

SEE ME

HEALTH AND SOCIAL CARE

THREE YEAR PROGRAMME EVALUATION
NOVEMBER 2016 - OCTOBER 2019



Mental Health
Foundation

See Me
End mental health
discrimination

See Me
End mental health
discrimination

People Like

YOU

will
stigma

We know
have

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SEE ME - HEALTH AND SOCIAL CARE PROGRAMME EVALUATION

Outcomes Aligned to See Me Health and Social Care Programme:

- People individually and collectively will increasingly challenge self-stigma and stigma and discrimination.
- Increased understanding of nature, source and impact of stigma and discrimination, rights-based approach and what works in tackling it.

Reach of Health and Social Care Programme (November 2016 – September 2019)

- **205** National Partnership Engagements
- **193** Local Partnership Engagements
- **15** Policy Responses Submitted

Summary

Lived experience is one of the primary underpinnings of the Health and Social Care programme and is widely reported as a central appeal of working with See Me.

Relationship-building and partnership working are key to the successes of the Health and Social Care programme and are evidenced clearly in the successful work undertaken with the DBI programme and NHS Inform.

See Me has made a significant contribution to the DBI programme, through which anti-stigma and discrimination is woven. See Me continue to partner with the DBI programme and are currently assisting with the extension to 16- and 17-year olds.

See Me has worked and continues to work closely with NHS Inform on the redevelopment of their online CBT resources and other mental health service developments.

See Me's funding of Stigma Free Lanarkshire makes an important contribution to the development of anti-stigma and discrimination work in the Lanarkshire local authority area. Clarification is needed between the work and remit of See Me within this partnership and that of SFL. Independent evaluations of each programme should reflect this distinction.

See Me are working well towards a mental health inclusive Health and Social Care agenda and services.

1.0 Introduction

Within Health and Social Care (H&SC), evidence shows that people who experience mental health problems encounter high levels of stigma and discrimination. These people are also less likely to receive acceptable and timely care and support, less likely to be involved in their own health decision-making processes and are less likely to seek help within health care than other population groups. The See Me H&SC programme aims to change minds, policy and practice within H&SC towards an agenda of mental health inclusion. See Me work to influence leaders and practitioners within H&SC to join this agenda and work practically with them to address stigma and build mental health into their practice.

Over the past year, there have been several important advancements within the See Me H&SC programme. See Me continue to be a close partner of Scotland's national Distress Brief Intervention (DBI) programme, to ensure the delivery of anti-stigma and discrimination practices in this work. See Me have also worked closely with NHS Inform, to redevelop their online depression and anxiety resources, which have now been updated. See Me also continue to support the mental health inclusion agenda of Stigma Free Lanarkshire (SFL). Further, work is ongoing with Chest, Heart and Stroke Scotland (CHSS), to raise awareness of stigma and discrimination amongst their nurses and improve outcomes for people with mental health problems who use CHSS services and with a Scottish Health Board to deliver a programme of work to a local GP practice. The H&SC programme additionally carries out influencing and consultation work on the inclusion of stigma in policy development.

This report will detail work and achievements made by See Me within three discrete H&SC projects and how this work demonstrates progress towards the H&SC programme outcomes, as detailed on page one. First, the methods by which the programme was evaluated will be discussed. This is followed by the main findings, before overall discussion and recommendations.

1.1 Methods

A primarily qualitative methodology was applied to the evaluation of the H&SC programme. Qualitative data, as well as secondary quantitative and qualitative data, were collected to assess whether the medium-term outcomes relevant to the H&SC programme are being met. Qualitative data collection included four face-to-face semi-structured interviews, one semi-structured telephone interview, one focus group and 38 qualitative event feedback forms from two events.

1.2 Analysis

All qualitative interviews and focus groups were transcribed and analysed thematically, using an outcomes-focussed approach. Themes related to the relevant programmatic outcomes were induced within and across datasets. Any additional significant themes arising within these were also induced.

