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The contribution of the voluntary sector to mental health crisis care: a mixed-methods study

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Background

Mental health crises have been conceptualised as a 'turning point', with both risks and constructive potential. The failure of the current arrangements for mental health crisis support in England has been highlighted by the Care Quality Commission.

The policy focus has typically framed mental health crises in a biomedical discourse, requiring rapid psychiatric assessment and intervention. However, current policy and service users advocate for a wider range of support, including provision by the voluntary sector and community organisations. In 2014, a mental health Crisis Care Concordat[i] was introduced to facilitate improvements in access to high-quality and effective mental health crisis support. The voluntary sector, which is mainly made up of charities, is identified in the Concordat as an essential element of the crisis system. Although voluntary sector organisations are increasingly expected to contribute to mental health crisis care pathways, there is a lack of evidence about their role and how they might best contribute to mental health crisis care.

The available evidence highlights the particular role of the voluntary sector in mental health as providing longer-term holistic support, and a compassionate and human response. It is mainly concerned with the voluntary sector providing an alternative to inpatient care and there has been little research on the contribution of the voluntary sector to other parts of the crisis continuum, namely access to support before a crisis, or recovering and staying well. Consequently, there is a gap in understanding of the 'whole system' of crisis support and, in particular, how relationships between the voluntary sector and the public sector work, particularly NHS and local authority services.

Aim

The primary aim of this research was to identify the contribution of the voluntary sector to mental health crisis care and to identify the implications for policy and practice to strengthen the crisis care response in mental health. It provides a platform for subsequent research to evaluate the effectiveness of different voluntary sector models. The scope of the study was mental health crisis care in England. Clinical outcomes and comparisons with different types of service provision were beyond the scope of this study and, therefore, provide a focus for further research in this area.

The research questions were:

What is people's experience of a mental health crisis, and what do people need?

What is people's experience of different types of support from the voluntary sector, and what difference does it make to them?

What helps voluntary sector organisations make a successful contribution to effective mental health crisis support?

How can the voluntary sector contribute to meeting needs as part of an overall crisis system that includes the NHS and local authority?

What are the different types of voluntary sector organisations and who do they work with?

[i] Mental Health Crisis Care Concordat. Available at: **www.crisiscareconcordat.org.uk** [accessed 7 July 2020].

Research design and methods

The design used multiple methods (qualitative and quantitative) and involved four work packages.

Work package 1

- Literature review
- Identifying voluntary sector organisations from registers of charities
- National survey of voluntary sector organisations: 220 responses from 1,612 voluntary sector organisations
- Semi-structured interviews with 27 national stakeholders including policy-makers, professional organisations, voluntary sector managers, service user and carer organisations, and research bodies

Work package 2

- Regional mapping of voluntary sector provision in two contrasting regions, identified on the basis of mental health spend and the number of voluntary sector organisations
- Fourteen targeted semi-structured interviews with commissioners, voluntary sector organisations and mental health providers to identify additional activity and access to crisis support

Work package 3

- Four contrasting case study sites of Crisis Care Concordat areas (situated in East England, London, North-East England and the West Midlands) to investigate the role of the voluntary sector in the local mental health crisis system and how well this is working – where are the gaps, and for who?

The methods for data collection were:

- Semi-structured interviews with 78 stakeholders across the sites (commissioners, NHS and local authority staff, voluntary sector organisations and service user and carer groups)
- Two focus groups in each site, one for service users and one for carers with a total of 30 service users and 22 carer participants

Work package 4

- In the four sites, understanding the crisis experience and impact of voluntary sector support for individuals and their carers/families through:
  - Narrative interviews with 47 service users and 11 carers
  - Mapping journeys from repeat interviews four to six months later with 20 service users
  - A service user questionnaire to capture demographic details

Analysis

The analytic strategies reflected the research objectives to identify:

- The conceptualisations of a crisis, range of crisis needs and how these were met by the voluntary sector
- The type of voluntary sector provision and activities
- Individual respondent characteristics and crisis journeys
- Location of the voluntary sector provision within the mental health crisis system and relationship with public sector services
- Organisational form of the voluntary sector provider and the commissioning arrangements

Workshops were held with the research team, the Study Reference Group and the Study Steering Group to bring together the various analyses to: answer the research questions; identify patterns and similarities between different data sources; and to capture the different interpretations of academic researchers and co-researchers.

