The impact of cuts on mental health services: Good mental health in Leicester?

Jim Dooher and Liz Rye present the findings of a study exploring the views of service users and carers on service provision in the context of funding restrictions in Leicester

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Abstract
This paper presents the findings of a study exploring the views of service users and carers on service provision in the context of funding restrictions in Leicester.

Introduction

Publicly funded services for people with mental health conditions continue to endure considerable pressure, and while there is no evidence to suggest that mental health services are being disproportionately cut, the negative effects (whether real or perceived) upon those who use these services and their carers are profound.

In 2010 the new coalition government announced the results of its spending review. The review detailed budgets that were to be cut over the following five years and outlined measures relating directly to the voluntary sector. These included the announcement of a new £100 million transitional fund, and additional resources to implement the 'Big Society' agenda.

In mental health however, despite transitional funding, our experience is that services are being lost. Service users and their carers are very worried about future support, and the voluntary sector has been pitched into unstable short-term funding at best, and lowest price based competitive grants at worst.

The UK voluntary and community sector will lose around £911 million a year in public funding by 2015-16 (National Council for Voluntary Organisations, 2011), and without doubt Leicester City and County are contributing to this saving. Voluntary sector services are also struggling to access other sources of funding with a significant decrease in charitable giving due to the recession and increasing competition for charitable grants such as the lottery.

The evidence contained in this article is based upon several pieces of work conducted by the Service User and Carer Research Audit Network (SUCRAN), a service user and carer led research group, which conducted a qualitative study of mental health service users and their carers in Leicester City (SUCRAN, 2013).

Background and approach

The views of 60 people were obtained to ascertain the features of services that protect their mental health, prevent admission to hospital and ensure positive health outcomes when secondary care is needed. In addition, the views of 407 mental health service users (City and County) were captured through one-to-one interviews (SUCRAN, 2012).

The reports that were generated from these first-hand accounts identified more than just a wishlist of the kinds of services wanted now and in the future. They illustrate a rich understanding of the impact of changes to mental health service provision, identifying not only specific concerns over perceived gaps in current service provision, but also what is working well.

However, the legitimate demands of current service users have emerged from a plethora of legislation and social policy, which has been introduced under the fanfare of progressive and empowering social care, dynamic and positive. Considering a few of these drivers enables us to consider just how much progress has been made.

In the late 1980s there was a flurry of

white papers and governmental direction that promoted decarceration from the Victorian asylums and the development of 'community care'. (Griffiths, 1988, Department of Health, 1989a; 1989b).

These documents were the forerunners to the Community Care Act of 1990, a major piece of legislation that sets out the basis for community care as we know it today. These were driven by the principles that state provision was bureaucratic and inefficient; that the State should be an 'enabler' rather than a provider of care; a separation of the purchaser provider roles; and devolution of budgets and budgetary control.

Of the Act's six key recommendations, the use and promotion of the independent sector was to be achieved through greater collaboration with the voluntary and private sector to make 'maximum use' of this welfare model.

The development of the voluntary and independent sector saw a shift of both resources and service user dependence towards non-statutory provision with funding structures and responsibilities defining more responsive localised services.

Successive governments have sought to make these services more efficient through competitive tendering for an ever-decreasing pot of resource.

This competitive process has served to fracture previously healthy collaborative relationships within the voluntary sector, generated unhealthy tension and created pervasive anxiety, not only for those working within organisations that provide services, but also – and more importantly – for the recipients of those services.

Views of users and carers
The impact of these cuts has not only resulted in the voluntary sector's inability to plan strategically for the medium term but also in anxiety and anger for the people who wish to use their services:

'Lack of government funding for the voluntary sector really gets my blood boiling; poor strategy and reduced services. It all adds up to a very short-sighted and blinkered approach which, in the long run, has huge costs.'
Service user

Service users have identified a perception that the local partnership trust seems to have

had difficulties with implementing change, financial problems, shortages of nursing staff and an over-reliance on agency staff who generally do not know the service users they are caring for.

There is a real concern about the premature discharge of individuals from hospital. Proposed reasons for this included lack of funding, but more specifically a shortage of hospital beds.

A largely unseen effect of service reprovision is the effect upon the role and responsibility of the carer. In the absence of a consistent statutory safety net, informal carers become the primary backstop when things go wrong:

'Carers unable to work when services diminish as carers will have no choice and will have to become more involved, when mental health issues become unstable due to lack of support!'
Carer

As this comment suggests, carers often have no choice, and often provide both emergency, out-of-hours assistance, and day-to-day support, which invariably impacts upon their own economic productivity, and potential stress.

The financial costs of caring can be significant. Research by Carers UK (2004) found that 72% of carers are worse off financially as a result of becoming carers, are over twice as likely to have mental health problems if they provided substantial care and twice as likely to be 'permanently sick or disabled' compared to those not caring.

