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Using peer research processes to understand strategies to support those with severe, multiple and complex health needs

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Abstract

\textbf{Objectives}: There has been an increased focus in policy discourse on individuals with severe, multiple and complex needs. This paper seeks to understand how best to enable these individuals to take greater control of their health.

\textbf{Design}: Qualitative, user-led, peer research

\textbf{Setting}: Large urban UK city.

\textbf{Method}: Trained peer researchers with previous experience of severe and multiple disadvantage gathered data using a snowball sampling approach from 21 individuals engaged in a service specifically designed to provide for their needs.

\textbf{Results}: The study identified enabling factors that create conditions for individuals with severe and multiple disadvantage to take greater control of factors impacting on their health and social situations. These included working holistically with individuals, understanding the interconnected issues impacting on health, developing trusting relationships with professionals and working within a positive framework that fosters self-belief and is focused on salutogenesis rather than pathogenesis.

\textbf{Conclusion}: There exists a set of enabling factors that may support individuals facing particular challenges in their lives. While derived from within a specific geographical context, findings have relevance to other settings in relation to ways of working. Peer research demonstrates itself to be a research approach well suited to understanding lived experiences.

\textbf{Keywords}:
Peer Research, Social Exclusion, Health Promotion, multiple disadvantage, complex needs, UK

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Introduction

Using a qualitative, user-led, peer research model, this paper draws on evidence from the evaluation of a service (referred to as ‘the service’ throughout) to support those with severe and multiple disadvantage in a large urban UK city. Despite definitional ambiguity surrounding individuals with severe, multiple and complex needs, we define these groups as “those involved in the homelessness, substance misuse and criminal justice systems… with poverty an almost universal, and mental ill-health a common, complicating factor” (Bramley et al., 2015: p.6).

The service focused upon was informed by multi-agency partnership approach to working in an integrated and collaborative way. The service sought to meet the diverse requirements of people with a variety of complex needs including problems gaining or sustaining accommodation, mental ill-health, substance misuse and involvement in the criminal justice system. It aimed to break down barriers that can prevent people from leading fulfilling lives by delivering the right range of support in a timely way. The service was underpinned by a holistic view of health, which recognised the wider determinants impacting on individuals’ health behaviour and social circumstances. All service-users were allocated a case-worker who had appropriate training to support and enable individuals to gain more control over their circumstances – the type and mode of intervention was driven by the service users and their agenda, views and perspectives.

While conducted within a specific geographic locale, this study and its findings have wider relevance and make two distinct contributions to understanding. First, they identify enabling factors that create conditions for individuals with severe and multiple disadvantage to take greater control of factors impacting on their health and social situation – a key outcome of any health promotion practice (World Health Organization, 1986). Study findings stress the value working holistically with individuals, developing trusting relationships and working within a positive framework that fosters self-belief. Second, the paper suggests that in order to access the direct and lived experiences of people, an approach that governments, commissioners and third sector bodies are increasingly willing to acknowledge (Terry, 2016), peer research is a viable and beneficial approach and should be considered further by those working in this field.

Background

Health promotion research and practice are generally characterised by working with, and alongside, those facing inequalities or exclusion from society. Its goal is to enable individuals and communities to have greater control over the determinants impacting on their health (Green et al., 2015; Woodall et al., 2018). Health promotion practitioners, policy makers and academics have a long track-record of working with vulnerable groups – including those defined as being ‘at risk’ because of their social position or due to their exposure to contextual factors that differentiate them from the rest of the population (Frohlich and Potvin, 2008).

In the UK, there has been an increased focus in policy discourse on individuals with severe, multiple and complex needs. A plethora of terms have been used to describe these groups.
They include people with ‘severe and multiple disadvantage’, ‘multiple disadvantage’, ‘multiple disabilities’, ‘multiple impairment’, ‘dual diagnosis’, ‘high support needs’, ‘complex health needs’ and ‘multiple and complex needs’ (Rosengard et al., 2007; Parker and Bullock, 2017). These terms are sometimes used interchangeably and but are sometimes deployed differently (Macias Balda, 2016). Health promotion as a discipline and practice has not, explicitly at least, provided a clear strategy for supporting and enabling those with severe, multiple and complex needs to take greater control of their health. Commentators, however, have described individuals with severe, multiple and complex needs as being ‘on the extreme margins of social disadvantage’ (Bramley et al., 2015: p.11) and given health promotion’s aim of tackling inequality using a social determinants of health framework (Baum and Fisher, 2014), understanding the issues faced by such groups seems worthwhile.

