

LIVING IN THE GAP

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Acknowledgements

We are grateful to all the people who made this report possible: Lorraine Simpson of The Lines Between, for designing and conducting the study. Christine Carlin for project management and additional writing. The many voluntary health organisations who completed the online survey and the ten organisations that volunteered to be our case-studies. NHS Health Scotland for funding and other support. Finally, we would like to acknowledge all colleagues in VHS for their involvement in the project.

Health inequalities are everybody's business



Tackling health inequalities and inequalities generally is everybody's business. Any given angle on the issues involved and any productive intervention will involve public, private and voluntary sectors working with individuals, families and communities. It is a complex weave, which will all too easily unravel if one set of threads is missing. At the same time, it is very simple to understand: live in Bridgeton (Glasgow) and your life expectancy is 62; live in Jordanhill (10 miles away) and it's 76. In this one disturbing measurement we see the gap and understand its importance.

However, it may be everybody's business but individuals, sectors and communities will contribute different elements to the weave.

This report focuses on one set of threads – those provided by the voluntary health sector. In particular, the report considers the 'lived experience' of health inequalities, hence the title, *Living in the gap*.

This is perhaps where the voluntary health sector operates most effectively: alongside those who are living with the impact of inequality in their day to day lives. Here, more often than not, the sector's role will help to mitigate the impact but clearly won't resolve it. Sometimes (and this can be seen in some of the case studies) it may help create the conditions for a generational shift, at least with individuals and families if not whole communities.

Living in the gap illustrates the activities of the sector, its views, its hopes and the challenges and opportunities it faces. It reveals a sector that is vibrant, committed, innovative and effective. At the same time, it is vulnerable, too often ignored by the public sector, and sceptical of change. It is, however, connected to the people who are living in the gap; as one respondent commented:

'Often the individuals who are in most need are not accessing statutory services and therefore remain in the shadows of service provision.'

This report might have been titled, 'Out of the shadows', focusing as it does on the positive impact of the voluntary health sector on vulnerable and marginalised people. However, the reality is that the vast majority of those people continue to live in the shadows, created by a gap, which we must close through our own efforts and in partnership with others.

Lorna Hunter
Chair of the Board
Voluntary Health Scotland
March 2015

Living in the Gap: a voluntary health sector perspective on health inequalities in Scotland

While Scotland's health is improving, the gap in health outcomes between the most and least advantaged groups in society is widening. We call this gap, health inequalities.

Living in the gap pulls together material from a wide ranging survey of the voluntary health sector about health inequalities in Scotland and illustrates the role of the sector through a series of case studies.

The report shows a vibrant, diverse and committed sector, making a difference to people's lives on a daily basis. The question posed is, 'what difference is the voluntary health sector making in addressing and, more importantly, redressing health inequalities?' Overall, the answer is 'a significant difference.' Examples are given of the positive interventions being made. Commentary is made by the sector about barriers and frustration. Recognition is given to the sector's capacity to mitigate impact for individuals, families and communities, and its aim to work further upstream before inequality sets in. Finally, the report focuses on the key issues facing the sector in its health inequalities work and possible ways forward.

Background

The overall health of the Scottish population has improved over the past 50 years¹. Scotland's former Chief Medical Officer, Harry Burns, has stated that there is nothing inherently unhealthy about the Scots; indeed, for most of the past 160 years, life expectancy has been average compared to several Western European countries². However, against this backdrop, health inequalities have increased dramatically, with the differential in life expectancy between those in the poorest and those in the most affluent areas providing a stark indicator. These inequalities are the product of various forces – economic, social, and historical. But they are not inevitable and they can be redressed.

The report demonstrates that the role of the voluntary health sector in tackling inequalities still appears to be insufficiently recognised or understood. Lacking the scale, volume and resources of the public sector, its programmes and activities are

sometimes presumed to be peripheral and insubstantial. *Living in the gap* challenges that presumption and places the sector's work in the context of developing public policy and firmly alongside the roles and activities of the other sectors. A significant amount of more detailed mapping remains to be done but it is clear in this report that the voluntary health sector is a key contributor in tackling health inequalities in Scotland, and that it has much more to offer.

Methodology

A qualitative and quantitative study was commissioned by VHS from *The Lines Between*.

A mixed methods approach was adopted, comprising:

- Context review
- Electronic survey
- Workshop observations
- Interviews and case studies
- Analysis and reporting

The content of the survey was informed by discussion with VHS members through a series of seminars and was designed to produce a snapshot of activity within the sector. It was distributed electronically to VHS members and partners and resulted in 161 responses. In addition, ten case studies were identified, interviewed and written-up, providing detailed illustrations of the sector's activities across Scotland and a range of issues.

Policy Context

Health inequalities were described by a former Chief Executive of NHS Scotland as '*probably the most complex (problem) that we face (with) no simple solution*'³. The direction of policy over recent years reflects this, moving outward from a health-specific focus to engaging with economic and social solutions. Recent research suggests that, for example, redistributive tax interventions have greater impact on reducing health inequalities than those focused on individual health behaviours⁴. Consequently, the allocation of resources is not straightforward, particularly

as the Scottish Government has limited powers in terms of welfare, tax and the economy, a fact noted by the Convenor of the Scottish Parliament's Health & Sports Committee in a debate on inequalities:

*'Even when we had the money, did we spend it wisely? Despite significant investment, in-work poverty is rising, educational attainment is falling and the health gap between different parts of the country is widening*⁵.'

In 2007, the Scottish Government sought to make progress on health inequalities by establishing a Ministerial Task Force to identify and prioritise practical actions. Three social policy frameworks were published over the following two years – Equally Well, Early Years Framework and Achieving our Potential – all seeking to address the underlying causes of inequalities. The role of Community Planning Partnerships was put at the centre of driving progress across all fronts. This was followed by a focus on preventative spending and the establishment of the Christie Commission, which resulted in the Scottish Government committing to making a critical shift towards prevention and placing a greater emphasis on the importance of 'place' in addressing inequalities.

This commitment was reflected in the establishment of a number of 'Change Funds' designed to shift the focus from mitigation of symptoms to tackling root causes. The integration of health and social care functions under the Public Bodies (Joint Working) (Scotland) Act 2014 embeds this shift in a commitment to opening new ways of collaborative working and investing.

The Scottish Parliament's Health & Sport Committee's report on Health Inequalities⁶ in early 2015 reflected on the lack of impact of policies to date and the changes needed, including under new devolved powers, to make a real difference to the health inequalities gap.

Main Findings

According to respondents, the third sector works closely with the population groups that are thought to be at most risk of experiencing the effects of health

inequalities. These groups faced key challenges linked with health inequality, e.g. social isolation, barriers to accessing services, stigma. The report illustrates a sector making a difference to the lives of people living in the health inequalities gap by supporting improvements for individuals, families and even communities who would otherwise have an even lower level of health and wellbeing than the general population.

Who does the voluntary health sector work with?

The sector supports both people with particular health issues – diabetes, visual impairment, etc. – and also geographical communities and communities of interest. However, respondents emphasised that the work of the sector was cross cutting and responsive. An example was given of Fife Society for the Blind, an organisation that often supports individuals in coping with hearing problems, mobility issues or in recovering from a stroke. They have responded by working with clients to build confidence and alleviate social isolation. They also support unpaid carers.

Overall, organisations worked with more than one group and respondents suggested that this reflected the flexibility of the sector in being able to respond to complex needs.

Activities

In terms of the key activities of the sector, these ranged across: partnership working to improving design and delivery of interventions; providing information about health and referral to other health services; early intervention; advice and advocacy; recovery support.

Respondents recognised that health inequalities are manifestations of broad social and economic issues. In their responses they identify opportunities and challenges in working ‘upstream’ to prevent inequalities, acknowledging that, without a joined-up approach between all levels and sectors, no single intervention will provide a solution.

Strengths of the sector in addressing health inequalities

Overall, the strengths of the voluntary health sector in addressing health inequalities are highlighted including: the ability to engage

those vulnerable groups and communities that statutory services may struggle to reach; addressing access to services issues; asset-building, preventative and community-based approaches; innovative, flexible and holistic approaches; being able to get alongside those in need; commitment to partnership. Trust was identified as a key factor, i.e. relationships with service users have a non-statutory basis and are therefore built upon trust, word of mouth and having credibility within local communities.

Challenges

A number of key challenges were identified by respondents. Inevitably funding for the sector was one of these with issues around funding cycles, funder expectations and unhelpful bureaucracy being to the fore.

Beyond funding, however, the main challenges were: being able to evidence impact; over-demand for services; lack of understanding of what the sector has to offer and a dismissiveness of its importance; destabilisation of sector due to continual public sector change and reform. Most importantly, it was emphasised that only joint sector interventions could produce the best outcomes but that collaboration and partnership were too disjointed at present.

Opportunities

Respondents agreed that changes to the way that initiatives and organisations are funded could help support improved outcomes in relation to health inequalities. More generally, many considered that inequality needs to be given greater priority across policy and across sectors.

Particular emphasis was given to the importance of monitoring and evaluation of impact and the need for support to the third sector to develop and embed best practice. This report proposes that these changes would have a positive impact on funding.

Next steps

There is a visible momentum in the commitment to tackle inequalities in Scotland. Public agencies like NHS Health Scotland have moved beyond health to embrace the core economic and social determinants of inequalities. Likewise, the Scottish Parliament and the Scottish Government both acknowledged that a

health-only approach is insufficient even in relation to health inequalities. Voluntary Health Scotland (VHS) is also aligned with this consensus and *Living in the gap* is part of our contribution to the plentiful commentary and reflection on inequalities emerging in Scotland today.

However, in scaling up our vision, we also need to encapsulate the detail. As inequalities become a macro, cross-sectoral and organisational concern, the ways that we deal with the day to day reality – living in the gap – is in danger of being pushed to the margins. This report provides part of that detail and draws from it an understanding of what we should do now – to make the voluntary health sector better at what it does best and more capable of doing what it needs to do in order to reflect the broader agenda of inequalities.

We need to continue to map the activities of the sector but more importantly we need to ensure that it has the tools and resources to make the greatest impact and to be able to measure that impact. Stemming from this report will be a programme of work in which VHS, in partnership with others, will support these developments.

¹Health Inequalities in Scotland. Audit Scotland, 2012.

²Harry Burns. Social failure, not lifestyle, has made Scots sick. New Scientist Magazine, Issue 3005, 24 January 2015

³Scottish Parliament Health and Sport Committee. Official Report, 22 January 2013. Col 3149.

⁴Informing investment to reduce health inequalities (III) in Scotland: a commentary. NHS Scotland 2014

⁵Scottish Parliament. Official Report, Meeting of the Parliament, 20 January 2015.

⁶The Scottish Parliament. Health & Sport Committee, Report on Health Inequalities, Published 5th January 2015.

Introducing the voluntary health sector and health inequalities

Introduction

1.1 Voluntary Health Scotland (VHS) is the national intermediary and network organisation for the voluntary health sector. VHS works with its members to strengthen the voice, profile and influence of the sector. Estimates of the size of the sector vary and some rigorous mapping is still required. However, this report shows a sector working, across geography and interest groups, to address the impact of health inequalities.

1.2 In April 2014 VHS commissioned The Lines Between to undertake a quantitative and qualitative study to reflect on the issue of health inequalities in Scotland, and to give the voluntary health sector an opportunity to highlight its contribution to tackling health inequalities in Scotland. The study was made possible by a grant from NHS Health Scotland.

1.3 The aims of the study were to:

- gain a better understanding from the voluntary health sector of what the lived experience of health inequalities really means for those individuals, families and communities it engages with;
- provide the voluntary health sector with an opportunity to highlight how it believes its work contributes to tackling Scotland's health inequalities; and
- publicise the findings so that they can provide a platform for wider discussion about the challenges and opportunities for the voluntary health sector, the wider third sector and the public sector in coming together effectively to tackle health inequalities in Scotland.

1.4 Findings from a survey, along with ten individual case studies, are presented in this report. Together, the information provides an insight into some of the ways in which the voluntary health sector interacts with people affected by health inequalities, and illustrates how the sector describes its work in terms of addressing health inequalities in Scotland.

1.5 Voluntary Health Scotland uses the term 'voluntary health sector' to include:

- Voluntary sector providers of health and social care services;

- Voluntary organisations that carry out research, advocate and/or campaign on specific health issues, conditions and disabilities;

- Community-led organisations that promote and support health improvement and healthy living at a local level; and

- Volunteer-led and user-led support groups of people with shared health conditions.

Voluntary Health Scotland members range from large national charities to small, local service providers, and members' interests span service planning and provision, prevention, early intervention, self-management, advocacy, and support for service users and carers.

1.6 For the purposes of this study, the terms 'voluntary sector', 'voluntary health organisation' and 'third sector' are interchangeable and include the range of organisations above.

Report Structure

1.7 This report contains three chapters:

- The remainder of this chapter describes the study context and methodology.
- Chapter 2 presents findings from the study, based upon a sector-wide survey, observation at a series of workshops and interviews with a sample of stakeholders. We also present ten case studies in this chapter.
- Chapter 3: Conclusions

Study Context

1.8 Health inequalities are 'systematic differences in the health of people occupying unequal positions in society' (Graham, 2009¹). There are some stark examples of what this means in practice; NHS Health Scotland's Policy Review 2013² for the Ministerial Task Force on Health Inequalities³ found that in 2009/10:

'Life expectancy at birth for men was 69 years for the most deprived 10th of the population compared to 82 years for the least deprived 10th, a difference of 13 years.'

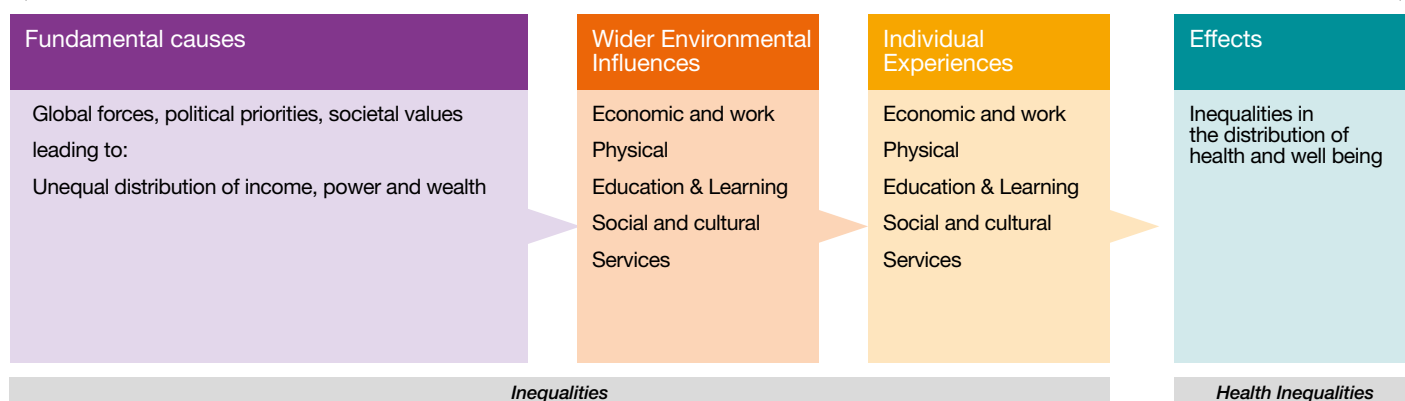
The overall health of the Scottish population has improved over the past 50 years. Scotland's former Chief Medical Officer, Harry Burns, has stated that there is nothing inherently unhealthy about the Scots; indeed, for most of the past 160 years, life expectancy has been average compared to several Western European countries. However, against this backdrop, health inequalities have increased dramatically, with the differential in life expectancy between those in the poorest and those in the most affluent areas providing a stark indicator. These inequalities are the product of various forces – economic, social, and historical. But they are not inevitable and they can be redressed.

