Report of the External Services Scrutiny Committee 2013/14

Stigma: The Effect on Residents' Mental and Physical Health in the Borough

Members of the Committee

Cllr Mary O'Connor (Chairman)
Cllr Dominic Gilham (Vice Chairman)
Cllr Josephine Barrett
Cllr Shirley Harper-O'Neill
Cllr Phoday Jarjussey (Labour Lead)
Cllr Judy Kelly
Cllr Peter Kemp
Cllr John Major

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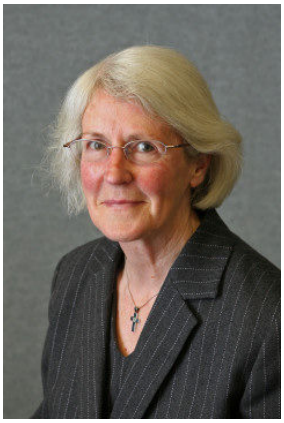

CHAIRMAN'S FOREWORD

Stigma is considered to be an opinion or judgment held by individuals or society. Stigma affects everyone - not only those that are the subject of stigma, but also their friends and family. When stigma is perpetuated by the media, it becomes particularly harmful as the media is significant in shaping, influencing and reinforcing community attitudes. Although it is something that we are all likely to witness on a daily basis, stigma is clearly not acceptable.

This review has not been easy to undertake. It has also shown that there is an unending list of things for which individuals are stigmatised which range from practicing a particular religion to having tuberculosis or being a single parent. It has highlighted how individuals and sections of society can be overtly judgmental and cruel.

Being stigmatised for something that is part of who you are can have a debilitating effect; it can put additional pressure on mental health which can then lead to an impact on physical wellbeing. To make matters worse, not only does the stigma impact on the individual, but it can also then impact on their friends and family, either by association or because they are providing support without receiving support themselves.

Throughout the review, the Committee has been clear that there are no recommendations that it could possibly make to Cabinet that would put an end to stigma. As such, the focus of the review has been on how the Council can work with its partners to reduce stigma and its impact on mental and physical health. Clearly, those that are stigmatised are the people that are best placed to explain how being stigmatised affects them. As such the Committee felt that it was important to get as much information from these individuals to identify what action could be taken or what support could be provided to reduce this impact.

On behalf of the Committee, I would like to sincerely thank all of the witnesses for their valuable contribution to this review, particularly the first hand accounts of stigma which were, at times, really rather harrowing. Their input has enabled the Committee to come up with recommendations to Cabinet which will build on the good work already being undertaken by the Council and its partners.

Councillor Mary O'Connor
Chairman of the External Services Scrutiny Committee

RECOMMENDATIONS

Following its review, the External Services Scrutiny Committee has made the following recommendations to Cabinet:

1) **In support of the Council's desire to become an exemplary employer, that Cabinet commends the work already being undertaken within the Council to support its staff and in conjunction with its partners to reduce stigma in our community and the impact it has on residents' mental and physical health.**

2) **That Cabinet acknowledges the new measures that are being put in place to recognise the importance and support the mental and physical health of Council staff and requests that officers report back to the relevant Cabinet Member and the External Services Scrutiny Committee on the effectiveness of these measures in September 2014.**

3) **That the Cabinet Member for Education & Children's Services asks the Interim Head of Education, Policy and Standards to encourage primary schools in the Borough to include the raising of awareness of stigma and its effects as a permanent element of Personal, Social and Health Education (PSHE) and Citizenship lessons.**

4) **That the Cabinet Member for Social Services, Health & Housing asks the Interim Director of Public Health to investigate opportunities to raise awareness of stigma and its impact through existing wellbeing events and channels.**

5) **That Cabinet welcomes the roll out of the mental health first aid training provided by Hillingdon Mind to front line Council staff and local voluntary organisations and asks the Cabinet Member for Social Services, Health & Housing to give consideration to extending this to community and peer group leaders.**

BACKGROUND TO THIS REVIEW

Stigma: 1. *(noun) a mark of disgrace associated with a particular circumstance, quality or person.*
2. *eye stigma / astigmatism (noun) a defect of a lens resulting in the formation of distorted images.*

Stigma is attached to a huge range of circumstances, attributes and beliefs. Despite tolerance, cultural diversity and medical advances being transformed in the Western World, preconceptions are still common. Stigma can become manifest in different ways depending upon age, religion, culture and community but seems to be commonly aimed at individuals with physical deformities, mental health problems and certain 'visible' illnesses. In reality, this societal stigma will never disappear as there will always be individuals and groups of people that others will disapprove of. As such, efforts to challenge stigma need to be centred on where it is considered unjust and unacceptable in a modern, tolerant and progressive society.

Those people that stigmatise others do so through a range of actions which include:

- bullying and physically abuse;
- ridiculing and verbal abuse;
- barring individuals from shops and pubs;
- speaking to individuals as if they were stupid or children;
- patronising them; and
- addressing questions or conversations to those accompanying the individual rather than the person themselves.

The impact of the stigma that these individuals suffer can lead to further complications and impact on their physical and mental health. For those affected, such actions can bring about feelings of shame, blame, hopelessness, distress and a reluctance to seek and/or accept the necessary help. Therefore, stigma can affect many aspects of people's lives. Case studies on the effects of stigma can be found at Appendix A.

