

Growing our influence

How community-led health makes an impact on inequalities

chex



CHEX-Point Issue 49 Summer 2015

community health exchange

In this issue we're looking at different ways community-led health can be more influential in addressing the issues that communities face across Scotland. Starting with the personal insights and reflections of Sheila Allan on community-led health's impact on health and wellbeing, we also hear Ed Garrett from Means and Coastal Health Living Network's experiences of speaking about community-led health to the Scottish Leader's Forum.

Next, we take a look at the CHEX 2015 national event – Healthy Influences – which examined community-led health's influence on Scottish policy today and going forward. This is followed by an article from Christina Greig, B-Aware Project Manager at Breast Cancer Care, who speaks about using different technologies to enable people to come together around the issues that are important to them.

CHEX's Andrew Paterson gives us some detail on the "Evidence for community-led health" workshops which CHEX ran earlier in the year, where we hear the thoughts of Nicky Fox, project manager of Stepping Out, about how she uses evidence. We then have an article from Gozie Joe Adigwe, Senior Eye Health and Equalities Officer at RNIB, who writes about their work with communities for better eye health.

We have a summary of the Community Empowerment (Scotland) Bill which was passed by the Scottish Parliament in late June 2015 – we take a look at what it means and the implications moving forward. Finally, we take a look at the Knowing Me, Knowing You 2 learning exchanges between public sector workers and those working in the community and voluntary sector.

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Personal reflection and perspective on community-led health

Sheila Allan, Equally Well Lead Officer in Dundee has been a strong advocate and practitioner of community-led health approaches over many years. Janet Muir, Manager of CHEX recently talked with Sheila about her reflections and perspective on the impact of this approach to mental health and wellbeing.

Sheila's experience in community-led health goes back to the heady days when organisations and the approach had ring-fenced funding through the New Life Urban Programme in the early 90s. The Tory Government of the time made it difficult to talk about poverty and inequalities, but dedicated funding in the Whitfield area of Dundee enabled Sheila and others to work with communities on health priorities that mattered to them. Moving on through the 90s the approach gathered currency in Scottish national policy and practice. 'Working Towards a Healthier Scotland' in 1998 began to shine a light on working with communities on life circumstances as well a lifestyle issues and at the start of 2000, resources were allocated to new community-led health organisations through the Lottery's New Opportunity Fund. Sheila moved to head up the Dundee Healthy Living Initiative (DHLI) and with community-led health at its heart facilitated partnership working with public sector partners in working with communities on their health priorities. Mental health and wellbeing emerged as a key priority and in 2009 Sheila moved to take forward Dundee's successful proposal for an Equally Well Test Site. The Test Site was one strand of the Scottish Government's National Action Plan to tackle health inequalities



in Scotland. Its focus was to improve community mental wellbeing in a disadvantaged area by supporting changes in ways of working across services to, with the aim if better addressing the determinants of mental wellbeing. The ongoing roll out of the Test Site findings across Dundee has remained Sheila's focus over the past few years and has been informed both by the formal Evaluation¹ and by Sheila's own research for her Masters in Public Health².

The principles and practice of community-led health have been consistently woven into Sheila's work. These have been supported by national policy drivers such as the Community Learning and Development Regulations (2013), recommendations from the Ministerial Task Group on Health Inequalities (2014) and more recently the proposals for Community Empowerment (Scotland) Bill. More than ever, it has been the commitment of local stakeholders

1 Evaluation of Dundee Equally Well Final Report (2012)

2 Can a targeted intervention result in changes across services to better address factors affecting inequalities and mental wellbeing? (2014)

in Dundee who have sustained the commitment and developed good practice in working with communities. This hasn't been an easy task. As resources for development work have got thinner on the ground, there is less opportunity to create the necessary space for local people to come together to discuss and act on what health matters to them. While there is general acceptance that working with communities is a 'good thing' translating this into common practice across the public sector remains an ongoing challenge. Raising awareness and providing ongoing support demands 'buy in' at all levels. The delivery of a wide range of training has stimulated interest with mix of people; some who know a little about community-led health; some completely new to it and some who are sceptical. Facilitating the training is challenging and Sheila constantly relies on both qualitative and quantitative evidence to confront myths and expose assumptions about the causes and effects of poor mental health and what approaches are effective and do improve health.