1.3 Limitations of the Data

All findings are based on qualitative data; there was no primary quantitative data collected for the Health and Social Care programme. Over time and dependant on ongoing work, quantitative data collection for the evaluation may be possible.

The following section presents the findings of H&SC data collection. How See Me are achieving their outcomes and evidence of what works to reduce mental health stigma and discrimination in H&SC are reflected in three thematic examples: Partnerships and changing practice: the DBI programme; Partnerships and Changing Minds: NHS Inform and Funded Partnership Working: Stigma Free Lanarkshire. These examples highlight the processes and outputs of See Me and the mechanisms through which the H&SC programme is achieving its goals.

Table 1: Summary of Health & Social Care Research Methods

Summary of Health & Social Care Research Methods		
Programme	Qualitative	Quantitative
Health & Social Care	13 interviews 1 focus group (n=3) Feedback forms from Artist in residence exhibition National and local health and social care policy documents	Evaluation and feedback data from workshops for stigma free week; discussion data from lived experience seminar and leaders' seminar. Evaluation data from Artist in residence

2.0 Partnerships and Changing Practice: The DBI Programme

The DBI programme is a Scottish Government project which is piloting an innovative method of supporting people who present in distress to front line services. The DBI programme aims to improve the response to people presenting in distress and trains front-line health, police, paramedic and primary care staff to react compassionately and set in motion an intervention to support individuals through their distress. See Me have been working closely with DBI since the development stages, to embed a focus on mental health stigma and discrimination. Challenging stigma and discrimination forms part of the “core” of the DBI programme and this shared objective brought about the partnership between DBI and See Me. More specifically, the DBI theory of change states that DBI:

can contribute to reduction of stigma and discrimination associated with seeking and receiving support for distress.

DBI team member (2)

The following findings are taken from three semi-structured interviews with core and senior members of the DBI team. To ensure confidentiality, roles within the team are not distinguished and responses are anonymised.

2.1 Influencing DBI Programme Development and Training

See Me provide a “reflective and critical eye” to the DBI programme. They have reviewed training documents and altered language and the way information is presented and previously produced a paper entitled *How the ‘Distress Brief Intervention Programme can contribute to the reduction of mental health stigma and discrimination across systems.’* This paper identified a range of opportunities for the role See Me could play in DBI and was fed into the development of the programme, following discussion of the paper by the programme board:

They [See Me] were able to help us with the language and ensure that we didn’t include anything that was potentially stigmatising or discriminating. See Me have also... highlighted the importance of the role of lived experience testimony in any intervention, within a system to reduce stigma and discrimination.

DBI team member (1)

Lived experience has formed a key part of the contribution that See Me have made. As one team member said:

We hadn’t really done enough of that [lived experience] and any other development...around how do you build the lived experience into things like training.

DBI team member (2)

See Me have produced several short, lived-experience video clips for DBI, that are now used in the training programme with front line staff. This change to the training is one of the more substantive in its most recent iteration; the lived experience videos are now part of both the Level One and Level Two training in the DBI programme. The DBI team discuss how See Me have brought their “expertise” to the programme and embedded challenging mental health stigma and discrimination in a systems-based approach across the programme. The training programme cuts across multiple sectors and health care service providers and See Me’s contribution has brought stigma to the fore on a wider scale:

They’ve been able to identify for us the opportunities to be able to make some changes in the way that we do things. Not only that, they’ve actually provided some of those materials.

DBI team member (1)

Further, one of the See Me video clips is now available for all Level One NHS staff on the NHS LearnPro modular training site.

2.2 Continuing partnership

Recently, the DBI team have started to work more closely with See Me and the See Me Youth Engagement programme on the extension of DBI to 16- and 17-year olds. See Me have been influential in identifying opportunities to engage young people and ensuring that the voices and expertise of young people, heard through their youth-led programme, are reflected in DBI development work:

We count on their support and engagement and their buy-in, I suppose, to the ongoing development work for young people... What they’ve done... is helped us to engage with the target population and made sure that they have their voices heard at the beginning and we can reflect that upwards, as we begin to understand what DBI might look like for younger people.