Service user, carer and public involvement

People with experience of a mental health crisis were extensively involved in the conduct of the research. The research team included five service users as co-researchers and a carer in an advisory role. There was a Study Reference Group, which involved eight service users and was chaired by a service user. This acted as a critical friend to the study. The Reference Group was represented on the Study Steering Group, which involved four people with lived experience of mental health issues, one of whom was the Chair.

Service users and carers were active participants in the research process and were able to shape, change and challenge the language used, the research methods and the process as it progressed. This led to significant changes in the study. Service user and carer involvement in the study was evaluated by an independent service user organisation using the 4 Pi National Involvement Frameworks[ii] as a guide. The approach was commended but the evaluation also identified areas where involvement processes could be strengthened, including the arrangements for payment and support.

Ethical approval

Ethical approval for Work Placements (WPs) 1 and 2 was granted by the University of Birmingham Humanities and Social Sciences Ethical Review Committee (RG16-153). Ethical approval for WPs 3 and 4 was granted by the West of Scotland REC4 (18/WS/0022) and approved by the Health Research Authority (IRAS 211953). Research governance bodies for the relevant NHS Trusts also reviewed the application to confirm participation.

> *The metaphor I would use is that it is like dancing. Sometimes they led, sometimes we followed; sometimes we led and sometimes they followed. … I thought they were very good in facilitating that.*

[ii] National Survivor User Network. 4 Pi National Involvement Standards. Available at: **www.nsun.org.uk/faqs/4pi-national-involvement-standards** [accessed 7 July 2020].


VOLUNTARY SECTOR PROVIDERS
Involvement
Information
Everyone
My Crisis Plan
locally relevant?
Review
Workforce diversity
Training, Supervision & Support
RESEARCH & ACADEMIC COMMUNITY
VS
Outcomes
Evaluate
ROLES
Safe Space
Crisis house
Compare
RECOMMENDATIONS
CRISIS as more than an episode
getting on with my life
prevention
immediate response
ongoing support
Information
Population
Need's
Resources
Services
Transformation
VCS
PUBLIC SECTOR
Understand, build on and invest in VCS support
EFFECTIVE COMMISSIONING
Interactive Map
SUPPORT
Access
Co-ordinated
Non Clinical
24:7
Alternatives
Everywhere
Recognition
VCS
around here we have...
Co-production
Sustainable Funding
IMPROVING ACCESS
to VS Crisis support
Advocacy
Access
NHS
Everyone
My Crisis Plan
my carer
my permission
professionals
me
Triangle of care Standards
IMPROVING COLLABORATION
between
VSOs
Public Sector
Staying Well
STOP
Barriers to Support
Information Sharing
CRISIS CARE
Action
Decision
CONCORDAT

Findings

Experiences of a mental health crisis

Service user participants described the intensity of the distress they experienced when in a mental health crisis, and the overwhelming nature of these feelings was associated with needing to be understood and to be treated with compassion and humanity. The narratives identified the experience of a mental health crisis as a biographical disruption: an intense and extreme experience that disrupts everyday life and potentially has far-reaching consequences. A corollary of this is that the experience, and the response, cannot be disconnected from the personal and social context of living.

This conception contrasts with the narrow definition of a mental health crisis as an episode requiring an urgent response, which means underlying difficulties may not be addressed.

> *Those that cared for someone in a mental health crisis did not necessarily consider themselves a carer, highlighting the reciprocal nature of caring and other roles as more important.*

Differences in the conceptions of a mental health crisis are enacted through the policy discourse, service configuration and professional behaviour, all of which may influence the contribution of voluntary sector organisations and the relationship with public sector services.

