



Opening Doors in Berkshire

A day conference to highlight the needs of
older lesbians and gay men

at the

Town Hall, Blagrove Street, Reading

on

29th October 2003

Post-Conference Report



Table of Contents

Conference Overview	3
Programme.....	5
Opening Address by Penny Henrion	5
Addresses by Berkshire Older Lesbian and Gay Forum.....	6
Margaret Collins	6
Wyndham Clampett	7
Dr Brian Heaphy: "Social and Policy Implications of Non-Heterosexual Ageing"	10
Elizabeth Price: "Out of the Shadows"	14
Roger Newman: "Being Equally Different - the Experiences of Lesbian and Gay Carers"	21
Workshops.....	27
Workshop 1: Health and Social Care Issues for Older Gay Men and Women .	27
Workshop 2: What's in a name – Words can Hurt, Words can Heal.....	29
Workshop 3: Carers and Caring.....	30
Action Points.....	30
Workshop 4: Residential Care	31
Workshop 5: Housing.....	32

Conference Overview

By Ray Williams

On 29th October almost one hundred people gathered in Reading to attend the first Berkshire Opening Doors Conference. The day was organised by the Berkshire Older Gay and Lesbian Forum in partnership with Age Concern Berkshire and aimed to raise awareness of the needs of older lesbians, gay men and bisexuals and to enable service providers to consider and analyse policies and programmes across a wide range of issues.

The Conference brought together delegates from as far afield as Yorkshire, North Staffordshire, Manchester and London and included representatives from a wide range of statutory, voluntary and private organisations.

The day was organised and managed by Jenny Ward, Chair of the Berkshire Older Lesbian and Gay Forum and was chaired by Penny Henrion, Chair of Reading PCT and Director of the local Princess Royal Trust Carers Centre. Penny began the day with a series of 'motivational exercises' which successfully broke the ice and helped to engage the active interest of everyone. The keynote speaker was Dr Brian Heaphy, from Nottingham Trent University, who summarised the findings of his recently published research into the social and policy implications of non-heterosexual ageing. Other speakers included Elizabeth Price, a specialist social worker from Hull, who spoke about mental health issues for gay men and lesbians and Roger Newman, from the Alzheimer's Society, gave a moving account of caring for his late partner who suffered from Alzheimer's disease. Roger was given a standing ovation by the delegates. In addition Wyndham Clampett and Margaret Collins of the Berkshire Lesbian and Gay Forum outlined the issues facing older gay men and lesbians.

The Conference heard that Brian Heaphy's research indicated that older gay men and lesbians believe that they are discriminated against in society and that only one third of older gay men and lesbians believed health professionals to be positive towards them. Given that some gay and lesbian people have faced discrimination and prejudice when they use services many choose not to disclose their sexuality, with the result that they become invisible to service providers.

Because of this invisibility many professionals assume that there are no such clients using their services, or at least very few, which makes it unnecessary to separately consider their views and experiences. This can be an excuse for professionals and institutions to say that the issues of "sexual orientation" aren't important. In fact between 5-10% of clients are likely to be homosexual.

The conference aimed to enable representatives from many of those organisations to discuss, consider and review their own approaches to the care and support of older gay men and lesbians.

A series of workshops held in the afternoon enabled delegates to examine specific topics in more detail, including Residential Care, Health, Caring and Carers, Housing and the influence of language in shaping attitudes. The day was brought to a close by an enjoyable and very professional performance by the recently formed Reading Gay Men's Chorus.

Out of the day a number of practical ideas and strategies developed for moving forward. These included the ideas that all organisations and service providers have a responsibility to:

- explicitly and openly include older lesbians and gay men;
- promote more partnership working;
- publicise their support through their service provision;
- introduce appropriate training for service providers;
- raise awareness of the needs of older lesbians, gay men and bisexuals.

Programme

10.00	Coffee and Registration
10.30	Welcome and Introduction Penny Henrion Director Princess Royal Trust Carers Centre and Chair of Reading Primary Care Trust
10.40	Presentation - Berkshire Older Lesbian and Gay Forum Margaret Collins and Wyndham Clampett
11.00	Dr Brian Heaphy “Social and Policy Implications of Lesbian and Gay Ageing”
11.30	Elizabeth Price “Out of the Shadows”
12.00	Panel and Questions
12.30	Lunch (in the Waterhouse Room)
13.30	Roger Newman “Being Equally Different: the Experiences of Lesbian and Gay Carers”
14.10	Workshops Victoria Hall – “What’s in a Name – Words Can Hurt, Words Can Heal and “Residential Care” Waterhouse Chamber – “Health” and “Housing” Silverthorne Room – “Caring and Carers”
15.00	Tea
15.15	Feedback from workshops
16.00	Reading Gay Men’s Chorus and Close

Opening Address by Penny Henrion

Penny Henrion, Chair of Reading Primary Care Trust and Director of the Princess Royal Trust Carers Service opened the Conference by saying how proud she was to be able to do so as an older lesbian working in the public sector. Reflecting on how much some things had changed and improved, she said it was a credit to all the lesbians, bisexuals and gay men who had worked tirelessly over the years to open doors for their younger counterparts.

Penny felt that the day should be one of loud celebration of the achievements and courage of lesbians and gay men so far and invited delegates to join in a special “standing ovation!”

This “raucous” celebratory applause was echoed throughout the day in appreciation of the excellent speakers who followed!

She went on to say that we still had a long way to go with regard to access to services by older lesbians and gay menbut that the Conference was an important step in the right direction.

Addresses by Berkshire Older Lesbian and Gay Forum

Margaret Collins

I would like to welcome you all very warmly and to thank the Organisers for giving me this opportunity to welcome you here on behalf of BOLGaF, the Berkshire Older Lesbian and Gay Forum.

I'd like to begin my presentation by sharing something with you - within the next 20 years I will have reached pensionable age. In 1992 there were 10 million pensioners in the UK and this is forecast to increase so that by the time I retire there may be 12 million people of pensionable age and 1 million of these may be over 85 years old - most of these 85 year olds will be women.

