

User & Care Forum Speakers:
What's it all For?
Andrew Denovan

Let me introduce myself first - I'm one of the members of the User and Carer Forum. My name is Andrew Denovan. Before I start I would just like to share that I'm on the autistic spectrum and have what they call Asperger's Syndrome. So standing up in public and being in front of this many people is extremely nerve-wracking for me so I'd just like you to bear with me if I get a bit overawed at which point I'll put my hand up I'll just calm down for a wee second or two – hopefully I won't have to.

First of all what's it all for? All of this – why are we all here and can we make a difference? No? Then we could all just go home and forget about it. But – Yes of course we can! We can change things. Look at us all here – we're a vast collection of experiences – either of people who use services, carers or service providers. I've unfortunately had to access services in the past 4-5 years. And I'm still disillusioned at times to the state of these services. Especially psychiatry and mental health. But at times I've met some wonderful caring people who have really gone out of their way to help me. It was a social worker who really first put me on my feet. I'd no idea of the situation I was in – I was running out of money, I was about to fall into debt and this wonderful woman came and she just showed me how to claim benefits – which being on the autistic spectrum I couldn't understand this. So there are some genuinely brilliant people out there so this is not a personal attack.

It all seems a bit of a lottery – you either get a great service provider or you get somebody who can be quite devastating and this can't really go and is why we've really got to change things. I don't necessarily mean sweeping changes – although sometimes I'd like to see sweeping changes but it's really just some principals and standards and just a change of mind set. It's evident that if you talk to a wide range of people who use services and the people who provide them that the services aren't working and they must get better. People must be treated with respect. Their perspectives must be listened to and understood. You must see us as human beings no matter how challenging our conditions may be. And sometimes if you just speak English to us and get rid of jargon – that can be a very exclusive way for people to speak. Can you imagine sitting in a ward with doctors or in a meeting and people are discussing your situation and all you hear is these buzz words and a language you can't quite equate? You can speak to a lot of people who use these services and they all say the same thing “what's this jargon and language all about – it's like listening to lawyers”. So just speak English to us - it might help. That's mainly aimed at those of you in psychiatry please – sometimes I think no the wonder we're confused...

One of the other things that people go on about is money. There is so much money that has been thrown at services but the money must be used better. The last Government has thrown so much money at the NHS and services, but most of this money has gone to managers and shiny in-adequate hospitals that look good but don't really give a good service. And I don't really care to be honest what performance tables may say about things – because things aren't any better. I actually think they are worse , and this is coming from somebody who actually uses services. I'm not somebody with a political platform to stand on. The thing about these performance

tables as well is that you never hear them mention mental health services, or social services – they seem to be up in some void somewhere.

We should all have a right to live as citizens with standards – people’s rights should be protected and unequivocally should have the support they need so that we can live full independent and productive lives with appropriate support where it is needed. We must break prejudices and discrimination. It seems really strange that in 2007 that there is still so much prejudice and discrimination out there. It’s so that we can all live with respect and dignity and we - and you - can do this. It’s not hard, we just need to look inside ourselves, into our humanity. It’s there and with a little commitment who knows? To me this is what it’s all about – and this is what it’s all for - making a difference.

And just one other thing I would like to say – from the perspective of a person who uses the services, and it seems a bit of a shame, but I often think of Ovid the Roman poet and his metamorphosis. One line of it says ‘Nitimur in vetitum’ which means ‘we strive for the forbidden’ and it seems a harsh thing to say – we shouldn’t really have to think like that. But at times it feels like equality is like striving after something that is forbidden.

Jim Wagstaff:

Hello. My name is Jim Wagstaff. I’m a family carer. My son is in a secure hospital and I have been a member of the Forum since 2006. We attend a meeting every month, and take back bits to the carers meeting which has got to be in simple language and jargon free. The personal benefits is seeing what people can do and learning about other experiences. But some hospitals are still running on the old regime – when enquiring about anything you seem to be banging your head up against a brick wall. You don’t know if the professionals are really listening. Because people give suggestions but they don’t really listen –they think they are just naïve but we have some positive thinking. To see some of these doctors you have to make an appointment and I mean an appointment sometimes months ahead.

