

# **Lothian Voices**

**The People's Conference 2017**

**'Swings and Roundabouts'**



**How can Health and Social Care  
services support my journey through  
the Welfare system?**

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### **How can Health and Social Care services support my journey through the Welfare system?**

#### **Report Summary**

On 5 May 2017 people from across the Lothians with lived experience of mental health issues gathered to give voice to their views and experience of the welfare system.

People talked about the many challenges of navigating this system. They spoke of how Health and Social Care services supported them on this journey, as well as how they wanted these services to improve.

The Conference looked at a range of places people access support and services: GP services and primary care; mental health practitioners; benefits and advice agencies; allied health practitioners; social care; third sector; alternative and other therapies and friends and family.

#### **Here are the key things people said they wanted to see:**

- A consistent approach amongst GP's towards the provision of evidence
- Mental health practitioners to understand the benefits process and support people as they navigate the system
- Benefits agencies to be aware of mental health and how the welfare system has an impact
- Acknowledgement of the effect the benefits process has on a person's health
- Increased knowledge of the process: training for professionals on the benefits system and mental health
- Encouraging change in attitudes and fostering culture change: address power imbalance, communicate humanely
- Choice over the types of support we use in our journey
- Improved communications between Health and Social Care staff and the Department for Work and Pensions
- Ways of allowing us to control our own information
- Improved access to independent assistance.

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## **Who are Lothian Voices and what is The People's Conference?**

The People's Conference is an event for people with lived experience of mental health issues. It is planned by the Lothian Voices steering group, a collective advocacy group of people with lived experience of mental health issues, supported by CAPS Independent Advocacy.

The conference is a space for people to give their views on issues relevant to NHS Lothian's Mental Health and Wellbeing Strategy 'A Sense of Belonging'. It also gives people the opportunity to meet others and learn about different projects and groups in Lothian related to mental health and wellbeing. After the event Lothian Voices plan and prepare a presentation about the event and its key messages for Taking Stock. They are then involved with writing this report.

## **Why was the People's Conference held?**

Every year there is a stakeholder event about the NHS Lothian Mental Health and Wellbeing strategy. This event is called 'Taking Stock' and is organised by NHS Lothian. Anyone who has an interest in mental health services in Lothian can go to Taking Stock. The aim of Taking Stock is to look at what work has been done over the year and what still needs to be done.

People who have lived experience of mental health issues said that they would like more opportunities to give their views on NHS Lothian's Mental Health and Wellbeing Strategy. It was in response to this request that CAPS organised the first People's Conference in 2014. This year the conference was run in conjunction with AdvoCard. The steering group decided the 2017 conference should focus on the welfare system, and how health and social care services support people through that: 'Swings and Roundabouts'.

## Process

### *The Steering Group*

A key part of the People's Conference is *how* it happens. As well as being a platform for people to make their voice heard on the day of the conference, the process of planning, the format of the event and the follow up are all ways in themselves for people to be involved, empowered and have a voice.

Members of the steering group have spoken about the impact on them personally of having a role in this conference:

Being part of a steering group like this has given me hope. Developing new skills of public speaking and report writing has helped me to begin to rebuild my confidence. I'm no longer isolated, no longer on my own

Both in the steering group and at the conference, people spoke about the impact of coming together to have a collective voice:

Everyone's going through the same thing – it's not just me -we're all in the same boat

### *The Conference*

The steering group felt it important that people felt included, safe and had as many opportunities as possible to say what they wanted.

They wanted speakers at the event to help frame the current and future landscapes of Health and Social Care and Welfare Reform. Linda Irvine, NHS Lothian's Mental Health and Wellbeing Strategy Officer, spoke in the morning about current NHS mental health strategy and NHS provisions to inform staff about Welfare Reform issues. In the afternoon Arlene Astley from AdvoCard talked about the changes that Scotland would be making with its new powers for Social Security.

The steering group identified eight key supports people access on their welfare journey:

- GP Services and Primary Care
- Mental Health Practitioners
- Benefits and advice agencies
- Allied Health Professionals
- Social Care
- Third Sector
- Alternative and other therapies
- Friends and families

People were invited to say what is working, what isn't and the changes they want to see. There were also more open table top discussions and creative activities. This offered a range of ways for people to say what they thought and felt, depending on the way they were most comfortable communicating.

At the end of the day comments from the day were gathered and collated to produce a list of those ideas that came through most often. Those attending voted on these and there was agreement about the importance of these messages. What follows pulls together these priorities as well as the many things people said on the day.



## Key Messages

### ***What people said services need to know***

Many people had strong things they wanted to say that applied to **GP services and primary care, mental health practitioners and benefits and advice agencies** specifically.

