Dorset Wellbeing and Recovery Partnership

Supporting the Recovery Journeys of Staff

A Collection of Papers

Contents

Foreword

The Dorset Wellbeing and Recovery Partnership (WaRP) has seen from its inception the importance of the recovery journeys of staff, alongside those of people who access services, their carers and supporters. If people are not empowered to understand their own recovery journeys, irrespective of whether they have mental health issues or not, they will not be able to effectively support the recovery journeys of others and will end up "doing" recovery to other people, rather than appreciating shared humanity.

James Barton and Dorset HealthCare have shown some courage in beginning to address the lived experience of staff and these three papers presented here represent this. The Wellbeing@work tool provides a simple supportive way to enhance work based conversations that focus on an individual's wellbeing. The Sharing of Lived Experience document looks at how all staff can use their own lived experience of trauma and life to create a recovery focused workforce and culture. The Lived Experience Survey highlights how commonplace and normal mental health problems are and the importance of seizing this opportunity to celebrate and utilise all lived experience and expertise. This document also highlights the levels of stigma and discrimination that people not only perceive, but also experience and this enables us to be totally honest about the fact that when we talk about stigma we actually mean prejudice. I believe that mental health services should be able to act as a beacon for mental health, promoting hope and positive images, supporting good mental health. This means seriously challenging its own ingrained cultures of discrimination and prejudice for people within the workforce with their own lived experience of mental health problems.

These papers alone are not enough to bring about culture change, but they are a good start in contributing to discussions and setting the challenge for Dorset HealthCare, along with the WaRP, to put ideas and values in to real and tangible actions. This will inevitably result in working with staff in a significantly different way, which will in turn improve the experience of people accessing services and the quality and effectiveness of services that are provided. At the Forum we are optimistic about and inspired by the opportunities ahead, but at the same time are aware of the scale of the task and journey ahead. We are delighted to be able to challenge and support Dorset HealthCare to continue to be bold, to have courage and to make real and meaningful change possible.

Becky Aldridge
Forum Chief Executive

Introduction

My vision is for the mental health directorate is to have a service were we have empowered motivated staff, who deliver consistent high quality personalised care each time, every time. In order to achieve this we need to be able to effectively support staff.

Therefore, I am pleased to be introducing these three papers from the Dorset Wellbeing and Recovery Partnership, which all address different aspects of "supporting staff with their recovery journey".

Supporting staff with their recovery journey, is one of the ten organisational challenges for Implementing Recovery for Organisation Change (ImROC) (CMH, 2010) The aim of which is, as the Centre for Mental Health (2010) describe, Staff will remain the key "carriers of hope" and we need to create a culture which values their "lived experience" of mental health problems and frees them to respond to service users priorities rather than bureaucratic or professional agendas."

I am committed to the promoting the recovery agenda within our services and as part of that we need to understand and learn from the experience of staff. When we talk about lived experience in this context we don't soley mean of mental health problems but also professionally, life experience, experience of trauma which may or may not include mental health problems.

This has been a difficult twelve months, were we have been through a management restructure, there has been a coming together of different organisational cultures, we have had some very negative feedback from the CQC, and services have been under significant pressure.

It can be hard to get the balance between the needs of individual and the demands of a modern healthcare system. We will not get things right all the time, but for me it is important people have the right values and are committed to improving things for people who access our services and their families and supporters.
These three papers highlight, key areas where we need to support and develop our workforce, they contribute to the local and national discussion of how to challenge stigma and discrimination and how our workforce can best use their lived experience and offer a tool to manage Wellbeing@work.

For me, you, our workforce are crucial in the success of this directorate. Even within these difficult times individuals and teams are doing outstanding work, which makes me proud to be Director of Mental Health Services. In order to build on these positives and to develop our services for the future, one of my key priorities over the next few months is to establish a Workforce development group. This will enable us to learn together from our challenges, build on our successes and create a culture where you are supported and fulfilled in your role, delivering excellent services to the people who access them. This will include a relaunch of the Hidden Talents project, which I understand, has been difficult to sustain in the midst of organisational uncertainty. As always I am keen to have your feedback and ideas if anyone would like to discuss this further I am always happy for you to get in touch with me.

James Barton
Director, Mental Health Services

Dorset HealthCare Mental Health Directorate Lived Experience Survey

Dorset HealthCare Mental Health Directorate Lived Experience Survey

Introduction:

The Recovery Approach is gaining prominence within Mental Health Services within the UK (Centre for Mental Health, 2010). Central to the Recovery Approach is being able to learn from lived experience. Through the Dorset Wellbeing and Recovery Partnership, Dorset has played a significant role in exploring how lived experience can be used to shape and inform recovery orientated services. This partnership is between Dorset HealthCare University NHS Foundation Trust (DHC) and Dorset Mental Health Forum (a local Peer-lead organisation).

One of the projects of the Wellbeing and Recovery Partnership is the Hidden Talents project, which is a group of staff who work within DHC, who have lived experience of mental illness and are seeking to enable the organisation to learn from their experiences and through working together to identify the best way to support the emotional wellbeing of all staff. To find out more information about Hidden Talents please follow this link http://www.dorsetmentalhealthforum.org.uk/pdfs/other/hidden-talents.pdf

In the wider literature about Recovery there has been a great focus on the role of peer workers. There has been little work exploring how existing NHS and Social Care staff employed in traditional roles can or may use their own lived experience of mental health problems. In order to be able to explore this more fully, it was thought important to get an understanding of how many existing NHS and Social Care Staff within the DHC Mental Health Directorate had lived experience of mental health problems and how they perceived their lived experience was viewed. A similar study was undertaken within Devon Partnership NHS Trust (Roberts et al, 2011) and we are grateful to Glenn Roberts for his generous sharing of information and experience which we were able to base our survey upon.

