How to take your lived experience to work

By Peter Bates[1]

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Introduction

Much of the thinking about public involvement in healthcare in England assumes that there are two categories of individuals - *staff* who work inside the organisation, as employees; and *patients*, who receive health services and try to influence delivery from the 'outside'. The focus here is on a third way – those staff who have made use of health services themselves and might consider themselves to be expert patients[2], whilst also having a paid job in the healthcare organisation. This paper reflects on the experience of this 'dual qualification' and considers how such staff and their colleagues manage the interaction.

Scope

This paper also takes account of the following issues:

- The situation for social care is essentially the same as for healthcare, so the issues we address in this paper can apply equally well to social care staff and service users. This widens the categories of eligible experiences beyond health conditions to include many life experiences where we need support, and so erodes the binary 'us and them' division of humanity into those who have lived experience and those who do not. We reject the implied concept of a hierarchy of disability and distress, preferring instead to treat each person's experience as unique but of equal validity.
- Some of the values and resources we refer to are targeted on disabled people, as defined by the Equalities Act 2010. Of course, many disabled people do not use health or social care services, while some people who count as disabled under the Act do not identify themselves as such. Indeed, much of what is written here may apply to family carers as well as people with personal experience of disability or distress.
- Universal Design[3], which creates the best conditions for all citizens, would solve most of the issues that we address in this paper, so we often refer to solutions that apply to all employees, and only suggest specialist arrangements for specific persons when this is necessary.

Acknowledging these subtleties at every point in the paper would make for some clumsy sentences, so we generally cut through these complexities by using the term 'expert by experience' where others might say patient, service user, carer or disabled person. Where a more specific example is needed, we focus on people with mental health issues employed as health researchers[4].

The benefits of engaging experts by experience in the workforce

Reflect your customer profile

It is an ugly truth that some less enlightened employers and co-workers illegally stigmatise and discriminate against disabled people[5], thus excluding them and denying themselves the opportunity of employing a more diverse workforce. In contrast, good employers recognise an opportunity when it arises and fulfil their obligations to make reasonable adjustments and reflect their customer base in their own workforce. There are strong advantages in recruiting and developing people with a lived experience of disability. For example, at least 1 in 6 people are experiencing a mental distress in a given year[6] and so having someone in the organisation with a lived experience of mental health difficulties can help the organisation better tailor their services and make them more responsive to a substantial section of the market. However, care is needed. Employing a token disabled employee can be unhelpful if it inhibits the genuine listening and learning that would otherwise take place when people 'know that they don't know'. Both the expert by experience and their colleagues can make this mistake, assuming that the experience of one person will be the same for all.

Create positive role models

When a person with lived experience takes up employment, especially at a senior level in the organisation, they can be seen as a role model, embodying hope for others who may be currently unemployed or trapped in unrewarding, low-status occupations. *'if they can make it, then so can I.'*

Harness lived experience

The workplace is one of the best places for developing people's strengths, talents and skills, so declaring one's lived experience at work can help to reduce many of the taboos and much of the stigma associated with disability[7]. There is a traditional view in some health and social care organisations and some professional bodies that disclosure[8] of personal information can be harmful to the therapeutic relationship and may lead to the abuse of power, but commissioners[9] are encouraging some organisations to move towards a more sophisticated view that acknowledges that appropriate use of personal experience can be beneficial in health and social care services[10]. Indeed, some therapeutic approaches, such as Dialectical Behaviour Therapy, actively harness the personal experience of therapists.

Add credibility to the organisation

Appointing people with a lived experience can send out a message about the credibility of the organisation and its approach. For example, a research team that includes people with lived

experience is more likely to be successful in recruiting research participants, and its findings are more likely to be taken up by service user organisations and others[11]. There are a number of mental health trusts[12] that employ 'peer support workers' who are appointed to share their lived experience with the people they support. It goes without saying that confining these opportunities to the lowest paid roles in the organisation will not add much to the reputational assets of the organisation.

Reduce sickness absence

While it might be assumed that disabled people have problems with sickness absence[13], some evidence has indicated the opposite. Indeed, South West London & St George's Mental Health NHS Trust has shown that sickness absence for well-placed and supported service users is below that of the rest of the workforce.

