Stories of Personal Recovery: Evaluation of Recovery Devon's 'Peer Reporter' Project

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Abstract

In 2012 Recovery Devon were commissioned by Devon Partnership NHS Trust (DPT) to collect personal narratives of recovery from mental health difficulties. A 'peer reporter' was recruited to collect these narratives, with the aim of capturing people's experiences, particularly when services have been adapted and changed. This evaluation aimed to explore people's experiences of choosing to share their story, and to obtain feedback from staff working within DPT regarding the impact of these narratives on their clinical practice. Interviews with story-tellers revealed three core themes: ''*Warts and all': feeling the fear and finding the courage to share*' (which described the fears faced by people considering sharing their story, as well as their attempts to find the courage to do so and things that helped them along the way); '*Helpful aspects of recovery stories'* (which described ways that sharing stories was helpful for the person, extended help to others and as a driver for change); *'The road ahead'* (which described hints and tips for others considering sharing their story and hopes to contribute in other ways). Data gathered from DPT staff, via an on-line survey and via telephone interviews, indicated that the majority of employees were aware of the stories, and those that were not attributed this to their busy roles. Staff shared that they experienced feelings of joy, empathy and inspiration from reading stories, leading them to reflect on the true purpose of their roles. The stories highlighted the person at the centre of the journey, and validated the importance of meaningful relationships to facilitate recovery. However, respondents also emphasised significant barriers to working in ways that were supportive of recovery, and this was attributed to organisational factors that prioritised targets and paperwork. This seemed to create a disconnect between the desired ways of working and the 'reality' of current practices within the NHS. The findings are discussed in the context of wider organisational systems, highlighting responsibility to work within recovery-focused ways at individual and organisational levels. Implications and recommendations for practice are outlined.

Introduction

The 'peer reporter' recovery stories project and this evaluation have been conducted in partnership with Recovery Devon and Devon Partnership NHS Trust. Recovery Devon aims to promote the philosophy and practice of recovery oriented approaches to support wellbeing. The concept of recovery that has emerged over the past two decades has emphasised the centrality of hope, identity and meaning (Slade, 2009). This has contributed to a move away from the notion of 'clinical' recovery and the 'management' of symptoms. In line with the definition of Anthony (1993), Recovery Devon (2013) describes recovery as:

> "*A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and roles .It is a way of living a satisfying, hopeful and contributing life, even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness."*

An emphasis on personal recovery is also supported by DPT, where 'Putting the notion of personal recovery at the heart of all the Trust says and does' is outlined as one of its key values and guiding principles.

Both Recovery Devon and DPT share a passion for promoting and sharing recovery stories. They believe in the power of personal stories to both aid personal recovery, offer hope to others experiencing similar difficulties, and to increase understanding regarding mental health. Recognition is given to the role of stories in the development and rise of the recovery movement, highlighting the work of early pioneers and leaders in the field (e.g. Deegan, 1988; Coleman, 1999; O'Hagan, 1996).

In 2009 DPT published 'Beyond the Storms – Reflections on Recovery in Devon' (Davidson & Lynn, 2009), a collection of 30 recovery stories. This passion and commitment for recovery stories was realised again more recently when, in 2012, Recovery Devon were commissioned by DPT to collect additional personal narratives of recovery from mental health difficulties. A 'peer reporter' was recruited to collect these narratives, with the aim of capturing people's experiences, particularly when services have been adapted and changed. The hope was that these accounts could illustrate things that had worked well, so that success could be shared and celebrated, offering hope to others moving

through mental health services, as well as to staff working within DPT. Stories were published on the DPT website and via 'Partnership Progress', a DPT bi-monthly staff newsletter, as well as the Recovery Devon website.

Aims and Objectives

The current evaluation aims to explore the experiences of story-tellers in their journey to share their narratives. Research exists about the value of recovery stories within the recovery journey, and into the helpful and hindering aspects within these accounts (e.g. Brown & Kandirikirira, 2007). However, little is known about people's experiences of taking this journey to share their story. A further aim is to explore the extent to which stories of recovery impact in clinical practice and service delivery within DPT. It is hoped that this evaluation will be helpful to people considering sharing their recovery story, staff working within DPT and service managers and commissioners.

Method

The evaluation consisted of 3 strands of investigation:

- Qualitative interviews with story-tellers
- On-line qualitative survey to gather feedback/ responses to stories
- Telephone survey of a sample of staff working within DPT

Qualitative interviews with story-tellers

Story-tellers

Four story-tellers that had shared their story as part of the recovery stories project were interviewed about their experiences: Daisy, John H, Richie and Daisy's support worker. These names are the ones that they had used to share their personal stories. Each of their stories can be seen in Appendix 1. They were recruited via the peer reporter, who informed story-tellers about the evaluation via an information sheet (Appendix 2.1). They were asked to contact the researcher directly and/or gave consent to be contacted. Prior to sharing their story all individuals were asked to read and sign a consent form (Appendix 2.2).

Procedure & Analysis
Interviews were conducted face-to-face at locations specified by the story-tellers. Interviews lasted approximately 60 minutes, and a semi-structured interview schedule was used to guide each interview (Appendix 3.1). Interviews were recorded, transcribed and analysed using thematic analysis.

On-line survey

Participants
Members of staff employed by DPT were invited to offer feedback about their experiences of reading published recovery stories. At the time of this evaluation three of the stories (Daisy's, her support workers' and Richie's) had featured in 2 issues of 'Partnership Progress'. The remaining stories featured on the trust website and on the Recovery Devon website.

Procedure and Analysis
Participants were invited to participate via a Survey Monkey Link that was placed at the end of each story. The questions that featured within the survey can be seen in Appendix 3.2. Responses were summarised to identify common themes.

Telephone survey

Participants
Services across DPT were contacted and a sample (opportunity sample) of employees were invited to participate in a telephone discussion to obtain an estimate of the proportion of staff that had seen and/ or read the recovery stories, and to invite them to offer their feedback and reflections.

Services were sampled using the DPT service directory, and participants worked across a range of services (including adult mental health, older people and forensic services) and across localities.

