Hope for Better Mental Health:
Exploring co-production and recovery

A report exploring promising practice in Essex
Perrie Ballantyne and Julie Temperley
Foreword

It has been clear for some time that mental health provision needs a fundamental re-think. Important conversations are taking place around parity with physical health, funding, coordination and so on, but we are delighted that this report by ThePublicOffice shines a bright light on bold new ways of thinking and working within mental health in Essex. The six emergent initiatives that are featured have fundamentally re-thought where the agency and power for recovery comes from. They have designed approaches that seek to put citizen agency and capability centre-stage, at every stage.

Let us be clear: co-production is not ‘service user involvement’. It is easy to think of co-production as involving a few volunteers, or inviting a patient to sit on a Board. This report shows clearly how that sort of thinking entirely misses the point. It highlights what these six initiatives are doing that is so very different, giving us a compelling insight into the really important features of co-production.

These initiatives focus on recovery.

They have a value-base that says:
- Recovery is possible and people are intrinsically capable
- Too much of most provision works against recovery
- Co-production actively supports recovery
- Significant changes to systems and culture are needed

And those leading the initiatives are explicitly:
- Listening to and learning from people and their families
- Empowering people with personal experience to work alongside those with professional experience
- Giving people more choice and control so that they can meet individual needs and realise individual outcomes
- Equipping people with the knowledge and skills to manage their own health and wellbeing
- Enabling peer support to flourish in meaningful ways

This report is challenging. And rightly so. Many of our services and initiatives claim to work in this way. But they do not. We need to recognise that these attitudes and ways of working are a radical departure from business as usual. This report challenges professionals’ roles, providers’ vested interests and commissioners’ risk tolerance. It also challenges our personal and collective aspirations for all those who are living with or recovering from mental illness. It offers rich and powerful insights into the system that we want to improve, and some concrete ideas for things we might pursue together.

We look forward to continuing this important conversation with everyone who is passionate about, and hopeful for, better mental health in Essex.

Dave Hill
Executive Director for People Commissioning
Essex County Council

“Hope is important. When you’re hopeless, you feel like you don’t have a future…it’s a physical pain.”
Jane, Peer Support Worker, Recovery College

“Unless you’re going to empower a [service user] group, what’s the point of it? I don’t think in the 18 months I’ve been on the Board we’ve influenced or changed one thing.”
Kevin, Service User Board

1 The All Party Parliamentary Group argued persuasively that parity needs to be “embedded in the mindset of all health professionals and policy makers” – Parity in Progress? APPG on Mental Health, March 2015

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Introduction

Recently there has been a noticeable shift in the way that commissioners and providers talk about the role of citizens in delivering great outcomes within Essex. Questions are being asked about whether professionals are always the best or only people to call on when times get tough, and roles for families, friends and service users themselves are being explored across the spectrum of public services.

Terms like ‘user engagement’ and ‘co-production’ are becoming part of the everyday language we use to describe elements of both strategy and operation in public service provision. Whereas previously these were terms that might be met with caution, now they are more enthusiastically embraced, supported as they are by evidence that holds out the hope of improved outcomes, including recovery and reduced costs.

However, generally speaking, practice lags behind rhetoric. The ‘idea’ of co-production has gathered pace, but it is an on-the-ground reality only in small pockets, led by a handful of bold and creative commissioners, practitioners and system leaders who are seizing this agenda and innovating to develop new and exciting ways to work with service users.

This report focuses on initiatives led by individuals working in mental health in Essex who have been motivated by the desire to radically improve outcomes and driven by the need to dramatically reduce costs.

The case for innovation in mental health

Mental health has long been dominated by clinical services, where drugs, therapeutic intervention, hospital in-patient care and residential placements are used in combination to treat those with both acute and chronic mental health problems. There is a growing consensus that this medical model is unsustainable in the long term for two related reasons:

Demand is rising fast

One in four people in the UK will suffer a mental health problem in the course of their lives. In Essex this figure is slightly lower at around one in six.

Although the actual number of people experiencing mental health problems is likely to remain stable for the foreseeable future, more people whose mental health problems currently go untreated are predicted to come forward as a result of increased awareness and better diagnosis. Public health campaigns intended to reduce stigma and encourage people to seek early help mean that demand for recovery is the prize

Treating people with mental health problems is incredibly expensive

£105 billion per year is spent nationally on mental health, and costs are expected to double in the next 20 years. In Essex in 2012-13 an average of £60,000 per 100,000 citizens was spent treating the symptoms of depression and anxiety alone.

Mortality rates amongst people with mental health problems are about twice as high as those for the general population. At the time of writing (October 2015), 62 people per 100,000 with mental health problems had committed suicide in Essex in 2015. Each suicide is estimated to cost an average of £1.4m, accounted for in the deployment of emergency services; acute care in hospital; police investigations; and coroners’ and other legal costs.

And there are other costs too. In Essex in 2013 only 15.9% of people being treated for mental health problems were in employment, representing a significant cost to the local economy.

There is complexity in calculating costs like these which can make it difficult to develop a convincing business case for innovation. In fact several of the initiatives highlighted here have struggled to gain support from Clinical Commissioning Groups for this reason.

But the case for more of the same can no longer plausibly be made against a backdrop of economically and politically driven disinvestment in public services. Needs unmet by the current system are growing: we need a different approach.

Recovery is the prize

Of course the best way to reduce costs and improve outcomes is for service users to recover – to get better. This is a surprisingly radical concept in mental health. Once diagnosed, service users often stay within the system for years, struggling to envision a future that’s different and better than the difficulties they face in the present.

The innovators at the heart of Hope for Better Mental Health are committed to the possibility of recovery for service users.

Recovery is about individuals being able to build and manage a meaningful and productive life regardless of whether or not symptoms and problems persist or recur. Recovery is a set of values about a person’s right to build a purposeful life for themselves, with or without the continuing presence of mental health symptoms.

Recovery is based on ideas of self-determination and self-management.

Recovery emphasises the importance of ‘hope’ in sustaining motivation and supporting expectations of an individually fulfilled life.

Co-production supports recovery

Co-production does NOT mean including a few volunteers in a service, or having a service-user on a Board. It is much, much more radical. Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their friends.