DBI team member (1)

When asked about barriers to engagement with See Me, the DBI team could not suggest one:

I knew you would ask me this and so I had a think about it on the train... and, no! I do genuinely say that! I haven’t come across anything so far, at all.

DBI team member (1)

Rather than challenges, one team member spoke of having “reflections” as a result of working with See Me. These, however, were only framed positively. For example, See Me’s own definitions of discrimination within mental health influenced the definition of ‘distress’ within the DBI programme:

...a lot of See Me's work has been about...discrimination associated with mental health, mental ill-health and what we were very mindful of in DBI was... deliberately de-medialising it, so moving out with the framework of one of mental ill-health.

DBI team member (2)

Another "critical, refined-type reflection" around the use of language, was the presence of compassion as demonstrative of reduction in stigma and discrimination. The DBI team spoke of being able to focus with See Me on compassion, without necessarily directly using language of stigma and discrimination. They said that feedback from frontline delivery and assessment of DBI indicates that the frontline response to people presenting in distress is more compassionate and that stigma and discrimination are therefore diminished:

The DBI programme itself should help to reduce stigma and discrimination. What I see See Me as, is actually bringing expertise in how to do that and ensuring that the approach that has been taken really does target stigma and discrimination. That it's optimised.

DBI team member (1)

2.3 "Compassion fatigue" and challenging mental health stigma and discrimination

The See Me contribution to the DBI training is part of the "core" of anti-stigma and discrimination within the programme. The training addresses attitudes and the importance of stigma and discrimination and why people may find it difficult to come forward for fear of stigma, rejection or due to self-stigma following past experience. DBI include this to inform practice and encourage compassion. However, "compassion fatigue" amongst health care staff is a barrier that the programme has to overcome; a barrier that itself is linked to stigma and reinforces the importance of the work of See Me:

But if we're serious about it, we have to make it easier for staff to be compassionate; we have to make it easier... organisationally, structurally, individually, systemically – that doesn't discriminate against people.

DBI team member (2)

With the help of See Me, the DBI programme has moved beyond thinking solely about staff attitudes and behaviours, to thinking about the programme from an organisational and systemic standpoint.

2.4 Reach

Up to 31st May 2019, there were a total of **1,364** DBI Level 1 (frontline services) staff trained. This included:

- **180** from A&E
- **45** from Psychiatric Liaison Service
- **222** from Primary Care 'In Hours'
- **16** from Primary Care 'Out of Hours'
- **748** from Police Scotland
- **125** from Scottish Ambulance Service
- **17** from Mental Health Unscheduled Care / Out of hours Services
- **11** from Social Work and other roles.

There was a total of **78** DBI Level 2 (3rd sector) staff trained up to the 31st May 2019 (there are **58** current DBI Level 2 practitioners). This included:

- **29** in Lanarkshire (**18** in South Lanarkshire and **11** in North Lanarkshire)
- **28** in Aberdeen
- **11** in Inverness
- **10** in Scottish Borders

This data shows the reach of the DBI programme so far. All of the trained front line staff have received DBI training that is embedded in a framework of anti-stigma and discrimination. Up to March 2019, the DBI programme has delivered compassionate, stigma-free care to over 2800 people.

2.5 Making Connections

As a result of the work of See Me with the DBI programme, See Me were approached by a third sector organisation involved in the delivery of the DBI, to deliver anti-stigma and discrimination training to managerial staff in their organisation. See Me delivered two sessions to the organisation, including one on systemic stigma. Feedback from the organisation and participating managers was hugely positive:

Good to see how influential the See Me campaign is and the different strands to their work.