Procedure and Analysis
Participants were contacted via telephone and asked to share:

- Whether they had seen/ read the recovery stories and their thoughts regarding dissemination
- Their thoughts and reflections and any impact of the stories on their clinical practice

Responses were summarises to identify common themes.

Results

1. Interviews with story-tellers

Thematic analysis revealed three core themes: 'warts and all: feeling the fear and finding the courage to share', 'Helpful aspects of recovery stories' and 'the road ahead'. Each core category contained sub-categories, which are outlined and elaborated below.

- 'Warts and all': feeling the fear and finding the courage to share
    - Feeling the fear
    - Finding the courage and becoming bigger than the fear
    - Some helpful aids
- Helpful aspects of recovery stories
    - Helpful for me
        - A cathartic process
        - Getting perspective
        - A way to let others in
        - Feeling liberated to say difficult things
        - To celebrate achievements
        - A leap forward in my recovery
    - Extending help to others
        - Offering hope
        - You're not alone: facilitating connection
        - Sharing experiences and things that helped
    - A driver for change
        - Seeing the person, not the 'illness'
        - Raising awareness and breaking down the stigma
        - Influencing clinical practice
        - Celebrating and promoting innovative ways of working
- The road ahead

- Hints and tips for others in the same boat
- Beyond recovery stories

1. 'Warts and All': Feeling the fear and finding the courage to share

Feeling the fear

An initial sense of ambivalence was described by some story-tellers about whether or not to share their story. One person described how they initially turned down the opportunity to share their story, and changed their mind several months later when the opportunity arose again. A sense of fear and potential for embarrassment was reported, as well as a desire to fit in with the 'normal' world.

> *A part of me wants me to write this and a part of me doesn't because I'm trying to become a part of the big bad world again, part of society again. It's a horrible word to use but I'm just trying to become normal again...when you put yourself out there and share your recovery story that's the downside I suppose, that you leave yourself open I suppose (John)*
>
> *I was a bit apprehensive at first; I was a bit scared of giving my story. It was quite an ill and bad phase really, quite a dark phase I went through... It was just the embarrassment of the story, I didn't want people to read that and get the wrong impression. I was worried what people might think even though it was anonymous (Richie)*
>
> *It's like writing a biography; you never know what people are going to think of you if you tell your story warts and all...Telling someone new about your story is always a scary part (Richie)*

A sense of fear about sharing the 'dark' reality of one's experience was also reported, as well as a desire to soften this so as not to put people off reading them.

> *(the fear) that it might be a bit too dark, a bit too painful so maybe keep those stories to a minimum, just a scattering of the darkest, most painful stories because it will put people off (Richie)*

Finding the courage and becoming bigger than the fear

A process of finding courage and choosing to be 'bigger' than the fear was described by story-tellers.

> *The desire to want to break down that stigma is bigger. What I'm saying is that there's a part of me that wants to hide it but you have to be bigger than that. If anything is ever going to change then people have to be bigger than that (John)*

A process of accepting one's own experience and journey was also reported, which gave rise to a feeling of courage to share their story.

> *I just found the courage and just thought I would put it down anonymously; it's part of the story, it's all part of the journey. It was a dark time and I was very ill, it was like being in hell which is a dark place to be mentally. It was my own personal hell. I wondered how people might react to it (Richie)*
>
> *It's like any big thing, sometimes you just have to go for it (Richie)*

The courage to help others, as well as to do something good for oneself, supported a move towards sharing their story.

> *It just came up inside me like a rising tide (courage), like a boiling point where I just had to tell people and get it off my chest. I thought it would be good for me and it would be good for other people, it might help other people, that's where the courage came from (Richie)*

<u>*Some helpful aids*</u>

People shared things that had supported them to take the step towards sharing their story. These factors included anonymity and consideration of timing as to when they choose to share their story.

Anonymity

Two people shared that it was easier to write their story knowing that their identity would remain anonymous.

> *It was just easier to write without my name being attached so that everyone would know it was me (Daisy)*

Timing

A sense of needing to feel further along the recovery journey, more robust and less vulnerable was highlighted as important.

> *I think it's because I'm not part of service any more. I think it would have felt harder if I was. I think it's because it's still present (Daisy)*
>
> *I think the time when you were in services you were really vulnerable and I think when you share your story you're exposing that vulnerability so there's something very vulnerable about sharing bad experiences so it's probably easier when you're not in services and you're feeling strong and you're getting on with your life, you can say 'yes that happened but that was then, and I'm here now' whereas when you're*

actually receiving a service and you expose that vulnerability it just adds to that feeling (Daisy's support worker)

It's got to be some time after the recovery, not straight away. I don't think anybody would do it straight away unless they were feeling really brave and quite open and talkative about it. For me it had to be some time after it, a few years later and then the moment just took me and that was it (Richie)

Feelings of acceptance and understanding

An ability to feel a sense of acceptance and understanding appeared to open up opportunities for people to embrace a feeling of vulnerability and share their story. This seemed evident in the relationship between Daisy and her support worker, where a message of hope and acceptance existed. The non-judgemental nature of the peer-reporter was also sighted as important.

His manner and the way that he accepted me for who I was, he was friendly and accepting and didn't judge me at all, and was really understanding and that made it easier (Richie)

2. Helpful aspects of recovery stories

Story-tellers shared things that had been helpful about telling their recovery story. These helpful aspects were further categorised into 3 sub-themes; 'helpful for me', 'extending help to others' and 'a driver for change'.

Helpful for me

People described the many ways that recovery stories had been helpful for themselves and their recovery journey.

