Fair for All Equality and Diversity: 
Handbook for NHS Scotland

Health Topic Briefings and Personal Stories
Acknowledgement and Thanks

The resources contained in this document are the result of a collaborative effort across the six equalities strands of age, disability, ethnic minority, gender, religion or belief and sexual orientation. Individuals and organisations came together to offer their time, energy, skills and experience to contribute to the development of these resources. As part of the continuous improvement process for health services, the Health Topic Briefings and Personal Stories intend to support the development, implementation and assessment of NHS Scotland policies and practices that are inclusive of equality and diversity.

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Most importantly, the people who took the time to share their stories are the reason health services are provided. Their experiences provide opportunities for the development of empathy for and greater understanding of the need to provide sensitive and responsive health services. While not all of the stories are presented here, each of the people who participated in an interview contributed to the preparation of these resources. Though the names are not real, the stories are. Thank you Divya, Sharon, Lara, Mary, Amy, Catherine, Caroline, Velda, Briony, Joyce, Scott, Ted, Karina, Marc, Paula, Patty, Ellen, Mr. Choi, Lucy, Ilene, Fiona, Richard, Neelam and Simon.

Finally, to all the critical readers and friends for this project, you know who you are: Thank you.
# Health Topic Briefings and Personal Stories

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overview of the Resources</td>
<td>5</td>
</tr>
<tr>
<td>Personal Stories</td>
<td>13</td>
</tr>
<tr>
<td>Health Topic Briefings</td>
<td>65</td>
</tr>
</tbody>
</table>
Overview of the Resources

In the sick room, ten cents’ worth of human understanding equals ten dollars’ worth of medical science.

Martin H. Fischer (1879 – 1962) German-born physician and author

The nurse just took time to talk to me. She spoke to me, not to the people with me, and told me what was happening, what was wrong. She told me what was to happen to me, every step. I felt safe, I went home knowing that I was going to get better.

Catherine, NHS Scotland service user

Introduction

The patient focus and public involvement agenda within The Scottish Executive Health Department and NHS Scotland is encouraging a system-wide change in the culture of health care to improve the health of all people in Scotland. It aims to address health inequalities more effectively through the involvement of individuals and their communities in the design and delivery of health care services and by putting patients at the heart of health care. Practitioners and providers are asked to recognise the relationships between the people who access health care and the systems that serve them, and to recognise and value the differences in each person and across different groups.

The process of Equalities Impact Assessment (EQIA) highlights where services can be improved to better meet the needs of diverse individuals. It is a strategic approach to support the practical implementation of services that take into account issues of equality and diversity. EQIA is about looking at areas of historical inequity in communities and changing policies and practices to make them equitable. For individuals across the six equalities strands – age, disability, gender, race and ethnicity, religion or belief and sexual orientation – it is about addressing issues of prejudice and discrimination that happen at the individual and institutional levels and across practices and policies.
Overview of the Resources

Culture change that takes into account issues of institutional discrimination and health inequalities is a collective responsibility. When we focus on the diverse needs of individuals, we recognise their common desire for appropriate access, services and treatment. Fairness in access and treatment is not about making all services the same, but about making them appropriate for the service user. Said another way, equality in health care services is not about delivering services the same way to everyone, it’s about delivering the same services in different ways. Patient focused health services recognise that individuals are complex beings with multiple identities and roles, and consequently different needs, throughout their lives. Getting services ‘right’ across the six equalities strands will get services right for everyone.

Institutional discrimination is a systematic and more covert form of discrimination carried out, often unintentionally, by social systems and institutions. It is a reflection of a system or institution and not a charge against the individuals working within those institutions, who themselves may not be prejudiced. The health care system is also vulnerable to institutional discrimination, and it may have an impact on patient care, treatment or access to services.

In addition, institutional discrimination contributes to disadvantaged groups being over-represented among the unemployed, low income groups and those in inferior housing, and all of these factors are associated with ill health.

Many of these groups also worry about negative responses or treatment from health service staff or other patients. Such concerns can contribute to increased social exclusion and further impact on life choices and stress related illness.

Increasing the competence of organisations and equipping staff with the knowledge, skills and attitudes to consider the needs of the individual in everything they do will contribute to a more patient focused health service. A patient focused health care system allows for more efficient and effective allocation of resources. Targeted and appropriate services are a long term approach to improving access, treatment options and healthy outcomes for all.
The culture change is underway as good practices are developed and as patient focus is implemented through training, communication, consultation and responsiveness. Fair for All provide a framework for further learning and change in five key areas:

- understanding the demographic profile of the population,
- energising the organisation around the issues of equality and diversity,
- addressing issues of access and service delivery,
- integrating equality and diversity into human resources strategies, and
- working with organisations and local communities in the development of health policies and practices.

Working together with this shared framework and focus, the Fair for All Wider Challenge ensures that the work is not carried out in isolation and efforts are not diluted. Continuous improvement allows providers to critically review and ask questions of the practices and the systems for patient care, both within their own health board and across the health boards of Scotland.

These resources look at research and available literature in areas of existing practice across equalities groups and listen to diverse people describe their experiences of health services. These resources can help providers address what is working and what is not working at the strategic policy and practical levels in the whole of the Scottish health care system.

The Personal Stories together with the Health Topics Briefings may provide insights into ways in which personal practices may be improved; they may help NHS Scotland staff and health service providers assess how well they have completed an EQIA; or they may help in the design of policies and services sensitive to the needs of individuals and groups. Both of these Resources are intended to highlight areas for change and continuous improvement in responding to the needs of diverse people. Ultimately, these Resources taken together provide insights into how people’s experiences based on who they are have an impact on their health.
Personal Stories Overview

The stories, scenes and observations that create the Personal Stories Resource are the actual experiences of people who have accessed services provided by NHS Scotland. This resource is an exploration of the thoughts and feelings of individuals as they recount their interaction with health care systems and providers in Scotland. It provides their perspectives and describes the impacts, interpretations and conclusions they have drawn across a wide range of interactions. This collection of stories includes positive experiences that offer simple, straightforward examples of how health services can be accessed by everyone.

This resource is not an attempt to describe what happens ‘most of the time’ or ‘some of the time’ or to provide generalisations about typical services or experiences, and it does not assign value or weight to the experiences. The people who have shared their stories are not presented as representative of the population of Scotland, or of health service users, or of those who would identify with any particular equalities strand.

Rather, these stories provide examples of actual experiences that may cause service providers to ask questions of their own and others’ practices. The presentation of these experiences is an attempt to shed light on and to increase understanding of the needs of an increasingly diverse population in Scotland. Ultimately, the resource is seen as a tool to be used for continuous improvement of NHS Scotland services.

The people who shared their stories and described their perspectives may identify themselves as belonging to more than one of the equalities strands. Their stories are not sorted neatly into categories by equalities strands, health topics or even geography. Their experiences highlight the complex nature of identity and, therefore, the need for services that are sensitive to the complex needs of individuals.

Some of these stories stand alone, and the voice of the story teller is all that you will hear. Some are told through an interpreter, and some are prompted by an interviewer.
The stories are clustered together based on elements of common experiences, and all are presented in a birth to death order.

These stories are aligned with the issues described in the Health Topics Briefings, as follows:

<table>
<thead>
<tr>
<th>Health Topic Issues</th>
<th>Personal Story</th>
</tr>
</thead>
<tbody>
<tr>
<td>Targeting services appropriately</td>
<td>Lara, Joyce</td>
</tr>
<tr>
<td>Health messages for different audiences</td>
<td>Scott, Marc</td>
</tr>
<tr>
<td>Accessible services</td>
<td>Sharon</td>
</tr>
<tr>
<td>Sensitivity to people’s beliefs, cultural preferences and needs</td>
<td>Divya, Mary, Briony, Mr. Choi, Neelam</td>
</tr>
<tr>
<td>Consulting with people</td>
<td>Amy, Catherine, Ilene</td>
</tr>
<tr>
<td>People’s experiences of discrimination, bullying and poverty</td>
<td>Paula and Patty, Richard, Simon</td>
</tr>
<tr>
<td>Sensitive and skilled staff</td>
<td>Fiona, Lucy</td>
</tr>
</tbody>
</table>

These stories offer patients’ perspectives. The experiences highlight their needs, and, in some cases, the incidences of individual and institutional discrimination they face. Though some of these people experienced dissatisfaction with the service they received, their stories were not grievances toward NHS Scotland. When asked why they wanted to share their stories, many replied that this was an opportunity to be heard, to be involved in their health care and to make a positive difference for service users.

The learning for NHS staff comes from reflecting on ways in which the experiences shared here may resemble what staff members encounter on a daily basis and remembering that their own sensitivity to patients’ experiences contributes to the culture throughout the whole of NHS Scotland.
Overview of the Resources

Health Topics Briefings Overview

The Health Topics Briefings Resource identifies what might be important in assessing equalities and diversity issues for health services policies and practices. It is a reference for a wide range of people within NHS Scotland who have an interest in the continuous improvement of practice or who have the responsibility for Equalities Impact Assessments (EQIA).

This resource is built upon the idea that these research briefings will be a catalyst for NHS Scotland service providers to ask meaningful questions about health services practices within a changing environment. Looking at concerns across the equalities strands will raise questions about the relationships between the people who access health care and the systems, services and practitioners who serve them.

These health topic briefings have been constructed around the six equalities strands, the three health priorities of the Scottish Executive, and sexual and reproductive health.

<table>
<thead>
<tr>
<th>Equality Strands</th>
<th>Health Priorities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Cancer</td>
</tr>
<tr>
<td>Disability</td>
<td>Coronary Heart Disease, Stroke</td>
</tr>
<tr>
<td>Ethnic Minorities</td>
<td>Mental Health</td>
</tr>
<tr>
<td>Gender</td>
<td>Sexual and Reproductive Health</td>
</tr>
<tr>
<td>Religion or Belief</td>
<td></td>
</tr>
<tr>
<td>Sexual Orientation</td>
<td></td>
</tr>
</tbody>
</table>

The relationships between health services, the equalities strands and the health priorities are not linear or simply constructed, and we find themes common to many or all of the areas as well as key issues discussed in only one. Because people
have identities that overlap equalities strands, and different needs related to each, it is important not to assign a single, standard identity to anyone. It is important to understand how the groups that they belong to are part of what has an impact on their experiences and health.

Each briefing suggests resources that include information about what to look for and where to find out more. They provide reference to available research and literature, and include references to organisations that include, involve and/or campaign for the different groups affected by the equalities issues.

This resource presents research that addresses how belonging to one or more of the equalities groups may directly impact or influence the protective factors, access issues or treatment options related to the health topics. This information will not be all that is needed to complete an EQIA. However, together with the Personal Stories Resource, these briefings will encourage thinking about what is needed and what questions should be asked in order to complete the assessment. The parallel presentation of the briefings will highlight issues of access and equal opportunities that cut across all equalities groups, which will then create efficiencies for completing the EQIA.

The health topic briefings highlight issues that are common for all:

- Targeting services most appropriately;
- Developing health messages for different audiences;
- Making services practically accessible to all;
- Sensitivity to people’s beliefs, cultural preferences and needs;
- Consulting with people;
- Taking into account people’s experiences of individual and group discrimination, bullying and poverty;
- Ensuring that all staff are sensitive to differences and inequalities and know how to take these into account in service delivery.
Overview of the Resources

These briefings become part of the process of sharing information for eliminating health inequalities across Scotland. However, recognising that good practice is already happening, another important part of the process is sharing the completed EQIA documents as models of existing and emerging practices across the NHS Scotland. These completed assessments will be posted on-line for each Health Board and can be referred to as part of the continuous improvement process.

The existing research and literature predominantly describes the national picture of health and health services, and Health Boards will need to apply the information within their local population. These briefings are not a guide to standards for clinical care and treatment and are not intended to be an epidemiological resource about health priorities in relation to the equalities strands. The information presented here is also a snapshot of what is available. In some areas it becomes apparent the information that is not available, highlighting the need for more research on the connections between who an individual is and how that impacts their health.

As this resource is used and referenced from within the sector, gaps in the research will be identified and additional contributions might be necessary: this is not an exhaustive or static checklist. New information will become available as the health care environment changes and other research is completed. With a view to continuous improvement in health care services for all, this cross-strand resource will need to ‘live’ in the changing environment and serve as encouragement for ongoing research about the connections between diverse people and appropriate health services.
Personal Stories: Contents

Preface

The Beginning of Life

“It meant a lot to me to be allowed to have this special ceremony in the hospital.”
Divya

Parent and Child

“Everyone who has his condition is completely different. It changes over time and is never predictable. One size doesn’t fit all and these people are excluded from every service system.”
Sharon

“There was complete specialist care for my son. But for me, our GP and the Health Visitor have been very important and very helpful.”
Lara

“The immigrants from other countries don’t automatically know these things. Even if they can speak English, they won’t know what to do and what supplies they need to have ‘in the house.’”
Mary
Caring about Culture

Briony herself went around to all of the local surgeries to see if she could register with one, but none would take them on.

Briony

“It will really help to have the hand held records. We worked hard to get that, so it will be good when it finally happens.”

Joyce

“Their attitude, the way they talked to me. No sympathy for my son. I can tell.”

Paula and Patty

Translating the Ordinary

He thinks they are less competent here, but maybe that has to do with the language barrier.

Scott

“They were also so respectful, treating everyone with such respect.”

Marc

He and his wife laugh at his luck to always get someone who speaks Chinese.

Mr Choi
“I can remember going to see a consultant who just told me that I’d be dead by the time I was sixteen – because I had both epilepsy and a learning disability. That stuck with me, that did. I’ve never forgotten him saying that to me – when I was just young. And you know, I invited that consultant to my 40th birthday party last year – and he came!”

Amy

“Then a nurse came in. She had a big loud voice and she shouted at me to come into the other room. All of a sudden, I felt up-tight and scared.”

Catherine

“He got an appointment with a Psychiatrist for me and I told him I wanted to see a female. I know he specifically asked for me to get an appointment with a woman.”

Caroline

“You can imagine my horror and embarrassment when the receptionist called in a loud voice across the room ‘Mr Adams, you can go in to see doctor now.’”

Lucy
Getting Better

“Now if this is happening to me, and I feel pretty capable of dealing with difficult situations, what must it be like for those who feel less capable or less confident?”
Ilene

“But my experience with this kind of care is what helped me focus on fighting the cancer and not anything else.”
Fiona

“It’s like I’m sitting on a comfortable, three-legged stool – it’s balanced, safe, and secure.”
Richard

Comfort in the End

However, the arrival of his two daughters from India made him feel a great deal better. The hospital allowed them to visit at any hour.
Neelam

“The man retired to his room – and never came out again. He stayed in his room for two years, until he died.”
Simon
Personal Stories: Preface

Across Scotland, in local surgeries and hospitals, by appointment and through casualty, for acute and chronic care, thousands of people use NHS Scotland on a daily basis. Each of these people has an experience that impacts on their next visit.

The personal stories presented here are a collection of these experiences and a sharing of reflections, thoughts and feelings, mediated only by the story tellers’ perceptions and interpretations. Through their own voices, service users describe to health service professionals how practices, personal style, and location of services can have an impact on them. Their experiences present evidence of potential, perceived or actual barriers and circumstances which enabled or inhibited their access to services.

This resource is an attempt to develop understanding of and empathy for the need to provide sensitive and responsive services.

The stories presented here – from the young woman whose religious wishes were met for her prematurely-born son, to the older gay man who was told not to display affection towards his partner because it would upset those around him – are indicative of a wide range of patient experiences. This resource highlights the complexity of issues to be addressed when designing and delivering health services to a population with diverse needs.

This resource contains a retelling of experiences by those who have accessed or are accessing health services. Many people struggle to access health services because they are fearful, lack confidence or need additional support. The ways in which these service users describe their experiences highlight ways in which access to services may be improved for us all.

The people who shared these stories live in different areas of Scotland, though most lived in the central belt at the time of their sharing. Some of the accounts are of their
Personal experiences and some are about experiences as a carer. Their stories include both recent and past experiences. By their own account, these interactions impact the ways in which they interpret and access services now.

Some of the experiences can be classified as positive and some negative, however none of the conversations were taken as opportunities to air grievances or to complain about NHS Scotland. The people who shared these perspectives indicated a desire to have a voice, sometimes in appreciation for sensitive treatment and appropriate services and sometimes to highlight ways in which access and treatment can be better.

These stories and situations were collected through interviews and conversations, sometimes one-to-one and sometimes in a group. At times, interpreters were involved. Each participant had the opportunity to review the story as it was written to make sure it reflected their experience. The names of the narrators have been changed to conceal their identity and some location and other information has been omitted to respect the privacy of others involved in their experience.

Throughout their life, people interact with health services through child birth and childhood illnesses, ordinary illness and disease, disability and ageing. This collection of stories reflects a sequence of experiences that begins at birth and continues until death.

Each story can be read with a desire for understanding. From service users’ perspectives, services are experienced through the development of policy, the design of service systems, and the individual attention of an empathetic GP. All of these are points of contact with people, and their experiences have an impact on their health.

(return to contents)
The first contact anyone has with the health service is at birth. Though some births may be routine and others more complicated, each mother’s experience is unique to her. Sensitivity to the seemingly unrelated needs of individuals when medical complications arise makes a lasting impression.

**Divya’s Story:**

“My son was delivered by emergency caesarean section eight weeks early. He was tiny at just 2 pounds 10 ounces, and was looked after in the Special Care Unit. He was in the incubator and fed by a tube. The staff were excellent, not just professionally but in the way they reassured me, my husband and my parents with their positive stories and attitudes throughout my son’s stay in the unit. He was in the Special Care Unit for six weeks.

“During that time, two special events remain clear in my mind.

“The first was when straight after delivery the nurse briefly held my son out to me before he was quickly taken to special care. I remember kissing his tiny nose tip and seeing him blinking.

“The second was when we held a ceremony called the sixth (Chhathi in Gujrati). It is a ceremony when special prayers are held, and a white blank sheet of paper and a quill and a pot of red ink are kept in the room for the goddess of Destiny to visit and bless the baby with good fortune and a bright future.

“It meant a lot to me to be allowed to have this special ceremony in the hospital. I was anxious about my son, my hormones were all over, I had pre eclampsia and was worried about my little daughter who was 2 years old at the time. The care and support from the dedicated staff during this difficult time was wonderful.”
The next group of stories are told by mothers and are mostly about their children. They tell of special circumstances that arise in the care of children with special needs, and the ways in which their child’s health needs have an impact on their own health care needs. One mother talks about cultural differences that go beyond language differences, and highlights assumptions that are made that have an impact on care for children.

**Sharon’s Story:**

“For me, I need written materials in decent-sized print. Even when I have asked for it, I don’t get large print on prescriptions, labels on bottles, letters or appointment cards. I can’t even get large print for the complaints procedures either!

“I have been ill since 1967 and developed all sorts of ‘complications’ with heart, kidneys and lots more, and was declared blind in 1972. So, OK, I’m registered blind and need big print. That’s the short version of the story.

“But, it is for my son that I really want to tell the story. Everyone who has his condition is completely different. It changes over time and is never predictable. One size doesn’t fit all and these people are excluded from every service system.”

Sharon’s son, Malcolm, has Asperger Syndrome, an Autism Spectrum Disorder. He is now 23, and was diagnosed with Aspergers when he was 18. Concerns about Malcolm were first raised by Sharon when he was about 2, but they were not heard by the GP. Later, when Malcom was about 8 the assistant principal at his school recommended a referral to child psychiatry for Malcolm’s behavioural problems. For years, Malcolm was seen by psychiatrists and Sharon dealt with his difficulties without a diagnosis or any additional help.
“Nobody tells you what’s going on. They just complain when he is ‘bad’. I wanted to know what was wrong and what could be done, but it turned out that there were no assessment notes in his files. I felt like I needed to be very careful with the NHS folk and not complain too much because I could get in trouble with court orders and all that ‘stuff’ about child welfare concerns. Really, all I wanted was help for Malcolm.

“He attended a daily assessment centre for three to four months and I think there should have been a proper diagnosis then. One of the nurses there said ‘Malcolm is very angry.’ I said I knew that, but why? Still no diagnosis.

“I got involved in a public involvement project with the NHS and had use of the HEBS library as a volunteer. That was when I got really great help from some people in the NHS. It was brilliant! Someone was listening to me! It was the librarians and not the doctors, but I was getting help and information.”

The NHS librarians helped Sharon to look up different possibilities related to Malcolm’s behaviour and came up with four, based on what Sharon had observed: Aspergers Syndrome, Depression, ADHD / ADD and Bi-polar Disorder. “I gave the descriptions to Malcolm and asked him to look at them, then we talked. By this time, he was 18, an adult, and needed to be involved in this.” He decided it was probably Aspergers and Depression, and they then took the information and their thoughts to their GP.

“Of course I went with him, I had to. These guys [people with Aspergers] do their own thing and wouldn’t think of going to a doctor on their own. They don’t ‘do’ talking to people, or filling out forms, or keeping appointments. I had to drive it or nothing would have been done.”

Malcolm finally got his diagnosis after Sharon went to the Scottish Society for Autism who gave her the name of a person who could do a diagnostic assessment. The diagnosis made a huge difference to Malcolm. “He was relieved, we both were, to know there was a real reason that had made life so hard.”
“Malcolm needed to go to the hospital to have his wisdom teeth taken out and some other work done. He was in so much pain with abscesses and his mouth was a mess. It was Malcolm’s idea to have his vaccinations updated and blood drawn at the same time. I think that’s brilliant, don’t you? They could do what they needed to do with the needles while he was asleep! And it was his idea.

“The main thing with Malcolm is that someone address his worries. I don’t think they understand that his fears will stop him from functioning. Someone should realise that through all of his health care needs, Aspergers rules because it affects the whole of his life – he won’t be able to get out of bed!”

“When we got the diagnosis of Aspergers, it gave us the confidence to tackle things, and we got a paper with signatures in his files so that I was allowed to go into the doctor or the dentist with him. Malcolm won’t do any of this for himself. Sometimes he can explain what is going on and sometimes he can’t. If I don’t go in to prompt, he won’t get what he needs. So if I am able to be there it helps him. He needs someone else in with him so he can get his fears addressed. He’s an adult and needs to make his own decisions, but he won’t get the help he needs if he doesn’t have help to make his needs known.

“All the stress of trying to keep Malcolm ‘safe’ makes my health support needs more expensive. And, of course, my very biggest worry is who will look out for him after I die?”
Lara’s Story:

Lara’s son, Eric, who is now 13 was diagnosed with Cerebral Palsy at the age of 2. Lara started a voluntary organisation years ago based on her experience as a parent of a child with disabilities. She had learned so much about accessing all of the services she and her child needed, and she wanted to share the knowledge with other parents who would be looking for it. “They have enough to deal with without having to try and find information too,” she says.

Lara says her organisation’s staff interact well with NHS Scotland and the ‘professionals’ are encouraged to refer parents to her organisation, and they do. “NHS can ask ‘Is the carer getting support?’ and then refer them on to us. We pick up where the pros can’t, but would like to, because of time constraints and all that. We provide things like information, details of support groups, and most importantly, emotional support, so that parents can gain some control and feel empowered in their situation. It helps that we are parents too, so we genuinely know how they feel. Sometimes all they need to do is weep, and we have the time to let them do that too.

“When Eric was diagnosed it was a terrible shock. He was about 18 months old and still not walking, so I went to the Health Visitors and said ‘I’m concerned.’ They all told me he was fine, don’t worry, and dismissed me as an ‘over-anxious parent.’ On about the third visit, the Health Visitor said that if I was that worried, then let’s get him checked out. She then referred me to a paediatrician.

“The paediatrician did his assessments and then came to me and said ‘I’m sorry, your son has moderate cerebral palsy.’ In that one conversation, I went from an overanxious mother to a mother with a child with moderate CP – a big difference! You know, even if you are overanxious, someone should be able to provide you with good information and some reassurance to calm you down. The truth is that I can be overanxious, but it doesn’t help me to be told that.
“The Health Visitor was wonderful and very supportive. The day I was seeing the paediatrician, she left about 8 messages on my answer phone asking if I was ok. I wasn’t ok: I was angry with the doctors, I didn’t want Eric to have CP, I wanted everything to be different. She visited me regularly over the next several weeks and let me know what I was feeling was normal. She was there for me, and that made a big difference. There were plenty of people who were there for my son now—for assessments and physiotherapy and occupational therapy and nursery assistance. But she was there for me and for my husband too. She wanted to know how the whole family was doing.

“As I learned more about what Eric needed, I was overwhelmed. Each of the different therapies he needed took 20 minutes at a time, 3 times a day. I felt that if I did all of the therapies each therapist wanted me to do, I wouldn’t ever do anything else—and I was still working at the time too! One of the therapists said ‘Hang on, you’ve got to be a mum too. Don’t worry if you miss a session, don’t try to do it all.’ As a parent, I felt very guilty and that I needed to do everything for Eric. I needed to follow all the rules and do what all the professionals said. But his physiotherapist was so helpful in telling me to NOT try to do it all.

