Self Management

Lived Experience
Driving Change in Health and Social Care

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

We need to implement a new relationship between people and those providing support and services – this requires new skills and changes to education, training and support of staff

We need to see a whole system approach taken to support self management as people with long term conditions move through the health and social care system. It is vital that health and social care integration, and the commissioning process in particular, levers the change required

Lived experience has been the central ingredient of success and must remain at the heart as we continue to embed successful self management approaches and develop new innovations

Strong, connected communities are central to self management – greater investment needs to be made in the capacity of communities to support their own wellbeing

We have made excellent progress in Scotland in terms of increasing understanding and developing 'what self management is' or could be, but now need to shift up a gear so that the range of good work becomes embedded; that greater investment is made in third sector self management support; and all groups, particularly those most marginalised, are able to benefit from the greater control and better personal outcomes that self management enables

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Introduction

Self management is critical to the Scottish Government's 2020 vision for the future of health and social care in Scotland. The Christie Commission, Route Map to the 2020 Vision, health and social care integration and Scotland's National Action Plan for Human Rights (SNAP) all form part of the backdrop for a fundamental shift in favour of asset based approaches, co-production and the desire for empowered citizens living in thriving communities. The self management agenda provides an insight into how health and social care can work when this change takes place.

Scotland's approach to self management has been to learn from people's experience of living with long term conditions. This has been possible through the leading role of the Health and Social Care Alliance Scotland (the **ALLIANCE**) and our members in developing and driving the agenda forward. This activity has increased understanding of 'what self management is' or could be, not least through the implementation of the Self Management Strategy for Scotland and delivery of the Self Management Fund for Scotland.

This Thinkpiece illustrates the distance we have travelled and the very real impact self management approaches can, and do, have for people living with long term conditions and their unpaid carers.

Yet we are also clear that we must continue the transformative work to embed self management in a systematic way across the whole country in partnership with people with lived experience, third sector and health and social care staff. The **ALLIANCE's** Self Management Partnership and Practice Programme will support the development of partnerships and opportunities to take this work forward. Sharing successes, promoting good practice and capitalising on this learning will be supported by the newly established Self Management Network Scotland.

Self management is a powerful example of an approach that gives people and communities more opportunities to shape the services they use based on their own experiences. With greater control over their own wellbeing, people are able to support and shape a focus on individual and community strengths. It is essential that self management remains at the heart of reforms to health and social care.

Ian Welsh, Chief Executive

Foreword

The principles and benefits of self management support are now well understood. This report draws our attention to the increasing and welcome recognition that people who use health services can no longer be viewed as passive recipients of care but rather are active co-producers of their own health. It summarises succinctly what needs to be done to shift systems and social norms. It gives heart-warming examples of community and health service initiatives that are supporting individuals to manage their health better.

At the same time, the report highlights the stubborn gap that remains between the commitment to person centred care and support and the reality on the ground. It still feels tentative and vulnerable, teetering on the tipping point between an unstoppable movement of change and a whisper of history.

The Health Foundation began its self management journey nearly a decade ago, co-designing a programme that was to become Co-creating Health[1]. It is pleasing to see how far this report by the ALLIANCE reflects and reinforces that learning.

Self management support is transformational change not transactional change. It shifts us from **'what's the matter with you?'** and **'this is what you need to do'**, to **'what matters to you?'** and **'how can we support you to achieve your goals'**. This transformation requires a new set of relationships – between people with longterm conditions, health services and communities, and a shift along two axes: systems and 'culture'.

The shift in systems requires putting in place the processes, measures, regulation and stewardship that will facilitate, lead, drive and 'nudge' self management support (the roof and foundations of the House of Care[2]). The shift in culture, or social norms, requires

developing the workforce behaviours, roles and mind-set that will make person centred care 'the way we do things around here' (the two walls of the House of Care).

There are few measures that demonstrate value from patients' perspective and fewer that are routinely collected. While modern IT has heralded a growth of person level data, data is usually collected by the NHS, but not yet routinely made available to patients to be used by them to better manage their long term condition[3].

Clinicians also need to be supported to equip them with the skills for person centred care and support. Yet as this report points out, we need to take this learning to scale, working in partnership with professional, education and training bodies to embed a more systematic understanding and development of these skills.

Bringing together local and national networks of practice will provide a model for engagement that will be at the heart of any movement to embed and spread self management support[4].

For many of us who have had the opportunity to refocus our gaze through the lens of self management support, the journey has been one of learning and change. Linking the energy that exists in communities, the experience that has been gained from forerunners such as NHS Ayrshire and Arran and others, and the leadership of the **ALLIANCE,** NHS Scotland and the Scottish Government with the capabilities of people with long term conditions may create the unstoppable movement to make self management support **'the way we do things around here'.**

Adrian Sieff
Assistant Director, Health Foundation

Context

Self management has been central to the way we approach health and wellbeing in Scotland and is a leading example of an agenda driven by a movement led by people themselves through peer support and practice based evidence.
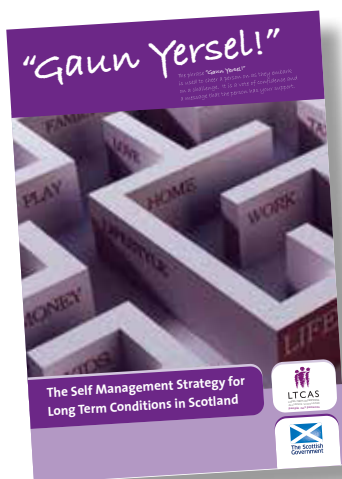
Gaun Yersel, the Self Management Strategy for Scotland, was the first example of a Scottish Government policy written by people and communities, and became the blueprint for the development of self management in Scotland. The Principles of Self Management developed as the heart of the strategy resonate as much today as they did then, and remain the central tenet of a myriad of self management approaches, initiatives and collaborations around the country led by people and communities.

Significant progress has been made since the launch of Gaun Yersel[5]. The Self Management Fund for Scotland[6] has generated rich learning and deepened our understanding of good practice as well as built capacity and expertise within the third sector in developing and delivering self management support.

"As more of us live with long term conditions we need to make sure people are supported to be leading partners in managing their health and wellbeing, feeling able to make informed decisions and know when to draw on different kinds of support.

The Scottish Government has invested in the Self Management IMPACT Fund to provide a huge boost to this type of support."

Michael Matheson MSP

"The self management agenda is critical to the Scottish Government's 2020 vision for the future of health and social care in Scotland. We are committed to enabling people to make informed choices, ensuring they are supported to be leading partners in managing their own health and wellbeing.

