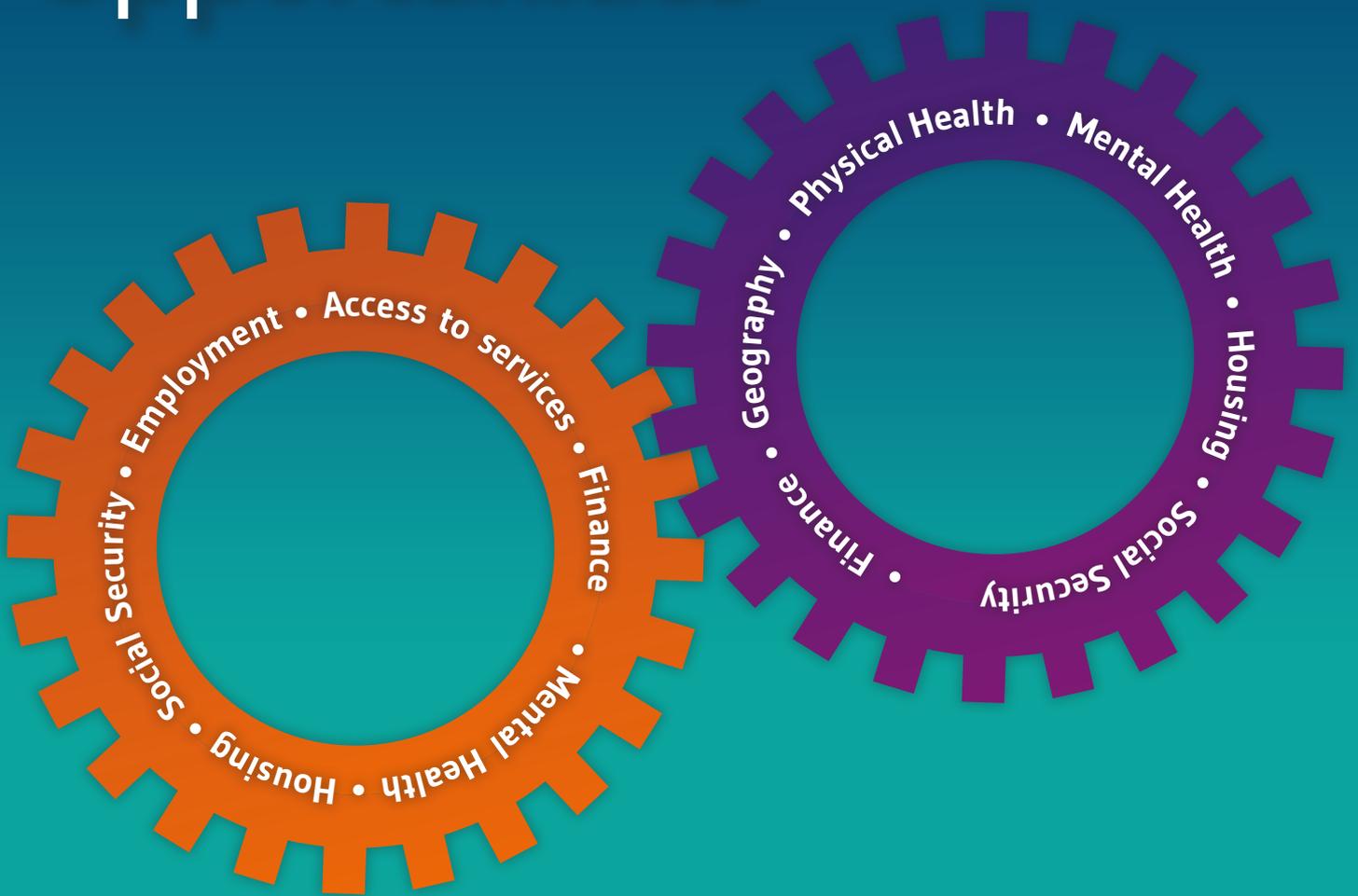


Self Management and Poverty: Exploring the Links, Challenges and Opportunities



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people at the centre

Introduction

Within the health and social care system, the self management agenda has been a core driver behind why and how we take forward change and transformation - to make sure services and support are designed in ways that are accessible and responsive to people's needs, strengths and abilities to self manage.

Self management recognises that people are experts in their own lives and conditions and must be supported to be leading partners in managing their health and wellbeing.

The need to move away from crisis intervention to longer term prevention strategies that cut across public policy has been one of the pillars underpinning public service reform in Scotland.

Nevertheless, there is not yet evidence of a shift in investment away from crisis interventions to early intervention and prevention approaches that support self management and independent living.

