Complex Needs & Dual Diagnosis
ALL PARTY PARLIAMENTARY GROUP

People powered recovery

Social action and complex needs

Findings from a call for evidence

January 2018

This report was researched by Turning Point, which provides secretariat to the APPG for Complex Needs.

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The All-Party Parliamentary Group (APPG) on complex needs and dual diagnosis was established in 2007 in recognition of the fact that people seeking help often have a number of over-lapping needs including problems around access to housing, social care, unemployment services, mental health provision or substance misuse support. In most cases each service is administered by separate service providers. The result is that people with multiple or complex needs fall through the gaps in service provision. Providers recognise that the best model for helping those individuals with a dual diagnosis or complex needs is through an integrated service that aims to address all of the issues they face. Secretariat is provided by Turning Point, a large social enterprise which specialises in working with people with complex needs. The APPG has a network of nearly 300 members including the VCSE, academia, local government, the NHS, regulatory bodies and individual service users/family members. The work of the APPG is diverse and has covered issues such as mental health and the criminal justice system; looked after children and care leavers; sex workers; legal highs; veterans and joining up policy on multiple needs from the perspective of those on the frontline. The group undertakes inquiries into key topics, gathering written and oral evidence from the network and undertaking surveys of service users and professionals.

Huge thanks to everyone who submitted evidence for this review

CAIS
Voices of Stoke on Trent
Addaction
Build on Belief
Carers in Hertfordshire
CFE Research
Clinks
Cranstoun
Dorset Police and Crime Commissioner
Dual Diagnosis Anonymous
Expert Citizen's Stoke on Trent
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#iwill campaign
Lankelly Chase
LCPT Dual Diagnosis
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NHS Confederation
North Staffordshire Combined Healthcare
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Open Doors
Pathway
Recovery Enterprises
Recovery Republic
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Share Lives Plus
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St Giles Trust
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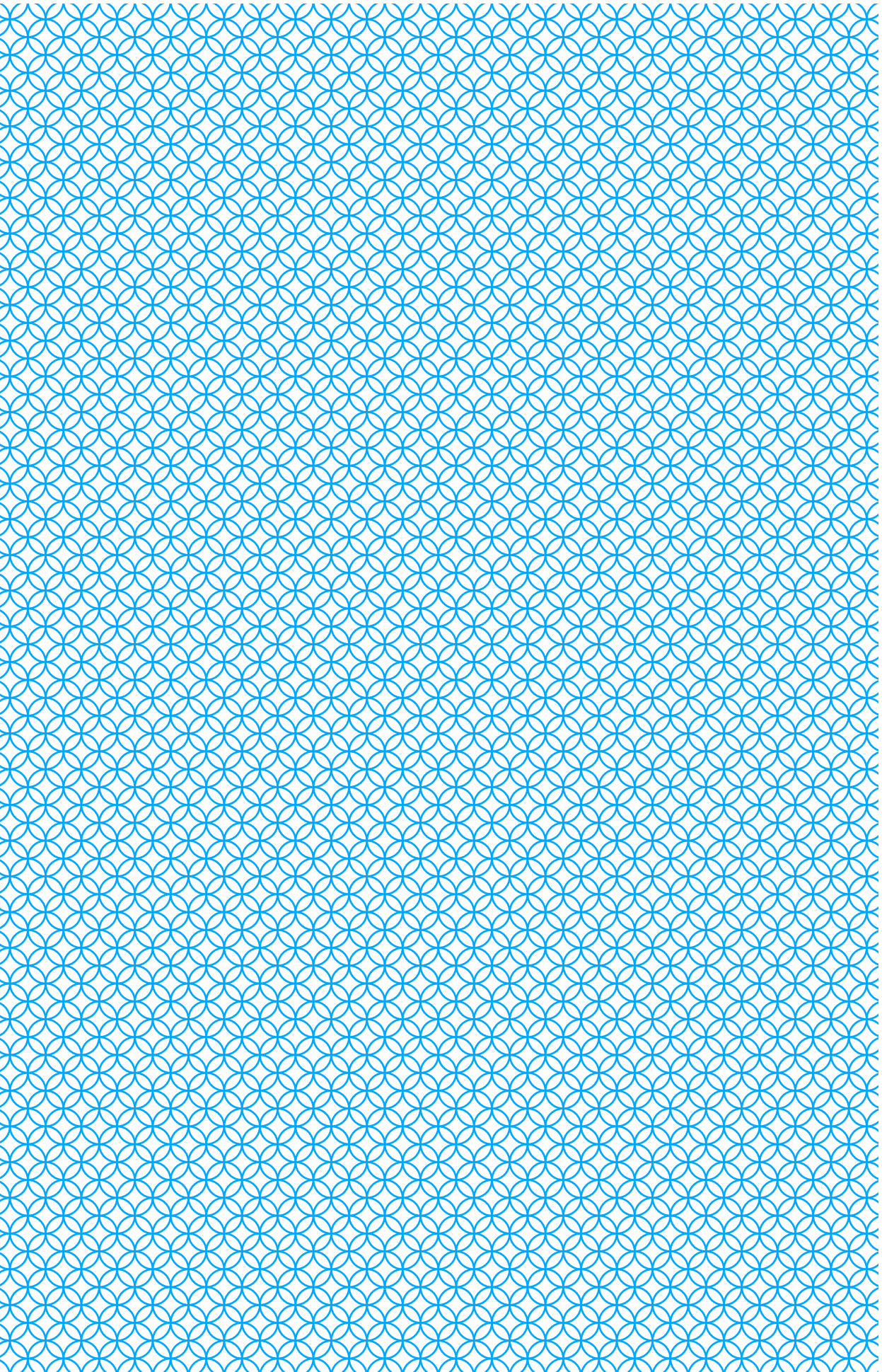
The Edge Café
The Hidden Homeless
Turning Point
User Voice
Voluntary Action Islington
Volunteering Matters
Wakefield and 5 Towns Recovery College
Women's Aid
Youth Resource Service, Sherbourne
Young People's Health Partnership



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Foreword

We have made great strides in tackling the stigma associated with mental health problems but there is still a long way to go.

This is particularly the case for many people living with co-existing mental health and substance misuse problems. People with dual diagnosis or other complex needs can be the most vulnerable in society and examples of people being let down by the system, with tragic consequences, are all too common. Social action whether that be volunteering, peer support or community projects can play a vital role in building people's confidence and breaking down stigma. It can be an important step on the path to employment. There are some great examples in this report but clearly this is still happening on a relatively small scale. Moving forward we need to support community groups, health and social care services and commissioners to grow social action, recognising that it has a unique contribution to make which is different, and complimentary to, the support provided by professional-led treatment services.

Luciana Berger MP

Co-chair for the All Party Parliamentary Group for Complex Needs and Dual Diagnosis

People with a dual diagnosis frequently struggle to get the support they need with a range of issues because, too often, services are designed around the needs of the system rather than the individual.

This report includes lots of fantastic examples of people drawing on their own lived experience to support others and of services recognising the valuable role people with lived experience can play in ensuring services are designed around people's needs. I too would like to see the approaches described in this report happening across the country, across statutory service as well as in the third sector. There is much the statutory sector can learn from the third sector in this space. In order for this to happen leaders across the health and social care system needs to drive change by championing social action and committing resources.

Lord Victor Adebowale CBE

Co-chair for the All Part Parliamentary Group for Complex Needs and Dual Diagnosis

Executive Summary

Social action is about people coming together to tackle an issue, support others or improve their local area, by sharing their time and expertise through volunteering, peer-led groups and community projects.

This report sets out the findings from a call for evidence on how social action can improve outcomes, prevent crisis, support recovery and develop more responsive services for people with complex needs.

Someone with complex needs is a person who faces multiple challenges in their life whether that be related to mental health, addiction, disability, housing or poverty. People with complex needs often struggle to get the support they need when services only focus on one particular issue in isolation and aren't joined up. Complex needs are not uncommon. Research suggests that up to 70% of people in drug services and 86% of alcohol services users have mental health problems (Public Health England, 2014). Mental health and substance misuse issues are high among the homeless population. 12% have both a mental health and substance misuse problem, while 41% of homeless people surveyed by Homeless Link said that they used alcohol or drugs to cope with their mental health issues (Homeless Link, 2014). Lack of joined-up support can have devastating consequences. More than half (54%) of suicides occur among patients with a history of alcohol or drug misuse (National Confidential Inquiry into Suicide and Homicide by People with Mental Illness, 2015). The failure to provide effective support to people with multiple and complex needs is estimated to cost society £10 billion each year (Lankelly Chase Foundation, 2015).

Through the call for evidence, the APPG has been struck by the sheer range of different examples of social action in this space. This creates a varied and complex picture but we find it positive and encouraging. The APPG has heard about projects that embed supported volunteering within structured treatment, peer mentoring programmes, peer support and mutual aid initiatives, organisations using the expertise of people with lived experience to improve their own strategic approaches as well as to help their clients, projects helping people to navigate and access services and innovative and unconventional support models from peer-led groups. Such work is bringing benefits to people with complex needs but also to the services and staff working with them. Many very different approaches are achieving similar benefits which tells us that there is no 'right way' and as the needs and characters of individuals and communities differ, so do the approaches that suit them. The examples included in this report range from volunteer roles embedded within treatment services to support networks operating independently of the public sector, wholly managed by volunteers with lived experience.

Recovery from drug or alcohol or mental health problems is about people charting their own route to greater hope and purpose in their lives. Social action can play a central role in a person's recovery. Evidence submitted to the APPG highlights the 'triple benefit' of volunteering – benefit to the volunteer, to the individuals they support and to the organisation they are working with. The experience of volunteering helps builds confidence and self-worth, key elements of recovery. Moreover, volunteers with lived experience have a unique contribution to make to structured treatment services. We have seen evidence of the positive impact on peer mentors in terms of the structure, routine and improved self-esteem and confidence that this activity gave them. Mentors also provide 'living proof that change is possible' and offer inspiration and hope to the people they support. One of the real strengths of peer mentors is that they are particularly effective at working with clients who are disengaged from traditional services, helping them to re-engage. Clients may feel more comfortable talking to a peer mentor, trust them more and feel less judged by someone with experiences similar to their own. One programme designed specifically for people with complex needs found that clients who had a peer mentor averaged five weeks longer on the programme than those who did not.

Importantly, support provided by volunteers offers something quite different to more formal, publicly funded, treatment and support services. This isn't just about substituting paid staff for unpaid volunteers in response to budget cuts. For example the APPG received evidence about how volunteers with

lived experience are often better placed to help people into treatment which can be a difficult first step and also provide continued support e.g. which can help people manage their mental health or once a period of formal treatment or support has come to an end. Many respondents to the call for evidence highlighted the long-term nature of recovery. Activities and social groups supported by volunteers and people with lived experience can provide a vital remedy to loneliness and social isolation in the longer-term.

A major benefit of social action is how it can help people with complex needs move into paid work. Often, people with complex needs are a very long way from the labour market. For example, the APPG heard about individuals in their 40s with a life long history of addiction and mental health problems who had never worked. Good employment opportunities are positive for physical and mental health and vital for reducing health inequalities (Marmot, 2010). Of particular importance for people with complex needs and those in recovery is how work can offer a sense of achievement and self-worth, structure, routine, social connections and the feeling of belonging, as well as skills development and income. Volunteering within a setting where the people around you understand the challenges you are facing can really help people take the first step towards getting paid work.