“Eric then became part of the Child Development Centre for under 5’s with special needs. It includes therapists, play groups and a combined clinic where everyone comes together in one room with the paediatrician and the parent and a facilitator. It is the best invention to come from the NHS. They produce a single report that presents an action plan for the child every six months. I got a copy and everyone who dealt with Eric got a copy so everyone knew what was going on with him. I was also able to give a photocopy of the report to people outside the health service, like his childminder, so they could see what was going on. We were all together in his care and it was very supportive of Eric and very supportive of me because I was the one who cared for him and it stopped me having to repeat the same information to each therapist that he saw.
“The children are supposed to be discharged when they go to school at 5 years old. When that happens, it feels like it all gets chucked back at the parent to coordinate the care. But at that time, I was really struggling. I didn’t have the confidence or the strength, in fact I was in crisis and they knew it. They let him keep coming to the Centre until just before he turned 7. I then looked around and said ‘We’re not meant to be here any more, are we?’ The answer was, ‘actually, no.’ I said ‘OK. I can do this now,’ and they said ‘Marvellous, then off you go.’ It was really, really helpful.

“In my experience, when you have a special needs child, the GP is entirely peripheral to the process. Any health worries about him were part of the therapists’ conversation and visits with the paediatricians every 6 months. There was complete specialist care for my son.

“But for me, our GP and the Health Visitor have been very important and very helpful.

“I suffered from two pretty bad episodes of depression. One was post-natal depression, and another was about six months after Eric was diagnosed. I had a hellish experience in hospital with Eric’s birth—three days of labour and an epidural and all that. When I came home from hospital, I saw lots of different people because my regular Health Visitor was on holiday. She showed up on my doorstep on her first visit and she took the time to listen to me tell my story. After I finished, she said, ‘Oh my! That sounds dreadful!’ It was so good to hear someone acknowledge that it was reasonable to think I had a horrible time and to feel bad.

“She was the one who recognised I had post-natal depression. About six weeks after Eric was born I phoned her up and was crying and terribly upset. I said ‘Eric is never going to learn how to smile.’ She asked, ‘Why do you think that?’ and I said ‘Because he’s never seen his mother smile!’

“She didn’t dismiss me or tell me I was being silly. What she did was ask me to fill out a questionnaire, and from that it was clear that I was depressed. It was so helpful for her to just take the extra five minutes and ask me what I was on about. She wasn’t
reacting or dismissing, but listening and wondering why. I think sometimes health care professionals get bothered when we are upset. But of course we are upset— it’s our child and our situation. Don’t tell us not to get upset! It would be helpful if they could deal with us at the emotional as well as the practical level.

“Now, I can go and talk with my GP with more confidence. I still suffer from depression at times and can go in and tell him when I need something. He trusts me, and allows me to be the expert on me. He recognises that I have knowledge too. It is important for the health care professionals to be partners about my son’s needs and also about my own.”
Mary’s Story:

Mary was born in Bahrain and raised in India. She attended university in the United States and then went back to India for work. She has some experience working in health care settings in India. Her father was a paramedic and nurse and her mother was a nurse. Her background and interest in health care and health services is part of why she wanted to share her story. She says that maybe her direct and indirect experience can help to shed light on what happens for the Asian immigrants in a rural Scottish community.

“Translation will always be an issue for Asian people. Many families come here for the husbands to work, and the women are at home to take care of the children. Their husbands can speak English, but the wives might not. So the wives know what is going on for their children, but the husbands are the ones who talk to the doctors and nurses. And if the husbands aren’t around, then the wives don’t know what to do.

“Because of NHS requirements, the translators have to come from the city and so they aren’t local. If it takes time for the translators to arrive, then the child may be in distress and that makes the mother distressed.

“One woman had four children under 16 and needed help in the night when she got really ill. She was told she had to go to hospital to get help, so what could she do? Her husband was working in the city and had not returned home yet. She could not speak English fluently and therefore knew no neighbours or friends nearby to watch the children. She had to leave the children alone so she could go and get help for herself.

“My daughter had a high fever when she was 7 years old (last year). She was so ill and she had soiled her trousers and was very upset. I had to stay with my daughter and clean her up in the shower because she needed her mother, so my husband had to call NHS 24. They said she would need to go to hospital to see the doctor, but
they kept asking questions so my husband was on the phone for 15 minutes. He had to keep coming to me to get the answers because he didn’t know. I knew, but couldn’t talk with them because I had to stay with my child. All we needed was the appointment with the doctor and we could answer the questions when we got to the hospital. But they wanted us to answer the questions on the phone.

“It seems to me that they could have asked if I could talk on the phone right then, or if I needed to be with my daughter and if it was critical or not. Then I could have been able to get her cleaned up and either talk with the doctor myself or get her to the doctor without further delay. I am fluent in English, but many of the mothers are not. They rely on their husbands, but the husbands are not involved as much with their children and can’t answer the questions.

“It is important to understand that Asian people don’t go to the doctor unless they are seriously ill. In India, they have to pay to go to the doctor, so they wait until it is critical. They just don’t have a culture of accessing health care. They don’t know how to register with the doctors and dentists and I encourage and help them to do that. I sometimes help Asian women because I can translate for them, or sometimes my husband and I give them rides to the doctor or hospital.

“Two weeks ago, I was around to a woman’s house and noticed her 9-year old daughter’s jaw and lips were very swollen. I asked her if she had been to the doctor, and she said ‘Oh no, she will be alright.’ Two days later I saw the woman and her daughter was home from school. Again, I asked had she been in to see the doctor? She hadn’t yet, but her child was in pain with what looked like an open wound on her chin. So I encouraged her to talk to a doctor. The woman called and struggled to speak in English to the GP receptionist and said she needed an appointment and was told ‘There are no appointments today. Not unless the child is really critical.’
“I was there so I offered to speak on her behalf to the GP receptionist. I told the receptionist that the daughter needed to see the doctor, that it was critical. My husband and I gave them a ride to the GP’s office. The doctor she saw was very young and didn’t say anything to the woman or the girl. He didn’t let the girl know what he was doing, and as he treated the wound and drained the infection he didn’t comfort her with the pain.

“After he treated the wound, he didn’t give the mother any instructions on hygiene and how to care for the wound properly. I asked ‘Can you give her some bandages or ointment?’ and he said, ‘No, just use what you have in the house.’ He made a big assumption that the mother would know about basic hygiene and wound care. These families are living in dense and not always clean conditions. The immigrants from other countries don’t automatically know these things. Even if they can speak English, they won’t know what to do and what supplies they need to have ‘in the house.’ The doctor should have just told her what to do. I went with the woman to the chemist and helped her find the things she would need to take care of her daughter’s wound.

“It is more than just translation services that are needed. The doctors and nurses make assumptions about what people know and they could just talk with them and find out. They could let people know about the cause of the problems or the course of the treatment. People who speak English and also know about health care aren’t always around to help. Sometimes people just don’t know what to do, and they need to be informed.”

(return to contents)
Proceeding through life, people may have health needs arising from the ordinary occurrences like seasonal illnesses and occasional injury, or extraordinary occurrences like casualty and disease. Language and/or culture differences may create unknown obstacles to accessible services. For people from minority and ethnic communities, what may be routine and ordinary policy and procedure may be interpreted as the result of prejudice or racism.

The experience of racism by service users may be overt or subtle, intentional or unintentional, and the perception of an experience as racism is real for the service user. These experiences occur through overheard comments and interpretations of attitude or behaviour, and may be the result of an accumulation of events. This group of stories are about ways in which service users encounter and interpret the intent of health care providers. In some cases, the individuals’ interpretations are evidence of on-going and institutional racism and prejudice.

**Briony’s Story:**

Briony is part of the travelling people’s community and has lived in Scotland all her life. Her experiences of NHS Scotland are ‘pretty good,’ but there some things that she just wants to tell someone about.

Briony and her family have lived on the caravan site for 8 of the last 10 years. They were there for three years, moved into a flat for two years, and then have been back at the site for the last five years. When they moved into the flat it was mostly due to her health problems, but they also felt like maybe they would want a change and settle in for a little while. But after a couple of years, they wanted to move back to the caravan site because that is who they are and it was where they wanted to be.

She tells about how it was for her and her family to register with the local surgery when they first moved to the caravan site. There was not just one doctor’s surgery
for everyone on the site, so all of the people living there were allocated to different surgeries. Briony herself went around to all of the local surgeries to see if she could register with one, but none would take them on. “They kept telling me ‘you aren’t from this area, so we can’t take you.’” She had to wait to get a letter from NHS telling her which surgery they had been allocated to and where to go before she could register.

When they moved into the flat, they didn’t have any problem registering with a surgery, and everyone was really nice to her. When asked why she thought there were no problems with getting registered and why they were nice, she says, “Oh, I couldn’t speak for them. But it could be because I was in a flat at the time and not from the caravan site. This surgery was one of the ones I went around to when we were first at the caravan site and they said they wouldn’t take us on. But when we were in the flat, they would.

“I’m still with that surgery now, even though we’ve moved back to the site. And they are still nice.”

Because Briony is diabetic, she has to go to the diabetes consultant at the hospital every six months to check her blood, weight and medicines. It’s the same consultant who takes care of her for the epilepsy too. So she has quite a lot of contact with the NHS and she feels that her contact is mostly good. They listen to her and she feels like she can ask questions and get the care and information she needs.

Briony wants to share one other experience about when her second daughter was born. She was born nine weeks premature and was in hospital for quite a while. Because the pregnancy and child birth was hard on her as well, Briony stayed in hospital and was close to her daughter. She was expressing her breast milk one day when the midwife said to her “Your kind of people abandon babies.” Briony said “What? What do you mean?” The midwife said, “You know what I mean,” and walked away. Briony said she heard her talking to someone else about the time a baby was abandoned years ago. “It happened in 1972! That was the year I was born, but here
she was saying this to me now. I was so tired and weak, that I didn’t realise until later that she had no right to say that. It had nothing to do with me.

“I would just like for the NHS to consider us and our needs. We are just the same as anybody else, no different. We have the same needs as anyone, and they should class us all the same.”
Joyce’s Story:

Joyce has been involved in a working group looking at the promotion of hand held medical records for Gypsy/Travellers. Though the use of hand held records has been accepted and approved, it is not implemented across Scotland and Joyce and her family are looking forward to being able to carry their own medical records with them when they travel.

“For some of the older people,” Joyce explains, “it is easier to come back to their own surgery to get medicine or to see the GP than to try and get help wherever they are when they need help. They might have to wait for too long or they would have to register in a new surgery every time they need medicine, and it isn’t worth it if they are only going to be there for three weeks. It will really help to have the hand held records. We worked hard to get that, so it will be good when it finally happens. That won’t only benefit us, but a lot of people—disabled, pregnant women, and people who can’t read and fill out forms.”

Joyce has five children, four of whom still live with her and her husband at home. They now live in a house, and have lived in the house for the last two years. They travel during the summer for her husband’s work. She says she has no bother with the doctors where she lives because she is registered with the surgery. “But when I’m travelling, it’s a problem. Now, some of the surgeries will take us if we need something, but that’s only in the last wee while. Sometimes, you just can’t get past the receptionist. When that happens, you just leave and don’t bother with the GP. Usually, folk will go to casualty if they need something when they are travelling. It’s easier that way.”

Joyce was registered with the same doctor for 18 years, but when they moved into the house they had to register with a new surgery. “They saw from my files that I used to live at the caravan site, so they knew I was a traveller. But it was no problem at all to get registered.”
She says most of her experiences with health services have been ok, and she seems to find a way to get what they need. However, she had an experience that has stuck with her now for a long time. “When I gave birth to my first son, I heard the doctor say ‘I don’t think that child should go home to a caravan.’ I knew he was thinking my boy wouldn’t be ok with me and my husband. The sister who was running the ward came over and said to the doctor ‘You don’t need to worry about that boy. He is going to a loving home.’ She had seen my husband and me together and she knew we were going to take good care of him.”
Paula and Patty are part of a local women’s group dedicated to providing support and help for any women of any age. The group helps women by providing advice and information on housing, benefits, children’s advocacy, and health, along with translation services and anything else they might need. The group is supported by the local authority.

Paula has been in the UK for about 10 years, moving from Pakistan to Sheffield, then to London, and she now lives in Scotland. She says that people here call her names, asking if she is a terrorist and making fun of her and her family. She begins telling me about her experiences with NHS by telling of the time her son was only one year old and she took him to the local surgery when he burned his hand. “They wouldn’t see him, they wouldn’t help him. He was hurt and was crying and they said I wasn’t registered, so, no, they would not see him. Not even the nurse would provide me any advice for what I could do to ease his pain. It was racist.”

What led you to believe that it was racist?

“I could tell,” she responds. “Their attitude, the way they talked to me. No sympathy for my son. I can tell.”

Did you then register with them?

“No, I wouldn’t do that. Not with their attitude.”

Paula recounts other experiences with NHS services:

“I had a miscarriage some time ago. I went to hospital and was bleeding and cramping and they made me wait, with no care and no sympathy. They checked me out and sent me home with nothing, but my membranes were coming out and I was losing the baby. They didn’t care.”
“Then when I had my son, I still had three months to go but went into hospital because my waters broke. The doctor checked me out and said I was ok, nothing was going to happen because it was not time yet. In the middle of the night, a doctor came in and said that I had a bad infection and they might have to choose between me and the baby. What kind of thing is that to say to someone in the middle of the night?

“The next morning I started contractions and the nurse saw that I was contracting every five minutes so called the doctor in. The doctor did not even check me out except on the outside and said ‘Look how high the baby is. You still have three months. You are fine!’ And then she left. The midwife came in and checked me out. She said, ‘You are bleeding and you are going to have the baby.’ I then gave birth to my son. He weighed 1 pound and 10 ounces. That doctor could have helped me, but she didn’t. She didn’t care about me. She was racist, because she was Indian and I am Pakistani. I looked for that doctor, but she was never around me after that. I never saw that Indian doctor again.

“I asked them what we could do for my son, and they told me we will just have to pray. Now he is eight years old and he is almost as tall as me. When he was five years old, I took a picture in to hospital so they could put it up on the wall to give other women encouragement.”

What would you have wanted from the doctor?

“I would have wanted her to come to me and comfort me. She could ask me to rest and then check me again later. But no, she said I was fine, that I was not having the baby for three months and I should go home. She never even touched me, except when she touched my tummy and said that the baby was too high. She didn’t even care about me.”

Paula then translates for Patty, though they don’t speak the same language: Paula
speaks Hindi and Patty speaks Bengali. Paula explains that the language is similar and they both use some English words so they can understand each other. Patty moved to the UK from Bangladesh about three years ago. Her husband’s work is what brought them here.

Before moving to Scotland, Patty and her husband lived in London for a while. There, they did not have any trouble getting an appointment for the baby or for her, but now they can’t get emergency appointments. One time, her baby was awake all night with an earache and high fever and Patty made an appointment. She doesn’t have a car and had to travel to the surgery by bus. It was raining and the bus was late, so they were late for the appointment. The receptionist said sorry, the doctor can’t see you now. Patty pleaded with the woman, and said please just help her child. But she said they would have to come back tomorrow during open surgery because the appointment time had passed.

Patty says that the doctor is very nice, and the health visitor is very nice, but the receptionist is very rude.

When she went in to open surgery, there were 10 people already there. After she got there, 10 more people arrived. They were all seen and Patty still had not been called in. She had been there for three hours, and she started crying. Another receptionist came over and asked her name and checked the files. She told Patty that her name was not on the list and her file was not there. The woman asked Patty who she had checked in with. She pointed out who had checked her in and the woman went over and spoke with her. She put Patty’s name on the list and pulled out her file. She then came back and told Patty it might have been because the other woman was new. Patty wondered how could it be that the receptionist had all those other people on the list and all those other files pulled out, but forgot to do that for her?

She says that the receptionists might be rude because she is black, not white like them. She says she has problems with the people at reception because her English is not 100%. She tries, and sometimes they do understand her and she understands
them. When she goes to the doctor with an appointment, there is a note in her file that she needs interpreter. Sometimes her husband goes with her because his English is better, and sometimes Paula goes with her. But, sometimes she has to manage by herself. It is possible, she explains, that there are misunderstandings because of the difference in language. She feels more secure when the interpreter is there. She doesn’t think they need to be rude when they don’t understand. She is not there to waste their time. She needs advice and help for herself or her children. That is why she is there. She could provide reassurance, and she could be kind, but she chooses to be rude.

Paula adds, with Patty nodding in agreement, “Racism is all through this neighbourhood, at the shops and the bus stops and on the streets. We automatically think we get treated bad because of racism. What else could it be?”
Sometimes, experiences can only be interpreted relative to other experiences. People make sense of an experience by comparison to what they know from previous experiences. The comparisons cause them to draw conclusions about standards of care and the competence of providers. Addressing their need for information will help people understand their experiences in the current context and is a necessary part of the sense-making process.

These next stories are told by or through translators by men and woman from Poland and from China. They highlight the need for language translation services, not only so that they understand what is happening but so they feel their needs are understood. While interpretation services are readily available for those who need them, translation is not a straightforward issue when it comes to interpreting standards of care, religious and dietary needs, and cultural norms. Sometimes language is not all that needs to be translated.

**Scott’s Story:**

Scott speaks some English and understands some, but feels more comfortable with Polish. He had been in Scotland for a short while, and then came back with his wife and two children. After they had been here for a week or two, they had to go to the doctor for their younger child who was very ill. It was easy because he had already registered with the surgery. They were all very nice, though he laughs and says maybe the doctor was scared because he saw the whole family came in together. Because his wife does not speak any English, Scott says he would speak to the doctor. He speaks some English and he had prepared himself with what to say in advance. The doctor understood him and he understood the doctor. They were able to get the help for their son they needed and were referred on to a consultant who could take care of his son’s infection and bronchitis.

Scott thinks there is a difference between the competence of the doctors here than in Poland. He thinks they are less competent here, but maybe that has to do with the language barrier. In Poland, when they went to the doctor for their children they
would always get lots of information about what was wrong and what was needed, the medication that was needed and what they could expect. But here, they were just seen and given some medication, but not much information or conversation. He thinks it could have been the doctor, or it could be the language difference. When he goes in to the doctor with an interpreter, it is better. But he still feels like he doesn’t get enough information about what is going on and what is needed.

Around the Christmas holiday, their son was really sick again with a high fever. They suspected the same thing was wrong [bronchitis] because it was something their son seems to have a problem with. They phoned NHS 24. It didn’t seem to mean anything to the people on the phone that the child was having difficulty breathing and was shaking—he was merely prescribed paracetemol for the high temperature.

Two days later they went into the GP because he wasn’t getting any better. The GP prescribed antibiotics and it helped. He and his wife thought the situation was very serious, but didn’t think the doctor treated it as serious. Scott could not think of a reason why it wasn’t treated as a serious situation. He asked several times about his son’s difficulty breathing and the doctor only said it was because of the high fever.

The difference in the way of treatment in Poland is that when the child had difficulty breathing, he got something to help him right away. It was the same child, so they were able to draw some real comparisons. With NHS 24, he wasn’t confident with his English and asked for an interpreter. The conversation took 20 minutes and although it took a long time he was quite pleased with the outcome. The doctor was asking questions about whether the child was sitting or lying down and the doctor understood that would have an impact on his breathing.

Scott’s son is now under the care of consultants for asthma and sees the consultant every 6 months. They are very sensitive now to his needs and take time as he tries to communicate. He would like more information about the different ways of treatment. The information they do receive is limited, and what they get is not translated into Polish. He goes home from the doctor and checks things out on the internet to find out what medications he is receiving and what should be done.


Marc opens the conversation by saying that when they were moving to the UK, they had been warned by everyone that the health care was really bad. People who had been in Scotland for some time had told them it was difficult to find consultants and hard to register with a GP. “We didn’t have any problems, but people coming here now hear it is a problem.”

Marc then shares his experiences. “It was very easy to register here and my experience has been very positive with the NHS. In Poland, I had some stomach problems and was referred to a consultant. He was polite but not respectful at all. After the exam he really scared me by saying for me to arrange a colonoscopy and I thought it would be horrible. I didn’t want to arrange the test, so I just forgot about it.

“I moved here and began to be bothered by it again. I went to the GP here and the examination I received from the GP was more specialised than what I got from the specialist consultant in Poland. She told me what I needed to fix my problem and then she just arranged it. I got a letter telling me when it was and where I was to go, so I just went. It ended up being a very simple procedure and it took care of everything. I also still needed a colonoscopy, but again I got a letter saying when it was and where to go so I just went.

“Throughout all of this, we were treated very well and everyone was very nice. They would explain to me what was going on and would draw pictures of what was happening so I knew what my situation was. They were also so respectful, treating everyone with such respect. When I was in hospital, the man in the bed next to me had false teeth and they would draw the privacy curtains when he took out his teeth! We are not used to curtains in Polish hospital – you might use the toilet without a curtain, never mind taking out false teeth! We value privacy and respect very much, and we always receive that here.

“After the tests, people talked to us and explained what was going on. They found out what was wrong and then they provided the treatment.

“I have seen many examples of good care and respect. It is easy to notice when you have experienced something else.”
Mr. Choi’s Story:

Mr. Choi presents a hospital record with 23 dates of admission to different hospitals in Scotland since 1968. Reasons for admission include mostly heart and stomach troubles, with one admission for a knee replacement operation. Mr. Choi and his wife have been in the UK for 42 years, and in Scotland for most of them. His wife is alongside him throughout the interview and chimes in frequently.

Through all of his experiences of hospital services in Scotland – and one in London – he feels very positive about how he was treated and is very satisfied with his care. He has been through a lot of stages of change in health care services and has seen positive progress over the last 20 years.

But, he is quick to add that he feels he is lucky. The time he was admitted to hospital when he had a stroke, he was treated by a Chinese doctor and nurse. He didn’t ask for that, but it just happened. So he didn’t have any problems based on the fact he doesn’t speak English because the doctor spoke Chinese!

Another time, he had to go to hospital to get injections for back problems to ease the pain. He was also lucky because there was a nurse there who speaks Cantonese to help him. He and his wife laugh at his luck to always get someone who speaks Chinese.

In one rehab hospital, the staff used picture cards to help them communicate what was happening and what he needed when an interpreter was not around. It was not available in other hospitals, but it was helpful that time.

On other occasions, he believes that he received better treatment because he accepted the treatment he got. He had no expectation for anything, and requested very little, so he got good treatment. He says that elderly people can sometimes be fussy, and if you have expectations then problems will come.
Fair for All Equality and Diversity:  
Handbook for NHS Scotland

Personal Stories

Mr. Choi says that most hospitals have someone come around to visit patients to take care of their religious needs, a chaplain or something. Most Chinese are Buddhist and no people from the Buddhist religion come around to visit. If there is a language barrier, then the patient can’t ask for a Buddhist, so the person who comes around is Christian. He says the patients could maybe go into the chapel, but it is Christian too. Some Chinese are Christian, but they don’t understand the services so they just don’t go.

He continues by saying that the diet is difficult too. Chinese people eat a lot of rice, noodles and soup. The diet they serve in hospital is too much of a change from their normal diet. He believes it could hold recovery back because the different diet may be upsetting. Most families take food they cook at home in to the patient so they have food that is good for them. The hospital nurses now ask him if there is any food he doesn’t want so they can order different food from a Chinese takeaway shop. That is a good change, he says, but of course the food from the takeaway shop isn’t as healthy so his family would still bring in food from home.

Elderly people also like lukewarm water and not cold. But the nurses always bring in a jug of cold, ice water. The patients don’t like to ask for other water because they don’t want to be a bother.

Mr. Choi says that his son or an interpreter comes with him and his wife to the GP and they are very satisfied with the services they receive. His GP is very understanding, and part of that is because he needs to see the GP often so he gets to build a relationship with the doctor and the surgery nurses. It helps him to not worry, because the doctor knows him and takes good care of him. He knows from other Chinese people that they see different doctors all the time and so they can’t build a good relationship with one doctor. He is lucky, because he sees the same doctor every time.

Mr. Choi and his wife hope it helps to say how they have been lucky so that it can be positive for other Chinese people too.

(return to contents)
Valuing the Individual

Not all disabilities are visible. Sensitive and responsive services take into account the special needs and support requirements for those whose disabilities are not readily apparent and may be complex.

People with disabilities, like most people, want to be treated as individuals, to be listened to and to be told, in straightforward terms, what is wrong and what is about to happen. Sometimes they want and need the support of another person as they interact with their health care provider, without feeling like they suddenly are not in the room. Sometimes, for a person with a learning disability, that might take a little longer. But those extra few minutes means that they can leave the clinic or hospital knowing what is wrong, what they have to do to get better, and reassured that they can go back for help if they need it.

This next group of stories are from three women with learning disabilities. They share how their interaction with a provider made a lasting impression on their future access to health care.

Amy’s Story

Amy is a confident woman with a great sense of fun and lots to say. “I have epilepsy and diabetes,” Amy begins, “and when I was a young child, I can remember going to see a consultant who just told me that I’d be dead by the time I was sixteen – because I had both epilepsy and a learning disability. That stuck with me, that did. I’ve never forgotten him saying that to me – when I was just young. And you know, I invited that consultant to my 40th birthday party last year – and he came!” she laughs.