1.9 Such a dramatic difference in life expectancy is generally the result of being affected by preventable illness, and of experiencing health problems much earlier in life and for much longer than those not affected by health inequalities. Since poor health will often impact too on the individual's working life, and on the lives of their family, the overall quality of their life often becomes poorer. This can be described as the 'lived experience' of health inequalities. The above NHS Health Scotland Policy Review stated that in 2009/10:

'The difference in healthy life expectancy was even more marked, at 47 years for men in the most deprived 10th compared to 70 years for those in the least deprived 10th, a difference of 23 years.'

1.10 The NHS Health Scotland website⁴ outlines key legislation and policies for promoting equality and reducing health inequalities; highlighting that health inequalities 'are most commonly associated with socio-economic inequalities but can also result from discrimination.' It notes that whole population approaches to improving health may widen health inequalities, because marginalised groups face 'barriers to engagement with services.' Factors that may be associated with unequal health outcomes include low levels of income, living in social isolation, poor mental health, having learning disabilities or belonging to a minority group.

1.11 In its work to understand and explain health inequalities, NHS Health Scotland



has developed a theory, known as the 'Theory of Causation' that connects the causes, influences, experiences and effects. This is illustrated in the diagram above.

1.12 The theory of causation describes the first column as the 'fundamental causes.' Health inequalities have their roots in the political and societal forces that drive decisions and priorities for governments and public bodies. This results in an unfair distribution of power, money and resources. This unfair distribution often leads to discrimination and marginalisation of individuals and groups. Fundamental causes influence the distribution 'downstream' of 'wider environmental influences' e.g. availability of good work, quality housing, education opportunities; and access to social and cultural opportunities and to services in an area. The second column on the model illustrates how the wider environment in which people live and work shapes their individual experiences, choices and decisions e.g. discrimination, prejudice, low income, poor housing and less access to health services. This results in the unequal and unfair distribution of health, ill health and mortality in the population.

Who is affected by health inequalities?

1.13 Much of the debate around health inequalities in Scotland focuses on the impact of poverty. In 2012, Audit Scotland⁵ found that:

'Deprivation is a major factor in health inequalities, with people in more affluent areas living longer and having significantly better health. Health inequalities are highly localised and vary widely within individual NHS board and council areas. Children in deprived areas have significantly worse health than those in more affluent areas.'

1.14 The latest statistics on health inequalities were published in October 2014 (Scottish Government⁶). This data covers the fifteen year period between 1997–2012, combining three methods to measure health inequalities: (1) a relative index of inequalities (RII), (2) identifying the absolute range in health outcomes and (3) assessing the scale of problems. Despite some

encouraging conclusions – the absolute gap between most and least deprived areas is at its lowest in the time series covered and relative inequality has been stable since 2006 – the data indicates an ongoing need to address health inequalities.

1.15 In fact, more than 20,000 individuals in Scotland aged under the age of 75 years die each year and there are other stark differences when outcomes are compared for people living in the most and in the least deprived areas. For example:

- Deaths by all-cause mortality are three times more common
- Premature mortality from coronary heart disease is around five times more common
- Low birth weight babies are more common

- The incidence rate for cancer of the trachea, bronchus and lung is more than four times higher
- People aged between 45–74 years are more than twice as likely to die of cancer
- New hospital admissions for alcohol related conditions are around five times more common

How can the voluntary health sector play a role in addressing health inequalities?

1.16 The voluntary health sector has a long track record of representing, engaging and delivering interventions for those groups who are most likely to be affected by health inequalities. Often the sector works with vulnerable or marginalised individuals, those

Health-specific issues

Many organisations highlighted how their work related to a specific health issue as follows:

people with multiple sclerosis; children and young people with cancer; people living with (and dying from) advanced diseases; people with a visual or hearing impairment; people with Fibromyalgia; those living with chest, heart and stroke related health issues; people living with or at risk of HIV and/or Hepatitis C; and individuals with ME.

In many cases, the respondent pointed out that the families of the individual concerned were also being supported by the voluntary organisation.

Communities of interest

A wide range of communities were highlighted by organisations taking part in the study. These are listed below:

older people; people with learning and physical disabilities; those with sensory impairment; Lesbian, Gay, Bisexual and Transgender (LGBT) communities; those living with arthritis; families affected by substance misuse and parental imprisonment; women and young people; those affected by homelessness; individuals, couples, families and children with relationship support needs; primary school pupils; survivors of childhood sexual abuse; those leaving care or youth justice system; women facing unintended pregnancy; child loss, miscarriage & abortion; asylum seekers; people experiencing poverty and financial exclusion; race and equalities issues; maternal and infant health; those who have experienced bereavement; people who smoke; those with sleep problems; and veterans aged 18–65.

The extent of health inequalities and the policy landscape

not being reached by mainstream health services; or whose demands for time and resources are placing considerable pressures on mainstream services.

1.17 In responding to this study, participants were asked to highlight the key health issue or the particular community of interest supported by their organisation. The responses are listed overleaf and give an indication of the diverse range of issues being addressed by the voluntary sector and why it has important insights to offer into what it is really like to live a life impacted by health inequalities.

1.18 There is considerable recognition from the Scottish Government and NHS Scotland of the role that the voluntary health sector can play in addressing health issues. Publications that highlight the value of the sector's work include a recent briefing paper *'Why Involve the Third Sector in Health and Social Care Delivery?'* (Scottish Government, 2012⁷). The paper highlights how the third sector works closely with communities and points to the often distinct features of third sector service delivery which complement and enhance public sector services. The paper recommended the building of an evidence base to assist further understanding of the mechanisms which have allowed third sector organisations, acting alone and in partnership, to facilitate improvements in the health of individuals and communities.

1.19 A Growing Up in Scotland (GUS) briefing paper on *Health Inequalities* and the *Early Years 2014*⁸ notes that 'while there is much that can be achieved through the health service, evidence from GUS suggests that many of the actions required to reduce health inequalities in the early years lie outwith the remit of health services and other service providers.' The paper concludes that: 'a central theme across GUS findings has been the variation in the ways that formal support services are used by families with different characteristics. Mothers experiencing disadvantage are less likely than their more advantaged peers to attend antenatal classes, parenting classes and baby/toddler groups. Parents whom service providers and policy makers often most want to reach are those most reluctant to engage with services.'

1.20 Given the third sector's reach into

vulnerable communities there is clearly scope to explore the extent to which their work serves to mitigate the impact of inequalities on the health of individuals or prevent – or even reverse – potential future health inequalities in ways statutory services cannot achieve. However, linked to this is clearly the key challenge of how the sector measures and presents the impact of its interventions; and how its actions can be shown clearly to link to better health outcomes.

Policy framework

The extent of health inequalities in Scotland

1.21 Health inequalities have been a long-standing issue for Scotland. As one of their examples of health inequalities, the World Health Organisation cites the life expectancy at birth for men in the Calton neighbourhood of Glasgow as 54 years, 28 years less than that of men in Lenzie only a few kilometres away⁹.

1.22 The Welfare Reform Act 2012 became law on 8 March 2012¹⁰. Changes to the welfare system started taking effect in 2013. The potential negative impact of these changes on those living with health inequalities has been highlighted by the third sector and others.

1.23 In 2013, the Scottish Public Health Observatory (ScotPHO) published a baseline report on the impact of welfare reform (and the economic recession) on health and health inequalities¹¹. The report stated that:

'Although the health impacts remain uncertain, the threats to public health are grave and all policy options to: maximise employment (through the provision of good jobs); maximise the incomes of the poorest groups (in particular those most vulnerable to the benefit changes); and reduce stigmatisation of benefit recipients should be considered.'

Measuring health inequalities

1.24 A number of key headline indicators on health inequalities are being used by the Scottish Government as a means of monitoring progress over time. These are

focused on – all cause mortality for ages under 75 years and from 15–44 years; and on key information linked to incidences of heart attacks; death from coronary heart disease; cancer incidences and death; alcohol-related hospital admissions and death; and birthweight¹².

1.25 In December 2012, Audit Scotland published a report citing major differences in the health and life expectancy of different groups of people in Scotland. The report stated that this was a complex problem and that addressing it required a range of public bodies working together effectively. In their report, Audit Scotland made a number of recommendations¹³. In their follow up Impact Report in June 2014, Audit Scotland reported on the extent to which progress had been made on their recommendations¹⁴.

The Health Inequalities landscape

1.26 Some of the recent changes related to health inequalities around policy developments, structures and funding, are listed below:

The Ministerial Task Force and the three Social Frameworks

1.27 In 2007, a Ministerial Task Force on Health Inequalities was established by the Scottish Government to identify and to prioritise practical actions, aimed at reducing the most significant and widening health inequalities in Scotland.

1.28 During 2008 and 2009, the Scottish Government and the Convention of Scottish Local Authorities (COSLA) jointly published three linked social policy frameworks. *Equally Well*¹⁵ was the first of these frameworks and is the national policy on health inequalities. *Equally Well* highlighted the widening health gap, stating that differences linked to income were not the only factor. Awareness was drawn to other factors including age, disability, gender, race, religion or belief and sexual orientation – all of which interacted with socioeconomic status.

1.29 The next two social policy frameworks were *Early Years Framework* and *Achieving our Potential*. Each one of these action documents sought to address the underlying causes of Scotland's health and other inequalities. It was recognised that the key to addressing inequalities was early

intervention and so it was considered important that resources were shifted accordingly.

1.30 When it reconvened in 2010, the Ministerial Task Force concluded that there was a need for greater focus on prevention and preventative spending. The Task Force also sought to reinforce the links between poor health and people's aspirations, sense of control and other cultural factors rather than just life style choices¹⁶.

The role of Community Planning Partnerships

1.31 *Equally Well* had marked a shift in focus for health inequalities beyond the NHS and the policy particularly sought to engage local authorities, placing Community Planning Partnerships (CPPs) at the centre of the strategy. In 2010, the reconvened Ministerial Task Force restated the key role of the CPPs.

1.32 In the *Statement of Ambition* (March 2012)¹⁷ the Scottish Government (and local government) indicated a continuing commitment to CPPs and also to Single Outcome Agreements (SOAs) as the key strategic building blocks to achieve public sector reform, including the reduction of inequalities for local communities through delivery of high quality public services.

1.33 Subsequently, in its second review of *Equally Well*, published in early 2014, the Ministerial Task Force confirmed its continued conviction that CPPs remain the best vehicle, for leading progress in delivering *Equally Well*, and for engaging all partners – including the third sector.

The 2020 Vision for Health and Social Care

1.34 In 2011, the Scottish Government set out its 2020 Vision for Health and Social Care. In the associated Route Map, health inequalities were identified as one of 12 priorities. Key deliverables for 2013/14 were: resources to be targeted on the most deprived areas and 'Deep-end' GP practices to be rolled out more widely across relevant areas of Scotland, with the aim of reducing hospital admissions and improving outcomes for the people living in those areas¹⁸.

1.35 NHS Health Scotland is the special health board responsible for health improvement. In their 2012–17 strategy, *A Fairer Healthier Scotland*¹⁹ NHS Health Scotland confirm their aim 'to improve Scotland's overall health record by focusing on the persistent inequalities that prevent health being improved for all.' The NHS Health Scotland Delivery Plan for 2014/15²⁰ lists the third sector as a key partner and states the organisation's intention to work with the sector to ensure the lived experience of people experiencing inequality is integrated into the organisation's 'knowledge into action' work.

The Christie Commission

1.36 In June 2011, The Christie Commission²¹, published its report on the *Future Delivery of Public Services* which concluded that radical reform around the design and delivery of public services was required to bring about effective change, including much closer partnership working, embedding community participation and more effective planning.

1.37 In response to The Christie Commission, the Scottish Government stated that its public service reform agenda would be built on four pillars: (i) a decisive shift towards prevention; (ii) a greater focus on 'place' to drive better partnership, collaboration and effective local delivery; (iii) investing in people who deliver services through enhanced workforce development and effective leadership; and (iv) a more transparent public service culture which improves standards of performance through innovation and the use of digital technology²².

The 3 Change Funds

1.38 In the 2011 Spending Review the Scottish Government announced around £500m of public funding for 3 Change Funds aimed at supporting a transition across public services away from dealing with the symptoms of disadvantage and inequality towards tackling their root causes. The funds were to be allocated over the course of the Parliament towards innovative programmes of preventative and early action across three areas:

- Early Years and Early Intervention Change Fund, £274m

- Reducing Reoffending Change Fund, £10m. £7.5m funding came from Scottish Government, £2m from the Robertson Trust, and £500k from the Scottish Prison Service

- Reshaping Care for Older People (RCOP) Change Fund. £230m was made available to Health and Social Care Partnerships from the 2011–12 financial year, with a further £70 million made available for the 2014–15 financial year

The Integrated Care Fund

- Integrated Care Fund, £173.5m²³ to succeed the RCOP Change Fund. This new fund is accessible to local partnerships to support investment in integrated services for all adults. Funding will support partnerships to focus on prevention, early intervention and care and support for people with complex and multiple conditions, particularly in those areas where multi-morbidity is common in adults under 65, as well as in older people.

What have policy initiatives achieved to date?

1.39 There have been a considerable number of policy initiatives over a period of several years which have been aimed at reducing the health inequalities gap. However, in January 2015, the report of the Scottish Parliament's Health and Sport Committee noted the failure of successive initiatives to address effectively the health inequalities issue – despite this being a stated priority of each Scottish administration since devolution²⁴.

1.40 The Health and Sport Committee has sought to widen the debate on inequalities having concluded that 'most of the primary causes of health inequalities are rooted in wider social and income inequalities.' The Committee has called for the Scottish Parliament to adopt a joined-up approach across a raft of policy areas and has asked all parliamentary committees to consider their role in addressing the issue.

Impact of the Smith Commission

1.41 On 27 November 2014, the Smith Commission published its proposals for new powers to be transferred to the Scottish Parliament²⁵. The UK Government published

Further policy developments and study methodology

its draft legislation on 22 January 2015²⁶. The impact on welfare reform and health inequalities of the proposed legislation remains to be seen although the Scottish Government has indicated their concern that the draft powers give the UK government a veto on key Scottish welfare policies²⁷.