Many respondents highlighted how extremely powerful stigma can be in limiting the ability of people with complex needs to access services and support, people's perceptions of themselves, their recovery and the opportunities open to them. People with complex needs can be stigmatised by their community and by health and social care professionals. Peer led groups and activities can be a breath of fresh air with participants feeding back that they are more social, friendlier, less formal and less judgemental. More generally, social action projects value the expertise that people with lived experience bring. Projects cited in this report are clearly breaking down barriers, improving communication and understanding between services and people with lived experience and helping people to believe in themselves.

A clear message coming through to the APPG is that social action is a tool which can help improve the quality and effectiveness of services working with people with complex needs. It is still the case that many people with complex needs or a dual diagnosis simply do not have their needs met. Involving people with lived experience in service design promotes inclusion and helps to make individuals feel valued and respected. It also has the potential to drive quality improvements, through improving staff knowledge and understanding of the service user perspective, improving the effectiveness of new services and initiatives which are easier to launch and achieve higher client take-up, improving working practices and empowering service users.

It is the view of the APPG for dual diagnosis and complex needs that there are many benefits associated with social action and we are calling for volunteering, peer support and peer-led groups and community-led service design to play a more central role in services working with people with complex needs. There are, however, challenges associated with growing social action in this space around resourcing, stigma, risk averse organisational cultures, commissioning, demonstrating impact and leadership.

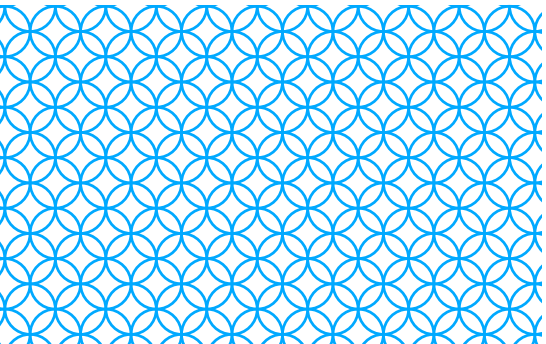
In order to grow, social action needs to be properly resourced. There are challenges associated with resourcing this type of work, particularly at a time when funding for services is under considerable pressure and demand is increasing. Funding cycles can be too short-term for projects to develop and achieve benefits and when working with people with complex needs, improvements and results can take time to realise. People with complex needs may have additional support requirements such as help getting used to working in a professional environment, flexible approaches to working patterns, referencing, recruitment and probationary periods.

Several respondents highlighted the importance of recognising that individuals can become unwell or relapse. Any potentially negative impact can be protected against through open dialogue with volunteers and peer mentors, assertive re-engagement and a fast track process for support. People with offending backgrounds and organisations working with them can face additional practical challenges around security clearances for volunteers, a perception from those with offending histories that their involvement is not possible and individuals finding vetting processes intimidating. Involving people with lived experience in the design and delivery of services and in coproduction projects also needs to be properly resourced. Setting up initiatives that cannot be maintained can massively damage trust. Involvement and coproduction must not be tokenistic – many people with complex needs will need support and guidance to participate. Involvement facilitators and safe spaces for people to express their views treat individuals working with, or volunteering with, peer-led services as equals.

Commissioning is a hugely important enabler for social action, whether it be commissioners encouraging providers to incorporate it in tender requirements, commissioning for new services and projects to meet specific needs or using social action in the commissioning process. Independent peer-led initiatives can often be excluded from funding because harm minimisation and wellbeing are low priority for commissioners. Greater involvement of people with lived experience in the commissioning process and the Social Value Act are both levers which could be employed to grow social action. It remains the position of the APPG that greater joint commissioning of substance misuse and mental health services would enable a more joined up approach and it is our view that greater involved of people with lived experience in the commissioning process would help drive this change.

There are examples of social action delivering savings to the public purse as well as improving health and wellbeing; however, the evidence base is limited. A strong evidence base is a key enabler to grow work in this area. The report includes examples of entirely voluntary run projects that have very few associated costs. However, social action and volunteering isn't necessarily the cheaper option. Some social action projects can be time and resource intensive to set up and maintain; however, leaving people to reach crisis point costs more in the long-term and impacts negatively on people's lives and on society. Social action and community approaches can benefit mental and physical health and wellbeing, NHS sustainability and wider social outcomes but the supporting evidence base is undeveloped. In order to move this work forward community groups, service providers and commissioners need to have ready access to the evidence base and academic institutions need to be engaged to grow the evidence base. A key element of this is a identifying and/or aligning short and long-term measures of success in relation to benefits of social action.

Growing social action requires leadership and senior level support. Organisational leaders need to drive developments in this space and be fully signed up to involving people with lived experience in the design and delivery of services. It is the role of leaders to challenge resistance to new ways of working, champion best practice and be flexible enough to make the project work when barriers emerge. Senior leadership is crucial to all this as it helps to shift organisational culture and open up organisations to the possibilities that social action can offer for staff for volunteers and for people with complex needs.



Introduction

This report explores the benefits of social action initiatives working with people with complex needs or a dual diagnosis. We have seen how it can support recovery, self-worth and confidence, boost employment prospects and skills, reduce stigma, better shape services to meet people's needs, contribute to better health and wellbeing and save money.

Challenges and ways to further grow social action are examined in terms of service provision gaps, resource requirements, stigma and prejudice, procedural challenges, leadership, commissioning and demonstrating impact. The report has been led by submissions received from our call for evidence and we would like to express our sincerest thanks to all the organisations and individuals that submitted evidence and otherwise supported and made our work possible.

Call for evidence background

The All Party Parliamentary Group (APPG) on Complex Needs and Dual Diagnosis was established in 2007 in recognition of the fact that people seeking help often have a number of over-lapping needs as well as problems accessing support. It is made up of interested MPs and peers and supported by a large membership network, with secretariat support provided by Turning Point. The group aims to ensure that the issues faced by people with complex needs or a dual diagnosis remain on the political agenda.

Between April and May 2017, the APPG ran a joint call for evidence with the Office for Civil Society (OCS). This asked how social action can improve outcomes, prevent crisis, support recovery and help develop more responsive services for people with a dual diagnosis or complex needs. Both written and oral evidence was received from a wide range of respondents from VCSE organisations, the NHS, peer-led groups, service providers, academics, public sector professionals and people with lived experience.

Definitions

- **Social action** is broadly defined as 'people coming together to tackle an issue, support others or improve their local area', by giving time and other resources in forms such as volunteering, community owned services, peer-led groups and community organisation (Office for Civil Society, 2017)
- **Dual diagnosis** can be used to describe many combinations of needs, however the APPG defines dual diagnosis in terms of co-existing mental health and substance misuse issues
- **Complex needs** is a term, which for the APPG describes two or more needs that affect a person's physical, mental, social or financial wellbeing. Such needs typically interact with and worsen one another, leading to individuals experiencing several problems at the same time. These needs can also be severe, long-standing and difficult to identify, diagnose or treat (APPG on Complex Needs and Dual Diagnosis, 2014)
- For the purpose of the call for evidence the APPG was interested in **complex needs where one of those needs is mental health issues**

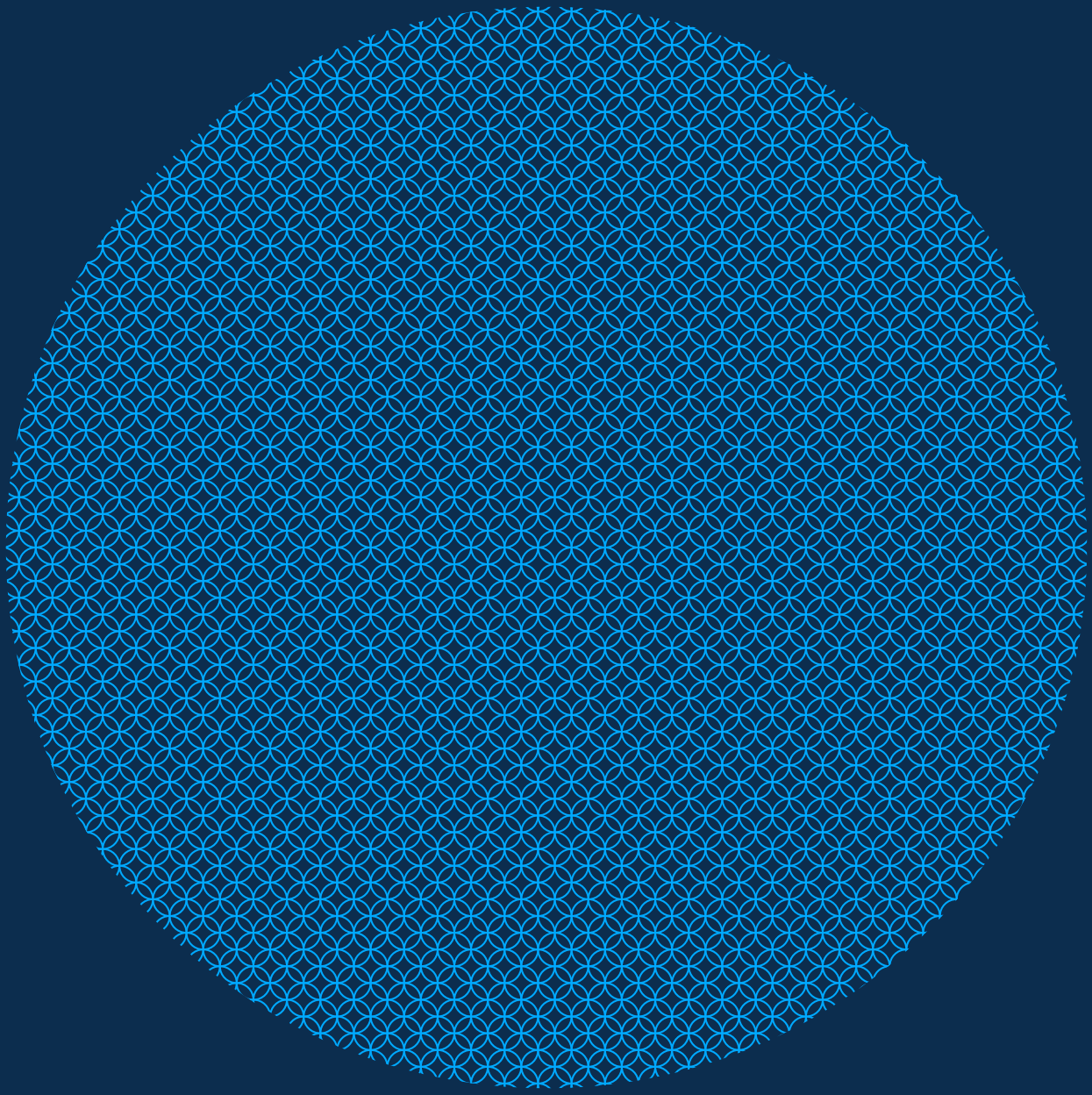
For more background information, please see the appendices.

The prevalence of complex needs

It is estimated that one in four people will experience mental health issues at some point and mental ill health is thought to cost the UK £105 billion each year (Department of Health, 2011). Drug and alcohol misuse affects more than 15 million people (Home Office, 2015; Public Health England, 2016) and is estimated to cost more than £36 billion a year (Public Health England, 2014).

