BRIEFING

Centre for Mental Health

Dismissed on the basis of my diagnosis

Policy implications of research on community support for people with complex emotional needs

Summary

People living with 'complex emotional needs' or who are diagnosed with 'personality disorder' have for a long time found themselves excluded, marginalised and subject to discrimination in all aspects of life, including from health and care services.

Researchers working for the NIHR Mental Health Policy Research Unit (MHPRU) at University College London, King's College London, University of Greenwich, University of Birmingham and City University London have led a programme of research, with involvement from experts by experience and occupation, exploring people's experiences of community services for complex emotional needs from a number of different perspectives: including those of service users and clinical staff, from focus groups, interviews and previous studies.

This briefing draws together evidence from six published studies produced by the programme to identify key themes and threads from the research.

The researchers find clear evidence that people with complex emotional needs experience stigmatising treatment, fragmented services and a lack of support. They find that many mental health practitioners demonstrate negative views of people with complex emotional needs. And as a result, they too often either receive poor quality treatment or are turned away from services.

Where people with complex emotional needs get access to specialised services to meet their needs, it is more likely to be helpful. But this is often short-term – for example during a course of therapy – when what many need is ongoing support backed up by positive relationships with staff and holistic approaches to care.

The NHS Long Term Plan brings an opportunity to improve community-based support for people with complex emotional needs. This will require investment, including in workforce development and new service models. Integrated care systems and mental health service providers need to work together with experts by experience to identify the gaps in their current offers, and jointly develop improved services.

We recommend:

1. The Department of Health and Social Care should set out plans to improve support for people with complex emotional needs in its forthcoming mental health plan. This should include not just health and care but all public services that have an impact on people's lives and wellbeing.
2. NHS England should conduct an immediate 'stocktake' of services for people with complex emotional needs. It should ask all integrated care systems to assess the support they offer, including from specialist and 'generic' mental health services, in each place and neighbourhood in their area.
3. NHS England should earmark additional investment in community support for people with complex emotional needs in the next phase of the NHS Long Term Plan. This should include a workforce plan that sets out how both specialist and generic services will develop the capacity to offer consistently high quality care over the next five years.
4. Integrated care systems should review the support offered in their areas for people with complex emotional needs, including those with other concurrent needs or who face multiple disadvantage. This should be done in partnership with user-led groups, either system-wide or at 'place' level. Gaps and shortcomings should be addressed in the system's five-year strategy and one-year plans.
5. Mental health service providers should ensure they are providing high quality care to people with complex emotional needs and their carers and families. They should ensure that their workforce has the necessary training and supervision in place to offer the effective, non-stigmatising and compassionate care that people require. And they should seek to provide continuity of care long-term, including for people with more complex and changing support needs.
6. Education and training bodies for health and care professionals must ensure that all basic education and CPD includes relevant training in complex emotional needs. This should include training that has been developed and delivered by people with lived experience, to help to address stigmatising attitudes among professionals.
7. Health research funders must prioritise funding that addresses deficits in the evidence base for treating and supporting people with complex emotional needs, both in the community and in other settings.

Introduction

The NIHR Mental Health Policy Research Unit (MHPRU) at University College London and King's College London was established in 2017. Its aim is to help the Department of Health and Social Care and others involved in making nationwide plans for mental health services to make decisions based on good evidence. It makes expert views and evidence available to policymakers in a timely way and carries out research that is directly useful for policy. The MHPRU is managed by academics at UCL and KCL in partnership with collaborators from City University London, University of Birmingham, and University of Greenwich. Centre for Mental Health and The Mental Elf work alongside the Unit to ensure its work is accessible and relevant to policymakers, practitioners and the public. The MHPRU's Lived Experience Working Group contributes to its work.

The MHPRU has been leading a programme of research about the support in the community offered to people living in England with 'complex emotional needs'. The term 'complex emotional needs' is used as a working term "to delineate a group of service users who may have received a 'personality disorder' diagnosis or have used services for 'personality disorder' or [complex emotional needs], or who appear to have similar needs (e.g. related to repeated self-harm)" (Trevillion *et al.*, 2022). The term 'complex emotional needs' is used to indicate the MHPRU's concerns about the problems associated with the label 'personality disorder'. However, the Unit recognises that more work is needed on ways of describing these needs that are both conceptually sound and also acceptable to people experiencing complex emotional needs.

Worldwide, around 8% of the general population report having complex emotional needs (Winsper *et al.*, 2019). These figures rise to around 25% of people accessing primary care services and 50% accessing community mental health services (Beckwith *et al.*, 2014; Moran *et al.*, 2000). Despite this level of need, there is considerable variability in service quality for people with complex emotional needs, and research on care models largely fails to explore how services can provide effective care that ensures people's needs are met across the health care system.