Family members and those providing care for someone experiencing a mental health crisis described feeling under strain. Many of the carers had been providing support for many years, including people who had been young carers. All carers expressed a strong sense of responsibility, with some identifying the impact of austerity as exacerbating the strain.

'I've had quite a few crises, and some of them have been where I haven't been able to cope because of being really low, and I haven't been able to do any of like my daily activities at all. But then I've had other ones where my mood's been so elated that I've not really understood what's going on around me.'

'I get sort of paranoid, you know, and I don't feel safe anywhere, I don't go out.'

'It's like being bullied inside your own body.'

'For me, a crisis means my whole life is out of control. My diary becomes scribbles and it's like nothing is in order in my life. It's a mess. It's chaos, absolute chaos.'

What people need in a crisis

Reflecting the intensity of the experience and the sense of threat, the most commonly cited need was to feel safe – *'to be in the safety zone'* or *'a calm place where you could talk to people*'.

'Kindness', *'being listened to and not being dismissed'*, *'time and space to make sense of the experience'*, *'being treated with care'*, *'compassion'*, *'understanding'*, and *'humanity'* expressed how participants described what they needed.

It was clear that family members and carers also needed support, but their needs were often overlooked and rarely involved in crisis planning.

> *Reflecting the intensity of the experience and the sense of threat, the most commonly cited need was to feel safe ...*

> ***'I need to be in a safe place, which they never understand. Maybe they do now... If you can navigate that person, the right place, that would be the helpful.'***

> ***'Life has been strung out on managing, supporting to manage crises, but what the issue was that I didn't really understand mental health, I didn't understand what a crisis was, the language used in the field, to help me understand what was taking place with my siblings.'***

The contribution of the voluntary sector to mental health crisis support

From the responses to the survey and regional mapping, five types of voluntary sector organisations were identified as having a role to play across the crisis continuum from prevention, providing an urgent response and supporting recovery. We developed a typology to describe the different voluntary sector organisations and their contribution to crisis supporting people experiencing a mental health crisis.

Type 1 voluntary sector organisations are most commonly identified as having a role to play in mental health crisis care because they are an element of providing an urgent response to someone in crisis and are formally commissioned by the public sector to do so and where access is, generally, via the NHS. These include crisis helplines, safe spaces and crisis houses.

Type 2 voluntary sector organisations are general mental health organisations, contributing to prevention, recovery and aiming to improve the quality of life for people experiencing a mental health crisis.

Types 3 and 4 voluntary sector organisations offer specific skills and knowledge in engaging and responding to people who may not access statutory mental health services or are experiencing a specific life event. **Type 5** voluntary sector organisations are social and community organisations that are often *'below the radar'* but provide an important source of social connection and occupation.

The voluntary sector organisations in our sample were all registered charities. However, they differed in how they saw themselves. Some voluntary sector organisations were keen to be seen as *'more than'* a charity – emphasising their business-like approach. Other voluntary sector organisations emphasised their grassroots origins, volunteer workforce, altruistic values and the foundational ethos of user involvement. This included service-user-led organisations.

