

Liberating the NHS: Greater choice and control

Response by Revolving Doors

January 2011



About Revolving Doors Agency

Revolving Doors Agency is a charity working across England to change systems and improve services for people with multiple problems, including poor mental health, who are in repeat contact with the criminal justice system. We call them the revolving doors group.

Multiple problems experienced by women and men in the revolving doors group often include drug and/or alcohol misuse, homelessness, learning difficulties, physical health problems, poverty, debt and poor relationships with family. Drug and/or alcohol are often used as coping mechanisms to deal with current problems or previous trauma, for example childhood neglect or abuse.

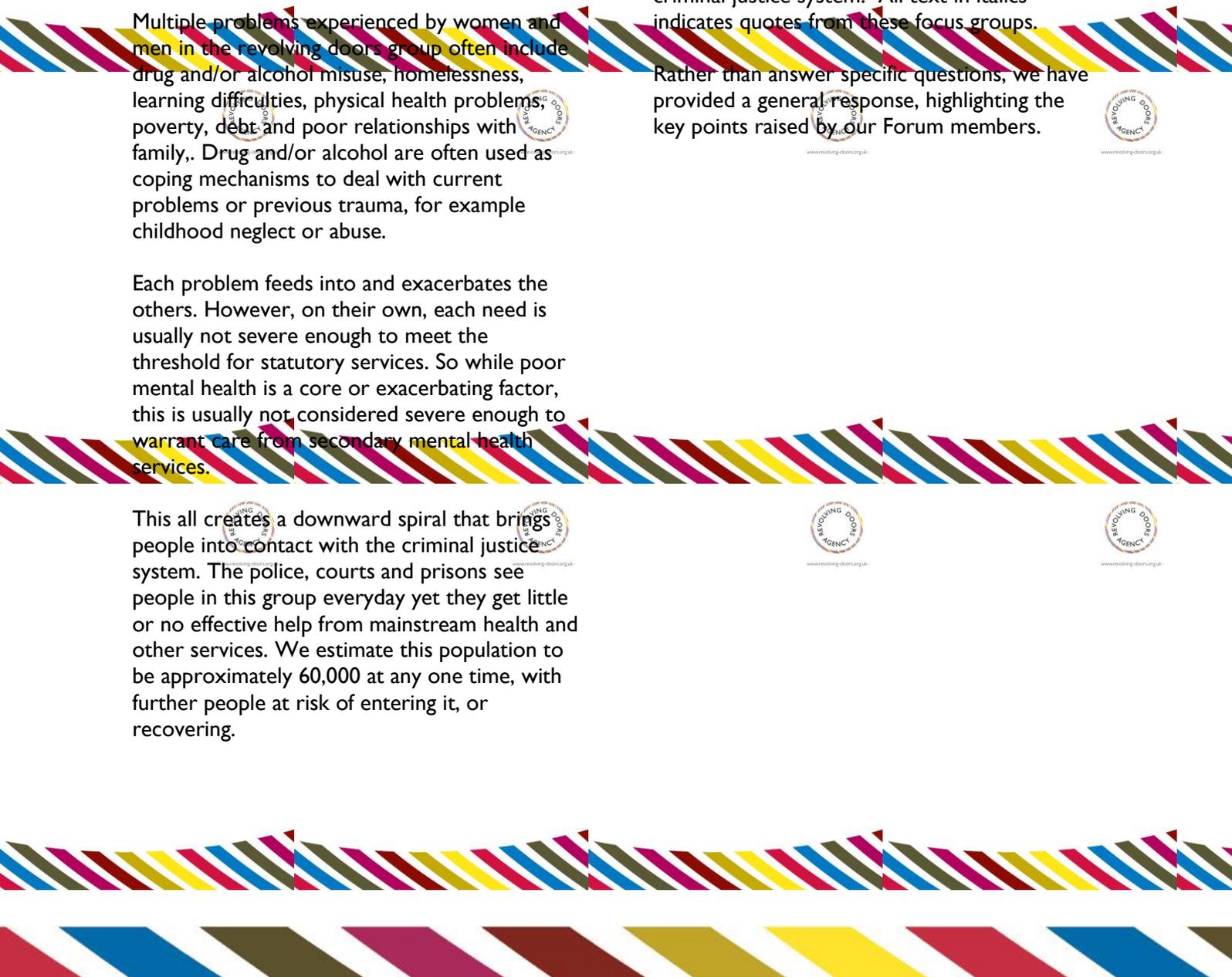
Each problem feeds into and exacerbates the others. However, on their own, each need is usually not severe enough to meet the threshold for statutory services. So while poor mental health is a core or exacerbating factor, this is usually not considered severe enough to warrant care from secondary mental health services.