As noted in Turning Point's Dual Dilemma report (2016), what is less clear is the prevalence of people who experience mental health and substance misuse issues together and the impact of this. It is even more difficult to quantify the numbers of people with wide-ranging complex and multiple needs, however there are some statistics that offer insight:

- More than a quarter of a million people in England have contact with at least two of the following: homelessness services, substance misuse services and the criminal justice system. At least 58,000 people have contact with all three (Lankelly Chase Foundation, 2015)
- The cost to society of those experiencing severe and multiple disadvantages could be in the region of more than £10 billion a year (Lankelly Chase Foundation, 2015)
- Up to 70% of people in drug services and 86% of those in alcohol services have experienced mental health problems (Public Health England, 2014)
- Dual diagnosis affects a third of mental health service users, half of substance misuse service users and 70% of prisoners (NHS Confederation, 2009)
- There are around 300,000 problem gamblers in the UK and this is associated with poor mental health, drug and alcohol problems and social problems (Cowlishaw and Kessler, 2015).
- People with serious mental health problems have a life expectancy of 15 to 20 years less than the rest of the population. The figure is nine to 17 years less in those who misuse alcohol and drugs (Wahlbeck et al, 2011)



The current landscape

In recent years there has been an increasing focus on addressing mental health, stigma and inequality, more person-centred approaches to services and a focus on community integration and peer support within mental health and substance misuse services.

Government support for social action initiatives has continued to grow. Social action has been encouraged by Government activity including the growth of projects through the Centre for Social Action, empowering communities through the Community Organisers Programme, backing employer-supported volunteering in the workplace, supporting giving, encouraging young people to get involved in social action and recognising and rewarding people's contributions.

The Five Year Forward View for Mental Health (NHS England, 2016) provides a blueprint for changes that NHS staff, organisations and others can make to improve mental health. Key aims include strengthening community-based services to reduce demand on the acute sector and moving the commissioning model for in-patient beds in mental health towards a more 'place-based' approach so that pathways and incentives are better aligned. Recent NICE guidance (2016) also aims to develop coordinated services that address people's wider needs and states that people with co-existing severe mental illness and substance misuse issues should be involved in improving existing services. We are yet to see how widely this has been implemented.

The previous No Health Without Mental Health strategy (Department of Health, 2011) identified the need for integrated care pathways which could improve support for those with both mental health and substance misuse issues. The 2012 Health and Social Care Act also brought in greater integration and changes to commissioning, though with the public health remit moving to local authorities the gap between substance misuse and mental health commissioning has arguably widened (Turning Point, 2016).

Numerous efforts to improve services for people with complex needs or a dual diagnosis continue and there are many examples of excellent practice. However, joined up and collaborative services that can respond to people with multiple needs are not yet the norm. It is the APPG's view that people with complex needs remain at the sharp end of the inverse care law. This means that they often require the most support but tend to receive the least. This can happen because traditional services are difficult for them to access, they are refused referrals and shunted between several different services, or they have fallen through gaps in services due to a lack of integrated provision. This is of course harmful for the individuals and those close to them who suffer as a result. It also means that accident and emergency departments, the police and other frontline services face significant pressure when individuals reach crisis point. In the longer term, public services as a whole continue to face pressure as people's unmet needs worsen further.

There is both a moral and economic case for making sure that people with complex needs are able to access responsive and appropriate services and achieve recovery in a way that works for them. The evidence suggests that social action has the potential to be a big part of the solution.

Benefits of social action for those with complex needs or a dual diagnosis

Social action is about people coming together to help improve their lives and communities. It can strengthen communities, help people in need, and complement public services. Taking part in social action can also improve people's wellbeing, confidence and skills.

- The economic value of social action in support of public services is thought to amount to £34 billion annually (Nesta, 2014)
- 14.2 million people formally volunteered at least monthly in 2015-2016 and the value of such volunteering was estimated to be £22.6 billion in 2015 (NCVO, 2017)
- 60% of adults said they had informally volunteered at least once in the last year in 2015-2016 (NCVO, 2017)

People often stereotype what sort of people are involved in volunteering. An unusual, yet inspiring, story showing what individuals with complex needs can achieve came from the founder of The Hidden Homeless. He told us of his journey from experiencing homelessness, a variety of complex needs and disengagement to his campaigning, service user involvement and research projects, running of activities such as peer support groups, life-coaching and SMART recovery workshops, publishing of homeless people's art work and writing, establishing the Hidden Homeless and securing high value donations and grant funding to continue its wide-reaching work.

We have been struck by the sheer range of ways that social action is being used by different groups. This creates a varied and complex picture but we find it positive and encouraging. Many very different methods are also achieving similar benefits which tells us that there is no 'right way' and as the needs and characters of individuals and communities differ, so do the approaches that suit them. The common and recurring benefits of social action coming from the evidence are explored next.

> I used to have a real hatred for the system, but through my involvement with the system I have managed to realise the possibilities and opportunities through being involved, gaining a voice and giving a voice to my peers… And now I have a few labels I am proud of, like active citizen, Community Learning Champion, Service user Rep, Housing Practitioner, Chief Executive, Magazine editor and Friend to many, and all that from a leopard that can't change his spots.
>
> Gary Stainforth, CEO, The Hidden Homeless

Recovery, self-worth and confidence

Recovery from addiction or mental health problems is about people gaining and staying in control of their lives, having hope, purpose, opportunities to achieve their goals and regaining a place within their communities.

For social action initiatives like peer mentoring programmes, benefits can be twofold. CFE Research, the national evaluator of the Fulfilling Lives: Supporting people with multiple needs programme, told us about the positive impact on peer mentors in terms of the structure, routine and improved self-esteem and confidence that this activity gave them. Mentors also provide 'living proof that change is possible' and offer inspiration and hope to the clients they work with. They can identify well with clients as they can often share valuable personal experiences.

Mind Brighton and Hove's Service User Involvement Project in Substance Misuse staff and clients told us of the value of peer support groups which give them the opportunity to both receive help for their own problems and give support to others, which contributes positively to their recovery. One individual with addiction problems who attended the dual diagnosis peer support group went on to become a service user involvement project member. Her participation in such activity has had a positive impact on her self-esteem and recovery.

There are strong links between abstinence based recovery and peer support. As Nurse Consultant for Dual Diagnosis and Clinical Director of Substance Misuse Services at Nottinghamshire Healthcare NHS Trust, Dr David Manley has noted, peer support and group participants can 'build recovery capital' by sharing their stories and experiences and learning from one another (Manley, 2015). Similarly, Dual Diagnosis Anonymous UK also told the APPG about their '12 Step + 5' mutual aid model. A key problem is that people with a dual diagnosis can feel alienated at traditional 12-step meetings, yet would benefit greatly from the peer support such groups offer. Dual Diagnosis Anonymous UK have added five steps to the traditional 12, which acknowledge both substance misuse and mental health. Their groups provide an open and non-judgmental space that helps to reduce isolation and is based on the understanding that 'recovery is predicated upon hope'.

> **As I'm doing this [user involvement work], my sense of self-worth and self-esteem is increasing bit by bit, my ability to deal comfortably with social situations has come on in bounds, and for the first time in years, I have some structure in my life and I am sticking to a routine.**
>
> Mind Brighton and Hove dual diagnosis peer support group client

A peer support function was also successfully trialled via an existing digital platform by d2 Digital, as Nesta told us. The Evie system is a dedicated digital peer-to-peer support platform that encourages behaviour change among those with alcohol problems. It provides regular text messages to help clients stick to their recovery goals, personalised motivational messages and calls from volunteers, peer mentors or professionals. Re-presentation rates of Evie clients to structured treatment are low, at around 1% or three out of 241 individuals. Peer support models offer individuals the chance to share their experiences and motivate one another and provide a sense of community and belonging that can continue to support recovery in the long-term. A digital platform also offers a different method of engagement which has the potential to reach more people, to link people with one another and to provide support on-demand exactly when an individual requires it.

Listening to and taking into account the views and opinions of people with lived experience has great value, as Making Every Adult Matter (MEAM) told us. Social action projects that include people with lived experience in the design and delivery of services can encourage confidence, hope and a sense of purpose. One individual said

that such involvement work enabled them to have their voice heard and make an impact which had become 'part of their recovery journey'.

The #iwill campaign told us that youth social action participation has 'a significant positive impact on young people's character qualities and skills' and can also improve emotional wellbeing and reduce anxiety. The UK-wide initiative focuses on growing social action among young people aged 10 to 20 years old also highlighted the work of Volunteering Matters in schools, suggesting that peer mentoring training and support leads to increased confidence and skills among young people as they transition to adulthood.

Addaction's Drink Wise Age Well programme demonstrates wellbeing benefits. It offers community based support for people with established alcohol problems and involves coproduction and the use of peer educators. 94% of people on the programme reported feeling better about themselves and 76% reported improved emotional health, wellbeing and relationships with others.

Voluntary Action Islington and Cranstoun (2014), who jointly ran and evaluated a substance misuse and volunteering project, are also very confident about the positive impact of volunteering on recovery. Volunteering opportunities for clients with substance misuse issues can provide them with the chance to re-engage as constructive members of society and a sense of motivation and responsibility towards others. Due to its powerful benefits, they also recommend that volunteering activity should be an integral part of structured drug treatment.

An example that promotes inclusion in particular is the Shared Lives model. Adults needing support and accommodation either move in or regularly visit an approved carer who they have been matched with to share family and community life. Shared Lives Plus told us about their work with the Cabinet Office to develop their approach for people with mental health issues in 2016, which resulted in 106 new arrangements. It is being extended to offer support to people with a wide variety of needs including those with a dual diagnosis, experience of domestic violence and ex-offenders. Shared Lives Plus emphasise that their model is a 'preventative, personalised, community based, cost-effective form of housing and support which promotes inclusion, recovery and wellbeing'.

Many respondents highlighted the long-term nature of recovery. Peer-led activity services supported by volunteers and people with lived experience can provide a vital remedy to loneliness and social isolation in the longer-term. Build on Belief, a peer-led organisation that offers socially based activities for people with substance use problems, including many with a dual diagnosis, told the APPG how crucial this is. People in recovery from addiction are particularly vulnerable to relapse when they are isolated but volunteers and clients can benefit from strengthened support networks which increase the likelihood of sustained recovery.

The Recovery Republic, a community wellbeing centre in Heywood which offers open access provision to people with a dual diagnosis also emphasised the importance of sustaining recovery. The centre is a local community asset ownership example of social action, that is linked to primary care, via the GP practice of its founder, Dr Michael Taylor. It is staffed primarily by people with lived experience and offers long-term support, that fills gaps left by time-limited statutory services, as Dr Taylor describes recovery from addiction as 'a long journey not supported by statutory services'.

A great variety of projects are clearly supporting people's recovery, which is extremely encouraging. We can see how social action is able to complement and enhance services that are already in place, offer long-term support and bridge gaps between provision that people with complex needs are vulnerable to falling between.

Case study

Supporting long-term recovery The Edge Café

The Edge is a community café and hub in Cambridge which provides individuals in recovery from substance misuse a safe and supportive space. It was developed after the Cambridgeshire Drug and Alcohol Action Team identified a gap in service provision, with individuals successfully leaving treatment services but struggling to sustain long-term recovery and at risk of re-presenting to services.

Workshops help to reduce isolation, offer social interaction and include arts and crafts, skills-shares and wellbeing groups and there are plans to hold transition to employment workshops. Some attendees take up volunteering at the Edge and get training and opportunities to progress to paid work, improved skills and self-esteem.

The Edge is managed by the Closer to the Edge steering group, who are all in recovery from addiction and the aim is for the board of directors to be made up solely of people in recovery within three years. The majority of the Edge's staff, volunteers and workshop leaders are from the recovery community. The Edge aims to fill the gap between treatment and becoming employed, productive and empowered citizens.