"People can be shocked about the nature and extent of health inequalities in Dundee, showing the evidence and people telling their own story helps to challenge some of the myths."

Scaling-up the approach remains an ongoing challenge. The models developed by DHLL and facilitation of partnership working through 'Equally Well' do keep a focus on the approach. However, in the bigger scheme of overall service delivery, community-led health is still relatively marginal. Sheila feels robust evidence from longitudinal

studies nationally commissioned would help to influence a greater strategic 'buy-in'. While recognising the value of case studies and findings from various programme evaluations, she strongly advocates the need for research that would be recognised at all levels – national, regional, and community. She cited the evaluation of Link Worker's Programme currently being carried in certain DEEP End GP Practices as positive and felt that a commitment on this scale would help strengthen the embedding of community-led health.

Sheila's feelings and assessment of the strength of community-led health today are somewhat ambivalent. On the one hand she is extremely positive about what has been achieved by the sector and also by those who have consistently advocated for it within public sector services. On the other hand, she is apprehensive about the effects of welfare reform, cut-backs in public services and growing inequalities. Despite the willingness within communities to mobilise around their health priorities, the foundations of community-led health can be easily squashed if not nurtured and consolidated. The focus on tackling inequalities should be paramount within all services, and communities should be at the heart of shaping and delivering these services. She feels at the moment there is a vacuum in retaining this focus and urges CHEX to continue to work with others in confronting this challenge.

Further information on the interview, contact janet.muir@scdc.org.uk.



Demonstrating community-led health: Scottish Leaders' Forum

In this article Ed Garrett from the Means and Coastal Healthy Living Network talks about his experiences speaking to members of the Scottish Leaders' Forum about the community-led approach to supporting older people.

On behalf of the Mearns and Coastal Healthy Living Network I was invited to speak at the Scottish Leaders' Forum on 1st October 2014. The forum is a network of chief executive level leaders from the public services and third sector in Scotland. They meet to discuss and work together on important policy issues facing Scotland. The topic for the meeting was 'Leading for Prevention: Older People' and I gave a presentation on the experience of the Healthy Living Network.

The Healthy Living Network has existed in the south of Aberdeenshire since 2002. We work with older people to enable them to live independently and actively in their communities for as long as possible, providing support with shopping, transport and gardening, social activities and involvement in older people's forums. Essentially we provide a series of low level interventions which prevent more serious health and wellbeing outcomes. In my presentation I stressed the importance of our approach which is led by the community and builds on the capacity of individuals and communities to address issues for themselves. I argued that it is with this approach that prevention works best, when change happens from the bottom up with communities acting for themselves and becoming more

MEARNS & COASTAL HEALTHY LIVING NETWORK

resilient. The Christie Commission emphasised the need for a greater focus on preventative approaches. It estimated that as much as 40% of public service spending is accounted for by interventions that could have been avoided by prioritising a preventative approach. I said that the Healthy Living Network exists in a constant state of insecurity over funding. With some very limited core funding I suggested that small community organisations such as ourselves can make significant savings for public services.

There were also presentations from Dundee City Council and from the Circles Project. This project which has circles in several locations in England aims to use assets based, co-production approaches to re-imagine what a 21st century service for older people might look like. Circle members support each other with activities such as shopping and gardening and provide rich social networks based on shared interests rather than preconceptions of age.

After the presentations there were discussions on key challenges: how Scottish leaders can extend and build on what is working already, how to work more effectively with older people and their families and how preventative approaches can best be evidenced and spend on these approaches justified on the basis of this evidence.

Speaking at the forum and taking part in these discussions was a wonderful and important opportunity to put the case forward for community-led health organisations playing a lead role in meeting these challenges.

Find out more about the Network at:
www.mchln.co.uk.

CHEX national event 2015

Healthy Influences - community-led health's contribution to Scottish policy



We had a great day at our National Conference held in Edinburgh on 4th June 2015. The rooms were buzzing as CHEX network members and others with an interest in community-led health came together to learn from each other and grow our influence.

