

# **About Pathway...**

Pathway has developed a simple model of integrated healthcare for single homeless people and rough sleepers. Its aim is to put the patient at the centre of their own care pathway and transform health outcomes for one of the most vulnerable and deprived groups in our society. Pathway believes that models of healthcare developed for and with homeless people will also help improve access to healthcare for other multiply excluded groups.

Pathway is based on a set of fundamental values. For Pathway generosity, kindness and compassion combine with a passionate commitment to professional quality to become the defining characters of health services for rough sleepers and single homeless people. Pathway is a small independent charity, formed to champion homeless peoples' health needs within the NHS. Pathway launched and supports the work of the Faculty for Homeless and Inclusion Health.

For more information about Pathway or to make a donation please visit: http://www.pathway.org.uk

To find out about our services including patient surveys, advisory panels, service development and evaluation, and homeless health needs assessment please email info@pathway.org.uk

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## **Foreword**



Welcome to this short report of proceedings at the 2014 Faculty for Homeless and Inclusion Health International Symposium. The symposium aimed to build on the Faculty's first conference, held in February 2013, while staying true to the passion and commitment felt by everyone who attended that first event.

Feedback from delegates this year suggests that we achieved that ambition. Again, attendees have said they felt moved, challenged and inspired. Many people have suggested ideas for next year's event and themes we should try to cover. There were lots of comments on the balance between smaller sessions and large plenaries, and different people liked different bits best. We will try to learn from all these comments and would welcome volunteers from the Faculty who would like to get involved once again in shaping the programme for 2015.

In keeping with the spirit of the symposium, this report presents the views of the Service User Experts first. The short personal biographies they have each produced illustrate their own fortitude and resilience, and the life course of disadvantage and harm that so many homeless and otherwise excluded patients carry with them. After the conference many of us returned to our homes, our jobs and our professional worries. Many of the service users with us for those two days in March returned to vulnerable, marginal, 'precarious' existences with uncertainty confronting them from all sides.

In the second half of this report, we present the briefest of summaries of the main presentations and some of the key themes that seemed to emerge. We will be sending this report to key partners in the NHS, Public Health England and elsewhere highlighting the concerns expressed about deepening exclusion, the hazardous health consequences of some current Government policies, and the clear statement from many homeless health clinicians that they will not operate the new draconian rules on access to healthcare for vulnerable migrants.

Video of all the main presentations, and slides from all sessions, continue to be available to delegates via www.policyreview.tv using the login code from your delegate pack. I would encourage you to make use of this material for training and induction purposes, or to help persuade commissioners to do the right thing. All the presentations from the 2013 conference are now freely available – including talks from Professor Sir Michael Marmot, and Dr Jim O'Connell from Boston Healthcare for the Homeless, both still well worth watching.

To conclude, I would like to thank: colleagues from Neil Stewart Associates for their professional attention to detail, and taking on the administrative burden of the event; the small group of colleagues who helped us choose the workshop sessions from the very many proposals we received; and Stan Burridge, Pathway's service user research worker and the Service User Experts for their input over the two days.

Alex Bax

**Chief Executive** 

**Pathway** 

### **Welcome address**

Welcome to the Faculty for Homeless and Inclusion Health's Second International Symposium. Delegates who attended last year told us they left energised, inspired and infuriated. The best events inspire people to change and this year's programme includes presentations from a number of projects that started because of what we learned together at last year's event.

The theme for this symposium is the link between economic recession and the vulnerability of the most vulnerable, and how recessions can trigger or exacerbate poor health. In the plenary sessions we have a series of speakers presenting new data on what has been happening to the poorest – many of whom were already on the margins of British society during the boom years – and what are the likely health consequences of Britain's longest recession for 100 years for our patients. Our international speakers will give us insights into how other societies respond to the needs of the most excluded.

But the Faculty for Homeless and Inclusion Health is about more than just identifying problems, with ever more detailed statistics and analysis. The Faculty was formed to support health practitioners working with the most excluded: to identify new or better ways of doing things, to create partnerships and connections between the NHS and other key sectors, and to bring real improvements to clinical practice. We believe that the

best health services play a major role in helping patients break out of cycles of despair and desperation to build more positive lives.

I would particularly like to welcome members of Pathway's service user group. The Faculty believes that good health services must be designed and delivered in ways that are relevant and appropriate to our patients. The only way to do this is to make sure that the voices of homeless people are included the discussion. We are indebted to sponsorship from Crisis that has allowed us to expand the number of service users able to attend this year. Pathway has been working for the last two months to assemble a group of people with substantial experience of homelessness to come to the symposium and share their perspectives with us. Pathway's service user group will make sure that people with homeless experience are present in every workshop session.

Last year everyone agreed that members of the Faculty never give up – either in caring for an individual patient, or in trying to change the system for the better. Welcome to your symposium. I hope our two days together leave you inspired to change the world.

#### **Professor Aidan Halligan**

Chair, Faculty for Homeless and Inclusion Health Chair, Pathway – the homeless health charity



# The Conference (according to SUE)

It was a challenge for us this year to put together a group of people with Service User Experience for the conference. Although we have been busier than last year, we didn't have the same number of opportunities to meet up with people who are at the sharp end and who were in the right place at the right time to take part in the conference.

Along the way we lost a few service users which is normal; among them was one who dropped out because of serious ill health, another because he was not in the right place mentally and a third because he had been sent to prison. I think this shows we are hooking in real people.

We were left with a group of 10 people; Chris H, Chris J, Bean, Viv, Rosaline, Alister, Pete, Joseph, Julian & Majiec, but no SUE, or was there?

'So who is this SUE?' I hear you ask. Each one of our Experts brought their own identity and personal story to the event and each one played their part in what was a wonderful experience not only for them but for us too.