I welcome the role of the ALLIANCE and its member organisations in continuing to drive forward this important agenda."
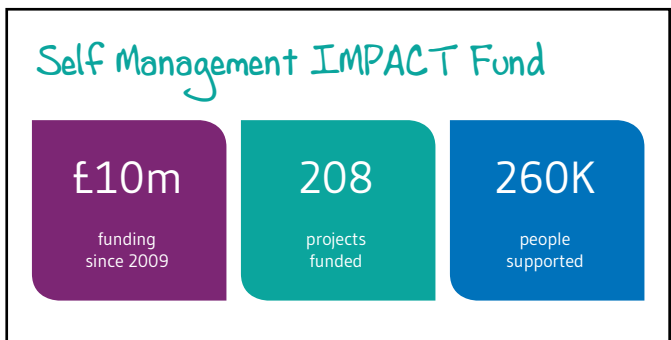
Alex Neil, MSP

There is growing evidence of the transformational change that can happen when someone is supported to self manage. Associated with this is a more holistic understanding of health[7] that recognises the wider determinants and the importance of concepts such as social capital and resilience[8] to explain individual and collective health and wellbeing.

Thus the role of health and social care is transformed when self management is at its heart: from solely trying to 'treat' a person's conditions and towards a role that seeks to work with them to find the best support, aimed at improving their physical, emotional, social and spiritual wellbeing. Self management challenges the perceptions of who we see as providers of health and social care; encompassing a wider range of players including people and communities themselves and their individual and collective strengths and assets.

There are some ambitious policies designed to drive change in health and social care and bring about enhanced citizen engagement in Scotland and across the UK. Self management is recognised as a key lever for achieving this public service reform. Yet recent years have seen a contrast between a strong, widely supported drive for radical shifts in policy and an experience locally of change which has not yet been consistent across the health and social care system to realise these ambitions.

It is increasingly apparent that there are limits to the public sector's capacity to develop solutions to society's complex social problems such as Scotland's health inequalities. The need for localised, co-produced solutions to these seemingly stubborn social problems is evident in the policy direction being called for by leading institutions such as the Carnegie UK Trust's Enabling State[9] and a 'Relational State'[10] approach to public service reform proposed by the Institute for Public Policy Research.

Self Management IMPACT Fund

£10m	208	260K
funding since 2009	projects funded	people supported

While proposing that the state should continue providing the universal services it excels at delivering, Carnegie UK argues the state must simultaneously take on a role that empowers communities, individuals and families to take an active role in improving their own wellbeing. They highlight the Self Management IMPACT Fund for Scotland as an example of an approach that gives people and communities more opportunities to shape the services

Highlighted by Carnegie UK as a leading initiative in the public service reform agenda. Their 2013 report 'The Enabling State: From Rhetoric To Reality' recognised that the Fund has fostered *"a much greater understanding of what self management means within the NHS and other public bodies as well as a greater willingness to fund projects based on people's experience."*

they receive based on their own experiences and greater control over their own wellbeing focusing on individual and community strengths.

Nesta argue that enhancing access to peer support for people with long term conditions should be an election pledge[11] and indeed at the last Scottish Parliament election the **ALLIANCE** welcomed the inclusion in all main parties' manifestos of a commitment to this through the Self Management Fund.

Nevertheless there remain many people who are not familiar with self management and as someone living with a long term condition said *"giving it a name is empowering."*

Of course, people can and do self manage without being aware, but there is an empowerment which comes with consciously being in control of your condition. More therefore needs to be done to make sure self management is central in the support and services available to people with long term conditions and their carers. The developing integration landscape is a crucial enabler for this yet we must work towards ensuring this is the case.

This change will require support for workforce development to guarantee there is a shared understanding of self management amongst health and social care professionals, people with long term conditions and their carers. A coherent understanding will emphasise the principles of self management and co-production as central to both practice and lived experience.

The **ALLIANCE** through the strength of our membership continues to provide leadership and support through our coordinating role, drawing together knowledge about developing practice and sharing learning across workstreams and regions. The Self Management Network Scotland[12] established by the **ALLIANCE** has been designed to provide a platform to build the momentum needed and support people and professionals working to embed self management support.

PRINCIPLES: SELF MANAGEMENT

"Be accountable to me and value my experience"

Evaluation systems should be ongoing and shaped by my experience. They should be non judgemental and focus on more than medical or financial outcomes.

"I am the leading partner in management of my health"

I am involved in my own care. I, those who care for me and organisations that represent me, shape new approaches to my care.

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Self Management Network Scotland

"I am a whole person and this is for my whole life"

My needs are met along my life journey with support aimed at improving my physical, emotional, social and spiritual wellbeing.

"Clear information helps me make decisions that are right for me"

Professionals communicate with me effectively. They help ensure I have high quality, accessible information. They also support my right to make decisions.

"Self management is not a replacement for services. Gaun yersel doesn't mean going it alone"

Self management does not mean managing my long term condition alone. It's about self determination in partnership with supporters.

Lived experience has been the central ingredient of success

The lived experience of people living with long term conditions and their carers must remain central as we work to embed successful approaches and develop new innovations in self management. Co-production is a key determinant of a culture favourable to self management, emphasising the collaborative relationship and need for health and care professionals to cede power and support people with long term conditions to make informed choices about their health and wellbeing.

There is a growing body of practice-based evidence, led by the IMPACT Fund in Scotland, which demonstrates that involving people with lived experience is essential to the development and implementation of self management support, to contribute to the culture change needed, and to support personal outcomes and community capacity. This is supported by international evidence highlighting the importance of understanding the lived experience of self management that often entails social practices developed through social support[13].

People who are successfully managing their long term condition often become champions of self management and share their success with other people. In fact, evidence in Scotland suggests the principles of self management are increasingly spread through people with lived experience and the third sector.

The voice of lived experience is intrinsic to self management whether in terms of shaping self management support or facilitating spread through peer support.

Case Study

I am a whole person and this is for my whole life

Hello! My name is Alyce. I am 58 and have been diagnosed with Multiple Sclerosis (MS) for 18 years.

When I was first diagnosed, our sons were 11 and 9. As my husband worked away from home, they became my carers. They were very good too! I became dependant on them and as they were nearing leaving school age, I became very concerned that I couldn't 'do' without them. I was not looking forward to 'being home alone'. It was time to take action.

I'm a member of the MS Society Scotland; my local branch is Perth and Kinross. They were offering a six week Self Management course. I signed up as soon as I could. I enjoyed the course so much I asked if I could do more. I went on a further study course and became a course leader. I liked meeting people and sharing with them the new skills to get through the difficulties having health issues cause. Loneliness and the feeling of worthlessness being some of the more challenging issues. Just being able to encourage the participants to try new things at their own pace, to accept it's okay to go slow, write yourself notes, or take a nap when you're tired, was a big plus for me.

My MS has progressed. Although I no longer run courses, I still practice what I learned. I make action plans, do volunteer work, and have established my own 'help' network with family and friends. I have a good relationship with my GP, MS Nurse and Neurologist. I'm treated with respect by them and when I say **'I need help'**, I'm taken seriously and get it.

On a personal level, my husband still works away from home and our sons have flown the nest so I am well and truly 'home alone' and managing well. Yes, there are bad days, but I now have the life skills that help me cope. I have the confidence to ask for assistance and belief in myself that I can take each day as it comes.

A new relationship between people and those providing support and services

National policy levers which raise the profile of self management can help to create an enabling environment to bring about whole system change. To continue shifting the balance of power in favour of self management and coproduction as integral to the delivery of health and social care will require a change in organisational practice and culture. As a person centred concept, self management will mean different things to different people, at different times in their lives, which can make the required changes in practice difficult to define. There are many examples of good practice across Scotland, yet progress to spread and sustain self management support within health and social care has been slower and there are barriers that need to be overcome.