Bring empathy to bear

Particular opportunities arise in connection with specific job roles, such as that of a staff member employed in a research team. Staff employed in this setting as research interviewers and who have lived experience might be able to offer genuine empathy to the interviewee due to their shared experience. They may be more likely to understand the interviewee's needs and be able to help the interviewee elaborate on a point of mutual understanding in a qualitative interview, which may have been missed by someone who didn't have a shared experience.

Be explicit about subjectivity

In data analysis and reporting, people with lived experience might be aware of their subjectivity and so may manage it explicitly, improving the rigour of the work in contrast to others who may be in denial about their personal bias.

Promote a positive culture

It cannot be assumed that organisations are successful in aligning their culture to their stated values. For example, in one mental health organisation, which might be expected to display a supportive approach, fully a third of staff with their own mental health difficulties felt unable to open up to their manager or colleagues for fear of discrimination[14]. In another study, of 50 staff working in mental health services in the USA who disclosed their mental health issue, four staff experienced harassment, an unwanted reduction in the responsibilities they carried or social distancing and so regretted the disclosure[15]. People may have strong feelings about disclosure because they have previously lost their job, missed out on promotion, or been subjected to a fitness to practice investigation by their professional body, perhaps arising from the discriminatory actions of others. There may also be a concern that disclosure by one member of the team will not so much give permission for another to disclose, but rather trigger reticence on the part of others and let them 'off the hook'.

On a more positive note, it is believed by some that encouraging staff to be open about their own difficulties will create a more recovery-focused, hopeful and positive culture in the organisation and that this will benefit people using the service[16]. Employers should develop a Workplace Mental Health Plan[17] and check their progress is delivering it. While surviving mental health challenges is a sign of resilience, it can sometimes feel like a failure, and this is difficult in success-orientated cultures. To combat this, one academic has published a 'CV of failures'[18].

At the beginning, a disabled employee may feel obliged to champion the cause of disability equality in every meeting – which is good but can lead to the disabled employee feeling that they are the 'token' disabled employee rather than being appointed on merit. However, nondisabled colleagues may rapidly catch up and even overtake. As one person said, 'I now frequently find that my colleagues are more 'championing' than I am and suggest something much more proactive than I was proposing.' You can support your nondisabled colleagues to take up an inclusive perspective, so that you can sometimes talk about something else! There are some suggestions that creating the right climate at work that promotes 'psychosocial safety' is good for mental health and combats workplace bullying[19].

Challenges and opportunities

Good reasons to avoid disclosure

One small piece of research[20] suggested that if you tell other people about your mental health issue you might lower their expectations and perhaps your personal targets also by providing an 'excuse' for failure. For this reason, or simply because you want to create a divide between your staff identity and your 'patient identity', you might choose to treat your lived experience as a private matter[21].

After all, disclosing your experience can burden you with an undue sense of responsibility that your success or failure will set a precedent for all future job applicants and employees, and so create an unreasonable pressure to succeed. It can also burden people using health or social care services, as not everyone wants to hear about the lived experience of staff. Some people experience 'imposter syndrome' – the feeling that the employer has been indulgent in offering you the job and only did so because of your mental health issue or disability, rather than appointing you on merit[22]. Beyond all this lies the bond of common humanity[23] and the basic human right to privacy, which organisations can intentionally support[24]. However, hiding a part of your history can lead to feelings of dishonesty and exacerbate feelings of fear and shame. The issue of disclosure is discussed in more detail by Hyman[25], and a decision support tool is available[26].

Free counselling service

Then there are the occasions when a staff member with a lived experience is cast in the role of a free counselling service for every colleague who wants to have a conversation about disability. This is an occupational hazard for all experts – for example, doctors occasionally manage uninvited and impromptu consultations in the supermarket! It is worth thinking through how deeply you want to engage in these conversations in the workplace, if at all, and where you should signpost people to specialist help, should it be needed. If the line manager is a therapist, they might forget that staff

supervision meetings are meant to be about workplace performance and drift into a therapeutic role with the disabled worker.