Employment prospects and skills

Good employment is positive for physical and mental health and vital for reducing health inequalities (Marmot, 2010). Of particular importance for people with complex needs and those in recovery is how work can offer a sense of achievement and self-worth, structure, routine, social connections and the feeling of belonging, as well as skills development and income. Of course, people with complex needs face considerable barriers to employment, however, no one is intrinsically unemployable (Royal College of Psychiatrists) and the APPG has seen a range of impressive success stories of social action improving people's skills and helping them to secure work.

Many peer-led organisations and groups working with people with complex needs demonstrate positive inclusive approaches in general which help to counter potential barriers to work:

- User Voice is led by people with personal experience of the criminal justice system, from delivery teams to senior management, along with its democratically run service user councils
- With one exception, everyone employed by Build on Belief has lived experience of addiction and was recruited into post from their team of volunteers
- The Newcastle and Gateshead Fulfilling Lives area ring-fences Navigator Posts specifically for people with lived experience

St Giles Trust told us about their Peer Advisor Programme which offers people with histories of offending, homelessness and substance misuse placements and training within their staff teams which lead to Level 3 Advice and Guidance qualifications. Their London team has supported 256 people in the past year, with 95 of those progressing into work (an employment rate of 37%) and eight out of 10 Peer Advisors also securing paid employment.

> **When I first went into prison I thought I would be on the scrap heap and that employers wouldn't want to touch me with a barge pole. But now I'm starting to believe in myself, feel proud and know I have something to give back to society. I can help others because I understand the client's needs and worries.**
>
> St Giles Trust Peer Advisor

Using the skills of people with lived experience to help existing and prospective clients can be very powerful, as much of the evidence demonstrates. Given the difficulties that former offenders in particular can face when looking for work - as the Peer Advisor above alludes to - offering in-work training and recognised qualifications can greatly improve their future employment prospects. Such qualifications also improve people's confidence and sense of self-worth by acting as a formal recognition of their achievements. This can positively impact on recovery as we have already seen, but confidence and self-belief are also crucial for employment. This is especially true for people who may have been out of work for a long time or who have experienced negativity or stigma when looking for a job.

During the APPG's oral evidence session, we heard that starting a job or taking part in social action can be stressful and it will not necessarily suit everyone. People who have never been in work can find it petrifying and there are lots of rules around benefits which can limit volunteering, CFE Research pointed out. While some people may not wish to take part, for those that do, having the right support, employer preparation and progression opportunities were all key elements needed, as highlighted by Revolving Doors.

It is also important to avoid defining people only by their lived experience. Some may want to 'give something back' and feel well placed to help others. Others may find social action projects to be valuable stepping stones to gain experience and transferrable skills to help them pursue different ambitions. For example, CFE Research told us of one person who worked as a Fulfilling Lives Navigator and went on to secure a place to study for a mental health nursing degree. While another group of individuals from a Fulfilling Lives Local Expert Group (which

consults and involves people with lived experience in service design and delivery) set up their own community interest company supporting young people leaving the care system.

Peer mentoring can allow peers to develop their own employment skills in a supportive environment, while still receiving help towards their own recovery, CFE Research told us. This can offer people with lived experience a 'first taste' of formal work and a transition into employment for those that are ready. Fulfilling Lives programme areas also offer formal health and social care qualifications to people with lived experience. Types of employment that peer mentors have successfully moved onto include:

- Domestic abuse support workers
- Family support workers
- Recovery coaches
- Lead workers
- Youth intervention workers
- CIC founders
- Data administrators

Case study

Peer support to employment – Turning Point Nottingham mental health services

Service user Ricardo became one of the first individuals to access the peer support worker training pathway, from volunteering as a peer mentor through to paid employment. This programme was developed by Turning Point and Nottingham Healthcare NHS Trust and is now being rolled out across other mental health services.

Ricardo successfully completed his training and was offered a work placement at a Turning Point service, where his ability to used his lived experience to provide support to residents leaving acute ward was highly valued. Upon finishing his placement, he successfully applied to become a sessional worker at the same service. This work has provided meaningful pathways for former service users to use their lived experience to gain employment. Ricardo has also spoken about his experiences at Implementing Recovery through Organisational Change (ImROC)'s national conference and to staff and residents at high security hospitals.

Wakefield and 5 Towns Recovery College also told us about the success of some of their volunteers. The college provides courses run in partnership with local partners for people with experience of mental or physical ill health, their families and friends and professionals. Many courses are coproduced with people with lived experience and people can volunteer to help run or develop courses to help them gain skills, find work, give something back or improve their wellbeing.

Equipping people with skills and qualifications that complement their own experiences and ambitions is key to improving their employability, confidence and self-belief, which can all contribute to sustained recovery. The APPG heard of many more projects doing this in different ways:

- Recovery Enterprises in Sheffield - established in 2012 by a group of people with mental health issues, it supports the development of new enterprising ideas to flourish into businesses that benefit wellbeing. A central hub offers resources, advice and supports people to grow their ideas and confidence. This is an example of people with lived experience developing innovative community owned services and employment opportunities (NHS Confederation evidence).
- StreetGames Young Volunteers - a Cabinet Office Social Action Fund supported programme to improve sports participation among young people in disadvantaged communities. 21 out of 30 of

Becoming involved with the Recovery College opened up more opportunities for training, which were relevant for my goals. From Mental Health First Aid and SafeTALK to Peer Mentoring and other training sessions that now feature on my CV. Being involved with the co-development and particularly the co-delivery of the courses has benefitted me in that it has enabled me to become comfortable talking about my own issues and how I live well with them.

Now that I have been stimulated and have had a positive experience in the work place I am applying for jobs as a support worker. My anxiety and lack of confidence is now at a manageable level and it no longer gets in the way of achieving. By becoming a support worker it will give me an opportunity of giving back some of what was given to me.

Previous Wakefield and 5 Towns Recovery College volunteers

the young people completing full time volunteer placements achieved successful exit routes into employment, education or training and during the project's accelerated scaling funding period 3,549 qualifications were achieved by young volunteers (StreetGames, 2016)

- Single Homeless Project (SHP) Camden and Islington Peer Mentors Academy - mentors can provide drop-in support to service users and accompany them to appointments, while they also run events and activities to promote the service. Mentors gain experience, are able to move onto other positions and access a variety of training workshops and courses to strengthen their skills.

- Open Doors, Sherborne Youth Resource Service – Cabinet Office supported social action programme which involved volunteer mentors supporting vulnerable and disadvantaged young people. The project was found to have the greatest impact on the linked outcomes of education and training, job and career planning, motivation and purpose and self-esteem (Wilmot, 2015).

- Turning Point's Socialicious café and community venue based in Wakefield City Centre offers a unique and supported training environment where Turning Point's substance misuse service users can gains skills, experience and references and integrate with the wider community helping to reduce the stigma associated with drug, alcohol or mental health problems, improve their wellbeing and support their recovery. Socialicious also hosts a number of groups and courses to support people in their ongoing recovery (Narcotics Anoymous, Alcohol Abstinence group, yoga, creative writing, positive thinking and self esteem courses, hearing voices group, mindfulness, well women) as well as community events organised by current and former service users. Socialicious acts as a hub for "visible recovery" in the Wakefield city centre as well as a means for social integration between service users and members of the public.

Gaining employment or qualifications are measurable outcomes that are of great interest to policy-makers and funders. However, it is also important to acknowledge 'distance travelled' towards work. Step Together Volunteering provides tailored and supported volunteering opportunities for adults and young people with complex needs. They told the APPG about the benefits their clients get from volunteering, such as the development of social and emotional capabilities, being able to make contributions to society and self-worth. Many of their clients need intensive support and are not ready for work, so volunteering is a good 'first step'. 95% of their clients say they have gained skills that could help them get a job and 91% feel more positive about their futures. This shows the progress and valuable softer outcomes that can be achieved for people who are not ready for work.

People with the most complex needs are often not even given a chance to find work or improve their skills. They can be written-off by others, or themselves. An inclusive approach and support that can recognise and respond to the needs and potential of each individual are both crucial. Many organisations are acknowledging the skills and experience that people with complex needs have as strengths, and are looking at what they can achieve, rather than focusing on their limits. This work can be challenging and resource intensive, as we will examine later, but the benefits of employment and skills development are demonstrated by the evidence.

Reducing stigma

Many respondents have highlighted how extremely powerful stigma can be in limiting the ability of people with complex needs to access services and support, their perceptions of themselves, their recovery and the opportunities open to them.

VOICES of Stoke on Trent and partners (2016) have shown how stigma can present barriers to primary care for people with multiple needs, particularly those who are homeless. Not being registered with a GP prevents people from accessing other services they may need, such as social care, mental health and drug services. Step Together Volunteering highlighted the fear of stigma as a barrier for their clients as it affects their engagement with services, potential employers and their communities. Their support can provide volunteering placements offering sheltered and supportive environments and intensive one-to-one support that focuses on people's strengths and develops self-belief.

Build on Belief point to self-imposed stigma which limits people's hope to improve their own lives. Their peer-led model helps to counter stigma as it provides open access weekend activities and groups on a 'twinned service basis', meaning that people can utilise support as clients or as volunteers. Clients are also encouraged to volunteer while in structured treatment and 61% of Build on Belief volunteers use their services as clients when not volunteering. This approach is interesting and serves to break down barriers and create an equitable environment for clients, staff and volunteers to work within. It also offers an alternative form of support for those who struggle to engage with structured treatment.

Nearly all Build on Belief clients say that the services are more social, friendlier, less formal and less judgemental. Through one woman's story, we heard how peer-led work (instead of structured treatment) can support recovery. The woman had a 30-year history of crack-cocaine and heroin use, more than 500 criminal convictions and had experienced homelessness and severe depression. She volunteered with Build on Belief and four years later is a paid member of staff, who has also led on the development of a new service. She was able to give up her prescribed opiate substitution therapy as she felt the support she got from other staff and volunteers would enable her recovery.

Stigma can prevent people getting involved in social action in the first place, but coproduction and involvement projects can help fight stigma. Involving people with lived experience in the design and delivery of services can break down barriers between those with lived experience and professionals, according to Making Every Adult Matter (MEAM). When professionals are able to better understand people's needs and perspectives, stigma can be reduced, as misunderstanding is a major cause of stigma in the first place.

As MEAM told us, 'people facing multiple needs are experts in their own right' and are well placed to help existing clients and to contribute to service improvement. One individual

Case study

'Ask me' ambassadors reducing stigma in communities - Women's Aid

The Women's Aid 'ask me' scheme aims to break the silence about domestic abuse within communities and make it easier for survivors to tell others about their experiences. It offers training courses and certification for individuals to become 'ask me ambassadors' who learn how to respond to disclosures of domestic abuse, how to signpost people to further support and challenge myths and stereotypes in their communities.

It is being piloted in three areas and development has involved extensive consultation with survivors.

Ambassadors benefit from training and a toolkit to support their work and recruitment is in progress across the three pilot areas. 21 ambassadors have been certified so far, with 80% of these identifying as survivors themselves. The scheme is engaging survivors of domestic abuse in the design and development of services and interventions, providing voluntary opportunities for those with lived experience to support others, helping to tackle stigma in communities and encouraging early intervention.

> … already my confidence has increased massively; the buzz I get from actually having a voice that is listened to and not just heard is better than anything I have ever experienced in my life
>
> Individual with lived experience of multiple needs working with MEAM

who took part in training events for professionals at first lacked confidence and described feeling 'like a fish out of water' and 'not worthy of being there'. Although he considered giving up, an Engagement and Coproduction Worker persuaded him to continue, showing the importance of having the right support available, to help build a person's confidence and encourage participation.