When outcomes are co-produced in this way, both professionals and citizens become far more effective agents of change. Co-production mobilizes the strengths and assets of service users to help them live happier and more fulfilling lives.

The critical connections between co-production and recovery are hope and belief; the hope for a better future and the belief that poor mental health need not be a barrier to living well.

“Who is going to do this with you? There is no point in just having people talking. You’ve got to have people doing it.”

Former Manager, Recovery College

“One of the things we need to avoid is creating a dependency culture … what we should be encouraging people to do is get strong and be part of the wider community.”

Strategic Lead, Zero Suicide

The innovators at the heart of Hope for Better Mental Health

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# Overview of the six initiatives

Hope for Better Mental Health explores six initiatives in which recovery and co-production are combined with powerful results in the form of radically improved outcomes for service users.

1. **Recovery College**
   - **Building personal strength and resilience** and helping people to fulfill their potential through a peer-led educational programme.

2. **Personal Budgets and Personal Health Budgets**
   - Enabling choice and control through Personal Budgets and Personal Health Budgets.

3. **Sociability**
   - Supporting people with mental health problems to develop and run their own peer support initiative.

4. **Carer-led Workforce Training**
   - Learning how to deliver better support to carers by building relationships, and laying the groundwork for a programme of carer-led workforce training.

5. **Zero Suicide**
   - Raising awareness of suicide and the signs of mental distress, and skilling-up the community and workforce to deliver ‘first aid for mental health’.

6. **Intensive Enablement**
   - Helping people with complex needs to move from residential or in-patient care to independent living with personalised support.

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**1. Recovery College**

Building personal strength and resilience and helping people to fulfill their potential through a peer-led educational programme.

Recovery College in Essex has been part of a significant national drive to support recovery in mental health and to encourage people to be active in their own self-care and well-being, manage their conditions, and live happy and fulfilling lives. Complementing existing mental health services, Recovery Colleges offer workshops and courses to provide the tools to help people become experts in their own recovery or in the recovery of someone for whom they care.

Based on the successful practice developed by the Nottingham ImROC programme (Implementing Recovery through Organisational Change), the Recovery College model is innovative and ambitious, aiming to completely transform the way a broad group of players - especially service users, families and professionals - think, act and work together to influence mental health outcomes.

Recovery College in Essex has been a partnership between service users and carers, Mid Essex Clinical Commissioning Group, Adult Community Learning, North Essex Partnership NHS Foundation Trust and Essex County Council. It ran as a pilot programme for 15 months, concluding in April 2015. During this time the College delivered a varied curriculum of educational courses focused on improving mental health and wellbeing. It helped each student (not ‘patient’) to identify goals and ambitions whilst helping them to develop confidence and skills and give them support to access wider opportunities.

**Co-production is what the Recovery College is based on – the ethos runs through the whole process. We encouraged people to share, and we shared ourselves too – talking about our lives and our experiences. People lost their mental health identity and became just people. I didn't feel like a clinician. It's very different to what I've experienced in mainstream services.”**

Former Manager, Recovery College

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**Immediate challenges for the initiative:**

- How to ensure that commissioners reflect on the learning from the pilot and understand how to take forward the strongest lessons.
- How to address the health and wellbeing needs of people involved in the pilot. There is a good deal of disappointment and bewilderment from people who invested significant time and energy to the initiative.

**2. Personal Budgets and Personal Health Budgets**

Enabling choice and control through Personal Budgets and Personal Health Budgets.

**3. Sociability**

Supporting people with mental health problems to develop and run their own peer support initiative.

**4. Carer-led Workforce Training**

Learning how to deliver better support to carers by building relationships, and laying the groundwork for a programme of carer-led workforce training.

**5. Zero Suicide**

Raising awareness of suicide and the signs of mental distress, and skilling-up the community and workforce to deliver ‘first aid for mental health’.

**6. Intensive Enablement**

Helping people with complex needs to move from residential or in-patient care to independent living with personalised support.

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2. Personal Budgets and Personal Health Budgets

Enabling choice and control through Personal Budgets and Personal Health Budgets

Personal Budgets and Personal Health Budgets are sums of money to support a person’s health and wellbeing needs. They are part of a national policy imperative and a significant system transformation away from ‘one size fits all’ approaches and towards greater personalisation of health and social care services.

Personal Budgets relate to people’s social care needs and are managed by Essex County Council, while Personal Health Budgets are designed to support people to live with long-term health conditions and are managed by the CCG.

Personal Budgets were first introduced in Essex in 2008 and Personal Health Budgets were launched very recently in Basildon and Brentwood (in May 2015).

Prior to the introduction of personalised budgets, people had no choice but to accept the limited set of health and social care options that ECC or the CCG commissioned (regardless of how well these met needs or supported individual recovery plans). Personalised budgets aim to give people with social care needs and long-term health conditions greater choice and control over the support they access, and can be used to pay for a wide range of items and services, including therapies, personal care and equipment.

Commissioners from both ECC and CCG champion the arrival of personalised budgets and the greater choice and control they offer people. They are excited to see the ways in which people are deploying their budgets to unlock very different kinds of opportunities.

Personal Budgets and Personal Health Budgets require people to make active choices about the support that will best help them maintain health and wellbeing. They signal a very different direction for a system that has, until recently, been characterised by block contracting with providers of ‘one size fits all’ services, such as day care centres. As they introduce Personal Health Budgets, the CCG has necessarily also been negotiating a process of stopping block contracts and de-commissioning services in order to open up space in the market for offers that are truly user-centric.

Immediate challenges for the initiative:
- How to integrate Personal Budgets and Personal Health Budgets. People are currently assessed for their health and social care needs through two separate processes — one led by ECC and one by the CCG. Though efforts have been made to streamline these processes, making two assessments to two different boards is confusing for service user and for practitioners. Some would argue that the only way forward is to integrate funding streams.
- How to develop the market for budget holders. Commissioners are thinking about how they help people to think about options, and the role commissioners might need to play in developing a new marketplace of services and support for budget holders. Choice and control may be the ambition, but it is not yet a fully-fledged reality or service users.