Education and support for practice development of health and care professionals must be a key part of the catalyst, demonstrating the necessary values which can spark the desire for change. This investment in workforce development must be accompanied by an enabling infrastructure that supports a coproduced approach across the whole system to sustain and embed this into routine health and social care.

Whilst many health and social care professionals are already practising self management support, evidence[13] suggests that for some their understanding is based on a narrow, biomedical model of health rather than a holistic, social model. This biomedical model of self management places an emphasis on compliance with expert advice and an implicit assessment of the individual's willingness and ability to 'take responsibility'. In comparison, both people with long term conditions and carers largely regard self management holistically as a practice achieved through a collaborative partnership with professionals and through interaction with wider social support.

Adopting a holistic model can lead professionals to feel anxious about 'opening a can of worms' whilst talking to a person about their self management, as it may involve aspects of their life out with the health service which they feel untrained to deal with.

Whilst there are many professionals who are actively engaged in developing these collaborative partnerships, more needs to be done to ensure it is this person centred and holistic understanding of self management that is spread. Senior level support as well as clinical leadership is a critical enabler.

To integrate self management into routine practice we must ensure the skills, understanding and associated behaviours

required of the health and care workforce to support self management, including the necessary values and principles, are embedded within health and social care education, recruitment and workforce development processes.

The Co-creating Health Programme[14] evidenced that adopting a strategic approach to implementation is essential to make progress in embedding self management support. This means building self management into local strategies, identifying ways to support or reinforce self management support through existing structures, identifying influential practitioners as change agents and developing a network across the system to ensure a 'critical mass' is reached. Locality planning and strategic commissioning by the new Health and Social Care Partnerships will be key to enabling this to happen.

Case Study
Reflections on the Relevance of Self Management

My involvement as a clinician in the Co-Creating Health Initiative launched by the Health Foundation in 2007 has given me the opportunity to experience the reality of self management by people with long term conditions[15,16]. I have witnessed the extent to which self management develops and grows by engaging in conversations which facilitate an enabling relationship. Cultivating relationships which enable the individual to find and maintain their own best way to wellbeing and living with a long term condition means shifting the focus from the professional's to the person's agenda; from problems to personal assets; from what's the matter with you to what matters to you?

I, as a clinician and person have become more proficient in being a listener and gentle coach. My perspective as a healthcare professional has gradually transformed from knowing best and fixing something for others to learning and moving forward together in a trusting partnership of mutual respect and accountability. The conversation has changed.

At the start of a consultation it is the person who formulates the desired outcome now. We jointly negotiate an agenda with the focus on what matters to them. My approach to self management support is to encourage and enable the individual to set goals and identify skills to solve problems along the way. The attention is shifting from clinical needs to achieving personal goals. Owning those small steps towards a better quality of life and health helps to build confidence, restores a sense of control and sustains independence for individuals with long term conditions.

Witnessing the transformation in people from feeling not in control, and at times without hope, to being an active person, self managing their life and within their community has been the most humbling and remarkable experience for me. I have learnt to appreciate my own limitations and I find the engagement on this level of mutuality more profound and gratifying than the traditional and paternalistic encounter between patient and clinician.

Understanding self management as a journey helps me as a clinician to connect with each person at the current stage of their journey which can reach from self management being of no importance to a high level of confidence and competence in self managing new challenges.

I believe that self management in healthcare, communities and daily lives presents a huge opportunity for a sustainable engagement in the improvement of all our health and wellbeing. Understanding and embracing the resourcefulness of people and what matters to them will not only transform the relationship dynamics in healthcare, it will help shift the emphasis from an unsustainable 'disease care' model which makes only a small contribution to the health of our population to empowering individuals to set their own meaningful goals towards health and wellbeing related behaviour which is considered the most important determinant of health[17].

Health, not only as a state of complete physical, mental and social wellbeing but the ability to adapt and self manage will emerge as the guiding paradigm for our approach to long term conditions in health and social care[18].

Hans Hartung, Consultant Respiratory Physician, NHS Ayrshire & Arran

Case Study

NHS Lanarkshire

A common barrier to people engaging with self management support is often the clinicians' hesitance to introduce it into the conversation during consultations. There can be a fear that by asking someone what they do to keep well, the person might wish to discuss some issues which the health professional feels they don't have enough time to fully explore, or the knowledge to address it properly.

In 2010, a number of psychologists prepared a draft paper on how people with diabetes could benefit from psychology input and it was recognised that there was a real need for this approach. As a result, NHS Lanarkshire, alongside four other Health Boards, was awarded three years of funding to provide Psychology in Diabetes training to all clinical diabetes staff.

The health professionals were not expected to replace psychologists but the training would provide the staff with the skills and confidence to have that self management conversation with people.

The training is ongoing in Lanarkshire until July 2015, however as a result of the staff moving towards this co-production approach there has already been excellent outcomes, such as improved emotional wellbeing and improved diabetes self management while staff feel more able to help people self care, and are now routinely signposting to specialist services.

"I learned a lot. The training gave structure and confidence. The early training made me sit down and reflect. Now I know I need to find out what the patient expects from me. Now I spend more time building up rapport. It has made me ask more open questions and elicit what is important for the patient. It is their agenda, not ours. Consultations are more enjoyable and productive. Nurses try to make everything right, now I sit back and let the patient make suggestions."

"Consultations have become more patient led allowing discussion on the patient's agenda, rather than focusing on my own priorities. This allows for more informed decision making from patients even if I don't necessarily agree with the patient's choice. I have become more accepting of what I can help change and what I cannot."

Education and Practice Development

There is a range of training support currently available to professionals, yet this must be provided to multidisciplinary and cross-sector teams to build the momentum to implement the changes. Involving people with lived experience to deliver the training is a powerful way of helping to shift attitudes and demonstrate the value of self management. There is good practice within the third sector that can be drawn upon such as the partnership work being led by the People Powered Health and Wellbeing Programme[19].

Personal Outcomes Partnership[20] is an initiative of the Joint Improvement Team, the ALLIANCE and Thistle Foundation with the aim to support individual practitioners, teams and organisations, in health and social care settings across sectors to implement a personal outcomes approach.

Champions of Self Management in Care[21] (or COSMIC) resources build on the capacity of people who are passionate about self management by enabling them to explore the value and breadth of self management, whilst being given the skills and confidence to become involved in service improvement.

Over the last 6 years, **Thistle Foundation's Training and Consultancy service** has emerged as a well evaluated and highly sought after resource for health and social care practitioners interested in embedding an outcomes and assets based approach into their practice.

Similarly the talks delivered through the **Dementia Carer Voices**[22] project engages health and social care professionals by highlighting the importance of a person-centred approach to dementia care and the role of carers as equal partners.

Post-training support must also be available to help professionals continue their practical learning through reflection and peer support. Without an emphasis on the culture change needed, there is a risk that the tools and techniques that support self management are spread rather than the principles and holistic approach, which must be the foundation.