This research programme was initiated to provide policy research evidence to inform the NHS Long Term Plan delivery of community-based services that effectively meet the needs of people with complex mental health issues, including the delivery of psychological, pharmacological and social support.

The studies

The Mental Health Policy Research Unit has produced a series of research papers sharing the results so far of its work to review evidence on:

- What support people with complex emotional needs require from health and care services in the community
- What evidence is available about effective treatment options
- What is currently provided in England.

The six papers each look at a specific aspect of the topic: two are based on interviews and focus groups with service users and clinicians, while the other four are drawn from reviews of existing literature:

1. Existing literature on service user views about current service provision (Sheridan Rains *et al.*, 2021)
2. Interviews with service users about current service provision (Trevillion *et al.*, 2022)
3. Existing literature on clinicians' views about current service provision (Troup *et al.*, 2020)
4. Interviews and focus groups with clinicians about current service provision (Foye *et al.*, 2022)
5. Literature on evidence about community treatments for people with complex emotional needs (Ledden *et al.*, forthcoming)
6. Economic evidence about community treatments (Botham *et al.*, 2021)

Looked at together, these studies begin to paint a consistent picture about the experiences of people with complex emotional needs and the gaps in both the provision of services and the evidence necessary to ensure people get consistently high-quality support. They demonstrate a structural inequity in the treatment of people with complex emotional needs that spans research (which has provided limited evidence on effective interventions), service provision and the day-to-day interactions with health and care professionals that many people encounter.

Key findings across all the studies

Effective interventions and approaches

The studies conclude that research about effective interventions to support people with complex emotional needs is sparse, but what does exist points towards the benefits of offering tailored psychological therapies. The evidence gaps are attributable largely to complex emotional needs being excluded from research prior to the year 2000, and only slowly catching up since (Ledden *et al.*, 2021).

While some research has focused on specific psychological interventions, there has been little effort to look any further. Indeed, the literature largely focuses on the effectiveness of specialist psychological treatments and there is a lack of evidence on social interventions, as well as the types of service models that work well, and best approaches for people with comorbidities and across different ages and communities. As Ledden and colleagues (2021) note, they "found little evidence regarding interventions to improve social aspects of people's lives, peer support or ways of designing effective services."

These gaps in evidence translate into a paucity of economic evidence about the cost-effectiveness of different treatment and support options. While there is economic evidence to support dialectical behavioural therapy (DBT) in particular, there is a lack of evidence on other core aspects of clinical care to support NHS or social care commissioners to secure best value for people with complex emotional needs (Botham *et al.*, 2021).

Despite this paucity of formal evidence, the studies exploring the views of service users and practitioners add to what is known and offer a positive vision of what is possible. Trevillion and colleagues (2022), for example, conclude from interviews with service users that:

*"**Relational Practice** was identified as the central overarching theme and describes how community services can best support people with complex emotional needs. This approach involves care delivered in a non-stigmatising, individualised, compassionate and trauma-informed manner. It involves care that is planned collaboratively with service users to ensure their multiple needs are addressed in a flexible, holistic and consistent way which accounts for the long-term and fluctuating nature of their needs."*

As described by a participant in that study, continuity of care and relationships is fundamental to this approach:

> *"That stability, that consistency of care, and that understanding and approach that actually this is a long-term issue"* (Trevillion *et al.*, 2022).

Another noted that, when they got more consistent support over a longer period, it helped them a lot and potentially prevented future crises:

> *"The thing that has been helpful is that in healthier periods whilst I haven't needed the same intensity of care, having that continuity of care has kept me well, as opposed to then withdrawing and me deteriorating and then needing something more intense"* (Trevillion *et al.*, 2022)

As Foye and colleagues (2022) describe, support needs to be able to 'bend and flex' as people's situations change:

"Creation of inclusive pathways and overarching views of the person in multiple systems is needed and needs flexibility to ensure that the pathways bend and flex to the chaos that someone is experiencing" (Foye *et al.*, 2022).

Sheridan Rains and colleagues (2021) add that, from previous literature on service users' views, support needs to offer a much longer-term approach. They describe a need for "support that is individualised and holistic, provides continuity over long journeys towards recovery, and that is delivered by empathetic and well-informed clinicians who are hopeful but realistic about the prospects of treatment."

In addition, service users articulate the need for services to adopt a holistic approach which addresses not only their mental health needs but also their social needs.