3. Sociability

Supporting people with mental health problems to develop and run their own peer support initiative

Sociability is a recently formed Charitable Incorporated Organisation (CIO) which aims to provide a safe, social environment for members of the Basildon community who are or have been affected by mental health distress or prolonged loneliness. It is a support mechanism for local providers to develop a peer-led model and was established by people who used to attend a local mental health day centre run by a local arm of a national charity in Basildon. The day centre closed, and some of the people who used the facility stepped in to provide a new place for peers to meet.

This peer support initiative is one important development connected to a significant system transformation in health and social care in Basildon and Brentwood. The CCG has been striving to offer people with long-term health conditions greater choice and control in the support they can access so that it better meets their needs.

As it introduced Personal Health Budgets, the CCG also reviewed block contracts for existing services, such as day care centres. Commissioners found that certain facilities — including the day centre in Basildon — were not helping people to recover and achieve good outcomes (they often had the opposite effect of fostering dependence on services). Commissioners made it clear to the provider of the day centre that the block contract could not continue and that a new model of support for mental health in the area would be sought: one that aimed to encourage resilience and enablement. They stipulated that peer support would be a key element of a future model. Despite being given 18 months to explore solutions, the provider was unable to respond with a new model that fitted the ambition.

The announcement of the closure of the day centre in Basildon caused outcry amongst those who used it (by the CCG’s own admission, citizens had not been well enough informed of the future direction of local provision). They began a campaign to save the centre, which was later picked up by local newspapers and politicians. An organised protest was averted when the local CCG asked to meet with leaders of the campaign and explained their ambitions. Following the meeting, a small number of the service users came forward to commissioners and declared themselves as being interested in establishing a new peer support model in collaboration with professionals.

The CCG and the council supported the group to complete all the appropriate administration and background checks and to find suitable premises. They brought a new provider on board to offer peer support training for the group. The provider is also offering key workers, to help monitor things on-site and support the group during the transition, with the aim of reducing the need for this support as time goes on.

Whilst being an inspiring story of empowerment, everyone involved recognises that the model still has a long way to go to achieve the levels of reach and impact desired. All however also recognise the project as a huge step in the right direction, generative of learning for how to manage a major system transformation.

Immediate challenges for the initiative:
- How to ensure the leaders of Sociability are supported to attend their own health and wellbeing needs, while engaged in the process of setting up a new initiative.
- How to help leaders arrive at a viable and effective model for the delivery of peer support (i.e. what ongoing training and support will be available for peer supporters)?
- How to meet the needs of those not eligible for Personal Health Budgets. Only 40-45% of people who once used the day care centre in Basildon meet eligibility criteria. Commissioners are keen to work with them to ensure they are able to access support.
4. Carer-led Workforce Training

Learning how to deliver better support to carers by building relationships, and laying the groundwork for a programme of carer-led workforce training

Colleagues from the Social Care Leadership Team at the North Essex Partnership NHS Foundation Trust (NEP) are initiating a new programme of work to learn from carers about the experience of supporting someone with mental health challenges.

The central aim is to empower a small cohort of carers to work with the Trust to deliver workforce training that enriches people’s understanding of the pressures, realities and value of the caring role. Following a similar approach to Recovery College, the leaders of the initiative intend to create a group where everyone brings something to the table. They will facilitate a co-design process where carers work with professionals to develop a curriculum and an approach to learning for the workforce. The ambition is to pay carers who sign up (because, as the Trust’s Associate Director for Social Care says, “You can’t have one person being paid and another not being paid”) and to establish a Code of Professional Conduct (“Just as we must abide by rules of conduct, so must they. Everyone must respect each other and not judge each other”).

This initiative has been prompted by the low number of people who participate in the Carers’ Assessment, which is designed to help the Trust review carers’ own health and well-being needs. Through the assessment, they can then signpost carers to a range of support or enable the delivery of respite and other kinds of provision to which they may be entitled. The 2015 Care Act put carers on the same legal footing as service users and the Trust has performance targets around their support of carers. It is therefore keen to understand much more about the lives of carers and how they can best be supported.

The work has been influenced by a co-production ethos and its leaders’ practical experience of working on programmes such as Recovery College. It is starting with a blank page – connecting with carers’ experiences of life and services in an open and exploratory way as a first step to evolving and improving the system that supports them and those they care for. The project leaders are currently mapping support groups for carers across the Trust and holding meetings with carers to engage them and build relationships.

By Christmas 2015, leaders of the initiative hope to be agreeing an approach to training with carers and planning for delivery, with a view to seeing improvements to services and support in 2016.

Many professionals have the perception that carers are difficult. We want to try to challenge the myths and stereotypes and understand their value – because they are allies in the delivery of care. They have skills and knowledge that professionals don’t have. It’s important for professionals to hear the reality of their lives and what it’s like to be at the receiving end of a service. The aim of the project is to put things on a different footing.”

5. Zero Suicide

Raising awareness of suicide and the signs of mental distress, and skilling-up the community and workforce to deliver ‘first aid for mental health’

The Mid Essex Suicide Prevention Project is part of a group of recent pilots led by the East of England Strategic Clinical Network that are hoping to dissolve myths about suicide, shift the discourse around mental distress and provide a more systematic approach to supporting people. The aim is to raise awareness of mental health issues and ensure that a range of professionals are better equipped to respond to people who are suicidal, depressed or in mental distress. It also aims to educate and empower carers and the wider community so that they too know how to respond to and support people in distress.

The Mid Essex pilot has focused first on skilling-up primary care staff around suicide prevention. It delivered training – SafeTALK and ASIST (Applied Suicide Intervention Skills Training) – to over 100 people working across all disciplines and received positive feedback. It has also explored the feasibility of training all practice nurses and GPs as well as ensuring that medical receptionists are equipped to provide a basic mental health ‘first aid’.

This work is modelled on an innovative and successful approach to suicide prevention pioneered by Dr C. Edward Coffey in Detroit’s Henry Ford Health Care System’s Depression Care Programme. Setting an ambitious goal to ‘eliminate suicide’, Coffey developed a set of protocols and practices that are much like a ‘first aid’ for mental health. Hallmark features of the ‘Zero Suicide’ approach include:

- skilling up a broad range of people (GPs, paramedics, police and more) to recognise signs of mental distress and to respond appropriately
- encouraging open discussion about distress and suicide
- ensuring people who need support are swiftly linked to Cognitive Behavioural Therapy programmes and that regular check-ins occur
- working with family and carers to recognise and remove access to things that might enable a person to commit suicide.

