the ward, but who knows my daughter better than me? Who actually sees her as a person other than me? It can break my heart when a doctor will examine Fiona and will neither have eye contact with her, nor even speak to her.

Key areas identified by the Sheriff after Jimmy's death included record keeping, nursing/medical notes and communication. They also included the involvement of carers and relatives in history-taking.

Can you imagine my frustration when, after submitting a detailed written note about Fiona's medical history, relevant to the specific condition she was being admitted for, it was totally ignored by the consultant? I had asked for it to be placed in Fiona's file so that everyone would have been clear on what had happened prior to her admission. I would also have peace of mind that I had left nothing out and, should it have been my husband or son with Fiona when the consultant came round, then they would not have to worry that they had forgotten anything. When I asked him if he had read it – he just ignored me!

I don't want to sound as if I am against hospitals and that I am being negative about Fiona's care. I am not. I regard the team involved in the care of Fiona over the years as a very good one. I have a good working relationship with them and, on the whole, the ship usually sails on calm waters. However, when we do get into stormy waters, that's when we can find a few leaks in the ship and we may be in danger of sinking!

I spoke earlier of the safety aspect and I know that a falls policy was mentioned in the Sheriff's recommendations. I'll give you an example of a situation we found ourselves in when Fiona was admitted as a day patient to undergo a procedure. Whilst waiting on the ward with Fiona, my husband noticed that all the beds had cot sides except one – and that was Fiona's bed. Surely, as the most vulnerable person on the ward, it would have made sense for the cot sides to be on Fiona's bed as a matter of priority for safety – and for common sense.

We are talking about caring for the most vulnerable and dependent patients within the hospital setting. If you can get the care right for this group of people, those with the greatest and most complex needs, then the rest of the population will naturally benefit as the principles can be cascaded through every level of dependency and every age group.

I welcome the fact that you are here today listening to what I have to say and that some problems are being addressed following the fatal accident inquiry. I have little doubt that I will hear of good initiatives to overcome past problems and to make lasting improvements.

However, like most big organisations, communication in NHS establishments is often less than ideal. In my view, to ensure their effectiveness, the improvements need to be subject to some kind of regular review, ideally independent review, to make sure that all relevant staff know about them and are actually and properly applying them whenever necessary.

As you have heard, I think that the planned improvements need to include:

- better communication between staff, and with parents and carers
- listening to parents and carers – we are often the experts on our own young people
- increased nursing care/dedicated nurses – clearly training and awareness is a big issue here
- increased vigilance on safety aspects – I think Jimmy’s case says it all here
- independent review of implementation – the best way to reassure you and me

over-arching everything, I think that healthcare needs to be person centred, not service centred as it so often seems to be.”

Anne is a member of *PAMIS* that supports people with profound and multiple disabilities and their families. It hold workshops for parents which include training on managing health needs. It also runs the PMLD network which has a bulletin board for carers and professionals to share information and good practice. *PAMIS* is a partner in the Scottish Consortium for Learning Disability.

www.dundee.ac.uk/pamis

RESOURCES

Following on from these accounts of direct experience, Lisa Curtice outlined for the seminar the sort of resources which can be available to address many of the issues arising.

General Hospital Care for People with Learning Disabilities – Follow On Support: Lisa Curtice, Director, SCLD



“My role is to set out some of the resources and support that is available to Boards to help them take this agenda forward. I have three key messages:

- it is entirely possible for all Boards to ensure that their hospitals provide services which are responsive to the needs of people with learning disabilities. I shall be illustrating some small changes that will make a big difference.
- there is plenty of support available to help you do this. Your biggest allies are people with learning disabilities and family carers.
- working in partnership with people with learning disabilities and family carers, whether in training, service planning or audit brings huge rewards for staff. It is motivating, confirming and sometimes, life changing to see the impact of the care provided from the patient’s perspective. Staff don’t get this chance enough. Implementing these recommendations provides that opportunity. I will show what I think this means in practice.

A cross-cutting issue

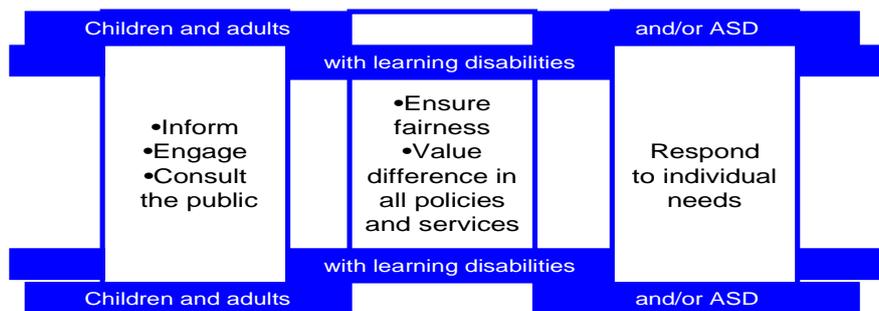


Diagram from *It's Our Health Service*, part 1, page 9

The issues being raised this afternoon do not represent special pleading for people with learning disabilities and their families. This is the mainstream public reform agenda and central to NHS Scotland's equality strategy.

