MAKING IT REAL

FOR PERSONALISATION IN MENTAL HEALTH

SUMMARY

This paper is for commissioners, provider organisations and people with lived experience who want to see personalised care policies become practice for more people with mental health conditions.

The paper describes how Bridge Support, Rethink and Self Help, three voluntary organisations, are weaving together **recovery, co-production** and **peer support** to deliver personalised care and support that makes a positive difference to people's lives. It also makes recommendations for change, as change is needed to develop, support and sustain such good practice more widely.

Making it Real is Think Local Act Personal's framework for good personalised care and support in health and social care. It describes this from the perspectives of people who access services and people who work in them, and helps people to think about what's happening locally and what needs to change.

This document is based on discussions and presentations at an event held by Think Local Act Personal (TLAP), and the Association of Mental Health Providers called 'Making it Real for people with Mental Health Conditions'. It is written by Kate Linsky, Mental Health Programme Lead at the NDTi, a TLAP partner organisation.

"There's a lot of rhetoric about what should be happening. But when does personalisation become a reality?"

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INTRODUCTION

There is nothing new about personalisation. Since Putting People First in 2007 it's been part of the government's agenda; one that resulted in the creation of Think Local Act Personal (TLAP), a sector wide partnership, to help drive it forward in social care.

Strengthened by the Care Act 2014, some real progress has been made with personalisation in certain areas. Asset-based approaches[1] have led to more innovative working with communities, with individuals at the heart of that process.

But people with mental health conditions receive most of their care and support from the NHS, where the majority of funding is spent under block contracts with the local NHS Trust.

Two recent announcements set the scene for change there:

- the NHS Long Term Plan; and specifically linked to mental health
- the 'right to have' a personal health budget being extended to people eligible for section 117 aftercare services

The NHS Long Term Plan says that personalised care will become business as usual across the health and social care system within the next five years. Whilst this is an ambition we all want to see realised, many participants at the workshop feel we remain light years away from experiencing genuine personalisation.

At the TLAP event, Isaac Samuels, a member of the National Co-production Advisory Group, shared his views as a person with lived experience. Not just his experiences, but those of his friend Ricardo, who had recently taken his own life and whose body was found ten minutes away from the hospital where he'd been receiving treatment. "The reality is there aren't any positive experiences for people like us. There's a lot of rhetoric about what should be happening. But when does personalisation become a reality?"

Isaac has four dogs, a partner and a house. But he points out there are health professionals who, despite working with him for 15 years, lack even this basic knowledge of his life. For him, it is difficult to imagine the transformation needed to personalise care taking place in just five years.

[1] See TLAP Care and Support Jargon Buster for explanation of unfamiliar terms

WHY MORE PERSONALISED APPROACHES ARE NEEDED

The evidence is clear that people with severe mental illness have significantly unequal health outcomes compared to the rest of the population: (full and most recent government figures here.)

Andy Bell from Centre for Mental Health summarises the picture. People with severe mental illness can expect:

- 15-20 year shorter life expectancy
- 3.7 times higher premature mortality; and are
- up to three times as likely to have diabetes
- twice as likely to have heart disease
- more likely to die from cancer.

Crucially, he comments that people with severe mental illness are not more likely to get cancer – they are just more likely to die from it.

Andy points out that the main reason for the above situation is that people with severe mental illness are less likely to be offered the routine checks and tests needed. Healthcare professionals either ignore or take for granted unhealthy lifestyles, such as smoking or obesity and so do not challenge. Physical symptoms are not believed or just seen as side effects of medication. In summary, people's physical health is overshadowed by their mental illness.

Centre for Mental Health have formed a collaborative to bring about change and share what works: equallywell.co.uk

The ultimate aim is for people with mental health conditions to have better health for longer, just like everyone else. As Kathy Roberts from Association of Mental Health Providers says "It's not about having more – but it shouldn't be about having less".