The intention this year was to hear as much as possible from them and this proved to be a steep learning curve for me too. When I first started out on the road to where I am now I did it by banging on doors and demanding to be heard. At last year's conference I pulled in a group of service users and fed back what they thought and felt at the end of the conference - this year it was different. I shoved them into the spotlight and took a seat further back

Pathway commissioned ex-BBC radio producer Paul Waters to come in and train Chris H, Chris J, Viv and Bean on interview techniques (the final product can be heard on the website) and what they did was amazing. Paul tells how at the beginning they were nervous, and almost had brain freeze even when interviewing each other, at times not even remembering their own names let alone the name of the person they were interviewing. By the end they were flying high with the best and it was only fitting they were sharing the stage with Mark Easton from the BBC.

They grasped the opportunity with both hands

In the lead up to conference there were a number of planning meetings with the group and some of the discussions were about attitude, explaining to them that the people who were going to be at the conference were different to those in the healthcare sector who had previously closed doors or ignored them; it was slow but worth it. Watching them chatting like old friends to other guests during the lunch and networking breaks was brilliant.

So after weeks of planning, training, coaching and, of course, the obligatory lunches they were ready, primed and eager to take a full part. And what a great group of experts they turned out to be. I

was able to stand back and watch as they all grew throughout.

I enjoyed watching them excel in such a wonderfully powerful way - it was inspiring.

There were many highlights for me, including Bean, sitting at the top table, holding his own with professionals. Watching him grow in stature as the debate went on, and even deflecting some of the criticism which was levelled when he said that doctors in general don't care, was a delight to see. But that was his experience; his feeling and he owned it and the stage.

Viv interviewed Peter Cockersell from St. Mungo's, Peter went about his task in his usual quiet way - he was one of those people who said very little, but when he spoke his words resounded loudly. Chris H, Chris J, the 999 club's trio and Rosaline who had come from Leeds for the event had their own tasks and not forgetting Julian who, out of all of the Experts, was the most candid with his profile.

In fact they all deserve a mention but that's enough from me. What did they think and what did they have to say about the conference as a whole and what were their personal highlights?

#### Stan Burridge

Research Lead on Service User Involvement Pathway

On the following pages each of our Service User Experts introduce themselves and give their individual responses to the conference.

### **Alister**

Originally from Scotland, 56 year old Alister was in children's homes from about 9 years old and he first lived on the streets in 1979 where he lived rough for 6-7 months, and then moved on to squatting.

He then moved to Europe in the early 80's and found work, spending half the year in the UK and half the year in Europe. He returned to the UK permanently in 1986.

When he returned to the UK he was on the street again having to deal with a heroin addiction which had escalated from morphine; this began when he was just 13. Alister admits that throughout most of his life he has battled with one addiction or another but now says "I am on an even keel and managing as best as possible".



"I thought the conference went well but I wish I had known a bit more about the people who were going to be there. Did a radio interview with Paul which went out and I was happy with that. From the workshops I thought they were well done, but I think there were too many and I feel that if there was less then I could have seen more and taken part in lots more of them, or if they were spaced out more so maybe only two different ones at a time.

It was hard to hear all of it too, so perhaps an intercom system to hear better. Being part of the service user group was really good; I felt really comfortable as well. I got a lot of support, which was great and made me confident to be able to speak up and say my piece. I have hope that things can change and the people in power will be getting up and changing them. The amount of people from all walks of life and the expertise from the service users was really respected and I was really impressed with that.

I think Pathway did a great job getting us into that position and made it so that we were respected. And I can't wait until next year."

He is currently volunteering for the 999 Club in Deptford and hopes to get work experience and be able to give back something to the community especially homeless people who are having problems getting or managing their medication.

ALISTER IS STILL ON A MANAGED PROGRAMME OF SUBUTEX AND ALTHOUGH HE WANTS TO MOVE TO BE FREE OF THIS HE FEELS THAT THIS MAY BE A STEP TOO FAR AND SAYS "IT IS ALSO BECAUSE, AND TO BE TOTALLY HONEST, I AM QUITE WEAK AND WITHOUT BEING ON THIS PROGRAMME IT WOULD BE EASY TO GO BACKWARDS, I WANT TO KEEP GOING FORWARD".

### Bean

"Being asked to be on the main stage with the professionals I felt nervous, but I was only nervous because I didn't know what I was going to talk about, but getting up there, that was ok, I knew it wasn't going to be hostile. I think it went well, I was worried right after I did it. I thought it could have gone better, but after speaking to the group I was happy about what I had said.

I had the view the NHS is about saving money and not doing anything, this conference showed me that there was people out there spending money and doing lots of things, so it isn't like you hear on the news.

Being part of group was good, not everyone seemed to be focussed but we still all got on well. Being part of the radio thing was brilliant, I now have a new skill, I can interview people without sounding like an idiot. The training was brilliant. Paul took us out onto the street and made us just approach people walking past to give us confidence and, looking back, that was a brilliant idea; going to the studio was fun too.

Some of the group said they couldn't hear, but I thought it was alright. The main stage speakers were really interesting in fact I found all of it interesting. The one thing I can take away is a more positive attitude of the NHS, it made me realise there are a lot of nice people who are not just trying to get you out of the door as quick as possible, so I can take that away."



Bean entered the care system when mental illness hit his family, "I can't remember how old I was when I first went in, it was a bit of a yo-yo going in and out". Eventually Bean was to remain in the care of social services.

When he was 18 and that 'care' ended he almost fell on to the street. Typically with care leavers he says he wasn't equipped to cope with normal life and becoming homeless was almost mapped out before him.

After many chaotic years, sleeping in doorways, squats and substance abuse problems, Bean now sells the Big Issue and runs a street distribution point for other vendors in Victoria where they go and buy the magazines they need.

Bean says he has learnt many new skills and having to be reliable and consistent for others is important for him too, giving him focus. He says "I don't only sell magazines to other vendors, I also listen to the problems they have; sometimes I feel a bit like an agony aunt but I like it that I can be there for others because I remember the time when someone was there for me, at the right time to help me move forward".

