Mental Health Pre Summit

Responses and Report for Jon Ashworth MP

Produced by

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Service User and Carer Research Audit Network

March 2013

Contents

Executive Summary

The views contained within this report were collected during a Pre Summit event in which 60 mental health service users and carers attended. In addition, local voluntary sector organisations also attended.

Attendees were asked to complete a very simple survey which asked for their views of three key questions:

- What is working well?
- What are the key issues/concerns/gaps in the current service provision?
- What kinds of services do we want now and in the future?

Focus groups then to collectively considered these points and prioritised them in the form of a pyramid leading to a ranking of highest priority issues, high priority issues and priority issues.

An examination of the completed questionnaires generated themes which include:

- Housing
- Provided Services
- Early Intervention
- Activities
- Loss of services
- Voice and Communication
- Primary and Secondary Care
- Finance and benefits
- Communication
- Partnership care
- Activities
- Education

What is working well?

Housing

- The importance of a stable home environment with a mix of personal and shared space appears to be a cornerstone of recovery and good mental health. Supported housing is seen as 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 likely-hood 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.

Provided Services

- Where specifically mentioned, BME and older people’s services were doing well

- Participants listed a range of mainly voluntary sector organisations that were working well on their behalf

- From a statutory perspective, delivery service for tablets, Some GP services, Community Psychiatric Nurses and Psychiatrists were endorsed as working well.

- In this changing environment the emergence and growth of self help is increasingly replacing provided services and considered to be both economically sound and empowering.

- The work of the PIER Team (Psychosis Intervention and Early Recovery) was endorsed However it is clear that continuity and communication between services and agencies is very important.

Activities

- The notion that meaningful and worthwhile activity is a costly and complex process was overturned by participant views that highlighted seemingly simple things that are working well. For example: talking, playing cards, bingo and games. Music and poetry, art, yoga, concentration games, trips out, leisure cards, newspapers and using computers and walking groups.

- A range of drop in facilities were promoted as not only working well, but providing the basis for social interaction, 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.

- What is clear, is that something so 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.

What are the key issues/concerns/gaps in the current service provision?

Loss of services

- The impact of service redesign has not only resulted in the voluntary sectors inability to plan strategically for the medium term, but in anxiety and anger for the people who wish to use those services.

- Participants identified their perception that Leicestershire Partnership Trust (LPT) seem to have had difficulties with implementing change, financial problems, shortages of nursing staff and an over reliance on agency staff who generally don’t know service users they are caring for.

- There is a real concern about the premature discharge of individuals from hospital too quickly.

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

- 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 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.

- In primary care there is concern with General Practitioners who are said to be difficult to access and sometimes unhelpful. It appears that it is family, the voluntary sector or non mental health services that people turn to in these situations

Voice and Communication

- Miscommunication and rivalry between competing voluntary sector groups has resulted in confusion brought about by service tendering,

- If voluntary sector providers are actively competing for resources then opportunities to share good practice may well be usurped by commercial interests rather than the interests of the populations that they serve.

- There is a lack of consistency between different services e.g. Social Workers and Community Psychiatric Nurses and approaches that clash.

- Too restrictive criteria with social care assessments which, are seen to avoid offering vital help with social isolation, anxiety and motivation

- Lack of consultation

- Service Users feel voiceless and disempowered.

Primary and Secondary Care

- A lack of consistency and understanding of mental health conditions in acute secondary care (University Hospitals of Leicester)

- Access to GPs and the communication between GPs and psychiatrists were highlighted poor in some cases Difficulty in obtaining a GP appointments were seen as “rationing by delay”,

- Communication between services could be better to improve continuity e.g. between GPs and Psychiatrists, between inpatient wards and homeless services and between early intervention services and continuing care services.

Finance and benefits

- The roll out towards personalisation and testing of ability to work often ignores mental health issues.
- People who may be entitled to a personal budget have not had the process or the safety measures and alternatives explained sufficiently which appears to be causing anxiety.
- Worry was a consistent theme which emerged from service user comments highlighting concerns about Disability Living Allowance interviews, transport being reduced, funding cuts, reduction of services and general benefit change. It appears that this anxiety has been produced by a lack of accessible information and the attitudes of some people who work for the Department of Work and Pensions.

