Sue Davies
My name’s Sue Davies. I’m senior co-ordinator for Conwy Connect for Learning Disabilities and today has been all about bringing parent carers together, and people with a learning disability, to share their experiences.

The medical students who’ve been visiting, their main goal is to listen to the stories of the parent carers and their experiences of how they feel when they are met by doctors and medical students. And really for them to take on board the stories of communication, learning about time and patience needed when people with a learning disability are visiting hospital.

Parent carer
My daughter’s adopted - she was adopted at 4 months and she weighted about 7lbs and I was told that she would take time to catch up.

But by 18 months she wasn’t making any effort to crawl or talk and I had been going regularly to the clinic. And I was then referred to a specialist in child development and he said to me and my husband, ‘Don’t you think it’s the way you’re treating her that is stopping her develop?’ Now, that I think is a very callous and uncaring way to speak to somebody who is doing their best with a child who is not developing as she should be. And that had me in tears: even now I can feel tears coming in my eyes.
So, I think one of the main pieces of advice I would like to give to people in the medical profession is not to be so dogmatic in your statements and just think that people do have feelings and not to say things that can actually make the situation worse for parents.

Sue Davies

The project’s been running probably about 2 years now, and it came into existence primarily from the report that was done by Mencap, *Death by Indifference* and it was about, you know, making sure that people with a learning disability were treated the same.

Parent carer

It horrifies me. I hate to say it in a meeting like this, but the mortality amongst learning disability has been a disgrace over the years, because of the lack of care.

Sue Davies

We actually had a consultation session with parent carers and people with a learning disability, how they wanted to deliver their stories. So it came about that we have the sessions in a friendly, welcoming environment, where parent carers and our members are at ease so that they can pass on their views. And we’ve probably been running about 18 months now to two years and we’ve held six to seven sessions.

Julia

My name’s Julia. I’m a 4th year medical student at Cardiff University and at the moment I’m on my second clinical placement rotation doing psychiatric medicine in North Wales and we’re currently based in Rhyl.

Other than today and an hour lecture on learning disabilities, we haven’t really had any other formal or informal teaching on learning disabilities or learning difficulties.

And today was amazing really. It was, like, an invaluable experience because, listening to these carers and these people suffering with learning difficulties in an informal context, where they’re comfortable in their environment and sort of disinhibited and don’t worry about time constraints, it was really good to hear their stories and what they thought were good communication skills and bad communication skills from doctors and what they expect, or how they expect doctors should react to them. And it was just nice to hear what they, how they think we should be acting, and what we should be doing to improve their experiences in the future.
When you meet a doctor, what do you prefer them to do to? Can you remember what you’ve told us in the past?

I like them to talk to you, because really when we are going into hospital we find it strange.

The parent carers and our members, people with a learning disability, are really getting quite a valuable experience from this. They feel that that they are listened to, that they are valued and that their stories will, you know, do make a difference.

I’m Carol Harrison. We’ve sat in on quite a few of the sessions with the medical students and it’s been quite an amazing experience actually, because quite a number of them have never had any experience, or never met anyone with a learning disability.

And we have talked amongst ourselves as parent carers and said, well possibly this has been the problem with many of the GPs in the past. They don’t know how to react to people with a learning disability. They don’t know how to talk to their parents or their carers. They don’t always sit and listen to what we are telling them.

I think the doctors should have more training, and nurses should have training, better training for people like us.

The younger generation now seem more aware. And these sessions have been extremely helpful.

The major problems I think that they were concerned about were, sort of, almost a lack of respect or a lack of compassion from the doctors mainly. They said a lot of the doctors were sort of ‘old school’ in their communication skills and weren’t very compassionate or empathetic towards the situation. And a lot of the time they said, when they went to consultations or if they were seeing a new doctor, the doctor hadn’t looked at the notes and didn’t know that the client had a learning disability and it just…it didn’t start them off on a good foot really.

And other things that they complained about, or mentioned, were that there wasn’t a lot of effort put in to talking to the patient themselves or even valuing the parent’s opinion, because obviously the parent knows their child the best and...
they have a good inclination of what...you know, if they are ill or something’s up, and the doctor would often dismiss this as an over-anxious parent. And they felt that this was, well, disrespectful really, they you know, that should be considered.

Parent carer

When she started school, I always thought that there was something that wasn't quite right. And when I got called in to the school to see the school nurse and she sat me down and said ‘I’m sorry to tell you your daughter's retarded.’

And in fact that was, I'm going home. And then I had to go away and tell my husband and then wait for the appointment at the hospital.

Sue Davies

Obviously this type of session is a different style of teaching than, say reading an actual case study. So this has given the medical students experience of actual emotions and feelings from the parent carers, so that would actually have, we would like it would have more of an impact on them when they are actually in the future talking to parent carers and people with learning disabilities. So this style of session complements other training areas instead of just reading – it actually allows them to empathise with the parent carer.