It was listening to statistics like these at a conference (organized by the Lesbian and Gay Consortium) in Guildford 2 years ago that brought together a small group of women. Collectively we talked, we dreamt - you might even say we had nightmares. Why nightmares? Well, research done in the USA indicates that nearly half of day care centres or residential homes would not welcome an openly lesbian woman or gay man. I'm not aware of this sort of study being undertaken in the UK but I'm not sure I expect it to be very different. So what does this mean? I can be "out & proud" at 40 but must prepare to "go back into the closet" if I need longer term care and support at the age of 70? Research in the UK shows that 73% of lesbian women don't believe that a residential home is a suitable environment in which to end their days and I can see their point! While I am sure few of us aspire to such full time care, it is a fact that being lesbian or gay means you are more likely to age alone and therefore need a higher level of support than many heterosexual people in the same age group. Using even very conservative estimates for the percentage of people identifying as non-heterosexual (4%), this means that there are 400 thousand lesbian women and perhaps 500 thousand gay men over the age of 65. That's close to a million non-heterosexual people of pensionable age in a system that is definitely not geared to cope with them.

So after the nightmares we planned. Ideas conceived on a cold November day eventually burst forth as BOLGaF, the Berkshire Older Lesbian and Gay Forum, still in it's infancy but breathing, vital and growing. Jenny Ward, here in our midst today had a pivotal role - in other metaphors one might have said seminal role or perhaps as midwife.

The information that we learned that autumn day was nothing new, in and of itself but the ground was prepared and ready. Part of my personal preparation for this work was to be a contact volunteer with the Reading Lesbian and Gay Helpline (now beYOU) for more than 10 years. When I first started most of the calls we took were of the "Oh my God, I'm gay... what can I do about it?" type. They were difficult days. As people talked about their sexuality for the first time many felt vulnerable and persecuted, and the volunteer at the Helpline was probably the first person who hadn't shouted abuse at them! Fortunately I can report that relatively few callers to the Helpline today have this same "victim mentality". One of the more interesting trends in recent years has been an increased number of callers towards different ends of the age spectrum - under 20 and over 50, each coming with new questions... a 16 year old is now

more likely to confidently ask for directions to the gay youth group than to agonise over their sexuality!

Our older callers are different, often less confident. We frequently get calls from people who are talking about their sexuality for the first time. They may have been married, had a family... they've known for years they were different but what could they do about it? They certainly didn't talk about it and have probably spent most of their lives hiding this from the people closest to them. It is so important that nobody even suspects the truth! I guess it's becoming slightly more acceptable to break the social stereotypes but after concealing your feelings for decades calling the Helpline is still a daring and daunting step to take. And so we talk and discuss their options... They often find it difficult to come to terms with the language they must use to describe their feelings, older women in particular can be very reluctant to use "the L word" to describe themselves. It must be both shocking and liberating in equal measure to admit to another person that they are "that way inclined" and discover that you don't get hit by lightning! The conversation moves on to what they want to do next... I remember one call in particular from an older lady. The obvious social group for her to make contact with was one which met one evening in a local pub... I could feel the panic. It was as if she was being asked to strip naked in public. Walk into a pub, in the centre of town, where everyone could see her and know why she was there... I could sense the tension rise. Fortunately, I had a card up my sleeve! "If you prefer there's a tea dance on Sunday afternoon. It's organised by the Berkshire Older Lesbian and Gay Forum. There's a dance teacher who will show us how to do the cha cha cha and the foxtrot, plenty of tea and cakes, and a room full of women to talk to. How does that sound?" There was silence. I waited as I heard the sobs. Through her tears she said "I've waited 40 years to make this phone call - and you're inviting me to a tea dance. I never dreamed it would be possible!". This lady came to the tea dance. She talked, drank tea, found women who worked in the same profession as her, swapped telephone numbers and email addresses, made arrangements to meet - in the pub - next week. You just knew that life would never be the same!

While the Forum is still in its infancy it is making a difference, changing lives. And it's doing so much more than organising tea dances! But to find out exactly what let me hand you over to Wyndham Clampett...

Wyndham Clampett

I hope that at the end of today you will take with you a feeling of enthusiasm for what we have been doing. This is very important to us in the Berkshire Older Lesbian and Gay Forum, because we feel that it is only people who have enthusiasm for the task in hand will achieve what needs to be done. Simply knowing the details and paying lip service won't do.

Some of you will be here today because you support our aims and objectives: some will be here because you feel obligated: and some will be here because you were told to attend.

It is our fervent hope that whatever your reasons for coming, you will all take home with you a little of our enthusiasm for what we are trying to achieve.

So, this then is our first and most important objective.

You here today representing health, social and community services and agencies, are vitally important in the work to better the lives of older lesbians and gay men in Berkshire. This conference is part of our efforts to work with you all in achieving better practice.

Today, you will hear lots to think about in the talks and workshops, but it is also important that you understand that we, in the Berkshire Older Lesbian and Gay Forum, don't claim to know everything and place a high value on your feedback.

We need your considerable skills and experience to help us all learn how to do it better.

So please tell us.

We also need your help to find those hidden older lesbians and gay men so that they can meet with other lesbians and gay men, or in any other ways that can add to or improve their quality of life.

I would like to read to you an extract from the Age Concern Opening Doors Report - April 2002 which I think illustrates this very well :

This is a quote from Gordon Lishman (Director General of Age Concern England), explaining part of the reason that many older lesbians and gay men tend to be well hidden: "Lesbians and gay men now in their seventies have spent at least half their lives in varying degrees of secrecy, anguish, anxiety, fear, confusion, deceit, shame, excitement, fun, joy and love. Some have coped better than others...it is also true that prejudice, inappropriate discrimination and even violence remain a threat for many and a reality for some". In such circumstances it is hardly surprising that older lesbians and gay men choose to keep their homosexuality secret, or at least to be wary and cautious. At a time when older people are at their most vulnerable and most likely to need help from health, social services or voluntary organisations, they run the risk of double discrimination – both in terms of age and sexual orientation.

So, what can BOLGaF offer older lesbians and gays in Berkshire?

We hope several things: Firstly, simply by being there, visible to all. We ask you to help us in this by putting up flyers and posters to let your clients know we are here and that they are not alone.

We have a contact number, which people can telephone for information – but please note this is not a "help line" as such and is only an information service which is not available 24/7.

The Forum wants to work with the services and agencies you all represent in any way that seems appropriate. For example: We can arrange training or workshops at your locations so that more people can have a better understanding.

We are not a campaigning group, but we do consult widely in the lesbian and gay community on the issues that affect us and especially older lesbians and gay men, and have recently made a submission in response to the government proposals for civil partnership registration.