One participant in Trevillion and colleagues' (2022) research noted that:

> *"People [staff] will look at things like medication and therapy but life is much more than those two things. You know, how lonely people are... I think [services] needs to look at all elements of your life"* (Trevillion *et al.*, 2022).

Despite this, very few studies have focused on social outcomes.

Similarly, Troup and colleagues (2020) found that practitioners wanted to provide care that featured "a long-term perspective on treatment journeys, high quality and consistent therapeutic relationships, and a balanced approach to safety."

Experiences of existing services

> *"My experience of services is largely one of being dismissed or discriminated against on the basis of my diagnosis. I've had that from all kinds of people, from dietitians, to psychiatrists, to psychotherapists"* (Trevillion *et al.*, 2022).

The studies show that while there are examples of good quality care and effective treatment for people living with complex emotional needs, too often what people experience is "severely stigmatising treatment, a lack of effective support and service fragmentation" (Trevillion *et al.*, 2022).

There was also clear evidence of short-termism in services. Sheridan Rains and colleagues (2021) found that some people received high-quality care meeting the principles of being individualised, holistic and trauma-informed for short periods of time, but that:

"Care that met these simple and clearly stated priorities tended to be restricted to often limited periods of treatment by specialist 'personality disorder' services: generic and primary care services were often reported as far from adequate."

Practitioners in community mental health services who participated in this research – including both specialist services for people with complex emotional needs, and 'generic' community mental health teams – broadly concur with service users in identifying the gap between the care they aspire to offer and what happens in reality.

Practitioners interviewed by Foye and colleagues (2022) spoke about services needing to be "person-centred, relational, empathic, and trauma informed". But they noted that the reality was often very different. They ascribed this to "stigmatising attitudes and behaviour towards people with [complex emotional needs], especially in generic mental health services, lack of development of coherent service systems offering clear long-term pathways and ready access to high quality treatment, and lack of well-developed structures for staff training and support."

The studies also note that there is neither research nor practice evidence about support for people who have complex emotional needs combined with other needs – for example, women during the perinatal period, people who would like help with parenting roles, people with concurrent substance use problems or who are homeless, and those in contact with the criminal justice system. They also note a major gap in research and service provision for older adults with complex emotional needs (Foye *et al.*, 2022). This creates yet more gaps in practice for groups of people whose needs are overlooked and underserved.

The studies note that for some people experiencing the greatest disadvantage, access to specialist support was hampered by a belief among staff that they were 'not ready' or their lives were 'too chaotic' for psychological therapy, which meant they were unable to offer support. If specialist support only takes the form of psychological interventions, such exclusions are liable to affect those with the biggest challenges in their lives.

It is notable also that none of the research reviewed for these studies explores economic or social inequalities that intersect with complex emotional needs, despite the fact that the use of some specific 'personality disorder' diagnoses is highly gendered, and experiences of misogyny, racism and other forms of abuse and oppression are strongly linked to poor mental health.

