

AGENDA ITEM NO: 10

Report To: Alliance Board Date: 13/06/16

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Subject: Refreshing the Inverclyde Anti-Stigma Partnership

1.0 PURPOSE

1.1 It is the intention of this report to look to gain endorsement from the Inverclyde Alliance Board to have community planning support for refreshing the Inverclyde Anti-Stigma Partnership.

2.0 SUMMARY

- 2.1 Inverclyde Health & Social Care Partnership (HSCP) has implemented its mental health improvement delivery plan called 'Making Wellbeing Matter in Inverclyde'. This sets out the priorities for improving mental health. It recognises that mental illness is often unseen, and misunderstood. It also recognises that early intervention can make a real difference in outcomes, such as keeping people in work, or reducing the need for more complex care if mental illness worsens.
- 2.2 The impact of 'Making Wellbeing Matter in Inverclyde' is foreseen as
 - · Mentally healthy environments will be created.
 - · Stigma and discrimination will be tackled.
 - The health inequalities gap will be reduced.

Moreover, the intended outcomes are -

- Communities will be better equipped to prevent suicide, and people will be more confident to approach those whose lives are at risk to suicide.
- Population mental wellbeing will be improved, which in turn will improve quality of life.
- People with mental ill-health will feel more socially included.
- 2.3 In the Inverciyde Dementia Strategy (2013-2016), called 'Working Towards a Dementia Friendly Inverciyde', there is the underpinning action that focuses on the health improvement, public attitudes and stigma. While this largely responds to what is contained within the National Strategy, there is the local outcome to increase awareness and understanding of dementia and the rights of people with dementia in the general public and community.

It is therefore foreseen that, in this context, the development of dementia friendly communities requires the participation of people with dementia, their families and carers, and an understanding of dementia, and how it affects individuals. This will encourage help seeking and help offering within our communities, and reduce the stigma and exclusion experienced by people with dementia, their families and carers.

Our local area makes its contribution to the annual Scottish Mental Health Arts & Film Festival (SMHAFF) and now in its 10th year, is seen as significant platform to challenge preconceived ideas about mental health.

- 2.5 In light of the above, it has been decided that the primary focus of the developing work for the Inverclyde Anti-Stigma Partnership will focus on mental health and dementia.
- 2.6 Explicitly all of the developments and overall work outlined in this paper needs to be embedded into the inequalities, human rights and recovery agendas:
 - Stigma can adversely affect a variety of outcomes such as housing, employment status, social relationships, educational opportunities, and access to and quality of health care.
 - In their ongoing campaigning, See Me Scotland advocate that adopting a human rights approach to tackling stigma and discrimination empowers individuals to know and claim their rights and increasing the ability and accountability of those who are responsible for respecting, protecting and fulfilling rights. Put simply, everyone has the right to and deserves to live without stigma and discrimination. They are secured in law. At the individual level, while we are each entitled to our human rights, we should also respect the human rights of others.
 - Most people who experience mental health problems recover fully, or are able to live with and manage them, especially if they get the necessary help at an early stage but social stigma attached to mental ill-health and the discrimination they experience can make their difficulties worse and make it harder to recover.
- 2.7 The work of the Inverclyde Anti Stigma partnership will help partners to meet their equality outcomes and duties as required under the Equality Act 2010.

3.0 RECOMMENDATIONS

- 3.1 It is recommended that the Alliance Board:
 - a) Endorse the approach outlined in this report to refresh the Anti Stigma Partnership and look to incorporate actions and outcomes from the planned event into the work of the community planning partnership.
 - b) Attend the event on 1st December and encourage staff within partner organisations to be part of the journey.

4.0 BACKGROUND

4.1 Stigma exists in today's society and is generally linked to mental illness and the wider recovery agenda. The Oxford Dictionary offers the definition of stigma as 'a mark of disgrace associated with a particular circumstance, quality, or person'.

According to the World Health Organisation, "the single most important barrier to overcome in the community is the stigma and associated discrimination towards persons suffering from mental and behavioural disorders". Authoritative studies on the issue of stigma are receiving an increasing attention, given its negative disturbing impact on individuals, communities and society.