It is difficult to ascertain the number of people faced with severe and multiple disadvantage (Rankin and Regan, 2004), although the estimated figures are not inconsequential. Over 250,000 people in England have contact with at least two out of three of the homelessness, substance misuse and/or criminal justice systems and at least 58,000 people have contact with all three (Bramley et al., 2015). Evidence suggests that severe and multiple disadvantage results from a myriad of factors including structural, systemic, family and personal influences (Bramley et al., 2015) – resonating strongly with ecological views of health promotion which seek to intervene at macro, meso and micro levels (McLeroy et al., 1988). The lack of affordable, available or suitable accommodation is a tangible illustration of a structural factor that impedes intervention with people with multiple and complex need (Macias Balda, 2016). Other systemic challenges include poor management sharing and a lack of collective recording processes across agencies working toward supporting those with severe and multiple disadvantage (CLES, 2016). This can mean that individuals ‘fall through the gaps’ of service provision (Bringewatt and Gershoff, 2010; Warwick-Booth and Cross, 2018). Finally, unsupportive interpersonal relationships, irregular contact with care services and fractured family dynamics may also characterise the experiences of people facing severe and multiple disadvantage (Social Exclusion Unit, 2002).

While some might argue against policy intervention to address those most vulnerable, due to differing views about who is ‘deservingness’ and support (Woodall, 2016; Parker and Bullock, 2017), there is a clear humanitarian case to addressing the needs of individuals facing such circumstances and exclusion. Members of this population, for example, encounter disproportionately high rates of ill-health, disability and disease. Drug and alcohol problems, for example, are 85 times more likely to occur in populations with severe and multiple disadvantage (Bramley et al., 2015). In addition, there is an economic case for working with those facing severe and multiple disadvantage. Put crudely, severe and multiple disadvantage costs UK taxpayers over £10 billion per year (Bramley et al., 2015). Despite investment in statutory provision, services and support to address this population group often fall short of delivering meaningful outcomes (Bramley et al., 2015). Research suggests unhelpful staff attitudes and a dearth of co-ordinated support act as barriers to achieving successful health and social outcomes (Rosengard et al., 2007; Macias Balda, 2016). Nonetheless, spending time and building relationships with service users to gain trust is widely viewed as a working practice that will increase the likelihood of success:
“relationships are considered a transformational tool that allows service providers to identify and work on the other issues that are affecting the individuals.” (Macias Balda, 2016: p.32)

There has been something of a tendency in commissioning frameworks and service evaluation to privilege quantitative approaches to demonstrating success with individuals with severe and multiple disadvantage, often at the expense of user-led research (Terry and Cardwell, 2016). Duncan and Corner (2012), for example, discuss the tensions between providing objective, ‘hard’ measures of success and the need also to capture ‘subjective’, softer outcomes. Practitioners argue that quantitative strategies alone are unhelpful as they fail to recognise more nuanced and less-easily identifiable changes in individuals’ lives or indeed how and why these changes occurred (Macias Balda, 2016). Perversely, there is often an inclination to work with those individuals considered ‘less vulnerable’ to demonstrate quantifiable change rather with those with more profound and entrenched needs (Macias Balda, 2016).

**Methodology**

**Research setting**

Our study was carried out in a large urban UK city with a fast-growing population, currently standing at over half a million. The population is diverse in relation to ethnicity and life expectancy for both women and men is lower than the national average. The service where participants in this study were drawn from, is designed to support those with severe and multiple disadvantage. Service provision is delivered primarily through a lead organisation, in this case a nationally recognised non-governmental organisation, but is supported by local partner organisations that offer distinct expertise in areas such as mental health, substance use and housing.

**Research design**

The research process was underpinned by a participatory philosophy and sought to build upon core values associated with health promotion research, particularly inclusion and participation (Woodall et al., 2018). The research included the training of lay individuals with previous experience of severe and multiple disadvantage. These included experiences of a combination of homelessness and/or substance misuse, and/or mental health issues, and/or previous contact with the criminal justice system. The initial idea was to establish a community–academic partnership between the academic team and ‘lay’ people who have or had experienced severe, multiple and complex needs. Developing and training lay individuals as peer researchers was the primary means by which to establish this community–academic partnership.