Self Stigma

In addition to the societal stigma highlighted above, self-stigma is an unfortunate by-effect and is when people turn stereotypes towards themselves, making matters even worse. It often acts as an obstacle for accessing treatment. Individuals that are stigmatised can often fall into depression and may feel they are different and devalued by others. Stigma can result in negative experiences in the workplace, education settings, healthcare, the criminal justice system and even their own home. Depending upon the studies reviewed, around 75% of people with mental and physical health problems say they have experienced stigma or self-stigma of one kind or more.

The World Health Organisation in 2001 highlighted the damage resulting from stigma, where people can experience rejection by friends, relatives, neighbours and employers leading to alienation and depression. They also highlighted the effect of this within family life and social networks.

The stigma itself can sometimes have a bigger effect on the individual than the actual condition. An international study published in The Lancet in 2012 concluded that the stigma of mental health is worse than the illness itself. The impact of self-stigma can be far reaching, often blighting lives and holding back recovery.

Structure

The information, evidence and findings of this review are set out under the following headings:

1. Current Situation
2. Working in Partnership / Future Work
3. Conclusions

CURRENT SITUATION

Work is currently being undertaken by a range of organisations in relation to supporting those people that are being stigmatised. Witnesses went into great detail about the effect that stigma has on individuals and then explained what help was currently in place to support these people.

Recommendation 1: In support of the Council's desire to become an exemplary employer, that Cabinet commends the work already being undertaken within the Council to support its staff and in conjunction with its partners to reduce stigma in our community and the impact it has on residents' mental and physical health.

AIDS/HIV

Put simply, there is no cure or vaccination for HIV. Because the virus is infectious and was originally largely fatal, there is still a lot of stigma associated with HIV. This stigma can often be more damaging that the HIV itself.

When HIV first came to light, it was predominantly amongst gay men and, as such, some people still make assumptions. Those individuals that catch HIV through dentistry or surgery are often seen as 'innocent' victims…which then lays blame.

The physical and mental effects of the stigma associated with HIV include: depression, withdrawal, social isolation, damage to self esteem, harmful coping mechanisms (such as alcohol and drugs) and disengagement with health and social care (which can result in an increase in hospital admissions). Those on medication for a long time can often suffer from severe side effects which can be unpleasant and debilitating – sometimes, these effects can often be worse than the HIV itself.

There are a number of statutory and third sector support groups in existence and organisations such as HART are key in providing preserved safe places for people to go. These organisations also provide much needed support for the families that are affected, as part of a holistic community based social care package.

Drugs and Alcohol

Individuals that are drug and/or alcohol dependent are some of the most stigmatised people in our society because many people think that they are to blame for their own predicament (it has been suggested that this is less of an issue affecting those with mental illness). Families and carers will often blame themselves (or are blamed by others) and sometimes there are instances where these families are the ones that are the ones stigmatising the individual.

Those in employment, education or training are thought to be more likely to recover from substance misuse. However, although having a job is good for a person's self-esteem, it is often difficult for people to get back into employment once they have successfully stopped relying on drugs or alcohol. These individuals are encouraged to be honest with

potential employers about their addiction but may then find that they are stigmatised because of this honesty.

Tuberculosis

The stigma associated with tuberculosis (TB) is particularly damaging as it might stop someone from going to see a doctor about the disease whilst it is still in the early stages. It could also stop them from completing the treatment that they need. More worryingly, it might discourage patients from identifying people that they have been in contact with so that they can be screened (as this would then publicise the fact that they had TB). The effect of stigma associated with TB clearly, therefore, has wider knock on health implications for the whole community.

The effects of stigma associated with TB are wide ranging and include: shame, self-blame, isolation, loneliness, loss of status, loss of self-esteem, loss of hope, depression, stress, denial, anger, violence, alcoholism, suicide, family quarrels, mutual blame and conflicts, being chased from their home and divorce or separation. Stigma presents a major barrier to identifying and treating people with TB. By using its nursing expertise and established field presence, health professionals are hopeful that stigma will be reduced by promoting knowledge, attitudes and practices supportive of patient rights and responsibilities in the community.

Work already undertaken by the Community TB Nursing Team includes: the establishment of Com.Cafe in West Drayton; Talk Time sessions at St Matthew's Church, Yiewsley; a GP Masterclass; Hillingdon Community Health Conference; and a presence at Immigration Removal Centres.

Gender Dysphoria

Gender Dysphoria is a condition that describes the feeling of a mismatch between biological sex and the gender you feel yourself to be. It is a very lonely condition which is not visible and, as such, others are less likely to be sympathetic - if you can't see it, it doesn't exist. Many transsexuals will suffer from depression or turn to substance misuse or comfort eating in a bid to 'cope'. Suicides and attempted suicides are also common in transsexuals and it has been suggested that prompt and appropriate care could reduce these instances dramatically.

Because gender dysphoria is not particularly common, many mental healthcare providers know little about the condition. Many transsexuals will only ask for help when their depression reaches an intolerable level and they often feel that they are educating the professional about their condition rather than receiving the help that they need.

Carers

Carers are the largest source of care and support in the UK, far exceeding the care provided by paid workers. It is estimated that one in ten of the adult population in Hillingdon identified themselves as a carer in the 2011 census. This means that carers are contributing approximately £442.6m to the local health and social care economy in Hillingdon.