As mentioned above, staff who need help can be referred to the Remploy mental health service funded by Access to Work if they need general mental health awareness training or other help in the workplace – as well as their line manager, occupational health department, employee counselling service or GP. Some staff prefer to seek counselling from an independent body rather than utilise inhouse or commissioned services that link back to the employer in some way. The maximum allocation that the Access to Work scheme can spend on helping an employee with mental health issues is in excess of £40,000. Whilst it may be helpful for the disabled employee to understand what support systems are available, should they be approached by a colleague who needs help, as mentioned above, it is not their job to either provide direct help or to signpost the person.

How would you describe yourself?

Reminding people of your lived experience can helpfully focus conversations that have become too abstract or disrespectful. However, there is a danger that you might only be seen through the lens of disability, rather than that of a productive team member and you might want to build a career in which your lived experience of mental health issues or disability is peripheral or even irrelevant, rather than a keystone. Also, prefacing your comments with *'As a service user....'* can be a ruse to gild your personal views with the aura of somehow being endorsed by a whole community that makes them unassailable. It is important to remember that whilst your views may have more validity than some, it does not always make you right, especially as people with the same disability can have quite different knowledge and experience[27]. So the goal is to offer your views and promote reasonable debate.

Develop your career

You may have some discretion about how you develop your expertise in the workplace. To take the example of university staff as a narrow illustration of a general principle, researchers or lecturers may wish to study a specific theme and choose which conferences they attend. Whilst some staff with lived experience of disability or mental health issues may wish to specialise in disability-related issues in this way, others will prefer to choose a different specialism and so relegate their disability to a single aspect of their life, rather than the single defining characteristic that dominates all others[28]. Some of these matters are explored in a collection of papers called *Supporting the Recovery Journeys of Staff*[29].

Humanise the workplace

Letting other people know about your lived experience can encourage others to share their experiences too, humanising the workplace and promoting honesty, transparency and mutual support. However, some colleagues may feel under pressure to match your honesty by sharing private matters that they wish to withhold or feel that they are inherently incapable of providing the

best kind of caring because their life experience is somehow lacking. Therefore, an open and permissive culture is better than a coercive approach.

Practical guidance for employers

Tackle under-representation

Disabled people have been under-represented in tertiary education[30] and the labour force and are four times more likely to be involuntarily out of work than their non-disabled counterparts[31]. In addition, as one moves up the promotional ladder, disabled people disappear from the workforce[32]. These facts place an obligation on employers to consider whether they should review the essential requirements for the vacancy and take other positive steps to promote equality of opportunity[33]. Alongside other equalities initiatives such as the Race at Work Charter[34], some employers sign up for the Disability Confident[35] symbol and offer suitably qualified disabled people a guaranteed job interview, become a Mindful Employer[36], thereby reassuring disabled jobseekers that they take the equality agenda seriously, or gain international recognition through their inclusive approach[37]. Targeted support is also available to both the disabled employee and employer in some areas[38].

Advertise vacancies

Some employers (such as Nottinghamshire Healthcare NHS Trust) add 'we positively encourage people who have experienced mental health problems to apply for a role within the Trust' to the footer of all vacancy adverts[39]. This could help people with lived experience to have an equal chance in the recruitment process. Another way in which job roles have been amended relates to the extent to which the employee's lived experience is a core aspect of the job or incidental to it. Peer workers in mental health services are appointed into support roles on the basis that they will share their own experience with people using services[40]. The same organisation may appoint a cleaner or an accountant with lived experience in order to strengthen the culture of the organisation without directly or explicitly bringing their experience to bear on their duties.

Obtain support

Financial and other support is available to employers to make adjustments through the Remploy Access to Work mental health contract[41]. People who bring lived experience into the workplace can offer one another peer support, as demonstrated by the Hidden Talents project at Dorset Healthcare University NHS Foundation Trust[42].

Keep confidence

Disclosures made during interview should be treated confidentially, and future work colleagues should only be told about the adjustments that they will be involved in delivering.

Manage capability

If the disabled person's capability is in question, then this needs testing against the contracted job description. This may reveal that the person has been underperforming, or that additional expectations have been loaded on to the role. Training, mentoring or supervision should be offered to the disabled employee or manager so that reasonable expectations are set and the disabled employee achieves the necessary performance level in just the same way as all other employees. Capability processes should protect staff from unfair dismissal and these, along with complaints[43] and whistleblowing processes should be checked to ensure that they treat disabled staff fairly.