A cathartic process

It's a cathartic thing, to tell your story. It can be helpful (John)

Getting perspective

Well it sort of gets you to a place where you can assess where you're at, you know, so for me personally I'm doing well, but I'm not quite there yet (John)

It had been going around my head for ages, my own story. It had occurred to me beforehand that my drinking hadn't helped but it had more impact in me as I started to write it down...it gave me a different perspective. (Richie)

A way to let others in

My mum thought it was good because then she could realise how far I'd come. My boyfriend has also read it and then he kind of realised what had happened to me because he didn't really know about it, I'd never actually told him (Daisy)

I think it's been a good thing, they understand it more (Daisy)

Feeling liberated to say difficult things

It was a lot easier because if you have to tell them then you have to think of a way to put it but if it's written down then they can just read it and it's up to them how they take it (Daisy)

How do you say thank you to somebody for trusting you verbally? But I could write it. Although I work alongside and work on the relationship, the relationship is never equal because I am the worker and I'm always conscious of that so in a way you hold back a little bit within the professional boundaries so to be able to write alongside I could say that I'm proud of you. I wouldn't have said to you verbally I don't think, but I could write it and actually to be able to say thank you for trusting me it sort of equalised the relationship (Daisy's support worker)

To celebrate achievements

I wanted to get across the distance she'd come from our first meeting to where she is now and how difficult that journey had been for her. Sometimes when you are on the outside looking in, or the person alongside them, you can see how hard it is. When the person is living it they are just living it and experiencing it and it becomes day to day and just surviving so I just wanted to remind you where you'd started and how hard that journey was (Daisy's support worker)

It made me happy. I don't know, I just felt proud of myself in a way (Daisy)

A leap forward in my recovery

I feel a bit braver now, a bit more robust. I tend to be a bit pliable and a bit too quiet and a 'yes man' to everything. Now I feel a lot braver and stronger because I've done something brave in sharing my story. It's a leap forward for me, a big step (Richie)

Extending help to others

An ability to help others was also described as a key motivating factor, as well as a hope for sharing their story.

Offering hope

> *I felt I'd turned a corner at the end of it and that it might help other people and inspire them (Richie)*

> *I wanted to capture it (the hope) because that's the bit that will inspire others. Keep the happy part, like in a film, like a nice happy ending because that's what it is. It's no good writing it and saying that I didn't get better and nobody helped and I'm still in a shit place. That would be unhelpful (Richie)*

You're not alone: Facilitating connection

> *They help others. It helped me reading other people's stories and it takes your mind of yourself when you see that someone else has a problem, that you're not the only one with the problem so it stops you being selfish and thinking that you're the only one and that no one understands (Richie)*

> *I always find it interesting to hear someone's story, whatever the story is, when you can empathise with a story, because I've had mental health problems being able to empathise with someone's story and being able to read someone else's story is really good (John)*

Sharing experience & things that helped

> *Hopefully they can empathise with a lot of the psychosis and also another key thing that I do is to find a focus. It's not a new theory but it's something that I really wanted to highlight as something that really helped me (John)*

A driver for change

A desire to facilitate positive changes was also cited as an important factor. This included changes within mental health services and also within society as a whole, and the ways that people come to understand mental health and well-being.

Seeing the person, not the 'illness'

> *I think when somebody shares their story, and I found this with the book 'beyond the storms', when people share their story, you see the person not the illness; you see the person and their journey. Stories are a really powerful way to say 'hear me, this is my experience (Daisy's support worker)*

Raising awareness and breaking down the stigma

> *I think it's for people that have had mental health problems, but also for people that haven't by raising the awareness of mental health. It helps those people that maybe haven't had mental health problems yet but may do in the future. The big problem with mental health is that there's a stigma attached to it so it's always good to try and break that stigma down a bit (John)*

Influencing clinical practice

> *It felt natural to talk about medication decreases; I thought it was the perfect vehicle for advocating for that because it's a real bugbear of mine as it was something that happened to me (John)*

> *That it makes them (staff) a bit more sympathetic and a bit easier on people, like people who go to the ward, that it shows the patients in a different light so that they're not so tough on them, a bit more sympathetic with them. (Richie)*

Celebrating and promoting innovative ways of working

> *To free people up that there is an alternative way, to remind them that it is about fun and compassion and engagement and also it sums up the work that a support worker does. There's only a few of us within the trust and it sums up the work that we do (Daisy's support worker)*

> *I think everybody that comes into the nursing profession they do so because they care, ultimately they care, and then what happens is they rely on medication and quite often get stuck. I often say a bit of sunshine is worth a week's anti-depressants because of just the vitamins in itself, and the sea air, so if it inspires people to be more alternative, you can do a lot even if it's just within an hour.*

However there was also recognition that the capacity of other teams/ services to work in these ways may be limited by organisational factors.

> *My work is mainly around engagement and a lot of other people won't get that because we get a lot more time to spend with people. It can be a 3-year journey if that person wishes to engage whereas the capacity of other teams, they don't have the capacity to do a lot of the work that we do. I was quite conscious in telling my story that some people might think that it was a privilege to have that time, to go out and give that person that time and that we'd all like that time.*

A 'ripple effect' was reported as a result of the recovery story.

> *What it's done is in a way freed the team, they're working in more creative ways. I think people just thought this is what I do, it works and so we are going to have a bit of that, it's sort of giving them permission to get alongside the person and get a therapeutic relationship going (Daisy's support worker)*

3. The road-ahead

Story-tellers shared their hopes for the future and their advice for others who may consider sharing their recovery stories.

Hints and Tips for others in the same boat

Story-tellers were optimistic about recovery stories and felt that it was something that should be encouraged and supported, but in a thoughtful and considered way.

> *It's valuable and I think they should be encouraged to do it (John)*
>
> *I would say go for it but carefully, don't blame anybody too much because that takes the emphasis off your story and puts the blame, it fills it with anger towards other people and takes the emphasis off the recovery part (Richie)*
>
> *However dark your story is just publish it, get it in there even if it has to be anonymous (Richie)*

Beyond recovery stories

A desire to write and contribute beyond stories of recovery was also emphasised by one person.