Participant Feedback (Manager)

[I will be] Considering our marketing strategy and materials in relation to health literacy and conveying our message.

Participant Feedback (Manager)

I have identified actions and ideas from today that I can take back to my service and plan to implement.

Participant Feedback (Manager)

Several of the managers commented that they would like to take the learning directly back to their team in the form of a similar session. Many also enjoyed the opportunity for shared practice around stigma and discrimination that the See Me session afforded them. Further, lived experience was again raised as integral to the See Me offering:

I think what they do really well is listen to people's realities. We've got a few video clips and it brought it into real life. It was about people's real life experiences and that is really powerful. I just think as long as they are including the voice of the people...

Interview, Regional Manager

The regional manager also commented, of DBI as a whole, that the partnerships – including with See Me – are key to the successes of the programme. Anti-stigma in the programme, again, is discussed as being supported through compassion and as running “through the whole DBI journey for a person”:

When you break all that down, it's that anti-stigma running through it all. It's not about being ashamed; it's about knowing what to do; who you can contact and what you can do for yourself.

Interview, Regional Manager

A lot of people that are using DBI haven't used support before... what's maybe stopped them in the past is... stigma and self-stigma as well... when you boil things right down there's a lot about stigma and validation. Often, their journey is just about that change in mindset happening for a person... When they're leaving, they might still be going through some kind of distress...but they feel much better able to deal with it head on and not feel ashamed and not feel afraid and all these other things that can come with stigma.

Interview, Regional Manager

3.0: Partnerships and Changing Minds: NHS Inform

NHS Inform is Scotland's national health information service. It is an online resource that aims to "provide the people in Scotland with accurate and relevant information to help them make informed decisions about their own health and the health of the people they care for." In the past year, See Me have worked closely with NHS Inform to develop their online depression and anxiety guides. This work was carried out with See Me and the See Me community champions, who have lived experience of mental ill health. The following findings are from secondary participant feedback and an interview with the lead contact at NHS Inform.

3.1 Lived Experience and Challenging Stigma

Mental health services users have been maligned for so long.

Lead contact, NHS Inform

The rationale for NHS Inform engaging with See Me was to incorporate user engagement and reflective practice as early in the design process as possible. The lived experience underpinnings of the See Me programme were integral to this:

See Me...have a culture around really listening and supporting individuals with lived experience, to help them...support to make their difficult experiences into something positive. What I needed was an organisation that would offer that support.'

Lead contact, NHS Inform

NHS Inform wanted the journey through the guides – the structure, the content, the use of language etc. – to be tested by individuals with lived experience, who could offer relevant and unique insight to development:

I want to know how a user with poor digital literacy would feel about the guide, or I want to know what a person who's experienced depression thinks... and maybe a carer... Would people find it easy to follow? Would the language be appropriate, suitable and accessible?... how would it affect mood? How would it affect somebody with depression? Are we putting barriers in place for using CBT tools, by our structure and content?

Lead contact, NHS Inform

3.2 Building Relationships

There is a desire from NHS Inform to engage partner organisations like See Me at the beginning of processes - such as designing the online self-help guides and other endeavours - to ensure user involvement from the very beginning and to build and maintain ongoing relationships. See Me have successfully maintained a relationship with NHS Inform and continue to support them in work on their online mental health resources. As the lead contact articulated, "it's a kind of relationship stakeholder management thing with them now." NHS Inform send feedback, keep in touch with See Me and keep them updated so that volunteer participants can also be informed. The goal is to approach the relationship with See Me as a "continuous engagement scenario." A focus on relationship building is something that See Me are perceived to support:

...it's all about relationships, not processes...So many organisations like this are driven by process and policy, but I come from a background that's all about relationships and See Me understand that.

Lead contact, NHS Inform

There is forthcoming mental health development work with the service that it is anticipated See Me will be involved with.