Self management needs to be seen as a journey led by the person with the long term condition rather than a predefined set of tools or skills that a person must master.

We must harness the enthusiasm of health and social care students and their passion for positive change to recruit a new wave of self management champions. This will ensure we have the necessary support to sustain it.

A Human Rights Based Approach

Human rights based approaches, such as the PANEL principles: Participation, Accountability, Non-Discrimination, Empowerment and Legality of Rights, can provide a strong unifying framework to bridge the cultural divide between health and social care and ensure the principles of self management are realised. Health and social care should be understood as a means to a greater end of living well. Connecting rights based approaches to the frontline delivery of support and services can empower people and staff to realise this.

Strong, connected communities are central to self management

At the heart of this agenda are communities of people - brought together by a shared locality, interest or common bond - that have the ability to adapt and thrive. There is a need for greater investment to be made in the capacity of communities to support their own wellbeing. The important dynamic between individual and collective wellbeing must be recognised and supported: "**resilient individuals promote and require reliable networks of support while resilient communities include individuals who are trusting and supportive**".

Many community groups and voluntary organisations have been working in an asset-based way for some time, although the language of 'assets' is perhaps a newer phenomenon. The true value of an asset-based approach has been found to lie with its emphasis on inclusion[23]; working in partnership with citizens to ensure they are truly co-producers of their health and wellbeing.

Case Study

Aberdeen Foyer

Aberdeen Foyer's Impact Project supports adults with mental health conditions, with a specific focus on those most isolated, to support the effective self management of their condition. The majority of participants find it extremely difficult to initially engage with the project, although once this first step is taken, the significant, positive change is evident in their lives. Through peer support and focused activities the project has provided safe, happy, vibrant locations for individuals who were previously too anxious and isolated to leave their homes.

Despite the clear difference the project has had on people within the community, partnership working with statutory services was initially challenging. However the positive contribution from the project was soon recognised by local services and referrals began to flow steadily. This resulted in an increase in peer support for anyone new to the project and a higher level of trust within the local community creating a cycle of positive outcomes, such as increased independence, health literacy, increased physical and emotional wellbeing and of course better self management **"I never imagined I would be sitting here chatting to people. Two months ago I was too scared to even leave my house"**.

The group members are involved in every aspect of project development. For example, when recruiting a skills coach the group members wrote the job description, assisted with the interview process and selected the successful candidate. Therefore people feel a sense of ownership, trust and meaningful involvement as a result of the co-production approach, which is encouraging people to remain engaged.

"I was in a big dark hole and I knew that if I wanted to climb out of it I had to find my way back to the group. I managed to get the confidence to come back because I knew that I would be welcome.......that nobody would be there criticising me for being away or not coping."

Group member who returned to the group after a period of anxiety.

Health Inequalities

The impact of health inequalities in Scotland continues to be a focus of public health debate. Although paradoxically we are healthier as a nation than we have ever been, our health inequalities remain resistant to change. People in Scotland die younger than any other country in Western Europe and although this covers all social classes, it is people living in poorer communities and people with low incomes who are most at risk.

Power and resource inequalities are central to the root cause of health inequalities. Evidence[24] about tackling health inequalities highlights the importance of work to increase people's social networks, community cohesion and involving people as co-producers of their health and wellbeing. Enabling people and communities to have control and influence within their own lives and health is key to tackling health inequalities; which places self management as central to these considerations.

Case Study

The Veterans Programme

Thistle Foundation believes that self management is not a quick fix or a cure, but a journey where people can vastly improve their health and wellbeing - and therefore their quality of life.

Thistle supports veterans at all stages of life after service – whether they are dealing with a physical condition, a mental health issue like Post Traumatic Stress Disorder (PTSD), depression or anxiety, or are just finding it difficult to adjust to 'civvy street'.

When veterans are in the services, they get training, support and the tools to do the job. Once they leave, it can be overwhelming. There are many paths to tread and no map to navigate them safely.

Thistle's work with veterans is a flexible programme of support, depending on each person they work with. Some may benefit from one to one sessions, others group sessions; some are harder to engage and require intensive outreach. The programme also weaves in opportunities to take advantage of: relaxation, exercise, volunteering, reflective practice and more.

The programme is different because of the peer support it offers, and the shaping of the service by veterans themselves. Alongside Thistle staff facilitators (often with no military experience), veterans who have been through the course help deliver them to other ex-servicemen and women.

This shared experience – and allowing for time and space to develop relationships - helps foster trust and continually informs the programme of support Thistle offers.

This approach to sharing the tools of self management has developed over the years, as Thistle has learned that durable change emerges from years (not months) of interaction – intermittent or otherwise.

One veteran, Jason, says, 'with other support you get [as a veteran], as soon as you walk out the door, that's you. But when you walk out the door here at Thistle, the door is always open for you to come back in.'

Through funding from the IMPACT fund, the veterans programme has been able to increase its capacity and reach and has allowed Thistle to build on partnership work with Poppy Scotland and Scottish Veteran Residences, Bellrock Close in Glasgow.

The Thistle's focus is on what matters most to the person, maintaining open, hopeful relationships with expectations of change – and sharing their learning to support widespread good practice of supported self management for everyone with one (or more) long term conditions.

Investing in Community Capacity

A significant challenge for community projects and voluntary organisations is ongoing financial uncertainty. Time-consuming processes are involved when trying to secure funding streams and there can be difficulties making themselves visible in the processes that dictate where local health and social care is directed.

A common challenge is demonstrating to funders that what they do is beneficial and worth funding. Measurement of success is a critical issue in relation to asset-based approaches as traditional views of monitoring and evaluation and system based indicators of quality are often not conducive to telling the story of the impact such projects make.

It is essential that there is a shift towards more outcomes focused evaluation approaches, that take into account the lived experience of people, being adopted in the statutory sector to accompany the current performance measurement process.

The IMPACT Fund, in partnership with Evaluation Support Scotland, promotes evaluation as a tool for continuous learning and improvement. Projects are supported to focus on the outcomes and the difference they make as well as share their learning so that others can benefit.

Finding, Understanding and Using Information

There are many inspiring examples of third sector projects improving the physical, emotional, social and spiritual wellbeing of people with long term conditions through self management. Yet there can be reluctance within statutory services to refer people to these projects. Whilst many would welcome opportunities to make such connections there is often a lack of awareness about how to access these sources of support as well as a lack of connectedness between statutory sector workers and local networks and groups with an interest in health and wellbeing. Cross sector collaboration, particularly involving primary care, is crucial to supporting people to self manage.

There is a need for continued investment and engagement with social innovations designed to overcome this through making local sources of support more findable. Programmes such as **ALISS** and local initiatives like **West Dunbartonshire Link Up**[25] and the **Aberdeenshire Signposting Project**[26] are excellent examples that have been co-produced with people and communities.
In addition, approaches such as the **Links Worker Programme**[27], **Community Compass**[28] and the **Social Prescribing Project**[29] demonstrate the ways in which statutory services need to be reshaped to become more community facing.