There is strong evidence that people want to be in the driving seat of their health and wellbeing. However, there are numerous barriers to self management experienced by people across Scotland, such as the health inequalities caused by an unequal distribution of income, power and wealth which can mean that factors that promote good health and wellbeing are not equally available, acceptable, appropriate or of good quality.

We must address the social and economic barriers that exist for people and can prevent them from becoming leading partners in managing their health and wellbeing and continue to work to tackle the health inequalities that prevent people from realising their right to health¹.

This report draws upon learning generated by members of the Health and Social Care Alliance Scotland and of the Poverty Alliance and their lived experience of managing with long term conditions and being affected by poverty. The learning from this report will help to inform the 'Get Heard Scotland' initiative to ensure that people affected by poverty get their voices heard on the policies and decisions that most impact their lives.



¹ http://www.healthscotland.scot/media/1276/human-rights-and-the-right-to-health_dec2016_english.pdf

Background

In 2018, Self Management Week and Challenge Poverty Week coincided, both taking place in the first week in October. The Health and Social Care Alliance Scotland (the ALLIANCE) and the Poverty Alliance partnered to host a national event to explore the links, challenges and opportunities between self management and poverty.

This event was an opportunity to bring our collective memberships and stakeholders together, to gather thoughts and opinions on addressing the links between self management and poverty.

The main objective for the day was to drive and capture bold thinking and ideas about self management and poverty, drawing upon the learning from lived experience, the public, the third sector, research and academia.

The conference was addressed by Professor Ian Welsh OBE, Chief Executive of the ALLIANCE and Peter Kelly, Chief Executive of the Poverty Alliance.

It was highlighted that 2018 marked the 10 Year Anniversary of 'Gaun Yersel!' - The self management strategy for Scotland². Self Management has been and must continue to be a core driver behind why and how we take forward changes to health and social care systems and beyond.

Self management supports people living with long term conditions and their unpaid carers to be leading partners in managing their health and wellbeing. A person centred approach, it aims to support and encourage people to access information and to develop skills that will enable them to live their lives on their terms.

Speakers raised the importance of involving people as equal contributors to changing the culture and model of delivering services. This continues to be a central theme of the work of the ALLIANCE through the Self Management Fund and Self Management Network Scotland.

It was stressed that poverty affects us all in Scotland whether directly or indirectly and that poverty can be solved by lowering costs and raising incomes. Importantly, it is about ensuring

we can all participate in society.

We know that understanding of self management is intimately connected to the availability of, and access to, good quality information and support. Work therefore needs in order to overcome the numerous barriers to self management experienced by people living in poverty across Scotland. It was noted that more activity is needed to ensure that everyone is supported to enjoy their right to live well, with support and services that put them at the centre.



² https://www.alliance-scotland.org.uk/health-and-social-care-integration/wp-content/uploads/sites/4/2017/09/Self_Management_Strategy_document_-_Gaun_Yersel3.pdf

Learning from Lived Experience

Delegates heard from a community activist, Sue Lyons, and person with lived experience, James Docherty, who shared perspectives of their experiences of managing with a long term condition when living in poverty.

The themes identified from these helped to inform the group discussions.

Challenges of self management when living in poverty

The interconnectedness of physical health, mental health, housing, social security, employment, access to services, finance and geography was emphasised. We heard that these factors often combine and have a strong impact on people experiencing poverty and long term conditions.

People are often blamed for their circumstances, rather than the focus being on the structural causes of poverty.

Sue described the challenge of self managing and living with invisible conditions, such as mental health conditions, and the stigma at times experienced by others in society which contributes to the experience of poverty.

We heard that effectively self managing a long term condition is made significantly harder when you can't afford to keep yourself clean, warm, adequately fed, or travel to the hospital or other health and social care appointments.

Living in rural areas of Scotland can also mean that people experience a lack of local services available to support them in their self management – resulting in unequal access to treatment options.

Sue spoke about the harassment and target culture of the current social security system that puts people under enormous stress, narrating her own personal experience when she had to give up her paid employment. Sue also described the importance of independence and control as central

aspects of self managing a long term condition, and that poverty can all too often “kill opportunity and hope.”

“Let's not measure the worth of the person by their earning power. We are more than our conditions and deserve to be seen as whole people”

The barriers to accessing services were highlighted as an issue. The challenge is how to reach people who are facing social isolation experienced by living in poverty and with long term conditions.