Unpaid caring takes place within a relationship – this is what makes it different to paid caring and means that all carers are parents, sons, daughters, siblings, partners, spouses or friends of the person they support. For this reason, stigma arises from the nature of caring itself (e.g., isolation, lack of income, loss of self esteem, etc) which can lead to feelings of marginalisation. More frequently, stigma experienced by carers is closely related to the situation of the person being supported (e.g., mental health issues; drug, alcohol and substance misuse; learning disabilities; dementia; and illnesses that other people judged to arise from the lifestyle of the person supported).

Young carers are more likely than other young people to experience bullying, isolation, poverty and difficulty making and sustaining friendships. The outcomes for these young carers in Hillingdon are broadly in line with those nationally with 68% experiencing bullying at school and 39% saying that nobody in their school was aware of their caring role. Only 4% of adult family members being looked after by young carers are in employment which means that 96% will be in receipt of free school meals which will further single them out.

The Young Carers Team at Hillingdon Carers has developed an 'Assembly Presentation' to raise awareness in schools locally and begin to address some of the issues outlined above. Other work already undertaken by the organisation includes:

- the provision of information and advice and an advocacy service – it is felt that the advocacy service plays an important role in reducing the impact of stigma.
- the Carers Assessment Service which is provided solely for carers of individuals receiving mental health services – although a small service, it plays a big part in reducing the feelings of stigma.
- Health and Well-being services for carers which gives carers access to peer support and group activities to destigmatise their situation.
- Young Carers Services which provides clubs, activities and residential breaks for young carers to have fun and make friends.

<u>Occupational Health</u>

Stress related illness was the highest recorded cause of sickness absence at the Council during 2012/2013. A number of support services are available for Council staff to try to get them well and back to work as quickly as possible. At the heart of this is an Employee Assistance Programme which provides a variety of services including counselling and online advice and support.

The Council has also worked with Remploy, a National organisation, to support staff (on a self referral basis) who are experiencing mental health issues including depression, anxiety and stress. The aim is to work with the member of staff and their manager to ensure reasonable adjustments are made to keep them in work or to help them to return to work.

There tends to be a general acceptance and understanding of stress and depression but this is not the same for more established mental health conditions. More work is needed to ensure that managers have a better understanding of their staff's mental health conditions and that they are in possession of the skills needed to deal with this condition.

To help with this, a new initiative will be starting in November 2013 that will provide training for managers and staff on building resilience around issues of stress which can include mental health issues. Officers will be trained to become trainers themselves and then roll out a programme to managers and staff. The programme aims to support managers so they are better able to deal with stress and mental health issues in the workplace. The programme will include the development of a toolkit for managers on how to recognise stress in themselves and therefore others and how they can support staff to manage their stress.

Recommendation 2: That Cabinet acknowledges the new measures that are being put in place to recognise the importance and support the mental and physical health of Council staff and requests that officers report back to the relevant Cabinet Member and the External Services Scrutiny Committee on the effectiveness of these measures in September 2014.

Ex-Offenders

Blue Sky exclusively employs ex-offenders on six month contracts to undertake a range of work such as grounds maintenance. This organisation is one of the few employers who engage ex-offenders and, as such, ex-offenders' employment options are quite limited.

It is often really hard for ex-offenders to gain employment and to settle into a life without crime. This can then be exacerbated as some of employees suffer with mental ill health and substance misuse issues. Whilst many people don't want anything to do with ex-offenders, those that do want to help can sometimes find it difficult to know where they can be signposted to.

Blue Sky's Resettlement Department is responsible for identifying onward employment for employees once their contracts with the organisation have ended. Securing permanent sustainable employment elsewhere is a huge source of pride and achievement and a significant factor in preventing re-offending, enhancing feelings of wellbeing and improving mental health.

Mental Health

It is estimated that one in four people will experience a mental health problem at some point in their lives and that one in six adults are experiencing a mental health problem at any one time. The National Mental Health Development Unit has estimated that 87% of people with mental health issues have been affected by stigma and discrimination and that 71% of people with a mental health issue have stopped doing things that they wanted to because of the fear of stigma and discrimination. Furthermore, 53% of carers of people with mental health problems feel unable to do things that they want to because of stigma and discrimination.

The phenomenon of multiple stigmas is something that is experienced by many people with mental health issues and includes issues such age, gender, ethnicity, sexuality, disability and faith. The stigma associated with these issues can exacerbate the already negative and destructive effects of mental health related stigma.

The consequences of stigma and discrimination are deep and complex and include: isolation from friends and family; difficulty in continuing in education, holding down a job or contributing to society; a reluctance to seek help; being rejected by friends and colleagues when the mental health condition had been disclosed; and the undermining of strength, motivation, resilience, creativity and capacity for recovery. These issues all contribute to a deterioration in physical and mental health and wellbeing with sometimes tragic personal costs to the individuals and their families and relationships.

