Key Messages: Realising the Right to Health
17th September 2019

Introduction

The 2019 VHS Annual Conference sought to explore how we can realise a right to health in Scotland by identifying what we understand by a right to health, what this means in practice and what actions are already underway to achieve this.

Cath Denholm opening the Conference

Cath Denholm, Director of Strategy, NHS Health Scotland
Cath set the tone for the day discussing the shared agenda between NHS Health Scotland (NHS HS) and VHS to tackle health inequalities and focus on how to achieve a rights based approach to health and wellbeing.

She highlighted the work of NHS HS, VHS and others on the public health reform agenda and the work to influence the 6 public health priorities. She linked the six priorities to the discussion that was intended for the day and focused everyone's attention to the importance our work across different sectors needs to make to people's lives. Every day decisions. Decisions that are made on how resources are distributed across areas and policy areas. Decisions on people's care when made routinely using a human rights based approach will achieve what we want to do.

Cath gave an example of a man with severe mental illness and the conversations he had with his consultant about wanting to get married. The consultant's initial discussion focussed on the risk to the man but was able to recognise the man and his partner's right to family life. This engendered a completely different conversation that resulted in the man getting married and being better able to manage his mental health.

Claire Stevens, Chief Executive, Voluntary Health Scotland
Claire emphasised the importance of tackling the socio-economic determinants of health. A former Chief Medical Officer for England's top tips for good health included the usual advice along the lines of "don't smoke, eat plenty of fruit, keep active and practice safe sex". In response, Professor Sir Michael Marmot devised his own tips which included: 'Don't be poor. If you can, stop. If you can't, try not to be poor for too long; don't live in a deprived area. If you do move; don't work in a stressful, low paid manual job; don't live in damp, low quality house or be homeless'.

She surmised that if the right to health is to be inclusive as suggested by the World Health Organisation, then action needs to be taken to ensure that the social determinants of health, such as housing, education, social support, employment and childhood experiences, work for people's health not against them.

Ministerial Address

Minister Christina McKelvie with VHS Chief Executive Claire Stevens

The Minister for Older People and Equalities, Christina McKelvie MSP drew attention to the Scottish Government's commitment to measure the success of our nation based on the wellbeing of our people not just Gross Domestic Product. This includes the right to the highest attainable physical and mental health. The Minister highlighted some of the actions in the new Programme for Government 2019/20 which aim to make Scotland an inclusive nation that recognises human rights standards.

- The Scottish Government is investing £1.5M to help disabled people into work and they are supporting more employers to pay the living wage. The Scottish Government are also bringing forward the date of the first instalment of Scottish Child Payments for children under 6, which means that from

Christmas 2020 families will have an additional £10 per week. This payment has been estimated to lift 30,000 children out of poverty when fully rolled out.

- The First Minister's advisory group on human rights and leadership presented recommendations at the end of 2018. A new task force has been established that will begin work shortly on a new Act for Scottish Parliament to incorporate rights set out in the UN into domestic Scots law.
- The Scottish Government has now launched the GP card. The card reinforces people's right to health by providing basic information on what people should expect from their GP and what their rights are when accessing primary healthcare. The card was launched to support the gypsy traveller community who experience poor health outcomes as a result of poor access to GP practices. The Scottish Government realise that is also valuable for refugees, people who are homeless and other vulnerable groups.

A delegate from NHS Tayside asked the Minister about the need for more infrastructure to support people to have a voice through peer support and volunteering. The Minister responded by giving an example of how the Scottish Government are seeking to expand existing infrastructure to ensure people's voices are heard and people are supported, by providing Befriending Networks with funding to expand their networks.

Keynote Presentations

Eddie Fraser speaking to the audience

Eddie Fraser, Director of the East Ayrshire Health and Social Care Partnership (EAHSCP) and Chief Officer of the Integrated Joint Board

Eddie spoke about the importance of a right to health and the exciting and innovative initiatives that are underway in Ayrshire. Ayrshire faces a number of challenges including child poverty, deprivation and drug related deaths and there is a real need to give people choice and control in their lives. People have the right to be seen as a whole person and not be defined by illness, disability or the support they receive –

people have the right to be who they are. Eddie focussed on the importance of working collaboratively across sectors and described how EAHSCP work in partnership with organisations such as Paths for All, Citizens Advice and Scottish Care, amongst others. He spoke about the importance of working with the Strathclyde Partnership for Transport. Transport is a big issue in Ayrshire as it is more expensive to travel locally than to get to Glasgow and people can't afford to travel to the local hospital and are often ‘penalised’ for missing appointments.

Eddie also spoke about the importance of listening to people and gave an example of Shannon's Box, which was an idea from a care experienced young person. Shannon described the terrifying feeling of first going into care, and came up with things that could help, and now all young people going into care get this box. The box contains a space for something personal to you, a letter from Shannon, a teddy and a torch because everyone is frightened in the dark. He also spoke about the rights of family carers (unpaid carers) and the importance of recognising their expertise and their importance to the delivery of statutory support, which could not operate without them.