Health and social care integration

1.42 Currently underway is the integration of health and social care, a programme of service reform, designed to facilitate the merger of adult health and social care services (and certain other health and social care services) currently delivered separately by health boards and local authorities in Scotland. The integration is being taken forward under the Public Bodies (Joint Working) (Scotland) Act 2014. Service reform, designed to facilitate the merger of adult health and social care services (and certain other health and social care services) currently delivered separately by health boards and local authorities in Scotland. The integration is being taken forward under the Public Bodies (Joint Working) (Scotland) Act 2014.

1.43 All integration arrangements must be submitted for Scottish Government approval by 1 April 2015, at which date the existing Community Health Partnerships also cease to exist. These new Integration Joint Boards and their Health and Social Care Partnerships will be tasked with 9 formal health and wellbeing outcomes, one of which states that 'health and social care services contribute to reducing health inequalities.'

1.44 Third Sector Interfaces have been established in each of the 32 local authorities – with Voluntary Action Scotland as the lead network organisation. The policy intention is that these interfaces will play a key representative role in relation to the new integration authorities but specific arrangements for the third sector are subject to local negotiation and decision-making.

The Inequalities Action Group

1.45 Early in 2014, the Ministerial Task Force on Health Inequalities published its second review of *Equally Well*, concluding that no significant narrowing of the health inequalities gap had occurred since the

first report²⁸. The Ministerial Task Force determined, following this further review, that a further 2 year review cycle was not the best way to drive progress. As such, responsibility has now been allocated to the Health and Community Care Delivery Group which has representatives of the Scottish Government, local government, NHS, the third sector and other key groups²⁹. A sub-group of the delivery group – the inequalities action group – will be responsible for undertaking research-based work and submitting it to the delivery group, with recommendations on areas to be taken forward.

Methodology

1.46 A mixed-methods approach was adopted to meet the study requirements. This comprised:

- Context review
- Electronic survey
- Workshop observations
- Interviews and case studies
- Analysis and reporting

1.47 Each element of the methodology is described in more detail below.

Context review

1.48 Key documents were reviewed at the outset of the study to contextualise the research findings. The main areas of focus centred on national strategies and publications including: UK Welfare Reforms; Guidance for NHS Boards on mitigating actions³⁰ (2013); A Fairer Healthier Scotland³¹ (2012); the Christie Commission on the Future Delivery of Public Services³² (2011); Health Inequalities in Scotland³³ (2011); *Equally Well* and its subsequent review³⁴ (2008 and 2010); and *Achieving Our Potential*³⁵ (2008). Material hosted on the European Portal for Action on Health Inequalities³⁶ was also referenced.

1.49 The review encompassed: VHS outputs, such as Member Spotlights³⁷; NHS Health Scotland's Health Inequalities Policy Review (2013); and the Report of the Scottish Parliament Health and Sport Committee's Inquiry into Health Inequalities (2015).

Reports from VHS events including 'A Fairer Healthier Scotland: A Way Forward Together' held at The Gathering³⁸ (2014), Sounding Board on 'Third Sector Contributions to Narrowing Health Inequalities'³⁹ (2013) and Symposium 'Drawing It All Together'⁴⁰ (2013) were also reviewed.

Survey

1.50 A short survey was developed and piloted in partnership with VHS. To facilitate effective comparison of responses across what is a complex subject area, participants were asked to select from a list of answers for each question. The options were based upon analysis of themes that emerged at a VHS Sounding Board event on health inequalities held in October 2013. An open-ended comments box per question was provided and participants were encouraged to provide additional comments. Respondents were invited also to volunteer to be further involved as one of the 10 follow-up case studies.

1.51 The survey was distributed via email to VHS partners and members. Participants were able to distribute the link within their own networks, so that responses were sought too from relevant third sector organisations that do not currently hold membership of VHS. Awareness of the survey was raised through a short presentation at each VHS health inequality themed event and a link to the survey was incorporated in the VHS monthly newsletter.

Survey participant profile

1.52 The survey, designed to produce a snapshot of activity within the sector, had extensive input from voluntary health organisations across Scotland, with responses from 155 voluntary organisations plus a further 6 from partner bodies.

1.53 Profile analysis shows that:

- The survey was completed by individuals representing 161 organisations (more than one return was submitted by 13 organisations). Third sector organisations account for the majority of responses (155 out of 161) with the remainder (6 returns) submitted by representatives of public sector bodies, including local authorities and health boards.

- Two thirds (111) identified their service as being a 'registered charity', over half (89) as a 'voluntary organisation', 26 selected 'other' and a minority (10) described themselves as a 'social enterprise.' Many organisations (49) ticked two options (typically both 'registered charity' and 'voluntary organisation'), and 9 organisations ticked all three options ('registered charity' 'voluntary organisation' and 'social enterprise').
- There was a broad mix of representation in terms of participant reach and areas of operation. Just under a third of respondents (54) operate at a national level, and a similar number (50) deliver within one local authority. A quarter (39) deliver their services in a specific locality within a local authority area (for example, a particular postcode) and a minority (18) operate across multiple local authority areas (for example, 'Edinburgh, Dundee, Tayside, West Lothian and Fife').

Workshop observations

1.54 In 2014, VHS held the Unequal Lives Unjust Deaths programme of seminars to explore the causes of health inequalities and consider the impact on the health of individuals across different life stages:

- Early Years
- Transitions from youth to adulthood
- Vulnerable adults
- Later life

1.55 There were 183 registered attendees across the four seminars. Participants worked together in small groups to explore the issues raised in presentations by keynote speakers. Groups were asked to describe how their work 'addresses health inequalities' and to discuss the strengths of and challenges facing the sector. VHS published a summary report on the key themes and messages discussed at each seminar.

1.56 Notes from the events were reviewed as part of the evidence-base for this study and the researcher observed participants' discussions at three of the events.

Case studies

1.57 Ten organisations were chosen from 76 that expressed interest in taking part in this further aspect of the research. The selection process was designed to ensure the case studies reflected:

- a broad range of voluntary health sector organisation sizes, locations and reach;
- the opportunity to highlight different types of engagement in 'health inequalities work' being undertaken; and
- emerging survey findings.

1.58 Each example illustrates a different aspect of activity delivered by the sector so across the ten studies a broad range of views and experiences are presented. The case studies draw upon information garnered from 36 interviews undertaken with a range of stakeholders plus staff from each organisation, including managers, delivery staff and (where feasible) beneficiaries.

Analysis

1.59 The assessment of quantitative data began with data cleansing to remove duplicate responses and data aggregation to allow for total counts.

1.60 Analysis involved a total count and percentage calculation of responses to each multiple-choice question and cross-counts of responses made where multiple answers were possible. The data was converted into tables that rank responses in terms of the highest to lowest frequency of answers per question.

1.61 The qualitative data assessment was based upon thematic analysis. This involved an initial review of the entirety of information gathered; identification of key themes; grouping, narrowing and apportioning qualitative data under themed headings; and the selection of quotes that typified responses within each category.



Circle

A whole-family approach to supporting a group at risk of specific health harms, stigma and social exclusion.

Circle supports the most disadvantaged families affected by substance use, imprisonment or where children are at risk of school exclusion. This organisation believes that its work helps to improve or prevent health inequalities, by facilitating engagement with health services and encouraging service users to address factors that contribute to poor health outcomes. Circle communicates its knowledge of the needs and experiences of this group to advocate for upstream changes that may address health inequality influences, such as service design.

What is Circle, how is it funded and who does it support?

Circle has two specific objectives:

'To provide help, support and protection to children, families and individuals who are in conditions of poverty, vulnerability or distress or who are otherwise in need by reason of their personal, social or economic circumstances.'

and

'To advance education, policy and practice in health and social services through the study of conditions that harm children and families through dissemination of knowledge gained through that study and the experience of service provision.'

Circle works with parents, kinship carers, children and young people. Many referrals come from the local Alcohol and Drugs Partnerships who signpost users to the charity in cases where they identify children living in a household affected by substance use. During 2013–14, Circle provided whole family support to 672 families (comprising 2,345 family members) in Edinburgh, Lanarkshire, West Lothian, East Lothian, Midlothian, Glasgow, North Strathclyde, Fife, Forth Valley and Tayside.

How does Circle believe its work helps to improve the lived experience of health inequalities or prevent them?

Delivering a targeted service:

Many service users are individuals who have, or who are at risk of, developing specific health conditions as a result of substance use. Circle's services are designed to engage these groups, with workstreams including:

- Support to all family members affected by substance misuse
- Support for families with children looked after by kinship carers
- Group work and outreach family support for children under 12 years

- Linking 5th and 6th year students with younger children who are struggling in mainstream education

- Placements for social work students

- Lone parent employability project

- Families affected by imprisonment – supporting mothers and fathers in prison who are returning to their families

Providing information about health issues:

Circle works with families to identify and address unmet needs including providing information and support to help people to engage with health services. Actions are tailored to individual families and may therefore vary. Examples include: supporting a family to register with the local GP or optician; encouraging someone to engage with mental health services; helping an individual to plan a journey to the dentist; or building confidence so that an individual is more likely to participate in medical interventions.

'We supported a single mother to undergo treatment for Hepatitis C that she had previously 'put off' for two years because of fears about being able to care for her children over the lengthy recovery. Her support worker researched treatment types and identified alternative medication with a shorter convalescence time-span and the mother engaged with this treatment as a result.'

Gathering evidence about health and wellbeing:

There is ongoing consultation with the communities Circle supports:

'Our research paper 'Listening to Fathers' identified marginalisation and a range of unmet needs, including more training for NHS health staff working with fathers and additional specialist support for dads in the antenatal and early years.'

Working in partnership:

Circle is a partner in a number of Public Social Partnerships (PSPs). These are contractual arrangements between third and public sector bodies under which the third sector delivers a specified service:

'In West Lothian Supporting Families PSP, we provide intensive support to families who are 'just coping.' The aim is to minimise the risk of crisis and to reduce the need for statutory interventions.'

Circle also works alongside several schools to improve children's educational opportunities, prevent exclusion and support relationship development between families and schools.

Influencing policy and raising awareness:

Circle participates in national consultations related to their area of practice and expertise eg the Children and Young People (Scotland) Act 2014, and the Development of Electronic Monitoring in Scotland Consultation in 2013.

Delivering early intervention and/or preventative activities to improve health and wellbeing, or reduce the risk of health problems arising. Circle highlighted that its service users often face a range of barriers linked to early intervention and preventative activities, e.g. stigma associated with substance use or imprisonment; discrimination from health care providers; fear of contact with health and social services; a lack of history of engagement with health care; and chaotic lifestyles that have negative impacts upon nutrition, exercise and well-being. Staff highlighted that service users typically have low expectations about the long term and may not prioritise health matters:

'An integral part of our activity is to support individuals to take greater care of themselves and their children; to help families engage with health care providers before crisis point; and to encourage them to adopt positive health and wellbeing behaviours.'

www.circlescotland.org



Fife Society for the Blind

A 150 year old charity that provides pioneering, holistic support for people in Fife who are affected by sight loss.

In recent years there has been growth in the number of people affected by sight loss in Scotland, underpinned by factors such as increased life expectancy, an ageing population and the greater prevalence of health conditions that affect sight: for example, strokes or obesity. People with sight loss can experience a range of difficulties that affect health including limited physical exercise, risk of injury, low self-confidence, isolation, poverty, transport and accessibility barriers. Combined sight and hearing loss is also common. Fife Society for the Blind (FSB) focuses on two key areas of work. First, prevention: the identification and early intervention for individuals who may be affected by sight loss. Secondly, independent living support for people with sight impairment. Their range of services includes access to opticians and a specialist sight clinic, needs assessments, adapted technology, training and rehabilitation. Social inclusion is promoted through volunteering opportunities, befriending, transport assistance and fundraising activities.

What is the FSB, how is it funded and who does it support?

FSB provides services across Fife through a team of 19 paid staff, over 100 active volunteers and an annual budget of around £900,000. There are approximately 4,750 individuals on FSB's register but their reach is wider. For example, people outwith Fife may purchase adapted equipment or transcription services from the charity. Referrals come from a range of sources including GPs, hospitals, self-referrals and other third sector organisations. FSB also works in partnership with Nairn Optician, a community-based service that provides a gateway into local sight-loss services.

Funds comprise Service Level Agreements with Fife Council and NHS Fife, legacies, fundraising through events by volunteers, and grants from trusts and charities.

How does the FSB believe its work helps to improve the lived experience of health inequalities or prevent them?

Recently, preventative activity and early intervention have been prioritised as key areas of FSB's activity, resulting in changes to the design and delivery of support and an expansion in the number of people who benefit from FSB's services. This requires partnership working to develop relationships with referral agencies and raise awareness among communities at risk.

There are plans to widen FSB's reach so that more people access support when they need it or take early steps to avoid preventable or further sight loss.

In addition to preventative work, FSB believe that their services are crucial in helping people affected by sight loss to maintain their independence, sustain physical and mental well-being and prevent social exclusion. Their social work team provides a needs assessment for people who are newly registered blind, working with individuals in their homes to develop a tailored rehabilitation plan that identifies the resources available to support recovery and improve quality of life.

The lived experience of health inequalities can be worsened if people are unable to engage with services and resources in place to support them. Sight loss is often concurrent with other health conditions and can have other health impacts. Sight associated barriers to access and information may compound health difficulties or reduce the capacity for self-management. FSB staff highlighted that services such as adapted technology, advocacy and translation help people to overcome information barriers. A recent example includes converting guidance sheets about self-directed support funds to facilitate greater access to support services.

Staff suggested that FSB is well placed to respond quickly to trends and contextual developments affecting people with sight loss. These range from immediate, practical matters – such as tips for what to do when it snows – to new work streams including advances in technology. FSB's innovative work on adapted use of smart phones and tablets was highlighted as an effective way to sustain independent living, with many practical and social outcomes from greater use of technology:

'So much of everyday life is done on computers or phones now – the amount of online shopping grows year by year – so we're looking at ways to make that accessible and also keep people safe. It's important to be able to do what everyone takes for granted – or the sense of exclusion is compounded.'

Another important element of the support available from FSB is that it is holistic, as one service user's experience demonstrates:

'I've been involved with FSB for my whole life. I was born blind and my parents didn't know what to do with a blind baby or how to interact; what I would respond to. They taught my mum about tactile games and books so she could play with me... as a child I did things like mobility training, cooking skills, participatory sports through FSB. At school I was in the young person's activity group... later I did my work experience here... finally they gave me the training I needed for work.'

Staff highlighted that part of their work to mitigate health inequalities includes partnership activity with other organisations to improve services. This includes a joint sensory project with Deaf Action, and strategic work with the Fife Physical Disability and Sensory Impairment Strategy Implementation Group, made up of health partners from NHS Fife and the third sector.

Former Prime Minister Gordon Brown MP is Honorary President of FSB, and the charity believes this contributes to its ability to influence further upstream. Additionally, FSB has a service user involvement panel that facilitates consultation and provides a route to influence upstream factors such as service design and delivery:

'We were involved in a review of sensory services in Fife and where possible we take part in consultations. Organisations come to us when they want to find out our thoughts on how proposals might impact on people with visual impairments.'