Concerns were expressed about future provision of advocacy services and the communication with essential voluntary services and the replacement of local involvement networks (LINks) with HealthWatch was said to be both 'expensive and unnecessary' rather than extending the role of LINks, which was originally proposed by New Labour.

'When I am unwell, I don't have enough support.'
Service user

'Services have been cut back, and are affecting my routine and activities.'
Service user

Participants suggested that there is not enough provision for advice on welfare benefits and housing related support, and that the

'one-stop' gateway 'single-access referral', in which there is no specialist mental health services available through its process, is not working well. Errors and misunderstanding were reported that were perceived as costly, unnecessary and wasting everyone's time.

In primary care there is concern with general practitioners who are said to be generally difficult to access and both unavailable and unhelpful when needed. It appears that it is the family, voluntary sector or non-mental health services that people turn to in these situations:

'I had to find the help that I needed from my advocate and couldn't find it through my consultant psychiatrist or GP. The services that I could take part in and the help that I needed that would benefit me. Lack of understanding through GP and consultant psychiatrist.'
Service user

'When the doctor's surgery is closed and you just want someone to talk to apart from focus line, there is no support.'
Service user

This highlights a perceived lack of support from primary care and social services, and particularly out of hours and at weekends, where again, carers and family members provide the safety net.

Service users and cares perceive unresponsive and inconsistent primary care services to be contributory to the need for crisis interventions, hampering considered, well-formulated strategies for care that anticipate care needs.

The Leicester City Joint Commissioning Strategy for Mental Health 2011-2013 identified that people who experience mental health problems still encounter significant difficulties in their daily lives, experience gaps in services and variation in the support available to them.

The document recognises that 'for too long many people have had to wait too long for treatment, many find that they are not treated as individuals or with dignity and respect, and services are not as well aligned as they might be to meet the diverse needs of local communities'.

It is not surprising therefore to find that these astute observations are underpinned by the experiences and consequent viewpoints of people who use services on a regular basis.

Study participants reported that the

importance of a stable home environment with a mix of personal and shared space was a cornerstone of recovery and good mental health.

Supported housing is seen as a positive long-term solution for both service users and the people who care for them, providing a safe place to nurture the survival skills necessary to become a more independent and productive member of the community and thus reducing the likelihood of intervention by statutory services.

When service reconfigurations threaten the possibility of someone's 'home' ceasing to exist, this creates anxiety, insecurity and undermines good mental health:

'Living in shared housing benefits us, and there are less admissions to hospitals. Living in a smaller shared house gives support workers time to see each one of us.'
Service user

The notion that meaningful and worthwhile daytime activity is a costly and complex process was overturned by participant views that highlight seemingly simple things that are working well and protect good mental health, such as talking, playing cards, bingo and games, music and poetry, art, yoga, concentration games, trips out, leisure cards, newspapers and using computers and walking groups.

Drop-in facilities work well and provide the basis for social interaction (SUCRAN 2011b; 2012), and for some, the only opportunity to meet with other people.

The isolation of living alone was highlighted by a number of participants and the benefits of just getting out of the house, meeting and mixing other people was highlighted consistently.

Participants seek peer support and someone to talk in the absence of formal help. Implicit in these comments is a theme of loneliness and the importance of being able to socialise in an environment that is safe and comfortable.

The importance of social contact facilitated by the voluntary sector in Leicester cannot be underestimated, and it is clear that something as simple as human contact seems to be averting intervention from statutory services including hospital admissions, preventing isolation and promoting friendships that form the glue of a cohesive community (SUCRAN

2011b; 2012).

The studies uncovered palpable anxiety surrounding the future of services that are currently in place, and both service users and carers feel powerless to save those which have been earmarked or under threat of closure:

'All the varying activity groups (arts, crafts, etc). The drop-ins (especially when people are feeling low – they can come in and have a chat), a place for people to go to (local and easy to get to), friendly where people feel comfortable, peer support available.'
Service user

Loneliness for people with mental health conditions and older people is a public health issue in its own right that is being directly tackled by the voluntary provision.

Research suggests that nationally five million people say the television is their main company, while 12% of older people feel trapped in their own home (Masi et al, 2011).

The importance of social contact facilitated by the voluntary sector in Leicester cannot be underestimated.

Comparison with strategic aspirations
When considering the views that service users and carers have expressed, and comparing them with aspirations of the mental health strategy for England *No Health Without Mental Health* (Department of Health, 2011), provider organisations have been charged with the responsibilities of ensuring good mental and physical health, recovery, respect, dignity and compassion, positive experiences of care, avoidance of harm, stigma and discrimination, which chime harmoniously with the wants and needs expressed by service users and carers.

What is wanted and what should be provided are wholly compatible. However, when we overlay the variables of change, financial prudence and increasing user expectations, we find ourselves in a position where both statutory and voluntary services are precariously scrapping for diminishing resources, and the people who receive services are understandably anxious about the inevitable reductions in the provision they rely upon.