Eddie also described the smoking cessation programme which has been extended to the local prison where 110 inmates have stopped smoking. He also spoke about an initiative that employs people with lived experience to deliver peer support to help vulnerable people in prisons. He has also supported the delivery of alternative support by taking money out of the medicines' budget and using it for social prescribing activities, providing alternative support to over 500 people so far.

Graeme Callander addressing the audience

Graeme Callander, Locality Manager, Drink Wise Age Well

Graeme shared a short video featuring members of The Charter for Change Advocacy Group, their recovery journey as well as their peer support work to help improve service and support for others. Graeme also discussed the findings of a national survey of 16,000 older adults conducted by Drink Wise Age Well in 2015 which helped understand the triggers and issues people face that lead them to abuse alcohol in later life. Triggers such as retirement, bereavement, empty nest syndrome, and a perceived loss of purpose all coalesce in later life. He stated that 77% of alcohol attributed deaths affect people aged 55 and over and that isolation is a key factor in this. Graeme also spoke about the need to shift culture from policy to public action by supporting more alcohol free environments.

Morning Panel Session

Panel members Left to Right: Rosie Tyler-Greig, Rachael McKechnie, David Donaldson and Derek Todd

The session before lunch heard from a panel of speakers.

Rachael McKechnie, National Engagement and Partnership Lead at Social Security Scotland
Rachael introduced the newest public body, Social Security Scotland, which has been established to deliver a subset of benefits to people with disabilities, carers and those on a low income. Rachael focussed on the financial aspect of the right to health and the impact of poverty on mental health and the health problems that come through the inability to put a roof over your head or food on your table. The most vulnerable people find it hard to navigate the benefits system. The Scottish Government want to ensure the right to health which means designing a system with the people who are using it and their approach has been to make sure they ask questions at every step along the way.

Rachael spoke about the development of lived experience panels which have been and will continue to be involved throughout the process of setting up and running the new body. The panels have provided feedback on the application process, opening hours, what they think of the different forms of communication and the ease of use of application forms amongst other things. Social Security Scotland aims to maximise take up and ensure people know what they are entitled to by actively looking at trigger points to ensure people can automatically be signed up for the appropriate benefits.

The new public body is working to ensure that the right people are in place and that they recruit for the right attitude and train people for skills they need in the role. More importantly they are trying to get a workforce representative of the people they aim to serve.

Rosie Tyler-Greig, Policy and Influencing Manager, LGBT Health and Wellbeing
Rosie spoke about the barriers to the right to health, especially mental health, experienced by the LGBT community. There are a number of health inequalities faced by the LGBT community, for example, the number of LGBT people reporting good or very good health is 10% lower than the rest of general population. They are 1.5 times more likely to have depression and twice as likely to have attempted suicide. The LGBT community also face socio-economic disadvantage, as they we are 6% more likely to live in a deprived area and 4.4% more likely to be unemployed. Stonewall's 2018 'Work report' showed 1 in 8 transsexual people had been attacked by customers or colleagues and LGBT Health and Wellbeing are conducting further research in this area to understand more. She also raised the issue of a lack of understanding among health professionals of how to treat LGBT people. A recent UK wide survey conducted by the LGBT Foundation found that 40.5% of lesbian and bisexual women were incorrectly told that they did not need cervical screening.

Rosie called for the inclusion of LGBT people from the start, into Government and Local Authority level strategies and plans, in order to inform action. She also raised the importance of intersectional networks and the importance of ensuring that Government reporting on rights includes intersectional representation. She wanted to see more inclusive spaces that consider how people feel and work to include everyone. She surmised that the right to health is strongly underpinned by how strongly we receive rights across the board and it is important for LGBT people and marginalised groups to be seen and heard at all levels.

Derek Todd, BSL Consultant from deafscotland
Derek described the four pillars of deafness and the barriers people with hearing difficulties faced in society. The four pillars of deafness include people who are *deaf* which is around 12,500 people, officially there are 4,000 people who are *deafblind* but the actual figure is somewhere around 8,000. Officially, there are 355,000 *deafened* people who have acquired deafness through work, illness or simply woke up deaf and 600,000 people who are *hard of hearing*, but again the actual figures are much higher.

Deafness is a hidden disability and Derek questioned why we still needed to declare our disabilities, why couldn't all spaces, services and activities be accessible to everyone. Some barriers people experiencing deafness face are common and taken for granted for example, the use of door intercoms: if there is no camera and screen people cannot lip read. Another example is ensuring that subtitle equipment that is used in meetings and events is appropriate and fit for purpose. Derek also mentioned the importance of choosing an appropriate venue. He gave an example of an event which had interpreters and electronic note takers but took place in a tent in heavy rain which meant no one could hear anything.