In an attempt to counteract these effects, Hillingdon Mind provides a range of support and advice services including:

- social clubs and activities across the Borough to reduce individuals' isolation and offer opportunities for building friendships and developing peer support;
- a befriending service to help reduce isolation, nurture friendships and give people the confidence to access leisure and opportunities;
- a counselling service which offers long-term therapy and contributes towards maintaining health, resolving deep-seated issues and preventing mental health deterioration;
- engaging more effectively with people with mental health issues who are not only "hard to reach" or "seldom heard", but who also experience multiple stigma and discrimination;
- the Community Recovery Programme which offers support for people with a dual diagnosis of mental ill health and substance addiction;
- Café Mind which provides opportunities for volunteering and developing skills; and
- an Anger Management Course to help manage conditions which can lead to anti-social behaviour and reinforce negative stereotypes.

Most of the mental health work undertaken by Hillingdon Mind is unfunded, including the work taking place in schools. This is unsustainable and is inhibiting the organisation's capacity to develop this vital area of work. However, it is generally accepted that the cost of mental health promotion is far less than the public finance implications of mental health deterioration. To this end, Hillingdon Mind is looking to generate income from outside of the Borough as well as looking at a social enterprise approach to making the programme sustainable.

Mind is working with Rethink Mental Illness on the "Time to Change" programme which aims to reduce mental health stigma. This programme is funded by the Department of Health, Comic Relief and the Big Lottery Fund and is being supported by over 100 organisations such as the Bank of England and the Financial Conduct Authority which have pledged to stamp out stigma and discrimination in the workplace.

Individuals that are hard to reach are hard to reach because they want to keep their mental health issues hidden and tend not to seek help. Reaching this group of people and getting them to open up is challenging and, to this end, consideration needs to be given to the terminology used by support organisations.

Hillingdon Mind provides mental health awareness sessions for individuals who might not have heard about illnesses such as schizophrenia, let alone know how the illness could be addressed. Some mental health issues need to be addressed from within the community, e.g., once an Asian young person has been labeled with having mental

health issues, it is likely that they will be unable to marry within the community as it will be assumed that their ill health is genetic.

The Women's Royal Voluntary Service (WRVS) had secured funding to provide a befriending service to Borough residents suffering with dementia. Although this service has been in place for some time, few people seem to be aware of its existence. It has been suggested that, if those people suffering with mental health issues were accepted and treated in the same way as people suffering with the flu, there would be no need for this kind of befriending service as there would be no stigma.

Children

It is clear that mental health has a huge impact on children and a range of related work is currently underway at Yeading Junior School which includes:

- a speaking and listening project;
- a pyramid project to help young people that lack self esteem and confidence; and
- an interfaith network to help young people feel more included and less isolated.

At Yeading Junior School, work has been undertaken with mothers who do not feel a sense of belonging. They have been offered opportunities with regard to adult education courses (e.g., pottery classes) which, it is thought then helps their children.

Other work is being undertaken by schools to bring them together to empower children from difficult backgrounds. It is thought that the pupil premium is a good way of targeting children in need and consideration needs to be given to providing further help by placing social work students in schools to work with the students and give them a voice. However, it is also seen to be important to ensure the provision of continuous professional development for the staff that work with these children.

Recommendation 3: That the Cabinet Member for Education & Children's Services asks the Interim Head of Education, Policy and Standards to encourage primary schools in the Borough to include the raising of awareness of stigma and its effects as a permanent element of Personal, Social and Health Education (PSHE) and Citizenship lessons.

Communities

The Strong and Active Communities Partnership Group develops and promotes opportunities for integration through culture, leisure and the arts as part of its partnership work. The Partnership is working to accrue social capital in the community by building relationships and engaging and interacting with individuals and groups. Members of the Partnership, as well as key players in the voluntary sector locally such as Hillingdon Mind, Age UK, Hillingdon Carers, DASH etc, contribute by the work that they do individually but also in partnership. This adds value and underpins the objective of promoting community cohesion and integration. For example, the Hillingdon Interfaith Network is working with schools in the Borough to promote greater understanding of different faiths but also to feel comfortable and confident about who they are and what they believe. There is also work being undertaken via the schools to help isolated and vulnerable parents in the community to build more positive relationships.

Funding had been provided from the Ward Budget towards the Hayes Community Wellbeing Event in 2013. The event incorporated a range of stalls and had included one for Central and North West London NHS Foundation Trust. The event had been very successful with a huge range of people attending. It has been suggested that officers explore options for Council and Public Health involvement with this event, should it take place in 2014.

The Council's Early Intervention and Prevention service is committed to the establishment of an LGBT young people's programme in partnership with the voluntary sector. Discussions with Mosaic Youth Group have unfortunately not materialised into a partnership arrangement so other officer are currently exploring other options.

Furthermore, a national initiative has started to raise awareness of "mate hate" crimes, where people with learning disabilities are befriended by individuals and then abused. This abuse is perpetrated for a range of reasons including gaining the use of their home or to take their money. The work undertaken so far includes the production of a DVD, leaflets and posters which have been created with the help of service users. The idea is to raise awareness of this crime with frontline staff so that they are able to recognise it and support those service users who might be victims. The posters will be put up in libraries, children's centres, etc, to raise awareness with residents.

Recommendation 4: That the Cabinet Member for Social Services, Health & Housing asks the Interim Director of Public Health to investigate opportunities to raise awareness of stigma and its impact through existing wellbeing events and channels.

WORKING IN PARTNERSHIP / FUTURE WORK

Employment

The Equality Act 2010 provides some protection from discrimination for groups of people including those with a disability, mental health issues and HIV. However, it does not protect people from being judged. With regard to stigma experienced in the work place, further work is needed to encourage organisations to ensure that their staff do not breach conditions in the Act by stigmatising other members of staff.