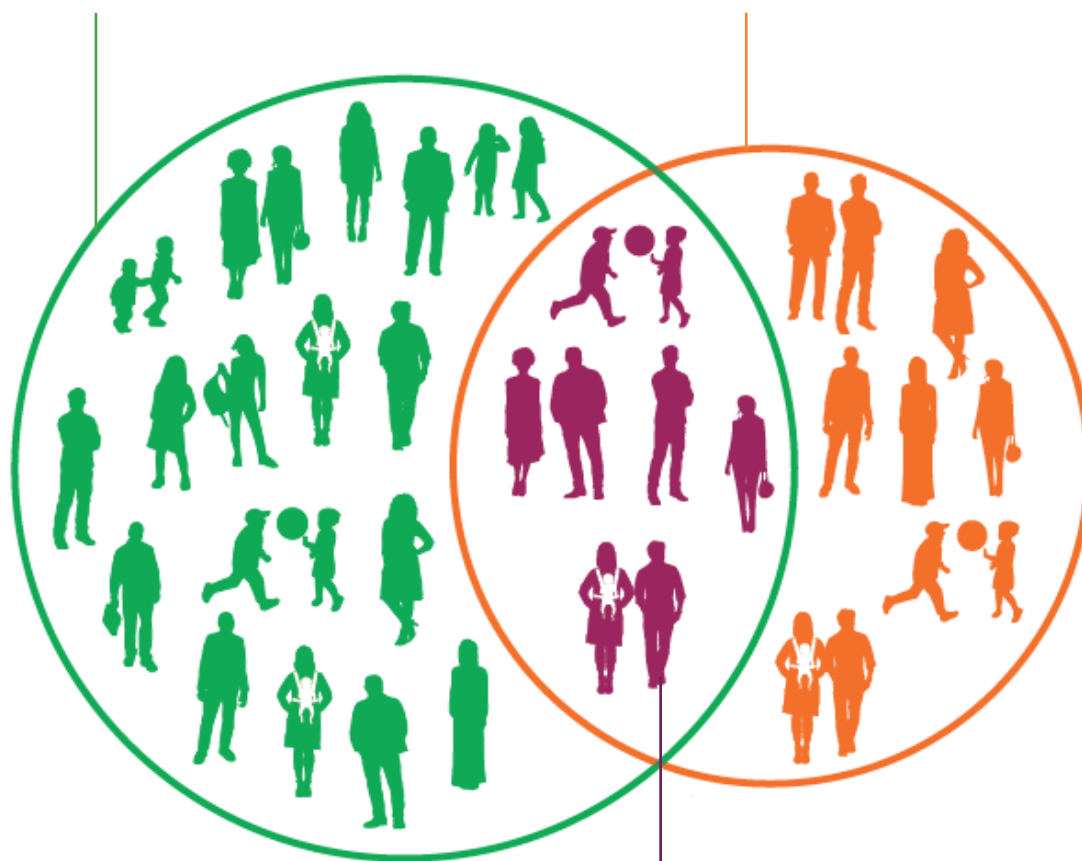**"It's not about having more – but it shouldn't be about having less"**

THE OVERLAP BETWEEN LONG-TERM CONDITIONS AND MENTAL HEALTH PROBLEMS

Long-term conditions:
30% of population of England
(approx. 15.4m people)

Mental Health problems:
20% of population of England
(approx. 10.2m people)

30% of people with a long-term condition have a mental health problem (approx. 4.6m people)

40% of people with a mental health problem have a long-term condition (approx. 4.6m people)

Diagram © Centre for Mental Health and reproduced with permission

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WHAT'S THE ROLE OF PERSONALISED CARE AND PERSONAL HEALTH BUDGETS?

TLAP welcomes the decision to increase the take-up of personal health budgets for people receiving section 117 aftercare. We know that personal health budgets, particularly in the form of a direct payment, can make a <u>huge difference to people's lives</u>. They can be used to tailor the care and support a person needs in a way and at a time that suits them best and helps them lead a better life.

But TLAP also knows that simply having a personal budget is no guarantee of personalisation. How people are supported to access and use their budget is as crucial as what is being offered. The processes that are set up need to be person-led, rather than shaped around the perceived need of particular health and social care systems.

Personal budgets need to be flexible and straightforward and be able to help support involvement in local communities rather than primarily be a means of tracking money flow around the statutory sector. This sounds obvious, but if set up in isolation of the people they are designed to help they are more likely to be systems-focussed than recovery-focussed.

No-one's recovery journey is the same and you wouldn't expect it to be. No-one has the same hopes, fears, interests, aspirations or - of course - circumstances. But if services are to support someone effectively on their very individual journey then personalised approaches are essential.

NHS England are supporting several sites to make Personal Health Budgets work for people with mental illness; progress can be followed on #NHSPHB.