Coffey’s programme provides a full spectrum of mental health services through a large integrated delivery system. Impact has included 11 years without a single suicide in Henry Ford patient population.

Working closely with service users and families is a fundamental feature of the original Zero Suicide approach and leaders of the pilot intended to start their work by connecting closely with this group. However, this did not happen as planned and the initiative has struggled more than other pilots in this programme. Leaders are reflecting on the reasons for this and are keen to learn from the success of other pilots (particularly Cambridge) where leaders were able to mobilise energetic campaigns for change by working closely with people suffering mental distress and their families. Reaching out to people and families and exploring how clinicians can work with them to provide better support to people at risk of suicide, is a clear priority and future ambition for Mid Essex.

Immediate challenges for the initiative:

- How to reach out to carers, bring them on board and build their capacity to lead professional development for the workforce.
- How to prepare the workforce to participate and create the conditions in which professionals will want to take up a learning opportunity that will help them to make changes and improvements to their practice.

There is a certain attitude amongst health professionals that, ‘You can’t stop people killing themselves’. It’s pervasive. There is also a feeling that you shouldn’t involve families and carers and that you shouldn’t talk openly about suicide because it gives people ideas and makes them more likely to suicide. This just isn’t the reality. Doing something is better than doing nothing.”

Strategic Lead, Zero Suicide

“I kind of wondered if they were ever going to listen to me. But they did eventually. They definitely needed some encouragement to listen to the voice of someone like me.”

Diane, participant in Zero Suicide initiative

“* Other projects are happening in Cambridgeshire, Hertfordshire, Bedfordshire and Peterborough
6. Intensive Enablement
Helping people with complex needs to move from residential or in-patient care to independent living with personalised support

Intensive Enablement is an initiative from Essex County Council (ECC) that helps people with a history of mental health challenges to move from residential or in-patient care to independent living in the community. It provides short term high-intensity help within a supported housing setting, where the focus is to help people to stabilise their mental health and increase skills for living independently. The aim is to enable people to move into more independent settings within 18 months.

Historically, ECC spends a greater proportion of its budget for mental health services on residential and nursing care than other similar authorities. It has been seeking to change this as part of an approach to promoting recovery and self-management and increasing people’s ability for independent living. It is also expected that Intensive Enablement will help to release significant savings in the system: people coming through this pathway are leaving residential care where it might have cost the council £50,000 a year to accommodate them and meet their care and support needs.

“Residential care is doing to and not doing with. This programme speaks to people’s strengths rather than what people can’t do. It puts them in a positive position. It’s a paradigm shift – they get a tenancy and are well-supported and you can see people thriving.”

Strategic Lead, Intensive Enablement

Intensive Enablement offers a supportive journey out of residential care into independent living for people who might not previously have considered this a possibility. It supports some of the most complex and expensive cases in mental health services. People may never have held a tenancy or paid bills, not be able to cook, have no connections in the local community and have needs which are challenging. People referred to the service are likely to have a named care coordinator, be in receipt of secondary mental health services, meet National Minimum Threshold eligibility criteria (Care Act 2014), or be subject to Section 117 of the Mental Health Act.

The initiative provides flexible and tailored support (individuals have choice and control over how they use their support hours) and focuses on helping people to achieve their desired outcomes. Support activities in and around settings promote recovery and social inclusion and provide service users with the resources, information, skills, networks and support they need to manage their own condition as far as they are able. While the aim is to help people to move on in 18 months, some individuals need to stay for longer and these decisions are made on a case-by-case basis between the provider (Metropolitan) and the commissioners.

Intensive Enablement is delivered in a number of locations and settings across Essex, including Russell Road in Clacton and the newly-opened Mersea Road in Colchester. There is funding available for 79 tenancies and 41 tenancies are currently operative.

“People are very closeted away from opportunities for recovery – they don’t believe it’s for them. We’re chiselling away at their thinking. Sometimes Mum, Dad and current provider are saying, you can’t recover. Once we’ve worked away at that negativity, you do find people jump at the chance.”

Strategic Lead, Intensive Enablement

Immediate challenges for the initiative:
- How to help people believe that recovery is possible for individuals and especially negotiating the resistance and ambivalence of providers and families who might have different ideas about where people should be and how they should live.
- How to bolster the support offered to people to aide transition into the initiative in key areas, such as managing drug and alcohol dependencies (now that people are newly free to come and go in supported housing).
This section describes three personal experiences from mental health challenges that we see the strongest illustrations of impact. It is in the stories of people participating in these new initiatives and recovering co-production on recovery.

Three life stories - the impact of co-production on recovery

It is in the stories of people participating in these new initiatives and recovering from mental health challenges that we see the strongest illustrations of impact. This section describes three personal experiences.

"I think as Tutors by Experience we were able to offer a very rare and useful type of empathy with people who were not well."

Annette, Tutor by Experience, Recovery College

Annette is in her early 50s and lives by herself in Mid-Essex. When the Recovery College Hub was operating in Chelmsford, she worked there as a ‘Tutor by Experience’. She found this incredibly fulfilling and enjoyed being able to use her own personal experiences to help others through mental health difficulties. This also helped her with her own recovery.

Annette was diagnosed with depression over twenty years ago. She had a long period with what she described as a “bad psychiatrist” during the 80s, and was diagnosed with endogenous depression. She has more recently been diagnosed with bi-polar disorder. She is now really interested in alternative therapy and sees a number of alternative therapists alongside her care co-ordinator.

Annette previously worked as a secretary in the City. Since her mental health worsened, she hasn’t been in full time work for many years. She is currently self-employed, working as a carer for a local elderly couple and conducting mental health research for a Charitable Foundation. She likes the freedom of self-employment and recognises its value to her own mental health, as it enables her to manage her own time according to her wellbeing.

Annette was introduced to Recovery College by Colchester MIND and put herself forward to be involved. Soon, with training from an Adult Learning Centre and support from colleagues at the College, she was teaching classes about managing anxiety, bi-polar and self-esteem. Having never taught before, Annette found it challenging at first to learn the techniques of teaching a group of people and on such a deeply personal basis. However, over time she became confident in her abilities and more able to openly express the difficulties she had herself experienced.