Case Study

Making Mapping Meaningful in Highland through ALISS

A Local Information System for Scotland[30] (ALISS) is a co-produced search and collaboration tool for health and wellbeing resources. Communities contain a wealth of resources that can support health and wellbeing, but finding information about these resources can often be difficult. ALISS helps signpost people to community resources and enables communities and organisations to contribute information about the assets, services, events and supports that are available locally.

ALISS functions like an index, pointing to information about local resources, whether this exists in an online directory, within ALISS only, on a website or within social media. This list of pointers can be presented via multiple channels and collaboratively maintained by communities.

Having identified a need to coordinate asset mapping activity happening across an extensive and largely remote and rural area, a project in Highland has been working with local groups to bring information together and to learn what the mapping process can offer.

NHS Highland is one of the largest and most sparsely populated Health Boards in the UK serving approximately 320,000 people. Discovering and keeping track of local activities and services is a significant challenge across such a wide and diverse region, but a project being coordinated by the Highland Third Sector Interface[31] and Let's Get On With It Together[32] has been working to change that.

"When we were going around talking to people about self management and promoting the idea, the common theme was that people were interested in people self managing but didn't know where to point them to support them to find activities that were relevant to them."

Joanne McCoy, Self Management Coordinator

Part of the community relationship building has been achieved by working in partnership with the 11 community networkers who are key local representatives. Each networker highlights and signposts to services and events in local areas. Engagement with them has ensured that the asset mapping work is embedded in a process of relationship building with local communities.

The project has used ALISS to collect and manage the mapping discoveries and the asset mapping has been a way of introducing and discussing messages about wellbeing and self management within communities.

We need to increase the pace of change to embed self management

Excellent progress has been made in Scotland over the past decade in developing self management support but we need to increase the pace of change to ensure everyone is able to benefit from the greater control and better personal outcomes self management enables.

Greater investment in third sector self management support is critical to this. A key aspect of the third sector's contribution is its significant experience in enabling peer support. Many self management projects identify peer support as the most powerful aspect of their work – enabling people to develop the confidence to assert their right to the support they need. This approach will play an integral role in tackling health inequalities in Scotland. Yet developing this sophisticated approach requires resourcing and sufficient investment.

Case Study

The Hope Café

Facilitated by volunteers who have experience of mental health issues, The Hope Café operates a community café in the small town of Lanark. The volunteers are given access to volunteer placements, training and self management workshops. For the wider public, the café has an area containing numerous self management resources and a variety of free courses and training on self management which are all co-facilitated by the volunteers.

"Volunteering has made me a braver person and has allowed me to own my illness rather than seeing it as a flaw......doing good, does me good."

Lisa, Hope Café volunteer

People are recognised as assets and each volunteer is supported to enable them to become equal partners in the design and delivery of the project. Strong peer support networks have been built as a result of the atmosphere of inclusion and equality, which the volunteers have found vital to their self management.

"This is the first place I have ever felt accepted for who I am, just as I am."

Visitor to the Hope Café

The relationships are founded on mutuality and reciprocity.

Local statutory services recognise the positive impact Hope Café is having on the community and collaboration between health and social care has been key to ensuring excellent outcomes for people with mental health issues. There is recognition that projects such as the Hope Café can offer something different from that which health professionals can and this acknowledgement of different strengths can potentially spread this method of working far beyond Lanarkshire.
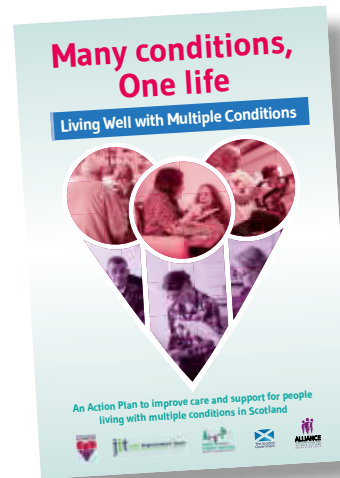
Extending the Reach of Self Management

More must be done to ensure self management is encouraged for everyone living with long term conditions – particularly taking into account characteristics such as ethnicity, gender identity, sexual orientation, people with a caring role and experiences of deprivation and health inequalities. There is a perception that some people have the motivation and personal responsibility to be 'good self managers' and other people do not. For some people, picking up the phone to make an appointment is a huge step along their journey of self management and therefore we must be mindful that everyone is unique, with a different journey to travel.

The recently published Many Conditions, One Life: Multiple Conditions Action Plan[33] embodies a concept of health that emphasises self management and person centredness. The actions are designed to describe the changes that need to be made within the health and social care system to improve support for people who live with multiple conditions. In particular, the action plan is calling for a whole system approach to service improvement for people with multiple conditions, including working with community and third sector structures.

Yet people are finding ways to self manage regardless, and given the right support people

Many conditions, One life

Living Well with Multiple Conditions

An Action Plan to improve care and support for people living with multiple conditions in Scotland

can feel empowered to self manage. Without reaching these sometimes marginalised groups there is a risk that self management support further increases health inequalities. This highlights the need for interventions that are tailored to the personal circumstances of people and take into account their social context. The Multiple Conditions Action Plan is an important step and there is learning to be shared and built on.

Case Study

The LGBT Self Management Initiative

The stigma and discrimination encountered by lesbian, gay, bisexual and transgender (LGBT) people can have a devastating effect on self-esteem and mental wellbeing. Although significant legislative advances have been made ignorance, negative attitudes and stereotypes around LGBT identities continue to be prevalent. Individuals can face rejection (or fear of rejection) by family, friends, colleagues and neighbours and often avoid being 'out' in many spheres of their lives. This causes many LGBT people to experience significantly higher rates of poor mental health, depression, psychological distress, suicidal behaviour and self-harm than the general population.

The LGBT Self Management Initiative, delivered by LGBT Health and Wellbeing, has been developed to enhance the mental wellbeing, resilience and self management skills of LGBT people experiencing mental health issues.

The project involves delivering one-to-one counselling, self management workshops and group activities. The group activities and workshops have been designed to create a safe place for peer support, supporting people to focus on key issues such as managing anxiety and growing through bereavement and loss. Many people have seen significant change in their mental wellbeing and feel better able to self manage their mental health as a result of this support.

"I've benefitted loads from the counselling service – I finally found a counsellor that I didn't have to explain the whole bi thing to, and she has been a tremendous help in sorting out my mental health."

"I thought I hated myself because I am trans, now I realise it was other people's hatred I felt."

A further development for LGBT Health and Wellbeing has been their work educating counsellors who may not be familiar with the language or issues of this community. This has been important to create awareness that will filter out not just to the general counselling profession but also to provide LGBT people with a specialist counselling service that provides counsellors who are affirmative, knowledgeable and create a safe space for people to explore their sexuality and gender identity.

"I have a better understanding of some of the issues faced by the LGBT community, practical knowledge of language and more personal insight."

Case Study

Diabetes Scotland The Chinikum Families Initiative

The Chinikum Families Project in Glasgow work with South Asian families who have family members living with diabetes. The work is entirely focused on self management and is there to provide families with the tools and information to self manage their diabetes. They promote peer support, health literacy, exercise, information and improve wellbeing and confidence.