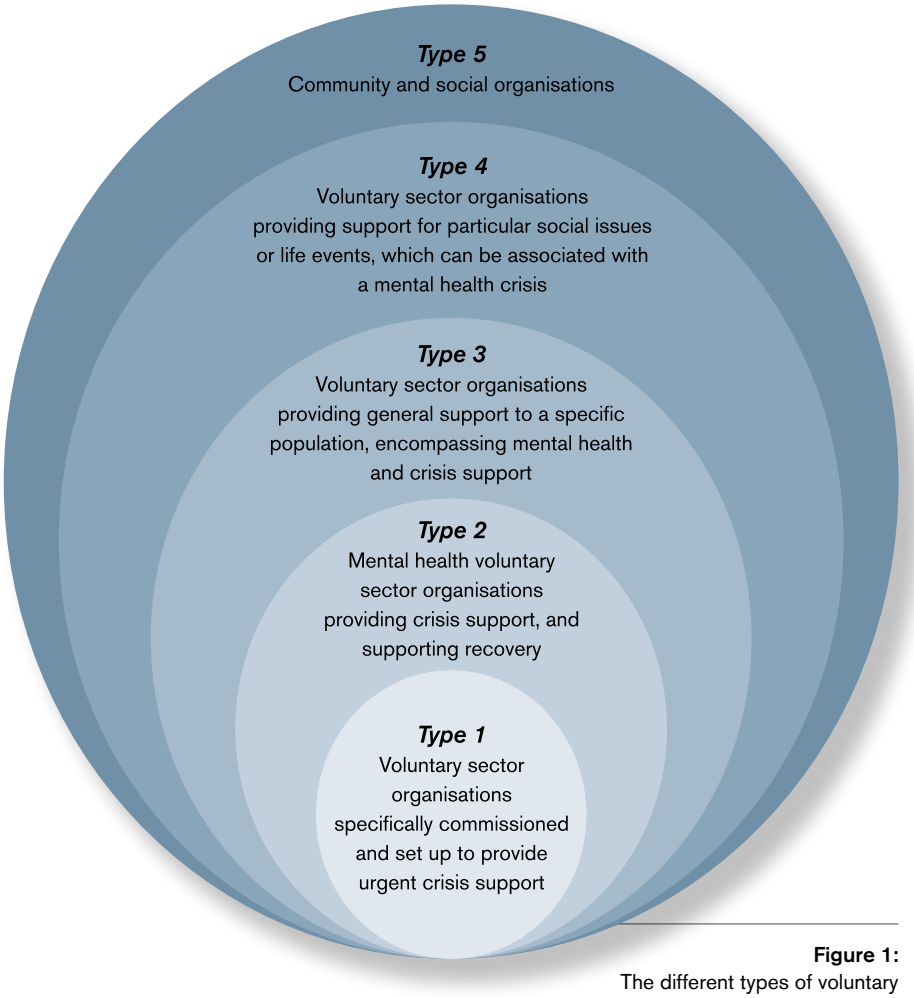


Figure 1: The different types of voluntary sector organisations providing mental health crisis support

> *From the responses to the survey and regional mapping, five types of voluntary sector organisations were identified as having a role to play across the crisis continuum from prevention, providing an urgent response and supporting recovery.*

Voluntary sector organisations typically offer a wide range of support, including signposting to, and working in partnership with other voluntary sector organisations to provide individually tailored support.

The approach of the voluntary sector is distinctive and can be characterised by its relational, and socially-oriented style of operation. Many participants commented on the compassion, humanity and kindness and how they felt less constrained by time. They valued the blurring of roles between staff, volunteers and peers, and particularly appreciated peer support and connecting with other people who shared a mental health crisis experience. Voluntary sector organisations compared very favourably with public sector services and were described as being more responsiveness and flexible to service user needs.

