



Self Management Development Fund

Focus on DEVELOPMENT

September 2012

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Foreword – Fiona Garven

It is my pleasure to endorse the work of LTCAS and the Self Management Fund. As this report shows, the projects supported through the Development Fund contribute directly to both community development and community empowerment more widely.

Collectively, the funded projects support our own mission priorities at SCDC, which 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**
- **Influence policy in favour of community development approaches to achieving positive outcomes for all, through bringing our direct experience in working with communities and practitioners to bear**

The Principles of Self Management (Appendix 1), which underpin the Self Management Fund, are inspiring. They recognise the strengths and capacities that lie within individuals, groups and communities and they support collective action on behalf of organisations and groups to support the achievement of positive outcomes. The principles on which the Self Management Fund is based are brought to life by the projects it supports, all of which show creativity, compassion, and, most importantly, a commitment to being community led.

We look forward to seeing how these projects, and future projects, develop further and enhance the strong links between the work of LTCAS and SCDC to progress the community development and community empowerment agenda in Scotland.

Fiona Garven, Director Scottish Community Development Centre



The Scottish Community Development Centre (SCDC) is the national lead body for community development.

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

Overview and Background

The Self Management Fund has been available to Third Sector organisations and community groups throughout Scotland since March 2009. 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.

The Third Sector has an excellent track record in supporting communities, and the Self Management Fund builds upon this. In challenging times, economically and socially, this has never been more important.

The Self Management Fund aimed to support projects and organisations which maximise the experience of people living with long term conditions, and their unpaid carers, to work in partnership with health and social care professionals.

The funded projects are key demonstrators supporting the NHS Scotland Quality Strategy ambition to encourage mutually beneficial partnerships.

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

The Self Management Fund has been set-up and administered by Long Term Conditions Alliance Scotland (LTCAS). The process has been supported and managed by the Director of Development and Improvement and one Grants Development Officer, with additional support from the Finance and Admin team. An independent Grant Allocation Panel was formed to assess the applications.

The initial allocation of the Self Management Fund for Scotland supported 81 diverse projects throughout the country with £4million over the past two financial years.

Self Management Development Fund

The Self Management Development Fund has been made possible through funding from the Scottish Government. £1.76 million was available over 12 months within 2011-12.



The Self Management Development Fund aimed to capitalise on the sharing and learning that the Self Management Fund had so far produced, asking existing projects should apply to **develop** their project, and work towards **sustainability**, with a particular emphasis on **partnership working**.

Projects funded in the initial allocation of the Self Management Fund were invited to apply, clearly showing;

- how the project will build upon the current **impact** to support self management
- how the project will be **developed** over the 12 month period
- how the project will be **sustained**, including any **partnership** arrangements

The Self Management Development Fund supports 30 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 Focus Report looks at how the Self Management Development Fund has encouraged projects and organisations to develop their approaches to self management which build capacity to support self management across sectors.

This report is the first of a series of Focus Reports which highlight some of the key themes of the Interim Development Fund Evaluation Report launched in May 2012¹. A full evaluation report will be produced at the end of the current funding period, September 2012.

¹ <http://www.ltcas.org.uk/what-we-do/self-management/self-management-fund/>

Development in context

What is community engagement and empowerment?²

Scotland's communities are a rich source of energy, creativity and talent. They are made up of people with rich and diverse backgrounds who each have something to contribute to making Scotland flourish. The role of Government is to help communities to work together to fulfil their potential.

What is Community Empowerment?

The Scottish Government is committed to our communities being supported to do things for themselves – community empowerment – and to people having their voices heard in the planning and delivery of services – community engagement and participation.

What are the Benefits of Empowering Communities?

Where communities are empowered we would expect to see a range of benefits: local democratic participation boosted; increased confidence and skills among local people; higher numbers of people volunteering in their communities; and more satisfaction with quality of life in a local neighbourhood. Better community engagement and participation leads to the delivery of better, more responsive services and better outcomes for communities.

What is the Scottish Government doing to Empower Communities in Scotland?

The Scottish Government is taking forward action in a number of areas and is working closely with partners to help to support and promote community empowerment and engagement. These pages highlight a number of policies as well as guidance and tools developed to promote community empowerment.

The Scottish Government will continue to develop this agenda working closely with COSLA, in the spirit of the concordat, and with colleagues in the third sector.