Engagement of See Me volunteers was also felt to result from a close and supportive relationship with See Me. The level of engagement from the volunteers was higher than expected and "massively" influenced the design and content of the guide. The relationship that the volunteers had with See Me was perceived to be key to this:

It just felt that everybody had a reason to be there. And I think that is about the quality of the relationships that they've obviously developed with the people they know... I knew that... they were monitoring everybody's welfare as well.

Lead contact, NHS Inform

3.3 Contribution

Actions that resulted from See Me involvement included:

- Changes to the use of language, some of which was thought to be potentially triggering for those with anxiety or depression
- More detailed introductory information was added to assist users in the assessment of the personal relevance of the guides

- Structural content was modified to make the guides more user friendly and readable
- The personal planner elements were modified to include example activities
- Signposting links were modified and updated

The importance of the contribution that See Me and the volunteers made to the guides was strongly emphasised and the knock-on effect on "failure demand" – when failure in one part of a service puts pressure on other parts - was highlighted:

If you don't get a service in a way that suits you, when you need it and all the rest of it, and it's not effective, then you end up putting pressure on other bits of the service.

Lead contact, NHS Inform

See Me permitted NHS Inform to "start with the population group and develop the service", thus ultimately minimising the instances and impact of failure demand and developing an online self-help guide that developed with people with lived experience, for people experiencing anxiety and depression.

The experience of working with See Me and the volunteers was discussed positively. Barriers to participation were external to the relationship with See Me and included difficulties gaining buy-in from senior management for the partnership and user engagement and deadlines from funders hurrying or cutting short development.

4.0: Funded Partnership Working and Changing Policy: Stigma Free Lanarkshire

Stigma Free Lanarkshire (SFL) is a jointly funded programme by See Me and NHS Lanarkshire. SFL works with health and social care professionals, education and workplaces, to increase awareness and understanding of mental health stigma and discrimination, to provide support to realise the rights of people with mental health problems and to ensure equal opportunity for all those living in Lanarkshire to lead a fulfilled life. See Me's partnership with SFL as part of the Health and Social Care programme makes an important contribution to the development of anti-stigma and discrimination work within Lanarkshire local authority areas; See Me

provide financial and technical support to tackle stigma and discrimination. See Me also sits on the Lanarkshire Mental Health Strategy Group and has worked in partnership with SFL and the local authorities to embed anti-stigma and discrimination cross-programmatically into the new Lanarkshire Mental Health Strategy.

The following findings are from an in-depth interview with SFL staff and event feedback forms from a Senior Leaders in Health and Social Care event run by SFL.



4.1: Two programmes, side by side

As well as funding, See Me provide SFL with technical and structural support across programme areas, to tackle stigma and discrimination. SFL representatives discussed that there are numerous advantages and resources associated with being aligned with a national programme. Being funded by and affiliated with See Me gives traction to their cause and recognition from other organisations. How a local and a national programme work together however, and what the role of each organisation is, has been an obstacle in the partnership that has had to be overcome:

...both of our programmes will always be evolving because...we are reacting to people, what people are saying they need and want, and how pilots are going and learning that they're taking forward, so in terms of how Stigma Free Lanarkshire and See Me as two programmes were going to work together in a locality, it was always going to be tricky.

SFL team member (1)

See Me funding SFL and simultaneous national and local programme working, has brought to the fore questions of input and ownership with regards to method and activity in the locality. Boundaries between the programmes have been blurred and have required clarification, to support optimal partnership working. SFL fed back that they felt with streamlining and good communication, the partnership sustainable.

See Me recently supported SFL to host a Health and Social Care Senior Leaders event - their biggest event to date. This was well attended by senior management in NHS Lanarkshire and other organisations. It is out with the remit of this evaluation to report on the activities of SFL, however the support offered by See Me in hosting the event was positively received. Further, in the coming year, See Me will be providing support and resources to SFL for forthcoming stigma and discrimination work in two hospital wards in the local authority. This project aims to provide awareness training to nursing staff; to increase understanding of mental health stigma and discrimination, improve practice and result in better outcomes for patients.