Stigma is still far too common in the workplace, particularly in relation to recruitment, absence management and dismissal. Improved awareness of mental health issues could help improve this situation. To this end, Hillingdon Mind has been working with the Council to train its frontline staff and increase their awareness of mental health issues. Mind is looking to increase engagement with other employers in the Borough to highlight the personal and financial benefits of better mental health awareness and support to their employees. It is anticipated that this work will highlight the resultant reduction in sickness absence and the increased productivity that will be gained through better employment practices.

In addition to the mental health first aid training that has been organised for frontline Council employees, the Council is working with Hillingdon Mind to look at the provision of training for frontline staff on mental health related issues as part of a wider training programme.

The Council has also put together the “mate hate” programme which will be launched at the Disability Assembly being held in February 2014. This work follows up on the disability related harassment workshop that took place at the last Disability Assembly and identifies three key areas that services users feel need to be addressed: transport (particularly buses), training for frontline staff and raising awareness in schools. The Council is working with the Metropolitan Police Service, schools and other partners to take this forward and frontline Council staff are being encouraged to sign up for the awareness sessions on Mate Hate crime, Mental Health and Domestic Violence. These issues have been combined so that staff need only attend one session and the sessions are pitched at an awareness raising, signposting level. Further training opportunities will be promoted at these sessions.

Other work currently being undertaken by the Council includes:

- Absence Management Policy – the Council is currently consulting with the Trade Unions on the introduction of a new Absence Management Policy that has been developed following an extensive review of workplace attendance across the Council. It is proposed that this policy takes effect from 1 January 2014.
- Absence Management Service – the Council is introducing a new absence management service in January 2014 which will introduce a monitoring process that will directly notify relevant stakeholders (i.e., line-manager and HR) of any absences related to stress or anxiety (or other mental health related issues). This will trigger appropriate Stress Risk Assessments to be conducted in the

employee's work area. At the subsequent return to work interview the employee will be asked what support we can offer in order to minimise potential pressures / stress. A link has been established between the Absence Management Policy and the procedures used to resolve disputes in the workplace. The responsibilities of both line manager and individual in the resolution of disputes are highlighted. When resolving complex disputes between either individuals or within groups, HR is able to use the services of an external, independent mediator, if appropriate.

- Occupational Health - from 1 December 2013, Health Management Ltd (HML) will start as the Council's new Occupational Health (OH) provider. As well as providing access to OH advisors and physicians capable of compiling management reports on employee medical conditions, the Council will also have a dedicated senior OH consultant who will be able to provide more strategic advice on health management in the workplace.
- Workplace Mental Health Support Service – consideration is being given to how the Council can best utilise Remploy's Workplace Mental Health Support Service (which provides support for individuals with a mental health condition to remain or return to work).
- 'Train-the-Trainer' – an event is taking place in late November 2013 to develop internal capability to deliver two new training course, Managing Stress and Building Resilience. The former focuses on management awareness of stress in the workplace and the behaviours that can contribute to minimising factors contributing to stress (e.g., workloads). The second course focuses on the individual and how they can develop their own personal resilience to workplace pressures.
- Workforce Wellbeing Charter – the self-assessment standards are currently being reviewed to determine if they can support the delivery of a wellbeing strategy across the Council.

Recommendation 5: That Cabinet welcomes the roll out of the mental health first aid training provided by Hillingdon Mind to front line Council staff and local voluntary organisations and asks the Cabinet Member for Social Services, Health & Housing to give consideration to extending this to community and peer group leaders.

Education

Throughout the review, it became quite apparent that education is critical to the reduction of stigma. For example, in the 1980s and 1990s, there was a lot of publicity about HIV in schools and colleges and outreach work was undertaken to educate people about HIV. This had a huge impact. However, this was a long time ago and little has been done since then. We now have a new generation that needs to be educated, not just about HIV, but about all stigma. Changing people's attitudes is difficult and will not happen overnight so the focus needs to be on changing behaviour. Although Government legislation in relation to discrimination goes some way to changing this behaviour, there is much more that needs to be done.

Organisations such as Hillingdon Drug and Alcohol Service (HDAS) have spent time educating partner agencies which has gone some way to breaking down barriers and

reducing stigma but more could be done. To build in this work and help determine future attitudes, a focus is needed on educating young people in schools about stigma and its effects, perhaps by having this as a permanent element of Personal, Health and Social Education (PHSE) lessons. The need for this is further highlighted by the fact that, when surveyed, many young people had a negative attitude towards those who misused Class A substances – it has been suggested that some young people don't align that Class of drug taking with their own recreational use.

Contact Points

A number of issues were raised during the review in relation to contact points for individuals being stigmatised and their friends and family. Although it has been suggested that there should be a single point of contact to provide support and guidance, the range of issues that are stigmatised is so diverse that this might not be a practical solution. However, other more actionable suggestions include:

- identifying shops within the town (with window stickers) that are happy to help individuals when they are confused and lost (this would be particularly useful to individuals suffering with dementia who can often be ridiculed or treated badly when they ask for help); and
- promoting positive social contact as this is possibly the most powerful way to challenge stigma and change public attitudes.

