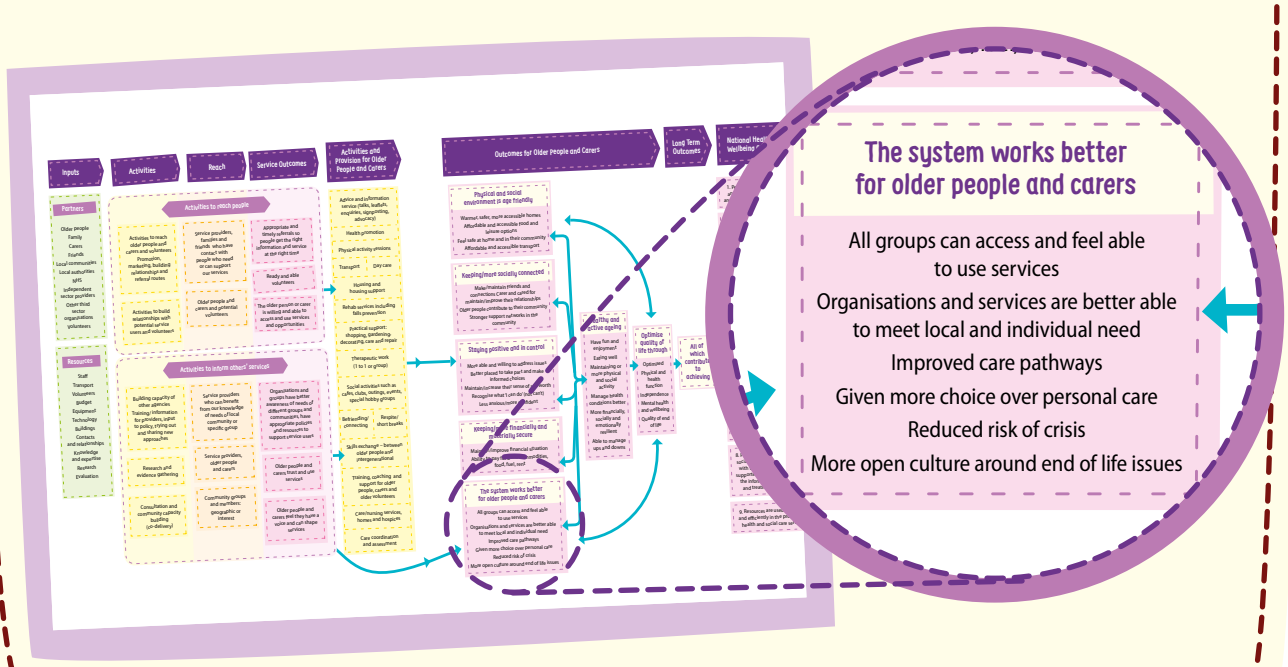
A Stitch in Time?

Focus on third sector interventions that make the **system work better for older people and carers**



Evaluation Support Scotland

joint improvement team
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Introduction

In the Stitch in Time? model we identify six key sets of outcomes for older people and carers.

In this document we focus on outcomes around making the system work better for older people.

What are we talking about?

As people get older they may need to access more support, particularly at points of transition.

The system of support for older people is complex. It includes family and friends, third sector organisations, local and specialist health professionals, local authority services (health and social care, transport, housing) and independent organisations. Individuals can find it difficult to know where to get help, particularly if they have not had much contact with services before.

In turn, organisations may find it difficult to reach those most in need of their services. The system can fail because those at risk are not identified and supported.

Outcomes include:

- All groups can access and feel able to use services
- Organisations and services are better able to meet local and individual need
- mproved care pathways
- Reduced risk of crisis
- More open culture around end of life issues

The third sector contributes to the first of these outcomes by undertaking activities that reach out to people, by responding flexibly to people's needs and by identifying and encouraging people to use other supports and services. Often third sector organisations provide services in areas where there are gaps in the system of support.

The third sector contributes to the second outcome by sharing their knowledge and experience of what works for particular groups and communities, and by supporting older people and carers to have a voice (in relation to their own case or services more generally).

Some third sector organisations focus on more specialist conditions or end of life issues. They can provide and coordinate nursing and other care. They can help people to have discussions around end of life issues. **Some organisations support people to make emergency and future care plans**.

Who are we talking about?

For the system to work, a broad range of people help to ensure older people and carers get the help they need when they need it.

This includes older people and carers themselves, family and friends, and professionals and service providers from all sectors.