"I first got involved with Pathway through the dentistry project they are doing, and just love everything about them, I hope one day to become a care navigator and work in one of the hospitals."

BEAN HAS GREAT COMMUNICATION SKILLS AND WAS CHOSEN TO FEED BACK TO THE CONFERENCE THE THOUGHTS AND FEELINGS OF THE REST OF THE GROUP IN THE FINAL PANEL DISCUSSION.

### Chris H

Chris Hayes is from south-east London. He had always been a social drinker, or so he thought. But after his marriage broke down and other issues, he turned to alcohol and drugs. That led him to become homeless. He suffered from post-traumatic stress disorder and alcoholism - and freely admits that his addiction nearly killed him.

Chris spent some time in a detox unit receiving treatment for his addiction and all of the other symptoms, which were associated with him having a mental meltdown. When he was discharged he moved to a drug and alcohol project spending about four months in a halfway house (dry) before getting his own

"Since coming out of the service I have really noticed the stigma attached to being an alcoholic in the past; once an addict always an addict as far as the system goes, and that is all wrong, people should be given the chance to move on and not be constantly reminded and kept down because of their past."

ON THE FIRST DAY OF THIS YEAR'S CONFERENCE CHRIS WILL BE CELEBRATING HIS FIRST YEAR SOBER. CHRIS IS NOW **USING HIS EXPERIENCE TO WORK AS A** HOMELESS HEALTH PEER ADVOCATE FOR **GROUNDSWELL UK SUPPORTING PEOPLE** WHO HAVE DRUG AND ALCOHOL ISSUES.



"My overall experience was really enjoyable. I did get a lot of information but a lot of it I have heard before through the course of volunteering. A lot of it wasn't really relevant because it wasn't up to date. Same spiel I heard a year ago.

The Lewisham mental health workshop was good but there was no real information about how to put it into other people's work. They didn't seem to talk about how chaotic homeless people's lives are. Toby Lewis talked about the way he and his trust are looking at tackling the problem and bringing it to the forefront, which is all well and good in the board room but how is that going to be taken down to the A&E so they are not just giving people Valium and fobbing them off again. He didn't speak about that part of it. And when he was asked a question he dodged it. The woman from NHS England was the same. But there were lots of positives, I got a lot out of it, how individual services are tackling things but they need support from the government which is not coming and they don't seem to want to make a difference at that level.

I met some really nice people, listening to them and how they are trying to achieve things and what challenges they face.

Being part of the team doing the radio thing was really-really good. Everything he explained was on a level and he gave us confidence. It was brilliant. I can take forward from that now that if I need to speak to somebody I got some skills in how to actually get hold of them for a couple of minutes. So you don't waste time you can go straight to the point. Being asked questions first was very good but I felt that when we asked a difficult question it wasn't really answered, it was dodged by the speaker and sometimes the chair too. Overall I am glad I was there and really excited about next year because now I know what to expect and what I can do I think I can get more and input more."

### **Chris J**



Chris is from Dumbarton in Strathclyde, Scotland. When his relationship broke down he came to London along with his brother, he was 24. He says they fell into homelessness, alcoholism and drug abuse a pattern which lasted for the best part of 15 years. His brother didn't survive.

Chris began the well trodden path of a self-destructing lifestyle cycle, going into rehab, failing that, going to prison, in and out of hospital until a little over three years ago, Chris finally completed a rehab programme.

Since he completed this programme he has continued to move forward and has spent some time volunteering with a number of organisations and recently he began working as an outreach worker for ECHG street buddies team.

Chris has learnt British Sign Language (BSL) up to level two and said "I would really like to go to the next level with this, but I cannot afford it and cannot get a sponsor, perhaps that will happen as a result of the work I am doing, who knows?"

"Overall thoughts of the conference. I think it was all very interesting, and all very worthwhile. I think everybody who attended participated well. Being part of the team who took part in the recording stuff was great, Paul was a really good teacher, he was very patient with all of us. I didn't realise what he had been doing would all come together like it did. I know that I couldn't have done it without all that training.

Being with the service user expert group was also very good. We didn't know each other at the beginning, but we all helped each other so by the end we were all friends. When the chair came to our table first, it was a bit nerve wracking. It was different being put in that privileged position, normally service users do not get asked first, sometimes we don't even get asked at all; it should be done more.

The one thing that impressed me more than anything else was that everybody seemed to be there for the sole intent of improving the system, no one was better than anyone else, they were all there to listen and learn."

"IT IS IMPORTANT THAT EVERYONE HAS A VOICE AND IF YOU ARE DEAF AND CANNOT EXPRESS THAT VOICE SOMEONE NEEDS TO HELP WITH THAT... IT IS A BIT LIKE WHAT PATHWAY DO, GIVE PEOPLE A VOICE WHEN IT COMES TO HEALTH, THAT IS WHY I WANTED TO GET INVOLVED."

# Joseph



Joseph first hit the streets at 14 years of age, was one of the hidden homeless for a number of years, staying out of the cycle and away from all official agencies. He began taking crack and alcohol from his late teens and this led to episodes of manic depression and blighted his time on the streets making him paranoid and extremely wary of the mainstream services.

This lifestyle was all that he knew for more than a decade. However, when he decided to settle in one of the many hostel places which he had been in they managed to get him a flat.

Since coming off the streets he has had a chance to unravel some of the issues he had which led to his dependency and is now playing an active role in the newly formed 999 Club Service User Group and also volunteers twice a week for the day centres.

HE SAYS "I WOULD LIKE TO FINISH A COLLEGE COURSE WHICH I AM ON AND WANTING TO GET BACK INTO EMPLOYMENT, HOPEFULLY SOMETHING WHICH USES THE EXPERIENCE I HAVE TO MAKE A DIFFERENCE TO OTHERS". "I found the conference really informative, it gave me a much wider view of the healthcare service that is for homeless people, but a disappointing view, I knew it was bad having been through some of it, but didn't know it was that bad.