He focussed on the issue of intersectionality, where he noted that deaf people can have issues with alcohol, be LGBT, are more than 4 times likely to have mental and physical health issues – but they are less likely to have access to support.

David Donaldson, Gypsy Travellers Campaigner and Advocate
David described the statistics which show that traveller communities experience the worst inequalities by every measure recorded, including higher levels of depression, suicide and lower life expectancy by 10 years. There are long standing cultural inequalities and traveller communities face much stigma and trauma. He described a number of situations where health professionals in various capacities refused traveller communities access to treatment.

There are 26 permanent sites in Scotland, meaning there are only 430 homes for a population estimated to be around 60,000 people. A new site hasn't been built in over 25 years – it would not be acceptable if a new house had not been built since the 80s. There is an accommodation crisis, which propagates health inequalities. He described the situation on a site where residents had no other option but to drink black grainy water and disabled and elderly travellers were not supported.

David called for everyone to help redesign the system and admit we don't know the answers, to admit own prejudices and remove the blame from communities, and empower them to turn private pain into public policy.

A member of the audience asked all of the panel members how they would suggest existing systems could design out barriers and discrimination. Derek responded by highlighting the importance of co-production as well as collaboration across directorates within the Scottish Government but also across sectors and disciplines. David elaborated on the point regarding co-production emphasising the need for it to conducted in an equal way across the board by ensuring you work with a range of people not just your “go-to” person. He also said that cultural awareness should not lead to stereotyping. Rachael called for a cultural revolution in the way that services are delivered. She spoke about the importance of asking questions and engaging with people, but with integrity, by making sure you can show change. Rosie also agreed with the importance of co-production and added that there needs to be training and development built into positions and systems from the very beginning.

Workshop Session

Afternoon Icebreaker session

Susan Paxton, Head of Programmes: Community-led Health and Networking, CHEX
Susan alongside her colleague Olivia Hanley from CHEX delivered an interactive workshop which asked delegates to prioritise a pre-set group of 10 actions that can be taken to help people realise their right to health in ascending order.

Example of table exercise

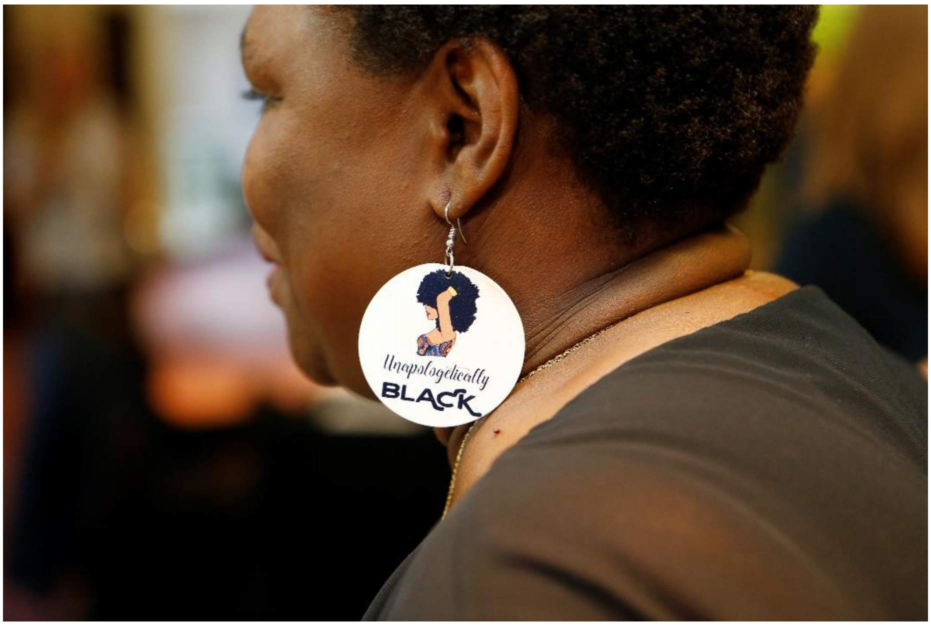
Once this exercise was completed delegates were asked to pair up and discuss a pledge they are willing to make to help people to realise the right to health, they were then asked to write these on postcards which would then be sent to them at a future date. Some delegates shared their pledges with the audience.

A Drink Wise Age Well volunteer pledged that they would like to see Drink Wise Age Well integrate more with the travelling community and people who are deaf so that they can support people to be a bit more joined up.

Another delegate pledged to support people living and affected by HIV to know what their rights are by inviting the Citizens Advice Bureau to come and speak about the right to health and how to access these and make a complaint when these rights are breached.

Jim Hume from the National Rural Mental Health Forum spoke about tackling inequalities and issues faced by isolated communities across Scotland whether in rural or urban areas.