While peer research processes can vary considerably, often viewed along a spectrum (Vaughn et al., 2018), they are generally viewed as inclusive and helpful in neutralising perceived power differentials between researchers and the communities being researched (Porter, 2016). When well conducted, peer research, broadly located under the auspices of community-based participatory research (CBPR), is said to be “an empowering experience
that builds capacity” (Guta et al., 2013: p.432). Peer research approaches have been utilised in several disciplinary areas, including in health promotion (Green et al., 2015; Woodall et al., 2018).

This study could have been carried out without the inclusion of peer researchers; however, our rationale for such an approach was threefold. First, evidence consistently demonstrates that this research strategy can provide rich and detailed data about lived experience (Terry, 2016). Those who understand and share common experiences can often elicit and understand other people’s (similar forms of) lived experience, views and thoughts (Green and South, 2006). Indeed, commentators note how peer researchers are often more approachable due to their insider status, their local insights and commonality in experiences (Vaughn et al., 2018). Second, evidence suggests that involving peers in research can greatly improve the quality, relevance and acceptability of the research to different stakeholders (Vaughn et al., 2018). Third, training people with lived experience of multiple needs can provide new skills and may potentially be empowering for those involved (Vaughn et al., 2018). Evidence suggests engagement in peer research processes can provide opportunities for confidence building, raising self-esteem as well as developing skills that can be transferred to other contexts (Terry, 2016).

**Training peer researchers**

As researchers, we were cognisant of the competing demands and complexity of involving lay researchers and aware of the potential tensions they may face in their research practice (Guta et al., 2013). To mitigate these potential difficulties, research training was provided to the peer researchers and support processes put in place. In recruiting individuals from within the service to become peer researchers, we first gave a short presentation about the role and the benefits and challenges anticipated. Written information in the form of a simple flyer was also provided. It was stressed that the role required training, but was voluntary and that individuals could withdraw at any point. Twelve individuals attended the one-day training session which introduced the purpose of peer research and outlined what would be expected. Training was provided in active listening, working ethically and safely, asking open questions and operating the audio recorder. Support was given to each peer researcher as and when required. This was a particularly time-consuming element of the research, as others have identified (Elliott et al., 2002), but one which was deemed essential to both avoid peer researcher attrition and to ensure safety and data quality.

**Data gathering**

No pressures were placed on peer researchers to gather a prescribed number of interviews. Instead this was driven at each of the peer researcher’s own pace. Issues such as personal set-backs and other commitments meant that in some cases peer researchers only conducted a small number of interviews – something not unusual in this context (Clover, 2011) – and some completed none at all. During the course of the study, five peer researchers – three men and two women all of whom had experienced a combination of homelessness and/or substance misuse and/or mental health issues and/or previous contact with the criminal justice system – were ‘actively’ engaged in data gathering and
were all compensated for their time, skills and efforts through shopping vouchers – a process of good practice recognised in the literature (Terry, 2016).

In total, the peer researchers completed 21 semi-structured interviews with those engaged in the service over a 9-month period. The participants interviewed were sampled using snowball method, a common approach in peer research studies (Elliott et al., 2002), and interviews took place in various locations – some in people’s homes, some in service waiting areas and others in outdoor locations. As the peer researchers themselves were service users, they often had connections with others interacting within the service. All the participants interviewed had been identified as having severe, multiple and complex needs by the service and had been referred into the service to support their health and well-being.

The interview schedule, designed jointly by the peer researchers and the academic research team, covered a broad spectrum of issues, but focussed mainly on what was needed by services to engage and support people with severe and multiple disadvantage. Recordings of the interviews were transferred from the peer researchers to the evaluation team after each day of interviewing; however, the analysis of the data was undertaken by the research team only.