A key theme of the Hidden Talents group was feeling stigmatised, so the survey not only looked at numbers of people who have lived experience of mental health problems, or supporting someone, but if people felt that there was an "Us and Them" culture and whether people had experienced stigma and discrimination. As the Hidden Talents project is about the emotional wellbeing of all staff, the survey also asked what could DHC do to be better able to support its staff.

Methodology

The survey was based on the one designed by Roberts et al (2011) with a few local modifications. It contained a combination of closed questions, likert scale items, and open questions (see table 1).

> **Table 1: Survey Questions**
>
> **Closed questions**
>
> 1. Which is your staff group? (Staff groups were categorised as Administrator, Medic, Manager, Nurse, Occupational Therapist, Social Worker, Support Worker and Other)
>
> 2. Have you had personal experience of mental health issues? (yes/no)
>
> 3. Have you ever used mental health services or treatments? (yes/no)
>
> 4. Do you have personal experience of being a carer or supporter to someone close to you with mental health issues? (yes/no)
>
> **Likert scale items**
>
> 5. To what extent do you think there is a 'them and us' culture within this Trust between staff and people who access the services? (This question asked people to gauge the degree of prejudice they feel exists in the Trust; none, little, some or substantial)
>
> For those respondents who identified as having experienced mental health issues there were a further two questions, both based on likert scale responses.

The open questions where thematically analysed, the responses for question 6 were initially coded into 60 thematic groupings and have subsequently been categorised by 3 higher level themes to allow trends to be highlighted.

The survey was sent out to all Staff within DHC Mental Health Directorate by both email and electronic and paper copy. This was accompanied by a covering letter written by the Director of Mental Health. People were not required to put their name on the survey and all surveys were treated in strictest confidence. As this was a local service evaluation, ethical approval was not sought. Data collection commenced in August 2012 and was completed at the end of October 2012.

Findings:

Response rate and rates of Lived Experience

The survey had a response rate of 31% (n=436 from 1393). Which considering the sensitivity of the questions, it was felt to be a good response rate. The responses came from a range of disciplines which broadly matched the staffing profile of the service, with the largest number of respondent coming from the nurses, followed by support workers, then other disciplines, managers and administrative staff.

53% of people identified as having lived experience of mental health problems. 37% of the total number of respondents had reported they had accessed a mental health service or treatment.

46% of the sample had experience of acting as a carer or supporter for someone with a mental health issue, with 30% percent of those who have experience of acting as a carer also had personal lived experience.

"Them and Us" Culture and Stigma and Discrimination

In looking at "Them and Us" Culture, 43% felt there was at "some" and additional 10% of the sample felt there is a substantial "them and us" culture. There was not a significant relationship between people who have lived experience and those who do not, in their perception of a "Them and Us" culture.

39 % of those with lived experience of a mental health issue have varying degrees of experience of stigma. With 18 % having 'some' experience of stigma and 4 % had experienced substantial stigma.

There was a clear relationship between those who experienced stigma and those able to share their experiences, however through this survey the causal relationship is not clear. According to the findings, people who share their experiences most frequently report the lowest levels of experiencing stigma and discrimination and conversely the people who experience the most stigma and discrimination report the lowest levels of sharing personal experience with colleagues and managers. Similarly, people who rated a high "them and us" culture were less likely to share their experience and people who rated a low "them and us" culture were more likely to be willing to share their personal experience.

What DHC can do to support its workforce more effectively?

This was written as an open question and the answers were thematically analysed, they initially coded into 60 thematic groupings and have subsequently been categorised by 3 higher level themes to allow trends to be highlighted. The higher level themes have been categorised as follows:

1. Organisational culture with key sub themes of communication, involvement and effective management.

2. Resources, pay and conditions with the sub theme of pressure on resources.

3. Introducing supportive measures

The majority of respondents focused on organisational culture being the main way to address staffs emotional wellbeing. The key sub themes with this were communication, and in particular listening to staff, being transparent, and involving them in decision making. It was also stressed that this was supported by effective management and in particular good supervision. People identified those things as being lacking in the organisation currently. A small number of people identified bullying as a problem.

Another key sub-theme relating to organisational culture was that the focus shifted from a target driven and outcome culture to a focus on people and on recovery and that this focus was modelled from the top down.
For those with mental health problems access to services was flagged up as an issue to due to the complexities of being treated out of area or lack of choices and flexibility around accessing mental health services.

A number of people stressed the importance of being able to be open about staff having mental health problems and thereby being able to get effective support. People highlighted that there exists a fear that being open about mental health problems will affect career prospects.

In regards to the theme **pay and conditions** people highlighted that they felt the workload was too high, that there not enough resources or staff to meet the demand, that there was too much criticism and not enough praise. People were also critical of the South West Pay Consortium and wanted DHC to pull out.

The third theme was people making suggestions of **supportive measures** to improve staff's wellbeing. Suggestions were as follows, to offer tools for self-management of stress in the workplace, encouraging more openness around emotional wellbeing, offer courses in the Recovery Education Centre at staff friendly times, give staff access to fitness centres, massage, and other therapies. Give people opportunities to learn from lived experience and access projects such as *Hidden Talents*. Encourage creativity within the workplace and outside of it. Give staff one "mental health day" a year.

Discussion

Whilst the findings of this survey are not surprising, they do bring a stark reality to the distance needed to travel for staff to feel valued for having lived experience. From this survey we can say at least approximately 1/6 staff have lived experience, and as the response rate was a third, we can surmise that the figure is significantly higher. A number of people approached the recovery team stating they had not completed the survey as although it was anonymous they were too scared to complete it as they did not trust the organisation to not try and find out who had mental health problems and use that information against them. Time to Change refer to 1/4, which is a quarter of the workforce.