Stigma can present a barrier to social action participation and access to services for people with complex needs. Scepticism or resistance may come from professionals or people with lived experience themselves. However social action projects are clearly breaking down barriers, improving communication and understanding between services and people with lived experience and helping people to believe in themselves. Services can also gain considerably from working with the people that they are set up to support.

Services that better meet people's needs

During the APPG's years of activity and during this call for evidence, the argument has repeatedly been made that people with complex needs or a dual diagnosis simply do not get their needs met, either adequately or at all. This worsens people's problems, makes crises more likely and puts great strain on individuals and on public services. To address this, services need to be more coordinated and responsive to people's needs, which can be achieved through social action.

One of the real strengths of peer mentors is that they are particularly effective at working with clients who are disengaged from traditional services, helping them to re-engage and access services. Clients may feel more comfortable talking to a peer mentor, trust them more and feel less judged by someone with experiences similar to their own. CFE Research reported that professionalism can be learned but lived experience cannot and that Birmingham clients with a peer mentor averaged five weeks longer on the Fulfilling Lives programme than those who did not.

Involving people with lived experience in service design and delivery improves inclusion and helps to make individuals feel more valued and respected. It also potentially improves service quality and can create a sense of ownership, for clients - of the services provided for them, and for services - to ensure that services meet the needs of those who use them (Clinks and Revolving Doors, 2016). Nacro's evidence emphasised the benefits of service user involvement to its organisation, with service user involvement creating:

- A deeper understanding of what affects service users when putting processes or services in place
- Improved effectiveness of new services and initiatives which are easier to launch and achieve higher client take-up
- Improved working practices as well as more empowered service users

North Staffordshire Combined Healthcare's Dual Diagnosis Consultant Nurse reported similar benefits from its Early Intervention Dual Diagnosis Engagement and Recovery Development Project. The work involved staff reflecting on their practices and working closely and engaging better with service users to address disengagement with treatment services. Benefits included:

- Improved service user engagement
- Clinical staff feeling more able to do their jobs and having a better understanding of clients' resistance to treatment
- A good example template that other teams can learn from and

> **I now understand why decisions are made for a reason. I have learnt about the importance of hearing other people's opinions and how decisions are actually made, not just told what to do without an explanation**
>
> Nacro Community Voice Council service user member

recognition from commissioners, the Trust's board and the CQC

Connected Care, Turning Point's model for involving communities in the design and delivery of more joined and responsive health and social services, has been employed in 19 areas across England engaging more than 250,000 people. The model's community engagement methodology – community research – is effective in engaging people with complex needs because the training is highly inclusive and can be tailored to each participant's needs and each individual is able to support the research process in a way that builds on their own skills and experience. Turning Point gave the example of one Community Researcher in Warrington who had been homeless and struggled with reading and writing who was invaluable in gaining the group access to local hostels, building trust with homeless people and undertaking interviews, while another Community Researcher took notes. The fact that the model engages all sections of the community had enabled Connected Care to deliver service redesign proposals that are genuinely about engaging people with even the most complex needs.

Many of the projects we have heard about focus on helping people to better engage with existing services. For example, Fulfilling Lives area projects help people to navigate services, with roles such as navigators and project consultants across the pilot areas who engage with local services about the access barriers people face, as well as supporting clients.

The LCPT Dual Diagnosis Intercept Service in partnership with LiFT supports individuals with a dual diagnosis who have had contact with the criminal justice system. It also uses peer mentors/volunteers, advocacy and support for people to access or reconnect with services. It provides a vital prevention role by assisting clients to seek preventative help and avoid the need for crisis intervention or hospitalisation and to remain in contact with statutory services. This shows how social action can complement the existing system and improve people's experience of it. As LCPT outlines in its evaluation report for the Cabinet Office (LCPT, 2015), its interventions have led to improvements including:

- Reduced re-offending – with 61% of service users who engaged with the project's intensive one-to-one support reducing their offending or stopping offending in the year following referral – compared to 31% of those who were referred but did not engage
- Effective re-engagement of service users regarding their mental health needs – with 50% of service users helped to re-engage with primary care services and 51% with secondary care services
- 283 new referrals into mental health services for service users, 99 service users getting IAPT referrals and service users with complex needs helped on 187 occasions

There are many improvements that can be made in how services work with people with complex needs. This is an issue that arises in discussions again and again. Social action projects can be a very effective way of improving existing services, helping people to navigate and access support or creating entirely new services. Key to this is the involvement of the people who will use those services. Without this, efforts are at risk of further isolating people with complex needs and achieving little real change.

Cost benefit evidence

Individuals want services that understand and respond to their needs and professionals want to be equipped to do this. Commissioners and policy-makers want positive outcomes and value for money. We do not think these things are mutually exclusive, as social action can improve health and wellbeing and save money. Many social action projects and complex needs provision can be time and resource intensive to set up and maintain, but leaving people to reach crisis point costs more in the long-term and impacts negatively on people's lives and on society.

Build on Belief explained how their weekend provision meant they can utilise the buildings of other organisations to keep costs down. 2,441 people accessed their services 33,746 times in 2015-2016, at a total cost of around £370,000, so each client contact costs approximately £1.00. 42% of their clients also use substances less when visiting their services and represent less to structured treatment services, which shows how demand can be eased.

We heard about the cost effectiveness of a St Giles Trust programme in Yorkshire using Peer Advisors to help prison leavers overcome housing, addiction and unemployment problems. An evaluation concluded that £8.54 in societal value was generated for every £1 invested in the service, with both clients and Peer Advisors benefitting (PwC, 2016). As St Giles Trust argue in their evidence, 'prevention is better and cheaper than cure' and people with complex needs who do not have the right support often make frequent and inappropriate use of emergency services.

Improved client health and economic benefits are also achieved by Groundswell's Homeless Health Peer Advocacy Service, which involves trained Peer Advocates with lived experience of homelessness supporting clients to access healthcare. The programme helps increase client confidence and decreases reliance on unplanned care services (Young Foundation, 2015). Outcomes included a 68% reduction in missed outpatient appointments and a 42% reduction in unplanned care activity which creates savings of £2.43 for every £1 spent.

Shared Lives Plus told us of the benefits of their model – improved health and wellbeing and lower costs.

- 87% of respondents say that Shared Lives has a positive impact on the mental health of the person they support and improved health and wellbeing reduces usage or dependence on NHS services.
- Shared Lives support costs less than other forms of care – on average £26,000 a year less for people with learning disabilities and £8,000 less for people with mental health issues. This is according to independent cost comparisons from Social Finance (2013) and does not include savings associated with better outcomes or less use of health and crisis services.

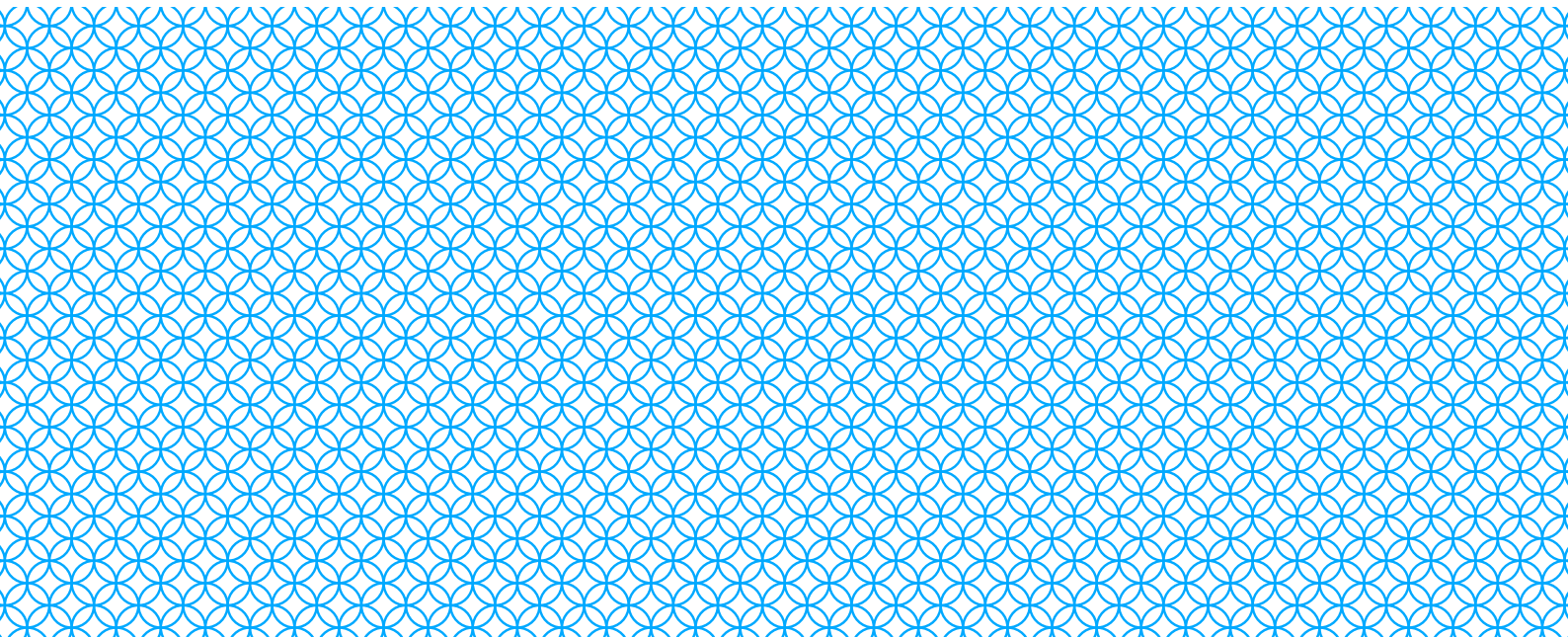
VOICES of Stoke on Trent – one of the Fulfilling Lives: Multiple Needs areas – is a partnership project that helps people to access appropriate services through coordination with stakeholders, casework and assertive advocacy. Engagement and support has led to reduced contacts with the health and criminal justice systems for 22 people with multiple needs worth £201,056 or £9,139 per person per year. With better service coordination for others in Stoke on Trent with similar levels of need it is estimated that around £9.85 million could be saved in service contacts each year (VOICES, 2016).

The Young People's Health Partnership emphasised the potential impact of peer related initiatives for young people, given the strong influence that young peers have on each other's lives. They highlighted the Association for Young People's Health (AYPH) Be Healthy initiative. It engaged marginalised young people affected by sexual exploitation by recruiting and working with young people as health advocates to empower them to better understand their health needs, gain formal Personal, Social and Health Education ASDAN accreditation and communicate knowledge to their peers.

We have heard of many ways that money can be saved and health and wellbeing can be improved for people with complex needs. Still, it is worth noting that several respondents cited difficulties in collecting data, evaluating their programmes and demonstrating improved outcomes and economic benefits. Nesta is also focused on this challenge. Citing their Realising the Value work, they told the APPG that social action and community approaches can benefit mental and physical health and wellbeing, NHS sustainability and wider social outcomes, but the supporting evidence base is undeveloped. There are significant health and economic benefits that can be achieved through social action, as the evidence shows. However, barriers are also apparent, which we will look at next.

Overcoming key challenges and growing social action

The barriers to developing social action focused on complex needs can affect both services and professionals and people with lived experience. Challenges include resources, stigma, procedural issues, leadership, commissioning structures and demonstrating benefits. Overcoming these is key to the success and further growth of social action for this client group. There are models that are replicable and can be scaled up but there is also a lot to be learnt from the grassroots, where innovative small-scale projects are achieving great things. Social action projects, like services supporting people with complex needs, cannot just expect people to 'fit in', they have to be designed around people's needs.



