

Voluntary Action Scotland



Self Management Fund – Special Report Building Capacity

June 2011

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Overview and Background

'Gaun Yersel' the Self Management Strategy for Scotland¹ recognises that people living with long term conditions, and their unpaid carers, should be involved in the design, development, implementation and evaluation of the services that are intended to support them.

This became a key criteria of the Self Management Fund, and the 81 successful projects all have the lived experience of people living with long term conditions, and their unpaid carers, at their heart.

The Self Management Fund has been available to voluntary organisations and community groups throughout Scotland since March 2009. The Self Management Fund has been set-up and administered by Long Term Conditions Alliance Scotland (LTCAS).

The Self Management Fund has been made possible through funding from the Scottish Government. £4 million was available over two financial years - £2 million across 2009/10 and £2 million across 2010/2011.

The aim has been to improve work to expand the capacity of people living with long term conditions to learn more about the management of their conditions and to be become active partners in their own care.

Building Capacity

The Self Management Fund supports projects and organisations across Scotland which encourage people living with long term conditions, and their unpaid carers, to work in partnership with health and social care professionals.

This Special Report looks at how the Self Management Fund has encouraged approaches to self management which build capacity to support self management across sectors.

This report is the seventh, and final, of a series of Special Reports which highlight some of the key themes of the Interim Evaluation Report launched in October 2010². A full evaluation report will be produced at the end of the current funding period, June 2011.

¹ http://www.ltcas.org.uk/self_man_gaun.html

² http://www.ltcas.org.uk/self_basics.html

Building Capacity in context

What is capacity building?

The Scottish Government's national guidance on community capacity building³ describes it as:

'A way of working with people to develop their ability to jointly influence what happens in their community. This can involve developing confidence, skills, structures and knowledge, to increase the opportunities communities have to make a real difference to the services, activities and changes that take place in their area'

One of the outcomes set out in the National Performance Framework is

'we have strong, resilient and supportive communities where people take responsibility for their own actions and how they affect others'

Community capacity building activity supports people, particularly those who live in disadvantaged areas or are members of disadvantaged groups, to shape their own future and the future of their communities, and engage effectively with agencies to influence decisions and improve public services.

The Scottish Government defines community capacity building as:

'measures that strengthen the collective ability of a community'

Principles of Self Management

The Principles of Self Management (see appendix 1) were developed by LTCAS to encapsulate the core messages of the Self Management Strategy. The Principles provide a useful tool for underpinning any work being done to support self management.

The Principles reflect the approach people need from services and practitioners to enable them to take on the responsibility of self management.

³ http://www.scotland.gov.uk/Topics/Education/Life-Long-Learning/LearningConnections/guideccb

The Principles also form the basic criteria of the Self Management Fund for Scotland, and as such underpin each project.

Self Management Fund

The inclusion of peoples' experience in the design, development, implementation and evaluation of the 81 Self Management Fund projects has been a key to their success. Working in a personcentred way to promote self management, all the projects have used the experiences of people to inspire and encourage others to become involved.

Building capacity has been reflected in the projects in a variety of ways;

- by building understanding
- by building skills
- by building networks
- by building confidence

The 81 funded projects, and other examples of self management support across partnerships within the voluntary, health and social care sectors, have illustrated the value of maximising experience when designing and delivering services.

Voluntary Action Scotland

Voluntary Action Scotland is recognised by the Scottish Government as the key support and representative body for local Third Sector infrastructures in Scotland. VAS was established in 2009. Its vision is of a sustainable and high impact third sector delivering high quality services for the communities and people of Scotland.

VAS aims to develop, represent and support local Third Sector Interfaces and their members to ensure there is a stronger, more coherent and unified voice for local organisations, influencing policy and service planning at national, regional and local level and ensuring the sector is better recognised and respected for its key contribution to the delivery of high quality services.

VAS is a Membership organisation comprising representatives from local Interfaces in each of the 32 local authority areas in Scotland. It aims to develop and deliver programmes of support by, for and with its membership.