> *I would like to write articles for Recovery Devon again, but maybe not recovery stories. I would like to write my opinions on mental health. I have a lot of opinions and think they would be useful for me to write about (John)*

2. On-line survey

Six members of staff responded to the on-line survey (see Appendix 3.2 for a copy of the questions). The responses were received during the period that the stories written by Daisy and her support worker were published within 'Partnership progress' and the responses appear to be in relation to these stories. Respondents came from a range of professions (manager, recovery-co-ordinator, approved mental health professional, two support workers, clinical psychologist). The responses can be seen in full in Appendix 4.1. A summary of the key themes are outlined below:

Clinical Implications

Respondents talked about ways that the stories had left them with feelings of joy, empathy and inspiration, supporting them to reflect on ways that they may have become 'hardened' to such stories and as a reminder that there is always a person at the centre of their clinical work. The stories also

seemed to validate the importance of being with the person, rather than prioritising administrative tasks. Reflections on the ways that conversations were conducted was also noted, and the extent to which this may or may not be conducive to open communication and the formation of therapeutic relationships. Feelings of encouragement were also reported, giving rise to feelings of hope that 'success' was possible.

Obstacles to implementing positive change

Respondents outlined a number of obstacles to working in ways that were supportive of recovery, limiting the extent to which meaningful relationships could be realised. These were primarily focused on organisation factors and 'bureaucracy' within the NHS. Office work and time spent using computer systems were highlighted, as well as a focus on targets within the NHS, which was viewed as a barrier to more meaningful work. Current service provision was described as only allowing for very limited support time, with limited consistency, impacting negatively on the opportunities to build meaningful relationships. Prescriptive models of intervention and a growing distance between the 'frontline' and the new reality of clinical roles were described. This 'reality' appeared to make it difficult to read examples of recovery stories, which were described as a 'fairy tale' by one respondent. This appears to echo the disconnect that seems to exist between ways that people would like to work, and the opportunities to do so within current organisational systems.

Facilitative factors

Respondents were invited to share factors that would support them to work in recovery-focused ways. A need for a new culture was described by nearly all participants – one that prioritised meaningful, therapeutic relationships rather than paperwork, and offered opportunities to work with people for extended periods of time when needed. A desire for the freedom to work in ways that support recovery was described, rather than working towards targets that were not conducive or indicative of lasting positive change. Additional administrative support was described as one way to free up time that could be spent doing 'meaningful' clinical work.

3. Telephone survey

32 respondents participated in the telephone survey, which was conducted during the month of July 2013. Respondents represented a range of professionals working within DPT (Support workers, mental health nurses, psychologist and service managers). They were invited to share whether or not they had seen the recovery stories that had been published, and to offer any thoughts and reflections that they had.

Out of these 32 respondents 20 (62.5%) were aware of the stories that had been published, but 5 had not had the time to read them due to a lack of time availability attributed to the busy nature of their roles. Twelve (37.5%) respondents were not aware of the recovery stories project, and had not seen the published stories. A summary of the feedback received is outlined below:

Summary of feedback from those that had seen the stories

Dissemination/Access

- Partnership progress is delivered to offices so is accessible and easy to read over lunch

Reflections regarding clinical practice

- Stories highlighted a need for a focus on recovery
- Stories highlighted a need to celebrate examples of good practice
- It was positive to hear about successes
- Stories reinforced clinical practice and supported professionals to re-consider the priorities within their roles
- Stories supported them to see the person.
- Two participants reported that the stories were useful in supporting them to think about ways that they could implement recovery-focused practice within their clinical contexts
- Some described recommending recovery stories to those that they were working with to support their recovery

- There were often conflicting demands for professionals and many described increased pressured to do paperwork and spend a lot of time on the computer, which takes away from spending time with people
- In some cases the story did not resonate as the perceptions regarding time availability were viewed as different - 'we don't have that sort of time'

Suggestions for the future

- To publish accounts in a book like 'beyond the storms' – participants reported that it was easier to read accounts in this format and also made it easier to make it accessible to people using services who did not have access to the intranet/ internet.
- To disseminate stories in video format using a narrator
- To have a 'recovery newsletter', although it was acknowledged that this may lead to similar difficulties with people having the capacity to read it.

Summary of feedback from those that had not seen the stories

- All participants reported that they had probably not seen the stories due to the demands of their roles
- There were few suggestions about alternative ways to disseminate the stories as most reported that they had good access to resources (e.g. partnership progress delivered to offices/ given with payslip etc) but that the biggest obstacle was finding time to read it.

Discussion & Recommendations

Summary of key findings

A number of themes emerged from the accounts of those that had chosen to share their recovery stories. These were ''Warts and all': feeling the fear and finding the courage to share', 'helpful aspects of recovery stories' and 'the road ahead'. Story-tellers described a sense of fear and

vulnerability about sharing their stories, which seemed to be related to fears about how others would react to these accounts and a desire to feel 'normal'. A process of needing to find the courage was described, which was facilitated by a communication of acceptance and non-judgement by others. Timing and an ability to retain anonymous seemed to be important factors in supporting people to share their stories. Helpful aspects of recovery stories were also described, which outlined ways that the stories could be helpful for the person, for others in a similar position, as well as the ways that they could be drivers to support positive change. Story-tellers also shared advice with others who may want to share their story, and one person highlighted his desire to share his experience is ways other than via recovery stories, such as by offering his opinions about mental health services.

Data from the on-line and telephone survey revealed some common themes. Respondents shared that they experienced feelings of joy, empathy and inspiration from reading stories, leading them to reflect on the true purpose of their roles. The stories highlighted the person at the centre of the journey, and validated the importance of meaningful relationships to facilitate recovery. However, respondents also emphasised significant barriers to working in ways that were supportive of recovery, and this was attributed to organisational factors that prioritised targets and paperwork. This seemed to create a disconnect between the desired ways of working and the 'reality' of current practices within the NHS.

Implications for practice

Findings suggest a number of key implications for people using mental health service and professionals working within them. People that shared their story highlighted a range of helpful factors, and suggested that the process of sharing their story supported them to take further steps in their recovery journey. They were encouraging of others sharing their stories, and their accounts and advice may be useful tools for others who are contemplating sharing their story, or who may find a sense of comfort and connection in their narratives.