The needs of children and adults with learning disabilities and/or autistic spectrum disorders should be woven through the strategic responses to these agendas. But more, responding to them helps to address barriers to access, not just for them but for many marginalised groups.

This is very clear from what has been said by Betty, Anne, Anna and indeed Sheriff Dunbar. The fundamentals that people are asking for to avoid failures are integral to creating a fairer and more responsive NHS. But it won't be fairer and more equitable for people with learning disabilities and their families unless we pay attention to their recommendations, which are:

- to listen to patients and family carers and ensure they have the information they need.
- to ensure that they are informed and engaged with service developments.
- to ensure equal access to health care and the best treatment for everyone as their human right. This means accepting that things may need to be done differently for some people to achieve this.
- to respect everyone in need of care sufficiently to develop and deliver services to meet their individual needs.

Standards

"Hospitals..... should review how they deal with the admission of patients with learning disabilities.... and devise a protocol for identifying such patients and to ensure that there is proper communication with them not only on admission but throughout their stay in such hospitals." Dunbar 2003



Fair Multi Media



There is no need to start from scratch. There are national standards that set out practice standards, the evidence base and advice on implementation.

The Best Practice Statement on Promoting Access to Healthcare for People with a Learning Disability produced by NHS Quality Improvement Scotland (QIS) in February 2006 is intended to support front line staff to improve access at the point of entry to health care.

For example, staff should have the means of identifying a person with learning disability. This statement is based, among other things, on the recommendation of Sheriff Dunbar. Several ways of achieving it are suggested including the 'communication passport' which *PAMIS*, for example, have used to good effect.

NHS QIS have also produced revised quality indicators for learning disabilities which apply to ALL health care services, since children and adults with learning disabilities may use any of these. The overview findings of the first set of inspection against these indicators were published in February this year and provide a good basis for seeing how each Board is measuring up and what are their successes and particular challenges.

Accessible Information

Books without Words



Top Tips for Health Professionals!
From People with Learning
Disabilities and Family Carers

A common mistake is to provide less information to those who might benefit most from good information. This mistake makes the process of healthcare delivery harder, it can impact negatively on clinical outcomes – and it is discrimination. Whereas, information that is more easily accessible can benefit people in many different situations including older people and others. There is a wealth of experience and support on making information accessible and communication effective with people with learning disabilities. Speech and language therapist can assist staff across the service in communicating effectively.

Staff Training



Margaret Reid, SCLD co-trainer

Training by people with learning disabilities has a big impact on staff

Everyone agrees that attitudes are fundamental to how people are treated but people often say that these are hard to change. One particular factor in play is that health staff, like staff in any public service, can unintentionally ignore or distance themselves from people with learning disabilities because they are not quite sure how to behave. They may not have met someone with learning disabilities before. Actually they tell us, they may be afraid.

For six years now SCLD has been tackling this issue head on and I can tell you what works. When people with learning disabilities and family carers deliver training directly to staff it breaks down barriers very quickly and makes the case for change far more effectively than when that training is delivered solely by professionals.

There is a consensus in the field that this is the right way to do it. It was made a requirement of nurse training in *Promoting Health Supporting Inclusion* and it is required by the NHS QIS indicators.

“But that must be hard”. “How can we get people who are representative?”. “It’s easy for people like Anna but they’re the exceptions”. No. It can be done. A wide range of people can contribute with appropriate support. Go to the organisations who can make it happen for you. SCLD is a leader in this, you will have local advocacy groups and ENABLE Scotland has a very wide membership of people with learning disabilities across Scotland who are very keen to take part in training health staff.

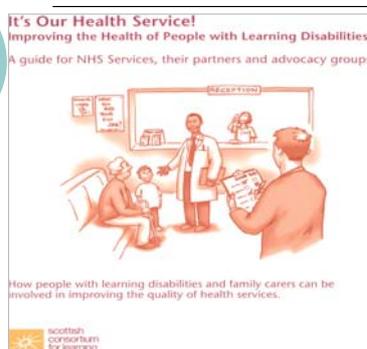
They are a valuable resource. So many people with such a huge contribution to offer and so few with the opportunities for work and remuneration. The best way to overcome unease about how to respond to people with learning disabilities is to work alongside them. I ask you to consider very seriously employing people with learning disabilities and family carers in your training

teams. 'The same as you?' said that local authorities and NHS Boards should set an example and lead in their employment of people with learning disabilities. It would be fantastic to see the NHS in Scotland taking up this challenge now.