Our survey findings in this respect, where similar to that of Roberts et al (2011), in Devon Partnership NHS Trust. They had a 23% response rate, with 43% identifying as having lived experience of mental health problems and 1/3 of their respondents with lived experience felt unable to be open with their managers and colleagues with the majority of reasons given being due to fear of stigma, misunderstanding or rejection.

For people to be experiencing any degree of stigma and discrimination for having mental health problems within a mental health service (which should be an exemplar employer in our view) is a disgrace, especially as nearly 40% of those with lived experience had experience at least a little stigma. DHC also has a fair way to go in addressing "them and us" culture. It is interesting to note the relationship between sharing information," them and us" culture and experience of stigma and discrimination. DHC needs to continue to explore strategies and where appropriate use disciplinary action and legislation, in regards to the equality act, to protect the rights of all its staff.

The themes identified in the questions with regards to what DHC can do to support the emotional wellbeing of its workforce link strongly to the findings of the Francis Report (2013), sufficient resources, focus on people not targets, listening to and involving staff. The Wellbeing and Recovery Partnership welcomes the email Jonathan Walsh (Chair DHC) sent to all staff addressing a number of concerns raised by staff, which coincide unsurprisingly with the concerns raised in this survey. In particular, withdrawing from the pay consortium, asking staff about why they would not recommend their own service, and asking them to highlight unsafe staffing levels and resources needed.

However, further work is needed in order to create a culture of openness, to move beyond paying lip service to the notion of focusing on people rather than targets and developing focused strategies on promoting staff wellbeing and self-management. It is also important for effective management to be put in place, concerns about bullying need to be taken seriously, and supervision where staff development and creativity are encouraged.

Conclusions and Recommendations

Although it should not be, it has been a brave step for James Barton to endorse and undertake this survey, as few other organisations have been willing to "grasp the nettle" and seek to understand the lived experience of their staff. Unfortunately, it has also been a brave step for staff to complete this survey, for which we are extremely grateful, but this in itself indicates our distance yet to travel. We are also extremely grateful to Glenn Roberts and his team who allowed us to use his experience of undertaking a similar survey in order for us to develop ours. Whilst the first step has required some bravery, the next step to learn from the survey is even more challenging and requires a range of action across the whole organisation. We have therefore identified the following recommendations:

•   For the board and directorate level endorse the framework for sharing lived experience and develop a strategy to create a culture of openness in regard to the emotional wellbeing of staff, which includes promoting Hidden Talents across the whole of DHC.

•   For the Board to develop and introduce an action plan introduce which expressly seeks to tackle all forms of stigma and discrimination including people with mental health problems.

•   For the Board to develop articulate a clear strategy on how to address the conflict between a target driven culture and a person centred one.

•   For Human Resources, Occupational Health, Providers and Hidden Talents to review pathways for staff accessing mental health services.

- For the Learning and Development Team to continue to work with the WaRP and managers around Recovery Leadership and re-establish the Team Leads Team leader network within the Mental Health Directorate.

- For Human Resources Department to work with the WaRP to develop employment pathways (recruitment, induction, training, supervision, and appraisal that support openness and personal wellbeing alongside performance).

- With the high levels of people who have lived experience for Occupational Health to employ mental health specialists within their team

- For the WaRP to develop courses within the Recovery Education Centre which address self-management and stress within the workplace.

- For the WaRP To work with Human Resource and Occupational Health to develop the Health and Wellbeing at Work Policy, which includes role out of Wellbeing@work plans for all staff.

- For the WaRP to repeat this survey in 2 years time to evaluate whether the measures undertaken have had any impact.

Completed by: Phil Morgan, Jade Leahy, Lisa Gale, Jackie Lawson,

March 2013

References:

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**Framework for Using and Sharing
Our Lived Experience within Health and Social Care**

Framework for Using and Sharing Our Lived Experience within Health and Social Care

Introduction

Sharing lived experience, especially lived experience of mental illness, can be a very positive experience in offering hope and challenging stigma and discrimination, and offers the opportunity of a more inclusive and humanistic mental health service. There are opportunities for increased benefits for the people who access services, the organisation as a whole and the staff who work within it.

> **What is the value of sharing lived experience?**
> - People who have accessed services have stated when a clinician has disclosed.
> - their own lived experience in the past, service users have found it to be helpful to their recovery and welcoming.
> - Breaks down the 'them and us' perception which in turn influences changes towards stigma and discrimination.
> - It creates opportunities to enhance practice and give a balanced understanding of academic expertise and lived experience expertise.
> - Increases faith and belief in the efficiency of mental health services.
> - Improves experience for people who access services, their carers and supporters and staff.
> - Improve support for the wellbeing of staff.
> - Promote a recovery-orientated ethos within Statutory Services.
>
> Findings from the 3 Dorset focus groups 2012-13

Sharing lived experience is not without risks e.g. people can use information against you or discriminate against you, so should be approached with caution. It can also lead to unhealthy and possibly exploitative relationships. However, there are also risks of not sharing information. Gossip and leaked information can undermine a supportive workforce culture. Individuals can live in fear or feel dishonest, as they are hide aspects of themselves, and the stigma and discrimination relating to mental health is maintained in an
unhealthy organised culture. We would argue that the risks of disclosing can be mitigated by strong organisational support and a health organisational culture that supports the emotional wellbeing of its staff and openness.