The poverty of relationships and lack of connectedness in society was emphasised as an issue. Referring to his own experience of trauma during his early years, James described how this had resulted in him feeling disconnected, lacking in autonomy and self efficacy. A lack of awareness about the causes and consequences of trauma resulted in coping responses that meant other people saw James as angry and to be avoided. This poverty of relationship impacts on our ability to emotionally regulate and tone down our threat response. This led to the realisation that the solution is also the cause of trauma - developing strong relationships and our connectedness to others.

The solutions

It was suggested that we need to encourage community responses - focusing on gently connecting people together. One-to-one contact may be required to begin with and then look at community responses to create more friendly communities.

We need to focus on understanding and increasing our awareness of the conditions that contribute to the challenges identified around stigma and lack of connectedness.

“We would not judge a plant that was dying as having made bad choices. We would look to move it into a better location, to provide it with water

and the right conditions to thrive.

The importance of empathy and kindness within our services was emphasised. We can change the environment around us, and we can provide relationships. Self management was described as a journey and that everyone would need to find their own solutions, but with support.

In addition, removing targets for sanctioning people by the Social Security System was recommended.

People living with long term conditions need to be supported to identify tips that would work for them. Participants were taken through a singing for breathing exercise as example of a relaxation method.



Introduction to discussions

Participants were invited to draw on their experiences and from what they had heard from speakers to discuss:

- The challenges and barriers for self management when on a low income
- What resources and/or support mechanisms exist to support people on low incomes to self manage better?
- What more could be done to improve self management on a low income?

Barriers to self management

A misconception about self management is that it is something a single person does to support their own health. People need to be supported to manage their health and people experiencing poverty have to deal with a number of barriers to accessing support to self manage and being able to take control of their health.

Stigma

The causes of poverty and the situations people can find themselves in are myriad and complex. However, there is a tendency still to blame people for their situations and stigmatise them. The stigma around poverty can result in people being afraid to ask for help, and such behaviour is reinforced by social security services.

Participants spoke of experiences in job centres and employment services that resulted in feelings of humiliation and a lack of confidence. There were stories of being treated unfairly by Department of Work and Pensions staff, with a lack of respect and empathy. Such experiences reinforce a wider social stigma around poverty. People commented that social pressures and prevailing stereotypes in the media are often internalised and result in people becoming isolated and unable to participate in social activities.

The isolation resulting from stigma has a big

impact on people feeling confident to self manage. Many self management activities have a social element or involve sharing experiences. Self management also requires a person to ask for help, which, participants reported, is very difficult when living in poverty has resulted in isolation and a low self-esteem.

Role of social security

Social security is a vital element of support for people experiencing poverty. Getting financial support is often the priority for people and is seen as a lifeline. Therefore, social security plays a huge role in people's wellbeing.

All participants spoke about the anxiety of living on social security and the increase in cases of sanctions. Similarly, the support that is available through social security is rigid and not conducive to supporting personal outcomes via self management. People commented that within this environment, it is very difficult to manage both financial and physical health.

Participants talked about the challenges of accessing disability benefits such as Personal Independence Payment which has stringent descriptors which takes no account of the experiences of people with long term fluctuating health conditions. The welfare reform changes to disability benefits made it more challenging for some people with long

term conditions to access the much-needed help they require to self manage. The waiting time between initial application and appeals processes was noted to be very long making people even more worried about their financial situations.

In cases of people transferring to Universal Credit, participants talked about the long waiting time - in some cases up to 6 weeks - to get the first payment during which time they will have fallen behind in some of their bills and are in arrears. The expectation that people should fill out online journals to update Job Centre Plus on their progress seeking work was noted to be very strenuous for people with long term conditions who may also suffer from memory problems.

Barriers to recovery were described as being embedded within the social security system as it is a very rigid system where payments are denied with health improvements that may be temporary and part of a longer recovery process.

Access to services

Living on a low income can significantly impact a person's ability to access services. It was noted that too often statutory services operate in rigid pathways that do not enable people to access the support they need when they need it. In many cases, it was said that self management is too often seen as an add on to core health and social care services. This results in poorly supported services and increased access issues for people experiencing poverty who may not have the time or capacity to search for self management support.

A core element of self management is the ability to use support and services that suit individual needs, along with accessing statutory services, this can often mean stepping outside of a narrow offer from statutory services. Such services can include walking groups, acupuncture, yoga, dieticians etc. Within this context participants noted

that getting to these services involves using public transport which can be expensive. People mentioned the need to constantly make decisions regarding prioritising money and noted that often, transport would be low down on a list of priorities.

There is also a rural dimension to access that is often hidden. People in rural areas experiencing poverty have additional needs with regards to accessing services. The workshops heard from people in rural areas who found it difficult to get support to self manage in ways that counterparts in more urban areas were able to.