In tight-knit South Asian communities many feel that the family is ultimately responsible for providing support, and in some instances health care, for an individual. This can create a situation where people don't have much contact with health and social care services, and so there is often a poor understanding of their condition. What's more, diabetes carries a stigma in the South Asian community as it can be viewed as being punishment for a poor lifestyle, and therefore people with diabetes will attempt to conceal their condition, sometimes with drastic consequences.

The project fosters relationships with the families to ascertain what is important to them in an attempt to overcome the barriers to self management. They have found that the principles of self management spread better through word of mouth, as families share the benefits with each other and alleviate concerns.

"I can help by spreading what I now know about self management to people I meet and when we discuss things at parties, weddings or mosque gatherings."

Phase 1 participant

Many families have seen significant, positive change in both their health and wellbeing as a result of their new-found self management approach. It is difficult to see how this would have happened without the support of the Chinikum Families Project and their tailored support which further highlights the need for health services to collaborate with smaller community led projects and the urgency to sustain these vital services.

Carers as equal partners

Many carers in Scotland still feel like they are not included or valued enough and seek more anticipatory support to self manage. Often, carers are in a crisis situation before support is offered and by that time their stress has reached unmanageable levels, setting off a chain of events including lowered immunity to illness, mental health problems and wider consequences, for example loss of employment.

Carers continue to feel that they have no time to self manage as all the focus is on the person they care for, leaving their issues unnoticed and sometimes a worsening of their health. Positive changes are taking place for carers in Scotland as a result of carers' involvement in shaping policy such as the Carers Strategy 2010, and the carers' legislation and charter of rights being developed. The Short Breaks Fund, administered through Shared Care Scotland, continues to provide carers with those vital days off. However, it is crucial both for the cared for and the carer that this holistic model of self management support is readily available for both parties.
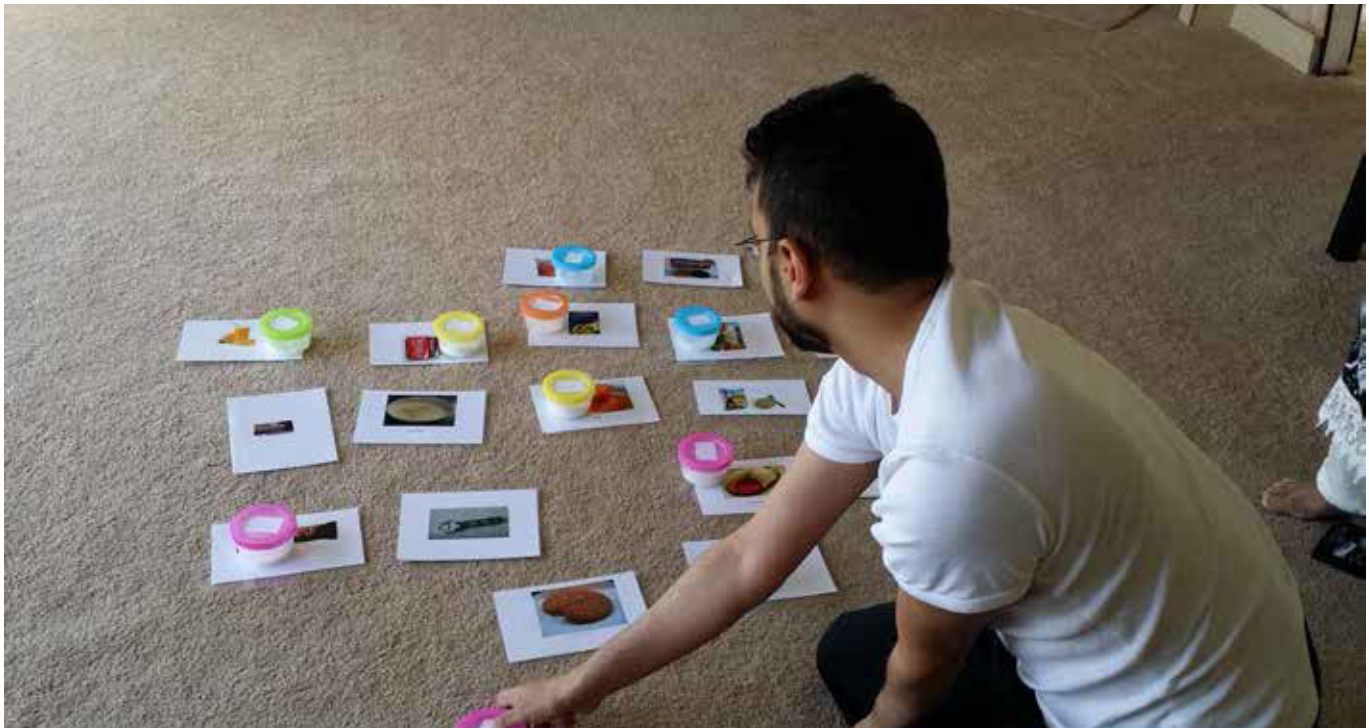
Case Study

Maureen's story

Hi, my name is Maureen, I am 55 years old and care for my husband who has ischaemic heart disease and fibromyalgia. I also help my mum who lives on her own and she has battled breast cancer and heart disease. I live with my husband and 3 children so it's a very busy house!

I have been caring for 14 years and have suffered depression in the past due to my caring role.

About three years ago I came in to Renfrewshire Carers Centre for some help and went on a stress management course for six weeks. After the six weeks I felt like a new woman and went on to do a Steps to Wellbeing course at the centre, so that I could continue to feel good. The course is all about self management and centres on developing your own **"wellbeing toolbox"**. My toolbox includes things like going out with friends, going for a walk outside, meditating, and positive affirmations, to name a few. I have identified what works for me and everyone's toolbox will be different.

For me, self management is about having balance in my life and sometimes this will be more challenging than others. That's when I have to remind myself to do some of these things if I'm not already doing them.

It's been a learning curve for me and I have changed as a person. I have learned that it's not weak to ask for help and it's ok to say no sometimes.

I have done lots of other courses, including Presentation Skills. At the end of the course I gave a talk about my life as a carer to professionals and other carers – a big achievement for me as I have always struggled with public speaking. It felt fantastic to overcome that fear and gave me the confidence to join the Board of Directors at the centre, where I can use my skills, feel useful and help other carers. It helps to conquer the loneliness and boredom that many carers feel too. I have made some new friends at the centre who know what caring is all about and the staff are lovely, caring people and very supportive.

It feels good to be passionate about things again and I hope to continue to enjoy life for many years to come.

Young people

Whilst there is growing recognition within various support services that young people require specific, age related support, more needs to be done to support young people with long term conditions to self manage. Young people have to cope with the physical and emotional changes of adolescence as well as issues of managing their own condition which can mean they manage their conditions less well than their adult peers and in many cases have a higher mortality rate[34]. They require information, peer support and conversations appropriate to their needs and without this the consequences can be devastating.