> **There are individual and organisational risks if there is a culture of not sharing lived experience:**
> - You may feel dishonest, if you cannot be open
> - It can feel like it's a shameful secret, if you cannot be open
> - You may feel dislocated from your own values and a 'fraud'
> - Clients often find out anyway It perpetuates stigma of people with mental health problems (Them versus Us)
> - Staff may disclose anyway without appropriate support or motive, potentially making it unsafe for them and people they are working with
>
> Findings from the 3 Dorset focus groups 2012-13

Recovery focused practice is being promoted in the UK and Internationally. Fundamental to this, is understanding the value of lived experience of mental health problems, and the sense of shared humanity. Services are increasingly asked for increased compassion, caring and values based practice (Francis, 2013) and an increased focus on the quality of the service- client relationship. Sharing lived experience can bridge the gap between theory and practice in delivering a values-based service.

The UK based literature around self-disclosure and sharing of lived experience is limited, so it was decided to undertake a project developing some guidelines focusing on how to share information. To read a more comprehensive description of the background and impact of self-disclosure we would recommend Hyman's (2008) excellent paper *Self-Disclosure and its Impact on Individuals who Receive Mental Health Services.*

When we talk about guidelines, we are not talking about a decision tree or prescriptive set of instructions. What we are offering is a set of statements, suggestions and reflective questions that will hopefully inform your approach to sharing lived experience. This is not a formal piece of research but a local discussion, which we hope provides a useful framework to think about sharing lived experience.

There are two parts to this paper, the first part discusses sharing lived experience with people who access services. The second part looks at sharing lived experience with colleagues. The reason for this is that in order to effectively create a safe environment within which to share lived experience, there needs to be an organisational culture that supports it. Through sharing lived experience, along with other strategies it is possible to utilise an untapped resource within the staff team and create a better experience for people who access services and those who work within them.

Methodology

This project was undertaken by Dorset HealthCare University NHS Foundation Trust and Dorset Mental Health Forum as part of the Implementing Recovery for Organisational Change Programme. In order to inform the project we set up three focus groups, the first two of which were facilitated by Rachel Perkins (Centre for Mental Health), to inform the development of guidelines. The first focus group was made up of members of the Hidden Talents group (for further information on the Hidden Talents group please see Background section of this document), the second was made up of representatives of the different professional bodies, and the third was a group of people who access services and was facilitated by the Dorset Mental Health Forum. These focus groups took place between October 2012 and February 2013.

The focus groups not only shaped the content of how and why to utilise self-disclosure, but also led us to reflect on the starting point of sharing any experience, and the organisational conditions that would support this culture. Therefore the focus of the project shifted from sharing lived experience of mental illness, to sharing lived experience in the broadest sense, but with a focus on trauma. Everyone has experience of trauma to varying degrees, whether that is loss, illness or other life changing event. This may or may not lead to mental health problems, but trauma is universal and part of our shared humanity. We all live along the continuum of emotional wellness and illness.

We also wanted to move away from the term 'disclosure' as the focus groups felt the term was loaded with a sense of telling something 'shameful' so we talked instead about sharing or declaring. Whilst we wanted to move towards talking about personal experience, it is nevertheless important to acknowledge the stigma and discrimination that people with mental health problems experience.

Definition of Lived Experience: We would define "Lived experience" in broad terms as "life experience" which broadly means our achievements, values, or skills and interests, but within this context has a particular focus on our experience of trauma or loss. This trauma or loss may or may not have led to mental health problems.

We do not want to define it as simply relating to lived experience of a diagnosed mental health condition as that can set up an unhelpful dichotomy of those who have mental health problems and those who do not, and unhelpful hierarchies of distress.

 This definition also links to the definition we use to define Recovery:

"Probably the most useful way of understanding recovery is linking it to our own experience because it is something that is common to all of us; it is not specific to mental health problems. Any of us, who have been through a divorce, being made unemployed, a major illness or bereavement, know that that changes us; there is no way to going back to how we were before that event. We have to incorporate that into our way of living and we learn from that and move on with that, which is exactly what we are talking about in terms of recovery from mental health problems. Very importantly, recovery is about taking back control over your own life and your own problems, about not seeing your problems as being uncontrollable, or that their control is just the province of experts. It is about understanding yourself what is possible and what you can do to help yourself." p124.

Background

This project originated from the Hidden Talents project, which is a group of staff who work within Dorset HealthCare University NHS Foundation Trust (DHUF), who have lived experience of mental illness and are seeking to enable the organisation to benefit from their experiences and through working together, identify the best way to support the emotional wellbeing of all staff. This is part of the wider work being undertaken in Dorset, as part of the Wellbeing and Recovery Partnership, which is delivered in partnership with the peer-led Dorset Mental Health Forum.

To find out more information about Hidden Talents please follow this link http://www.dorsetmentalhealth-forum.org.uk/pdfs/other/hidden-talents.pdf Over the past six months the Hidden Talents project has been focused on two key areas. The first was how people can safely use disclosure (as we termed it then) in their clinical work. The second was a survey which looked at how rates of lived experience of mental health problems within the Mental Health Directorate in DHC, and whether people believe there is a "Them and Us" culture and whether people have experienced stigma and discrimination.

The findings from the surveys, highlight the need for guidelines for sharing lived experience, based on the high numbers of staff who have lived experience and the high percentage of respondents who believe there is a 'them and us' culture. 26% of staff in the mental health directorate replied, 53% self identified as having lived experience of mental health problems. 53% believed there was a "Them and Us" culture to at least some extent, with 10% viewing it as substantial (this did not significantly vary between people who identified as having lived experience and those who did not). 39% of those with lived experience identified having experienced some stigma and discrimination from colleagues or managers. When asked what DHC could do to more effectively support the wellbeing of its staff, people identified a focus on communication and respect for the emotions of staff and opportunities to learn from lived experience. Roberts et al (2011) survey in Devon Partnership Trust, upon which the DHC one was based, had similar results. They had a 23% response rate, with 43% identifying as having lived experience of mental health problems. One third of respondents with lived experience felt unable to be open with their managers and colleagues, with the most frequent of reasons given being fear of stigma, misunderstanding or rejection.