We know, as a training organisation, that it is not realistic for staff to obtain all their professional learning from going on courses. Self study is an important part of CPD and can also reinforce other learning. Resources, such as audio visual materials can also be used in staff teams when a particular issue arises and in-house trainers themselves often appreciate targeted materials that they can employ:

- becoming Visible is a DVD and pack produced by PAMIS and SCLD that tells the stories of three people with profound and multiple learning disabilities. It is free of charge and raises key issues such as the transition from child to adult services and explains the parent's perspective. The booklet has ideas for exercises and a resource listing. Its value to health staff is that it shows people's ordinary lives.
- Just Ordinary People is an audiovisual resource – available as DVD or video which was commissioned from us by NHS Education for Scotland. It is incorporated in a learning package called "Getting it Right Together" which NES has provided to all the HEIs training pre-registration nurses to help them fulfil the requirement of Promoting Health Supporting Inclusion that all first year nurses in Scotland should receive training by people with learning disabilities. Just Ordinary People is a discussion by four people with learning disabilities of their experiences of health services and their health needs. It raises both practical and ethical issues.

Service Improvement



It's Our Health Service!
Improving the Health of
People with Learning
Disabilities: A guide for
NHS Services, their
partners and advocacy
groups



The NHS QIS Indicators expect self assessment to precede the external audit. They are intended to influence the culture of performance improvement itself and they recommend that children and adults with learning

disabilities and family carers should be actively engaged at every stage in the process of service review and change. NHS QIS have led by example and successfully included people with learning disabilities and family carers in inspection teams.

This resource was specifically commissioned to provide guidance to Boards to help them make this process effective. Its starting point is that health staff not familiar with working with people with learning disabilities may need access to guidance and resources to do this. The resource is specifically targeted at the indicators. It provides background and good practice advice for health staff on engaging with both children and adults with learning disabilities and family carers. It contains information that can be used directly with them. It contains sample materials specifically to involve people in monitoring the indicators such as questionnaires that can be customised for local use, together with video clips for use in training. 1500 of these guides have been distributed to health boards, advocacy groups and key local authority contacts.

Who has them in your Board? What use have they made of them? How can SCLD and its partners and other groups support you to implement the material contained there? We need and would appreciate your help in making these and other resources available to the right people in your organisations and in the right context to have the most impact in improving services for people with learning disabilities.

For Further Support



www.sclld.org.uk



www.enable.org.uk



www.dundee.ac.uk/pamis

Our organisation, the Scottish Consortium for Learning Disability, as you see, is a partnership organisation. It is a partnership of organisations such as ENABLE Scotland, PAMIS, providers and universities. Norman Dunning, Chief Executive of ENABLE Scotland, is here today. It is a partnership with people with learning disabilities and family carers in the way we work and in our governance and it is partnership with stakeholders across Scotland, funded by the Scottish Executive, as a centre for excellence to spread good practice. We have – jointly – a Health Working Group - which is a forum for

sharing ideas and action and which has collaborated in putting this seminar together. SCLD and its partners can assist in developing action plans and protocols to implement good practice.”

Scottish Consortium for Learning Disability
Adelphi Centre, Room 16
12 Commercial Road
Glasgow G5 0PQ
Tel. 0141 418 5420
lisa.c@sclد.co.uk
www.sclد.org.uk

You can see the NHS QIS Quality Indicators ~ Learning Disabilities at

<http://www.nhshealthquality.org/nhsqis/files/Learning%20Disability%20Quality%20Indicators.pdf>

The NHS QIS Best Practice Statement on access to healthcare for people with a learning disability is at

[http://www.nhshealthquality.org/nhsqis/files/BPS%20Learning%20disabilities%20\(Feb%202006\).pdf](http://www.nhshealthquality.org/nhsqis/files/BPS%20Learning%20disabilities%20(Feb%202006).pdf)

EVIDENCE

Lisa's presentation was followed by Linda Allan and Michael Brown who gave compelling evidence of the health needs of people with learning disabilities. The following section outlines their notes as presented to the seminar.

Why people with learning disabilities are high users of general health services

Linda Allan (NHS Glasgow and Clyde) and Michael J Brown (NHS Lothian)

Improving General Hospital Care for People with Learning Disabilities

Changing demographics of the learning disability population

- 53% *increase* in LD 1960-1995 = 1.2% per annum
 - Due to improved socio-economic circumstances
 - Due to improved intensive neonatal care
 - Increasing population trend to continue
- projected 11% increase over next 10 years due to increased survival at older age
- increase in number of older people
- increase in number of population with severe learning disabilities.

General Hospital Risk Factors

- people with learning disabilities may receive injuries and be harmed when physical restraint is used inappropriately.
- people with learning disabilities may be more at risk of things going wrong than the general population, leading to varying degrees of harm being caused whilst in general hospitals
- swallowing difficulties are more common in people with learning disabilities, leading to respiratory tract infection and early death
- harm may result if a person with a learning disability is unable to understand information relating to illnesses, treatment or interventions. Communication and consent are key issues

- access to treatment is often delayed because symptoms are not diagnosed early enough. This could lead to undetected serious health conditions and avoidable deaths.

Additional Factors

- access to services ~ factors
 - issues relating to the person which require SERVICES to make reasonable adjustments
 - issues relating to health and social work professionals
 - issues relating to service structures
- Factors inter-related
 - limited verbal communication skills, but structure of services impacts further upon the overall effectiveness of communication (e.g. short appointments, busy wards), as can the attitude of the health professional
 - problem behaviours accentuated by situations e.g. appointments with under-confident, inexperienced professionals
 - attitudes of professionals contributing to unintentional institutional discrimination, compounded by low expectations of the individual with learning disabilities.