Avoid tokenism

Some organisations quite properly declare that disabled people have equal rights to other citizens, and involve them in consultation processes, but then restrict their roles to special posts, such as 'diversity lead', 'peer support worker' or involvement facilitator'. In contrast, our ambition should be higher and include getting on at work as well as getting into work. The push should therefore be to appoint disabled people into senior posts as well, and thus make the rhetoric a reality, leading by example and so encouraging others to follow.

Exercise leadership

Because of their lived experience, disabled people in senior management positions can help smooth the process for others to get on and climb the ladder. They will have seen firsthand disabling systems and procedures at work, and so can ensure that those following in their footsteps are not held back by unnecessary barriers and obstacles. In the world of academia, this may include engaging experts by experience as occasional lecturers and as research advisors, and arranging for their disability-related needs to be met and payments to be made. Such processes can be labyrinthine in their complexity and delays. Senior people who understand the issues can help to smooth the path.

Arrange support

Senior managers and professional heads can, wherever possible:

- Make repeated and public declarations about the open and welcoming culture of the organisation – and see to it that their statements are true!
- ensure that two or more people start their job at the same time, or link together staff with lived experience so that employees have an opportunity of offering and receiving peer support.
- Identify established employees who live and work with mental health issues and are willing to take up a mentoring role. This should be offered to staff, rather than waiting for employees to ask, and can be especially valuable for new staff in the earliest days with the company. Care is needed to ensure that other staff are not thereby exempted from their responsibilities to respond positively to their colleagues – so this specialist role should be established with the

clear expectation that the effect will be to build capacity to respond well across the whole workforce.

- Investigate complaints and deal appropriately with bullying, harassment and discrimination against disabled staff.

Practical Guidance for people with lived experience

Clarify what is expected

Over time, the actual duties required of the employee can gradually change, until the job description is seriously out of date and additional, unacknowledged burdens can be added to the role without proper consideration. Applicants may wish to make contact with the recruiting organisation to ask questions and develop a more accurate picture of the current realities of a specific job role.

Decide on disclosure

During the job application process, applicants with any disability can choose whether to tell their potential employer about this[44] and the employer may seek some information about any reasonable adjustments they may need to make. Simple measures can help, such as ensuring sufficient sunlight, meeting the worker's need for privacy and arranging workspace to minimise stimulation for those who concentrate best in a spartan setting[45]. This process can be eased with a standard letter from the JobCentre[46] explaining the support available through the Access to Work scheme. In doing so, by and large, the applicant is guaranteed an interview, and the letter will also alert the employer to any job adjustments that could be made in order to accommodate the employee's needs. It is worth thinking about disclosure in several concentric circles and negotiating who needs to know what so that the needs of both employer and employee are met. So, for example, a clinician or a researcher may decide to make a vague reference to personal experience and then use their own lived experience to demonstrate insight, rather than going into the detail of their own symptoms, treatments and outcome. Further advice is available[47].

Use storytelling wisely

Advice is available[48] for staff on how to maintain boundaries and remain focused on the organisation's purpose when 'storytelling' – i.e. sharing relevant parts of one's own experience with people using services. The *Hidden Talents* group have produced an excellent checklist of issues[49] to take into account when staff employed in a mental health service share their personal experience of mental health issues with their colleagues and the people they support.

Consider impact on volunteers

It can be helpful to think about the relationship between different groups of people who have lived experience. For example, if the organisation works closely with volunteers who have lived experience, such as in a patient advisory group, then staff with lived experience should work out the

relationship between their role as a staff member and the role of volunteers. Such an employee might be viewed as a successful role model, someone who has 'made it' and therefore as someone who has the potential to inspire others. However, such accolades can be seductive and create a damaging sense of hierarchy which would not have occurred if that employee had been viewed as 'just a worker'.