Moreover, stigma -

- prevents people seeking help
- delays treatment
- impairs recovery
- isolates people
- excludes people from day-to-day activities
- prevents people from achieving their goals in life
- stops people getting jobs
- 4.2 International activities associated with the anti-stigma movement include the World Psychiatric Association's Open the Doors programme, operating in 20 countries and national initiatives such as Like Minds, Like Mine in New Zealand. In England, the approach has been more piece-meal. The government's National Service Framework for Mental Health encouraged mental health promotion to sit alongside service reform and established two programmes *mindout for mental health* and *Shift*. More recently, the campaigning organisation, Time to Change, has been at the forefront of tackling stigma and the human rights agenda.

See Me in Scotland is a recognised brand in the area of tackling mental health stigma, particularly at individual and community levels, along with their increased focus on work places. Its campaigning roots are from the then Scottish Executive's National Programme to Improve Mental Health and Wellbeing (October 2002) and would stake a claim that there have been some qualified successes, in terms of shifting attitudes and raising awareness. In an effort to ensure sustainability and to build upon previous campaigning work, See Me are now funded by Scottish Government and Comic Relief in a joint management arrangement between the Scottish Association for Mental Health (SAMH) and the Mental Health Foundation.

In the World Alzheimer Report 2012: Overcoming the stigma of dementia, it is highlighted by Alzheimer's Disease International that it is vital there is better public awareness and understanding to reduce the stigma associated with dementia. This can happen only with well-developed and executed political and public campaigns to support a societal shift towards acceptance and inclusion of people affected by dementia.

- 4.3 Low levels of understanding about dementia lead to various misconceptions resulting in perpetuation of stigma which is prevalent in most countries at various levels. People with dementia are often isolated, or hidden, because of stigma or the possibility of negative reactions from neighbours and relatives to behavioural and psychological symptoms. The idea that nothing can be done to help people who experience stigma, often leads to hopelessness and frustration. As a consequence, urgent action is required to reduce stigma.
- Other areas with strong connections to the Equality Act (2010) protected characteristics are purporting similar findings and these are also focused on stigma and inequalities, which are usually inextricably linked. By way of an example, lesbian, gay, bisexual and transgender people surveyed recently for the Equality Network's LGBT Equality Report¹ reveal that despite recent advances in the law and social attitudes they are still being treated unfairly. 89% of LGBT people believe Scotland still has a problem

¹ http://www.equality-network.org/resources/publications/policy/the-scottish-lgbt-equality-report/

with inequality, while 94% say that more needs to be done to tackle the day-to-day prejudice and discrimination.

In their 'UNHEALTHY ATTITUDES: The treatment of LGBT people within health and social care organisations in Scotland' (2015) report, Stonewall Scotland found lesbian, gay, bisexual and transgender (LGBT) people constitute around 6-10% of our adult population. Despite improving social attitudes, it is still the case that LGBT people experience very significantly higher rates of mental ill-health than the general population, as a result of stigma and discrimination. Evidence shows that suicidal behaviour is 3 times more prevalent among lesbian, gay and bisexual (LGB) people when compared to the general population; this rises to 8 times among transgender people. Self-harm is 8 times more prevalent among LGB people; this rises to 20 times among transgender people. Suicidal behaviour is 3 times more prevalent among LGB people and 8 times among transgender people.

Additionally -

- 44% of young (16-24 years old) LGBT people have considered suicide (Youth Chances Survey

 Metro Charity and University of Greenwich, 2014).
- More than half (55 per cent) of lesbian, gay and bisexual pupils have experienced direct bullying. Those who are bullied are at a higher risk of suicide, self-harm and depression (Stonewall School Report, 2012).
- 41 per cent have attempted or thought about taking their own life directly because of bullying and the same number say that they deliberately self-harm directly because of bullying (Stonewall School Report, 2012).
- 4.5 Stigma, discrimination and indeed aspects of reported hate crime are also attributed to people with a range of disabilities, carers, young people, visually impaired, people with addictions and a number of other vulnerable and disadvantaged individuals and groups.
- 4.6 The work to inform the aforementioned 'Understanding Harm' highlighted that through using real-life examples and stories from local individuals, there was a clear association with stigma and that of hate crime. The fundamental outcome for this project is to help those affected feel empowered to deal with similar situations and make others think twice about their own actions when witnessing such incidents. Helping everyone understand the signs and dangers of such abuse will hopefully help put an end to these frightening encounters.
- 4.7 There are a number of studies dedicated to the issue of learning disabilities and stigma and it is important to highlight the recently published 'Self-reported stigma and symptoms of anxiety and depression in people with intellectual disabilities (Journal of Affective Disorders, 2015)'.