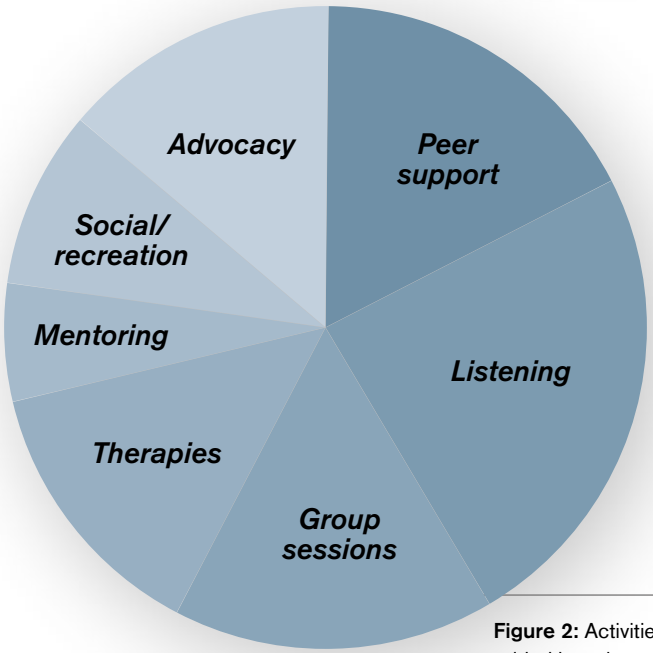


Figure 2: Activities provided by voluntary sector organisations that completed the survey

Accessibility, adequacy and quality of voluntary sector mental health crisis support

The contribution of the voluntary sector is shaped by its evolution, the capacity of the wider mental health system and the relationship between the voluntary sector and public sector services. Variation and inequalities in access to voluntary sector provision were identified for Type 1 voluntary sector organisations (ie, crisis specific), with people living in rural areas particularly disadvantaged by a lack of provision. Inequalities in access for other groups were identified, namely Black, Asian and minority ethnic communities, people who use substances and people who identified as having a personality disorder. Access to Type 1 voluntary sector organisations is typically restricted by NHS services such that people with higher needs or presenting with greater risks are assessed by mental health staff and diverted to other services. Self-referral, a rapid response and face-to-face support were valued by service users. It is notable that some people preferred to use voluntary sector organisations that were independent of the public sector but public sector funding often comes with strings attached.

The voluntary sector services in our study were evaluated positively, and it was evident that they had an impact for individuals and their carers. This included helping individuals to better manage their mental health; deescalating the crisis by being listened to; preventing suicide and self-harm; creating a sense of solidarity and increasing social connection and support; developing strategies for addressing challenges and future crises; and providing access to volunteering and employment opportunities. Most of the dissatisfaction with voluntary sector services related to access and lengthy waiting times for follow-on sessions for one-to-one support or therapeutic programmes. Good working relationships with the public sector were associated with a positive impact on the attitudes and behaviours of mental health staff. There was also evidence that the voluntary sector reduced the use of public sector services.

'They helped me unpick my life and put things in place and the first thing was like, "right, you're not very well, you're entitled to actually go off sick..." they were the first people to identify that actually, I was in a crisis, I needed help, and in order to get that help I needed to stop all the activities I was doing and they helped me access support.'

'I was made to feel very, very welcome and it filled a need, I was under no pressure and it was having somebody who actually sits and listens to you and doesn't judge you and doesn't put you under pressure to speak.'

'I felt like people really kind of cared about me. You can't underestimate how important that is to people in that situation and it was for me at the time, because you know I was dealing with a real worthlessness and really strongly believing in the idea that I was a complete burden to absolutely everybody.'

Key features of voluntary sector support in a crisis

Kindness, compassion, humanity, hope and a social model of mental health

- A strengths-based approach underpinned by a social model and attention to the social context of people's lives
- Providing time and a safe and calm environment
- Relational safety and being made to feel welcome
- Having staff/volunteers/community members with lived experience: blurred boundaries
- Informality and light touch in terms of assessment and note-keeping
- Responsiveness and flexibility
- Involving service users and/or carers/families in the organisation and governance