All of the speakers were good but the one who stood out the most was the Canadian doctor; he really brought to light the massaging figures, and how many people who were not in normal counts, so he didn't get any funding to help those people who were not counted. Stan made the same point when he said that street counts were flawed which I think they are; I think more should be done about that.

Being with a group of other people with lived experience was great. I think it would have been better if we weren't at the front, I felt pressured by that but on the other hand having our say first was really good. I felt supported and made to be very welcome.

I was left with a good hard chunk of hope, I didn't really think that many people gave a toss so I was left with hope for the future. I definitely want to be at next year's conference."

### **Julian**



"I thought the conference was really good, I enjoyed it. The atmosphere, people listening to each other was great. I thought it was really professional, very slick. The catering was really lovely, beats the normal rubbish sandwiches.

I thought the idea of having our profiles put up was good, people knew who they were talking to and sitting us all together at the front was fine and I liked us being asked questions first. I just wish, thinking back, I had said more, but maybe next time.

I was left with a positive feeling; it is good that people were talking about things, I have heard people talking before so it is just a matter of time to see if they take into action.

I really want to be at next year's conference, I got a lot out of it."

Julian is 38 years old and was first homeless in 2009. After his mother passed away a family rift led to him being left without a home. Julian was living in a squat for about 2 months and then the streets.

"I will never forget my first night on the street, it was scary, and it was the fear of the unknown more than anything else. It was also the lack of information; I didn't know where to get food or bedding. I only found out because I went to a service and other homeless people showed me where to go and what I could get.

Having previously taken cocaine Julian began taking crack and heroin, firstly by smoking and then injecting. He said "I was with someone who had Hep C, they did tell me not to use the same works but the need to inject overtook that advice and I contracted the disease myself".

**JULIAN HAS HIS OWN FLAT NOW AND IS VOLUNTEERING WITH GROUNDSWELL HELPING** TO SUPPORT OTHERS WHO **HAVE CONTRACTED HEP** C. HE SAYS "I LOVE WHAT I DO BECAUSE IT GIVES ME THE CHANCE TO SHOW OTHERS THAT THERE IS A WAY OF COPING WITH THIS DISEASE. I WOULD **EVENTUALLY LIKE TO BE** A SUBSTANCE MISUSE **WORKER POSSIBLY GOING** INTO PRISONS TO HELP **OFFENDERS LEARN THAT** THERE CAN BE A LIFE AFTER DRUGS".

### **Maciek**

"I think it was useful because everybody needs to talk about these things, and without talking to each other things are not going to change.

That MP coming was good. In my country they don't give a shit and won't even turn up, but I think MPs should get more involved and sort things out and not just give speeches to push something off.

I went to the workshop on dentistry and it was very interesting. Talking about taking the dentists out onto the street is good and how each side felt about dentist.

One thing is sure that we are not going to the dentists until something is really bad this might begin to change that.

Most of the people on the main stage they did a good job, they care about what they do and I liked the bit when everybody could ask a question of the speaker. I didn't feel very confident asking a question because my English is not too good sometimes.

The one thing that I can take forward and the most important thing is that it was a good idea bringing people together. **Everybody has a proposition on how you will** sort it out so we shouldn't just keep talking about how to sort things out we should start doing. And I think there should be more different workshops."

Polish born Maciek (pronounced magic) arrived in the UK in April 2007; he came to the UK to find work and to change his life. For the first 5 years there was no problem, he says "sometimes I didn't have a job but that was ok, even when I wasn't working it was better than back home in Poland".

His problems began in late 2012 early 2013 when he became ill with ulcers and pancreas problems and then he lost his job because of that illness.

He soon became homeless and found himself sleeping on the streets, in cardboard boxes, occasionally spending a night here and a night there on sofas.

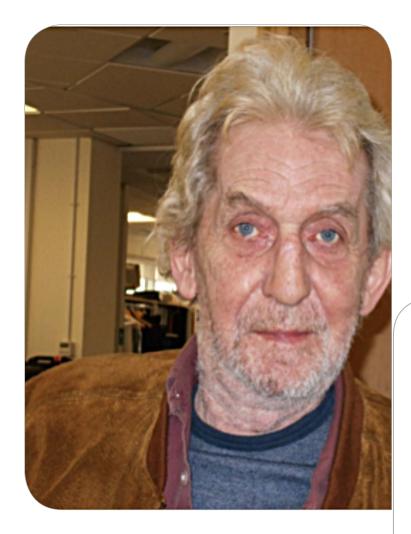
Maciek mentioned that he had to lie to his GP or he wouldn't get the medication he needed and being homeless also makes It difficult to manage that medication or eat the necessary diet to make sure the medication is working properly.

Maciek has a wealth of experience of the difficulties faced by Polish and other EU nationals when it comes to accessing even the most basic things in the UK.

**MACIEK STAYED IN THE 999 CLUB NIGHT** SHELTER IN DEPTFORD, UNTIL IT CLOSED ITS DOORS ON THE 17TH MARCH, AT THE **CONFERENCE HE SAID "I HAVE NO IDEA** WHERE I WILL END UP WHEN THE DOORS **CLOSE BUT I HOPE IT WILL BE SORTED."** 



### Pete



Peter (64) only spent a short time on the streets, sleeping on London buses. "I used to visit a day centre and it was the nurse there who put me in touch with L.A.C and from there I was found a placement at Graham House. The way I was assessed was awful - they saw me drinking from a can and immediately assumed that my problem was alcohol. That was always the biggest issue I have faced, other people's attitudes."

"I first became homeless because of a roque landlord, he verbally and physically abused my girlfriend and the next day did the same to me, when I told the local authority this is why I was homeless they didn't want to know, and gave me advice on where to go, they may as well have just said 'piss off' we are not helping you."