We were delighted that Susan McDonald, General Manager of Active Communities and longstanding CHEX Network member agreed to chair the event. Susan also co-ordinates Renfrewshire's Community Health and Wellbeing Network.

Susan welcomed everyone and got the energy levels up through some quick and fun networking. She explained our purpose which was to learn from each other's approaches and successes in community-led health and to help increase our influence individually as organisations and collectively as a movement.

Story dialogue workshops



The morning session used the story dialogue method to focus on our contributions to key government policies. Policy makers told

their 'story' of what they are trying to achieve through 'their' policy. Community-led health organisations then shared the contributions they make to each policy.

After lunch, we had two short presentations, from CHEX's Andrew Paterson and from Susan McDonald.

Andrew set out the findings of CHEX's Healthy Influences research, which found that community-led health organisations contributed to local and national Healthy planning structures in

many ways, from responding to consultations to having representation within planning structures. However, a range of barriers to involvement and influence remain, including a lack of information and accessibility and our limited organisational capacity.

Susan McDonald inspired us by giving us a warts and all journey of Active Communities' efforts to become influential in Renfrewshire, including through setting up the Community Health and Wellbeing Network and the work and perseverance it took to get a seat at the table where decisions should be taken

Afternoon workshops: how can we be more influential?



Workshops were set up with two concentric circles of chairs in pairs facing each other. Participants engaged in a series of 5 minute conversations, learning from each other's experiences of influence.

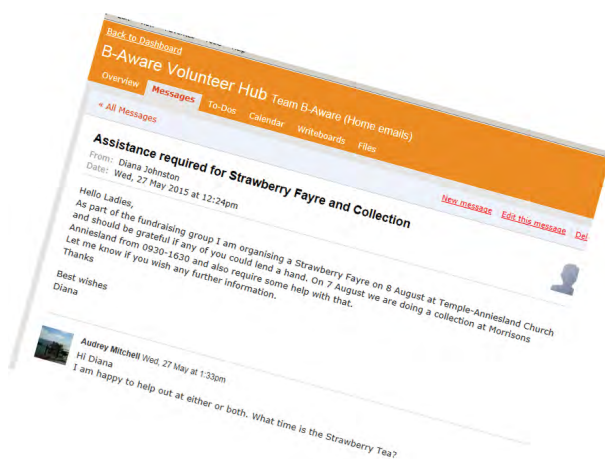
Each workshop then had a general discussion about how local organisations can be more influential:

- be at the table before policy is made
- build trust, both with other community-led health organisations and with those traditionally in powerful positions. This should be based on our own credibility and reputation.
- Create and collate the right evidence and use it to best effect.

For more information on the event visit:
www.chex.org.uk.

The unintended consequences from difficult circumstances

Breast Cancer Care is the only UK-wide support charity helping the thousands of people waking up to the harsh reality of breast cancer every day. Christina Greig, B-Aware Project Manager highlights growing the network of support.



The charity was started in 1973 in the home of founder, Betty Westgate who, along with half a dozen volunteers, began to make 'comfies'. These were small comfortable pillows, created before breast prostheses became widely available. Since then, the organisation has grown in size and now offers a diverse range of support services for people affected by breast cancer. Our volunteers remain at the heart of the charity.

We have over 160 volunteers at Breast Cancer Care in Scotland. They are involved in activities including delivering breast health awareness talks, raising vital funds, being the local face of the organisation and providing a listening ear to women and men in similar circumstances.

Breast Cancer Care's volunteers receive training prior to starting, and are then supported by staff throughout their volunteering. However, from a community development perspective, it is the 'magic' which happens after the training which is so fascinating and wonderful to witness.

On completion of their training we bring our volunteers together in local networks to support each other and discuss local issues. Beyond this formal connection, informal digital and local connections can also develop and flourish.

For example, last year we developed a new volunteer role, Team B-Aware, designed to share the breast awareness message within local communities through the delivery of a short talk.