What kinds of services do we want now and in the future?

- A significant number just wanted to maintain what they already have.
- There were calls to campaign for increased resources, whilst using present resources in the most effective way and to promote services that assess and meet people's needs holisitically
- Providers need to develop sensitivity and competance regarding culture, spirituality, ethnicity, gender, age, sexual orientation, gender identity and specific abilities/disabilities. To enable users to feel cared for by competent staff.
- More flexible working by providers including weekends and out of hours support from Community Psychiatric Nurses in particular.

Communication

- More honesty and accountability (to service users) from primary and secondary mental health providers,
- Being properly listened to by professionals and for professionals to hear the voice of those who have most contact with service users and carers such as support workers.

Housing

- Continuation and recognition of the benefits of supported housing.
- A weekend safe house
- A community based alternative (Crisis house) to an acute admission ward

Partnership Care

- The idea that multidisciplinary teams should positively embrace the reality of the “expert patient or expert carer” as an equal partner, incorporate their views in decision making and invite them as true members of the MDT as a matter of routine.
- Listening to legitimate concerns when they are expressed, and to commit to something more than simple placation or signposting to inappropriate services.

Activities and Education

- The words “trips and outings” appeared in a large number of participant answers. This indicates two things, that people like to socialise and that organised travel may be the only option for some service users to venture into the broader community.
- Literature classes, Poetry reading and writing, access to books, learning to cook (different foods from around the World, baking and microwave cooking), exercise classes movie club and art clubs were all suggestions for meaningful social activity that participants thought were important for good mental health.
- An overwhelming outcome from participants was the need to learn more about the welfare benefit system coupled with more support from agencies to gain a better understanding of benefits, the proposed changes and legitimate entitlement. This appears to be driven by an underlying fear that a mistaken claim will result in prosecution, and the embarrassment that would accompany such a situation.

Provided services

- Social drop ins and day centres with social activities and organised and peer support. befriending service.
- Shorter waiting lists and GP access for counselling.
- Respite services and increased availability of weekend help.
- Participants want to see a better understanding of mental health conditions, continuity and collaboration within statutory services, and between those services and the voluntary sector.

Recommendations

1. Recognition of the benefits of supported housing and continuity in the funding and development of further schemes.
2. Consideration of the benefits of alternatives to hospital, that might include crisis, recovery, respite and “halfway” accommodation, a weekend safe house or some form of community based alternative to an acute admission ward.
3. Develop and extend the range of drop in facilities and opportunities for social interaction peer support and befriending

4. Investment in self help such as book prescription services (bibliotherapy), e therapy (online CBT) for example.
5. Investment in spaces where music, poetry, art, cooking yoga, talking, games, newspapers computers and exercise can be accessed
6. Investment in helping people increase their range with cheap organised travel
7. Investment in education specifically about personalisation, the welfare benefits system and changes and housing related support which impact upon service users and carers
8. Access and consultation time with GPs and psychiatrists should be extended
9. Improved partnership between voluntary, alternative, employment and statutory sectors should be actively promoted.
10. More flexible working by providers including weekends and out of hours support from Community Psychiatric Nurses in particular.
11. Multidisciplinary teams should positively embrace the reality of the “expert patient or expert carer” as an equal partner, incorporate their views in decision making and invite them as true members of the MDT as a matter of routine.
12. More honesty and accountability (to service users) from primary and secondary mental health providers with better organisational accountability and the engagement of independent investigators
13. A campaign to reduce the stigma of mental health conditions

Introduction

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

The Leicester City Joint Commissioning Strategy for Mental Health 2011-2013 (p4) 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. They go on to identify 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.

The views contained within this report were collected during a Pre Summit event in which ‘over the course of the day 60 people attended, mainly mental health service users and carers, but also local voluntary sector organisations such as Norton House, LAMP, Network, Akwaaba, Savara, Recovery, Foundation Housing, Leicester LINK and Aspiro also attended.

Attendees were asked to complete a very simple survey which asked for their views of three key questions:

- What is working well?

- What are the key issues/concerns/gaps in the current service provision?

- What kinds of services do we want now and in the future?

