



**Self Management Fund – Special
Report -
Communities and Community
Assets
March 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 become active partners in their own care.

Communities and Community Assets

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 positive approaches to self management across Scotland involving local communities and groups, building on the strengths they can bring and share with each other.

This report is the fourth 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

Community Assets in context

What is an Assets Approach?

"A health asset is any factor or resource which enhances the ability of individuals, communities and populations to maintain and sustain health and well-being. These assets can operate at the level of the individual, family or community as protective and promoting factors to buffer against life's stresses." Anthony Morgan, 2009

The emphasis in an Assets Approach to Community Development is on building on the **positive** aspects of communities instead of concentrating on the **negatives**, and on supporting individuals and communities to have more control over their own circumstances.

In these respects this model is similar to the approach taken by those who work in community development who also seek to identify and build on the strengths of communities. Community development invests in disadvantaged communities so that local people can participate in building and developing community resources. Community development will help communities develop local solutions for local issues.

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.

The fourth Principle is;

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

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 people's and communities 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 person-centred way to promote self management, all the projects have used the experiences of people to inspire and encourage others to become involved.

Communities and Community Assets have been reflected in the projects in a variety of ways;

- by involving peers in delivery and support
- by encouraging people and communities to share information
- by encouraging new networks and supports
- by working in partnership with other services

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.

Scottish Community Development Centre

The Scottish Community Development Centre (SCDC) is the national lead body for community development and has a track record of nineteen years of activity.

SCDC's vision is for an active, inclusive and just Scotland where our communities are strong, equitable and sustainable.

SCDC's mission is supporting best practice in community development. SCDC's three key priorities for achieving its mission are to;

- Work directly with communities to build skills, organisation, involvement and equalities
- Work with people who work in communities at practitioner level to build skills, and at a partnership level to support strategic community development approaches
- Through direct experience working with communities and practitioners, seek to influence policy in favour of community development approaches to achieving positive outcomes for all

SCDC's role in supporting best practice in community development operates at four levels:

- with policy makers who set the conditions within which community development is practiced
- with public bodies and partnerships whose work is informed by community development principles
- with dedicated community development agencies and their staff in the voluntary and statutory sector
- directly with community groups and organisations

At all these levels, SCDC promotes the core principles and values of community development.

Assets Alliance

On Monday 13 December 2010, the Scottish Government, in partnership with Scottish Community Development Centre (SCDC) and Long Term Conditions Alliance Scotland (LTCAS), held an event designed to take forward an Assets Alliance in Scotland.

Initiated and supported by the Chief Medical Officer for Scotland, Dr Harry Burns, the event brought together people already using asset based approaches with key influencers from across the public and community and voluntary sectors. The event recognised that assets approaches are not new and that many initiatives in Scotland already demonstrate this way of working.

Working at a local level is at the heart of the assets approach, but support may also be needed at a national level to ensure that the approach is embedded as part of mainstream practice. The purpose of the event held on 13 December was to find out from key stakeholders what form an Assets Alliance should take and what its key functions should be, and this next stage is currently in development with stakeholders who attended the event.

A report³ of the event describes the background context for the formation of an assets alliance in Scotland. It summarises the dialogue which took place at the event and outlines a set of key action points for progress. This report constitutes the first step in cross sector engagement on the formation of the initiative. More information will be made available through national networks as an Assets Alliance develops.

³ Available here

<http://www.ltcas.org.uk/documents/AssetsAllianceScotlandEvent13Dec2010Reportpdf.pdf>

Learning from the Self Management Fund

Peer Support

'Within minutes of realising that the people in the room were in the same position as I was the nerves lessened'
– IntoWork West Lothian course participant

The value of peer led support, education and awareness raising can be seen directly and indirectly in the majority of projects. Although 14% of current projects are involved in formal direct peer support to encourage self management through sharing experiences, many others are reporting on the benefits of peer support informally in their programmes – see **Hearing Concern, Comas and Post Natal Depression Support Network** case studies.

Some further examples of are;

- **Moray Carers** – who are developing a series of Digital Stories to improve the capacity and well being of unpaid carers supporting people living with long term conditions
- **Pink Ladies** have developed peer-led self management programmes for women living with anxiety and depression. The group has run two successful courses and has had an overwhelming response for courses which are due to run later this year
- **Crichton Hale and Hearty** have created an exercise peer support group for those living with heart failure, their families and carers. This has built on a successful local model of support which exists for those living with coronary heart disease and create a sustainable group, run by those living with the long term conditions.

Information

'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 sharing information to encourage others to become involved in self management, to raise awareness of conditions and approaches and to increase understanding of the impact of self management can be seen in a number of the projects – see

Hearing Link, Comas and Post Natal Depression Support Network case studies.