In the midst of this policy focus, it is essential we don't lose sight of what we already know works for people. There is <u>ample evidence</u> to show that the involvement of people with lived experience in **co-production** and **peer support** are key ingredients that both lead to **recovery** and help maintain it. These three approaches can be taken by any organisation, whether based in social care or the NHS; nationally, regionally or locally.

The following stories of success illustrate the role that voluntary and community organisations already play in weaving together co-production and peer support to help support recovery in their areas.

CAN RECOVERY COLLEGES WORK IN LOCAL COMMUNITIES?

Recovery colleges first started around ten years ago. They are primarily delivered by NHS Trusts and located in their buildings. They usually have mental health professionals working alongside peer tutors. But people are not 'referred', instead they choose the courses that interest them; whether that's developing new skills, rediscovering old ones, or learning to self-manage their own mental health condition. It's all about recovering a life. The approach was developed and continues to be supported by Implementing Recovery through Organisational Change.

Recovery Colleges are founded on the principles of co-production. They take a strengths-based, person-centred and community facing approach. But only a small number of the 40+ colleges currently in existence are based in the heart of local communities.

The Recovery College run by Bridge Support is one of the very few. It is based in the centre of Woolwich above Bridge Support's popular local café, Stir. The café serves food made from the fruit and vegetables grown by the Recovery College students on the allotments nearby. With Google reviews currently running at a positive 4.4, it's clear to see how everyone regards this as a positive contribution to the local community:

Aurelia Ven Local Guide · 18 reviews
Enjoyed a lovely breakfast at Stir this morning. Generous coffee serving, friendly staff. The food was great and prepared fresh - I saw the staff go fetch a pile of fresh mushrooms and spinach for my order. Nice atmosphere and a good stock of indie label soft drinks in the fridge. I sense this may become a new local fave.
Like

Response from the owner 2 days ago
So glad you enjoyed it Aurelia. Our mission is #goodmoodfood which includes ingredients upwards. See you soon we hope.

The Recovery College itself is led and staffed by adult learning professionals, who all have lived or professional experience of mental illness. The courses are co-designed to blend current educational practice and creative opportunities with the CHIME recovery domains (Connectedness; Hope; Identity; Meaning; Empowerment) identified by Leamy et al (2011).

The Recovery College places great importance on the **co-design** and **co-delivery** of courses and workshops, which provide opportunities for development and progression. It has developed a light touch version of a Level 3 qualification in education and training for students who want to train as peer tutors.

New peer tutors are supported by professional college staff or experienced peer tutors to develop and deliver their first workshops. When they judge themselves ready, they progress to working more independently.
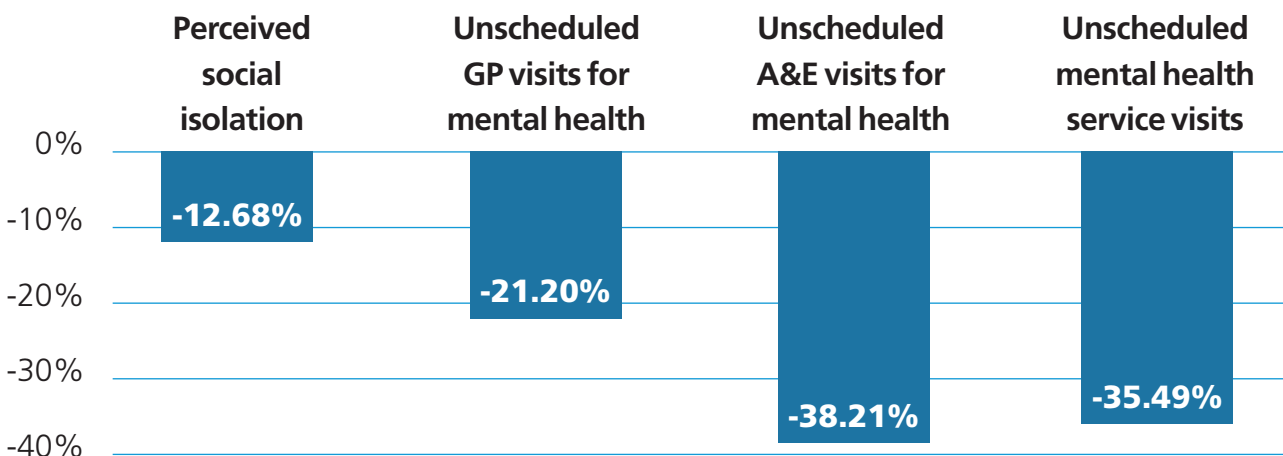
Raymond Sheehy, Chief Executive at Bridge Support describes how for a number of students becoming a peer tutor "is a bit like lighting the blue touch paper of recovery. After a few terms of delivering independently, they have moved on from the college to employment or full time education".