**Ethical considerations**

The ethical issues of involving peer researchers has been much discussed (Terry, 2016). The training provided to peer researchers focused in detail on ethical principles, particularly in regard to how the researchers stayed safe and adhered to key ethical principles, such as gaining informed consent. The ethical principles of beneficence and non-maleficence (i.e. do good while minimising potential harm) (Noble-Adams, 1999), was also a critical research concern. It was important to give consideration to the ways in which taking part in the study, both for peer researchers and interviewees, could be harmful to participants as balanced against the potential benefits. It was anticipated however that the benefits of participation would outweigh the risks. Clear information was provided by the peer researchers to service users and consent processes were followed to ensure all interviewees were aware of their rights. All respondents consented to being recorded and the ethical aspects of the study were approved by Leeds Beckett University ethics committee.

**Data analysis**

The style of analysis adopted was a thematic approach, drawing predominantly on the work of Braun and Clarke (2006). In brief, all data were transcribed verbatim and from an initial read through of several of the interview transcripts the research team developed a coding framework. This framework was agreed and subsequently applied across the data set. A sample of transcripts was initially coded by two researchers to aid internal consistency and rigour and disagreements in coding application were discussed and resolved using a third team member where necessary. After coding, a process of making ‘sense’ of how codes linked and related took place. In this process, some codes were amalgamated and others re-classified. Through this process, thematic categories were agreed by the research team and shared with peer researchers to ensure that the themes were grounded in the data.
gathered. While the initial intention had been to involve the peer researchers in this process, this was not feasible. Instead, several of the peer researchers commented on the salient themes emerging from the analysis (presented verbally at meetings and events) to provide a ‘sense check’ on the analysis.

**Findings**

**Participant profile**

Peer researchers took the opportunity to explore individuals’ health and social circumstances. While the main focus of the discussion was on their interaction with the service and the support provided, such contextual information was essential.

All of the 21 interviewees (14 male, 7 female) described a unique journey, often characterised by mental health issues, challenges with substance misuse and fractured family relationships. Most of the participants interviewed had also experienced periods of homelessness with a minority still without permanent accommodation.

“About this time last year, I turned up at the mental health unit and said: ‘hello I’m bonkers, please lock me up’ and they put me onto this new service...prior to this I was not receiving any other services, just the GP.” (Participant 3, female)

“I’ve been coming [to the service] for five months now and when I first started I was on the floor and I was homeless, I had a big drug habit, I had nowhere to go.” (Participant 11, male)

“I had nowhere to live and was experiencing mental health problems, well I still am. They helped me with that. They’ve got me in a hostel now and they are trying to help me address my drug and alcohol problems.” (Participant 6, male)

**Working holistically**

Taking an holistic approach was identified as a key ingredient by participants to working successfully with individuals with severe and multiple disadvantage. Service users had multiple interconnecting issues to contend with, which meant examining their health and social issues in isolation was relatively pointless.

“I’ve had counsellors who counsel me on mental health issues. Great. Fine. But none of those ever asked me about the roof above my head or so on. I go to my GP, who is great, but it just doesn’t do it. I go to a housing officer, but they don’t help me about the times I was getting down. What I’ve got here [the service], I know there are people I can go to about all of those things.” (Participant 8, male)

The value of ‘person-centred’ approaches within the service was a key thread in participants’ accounts – using such an approach service users did not feel constrained by service thresholds (i.e. presenting with issues too complex to be managed by providers), or
meeting professionals with existing agendas or priorities. Instead, they felt able to talk openly about the issues impacting on them:

“I’ve never had support before. I tried to look for support but each place I was going to wouldn’t accept me for my support needs, I’ve got bipolar and services I was going to was only doing stuff for basic depression. My needs were too high for them. I am getting the support I need now.” (Participant 19, male)

Linked to this, was the importance of there being an unconditional approach. This emerged as a key value appreciated by interviewees:

“I’ve been involved in a lot of services and none of them are particularly positive in their approach. They offer you the minimum and there’s no continuation of help. They may help for a ‘flash-in-the-pan’ week but after that the help stops. This service gave me the impression that they are here for the long-run...so hugely different.” (Participant 1, female)

Interviewees appreciated and gained benefit from having a single-contact point. More fragmented services created logistical difficulties in terms of managing travel and diary appointments. Participants also felt they were ‘repeating’ their story each time to a new agency or organisation.