The Carer Forum I’m in was set up in 2005, it eventually got a carer co-ordinator and that was quite hard - to get the hospital to realise they had to have a carer group. And unfortunately because of the diverse area of where the people have to come from there is not a great deal of family/carers representation. We obviously need more people but if people are coming from Ireland, Aberdeen, Dumfries – it takes a lot to come to a meeting for just an hour or two.

My job in the Carers group seems to be a bit of an agitator. I keep pressing for issues. Such as the freedom to walk in the grounds and to and from their work places. Freedom is a greater incentive than some medicines, and all I can say now is that if the professionals would listen they would see that they would have a better understanding of how these patients really need to be looked after. The social workers don’t have a strong enough say in some of the treatment, but I can only hope that that changes in the near future. And last of all I’ll say that the staff - the nurses and such like – some of them just treat it as a job, others a vocation, but when it’s thought of as

just a job it stops them being open to new ideas. And finally the social worker I've been dealing with is pretty good but it seems they are being held down a bit.

I think the quote that ties in everything that has been said today is the quote used today by Catherine written by J.S Brown; "instead of pouring knowledge into people's heads, we need to help them grind a new set of eyeglasses so that we can see the world in a new way."

Thank-you.

Jane Hope:

My name is Jane Hope. I was contacted by a local organisation and asked if I'd like to be involved with the Users & Carers Forum. On saying yes, I was sent an e-mail and asked to contact Laura at SCLD. When I attended the first meeting I was nervous and imagined sitting in a room with social workers and care workers but it wasn't like that at all. I was relieved to find that people were friendly and I knew some people at the meeting. The meeting was different to what I was used to – it was accessible with traffic light cards and easy reading materials. Both my husband and myself have disabilities. We both have had some negative experiences of services in the past. When we moved from Wales to Scotland we found that the local authorities didn't speak to each other. As a result we had to go back to having home care. The home carers rushed us during visits and often arrived late. Often my husband was late for work as a result of this. I felt they were not listening to what was important to us. Some things are more positive now. I have a direct payment which lets me buy my own services and gives me more flexibility. Also my husband and I both have our own social workers now - which means I'm seen as an individual. My social worker helps and I can contact her when I need to.

At the Users and Carers Forum we discussed and developed the idea of Citizen Leadership. We feel strongly about positive language and clear plain English. I think the Forum is important for people as it gives them a safe environment to have their views heard. Thank-you.

James McKillop

Good morning everybody. Thank-you for inviting us here today. My name is James McKillop and I'm going to tell you a bit about being part of the User and Carer Panel that worked on the 21st Century Social Work review and the Changing Lives Report.

After being diagnosed with dementia, I was offered person centre support via Turning Point Scotland who provided this service, which was funded by social work as they decided I needed support in my life.

Up to that point I was sitting at home alone for years, staring at blank walls, doing nothing and feeling deeply depressed. I had stopped shaving, washing and changing my clothes – my wife moaned at me and could not see that I was saving her a fortune in soap, washing powder and time spent on laundry. With the support and

encouragement I was given I've achieved some great things in my life. I've published a book of photographs which I would normally old up – but I forgot it. I also brought out a help card for people with dementia. I used to be fed up standing in a queue holding out a handful of change hoping people would take the money because I couldn't count it. This help card is discreet – people can read it and see that you need some sort of help.

And I and two others brought out a booklet for people with dementia to be handed out at the point of diagnosis. I was so grateful at the help I received that I wanted to repay it in kind and give something of myself back to the community. I was only able to do this when SCLD asked me to join the User and Carer Forum and to give my input into how I would like to see social work develop over the coming years. This panel was made up of very special people who gave over themselves and who showed a true model of Citizen Leadership. Some travelled a long distance and had to stay overnight in Glasgow or Edinburgh. They were very different people with a wide range of different labels. The range was young, to not so young. Some use services themselves, some were family carers, but what we had in common was that our lives had been affected for better or worse by social work services. In the panel we were asked about the service we got, but we were also given the chance to say what changes we would make. We wrote reports and gave presentations on different subjects to the review group. The review group thought that social workers should be able to show more leadership and asked us what we thought. We told them – Yes! They should, but people who use services should be able to show leadership too! We called this Citizen Leadership and it became one of the big ideas in the report. The asked us what difference services should make to our lives. We told them what we wanted our lives to be like and we said that services should help us get those lives.