Look after yourself

Workplace stress is a challenge for many employees, not just those with mental health issues or other disabilities. Staff need to know about their progression ladder[50], as well as mentoring, support and counselling services, and connect with a trade union or professional body before these supports are needed. Individuals who become over-involved with helping others may need to withdraw a little and attend to their own mental health – what someone described as the injunction to 'put your own oxygen mask on first', while others need to share their wellbeing plan[51] with trusted colleagues in the workplace. There are also networks[52] for people to share experiences and resources in this field.

Employees who take time off work for health reasons may find their return to work no easier than their time off sick. For example, patients admitted to hospital for psychiatric reasons receive fewer get-well cards than their counterparts on other wards[53], and negotiating a gradual return to the workplace demands considerable skill[54].

Occupational Health

In some settings, informal disclosure by established staff can trigger a referral to the occupational health department[55] and other unexpected consequences, or a restriction of developmental opportunities such as taking on new responsibilities or promotion. If this occurs simply because of the declaration of a health condition, rather than based on evidence of its impact on performance, then it is discriminatory and unfair. Employees have a duty to disclose to their employer anything that might impact on their ability to do the job and must not be dishonest, while matters that have no impact can remain private and the employer has a duty to treat disabled people fairly.

Challenge poor work practices

Some disabled employees are able to do the job as it was originally intended, but cannot match the excessive hours, unreasonable pressure and culture of 'presenteeism' that pervades some workplaces. A disabled employee may press the organisation to specify the duties of employees, honour the European Working Hours Directive[56] and make only reasonable demands on staff, while taking seriously its obligations to make reasonable adjustments and flexible working arrangements. For example, one healthcare worker was comfortable in almost every team, apart from one particular inpatient setting which for them carried distressing memories of their previous treatment. Insisting that the worker is available to be deployed anywhere would be like requiring the wheelchair user to work upstairs – so reasonable adjustments should be made. Introducing this flexibility can help all employees and the business as a whole when adjustments benefit everyone[57].

On occasions, poorly designed 'adjustments' turn out to unfairly burden work colleagues and generate resentment; while unduly confrontational approaches lead to the disabled employee being branded as a troublemaker, so responses across the whole workforce should be monitored by careful listening.

Reflect on your assumptions

A staff member with lived experience may be particularly eager to promote coproduction, user-controlled approaches and qualitative research methods that focus on perceptions and views. Other staff, having taken other journeys through life, will have other preoccupations. It is important to reflect on your balance between challenge and acceptance; and to test out whether other team members value your contribution.

Staff get-togethers.

In addition to the culture that drives conduct within working hours, consideration needs to be given to the informal social activities that bind employees together after work is over for the day. Staff who have been part of a peer support network made up of people using services may not find it easy to work out how to maintain their connections with this world as well as occupying the social world of staff, and this can be uncomfortable for them, and for their nondisabled work colleagues. The user/worker may have a friend or partner who is a service user and find themselves in a delicate position when talking about their working day or responding to an invitation to a staff party. Such boundary issues may impact the ordinary working day too, especially where the 'water cooler' conversations include discussions of people that the disabled person may know as a friend. Employing 'boundary spanners' can positively challenge and disrupt workplace cultural norms[58].

Conclusion

Tracking progress is an important aspect of any serious change endeavour, and managers should consider how to collect feedback and evidence on what is working and what is not working[59], especially as there may be differences between their own priorities and those of other staff[60]. An open, honest and learning working environment and culture will enable people with different views, experiences and priorities to create a safe and collaborative environment where diversity drives continuous improvement.

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[1] Comments and challenges were offered by Sue Barton, Marion Blake, Janet Brothwell, Simon Francis, John Gledhill, Sarah Gordon, Andrew Grundy, Eran Kraus, Jonny Lovell, Sue Purdy, Mat Rawsthorne, Paula Rylatt, Mike Slade, Theo Stickley and Emma Watson. As readers provide feedback, further insights will be used to update it, so please contact peter.bates96@gmail.com with your contributions. Early versions should be replaced with the most recent, available here.

[2] We acknowledge that this is not the term of choice for all. For more on labels, see http://www.peterbates.org.uk/uploads/5/5/9/5/55959237/11n_-_clients_or_what.pdf.