The relationship between the voluntary sector and public sector

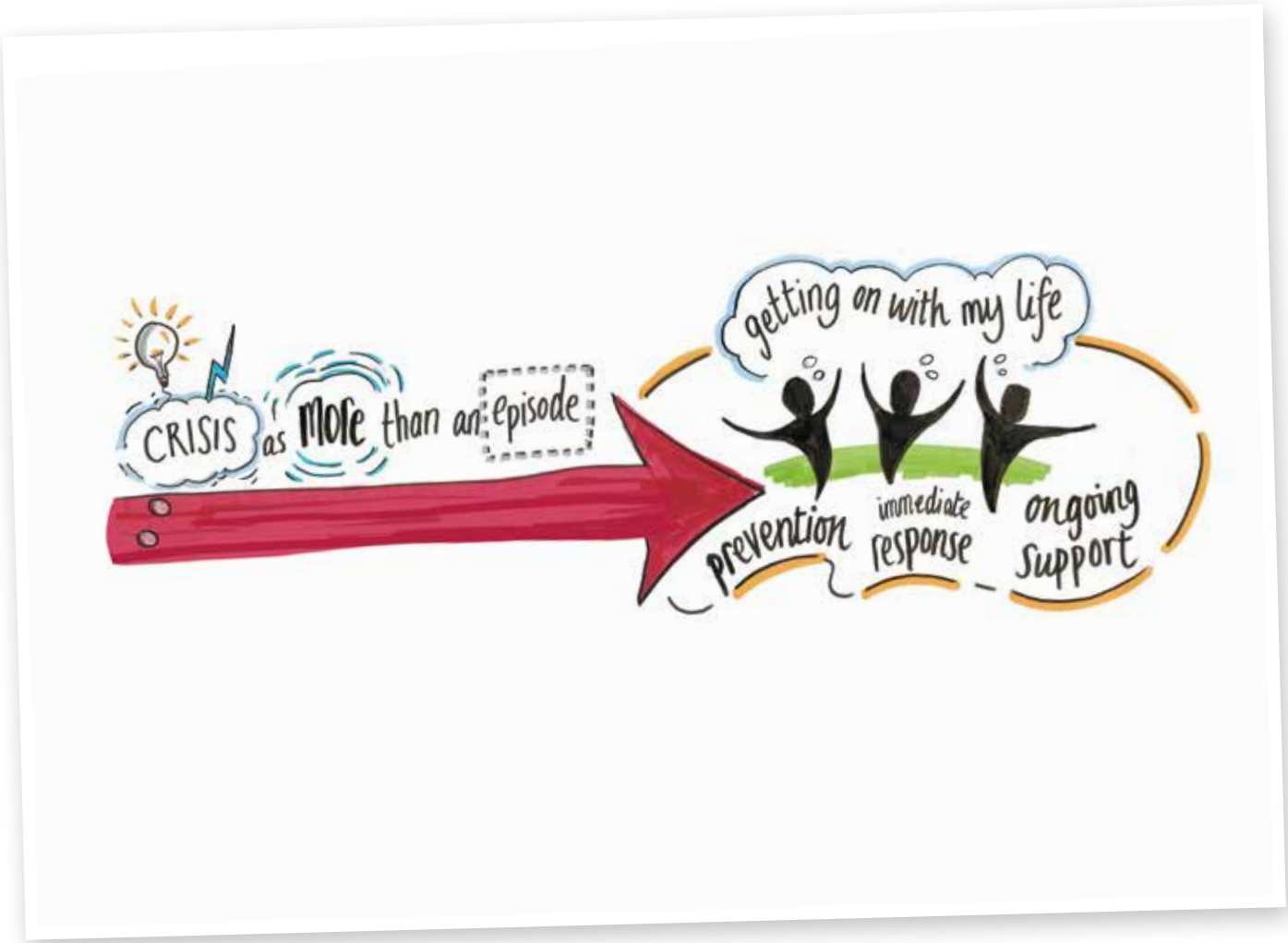
The crisis system in the different sites was generally under-developed, although the Crisis Care Concordat had stimulated some redesign. This was most advanced in one site, where an NHS helpline with a first response service attached and a route through to a voluntary sector safe space had been introduced. Where the relationship between Type 1 voluntary sector organisations and NHS services was most developed, there was evidence of a mutual understanding of each other's role and contribution. The awareness and appreciation of other types of voluntary sector organisations, however, was usually less developed and there was a general lack of up-to-date information about what was available. Effective collaboration at the level of the individual service user was focused around providing an urgent and immediate response and there was little evidence of a coherent pathway, although voluntary sector organisations and NHS services would signpost and/or refer to each other. Both the absence of a preventative approach and a lack of continuity to enable people to address the relevant contextual factors were evident.