For me – Changing Lives is just about that – Changing Lives! We want to lead better lives than we did before we got any services. We came up with a diagram to show what we mean. Hopefully you can find it on the SCLD website at some point.

We want to have aspirations. We want to be contributors, not takers. We want to have confidence in ourselves – what we are asking for is very ambitious, but also very ordinary. And when they work well your services deliver these things. The support that allowed me to produce that book of photographs is a good example. Unfortunately when they don't work well the result is a very different outcome and we bear the brunt of it.

We saw a slide from a speaker earlier. She was talking about Unions and Professional Associations. Now this is where I showed leadership. It was over a hundred years ago a man called Alzheimer diagnosed the illness that would bear his name. Now bus drivers have got unions, teachers, nurseries and hopefully you are all in the union – the BASW to support you. But there was not a single group for people with dementia in the world. So I didn't like this, and with the help of others – because everything I have done is with the help of others - I've got a group up and running called the Scottish Dementia Working Group. It's for and run by people with dementia. I also took leadership in asking for respite. One of the problems with dementia is you keep asking the same question and repeating yourself all day long and it drives your partner mad. So my wife was looking for a week's respite per year. What they suggested was going into a care home and I said “well why can't I use that money to go else where?”

So somebody with the foresight and imagination from social work allowed me to go on respite with a support worker and I had a fantastic time. I went to a wee place called Portsoy and I was on the beach every day collecting stones. So I had that for a couple of years.

In 2005 in May my wife phoned the social work about getting the respite again and it's been one struggle after another. I was at my MSP, and I was at the Head of Social Work Services in Glasgow and what I've got in writing is that because I turned 65 in 2005 – I'm an old person and that conditions no longer apply. It's 2 weeks in a care home or nothing and I've got that in writing. Now no disrespect to people in their 80s or 90s but I'm not ready to be among them. I don't want to go in a care home with 18 year olds - I want to go in with people more my age group. So I didn't like this. I kept foraging around and I discovered I can get respite. It's actually funded by Glasgow City Council and what really bugs me is that the Head of Social Work in Glasgow didn't know about it, and I'm going on respite a week on Monday to a place called Mull. But it's only because of my persistence and fighting that I'm getting this respite. I don't know what it'll be like. When it happens I'll come back and report to others in my group because respite, and not just for dementia but for lots of others – people looking after children with down syndrome and other illnesses - they are crying out for respite. It should be a legal right and I think we should tell the new government this.

I'm quite sure as social workers you've got to make hard decisions, but who's up all night, who's got 24 hr care, who do you decide needs the respite? I would say respite should be for all, it should be a legal right. So that's just a little bit of biography.

But we do think that Citizen Leadership is needed to make this happen. Can I remind you of what we have written about this; “Citizen Leadership is an activity that happens when citizens have some power and influence and responsibility to make decisions. Citizen Leadership happens when individuals have some control over their own services. It also happens when citizens take action for the benefit of other citizens.” If and when citizen leadership becomes the norm you can see how many of the outcomes in our diagram should occur. TJ has got more to say about how to bring about some of these aspirations we have. Thank-you.

Thomas (TJ) McDougall

Good morning everyone. I'm Thomas. I'm from the Southside of Glasgow. I was in a building based respite at one point in my life and I brought empowerment and Citizen Leadership into the programme. I phoned up the care commission to get a service up and running called 'Let's go'. 'Let us Go is a non-building based respite. It's based in the heart of the city centre and we got the funding from Glasgow City Council to get a service up and running for 12 people with learning disabilities to go down to Liverpool to see how the company down there called 'Natural Breaks' is run, to see how their non-building based respite actually worked, and to see how many people got allocated. We then brought the tender up to here and got a company called Momentum Care Services to run the service - the way it should be run. When the service actually started, I saved my hours to go to Cuba to do a charity cycle for people with brain and spinal injuries who use the actual service. I put myself back to

the service to raise the money for the people worse off than me – they can't speak, they can't walk, they can't talk.

Andy Miller - SCLD:

So relating that back to our diagram Thomas – one of the outcomes you got from changing your respite was that you became a person with power and control you're your services.