Some further examples are;

- **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
- **Clydeside Action on Asbestos** are developing support groups in Aberdeen and Ayrshire, working with people living with asbestos related conditions to create and run self management peer support programmes
- **Target Ovarian Cancer** are running a series of road shows aimed at providing self management advice, information and support to women who have had hospital treatment and are now learning to live with their condition

Networks

'It's been a great opportunity to network and link with other people and organisations – we've been able to achieve so much more as a result' – Karina Williams, Parents of Autistic Spectrum Disorder Adults (PASDA)

The value of capitalising on the personal, lived experience of people living with long term conditions, and their unpaid carers, as the starting point for developing new networks can be seen in many projects - see **Hearing Link, Comas and Post Natal Depression Support Network** case studies.

Some further examples are;

- **Promoting A More Inclusive Society (PAMIS)** – who are working closely with education, social work and health professionals to bridge the transitions gap between Childrens and Families services to Adult services for people living with profound and multiple learning disabilities
- **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

- **Tagsa Uibhist** have employed an outreach worker to provide self management information, support and advice to those living with mental health conditions in the western Isles.

Partnership working

'The project has allowed us to significantly increase our presence and profile in West Lothian. We have built up new contacts and volunteers, and identified new areas of work' – Catherine Thomas, Alzheimer Scotland

Many projects are working in partnership to develop, implement and evaluate their projects – see **Comas and Post Natal Depression Support Network** case studies.

Some further examples are;

- **British Lung Foundation** have expanded their programme of pulmonary rehabilitation by establishing remote rehabilitation services using telehealth technology in geographically isolated areas of Scotland in partnership with NHS Boards and the Scottish Centre for Telehealth
- **Angus Cardiac Group** together with the Angus Community Health Partnership have developed their existing exercise programme to other long term conditions and has developed a programme of lighter exercise for those who are not physically able to manage the current programme
- **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

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, their communities and those that care for them, throughout all aspects of their projects. The Fund is capturing the learning from these experiences, and has so far been able to show the value of communities and community based assets by;

- involving peers in delivery and support
- encouraging people to share information about their conditions
- encouraging people to develop new networks and support
- working in partnership

LTCAS will continue to work with partners, including the Scottish Community Development Centre and the Assets Alliance to promote and develop community, asset based approaches to self management support for people living with long term conditions 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

Case Studies



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

- Hearing Link
- COMAS
- Post Natal Depression Support Network

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

Hearing Link



Hearing Link provide support and information for people living with a hearing loss and their families. Hearing Link aim to increase awareness and understanding about hearing loss and it's impact on life, to inform, enable and empower people to manage their hearing loss with appropriate services.

Linda Sharkey, Scotland Manager, Hearing Link

Hearing Link had an established track record in delivering some self management sessions for people living with a hearing loss, but they were finding it more and more difficult to find support to develop this and roll it out further. Hearing Link applied to the Self Management Fund and were delighted to be awarded £78949 to develop their capacity to deliver self management programmes across Scotland.

'As a funder, LTCAS 'get it' – they recognise that there are a wide range of long term conditions, not just physical – Linda Sharkey, Scotland Manager

In addition to being able to develop their self management sessions, Hearing Link have benefitted from other opportunities LTCAS were able to offer. They found the training programme provided free to funded projects from Evaluation Support Scotland invaluable. This has ensured that their own evaluation and resources are robust and appropriate, and that they are well connected with other organisations providing self management support.

Being part of the evaluation support sessions confirmed that they were on the right track, but enabled them to look more carefully at their supporting information and the positive value of being able to tell their story more effectively.

Hearing Link found that despite being well networked with other organisations supporting deaf people, those organisations were not involved in self management. Working with other organisations involved in providing self management support has enabled them to learn from others and share their experiences, as well as having a wider feel for what is happening generally. They have also been able to take the opportunity to discuss deaf issues with other organisations to raise awareness.

'We really feel 'plugged in' and connected to the bigger arena now' – Linda Sharkey, Scotland Manager

Hearing Link have also been involved in some LTCAS events around Scotland, which has given them the opportunity to consolidate and share their learning from the delivery of the self management programme. Events like these have enabled Hearing Link to involve people living with long term conditions in showcasing the benefits they have received from attending a self management programme. This has helped Hearing Link to learn more about how to support people to best 'tell their stories'.

'My circumstances may change, but my condition remains – the self management programme gives me coping strategies that I can adapt as my life changes – course participant

Hearing Link would like to build upon their success with their self management programme, specifically targeted for people living with hearing loss. They know that people benefit greatly from the support. Although many people stay in touch to support each other after a course ends, they know that by nature long term conditions are on-going, and support should be available at different stages of life.