The resilience to self manage

The lived experience of poverty is often filled with the stress and anxiety of finding enough money to survive and it was acknowledged that the resilience and self reflection needed for successful self management is not a priority when one is faced with challenges of survival and choosing whether to heat or eat.

Self management is about understanding your health, knowing what improves your health, what is not good for your health and how/when to seek support. Participants mentioned the time and 'head space' this takes, to reflect on health and be able to make positive decisions. In many instances people spoke about self-denial and simply refusing to engage with their health as they had to get on with finding or maintaining employment. Other people spoke of the importance of health literacy and the time it took to reach out to and speak to others with a similar health condition or finding out information regarding their health; people said that they had little time for this due to irregular working patterns and other commitments.

Even within this, people discussed the difficulty of getting help with financial management. It was said by one participant that they knew they would have more time for self management if they were able to better manage their money and not have to worry about it, however, they were not able to get that type of help.

The Solutions

After outlining the various barriers to self management that people faced while experiencing poverty, there was discussion on interventions that could help remove these barriers. There were clear ideas about how the barriers to self management for those experiencing poverty can be removed, and participants noted that transformational change is needed to underpin everything both in system and culture.

It was strongly emphasised that eradicating poverty would be the most effective way to remove these barriers. The Universal Basic Income was raised as a systemic change that could help alleviate poverty and give people the time to self manage rather than work long hours on low pay. At a more cultural level, people spoke about a need to bring empathy and kindness back into the way public services are delivered.

The solutions focused on:

1. The need to have self management more embedded in the health and social care system – with better pathways, increased knowledge and understanding of self management support by healthcare professionals and more accessible services.
2. Enhancing community assets, such as libraries, to create trusted spaces for advice and services.
3. Access to peer support approaches that aid with knowledge and understanding around self management techniques and financial advice along with reducing isolation and anxiety.
4. Improved funding structures to better support community and third sector organisations that provide vital self management resources and give people the tools they need to take control of their health.

5. Greater awareness raising around the importance of self management and the support available. Such awareness raising needs to increase in order to reach low income communities and those in varied and precarious work.
6. The need to challenge the stigma of poverty and build confidence and capacity of people to ask for help and to seek out self management support.

Embedding support for self management within health and social care

Participants suggested that if the self management approach was embedded into standard practice then it would become more accessible. One example was given of a physiotherapist who took the time to ask a person how they were self managing and was able to recommend a local third sector organisation that could support continued self management.

The Links Worker Programme was raised as an example of good practice in embedding self management as Community Links Practitioners build up a strong knowledge of community supports that can help people with specific needs to achieve their personal outcomes. By doing this, people said that they would be more likely to be able to seek out self management support.

Enhancing Community Assets

The importance of trusted spaces was emphasised throughout discussions. As part of the stigma of poverty people felt that they can be made to feel judged for using public spaces and there are a lack of 'agenda free spaces' where people can spend time without having to spend money or be subject to a set of standards.

People cited work happening in libraries as a good example of a trusted space that can be enhanced to support people experiencing poverty and living with a long term condition. Many libraries offer

support for people filling out paperwork and online forms. Furthermore, some libraries offer drop in health information sessions. Such initiatives work to support the development of health literacy, something that is essential to self management. It was also suggested that further education institutions should be seen as community assets that can support a culture of self management in communities in an accessible way. One participant said that students could work with people in the community to develop self management resources as part of their courses.

Peer Support

People spoke enthusiastically about the power of peer support. It can be empowering to connect with like minded people and be able to contribute to someone else's self management journey. Doing good for others can change the feelings of powerlessness when you are living in poverty and with long term conditions. Examples were given of how powerful stories can influence others' thinking to build confidence and begin to overcome some of the barriers to self management. Furthermore, peer support helps to embed self management practices and help people make sustainable changes. Along with this, peer support was heard to be an extremely valuable source of information regarding self management techniques and more general health literacy and financial support. The important role of peer support needs to be recognised and supported.

Funding

When talking about positive experiences with self management, participants noted the importance of third sector organisations. However, the current way that many third sector organisations are funded means that services are not sustainable and can vary significantly across Scotland. Participants told of experiences of having a service close, leaving them at a vulnerable part of their recovery journey. There was a sense of frustration among those in attendance that the importance of these services was not recognised at a policy

and decision making level. People spoke of a need for parity of esteem between third sector services and statutory services; part of this requires a better way of funding the third sector. As part of this conversation, there were discussions as to the representation of third sector organisations at local policy level along with a need for more participatory approaches to services. It was suggested that by including the voice of lived experience in decision making, commissioners would be forced to understand the importance of third sector organisations and develop services that support people to achieve their personal outcomes.