Pupil Premium / Schools

It is widely believed that schools have a particularly important role to play in the reduction of stigma. Approximately one in ten children between the age of 5 and 16 have a mental health problem and that many of these continue to have problems into adulthood. However, the provision of mental health services for children and young people is generally very poor and more work needs to be undertaken to reduce instances of self stigma in young people and encourage them to seek advice and support. Young people tend to struggle with "difference" and, as such, those with mental health issues can find themselves the object of misunderstanding, ridicule and bullying.

The pupil premium is the provision of approximately £900 for children that meet certain criteria in terms of their needs. Each school has discretion to use this funding as it deems appropriate, with a view to providing learning and support activities for those children. It is suggested that some of this funding could be used to tackle the issue of stigma faced by those young people that it affects.

Awareness Raising

To build on the current level of support provided to individuals and their families and ensure that they receive the help that they need, it is important that more is done to ensure that specialist organisations and the public sector work together to raise awareness of how help can be accessed. Further work could also be undertaken to:

- encourage people to discuss stigma with their family and friends;
- support activities which get people to identify stigma in the community;
- provide training workshops on stigma for community and peer group leaders;
- raise awareness of the provision of voluntary sector training by organisations or charities such as Mind and TB Alert; and

- identify potential groups in the community that would benefit from or welcome awareness raising sessions.

The spread of TB in detention centres has not been helped by individuals being moved from one centre to another or when individuals are deported without treatment. Work is planned in detention centres over the next year to raise awareness and provide treatment and support for those with TB. A link nurse will also be placed at Colnbrook Detention Centre for two weeks to provide TB education and training.

With regard to transsexualism (there are estimated to be about 30 transsexuals in Hillingdon) and similarly uncommon issues for which an individual is stigmatised, more needs to be done to raise awareness generally. As most GPs are likely to have little (if any) contact with a transsexual at their practice, it is difficult for them to be able to provide the healthcare support and advice that is needed and will often be unaware of the steps involved in the transitioning process or what additional support might be required after the transitioning process has been completed. A wider awareness may go some way to improving this situation.

As part of World Mental Health Day in 2013, politicians joined a cross-party parliamentary event to reinforce the need to tackle the stigma and discrimination surrounding mental health problems. In future, it has been suggested that the Council consider looking at how it could promote and highlight awareness days to promote specific issues.

The increasing number of national celebrities talking about their mental health issues in the media has increased awareness and will go some way to reducing stigma. To build on this further, it would be valuable to have prominent local people speaking up in the same way.

<u>Media</u>

Stigma and discrimination are frequently fuelled by negative, ill-informed and misleading messages fed through the media. These messages often link mental illness with violence or portray people with mental health issues as dangerous, criminal, disabled, evil and unable to live normal, fulfilled and productive lives. Whilst there is little that the authority can do to influence national media, the Committee is clear that the Council will continue to encourage the local media to project positive messages about issues such as mental health. Furthermore, it has been suggested that consideration be given to the Council launching specific campaigns in relation to stigma around areas such as the workplace, family life and local neighbourhoods.

<u>Talking Therapies</u>

Individuals with mental health issues do not always want to take their medication as the side effects can often be worse that the illness itself. The self stigma suffered is often in relation to the shame and guilt felt about having the illness. Improvements to the talking therapies offered to these individuals would help in these circumstances and would also help to reinforce the fact that people who suffer from mental illness are not defined by the illness, they are still individuals.

CONCLUSIONS

"Everyone thinks of changing the world, but no one thinks of changing himself."
- Leo Tolstoy

"The world as we have created it is a process of our thinking. It cannot be changed without changing our thinking."
- Albert Einstein

Everyone, in one way or another, has a characteristic or circumstance of some sort for which they could be stigmatised. Rather than focusing on what an individual **can not** do because of their situation, each of us should concentrate on the things that we **can** do and try not to limit our aspirations.

Although the introduction of legislation to address discrimination is welcomed, it is suggested that a culture change will be needed to change public perceptions and behaviour in relation to people with mental health and other issues. A significant number of those with mental health and other issues have experienced "disability hate crime" or victimisation as a result of hostility and prejudice. Many of these crimes are not reported which means that others can then be subjected to abuse from the same perpetrators.

Whilst local campaigns to deal with the issue of stigma are thought to be very beneficial, it would be useful to have a wider national campaign to tackle the issue. Maybe then, there would be an increase in patience and acceptance.

Everyone is responsible for challenging stigma and we can all play a role in educating others and advocating new attitudes and practices. By applying what we have learnt in our own lives and talking openly about our own experiences, everyone can become a role model. This not only applies to each of us as individuals, but also to community leaders who should be encouraged to speak out and condemn stigma.

Stigma will never go away but each of us must do our bit to tackle it…bit by bit.

CASE STUDIES

1. Gender Dysphoria

Ms T's GP was unaware that he needed to refer her to the Mental Health Unit (MHU) to get a referral to the NHS Gender Clinic and, as such, spent several months trying to refer her to hospital. Eventually, the hospital advised the GP that he would need to refer Ms T to the Mental Health Unit (MHU). It was many months before Ms T finally received a referral to the MHU psychiatrist.

At the outset, the MHU psychiatrist made it clear that he knew little about transsexualism but was satisfied that Ms T was a transsexual and referred her on to hospital and back to the care of her GP. The psychiatrist made no effort to find out or deal with Ms T's depression or offer any counselling. Ms T believes that, 8 years later, little has changed as she is aware of someone else who was recently referred to the MHU without being offered any follow up support.