Julia

It was just wonderful to hear patients’ stories really. Like...I think sometimes you’re sort of thrown into medicine and, you know, you’ve got so much to learn that you forget that these patients are people and that they have these experiences and they’re really emotional and upsetting for people. And it’s really nice to hear stories and to hear both the good and the bad experiences they've had because it's so much more emotive. Like, it's inspirational, it makes you want to be a good doctor; it makes you want to be remembered by people like this for being a wonderful doctor, for helping them and making that difference. You don’t to be one of these ‘old school’ doctors who doesn't listen and upsets them and then these people are forever scarred by that experience. It's just...it’s really emotive and it just, like, leaves a lasting impression really, more than reading something from a book or being lectured at.

Sue Davies

We hope the medical students will take back how best to communicate with people with a learning disability, an understanding of, that parent carers are like, partnership in their care. Obviously that they are all individual, but the parent carers are there to pass on and help with the health problems but to
treat the person as an individual and not to ignore them. I think the biggest thing that that comes from some of our members is not to be ignored and that they should have the choices and opportunities in health as everybody else would have.

Parent carer

Any doctor that I’ve been to see with my daughter, I have to go through the process of explaining to him she does have learning disabilities and that she probably won’t understand what you have to say. And I feel as though I shouldn’t have to say this if it could just simply be on her notes, somewhere on the screen, just to let him know before she goes in that she does have these, these problems.

Julia

One of the things that I thought was really important that previously I might not have put so much weight on was just checking the patient’s notes before you see a patient. Because you know, in the back of our mind we’ve got so much to do, we’re so busy all the time, but just spending that thirty seconds looking in the notes and seeing, you know, a little background about the patient, might make all the difference to the patient. You know, and greeting them and spending the time getting to know them makes all the difference and I think that’s of real, real importance to both the patient and the carer.

Sue Davies

Feedback…the students fill in an evaluation form at the end which records their feedback. They certainly learn how to start to think about communicating with people and they take on board the stories come across people with a learning disability in the hospital through their training and eventually go on to be a GP it’s taken on board how to communicate, to give time and patience and possibly to think out of the box and be a little more understanding to their needs.

Julia

I think even myself, before today I might have thought that, oh, if they don’t understand you should talk directly to the carer who knows more about the problem but today has made me realise that even if they can’t communicate and even if they can’t understand, they are still your primary concern; you should still talk to them. Obviously the carer can hear you talking to them and knows about the situation, but I think it’s really important to make the client or the patient the centre of the consultation and then gather as much information as possible from the parent or the carer because obviously they know the most about the situation.
Sue Davies  Dawn, I know that’s the one thing that always comes across, is that you hate being ignored don’t you?

Dawn  Yes, yes I do.

Sue Davies  You hate...you would always want them to...

Dawn  Yeah, be more kind, friendly, doctors.

Carole  She had radical breast surgery, Dawn did, a number of years ago, and I took her to the local GP when we lived in Dorset because she had an abnormality in the one breast. It hung quite low. When I say low, it really did hang below her waist, and it got to a point where she could only lie on one side in bed with a pillow.

So I took her to the GP who was an elderly lady and she said ‘Well I can’t do anything.’ She said ‘You’ll have to have some brassieres made for her’. Fortunately she retired and we had a young GP and when Dawn got undressed she said ‘My goodness me’ She said ‘You or I would not tolerate this, this is a disgrace’.

Within a matter of weeks we had appointment to see a plastic surgeon and we were sent into a private hospital. At the time they were trying to cut lists, and she was actually sent, very fast tracked into a private hospital and both her breasts were reduced and then she went to the local doctor to have her stitches out. At all times she was treated with the greatest respect. Weren’t you?

Dawn  Yes. Yes.

Carole  And it just shows, down to one GP that was uncooperative and I hate to say it, very uncaring at that particular time and it made such a difference to your life.

Sue Davies  I think that the benefits of these sessions and certainly what comes out of it, is no doubt about it is communication. I mean, communication is the big, big part, sort of part of this of this, that if people are unable to talk or express their needs that they have to look at different ways of communicating.

And certainly some of the things that have been happening certainly in person-centred planning services - we’ve spoken about information about taken into hospital in an easy,
understandable way, for people to understand what's important to the person with a learning disability when they are in hospital. So I think that's a really big, big point that's coming across about the communication. Signage, easy read, listening and giving time for people to understand what's happening to them in their health and in the health organisations.

Really it's about treating somebody as you'd like to be treated yourself, and I'm sure you know that. And it's really no different. But it is about that as that extra time, extra patience sort of, with them and thinking out of the box as well.

Medical student

It's just kind of showed you how you can make a really big difference if you are, like, trying to put the patient first and make them feel at ease and help the family, you can do so much good in that. So I think we all felt like it was quite inspirational actually and we were like, this whole morning's been quite...

Parent carers

Well that's good isn't it.

That's what we want to pass over to students. And you will carry that, a lot of this with you, whatever you do.