[3] http://www.udinstitute.org/history.php

[4] See research findings drawn from this approach - Byrne L, Roennfeldt H, Wolf J, Linfoot A, Foglesong D, Davidson L, Bellamy C. Effective Peer Employment Within Multidisciplinary Organizations: Model for Best Practice. *Administration and Policy in Mental Health and Mental Health Services Research*. 2021 Sep 3:1-5.

[5] Henderson C et al (2014) Mental health-related stigma in health care and mental health-care settings *The Lancet* Volume 1, No. 6, p467–482, November 2014. DOI: http://dx.doi.org/10.1016/S2215-0366(14)00023-6.

[6] https://www.mentalhealth.org.uk/sites/default/files/fundamental-facts-15.pdf

[7] See the PhD by Jonny Lovell on the staff's use of self-disclosure with clients in mental health settings – www.york.ac.uk/spsw/postgraduate/phd-students/jonny-lovell/. He particularly focuses on how mental health practitioners can share their lived experience with service users and how to maximise helpfulness, reduce risk and find out whether it is beneficial. Jonny's blog is at https://jonnylovellblog.wordpress.com/.

[8] The *Hidden Talents* group in Dorset feel that the word disclosure has negative links with criminality and prefer the term 'share'.

[9] Mental health service commissioners are encouraged to employ people with personal experiences of mental health problems who will use those experiences in supporting others. See JCPMH (2012). *Guidance for Commissioners of Acute Care – Inpatient and Crisis Home Treatment.* Royal College of Psychiatry: London. Also, JCPMH (2012). *Guidance for Commissioners of Community Specialist Mental Health Services*. Royal College of Psychiatry: London.

[10] See the section on Boundaries at http://www.peterbates.org.uk/subject-index.html and the links to publications on the topic.

[11] Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C. and Suleman, R. (2014), Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expectation*s, 17: 637–650. doi: 10.1111/j.1369-7625.2012.00795.x

[12] Julie Repper and colleagues at the Nottingham Recovery College work on these issues. There were 32 Recovery Colleges in the UK in July 2016 and 75 by 2018.

[13] Is there any data on this? Mindful Employer do not have anything to hand.

[14] Staff surveys can uncover this kind of information about workplace culture. Morgan P & Lawson J, (2015) Developing guidelines for sharing lived experience of staff in health and social care", *Mental Health and Social Inclusion*, Vol. 19 Iss: 2, pp.78 – 86.

[15] Kottsieper, P., & Kundra, L.B. (2017). *Full disclosure: When mental health professionals reveal their mental illnesses at work* Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities.

[16] See for example, Price M and Kerschbaum S (2017) *Promoting supportive academic environments for faculty with mental illnesses* Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Illnesses. Available here.

[17] See Thriving at work: The Stevenson / Farmer review of mental health and employers published 30 November 2017. There are resources on page 71 to help create a Plan. The UK Government has endorsed this recommendation in Improving Lives: The Future of Work, Health and Disability, published 1 Dec 2017.

[18] See https://www.princeton.edu/~joha/Johannes_Haushofer_CV_of_Failures.pdf.

[19] https://www.headsup.org.au/docs/default-source/resources/developing-a-mentally-healthy-workplace_final-november-2014.pdf?sfvrsn=8

[20] A study carried out in Connecticut and reported in Thornicroft G (2006) *Shunned: discrimination against people with mental illness* Oxford: Oxford University Press, page 211.

[21] Dembele, L., Nathan, S., Carter, A., Costello, J., Hodgins, M., Singh, R., Martin, B., & Cullen, P. (2024). Researching With Lived Experience: A Shared Critical Reflection Between Co-Researchers. *International Journal of Qualitative Methods*, *23*. https://doi.org/10.1177/16094069241257945

[22] For an example amongst doctoral students, see http://www.tandfonline.com/doi/abs/10.2202/1949-6605.6321

[23] Kotera Y, Llewellyn-Beardsley J, Charles A & Slade M (2022) Common humanity as an under-acknowledged mechanism for mental health peer support *International Journal of mental health and addiction* https://doi.org/10.1007/s11469-022-00916-9.

[24] See the statement here made to job applicants by the McPin Foundation. They have set out a deliberate policy position to uphold the right to privacy and create a culture where it is safe to disclose personal experience of mental health issues.