"It is like this - I was a homeless person who drinks, not a drinker who was homeless. But I see this everywhere. I recently went to court with someone from the hostel, and the prosecution said that he was from Graham House, the hostel for drinkers and drug addicts - I thought it was a hostel for the homeless."

"THE REASON I WANTED TO GET INVOLVED IN THIS EVENT IS BECAUSE I WANT PEOPLE TO UNDERSTAND THAT WE ARE ALL HUMAN AFTER ALL AND SHOULDN'T BE ASSESSED ON WHAT WE WEAR OR WHERE WE LIVE. "

"I really enjoyed the conference, I am really pleased I was invited.

I think the speakers were all very good, but I don't think some of the more political ones answered the questions at all. That is annoying because they hold the key to making the situation better. It would have been better during the workshops if I could hear more but I found them interesting anyway.

I didn't realise there was so many people out there who cared. It was brilliant. Being asked the questions first was a very good idea. I thought the team was a good one, and we all got on together, and as a group we were respected as a team of experts by all the health care professionals.

I think the title Service User Experts was good, it is a good description of who we were, it didn't put us down it made us feel important, it made us feel human. People came to us and spoke to us, they wanted to hear what our views were and respected those views.

The thing that sticks in my mind is that there are so many people out there who care and want to do something about the problems, but also they want to ask us (people with experience) how to get it right. And that is amazing, not only do they care, but they want to listen and want to act. That is something I will take forward."

### **Rosaline**



"I think it was good, if they take on some of the stuff they were all talking about put it into action it will be for the good of homeless people.

I went to a workshop where they spoke about asylum prejudice seen from a negative perspective, it was good because not many people are aware of the process and the media don't help.

Overall I thought it was really friendly, and I liked being part of a group of people with experience. I felt that having a group together was good because it let everyone know we could be talked to and our opinion mattered.

One thing I took away from the conference was when someone said if you want to make a change. vou just have to do it, use the money and don't worry about who takes the credit.

I think this was said because some people won't do anything because they think no matter what effort they put in no one will notice them.

Don't worry about who takes the credit just do it.

I think more should be done to help homeless people and especially the reasons people become homeless in the first place. If they look at what causes homelessness they wouldn't be in this mess."

Rosaline came to the UK from Nigeria on a Ford Foundation Scholarship; her aim was to Study for an MA in Development Studies with Gender which she successfully completed.

Before Rosaline came to the UK she worked as an admin worker for the Local Government and overall has more than 19 years of experience working in an office; it was her desire to learn more that led to her coming to the UK.

Rosaline became homeless in 2004 when she was diagnosed with kidney failure. She says "as a student my sponsors covered my needs, but once the course had finished I applied for leave to remain on discretionary grounds but the application failed.

Despite several attempts UKBA refused my application".

Rosaline found herself without support and without permission to work. She said she was powerless, destitute, miserable and without hope. Having no means to support herself she became dependent on her friends and the local Church. It was the church that provided food and accommodation.

**ROSALINE FINALLY WON LEAVE TO** REMAIN IN THE UK, AND LAST YEAR SHE WAS NOMINATED FOR THE WOMAN ON THE MOVE AWARD.

### Viv

"I thought the conference was brilliant. The talks were quite good and I went to four workshops and they were all very good. Much different to last year. This year I think they were a little better than last year.

I was part of the radio team, the training was well worth it. I loved every bit of it. I would like to have had a bit more training, which would have been nice, but that was because it was good. Paul is a really good teacher, he was really good with all of us, he took his time and made sure that everyone did their bit and got their fair turn. Visiting the BBC studio was good too, sitting in the ONE studio and seeing how a programme is made.

The speakers on the main stage were interesting, and it was good that people came from around the world again. The networking opportunities and meeting up with people I had met last year was good.

I was impressed with Paul and John with their anger management workshops - that was impressive.

Being part of the expert team was brilliant, we supported each other and Pathway supported us. I felt it was better than last year because we were made to feel really important and then all of the people who came made us feel respected. It was great.

The thing from the whole conference I will remember is being made to feel important, from Paul with the radio training to being supported so much by Pathway and supported being with the Group, the Chair coming to us for questions first, people reading our profiles and coming to find us. It was really good to feel that important."



Viv (57) has been a feature of Pathway service user involvement for more than 18 months and during that time she has played an important role in a number of events including last year's conference.

Originally from Norway she came to the UK in 1978/9 and had been a cinema cashier and also worked in a health food shop, and first became homeless in 1998 as a result of a marriage breakdown.

Viv has always had some form of mental illness but it became extreme after her divorce partly because of the issues experienced in that relationship. "When I was rough sleeping there were a few women, but not that many. Most of them were in couples except the older ones, those you see pushing a trolley around."

Viv says she had an alcohol problem for a long time, but when she was sleeping rough she says it got better and has been clean since 2000. "That's not the norm, people generally go the other way, they start to drink more." Viv recently took part in the Pathway dental programme and is nearing the end of her involvement, she says "now I have more confidence to go to the dentist and I have just agreed to support someone else who is scared of the dentists to go"

"WHAT I WOULD LIKE TO SEE AT THIS **CONFERENCE IS THE PROGRESS THAT HAS BEEN MADE IN HEALTHCARE TO HOMELESS** PEOPLE KEEPS GOING AND THAT ACCESS TO ALL SERVICES LIKE DENTISTRY IS MADE EASIER. "

### **SUE's Last Stand?**

It was a challenge for us this year to put together a group of people with Service User Experience for the conference. Although we have been busier than last year, we didn't have the same number of opportunities to meet up with people who are at the sharp end and who were in the right place at the right time to take part in the conference.



So there you have it. Our Service User Experts enjoyed the conference and overall feedback was good - they appreciated that they had been respected as experts and their opinions mattered.

It was all very positive although a few minor glitches with things like sound during the workshops affected a couple of them, but they enjoyed the experience regardless.