Story-tellers also highlighted a sense of fear and ambivalence that can exist when thinking about sharing aspects of their experience, and this highlights the importance of considering the significance

of this and taking a thoughtful and considered approach in these decisions. A process of becoming vulnerable was described when sharing stories, which felt like an inevitable process of exposing parts of the self that had often been associated with pain and darkness. A feeling of robustness was reported as both a pre-cursor and consequence of sharing stories, and it feels important to consider the extent to which a person has this sense of robustness to share their story at a particular time. These considerations would be valuable for people considering sharing their stories and those within their support network.

Anonymity, timing and support from somebody who is accepting and non-judgemental were highlighted as factors that enabled people to find the courage to manage this vulnerability. This highlights the importance of conveying these qualities in all aspects of our work, opening up opportunities for people to reveal their whole selves, and to be greeted with a sense of acceptance and understanding. If a story is told and not understood, then a part of oneself has reached out into nothingness (Leibrich, 1999).

A desire to offer a sense of hope to others in a similar boat was outlined as one of the helpful aspects of sharing stories. Emphasis was placed on sharing positive aspects of the journey, and there seemed to be a sense of discomfort with sharing darker, more difficult experiences. This is consistent with the aims of the recovery stories project, which set out to collect stories where examples of good practice could be celebrated. This contributed to readers feeling inspired and reflective about their own roles, which is a positive outcome. However, it is also important to give space for more difficult accounts to be heard and accepted, and for those wishing to share their stories to feel that they can write in an uncensored and honest way. Story-tellers also talked about using their stories as vehicles to drive positive change, indicating that some aspects of current service delivery remain unhelpful. Future projects may look to open up opportunities for these accounts to be heard, as learning can take place from feedback that outlines both helpful and unhelpful practice.

One of the story-tellers also shared that he would like to make further contributions by writing his opinions on mental health and clinical practice, through the lens of his experiences. This raises an

important point in making sure that people with experiences of mental health difficulties are able to make contributions in a variety of ways, and that these are not confined to stories of recovery and instead encompass a range of narratives.

Feedback from staff working within DPT highlighted the positive impact of reading recovery stories, leading them to reflect on ways they may have become 'hardened' to these accounts and reminding them that there was a person at the heart of every journey, and validating the importance of therapeutic relationships. This indicated that there was a tendency for this to be lost when working in busy and target-driven services, and highlights the importance of considering ways that these qualities can be maintained. Over-identifying with professional roles and forgetting the people we are was highlighted by Deegan (1990) as the main danger when clinicians establish their professional identities, where "our minds can become severed from our hearts such that our human hearts no longer guide, inform or shape our work with people". This seemed to be further perpetuated by organisational systems that were perceived to prioritise targets and paperwork.

Consideration about ways that professionals working within DPT can be 're-connected' with their own hearts, and with the people behind the mental health difficulty would be helpful. Recovery stories and accounts by people with lived experience are currently utilised within DPT inductions for new staff and it may be helpful to consider implementing opportunities for this to happen more consistently throughout people's careers. One respondent suggested a recovery-focused / recovery stories newsletter or perhaps annual meetings where recovery stories could be shared. It would be helpful for team managers to consider how this could be implemented more locally within their teams.

A disconnect seemed to exist between people's desired frontline roles and expectations from current organisational systems. This raises important issues with regard to how these differences are reconciled and whose needs are prioritised – the needs of the service or the needs of the person being supported, and whether these two are in fact mutually exclusive. Some respondents expressed a desire to work in ways that offered autonomy within their work, and that prioritised meaningful relationships. Research suggests that this approach is more conducive to recovery, where people using

mental health services shared that they valued professionals that conveyed hope, shared power, were available when needed and were willing to stretch the boundaries of the 'professional role'. In this way recovery-oriented professionals, similarly to Daisy's support worker, were described at those who had the courage to work collaboratively with the person, and the ability to shape services to the needs and preferences of the person (Borg & Kristiansen, 2004; Tooper et al., 2006). Working beyond professional roles, typically defined by the organisation, supported people to feel worthy of having somebody 'go the extra mile' for them, which impacted positively upon their recovery journey (Tooper et al., 2006). In many ways this becomes in an invitation for professionals to take a journey, like the story-tellers here, to find the courage to embrace their own vulnerability and reconnect with their authentic selves. Brown (2012) describes vulnerability as a strength and measure of courage; 'the birthplace of innovation, creativity and change', which may support professionals to work beyond their professional roles and titles, in ways that are supportive of recovery.

However, in a process that mirrors that of story-tellers, a feeling of robustness may need to exist before such vulnerabilities can be embraced. This may be challenging at a time when clinicians are working in services undergoing significant change, and where uncertainties exist about individual roles. However, small steps towards working in recovery-focused ways may lead to the ripple effects described by Daisy's support worker, so that a culture of person-centred and recovery-focused practice begins to grow.

As well as this bottom-up approach, changes need to happen at all levels of an organisation. A backdrop of national press stories dominated by reports of failures within health and social care systems (e.g. Francis, 2010; Care Quality Commission, 2011) have contributed to an emphasis on re-establishing compassion within NHS services. The NHS constitution, in response to Francis (2010), reiterated that *"the NHS belongs to the people… It touches our lives at times of basic human need, when care and compassion are what matter most"* (Department of Health, 2013a). Story-tellers described the significance of positive relationships, and of creative ways of working that move beyond traditional professional roles. A desire to work in these ways was echoed by professionals working within DPT, and organisational culture was described as the biggest obstacle. As well as

individual responsibility of frontline staff this process of change needs to happen from a top-down perspective, across management structures, so that services can be commissioned and delivered on the basis of what people report to be helpful. DPT staff reported that service delivery is becoming more prescriptive and target-driven. This is consistent with changes within the NHS and the notions of 'any qualified provider' introduced with the Health and Social Care Act (Department of Health, 2012) and the introduction of 'payment by results' (Department of Health, 2013b). Despite these challenges, opportunities may still exist to work in person-centred, creative and innovative ways, and these need to be embraced wherever possible. A joint opportunity for Recovery Devon and DPT to explore these challenges, and consider ways that recovery can be further promoted within DPT services, would be helpful as it may support professionals and services to reconcile some of these dilemmas.