Service provision gaps and the VCSE

It is often those with the most complex and enduring needs that receive the least help. Like the APPG, many respondents are concerned about the lack of adequate service provision for this client group in general. Carers in Hertfordshire called for consistency of care for those with a dual diagnosis and no gaps between the completion of a person's planned detox and any necessary mental health interventions, which they note the Hertfordshire Dual Diagnosis Protocol aims to do. They also stressed the need for education about dual diagnosis and complex needs among frontline service staff including primary care and A&E as the entry points to treatment and support are not only via specialist services.

Dr Taylor, a Manchester GP, said there are no complete services for complex needs or dual diagnosis in his area and the Recovery Republic helped to fill this gap, though he hopes that things will improve through the Greater Manchester Population Health Plan and devolution. Service users in Brighton and Hove also described Mind's local dual diagnosis support as a valued and relied upon resource in an area with little other suitable provision. Access and referral barriers for people with substance misuse problems and mental health issues are also widespread, with people facing disparate services or being refused referrals and access.

This brings into focus the role of the VCSE and how it is either bridging gaps between existing services by supporting people to access or navigate through the system, or offering additional provision to address unmet need. The APPG heard several perspectives on this, including:

- CAIS said that the third sector can bridge the gap between existing statutory mental health and substance misuse in North Wales, by providing enhanced peer mentoring, early intervention and engagement provision to relieve some of the pressures on NHS staff providing support to those that most need it.

Changes in commissioning, the separation of substance misuse and mental health budgets and funding shortages mean that clinicians are frequently in the difficult position of having to use diagnosis, often primary diagnosis to decide where or indeed whether an individual is delivered a service. Dual diagnosis patients are more likely to be rejected by services as 'someone else's case' or passed between mental health and addiction services repeatedly.

Dr David Manley, 2015

- The Open Doors social action programme at the Youth Resource service in Sherborne that provides support to vulnerable and disadvantaged young people was able to free up the time of youth workers to provide more specialist advice, through the use of volunteer mentors who could work with young people and provide additional support.

- The NCVO emphasised the important role that social action and volunteering has in transforming the way the NHS works with people and communities. They told us that volunteer support offers particular value for those with complex needs or multiple conditions who rely heavily on services, as volunteers can help join up services and support more integrated care.

  We believe that social action has a significant role to play, but it cannot simply be used as a reactive sticking plaster fix that exists on the edges of the health and care system for those with complex needs or a dual diagnosis who have been failed by other services. It requires adequate investment of time, money and expertise to become a truly effective and sustainable part of the system as a whole. Further to this, as the NCVO stated in their evidence, volunteering is key to the success of the Five Year Forward View, which includes a vision for a new relationship with patients and communities and the encouragement of community volunteering.

Resource requirements

Pathway and Build on Belief told us how projects can be dependent on either a few or even just one committed person.

This leaves them vulnerable to change such as a member of staff moving on and difficult to replicate and sustain. Pathway's Care Navigator programme supports homeless people in hospital and on discharge - it can be relatively expensive to run, they told us, due to the staff support it requires but it is likely to be 'cost-neutral to the overall economy'. Build on Belief stressed the need for an understanding about how peer-led services operate and that they can take time to set up, become established and effective. St Giles Trust noted that funding cycles can be too short-term for projects to develop and achieve benefits. When working with people with complex needs, improvements and results can take time to realise, which needs to be acknowledged.

Another resource challenge for projects that involve volunteers is actually caused by their success in achieving employment outcomes. For example, LCPT (2015) cited the retention of peer mentors and volunteers as 'extremely challenging, often for positive reasons, with many leaving to pursue paid employment and/or further education' in their Intercept Dual Diagnosis Service evaluation for the Cabinet Office. They suggest arrangements to share more groups of volunteers with their partner organisations as one solution to this problem.

Involving people with lived experience in the design and delivery of services and in coproduction projects also needs to be properly resourced. The DCMS warn against one-off projects that 'focus more on innovation and novelty than on sustained community engagement and participation' (2017). And, as MEAM told us, setting up initiatives that cannot be maintained can massively damage trust.

Additional requirements for employing people with lived experience as peer mentors, navigators or in other positions may also be needed. The

Setting up, facilitating and maintaining clear structures through which people with lived experience are able to influence the design and delivery of services needs sufficient resource, in terms of both time and finance. It is important that organisations plan and budget for this, especially as the more successful the engagement becomes, the more resource it is likely to need to support it.

MEAM evidence

right support needs to be available to give projects and individuals the best chance of succeeding. Support could include help getting people used to working in a professional environment, flexible approaches to working patterns, referencing, recruitment and probationary periods. CFE Research cited Shelter's approach to peer mentors in Birmingham as an example, who allow for individual needs assessments, advice for benefits, housing or debt issues, salary advances and travel loans.

VOICES and Expert Citizens Stoke on Trent told the APPG about some of the approaches that help with their work supporting and engaging clients with multiple needs, including:

- Small caseloads to enable the intensive support
- Asset-based approaches to supporting change, persistence and advocacy through respectful challenge
- Events and training for frontline staff with content designed by those with lived experience, to improve staff knowledge, skills and service delivery
- Partnership and joint working between services and agencies, to help better decide when particular interventions are needed and who is best placed to make them

Partnership working and good communication in particular are key to ensuring the best use of resources. Such working arrangements also enable organisations and the people they work with to benefit from a range of specialised expertise. Addaction take a partnership approach to recruitment for their volunteers and the experts in volunteering - the Royal Voluntary Service – are one of their key partners. Voluntary Action Islington and Cranstoun's substance misuse and volunteering project (2014) also successfully integrated volunteering opportunities within a

structured drug treatment programme through a dedicated staff member who was particularly effective as an intermediary between clients and volunteer involving organisations.

Stigma and prejudice

We have come across many positive examples of tackling stigma, but prejudice and stigma from professionals or the 'system' can be a significant barrier to social action. MEAM said that individuals can feel perceived as problems or 'just service users', rather than experts with a lot to contribute. Involvement projects can also create apprehension among existing staff so appropriate policies, guidance, training and support are all needed for both staff and people with lived experience.

Addaction emphasised the need for clear discussions and policies in place that would help limit prejudice from clinical staff towards service users or volunteers. The 'strengths based approach' to finding volunteering opportunities taken by Step Together Volunteering for their clients with complex needs also helps to tackle self-imposed stigma and clients' lack of belief in themselves.

Dr Taylor of the Recovery Republic said that there was prejudice among some clinical staff, but stated that 'it is easy to blame the actions of the addict rather than the lack of skill of the worker or provision of services for commissioners'. This again illustrates the importance of adequate training and skills and the need for services to be responsive to the individuals they are working with. Professionals can sometimes mistrust people with lived experience, particularly those with a history of offending, St Giles Trust also told us. Mistrust and scepticism can be reduced once professionals begin to see the impact and results of projects like St Giles Trust's peer-led programmes.

The evidence shows us how beneficial involvement projects and using the insight and knowledge of people with lived experience to help others towards recovery can be. Organisations need to commit fully to tackling prejudice and stigma for social action to be effective. As many respondents have also warned, involvement and coproduction must not be tokenistic:

- Without the right level of support and guidance peers and people with lived experience can feel that their involvement is a tick-box exercise, they do not have genuine opportunities to have a real impact, or their opinions are irrelevant due to their lack of professional experience - CFE Research

- There can be differences in power and influence between service users and professionals that can inhibit people who use services from being honest in giving their views. Involvement facilitators and safe spaces for people to express their views can help enable people to talk freely and share ideas for better future services - CAIS

- Commissioners, managers and service providers need to treat individuals working with or volunteering with peer-led services as equals - Build on Belief

- People with lived experience should be able to engage on an equal footing with professionals which can be achieved by involvement in decision-making and strategy, structured employment opportunities and working with commissioners to ensure that new services are coproduced with people with lived experience from the beginning - MEAM

Related to the need for people with lived experience and professionals to be treated equally - and to the resources needed to support social action - is pay. There were differing views from respondents, with some reporting that volunteers were happy to contribute, help others and improve their skills and others arguing that offering paid roles to people with lived experience adds value to the positions and encourages retention.

Policies and procedures

One possible reason for the unease from professionals that can lead to prejudice is the potential procedural difficulties presented by social action work. Existing organisational policies, procedures and cultures can stand in the way of professionals becoming fully signed up to initiatives involving people with complex needs, according to CFE Research. Addaction told the APPG of challenges to coproduction and peer mentoring and the need to recognise that individuals can become unwell or relapse. They call for 'open and supportive dialogue with volunteers and peer mentors, assertive re-engagement and a fast track process for support'.

Barriers that people with lived experience can face when getting involved in projects were highlighted by CFE Research, which include:

- Services being too intimidating, corporate or formal
- Hard to understand language used by professionals
- Professionals getting paid for their time and input and enjoying other benefits, in contrast to people with lived experience who are just expected to 'fit in'

These barriers can be addressed by dedicated coordinators who can help ensure that people with lived experience get their voices heard and are supported adequately, according to CFE Research. They also told us about innovative tools being developed to help support volunteers and people with lived experience in their roles, including in the Newcastle and Gateshead Fulfilling Lives area which is at the early stage of piloting for an app that has been coproduced with Newcastle University which will allow 'digitally enhanced reflection'. This will allow volunteers to audio record their journeys and experiences and reflect and comment on them with others (such as staff) in an 'open dialogue reflection about their journey'. Clear organisational strategies for involvement are vital and MEAM also suggest appropriate payment and reward, recruitment, training, diversity and safeguarding policies.

Build on Belief acknowledge the potential problems of working with people with complex needs and call on others to understand that peer-led services are vulnerable to staffing and volunteer problems due to individuals relapsing. They work flexibly, pragmatically and accept their clients' needs and works around them. They told the APPG about their open approach that enables people to both access support as clients or contribute as volunteers. As long as people do not pose a risk or are intoxicated, they can volunteer, the APPG heard. With social isolation causing more relapses than anything else, Build on Belief argue that their model's success is in its openness and providing people with opportunities to join in and contribute which supports their recovery.

MEAM highlighted some specific practical issues that people with offending backgrounds and organisations working with them can face. These include problems with security clearances for volunteers, a perception from those with offending histories that their involvement is not possible and individuals finding vetting processes intimidating or struggling to complete applications due to insufficient IT skills.

The nature of complex needs and dual diagnosis mean that these risks and challenges need to be acknowledged and plans have to be in place for problems that may arise. Many organisations and professionals are naturally risk averse, but if they wish to engage in such projects, but organisational cultures need to accommodate people with lived experience for social action to work. Listening to peer-led groups and individuals with complex needs to understand what enables their involvement and backing this up with clear strategies, procedures and resources is required.

Leadership

Growing social action requires leadership and senior level support. The APPG heard from CFE Research that strong leadership is a key enabler to the growth of peer support projects. Senior management need to be 'fully bought in to involving people with lived experience in meaningful ways', which includes 'challenging unhelpful perceptions around peer support, championing best practice and being flexible enough to make the project work when barriers emerge'. This is true also of other social action projects.