² <http://www.scotland.gov.uk/Topics/People/engage>

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 Strategy³. 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 Principles also form the basic criteria of the Self Management Fund for Scotland, and as such underpin each project.

Self Management Development Fund

The inclusion of peoples' experience in the design, development, implementation and evaluation of the 30 Self Management Development 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.

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 30 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.

³ <http://www.ltcas.org.uk/resources/library/search/Gaun+Yersel/>

Learning from the Self Management Fund

Developing Capacity

'We are really reaching more people through this funding, it's been really wonderful to be able to raise awareness in the community' – Ann Muir, Speakeasy

The value of developing capacity can be seen directly and indirectly in the majority of projects – see **Pink Ladies First, Waverley Care, Clydeside Action on Asbestos and Solar Bear** case studies.

Some further examples of are;

- **Castlemilk Relaxation Centre** – who are developing their programme of complementary therapies and support sessions which are known to benefit people living with mental health conditions
- **Healthy Valleys** – who are developing and extending their programmes through greater use of volunteers
- **COMAS** – who are increasing the capacity of the recovery community through training and promotion, and by embedding their work in other organisations
- **Alzheimer's Scotland** - are developing their work in West Lothian by offering 1:1 self management support in people's homes in addition to running dementia cafes for those affected by the condition and their carers.

Developing Partnerships

'Our initial project gave us the credibility to approach partners as equals – this set our partnerships in a whole new direction' – Flora Henderson, Thistle Foundation

The value of developing partnerships can be seen in a number of the projects – see **Clydeside Action on Asbestos, Solar Bear and Target Ovarian Cancer** case studies.

Some further examples are;

- **Dunoon Link Club** – who are developing their Wellness Recovery and Action Planning (WRAP) training to increase

awareness and support among health and social care professionals

- **RNIB** – who are working to strengthen and formalise their partnerships with Young Scot and the Scottish Youth Parliament to increase awareness and understanding
- **Speakeasy** – who are working across sectors in Lanarkshire to increase support and awareness of head and neck cancers and the impact they have on everyday lives

Developing Sustainability

'We are discussing ways that we can support NHS Highland to continue to lead services away from hospital bases into the community' – James Suttie, Dunoon Link Club

The value of developing sustainability can be seen in many projects - see **Target Ovarian Cancer and Pink Ladies First** case studies.

Some further examples are;

- **Intrelate** – who are working in partnership with Alzheimer Scotland to develop their person-centred planning e-tool for people living with Dementia
- **Angus Cardiac Group** – who are working to increase the self management knowledge and skills of people living with long term conditions, and are looking to engage with unpaid carers
- **Momentum** – who are looking at developing Peer Educators to spread their messages about acquired brain injury and self management
- **Asthma UK** – are working to mainstream Asthma education in all secondary schools via the Curriculum for Excellence. They are working with Education Scotland to develop an online resource that will enable teachers to deliver Asthma Education across the curriculum

Developing Opportunities

'We've had opportunities to let other people and organisations see what we do, and we're really pleased they've been able to see our potential in helping

manage asthma and improving confidence’ – Fiona Garrett, No Strings Attached

The value of developing opportunities can be seen in many projects – see **Clydeside Action on Asbestos and Waverley Care** case studies.

Some further examples are;

- **Parents of Autistic Spectrum Disorder Adults (PASDA)** – who are working to include inspirational ‘autism advocates’ into their programmes to encourage parents realise what is possible
- **SKS Scotland** – who are establishing a co-operative model to support self-employed people living with M.E. and other long term conditions and are supporting the work of several other Development Fund Projects
- **Action for M.E.** – who are undertaking a feasibility study to investigate the potential of using Skype and other new technologies to create virtual support groups for those living with M.E.
- **Deafblind Scotland** – who are developing their drama group to involve more people and to create a greater understanding of self management by providing awareness training

Developing Impact

‘We wanted to extend our impact to reach more people in more areas’ – Ian Fuller, Lothian Centre for Inclusive Living

The value of developing impact can be seen in many projects – see **Target Ovarian Cancer and Waverley Care** case studies.

Some further examples are;

- **Diabetes UK Scotland** - who are continuing to build the capacity of those living in the South Asian community in Glasgow to self manage.
- **Healthy Valleys** - who are creating an outreach version of the My Way programme by taking it to four satellite locations

in rural Lanarkshire where demand is high and services are lacking

- **Mental Health Foundation** - who are taking forward the findings of their original research by developing standards for peer support and by producing and piloting a standard training module for peer support
- **SAMH** – who have continued to work with three development sites to offer participants enhanced versions of each programme and further training opportunities as part of their Get Active programme

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 Development Fund after September 2012.