Third sector interfaces are being established in each local authority area in Scotland, providing local intermediary support services for the third sector. The core services are those which were traditionally delivered by the network of CsVS (Councils for Voluntary Service) and VC (Volunteer Centre) network.

The key criteria for third sector interfaces, as defined by the Scottish Government are:

- Support to voluntary organisations operating in the area, both local and those national organisations that deliver services at the local level;
- Support and development of social enterprise;
- Support to and promotion of volunteering;
- Connect between the CPP (Community Planning Partnership) and the third sector.

Healthcare Quality Strategy for NHS Scotland

The Scottish Government launched the Healthcare Quality Strategy⁴ in May 2010. The Strategy aims to make Scotland among the best in the world in terms of delivering high quality services.

The Quality Strategy sets out its core principles as being about:

- putting people at the heart of healthcare service strategy;
- building on the values of the people working in and with healthcare services; and
- making measurable improvements in the quality of care.

The Strategy identifies priorities from consultation with people using, and working in healthcare:

- Caring and compassionate staff and services
- Clear communication and explanation about conditions and treatment
- Effective collaboration between clinicians, patients and others
- A clean and safe care environment
- Continuity of care
- Clinical excellence

In response to these priorities, the Quality Strategy sets out three ambitions:

⁴ http://www.scotland.gov.uk/Publications/2010/05/10102307/0

- Person-centred Mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values and which demonstrate compassion, continuity, clear communication and shared decision-making
- Safety There will be no avoidable injury or harm to people from healthcare they receive, and an appropriate, clean and safe environment will be provided for the delivery of healthcare services at all times
- Effectiveness The most appropriate treatments, interventions, support and services will be provided at the right time to everyone who will benefit, and wasteful or harmful variation will be eradicated

Learning from the Self Management Fund

Building Understanding

'We were surprised to find that what we as an organisation felt was "self management" was completely different to what the young men felt they needed to self manage' – Dorothy Strachan

The value of building understanding can be seen directly and indirectly in the majority of projects – see **People First, SAMH and Thistle Foundation** case studies.

Some further examples of are;

- Diabetes UK Scotland are working to increase awareness of Diabetes self management among the South Asian community of Glasgow by supporting people living with diabetes and their families to be 'community champions' for self management
- **The Dystonia Society** have created a Dystonia specific self management programme
- **Strathclyde Lupus Group** are creating a series of Lupus awareness workshops aimed at student doctors led by people living with the condition themselves. The workshops will raise awareness of the condition and give people living with Lupus the opportunity to inform doctors about how they self manage
- Psoriasis Scotland Arthirtis Link Volunteers (PSALV)
 have developed a psoriasis-specific self management
 programme

Building Skills

'This project has opened up possibilities for people – in employment or volunteering and in developing their skills and confidence. The group support each other to get through their anxieties' – Kevin Fullerton, Community Development Worker

The value of building skills to demonstrate the impact of self management can be seen in a number of the projects – see **SAMH** and **Thistle Foundation** case studies.

Some further examples are;

- Glasgow West Regeneration Agency have explored the arts as a medium for the self management of long term mental health
- Drumchapel Disabled Action 2 are running a music and movement self management programme for those living with stroke, MS and Parkinson's. The course supports participants to see how they can use music technology and movement to help manage certain aspects of their condition
- **No Strings Attached** are developing and delivering a music self management programme for young people living with Asthma from a deprived area. The course teaches participants about their Asthma and how playing wind instruments can be used to help manage their condition
- Community Health Shop are running a programme which supports people to manage the negative aspects of their condition using a range of complementary therapies and appropriate exercises. Once participants have found the therapy which works best for them they will be given the opportunity to learn how to practice the therapy

Building Networks

'There are many small support groups but they often don't have the resources to advertise locally or online, however they can publicise the brilliant work they do via the hub' – Susan Webster, Action for M.E.