Both locally and nationally with the development of the Recovery Movement and emergence of peer workers, many existing members of staff, in traditional roles, are saying, "Why can't we talk about our experiences?", "I've got lived experience that's useful. How do I use it?" What has also emerged is workers HAVE used their lived experience, irrespective of whether their organisation or professional body condone it. In order to integrate lived experienced and personal experience it is useful to look at the distinctions and similarities between what people bring to their roles within statutory services. All people have life experience and varying forms of expertise. Some are professional experts, some have particular personal qualities, some excel in the practical skills, and some have lived experience of mental health problems.

This can set up a tension and dilemma if not all staff can contribute to the discussion, utilising their own lived experience, particularly with the shared learning experiences offered by the Recovery Education Centre. This is also the case in the development of the roles around peer support workers.

Repper and Perkins (2012) describe three elements that all staff bring to their work to varying degrees:

• "Their personal experience of life outside the mental health arena (skills, interests, culture, values, education etc).
• Their personal experience of trauma, bereavement, loss ... and perhaps mental health problems
• Professional/mental health training and experience.

Anyone might draw on all of these – there will be overlaps - BUT different groups of staff **are employed in different core roles,** and therefore have **different kinds of relationships.**

• The core role of a mental health profession is based on their professional expertise – their relationships are professional relationships.
• The Core role of a peer support worker is based on their lived experience of mental health challenges and using mental health services – their relationships are peer relationships.
• The core role of the support worker is based on their experience of life outside mental health services - their relationships are ordinary, everyday relationships."

(Repper and Perkins, 2012).

Sharing Lived experience with People Who Access Services

As stated in the introduction, sharing lived experience is a complex process and there is not a clear right way to do it. This guidance offers some suggestions and pointers, along with questions to consider when sharing lived experience.

It is important to recognise that a therapeutic relationship is a privileged relationship, it is not an ordinary relationship, hence the importance of having guidelines. It is important that these guidelines are read alongside local policies, particularly around professional boundaries, risk management and safeguarding. However, we are also aware the often policies do not effectively address the complexities around sharing lived experience. These guidelines can also be used to inform policy. When there is a lack of clarity it can lead to risk adverse practice, as one of the participants described:

"When I spoke with my manager about disclosing my Lived Experience to the people who access services they were extremely supportive in principle about disclosure as they recognised the potential for inspiring hope and promoting recovery. However, due to the lack of policy and guidelines I could not obtain
permission to disclose my Lived Experience to people who access services. This was to protect my own professional registration, and uphold the professionalism and reputation of the unit. This clearly highlights the professional and organisational impracticability involved in disclosing."

However, no professional body has stated explicitly that people should not share lived experience. The therapeutic use of self and sharing lived experience is not a new concept, and certain therapies actively encourage sharing. For example, Dialectial Behavioural Therapy, uses the concept of "radical genuineness" around self-disclosure. This therapy is endorsed by NICE. It is important that these guidelines are seen in that context. Sharing personal information is not new, nor is it totally radical, especially if it managed well and supported effectively by the organisational culture. If steps are taken and guidelines followed, the negative impact of sharing lived experience can be significantly reduced, and create opportunities to build a less stigmatising mental health service. The guidelines we have developed are fairly simply based around 'What to say, Why you would share lived experience, When you would use it, and how'.

Factors that may facilitate self-disclosing include the following:
- The need to become educated about one's own condition so that one can educate others
- The importance of first disclosing to someone one trusts
- The recognition that one can decide to share less with those people who may appear judgmental
- The need to pick and choose when to disclose and under what circumstances
- The importance of feeling safe when one self-discloses
- The essential fact that each of us should be in control of how much to tell; we should not let anyone manipulate us into sharing more than we feel comfortable sharing.

The First Thing before entering into any sort of sharing of personal information is to clarify **WHAT** you are prepared to share, and be aware of this before you get into the position of sharing any information.

Key Points to Consider

Whatever you share, you need to be prepared to have it in the public domain, People may talk to their friends and family, your colleagues, about what you have said.

It should be things that you feel comfortable talking about and issues that you have made significant progress in addressing.

It is better not to share your whole story, but think of relevant episodes or experiences that you would be willing to share.

Share specific examples or more general points about how you have experienced loss, change or disappointment.

Think about what you do to stay well and how that can be difficult.

You may even want to consider having a pre-planned menu of options that you can draw from.

Be aware of the impact, What you can say and how it might effect the other person.

"It is important to be mindful about what you disclose. You are not disclosing just to the individual, they will tell others."

"Early on in my career I couldn't talk about it. I couldn't nurse people who'd experienced the same as me. The memories of the experience were not good."

"One of the risks of disclosure is people use it against you, for example, in a moment of anger."

"It is important to be mindful of the fact that people with LE may not want to disclose. Some don't want to revisit those times. A peer researcher talking on disclosure at the Recovery conference said that you should only disclose what you feel safe about, what you have dealt with and what doesn't cause you distress, that it's no longer an issue with you".

The next consideration is **Why?** What is the purpose of sharing information, are you clear what the potential benefit to the person will be?

Key Points to Consider

You need to have a clear context for sharing and a clear reason.

Why might it be of benefit to the person, what is your clinical justification?

-Will it help them feel more "ordinary"?

- Is it relevant to forming the relationship or supporting engagement in services?

- Will it help someone learn more about their condition or treatment?

It is essential that you are not doing it for yourself (even unconsciously).