Raymond needs more solid evidence that the Recovery College model works, otherwise his funding from the Clinical Commissioning Group (CCG) is at risk. A new data collection method is being devised but their existing one, whereby students places themselves on a scale at the start and then again at the end of the term, shows positive reduction in the key areas shown in the graph below.

Of course, data is necessary to evidence impact, but it's the personal stories that stick in the mind. Ray shares the story of a man with a forensic background, who grew up in care and has spent most of his adult life either in prison or unemployed. On graduating from the College to start his first job, his parting words to Ray were: "I'm looking forward to paying taxes". It's a virtuous circle.
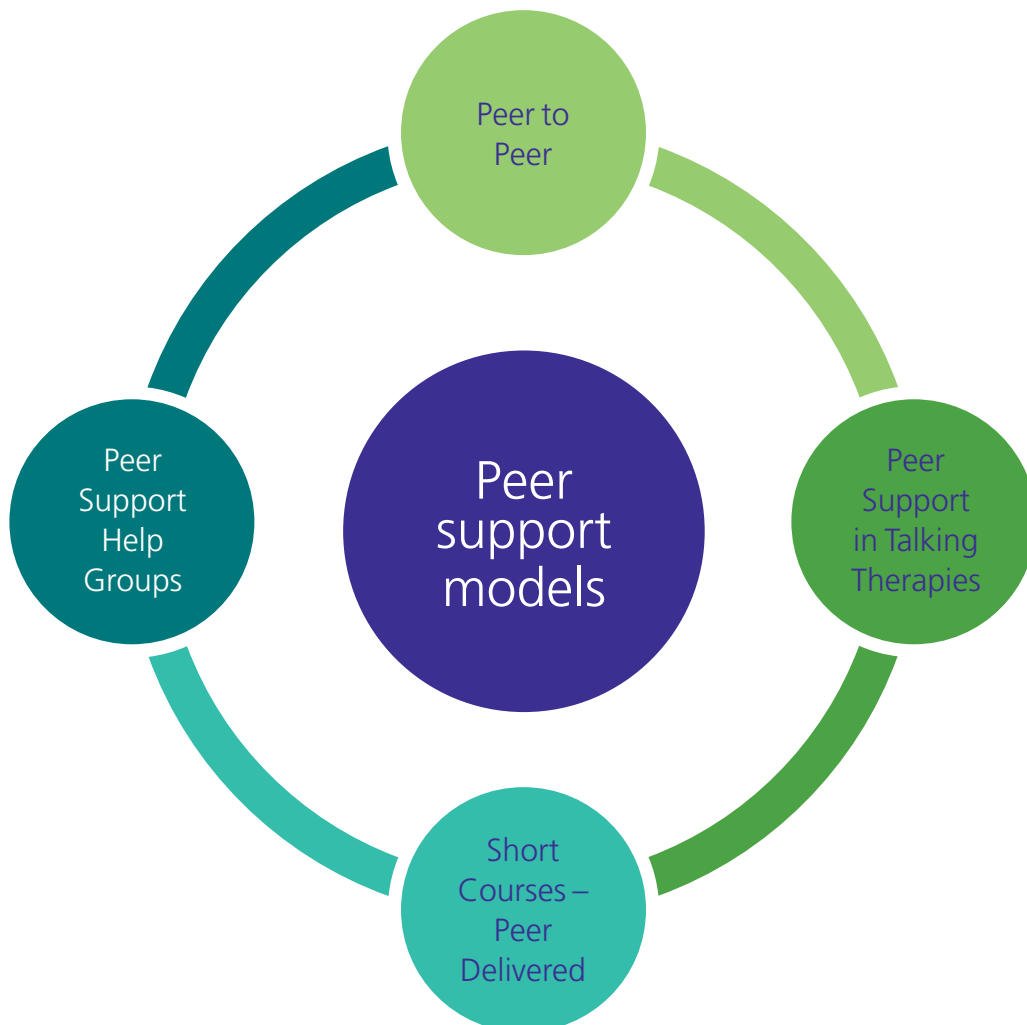
www.therecoveryplace.co.uk/recovery-college/

	Perceived social isolation	Unscheduled GP visits for mental health	Unscheduled A&E visits for mental health	Unscheduled mental health service visits
0%				
-10%	-12.68%			
-20%		-21.20%		
-30%				-35.49%
-40%			-38.21%	

WHAT ARE THE DIFFERENT WAYS OF DELIVERING PEER SUPPORT?