“I used to go to one service and they would send me somewhere else to tell my story so I’d keep repeating myself and getting sent all over...I was in a chaotic lifestyle I couldn’t meet a lot of my appointments...and that’s what I like about this programme, when somebody comes to us we’ve got mental health here, we’ve got probation, we’ve got drug and alcohol, we’ve got homelessness, all under one roof you don’t have to send someone all over the city telling their story all over again and then you know information can get lost, people fall through gaps.” (Participant 6, male)

**Fostering self-belief and inspiring change**

The need for services to support and address individuals’ immediate health and social issues was described as being crucial, but services which also worked to foster self-belief and provide enthusiasm for the future was highly valued.

“I was making the effort to get off drink and drugs already but the programme has given me that extra push and motivation. It made me want to do it as opposed to ‘I must stop drinking’ now I actually think I don’t want to drink and I really don’t want to do drugs-there is a better life out there and I am going to go out there and grab it.” (Participant 16, male)

The service described here was perceived by interviewees as providing genuine meaning and purpose, and placed the individual at the centre of everything. Such an approach was contrasted with other services designed to address individuals with severe and complex need:
“This programme gives me a lifeline...here I feel as though I have a meaning in life, there [previous services] I was living in a robot world.” (Participant 21, male)

“It’s given me structure and purpose to my routine. It’s made me realise what I’m good at...I feel positive about the future and feel able to achieve goals that previously I wouldn’t have.” (Participant 14, female)

The service was seen as offering individuals a myriad of opportunities and this opened possibilities that otherwise would not have been available.

“I had nothing before this programme, I was in a hostel and I didn’t have no job or support or anything like that. I’ve done a cooking course, a history course and a computer course...It’s got me out in the days, I’m not bored, I’m doing something with myself and I’m hoping to get a job as well.” (Participant 13, male)

“I’ve got structure and routine more than anything and a sense of purpose. It’s been good for my confidence building.” (Participant 14, female)

An approach which looked beyond individuals’ acute health and social needs was regarded as more sustainable since it allowed individuals to take greater control over their longer-term situation. Providing service users with the opportunity to gain qualifications to support future employment was a tangible example of looking beyond immediate needs:

“The help for people struggling is not there, it’s getting better...the help I got from this programme has woken me up and inspired me to try and help others. I hope to start my course and then go to college.” (Participant 4, female)

Some interviewees had begun to take a longer-term view of their lives – shifting away from more fatalistic interpretations of their future:

“I feel much more positive, much more enthralled by the future and future possibilities and I’m feeling that there are opportunities that are there to be taken. I don’t know where I’ll be in five years, but if you asked me that a year ago I would have said I’d be dead. The service is great in terms of support, but it has to come from the individual...the service shows you the door to go through to change.” (Participant 21, male)

For others, the transformation was less dramatic and was at a slower pace, but nonetheless service-users described a consistent direction of travel in relation to self-belief and inspiring change.

“The future looks a bit brighter I can see the sun come peeking through the clouds a bit. I don’t want to say it’s going great but it is moseying along at a steady pace.” (Participant 3, male)
“It’s been a joy to get in touch with my inner-self. Does that sound pretentious? I’m exploring who I am, who I want to be and where I’m going and getting back to being a proper dad again.” (Participant 18, female)

**Trusting relationships**

Data consistently showed that the relationship between those with severe and complex need and caseworkers was a critical mechanism for success. The narratives of many service users identified the caseworker as crucial to achieving positive outcomes and success.

“Without this support I think I would be gone [dead]. This programme is helping me with support and helping me to focus. I’ve got people looking after me - I call them my angels.” (Participant 5, male)

Developing a trusting rapport was often challenging and it was clear from some of the narratives that interviewees had been previously let down by other services and providers:

“My worker the other day we had an appointment and she told me she was going to be ten minutes late, you know she let me know, she came ten minutes late and she didn’t lie to me so I can put my trust in her.” (Participant 7, male)

“I got into my head for thirteen years that no-one cared.” (Participant 18, female)

Service users suggested that relationships often developed quite quickly over time, this was attributed to the time that caseworkers invested in the relationship:

“If I wasn’t with my key worker, I’d be back in jail...my key worker is like a father figure to me. He’s always there for me....he’ll make time for me.” (Participant 6, male)

“It’s like a comfort blanket for me I can see [name] anytime, she just opens the door with open arms and lets me speak to her. She’d never slam the door on me so that’s why I like coming here, I never dread coming here, they make me feel welcome.” (Participant 5, male)

Empathy and valuing the individual were important constituents of the relationship with caseworkers. If service users perceived that they were being listened to, respected and their views understood, then this increased the credibility in the service. Knowing that caseworkers were experienced in managing a range of issues was important for service users.