This was a cross sectional study of 229 participants with learning difficulties (without mental illness) recruited from 12 centres in England and found –

- Self-reported stigma was positively associated with psychological distress, i.e. as self-reported stigma increased, so did psychological distress.
- There was a negative association between stigma and quality of life, i.e. as stigma increased, quality of life decreased. Both stigma subscales were significantly negatively associated with quality of life.
- Self-reported stigma was not associated with adherence to treatment. The relationship
 between stigma and quality of life and stigma and service use were mediated by psychological
 distress. That is to say that increased psychological distress usually also meant lower quality of
 life and higher number of service contacts in those with high and low levels of stigma.

5.0 WORK UNDERWAY

In the refreshing process, it is acknowledged there are already examples of good practice, in the context of the wider anti-stigma agenda. Some of these are raising awareness of hate crime through training; local campaigns in the form of Keep Safe, (part of the multi-agency 'I am Me' initiative to raise awareness of disability hate crime and harassment) and 'Understanding Harm'. This project was developed by the Inverclyde Adult Protection Committee, with the aim to produce material that would

clearly demonstrate the five main types of harm a vulnerable adult may experience.

Augmenting the actions in 'Making Wellbeing Matter in Inverclyde' and 'Working Towards a Dementia Friendly Inverclyde', to refresh the local anti-stigma partnership, a strategic oversight group has formed. The group has developed its terms of reference and will also work with See Me Scotland, who are developing their anti-stigma agenda in terms of human rights and tackling discrimination.

As the various actions that are described in this paper are developed, it is the intention to involve a wider membership to undertake some of the operational activities.

In order to ascertain some baseline data on the magnitude of the issue locally in Inverclyde, a series of questions were asked in the Spring and Autumn 2015 Citizen's Panels, focussing on mental illness and dementia. The support of the Public Health Resource Unit at NHS Greater Glasgow and Clyde was enlisted to determine the questions to be asked.

The results of these questionnaires are contained in Appendix 1 and 2. Both of these report findings will contribute to the future planning of, and inform the direction of travel for, the Inverclyde Anti-Stigma Partnership. This locally gathered data will also support other sources of research.

6.0 INVERCLYDE ANTI-STIGMA PARTNERSHIP

- 6.1 Some early developments in October 2008, saw the Inverclyde Anti-Stigma Partnership bringing together a range of agencies, organisations and individuals to have a unified approach of tackling stigma and discrimination in its widest sense. At the inception of the Group, the following aims were developed:
 - encourage the take up of local anti-stigma initiatives through building local capacity to take effective action:
 - develop an outcome focused action plan to include a local anti-stigma pledge;
 - ensure public awareness and greater understanding and appreciation for the wider mental health improvement agenda;
 - develop and strengthen relationships between individuals and organisations in Inverclyde to encourage wider involvement in campaign action;
 - ensure appropriate links with the Recovery and mental health improvement agendas;
 - highlight the importance of implications and linkages to wider remits such as health inequalities, the areas of employment, employability, social inclusion, the social model of disability, the social model of mental health, etc.;
 - ensure there is a focus on people within our community who are at risk from discrimination and social exclusion;
 - promoting equality of opportunity between one or more equality groups and other people;
 - challenging discrimination against people from one or more equality groups
 - ensure contribution to achieving cultural change using a whole systems approach.

Following endorsement by the Inverclyde Alliance in May 2009, the Partnership was officially launched at an event - Equality Counts in Inverclyde: Breaking Down Barriers.

One of the group's significant achievements was for the Inverclyde Alliance to sign the See Me pledge, along with Inverclyde Council in its own right, as part of a joint signing for all local authorities in the Greater Glasgow & Clyde area, as well the Board itself. These were responses to the Scottish Executive's 'Towards a Mentally Flourishing Scotland (2009)'.

This work provides an important backdrop for the need to continue these developments, especially in response the context mentioned above.

6.3 In order to move forward, further work is required to engage with our local communities on the issue of stigma and it is the intention to hold a co-production event on Thursday 1st December 2016.