In Summary

- higher level of health needs
- overwhelming evidence to support significant level of need is unrecognised and untreated
- a different pattern of health need from the general population – different responses required for some
- high users of ALL aspects of the NHS, including general hospitals
- shorter admission times yet higher health needs
- additional contributing factors
- additional support required for some from specialists

Fundamental issues are:

- values-base
- rights-led
- anti discriminatory practice
- needs led services
- management of long-term conditions
- ability to self-care
- equity of health outcomes
- practice development
- additional support throughout.

What Needs to Happen?

- national action – named lead – implementation of the Health Needs Assessment's recommendations – robust monitoring through NHS Performance Assessment Framework
- local action – NHS board lead – local health improvement strategy
- targeted health screening programme via GP contract, GMS2 – supported by specialist workforce
- national governance on all deaths
- learning disability liaison service in all general hospital settings
- sharing of information

Underpinned by the active involvement of people with learning disabilities & their carers

Main Points

- people with learning disabilities have different morbidity and mortality presentation than the general population
- people with learning disabilities experience significant barriers to accessing health services
- people with learning disabilities have a higher level of health need but shorter admission to acute care
- Scotland has a strong policy, legislative and evidence base on which to develop services
- general hospital provision for people with learning disabilities is a general hospital problem, which requires the support of specialist services to ensure exemplary service responses

- solutions do not lie in an 'interested few'
- solutions are not about significant investment - but rather the art of caring and basic nursing / medical care

Performance Assessment Framework is not about hospital closure any more - it is about health improvement embedded in delivering for health targets for people with learning disabilities.”

Systematic evidence of the health needs of people with learning disabilities and recommendations of how the health inequalities experienced by people with learning disabilities could be reduced can be found in:

The Health Needs Assessment Report published by NHS Scotland.

<http://www.phis.org.uk/pdf.pl?file=pdf/LDSummary.pdf>

The Disability Rights Commission has published (2006) a UK-wide inquiry into the health inequalities affecting people with learning disability.

Equal Treatment: Closing the Gap

http://www.drc-gb.org/newsroom/health_investigation.aspx

GOOD PRACTICE

Finally, the seminar finished on a positive note with examples of emerging good practice from across Scotland. Michael Brown took the key recommendations and persuaded colleagues from a variety of fields to give brief presentations on:

- how in NHS Lothian there is an acute hospital liaison service which gives advice to doctors and nurses, makes information easy to understand, trains nurses and makes sure that people with learning disabilities are involved.
- how Fife Primary Care Trust is developing training for nurses and doctors so that they will understand people with learning disabilities and their needs better.
- how NHS Grampian is involving carers as trainers in meetings and consultations. Grampian is also doing work to make sure that people who fall get a good service.
- how NHS Ayrshire now is developing electronic patient records to improve access to information.

The notes of the presenters are reproduced in the following extracts as given at the seminar.

**Scott Taylor, Learning Disability Liaison Nurse, NHS Lothian &
Juliet MacArthur, Senior Research Nurse, NHS Lothian**

Acute Hospital Liaison Service

Practice Model

- direct patient contact
- developing systems
- influencing policy
- education

Direct patient contact

- 3 way referral route : self referral / parent / carer
- primary care
- secondary care
- assessment process
- treatment aims / implications
- understanding / expectations
- admission / discharge implications
- environment / logistics
- produce a responsive, cohesive and robust plan

Key elements

- Clinical advice
 - interventions
 - management
 - co-ordination
 - Risk management
- Promoting and modelling
 - positive interaction
 - inclusion
 - equality
- Producing personalised / accessible information

Developing Systems

- A+E alert
- Referral pathways
 - Primary Care
 - OPD
 - waiting list managers
 - wards / clinical teams
- Audit
 - Incapacity Certificates
 - QIS Reviews
- Research