The entire group said that being viewed as experts was a good experience; it made them feel part of the process and more engaged. Health professionals taking time to read the profiles and then talking to each individual, already knowing something about each person, added something that we hadn't tried before but it worked really well.

I listened to how they understood what was being said and how it impacted them and those around them, and it would seem that there was a difference between last year and this year around how service user experts relate to the language used. Whether this was because the group had had more time together before the meeting or the speakers were better at using inclusive language

is hard to say, but not one of the group said they felt excluded by anyone and felt part of the whole process.

Paul Waters was singled out as giving something special to those who took part in the radio training so maybe next year we can have a larger group and begin that process earlier.

As always Pathway is humbled by the stories which our experts bring and so once again I would like to thank Alister, Bean, Chris H, Chris J, Joseph, Julian, Majiec, Peter, Rosaline, and Viv for the amazing input they gave to this conference.

If you would like your organisation to be represented by a service user expert at next year's conference please send details to: info@pathway. org.uk. I will be especially interested to hear from different groups from all over the country.

If you are able to sponsor a place for a service user expert please let us know, financial help is always welcomed and as you can see, we will put your money to good use.

Stan Burridge

**Research Lead on Service User Involvement** 

**Pathway** 

# **Conference Presenters**







David Starkie | Danny Dorling Duncan Selbie | Steve Field

Stephen Huang | Jane Ellison | Ruth Passman Ingrid van Beek | Graham Watt | Mark Easton Julian Corner | Rick Henderson | Bean Stock

| Toby Lewis

























### **Overview of Event**

Each of the two days started with 'big picture' presentations about economic and social trends impacting on the health of disadvantaged, vulnerable or marginalised groups, with Dr David Stuckler on the first day and Professor Danny Dorling on the second.

We heard about international trends related specifically to homelessness from Professor Stephen Hwang (University of Toronto) and Damla Fabian (European Federation of National Organisations Working with the Homeless) as well being updated on the UK policy context by Jane Ellison MP (Public Health Under-Secretary of State), Ruth Passman (NHS England), and Duncan Selbie (Public Health England). We also had presentations on what health services can and should be doing for excluded groups with a focus on primary care from Professor Steve Field (Care Quality Commission and Inclusion Health Board) and hospital provision from Toby Lewis (Sandwell and West Birmingham Hospitals NHS Trust).

The programme also included plenary presentations about what works in seeking to break the vicious circle of exclusion and health problems. Delegates heard from experts with significant experience of providing services within deprived communities, namely Dr Ingrid van Beek (Kirkton Road Centre, Sydney) and Professor Graham Watt (University of Glasgow). Plenary sessions were skilfully chaired by Mark Easton (BBC Home Editor) and included opportunities to hear some challenging views about how policies and services could change - both from presenters and from the Service User Experts and other conference delegates. Julian Corner (Lankelly Chase) offered an alternative view on how systems for health and care services could be delivered, and Rick Henderson (Homeless Link) provided a view from frontline providers.

The conference ended with a 'Reality Check' discussion about the implications of what delegates had heard over the previous sessions. We were privileged to hear perspectives from the Homeless Service User Experts group (Bean Stock), Open Doors Sex Worker Service (Georgina Perry), Pathway Homeless Healthcare (Nigel Hewett), Prison Reform Trust (Jenny Talbot) and Refugee Council (Maurice Wren).

As well as plenary sessions and discussions, delegates had the opportunity to hear about, and discuss, a wide range of workshop presentations from a range of sectors, locations, and areas of research or practice, as summarised in the tables on page 20.











L-R from top:

Georgina Perry | Nigel Hewett

Maurice Wren

# **Workshops**

**Summary of the range of presentations** provided during the two days – with copies of presentations available on www.policvreview.tv for more details

#### workshop #1

Tackling health inequalities and improving access to services – updates and discussions on areas of policy and/or practice with relevance to a range of service settings and service user groups:

- Healthcare standards and proposals for quality assurance (Faculty for Homeless and Inclusion **Health; and North West London NHS Commissioning Support Unit)**
- High quality healthcare for those with the greatest needs (NHS England)
- **Integrated local authority and NHS provision to** vulnerable groups (Under 1 Roof and City Reach **Health Service, Norwich)**
- Public mental health and social inclusion approaches to tackling exclusion (St Mungo's)
- Mental capacity issues and mental health guidance (Lambeth Integrated Commissioning Team, Thames **Reach, and Enabling Assessment Service London)**
- Tackling social and economic exclusion (Brighter **Futures**)

#### workshop #2

Healthcare provision to specific groups to facilitate access, improve outcomes, promote safer hospital discharge, and deliver integrated responses based on individual need including:

- Ex-offenders and other marginalised groups (Groundswell, London)
- **Homeless people (Great Chapel Street Medical Centre, London;** and Pathway Bradford, Brighton, Manchester, Leeds and
- People with alcohol-related problems, including long-term drinkers (Anchor Centre, Leicester, and Luther Street Medical Service, Oxford)
- People with Hepatitis C (Barts and the London NHS Trust and **Queen Mary University)**
- **People with TB (University College London Hospital Find and** Treat Service, London)
- **Rough sleepers (Brighton & Hove Rough Sleepers Street** Services Team, Sussex Police, and First Base Day Centre, **Brighton**)
- **Rough sleepers with complex mental health needs (Central** & Northwest London NHS Trust; Central London Community **Healthcare NHS Trust: and South London & Maudslev NHS Trust)**
- Sex workers (Bevan Healthcare, Bradford; and Homerton **Hospital NHS Trust, East London)**
- Travellers and Gypsies (Hunterton Hospital, Maidenhead; and **Leeds Gypsy and Traveller Exchange)**
- **Vulnerable migrants (Doctors of the World UK, London; Freedom** from Torture, UK, and Greenhouse NHS Practice, East London)

- Homeless people with head injuries (University of Glasgow with The Disabilities Trust Foundation, Glasgow)
- Impact of UK policy changes over past five years (Crisis UK)
- Improving access to dentistry for homeless people (Barts and the Royal London Dental School; and Pathway, London)
- Physiotherapy for homeless people experience from Glasgow and needs identified in London (St George's Medical School)
- 'Reflective Practice Team Development' interventions to support teams and enhance Psychologically Informed **Environments (University of East London)**
- Younger homeless people, including those with needs related to ADHD (Cheshire & Wirral Partnership NHS Trust and Forum **Housing, Cheshire**)

# **Key Issues Emerging From The Event**

#### 1 Evidence & Lack Of Evidence

Both plenary and workshop sessions provided opportunities to hear the latest data, intelligence and research findings from international to local sources.