Older people and carers may need help at transition points, particularly if they have not accessed support before. This relates not just to health and social care, but to a range of practical, financial, social and emotional needs.

Service providers and professionals can play a valuable role in directing older people and carers to other services. However, they may not know the range of support that is available from the third sector or how helpful this can be. They may have concerns about quality and risk.

Older people and carers are not a homogeneous group. Particular needs will be determined by age, health condition, location and cultural expectations:

- Different age groups: the newly retired might have different needs from those over 85
- Different physical abilities: those with dementia might have different needs to those with physical impairment
- Urban communities might have different needs from rural communities
- Different cultural groups: Lesbian, Gay, Bisexual and Transsexual (LGBT), ethnic minority, gender.

Some groups, such as LGBT and ethnic minorities, are particularly anxious about using services. They may have suffered discrimination, which colours their expectation of how services will be provided. Services may make false assumptions or have misconceptions about the needs of particular groups. It is helpful to hear what older people and carers say is important for them.

Service providers and professionals may not be wholly aware of these differences and how to adapt their practice, systems and policies to ensure their services really reach people and are accessible.

The Neurological Alliance of Scotland (NAoS)[1] note that one million people in Scotland are living with a neurological condition, which affects their quality of life and requires ongoing treatment and care. Some of these conditions are less common and/ or particularly challenging (for example motor neurone disease/ Alzheimer's disease). Older people, families and professionals alike may struggle to understand the needs and best ways of supporting someone with those conditions.

The Scottish Partnership for Palliative Care (SPPC)[2] notes each year around 55,000 people in Scotland die and around 220,000 people are bereaved. The experiences of decline, death and bereavement are a central feature of later life (70% of deaths are of people aged over 70). End of life issues are important not just for the older person but for family and friends.

1 A review of the evidence around third sector's support to older people with degenerative neurological conditions in Lothian. Neurological Alliance of Scotland, 2015
2 No Place for Fatalism: third sector contributions to enable older people to live well with decline and to experience better death, dying and bereavement, Scottish Partnership for Palliative Care, 2015

Why is this important?

Access to services is an important issue for many older people and carers.

With more centralised services and a greater reliance on call centres and websites, it can be harder to find out what help is available. Older people may feel anxious about asking for help or lack the technological knowledge and skills to access information about services. Participants in a workshop in Stirling (2003)[3] on later life mental health and wellbeing identified that accessing support and services was a key anxiety.

Joseph Rowntree Foundation (JRF)[4] found that getting hold of good, accurate information can help older people stay independent and in control of their lives. However, there is a lot of information in a variety of formats. Help is needed to find information, make sense of it and sometimes challenge the support that is offered. A range of different services have a role including housing, libraries and communities, as well as primary care and other frontline statutory and third sector staff.

This was echoed in research undertaken by Midlothian Voluntary Action (MVA)[5]. This research found that whilst older people wanted to remain active, there was no single place to find out about such activity. Older people mainly relied on informants or activists in the community who know what goes on, and where. Problems can arise, if a particular older person does not have contact with that individual, or he or she moves or dies.

Not knowing what is already provided can also be a barrier to joined up working. As an example, MVA found that public transport did not meet the needs of older people when services or activities had to move from one community building to another.

Some groups are less able to access services than others. The LGBT Health and Wellbeing 2007 Community Needs Assessment[6] found that one in four respondents had experienced problems in accessing health and other public services because of their sexual orientation or gender. Of those, three out of five said this affected whether they continued to use health and other services.

In a literature review[7], EVOC identifies that LGBT people can have greater needs because they are estranged from family. Long term prejudice can affect attitudes to seeking support. People may begin to hide elements of their identity because of fears of non-acceptance. This can be stressful, especially for older people with memory loss, since they can forget who knows and who doesn't.

Similarly a report into diversity and health inequalities[8] in 2010 identified that ethnic minorities can face greater difficulties when trying to access services. Barriers exist around knowledge of services, ability to communicate effectively with health staff and cultural sensitivity to the needs of this group.