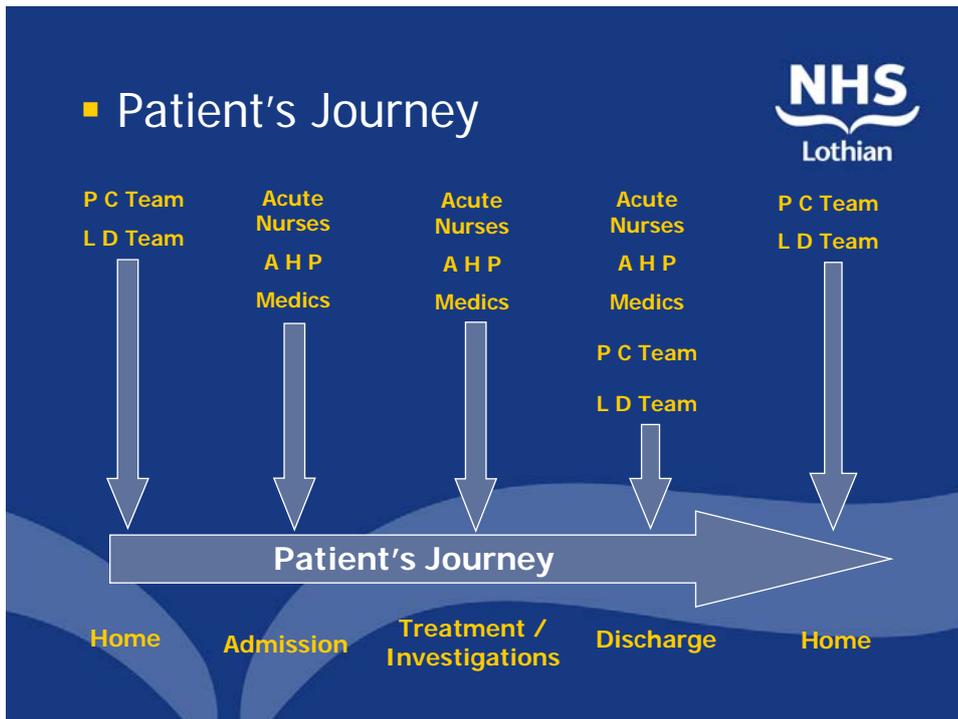
Influencing Policy

- Contribute to development / implementation of guidelines
 - QIS BPS
 - SIGN Guidelines
 - Local
- Feed into committees
 - Diversity and Equality
 - Clinical Governance
- Policy reviews
 - Consent policy
 - Patient escort policy

Education

- All disciplines, grades, departments
- Formal / informal
- Internal / external
- Staff development / CPD
 - confidence
 - understanding
 - competencies

- National point of contact



Challenges

- maintaining profile of people with learning disabilities
- additional health-needs
- liaison service
- encourage acute services to take ownership, accept accountability and engage
- liaison service capacity to provide quality

Sandra Morrison, Learning Disability Liaison Nurse, Fife Primary Care Trust

Training in Acute Services: The Fife Experience

Why do we need to think about training?

- learning disability placements no longer available to adult branch students
- uneasiness/lack of confidence due to limited or no experience of people with a learning disability

- fear and difficulty when working with someone who has a profound learning disability
- communication barriers
- positive & negative experiences
- “the person with a mental handicap should always be in a side ward”
- “people with learning disabilities should be segregated within the general hospital when they come for treatment”

For many trained nurses the first time they will have contact with someone with a learning disability is when they arrive on the ward.

Difficulties with training

- getting staff released from wards
- staff booking on and not turning up
- subject matter- learning disabilities is not a high priority in terms of personal development

Newly qualified nurses or nursing auxiliaries undertaking SVQ need to learn skills such as venepuncture, cannulation, catheterisation etc so sessions around learning disabilities are lower down on their priorities.

What has been tried

- a 2 day course initially aimed at nursing auxiliaries involving professionals, a parent/carer and a person with a learning disability
- on the ward sessions

Nurse managers felt that it was difficult to release staff for 2 days and the numbers booking on were low. Those that did attend the course gave very positive feedback. Trying to do a session on the ward was difficult in terms of getting a suitable room and it was easy to pull staff out of the session if the ward was busy.

Current situation

- Staff Induction - an overview of issues facing the person with a learning disability + Adults with Incapacity Act
- statutory training- emphasis on communication

- F1 Junior Doctors Training- autism, cause of learning disability, behavioural changes, medication, consent & capacity

Staff induction is delivered to new staff, trained and untrained in the operational division. Statutory training is delivered to staff from the operational division and also primary care staff.

What next?

- 2 hourly afternoon sessions- epilepsy, what is a learning disability, challenging behaviour, communication.
- adult branch programme - Dundee University

It is hoped that the 2 hourly sessions can be expanded to include a session from a parent/carer and a person with a learning disability. Currently within the adult branch they get a lecture on the cause etc of learning disabilities but get no input as to what it is like to live with a learning disability and the implications of that.

Something to think about

- how can we give the nurses of the future practical experience of working with people with learning disabilities?
- adult branch nurses will only fully appreciate what having a learning disability is like if they are able to gain “hands on” experience of working with someone with a learning disability before they become trained nurses

Susan Carr, Learning Disability Joint Future Manager, NHS Grampian

Involvement of Carers and Relatives

Involvement in development of a Policy on Hospital Care for People with a Learning Disability

- questionnaire consultation on experiences of Hospital Care.
- consultation on policy through Carer and User representation on Learning Disability Strategic & Management Groups.

- consultation as part of local Learning Disability Strategies.

Ongoing consultation with service users, family carers and relatives highlighted that the policy was not changing practice adequately. This clearly identified the need for training.

Family Carers and Relatives Involvement as Trainers:

- training on the Disability Discrimination Act and meeting the needs of People with a Learning Disability.
- assisted with the development of the training programme and training information pack
- two Family Carers and a Service User participate as Trainers.

The Role of the Family Carer as a Trainer

- give their perspective of hospital services: outlining positive and negative practices that they have experienced.
- outline the principles of the Adults with Incapacity Act and issues related to obtaining consent for medical treatment.
- demonstrate communication tools e.g. personal passports, sensory storybooks, symbolised material and communication tool kit.