Is it something the person would want to know? Could it make the person feel worse, will it reinforce their sense of hopelessness, "you have the same diagnosis and you've achieved all this, and I have failed"?

Could your disclosure make the person feel they need to protect you from painful aspects of their story?

"We need to always be asking ourselves, "Why are you telling them this?" It should be for no other reason but that it may be helpful to the person."

"It's good when we model 'normalising' our experience. We make it ordinary and by doing so we give our permission for people to ask."

"A GP disclosed to me that he had personal experience of severe depression. It was so powerful. So my first experience of disclosure was actually being disclosed to. It made me see him in a completely different light, and definitely gave me hope."

A significant impact on me of disclosure was when a consultant psychiatrist told me he had experienced severe recurrent depression. I was considering quitting nursing altogether, and his disclosure gave me hope that my experiences of mental health problems may actually help me be a better mental health worker.

How? What is the best way to share experience, how is it best approached

Someone I was working with was having trouble with her sleeping tablets. She had taken then too late in the evening and they had made her feel strange the next morning. I said something like, "Did it make you feel like you were watching yourself?" I then went on to say "I find its best to take them no later than 11pm. It's a fine balance, not to take them too early so you wake up ridiculously early, but not taking them too late so you feel like a zombie. That's what I find anyway." She said "yes, I'll try that"

I never tell the whole story just snippets.

Key Points to Consider:

Offer the person the choice, ask if they would like to hear about your experiences (in the same way we offer treatment choices, we should offer choices around quality of relationship, some people will not want to hear about it)

- That although what you are sharing may be similar, it is not the same.

- Introduce it in passing or in context, or give subtle indications, rather than suddenly disclosing.

- Lived experience can inform the questions you ask rather than what you say to the person, it can be as indirect as that.

- Remain in control of what you are prepared to share and how much you want to reveal.

- You are not sharing from the perspective of "expert" but rather from a shared experience.

- Be aware of stigma and discrimination you may experience from the person you are talking to (perhaps around particular diagnosis, for example).

- Be aware of factors such as gender, ethnicity and race and how they shape our experiences. Each person is individual, be aware of what we don't know.

- Use supervision and/or colleagues to reflect on the impact and approach to sharing personal experiences that you took.

- If you are in a professional role, understand that lived experience informs it, but does not define it.

- Being aware you are demonstrating respect and trust and as with any interaction, won't always get it right understand it as a learning experience.

When? Each situation and each person is different and careful thought needs to be given to each one.

Key Points to Consider:

Most importantly, when you are ready. You need to have control over what you are prepared to share and how you share it? If you feel "forced" or "outed" that is not right.

- If you are likely to become distressed by what you talk about then it would not be a good time to discuss.

- When there is clear reason to feel that sharing information may lead to a positive outcome When you have had a chance to gauge the relationship, build a rapport.

- When it feels safe enough to do so, whether this relates to the individual you are speaking to, or the organisational culture you are working within. Conversely, what would be the implications or risks if you did not share?

- When you feel you are comfortable that you are in control of what you share, and that if you do share some information, that you won't be pressurised into sharing more than you want.

- It will be dependent on the circumstances and the individual, you will need to pick and choose.

- It is ok, not to share personal information if it does not feel safe to do so.

- What is the capacity of the person to understand and interpret what you are saying.

"If I see a person who is without hope I try and instill hope. I know what it's like, not seeing the light at the end of the tunnel. I see it as my duty to instill some hope into people's lives."

"I find it a helpful starting point to think: "Is this sharing of something about myself going to benefit or move forward this individual at this moment?" And to be reflective about why I am thinking of sharing something, no matter how trivial."

"Usually it's when someone says "You don't know what it's like to feel …" that I disclose. I say something like: "I don't know how you are feeling, no, but I know that when I suffered … I experienced something similar" I don't tell the whole story."

Sharing Lived experience with Colleagues and Managers

Sharing lived experience does not take place in isolation. The likelihood of success is dependent on how supportive the organisation is in regards to sharing lived experience, understanding the value of supporting it and the risks of not supporting it. It can be greatly enhanced when sharing lived experience of trauma occurs in the context of people sharing more general information. Many of the features of sharing information with colleagues were also present when sharing information with clients. In order to create a safe culture where sharing of information can take place, it is important that staff to staff interactions are handled with tact and integrity and this needs to be the case at all levels within hierarchies.

Organisational Culture

The organisational culture is key in for people to feeling safe enough to share lived experience. This should be reflected in Human Resources process and procedures, for example, all staff having 'Wellbeing @ Work' plans, and the value of lived experience built into all recruitment, induction, supervision, and appraisal procedures.

'We welcome applications from people with lived experience' and 'Having it in the job advert, I found that positive and encouraging.'

"I had a positive experience at my first interview. The second question was around my mental health experience and I felt it was an asset."

It can also help if senior people are able to share their own lived experience and model that sharing. Often people have concerns around the response of their professional bodies, therefore it is important that the Professional Heads value lived experience. It is also important that Managers are empowered to make reasonable adjustments that may be helpful in order to maximise people's ability to work effectively.

If people feel they are being stigmatised or bullied, it is important that it is treated as such under the bullying and harassment policy, or by using The Equality Act.

Team Culture

It is important that team cultures support the sharing of lived experience so that individuals are not isolated or stigmatised. It helps when:

- Your line manager knows you are doing it and it can be discussed in supervision.

- Your manager and team understand the value of lived experience.

- There is a team culture to talk about emotions, including the openness of Manager s regarding their emotional struggles.

- That you are not the only one in the team using lived experience but there is a team culture that supports this way of practising.

- That there is a culture of normalisation and openness.

- That there are clear boundaries between roles, and peer workers available if people want to have lived experience coaching.