However, a theme throughout was that these sources remain incomplete and, therefore, provide an inadequate basis for making policy decisions or allocating resources and planning services.

The conference called for additional investment in gathering more complete routine data and completing more detailed needs assessments to inform commissioning decisions. For example, there were suggestions that the Rough Sleeper Count should include information gathered from additional sites, including winter shelters (since it is done in November when these are open) and semi-covered locations like car parks. Professor Dorling also recommended that better use is made of capture-recapture methods to more effectively identify the numbers of so-called hard to reach groups.

Speakers and delegates emphasised the need to make better use of a wider range of sources to more accurately describe needs and to influence achievement of the scale of change required to transform services for all excluded groups. Several speakers and presenters talked about the need to recognise the power of individual stories as well as hard data. The involvement of service users throughout the event and in this report illustrates how important are the perspectives of experts by experience when planning and improving services. The importance of being able to make both economic and moral arguments for change was also emphasised, and some good emerging models of localism were highlighted.

#### **2 Housing Provision**

Several speakers demonstrated the links between recession and homelessness and the impact of both on health and well-being which chimed with the lived experience of service users and providers attending the conference.

There was recognition of the fact that rough sleepers represent the tip of a very large iceberg and Professor Dorling emphasised the need to focus on the many people living in 'housing precarity' as well as those already experiencing homelessness. Delegates heard about the range of challenges impacting on housing including unemployment, rising costs, localism and entitlement issues, removal of the Supporting People ring-fence, limited availability of hostel places and social housing, and attitudes to some marginalised groups.

There was much interest in the Housing First model in which homeless people are securely housed from the outset, with support for their health needs, rather than having to progress through a step-wise approach involving shelter, then hotels, then intermediate accommodation, before being independently housed. Delegates heard from Professor Stephen Hwang (University of Toronto) and Dalma Fabian (European Federation of National Organisations Working with the Homeless) that the experience so far in Canada and Europe shows encouraging results regarding the periods for which people remain housed, greater stability regarding management of mental illness or substance misuse, improved quality of life and increased cost-effectiveness.

#### 3 Localism

# Localism is here to stay, and both speakers and delegates recognised this and identified some benefits that come with this agenda.

However, concerns about the impact of devolving responsibility to local commissioners or providers were raised throughout the conference with delegates and some panellists highlighting the risk that localism potentially:

- denies access to services for individuals who are not able to adequately demonstrate local connection or evidence of entitlement;
- makes it difficult for individual local authorities and Clinical Commissioning Groups to adequately assess the needs of smaller groups with high mobility and multiple needs such as rough sleepers or vulnerable migrants;
- reduces the efficiency of commissioning specialist services, such as TB treatment, and makes it harder for providers to secure sustainable funding across administrative boundaries;
- 'exports the problem' with local commissioners or providers under pressure to deny responsibility for meeting the long-term needs of people with complex or costly needs.

There were strong calls to build stronger safeguards and clearer expectations into the devolution and localism agendas.

This included suggestions about:

- Protecting funding intended for the most vulnerable or excluded groups;
- Specifying statutory minimum requirements for vulnerable adults, as already happens on child protection issues;
- Considering access and health inequalities issues in all contact between regulatory or assurance bodies and local commissioners and providers;
- Charging Directors of Public Health with (or encouraging DsPH to take) responsibility for tracking and seeking to influence local action to reduce health inequalities.

# **Key Issues (continued)**

#### **4 Recession**

A theme throughout the two days was the impact of recession and austerity on the most excluded groups, and the services they require to address their health needs.

We heard from Glasgow GPs 'In the Deep End' that the inverse care law is still a problem and Professor Watts emphasised there is much still to do to achieve 'proportionate universalism' as called for by Professor Sir Michael Marmot through his WHO and national work. Several speakers emphasised that the impact of recession is likely to be felt by many long after recovery begins, including Dr Stuckler from his international Body Economic research and Professor Dawling from his work on health and housing needs: Unequal Health and All that is solid.

Concerns were raised about attitudes to people who are unemployed, homeless or living in poverty, at worst with responses based on enforcement rather than empathy. Delegates and speakers alike described the need to recognise that exclusion is socially determined, as are some of the behaviours and so-called lifestyle choices of individuals. Throughout the event there was emphasis on the need for wider social and economic responses to exclusion and health inequalities, and a call for local public health partnerships, community leaders and elected members to seek to influence local decisions and national policy accordingly.

#### **5 Improving Healthcare For People With Multiple Needs**

Delegates heard many inspiring examples of what's possible in providing quality healthcare to people with multiple needs – but also heard how much more needs to be done to scale this up across the country and ensure effective services are sustainably resourced.

There was much emphasis on the reality that many excluded groups live with a number of physical and mental health conditions, as well as substance misuse and social exclusion issues. A clear theme was that many services still have a long way to go to plan responses around the person rather than the diagnosis, and there are significant gaps between national policy on access and the local reality.