Conclusions

The Self Management Development Fund has enabled 30 funded projects to look at **development, sustainability** and **partnerships**. The Fund is capturing the learning from these experiences in relation to development, and has so far shown the impact of;

- Developing capacity
- Developing partnerships
- Developing sustainability
- Developing opportunities and
- Developing impact

Development Projects 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 Scottish Community Development Centre, 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 Development 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 Scottish Community Development Centre please visit www.scdc.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.

- Pink Ladies First - updated
- Waverley Care
- Clydeside Action on Asbestos
- Solar Bear
- Target Ovarian Cancer

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

Pink Ladies First – updated



Sheila and Maria - Pink Ladies

Pink Ladies First is a registered charity working in the Lothian area with women experiencing stress, anxiety and depression.

Pink Ladies First provide motivation workshops and group meetings to empower and enable women to take charge of their lives.

Pink Ladies First – giving women a springboard for change.

Pink Ladies First applied to the Development Fund to get some help and support to develop and grow their services and organisation. Employing a Development Worker and some Admin Support has allowed Pink Ladies First to move forward at a pace that they can handle, focusing on developing strong partnerships and thinking about their sustainability.

Pink Ladies First know the importance of the first contact women have with them, and having additional staff who share their values has been crucial for them.

'We needed to hone in on the things we do well, and learn to do them better, bigger and smoother' – Pink Ladies First

Pink Ladies First support women beyond their successful programmes, realising that their peer support is critical to enable women to keep appointments with their psychiatrists, to discuss housing, at the job centre and with debt advisors for example.

'We have realised that sustainability means for the women we support too, not just the Pink Ladies First as an organisation' – Pink Ladies First

Pink Ladies First have been working with Charge Nurses in Psychiatric Wards to let staff and women know about the additional support they are able to provide when they are discharged. Staff have welcomed their input, and for some of the women who have been supported through the Pink Ladies programme, it has been an additional boost to their confidence and recovery to be able to return to these wards and 'give something back'.

'The additional support we can provide is the essence of what makes the Pink Ladies First work – we go the extra mile' – Pink Ladies First

Peer Support remains central to the development work of the Pink Ladies, providing opportunities for women who have been through their programmes to share their experiences and information to support other women. Pink Ladies First led by example and remind the women that life is never going to be perfect, but with the right tools and support they can continue to learn and grow.

'It's so powerful for our women to let other people know 'we've been in your shoes' it breaks down barriers and supports them to give something back' – Pink Ladies First

Pink Ladies First are using the Development Fund to explore a range of options for the future for the organisation. They have been invited to tender to provide programmes for drug and alcohol partnerships, are working with Community Outreach Teams and are exploring social enterprise possibilities. Pink Ladies First continue to apply to various trusts and funders to secure core funding to allow them to continue to support women, and to keep their unique approach while developing and growing to meet demand.

'We think of LTCAS more as mentors than funders, they've encouraged us to take that important step back and look at what we want to achieve – it's so important to have them on our side' – Pink Ladies First

For more information please visit www.pinkladies1st.org

Waverley Care



Waverley Care is Scotland's leading charity providing care and support to people living with HIV or Hepatitis C.

As part of their work they also strive to raise awareness of these conditions and their prevention to ensure that people living with HIV or Hepatitis C are able to live full and fulfilling lives within their communities.

Paula McFadyen and David Cameron, Waverley Care

Waverley Care applied to the Development Fund to expand delivery of their successful self management and life coaching programmes to people who they were currently not engaging with in the community, and new groups such as the South Asian community and people in prison. Waverley Care were keen to support these marginalised individuals to move on and manage their conditions better.

'We have a relationship with LTCAS and their support made it feel safer to discuss new ideas – LTCAS understand and have given us the confidence to try something different' – Paula McFadyen, Waverley Care

Thinking about 'who else' could benefit from their programmes has led Waverley Care to plan support for people who are at risk through addiction, and may be in recovery. This links strongly to current policy priorities around the Blood Borne Virus Framework enabling people to live longer, healthier lives. Additionally, with the

benefit system changing rapidly, more people need to return to work and need to boost their self-esteem to enable them to feel ready for work again. Waverley Care have found that their Lifestyle Programmes help people to focus on outcomes that are meaningful to them, supporting them to swap risky behaviours for safe behaviours.