The value of building networks can be seen in many projects - see **People First and Thistle Foundation** case studies.

Some further examples are;

- Parents of Autistic Spectrum Disorder Adults (PASDA)
 are developing workshops focusing on management of stress
 and anxiety for those living with Autism and their families or
 carers
- **Disability Information and Support In Perth (DISIP)** are increasing the capacity of people newly diagnosed with a long term condition to access the best, and most appropriate, local information and support to support their self management
- **Asthma UK Scotland** has the strategic aim of reducing hospital admissions and improving the lives of young people

with Asthma. It is working with partners to achieve this aim by developing a programme of Asthma management and awareness raising sessions in nursery, primary and secondary schools throughout Scotland

 IntoWork West Lothian have delivered a self management programme for people living with mental health conditions in West Lothian

Building Confidence

'I'm a lot more confident than before, I feel I am able to reach my goals and I know I am ready to start looking for work' – IntoWork West Lothian course participant

The value of building confidence can be seen in many projects – see **SAMH and People First** case studies.

Some further examples are;

- Headway Glasgow have developed a self management programme for people living with Acquired Brain Injury (ABI). It is also running awareness raising workshops aimed at healthcare professionals. The organisation has worked with people affected by ABI to create the courses and plans to train interested participants as course facilitators so that the project will be sustainable
- RNIB are supporting young blind and partially sighted people to educate their sighted peers about sight loss and to distribute a toolkit to youth work organisations
- Moray Carers are developing a series of Digital Stories to improve the capacity and well being of unpaid carers supporting people living with long term conditions
- The Haven have been running a Lymphoedema Self
 Management programme. Participants will be taught to pass
 on the skills they learn and some will be recruited to cofacilitate part of the course

More details of all the improvement tools used by the funded projects, and the results they produce, will be available in the Final Evaluation Report for this allocation of the Self Management Fund after June 2011.

Conclusions

The Self Management Fund for Scotland has enabled projects to incorporate the experience of people living with long term conditions and those that care for them, throughout all aspects of their projects. The Fund is capturing the learning from these experiences in relation to building capacity, and has so far shown the impact of;

- Building understanding
- Building skills
- Building networks
- Building confidence

Projects supporting capacity building are as varied and diverse as the range of projects supported by the fund in general. Projects are developing new ways to support people living with long term conditions, and encouraging people to think differently about self management.

LTCAS will continue to work with partners, including Voluntary Action Scotland, the Scottish Government, and the NHS to promote and develop self management support for people living with long term conditions.

For further information about LTCAS - our work and our membership - the Self Management Projects and the continued development of the Self Management Fund for Scotland, please see our website www.ltcas.org.uk

For further information about the Voluntary Action Scotland please visit www.voluntaryactionscotland.org.uk

Case Studies



The following Case Studies illustrate the impact, emerging themes and learning points from the Self Management Fund in relation to building capacity.

- o SAMH
 - Aberdeen Foyer
 - Street Soccer
 - Branching Out
 - Ayr United Football Academy
- People First
- Thistle Foundation

The Case Studies also demonstrate the impact that LTCAS has had on shaping, expanding and sustaining these themes.

SAMH





Positive Steps for Mental Health

Get Active members, SAMH

Scottish Association for Mental Health (SAMH) are Scotland's leading mental health charity, dedicated to providing help, information and support; to campaign on behalf of people with mental health problems and to raise money to fund their vital work.

The Scottish Association for Mental Health (SAMH) is Scotland's leading Mental Health Charity, which provides a range of mental health services across Scotland. In 2010 SAMH secured funding from the Long Term Conditions Alliance Scotland (LTCAS) to run four pilot projects as part of the Get Active National Programme, on the mental health and wellbeing benefits of physical activity and sport.

The link between physical activity and physical health has long been known, but the link between physical activity and mental health has been less explored, until now.