"The crisis system in the different sites was generally under-developed, although the Crisis Care Concordat had stimulated some redesign."

Thresholds for accessing public sector services

While the contribution of the voluntary sector was widely appreciated, participants were often critical of their experience of NHS services, the lack of responsiveness of crisis resolution home treatment teams, the high thresholds to access services, and waiting lists as compromising their access to crisis support. One participant described their experience of being passed from service to service as 'responsibility tennis'.

Service user participants were also critical of dismissive and insensitive attitudes within public sector services and referred to a mistaken view of agency as shifting responsibility back to the person experiencing a crisis.



The development and sustainability of the voluntary sector

The closeness of the relationship with public sector services varied from voluntary sector organisations that are committed to maintaining their independence to those closely aligned with NHS crisis services that determine who will access the voluntary sector organisations. Some voluntary sector organisations provided a radical critique of public sector provision and maintaining this, in a context of competitive tendering, may prove challenging.

Recommendations for improving the crisis system and better realising the contribution of the voluntary sector included: (1) a better appreciation of the voluntary sector contribution; (2) clear standards for crisis support, so that people know what support they can expect; (3) a demonstrable commitment to equity and addressing variations in access to crisis care; and (4) investment in the voluntary sector.

Respondents recognised the centrality of commissioning in regulating and delivering funding and indicated that it must be improved. However, a bigger challenge came from those who suggested that the commissioning approach is fundamentally flawed; in particular, that commissioning is actively inhibiting or damaging the quality of services delivered in the voluntary sector.

Key recommendations for improving commissioning emphasised more resources, more integrated commissioning and consequently joined-up services, greater recognition of what the voluntary sector offers and how its role in commissioned services can be sustained, and greater involvement of voluntary sector organisations and communities in the commissioning cycle.

Conclusions and implications

Our study has explored the value of voluntary sector organisations in supporting people in a crisis and identified the wide range of activity that not only provides an immediate response but also contributes to prevention and recovery.

The findings identify that the voluntary sector is attractive and acceptable to people in a crisis; has social value; and can potentially address the complex interactions between mental health, inequality and socio-economic conditions. There is also evidence that the voluntary sector can provide a cost-effective alternative to public sector provision, particularly inpatient care. However, the understanding and awareness of the contribution is not fully realised and the voluntary sector can be viewed as 'a bit player' in the provision of crisis care.

Whilst our study was focused on the contribution of the voluntary sector to mental health crisis care, it has thrown the inadequacy and quality of crisis care into sharp relief. In doing so, it has identified significant gaps, with crisis provision often a patchwork of services rather than a pathway or coherent system.

In order to realise the value of the voluntary sector, the implications of our findings are:

Transforming mental health crisis care

- The transformation in mental health crisis services needs to include the expertise of the voluntary sector and transformation resources need to be directed at both the statutory and voluntary sector.
- Local authorities need to ensure that there is a rigorous and robust understanding of the local demography and the diversity of population to underpin the development of crisis support. This must pay specific attention to the gaps in support and to the needs of those people who are presenting in a crisis because appropriate services are not available ie, people from ethnically marginalised communities; people who also use substances; and homeless people.
- All public sector organisations need to have a better recognition of what the voluntary sector offers, not only those that are clearly identified as providing support in a crisis.
- Involving service users and carers and families with personal experiences of mental health crisis and across the protected characteristics, in the codesign, commissioning and coproduction of mental health crisis support is essential.
- Voluntary sector and community organisations should be involved in a fair manner in commissioning, and smaller local groups, which are disadvantaged by the current arrangements, should be supported to be involved.
- There needs to be sustainable funding in voluntary sector crisis care provision. This includes user-led organisations and grassroots community organisations with local knowledge and engagement with people in, or at risk of, crisis, who may not be using mainstream voluntary sector or public sector provision.