Annette found it incredibly therapeutic to work as a Tutor in the College. She explains that it helped her to feel like she’d left behind a diagnosis that she had been associated with for over twenty years. Talking about her mental health problems in the past tense was one of the biggest markers of the impact of her recovery.

"This is practically my full time job, but I love it.

It keeps me busy and I’ve learnt how to manage my own health with it."

Tim, Founder of Sociability

Tim is in his 50s and lives with his family in Basildon. He’s a mental health entrepreneur who is currently developing a new initiative to support people with mental health challenges. His initiative, Sociability, is a peer-led support network in Basildon. He hopes to grow the network over the next few years.

About 20 years ago Tim started to struggle with anxiety and depression, which culminated in a breakdown when he was in his early 30s. Tim attributes his declining mental health to his mother’s battle with cancer and his wife being diagnosed with Multiple Sclerosis. After being admitted to hospital and meeting with various psychiatrists, he was diagnosed with anxiety, depression and agoraphobia.

Since Tim lost his own job as an operations manager for the London Underground he had been looking for a way to build his confidence and fill his time. He had attended a local support group in Basildon before it was closed down in May 2015. After initially campaigning against its closure, he decided, with the help of the CCG, to set up his own peer support network. He felt frustrated about the lack of professionals who “understand what it’s like to be in that dark place, with those dark thoughts” and saw that connecting with people with experience could play a powerful role in recovery. It is important for him, through his own organisation, to facilitate the forging of strong relationships between people with ‘lived experience’ of mental health problems.

Tim’s involvement in Sociability has also had a positive impact on his own health and well-being. Organising activities, writing to funders and preparing the weekly food keeps him busy and he has learned to cope and manage his own health alongside this. He also finds it incredibly rewarding to help other people through their own difficulties and to put his personal experiences of mental health challenges - as well as his many other skills and capabilities - to good use.

"I’d go on these chat forums and I thought, what if we had similar to the internet, without the internet, what if we had a totally user led organisation?"

The training people have done is years of dealing with mental illness. That person, rather the person who has been to university, could offer someone with panic attacks much better support.

If you have trouble getting to the shops, I’m going to help you with those obstacles. We focus on your strengths, not your illness – not what you can’t do. And we’ll take tiny steps and move forward. And it can work. I wouldn’t tell anyone you’ll be better, but you’ll be fine. You’ll get to a point where you can be sat here and not in the bedroom."
Diane, Member of the Zero Suicide Programme Board

Diane is in her 60s and lives in Cambridge. She is slowly rebuilding her life after her son’s suicide three years ago. Diane has been a member of the Programme Board connected to the Zero Suicide programme. Involvement in this activity and reaching out to others with experience of suicide is playing an important role in her healing process.

Diane had a long career as a General Nurse and still works in the local community as a Chiropodist. Her natural disposition is to care and support others – so much so that she often finds herself sending messages to her son’s friends on Facebook when they appear to be down or distressed.

Immediately after her son’s death, Diane found it most helpful to connect and network with others who had been bereaved from suicide. She was put in touch with Zero Suicide after attending a local carers’ group for individuals supporting family members, partners or friends with depression. She described feeling incredibly motivated by the message that the goal for suicide prevention should always remain at ‘zero.’

Diane had become involved in a number of carers’ groups and suicide prevention initiatives since the death of her son. She hoped to meet others in a similar situation and also, in some way, gain an understanding of why he decided to take his own life. Meeting with others in a similar situation has been helping Diane come to terms with the loss of her son. In some ways she also understood her involvement as promoting her son’s legacy after he had expressed an interest in joining and promoting a similar initiative prior to his death.

For Diane, one of the hardest things to come to terms with was how difficult it is to openly discuss the reasons behind suicide. Being able to meet with others who held similar views and experiences had begun to ease the distress these questions were having on Diane’s well-being.

Attending her local carers’ group and forging a network of bereaved Mums were the two outlets she valued most as part of her own recovery.

Diane believes families and carers need to be involved in the development and delivery of support services. For her, the involvement of close support networks could not only improve the design and delivery of mental health services but could ultimately prevent future suicides.

“...My involvement came from thinking about what could have helped us after our son died and wanting to share this to help other families.”

“...He said to me that if he got better he would have liked to do something like peer support, so in a way I’m doing this for him. I mean, if someone dies from cancer people go off and do a marathon. This is my version of that.

I meet up with a couple of mums, we meet up for coffee and go out for walks. It’s brilliant. You see it from other people’s point of view – we go off for a chat and a little laugh. I find as the grief gets a bit easier I think can I do it, the grief was spurring me on, but if I can help someone I will.

The culture of families is an important part of people’s lives, people fall back on that more than medicine.’’

We think the following features of co-production are highly significant in relation to these initiatives:

Beliefs and attitudes: What fundamental values and principles are driving these initiatives?

1. Recovery is possible and people are intrinsically capable
   - The six initiatives are all premised on a belief that recovery is possible for people who experience mental health problems.

2. Too much of what happens now actively works against recovery
   - The new models that are visible in these initiatives respond to the belief that traditional and current mainstream provision for mental health too often denies people opportunities to become well and recover.

3. Co-production actively supports recovery
   - The six initiatives make an important link between co-production and recovery. When people work with professionals who consistently remind them of their abilities and their potential, and who give them opportunities to demonstrate these things to themselves and others, it builds confidence and strength.

4. Significant system and culture change is needed for better mental health
   - A profound shift in culture is needed around mental health. Within these initiatives there is a strong view that mental health problems are highly stigmatized and misunderstood in both clinical practice and in wider society.

Behaviours and practices: What distinctive actions are being taken within these initiatives?

1. Deep listening and learning
   - Listening to and learning from people and their families, and ensuring key insights influence practice.

2. Empowering people with experience and shifting power
   - Empowering people with personal experience to work alongside people with professional experience in ways that fundamentally transform professional practice and traditional power dynamics.

3. Equipping people with knowledge and skills
   - Giving people the knowledge and skills they need to manage their own health and wellbeing.

4. Giving more choice and control
   - Giving over more choice and control so that people can meet their own needs and realise their individual and personal outcomes.