'We want to ensure that everyone, regardless of where they live, their age or income, is aware of ways to improve their mental health by participating in physical activity and sport' - SAMH

'Get Active' is a 5 year national programme with a community engagement programme at the heart of achieving our goal. For years Scotland has hit the headlines for all the wrong reasons such as high levels of anti-depressant prescribing, poor health, high mortality and appalling diets.

'It's time for us to turn the tide and become recognised as a nation that takes pride in our physical and mental health' - SAMH

The four community engagement projects which are part of the SAMH project not only show the positive impact sport and physical activity can have on people who have long term conditions but demonstrate the transformation that occurs in people's lives when you create opportunities that focuses on their strengths

'It's what they can do, not what they can't'

When you create the right approach, work in partnership with a common goal, the outcomes become evident for individuals; from homelessness to securing a home; from living chaotic lives to stability; from unemployment to employment; from not seeing a future to coaching young kids, securing a university place, to reclaiming your life back.

'The support of LTCAS has been central to the success of the four community engagement projects. They recognised the value on what we aimed to do and also recognised the real potential for people to better manage their long term mental health problem as a direct result of participating with the community engagement project' - SAMH

The results are excellent; there are real improvements in how individuals self manage and in their quality of life. Get Active delivers, the success of the four projects is testimony and we should all be considering how we progress this valuable work so that others can also experience the positive impact of getting active

The four Get Active projects are showcased in the following case studies;

- Get Active Aberdeen Foyer
- Get Active Street Soccer
- Get Active Branching Out
- Get Active Ayr United Football Academy

For more information please visit <u>www.samh.org.uk</u>

Get Active - Aberdeen Foyer







Activities at Aberdeen Foyer

Aberdeen Foyer is a successful local charitable organisation working to prevent and alleviate youth homelessness and unemployment.

As part of their range of projects, Aberdeen Foyer offers access to health and wellbeing assessments for people who access Aberdeen Foyer projects and accommodation. The health and wellbeing assessments are one-to-one brief interventions where people can talk about their health and lifestyle and any concerns they may have. They can receive advice and information based on how they would like to address these concerns or put them on a pathway to positive behaviour change.

The focus of the intervention is choice and so if someone is not ready to address a particular issue, Aberdeen Foyer wouldn't push them. They would instead provide them with more information on the topic and make them aware of organisations or interventions where they could get support if they decide to make changes in the future.

'I think we're really fortunate in Aberdeen Foyer because we have a health team, we have a support network there for people to tie into other programmes' - Aberdeen Foyer, project lead

The health and wellbeing assessments gave Aberdeen Foyer the idea for the Get Active pilot project which took the same one-to-one approach but focused on physical activity. The assessments looked at where someone currently was regarding physical activity and if they were active at all, and whether there were any changes to their level activity they would like to make. The consultation also looked at whether the individual was experiencing any barriers to becoming more physically active e.g. cost, knowledge of activities available, weight, medication.

For more information please visit www.aberdeenfoyer.com

Get Active - Street Soccer





Positive change through football



Street Soccer was set up in 2009 as a social enterprise with the aim to engage with socially disadvantaged adults and young people through the power of football.

Street Soccer in action

Street Soccer was developed to help engage people through football and use it as a tool to help them make positive changes to their lives.

'Seven, eight, nine months ago I wouldn't have been confident, but coming here. For me, I think I built up a lot more confidence from what I was the first session I went to' - Street Soccer participant

Seeing how football can have a positive effect on people's lives whether it be homeless, rehabilitation, mental health, and there wasn't enough...there was all these guys and not being able to access regular training, regular football, so I think the main reason for Street Soccer being set up was to encourage more guys to get into football to try and provide regular access to football session and to spread it out, right across Scotland

'All our good work is done on promoting, building confidence, building communications on the pitch, giving people encouragement, making you feel part of a team...this is all the stuff that builds them up and it increases their mental health' - Street Soccer, project lead

Street Soccer saw Get Active as an opportunity to share learning with SAMH and develop a strong partnership.