Voices of Experience Panel



Speaker Agnes from Waverley Care

The session in the afternoon heard from a panel who volunteer for voluntary organisations in Scotland and who shared their personal experiences. The session was chaired by Lucy Mulvagh, Director of Policy at The Health and Social Care Alliance. The first panel member was Barbara who volunteers for Versus Arthritis, who spoke about how difficult it was to accept the change of lifestyle after her diagnosis of rheumatoid arthritis. In her own words she had been a workaholic. Although she was familiar with the condition as her mother also had it, she didn't want to accept it and continued working until she was forced to stop because of the condition.

Barbara also spoke of the NHS professional team in Perth Royal Infirmary and how they not only treated the physical problems, but they actually spent time listening. They put her in touch with Arthritis Care (now Versus Arthritis) who ran self-management courses and she was amazed to find she wasn't the only person with these problems. She began volunteering for Versus Arthritis and that became essential to her as it gave her back purpose and filled the gap left in her life, from having to give up work. She was able to run self-management courses, and give back to the community and help herself. She noted that the barrier is often not physical but the acceptance and mental and emotional side.

The next panel speaker was Agnes from Waverley Care. She spoke of how her life came to a ‘standstill’ after being diagnosed with HIV while pregnant and the impact not knowing her rights had on her treatment and life. When she went for her first gynaecology appointment she was advised by her medical professional to have an abortion because the chances would be too high that the child would be born HIV positive. She did not know her rights then and did not have the information to make an informed choice. She was given ‘five minutes to decide’ and in her own words Agnes said that she ‘signed my child's life away because of ignorance’.

After suffering from postnatal depression she joined a HIV support organisation and met with people who had lived with HIV for 20 years and more. This changed her perspective that HIV was not a death sentence. She started volunteering for the organisation and soon started to support those who were newly diagnosed, give talks and provide peer support to give back to the charity for empowering her and giving her the knowledge to live with HIV. She was also awarded for being volunteer of the year.

She then went on to talk about battling stigma. Agnes said that she didn’t mind stigma from individuals in the street but not someone who had studied to be a health care professional. She spoke about a time when she went for carpal tunnel surgery, she was first on the list but was treated last in the day because of her HIV status. She felt emboldened to make a complaint which although was not upheld made her feel happy from being able to challenge something that was wrong and stand up for her rights. She spoke about the importance of knowing your rights, she had been in the UK for 17 years and did not know her rights because no-one has put them in black and white. They are there, hidden in small print. That is wrong. She now takes it upon herself to read them, know them and stand up for them.

The final panel member was Gemma from See Me. She was diagnosed with depression and anxiety when 15 and has had some good experiences and some bad, and has learnt that the negative experiences are not unique to her. She shared a personal experience that illustrated the importance of the right to health and access to appropriate health care. She noted that your ability to advocate for yourself and to know what you are entitled to is really important however, the nature of mental illness sometimes leaves you feeling like you have very little capacity and that you are unable to advocate for yourself.

Gemma described a time at university where she got to the point where she was suicidal, locking herself in her room for days, not eating or washing or seeing people. She was urged by a friend to go to the doctor and it took her about 2 weeks to build the courage to go. She had her first shower in 5 days and went to the doctor and explained how ill she was feeling but the doctor responded by saying, ‘you have come with clean hair and clothes, I don’t think there is anything wrong with you’.

Gemma described how she was actively suicidal and the lowest she had been and a doctor, in a position of authority, had just told her he didn't think she was depressed so she began to doubt herself. She then attempted to take her own life but her friend supported her and she was able to go and see a different GP and get access to medication and therapy as well as lots of different types of support. She believes this is an indicator of how you can't always rely on someone being able to advocate for themselves. She felt that it is great we are talking more about mental health but the appropriate help has to be timely and appropriate and there for people, and when they ask for it they have to be believed.

Lucy asked the panel members to give some of their final thoughts on what needed to happen to ensure people got their rights. Panel members responded by noting the importance of health professionals actively listening and engaging with people they treat, they spoke about the need for continued training and education for health professionals on how to ensure people are treated without stigma and discrimination and the need for services to look for people who are not currently engaged and presumed as "hard to reach" and ensure they are supported and enabled.

Closing Remarks

Cath Denholm then brought the conference to a close with the words of Eleanor Roosevelt, "you must do the thing that you think you cannot do, no-one can make you feel inferior without your consent".

Winner of the Poster Award: DART – Direct Action at the Right Time

For further information contact: Kiren Zubairi, Policy Engagement Officer

voluntary health scotland
Mansfield Traquair Centre
15 Mansfield Place Edinburgh EH3 6BB
0131 474 6189 mail@vhscotland.org.uk
www.vhscotland.org.uk @VHSComms
Registered Scottish Charity SC035482
A company limited by guarantee SC267315