It may be worth mentioning that the active members of the Forum come from a wide age range and this fulfils one of our other objectives, which is to reach

the whole of the Lesbian and Gay community. We are very conscious that we need to have constant contact with all sections of the community both in terms of age and ethnicity.

With this in mind we have been actively networking with similar groups (i.e. those who are working to benefit the older lesbian and gay community) and recently hosted a networking day which saw 25 people from 11 different groups from the South of England come together. There was a tremendous sense of working together and I personally was highly motivated by the event. Perhaps of more immediate relevance to some of your clients, will be the social activities we organize.

Again, your feedback is important to let us know what your clients want. Currently we are organizing events such as meals out, various outings – not too strenuous – and, coming up next month, a Tea Dance. There are leaflets about this (and tickets) for you to look at later. These have proved very successful in the past and I can assure you that if any of your clients came along they would thoroughly enjoy themselves.

We are keen to emphasize that the Forum is not just being serious – we also try to have fun sometimes...

The Forum steering committee meets regularly and you are all welcome to get in touch with Jenny Ward, our chair, to arrange to come along – just a few at a time please...

There will also be open Forums at least once a year where the whole lesbian and gay community are invited to have their say. Again, you are all invited. If you are interested, or think you might be interested, please let us know so we can put you on the mailing list.

Finally, we have prepared a brochure about the Berkshire Older Lesbian and Gay Forum which gives a lot more detail about our activities, and our aims and objectives. Do pick one up from the stand during the day.

Thank you all for listening and I hope you have a great day.

Dr Brian Heaphy: “Social and Policy Implications of Non-Heterosexual Ageing”

Research Funded by Economic and Social Research Council

by Brian Heaphy, Andrew Yip and Debbie Thompson.

Acknowledgement: Sally Middleton for ‘responses’ to National Service Framework for Older People (NSF)

The Study

- Experiences and implications of ageing
- Life Circumstances
- Policy and Practice

Context

- ‘Coming out’ of lesbians and gay men
- Recognition vs. invisibility
- Distinctive cultures and lifestyles
- Distinctive needs?
- Social Exclusion and Social Diversity
- Government emphasis on ‘partnership’ working
- National Service Framework for Older People (NSF)

Who?

- Over 300 individuals aged 50 -80+
- 266 – questionnaire
- 6 focus groups
- 20 interviews
- Organisations and groups

Ageing - Continuum of experience

70%	30%
Resources	Financially insecure
Support	Unsupported
Confidence	Vulnerable
Strategies that work	Ineffective Strategies
Healthy	Frail

Majority felt sexuality enriched life

29% women & 27% men – being ‘lesbian, gay or bisexual’ had adversely affected sense of well being.

NSF -2: Person Centred Care

-7: Promotion of Mental health

-8: Promotion of Health and Active Life

Providers: Health/Mental Health; Primary Care/Voluntary Organisations.

Responses:

- Positive images of ageing and LGB sexuality
- Supporting of self-help/community supports
- Advocacy/befriending

Creativity, Resilience and Resourcefulness

Forging worthwhile lives despite:

- Legal sanctions
- Social prohibitions
- Cultural devaluing

Majority out to friends.

69% out to some family members.

51% out to neighbours.

37% men and 23% women always hidden sexuality

'Risks' of coming out.

NSF - 8: Promotion of Health and Active Life.

Providers: Health; Social Services; Voluntary Organisations; Samaritans; Police.

Responses: Anonymity; Awareness training for service providers; Services – being 'seen' to be welcoming, professional, confidential, accepting, aware.

Financial security

67% men and 50% women feel financially secure (1/3 have income under £10,000).

1/3 felt vulnerable to homophobia in workplace.

Solo Living – 41% Women & 65% Men

Likelihood increases with age.

Implications for 'Live in' care.

NSF -2: Person Centred Care.

-3: Intermediate Care.

-7: Promotion of Mental health.

-8: Promotion of Health and Active Life .

Providers: Domiciliary care providers; health.

Responses: Awareness training; Voluntary 'befriending' and 'Buddy' systems.

Relationships

Younger participant more likely to be in relationship.

Family of origin important to many (62%).

Friendship – relationship most consistently rated as important.

Few assumptions about care.

**96% women & 93% men see friendship as ‘important’/ ‘very important’
‘Families of choice’ – almost 50%**

NSF: All 8 Standards.

Providers: All.

Responses: Cultural sensitivity; Meanings of family; Significance of friendships; generally.

Friends and partners – role in care support, next of kin and so on; Mutuality and Reciprocity.

Care – Ill Health or Old Age

- Little expectation of care from family
- Partner – if able – most likely to fulfil this role
- Only 20% women and 11% men had planned for care in illness
- Only 9% planned for care in old age

Community relationships

- 65% women and 55% men some sense of commitment to local community life
- 35% feared homophobic violence in their communities

NSF -7: Promotion of Mental health.

-8: Promotion of Health and Active Life .

Providers: All statutory service providers – housing; police and local councils .

Responses: Community safety strategies/Police-sensitivity and awareness; contact points

LGB support networks and groups

Important to many.

Unevenly spread across UK.

Places to “be themselves”.

34% of women and 54% of men feel less welcome in gay venues and groups as they age.

Lack of commitment in LGB communities to look after their own (unlike AIDS)

NSF: S2: Person Centred Care.

S7: Promotion of Mental health.

S8: Promotion of Health and Active Life.

Responses: Fund, promote and publicise these networks – facilitate collaborations (e.g. Age Concern).

Health Care Providers

- Only 35 % believed these have positive attitude to LGBs
- Only 16% trust they are knowledgeable about LGB lifestyles
- Broad belief that providers operated according to heterosexual norms
- Generally believe that providers failed to meet specific needs

NSF: All standards.

Service/Providers: All

Responses: Education and training of local health providers.

Inclusion of lesbian and gay lifestyles in 'cultural sensitivity' and training.

Wide support for dedicated health and /or information services for older LGBs.

78% women and 63% men believed elderly persons homes to be undesirable option for living

Distrust that institutions would respect who they were re: identity, relationships and lifestyles.

NSF: S2: Person Centred Care.

S3: intermediate care.

S7: Promotion of Mental health.

Reponses: Awareness training.

LGB issues on agenda when statutory providers commission.

independent sector care homes to provide accom/beds.

Discriminations

Debates on social exclusion largely disregard dynamics as applicable to older LGBs.