After training the new cohort of volunteers, we connected them with each other through a piece of software – Basecamp. On a practical level, Basecamp allows volunteers to share ideas and information. However what developed beyond that was a new community of support, a network of peers, and best of all, friendships. Volunteers built strong support networks both on and off-line, so that those who live in the same area even started to meet up for coffee and chats.

One of the volunteers from Team B-Aware told us "...at some point I felt I needed to stop talking

about cancer to friends and family but sometimes you still need a listening ear. This is especially true after treatment. Although I contribute to providing services, I get a lot of warm unrehearsed genuine feedback and support from the connections I have made through the other volunteers I have met at Breast Cancer Care.”

Another example of how Breast Cancer Care brings people together is our annual Scottish fashion show. Each year the charity offers a group of women and men the chance to be fashion models for a night at an exciting event which helps to raise funds for the charity.

It is a more complex process than you might think, with people from across Scotland participating. We start early with an orientation day when the models get to meet and start to build a relationship with each other. Breast Cancer Care also sets up a private Facebook page for all those involved to help them keep in touch.

A recent post on the site describes one woman’s experience of having a high temperature, being re-admitted to hospital, and her description of being really scared. Beyond the good wishes, ‘thinking of you’ and ‘get well’ responses, there were lots of comments about other peoples’ experiences, and tips for coping with the nausea and sickness. Discussion led on to the recent TV dramatisation of ‘The C Word’ and how the actor’s portrayal resonated with one of the models’ personal experience. This discussion thread then finished with others committing to host a Strawberry Tea fundraising event, so that they - the volunteers - needn’t face the pain of this brutal disease alone.

The ‘magic’ that I referred to earlier is in the power of these men and women from different corners of Scotland coming together and building communities of interest from their joint experiences. From diverse backgrounds and ages, they identify with each other, see themselves in others, and are empowered through a range of volunteer roles to help others in their own communities.

Through a variety of digital media Breast Cancer Care has created an online space to complement the traditional face to face environment. It’s all about creating places



where people have the freedom to express their deepest fears, and be cared for amongst a group of like minded individuals. For us as staff it is a privilege to observe how these communities continue to grow, deal with changes and support others when they need it.

If you are interested in volunteering or having a breast health awareness talk from a Breast Cancer Care volunteer, please do get in touch!

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One step at a time: using evidence to influence decision makers



CHEX held a workshop on in February 2015 at the Big Lottery offices in Glasgow entitled Evidence for community-led health: what to use and how best to use it. This free half-day workshop was designed to help community organisations make their case to policy makers and funders. It builds on CHEX's wider work to address the challenges faced by community-led health organisations in engaging and influencing the policy and funding landscapes. Fifteen people attended the workshop, mostly from community-led health organisations in the CHEX network.

One of these organisations was Stepping Out, a mental health charity based in East Lothian which organises recovery focussed groups for adults with mental health problems. Project Manager Nicky Fox, who attended the workshop, has been kind enough to provide some feedback about her experience of the afternoon and what she has taken from it.

The training was adapted from a previous Evidence for Success workshop run by the Knowledge Translation Network (KTN),¹ a partnership of organisations, including CHEX, which supports the third sector get the best from generating and using evidence. Reference was made to the Evidence for Success guide published last year².

Workshop activities explored what evidence organisations should use and how to use it in order to influence decisions, attract funding and improve your work. Participants discussed how they used evidence in their own practice. People said they valued a range of types of evidence, including statistical evidence, quotes, stories, photos and secondary evidence. Nicky provided

¹ The Knowledge Translation Network is a partnership between Evaluation Support Scotland, the Robertson Trust, the Big Lottery Fund, the Third Sector Unit of the Scottish Government, CHEX, Carnegie UK Trust. It is convened by Evaluation Support Scotland.

² <http://goo.gl/qJNwJP>

the example of Stepping Out's colourful and user-friendly annual reports³ (pictured), which capture the experiences of members through photographs. Other workshop attendees agreed that this method would be ideally suited to demonstrating evidence of need that different audiences would find attractive and accessible.