Improving access to voluntary sector crisis support

- Information and an interactive map of voluntary sector crisis provision should be made available nationally 24/7 to anyone who needs it, and include information on what different voluntary sector organisations provide, how they could help if you are experiencing a crisis, how you can access them and when they are available.
- Local systems should ensure that access arrangements to mental health crisis support are well coordinated, recognising that some people will choose alternatives to NHS provision.
- NHS England should ensure that every locality in England provides 24/7 access to non-clinical alternatives to mainstream inpatient provision, which is appropriate to meet the diverse needs of the local population. This includes crisis houses, peer support, safe spaces, walk-in services, including those provided by user-led organisations and community organisations.
- Information needs to be readily available to service users, carers and their families so they know that they can ask for an advocate, peer support or someone they trust if they feel unable to explain their situation and make their wishes known.
- NHS, local authority and voluntary sector providers need to make information available so that service users (carers and their families, if appropriate) know that they should be involved in coproducing a crisis plan that sets out what support is available in the event of a further crisis, and how they can access support to enable them to address the contributory factors.

Voluntary sector providers

- Voluntary sector providers should actively promote and update information on the services relevant to crisis prevention and crisis support they provide.
- Voluntary sector providers need to review whether their services are helpful and relevant for the local population, and work with commissioners to develop equal access for marginalised groups, and ensure their workforce properly reflects the demographic diversity.
- Voluntary sector providers need to ensure that every person has a co-produced crisis plan, which includes the action to take in the event of a future crisis and risk management. This includes working with carers and family members, as appropriate, so that they are well-informed and able to support the person in a crisis.
- Voluntary sector providers should ensure there is good quality training, supervision and support so that staff wellbeing is protected and recognises the impact of traumatic events and supporting people experiencing a mental health crisis.

Improving collaboration between the voluntary sector and public sector services

- Local systems should have arrangements in place across the range of support to prevent a crisis and help people stay well, as well as an urgent response.
- Commissioners and NHS providers need to review the thresholds for different services, hand-offs and barriers to accessing support in a smooth way between different services (including NHS and voluntary sector organisations) and reduce the waiting times for support to address the contributory factors for the crisis episode.
- Arrangements for information-sharing between voluntary sector organisations and public sector services needs to be clarified, recognising that for some voluntary sector organisations, this will not be appropriate.
- NHS and/or local authority mental health services providers should ensure that every person has a co-produced crisis plan, which includes the action to take in the event of a future crisis, and includes the role of the voluntary sector as appropriate.

Research and academic community

This study and provides a platform for further research on the contribution of the voluntary sector to mental health crisis care and, in particular, the evaluation of the outcomes and cost-effectiveness of different models of voluntary sector provision.

> *I know that there are people that are touching lots of different services, but we don't know what they're touching unless they tell us. And it's how can we make it more effective?*

Limitations

This was a descriptive study, so evaluating outcomes of the different types of voluntary sector organisations was beyond its scope.

The informality of some voluntary sector organisations, which makes the sector particularly attractive to people experiencing a mental health crisis, had an impact on the study, particularly the approach to recruiting people with lived experience.

Other limitations include a low response to the survey, reflecting the nature of voluntary sector organisations and demands on their time. Carer recruitment for interviews was particularly difficult and many service users were unable to identify a relevant family member or did not want them to be approached.

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Health Services and Delivery Research (HS&DR) programme
The HS&DR programme, part of the National Institute for Health Research (NIHR), was established to fund a broad range of research. It combines the strengths and contributions of two previous NIHR research programmes: the Health Services Research (HSR) programme and the Service Delivery and Organisation (SDO) programme, which were merged in January 2012. The HS&DR programme aims to produce rigorous and relevant evidence on the quality, access and organisation of health services including costs and outcomes, as well as research on implementation.

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