There were also other key points that were present in many different contexts and apply to a number of the groups, whether it be GP services, mental health practitioners, benefits agencies, allied health professionals, social care, third sector, alternative and other therapies or friends and family.

## GP Services and Primary Care

### ***A consistent approach amongst GP's towards the provision of evidence***

People talked about how benefit claims often rely on the provision of medical evidence from GP's to back up the medical statements included in the claim.

They reported a range of experiences of their GP in relation to providing evidence. This was especially relevant to whether people were charged for letters, the quality of relationship with their GP and the GP's understanding of their mental health.

For those that had a positive relationship with their GP, it made a real difference.

My surgery has a welfare advisor in their practice. You can self-refer to her

Excellent GP – doesn't charge for letters. Get regular mental health checks

However, many people reported that they have experienced problems in obtaining evidence from GP's. Problems range from being charged for a letter, GP's refusing to write letters and GP's failing to return evidence to the Department for Work and Pensions (DWP) when they have been requested. Whilst people understood the difficulties faced by GP's in the provision of evidence, they talked about how failure to provide adequate evidence by GP's often leads to claims being disallowed and forces people into a prolonged period of reconsideration and appeal.

When you need a letter for PIP or ESA they wish to charge you £15.00. I think if you are on benefits the letter should be free

Had to pay for a letter for the DWP. Had to choose between the letter or food for the week

For others, not seeing the same GP or not having the chance to develop a relationship with them all had a significant negative impact.

Quality of letter = quality of relationship

It would be better if letters explained how illness, disability and medication affected me - not just a list of medication

People felt that it was important that there was a consistent approach throughout all GP surgeries towards evidence provision so that people knew what to expect when trying to gather evidence.

## Mental Health Practitioners

### *Understand the benefits process and support people as they navigate the system*

People said that they experienced a deterioration in their mental health when going through the benefit assessment process. They said it would be useful to have access to support before and after the assessment to help them to manage this.

Awareness claiming benefits can worsen mental health/illness and increase suicidal ideation - extra support is needed which recognises this

Again, when people had this support, it made a big difference:

My current psychologist is great, wrote a brilliant supporting letter for me to help with my mandatory reconsideration for ESA. This led to my decision being overturned.

One of my CPNs was very helpful and supported me at one of my DLA assessments. Went through my form with me and wrote a letter of support.

Recognise that help might be needed after assessments as this is difficult – ask us if this would be helpful

But consistency is a big issue. People felt this impact wasn't acknowledged enough, or the need for support sufficiently understood.

People said that Health and Social Care Services needed to provide more information before leaving hospital around benefit issues and continue to support people in the community.

Like with GPs, they wanted to see a consistent and relevant approach to evidence provision.

Any letter from a psychiatrist must address audience and purpose. No good using jargon / acronyms that the assessor doesn't understand

A CPN told me she was sick of 'these' people who only wanted a CPN for evidence for their benefits appeal. NHS staff need to understand how horrible and degrading the welfare process is.

People said mental health professionals needed to understand the benefits system better and what it is like to live with. More training is necessary, as discussed later in this report.



## Benefits agencies

### ***Be aware of mental health and how the welfare system has an impact***

People talked about how important it was that the welfare system takes account of the human reality of mental health difficulties. This is important at every stage of the process, from policy, to the design of forms, to the way people are spoken to. People wanted flexibility and a recognition that everyone is different.

Questionnaires / forms are not geared for mental health issues

I start shaking when I see these big forms, when I see the brown envelope from DWP my heart races anxiety

People don't always fit into boxes – my condition is variable

There was also concern about the role of private companies in assessments.

People felt benefit agency staff should receive more training on the impact of mental health conditions. People were concerned that the way they were talked to was not sensitive enough to their mental health, causing more distress and fear.

People doing assessments don't know enough about mental health

Recognise it's not easy for people to explain what they are experiencing, so give them time, be patient, read notes, listen, believe people, ask questions sensitively

Crucially, people wanted to be trusted and treated with more respect.

Trust – accept information from the person. Treat me as an individual

## Wider messages

Other key messages were relevant across the many services and groups that people interact with on their welfare journey.

### Acknowledge the effect the benefits process has on a person's health

More education on how destructive claiming benefits and the DWP system is in general, even before Welfare Reform was a major issue

Acknowledge the process has an adverse impact on health

We've talked about how important this is for GPs, mental health professionals and benefits agencies, but this message came through for all people, whether it be social care, third sector or family and friends. People

DWP assessment also has a negative impact on my family

had experience of being understood, but also of being dismissed or stigmatised. Overall,

Can be strong / can be ignorant / can be supportive / can be unsupportive. So raising awareness is all very important

there was a feeling that the difficulties and adverse impact of going through the process were not recognised.