5. Enabling peer support to flourish
   - Enabling peer support to flourish and grow in ways that contribute meaningfully to wellbeing and recovery.
Beliefs and attitudes: What fundamental values and principles are driving these initiatives?

1. Recovery is possible and people are intrinsically capable
   The six initiatives are all premised on a belief that recovery is possible for people who experience mental health problems.
   In this context recovery doesn’t necessarily mean believing that people will not be unwell again, it means understanding that people can build and manage a meaningful and productive life regardless of whether or not symptoms and problems persist or recur. When commissioners, designers and practitioners think that people are intrinsically capable, they focus on providing the kinds of support that give people hope and opportunity to improve their mental health and lead fulfilling lives.

2. Too much of what happens now actively works against recovery
   The new models that are visible in these initiatives respond to the belief that traditional and current mainstream provision for mental health too often denies people opportunities to become well and recover.
   Key elements of the traditional system, such as residential homes and day care centres, reinforce people’s sense of being unwell, incapable and dependent. They ‘hide people away’, ‘keep people where they are’ and ‘treat people in a sick role’.
   Those who are leading these initiatives are actively developing new approaches that flip all this on its head by reminding people of their strengths and potential and supporting them to rebuild confidence and develop skills for an independent life.

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4. Significant system and culture change is needed for better mental health
   A profound shift in culture is needed around mental health. Within these initiatives there is a strong view that mental health problems are highly stigmatized and misunderstood in both clinical practice and in wider society.
   The prevalence of mental health problems is often underestimated and there are hidden costs to public services as a result of our poor response. Currently we have a system that fails to spot the first signs of distress and provide appropriate support, consistently missing opportunities to prevent problems before they become crises. These issues need to be brought to the fore and there need to be more open, honest conversations about the systemic problem and the possible solutions.

Behaviours and practices: What distinctive actions are being taken within these initiatives?

1. Deep listening and learning
   Listening to and learning from people and their families, and ensuring key insights influence practice.
   Embracing co-production means starting with a blank page and open, exploratory conversations which put real people at the heart of the matter. These leaders undertake deeply attentive listening and apply genuine effort to building relationships as a way to understand the realities of people’s lives.

   This has nothing to do with consultation or surveys or many of the standard mechanisms for bringing the views of service users and carers into the mix. It has everything to do with listening and learning as a constant habit of mind.

   By looking for ways to embed listening and learning into their regular ways of working, professionals are able to ensure that the views of service users and carers constantly improve their practice and influence the overall shape of things.

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   **Carer-led Training for the Workforce**
   Leaders are looking to improve support for carers by first understanding more about what life is like for them. Prompted by the low numbers of people participating in the Carers’ Assessment (which reviews and responds to carers’ health and well-being needs), the Trust is conducting a series of open conversations across Essex to get to know people and understand their concerns. They have a bigger ambition through this project to recruit a cohort of carers to help to facilitate workforce training to improve support to carers.

   **Zero Suicide**
   The initiative has the ambitious aim to eradicate all instances of suicide using an approach pioneered by Ed Coffey in Detroit. The approach encourages clinicians to work closely with service users and their families so that everyone is aware and better able to support a person in distress, and the person is better able to support themselves. It involves deep listening to and learning with people and has inspired a series of UK pilots, including one in Mid Essex.

   **Have conversations with the people you provide services to. It really changes the conversation when you involve service users.”**
   **Strategic Lead**

   **“I don’t think I ever truly told my psychologist the truth because it felt stupid. I thought he was better at life than me.”**
   **June, Peer Support Worker, Recovery College**

   **“People are very closeted away from opportunities for recovery – they don’t believe it’s for them. We’re chiseling away at their thinking.”**
   **Strategic Lead, Intensive Enablement**

   **“We need to encourage professionals and communities to be so much more open about mental health and suicidal thoughts. People worry that if you mention “suicide” you could be putting ideas in their head – in fact, the opposite is true.”**
   **Director of Development, Mental Health Provider**
2. Empowering people with experience and shifting power
Empowering people with personal experience to work alongside people with professional experience in ways that fundamentally transform professional practice and traditional power dynamics.

When co-production is most powerful, professionals value highly the expertise gained through lived experience, and see people and their personal experiences of mental health challenges as central to the design and delivery of effective support.

Professionals work alongside those who have personal experience in ways that are never tokenistic or marginal. Rather, new roles and relationships are characterised by greater mutuality and a more even power dynamic – a sense that both professionals and service users have knowledge and expertise that is valuable, and that both contributions are essential to delivering good outcomes.

“I focus on what an individual can do as opposed to what they can’t do. That’s so important when you’re dealing with mental health problems.”
Tim, Peer Supporter, Sociability

3. Equipping people with knowledge and skills
Giving people the knowledge and skills they need to manage their own health and wellbeing.

A core belief underpinning co-production is that people are inherently capable and can, in fact must, play an active role in their own recovery. Across health and social care systems there is a movement of initiatives that are seeking to dismantle a culture of dependence on public services and build a system that actively and explicitly facilitates greater independence. Equipping people with the knowledge and skills to manage their own health and wellbeing is a key feature of any system that supports independence.

By giving people opportunities to connect to and work with peers as they learn new things and put new behaviours into practice, people are also able to strengthen their social and community contacts and build relationships.

“I had to listen and learn a whole lot [at the Zero Suicide meetings]. They have their own language. I didn’t say much because I didn’t want to slow things down.”
Diane, participant in Zero Suicide initiative

4. Giving more choice and control
Giving over more choice and control so that people can meet their own needs and realise their individual and personal outcomes.

Co-production means giving people choice and control over the kinds of services and support they receive, so that their individual needs can be met and their personal recovery ambitions can be realised.

This is part of a wider shift in health and social care away from ‘one size fits all’ models of service delivery where people have little choice but to use the small set of options that councils and Trusts provide, regardless of how well these meet their needs or support their individual care and recovery plans.

Personal Budgets and Personal Health Budgets
These initiatives are a key mechanism for enabling choice and control as part of the personalisation agenda. Personal Budgets and Personal Health Budgets, planned and agreed between the person and the local Council or NHS team, allow people with long term conditions to decide how they will best meet their own health and well-being needs. The budgets can be used to pay for a wide range of items and services, including therapies, personal care and equipment.