There is evidence that young people with access to extended networks of social support have better outcomes in most domains. Young adult carers are now recognised as a specific group who should receive age appropriate support to self manage, with several projects in Scotland already evidencing the positive change this can achieve. There is growing momentum and desire within both health and the third sector to provide this support for young adults with various long term conditions and we must collectively build on this.

But you're too Young for Arthritis...

Arthritis Care Scotland provides a range of support and activities for anyone living with arthritis or related conditions. In the last five years they have run a project called Joint Potential which is specifically for 16-25 year olds. Due to the rarity of the condition in young people, with only around 1 in 1000 diagnosed, it is not well understood and young people can experience feelings of being different and are often bullied. This can lead to low aspirations for their future.

The Joint Potential project supports young people aged with arthritis through self management activity and personal development weekends which give participants the opportunity to meet, talk and have fun with their peers. Many young people with arthritis feel isolated and without the Joint Potential residential weekends many would not meet another young person with arthritis.

The residential weekends are run by volunteers who are themselves young people with arthritis. The weekends explore issues of living with arthritis, provide tools that help the young people manage their condition well and are centred on fun activities that challenge participants to see what they can do. The role modelling and peer support is a key aspect of the project, encouraging young people to feel more positive about their arthritis, more self-confident and with increased hopes for the future.

"Joint Potential is an enormous help to feelings of isolation and self-esteem. It helps you feel accepted and cheers you up!"

Rural Communities

People in rural communities still face specific issues and are often unable to reach peer support groups or access the internet. There is a clear need for sustainable travel investment to decrease the level of isolation people living rurally with long term conditions face[35].

There are existing projects providing vital outreach services to rural communities and ensuring the most marginalised are also in the driving seat. The investment in infrastructure must go hand-in-hand with financially supporting these vital services.

Case Study

MS Centre Mid-Argyll

MS Centre Mid-Argyll has been established for over ten years. Based in Lochgilphead, they provide an asset based approach to support people with multiple sclerosis to self manage within Argyll and Bute.

It had become clear to the organisation that there were people living on the Inner Hebrides who had no access to self management support. For many rural inhabitants, a visit to their GP can mean a lengthy journey or an overnight stay and therefore accessing peer support groups or exercise classes can be especially difficult. After a successful application, MS Argyll was awarded funding through the IMPACT Fund to employ an outreach worker to visit people with long term conditions within their community. The Outreach Worker works on a one-to-one basis and with the whole family to support self management by providing access to information, exercise therapies, health and wellbeing advice or a listening ear which would otherwise have been inaccessible.

People who use the service have described the crucial difference the project has made, not only for their self management but their overall wellbeing and it has become a fundamental part of their life. "We all live with our conditions; have similar thoughts, feels and struggles. We live in the same small village but we never got to meet up. Now we meet up, chat, have coffee and most of the time our conditions do not even get mentioned. It's just so nice being out the house and meeting up with people who understand what's going on without even saying a word".

Although grateful to be offering the outreach service, MS Centre Mid-Argyll feels that one outreach worker is not adequate to meet the needs of people in the Western Isles and the long waiting list is strong evidence of that. They state that "more funding is required to meet the needs of people in rural communities as they are quite often forgotten about".
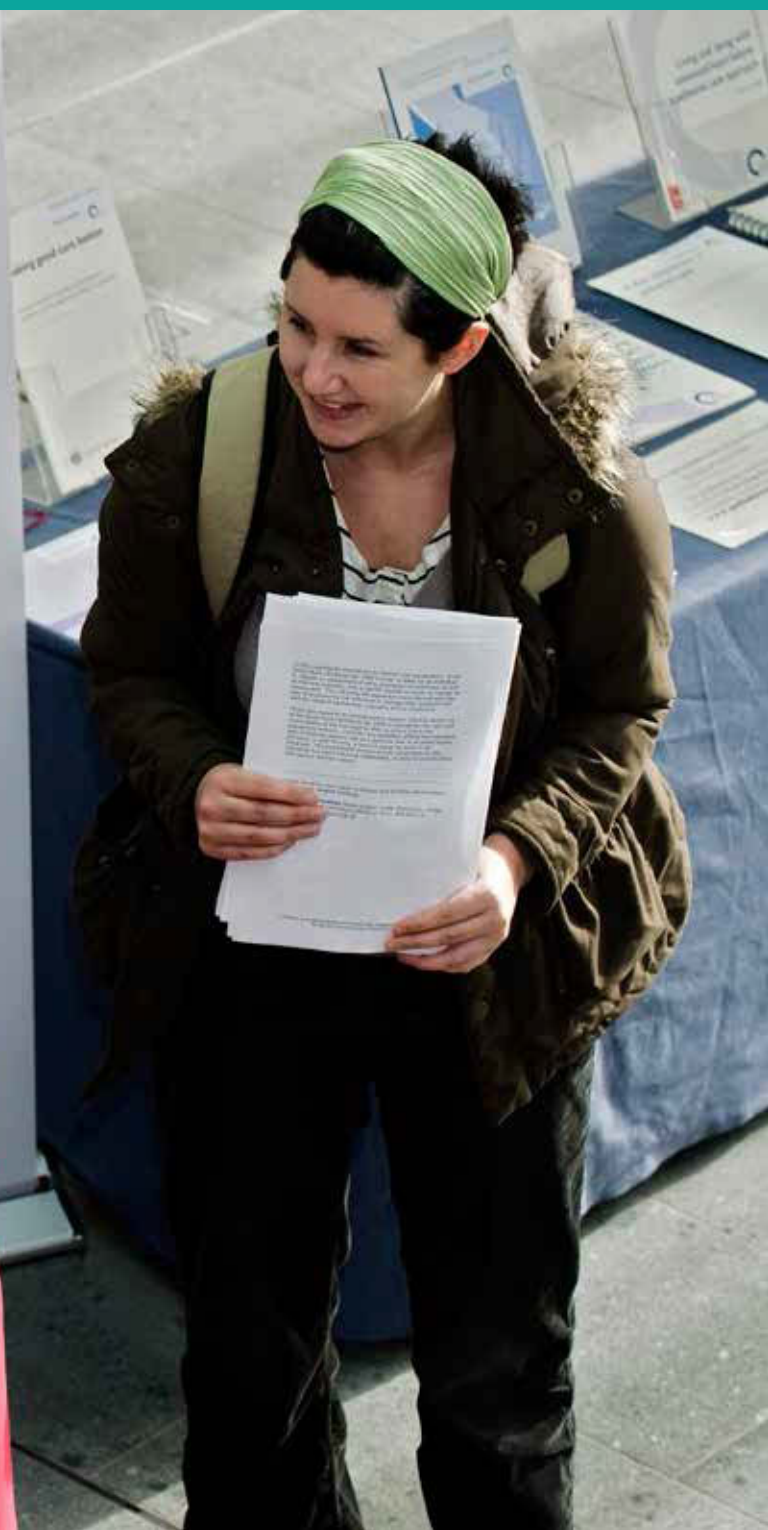
Conclusions

The evidence to support self management and its impact continues to grow. It is increasingly accepted that certain principles underpin effective self management practice; principally a collaborative relationship between the person and professional and interventions that are tailored to the person's circumstances and build their social network. It is this holistic understanding of self management which will bring about the change required and must be explicit in all self management projects and practice.