71% felt that LGBs routinely discriminated against

Range of experiences of "exclusion".

Tenancies; pensions; survivor benefits; next of kin issues; inheritance.

NSF: All.

Limited legal rights – easy to discriminate against.

Section 28.

Employment.

65% support notion of civil partnerships to protect rights.

Do Numbers matter?

- Increasing Visibility
- Legislative Changes
- 'Rights' consciousness of newly old LGBs
- Citizens

Needs – as Old People and LGB

- Recognition of existence
- Degree of validation
- Respect for ways of living
- Challenge 'heterosexual' assumption

Elizabeth Price: “Out of the Shadows”

I have recently started work for a PhD which began as an exploration of the experiences of people who have had a diagnosis of severe mental illness when they are young and who subsequently have a diagnosis of dementia in later life. I was interested in what happened to them and what became of their original diagnosis. The more I read, however, the more concerned I became that, in either context, mental health or dementia care services there never seemed to be any mention of the experience of gay men or lesbians.

This anomaly has now become the focus of my interest and my research is now centred on the experience of dementia from an exclusively homosexual perspective and this, along with a more general look at the experiences of gay men and lesbians in mental health services is what I'd like to talk about this morning.

The first thing to note is that very little is known about the specific experiences of gay men and lesbians in mental health services. Although, from a pathological perspective, there is, of course, still plenty of literature around that suggests that being gay or lesbian *per se* constitutes being mentally ill,

What research there is tends to come from North America where there appears to be a much better understanding of the issues involved and where the gay community are, perhaps, more vociferous in their approach to issues that negatively impact on its members.

There are, though, clear parallels with the UK in that the needs of people with mental health problems whose lifestyles don't fit a stereotypical norm are often unacknowledged and marginalised.

There is some research from the UK, however. MIND, the mental health charity, published 'Without prejudice' in the late 90s and, more recently, a report published in collaboration with University College London. And PACE (Project for Advice, Counselling and Education), an organisation that provides mental health services and advocacy to lesbians, gay men and bisexual people, published 'Diagnosis Homophobic' perhaps the most in depth look yet at gay men and lesbians mental health.

Whilst none of these reports specifically excludes older people, there is a general rule within service provision that once people reach the age of 65 they automatically move into older people's services. As these reports explore adult service provision older gay men and lesbians are excluded by default.

I've wondered WHY there's so little research and, consequently, so little known about the experience of gay men and lesbians in mental health services. These are perhaps some of the reasons.

Uneasy relationship with psychiatry.

The gay and lesbian community has had a very uneasy relationship with psychiatry. It's only 20 years since homosexuality was declassified as a mental illness from the psychiatric bible, DSM. Despite the change, I think there are many people within mental health services who continue to view homosexuality as a pathological condition. I think the conclusions of the research done so far, which I'll talk about shortly, make this quite clear.

Discrimination

Given that some gay and lesbian people have faced discrimination and prejudice in mental health services, it's not really surprising that many gay men and lesbians choose not to disclose their sexuality within services. With the result that they become invisible to service providers.

Invisibility

Because of this invisibility, professionals presume that there are no such clients using their services or at least very few which would make it unnecessary to separately consider their views and experiences. This can be an excuse for professionals and institutions to say that the issues of "sexual orientation doesn't matter".

Gay Community

Lack of awareness of the nature of mental health problems in the gay community as there is in society in general.

Disabled asexual

Like many disabled people there is a tendency in society to view people with mental health problems, especially dementia, as asexual so, again, the temptation is for service providers to claim that, for them, sexual orientation doesn't matter

Stigma

It may also be that there's little research in this area because of the risk of personal stigmatisation for the researcher. I was certainly warned that I would be presumed to be a lesbian because of my interest in what has been described as such a marginal issue

Unfortunately, the conclusions of the research done to date tends not to give a very rosy picture of mental health service provision for gay men and lesbians

From a symptomatic perspective, it's concluded that gay men and lesbians have generally higher rates of anxiety, depression and suicidal behaviour than heterosexual people which perhaps isn't so surprising given that the work has also unequivocally stated that gay men and lesbians suffer high levels of intolerance, discrimination and victimisation because of their sexuality

Homophobia

Unsurprisingly, then, many of the respondents in the PACE report felt that homophobia, heterosexism and bio phobia from society in general had had a negative impact on their mental health.

Prejudice/discrimination

And all the work to date suggests that the prejudice and discrimination that people faced in everyday life were mirrored in mental health services. This means that many gay men and lesbians may choose, where possible, to avoid mainstream mental health services and others may choose not to disclose their sexual identity when using services. Leading to inappropriate and culturally insensitive service provision.

Wide variations in practice

It seems that there is wide variation in individual professionals' approaches to mental health matters for lesbians and gay men and the way in which individual workers approach the issue of a person's sexuality can have a profound impact on the experience of service users.

Staff and Users attitudes

The negative attitudes of mental health workers and other service users created environments which were perceived as abusive, invalidating, marginalising and emotionally damaging for lesbian and gay service users. Attitudes were shown to stereotype, stigmatise and patronise service users generally whether gay, lesbian or straight.

Issues of Safety

Women in particular experienced intimidation, sexual harassment and sexual assault particularly in an inpatient context.

Lack of Awareness in Gay community

It's also suggested that there may be a lack of understanding and awareness of the nature of mental health problems within the gay community which has led to prejudice, fear, ridicule, exclusion, marginalisation and racism for people who have mental health problems...though I'm not sure that this has been proved to be any more prevalent within the gay community than in the general population.

Specialist services

At present, gay and lesbian mental health service users have little or no choice when it comes to service provision. That is, there is little specialist provision that considers the specific needs of the gay community.

General Dissatisfaction

As well as dissatisfaction with bad practice that arises from homophobia and heterosexism there was a sense of dissatisfaction with mental health service provision generally.

Lack of recognition for partners.

Two thirds of respondents in the MIND study stated that they felt that their partners had not been treated on an equal footing with the partners of heterosexual service users.

Sexuality problematised

50% of the respondents in the MIND study felt that their sexuality had been inappropriately used by mental health workers to explain the causes of their mental distress. That is, people's mental distress is presumed to be caused by their sexuality.

One of the PACE report's primary recommendations was that there is a need to explore, in greater detail, the needs and experiences of minority groups, including older lesbian and gay service users in mental health settings.