Service users also highlighted that FSB's work builds capacity within families who are adjusting to a loved one's sight loss:

'At first we were all at a loss – my sight went very quickly and we have two young children. But FSB has helped in so many ways, especially with my family; they taught my husband and my children how to help me. Simple things like sighted guide training – explaining how to direct me across a room; made a real difference- they feel more confident in being able to help me, it's less frustrating and I feel more independent. It's actually something we laugh about now because at the start my husband was always forgetting what to point out and I was forever bashing into things!'

www.fifeblind.org.uk



The MARCH Project

A voluntary sector organisation working with a health board, local authority and other third sector partners to address poverty and hardship issues. The partnership is currently involved in a pilot project with NHS Lothian to identify people at risk of poor health outcomes linked to poverty.

The Midlothian Area Resource Coordination for Hardship (MARCH) project aims to tackle poverty and financial exclusion. One of its work streams includes a partnership with NHS Lothian's Health Promotion Service to identify and support service users affected by poverty, particularly those with disabilities and long-term health conditions. Its work straddles two areas of the health inequalities spectrum: seeking to change upstream influences (service delivery) and working at the downstream level to support people whose health and wellbeing may be affected by low income.

What is the MARCH project, how is it funded and who does it support?

The Midlothian Area Resource Coordination for Hardship (MARCH) project is a partnership between Midlothian Financial Inclusion Network, Midlothian Council and Changeworks. Neither a frontline delivery agency nor a health care provider, the MARCH project exists to:

'Coordinate and improve the resources available for hardship in Midlothian.'

A team of 2.5 full time equivalent staff work across a range of project activity, often engaging with different partners from within the Midlothian area.

The MARCH Project commenced in September 2013 having been awarded a £200,000 grant from the Big Lottery's Support and Connect funding programme. In April 2014 further funding was provided via NHS Lothian from a small grant they were awarded by the Scottish Government Health and Welfare Reform Development Fund. This enabled the MARCH Project to carry out joint work with their Health Promotion Service, to help mitigate against the impact of welfare reform on health inequalities in Midlothian. The Project has funding to continue until the end of August 2015, and future funding options are currently being explored.

How do MARCH and partners believe their work helps to improve the lived experience of health inequalities or prevent them?

The MARCH project is involved in a range of activity to address the financial hardship that contributes to health inequalities. Case study interviewees described the value of the MARCH project in changing the way that third and statutory sector partners work together on health matters. For example:

'Establishing that tackling financial hardship is linked to the preventative healthcare agenda.'

'It has helped to strengthen the partnership between the third sector and other health and social care providers including the council and NHS Lothian.'

'We're collaborating with another health board over a similar project; to share learning.'

'Knowing how to use the 3rd sector better.'

The MARCH project's partnership with NHS Lothian's Health Promotion Service is a pilot approach that seeks to develop capacity in the frontline teams that visit service users at home. These include Health Visitors, the Community Mental Health Team, Substance Misuse Treatment staff and the Community Learning and Disability Service. These staff are in a position to identify people living in poverty. NHS Lothian is leading on the workforce development aspects and MARCH's role is to create resources and referral pathways so that health staff can signpost individuals to appropriate advice and support service that deal with welfare and poverty issues. For example, it was suggested that health staff:

'Might visit a home and notice that it is very cold and damp, because the person cannot afford the heating. Or perhaps they can't heat their meals up because they have no money for the gas cooker. Or maybe they have nothing in the cupboard.'

The pilot is being trialed on a small scale using the 'test of change' approach. Because poverty is a sensitive topic, initial engagement work was carried out with staff to communicate its value and purpose. Only those who expressed an interest in participation were involved in the later stages of the pilot. These staff and a small number of service users took part in work to develop and test a screening tool that will be used to assess financial inclusion and signs of hardship. If hardship is identified, service users will be signposted to support using the 'crisis' signposting guide developed by the MARCH Project. This contains contacts for services that can address needs related to money, food, fuel, housing, health and well-being services. One case participant described the approach as supporting:

'A shift away from the medical model of simply addressing symptoms, to a more preventative approach... to identify and tackle the poverty that underpins many of the physical and mental health issues that our service users experience.'

Other comments about the impact of this work included:

'Internally it has given staff a language to talk about health inequalities'... and... 'we can talk sensitively with service users about how their living circumstances might be affecting their health.'

MARCH Project partner Changeworks is a national environment charity that deals with fuel poverty and vulnerable households. Many of the people identified as living in hardship are referred to this service. Their staff provided examples of the ways that fuel poverty can affect physical and mental well-being, including:

'Professor John Hills linked fuel poverty to nearly 3,000 deaths per year in the UK and there are other health effects such as lack of resilience, respiratory illness, increased risk of stroke... There are clear mental health impacts too: people experience stress and depression when their home is freezing, they won't have visitors and become isolated... we see examples of children stigmatised at school when their clothes are mouldy or smell of damp; it's because their parents can't afford the heat to dry their washing properly.'

Changeworks's services include advice on energy efficiency, switching tariffs and help with understanding bills and over-charging. As one staff member explained:

'Often dealing with energy suppliers takes self-confidence and knowledge of rights and tariffs; many living in fuel poverty –especially the older people – don't have that. For example, if they don't have access to the internet they can't look things up... it's not only extremely complicated but the price of a call to an energy provider can be expensive, you can be on hold for a long time. We have the time, the skill and the patience to make that call and advocate on their behalf.'

www.mfin.org.uk

ASH Scotland

A national third sector organisation that seeks to reduce and prevent harm from tobacco use. As well as operating at an upstream level to tackle factors that influence smoking, they have developed partnerships with agencies that work with the groups at most risk of tobacco-related diseases, to deliver targeted, focused messages that people can engage with.

There are strong associations between smoking prevalence, socioeconomic disadvantage and the rate of tobacco-attributable disease; while smoking rates have decreased across all groups, the smoking gradient between higher and lower socioeconomic classes has increased over the past 15 years. ASH Scotland's work to reduce and prevent harm from smoking is broad ranging; including efforts to bring about changes in behaviour and influence bodies with the power to change policies or deliver targeted interventions.



What is ASH Scotland, how is it funded and who does it support?

Action on Smoking and Health (Scotland) is the national charity that tackles the harm caused by tobacco. It was established in 1973 and is an independent organisation. The majority of its work is conducted at a national or partnership level. A representative explained that:

'In putting inequalities at the heart of our work what we're doing is reflecting the fact that tobacco use in itself is really an inequalities issues. When you consider that the smoking rate in the poorest communities is four or five times higher than in the richest communities, and about 30–40% of all the tobacco consumed in the UK is consumed by people with mental health problems – it becomes clear that we need to tackle tobacco use within a particular context that is very closely matched with income inequality in our society. We've moved past the scenario when inequalities was just one part of the issue we're tackling, to it being largely focused on inequalities.'

Their team of 21 full time equivalent staff work across four areas; management, policy and research, engagement and business.

In 2013/14 ASH Scotland had a budget of around £1 million. Funding consists of a range of grants from various sources, including core funding from the Scottish Government combined with monies from the British Heart Foundation to collate and share information about smoking and tobacco harm. Their lobbying and campaigning work is funded by Cancer Research UK and self-generated income from other sources. The charity also receives funding for various activities from NHS Health Scotland, the Big Lottery and donations.

How does ASH Scotland believe their work helps to improve the lived experience of health inequalities or prevent them?

Staff acknowledge that significant progress has been made in Scotland in terms of changing attitudes and behaviour, explaining that:

'While we have had some great successes in Scotland and have a national target of

being smoke free by 2034, there's still a need for us to make sure all the things that we know about tobacco continue to percolate through to policy and practice at a local level.'

Work streams include training for people who work in the field of tobacco and health, such as professionals in dementia or family support services. ASH Scotland host and participate in events to foster partnership working between the various agencies that are interested in or have an influence on the areas of tobacco and health. They undertake lobbying and advocacy work to encourage the Scottish Government, health boards and other agencies to implement policies and legislation that affect tobacco consumption. They provide information and gather evidence so that people can understand and monitor smoking in Scotland and view data on its impact upon health, society and the economy.

The case study interview included discussion of the unintended effect whereby interventions aimed at the general population result in widened health inequalities, because lower income groups may be the least likely to respond to health information campaigns and are therefore 'left behind' in terms of unchanged behaviour. While efforts to tackle smoking have achieved an important reduction in the overall number of smokers in Scotland, they have not sufficiently changed the behaviour of groups in which tobacco-related disease is most prevalent:

'We've seen enormous progress in terms of shifting tobacco from being right in the mainstream of society and a normal thing that people do, to being more and more towards the margins... but this shift has occurred differently, among different groups within the population. So now, while there are many sections of society where smoking really is a very unusual thing, in many other areas the social acceptability of smoking and the smoking rate are still what they were in the whole population 40 years ago.'

When discussing the success or failure of social marketing campaigns among groups in society with different socioeconomic profiles, staff talked about the complex context in which people smoke and how this can make it more, or less, easy to give up smoking.

'There are so many things that can affect behaviour; how many challenges you face in a day, how well placed you are to plan for the future and if you have aspirations for the future... through to how many times in a day you really need a guaranteed dopamine hit. And all of that adds up to the day-to-day, lived experience in which people smoke. So while the number of people who say they want to quit is pretty much constant across all groups, the ability to act on that desire or intention varies. If you simply put out the message that 'smoking is bad for you' it will have an effect – but not for everyone.'

An example of ASH Scotland's efforts to engage groups most affected by tobacco includes a pilot project run in partnership with a health board and a credit union called 'The Cashtray Project'. When savers set up their credit union account, the project helps them to calculate the potential savings from not smoking, to encourage and motivate them to reduce their tobacco consumption. ASH Scotland's development team delivers the training for Credit Union staff, so they can discuss sensitively the benefits of saving money through quitting smoking. Another key area of work, delivered in partnership with youth organisations such as Young Scot and Youthlink Scotland, is supporting young people to make positive choices about smoking.

The training team also works with family support services to demonstrate how far smoke can travel through a home, even if the smoking takes place by a window or outside a particular room. All this activity is conducted in partnership with delivery organisations.

ASH Scotland is also keen to address the issue of smoking by individuals with mental health problems, noting the prevalence of tobacco use among this group.

'Not only does the evidence tell us that people – especially people dealing with mental health issues – feel better when they stop smoking, but you need to consider the inequality of the health harm arising as a result of tobacco use among these people who are smoking when they are at their most vulnerable.'

www.ashscotland.org.uk



Argyll Voluntary Action

Releasing social capital to reduce isolation and exclusion in rural areas, improve mental health and support people to engage with health services and positive activities.

People living in rural areas face multiple factors that can contribute to poor health outcomes including poverty, transport barriers, inaccessible services and isolation. Through facilitating volunteering, Argyll Voluntary Action (AVA) aim to avoid, prevent or reverse health inequalities in a variety of ways; through engagement in positive activities, supporting people to access services and providing an additional resource for communities most affected by health inequalities. Its work to represent partners and engage communities is also part of an effort to influence strategic decision making at an upstream level.



What is AVA, how is it funded and who does it support?

AVA facilitates, supports and encourages volunteering and is based across several offices in the main towns of Argyll and Bute; Lochgilphead, Campbeltown, Dunoon, Oban and Helensburgh. In and around general volunteering facilitation, two key areas of work AVA focuses on relate to groups with a particular risk of poor health outcomes and social exclusion: families who have experienced domestic violence and older people. These are delivered under the programmes 'Survive and Thrive' and 'Reshaping Care for Older People.' AVA has over 25 staff members and is the lead organisation in the local Third Sector Partnership which forms the Third Sector Interface. Funding is drawn from a range of sources including NHS Highland, Argyll & Bute Council, The Scottish Government, the Big Lottery Fund, Robertson Trust and European Funding.

How does AVA believe its work helps to improve the lived experience of health inequalities or prevent them?

Staff highlighted that a key issue for people living within rural areas of Argyll & Bute relates to the difficulty of accessing services. These barriers relate to the time, cost and distance that must be travelled. On a practical and individual level the distances involved can present particular challenges for anyone who is experiencing poor health – affecting access to health care and impacting upon the extent to which people go to services for diagnosis and treatment:

'We're pushing for greater use of technology by health staff, to overcome barriers to access – but there's a lot of work to be done. Not only do health staff need permission and access to the equipment – but older people, or people living in poverty may not have the skills or resources needed to use these methods of access.'

On a broader level, access barriers can also affect the extent to which people are able to participate in consultation or activities that

enable their views and experiences to be heard. This results in a potential lack of representation or influence at an upstream level; AVA attempt to redress this imbalance but note that there are resource considerations:

'It might sound like an odd thing to raise in a discussion about health inequalities – but the simple fact of the matter is that a half hour meeting with health partners resulted in a six hour round trip for me. Is it worth spending that time, when we have limited resources? The travel implications mean we have to think carefully about which meetings we attend.'

'Groups that we support like Grey Matters enable people to have a voice; outcomes from GP surgeries appointment system, changes to dropped kerbs all improve equality of access and result directly from interventions. We ensure opportunities to meet with professionals, decision makers and leaders on terms which are accessible to communities; participatory engagement.'

Staff highlighted that some of the people living in Argyll and Bute are particularly affected by a lack of joint up delivery of health services; volunteers provide practical services such as driving that are used by people who struggle with access to health appointments:

'We know of people that require three appointments with different specialists, because of their complex health needs. It might take them a day to travel to the hospital. But these appointments aren't coordinated – so instead of seeing three doctors in a day, they may have to make several long trips over the course of a short period of time. For a seriously ill person that's not helpful. One volunteer regularly undertakes a 397 mile round trip to accompany an older person with long term conditions.'

Other challenges facing some individuals living in rural areas are issues connected to mental wellbeing, such as social isolation, loneliness, depression and low self esteem. Staff suggested that the volunteering facilitated by AVA's helps to combat these challenges; both for the individuals who volunteers and for the people they go on to support. The types of voluntary activity vary depending on the skills and interests of the

volunteer; this means that a broad range of activity is available. It includes services such as recycling schemes to help people afford equipment they need, befriending and running social events; and delivering courses to improve skills – for example, the 'silver surfers' class to improve computer literacy. AVA supports community volunteering, offering practical help from gardening to help around the home and learning new skills:

'Volunteering that involves physical activity also has a positive health outcome for those involved.'

'Our strength and balance classes aim to prevent falls among older people.'

Much of AVA's work aims to empower individuals and build community capacity; this activity has the potential to address upstream factors contributing to health inequalities. For example, they recently ran a project called 'Involving to Devolving, Influencing Change' through which they sought to engage groups and individuals with little or no previous engagement with decision-making processes. This involved a roadshow across remote areas. Through support and training, the people involved were empowered to engage with and influence the planning and delivery of services.

Another area of potential upstream influence is its role as the TSI; through this, AVA represents local organisations in forums of influence at local, regional and national levels:

'When local health care plans and strategies are being delivered we get involved and facilitate representation of the third sector partners. We also engage with communities and facilitate their voices being heard.'