The main aim of the event will be to gain a better understanding on the ways the Anti-Stigma Partnership should develop into an action-oriented and active collaborative approach to tackling stigma and discrimination. It is also anticipated that a key output of the event will be for a local action

plan to be developed, in order to move this important work forward.

- Delegates attending the event will be drawn from our local communities, statutory and 3rd sector agencies. An invitation is extended to all members of the Alliance Board.
- In preparation for the event, it will be necessary for the strategic oversight group to further analyse the Citizens Panel results and it is foreseen this may lead to the commission of some insight gathering research.

7.0 SUMMARY

- 7.1 Stigma exists in our society and it is therefore important for the work of the Inverclyde Anti-Stigma Partnership to be refreshed in line with the actions contained with both the Inverclyde Health & Social Care's Making Wellbeing Matter and the Inverclyde Alliance Working Towards a Dementia Friendly Inverclyde.
- 7.2 The primary focus of the developing work will focus on mental health and dementia and will help partners to meet their equality outcomes and duties as required under the Equality Act 2010.
- 7.3 The Strategic Oversight group that has formed will oversee and deliver on a co-production event, taking place on 1st December that will inform the direction of travel. It is intended this will not just be the primary focus mentioned above but also ways to address stigma in other groups that will be determined from the event.

8.0 IMPLICATIONS

8.1 Legal: N/A

Finance: It is expected that this element will be contained within current resources.

Personnel: N/A

Equality and Diversity: Anti Stigma work will have a positive impact on the achievement of equality and diversity in Inverciyde, focussing on mental health and dementia, which are covered under the protected characteristics of disability and age.

Repopulation: N/A

9.0 CONSULTATIONS

9.1 Ongoing engagement and liaison with the Inverclyde Dementia Strategy Group and the Recovery Inclusion Group, particularly for guidance on the Citizens Panel questionnaires.

10.0 LIST OF BACKGROUND PAPERS

Appendix 1 & 2

Citizens Panel Spring 2015 Survey

Mental health and stigma

- When Panel members were asked if they knew someone who has a mental health issue, 40% said that they did.
- Just over a third (36%) of people who know someone who has a mental health issue said the person had experienced stigma and discrimination because of their mental illness.
- Of the respondents who know someone who has a mental health issue, 36% said that they have experience of supporting someone who has been subjected to stigma and discrimination around mental illness.
- Panel members were then asked if they had heard of the national 'See Me' campaign which aims to end mental health discrimination; 34% said they had heard of the initiative.
- Of the people who had seen the campaign, more than a third (38%) thought it had been very or fairly effective while 15% said it was not effective or not at all effective.
- The majority of respondents (92%) said they were not aware of other campaigns or initiatives that aim to tackle mental health stigma.

Citizens Panel Autumn 2015 Survey

Dementia and stigma

The first three questions, from the overall Survey, were for people with dementia i.e. Panel members were asked to respond only if they had dementia. The questions were:

- 1. Has someone ever avoided you or treated you differently because you have dementia? If Yes, please tell us what happened.
- 2. Have any of the following people either avoided you or treated you differently because you have dementia? *Please tick all that apply.* (The list included Husband or wife; Other family member; Healthcare professional, for example, a doctor or nurse; Supermarket staff.)
- 3. Have you developed ways to cope with being avoided or treated differently? Please state.

Because of the relatively low number of Panel members who replied to the three questions, it would not be appropriate to make the responses publically available, in order to protect the anonymity of respondents.

For the remaining questions about dementia and stigma, Panel members were asked to respond only if they cared for someone who has dementia.

- Eight per cent of respondents who stated that they care for someone with dementia said they had concealed or hidden the diagnosis of the person with dementia that they care for.
- When asked if they had ever been avoided or treated differently when caring for a person with dementia, 16% of respondents who care for someone with dementia said that they had.
- Examples of how people had been avoided or treated differently included family and friends distancing themselves and others not realising that the person was ill.
- The next question asked Panel members how they coped with being avoided or treated differently; examples of how people managed included staying at home more, as well as discussing the issue.
- In terms of including people with dementia in everyday life, the Panel was asked to suggest ways that this could happen. Suggestions included providing opportunities for social interaction, as well as treating people with dementia the same as everyone else.
- The final question in the dementia and stigma section of the Survey asked for suggestions about how society can ensure that people with dementia are not stigmatised. A recurring theme in Panel members' responses was information, education and raising awareness about dementia.