Amy is keen to talk about her general practitioner, whom she likes and trusts very much. When asked why, she replies “He listens to me, is interested in what I’m doing, and what I have to say. He tells me all the time that I’m the expert when it comes to learning disabilities, not him. And I know he pays attention to what I have to say
– and if he’s not sure about something, he’ll tell me and then ask somebody else. He’s interested in learning more about learning disabilities – he’s done training and wants to know more. See, when I walk into the room, he gets up out of his chair, he says hello, takes my hand. He talks to me about my activities.

“I feel very comfortable with him – I know I can ask him questions about what’s wrong with me. That way, I can make sure that when I leave the surgery, I know what I’ve to do, how I’ve to take my medicine.”

Amy’s experience of an out-of-hours service was not so positive. Two years ago, she was suffering from very severe migraines and sought help during the night. She went to a clinic where she was seen by an emergency doctor. Amy remembers, “He didn’t even look at my files – and they’re huge – on the computer. He didn’t ask any questions, didn’t tell me anything about what might be wrong with me. It was me that asked about any side effects when he gave me some pills, seeing as how I was taking other medication for my epilepsy and diabetes. But he just told me not to worry, just to take the tablets.” Amy returned home and did as she was told. “But when I woke up the next morning, I was really, really ill because of the mixture of drugs. I had to phone the doctor again – and I finished up in hospital. I had Bell’s Palsy and I think that doctor was in a lot of trouble. I’ll never use the out-of-hours service again! I’ll just wait till I can go to my own practice and see my own doctor.”
Catherine’s Story

Having listened quietly to Amy’s stories, Catherine begins to tell about her experiences. She is a quiet, gentle person and speaks cautiously and carefully.

“Just a wee while ago, I had a very sore leg. I had to go to see a specialist at a clinic somewhere. My friends came with me and said they’d help me, but I was really nervous, scared. I didn’t know what was going to happen.

“Well, the woman at the desk didn’t speak to me, didn’t look at me. She just told my friends that we should go and sit down and wait. We had to go and sit in a really noisy room, it was busy and folk were rushing around. I didn’t like it and felt scared. I just got more and more keyed up, the longer I waited, because I didn’t know what was going to happen to me.

“Then a nurse came in. She had a big loud voice and she shouted at me to come into the other room. All of a sudden, I felt up-tight and scared. I just got the feeling that I used to get inside when I was young. People used to shout at me all the time, telling me I was bad. I didn’t understand why I should feel like that, like I’d done something bad. I was frightened – I felt like something bad was going to happen to me.

“I think maybe she spoke to everybody like that, but I didn’t realise that then. I just felt scared and I didn’t know why. I wanted to cry.”

“The nurse just didn’t seem to see that I was nervous. She was in a hurry – she gave me some medication and told me what to do, in that same loud, booming voice. But I was so upset and scared, I just couldn’t take it in. I didn’t know what was wrong and I didn’t understand what I was to do.
Personal Stories

“If I don’t understand the information, I can’t ask the right questions, can I?” So she left the clinic still not knowing what was wrong and not properly understanding what she had to do to get better.

Catherine then recalled another visit to a hospital when she had felt much better. “The nurse just took time to talk to me. She spoke to me, not to the people with me, and told me what was happening, what was wrong. She told me what was to happen to me, every step. I felt safe, I went home knowing that I was going to get better.”
Caroline’s Story:

Caroline has asked Ellen, her carer to be with her during the interview so she feels more comfortable. She has just shared the pictures of her recent wedding with Ellen and she is all smiles and good cheer. As she begins to recount her experience, her demeanour changes and she is very serious and hesitant. Though she wants to tell her story, she is hesitant and replies mostly after prompting.

Why did you want to tell us your story, Caroline?

“Well it is about something that happened to me in the past. When I was 11, I was raped. After the court case was all over, I guess it was about two years later, I wasn’t doing too good and went with mum to see the GP. We were up north at the time. He got an appointment with a Psychiatrist for me and I told him I wanted to see a female. I know he specifically asked for me to get an appointment with a woman.

“But, when I got there, my appointment was with a man. I said ok anyway, I’ll give it a go. But it didn’t work.”

How did it not work?

“I felt like he was making it out to be my fault. He was blaming me for what happened. I was 11 and a half or 12 at the time! And this was after all that happened in the courts too. My mum explained to him what happened, and then I explained what happened. When I was explaining what the person did to me, I thought he [the counsellor] was sticking up for him. I remember him saying that maybe the guy didn’t mean to do what he did. My mum helped me because we were meant to be in there for an hour but after about 30 minutes, I wanted to get out of there and Mum felt the same so we left.

“We went back to the GP and he was shocked. He phoned up the hospital and complained. First about the counsellor being a man and then about the way we were treated. About a week later, we got a letter from the GP saying he was sorry for how it happened. But that was all we heard. I could have tried again, but the whole thing put me off. It was ok, I
guess, while I was living with my mum. I just decided it would be ok.”

Caroline is now 28, so what does she think and how does she feel now?

“One of the new doctors here is a woman and she is nice. But sometimes I have to see a different doctor at different times and sometimes they understand me and sometimes they don’t.”

Do any of the doctors know about her history or her experiences with counselling. “No, they don’t know. I don’t say.”

What about visits with the doctor for female things?

“I feel uncomfortable with that. When I was living with Mum, she always went with me and that was ok. But now, I go alone.”

Ellen, Caroline’s carer, adds, “The NHS provides support for visual impairment and hearing impairment, but not learning disability. They expect you to bring in your own support. The learning difficulty strategy provides support for people, but if the support is used to go to the doctor one week, they can’t do anything else that week. It eats into the time they might need from the support worker for other things.”

For Caroline and her husband, they have a support worker come into their home two times a week. Their support is to help with any letters they don’t understand or for shopping or paying bills and things like that. Would she [your support worker] go with Caroline to the doctor?

“I’m not sure.”

Would you want her to?

She is quiet for a minute and then says, “That would be good.”
Being Sensitive

Sometimes, a case that is not typical can highlight areas where sensitivity is needed for typical cases. Every person has a desire to feel known as an individual and valued for who they are. Understanding that there are things both known and unknown about people who access health services contributes to more sensitive and responsive services.

Lucy’s Story

It is seven and half years since Lucy changed gender including gender reassignment surgery from male to female. She talks about her experiences over the past seven and a half years. Lucy has not enjoyed good health and has been troubled by a hiatus hernia and gastritis.

“About three years after my operation, I had to go to see my doctor urgently. I had terrible stomach pains, and didn’t know what was wrong. So I made an appointment and went along to the surgery. I sat down in the waiting room along with everyone else and waited.

“You can imagine my horror and embarrassment when the receptionist called in a loud voice across the room ‘Mr Adams, you can go in to see doctor now.’ Everyone turned to stare at me. I didn’t know what to do. Why on earth had she done that? Why had she not called me by my proper name, my current name – Lucy Adams?

“After I had seen the doctor, I asked the receptionist why my file had not been changed. In that practice, they have one colour for men, and another for women. I noticed that mine was still a man’s file, with a little white label on it. Why had they not changed it to a woman’s file? The receptionist told me that they couldn’t change it until I had a new passport. At that time, I didn’t even have a passport. I decided to speak to the consultant who had carried out the operation four and a half years ago. He told me that this was nonsense – he got in touch with my GP’s surgery and
instructed them to change my file immediately. They did, but I didn't go back to the surgery for a very long time.”

Lucy continues to be ‘singled out’ as transgender, even when it is of no significance. She says, “I couldn’t help but notice on my file at the haematology clinic the referral letter from my doctor, in which he referred to me as ‘a transgender person’. Why had he done that? What was the purpose? There was absolutely no need.

“On the other hand,” Lucy continues, “my dentist is fantastic. He has never said a word, always treats me with courtesy, as an individual. And the staff at the practice are all like that. They have never raised an eyebrow, and have completely accepted that I am now a woman.

“It can be difficult sometimes, always answering people’s questions. Sometimes I feel like I always have to be the expert, even when I am looking for help. And it takes a huge leap of faith to actually go and ask for help.”

(return to contents)
Receiving treatment for chronic illness or potentially terminal disease increases the frequency and changes the nature of contact with health care services. For those who require residential or long-term care, their experiences have an impact on their ability to attend to their recovery. Their systems of support and information help them over the long term and improve their chances for healthy living.

The first two of this group of stories are from two women who have been receiving treatment for different types of cancer. One has been battling breast cancer and one leukaemia. Their experiences and perspectives are very different, yet it is difficult not to make comparisons or look for explanations and connections between the two. The possibilities to explain the differences are many: the type of cancer, the nature of their treatment, the place where they were treated, the personality and identity of each patient, and so forth. There is no attempt to draw conclusions, and these stories speak to the continuum of care that is possible.

The next two stories in this group are from a woman and a man with very different illnesses and very different experiences. However, their stories validate the need for people to feel a sense of participation and involvement in the decisions that affect their health and have different needs for systems of support that will also have an impact. These stories also describe the ways in which disclosure (or not) may have an impact on services and treatment.

Accessing health care services is not something people would normally choose. It is far better to not need health care services, especially treatment for potentially terminal or life-long illnesses. The ways in which individuals experience health care and access health services, and the ways in which supports are recognised and valued, may have an impact on their treatment and ultimately their health.
Ilene’s Story:

“I think I wanted to share my story because I want to talk about how I was treated as an individual, as a woman. I have worked in partnerships and multi-agency settings for a very long time and I am used to working with strategic bodies. I consider myself confident to deal with a lot of different and difficult situations, but it is different as a patient. It feels very different. There are so many ways you become vulnerable. You become the last person to know what is going on in your own body.

“I wanted to know what was happening and what my options were. I think very little information leads to over-anxiety rather than preventing it. But I feel that they tell you the very least you need to know and only if you ask for it. Then they respond with an attitude that says ‘these patients are too demanding!’ I struggled to get the information I wanted without being labelled as ‘that stroppy cow’. An oncologist actually once told me, ‘You better not ask too many questions, dear. It will just worry you.’ Now if this is happening to me, and I feel pretty capable of dealing with difficult situations, what must it be like for those who feel less capable or less confident?

“I guess one of the most significant experiences had to do with my pathology report. After the report was in, the doctor said ‘We aren’t sure what to do with you.’ That was a bit unsettling, to say the least, and I wanted to get more information, so I asked to see the pathology report. I was told by a nurse that I needed to get permission to see it but if I did I wouldn’t be able to understand it anyway.

“But I did what she said was needed and hand-delivered a letter requesting a copy of the report to the office and then followed-up after two weeks of not hearing anything. The person I talked to said they had no recollection of receiving the letter. I sent my request in again and was then told I needed to send a letter to the legal department—something about patient confidentiality and release of information—and may be charged up to £50 for copies of the report. And this was MY pathology report!
“Other things happened along the way that I can’t even remember, but it was just one thing after another. It seemed like they were putting up lots of different barriers hoping that it would lead to stopping me from asking.

“Finally, I was told I could have sight of the report the next time I was in for treatment and they sent me a letter to that effect. But when I went in, I was told I couldn’t see the report because they hadn’t seen the letter. The woman in the office was acting very irritated and I was feeling like ‘that problem patient’. At this point, I had been in the ward waiting for my treatment from 9.30 to just before 5.00 and I was just tired. My friend who is a social worker was with me and put on her best social worker hat and got a bit stroppy with the nurse. She eventually gave the file to my friend. And I think it was because I had reached the end of my tether and I was crying by this time. After all that about confidentiality and release of patient information and they don’t even hand the file to me!”

Ilene recalls that when she was in the hospital for her surgery, her room was next to the nursing station and she could hear details about every patient at the 12-hour shift handover. “I was waiting for them to talk about me so I could learn what was going on with my case! So much for patient confidentiality!

“The way they acted almost put me off of ever wanting to ask for anything again!”

It didn’t put her off, but it did change her behaviour. She goes on to describe how she would make lists of things she wanted to ask before her appointments and then memorise it so she wasn’t seen with a long list of questions that would make her seem demanding. “I felt like I needed to be careful to not come across as a troublesome patient. I was always self-monitoring so as to not put them off of providing me services. I really thought it might affect my treatment.”

Ilene is careful to mention at this point, “It wasn’t intentional foul treatment. I believe the staff are too busy with too many patients and some of their behaviour has to do with their work load. The professional boundaries are also part of the culture, and the
good nurses would be able to cut across boundaries of professional territorialism and provide me the information and care I was after.

“The nurses were really nice. After all, cancer treatment is a tortuous business and you really want people to be nice. But ultimately it is something about the organisational culture within the health service not being patient centred. It is changing to some extent – the younger doctors always introduce themselves by name. That must be part of the changing nature of their training. But there is a long way to go in terms of adequate information being given to you with reasonable explanations about their thinking and decision making processes.

“I would go in for treatment or consultation and I often wouldn’t see the same nurse or doctor. Some of the doctors would come in to see me and they obviously had not set eyes on my file before that minute. There were times when it really had an assembly line feel to it, like they didn’t treat cases as an individual case. It seemed like the huge throughput at the centre was all about target-driven goals and not patient care.

“But the most important thing for me was information. I’m sure that might not be as important to everyone, but I wanted to hear the options and explanations and feel I actually had a choice in my care. I have to say that in the years that I have been part of the breast cancer hospital regime, practically all the useful information I have received has been from other women in similar situations who have passed on their own experiences. Some have been from hospitals in London and elsewhere where the doctor patient relationship may be better developed, or they have been from voluntary organisations. But surely we should be able to rely on our own treatment centre to give us some information—or at the very least signpost us to where to get it.

“What about the women who are unsure of where to go for the information not given out at hospital? With all of the experts around, the routines and schedules and the culture and the systems, I felt like the people at the centre were saying ‘You are only the patient, so you are the least important person here.’”
Fiona’s Story:

“I want to talk about really good service and share good news too. There is a perception out there that health services can’t be good. But they really can be, and I want to talk about that.

“I was really ill for three months and just thought I couldn’t shake some bug. I was reluctant to go the doctor, but I soon didn’t have a choice. On the 2nd of January I had a high temperature again and couldn’t walk. I was jaundiced and losing control of my bladder. It had become an emergency and I called NHS 24. I needed to go into hospital, and when I got there I was absolutely terrified. I was in a reception ward which was chaotic and noisy and full of really distressed people. And I was really, really sick.

“So they did lots of tests and said they were investigating an immune disorder. There wasn’t any mention of leukaemia, but then they said they were going to transfer me to the haematology isolation unit to do a bone marrow test and I was terrified. I had heard about it being awful and painful and I also guessed why they would be doing it. But once in the unit they spoke directly to me and explained it all. The doctor sat on the edge of my bed and told me what to expect and asked me if I had any questions. I could recognise what he was doing because I do it in my work all the time—he was helping me understand. Immediately, I felt like I had a say in things and they cared. The nurse was there too and asked me ‘Do you have a phobia about needles? This is what you can expect.’ And then she explained the procedure to me step-by-step.

“Then, they very practically asked me if I would classify my partner as my next of kin. There was no question about ‘who is your next of kin?’ but recognition that my partner was there with me. I was completely reassured that there would be no problem including Ruth in what was happening to me.”

Fiona explains that the consultants she worked with were two male doctors and one female. “All of them were very good and very supportive, but I was still given
the choice about who I could deal with. They would ask me, ‘Would you feel more comfortable with Dr. C? Are you ok talking with Dr. M?’ It was all about what would make me feel comfortable.

“They were very informative about when things were going to happen and what was going to happen. My life was completely changed by this disease, and they said to me, ‘There are lots of things for you to consider, lots of things for you and your partner to consider.’ There were mortality issues, treatment issues and support issues, and in all of it, they included me and they included my partner.”

Why were you treated this way, was there something you could point to that could explain their approach?

“I don’t know. I thought at first it may have to do with my job and the fact that I’m comfortable being assertive with professionals. But I saw them with other patients who were less confident and others who were pretty rude, and they were all treated the same way, with kindness, calm and respect.”

It is worth noting that Fiona’s leukaemia diagnosis meant that she was going to be in for not only long term treatment and intervention, but also residential treatment. She needed to be in isolation and away from any thing that she could ‘catch’ because the course of chemo therapy would make her extremely vulnerable. In addition, she would be very, very ill from the treatment.

Fiona spent a total of 46 weeks in hospital that year. She says she lost her identity, she lost her hair; she was swollen, not fit, and couldn’t work.

“I felt utterly lost and didn’t even recognise myself when I looked in the mirror. It was soul-destroying.”

Fiona’s doctors approached her treatment holistically and with sensitivity to what she needed. One time when she was really feeling sick and very unhappy, she couldn’t
stop herself from crying and sobbing. The nurse asked, ‘What can I do to make you feel better? Would you like us to set up an air mattress here so that Ruth can come and spend the night? Would that make you feel better?’ Ultimately, Fiona decided not to have her partner there that night, but it calmed her to know that it would have been an option.

When she started down the long road of treatment for her disease, Fiona was prepared for a very bad experience. Instead, her experience was very good and it allowed her to focus on getting better.

There was one incident during her time in hospital that encapsulated her experience. She described it as follows:

“There was a woman on the ward who was always speaking loudly and in a derogatory way to the nurses and other patients. Her daughter would come around for visits and was a pretty nasty character too. One day I was feeling particularly sick, throwing up and trying to sleep and just really ill. She walked by my bed and said to her mum in a loud enough voice ‘Where’s the f****** dyke today? Her f****** girlfriend is always around.’

“They might have thought I was sleeping, but I just couldn’t let that go. So even though I could barely sit up, I said ‘Do you have something to say to me?’ because I guess I’m always ready for the challenge. They didn’t respond. Then Ruth called and said she was on her way up to me and I told her to wait, because I knew the daughter would be gone soon. I didn’t want to deal with the atmosphere any more. Ruth wanted to come up, but I convinced her to wait.

“But then the nurse came in and asked me where Ruth was and I just started crying. I couldn’t say and couldn’t calm myself and so the nurse bundled me up in a wheelchair and took me in the other room and asked me to tell her what was going on. I told her what had happened and she got angry. She brought the doctor in to me and I told him what had happened too. I also told him I had told Ruth to wait downstairs.
He said that was enough. ‘I will deal with this for two reasons. One, you are too sick. Two, this is my responsibility to deal with. We do not tolerate discrimination of any kind on this ward, and that includes homophobia.’

“The doctor left me for a bit and I only heard what happened later. Apparently, he told the woman and her daughter that there was a zero tolerance policy on his ward for any kind of mistreatment or prejudice and everyone had enough of their rudeness. He told them that the mother would be moved off his ward if it happened again. The woman apparently said, ‘you can’t do that’, and he said ‘oh, yes I can.’

“After the doctor had talked with the woman, he came back in and told me: ‘Ruth is an important part of your recovery programme. We don’t have enough people who have loving and caring partners like you do. I will not have her or you ever feeling uncomfortable here.’ I just cried and said thank you, thank you. And he said ‘Don’t thank me for treating you like a human being.’

“Sometimes when you are vulnerable and tired, you need someone to fight your battles for you. I feel as if the team not only stood behind me, sometimes when I needed it they stood in front of me.

“You can see why I wanted to share my story. I really believe the way I was treated and the acknowledgement of who I am was exceptional—and I know it shouldn’t be. I know others who don’t have a story like mine. But my experience with this kind of care is what helped me focus on fighting the cancer and not anything else. I can’t say enough about how grateful I am to these people for how they treated me.”
Richard’s Story

Richard is a young gay man who has lived with epilepsy, diabetes, and occasional depression for many years. Although he has worked in a range of jobs over the years, at present he is unable to work because he is never stable enough for long enough, due to his various complex conditions. However, he is in very good spirits and leads a busy life.

Richard says that for many years he just didn’t tell doctors he was gay. “You just never know what the reaction might be. And they have so much control over your life, especially when you are ill and vulnerable. So for a long time, I just didn’t say anything. I assumed that it might be in records somewhere and pretended to be single. But I couldn’t trust anyone.”

However, there came a point when Richard was particularly up-tight, nervous, and impatient. He explained “My partner had come to the doctor’s surgery with me. I was upset and needed his support. I was nearly at breaking-point. My doctor began our discussion by asking why Donald was there. I just flew off the handle and shouted back at him ‘I’m gay – he’s my partner!’ The doctor was completely taken aback – and immediately asked me if I knew about safe sex! What on earth did that have to do with anything? He completely ignored the reason for my visit and went on and on about safe sex. I never went back to see that doctor.”

Some years later, Richard was referred to a psycho-neurology unit in relation to his epilepsy. “I was referred to this wonderful consultant. He listens to me, he’s patient, lets me speak. He knows I’m gay, and that’s perfectly OK. My epilepsy is still a problem, but I can deal with it so much better when I am calm, and when I know that my doctor is listening to me, answering my questions.

“The problem is that people just jump to immediate conclusions as soon as they find out that you’re gay. If you’re upset or anxious, they put it down to the fact that you’re an up-tight, screaming, drama queen. They miss the individual altogether.”
Richard stressed the value of having an advocate: “I don’t know what I’d have done without Donald. He’s my informal advocate – he comes with me to visit the doctor, or the consultant. Often on these occasions, I’m depressed and I can’t ask the right questions. I’m not listening to what he or she tells me. I’d be lost on my own.

“Right now, I’m fine. It’s like I’m sitting on a comfortable, three-legged stool – it’s balanced, safe, and secure. And the ‘legs’ are Donald, my GP, and my consultant. Take one away, and I might fall over – but right now, I’m fine.”

(return to contents)
End of life situations are never easy. Though after long illnesses, release from pain and suffering may seem a relief, death and the dying process are difficult. Attending to the needs and desires of people as individuals, and including their families and significant others, eases the process for all.

**Neelam’s Story:**

Neelam is a widow who, until 2004, was caring for her father-in-law, Ravi. Ravi was in his late 90s and suffered from chronic asthma. He had lived in Scotland for much of his life but spoke no English. Finally, having coped reasonably well at home, he was taken to hospital after a particularly bad bout of asthma.

In hospital, Ravi found himself in a ward where no-one spoke his native language. He could not communicate with anyone in the hospital when Neelam was not there. This was difficult for both Ravi and for the hospital staff who suggested to Neelam that when she was not at the hospital, she must stay at home, or at least keep in contact with the hospital in case they ever needed her to come and act as interpreter. He complained to Neelam that no-one ever spoke to him, he received very little attention. At the time, Neelam herself led a busy life, with a part-time job and other family commitments. The situation became very stressful for both Ravi and Neelam.

There was another problem – not only could Ravi not talk to anyone in the hospital, he could not eat the hospital food as, in keeping with his religion, he was a vegetarian and required a special diet. There was no choice but for Neelam to prepare food for him and bring it to the hospital every day.

For a man of 98, in a place where no-one spoke his language and where he could not eat the food that was provided for him, this was a very difficult and depressing situation. However, the arrival of his two daughters from India made him feel a great deal better. The hospital allowed them to visit at any hour. In time, Ravi began to improve and finally was able to return home.
Several weeks later, Ravi suffered another severe bout of asthma and was re-admitted to hospital. This time, however, the hospital would not allow his daughters to visit at any time other than during visiting hours. This decision was very upsetting for Ravi, his daughters, and Neelam. Once again, Ravi found himself in a situation where he was unable to speak to anyone and could only find out what was happening when his daughters or daughter-in-law were present. He returned home after 6 weeks, having insisted that he could not stay in hospital any longer. Ravi died several weeks later.

Simon’s Story

Simon is keen to share what he has seen having worked as a nurse in the NHS in both England and Scotland for many, many years. Simon is gay and he has concerns about the ways in which gay people are often ignored. In particular, he is worried about the care of older gay people who may spend the last years of their life in a residential or nursing home.

“No-one ever thinks that an older person might be gay. But though many have lived with a partner for much of their life, nobody knows that. Identifying older gay people is very difficult – when you reach a certain age, you are regarded as a-sexual. At that point, people always say ‘what does it matter?’ But gay people have different lives, different family formations. Their own family may have disowned them, disappeared, or be dead. They have their own gay family. They will approach these family members the way they always have – the way other families greet each other.

“I once saw an old man in a residential home, whose partner came to visit him. The man approached his friend, who was sitting in a chair in the sitting room. They simply embraced each other affectionately, as anyone would. But the nurse was horrified and scolded the resident. She told him that he couldn’t behave like that in the home. People would be upset. The man retired to his room – and never came out again. He stayed in his room for two years, until he died.”
Fair for All Equality and Diversity: Handbook for NHS Scotland

Health Topic Briefings
Dealing with Equalities and Difference
DEALING WITH EQUALITY AND DIFFERENCE

Principles

It is reasonable to recognise that individuals share a common desire to be treated with respect and appropriate attention to their individual needs. No one should be denied opportunities or fair treatment because of their race or ethnicity, disability, gender, sexual orientation, age or religion or belief. This principle underpins all the work of the Scottish Executive and the statutory bodies and agencies directed by it, including the NHS in Scotland.

Groups that can have distinct wishes, needs and experiences include:

- women, men and transgender people
- people from minority ethnic groups
- people with differing religions or beliefs
- older people, young people and children
- LGB (lesbian, gay, bisexual) people
- people with a wide range of physical or mental difficulties that can be classified as disabilities.