Every training pack includes a copy of the NHS QIS best practice statement - February 2006. "Promoting access to healthcare for people with a learning disability - a guide for frontline NHS staff".

Involvement in Partnership Workshops

- in response to concerns regarding care in hospital settings.
- joint event: family carers / relatives & NHS staff.
- two-way communication: Listening to concerns and identifying solutions.

Senior NHS staff participated in this workshop. The involvement of the Nursing Director and the NHS Catering Manager helped family carers feel that they were being listened to and that their concerns were being taken seriously.

It is significant to note that, despite the range and number of concerns raised, not one of these relatives had used the NHS Complaint process. This highlights the need to actively involve family carers and relatives to ensure we do know the problems people are facing in general hospital care settings.

Outcomes from Workshop

Action plan which includes:

- Inclusion of Carers, Relatives and Service Users in consultation on NHS Grampian's bed-side catering leaflet.
- Inclusion of Carers / Relative on Food, Fluid and Nutritional Care Public Involvement Group.
- development of individual Hospital Admission Plans.

NHS Grampian Learning Disability Carer & Service User Group

- Chaired by Family Carer.
- Originally established in advance of local NHS QIS review.
- Function of group:
 - To actively involve children and adults with learning disabilities and their relatives / carers in the planning and delivery of services, to ensure that the services are provided on the basis of their needs. The membership of this group will help improve the way that NHS Grampian effectively involves family carers and relatives.

"It's Our Health Service! - Improving the Health of People with Learning Disabilities. A guide for NHS Services, their partners and advocacy groups". This guide has been given to all members of the NHS Grampian Learning Disability Carer & Service User Group.

Millie Shepherd, Falls Management Coordinator, NHS Grampian

Falls Management Coordinators, NHS Grampian

The way forward is to introduce a Falls Management Strategy for Grampian that is equitable and pro-active rather than reactive.

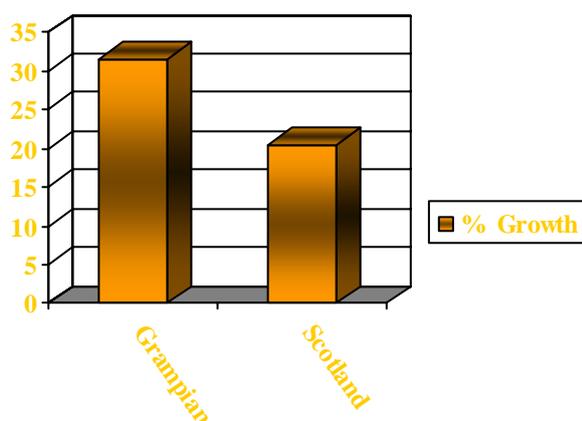
Aims

- Streamline Grampian Falls Management Strategy and promote its implementation to address:
 - Falls management
 - Staff education
 - Public awareness

Statistics

- OR1 Figures NHS Grampian – 2005
- 80% - Slip, Trip or Fall = 4,506
- 7,791 >65 year olds will fall each year
- 4,400 >85 year olds will fall each year
- 83.5% of un-intentional injuries are falls
- Unintentional injuries account for 1% of all fatalities

Demography/Growth rate 1998 - 2016



← Growth rate for the 75 and over population

Percentage growth rate is 11% higher in Grampian

Methodology

- Work within each Grampian CHP area and Acute Services
- Networking with Professional Groups
- Multidisciplinary, Multi/agency Falls Mapping Workshops

- Audit

Audit

A & E Orthopaedics Medical Wards

Screening Tool? Assessment? Integrated Care Pathway ?

Fall Mapping Workshops

Multidisciplinary/Multi-agency

Highlight Good Practice Identify Gaps Create Wish lists

Staff Questionnaire

Awareness? Responsibility? Training?

Outcomes

- Identify Current Service Provision for Fallers
- Highlight existing Falls Service initiatives
- Identify Gaps in Service

Multidisciplinary Falls Mapping workshops are underway in Moray, Aberdeenshire North, Central, South, Aberdeen City, Acute Services. Group work involves patient scenario, mapping of journey of care as it is, at present, within localities; each team describing their current interventions. N.I.C.E. Guidelines are then introduced and the care pathway revisited. Comparison is then made as best practice initiatives influence the outcomes of assessment, planning, referral and treatment for the patient. The Teams, in their localities, can then identify the missing links needed in their patch to improve patient outcome.

Audit of Aberdeen and Elgin Acute Service Sprint audits applied to 3 distinct areas of practice (Patient Pathway and Staff Questionnaire):

- A & E Departments
- Elderly Medicine
- Trauma and Orthopaedic Departments

A & E Audit

- 50 patients studied >65 years attending with Fall
- 23 of these had fallen before
- 15 of these previous falls, due to health related factors
- None of the 50 were assessed for their future risk of falls
- None were offered any fall-related interventions
- 30 of the 50 were admitted for acute care

Orthopaedic Audit

- 30 patients >65 admitted with Fall
- 20 of the 30 had fallen before
- 10 of the 30 required longer treatment with transfer to peripheral bed
- These 10 alone totalled 420 hospital bed days
- Cost - £400 per day **without** Surgical costs

By completion of the project Audit, Mapping and resource finding study will encompass the 4 CHP Grampian areas. The collation and reporting of Service Provision trends will guide and facilitate recommendations for change.