“I think it’s great because they can talk to you, they know where you’re coming from, and they’re not someone who’s doing it from a text book. You’ve got to know that side of it but someone who’s been there and experienced it can give you their experience and they know where you’re coming from.” (Participant 10, male)
“This service is more personal, [name of engagement worker] has been there before he’s not just got it from a book, he’s been there and done it and got the t-shirt so that helps.” (Participant 5, male)

Consistency of approach was seen as an important attribute in the relationship between those with severe and complex need and caseworkers. Having weekly meetings and daily telephone contact, particularly during challenging periods, was seen as important in supporting individuals in challenging circumstances:

“When I was signed up to the service I was living in an absolute shithole, not a very hygienic place with no gas and no electricity and arrears on the rent. They helped me out financially on that and I had weekly meetings with the support worker, sometimes daily telephone calls to see how I was doing to see how I was getting on and that helped me straighten my life out and see the negative influences…and they were very consistent with their support and non-judgemental.” (Participant 12, male)

Nonetheless, there were some criticisms. When continuity of support between a caseworker and a service user ‘broke-down’, this provided immense frustration. When prior commitments were not upheld or when engagement workers changed, this caused service users particular dissatisfaction, leading them to often revert back to a ‘distrust’ of the services seeking to support them:

“There’s been one or two occasions when someone hasn’t been able to attend a job centre interview with me and someone has been lined up and it’s slipped through the net and I’ve had to ring the programme to chase it up. So that needs to be tighter.” (Participant 20, male)

Discussion

This paper makes two key contributions to the evidence-base concerning working with and researching individuals with severe and multiple disadvantage. First, the paper has identified some key mechanisms that programmes (and service commissioners) should be aware of when working with people with severe and multiple disadvantage. Second, it has shown the feasibility of utilising peer researchers, who themselves have direct experience of severe and multiple disadvantage, to access and document lived experiences. Each of these contributions will be discussed in turn.

While not purporting to be exhaustive, this paper suggests three key issues that should be addresses when working with individuals facing severe and multiple disadvantage. The notion of working holistically with individuals was a strong theme to emerge from the data – this included a more person-centred approach. Whilst intuitively working like this makes common sense, services are rarely designed to work in this way and are often fragmented (Duncan and Corner, 2012). Participants here, many of whom had been facing health and social inequalities for some time, regularly described services that failed to connect or address the totality of an individual’s concerns. Services tended to focus on one aspect of their health without considering the individual as a whole (Michaelson et al., 2018). Research shows that individuals with a dual diagnosis, for instance, often fall between
services, frequently fitting neither the criteria for mental health services nor those of drug and alcohol services (Blank et al., 2016). Fisher (2015) and Michaelson et al. (2018) commenting on the futility of overly narrow strategies to address issues facing those with severe and multiple disadvantage, offer complexity theory as an alternative paradigm. This stresses how people’s needs are interdependent in subtle and complex ways (Fisher, 2015). For example, accommodation issues may be linked to mental health or substance use. Part of the difficulty here derives form the fact that policy and funding remain focused on specific areas of need such as substance misuse, homelessness etc., ignoring the reality of people’s lives as they navigate multiple needs (Terry and Cardwell, 2016). Services must transcend traditional disciplinary areas if they are to work holistically and successfully with people facing severe and multiple disadvantage.

The need to work in a salutogenic rather than a pathogenic way with individuals with severe and multiple disadvantage was also highlighted. While there may be challenges to this way of working – most notably the fact that individuals do have acute needs that must be addressed – it is important to recognise how individuals are not defined by their disadvantage and indeed often have aspirations and future goals. This critical point is easy to neglect in the face of managing dependencies, homelessness, mental health issues or a combination of all of these. A critical facet of supporting people facing severe and multiple disadvantage is to try and encourage the development of new and constructive behaviours – working toward developing a different life narrative and a changed identity (Fisher, 2015). By promoting a different status through providing a greater sense of aspiration, the positive characteristics which typify this process may be internalised over the more negative characteristics with which the individual is often labelled. Terry and Caldwell (2016) illustrate the saliency of fostering a renewed sense of self in order to recover from severe and multiple disadvantage. In this study, the impact fostering self-belief and optimism were potentially starting points for encouraging a new set of self-understandings and encouraging a ‘future-focus’.