Individuals often belong to more than one group and have an identity that reflects this.

All of the wishes, needs, and experiences of these groups have to be taken into account in designing and delivering health and community care services, and taking action to improve health. This is not only because it is right and fair to do so. If we do not, we will be less effective in improving health, removing inequalities in health outcomes and preventing and treating ill-health. Recognising and valuing the differences in needs and experiences across these groups will contribute to more efficient allocation of resources, inclusive recruitment and retention of health service workers, and service improvement for all health service users.
Equality is about creating a fairer society where everyone can participate and has the opportunity to fulfil their potential. It is mostly backed by legislation designed to address unfair discrimination based on membership of a particular group. Diversity is about recognising and valuing difference in its broadest sense. It is about creating a culture and practices that recognise, respect and value differences, both between groups and between individuals.

**Legislation and policy**

The legal framework has been strengthened in recent years and helps to set the context for this work.

- The Disability Discrimination Acts (1995 and 2005) gave people with disabilities protection in the areas of employment and access to goods and services, similar to the rights against discrimination on the grounds of gender or ethnic origin that were already in place. Specific duties for public bodies to promote disability equality came into force in December 2006.

- The Race Relations Act (1976) made it unlawful to discriminate against anyone on grounds of race, colour, nationality (including citizenship), or ethnic or national origin. The Race Relations (Amendment) Act (2000) gave public authorities a general duty to promote race equality by working not only to eliminate unlawful racial discrimination but also to promote equality of opportunity and good relations between people of different racial groups.


- Age discrimination legislation in employment came into effect on 1st October, 2006. This made age discrimination unlawful in employment and vocational training.
• The Equality Act 2006:
  – creates a “general duty” on public authorities to promote equality of opportunity between men and women and to eliminate gender discrimination (the Gender Equality Duty comes into force 6 April 2007)
  – makes discrimination on the grounds of religion or belief unlawful in the provision of goods, facilities and services and the exercise of public functions
  – allows regulations to be made to prohibit sexual orientation discrimination in the provision of goods, facilities and services, and the exercise of public functions (the Government intends to bring these regulations into force on 6 April 2007).

• The National Health Service Reform (Scotland) Act 2004- Puts in place specific duties on NHS organisations to involve the public and encourage equal opportunities

The Scottish Executive has been committed to ‘mainstreaming equality’, which means the systematic integration of an equality perspective into the everyday work of government across all departments, since it published ‘Working Together for Equality’, its Equality Strategy, in 2000.

‘Fair for All’ (Scottish Executive, 2001a) set out principles for ensuring that the needs of people who are from ethnic minority groups and refugees in Scotland are being effectively met by the NHS. ‘Partnership for Care’ Scottish Executive (2003) declares that the service needs to ensure that “whatever the individual circumstances of people’s lives, including age, gender, ethnicity, disability, religion, sexual orientation, mental health, economic or other circumstances, they have access to the right health services for their needs. This is central to our commitment to social justice and the need to bridge the opportunity gap for all.” It therefore commits the NHS to “extend the principles set out in Fair for All ... to ensure that our health services recognise and respond sensitively to the individual needs, background and circumstances of people’s lives.”

Health services are now expected to carry out an Equality and Diversity Impact Assessment (EQIA) on policy development and service provision in both new and existing policies and functions.
Individual needs and group differences

Some people assume that they are treating each group the same and that this must create a fair and equal outcome. But this often does not result in equal opportunities and equity of treatment.

Positive action is often required. This recognises that it is necessary to tackle disadvantage through specific action to support and enable the disadvantaged group to ‘achieve a level playing field’.

However, what is also important is an Equality Perspective, which recognises that different support may be required for different needs among groups, and tries to make sure that the needs of all the groups are considered and balanced in developing policy and decisions about resources.

- 87% of GPs felt they could communicate effectively with deaf people using their service
- 52% of them could not name any resources they had for communicating with deaf and hard of hearing people.
- 23% of deaf and hard of hearing people had left an appointment unsure of what was wrong with them
- 1 in 6 avoided going to the doctors because of communication problems.


People can fail to get the service that they need not only because of negative views and stereotypes, but also because their needs or the disadvantages that affect them are invisible or dismissed as irrelevant without proper thought. People have multiple identities that overlap across the groups, and different needs related to each. Their difficulties can therefore be compounded, creating multiple disadvantage.
Gender differences vary by ethnic groups. The 1999 Health Survey for England showed that more men than women had attended hospital in the past year in all ethnic groups other than Black Caribbean, where male and female attendance rates were equivalent. However, both Chinese women and Chinese men were less likely to have attended as out-patients compared with the general population (Dench et al (2002) Key Indicators of women’s position in Britain IES/DTI Women and Equality Unit, London [http://www.womenandequalityunit.gov.uk/publications/weu_key_indicators.pdf](http://www.womenandequalityunit.gov.uk/publications/weu_key_indicators.pdf))

This makes it vital to look at individual needs and not try to assign a single standard identity to anyone. Treating people as individuals does not mean ‘treating everyone the same,’ but understanding how the groups that they belong to are part of what makes them individual. Rigid rules about how to treat someone just because they belong to a particular group can also become unfeeling stereotypes.

A study of nursing in general hospital in England recounts how a young male Asian patient had died on the ward. His mother was called in to see the body. She was horrified to find him in bed lying in a pool of vomit. The nursing staff’s comments were that as he was a Muslim, they did not think they were allowed to touch the body. ‘We usually let the family deal with the body.’ Vydelingum V (2006) Nurses’ experiences of caring for South Asian minority ethnic patients in a general hospital in England Nursing Inquiry 13: 23–32.
Finding out by asking people

‘Patient focus and public involvement’ is a central principle for the Scottish Health Service, because “a modern healthcare service must do things with the people it serves not to them” (Scottish Executive, 2001b: 2).

It is particularly important when dealing with equality and difference. The first principle is to talk to the patient and (with their agreement where possible) to their families or carers.

A young woman who has communications difficulties needs to lie in a particular position when she is in bed. On several occasions when she was an in-patient, her mother had found that staff on a later shift had changed her position because they had not looked at the written notes. For the next admission, her mother took photographs of the combination of the pillows and wedges, and marked the right and wrong positions. The nursing staff taped the photographs above the woman’s bed. Each team of staff followed the visual directions and there were no problems during that stay. (Fair for All – disability, 2006: 13).

It is also vital when planning, reviewing or changing services to talk to patients individually and in groups about their experiences and views of services. Consulting community groups and voluntary organisations that involve include and/or campaign for the different groups affected by equality issues is one of the key steps. Many health care services consult with service users and service user groups. Engaging the community should go beyond consultation to include involvement and participation at decision-making levels. The duty for public bodies to promote disability equality under the Disability Discrimination Act (2005) specifically requires them to involve disabled people in planning what action they will take.

However, some people may not be served effectively by broader community or patient groups.

Community engagement of any kind is a long-term process, which cannot be switched on and off at will. The National Standards for Community Engagement (Communities
Scotland, 2005) give a guide to effective practice and Taylor (2006) gives an introduction to how they might be applied to health and care services.

The Scottish Consumer Council looked at case studies in six areas of Scotland. There was little evidence of consultation with disabled people, particularly at a local level where there are less likely to be structures in place to facilitate it. However, in NHS Ayrshire and Arran a Disability Awareness Working Group brought together a wide range of groups and NHS staff. This meant that consultation at health board level had become routine, and some staff used the Group to make contact with more local disability groups or access panels. Bridging the gap: improving access to primary healthcare services for disabled people Scottish Consumer Council, 2005 http://www.scotconsumer.org.uk/publications/reports/reports05/rp03brid.pdf

An effective strategy to promote equality may also require working with others to achieve community development – strengthening the prospects for engagement and dialogue by going out into the community and helping people to find ways of to get together and speak out, and often to take action to improve their own health.

Sources of information and advice

A Scottish Executive website http://www.scotland.gov.uk/Topics/People/Equality provides information on all the groups and issues covered by their Equality strategy. It links to the Portal to Resources and Information on Mainstreaming Equalities (PRIME). This is a collection of web-based resources, designed to help policy makers and researchers understand the broad range of equality issues. To go direct to the information on health, go to:
http://www.scotland.gov.uk/Topics/People/Equality/18507/mainstreamingequalities/health/health

The Equality and Diversity Impact Assessment Toolkit can be found at:
www.scotland.gov.uk/equalityanddiversity/1Atoolkit
(published: Scottish Executive, 2005).
Health Topic Briefings

The Scottish Health Council’s role is to support health boards in engaging with communities. Their website can be found at http://www.scottishhealthcouncil.org/

The following are referred to in this briefing:

Communities Scotland (2005) National Standards for Community Engagement
Communities Scotland, Edinburgh

http://www.womenandequalityunit.gov.uk/publications/weu_key_indicators.pdf

Employment Equality (Religion or Belief) Regulations 2003:
http://www.opsi.gov.uk/si/si2003/20031660.htm#1

Employment Equality (Sexual Orientation) (Amendment) Regulations 2003:
http://www.opsi.gov.uk/si/si2003/20032827.htm

http://www.drc.org.uk/fair4all/achievingfairaccess/pdf/whole-guidance.pdf


SEE ALSO:

‘How to’ Guide to community engagement (Communities Scotland) http://www.communityscotland.gov.uk/stellent/groups/public/documents/webpages/scrcs_006693.hcsp

(return to contents)
CANCER

General issues

Cancer is one of the greatest health problems facing people in Scotland today. Every year about 26,000 cases of cancer are diagnosed in Scotland. In the year 2000, almost 15,000 people died of the disease (Scottish Executive, 2003). There are numerous variations in the incidence of cancer between groups in the population. We need to take many things into consideration, most of which are not specific to cancer, in ensuring that differences and inequalities between people are dealt with appropriately by cancer services. Therefore it is essential that this briefing should be read together with the ones on each equalities issue.

Briefly, services and working practices should take into account:

• Targeting services most appropriately, given the known differences in the incidence of conditions and whether these are caused by genetic or environmental factors

• Developing health promotion messages for different audiences, given the different ways in which, for example, men and women may view their health

• The difficulties some people have in accessing services or reporting health problems because they fear discrimination, lack experience, or have low confidence

• Making services practically accessible to all, bearing in mind not only physical access but making reasonable adjustments for people with sensory, communication and learning disabilities and how best to communicate with people for whom English is not a first language

• Sensitivity to people’s beliefs, cultural preferences and needs
Consulting with people to assess their needs and wishes, taking into account the group or groups that they belong to, without imposing stereotypes or making assumptions because of their identification with a particular group.

The experiences of discrimination, bullying, poverty, etc, that may have shaped some people’s physical health as well as their mental health.

Ensuring that all staff are sensitive to differences and inequalities and know how to take these into account in service delivery.

The specific differences and issues that directly affect cancer described here are only some of the most important ones for cancer services to take into account. For instance, the literature does not have a great deal to say about the relationship between cancer and disability. But practitioners need to be aware of how disabilities can affect the way in which people get access to and respond to services.

**Key facts**

- The most common cause of cancer death in women is lung cancer, reflecting the poor survival and increasing frequency of this disease amongst Scottish women (Scottish Executive, 2004).

- Progress in early cancer diagnosis in England has been achieved through improved screening rates for breast and cervical cancer in inner city areas by making services more responsive to cultural and language needs, improving training and spreading good practice (Tackling Health Inequalities: A Programme for Action Department of Health, 2003).

- Lesbians may be at increased risk of ovarian cancer due to factors such as lower use of oral contraception and lower incidence of giving birth (White J, Levinson W (1995) Lesbian health care: What a primary care physician needs to know Western Journal of Medicine 162: 463-6)
• Individuals from ethnic minority backgrounds may have a lack of information about palliative care services available (Gaffin J, Hill D and Penso D (1996) Opening doors: improving access to hospice and specialist palliative care services by members of the black and minority ethnic communities. British Journal of Cancer 74: S51-53).

• People with mental health problems have higher rates of obesity, smoking and breast cancer than other people. People with schizophrenia are almost twice as likely to have bowel cancer as other citizens (Disability Rights Commission, 2006).

• Older people with cancer are more likely to have other illnesses as well, and some of the physiological changes associated with age may make the various forms of cancer treatment less effective and also more risky. But even when these factors are taken into account it appears that substantial numbers of older Scottish patients do not receive cancer treatment that might benefit them considerably (Chief Medical Officer, 2002).

• Travellers’ health beliefs and attitudes to health services demonstrate a cultural pride in self-reliance. There is stoicism and tolerance of chronic ill health, with a deep-rooted fear of cancer or other diagnoses perceived as terminal and hence avoidance of screening (The Health Status of Gypsies & Travellers in England Department of Health, 2004).

• People with learning disabilities have very low cervical and breast cancer screening rates (Disability Rights Commission, 2006).
Issues

Incidence – why does it matter?

Dietary habits, activity levels and cigarette smoking, alone or in combination, play a major role in the aetiology of several forms of cancer. Population groups with a degree of genetic separation may have differing incidences. Environmental conditions and life experiences, some linked to disadvantage or discrimination, may play a role. It is not within our scope to separate out genetic, environmental and behavioural factors, but simply to point to some of the variations that may be important, while making it clear that there are others that are known and still others yet to be found.

Some minor variations between populations may have limited relevance to care and treatment. Where variations exist it could imply the need to:

• target diagnostic and treatment services to groups with high incidences, especially if there are known or suspected cultural or other barriers to accessing these

• be particularly aware of possible diagnoses, even if there are differences in people’s ability or willingness to identify and describe symptoms

• target and deliver health promotion activities appropriately.

The need to provide effectively for different groups is not restricted to those conditions to which they are particularly prone. Research into ethnicity and health has tended to focus on the diseases that are more common in minority ethnic groups. But this can distract attention from other illnesses such as cancer which are very common, but (in many cases) less so than in the general population (Bhopal R Is research into ethnicity and health racist, unsound or important science? British Medical Journal, 1997 314: 1751-1756).
Variations in incidence by sexual orientation

Special targeting may be required to ensure adequate levels of screening for higher risk conditions, in particular:

- smoking related cancers– due to higher rates of smoking in LGBT population
- cervical & breast screening, because of potentially higher levels of risk due to lifestyle issues and lower protective factors such as oral contraception
- anal cancer screening for gay men.

Special attention is also needed to appropriate screening and other services for trans people for cancers related to their original biological gender (NHS Scotland/Stonewall, 2003), such as not requiring female to male trans people to use women’s cervical screening services.

Variations by gender

Some cancers obviously affect people according to gender – breast, ovarian and cervical cancer for women, and prostate cancer for men.

Though the most common cause of cancer death in women is now lung cancer, research suggests nicotine replacement therapy is less effective for women: those who smoke have a higher dependence on nicotine; women have a slower rate of nicotine clearance and may suffer worse withdrawal symptoms, for example. Men and women appear to smoke for different reasons with avoiding weight gain and alleviating stress and depression being significant factors for women (Equal Opportunities Commission, 2004).
Variations by age

Around one-third of all cancers are diagnosed in people over 75, who form only around 7% of the population. To ensure that people are not prevented from receiving treatment that might benefit them, an Expert Group (Chief Medical Officer, 2002) recommended to the Scottish Executive that:

- older people with cancer should have full access to the service developments that follow from the implementation of Cancer in Scotland, Action for Change

- older patients should have access to appropriate investigation and treatment of cancer on the basis of their individual clinical needs

- Clinical Standards Board for Scotland (now NHS Quality Improvement Scotland) standards should adequately assess care provided to all age groups including older people

- older patients with cancer should have access to rehabilitation to enable them to cope with the impact of disease and treatment.

Cancer is not seen as a young people’s disease, and some stigma may be attached to young people accessing screenings, services and treatment. Incidence rates of all cancers combined in adolescents and young adults have increased over time, rising from 178.3 to 237.4 per million population between the periods 1976-1980 and 1996-2000. The most striking increases in incidence are seen for germ cell tumours and melanoma (ISD Scotland, 2005).
Dealing with disability

Even if most physical disabilities may not directly impact on the incidence of cancer, disabled people need cancer screening services as much as any general or specialist health-care service. All health services need to be accessible to all disabled people, whatever their impairment.

“"I had a mammogram and they were wanting me to come back to have a biopsy...The doctor was trying to show me the screen and pointing to things but I didn’t understand. It wasn’t going in and we were both lost. So my daughter arranged to come up from England to go with me to see the doctor. My daughter works in a cancer oncology department and without her I’d have been lost” “We’re still waiting”: deaf people’s experiences of the struggle to improve their health and well-being Scottish Human Services Trust, 2004 http://www.shstrust.org.uk/pdf/deaf_stories.pdf

But some particular issues need to be considered:

- The Disability Rights Commission research indicates that people with mental health problems are at increased risk of some cancers;
- They also report poor screening rates for people with learning disabilities;
- Cancer can itself create a disability (in statutory and practical terms) which must be taken into account in planning services.

Variations by religion and ethnic origin

Variations in the incidence of cancer can stem from a wide variety of genetic and cultural factors or from the experience of ethnic groups in our society. Considering ethnic origin together with religion:

- religion can be linked to genetic factors where it has developed to a greater or lesser extent within a particular group, such as Judaism, and
• religion can be a direct cultural influence, for example, the Sikh religion is very prohibitive of tobacco use and over 90 per cent of Sikh men and nearly all Sikh women do not use any tobacco, or

• religion can coincide with cultural practices of no particular religious significance; for example tobacco chewing is relatively common among Pakistani and Bangladeshi Muslims (Cooper et al, 2000).

Ashkenazi Jews have a lifetime colorectal cancer risk of 9-15%. This elevated risk is similar to that of individuals in the “familial risk” category, and differs strikingly from the 5-6% risk for members of general Western populations. However the authors remind the reader to use caution in the interpretation of statistics which portray variation in incidence and prevalence figures for cancer in any racial, ethnic, or religious group.

Diagnosis, treatment and care

The most important thing to consider with all people is often not the possible variations in the incidence of cancer, but the barriers that may exist to effective diagnosis, treatment and care.

Cultural issues need to be taken into account in services for people from minority ethnic groups or religions, though awareness of these should never lead to stereotyping what an individual’s wishes may be. One review has listed the major issues that should be considered to increase cultural sensitivity in the medical setting:

- family function
- gender roles
- language
- disclosure of disease-related information
- pain
- attitudes towards illness and health practices
- immigration
- religion
- autonomy versus dependency
- death and bereavement (differences in attitudes to these are discussed in the ‘Religion’ briefing’) (Trill and Holland, 1993).

Difficulties in caring for patients from black and ethnic minority groups ... entailing serious challenges to [staff’s] own professional practice... were found to arise at all stages of patients’ experience of cancer, including at diagnosis, during treatment and at the palliative phase. Staff were concerned that their inability to communicate with some patients meant that they were not able to provide them a good service, as they could not develop an easy relationship and talk around issues. Yet it could be difficult to work with interpreters, as well as family members, both of whom could be reluctant to translate important information.


• Individuals from ethnic minority backgrounds may be less likely to ask their GP for access to palliative care. The National Council for Hospice and Specialist Palliative Care Services has made recommendations that services should be appropriate for minority groups in terms of their dietary needs, religion and language. Gaffin J, Hill D, Penso D (1996) Opening doors: improving access to hospice and specialist palliative care services by members of the black and minority ethnic communities British Journal of Cancer 74(S51-53).

• Many minority ethnic women had little understanding of the purpose of the cervical smear test, though many expressed an interest in finding out more about it. Most had had negative experiences of smear testing and expressed a feeling of helplessness about the procedure. Most non English-speaking women communicated with smear takers through their husbands or daughters, but were generally given little information. Fong Chiu L, Heywood P, Jordan J, Mckinney P, Dowell T (1999) Balancing the equation: the significance of cervical screening amongst minority ethnic women Critical Public Health 9(1): 5-22.

Health Topic Briefings

There are barriers that may prevent people from many different groups from getting equal treatment:

- LGBT people may be reluctant to discuss personal issues and fear negative attitudes.

- Men are less likely to visit their GPs than women.

- Though women over 70 are not offered breast cancer screening automatically, they may choose to have it; but there is a widespread lack of awareness of its availability, and the overall rate of self referrals is very low (Robinson, 2002).

- Disability ‘access’ is about much more than ramps and changes to the physical environment. It is about ‘reasonable adjustments’ for people with learning disabilities, mental health problems, sensory impairments and other disabilities. These are not optional; they have been required under the Disability Discrimination Act since 1999.

- Confidentiality and anonymity are important for many young people.

Research and where to find it

There is scant research that reviews the relationship between equalities issues and cancer care in general. However, there are many studies that indicate that belonging to a particular group, poverty and disadvantage do have an impact on health, the development of certain diseases, diagnosis and treatment.

The incidence in Scotland of four health behaviours that are main risk factors - smoking, drinking, diet and exercise – are analysed by age and gender in HEBS (2000). Evidence on these factors is presented in the separate health briefings for these groups.
Readers should also look at the general overviews and the sources of information and advice listed in the briefings on each equalities group.

Several pieces of research have been referred to above in order to illustrate particular points, and references to these have been given. The following are also referred to and could be useful starting points for further reading:

http://www.scotland.gov.uk/library3/health/alty-00.asp

http://www.nice.org.uk/download.aspx?o=501977


http://www.drc-gb.org/about_us/drc_wales/newsroom/news/equal_treatment_closing_the_g.aspx


ISD Scotland (2005) Childhood, adolescent and young adult cancer
Health Topic Briefings

NHS Scotland/ Stonewall (2003) Towards a Healthier LGBT Scotland NHS Scotland, Edinburgh  [Please provide the URL in the format required for proper links.]  


(return to contents)
CORONARY HEART DISEASE AND STROKE

General issues

To ensure that Coronary Heart Disease (CHD) and stroke prevention and treatment services are delivered in a way that recognises and responds appropriately to differences and inequalities we need to take many things into consideration. Most of these are not specific to CHD and will be helpful in improving practice across all aspects of the NHS. This briefing should therefore be read together with the others for each equalities strand.

Briefly, services and working practices should take into account:

• Targeting services most appropriately, given the known differences in the incidence of conditions and whether these are caused by genetic or environmental factors

• Developing health promotion messages for different audiences, given the different ways in which, for example, men and women may view their health

• The difficulties some people have in accessing services or reporting health problems because they fear discrimination, lack experience, or have low confidence

• Making services practically accessible to all, bearing in mind not only physical access but making reasonable adjustments for people with sensory, communication and learning disabilities and how best to communicate with people for whom English is not a first language

• Sensitivity to people’s beliefs, cultural preferences and needs
Health Topic Briefings

• Consulting with people to assess their needs and wishes, taking into account the group or groups that they belong to, without imposing stereotypes or making assumptions because of their identification with a particular group

• The experiences of discrimination, bullying, poverty, etc, that may have shaped some people’s physical health as well as their mental health

• Ensuring that all staff are sensitive to differences and inequalities and know how to take these into account in service delivery.

There are approximately 500,000 people in Scotland with CHD, one of the highest rates in the western world. The national target is to reduce premature death by 60% among people aged under 75 between 1995 and 2010. (Delivering for Health, Scottish Executive, 2005). Current and emerging information indicates that there are specific differences in the prevalence of CHD due to gender, age or ethnicity. However there is a lack of substantial information on the relationship between CHD and sexual orientation, religion or several forms of disability. CHD practitioners should consider the ways in which belonging to a specific equality group may impact development of the disease and the way in which people get access to and respond to services.

Key facts

• People with serious mental health problems are more likely than others to get illnesses like strokes and CHD before the age of 55. Once diagnosed they are less likely to survive for more than five years (DRC, 2006).

• Men typically develop heart disease ten years earlier than women (Wizemann & Pardue, 2001).

• Women are far less likely to realise they are having a heart attack than men, with 54% of attacks in women going undiagnosed compared with 33% in men (Fitzgerald, 2006).
• 81% of all CHD deaths occur in people aged 65 and over, and 54% of all hospital discharges with a main diagnosis of angina are in the same age group. Yet around two thirds of non-drug angina interventional treatments are carried out on patients aged 65 and under (Chief Medical Officer, 2002).

• The Commission for Racial Equality reports, based on the 1999 Health Survey for England and Wales, that:
  – Pakistani and Bangladeshi men had rates of cardiovascular disease (CVD) about 60% to 70% higher than men in the general population
  – There were also higher rates among Pakistani women (risk ratio 1.45) and Bangladeshi women (risk ratio 1.43)
  – Chinese men and women both had lower rates than the general population (risk ratios 0.63 and 0.71)
  – Prevalence was also higher among Black Caribbean women (risk ratio 1.33).

• Black people tend to develop hypertension at an earlier age, and target organ damage differs from that in white people. Most studies in the United Kingdom and United States report a higher prevalence but lower awareness of hypertension in black than in white people (Brown, 2006).
**Incidence by gender**

Statistically, men suffer more CHD earlier than women. Men have a tendency to central obesity and a greater risk of hypertension and diabetes, which both increase the risk of CHD (White & Lockyer, 2004). They may also be more prone to behaviours that increase the risk (Doyal et al, 2003).