Peer support helps emotional health, wellbeing and a sense of belonging. It is all about people using their own experiences of mental health challenges to help each other. This can take many different forms – but is always reciprocal; it helps both those that give and receive support. As shown in the previous example, it is a key ingredient of successful Recovery Colleges.

For Self Help peer support is the glue that holds the organisation together. It is central to their delivery of support, services and opportunities across the North West. There, people can choose the right support model for them at the right stage of their recovery.

Peer to Peer

Peer Support Help Groups

Peer support models

Peer Support in Talking Therapies

Short Courses – Peer Delivered

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For those new to Self Help, it starts with Peer Connect, where a peer support worker meets to discuss what support is available at Self Help and within the local community. For more in-depth sessions designed to help people recover and stay well, Peer Mentors are available. Sessions are held either in person or over the telephone for a period of around four months. One-to-one support in Improving Access to Psychological Therapies (often called talking therapies) is also available, where peer supporters work through any barriers to engagement before and during any treatment – as well as help support making connections with the community.

Self Help also run group sessions. There are nine drop-in groups across Greater Manchester, where informal shared problem-solving and self-care support take place as well as two more formal courses. Rough Guide to Being Well provides an overview of the steps needed to "make the journey from stuck, to recovering, to thriving!" and Boost, which offers skills and tips and runs over a period of six weeks.

Additionally, Self Help runs the Sanctuary, where non-clinical support is provided to help adults in crisis and/or experiencing anxiety, panic attacks, depression or suicidal thoughts.

All these different ways of providing peer support require different levels of training and skills. But that model also means there are different ways of getting involved as a person with lived experience, at a time and pace that suits the individual, making the gradual move from supported to supporter. This works to the benefit of the local area as well as the individual.

Philippa Girling, who's attended self-help groups for many years, has made that move from supported to supporter and is now an assets-based trainer with the wider Big Life Group, of which Self Help is a part. It is a journey that benefits the community as much as the individual: for who better to help a person along any road than one who has already travelled it.

WHAT DO WE KNOW ABOUT THE BENEFITS OF CO-PRODUCTION?

Co-production is a term that is widely used in the delivery and evaluation of many public services. But it often means different things to different people; for some it's just professionals across different agencies working together.

Co-production means professionals and citizens sharing power to plan, design and deliver support together. Caroline Speirs, Head of TLAP, is clear; "It's about recognising that genuine change can only happen when power is shared with people with lived experience".

There are many ways in which co-production can happen in mental health services. For example, see www.skillsforcare.org. uk/Documents/Topics/Mental-health/Co-production-in-mental-health.pdf.

Rethink made sure that co-production with young people was central to its Step Up: Transitions project, funded by the Big Lottery. The focus was on the transition between Children's and Adolescent Mental Health services to Adult Services but expanded to include other major transitions i.e. school to college, college to university, school life to work life.

The project was "by young people, for young people" and so focussed on the right issues for them, for example exam stress, body image, eating disorders and cannabis use. Workshops were co-designed to provide "information, tips and life hacks about mental wellbeing" and were co-delivered in various settings across London.

"Recognising that genuine change can only happen when power is shared".

Co-production meant that the workshop content was relevant, creative and engaging to the target audience – as well as being informative. A toolkit included recommended playlists and wellbeing boxes of books, fanzines and bath bombs alongside NICE recommended breathing exercises. A celebrity matching game in the workshops helped young people realise what can be achieved alongside a mental health condition. Not everyone can be Zayn Malik from One Direction, but his eating disorder has not stopped him achieving his musical ambitions. These proved to be powerful messages.

The project trained and supported 30 young people who had lived experience of mental health conditions (either themselves or within their families) to become Champions. Again, this demonstrates how closely **co-production**, **recovery** and **peer support** weave together to result in positive outcomes for all those involved.