'We feel there needs to be shift in approach and support which reflects this, which as a voluntary sector organisation we are well placed to provide' – Linda Sharkey, Scotland Manager

For more information please visit www.hearinglink.org

COMAS



Comas is a community development organisation working to promote recovery and resilience amongst individuals, helping them to create community connections.

Volunteers with the Serenity Café, Comas

Comas began working with people recovering from addiction and learned from them that there was limited support for them to look at their whole life, beyond their addiction. Existing addiction treatment programmes, once completed, could only provide limited ongoing support. Comas knew that many people who encountered a problem after a treatment programme returned to their substance misuse as a way of coping because they lacked the tools to cope in other ways.

'Recovery is life long, not something that ends when the treatment ends' – Ruth Campbell, Chief Officer, Comas

Comas was not initially familiar with the term 'self management', but soon realised the links between this and the work they were doing on recovery. Comas was relieved that LTCAS saw addiction as a long term condition, as this allowed the opportunity to look at recovery holistically, rather than in isolation from the rest of life – many health services look at one small aspect of a condition, not the bigger picture. Comas applied to the Self Management Fund to support the development of their peer support initiative within their Serenity Café project in Edinburgh.

The Serenity Café is a co-produced project, people in recovery lead the project and Comas facilitates their learning and development. They have been able to offer peer support through life coaching,

developing a unique course called 'Recovery Coaching' with the help of the Self Management Grant. Recovery coaches are people in recovery, and their training as coaches is person-centred, based on learning from each other. The course has been adapted to respond to people's individual learning styles and their stage of recovery.

The Recovery Coaching model is based on the learning from people in recovery that people want to find ways to occupy their time and think positively about the future, as well as learning to manage their addiction.

'Life can look big and daunting to people – addictive patterns of behaviour gnaw away at the back of people's minds' – Ruth Campbell

The Serenity Café has supported people on the Recovery Coaching course to learn about emotional intelligence and brain recovery, encouraging people to understand how the brain can build pathways to support positive new behaviours. This provides people with a context and an explanation for certain behaviours. Participants learn about themselves in a safe environment, as well as learning skills in coaching others. Being coached by a Recovery Coach helps people to clarify their goals and plan the steps that they can take towards their goals.

'Many people regard recovery from addiction as an event rather than something that needs on-going self management – we were really pleased that LTCAS understood' – Ruth Campbell

Comas and the Serenity Café are accessible to the community they support, it is free to attend and no referral is required. The benefits of the project are multiplying – Recovery Coaches are adding to the capacity of the community to help each other, and people coming forward for coaching are able to access support. This is often during the hours that other services are closed, because this support is now available from within the community.

Comas has found that the strongest promotional tool is people in recovery themselves, spreading the news about the Serenity Café widely and positively throughout the recovery community. Comas would like to develop their Recovery Coaching programme nationally with other local communities, training peer coaches and continuing to provide recovery courses

For more information please visit www.comas.org.uk and www.serenitycafe.org.uk

Post Natal Depression Support Network



PND Support Network provide a 24 hour Virtual Support Network. PND support people to identify individual needs, explore and develop individual coping strategies/ self help tools, leading to self management of their post natal depression.

Karen Nicoll, Project Co-ordinator, Post Natal Depression Support Network

Before the PND Support Network was established, there was very little specific help that women could access. Services that were around were closing, partly as result of the geography of the area and the difficulties women faced in accessing public transport to get to these services. Aberdeenshire CVS knew that because of the size and rurality of the area they covered, it was important to enable women to help themselves without relying on services that they might not be able to access. Talking to women they realised that self management could be effective in supporting women to recognise trigger and crisis points, and also equipping women with the tools to manage these themselves.

'I found the hardest time to cope was actually when I felt I was beginning to recover and all the normal forms of support were pulling back and gradually being withdrawn' – PND Support Network participant

They focused on the main barriers that women themselves identified - which were isolation, location of services, time to attend and the associated costs – to provide flexible solutions. Women were able to access one-to-one time with a support worker, and

also to access an on-line resource and forum to share information and support at times that suited them.

The PND Support Network benefits women themselves, and also healthcare professionals and others who support women with post natal depression. The network have seen an increase in people's mental health and wellbeing resulting in increased attendance at appointments as confidence levels rise. At the same time, there has been a reduction in appointments overall, and the length of time that professionals have spent with women as they develop their own individual coping strategies.

'In the longer term, by helping women to progress beyond individual crisis points, there is less chance that they will deteriorate to the point where more medical intervention is required' – healthcare professional

The benefits filter into every aspect of the women's lives, including work and family. The Network encourages women to find the information and support that they need rather than feeling like decisions are being made for them. They support women to feel less isolated and to realise that what they are feeling is 'normal' for someone living with this condition. Realising that despite their geographical isolation they are not alone is crucial to support the management of their condition.