Following a number of presentations and discussions the audience were invited to join focus groups to collectively consider these points and to prioritise them in the form of a pyramid. Each group was facilitated to ensure the focus was maintained, and the following results emanate from those discussions.

An examination of the focus groups used a simple content analysis to bring some logic to the narrative responses, and attempted to distil the wide ranging viewpoints into themes which include:

- Housing
- Provided Services
- Early Intervention
- Activities and Education
- Loss of services
- Voice and Communication
- Primary and Secondary Care
- Finance and Benefits
- Communication
- Partnership care

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, DH 1989a, DH1989b) These documents were the forerunners to the Community Care Act of 1990, a major piece of legislation which 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 localized services. Successive governments have however, 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 within organisations that provide services, and more importantly, for the recipients of those services.

What is working well?

Whilst there is palpable anxiety surrounding the future of services, and lament for the provision that has already been lost, it is clear that both the voluntary and statutory sectors continue to get some things right.

Housing

Supported housing is seen as a wholly positive long term solution for both service users and the people who care for them.

> *Carer "From our point of view, one thing that has had a positive impact of our lives is getting our son into supported living accommodation provided by Norton House. It has given our son a sense of independence and has also provided him with some support from the care worker and also from the other residents themselves, who because they suffer from similar health issues are able to empathise and support one another. Norton House care workers work hard to help their residents to address any issues and to encourage the resident's self-development. We think that the key to the success of Norton House is continuity. Continuity provided by committed staff and the routine of structured days. Norton House also seem to work really well in partnership with carers and families and other mental health agencies".*

> *Service user "My supported housing has improved my quality of living. I am very happy and stable mentally. I live in a great house with two other men and feel very safe and well. I am very happy there and have lived there for eight and a half years".*

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

The importance of a stable home environment with a mix of personal and shared space appears to be a cornerstone of recovery and good mental health. For people who have had transient accommodation, which is generally at the lower end of the market their experiences appear to undermine their mental health and are perceived to increase the likely-hood of intervention by statutory services.

Supported housing is seen as the basis for personal growth and development which may be partly due to the relief from the complexity of keeping on top of pressure caused things like utility bills, but when coupled with budgeting skills development, provides a safe place to nurture the survival skills necessary to become a more independent and productive member of the community.

> *Service User "Very concerned and worried over the prospect of my supported housing closing. There should be no talk of this ever happening in the future".*

Service users living in supported accommodation have no control over budget cuts that may well see their "home" ceasing to exist and this insecurity has generated a significant amount of anxiety about the future. Accommodation, its stability and location are important factors, but it is the care and support which sustains individuals within the community and the, skill based activities that enable recovery, encouraged differentiation of work and leisure time are said to promote wellbeing, social capital and contribution to the community.

> *Service User "I am working well with the support worker and she has given me the confidence to undertake tasks and hobbies throughout the week. The food shopping is taken care of and managed well. I am happy with the living conditions and area is also good".*

> *Service User "Rota with cooking and cleaning chores. Having a support worker part time gives me more independence. Budgeting skills improved. Doing activities and working. Nice bedroom. The food shopping is of a high standard. Living conditions are excellent – clean, tidy and comfortable, excellent decor."*

However when service users do find themselves without a roof the statutory response was seen by at least one person to be working well.

> *Service User "Homeless mental health service works well with support workers and are happy to take an MDT approach to care. I experience good communication with the team and a quick referral process".*

Provided Services

The 2011 Leicester and Leicestershire Economic Assessment noted that the main demographic trends are that people are living longer, there are increasing numbers of smaller households, many of them older people and there are more 'non nuclear' family households and different living arrangements. This coupled with the diverse and multicultural nature of Leicester one would expect a plethora of provision for the BME communities and older people.

Where specifically mentioned, BME and older people's services were doing well although the following comment stressed a need for more

> *Service User "There should be more services for Asian people and for older people who can't get about".*

Participants listed a range of mainly voluntary sector organisations that were working well on their behalf including Network for Change, the Leicester Action for Mental Health (LAMP) Advocacy Service, female only services and a number of local voluntary services concerned with the mental health of minority ethnic groups and or effects of domestic violence.