Significant progress has been made in Scotland but it is important we utilise the current policy drivers to increase our efforts and work towards embedding self management. More must be done to ensure everyone living with long term conditions and their carers are able to benefit from greater control and better personal outcomes that self management enables.

Health and social care integration, which came into force on 1 April 2015, will require health and social care services to adopt an outcome focused approach – taking into account the strengths, capacity and resilience of individuals, building upon their natural support systems and including consideration of wider community based resources in investment decisions.

It is essential that self management is at the heart of strategic commissioning plans and the investments made by health and social care partnerships and the voices of people who self manage and the organisations that support them are involved in the strategic planning process.

If people are central to its approach, integration offers a genuine opportunity to ensure there is a shift in power away from the health and social care system and towards people and communities. This will be achieved if we ensure self management is central to decisions about how services and support are planned, delivered and evaluated. Self Directed Support will complement this shift in power by ensuring people who use support and services are

able to choose how their support is provided; giving them as much ongoing control as they want.

Sustainability

The vital role of the third sector in helping to support self management and sustain this change must be central and appropriately resourced.

Evidence from a range of self management programmes highlights that sustainability must be considered from the outset. New ways of working and associated outcomes should be built into contracts, incentive systems and reward structures[36].

As referred to above, the role of the third sector in helping to support self management needs to be appropriately resourced. Yet this is not

happening sufficiently. There is a risk that some self management support funded through the IMPACT Fund and Reshaping Care for Older People Change Fund may not receive continued funding under the new integration arrangements. This is not because of the impact of the work but because it has not been considered for mainstream funding within local integration priorities.

> **National Outcome for Health and Wellbeing 1: People are able to look after and improve their own health and wellbeing and live in good health for longer.**

Self management is implicit in the National Outcomes for Health and

Wellbeing[37] but must be apparent in the indicators of quality that health and social care services are measured against. We must utilise evaluation approaches that support learning and focus on a number of measures that demonstrate impact and are meaningful to people and professionals involved.

New methods of sustainability for community projects such as crowdfunding and social enterprising should be welcomed and considered as a valid option, though this should not be at the expense of continued funding towards grass-roots projects.

As set out above, the policy drivers are in place, but we need to see a whole system approach

taken to support self management as people with long term conditions move throughout the health and social care system. It is vital that health and social care integration, and the commissioning process in particular, levers the change required.

The House of Care potentially provides a useful framework to apply this learning to the whole system and to assist health and social care partnerships systematically embed self management.

Workforce development is essential to support the change in practice and culture required. This transformation in the relationships at the heart of health and social care will require change throughout the system. There must be a substantive shift in power from the statutory sector to the third sector, to people and to communities.

Activities that are designed to help spread and sustain good practice must be given priority. Cross sector partnership working based on collaborative relationships underpins all this change and will be a factor in the success of initiatives designed to spread and sustain self management support.

To continue mobilising the social movement that has characterised self management in Scotland a cross sector network of leaders must be supported to emerge throughout the health and social care system, third sector and crucially amongst people with long term conditions and their carers where the greatest energy for these approaches is found. This will allow the sharing of learning about developing practice so that approaches can be adapted to local needs and experiences. **The frameworks are in place, now is the time to focus on action.**

Join Self Management Network Scotland today at http://smns. alliance-scotland. org.uk/ and share learning, success and good practice.

Scotland's House of Care

The House of Care framework can assist health and social care partnerships to adopt a whole systems approach to realising the ambition for self management set out in the 2020 vision. It provides a visual checklist, allocating critical activity to one of five central elements required to 'build your house' – The house is a holistic conceptual model that keeps people, their networks and the things that work in their lives at the centre of a conversation between equals about what it will take for them to have a good life. The rest of the house – the roof, walls and foundation - is there to make the collaborative centre work.

The elements set out in the house offer an integrative understanding of key topics already described in this Thinkpiece.

The Scottish Government has invested in three early adopter sites, as highlighted in the 'Many Conditions, One life' action plan. Thus far we have seen a renewed recognition from the healthcare professionals involved of the critical contribution of both individuals and their communities to sustaining health. This signifies 'a shift in power away from the health and social care system and towards people and communities'. This recognition is strategically important as we move into the world of joint strategic commissioning.

The three early adopter sites in Tayside, Lothian and Glasgow are each about to be supported with additional funding, training and evaluation from the British Heart Foundation – who are keen to see heart disease included in the 'many conditions' approach in Scotland.

More on the development of the House of Care in Scotland can be found on the **ALLIANCE** site[38] and on the House of Care blog.[39]

Acknowledgements

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ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

The **ALLIANCE** is the national third sector intermediary for a range of health and social care organisations. The **ALLIANCE** has close to 1000 members including large, national support providers as well as small, local volunteer-led groups and people who are disabled, living with long term conditions or providing unpaid care. Many NHS Boards are associate members and many health and social care professionals are Professional Associates.

The **ALLIANCE's** vision is for a Scotland where people of all ages 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, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

1 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.

2 Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.

3 Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.

Since its formation in 2006, the **ALLIANCE** has built a strong track record in helping to shape and deliver policy, particularly in relation to self management, co-production, asset-based approaches and human rights.

By harnessing the voice and capacity of people living with long term conditions and unpaid carers across Scotland, the **ALLIANCE** and its members contribute significantly to the drive for transformation in public services.

Route Map to the 2020 Vision for Health and Social Care

ALLIANCE
HEALTH AND SOCIAL CARE
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people at the centre

Quality Of Care

Person Centred Care
- Self Directed Support
- Self Management
- Personal Outcomes
- AHP Long Term Conditions and Co-production
- Dementia Carer Voices
- People Powered Health and Wellbeing
- Health and Social Care Academy
- Policy
- Involvement Network
- Human Rights

Safe and Integrated Care
- Change Fund Enhancing the Role of the Third Sector
- ALISS A Local Information System for Scotland
- Scottish Medicines Consortium Public Involvement
- Scottish Improvement Science Centre

Care for Multiple and Chronic Conditions
- My Conditions My Terms My Life
- Macmillan Lymphoedema Project
- Improving Links in Primary Care

Primary Care

Health of the Population

Health Inequalities
- Membership
- Primary Care Development Programme
- My Skills My Strengths My Right to work
- Health Literacy

Prevention
- Age Friendly Cities
- Walking Towards Better Health
- Community Chaplaincy Listening
- Reshaping Care for Older People Spirituality
- Active Ageing
- Getting it Right for Disabled Children and Young People

Early Years

Value and Financial Sustainability

Efficiency and Productivity

Workforce
- Discover the Third Sector
- Scottish Social Services Council Asset Based Workforce Development Group
- EUPATI European Patient's Academy on Theraputic Innovation

Innovation
- Living it Up
- Long Term Care Revolution
- Life Changes Trust

GET IN TOUCH

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people at the centre

The Scottish Government

POSITIVE ABOUT DISABLED PEOPLE