Service users have over time been guided by government policy to depend upon the voluntary sector for significant elements of care, but this is increasingly under threat and

the anticipated loss of the support required to survive in the community is causing genuine worry, if not mental ill health.

This loss incorporates housing, welfare benefits, help for families and carers, and even the most basic social opportunities for this vulnerable group.

The importance of a stable home environment with a mix of personal and shared space is a positive contributor to recovery and good mental health. Conversely, when service re-disorganisation threatens to take away someone's 'home' this undoubtedly has a very negative effect, creating anxiety and insecurity, and undermining good mental health.

The voluntary sector has been thrust into a world of competitive tendering where price not quality is the key to success, and this has resulted in it 'eating itself'.

Infighting, disinformation, loss of trust and respect are all outcomes undermined further by unstable local authority and health provision, which is staffed by demotivated workers who are exhausted by their internal struggles and reluctant to innovate or be creative beyond their minimalistic checklist-driven routine.

As the erosion of the voluntary sector progresses, we will no doubt see an increased demand for statutory services in both primary and secondary care, which obviates any potential savings that may have been made.

Demand for care and support will remain, but without the basic pillars of community support we will no doubt see an increase in disenfranchised, vulnerable, lonely, ex-service users with nowhere to go and no opportunities for their voices to be heard.

Safe and supported housing is a critical element of good mental health and a wholly positive long-term solution for both service users and the people who care for them.

Supported housing provides a safe place to nurture the survival skills necessary to become a more independent and productive member of the community and reduces the likelihood of intervention by statutory services.

When things do go wrong the opportunity for alternatives to hospital admission should be available in the community and might include a range of crisis, recovery, respite and 'halfway' accommodation.

Better awareness and education of NHS staff such as those in general hospitals and importantly GPs is needed to coordinate the earliest possible intervention.

This, coupled with improved communication

between professional disciplines and the third sector, would improve the experience of service users and carers. Better information sharing will go some way to ensure continuity and that appropriate care packages are in place before discharge and that discharge is a considered process driven by patient need rather than bed occupancy issues.

When we consider daytime activity and education, we see that simple low-cost options work well, and emerging from this review is the belief that people need social interaction followed by care and support, followed by learning and education, assuming they have a place to live from which to extend this activity – and the importance of social contact facilitated by the voluntary sector in Leicester cannot be underestimated.

Summary

The loss of services and the impact of service redesign has resulted in the voluntary sector's inability to plan strategically and in problems for the people who wish to use those services. Drop-in centres give people a purpose and meaningful activity, but in the absence of services informal carers become the primary backstop when things go wrong.

Listening to service users and carers is very important to ensure provision of services. Raising awareness of mental health issues to challenge stigma is also important, and providers need to develop sensitivity and competence to effectively communicate and meet the diversity of the people of Leicester.

Worry was a consistent theme identified by service users, which emerged parti dcularly when considering finance and benefits.

For people who use services it is important for their expertise about their own condition to be recognised if we are to have true partnership in care, and multidisciplinary teams should positively embrace service user and carer views in formulating plans.

The *Joint Commissioning Strategy for Mental Health 2011-2013* strongly suggested that local access to mental health support is important with convenient opening hours, parking, meets specific cultural and religious requirements, and provides good disability access and public transport links.

The study asked what types of services would meet service user and carer needs. Overwhelmingly, group support, drop-in services, community based individual and peer support services, together with education, topped their survey.

Furthermore respondents felt it was important to be able to choose the services or packages of support that would help maintain their mental wellbeing if they were given the money to do so. The SUCRAN studies underscore these findings and demonstrate consistency in the wishes of people who use services and their carers.

The *Mental Health Alliance Convention Report 2011* highlighted a demand for increased choice and involvement to overcome a perceived lack of understanding and support for carers, and in particular, poor recognition

of carers' own mental health needs and respect for their views regarding those they care for.

Both service users and carers preferred voluntary sector styled services and wanted to see more investment in this area. They found these to be more flexible, responsive and empathic, and the majority of service users were unhappy with hospital-based services.

Involving service users in service design, delivery and care will increase self-efficacy and the internal locus of control required to promote recovery, improve self-esteem, raise awareness of oppressive practice and improve the person's belief. Furthermore, it will increase the ability to have power, influence or control over physical, psychological, spiritual and social aspects of health.

Little appears to have improved in the last 10 years and the observations of Dooher and Byrt (2002) and Dooher and Byrt (2003) are still apposite in that there is a need for professional willingness to empower service users and carers in individual care, service delivery, health policies and wider society.

There needs to be better communication and relationships, a shift in professional cultures and attitudes underpinned by real consultation based upon full information.

The consistency and strength of service user and carer views highlights the need for strategic planners to listen and make commissioning or decommissioning decisions that limit the negative impact for the people they serve. **MHN**

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