Dissemination

The majority of staff working within DPT had read and seen the accounts shared within the recovery stories project, indicating that these were disseminated successfully. Many reported that their offices received paper copies of 'Partnership Progresses' or that these were distributed with their monthly payslips. Staff that had not seen the accounts (37.5%) attributed this to their busy roles and lack of time to read them.

Some suggestions for alternative ways to disseminate stories were given, including the publication of a book. This would also provide more equitable access as current channels of dissemination are not accessible to people using mental health services that do not have internet access.

Critical Reflections and Limitations

The current evaluation has provided a 'snapshot' of experiences and opinions. The small sample sizes do not lend themselves to generalisation across clinical contexts or beyond the participants that offered their feedback within this evaluation. However, useful learning and development can still be

taken from these accounts, and there is an ethical responsibility to listen to those that have taken the time to share their views.

Future evaluations may wish to consider ways that recovery narratives influence practice and service delivery in more tangible ways, or via retrospective accounts of changes that local services have made on the basis of the learning that has taken place from these stories. Future research around people's journeys to share their recovery story may also further increase our understanding in this area and support others who are considering telling their stories.

Summary of key recommendations

- To continue to publish recovery narratives from people with experiences of mental health difficulties and staff working within DPT as they served to remind people that there was a person behind each recovery journey, and validated the importance of therapeutic relationships.
- To continue to gather stories using a 'peer reporter', which story-tellers described as helpful, offering a feeling of acceptance and understanding.
- Making use of the experiences of story-tellers within this evaluation as a tool to support others considering sharing their story so that their decisions can be informed by others who have taken these steps
- To support opportunities for honest and uncensored recovery narratives, and for people to be able to share unhelpful experiences as well as helpful ones so that these parts do not become silenced. To enable opportunities for people to contribute in other ways (e.g. opinion piece)
- Consideration to how recovery narratives can be used to support recovery-oriented practice more consistently and frequently within DPT e.g. induction, annual meetings, recovery newsletters. Service managers may also wish to think about this more locally within their teams.

- Consideration of how recovery narratives and feedback from staff about the disconnect between their proffered and actual roles can be used by DPT as an organisation to inform service-delivery and commissioning so that these are informed by accounts of what people have found helpful. A joint opportunity for Recovery Devon and DPT management to meet and explore these findings and the challenges raised, as well as ways that these can be reconciled, would be beneficial.
- To publish a paper version of recovery stories so that there is equitable access to people using mental health services that do not have internet access.
- To continue current means of dissemination as they have been accessible to the majority of DPT staff.

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Appendices

1. Recovery stories
    1.1. Daisy's story
    1.2. Daisy's support worker's story
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2. Story-teller documents
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1.1. Daisy's story

The first time I hurt myself I remember it feeling like all the painful feelings inside of me being let out; as it by tearing open my skin they were being set free. I had stopped wanting to be near anyone else because I felt that I hurt them and they hurt me so what was the point, I'd be safer on my own even if I did cause myself physical pain, it was the easiest for of pain for me to handle.

At 13 I had reached a point where I was barely communicating with people anymore, just staying myself all the time; but this gave too much time to thinking, thinking about every little tiny thing I had ever done wrong, no matter how insignificant. Guilt and self hatred swallowed me up; I became convinced that everyone around me hated me too and they were watching me at all times finding even more reasons to hate me. I tried to kill myself twice within a week; both times stopping myself only because of the thought of my younger brother finding my corpse and not wanting that to make him feel like how I did, he was too important.

About two weeks later I started counselling; I started faking getting better because that way no one asked questions I saw as completely pointless and patronising. I kept this up for months but it didn't last.

Just less than a year later I started seeing a demon; she followed me most places I went but no one else seemed to see her. I was terrified and alone. My older brother was one of the first people to ask me what was wrong, he was one of the only people ever to ask me this in a way that felt to me at all genuine; so I told him everything and he listened to me, and without judgement he tried to help me by telling me a way to keep the demon away from me; that night he kept me safe from trying to kill myself again. I was only 14; and this is when mental health services started taking over my life.

I saw three different workers before seeing my first psychiatrist; soon after my 15th birthday. Within three months of this first psychiatrist appointment I had seen two more and been put on antipsychotic medication.

Three months after this I was admitted to a psychiatric unit. I was far from my friends and family; I felt completely alone. They kept switching my medications until they found a concoction they felt worked okay to stabilise my condition and within three months I was back home in full time education again. I took my GCSEs just like all the other kids in my school.

My condition remained stable for a while; I managed get through the summer rather optimistically thinking that my life was going to get better and that I would live what I saw as a normal life.

When I got my exam results I relapsed. I knew then I was never going to be like anybody else and I hated this prospect so I didn't want to live. The demon was screaming at me constantly trying to get me to kill myself. I was at a point where the vast majority of my thoughts involved how I could get away from everyone and end my life. After just over a month of not being able to be left alone I was readmitted to hospital and put on stronger medications and given more intensive therapies.

Over four months later I was discharged with at least some hope of having a future having been regained. I began attending some short courses that my mum helped to organise so that I wasn't just at home all the time dwelling on my thoughts. This also helped me to think that I was good at some things and that I wasn't completely useless.

I then met my support worker. She helped to arrange going to music groups and learning the guitar. I found this really helped; concentrating on playing music helped to keep relax, find happiness, and feel that I was good it. I found throughout my recovery that music had a way of consoling and understanding on a deeper level than just simple conversations with people; it's like it can reach into you and help you to find the forgotten pieces of yourself to help make you more whole again.

To get to these groups she encouraged me to take the bus. This was difficult for me to begin with because I struggled a lot communicating especially with strangers and being around people who I didn't know made me paranoid; but after I had done it once with my support worker I felt empowered

to do it by myself and by repeating this I became more confident in being able to get the bus on my own. This was a big step in my recovery as this allowed me to be able to access various services and facilities away from where I live.