The NCVO has suggested a number of ways to enable social action and volunteering to have a greater impact on and involvement with public services, which the APPG supports, including:

- Appointing senior public-sector leaders as volunteering champions – to provide a strategic approach and leadership
- Setting targets for volunteering in public services – focused on experience and breadth of volunteering rather than just on total volunteer numbers
- Strengthening volunteer development/management – targeted investment that recognises and supports volunteer management as a profession
- Making volunteering more accessible to people with disabilities/mental health issues who face barriers – particularly as volunteering is an important pathway into work

- Given the emphasis and importance given to volunteering in the Five Year Forward View it is vital that this is 'backed up by top-level buy-in and investment in volunteering on the ground'

The successful projects we have seen are underpinned by approaches that are inclusive, open and in tune with the needs and wants of the people they work with. Whether large or small, organisations must be able to establish and maintain working cultures and attitudes that tackle stigma, value social action and volunteering and provide an environment for genuine involvement work with people with lived experience. Senior leadership is crucial to all this as it helps to drive behavioural change, as the NCVO also told the APPG.

Demonstrating impact

A key problem that some respondents have come up against, as already noted, is demonstrating their impact. This is a considerable challenge when commissioners want to see evidence of success.

- Dr Taylor told the APPG that capturing outcomes data was the biggest problem the Recovery Republic faced and while local politicians and professionals were aware of what had been achieved, it was a struggle to compete with others without strong outcomes evidence.

- Build on Belief cited the inability of peer-led groups to provide evidence and data on soft outcomes due to a lack of knowledge, support or structure to do so.

- Nesta has warned that the evidence base in general is under-developed but there is growing and increasingly convincing evidence that person and community centred approaches lead to better outcomes.

An 'evidence trap' of under-investment in research into person and community-centred approaches is leading to an immature evidence base that is in turn holding back implementation. An urgent priority is therefore further development of the evidence base, alongside rapidly scaling up approaches that have been shown to work and, in parallel, developing other promising approaches on a 'test and learn' basis that generates evidence through implementation, using rapid experimental methods combined with long-term research.

Nesta evidence

People using services and commissioners both want positive outcomes. Commissioners also want value for money and many social action projects are doing just this but struggling to demonstrate it, so the APPG agrees with Nesta's position.

Commissioning

Commissioning is a hugely important for enabling social action, whether it be commissioners encouraging providers to incorporate it in tender requirements, commissioning for new services and projects to meet specific needs or using social action in the commissioning process. Respondents told us of their experiences of commissioning structures, with the Recovery Republic stating that 'commissioners commission services, unattached volunteers and peer groups are neglected'. Build on Belief said that whole-system commissioning could exclude small peer-led organisations as successful completions linked to funding are favoured but harm-minimisation and improvements to wellbeing were considered less.

Good quality services that meet people's needs are 'not necessarily those which are cheapest to commission', St Giles Trust said. They warned against the tendency for commissioners to 'race to the bottom' as when looking to identify the cheapest provision they could miss the services that potentially have the most impact. Women's Aid also stressed the importance of commissioning and funding arrangements recognising the value of specialist services that meet women's needs and deliver long-term positive outcomes, as 'too often [they] favour large, generic and time-limited services'.

'[There should be] A willingness to commission small scale peer-led projects over a timescale large enough to allow for experimentation and organic growth, while accepting that the risk of failure will be far greater than would be the case in the commissioning of other larger service providers.'

Build on Belief evidence

Social action can be part of the commissioning process itself. CFE Research acknowledged nervousness from both professionals and experts by experience and the tendency for commissioners to be risk averse, but emphasised what can be gained by involving people with lived experience in commissioning:

- Better service user engagement
- Improved services that better respond to people's needs
- Opportunities to learn and develop
- Better use of limited resources

Nacro also told the APPG, 'people with lived experience have unique knowledge of how services should be commissioned, designed and delivered to ensure effective engagement and appropriate outcomes'. MEAM suggest that commissioning and procurement teams should meet directly with people with lived experience to help them better understand the needs of the people that they are producing service specifications and contracts for. However, professionals need to ensure that enough time is built into the commissioning cycle to allow for involvement to take place.

An example of commissioners and service users working together effectively is Revolving Doors' Commissioning Together project. It investigated how to improve the service experiences of people with mental health issues and complex needs in two London boroughs. Service users were trained as experts by experience to conduct peer-led research with offenders to find out about their experiences of current services. Service user groups met directly with health, housing, criminal justice and social care commissioners and they worked together on needs assessments, service evaluations, new service models, pathways and procurement and quality monitoring. Key to the project's success was commitment from both sides and the work resulted in the decommissioning of one service, with a new mental health service funded in its place.

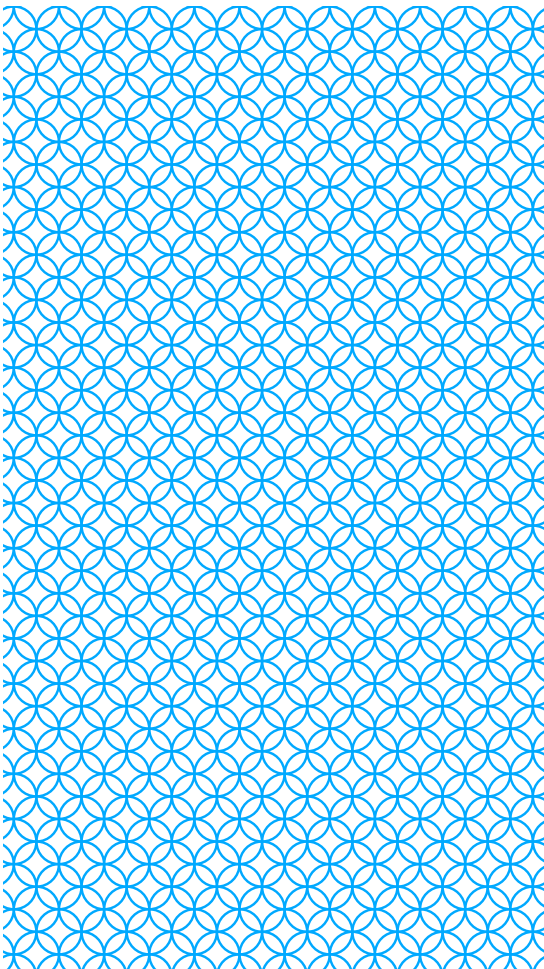
Dorset Police and Crime Commissioner Martyn Underhill told the APPG that people with complex needs highlight the problem of separate services as they can require many types of separately commissioned support. The Dorset Mental Health Acute Care Pathway was coproduced with providers, service

The Social Value Act also has a role to play and can be used to 'stimulate pre-procurement dialogue … and for commissioners to value and reward providers who show a commitment to social value through social action

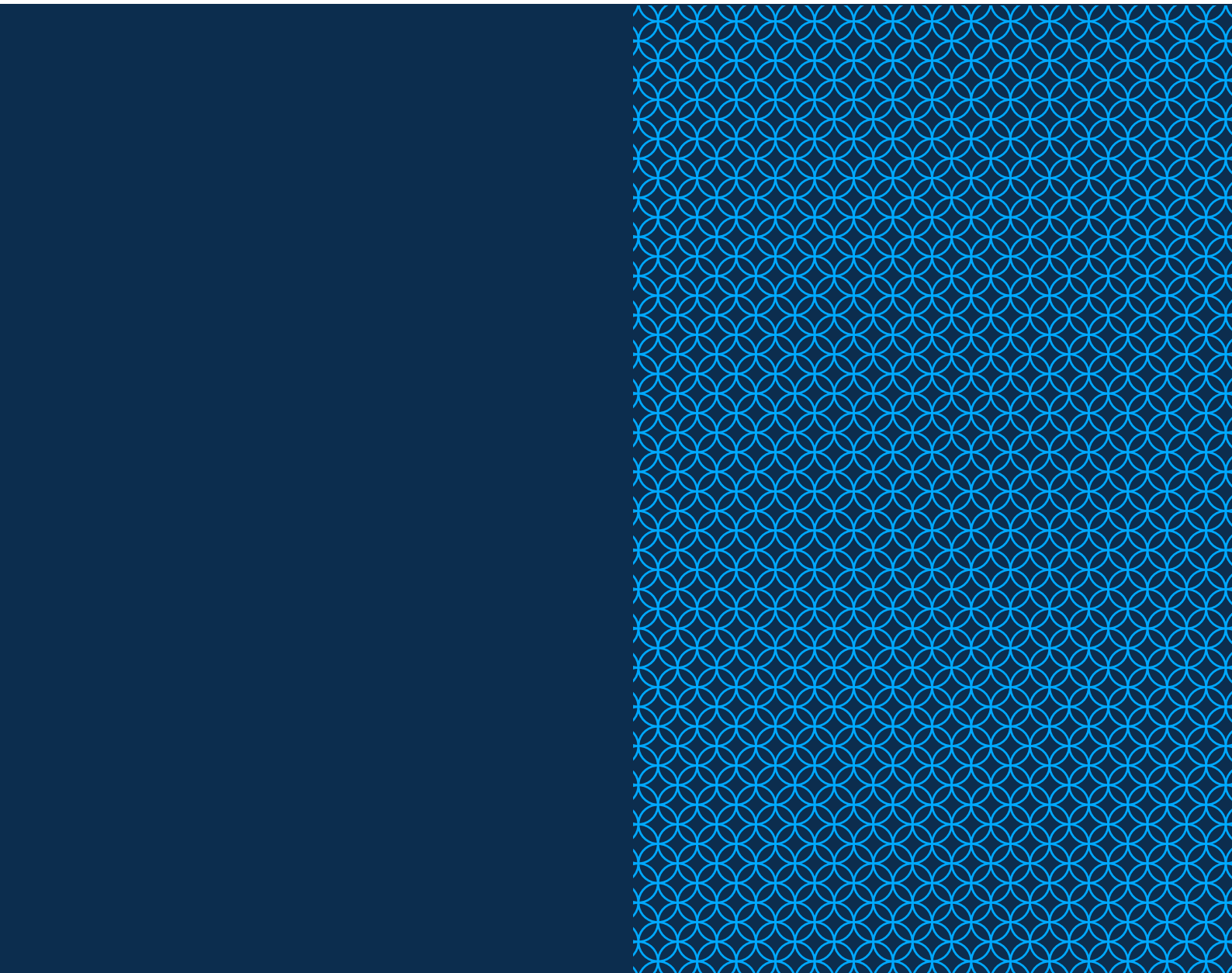
DCMS, 2017

users, carers, local authorities and emergency services which has 'allowed buy-in, risk sharing and ensured that services are shaped effectively'. Mr Underhill also made the point that while the coproduction process can take longer, it is 'less prone to challenge as those involved are those who would provide and use the service'.

Commissioning that focuses on outcomes, promotes coproduction and social value, as outlined by the New Economics Foundation (2014) is vital. The Social Value Act also has a role to play and can be used to 'stimulate pre-procurement dialogue … and for commissioners to value and reward providers who show a commitment to social value through social action' (DCMS, 2017). A proper understanding of people's needs and potential health inequalities needs to be the starting point, so involving people who will use services in the commissioning process is sustainable social action that can improve services.



Conclusion



The APPG has seen how social action can support recovery, self-worth and confidence, boost employment prospects and skills, reduce stigma, improve services, contribute to better health and wellbeing and save money. There is much to learn from innovative projects and peer-led organisations, as although many are taking unconventional approaches, they are getting positive results, often for people who have been unwilling or unable to engage with more traditional services.

Widespread commitment to and commissioning for social action is needed to ensure that its potential is fully realised. There are challenges, resources and risks involved, but the potential for improving people's lives is huge. This is illustrated by the 'the paradox of demand: a situation of rising demand and falling preventative social action' (DCMS, 2017) and the warning that with 'fewer low-cost preventative social action initiatives, there will be more need for costly acute services'.