It can be difficult for staff and volunteers to be aware of every service and every issue. Health and local authority services are often geared to a specific health or practical issue which makes it harder to operate holistically. Knowing what is available locally is an important issue, and sharing and implementing learning about good practice is not easy. Research[9] in Edinburgh, and Argyll and Bute found:

3 Mental Health & Wellbeing in Later Life, 2003
4 How can local authorities with less money support better outcomes for older people? JRF, 2011 http://www.jrf.org.uk/sites/files/jrf/authorities-supporting-older-people-summary.pdf
5 SIT? Informal Community Action & Reshaping Care for Older People Research Report, Midlothian Voluntary Action, 2013
6 http://www.lgbthealth.org.uk/wp-content/uploads/2014/08/Needs-Assessment-Sept-07-_Updated-Dec-07_.pdf S. Aitken, S. Kealey and R. Adamson, 2007
7 Desk Review of the literature around the needs of older lesbian, gay, bisexual and transgender people and access to health and social Care services, Edinburgh Voluntary Organisations Council (2014)
8 Dimensions of Diversity Population differences and health improvement opportunities, ScotPho: Public Health information for Scotland, Jan 2010
9 Mapping Knowledge Support for Care of Older People in Health and Social Care Partnerships, Consilium, March 2013

What do we know about effective interventions?

"There are a range of well documented and agreed barriers to implementing knowledge management across health and social care including: access to technology, protected time to implement knowledge management, skills and confidence; bureaucracy and protocols, too many portals, too many IT specific barriers (such as passwords, subscriptions, complex navigation) and lack of a joined up approach."

The Programme for Government published in November 2014[10], makes it clear that, older peoples' voices should influence the design and delivery of services.

"We want to […] empower and enable people to improve their own lives and those of others in their community."

At a later stage of life, managing decline in health, living with long term conditions and coming to terms with dying and bereavement are important elements for many older people. SPPC[11] note that optimising the quality of the end of life is one of the major responsibilities of the health and social care system.

Yet, people's experience of death, dying and bereavement is only partly determined by their interaction with traditional formal services. Social and cultural factors also play an important part.

It is ill-health and decline that impact most on our health care system. SPPC note that around half of all deaths currently occur in hospital[12]. 29% of acute hospital beds are used by people in their last year of life. NAoS report[13] that neurological conditions account for one in fife emergency hospital admissions and one in eight GP consultations. Finding ways to support people at home is critical if we are to reduce emergency admissions and avoid delayed discharges.

10 One Scotland - Programme for Government 2014-15
11 No place for fatalism: third sector contributions to improving older people's experiences of declining health, bereavement and death. Scottish Partnership for Palliative Care, 2015
12 National Records of Scotland (2013) Deaths, by sex, cause and place of occurrence and whether post mortem performed, Scotland, http://www.nrscotland.gov.uk/
13 A review of the evidence around third sector's support to older people with degenerative neurological conditions in Lothian, Neurological Alliance of Scotland, 2015 http://www.evaluationsupportscotland.org.uk/media/uploads/resources/naos_stitch_in_time_report.pdf

There are some important outcomes that lead to the system working better for older people and for other services. Interventions related to these outcomes are:

Outcomes	Third sector interventions
Appropriate and timely referrals so people get the right service at the right time	Notice boards, talks and newsletters to promote own and other services to older people and carers. Talks and leaflets to promote own services to health and social care professionals and other service providers. Meetings to establish referrals pathways. Practical ways to help individuals to access other services. Open days, events, drop in sessions to encourage trust and build relationships.
Service providers have a better awareness of needs of different groups and communities, have appropriate policies and resources to support service users	Training/talks for other service staff. Advice and guidance notes. Activities to share learning from evaluation and research.
Older people have increased trust and use services	Open days, events, drop in sessions to encourage trust and build relationships. Encouragement and practical support to use other services (phone calls, information, searches, help with completing forms, accompanying people). Campaigning: e.g. films and social media.
Older people and carers [feel they] have a voice and can shape services	Older people's and carers' forums. Consultation events. Advocacy support to ensure arrangements meet the needs of the individual and fit with other arrangements.

JRF'S work[14] suggests that effective information is related to the topic and not agency based information. Older people need help with accessing information and practical assistance to act on that information.

Community based organisations provide a range of services in an informal setting; for example, a listening ear, access to advice and information, social contacts, practical help. Staff and volunteers can identify potential services, find out steps that need to be taken and offer practical support and encouragement. When an older person has an ongoing relationship with the project this can happen in an informal way, geared to the needs of the particular individual when it is needed.

However, our third sector practitioners[15] tell us that it takes time to become known and trusted by health and social care professionals and by people in the community. This means outcomes are not achieved straightaway.