Which is particularly interesting because there is, so far as I'm aware, currently no research, other than anecdotal evidence, that explores the experiences of older gay men and lesbians in mental health services. The reasons for this are most likely the same ones as those I've just outlined. But there are perhaps one or two issues that relate specifically to the older age group

The compounding effects of ageism

Like disabled people, older people are simply perceived as asexual
There's also Legacy of the past - more telling because of longer personal biography

I mentioned the uneasy relationship that gay and lesbian people have had with psychiatry earlier and, for the older population, this is particularly the case. They have been variously labelled mentally sick, weak, perverted, sinners, illegal, a public menace and at best the unfortunate victims of arrested development so, again, it's not so it's not really surprising that many may not choose to disclose their sexual identities within mental health services or indeed use mainstream services at all.

I'm going to talk about dementia separately from other mental health problems because it's perhaps one of the conditions that people most readily associated with old age and the one where, I think, because of the particular vulnerability of this group of people, many of the issues I've outlined so far become particularly acute.

Demographics

Estimates suggest that there may be as many as 52,000 gay and lesbian people in the UK who have a diagnosis of dementia. This figure is taken from the Alzheimer's society's estimate of the number of people with Alzheimer's disease and a fairly conservative estimate of the numbers of G&L people internationally.

One of the reasons that dementia pushes many of the issues we've outlined so far into such sharp relief is that the onset of dementia, coincides with what for some people amounts to a forced coming out procedure.

Following the assessment there may be attendance at day care, the possibility of residential care or perhaps community carers coming into the home to be negotiated.

Private-Public

For gay men and lesbians, what has, until that point, been private suddenly comes into the public arena. Domestic arrangements and personal circumstances are suddenly available for public scrutiny and it's becomes difficult to keep information about yourself secure.

For older people who may have spent some or much of their lives concealing their identity and whose private lives have always been just that this must be a particular concern.

Residential care

A particular flashpoint might be when someone is admitted into residential care when making decisions and arranging financial matters can involve negotiation with families and partners. Once again, appropriate research is important for carers as well as for people diagnosed because, to the residential sector they remain essentially invisible.

Sexuality ignored

I said earlier that older people, are viewed as asexual. This is doubly so for people with dementia. It's only recently that the subject of the sexuality of people with dementia has been given any serious attention. Previous to this they were might retain a sense of their homosexual identity has ever really occurred to anyone.

Sexuality pathologised

I mentioned earlier the likelihood that a person's sexuality can be problematised in mental health settings. I think this is particularly acute in dementia care. Here, rather than a person's sexuality being presumed to be part of the cause of their difficulties, sexuality tends to be pathologised. Meaning that the expression of sexuality is perceived as symptomatic of their condition and is a problem for staff to manage rather than an inherent part of an individuals make up.

The future

I think that dementia care looks set to 'discover' older gay men and lesbians the same way as it has recently done with people from ethnic minorities and younger people with dementia, as such, as I've pointed out, there is a yawning gap in the academic and practice literature relating to this group of service users.

That's very worrying because, perhaps for the first time there is a cohort of lesbian and gay people approaching older age who may be more willing and able than has been the case in the past to identify as homosexual and who will rightly expect service provision that is appropriate to their needs.

So what can service providers do?

Slide 7

The following are just a few pointers, not just for dementia care settings but for mental health services for older G+L people generally...

A number of things we can do as individuals and others are more an issue for institutions, nonetheless...

Challenge attitudes and behaviour

I think as individuals we should be prepared to challenge homophobic attitudes and behaviour and this includes a duty to reflect on and question our own attitudes and that of our work colleagues.

Anti-Oppressive Practice

Practitioners should make a commitment to anti oppressive practice. Maybe particularly in residential and inpatient settings where clients are effectively at the mercy of their carers.

Assessment and the heterosexual imperative...

language used in assessment and treatments procedures should be inclusive of L&G lifestyles and relationships. Certainly not currently.

Support

Managers should be prepared to support people who are coming out.

Visibility

Positive images of L&G people, including literature, information and advertising should be freely available alongside heterosexual stuff. This would make for a more positive environment for gay and lesbian service users.

Education and training.

There should be continuing professional development for health and social service staff that explores not only the relationship between sexuality and mental, but also how sexuality fits into the wider context of a person's life and how to respond appropriately to lesbian and gay people in mental health settings. Training is clearly required for all sectors and all levels of staff and training of L&G issues should be included as an integral part of students' coursework.

Sharing good practice

Professionals should be prepared to proactively share good practice that relates to work with lesbian and gay users of mental health services.

Equality

For any of these issues to be taken seriously there should be a commitment from policy makers to ensure that G&L people are given parity with heterosexuals when it comes to rights and opportunities

Advocacy

Provision of G&L advocates would be a positive step forward

Accessibility

MH services need to be accessible to all members of the community

Specialist Services

There is an argument for specialist gay and lesbian mental health services like PACE. How realistic that aim is questionable though in current economic climate.

Finally, it's essential that L&G orientations should not be ignored, pathologised or denied

As I said earlier, there is a group of Gay and Lesbian people now approaching old age who will not be prepared to return to a closet that they fought so hard to get out of and who will not accept inappropriate and insensitive mental health care as they age. For people with dementia, their partners, carers, friends and family, the issues I've highlighted today are particularly acute because of the unique vulnerability that this condition imposes on people and given that there is a focus at the moment on the early diagnosis of dementia, this is a diagnosis that people may get as early as their fifties or even their forties.

With this in mind, if you feel that you could be of any help with the research I'm doing at the moment. If you are gay or lesbian and have dementia, or you care for someone be it as a partner, friend, relative or formal or informal carer then please get in touch either by e-mail or phone or just come and have a chat during the day. I also have some leaflet with me that explain a bit more about the work and have these same contact details.

Selfishly, I want to ensure that, if I'm unfortunate enough to suffer from a mental health problem, in particular, dementia as I age then I would like to know that there will be services available that respect my, and my partners right, to the expression of our sexuality and the right to be treated equitably with others.

As I've hopefully outlined today, at the moment that simply wouldn't be the case, whilst there are pockets of good practice and of course it mustn't be assumed that all mental health workers are homophobic, evidence suggests that gay men and lesbians who have mental health problems have to endure overwhelmingly oppressive and ill informed service provision.