Wider work with other partners also shares resources across the community, for the benefit of the most vulnerable:

'Our office in Helensburgh is used as the drop off point for donations to the food bank and Helensburgh and Dunoon offices also support credit unions.'

www.argyllvoluntaryaction.org.uk

The lived experience of health inequalities

2.1 This chapter presents findings on how the voluntary health sector describe the lived experience of health inequalities of those it supports. It also illustrates how the sector views its own contribution to 'addressing health inequalities', focusing on interventions, strengths, opportunities and challenges.

2.2 Summary tables illustrate the quantitative data gathered through the survey; these are supported by additional findings from the qualitative material, gathered through the survey comments, VHS seminars and case study interviews.

Table 2.1 Factors linked to health inequalities

Category	Total Count	% (n=147)
Social isolation	134	91%
Barriers to accessing services	117	80%
Poverty	104	71%
Stigma	102	69%
Behaviour (associated with increased risk of health problems)	77	52%
Other	15	10%

The lived experience of health inequalities

2.3 Case study participants were asked for their views on how health inequalities affect the lives of the families or individuals they support. There was frequent mention of issues such as poor mental health, including anxiety, stress, depression, and of loneliness. In discussion, interviewees often highlighted that they believe there is a higher prevalence of preventable or treatable diseases. More than one respondent referred to their client groups having a reduced life expectancy when compared to 'people with higher levels of income.'

2.4 A common view expressed by participants was that much of the voluntary sector's health and wellbeing interventions do address health inequalities; their rationale was that interventions help to narrow the gap in health outcomes by supporting improvements for individuals who would otherwise have an even lower level of health and wellbeing than the general population.

2.5 The third sector works closely with the population groups that are thought to be at most risk of experiencing the effects of health inequalities. Survey respondents were asked whether or not they believe key identified factors might be contributing to the inequalities in health outcomes experienced by the people they support.

2.6 The range of comments made in relation to each category suggest that many respondents consider the underlying causes of health inequalities to be interconnected:

- **Social isolation** was identified by almost all respondents (91%) as a key factor linked to the lived experience of health inequalities of the communities, families and individuals with whom they engage. Many participants highlighted the links between social isolation, poverty and/or stigma.

A connection between social isolation and poor mental health was mentioned frequently, along with health-related consequences including low resilience, isolation impeding recovery from health conditions. It was suggested that social isolation can limit the ability to create and retain support networks. One participant explained: 'our young people are living in the worst houses in areas of social deprivation; they feel too frightened to go out and too ashamed to invite people home. It prevents them building relationships.' It was also pointed out that living with poor health may lead to or exacerbate social isolation. One response noted that 'having cancer as a young person affects your education, social life, family and friends, contributing to social isolation and bullying' and another pointed out that 'losing confidence as a result of eyesight deterioration makes your world narrower and narrower, until you no longer do the social things you used to go out and enjoy.'

- **Barriers to accessing services** were frequently identified by respondents as an issue that contributes to unequal health outcomes. In describing barriers, several contributing factors were highlighted, such as chaotic lifestyles, stigma, poverty, literacy and communication issues. Examples

included 'losing contact with health services when clients change their address and mobile number'; 'lack of understanding from health care providers, who want to deal with the medical issue not the complex problems that relate to it'; and 'they [those at risk of experiencing health inequalities] don't have the Internet so they can't access the [health] information.'

- **Poverty** was identified by 71% of respondents as a major issue underpinning health inequalities. Comments and examples included: 'current welfare reform is increasing risks of health inequalities due to increasing numbers experiencing severe financial hardship'; 'parents can't afford the bus fare to take their children to the GPs'; 'many of our clients are experiencing fuel poverty, which affects health and wellbeing'; and 'we see children with mouldy clothes because they live in a damp, cold home... mould is bad for health and it makes them feel stigmatised at school.' Some participants suggested that financial constraints affect the extent to which people can adapt to, or recover from, health conditions; for example, one person supported by a case study organisation said: 'I couldn't afford the equipment I needed to allow me to [stay] mobile.'

- **Stigma** was highlighted as a factor that impacts upon mental wellbeing, prevents engagement with health services and, in some cases, was said to reduce the quality of health care support received. Responses included: 'one of the people we are supporting with sustained drug recovery

went to their doctor to get support for a completely unrelated health condition; they were written off because of their previous drug use'; 'our young people often haven't benefitted from the health campaigns and interventions offered in mainstream education because they have been excluded from school at an early age'; and some people being 'reluctant to ask for help from statutory agencies as they are fearful of being judged and/or that their children may be taken into care.'

• **Comments on the link between health inequalities and behaviour** often focused on an individual's poor mental health and low self-esteem. There were references to a lack of knowledge about harmful effects of behaviour and individuals having limited propensity to plan for the longer term. Some voluntary health sector representatives explained starkly that 'a short term outlook affects the ability to relate to health issues that might arise in the future' and 'as a result of living day to day, week to week – [they] are not planning for the years ahead.' A few participants attributed the prevalence for 'risky behaviour' to a lack of positive activities, suggesting that harmful behaviours such as alcohol, tobacco or drug misuse were a result of seeking a 'dopamine hit' as a distraction, or escape, from unhappy circumstances.

2.7 Other issues mentioned in relation to health inequalities were: lack of positive role models; increased vulnerability; learning disabilities; abuse and violence; experiencing unresolved grief; poor parenting skills; speech, language and communication barriers; and political disengagement.

Who does the voluntary health sector support?

2.8 Table 2.2 presents two broad groupings of individuals supported by the voluntary health sector: those with specific health issues or people in a particular community.

2.9 Many case study participants pointed out the challenges in categorising the individuals they support because many of their clients have multiple health issues. For example, Fife Society for the Blind often supports individuals in coping with hearing

Table 2.2 Who does your organisation support?

Multiple response categories	Count	% (n=161)
People with a specific health issue	54	34%
A particular community, either geographical or a community of interest	72	45%

Table 2.3 Which of the following are the main areas of your organisation's work?

Category	Total Count	% (n=157)
Health	96	60%
Children and young people	74	46%
Social care	71	44%
Disabilities	70	43%
Volunteering	70	43%
Mental health	59	37%
Older people	58	36%
Accommodation and housing	35	22%
Social enterprise	26	16%
Environment	25	16%
Human rights	22	14%
Intermediary	21	13%
Adult education	19	12%
Local interface	16	10%
Arts	15	9%
Culture and heritage	15	9%
Sports and recreation	9	6%

problems, mobility issues or in recovering from a stroke. That has led them into working with clients to build confidence; alleviate social isolation; increase physical activity; and support independent living. Additionally, the Society supports the family

or other individuals who provide care to people who are blind or partially sighted.

2.10 Table 2.3 illustrates the responses to a question on 'areas of work.' The results here provide more insight into the communities supported by the voluntary health sector,

Working upstream and downstream

with most organisations (135 out of 157) responding that they work across more than one group. This indicates perhaps one of the unique strengths of the third sector, in that the flexibility of its approach provides a range of opportunities to engage with individuals, families and communities and to support them in coping with the challenges they face, including health inequalities. With their focus on the individual, the family or the community, organisations in the third sector are often called on to support their clients as they cope with a complexity of issues.

What work does the voluntary health sector do?

2.11 Types of work undertaken by the sector vary considerably, as shown in Table 2.4. Most respondents (131 out of 142) indicated that their organisation is involved in a range of work areas.

Table 2.4 Type of work undertaken

Category	Total Count	% (n=142)
We work in partnership with other organisations to improve the design and delivery of interventions for the groups we work with	117	82%
We influence policy and raise awareness of the needs of the people we support	100	70%
We refer people to other health services	99	70%
We provide information about health issues	95	67%
We deliver a service targeted at addressing the needs of a specific group	90	63%
We deliver early intervention and/or preventative interventions to improve health and wellbeing to reduce the risk of health problems arising	88	62%
We gather evidence about the health and wellbeing needs of the people we support	78	55%
We raise funds to deliver interventions to the groups we work with	74	52%
We provide advice or advocacy on health issues	61	43%
We deliver health services to people who are already experiencing physical or mental health issues; to support their recovery and improve their experiences	52	37%

Themes in the qualitative data

2.12 The majority of case study participants demonstrated a keen awareness of relevant publications, funding streams (such as the Reshaping Care for Older People Change Fund), contextual changes (particularly the integration of health and social care services and welfare reform), Scottish Government frameworks and policies (for example, Equally Well) and Local Authority structures and plans (including Community Planning Partnerships and Single Outcome Agreements).

2.13 A clear theme running through the qualitative comments was an acknowledgement that health inequalities are manifestations of broad social and economic issues. Case study participants were asked to describe how they believed their work related to health outcomes and health inequalities. Themes that emerged across the survey, workshops and interviews are grouped under the following categories:

- Participants' thoughts on addressing upstream causes of health inequalities versus downstream impacts

- The voluntary health sector's views on its strengths in relation to tackling health inequalities
- Challenges and opportunities for the sector

Addressing upstream causes of health inequalities versus downstream impacts

2.14 At VHS seminars many participants regarded their work as contributing to, and having an impact on, addressing health inequalities. However, many acknowledged the challenges of demonstrating this by means of robust evaluations.

2.15 A summary of participants' views on how the third sector's work might address upstream causes, mitigate or even reverse downstream impacts is provided in the boxes opposite.

How does the sector see its strengths in relation to tackling health inequalities?

2.16 Several cross cutting themes were identified among the comments from voluntary health sector staff; each point is summarised below and supported by an illustrative quote or quotes.

The ability to engage those vulnerable groups and communities that statutory services may struggle to reach

2.17 Many case study participants suggested that this is what the voluntary sector does best. Explanations often centred on the notion that relationships with service users have a non-statutory basis and are therefore built upon trust, word of mouth and having credibility within local communities. It was indicated that this level of trust provides voluntary organisations

How might the sector address upstream fundamental causes or wider environmental influences?

A clear theme running through the qualitative comments was an acknowledgement that health inequalities are manifestations of broad social and economic issues. Several participants did express the view that, as the sector works with individuals, it is unable to address these underlying causes or influences. However, other participants suggested their work might influence key stakeholders with the power to create those systemic or legislative changes, for example, the Scottish Government. The importance of dedicated policy staff and participation in national consultations was often mentioned.

Linked to this influencing role, a frequently raised point was the sector's independence from government and statutory bodies, which was said by some to make it more of an 'honest broker.' For example, several argued for potentially unpopular actions – such as increases in taxation – suggesting that such change would help to address the fundamental causes of health inequalities.

Views on how the sector exerts influence on the health inequalities agenda largely focused on (i) contributing to changed attitudes and (ii) the way the sector works to improve service design and reach. A strong theme in these discussions was communication, research, partnership with other agencies and flexibility to adapt to new delivery models, for example, Public Social Partnerships. Several participants described collecting evidence, by facilitating service-user or community engagement, to feed into upstream decision-making processes and service design. The voluntary health sector's involvement in the commissioning of local services was also highlighted.

How might the sector mitigate or undo the downstream experiences for the individual?

The majority of participants were more comfortable in explaining how their work contributes to improving the daily experiences and immediate health outcomes for people affected by health inequalities.

Participants described the provision of direct support to individuals affected by health inequalities and their work to secure funds to deliver these interventions. Many highlighted their work to mitigate the effects of the health inequalities experienced, including by meeting needs not within the purview of statutory agencies. Examples quoted were providing companionship to overcome social isolation, or supporting people to change harmful behaviours.

The view expressed frequently was that the sector reaches people who, for a variety of reasons, are often not engaged by or with public sector services. Continuity of service, flexible delivery structures and trust from beneficiaries were highlighted as key strengths in terms of addressing experiences and effects.

with a position of influence. One survey participant suggested:

'The relationships that [the] voluntary sector develops with individuals in the community is the start of a health behaviour change.' (Survey response)

Addressing barriers to accessing health services

2.18 A key theme in discussions was the growing awareness across public and third sector agencies of the lived experience of health inequalities. There was repeated mention that encouraging or facilitating access to health services or health information is an important part of many organisations' work. For example, one manager said:

'I'm sure our service hasn't changed in fundamentals; but if you'd have asked me five years ago if we tackled health inequalities I'd have told you no, because we didn't classify our area of work as 'health.' But actually, we play a key role in helping our service users to access health services; we refer them, take them to appointments, provide information and advocate on their behalf if they are having a problem, for example, finding a GP that will register them. GPs in particular are reluctant to take on people with a history of substance misuse.' (Case study interview)

Asset-building and preventative approaches

2.19 Respondents highlighted that they regard their approach as strengthening the assets of those they work with; and responses focused on the preventative nature of the work undertaken, particularly among vulnerable groups. There was repeated mention of helping individuals to develop internal resources and capacity so that they build resilience and gain the skills and confidence to cope with the day-to-day issues they may experience:

'Early intervention and support... has been shown to improve overall health and wellbeing outcomes for people, increase their ability to self-manage, develop their self-efficacy, which results in a reduction in medical interventions.' (Survey response)

'We support people with increased vulnerability to self harm, attempted suicide... alcohol and substance misuse.' (Survey response)

'Our focus is parents and lone parents with few supports in place, isolated in their community without the confidence to access services in their area. They have poor parenting skills but are reluctant to ask for help from statutory agencies as they are fearful of being judged or/and that their children may be taken into care.' (Workshop observation)

'We put an increased emphasis on community support and capacity building in order to help address significant challenges which include the increased strains on health resources, ageing population, increased in breakdown in support at home, etc.' (Survey response)

Interventions, approaches and challenges

Provision of interventions that are rooted in the issues faced by specific communities

2.20 Linked to the point above, some participants suggested that because they are so rooted in their communities, they have a deeper understanding of their specific needs which allows them to create more detailed, nuanced support than is possible at the higher planning level where local authorities or health boards operate:

'[There are] barriers to accessing services due to having some of the most remote and rural postcodes in Scotland. Also high levels of stigma associated with mental health, domestic violence and addictions, particularly as this area is not very diverse, as well as being remote.' (Survey response)

Co-production in service design

2.21 It was highlighted often that the shape of the intervention is more effective if it is underpinned by joint thinking between the organisation and its users, and that the sector does this well:

'Our contribution to reducing health inequalities is made by supporting the involvement of service users and voluntary organisations in service delivery, review, and planning.' (Survey response)

'Co-production is a key aim of our organisation.' (Survey response)

Capacity to deliver support at the point of need

2.22 A number of research participants suggested there is often a requirement for rapid response at a point of crisis, outwith the waiting list systems operated by larger organisations or statutory delivery agencies:

'Often the individuals who are in most need are not accessing statutory services and therefore remain in the shadows of service provision.' (Survey response)

'People come to us for support around a whole range of issues which prevent them accessing the services they need, such as panic attacks or having a criminal record.' (Survey response)

'Benefit reforms impact on genuinely ill people. Highly raised anxiety and stress due to benefits being withdrawn after interview by ATOS [the agency that conducts assessments

on entitlements to disability welfare payments, on behalf of the Department of Work and Pensions]. Appeals seem to take eight months to come to fruition. Many appeals are won and benefits backdated. However, these people have had to survive on reduced benefits for a period of approximately eight months.' (Survey response)