"We do know that the upbeat messages and presentation make it more likely that people generally will read on even though mental health is seen as a pretty heavy subject." Nicky Fox, Stepping Out

Towards the end of the workshop Senior Policy and Learning Manager at the Big Lottery, Eric Samuel joined the workshop to contribute to the final exercise on presenting evidence. Groups took turns to spend time at three different flipcharts where participants were asked to take the role of policy makers, practitioners and funders respectively. Eric suggested that funders look for evidence that is clear, concise and understandable backed up by annexes and hyperlinks to 'softer' evidence such as pictures and video. Nicky from Stepping Out noted that she found this part of the workshop to be especially useful, and added that she has since been wearing her "funders hat" when thinking

3 <http://www.stepsingouteastlothian.org/#!/portfolio/ckiy>

about funding applications and evidence.

Participants stated they had gained insights into practical approaches to gathering and using evidence. In particular, people said it was useful to share, and learn from, the experiences and knowledge of a range of different organisations attending on the day. Some, including Nicky, simply felt it was good to have the time out of work to give some uninterrupted focus on using evidence. Nicky also liked the workshop's emphasis on having a well-rounded 'mixed-bag' of approaches to using and presenting evidence.

The most commonly stated actions to take forward from the workshop were to make use of the Evidence for Success guide and other resources mentioned on the day, and to think about the wider range of methods available (e.g. photos, videos and other soft evidence). As for Stepping Out, the organisation is currently producing a one-page crisis guide for a group, with a similar user-friendly design to the Stepping Out annual reports, and which could be used as evidence in the future.

Read the full workshop report at:
<http://goo.gl/ykriCc>

Visit Stepping Out's website at:
www.stepsingouteastlothian.org



RNIB:

Working with communities for better eye health

Every day ten people in Scotland start to lose their sight. The five leading causes of sight loss in the UK are refractive error, age-related macular degeneration, cataract, glaucoma and diabetic retinopathy. But, up to 50% of sight loss could be prevented if caught early.

Over a number of years, RNIB Scotland has been raising awareness of sight loss and what services are available among groups which, historically, have been less likely to know about and tap into the range of support that's there. Some of this work is delivered in Glasgow through targeted engagement with ethnic minority communities – because of their increased risk of sight loss.

Jamila Shaikh, Community Development Officer, works with ethnic communities and plans regular tours of the facilities at the Centre for Sensory Impaired People in Partick, Glasgow. These visits take in the resources centre, a visit to Insight Radio – RNIB's radio station – and the Education and Learning Suite where one-to-one support can be tailored for people with sight loss who are looking to get back into work or learn how to use accessible technology.

More innovative work is delivered by Satya Dunning, whose ALLIANCE-funded project aims to improve self care and coping strategies for people living with sight loss. Satya's project targets African people, as this group has seen the biggest increase in numbers of any ethnic group in Glasgow over the last 10-15 years and also experiences particularly high levels of glaucoma and diabetes. Satya works intensively with clients to bring them along in their journey to a place where they are more confident about their health and lives in general.



RNIB has four key objectives:

To be there at the point of diagnosis of sight loss. We work to deliver emotional and practical support in/near to an eye clinic for patients receiving what can be a devastating diagnosis.

To support independence of people with sight loss. This is achieved by our comprehensive range of services that support people of all ages to achieve their potential – at home, work, school, or simply out and about.

To promote inclusion of people with sight loss in society. We work in partnership with service providers, employers, schools and many more to ensure the needs of people with sight loss are considered whenever possible.

Prevent avoidable sight loss. Our work in this field has developed a series of pilots targeting ethnic minority and low income populations to understand how best to support these 'high risk' groups to look after their eyes.

Working at community level has been a central feature in helping RNIB Scotland deliver on these objectives. A lot of our work relies on developing good practice in community engagement and joint working to improve people's health. With persistent health inequalities and variable access to services, working alongside people with 'at risk' of sight loss is an effective way to make change happen now and in the future.

Gozie Joe Adigwe
Senior Eye Health and Equalities Officer
0141 332 7757

A clean Bill of health?