JRF[4] suggest that there is growing evidence of the value of place based and partnership approaches. These cut across sectors to identify older people at risk and to enable older people to access services through single access points. Examples of this approach include:

- Local Area Coordinators funded by Midlothian Council
- Local Opportunities for Older People (LOOPS) funded by Edinburgh City Council
- One tick referral system for General Practitioners to refer people to a 'carers team' in Edinburgh

The Older People Eat Well – literature review[16] highlights cases where the third sector has been able to use their expertise to influence service provision; for example, Age UK's work on malnutrition in hospitals and on obstacles for older people in shops. The review also highlights the importance of sharing third sector learning through reports and case studies.

The Scottish Partnership for Palliative Care[2] suggests that promoting more openness and knowledge about end of life issues can support people's ability to plan for or support each other during this difficult period. It is important to talk about issues such as wills, wishes regarding medical treatment, power of attorney and what to do in the event of an emergency or when things get worse. This can avert crisis later on for both the older person and the people who support them (including statutory services).

14 Older people's views on information, advice and advocacy, JRF, 2003
15 In 2013 ESS ran working groups of third sector practitioners. We pulled together their self-evaluation and practice experience
16 Older People Eat Well – literature review jointly commissioned by A Stitch in Time? and Community Food and Health Scotland, April 2014

Case study

The Change Fund in Edinburgh funded the LGBT Age Project. They have used a range of ways to share their expertise and to influence policy and practice, including Community Champions, a video, training and events and a forum for professionals.

The following service user case study was submitted to EVOC in December 2013 and shared with the Change Fund. It shows how the project helped to give one individual the confidence to take a lead role in speaking out on LGBT issues.

Sharon's story

"I think LGBT Age is brilliant!"

Sharon is in her mid-60s and was initially referred to our LGBT Age Befriending Project by a mental health support worker who themselves identified as LGBT. Sharon only identified as lesbian later in life and with the support of her grown children. She presented to the project with low self-esteem and no peer LGBT network to draw on.

As well as using LGBT health services and building up her social networks, Sharon was matched with a volunteer through the LGBT Age Befriending Project. Meeting with her befriender on a regular basis for 18-months, workers observed positive changes in Sharon and testified to improved confidence and self-esteem. Accompanied by her befriender, Sharon attended the older lesbian social group, 'The AD Group', as well as independently attending regular LGBT Age social events and taking a lead role in welcoming and caring for others attending social events.

Following her befriending match, Sharon has continued to be active with LGBT Age and has volunteered with the LGBT Age Capacity Building Project for 18 months (at Dec 2013) as a Reference Group member and Community Champion. She has contributed responses to public consultations, provided information about some of the very specific issues faced by older lesbian women with families and is a very well-liked member of the project's Reference Group. Sharon has attended a number of events with or on behalf of the organisation including the Scottish Older People's Assembly, and was recently involved in the development of an intergenerational event in conjunction with LGBT Youth, which took place in November. We hope this will be the first of a number of such events.

Sharon's journey with LGBT Age - from someone tentatively 'coming out' and building self-esteem from regular befriending to becoming a committed volunteer actively informing the project - has seen her grow in confidence and become an integral part of LGBT Age's work.

The LGBT Healthy Living Centre

LGBT Health and Wellbeing was set up in 2003 to promote the health, wellbeing and equality of lesbian, gay, bisexual and transgender (LGBT) people in Scotland. It provides support, services and information to improve health and wellbeing, reduce social isolation and stimulate community development and volunteering.

We would like to thank Sharon for agreeing to let us share this case study

Go to our websites to see an organisational case study for the LGBT Age project

A Stitch in Time?

A Stitch in Time? is a partnership project to support the third sector to collect and present evidence about its contribution to Reshaping Care for Older People (RCOP). The programme runs from April 2013 to March 2015 and focuses on third sector organisations working with older people and carers in Lothian.

A Stitch in Time? publications

A model to explain the third sector contribution to Reshaping Care for Older People

Indicator Bank for third sector outcomes for older people

Focus on third sector interventions that make the physical and social environment more age friendly

Focus on third sector interventions to enable older people to keep or be more socially connected

Focus on third sector interventions that allow older people to stay positive and in control

Focus on third sector interventions to enable older people to keep or be more financially and materially secure

Focus on third sector interventions that make the system work better for older people

Focus on third sector interventions that ensure healthy and active ageing

To accompany this series there are **evaluation case studies** and a number of **evidence reviews**.
To see all publications associated with A Stitch in Time? please see **Evaluation Support Scotland** website or the **Joint Improvement Team** website.

Evaluation Support Scotland (ESS) works with third sector organisations and funders so that they can measure and report on their impact.

Evaluation Support Scotland

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