'Before this support, I felt a huge sense of insecurity and mistrust in my own ability to make decisions rationally and look objectively at problems' – PND Support Network participant

The work of the PND Support Network has led to an increase of general health and wellbeing of local residents, and an increase in social activity within communities. Women they support are now using more community groups and facilities locally, which is helping to reduce social isolation.

'We made sure we were offering a service which enables rather than takes over, offering support to deal with problems and issues rather than "taking them away" for women' – Karen Nicoll

The PND Support Network would like to expand into other geographical communities, as well as looking at other developments such as a volunteer led buddy system.

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

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 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.

"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.

"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.

Scottish Community Development Centre

The Scottish Community Development Centre (SCDC) provides training and consultancy support in all aspects of community development. SCDC provide support to all organisations and partnerships that work in and with communities. SCDC works across sectors, with a wide range of professions to support community engagement and community capacity building in any context. SCDC work at strategic and practice level. All of SCDC's services are tailored to meet the individual needs of the organisations and partnerships they support.

Working across Scotland

SCDC works across Scotland on a range of programmes and training and consultancy work. Past and current programmes relate to each of the key areas of SCDC work: community capacity building, community-led health, community engagement, planning and evaluation, community research, and policy and practice.

SCDC has a wide and developing portfolio of activities reflecting major priorities for community development. It promotes:

- Community led health improvement through CHEX (Community Health Exchange)
- Effective community involvement through the National Standards for Community Engagement and VOiCE
- Participatory, outcome focused evaluation through LEAP (Learning, Evaluation and Planning)
- Community led research
- Community led environmental improvement
- Knowledge, skills development and learning exchange through training and consultancy services

SCDC also works in Northern Ireland, England and Wales and internationally. SCDC is part of a Four Nations and Europe group, which meets on a regular basis to exchange practice and policy developments and has a long association with the Central European Bureau for Social Development. SCDC is a founding member of Community Development Alliance Scotland (CDAS).

(see www.scdc.org.uk for more details)

Appendix 3

SCDC Case Study – Healthy Valleys Initiative

Healthy Valleys is a community-led Healthy Living Centre covering the area of rural South Lanarkshire. It is governed by a Board of local voluntary directors, including five people who were part of the original steering group who successfully bid for the lottery money to establish the organisation. The Board also includes advisors from NHS Lanarkshire and South Lanarkshire Council.

Healthy Valleys' initial task was to identify the issues of importance to local people. They used existing links within the communities, adopting highly participative consultation processes. These confirmed that local issues included:

- high levels of unemployment
- lack of adequate child care provision
- poor access to healthy affordable food
- poor transport links

In response to the needs that were identified, Healthy Valleys provides a range of services and activities including

- managing stress programmes
- sexual health and information services for young people
- physical activity sessions
- mental health and emotional well being support programmes (targeting those with addictions, post natal depression and other long term conditions).
- a wide range of community food initiatives
- a volunteer and community development programme

There is a prevailing climate of strong local attachment in some villages which has to be taken into account in all aspects of Healthy Valleys' delivery. This is in part driven by the poor transport links. Healthy Valleys refers to having a 'Hub and Spoke' model for their organisation but the 'spokes' are seen as the most essential part of what is delivered. Activities are provided as close to home as is possible, or transport is provided. Healthy Valleys routinely provide child care to allow people to participate.

Great value is placed on the role of volunteers within the organisation and they contribute to the work at every level. 'Volunteer recognition and development days' generate feedback and new ideas so that activities can be continuously improved. The

personal development process which volunteers undergo means that there is a constant process of recruiting and training going on as new people take advantage of the opportunities offered, and having stayed for a while move on to either further education, training or employment.

Local volunteers contribute to many of the essential tasks in both the delivery and planning of work. This has increased response rates and extended the reach of consultations into parts of the community that might have been missed by an outside agency. As a result new activities are well founded and based on locally credible evidence.

Volunteers are trained in Participatory Appraisal. This is an effective way of gaining local information. It also encourages continued participation: people who initially come to provide their views, stay to be become involved in achieving change.

Healthy Valleys' way of working ensures that people not only receive advice and information but are encouraged to take control of local initiatives. They gain confidence, self esteem, and general well being through the development of new skills. The community gains new services and a sense of increased control. One initiative - the food markets - is now under the full control of a newly formed community organisation.

Healthy Valleys is exploring the potential to develop a social enterprise model for some activities, which would support greater sustainability of its work by reducing its high level of grant dependency.

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For more Case Studies from SCDC's Meeting the Shared Challenge Programme please visit www.scdc.org.uk/media/resources/what-we-do/mtsc/Making%20it%20Happen.pdf

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

Scottish Community Development Centre

www.scdc.org.uk

Assets Alliance Scotland

www.scdc.org.uk/assets-alliance-scotland/

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