5.0: Conversation Café

An important piece of work to note within Health and Social Care is the establishment of a conversation café by a See Me Community Champion in a local GP practice. Following See Me Community Champion training and continued involvement with and support from See Me, this individual was inspired to challenge stigma and discrimination within health and social care in their local community. As a result, they trialed a conversation café in a local GP practice, where patients and local residents could attend to talk about mental health and wellbeing in a safe and confidential space, facilitated by a

volunteer with lived experience. The café also provides important socialisation within the community. The café has been a success and is well-attended most weeks, with numbers increasing. Further, a conversation café in the same practice is about to be established for resident GPs, to discuss issues of mental health stigma and discrimination, mental wellbeing and practice. See Me continue to support this volunteer to run the cafes and it is hoped that more will be established in the future. A more in-depth evaluation of this service is intended for the next phase of the programme.



6.0: Discussion and recommendations

The Health and Social Care programme is structured differently to the three other programme areas of See Me and as such is evaluated slightly differently. What See Me does well within H&SC, is work with organisations, such as the DBI programme or NHS Inform, on discrete pieces of work, to challenge stigma and discrimination and raise awareness and understanding in health and social care practice. This should be continued going forward and these pieces of work should be evaluated distinctly within the wider evaluation of the H&SC programme. Developments and change in H&SC, as with the other programme areas, will be longitudinal and development of data collection methods to assess these changes is required.

Lived experience is a well-received and important mechanism in the work of the Health and Social Care programme. The engagement of lived experience volunteers was part of the rationale for NHS Inform in involving See Me in their online mental health services development work. Further, lived experience is a building block upon which the relationship between See Me and the DBI programme was established. The DBI programme, in partnership with See Me, has threaded anti-stigma throughout its intervention and is subsequently changing the lives of people presenting in distress to frontline services. This demonstrates progress towards achievement of outcome: *People individually and collectively will increasingly challenge self-stigma and stigma and discrimination.*

See Me's support of SFL demonstrates the successful strategic and partnership working of See Me. Clarification is required between the work and remit of See Me and that of SFL. The work of SFL is not in itself indicative of the work of See Me; SFL are a local programme, part-funded by See Me to carry out anti-stigma and discrimination work within their locality - they are not an extension of the See Me programme. The work of SFL is supported by See Me and as such requires an independent evaluation. This is especially important for See Me as funders, to permit assessment of process and impact of SFL. How See Me support SFL and the expectations of both programmes could be helpfully documented to sustain an ongoing partnership.

See Me is successfully challenging stigma and discrimination in Health and Social Care. As highlighted, this is done through discrete pieces of work with organisations that are part of the fabric of the Health and Social Care system. With time, See Me are changing minds, policy and practice within this system and the groups that comprise it. Currently, See Me are working with Chest Heart and Stroke Scotland, to raise awareness of mental health stigma and discrimination and encourage behavioural, system and cultural change towards inclusive policy and practice. They are also in the proposal stages of a piece of anti-stigma and discrimination work with all staff and patients at a GP practice in a Scottish Health Board. This is amidst a backdrop of continuous influencing work to progress an agenda of mental health inclusion in Health and Social Care.

4.2 Recommendations

- See's strategic and partnership working is strong and should be carried forward to develop and support discrete pieces of work within Health and Social Care.
- See Me should revisit their partnership agreement with Stigma Free Lanarkshire, to overcome operational issues.
- Any future partnership agreement with Stigma Free Lanarkshire should clarify all partner roles and responsibilities, particularly around programme evaluation.
- Lived experience is integral to the work of the Health and Social Care programme and should continue to be optimised and included where possible.
- See Me should think about outcomes across programmes and not within – the H&SC programme is contributing to outcomes beyond those stipulated in the outcomes for the programme area.



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