However there are also factors that increase the risks for women and emphasise the need to look beyond the image of the typical male CHD patient. For example:

- Women have smaller coronary artery lumens than men, independent of body size, and less collateral circulation. These anatomic differences lead to an increase in ischaemia during exertion or stress (White & Lockyer, 2004).

- Depression is three times more common in women than in men and we know that depressed patients report significantly more episodes of angina and more intense anginal pain (White & Lockyer, 2004). Furthermore anti-depressants are actually a risk factor for heart disease (DRC, 2006).

**Incidence by ethnic differences**

Much of the research in this field has been undertaken in England and Wales and while Scotland’s ethnic minority population is smaller and less diverse, the evidence is still important in informing practice. It is important to remember that ‘ethnic minority health’ is an umbrella term which encompasses a variety of difference. For example:

- There are big differences within some commonly used ethnic categories. Nazroo (1997), analysing a major survey of self-reported conditions, confirmed that ‘South Asians’ as a whole have higher rates of coronary heart disease, but found that all of difference was attributable to people of Pakistani or Bangladeshi heritage.
Perhaps as a result, there was a statistically significant religious difference: Hindus were least likely to have diagnosed CHD, Muslims most.

• Nazroo also made a sophisticated assessment of the overall standard of living of survey respondents. After taking variations in standard of living into account, the incidence of CHD for ‘Pakistani or Bangladeshi’ people was no longer significantly greater than for the white population. Amongst people of ‘Indian or African Asian’ background it was actually significantly lower. This is important for understanding the sources of differences – it does not remove the need to take them into account in service delivery.

• The fullest attempt to produce comparable information for Scotland is undertaken by Bhopal et al (2006). This study uses place of birth as one definition of ethnic background, acknowledging that this is far from perfect when, for example, there are a considerable number of older white people who were born in India and Hong Kong. Contrary to the pattern of raised CHD mortality rates for people born in India, Pakistan and Bangladesh previously reported in England and Wales, this study shows CHD mortality rates for all ages very similar to those for people born in Scotland. But CHD mortality is markedly higher in all people born in Scotland, as opposed to England and Wales. The “comparisons [of South Asian born populations] with the Scottish population might be interpreted as reassuring ... however, the high risks are being disguised by using a reference group that itself is at high risk, i.e. Scottish born” (Bhopal et al, 2006).

• Among Scottish residents aged 25-69 the highest rates of CHD mortality were in women and men from Pakistan. The comparatively low CHD mortality in Hong Kong (men only) populations reported in England was also seen in Scotland.
Health Topic Briefings

Risk factors

It is vital to the success of health promotion messages that they take into account how they will be received by different groups and to recognise particular risk factors within groups.

- Messages about diet, exercise, smoking, etc, need to be designed to reach young people.

- Attitudes about exercise, and the forms of exercise that are practically available, will vary between men and women and according to disability, age and cultural and other preferences.

- Different groups should never be considered unreachable. For example, smoking cessation has been shown to work for people with mental health problems, and structured approaches to weight management are effective in improving the health of people with learning disabilities and/or mental health problems (DRC, 2006).

In a study of Glasgow’s young lesbian, gay and bisexual people, the percentage who meets the recommended amount of physical activity was considerably lower than mainstream young people in the same age range. Coia N, John S, Dobbie F, Bruce S, McGranachan M, Simons L (2002) “Something to Tell You”: A Health Needs Assessment of Young Gay, Lesbian and Bisexual people in Glasgow Greater Glasgow NHS Board.

Although people with learning disabilities are more likely to be obese than other citizens, when they get diabetes they are less likely than others with diabetes to have their weight (body mass index) checked (DRC, 2006).
At age 58, 49% of men and 57% of women in the west of Scotland were taking no exercise. Only four activities were undertaken by over 10% of men: walking, bowls, golf, dancing; or by over 10% of women: walking, dancing, swimming, bowls.


CHD risk factors for the Glasgow South Asian population, predominantly Punjabi, aged between 30 to 40 years, were compared with the general population (Williams et al, 1994). Smoking was identified as the only non-biochemical risk factor relating to CHD to which South Asians had less exposure than the general population. Dietary choices of the South Asian population played a contributory role but did not fully account for the higher rate of CHD. This was likely to result, particularly in women, from a complex interaction of risk factors including insulin resistance, stress and socio-economic circumstances.

Diagnosis and care

As research is carried out in which people talk in depth about their experiences of CHD, the more clear it becomes that people have different perceptions of CHD in men and women, and also in older people. This can mean there are differences in coming forward for treatment and in the treatment given (Emslie, 2005).

There are some physical differences in cardiac symptoms between the genders. For example, during an infarction, women have significantly more nausea or vomiting and men more chest pain, while women report more neck and back pain (White & Lockyer, 2004).

For younger women in particular, there is a greater prevalence of non-coronary related chest pain. This can lead both women and practitioners to assume falsely that chest pain is due to non-coronary factors, therefore affecting diagnosis and treatment. Older women need help in differentiating cardiac symptoms from other age-related changes (Doyal et al, 2003).
Emslie (2005) quotes various studies which identify reasons why women may delay seeking medical help, including

- belief that CHD is a ‘man’s disease’
- considering their health to be a low priority compared to other family members
- fear of being viewed by healthcare staff as ignorant, or as a worrier or hypochondriac
- wives ‘forcing’ their husbands to seek medical care, but this not happening vice versa.

She also cites evidence of the difficulties women have adjusting their behaviour after a cardiac event:

- because they thought it was unacceptable to avoid domestic work
- because they would or could not change the diet of a partner and children to a low fat basis.

On the other hand some studies show the dangers in traditional notions of masculinity where men:

- believed that they should be hardy and strong and not complain about illness
- feared being seen as weak and impotent if they avoided heavy tasks.

There is mixed evidence on whether there are cultural differences between ethnic groups that are significant in explaining their perceptions of CHD. But a culturally sensitive approach in a community setting can raise awareness of CHD risk factors, as NHS Lothian’s pilot initiative ‘Khush Dil’ in South Asian communities has shown (NRCEMH, 2006).
Respondents in a west London study were given a fictional account of a man experiencing chest pain and asked about how they would react to experiencing such a pain themselves. There were no significant differences between groups in whether the pain was believed to be in the area of the heart. After adjustment for other variables, Sikhs were three times more likely than Europeans to say that they would immediately seek help for chest pain and Hindus were two and half times more likely to say this. South Asians were also more likely than Europeans to say that they would seek advice for others, use alternative therapies, or seek help from a pharmacist, for example. Chaturvedi N, Rai H, Ben-Shlomo Y (1997) Lay diagnosis and health-care-seeking behaviour for chest pain in south Asians and Europeans The Lancet 350 (9091): 1578-1583.

**Differences in treatment**

Older people experience differences in treatment. In one study, 34% of GPs claimed to be aware of upper age limits restricting access to heart by-pass operations. Other studies have shown that 20% of cardiac care units operated upper age limits and 40% had an explicit age-related policy for thrombolysis. Upper age limits have been fairly common in cardiac rehabilitation programmes and in high or intensive care units following surgery (Robinson, 2002).

More generally the reasons for a disparity between need and intervention are complex. Some older patients may prefer to accept medication and be less keen on surgery. Coronary artery disease in later life may be more widespread and therefore harder to treat, but this needs to be investigated in individual cases. Complication rates are higher for treatment in older people, but more research is required on risks and benefits in this age group. “Overall, there is an impression that many older people in Scotland could benefit from a more active approach to the investigation and treatment of their angina symptoms” (Chief Medical Officer, 2002). Similar conclusions are reached for heart attack and stroke.

Older patients with heart failure are less likely to be fully investigated (with echocardiographic imaging of the heart’s function), and also less likely to receive some of the most effective treatments, such as the ACE inhibitor drugs (Chief Medical Officer, 2002).
Other groups are also vulnerable to conscious or unconscious restrictions on treatment, notably people with mental illnesses.

**CHD patients with schizophrenia have higher risks (as reflected in their higher prevalence of smoking), but were less likely to be screened for raised cholesterol and less likely be prescribed statins for treatment.**


The research reviewed by Emslie includes studies in which women felt that they were treated differently or less seriously by health professionals because they were women and relatively young. Some postmenopausal women were angry that their coronary symptoms had been attributed to other causes.

**Women are less often referred to acute catheterisation, coronary angioplasty, thrombolysis or coronary bypass surgery, despite evidence that such procedures are as effective for women as men.**


**The need for awareness**

As stated at the outset, many differences between people affect their experience of health care and its outcomes in ways that are not specific to CHD, but still need to be understood to ensure accurate diagnosis and treatment.

Andrew: I went to hospital for a heart bypass. I did ask for interpreters but sometimes they didn’t turn up. The nurse had my records and it had in big letters ‘DEAF’ but they would still shout my name out. For the first four days after the operation there was no one I was able to communicate with.... The nurse knew it was difficult but said that because he’s deaf they couldn’t explain things to him like the need to breathe properly, which should have been sorted in the first twenty-four hours.... There was nothing written down for me, there was no communication. They didn’t tell me what the different medications were for. Scottish Human Services Trust (2004) “We’re still waiting”: deaf people’s experiences of the struggle to improve their health and well-being Scottish Human Services Trust, Edinburgh [http://www.shstrust.org.uk/pdf/deaf_stories.pdf](http://www.shstrust.org.uk/pdf/deaf_stories.pdf)

**Research and where to find it**

There is little significant research on the relationship between CHD and the identification with particular equalities groups. However, there are many studies that indicate belonging to a particular group, poverty and disadvantage do have an impact on health, the development of certain diseases, diagnosis and treatment.


Health Scotland (formerly HEBS) undertook research on the relationship between specific risk factors (smoking, drinking, diet and exercise) and age and gender (2000). This information and other sources of information and advice are provided in the separate health briefings.
Several pieces of research have been referred to above in order to illustrate particular points, and references to these have been given. The following are also referred to and could be useful starting points for further reading:

http://www.chs.med.ed.ac.uk/phs/research/Retrocoding final report.pdf


http://www.scotland.gov.uk/library3/health/alty-00.asp


http://www.drc-gb.org/about_us/drc_wales/newsroom/news/equal_treatment_closing_the_g.aspx


http://www.eoc.org.uk/PDF/fair_for_all_gender_%20and_health_research.pdf

Nazroo JY (1997) The Health of Britain’s ethnic minorities  PSI,


http://www.nap.edu/books/0309072816/html

(return to contents)
MENTAL HEALTH

General issues

Mental health is one of NHS Scotland's three national clinical priorities. Good mental health improves the quality of life for people with serious physical illness and may contribute to longer life (Scottish Executive, 2005).

Our mental health, the way we respond to mental health problems, and the way services respond to us is dependent on who we are as individuals. Belonging to, or being identified by others as belonging to, one or more of the equalities groups can involve life circumstances and experiences that lead to differing mental health difficulties, affect whether these are detected and how they are diagnosed, and can affect people’s ability to get access to and equal treatment from services.

Mental health services must also deal effectively with some of the general problems of ensuring equal access to any aspect of health care and of addressing health inequalities. This briefing should be read together with the separate ones on each equalities issue.

Briefly, services and working practices should take into account:

• Targeting services most appropriately, given the known differences in the incidence of conditions and whether these are caused by genetic or environmental factors

• Developing health promotion messages for different audiences, given the different ways in which, for example, men and women may view their health

• The difficulties some people have in accessing services or reporting health problems because they fear discrimination, lack experience, or have low confidence
• Making services practically accessible to all, bearing in mind not only physical access but making reasonable adjustments for people with sensory, communication and learning disabilities and how best to communicate with people for whom English is not a first language

• Sensitivity to people’s beliefs, cultural preferences and needs

• Consulting with people to assess their needs and wishes, taking into account the group or groups that they belong to, without imposing stereotypes or making assumptions because of their identification with a particular group

• The experiences of discrimination, bullying, poverty, etc, that may have shaped some people’s physical health as well as their mental health

• Ensuring that all staff are sensitive to differences and inequalities and know how to take these into account in service delivery.

Key facts

• Studies in the general population suggest that the overall prevalence of mental illness does not differ significantly between women and men. For specific disorders, however, clear gender differences emerge. Anxiety, depression and eating disorders are more common in women, substance misuse and anti-social personality disorders are more common in men (Gold, 1998).

• Studies in the US have pointed to inequality and discrimination as potential sources of depression in women, though evidence more persuasively links poverty and depression (Belle and Doucet, 2003).

• There is a link between abuse by a partner and the risk of depression among women (Hegarty et al, 2004).
• There is some indication that schizophrenia may have an earlier onset and a more disabling course in men (Flor-Henry, 1990; Murray, 1994).

• A study of young lesbian, gay and bisexual people in Glasgow found that 41% of the women and 31% of the men had symptoms of depression, a rate almost seven times higher for women and eight times higher for men than in a study of ‘mainstream’ young people of a similar age (Coia et al, 2002).

• A study in Edinburgh found that the young gay and bisexual men were 4.1 times more likely to have seriously considered suicide than young men in the general UK population (Hutchison et al, 2003).

• Asian women aged between 15–35 years are two to three times more vulnerable to suicide and self-harm than their non-Asian counterparts (quoted in Myers et al, 2005).

• Some asylum seekers arrive with mental health needs as a result of their experiences (e.g. post-traumatic stress disorder) (King’s Fund, 2000).

• People of African (not Caribbean) origin formed just over 5% of the minority ethnic population in Scotland in 2001, but 33% of the psychiatric patients in hospitals who were from ethnic minorities (data quoted in Myers et al, 2003).

• Mental health services are often structured separately for adults up to the age of 65 and adults aged 65 and over. This has resulted in the development an unfair system which disadvantages people as they grow older (UK Inquiry into Mental Health and Well-Being in Later Life, 2006).

• Even though epidemiological studies have indicated that deaf people have the same incidence rates of psychiatric illness as hearing people, up to 50% of deaf people had been referred to mental health services because of emotional and behavioural problems, compared to 5% among the hearing population (Muth et al, 1998).
• A study of people with physical impairments and mental health support needs in England and Wales found that the majority had difficulty accessing mental health services because of their physical impairments, and difficulty using physical disability services because of the inadequate recognition of their mental health needs and negative attitudes amongst staff towards mental health issues (Morris, 2004).

Lee felt that staff in the psychiatric hospital ignored his needs relating to his physical impairment: ‘As far as they’re concerned they’re there to look after you mentally. And if you’ve got a physical problem that needs medication you should be seeing the GP or somebody like that. You shouldn’t be bringing that problem to hospital with you’ (Morris, 2004).

Issues

Recognising mental distress and illness

Because mental health is so central to our identity, getting access to appropriate help when needed is not just a practical issue, but raises concerns about whether problems are recognised for different types of people and, if so, how those problems are defined. For example, there might be different behaviour expectations of men and of women.

Nazroo (1997) refers to the difficulties of translating the term ‘depression’ into South Asian languages. Studies have indicated high levels of un-reported psychological distress among Asian communities in general, and among Asian women in particular (Wilson, 2001).
People with disabilities may have particular (and little researched) difficulties in having their mental health assessed on an equal basis.

People with learning disabilities can experience the full range of mental health problems, although the precise impact of mental illness in this population is not clear. The problem for people with learning disabilities is that they are not often able to express their feelings into words, so their actions may have to speak for them. Sudden changes in behaviour can often be viewed as a phase, and so appropriate help may not be given (MIND Factsheet ‘Mental health problems and learning disabilities’ http://www.mind.org.uk/Information/Factsheets/Learning+disabilities/#Mental_health_problems)

A study looked at referrals to one of three specialist units offering mental health services to deaf people in England and Wales. Based on estimates of the number of sign language users in the population and overall referral rates to mental health specialists, 400 deaf sign-language users should have been referred in a year. Actual rates were much lower. For deaf patients, admission seems to be reserved for complex cases and for patients whose treatment cannot be delivered from a distance. (Appleford J (2003) Clinical activity within a specialist mental health service for deaf people: comparison with a general psychiatric service Psychiatric Bulletin 27: 375-377 http://pb.rcpsych.org/cgi/content/full/27/10/375)

Depression affects 3-5% of over 65s at any point in time. Depression can be difficult to diagnose. Some older people simply put up with its symptoms – such as inappropriate sadness, low mood, poor appetite and poor sleep – because they do not realise that they may have a treatable illness (Chief Medical Officer, 2002).
Risk factors: the cost of inequality, discrimination and stigma

Practitioners need to be aware of the particular risk factors that some groups may have been exposed to, which often include violence, abuse, discrimination or economic disadvantage related to their status.

Social isolation is associated with mental ill health. Women are more vulnerable to social isolation than men because of:
- higher levels of poverty
- lone parenthood
- less likely to be able to drive or to own a car
- longer life expectancy
- fear – studies indicate that many women in cities are afraid to go out at night

There are also protective factors for women in that they tend to have better social networks than men. (Department of Health, 2002).

Girls are more vulnerable to childhood sexual abuse and women who have been sexually abused as children represent a considerable proportion of those requiring acute psychiatric care and treatment (Nelson S (2001) Beyond Trauma: Mental Health Care Needs of Women who Survived Childhood Sexual Abuse Edinburgh: Edinburgh Association of Mental Health (now ‘health in mind’)).

Young LGBT people face a particular combination of challenges with mental health implications:

- hiding part of their identity is one of the first things many learn to do, which impacts on self-identity and self esteem
- family disruption and rejection from the family home is a common experience isolation from their peer group and significant levels of homophobic bullying, both verbal and physical are typical (NHS Scotland/Stonewall, 2003)
In a study of young lesbian, gay and bisexual people in Glasgow, four-fifths of the sample had experienced some form of abuse, harassment or violence, ranging from name calling/verbal abuse, to threats of, or actual physical violence or sexual assault (Coia et al, 2002).

In a study of refugees and asylum seekers in Glasgow (Roshan, 2005), professionals agreed that most of the families they had come across had been psychologically scarred as a result of rape, murder and torture. The study emphasises that GPs must treat the patient in light of their whole experience. Ailments appear to be a combination of pre-migration and post-migration factors. The latter can include social isolation, acute anxiety about refugee status, and poverty.

**Suicide and self harm**

Men are more likely than women to commit suicide, with suicide the leading cause of death among Scots men aged 15–34 in 2000 (Source: Scottish Public Health Observatory)

About 25% of suicides occur in older people, although they form only 15% of the population. Ninety percent of such cases have serious depression, and most have visited their doctor in the three months prior to death (Chief Medical Officer, 2002).

A range of research studies (cited in NHS Scotland/ Stonewall, 2003) suggest unusually high rates of attempted suicide amongst LGB people, in the range of 20 – 42%. The association is strongest amongst men.

The ‘Equal Services’ review of race equality practices in Scottish mental health services (Grant & Jackson, 2005) finds that the priority area where least appears to have been done is that of a suicide prevention focus on BME groups, which is of concern given research evidence that shows that South Asian women in Scotland have a relatively high incidence of suicide and self harm (Shah, 2004). Part of the reason is that data about the ethnic background of people who kill themselves or self-harm is not routinely available and people were not able to give this information in many parts of Scotland.
Treatment and care

There are many aspects to ensuring equality in treatment and care. One aspect is to recognise and take into account the negative experiences that may have contributed to people’s mental distress.

There is a significant body of small scale research which collectively repeats consistent and compelling themes expressed by women service users, survivors and carers. In addition to their fundamental right to be ‘kept safe’, women say they want services that:

- Promote empowerment, choice and self-determination – to be listened to
- Place importance on the underlying causes and context of women’s distress in addition to their symptoms
- Address issues relating to women’s role as mothers: - recognise their fear of ‘losing’ children; address the lack of childcare facilities, and of friendly visiting areas in residential settings (Department of Health, 2002).

Another aspect is to recognise that questions of communication with, for example, people with sensory disabilities or of different cultures may be particularly difficult and perhaps too easy to ignore with a person with a mental illness.

As factors in care rather than diagnosis these aspects appear to attract relatively little attention in the literature.

Effective treatment and care must also take into account not only the general stigma that often attaches to mental illness in our society, but the fact that this may be as great or sometimes greater within particular groups. “Potentially at least, people with mental health problems from black and minority communities are at risk of experiencing double or triple jeopardy: discrimination based on ethnicity; and stigmatisation on the part of the majority and minority communities based on having a mental illness” (Myers et al, 2005).
Health Topic Briefings

It is also important to remember:

• the evidence that physical conditions may not be diagnosed appropriately in people with mental illness because of ‘diagnostic overshadowing’ or other assumptions (DRC, 2006)

• the fact that long-term mental illness is, legally, a disability and people suffering from it should not suffer poorer access to other services as a result. For the purposes of the Disability Discrimination Act (1995) ‘A person has a disability if he has a physical or mental impairment which has substantial and long-term adverse affect on his ability to carry out normal day to day activities’.

Research and where to find it

‘Equal Minds’ (Myers et al, 2005) provides a full survey of what is known about mental health inequalities in Scotland and looks at the links between injustice, life experiences and mental well-being. However it points out that within the last 20 years no Scotland-specific studies appear to have been undertaken to indicate the prevalence of mental health problems among people from black and minority ethnic communities in Scotland.

It also recommends research and analysis of the associations between physical disability and mental health inequalities, which appears to be almost entirely absent. General guidance on ‘Mental health issues for people with sight problems’ is available from MIND at:

‘Equal Services’ (Grant & Jackson, 2005) assesses race equality policy and practice in the mental health services that are delivered by the NHS in Scotland.
The following are referred to in this briefing:

Bagley C & Tremblay P (1997) Suicidal Behaviours in Homosexual and Bisexual Males Crisis 18 (1) pp24-34


http://www.scotland.gov.uk/library3/health/alty-00.asp


http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/MentalHealth/MentalHealthArticle/fs/en?CONTENT_ID=4002408&chk=OPSOnR

http://www.drc-gb.org/about_us/drc_wales/newsroom/news/equal_treatment_closing_the_g.aspx

Health Topic Briefings


http://www.healthcarecommission.org.uk/_db/_documents/Living_well_in_later_life_-_full_report.pdf


http://www.lgbtyouth.org.uk/content/resources/download.asp?id=101


Roshan, N (2005) Supporting New Communities: a qualitative study of health needs among asylum seekers and refugee communities in North Glasgow, NHS Greater Glasgow

Scottish Executive (2005) Delivering for Health Scottish Executive, Edinburgh

Scottish Public Health Observatory  http://www.scotpho.org.uk/


(return to contents)
SEXUAL AND REPRODUCTIVE HEALTH

General issues

There are numerous variations in the incidence of sexual and reproductive health problems between groups in the population and in their ability to access services effectively. Sexual and reproductive health services also need to deal effectively with the general problems involved in ensuring equal access to any aspect of health care and of addressing health inequalities. This briefing highlights some of the issues but should be read together with the separate ones on each equalities issue.

Briefly, services and working practices should take into account:

• Targeting services most appropriately, given the known differences in the incidence of conditions and whether these are caused by genetic or environmental factors

• Developing health promotion messages for different audiences, given the different ways in which, for example, men and women may view their health

• The difficulties some people have in accessing services or reporting health problems because they fear discrimination, lack experience, or have low confidence

• Making services practically accessible to all, bearing in mind not only physical access but making reasonable adjustments for people with sensory, communication and learning disabilities and how best to communicate with people for whom English is not a first language

• Sensitivity to people’s beliefs, cultural preferences and needs
• Consulting with people to assess their needs and wishes, taking into account the group or groups that they belong to, without imposing stereotypes or making assumptions because of their identification with a particular group

• The experiences of discrimination, bullying, poverty, etc, that may have shaped some people’s physical health as well as their mental health

• Ensuring that all staff are sensitive to differences and inequalities and know how to take these into account in service delivery.

Sexual health issues are intimately linked by biology to gender and age, and inevitably closely linked to sexual orientation. Religious groups can have strong views about them. For these reasons, it can be very difficult to disentangle the issues of overcoming health inequalities between groups from strong individual and institutional assumptions and moral judgements. While it is important to see beyond these, it is also necessary to think laterally about what may actually be affecting people’s health. Discrimination, poor mental health, difficulties in getting full access to health services, and other such issues can all affect sexual health and wellbeing.

For example, a stock-taking of health services for lesbian, gay and bisexual people in Scotland found that policy and planning thinking still look at LGB populations through a sexual health lens as opposed to ensuring there is a holistic framework based on rights and equality, not just sexual health (NHS Scotland/ Stonewall, 2004 LGBT Stocktake Exercise: Analysis of Responses NHS Scotland, Edinburgh http://www.lgbthealthscotland.org.uk/documents/NHS%20Scotland%20LGBT%20Stocktake.pdf )
Health Topic Briefings

Key facts

• For Scottish females, the level of sexual experience at 15 is higher than in all other countries surveyed except for the USA, while for males it is similar to most others but actually lower than Hungary, Israel and the USA (West and Sweeting, 2002).

• Estimates from across the international literature suggest that 7–30% of girls and 3–13% of boys may be affected by child sexual abuse. Most studies suggest that women are up to 3 times more likely to have been abused than men.

• The 2000 British Crime Survey indicates that around 1 in 10 women have experienced some form of sexual victimisation since the age of 16, and approximately three quarters of a million women have been raped on at least one occasion (highlighting that these figures are likely to be under estimates) (Department of Health, 2002).