[25] Hyman, I. (2008) *Self-Disclosure and Its Impact on Individuals Who Receive Mental Health Services*. HHS Pub. No. (SMA)-08-4337 Rockville, MD. Center for Mental Health Services, Substance Abuse and Mental Health Services Administration. See https://store.samhsa.gov/shin/content/SMA08-4337/SMA08-4337.pdf.

[26] The decision tool is available at http://www.kcl.ac.uk/ioppn/depts/hspr/research/ciemh/cmh/CMH-Stigma-Measures/CORAL-DA-Oct13-final.pdf. See also Brohan E, Henderson C, Slade M, Thornicroft G (2014) Development and preliminary evaluation of a decision aid for disclosure of mental illness to employers also *Patient Education and Counselling* 94 (2014) 238–242.

[27] There are, of course, many similarities and differences between people's experiences. For some, the simple experience of being signed off work, irrespective of diagnosis, creates a shared experience, while for others, it is the unique response from an individual health professional that makes their experience stand out from all others.

[28] Alcoholics Anonymous sometimes refer to 'dry drunks' – people who have given up dangerous drinking but continue to live their life in relation to alcohol, rather than taking up other interests and social roles. In a parallel way, some disabled people adopt a 'survivor mission' and devote their lives to campaigning or simply build a positive career and personal identity around their role as a survivor. Yet others incorporate this into the wide range of roles and identities they adopt. For a discussion of the merits of multiple roles and identities, see Amartya Sen (2006) *Identity and Violence.* London: Penguin.

[29] http://www.dorsetmentalhealthforum.org.uk/pdfs/other/supporting-staff-recovery.pdf.

[30] One respondent said that they had applied for a place on a professional training course and had been told that they had to resolve any mental health issues before applying for a place. We have no idea if this single incident was indicative of a general approach, or whether it applied in more than one university or to more than one discipline. In contrast, for a study showing the positive impact of lived experience of mental health issues amongst students see Gilbert P & Stickley T (2012) Wounded healers: the role of lived-experience in mental health education and practice *The Journal of Mental Health Training, Education and Practice* vol 7, no 1, pp30-41.

[31] http://www.papworthtrust.org.uk/sites/default/files/Facts%20and%20Figures%202013%20web.pdf

[32] http://www.disability-europe.net/content/aned/media/UK%20Employment%20report.pdf. For international comparisons, see www.washingtongroup-disability.com.

[33] For As an example of reasonable adjustments, note that the NHS has provided guidance on the employment of people with learning disabilities here and taken easy-read job descriptions through the Agenda for Change job match process, as described here.

[34] The Race at Work Charter is promoted by Business in the Community – see https://www.bitc.org.uk/race/.

[35] The Disability Confident scheme is run by the UK Department of Work and Pensions and replaced the Two Ticks scheme in 2016. See https://www.gov.uk/guidance/disability-confident-how-to-sign-up-to-the-employer-scheme

[36] http://www.mindfulemployer.net/

[37] http://pmeri.sedpcd.sp.gov.br/ingles/index.php

[38] The most robust, evidence-based approach is called Individual Placement and Support. IPS is described at http://emahsn.org.uk/images/Section_4_-_How_we_are_making_a_difference/Mental_Health/IPS_Booklet_FINAL21.05.15.pdf.

[39] Confirmed by Angie Rose, Recruitment and Resourcing Manager, 25 July 2016. In contrast to this positive attitude, another employer told a staff member to forget about his lived experience and identify himself solely by his job title.

[40] Repper J with Aldridge B, Gilfoyle S, Gillard S, Perkins R & Rennison J (2013) I*mROC Briefing 5 - Peer Support Workers: Theory and Practice* Centre for Mental Health and Mental Health Network of the NHS Confederation.

[41] http://www.remploy.co.uk/info/20137/partners_and_programmes/227/workplace_mental_health_support_service

[42] Morgan P & Lawson J, (2015) Developing guidelines for sharing lived experience of staff in health and social care", *Mental Health and Social Inclusion*, Vol. 19 Iss: 2, pp.78 – 86.

[43] See also http://peterbates.org.uk/wp-content/uploads/2018/11/How-to-respond-to-a-vexatious-complainant.pdf.