There were appeals for people to understand what this experience is like in people's day to day reality.

GPs and other professionals don't understand what life is like on benefits and the assessments and appeals do affect your mental health

Understand the impact of precarious and meaningless work on our health

However, when people have experienced this understanding, it has been important for them:

Family have been very supportive while I have been going through the process as they can see how badly it has affected me in the past

## Increase knowledge of the process: training for professionals on the benefits system and mental health

There is a need for more training on benefits through all systems

Throughout the conference there was a strong feeling that services did not understand parts of the process outside of their field: in particular, health professionals needing to understand the benefits system and benefits agencies needing to understand mental health.

GP's / professionals to have knowledge of the benefits systems and the evidence

People felt these aspects of their life needed to be understood together, and professionals didn't always have the training outside their field to do this.

Improved training for GP's in mental health as mandatory

Training for NHS and social care workers to understand what living on benefits is like: going through claiming, assessment, appeals, fear of sanctions ... and low income

People with lived experience should share their experiences with the DWP and GPs

This stretches to everyone involved in someone's welfare journey, from social care to third sector to family and friends.

People felt more training was needed on what it was like to live through the experience of navigating the welfare system with mental health difficulties.

This training should be delivered by people with lived experience

## Encourage change in attitudes and foster culture change

There was much discussion on the day about how important it is to continue efforts to break down barriers between services and people who access them. People identified key aspects of culture that needed to be addressed, something everyone needs to play a part in.

People were keen to highlight the **power imbalance** in relationships, particularly with professionals:

It is important to recognise the power imbalance – be sensitive about how it's working in a situation. Understand the impact of assumptions and decisions on people

My psychiatrist has been good but views from the top down not bottom up – needs to understand problems associated with poverty

People told us that **communication from services still generates fear**. People wanted to be spoken to respectfully and sensitively.

Use humane language, respectful and improve efficiency

Having to deal with mental health professionals is stressful so they need to be empathetic

People felt strongly about the difficulties of recovery and entering **a job market which is often not open to mental health difficulties**:

Meaningful work, which is secure, flexible around mental health problems

We know our mental health – trust us when we say we need help

People wanted to be **listened to**, see a culture in which their own experience of themselves was valued.

## Give us choice over the types of support we use in our journey

People also spoke about how difficult it is not only to access different therapies but also to have these validated both by Health and Social Care Partnerships and the DWP. Some people felt that there is an overreliance on certain types of therapies within the NHS. There were many comments about the benefits of therapies not currently offered by the NHS and that benefits staff considered those therapies less relevant.

Letters from private therapists should be included in DWP evidence

I want to choose my own therapies and have them recognised by the NHS / GPs / DWP

Personal choice of support – i.e. therapy outside the NHS

However, there were a few comments in favour of using only evidence-based therapies.

The key here is that people should have the **choice** over what therapies work best for them and to have those choices recognised as valid choices, relevant to their claim.

Choice over who provides the evidence – ALL sources of evidence considered



## Improve communications between Health and Social Care staff and the Department for Work and Pensions

Services need to be more integrated, they need to communicate with each other

The prevailing feeling throughout the day was that there needs to be better, more transparent lines of communication between the work of these two systems. It was apparent from peoples' comments how much these systems are closely linked by the people they work with and issues around mental health and welfare.

Improve relationships with GPs and professionals

Clarity over what information the DWP want!

In particular, these issues concerned supporting evidence for claims. Several discussions at the conference highlighted the difficulties in obtaining this information, as well as lack of clarity on what was required.

People talked about the importance of this supporting evidence to the decision on their claim and the many barriers to them collating good medical evidence.

These included problems getting appointments with those involved in their care in time to provide the evidence for their claim. This means that people are submitting claims with very little supporting evidence which increases the likelihood that they will have to attend a face to face assessment.

More time to obtain professional information

Another barrier to obtaining evidence was identified as a lack of consistency amongst GPs and Health professionals over what types of evidence they will provide, if any at all. People talked about their reluctance to approach those involved in their care for fear of being turned down which in turn leads to a lack of supporting evidence being produced for claims.

Speedy / prompt responses from both professionals and the welfare system

This raised issues on how information is shared, something people also had lots to say about.

## Find ways of allowing us to control our own information

This was an important subject for many people. There were many who felt that they would prefer the DWP to obtain medical evidence and information directly from sources themselves, thus reducing the responsibility of the claimant to collect medical evidence.