• In the only representative Scottish study, while most gay men reported consistent safe sex, a significant minority do not, a pattern especially marked among young male homosexuals who are at particularly high risk of STIs generally and HIV in particular (Williamson et al, 2001).

• If all men in Scotland who have contracted HIV via sex with another man are gay or bisexual by identity, then there is roughly a 1% prevalence of HIV in the gay and bisexual male population of Scotland, based on government estimates (Information from NHS Fair for All – Inclusion Project).
• The uptake of cervical screening is lower for women with schizophrenia (63%) than for those without serious mental health problems (73%). For women with learning disabilities, uptake rates are much lower – variously estimated at 13% and 47%, as compared with 84 – 89% in the general population (DRC (2006) Equal Treatment: Closing the Gap - A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems Disability Rights Commission, London http://www.drc-gb.org/newsroom/health_investigation.aspx

• Condom use among young Asian men was lower than among non-Asian young men, pointing to a failure of existing sexual health education and health services to reach them (Bradby and Williams, 1999).

• The reluctance of south Asian women to consult male doctors and gynaecologists means that heavy blood loss can lead to anaemia (Chapple et al, 1998).

• In London, 28% of Black Africans suspected they were HIV+ before testing compared with 45% of White patients. Of those who did suspect, 62% waited 12 months or more before testing compared with 31% of White patients. Their use of HIV clinic care after diagnosis is similar to their White counterparts (Erwin, 2002).
Issues

Incidence

Rates of incidence of problems or sexual behaviour that differ from the population average, whether ‘positive’ or ‘negative’ in health terms, do not mean that services should not target certain groups or should target others exclusively. Indeed they create the need for sensitive approaches that take account of these differences. For example, if it is true that abstinence from sexual behaviour before marriage among young Asian women is high and among young Asian men is moderate (Bradby and Williams, 1999), this does not mean that services do not need to try to reach young Asian people. On the other hand, the fact that asylum seekers and refugees may be at risk from developing sexually transmitted infections (STIs), and some come from countries where there is a high prevalence rate of STIs, establishes a need for service delivery but also a risk of stigmatisation (Roshan, 2005).

Assumptions about what must be likely or unlikely in terms of sexual and reproductive health are liable to be made in the case of LGB people. Some of these assumptions may even be shared by some LGB people themselves. For example, there is emerging data showing similar prevalence of STIs in lesbians compared to women who have not had sex with women. Studies suggest that some viral infections, such as herpes simplex virus, can be particularly high in lesbians (NHS Scotland/ Stonewall, 2003). Yet conversations with young lesbians in Glasgow reported in Coia et al (2002) show clearly that many have little awareness of any need for or knowledge of safer sex practices. Assumptions that lesbians have not had or are not engaging in heterosexual intercourse may also be erroneous.

- Issues of low self-esteem means that some people may value themselves so poorly they see no reason to take precautions
- The effects of higher levels of alcohol and drug use
- Poor information on same sex sexual relationships, making it difficult to negotiate safer sex
- Limited knowledge from mainstream health services on any issues broader than HIV
- Sexual health promotion for LGBT people is generally targeted at gay men & HIV, neglecting broader sexual health issues
- The approach to school-based sex and relationships education excludes young people who are attracted to the same sex

Issues about equality

Since sexual health issues vary so clearly by age and gender, equality can be difficult to define. For example access to services by under 16 year olds raises complex legal and ethical issues that we shall not discuss here. But clearly attention needs to be given to ensuring that whatever is theoretically available is practically accessible.

Teenage pregnancy is generally regarded as a problem because there may be longer term negative consequences for the health of mothers and children, and restrictions on the future life chances of both. However, services for the people involved must also recognise that the experience of early motherhood (and fatherhood) may be very positive, and that there is evidence that biologically it is probably the optimal age to bear children (West and Sweeting, 2002).

Men and women often need different services, but there are also issues about what needs to be done to get them to use the respective services effectively. Doyal et al (2003), writing for the Equal Opportunities Commission, note that Services for sexual and reproductive health are still used mainly by women and only reluctantly by men. One problem, they argue, is a school-based education system that often confuses reproduction with sex, and seldom deals with sex in the context of relationships.
Men aged 16+ living in two primary care trusts areas in the north-west of England were surveyed. Despite high rates of STIs in the area, approximately one in five men had not heard of herpes, syphilis or chlamydia. One in ten had not heard of gonorrhoea. The majority of men were unaware that many STIs could be asymptomatic. Only 13% knew where their local genitourinary medicine clinic was (Mason L (2005) Knowledge of sexually transmitted infections and sources of information amongst men Journal of the Royal Society for the Promotion of Health 125/ 6:266-271).

Chlamydia trachomatis screening is recommended (in England) for both women and men attending genitourinary medicine clinics and for women seeking termination of pregnancy as well as opportunistic screening of young sexually active women. Partner tracing is also recommended for any person found to be suffering from the disease. Whilst these recommendations do include both women and men, there is a focus on screening women.

However, the danger is that this will reinforce the stigmatising belief that women bear the major responsibility for sexual health and that chlamydia is predominantly a female disease. In reality, 43 per cent of cases identified in the UK in 2001 were found among males. Without opportunistic screening of men as well, there is a strong likelihood that sexually transmitted infections in men will remain undetected and untreated. In turn, this increases the likelihood of (re)infection of women, and thus limits the effectiveness of the strategy (Doyal et al, 2003).

Knowledge, attitudes and language

Use of screening services remains low among minority ethnic women. One study (Fong Chiu et al, 1999) reports that among a largely South Asian group factors that affected take-up of cervical screening included women's failure to prioritise their own health and the perception by many non-westernised minority women that health education and screening is a 'luxury'. Most had had negative experiences of smear testing and expressed a feeling of helplessness about the procedure. Non English-speaking women communicated with smear takers through their husbands or daughters, but were generally given little information. Minority ethnic women suggested that improved explanation would help communication between health professionals and service users, and the use of interpreters or advocates was suggested for those with little or no English.
In focus groups conducted with minority ethnic women, many had little understanding of the purpose of the cervical smear test though many expressed an interest in finding out more about it. Arai and Harding (2002) report other studies which reach a similar conclusion, that minority women are enthusiastic about cervical screening once they understand the purpose of the test.

Reviewing research on ethnic minority issues for the Scottish Executive, Netto et al (2001) note that many studies indicate the greater difficulties of accessing specialist services in relation to specific health conditions, attributed to lack of knowledge of existing services, screening procedures and inability to communicate effectively with general practitioners. “Interestingly, many of the studies relate to issues which might be considered embarrassing or taboo, such as breast and cervical cancer, cervical cytology, drug-use, family planning and sexual health”.

Most of the young South Asian women in Glasgow whom Baraister (1999) talked to about their use of family planning services spoke good English and several expressed surprise when asked if they had ever had communication difficulties with health professionals. But some did have needs or preferences for communication in non-English languages, and this would be important to equal access for them. A minority mentioned communication difficulties not related to language use but often related to embarrassment at having to relate their sexual health problems to medical personnel. Some were also embarrassed about the prospect of somebody from their own community seeing them using family planning services.

The desire of some women to see only female doctors is also reported by Fong Chiu et al (1999) and others, but it must be borne in mind that this will vary between groups, religions and individuals.
Fair for All Equality and Diversity:
Handbook for NHS Scotland

Health Topic Briefings

Making services accessible

Key elements of making services accessible can be reaching out to people in their own settings and involving them individually and in groups in deciding how this is to be done. One well known example is the Corner project for young people in Dundee, running successfully since 1996.

The Corner is a city-centre drop-in centre providing confidential health and information services for young people. It trains young people and involves them in a range of peer led approaches to health promotion and in the planning and refining of all aspects of the project’s work. It runs sexual health clinics which give young people access to contraception, information, support, advice and (if necessary) referral to other agencies. But it combines these with individual support on many things from school issues to the common worry “am I normal?”

An evaluation carried out several years ago estimated that that 1 in 3 young people within the main target group (11-18 years old) had used the drop-in on at least one occasion. The level of enquiries remained steady at approximately 1000 per month, with on average 175 new contacts http://www.thecorner.co.uk/.

The limitations of community-based services need to be tested and taken into account. Flowers et al (2002) evaluated a ‘bar-based, peer-led community-level intervention to promote sexual health amongst gay men’ in Glasgow. Though this did create positive sexual health effects among men who had direct contact with the intervention, including higher uptake of hepatitis B vaccination and HIV testing, it did not meet the tough test of producing ‘community-wide changes in sexual health behaviours’, which had apparently been found previously in a US context.

Treatment and care

Many of the same issues of sensitivity and accessibility affect treatment and care services.
A study, based admittedly on a very small number of cases, of midwifery services for ethnic minority women suggested that minority women are stereotyped by health professionals (so that, for example, Asian women are considered to be making a fuss when they ask for assistance). Some minority ethnic women said that health professionals had talked ‘at’ them rather than ‘with’ them. The one-to-one care provided by midwives was invaluable for these women and allowed them to feel in control of the birth process. Midwives may be more important to women from minority ethnic groups because their expectations (‘of support, good communication and care’) are not always met in conventional services. (McCourt C, Pearce A (2000) Does continuity of carer matter to women from minority ethnic groups? Midwifery 16(2):145-154)

In treatment too, especially sensitive issues can arise, which must be looked at carefully in the light of equalities obligations.

One example is the availability of IVF treatment for lesbians, singly or in couples. Only two of the eight registered fertility clinics in Scotland have been found not to discriminate on grounds of sexual orientation, although this may be improving (NHS Scotland/ Stonewall, 2003).

Another is the treatment of transgender people for complications arising from their original biological gender. No doubt most medical staff may never come across such an issue, but it is essential that it should be handled with sensitivity and in accordance with the wishes of the individual when it arises.

It would not be appropriate for a transgender man (female to male) to be invited to a Well Woman Clinic even though he may require a smear test. A transgender woman (male to female) requiring a prostate check should not be referred to a male health clinic. If a transgender man (female to male) is having a hysterectomy, it is not appropriate to place him on a women’s ward. If unsure of what ward would be best for an individual’s respect and dignity, they should be consulted on the options available (NHS Scotland/ Stonewall (2005) Fair For All - The Wider Challenge: Good LGBT Practice in the NHS NHS Scotland, Edinburgh http://www.lgbthealthscotland.org.uk/documents/Good_LGBT_Practice_NHS.pdf)
Research and where to find it

There appear to be few general overviews of equalities issues in this area, and citations are given above for particular points.

‘Towards a Healthier LGBT Scotland’ (NHS Scotland/ Stonewall, 2003) has excellent summary sections on sexual and reproductive health.

Arai and Harding (2002) provide a wide selection of abstracts of literature on ethnic minority women’s use of sexual and reproductive health services.

One example of a guide written for a particular community is “Pregnancy and Birth a guide for deaf women” by Sabina, a book available from the RNID.

Searching the world for leaflets in different minority languages on health topics, NHS Greater Glasgow found no resources at all available on a variety of sexual health topics, including lesbian and bi-sexual relationships, sexual assault, sexual abuse, rape, male and female sterilisation, puberty, and periods


The following are referred to in this briefing:


Chapple A, Ling M, May C (1998) General practitioners’ perceptions of the illness behaviour and health needs of South Asian women with menorrhagia Ethnicity and Health 3(1/2): 81-93


http://www.dh.gov.uk/assetRoot/04/07/54/87/04075487.pdf


Health Topic Briefings

http://www.scotland.gov.uk/cru/kd01/red/auditethnic-00.asp


Roshan, N (2005) Supporting New Communities: a qualitative study of health needs among asylum seekers and refugee communities in North Glasgow NHS Greater Glasgow


(return to contents)
AGE

Why it matters

The NHS Reform (Scotland) Act 2004 extends the duty to encourage equality of opportunity to issues of age. It acknowledges that there are specific issues relating to age that impact on prevention, diagnosis, treatment and care. The issues facing both older people and children and young people are relevant.

Older people are the main users of many health services. However, this does not necessarily mean that they are designed with older people’s needs in mind. A traditional service designed around isolated episodes of care within well-defined specialties and agencies cannot fully meet the needs of the increasing numbers of older patients, especially those with chronic, multiple and recurrent medical problems. It is also possible for older people to be directly discriminated against or have their needs ignored.

At the same time, the view that older age is synonymous with ill-health is a stereotype which needs to be challenged. There are no illnesses or disabilities which are an inevitable part of ageing.

The Children and Young People’s Health Support Group has reported that, within a healthcare system inevitably challenged by adult health needs and particularly in the context of an ageing population, specific and conscious attention has to be given to ensure that the very different health needs and requirements of children and young people are prioritised and addressed (Scottish Executive, 2006).

Though there are well established child health specialisms, it is important to ensure that attention is paid to the general, and especially mental health, needs of young people. There are special skills involved in communicating with young people at various stages, and in involving them in decisions and in improving their own health.
“Unlike race or gender, age does not define a discrete group. We have all been young, and we will all, if we are fortunate, become old. Thus the basic opposition between ‘self’ and ‘other’ which marks much of racism and sexism is not present in the same way. Yet detrimental treatment on grounds of age is widespread. Older people in particular, are subject to stigma, prejudice and social exclusion. The very old are too often also the poorest in society, and some are vulnerable to abuse” (Fredman S, 2001 What do we mean by age equality? IPPR, London

http://www.ippr.org/uploadedFiles/projects/Final%20Fredman%20paper.doc

Three out of four senior health managers surveyed by the King’s Fund in England believed age discrimination existed in their local services. There was a daunting legacy of ‘old habits’ to tackle – custom and practice which had been evolved rather than planned, coupled with a legacy of ageism in society and welfare provision (Roberts et al, 2002).

Key facts

• 32% of people aged 60-74 have a long term illness or disability, and 45% of people of 75 or over (Scottish Executive, 2004)

• 57% of all the people who have long term illnesses are 60 or over (Scottish Executive, 2004)

• life expectancy has increased but healthy life expectancy has not increased at the same rate (Source: ScotPHO)

• in the most recent Scottish Health Survey the proportion of children who reported having smoked in the previous week increased from 2% at age 12 to 29% at age 15 (Scottish Executive, 2005)

• 30% of girls and almost 35% of boys between the ages of 2 and 15 are either overweight or obese (Scottish Executive, 2005)
• along with the rest of the UK, Scotland continues to have the highest rate of teenage pregnancy in Western Europe (Information Services Division, 2005)

• among all first admissions to mental illness specialties in Scottish hospitals (2001/02), 17% of the men and 13% of the women were under 25 (Scottish Executive, 2004)

OLDER PEOPLE

Issues

Attitudes

Older people are often reluctant to criticise health services, and most report very positive experiences (Chief Medical Officer, 2002). However, areas of concern about the way older people are treated can arise, including:

• decisions about access to various treatments and interventions should always be based on the detailed circumstances of the individual patient, with individual patients and their carers fully informed about the options, and not on age alone;

• national guidelines recommend discussion about possible resuscitation with patients for whom the risk of cardiac arrest is predicted to be high;

• older people from ethnic minorities are particularly likely to need translation, interpretation and advocacy services;

• sensory impairment or frailty should never be associated with stupidity, and may mean advocacy or other support is required (all from Chief Medical Officer, 2002).
When older people report a particular positive experience with the health service, it tends to be because they feel that staff treat them with respect and kindness, rather than because they feel the level of service they receive is exceptional. When they describe their worst experience of the health service, they tend to focus on poor or lack of medical treatment, and long waiting times, rather than on criticising the way that staff treat them at a personal level (Braunholtz S, Stalker B Public Attitudes to the Healthcare of Older People in Scotland Scottish Executive, Edinburgh, 2002 http://www.scotland.gov.uk/cru/kd01/red/path-00.asp)

Support

Older people are more likely to be re-admitted to hospital than younger ones, and to require multiple admissions. As the numbers of the very old increase, most acute care services will be looking after increasing numbers of older, frailer patients. But the majority can be returned home safely by a combination of multidisciplinary rehabilitation, good discharge planning and management, and a collaborative approach involving community services (Chief Medical Officer, 2002).

Medicines can be prescribed by both hospital and primary care doctors and bought over the counter. Critical review of medication reduces risks but is not widely enough practised. Medication for older people should be dispensed in accessible form and with legible labelling and advice. ‘Child-proof’ containers may not be suitable for older people (Chief Medical Officer, 2002).

Screening

Routine health checks are available in primary care for people aged 75 or over. ‘Adding Years for Life’ (Chief Medical Officer, 2002) recommends:

- screening of the over 75s should be reviewed, with a greater focus on identifying important problems such as falls, mental impairment, increasing dependency, oral disease, poor nutrition, poor foot care, tobacco and alcohol use.
Poor oral health is common in later life and less than 30% of over 75s are registered with a dentist. Mouth infections and gum disease are common complications of some of the commonest diseases of later life – such as stroke, Parkinson's disease and dementia – yet professional awareness of oral health is low. Examination of the mouth is neglected and treatable conditions are missed. (Chief Medical Officer, 2002).

Health Promotion

Healthier lifestyles can bring benefits at all ages and the need for health promotion does not disappear amongst older people. Recommendations that have been made include:

- health promotion campaigns should actively target and involve older people (Chief Medical Officer, 2002);
- health professionals should be aware of the possibility of problem drinking in older people and be ready to help (Chief Medical Officer, 2002);
- mental health promotion programmes should include and provide for older people (UK Inquiry into Mental Health and Well-Being in Later Life, 2006).

Abuse

Attitudes towards older people are also undermined by negative stereotypes which in their extreme have led to what is called Elder Abuse. This includes violence, harassment, threatening behaviour and any other conduct which may incur physical or mental injury, fear, alarm or distress to an older person. Age Concern Scotland estimates that between 7% and 9% of older people in Scotland are victims of at least one form of abuse (see box).
Of calls about abuse to the Scottish Helpline for Older People 70% were about abuse occurring in the person’s own home, 10% in hospital, 10% in community based care settings and 3% in care homes (Helpline number: 0845 125 9732) Age Concern: http://www.ageconcernscotland.org.uk/section/default.asp?p=134

YOUNGER PEOPLE

Issues

The Children (Scotland) Act 1995 defines a child as a person under the age of 18 years. Youth services often work with young people up to the age of 25.

The national ‘Walk the Talk’ initiative identifies several ways in which young people might feel excluded from conventional services:

- little access to youth focused services
- lack of information designed for young people
- lack of consultation with young people
- general services being “inhospitable”
- fears about patient confidentiality (Walk the Talk Resource Pack).
Designing appropriate services

For those with more serious conditions, the competing demands of local accessibility and maintenance of service quality pose special challenges in many areas of child healthcare practice. Attendance at a geographically distant hospital can be distressing for the child, involve substantial disruption for the parents, carers and other family members and can raise issues of loss of schooling, financial pressures and time off work for parents (Scottish Executive, 2006).

Improving services for young people does not always have to be a huge task requiring significant resources and time. A practical example of making a change without too much effort would be to provide reading materials in waiting rooms that were suitable for young people. Another example would be to have an appropriate ‘set time’ in the week when the young people could receive services (Walk the Talk Resource Pack).

Involving and consulting young people

It is important not only to view children and young people as recipients of the National Health Service but also as partners in decisions involving their health and healthcare. It is important that staff working in the NHS are given the opportunity to develop effective communication skills to work with children and young people. With children, a difficult and changing balance needs to be struck between independence and participation on the one hand, and protection of the child’s interests on the other.

Dialogue Youth is a national partnership to encourage the involvement of young people in having a real say in the services that affect them, and is working to include health services in this. It has a network of local coordinators (listed at http://www.dialogueyouth.org/).
Mental health is a key determinant of health, even in childhood

- Surveys in the UK continue to show that as many as 10% of children aged 5 - 15 yrs have clinically diagnosed disorders of mental health that affect their daily life

- Young carers are twice as likely as their peers to have mental health issues (Scottish Executive, 2006)

The opportunity to influence long term health

Behaviour and attitudes formed when people are young may shape their health for life, and young people are therefore a priority for health improvement.

A review of evidence finds some grounds for optimism: it is possible that (among males at least) smoking is on the decline, and the great majority are having reasonably good (and safe) sex lives, which could probably be made better with a sensible societal response (West and Sweeting, 2002).

However there are several areas for concern. Levels of obesity are rising. At every level (from relatively minor symptoms to severe disorder and suicide) there are significant numbers of young people with mental health problems. There is overwhelming evidence that the diet of Scottish young people (as with the adult population) falls well short of what is regarded as good for health. There is also substantial evidence that the majority of males, and the great majority of females, are not meeting national targets for physical activity levels (West and Sweeting, 2002).
Abuse

Child Protection has been identified as a key issue for health and other agencies following a series of high level inquiries in Scotland and elsewhere in the UK. Health care providers need to know how to identify when abuse is present and how to address issues of reporting and prevention as a fundamental part of child safety. See: http://www.scotland.gov.uk/Topics/People/Young-People/children-families/17834/10227

Research and where to find it

For an overview of national data on disability see Scottish Executive (2004) (especially Chapter 6: Health and Care).

‘Adding Life to Years’ (Chief Medical Officer, 2002) and ‘Delivering a Healthy Future’ (Scottish Executive, 2006) provide thorough reviews of the issues affecting the health care of older and young people respectively in Scotland.

The SHARE database, which is part of the Royal Bank of Scotland Centre for the Older Person’s Agenda, aims to promote the sharing of good practice about working with older people and initiatives that aim to enhance the quality of their life. http://www.qmuc.ac.uk/opa/share/

The Scottish Youth Health Network lists several resources for involving young people and links to research http://www.healthscotland.com/uploads/documents/mix3.pdf

The Scottish Public Health Observatory provides a wide range of data at http://www.scotpho.org.uk/

The following are referred to in this briefing:
**Fair for All Equality and Diversity:**
**Handbook for NHS Scotland**

**Health Topic Briefings**

Age Concern – Web page to elder abuse

Braunholtz S, Stalker B, Public attitudes to the healthcare of older people in Scotland.
Scottish Executive, Edinburgh, 2002
http://www.scotland.gov.uk/Publications/2002/02/10635/File-1

Scottish Executive, Edinburgh
http://www.scotland.gov.uk/library3/health/alty-00.asp

The Children (Scotland) act 1995

http://www.ippr.org/uploadedFiles/projects/Final%20Fredman%20paper.doc


The NHS Reform (Scotland) Act 2004

King’s Fund, London (Summary:
http://www.kingsfund.org.uk/document.rm?id=5691

http://www.scotland.gov.uk/Publications/2004/08/19818/41697


Executive, Edinburgh http://www.scotland.gov.uk/Publications/2006/04/07102245/0


Walk the Talk Resource Pack
http://www.walk-the-talk.org.uk


Sources of information and advice

Fair For All - Age is a partnership between the Scottish Executive Health Department and Fast Forward Positive Lifestyles
http://www.fastforward.org.uk/our-work/fair-for-all-age/

Age Concern Scotland
0845 833 0200 http://www.ageconcernscotland.org.uk/

Help the Aged 0131 551 6331 http://www.helptheaged.org.uk/

Children in Scotland 0131 228 8484 http://www.childreninscotland.org.uk/

Scotland’s Commissioner for Children and Young People 0131 558 3733 http://www.sccyp.org.uk/

Children 1st 0131 446 2300 http://www.children1st.org.uk/
Health Topic Briefings

Barnado’s Scotland 0131 334 9893  http://www.barnardos.org.uk/scotland.htm

Fast Forward Positive Lifestyles is a national voluntary organisation which promotes health through education by, with and for young people
0131 554 4300  http://www.fastforward.org.uk/

‘Walk the Talk’ is an initiative funded by NHS Health Scotland. It is designed to promote young people’s health and wellbeing and improve young people’s access to health services provided by the National Health Service, local authorities and voluntary organisations. The website www.walk-the-talk.org.uk provides information, practice examples guidelines and tools to assist and support in developing practice.

(Return to contents)
DISABILITY

Why it matters

Under the Disability Discrimination Act 1995, it is unlawful for a provider of services to discriminate against a disabled person, defined as anyone who “has a physical or mental impairment which has a substantial and long-term adverse affect on his ability to carry out normal day-to-day activities.”

Discrimination can occur in the standard of service or in the manner or terms on which it is provided. Discrimination occurs when a person or organisation treats a disabled person less favourably than they would treat others for a reason which relates to the disability, unless this is ‘justified’ for a strictly limited number of reasons. For example, responding unsympathetically to someone you believe is acting unreasonably, when their behaviour is in fact due to their disability, can be a form of discrimination.

Everybody who works in NHS Scotland, and all other public services, has a responsibility under the Act to stop discrimination from happening and to ensure that disabled people have equal access to health services.

The UK Disability Equality Duty came into effect on 4 December 2006. It introduces a new duty on the public sector to actively promote equality of opportunity for disabled people and eliminate harassment and discrimination. Public authorities must give due regard to the need to treat disabled people more favourably. This is distinct and unique to disability discrimination in equality law.