> *Voluntary Sector Service Provider "Developing trusting relationships – a key ingredient when expectations are that service users challenge their fears and barriers. We are able to provide a feeling of belonging and community within our project which has been shown to have a positive effect for clients generally, beyond direct contact with our service. Being able to offer social/peer support groups, confidence building, skills and crafts in our resource centre (which is now under serious risk of closure due to funding cuts). The Recovery approach has enabled many clients to step out of the notion that they have a permanent*

> *condition and some have successfully discontinued medication they have used for years and been able to engage in activities they have wanted to do".*

From a statutory perspective, delivery service for tablets, GP service, Community Psychiatric Nurses and Psychiatrists were endorsed as working well.

In this changing environment the emergence and growth of self help is increasingly replacing provided services and considered to be both economically sound and empowering.

> *Service User "I am keeping myself fit and healthy and I am doing lots of walking and eating healthy"*

In addition, the comfort of a friend enabled through a befriending scheme was seen as helpful, and those described as support workers were said to be working well.

> *Service User "Befrienders: I can say almost anything I need to say to her in confidence".*

The participants recognised attempts by local LINKs to engage with and share ideas with Somali, Gipsy and other local communities and to run health events with them.

Early Intervention

The work of the PIER Team (Psychosis Intervention and Early Recovery) was endorsed by a number of participants and captured by the following statement:

> *Carer "We think early intervention must be key in the treatment of the kind of issues that our son has. We would have liked it if some continuity of care could have been provided by the PIER team. Not by the PIER Team per se, but somebody like a mentor who works in and around the PIER team who is able to continue to support and accompany the patient on the transfer from the PIER Team to the next care team".*

However it is clear that continuity and communication between services and agencies is very important.

Activities and Education

The assumption that providing meaningful and worthwhile activity is a necessarily costly and complex process is overturned by participant views that highlighted seemingly simple things that are working well. A range of drop in facilities were promoted as not only working well, but providing the basis for social interaction, and for some, the only opportunity to meet with other people.

> *Service User "The mental health Drop In Centres provide social life and education facilities for mental health service users, voluntary organisations such as REMIT, Network for Change, Advance Housing and SISO (Safe Inside Safe Outside), are doing a good job"!*
>
> *Service User "It's good to have somewhere to go and talk to other people, it's a warm and friendly environment".*

Activities are currently as diverse as the people who use them and include for example: talking, playing cards, bingo and games. Music and poetry, art, yoga, concentration games, trips out, ECO minds, leisure cards, newspapers and using computers and walking groups (Stride).

Organisations who were highlighted were Network for Change, Bright-sparks, the LPT Involvement Centre, the Resource Centre, Leicester Action for Mental Health Project (LAMP) and Remit. In addition, the use of local FE Colleges was highlighted with particular reference to the development of literacy and numeracy skills.

> *Service User "I am lucky in the fact that I have a good CPN and doctor and attend a brilliant group called Network for Change where I can interact with other people. This has only been possible with understanding from the staff at Network and my CPN".*
>
> *Service User "Compassionate and understanding places such as Network for Change, who have an ethos believing in the potential of mental health service users, and work towards an all-round recovery and is very helpful for the social benefits gives me".*
>
> *Service User "LAMP is an invaluable service that finds and guides you to the help you need like counselling, housing et cetera and is making a real difference to my life and hoping to get very well again".*

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".*

> *Service User "The days I go to Drop-ins it works for me because I am in a home. I socialise with friends here. I chat and play games with other service users".*
>
> *Service User "I think it works well, especially for people who are on their own. Also for ones that don't get out. There is caring staff and someone to talk to if needed. It is nice to go somewhere where you can feel comfortable and meet others".*
>
> *Service User "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".*

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 5 million people say the television is their main company 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.

What is clear, is 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.

What are the key issues/concerns/gaps in the current service provision?

Loss of services

In 2010, the 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. However an overwhelming outcome of this study suggests that despite transitional funding, 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 NCVO (2011), and without doubt Leicester City and County are contributing to this saving. The VCS 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 impact of these cuts has not only resulted in the voluntary sectors inability to plan strategically for the medium term but in both anxiety and anger for the people who wish to use their services.