Social action has already become a valued and relied upon part of the system in many instances that we have seen. Existing problems with service provision for people with complex needs – one of the APPG's longstanding concerns – have contributed to the growth of social action. This is due to the significant demand both for help for people to navigate and access existing provision and for support that addresses needs left unmet by current services.

The Government should provide resources to replicate and scale-up existing models that work and sustain projects that are delivering benefits already and have come to be part of the system. It can also encourage and support further social action initiatives where there is unmet need or problems to solve. The current evidence base also needs strengthening through research and existing projects need support and expertise to demonstrate their value.

Health and social care leaders can provide buy-in, through a strategic focus that supports and favours social action as a solution for complex needs. They can also use their leadership positions to challenge stigma which will help social action to grow. Commissioners can encourage and incentivise providers to focus on social action, make use of the Social Value Act and make social action part of the commissioning process to properly understand and meet people's needs and tackle health inequalities. Potentially off-putting initial resource requirements should also be considered alongside the long-term benefits and outcomes being achieved through social action.

Providers and groups working with people with complex needs can work together by sharing learning and best practice and in partnership arrangements where projects and clients benefit from joint expertise. They should ensure that service users and people with lived experience are at the centre of the design and delivery of services. Suitable policies and working practices should also be developed by organisations to enable both staff and people with complex needs to engage meaningfully in projects.

It is the APPG's view that everyone has a role to play to help grow and sustain social action. The benefits we have seen from the evidence for individuals, services and society are too great to ignore.

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Appendix 1

About the APPG for Complex Needs and Dual Diagnosis

The APPG was established in 2007 in recognition of the fact that people seeking help often have a number of over-lapping needs as well as problems accessing support. A long-standing concern is that many services can be administered and funded separately which can lead to people falling through gaps in service provision and not getting the support that they need. The APPG aims to ensure that the issues faced by people with complex needs or a dual diagnosis remain on the political agenda and are considered a priority by policymakers. Topics covered by APPG meetings have included mental health and the criminal justice system, looked-after children and care leavers, sex workers, legal highs, veterans and joining up policy on multiple needs from the perspective of those on the frontline.

The APPG is made up of interested MPs and peers and is supported by a large external membership network. It is co-chaired by crossbench peer Lord Victor Adebowale CBE and until very recently, David Burrowes (MP for Enfield Southgate between 2005 and 2017). Following the general election in 2017, Luciana Berger MP joined as chair. Secretariat support is provided by Turning Point, a social enterprise providing specialist and integrated services which focus on improving lives and communities across mental health, learning disability, substance misuse, primary care, the criminal justice system and employment.

The APPG has a highly engaged network of nearly 300 expert members including frontline workers, VCSE organisations, academia, police, local government, the NHS, regulatory bodies and individual service users/family members. Organisations represented include:

Abingdon Hospital
Action on Addiction
Addaction
Addicts 4 Addicts
Adfam
Advance UK
Agenda
Angelus Foundation
Association for Young Peoples Health
Association of Mental Health Providers
AVA Project
BAC O'Connor Centre
Barnet, Enfield and Haringey Mental Health Trust
Beresford Project
Big Lottery Fund
Blenheim
Blind Veterans
BMA
Bradford District CCG
Brent Council
Broadway Lodge
Build on Belief
CAIS Wales
Camden & Islington Mental Health Foundation Trust
Camden and Islington Foundation Trust
Carers in Hertfordshire
Castle Craig Hospital
Centre for Better Health
Centre for Mental Health
Centrepoint
City of Westminster Public Health Team
Clinks
CNWL Foundation Trust
Coaching Inside and Out
COBSEO
Collaborate
Collective Voice
Combat Stress
Community Links
Contact a Family
Council for Disabled Children
Coventry City Council
CQC
Crisis
DASCT/NHS Bolton
DCLG
Demos
Department of Health
Devon and Cornwall Police
Disability Rights UK
Drug & Alcohol Findings
Drugscope
Dual Diagnosis Anonymous UK
Dual Diagnosis Journal
Electoral Reform Society
Federation of Drug and Alcohol Professionals
Fulfilling Lives, Islington & Camden
Groundswell
Health in Justice
Homeless Link
Hopkinson House Complex Needs Hostel
Housing Care and Support Journal
Imagine Mental Health
IPPR

IPRI BP
Kent County Council
KeyRing
Lankelly Chase
LB Hammersmith and Fulham Public Health Team
Leicestershire Partnership NHS Trust
London Borough of Barking and Dagenham
London Borough of Barking and Dagenham
London Borough of Sutton
London Clinical Senate
Loughborough University
LSE
MacMillan
Making Every Adult Matter (MEAM)
Manchester Mental Health and Social Care Trust
MCCH
Mencap
Mental Health Act Commission
Mental Health Foundation
Middlesex University
Mind
Mind Brighton and Hove
NACRO
National Appropriate Adult Network
National Federation of Women's Institutes
National Institute for Clincial Excellence (NICE)
National Probation Service
National Voices
NCVO
Nelson Trust
NHS Central Manchester CCG
NHS Confederation
NHS South West/DH South West
Norfolk Fire & Rescue Service
North Staffordshire Combined Healthcare
Opportunity Nottingham
Oxford Brookes University
Oxleas NHS Foundation Trust
Passage
Pathway
Phoenix Futures
Policy Exchange
Public Health England
PHE London
PHE West Midlands
Real Insight
Recovery Focus
Rehabilitation for Addicted Prisoners Trust
Responsible Gambling Strategy Board
Rethink Mental Illness
Revolving Doors
RMBI Care
Royal Borough of Kensington and Chelsea Public Health Team
Royal British Legion
Royal College of Speech and Language Therapists
Shared Lives Plus
Single Homelessness Project
South London and Maudsley NHS Foundation Trust
Southampton University
St Giles Trust
St Mungo's
St Mungos Broadway
Standing Together
Step Together Volunteering
Stockton Borough Council
Stonewall
Substance Misuse Solutions
Surrey County Council
Sussex Oakleaf
Sutton Council
Thames Valley Probation Service
The Association of Police and Crime Commissioners
The Edge Recovery Café cambridge
The Hidden Homeless
The Network for Prison and Offender Research in Social Care and Health (PORSCH)
The Royal College of Psychiatrists
Tom Harrison House
TONIC Consultants
Tower Hamlets Link Worker Service
Turning Point
University of Huddersfield
University of Southampton
University of York
User Voice
Voices of Stoke
Voluntary Action Islington
Voluntray Organisations Disability Group (VODG)
Wakefield and 5 Towns Recovery College
Wave Trust
Westminster Dual Diagnosis Service
Women's Aid
WY-FI Project
York House GP Surgery
YoungMinds
Youth Justice Board

Appendix 2

About the call for evidence on social action

Between April and May 2017, the APPG ran a joint call for evidence with the Office for Civil Society. This asked how social action can improve outcomes, prevent crisis, support recovery and help develop more responsive services for people with a dual diagnosis or complex needs. The call for evidence was particularly interested in the impact of peer support, preventative social action helping people to stay in work, involving people with lived experience in the design and governance of services, social action for young people with complex needs, cost effectiveness and what helps or hinders the further growth of social action.

The APPG invited its network to submit evidence. This network includes professionals from the voluntary, community and social enterprise (VCSE) sector, local government, the NHS, the criminal justice system, regulatory bodies, academia, service providers, as well as many service users, people with lived experience and family members. Further organisations that were involved in work that was of interest were also invited to contribute, along with Department for Culture, Media and Sport (DCMS) Arm's Length Bodies, sector membership and umbrella organisations and APPGs working in similar areas.

Evidence was encouraged that relates to adults with complex needs or a dual diagnosis as well as young people aged 15 years or over. Existing reports and publications, grey literature and case studies from the UK and elsewhere were invited. A series of questions also asked how social action could improve the lives of people with complex needs or a dual diagnosis by preventing crisis, helping people stay in work, improving skills and confidence, reducing stigma, helping to develop more joined up services, improving health and wellbeing and reducing inappropriate use of the health and care system. The APPG also asked about the challenges and barriers and economic impact of social action initiatives and how its further growth can best be supported. Existing reports that are referred to or quoted are referenced at the end of the report and written evidence submitted to the APPG specifically is credited within the text.

Both written and oral evidence was received. Written submissions came from a wide range of respondents from VCSE organisations, the NHS, peer-led groups, service providers, academics, public sector professionals and people with lived experience. In June 2017, an oral evidence session with several expert witnesses and an audience of the APPG's network was also held.

Definitions

Social action can be broadly defined as 'people coming together to tackle an issue, support others or improve their local area', by giving time and other resources in forms such as volunteering, community owned services, peer-led groups and community organisation (Office for Civil Society, 2017). Further, 'people coming together to help improve their lives and solve the problems that are important to their communities ...broadly defined as practical action in the service of others ... carried out by individuals or groups working together, not mandated and not for profit, done for the good of others and bringing about social change or value' (DCMS, 2017).

Dual diagnosis can be used to describe a variety of combinations of needs, however the APPG defines dual diagnosis primarily in terms of co-existing mental health and substance misuse issues.

Complex needs is a term, which for the APPG describes two or more needs that affect a person's physical, mental, social or financial wellbeing. Such needs typically interact with and worsen one another, leading to individuals experiencing several problems at the same time. These needs can also be severe, long-standing and difficult to identify, diagnose or treat (APPG on Complex Needs and Dual Diagnosis, 2014).

Although individuals with complex needs may not necessarily have mental health issues, for the purpose of the call for evidence the APPG was interested in **complex needs where one of those needs is mental health issues**, as well as those with a dual diagnosis.

Call for evidence questions

1. What examples are there of social action improving the lives of people with complex needs/dual diagnosis?

a) How can social action help prevent crisis among people with complex needs/dual diagnosis?

b) How can social action help people with complex needs/dual diagnosis stay in work and how important is this in supporting recovery?

c) How can social action help people living with complex needs/dual diagnosis develop new skills and confidence and how important is this in supporting recovery?

d) Can social action support people living with a complex needs/dual diagnosis meet new people and develop new support networks and how important is this in supporting recovery?

e) Do you have examples of where social action reduced the stigma associated with mental health problems and addiction? Has it increased stigma?

f) Is social action a useful tool to develop more responsive and joined up services for this group?

g) What evidence is there for substantially improved health and wellbeing outcomes, reduced inappropriate use of the statutory health and care system as a result of social action?

2. What are the challenges / barriers to developing opportunities for social action to support people living with complex needs/dual diagnosis?

a) How inclusive are current opportunities for social action?

b) How does stigma limit the opportunities for social action among/with people with experience of complex needs/dual diagnosis?

c) What is the impact of prejudice among clinical staff on the possibility for social action?

d) What are the support resource requirements for social action among/with people with experience of complex needs/dual diagnosis?

3. What evidence is there for the economic impact of social action e.g. cost benefit studies?

a) Are there additional costs of supporting social action when working with people with complex needs?

b) Are there any specific challenges around capturing outcome data related to social action initiatives to support people living with complex needs?

c) How have challenges around capturing outcomes data impact arguments for invest to save/pooling resources?

4. What are the critical enablers to support the further growth of social action in relation to people living with complex needs/dual diagnosis? E.g. leadership, evidence base commissioning?

a) What limits / enables the involvement of volunteer involving, or volunteer-led groups working with people with complex needs?

b) How has the development of technology and digital communication impacted on social action linked to improving the lives of people living with complex needs/ dual diagnosis?

c) How do existing commissioning structures and processes limit or enable opportunities for social action linked to improving the lives of people living with complex needs/ dual diagnosis?