Recovery College
A new and more even power dynamic is built into the design of the Recovery College model, which explicitly values two different kinds of expertise – professional and experiential. Service users have come together with clinicians in an intensively collaborative learning and development process, through which they create a curriculum and undertake training. ‘Tutors by Experience’ and ‘Tutors by Profession’ work side-by-side to deliver each course and, significantly, ‘Tutors by Experience’ are also paid for their contribution.

Ultimately, professionals really believe in the importance of learning from and working more closely with people with experience, often valuing this distinctive contribution more highly than their own.

There is strength in people’s individual experience and it is more important and stronger than my professional experience.”
Strategic Lead

Intensive Enablement
The initiative has set out to build people’s skills and abilities to manage their own health and wellbeing and to live independently. It wants to help people move on from in-patient care or residential care and works with people that professionals might previously have thought were not able to live independently.

It helps people to get used to managing their own personal care and equipment.

There is strength in people’s individual experience and it is more important and stronger than my professional experience.”
Strategic Lead

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5. Enabling peer support to flourish

Enabling peer support to flourish and grow in ways that contribute meaningfully to wellbeing and recovery.

Initiatives with co-production at their heart often proactively create opportunities for people with similar experiences to support one another. Within mental health peer support is valued for a range of reasons, not least because experiencing mental health problems can be extremely isolating. Too often people find themselves disconnected from friends, family and supportive influences, so providing opportunities to reconnect socially can be an important part of recovery.

There is also a fundamental value attached to the expertise gained through lived experience. It is powerful for people to connect with and be supported by people who have experienced similar challenges and have nonetheless managed to recover and to rebuild or maintain rich and rewarding lives. For those in peer support roles, actively supporting others can help keep them well. For others, working with someone who has come through challenges and now carries out a support role, actively supporting others can help keep them well. For others, working with someone who has come through challenges and now carries out a professional role can be a huge symbol of hope for what they might personally aspire to and achieve.

Sociability

In Basildon the CCG has commissioned a mental health provider to work with a group of people with personal experience of mental health challenges to set up and run a new peer support group called Sociability. This is part of a bigger system transformation that has included the introduction of Personal Health Budgets and the de-commissioning of a day centre. The CCG believes that providing high-quality peer support is a critical part of the new system of options for people with mental health challenges, and that supporting a peer-led model (rather than delivery through an established provider) will be the most effective approach.

Recovery College

Peer support has been a key feature of Recovery College, and one that students valued immensely as part of the experience. Students worked with allocated Peer Supporters to identify learning goals and the physical Hub itself also gave people opportunities to connect with fellow students and provide mutual support. Everyone working in the College aimed to foster this kind of culture.

Peer Support Workers are there to be open, share, be human, have honest conversations. And because they are getting on with their lives, they inspire hope. They are models of hope.”

Former Manager

I wouldn’t tell anyone you’ll be better. You’ll be fine, but you’ll get to a point where you can be sat here and not in the bedroom.”

Tim, Peer Supporter, Sociability

What do commissioners need to do?

The role of commissioners is to understand both the capabilities and the needs of citizens, and to shape - with them - a whole system that best supports recovery. Commissioners need to recognise how radically different these approaches are, and set out explicitly to build the beliefs and attitudes that are critical foundations for harnessing the energy and capacity needed for co-production. Commissioners need to recognise that where these pre-conditions do not exist, the potential of co-production for recovery will not be achieved.

1. Influence across a system

Co-production suggests a completely different way for clinicians, practitioners and people experiencing mental health challenges to work together to achieve outcomes. If we truly want to embrace the potential of co-production, we need to be prepared to both give power away, and support communities to come and pick it up and share it with us. We need leaders who can inspire, engage and influence across different areas of professional practice and involve individuals, families and wider communities.

The best, most ambitious leaders are seeking to influence change on a grand scale. They are not just interested in single projects that demonstrate a new way of working; they want to create better conditions across health and social care systems for the growth of initiatives that have co-production at their heart and which focus on recovery. Whether it’s encouraging open discussion around suicidal distress or seeing the potential for independent living in long-term residents of care homes, leaders are aiming to shift attitudes and beliefs, and to win people over to the idea of a profoundly different way of thinking and working.

These leaders recognise that sometimes it’s necessary to start small and work slowly and patiently to build trust and relationships across the system, but they remain fixed on a wider ambition.

2. Become skilled facilitators of difficult conversations

As they lay the groundwork for new ways of working, leaders facilitate difficult and challenging conversations on a number of fronts - with practitioners, providers and with service users and their families. The leaders profiled in this report have had to become incredibly skilled at holding a space for the conflicts that produce new insights and understandings, which are critical for enabling new ways of working to emerge.

Key challenges for commissioners

The six initiatives and the features of co-production they illustrate are deeply challenging to received wisdom and traditional ways of doing things. They do not fit easily into the mental health services paradigm that is influencing commissioning decisions at local level. They raise considerable challenges for commissioners and other leaders who are seeking to bring about systemic transformation in the provision of support.

There are a number of key challenges that commissioners need to grapple with to create the right conditions for co-production and recovery.

SECTION FOUR:

What do commissioners need to do?

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We need strong leadership for this – strong system leadership.”

Commissioner

The most important thing is the groundwork that you do with people in the system – it’s more important than the ideas. It’s about identifying people to support an agenda, your change agents, and bringing them on board.”

Commissioner

To get to where we were had taken such a painful effort – to cut through everyone’s agendas and get to a mutual place. Professionals were coming to the table with strong feelings about what the course materials should be, but this was about having a blank sheet. On the other side, Tutors by Experience believed that professionals should behave in a certain way and give more to the programme. It was a job of constant mediation.”

Strategic Lead
3. Stop things that don’t work well or are not needed

Commissioners observe that risk assessment practices do not help a person to avoid becoming unwell or doing harm but some commissioners are beginning to see current approaches as a real constraint on the provision of good support. They are exploring and developing a different set of attitudes and practices around risk.

De-commissioning existing services may not always need to happen for a new initiative to grow, but it’s not possible to keep adding more to a system and not take things away. Where a service is failing or ineffective it is desirable to stop things, especially if the plan is to provide something that better meets people’s needs. But stopping a long relied upon public service is a highly complicated and difficult business that can easily cause significant anxiety – both amongst people who use the service (and their families) as well as those who provide it. Sometimes it is difficult for anyone to imagine better alternatives when they are so used to what is there – even if everyone agrees that it’s not good enough.