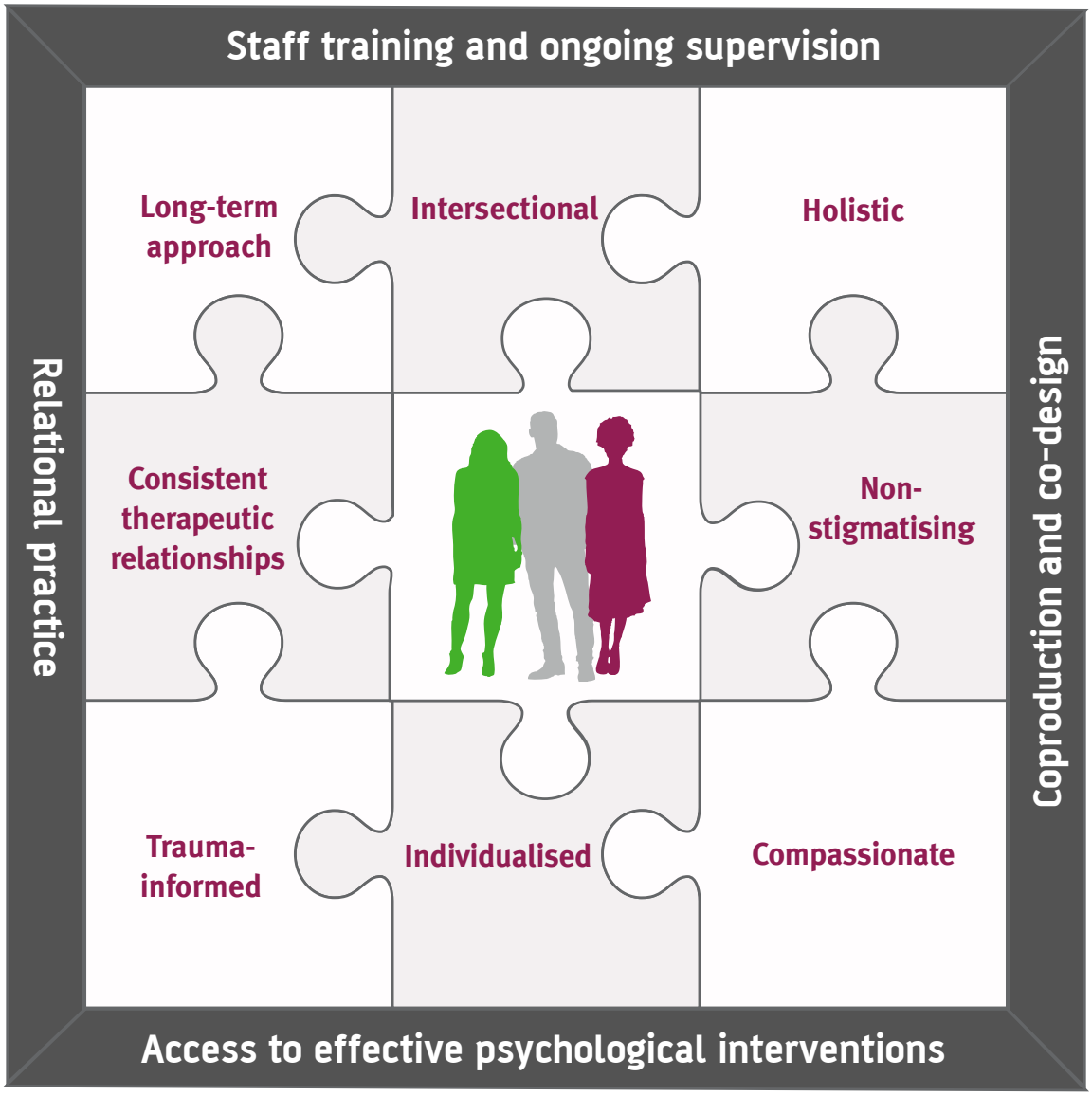
Key features of effective support (from the MHPRU studies):

- Non-stigmatising
- Individualised
- Compassionate
- Holistic
- Trauma-informed
- Consistent therapeutic relationships
- Long-term approach
- Intersectional.

Supported by:

- Relational practice
- Staff training and ongoing supervision
- Coproduction and co-design
- Access to effective psychological interventions.

What does effective support for people with complex emotional needs look like?



Policy and practice implications

National policy

It is clear that the neglect of complex emotional needs in national policy has translated into a lack of effective support in services locally. Until the NHS Long Term Plan, national mental health policies have paid little attention to this topic – or where they have, the focus has been on political concerns about violence and 'personality disorder', leading to stigmatising approaches to service provision and the neglect of the majority of people's needs.

The Community Mental Health Framework (which provides the blueprint for the NHS Long Term Plan's investment in primary and community mental health services) is a partial exception to this history of neglect. It asks community mental health services to take a 'whole person, whole population' approach that should include people diagnosed with 'personality disorder' (NHS England, 2019). It does not, however, provide any further detail on how local services should aim to meet people's needs or adapt the ways they work to close the many gaps in the system.

The recent user-led **'Stop SIM' campaign** against the use of Serenity Integrated Monitoring (SIM), for people who make frequent use of emergency services, has highlighted the coercive and stigmatising nature of many responses to people with complex emotional needs. NHS England's response to the campaign has been to ask all NHS mental health trusts to review their practices.

More recently still, evidence about the continued use of 'out of area' hospital admissions for people diagnosed with 'personality disorder' (Harding *et al.*, 2022) is a reminder that gaps in community support put people at risk of hospital admissions and coercion. And these in turn create further risks of traumatic experiences and prolonged spells in hospital.

The Government's promised new mental health plan and the next phase of the NHS Long Term Plan provide important opportunities to redress the balance. They can both make a commitment to offer improved support for people with complex emotional needs. The tentative steps made by the Community Mental Health Framework need to be stepped up over the next five years with improved access to more consistent support, from both specialist and generic mental health services, using the full range of interventions that people need.

As a starting point for improvement, it will be important to understand what current provision is like – what is available in localities, how well it is working, and who is receiving it.

Integrated care systems

Integrated care systems (ICS) will become statutory bodies in 2022, taking over from clinical commissioning groups as the bodies that determine how NHS funds are spent in their areas. With populations averaging 1-2 million each, integrated care systems will operate at a scale where they can plan mental health services that provide comprehensive coverage and meet a wide range of needs.