Hannah Lewis, Rethink's Senior Policy and Practice Manager describes how one young woman with social anxiety went from attending a workshop when she was in Year 13 to becoming a Step-Up Champion and delivering that same workshop in other schools. With support and training she then became a Rethink Young Champion and delivered co-production training to CCGs across London. She spoke of her experiences at the annual conference. Now she is a part-time permanent Rethink staff member, whilst also studying psychology at university. Again, the benefits to all are clear.
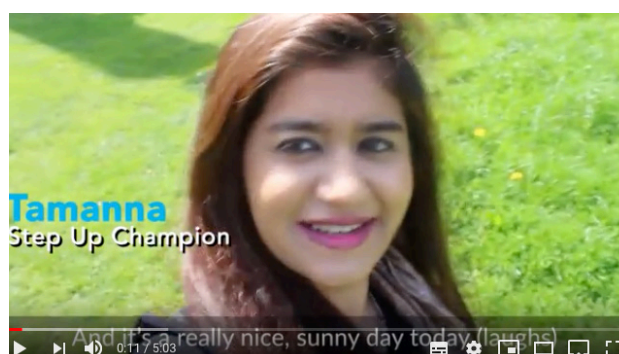
WHAT DO WE NEED TO DO TO MOVE POLICY TO PRACTICE?

Isaac Samuels is not the only person being clear that these are difficult times. At the same TLAP event, a member of the audience who has used services for 35 years commented how the first twenty years were 'awful', the next ten 'better' but the last few 'deteriorating'. Ground that was gained is being lost again as people battle with "dysfunctional bureaucratic systems".

But Isaac is equally clear that recovery-focussed practices, co-production and peer support are the game changers. These need to be seen alongside the changes that the NHS Long Term Plan and Personal Health Budgets might bring.

Claire Murdoch NHS England's National Mental Health Director and Mark Winstanley Rethink CEO, are both clear about wanting to make the NHS Long Term Plan real for people who use mental health services.

TLAP's own **Making it Real** is a good place to start delivering this agenda. It's specifically designed to support all organisations get better at personalisation across health, social care and housing: www. thinklocalactpersonal.org.uk/makingitreal/about/.

The co-produced "I" statements describe what good or outstanding care looks like from an individual's perspective. The "We" statements provide clear guidance on what organisations should be doing to deliver these standards for people. Because the focus is on people, they are as relevant in mental health settings as they are anywhere else.

Recommendation:
Mental health services commit to Making it Real and use it to improve personalised care and support for people.

Leadership is needed to ensure that policy becomes practice. Not only organisational leadership, but those responsible for holding others to account. Over 120 councils have nominated councillors as Member Champions to advocate for mental health in their councils and communities as part of the www. mentalhealthchallenge.org.uk. This initiative is led jointly by Centre for Mental Health, the Association of Mental Health Providers and several other key stakeholder organisations, who collectively provide advice, information and training. These elected members are well-placed to ensure that local services deliver on national policy.

Recommendation:

Engage with Mental Health Member Champions to hold the local delivery of the NHS Long Term Plan to account

Commissioning has a vital role to play. Short-term funding creates uncertainty for voluntary and community organisations and makes it difficult for them to effectively plan and sustain vital projects. All three examples detailed above were impacted by funding decisions and the resources and capacity needed to keep reapplying for contracts, in addition to monitoring and evidencing their impact.

The need for evidence and impact is clear, but consideration should also be given to the wider social return on investment when peer support and co-production are the means of delivery.

Recommendation:

Invest in the virtuous circle that peer support offers. Ensure that co-production is at the heart of service design and commissioning. Involve people with lived experience in designing and delivering personalised care and support to others.

Conclusion

A final point for all to consider is the need to share good practice, to show what can be achieved and to reduce the acceptance of poor services. Bridge Support, Self Help and Rethink all demonstrate what good looks like and how it can be delivered by people with lived experience. That's when personalised care is really shifted from policy to practice, because people with lived experience know and understand the difference it makes.

Think Local Act Personal

Think Local Act Personal (TLAP) is a national partnership of over 50 organisations committed to supporting the continued implementation of personalisation and community-based health, care and support. We offer information, web tools and forums to support social care policy and practice. All our events are free to attend and our networks and forums are open to anyone to join. This document is published online and can be found at www.thinklocalactpersonal.org.uk/Latest/Making-it-real-for-personalisation-in-mental-health

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