I applied to go to college to retake my GCSEs and started going soon after I became 17. During this academic year I got stronger and made some friends on the course and I managed to get several more GCSE qualifications at the end of this course.

During the summer I came off my antipsychotic medication before starting a new college course and did some work experience; my support worker helped me to set up the placement and get me used to being a worker in a working environment.

I made friends quickly on my new course and became more confident in myself. I started to like not caring about being different to other people and just be who I am. Only a few people found out about my mental health history but the ones who did find out were all very supportive of me.

I am no longer a service user of mental health services but I have the support of my family and friends and I have found effective ways to stay happy and express my emotions safely.

1.2. Daisy's support worker's story

Dear Daisy

You clothed yourself in black and hid behind your hair- a wall of defence against the army of professionals who invaded your life at the tender age of 12. They went as fast as they came, reinforcing your feelings of abandonment.

Eight psychiatrists and five care coordinators later, Age 18: I somehow had to penetrate your wall of defence, reach the girl full of despair, fear and loneliness. I was given a mission to replace despair with HOPE, fear with TRUST, loneliness with CONNECTION to the world.

With perseverance I called on every resource to get alongside you. I worked with the girl and not the diagnosis. I introduced my network of peers, friends and colleagues, they introduced acceptance, shared experience, music and meaningful occupation. They enabled you to emerge and transform. You gave me the privilege of accompanying you on your journey. Now at the age of 19, you are a beautiful, confident young woman, I'm PROUD of you!

A few of my special moments:

- The shine in your eyes when we gave you a bunch of daffodils to celebrate you catching the bus alone.
- When you told me you had travelled independently to meet a friend
- Hearing your laughter and moans as we beached our boat
- A comfortable silence, shared understanding with a peer
- Communication and connection through music, you mastering a tune on the guitar.
- The girl who sat exams and received distinctions

I feel blessed to work for STEP. I have a supportive manager who enables me to do my job.

Daisy - Thank you for giving me your TRUST x

1.3. Richie's story

Mum and I get on well now, but childhood was difficult for me and my elder brother. Dad was around but a lot of time away in the army. By the time I was 15 Mum had overdosed twice, their divorce had come through and ten years later I was smoking and drinking heavily, five pints of Carling daily.

It came to a head in 2006. I had an interview for a permanent job with Marks and Spencer and loved the job but there were till errors and I ran up £1000 on a credit card on drink alone. For a while, I stopped living at all. But I was sick of being a slave to the drink and cigarettes and decided at the New Year to make a new start. When I came out in a shirt and tie my girlfriend really did a double take.

I told EB for the first time and the result was anger with my Mum so that I could now stand my ground with her. I gave up my girlfriend as I came off the drink and the voices began:

'When are you going to come and see your kids?' I slipped into psychosis, frightened that they wouldn't stop and waited outside school to see if the kids were real and there. Mum called the police-I was sectioned.

What followed has been a long, hard road for me in my battle with the voices
It has included hospital assessments, five months in the Cedars where I began to feel safe and secure (even if I was feeling like I was in hell and my brother had cut himself off from me) and a trust in EB in the Russell Clinic who helped to spell out reality for me and to get to the other side. It took one-and-a-half years. After a spell in the community in a supportive house with good friends and six months with Mum (she was now a different person, I was a different person and we could now respect each other), Liz helped me to come here.

Several things have helped me to get to this point. My own wish to get through; Liz; C. from the STEP Team and EB from the Russell Clinic (who was sterner with the voices and helped me to answer back, shaking me out of myself)

I have made friends here, I see Mum and my family more, I go out with staff, Liz sees me every month and I am taking my time. Slowly but surely I am recovering.

1.4. John Hankins's story

I am an aspiring writer and poet and have just released my first publication, 'The Psychotic Voice Hearer', an insight into psychosis from the perspective of someone who has suffered from the condition. It also includes some of my poetry, of which I am very proud. During the five years it has taken to get my work out there, I have struggled through two major episodes of psychosis, held down employment whilst in recovery and combated the notoriously detrimental side-effects of anti-psychotic medication. I have also recovered from a serious addiction to cannabis, which gave me psychosis and affected my ability to be productive.

I have now been in recovery for over two years and have found the catalyst for recovery to be to 'find a focus'. In my case this has meant learning new culinary techniques and broadening my repertoire of dishes. I also started volunteering to engage the brain, keeping it alert and helping to reduce psychotic symptoms and aiding my personal journey of recovery. I would advocate that service users try to negotiate medication decreases or a change to a slightly weaker medication rather than halting medication completely, when they feel ready to do so.

Although some psychiatrists may say this is risky, my personal experience has been that the resulting improvement in areas of life such as fitness, hobbies and work will have a positive impact and that symptoms are likely to decrease in severity as a result.

If anyone would like to order a copy of 'The Psychotic Voice Hearer', my email address is johnhankins_28@hotmail.com

2.1. Information sheet

Recovery Stories Project Evaluation: Information Sheet for Story-Tellers

Thank you for taking the time to read this information sheet. This has been sent to you because you recently shared your story as part of the Recovery Stories project with Recovery Devon. Devon Partnership Trust (DPT), who commissioned this project, would like to evaluate it. This will enable the Trust to learn about things that have gone well and things that could be improved.

As part of this evaluation, I would be keen to hear about your experience of sharing your story. This may include things like your motivations for sharing your story, what this was like for you, as well as your hopes for others that may read your story. It is hoped that, with your feedback, we can develop a better understanding about the experiences and processes involved in sharing recovery stories.

You will not be under any pressure to discuss anything that you do not wish to talk about. Your participation in this evaluation is entirely voluntary. You can change your mind about participating at any time. With your consent, I would also like to record our conversation so that the details can be captured most accurately. This will also enable me to analyze our conversation using thematic analysis. This involves identifying key themes that emerge during our conversation.

Payment for participation

If you choose to take part, the time and location of the interview will be discussed and agreed with you. You will also be paid £7 for your time, plus any travel costs at 44p/ mile. This reflects the DPT rate for participation in service evaluation.