Community Empowerment (Scotland) Bill passes in Scottish parliament

After four years of consultation and development, the Community Empowerment (Scotland) Bill was passed by MSPs on the 17th June 2015. The Bill provides a legal framework which aims to promote and encourage community empowerment and participation. It creates new rights for community bodies and places new duties on public authorities.

The Bill places a duty on the Scottish Government to develop, consult on and publish a set of national outcomes for Scotland, building on the Government's "Scotland Performs" framework. At a local government level, the Bill requires Community Planning Partnerships (CPPs) to involve community bodies at all stages of community planning with a particular focus on tackling inequalities. It also provides a mechanism for communities to have a more proactive role in having their voices heard in how services are planned and delivered. Finally, the Bill makes it easier for community organisations to acquire and make use of land and buildings for the benefit of the wider community.

The next steps for the Bill are: receiving royal assent to become an Act; the development of guidance and regulations around the Bill which will involve further consultation; after which each of the Bill's sections will be brought into effect separately through a "Commencement Order". The Scottish Government will post updates on progress and CHEX will pass these on to our network as they come.

CHEX will also be producing a more in-depth briefing on the Bill and its implications and opportunities for community-led health going forward.

You can find out more about the Bill at the Scottish Parliament website at: <http://goo.gl/cIDLtb>.



Community Empowerment (Scotland) Bill
[AS INTRODUCED]

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CHEX News: What we've been up to!

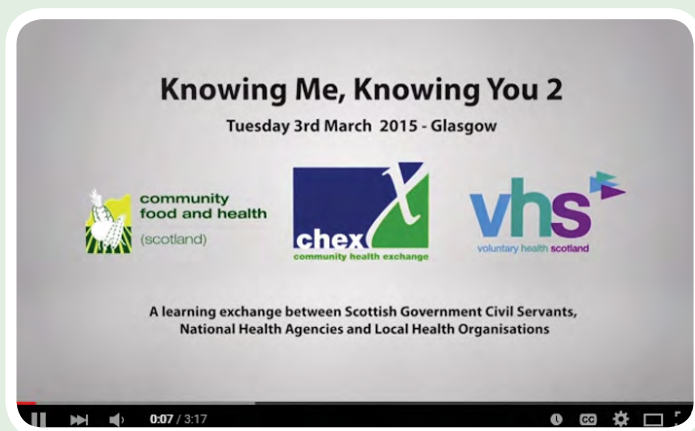
Knowing me, Knowing You 2

learning exchanges

Community Food and Health Scotland, CHEX and Voluntary Health Scotland recently organised a series of learning exchange and study visits between public sector workers and those working in the community and voluntary sector.

The learning exchange took place on 3rd March 2015 and brought together people from a range of backgrounds, giving them the opportunity to discuss their differing perspectives on the shared task of tackling Scotland's health inequalities. Three speakers talked about working in communities experiencing some of Scotland's worst inequalities. They shared their personal experiences of taking practical steps to support positive change for individuals and groups of people living in those communities. Their stories were used to stimulate round table discussion of what participants now felt could be done to enhance understanding between their sectors and to improve efforts to reverse inequalities in health in Scotland for the future.

Following the learning exchange, civil servants and members of staff attended a series of study visits- firstly to Lothian Community Health Initiatives Forum in Edinburgh. LCHIF support the work of community projects across Edinburgh and the Lothians who use a community development approach to tackle health inequalities. This event was seen as an opportunity for civil servants to meet several organisations together and to understand the working of the Forum.



This was followed by a visit to 3D Drumchapel, COPE Scotland and Drumchapel L.I.F.E, all organisations working around health and inequality in the west of Glasgow. Members of staff from the Scottish Government and NHS Health Scotland attended and heard about the work each organisation is carrying out.

At each visit, participants had the chance to take part in different activities such as parent and child playtime sessions and arts and crafts sessions. This gave visitors the opportunity to meet the people who use these services and exchange information and ideas with them. The service users expressed the value of these sessions, which give them the chance to meet and connect with other parents and families and offer each other support.

You can read the full reports from each session on the CHEX website, at:
<http://goo.gl/mLDZyW>

Views expressed in CHEX-POINT are not necessarily those of CHEX, unless specifically stated.

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