Freedom to test and pilot innovative approaches

2.23 Several participants emphasised the sector's manoeuvrability; noting that statutory agencies often have less freedom in this respect because of procurement rules or budget constraints:

'Our hope is that by running a successful pilot, we can demonstrate that this model is a cost effective way of supporting those adversely affected by health inequalities, and that the project will be rolled out to other areas across Scotland.' (Survey response)

'We are a Government funded pilot. Our challenge is to demonstrate the difference our work is making to the people we support, and show how it can save the Government and health services money in terms of the preventative work we are doing.' (Survey response)

'Currently conducting a scoping project on piloting Time Bank within local area.' (Survey response)

The flexible and holistic nature of service delivery

2.24 Several mentioned the capacity to take a 'whole family' approach and to straddle the boundaries between statutory services, such as the distinction between services for children and adults. This type of support can also include assistance to family members caring for loved ones affected by health issues:

'The parents tend to have mental health difficulties, the children have mental health, physical, sensory, learning or life threatening difficulties.' (Survey response)

'Many parents of children with a disability need support and respite to maintain/sustain good mental health. They may also be overwhelmed by the diagnosis and need help to navigate the services available to them.' (Survey response)

Provision of training for partners

2.25 Linked to the notion of capacity building, some of the larger organisations/projects described how they engage effectively with other organisations to provide focused training:

'We offer placements for social work students.' (Case study interview)

'We may be asked to support any organisation whose service users may use tobacco [and] provide training and support to any voluntary organisations, as well as statutory organisations, on request.' (Survey response)

The freedom to communicate with service users

2.26 Being able to adopt engaging and personable approaches, using a range of tools, was another frequently raised theme. Many of the service delivery models involve extensive face-to-face or telephone contact. Some staff use mobile phones to stay in touch with clients. Texting can be particularly effective with groups that statutory services struggle to reach. Several voluntary sector organisations use social media platforms such as Facebook, blogs and Twitter to engage and communicate with communities and raise awareness of the support they offer. Freedoms to use these methods is often restricted among many statutory services:

'Communication still tends to be in written form e.g. leaflet with small print. Many people miss health messages, benefit change information, etc. because of the communication method. Even if they are told these messages, it is often difficult to take it all in and people naturally forget and misunderstand.' (Survey response)

Offer an alternative (non-clinical) approach to tackling health issues

2.27 Some voluntary health organisations feel that their ability to offer non-clinical approaches helps to build improved awareness and understanding of conditions by all those involved and complements medical interventions offered by the NHS:

'HIV is a social issue – people tend to acquire HIV when they have at least two other psychosocial problems such as homelessness, problem drug use, mental illness – but as much as this is known, all

national strategies still prioritise clinical outcomes. It is well established that there is no “getting to zero” [new infections and zero deaths from HIV], without addressing stigma; and yet addressing stigma is always the afterthought in health strategies. In fact the social elements of living with HIV, or being at higher-risk of HIV, are where change is needed.’ (Survey response)

‘We are interested in the social prescribing approach, where a doctor may prescribe an activity to assist with depression and isolation.’ (Survey response)

Partnership working

2.28 Several participants described the way voluntary sector organisations seek to work effectively with each other, highlighting the value of this activity in terms of extending capacity, shared learning and reaching new service users:

‘We are building stronger working partnerships with local NHS teams to work together to mitigate impact of welfare reform on health inequalities.’ (Case study interview)

‘We work with many partner agencies.’ (Survey response)

‘Our partners include a variety of community groups and organisations, statutory sector/ government partners.’ (Survey response)

We are part of a virtual, multi-agency partnership to reduce health inequalities and tackle poverty.’ (Survey response)

Tackling the ‘softer’ issues

2.29 Many voluntary sector organisations strive to engage around issues that statutory agencies are not in a position to address:

‘Don’t underestimate the effect that loneliness can have on health inequality and the benefits of befriending as a solution.’ (Case study interview)

‘Health agencies refer service users to our organisation as an additional support.’ (Survey response)

Providing a voice and articulating the experiences of people who are supported by the sector

2.30 Several participants recounted their efforts to contribute to local or national policy discourse, underpinned by consultation with their service users:

‘We send out information and consultations on health issues via our targeted e-mail lists.’ (Survey response)

‘Took part in the local consultation on the Single Outcome Agreement.’ (Case study interview)

‘We attempt to work with the Scottish Government to inform policy development.’ (Case study interview)

‘We’re carrying out a local consultation to find out what people like and dislike about the area that they live in and know best. It’s a bottom-up approach to identifying what needs to change.’ (Case study interview)

Service longevity

2.31 This was mentioned frequently and several participants highlighted the value of having longstanding services in local communities that are not subject to the changes that statutory services often undergo:

‘Third sector tend mostly to be the ones with the long-term relationships. This should be utilised. Our expertise is often overlooked.’ (Survey response)

Challenges and opportunities for the sector

Across the study, participants reflected on barriers faced by their organisations but equally many spoke of opportunities that could offer a way forward and enhance their ability to tackle health inequalities. These challenges and opportunities are described below.

Challenges

Funding

2.32 Almost all participants described funding as the main challenge faced by their organisation, although some were sanguine; describing it as a ‘constant’ that could be overcome. Frequently mentioned funding sources included:

- Funding from public sector bodies, for example, the Scottish Government
- Grants from charitable trusts and foundations

- Big Lottery Fund

- the delivery of contracted work commissioned by NHS boards or local authorities

- Fundraising activities; sponsored races, cake bakes etc.

- Donations and legacies

2.33 The spread of funding sources identified by respondents broadly reflects the national picture. Larger voluntary organisations will receive just over half of their income from the public sector, whilst for smaller organisations, this accounts for less than a fifth⁴¹. Comments on funding typically linked to one or more of the following themes: (i) limits available; (ii) the challenge of meeting funder(s) priorities; (iii) short funding timespan, causing organisational instability; and (iv) the resource intensive and bureaucratic nature of securing funding and, if successful, reporting to funders on service activity:

‘Funding is always an issue.’ (Survey response)

‘Having one member of staff constantly seeking funding from a variety of sources is very labour intensive and takes away the time for delivery of the actual service.’ (Survey response)

‘Financial constraints and uncertainties – would be helped by commitment to longer term funding.’ (Survey response)

‘Grants tend to be time limited and this makes sustainability an issue.’ (Survey response)

‘Very uneven playing field in relation to investment and funding.’ (Survey response)

Evidencing value and impact

2.34 Many participants identified challenges in being able to provide robust evidence about the outcomes resulting from their interventions. Some described low confidence and a lack of capacity to undertake this work:

‘There is, as yet, little understanding of the specific context of health inequalities and older people. More research – including collaborative work – should help to inform policy, preventative work and interventions.’ (Survey response)

Further challenges and opportunities

'We want to ensure we are basing our work on existing and new research and fitting in with current and emerging policy environment.' (Survey response)

Too much demand

2.35 Several research participants highlighted that their organisation struggles to meet the demand for their services. This was often attributed to the high level of need within communities. In some cases participants expressed a view that statutory agencies 'pass the buck', using the voluntary health sector to deliver results they are not able to achieve; for example, due to resource deficiencies:

'Completely swamped by size of demand and limited resources.' (Survey response)

'They [public sector] refer onto us and then claim they have achieved the health outcome; but it's just shifted the problem elsewhere.' (Workshop participant)

'With almost half our clients 'referred' by GPs and other health professionals, we strongly believe there should be more public sector funding support.' (Survey response)

Lack of awareness of 'offer'

2.36 While some organisations struggled to meet demand, conversely, other respondents raised concern about referral partners' lack of knowledge of the voluntary health sector 'offer' and believed that more use could be made of their organisation:

'Raising awareness [among services users] of what we offer is essential, but we can't do this on our own. We require others such as the NHS to raise their own awareness of what we provide.' (Survey response)

'Some GPs and health visitors are aware of us and others are not, even when we have consistently tried to tell them about our service, which has a good track record!' (Survey response)

A culture of too much change

2.37 One particularly strong theme in some of the workshop discussions was the frequent changes initiated by both policy makers and funding organisations. This included criticisms of evolution in terminology:

'It's the same thing with a new name. They've

just woken up to it but we've been doing this for 20 years.' (Workshop participant)

'Funders always want something new – as if what was successful now needs to change. Why?' (Survey response)

'Our desire would therefore be: to share experiences and promote each other's services, work in partnership, while avoiding 'reinventing the wheel', and utilise what has been shown to work.' (Survey response)

Little value placed on third sector knowledge and experience

2.38 Some participants suggested they are overlooked in public sector consultations, others mentioned being given little feedback and not knowing the extent to which their participation had made a difference. This led some to question the value placed by policy makers on their input:

'It seems that the local authority is consulting the Third Sector Interface which has no mandate or process in place for involving individual organisations.' (Case study interview)

Hidden health inequalities

2.39 A small number of participants highlighted the problem where health inequalities are 'hidden' or less visible, e.g. where they occur in pockets of deprivation within more affluent areas, and suggested that it was hard to engage funders who are unaware of the issues:

'Aberdeen is seen as an economically dynamic city and the health inequalities are often not recognised by those outside. It is also not only in areas of deprivation but across the city.' (Survey response)

Lack of influence of third sector

2.40 Others highlighted a feeling that the sector struggles to influence key partners and wrestles with bureaucracy:

'The balance of power in partnership working lies too much with risk averse statutory services.' (Survey response)

'Difficult to influence statutory services.' (Survey response)

'The council's antisocial behaviour service was about to be relocated away from

our area – I identified an opportunity for them to step in and tackle an issue that is changing the way people feel about living here; reinforcing fears of violence, the sense of poverty and exclusion... but the request had to go through so many hoops [in the Council] that I don't know what became of it.' (Case study interview)

Factors beyond voluntary health sector control

2.41 Participants frequently made reference to the frustration of facing issues the voluntary health sector cannot address, with repeated mentions of factors such as:

- Lack of employment opportunities
- Welfare reform
- Low incomes and the high cost of fuel and food
- Unaffordable housing
- Widening income inequality and the growth of zero hour contracts
- Increasing demands on the NHS
- Political disengagement and exclusion
- Lack of green space in communities

Opportunities

Many participants highlighted opportunities that they believed could offer a way forward and enhance the sector's ability to tackle health inequalities (particularly the lived experience of health inequalities). Below, we set out those most frequently mentioned.

Improve the way funding is managed

2.42 Although some respondents offered quite challenging views on the nature of funding, suggestions were offered on ways to improve how funding was managed and to increase access to funding:

'Why don't funders incorporate a health inequalities assessment within their criteria; that would ensure resources were funnelled to the services that actively tackle health inequalities?' (Case study interview)

'Outsource more services to third sector

organisations; statutory agencies are often ineffective and cost an awful lot more than voluntary sector agencies.’ (Survey response)

‘We are calling for statutory bodies to be legally required to offer funded preventative services.’ (Survey response)

‘In terms of funding the third sector should be supported by Scottish Government taking a longer-term view; short term funding and that which does not support core costs is short-sighted. Prevention and early intervention makes economic sense and is worth investing in.’ (Survey response)

Raise the priority of health inequalities

2.43 Several participants suggested that addressing health inequalities should be given a higher priority at a national level:

‘Solutions require strategic and structural shifts in national spending priorities, complemented by more local decision-making, including funding to help support community-based responses to need.’ (Survey response)

‘We would benefit from a nationwide review of need.’ (Survey response)

‘We need support in terms of being regarded as equal partners in the creation of a sustainable health and social care system.’ (Survey response)

Be clear about how we measure health inequalities

2.44 Potential solutions offered to develop a greater awareness and understanding of health inequalities were broad ranging, for example:

‘Include socio-economic characteristics in the data collected by the NHS. That would allow greater understanding of health inequalities.’ (Case study interview)

‘Decide what the key indicators of health inequalities are and get the Scottish Government and health boards to report on them’ and ‘loneliness-should be an indicator in the Government’s national performance framework.’ (Survey responses)

Provide funding support for evaluation

2.45 Some responses raised the potential

benefits of further investment in accessible research and evaluation services:

‘Funding to help evaluate our work to prove impacts and support replication would be great – however it needs to be easier to access/apply for.’ (Survey response)

Invest in community led approaches

2.46 An often-mentioned solution to addressing health inequalities was the effectiveness of locally developed, place based strategies:

‘Invest in research into community led approaches and not the same old tired research into policy led approaches.’ (Survey response)

‘Support asset-based approaches to reducing health inequalities.’ (Survey response)

Funds focused on more radical actions

2.47 Linked to the notion of locally-based solutions, several participants urged for a more radical approach to addressing health inequalities; including the development of funds, policies and strategies that reflect the interconnected nature of the issues:

‘We could view health inequalities as a consequence of capitalist processes at play in Scotland. How much money do the manufacturers of alcohol, tobacco and unhealthy foods make? They have an interest in keeping people addicted to these harmful substances; the people most affected are the communities who live in poverty. Yet it has not been challenged. We were encouraged by minimum unit pricing but that appears to have stalled.’ (Workshop participant)

Understand the complex nature of the lived experience of health inequalities

2.48 Some gave examples of how different factors combine to make the lived experience of health inequalities more challenging. For example, one participant explained:

‘[Our] clients find it difficult to engage in self-management therapies because they are worried about additional expense, have no access to transport, do not have the

confidence to learn new techniques and, in many cases, do not have support from friends or family members to help take care of other domestic responsibilities.’ (Workshop participant)

Take the lead in addressing poverty

2.49 Several case study participants suggested that the sector could help to address the issues of poverty and income inequality by championing the Living Wage:

‘As a sector we could implement the Living Wage and urge for it to be adopted across Scotland as a national policy. Just think of how far that would go to addressing poverty! If I had only one wish and was asked to do something to address health inequalities, quickly, that would be it.’ (Case study interview)

Working together – better

2.50 Another solution frequently identified by participants was partnership working and developing a greater knowledge of the service landscape:

‘Help us link up with other service providers to build referral routes into and out of our services.’ (Survey response)

‘If we knew what was out there we could work together.’ (Workshop participant)

Leadership by the sector

2.51 Many organisations suggested that the voluntary health sector could take on more of a leadership role:

‘Further closer relationships with the likes of VHS would be beneficial in terms of a stronger, united voice.’ (Survey response)

‘We’d really like to highlight the value of our work in driving the agenda at a local level; we’re recognised as leading the approach and being responsible for many of the successes brought about in our partnership. That’s a big step when you consider that a few years ago the relationship was contractual; we were commissioned to supply the services – now we’re involved in that commissioning.’ (Case study interview)

‘The Public Social Partnership (PSP) approach has shown that the third sector can really deliver.’ (Workshop participant)



Clackmannanshire Healthier Lives

CHL is a community-based programme delivered by partners from public and third sector organisations in Clackmannanshire. The partnership aims to improve health outcomes for people facing socioeconomic exclusion, by supporting changes in behaviour.

CHL is an anticipatory care project focused on preventing poor health outcomes associated with poverty, such as isolation, poor mental health, lack of information or behaviour including low levels of physical activity, poor diet, smoking and harmful or hazardous alcohol use. In recent years a key area of work has been support for older people. The intention is to prevent or mitigate the negative impacts of poverty on health and overcome imbalances that contribute to health inequalities, such as limited reach of public health campaigns and service access barriers.