Ms T feels that she was lucky as she paid for a private psychiatrist who ran his own Gender Clinic and self prescribed hormones that she purchased on the Internet. She believes that this helped reduce her depression to a manageable level.

Ms T believes that many Gender Clinics have preconceived ideas and expectations of what they want from an individual, including their Real Life Experience. These Clinics (both private and NHS) often set targets but then provide no real help on how to achieve those targets.

In this instance, Ms T feels that she has been privileged to receive the treatment that she has from her Clinic. Furthermore, she praised her GP for his support and the effort that he made to understand gender dysphoria.

2. HIV - 1

A male heterosexual, employed full time, was due to marry his partner which would have given him the right to remain in the UK. He was diagnosed with HIV and his fiancée disclosed his HIV status to friends and family without his knowledge or permission.

Dealing with an HIV diagnosis is difficult enough but he has instantly been alienated from his family. He has been disowned by his family and his mother has told him that he is "dirty", "a child of the devil" and is "no longer her son". Threats have also been made by other close family members. He has been demonised by cultural stigma and educational ignorance to the degree that he fears for his life if he returns to his native country. His family in the UK remain hostile and unsupportive.

The relationship with his partner has irretrievably broken down, leaving him feeling doubly rejected and worthless. Low self esteem and depression have led him to disengage with healthcare professionals and he has stopped taking his HIV

medication which resulted in illness and a period of hospitalisation. In addition, the break up of his relationship meant that he faced deportation.

HART has provided him with a safe, non-judgmental and supportive environment in which to emote his feelings. He now has a difficult work environment as he fears his employers finding out about his HIV status. He fears being ostracised based upon historic opinions voiced by colleagues/managers.

3. HIV - 2

Heterosexual female contracted HIV following a relationship which had irreconcilably broken down. Diagnosis was taken very badly, coupled with the feelings of bitterness and anger towards her ex-partner. As a result, she has been suicidal, has depression and has required clinical psychology input.

She was too distressed to engage with anyone after her diagnosis and it had taken lengthy encouragement from HART in order for her to engage with them. As she had stigmatised herself, she is terrified that anyone she knows will discover her status. This led her to isolate and cut herself off from friends and colleagues for a lengthy period.

She is very distressed at the prospect of bumping into people that she knows at the local clinic so has opted to attend a hospital elsewhere at her convenience. She is employed but is fearful that her status will be discovered and finds it stressful pretending to colleagues that everything is 'normal' when, in fact, she has been at breaking point and is emotionally vulnerable.

With a great deal of courage, she has disclosed her status to her child who has completely rejected her. This has fuelled her own feelings of worthlessness and her stigma perception of HIV.

Since her initial diagnosis, HART has worked hard to get her to open up and engage with them. This has resulted in her slowly becoming stronger, increasing her feelings of self-worth and building an understanding of her condition.

4. Ex-Offender

An ex-offender (Mr A) was employed by a local company. He was seen working outside by his sister-in-law. The sister-in-law, who was not on speaking terms with Mr A, caused a huge scene in public about his criminal past and threatened to contact the local media and disclose his criminal convictions so that they could report the story. Unfortunately, in this instance, Mr A had to leave his employment. A few months later, Mr A was still unemployed and was suffering with depression.

5. Tuberculosis - 1

A male was diagnosed with spinal Tuberculosis and started an 18 month treatment regime. He was in a lot of pain when he was first diagnosed. He was employed but,

because he was in a too much pain to work and was off sick for so long initially, he lost his job. When he was available to work, the Job Centre and employment agencies were unable to help him because as soon as any potential employers found out about this sickness absence due to TB he was not given the opportunity to attend interviews.

During a home visit by the Community TB Nursing Team, it became apparent that he did not have enough money to have the electricity on or to buy food. Although he has been discharged from care as his TB has been cured and his treatment is complete, it is thought that he is still seeking employment.

Arising from this case, the Community TB Nursing Team arranged a teaching session at the Job Centre and Council's Housing Department to provide education and information. The Team also gave the patient information leaflets that he could pass on to potential employers and supplied him with Food Bank vouchers to assist him whilst he was in financial crisis.

6. Tuberculosis - 2

An HIV+ female was diagnosed with sputum smear positive Pulmonary TB. She had several mental health issues and her TB had recurred due to poor adherence to TB treatment when she had been a hospital in-patient for several weeks. She had been given treatment by the TB Nursing Team but it had recurred again and treatment was given again.

The patient reported suspected TB symptoms again the following year. She was reluctant to attend the TB Clinic but did have an appointment planned at the GU Clinic relating to her HIV status. The TB Nurses tried to arrange to leave sputum pots at the GU clinic for patient to use and then be tested for TB. The GU Clinic refused and cancelled her appointment as they were concerned about other patients contracting TB if she entered their clinic.

Following this incident, the Community TB Nursing Team arranged a teaching session at the GU Clinic to assist in changing attitudes and beliefs amongst health care professionals. The Team has also offered more support to the patient and arranged for her to be seen when and where it is convenient for her. They are also looking to run monthly "drop-in" clinics for current and former TB patients, where they feel safe (e.g., HESA Centre, Hayes).