For more information please visit <u>www.streetsoccerscotland.org</u>

Get Active - Branching Out





Branching Out was set up by the Forestry Commission in 2007 to engage people experiencing mental health problems in woodland activities.

Branching Out aims to give people a chance to either get back into the outdoors if they hadn't been outdoors for a while, or introduce people to the outdoors if they'd never experienced woodlands before, to increase physical activity, develop team working and improve mental wellbeing.

'Achieving different things that people think that they can't do... I think that gives people a big boost that they can do something' - Branching Out, project lead

Branching Out look to try and get more people taking part in woodland-based activities. People with mental health issues are less likely to go into the woodlands, so that's a client group in general that they'd like to engage with. They've also get a health strategy which tries to promote use of the outdoors, and the woodlands in particular, to be more physically active, and for mental wellbeing as well. So it's really all three; mental, physical health and use of woodlands. And also, I suppose just knowledge and understanding of sort of conservation issues and, you know, not dropping litter and looking after the environment as well

We find that the groups really bond over time, they help each other' - Branching Out, project lead

The ways in which Branching Out aim to improve mental health and wellbeing are multiple. For example, by building confidence and self-esteem in participants as they learn new skills and gain a sense of achievement in what they can do.

For more information please visit www.forestry.gov.uk/branchingout

Get Active - Ayr United Football Academy





Ayr United Football Academy work in partnership to develop sport, health and education for people as a community contribution to the aims of their partners and in the long-term interest of people of all ages.

The aim of the pilot project for participants was threefold: to increase physical activity and thus fitness; improve individual's football techniques; and improve the mental health and wellbeing of participants.

To measure whether participants had become fitter as a result of taking part in the project, Ayr United ran a fitness test at the beginning and at the end of the programme. Improved football skills were measured through observation by the coaching team. Finally, improved mental health and wellbeing of participants was mainly assessed by the observation of the coaching team focused on any changes in behaviour and attitude.

'Their communication skills improve...from the first week and then leading up to the second last week, they would come and talk to you rather than you having to go talk to them' - Ayr United, project lead

Ayr United reported that although the project was short, it was successful in achieving its outcomes. The coaching team observed lots of positive mental health and wellbeing outcomes in participants, including increased confidence and self-esteem which was illustrated in the changes in how participants communicated with the coaching team and each other.

For more information please visit www.aufa.org.uk

People First





People First (Scotland) started in 1989. It is the independent self-advocacy organisation in Scotland. People First (Scotland) are run by and for people with learning difficulties. They aim to change individual and collective attitudes, policies and the law relating to learning difficulties.

Members of People First (Scotland)

People First set out to map views and opinions about the most pressing areas for change in the lives of people with learning disabilities. Their project aimed to prioritise issues and targets for lobbying and influence as well as looking at ways to involve members in the widest way possible.

'I hope people listen to what we have to say. We should get the same rights as other people' – People First member

Members of People First aimed to write up the research on the methods used to increase the effectiveness of support to members with learning disabilities and to publish this. They also wanted to look at ways of demonstrating and explaining the processes involved and the thinking behind the processes, making these available to other organisations who support people with learning disabilities. In addition the members planned a Citizens' Grand Jury, where political figures and the most senior policy makers were 'summoned' and questioned publicly about their policies and implementation.

The Citizen's Grand Jury has produced a report of the event with recommendations for the future.

People First found that engaging with debates, and managing to understand complex issues increased people's confidence. This reinforced that people can have a grasp of difficult subjects, and can form an opinion that is valid and they can expect will be taken seriously. People First found this to be especially important in the context of independent (self-determining) living and to the idea of co-production.

'And one of the things and I've really learnt and I hadn't really encountered this situation much in my life before is that on the whole, the laws in this country are skewed against the community of people with learning difficulties' – Richard Holloway, Grand Jury Questioner

Again, People First were able to demonstrate that being faced with a challenge, and having the opportunity to overcome that challenge, increases people's confidence and builds resilience, which are essential components of the capacity for self-management.