What is CHL, how is it funded and who does it support?

CHL is a partnership between NHS Forth Valley, Clackmannanshire Council and a range of third sector organisations, including Tullibody Healthy Living and Addictions Support and Counselling – Forth Valley (ASC). The partnership's leadership and coordination function is delivered by Signpost Recovery.

Since its inception in 2007–8 CHL's funding arrangements have changed in response to available resources; for some time it received money from the Fairer Scotland Fund, however, funding has been provided by Clackmannanshire Council for the last 3 years. Recently it has been successful in applying for funding from the Change Fund, linked to its alignment to the Reshaping Care For Older People strategy. Resources 'in kind' are also provided by partners; activity funded by partner agencies, for example, may be listed under CHL's programme, to encourage awareness and referrals.

A full range of anticipatory health services are offered, including addiction assessments, physical health activities, life skills support and personal development interventions for activities that contribute to healthier lifestyles such as food preparation, budgeting and planning. The programme is advertised widely across local health, social care and third sector partners.

People supported by CHL are referred from a wide range of sources including health and social care staff, community referrals from family members or friends and self-referrals. Staff roles include life skills coaches, support workers and substance misuse treatment practitioners with various specialisms; people receiving support may be internally referred to another staff member if they could benefit from additional skills or specific interventions.

How does CHL believe its work helps to improve the lived experience of health inequalities or prevent them?

CHL was one of the few case study participants that believes their work has the potential to achieve changes at an upstream level. They suggested that demonstrating third sector organisations have the skills, knowledge and resources to deliver effective health interventions may inspire similar approaches in other areas. It may have a strategic impact, if it informs the thinking of those responsible for developing policies funding work that aims to prevent, reverse or address health inequalities.

CHL has identified four national priority areas for the programme as anticipatory care, personal health and wellbeing, supporting re-enablement and community engagement.

'We're showing that a third sector organisation can be at the helm of a successful cross-sector approach to addressing health issues.'

It was also highlighted that CHL's work is part of the trend towards person-centred and holistic approaches to tackling health issues in Scotland. They view this as part of a growing awareness of the need to improve responses to public health issues:

'It's part of a longer-term approach – going beyond the traditional, medical model of 'treating the symptoms' to an anticipatory, preventative focus that attempts to stop problems building up, avoid harm or reverse it, where possible.'

A key element of the approach, in terms of its connection to health inequalities, is that CHL's work revolves around addressing the health harms that are common among people living in poverty, over and above average rates among the general population in Scotland. These include poor mental health, obesity and preventable or treatable health conditions:

'We work in local settings so we know the health issues affecting people in our communities. The partnership enables us to prioritise, identify the problems that we want to address and channel the resources that are available to meet these needs.'

Another aspect of CHL's connection to addressing health inequalities is its asset-based approach; building community resources may contribute to effecting a change in terms of redressing imbalance in resources/power in society. A key part of the programme is the delivery of activities by volunteers, within local settings.

'This is more sustainable, creates longer lasting change – it means with a little bit of resource, to coordinate and advertise activity – we can achieve a lot more.'

www.signpostrecovery.org.uk/services/

www.clacksweb.org.uk/social/chl/



Kincardine & Deeside Befriending

A service that tackles social isolation.

Social isolation was identified by all study participants as a key factor linked to the lived experience of health inequalities. Kincardine & Deeside Befriending (K&D Befriending) uses a befriending model to reduce social isolation and tackle isolation-associated health issues, such as poor mental health, health-limiting behaviours or lack of contact with health services. Although the service's main focus is on support at the individual level, its recent participation in the Aberdeenshire Change Fund is noteworthy in terms of potential contribution to addressing health inequality influences; the Change Fund is designed to inform upstream matters such as long term service planning and resource allocation.



What is K&D Befriending, how is it funded and who does it support?

K&D Befriending is a small registered Scottish charity that facilitates befriending by 100 volunteers to around 100 older people within specific areas of Aberdeenshire. Befrienders receive training and their style of delivery is designed to be person centred, approachable and engage people who may otherwise be reluctant to make their isolation known or admit their need to other agencies. Clients may self refer or be signposted to the service by social work and health services. We were told that:

'Staff, older people and their carers and their referrers believe befriending activity helps to overcome the impact of loneliness and isolation on older people due to long term illness, frailty, sensory and mobility problems, depression, anxiety and dementia or lack of transport and local services.'

In 2013/14 the charity had a budget of roughly £89,000. Three part time staff members are based across two offices. Funds are sourced from donations, internal fundraising efforts and local authority contracts to deliver a limited number of placements. These resources are used to recruit, train, manage and pair volunteers with local people who require befriending services.

'A considerable amount of funding goes to helping older people to get out of their home and to provide transport.'

How does K&D Befriending believe its work helps to improve the lived experience of health inequalities or prevent them?

The charity report that they refer clients onto appropriate services if they identify unmet health care needs and also assist people to attend their appointments; for example, by providing transport and accompanying people so they are supported to access health services. Delivering services to people who are already experiencing physical or mental health issues is another

element of their work; befrienders aim to improve health experiences, for example, by assisting clients at key points of crisis, including recovery from an operation or poor health.

Staff believe the service adds value and can reinforcing the positive impacts of other forms of health care support – befriending can take place alongside other interventions and help to achieve some of the 'softer' outcomes that statutory partners may not have the resources to deliver. For example, befrienders may support someone who is undergoing treatment, recovering from an illness, or is on a waiting list. They may provide an informal 'top up' of contact to someone receiving support from community mental health teams or have befriending included as part of their treatment by health services. Through positive activities, befrienders can encourage people to engage with their treatment or help them to prepare for an intervention.

Staff explained that befriending activity is tailored to the needs of the individuals supported, providing emotional and practical assistance, confidence and social stimulation. They suggested that preventing and addressing poor mental health is a key aspect of befriending, highlighting:

'The negative impacts of loneliness on physical and mental wellbeing are well-documented: loneliness exacerbates dementia, it has an adverse effect on the cardiovascular system, is more likely to lead to depression, eating and sleep disorders, and can affect the immune system...'

In a specific recovery-themed initiative, the charity ran a pilot service at Kincardine and Glen O'Dee Community Hospital, resourced by a grant from the Change Fund. During the first year 13 older people were supported to maintain their independence at home after discharge and no one was readmitted to hospital. The pilot identified befriending's positive return on investment through reduced delayed discharges and readmissions and supporting older people to maintain their independence at home after leaving hospital:

'An evaluation of the Befriending at Hospital pilot project showed that this pilot saved 25 bed days because people who were befriended felt confident to leave the ward sooner.'

Staff suggested that one of the service strengths is that befriending is not time limited, which means that individuals can remain with their befriender for as long as it benefits them; often receiving continuity of support that statutory services would not be able to offer or sustain. They also highlighted that:

'Statutory health partners can struggle to reach people in the small rural communities that this voluntary sector provider works within.'

Another interesting element of the service is that it offers a mechanism for releasing professional and social capital – many of the befrienders are retired people with a professional background in the field of health and social care. The service therefore provides a means for these individuals to continue contributing their valuable skills, time and energy to people who may benefit from it.

The presence of befriending within local communities can also have a positive ripple effect:

'Reinforcing a sense of belonging, cohesion and support – both for befrienders, befriendees and their wider networks. Befrienders report that their own awareness of health inequality and older people's issue has increased due to volunteering with the organisation.'

Enabling carers to continue delivering support – in most cases where a carer is involved, the befrienders' service provides regular short periods of respite for carers. Staff highlighted that the breaks have been positively evaluated and found to contribute to an individual's ability to look after their own health and to sustain their role as a carer.

www.kdbefriending.org.uk



MS Therapy Centre Lothian

A grassroots therapy centre that was established to provide accessible treatments and facilitate self-management.

Many people living with Multiple Sclerosis face complex barriers – including physical, mental, economic and service access issues – that can affect their quality of life and the extent to which they are able to manage their health. This service began in response to a demand from a small group of people living with MS for more accessible treatments and greater frequency of support than could be provided by NHS Scotland. The Centre offers peer support, helps people to live with the symptoms of MS and provides assistance to facilitate self-management; including information and advice, adapted fitness classes, physiotherapy and complementary treatments.

What is the MSTC, how is it funded and who does it support?

The MSTC is based in Leith, Edinburgh and was established in 1984 by a small group of volunteers. Now the Centre has a small team of paid staff who are supported by volunteers; the centre is open for 52 hours across six days each week. On an annual basis approximately 500 service users access some form of support from MSTC across Edinburgh, East Lothian, West Lothian, Midlothian, South Fife and the Scottish Borders.

Most beneficiaries are people living with MS, but oxygen therapy treatments are also available to other users; approximately 30% of the Centre's users are being treated for conditions including types of cancer, arthritis, ME and autism. In addition, MSTC also provides support to family members who care for people living with MS.

Their annual budget of approximately £220,000 is drawn from various sources; ranging from a small Service Level Agreement with NHS Lothian, grants from charitable organisations and fundraising or donations by volunteers, staff and service users.

How does the MSTC believe its work helps to improve the lived experiences of health inequalities or prevent them?

MSTC believe that social isolation and income poverty are interlinked with health inequality issues because in the longer term, people living with MS are often unable to sustain employment due to their health condition. They also face additional costs for things such as transport, equipment and insurance:

'They may have time to fill but no means of funding social activities... it's the most basic, and fundamental form of exclusion. Before the introduction of self-directed support budgets many of the popular complementary treatments were unaffordable.'

The holistic nature of the support and activities available was highlighted as one of the Centre's key strengths. These vary from specialist physiotherapy, oxygen therapy, creative writing classes, adapted physical fitness classes for yoga and Pilates and alternative treatments such as massages, life coaching and reiki. Staff suggested that these services complement the medical support available from the NHS, and offer positive activities for people to engage in between clinical appointments. They are also trying an outreach programme for some of the therapies for people who are unable to travel to the Centre:

'The NHS model is first and foremost clinical i.e. addressing the physical condition of the person. That's very important, but people with MS also need other support to help them and their loved ones deal with the day-to-day nature of their condition. It's important that they get support from people who understand and have the capacity to spend a bit of time on them, delivered by staff who are knowledgeable, informal and friendly. At hospital they can end up feeling like a patient being treated by someone who is in a rush to see their next appointment – it can discourage questions.'

Linked to the above, staff suggest that the nature of the MS means that the experience will differ from individual to individual. They believe that MSTC's flexible and varied services enable service users to access support that is tailored to their individual needs:

'MS is a very difficult condition to manage. For a start there are four different types of the disease; all with very different symptoms and forms of progression. That means that each individual will have to develop a unique strategy for living with and managing their condition; we offer them lots of support, choice and ideas.'

It was also highlighted that the Centre enables social interaction and peer support, important for a group who may experience isolation linked to their condition:

'Some of our younger users feel very isolated; after diagnosis they may have struggled to find peers who understand what they are going through...or the older users face isolation because of the progression of their condition, stopping them getting out so much. Our reception area is busy all day; after therapies people often stay there for a chat and make friends. It's important to know that there is a place where people understand what you're going through.'

To address service-access barriers to physical fitness that many people with MS experience, MSTC has worked in partnership with KICC Active Lothian to fund and deliver adapted classes for yoga, Pilates and hydrotherapy, supporting people in self-managing their condition.

'It's so important for people with MS to keep healthy and active. We're all told that; but the things that are available to the general public are simply inaccessible to many of us. We plugged away, came up with a plan and found the resources to address the gap in accessibility; by training tutors who can provide adapted classes local community venues.'

Like many of other services in the case studies, MSTC also has a service-user consultation group. This is a forum for consultation and enables people with MS to share their views and experiences; it enables communication 'upstream' to influence those with the power to address health inequalities or to advocate for improved services for people living with MS.

www.mstc-lothian.org.uk



North Glasgow Community Food Initiative

Services that are rooted in the issues faced by specific communities.

North Glasgow Community Food Initiative (NGCFI) works with families living in poverty and has a particular history of providing support to asylum seekers and others affected by welfare reform. At the individual level their projects are designed to improve health outcomes for people most at risk of health inequalities. The service tackles factors that underpin poor nutrition – such as access to affordable food – plus social, cultural and educational gaps that may affect healthy eating, including limited food knowledge, low skills/confidence in food preparation, inability to plan for a healthy diet and poor budgeting skills. The Initiative's community development and empowerment work seeks to tackle upstream factors linked to health inequalities such as low levels of social capital and democratic engagement.



What is NGCFI, how is it funded and who does it support?

The NGCFI is a registered Scottish charity and limited company operating across deprived communities in North Glasgow. Its mission is to:

'Engage people in practical and sustainable food related projects that inspire health and wellbeing and celebrate the diverse nature of communities in Glasgow.'

A team of 9 full time equivalent staff and 83 volunteers works with groups at risk of adverse health effects resulting from food poverty.

'We are inclusive and support people who experience issues such as stigma, social isolation, disability, poverty, low levels of literacy or lack of information. All our beneficiaries are drawn from communities with low levels of income and many of our volunteers are disabled or asylum seekers/refugees.'

There are a significant number of beneficiaries: for example, in 2013/14 cookery classes were delivered to 250 people and there were approximately 25 customers per week at each of the 10 fruit and veg barras. Staff noted that:

'On average 3 people in each household benefits, so there are over 750 beneficiaries' [per barra, per week].'

In 2013/2014 NGCFI had an income of almost £280,000. Funding consists of a range of one to three year grants from various sources, including: Glasgow City Council, The Robertson Trust, Big Lottery Fund, Scottish Government Climate Challenge Fund, Voluntary Action Fund, The Trusthouse Charitable Foundation, SCVO, Lloyds TSB Foundation Scotland, and the Garfield Weston Foundation. All fruit and vegetables are sold on a not for profit basis.

How does NGCFI believe its work helps to improve the lived experience of health inequalities or prevent them?

NGCFI believes that a key issue affecting communities in North Glasgow is the lack of affordable food; there are many housing

schemes with no supermarkets and residents face high transport costs. They suggest this makes people reliant on expensive convenience stores, restricting the quantity and quality of food that families living in poverty are able to buy. As one staff member explained:

'Even Lidl, which is marketed as an affordable supermarket, is selling 1 kg of potatoes for 50p whereas we buy them wholesale, add a small mark-up to help cover our costs and sell them for 23p per kg.' (Prices stated in November 2014)

The Initiative delivers a range of projects that offer preventative and direct support to individuals.

'The preventative nature of our work concerns improving nutritional outcomes and providing services that sustain mental-well being.'