7. Tuberculosis - 3

A school child (Child A) was diagnosed with pulmonary TB (not smear or culture positive) and commenced TB treatment. Child A was off sick from school for approximately four weeks and the school nurse was informed. Although Child A was no danger or risk to any other pupils, word got out about the TB and they were harassed by other children. Child A's siblings were also the target of bullying relating to their TB status. All children were removed from school and the family then moved out of the area.

Community TB Nursing Team aims to go into schools and educate staff in a bid to reduce stigma. They also plan to send leaflets home to the parents on a regular basis. The Team most frequently talks to the Welfare Officer at each school as the Head Teachers are often not interested.

BACKGROUND READING

To assist with the writing of this review, reference has been made to a wide-ranging selection of background information:

- Definition of "stigma": http://www.oxforddictionaries.com/definition/english/stigma
- Definition of "astigmatism": http://www.thefreedictionary.com/astigmatism
- *The World Health Report - 2001 - Mental Health: New Understanding, New Hope*: http://www.who.int/whr/2001/en/
- *Standards of Care for the Health of Transsexual, Transgender and Gender Nonconforming People*; Version 7; 2012;The World Professional Association for Transgender Health: http://www.wpath.org/site_page.cfm?pk_association_webpage_menu=1351&pk_association_webpage=3926
- *Mental health: Overcoming the stigma of mental illness*; Mayo Clinic: http://www.mayoclinic.com/health/mental-health/MH00076
- *Sexual Orientation, Attachment, and Psychopathology Amongst Adult Inpatient Survivors of Child Abuse*; Ellen J Greenwald; December 2008
- *Gender Recognition Act 2004*: http://www.legislation.gov.uk/ukpga/2004/7/contents
- *London Adult Mental Health Scorecard, Prototype*; NHS Commissioning Support for London & London Health Observatory and Working for Wellness (2011)
- *Speakout*; Issue 2; Summer 2013; www.time-to-change.org.uk
- *Stigmatization of people with mental illnesses: a follow-up study within the Changing Minds campaign of the Royal College of Psychiatrists*; Arthur Crisp, Michael Gelder, Eileen Goddard, Howard Meltzer; World Psychiatry 4:2; June 2005
- *Global pattern of experienced and anticipated discrimination reported by people with major depressive disorder: a cross-sectional survey*; The Lancet; Volume 381; Issue 9860; Pages 55-62; 5 January 2013
- *What is Stigma?:* www.sane.org/stigmawatch
- *The Effects of stigma*; Government of Saskatchewan: www.health.gov.sk.ca
- *Challenging stigma and discrimination: Starting the conversation about mental health:* http://www.rethink.org/carers-family-friends/brothers-and-sisters-siblings-network/events-and-workshops/challenging-stigma-and-discrimination-workshop
- Stand to Reason – social justice in mental health: http://www.standtoreason.org.uk/

TERMS OF REFERENCE

Members of the Committee are asked to consider and provide input into the following draft Terms of Reference for the review:

1. To gain a complete picture of how Stigma affects people with mental and physical health problems;

2. To fully understand the underlying reasons and attitudes associated with Stigma;

3. To assess a wide spectrum of local policies, services and activities across the broadest range of local public and voluntary organisations; and to advise how they could adapt and evolve to challenge Stigma;

4. To review the role of local NHS and social care providers in both diagnosis and their approach towards patients with mental and physical health problems;

5. To investigate other local, national and international projects, campaigns and initiatives that have successfully challenged Stigma;

6. To research and actively consult residents and service users; to seek valuable evidence and witness testimony to assist in developing the review's findings;

7. To ensure the Committee's review, report and findings are sensitively approached to reach out most effectively to those affected by Stigma;

8. After due consideration of the above, to bring forward effective, practical and cost effective recommendations to the Cabinet for implementation across the Borough and partner organisations, monitoring progress as required.

WITNESSES

Witness sessions for the review were held on 16 July 2013 and 10 October 2013 in which the Committee heard from the following expert witnesses:

Session 1

- Justine Bohan – Community TB Nurse, Central & North West London NHS Foundation Trust
- Caroline Wightman – TB Lead, Central & North West London NHS Foundation Trust
- Gail Burrell – Hillingdon Drug & Alcohol Service (HDAS)
- Dr Jeffrey Fehler – Hillingdon Drug & Alcohol Service (HDAS)
- Simon Belham – Hillingdon AIDS Response Trust (HART)
- Nigel Gee – Hillingdon AIDS Response Trust (HART)
- Richard Eason – Hillingdon Association of Voluntary Services (HAVS)
- Michelle Dibble – Hillingdon Stress Management (written submission)

Session 2

- Claire Thomas – Chief Executive, Hillingdon Carers
- John Clark – Trustee, Hillingdon Mind
- Christopher Geake – Director, Hillingdon Mind
- Kiran Seth – Diversity Manager, Hillingdon Mind
- Minta Sakaria – Blue Sky Development
- Carole Jones – Head Teacher, Yeading Primary School / Chairman of Strong & Active Communities Partnership
- Fiona Gibbs – Stronger Communities Manager, LBH
- Vicky Trott – Senior Policy Officer, Equalities and Diversity, LBH
- Nesrin Crilly – Health Advisor, Occupational Health, LBH
- David Brough – Chairman, Hayes Town Partnership (written submission)