'I'm going to make sure we have a conference in my area. It's important to speak up' - People First member

People First have found it both rewarding and challenging to engage with LTCAS and the Self-Management Fund. They supported one of our senior members on the LTCAS Board for a time and contributed to and participated in most of the invitations received from LTCAS.

People First's capacity to respond to more invitations from Government and other systems has been greatly enhanced by LTCAS funding during the funding period with an enhanced staff complement.

'The motions we passed should get sent to the government now' – People First member

However without the funding People First will have to refuse invitations due to staff capacity, even though members continue to be interested and willing.

This does create a tension in the organisation and their members who have had raised expectations about support to be involved in a range of activities.

For more information please visit www.peoplefirstscotland.org

Thistle Foundation





Thistle Foundation is a boundary-pushing, pioneering charity supporting people with disabilities and long term health conditions. They support people to lead great lives where they are in control

Thistle Foundation Course Particpants

Central to the Thistle approach is its insistence that alongside optimal medical care, people, with the right support, can become empowered to actively live their life well, living with a Long Term Condition. This 'right support' is generic - people can benefit from similar support regardless of their medical conditions and that a generic service design and set of competencies required to deliver this approach can be easily integrated into all sectors and levels of care.

'I'll have a clearer picture of what clients want to achieve and how to achieve it by drawing on their past strengths and coping mechanisms' – health professional

Thistle aimed to support the development of an inter-disciplinary, cross-sector learning community with identified leaders in health and social care professions who would actively cascade their learning within and beyond their areas of work.

'Practitioners are learning more effective, empowering ways of interacting with people so that individuals are more aware of and motivated to use existing resources to move toward the outcomes they want in their lives' – Ross Grieve, Thistle Foundation

Thistle identified 11 professional Change Champions who were actively cascading their learning and influence. By supporting the development of cross sector networks and learning communities, there are indications that practitioners are now sharing good practice including practical changes to service design.

The 'ripple' effect was noted at increasingly higher levels of management which has resulted in formal requests for further training of the workforce.

'When we orientate to what the person wants, then regardless of the health profession or agency we belong to, we're essentially doing the same thing' – health professional

This project demonstrates that a generic approach to supporting practitioners to work in a person-centred way to support the adoption of self-management strategies can be effective across sectors and across a wide range of client groups.

Thistle have demonstrated that considerable change is possible with modest inputs: even two days of training can be enough to provoke changes in practice, and further training results in improved confidence and openness to supporting others to change independently.

'We anticipate more change champions will emerge and look forward to supporting a community of practice' – Ross Grieve, Thistle Foundation

Thistle would like to continue to develop their leadership in the field of supported self management. To achieve this they intend to maintain an integration between their training service and lifestyle management service delivery.

This will ensure that as trainers, they stay active as practitioners and have the opportunity to offer learning experiences to other practitioners, be able to continue to deliver training and flexible support to interested partners and practitioners, including the delivery of more advanced training. They will also continue developing their web-learning resource.

For more information please visit www.thistle.org.uk

Appendix 1

Principles of Self Management

July 2008

Principles: Self Management Health, Social and Voluntary Sectors

"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 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.



"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. "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.

"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.

Appendix 2

Useful Links

Long Term Conditions Alliance Scotland

www.ltcas.org.uk

Gaun Yersel – the Self Management Strategy for Long Term Conditions in Scotland

www.ltcas.org.uk/self man gaun.html

Voluntary Action Scotland

www.voluntaryactionscotland.org.uk

NHS Scotland Quality Strategy

www.scotland.gov.uk/Topics/Health/NHS-Scotland/NHSQuality

Long Term Conditions Action Plan

http://www.sehd.scot.nhs.uk/mels/CEL2009_23.pdf

Long Term Conditions Community

www.knowledge.scot.nhs.uk/ltc.aspx