This all creates a downward spiral that brings people into contact with the criminal justice system. The police, courts and prisons see people in this group everyday yet they get little or no effective help from mainstream health and other services. We estimate this population to be approximately 60,000 at any one time, with further people at risk of entering it, or recovering.

Our response

This response has been developed through focus groups with members of our National Service User Forum, and as such reflects the experience and aspirations of people with multiple needs including common mental health problems who have been in contact with the criminal justice system. All text in italics indicates quotes from these focus groups.

Rather than answer specific questions, we have provided a general response, highlighting the key points raised by our Forum members.





Key recommendations

transition between prison and the community

- The impact of multiple needs on health and access to health services should be a core consideration across the National Health Service
 - Healthcare professionals should be trained to develop a better understanding of the challenges faced by patients with multiple needs
 - Positive, trusting and respectful relationships with healthcare professionals are essential in allowing patients to exercise choice and control
 - An independent advocate or accompanying individual can be highly valuable in supporting people with multiple needs to understand and exercise choice
 - Providing joined up and integrated care is an essential element of personalised care. This is particularly important for people making the
- People with multiple needs often experience poor literacy and digital exclusion. This should be taken in to consideration when providing information on available choices
 - People with multiple needs may be unaccustomed to taking responsibility for their choices, and should be supported to do so. Peer involvement initiatives such as health trainers may be particularly effective in this
 - Choice and control should not only be exercised at the service delivery stage, but also at the service design, commissioning and evaluation stages



Introduction

Revolving Doors welcomes the Government's commitment to improving choice and control in healthcare

Health plays a key role in the lives of people with multiple needs. A lack of access to appropriate healthcare often perpetuates a cycle of crisis and crime, while effective health interventions can be crucial in enabling people to break free of this cycle. However, negative experiences of engagement with health services are common. Stigma, discrimination and a lack of understanding of multiple needs can lead to patients feeling disempowered and health needs remaining unaddressed. Poor engagement with mainstream health services can result in people using expensive emergency services when they have an urgent health need.

We are pleased to see the consultation document recognise that "choice has an important role in promoting equality and reducing inequalities by helping people from different backgrounds to access the highest quality of services."

The following consultation response outlines some of the key barriers to choice and control faced by people with multiple needs, and how these can be addressed.

An understanding of multiple needs

A key theme emerging from service user focus groups was the importance of health professionals having an understanding of multiple needs. Participants spoke of feeling discriminated against due to their addictions, mental health problems, offending history or general appearance.

"I went to my doctor the other day about my anxieties and my alcohol [use] ... he said he would

not put me back on my medication, he turned round and said ... 'alcohol's a part of your life and that's just the way you are'

The failure to understand and respond effectively to multiple needs and the impact of social exclusion has serious medical and social consequences that have a profound impact on the wellbeing of individuals and communities.

Revolving Doors recommends that multiple needs and the impact of social exclusion should be a core component of the education and training of GPs, nurses and other medical staff.

This would enable healthcare professionals to understand the challenges faced by people who experience multiple problems (mental health problems, homelessness, drug and alcohol problems, and contact with the criminal justice system), including the frustrations of trying to access multiple services, repeatedly being assessed and asked the same questions and the challenges of articulating one's needs. A good understanding of a patient's social situation would encourage healthcare staff to be more empathetic and less judgemental.