> *Service User "Lack of Government funding for charities like Network, LAMP, Strides, etc. really gets my blood boiling"*
>
> *Service User "Lack of funding. Lack of support at weekends".*
>
> *Service User "strategy and services. All adds up to a very short-sighted and blinkered approach which, in the long run, has huge costs"*

Participants identified their perception that Leicestershire Partnership Trust (LPT) seem to have had difficulties with implementing change, financial problems, shortages of nursing staff and an over reliance on agency staff who generally don't know service users they are caring for. There is a real concern about the premature discharge of individuals from hospital too quickly. Proposed reasons for this included lack of funding, but more specifically a shortage of hospital beds within LPT in particular an observation that Psychiatrists should spend more time talking to their patients before deciding what needs to be prescribed. One person offered a solution *"so why not treat them in the comfort of their own home with intensive care/support"*. Concerns were expressed about future provision of advocacy services and the communication with essential voluntary services and the replacement of 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.

Service User "When I am unwell I don't have enough support".

Service User "Services have been cut back, and are affecting my routine and activities".

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.

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.

> *Carer "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! "*

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.

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

> *Service User "I had to find the help that I needed from my advocate at LAMP 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".*

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.

Voice and Communication

> *Service User "It is crucial that good practice is identified, acknowledged and shared".*

An interesting carer observation that highlights the confusion and current state of the voluntary sector in Leicester, proposes the idea that, miscommunication and rivalry between competing voluntary sector groups has resulted in confusion brought about by service tendering, and *"false duplication of groups with a free market approach and forcing the loss of local established services",* and that replacing such services will cost far more in the future. If as has been suggested, voluntary sector providers are actively competing for resources then opportunities to share good practice may well be usurped by commercial interests rather than the interests of the populations that they serve.

This confusion is not restricted to the voluntary sector as statutory services were said to present a

> *Carer "Lack of consistency between different services, e.g. SW, CPN and approaches that clash. Lack of effective communication and outcome goals that fight against each other. Too restrictive criteria with social care assessments which, due to lack of funding and resources, avoid offering vital help with social isolation, anxiety and motivation – which is part of their remit in their won service aims but rarely provided for due to internal pressures and goals. This is a gross under-estimation of the damage and negative effects of the above issues which prolong and exacerbate mental health problems with a huge cost to society and long term costs (financial), lack of early intervention".*

In addition it appears that changes are being made without consultation, "*hospitals do not communicate with us"* facility closures have been made without asking and there is "*No say for service users*" leaving them feeling voiceless and disempowered. One person suggested that it took 11 years of "*sheer desperation"* and *"really strong letters before we finally got appropriate mental health support"* and that "*there must be many more vulnerable people who don't have carers or family speaking up for them who must feel completely abandoned by the system".*

Primary and Secondary Care

Leicestershire Partnership NHS Trust was described by one person as "hopeless" and who stressed a lack of consistency particularly at hospital appointments where s/he "*see a different person at each time",* and there are *"a shortage of Community Psychiatric Nurses".*

University Hospitals of Leicester, particularly the Leicester Royal Infirmary were criticised about their understanding and treatment of people with mental health conditions

> *Service User "Not enough mental health knowledge in A&E Departments of hospitals".*
>
> *Service User "Also the Walk In Centre at the Leicester Royal Infirmary's staff are unsupportive".*

Access to GPs and the communication between GPs and psychiatrists were highlighted as issues with one person the help of their Advocate.

> *Service User "I had to find the help that I needed from my advocate at LAMP 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 between GP and consultant psychiatrist".*

One service user suggested that being able to access a GP for an appointment helps compliance with treatment and prevents seeking help from secondary care. One interpretation might be that, difficulty in obtaining a GP appointment is "rationing by delay", and that a consultation would improve concordance, enable a better understanding by the

GP and consequently enable the most appropriate service to be provided in the community rather than in secondary care, thus saving money

Housing

Respondents outlined difficulties when someone attempts to seek hostel accommodation when being discharged from mental health services particularly the Bradgate Unit within Leicestershire Partnership NHS Trust.

There is a perception that communication between services could be better, and that this vulnerable group suffer from a lack of continuity as a result with records not being transferred, difficulty in accessing Community Psychiatric nurses and counselling.