With this in mind, I think it's essential that a firm knowledge base of the issues that effect older gay men and lesbians is built quickly because these are issues for the here and now that we ignore at our peril.

Roger Newman: “Being Equally Different - the Experiences of Lesbian and Gay Carers”

It is a privilege to be here to day and to be able to take part in this conference, as one of the founders of the Lesbian and Gay Carers Network of the Alzheimer’s Society. Another of our founders, Bruce Graham, is here as well and I am so pleased that members of the slough branch of the society have agreed to host a stand with information about the society and our network. These days I am regularly moved by the advances which have been made in securing more legal and social rights for gay men and lesbian women – there are times when I can hardly believe what I see. but whereas the ‘gay’ world marches on to enjoy its increasing rights, we older lesbians and gays creep on more slowly and with caution and have greater difficulties to gain acknowledgement of our own distinctive experiences and needs both within the ‘gay’ community and outside too.

Two weeks ago I was speaking to someone from the commission for patient and public involvement about our lesbian and gay carers network, and about the general needs of older LGBT’s. Not for the first time I was asked if I didn’t think that things had changed so much that there wasn’t really a need for an organisation dealing specifically with older people’s needs.

I really wish that were true, but what the comment fails to understand are that those of us who are over 55 remember only too well what life was like pre 1967. We remember also that the number of people charged with sexual offences significantly rose after 1967, so we experienced no real security. Lesbian women carried with them similar feelings of rejection, plus an almost unbelievable assumption amongst some people that lesbianism, if i can use that word, didn’t even exist. So we all bring to our present experiences our own memories of what it was like to be secretly lesbian and gay. we bring to the present our still standing defensive walls, admittedly now with more open gates in them, but still there, and many of us are still none too sure when we are told that the water is warm, that we are being told the truth.

In the world of dementia, with its 700,000 sufferers, if we use government estimates as our guide, then currently there are 35,000 lesbian and gay people out there with the disease. You may well ask where they are, and I can’t say that I know either – but they are people of an age where the last thing you told others was the truth of your sexuality. As each day I went to visit or collect my partner, David, in the residential home I passed other residents who never had visitors – and I always reminded myself with sadness that some of them were lesbian or gay and no one knew and no one would know.

Not surprisingly therefore we are dealing with carers who still harbour the same anxieties as they did in the 60’s and who take the most irrational and far reaching actions in order to protect themselves from any backlash, wherever it might come from. Take for example, the funeral of Peter’s partner, Michael, whom he cared for to the end with cancer. Even at the funeral Michael was referred to as Peter’s brother so that the real truth of their relationship wouldn’t come out. Or take Joan who is caring for her partner, Christine who has MS. Whenever Christine’s mother came to stay Joan said that the mother

could sleep in 'her room' and she would sleep on the couch. each evening of each stay she ostentatiously made up the couch and waited for the mother to retire to bed and then she quietly crept up the stairs to sleep with Joan as usual. Or Tom who with his partner moved down from the north to live in London because they felt that it was safer for them as gay men. When his partner developed Alzheimer's and subsequently died he said he was getting little support from his neighbours of 20 years standing because he had never told anyone in the block that they were gay.

This defensiveness can be very effective when we are strong. Like most human beings we tend to live as if our present secure existence will last forever. Even when, as lesbian or gay partners, our lives are put under pressure, usually one of us can sustain the other until we get back onto a normal footing. When our partner is ill we know that we can go back from our non gay world to our gay world in order to help them get better. When our partner is out of work we similarly use the advantages of our non gay world to see our partnership through until our lives are more stable again. When one of us experiences bereavement, even if we do not feel safe to publicly support them then at least we have our moments in private when we can make up for it. In partnerships normally one person's strength makes up for the other persons weakness and most of the challenges are temporary.

When the time comes to be a lesbian or gay carer the situation changes drastically. You are catapulted into a world where you are both vulnerable but for different reasons. You have to say who you are in relationship to the ill person. You may discover that you have no legal rights to deal with the financial needs of your partner (we never cease to say 'take out an enduring power of attorney'). You may discover all sorts of emotions and fears related to your own sexual identity, which have been either buried, forgotten or just ignored in favour of your present secure experience.

So what then are some of the experiences of being lesbian and gay carers?

Without a doubt one of the most important challenges we have to confront is that of 'coming out'. Yes I know you have already heard that, perhaps many times before, but take it on board again try and grasp what it is like for someone who is a lesbian or gay carer.

At the hospital, in the surgery, with social services, with domiciliary care, and heaven knows elsewhere people ask us who we are. And there is that pain in the gut feeling you get as each time you seemed to be forced to make the choice about delivering the fundamental information about yourself. Some of us don't even get to make the choice. My own partner outed me on every available occasion by constantly kissing me. I could have pushed him away in embarrassment but I quickly learned to realise that the real choice was not whether to come out or not to come out but to choose what were the most important things about my present life. Was it what the neighbours said or was it to be faithful to the love I had for him?

And don't believe that this is a choice which has to be taken only once and for all time, as a lesbian or gay carer it is presented often, even day after day as new people who will need to be involved with your partners well being, are met.

And it even goes on after your partner dies too. Tony and Alan had been together for almost 20 years but again little had ever been said publicly about

the truth of their relationship. Tony had Alzheimer's and Alan had the task of arranging Tony's funeral. We spoke for hours about the content of the funeral service, and what kept on emerging was the fact that the minister taking the service hardly knew either of them. With great courage Alan decided that he would give the talk. He wanted it to be celebration of his partner and, just as importantly, an acknowledgement of how important their relationship had been. He wanted to be able to look back and feel that he had made the now ended loving relationship the most significant focus of that service. Alan had never publicly acknowledged this before but the funeral had to be about Tony and himself, and not about meeting the sensibilities of the others who were present. The cost of publicly speaking about this was enormous, but afterwards he was so proud that he had done it.

In my own case my partner made me promise and promise that he would never be cremated and I followed his wishes. I copped out from putting on his gravestone what I really wanted to say, and even now each time I go to the cemetery I still feel that I am not like the other people there; husband tending his wife's grave, or a wife tending her husband's grave – I still get asked who was the person who died – and another coming out takes place.