Good quality relationships between service users and professionals were the final component cited when working with individuals with severe and multiple disadvantage, highlighting the importance of recruitment, training and support of individuals working in this role (Fisher, 2015). Empathy and trust were key attributes appreciated by service users. While such characteristics may seem obvious in professional working, they are not always present and good interpersonal relationships are central to effective working (Hwang and Burns, 2014; Warwick-Booth and Cross, 2018). Respectfulness and dignity shows towards those individuals experiencing homelessness builds trust which, in turn, increases clients’ ability to address life needs (O’Campo et al., 2009).

“Therapeutic relationships in which patients felt their concerns were heard and accepted, and their health and illness understood in the context of their lives, were described by all the studies to a greater or lesser extent.” (McGregor et al., 2018)

Working consistently with an individual is also central to success. Fisher (2015: p.12), for example, has noted that “any support worker interacting with someone facing severe and multiple disadvantage becomes a part of that person’s social context even if that interaction
was a one-off”. By not maintaining contact or through inconsistency of contact, an individuals’ support needs will not be met.

Beyond its substantive findings, this paper has shown the value in using peer research to capture the lived experiences of those facing severe and multiple disadvantage. We do not seek to be ‘evangelical’ about the approach and we do not have evidence to suggest that the data gathered would have been different if ‘professional’ rather than lay researchers had carried out the data gathering. Nevertheless, our experience reiterates findings in the broader literature which demonstrates the contribution that can be made when service-users participate fully in the research process (Terry and Cardwell, 2016). While further training of peer researchers over a longer time-period may have yielded better quality data, the data elicit here were rich and insightful and it was clear that some peer researchers became increasingly comfortable with interviewing as they progressed.

When conducting research with marginalised populations, “the power imbalance between researcher and researched is inescapable”(Cross and Warwick-Booth, 2016; , p.8) – a situation which is antithetical to research that strives to reduce rather than exacerbate inequalities (Woodall et al., 2018). A philosophy of research which works with, not on, communities has been suggested to contribute to the generation of new data, more sensitive and knowledgeable stakeholders, increased advocacy, and more meaningful, sustainable policy change (Green et al., 2015). While we do not argue that peer research processes are ‘the only’ way in which to ascertain the voices of those with severe and multiple disadvantage, the evidence derived from the use of such approaches can offer increased insight, reach and rigour (Vaughn et al., 2018). Experience in this study suggests that people who share common experiences, when trained in relevant research skills and competencies, have much to offer as credible and insightful researchers (Green and South, 2006).

The success that peer researchers had both in understanding people’s severe, multiple and complex needs and in navigating systems designed to support health and social need was central to the success of this project. While we did not gather pre- and post-data from the peer researchers on their own health and well-being, it was clear through de-briefing and discussion that they themselves had gained significantly from the experience – including greater confidence and self-esteem as well as new skills in listening and interviewing and a broader understanding of the research process. Albeit the number of peer researchers involved in data collection was small but these individuals were highly committed and enthusiastic. Future models deploying peer researchers should, as a minimum, ensure that effective support is provided to ensure appropriate governance and safety, and to allow a safe and reflective space so that peer researchers feel able to learn from their mistakes.

Conclusions

While the service reported here was not explicitly classified as a health promotion intervention, it is clear that working in a way which recognises the social determinants of health and seeks to reduce health and social inequalities is a worthwhile endeavour. The wider health promotion literature, explicitly at least, has so far failed to fully discuss ways of working with and alongside people facing severe, multiple and complex needs in community
contexts. This paper has identified a set of enabling factors to support individuals facing particular challenges in their lives. While focused on a specific geographical context, findings have potential relevance to other settings especially in relation to future ways of working. Peer research offers a suitable research approach to understanding lived experiences.

References