> *Service User "The teams at the hospital have poor communication and rarely offer community support (no CPN teams). Obviously, it is difficult for someone with MH issues to comply with appointment times especially when they have other issues associated with homelessness".*
>
> *Service User "Unfortunately if someone is receiving care from hospitals they cannot fall under Homeless Mental Health service".*

This may be because the "homeless" person is not registered with a GP and less likely to be able to referred to IAPT (Improved Access to Psychological Therapy) services.

Finance and benefits

The Department of Work and Pensions are reforming the system to "help people to move into and progress in work, while supporting the most vulnerable". They suggest that reforming the benefit system will make it "fairer, more affordable and better able to tackle poverty, worklessness and welfare dependency".

Whilst these aspirations appear reasonable their translation into practice seems to have generated anxiety and concern. In particular the roll out towards personalisation and testing of ability to work that eschews an understanding of mental health issues.

> *Service user "I am a bit concerned of the new idea of buying my own support. I tend to open up to any kind of professional help I get. I am just worried about receiving some sort of professional help from somebody I don't like. If I am unhappy about certain help is it easy to withdraw it".*
>
> *Service user "The way service users being treated by benefit people. They don't have an understanding of how service users react and worry with changes, and may relapse with worry. They talk over them to support workers and treat them at medical assessments".*
>
> *Service user "I wish that Benefits Agencies would be more understanding when dealing with benefit changes and cuts in services. It scares me with all interviews for benefits not realising or recognising mental health enough".*

Furthermore there are the issues that people who may be entitled to a personal budget have not had the process or the safety measures and alternatives explained sufficiently which appears to be causing anxiety.

Worry was a consistent theme which emerged from service user comments highlighting concerns about DLA interviews, transport being reduced, funding cuts, reduction of services and general benefit change. It appears that this anxiety has been produced by a lack of accessible information and the attitudes of some people who work for the DWP.

What kinds of services do we want now and in the future?

Participants were very forthcoming in their suggestions to improve the current provision with a significant number just wanting to maintain what they already have.

> *Service user "The services available to me now are good. I just want them to carry on now and in the future so for me just improve what we already have".*

There were calls to campaign for increased resources, whilst using present resources in the most effective way and to promote services that assess and meet people's needs holistically, in relation to mental and physical health, spiritual, cultural, psychosexual, legal, economic and social needs. In addition, that providers are both sensitive and competent regarding an individual's culture, spirituality, ethnic group, gender, age, sexual orientation, gender identity and specific abilities/disabilities. To enable users to feel cared for by competent staff.

This was coupled with requests for more flexible working by providers including weekends and out of hours support from Community Psychiatric Nurses in particular.

Communication

An important point about honesty from statutory services was made by several participants who want to see both primary and secondary mental health providers, being accountable to service users as well as regulatory and professional bodies. Being properly listened to by professionals and for professionals to hear the voice of those who have most contact with service users and carers such as support workers.

There was an acknowledgement that providers are under pressure to meet their targets but in these days of personalisation it appears that the personal service has been lost in the drive for efficiency. A simple quotation which captures this well suggests:

> *Service user "GPs should spend 5 to 10 minutes talking to patients".*

Housing

Continuation of long term housing related support and the development of a more secure financial environment that recognises the benefits of supported housing. This includes the idea that supported housing maintains the stability of individuals with mental health needs and could be easily badged as health promotion due to the savings it makes on the cost of inpatient care.

> *Service user "I have done very well since moving here, I haven't been in hospital, but I want things to remain the same".*

A weekend safe house was suggested together with respite place for both service users and carers. A community based alternative (Crisis house) to an acute admission ward was suggested together with other community based non statutory acute services.

Partnership Care

Participants proposed improvements in partnership working *"where all stakeholders have an input, with a focus on continuity and early intervention" and that family's and* carer's experiences should also be valued. The idea that multidisciplinary teams should positively embrace the reality of the "expert patient or expert carer" as an equal partner, incorporate their views in decision making and invite them as true members of the MDT as a matter of routine.

Listening to legitimate concerns when they are expressed, and to commit to something more than simple placation or signposting to inappropriate services.

One participant suggested a development of the independent sector as a legitimate alternative to statutory provision.