Delegates raised significant concerns about homeless people and 'failed' asylum seekers being denied access to healthcare and called on NHS England to close the gap between policy and practice by, for example, issuing a directive to primary care providers about their duty to register patients. In addition, the conference highlighted the need to take a rights-based approach to provision and to both enable and expect providers to provide quality care to each patient or service user and actively seek to reduce health inequalities. For example, there were calls to:

- GPs to 'see the patient rather than the queue' by redesigning systems to recognise co-morbidity rather than continuing to plan delivery around single conditions;
- scale up good practice, tackling the 'not invented here' mentality and ensuring effective models are not diluted or stifled by too much bureaucracy as they are rolled out;
- involve people with lived experience in evaluating provision, as well as making better use of the expertise of frontline staff;
- ensure national policies on access and equalities are implemented, as well as frameworks such as the Faculty for Homeless and Inclusion Health's updated healthcare standards.

#### 6 Avoiding Unnecessary Hospital Visits And Promoting Safer Discharge

Speakers, presenters and delegates alike highlighted some good examples of ways in which services are working together across community and hospital settings to provide better quality, more person-centred services to excluded groups.

However, there were concerns about the patchiness of provision to promote safe and effective discharge from hospital or prison and about the insecure funding for many such services. Jane Ellison MP told delegates the Department of Health is awaiting evaluations of the 'Safer Discharge' pilots funded this year and is expecting NHS and local authority commissioners to continue to invest in those which are effective.

At the other end of the patient 'journey' we heard about some good examples of community-based provision to meet health needs earlier and more effectively, avoiding unnecessary attendance at A&E or admission to hospital. Again, delegates emphasised such provision is not available across all locations or service user groups and many services struggle to get local commissioners to commit to services which serve several localities or groups. The Minister spoke about the need to work together to 'get health provision right first time, or at least earlier' and she announced £40 million health funding would be invested from 2015/16 in improving hostel provision.

# **Achieving Change**

# Some of the ingredients for achieving transformational change, which emerged from presentations and discussions, included the following:

- inspiring and committed leadership;
- bearing witness on behalf of excluded people, and not accepting exclusion as inevitable or acceptable;
- taking pride in working with, and for, marginalised groups and providing quality services to them;
- · focusing on individual people's lives, not just systems;
- working collaboratively, rather than shifting responsibility elsewhere;
- responding with empathy and compassion, not judgement or assumptions;
- mobilising and respecting a range of experts, including frontline staff and service users;
- making specialist provision understandable to commissioners and policy-makers;
- thinking creatively and ambitiously, not accepting the status quo where it's not working;
- piloting new approaches and gathering evidence of what works;
- · bridging the 'knowing-doing gap';
- celebrating success and sharing learning.-

# **Some Next Steps**

Pathway will continue working with hospital trusts across England to introduce new Pathway services based on its integrated model of care, and will support existing Pathway services. It will continue its work to develop a pilot medical respite facility – a step down facility for homeless patients being discharged from hospital – with a view to this being opened in 2014.

The Faculty, supported by Pathway, will promote the use of the Standards with commissioners and service providers, and will develop methods of checking the effectiveness of the Standards implementation. It will also develop a multi-professional specialist qualification in inclusion health, with a view to piloting it in the 2014/15 academic year. Ahead of this a one day CPD seminar in inclusion health will be run in June 2014. The Faculty will continue to meet quarterly in London, facilitated by Pathway, and will also hold regular northern and southern hub meetings for those members who find it difficult to travel to London. These meetings provide opportunities for Faculty members to get involved in its development work, to share learning and add to the evidence base of inclusion health.

Also, the Faculty will work with or write to key national partners with specific suggestions that emerged from the conference, including the following keynote speakers who made specific commitments:

- Steve Field re: use of Faculty standards in CQC approaches to assessing services' compliance with national requirements and use of lived experience in evaluating provision:
- Ruth Passman re: NHS England's interest in ensuring the CCG Assurance processes include specific discussions
  about tackling health inequalities and ask questions about the accessibility of primary care to excluded groups
  including homeless people, vulnerable migrants, gypsies and travellers;
- Jane Ellison, MP regarding the stated intention to ensure we 'get health provision right first time, or at least earlier' and to ensure that in designing services for everyone, unintended barriers are not created for some;
- Duncan Selbie re: 'speaking and publishing from the evidence' and facilitating involvement on local government on what more they can do to deliver what works.

PROFESSOR AIDAN HALLIGAN CLOSED THE CONFERENCE WITH A COMMITMENT FOR THE FACULTY FOR HOMELESS AND INCLUSION HEALTH TO ORGANISE ANOTHER EVENT IN 2015. PATHWAY WILL WORK WITH FACULTY MEMBERS AND OTHER PARTNERS TO DEVELOP THIS AND WELCOMES IDEAS FROM, AND INVOLVEMENT OF, LOCAL, REGIONAL, NATIONAL AND INTERNATIONAL PLAYERS IN SHAPING THIS.

'We (in the Care Quality Commission) are creating opportunities to celebrate and showcase great practice as well as to identify and tackle poor practice.'

'An economic crisis need not be a health disaster, but we need to treat unemployment as the pandemic it now is.'

**Dr David Stuckler** 

'Vulnerable people are often met with enforcement-based responses, rather than empathy, which discourages them from seeking the help they need and are entitled to.'

Georgina Perry

'The NHS should be best where people need it most.'

Prof Aidan Halligan

'I was left with a good hard chunk of hope, I didn't really think that many people gave a toss so I was left with hope for the future.' Joseph (SUE Group) 'Rough sleeping is not an individual's choice, it's society's choice.'

Delegate

'We need what I've heard described as "localism with safeguards" because we can't always trust local communities to do right by the most excluded.'

**Rick Henderson** 

'Let's do more to harness the power of voices of experience.' 'We need to tackle the social production of homelessness, which is not genetic or caused by a pathogen' Prof Stephen Hwang



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# Healthcare for homeless people

**Conference sponsored by:** 

Homeless Link Crisis The Queen's Nursing Institute Institute of Healthcare Management









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