And even if you gradually have the courage to come out there is still the feeling that having created your own world where friends are around you, you now realise that you have been catapulted into a world where at times you can feel like an alien. I shall never forget that moment when David first went into the first of the two residential homes he was to be in. I remember his look of being lost and my guilty feelings about putting him there. I decided from the start that it was easier for it to be known that we both were gay (in a document on our web site we recommend to gay couples that they agree on such issues well before the time arrives). Of course, as you might hope, the home said that it didn't matter that we were gay, but I wanted it to matter, I wanted our sexuality to be recognised, appreciated, even celebrated in the place which was now his home; just like it had mattered to us in our previous home life. In the second place he was in – we eventually even had a gay birthday party and the staff decorated his room appropriately. Such acceptance took a whole load of educating the staff towards and the place eventually became home; but I also remember only too well that feeling of relief when two gay friends of ours placed their cousin in the same home – it was very heaven to go there and see them there as well.

Think for a moment what it might be like for a lesbian woman or a gay man in the present circumstances to be in a residential home. My normal life is that I read gay times and even Boyz when I can get it; my gay friends always kiss me when we see each other; my raunchy calendar is in my study and I eagerly wait to turn the page for the next month; I can't wait for each new episode of 'six foot under'; I camp it up on the phone with the best of them; my birthday cards proclaim that this is a gay birthday; I read Armistead Maupin and the rest of 'em; when my friends visit our conversation is about gay issues and all that; and I think I want a man to deal with my personal needs as I get older and can't manage. My lesbian sisters are, I hope, creating their own list too.

And I ask, how many residential homes, or wards, or domiciliary care groups are sufficiently ready to help me be like that. And it isn't asking for the world, it's asking simply for the continuation of my world!

That other world was made clear to me in the support group for carers which I joined. I always made sure that my experience was heard, but on one occasion another group member turned on me and angrily said 'but I am talking about my husband'. I got her point and she clearly hadn't got mine.

Jim realised very soon how alien this world could feel when his mother had to go into a residential home. She became embarrassed by the questions other residents started to ask about him and he felt the same when he visited alone. 'Your son not married yet?' in reality his mother was forced into the closet with Jim as a result of such questions.

I also need to add that our network learned to recognise very early on that 'gay' carers are not necessarily caring for a partner, but are just as likely to be caring for a relative or friend – the problems of starting a new life following the death of their loved one are no less challenging than for those in a lesbian/gay relationship.

As a lesbian or gay carer you soon begin to realise that your relationship has no real status in law and that any warm accepting attitudes shown are almost by choice rather than by statute.

Brian's partner is suffering from a type of dementia called Lewy Bodies disease. This leads to extreme swings of behaviour, which challenges Brian immensely. He is trying desperately to help his partner, but is not helped when his partner's doctor refuses to discuss his partner's situation because the rules of confidentiality do not allow it.

And then there are 'other' people to deal with too. On our website we have a selection of carers' experiences. Here is what 'Franmar' (I don't know her name says) 'as well as being quite exhausted (visiting mum about 20 times a week) we have the added difficulty of her neighbours (except 2 who are lovely). Not only are they constantly criticising the 'state' mum is in, but they openly make comment about 'all these lesbians'. Mum herself doesn't acknowledge my partner and before she became so demented insisted that everyone refer to her as my boyfriend.'

You get to the point as a gay carer that in the end there are far more important issues to deal with than trying to please other people or to satisfy their own attitudes. And that leads me on to the last point in this section namely that we soon learn to risk telling people to their face about the reality of our relationship and we dare others to respond in any other way than that of acceptance. Teresa is 70 and is dealing with her partner who is in the early stages of dementia. To her surprise she now brazenly confronts every professional and every service provider with the information that 'this is my partner' – it becomes important to get the scenario correct right from the start. When my partner needed hospital treatment for dental problems the consultant brazenly asked me why I had power of attorney for David. I said 'do I really have to tell you?' he said 'I would like to know'. 'Well' I said, 'I'm his partner, ok? - ok?' and the silence said enough to dare him to offer anything other than acceptance and he said 'ok'. I have to say that the conversation led to some heart-warming attitudes from the staff involved and that leads me on

to answering the question – what should professionals be doing to enable us to feel accepted.

Firstly can I suggest that you get to know us better? Any fool can tell the difference between pc acceptance and genuine empathy and such empathy can only be produced when real knowledge about us has been attained. In a couple of weeks time the Alzheimer's Society is holding its first training course on lesbian and gay issues, we are calling it 'equally different'. The person in charge of training has always been 'on our side' so to speak but in recent weeks a change has taken place in her. She has dared to ask questions and in our preparation has listened and listened. Nothing startling has emerged about our behaviour but she has moved from a simple 'Its fine by me if you're gay' to 'I realise now what it is really like'. Don't be afraid to ask questions; get to know us; remember that we could be at least 5% of your clients.

Secondly examine your own values and professional practices. Look at your literature and language, examine the assumptions you make, so that when we play our usual games, as gay people, of searching you out to see if it is safe to tell you that we are gay then you will pass your test with flying colours. Our network began with a letter to the society, which said 'why are the photographs always of devoted husbands or wives?' 'Why do the stories always involve family response to this disease' and the question which followed said 'is there anyone else out there caring for someone they are not married to, or not related to, or gay like me?' Those simple questions are I believe leading to a sea change in the way the society is trying to be inclusive in its operations. Perhaps those changes need to take place in your world as well.

Thirdly if you are lesbian or gay and a professional or a service provider can i appeal to you to consider coming out as well? When we are carers sometimes we do not know where we are or what is happening to us. Our lives are in turmoil. A friendly word, a smile, a gentle touch is all we need to assure us that we are amongst family, as we term it, and we immediately feel safe as a result.

Fourthly please put our needs on your agendas. Have the courage to use the words lesbian and gay when you are creating your policies and your strategies. Continually ask us about our needs. Evaluate your work when lesbian or gay carers have been part of a particular service. Remember the magic 5 to 10% - can you really afford to ignore us?

Fifthly let your every contact suggest to you that it is possible that this person you are dealing with is lesbian, gay, bisexual, or going through gender orientation challenges. Things are seldom what they seem in today's world. One of our earliest callers told us that the death of his wife who had dementia was now telling him that he could give freedom to his own feelings about his sexual orientation which he had long suppressed.