Project Objectives

- To facilitate the development of Equitable Care as:
 - all older people should be asked at least once a year about falls
 - all who report a single fall – should be observed as they stand up from a chair without using their arms, walk several paces and return – “*The Get up and Go*” test
 - further investigation for those who have difficulty
 - recurrent falls require multidisciplinary assessment
 - NHS Boards should ensure falls assessment services are available

Elements of Success

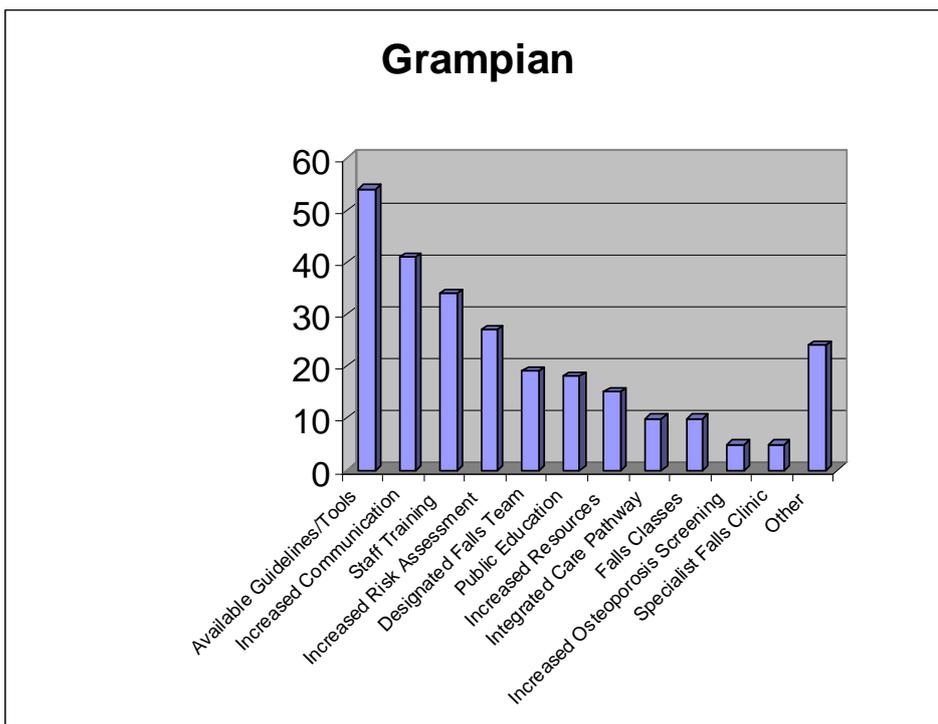
- Routine Primary Care Assessment
- Clear referral pathways of care (*A & E, Outreach Teams, Secondary Care*)

- Falls Clinics – *Medical assessment, Mobility assessment, Osteoporosis assessment, Environmental assessment*
- Falls classes – *Strength and Balance Training*
- Promoting assessment and wider use of Calcium and vitamin D supplementation in the frail elderly

Multidisciplinary assessment and Multi-factorial intervention can break the cycle of recurring falls and recurring injury leading to frequent and recurring hospital admission.

Results

- Case Risk Identification
- Assessment
- Interventions
- Information Giving



The Way Forward

- Falls Management Guidelines
- Early Case Risk Identification
- Integrated Care pathway
- Staff Education
- Public Awareness

Tommy Stevenson, Professional Nurse Advisor and Dominic Jarrett, Information and Research Officer, NHS Ayrshire and Arran

Record keeping, Nursing/Medical Notes and Communication

Communication

- Alliance with Carers
- Special Needs Working Group
- Advisory/Consultancy
- Broad Representation
- Sets Agenda

Primary

- Liaison Nurse within each CHP
- Resource Pack for Clinical Staff
- Population Profile within General Practice and Appropriate use of Read Coding

Secondary

- Liaison/Link Nurse interface
- Across all departments
- Improved clinical Profiling
- Initial Assessment form
- A/E Registered
- Additional Training
- Environmental Management influencing patient journey

Specialist

- Liaison Nurse (CLDT)
- Resource Management
- Strategic Intent

Record Keeping

- Themes from the Borders/Mauchland Inquiry:
 - Quality of Information Recorded
 - Applicability across disciplines

- Influence on care

Actions

- across discipline review of notes
- nursing, psychiatry, AHP's
- multi Agency Review Learning Disability Services
- development of Cross Discipline Audit Tool for Notes

FACE – Functional Analysis of Care Environments

- Electronic Patient Record
- care planning functionality
- records demographic information, assessment details, details of contacts
- records progress along Integrated Care Pathway, and variances
- individual and population based reporting mechanisms