Activities and Education

The words "trips and outings" appeared in a large number of participant answers. This indicates two things, that people like to socialise and that organised travel may be the only option for some service users to venture into the broader community.

> *Service user "There is a lack of opportunity for trips, I would like to go on an occasional trip"*
>
> *Service user "We need more activities in our groups. Going out activities"*
>
> *Service user "Would like to go bowling again and other outings"*

Social drop in groups, the opportunity to hold and be involved in fund raising events.

Literature classes, Poetry reading and writing, access to books, learning to cook (different foods from around the World, baking and microwave cooking), exercise classes movie club and art clubs were all suggestions for meaningful social activity that participants thought were important for good mental health.

The need for day services for the older people giving them somewhere to go. "*We need more weekend activities, more facilities, more community groups where people can socialise".* These were said to be able to prevent isolation and encourage peer support rather than professional support *"which would be cheaper in the long run"*.

> *Service user "We used to have an out and about group where we went on visits such as tea shops and garden centres. I am happy with the service and know if not well you can be seen and if need action taken.*

An overwhelming outcome from participants was the need to learn more about the welfare benefit system coupled with more support from agencies to gain a better understanding of benefits, the proposed changes and legitimate entitlement. This appears to be driven by an underlying fear that a mistaken claim will result in prosecution, and the embarrassment that would accompany such a situation.

> *Service user "Better understanding of benefits and workers to have more knowledgeable information and mental health and respect their feelings (service users). Service users need all the support with all changes occurring in benefits"*

A call for more generalised education for those suffering mental health was asked for by a number of participants with "*good courses with plenty of daytime activities".*

Provided services

A list of wants and needs has been distilled into the following quotations:

> *Voluntary sector provider "Services – that recognise the importance of working relationships, reassurance, trust and community. The relationship is the instrument for change – that understand how variable people's coping skills are on a day-to-day basis depending on stress, triggers, support levels. Understand that recovery needs an environment of acceptance, empathy and balance between challenge and reflection – realise that all people with mental health problems regardless of the diagnosis, essentially need the same human things. There is no reason why all mental health services couldn't work in this way but it appears the voluntary sector is better at delivering Person Centred Planning/recovery based care at the moment, and more is needed otherwise people with mental health conditions are left without any real change of making any recovery if they only receive a 15 minute CPN visit once a week or fortnight and a 15-30 minute outpatient appointment once every 6-12 months which is often the case"!*

> *Voluntary sector provider "Services which aim to provide therapeutic social and physical environments, with therapeutic community principles, as an important part of care and treatment and related staff education and training".*

> *Service user "We all need day centres. With the population getting more depressed and stressed out it really needs more day centres".*

> *Service user "Somewhere to go to outside the home, and knowing that there is somewhere to go.*

> *Service user "I strongly recommend the current services being maintained (i.e. not subject to financial cuts). Other many fellow patients will suffer considerably.*

> *Service user " I would like the social drop ins to continue and if possible include the odd trip.*

> *Service user "Provision of funding for groups such as Network Resource Centre. Funding for individual support and to keep Network open".*

> *Service user "A place for people to go to (local and easy to get to), activities, peer support.*

Service user "Short-term stay Drop In Centres would be good to provide for service users emergency needs, also – keep funding up for Network for Change and other mental health voluntary agencies.

Service user"More privacy at hospital and less stigma from people in general, this could be done through advertising. A start has been made regarding workers. I would like a befriending service and shorter waiting time for counselling.

Service user " LAMP, counselling/therapy services within your local surgery

Service user "Investment in the voluntary sector".

Service user "More funding for Network, LAMP, Stride, etc. that is what we want now and in the future".

Service user "Provision of a more client centred approach. Perhaps respite services and services which recognise the value of peer-mentoring".

Service user "More help at the weekend because can only speak to support over the phone".

Conclusion

When considering the views that service users and carers have expressed, and comparing them with aspirations of the document ‘No health without mental health’ DH (2011) (Appendix 1), and our own multi agency Mental Health Charter (Appendix 2), we see universal concordance.

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 within this short report.

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 which 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, 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, 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 voice 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 likely-hood 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 in general hospitals and importantly GPs 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 prior to discharge and that discharge is a considered process driven by patient need rather than bed occupancy issues.