They have the opportunity to assess how well they are currently supporting people with complex emotional needs: this could be undertaken either at system level or at 'place' level (equivalent to upper tier local authority areas) but it will need to cover all localities to address variations in access, experience and outcomes from place to place. This must, from day one, be done in collaboration with experts by experience, as an equal partnership. In this way, ICSs can identify gaps in provision and instances where support is fragmented or poor, and co-design ways in which services could be improved.

Mental health and social care service providers

Providers of mental health services (in the NHS, local government and the voluntary and community sector) have the opportunity through the Community Mental Health Framework to develop a more comprehensive and holistic approach to support for people with complex emotional needs. As with integrated care systems, service providers have an opportunity to work in partnership with people with complex emotional needs to redesign support, drawing on the principles set out by the MHPRU studies (page 6 and 7) (Trevillion *et al.*, 2022; Sheridan Rains *et al.*, 2021).

A key issue for any provider will be how to balance specialist and 'generic' support. Specialist teams appear to offer more effective support for people with complex emotional needs, but they are typically time-limited and have tended to serve a narrow group without major comorbidities, who are able to adhere to relatively strict boundaries.

Resourcing long-term support from specialist services and making specialist interventions more widely available will require significant investment and workforce development. Alongside this, it would be beneficial to enhance the skills, capacity and knowledge of other community teams. (This includes those working with specific groups, for example in perinatal mental health services and with younger and older people). Research on best models is urgently needed: but a role for specialist complex emotional needs services in providing training and consultancy to other community teams is likely to be helpful. A central priority for this quality improvement work should be addressing the stigma and therapeutic pessimism that people with complex emotional needs often experience from mental health professionals in generic services. This would also require significant investment, including in ongoing support, learning and supervision for staff members.

It is also clear from the studies that continuity of care and coproduced care planning are important elements of effective support for people with complex emotional needs. The replacement of the Care Programme Approach (NHS England, 2021) is an opportunity to develop a more personalised means of coordinating care and support that combines mental health, social care, physical health and other needs holistically.

One aspect that receives little attention in research is the importance of families and informal carers: despite legislation and guidance about the importance of supporting and working alongside carers, there is little evidence of this happening at scale in practice.

Training and education

Foye and colleagues (2022) noted in their study of practitioner views that there was a need for "system-wide training and support for clinicians working with [complex emotional needs], encompassing generic as well as specialist services, and to challenge the stigma still experienced throughout the system."

This has implications at all levels of education and training for health and care professionals, from basic training to CPD. Training that is developed and delivered by people with lived experience can help to tackle stigmatising attitudes and practices.

Training and education alone cannot, of course, change entrenched cultures in services overnight. But they can help to shift the culture over time and challenge stigmatising practices, if they are backed up by organisational changes on the ground. In addition, sufficient service funding and robust supervision arrangements can further support cultural change.

Research funders and providers

Ledden and colleagues' (2021) review of research evidence about effective community treatment options for people with complex emotional needs makes a clear and compelling call for action:

"Compared with other longer term mental health problems that significantly impair functioning, the evidence base on how to provide high quality care for people with [complex emotional needs] is very limited. There is good evidence that people with [complex emotional needs] can be effectively helped when specialist therapies are available and they are able to engage with them. However, a much more methodologically robust and substantial literature addressing a much wider range of research questions is urgently needed to optimise treatment and support across this group."

A major focus for research should be in the development of 'relational practice', as this comes through strongly as the preferred approach of people living with complex emotional needs (Trevillion *et al.*, 2022). Further research should also include economic evaluation and analysis (Botham *et al.*, 2021).

While this work has added to the evidence base on community mental health service provision, there is a similar lack of research on other parts of the mental health care system, such as crisis care settings (De Leo *et al.*, 2022). These, too, require investigation to ensure no one with complex emotional needs is left with inadequate (or no) support when they need it.

Recommendations

1. The Department of Health and Social Care should set out plans to improve support for people with complex emotional needs in its forthcoming mental health plan. This should include not just health and care but all public services that have an impact on people's lives and wellbeing.
2. NHS England should conduct an immediate 'stocktake' of services for people with complex emotional needs. It should ask all integrated care systems to assess the support they offer, including from specialist and 'generic' mental health services, in each place and neighbourhood in their area.
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6. Education and training bodies for health and care professionals must ensure that all basic education and CPD includes relevant training in complex emotional needs. This should include training that has been developed and delivered by people with lived experience, to help to address stigmatising attitudes among professionals.
7. Health research funders must prioritise funding that addresses deficits in the evidence base for treating and supporting people with complex emotional needs, both in the community and in other settings.

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