Disability can involve physical difficulties in movement, use of the limbs etc. But it can also involve sensory difficulties, with sight, hearing or both together; learning difficulties and problems such as autism; and communications difficulties.
It is also important to remember that, whether or not we normally speak about disability in such circumstances, the law offers protection to people with long term mental health problems such as depression or schizophrenia. In fact there is no fixed list of types of disability. Cancer, coronary heart disease, cognitive conditions such as dementia and many other long-term conditions may also give rise to disabilities. Someone may potentially be covered by the Disability Discrimination Act even if they do not consider themselves to be disabled.

Many different medical conditions can give rise to disabilities: “I still face significant access problems when visiting specialists such as dentists or chiropodists. I need specialist equipment (humidifiers and oxygen permanently available) to assist me. That is rarely available at the premises of these specialists, making it very difficult for me to visit the dentist or the chiropodist.” FMR Research (2006), Final report: Fair for All – Disability: service user consultation NHS Greater Glasgow.

People with disabilities can suffer poorer health outcomes for a wide variety of reasons:

• because people physically cannot get access to services, or communicate with service providers, or are deterred from doing so

• because their health is accorded less value and priority than other patients

• because disabled people they may sometimes press less hard for further interventions than other patients

• because of ‘diagnostic overshadowing’: reports of physical ill health being viewed as part of a mental health problem or learning disability (or perhaps an unrelated physical disability)

• because people with long term disabilities are particularly likely to live in poverty

• because some disabilities, including mental health conditions, are linked to higher incidence of particular health problems.
The Disability Rights Commission has looked at the experiences of people who, by virtue of their mental health problem or learning disability, would be likely to be protected from discrimination by the Disability Discrimination Act. Their researchers encountered complacent attitudes at times – that people with learning disabilities or mental health problems ‘just do’ die younger, that they ‘just won’t’ look after their health or attend treatment. The Commission wants to make these a matter of history (DRC, 2006).

Key facts

• The 2001/2002 Scottish Household Survey estimated that just under one in five adults in Scotland have a disability and/or a long term illness

• Nearly one-third of adults with a disability have visited their GP on more than 10 occasions last year, compared with 5% of non-disabled adults

• Disabled adults and those with a long-term illness are more likely to smoke (32% and 35% respectively) compared to non-disabled adults (27%)

• In 2001, it was estimated that over 30,000 people were admitted to hospital with a mental health illness (1 in 4 people in Scotland will experience a mental health problem at some point in their lives)

• In 2003, there were 38,000 registered blind or partially sighted people in Scotland

• There were estimated to be 758,000 deaf or hard of hearing people in Scotland in 2003 (All information from Scottish Executive, 2004).
General Issues

The social model of disability says that disabled people do not have to be ‘fixed’ so they can fit into society, but that the social structures and attitudes of society need to be changed to ensure that disabled people are treated as equal citizens. Services may need to be delivered differently or additional services offered to ensure that disabled people have equality of access.

The medical model of disability explains the barriers faced by disabled people in their daily lives as limitations caused by their disability. The practical consequence is that the wider needs of the person can be missed or ignored, as can the potential contribution that person can make to society.

NHS Scotland promotes the social model of disability, to value the individual, make services person-centred, and to treat all people with dignity and respect.

SENSORY DIFFICULTIES/IMPAIRMENTS

Key facts

- The average GP will have up to four patients with hearing loss in their surgery every day. But 35% of deaf and hard of hearing people have experienced difficulty communicating with their GP or nurse and 32% find it difficult to explain their health problems to their GP (RNID, 2004).

- 15% of deaf and hard of hearing people say they avoid going to see their GP because of communication problems; this proportion doubles among British Sign Language (BSL) users (RNID, 2004).

- Only one tenth of blind and partially sighted people received a hospital appointment letter in their preferred format (Nzewgu, 2004).
• 45% found the signage in hospital unhelpful (Nzwegu, 2004).

• There are about 23,000 deafblind people in the UK. If elderly people with decreasing sight and hearing are taken into account the figure rises to about 250,000 (Sense UK and Deafblind UK, 2001).

• Nearly half of deafblind people sampled have undergone procedures (operations, injections, drips) that had not been explained (Sense UK and Deafblind UK, 2001).

Issues to think about

Communication is about the simplest things, not just letters, leaflets and medical consultations

For example deaf and hard of hearing people may miss an appointment because of poor communication, such as not being able to hear staff calling out their name: 24% of 866 surveyed said that this had happened (RNID, 2004). Over half of blind and partially sighted survey respondents (55%) required help in finding a seat in the waiting area, yet only about half (26%) received it. Then 65% needed help getting from the waiting area to consulting room, yet just under one-third received no help (Nzwegu, 2004).

For some people, British Sign Language is their first language

BSL is not a form of English, but a separate language. Though there is a national shortage of interpreters, there are other ways that hospitals and GP surgeries can supply communication support to BSL users. For example, using video telephones to support remote interpreting. It is also possible to take very practical steps to improve basic communication of staff in BSL and better written information in plain English (RNID, 2004).
In the health sector in general, the assumption was that the end-user needed an interpreter to understand only what the [service provider] said. In fact, consultations involve two-way communication. What was often forgotten was that patients also needed to communicate and that the interpreter also provided a service to the doctor or service provider. Some providers admitted depending too much on informal interpreting provided by family or in-house staff (even staff with a very basic level of language competence e.g. BSL level 1), as well as relying too much on writing things down.

Translating, Interpreting and Communication Support: A Review of Provision in Public Services in Scotland


Deafblindness is a unique impairment with specific effects on the lives of individuals

Sense UK’s survey (Sense UK and Deafblind UK, 2001) suggests that a third of deafblind people feel that their GP does not understand their needs; half feel that their needs were not fully understood as an outpatient; and 75% feel that their needs were not understood when they were in hospital. For example, half were not told when their food had arrived, which is the same as not providing any food at all.
LEARNING DIFFICULTIES AND DISABILITIES CAUSED BY MENTAL ILL-HEALTH

Though these are very different problems, some of the research has considered them together. The Disability Rights Commission has undertaken a formal investigation, using its statutory powers, into the physical health inequalities experienced by people with learning disabilities and/or mental health problems because of the significant evidence that both experience greater discrimination (DRC, 2006)

Key facts

• International evidence shows that people with learning disabilities or long-term mental health problems on average die 5 to 10 years younger than other citizens, often from preventable illnesses (Nocon, 2006).

• People with learning disabilities and people with mental health problems are much more likely than other citizens to have significant health risks and major health problems. For people with learning disabilities, these particularly include obesity and respiratory disease; for people with mental health problems, obesity, smoking, heart disease, high blood pressure, respiratory disease, diabetes and stroke (DRC, 2006, based on data for England and Wales).

• For people with mental health problems, some tests and standard treatments – such as spirometry to identify respiratory illness or cholesterol checks and statins for people with heart disease – are given less often than to people without mental health problems (DRC, 2006).
Issues to think about

Fair for All – Disability (2006) recommends practical steps in meeting the needs of people with a mental health problem. These are some of them:

• Provide longer appointment times to allow fuller exploration and explanation.
• Appointment times need to be flexible as there may be some times of day unsuitable to some people taking certain medications.
• All staff, including administrative staff, should receive mental health awareness training.
• People with a mental health problem should be encouraged to bring along a friend, relative or advocate to appointments if they wish.
• Allow time to listen to what the person is saying and respect their knowledge of their own health, medication and their responses.

Groups of people with learning disabilities said that the following things were important for them:

• use words we understand
• listen to us and don’t rush us
• ask us questions first, but it is also good to ask questions of our carers and family who know us
• explain what is going to happen, as this helps to reassure and calm people
• make sure people are comfortable before starting any procedure

(Fair for All – Disability, 2006).

‘In almost all interviews with primary care staff we heard about patients from these groups who don’t follow advice as given, don’t attend for appointments and who can’t cope with the implications of the advice they have been given. There did not seem to be any strategies in place to support these groups to follow any advice or guidance they might have been given’ (DRC, 2006).
Going to the doctor can be a very stressful experience for people with an autistic spectrum disorder and their carers. This can be due to: fear of the unexpected, bright lights, noises etc, invasion of personal space in crowded waiting rooms or communication difficulties. The National Autistic Society has suggested strategies for dealing with this: [http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=1064&a=11440](http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=1064&a=11440)

**MOBILITY DIFFICULTIES**

**Key facts**

Of Scottish adults with a long-term illness, health problem or disability in 2001 and 2002:

- 42% had problems or disabilities related to their legs or feet
- 24% had problems or disabilities related to their neck or back
- 19% had problems or disabilities related to their arms or hands.

(Scottish Executive, 2004)

These are among the most common forms of disability, and while it is undesirable to think about disability only in terms of mobility, the experiences of people with these forms of disability may be under-researched.
Physical accessibility requires “more than a ramp and a handrail”

Some adaptations are required by people with mobility difficulties and some particularly needed by people with sensory difficulties. But there is no hard and fast distinction – good lighting can benefit people with mobility difficulties too. Guidance from the Fair for All – Disability project (see ‘Sources of Information and Advice’) contains checklists for improving many aspects of:

- Car parking and transport
- Approaches to buildings
- Entering and exiting buildings
- Signage
- Receptions and waiting areas
- Consulting rooms and examination areas
- Accessible toilets
- Emergency evacuation procedures.

Many issues have to be taken into account, but they include:

- Manoeuvrability
- Eliminating distractions to vision or communication
- Safety – e.g. eliminating slip and trip hazards
- Accessible heights for counters, push buttons etc
- Clear and consistent routes, signs etc
- Staff awareness (Fair for All – Disability, 2006).

Removing, altering or avoiding barriers in the premises can involve something as simple as keeping areas clear of rubbish, or other obstructions.
The need for involvement of disabled people

When designing or re-furbishing facilities it is important to think about how disabled people will navigate their way around an unfamiliar environment. The particular needs of disabled people must be considered from the initial planning stages, in partnership with local disability groups and forums. For example: it is not enough for the planners to build in one accessible route from the car park to the building entrance, on the assumption that this will be the preferred route for disabled people (Fair for All – disability, 2006).

COMMUNICATION SUPPORT NEEDS

Key facts

There are a variety of reasons why someone may need communication support:

- visual or hearing impairment or dual sensory impairment
- brain damage, perhaps following brain injury, stroke or a brain tumour
- failure to develop speech, language and interaction skills as a child
- problems with the speech organs, due to conditions such as cleft palate or laryngeal cancer
- progressive conditions such as Parkinson’s disease, motor neurone disease, or dementia
- stammering affecting fluency of speech.

In Scotland the Adults with Incapacity (Scotland) Act 2002 requires healthcare professionals to get consent before examining or treating patients. This cannot be done effectively without considering possible communication support needs. There is also a statutory requirement to take account of wishes and feelings of those patients, and that these are ‘ascertained by means of communication appropriate to the adult’. This may for example require the help of other specialists such as speech and language therapists.
One short study in Scotland has talked to both General Practitioners and people with a communication disability (using special visual techniques) about their experience of consultations (Murphy, 2006). It describes issues that arise in many health settings:

- GPs expressed their frustration with not being understood and not understanding but there was a lack of awareness of the reasons behind these difficulties. They all said they mainly relied on carers.

- People with communication support needs described significant problems before even seeing the doctor including using the phone to make the appointment, understanding the receptionist and feeling anxious in waiting room.

- Concerns during the consultation included difficulty remembering what to say, not being understood, feeling the doctor did not believe them, being rushed and not understanding the doctor because s/he spoke too fast and used words they did not understand.

- Although some acknowledged that they needed help from their carer, most wanted independence and privacy and objected to the doctor speaking to the carer and not to them.

Law et al (2005) argue that people with communication difficulties serve as a litmus test for whether practitioners are truly sensitised to the impact of their own communication skills. Effective communication is not simply a set of taught behaviours but reflects a set of values that create the conditions for improving both communication and clinical outcomes.

Fair for All - Disability (2006) provides checklists of forms of communication support and assistive technology, and where to get more information about them.
Many people with dementia, including those with significant communication difficulties, can, with the right kind of support, take an active role in communicating their thoughts and feelings about services (Allan K, 2001 Communication and consultation: Exploring ways for staff to involve people with dementia in developing services Joseph Rowntree Foundation, York http://www.jrf.org.uk/bookshop/eBooks/186134810X.pdf)

Research and where to find it

For an overview of national data on disability see Scottish Executive (2004) (especially Chapter 6: Health and Care).


Nocon A (2006) Background evidence for the DRC's formal investigation into health inequalities experienced by people with learning disabilities and/or mental health problems


Health Topic Briefings


http://www.rnid.org.uk/VirtualContent/84923/asimplecure.pdf

http://www.scotland.gov.uk/Publications/2004/08/19818/41697


Scottish Human Services Trust (2004) “We’re still waiting”: deaf people’s experiences of the struggle to improve their health and well-being SHS Trust, Edinburgh


Sources of information and advice

Fair for All – Disability team
2nd Floor, The Beacon
176 St Vincent Street
Glasgow G2 5SG
0141 249 6599
Email: fairforall-disability@drc-gb.org
www.fairforalldisability.org
The Fair for All – disability project has produced guidance (Fair for All – disability, 2006) specifically to help NHS staff implement Part 3 (Goods, facilities and services) of the Disability Discrimination Act. This is a key resource, which does all that this briefing tries to do and much more, including checklists of issues to be taken into account. It is still being added to. [http://www.drc.org.uk/fair4all/achievingfairaccess/pdf/whole-guidance.pdf](http://www.drc.org.uk/fair4all/achievingfairaccess/pdf/whole-guidance.pdf)

**Other guidance:**


Health Topic Briefings

Organisations:

Disability Rights Commission (Scotland)
E-mail: scotland@drc-gb.org
http://www.drc.org.uk

RNID
0141 341 5330
Textphone: 0141 341 5347
Email: rnidscotland@rnid.org.uk
http://www.rnid.org.uk/

RNIB
0131 311 8500
Email: rnibscotland@rnib.org.uk
http://www.rnib.org.uk/

Scottish Association of Mental Health
0141 568 7000
Email: enquire@samh.org.uk
http://www.samh.org.uk

(return to contents)
ETHNIC MINORITIES

Why it matters

Most of us probably have more mixed ethnic origins historically than we realise. The group into which you are born and to which others see you as belonging can have profound implications for your health experiences.

- Some ethnic groups may be more or less prone to particular medical conditions for genetic reasons
- People may experience discrimination or disadvantage because of their ethnic origin
- Cultural differences may affect people’s health behaviour and use of services
- Linguistic and cultural differences may prevent effective communication about health services and issues.

People may be discriminated against on grounds of race, colour, nationality, ethnic origin or national origin. It is important to be cautious when classifying people. For example much research looks at ‘South Asian’ people as a group, but other research (e.g. Nazroo, 1997) goes into more detail and finds significant health differences between people of Pakistani, Indian and Bangladeshi heritage. Religious differences may also be significant.

Under the Race Relations Act (1976), it is unlawful to discriminate against anyone on grounds of race, colour, nationality (including citizenship), or ethnic or national origin. All racial groups are protected from discrimination.
Key facts

- The 1999 Health Survey for England (Calderwood and Tait, 2001) found that Pakistani and Bangladeshi people generally reported having worse health than the general population.

- Pakistanis and Bangladeshis of both sexes were more than five times as likely as the general population to have diabetes, and Indian men and women were almost three times as likely; Africans/Caribbeans also have higher rates than the white population (Primatetsta and Brookes, 2001).

- Compared to other minority ethnic groups and the general population, black Caribbean women and men were more likely to be “light” smokers. However they were less likely to smoke more than 20 a day (Boreman, 2001).

- In all ethnic minority groups except the Irish, people were less likely to drink alcohol, or consumed smaller amounts, than in the general population (Erens and Laiho, 2001).

- The 1999 Ethnic Minority Psychiatric Illness Rates In the Community survey of Great Britain found that depressive episodes were most common among Indian and Pakistani informants, and least common in the Bangladeshi and Black Caribbean groups; Pakistani and Bangladeshi people generally were likely to have higher levels of chronic strain, than the general population, though this appeared to be related to socio-economic factors (Sproston and Nazroo, 2002).

- After adjusting the results for age differences, Asian men and Pakistani and Bangladeshi women were more likely than all other groups, including white, to have spoken to a doctor within the last six months (Bajekal, 2001).
• National surveys of NHS patients in England report that ethnic minority groups were more likely than average to report unfavourably on their experiences in respect of:

  – waiting times
  – understanding explanations
  – trust in doctors and nurses
  – being treated with respect and dignity, and
  – help with pain relief (The Picker Institute, 2006).

• Gypsy Travellers have significantly poorer health status and significantly more self-reported symptoms of ill-health than other UK-resident, English speaking ethnic minorities and economically disadvantaged white UK residents (Parry et al, 2004). There has been little research in Scotland, but a pilot study has been done in Highland (NRCEMH, 2006).

• The literature suggests that most asylum seekers and refugees arrive well and in apparent good health. There is evidence to suggest that health status of new entrants may worsen in two or three years after entry to the UK (Roshan, 2005).

• Evidence on self-reported health suggests that increasing age amplifies ethnic inequalities in health (Cooper et al, 2000).
Differing patterns of morbidity

The condition where ethnic differences appear sharpest is Type 2 diabetes (NRCEMH, 2004)). Even though there appears to be a physical basis for this, the actions needed to deal with it effectively are largely to do with communication. The clinical services to deal with type 2 diabetes are likely to be available, but making the services appeal to a group that needs them and is underutilising them requires cultural competence. For example a report by the National Resource Centre for Ethnic Minority Health (NRCEMH) recommends that staff providing care should receive appropriate training and have access to effective support (e.g. guidance, appropriate patient audio-visuals in the required language, support information, interpreter services), enabling them to provide a culturally-competent service.

In a survey for the NRCEMH report, 71% of Local Health Care Co-operatives (now Community Health Partnerships) responded that diabetes was part of their LHCC plan. But 69% indicated that ethnic group was not recorded by community services and GPs, and 80% did not monitor trends of complications of diabetes by ethnic group. (Baradaran HR, Jamieson J, Gardee R, Knill-Jones RP (2006) Scottish survey of diabetes services for minority ethnic groups BMC Health Services Research, 6:130 http://www.biomedcentral.com/1472-6963/6/130).

Although there are some genetic differences between groups, these interact with people’s experiences, as migrants perhaps, or as members of a minority group. This can happen in ways that might be seen as unexpected.

• For both migrant Caribbeans and migrant South Asians in Britain, cardiovascular mortality was positively associated with duration of residence. Changes in health related behaviours may have been involved.
• This applied in all age groups for South Asians, but mortality was also associated with age at migration for Caribbean groups. Factors at work may include:

– high levels of mistrust for doctors amongst older black Caribbeans
– generally lower coronary heart disease rates (with favourable lipid profiles) among African origin populations despite more obesity, diabetes and strokes than their British white counterparts.

• UK-born Caribbeans appear to be losing this more favourable lipid pattern and smoking more (Abbotts et al, 2004; Harding et al, 2004).

Other differences stem purely from the experience of being a relatively disadvantaged minority. Nazroo (1997) made an assessment of the overall standard of living of black and minority ethnic (BME) survey respondents. After taking variations in standard of living into account, the incidence of coronary heart disease for Pakistani and Bangladeshi people (combined) was no longer significantly greater than for the white population. Amongst people of Indian or African Asian background it was actually significantly lower.

The effect of negative experiences, whether of racism or of social disadvantage, is likely to be particularly acute for refugees and asylum seekers, who have typically had traumatic experiences both before and after arrival. Asylum seekers and refugees may experience isolation, lack of social support and community infrastructure, and may have had negative previous experiences of health services.

• A 2004 study conducted in North Glasgow found that only 34% of asylum seekers rated their mental and emotional well-being as positive, compared to 80% of residents of the North Glasgow Social Inclusion Partnership area (Roshan, 2005).
A study sought to explain an excess of psychological distress previously found among groups of British South Asians living in Glasgow. Stressful situations assessed were experience of assault, stress/dissatisfaction with work, overcrowding, low standard of living, absence of family and absence of confidants. The standard General Health Questionnaire appeared to underestimate stress from these sources, compared to other measures. (Williams R, Hunt K (1997) Psychological distress among British South Asians: the contribution of stressful situations and subcultural differences in the West of Scotland Twenty-07 Study Psychological Medicine 27(5):1173-81).

Cultural and language issues

• Ethnic groups may typically have different patterns of health-related behaviour from each other.

  – For example, in Greater Glasgow, around half of Chinese and African/Caribbean respondents were meeting the Scottish Diet Action Plan target of eating at least 5 portions of fruit and vegetables a day, compared to around a third of the general population and Indian respondents and only one fifth of Pakistani interviewees (Heim & MacAskill, 2006).

• Different presumptions about the purpose of various health and social services may exist, especially amongst migrants.

  – Although second-generation migrants were more pro-active about seeing the dentist than the first generation, the dentist was still seen by many as a problem-solver rather than someone to visit for a regular check up (Mullen K, Macpherson LMD, Gardee R  Ethnic background and oral health ideas and practices: a qualitative study Summary of Final report to CSO http://www.sehd.scot.nhs.uk/cso/Publications/ExecSumms/JanFeb05/9.4%20Mullen.pdf)

• Female service users of several differing minority ethnic groups have strong preferences for dealing with only female health care staff.
• Health service staff may perpetuate negative stereotypes and beliefs about people from BME communities.

“In our findings ... it was a widespread acceptable and legitimate professional practice to talk of black and minority ethnic women as ‘a nuisance’. In GPs surgeries, hospitals or clinics professionals treated the women’s ‘stories’ about illness, poverty and stress with intolerance and disbelief.” (Mirza HS, Sheridan A-M (2003) Multiple identity and access to health: the experience of black and minority ethnic women Working Paper 10 Equal Opportunities Commission, London http://www.eoc.org.uk/PDF/multiple_identity.pdf)

• Different perceptions of illness and health may be passed on within different cultural groups.

A study of experiences of dementia among older South Asian people in Scotland demonstrated poor quality of life, desperate needs for support, and lack of access to appropriate services. Lack of knowledge, stress on carers etc were common to all ethnic groups, but the South Asian group had particularly negative views about residential care, and tended to see the term ‘dementia’ as stigmatising rather than neutral (Bowes A, Wilkinson H (2003) ‘We didn’t know it would get that bad’: South Asian experiences of dementia and the service response Health and Social Care in the Community 11(5):387-96).

In Greater Glasgow “Chinese respondents were less likely than all other minority ethnic groups and the general population to have made use of health services in the year preceding their interview. This is likely to have been the result of a combination of factors. First, Chinese respondents reported using a combination of traditional Chinese and Western medicine. Second, Chinese respondents reported the lowest levels of satisfaction with service providers. This suggests a need for consultations with the Chinese community regarding how service provision can be improved to cater for specific community needs” (Heim & MacAskill, 2006).

• Even when cultural factors appear protective of health, the need for sensitive services does not disappear.
In a sample of Pakistani, Indian and Chinese young people aged 16–25 years in Greater Glasgow, alcohol consumption was currently lower than that of the general population. But alcohol consumption may be increasing and service provision could benefit by including specialist services for black and minority ethnic groups, in addition to mainstream services that need to be culturally sensitive (Heim D, Hunter SC et al (2004) Alcohol Consumption, Perceptions of Community Responses and Attitudes to Service Provision: Results from a Survey of Indian, Chinese and Pakistani Young People in Greater Glasgow Alcohol & Alcoholism 39:3, 220-226 http://alcalc.oxfordjournals.org/cgi/content/full/39/3/220)

With all cultural factors it is important not to stereotype individuals, who will in reality be as varied in behaviour within groups as anyone else. This applies also to the issue of language. It is true, in Glasgow at least, that the majority of Pakistani, Indian, African and Caribbean people said in a survey that they would like to receive health related information in English (Heim & MacAskill, 2006). However, there are still many people who require interpretation and translation in order to receive equal access to services and health information. This is particularly true of older people, who are heavier users of NHS services. ‘Older’ people as defined in the report as those aged 50 plus.

“In the health sector [in Scotland] in general, the assumption was that the end-user needed an interpreter to understand only what the [service provider] said. In fact, consultations involve two-way communication. What was often forgotten was that patients also needed to communicate and that the interpreter also provided a service to the doctor or service provider” (Perez & Wilson, 2006).

Using family members to interpret is a common response. Staff in Primary Care stated that they would be guided mostly by the patient’s instructions as to whether this was appropriate. This response does however raise concerns about how the question would be put to the patient, as the family member might not translate the query; and how the patient could respond honestly without offending the family member who was actually interpreting (Perez & Wilson, 2006).
Research and where to find it

The Commission for Racial Equality’s summary of health statistics is at:
http://www.cre.gov.uk/duty/reia/statistics_health.html

Gill PS, Kai J, Bhopal RS and Wild S provide an on-line overview of needs assessment for black and ethnic minority groups, including some of the basic problems about definitions: http://hcna.radcliffe-oxford.com/bemgframe.htm

A review of research on ethnic minority issues, with a substantial chapter on health has been produced for the Scottish Executive (Netto et al, 2001)

Arai and Harding (2002) provide an extensive listing, with abstracts, of the literature on access to and use of services by ethnic minorities.