When we consider day time **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.

Simple 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.

The **loss of services** and the impact of service redesign has resulted in the voluntary sectors inability to plan strategically and in anxiety and anger for the people who wish to use those services. Drop in Centres give people a purpose and meaningful activity. In the absence services informal carers become the primary backstop when things go wrong. They often have no choice, and provide both emergency, out of hours assistance, and day to day support, which invariably impacts upon their own economic productivity, and health.

Listening to service users and carers is seen as very important to ensure provision is needs, rather than service led and raising mental health awareness to challenge stigma is important and providers need to develop sensitivity and competence to effectively **communicate** and meet the diversity of the Leicester people.

Worry was a consistent theme which emerged when considering f**inance and benefits** and the roll out towards personalisation and testing of ability to work often ignores mental health issues.

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 was important with convenient opening hours, parking, meets their specific cultural and religious requirements, good disability access and public transport links. This same 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 would help maintain their mental wellbeing if they were given the money to do so. The results of the pre summit survey underscore these initial findings and demonstrate consistency in the wishes of people who use services and their carers.

The Mental Health Alliance Convention Report 2011highlighted 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 and furthermore, 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), 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 will involve better communication and relationships, a shift in professional cultures, discourses treatment models and attitudes underpinned by real consultation based upon full information.

The consistency within this report and previous reports is clear. This snapshot of views only serves to underscore what has already been said, and what we all know is best practice and what should be happening.

Recommendations

1. Recognition of the benefits of supported housing and continuity in the funding and development of further schemes.
2. Consideration of the benefits of alternatives to hospital, that might include crisis, recovery, respite and “halfway” accommodation, a weekend safe house or some form of community based alternative to an acute admission ward.
3. Develop and extend the range of drop in facilities and opportunities for social interaction peer support and befriending.
4. Investment in self help such as book prescription services (bibliotherapy), e therapy (online CBT) for example.
5. Investment in “safe” spaces where alternative, complementary, therapeutic activities including music, poetry, art, cooking, yoga, talking, games, newspapers, computers and exercise can be accessed, as many service users feel unsafe in mainstream organisations, and need to know the staff understand and accept their mental health condition.
6. Investment in helping people increase their range with cheap organised travel.
7. Investment in education specifically about personalisation, the welfare benefits system and changes and housing related support which impact upon service users and carers.
8. Access and consultation time with GPs and psychiatrists should be extended.
9. Improved partnership between voluntary, alternative, employment and statutory sectors should be actively promoted.
10. More flexible working by providers including weekends and out of hours support from Community Psychiatric Nurses in particular.
11. Multidisciplinary teams should positively embrace the reality of the “expert patient or expert carer” as an equal partner, incorporate their views in decision making and invite them as true members of the MDT as a matter of routine.
12. More honesty and accountability (to service users) from primary and secondary mental health providers with better organisational accountability and the engagement of independent investigators.
13. A campaign to reduce the stigma of mental health conditions.

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Appendix 1

No health without mental health’ DH (2011) **six objectives**

1. **More people will have good mental health**

2. **More people with mental health problems will recover**

3. **More people with mental health problems will have good physical health**

4. **More people will have a positive experience of care and support**

5. **Fewer people will suffer avoidable harm**

6. **Fewer people will experience stigma and discrimination**

DH 2011

Appendix 2

Mental Health Charter

Every person in Leicester, Leicestershire and Rutland has the right to mental health services that:

1. Make a positive difference to each person they serve.
2. Stop doing things that are not working.
3. Are guided by the individual’s views about what they need and what helps them.
4. Treat everyone as a capable citizen who can make choices and take control of their own life.
5. Work with respect, dignity and compassion.
6. Recognise that mental health services are only part of a person’s recovery.
7. Recognise, respect and support the role of carers, family and friends.
8. Communicate with each person in the way that is right for them.
9. Understand that each person has a unique culture, life experiences and values.
10. Give people the information they need to make their own decisions and choices.
11. Support their workers to do their jobs well.
12. Challenge “us and them” attitudes both within mental health services and in the wider society.

Produced by Leicester, Leicestershire and Rutland Recovery Group 4th March 2008