People with multiple needs who are in contact with the criminal justice system are as a whole a very transient population. Frequently being sent to prison for short periods results in regular transitions between prison and community. This presents challenges in continuity of healthcare. This challenge of transience is key to exercising choice, as available choices often assume a permanent address and sustained engagement with Primary Health Care. The disrupted nature of our target group's lives does not tie in with this assumption. Without a link to primary care, there may be barriers in accessing secondary health care when this is required.

The development of an understanding of multiple needs could be achieved through training delivered by service users and/or spending time with front line delivery



agencies such as homeless hostels, link workers or outreach teams.

This could provide an opportunity for service users and healthcare professionals to better understand one another's point of view and experiences. For example, a person who has been excluded from a GP surgery for disruptive behaviour would be able to explain the triggers and motivations for his or her actions, while a healthcare professional could explain the effects disruptive behaviour has on other patients.

Positive relationships

This understanding is essential to building positive relationships between healthcare professionals and patients, which are vital if choice and control are to be exercised.

Members of our National Service User Forum taking part in focus groups for this response were clear that this applies as much to them as it does to the general population. **Respect, trust, an ability to listen and being non-judgemental were identified as key characteristics of a positive relationship.**

"Some doctors you go to don't take any notice of you. Other doctors, they actually listen."

Participants emphasised how frustrating it is to be denied access to certain medication due to histories of drug or alcohol use. Whilst we recognise that this refusal may be made on medical grounds, we recommend that patients are given better explanations of why they are not prescribed and supported to find alternatives. Training in multiple needs may help address situations such as the following:

"Doctors think you're looking for something you'd like, but ... it's not what you like, it's what works, but they don't understand that. Most people when they go for these strong painkillers, [doctors] are thinking they want it just to get high or something, or to sell them or whatever, but they're not, they're getting

them for genuine reasons, because that's what strong enough to help them."

Flexibility of healthcare services was identified as a crucial factor in facilitating positive relationships. Service users told us how short appointments allowed little time to build trust and healthcare professionals lacking understanding of how hard some people find it to keep appointments or arrive on time. An improved understanding of multiple needs is essential in understanding the need for this flexibility.

What information and support do people with multiple needs need to make the right choices?

People with multiple needs often have little experience of being offered choice of services and of making informed choices. Exclusion from and negative interactions with services is more common. This is compounded by inter-generational social exclusion where choice has rarely been a reality. High quality support is therefore needed in order to exercise choice and control; support to identify needs, to access choices, to make choices and to implement decisions.

"Someone on my side"

The consultation document recognises that those "who find it more difficult to make decisions may need additional support so that they can be more involved in decisions about their healthcare. People who help them with their decisions will also need to be involved." **This presence of additional support was one of the key themes arising from focus groups; a trusted person to accompany individuals to medical appointments, help individuals to communicate better with medical staff, and to help understand choices. Described variously as a mentor, representative, advocate, third party, friend, support worker and link worker,**



this person could be a professional, a volunteer or a personal contact.

“My appointment was at 11.20, I did not get to see the doctor until 40 minutes later ... how does that work? If I was late [I wouldn't have been allowed to see the doctor] ... and that makes you want to leave, if it wasn't that somebody was with me ... I go to [support service] ... they always make my appointments for me 'cos I don't want to do it by myself, I don't want to. And they come with me, they remind me the day before or the morning before, and they go with me if I'm feeling anxious or apprehensive or whatever.”

This concept of “someone on my side” is a recurring theme through much of Revolving Doors' work. A forthcoming review of the social care needs of short-term prisoners found that:

“Throughout all the research, the key to successful interventions appeared to be a trusting, positive relationship between the client and the support worker. This was emphasised by service staff where interviewed, and was a common feature of what service users wanted and respected from a service (Braithwaite & Revolving Doors' National Service User Forum, 2009; Moore & Nicoll, 2009; Revolving Doors, 2010). Maguire & Raynor (2006) stress the importance of this in maintaining motivation, highlighting the increased responsibility that people feel towards delivering on promises made to someone with which they have an established relationship.”