A wide variety of links to research on ‘South Asian’ health issues are provided at http://sawnet.org/health/

The following are referred to in this briefing and may be useful for further study:


Health Topic Briefings


http://www.scotland.gov.uk/cru/kd01/red/auditethnic-00.asp

Summary: http://www.shef.ac.uk/content/1/c6/02/55/71/GT%20report%20summary.pdf


The Picker Institute (2006) A secondary analysis of primary care survey data to explore differences in response by ethnicity:
http://www.napp.org.uk/Analysis%20of%20primary%20care%20survey%20by%20ethnicity%20(NAPP).doc


Race Relations Act 1976 Chapter 74, HMSO, London:
http://www.johnantell.co.uk/discriminationintrox.htm

Roshan, N (2005) Supporting New Communities: a qualitative study of health needs among asylum seekers and refugee communities in North Glasgow NHS Greater Glasgow
Health Topic Briefings

http://www.dh.gov.uk/assetRoot/04/02/40/34/04024034.pdf


Sources of information and advice

The Commission for Racial Equality (http://www.cre.gov.uk/scotland 0131 524 2000) is a key source of advice, especially on the implementation of equality legislation

The National Resource Centre for Ethnic Minority Health (NHS Health Scotland) http://www.nrcemh.nhsscotland.com/ 0141 300 1057 has a range of publications and resources available

NHS Greater Glasgow has produced a Directory of health information resources in 12 different languages available worldwide, many of them free to download http://library.nhsgg.org.uk/mediaAssets/library/nhsgg_black_ethnic_health_info_resource_directory_2004.pdf

**GENDER**

**Why it matters**

Health services are used in different ways by men, women and boys and girls. We generally think about men's and women's use of health services in terms of their sexual and reproductive health. They also have genetic, hormonal and metabolic differences that can affect the frequency, symptoms and prognosis of many other diseases. There are also significant differences between men's and women's living and working conditions and in access to resources which can create risk factors.

Because men and women expect and are expected to behave in different ways, they take different health risks and respond in different ways to health messages and services.

Health services need to take these gender differences into account, to ensure that they provide equal opportunities for good health for everyone, that services target different needs, and that health improvement work reaches and influences people effectively.

The Gender Equality Duty is the biggest change in sex equality law in 30 years. It will require NHS Scotland to ensure that the design, development and delivery of services are responsive to the different needs of women and men. Fair For All – Gender has provided guidance on how to implement the Gender Equality Duty within the NHS Scotland. This document is available at [www.eoc.org.uk/fairforallgender](http://www.eoc.org.uk/fairforallgender)

**Transgender conditions**

Transgender people are those who experience their own gender identity in ways that do not conform to common ideas (either as a classic ‘transsexual’ who is born into the wrong physical sex, or in other ways). There is increasing evidence of a biological basis for transsexualism. There are internationally recognised standards for treatment, whose aim should be social integration and prevention of psychological morbidity,
leading to a good quality of life. Many people who have made a transition do not identify as transgender at all, but as men and women. The Scottish Needs Assessment Programme report (2001) on transsexualism and gender dysphoria states that access to services for treatment and support is haphazard. Lack of knowledge and understanding of transgender conditions is widespread in health services.

Key facts

There are many variations in health between male and female. These include:

- Men typically develop heart disease ten years earlier than women
- Women are around 2.7 times more likely than men to develop an auto-immune disease such as diabetes
- Male-female infection with HIV is more than twice as efficient as female-male infection
- Men are more likely than women to commit suicide
- Women are 2-3 times more likely than men to be affected by depression or anxiety
- Men are more likely than women to die of injuries but women are more likely to die of injuries sustained in the home. (Doyal et al, 2003).

Women are on average more likely to be on a low income, and suffer the consequences for health:

- Retired women and lone parents are most at risk of poverty, and average incomes of women in work are lower (evidence is summarised in ‘Equal Minds’ (Myers et al, 2005) and many other places).
Domestic work, usually undertaken disproportionately by women, can have a negative impact on both physical and mental health:

- Caring responsibilities are a risk factor associated with possible mental ill health. Forty percent of women spend over 50 hours a week caring for someone living with them. (Department of Health, 2002).

- After a cardiac episode, women have difficulty with male-orientated “getting back to normal” rehabilitation. Going back to “house work” may not be an inspirational goal. (EOC, 2004).

Traditional masculine roles may involve more risk-taking:

- In the US, the four causes of death with the highest male to female ratio, are those most closely associated with gendered behaviour, not biological sex: accidents, suicide, cirrhosis (drinking) and homicide (EOC ‘Improving the health of men+ women’ briefing).

Health workers may make different diagnoses of men and women based on similar evidence and offer different treatment in the same clinical situations:

- Among people who reported chest pain to a GP in the West of Scotland, after controlling for type of pain, men were significantly more likely then women to receive a provisional diagnosis of CHD (Richards et al, 2000).

Domestic and sexual violence are major health hazards for women worldwide:

- 1 in 5 women experience abuse at some time in their lives and at any one point in time 1 in 10 women will be experiencing domestic abuse (Scottish Women’s Aid: http://www.scottishwomensaid.co.uk/whatisdomestic.html)
Issues to investigate

Roles and their impact

Men remain more likely than women to die prematurely from occupational diseases and injuries. Socialisation of men makes them more likely to smoke, drink excessively, drive dangerously and have unsafe sex (EOC ‘Improving the health of men+ women’ briefing).

There is a substantial body of research which links women’s experience of child sexual abuse and domestic violence with long term mental illness and also with physical and sexual health problems (WHO, 2005).

Gender and mental health

No single explanation can account for women’s higher rates of mental health problems overall, or the different patterns of diagnosed mental disorder between men and women. But the social and economic status of women, their experience of violence and abuse and the ways in which mental health and mental health problems are defined all play a part (Myers et al, 2005).

Reasons why men may not seek medical help

“To be powerful, men are required to appear invulnerable, to take risks, to be independent and not ask for help. A man can easily feel that once he starts to take care of his health he also somehow stops being a man” (EOC ‘Improving the health of men+ women’ briefing).

There are high rates for melanoma for women in Europe, but right across the continent more men than women die. The reason: their late presentation to see a doctor about that melanoma. (White & Cash, 2003).
Discussions with groups of Scottish men suggested a widespread endorsement of a view that men ‘should’ be reluctant to seek help, particularly amongst younger men. Examples where help seeking was more quickly embraced were when it was perceived as a means to preserve or restore an aspect of masculinity (e.g. working as a fire-fighter, or maintaining sexual performance or function). O’Brien R, Hunt K, Hart G (2005) ‘It’s caveman stuff, but that is to a certain extent how guys still operate’: men’s accounts of masculinity and help seeking Social Science and Medicine 61/3: 503-516.

**Reasons why women may not seek medical help**

Women are more likely than men to report practical problems in access to services. They are more likely to have caring responsibilities, for example, or to have transport problems (Doyal et al). But there are also some conditions that they under report.

In a study in the West of Scotland people were asked to describe likely ‘candidates’ for heart problems. All described men. When they talked about ‘unlikely’ people who had had problems, they also described men. Women remained ‘invisible’ when people spoke about heart disease. Emslie, C, Hunt, K, & Watt, G (2001) Invisible women? The importance of gender in lay beliefs about heart problems Sociology of Health and Illness 23(2): 203-233.

**Health service responses**

Mainstreaming gender equality requires changes at different levels within organisations: in policy making, planning, implementation and evaluation. New staffing and budgeting practices, training programmes, procedures and guidelines can all be required to ensure that delivery of equal outcomes is built in to practice.

It is unlikely that health promotion campaigns which do not take account of gender will be as successful as they could be, given that smoking, food, weight and body image, and alcohol consumption have all been so closely linked to ideals of masculinity and femininity.
Are there differences in generations?

Previous thinking may have indicated that gender differences were lessening in younger generations. For example, the proportion of women and men who smoke is now very similar in Britain, and female lung cancer mortality is increasing (EOC, 2004). Researchers find conflicting evidence. Waldron (2000) suggests that fundamental aspects of traditional gender roles continue to influence differences in health, and the effect of contemporary conditions upon them leads some types of behaviour to become more similar and others not. There was actually an inconsistent or weak tendency for increase in the sex ratio for total mortality in the USA, 1950-1990.

Gender and other inequalities

The gender division cuts across all the other sources of inequality, and within each group men and women may have different experiences. Other factors prevent people from receiving services appropriate to their gender. For example, disabled women are reported to be sometimes told that they do not need cervical smear tests, because of assumptions about their sexual behaviour (Breslin, 2003); lesbians who had ‘come out’ to their health care providers were more likely to seek preventative health care, such as breast screening or smears, but non-disclosure is common due to fear of negative responses and reduced standards of care (NHS Scotland/ Stonewall, 2003).

Asian women aged between 15–35 years are two to three times more vulnerable to suicide and self-harm than their non-Asian counterparts (Fitzgerald, 2006).
Comparative reports on a South Asian, predominantly Punjabi, population aged 30 to 40 years compared with the general population in Glasgow revealed that:

- South Asian men had a number of health advantages, including less long-standing diseases than the general population
- South Asian women were disadvantaged in a number of respects, reporting more chronic conditions than Glaswegian women in general
- the gender difference in the South Asian population is greater than in the majority population, particularly in regard to symptoms and chronic conditions (Williams et al, 1993).

Research and where to find it

Several authors provide short summaries of the position in the briefing ‘Improving the health of men+ women’, produced by the Equal Opportunities Commission (EOC)

Overviews of research have been produced for EOC (Doyal, Payne and Cameron, 2003) and for the Scottish Executive (Fitzgerald, 2006)

Social Focus on Women and Men 2002 – Chapter four: Health and Care, Scottish Executive, 2004
http://www.scotland.gov.uk/stats/sfwm/docs/sfwm-06.asp

The following are referred to in this briefing, or provide other overviews of research. They are only a small sample of a large literature:

http://www.equality.ie/getFile.asp?FC_ID=147&docID=75
http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/MentalHealth/MentalHealthArticle/fs/en?CONTENT_ID=4002408&chk=OPSOmR


http://www.eoc.org.uk/PDF/gender_health_and_the_new_public_duty_in_scotland.pdf

http://www.eoc.org.uk/PDF/fair_for_all_gender_%20and_health_research.pdf


http://www.wellontheweb.org/


http://www.emhf.org/index.cfm/item_id/57


Sources of information and advice

The Equal Opportunities Commission (EOC) hosts the Fair for All – Gender project: 0141 245 1817
Email: marese.o’reilly@eoc.org.uk
www.eoc.org.uk/fairforallgender

EOC also provide general resources:  http://www.eoc.org.uk/

European Men’s Health Forum  http://www.emhf.org/

Gender Issues Network on Alcohol, Alcohol Focus Scotland
http://www.alcohol-focus-scotland.org.uk/ourservices/gina.asp

(return to contents)
Fair for All Equality and Diversity:
Handbook for NHS Scotland

Health Topic Briefings

RELIGION AND BELIEF

Why it matters

Religion and belief are major factors in many people’s lives. The ways in which they may be linked to health and health care are particularly complex.

• There is a current and growing body of literature acknowledging a positive association between religious belief, spirituality and health.

• A person’s value system, sense of purpose and inner strength, whether derived from religious or other sources, has been linked to how they respond to illness and treatment.

• Appropriate recognition of religious practices and preferences is particularly important in the care of the dying and in dealing with the deceased and their family after death.

• The factors that lead people to claim membership of an ethnic group sometimes include religious and cultural factors (e.g. Serbs and Croats). However only those religious groups that have a common ethnic origin are protected by the Race Relations Act.

• In a limited number of cases, religions may be sufficiently distinct in origins for genetic factors to be related to them.

• People may have experienced discrimination or disadvantage because of their religion.

• Some of the observed differences in health between ethnic groups may be linked to differing cultural practices of religious origin. Religious views may also affect the way in which health promotion messages are received and acted upon. Some religious practices, such as abstinence from alcohol or vegetarianism, may have positive links to health.
• Some religious groups, or sections of them, have particular views on organ transplantation, blood transfusion and other medical procedures or treatment.

Ensuring equal and appropriate treatment on the basis of religion and belief is therefore partly a matter of recognising those dimensions of each individual’s life that many would describe as ‘spiritual’ and partly a matter of recognising the needs of minorities. However, it is important not to substitute a stereotyped view of a particular religion for consultation on an individual’s wishes.

The Employment Equality (Religion or Belief) Regulations 2003 make it, unlawful, broadly for an employer to discriminate against or harass a person on the basis of their religion or belief.

A major issue in Scottish society that is linked to religion is sectarianism. While health services should clearly combat this where it arises (whether of a Catholic, Protestant or any other nature), there appears to be little research evidence of its implications for health. Health related differences between the main Christian groups have certainly been found (see box), but their implications for practice, if any, have not been fully studied.

For children in a Church of Scotland group, mental health was worse among those who attended church, and there was an excess of bullying; whereas among Catholics, mental health was better among those who attended church. The researchers suggest that this interaction was due to conformity/non-conformity to peer group norms. Abbotts J, Sweeting H, Williams R, West P (2004) Is going to church good or bad for you? Denomination attendance and mental health of children in West Scotland Social Science and Medicine 58(3):645-656.
Key facts

• According to the 2001 Census, in Scotland there were:
  
  – 2,146,300 people reporting that their religion was Church of Scotland
  – 1,394,500 with no religion
  – 803,700 Catholics
  – 344,600 in other Christian denominations
  – 42,600 Muslims
  – 6,800 Buddhists
  – 6,600 Sikhs
  – 6,400 Jews
  – 5,600 Hindus
  – 27,000 reporting another religion (Scottish Executive, 2005).

Issues

Cultural competence

Dealing effectively with differing beliefs and cultural practices requires ‘cultural competence’. This is of two kinds:

• Generic cultural competence, which includes knowledge and skills applicable to any encounter, gained through experience, observation and an attitude of respect for and openness to other cultures.

• Specific knowledge and skills applicable to people from particular backgrounds. This is ‘a framework for beginning to understand individuals and families’ but must not automatically be generalised to all patients from a particular background (Kemp, 2005).
Become familiar with the patient’s culture. Issues include:

- Communication and language, including verbal and non-verbal cues
- Space, e.g. for relatives to visit and pray if they wish
- Social relationships, such as family hierarchy
- How time is organized in relation to work and life
- The environment in which treatment and care are provided, including food, presence of religious artefacts
- Biological variations, e.g. genetic variation in susceptibility to disease


Access and treatment

There is little systematic evidence of differences in access to services between religious, as opposed to ethnic groups. There are clearly circumstances in which treatment and health promotion advice need to take account of a patient’s beliefs and practices. For example, a recent study in Edinburgh found that the levels of knowledge among South Asian patients in relation to the risks and complications of diabetes and the importance of matters such as glucose monitoring were low compared to their white counterparts. From the minority groups’ perspectives, the contributing circumstances included:

- specific cultural attitudes and views towards health, diet and the body
- medical approaches to managing disease often conflicting with religious beliefs (e.g., fasting during Ramadan) (NRCEMH, 2004).

• Muslim and Sikh women may prefer to be seen or treated by a female doctor (Diversiton, 2005).

• Some Muslims accept organ donations or autopsies, while others accept neither (Kemp, 2005).

Care and Death

Behaviour of patients and carers affected by acute and terminal illnesses may be affected by religious beliefs, such as the acceptance of suffering or the timing of death as God’s will, though there is considerable variation within each religion and between individuals.

The role of the family is often emphasised. There is a strong expectation in Islamic culture that the dying will be visited and prayed with by friends and family. Institutional settings may be considered alien places to die. However changes such as the breakdown in the extended family are likely to need to an increased use of palliative care services and therefore and increasing need for culturally sensitive services (Gatrad & Sheikh, 2002).

Issues such as the withdrawal of treatment are difficult for all, but are easier for people to cope with if the issues are presented in the context of their own tradition and beliefs.
After death, care of the body by the family is important in some traditions, especially Muslim, and other practices may be necessary in order to demonstrate respect for the dead (Gatrad, 2002).

**Belief and health**

But appropriate recognition of religious practices and preferences is also important in the care of the living. The Scottish Executive issued guidance in 2002 which requires NHS organisations to develop and implement spiritual care policies that are tailored to the needs of the local population (Scottish Executive, 2002). It distinguishes between:

- **Religious care**: given in the context of the shared religious beliefs, values, liturgies and lifestyle of a faith community

- **Spiritual care**: usually given in a one-to-one relationship, completely person-centred and making no assumptions about personal conviction or life orientation.

Most authors surveyed for NHS Quality Improvement Scotland (NHS QIS, 2005) found some difficulty in identifying the precise needs of a diverse population from a provider of spiritual care, particularly those with no religious affiliation. NHS QIS is continuing to support NHS services in improving the quality and consistency of spiritual care services, and this will clearly require close attention to the diversity of beliefs that exist.
According to Netto et al (2001) the extent to which the influence of religion and religious discrimination affects the health of those of Muslim, Hindu, Sikh or other non-Christian faiths has not been considered in Scottish research.

Some of the following are referred to in this briefing. Several other examples of the literature on palliative care and bereavement in different religions are also listed:


Sources of information and advice

Work on ‘Fair for All - Religion and Belief’ is in the process of being established, and there is as yet no single source of advice available.

NHS Education for Scotland have provided an on-line ‘Multifaith resource for healthcare staff’:
http://www.nes.scot.nhs.uk/publications/

Many issues are related to those facing ethnic minorities and come within the scope of the:


ACAS has a guide to “Religion or belief and the workplace”, which mainly covers issues for employers, but has a useful brief guide to different religions.

Health Care Chaplaincy Training and Development (part of NHS Education Scotland)
http://www.chaplains.co.uk/

The booklet ‘A Guide to Faith Communities in Scotland,’ is available from the Scottish Inter Faith Council 0141 429 4012 admin@interfaithscotland.org

(return to contents)
SEXUAL ORIENTATION

Why it matters

There is no intrinsic health benefit or disadvantage to being lesbian, gay, bisexual (LGB) or heterosexual. But available evidence shows that LGB people experience significant problems related to both their mental and physical health. Discrimination and social exclusion are major causes of ill health for people in these communities, and yet relatively little attention has so far been paid to these issues. Some LGB people face discrimination when accessing NHS services. But sexual orientation is only ever a part of any individual's identity. It should also never be assumed that some issues do not arise because someone is LGB – for example parental responsibilities, or domestic abuse.

In the NHS Reform (Scotland) Act 2004, the duty to encourage equality of opportunity extends to issues of sexual orientation. The Department of Trade and Industry estimates the LGB population to be between 5 and 7% in the UK.

People may want to disclose their sexual orientation so that they are treated as a whole person, because of difficulties in a specific area of their life or to correct assumptions by NHS staff that they are heterosexual. Disclosure ought to lead to receiving the correct preventative screening, advice, care or referral, especially where people have concerns about accessing generic services, when they have relationship difficulties, or experience harassment or bullying.
LGB people are subjected to prejudice, psychological pressure and physical threats:

• In a Glasgow survey, the number of people who would be ‘concerned or very concerned’ if someone who was lesbian or gay moved in next door (over 30%) was similar to those who would feel the same if people with a criminal record became their neighbours. NFO Social research (2003) Sectarianism in Glasgow, Glasgow City Council (unpublished) Quoted in NHS Scotland (2003).

• In a Scottish survey of LGB people, 68% had been verbally abused or threatened by someone who assumed they were LGB - 35% in the past year; 23% had been physically assaulted - 5% in the last year (Morgan & Bell, 2003).

These pressures can lead to anxiety, depression and self-harm:

• LGB people are at significantly higher risk of suicidal behaviour, mental disorder, substance misuse and substance dependence than heterosexual people, according to a systematic review of research (King et al, 2006).

• In a study of young LGB people in Glasgow the majority reported having thoughts of suicide at some time-six to eight times more than the general population (Coia et al, 2002).

Negative attitudes can be shared by health workers:

• A third of gay men, one quarter of bisexual men, over 40% of lesbians and well over half of bisexual women had experienced negative or mixed reactions from mental health professionals when being open about their sexuality (King & McKeown, 2003).
LGB people may be reluctant to tell health workers about their status:

- Over a third of LGB people had not disclosed their status to their GPs (Morgan & Bell, 2003).

Issues to investigate
Effects of discrimination or bullying

Family disruption and rejection from the family home is a common experience for young LGB people who reveal their identity in an unsupportive environment. Isolation from their peer group and significant levels of homophobic bullying, both verbal and physical, are also particular to the early experiences of young LGB people.

A study of LGB people in the UK, looking at the relationship between experiences of bullying at school and adult mental health status, suggested that posttraumatic stress was a potential issue for 17% of participants.

Anxiety, depression, self-harm, suicide and attempted suicide have all been linked with the combined effects of the experience of prejudice, discrimination and internalised negative feelings. A recent report in England and Wales reveals higher levels of reported psychological distress amongst LGB people compared to heterosexual people (King & McKeown, 2003).

Reluctance to disclose

Professionals need to strike a balance between the extremes of:
- regarding same-sex attraction as the underlying cause of psychological difficulties
- ignoring sexuality and sexual orientation altogether
- displaying excessive curiosity about how LGB people live (King & McKeown, 2003).
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It is common for LGB people not to disclose their orientation to medical staff due to fear of negative responses and reduced standards of care. It is important that LGB people feel safe and supported to disclose their identity, especially if their underlying reasons for seeking health services are related to sexual orientation or gender identity (NHS Scotland/ Stonewall, 2003).

Risk behaviour

The predominantly pub and club based gay scene, combined with the effects of homophobia and discrimination, may result in increased consumption of alcohol, tobacco and drugs by LGB people. Cigarette smoking prevalence among gay men is twice that of population levels (Harding et al, 2004). Several studies have found that lesbian women tend to drink more alcohol than heterosexual women. However there is conflicting evidence on whether gay men tend to drink more alcohol than average (NHS Scotland/ Stonewall, 2003).

A series of smoking withdrawal-oriented treatment groups aimed at gay men combined nicotine replacement therapy with peer support. After 7 weeks 76% were confirmed as having quit (comparable national data reports an average of 53% success) (Harding et al, 2004).

One study found that gay men and heterosexual women were similar in disordered eating patterns, contrasting with lesbians and heterosexual men. Schneider J, O’Leary A, Jenkins S (1995) Gender, Sexual Orientation and Disordered Eating Psychology and Health 10: 113–128.

Gay men remain the group at highest risk of acquiring HIV infection. The attention paid to this has perhaps obscured the broader sexual health needs of LGB people. Risky behaviour may be exacerbated by low self-esteem, alcohol and drug use or poor information on same sex sexual relationships, making it difficult to negotiate safer sex. Contrary to popular belief, there is data showing similar prevalence of Sexually Transmitted Infections in lesbians, compared to women who have not had sex with women (NHS Scotland/ Stonewall, 2003).
Other equalities issues

Sexual orientation and gender identity may have particularly high levels of stigma attached in some ethnic minority communities. Older LGB people will have had a different lifetime experience of attitudes than younger ones. In Scotland such issues remain difficult to identify and research.


Consultation and involvement

In 2003, each NHS Board in Scotland undertook a ‘stock take’ of current planning and provision of LGB targeted services (NHS Scotland, 2004). Very few areas specifically targeted the needs of LGB people in their policy and planning. Including LGB organisations in consultation is an important way of overcoming this. But there are many identified obstacles to this, including:

• lack of staff knowledge of LGB issues and how to engage people effectively
• people may not be comfortable disclosing their sexual orientation in a public forum and a welcoming, non-judgemental environment is important
• LGB representation in rural or isolated communities is difficult and stigma can be very severe.
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Research and where to find it

There are large gaps in the evidence, and it is difficult to undertake representative research on LGB experiences. A large proportion of the community is hidden and cannot be contacted using normal methods. Reports were produced for the Scottish Executive (2003a and b) on what research is needed and what the difficulties are. They show a need to achieve a balance between ensuring LGB people are consulted and involved in the development of research agendas and processes, with the potential overburdening of a community with limited resources and capacity.

The ‘first out’ report (Morgan & Bell, 2003) was the first survey in Scotland to take an overall view of the needs, experiences and concerns of LGB people in a range of key areas, including health.

King & Nazareth (2006) is the first European study in which the mental and physical health of people of a range of sexual orientation attending general practitioners has been compared.

The following are referred to in this briefing, or provide overviews of research:


King M, Semlyen J, See Tai S and others (2006) Mental disorders, suicide, and deliberate self harm in lesbian, gay and bisexual people: a systematic review of the literature Department of Mental Health Sciences, University College London


Fair for All Equality and Diversity: Handbook for NHS Scotland

Health Topic Briefings

Scottish Needs Assessment Programme (2001) Transsexualism and Gender Dysphoria in Scotland Public Health Institute Scotland

Sources of information and advice

The Inclusion Project is the partnership between the Scottish Executive Health Department and Stonewall Scotland, which campaigns for equality for LGBT people in Scotland. http://www.lgbthealthscotland.org.uk/research_database/browse.php

Its publications, including ‘Towards a Healthier LGBT Scotland’ and ‘Good LGBT Practice in the NHS’, were major sources for this Briefing. ‘Good LGBT Practice in the NHS’ ends with a useful one page checklist for good practice.

Stonewall Scotland http://www.stonewallscotland.org.uk/ are partners in the project and offer a range of additional information

(return to contents)