Information recorded adequately so I don't have to keep getting evidence when staff move on

More appropriate sharing of information

However, others felt it was important for them to manage the information that was being passed on, in a way that they felt was appropriate, and would prefer that the DWP did not contact their health professionals at all.

Do they need to keep records if I am assessed in the here and now?

We need to know what information is being passed on – we need to know what is in the letters

This suggests that the most important factor here is that **people are given the choice** to decide themselves how they would like the medical evidence necessary for claims to be collected.

Let us control our information



## Provide improved access to independent assistance

More funding for third sector  
– advocacy specifically

Many of the people who came on the day talked about the different services they had used and how beneficial their support had been, including Citizen's Advice Bureau, Third Sector and Independent Advocacy.

It became apparent that many people struggled to navigate the benefits process without the help from advice agencies and/or independent advocacy services. People spoke about the need for these services to continue, for their funding to be increased and their presence to be widened. People also suggested that these services must be more widely publicised, with many saying that it is important that the provision is not only there but that people are aware of it and how they can access it.

CAB and others provide a free but oversubscribed service. This stretches the service to the max leading to long delays

The independence of these services was seen to be important:

There needs to be support that is not controlled. No reporting back to NHS/DWP to get people back to work

From some, there was also concern over how the third sector was used to provide services people felt should be statutory:

System puts too much reliance on third sector to help people – plug gaps



## Conclusion

There was a strong collective voice at the People's Conference about just how challenging the benefits process is and the impact it has on people's mental health. Previous reports have looked at changes that need to be made within the benefits system to prevent this happening. However, this report has shown that whilst we wait and campaign for change there are ways that health and social care professionals can support people. This support can help mitigate some of the problems caused by the current benefit system, helping to ensure that the person's recovery is not detrimentally affected by changes to benefits.

Participants at the conference identified many ways that health and social care staff could support them through these changes. Many suggested that providing good, accurate, jargon free evidence that properly reflects how a person is managing can help make the reassessment process easier to navigate. People also identified that acknowledging the effect that all these changes are having, and making sure that support is available when someone is being reassessed, could help to stop the deterioration many are seeing in their mental health through this process. People also wanted to see the adequate provision of training for all health and social care staff on changes to benefits. This would ensure that staff are aware of what is happening and how best to support the people they work with.

We appreciate that in a climate when resources are continually being cut it is not often possible to make changes. However, many have said that whilst going through benefit changes their mental health deteriorated to the extent that they accessed services for longer and required more treatment and support than previously needed. For some, this distress led to suicidal ideation. By adopting some of the suggestions in this report health and social care staff could prevent the deterioration in mental health that many say they experience and in turn prevent the need for long term support needs caused by benefit changes.

## Feedback



People's feedback made it clear there was a need for people to discuss and share their views with people with similar experiences. People welcomed the forum to advocate for change – 'from the bottom up'.

## Next Steps

Following the People's Conference, the steering group gathered to prepare and deliver a presentation of the key themes from the conference at Taking Stock. This presentation was positively received and was the first step in putting forward the views contained in this report.

The Lothian Voices steering group, AdvoCard and CAPS Independent Advocacy now plan to bring these views to the attention of as many people involved in the welfare journey as possible – from Health and Social Care to benefits agencies, those involved in policy and government, to the third sector and friends and family.

We welcome invitations to present these views and are open to conversations about change and how to implement these suggestions.

## What is Independent Advocacy?

Independent Advocacy is a way to help people have more influence and as much control as possible over their lives.

Independent Advocacy is “independent” because Independent Advocacy organisations only provide advocacy – they do not do anything else.

This report was produced by Lothian Voices, supported by a collective advocacy partnership between CAPS and AdvoCard.

AdvoCard provides individual and collective advocacy to people with lived experience of mental health issues in Edinburgh through several services. These include hospital-based, prison-based, community-based and dedicated welfare reform advocacy.

CAPS provides individual and collective advocacy for people who use or have used mental health services in East Lothian and Midlothian. CAPS also has several Lothian-wide experience-led projects relating to mental health.

Individual Advocacy is about working alongside a person to help them express their views and have more influence over decisions being made about their lives.

Collective Advocacy is about groups of individuals with a common cause who come together to raise awareness, campaign and influence service planning and provision.

Independent Advocacy:

- Puts the people who use advocacy first
- Is accountable
- Is as free as it can be from conflicts of interest
- Is accessible

## Acknowledgements

Lothian Voices appreciate how difficult it can be to share views on such emotive issues. We would like to extend our heartfelt thanks to all who came to the event and shared their experience, views and ideas. We hope this report represents your views faithfully.

If you would like any more information or would like to be involved in the future, please contact Lothian Voices via CAPS Independent Advocacy.

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