(Revolving Doors Agency, forthcoming 2011)

The theme has also been highlighted in the work of the Social Exclusion Unit, as outlined by the extract below.

“Adults with multiple problems need a range of services and can be in contact with several providers. However the most vulnerable people with the greatest needs can benefit less from the support on offer. This may be because they are less able to find out about and access available services and / or

because they are less able to engage with and get the most from provision.

[To effectively meet these people's needs,]... it's vital that services work together to provide joined up support. The likelihood of achieving this is bolstered if one service practitioner guides the client through all the different services he or she may require, and co-ordinates the various providers around that person's needs.

This practitioner, who takes responsibility for ensuring that all of the client's needs are identified and met as fully as possible, is sometimes known as the lead professional. They work with a range of other professionals as necessary and have clear authority to take on the role.”
(HM Government 2009)

Joined up working

The consultation document promises to “introduce choice in care for long term conditions as part of personalised care planning.” It goes on to say that “... For people with more complex needs, good quality personalised care planning will support better joined up working across health and social care professionals. Having a single assessment and care planning discussion that is led by one professional such as a nurse, doctor or social care worker followed by an agreed joined up care or support plan can really make a difference to the way professionals share information and work together. It is much better for individuals, since they do not have to repeat their story over and over, and should reduce fragmentation of care.”

Revolving Doors welcomes this recognition of the benefits of joined up working, and urges the Government to extend this commitment to people with multiple and complex needs who may not be considered to have long term conditions but who may have a complex mixture of health and social care needs.

By definition, seeking help to address multiple problems requires interventions from multiple services. In order to effectively engage with



these services and hence address multiple needs, an integrated approach is required.

The joining up of services needs to happen at both an operational and a strategic level. A recent evaluation of Revolving Doors' National Development Programme found that a key success factor in projects working with adults with multiple needs in contact with the criminal justice system was multi-agency partnership working at both an operational and strategic level. All pilots were overseen by a steering group consisting of local leaders in health, social care and criminal justice. They were able to facilitate the freeing up and pooling of resources and troubleshoot operational difficulties. At an operational level, successful projects were characterised by staff who formed good communication channels with other organisations in the community, building up trust and understanding between organisations. Working across service boundaries between health, housing, criminal justice and drug and alcohol agencies allowed projects to effectively address and meet service users' needs. (Centre for Public Innovation, 2010)

Service users contributing to this response emphasised the importance of healthcare professionals being aware of other areas in their lives where they faced challenges, and having a knowledge of local services that may already be working with them or may be able to help. Housing was identified as a particularly important area. Unstable housing or homelessness has clear links with health outcomes. They suggested that primary health services should be collocated with other support services, or where this was not possible for healthcare professionals to be able to signpost patients to other services. Strong links with other services in the community will help healthcare professionals to better understand the needs of their patients, to identify problems early on, and to respond better to their needs.

Accessing written, online and telephone information

Much recent improvement in patient choice has arisen from improved provision of advice and information in online formats. This poses considerable challenges for people with multiple needs in contact with the criminal justice system who often experience poor literacy and digital exclusion. We recommend that **advances in online information should not mean a decline in the availability of face-to-face advice.**

"... not everybody is computer literate or even wants to be. Therefore facilities should still be in place for people who want face-to-face contact with service providers. The danger of making services available exclusively online is that the needs are not being met of those with reading and computer literacy problems and those who lack access to computers and the Internet on release – this is particularly relevant for ex-offenders, with their much lower than average reading age and higher prevalence of learning difficulties and disabilities." (Communities and Local Government, 2008)

Members of our National Service User Forum suggested that access to online health information could be improved by "ATM style health points"; computers in GP surgeries where you can access information on local services and health options.

Telephone based information can also be hard to access. In focus groups for this response, participants spoke of how telephone calls can be distressing for people who are anxious and unconfident in speaking on the phone.

"I cannot stand talking on the phone to people I don't know." "You want to do it but you want someone to help you." "[You] get anxious."



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The following case study illustrates the potential impact of difficulties using telephone services.