Awareness Raising

Participants noted three different strands to awareness raising that will be required in order to embed self management into the culture of health and social care. Employers need to be aware of how people are impacted by health and the need for self management. For people experiencing poverty this is particularly important as they can lack the confidence to approach an employer to ask for time off or the reasonable adjustments they are entitled to. Therefore, it is important that employers are educated and made aware of their responsibilities. There was support for the idea that it could be useful to have a self management employer award or accreditation. Alongside employers, health and social care professionals need to have a better awareness and understanding of the role of self management and also their responsibilities within this. Many health and social care professionals know about self management, however, it must be seen and valued as a 'core' aspect of their role. It was suggested that awareness raising needs to be focussed in order to develop the understanding that it is part of the role of the health and social care professional to explore community services and begin to signpost. Finally, there needs to be better networking to raise awareness of what is available to people. It was suggested that this can be done through story telling, events and other mechanisms that take a social movement approach.

Challenging Stigma

Participants were very vocal about the impact of cuts to social security and the accompanying stigmatisation of people experiencing poverty. The phrase 'skivers vs strivers' was referenced across most discussions. It was felt as if such a dichotomy was used by the media and the government to justify significant reduction in support available to people and the ever increasing conditionality of social security. It was suggested that social media campaigns could be used in order to raise awareness as to the experience, and causes of poverty. Examples were given of other anti-stigma campaigns that have been successful, particularly around mental health. Furthermore, people suggested that it would be useful to learn from different approaches taken in other areas. For example, work done in localities to create Dementia Friendly Communities has been very successful in getting people to think about the experience of dementia, learning about its impact and changing practices in order to accommodate different needs.

Concluding Remarks

In her concluding remarks, Twimukye Mushaka, Senior Fieldwork Development Officer at the Poverty Alliance noted that this event was the first of its kind linking Self Management Week and Challenge Poverty Week. This should be a

commitment that both the Poverty Alliance and the Health and Social Care Alliance Scotland continue to work together on. It was recognised that self management on low income is challenging given the range of barriers strongly articulated in workshop discussions. On the other hand, people living with long term conditions have an abundance of strength and are resilient in their fight to navigate the challenges thrown at them in their daily lives. Self management is a core part of that journey.

The event identified the need for more awareness raising work to be done at different levels in order to increase understanding of self management as a concept and to identify different players that would support people living with long term conditions and experiencing poverty to realise their self management goals.

Participants were encouraged to identify what works for them and seek support to make it happen. *"The self management journey has to begin with those of us with lived experience and connecting to the various sources of support in the local communities"*. There is need to challenge 'self stigma', that little voice in our head telling us we cannot do this or that. We need to constantly tell ourselves that 'Aye We Can', which is the theme of Challenge Poverty Week 2018.



Statement of thanks

The Poverty Alliance and the Health and Social Care Alliance Scotland would like to thank the following contributors;

- Pauline Craig, Head of Population Health at NHS Health Scotland, for Chairing the event
- Community activists Sue Lyons and James Docherty for sharing their stories of hope and resilience
- 'Fool on', which promotes mental health

recovery through the performing arts, for entertaining us in the afternoon's 'energiser session'

- Sophie Boyd for leading the 'Singing for Breathing' relaxation session
- All participants and workshop facilitators

Additionally, the Poverty Alliance would like to thank the Joseph Rowntree Foundation for supporting the Challenge Poverty Week activities.

About the Poverty Alliance

The Poverty Alliance is a network of different organisations that work together to tackle Poverty in Scotland. The vision of the organisation speaks to a 'sustainable poverty free Scotland, with dignity and social economic justice for all'. It is the goal of the Poverty Alliance to influence policy and practice in ways that tackle poverty with people with lived experience at the core of this work. The organisation works in partnerships with its members, communities, third sector organisations and policy makers to change the distribution of power and resources.

The Poverty Alliance works closely with Community Activist Advisory Group CAAG which is a group of individual activists drawn from our work across Scotland to contribute to policy responses but also inform campaign initiatives, media work and direct engagement with policy makers. The joint event on self management on low income was one way of providing the space for CAAG members and other stakeholders to share their lived experiences.

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations.

The ALLIANCE works with its 2,700 plus members towards the vision of:

A Scotland where people who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens with support and services that put them at the centre.

The ALLIANCE does this through three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services
- Support transformational change, towards approaches that are preventative and that work with individual and community assets, supporting human rights, self-management, co-production and independent living
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.



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