Staff explained that their services aim to improve nutrition, health and well-being; the activities also tackle poverty, social isolation and stigma. A key focus is the establishment of community projects to develop a circle of activity; growing, cooking, choosing, accessing and sharing fresh food. Other work includes providing information about fruit and vegetables, how to cook them and recipe ideas. Current work streams include:

- Fruit and vegetable barras, providing fresh produce at affordable prices
- Development of community gardens and gardening sessions
- Food Hubs in Milton, Royston and Springburn which engage with local people.
- Healthier eating cookery courses including antenatal cookery
- Specific food and cookery information for asylum seekers
- Weight reduction courses
- Nutrition workshops
- Community events and communication projects
- Healthy eating sessions in schools and nurseries
- Royal Environmental Health Institute of Scotland (REHIS) training

Gathering evidence – NGCFI gathers monitoring and evaluation material from all of its projects. The information is relayed to key funders, who evidence activity and highlight the needs of people supported by food initiatives. They have also implemented a rolling programme of Local Evaluation and Planning (LEAP).

'One of our volunteers told us he had an improved sense of self-worth from knowing that once a week he would feel like a customer and have some purchasing power, as opposed to someone who was reliant on the state for a food voucher.'

NGCFI encourages activity to raise awareness of its work and impact. It has developed case studies and reports on developments in its own newsletter and through the website.

Working in partnership was described by NGCFI as an integral aspect of activity. Referral partnerships have been established with bodies such as the Bridges Programme, Scottish Refugee Council and NHS Greater Glasgow and Clyde. Staff also highlighted that:

'We view local communities as key partners and take a "bottom up" approach to involve local residents in the design and delivery of projects; in this way community capacity is developed.'

Examples of partnership work include the many local groups involved in the Milton Food Hub; a local regeneration project, local churches, resident and tenant associations and schools. Similarly, NGCFI's cookery courses use a range of partners to support delivery and engage beneficiaries including nursery and primary schools, the local women's centre, integration network, youth projects, ex-offender services and mental health associations. Work is also underway with Pilotlight to help NGCFI to grow, develop social enterprise options and create a new business plan.

www.ngcfi.org.uk



Includem

Provision of support for a specific group – troubled and vulnerable young people with histories of abuse, neglect and deprivation.

Troubled and vulnerable young people face many of the issues that voluntary health sector providers identified as being inextricably linked to the lived experience of health inequalities; social isolation, barriers to accessing services, poverty, stigma and behaviour associated with increased risk of health problems. Compared to their peers, troubled young people are more likely to self harm, experience poor mental health or to become young parents. They may have few positive role models or lack the educational and social capital – including skills, confidence, family and support networks – that underpin positive health outcomes and provide a foundation for adult life and parenthood. Includem's work is designed to address these support needs and help young people make successful and healthy transitions.

What is Includem, how is it funded and who does it support?

Includem is a registered Scottish charity operating across Glasgow, West Dunbartonshire, Clackmannanshire, Stirling, Dundee and Fife. Its focus is to:

'Deliver support to the most vulnerable and challenging young people in society. Our 1 to 1 support at the times of need helps to make positive changes to their attitudes, behaviours and relationships.'

Nine teams totalling approximately 75 full time equivalent staff work across a range of projects, often working closely with young service users' parents and carers, where appropriate. Includem's service model, used across all projects, is evaluated and evidence-based; a range of evaluation reports are available for review on Includem's website. In the last year (2013/14) 556 young people were supported through 100,189 hours of contact; as a result of this work Includem believes 173 families avoided breakdown and 106 young people were prevented from going into care. The 24/7 helpline received 9,984 calls in that period.

In 2013/14 Includem had a budget of almost £3.8m. Funding consists of a range of local authority contracts (typically commissioned by children & families and youth justice social work services) and one to three year grants from various sources, including The Scottish Government, The Robertson Trust, Big Lottery Fund and Police Scotland.

How does Includem believe its work helps to improve the lived experience of health inequalities or prevent them?

Includem has developed a service model to support this group which includes tailored personalised support, and a 24/7 helpline, delivered by staff who are trained to prevent suicide and self-harm.

Staff explained that their work is tailored to the needs of the individual; young people have multiple issues that are addressed over months of at least 3 support sessions per week. While Includem is not a health service, it offers preventive and direct health activity through building a respectful,

dependable and caring relationship and work such as emotional support, education, awareness raising, structured cognitive sessions to drive behaviour change, supporting changed behaviour or facilitating engagement with health services, and immediate crisis support.

'The needs vary from person to person but there are common issues facing most of them. Poverty and difficult life experiences can affect physical and mental health in so many ways – through the cumulated impact of things like exposure to violence, low quality housing, bad diet, low mobility and limited social activity.'

The young people supported by Includem often face specific hurdles that can affect their health; for example, school exclusion might result in a person missing key health education campaigns; or those with a high level of exposure to substance misuse may find school-age drug and alcohol information not relevant to their experiences and therefore 'switch off' from key messages.

'There are other logistical issues too – so many of the young people we support move frequently between a range of short term accommodation – this can mean they don't know what health services they are registered with, can't track down a GP or dentist when they need one and don't have the things like identification or proof of address that you need to sign up to a health service.'

Lack of positive role models and poor life skills can also contribute to poor health outcomes. One young person who participated in the case study explained:

'My muscles have started to waste because of my size – I need to lose some weight – and I've been having problems with my legs... My support worker has helped me to change things like my diet and to be a bit more active. It's stuff like practicing my physio exercises, making sure I have enough medication to last me at the weekend and over Christmas, taking the stairs instead of the lift... She's taught me a few simple things to cook instead of buying ready-made – I know that's what I need to do but it was hard. She encourages me.'

Compared to their peers, Includem's service users are more likely to become young parents. Behaviour during pregnancy can affect low birth weight – a key health inequality indicator. Ante and postnatal support is part of the Includem offering to young mums and dads; work typically focuses on positive behaviour, building parenting skills and developing good relationships. Includem believes this can improve early years experiences and lead to better outcomes for the next generation of families.

Staff discussed reasons for successes in engaging a group that are known to be challenging to work with. Some suggested that Includem's flexible and responsive service model, delivered in community settings – enables effective work with young people. Others highlighted that the charitable status of Includem contributes to a trusting relationship between staff and services users, which encourages young people to be open about any issues or vulnerabilities and more likely to respond to advice and support. The provision of ongoing transition support through the helpline means that young people have a route to access help at a crisis point even if they have successfully moved on or disengaged from the service.

Another area of Includem's work is youth empowerment and participation; this is an area of upstream activity that may contribute to addressing health inequality influences such as low levels of social capital and democratic engagement. Work is underway with agencies such as Snook to co-produce material that reflects young people's experiences. Includem uses a broad range of communication platforms including blogs, films and podcasts, and is planning a new interactive website design to engage service users and wider audiences in its work and impact.

www.includem.org

The key issues and the next steps

Everyone's business

Health inequalities do not stand alone; they are a part of a broader set of inequalities: economic, social, cultural, gender-based, racial. As such, they cannot be addressed solely by health strategies and interventions. Equally, they cannot be addressed by a single sector. The public sector may have the statutory duty to deliver health and social services, address public health issues, provide social housing, deliver a benefits system, all of which are key to addressing health inequalities. The private sector also has a key role, particularly as 70% of jobs in Scotland are private sector jobs. However, the third sector, including the voluntary health sector, although smaller, is a vital component in tackling health inequalities. This is particularly true of the sector's capacity to address the 'lived experience' of health inequalities – the day to day reality.

The positive role already being played by the sector which emerges from this study can be summarised as:

- A shared commitment across the sector to addressing health inequalities
- Voluntary health sector activities mitigate the negative effects of health inequalities; this may primarily be downstream work but it is essential in terms of the lived experience
- The third sector takes a wraparound approach – holistic, person centred, joined up, responsive – and this creates significant opportunities in responding to the needs of our most vulnerable individuals and communities

However, it is also apparent that there is an untapped opportunity to harness and channel what the sector is doing; and to support it working alongside public and private interventions

– promoting healthy living to groups of people who may not use mainstream services

– supporting people to access relevant services.

These roles are evident in this report, which shows a voluntary health sector in Scotland working with some of the most vulnerable and marginalised groups and individuals; and making an impact. One of the case studies, Includem, concludes that, over the course of one year, its work meant that 173 families avoided breakdown and 106 young people were prevented from going into care. Although Includem can demonstrate such results, a key concern is expressed that the voluntary health sector more generally needs support if it is to measure the impact of its activities to that same level and with consistency. This is particularly the case with smaller voluntary health organisations who need to have the confidence, tools and resources to adopt evaluation methodologies and to incorporate them into their mainstream activities.

This support could be derived from sharing best practice across the sector and from those parts of the public sector where measurement of impact is built in to its work. However, it is important to recognise that measurement of impact is a challenge for all sectors, described succinctly in a tweet from NHS Health Scotland⁴² as 'conceptually straightforward but execution deceptively difficult.' Knowing and being able to show that a particular intervention has made a difference in narrowing the inequalities gap is a process that runs counter to the prevailing culture, which focuses on headlines and immediacy. All stakeholders – senior politicians and managers, the media, funding bodies and those on the front line – need to commit to clear measurement and evaluation as an underpinning principle in tackling inequalities: and to provide the funding to do so.

Upstream/downstream

The publication of the Christie Report⁴³ on preventative spending engendered a broad political consensus that upstream work – *'It is easier to build strong children than to repair broken men'*⁴⁴ – was a priority

in tackling poverty and inequality. This consensus stretches across civil society, including the voluntary health sector. The issue for the sector, and perhaps for how it is regarded by the public sector, is that much of its activity is downstream, buffering the impact of health inequalities by giving individuals and families the support to cope. Contributing to the upstream issues is evidenced mostly around campaigning activities where root causes are spotlighted and long term solutions sought, and decision-makers influenced.

Nevertheless, the sector does have a more direct upstream role. To continue with the example of Includem, the organisation provides ante natal support services in order to seek to break the cycle of poverty at the earliest stages, offering a different future for generations following. This kind of activity may become more prevalent as upstream policies ('early years'⁴⁵, for example) bed in as mainstream interventions. The voluntary health sector needs to position itself in order to measure impact, overcoming issues of (small) scale, and properly identifying what should be measured and how it should be measured.

Partnership and change

Partnership is a key theme emerging from the study. Concern is expressed that the voluntary health sector is too often a junior partner, with the statutory sector setting the agenda. At the same time, the survey also uncovers examples of the voluntary health sector taking the lead in local and regional partnerships. This is reflected in an Audit Scotland report into health inequalities, which found that the voluntary sector believed that the Change Funds had helped to improve partnership working between voluntary and statutory organisations but that this was not the prevalent experience:

'Overall... frontline staff [i.e. in the third sector] felt excluded from partnership working aimed at tackling health inequalities'⁴⁶

Audit Scotland states that 'reducing health inequalities requires effective partnership working across a range of organisations. However, there may be a lack of shared understanding among local organisations

Third sector role and impact

Audit Scotland has identified the role of the third sector in addressing health inequalities as⁴¹:

- providing a means of engaging effectively with communities and individuals
- delivering a range of services which may help to reduce health inequalities, including:

about what is meant by health inequalities and greater clarity is needed about organisations' roles and responsibilities.' Our findings reinforce this point.

The effectiveness of current systems and relationships – Community Planning Partnerships, Third Sector Interfaces – is questioned by respondents. Systems are often too remote to feel relevant to the actual work of the sector. Equally there is concern that major changes stemming from health and social care integration may be too concerned about structure and not about optimising impact at the front line. The third sector and the public sector need to find solutions which will generate trust and underpin mutual progress.

If sectors are working alongside each other they are not necessarily working with each other. The integration agenda and the partnership structures need to focus on mutuality for the benefit of those in need.

Language of health inequalities

Another clear area of concern is language. At policy level language can be academically derived and somewhat rarefied. As such, it doesn't readily facilitate dialogue across sectors and reassure the front line that the reality – the lived experience – of health inequalities is fully understood by those with the decision-making powers. The 2014 Child Poverty Strategy for Scotland⁴⁷ talks about the 3 P's – pockets; prospects; places. Easily remembered, this shorthand helps to summarise the complexity of inequalities into three interlinked components: the money/resources in the pockets of those living with the impact of inequality; the availability of prospects in terms of jobs, relationships, travel, and so on; and the importance of housing and community. This is the kind of conceptual approach that seems to start with the reality and which has the capacity to break down barriers and create a common space for discussion.

Summary of key challenges

- There is a lack of shared definitions, knowledge base or language to talk about health inequalities

- Organisations are not working with common tools, frameworks, practice
- Work is needed on the sector's 'upstream' contribution
- No clear sense of the economic and added value of voluntary health sector role, i.e. the savings to the public purse
- Public sector roles and responsibilities: lack of clarity as to who is doing what, including Community Planning Partnerships, Single Outcome Agreements, health and social care integration
- Partnership deficit – to work successfully upstream our sector has to be more of an equal partner with public sector and not dismissed as relatively informal and small scale
- Third sector's contribution needs to be promoted and acknowledged

Next Steps

There may be something of a momentum building around approaches to health inequalities and inequalities generally in Scotland. In November 2014, NHS Health Scotland published a briefing on Health Inequalities for the 2015 General Election with a range of recommendations for political parties to consider in developing their manifestos.⁴⁸ In January 2015, a Scottish Parliament debate on the subject⁴⁹ reflected on why, even when money was available, inequality increased. In the same month, the Parliament's Health & Sport Committee published a report on health inequalities⁵⁰, which stressed the need to look beyond health solutions and which called for a 'new approach.' Following the publication of draft legislation on further devolution for Scotland, the Scottish Council of Voluntary Organisations (SCVO) criticised the absence of 'welfare home rule' as a missed opportunity in tackling poverty in Scotland⁵¹. The Health & Social Care Alliance Scotland has published its own report on health inequalities emphasising the need for a Human Rights Based approach.

Living in the gap adds to the momentum and, in doing so, provides a unique perspective on the role and capacity of the

voluntary health sector in tackling health inequalities. Our ten case studies illustrate what the sector offers now and provide a touchstone for thinking about the future, particularly in terms of impact.

Voluntary Health Scotland will:

- share, discuss and consult on these findings and the questions they raise widely and with key stakeholders including the Scottish Government, NHS Health Scotland and other NHS bodies, MSPs and voluntary health organisations
- determine what actions to take next, e.g. development of tools/toolkits and training programme or other types of resource
- work with NHS Health Scotland and other key partners to draw up an action plan, identifying how to resource and implement.

The study prompts a number of questions about what kind of actions might be needed to move forward. These include:

- Detailed mapping of voluntary health sector, e.g.
 - The number and characteristics of individuals supported
 - Levels and sources of funding to tackle health inequalities
 - Savings generated by reducing need to use high tariff service
- Promotion of successful and cross sector health inequality interventions and partnerships
- A focus on loneliness as an exemplar of the sector at its most effective.

There are many more issues and, in reading this report, they will hopefully become apparent. Individual organisations will find a set of questions relevant to them and by sharing these thoughts and experiences, the voluntary health sector will be leading the way in making health inequalities everyone's business.

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Voluntary Health Scotland
Mansfield Traquair Centre
15 Mansfield Place
Edinburgh EH3 6BB
0131 474 6189
mail@vhscotland.org.uk

www.vhscotland.org.uk
Twitter: @VHSComms



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Designed by CGH Creative, West Lothian,
Printed by Digital Print Solutions, Edinburgh.
Published March 2015