Confidentiality and anonymity

All information collected during the course of this evaluation will be kept strictly confidential. Personally identifiable information will be removed and would not be included without your prior permission.

What happens when the evaluation is finished

Once the evaluation is complete a report will be produced that outlines the key themes that emerged from conversations with story-tellers. If you would like to be involved during the formation of themes, or would like a copy of the final report, then please let me know.

What to do if you wish to take part in the evaluation or want more information

If you think that you might want to take part, or you have any questions then please feel free to call me on 01392 674 100 or email me at ines.obradovic@nhs.net. Please note that I only work Mondays and Tuesdays.

Kind regards

Ines Obradovic
Trainee Clinical Psychologist

2. 2. Consent forms

Devon Partnership NHS
NHS Trust

Recovery Stories Project Evaluation: Participant consent form

(Please tick)

1. I have read and understood the information sheet. ☐

2. I understand that my involvement is entirely voluntary and that I am free to withdraw at any time. ☐

3. I consent to the interview being audio recorded. ☐

4. I confirm that I would like to take part in the study ☐

Participant

Signed..... Print name..... Date.....

3.1. Interview schedule

Recovery Stories Project: Interview Questions for Story-tellers

1. What was your experience of deciding to share your story?
    a. Journey to get to the point of sharing?
    b. Value of stories?
    c. Explore motivation, hopes/ fears, barriers/ facilitators

2. What was your experience of sharing your recovery story?
    a. Explore format, time, ability to capture experience
    b. Impact and experience of sharing story
    c. Is this something that you see as important for the process of recovery?
    d. What might you say to others who are considering sharing their story, based on your experience?
    e. Would you want to share your story again?
    f. Did anything occur to you during your story that you had not considered before? (facilitating reflection?)

3. What are your hopes for the Recovery Stories project?
    a. Key messages – services; people using services
    b. Dissemination – who do you want your audience to be?

4. Do you have any fears or worries about the Recovery Stories project?

5. Anything else?

3.2. Survey Monkey Questionnaire

1. What was your immediate reaction to reading this recovery story?

2. In what ways might this story influence or change your practice?

3. What factors would make it difficult for you to make these changes to your practice?

4. What factors would support you to make these changes to your practice?

5. Do you have any other comments or reflections about this story?

6. What is the job title for your current position?

4. 1. Survey Monkey Results

Respondent	Initial Response/ Reaction	Clinical impact/ relevance	Obstacles to implementing change	Supporting factors to implementing change	Comments/ Reflections
1: Recovery Co-ordinator	It made me cry	Doing things with somebody, being with someone rather than referring people on and doing lots of office work, works!	RIO, targets, office work	Reduce the paper work, have more admin support so can spend quality time with people	Positive story with lots of hope that services can be helpful
2: Manager	My immediate reaction is 'here we go another fluffy feel good story' and then I reflected on what I had read. The story comes from the heart of both the people involved and gives inspiration to those 'like me' who have perhaps become hardened to the stories, and lost our way a little. I remember being a support worker and believing I could help everyone. I couldn't, and we can't, but that doesn't stop us trying. Offering HOPE to someone who has none is the reason we do this. It's our bread and butter and should be cherished when we succeed.	It will promote some self reflection and remind me that everything we do has someone at the centre of it.	Red tape, targets, and the growing distance from the frontline and the reality of our true role.	A freedom to act solely in the best interest of those we serve and an overall recognition of some the good work done by our staff. Targets are a measurement of time and do not lead to lasting change. That is done by the therapeutic relationships developed, and nurtured, by our hard working clinical and support staff	I wish both those contributing all the very best in the future. Recovery is at the focus of the story and lessons can, and have, been learned. The target is to sustain that recovery and 'always learn' from the ups and downs that Recovery brings.
3: Approved mental health professional	empathy for the narrator's experience	A reminder that the 'interviewing style' of many of our professional conversations with people is sometimes a barrier to understanding and communication	Prescriptive models of intervention which can be very process driven.	Reminding myself that with mental health issues there is no 'them' and us'. Developing and maintaining a reflective approach in my work.	
4: Support worker	A feeling of joy.		Inflexibility too often; inappropriate non-listening culture sometimes is a barrier.	New (non Ice-Age) culture!	It's nice, but something of a 'fairy story' (all too often) within the context of a wider audience in need of

					support.
5: Support worker	GLAD SOMEONE HAD MADE A DIFFERENCE TO DAISY'S LIFE		CURRENT SERVICE PROVISION MEANS SEEING A CLIENT ONCE A MONTH, INTERCHANGABLY WITH OTHER STAFF MEMBERS, A KEY TO THE SUCCESS ACHIEVED BY DAISY'S SUPPORT WORKER WAS THE QUALITY OF TYHE RELATIONSHIP SHE HAD DEVELOPED , SHE HIGHLIGHTED THE AMOUNT OF PROFESSIONALS THAT HAD COME IN AND OUT OF DAISY'S LIFE. IT IS WORTH CONSIDERING THE THERAPEUTIC EFFECT OF RELIABLE WORKING RELATIONSHIPS WITHIN THE JOURNEY TOWARDS RECOVERY	BEING ENCOURAGED TO WORK WITH A CLIENT FOR AT LEAST A YEAR, RATHER THAN A COUPLE OF MONTHS	OF COURSE WE WOULD LIKE TO HELP EMPOWER EVERY CLIENT WE CAME ACROSS BUT IT TAKES TIME , ONE TO ONE ATTENTION AND ADEQUATE RESOURCES, HOW BIG WAS THE CASELOAD OF THIS SUPPORT WORKER? I COULD PROBABLY PROVIDE SIMILAR EXAMPLES FROM MY OWN PRACTISE, BUT THE WAY OUR SERVICE IS HEADING MAY MAKE IT LESS LIKELY.
6: Clinical Psychologist	Encouragement	I might be more hopeful and patient	The bureacracy gets in the way of such meaningful client contact	reduction of time spent at computer. (The time spent typing this feels different - meaningful)	I loved the worker's reflections which left me tearful and remoralised.