In the best of all possible worlds what are we looking for? Nothing that dramatic or earth shattering. There is simply a request, some would say a demand, to be treated as we really are. I have changed the details of my other examples to ensure as much confidentiality as possible. I don't need to do that with this final story, because I have permission to tell you as much as I need to. John's partner Stan died four months ago from prostate cancer and John was Stan's carer right to the end. They had been together for 40 years,

keeping themselves to themselves, as John put it. They had gone through the usual issues which older gays and lesbians have had to face, with Stan's family being understanding, and with John's family cutting him off totally and without any further contact from the time of they first lived together. John is now beginning the long slow progress of dealing with his loss and starting to think of a new world without Stan. He is tearful a lot, and that is understandable. Not long after Stan's funeral John had been doing some shopping, when suddenly, as he walked home, the owner of one of the shops they often went into saw John go by. She rushed out, put her arms round him and kissed him and said ' I am so sorry. We all know you loved each other so much. How are you? Please come in and sit down'. John cried of course.

What does the story show? Well not that it cured John's loss but the point is that someone, not lesbian or gay, was publicly validating the fact that it was ok to feel that loss. Someone had declared that his loss as a gay lover was justified. Someone had said that his loss had the same status as all those other people in the world who had similarly lost loved ones but who were not gay.

John went home that day feeling quite a bit better. The world was not pushing him and his experience to the margins of insignificance but was incorporating him into its well-established understandings of love, care and service.

We look forward to the changes you also might produce to make that experience a reality in your world.

Workshops

Each workshop was asked to feed back three points from discussions on the flip chart. What follows are these points with some expansion.

Workshop 1: Health and Social Care Issues for Older Gay Men and Women

Facilitated by Liz Hill

What are the issues?

- Need to understand issues for all older people PLUS any sexuality issues
- Is sexuality the last taboo? Language has changed with issues such as physical/learning disability and mental health – language of sexuality used in services needs to change too.
- Sexuality is NOT a disability or an illness – often people treat it as such.
- It is wearing to keep on repeating statements about your sexuality and status.
- Huge sexuality and ethnic diversity issues – support for LGB BME people
- High need for education for caring staff – public/statutory and voluntary sector

Leadership issues

- Senior leadership is essential to effect change in behaviours/attitudes
- Need culture of open dialogue throughout organisations to feed the change process – need for some 'stable' champions to lead the charge in a rapidly changing environment
- We need a grounded, not ivory tower, style of leadership

What needs to be done?

- Gay and lesbian issues need to be worked on more formally – is this seen as an 'add on'?
- Paperwork on 'marital status' needs changing
- Assessment tools and single assessment process should tackle this.
- Information sharing protocols between different sections of health/social services and voluntary sector need to be developed.
- Use open questions about personal circumstances
- Review paperwork locally
- We need to maintain the voluntary sector's expertise on sexuality – more formalised advocacy for users and policy advice to public sector
- Flexibility of residential care placements
- More specialist community development workers to enable access to services
- A system of user involvement across all planning activity – there is currently no system for LGB involvement
- Develop a 'health activist' approach to develop health promotion/healthy living advice and to feed back to services
- Use staff training as a catalyst for change

- Apply person centred planning principles
- Experiential training and awareness raising for staff
- Use PCT protected learning time arrangements to access doctors/practice staff

Education/Training

This is vital.

Systems and Information

Policy and Guidance

Leadership

- empowering ourselves
- empowering communities
- empowering organisations

Workshop 2: What's in a name – Words can Hurt, Words can Heal

Facilitated by Margaret Collins and Rebecca Ballard.

Communication in context

Negative & positive descriptions

Being Comfortable & respecting others' position

Isolation & Secrecy

Facilitating openness but not everyone wants to come out

Sensitivity

Men → negative

Women → invisible

Workshop Notes

Words used to describe gay men predominantly negative. There are far fewer words used to describe lesbians – in the main, lesbians are more “invisible” than gay men.

Important to recognize that some older people may be more used to, and therefore more comfortable, describing their sexuality with words that we may perceive as negative.

Balance to be struck between words that are acceptable to the older gay man or lesbian and those that we are comfortable using.

Very many older gay men and lesbians have lived their lives extremely privately. A supportive environment will allow those who wish to be open about their sexuality to be so. Some will still not wish to share this information. Service providers need to be sensitive to both sides.

Workshop 3: Carers and Caring

Facilitated by Roger Newman.

Patient Confidentiality – individual and lesbians and gay men need to have Power of Attorney for partners.

Action Points

- Specify benefits of coming out to professionals (i.e. their own coming out).
- Discuss issues raised with colleagues.
- Allow carers that I am working with to have time to tell me about themselves.
- Need more information.
- Look at assessment tools to ensure tick boxes are there to ensure recognition – central government issue.
- Take back to older people's partnership boards.
- Training at ground level needed.
- Feed assessment forms through Berkshire Older Lesbian and Gay Forum for comment.
- Need to prove we know about LGBT issues.
- Services need to appear to be open and try to be so.
- Look at all services.
- Mention sexual orientation in anti-discrimination literature.
- Raise LGBT care issues through care manager.
- Issues raised with care staff groups.
- Look at Policy and Procedure.
- Assessment not one-off.

Choose carefully when to ask about sexuality.

Workshop 4: Residential Care

Facilitated by Elizabeth Price

Important Issues: dignity, choice, privacy, equity, independence.

National Care Standards Commission → legal support.

Residential/Nursing Care → independent Living, sheltered housing

Guidelines/Training need for:

- Providers/staff

about:

- Language/Assumptions
- Attitudes of other residents
- Prejudice
- Strategies/Processes for dealing with incidences of abuse/harassment

Training – NB NVQ covers diversity but **not** sexuality

Separation vs Integration – LGB homes?, “specialist” services – some older lesbians and gay men will want separate accommodation others will not – it’s a matter of choice.

Older lesbians and gay men more likely to be in residential care, due to lack of family/community support

Advocacy service for individuals needed.

Workshop 5: Housing

Facilitated by Cindy Creasy

Right to tenancy succession NO BUT...

Homelessness

Harassment?

Sheltered accommodation

Together or apart

CHECK LOCALLY

Notes

Tenancy succession for same-sex partners may not exist in agreements *per se* but an appeal taken to the Court of Appeal held that same-sex partners had the same rights as heterosexual partners in this area. Legislation on the horizon for the registration of same-sex partnerships. Consultation document explicitly suggested tenancy succession rights would be given to registered partnerships.

Because of attitudes and harassment by some fellow residents, and in some cases family, older lesbians and gay men more likely to face homelessness than their heterosexual counterparts.

Look for good practice and share it.