Some commissioners in this report are trying to lead difficult decisions to close and stop things, so that resources might be freed up and newly deployed in potentially better offers for service users. As they prepare for change, commissioners reflect that detailed, open conversations with everyone – especially providers and service users – are essential. In fact, as commissioners reflected on closing the day centre in Basildon and the impact for everyone involved. Recovery College provides a highly sophisticated model, with high-quality training and on-the-job support – Peer Support Workers and Tutors by Experience felt very clear about their roles and responsibilities, and they knew where to turn for support and guidance if they needed it. Such systems of support are not always in place for peer supporters but having them crucially influences the impact of schemes.

In this new and highly-specialised area it can be difficult for commissioners to understand what good looks like. They need to be able to connect with strong approaches and seek out providers who can give service users the support they need play a powerful role in co-production.

4. Understand how to support service users involved in new roles

Co-production invites service users to step into a much more active, empowered role in their own recovery, and sometimes take on roles and responsibilities that require the development of new knowledge, skills and abilities. Commissioners need to think about how to build the capability of people who are performing these new roles, e.g. peer supporters.

Offering the right kind of support to service users who step into positions of responsibility can be challenging. There are lots of peer support models, for example, but they may be very different in the kinds of support they offer and this can affect the quality of the experience and the nature of impact for everyone involved. Recovery College provides a very sophisticated model, with high-quality training and on-the-job support – Peer Support Workers and Tutors by Experience felt very clear about their roles and responsibilities, and they knew where to turn for support and guidance if they needed it. Such systems of support are not always in place for peer supporters but having them crucially influences the impact of schemes.

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5. Help providers to shape up to work differently and deliver different things

As they develop new visions for how things should be, commissioners need to work very differently with providers. Rather than simply procuring services, they need to learn to look at the market and work with providers to explore and respond to new opportunities.

This puts relations between public service commissioners and service providers on a very different footing. Providers need to learn to be open to suggestions, to adapt the things they do and the ways they work with service users. Meanwhile commissioners must learn to set a vision, and to work with the market to build the right capability to make new things happen, including finding new measures of success to drive the required behaviours and activities.

6. Think afresh about risk

Assessing and managing risk is a significant feature of professional practice across health and social care, but some commissioners are beginning to see current approaches as a real constraint on the provision of good support. They are exploring and developing a different set of attitudes and practices around risk.

Commissioners observe that risk assessment practices do not help a person to avoid becoming unwell or doing harm to themselves once they are outside the GP practice or the hospital ward. They are interested in exploring practices that empower people to be responsible for themselves: that help them to recognise their own signs of distress and become more resilient (e.g. where a service user opts to go on a yoga retreat, using her personal budget, rather than breaking down). They are interested in practices, like those that the Zero Suicide scheme advocates, that encourage friends, family and the wider community to become better at spotting the signs of distress and more skilled at knowing what to do and how to help. Current practices don’t do enough to help people be more risk resilient in their own lives – commissioners need to explore and respond to that challenge.

7. Make the case

In making the case for a different way of working, commissioners must look for evidence of better outcomes and of cost savings. But making the economic case for some of these initiatives can be really difficult. Commissioners can see that by offering an intervention in one area, they may influence outcomes in another part of the system for which they are not accountable. For example, Recovery College aimed to support people living well in the community to keep well and connected and continue in recovery. Its evaluation hoped to show reductions in crisis care. Similarly, leaders of the Zero Suicide initiative are making a case for investment that shows the social and economic cost of suicide and crisis care, and therefore the huge savings that might be released by taking a more preventative approach.

“We need to be canny about how we measure things. It’s easier to measure the qualitative impact and that’s good. But also need to make the financial case. We have to show it and we have to learn from the pilots and spread the word. We need to look at the health economic argument of NOT treating this. The cost of not treating is twice that of treating. This saves money and massively improves quality of life.”

Commissioner
Conclusion

The work under the microscope in this report is giving hope in many ways: hope to people who are journeying consciously towards recovery; hope to practitioners that it is possible to work in different and better ways; hope to commissioners that it is both desirable and achievable to surface and harness people’s capabilities to deliver improved mental health outcomes. And we know that these six initiatives are only a snapshot of great work that is emerging in pockets across the County.

However, it is clear that if we want to see more, bold and decisive action is needed:

- We need to acknowledge the importance of the beliefs and behaviours that underpin true co-production, and to recognise that these ways of working require significant disruption to ‘business as usual’ practices (both in commissioning and delivery). This will not be an easy or comfortable road to travel. We will need to be assertive and tenacious to shift deeply held attitudes. And we need to be prepared to challenge activity that claims to demonstrate co-production, but where power and control continues to reside in services and professionals.
- We need courageous strategic and political leadership at the highest level to drive this transformation coherently across health and local government. These leaders need to share clarity on the vision, including the underpinning values that see co-production as critical to recovery.
- We need actively to recruit change agents across the system, including supporting service users and other citizens to find and channel their energy and capacity.
- We must be prepared to uphold and support leaders who are pioneering co-production: they need political and managerial cover for what can be exhausting and personally challenging work.
- We need to find new and different measures of success to shore up, shine a light on, and grow the ways of working that enable co-production. These need to include performance metrics that drive collaboration across the whole system as a priority.

We are excited by the passion and commitment that we found exploring this work in Essex: we can see that change is already afoot. Our hope is that this report contributes to the continued conversation and helps move things forward.

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We have put six mental health initiatives focused on recovery under the spotlight to try to identify what they are doing that makes them so different from more mainstream programmes. Many other approaches claim to be examples of co-production, but these exemplars are characterised by a range of features that are wholly and disruptively different to ‘business as usual’. They have not just added some volunteers to existing professionally-led delivery models: they have fundamentally re-thought where the power and agency can come from to support people on recovery journeys. They are based on beliefs in different things, and they do different things as a result.

We hope this report will challenge and inspire: not just those passionate about achieving better outcomes in mental health, but also anyone who wants to understand what it will take to make people’s capabilities the central starting point for publicly-funded services.