Case Study

John came to the attention of the Milton Keynes Link Worker + scheme¹ when he started getting in regular trouble with the police in his twenties. He had not previously had any contact with the criminal justice system and the police could not work out what had triggered his offending. The police referred John to the Link Worker + scheme.

The Link Workers met with John and spent some time exploring the reasons for his offending. It transpired he was in severe pain with toothache, and was self medicating with alcohol and drugs. He had been in pain for some time, but had not been able to access a dentist.

When John's toothache had become severe, he had been told to call a helpline in order to be allocated a dentist. He had called the helpline but had not been able to make himself understood to the automated voice recognition system. This directly resulted in his self-medicating use of alcohol and drugs, which in turn had led to his offending. Link Workers supported John to access a dentist, and his offending immediately ceased.

Taking responsibility for choices

The consultation document states: *"It is important that we take responsibility for the choices we make as patients and service users, for following the treatment programmes and care plans we have agreed to, and for the implications that those choices have for our healthcare and lifestyle."*

While we agree with this statement, we ask the Government to carefully consider the implications of this focus on responsibility. Compliance with treatment programmes may

¹ The Milton Keynes Link Worker + project is a partnership between Milton Keynes Community Safety Partnership, P3 and Revolving Doors. The scheme exists to facilitate the engagement of clients with services which can maintain their long term well-being. The scheme focuses on people living in Milton Keynes who are in crisis because of a combination of mental health needs,

be challenging for an individual who is insecurely housed or in transition between prison and the community. Lifestyle choices may be limited by poverty, poor housing or poor education. **The Government should recognise that those who are socially excluded and disempowered may require additional support to aid compliance with treatment programmes.**

Approaches which maximise peer involvement such as Health Trainers can play a crucial role in supporting people to take responsibility. Health Trainers provide advice, motivation and practical support to individuals in their local communities on how to improve their health. They often come from the communities they work with. This model has been used in work with offenders, for example at HMP Everthorpe, and much can be learned from this work.

Participants in focus groups held for this response suggested a number of ways in which people with multiple needs could support their peers in accessing, understanding and engaging with healthcare options. One example proposed was peer-run drop in centres in GP surgeries, where volunteers give advice to patients wanting support and information.

Service user involvement has a key role to play in developing the capacity of socially excluded individuals to take responsibility for their own health and to contribute to improving services for others.

accommodation problems, substance misuse, offending or anti-social behaviour. Link workers support clients who have traditionally struggled to engage with services to access appropriate support.



Involving patients in service design

Choice and control should not only be exercised at the service delivery stage, but also at the service design, commissioning and evaluation stages. Service users who have experienced chaotic lives and have recovered are often well placed to comment on the design of services for people with similar experiences. **We recommend that the Government maximises opportunities to involve patients in the design, commissioning and evaluation of healthcare services.**

This can be achieved by working with groups such as Revolving Doors' National Service User Forum. Members of the Forum have direct experience of mental health and other problems and have had contact with the criminal justice system. They work with us closely to influence policy and design and improve services. Members of the Forum already work with the Department of Health through the Users and Carers panel linked to the National Advisory Group for Health and Criminal Justice (NAG). We would be keen to further our work with Government to explore this issue further.

Much can also be learned from co-production approaches, such as the RSA's Whole Person Recovery project (<http://www.thersa.org/projects/whole-person-recovery>).

Conclusion

As the Government points out in the consultation document, choice and control have a vital role to play in promoting equality and reducing inequalities by helping people from different backgrounds to access the highest quality of services. This is particularly true for groups for whom choice and control are rarely experienced.

Health is central in both perpetuating and breaking free from a cycle of crisis and crime, yet many people with multiple needs in contact with the criminal justice system face many barriers in accessing and engaging with health care.

Our key recommendations to Government are that the impact of multiple needs on health and access to health services should be a core consideration across the National Health Service, and that healthcare professionals should be trained to develop a better understanding of the challenges faced by people with multiple needs.

We also urge the Government to seriously consider how service user involvement can be improved in service design, commissioning and deliver, and we are keen to work with the Government to facilitate this.





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