'Being part of the LTCAS funding has given us credence and supported us to work in partnership to collectively progress self management' – David Cameron, Waverley Care

Waverley Care have always seen the benefits of strong partnership working, and have been able to share good practice and learn from other Development Fund projects such as the Thistle Foundation, Mental Health Foundation and Diabetes UK Scotland.

'We were able to share what works and what doesn't but really partnership working makes sense for our service users to feel confident that they are receiving the best possible service from us' – Paula McFadyen, Waverley Care

Waverley Care aims to expand their capacity across Scotland, and is seeking funding to do so. They want to see more groups having more benefits through access to more services. In order to do so, Waverley Care will need to build their own capacity and are exploring ways with NHS and other partners to secure core funding with full cost recovery in mind. This would enable them to continue to build the skills of their front line staff.

'Our evaluation gave us the confidence and tools to support the NHS with evidence for change, showing clearly the difference the service has made and how that supports targets to be met' – David Cameron, Waverley Care

Waverley Care has worked to spread the tools and knowledge gained through working on evaluation with LTCAS and Evaluation Support Scotland throughout the whole organisation. This has supported them to be more focused in proving a range of evidence to funders and also to the people that receive support from Waverley Care services.

For more information please visit www.waverleycare.org

Clydeside Action on Asbestos



Clydeside Action on Asbestos is a registered charity which supports and campaigns for those living with Asbestos related conditions.

Phyllis Craig, Senior Welfare Rights Officer, Clydeside Action on Asbestos

Clydeside Action on Asbestos wanted to build on the success of their self management course developed by those living with Asbestosis in Aberdeen, making it available in an alternative format to a national audience. They also wanted to address the lack of information given at the point of diagnosis by working with health care professionals to incorporate self management information.

'The Development Fund was a perfect opportunity to make the course accessible to people living with asbestosis and those who support them regardless of whether they were able to attend a support group' – Phyllis Craig

Clydeside Action on Asbestos produced a film in partnership with men who attended support groups, of the self management techniques they used during the course. The film shows them participating in the course and describing their experiences. Clydeside Action on Asbestos plan to distribute the film throughout Scotland to their members as well as GPs.

'Our working parties have enabled us to establish lasting partnerships that will benefit Clydeside Action on Asbestos, respiratory healthcare professionals and most importantly those living with Asbestosis' - Phyllis Craig

Clydeside Action on Asbestos recognised the importance of working with relevant healthcare professionals to integrate information on self management. They have formed working parties in Ayrshire and Aberdeen to establish effective ways of cascading relevant self management information at the point of diagnosis and beyond.

Members of both working parties include Respiratory Consultants, General Practitioners, Lung Cancer Nurse Specialists, and Physiotherapists with special interest in respiratory conditions. This partnership approach led to the organisation being invited to participate in the Managed Clinical Network for respiratory conditions in Ayr.

'The fund gave us the opportunity to consider how we could make our self management programme more sustainable and more accessible. It gave us the time and the capacity to establish strategic partnerships that will ensure that the right information is given at the right time whether we have funding or not' - Phyllis Craig

The Development Fund enabled Clydeside Action on Asbestos to decide what sustainability meant for them. The decision to disseminate information via films and to work in partnership with health care professionals was based on a desire to improve quality of life in the long term for those directly accessing the project and for those who will be diagnosed in the future.

'The self management course has shown me that I can take control of my own health. I now know there is a great deal that I can do to help improve the quality of my life' - Sandy Sangster of Aberdeen asbestos support group

Clydeside Action on Asbestos would not have been able to undertake this work without the Self Management Fund and the Development Fund.

The continued support from LTCAS has given the organisation the capacity to develop and deliver a sustainable programme of self management while still providing the same level of individual support and remaining focused on what is most important to them - those living with Asbestosis.

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

Solar Bear



Solar Bear is an independent charity committed to producing inclusive and accessible theatre, outreach projects and workshops.

The Therapeutic Theatre Project is aimed at adults living with and recovering from severe mental health conditions.

Solar Bear Therapeutic Theatre participants

Solar Bear applied to the Development Fund to build on their successful therapeutic theatre programme to offer mentoring, leadership and advocacy training through drama and to develop project advocate roles for past participants.