- That reflection and evaluation takes place on the impact of sharing lived experience.

- Good quality supervision which explores everyone's wellbeing at work (reflective space).

- Being supported to feed back about sharing lived experience.

The members of the Hidden Talents group fed back mixed responses of sharing their lived experience, These experiences have been used to inform the suggestions and tips to share and respond to lived experience.

"My very first experience of disclosing to a colleague was not a positive one. After I told them that I had personal experience of mental health problems they said that they wished I hadn't said anything as they felt uncomfortable knowing that about me, and wouldn't know how to act when we were on shift at the same time."

"Sometimes there have been misunderstandings. I have had my manager saying to me 'You're probably not up to it at the moment' when I have questioned something. No! It's because I disagree with it that I'm questioning it!"

"I've disclosed often but sometimes you feel exposed, a bit vulnerable, and it's good to have someone coming to you to support you."

"There's a culture of silence in the Trust. It's perceived but not acknowledged that there are those who have had LE. There may be people in my team who don't know my LE, but I have not concealed it deliberately. One of my colleagues told me of their own LE: "I don't mind telling you ...", but they didn't want other colleagues to know."

"'Secrets' as in something you want to keep hidden and ashamed of is not something you want to worry about at work. I choose not to disclose but that is not because I'm not comfortable with my Lived Experience, because I am very comfortable with that, but because I don't trust the environment not to be stigmatising. It's 'catch 22' I know."

"I felt it was important to establish myself in my role before disclosing, so that I wouldn't be stereotyped and I could challenge stereotypes instead."

"When I started in my new job I did not disclose my Lived Experience with my colleagues, as I felt it was best to let people get to know me in a professional capacity first. After a couple of months, and having been given positive appraisal, I chose to tell my colleagues over the course of a couple days. Within 3-4 days I was called in by my manager to let me know that 2 of my colleagues had spoken to her about their concerns of my becoming unwell. No-one had mentioned anything to me. The experience was very upsetting and I felt very alienated for a while…[after a while], I began to notice that colleagues talked more openly about their own mental health and wellbeing."

What you can do to share your lived experience effectively?

- Have Choice over what you say, to whom, and when.
- Start with a trusted colleague first.
- Be aware of the how the person you are sharing information might be feeling (they may not feel in a safe space).
- Staying in control of what you say.
- Normalising and making it ordinary – dropping it in.
- Making a virtue of it.
- Be proactive (not when in response to feeling frustrated or distressed).
- If in doubt, don't do it!

What can be unhelpful in how you share your lived experience?

- Making a Grand Announcement!
- Having "a go" at someone because you've snapped.
- Waiting until you've got no option.
- Identifying with illness rather than strength/wellness.
- Disclosing too soon, when people haven't had a chance to get to know you.

As a Manager or colleague, what can you do to support someone sharing lived experience effectively?

- Show that it is valued – *"I am glad we've got expertise in the team."*
- Feedback, ongoing progress.
- Support all staff around wellbeing and values.
- Not taking control.
- Offer choices.
- Not making a big deal.
- Not pathologising or misinterpreting.
- Not overreacting "People can make assumptions and it can be unhelpful."
- Promote a positive team culture that is inclusive and not discriminatory.

As a colleague, what can you avoid doing to support someone sharing lived experience effectively?

Don't:

- Do an instant mental state examination!
- Overreact
- Not respond at all
- Tread on egg shells
- Made assumptions
- Be fake "two faced"
- Pity "Oh, you poor thing!" -
- Reject the person
- Gossip (no matter how well intentioned).

Conclusion and Recommendations:

These guidelines should not be seen as the definitive solution to address the complex issues of sharing lived experience but rather as contributing to a conversation of how lived experience can be shared in the most effective manner. We would welcome any feedback on this framework. It is also important that this does not take place in isolation and it is important that there is organisational change around supporting the wellbeing of all staff and challenging stigma and discrimination to ensure this framework is supported effectively. The next steps that would recommend to take this forward are:

• To share and disseminate as a discussion document through the management structures and within teams.

• To undertake formal research looking at the value of these guidelines and properly developing some guidance.

• Work with the board, human resources and unions around recognising and supporting this guidance and its implementation

• Work with board, human resources, occupational health and unions on developing 'Wellbeing @ Work' plans and effective strategies to support the well being of all staff.

• Work with the board, human resources and unions around recognising and challenging stigma and discrimination in relation to employees have mental health

• Develop a Recovery Education Centre course and/or training based on sharing lived experience