Implementation across Ayrshire and Arran

- Approximately 700 users across a variety of care settings, with 24hr user support available
- Used for all record keeping within Mental Health Community teams, also in-patient services
- Being developed in relation to:
 - Podiatry
 - Sexual Health
 - Elderly Mental Health
 - Psychiatry
 - Midwifery
 - Perinatal mental health
 - Learning Disability
 - Primary care staff accessing in relation to SSA
- identified as e-Care solution for NHS Ayrshire and Arran

Implementation with Learning Disability Service

- initial pilot involving 3 clinicians and admin within each of the 3 CLDTs:
 - highlighted issues with hardware, network
 - difficulty of making use meaningful with small pockets of clinicians
- extended pilot involving all members of the East CLDT:

- started Feb 2006, evaluation commenced
- 238 clients recorded on the database
- replaced paper records (with exception of care plan) for Nursing and Physio, other clinicians using in tandem with some paper records
- paper records clearly indicate if the client is on the FACE database
- can indicate in FACE where additional info is available in paper records

Benefits

- rapid access to information (across professions, out of hours etc.)
- accuracy of record keeping
- secure access
- links to other Services
- Intensive Community Supports Service
- auditing
- can detail who accesses records & when
- common format for records
- great potential in relation to describing populations
- links to Health Needs Assessment

Development

- extend to North and South CLDTs
- integrate into Assessment and Treatment unit at Arrol Park
- explore sharing of information with others – Mental Health, Local Authority

Lewis Macdonald, Deputy Minister for Health and Community Care

Speaking note

- Thank you all for giving your time today to consider the experiences of people with learning disabilities when they need general hospital care. I appreciate that this is a very busy period with annual reviews but the issue is an important one.
- The reasons we are here today will be set out by Betty Mauchland, Anna Duffin and Anne Brown. They all have personal experiences that have helped shape - and will continue to shape - health and social care policy in Scotland.
- How we respond to today will be of benefit to many more people in our communities who need support with things some of us take for granted. Things like communication, feeling safe, and nutrition.
- It is well documented that people with learning disabilities generally need to use health services more than other people. Michael Brown and Linda Allen will explain why. Linda and Michael were closely involved in *Promoting Health Supporting Inclusion* and the *Learning Disability Health Needs Assessment* which set out how services could respond better. And I know that both are involved in many positive developments since.

- I see today as another positive step in recognising and addressing the health inequalities that people with learning disabilities and their families have experienced.
- I think most of us will agree that things have been improving for many people with learning disabilities in recent years.
- These improvements are the result of effective partnerships and genuine involvement of people who use services and those who care for them.
- Patient and Public involvement is a broad and challenging agenda for all people who use health services. I believe much can be learned from the work that has been done to implement *The same as you?*
- The learning disability review led the way in involving people, and set an example which others have since followed. Real commitment has been demonstrated locally and nationally, in local authorities and through QIS peer reviews and social work inspections. The Mental Welfare Commission's appointment of the first service user commissioner with a learning disability was a significant step in acknowledging the contribution individuals can make.
- But we still have some way to go if people with learning disabilities are truly to have access to the same services as everyone else. In the past 7 years, the balance of care has shifted considerably, with some 2000 fewer people with learning disabilities living in long stay hospitals. We are

working closely with local partners to ensure those remaining in hospital are resettled in the next year.

- Shifting the balance of care is what we are all focused on. And again, I think we can build on what *The same as you?* is delivering.
- Here are some of our goals for people with learning disabilities:

If patients require care urgently, they will be able to see the right person, with the right skills, at the right time.

If they need specialist treatment in hospital they will get access to a good, safe service provided by the right person.

They will have more local health care, a more responsive NHS, and a greater say in the way their NHS is run.

Carers will be treated as partners in the provision of care.

And as we do so, we must address the unacceptable inequalities in healthy life expectancy across Scotland.'

- I am sure these words will be very familiar to all of you. They are extracts from *Delivering for Health*. It is the direction of travel for all of the NHS and people with learning disabilities are very much a part of that.
- So today can help with a bigger agenda than the title of the seminar might suggest. You will hear from our colleagues from 5 different Boards about the good work that is going on in Scotland.

- Today we also want to hear from you and how we can build on that work and I will be interested to hear the outcome of your discussions. Support does exist. Organisations like the Scottish Consortium for Learning Disability can help professionals to deliver meaningful involvement. I am sure Lisa Curtice will give you a flavour of the progress that has already been made and the resources available for local teams.
- Before concluding I would like to acknowledge the impetus for this event. ENABLE Scotland wanted to see an appropriate response to the findings of the Fatal Accident Inquiry into the death of James Mauchland.
- Betty Mauchland has also responded to the loss of her brother with a determination that lessons will be learned for the benefit of others.
- We need to respond. I welcome the commitment you have shown in giving your time today. We now also need to give a commitment to sharing and building on the positive work that shows that change can be delivered.
- And to today's speakers, thank you for sharing your very personal experiences and your local initiatives. Above all, thank you for your commitment to improving people's experience of their time in hospital.