[44] Do we need a reference to an official statement confirming that you don't need to disclose, but you mustn't lie. Where is this found?

[45] See https://www.mentalhealthcommission.ca/sites/default/files/2018-04/Business_case_for_aspiring_workforce_eng.pdf

[46] https://www.gov.uk/government/publications/access-to-work-eligibility-letter-for-employees-and-employers

[47] See the research findings from a project called 'HOP-MHP - Supporting mental health professionals who experience mental health problems in reaching disclosure decisions through a self-help intervention.' Details are available at https://www.ucl.ac.uk/pals/hop-mhp-project-0

[48] A whole suite of resources on peer work is available at http://www.mentalhealthcommission.gov.au/peerwork. Specific work on self disclosure and storytelling is at http://store.samhsa.gov/shin/content//SMA08-4337/SMA08-4337.pdf and an account of coproducing guidelines is Morgan P & Lawson J, (2015) Developing guidelines for sharing lived experience of staff in health and social care", *Mental Health and Social Inclusion*, Vol. 19 Iss: 2, pp.78 – 86. See also the literature review by Julie Repper and Tim Carter at http://www.together-uk.org/wp-content/uploads/downloads/2011/11/usingpersexperience.pdf

[49] Morgan P & Lawson J, (2015) Developing guidelines for sharing lived experience of staff in health and social care", *Mental Health and Social Inclusion*, Vol. 19 Iss: 2, pp.78 – 86.

[50] For example, there is information about career development for researchers at https://www.vitae.ac.uk/.

[51] A wellbeing plan takes a positive focus on what is needed to stay as well as possible. A small part of this might be to also clarify the 'relapse signature' which is made up of the unique signs that show that things are deteriorating, so that your family and friends can help to keep an eye on how you are getting on. You tell them in advance what to look for, and what you would like them to do when they see certain signs. They can then act on the instructions you gave them when you were feeling well.

[52] See https://www.mendeley.com/groups/3108961/international-association-of-service-user-academia/. Also http://mhhehub.ning.com/ and http://www.alps-cetl.ac.uk/len.html.

[53] Lankappa, S. (2005). Psychiatric in-patients receive fewer greetings cards than other in-patients. *Psychiatric Bulletin*. 29. pp449-451. Available here.

[54] See https://www.centreformentalhealth.org.uk/blog/a-touch-on-the-arm-returning-to-work.

[55] The Dorset Wellbeing and Recovery Partnership include Occupational Health colleagues in their work on creating a positive environment for people to take their lived experience to work. See http://www.dorsetmentalhealthforum.org.uk/recovery.html and Dorset WARP (2012) *Hidden Talents.* For an insight into how occupational health doctors view the relationship between illness and employment, see Hobson J & Smedley J (editors), (6th edition, 2019) *Fitness for work: the medical aspects* Oxford: Oxford University Press.

[56] http://www.hse.gov.uk/contact/faqs/workingtimedirective.htm

[57] A study by Gordon and Peterson found that well-supported employees were able to describe numerous adjustments that had been made, while their employers could not recall any special arrangements, leading to the conclusion that they had dealt with all their staff in a similar person-centred way. Gordon S and Peterson D

(2015) *What Works: Positive experiences in open employment of mental health service users.* Auckland: Mental Health Foundation.

[58] For an introduction to boundary spanning, see http://solutions.ccl.org/Boundary_Spanning_Leadership_Six_Practices_for_Solving_Problems_Driving_Innovation_and_Transforming_Organizations

[59] For an example of a research project evaluating the impact of lived experience workers on people using mental health services, see Gallagher C (2014) *The lived experience workforce in South Australian Public Mental Health Services* Central Adelaide Local Health Network, Mental Health Directorate Adelaide, South Australia.

[60] While the manager may be committed to the principles of equality, recovery and inclusion, frontline staff may be less persuaded. See http://bjp.rcpsych.org/content/early/2016/06/10/bjp.bp.114.160739. The development of a new culture can take sustained effort – see Louise Byrne, Brenda Happell & Kerry Reid-Searl (2016) Lived experience practitioners and the medical model: worlds colliding? *Journal of Mental Health*, 25:3, 217-223. DOI: 10.3109/09638237.2015.1101428.