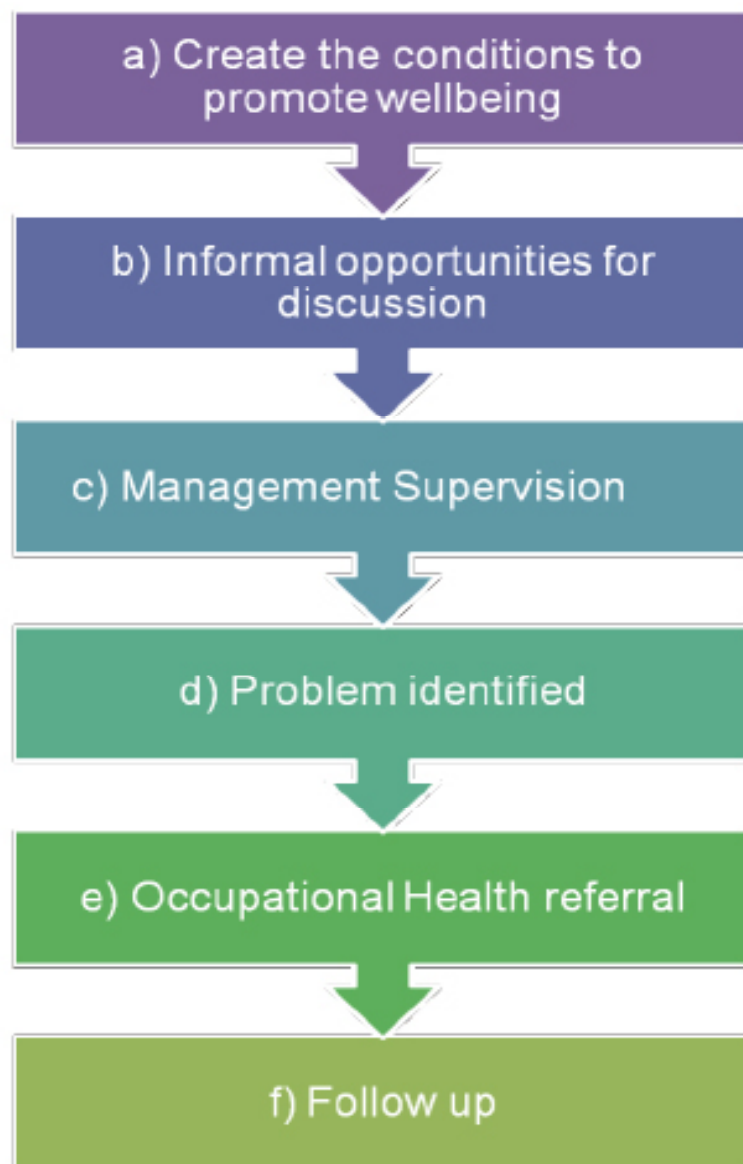• To look to develop guidance around use of social media and sharing lived experience.

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Managing stress at work: Wellbeing @ Work Action Plan

Managing stress at work: Wellbeing@Work Action Plan

This document aims to give an overview of how to effectively support staff to manage stress within the workplace. This document gives a step by step guideline of how best to do this.

a) Create the conditions to promote wellbeing

b) Informal opportunities for discussion

c) Management Supervision

d) Problem identified

e) Occupational Health referral

f) Follow up

(a)
The biggest impact on reducing sickness is "Making Work a Great Place to Be". But you work for the NHS, how can this be? The things we know that improve working environments and promote wellbeing within teams are:
* Positive relationships within teams
* People having clear roles and responsibilities
* People having a control and say over their working life
* A supportive environment
* Acknowledging change can be a difficult process and trying to manage it more effectively
* Setting priorities for people that enable them to effectively manage the demands of their role

These are also the same areas identified for stress risk assessment (under HSE guidance). When these are not present it is more likely for people to experience ill health associated with stress at work. Issues relating to stress are rarely clear cut and are often a mixture of home and work stressors.
As a manager if you are aware of these areas you can try to promote these conditions.

(b)
It is important as managers that we are available and create opportunities for informal discussion with individuals about wellbeing at work and offer encouragement, support and thanks. This also allows emerging issues to be "nipped in the bud."
(c)
In managing the wellbeing of your workforce, management supervision is an excellent opportunity to follow up any informal discussion or create a space for people to discuss how they are coping at work. It is a fine balance between being supportive and rescuing and solving someone else's problems. Your role is not to rescue or solve the person's problems but to support the person and what they need to do within the context of the team.

In order to discover the root of the problem or difficulty, it is important to ask **open questions** (in dealing with difficult situations it can be helpful to have some rehearsed questions or statements) such as, tell me about? How are you? I've noticed that...? Think about asking people about their work life balance.

Once a person has had the opportunity to express how they are experiencing their work it is important that any difficulties are backed up by facts or clear observed. For instance sickness absence and attendance reports are helpful in identifying patterns.

You may want to consider proactively completing a Wellbeing@Work Action Plan which is a supportive tool for staff and their managers to work through a stress risk assessment process in partnership.
(d)
Once a problem is identified we can then look at what actions need to be taken and who can support you. Examples of common problems or stressors are: changing work arrangements; relationship pressures; potential job loss arising from financial pressures; work volume control; change of work base; accommodation changes; changing job requirements; grievance issues raised. If you are struggling for ideas on how to offer someone the most effective support it may be helpful to seek support from your peers and be mentored by someone more experienced. You can also phone HR (443120) or OH (443066) for an informal chat.
(e)
Trigger points are identified in the Health, Wellbeing and Attendance Policy; however you can refer a member of staff at any time if you have concerns. When referring a member of staff please be clear as to why you want OH to see them and include any relevant background information. Ask yourself what questions you need answered and then include them on the referral form (for example: is the person able to undertake all the responsibilities required of them for their job? Is the person able to take part in physical interventions? Would this person benefit from a phased return to work? What are reasonable adjustments to make?)
People are also able to access counselling either through a staff counsellor (former B&P and Dorset HealthCare staff) or RightCore Care (former Dorset Community Health Services) is available to staff
(f)
It is as important as the initial identification of any problem to offer ongoing support and identify whether the person is putting any steps or suggested measures into practice and whether they are working or need to be refined.

Useful forms/reports to use to support someone at work.
* *Wellbeing@work action plan document – draft overleaf.*

[Name]...'s **Wellbeing@work Action Plan**

Date..........................

This could be used to form a stress risk assessment

What is going well, what strengths and resources do you have?

| |
| |

What is the difficulty/problem?

| |
| |

What is the impact on you and on the team and on the service?

| |
| |

What been done already (what's worked and what hasn't)?

| |
| |

Further action (who is going to do what)		By when
What are you going to do?		
What is the Service going to do?		

Comments

| |
| |

Signed:	Manager Signed:
Date:	Date:

This document has been produced by the Dorset Wellbeing and Recovery Partnership.

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