'During the 12 week programme participants became more confident and more able to self manage. We saw the opportunity for them to take greater ownership of the project, to shape it, to support new members - ultimately to sustain it' - Solar Bear

Solar Bear established new partnerships with creative organisations and mental health services. This enabled Solar Bear to engage with new participants and to broaden the scope of the theatre project into new areas such as set design. For example, Solar Bear have supported Project Ability to continue their mental health project in spite of a sudden withdrawal of their funding.

'Establishing new partnerships has been key to the development of our project and our organisation. In fact a new partnership with Arches Theatre has enabled us to secure a permanent base' - Solar Bear

Solar Bear is focused on developing a sustainable future for the project and the organisation. Solar Bear recognise that developing the project ambassador roles is key to sustaining the therapeutic theatre programme.

Supporting past participants to share their experiences and advocate for the project has increased staff capacity to focus on the future, explore options for development and consider funding opportunities.

'The Development Fund has given us the time to consider our next steps. This combined with the additional support that we have received has enabled us to focus our energies on creating strong plans for a sustainable future.' – Solar Bear

LTCAS encouraged Solar Bear to consider the overall strategy of the project and their approach to evaluation to ensure that each reflects the true impact of the work. Additional support from Evaluation Support Scotland prompted Solar Bear to develop robust evaluation processes and to create a long term business strategy.

Being invited to participate in the LTCAS Showcase event at the Scottish Youth Theatre gave Solar Bear the opportunity to engage with a different audience and gave participants the opportunity to implement their new leadership skills to coordinate the performance at the event.

'Support from LTCAS stimulated and clarified our thinking about how to develop the project in new ways to enhance the experience of participants'. –Solar Bear

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

Target Ovarian Cancer



Target Ovarian Cancer is a registered charity working nationally to support and empower women living with Ovarian Cancer.

Target Ovarian Cancer, Steering Group Participants

Target Ovarian Cancer applied to the Development Fund to build on the impact of their initial work with Scottish women, which involved running the first ever condition specific programme of self-management events in Scotland. Target Ovarian Cancer were inspired by the enthusiasm of Scottish women to campaign for and to support their peers.

'Scottish women have an appetite for activism and empowerment - we want to work in partnership with them to channel this energy into creating a future of sustainable support'- Philippa Carr, Target Ovarian Cancer

Target Ovarian Cancer held consultation events which facilitated discussion between women, healthcare professionals and other third sector organisations. These events have given women a platform to share their views about the support they need and a collective voice to campaign for better awareness of the condition.

'They have greatly inspired us and we have empowered them to contribute to the development of the project and to become ambassadors for each other'- Philippa Carr Target Ovarian Cancer.

Target Ovarian Cancer are also working in partnership with Cancer Nurse Specialists across Scotland. This partnership enables time pressured nurse specialists to refer women to longer term support after treatment has ended. It also enables nurses to offer women support to manage the impact that their conditions has on their whole life. For Target Ovarian Cancer the partnership offers the

opportunity to integrate their services into the patient pathway and to reach women who may not be accessing any additional support.

Target Ovarian Cancer have also worked in partnership with local and community cancer charities to help embed the organisation at community level.

'This year has been about building partnerships and building trust. Nurse Specialists have helped raise awareness of our work nationally and local cancer organisations have helped embed Target Ovarian Cancer at grass roots level' – Philippa Carr, Target Ovarian Cancer

Sustainability remains central to Target Ovarian Cancer's work in Scotland. Connecting women with others who have shared experiences and providing opportunities for women to campaign for themselves and others provides the impetus for future work. This ensures that women are better informed about the condition, are aware of what is available and have are more optimistic about the future.

'Sustainability means listening to the women we support and creating opportunities for their enthusiasm, their activism and their willingness to support others' – Philippa Carr, Target Ovarian Cancer

The Development Fund has enabled Target Ovarian Cancer to develop a model of empowerment among Scottish women that will enable them to get on with life. Analysing and reflecting on the learning gained will enable the organisation to develop a road map of recommendations for a Scottish network of support.

'LTCAS has supported us to embed our services in Scotland and has helped us to connect with other organisations. They have also been a critical friend, challenging us to reflect on and analyse our programmes and to think strategically about the future of our work in Scotland' - Philippa Carr, Target Ovarian Cancer

For more information please visit www.targetovariancancer.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.

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/what-we-do/self-management/policy-context/

Scottish Community Development Centre

www.scdc.org.uk

NHS Scotland Quality Strategy

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